# Working with cancer: a pilot study of work participation amongst cancer survivors in Western Sydney.

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# Thesis Abstract

## Background

Improvements in cancer screening and treatment means that more individuals diagnosed with cancer are living longer. Although lifesaving, cancer treatments are aggressive and may result in persistent impairments such as fatigue, pain, cognitive impairment and emotional distress. Cancer survivorship is increasingly recognised as an additional phase of the cancer care continuum. Approximately forty percent of cancer diagnoses occur within people of working age, most of whom are expected to live years beyond their diagnosis. Work represents a key occupation for this population and provides physical, mental, social and financial health benefits. Returning to work is an important aspect of recovery for many cancer survivors, however little is known about how cancer impacts work participation in the Australian context.

## Aims

The purpose of this review was to explore the impact of cancer on work participation and identify factors which are associated with work outcomes in cancer survivorship. This review also aimed to explore the impact of cancer for working-age survivors in the Australian context specifically. The results gained from this review informed the design and analysis of the study ‘Working after cancer: a pilot study of work participation among cancer survivors in Western Sydney’.

## Overview

This thesis is divided into two sections. The first section contains a literature review of research on the topic of cancer survivorship and work-related outcomes. The review explores the personal, cancer, and work-related factors associated with work participation amongst cancer survivor populations. In addition, the review explored the impact of cancer on work participation in the Australian context.

The second section contains a manuscript based on a pilot cross-sectional study. The manuscript has been written with the intention for submission to the Australian Journal of Occupational Therapy (see appendix II). The study reports on the use of a cross-sectional survey to identify factors associated with work participation in a small sample of cancer survivors in Western Sydney.

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# SECTION I: LITERATURE REVIEW

## Introduction

Cancer is a leading cause of illness in Australia and has a substantial social and economic impact on individuals, their families and communities (AIHW, 2019). Cancer involves abnormal cells dividing without control which can invade nearby tissues (National Cancer Insititute, n.d.). Cancer refers to a heterogenous group of disease with different affected tissues, prognoses and treatment regimes. Around 40% of cancer diagnoses occur within the working age population (20-65 years), most of whom are expected to live years beyond their diagnosis (AIHW, 2019). The most common cancers diagnosed within this population include breast, melanoma, prostate and colorectal cancers (AIHW, 2019). Beyond acute life-saving treatment there is a need to address the long-term health and wellbeing for survivors. Work represents a key occupation for this population which contributes to health and quality of life. However, little is known about how cancer impacts work participation for survivors in the Australian context.

## Cancer survivorship

### *Prevalence*

Cancer is life threatening, accounting for 3 of every 10 deaths in Australia, however advances in screening and treatment means that more survivors are living longer (AIHW, 2019). Australia currently has the highest cancer survival rates in the world (Arnold et al., 2019), and there are an estimated 1.1 million individuals living with or beyond cancer within the population (AIHW, 2019). Survivorship is increasingly recognised as an additional phase of the cancer care continuum (Lisy et al., 2018) which aims to address ongoing health issues and long-term wellbeing of cancer survivors. Cancer is the largest cause of disease burden in Australia, contributing 19% of total disease burden (AIHW, 2019). In 2019, it is estimated that around 57,000 new cancer diagnoses will occur within Australians of working age (20-65 years old), 85% of whom are expected to live at least five years post diagnosis. Returning to daily activities and life roles are important aspects of their recovery.

### *Cancer is a chronic and complex disease*

The terms cancer survivor and cancer survivorship were first described by a paediatrician Fitzhugh Mullan in 1985. Reflecting on his own experience of cancer he challenged the paradigm that cancer patients were simply ‘cured’ of cancer, but rather endured ongoing ‘seasons of survival’. This included ongoing management of long-term overt and covert effects of cancer and its treatment (Mullan, 1985). For the purpose of this review cancer survivor is defined as ‘an individual from the time of diagnosis to the end of life’ (National Cancer Insititute, n.d.). Cancer survivorship is defined as ‘a process that begins at the moment of diagnosis and continues through the balance of life’ (Marzorati, Riva, & Pravettoni, 2017).

Cancer treatment is complex and typically involves aggressive, multimodal interventions such as surgery, chemotherapy and/or radiation therapy. Other treatments, such as hormone therapy, immunotherapy and targeted therapies, can also be used for some types of cancer (Cancer Council Australia, n.d.). Treatment, although lifesaving, can result in a wide range of physical and psychological morbidities including fatigue, nausea, pain and distress. These symptoms present or intensify during treatment and may persist in a chronic, long term condition years beyond treatment. A population-based study in the US found that 92% of survivors experienced residual symptoms one year after diagnosis (Shi et al., 2011). A review of symptom burden reported that one third of cancer survivors experienced ongoing symptoms at the same severity once treatment finished (Wu & Harden, 2015). Fatigue, psychological distress, sleep disruption, pain and cognitive impairment were commonly reported across cancer types.

Importantly, many people find the ‘survivorship phase’ challenging as they transition from acute care and adjust to living with or beyond cancer (Collins, Ottati, & Feuerstein, 2013). The current Australian cancer care continuum is largely focused on cancer treatment and surveillance (Lisy, 2018) with few cancer rehabilitation services available (Dennett, Peiris, Shields, Morgan, & Taylor, 2017). There is an increasing emphasis on the need to address long-term health and wellbeing for cancer survivors (Lisy, 2018). Cancer Australia, the Federal Government agency for cancer, recently released a national framework to guide policy, planning and health system responses to cancer survivorship (Cancer Australia, 2018). This framework aims to reduce the impact of cancer and improve the health and wellbeing of survivors. Returning to normal activities, including returning to work, is one aspect of addressing ongoing health and wellbeing.

### *Work is good for health*

Work is good for health, and provides personal, social and economic benefits to individuals, their families and communities. Being engaged in valued and productive work roles provides structure to daily life, physical and mental health benefits, income, and opportunities to engage in and build social networks (Amir, Neary, & Luker, 2008; Maytal & Peteet, 2009; Wells et al., 2013). Work is integral to self-identity and provides a sense of purpose and social value (Maytal & Peteet, 2009; Wells et al., 2013). Many of the benefits provided by work can aid in recovery from illness or injury (AFOEM, 2011). Conversely, unemployment, underemployment or difficulties with employment are associated with adverse health and wellbeing outcomes (Jin, Shah, & Svoboda, 1995; Maytal & Peteet, 2009; Peteet, 2000). Cancer survivors who are unemployed report poorer health outcomes including higher symptom burden (Shi et al., 2011) and lower quality of life (Beesley, Vallance, Mihala, Lynch, & Gordon, 2017).

Work is a key occupation throughout much of adulthood. 'Working age' differs between Australian states and is projected to change in coming years (Productivity Commision, 2005), however for the purpose of this paper 'working age' is defined as being aged 20-65 years. This definition excludes adolescent and young adults as many survivors of childhood cancer experience unique challenges and long-term health implications as adults (Fardell et al., 2018; Kosola et al., 2018; Robison & Hudson, 2014). Furthermore, this survivor population typically engage in vocational rehabilitation and work-entry (Fardell et al., 2018).

## Purpose of the review

The purpose of this review was to explore the impact of cancer on work participation and identify factors which are associated with work outcomes in cancer survivorship. This review also aimed to explore the impact of cancer for working-age survivors specifically in the Australian context. The results from this review informed the design and analysis of the study *'Working with cancer: a pilot study of work participation among cancer survivors in Western Sydney'.*

## Aim/Search strategy

This review aims to examine and critique existing literature relating to the factors associated with work participation amongst cancer survivor populations. Of particular interest was the Australian context. Relevant literature was identified through searches of Medline, SCOPUS, Cinahl and

APAIS databases. Search terms included concepts of ‘cancer’ AND ‘work’, (see Appendix I for the full list of search terms), and the search was limited to studies written in English only. Reference lists of relevant articles were hand-searched to identify additional publications. The initial search resulted in 2,695 journal articles which were scanned in title and abstract for relevance. Studies were included if they involved adult cancer survivor populations and measured work participation. Studies were excluded where they involved adult survivors of childhood cancer, work-related cancer or which focused on populations who were unemployed prior to their cancer diagnosis. A total of 209 journal publications were identified as being relevant. Due to time constraints of this project, the search results were refined to studies systematic reviews and studies which included Australian populations as this was a key focus of the review. Seventeen articles related to studies of Australian cancer survivors were identified and summarised (Table 1). A total of 28 systematic reviews were included in this review.

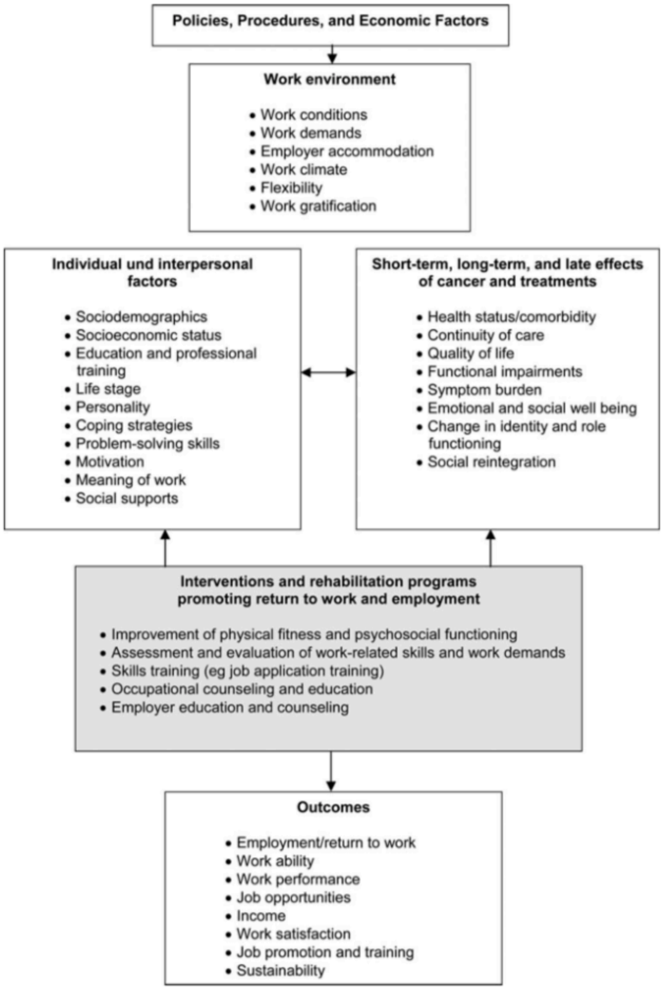
## Conceptual framework

Several conceptual frameworks have been proposed to guide research and intervention in the field of cancer survivorship and work. Feuerstein and colleagues (2010) developed the ‘cancer and work model’ after a review of 45 studies in the international literature. This model described seven key factors which impact work outcomes for cancer survivors including sociodemographic characteristics, health, symptoms, function, work demands, work environment and policies and economic factors. The model recognised multiple short- and long-term work outcomes and represented one of the earliest frameworks for study of cancer and work (Feuerstein et al., 2010). Another research model for the investigation of work-related aspects in cancer survivorship was proposed by Mehnert (2011) in one of the most widely cited publications within the cancer survivorship and work field. The model was developed following a review of 64 articles on the topic and described the influence of medical factors and mediating variables on work outcomes. This model described six categories of mediating variables including demographic factors, impairment and health-related factors, psychosocial factors, motivational factors, work-related factors and variables associated with work-related interventions.

Collaborations between Mehnert, De Boer and Feuerstein in 2013 produced an integrated model for research on cancer survivorship and work (Figure 1). This model integrated concepts from previously described models into four key areas, individual and interpersonal factors, short-term, long-term and late effects of cancer, the work environment, and work-related outcomes (Mehnert, de Boer, & Feuerstein, 2013). This model was designed to offer efficiency and applicability to research in the field and has been used to guide the present literature review and following study.

***Figure 1***

*The cancer survivorship and work model from Mehnert, De Boer & Feuerstein, 2013.*



## Work-related outcomes

The evidence of the impact of cancer on work participation including employment characteristics, return to work (RTW) rates, length of sickness absence, and work ability was reviewed. RTW is a common term used to describe the process of recommencing previous employment after a period of leave (Comcare, n.d.). Work ability is described as the perceived ability to meet the mental, physical or psychological demands of the work role (Loisel & Anema, 2013). Sickness absence refers to the short-term incapacity to participate in paid employment (Loisel & Anema, 2013).

### *Cancer impacts work participation*

A meta-analysis of studies between 1966 and 2008 found that survivors were 1.37 times more likely to be unemployed than people without cancer (de Boer et al., 2008). Reviews have also found that survivors were more likely to take early retirement and were less likely to be re-employed (Mehnert, 2011). Around two thirds of cancer survivors RTW, however reported rates vary widely (24-94%) (Mehnert, 2011; Spelten, Sprangers, & Verbeek, 2002; Taskila & Lindbohm, 2007). A recent review of European studies between 2010 and 2017 reported that 69-80% of survivors who were employed at the time of diagnosis returned to work, suggesting that improvements in managing long term effects of cancer had been made. However only four studies in this review reported on RTW so this interpretation was reported with caution (Paltrinieri et al., 2018). Similar inferences were also made by authors of a review of studies across Europe and Asia (Tavan, Azadi, & Veisani., 2019). This review reported that 57% of survivors returned to work, however this varied between studies involving Asian (mean 72%, range 68%–77%) and European populations (mean 52%, range 43%–60%). The authors attributed these regional differences to the year of study, suggesting more recent advances in cancer treatments provided more favourable long-term outcomes, however it is also likely that cultural and country-specific factors such as healthcare, welfare and employment policies may have also influenced RTW rates (Tikka, Verbeek, Tamminga, Leensen, & de Boer, 2017). Comparisons between studies is complicated by varying definitions of RTW, including whether survivors returned to their previous employment or sought alternative employment.

The length of absence from work was negatively associated with RTW rates (A Mehnert, 2011; Spelten et al., 2002). A review of mixed cancer studies reported that the average length of illness absence was 151 days (Mehnert, 2011). Few employees would have paid leave entitlements to cover such absences. In Australia, permanent full-time employees are entitled to a minimum 10 days personal leave per year, however, leave entitlements vary between state, industry, and enterprise agreements (Collie, Di Donato, & Iles, 2018). Extended leave from work due to illness would be negotiated at the employer's discretion.

### *Perceived work ability is reduced after cancer*

Around a quarter of cancer survivors who were able to RTW reported reduced work ability, including physical and mental functioning (Duijts et al., 2014; Mehnert, 2011; Steiner, Nowels, & Main, 2010). Compared to people with other chronic illness, cancer survivors reported poorer work ability (Munir, Yarker, & McDermott, 2009). Reduced work ability may also feed into fear of work-related failure which inhibited RTW (Banning, 2011). The duration of impaired work ability was impacted by several factors including cancer site, treatment modalities and work demands. However longitudinal studies showed that work ability improved overtime (de Boer et al., 2008; Munir et al., 2009).

### *Emerging evidence of cancer and work in the Australian context*

Research on work participation of Australian cancer survivors is limited, however emerging evidence echoes international study findings. A summary of peer reviewed Australian studies is provided in Table 1. Of the seventeen studies identified in this review, many explored the qualitative experience of working after cancer, measured the economic impact of cancer, or focused on particular cancer populations. For example, five published studies were derived from the ‘Working After Cancer Study’ of colorectal cancer survivors in Queensland (Gordon et al., 2011).

A large population study, using national cross-sectional data from the 2015 survey of Disability, Ageing and Carers reported that 46% of working-age cancer survivors were not currently working (Bates, Callander, Lindsay, & Watt, 2018). Compared to cancer survivors, people without health conditions and people with other long-term health conditions were 3.0 and 2.15 times more likely to be employed full time respectively. Another study of cancer survivors from two large Australian hospitals found that 36.8% of survivors who were employed prior to diagnosis left the workforce shortly after treatment, and a further 23.1% permanently reduced their work hours (Paul et al., 2016). Associated with this reduced employment, 66% of survivors reported a reduction of household income by approximately half after their diagnosis. A longitudinal study of mature-age women across Australia found that cancer was associated with unemployment, however this affect was not statistically significant once quality of life was also measured (Pit & Byles, 2012). This study suggested that quality of life was more closely associated with employment status than health condition.

***Table 1***

*Summary of published literature of cancer and work participation in Australian population.*

| **Study** | **Study objectives** | **Study design** | **Key findings** |
|---|---|---|---|
| Gordon, Scuffham, Hayes, & Newman, 2007 | To identify direct and indirect economic losses to breast cancer survivors | Longitudinal, population based study. Participants 0-18 months post-diagnosis<br>*n*=287, Age=57 years (SD 9.6) | Lost income was the most substantial source of cost followed by, health service expenditures and lost unpaid work. Lost income was highest during 0-6 months (AUD 6,770.70), and decreased by 13-18 months (AUD 2,070.70). Costs were higher for younger survivors (<50 years) |
| Gordon, Lynch, & Newman, 2008 | To assess changes in work participation among men and women diagnosed with colorectal cancer | Prospective, cohort study. Survey at 0, 12 months post diagnosis. Male *n*=621, Female *n*=354 | After diagnosis 46% stopped working, however this reduced to 35% by 12 months. Fewer women (60%) RTW by 12 months than men (67%). Radiation therapy among men and chemotherapy among women was associated with higher prevalence of work cessation. Private health insurance was associated with RTW |
| McGrath, Hartigan, Holewa, & Skarparis, 2012 | To explore issues associated with the experience of survivorship for haematology patients | Cross-sectional, qualitative study. Participants >1 year post-treatment. Male *n*=26, Female *n*=24 | Physical recovery was important for RTW and meeting work demands. Fatigue was particularly debilitating. Some survivors changed jobs due to fatigue and sun sensitivity. Psychosocial problems associated with unemployment included reduced confidence and competence, lack of meaning, and interference with social relationships. Supportive employer was an important facilitator of RTW. |

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| McKay, Knott, & Delfabbro, 2013 | To explore the perspectives of survivors, managers, and psychologists on the work-related issues of cancer. | Qualitiative study, phenomological approach.<br>Survivors *n*=15<br>Managers *n*=12<br>Psychologist *n*=4 | RTW facilitators included financial necessity, desire for social contact, striving for normality, regaining control, enjoyment, distraction, relieving boredom, maintaining momentum, and restoring a part of their identity. Cancer impacted perceived work ability, and work and life priorities. Ongoing communication and support in flexible RTW was important. EAP services were not widely consulted regarding cancer and work issues. |
| Gordon et al., 2014 | To evaluate changes in and key factors for work participation during 12 months post colorectal cancer diagnosis. | Prospective cohort study (Gordon et al, 2011)*.<br>Survivors *n*=239<br>Comparison group *n*=717 | At 12 months, 27% of survivors had stopped working, compared to 8% in comparison group. Survivors took a median of 91 days off work. Predictors of not working included being older, lower BMI, and lower physical wellbeing. Factors related to delayed work re-entry included not being university educated, working for small business, longer hospital stay, poorer perceived financial status and chemotherapy. |
| Knott et al., 2014 | To explore barriers to work and preferences for RTW intervention for cancer survivors and oncology health professionals (OHP). | Qualitative study, phenomological approach.<br>Survivors *n*=17, 76% female<br>OHP, *n*=21, 57% female. | Barriers to work included unpreparedness, difficulty managing demands of work, changes in priorities, reduced capacity, lack of confidence, managing appointments, inability to drive and lack of knowledge about employment policies. Financial pressures encouraged survivors to RTW too early. OHPs reported difficulty addressing psychological barriers to work. Structured RTW assessment which addressed individual needs were preferred. |
| Mackenzie, 2014 | To explore the experience of working mothers diagnosed with breast cancer. | Qualitative study, phenomological approach.<br>Participants *n*=32 | 81% continued/RTW, most in the same workplace. Factors associated with RTW included redefining priorities, support from partner, workplace support, financial pressures, importance of work, ongoing pain or fatigue. Survivors prioritized self-care over paid work to manage stress. Survivors |

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| | | Children 1-2 n=20, 3-4 n=12,<br>Age range 28 to 52. | prioritized family needs above their own and continued to do most of housework and childcare. RTW important for recovery. |
| Boyages et al., 2016 | To explore the impact of the severity of lymphedema on work and career | Cross-sectional study.<br>Breast cancer (BC) *n* = 209<br>Breast cancer plus lymphedema (BC+L), *n* = 152 | Breast cancer impacted work ability in 51 % of BC, and 63% of BC+L.<br>Lymphedema impacted work ability in 42% BC+L, the extent of this increased with disease severity. Of these 40% reported presenteeism, and 47% were unable to work long hours. Reduced hours was common across both groups (51% BC; 19% BC+L). |
| Lynch, Mihala, Beesley, Wiseman, & Gordon, 2016 | To investigate associations of health behaviours with RTW outcomes after colorectal cancer. | Prospective cohort study* (Gordon et al, 2011) Survivors *n*=239<br>Comparison group *n*=717 | Work cessation was not correlated with vegetable/ fruit consumption, alcohol consumption, smoking status, physical activity or sitting time with work cessation. Survivors who slept > 9 hours per day were almost 3x more likely to have ceased or reduced hours, and had longer time to work re-entry than those who slept between 7-9 hours/day. |
| Paul et al., 2016 | To quantify effects of cancer on income and employment, and describe how cost-related factors influenced treatment decisions. | Cross-sectional study. Two surveys, initial and 4-week follow up.<br>Participants at initial *n*=321,<br>follow-up *n*=255<br>30.8% were aged <60 years. | Prior to diagnosis, 25% employed full-time, 17% part-time and 58% not employed. Of those working, 67% reported change in employment including reduced hours (23%), retirement (20%) and resignation (16%); 63% reported reduced household income. 74% did not access financial assistance, of those 37% were not aware of financial assistance options.<br>1 in 5 reported that cost-related factor influenced treatment decisions. Private health insurance was associated with higher treatment costs. |
| Beesley et al., 2017 | To examine relationships between | Prospective, matched cohort study* (Gordon et al, 2011) | 45% survivors ceased or decreased work during the study period, compared with 27% in the control group. At 12 months, survivors who maintained/ |

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| | changes in work and quality of life (QoL) over 12 months of colorectal cancer diagnosis. | Survivors *n*=150<br>Comparison group *n*=300 | increased work had significantly better functional wellbeing and QoL than those who decreased work or retired. Physical wellbeing and QoL was higher in control population than cancer population throughout the study period. Physical and functional wellbeing and QoL improved for cancer survivors over 12 months period. |
| Edward, Giandinoto, & McFarland, 2017 | To explore experiences of nurses who return to nursing after cancer | Exploratory qualitative study.<br>Participants *n*=8<br>Age 57 years (SD 10.5)<br>Breast cancer *n*=6 | Participants reported being pragmatic about diagnosis and treatment however needed additional emotional support.<br>Support from employer was important. RTW impacted their performance at work particularly in having more empathy for patients, and changed relationships with colleagues. Active coping strategies improved wellbeing. |
| Gordon, Beesley, Mihala, Koczwara, & Lynch, 2017 | To assess the financial wellbeing of colorectal cancer survivors during 12 months post-diagnosis. | Prospective, matched cohort study* (Gordon et al, 2011) Survivors *n*=187<br>Comparision group *n*=355 | Approximately one-third of survivors were not financially comfortable 6 months after diagnosis. Financial strain improved between 6-12months, by 12months the extent of financial strain was similar to comparison group. Survivors who decreased or ceased work were more likely to report being not financially comfortable than those who maintained or increased work. |
| Gordon, Walker, et al., 2017 | To measure work and income of prostate cancer survivors. | Cross-sectional, national study. Participants *n*= 289 | Work participation: 39% were still working, 26% stopped working, 14.3% of men retired early due to cancer. Of those still working 14% reduced their hours. On average, survivors retired 4–5 years earlier than planned. |
| McGrath et al., 2017 | To measure work-related limitations over first 12 months post | Prospective, matched cohort study* (Gordon et al, 2011). Mixed methods. N=171 | At 12 months 22% - 39% of participants reported work limitations. Reasons for stopping work included bowel problems and stoma, loss of strength, and medication adverse effects. Key work-related issues included |

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| | colorectal cancer diagnosis | | changes in work functioning, attitudes of employers and colleagues, financial pressures, and emotional responses. |
| Bates et al., 2018 | To determine the work participation of cancer survivors and estimate indirect costs of unemployment. | Cross-sectional data from 2015 Survey of Disability, Ageing and Carers .<br>Cancer survivors *n*= 108,900<br>Other long-term health condition *n*= 4,991,800<br>No health condition *n*=7,287,100 | 46% of people with cancer were not working, compared to 27% people with other LTHC and 12% of people without health condition.<br>Healthy controls were 3.00x more likely to be employed full-time than people with cancer. Among survivors, those without a tertiary qualification were 3.73x more likely to be unemployment than those with.<br>An estimated $1.7 billion in GDP is lost due to unemployed cancer survivors. |
| Kalfa et al., 2018 | To examine the impact of secondary lymphoedema on employment. | Qualitative, phenomological approach. Participants *n*=14, female *n*=13 (93%). | Lymphedema impacted lifting, repetitive hand use, driving, computer use, long periods of standing, and other physical activity. Some survivors changed jobs due to difficulty with physical tasks. Maintaining stoic identity was important, most did not take sick leave for sore limbs. Relationships at work were important. Most concealed their limbs. |

* Gordon et al., 2011, The Working After Cancer Study: Observational population-based study of 260 newly diagnosed colorectal cancer survivors who were employed at time of diagnosis. Cancer survivors recruited through Queensland Cancer Registry. Cancer cases were compared to age and gender matched general population group from the national Household, Income and Labour Dynamics survey.Telephone surveys and follow-up postal surveys assessed at 6 and 12 months post diagnosis.

## Effects of cancer and treatments

### *Cancer site*

Cancer refers to a group of diseases with different affected tissues, prognoses and treatment regimes. Across all cancer types, less advanced/early stage cancer was associated with positive work outcomes  (Tikka et al., 2017). Associations between cancer site and work-related outcomes have been reported (Amir & Brocky, 2009; Cooper, Hankins, Rixon, Eaton, & Grunfeld, 2013; de Boer et al., 2008; Kiasuwa Mbengi et al., 2016; Taskila & Lindbohm, 2007; van Muijen, Duijts, van der Beek, & Anema, 2013). A meta-analysis of cancer and unemployment studies found that unemployment was higher amongst survivors of breast, gastrointestinal and female reproductive organ cancers than their healthy aged-matched controls, however no difference in employment was observed amongst survivors of blood, prostate or testicular cancers (de Boer et al., 2008). A study comparing work outcomes between cancer types reported breast, gynaecological, and head and neck cancer survivors took twice as long as urological cancer patients to RTW when matched for age and treatment regime (Cooper et al., 2013). Favourable work outcomes for prostate cancer survivors was reported in a systematic review (mean RTW rate 80%, sickness absence 32 days) (McLennan, Ludvik, Chambers, & Frydenberg, 2019) including greater RTW rates and faster time to RTW than other cancer types (Bradley, Neumark, Luo, & Schenk, 2007; Sjovall et al., 2012). Conversely, lung cancer survivors reported lower employment rates, longer sickness absence and reduced work ability than other cancers (Vayr et al., 2019) which may in part be due to differing prognoses and survival rates. Survival rates of prostate cancer (95%) were much higher than for survivors of lung (17.4%) (AIHW, 2019) and typically involved less aggressive treatment regimes. Inconsistent findings have been reported on work outcomes for breast cancer survivors. A review of systematic reviews by Cocchiara and colleagues (2018) identified a range in RTW rates from 43% in the Netherlands to 93% in the USA within one year after diagnosis. A broad range was also reported for the mean length of sickness absence (86 to 349 days). Amongst the possible contributing factors for this disparity, the authors cited varied treatment modalities amongst survivors and the influence of access to welfare and health insurance.

### *Treatment modalities*

Cancer treatments, although life-saving, are aggressive. Treatment may have a substantial impact on the individual’s physical, psychological and cognitive health which may persist beyond treatment (Mehnert, 2011; van Muijen et al., 2013). Treatments may also require multiple appointments, sometimes hours long, which interrupt work hours. One study of early-stage breast cancer survivors reported that treatment was *the* principle factor which impacted work outcomes (Balak, Roelen, Koopmans, Ten Berge, & Groothoff, 2008).

Chemotherapy is an aggressive form of treatment which commonly results in side effects including fatigue, digestive upset, 'cognitive fog' and deterioration of hair, skin and nail tissues (Wu & Harden, 2015). Chemotherapy was associated with poorer work outcomes including poorer work ability (de Boer et al., 2008; Kamal et al., 2017; Munir et al., 2009), longer sickness absence (Balak et al., 2008; Kamal et al., 2017), and lower probability of RTW (Gordon et al., 2014; Johnsson et al., 2009; Kamal et al., 2017; van Muijen et al., 2013). Survivors who received chemotherapy reported poorer work ability than those who received radiation therapy and surgery (de Boer & Frings-Dresen, 2009). Qualitative research also reported that perceived work ability and readiness to RTW was impacted by self-reported cognitive difficulties associated with chemotherapy (Banning, 2011; Wells et al., 2013). These included difficulty with short-term memory, speed of processing information and executive functioning. Conversely, a cohort study of breast cancer survivors in the US reported that chemotherapy did not impact RTW, although the overall rate of RTW in this study was relatively high (80%) (Bouknight, Bradley, & Luo, 2006).

Whilst minor surgery alone has been associated with positive work outcomes (McLennan et al., 2019; Spelten et al., 2002), extensive surgery has been associated with lower RTW rates, longer sickness absence and decreased work ability (Ahn et al., 2009; den Bakker et al., 2018; van Muijen et al., 2013). Radiation therapy was associated with both positive and negative work outcomes in a British study of mixed cancer population. Gynaecological cancer survivors who received radiation therapy had longer sickness absence than survivors who did not, however the opposite was reported for urological cancer survivors (Cooper et al., 2013). Multimodal treatment was associated with more negative work outcomes (Bains, Yarker, Amir, Wynn, & Munir, 2012; Balak et al., 2008; van Muijen et al., 2013). Prostate cancer survivors reported longer sickness absence where surgery was combined with chemotherapy or radiation (McLennan et al., 2019). Similar results were also reported amongst breast cancer survivors including reduced RTW rate and longer sickness absence (Kamal et al., 2017). Breast cancer survivors who received mastectomy and chemotherapy were more likely to stop working independent of other sociodemographic or treatment-related factors (Kamal, et al., 2017). Overwhelmingly, time since treatment was positively associated with work outcomes (Balak et al., 2008; Spelten et al., 2002).

### ***Symptom burden***

Symptoms of cancer and its treatment provide many challenges that can impact work outcomes including employment, work ability and work retention (Collins et al., 2013). Symptoms may exist for years following treatment at varying levels of frequency and severity (Feuerstein, 2010). A population study in the USA reported that 92% of cancer survivors experienced residual effects of treatment one year after diagnosis, with a quarter of cancer survivors reporting high symptom burden. Of these symptoms fatigue, pain and depression most negatively affected QoL, regardless of whether active treatment had finished or was ongoing (Shi et al., 2011).

#### *Physical side effects*

Treatment-induced physical impairments are frequently reported including pain, fatigue, muscle weakness (Banning, 2011; Collins et al., 2013). A review performed by Bijker and colleagues (2018) found that higher physical functioning was associated with less sickness absence and higher work productivity in survivors of breast cancer. Those who reported reduced physical ability also had a twofold increase in work changes and poorer work ability. Fatigue impacts 60-96% of survivors (Wagner & Cella, 2004), and is commonly reported as the most prominent and debilitating side effect of cancer treatment (Collins et al, 2013). Several reviews have reported fatigue as being negatively associated with work outcomes (Cocchiara et al., 2018; Duijts, van Egmond, Gits, van der Beek, & Bleiker, 2017; Mehnert et al., 2013). Fatigue has also been reported to become exacerbated upon RTW which impacted work ability (Grunfeld & Cooper, 2012). Lymphedema was reported to have a negative impact on work including reduced confidence at work, longer sickness absence and reduced work ability (Boyages et al., 2016; Fitch et al., 2019; Schmidt, Scherer, Wiskemann, & Steindorf, 2019). Treatment-induced hormonal changes including early menopause impacted work ability and comfort at work (Duijts et al., 2014; Fitch et al., 2019). Similarly digestive issues (Cooper et al., 2013), muscle weakness (Balak et al., 2008; McGrath, et al. 2017) and incontinence (Fitch, et al., 2019; McGrath et al, 2017) were reported to impact RTW and perceived work ability.

### *Cognitive side effects*

Impaired cognitive function is a commonly described side effect of cancer treatment (Banning, 2011; Boykoff, Moieni, & Subramanian, 2009; Collins et al., 2013). Several factors may contribute to cognitive change during treatment including emotional distress, medications, disrupted sleep, digestive changes and generally feeling unwell. Although cognitive problems may be subtle, they can vary in severity and may persist for months or even years after treatment (Wu & Harden, 2015). The most commonly self-reported cognitive dysfunctions included distraction, forgetfulness, and difficulties with attention, multitasking, and word finding (Ahles & Root, 2018). Studies focused on work ability have reported that cognitive limitations are associated with decreased work ability (Mehnert & Koch, 2013), however a discrepancy between self-reported and performance-based cognitive assessment have been observed. A review of breast cancer survivors found that performance-based testing of cognition was not associated with work outcomes, and inconsistent results were found regarding subjective cognitive impairment (Bijker et al., 2018). Interestingly results from qualitative research found that work-related outcomes were greatly impacted by cognitive impairments which influenced RTW rates and work ability (Banning, 2011).

### *Emotional side effects*

Cancer is a life changing experience, which takes an emotional toll on survivors and their support networks. Fear and worry are common following diagnosis and treatment, and many survivors struggle with fear of recurrence after active treatment (Wu & Harden, 2015). Cancer survivors often experience ongoing psychological distress including anxiety and depression (Banning, 2011; Collins et al., 2013; Feuerstein et al., 2010; Hewitt, Greenfield, Stovall, Medicine, & Council, 2005; Lotfi-Jam, Gough, Schofield, & Aranda, 2014). Psychological distress can further exacerbate cognitive difficulties, which in turn fuels frustration, loss of confidence and depressive-like symptoms (Collins et al., 2013). Similarly, distress may fuel sleep disturbance which was a common and debilitating symptom and associated with poorer work outcomes (Amir et al., 2008; Feuerstein et al., 2010; Munir et al., 2009).

Inconsistent results have been reported on the impact of emotional functioning on work. Quantitative studies of breast cancer survivors reported no association between emotional distress and work outcomes, whilst qualitative studies reported that feelings such as stress, anxiety, frustration, insecurity and low mood were described to influence RTW (Bijker et al, 2018). Confidence was reported to impact RTW and perceived work ability in studies of colorectal cancer (Bains et al., 2012) and mixed cancer populations (Duijts, van der Beek, Bleiker, Smith, & Wardle, 2017; Knott et al., 2014). The impact of emotional distress may be mediated by different coping strategies or social supports available to the individual (Duijts et al., 2017).

## Individual and interpersonal factors

### *Sociodemographic factors*

In studies of mixed cancer populations, men reported greater RTW rates (Mehnert, 2011; van Muijen et al., 2013) and work ability (van Muijen et al., 2013) as well as shorter sickness absence (Marino et al, 2013; Bekker et al, 2009) (Bekker, Rutte, & van Rijswijk, 2009; Marino, Teyssier, Malavolti, & Le Corroller-Soriano, 2013). However, inconsistencies between gender and work outcomes were identified in a review of colorectal cancer studies (den Bakker et al., 2018). Gender differences may have been largely attributed to cancer type and associated treatment regime between men and women. Many of the studies into cancer and work involved survivors of prostate and breast cancer, the latter more commonly undergoing extensive surgery and multimodal treatment. Cultural expectations of men and women may have also played a part in this because men were commonly expected to be the main earner within a household, whilst women were often expected to take on more of the household responsibilities including childcare. The impact of marital status was described to correlate with gender as married men returned to work faster than single men, however married women had longer sickness absence and lower rates of RTW than single women (Cocchiara et al., 2018; Marino et al., 2013). Rates of RTW amongst older survivors were lower compared to younger survivors (Mehnert, 2011; McLennan et al., 2019), however the opposite was true for young adult survivors (Kiasuwa Mbengi et al., 2016). Younger age was associated with more aggressive treatment and higher reported symptom burden, including psychological distress (Shi et al., 2011).

Education was associated with work outcomes, including a higher rate of RTW and shorter sickness absence amongst survivors with tertiary qualifications than those without (Cocchiara et al., 2018; Gordon et al., 2014; McLennan et al., 2019; Mehnert, 2011; Mehnert et al., 2013; Taskila, Martikainen, Hietanen, & Lindbohm, 2007; Vayr et al., 2019). A cohort study of labour participation amongst Australian cancer survivors found that those without a tertiary qualification were 3.73 times more likely to be unemployed than university-educated survivors (Bates et al., 2018). A review of colorectal cancer studies found inconsistent results in the impact of education on work outcomes including RTW rates and work disability (den Bakker et al., 2018).

### ***Income***

A systematic review reported that around half of cancer survivors experienced financial hardship as a result of medical costs and lost income (Altice, Banegas, Tucker-Seeley, & Yabroff, 2017). Paul and colleagues (2016) reported that over two-thirds of cancer survivors either reduced their work hours or left the workforce after treatment, which in turn significantly reduced their household income. Negative financial implications associated with cancer were reported in several studies (Boyages et al., 2016;  Gordon et al., 2017; Kalfa et al., 2018; Knott et al., 2014; Mackenzie, 2014; C. Paul et al., 2016; Pit & Byles, 2012) and more broadly within the community (Koczwara, 2017; Shorten, 2019). Financial necessity was positively associated with RTW rates, however negatively associated with perceived work ability (Islam et al., 2014; Tikka et al., 2017). One Australian study found that survivors who were under financial stress returned to work earlier than they felt able which impacted their safety and productivity at work (Knott et al., 2014).

### ***Motivation***

A systematic review of the behavioural determinants and work identified that most cancer survivors held positive attitudes towards work which facilitated RTW (Duijts, Kieffer, van Muijen, & van der Beek, 2017). The meaning of work was an important mediating factor in RTW (Duijts et al., 2017) which changed throughout survivorship. Initially work provided a source of distraction from cancer, then became a symbol of normalcy and regaining control (Amir et al., 2008; Banning, 2011; Kalfa et al., 2018; Wells et al., 2013). Survivors saw returning to work as an important indicator of their recovery, and integral part of their self-identity (Duijts et al., 2017; Banning, 2011). Conversely, some survivors reassessed the importance of work within their lives (Duijts et al., 2014; Wells et al., 2013) and reduced the importance of work as a stress-management strategy (Mackenzie, 2014). Negative experiences during RTW led to a revision of the meaning of work (Wells et al., 2013). For some, returning to work was not as fulfilling as hoped, because of changed life priorities or reduced functioning. Consequently, being diagnosed with cancer often resulted in frustration in spending valuable time at work (Wells et al., 2013).

### Work environment

Several aspects of the work environment influenced work-related outcomes including work demands, work conditions, relationships at work and employer accommodations (Mehnert et al., 2013; Spelten et al., 2002; Steiner et al., 2010; van Muijen et al., 2013). Physically demanding work was associated with lower RTW and longer sickness absence (Bouknight et al., 2006; Cocchiara et al., 2018; McLennan et al., 2019; Mehnert & Koch, 2013; Steiner et al., 2010; van Muijen et al., 2013). Survivors who were employed in manual work reported poorer work ability (Cocchiara et al, 2018; Steiner et al., 2010; van Muijen et al., 2013). In particular, difficulty with stooping and lifting were reported (Dujits et al, 2014). Productivity demands also influenced RTW and perceived work ability as survivors reported difficulties managing face-paced or stressful work along with cancer recovery (Cocchiara et al, 2018; Steiner et al., 2010; Duijts et al., 2014; Bradley et al., 2007; Georgiou-Kita, 2016). Survivors who worked in roles with high levels of responsibility, including making ‘high-stakes' decisions, reported difficulty returning to work (Wang et al., 2018), in particular in negotiating workplace accommodations (Stergiou-Kita et al., 2016). For survivors who underwent extensive surgery (Islam et al., 2014; Spelten et al., 2002) including amputation, treatment-induced hair loss (Banning et al., 2011; Bouknight et al., 2006), and lymphedema (Kalfa et al., 2018) continuing to work in client-facing roles was challenging.

#### *Supportive workplace is a key facilitator RTW*

A supportive workplace facilitated RTW and perceived work ability (Greidanus et al., 2018; Islam et al., 2014; Kiasuwa Mbengi et al., 2016). Conversely, an unsupportive workplace which was rigidly structured or competitive was a barrier to work participation. Accommodation by the employer was considered highly influential in RTW (Bouknight et al., 2006; Duijts, Kieffer, et al., 2017; Greidanus et al., 2018; Tikka et al., 2017) including offering flexible work arrangements and reduced working hours (Tikka et al., 2017). Survivors who had discretion over their working hours and work tasks reported better work outcomes than those that feel that they had no control (Tikka et al, 2017; Tiedtke et al, 2010). Consultation and a degree of control over workplace adjustments was an important factor in work participation. A qualitative study of the role of employers and workplace accommodations found that negotiating a graduated RTW plan, which suited the individual needs of the cancer survivor and the business, was a key facilitator for RTW (Stergiou-Kita et al., 2016).

Workplace relationships influenced work outcomes including RTW rates and length of sickness absence (Amir et al., 2008; Armaou, Schumacher, & Grunfeld, 2018; Greidanus et al., 2018; Kiasuwa Mbengi et al., 2018). This was particularly true for survivors who worked for their employer for a long period of time (Amir et al., 2008). Communication and connection between survivors and their employer was associated with work outcomes (Greidanus et al., 2018). Open and frequent communication through non-invasive channels such as email or phone calls facilitated work participation, particularly when interactions were positive, respectful and personal (Greidanus et al., 2018). A qualitative study of Australian cancer survivors found that maintaining connection was an important driver to returning to work, as it prepared survivors for transitioning back to work, provided a source of social interaction and enhanced feelings of connection with colleagues (McKay et al., 2013). Keeping in contact during leave from work enabled better understanding of the survivor's health and work capacity and was positively associated with work outcomes (Kennedy, Haslam, Munir, & Pryce, 2007). Conversely, cancer survivors who did not have regular contact with their employer or colleagues reported longer time to RTW and more negative attitudes towards work (Amir et al., 2008).

### *Advice about returning to work*

Limited evidence exists about the role of healthcare professional in supporting work participation of cancer survivors (Mehnert et al., 2013). Qualitative studies in the UK found that survivors received little advice from medical professionals about returning to work (Amir et al., 2008; Kennedy et al., 2007). One British study showed that around half of survivors received advice from their doctor about work, with less than a quarter receiving information about managing ongoing health issues at work (Pryce, Munir, & Haslam, 2007). Importantly, those who received advice had higher rates of RTW. A study of British health professionals, including oncologists, occupational health physicians and general practitioners, found that information offered to cancer survivors about work was limited and conflicting (Bains et al., 2011). Participants tended to provide generic advice about managing ongoing health conditions and 'common sense' inferences about one's ability to meet work demands. The absence of clinical guidelines and few resources to support decision making were reported as key barriers to supporting work participation. A recent survey of Australian occupational therapists working in cancer care reported that few addressed work participation in their practice, despite occupational therapists being well placed to support work participation and recovery of valued life roles (Buckland & Mackenzie, 2017).

## Conclusion

Cancer has a dramatic and enduring effect on the lives of survivors, families and communities. Returning to work represents an important recovery milestone for cancer survivors, and provides mental, physical, social and financial health benefits. However, many survivors have difficulty managing personal, cancer and work-related factors which impact their ability to participate in paid work. Employers face numerous challenges in supporting survivors in the workplace and facilitating their RTW. Whilst there is substantial evidence internationally, Australian cancer survivors are under-represented in peer-reviewed research. Despite having a high incidence of cancer and the world's highest cancer survival rate, there is little understanding about how Australian cancer survivors navigate working through cancer. This review has highlighted the complexity of cancer survivorship and work and the need for further research in this field, particularly in the Australian context.

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# SECTION II: JOURNAL MANUSCRIPT

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## Title: Working with cancer: a pilot study of work participation amongst cancer survivors in Western Sydney.

| | |
|---|---|
| **Target Journal:** | The Australian Journal of Occupational Therapy<br>(see Author Guidelines, appendix II) |
| **Authors:** | Cresta Markovic<br>A/Prof Lynette Mackenzie<br>Jo Lewis<br>Michelle Singh |
| **Institution:** | The University of Sydney<br>Faculty of Health Sciences<br>75 East Street, Lidcombe<br>NSW, 2141 |
| **Short title:** | Pilot study of work after cancer in Western Sydney |
| **Funding:** | This project was carried out without project funding. |
| **Conflict of interest:** | The authors declare no conflict of interest. |
| **Word length:** | 4,891 |
| **Word length abstract:** | 298 |
| **References:** | 35 |
| **Number of tables:** | 1 |
| **Number of figures:** | 1 |
| **Corresponding author:** | cmar3065@uni.sydney.edu.au<br>Lynette.mackenzie@sydney.edu.au |
| **MeSH terms** | Cancer survivor<br>Return to Work<br>Australia<br>Pilot Projects<br>Occupation |

# Abstract

**Background:** Around forty percent of cancer diagnoses occur in working-age adults. Improvements in screening and treatment means that most are expected to live years beyond their diagnosis. However, many experience persistent impairments from treatment such as fatigue, cognitive difficulties and emotional distress. Work is a key occupation for this population yet little is understood about working with cancer in the Australian context.

**Aim:** This pilot study aims to investigate work participation amongst cancer survivors in Western Sydney and identify factors associated with returning to work.

**Methods:** A cross-sectional online survey was developed to measure work participation and factors associated with work. Study participants aged 20-65 years, employed at diagnosis, with basic English and computer literacy were recruited from a cancer clinic in Western Sydney over a three-month period.

**Results**: Nineteen survey responses were received and analysed. Participants had returned or remained at work (*n*=9, 47.4%), unsuccessfully attempted to return to work (RTW) (*n*=2, 10.5%), or were on leave from work (*n*=8, 42.1%). Of those on leave most did not plan to RTW (*n*=6, 31.6%). Fatigue (*n*=15, 78.9%), difficulty concentrating (*n*=8, 42.1%), memory issues (*n*=8, 42.1%), stomach upset (*n*=7, 36.8%), sleep disturbance, (*n*=7, 36.8%), and psychological distress (*n*=7, 36.8%) impacted perceived work ability. Physically demanding work (*n*=8, 42.1%), length of workday (*n*=6, 31.6%), productivity demands (*n*=5, 26.3%) and commuting (*n*=4, 21.1%) were challenging to manage after cancer. Approximately a quarter of participants reported discussing RTW with people other than their employer (*n*=5, 26.3%). A supportive workplace was a facilitator for work, whereas a non-supportive workplace was considered a major barrier. Overall participants reported positive attitudes towards work.

**Conclusion:** Cancer survivors in Western Sydney may face challenges engaging in work after treatment. Work participation may be influenced by side effects of treatment, difficulty performing work demands and the work environment.

## Background

Cancer is a leading cause of illness in Australia and has a substantial social and economic impact on individuals, their families and communities (AIHW, 2019). Improvements in screening and treatment means that more survivors are expected to live longer, however, for many surviving cancer it means living with a chronic and complex condition (AIHW, 2019; Maytal & Peteet, 2009). In 2019 it is estimated that over 57,000 new cancer diagnoses will occur in Australians aged 20-65, of which 83.9% are expected to live at least 5 years post diagnosis (AIHW, 2019). Work represents a key occupation for this population, however, little is known about how work is impacted by cancer in the Australian context.

Work is integral to self-identity and provides a sense of purpose, social interaction and income (Maytal & Peteet, 2009; Wells et al., 2013). It also provides benefits in physical and mental health, and can help aid recovery (Comcare, n.d.). For cancer survivors, returning to work may represent a significant recovery milestone and provides a sense of normalcy and regaining control (Duijts, van Egmond, Gits, van der Beek, & Bleiker, 2017; McKay, Knott, & Delfabbro, 2013; Wells et al., 2013). Importantly, cancer survivors who do not participate in paid work report higher symptom burden (Shi et al., 2011) and lower quality of life outcomes (Beesley, Vallance, Mihala, Lynch, & Gordon, 2017) than those who are working.

The 'cancer survivorship and work model' (Mehnert, de Boer, & Feuerstein, 2013, p. 2154) provides a framework to guide research and intervention of cancer and work. The model was developed through a collaboration of leading researchers in the survivorship field. The model categorises factors associated with cancer survivorship and work into four key areas including individual and interpersonal, effects of cancer and treatments, the work environment and work-related outcomes. The model acknowledges the complexity of cancer survivorship as being unique to the individual and the interconnectedness of personal and contextual factors which may impact work participation after cancer.

Most cancer survivors are able to return to work (RTW), however a significant minority do not. Evidence from international research indicates that around 40% of survivors do not RTW (Duijts et al., 2014; Mehnert, 2011; Spelten, Sprangers, & Verbeek, 2002). Many survivors who are able to resume work, experience impaired work ability due to ongoing side effects from treatment, impacting the longevity of their employment and career progression (Duijts et al., 2017). Cancer is associated with unemployment (De Boer, Taskila, Ojajärvi, Van Dijk, & Verbeek, 2009) and underemployment (Mehnert, 2011).

Emerging evidence indicates that Australian cancer survivors experience issues remaining in or returning to work. A cohort study using population data from the 2015 National Survey of Ageing, Disability and Carers found that almost half of cancer survivors were not in the labour force (Bates, Callander, Lindsay, & Watt, 2018). This was double the rate of unemployment of people with other chronic illness and three times that of people without chronic illness. A study of middle-aged colorectal cancer survivors in Queensland found that 27% had stopped working and a further 19% had reduced to part-time work (Gordon et al., 2014). Compared to survivors who remained in or returned to previous work roles, unemployed survivors reported lower functional wellbeing and quality of life (Beesley et al., 2017).

Many cancer survivors require extended leave from work during treatment, however few people are entitled to extended paid sick leave or insured to cover long absences (Kalfa et al., 2018; McKay et al., 2013). Exiting the labour force early or taking extended periods of leave contributes to the financial toxicity associated with cancer. A study by Paul and colleagues reported that over two-thirds of cancer survivors either reduced their work hours or left the workforce all together after treatment, which in turn significantly reduced their household income (Paul et al., 2016). Negative financial implications associated with cancer have been reported in several studies (Knott et al., 2014; Mackenzie, 2014; Paul et al., 2016). On a larger scale, it is estimated that each year the Australian economy loses $1.7 billion dollars in GDP due to lost productivity associated with cancer survivors exiting the workforce (Bates et al., 2018).

Cancer care services in Australia are primarily focused on acute medical treatment and surveillance, with few cancer rehabilitation services available to support management on ongoing health issues (Lisy et al., 2018). Health professionals involved in cancer care provide conflicting and limited advice to cancer survivors regarding work, and there are no clinical guidelines to support practice in this area  (Bains, Yarker, Amir, Wynn, & Munir, 2012). A recent survey of Australian occupational therapists working in oncology found that few addressed RTW in their practice despite work being a key occupation for people in early and middle adulthood (Buckland & Mackenzie, 2017). In addition, the Australian occupational rehabilitation system is largely geared towards injury management, with few services providing support for people with non-compensable illness or injury such as cancer. Of these services, there is little information on their availability and use.

Cancer survivors face many challenges in managing their health and wellbeing through and beyond cancer. Survivorship is increasingly being recognised as an additional part of the cancer care continuum (Lisy et al., 2018). The Australian government recently developed a national framework to guide policy and service delivery to support the ongoing health and wellbeing of cancer survivors (Cancer Australia, 2017). Returning to daily activities, such as paid employment, is an important part of their recovery. However, few studies have explored cancer survivorship and work in the Australian context. This research asks how cancer impacts work participation in the Australian context. The study aims to pilot a survey to identify factors associated with work participation amongst cancer survivors. Achieving this aim may contribute to the development of screening tools to identify cancer survivors at risk of poor work outcomes, and provide direction for the development of interventions to support their engagement in work after cancer.

## Methods

A cross-sectional online survey was developed and piloted through this study. The survey was an anonymous, self-report measure, designed to gather quantitative data on work participation and factors associated with work outcomes within the sample population. Ethics approval for this project was obtained (WSLHD Research Office number: 2019/PID11106 – 6077; HREC reference number: 2019/ETH09889; SSA reference number: 2019/STE13285).

### ***Participants and Recruitment***

Participants were recruited from an outpatient cancer clinic in Western Sydney. This site was selected as the local government area has a high incidence of cancer and also has a diverse population (AIHW, 2019). Clinical cases for three month period were obtained and patient records were screened for eligibility by oncology staff. Individuals were invited to participate in the study via telephone calls with oncology staff. Eligibility criteria for participants included being aged 20-65 years old, having received a primary cancer diagnosis, been employed at the time of diagnosis or actively looking for work and basic English and computer literacy. Participants were excluded if they had co-morbid conditions which may impact work participation or where their wellbeing may be at risk. Participants who agreed to participate were emailed the Participant Information Sheet and link to the survey. Consent to participate was obtained in the first and final survey items.

### ***Survey development***

Survey items were developed following a review of international and Australian literature on cancer and RTW. The content of the survey sought to obtain cancer- and work-related data, sociodemographic data, and attitudes towards work. The survey was comprised of 58 questions containing 124 data variables, including treatment modalities, treatment side effects, work demands, workplace adjustments, expectations of work ability, and the meaning of work after cancer. The items were designed to quantify key factors identified in the literature (Mehnert et al., 2013; Spelten et al., 2002; van Muijen et al., 2013; Wells et al., 2013) and provide the opportunity for responders to describe additional factors not provided. Underpinning the survey design was the theoretical 'cancer survivorship and work' model (Mehnert et al., 2013). The survey was developed by experienced researchers with expertise in cancer and workplace rehabilitation (LM, JL) and an occupational therapy Masters student. The content validity of the questionnaire was evaluated by researchers with expertise in the field of cancer rehabilitation who reviewed the content and provided feedback. The survey was pre-piloted with three cancer survivors to test face validity and content validity of the survey items. Adjustments to the survey phrasing and flow were made based on their feedback.

### *Data collection and analysis*

Survey data was collected in a secure password-protected software program 'Qualtrics'. Survey data was downloaded into SPSS for analysis. Descriptive statistics were used to analyse the data using frequency distribution in numbers and percentages for each variable. Mean and confidence interval measurements were used for continuous data.

## Results

A total of 161 patient records were screened for eligibility in the study, however around half were excluded based on age (*n*=83). In addition some did not meet the basic English (*n*=3) or digital literacy criteria (*n*=3), declined to participate (*n*=4) or were not contactable (*n*=30). Study information was emailed to 38 potential participants, of which 21 survey responses were submitted within the study period. Two survey responses were excluded as the respondents were not employed or actively looking for work at the time of diagnosis. Nineteen survey responses were included for analysis.

A further three survey responses had been initiated but not completed over the study period. These were not included in analysis. The time spent on the survey ranged from two to eight minutes.

***Table 1***

*Summary of participant and work characteristics.*

| | ***Total Sample n* (%)** | ***Working Sample n* (%)** | ***Leave Sample n* (%)** |
|---|---|---|---|
| Participants | 19 | 9 | 8 |
| Male | 5 (26.3) | 1 (11.1) | 4 (50.0) |
| Female | 14 (73.7) | 8 (88.9) | 4 (50.0) |
| Age *years [95% CI]* | 51.0 [44.7, 55.7] | 53.3 [48.0, 58.6] | 50.1 [40.9, 59.4] |
| Male | 55.3 [48.1, 62.4] | | |
| Female | 49.7 [43.7, 55.7] | | |
| Partner at home | 14 (73.7) | 6 (66.7) | 6 (75.0) |
| Partner employed | 9 (47.4) | 4 (44.4) | 3 (37.5) |
| Unpaid work *hrs/week* [95% CI] | 14.7 [6.4, 23.0] | 10.6 [2.5, 18.4] | 15.0 [-1.5, 31.5] |
| Carer | 8 (42.1) | 3 (33.3) | 3 (37.5) |
| School aged | 4 (21.1) | 2 (22.2) | 1 (12.5) |
| Adult/Elderly/Other | 4 (21.1) | 1 (11.1) | |
| Education | | | |
| Year 10 | 6 (31.6) | 3 (33.3) | 3 (37.5) |
| Vocational training | 4 (21.1) | 2 (22.2) | 2 (25.0) |
| Diploma | 5 (26.3) | 3 (33.3) | |
| Bachelor Degree | 3 (15.8) | 1 (11.1) | 2 (25.0) |
| None of these apply | 1 (5.3) | | 1 (12.5) |
| Income protection insurance | 8 (42.1) | 4 (44.4) | 3 (37.5) |
| Cancer | | | |
| Breast | 11 (57.9) | 6 (66.7) | 4 (50.0) |
| Prostate | 2 (10.5) | 1 (11.1) | 1 (12.5) |
| Colorectal | 1 (5.3) | 1 (11.1) | |
| Lung | 1 (5.3) | | 1 (12.5) |

| | | | |
|---|---|---|---|
| Brain | 1 (5.3) | | 1 (12.5) |
| Head and neck | 1 (5.3) | | 1 (12.5) |
| Uterus | 1 (5.3) | 1 (11.1) | |
| Unknown | 1 (5.3) | | |
| Time since diagnosis | | | |
| <6 months | 9 (47.4) | 3 (33.3) | 6 (75.0) |
| 7-12 months | 3 (15.8) | 1 (11.1) | |
| 13-18 months | 4 (21.1) | 3 (33.3) | 1 (12.5) |
| 19+ months | 5 (26.3) | 2 (22.2) | 1 (12.5) |
| Treatment schedule | | | |
| Awaiting to start | 2 (10.5) | 1 (11.1) | 1 (12.5) |
| Currently undergoing | 9 (47.4) | 2 (22.2) | 6 (75.0) |
| Break between cycles | 1 (5.3) | 1 (11.1) | |
| Finished | 7 (36.8) | 5 (55.6) | 1 (12.5) |
| Treatment modality* | | | |
| Surgery | 15 (78.9) | 6 (66.7) | 8 (100.0) |
| Chemotherapy | 11 (57.9) | 4 (44.4) | 6 (75.0) |
| Radiation | 12 (63.2) | 6 (66.7) | 5 (62.5) |
| Immunotherapy | 2 (10.5) | 1 (11.1) | 1 (12.5) |
| Hormone | 8 (42.1) | 6 (66.7) | 2 (25.0) |
| Target | 5 (26.3) | 2 (22.2) | 2 (25.0) |
| Combination | 15 (78.9) | 7 (77.8) | 7 (87.5) |
| Other comorbidities | 6 (31.6) | 4 (44.4) | 2 (25.0) |
| Permanent employment | 15 (78.9) | 7 (77.8) | 6 (75.0) |
| Temp/casual | 4 (21.1) | 2 (22.2) | 2 (25.0) |
| Work, *hours /week [95% CI]* | 35.6 [29.8, 41.5] | 34.2 [24.5, 43.9] | 37.3 [28.4, 46.1] |
| Male | 45.0 [40.0, 51.0] | | |
| Female | 33.0 [28.0, 38.0] | | |
| Length of employment, years *[95% CI]* | 8.3 [4.5, 12.1] | 10.7 [5.1, 16.4] | 5.2 [-0.6, 11.0] |

| | | | |
|---|---|---|---|
| Size of employer (number of employees) | | | |
| Less than 20 | 4 (21.1) | 1 (11.1) | 2 (25.0) |
| 20-100 | 3 (15.8) | 2 (22.2) | 1 (12.5) |
| Over 100 | 12 (63.2) | 6 (66.7) | 5 (62.5) |
| Work schedule* | | | |
| Early morning | 10 (52.6) | 5 (55.6) | 4 (50.0) |
| Standard business hours | 8 (42.1) | 4 (44.4) | 4 (50.0) |
| Evening shift | 3 (15.8) | 1 (11.1) | 2 (25.0) |
| Night shift | 3 (15.8) | | 3 (37.5) |
| Rotating roster | 3 (15.8) | 1 (11.1) | 2 (25.0) |
| Split shifts | 1 (5.3) | 1 (11.1) | |
| None | 1 (5.3) | 1 (11.1) | |
| Workplace | | | |
| Office | 7 (36.8) | 4 (44.4) | 1 (12.5) |
| Construction site | 2 (10.5) | 2 (22.2) | |
| University, school | 1 (5.3) | 1 (11.1) | |
| Hospital/medical centre | 2 (10.5) | 1 (11.1) | 1 (12.5) |
| Retail space | 1 (5.3) | 1 (11.1) | |
| Warehouse | 2 (10.5) | | 2 (25.0) |
| Factory | 2 (10.5) | | 2 (25.0) |
| Home office | 1 (5.3) | | 1 (12.5) |
| Other | 1 (5.3) | | 1 (12.5) |
| Work participation since diagnosis | | | |
| Continued working | 2 (10.5) | 2 (22.2) | |
| Leave during treatment | 7 (36.8) | 4 (44.4) | 2 (25.0) |
| Reduced hours during treatment | 3 (15.8) | 3 (33.3) | |
| Resigned | 3 (15.8) | | 3 (37.5) |
| Redundancy | 3 (15.8) | | 2 (25.0) |
| Retirement | 1 (5.3) | | 1 (12.5) |

| | | | |
|---|---|---|---|
| Days of leave *[95% CI]* | 109.4 [44.8, 173.9] | 112.4 [11.5, 213.4] | 106.5 [-0.4, 213.4] |
| Leave entitlements | | | |
| Paid personal leave | 11 (57.9) | 7 (77.8) | 2 (25.0) |
| Unpaid personal leave | 8 (42.1) | 5 (55.6) | 3 (37.5) |
| Annual leave | 9 (47.4) | 6 (66.7) | 3 (37.5) |
| Long-service leave | 3 (15.8) | 3 (33.3) | |
| No access to leave | 2 (10.5) | | 2 (25.0) |
| I have not accessed leave | 1 (5.3) | | |
| Discussed RTW with other | 5 (26.3) | 3 (33.3) | 1 (12.5) |
| Symptoms which impact work ability | | | |
| Fatigue | 15 (78.9) | 8 (88.9) | 6 (75.0) |
| Muscle weakness | 6 (31.6) | 3 (33.3) | 3 (37.5) |
| Problems with memory | 8 (42.1) | 4 (44.4) | 3 (37.5) |
| Difficulty concentrating or maintaining attention | 8 (42.1) | 4 (44.4) | 3 (37.5) |
| Difficulty learning and remembering information | 2 (10.5) | 1 (11.1) | 1 (12.5) |
| Difficulty with decision making | 2 (10.5) | 1 (11.1) | |
| Stomach upset | 7 (36.8) | 3 (33.3) | 3 (37.5) |
| Pain | 4 (21.1) | 2 (22.2) | 2 (25.0) |
| Incontinence | 1 (5.3) | | 1 (12.5) |
| Tingling hand or feet | 3 (15.8) | | 3 (37.5) |
| Sleep problems | 7 (36.8) | 4 (44.4) | 2 (25.0) |
| Psychological distress | 7 (36.8) | 3 (33.3) | 3 (37.5) |
| Limb swelling | 2 (10.5) | 2 (22.2) | |
| Dry/weepy eye | 3 (15.8) | | 3 (37.5) |
| Mucositis | 1 (5.3) | | 1 (12.5) |
| Other | 1 (5.3) | 1 (11.1) | |
| None | 3 (15.8) | 1 (11.1) | 1 (12.5) |

| | | | |
|---|---|---|---|
| Challenging work demands | | | |
| Physically demanding tasks | 8 (42.1) | 3 (33.3) | 5 (62.5) |
| Cognitively demanding tasks | 2 (10.5) | | 1 (12.5) |
| Length of work day | 6 (31.6) | 2 (22.2) | 4 (50.0) |
| Interacting with customers | 1 (5.3) | | 1 (12.5) |
| Interacting with co-workers | 2 (10.5) | | 1 (12.5) |
| Productivity demands | 4 (21.1) | 1 (11.1) | 4 (50.0) |
| Workspace | 2 (10.5) | | 2 (25.0) |
| Commute | 4 (21.1) | 1 (11.1) | 3 (37.5) |
| Other | 3 (15.8) | 2 (22.2) | 1 (12.5) |
| Workplace adjustments offered | | | |
| Flexible work hours | 3 (15.8) | 2 (22.2) | |
| Reduced hours | 8 (42.1) | 7 (77.8) | |
| Reduced days | 2 (10.5) | 1 (11.1) | |
| Adjusted workload | 2 (10.5) | 1 (11.1) | |
| Working from home | 4 (21.1) | 3 (33.3) | |
| Increased breaks | 2 (10.5) | 2 (22.2) | |
| Counselling support | 1 (5.3) | 1 (11.1) | |
| None | 1 (5.3) | | |

*Indicates where respondents were able to select multiple responses.

### ***Participant characteristics***

A summary of participant characteristics is provided in Table 1. The majority of participants were female (73.7%), breast cancer survivors (57.9%). The average age of participants was 51 years, however male participants were older on average than female participants. Gender differences were also evident between the amount of unpaid work performed each week (Male mean 4.8, 95% CI [-6.5, 16.0]; Female mean 17.8, 95%CI [7.5, 28.0]) and caring responsibilities (Male *n*=1, Female *n*=7). Around half of the respondents (47.4%) reported that cancer had either moderately or greatly impacted their ability to do paid work, regardless of the hours performed each week. More than half of the participants did not have private income protection insurance (57.9%).

The time since diagnosis ranged from 2-29 months (mean 11 months, 95% CI [4.5, 11.8]), and almost half of participants were currently undergoing treatment. Surgery was the most common treatment intervention, followed by radiation therapy, chemotherapy and hormone therapy. Almost all participants received multimodalities of treatment (84.2%). Six participants described having comorbidities including endometriosis, soft tissue injury to foot, atrial fibrillation, dystonia and chronic gastritis.

### ***Work characteristics***

Most respondents were employed in permanent positions (78.9%), none were self-employed. Most respondents worked in large companies (63.2%) in permanent employment (78.9%) and had worked for their employer for several years (8.3 years, 95% CI[4.7, 11.1]). The average number of hours worked each week was 35.6 (95% CI [29.8, 41.5]), however men worked more on average (45.0 hours, 95% CI [40.0, 51.0]) than women (33.0, 95% CI [28.0, 38.0]). Half of the respondents reported their work schedule included early morning starts (52.6%) and regular business hours (52.6%). Other schedules included a combination of evening shifts, night shifts and rotating rosters (15.7%). Participants worked across a range of industries including transport (n=4, 21.1%), healthcare (*n*=3, 15.8%), manufacturing (*n*=2, 10.5%), administration (*10.5%*) and others (*n* =8, 42.1%). Participants reported a range of work demands involved in their pre-diagnosis employment including combinations of fast-paced work (*n* =11, 57.9%), computer-based work (57.9%), team work (*n*=10, 52.6%), speaking over the phone or in person (52.6%), physically demanding tasks (*n* =9, 47.4%), long periods of concentration (*47.4%*), lifting more than 5 kg (*n* =8, 42.1%), customer facing (*n* =7, 36.8%), frequent lifting (*n* =5, 26.3%), standing and sitting for long periods (*47.4%*), frequent bending/twisting/reaching (*42.1%*), climbing stairs (*26.3%*), driving (*n* =6, 31.6%), and operating machinery (*n* =4, 21.0%). Respondents worked across a range of work environments including construction sites, warehouses, factories and medical environment, whilst the most common workplace was an office environment (*n* =7, 36.8%). Almost all participants drove themselves to work and on average commuted for under an hour (48.7 minutes, 95% CI [25.5, 72.0]).

### *Work participation*

Since their diagnosis participants had taken leave from work during treatment (*n* =7, 36.8%), planned to resign, retire or accept redundancy (*n* =7, 36.8%) or were able to continue working throughout treatment at reduced (*n* =3, 15.8%) or usual hours (*n* =2, 10.5%). At the time of the survey, around half of participants had returned to work or remained at work (*n*=9, 56%). A similar portion had not returned to work (*n* =8, 42.1%), and most of these participants indicated that they planned to resign, retire or take redundancy (*n* =6, 75.%). Reasons given for exiting the workforce included feeling unwell during treatment, having a change of priorities, being unable to drive, ongoing continence issues, physical limitations, and workplace changes. Two respondents indicated that they had tried to RTW but were unable to keep working. Their data is described separately below.

Participants reported several side effects of cancer treatment that impacted their perceived work ability. Fatigue was the most commonly reported symptom (78.9%), followed by problems with memory (42.1%), difficulty concentrating or maintaining attention (42.1%), stomach upset (36.8%), sleep problems (36.8%), psychological upset (36.8%) and muscle weakness (31.6%).

Several work demands were reported to be challenging, or perceived to be challenging after cancer treatment including physically demanding tasks (42.1%), length of work day (31.6%), productivity demands (21.2%), and commuting (21.2%). Workplace adjustments which had been offered to survivors who returned to work included reduced hours (77.8%), option to work from home (33.3%), flexible work hours (22.2%) and increased breaks (22.2%).

### *Comparison between those who returned to work and those who were on leave*

Participants who returned to work were slightly older (53 yrs, 95% CI [47, 60]) and performed less unpaid work (10.6 hours per week 95% CI [2.5, 18.4]) than those who were on leave (50.1

years, 95%CI [40.9, 59.4]; 15.0 hours per week, [-1.5, 31.5]). Participants who were on leave had a range of cancer sites, including breast, prostate, lung, brain and head and neck cancers. Most were currently undergoing treatment (75.0%), whereas most that returned to work had already finished treatment (55.6%). All respondents who were on leave underwent surgery, and most had chemotherapy (75.0%) and/or radiation (62.5%). Two respondents in this group also had hormone and targeted therapies in addition. Most participants who returned to work had undergone combinations of surgery (66.7%), radiation therapy (66.7%) and hormone therapy (66.7%). Less than half had undergone chemotherapy (44.4%).

People who were on leave worked slightly longer hours (37.3, 95% CI[28.4, 46.1]) than those who returned to work (34.2 hours, 95% CI [24.5, 43.9]). People who returned to work had worked for their employer longer an average (11 years, 5,16). Both groups had similar length of commute (Working sample 49.8 minutes, 95% CI [8.6, 91.0]; Leave sample 51.3 minutes, [20.4, 82.1]). No participants who performed night work in their typical work schedule returned to work. The length of leave was slightly higher amongst the group who returned to work (112.4 hours, 95% CI [11.5, 213.4]) than those on leave (106.5 hours, 95% CI [-0.4, 213.4]), however this was largely skewed by three participants who took long periods of leave before returning to work (180, 270 and 365 days). Most people who returned to work accessed paid personal leave (77.8%), as well as annual leave (66.7%) and unpaid leave (55.5%).

### *Negotiating RTW*

All participants who returned to work indicated that they were satisfied with their RTW plan. Factors which contributed to this included having supportive management, flexibility in accessing leave and returning when ready, and being mindful of their limits. One participant reported difficulty managing disclosure and providing education to her employer about cancer survivorship. She indicated that having educational resources to provide to her employer to mediate the process would have been helpful. Many participants who were on leave indicated that they had not discussed their RTW plan with their employer (*n*=5, 62.5%). The main reason for this was that they did not plan to RTW after cancer, or were unable to complete the physical or driving tasks associated with their work. Around a quarter of all participants reported discussing

RTW with people outside of their employer. People consulted in these conversations included their general practitioner, surgeon, oncologist, psychologist and family and friends.

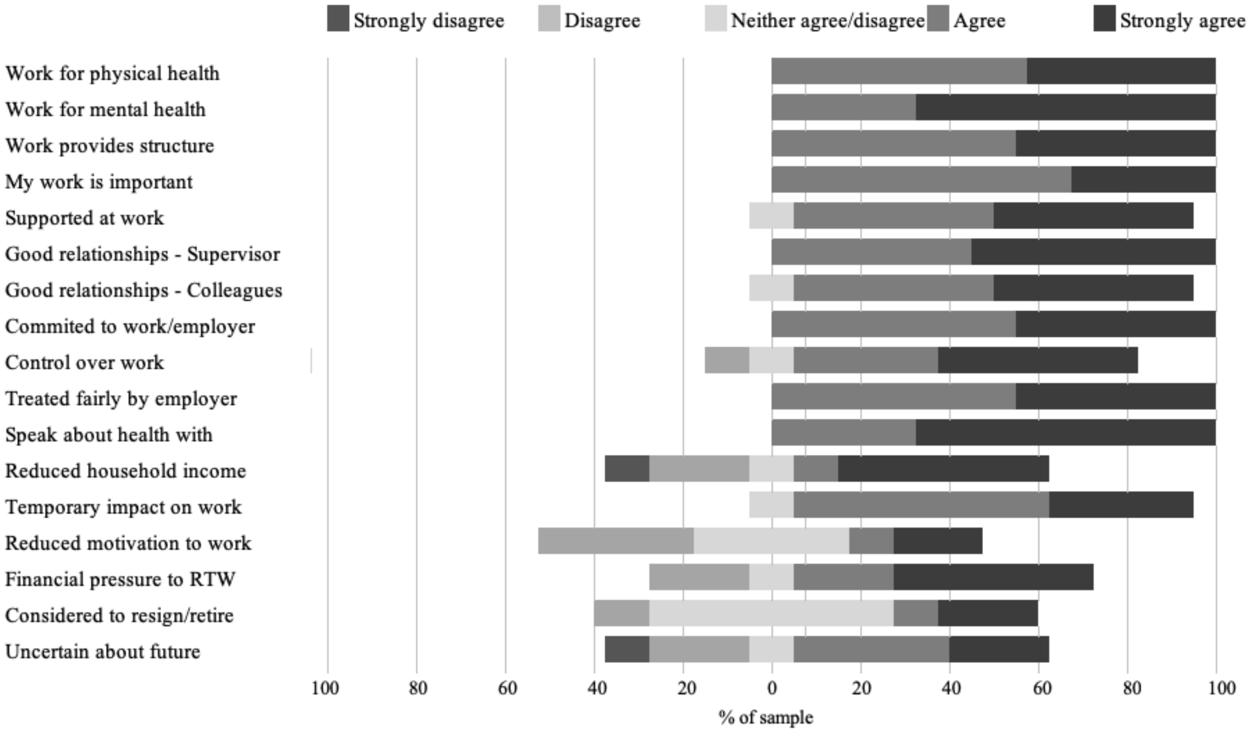
### *Attitudes towards work*

Participants who returned to work reported mostly positive attitudes towards work, including personal importance of work, mental and physical health benefits, and providing structure (Figure 1). These participants also indicated that had good relationships at work, were committed to their work and employer and felt that employees who were unwell were treated fairly. Participants who had not returned to work reported more ambivalence towards work, however most agreed that work provided mental and physical health benefits (Figure 1). One participant who was on leave indicated she had an unsupportive workplace, poor relationships with management and limited control over her work. Most participants on leave strongly agreed that cancer had reduced their household income (75.0%), however most either disagreed or were ambivalent about financial pressures to RTW.

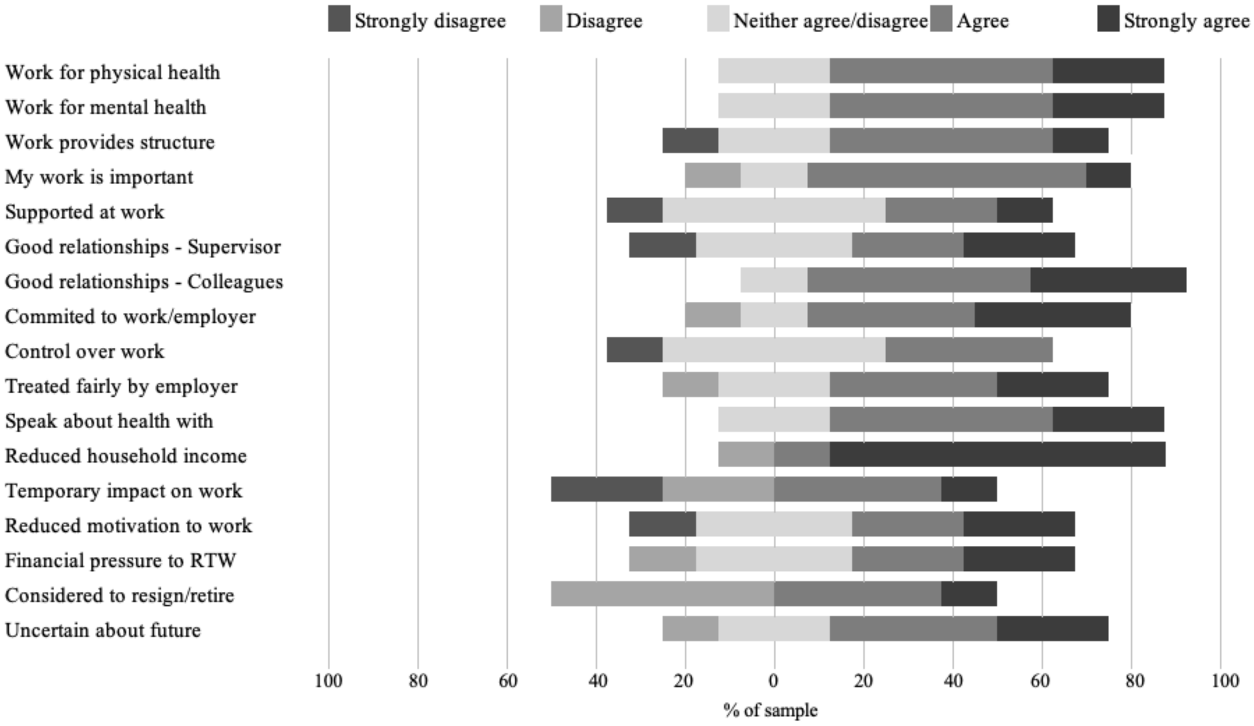
***Figure 1***

*Comparison of attitudes towards work and impact of cancer amongst cancer survivors who returned to work and those who were on leave.*

A) Work attitudes of cancer survivors who have remained at or returned to work since diagnosis (*n* =9)



B) Work attitudes of cancer survivors who had not returned to work since diagnosis (*n* =8)



### *Survivors who had unsuccessfully tried to RTW*

Two participants, referred here as Participant A and B respectively, reported to have tried to RTW but were unsuccessful. Both participants were female, lived with a partner who was also employed and had caring responsibilities. Both women had completed a diploma, were employed in a permanent role in an office environment and had accessed paid personal leave during treatment.

Participant A was still undergoing treatment for carcinoma of unknown primary which had been diagnosed five months prior. She received multiple therapies including surgery, chemotherapy and radiation therapy. Participant A was 48 years old and a mother to a school-age child. She had tried to RTW in an administrative role during treatment, however reported difficulties managing fatigue, nausea and cognitive impairment whilst at work. She also reported difficulty with sleep and psychological distress which impacted her ability to work. Participant A reported having a flexible and supportive workplace, and had been offered to reduce her work schedule, work from home, and adjust her workload. She had sought advice about returning to work as she had advanced disease however did not describe further details of this discussion. She reported positive attitudes toward her work and good relationships with colleagues and management. She did not need to RTW for financial reasons, and reported being concerned about her future as a result of her cancer.

Participant B, 58 years old, had been diagnosed with breast cancer over two years prior and had finished treatment. She cared for an elderly relative and reported spending 60 hours per week in unpaid work. She had worked for a small business for eight years in the healthcare industry. Participant B reported trying to RTW however her position was made redundant shortly after. She reported that her employer had not informed her of the reasons for the redundancy or supported her to transition to another role or employer. Participant B reported that no side effects of treatment impacted her work ability, however she had difficulty managing relationships with co-workers after her RTW. She indicated several negative attitudes towards her work including poor relationships with colleagues and management, having little control over work, feeling her employer treated unwell staff unfairly and feeling uncomfortable to talk to management about her health. She indicated that her cancer diagnosis had reduced her household income and she needed to RTW for financial reasons.

## Discussion

The aim of this pilot study was to describe work participation in a Western Sydney cancer survivor population and identify potential factors associated with work participation. To the authors' knowledge this is the first quantitative study of work and cancer survivorship within the Sydney region. Participants in this study reported working across a variety of industries, work environments and performed a range of work demands. The high completion rate of the survey indicated that the survey was acceptable, with few incomplete surveys observed.

### *Work remains important in cancer survivorship*

Most survivors reported positive attitudes towards work and acknowledged that work provided physical and mental health benefits. This finding is consistent with other studies in the cancer survivorship field which found that work was an important part of recovery and personal identity for survivors (Banning, 2011; Duijts et al., 2017; Maytal & Peteet, 2009). In addition, positive attitudes towards work was associated with greater RTW rates and shorter sickness absence (Duijts et al., 2017). A small minority of participants in the study reported that cancer had reduced their motivation to work. This is consistent with the literature which found that some cancer survivors reassessed their life priorities after cancer (Banning et al., 2011; Duijts et al., 2017; Wells et al., 2013), including reducing the importance placed on work as a stress-management strategy (Mackenzie, 2014).

### *Managing effects from cancer and treatment at work can be challenging*

Participants in this study reported that a range of side effects of cancer treatment impacted their perceived work ability, including cognitive, emotional and physical symptoms. Systematic reviews report that approximately a quarter of cancer survivors experienced impaired work ability to due cancer, including fatigue, cognitive impairment, emotional distress, pain and muscle weakness (Bradley, Neumark, Luo, & Schenk, 2007; Duijts et al., 2014; Mehnert, 2011;

Steiner, Nowels, & Main, 2010). Fatigue impacts a high proportion of survivors, and is commonly reported as the most prominent and debilitating side effect of cancer and its treatment (Collins, Ottati, & Feuerstein, 2013). Several studies have indicated that fatigue was negatively associated with work outcomes (Cocchiara et al., 2018; Duijts et al., 2017; Mehnert, 2011). Compounding this issue, fatigue has been found to increase in severity upon RTW (Tikka, Verbeek, Tamminga, Leensen, & de Boer, 2017).

### *Physical work and productivity demands can be challenging*

Participants indicated that physically demanding tasks, length of the workday, productivity demands and commuting were challenging to manage after cancer. Manual work has been associated with poorer work outcomes (Banning, 2011; Cocchiara et al., 2018; Steiner et al., 2010; van Muijen et al., 2013) and may be particularly challenging for survivors experiencing fatigue, muscle weakness or restricted movement. Similarly, survivors experiencing fatigue have reported difficulty maintaining energy and focus throughout the work day, and keeping up with productivity demands (Bradley et al., 2007; Cocchiara et al., 2018; Duijts et al., 2014; Steiner et al., 2010; Stergiou-Kita et al., 2016). Driving is a complex task which requires a heavy cognitive load. Cognitive ‘fogginess’ associated with fatigue may contribute to the difficulties in commuting to and from work safely.

### *Cancer takes a financial toll*

Reduced household income was reported by most survivors in this study, and many were influenced by financial pressures to RTW. This finding echoes that of Paul and colleagues (2016) who reported that almost two thirds of Australian cancer survivors report a significant reduction in household income after diagnosis. Cancer survivors are faced with increasing out-of-pocket expenses and are estimated to bear over 40% of the financial cost of cancer through lost income, carer costs, travel and healthcare expenses (Access Economics, 2007). Such factors commonly influence treatment decisions (Paul et al., 2016). Cost of living pressure is a widespread issue in Sydney and Australia more broadly. It is reasonable to assume that most people of working age may need to service a mortgage or pay for rental accommodation. Many people in this age are also supporting young or elderly family members and may be an important provider for the household.

### *Relationships with the employer are important*

Most respondents of this study described having a supportive work environment and good relationships with colleagues and management. A supportive workplace was reported as a key facilitator in remaining at or returning to work, which is consistent with findings reported in the literature (Banning, 2011; Duijts et al., 2017; Greidanus et al., 2018; Tikka et al., 2017).

The importance of a supportive workplace was highlighted in the comparison of two participants that had unsuccessfully tried to RTW. One participant reported having a supportive workplace however had difficulty managing effects of cancer treatment at work. Conversely, another participant reported feeling well and able to perform her job, however had received a redundancy on her RTW. This participant indicated that her employer had not communicated with her during her illness and had not supported her transition to a new position or employer. Having negative experiences during RTW process is associated with poorer attitudes to work and both short and long-term work-related outcomes (Wells et al., 2013). Workplace discrimination, including forced redundancies, changed work roles or conditions and being overlooked for promotions have been reported in cancer survivor populations (Feuerstein, Luff, Harrington, & Olsen, 2007).

### *Few cancer survivors seek advice about returning to work*

Participating in work after cancer may be challenging, yet few survivors reported seeking advice about returning to work outside of their employer. Among those consulted included the treating oncologists, surgeons, GPs, friends and families. Interestingly, many of the survivors who decided to not RTW did not report consulting their healthcare team. One participant who had returned to work reported difficulty in educating her employer about her cancer and ongoing health issues. Similar issues have also been reported in Australian (McKay et al., 2013) and international studies (Amir et al., 2010).

Participants indicated that employers were generally supportive and offered some workplace adjustments, including reduced work hours and working from home. Employers are legally obliged to provide adequate accommodations for employees with disability (Australian Government, 1992), however few are likely to understand the complexities and variability of ongoing health issues and functional impairments associated with cancer. Evidence from Australian qualitative research indicates that cancer survivors, employers and health professionals are unclear on their roles, rights and responsibilities and that of other stakeholders (Knott et al., 2104; McKay et al., 2013). Importantly, a systematic review of studies investigating workplace adjustments found that awareness and understanding of such factors were crucial building blocks for provision of workplace adjustments (Stergiou-Kita et al., 2016). Communication is key to negotiating and developing RTW plans (S. F. A. Duijts et al., 2017; Tikka et al., 2017).

Limited evidence of the role of health professionals found that cancer survivors received very limited and conflicting advice about working after cancer (Amir, Wynn, Whitaker, & Luker, 2009). Many healthcare professionals reported being unsure about how to make judgements about managing work demands, or to provide specific, tailored advice about managing side effects of cancer at work (Bains et al., 2012). Furthermore, perceptions of survivors' capacity to work were often influenced by interactions with previous cancer survivors (Knott et al., 2014; Bains et al., 2012) and 'common sense' (Bains et al., 2012). Occupational therapists working in cancer care are well placed to provide support however do not routinely address work participation in their practice (Buckland & Mackenzie, 2017). This begs the question – *who is providing advice to cancer survivors and their employers?*

### ***Women may face additional challenges in managing unpaid work and employment***

Some gender differences were described in the study which may warrant further investigation. Overall female participants were younger, performed more unpaid work, more frequently had caring roles, underwent more treatment modalities and worked fewer hours in paid employment than male participants. All of these factors have been associated with longer sickness absence and lower RTW rates (Mehnert, 2011; Spelten et al., 2002; van Muijen et al, 2013). Although inferences cannot be made from this small sample size, these results raise questions about how female cancer survivors navigate work and other roles. A study of working mothers with breast cancer found that most survivors continued to perform the majority of household responsibilities, including housework, cooking and childcare, throughout cancer treatment and beyond (Mackenzie, 2014). These survivors prioritised the needs of the family above their own, which impacted their health and wellbeing.

## Limitations

There are a number of limitations in the study design which may have impacted study results. Firstly, the absence of a control population limits the reliability of conclusions drawn from the study as being associated with cancer specifically. It is possible that many of the factors reported to impact work ability after cancer may also impact work ability within the general population. In addition, the use of a small sample size reduced the power of the study and increased the margin of error or likelihood of bias. It was expected that a degree of variability would be present in cancer populations, due to the individual and unpredictable nature of cancer survivorship, however the small sample size did not allow for statistical analysis to test this variability.

An important ethical limitation is also acknowledged as the study required participants to be literate in English. Western Sydney is home to a culturally and linguistically diverse population, including a high migrant population. Non-English speaking people may have additional difficulties navigating the Australian healthcare and employment system.

## Conclusion

Cancer is a life changing experience, which impacts the lives of survivors, families and communities in complex and enduring ways. Work is an important part of life for many cancer survivors and provides physical, mental, social and financial health benefits. Cancer survivors may have difficulty managing effects of cancer and treatment and meeting the physical, cognitive and productivity demands of work. Further research is needed to understand how cancer impacts work participation and to quantify the factors which impact working after cancer.

## Key Points for Occupational Therapy

- Returning to work is an important part of recovery in cancer survivorship.
- Cancer survivors receive little support from healthcare professionals about returning to work.
- Most cancer survivors do not consult health professionals or an occupational rehabilitation provider when deciding to return to work or exit the workforce after treatment.
- The workplace plays a crucial role in return to work after cancer, however employers may be unable to understand the complexities of cancer survivorship.

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# APPENDICES

## Appendix I: Search terms used for literature review.

Concept 1

“cancer patient*” OR “Cancer survivor*” OR ‘neoplasm’ ‘carcinoma*’ OR ‘oncology’ OR ‘tumor’ OR ‘tumour’

AND

Concept 2

‘work*’ OR ‘employ*’ OR “occupation* rehabilitation” OR “labor market” OR “labour market” OR “labor force” OR “labour force” OR “labour participation” OR “labor participation” OR ‘absenteeism’ OR ‘sick leave’ OR ‘sickness absence’ OR ‘retirement’ OR ‘resignation’ OR ‘pension’ OR “disability pension” OR “work ability” OR “work disability” OR ‘wages’ OR ‘income’ OR “job loss” OR “job performance” OR ‘career’ OR “recovery at work” OR “recover at work” OR “vocation* rehabilitation” OR “return to work” OR “work return” OR “job re-entry” OR ‘unemploy*t’ OR “work performance”

Concept 3 – used to identify Australian studies within search results.

‘Australia*’ OR “New South Wales” OR ‘Queensland’ OR ‘Victoria’ OR “South Australia” OR “Western Australia” OR ‘Tasmania’ OR “Australian Capital Territory”

## Appendix II: Journal submission guidelines

### Australian Occupational Therapy Journal Article Submission

### "Checklist for Authors"

The following checklist will appear as part of the online submission process. Authors must confirm adherence to all items.

- The manuscript was double-spaced in 12 point Times New Roman or Times Roman font and does not exceed the permitted word count.
- I used Australian-English spelling.
- The abbreviation of "OT" or "OTs" was not used.
- The submitted manuscript did not contain any identifying information about specific people, programs, locations or study sites.
- I consulted the *Publication Manual of the American Psychological Association, Sixth Edition* and/or the official companion APA Style Blog (**http://blog.apastyle.org/apastyle/) to prepare correct citations and references. All journal articles published after 1997 included the digital object identifier (doi) presented according to APA style rules.**
- The corresponding author obtained and included his/her ORCID number.
- The "Abstract" was no longer than 300 words and used the following headings: Introduction; Methods; Results; Conclusion.
- Abbreviations followed the *Publication Manual of the American Psychological Association, Sixth Edition* /or the official companion APA Style Blog (**http://blog.apastyle.org/apastyle/); this included abbreviations in the reference list.**
- Up to five keywords were selected from either the U.S National Library of Medicine Medical Subject Headings (MeSH) (**https://www.nlm.nih.gov/mesh/) or the Cumulative Index to Nursing and Allied Health Literature Thesaurus. Only MeSH or CINAHL words were used.**
- The Main Document used subheadings set out in the Guidelines.
- If my study used humans, I provided details of the Institutional Review Board, Human Research Ethics Committee or equivalent delegated authority in the Scholar One form where indicated and these details were also written into the Method Section of the manuscript (blinded for review)
- Research articles followed the reporting guidelines presented in **http://www.equator-network.org/. I note reviewers will be asked to evaluate the manuscript in light of these guidelines. I provided evidence of adherence as a supplementary document: e.g., prospective clinical trial registration.**

- A section called “Key Points for Occupational Therapy” was included at the end of the paper, before “references”.
- A section called “Declaration of Authorship” was included after “Key Points” and before “references”. The declaration stated the contribution of each author to the paper and any conflict of interest. I/we used wording that demonstrated adherence to the roles and responsibilities of authors described in the International Committee of Medical Journal Editors (ICMJE) recommendations (**http://www.icmje.org/**).
- A section called “Funding” was included after the author declaration.
- People or institutions who were acknowledged gave written permission.

## 2. EDITORIAL CONSIDERATIONS

### Aims and Scope

The *Australian Occupational Therapy Journal* is a leading international peer reviewed publication presenting influential, high quality innovative scholarship and research relevant to occupational therapy.

The journal is the official research publication of the professional peak body, Occupational Therapy Australia. The journal publishes empirical studies, theoretical papers, reviews and invited scholarly commentary.

The aim of the journal is to be a leader in the dissemination of scholarship and evidence to substantiate, influence and shape policy and occupational therapy practice locally and globally.

Preference will be given to papers that have a sound theoretical basis, methodological rigour with sufficient scope and scale to make important new contributions to the occupational therapy body of knowledge.

Topics may include:

- how participation in occupation is affected by body structures and function domains
- participation in occupations across the lifespan
- environments affecting engagement in occupation and occupational therapy services (physical, social, policy etc.)
- interaction of person, environment and occupation factors to influence health
- people who receive, could receive or who are impacted by occupational therapy practice, policy or education;
- assessments measuring constructs relevant to and applied in occupational therapy research, practice or education;
- occupational therapy interventions (development, implementation and impact)
- scope of occupational therapy practice
- professionalisation and professionalism in occupational therapy

- pedagogy and educational practice involving occupational therapy, including interprofessional , multidisciplinary, transdisciplinary and single discipline research that includes occupational therapy and/or occupational therapy students/ staff.

AOT does not publish protocols for any study design

Authors must position their study in an appropriate and sound theoretical and empirical context; with a critical analysis of relevant literature in the Introduction section. The manuscript must demonstrate how findings make an important contribution to knowledge in the field.

For quantitative papers, authors are encouraged to demonstrate how their studies enable replication, generalizability and contribute to understanding possible or actual causality. Typically this will involve reporting using guidelines such as those available in the EQUATOR network. Authors must use measures that are well validated and have proven psychometric properties.

Authors are encouraged to triangulate data to substantiate their findings where appropriate, for example: self-report measures and performance observation measures; therapist and consumer measures/ perspectives.

The journal preferences qualitative research that contributes to development of substantive or formal theory, is empirically grounded, is internally reflexive and has explored its value for different groups including study participants. Studies that demonstrably illuminate aspects of occupational therapy and can thus inform decision making will be of particular interest to readers. Qualitative studies must demonstrate transferability, dependability, trustworthiness, and credibility.

In mixed method research, authors are required to clearly outline how the a-priori design demonstrates integration of qualitative and quantitative methods during data collection, analysis and reporting. When a mixed method approach is reported, authors should clearly identify the design (e.g., sequential explanatory, sequential exploratory, concurrent nested, etc.) and report which data took priority during data collection and analysis (e.g., did qualitative data lead the results with support from the quantitative?). Consideration should be given to whether the approach used is mixed or multiple methods.

Instrumentation studies present the development and/or evaluation of the psychometric properties of a tool – reliability, validity, sensitivity, clinical utility. The journal has a preference for standardised taxonomies such as COSMIN.

The *Australian Occupational Therapy Journal* receives many more papers than it can publish. Studies may be methodologically appropriate, have significant or original results, but that may not mean the paper is a significant contribution to new knowledge. The journal aims to publish research that will provide a rigorous, relevant evidence base to inform professional practice and decisions relating to occupational therapy. Authors must demonstrate that their research is thus not only technically competent but is an original and significant contribution to knowledge and practice.

The journal will consider multidisciplinary or interprofessional studies that include occupational therapy, occupational therapists or occupational therapy students, so long as ‘key points’ highlight the specific implications for occupational therapy, occupational therapists and/or occupational therapy students and/or consumers.

If authors extract material from single larger interprofessional or multidisciplinary studies for an occupational therapy-specific study, these papers are only acceptable if distinct and separate questions are asked, if a theoretically and empirically grounded rationale is provided for the extracted study, and if the methodology is appropriate to the question

If authors are submitting a paper where data is derived from a larger study, authors are required to disclose all related publications that are published, submitted or under review. If authors state that aspects of the study have already been published, a case must be made to demonstrate how the present paper is distinctive and makes a significant contribution to knowledge.

**Conditions of submission**

Papers submitted to the journal must not be presenting content that has been previously published. The only exceptions to this rule are the following: conference abstracts; part of a published lecture or academic thesis; as an electronic preprint; poster/ abstract/ oral presentation presented at a conference or scientific meeting where proceedings are available on a pre-print server.

Papers that present clinical trials are not deemed to have been previously published if they appear in clinical trials registers and/or if results in such registers are presented as a brief summary or table.

Papers submitted to the journal must not be under consideration for publication elsewhere.

If accepted for publication, authors agree the paper will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder which is the journal publisher. Authors must be aware that in signing the copyright form they are entering a legal agreement not to disseminate or republish the journal-article on any file sharing site, by email attachment, in thesis dissertations or in any other form. Authors are able to disseminate the pre-production manuscript if they own the copyright and they are able to include citation details of the Australian Occupational Therapy Journal published paper on such documents.

All papers submitted to the *Australian Occupational Therapy Journal* are subject to automated text-matching software screening which reports a % similarity index.

**Editorial Processes**

All submissions are inspected by the Editorial Team first to determine whether all criteria in the "Checklist for Authors" have been met. A paper that does not meet criteria will be rejected and returned to authors.

Second, Editorial inspection determines whether or not papers are within the journal "Aims and Scope". The Editorial Board may decide to reject any paper not deemed to be within the Aims and Scope of the journal. A reason for rejection will be provided. The decision is final.

A paper deemed to be in line with the "Aims and Scope" of the Journal will be blind-reviewed by one member of the Editorial or Review Board and either a specialist guest-reviewer or another member of the Editorial or Review Board. Reviewers will provide feedback using the *Australian Occupational Therapy Journal* review-form. Reviewers will be directed to consider the methodological quality of the study and may choose to use standardised critical appraisal tools. Reviewers will provide blind comment to authors regarding the manuscript. Reviewers will make confidential recommendations to the Editorial Board regarding publication priority. The Editorial Board will use reviewer reports to inform decisions regarding acceptance, rejection, or provision of opportunities to revise and resubmit. Resubmissions have no guarantee they will be accepted. A rejection decision is final; no further correspondence will be entered into.

An accepted paper is submitted to the WILEY production process.

Authors will receive the page-proofs for their paper and are required to review for accuracy; any changes beyond accuracy may incur a charge. The author-approved proof is sent to the Editor in Chief for final review. The Editor and the Publisher reserve the right to make minor modifications to typescripts to correct spelling or grammar issues that have been overlooked, or eliminate ambiguity and repetition. A paper is not approved for publication, regardless of the stage of review or correspondence sent and received until the Editor in Chief approves publication of the final proof. If an author identifies an error after publication that is their responsibility, he/she/they are responsible for costs associated with correction and publication of corregium.

### 3. ETHICAL CONSIDERATIONS

This journal is a member of the **Committee on Publication Ethics (COPE).**

*Human Studies*

For manuscripts reporting studies involving human participants or data originally generated from human participants (e.g., chart reviews, program evaluations, secondary data analyses), we require a statement identifying how ethical and /or research governance approval was obtained, where and under what authority it was granted. Authors must provide the name of the committee and state the reference number where appropriate. The name of the approving committee/s should be included in the manuscript (but de-identified for blind review purposes) – it is not acceptable to refer to "researcher institutional ethics committees" in general.

For research conducted in Australia or through Australian institutions the National Statement on Ethical Conduct in Human Research 2007 - updated May 2015 applies (https://www.nhmrc.gov.au/guidelines-publications/e72).; for research with Indigenous Australians this also includes the companion document "Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research" (NHMRC, 2003).

For research conducted by investigators in countries other than Australia, there is a requirement for authors to demonstrate that the research complied with principles of the World Medical Association Declaration of Helsinki Ethical Principles for Medical Research involving Human Subjects as amended October 2000 and that research was conducted with institutional or equivalent approvals consistent with the World Health Organization "Standards and operational guidance for ethics review of health-related research with human participants" (2011). Failure to provide this information or demonstrate this requirement will result in the submission being rejected.

### *Clinical Trial Registration*

Clinical trials will normally be prospectively registered in a publicly accessible database and clinical trial registration numbers should be included in all papers that report results. Include the name of the trial register and your clinical trial registration number at the end of your abstract.

If your trial is not registered, or was registered retrospectively, please explain the reasons for this in the cover letter.

### *Research Reporting Guidelines*

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. The *Australian Occupational Therapy Journal* will publish positive, negative and inconclusive results as long as the research is rigorous.

Authors must adhere to research reporting standards presented in the EQUATOR network (**http://www.equator-network.org/).**

Authors must submit the relevant EQUATOR reporting guideline checklist as a not-to-be-published supplementary document to the submission. If authors do not believe one of these guidelines is appropriate a rationale must be provided in the cover letter and an alternative standards benchmark provided.

### *Data Sharing and Data Accessibility*

The journal encourages authors to share the data and other artefacts supporting the results in the paper by archiving it in an appropriate public repository. Authors should include a data accessibility statement, including a link to the repository they have used, in order that this statement can be published alongside their paper.

### *Roles and Responsibilities of Authors*

An author is someone who demonstrates roles and responsibilities defined by the International Committee of Medical Journal Editors (ICMJE) (**http://www.icmje.org/). A declaration must be made to this effect.**

The ICMJE recommends that authorship be based on the following criteria: (i) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; ( ii) Drafting the work or revising it critically for important intellectual content; (iii) Final approval of the version to be published; and ( iv) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

*Conflict of Interest*

Authors should disclose any actual or perceived conflicts of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to, patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

*Funding*

Authors must make a funding statement. This will appear at the end of the paper before the reference section. Authors should list all funding sources. All funding received for work described within a submitted manuscript must be acknowledged in the funding disclosure section. Provide the name of the funder, the grant number, and the name of the principal investigator as applicable. If there was no specific study funding, then the authors should report the following statement: “This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.”

*Acknowledgements*

The contribution of colleagues or institutions can be acknowledged. Personal thanks and thanks to anonymous reviewers are not appropriate. Acknowledgements should contain information on individuals who have contributed to this work but did not meet the criteria for authorship or decline to be included as an author. All those individuals who are named in the acknowledgements must be contacted by the author and agree to have their name included. Each individual’s specific contribution to the work must be briefly stated. Acknowledgements of general support or mentorship will be deleted by the editor as acknowledgements are only for those individuals who have provided a specific contribution to this work. In addition, the authors must provide information on previous dissemination of this work, in part or whole, at conferences or workshops. Prior presentation of the paper at a meeting should be briefly described last.

**4. ARTICLE TYPES AND REQUIREMENTS**

| Type of Article | Word limit (excluding abstract, references, tables and figures | Abstract required - word limit | Number of references allowable | No. of tables or figure files |
|---|---|---|---|---|
| Feature | 5000 | 300 | 35 | 4 |
| Review * | 5000 | 300 | 35 | 4# |
| Letter to Editor | 300 | NA | 3 | 0 |

* Refer to full detail regarding length, references and tables for Review Articles below

# Usually published in online-only format

All articles

All articles must be accompanied by a cover letter that addresses how the paper complies with conditions of submission.

If content is derived from a larger study, study series or previously published work, the authors must explain in the cover letter how their submission makes an original and substantial contribution to new knowledge and they must include citations and doi links for all related/ derivative studies.

The cover letter should include a statement regarding written permissions for photographs, personal communications, and copyrighted material. These written permissions should be attached to the cover letter.

The cover letter should confirm that any person or institution named in the acknowledgements has given permission

**Feature Articles**

Feature Articles can be in the form of research papers, theoretical papers, case reports or descriptive articles. Manuscripts should not exceed 5000 words including Key Points, Author Declaration and conflict of interest, funding and acknowledgement. The Title, Abstract and References are not included in the word count. The journal does not publish articles that present only study protocols without results.

Feature articles should contain the following:

*Title page*: This will be a separate file to the main document – upload using the “title page” option in Scholar One. The title page should contain:

i) a short informative title that contains the major content concepts. The title should not contain abbreviations (see our best practice SEO tips);
ii) the full names, qualifications and designations of the authors;
iii) the full addresses of the authors’ affiliations;
iv) a short running title (no more than 40 characters, abbreviations are permitted);
v) authors’ declaration of authorship contribution*;
vi) funding statement*;
vii) conflict of interest statement*;
viii) acknowledgements*;
ix) word length for the main text excluding references, abstract and tables;
x) word length of the abstract;
xi) the number of references, figures and tables include as part of article;
xii) Designate the corresponding author by providing his or her full address, telephone and fax numbers, and e-mail address.
xiii) A minimum of five MeSH or CINAHL terms should be included as key words

*In the printed publication these will appear at the end of the paper before “references” – they are included here in the title page because this is not sent out to reviewers.

*Structured abstract*: 300 word limit including Introduction, methods, results and conclusion.

*Introduction:* The aims of the article should be clearly stated and a theoretical framework (if applicable) should be presented with reference to established theoretical model(s) and background literature. A succinct review of current literature should set the work in context. The introduction should not contain findings or conclusions. The aim of the research should be stated at the end of the introduction section.

*Methods:* This should provide a description of the method (including recruitment of subjects, study procedures, instruments and data analysis) in sufficient detail to allow the work to be repeated by others. Name (but de-identify for review) the Human research Ethics Committee/s or equivalent if human participants were involved, and provide the approval reference number/s. The ethics statements must appear in the first paragraph of the methods section.

*Results:* Results should be presented in a logical sequence in the text, tables and figures. Participant characteristics are presented in results. The same data should not be presented repetitively in different forms.

*Discussion:* The discussion should consider the results in relation to the study purpose, practice and scholarly context. The relationship of your results to the work of others and relevant methodological points could also be discussed. Limitations of the study should be identified. Implications for practice and future research should be considered. A conclusion section may be used but is not mandatory.

*Key Points for Occupational Therapy:* This is included at the end of the paper, before “references”. It comprises a bulleted list of three points summarising implications of the paper for occupational therapy practice/ policy or and or education. These should not exceed 45 words in total (that is, 10-15 words each). Each point should reflect the journal's aim and scope above and must not simply restate the findings.

*References:* No more than 35 references.

*Standard inclusions of Author Declaration including conflict of interest, funding statement, acknowledgement if appropriate:* This will be a separate file to the Main Document – upload as “supplementary file” not for review. Normally no more than 100 words.

*Tables and/or Figures:* No more than 4 will be included. Large Tables or Figures may be published as on-line only files to permit efficient production of the print-version of the journal. The file link will be published in the print version.

Appendices are not permitted.

(Reporting Guidelines will normally be included as a non-published supplementary file in the submission. In some cases, e.g., CONSORT flow-chart, aspects of the guidelines may be included in the main document)

Reviews

Narrative reviews, scoping reviews, meta-syntheses, systematic reviews and meta-analyses are included in this category. The journal does not publish articles that present only review protocols.

Review articles should contain the following:

*Title page:* This will be a separate file to the main document – upload using the “title page” option in Scholar One. The title page should contain:

(i) a short informative title that contains the major content concepts. The title should not contain abbreviations (see our best practice SEO tips);

(ii) the full names, qualifications and designations of the authors;

(iii) the full addresses of the authors’ affiliations;

(iv) a short running title (no more than 40 characters, abbreviations are permitted);

(v) authors’ declaration of authorship contribution*;

(vi) funding statement*;

(vii) conflict of interest statement*;

(viii) acknowledgements*;

(ix) word length for the main text excluding references, abstract and tables;

(x) word length of the abstract;

(xi) the number of references, figures and tables include as part of article;

(xii) Designate the corresponding author by providing his or her full address, telephone and fax numbers, and e-mail address.

(xiii) A minimum of five MeSH or CINAHL terms should be included as key words; Note that MeSH key words are reviewed by an indexer and may be edited.

*In the printed publication these will appear at the end of the paper before “references” – they are included here in the title page because this is not sent out to reviewers.

*Structured abstract:* No more than 300 words including Introduction, methods, results and conclusion.

*Introduction:* A rationale and context for the review must be provided. The aim of the review should be stated at the end of the introduction section.

*Methods:* This should provide a description of the method (including recruitment of subjects, study procedures, instruments and data analysis) in sufficient detail to allow the work to be repeated by others. Name (but de-identify for review) the Human research Ethics Committee/s or equivalent if human participants were involved, and provide the approval reference number/s. The ethics statements must appear in the first paragraph of the methods section.

*Results:* Results should be presented in a logical sequence in the text, tables and figures. Details of sources retrieved and analysis findings are presented in results. The same data should not be presented repetitively in different forms.

*Discussion:* The discussion should consider the results in relation to the study purpose, practice and scholarly context. The relationship of your results to the work of others and relevant methodological points could also be discussed. . Limitations of the review should be identified. Implications for practice and future research should be considered. A conclusion section may be used but is not mandatory.

*Key Points for Occupational Therapy:* This is included at the end of the paper, before “references”. It comprises a bulleted list of three points summarising implications of the paper for occupational therapy practice/ policy or and or education. These should not exceed 45 words in total (that is, 10-15 words each). Each point should reflect the journal's aim and scope above and must not simply restate the findings.

*References:* Review articles use references as part of the introduction, method and in the discussion to frame the study. They also present references as ‘data’ or findings. Authors should consider these two reference types when preparing the manuscript. Up to 20 “usual” main document references may be used (i.e., sources cited in the introduction, method and discussion to place the review findings in context). There is no limit on the number of ‘references’ reported in the research results. Typically author, title, source details will be presented in ‘results tables’, but the full citation with doi will appear in the reference list along with “usual” references.

*Standard inclusions of Author Declaration including conflict of interest, funding statement, acknowledgement if appropriate:* This will be a separate file to the Main Document – upload as “supplementary file” not for review. Normally this will be no more than 100 words.

*Tables and/or Figures:* No more than 4 will be included. Large Tables or Figures may be published as on-line only files to permit efficient production of the print-version of the journal. The file link will be published in the print version.

Appendices are not permitted.

(Reporting Guidelines will normally be included as a non-published supplementary file in the submission)

Viewpoints

As of February 2019, the Viewpoint Department is no longer a feature of the *Australian Occupational Therapy Journal*. Existing submissions will be managed, but no new submissions will be received. OT Australia members have access to expert opinion in the association magazine *Connections*.

Letters to the Editor

Letters to the Editor will only be published online.

*Main Document:* No more than 300 words

*References:* No more than 3 references using APA format including doi numbers.

*Author declaration including conflict of interest:* This should be supplied, to be published at the discretion of the Editorial Board

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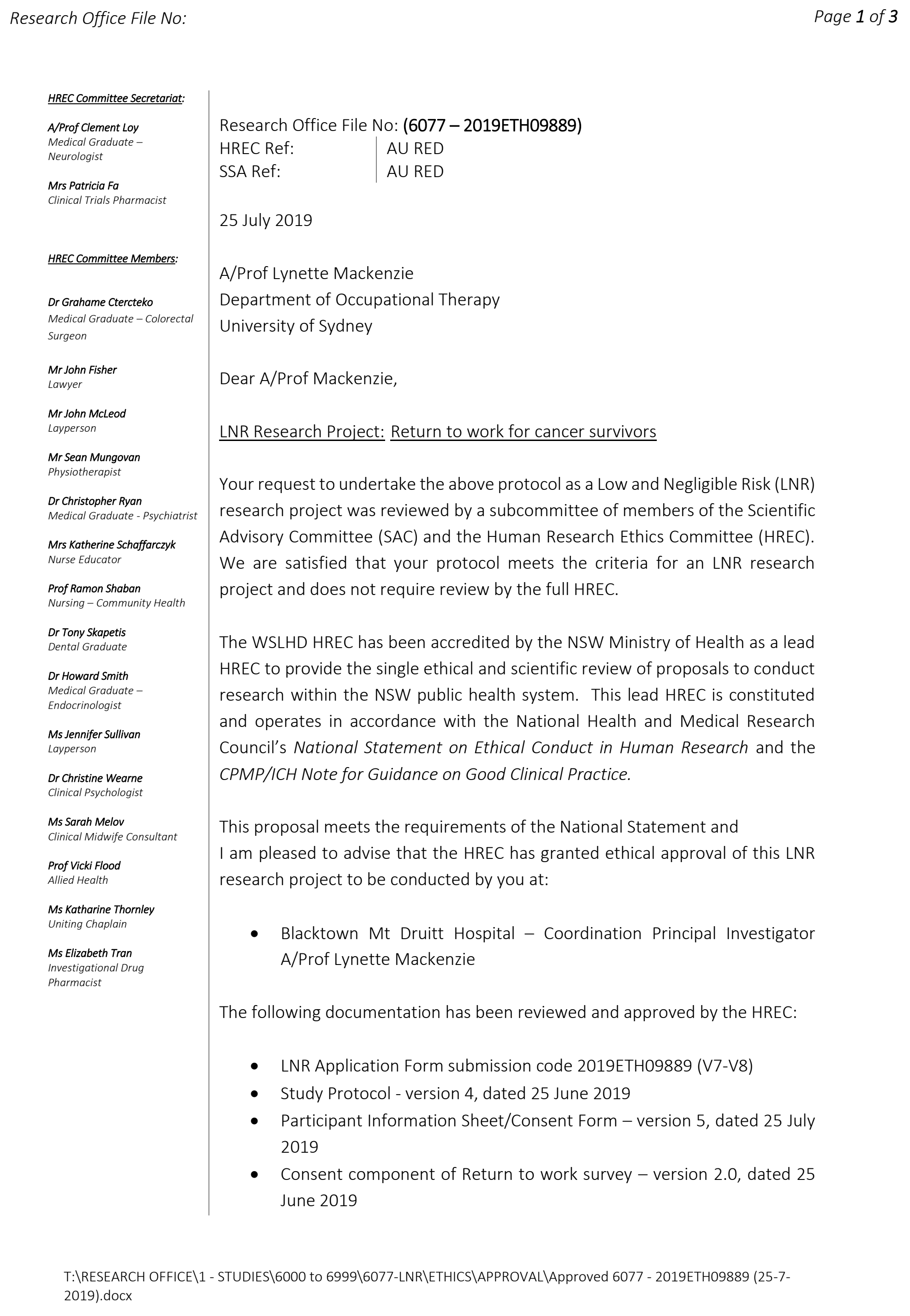
*Author Guidelines updated 9 October 2019*

# Appendix III: Research project ethics approval



Research Office File No: (6077 – 2019ETH09889)
HREC Ref: AU RED
SSA Ref: AU RED

25 July 2019

A/Prof Lynette Mackenzie
Department of Occupational Therapy
University of Sydney

Dear A/Prof Mackenzie,

LNR Research Project: Return to work for cancer survivors

Your request to undertake the above protocol as a Low and Negligible Risk (LNR) research project was reviewed by a subcommittee of members of the Scientific Advisory Committee (SAC) and the Human Research Ethics Committee (HREC). We are satisfied that your protocol meets the criteria for an LNR research project and does not require review by the full HREC.

The WSLHD HREC has been accredited by the NSW Ministry of Health as a lead HREC to provide the single ethical and scientific review of proposals to conduct research within the NSW public health system. This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

This proposal meets the requirements of the National Statement and
I am pleased to advise that the HREC has granted ethical approval of this LNR research project to be conducted by you at:

- Blacktown Mt Druitt Hospital – Coordination Principal Investigator A/Prof Lynette Mackenzie

The following documentation has been reviewed and approved by the HREC:

- LNR Application Form submission code 2019ETH09889 (V7-V8)
- Study Protocol - version 4, dated 25 June 2019
- Participant Information Sheet/Consent Form – version 5, dated 25 July 2019
- Consent component of Return to work survey – version 2.0, dated 25 June 2019

- Return to Work for Cancer Survivors Survey – version 3, dated 25 June 2019
- Interview Schedule –version 2, dated 25 June 2019
- CDA provided by Pacific Transcription services – no version, no date

Please note the following conditions of approval:

- The chief investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
- The chief investigator will immediately report any protocol deviation / violation, together with details of the procedure put in place to ensure the deviation / violation does not recur.
- Proposed amendments to the protocol or conduct of the research which may affect the ethical acceptability of the project, must be provided to the HREC to review in the specific format. Copies of all proposed changes must also be provided to the research governance officer.
- The HREC must be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
- The Coordinating Chief Investigator must provide an annual report to the HREC and a final report at completion of the study, in the specified format. HREC approval is granted for a period of 12 months and ongoing approval is contingent upon annual submission. Annual Reports for all studies should be submitted in November, they will be processed and presented to the HREC at their January meeting. A copy of the Annual / Final Research Report Form can be obtained electronically from the Research Office on request.
- It should be noted that compliance with the ethical guidelines is entirely the responsibility of the investigators.

**You are reminded that this letter constitutes *ethical approval only*. You must not commence this research project until separate authorisation from the Chief Executive or delegate has been obtained. Copies of this letter, together with any approved documents as enumerated above, must be forwarded to the Research Governance Officer as part of the Site Specific Assessment (SSA) application.**

In all future correspondence concerning this study, please quote Research Office File number ***(6077).***
The HREC wishes you every success in your research.

Yours sincerely

Mrs Patricia Fa
Secretary
WSLHD Human Research Ethics Committee

cc: Research Governance Officer

## Appendix IV: Cancer and work survey instrument

Work Participation of cancer survivors Survey

Survey Flow

- Block: About me (11 Questions)
- Standard: My cancer journey (10 Questions)
- Standard: Employment at the time of cancer diagnosis (14 Questions)
- Standard: Changes in employment since diagnosis (9 Questions)
- Branch: New Branch if: Have you returned to work since your cancer diagnosis?
  - Yes, I have returned to work and have remained at work Is Selected
    - Standard: Returned to work (11 Questions)
- Branch: New Branch if Have you returned to work since your cancer diagnosis?
  - No, I have not attempted to return to work yet Is Selected
    - Standard: Have not returned (10 Questions)
- Branch: New Branch if: Have you returned to work since your cancer diagnosis?
  - I attempted to return to work however was unable to remain at work Is Selected
    - Standard: Attempted return (10 Questions)
- Standard: Attitudes about work during and after cancer rehabilitation (3 Questions)

**Start of Block: About me**

Q1. Thank you for participating in the **Return to Work for Cancer Survivors** study. By completing this survey you are agreeing that you have:

- **received a copy of the Participant Information Sheet and**
- **consent to being a Research Participant**

**Your responses will be anonymous and confidential.**

This survey contains questions about you, your cancer journey, your work before or at the time of your cancer diagnosis, and changes in your work since your diagnosis.

It is expected that the survey will take around 20 minutes to complete. You can **save your responses** and complete the survey at your own pace.

○ I agree with the above information and provide consent to participate.
○ I do not agree with the above information and do not provide my consent.

*Display This Question: If Thank you for participating in the Return to Work for Cancer Survivors study. By completing this... = I do not agree with the above information and do not provide my consent.*

Q2. Please contact Associate Professor Lynette Mackenzie for further information on this study. Email: lynette.mackenzie@sydney.edu.au

*Skip To: End of Survey If Please contact Associate Professor Lynette Mackenzie for further information on this study. Emai...() Is Displayed*

Q3. Please indicate your **gender**

○ Male
○ Female
○ Prefer to not answer

Q4. What is your **age**?

Years ________________________________________________

Q5 Do you have a **spouse or partner**?

○ Yes
○ No

*Display This Question: If Do you have a spouse or partner? = Yes*

Q6 Is your **partner employed**?

○ Yes
○ No

Q7 Do you have **caring responsibilities** for dependent children or family members?

○ Yes
○ No

*Display This Question: If Do you have caring responsibilities for dependent children or family members? = Yes*

Q8 Please indicate which of the following **best describe your caring responsibilities**.
*Please select all that apply.*

- ○ Parent of child/children under 6 years
- ○ Parent of school-aged child/children
- ○ Care for adult with disability
- ○ Care for elderly parent/s or family members
- ○ Other

Q9 How many hours do you estimate you spend on **unpaid work** each week?
*For example:*

*unpaid domestic activities*

*unpaid care of children*

*unpaid care, help or assistance due to the disability, long term illness or old age of another person*

*voluntary work for an organisation or group*

- ○ Hours per week ________________________________________________

Q10 What is your **highest completed level of education**?

- ○ Year 10
- ○ Year 12
- ○ Vocational training (Certificate I, II, III, IV)
- ○ Diploma
- ○ Bachelor Degree
- ○ Postgraduate qualifications
- ○ None of these apply.

Q11 Do you have income protection insurance?

- ○ Yes
- ○ No
- ○ Not sure

**End of Block: About me**

---

**Start of Block: My cancer journey**

The following questions are designed to understand aspects of **your cancer journey**.

Q12 What was the date of your cancer diagnosis? (month, year)

▼ January ... December ~ 2009

Q13 What is the site of your primary cancer diagnosis?

- ○ Breast
- ○ Prostate
- ○ Colorectal (bowel)
- ○ Lung
- ○ Ovary
- ○ Brain
- ○ Bladder
- ○ Stomach
- ○ Melanoma
- ○ Kidney
- ○ Blood
- ○ Head and neck
- ○ Cervix
- ○ Other

*Display This Question:*

*If What is the site of your primary cancer diagnosis?  = Other*

Q14 Please provide details of your cancer type.

________________________________________________________________

Q15 Do you live with any non-cancer related chronic illness or disability?

- ○ Yes
- ○ No

*Display This Question: If Do you live with any non-cancer related chronic illness or disability? = Yes*

Q16 Please describe.

________________________________________________________________

________________________________________________________________

Q17 Which of the following best describes your treatment schedule?

- ○ Awaiting to start treatment
- ○ Currently undergoing treatment
- ○ Currently on break between treatment cycles
- ○ Finished treatment

Q18 Does your cancer **treatment plan** include or plan to include:

| | Yes | No | Not sure |
|---|---|---|---|
| Surgery | ○ | ○ | ○ |
| Chemotherapy | ○ | ○ | ○ |
| Radiation therapy | ○ | ○ | ○ |
| Immunotherapy | ○ | ○ | ○ |
| Hormone therapy | ○ | ○ | ○ |
| Targeted Therapy | ○ | ○ | ○ |
| Other | ○ | ○ | ○ |

*Display This Question: If Does your cancer treatment plan include or plan to include: = Other [ Yes ]*

Q19 Please provide details of the other treatments in your cancer treatment plan.

________________________________________________________________

________________________________________________________________

Q20 During the past 7 days, how much did cancer-related side effects impact **your daily activities**, excluding paid work? *For example, housework, cooking, childcare, exercising.*

- ○ Had no effect on my daily activities
- ○ Had a small effect on my daily activities
- ○ Had a moderate effect on my daily activities
- ○ Had a large effect on my daily activities
- ○ Completely prevented me from my daily activities

**End of Block: My cancer journey**

**Start of Block: Employment at the time of cancer diagnosis**

The following questions are about your **employment at the time of your cancer diagnosis.**

Q21 Which of the following *best describes* your **working situation before/at the time of your diagnosis**?

○ Permanent employment
○ Temporary/contract/casual employment
○ Self-employed
○ Currently looking for employment
○ Unemployed

*Skip To: End of Survey If Which of the following best describes your working situation before/at the time of your diagnosis? = Unemployed*

*Display This Question: If Which of the following best describes your working situation before/at the time of your diagnosis? = Currently looking for employment*

Q22 Do you have any concerns about how cancer may impact your chances of obtaining work?

________________________________________________________________

*Skip To: End of Survey If Do you have any concerns about how cancer may impact your chances of obtaining work? Is Displayed*

Q21 On average, how many **hours** did you work in paid employment per week?

○ Hours per week ________________________________________________

Q22 Please select all that apply to your **typical work schedule**:

- ○ Early morning starts
- ○ Standard business hours
- ○ Evening shifts
- ○ Night shift
- ○ Rotating roster (combination of day and night shifts)
- ○ Split shifts
- ○ None of these apply

Q23 Which **industry** were you employed in at the time of your cancer diagnosis?

- ○ Agriculture, Forestry and Fishing
- ○ Mining
- ○ Manufacturing
- ○ Electricity, Gas, Water and Waste Services
- ○ Construction
- ○ Wholesale trade
- ○ Retail trade
- ○ Accommodation and Food Services
- ○ Transport, Postal and Warehousing
- ○ Information media and telecommunications
- ○ Financial and insurance services
- ○ Rental, Hiring and Real Estate Services
- ○ Professional, Scientific and Technical Services
- ○ Administrative and Support Services
- ○ Public Administration and Safety
- ○ Education and training
- ○ Healthcare and social assistance
- ○ Arts & recreation services
- ○ Other

*Display This Question: If Which industry were you employed in at the time of your cancer diagnosis?  = Other*

Q24 Please describe which industry you are employed.

________________________________________________________________

Q25 What is the size of your employer?

○ Less than 20 employees
○ 20-100 employees
○ Over 100 employees

Q26 How **long** had you **worked for this employer** at the time of diagnosis?

○ Years ________________________________________________

Q27 Please select all that apply to **your role**:

- ○ Fast paced environment
- ○ Physically demanding tasks
- ○ Lifting more than 5 kg
- ○ Frequent lifting
- ○ Standing for long periods (more than 20 minutes)
- ○ Sitting for long periods (more than 20 minutes)
- ○ Frequent bending, twisting, reaching
- ○ Climbing stairs
- ○ Driving
- ○ Operating machinery
- ○ Long periods of concentration
- ○ Speaking in person or over the phone
- ○ Computer-based work
- ○ Working in teams
- ○ Customer/client facing

Q28 Which *best describes* your **workplace**?

- ○ Office
- ○ Construction site
- ○ Restaurant
- ○ University, school
- ○ Childcare
- ○ Hospital, medical centre
- ○ Retail space
- ○ Warehouse
- ○ Factory
- ○ Home office
- ○ Car, truck, bus, train, plane
- ○ Other

*Display This Question: If Which best describes your workplace? = Other*

Q29 Please describe your type of workplace.

________________________________________________________________

Q30 How do you usually travel between home and work? *(Tick all that apply)*

- ○ Car (drive myself)
- ○ Car (driven by someone else)
- ○ Public transport
- ○ Walk
- ○ Ride bicycle
- ○ Community transport
- ○ Other

Q31 How long is your **daily commute** in total?

- ○ Minutes ________________________________________________

**End of Block: Employment at the time of cancer diagnosis**

---

**Start of Block: Changes in employment since diagnosis**

The following questions are about any **changes in your work since your cancer diagnosis**.

Q32 Which of the following best describes your **working situation since your cancer diagnosis and treatment**?

○ I have taken leave from work during treatment
○ I have continued to work throughout treatment but reduced my hours
○ I have continued working throughout treatment
○ I have resigned from my job
○ I have retired from work
○ I am seeking voluntary redundancy
○ I have been made redundant
○ I am seeking medical retirement

*Display This Question: If Which of the following best describes your working situation since your cancer diagnosis and tre... = I have resigned from my job*

*And Which of the following best describes your working situation since your cancer diagnosis and tre... = I have retired from work*

*And Which of the following best describes your working situation since your cancer diagnosis and tre... = I am seeking voluntary redundancy*

*And Which of the following best describes your working situation since your cancer diagnosis and tre... = I have been made redundant*

*And Which of the following best describes your working situation since your cancer diagnosis and tre... = I am seeking medical retirement*

Q33 What are the main factors which contributed to this decision?

________________________________________________________________

________________________________________________________________

*Skip To: End of Survey If What are the main factors which contributed to this decision? Is Displayed*

Q34 Please indicate which **leave entitlements** you have accessed since your cancer diagnosis and treatment.
*Please tick all that apply.*

- ○ Paid personal leave
- ○ Unpaid personal leave
- ○ Annual leave
- ○ Long-service leave
- ○ I do not have access to leave entitlements through my employment
- ○ I have not accessed any leave entitlements

Q35 How many **days of leave** have you taken as a result of your cancer diagnosis and treatment?

- ○ Days ________________________________________________

Q36 At which point did you take the longest period of leave from work?

- ○ Before diagnosis
- ○ After diagnosis
- ○ At the start of treatment
- ○ During treatment

Q37 How much contact did you have with your employer whilst on leave?

- ○ Regular contact
- ○ Some contact
- ○ A little contact
- ○ No contact

Q38 How satisfied were you with the amount of contact you had from your employer?

- ○ Satisfied
- ○ Neither satisfied or dissatisfied
- ○ Dissatisfied

Q39 Have you **returned to work** since your cancer diagnosis?

- ○ Yes, I have returned to work and have remained at work
- ○ No, I have not attempted to return to work yet
- ○ I attempted to return to work however was unable to remain at work

**End of Block: Changes in employment since diagnosis**

---

**Start of Block: Returned to work**

Q40 Have any of the following **cancer-related side effects impacted your return to work or work performance?**
*Please select up to 5 symptoms which have had the greatest impact.*

- ○ Fatigue
- ○ Muscle weakness
- ○ Problems with memory
- ○ Difficulty concentrating and maintaining attention
- ○ Difficulty learning and remembering new information
- ○ Difficulty with decision making
- ○ Stomach upset (nausea, vomiting, diarrhoea)
- ○ Pain
- ○ Incontinence
- ○ Tingling in hands and/or feet
- ○ Sleep problems
- ○ Psychological distress (anxiety, depression)
- ○ Limb swelling
- ○ Dry/weepy eyes
- ○ Mucositis
- ○ Other
- ○ None of these apply

*Display This Question: If Have any of the following cancer-related side effects impacted your return to work or work perfor... = Other*

Q41 Please describe the other symptoms which impact your work.

________________________________________________________________

________________________________________________________________

Q42 During the past 7 days, how much did **cancer-related side effects** impact your ability to do **paid work**?

- ○ No effect on my ability to work
- ○ Little effect on my ability to work
- ○ Moderate impact on my ability to work
- ○ Greatly impacted my ability to work
- ○ Completely prevented me from working

Q43 Have you found any of the following **aspects of work challenging** since your cancer diagnosis and treatment?
*Please select all that apply to your performance of your role.*

- ○ Physically demanding tasks
- ○ Cognitively demanding tasks
- ○ Length of work day
- ○ Interacting with customers or clients
- ○ Interacting with coworkers or managers
- ○ Productivity demands (eg deadlines, speed of work)
- ○ Workspace/physical workplace environment
- ○ Commute between home and work
- ○ Other

*Display This Question: If Have you found any of the following aspects of work challenging since your cancer diagnosis and t... = Other*

Q44 Please describe the other aspects of your work which could be challenging.

________________________________________________________________

Q45 Please indicate if any of the following **work adjustments** have been offered since your cancer diagnosis:
*Tick all that apply*

- ○ Ergonomic assessment/adjustment
- ○ Flexible work hours
- ○ Reduced work hours
- ○ Reduced days of work
- ○ Adjusted workload (eg alternate duties, deadline extensions, temporary staff support)
- ○ Working from home or alternative work site
- ○ Increased breaks (frequency, duration)
- ○ Counselling support
- ○ Allocated parking
- ○ Quiet break space
- ○ None of these apply

---

Q46 Are there any other work adjustments that would be helpful in your return to work? Please describe.

________________________________________________________________

________________________________________________________________

---

Q47 Did you **discuss or seek advice about your return to work** with anyone other than your employer?
*For example family, Cancer Council, health professional.*

- ○ Yes
- ○ No

*Display This Question: If Did you discuss or seek advice about your return to work with anyone other than your employer?For... = Yes*

Q48 Please describe some of these discussions.

________________________________________________________________

________________________________________________________________

Q49 How **satisfied** were you with the **return to work plan** agreed with your employer?

- ○ Very satisfied
- ○ Satisfied
- ○ Neither satisfied or dissatisfied
- ○ Dissatisfied
- ○ Very dissatisfied

Q50 What factors have contributed to this?

________________________________________________________________

________________________________________________________________

**End of Block: Returned to work**

---

**Start of Block: Have not returned**

Q51 What are the main reasons for not returning to work yet?

________________________________________________________________

________________________________________________________________

Q52 Which of the following **cancer-related side effects do you think may have the greatest impact to your return to work or work performance?**
*Please select up to 5 symptoms which you think may have the greatest impact to your work.*

- ○ Fatigue
- ○ Muscle weakness
- ○ Problems with memory
- ○ Difficulty concentrating and maintaining attention
- ○ Difficulty learning and remembering new information
- ○ Difficulty with decision making
- ○ Stomach upset (nausea, vomiting, diarrhoea)
- ○ Pain
- ○ Incontinence
- ○ Tingling in hands and/or feet
- ○ Sleep problems
- ○ Psychological distress (anxiety, depression)
- ○ Limb swelling
- ○ Dry/weepy eyes
- ○ Mucositis
- ○ Other
- ○ None of these apply

*Display This Question: If Which of the following cancer-related side effects do you think may have the greatest impact to y... = Other*

Q53 Please describe the other symptoms which impact your work.

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Q54 Which **aspects of your work** do you feel **could be challenging**? Please select all that apply.

- ○ Physically demanding tasks
- ○ Cognitively demanding tasks
- ○ Length of work day
- ○ Interacting with customers or clients
- ○ Interacting with coworkers or managers
- ○ Productivity demands (eg deadlines, speed of work)
- ○ Workspace/ physical workplace environment
- ○ Commute between home and work
- ○ Other

Q55 Have you discussed a **plan for return to work with your employer**?

- ○ Yes
- ○ No

*Display This Question: If Have you discussed a plan for return to work with your employer? = No*

Q56 Are there any reasons why not?

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Q57 Have you **discussed or sought advice about your return to work plan with anyone else**?
*For example family, Cancer Council, health professionals?*

- ○ Yes
- ○ No

*Display This Question: If Have you discussed or sought advice about your return to work plan with anyone else?For example f... = Yes*

Q58 Please describe some of these discussions.

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*Display This Question: If Have you discussed a plan for return to work with your employer? = Yes*

Q59 How **satisfied** are you with your **return to work plan**?

- ○ Very satisfied
- ○ Satisfied
- ○ Neither satisfied or dissatisfied
- ○ Dissatisfied
- ○ Very dissatisfied

*Display This Question:*

*If How satisfied are you with your return to work plan? = Very satisfied*

*And How satisfied are you with your return to work plan? = Satisfied*

*And How satisfied are you with your return to work plan? = Neither satisfied or dissatisfied*

*And How satisfied are you with your return to work plan? = Dissatisfied*

*And How satisfied are you with your return to work plan? = Very dissatisfied*

Q60 What factors have contributed to this?

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**End of Block: Have not returned**

**Start of Block: Attempted return**

Q61 What are the **main reasons** that you experienced **difficulties trying to return to work?** *For example, felt unable to manage workload, difficulties with fatigue.*

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Q62 Have any of the following cancer-related side effects impacted your return to work or work performance? *Please select up to 5 symptoms which have had the greatest impact.*

○ Fatigue
○ Muscle weakness
○ Problems with memory
○ Difficulty concentrating and maintaining attention
○ Difficulty learning and remembering new information
○ Difficulty with decision making
○ Stomach upset (nausea, vomiting, diarrhoea)
○ Pain
○ Incontinence
○ Tingling in hands and/or feet
○ Sleep problems
○ Psychological distress (anxiety, depression)
○ Limb swelling
○ Dry/weepy eyes
○ Mucositis
○ Other
○ None of these apply

*Display This Question: If Have any of the following cancer-related side effects impacted your return to work or work perfor... = Other*

Q63 Please describe the other symptoms which impact your work.

________________________________________________________________

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Q63 During the past 7 days, how much have **cancer-related side effects** impacted your ability to do **paid work**?

○ No effect on my ability to work
○ Little effect on my ability to work
○ Moderate impact on my ability to work
○ Greatly impacted my ability to work
○ Completely prevented me from working

Q64 Have you found any of the following **aspects of work challenging**?
*Please select all that apply to your performance of your role.*

○ Physically demanding tasks

○ Cognitively demanding tasks

○ Length of work day

○ Interacting with customers or clients

○ Interacting with coworkers or managers

○ Productivity demands (eg deadlines, speed of work)

○ Workspace/physical workplace environment

○ Commute between home and work

○ Other

*Display This Question: If Have you found any of the following aspects of work challenging?Please select all that apply to y... = Other*

Q65 Please describe the other aspects of your work which could be challenging.

________________________________________________________________

Q66 Please indicate if any of the following **work adjustments** have been offered since your cancer diagnosis: *Tick all that apply*

- ○ Ergonomic assessment/adjustment
- ○ Flexible work hours
- ○ Reduced work hours
- ○ Reduced days of work
- ○ Adjusted workload (eg alternate duties, deadline extensions, temporary staff support)
- ○ Working from home or alternative work site
- ○ Increased breaks (frequency, duration)
- ○ Counselling support
- ○ Allocated parking
- ○ Quiet break space
- ○ None of these apply

Q67 Are there any other work adjustments that would be helpful in your return to work? Please describe.

________________________________________________________________

________________________________________________________________

Q68 Did you **discuss or seek advice about your return to work** with anyone other than your employer?
*For example family, Cancer Council, health professional.*

- ○ Yes
- ○ No

*Display This Question: If Did you discuss or seek advice about your return to work with anyone other than your employer?For... = Yes*

Q69 What were some of the key points of these discussions?

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**End of Block: Attempted return**

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**Start of Block: Attitudes about work during and after cancer rehabilitation**

The following questions is designed to understand your attitudes towards work since your cancer diagnosis.

Q69 Please indicate **how much you agree** with the following statements.

| | Strongly agree | Agree | Neither agree or disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| I believe that work is important for my physical health | ○ | ○ | ○ | ○ | ○ |
| I believe that work is important for my mental health | ○ | ○ | ○ | ○ | ○ |
| Working gives me structure in my life | ○ | ○ | ○ | ○ | ○ |
| I consider my work important | ○ | ○ | ○ | ○ | ○ |
| I feel supported at work | ○ | ○ | ○ | ○ | ○ |
| I have good relationships with supervisors/management | ○ | ○ | ○ | ○ | ○ |
| I have good relationships with colleagues | ○ | ○ | ○ | ○ | ○ |
| I am committed to my work and employer | ○ | ○ | ○ | ○ | ○ |
| I have control over my work | ○ | ○ | ○ | ○ | ○ |
| I feel that employees with health issues are treated fairly by my employer | ○ | ○ | ○ | ○ | ○ |
| I feel comfortable to speak to my supervisor/management about my health issues | ○ | ○ | ○ | ○ | ○ |
| Cancer has reduced my household income | ○ | ○ | ○ | ○ | ○ |
| I believe that the impact of cancer treatment on my work will be temporary | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| My motivation to work has reduced since my cancer diagnosis | ○ | ○ | ○ | ○ | ○ |
| I need to return to work for financial reasons | ○ | ○ | ○ | ○ | ○ |
| Since my cancer diagnosis I have considered resignation or early retirement | ○ | ○ | ○ | ○ | ○ |
| Because of my health situation I feel uncertain about the future | ○ | ○ | ○ | ○ | ○ |

Q70 Please select below to submit your responses.

By submitting this survey you are indicating that you are happy with the content of your answers and are consenting to the use of those answers in this research project.

○ Submit

**End of Block: Attitudes about work during and after cancer rehabilitation**