How is physical activity being embedded into cancer treatment pathways?

Sarah Dewhurst

"A drug with a similar benefit profile would likely be prescribed broadly…At the moment, current practice is failing those with cancer." (Schmitz et al, 2019)

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Acknowledgements

Thank you to the Winston Churchill Memorial Trust for their considerable generosity to me personally, but also for their work both past, present and future, to allow people to experience travel and learning overseas in order to benefit and challenge the status quo in the UK. It is an incredible concept, I have pinched myself several times to believe I have been so fortunate, and I am truly grateful for the experience.

> WHANAUNGATANGA: The concept of kinship is an important one to Maori. Whanaungatanga embraces the idea of empowering others by behaving towards them in a respectful manner – treating them as one of the whanau (extended family). To offer respect, whether to a stranger, work colleague or visitor, is to make them feel part of the whanau, even if only for a short time.

I saw a sign with this definition on at an ancient Maori site and the concept resonated with the kindness and generosity I encountered throughout my trip. I was overwhelmed by people's willingness to share their work and views and for their mutual interest in my experience in the UK. There are too many people to name individually, but my thanks go out to everyone in the UK, Geneva, Australia and New Zealand who made this project possible.

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Lastly, I would like to thank my family, for their unwavering belief in me, and especially my husband Tim and two boys, Freddie and Seb who came with me on this trip of a lifetime and made it a million times richer for their presence.

Abbreviations

ACSM	**American College of Sports Medicine**
APA	**Australian Physiotherapy Association**
COSA	**Clinical Oncology Society Australia**
EP	**Exercise physiologist**
HIIT	**High Intensity Interval Training**
MDT	**Multi-Disciplinary Team**
NHS	**National Health Service**
NIHR	**National Institute for Health Research**
TYA	**Teenage and young adult**
WCMT	**Winston Churchill Memorial Trust**
WCPT	**World Congress for Physiotherapy**

About Me

I qualified as a physiotherapist in 2003 and developed an interest in oncology rehabilitation whilst working on the bone cancer (sarcoma) unit at the Royal National Orthopaedic Hospital in Stanmore. For the past 9 years I have been employed by the Royal Marsden Hospital, a cancer tertiary centre, and have developed a growing interest in how we are supporting patients to be physically active. I undertook a Masters in Rehabilitation in 2013 and my dissertation looked at peoples' ability to remain physically active during chemotherapy for soft tissue sarcoma (Dewhurst et al. 2018). For the past 18 months I have been on a Macmillan funded secondment in primary care, working on a project which aims to improve the capability of primary care nurses to support people living with cancer as a long-term condition.

As a Public Health England 'Physical Activity Clinical Champion', I have an additional role providing education to healthcare professionals on the importance of physical activity support and advice for people with long-term conditions.

Having seen the limitations of what it is possible (and appropriate) to provide in an acute NHS setting, together with the reduced awareness of cancer patients' needs amongst primary care practitioners, I have started to consider how we can bridge the gap in terms of improving collective understanding and reducing the barriers which exist between service provision and teams in primary and secondary care. But it was both participating in an international Twitter conference on exercise oncology and the launch of the Clinical Oncology Society Australia (COSA) statement in 2018 (appendix 1) which highlighted the international perspective on this subject and led me to submit an application for a Winston Churchill Fellowship grant.

Executive Summary

Aims: To explore how other countries have embedded physical activity into cancer treatment pathways

Findings:

- The COSA statement was largely considered to be helpful in raising awareness of exercise as a core component of treatment. It moved the conversation on from 'why' to 'how' and gained exercise professionals a seat at the table
- There is still a lot of work to be done to improve healthcare professionals' health literacy on exercise oncology both within the cancer specialism and in more generalist settings; this inevitably creates a barrier to safe advice on the importance of exercise reaching patients
- There is an insufficient workforce with the necessary skills in both specialist cancer rehabilitation and advanced exercise prescription. This risks services developing without due consideration of peoples' holistic needs. It is also a barrier to scaling up services to reduce inequalities in service provision and translate the evidence into practice

- Examples of collaboration between health and exercise professionals proved how effective combining expertise can be in delivering services to a complex group of patients such as those living with or after a cancer diagnosis. Where this was not happening there tended to be a lack of understanding of the contribution and benefits to patients that such a collaboration might provide
- Despite the emerging body of evidence in the field of exercise oncology, healthcare still typically operates in a medical model and as a result clinical champions who can advocate at the highest level for the need for exercise interventions was invaluable in progressing this agenda

Recommendations:

A Collective Approach: progress will be made at a faster pace with collaboration and respect for the expertise that different professional groups bring to this work. Physiotherapists working in exercise oncology in the UK need to come together to develop a shared ambition for the future of this specialism and agree the scope of our practice in conjunction with other specialist groups.

Education: With the development of exercise oncology research, rehabilitation professionals specialising in this field need to improve their expertise in exercise science to future proof our leading role in cancer rehabilitation.

Advocacy: We need to lead the way in assisting all healthcare professionals to improve their health literacy in this area, making it as easy as possible for physical activity to be discussed in every consultation.

Research: Participating in research trials around physical activity implementation will go a long way to not only further understanding but also to influence the culture and wider system understanding of the evidence and service development requirements.

Background

The changing story of cancer

Increasing numbers of people are being diagnosed with cancer. There is a 1 in 2 chance of getting diagnosed with cancer for anyone born after 1960 (Ahmad, et al 2015) which means everyone will be affected by cancer in some way, either directly or indirectly as a carer, friend or employer.

Fortunately, survival rates are also increasing, and cancer is no longer the death sentence it once was. By 2040 average survival is estimated to increase to over ten years compared to one year in the 1970s, resulting in a predicted 4 million people living with cancer in the UK by 2030 (Macmillan, 2015). Treatment and diagnostic advances mean there is a growing cohort of people who are living with relatively stable disease for many years, perhaps receiving regular treatment to keep the disease process stable or simply being monitored for signs of disease progression. The phrase 'treatable but not curable' represents this group of people with a wide range of diagnoses, medical pathways and ongoing, changing needs.

But we also know that for those who are 'cured', surviving cancer doesn't necessarily mean living well and returning to a former 'normal' life. Several studies have highlighted the physical, psychological and financial costs people bear once they have finished their initial treatment.

'People say to me "I bet you wake up every morning feeling glad to be alive" - you know, it can't be further from the truth.'
Chris, Northern Ireland, finished treatment for head and neck cancer 10 months ago

(Life after Cancer Treatment – Am I Meant To Be Ok Now? Macmillan Cancer Support, 2016)

It is also important to recognise that cancer is typically a disease of older age, meaning that those surviving are likely to have other co-morbidities, possibly contributing to their cancer diagnosis or as a direct result of its treatment, which can compound social risk factors such as isolation and reduced independence (Macmillan, 2015).

The result is a growing number of people with a complexity of health needs that cannot be met with a generic one size fits all pathway. The Long Term Plan (DoH, 2019) acknowledged this by promoting the personalisation of care for people with long term conditions, of which cancer is now widely agreed to be one. But whilst our understanding of the challenge might have improved, the implementation of personalised care is more difficult, as we are seeing with the challenge of embedding seemingly simple interventions such as the provision of an end of treatment summary for everyone finishing their cancer treatment.

Exercise and Oncology

In light of the above, it is crucial that interventions to support people to manage the side effects of a cancer diagnosis and its treatment are researched and delivered to those who need them. One of the most rapidly growing areas of non-medical research in the oncology field is around exercise.

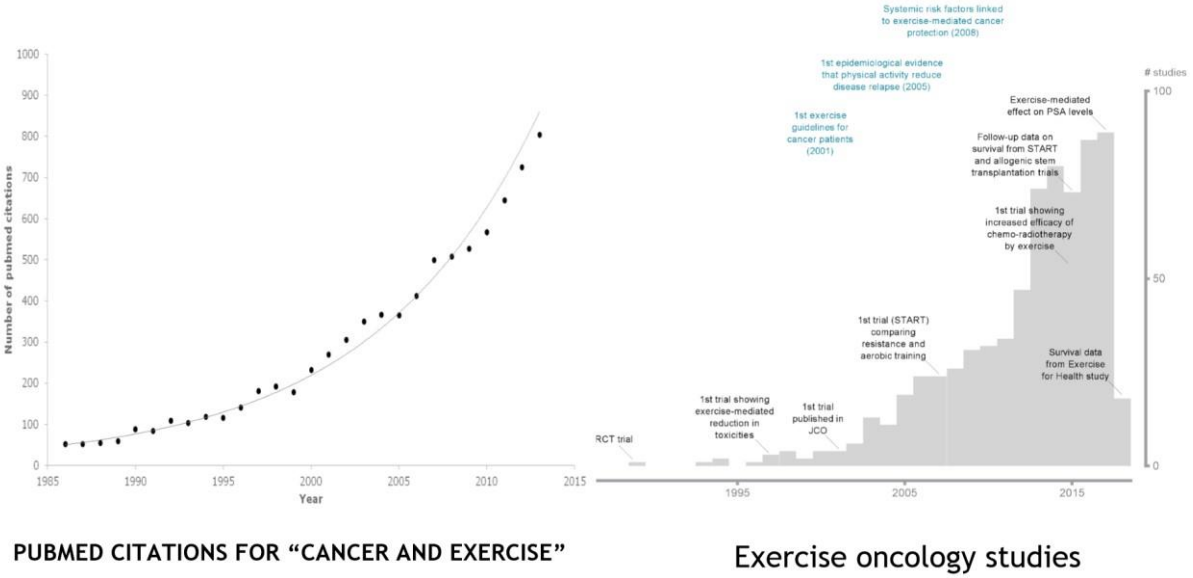


Figure 1: Graphs demonstrating the exponential rise of studies in exercise oncology

(Courtesy of Anna Campbell and Jesper Christensen)

Initially in the 1980s and 90s, the research focus was on whether physical activity was going to harm people or make them feel worse during treatment ie should we still be recommending that people stay in bed and take it easy. Kerry Courneya's team in Canada was one of the first to run trials demonstrating that people with early stage breast cancer who completed aerobic or resistance training were able to complete more of their chemotherapy, as well as benefit from improvements in strength, aerobic fitness and self esteem (Courneya et al, 2007). We now know that keeping active has many quality of life benefits from reducing fatigue to helping with mental wellbeing during and after treatment (Mishra et al, 2012, Campbell et al, 2019).

More recent evidence builds on this by demonstrating that regular exercise before, during or after treatment for cancer decreases the risk of developing new cancers and other co-morbidities such as cardiovascular disease (Cormie et al, 2016). In addition, researchers are beginning to recognise the association between physical activity and reductions in cancer recurrence, with research in breast, prostate and colorectal cancers suggesting people who exercise have a reduced risk of the cancer returning (Campbell et al, 2019).

Epidemiological research suggests cancer specific mortality and all-cause mortality for some types of cancer is also improved amongst physically active groups. For example, a meta-analysis of 38,560 cancer survivors who had mostly breast,

colorectal and prostate cancer demonstrated that higher volumes of self reported physical activity after their cancer diagnosis were associated with a 37% lower relative risk of dying of cancer (Friedenrich et al, 2016).

There are now several clinical trials underway evaluating these emerging findings, as well as translational studies exploring the biological or biobehavioural mechanisms which could determine the potential of exercise beyond a supportive intervention, to a disease modifier.

The Research

Kerry Courneya's team in Canada led one of the first randomised control trials to demonstrate that adding supervised exercise to chemotherapy treatment for breast cancer improves outcomes with an increase in disease free intervals from 75% in the control group to 82% in the exercise groups (Courneya et al, 2014).

Now, exercise physiologists such as Dr Lee Jones from Memorial Sloan Kettering in New York, are leading trials to investigate whether exercise is an effective treatment for cancer, for example by comparing the tumour biology from people who follow a prescribed exercise programme during neoadjuvant chemotherapy compared to those who don't.

The preliminary results suggest exercising at a certain intensity can have a positive effect, and subsequent trials are being designed to test a specific 'dose' of exercise for selected patient groups, as well as explore the biological mechanisms influencing the tumour.

"Findings from studies of this nature will provide the necessary evidence to convince policy makers for the inclusion of exercise rehabilitation in cancer management" Jones et al, 2008

This development in the research has slowly informed a change in practice. Back in 2012, Macmillan Cancer Support published a synthesis of the evidence and the message about keeping active had clearly changed to encourage people to be active and follow the Department of Health's recommended physical activity guidelines (Macmillan, 2012; DoH, 2019). Fast forwarding to the present day just before my travels, Macmillan Cancer Support, in conjunction with the National Institute of Health Research and the Royal College of Anaesthetists published the 'Prehabilitation Guidelines' (Macmillan, 2019) which set out how stratified physical activity support needs to be a key part of the cancer pathway - see 'Breaking News' on page 31. And there is an increasing number of published papers focusing on explaining and addressing the challenges of implementing the science into practice

(Brown & Ligibel, 2019; Santa Mina et al., 2019; Schmitz et al., 2019). However, research has shown that few people achieve the recommended levels of physical activity after a cancer diagnosis, indeed overall levels are likely to fall. So is the message not reaching the public or are the barriers to implementation too great?

Current position in the UK

"Most people with a cancer diagnosis are not given support before treatment to improve their fitness levels, diet and mental health – in spite of strong evidence that this improves treatment outcomes" Manifesto for Community Rehabilitation, 2019

There has not been a systematic approach to oncology rehabilitation or exercise interventions across settings in the UK and services have typically supported good initiatives developed ad hoc through small grants and charity funding. The result is something of a postcode lottery depending on where you live and often the type of cancer you might have had too.

Oncology rehabilitation, where staff have training in health conditions and exercise for health, often sits on the periphery of an oncology service, with one or two clinicians providing support for a particular group of cancer patients at a set time in the pathway. It is unfortunately quite likely that as a cancer patient you will go through your cancer journey without being offered rehabilitation support. The result for patients is often significant unmet need and variation of provision.

Working in these circumstances, it is often difficult for health care professionals to influence the system and historically rehabilitation services have not been good at collecting robust data to demonstrate their outcomes and added value. Measuring the impact of rehabilitation is especially challenging with a disease like cancer which affects many different bodily systems and is unique in its presentation for each individual.

Despite this, and in testament to the innovation and tenacity of people committed to this agenda, there are some excellent examples of oncology rehabilitation which include physical activity support, and it has been a privilege to speak to some of them to assist in writing up this report.

Two examples are outlined below, however there is still a long way to go before personalised exercise is truly embedded as an essential component of treatment and funded accordingly.

Case study: Exercise Referral Service, Harrogate

In 2015 the charity Yorkshire Cancer Research shifted their emphasis away from lab based research to applied research and implementation. One of their

priorities now focuses on physical activity to reduce recurrence rates and improve overall survival.

This has resulted in an initial £712,000 investment to Harrogate District Foundation Trust, who under the guidance of consultant anaesthetist Dr Thomas Collyer, have developed and are piloting the exercise referral service 'Exercise Against Cancer'. The service, led by physiotherapists and personal trainers, aims to provide a range of physical activity services and support for the 600 people diagnosed with cancer in Harrogate each year.

Case study: North Bristol

In North Bristol NHS Trust, joint funding from Macmillan Cancer Support and the Cancer Transformation fund allowed a dedicated physiotherapy outpatient service for cancer patients to be set up in 2018. The service sees prehab and early post-surgical patients to optimise function and prevent more complex issues arising at a later stage. Physical activity support is also offered to patients across all tumour groups at pre and post treatment self-management groups. The service also works closely with the energise cancer exercise scheme based in community leisure centres across Bristol and North Somerset.

My Approach

Since my application to the WCMT there have been additional publications which have contributed to a collective international consensus on how we embed physical activity into cancer treatment pathways, most notably the updated ACSM guidelines. These are outlined in the 'Breaking News' section on page 31 below. However, the motivation for me to base my trip in Australasia was provided by the first of these major publications, the COSA statement.

COSA was the first organisation to recognise that there was both sufficient evidence to support the need for universal physical activity support following a cancer diagnosis, and also that a mission statement was needed to move the conversation beyond exercise being a 'nice to have'. In their statement (appendix 1) they call for:

1. exercise to be embedded as standard practice in cancer care
2. for every member of the MDT to promote physical activity
3. that best practice includes referrals being made to appropriately qualified exercise professionals such as physiotherapists.

I therefore planned my trip with the aim of exploring how work was progressing to embed physical activity. My first trip was to the World Physiotherapy Congress in Geneva, where the inaugural meeting of the oncology sub-group (IPT-HOPE) was launched. As well as attending relevant lectures, the conference was also crucial to

network and make contacts for my upcoming trip to Australia and New Zealand. I arranged meetings and visits to a range of different settings and organisations as outlined in table 1.

Meeting Phil Calvert and Liz Binns, Presidents of the professional bodies for physiotherapy in Australia and New Zealand respectively, at the World Congress in Physiotherapy, Geneva

Table 1: People and organisations visited

Job title/Role	**Location**	**People met**	**Face to face (F) Phone/Skype (P/S)**	**Reason for visiting**
Exercise physiologist and researcher	Mary MacKillop Institute for Health Research, Melbourne	Kelcey Bland	S	Researching exercise and cancer cachexia; Canadian perspective
President of the New Zealand Physiotherapy Association	WCPT, Geneva	Liz Binns	F	Finding contacts to meet in New Zealand
President of the Australian Physiotherapy Association	WCPT, Geneva and APA headquarters, Melbourne	Phil Calvert	F	Finding contacts to meet in New Zealand Meeting the APA Board
Exercise physiologist; exercise oncology research team lead, chair of COSA	Mary MacKillop Institute for Health Research, Melbourne	Prue Cormie	F	*Instrumental in COSA statement*

Job title/Role	Location	People met	Face to face (F) Phone/Skype (P/S)	Reason for visiting
Exercise physiologist	Craigieburn Health Service, Northern Health, Melbourne	Natalie Craven	P	*Example of a community-based EP led exercise programme during treatment*
Physiotherapist	Peter MacCallum Cancer Centre, Melbourne	Jess Crowe	F	*Leads on prehabilitation*
Head of School, Professor of Physiotherapy	Melbourne School of Health Sciences	Linda Denehy	F	*Involved in Macmillan Prehabilitation guidelines; expert in cancer and cardiovascular physiotherapy research*
Oncology physiotherapist and Research Fellow	Wantirna Health, Eastern Health, Melbourne	Amy Dennett	F	*Leading on community-based exercise programmes for people with cancer*
Cancer clinical trials manager and lecturer	School of Physiotherapy, University of Melbourne	Lara Edbrooke	F	*Just published PhD on lung cancer and exercise*
Referral Engagement Manager	Genesis Care, Perth	Aileen Eiszele	P	*Manages exercise referral pathway*
Exercise physiologist, CEO REACH podcast	Exercise Medicine Research Institute, Edith Cowan University	Ciaran Fairman	F	*Running exercise oncology clinical trials and disseminating research via his REACH podcast*

Job title/Role	Location	People met	Face to face (F) Phone/Skype (P/S)	Reason for visiting
Oncology physiotherapist, Research Fellow, national chair for the APA cancer, lymphodema and palliative care group	University of Queensland, Brisbane	Elise Gane	S	*Oncology physiotherapy specialist interest group lead*
Exercise Physiologist	Peter MacCallum Cancer Centre	Travis Hall	F	*Works with prehabilitation service*
Physiotherapy lecturer and researcher	University of Otago, Dunedin, New Zealand	Chris Higgs	S	*Working on community-based exercise RCT for people with diabetes*
Pinc and Steel physiotherapist	Taupo, New Zealand	Tam Holden	F	*To discuss issues relating to cancer rehab in New Zealand*
Founder and Director of Pinc and Steel	Auckland	Lou James	F	*Physiotherapist and leader in promoting exercise and physiotherapy rehabilitation in oncology through education*
Consultant medical oncologist, Director	Australian Cancer Survivorship Centre	Michael Jefford	F	*Leading survivorship work at the Peter Mac*
Exercise Physiologist, PhD researcher	Genesis Care, Perth	Mary Kennedy	P	*Completing PhD on exercise implementation and culture change in a treatment setting*
Physiotherapist, Research Fellow Monash University,	WCPT, Geneva	Breanne Kunstler	F	*Co-founder of 'Physios for Physical Activity'*

Job title/Role	Location	People met	Face to face (F) Phone/Skype (P/S)	Reason for visiting
Melbourne				
Senior AHP Research Fellow	Mater Institute, Brisbane	Liisa Laakso	P	*Background in oncology research*
Head of Cancer Information and Support Services	Cancer Council Victoria, Melbourne	Katherine Lane	F	*The Australian 'Macmillan'*
Physiotherapy lecturer and researcher	University of Auckland	Grant Mawston	F	*To observe physiotherapy led CPET testing in prehab clinic*
Senior lecturer	Charles Gairdner Hospital	Carolyn McIntyre	F	*Course coordinator the post graduate exercise oncology course*
Men's Health Physiotherapist	Complete Physiotherapy, Carine, Perth	Jo Milios	F	*Expert in men's health and rehabilitation post cancer*
Exercise Physiologist	Peter MacCallum Cancer Centre	Andrew Murnane	F	*Contributed to the COSA statement; running a MDT rehabilitation programme for TYA*
	Leederville Oval, Perth	PROST	F	*Example of community based exercise programme for men with/post prostate cancer*
Pinc and Steel physiotherapist and lymphodema practitioner	Auckland	Shannon Ruddell	F	*To observe (and participate!) in Next Steps programme*

Job title/Role	Location	People met	Face to face (F) Phone/Skype (P/S)	Reason for visiting
Pinc and Steel physiotherapist	Auckland	Megan Schmidt	F	*Setting up a physio led exercise programme for breast cancer patients*
Oncology physiotherapist	Manna Care, Doncaster, Melbourne	Germaine Tan	F	*Example of community based cancer rehab programme, jointly physio & EP led*
Research Coordinator, Exercise Medicine Research Institute	Exercise Medicine Research Institute, Edith Cowan University	Cailyn Walker	F	*Co-ordinates the exercise oncology trials*
Pinc and Steel physiotherapist		Rachel Ward	F	*To discuss issues relating to cancer rehab in New Zealand*

Ciaran Fairman at the Fiona Stanley Hospital, Perth

Professor Prue Cormie, Perth

Lou James, Auckland

Professor Linda Denehy, Peter MacCullum Cancer Centre, Melbourne

Findings

I have attempted to organise the content of my visits and conversations into themes in order to present my learning as clearly as possible. Whilst I have tried to credit specific people as much as possible, sometimes my conclusions developed over time, resulting from several different meetings and observations.

Theme One: Health Literacy

I was interested to know how the COSA statement had influenced practice in Australia. The variation in answers largely depended on peoples' roles, with people involved in more strategic and advocacy work reporting that the consensus statement had moved the conversation around exercise from "why" to "how", and in some cases "got us a seat at the table".

> "The evidence is strong enough to say if you're involved in cancer care and you're not providing a service for exercise you're not providing best care" – Professor Prue Cormie

Clinicians had a slightly more reserved view, acknowledging that there had been significant helpful publicity, that in some cases referrals had increased and it had made conversations with oncology colleagues on the importance of exercise with their patients easier.

The statement was not without controversy with some departments questioning whether the strength and ability of the evidence to prescribe in sufficient detail exists, and that in some cases it might be harmful to give a general prescription.

> "Critical to establishing exercise as a medicine is reporting doseage, adherence, and tolerance rigorously in the language used with pharmacological therapies" Professor Rob Newton

There was also widespread recognition, including from Professor Cormie who led this piece of work, that the statement was only a first step and that ensuring that all clinicians do actually have those conversations and make appropriate referrals to exercise services – if those exercise services even exist - will require more work. Clearly the knowledge needs to extend beyond the specialist fields to both the wider

MDT within oncology settings and also to practitioners in primary care and other specialty settings.

But overall it seemed a statement from the leading clinical body on exercise as an integral part of cancer treatment pathways was welcomed, provided a useful reference point and was deemed to be helpful in moving the agenda forward.

As reducing sedentary behaviour becomes an international public health priority the need for system level physical activity promotion is beginning to be heard. In the UK this is set out in Public Health England's 2016 guidance 'Health Matters: getting every adult active every day' and includes the physical activity clinical champion programme I am part of. Alongside this work is a focus on physical activity and longterm conditions with collaborations such as the Richmond Group's 'Movement for All'. This global momentum provides an opportunity to ensure informed messages about physical activity and cancer are included in the dialogue and that collective awareness is increased.

Theme Two: 'Exercise' v 'Physical Activity'

Physical Activity: "Any bodily movement produced by the contraction of skeletal muscles that results in a substantial increase in caloric requirements over resting energy expenditure"

Exercise: "A type of physical activity consisting of planned, structured, and repetitive bodily movement for the purpose of improving and/or maintaining health and physical fitness"

Whilst there is more work to be done to translate the message about 'any physical activity is better than none' to the general public, what was clear from my travels was the distinction between 'physical activity' and 'exercise'. Although the definitions are clearly different, as a clinician I have felt cautious talking about 'exercise' with patients, perhaps matching their language depending on factors such as level of interest, motivation, stage of disease or activity related goals. One of the findings from my research (Dewhurst et al., 2018) was that very active people do not necessarily relate to the concept of exercise. Not wanting to alienate people whilst also recognising that an active lifestyle is better than a sedentary one, it has seemed sufficient to ignore the word 'exercise' unless it is used by the patient.

My beliefs around this were challenged in the presence of exercise physiologists who unsurprisingly use a different language. And this opened up a new question for me as I considered how we try and embed the research into treatment pathways – what do we call the 'moving' bit? The researchers I spoke to at Edith Cowan University

were quite clear, they are prescribing exercise and not advising people to be more active by completing more steps in their day or simply standing up from the sofa during the advertisements breaks. For example, at the ‘Exercise Medicine Research Institute’ in Perth, one of the world leading research centres in exercise oncology, I observed participants on several high intensity research trials such as the ‘GAP 4’ trial outlined below:

Case study: GAP 4

There is currently more than one treatment option for men with advanced prostate cancer, but whilst it is often possible to extend life, drug therapies all come with many side effects such as fatigue, muscle loss, decreased bone density, sexual dysfunction and cardiac problems.

The goal of GAP4, which aims to recruit 866 men from seven countries, is to prove that exercise delays prostate cancer progression and improves survival in men with advanced prostate cancer.

The supervised exercise programme consists of aerobic and resistance exercises performed at ‘high intensity’ based on individually prescribed rates of perceived exertion or repetition maximum targets respectively.

(Newton et al, 2018)

Participants in exercise oncology studies at the Exercise Medicine Research Institute, Edith Cowan University

My visit to the ‘Exercise is Medicine’ research team at Edith Cowan University exposed the gulf between the treatment room and the research gym. A patient living with widespread disease and the side effects of one of the more toxic chemotherapies who has never been especially active and might have several comorbidities is a very different person from a heavily screened and medically cleared trial participant who is keen to participate in a study involving thrice weekly HIIT training in a gym. Discussing this with one of the postdoctoral research fellows Ciaran Fairman showed a real appreciation for their responsibility to the participants, for example supporting them with subsidised gym membership at the end of the trials and also for the challenge of translating their findings to real life settings. I accept the

point that if exercise is medicine it needs to be researched with the same rigour that other anti-cancer treatments are, and whilst it was clear at times that we were talking a different language and 'seeing' different patients, it was nonetheless inspirational to observe people with advanced metastatic disease perform HIIT training to rival my own training.

I explored this during my visits to two community exercise programmes and the response from the physiotherapists was pragmatic and more familiar, focusing on an accurate initial assessment, setting targeted goals and aiming to demonstrate to people through achievement and experience how 'exercise' was safe and beneficial. The exercise itself might have been sufficient to have a physiological impact but the goal was always functional. They were more comfortable using the term 'exercise', the classes were held in community gym sessions and they supported patients to continue at public gyms at the end of their programmes. I wondered if there was a slight cultural difference here between Australia and the UK in terms of people's perceptions of 'exercise' or whether they too were seeing a self-selected group for whom the concept of 'exercise' was not off putting.

Another example of the cultural relevance was the 'PROST INC!' programme which has taken a slightly different approach. Set up by Jo MIlios, a men's health specialist physiotherapist based in Perth, PROST INC! is a community-based exercise programme for men with prostate cancer based in a football club. Although it offers a twice weekly supervised exercise programme it is as much a social and peer support as anything else. These men had no difficulty relating to doing 'exercise' and indeed this seemed to be an incentive and a link to a cancer-free past.

Case Study: PROST INC!

The PROST INC! mission: "to educate, inspire and support men in their experience with male health concerns, in relation to prostate cancer, chronic pelvic pain and disorders of continence and sexual health. This is achieved through high quality clinical care, continuing research, community outreach, exercise programs and a commitment to serve men in their quest for better health"

Supervised by an exercise physiologist, the group meet twice a week in a football club to complete a circuit based exercise programme, "designed to help men build up their mood, mate-ship and muscle" including resistance, cardiovascular and exercises targeted to the restoration of pelvic floor function.

The organisation is not for profit and the men pay a small fee each class to cover costs. There is also a coffee club where men and their partners can socialise and gain support. http://prost.com.au/

PROST members performing a warm up on the football pitch, group pelvic floor exercises, then completing a circuit-based resistance and aerobic exercise programme

"Put it this way, I wouldn't be announcing being able to 'get it up' for the first time after my operation to just any group of fellas" PROST participant

My travels really brought to life the exercise continuum, with the research moving up to the high intensity end and the implementation side typically focusing at a lower level. The use of language, 'exercise' versus 'physical activity', symbolises one of the challenges of implementation if exercise prescriptions are to be accepted by patients and properly embedded as standard of care.

Theme Three: Workforce

A fascinating aspect to this work emerged during my travels and also became more visible in the UK during this time with the publication of the joint Prehabilitation Guidelines (Macmillan, 2019): the question of whose role it is to 'do the exercise bit'. In Australia the Medicare 'chronic disease management' tariff allows patients to access 5 sessions with an allied health professional per year. Exercise support from

an exercise physiologist is permitted under this tariff and consequently they are well positioned to work with people with cancer on exercise programmes.

Discussions with the Australian Physiotherapy Association (APA) highlighted this has been challenging and exposed a lack of skilled physiotherapy clinicians with the necessary expertise in oncology and exercise. Perhaps as a result it was interesting to see examples of multi-disciplinary rehabilitation programmes without physiotherapy involvement.

Some of the best examples I observed of community exercise programmes had a joint approach where physiotherapists and exercise physiologists worked side by side, capitalising on each other's expertise, for example the POWER programme highlighted below:

Case Study: POWER

POWER is a 12 week, twice weekly exercise programme, alternating between a local gym and a community hospital outpatient department in the suburbs of Melbourne.

Supervised by a physiotherapist and an exercise physiologist, participants complete an initial assessment then receive an individually prescribed exercise programme. There is an educational component on topics such as fatigue and nutrition and the option of accessing psychological support. On completion they get reduced gym membership.

POWER participant, physiotherapy lead Germaine Tan and exercise physiologist Jess Freeman

Whilst we don't have the same clinical exercise physiologist workforce in the UK yet, there is a developing recognition that the health and fitness industries need to work collaboratively to achieve the necessary scale of exercise support and interventions required for cancer patients and others with chronic disease.

“It’s been marvellous. I came in a wheelchair initially. My next goal is to walk by myself in the park” POWER participant

As the stratification approach outlined in the Prehabilitation Guidelines is developed, it will be crucial to understand everyone’s role and ensure the patient is safely supported by the best equipped professional who has access to a wider multidisciplinary team as needed dependent on the individuals’ health needs/ status.

It was clear that the role of rehabilitation is still not visible to large numbers of the workforce. As I explored this on my travels it became clearer that despite all of the advocacy work of clinicians, patient groups and charities such as ‘Cancer Care’, the rehabilitation needs of cancer patients remain more hidden than they should be. This results in people not reaching their full potential following treatment.

“People don’t know what rehab is, so they assess people as having no rehab needs” Lou James

As rehabilitation specialists we have a duty to not only advocate on our patients’ behalves and improve the opportunity they have to access services, but also to be very clear about our role and the value we add to this specialism. As the case for exercise services becomes more mainstream, the role of healthcare professionals within this work is at risk of getting lost. The more complex patients with multiple health needs, who physiotherapists are arguably the most skilled to support, will not have therapeutic services available to them. Cancer patients can vary widely in their medical complexity due to the disparate nature of the disease and I saw examples where exercise services were more geared towards those who are fundamentally healthy, suggesting it is possible to work in the cancer field and only see a specific group of patients whose needs do not represent those of the wider population of cancer patients. Providers were therefore not unreasonable to say: “well they don’t really need rehab, we just need to get them in a gym”.

The challenge of a one size fits all approach to cancer patients is not new, but it extends to the question of an appropriately skilled workforce too, and I therefore believe that there is room for more than one professional group. However, it is clear from talking to physiotherapists both at home and abroad that we need to have a collective voice that clearly states what oncology physiotherapy stands for, and the ‘USP’ of our expertise.

The Australian Physiotherapy Association have made efforts to address this by working on titled roles and linking with the specialist interest group to define tiers of expertise within a defined specialism. The aim is to provide clarity and standardisation to the skills a particular physiotherapist might have, something I feel would be of benefit to the UK.

Theme Four: Education

A topic which kept coming up in discussions was the need for education on exercise oncology for healthcare professionals in this field. Unlike in theme one which promotes the need for a higher level of awareness for generalists and those in positions of strategic influence, there was also a recognition that for practice to evolve there needs to be more specific education at both undergraduate and postgraduate level.

In the UK currently there is minimal oncology content in undergraduate physiotherapy courses and a small number of post graduates offers such as occasional bespoke study days run by the 'Association of Chartered Physiotherapists in Oncology and Palliative Care' (ACPOPC) or the Royal Marsden School (https://www.royalmarsdenschool.ac.uk/) or 'CanRehab' which offers a level 4 training course for health care and fitness professionals in cancer rehabilitation (http://canrehab.co.uk/).

Case Study: EX-MED Cancer

EX-MED Cancer was set up by Professor Prue Cormie as a best practice, not for profit exercise programme for people with cancer.

The programme is run by trained exercise physiologists and consists of an initial screening appointment and setting of an individualised programme, followed by thrice weekly hour long exercise classes. At the end of the 10-week programme there is a final review session to adapt the programme and agree a plan for continuing independently.

It currently runs at 5 sites around Melbourne with plans for a national rollout.

https://www.exmedcancer.org.au/

In Australia, discussions with Elise Gane, the lead physiotherapist for their oncology specialist interest group confirmed that they have a similar gap in oncology rehabilitation education. She cited an 'Introduction to Oncology' study day run by the Physiotherapy Department at the Peter MacCallum Cancer Centre in Melbourne as the only existing face to face option. Rehabilitation professionals throughout my travels in Australia ranked a lack of formal education in this specialism as one of the main barriers to continuing professional development. And whilst they acknowledged the gap in oncology specific training, there was also a call for greater expertise in advanced exercise prescription for physiotherapists.

As is the case in the UK, exercise prescription in chronic disease management is a growth area for the fitness industry and there is a growing availability of oncology specific education for exercise professionals. For example, Professor Prue Cormie has developed some post graduate training for exercise physiologists and there is an online multi-professional exercise oncology post graduate programme run by the

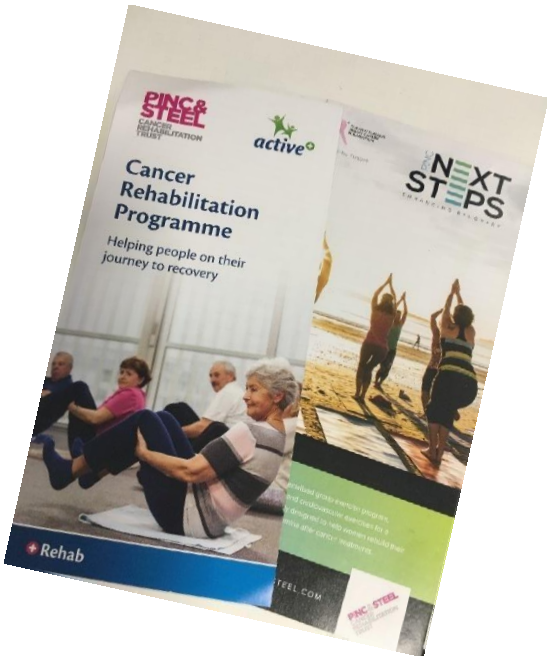
Exercise Medicine team at Edith Cowan University in Perth (https://www.exercisemedicine.org.au/__data/assets/pdf_file/0008/571913/6.Advertising-material.pdf). The course leader Carolyn McIntyre explained how this developed out of requests by a range of healthcare professionals for a course which explains the exercise science in relation to cancer

The best example I saw of exercise oncology education specifically for rehabilitation was 'Pinc and Steel'. Physiotherapist Lou James set up the educational charity after seeing the lack of rehabilitation available for cancer patients in New Zealand. The online education now has an international reach and not only presents the evidence base for physiotherapists but also provides ongoing support via a face book group and practical support to develop services. I had the privilege of visiting several Pinc and Steel trained physiotherapists in New Zealand and their passion for cancer rehabilitation was inspiring; especially given the absence of state funding for their specialism. And it was notable how a lack of cancer specific education was not on the list of barriers to service improvements for New Zealand therapists.

Case Study: Pinc and Steel

Pinc and Steel is dedicated to improving the strength, quality of life and sense of wellbeing of people diagnosed with cancer. The charity arm fund raises to increase awareness of the need for cancer rehabilitation and to provide financial support for people unable to pay for cancer rehabilitation. The education arm exists to equip physiotherapists to support people at all stages of and following a cancer diagnosis. Programmes offered by Pinc and Steel physiotherapists include manual physiotherapy, resistance training, clinical pilates, fatigue management and exercise prescription.

To be a Pinc and Steel physiotherapist there are two core online modules: 'Pinc' and 'Steel' focusing on physiotherapy for female and male cancers respectively, together with specific courses for programmes like 'Next Steps' – a 10 week group exercise programme for women affected by cancer and 'Paddle On' – a paddle boarding course



Another example of innovation in exercise oncology education is being delivered by Ciaran Fairman who set up the 'REACH Beyond Cancer' podcast series in an attempt to share the research with a wider audience. Each podcast focuses on an interview with a particular research focus and goes a long way to inform and improve the accessibility of scientific topics. https://www.reachbeyondcancer.com/podcast

Theme Five: Location of Intervention

Two contrasting scenarios played out in relation to this theme. Throughout my travels it became clear that where exercise interventions were available, they were being developed in community settings with links to local gym and services, as outlined in the POWER case study above. The benefits of reducing travel times, avoiding negative associations with hospitals and treatment, reinforcing the behavioural lifestyle changes and 'normalising' exercise are well known and echoed by the patients I spoke to.

Whilst this might appear to be a step forward in terms of community integration, as one physiotherapist I spoke to put it "well the services exist if you're someone who likes the gym". Chris Higgs, a physiotherapy professional practice fellow at the University of Otago in Dunedin spoke passionately about the importance of delivering interventions in culturally sensitive locations. His randomised controlled trial involves working with local Maaori and Pacific Island communities and is run in socioeconomically deprived areas with the emphasis on increasing accessibility through measures such as free parking and a Maaori outreach community nurse. The research is typically biased towards white, female breast cancer patients (Brown and Ligibel, 2019) and in considering 'place', a more real world approach is likely to be required.

“No mirrors, no lycra, no judgement” Chris Higgs, Physiotherapy Professional Practice Fellow

In contrast, I spoke to Mary Kennedy, who is carrying out a PhD at Edith Cowan University in Perth, looking at the implementation of exercise as a standard component of care within GenesisCare, a private oncology treatment centre. Patients who attend Genesis Care for radiotherapy or chemotherapy are referred to an in-house exercise physiologist, where they receive an exercise prescription tailored to their needs during and after treatment. This model has been designed to embed exercise as a key component of treatment from the start and a crucial concept in this work is that the gym is unapologetically ‘medicalised’. The exercise physiologist is also part of the multidisciplinary team and has access to all of the relevant clinical information to inform their decision making; helping to create a culture for both patients and staff that exercise is not a nice thing to add on to treatment but is part of treatment.

“This is lifestyle medicine” Mary Kennedy, Exercise Physiologist

Whilst on site exercise facilities might not be achievable at scale, the principles of how the cultural change is being achieved at Genesis Care provides a challenge to the status quo of people travelling to hospital for treatment, sitting down for long periods whilst they wait or receive treatment and then going home. It will be fascinating to learn the outcome of their research.

Case Study: GenesisCare

“GenesisCare offer a private model of practice that is leading the way on embedding exercise into cancer treatment. Initially specialising in cardiology in Australia, GenesisCare now has an expanding oncology service with treatment centres in Australia, Spain and 13 in the UK.

Following their successfully piloted Exercise Medicine programme in Windsor, GenesisCare is fully committed to implementing Exercise Medicine across their network. The ambition is for all UK centres to offer supported exercise programmes under the guidance of a physiotherapist and a level 4 qualified personal trainer.

They offer a supervised 12 week, twice weekly resistance-based prescribed exercise programme for patients to coincide with their cancer treatment. On completion they support an exercise referral locally."

Traditionally in the UK cancer care has been carried out in acute settings but this is now changing with developments such as mobile chemotherapy and primary care based stratified follow-up pathways. If we are starting to embrace physical activity as a key component of cancer care I believe a continuum approach is required where messaging and availability of exercise support is uniform throughout the pathway. This will require greater joining up between acute and secondary care not only of services, but of knowledge of different systems and referral pathways, and

of lines of communication and trust. What about a cross sector exercise multi-disciplinary team for example….

Theme Six: Importance of a Champion

There was universal acknowledgement that a champion for exercise in oncology within a department or service gave credibility and got a seat at the table. The services I visited were all able to cite a person who understood the research and advocated for the developments they were trying to lead. Unfortunately, we still operate largely in a medically led model in healthcare in the UK and to progress this work we need to find champions in other sectors who are committed to promoting the value of physical activity.

Conclusions

I didn't come back to the UK with examples of a perfect model or a complete cancer pathway which currently has exercise embedded into its core. Instead, I gained valuable insight into some of the key components which I believe are the foundations from which exercise as a standard part of cancer care can be achieved.

There is clearly an exercise continuum starting from a conversation or a leaflet, to performing a personalised HIIT training programme during chemotherapy. And whilst I agree with the researchers who believe we don't know enough about the effect on specific cancers to prescribe specific doses, I strongly believe we can't wait for the evidence to be neatly tied up. To quote Professor Cormie, we need to ask the question: "what can we do to change practice now"?

We know enough to shout loudly "sit less, move more" and there are many ways we can get the building blocks in place, starting with education at both general and specialist level and bringing the workforce together to agree a systematic approach. As physiotherapists specialising in this field, we need to be clear about our role and expertise. Our current approach on physical activity versus exercise is understandable given our everyday contact with the most complex and vulnerable people living with cancer, this is our bread and butter. But it is in my view crucial that we acknowledge and embrace the new role of exercise as medicine which is coming in the not too distant future and review our skillset and approach accordingly. In order to do this we need to jointly work with champions from other sectors who will support this agenda at the highest level, alongside further developing clinical leadership within rehabilitation.

And somehow, we need to not let the lack of funding for this work stop innovation, implementation and scale. Lack of funding came up as a barrier to service delivery during every conversation relating to implementation, so much so I decided not to dwell on it as a theme – if that's the given then let's not let it hold us back because when we can prove the benefits at a clinical level I believe the funding will come. Research momentum is beginning to build around the implementation of exercise oncology and this presents an opportunity for services leading on cancer care in the UK to take a different approach from third sector funding.

Early diagnosis, prevention and cure are perhaps still dominating the cancer agenda, but I was so heartened to spend time with a wide range of skilled professionals who are all passionate about exercise rehabilitation and improving the quality of life for people who are diagnosed with cancer. It was truly inspirational, and I hope I have passed on some of their wisdom throughout this report.

Thank you to everyone who has supported my Fellowship, and for the 'whanaungatanga' I experienced wherever I went.

Recommendations

A Collective Approach: Keeping the patients' needs at the centre over any ambition or ego, progress will be made at a faster pace with collaboration and respect for the expertise that different professional groups bring to this work. With that in mind I would like to see physiotherapists working in exercise oncology in the UK coming together to develop our collective leadership and voice within this field, share best practice, draft a shared ambition for the future of this specialism and agree the scope of our practice in conjunction with other specialist groups.

Education: Because of its far-reaching impact, there is a need for exercise prescription to be central to oncology physiotherapy practice, hence there needs to be robust training opportunities at both undergraduate and post graduate level. The limited number of existing post graduate courses offer an introductory baseline in oncology for non-specialists but with the development of exercise oncology research those of us specialising in this field need to improve our expertise in exercise science to future proof our leading role in cancer rehabilitation. This will ensure that effective levels of exercise can be delivered safely to patients.

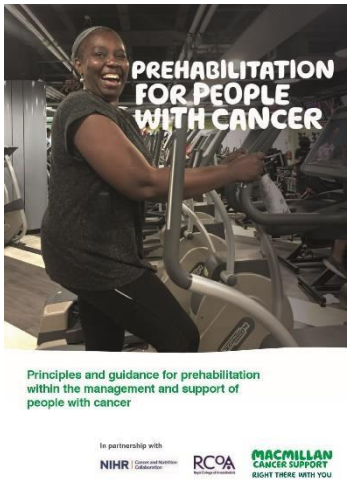
Advocacy: The recently published updated ACSM guidelines echo the COSA statement which inspired my Fellowship by calling on all healthcare professionals to understand their role on supporting cancer patients to understand the importance of exercise and pointing them in the right direction to be active. If we consider our role as oncology physiotherapists to extend to exercise then we need to lead the way in assisting all healthcare professionals to improve their health literacy in this area, making it as easy as possible for physical activity to be discussed in every consultation. The addition of physical activity to the cancer outcome dataset reporting function for 2020 is a very welcome step forward and presents an opportunity to shape how it is embedded.
(http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd)

Research: Participating in research trials around physical activity implementation could go a long way to not only further understanding but also to influence the culture and wider system understanding of the evidence and service development requirements. I was told on my travels: "if we were handed the money on a plate today, we wouldn't know the best way to spend it", so implementation research is crucial to get this right for patients. This is the legacy that my generation of oncology physiotherapists have the potential to leave. I include reference to the STAMINA trial in Sheffield which provides an excellent example: https://www.stamina.org.uk/about

Breaking News

During my trip and since my return three key documents have been published which I believe go a long way to corroborate my findings and support the recommendations outlined above.

1 The Prehabilitation Guidelines in partnership with Macmillan Cancer Support, NIHR and the Royal College of Anaesthetists (Macmillan, 2019)

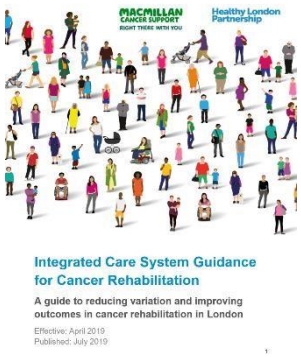


Key Points

"Prehabilitation enables people with cancer to prepare for treatment through promoting healthy behaviours and through needs-based prescribing of exercise, nutrition and psychological interventions. Prehabilitation is part of a continuum to rehabilitation. The aims of prehabilitation are to empower patients to maximise resilience to treatment and improve long-term health."

This document provides guidance on how prehabilitation can and should be embedded within cancer treatment pathways.

2 The Integrated Care System Guidance for Cancer Rehabilitation (Healthy London Partnership, 2019)



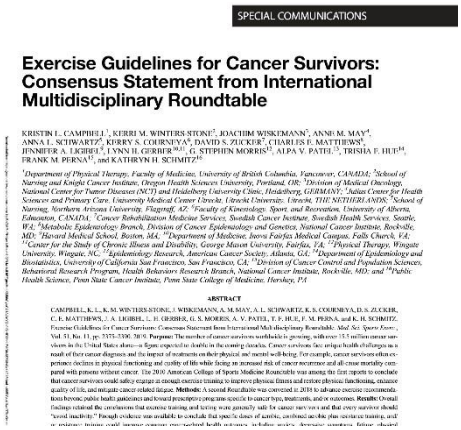
Key Points

"Rehabilitation is a vital component in the care of people living with and beyond cancer…there are many challenges facing services in London. This report includes 3 pieces of work:

- Mapping of cancer rehabilitation services
- A minimum dataset
- Service improvement tools

3 The updated ACSM exercise guidelines for cancer

(Campbell KL, et al. 2019)



SPECIAL COMMUNICATIONS

Exercise Guidelines for Cancer Survivors: Consensus Statement from International Multidisciplinary Roundtable

KRISTIN L. CAMPBELL[1], KERRI M. WINTERS-STONE[2], JOACHIM WISKEMANN[3], ANNE M. MAY[4], ANNA L. SCHWARTZ[5], KERRY S. COURNEYA[6], DAVID S. ZUCKER[7], CHARLES F. MATTHEWS[8], JENNIFER A. LIGIBEL[9], LYNN H. GERBER[10,11], G. STEPHEN MORRIS[12], ALPA V. PATEL[13], TRISHA F. HUE[14], FRANK M. PERNA[15], and KATHRYN H. SCHMITZ[16]

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ABSTRACT

CAMPBELL, K. L., K. M. WINTERS-STONE, J. WISKEMANN, A. M. MAY, A. L. SCHWARTZ, K. S. COURNEYA, D. S. ZUCKER, C. F. MATTHEWS, J. A. LIGIBEL, L. H. GERBER, G. S. MORRIS, A. V. PATEL, T. F. HUE, F. M. PERNA, and K. H. SCHMITZ. Exercise Guidelines for Cancer Survivors: Consensus Statement from International Multidisciplinary Roundtable. *Med. Sci. Sports Exerc.*, Vol. 51, No. 11, pp. 2375–2390, 2019. **Purpose:** The number of cancer survivors worldwide is growing, with over 15.5 million cancer survivors in the United States alone—a figure expected to double in the coming decades. Cancer survivors face unique health challenges as a result of their cancer diagnoses and the impact of treatments on their physical and mental well-being. For example, cancer survivors often experience declines in physical functioning and quality of life while facing an increased risk of cancer recurrence and all-cause mortality compared with persons without cancer. The 2010 American College of Sports Medicine Roundtable was among the first reports to conclude that cancer survivors could safely engage in aerobic exercise training to improve physical fitness and certain physical functioning, enhance quality of life, and mitigate cancer-related fatigue. **Methods:** A second Roundtable was convened in 2018 to advance exercise recommendations beyond public health guidelines and toward prescriptive programs specific to cancer type, treatments, and/or outcomes. **Results:** Overall findings retained the conclusions that exercise training and testing were generally safe for cancer survivors and that every survivor should "avoid inactivity." Enough evidence was available to conclude that specific doses of aerobic, combined aerobic plus resistance training, and [illegible] could improve cancer-related health outcomes, including anxiety, depression, fatigue, physical

Key Points

"Physical activity can play an important role in cancer prevention and control, but there is a need to update the state of the science to best facilitate dissemination and implementation of evidence into practice"

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There are significantly more references which have informed my practice and understanding of this area, but I have only included the most pertinent papers which support this report.

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Appendix 1: Cosa Position Statement