

Rehabilitation After Cancer: A Gap in the Canadian Healthcare System

September 20, 2018

Cancer Survivorship

- What is a cancer survivor? What is survivorship?
 - “An experience of living through or beyond an illness”
(Canadian Cancer Society)
- According to the Canadian Cancer Society, there are approximately **one million** Canadians who have survived cancer for over 10 years.
- With more cancer patients surviving, there is a need for specialized services to help survivors.

Canadian Cancer Survivor Network Initiatives

- Ontario All-party Cancer Caucus (November 2017)
- Ontario All-party Cancer Caucus (March 2018)
- Alberta All-party Cancer Caucus (May 2018)
- Cancer Survivorship Survey
- Survivorship & Rehabilitation Website Section
- Advisory Council
- Ontario All-party Cancer Caucus (November 2018)



Availability of Oncology Rehabilitation Programs in Canada

Jaymee Maaghop

Director of Public Policy

Canadian Cancer Survivor Network

The status of cancer rehabilitation programs across Canada

- Rehabilitation programs are scarce despite the growing need in cancer survivorship.
- In 2013, the University of Toronto examined the availability of oncology rehabilitation programs for people living with the symptoms of cancer and its treatment. It was the first study of its kind in Canada.

Alysa Canestraro, Anthony Nakhle, Malissa Stack et. al. "Oncology Rehabilitation Provision and Practice Patterns across Canada," *Physiotherapy Canada*, vol. 65, no. 1, 2013, pp. 94-102.

The status of cancer rehabilitation programs across Canada

- Of 116 health centres contacted (hospitals, private clinics, and community based programs):
 - 20 have a formal rehab program (15 of these are situated in urban centres)
 - 41 did not have a formal rehab program
- No database available for these programs.
- Research conducted by *Realize* Canada saw that publicly funded and/or community based rehabilitation services for chronic diseases across Canada, including cancer, are insufficient for people aged 18-64. This is because most of the programs available were for residents in long-term care homes or palliative services.

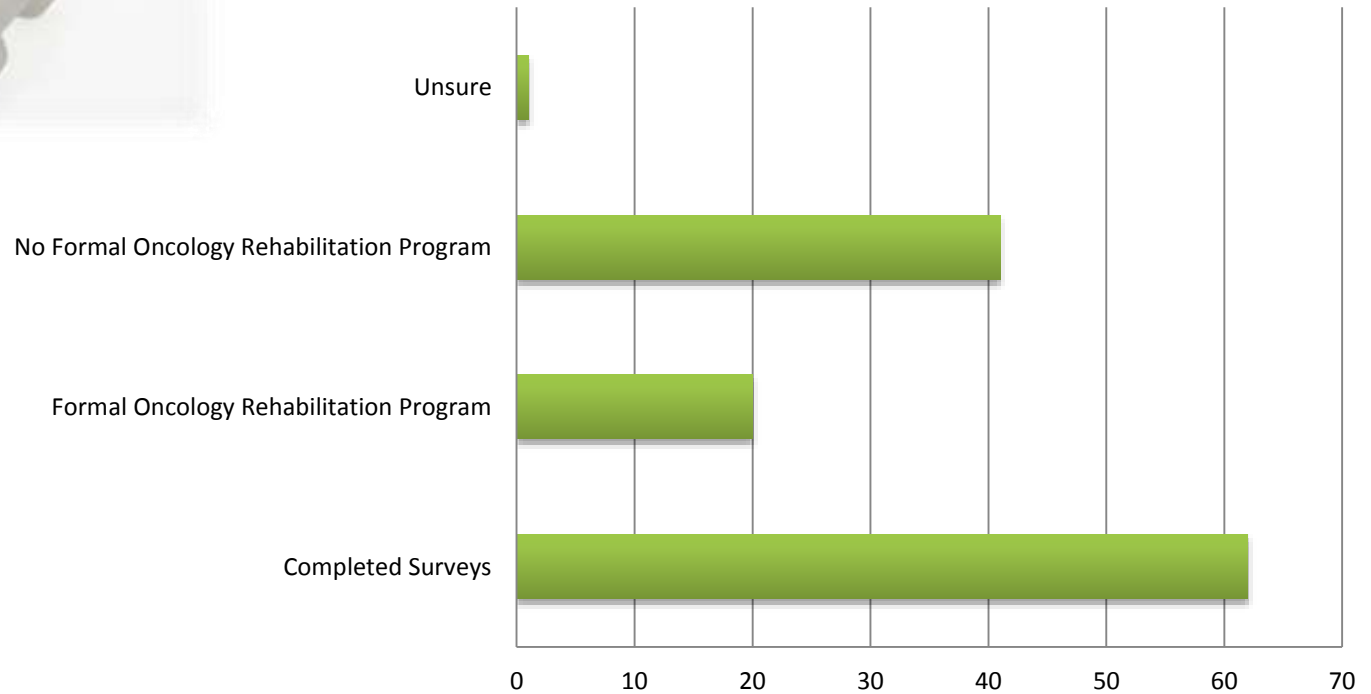
Realize, “An environmental scan of publicly-funded rehabilitation services across Canada.”
Realize Canada, 1 March 2016, pp. 1-10.

The status of cancer rehabilitation programs across Canada



Respondent Data - Nationwide*

Total Health Centres Identified:
179 (hospitals, private clinics, community-based programs)



	Completed Surveys	Formal Oncology Rehabilitation Program	No Formal Oncology Rehabilitation Program	Unsure
■ Health Centres	62	20	41	1

Key Points to Consider

- Rehabilitation is mostly available for residents in long-term care homes and for other diseases.
- Rehabilitation after treatment is not often considered in the *cancer care continuum*.
- Patients are on their own to deal with the long-term side effects of cancer treatments.
- No database exists for cancer rehab programs.
- There is also no defined credentials for a specialist in cancer rehab. This is true for Cancer Care Alberta and Cancer Care Ontario. However, work is underway to address this problem.

ADULT CANCER SURVIVORS: RESTORING HEALTH AND WELL-BEING

Jennifer M. Jones, PhD

Butterfield Drew Chair in Cancer Survivorship Research

Director, Cancer Rehabilitation & Survivorship Program

Princess Margaret Cancer Centre, UHN

Senior Scientist, Ontario Cancer Institute

Stephanie Phan, OTReg.(Ont.)

Clinical Lead, Cancer Rehabilitation & Survivorship Program

Princess Margaret Cancer Centre, UHN

DISCLOSURE

Relevant relationships with commercial entities:

None

Potential for conflicts of interest within this presentation:

None

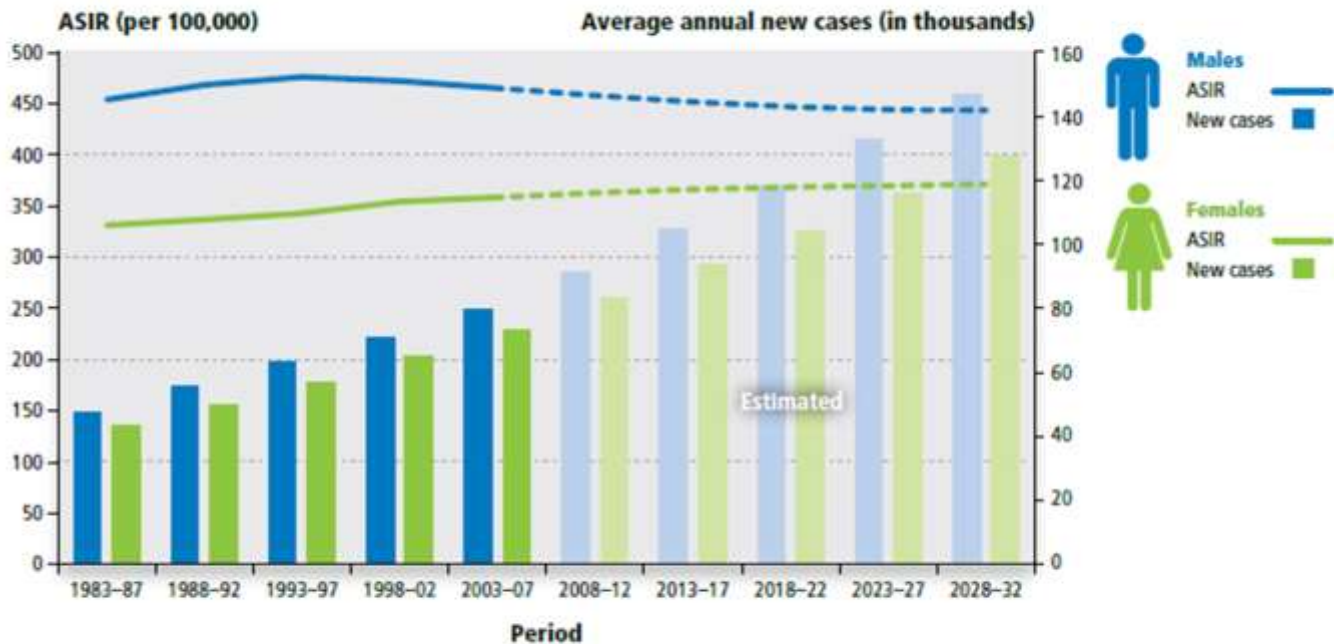
Steps taken to review and mitigate potential bias:

N/A

Looking forward...

- The number of new cases is expected to rise by about 70% over the next 2 decades.

FIGURE 7.2 Average annual new cases and age-standardized incidence rates (ASIRs) for all cancers, Canada, 1983–2032



Analysis by: Surveillance and Epidemiology Division, CCDE, Public Health Agency of Canada

Data sources: Canadian Cancer Registry and National Cancer Incidence Reporting System databases at Statistics Canada

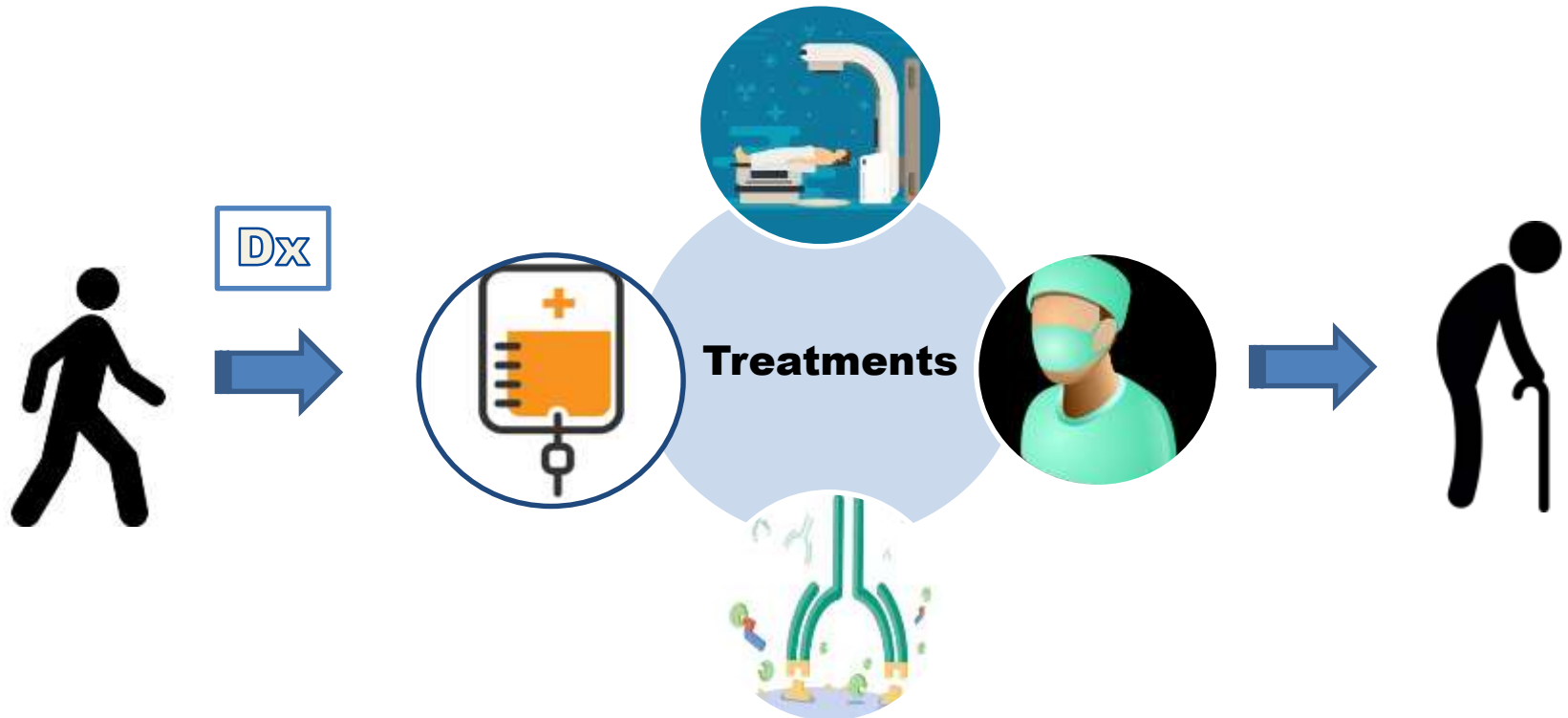
The good news...

- mortality rates have dropped significantly
 - tobacco control, early detection and better treatments
- five-year age-standardized RSR for cancers combined is 63% when measured from the date of diagnosis and increases to 81% when measured among those who survived the first year after a cancer diagnosis.



Survival...but at a cost

“Unlike other chronic diseases such as diabetes or arthritis where disability is commonly caused by the disease process itself, short and long term disability associated with cancer is often caused more by treatment than the disease itself.” *Short et al 2008*



Challenges Facing Cancer Survivors

From a public health perspective, **disability is now considered as important as mortality** and while advances in cancer detection and treatments have reduced mortality, persistent and late effects of cancer and its treatments need to be identified and managed lifelong.



Challenges Facing Cancer Survivors

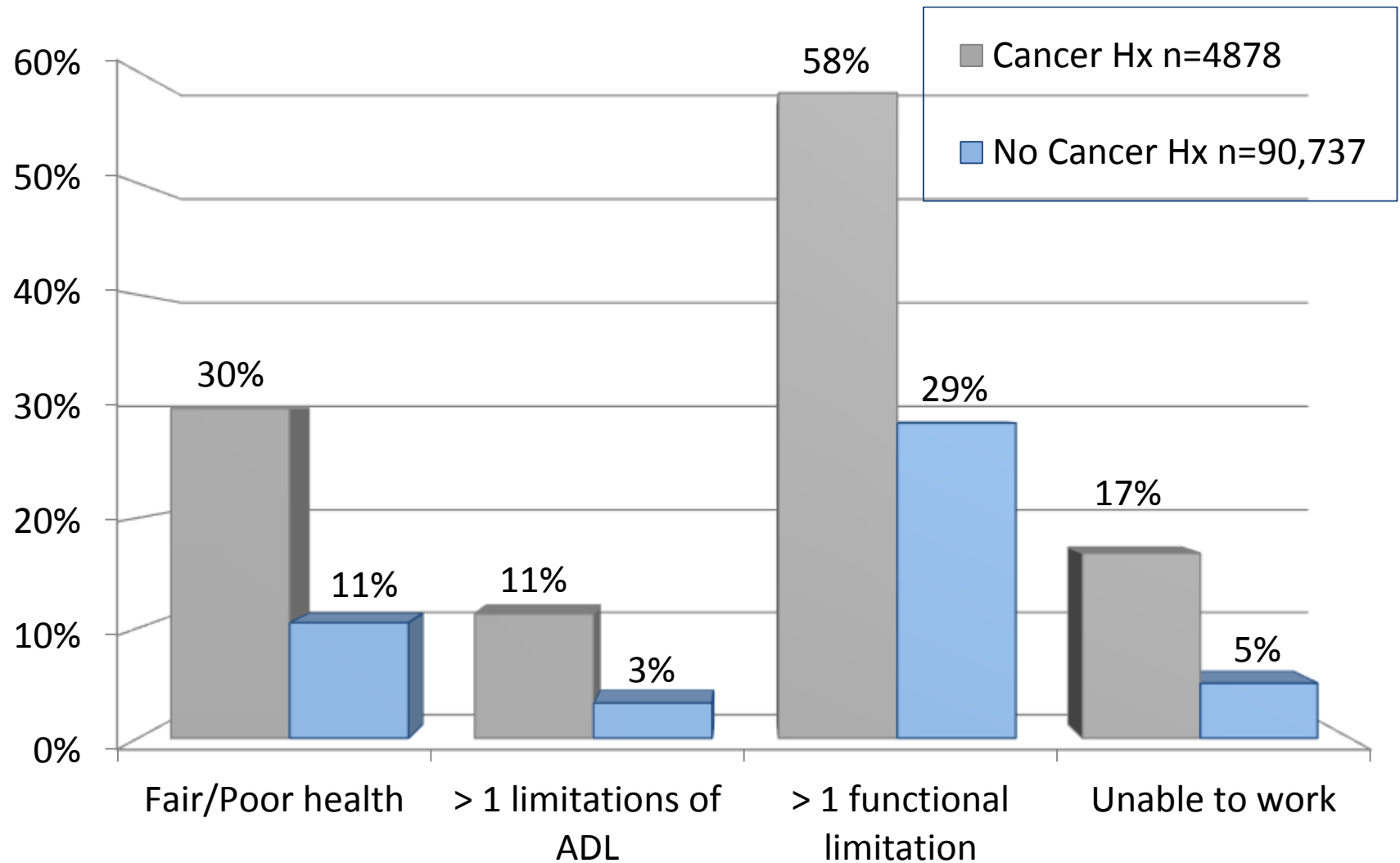
- all major types of Ca tx can result in side-effects that can impair well-being, physical and psychosocial functioning and overall quality of life and may last after treatment ends (**persistent treatment effects**)
- new side-effects may also manifest months or even years after treatment ends (**late treatment effects**)
- common and numerous, but knowledge regarding exact incidence, prevalence, and risk factors remains limited



Physical Effects

- at risk of local and distant recurrence and second primary cancers
- tx can affect almost all body systems and result in long-term and late effects
 - cardiac and respiratory dysfunction, cognitive impairments, pain, fatigue, neuropathy, functional limitations, sleep disturbances, sexual dysfunction, infertility
- symptoms often co-exist and are worsened by comorbidities and may be exacerbated by age-related processes

Health Status and Disability (NHIS Survey)



Psychosocial Wellbeing

- patients and their families also face significant psychosocial and economic consequences
 - fear of cancer recurrence, uncertainty, anger, anxiety, emotional vulnerability, issues related to sexual dysfunction and altered body image are often common.
- changes in social outcomes such as relationships, communication, or community involvement
- practical concerns in relation to returning to work, health and life insurance implications, employment and financial issues

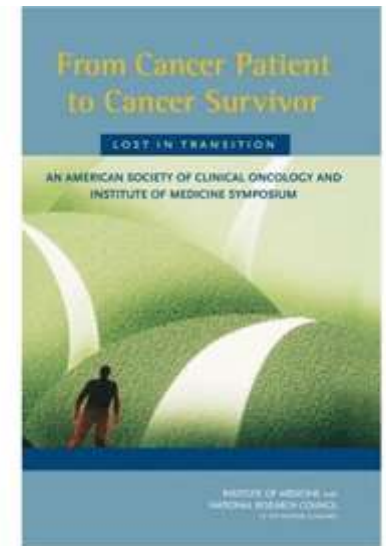
IOM Essential Components of Survivorship Care

Prevention of recurrence and new cancers, and of other late effects

Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects

Intervention for the consequences of cancer and its treatment

Coordination between specialists and primary care providers to ensure that all of the survivors health needs are met



Cancer Rehabilitation

- With the growing number of cancer survivors along with recognition of risk-stratified levels of need, there has been increased interest in a multidisciplinary cancer rehabilitation approach.
- Rehabilitation programs can fill a gap in survivorship care between the screening, surveillance and referral focus of follow-up care, and the need of some survivors for more specialized physical and mental recovery care



“The experience of entering the medical system for many cancer patients is that they feel very good at the beginning, and then the treatments make them profoundly ill and often disabled. When they are sicker and more debilitated than they have ever been, they are discharged to follow-up care, which may include such things as routine screening for cancer recurrence, managing ongoing medications, and others, but this does not generally include a multidisciplinary rehabilitation intervention. In effect, the medical system creates a situation where high-functioning individuals are given life-prolonging treatments and then left to struggle with how to recover from the toxic adverse effects of these therapies”.

Silver and Gilchrist 2011

Intervention: Cancer Rehabilitation

“Cancer rehabilitation, involves helping a person with cancer to help himself or herself to obtain maximum physical, social, psychological, and vocational functioning within the limits imposed by disease and its treatment”

(Crome)

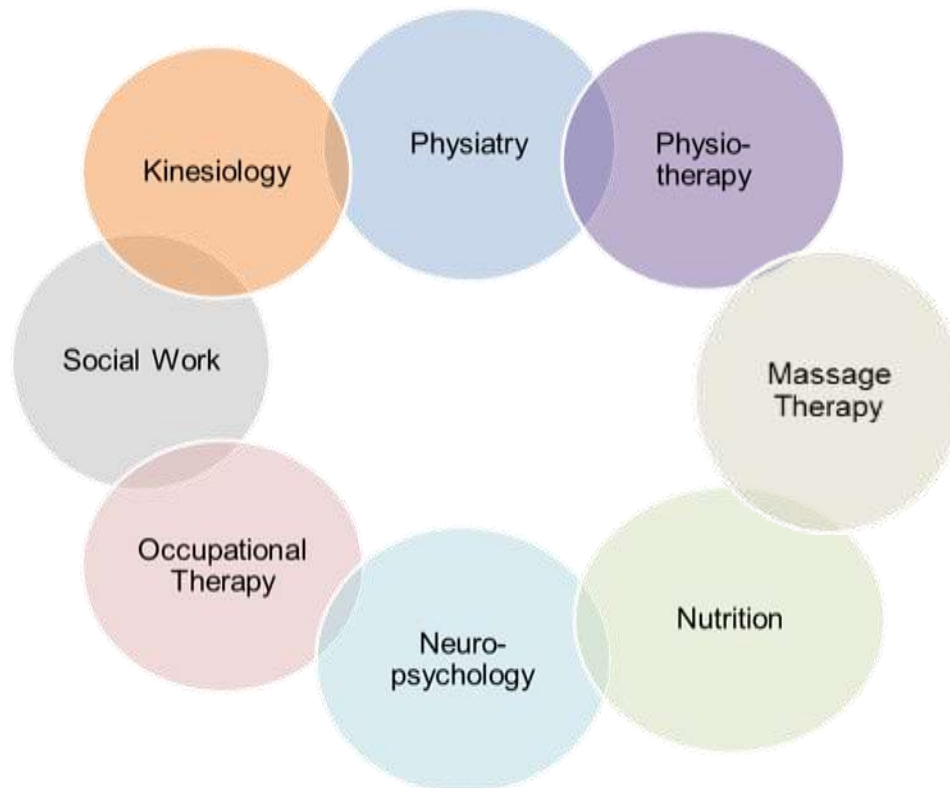
- Pain
- Fatigue
- Deconditioning
- Reduced physical strength
- Reduced range of motion of joints
- Decreased cardiovascular capacity
- Lymphedema
- Bone Loss
- Mood disorders including depression and anxiety
- Decreased work productivity
- Decreased social functioning
- Heart disease (future)
- Diabetes (future)
- Second malignancies and recurrence of primary malignancy

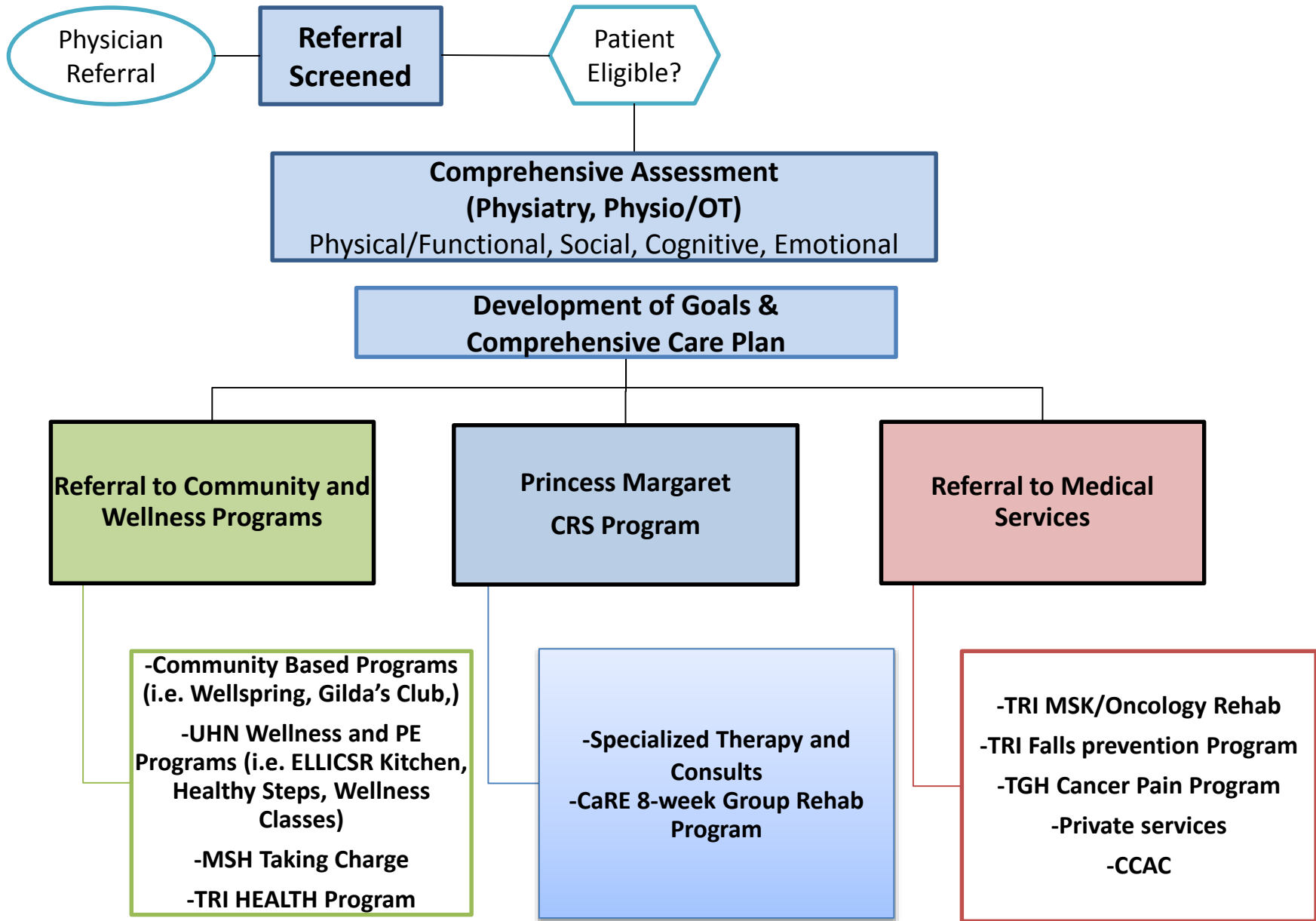
Adverse effects of cancer treatment that may be reduced with Rehab Intervention



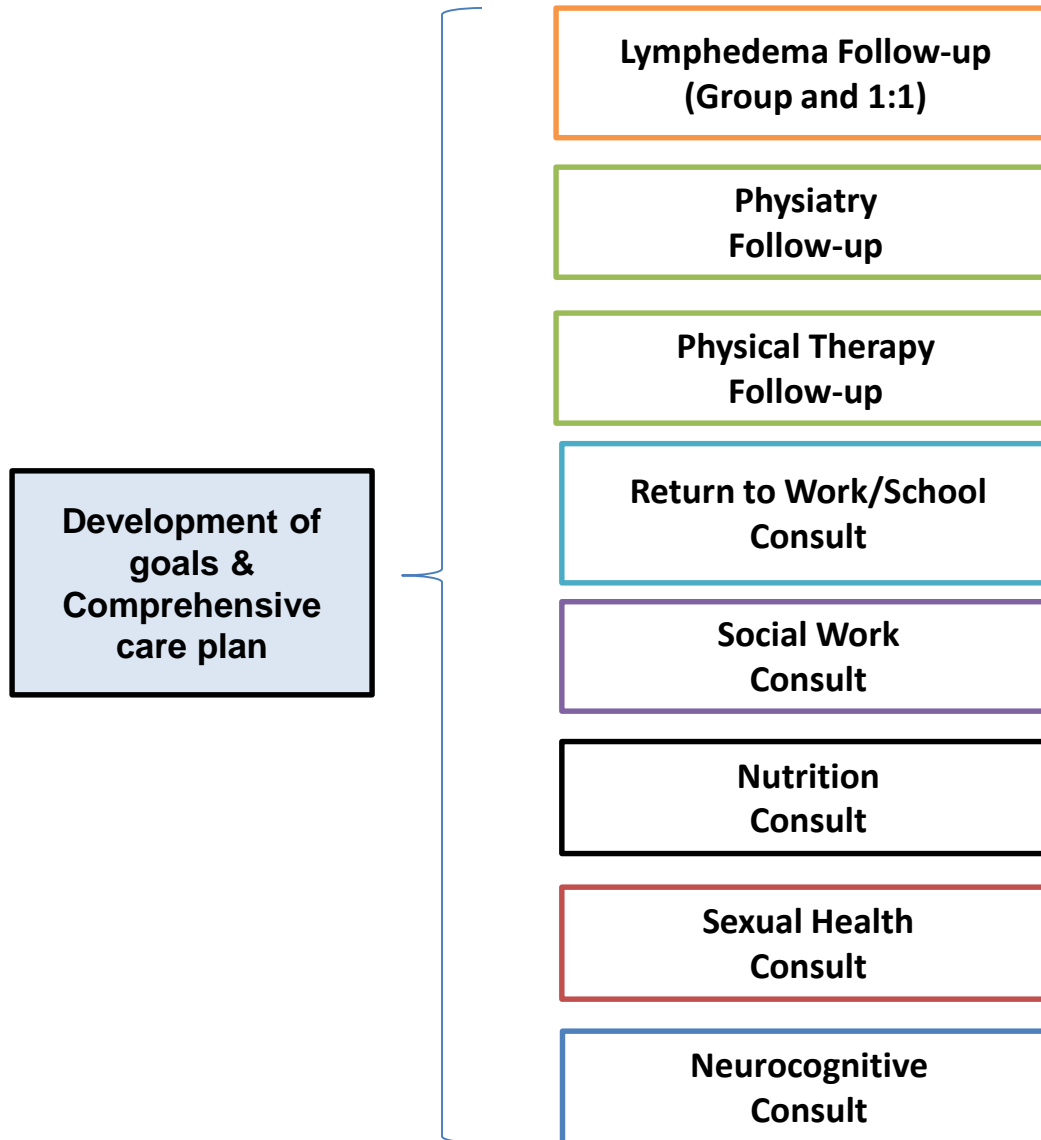
Cancer Rehab@Princess Margaret

- CRS program @PM:
 - **consultative risk-stratified impairment driven care to all disease sites**
 - **Multidisciplinary cancer rehabilitation approach**





CRS: Specialized Therapy and Consults



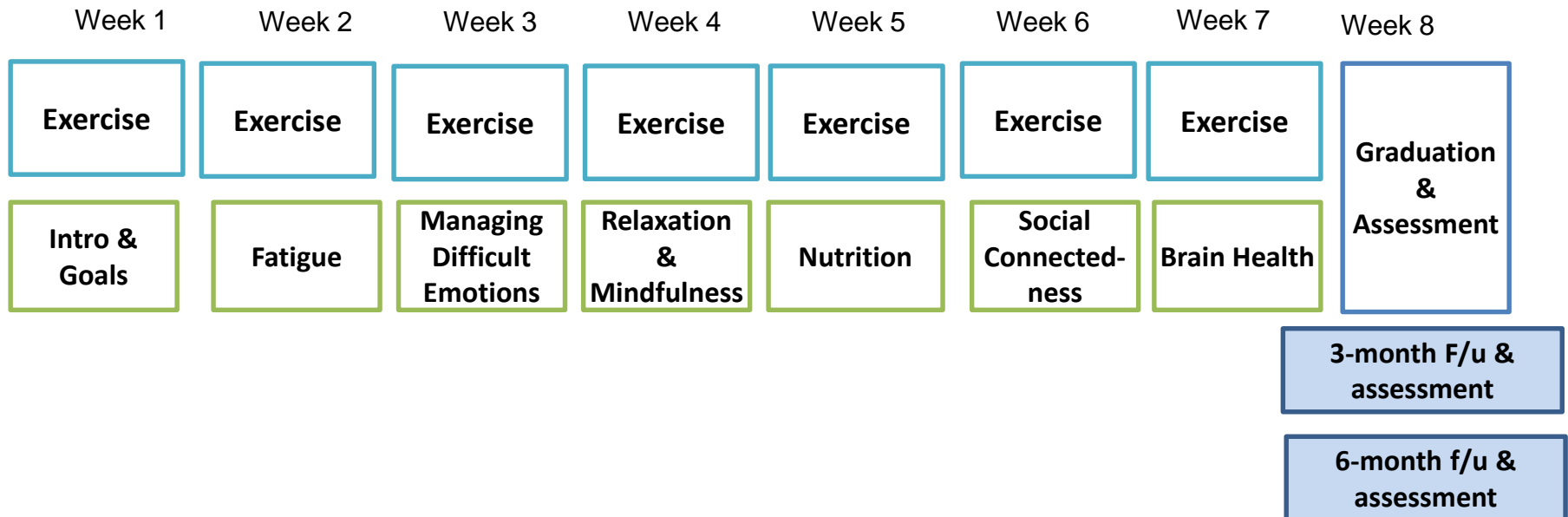
CRS: CaRE@ELLICSR

**Individual
Fitness
Assessment &
Exercise
Prescription**



- Group program to support lasting lifestyle changes to manage the effects of cancer and improve quality of life
- Individualized fitness assessment, exercise prescription & strategies for behaviour change
- 1x/week for 2.5 hours
 - 1.25 hrs of supervised exercise
 - 1.25 hrs of education
- 3 and 6 month follow-up

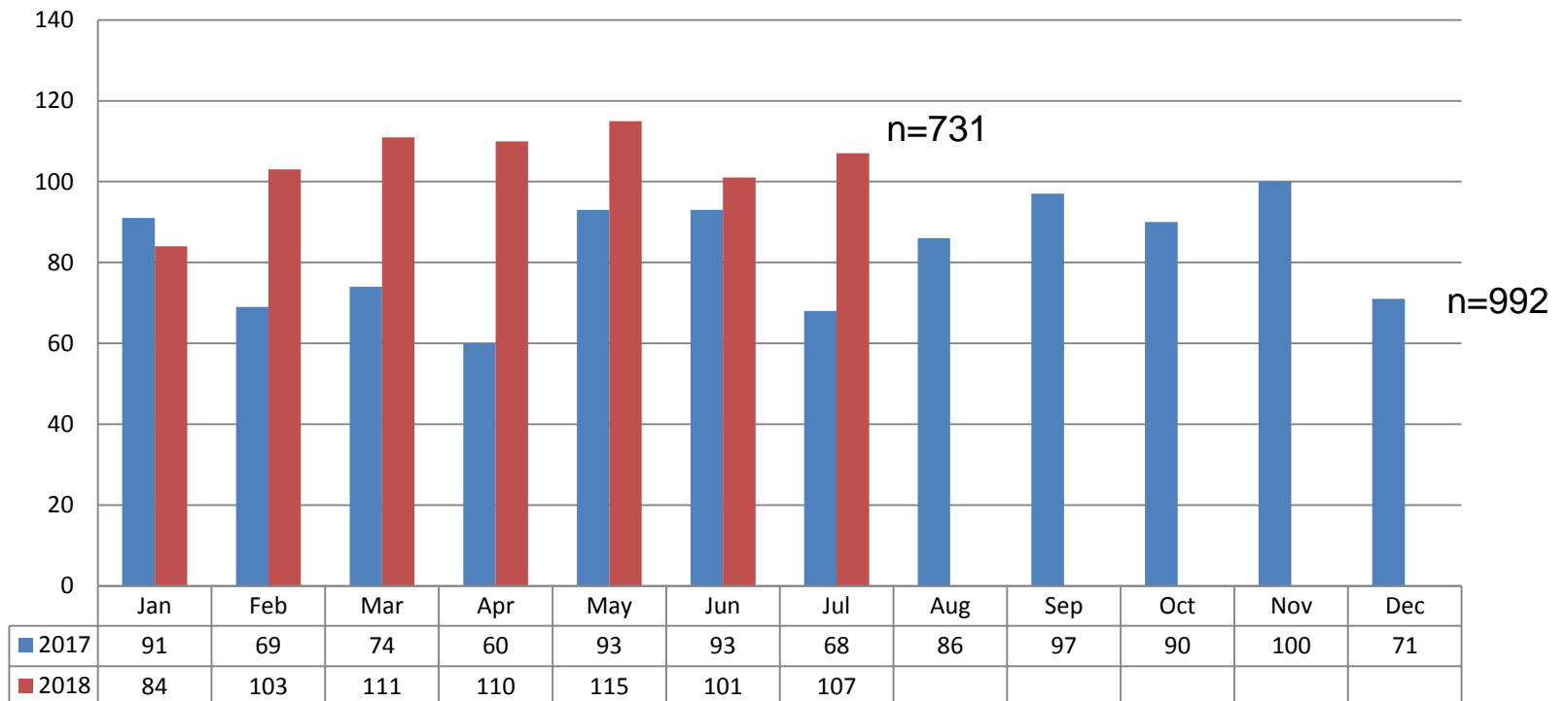
8-week Group-Based Multicomponent Cancer Rehabilitation and Exercise Program (CaRE Program)



CRS Referrals 2017-2018

- Over the past 3 years, we have had an average increase of 29% new patients entering our program each year.
- We now see approx. 80-100 new patients per month from across all disease sites at Princess Margaret and over 2000 follow up visits per year.
- The complexity of the patients we see has also increased as our focus has changed to more of an impairment driven program.

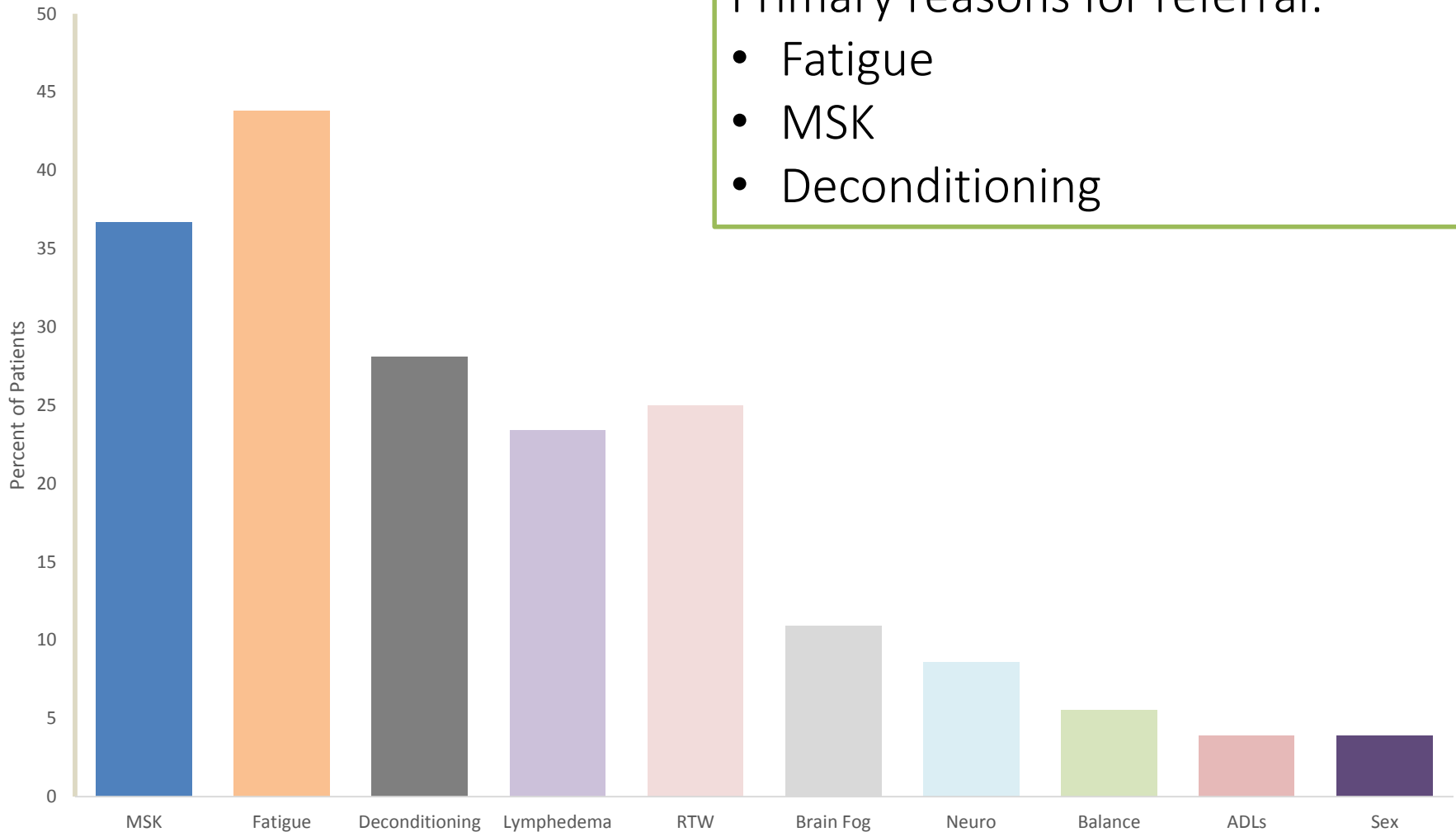
CRS New Patient Referrals Approved



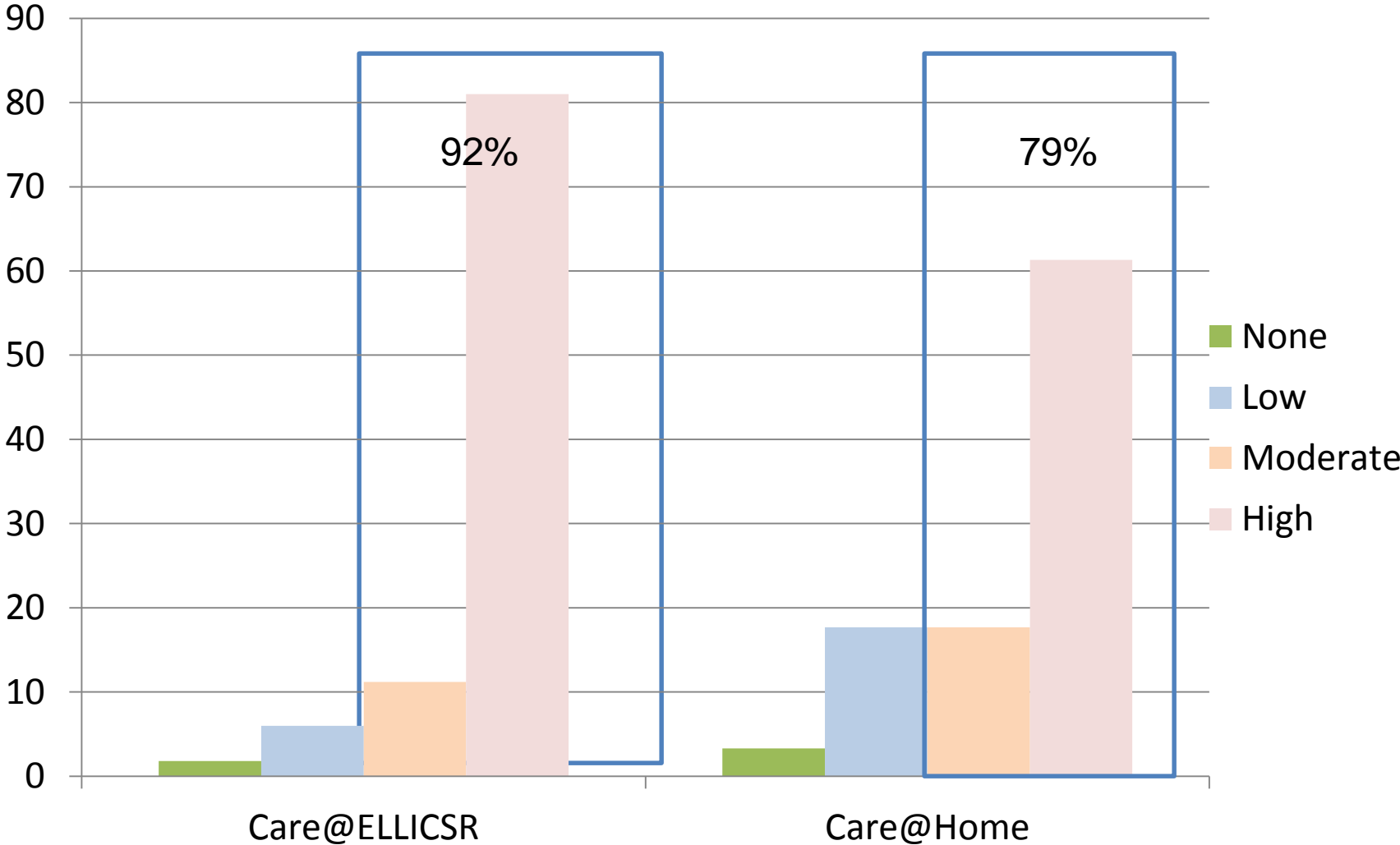
CaRE Referral Reasons

Primary reasons for referral:

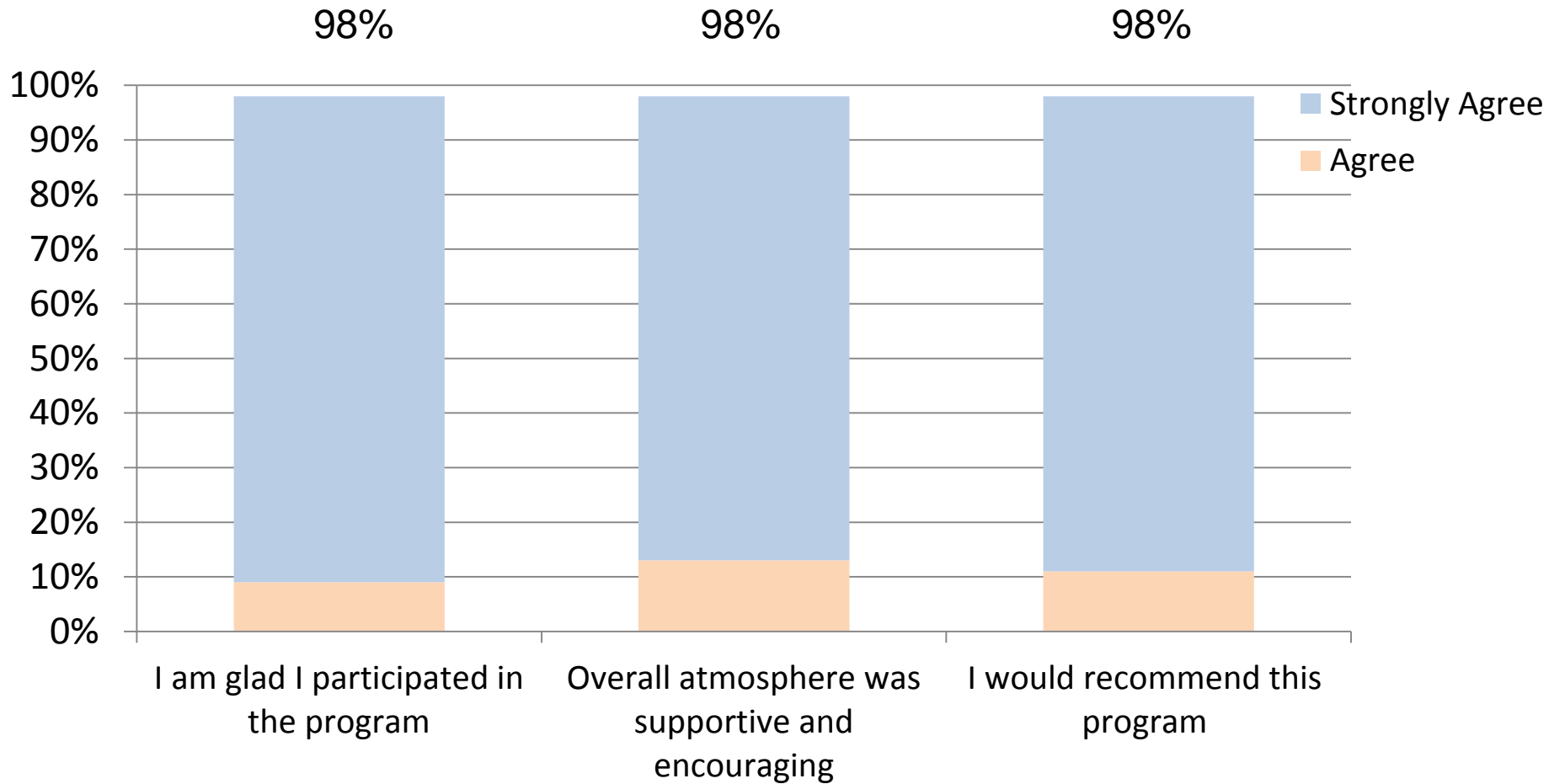
- Fatigue
- MSK
- Deconditioning



CaRE Program: Disability



CaRE: Participant Satisfaction and Feedback



An excellent fulsome course. I found lessened anxiety by joining the group & the sharing experience. The instructors & counselors helped tremendously physically & psychologically.

This course should be an extension of most everyone's cancer treatment plan. Shows that you are not alone and helps with questions, feelings that you are experiencing.

I feel more capable of managing overall. There is a whole world at ELLICSR that patients do not know about. I am happy that I was referred to the care program as it made a difference to my physical, emotional and cognitive wellbeing.

Wellness: ELLICSR Programming

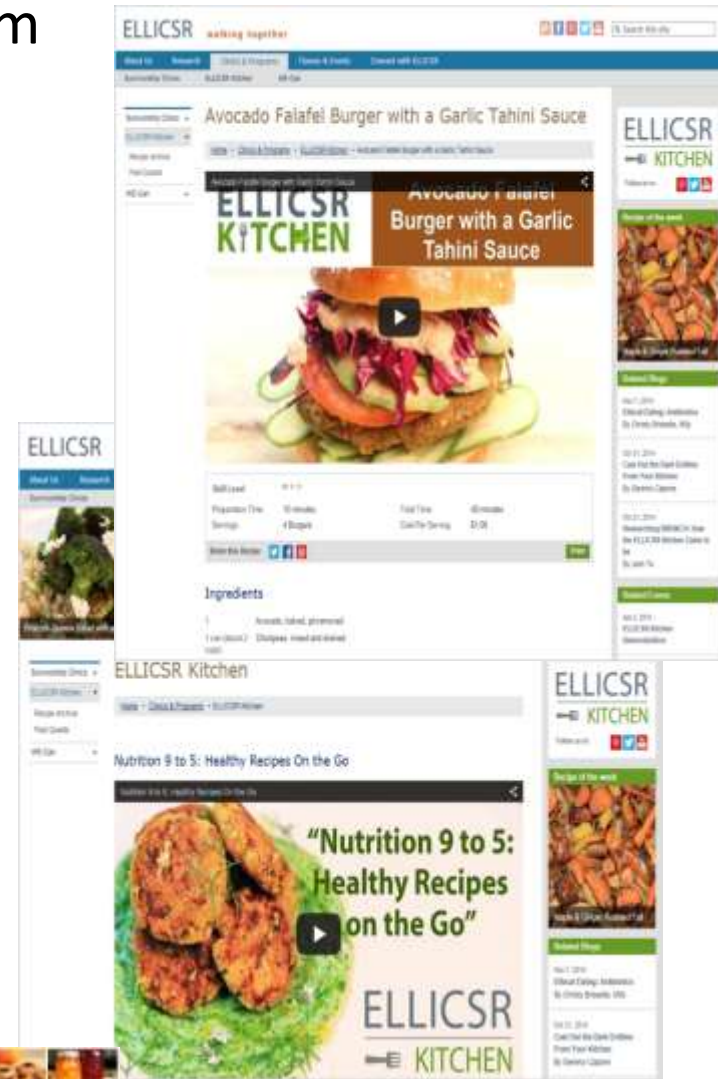
- Support the well-being of cancer survivors with evidence-based exercise programming and related-services
 - Yoga (Gilda's)
 - Healthy Steps
 - Tai Chi (study)
 - Mindfulness (study/Gilda's)
 - Art for Cancer



Wellness: ELLICSR Kitchen

- Innovative and unique teaching program dedicated to cooking, nutrition and healthy eating.
- Wellness chef and registered dietitian host live cooking demonstrations.
- Supported by social media platforms including YouTube video segments.
 - Total videos: 363
 - Total views: 4.38M
 - Users: 43K subscribers (YouTube)

www.ellicsrkitchen.ca



2018-2019 Extending Clinical Care

Initiative: Virtual Structured Cancer Rehabilitation Program (CaRE@Home)

Activities:

- On-line clinical program delivery **CaRE@Home** program
- Collaboration with Oncology Education
- CCO grant: Pilot study
 - Phase 1: User testing completed August 2018
- ***Pilot Launch Fall 2018***

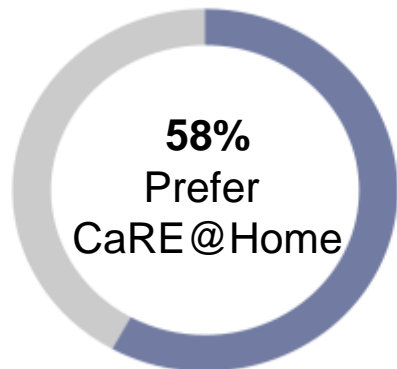
Week	Module Title
Week 1	Getting Started
Week 2	Eat and Cook for Wellness
Week 3	Be Mindful
Week 4	Reduce Your Fatigue
Week 5	Boost Your Brain Health
Week 6	Manage Complex Emotions
Week 7	Find Ways to Connect
Week 8	Plan for Your Future



2018-2019 Extending Clinical Care

Initiative: Palliative Rehabilitation

- Patients with advanced cancer are having increased life expectancies but with substantial symptom burden
- The CRS Program does not have a comparable CaRE Program for patients with advanced cancer in the early palliative care setting
- Summer 2018: Undertook a survey (n=60) to assess interest and priorities for program structure and content
 - 57% indicated interest in a cancer rehabilitation program
- Next steps: adapting existing CaRE curriculum (Fall 2018), pilot (early 2019)



Topic	% of patients rating "very important"*
Pain management	84%
Fatigue and energy	84%
Attention, concentration, memory	84%
Diet and nutrition	75%
Improving sleep quality	73%

2018-2019 Extending Clinical Care

Initiative: Canada's First Fellowship in Cancer Rehabilitation

- July 2018: Dr. David Langelier
- 1 year Clinical Fellowship





The PM CRS Program is generously supported by the Princess Margaret Cancer Foundation