

Have your say:

Informing the development of a web-based repository of cancer content for Primary Care



April 23, 2022

Presenters



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Disclosure of Financial Support

This program has received financial support from The Canadian Partnership Against Cancer (CPAC) in the form of national project grants.

Potential for conflict(s) of interest:

The Canadian Partnership Against Cancer (CPAC) has helped fund the project that will be discussed in this presentation.

Learning Objectives

In this session, participants will:

1. Understand the steps that have been taken to engage multiple stakeholders to address the gaps in transitions from cancer care to primary care.
2. Explore the work underway to design a repository of cancer content for primary care.
3. Validate and provide feedback on the cancer content currently in development, to ensure it is relevant and useful to primary care providers.

This presentation uses Mentimeter

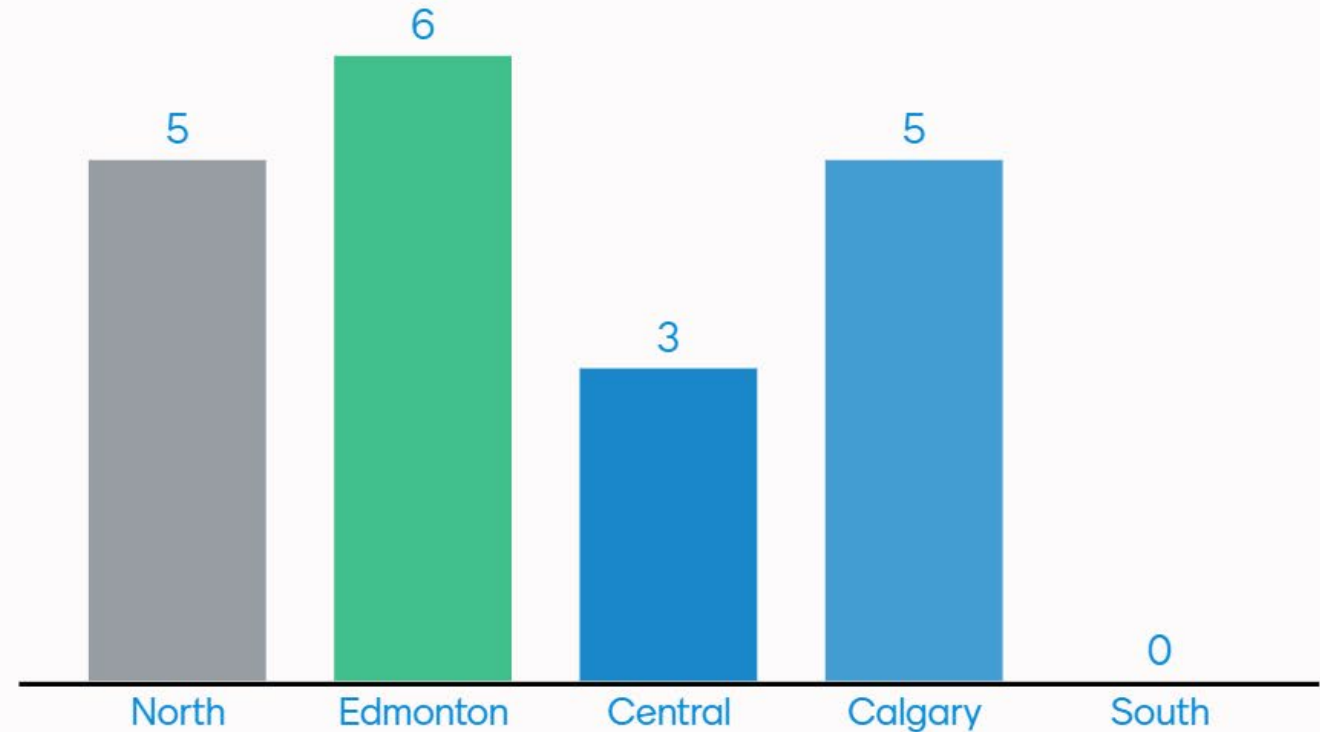
Please use your mobile phone, computer, or other device to go to this website: <https://www.menti.com>

Enter this code:
3784 0688

Please keep the browser window with this website open throughout the workshop; we will frequently ask questions using this platform.

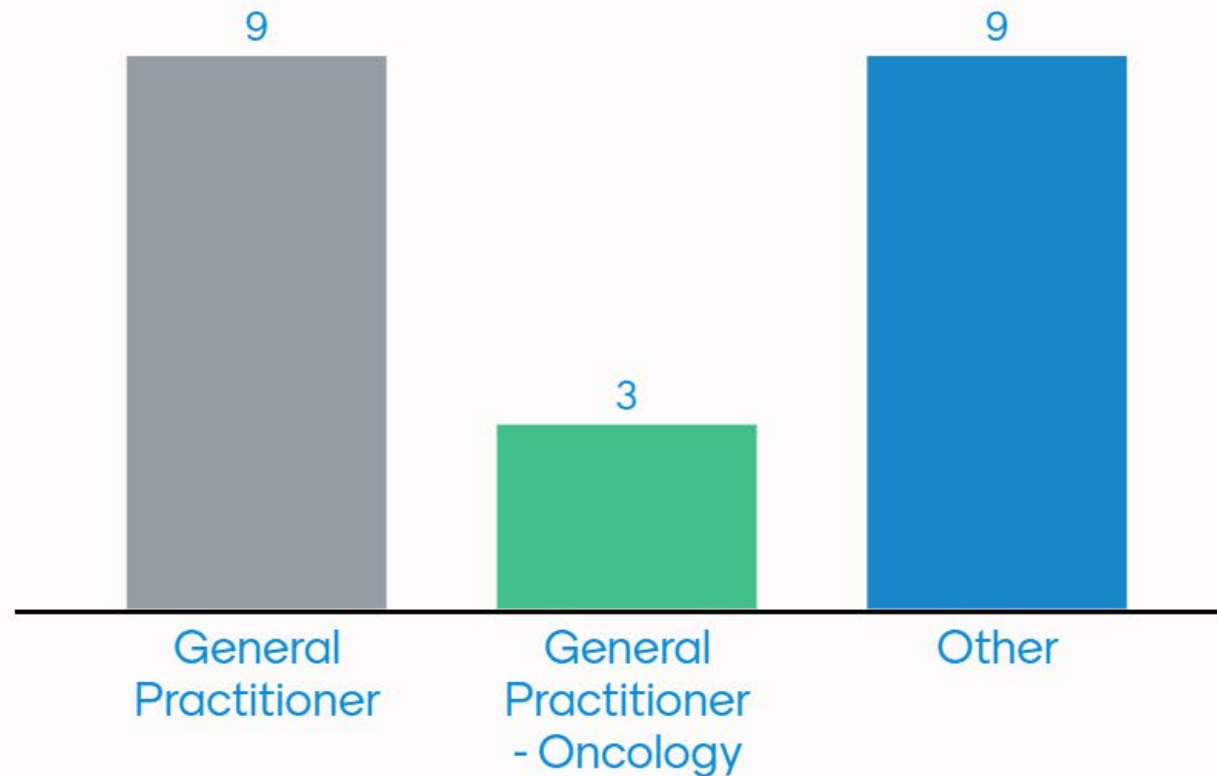
Make sure to click “Submit” after choosing or typing your response.

Which health zone are you located in?



Press S to show image

What best describes your role in healthcare (choose multiple as needed)?



Background

**Previous Transitions Work in Cancer Care
Alberta: 2014-2017**

Previous Transitions Work in CCA: 2014-2017

- Extensive stakeholder engagement conducted with cancer care providers, primary care providers, and patients.
 - Gaps in knowledge identified, as well as barriers to transitioning patients post-treatment.
- Three resources were developed as a result of this work.

1. Clinical practice guidelines developed by different tumour teams.

- Available on the AHS external web – accessible anywhere:

www.ahs.ca/guru

Cancer Guidelines Information for Health Professionals

- ▶ AB Bone Marrow & Blood Cell Transplant Program
- ▶ Breast
- ▶ Central Nervous System
- ▶ Cutaneous
- ▶ Endocrine
- ▶ Gastrointestinal
- ▶ Genitourinary
- ▶ Gynecological
- ▶ Head and Neck
- ▶ Hematology / Lymphoma
- ▶ Lung
- ▶ Radiotherapy Special Topics

About the Guidelines

Clinical practice guidelines are systematic statements about specific problems intended to assist in decision making. Guidelines provide care practitioners with evidence-informed recommendations that reflect best practices. The Guideline Resource Unit (GURU) coordinates the development of guidelines for cancer treatment and follow-up care in collaboration with thirteen Provincial Tumour Teams (PTT) in Alberta. The recommendations contained in these guidelines are a consensus of the relevant Provincial Tumour Team synthesis of currently accepted approaches to treatment, supportive care and follow up, which have been derived from a review of relevant scientific literature. All cancer drugs described in the guidelines are funded in accordance with the Outpatient Cancer Drug Benefit Program, to eligible residents of Alberta, unless otherwise explicitly stated. For a complete list of funded drugs, specific indications, and approved procedures, please refer to the [Outpatient Cancer Drug Benefit Program Master List](#). For information on our processes please refer to the [GURU Guideline Development Handbook](#).

Provincial Tumour Teams

There are thirteen Provincial Tumour Teams (PTT) in Alberta. They are organized by disease site and are comprised of clinicians, nurses, pharmacists, and researchers from across the province. PTTs are responsible for developing and implementing evidence-based clinical practice guidelines for use by cancer specialists and family physicians throughout Alberta.

Contact the Guideline Resource Unit

2. End of Treatment and Transfer of Care letter sets for each guideline.

Complementary patient and primary care provider letters

- Recommended follow-up and who is responsible (primary care or cancer program)
- Signs and Symptoms of Recurrence
- Late and long-term effects of treatment
- Supportive care services available
- Wellness and other screening recommendations

Breast Cancer Transfer of Care Letter – Physician

[DATE]

Re: Transfer of Care

Dear Dr. _____,

Your patient [ARIA: Insert Name] has had surgery for breast cancer and may also have received other treatments at the Cancer Centre. Your patient is now being transitioned back to you for ongoing breast cancer surveillance in addition to their regular care.

Your patient is in XXX year of their follow up surveillance.

The evidence-based recommendations outlined below outline the standard follow-up procedures for breast cancer surveillance, and are intended to assist you in providing optimal breast cancer follow-up care for your patient; these recommendations are not intended to be a substitute for clinical judgment.

Surveillance for Breast Cancer Recurrence

We ask that you now organize:

• **Diagnostic mammography** of intact breast(s) should be performed annually. First post-treatment mammogram should be 1 year after diagnostic mammogram (and at least 6 months after radiotherapy). Reconstructed breasts (autologous tissue or implants) or non-reconstructed chest wall post-mastectomy do not require any form of imaging surveillance.

• **Periodic clinical examination** should specifically include examination of the breast(s)/chest wall, supraclavicular and axillary lymph nodes in addition to routine clinical examination. Clinical examinations should be performed **every 6 months for 2 years then annually thereafter**.

• Patients **may** perform **self-examination** of their breasts and axillae every month.

• No other routine surveillance investigations (e.g. lab work, tumour markers, diagnostic imaging) are recommended for asymptomatic patients.

Please be aware of these potential symptoms of breast cancer recurrence and recommended actions:

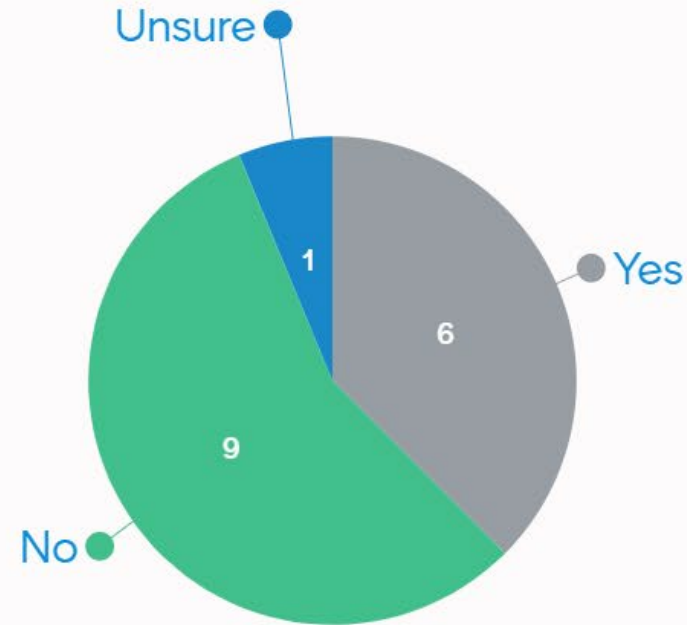
Symptoms / Signs	Actions / Investigations
<div>• new mass in breast</div>	mammography +/- ultrasound (+/- biopsy)
<div>• new suspicious rash or nodule on chest wall</div>	refer to surgeon, dermatology or interventional radiology for consideration of biopsy
<div>• new palpable lymphadenopathy</div>	refer to surgeon or interventional radiology for biopsy
<div>• new persistent bone pain</div>	plain x-ray of affected site(s) and bone scan
<div>• new persistent cough or dyspnea</div>	chest x-ray and/or CT chest
<div>• new hepatomegaly or RUQ abdominal pain or jaundice</div>	ultrasound and/or CT scan of abdomen and liver enzymes
<div>• new persistent headache or new concerning neurologic deficits</div>	CT/MRI brain
<div>• new onset seizures</div>	seizure management (as required) and CT/MRI brain

Last revised: September 2019

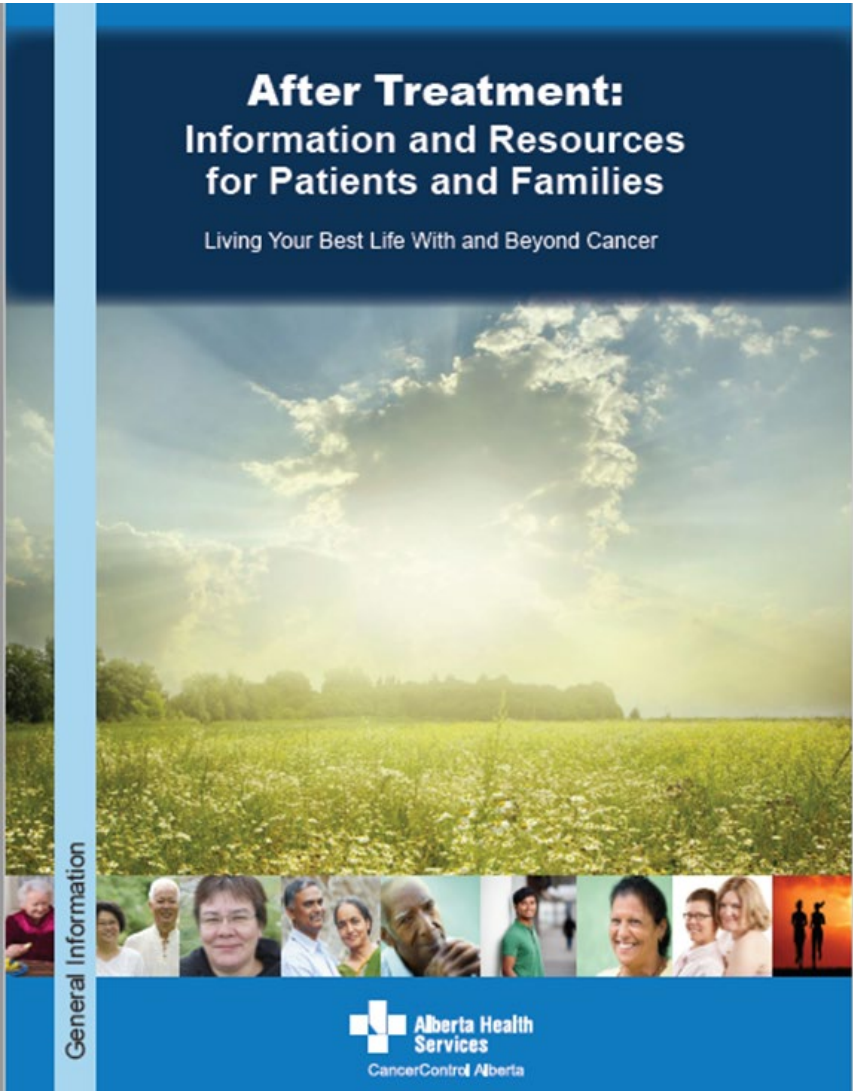
Guideline Resource Unit

2

Have you received a letter like this from a cancer centre?



3. Patient self-management book and class.



Living Your Best After Cancer Treatment



Thank you to the many people who contributed to the development of this class:

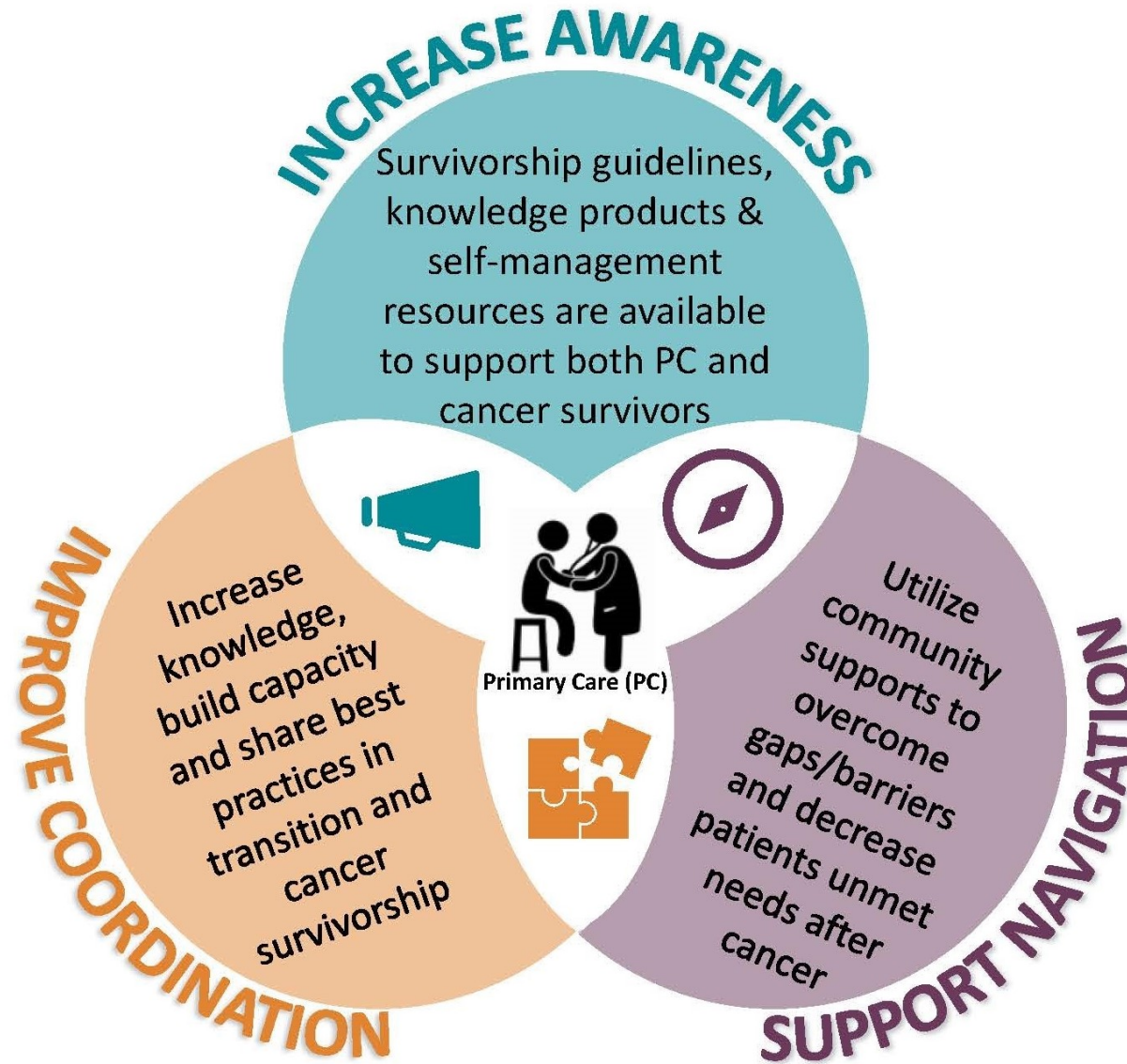
- ✓ Patient and family advisors
- ✓ Staff around the province



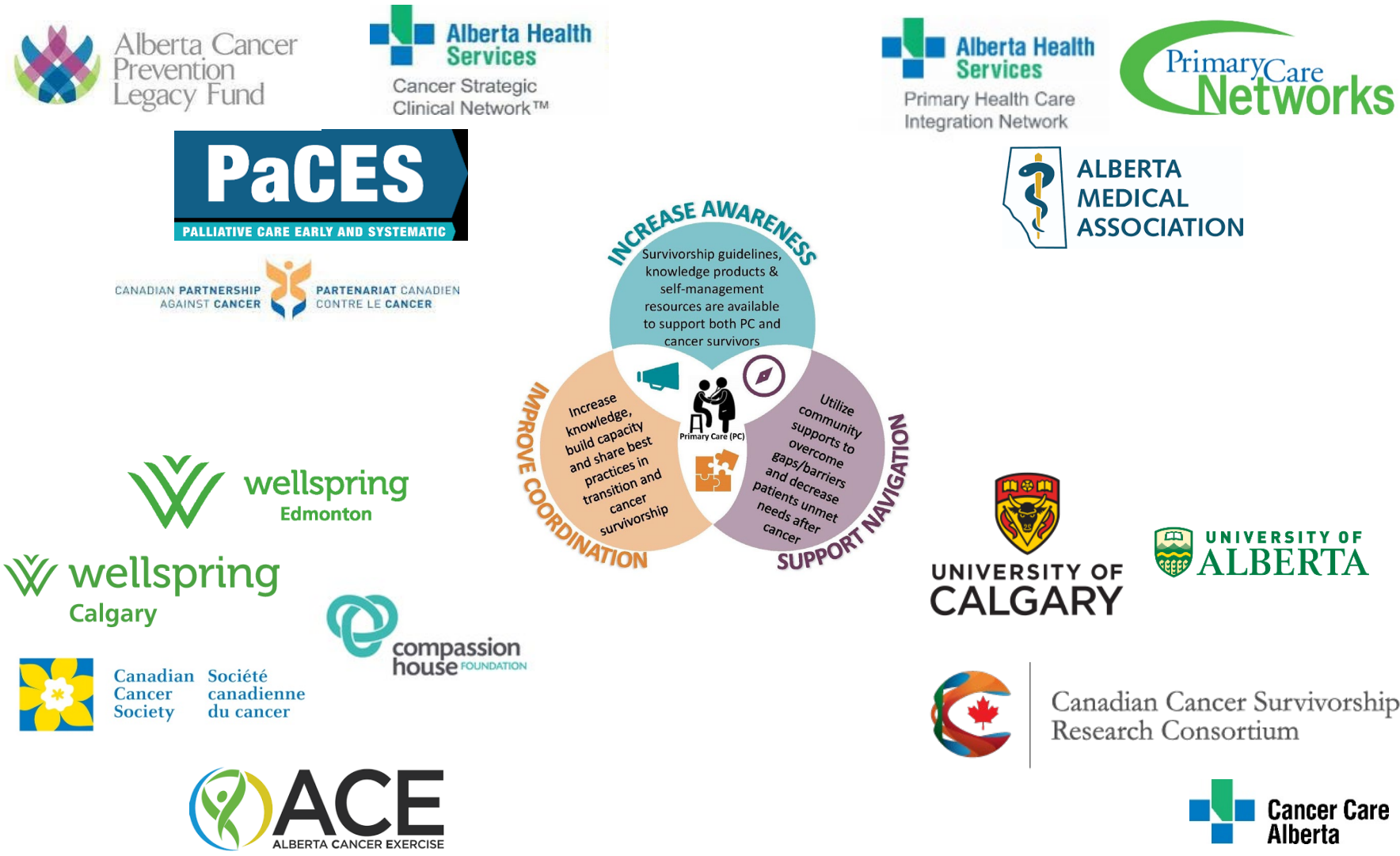
Current Transitions Work in Cancer Care Alberta

April 23, 2022

Project Goals



Creation of Advisory Council: “Living Well After Cancer”



Current Project Focus

- We are in the process of developing two webpages, one for patients and one for primary care providers.
- The remainder of this presentation will focus on the primary care webpage.



Stakeholder Engagement: Patient and Primary Care Working Groups



Patient
Advisors



Primary Care
Providers

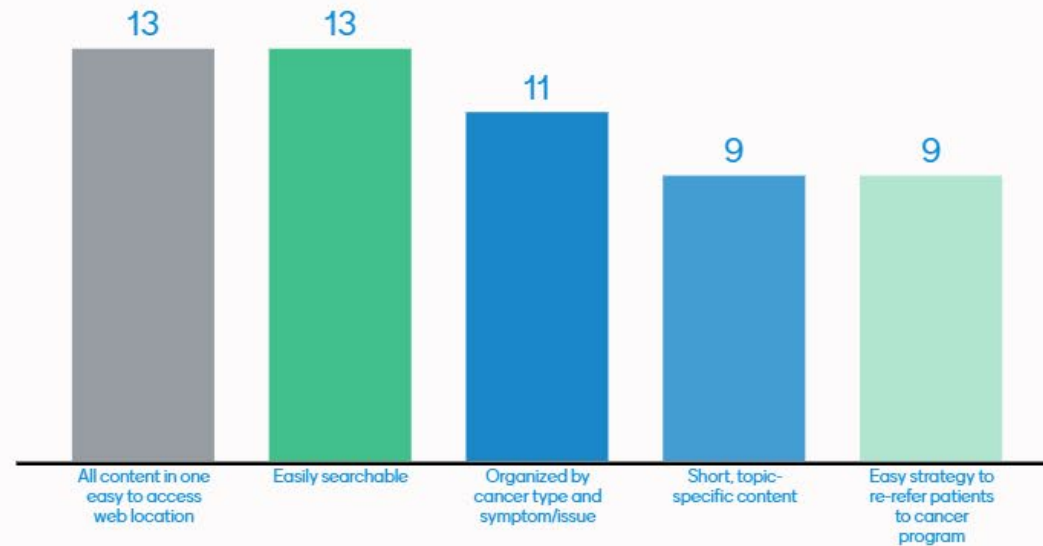


**Monthly meetings to ensure webpages align
with feedback from each group.**

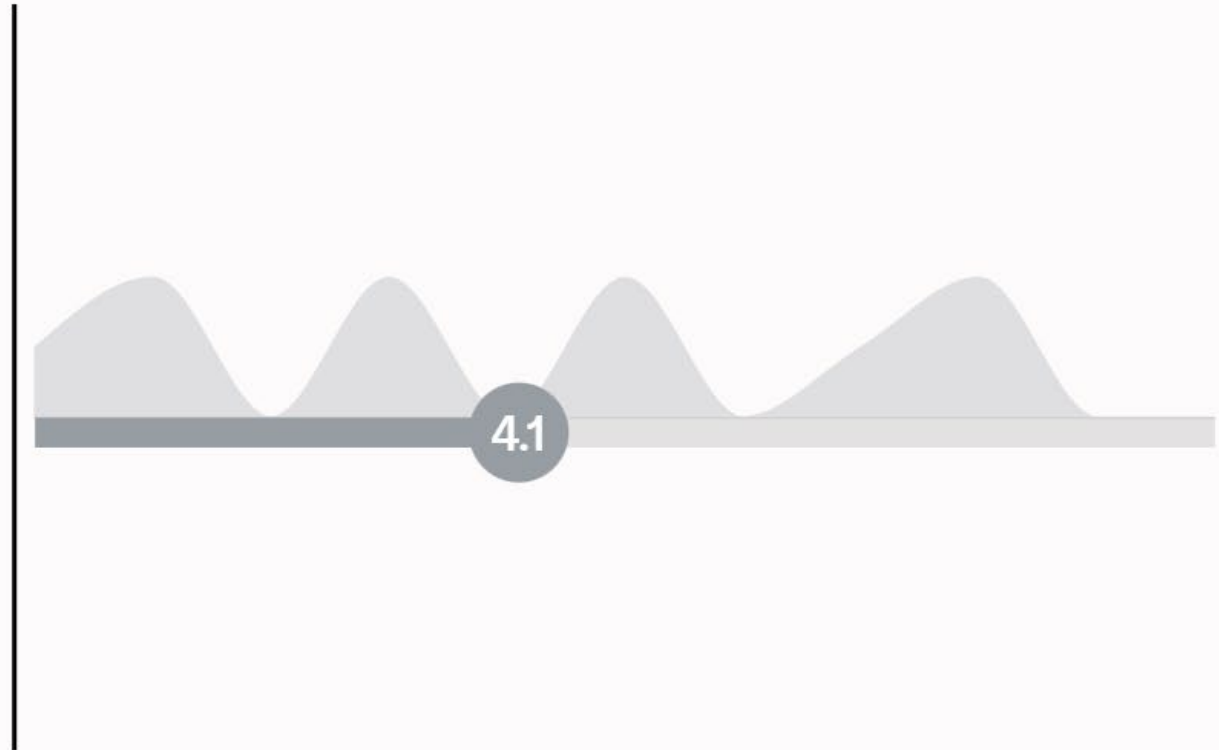
Primary Care Feedback

- All content in easy to access web location – in the same day a provider may need info about diagnostic work-up, surveillance, and symptom management
- Easily searchable (max. 4 clicks to find whatever is needed)
- Organized by cancer type and specific symptom/issue
- Short topic-specific content
 - Definition of issue and presenting factors
 - Brief background evidence
 - What actions can/should family physician take (don't just say return to specialist)
 - One-page printable patient facing hand out re: issue/symptom that physician can print off and hand to the patient
- Easy strategy to re-refer patient to the cancer program if problems arise

Which pieces of feedback resonate with you (choose as many as you want). Feel free to come off mute!



In your experience, how difficult is it to refer a patient back into the cancer program? (0=very easy, 10=very hard)



Website Work:

Creating a One-Stop-Shop for Primary Care



Current Webpage (on the AHS external web)

The screenshot shows the top section of the Cancer Care Alberta webpage. At the top, there is a navigation bar with the Alberta Health Services logo, the tagline 'Healthy Albertans. Healthy Communities. Together.', the 811 Health Link logo, and a search bar. Below this is a yellow banner with COVID-19 information. A blue navigation bar contains links to 'ABOUT AHS', 'FIND HEALTHCARE', 'INFORMATION FOR', 'CAREERS', 'NEWS', and 'AHS IN MY ZONE'. The breadcrumb trail reads 'Home > Information For > Health Topics > Cancer Care Alberta Home'. The main heading is 'Cancer Care Alberta' with the tagline 'Leading care through compassion, courage, learning and discovery'. Below this are three columns: 'PATIENTS & FAMILIES', 'HEALTH PROFESSIONALS' (highlighted with a red box), and 'RESEARCH & ANALYTICS'. Each column has a 'Learn more' link and an icon representing the target audience.

Home | Contact | Staff | Help | Patient Feedback | 繁體中文

Alberta Health Services Healthy Albertans. Healthy Communities. Together.

811 Health Link Health Advice 24/7

Search AHS

i COVID-19 Info: [For Albertans](#) | [For Health Professionals](#) | [Vaccine](#) | [Assessment & Testing](#) | [Results](#) | [Visitation](#)
A [CMOH order](#) remains in effect that requires continuous masking at all AHS, APL and Covenant facilities provincewide.

ABOUT AHS ▾ **FIND HEALTHCARE** ▾ **INFORMATION FOR** ▾ **CAREERS** ▾ **NEWS** ▾ **AHS IN MY ZONE** ▾

Home > Information For > Health Topics > Cancer Care Alberta Home

Cancer Care Alberta

Leading care through compassion, courage, learning and discovery

Information for
PATIENTS & FAMILIES
Learn more →

Information for
HEALTH PROFESSIONALS
Learn more →

Information for
RESEARCH & ANALYTICS
Learn more →

<https://www.albertahealthservices.ca/cancer/cancer.aspx/>

Current Webpage (on the AHS external web)

Health Professionals

Cancer Care Alberta



Cancer Care Alberta physicians, nurses and support staff bring care and compassion to the work they do, everyday.

As healthcare professionals who work in cancer care, we bring commitment to drive the best cancer care for Albertans.

Here you will find further information and resources to help unite education and practice, bringing better care, treatments and better outcomes for cancer patients.

Resources

- [Cancer Guidelines](#)
- [Cancer Surgery Alberta](#)
- [Surveillance & Reporting](#)
- Supportive Care
 - [Cancer-Related Cognitive Impairment \(CRCI\)](#)
 - [Framework Report \(2016\)](#)
 - [Psychosocial & Rehabilitation Oncology](#)
 - [Return to Work or School \(RTW/S\)](#)

Patients & Families >

Research & Analytics >

Currently, there is little-to-no information for primary care providers on this page.

<https://www.albertahealthservices.ca/cancer/Page16332.aspx>

Potential New Webpage (on the AHS external web)



- Idea to organize the webpage to follow the cancer journey.
- Providers could click whichever part of the journey was relevant and find related information.
- This way, all information can be found from the same home page.

Type or Speak: Anything missing from this journey bar? Are these helpful headings?

Looks great!

Helpful headings. Looks complete

Headings are great. Would like to have clarity around who needs to do what

seems comprehensive

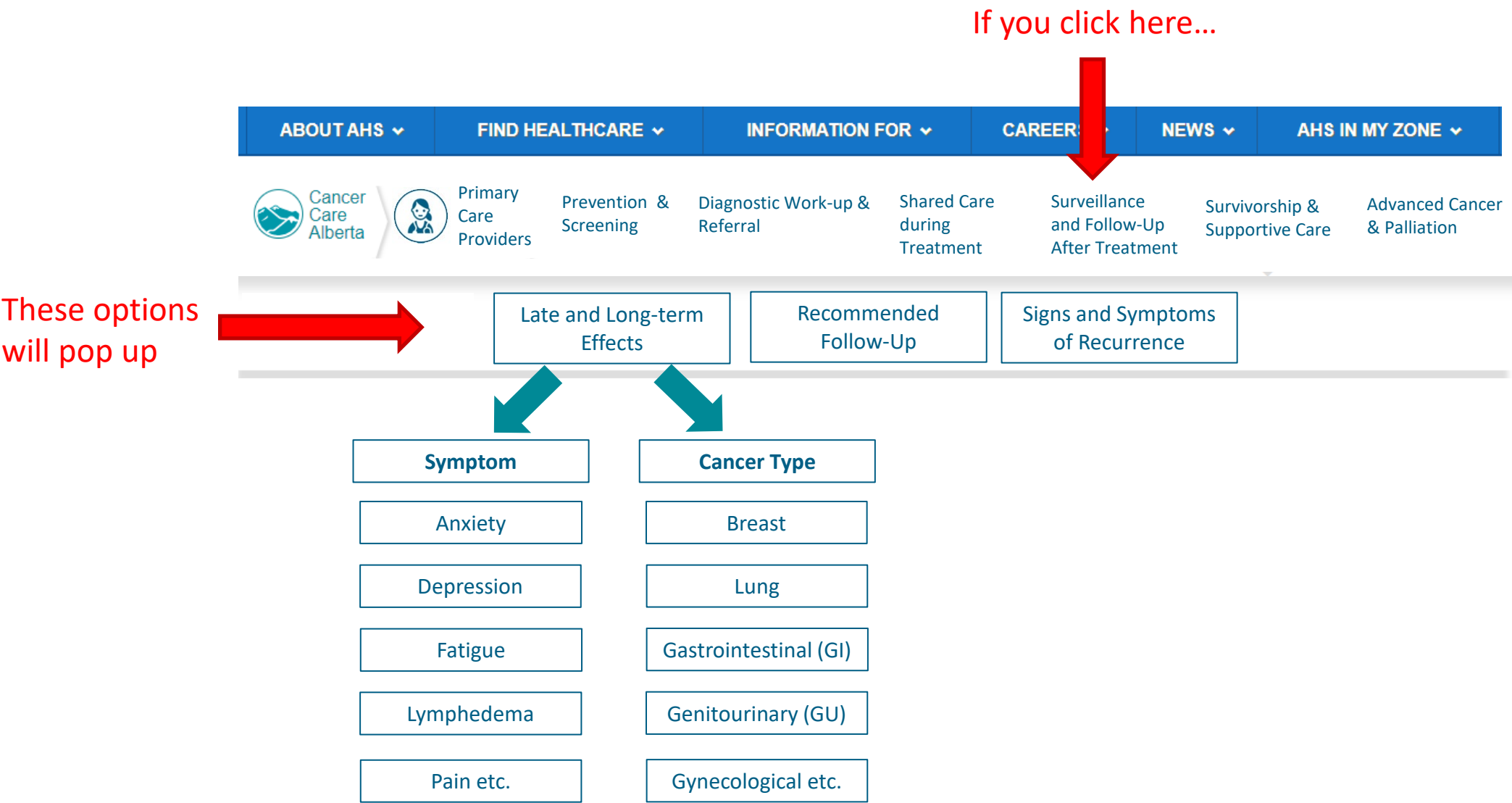
Often survivalist improved where there is caregiver support- these folks are so neglected. What is the plan to remember caregivers so that they don't become sick and die- apparently caregivers often die before the patient

Looks helpful.

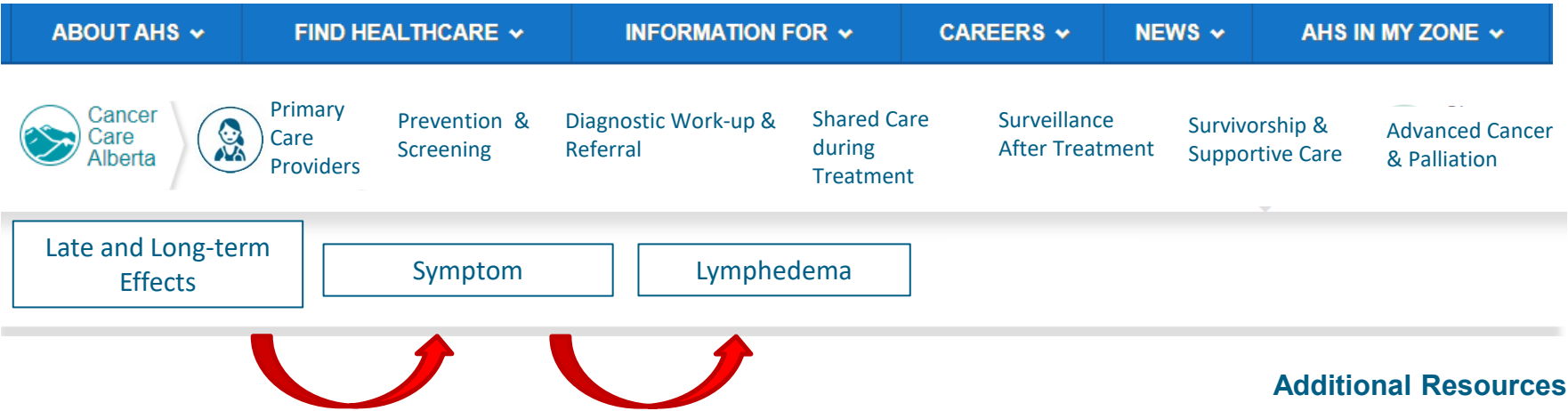
Can the information be written in a language that patients and families can understand as well?

Press S to show image

Potential New Webpage (on the AHS external web)



Example: Lymphedema



What is cancer-related secondary lymphedema?

Diagnosis

Complications

Steps to take in Primary Care

Patient Self-Management Resources

Links to printable patient resources

When and how to refer to Cancer Care

Referral to Rehabilitation Oncology

If the patient has not yet been discharged from Cancer Care

If the patient has been discharged from Cancer Care

Routine vs. Urgent Referral Criteria

Community Resources

Thoughts on these headings? Type or come off mute!

What is cancer-related secondary lymphedema?

Diagnosis
Complications

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Referral to Rehabilitation Oncology

If the patient has not yet been discharged from Cancer Care

If the patient has been discharged from Cancer Care

Routine vs. Urgent Referral Criteria

Community Resources

Looks great.

Looks good, what to
do with each symptom

excellent!

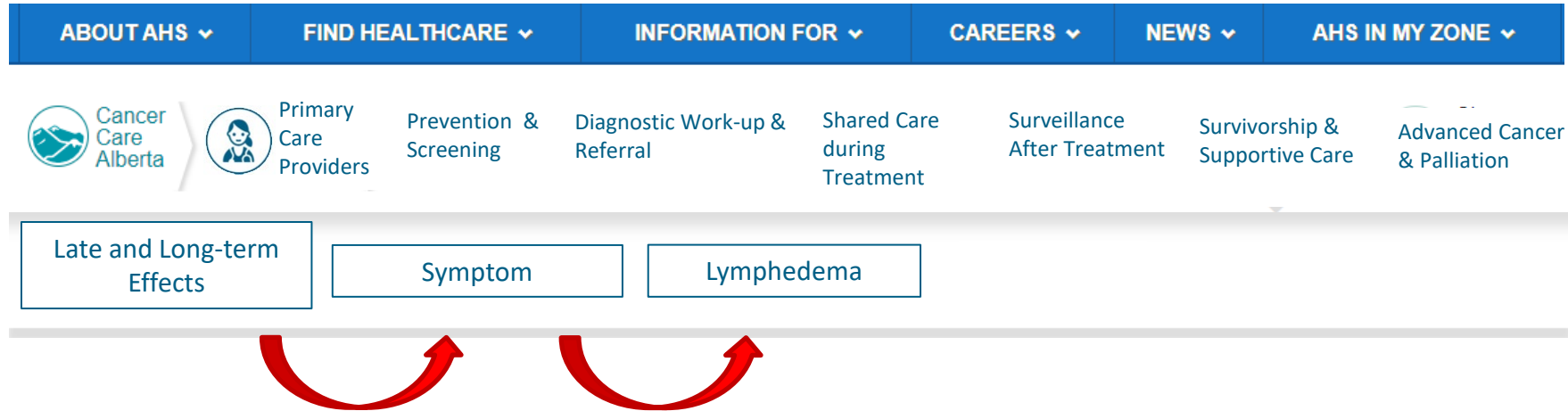
All OK

Looks easy to
navigate. Often it is
the waiting to hear
back from the cancer
system is the most
challenging and
stressful for patients

Resources in primary
care for treatment?

Press S to show image

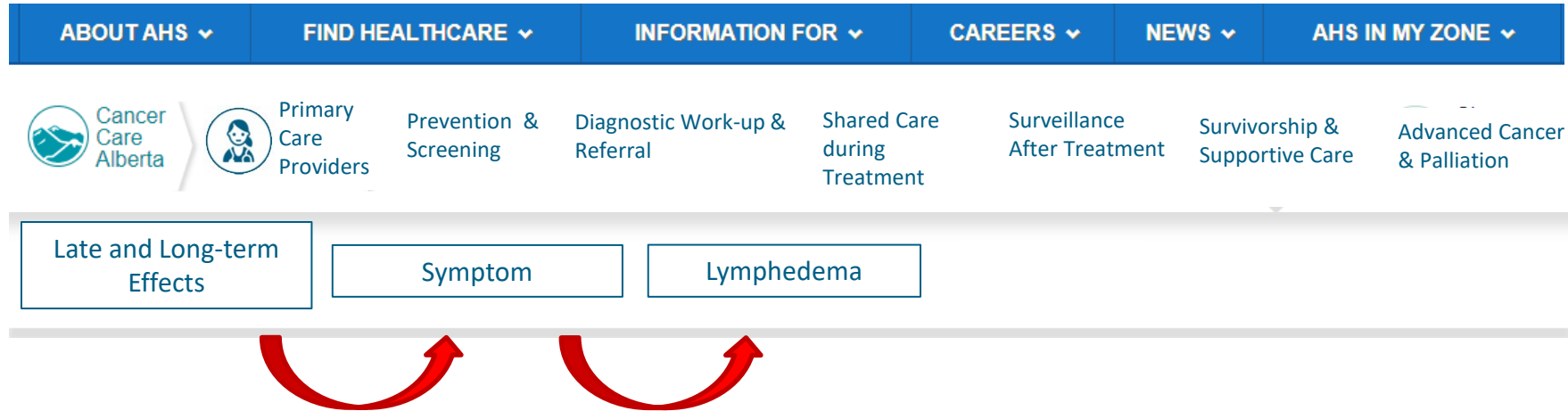
Potential New Webpage (on the AHS external web)



Steps to take in Primary Care

- Assess the patient to rule out any other conditions, such as DVT or cancer recurrence.
- Refer the patient to AHS Rehabilitation Oncology (see [Referral](#) for different pathways and eligibility requirements for urgent vs. routine referrals).
 - State that it is for cancer-related lymphedema on the referral.
 - If the patient cannot easily access the closest Rehabilitation Oncology clinic, a referral can be made to an AHS Community Clinic that has a Certified Lymphedema Therapist. Search 'lymphedema' in the [Alberta Referral Directory](#).
- Communicate the importance of skin care and self-management steps the patient can take (see [Patient Self-Management Resources](#)) while waiting for their appointment with a Certified Lymphedema Therapist.

Potential New Webpage (on the AHS external web)



Patient Self-Management Resources

After Treatment Booklet:

<https://www.albertahealthservices.ca/assets/info/cca/if-cca-after-treatment-for-cancer.pdf>

AHS CCA Lymphedema E-Learning Module:

https://ahamms01.https.internapcdn.net/ahamms01/Content/AHS_Website/modules/cca/Lymphedema/index.html

AHS Rehabilitation Oncology Patient Brochure:

<https://www.albertahealthservices.ca/assets/info/cca/if-cca-rehab-oncology-prov.pdf>

Example: Lymphedema – Patient Resources



Lymphedema

What is lymphedema?

Lymphedema is a medical condition that needs to be diagnosed by your doctor. It is excessive swelling of a body part due to the buildup of lymph fluid. This buildup can happen when the lymphatic system or nodes are:

- Inflamed
- Removed during surgery
- Damaged from radiation
- Blocked

Lymphedema can range from mild swelling that comes and goes, to a significant persistent swelling. It is often a lifelong condition where you need to do long-term self-management.

Physiotherapy or occupational therapy can help. Ask your healthcare provider for a referral to Rehabilitation Oncology (see [page 15](#)).



What are the signs and symptoms of lymphedema?

- Swelling in the affected area
- A feeling of heaviness, tingling or numbness in the affected area
- Clothing or jewellery becomes tight on that limb
- Find it more difficult to move the affected limb
- Have pain or discomfort in the affected area
- Have infections that reoccur

Have your doctor assess any changes in size, colour, temperature, skin condition, and sensation, and get a referral to a certified lymphedema therapist for treatment. Check with your local cancer centre to see if they have a certified lymphedema therapist.



Infections (cellulitis)

Infections can be an urgent medical situation. Signs may include redness, warmth, pain, chills/fever and a feeling of overall illness or flu-like symptoms. See your family doctor if you notice any of these signs or symptoms.

Manage Your Health Care



Manage Your Health Care

How can I reduce my risk of developing lymphedema?

We do not know why some people with the same risk factors develop lymphedema and others do not. Here are some things you can try to prevent lymphedema:



- Minimize injury to the affected limb.
- Maintain good skin and nail care – to help reduce the risk of developing infection.
- Clean small breaks or cuts in the skin with soap and water and apply antibiotic cream. Have your family doctor look at any serious cuts.
- If possible, use your non-surgical arm for any injections, IVs, automated blood pressure readings or blood draws.
- Do not wear tight-fitting jewellery or clothing on the affected limb.

Some considerations for your activity level and lifestyle:

- Keep active. Talk to your family doctor before you start any exercise program.
- Stay at a healthy body weight with a well-balanced diet and exercise.
- Swimming, walking, biking, and light yoga are all good activities. Avoid temperature extremes (for example, **hot yoga is not recommended**).
- Gradually build up the length of time and intensity of your exercise.
- Take frequent rest periods during activity.

Learn about lymphedema in the **Understanding Cancer-Related Lymphedema** module at www.ahs.ca/cancersupportivecare > [Rehabilitation Oncology](#) > Lymphedema/Swelling or scan the QR code.



SCAN ME

Find more information about ways you can increase your physical activity safely.



From: After Treatment Book

<https://www.albertahealthservices.ca/assets/info/cca/if-cca-after-treatment-for-cancer.pdf>

Any additional feedback on the webpage layout, level of detail, etc? Type or come off mute!

Seems good

Looks good to me!

One page handout with those patients links as sometimes hard to write down the links for patients when so long. QR code could be helpful but patient would need to save it.

user friendly, easy to navigate, nice to have all of the info in one place for easy access

You mentioned self navigation for patient would be helpful as well.
Waiting for guidance is often stressful

Yes that would be great thanks

sometimes best to have something simple for a patient to go to at home on their own time. Searching through the website would likely eat up a lot of time if done in the office.

Are there lists of resources for patients and doctor

Fatigue

nutrition, exercise

no

Once we finalize the lymphedema resource, what other cancer-related symptoms should we look at? Example: Fear of Recurrence

Fear or recurrence
Cancer related
fatigue and pacing

Pain from spinal fractures, mobilizing,
return to work chemo side effects

What networks are available for me
to access while waiting for treatment
and after treatment

Fatigue
Brain fog
Neuropathy

Dýpnea

AHS public page

Delirium

Fear of recurring. Anticipated
changes even in surviving cancer

We want to make sure our webpage is accessible from other common sites! Where have you gone in the past to access cancer info? PCN webpage, AMA, etc.

Wellspring

CPAC

Insite

google

AHS public page

If you are interested in participating in any user-acceptance testing for the webpage, please contact us!

Linda.Watson@albertahealthservices.ca

Claire.Link@albertahealthservices.ca

Michelle.Sharma@albertahealthservices.ca

Thank you!