Gynecologic
Cancer Initiative

WOMEN'S
Health Research Cluster

2019
SUMMIT
REPORT

SURVIVORSHIP SUMMIT
GYNECOLOGIC CANCERS

This report was prepared by the Gynecologic Cancer Initiative Cluster and the Women's Health Research Cluster (www.womenshealthresearch.ubc.ca).

SUGGESTED CITATION: Moore, K. 2020. *Survivorship summit gynecologic cancers: Post summit report.* Vancouver, BC: UBC.

Acknowledgements

We would like to acknowledge that this summit took place on the traditional, ancestral, and unceded territory of the xʷməθkʷəy̓əm (Musqueam) people.

Sponsorships

The Gynecologic Cancer Initiative Cluster and the Women’s Health Research Cluster would like to thank the University of British Columbia, through the Grants for Catalyzing Research Clusters funds, for making this event possible. Their commitment to excellence in interdisciplinary women’s health research has enabled this endeavour.

THE UNIVERSITY
OF BRITISH COLUMBIA

Staff and Volunteers

We would like to thank all of the staff, volunteers and patient partners that came together to make this event possible:

Scientific Program Committee
Dr. Liisa Galea
Dr. Gavin Stuart
Dr. Lori Brotto
Dr. David Huntsman

Planning Committee
Michelle Woo
Stephanie Lam
Ama Kyeremeh

Patient Partners
Laszlo Veto
Nicole Keay
Barry Smee
Mike Reid
Colleen Malli
Siv Klausen
Nancy Cleveland
Kathryn Lundy
Eleanor Jenkinds

Graphic Facilitator
Aaron Lao

Report Author
Katherine Moore
(katherinemooreconsulting@gmail.com)

Graphic Designer
Hristo Butchvarov
(RozerArt on Fiverr.com)

Table of Contents

Executive Summary

Cancer is the leading cause of death in Canada and accounts for 30% of all fatalities across the country (Public Health Agency of Canada, 2018; Statistics Canada, 2009). Of all cancers affecting women, gynecologic cancers—which include malignancies of the uterus, cervix, ovaries, vagina, vulva and fallopian tubes—make up 11% of new diagnoses. In 2017 there were over 9000 new cases of gynecologic cancers in Canada, which was predicted to rise above 11,550 in 2019 (Statistics Canada, 2020; CCSAC, 2019). Despite these figures, relatively little research has focused on gynecologic cancers.

To fill this gap, the Gynecologic Cancer Initiative Cluster and the Women's Health Research Cluster co-hosted a Survivorship Summit to stimulate research in British Columbia. Specific objectives for the event were to (1) identify key questions and priorities for survivorship research in BC, and (2) to gain a better understanding of the assets and resources in BC that can support survivorship research. The inaugural event took place on Nov 29, 2019 at the University of British Columbia and was attended by 56 patient partners, healthcare practitioners and scholars. This report fulfills the objects of the summit by summarizing key points that arose through the rich conversations and presentations that took place throughout the day.

Six high-level themes were identified: 1) comprehensive care and treatment, 2) healthcare provider education and practice, 3) prevention, 4) side effects of treatment, 5) patient and public education, and 6) connection and collaboration. Each theme contains its own set of priorities, research questions, assets, resources and challenges, which are summarized at the end of each section in the report.

Several symptoms of gynecologic cancer, and side effects of common treatments, were identified as key priority areas for new research and treatment practice improvements. These conditions include chemotherapy induced cognitive impairment, radiotherapy induced enteritis, sexual dysfunction, chronic bowel blockages, chemotherapy induced peripheral neuropathy and chronic leg pain. Although medical interventions to treat these conditions are lacking, exercise is one successful therapy that may also have undiscovered benefits for other cancer symptoms.

The experiences of several patient partners indicate that healthcare practitioners and cancer agencies must do more to adequately support this group. There are too few sources of accurate and relevant information about gynecologic cancer online, practitioners rush patients through a complicated system thereby revoking their ability to make informed decisions, and healthcare providers remain unaware of how to respectively support sex and gender-diverse patients.

Genetic testing arose as a promising practice for preventative healthcare, and it was suggested that a Gynecologic Cancer Survivorship Research Consortium be developed to tackle key research questions. Furthermore, there is a need to create a Gynecologic Cancer Research and Practice Network to foster partnerships that will enable the generation of relevant hypotheses, practical interventions and effective knowledge translation between scientists and practitioners.

Background

Cancer is the leading cause of death in Canada and accounts for 30% of all fatalities across the country (Public Health Agency of Canada, 2018; Statistics Canada, 2009). Of all cancers affecting women, gynecologic cancers—which include malignancies of the uterus, cervix, ovaries, vagina, vulva and fallopian tubes—make up 11% of new diagnoses. In 2017 there were over 9,000 new cases of gynecologic cancers in Canada, which was predicted to rise above 11,550 in 2019 (Statistics Canada, 2020; CCSAC, 2019). Despite these figures, relatively little research has focused on gynecologic cancers, likely because lung, breast and prostate cancer have a greater incidence rate (Canadian Cancer Society, 2020). Fortunately, efforts to improve treatments and generate new knowledge about higher incidence cancers has resulted in some positive changes. For example. mortality rates in female breast cancer has dropped by nearly 50% since 1986 (CCSAC, 2019). While slight decreases in mortality rates have also been observed in ovarian and cervical cancers (BC Cancer, 2019a; BC Cancer, 2019b), deaths due to endometrial cancer (i.e. cancer of the uterus) continue to rise (BC Cancer, 2019c).

Reducing mortality rates is the focal point of any work in the health field. Yet, for the past 20 year's improving the quality of life in patients, regardless of mortality, has gained more attention. Unfortunately, gynecologic cancers have a particularly negative impact on a patient's quality of life as they not only affect their psychological and physiologic wellbeing but can also alter their sexual functioning. As such, practitioners must be aware of the unique consequences of gynecologic cancers and engage patients in relevant conversations to help mitigate them. Despite this need, patients report that healthcare providers rarely, if ever, discuss fertility and sexuality with them (Cull, et al., 1993). Furthermore, ongoing stigma and embarrassment mean that most survivors suffer in silence and do not obtain accessible and timely interventions for sexual concerns.

In response to these gaps in knowledge and practice, the Gynecologic Cancer Initiative Cluster (GCIC) and the Women's Health Research Cluster (WHRC) resolved to co-host a Survivorship Summit to (1) review the current status of what is known and what gaps exist in the science of gynecologic cancer survivorship research, and (2) stimulate research and collaboration in British Columbia (BC). Specific objectives for the event were to (1) identify key questions and priorities for survivorship research in BC, and (2) to gain a better understanding of the assets and resources in BC that can support survivorship research. To emphasize the importance of approaching this work with a biopsychosocial lens, the summits theme was *Biologically, and Socio-Culturally Informed Gynecologic Cancer Survivorship Strategies* and the event was divided into 3 corresponding segments: biological, cultural and social. Each segment featured 4-6 short presentations from survivors, caregivers, and experts. Throughout the event, moderators facilitated discussion amongst attendees to inspire new ideas and collaborations that could help move the field forwards. The inaugural Survivorship Summit took place on Nov 29, 2019 at the University of British Columbia and was attended by 56 patient partners, healthcare providers, scholars, trainees, communications and knowledge translation specialists, fundraisers, and administrative personnel.

Introduction

This report fulfills the objectives of the Survivorship Summit by summarizing key points that arose through the rich conversations and presentations that took place throughout the day. Specifically, it highlights key priority areas, research questions, resources, assets and challenges relating to gynecologic cancer research and practice that were identified by presenters and audience members. The GCIC and WHRI hope that this information will be used to generate new hypotheses and educate healthcare provider about pertinent issues related to gynecologic cancer care.

Methodology

This report draws on several sources of information including speaker notes, twitter posts made during the event, notes taken by attendees and feedback received via email after the summit. These sets of data were combined and analyzed to elucidate key priorities, key questions, assets, resources and challenges. Then, the same data set was analyzed using a thematic approach, which involves giving data lower order codes that are later grouped into high order themes (Strauss, 1987; Boyzatis 1998; Braun and Clarke 2006). The latter provided insight into high-level themes discussed throughout the summit, whereas the former addressed the specific objectives of the summit.

Findings

Six high-level themes were discussed throughout the summit: 1) comprehensive care and treatment, 2) healthcare provider education and practice, 3) prevention, 4) side effects of treatment, 5) patient and public education, and 6) connection and collaboration. Each theme contains its own set of priorities, research questions, assets, resources and challenges. This section elaborates on these themes and concludes with a summary of key take-aways.

Theme 1: Comprehensive Treatment & Care

Throughout the Summit participants repeatedly discussed the need for the healthcare system to employ a comprehensive cancer treatment and care regime. In particular, they called for a system that is aware of and responds thoughtfully to human diversity as well as the heterogeneity of gynecologic cancer. Additionally, they highlighted a need for long-term biopsychosocial treatment and care that extends beyond cancer survival.

Diversity

A number of domains related to the diversity of patients and gynecological cancer were identified as priority areas that need to be addressed in order to achieve a truly comprehensive healthcare system. Topics that received the most attention include cultural, sex and gender, geographic and medical diversity.

Cultural Diversity

In his presentation on managing gynecologic cancers in South Asian populations, Dr. Aalok Kumar demonstrated the importance of tailoring healthcare practices to address unique cultural beliefs. He explained that a patient's culture can dramatically alter how they behave before and after a diagnosis. For example, many ethnic minority groups believe that life events—including a cancer diagnosis—are destined. Thus, preventative healthcare practices such as routine screening procedures have low levels of participation with this group. Furthermore, there is a strong stigma amongst South Asians around having cancer, which minimizes the transfer of critical hereditary knowledge between family members. This information spurred conversation about the need for ***healthcare providers to consider a patient's culture when providing care***, and to ***share culturally relevant education with them***. For example, primary care providers must be proactive with their South Asian patients by educating them about the importance of preventative health practices, such as cancer screening and sharing health information with family members. Yet, it was determined that the first step ultimately lies in ***raising awareness about these challenges with healthcare providers***.

Kumar added that communication is also a barrier. For instance, patients that speak English as a second or third language experience greater difficulty explaining their symptoms to physicians, which may lead to a delayed and/or misdiagnosis. With these challenges in mind, the room realized that new research must be conducted to determine ***how patients with different linguistic and cultural backgrounds interpret their healthcare providers questions about symptom presentation differently***.

Sexuality and Gender-based Diversity

Dr. Mary Bryson conveyed the importance of understanding and responding competently to the unique healthcare needs of patients with diverse sexualities and gender identities. As part of the Cancer's Margins project, Bryson and colleagues examined the health experiences of patients with minority sexualities and gender identities (i.e. queer, lesbian, bisexual, two-spirit, transgender) throughout their breast and gynecologic cancer journeys. The project revealed that many of these patients felt dissatisfied and marginalized by the current healthcare system (Bryson et al., 2018). Classifying breast and gynecologic cancer as "women's cancers" was one-way trans and gender diverse patients were marginalized by the status quo. As a result of this exclusionary categorization, Bryson and colleagues found that trans and gender diverse patients often self-selected out of key healthcare practices such as pap tests—and in some cases were turned away at women's health centres by staff who felt they didn't belong (Bryson et al., 2018). The Cancer's Margins project also revealed that information about a patient's sexual orientation and gender identity is absent from every national cancer surveillance database, many clinical cancer units and relevant research projects (Taylor & Bryson, 2016). As a result, data regarding cancer prevalence in relation to these factors cannot be systematically tracked—which is problematic given that this population has a higher level of risk and prevalence for cancer coupled with lower rates of participation in screening (Cathcart-Rake 2018; Kamen et al. 2015; Polite et al. 2017, Boehmer et al. 2013). As such, summit participants determined that it is crucial for ***medical documentation and treatment practices be inclusive of people with diverse sexualities and gender identities, and to respond to what is known about the health profile of this group***. Furthermore, they determined that the ***use of accurate sex and gender-based language*** is required to develop a system that is truly inclusive. Although very little work has been done in this area, Bryson suggests that interested persons can look to the San Francisco Bay area to identify potential partners and experts.

Geographic Diversity

Many cancer care facilities reside in few urban centres across Canada. Yet, over 6 million Canadians live in rural areas (Statistics Canada, 2011). With cancer being the leading cause of death in Canada, the disproportionate representation of care facilities in urban centres creates a major problem for rural residents (Statistics Canada, 2009). One of our patient partners, Laszlo Veto, gave a presentation about his late wife's ovarian cancer journey and recalled a time when he had to drive 2 hours to seek emergency care for her. It's important to note that they first attempted to receive care at their small local hospital but were turned away due to lack of qualified staff to treat her. When they arrived at the next hospital 2 hours away, a radiologist informed Mr. Veto that a specific procedure was required to save his wife's life—but the practitioner had never performed it before. Fortunately, the procedure went well but this experience motivated the couple to move to Vancouver to be treated at the BC Cancer Agency later on. This story generated discussion about the ongoing challenge of connecting with rural communities, not only in the medical field but in research too. With that, a question arose; ***how can we provide first-rate care for patients living in rural areas and effectively engage these residents in research?*** Although an answer to these questions has yet to be established, the audience agreed that allied organizations such as the Canadian Cancer Society and BC Cancer would be key partners in closing these gaps.

Medical Diversity

Another patient partner, Nicole Keay, bravely told her story about being diagnosed with and surviving cervical cancer. In her early thirties Keay was diagnosed with stage 1 invasive squamous cell carcinoma and, after looking back on the experience, she felt that there were a few ways her cancer care could have been improved. Specifically, Keay identified the need for more support related to the psychological and reproductive impacts of having cancer and undergoing treatment. For example, she was advised to take measures to preserve her fertility but did not receive counsel to discuss, or prepare for, the possibility that these efforts may not work. As a result, she experienced significant shock and suffered enduring trauma when ultimately losing her ability to have children. In addition to this, Keay was not connected with resources that could have provided emotional, psychological, informational or sexual health support throughout her treatment—or after becoming cancer free. Thus, she emphasized the importance of ***conceptualizing survivorship as starting with diagnosis and extending well beyond the eradication of cancer***. Fortunately, there were a few community groups that offered Keay excellent informational and social support (Cervivor, Rethink Breast Cancer) as well as financial relief for fertility treatments (Fertile Future Grants). Yet, upon hearing this story participants agreed that there is an urgent need to ***ensure that patients of all ages, who have all forms of cancer—and at all stages of malignancy—receive the same comprehensive biopsychosocial care***.

> *“Just because we are young and just because we have cancers that we’re likely to survive, does not mean we don’t need or deserve additional care." —Nicole Keay, patient partner*

In light of the information shared about human and medical diversity, summit participants strongly felt that ***personalized survivorship plans need to be established for all cancer patients***. In doing so, one’s culture, sexual orientation, gender identity, age and unique cancer profile can be used to develop comprehensive targeted treatment plans that will ultimately improve the quality of life and medical outcomes of patients in BC.

Treatment and Care

In addition to calling for greater personalization in how we treat and care for patients, many presentations also pointed to the need for a broader scope of treatment options. For example, Dr. Kristin Campbell discussed research about the superior effect that exercise has on treating cancer-related fatigue compared to pharmaceuticals (Mustian, et al. 2016), and shared new exercise guidelines for cancer survivors. These guidelines recommend that patients avoid inactivity, exercise as much as possible, and aim to achieve 30 minutes of moderate exercise 3x/week and 2 days/week of resistance exercise to address many of the common side effects of cancer treatment. Once this is achieved, the guidelines recommend that patients progress by following current physical activity guidelines targeting the general health of all adults (Campbell, et al. 2019). Thus, Campbell raised the importance of ***advancing the prescription of exercise as a cancer-related fatigue management strategy*** to improve treatment outcomes. Adding to this, Siv Klausen (patient partner) recommended Inspire Health: Supportive Cancer Care, which connected her with a Kinesiologist to help start a fitness routine. Furthermore, other summit participants questioned ***the extent to which healthcare providers are using diet to manage symptoms of gynecologic cancer such as bowel obstructions***.

Dr. Anna TInker and several patient partners called for long-term treatment and care practices to be adopted nation-wide. Specifically, Tinker insisted that we ***develop long-term symptom management and treatment strategies for patients that undergo pelvic radiotherapy***. Her call to action was rooted in the fact that pelvic radiotherapy (a common form of treatment for pelvic cancers) often causes radiation induced enteritis, which can develop years after treatment ends. This condition can cause life impairing symptoms in 90% of patients, such as severe bowel blockages, yet there are currently no protocols for following up with patients regarding gastrointestinal changes after being discharged (Olopade, et al., 2005). Interestingly, several patient partners also expressed the ***need for informational support to be provided as soon as they became cancer free***. In particular, they expressed an interest in receiving information about post-cancer nutritional counselling, sexual rehabilitation, psychosocial support options or simply an information booklet about what to expect in the future.

Along with echoing the desire for post-cancer care, some of our patient partners indicated a crucial ***need for case workers to help patients navigate the healthcare system*** after being diagnosed. In their eyes, a case worker would be aware of the resources (e.g. support groups, grants, websites) and connect patients with them when needed. Additionally, case workers would help patients understand what appointments they will need, connect them with healthcare practitioners when necessary and be available to answer questions.

Priorities

- ☐ Raise awareness with healthcare provider about different cultural beliefs and behaviours related to gynecologic cancer
- ☐ Healthcare provider must provide culturally relevant education to their patients
- ☐ Use accurate sex/gender-based language
- ☐ Medical screening, documentation and treatment practices must 1) be inclusive of gender diverse people and 2) respond to what is known about the health profile of this group
- ☐ Provide first-rate care for patients living in rural areas
- ☐ Conceptualize survivorship as starting with diagnosis and extending well beyond the eradication of cancer

- ☐ Ensure patients with all forms of cancer—and at all stages of malignancy—receive comprehensive biopsychosocial care.
- ☐ Personalized survivorship plans need to be established for all cancer patients.
- ☐ Advance the prescription of exercise as a cancer-related fatigue management strategy
- ☐ Develop long term symptom management and treatment strategies for patients that undergo pelvic radiotherapy
- ☐ More informational support is needed when patients become cancer free
- ☐ Case workers are needed to help patients navigate the healthcare system

Questions

- ☐ How do patients with different linguistic and cultural backgrounds interpret their healthcare providers questions about symptom presentation differently?
- ☐ How can first-rate care be provided to patients living in rural areas?
- ☐ How can rural communities be effectively engaged in research?
- ☐ Are healthcare providers using diet as a tool to manage bowel obstructions?

Challenges	Assets & Resources
Cultural differences in perceptions of disease Cultural differences in behaviour that results from diagnosis Language acts as a barrier to patients when communicating symptoms with healthcare providers Connecting with rural communities in research and medicine	Cancer's Margins Project (www.lgbtcancer.ca) SF Bay area: Sex and gender-based diversity experts Canadian Cancer Society (www.cancer.ca/en/?region=on) BC Cancer (www.bccancer.bc.ca) Cervivor (www.cervivor.org) Rethink Breast Cancer (www.rethinkbreastcancer.com) Fertile Future Grants (www.fertilefuture.ca) Exercise Guidelines for Cancer Survivors (www.kngf.nl/binaries/content/assets/kngf/onbeveiligd/nieuwsitem-bestanden/2019/oktober/paper-2.pdf) Inspire Health: Supportive Cancer Care (/www.inspirehealth.ca)

Theme 2: Healthcare Provider Education and Practice

Many of the priorities outlined in Theme 1 rely on healthcare providers to be adequately trained and remain informed throughout their careers. Therefore, it is no surprise that the second most commonly discussed priority area identified at the summit was the need for additional education to be given to healthcare providers. Furthermore, this conversation was significantly punctuated with dialogue around the need for practice improvements.

Education

Through a number of presentations and conversations, it was determined that additional education must be given to healthcare providers to enhance their ability to prevent, detect, and treat gynecologic cancer and its related symptoms.

Before Diagnosis

Dr. Lesa Dawson reported on the lifesaving power of genetic testing for women that may inherit cancer and emphasized the importance of ***giving general practitioners (GP) training in genetic testing***. She suggested that if GPs were aware that genetic testing could identify patients at risk for developing heritable cancers with high levels of accuracy—and that successful preventative therapies exist for these patients—then the incidence of new cancer diagnoses could be reduced (this topic will be explored more thoroughly in Theme 3).

Adding to this, Barry Smee (patient partner) questioned whether ***ongoing training is embedded in the current GP curriculum to help physicians identify and accurately diagnose gynecologic cancers***. These questions emerged as Mr. Smee reflected on his experience taking care of his wife, Susan Smee, throughout her cancer journey. Despite visiting a number of GPs over a four-month period, Mrs. Smee received various misdiagnoses including irritable bowel disease and diverticulosis before being correctly diagnosed with ovarian cancer. Her symptoms included difficulty digesting food, bloating, severe abdominal pain and feeling generally unwell. These symptoms overlap with the conditions Mrs. Smee was initially diagnosed with, but Mr. Smee was shocked that it took *four months* for an ultrasound to be ordered. Why did it take this long? Are GPs not aware of this overlap? Are they not trained to rule out fatal conditions first? With these questions left unanswered, ***it is critical that the current GP curriculum and ongoing professional development opportunities be evaluated to determine whether training related to gynecologic cancers are sufficient***.

After Diagnosis

Given that radiotherapy is commonly used to treat pelvic cancers, and radiation induced enteritis affects the majority of patients undergoing this treatment, it is important that healthcare providers stay abreast of knowledge in this domain. Yet, Dr. Anna Tinker indicated that the number of patients affected by enteritis, and the extent to which it impacts a patient's life, is often underestimated. ***Understanding the true realities surrounding enteritis*** is one area that practitioners could enhance their knowledge in order to provide better care to their patients. However, Tinker also mentioned that this condition is not very well researched, which would impact a practitioner’s ability to dig deeper into the issue. As such, she issued a strong call to action for researchers to ***investigate this condition further and suggested that the connection between radiation induced enteritis and the microbiome be examined more closely***.

Similarly, more healthcare provider education and research is needed regarding chemotherapy induced peripheral neuropathy (CIPN). This condition results from damage to peripheral nerves and leads to impaired sensory functioning as well as changes in one's ability to control their appendages (Brown, Sedhom & Gupta, 2019). Common symptoms of CIPN include tingling, decreased sensation or increased sensitivity of the hands and feet. These symptoms (amongst others) can arise within hours of treatment, but commonly appear weeks to months afterwards (Brown, Sedhom & Gupta, 2019). Similar to enteritis, Tinker indicated that the prevalence and severity of CIPN is underestimated. In fact, she outlined several myths associated with CIPN including the idea that most patients develop minimal levels of neuropathy, that symptoms gradually improve once chemotherapy is stopped and that CIPN primarily consists of sensory symptoms instead of motor—none of which are supported by research (Miaskowski, et al., 2017; Stout, 2017; Winters-Stone, 2017). Furthermore, she notes that motor impairments related to CIPN increases one’s risk for falls—particularly in the elderly. Despite this knowledge, Tinker revealed that most medical therapies have not been proven to reduce CIPN-related symptoms with the exception of exercise, which she stated may be a promising symptom management strategy. Evidently, it is important that ***healthcare providers understand the prevalence, trajectory and risks associated with CIPN*** so that they can provide competent counsel to patients before treatment. It is also critical that researchers ***conduct high quality assessments of medical therapies for CIPN***.

Sexual health is another area that summit participants agreed that healthcare providers could use more training in. As mentioned earlier, Nicole Keay felt that she did not receive adequate council about fertility. She mentioned that fertility seemed like an afterthought to practitioners and that her GP did not have the expertise to sufficiently support her even if they wanted to. In addition to this, Keay experienced painful intercourse and trouble re-establishing a sexual relationship with her partner. Yet, her healthcare providers did not warn her about these symptoms or provide recommendations about how to manage them. To Keay and many others in the room, it became clear that ***healthcare providers must receive better training about the potential impacts of gynecologic cancer on a patient’s sexual health as well as training about resources and rehabilitation options to help manage symptoms***. One major challenge in all of this is ensuring that healthcare providers in rural areas maintain the same level of knowledge and experience as those in urban communities. With this in mind, summit participants brainstormed efficient routes of communicating sexual health knowledge to GP’s and determined that the Family Practice Oncology Network may be an ally in this endeavour.

Besides training related to symptoms of gynecologic cancer, the Cancer Margins project points to the need for more healthcare provider education related to the ***impact that cancer has on a***

patient's sense of gender as well as how to respectfully support sex and gender diverse peoples throughout their cancer journey. The following was taken from Bryson et al's (2018) article that outlines common interactions between patients and healthcare providers and demonstrates their respective biographical and biomedical cancer knowledge.

"*Ariel described communicating to a cancer provider that their decision to undergo a bilateral mastectomy was informed by their experience of seeing others in their community undergo mastectomy (top surgery) in the context of gender affirming care. In Ariel's story, a male oncology surgeon seemed both unfamiliar and uncomfortable with this decision and sent them off to see a female cancer care provider, which resulted in multiple delays in care – a denial of care that may be directly related to the cisnormative knowledge that informs systems of cancer care*." (p.8)

Although this passage relates to breast cancer and not gynecologic cancer, it draws attention to the gap in knowledge between healthcare providers and gender diverse patients about their sense of gender. If this physician was aware of—and respected—the gender affirming potential of mastectomies for transgender men, then their patient could have left this meeting feeling validated and optimistic about their upcoming procedure. Furthermore, it's important to note that some gender non-conforming patients that do not identify as trans may be apprehensive about undergoing hysterectomies or mastectomies since it could increase their chances of being misidentified. For example, a female that identifies as a woman but dresses in accordance with male gender stereotypes may be worried about being misidentified as a transgendered man after undergoing a double mastectomy. In sum, the Cancer Margins project demonstrates that physicians are largely unaware of these complexities and have little understanding of how to support patients as they negotiate these important decisions.

Practice

A number of presenters and summit participants commented on the need to improve current practices regarding screening, recording and sharing medical information. For instance, Bryson called attention to the fact that ***medical screening, documentation and treatment practices*** are not ***inclusive of gender diverse people and that significant improvements should be made in this domain.*** To start this work, Bryson encouraged medical facilities to develop systems (e.g. forms, health record systems, screening protocols) that include sex and gender options beyond the current male/female and man/women dichotomies. Doing so will create visibility of LGBT/T2S people and enable practitioners to employ evidence-based healthcare practices based on this information.

Several patient partners highlighted the need for healthcare providers to ***empower patients to make informed decisions about their treatment and care plans***. Siv Klausen recollected that her decision-making ability was virtually non-existent while being treated for squamous cell carcinoma. As she moved from appointment to appointment, Klausen felt as though everything transpired too quickly, which resulted in her simply agreeing and following instructions as they were given. Instead, she wished her healthcare providers had asked her opinion about what she’d like to do and ensured that she understood the information given. Similarly, Bryson added that ***practitioners need to help their patients understand the impact of hormone therapy during cancer treatment***. This conversation spurred an important question—***what percentage of patients are satisfied with the amount of information they receive from their GPs about the impacts of gynecologic cancer treatment on their quality of life?***

Priorities

Education that healthcare providers require:

- ☐ Utility of genetic testing as a cancer prevention strategy
- ☐ Prevalence, trajectory, risks and treatments associated with enteritis and CIPN
- ☐ Potential impacts of gynecologic cancer on a patient's sexual health (e.g. fertility, painful intercourse, psychosocial impacts)
- ☐ Resources and rehabilitation options available to help manage symptoms (e.g. pelvic floor physio)
- ☐ Impact of gynecologic cancer/treatment on patients’ sexual health and sense of gender
- ☐ How to respectfully support sex and gender diverse peoples

Enhance practice by:

- ☐ Medical screening, documentation and treatment practices must be inclusive of gender diverse people
- ☐ Empower patients to make informed decisions about treatment and care plans
- ☐ Inform patients about the impact of hormone therapy during cancer treatment

Questions

- ☐ What education plan is currently in place for GPs related to gynecologic cancers?
- ☐ What ongoing training exists to help GPs identify and accurately diagnose gynecologic cancers?
- ☐ What is the connection, if any, between the microbiome and radiation induced enteritis?
- ☐ How can symptoms associated with CIPN be mitigated or eliminated?
- ☐ What percentage of patients are satisfied with the amount of information they receive from their GPs about the impacts of gynecologic cancer treatment on their quality of life?

Challenges	Resources
Educated and trained healthcare providers residing in rural areas	Family Practice Oncology Network (www.bccancer.bc.ca/health-professionals/networks/family-practice-oncology-network) Inspire Health: Supportive Cancer Care (www.inspirehealth.ca)

Theme 3: Prevention

Cancer care starts with prevention. However, prevention extends beyond merely preventing cancer from developing. It also encompasses efforts to thwart the rise of ancillary malignancies associated with gynecologic cancer such as cognitive impairment, radiation enteritis and breast cancer. Thus, preventative actions should be taken before, during and after cancer.

Before Cancer

The goal of population-based cancer screening programs is to detect cancer at early, curable stages and improve overall survival. Mammograms and pap tests are examples of public screening in action. Although these methods are incredibly valuable, they don’t help prevent cancer from developing. Furthermore, most public health prevention strategies target lifestyle habits or environmental factors on a broad scale but will not address specific individual risk.

Dr. Lesa Dawson suggested that identifying individuals at high risk for gynecologic cancer and implementing targeted prevention programs will be an invaluable part of Canadas future cancer prevention strategy. In her presentation, Dawson explained that genetic testing can identify individuals with abnormalities (i.e. mutations or pathogenic variants) in cancer control genes (e.g. *BRCA1* and *BRCA 2*) and detect abnormal genetic conditions like Lynch Syndrome. These abnormalities put people at an elevated lifetime cancer risk (e.g. 75% and 40% lifetime risk of breast cancer and ovarian cancer respectively for *BRCA1*). As such, individuals with these conditions would benefit enormously from intensive breast MRI screening and preventative removal of fallopian tubes and ovaries. These interventions, if provided by the age of 40, are associated with a 70% improvement in all-cause mortality. For families with Lynch syndrome, a 70-80% lifetime risk of colon cancer is reported, and annual or bi-annual coloscopies allows for significant improvements in overall survival.

Dawson discussed a case study regarding one of her patients who was diagnosed with ovarian cancer and had a *BRCA2* gene mutation. Given the heritable nature of this predisposition, the patient's daughters underwent genetic testing and discovered that 50% of them carried the familial mutation. All who were found to be at high risk decided to implement the recommended cancer prevention strategies, which resulted in no further cancer related deaths in the family.

In the Canadian system at present, genetic testing is accessed only for individuals with a cancer diagnosis, and those unaffected by cancer can only access testing if a mutation is proven in the family. Dr. Dawson proposed that this system misses many opportunities for prevention. Considering that 1/100-1/300 Canadians may carry one of these cancer predisposition mutations, a broader, more inclusive and population-based model of high-risk testing and screening will greatly impact cancer rates country-wide.

Using the abovementioned case study, Dawson suggested that ***genetic testing for cancer predispositions (e.g. BRCA 1, BRCA 2, Lynch Syndrome) should be widely available across Canada***. This opportunity excited the room and led to a productive discussion around the ***best implementation models of such a strategy***. Fertility clinics were identified as an asset in these endeavours, but there are a few challenges associated with this venture—namely the fact that there are relatively few clinics available across the country, and existing clinics are disproportionately located in urban hubs and have long wait times. Summit participants were in agreement that the current model of care is not meeting the needs of high-risk Canadians and that this topic is an important component of cancer prevention in future.

Another challenge arises when you consider the different cultural experiences patients have after receiving a gynecologic cancer diagnosis. As discussed in Theme 1 there is a strong stigma amongst South Asian groups around having cancer. As a result, they are much less likely to share critical information about their health with immediate family members or extended relatives. In addition to culture, there are a number of other factors that could also be limiting this transfer of knowledge. For example, there could be long lasting family disputes, a lack of knowledge about one's relatives, or a lack of understanding about the lifesaving potential of health-related information sharing. Summit participants determined that ***facilitating the communication of information between patients and their extended family*** should be a priority moving forwards. Furthermore, these efforts ***should focus specifically on transferring knowledge related to the risk of developing inherited cancers.*** Doing so will open up the possibility of using genetic testing as a preventative cancer screening tool and could contribute to a decrease in cancer diagnoses for future generations. But the audience wondered ***how extended family could be connected with in spite of these barriers.*** Some believed that genetic counsellors may be the answer, while others see BC Cancer as an important ally.

During Treatment

After being diagnosed with cancer, patients are at risk of developing life-impairing conditions associated with treatment. For example, Dr. Liisa Galea revealed that chemotherapy causes impairments in memory, executive functioning and reduces the speed of cognitive processing. Many summit participants recognized these symptoms in their own practice or personal experience. One scholar mentioned that her colleague revealed feelings of inadequacy at work due to chemotherapy induced cognitive impairments (CICI). Another suggested that this psychosocial experience is quite common and often causes many of her patients to leave the workplace prematurely. Interestingly, cognitive impairments vary depending on a number of variables including sex, age, menopausal status, type of chemotherapy, type of cancer and length of treatment time. In light of the impact that these symptoms can have on a patients personal and professional lives, the group recognized that ***preventing cognitive impairments associated with chemotherapy*** is paramount. However, given the number of variables known to impact treatment symptoms, a key question arose: ***how can patients who are at more risk for certain chemotherapy side effects be identified?***

As mentioned earlier, enteritis and CIPN are two other conditions caused by common gynecologic cancer treatments (i.e. chemotherapy and pelvic radiotherapy) that negatively impact patients' lives. Given the number of patients affected by these ailments throughout (and beyond) their cancer journeys, summit participants agreed that it is also important to work towards ***reducing the risk of developing enteritis and CIPN***. However, before this can be possible scientists must explore key questions about these conditions such as: ***how is the microbiome implicated in the gastrointestinal impacts of pelvic radiotherapy?*** and, ***how can we use this information to mitigate the effects of radiotherapy on patients?***

After Cancer

After being diagnosed with cancer and undergoing treatment, learning that you are cancer free is a welcome milestone. However, beating cancer doesn't mean that survivors will no longer be impacted by it. In fact, research shows that patients will continue to be impacted in a number of ways. For example Dr. Gillian Hanley, who shared cutting edge research conducted by her student Nimisha Arora, demonstrated that women who survive 10 or more years after receiving an ovarian cancer diagnosis are 5 times more likely to die from breast, lung or colorectal cancers, and are 12 times more likely to die by external causes—mostly falls—compared to women the same age who never had ovarian cancer (Arora, Talhouk, McApline, Law & Hanley, 2019). The 5-year survival rate for ovarian cancer remains less than 50%, which has likely contributed to the lack of attention being paid to long-term survivors. Yet, many patients live beyond the average 5 years, and our audience agreed that ***greater efforts should be made to provide long-term care to this population***.

Data regarding the causes of death among ovarian cancer survivors can be used to develop strategies to improve patient's survival. Hanley pointed out that screening for breast, lung and colorectal cancers are effective and readily available, particularly for breast and colorectal cancer. ***Implementing new screening protocols for survivors of ovarian cancer could save lives***. With respect to the increased of death due to falls, the crowd had more questions than answers. ***What is causing the increased risk of death due to falling among ovarian cancer survivors (e.g. neurological impairments, bone density loss, or both)? How many ovarian cancer survivors experience loss in bone density after chemotherapy? Can strength training increase the bone density of survivors that underwent chemotherapy?*** Researchers interested in tackling these questions may want to consult the Canadian Multicentre Osteoporosis Study, which collected data about the rates of falling in Canada as well as demographic information related to those who have fallen.

The Survivorship Summit was fortunate to have Hanley share recent research on these topics, and more research is currently underway to ***deepen our understanding about the health needs ovarian cancer survivors***.

Priorities

☐ Genetic testing for cancer predispositions (e.g. *BRCA1, BRCA2*, Lynch Syndrome) should be widely available across Canada.
☐ Facilitate the communication of risk for developing inherited cancers between patients and their extended family
☐ Reduce risk of developing CICI, CIPN and radiotherapy induced enteritis

- ☐ Provide long-term care to ovarian cancer survivors by implementing new health screening protocols
- ☐ Deepen our understanding about the health needs of ovarian cancer survivors
- ☐ Determine what is causing the increased risk of death due to falls among ovarian cancer survivors.

Questions

- ☐ What are the best models of implementing genetic testing for BRCA1/BRCA2 and Lynch Syndrome widely across Canada?
- ☐ How can healthcare providers connect with their patients’ extended family to facilitate health information sharing?
- ☐ How can patients who are at more risk for certain chemotherapy side effects be identified?
- ☐ How is the microbiome implicated in the gastrointestinal impacts of pelvic radiotherapy?
- ☐ How can we use information about the gastrointestinal impacts of pelvic radiotherapy to mitigate the effects of this treatment on patients?
- ☐ What is causing the increased risk of falling (e.g. neurological impairments, bone density loss, or both)?
- ☐ How many ovarian cancer survivors experience loss in bone density after chemotherapy?
- ☐ Can strength training increase the bone density of survivors that underwent chemotherapy?

Challenges	Assets
Long wait times at fertility clinics Fertility clinics are disproportionately located in urban hubs Reaching extended family to communicate risk of inheriting cancer Comprehensive and effective implementation of prevention strategies	Fertility clinics Genetic counsellors BC Cancer Canadian Multicentre Osteoporosis Study (www.camos.org/index.php)

Theme 4: Side Effects of Treatment

Many of the abovementioned themes have looked at the negative side effects of cancer treatment from different angles. This section spotlights side effects head on and captures the conversation summit participants had around research needed in this area. As you will soon see, the audience had more questions about side effects than answers.

Bowel Obstructions

The life altering impact of chronic bowel obstructions was frequently brought up by patient partners and researchers. One notable story was told by Barry Smee, who shared the experiences of his wife Susan who was diagnosed with ovarian cancer and ultimately lost her life due to a bowel obstruction. It was quickly determined that ***relieving bowel obstructions as a side effect of cancer treatment should be at the forefront of research***. There is only one problem—very little research has been conducted on this topic to date. Thus, it is imperative that scientists begin exploring ***the cause of bowel obstructions as a symptom of gynecologic cancer treatment*** before interventions can be developed.

Cognitive Impairment

In Theme 3 we discussed CICIs related to memory, executive functioning and the speed of cognitive processing. It was established that preventing CICIs should be a priority moving forward, but many questions about these symptoms exist. For example, we know that 20% of women continue to experience changes in their cognitive function after treatment but we don't know ***how long these symptoms last*** (Wefel, Vardy, Ahles & Schagen, 2011). Current evidence suggests that these impairments can persist for 2 years, and perhaps much longer (Gregorowitsch et al., 2019). Furthermore, a clear profile of patients with chronic CICI does not currently exist, thus there is a need for future research to examine the ***differences between them and women with acute CICI***, or whether ***CICI varies depending on the type of chemotherapy used.*** During this discussion one of our patient partners who experienced CICI explained that she felt like a zombie, was unable to complete simple cognitive tasks and felt extremely fatigued. After listening to her story, summit participants wondered ***how much of CICI can be explained by fatigue***. Galea responded by noting that it is not possible to completely disentangle the effects of stress, depression or fatigue that are related to diagnosis, disease and chemotherapy, and mentioned that all of these factors could contribute in part to CICI (Ahles, Root & Ryan, 2012). However, she exclaimed that depression, stress and fatigue cannot completely account for CICI as the condition persists year's after treatment (Miao et al., 2016; Kim et al, 2018, Carroll et al., 2019; Ganz et al., 2013). Galea mentioned that scholars currently believe that fatigue only accounts for a small part of CICI, but that the field isn't advanced enough to answer this question confidently. On another note, not all patients will develop CICI. This fact led summit participants to express curiosity about whether there are ***genetic variables that put some women at risk of developing CICI***.

Neuropathy

In Theme 2 we introduced CIPN and mentioned that most medical therapies have not been proven to reduce CIPN-related symptoms—with the exception of exercise. Given that motor impairments increase a patient's risk of falling (which can lead to death or significant injuries), the audience called for more research on ***the role of exercise in managing neurological side effects of chemotherapy***. For example, they wondered ***what types of exercise and what dose has the greatest effect on reducing CIPN***? Furthermore, Tinker mentioned that there is excellent research depicting the genetic predisposition for chemotherapy induced nerve damage in breast cancer patients but pointed out that there is very little on the topic related to gynecologic cancer. Thus, called on interested scholars to investigate whether there is a ***genetic predisposition to nerve damage caused by chemotherapy in individuals with gynecologic cancers***.

Sexual Dysfunction

In Theme 1 we introduced Nicole Keay who shared her story of surviving cervical cancer and losing her ability to have children throughout the process. Unfortunately, many women with gynecologic cancers experience some form of sexual dysfunction resulting from their treatment. In her presentation on sexual health after gynecologic cancer Dr. Lori Brotto dug deeper into this topic. She explained that sexual dysfunction manifests uniquely in patients depending on their cancer and treatment type and that symptoms are diverse. For example, Brotto mentioned that psychosexual problems, such as sexual distress, impacts 50%-80% of survivors and that sexual difficulty, coupled with its direct impact on psychosocial morbidity, is the biggest source of suffering for females following treatment (Abbott-Anderson & Kwekkeboom, 2012; Falk & Dizon, 2013; Froeding, Greimel & Lanceley, 2018; Aerta et al., 2012). Furthermore, she explained that anatomy-altering treatments, such as vulvar excision and radical vulvectomy, can affect a patient’s body image in addition to causing dyspareunia (i.e. difficult or painful intercourse). Critically, Brotto exclaimed that impairments in emotional wellbeing and quality of life lead to higher rates of morbidity and mortality, and that the sexual health side effects of treatment may impact a patient’s decision to undergo treatment at all (Hordern & Street, 2007; Forbat, White, Marshall-Lucette & Kelly, 2012; Litwin et al, 1995). Given that sexual dysfunction often begins during cancer treatment, persists long into one’s survivorship journey and continues if untreated, Brotto emphasized the importance of ***caring for a patient’s sexual health at all stages of survivorship*** (Nazareth, Lewin & King, 2001; Chung & Brock, 2013; Mercandante, Vitrano & Catania, 2010; Abbott-Anderson & Kwekkeboom, 2012). Drawing on her own research, Brotto explained that ***mindfulness interventions*** can improve sexual functioning in patients treated for gynecologic cancer and encouraged healthcare practitioners to incorporate them into their practice (Brotto et al., 2017; Brotto et al., 2008; Brotto et al., 2012). Moreover, provided that the sexual health needs of individuals identifying as part of a marginalized, minority, or remote group have been relatively ignored in sexual rehabilitation research, Brotto highlighted the ***need for culturally diverse online interventions*** to be developed.

Other

In addition to calling for more research related to the above-mentioned conditions, the room voiced several other questions that scholars should address. First, they wondered how cancer treatment might affect the menstrual cycle. Menstruation receives relatively little attention in research when compared to the impact it has on women’s lives. Thus, some participants urged researchers to examine ***how gynecologic cancer and its many forms of treatment might impact the menstrual cycle***. Furthermore, since exercise has a proven ability to treat cancer-related fatigue and reduce CIPN symptoms, the room questioned ***whether exercise has other positive effects on symptom management and treatment outcomes for gynecologic cancer patients***. As such, they determined that this is may be fruitful area that deserves further exploration. Lastly, when considering the life altering impacts of the above-mentioned side effects (and many others), the audience collectively agreed that ***patients who are at risk for severe and immediate side effects of chemotherapy*** must be identified promptly in the healthcare system. This may take the form of proactive screening protocols for all patients.

Priorities

- ☐ Relieve bowel obstruction as a side effect of cancer treatment
- ☐ Address patients' sexual health at all stages of survivorship
- ☐ Develop culturally diverse online sexual rehabilitation interventions

Questions

- ☐ What causes bowel obstructions as a symptom of gynecologic cancer treatment?
- ☐ What is the temporal timeframe for CICI?
- ☐ What are the differences between women who experience chronic vs acute CICI?
- ☐ What genetic components, if any, put women at risk of developing CICI?
- ☐ Does CICI vary depending on the type of chemotherapy used?
- ☐ How much of CICI can be explained by fatigue?
- ☐ What is the role of exercise in managing neurological side effects of chemotherapy?
- ☐ What types of exercise and what dose has the greatest effect on reducing CIPN?
- ☐ Is there a genetic predisposition to nerve damage caused by chemotherapy in individuals with gynecologic cancers?
- ☐ How does gynecologic cancer and its many forms of treatment impact the menstrual cycle?
- ☐ Does exercise have any other positive effects on symptom management and treatment outcomes in gynecologic cancer patients?
- ☐ What patients are at risk for severe and immediate side effects of chemotherapy?

Assets

More reading on mindfulness interventions research can be found in Brotto et al. (2017), Brotto et al. (2008) and Brotto et al. (2012). See references for full citation.

Theme 5: Patient and Public Education

We've outlined several areas where healthcare providers may benefit from additional education and training but have yet to discuss knowledge gaps associated with patients and the general public. Numerous rich conversations throughout the summit revealed several domains where additional education for this population may be needed.

In his presentation on managing gynecologic cancers in a South Asian population, Dr. Kumar revealed that this group believes cancer can only be inherited through the male lineage. In other words, it is thought that children can only inherit gynecologic cancer if a father or grandfather had cancer. Conversely, if the mother was ever diagnosed with gynecologic cancer it is assumed that her daughter would not be at risk for inheriting the disease. This belief contributes to the low prevention behaviours observed in this population. As such, Kumar called for a campaign that ***debunks myths about genetic inheritance of cancer*** and ***increases awareness about gynecologic cancer prevention strategies***, such as genetic screening.

Although many cancer organizations strive to provide the public with information about cancer symptoms, treatments and prevention strategies, most of this information pertains to breast, lung and prostate cancers. In fact, many of our patient partners indicated that they turned to the internet to answer many of their questions and often consulted information related to other cancers when content about their condition wasn't available. Guided by her personal experience with cervical cancer Nicole Keay informed the audience that ***patients need accurate and accessible information online about gynecologic cancer treatment options and side effects.*** Adding onto that, Siv Klausen (patient partner) said that she would have benefited from ***information about how to communicate with healthcare providers*** (e.g. online examples of how to communicate symptoms or pain).

Priorities

- ☐ Public awareness campaign to debunk myths about genetic inheritance of cancer
- ☐ Increase public awareness about gynecologic cancer prevention strategies
- ☐ Provide patients with accurate and accessible information online about gynecologic cancer treatment options and side effects.
- ☐ Online information about how to communicate with healthcare providers
- ☐ Enhanced patient education about the impact of cancer treatments

Theme 6: Connection and Collaboration

A notable portion of summit participants highlighted the need for greater connection between practitioners as they care for patients and more extensive collaboration between practitioners and scholars, as well as amongst multidisciplinary researchers.

In Theme 1 we shared Laszlo Veto's story about caring for his wife Marga as they sought treatment for her ovarian cancer while living in a rural area. However, the challenge of finding experienced practitioners while living outside an urban centre was only part of their story. In fact, Mr. Veto suggested that their problems with the medical system began 14 years before his wife's death when she began developing chronic leg pain. Her first visit to the doctor regarding leg pain was in 2003, where the physician indicated that the pain was “uneventful”. In 2011, 2012 and 2014 she visited a physician several times each year to discuss the worsening pain. Yet, each visit revealed a different etiology for the pain including early osteoporosis, claudication, nerve root impingement—or no cause of pain was identified at all. In September of 2014, Mrs. Veto's medical discussions began to focus on her abdominal pain, which was identified as stemming from *ascites with no cause*. This condition worsened quickly and led Mrs.

Veto to receive the lifesaving operation discussed in Theme 1. The following month Mrs. Veto was diagnosed with stage III high-grade serous carcinoma and transferred to BCCA upon her request. Interestingly, only medical records for Sept-Oct of 2014 (i.e. regarding her ascites) was transferred to BCCA. Furthermore, upon closer investigation after Mrs. Veto's passing in 2017 Mr. Veto noticed that the emergency room responsible for her surgery indicated that her troubling symptoms had "developed over the past couple of months". The fact that Mrs. Veto's inconsistent and unresolved medical history from 2003 to August 2014 was not transferred to BCCA or considered to have a possible connection to her developing cancer is dangerous. Because of this, staff at BCCA may not have fully understood her condition (particularly the temporal aspects of it), and thus were unable to make a fully informed decision about her treatment. Furthermore, all of this potentially relevant medical history would never be used for research purposes, which could examine the possible connection between leg pain and ovarian cancer. This story reveals the need for our medical system to improve its continuity of care practices, particularly related to record sharing. After hearing Mr. Veto's story, the audience agreed that our healthcare system must ***ensure that medical records are fully and accurately completed—regardless of length—and widely shared with a patient's medical team***.

Towards the end of the summit, participants reflected back on their conversations and realized that stronger relationships must be built amongst academics with interdisciplinary perspectives on gynecologic cancers, as well as between practitioners and researchers, in order to tackle the critical issues outlined in this report. It was suggested that a ***Gynecologic Cancer Survivorship Research Consortium be developed*** to tackle key research questions such as: ***Is lower leg pain a symptom of ovarian cancer? Does the impact of each cancer vary depending on the area affected?*** Defining and answering such questions is essential to move the field of gynecologic cancer forwards. Yet, a critical element would be missing if healthcare providers were not involved. As such, summit participants agreed that ***creating a Gynecologic Cancer Research and Practice Network*** is essential to foster partnerships that will enable the generation of relevant hypotheses, practical interventions and effective knowledge translation between scientists and practitioners.

Priorities

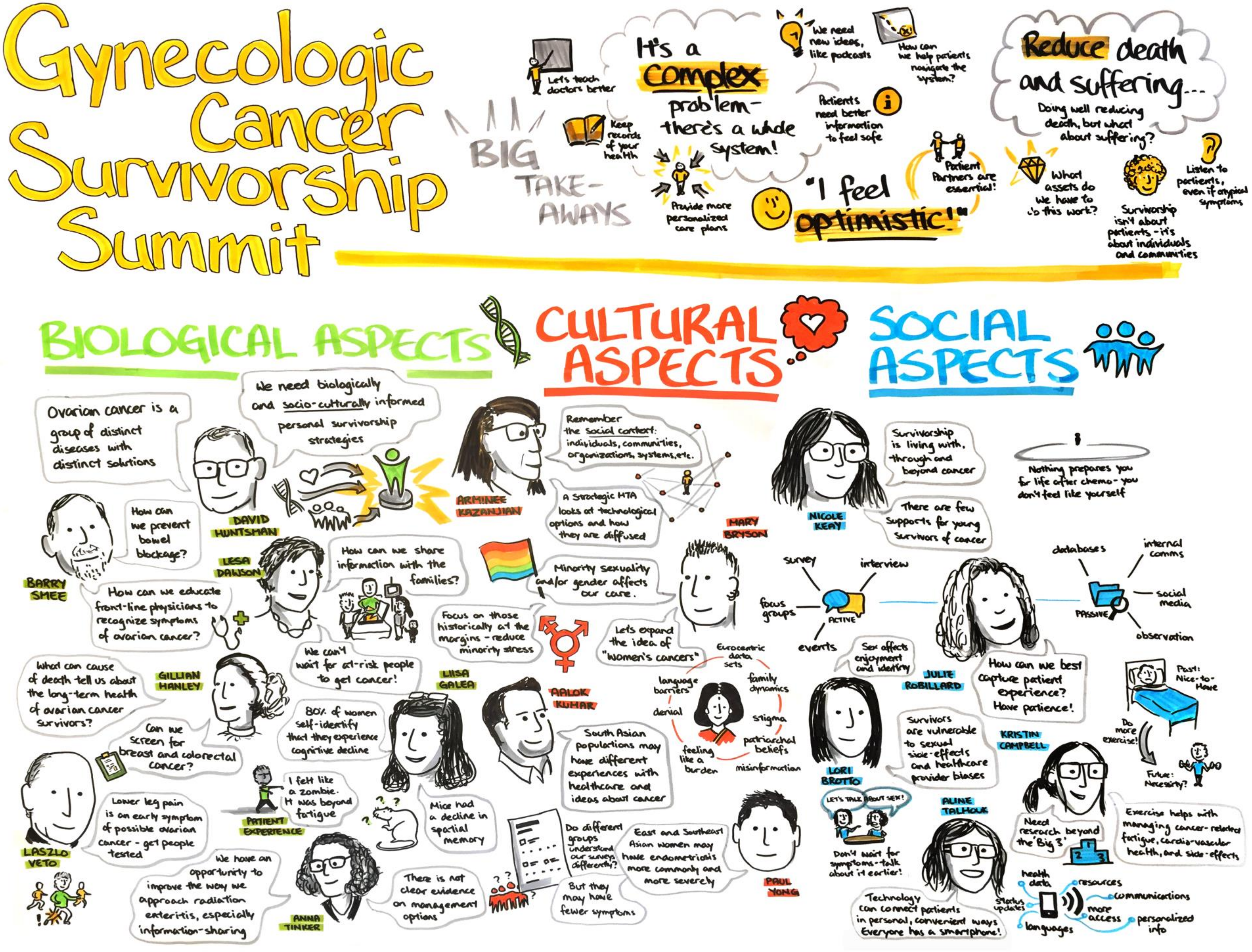
☐ Ensure that medical records are fully and accurately completed—regardless of length—and widely shared with a patient's medical team
☐ Develop a Gynecologic Cancer Survivorship Research Consortium
☐ Create a Gynecologic Cancer Research and Practice Network

Questions

☐ Is lower leg pain a symptom of ovarian cancer?
☐ Does impact of each cancer vary depending on the area affected? (e.g. squamous cell carcinoma of the ovaries vs. uterus)

Conclusion

Whether you are a nurse, family physician, scientist, patient or family member of a loved one with gynecologic cancer, there is something for you to take away from this report. A number of life impairing consequences of gynecologic cancer and treatments have been brought to your attention and a heartfelt attempt has been made to direct the future of how we care for patients. We invite readers to use the questions, priorities and information outlined here as a jumping off point to advance research, treatment and care practices so that we may collectively reduce the incidence rate of gynecologic cancer, improve the quality of life for those impacted and ultimately strengthen the numbers of survivors.



Presented by the Gynecologic Cancer Iniative and the Women's Health Research Cluster
November 29, 2019

Aaron Lao
Graphic Facilitator

References

Abbott-Anderson, K., & Kwekkeboom, K. L. (2012). A systematic review of sexual concerns reported by gynecological cancer survivors. *Gynecologic oncology*, *124*(3), 477-489. doi:10.1016/j.ygyno.2011.11.030

Aerts, L., Enzlin, P., Vergote, I., Verhaeghe, J., Poppe, W., & Amant, F. (2012). Sexual, psychological, and relational functioning in women after surgical treatment for vulvar malignancy: a literature review. *The journal of sexual medicine*, *9*(2), 361-371. doi:10.1111/j.1743-6109.2011.02520.x.

Ahles, T. A., Root, J. C., & Ryan, E. L. (2012). Cancer-and cancer treatment–associated cognitive change: An update on the state of the science. *Journal of Clinical Oncology*, *30*(30), 3675.

Arora N., Talhouk A., McAlpine J. N., Law M. & Hanley G. E. (2019) Cause of death among women with epithelial ovarian cancer by length of survival post-diagnosis: A population-based study in British Columbia. *Canada International Journal of Gynecologic Cancer, 29*(3):593-598. http://dx.doi.org/10.1136/ijgc-2018-000040

BC Cancer. (2019a). Age-standardized cancer incidence rates, relative to 1970, British Columbia, 1970-2016: Ovary. Retrieved from: http://www.bccancer.bc.ca/statistics-and-reports-site/Documents/2019_Ovary_inc_trend_1970_2016_20190208.pdf

BC Cancer. (2019b). Age-standardized cancer incidence rates, relative to 1970, British Columbia, 1970-2016: Cervix. Retrieved from: http://www.bccancer.bc.ca/statistics-and-reports-site/Documents/2019_Cervix_inc_trend_1970_2016_20190208.pdf

BC Cancer. (2019c). Age-standardized cancer incidence rates, relative to 1970, British Columbia, 1970-2016: Body of uterus. Retrieved from: http://www.bccancer.bc.ca/statistics-and-reports-site/Documents/2019_Body%20of%20Uterus_inc_trend_1970_2016_20190208.pdf

Boehmer, Ulrike, Glickman M., Winter M. & Clark M. A. (2013). Long-term breast cancer survivors' symptoms and morbidity: Differences by sexual orientation?. *Journal of Cancer Survivorship, 7*(2): 203-210.

Boyzatis, R. (1998). *Transforming qualitative information*. Thousand Oaks, CA: Sage Publications.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qual Res Psychol, 3*(2):77-101. doi:10.1191/1478088706qp063oa.

Brotto, L. A., Dunkley, C. R., Breckon, E., Carter, J., Brown, C., Daniluk, J., & Miller, D. (2017). Integrating quantitative and qualitative methods to evaluate an online psychoeducational program for sexual difficulties in colorectal and gynecologic cancer survivors. *Journal of sex & marital therapy*, *43*(7), 645-662.

Brotto, L. A., Erskine, Y., Carey, M., Ehlen, T., Finlayson, S., Heywood, M., ... & Miller, D. (2012). A brief mindfulness-based cognitive behavioral intervention improves sexual functioning versus wait-list control in women treated for gynecologic cancer. *Gynecologic oncology*, *125*(2), 320-325.

Brotto, L. A., Heiman, J. R., Goff, B., Greer, B., Lentz, G. M., Swisher, E., ... & Van Blaricom, A. (2008). A psychoeducational intervention for sexual dysfunction in women with gynecologic cancer. *Archives of Sexual behavior*, *37*(2), 317-329.

Brown TJ, Sedhom R, Gupta A. Chemotherapy-Induced Peripheral Neuropathy. *JAMA Oncol.* 2019;5(5):750. doi:10.1001/jamaoncol.2018.6771

Bryson, M. K., Taylor, E. T., Boschman, L., Hart, T. L., Gahagan, J., Rail, G. & Ristock, J. (2018). Awkward choreographies from cancer's margins: Incommensurabilities of biographical and biomedical knowledge in sexual and/or gender minority cancer patients' treatment. *The Journal of Medical Humanities.* doi: 10.1007/s10912-018-9542-0

Campbell, K. L., et al. (2019). Exercise guidelines for cancer survivors: Consensus statement from international multidisciplinary roundtable. *Medicine and Science in Sports and Exercise*, *51*(11):2375-2390.

Canadian Cancer Society. (2020). Cancer statistics at a glance. Retrieved from: https://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=on

CCSAC/Canadian Cancer Statistics Advisory Committee. (2019). *Canadian Cancer Statistics 2019.* Retrieved from: http://www.cancer.ca/~/media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics%20supplementary%20information/2019/cancer-specific-stats-2019.pdf?la=en

Cancer.Net. (2018). Lynch Syndrome. Retrieved from: https://www.cancer.net/cancer-types/lynch-syndrome

Carroll, J. E., Small, B. J., Tometich, D. B., Zhai, W., Zhou, X., Luta, G., ... & Jim, H. S. (2019). Sleep disturbance and neurocognitive outcomes in older patients with breast cancer: Interaction with genotype. *Cancer*, *125*(24), 4516-4524.

Cathcart-Rake E. (2018). Cancer in sexual and gender minority patients: Are we addressing their needs?. *Current Oncology Reports, 20*(11): 1-8.

Chung, E., & Brock, G. (2013). Sexual rehabilitation and cancer survivorship: a state of art review of current literature and management strategies in male sexual dysfunction among prostate cancer survivors. *The journal of sexual medicine*, *10*, 102-111. doi:10.1111/j.1743-6109.2012.03005.x.

Cull A., Cowie V. J., Farquharson D. I., Livingstone J. R., Smart G. E. & Elton R. A. (1993). Early stage cervical cancer: Psychosocial and sexual outcomes of treatment. *Br J Cancer, 68*(6):1216-1220.

Falk, S. J., & Dizon, D. S. (2013). Sexual dysfunction in women with cancer. *Fertility and sterility*, *100*(4), 916-921. doi: 10.1016/j.fertnstert.2013.08.018.

Forbat, L., White, I., Marshall-Lucette, S., & Kelly, D. (2012). Discussing the sexual consequences of treatment in radiotherapy and urology consultations with couples affected by prostate cancer. *BJU international*, *109*(1), 98-103. doi:10.1111/j.1464-410X.2011.10257.x.

Froeding, L. P., Greimel, E., Lanceley, A., Oberguggenberger, A., Schmalz, C., Radisic, V. B., ... & Schnack, T. H. (2018). Assessing patient-reported quality of life outcomes in vulva cancer patients: a systematic literature review. *International Journal of Gynecologic Cancer*, *28*(4), 808-817. doi:10.1097/IGC.0000000000001211.

Ganz, P. A., Kwan, L., Castellon, S. A., Oppenheim, A., Bower, J. E., Silverman, D. H., ... & Belin, T. R. (2013). Cognitive complaints after breast cancer treatments: examining the relationship with neuropsychological test performance. *JNCI: Journal of the National Cancer Institute*, *105*(11), 791-801.

Gregorowitsch, M. L., Ghedri, A., Young-Afat, D. A., Bijlsma, R., Baas, I. O., van Schaik-van de Mheen, C., ... & Verkooijen, H. M. (2019). The effect of chemotherapy on subjective cognitive function in younger early-stage breast cancer survivors treated with chemotherapy compared to older patients. *Breast cancer research and treatment*, *175*(2), 429-441.

Hordern, A. J., & Street, A. F. (2007). Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. *Medical Journal of Australia*, *186*(5), 224-227. doi:10.5694/j.1326-5377.2007.tb00877.x.

Kamen, Charles, Smith-Stoner M., Heckler C., Flannery M. & Margolies L. (2015). Social support, self-rated health, and lesbian, gay, bisexual, and transgender identity disclosure to cancer care providers*. Oncology Nursing Forum,* 42(1):44–51.

Kim, H. J., Barsevick, A. M., Chan, A., & Chae, J. W. (2018). Chemotherapy-associated cognitive impairments in Korean cancer patients: Risk factors and functional outcome. *Psycho-oncology*, *27*(8), 1995-2001.

Litwin, M. S., Hays, R. D., Fink, A., Ganz, P. A., Leake, B., Leach, G. E., & Brook, R. H. (1995). Quality-of-life outcomes in men treated for localized prostate cancer. *Jama*, *273*(2), 129-135. doi:10.1001/jama.1995.03520260051032.

Mercadante, S., Vitrano, V., & Catania, V. (2010). Sexual issues in early and late stage cancer: a review. *Supportive Care in Cancer*, *18*(6), 659-665. doi:10.1007/s00520-010-0814-0.

Miao, H., Li, J., Hu, S., He, X., Partridge, S. C., Ren, J., ... & Qiu, B. (2016). Long-term cognitive impairment of breast cancer patients after chemotherapy: a functional MRI study. *European journal of radiology*, *85*(6), 1053-1057.

Miaskowski, C., Mastick, J., Paul, S. M., Topp, K., Smoot, B., Abrams, G., ... & Bolla, K. (2017). Chemotherapy-induced neuropathy in cancer survivors. *Journal of pain and symptom management*, *54*(2), 204-218.

Mustian, K. M., Alfano, C. M., Heckler, C., Kleckner, A. S., Kleckner, I. R., Leach, C. R., ... & Scarpato, J. (2017). Comparison of pharmaceutical, psychological, and exercise treatments for cancer-related fatigue: a meta-analysis. *JAMA oncology*, *3*(7), 961-968.

Nazareth, I., Lewin, J., & King, M. (2001). Sexual dysfunction after treatment for testicular cancer: a systematic review. *Journal of Psychosomatic Research*, *51*(6), 735-743. doi:10.1016/S0022-3999(01)00282-3.

Olopade F., Norman A., Blake P., Dearnaley D., Harrington K., Khoo V., et al. (2005). A modified inflammatory bowel disease questionnaire and the vaizey incontinence questionnaire are simple ways to identify patients with significant gastrointestinal symptoms after pelvic radiotherapy. *Br J Cancer*, 92, 1663–1670.

Polite, B. N., Adams-Campbell, L. L., Brawley, O. W., Bickell, N., Carethers, J. M., Flowers, C. R., ... & Li, C. I. (2017). Charting the future of cancer health disparities research: a position statement from the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute. *Cancer research*, *77*(17), 4548-4555.

Public Health Agency of Canada. (2018). *Cancer in Canada*. Ottawa. Retrieved from: https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/fact-sheet-cancer-canada/fact-sheet-cancer-canada.pdf

Statistics Canada. (2020). Table 32-10-0197-01: Number and rates of new cases of primary cancer, by cancer type, age, group and sex. Retrieved from: https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310011101

Statistics Canada. (2011). Table 32-10-0197-01: Number of persons in the total population and the farm population, for rural areas and population centres, classified by sex and age. Retrieved from: https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=3210019701. DOI: https://doi.org/10.25318/3210019701-eng

Statistics Canada. (2009). *Leading causes of death in Canada, 2009.* Retrieved from: https://www150.statcan.gc.ca/n1/pub/84-215-x/2012001/hl-fs-eng.htm

Stout, N. L. (2017). Expanding the perspective on chemotherapy-induced peripheral neuropathy management. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology, 35*(23), 2593-2594. doi:10.1200/JCO.2017.73.6207

Strauss, A. (1987). *Qualitative Analysis for Social Scientists*. Cambridge, UK: Cambridge University Press.

Taylor, E. T., & Bryson, M. K. (2016). Cancer's margins: Trans* and gender nonconforming people's access to knowledge, experiences of cancer health, and decision-making. *LGBT Health, 3*(1), 79-89. doi:10.1089/lgbt.2015.0096

Wefel, J. S., Vardy, J., Ahles, T., & Schagen, S. B. (2011). International Cognition and Cancer Task Force recommendations to harmonise studies of cognitive function in patients with cancer. *The lancet oncology*, *12*(7), 703-708.

Winters-Stone, K. M., Horak, F., Jacobs, P. G., Trubowitz, P., Dieckmann, N. F., Stoyles, S., & Faithfull, S. (2017). Falls, functioning, and disability among women with persistent symptoms of chemotherapy-induced peripheral neuropathy. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology, 35*(23), 2604-2612. doi:10.1200/JCO.2016.71.3552