

# BC Cancer Partners Engagement Newsletter - October 2021

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Friday, October 1st 2021, 10:17:06 AM PDT

**Joyce**

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Provincial Health Services Authority

October 2021

PATIENT EXPERIENCE PROGRAM

**GET INVOLVED!  
ENGAGEMENT OPPORTUNITIES**



**\*This newsletter is for members of the Network of Patient and Family Partners. Please do not circulate.**

We invite patient and family partners to get involved with the following activities at BC Cancer:

## **1. P2P Connect: Connect with Partners across BC!**

Join the Partners Network group meeting, Partners to Partners Engagement Connect (P2P Connect), on **Friday October 15, 12:00 to 1:30 pm.**

The purpose of the monthly Partners to Partners Engagement Connect (P2P Connect) meetings is to allow Partners to connect, share ideas and learn from peers on ways to strengthen patient and family engagement in BC Cancer. A team of Patient and Family Partners co-lead P2P Connect. You can learn more about P2P Connect in the [terms of reference](#).

On September 17, twenty Partners joined the video conference from Abbotsford, Delta, Golden, New Westminster, Penticton, Qualicum Beach, Vancouver and Victoria. Partners were joined by the new management of the Patient & Family Experience Program: Sarah Weller, Director of Provincial Programs, and Jennifer Edgecombe, Manager of Supportive Care and Patient &

Family Experience. Sarah and Jen talked about their vision for enhancing the patient and family experience of care. The leaders thanked the Partners for their commitment to patient and family engagement and congratulated all for the ongoing partnerships since the inception of the Partners Network. The P2P Connect Partner Leads shared the highlights of their engagement experiences and their hopes for an engaged community of Partners at BC Cancer. The hopes and wishes included increased patient and family engagement at the regional cancer centres, ongoing partnership with BC Cancer to provide better care for all patients, opportunities to contribute to knowledge base and being a part of the change for better cancer care protocol, and recognition that the unique cancer experience of each person can impact the care of others.

Partners also reflected on their engagement experiences, highlighting the importance of communicating and information sharing among patients, families and care professionals, supporting/helping other patients, giving insights to the health professionals on the patient's experience of care, and including diversity of voices in care improvement. Further, the need to shift the language from "patient" to "person" and the power of the person's story in care improvement were identified. Other issues on the patient experience discussed were transition of care, post-treatment supportive care, care for rural/remote communities, remote access to care/virtual health and role of regional cancer centres.

On October 15, we will hear from Ben Lee, Senior Leader for Provincial Education at the Office of Virtual Health, Provincial Health Services Authority (PHSA). Ben will talk about his experience engaging attendees in virtual meetings and how he made the most of the participant voice. Ben will also share tips on best communication practices in group Zoom meetings.

Send in your questions on how you can participate meaningfully in Zoom engagement meetings, when you sign up for Ben's talk. To join October 15 P2P Connect meeting, please **RSVP by October 13**.

RSVP

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## 2. Video on [cancerandwork.ca](http://cancerandwork.ca)

### **Background and purpose:**

The Patient and Family Counselling department is creating a video featuring the patient experience with using the website [www.cancerandwork.ca](http://www.cancerandwork.ca). The Cancer and Work website was designed to address the needs of people returning, remaining, changing

### **Location:**

BC Cancer - Vancouver. Physical distancing and safety procedures will be in place.

### **Date and time:**

Starting Oct 18, 2021 and ending March 31,

or looking for work after a cancer diagnosis. The video will be used to increase awareness and access to the online resource.

**What will the patient/family partners do:**

The Patient/Family Partners will be filmed while talking about their experience using [cancerandwork.ca](http://cancerandwork.ca). Filming will take place at BC Cancer - Vancouver. Video will be featured on the Cancer and Work website and used in health professional education.

**What is the level of engagement?**

Involve

**Desired qualities and experience of patient/family partners:**

Patient Partners who have used [www.cancerandwork.ca](http://www.cancerandwork.ca) and are willing to discuss what has helped them.

2022.

**Frequency of meetings:**

Two short phone meetings and one in-person meeting for filming.

**Time commitment:**

3 hours: two 30 minute phone meetings; one 2 hour meeting for filming.

**Closing date for response:**

Friday October 8, 2021

SIGN-UP

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**3. Review of handouts on treatment for head and neck cancer**

**Background and purpose:**

The Speech and Language Pathology department has created two new handouts for patients receiving treatment for head and neck cancer. One is about difficulty opening your mouth (Trismus) and the other is about swelling after treatment (Lymphedema). The team is seeking patient/family input on whether the handouts are helpful and easy to understand.

**What will the patient/family partners do:**

Patient/Family Partners will:

- Fill out a needs assessment form about what they would like to know about trismus and lymphedema.
- Review handouts and give feedback on the content.

**Location:**

By email, with options to join a one time Zoom or phone meeting.

**Date and time:**

Starting mid-October 2021 and ending January 2022.

**Frequency of meetings:**

One time

**Time commitment:**

About one hour

**Closing date for response:**

Friday October 8, 2021

## What is the level of engagement?

Consult

### Desired qualities and experience of patient/ family partners:

Patient or Family Partners who have had lived experiences with head and neck cancer.

SIGN-UP

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## 4. Review of Community Oncology Network website

### Background and purpose:

The Provincial Systemic Therapy program is updating the Community Oncology Network (community cancer care locations) website. The Community Oncology Network is organized in a new Tiers of Service framework, and the program is updating two webpages to reflect this change. The goal is to ensure the information is easy to understand and patients have the information they are looking for.

### What will the patient/family partners do:

The Patient/Family Partners will:

- Give feedback on two webpages on whether the content is easy to understand and if there is more information needed.
- Give feedback on which services should be listed for the different community oncology network tiers.
- Meet with the Initiative Lead by phone or Zoom to give feedback.

## What is the level of engagement?

Involve

### Desired qualities and experience of patient/ family partners:

Patients or family Partners who have:

- Received care at BC Cancer and a community site.
- Used some supportive care services e.g. dietitian, counselling, support groups.

### Location:

By email and phone/Zoom meeting

### Date and time:

Starting mid-October and ending October 31, 2021.

### Frequency of meetings:

One meeting, or more as per the Partners' needs.

### Time commitment:

4 hours: 1-2 hours to review two webpages; 1-2 hours maximum of meeting with the initiative lead to give feedback.

### Closing date for response:

Friday October 8, 2021

## SIGN-UP

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### 5. Review of Immunotherapy video

**Background and purpose:**

The Provincial Systemic Therapy program is reviewing a patient education video from Sunnybrook Health Sciences (Ontario). The video may be posted on BC Cancer website. Patient perspective is needed to ensure the content is clear, easy to understanding and relevant to the patient needs.

**What will the patient/family partners do:**

Patient Partners will watch a 7 minute immunotherapy video and complete a short evaluation form.

**What is the level of engagement?**

Consult

**Desired qualities and experience of patient/family partners:**

Patient Partners who have had immunotherapy

**Location:**

By email

**Date and time:**

Starting October 18 and ending October 29, 2021.

**Frequency of meetings:**

No meeting

**Time commitment:**

No more than 30 minutes.

**Closing date for response:**

Friday October 8, 2021

## SIGN-UP

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### 6. Personas of Older Adults with Cancer Study



# Personas to Support Health Care Provider Use of Electronic Patient-Reported Outcomes in the Care of Older Adults with Cancer

## Research Study Information

### **What is the purpose of the research?**

This research will help to create “personas” which are hypothetical representations, in this case, of older cancer patients that incorporate demographic data and fictional life stories. You are being invited to help develop patient personas to assist your health care providers to better understand the medical, emotional and social needs of older cancer patients. The patient personas will then be used as tools to inform the development of a learning module for health care providers on the use of electronic patient-reported outcomes in the care of older adults.

### **Who is conducting the research?**

Principal Investigator: Dr. Jae-Yung Kwon is a registered nurse and an Assistant Professor at the University of Victoria

Phone: [604-729-2308](tel:604-729-2308)

Email: [jykn1@uvic.ca](mailto:jykn1@uvic.ca)

### **How can you help?**

If you are an older adult (65+ years of age) who is living with cancer and would like to take part in this study, you will be asked to participate in one-and-a-half-hour online workshop session (and a follow-up feedback survey) in the development of personas to help health care providers better manage the cancer journey of patients. Please note that your care at BC Cancer will not be compromised should you elect not to join the study.

Please contact the researcher or the research assistant Melissa [moyniha3@student.ubc.ca](mailto:moyniha3@student.ubc.ca) if you think you might like to take part in this study.

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We want to give all Patient and Family Partners the opportunities to join the engagement initiatives at BC Cancer. The selection of participants in the initiatives is based on the Partner's fit with the engagement request and our commitment to diversity of the patient/family voice.

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## ADDITIONAL OPPORTUNITIES IN THE COMMUNITY



### **The Survivor Identity Index: How Does Cancer Survivor Identity Relate to Emotional Well-Being?**

People who have been diagnosed and treated for cancer vary in their comfort with the concept of "cancer survivorship". The goal of this research is to help us learn how a person's comfort with the idea of survivorship relates to their type of cancer, treatment history, and their relationships with the primary members of their healthcare team.

You are invited to take part in this research study if you are over 18 years old, have been diagnosed with breast cancer, and can read and understand English. If you choose to participate, you will be asked to complete an online survey which is expected to take between 15-20 minutes.

If you are interested in participating in this study, please use this link to access the consent form and questionnaire:

[https://ubc.ca1.qualtrics.com/jfe/form/SV\\_9ZTMbmyAUPIIHE9](https://ubc.ca1.qualtrics.com/jfe/form/SV_9ZTMbmyAUPIIHE9).

Please contact the principal investigator, Dr. Richard Wassersug, **by October 31, 2021** at [richard.wassersug@ubc.ca](mailto:richard.wassersug@ubc.ca) if you have any questions.

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**REACH BC**



[REACH BC](#) is an online platform that aims to connect British Columbians with volunteer opportunities in health research.

You can sign up to be a study participant, or a collaborator with researchers in research opportunities that matter to you and your family.

Click [here](#) to find studies that you can participate in. You can also sign up as a [RESEARCH BC Volunteer](#) to receive updates on new opportunities.

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## **Imaging Saves Lives**

### **Knowing you're not alone may make all the difference**

**Have you ever had an X-Ray, CT, MRI, an ultrasound or mammogram? Then a radiologist was involved with the outcome of your exam. Whether interpreting your study behind-the-scenes or in-person consult, their involvement set your life on a new course.**



**Sharing your experience can inspire and help others in their health journey, because knowing you're not alone may make all the difference.**

Patient Partner Carmen Hou and her daughter

Click [here](#) to learn more about “Imaging Saves Lives” and how you can share your story.

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**LEARN AND GROW**



**Sharing your comments at BC Cancer**

Here's who you can give feedback to if you want to improve...

## 1. YOUR ENGAGEMENT EXPERIENCE

- Health professional leading the engagement (Initiative Lead)
- Provincial Lead of Patient and Family Engagement, Patient Experience Program

## 2. YOUR CARE EXPERIENCE

- Health professional caring for you
- Manager at the cancer centre where you received care

## 3. CARE QUALITY

- Provincial Health Services Authority Patient Care Quality Office at 1-888-875-3256 or [pcqo@phsa.ca](mailto:pcqo@phsa.ca)
- BC Cancer executive leadership, letter c/o Patient Experience Program

You can also complete a comment card at the cancer centre. The Patient Experience Council in the centre may review your feedback and identify actions to improve your care.



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### **New Citizen Support Desk for Virtual Health Visits**

The Provincial Health Services Authority Citizen Support Desk offers telephone support to patients using Zoom for Healthcare for their virtual health visits. This service includes help with installing or accessing Zoom, setting up the camera and microphone, and testing the connection.

Patients can call [1-844-442-4433](tel:1-844-442-4433) Monday to Friday, 7 a.m. to 5 p.m.

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### **Supportive Care e-bulletin**

Sign up for the [Supportive Care e-bulletin](#) to get the patient e-bulletin and information about programs and education events in supportive cancer care.



Provincial Health Services Authority

# Virtual Support & Education

Programs to support people impacted by a cancer diagnosis.

**Learn about:**

- Ways to reduce stress, manage symptoms and live well with cancer
- Effectively returning to work
- What to say to family and friends about cancer
- Community support(s)
- And much more

Support programs use Zoom.

You need a computer or mobile device and access to the internet.

Check out our website: [www.bccancer.bc.ca/supportprograms](http://www.bccancer.bc.ca/supportprograms)

**On our BC Cancer website – Support Programs, you can:**

- Find our monthly calendar of programs
- Register for virtual education sessions and ongoing support groups
- Sign up to get our Supportive Care eBulletins
- Learn more about cancer centre and community programs



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## Group-based Support Programs



BC Cancer Supportive Cancer Care provides group-based support programs for people with cancer and their family members. Topics of the virtual education sessions include returning to work, spiritual growth, ways for reducing stress, family support and community resources. To learn more about the virtual group support programs, sign up to receive the monthly [Supportive Care e-bulletin](#) or visit the [Support Programs](#) website.

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## Resources for COVID-19 updates and Coping Strategies

Stay connected and stay safe, through art: [drawingchange.com/how-to-stay-connected-during-self-isolation-covid-19](https://drawingchange.com/how-to-stay-connected-during-self-isolation-covid-19)

Centre for Addiction and Mental Health (CAMH) has helpful coping strategies on caring for yourself and your loved ones during the COVID-19 pandemic: [www.camh.ca/en/health-info/mental-health-and-covid-19](https://www.camh.ca/en/health-info/mental-health-and-covid-19)

Government of Canada: [www.canada.ca/coronavirus](https://www.canada.ca/coronavirus)

BC Centre for Disease Control: [covid-19.bccdc.ca](https://covid-19.bccdc.ca)

BC Cancer COVID-19 vaccine information and more: [www.bccancer.bc.ca/health-info/covid-19-and-cancer-information-for-patients](https://www.bccancer.bc.ca/health-info/covid-19-and-cancer-information-for-patients)



Thank YOU for being a valued member of the BC Cancer Network of Patients and Family Partners. We continue to seek partnerships with people who have lived experiences with cancer, to improve care for all. Invite your family members and friends to sign up as Patient or Family Partners today at <http://www.bccancer.bc.ca/getinvolved!>

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## **Catching the light: A scientist and artist cancer journey**

By Patient Partner Yaron Butterfield

“Had I not fallen, I would not have arisen.  
Had I not been subject to darkness, I could not have seen the light.”  
- Midrash

My cancer journey started in August 2000 when I began working in bioinformatics at BC Cancer. With my expertise in DNA sequencing and analysis, I got involved in non-cancer related projects. When I stayed up all night that April of 2003 putting together the SARS coronavirus genome sequence that led to international headlines, little did I know that 10 months later, my life would drastically change.

On February, 23, 2004, I collapsed in a grand mal seizure and was subsequently diagnosed with glioblastoma multiforme (GBM). Despite the horrible prognosis, after 3 years, I returned to work with a new perspective; I felt a closer connection to the DNA sequences of cancer patients I was working with. As the years went by—I was clearly beating the odds—I felt a strong desire to help others touched by brain cancer. Indeed, as a long time survivor, I felt obligated.

One of the first ways I gave back was to become coordinator of the Brain Tumour Foundation of Canada’s (BTFC) walk/run. This opportunity gave me a chance to meet many others going through the same experience that I had and to help fundraise for brain cancer research and care. In 2010, I started co-coordinating the BC Cancer’s Patient and Family Council for the brain tumour community (PFAC). The PFAC includes doctors, patients, caregivers and nurses. Over the years, we came up with various projects and wonderful ideas to help others, such as art shows where those touched by brain cancer shared their work to encourage other patients.

I have been privileged to be involved in other cancer initiatives. I had been a Patient Navigator at BC Cancer, meeting newly diagnosed brain cancer patients. As part of BC Primary Health Research Network, my navigator role led to the co-authoring of the researcher paper, "[What matters most to patients about primary healthcare: mixed-methods patient priority setting exercises within the PREFeR \(PRioritiEs For Research\) project](#)".

After I have started attending BC Cancer's support group meetings, I soon got to know other amazing people. When I and three others from the group heard about the inaugural Ride to Conquer Cancer (now the Tour de Cure) in 2009, we formed a team called the Brainiacs. Together, we have raised over \$3.5 million dollars for BC Cancer Foundation!

This year, I started a monthly online support group for the world-wide brain cancer community. The initiative has been going very well. I have received feedback from members that they look forward to the meetings.

It has now been over 17 years since my brain cancer led me on an unexpected path. Along the way, I have been blessed with incredible experiences. Yes, I have picked up various side-effects over the years. Yet, I have gained a certain wisdom and appreciation for life that I would not have, if it was not for cancer.

I am writing my memoir, and it has been healing for me. I have learned more about who I am, and feel it's important to share my story. May my story bring hope to your healing journey, and you too will catch the light of life.

Read more about Yaron's story at <http://yaronbutterfield.com>





## **Renata**

We are saddened to share the news of the passing of Patient Partner Renata Borella.

Renata passed away on August 22 in Vancouver, B.C. Renata was an active member in many quality improvement initiatives at BC Cancer, since she joined the Network in 2018. Renata stepped up to engagement opportunities while she was living with advanced cancer, with the goal to make changes for the benefit of all patients and families. Renata was known for her enthusiasm and passion to live life fully. In her words, "But until we run out of options for keeping it under control, I choose to LIVE, and to live WELL, doing the stuff I want to do."

Thank you, Renata. We will miss you.

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If you would like to share an inspiring story or words of encouragement about your cancer experience, please let us know.

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Contact: Joyce Lee, Provincial Lead, Patient and Family Engagement, at [jlee2@bccancer.bc.ca](mailto:jlee2@bccancer.bc.ca)

<http://www.bccancer.bc.ca/getinvolved>

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