

# PSYCHOSOCIAL STUDY GROUP NEWSLETTER

November 2019

## About the Study Group

The Psychosocial Study Group (SG) will celebrate its 20<sup>th</sup> anniversary in 2022. Our SG has 151 members from 27 countries, representing 14% of MASCC's membership. It is one of the largest of MASCC's SGs, which underscores the importance of psychosocial care to supportive care in cancer. The aim of the SG is to make the psychosocial dimensions of care, including appropriate assessment and interventions, an integral part of routine cancer care for all patients.

## We had a blast in San Francisco!

It was wonderful to get together with those who attended the 2019 MASCC Annual Conference held in San Francisco, California, USA. The meeting included an exciting program of research presentations, workshops, and discussions centered around four main themes:

- Digital Health
- Sexual Health
- Treatment Toxicities
- Cancer Survivorship



## Highlights from the Conference

The Psychosocial SG was well represented. We led a number of excellent sessions focusing on psychosocial issues in cancer survivorship. Group members presented “Psychosocial and Functional Consequences of Skeletal Toxicity” and “Cancer Survivorship in Adolescent and Young Adults (AYA).” The utility of cancer survivorship care plans was debated in an engaging session titled “Every Cancer Survivor Must Have a Written Survivorship Care Plan.” Clinicians, researchers, and patients weighed in on the success and pitfalls of survivorship care plans, including stimulating and provocative arguments for and against their use. Other sessions focused on sexual health treatments for men and women, palliative care best practices, and the use of digital health technologies for supportive care. The conference provided a rich opportunity to learn from peers, hear about the latest research, and consider best practices for providing psychosocial support to cancer patients.

## All presentation slides are available on the MASCC website (login required).

For those who missed the conference or are interested in accessing the material, this is an excellent resource.

## 2019 Best Abstract Award

The recipient of this year's Best Abstract Award was **Charles S. Kamen, PhD**, for his work, “Perspectives of LGBT Cancer Patients and Their Caregivers Regarding Sexual Orientation and Gender Identity Disclosure.” This study involved interviews with sexual and gender minority patients and their caregivers. Findings indicated that sexual and gender minority patients often carry the burden of initiating discussions of disclosure about sexual/gender orientation. Facilitating provider-led discussions could put patients at ease, enhance the visibility of their caregivers, and improve provider competence in general. Charles is an Assistant Professor in the Department of Surgery, Cancer Control, and Assistant Director of Community Outreach and Engagement at the Wilmot Cancer Institute in Rochester, New York, USA.

## Spotlight on Research

**A MASCC Member, Dr. Claire Foster** is Professor of Psychosocial Oncology and Director of the Macmillan Survivorship Research Group at the University of Southampton, UK. Her research focuses on the health outcomes and experiences of people diagnosed with cancer and improving self-management support. This includes large, prospective, UK-wide cohort studies, including collection of clinical and patient-reported questionnaire data. The aims are to understand the consequences of cancer from diagnosis and over time and how these can impact on people's daily lives, as well as to identify areas for intervention (e.g., CREW and HORIZONS cohorts). Claire's research team has developed and tested web-based resources to support self-management of fatigue following cancer treatment: [www.macmillanrestore.org.uk](http://www.macmillanrestore.org.uk). Other projects include the development of decision aids to support younger women with breast cancer who are facing decisions about surgery and genetic testing (e.g., Breast Cancer Choices).



New projects are also underway to develop web-based resources to support people with motor neuron disease who face complex decisions (DiAMoND, PI: Wheelwright) and increased risk of cancer due to genetic susceptibility (CRUK Catalyst Award, CI Turnbull). Claire is the UK lead, with Prof Caroline Moore, for Movember's Global Registry of early-stage prostate cancer patients. The research team is leading the evaluation of NHS England and Health Education England practice-based transformation projects to improve access to nursing and self-management support from the point of cancer diagnosis and following treatment. Research funding has been awarded from a range of sources including Macmillan Cancer Support, Movember Foundation, National Institute for Health Research, Breast Cancer Now, Prostate Cancer UK, Cancer Research UK, Health Foundation, Roy Castle Lung Cancer Foundation, Marie Curie and MND Association.

### **HORIZONS**

Claire and her team were awarded £2.4 million from Macmillan Cancer Support in November 2015 to establish the HORIZONS Programme <https://www.horizons-hub.org.uk/>. The HORIZONS Programme seeks to improve the lives of people affected by cancer by gaining a detailed understanding of life after a cancer diagnosis. HORIZONS is the first major national scientific resource of its kind and follows representative groups of patients from before treatment begins and over the long term, thus generating evidence not available elsewhere. HORIZONS includes 3,442 participants recruited from 110 hospitals across the UK including breast cancer patients, non-Hodgkin's lymphoma (NHL) patients (diffuse large B cell lymphoma), and gynaecological cancers (ovarian, cervical, endometrial and vulval). The research questions are the following:

- What impact does cancer and its treatment have on people diagnosed with cancer in the short, medium, and long term?
- What are the health outcomes, experiences and self-management activities over the life-course across different cancer types and what influences these?
- How do people connect with and mobilize resources which enable them to self-manage consequences of cancer and its treatment?

**We welcome collaboration and requests to analyze our cohort data [CREW and HORIZONS].** Further details can be found here [https://www.horizons-hub.org.uk/access\\_data.html](https://www.horizons-hub.org.uk/access_data.html)

## Self-Management in Cancer

### Global Project on Self-management in Cancer (GPS in Cancer)

At the MASCC Annual Conference in San Francisco, **Bogda Koczwara, MD**, convened a meeting of experts in self-management, which has since led to an international collaboration of researchers, clinicians, policy makers, and advocacy experts working together to enable and empower people affected by cancer to manage their health care needs when they are not directly interacting with health care professionals. This group has the following goals:

- To understand how patients use self-management and how it benefits them
- To understand how self-management differs across the world and what is needed to support it across different health care settings
- To develop new ways of supporting self-management in people affected by cancer.

The collaborative is working on a number of projects at present to review existing evidence and gain more insights about patients' perspectives regarding self-management in diverse health care settings. If you are interested in contributing to the work, please send your expression of interest, indicating your expertise and track record, to Bogda at [bogda.koczwara@flinders.edu.au](mailto:bogda.koczwara@flinders.edu.au).

## Looking forward to Spain!



We are very excited to head to Seville, Spain for the MASCC and the International Society of Oral Oncology (ISOO) 2020 Annual Meeting, which will take place from June 25 to 27. The meeting will focus on three main themes: **cardio-oncology**, **bioethics**, and **models of supportive care**. Sub-themes will include **digital health**, **palliative care**, and **cancer survivorship**.

Program highlights have already been announced and include lectures that might be of interest to Psychosocial Study Group members. The "Models of Supportive Care" plenary session highlights the work of our colleagues:

- Lecture 1: "Supportive Care – 30 Years of MASCC," with Dr. Dorothy Keefe (Australia)
- Lecture 2: "Models of Supportive Care – What's the Evidence?" with Dr. Florian Scotté (France)
- Lecture 3: "Supportive Care – A Luxury in Lower Middle-Income Economies?" with Dr. Enrique Soto Perez de Celis (Mexico)

### Key Dates:

- Abstract Submission Deadline: January 15, 2020
- Early Registration Deadline: March 10, 2020

## Would you like to mentor younger colleagues? Would you like to be mentored?

We are looking for SG members who are happy to connect with junior colleagues online or in-person in Spain. If you want to contribute as a mentor, or are interested in receiving mentorship, please let us know and we will work on matching you with an appropriate mentee.



### (Self-) Introduction

Finally, to wrap things up, I'd like to introduce myself as the new editor for the Psychosocial Study Group Newsletter. My name is **Catherine Benedict**. It's great to meet you! A little about myself...

I am a clinical psychologist and behavioral science researcher within the Department of Psychiatry & Behavioral Sciences at Stanford University School of Medicine. I work closely with Lidia Schapira within the Stanford Cancer Survivorship Program, specifically focused on building supportive care resources to address sexual and reproductive health issues following cancer treatment. I am leading the development of a Sexual Health & Fertility Counseling clinic within the Stanford Women's Cancer Center.

My research primarily focuses on the experiences of adolescents and young adults (AYAs) in cancer survivorship. Much of my work is guided by a self-regulation theoretical framework and rooted in decision-making science to understand how patients make decisions about health and healthcare under conditions of uncertainty and emotional distress. I am particularly interested in the overlap of decision-making theory and self-management strategies; e.g., how do daily decisions and subsequent cognitive-emotional experiences interact to characterize the trajectory of self-management in the long-term? My work aims to improve patient decision-making and self-management, focusing on various topics important to long-term survivorship including adherence, fertility and family-building, sexual health, and financial toxicity. This work also overlaps with research focusing on the use of digital health platforms to provide tailored, targeted support for "real world" impact. I work closely with the developers of a cancer peer-to-peer support app to understand user engagement and both the benefit and potential for harm from peer interactions in a digital space. I collaborate with several young adult cancer patient organizations to support patient-centered research, while advocating for greater research dissemination to patient communities.



## Do you have news to share? Do you want to be featured in the next Newsletter?

We are looking stories of achievement, interested papers, and profiles of individuals who are remarkable for their contribution to care, research, education, and mentoring in the area of psychosocial care in cancer. If you have an idea to share, please let us know.

### We would love to spotlight your work and accomplishments!

Please email me at [cbenedict@stanford.edu](mailto:cbenedict@stanford.edu) with any suggestions and recommendations. Self-promotion is encouraged.