# FORWARDS IPOS SPECIAL INTEREST GROUP (SIG)

## **ANNUAL REPORT 2020**

#### **Committee Members**

Chair: Dr Ben Smith, Ingham Institute & UNSW, Australia

**Deputy-Chair:** Prof Marije van der Lee, Helen Dowling Instituut, the Netherlands

Secretary: Dr Lauren Heathcote, Stanford University, USA

Early Career Member & Webpage Officer: Brittany Mutsaers, University of Ottawa,

Canada

## **Committee Meetings and Positions**

The current Committee was formed at the AGM in Banff, September 2019. A general call to form a new committee will be sent to our members prior to the 2021 Kyoto World Congress.

During 2019-2020 the Committee met 3 times via teleconference (meeting dates: 13/8/19, 14/2/20, 24/6/20), and held an Annual General Meeting (AGM) at the World Congress on 26/9/19. Most committee communication occurs via email.

### **Current Membership**

Since its formation in August 2015, FORWARDS has attracted 96 members from 16 countries in 4 continents (Europe, North America, Australia/New Zealand, and Asia).

#### Accomplishments for 2019-20:

Having grown the membership substantially in 2018-19, we have shifted our focus towards activities that engage members in FCR education, research and collaboration:

## Webinar series

On 23/9/20 we held our first webinar 'We don't suffer alone: the social context of fear of cancer recurrence', with presentations from Dr Lauren Heathcote, Ms Emily Soriano, and Dr Andrea Cohee. There were more than 70 attendees and some fruitful discussion, despite the difficulties finding a suitable time for IPOS members from around the world. This was the first in a planned series of webinars, with our next webinar on group-based interventions for FCR tentatively scheduled for early December 2020.

#### **Educational Activities**

FORWARDS members Phyllis Butow, Jane Turner, Christine Maheu and Sophie Lebel had planned a workshop on managing FCR at the 22<sup>nd</sup> IPOS World Congress, but this has been postponed due to the COVID-19 pandemic. FORWARDS facilitated the submission of two symposiums on Cross cultural FCR research and FCR interventions.

#### Newsletters & Social Media

We send a quarterly newsletter to all our members, which shares recently published FCR research, as well as opportunities to engage in FCR research and educations. We are working with IPOS to ensure these opportunities are also advertised to the wider IPOS community via the IPOS newsletter. Several FORWARDS members also actively promote FCR research on Twitter; the committee members alone having 5800+ followers. However, our inability to use the previously established @FORWARDS\_SIG account means these efforts are not as coordinated as they could be, nor can their impact be easily tracked.

#### Collaborations

FORWARDS members have made progress on several projects addressing key aspects of FCR:

- 1. Brittany Mutsaers, Sophie Lebel and several other FORWARDS members published the results of a Delphi study with FORWARDS members to identify key characteristics of clinical FCR in Psycho-Oncology
- 2. Another Delphi study of FORWARDS members identifying international FCR research priorities led by Joanne Shaw has been submitted to a special psychooncology section of Frontiers in Psychology on Uncertainty, Anxiety and Fear of Cancer Recurrence and should be published by the end of 2020
- 3. An invited review on the most commonly used FCR measure, the Fear of Cancer Recurrence Inventory, authored by a team of FORWARDS members led by Ben Smith will be published later in 2020 in Psychology Research and Behavior Management. Christine Maheu is also updating a systematic review of FCR measures and establishing recommendations on measures for screening, casefinding and intervention evaluation purposes
- 4. An Individual Patient Data Meta-analysis on the Fear of Cancer Recurrence Inventory is being conducted by Yvonne Luigjes. Several FORWARDS members are part of the steering committee for this project.
- 5. Several other FCR-related reviews (FCR costs, FCR in cancer caregivers, FCR in Indigenous and minority populations) are being undertaken by teams made up largely of FORWARDS members.

We had also planned a project to establish a core outcome set for FCR research, which a post-doc and graduate student had expressed interest in working on. However, this has been put on hold for the time being due to a lack of resources to support the project.

#### Coordination with other SIGS

We have expressed our interest in joint activities with the new Survivorship SIG, but nothing concrete has been planned yet.

#### Grants

Two of our early career members, Dr Lauren Heathhcote and Dr Jose Custers have been successful in securing grants from the Stanford Maternal and Child Health Research Institute (\$150,000) and Dutch Cancer Society (€424,731) respectively for projects relating to FCR.

#### Volunteers

We are very grateful for the efforts of our 3 volunteers (Isabel Centeno, Lauren Heathcote and Egle Urbutiene) in 2018-19, who conducted regular searches for FCR papers and invited authors to join our SIG to increase our membership. However, we have now ceased this activity to focus on activities to engage our membership.

#### Goals for the next 12 months

- 1) Organise an online FCR conference, although it needs to be established how this could best complement the postponed IPOS World Congress in 2021
- 2) Continue to facilitate research projects in the priority areas identified in the two recent Delphi studies of Australian and international FCR research priorities;
- 3) Conduct a project to establish a core outcome set for FCR research;
- 4) To continue with quarterly webinars on FCR available to FORWARDS members and the IPOS community.
- 5) To continue to promote activities of FORWARDS and engage the membership.