

FORWARDS
IPOS SPECIAL INTEREST GROUP (SIG)
ANNUAL REPORT 2022

Committee Members

Chair: Prof Marije van der Lee, Helen Dowling Instituut, The Netherlands

Deputy-Chair: Dr Lauren Heathcote, Health Psychology Section, Department of Psychology, Institute of Psychiatry, Psychology, and Neuroscience, King's College London.

Secretary: Dr. José Custers, Radboudumc, The Netherlands

Early Career Member & Webpage Officer: Brooke Russell, University of Calgary, Canada until April, then vacancy

Aim: facilitate collaboration on Fear of Cancer Recurrence research and disseminate knowledge

Committee Meetings and Positions

The current Committee was formed at the SIG AGM of the 2021 Kyoto World Congress.

During 2022-2023 the Committee met 2 times via teleconference (meeting dates: 27/1/2022, 11/4/22), and held an Annual General Meeting (AGM) at the World Congress in Toronto on 31/8/22. There was also a social event in Toronto. Besides this meetings communication occurs via email.

Current Membership

Since its formation in August 2015, FORWARDS has attracted 115 members from 23 countries in 4 continents (Europe, North America, Australia/New Zealand, and Asia).

1. Breakdown of 2022 activities:

successful webinar series

April: *Fear of cancer recurrence: the experience of caregivers.*

Speakers: Perri Tutelman (Dalhousie University), Jani Lamarche (University of Ottawa), Angélica Cusson (University of Ottawa) Dawn Pickering, parent caregiver, Ottawa.

Discussant: Sophie Lebel (University of Ottawa)

Attendees: 105 registered and 21 viewed live, at least 14 members viewed the webcast recording from the IPOS website (info via John dd April 13, 2022)

Planned in december but took place in jan:

Fear of cancer progression and recurrence in those living longer with cancer

Speakers: Evie Kolsteren (Radboud University), Melanie Schellekens (Helen Dowling Institute), Leah Curran (University of Sydney)

Discussant: Lauren Healthcote (Kings college London)

Attendees: 169 registered, 54 viewed live

Collaborative symposia at IPOS 2022

There were 4 collaborative symposia at IPOS 2022.

Recent advances in screening for clinical fear of cancer recurrence: Moving from research to clinical practice (Ben Smith, Marije van der Lee, Lauriane Giguère, Esther Deuning-Smit).

Understudied no More: Fear of Cancer Recurrence Research in Culturally diverse patients, caregivers, and children (Sophie Lebel, Lizette Gálvez-Hernández, Perri Tutelman, Jani Lamarche)

The experiences of patients with advanced or metastatic cancer receiving immunotherapy or targeted therapy (Gary Rodin, Alanna Chu, Julia Lai-Kwon, Jose Custers).

The new science of “scanxiety”: what is it, how should we study it, and what can we do about it? (Jose Custers, Lauren Heathcote, Heather Derry-Vick, Jillian Johnson)

Other Educational Activities

FORWARDS members Christine Maheu and Sophie Lebel have provided a free online training in February 2022 (two 2.5 hour training sessions) on their fear of cancer group intervention (FORT). Sophie Lebel has visited Mexico to train the IPOS Forwards community there in FORT

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. IPOS advertises these opportunities to the wider IPOS community via the IPOS newsletter. Several FORWARDS members also actively promote FCR research on Twitter; the committee members alone having 5560+ followers.

Collaborations

A Delphi-study led by dr. Custers (Radboudumc, the Netherlands) on features of fear of progression in advanced cancer patients receiving systemic treatment was conducted from December 2022 – January 2023. Six members of the SIG are in the steering committee of the project and 22 SIG members participated in the Delphi rounds.

Forwards members Tania Estape and Christine Maheu published a scoping review: Maheu, C., Singh, M., Tock, W. L., Eyrenci, A., Galica, J., Hébert, M., ... & Estapé, T. (2021). Fear of cancer recurrence, health anxiety, worry, and uncertainty: A scoping review about their conceptualization and measurement within breast cancer survivorship research. *Frontiers in psychology*, *12*, 644932.

The Individual Patient Data Meta-analysis on the Fear of Cancer Recurrence Inventory is being conducted by Yvonne Luigjes and led by FORWARDS members was published in *Psycho-Oncology*

Several other FCR-related reviews by teams made up largely of FORWARDS members were published: on FCR costs (team Ben Allen Smith); FCR in cancer caregivers, (team Sophie Lebel) FCR in Indigenous and minority populations (team Ben Allen Smith).

Systematic review on scanxiety is under review by Heather Derry-Vick Lauren Heathcote and

2. Goals, objectives and results for 2022

- 1) Continue to facilitate research projects in the priority areas identified in the two recent Delphi studies of Australian and international FCR research priorities; Results: the priority areas were discussed during our AGM and several papers in these priority areas were published
- 2) To continue with quarterly webinars on FCR available to FORWARDS members and the IPOS community. Results: see above, they were very well attended and are highly appreciated

- 3) To continue to promote activities of FORWARDS and engage the membership, also for early career members. Results: see above

3. Description of issues/challenges experienced in 2022

We have talked to a very good patient representative but are a bit unsure about how to proceed: how can we involve her in FORWARDS activities. Our Early Career member had to stop due to personal circumstances, which made the workload for the other members more intensive.

The webinars were restricted to English-speaking people, closed captions in English is available, but unfortunately, we did not succeed in finding funding for using a live-translation tool to translate in Spanish or other languages.

4. Goals for the next 12 months: 2023

We aim to facilitate collaboration on research projects in the priority areas identified in the two Delphi studies that were conducted by our members:

- Intervention research to facilitate greater access to FCR treatment, specifically for LMIC and indigenous communities
- Evaluation of the effectiveness of FCR interventions in real world settings
- Defining the mechanisms of action and active components across FCR/P interventions

Furthermore, we aim to continue with quarterly webinars on FCR available to FORWARDS members and the IPOS community and to continue to promote activities of FORWARDS like activities for early career researchers.

5. Any special requests/needs for the next 12 months

In order to make our research results available for a diverse group of IPOS members it would be really helpful if IPOS help to provide translation of the webinars that are on the IPOS website, so that people can look back. For example in Spanish, but also in other languages.

6. List of current committee/SIG members (name and country - not contact information since will be posted online. Reminder, volunteers must be current IPOS members). As a reminder, it is important that ALL committees/SIGs have balanced representation in terms of geography and years of experience.

Tatsuo	Akechi	Japan
Susana	Almeida	Portugal
Rosalind	Bell	Canada
Kim	Brandes	Netherlands
Phyllis	Butow	Australia
Eveline	Bleiker	Netherlands
Daniel	Costa	Australia
Jose	Custers	Netherlands
Andreas	Dinkel	Germany
Peter	Dorfman	
Joanna	Fardell	Australia
Marg	Fitch	Canada
Jacqueline	Galica	Canada

Gail	Garvey	Australia
Maree	Grier	Australia
		United Kingdom
Gerald	Humphris	Kingdom
Georden	Jones	Canada
Nadine	Kasparian	Australia
Wendy	Lam	Hong Kong
Sophie	Lebel	Canada
Florence	Lewis	Belgium
Wendy	Lichtenthal	USA
Christine	Maheu	Canada
Isabelle	Merckaert	Belgium
		United Kingdom
Gozde	Ozakinci	Kingdom
	Petricone-	
Danielle	Westwood	Canada
Judith	Prins	Netherlands
Josée	Savard	Canada
	Séguin	
Caroline	Leclair	Canada
Louise	Sharpe	Australia
Sébastien	Simard	Canada
Iya	Slabinska	
Allan (Ben)	Smith	Australia
Kevin	Stein	USA
Belinda	Thewes	Australia
Christina	Tomei	Canada
Ana	Torres	Portugal
Luzia	Travado	Portugal
Jane	Turner	Australia
Marieke	Van de Wal	Netherlands
	Van	
Sanne	Helmond	Netherlands
Lee	Westmaas	USA
Megumi	Uchida	Japan
Ozan	Bahcivan	Australia
Lynne	Wagner	USA
Aslı	Eyrenci	Turkey
Tania	Estape	Spain
Nina	Tauber	Denmark
Isabel	Centeno	Mexico
Duygu	Hiçdurmaz	Turkey
Yvonne	Luigjes	Netherlands
Leah	Curran	Australia
Egle	Urbutienė	Italy
Marije	van der Lee	Netherlands
Afaf	Girgis	Australia
	van der	
Marie	Haegen	Belgium

Cristiane	Bergerot	Brazil
Deborah	Raphael	New Zealand
Lauren	Heathcote	USA
Lahiru	Russell	Australia
Fiona	Lynch	Australia
Juhee	Cho	Korea
Im	Ryung	Korea
Bae	Ka Ryeong	Korea
Bobby	Zachariae	Denmark
Pawel	Izdebski	Poland
Anne	Reb	USA
Evgeniia	Ananeva	Russia
Nazken	Askargaliyeva	Kazakhstan
Pauline	Waroquier	Belgium
Logan	Nealis	Canada
Lauren	Rudy	Canada
Qian	Lu	USA
Brooke	Russell	Canada
Ketti	Mazzocco	Italy
Katharina	Clever	
Ashley	Charbonneau	Canada
Andrea	Cohee	USA
Lexa	Murphy	
Emily	Soriano	USA
Jean-Philippe (JP)	Laurenceau	USA
		United
Jo	Armes	Kingdom
Jackson	Hewitt	Canada
Catherine	Benedict	United States
Perri	Tutelman	Canada
Brittany	Mustaers	Canada
Jessica (Wing Lam)	Tock	Canada
		United
Maria	Loades	Kingdom
	Chagnon	
John	(IPOS)	Canada
		United
Lonnie	Cameron	Kingdom
Darcy	Burbage	United States
Arun	Ghoshal	India
Poorva	Pradhan	Australia
Vivek	Tanna	USA
Ashlee	Loughan	USA
Kelcie	Willis	USA
Alison	Clayton	USA

Daelin	Coutts-Bain	Australia
Esther	Deuning-Smit	Netherlands United
Sara	MacLennan	Kingdom
Evie	Kolsteren	Netherlands
Adrian	Pogacian	Romania
Lizette	Gálvez	Mexico
Iván	Rivera Olvera	Mexico
Jorge	Bazán Muñoz	Mexico
Guido	Canitano	Switzerland
Emma	Rheel	Belgium
Dhanya	Kumar	USA
Jill	Johnson	USA
Sarah	Webster	USA
Helen	Ferry	Australia
Kyra	Webb	Australia United
Emily	Dowling	Kingdom