

**FORWARDS**  
**IPOS SPECIAL INTEREST GROUP (SIG)**  
**ANNUAL REPORT 2023**

**Committee Members**

**Chair:** Prof Marije van der Lee, Helen Dowling Instituut, The Netherlands (Jan-Sep 2023)

Dr. José Custers, Radboud university medical center, The Netherlands (since Sep 2023)

**Deputy-Chair:** Dr Lauren Heathcote, King's College London, United Kingdom (Jan-Sep 2023)

Dr. Christine Maheu, McGill University, Canada (since Sep 2023)

**Secretary:** Dr. José Custers, Radboud university medical center, The Netherlands (Jan-Sep 2023)

Dr. Cristiane Bergerot, Grupo Oncoclínicas, Brazil (since Sep 2023)

**Early Career Member & Webpage Officer:** Brooke Russell, University of Calgary, Canada until April 2023

Lauren Rudy, University of New Brunswick, Canada (since April 2023)

**Aim: To 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 2023 Milan World Congress.

During 2023-2024 the Committee met 3 times via teleconference (meeting dates: 27/1/2023, 13/4/23, 2/11/23), and held an Annual General Meeting (AGM) at the World Congress in Milan on 1/9/23. There was also a social event for SIG FORWARDS members in Milan.

**Current Membership**

Since its formation in August 2015, FORWARDS has attracted 119 members from 23 countries in 5 continents (Europe, North America, South America, Australia/New Zealand, and Asia).

**1. Breakdown of 2023 activities:**

***successful webinar series***

*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 Heathcote (Kings college London)

Attendees: 169 registered, 54 viewed live

*Implementation of FCR interventions*

Speakers: Sophie Lebel (University of Ottawa) and José Custers (Radboudumc)

Discussant: Lauren Rudy (University of New Brunswick)

Attendees: 65 registered, 16 viewed live, 2 requested recording

***Collaborative symposia at IPOS 2023***

There were 5 collaborative symposia at IPOS 2023:

Assessment of Fear of Progression and Fear of Cancer Recurrence: Instruments and results across the globe (Jose Custers, Christine Maheu, Lauriane Giguère, Ana Torres).

The effectiveness of innovative interventions for treating fear of cancer recurrence (Melanie Schellekens, Louise Sharpe, Marije van der Lee, Pascale van der Wolf)

The evolution of the Fear of Cancer Recurrence Therapy (FORT) intervention: To cultural adaptation to country-wide dissemination (Lizette Galvez-Hernandez, Christine Maheu, Jani Lamarche, Sophie Lebel)

Towards implementation of evidence-based interventions for fear of cancer recurrence: Real world settings and outcomes (Louise Sharpe, Jose Custers, Christine Maheu, Gaynor Blankley)

Ovarian Cancer and Fear of Cancer Recurrence and Progression; Nuance, Collaboration and Future Intervention Pathways within a complex disease trajectory (Louise Sharpe, Audrey Bennet, Joanne Shaw, Ben Smith)

### ***Other Educational Activities***

FORWARDS member Sophie Lebel visited the Netherlands (Marije vd Lee, Melanie Schellekens, Judith Prins and Jose Custers) to strengthen collaboration and disseminate knowledge on FCR among researchers and clinicians. A travel grant of Sophie Lebel and Jose Custers was funded and Jose Custers visited the institute of Sophie Lebel (Ottawa) and Christine Maheu (Montreal) to strengthen collaboration and learn from each other.

### ***Newsletters & Social Media***

We send two times a 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 X.

### ***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 – March 2023. Six members of the SIG are in the steering committee of the project and 22 SIG members participated in the Delphi rounds.

Several other FCR-related studies by teams made up largely of FORWARDS members are ongoing such as a systematic review of FCR measures by Christine Maheu & Tania Estapé and translations of the FORT intervention into Spanish and Turkish.

## **2. Goals, objectives and results for 2023**

We aimed 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 | Several papers were published in this priority area.
- Evaluation of the effectiveness of FCR interventions in real world settings | Results: several studies were conducted and evaluated in real world settings. These were presented at the IPOS World Congress in Milan.
- Defining the mechanisms of action and active components across FCR/P interventions | Results: Several papers were published in this priority area. A work-session was organized at the IPOS World Congress to disentangle active components between fear of cancer recurrence and fear of progression.

### 3. Description of issues/challenges experienced in 2023

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.

It is difficult to reach out and engage early-career researchers and identify their needs. There was no response to a needs questionnaire for early-career SIG FORWARDS members sent in August 2023.

### 4. Goals for the next 12 months: 2024

We continue 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

In addition to these priority areas we will identify new research priority areas by means of a survey to our FORWARDS members.

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 to engage the membership.

### 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 we could translate the webinars in different languages. As we were not yet successful in obtaining funding I would be very helpful if IPOS could help in this matter.

**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	Germany
Joanna	Fardell	Australia
Marg	Fitch	Canada
Jacqueline	Galica	Canada
Gail	Garvey	Australia

Maree	Grier	Australia
Gerald	Humphris	United 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
Gozde	Ozakinci	United Kingdom
Danielle	Petricone-Westwood	Canada
Judith	Prins	Netherlands
Josée	Savard	Canada
Caroline	Séguin 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
Sanne	Van 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	Urbutiené	Italy
Marije	van der Lee	Netherlands
Afaf	Girgis	Australia
Marie	van der 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
Jo	Armes	United Kingdom
Jackson	Hewitt	Canada
Catherine	Benedict	United States
Perri	Tutelman	Canada
Brittany	Mustaers	Canada
Jessica (Wing Lam)	Tock	Canada
Maria	Loades	United Kingdom
John	Chagnon (IPOS)	Canada
Lonnie	Cameron	United 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
Sara	MacLennan	United 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

Emily  
Maria  
Danielle  
Johanne  
Isak

Dowling  
Neves  
Ng  
Lyhne  
Eliasson

United Kingdom  
Portugal  
Hong Kong  
Denmark  
Stockholm