

PANCREATIC CANCER EUROPE ASBL

Yearly Activity Report 01 July 2021 - 30 June 2022 *and* Working plan 2022-2023

Presented at the Annual General Meeting of 18 October 2022

Contents

Forewords	2
Our members.....	2
PCE activities in 2021-2022.....	2
The stakeholders	5
The association management.....	5
Significant events after the reporting period.....	5
Working plan 2022-2023	5

Forewords

In the fiscal year 2021 – 2022 PCE had to face, as many other Associations and NGOs, the unexpected challenge due to the COVID-19 pandemic that led to drastic braking of face-to-face and on-field activities, replaced by online meetings and events.

Despite the difficulties that online meetings imply, the Secretariat managed to coordinate and implement successfully the work programme as discussed and agreed upon during the AGM 2021.

Our members

Since its foundation, PCE has aimed to be a multi-stakeholder platform gathering patient groups, scientific societies, researchers, academics, journalists, healthcare professionals, and policymakers to curb the alarming trends of pancreatic cancer in Europe.

Today, the number of members of the association increased, and the number of patient groups dedicated to pancreatic cancer has significantly grown.

The geographic scope of the association has also expanded, with members from multiple EU countries and non-EU Member States such as Norway, Switzerland, Serbia, and India.

The members as of 30 June 2022 are **66**, divided into 51 full members and 15 associated members. Out of the total, 30 are organizations and 36 are individual members.



PCE activities in 2021-2022

PROJECTS AND EVENTS

Nutrition and quality of life in pancreatic cancer patients

European Parliament Event, Thursday, 18 November 2021, 15:30-17:00 CET

The event aimed at rallying pancreatic cancer stakeholders and MEPs to meet and discuss the importance of nutrition as a crucial factor for the quality of life of pancreatic cancer patients from the very first moment after the diagnosis.

The event was organised on the occasion of the World Pancreatic Cancer Day 2021, which took place on 18 November.

PCE event has been hosted by MEP Margarita de la Pisa Carrión (Spain) and was endorsed by Challenge Cancer EU Parliamentary Intergroup.

In total, 108 registered and 75 stakeholders participated in the on-line event.

This activity impacted on Work Streams Treatment, Awareness and Diagnosis.

PancreOS

PancreOS is a long-term project aiming at establishing a European platform of stakeholders working on the creation of a European Network of Registries on pancreatic cancer. During the reporting year 1 July 2021 – 30 June 2022 we appointed a project officer, Raquel Benitez, a young researcher working on the project implementation. She researched the existing registries on pancreatic cancer and contacted them to create the network. The network has been finalised during an online meeting on 30 June 2022. The report on this first phase of the

project will be available on PCE website.

This activity impacted Work Streams Registries and Research.

Nutrition and pancreatic cancer

During the reporting period from 1 July 2021 – 30 June 2022, we appointed a researcher, Marien Castillo Sanchez that worked on gathering information on nutrition and pancreatic cancer. She included the information in a booklet that will be used for the awareness campaign on social media and that will be available on PCE website. Out of the booklet, we will prepare information sheets with the most important information to be translated into various languages. We are now working on the graphic layout.

This activity impacted on Work Streams National Support, Awareness, Diagnosis, and Treatment.

Short-Stay Scientific Award (S3A) for Early-Career Investigators (ECI) 2022

During the reporting year 1 July 2021 – 30 June 2022 PCE launched a new edition of the Short Stay Scientific Award, after the COVID-19 pandemic break. The call has been launched in April 2022 and two applications have been received. The applications have been selected by a panel of experts at European Pancreatic Club.

The winner of the award 2022 is Mjriam Capula, doing a PhD in Translational Medicine at Sant'Anna School of Advanced Studies, Pisa, Italy. She will spend three months in the Lab. Medical Oncology led by Prof. Giovannetti at Amsterdam University Medical Centre. Her stay started on 19 September 2022.

Workshops for members and other stakeholders

In June 2022, PCE organised for its members and other stakeholders two online workshops on Nutrition and Pancreatic Cancer and Innovation in treatment, with the intention to contribute to the discussion on the improvement of patient's quality of life.

Both workshops had the participation of high level speakers such as Prof Rocco Barazzoni ESPEN Chair for the workshop on nutrition and representatives from the University of Alcalà in Spain and from the University of Verona in Italy.

The two events were the following:

1. Nutrition and quality of life in pancreatic cancer patients, in cooperation with EPC, 22 June 2022
2. Innovation in Pancreatic Cancer Treatment, 28 June 2022

In total, more than 100 participants attended the two workshops.

These activities impacted on Work Streams Awareness and Diagnosis, Research, and Treatment.

INSTITUTIONAL ACTIVITIES

Working groups for members

PCE set up two permanent working groups for members with the intention to involve them more in the organisation's activities. The two working groups are the following:

1. **Communication:** it helps provide materials for social media and the website, writing articles on specific subjects and thematic newsletter, and gathering information from the country level to be highlighted at the international level. The meetings were held online on 2 November 2021, 23 February 2022, and 30 May 2022
2. **Networking:** it helps reinforce membership, strengthen lobby activity, disseminate project resources, improving PCE visibility. The meetings took place online on 3 November 2021 and 22 February 2022.

This activity impacted Work Streams National Support, Awareness, and Diagnosis.

Communication activities

Officer on Communication: Since March 2022 we have enlarged the staff of the Secretariat with the appointment of a Communication Officer. Giulia Segna is the PCE Communication officer, working on improving the visibility of PCE on social media, reinforcing the communication with members, and supporting the Secretariat in restyling the PCE website.

Intern on Communication: The agreement with the LUISS University in Italy is in place and every six months PCE hosts an intern supporting the Secretariat and the Communication officer in their work.

Interviews to members: 14 members have been interviewed from June 2021 to July 2022; the videos are available on the PCE [YouTube channel](#).

Website update: The restyling of the update of PCE website is in progress, with the intention to become more user friendly, thanks to the new platform used, and to optimize the information provided.

Social media revamping: From June 2021 to July 2022, the PCE social media accounts (FB, Twitter, Instagram and LinkedIn) have been revamped, posting on a regular basis.

In detail, those are the figures related to the PCE social media:



March: 22 followers
June: 64 followers



March: 14 followers
June: 56 followers



March: 73 followers
June: 303 followers



March: 80 followers
June: 258 followers

Newsletters: In the period July 2021 –June 2022 PCE published 4 newsletters addressed to members and our stakeholders.

EXTERNAL MEMBERSHIP

PCE is a member of the following organisations:

World Pancreatic Cancer Coalition, consists of more than 99 organizations from over 40 countries and six continents, elevating global awareness of pancreatic cancer.

<https://www.worldpancreaticcancercoalition.org/>

All.Can, which is an international multi-stakeholder not-for-profit organisation working to improve the efficiency of cancer care by focusing on what matters to patients.

<https://www.all-can.org/>

Inspire2live is a platform bringing together patients, researchers and clinicians aiming at working together internationally to get cancer under control and to lead happy and healthy lives in harmony with cancer.

<https://inspire2live.org/>

PCE renewed its participation in the **European Cancer Organisation (ECO) Patients Advisory Committee**. ECO is a not-for-profit federation of member organisations aiming at reducing the burden of cancer, and improving outcomes and the quality of care for cancer patients.

<https://www.europecancer.org/>

EXTERNAL REPRESENTATION

iPAAC: some of the board members and the secretariat participated in the workshop within Work Package 7 Cancer Information and registries, held on 28 September 2021, and in the Joint Action Final Conference, held on 13 and 14 December 2021.

European Annual Biotech Conference: Nuria Malats held a speech in the Biotech Atelier 2021 on Patients Advocacy Worldwide, organised on 30 September 2021.

The stakeholders

Since its establishment, funding sources for PCE's activities have diversified. For the period 1 July 2021 – 30 June 2022 we could count on 8 sponsors: Astellas, AstraZeneca, BMS, IPSEN, MNI, Novocure, Servier and Viatris.

While PCE has the utmost value for the contribution of its sponsors, it is of paramount importance that the activities led by the association remain independent and transparent.

Diversification of sponsorship is a priority of all board members.

The association management

The present Board of Directors is composed of four members elected during the Annual General Meeting 2020 for a 2 years term. The members are Prof. Alfredo Carrato (Chair of the Board), Antonella Cardone (Vice Chair of the Board), Prof. Sorin Barbu, and Dr. Nuria Malats. The Board of Directors met regularly to discuss the management of PCE and implementation of the activities planned. The Board met monthly online.

In February 2022 Antonella Cardone withdrew from the Board of Directors as she stopped working at ECPC. She was on the Board in the representation of ECPC.

As the minimum number of Board members foreseen by the Statutes is three, the board decided to work under this condition until the Annual Meeting 2022, when the new Board of Directors will be elected.

The Board agreed to continue working with Antonella and gave her the role of Patient Advocacy Expert within the association.

Significant events after the reporting period

- PCE participated in the ESMO Congress from 9 to 13 September 2022. This has been a great opportunity to meet sponsors face to face and to network with other patient organisations. Antonella Cardone spoke in the ESMO Patient track on behalf of PCE on how to engage with policymakers. During ESMO she also represented PCE on a company advisory board.
- From July to September 2022, the number of PCE members raised to 68.

Working plan 2022-2023

For the period 2022-2023, PCE intends to strengthen the activities of its Work Streams, improve internal and external communication, and reinforce the membership.

WS1 Awareness and Diagnosis

For the period 2022-2023, PCE intends to continue the contact with patients and patient advocates, policymakers, and all other relevant stakeholder groups; the lobbying activity on pancreatic cancer within Europe's Beating Cancer Plan will be improved. We will also reinforce the PCE participation in other networks such as All.Can, European Cancer Organisation, WPCC. We will also strengthen PCE participation in relevant EU-funded projects, such as the COST

Action and Horizon.

Since August 2022, PCE is a partner of two Horizon projects:

1. PANcreatic CAncer Initial Detection via liquid biopsy (PANCAID) - Leader UNIVERSITAETSKLINIKUM HAMBURG-EPPENDORF (UKE);
2. Discovering the causes of three poorly understood cancers in Europe (DISCERN) - International Agency for Research on Cancer, World Health Organization – IARC

And one COST Action project:

3. CA21116 - Identification of biological markers for prevention and translational medicine in pancreatic cancer – under the leadership of the German Cancer Research Centre in Heidelberg.

WS2 National Support

PCE intends to strengthen the collaboration with and support of our members so as to build a strong pancreatic cancer community.

For the period 2022-2023, PCE intends to focus the activities on the issue of patient centricity in the cooperation process among pharma companies, patients, and patient organisations.

The cooperation among all relevant stakeholders is particularly crucial at this point in time with the implementation period of the EU Health Technology Assessment (HTA) Directive which was just revised and gives more room to the patients throughout the process. More patients need to know about the HTA process, the directive, and the benefit they can gain from actively participating in the process.

In order to support the cooperation between pharma companies and patient organisations, PCE intends to organise a series of online workshops on how to become a patient expert, with the intention to clarify the procedures, reflect on ethical issues involved in the partnership, and be aware of the importance for patients and patient organisations to be trained on this delicate role.

For the period 2022-2023, PCE will continue implementing the social media campaign to give visibility to our members. The campaign includes short interviews with members and relevant quotations on their activities.

WS3 Registries

For the period 2022-2023, PCE intends to implement further the PancreOS project and to continue raising awareness of the importance of national and European registries on pancreatic cancer.

The project goals for the year 2023 are:

- To compile the information on the participating registries and complete the map just started.
- To report on the activities of the present pancreatic cancer registries in Europe.
- To jointly identify the list of variables for PancreOS to be considered. To this extent, we will suggest the working teams to improve the quality of the variables collected.
- To identify the online system to be implemented to collect summarized data. Ideally, Common Data Models Systems (such as OMOP) allow handling data without moving them from the original site they were collected at. In this way, all records will have access to the summarized data and their own individual data but not to those of the other registries.
- To jointly establish which data is openly available on the website and which data is accessed on request.

WS4 Research

Within this WS, PCE will continue fostering pancreatic cancer research within the platform,

while continue supporting the work done in all work streams to lobby for pancreatic cancer control in Europe.

In this regard, PCE plans to depict pancreatic cancer research in Europe through an online map tool, to identify the gaps and enhance collaborations and training.

During the financial year 2022 – 2023 PCE will continue sponsoring the Short-Stay Scientific Award (S3A) for Early-Career Investigators (ECI).

Another planned activity will be a multistakeholder brainstorming meeting on research, which will gather researchers from all over Europe to reflect on the main upcoming challenges regarding research on pancreatic cancer.

WS5 Treatment

During the financial year 2022 – 2023 PCE will continue implementing the Nutrition project, launching the awareness campaign on social media till March 2023.

A new project will be developed on the issue of physical activities and pancreatic cancer as follow-up of the nutrition project, aiming at increasing the quality of life of pancreatic cancer patients.

In the frame of World Pancreatic Cancer Day 2022, scheduled on the 17th of November 2022, PCE will organise an online event on Early Detection of Pancreatic Cancer, addressed to European institutions and other stakeholders.

Patients' and carers' involvement

For the period 2022-2023, PCE intends to involve more patients and cares in the proposed activities, specifically those foreseen by the Work Streams Awareness and Diagnosis, and Treatment. The personal experience of patients and carers is an important added value to the work PCE intends to develop in the next months.

Members' engagement

The Board of Directors and the Secretariat will explore new forms of members' engagement, to boost their participation in the association's activities and to reinforce the sense of ownership of the association.

Management and communication

For the period 2022-2023, PCE intends to continue updating the website, boost communication on social media and reinforce the communication flow among members.

The PCE Board of Directors