

# PANCREATIC CANCER EUROPE ASBL

**Activity report**  
**01 July 2020 - 30 June 2021**  
*and*  
**Working plan 2021-2022**

Presented at the Annual General Meeting of 21 September 2021

## **Contents**

Forewords .....	2
Our Members .....	2
PCE activities in 2020-2021.....	3
The stakeholders .....	5
The association management.....	6
Significant events after the reporting period.....	6
Working plan 2021-2022 .....	6

## Forewords

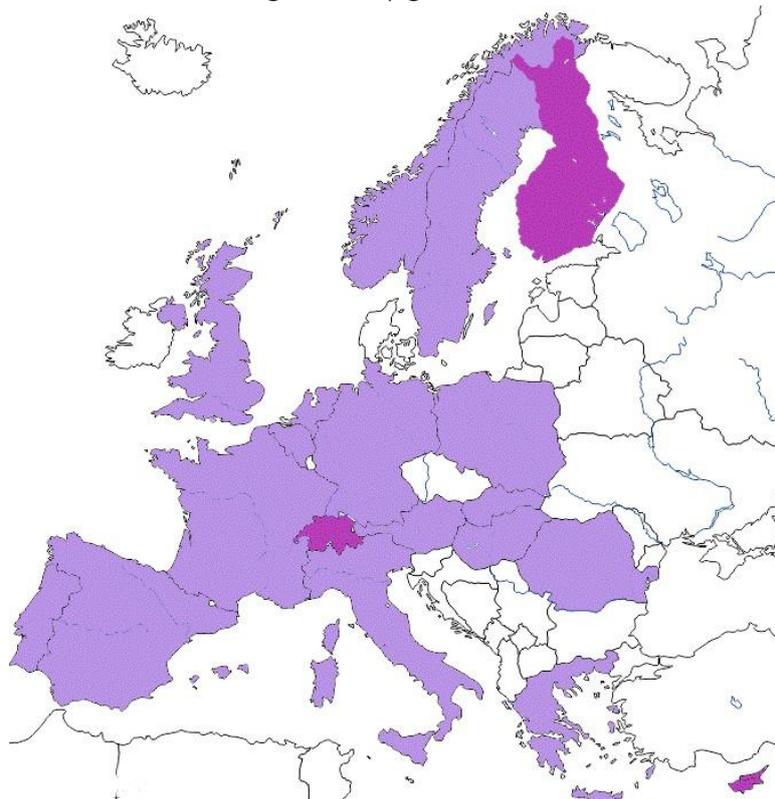
In the fiscal year 2020 – 2021 PCE had to face, as many other Associations and NGOs, the unexpected challenge due to the COVID 19 pandemic that led to a drastic braking of face-to-face and on-field activities, replaced by on line meetings and events.

From July 2020 UniTS – Università del Terzo Settore is the organisation managing the PCE Secretariat. During this transition period, the new Secretariat had to deal with the administrative changes foreseen by the Belgian Law and to get acquainted with the PCE activities. The working programme for the year 2021 was discussed and agreed at the AGM 2020.

## Our Members

Since its foundation, PCE has aimed to be a multi-stakeholder platform gathering patient groups, scientific societies, researchers, academics, journalists, clinicians and policy makers 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 (Finland and Cyprus newly joined) and non-EU Member States such as Norway, Switzerland and India. In the first months of the financial year 2021-2022 also members from Serbia joined the platform.

During the first half of 2021, PCE implemented a membership campaign that led to confirming 40 members, including pre-existing and new members.

## **PCE activities in 2020-2021**

### **PancreOS - Pancreatic Cancer Overall Survival Registry**

#### **European Parliament Event**

**Wednesday, 18 November 2020, on-line**

The event aimed to rally pancreatic cancer researchers and MEPs to meet and discuss the current situation and needs for an EU pancreatic cancer registry and the next challenges to address in the concrete implementation of such EU registry.

The event was organised on the occasion of the World Pancreatic Cancer Day 2020, which took place on 19 November.

PCE event has been hosted by MEP Joanna Kopcińska (ECR, Poland) and was endorsed by Challenge Cancer EU Parliamentary Intergroup. It was the first event within the European Parliament specifically focusing on the need for implementing a pancreatic cancer EU registry. In total, 29 stakeholders participated in the on line event.

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

### **Membership Campaign**

**From March 2021 on**

The membership campaign launched in March 2021 aims at increasing the membership, reactivating old members and involving them pro-actively in PCE initiatives.

The first step of the campaign is to update the data of the present members and reconfirming their membership. The present members are 40, including individuals and organisations from European Countries and non-European Countries such as India.

Furthermore, we will continue to contact new organisations and individuals to increase the PCE membership.

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

### **Workshops for members**

**From April 2021 on**

From April to June 2021, PCE organised for its members a series of workshops with the intention to know better the members' activities, to know how we can support them in their activities and to explore how they can be more engaged with PCE activities. We implemented 4 workshops:

1. Getting to know PCE members, 8 April 2021
2. Highlight connections among PCE's and member's activities, 15 April 2021
3. Brainstorming: To boost collaborative pancreatic cancer research in Europe, 10 May 2021
4. Developing a pool of PCE patient expert, 3 June 2021

In total, 48 members participated in the workshops.

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

### **Working groups for members**

**From June 2021 on**

PCE set up two permanent working groups for members with the intention to involve them

more in the organisation's activities. The working groups meet every two months and the participation is on voluntary basis. The two working groups are the following:

1. **Communication:** helps providing materials for social media and website, writing articles on specific subjects and thematic newsletter, gathering information from the country level to be highlighted at international level.

The first meeting took place on line on 9 June 2021.

2. **Networking:** helps reinforcing membership, strengthening lobby activity, disseminating projects resources, improving PCE visibility.

The first meeting took place on line on 23 June 2021.

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

### Communication activities

#### From March 2021 on

##### *Intern on Communication*

From April 2021, the student Bontle Mokele from the LUISS University in Italy started a six months internship in PCE, in the field of communication. She is supporting the Secretariat in all communication activities on social media, web site and newsletter.

##### *Web site update*

From March 2021, we started planning the update of PCE website, with the intention to become more user friendly and to optimize the information provided.

##### *Social media revamping*

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

##### *Newsletters*

In the period July 2020 – June 2021 PCE published 3 newsletters addressed to members and our stakeholders.

### External membership

During the fiscal year 2020 – 2021 PCE joint the following organisations:

**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 the 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, improving outcomes and the quality of care for cancer patients.

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

## Projects

### PancreOS

PancreOS is a long-term project aiming at establishing an European platform of stakeholders working on the creation of an European Registry on pancreatic cancer. During the fiscal year July 2020 - June 2021 we established contacts with the relevant stakeholders and developed a working plan.

This activity impacted on Work Streams Registries, Research.

### Nutrition and pancreatic cancer.

The general aim of the project is to make nutrition central in the care of pancreatic cancer patients. During the first half 2021 we started searching for sponsorships and we are still looking for funding, while the activities will be implemented in the period September 2021 – June 2022.

The major actions will be an awareness campaign on social media and educational support to patient organizations on nutrition and pancreatic cancer.

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

## The stakeholders

Since its establishment, funding sources of PCE's activities have diversified. For the period 1 July 2020 – 30 June 2021 we could count on five sponsors: AstraZeneca, BMS, Mylan, Servier and IPSEN.

The sponsors have been classified in different categories, according to the level of their sponsorship:

- **Gold sponsor** for sponsorship over 50.000€ will receive in return:
  - \* Big sponsor's logo will be included on the PCE webpage
  - \* Gold sponsors can be invited as non-voting observers during PCE Board meetings, upon invitation by the members of the board
  - \* Sponsors will be invited to all relevant PCE events
  - \* Ability to release partnership statement and press release (to be approved by PCE)
  - \* Ability to utilise content for internal use
  - \* Regular project updates
- **Silver sponsors** for sponsorship less than 50.000€ will receive in return:
  - \* Participation to meetings, TC, PCE events as associate members of the association;
  - \* Communication on the partnership (social network, website, events)
  - \* Medium size logo on the PCE website and documentation
  - \* Sponsors can be invited as non-voting observers during PCE Board meetings, upon invitation by the members of the board
- **AD-HOC** (i.e. funding for a specific activity)
  - \* Participation to the specific activity funded only

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. For the period 1 July 2021– 30 June 2022, PCE intends to double its sponsors. Contact have been already established with Baxter, GSK, BI, and Novocure.

## **The association management**

The present Board of Directors is composed by 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 implementing the activities planned. The Board met on a monthly basis on line.

During the financial year 2020 – 2021 PCE held two Annual General Meeting: one ordinary AGM on 26 November 2020 and one extraordinary AGM on 14 December 2020, both of them on line. During the extraordinary GA, a change of statute has been voted upon, implementing changes according to the new Belgian Low on association.

## **Significant events after the reporting period**

From September 2021 on, we launched a social media campaign to give visibility to our members. We invited all members to record a short interview explaining what they do for pancreatic cancer and why they joined PCE.

From September 2021, PCE postal address changed from Rue Montoyer 40 to Avenue des Arts 6, in Brussels.

## **Working plan 2021-2022**

For the period 2021-2022, PCE intends to strengthen the activities of its Work Streams, to improve the internal and external communication, and to reinforce the membership.

### **WS1 Awareness and Diagnosis**

For the period 2020-2021, PCE intends to continue the contacts with patients and patient's advocates, policy makers and all other relevant stakeholder's groups; the lobby activity on pancreatic cancer within the Europe's Beating Cancer Plan, Cancer Mission and iPAAC will be improved. We will also reinforce the PCE participation in other networks such as All.Can, European Cancer Organisation. We will also strengthen PCE participation in relevant EU funded projects, such as the COST Action.

### **WS2 National Support**

We intend to strengthen the collaboration with and support to our members so to build a strong pancreatic cancer community.

Advocacy and Communication are key to support our members, to this extend we plan to organise the advocacy workshop/webinar in the first quarter of year 2022. We will try to

organise it in a hybrid format, both in presence and on line.

Following the on-line workshop on patient experts PCE organised in June 2021, we intend to replicate the workshop at national level, in order to involve more organisations locally. The workshops will be planned for Spring 2022.

For the period 2021-2022, PCE will implement a social media campaign to give visibility to our members. The campaign will include short interviews with members, and relevant quotations on their activities.

### WS3 Registries

For the period 2021-2022, PCE intends to implement further the PancreOS project and to continue raising awareness on the importance of national and European registries on pancreatic cancer. Many tasks could be proposed: to promote networking among the existing pancreatic registries and biobanks, to detect areas for improvement in the prevention, research and management of PDAC patients. Registries also raise awareness of the whole society of the current challenge, help to show the real situation and get more funds from the EU to foster clinical and translational research.

Registries may be useful to identify the characteristics of high-risk groups, to develop an easy, sensitive and cost-effective screening procedure for an earlier diagnosis. Registries could help to make a strategy for disseminating PDAC updated knowledge to the society and the sanitary personnel and to implement the necessary measures to reach the excellence in prevention, research and assistance in every EU country.

### 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 to enhance collaborations and training. In case the pandemics and the resources make it possible, PCE will organise a second edition of the Short-Stay Scientific Award (S3A) for Early-Career Investigators (ECI).

### WS5 Treatment

PCE intends to provide information on Treatment on every stage of the diseases.

Nutrition is also a topic to focus on, as it is essential for the well-being of the patient. Usually, pancreatic cancer patients lose weight and feel tired. A good program on proper nutrition assessment and prescription will help all patients to increase their quality of life, diminish the risk of toxicities derived from any treatment (surgery, chemotherapy, radiation therapy) and make the patients more suitable for these treatments with the objective of prolonging survival. For the fiscal year 2021 – 2022 PCE will develop infographics address to patients, cares, health care professionals on the importance of preventing malnutrition in pancreatic cancer patients. In the frame of the World Pancreatic Cancer Day 2021, scheduled on the 18<sup>th</sup> of November 2021, PCE will organise an on-line event on Nutrition and Pancreatic Cancer, addressed to European institutions and other stakeholders.

### Patients and carers involvement

For the period 2021-2022, 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 cares is an important added value to the work PCE intends to develop in the next months.

### Management and communication

For the period 2021-2022, PCE intends to update the website, to boost the communication on social media, and reinforce the communication flow among members. We will also promote meetings of the working groups on Communication and Networking on a regular basis, enlarging the participations to other members.

The PCE Board of Directors