



Terms of Reference Patient and Caregiver Advisory Group (PCAG)

This terms of reference (ToR) outlines the purpose and responsibilities of the Patient and Caregiver Advisory Group (PCAG) within the SPARC (Support of Personalized Medicine Approaches in Cancer) project.

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Contents

1. Introduction	3
Background	3
Why patient and caregiver involvement matters	3
Cancers included in SPARC pilot studies	4
2. Objective of ToR	4
Patient & Caregivers Advisory Group (PCAG)	4
3. Benefits of becoming a member	4
4. Members	4
5. Governance and Structure	5
Co-ordination of PCAG	5
E-mail address	5
Websites	5
6. Responsibilities of the PCAG	6
Patient engagement activities and guidelines (M12)	6
Pilot studies	6
Patient Advisory reports & recommendations	6
7. Meetings & Input	6
8. Communication	6
How do the PCAG members communicate with each other?	6
How are meeting minutes communicated?	6
What if I have any concerns or worries about my role in the PCAG , Task Force or CRC?	6
9. Compensation and Reimbursement	6
10. Timeframe	7
11. Non-disclosure of information	7
12. Glossary	7

1. Introduction

Background

SPARC is a three-year EU4Health project that aims to make personalised cancer medicine more equitable across Europe. Not all people living with cancer can currently access advanced diagnostic tests or targeted treatments. SPARC brings together hospitals, universities, research institutions and patient organisations to turn scientific progress into tangible benefits for patients and families. SPARC complements European efforts such as the *Joint Action on Personalised Medicine* (PCM-JA).

Why patient and caregiver involvement matters

Personalised medicine is about tailoring care for each person. The lived experience from patients and caregivers is essential and irreplaceable to ensure that research and policies are responsive to the real needs of people's lives and health care systems. **The Patient & Caregiver Advisory Group (PCAG) guarantees that decisions across SPARC are informed by those most affected.**

Cancers included in SPARC pilot studies

1. Lung cancer
2. Breast cancer
3. Pancreatic cancer
4. Adrenocortical Carcinoma (ACC)
5. Neuroblastoma
6. Multiple Myeloma
7. Melanoma

2. Objective of ToR

Patient & Caregivers Advisory Group (PCAG)

We will actively involve patients and caregivers in SPARC **by integrating patient voices into all project activities**, particularly in the **pilot studies (seven types of cancer) and policy recommendations**. [Pilot studies: SPARC](#) conducts seven clinical pilots across major and rare cancers to demonstrate practical integration of personalised medicine approaches. Each pilot tests cost-effective NGS and liquid biopsy (LBx) workflows, assesses clinical utility, and feeds into harmonised protocols and policy recommendations.

3. Benefits of becoming a member

- **Shared experiences:** Connect with other patients and caregivers, exchange stories, and learn from each other's journeys.

- **EU-wide impact:** Your input will be used to develop EU-wide guidelines for patients with the seven types of cancer covered by the project. Thus, your perspective will help other patients in many countries and may make their patient journey easier.
- **Early insights:** Stay informed about new diagnostics and treatment options.
- **Shape the future of cancer care:** Your perspective will influence research and policies to make cancer treatments and care more accessible and patient centred.
- **Empowerment of patients:** Your recommendations and insights will contribute to strengthening the position of patients within policies, guidelines and manuals and will have potential to inspire others to contribute
- **Networking & Positive Influence Increasing:** active participation creates preconditions for invitations to multiple events – conferences, workshops, webinars, interviews, etc. by diverse stakeholders and organizers. There’s clear potential to help people meet and connect with each other, as well as to be heard by larger audiences.

4. Members

Patients, caregivers, and patient representatives who have experience with the following cancer types are encouraged to take part in the **Patient & Caregivers Advisory Committee** to ensure that their perspective is included throughout the project:

1. **Patients**
2. **Caregivers**
3. **Patient representatives and advocates**

Specifically related to:

- *Lung cancer*
- *Breast cancer*
- *Pancreatic cancer*
- *Adrenocortical Carcinoma (ACC)*
- *Neuroblastoma*
- *Multiple Myeloma*
- *Melanoma*

5. Governance and Structure

Co-ordination of PCAG

Lungs Europe (LE) is the main organisation responsible for co-ordinating the PCAG with the support of the *European Alliance for Precision Medicine (EAPM)*, *the European Society for*

Paediatric Oncology (SIOPE), the Hellenic Cancer Federation (ELLOK), the Association of European Cancer Leagues (ECL), National Melanoma Society (NMS), and the Vall d'Hebron Institute of Oncology (VHIO).

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- SIOPE contact point: Andrea Demadonna (andrea.demadonna@siope.eu)
- ELLOK contact point: Katerina Nikitara (eurograms@ellok.org)
- ECL contact point: Helena Ros (helena@cancer.eu)
- NMS contact point: Janez Sirse (janez.sirse@melanoma.si)
- VHIO contact point: Alba López (albalopez@vhio.net)

Websites

- LE website: [Homepage - LUNGS EUROPE](#)
- EAPM website: [Home - EAPM](#)
- SIOPE contact: [Our Mission :: SIOP Europe](#)
- ELLOK contact: [ΕΛΛΟΚ • Ελληνική Ομοσπονδία Καρκίνου](#)
- ECL website: [Home | Association of European Cancer Leagues - ECL](#)
- NMS website: National Melanoma Society website to be developed
- VHIO website: [Home - VHIO](#)

6. Expectations of the members of the PCAG

Patient engagement activities and guidelines (M12)

- Contributing to a set of guidelines and lay documents to help engage cancer patients and caregivers across diseases in the SPARC project.

Pilot studies

- Regular input of **PCAG** is greatly appreciated. Patients will be asked to share their lived experiences and opinions. They will help advise on how studies are designed and review information materials to make sure they are clear and patient-friendly.

Patient Advisory reports & recommendations

- These reports will be drafted and prepared by Lungs Europe based on the **PCAG** input and approval.

Patients' Empowerment Events

- To contribute to the design of events and activities for patients by providing advice, feedback, opinions and recommendations related to form, size, time and topics with the

objective of creating meaningful and impactful events (such as workshops, webinars and forums) for patients, caregivers, patient representatives (possibly also healthcare professionals). The main objective is to provide actionable knowledge on precision medicine and data sharing.

Best practices

- Sharing practical experience and supporting the selection and final formulation of best practices & success stories to inspire and guide advocacy efforts

7. Meetings & Input

- Two online PCAG meetings per year (about 1 hour each).
- Participation in selected SPARC meetings and events, including the annual SPARC consortium meeting and the annual Stakeholder Forum (primarily online, with limited in-person participation opportunities).
- Up to two ad hoc consultations per year if specific questions arise.

8. Communication

How do the PCAG members communicate with each other?

Members are encouraged to exchange email addresses so they can share ideas and experiences between meetings. Other methods of online communication can also be used.

How are meeting minutes communicated?

Lungs Europe will prepare minutes and send to the PCAG after each meeting. Representatives attending meetings are asked to feed back to other **PCAG** members about the meeting.

*What if I have any concerns or worries about my role in the **PCAG**, Task Force or CRC?*

If you have worries or concern about your role in the PCAG, you can speak to your Lungs Europe representative for help and support.

Framework

All relevant activities and project updates will be communicated by the SPARC WP7 leader (or appointed person) on a regular basis and in line as agreed within the PCAG.

Written materials and outputs, such as agenda, meeting minutes, timelines, planned activities, shared documents and overviews, will be prepared and made available by sharing to all members.

The SPARC team meets regularly, generally once per month to discuss and decide on project-related priorities, deadlines, and activities, as well as share general updates. These meetings also serve to enhance the team's alignment, knowledge-sharing and oversight of the SPARC's project portfolio and its work packages.

The WP7 Lead aims to ensure smooth and efficient workflow as well as coordinate and support the tasks, roles and outcomes.

A standard procedure of meetings

The meetings are planned bi-yearly (two meetings per year). *Ad Hoc* meetings can be scheduled, as necessary.

Estimated Timeframe of minutes after meeting

- 2 weeks in advance (minimum) – sending the invitation, agenda, SPARC Team (WP7 leader or appointed person) will provide background information as a part of the invitation, focused on description, explanation, discussion and further decision making)

- 5 working days for:
 - Minutes from the PCAG meeting (by appointed person) shared with attending participants
 - Following comments from PCAG members on the minutes

- 2 weeks
 - Sending the final version of the minutes to all PCAG members

Tools, Resources and Channels

Meetings will be scheduled via MStTeams and documents will be available on the shared GoogleDrive are main web-based platforms and channels for the exchange of information, including convening meetings and as the main repository of documents.

Members of PCAG will have access to dedicated shared folders to consult and contribute to documents. We will also use [SPARC website](#) and social media channels: <https://www.linkedin.com/company/sparc-eu/> & https://x.com/sparc_eu?s=21

9. Compensation and Reimbursement

Members of PCAG are volunteers and will receive no compensation for their time and input. However, all expenses incurred by members for travel and accommodation, including visa costs,

and reasonable costs made during **travels for PCAG face-to-face meetings or activities, will be reimbursed by the Consortium** (WP7 budget). Costs of attending face-to-face meetings or other activities incurred by PCAG members **must be first approved by Lungs Europe**. Without written approval by Lungs Europe, no costs can be reimbursed.

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10. Timeframe

The **PCAG** will be set up in 2026 and will last until the completion of the SPARC project (October 2028).

11. Non-disclosure of information

Members of the PCAG may access information that is private or not yet shared with the public. This could include draft policies, plans, ways of working, or early project results (“Confidential Information”). Members of the PCAG agree to treat all such information as confidential and to use it only for the purpose of contributing to the goals and activities of the PCAG.

Members must not disclose, share, or publish any Confidential Information to any third party or the public without prior written consent from the SPARC project consortium, unless that information has been officially made public. This duty of confidentiality applies both during membership of, and after a member’s participation in, the PCAG

By taking part, members conform that they understand of this confidentiality requirement and agree to uphold it.

12. Glossary

A

- Adrenocortical Carcinoma (ACC): A rare cancer that forms in the outer layer of the adrenal glands, which produce hormones such as cortisol and aldosterone.

B

- Biomarkers: Biological indicators (e.g., molecules or genes) that help detect or monitor diseases, predict treatment response, or assess prognosis.
- Breast cancer: A cancer that develops in breast tissue, often starting in ducts or lobules.

E

- EU4Health: An EU program aimed at improving health systems, disease prevention, and access to innovative treatments across Europe.

J

- Joint Action on Personalised Medicine (PCM JA): A European initiative to integrate personalized medicine approaches into healthcare systems.

L

- LB (Liquid biopsy): A non-invasive test that detects cancer-related genetic material (such as ctDNA) in blood or other fluids.
- Lung cancer: A cancer that starts in the lungs, often linked to smoking or environmental factors.

M

- Melanoma: A serious type of skin cancer that develops in pigment-producing cells (melanocytes).
- Molecular Tumour Boards: Multidisciplinary teams that review genetic and molecular data to guide personalized cancer treatment.
- Multiple Myeloma: A cancer of plasma cells in bone marrow, affecting blood and immune function.

N

- Neuroblastoma: A cancer that develops from immature nerve cells, mostly in children.
- NGS (Next-Generation Sequencing): Advanced DNA sequencing technology that rapidly analyzes large amounts of genetic data.

P

- Pancreatic cancer: A cancer that begins in the pancreas, often diagnosed late and difficult to treat.
- Personalised cancer medicine: Tailoring cancer treatment based on individual genetic and molecular characteristics.
- Personalised medicine: Customizing medical care to a patient's unique genetic, environmental, and lifestyle factors.
- Pilot studies: Pilot studies are small, early test studies done before a larger research project. They help researchers check if a study protocol works well, identify problems, and make improvements before involving many more participants.

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