## Call for Interest: Join the IDERHA Patient Advisory Board

The European Patients Forum (EPF) and Lung Cancer Europe (LuCE) are pleased to announce a call for representatives for the patient advisory Board (PAB) for the project titled "Integration of Heterogeneous Data and Evidence towards Regulatory and HTA Acceptance" (IDERHA).

IDERHA is a project aiming to develop a scalable platform for integrating diverse real-world data to support healthcare professionals, patients, and researchers in improving patient outcomes. It is part of the Europe Beating Cancer Plan and focuses on using artificial intelligence and machine learning to analyze health data for early detection of lung cancer and enhancing the quality of life for individuals affected by the disease.

The project seeks to demonstrate the value of data-driven approaches in clinical decisionmaking and personalized disease management. It is also contributing to the development of the European Health Data Space (EHDS) and aims to accelerate policy development to facilitate regulatory approval and Health Technology Assessments (HTA) for novel health solutions. Funded through the Innovative Health Initiative (IHI), IDERHA is one of the first research projects to receive support from this public-private partnership between the European Union and the European life science industries.

Find more about the project here on the project website, as well as here on EPF website.

# ABOUT THE PATIENT ADVISORY BOARD (PAB):

The PAB represents one of the three boards of the project, charged with gathering the perspective of patient representatives, monitoring and reviewing IDERHA activities from a user perspective, and helping to create meaningful patient involvement and input throughout the project.

## WHAT DOES THE WORK ENTAIL?

- 1. **Monitoring and Review:** Overseeing and assessing IDERHA project activities, both planned and spontaneous.
- 2. **Feedback and Co-design:** Collaborating on shaping the patient journey for all activities involving patients, focusing on tools that empower them for consenting, disease self-management, and shared decision-making.
- 3. **Input to Governance:** Providing insights to WP6's Integrated Data Access Governance Council (IDAGC) to influence policy priorities and recommendations.
- 4. **Facilitating Engagement:** Assisting in the creation of meaningful patient and public involvement initiatives.
- 5. **Requirement Definition and Validation:** Contributing to defining project requirements and validating assumptions.

6. **Dissemination:** Helping spread awareness of project work within their broader network.

At this stage of the project, the PAB already has seven members, and we are looking for more participants to reach fifteen individuals to ensure representation of profiles from different geographies, genders, disease areas, age ranges, and levels of health literacy. **We are especially looking for people who have experience with lung cancer.** 

## WHO ARE WE LOOKING FOR:

- Patients living with lung cancer particularly, but not limited to and/or carers of people in the above situation
- Min. 18 years of age
- Fluent English required
- Must be from an EU Member State
- Representatives don't need to be proficient in the topic but need to indicate a strong interest in health data.
- Availability to travel to project's general assemblies and other meetings within Europe.

### **EXPERIENCES (ADVANTAGEOUS):**

- Previous experience of being involved in multi-stakeholder projects is advantageous.
- Previous experience of participating in events, workshops, studies (e.g., surveys, focus groups, interviews), or similar activities related to health data.

#### SKILLS:

- Able to communicate clearly and always in a respectful and inclusive manner.
- Able to work comfortably in an online environment.
- Maintaining confidentiality when required.
- Able to interpret large blocks of information and contribute to discussions.

### ATTRIBUTES:

- Willing and confident to participate in meetings and group conversations, sharing views, and making arguments.
- Collaborative and constructive but prepared to provide and receive challenging input.

**FORESEEN ACTIVITIES:** The members of the group will attend several meetings:

- The PAB's regular online meetings.
- The project's Annual General meetings: once a year face-to-face where about 3 members from the PAB will be able to attend; a virtual mid-term session per year.
- Other meetings with project consortium partners as needed.
- The induction meeting (online).
- eLearning activities (online) and potentially the need to familiarise with short prereads.

## **COORDINATOR POSITION:**

We are also opening a call for the coordinator of the PAB. This person will need to comply with all the activities and responsibilities named before, and in addition, this person should:

- Coordinate the work of the PAB.
- Report the work of the PAB to EPF project coordinator.
- Coordinate The Integrated Data Access Governance Council (IDAG) with 8 in-person meetings scheduled throughout the project's duration.

## IS THERE A COMPENSATION FOR THE WORK OF THE PATIENT ADVISORY GROUP?

Each participant will be remunerated depending on their time investment. In case of any travels for in-person meetings connected to the project, the bookings will be covered and made directly by EPF.

### **APPLICATION FORM AND DOCUMENTS**

Please complete the application form online <u>here</u>. The application form consists of questions about your personal details (name, country of residence, experience), short questions about your motivation for applying, a declaration of interest, and information on how EPF will process your personal information. Please do not forget to attach your CV to the application form. Please submit your application form online with attached supporting documents by **May 30th**, **2024.** If you are also willing to apply for the coordinator position, please tick the box about it.

### TIMELINE AND SELECTION PROCESS

- May 2nd Launch of the call
- May 30th Close of the call
- June 5th and 6th Short calls with shortlisted applications

## WHAT HAPPENS ONCE WE HAVE RECEIVED YOUR APPLICATION?

1. You application will be evaluated by both EPF and Luce.

- 2. After the evaluation of applications, shortlisted candidates will be invited to an informal conversation as part of the selection process (max 20 minutes). This is not an interview, and you are not expected to prepare for it.
- 3. If you are selected, the next steps will be confirmed in future communications.

The informal conversations, as per point 3 above, will take place on June 6th and 7th (all day). More information and the possibility to select a slot on one of those days will be provided to those shortlisted.

Should you have any questions, please feel free to contact Estefania Callejas De Luca at <u>estefania.callejasdeluca@eu-patient.eu</u>