

**Webinar Concept: Patient Engagement in Clinical Research**

**Title: Empowering Patients as Partners in Clinical Research**

**23 October 2023 Time: at 4.30 EAT**

**Registration link: <https://forms.gle/8Q4BHUoE2UXou5fF7>**

### **The EU-Africa PerMed Project**

[EU-Africa PerMed](#) (Building Links between Europe and Africa in Personalised Medicine) is a four-year project funded by the European Commission H2020 Programme that has the final objective of integrating more African countries in the global PM research agenda. This is by facilitating their participation in the activities of the International Consortium for Personalised Medicine (ICPerMed) and by strengthening the research collaboration between Africa and Europe in areas of mutual interest. The project commenced in 2021 and is implemented by a Consortium of 13 partners, seven from Africa and six from Europe.

The project has implemented a series of successful project activities among them, the mapping of the scientific and policy landscape of PM in Africa; two stakeholder-based surveys that sought to understand the situation concerning PM in Africa; a series of webinars on pertinent issues; stakeholder workshops; developed and published a policy brief on 'Opportunities to Advance Personalised Medicine in Africa'; and held the summer school training on PM research targeting Early Career Researchers (ECRS). Among the findings from these activities, the need for technical capacity building was voiced loud and clear. Thus, in this webinar we focus on the knowledge and experiences of those who have been working on capacity strengthening in the continent.

### **Overview:**

The webinar aims to highlight the importance of patient engagement in Personalised Medicine (PM) research and Implementation; providing insights into effective strategies for involving patients as partners in the research process. It will bring together a panel of experts, including researchers, funding organizations and patient advocates from Europe and Africa side, to share their experiences and perspectives on patient engagement.

It will be presented/discussed practical strategies and best practices for engaging patients (throughout the research process; addressing methods for involving patients in study design, protocol development, informed consent, and data analysis; exploring approaches to ensure diversity, inclusion, and ethical considerations in patient engagement efforts; and an overview of available resources, guidelines, and tools to support patient engagement in clinical research.

Attendees will gain practical knowledge and actionable insights to foster meaningful patient engagement in their own clinical research initiatives.

### **Objectives:**

- Gain a deeper understanding of the importance and benefits of patient engagement in clinical research
- Learn practical strategies and best practices for involving patients in research design, execution, and decision-making
- Discover resources, tools, and platforms that support patient engagement efforts

**Expected Impact**

- Acquire insights from patient advocates and researchers with extensive experience in patient-centered research
- Engage in interactive discussions and Q&A sessions with panellists to address specific challenges and opportunities in patient engagement

By the end of the webinar, attendees will be inspired and equipped with the knowledge and tools to enhance patient engagement in their own clinical research projects, ultimately leading to more patient-centered and impactful research outcomes.

**Duration:** 1:30 hour (including Q&A session)

**Agenda and Format**

- Welcome & Introduction EU Africa PerMed and (5 minutes)
- Overview of the webinar agenda and Speakers presentation (5 min).
- Introduction to the topic of patient engagement in clinical research (10 minutes) Lessons learned during European initiative on PM.
  - Why Patient Engagement Matters in Clinical Research
    - Exploring the significance of patient engagement in research design, execution, and outcomes
    - Presenting evidence on how patient engagement improves study relevance, participant recruitment, and retention
- Panel discussion featuring patient / P. advocates sharing their experiences and insights on patient engagement in research ( Europe and Africa) (10 minutes/ speaker)
  - Highlighting successful patient engagement initiatives and their impact on PM research outcomes
  - Discussing challenges and potential solutions for meaningful patient involvement
  - Best Practices for Engaging Patients in PM Research
- Q&A Session: Open floor for attendees to ask questions to the panelists and speakers (20 minutes)
  - Interactive discussion on specific challenges, opportunities, and implementation strategies related to patient engagement in clinical research. Listen to and learn from the people and communities we involve and apply and share that learning
- Closing Remarks and Key Takeaways (5 minutes) : Summarizing the key learnings and takeaways from the webinar and Encouraging attendees to apply patient engagement principles in their own research endeavors

**Target Audience:**

This webinar is designed for researchers, clinicians, patient advocates, caregivers and other stakeholders involved in clinical research. It welcomes attendees from diverse backgrounds and aims to facilitate knowledge exchange and collaboration among participants.

**Moderator and speakers:**

- Maria Jose Ruiz from ERA PerMed and Eu Africa PerMed
- Sonia Abdelhak from PerMediNa Project
- Eltjo Heddema, Project manager and Patient advocate at Inspire2Live
- Franklin Mtei, Patient Advocate at Inspire2Live, CEO, Tanzanian Cancer Society

**Follow up activity**

A summary of key messages will be prepared and shared following the webinar. The recording of the webinar and the slides will also be shared with the participants on the webpage of EU Africa PerMed.