Best Practices for Patient Engagement: Lessons from IDERHA

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FACTS & FIGURES

Start date:	1 April 2023
End date:	31 March 2028
IHI funding:	23.1 million €
Industry contribution:	19.6 million €
Total Cost:	42.7 €
Project website:	www.iderha.org
Social media:	linkedin.com/company/iderha

CHALLENGE

Effective patient engagement requires the voice of patients & caregivers to be embedded from the start of the project and well-integrated into deliverables.

Consultation alone does not achieve that. However, commonly:

- Patient organisations are engaged too late in the proposal development process, at times just weeks before the submission deadline
- Proposals are highly technical and hard to engage with
- Tasks and deliverables requiring contributions from patient organisations, patients, and caregivers are distributed across multiple project work packages

APPROACH & METHODOLOGY

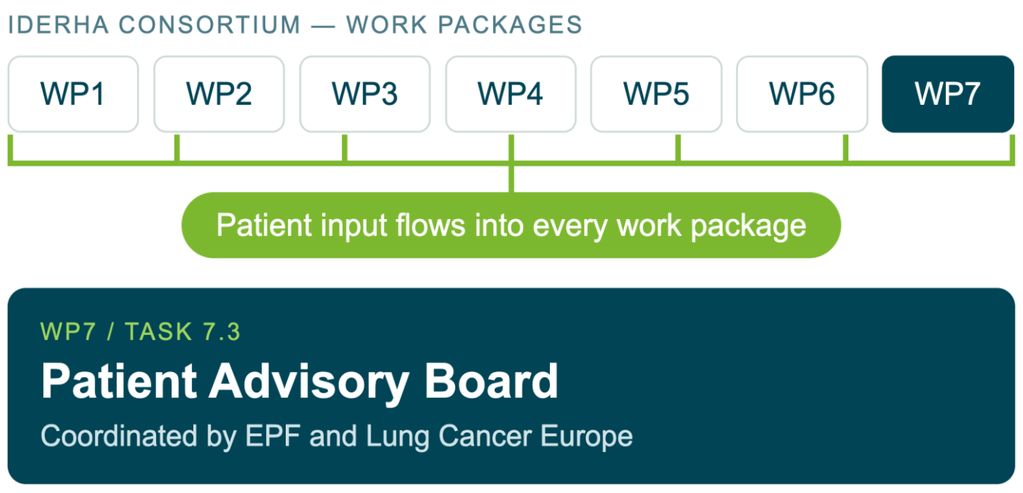
In the IHI-IDERHA project, patient engagement is embedded through a Patient Advisory Board (PAB) within one work package (WP), with a mandate to provide input across different WPs.

The PAB is jointly coordinated by European Patients' Forum (EPF) and Lung Cancer Europe (LCE). Both patient organisations are project partners and work closely together throughout the consortium. EPF and LCE were involved from the outset, co-designing the project proposal and helping ensure that patient perspectives are integrated from the beginning.



RESULTS

- **Cross-cutting input:** PAB input reaches all IDERHA work packages, rather than being confined to the WP where the PAB is formally located.
- **Regular dialogue:** Bi-monthly PAB meetings provide direct input into ongoing work package activities, based on a Yearly Patient Engagement Plan.
- **Embedded engagement**: Shifted from a standalone Public Forum to embedding patient engagement in different conferences with built-in audiences, including European Respiratory Society, Lung Cancer Europe Conference and Patient Engagement Open Forum.
- **Continuous improvement:** Annual two-way satisfaction surveys with PAB members and work package leads inform improvements to patient engagement.



VALUE OF IHI COLLABORATION

Embedding patient engagement across the IDERHA consortium strengthens collaboration between patients, researchers and industry, ensuring that patient perspectives inform priorities and activities throughout the project. This approach supports more meaningful co-creation, strengthens mutual understanding across stakeholder groups, and provides a practical model for integrating patient expertise into large-scale IHI collaborations

CAREER IMPACT

This project is supported by the Innovative Health Initiative Joint Undertaking and its members.