How we work with patients and communities

Our Patient Engagement Strategy

October 2025

LifeArc

Contents

Executive summary

LifeArc is a not-for-profit medical research organisation which translates science into impact for people with rare diseases, and in global health.

Through our scientific capabilities, translational expertise and partnerships, we ensure great science achieves its potential and reaches patients faster. We focus on finding solutions to medical challenges that may be overlooked due to costs, complexities or their high-risk nature.

We can’t progress life-changing science alone. Working with patients and communities is essential for translating promising science into real-world impact. People with lived experience of health conditions bring unique and valuable knowledge to the research process. By integrating this with scientific and commercial expertise, we can develop better solutions faster.

Our patient engagement strategy sets out our approach to working with rare disease and global health patients and communities. Building on our existing efforts, we will work to strengthen our partnerships with patients, improve the efficiency of patient engagement, share knowledge and collaborate to drive forward patient engagement in rare disease and global health translational research.

By embedding patient engagement in our work, we will accelerate innovation, improve clinical trials, and deliver therapies that truly meet the needs of rare disease and global health communities. Together, we can make life science life changing.

What patient engagement means to us

Patient engagement refers to purposeful interactions with patients and communities where knowledge, insights and perspectives are shared to enhance research and improve health outcomes.

It includes a spectrum of activities, from sharing information about research and hearing the experiences of individual patients, to working with patient organisations to understand unmet needs and involving patient advocates in oversight of projects.

Definitions

Patient engagement is used as an umbrella term to encompass both **involvement and engagement.**

> ***Involvement:***
> patients and communities share their thoughts, experiences, and perspectives
> to inform the direction of research, strategy and policy.
>
> ***Engagement:***
> information and knowledge are shared with patients and communities.

Purposeful interactions refers to meaningful patient engagement that has purpose, is planned and goes beyond superficial interactions.

Patients is used as a broad term to include people with a health condition or at risk of one, carers, parents and families.

The term **communities** is inclusive of patient organisations, community leaders and civil society organisations, service providers and policy makers[1].

Why it's vital to our work

Patient engagement is increasingly being recognised as an essential part of health research which improves quality and impact[2].

For LifeArc, embedding patient engagement in our work is vital for translating promising science into real-world impact for people living with rare diseases and global health infections. Patient insights already play a key role in shaping activities across our portfolio. Strengthening our engagement with patients throughout the innovation process will enable us to:

- align decision making in early-stage research with patient preferences to drive more focused product development
- strengthen feasibility assessment, trial design and recruitment strategies for clinical trials to increase likelihood of success
- use our unique position in the ecosystem to integrate patient voice with scientific and commercial expertise to accelerate research

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References:

[1] Community Engagement and Involvement - NIHR

[2] Putting people first - embedding public involvement in health and social care research - Health Research Authority

Our strategy for patient engagement

Vision

Patient engagement is embedded throughout research and development to ensure promising science translates into real world impact for patients.

Mission

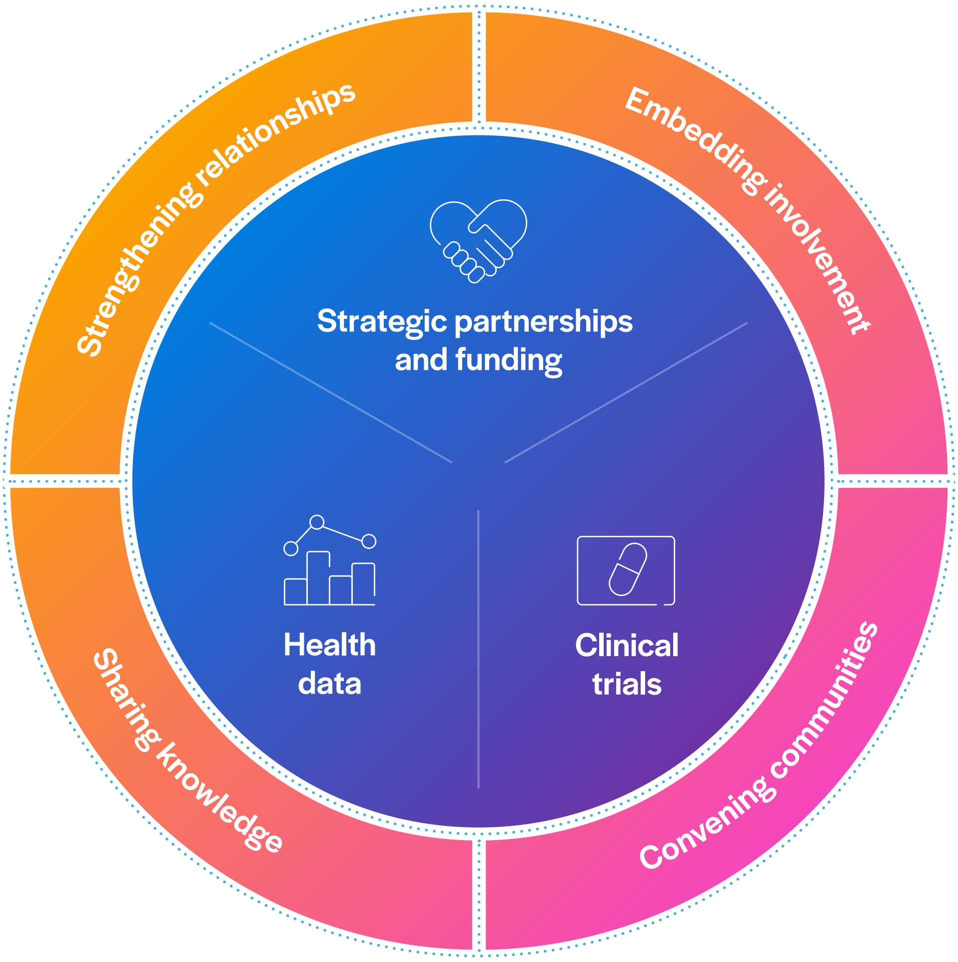
To advance patient engagement in translational research by establishing processes that support good quality, inclusive patient engagement.

Purpose

To make research more effective by including patients and communities as active partners throughout the process.

Our patient engagement work will focus on three core areas of activity - clinical trials, health data, and strategic partnerships & funding.

This will be supported by four strategic pillars designed to drive meaningful progress.



How we'll measure progress

Pillar	Objectives
Strengthening relationships - we will work in partnership with patient and community organisations to deliver patient engagement activities, only setting up new initiatives when necessary to achieve our goals.	• Establish LifeArc as a trustworthy partner for patient organisations across rare disease and global health communities.
	• Grow and nurture a network of rare disease and global health patient communities who are ready to work with us and support our patient engagement activities.
	• Take proactive steps to involve a diverse range of patient voices and communities in our work.
Embedding involvement - we will embed patient engagement into our processes in an intentional, focused and efficient way.	• Establish clear and systematic processes for involving patients in our work.
	• Work in partnership with rare disease and global health patient communities to better understand the needs and priorities of patients.
	• Ensure our decision-making is guided by patients, with measurable outcomes and impact of patient engagement activities.
Sharing knowledge - we will disseminate our learnings and champion patient perspectives internally and externally.	• Amplify patient perspectives in internal communications to inform, inspire and promote a culture that fosters patient engagement.
	• Share insights and learnings from our patient engagement work with the wider research community.
	• Communicate relevant outputs of our work in ways that are accessible and useful for rare disease and global health patient communities.
Convening communities - we will utilise our ability to unite patient, scientific and commercial expertise to influence and convene stakeholders across the ecosystem to advance patient engagement.	• Collaborate with other organisations to advance patient engagement in rare disease and global health research.
	• Convene multistakeholder groups to share learnings, address challenges and advance partnerships for patient engagement.
	• Support capacity and capability building for patient engagement in translational research.

Our mission in action

Patient engagement is an important strand of all the work we do across LifeArc, and we have a suite of resources available to help colleagues across the organisation to upskill in this area and consider how patient engagement fits into their areas of work.

We have identified key activities within each core area where we aim to make meaningful progress. We expect this list to evolve as our work develops and new opportunities emerge.

	Clinical trials	Health Data	Strategic Partnerships and Funding
Objective	Patient engagement will strengthen feasibility assessment, trial design, recruitment and regulatory engagement.	Patient engagement will help us build our reputation as a credible, trustworthy leader in data science.	Patient engagement will guide our decision-making and ensure we are focused on what really matters to patients.
Example activities	• Embed patient engagement in diligence and review processes	• Build relationships with key patient engagement stakeholders	• Align the Patient Engagement Framework and Funding Framework
	• Define expectations for patient engagement in funded trials	• Establish processes for how patient engagement is considered in data projects	• Embed patient engagement within strategic partnerships
	• Gather patient insights to support regulatory and payer engagement	• Understand key challenges and priorities for patient organisations in the data space	• Share outputs of patient engagement activities and communicate about plans

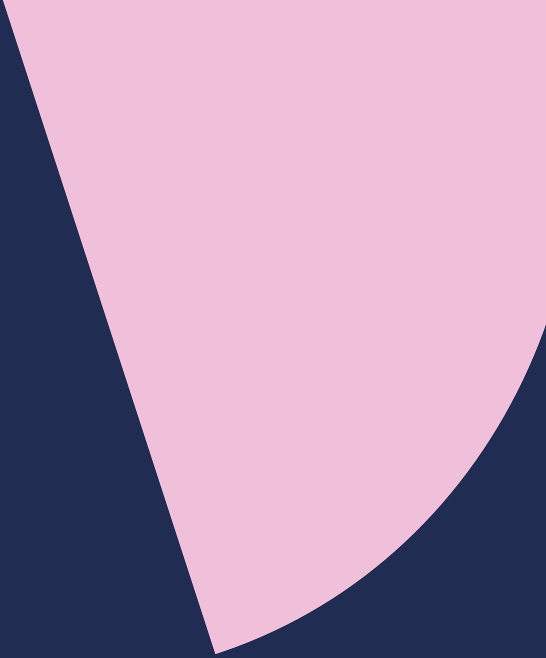
Governance

Implementation, monitoring and evaluation of the patient engagement strategy will be overseen by LifeArc's Principal, Patient Engagement and the Head of Charity and Patient Engagement, with executive accountability from the Chief Operating Officer.

Lead(s) will be identified within the focus areas, who will have responsibility for delivery against the strategy within portfolio programmes/projects.

In line with the pillars of this strategy and to support transparency and accountability, oversight of the strategy will be supported by the Patient Engagement Advisory Group.

This is a group of individuals with lived experience and patient engagement specialists external to LifeArc. The group will act as a critical friend by providing advice and guidance to support implementation of the patient engagement strategy, and will help ensure that our patient engagement work remains aligned with the views and needs of patient communities.



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