



**RARE IMPACT**

# **RARE IMPACT 2025 REPORT**

**NOV 25' - FEB 26'**

**CO-ORGANIZED BY DAKSHAMA  
HEALTH & PAIR ACADEMY**

# EXECUTIVE SUMMARY

Rare diseases pose complex challenges for healthcare systems due to limited awareness, fragmented care pathways, and uneven access to specialized services. Addressing these challenges requires collaboration between patients, clinicians, policymakers, industry, and technology experts.

The **Rare Impact Hackathon 2025**, co-organized by DakshamA Health and PAIR Academy, was designed as a **multi-country, patient-led innovation initiative** to address these challenges through **structured collaboration**.

The hackathon brought together **8 teams from across the Asia-Pacific region** to identify pressing problems faced by rare disease communities and develop feasible solutions. The initiative followed a **three-phase process** that enabled teams to progress from problem identification to solution development and stakeholder engagement.

Participating teams represented **7 countries** and included patient advocates, clinicians, policymakers, and technical experts working together to develop practical solutions.

The programme concluded with an in-person event where teams presented their solutions and engaged with stakeholders from public health, industry, and technology sectors. **Team India 2 was selected as the winning team** and received a prize of **₹1,00,000** along with **support for pilot implementation** of their solution.

The Rare Impact Hackathon demonstrated the potential of patient-led, multi-stakeholder collaboration models to generate scalable solutions and strengthen innovation ecosystems in rare disease care.





## BACKGROUND AND RATIONALE

Rare diseases affect millions of individuals worldwide, yet patients often face significant barriers in accessing timely diagnosis, appropriate care pathways, and reliable information. Many existing solutions fail to address these challenges because **stakeholders often work in silos, limiting opportunities for meaningful collaboration.**

The Rare Impact Hackathon was designed to address this gap by creating a b where stakeholders could collaborate to **co-create solutions grounded in lived experience and real-world healthcare constraints.**

The initiative was based on the principle that different stakeholders contribute different types of expertise:

- Patients and caregivers identify real-world problems
- Healthcare professionals ensure clinical accuracy
- Policymakers evaluate feasibility within health systems
- Technical experts contribute implementation pathways
- Industry partners support sustainability and scale

By combining these perspectives, the hackathon aimed to **develop solutions that are both innovative and implementable.**



# THE OBJECTIVES

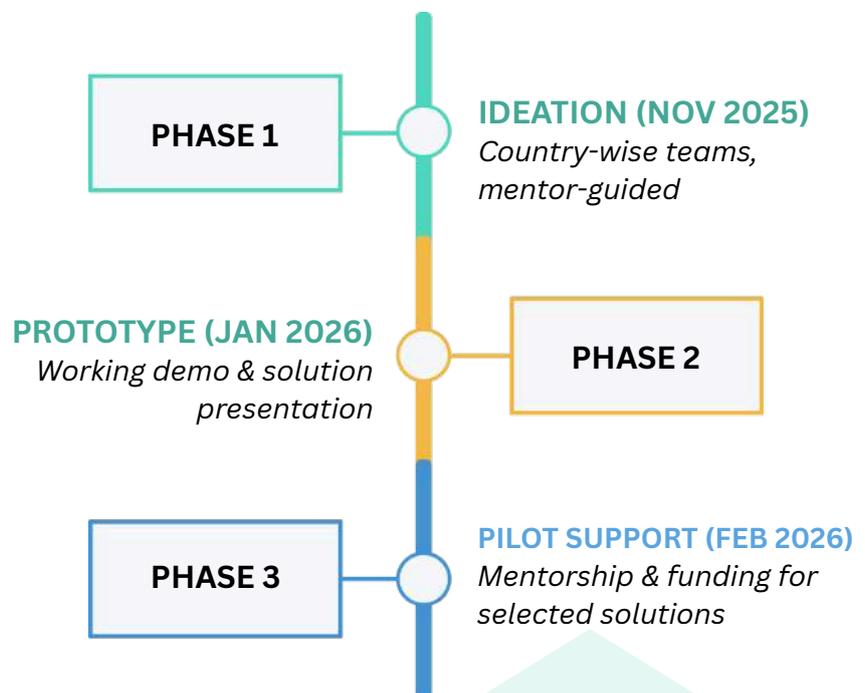


The Rare Impact Hackathon was designed with the following objectives:

1. Enable patient-led problem identification in the rare disease ecosystem.
2. Facilitate multi-stakeholder collaboration across countries and sectors.
3. Support the development of feasible and scalable solutions to challenges faced by rare disease communities.
4. Create a structured model for collaborative innovation that can be replicated in future initiatives.
5. Identify solutions that show potential for pilot implementation and further development.

# PROGRAMME DESIGN

The Rare Impact Hackathon was designed as a **three-phase programme** to allow teams to progressively refine their ideas while ensuring fairness and transparency across participating countries.



# Participating Country Teams

## VIETNAM



**HUY DO**

*President, Vietnamese Organization for Rare Diseases*

## NEPAL



**DR NIRAJ PARAJULI**

*Founding President, Rare Skin Disease Nepal*

## SINGAPORE



**ELLIL MATHIYAN  
LAKSHMANAN**

*Co-Chair, SingHealth Patient Advocacy Network*

## THAILAND



**EKAWAT SUWANTAROJ**

*Vice President, Thai Hemophilia Patient Club*

## INDIA



**NAVINTARA KAMATH**

*Co-Founder,  
Niemann-Pick India*



**MANOJ KUMAR SINGH**

*National President,  
Power In Me Foundation*



## MALAYSIA



**NADIAH HANIM ABDUL  
LATIF**

*President, Malaysian Rare Disorders Society*

## PHILIPPINES

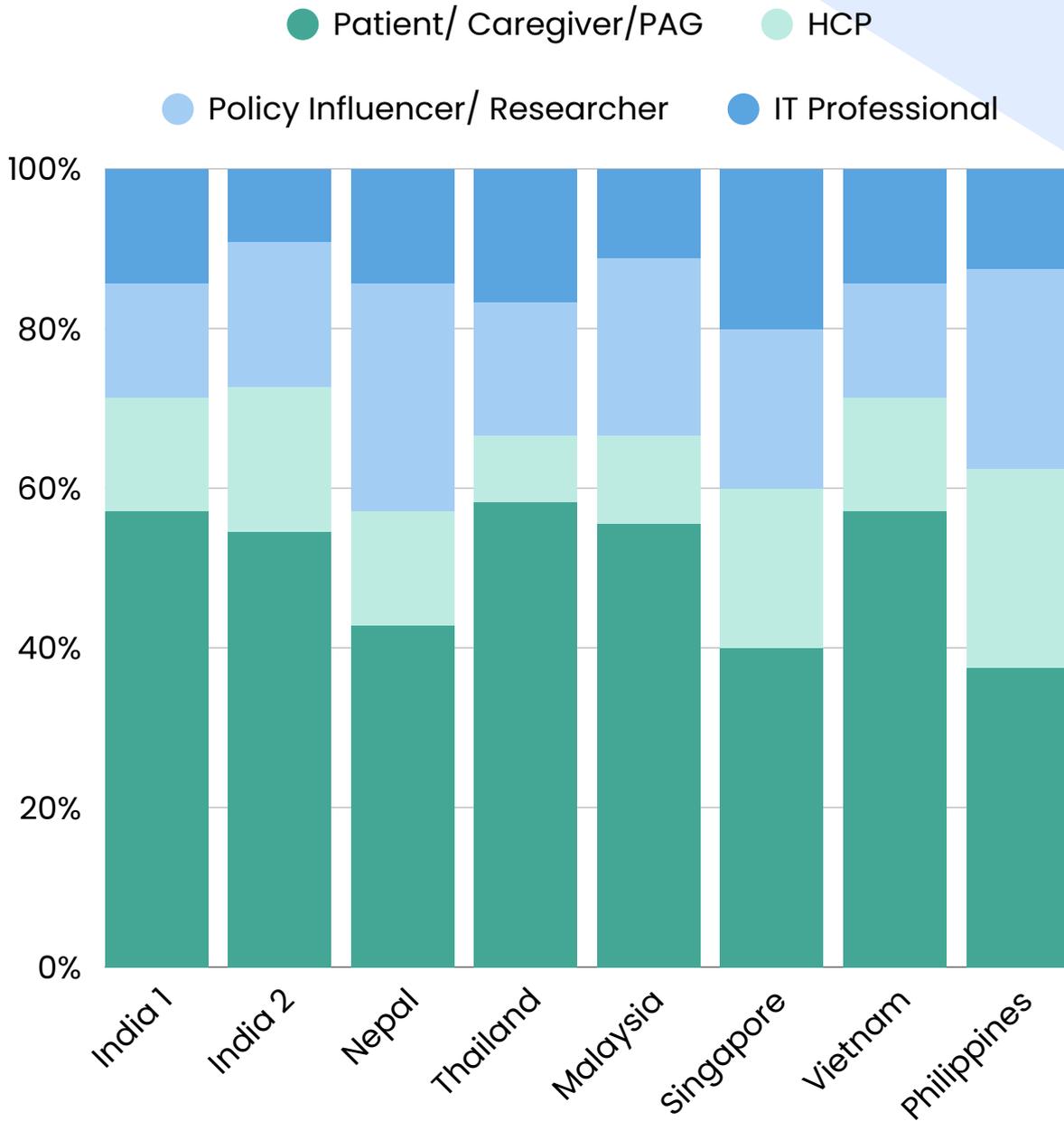


**ARACELI LANORIO**

*Lead Advocate,  
Neurofibromatosis Friends  
Philippines*



# STAKEHOLDER ENGAGEMENT



The Rare Impact Hackathon was designed to bring together a **diverse, multi-stakeholder group** to ensure that solutions were informed by lived experience, clinical expertise, policy realities, and technical feasibility. **Across all teams**, the hackathon brought together **73 participants** representing **different stakeholder groups**. Each team was intentionally composed of participants from multiple sectors to ensure that **solutions were balanced** between lived experience and implementation feasibility.

# PHASE 1: PROBLEM IDENTIFICATION AND CONCEPT DEVELOPMENT

In the first phase, teams worked to identify key challenges faced by rare disease communities within their respective contexts.

Participants developed concept notes outlining:

- The problem they intended to address
- The affected stakeholders
- The proposed approach to addressing the issue

This phase emphasized grounding solutions in lived experience and real-world constraints.

Country teams were led by patient advocates and representatives from patient organizations, ensuring that problem identification was driven by those most affected.



# PATIENT INCLUSIVE HACKATHON – FORMAL LAUNCH

**Date:** Monday, 24th November 2025

**Time:** 14:00 – 15:10 IST



## KEYNOTE SPEAKER

*B. S. Charan, Assistant Director General (ADG), Directorate General of Health Services, Ministry of Health & Family Welfare, Government of India*

*“India has holistically incorporated several key components to support patients living with rare diseases. This includes strengthening diagnostic systems, providing financial assistance for treatment, establishing a registry to understand disease prevalence, and designating Centres of Excellence as tertiary care institutions. Additionally, mechanisms for resource pooling have been introduced under the National Policy for Rare Diseases to ensure better coordination and support for patients.”*

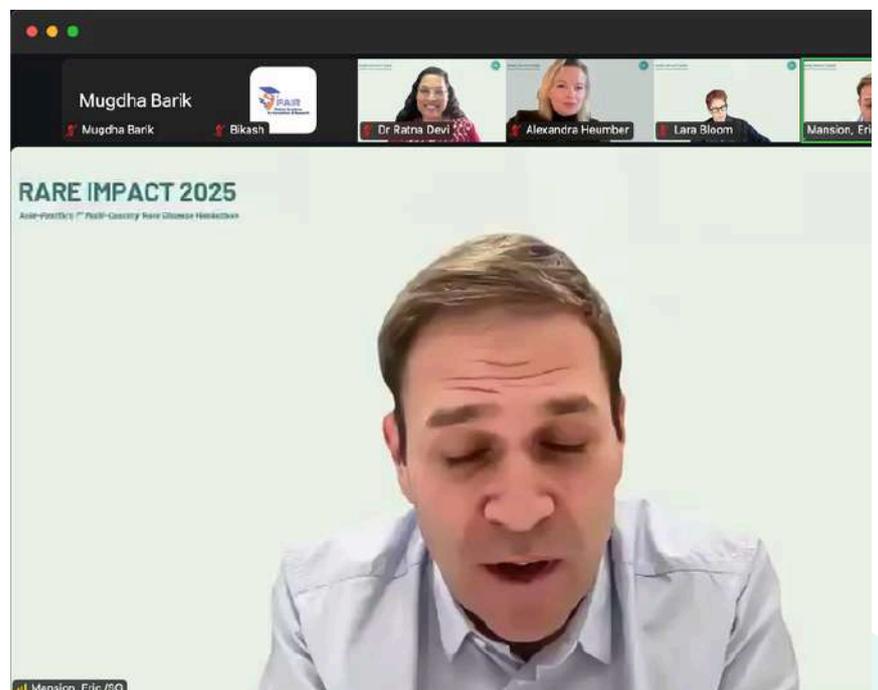
## GUEST SPEAKERS

*ERIC MANSION, PHARMA  
GM,*

*Sanofi SE – Asia and*

*India*

*“Through real experiences, we are witnessing a meaningful shift where both patients and caregivers are no longer only receiving care, but are actively leading and creating solutions. This transformation is a very necessary step toward driving real progress in healthcare and patient-centered innovation.”*





*"Innovation in rare diseases cannot begin only in boardrooms or laboratories. It must start in the lives of people who live this reality every day. Every rare disease journey begins with a personal story, and those lived experiences must guide how we design care, research, and solutions."*

**Lara Bloom, Chair, International Alliance of Patients' Organizations (IAPO); President & CEO, The Ehlers-Danlos Society**

*"The World Health Organization resolution on rare diseases calls on the WHO Director-General to strengthen collaboration with relevant non-governmental organizations and academic institutions. Such partnerships are essential to advance research, improve knowledge sharing, and strengthen global efforts to address the needs of people living with rare diseases."*

**Alexandra Heumber Perry, CEO, Rare Diseases International**

*Working with people who have lived experience is critically important. Let us work together to truly make this a reality by bringing people together who can drive meaningful change. Collaboration is essential, and this is an incredible concept that we must keep front and centre in all our efforts.*

**Monica Ferrie, Executive Director, Asia Pacific Alliance of Rare Disease Organisations (APARDO)**

**Mugdha Barik**  
Mugdha Barik

**Bikash**

**Dr Ratna Devi**

**Alexandra Heumber**

**Lara Bloom**

**Monica Fierre**

## The WHA Resolution's impact at the local level

A few examples:

	<b>COUNTRY A</b> <i>high-income country with a national action plan on rare diseases</i>	<b>COUNTRY B</b> <i>middle income country with a national action plan on rare diseases</i>	<b>COUNTRY C</b> <i>low middle income country, no national action plan on rare diseases</i>
<b>EXAMPLE OF CHALLENGE</b>	diagnostic delays are still common, especially in rural areas	number of persons living with a rare disease is unknown	very limited access to rare disease treatments such as orphan drugs
<b>EXAMPLE OF IMPACT</b>	improved training and awareness for primary healthcare providers	development of a national rare disease registry	support for innovative funding models for rare diseases
guidance and support from WHO prioritization of rare diseases in public health agendas dedicated budget lines for rare diseases in national health budgets			

# PHASE 2: SOLUTION DEVELOPMENT AND EVALUATION

During Phase 2, teams refined their ideas into more developed solution concepts.

Teams presented their work through recorded virtual sessions, which included:

- A pitch presentation
- Demonstration of their proposed solution
- A question-and-answer discussion with facilitators

The jury evaluated submissions based on several criteria including:

- Relevance to the problem
- Patient-centricity
- Feasibility
- Impact and scalability
- Technical execution

The evaluation process was conducted asynchronously to ensure transparency and fairness.





# PHASE 3: STAKEHOLDER ENGAGEMENT AND FINAL PRESENTATIONS

The final phase took place on **24 February 2026** at the India International Centre, New Delhi, bringing together teams and stakeholders for final presentations and discussions.

This phase focused on:

- Presenting solutions developed by participating teams
- Facilitating dialogue between teams and ecosystem stakeholders
- Identifying opportunities for further development and pilot implementation
- Panel discussion



## PANEL DISCUSSION

*Theme: Patient-Led Innovation: From Hackathon to Health System Impact*

### **Moderator:**

Dr. Madhulika Kabra, Emeritus Scientist, Indian Council of Medical Research (ICMR)

### **Advisors / Panelists:**

- Dr. Shubnam Singh, Principal Advisor – Healthcare, CII
- Dr. Vishal Gandhi, Managing Director, BioRx
- Dr. Sheffali Gulati, Professor and Faculty In-Charge, Child Neurology Division, Department of Pediatrics, AIIMS New Delhi
- Dr. Nishant Singh, Rare Disease Medical Lead – India & South East Asia, Sanofi
- Mr. Mayank Garg, Head of Data and AI, Google
- Mr. Vinay Sharma, AstraZeneca India

## SESSION OVERVIEW:

The session focused on exploring the **transformative potential of advancing health needs and strengthening India's rare disease ecosystem**. The discussion highlighted the importance of **integrating public health systems with patient-centered care** and aligning ongoing efforts with the National Policy for Rare Diseases.

The session brought together a diverse panel of experts from clinical, research, regulatory, and subject matter experts who shared their perspectives on improving the rare disease landscape in India. The conversation centered on how patient-led innovation, collaborative partnerships, and supportive policy frameworks can help create a **more sustainable and inclusive healthcare ecosystem**.

The discussion was initiated with a key question posed by Prof. Madhulika Kabra, who asked what **critical elements patient-led innovations must demonstrate early**—such as evidence generation, partnerships, alignment with health systems, and sustainable community impact—to scale effectively within the healthcare system.

Panelists reflected on their experiences and emphasized that meaningful transformation in the rare disease ecosystem requires **early** patient engagement, **stronger collaboration** between stakeholders, and **greater alignment** between innovation, policy, and healthcare delivery systems.



# KEY HIGHLIGHTS & TAKEAWAYS

## 1. Early Patient Involvement in Innovation

Panelists strongly emphasized that patients must be involved at the earliest stages of healthcare innovation. Whether in research, treatment development, or policy discussions, incorporating patient perspectives ensures that solutions address real needs and lived experiences.

## 2. Patient-Centered Approach to Treatment Development

While new medicines and therapies continue to emerge, the panel highlighted the importance of ensuring that treatments remain accessible and affordable. Innovation should balance scientific advancement with the realities faced by patients and caregivers.

## 3. Importance of Multi-Stakeholder Partnerships

Effective collaboration between patients, clinicians, researchers, policymakers, and industry partners is essential to build a sustainable rare disease ecosystem. Partnerships help accelerate innovation while ensuring practical implementation within the healthcare system.





#### **4. Strengthening Patient Representation**

Panelists emphasized the need to create more platforms where patients and caregivers can actively participate in discussions and decision-making processes. Their representation in policy dialogues and forums is essential to ensure their voices are heard and respected.

#### **5. Building Trust Across the Ecosystem**

Trust between patients, government institutions, healthcare providers, and industry stakeholders is fundamental. Transparent communication, inclusive decision-making, and sustained engagement are necessary to strengthen this trust.

#### **6. Moving Toward a Patient-First Ecosystem**

The session concluded with a shared view that strengthening India's rare disease ecosystem requires a patient-first approach supported by policy alignment, collaborative innovation, and continuous engagement with patient communities.

# OUTCOMES OF THE HACKATHON

The Rare Impact Hackathon generated several tangible outcomes.

## Development of Solution Concepts

Participating teams developed innovative solutions addressing challenges such as:

- Access to information
- Care pathway navigation
- Patient support mechanisms
- Digital tools for rare disease communities

## Strengthened Multi-Stakeholder Collaboration

The initiative demonstrated how structured collaboration between patients, clinicians, policymakers, and industry stakeholders can lead to more feasible solutions.

## Identification of Promising Solutions

Following the final presentations and discussions, Team India 2 was selected as the winner of the hackathon.

The team received:

- ₹1,00,000 prize money
- Support from Dakshama Health to develop and pilot their solution.



# LESSONS LEARNED

The Rare Impact Hackathon generated important insights for future initiatives.

## **Patient Leadership Strengthens Problem Definition**

Solutions were more relevant when patients and caregivers led the identification of problems.

## **Role Clarity Enhances Collaboration**

Clearly defined roles for different stakeholders helped teams leverage their respective expertise effectively.

## **Structured Processes Enable Fair Participation**

The phased design of the hackathon allowed teams from different contexts to participate meaningfully.

## **Multi-Country Collaboration Creates New Perspectives**

Cross-country participation enabled teams to learn from different healthcare systems and approaches.

# FUTURE OPPORTUNITIES & CONCLUSION

The Rare Impact Hackathon serves as a pilot model for patient-led innovation programmes.

Future initiatives may build on this model by:

- Expanding participation to additional countries
- Developing structured mentorship programmes
- Supporting pilot implementation of selected solutions
- Strengthening partnerships with industry and public health institutions

The Rare Impact Hackathon illustrates how patient-led innovation platforms can generate meaningful solutions while strengthening collaboration across stakeholders.

By bringing together diverse participants from multiple countries and sectors, the initiative created a space where lived experience and technical expertise could converge to address real-world challenges in rare disease care.

As the programme evolves, the Rare Impact model has the potential to serve as a replicable framework for collaborative innovation in healthcare.



# THANK YOU