

# Unite4Rare Annual Impact Summary 2025\*

Meaningful patient engagement in rare diseases is inherent to Sobi’s DNA. Unite4Rare (U4R) builds on Sobi’s history and is Sobi’s long-standing commitment to the patient and caregiver community, outlining our responsibilities, what has been done so far and how we will measure progress into the future.

Only by working together — and by closely monitoring and tracking our progress — can we truly fulfil the pillars of our commitment: improving outcomes for patients and caregivers, helping people living with rare diseases and their families access the life-saving care and therapies they need and amplifying their voices

The following figures are cross-functional and company-wide:



\*Based on cross-functional and cross-geography Sobi metrics collection as per Unite4Rare cocreated KPIs.  
 \*\*Out of 31 global pharmaceutical companies Source: PatientView September 2025. The Corporate Reputation of Pharma — Rare-Disease Edition 2024\*, PatientView-Press-Release-Corp-Rep-Pharma-Rare-Diseases-2024.pdf

# Sharing our first year of progress



## Connect

**Foster connections within the healthcare community**

### Disease Awareness

**256** Patient organisations engaged

### Patients as Equal Contributors

**268** Touchpoints between Sobi senior leaders and patient community

### Access programmes / Humanitarian programmes

**27** Humanitarian partnerships and managed access programmes in place

**19** Countries impacted

**22** Countries with funding/reimbursement achieved

### Clinical Trials

**27%** of protocols with patient input

**6** Feedback loops activated

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## Nurture

**Nurture meaningful partnerships with patient stakeholders**

### Capability Building

**468** New patient experts supported through education

### Patient Driven Models

**100%** Newly hired employees whose recruitment interviews included Patient Acumen questions

**1,891** Employees exposed to trainings that includes Patient Engagement concepts or notions, including familiarisation with Unite4Rare

### Patient Engagement in Acquisitions

**2** Launches with acquisitions with clear Patient Engagement plan in place

### Trusted Education Source

**1,415** Patient materials and projects created

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## Collaborate

**Collaborate to address unmet needs and improve patient outcomes**

### Define and Deliver on Shared Objectives

**443** Programmes co-created

### Informed Decision Making

**54** Materials fostering shared decision making

### Patient Engagement and Experience Data

**19** Real World Evidence studies that were designed and implemented with patients

**25** Patient organisations involved in design and deployment of Real World studies

**13** Global Clinical and Patient Engagement Councils in place

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## Innovate

**Innovate to enhance the lives of people with Rare Diseases**

### Innovate Disease Awareness Campaigns

**414** Innovative materials and projects created

### Value Added Services

**37** Patient Support Programmes in place

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We sincerely thank patient community leaders for co-creating Unite4Rare as a living commitment and all our Sobi colleagues for integrating Unite4Rare into all aspects of their work. As we implement, measure and adapt it over time, continued partnership is vital to achieving meaningful impact for people living with Rare Diseases and their families. Sobi remains dedicated to working collaboratively with the patient community to deliver transformative, innovative solutions.