

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.