Unite4Rare™

Unite4Rare Annual Impact Summary 2026*

Meaningful patient engagement is embedded in Sobi's DNA. Through Unite4Rare (U4R), we continue to build on our long-standing commitment to patients and caregivers, working collaboratively to understand their needs, amplify their voices and drive meaningful progress.

Our 2026 Annual Impact Summary brings together the achievements, partnerships and initiatives that demonstrate this commitment in action, highlighting both the measurable outcomes of our work and the real experiences behind the numbers.

Connect

Foster connections within the healthcare community

229 Patient organisations engaged

148 Connection points between patient communities and Sobi leaders

43 Patient Council meetings

111 Community members involved in Council meetings

7 Managed Access Programmes in place

More than **30** countries reached across managed access programmes

80% new protocols with patient input heard

1 Humanitarian programmes in place

1

Nurture

Nurture meaningful partnerships with patient stakeholders

164 New expert patients supported

580 Educational materials and projects produced

More than **one million** views, visits, downloads and digitally trackable indicators

1 Acquisition accompanied by a clear patient engagement plan

100% Newly hired employees at a global level recruited through interviews that include patient acumen assessments

All Global and Local Transfer of Value reports published within prescribed timelines

2

Collaborate

Collaborate to address unmet needs and improve patient outcomes

191 Co-created materials, programmes and events

33 Shared decision-making co-created solutions

3 New real-world evidence studies designed with patients or executed involving patient organisations

3

Innovate

Innovate to enhance the lives of people with rare diseases

25 Innovative initiatives, solutions and devices

23 Innovative awareness campaigns

4

*Based on cross-functional and cross-geography Sobi metrics collection as per Unite4Rare co-created KPIs.

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Beyond the numbers

Bringing impact to life through qualitative storytelling

Patient voices shaping clinical protocols

During the co-design of clinical protocols, patient perspectives helped inform decisions to reduce the burden of study participation. An example among others: while co-shaping the protocol patients challenged the requirement for four kidney biopsies in a Rare Kidney Disease trial, leading to a reduction to three, lessening the impact on participants' daily lives.

Humanitarian Aid Programme for Haemophilia

As one Founding Visionary Contributor to the World Federation of Haemophilia (WFH) Humanitarian Aid Programme, Sobi help improve access to treatment for people who might otherwise receive little or no care.

Since the programme began, more than 22,800 people have been reported treated, with one billion international units (IU) of factor replacement therapies donated. In 2025, support included treatment for more than 15,400 acute bleeds and over 480 surgeries.

Beyond providing medicines, the programme supports national member organisations and healthcare teams in underserved countries, helping build local expertise and strengthen access to ongoing care.

Strengthening haemophilia care in Trinidad and Tobago

Through Sobi's involvement in the World Federation of Haemophilia (WFH) Humanitarian Aid Programme, we are helping improve access to haemophilia care in Trinidad and Tobago.

During a visit, the team met a young boy who had needed a wheelchair for a year following an untreated bleed. After starting preventive treatment through the programme, his mobility improved, with specialised physiotherapy supporting his recovery.

The team also met local healthcare professionals and the patient association to understand gaps in services and identify training and advocacy opportunities. This work supports the programme's goal of building local expertise and sustainable haemophilia care.

Recognition of our Commitment

2026 Made with Patients Award

Unite4Rare received the 2026 *Made with Patients Award* for systematic meaningful patient engagement, recognising its commitment to collaboration with patients and caregivers.

With 242 nominations received and 21 finalists identified as a whole.

No. 1 in Rare Diseases — Two Consecutive Years

In the PatientView 2025/2026 Rare Diseases report**, Sobi was ranked No. 1 for the second consecutive year, based on feedback from 502 patient organisations across 63 countries.

Sobi also ranked No. 1 across six key areas: patient centricity, patient group relationships, services beyond the pill, patient information, access to medicines and integrity.

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**PatientView. (2026). Corporate Reputation of Pharma 2025/26: Rare Diseases Edition.

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