

# Unite **4** Rare™

## Sobi's commitment to patients and caregivers

Co-created by internationally renowned patient community leaders and senior leadership within Sobi

# Introduction

Meaningful patient engagement in rare diseases is inherent to Sobi's DNA. We have a long history in ensuring people living with rare diseases and their families can receive the life-saving care and therapies they need and that their voices are heard.

This remains central to the vision of Sobi: to be recognised as a global leader in providing innovative treatments that transform lives of individuals with rare diseases.

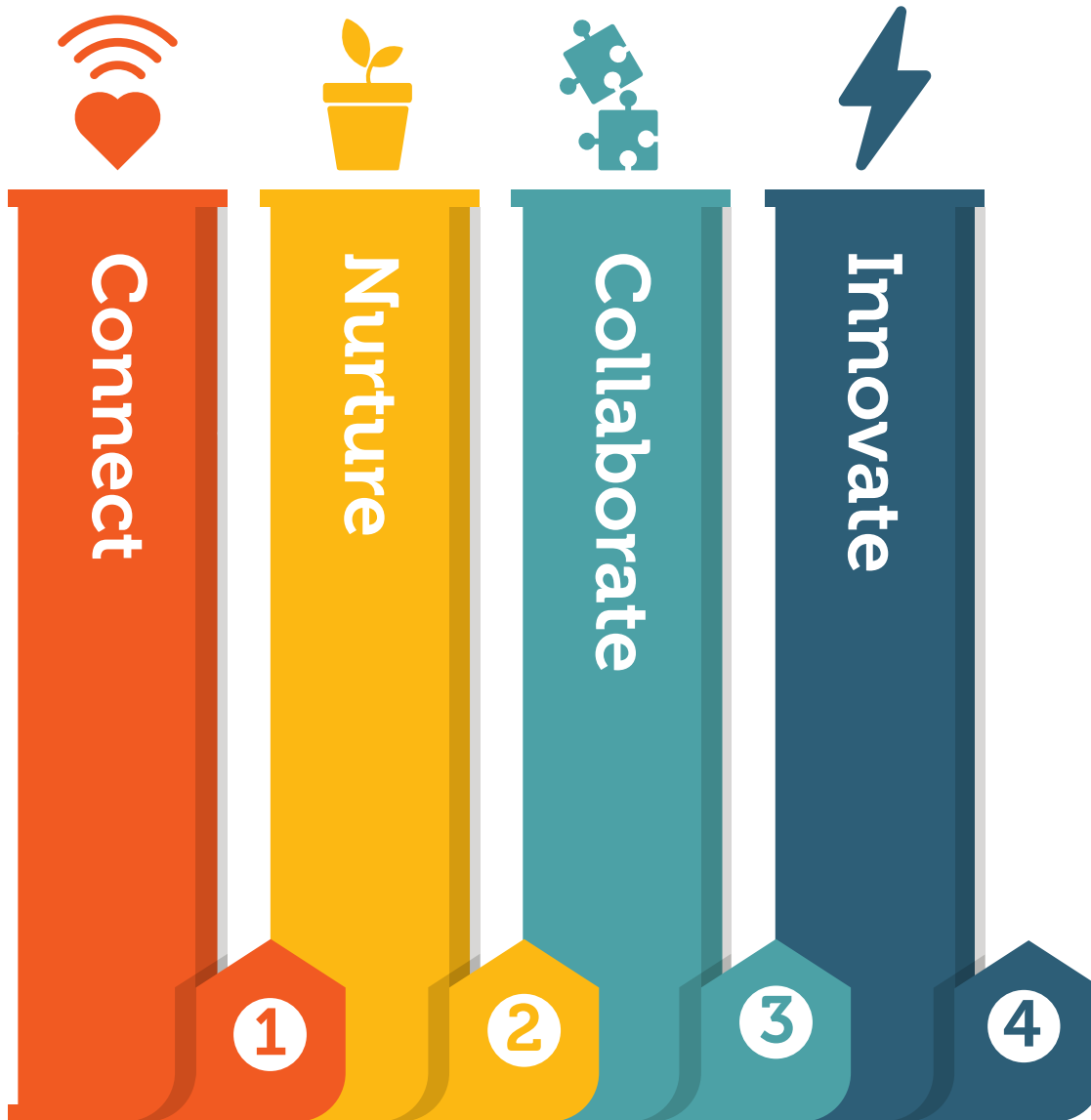
Unite4Rare builds on Sobi's history of specialised expertise in rare diseases and commitment to patient engagement, taking it to the next level. Unite4Rare articulates our recognition and respect for the genuine and fundamental contribution of people living with rare diseases and carers in achieving our vision.

Unite4Rare is underpinned by five core values that reflect our approach to meeting the needs of people living with rare diseases who are otherwise often overlooked: Care, Ambition, Ownership, Urgency and Partnership.

They are inherent to our pursuit of excellence and creating a patient-partnered culture across the company.



## Unite4Rare Patient Commitment Pillars



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We are dedicated to maintaining transparent communication and will consistently share feedback as we implement Unite4Rare in practice.

We are proud of the progress we are making, building on our solid foundation in patient engagement and are excited to be able to accelerate and demonstrate this through the Unite4Rare commitment to patients and carers.



# Unite4Rare

## Sobi's Commitment to Patients and Caregivers



**1: Connect**



**2: Nurture**



**3: Collaborate**



**4: Innovate**

Pillar 1: **Connect** 

# Pillar 1: **Connect**

Disease Awareness

## **CONNECT Patient Organisations with Communities**

### **What we commit to**

#### **CONTINUE DOING:**

We commit to continue to engage with and support rare disease patient communities through ongoing dialogue with patient organisations, enabling them to develop meaningful activities and disseminate education and materials effectively to their patient communities, to enhance understanding of diseases, care approaches and to foster accurate diagnosis.



1. Sobi. Annual and Sustainability Report 2022. Available at: <https://www.sobi.com/sites/default/files/pr/202303312874-1.pdf>.
2. Sobi. Interactions with Patient Organisations 2023. Available at: <https://www.sobi.com/sites/sobi/files/2024-06/Interactions%20with%20Patient%20Organisations%202023.pdf>.
3. Sobi. Patient Centricity and Engagement. Available at: <https://www.sobi.com/en/patient-centricity>.

# Pillar 1: **Connect**

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## Patients as Equal Contributors **CONNECT Patients with Leadership**

### What we commit to

#### CONTINUE DOING:

We commit to continue to foster dialogue at patient council level in haemophilia, immune thrombocytopenia (ITP), paroxysmal nocturnal haemoglobinuria (PNH), diffuse large B-cell lymphoma (DLBCL), rare kidney diseases and all new disease areas, to inform strategic approaches and tactical plans at a global and local level.

#### START DOING:

We commit to ensuring that the patient voice is heard at all levels of the organisation and that patient needs are central to our decision-making process. We commit to gathering patient input, either directly via members of the patient community or indirectly by bringing their voice into the company via a patient engagement function.

1. Sobi. Annual and Sustainability Report 2022. Available at: <https://www.sobi.com/sites/default/files/pr/202303312874-1.pdf>.
2. Sobi. Patient Voice Central to our R&D. Available at: <https://www.sobi.com/en/news-releases/patient-voice-central-our-rd>.

# Pillar 1: **Connect**

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## Access Programmes **CONNECT Patients with Treatments**

### What we commit to

#### CONTINUE DOING:

We commit to continue working closely with healthcare providers, patient organisations and regulatory authorities to enable us to make our therapies available to those who can benefit from them, connecting efforts to break down geographic, economic and social barriers.

#### START DOING:

We commit to streamlining access to treatments, including exploring and collaborating with healthcare providers to ensure timely and efficient delivery of therapies.

1. Nature. Leading the Way in Rare Disease. Available at: <https://www.nature.com/articles/d43747-020-00680-6>.
2. Sobi. Expanded Access to Treatment. Available at: <https://www.sobi.com/en/access-treatment>.

# Pillar 1: **Connect**

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## Clinical Trials

# CONNECT Patients with Clinical Development

## What we commit to

### CONTINUE DOING:

When we perform in-house clinical trials, we commit to continue to ensure that our protocols are patient-centred, patient views are heard and communication around trials is systematically provided in a transparent and patient-friendly way. We commit to reinforcing feedback loops on inputs received from the patient community.

### START DOING:

In phases of clinical research not directly or fully owned by Sobi, we commit to putting our efforts into making information available and catalysing connections to foster inclusion of patients in existing clinical research.

1. Sobi. Patient Voice Central to our R&D. Available at: <https://www.sobi.com/en/news-releases/patient-voice-central-our-rd>.
2. Sobi. Clinical Treatments. Available at: <https://www.sobi.com/en/stories/clinical-studies>.

# Pillar 1: **Connect**

## Humanitarian Programmes **CONNECT Patients to Better Healthcare**

### **What we commit to**

#### **CONTINUE DOING:**

We commit to continue supporting patient organisations and other credible partners which run humanitarian aid programmes in the field of health, demonstrating Sobi's dedication to improving healthcare access and empowering patients.

Our support in the World Federation of Hemophilia Humanitarian Aid Program is just one example of our current involvement in humanitarian programmes that make a positive impact on global health.



1. Sobi. Annual and Sustainability Report 2022. Available at: <https://www.sobi.com/sites/default/files/pr/202303312874-1.pdf>.
2. Sobi. Humanitarian Aid. Available at: <https://www.sobi.com/en/humanitarian-aid>.

# Pillar 2: Nurture

## Pillar 2: Nurture

### Capability Building **NURTURE Capabilities**

#### What we commit to

#### CONTINUE DOING:

We commit to continue supporting patient education through recognised patient-driven entities, thus elevating their role and their interactions with other stakeholders.



## Pillar 2: Nurture

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### Trusted Education Source **NURTURE Education**

#### What we commit to

##### CONTINUE DOING:

We commit to continue creating and providing rigorous information about our products to the scientific community and to enable knowledge-sharing with people living with rare diseases in a clear and accessible way.

##### START DOING:

We commit to developing even more patient-centred and comprehensive unbranded educational resources for patients and caregivers, focusing on disease and/or its management, patient needs and lifestyle considerations, through co-creation with the patient community, to make a difference for individuals with rare diseases.

## Pillar 2: Nurture

### Patient Engagement in Acquisitions and People Processes **NURTURE Patient-Driven Models**

#### What we commit to

##### CONTINUE DOING:

We commit to continue acknowledging and developing the patient engagement dimension of acquisitions, reaching out to patient organisations and communities as early as we can.

We will continue to implement processes to train all employees (including managers) on patient-centred communication, empathy and understanding.

##### START DOING:

We commit to actively seeking patient expert input in the development and delivery of our programmes, by leveraging technology to facilitate ongoing communication and feedback in every new acquisition. Furthermore, we are committed to providing educational resources and personalised support services to empower people living with rare diseases and enhance their treatment journey in our newly-acquired disease area fields. By embedding this patient-centric approach in our acquisition strategy, we strive to drive innovation, improve patient outcomes and, ultimately, transform lives.

## Pillar 2: Nurture

### Continuous Transparent Communication **NURTURE Relationships with the Patient Community**

#### What we commit to

##### CONTINUE DOING:

We commit to continuing transparent, structured and impactful dialogue with patients and patient organisations in rare diseases throughout the patient journey and the medicine lifecycle, in alignment with Sobi's business model and its focus on patient benefits, sustainability and societal impact. We commit to respect the voices and independence of patient organisations, with integrity and in full compliance with laws and industry rules.

##### START DOING:

We commit to acknowledging and further addressing the needs of caregivers as they play a crucial role in patient care. We commit to co-create educational materials, facilitate access to support networks and ensure caregiver voices are heard.

# Pillar 3: Collaborate

## Pillar 3: Collaborate

### Define and Deliver on Shared Objectives **COLLABORATE and Co-create**

#### What we commit to

##### CONTINUE DOING:

We commit to continuing our transparency in current and future partnerships with patients and to co-creating based on priorities and challenges of different patient communities in a mutually respectful, equitable manner.

##### START DOING:

We commit to involving patient experts as early as Sobi's business model allows it. We commit to acknowledging, respecting and valuing the knowledge and expertise that patient experts bring to the table in the co-creation process.

We commit to evaluating and adapting our approach to patient expert co-creation on an ongoing basis, striving for continuous improvement.

## Pillar 3: Collaborate

### Informed Decision-Making (IDM)

## COLLABORATE to Improve Dialogue and Outcomes

### What we commit to

#### CONTINUE DOING:

We commit to continue fostering patient-healthcare professional dialogue, education and a decision-making process that prioritises patients' real needs and goals.

We continue to advocate for IDM in all aspects of our work, ensuring that people living with rare diseases are active participants in discussions where shared decisions about their care are made.

#### START DOING:

We commit to creating more opportunities for open, constructive dialogue with the patient community, seeking their input and feedback on a regular basis.

# Pillar 3: Collaborate

## Patient Engagement and Experience Data **COLLABORATE on Real-World Evidence**

### What we commit to

#### CONTINUE DOING:

We commit to continuing engagement with health systems and patient communities to jointly collect patient experience data to embed the goals and outcomes that matter to patients as we develop therapeutic solutions and support.

1. Building a Community of Hope | INTO HLH Registry.
2. Avatrombopag treatment response in patients with immune thrombocytopenia: the REAL-AVA 1.0 study - PubMed (nih.gov).
3. Pazienti consapevoli - DevelopAKUre per AKU - EUPATI Toolbox.
4. Patient preferences and experiences regarding thrombopoietin-receptor agonists for immune thrombocytopenia in the United Kingdom and Ireland (TRAPeZe UK & IE study) - PubMed (nih.gov).
5. The burden of illness of patients with paroxysmal nocturnal haemoglobinuria receiving C5 inhibitors in France, Germany and the United Kingdom: Patient-reported insights on symptoms and quality of life - PubMed (nih.gov).



# Pillar 4: **Innovate**

# Pillar 4: Innovate

## Innovate Education and Awareness **INNOVATE to Spread Awareness**

### What we commit to

#### CONTINUE DOING:

We commit to continue supporting innovative disease awareness campaigns, optimising the use of new technologies to improve disease management and patient outcomes in rare diseases.

**Definition:** *Innovation is the creation or improvement of solutions that leverage patient insights and technology to address unmet needs. It reflects new ways of thinking that enhance value and expand potential, shaping approaches that have not previously been seen at Sobi or more widely.*



1. Nature. Leading the Way in Rare Disease. Available at: <https://www.nature.com/articles/d43747-020-00680-6>.
2. Milano Finanza. Via alla campagna di sensibilizzazione Sobi 'What AI feel'. Available at: <https://www.milanofinanza.it/news/via-alla-campagna-di-sensibilizzazione-sobi-what-ai-feel-202306220944557637>.

## Pillar 4: **Innovate**

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Innovate Digital Health

**INNOVATE to Improve Products and Outcomes**

### What we commit to

#### CONTINUE DOING:

We commit to continue supporting and co-creating “beyond-the-pill” innovative solutions (e.g. digital tools) based on careful assessment and prioritisation with relevant patient communities.

#### START DOING:

We commit to pioneering the next generation of digital health solutions, recognising the evolving needs of our patients and caregivers. By integrating artificial intelligence, after Privacy and Legal review, into our existing programmes, we aim to enhance further patient outcomes and transform the patient experience. Our commitment to innovation in all its guises is unwavering, and we believe this initiative will mark a significant step forward in our mission to improve lives.

# Unite4Rare Roadmap

Unite4Rare is a living Document



## Solid Commitments

These commitments will be embedded into our organisation's strategy and the hearts and minds of our people. These commitments will not change and will continually underpin how we approach meeting the needs of patients.



## Tracking Metrics

We will annually report metrics allocated to each commitment via a fact sheet, so that we are able to monitor and are accountable against our commitment goals. The metrics will be identified and calibrated on an ongoing basis cross-functionally via an internal tracking system. The functions responsible for individual commitments will also be responsible for transparent reporting, while Patient Engagement remains accountable.



## Regular Reassessment of "What we do"

We will revise the "What we have done so far" section regularly. It will be aligned with the Annual and Sustainability Report and the European Sustainability Reporting Standards (ESRS) report. This will ensure complete synergy between the three and will help to advance our commitment aims.



## Annual Validation Check-point

Members of the Sobi leadership team and the patient community will convene on an annual basis to review progress against commitments and to strategise how the organisation can continue to honour and build upon these commitments for the benefit of patient communities.

# Conclusion

We extend our appreciation and thanks to the patient community leaders at all levels involved in co-creating Unite4Rare as a living, breathing document. As we strive to implement the commitments year by year, to measure our progress carefully, and to realign as the external and internal environment evolves, we will continue to engage with leaders from the patient community in this important journey. These ongoing, valued partnerships and dialogues are vital to ensure optimal impact on patients living with rare diseases and their families.

Just as our founders began, we are committed to these partnerships and working in meaningful ways with the patient community to ensure we *provide innovative treatments that transform lives for individuals with rare diseases.*

