

Annual Disclosure of Transfers of Value to Patient Organisations

Sobi

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1. Purpose and Scope

1.1 Introduction

Sobi recognises that Patient Organisations play an essential role in representing and supporting the needs of patients and caregivers. Our interactions with Patient Organisations are a fundamental part of our commitment to being truly patient-centric, ensuring we understand patient needs and obtain valuable insights that inform the development and improvement of innovative treatments and practices.

This Methodological Note summarises the methodology and business decisions implemented by Sobi to identify, collect, and report Transfers of Value (ToVs) to Patient Organisations in accordance with the European Federation of Pharmaceutical Industries and Associations (EFPIA) Code of Practice, applicable national industry codes, and relevant international disclosure frameworks.

1.2 Commitment to Transparency

Sobi is committed to transparency in all interactions with Patient Organisations. We believe that building greater transparency in relationships between pharmaceutical companies and their partners fosters understanding and recognition of the value these collaborations bring to patient care.

Sobi voluntarily adheres to the EFPIA Code of Practice and is a member of/adheres to the codes of the following national associations: ABPI (UK), LIF (Sweden), SFEE (Greece), FarmaIndustria (Italy) etc.

1.3 Regulatory Framework

This disclosure is made in compliance with:

- **EFPIA Code of Practice** (Article 24): Governing disclosure of support and services provided to Patient Organisations in European countries covered by EFPIA Member Associations
- **National Industry Codes**: Including ABPI Code (UK), Mdeon (Belgium), Code de la Transparence (France), FarmaIndustria (Italy), etc.
- **Non-European Disclosure Requirements**: Sobi also discloses ToVs to Patient Organisations in the following non-European countries where we operate and voluntarily adhere to disclosure requirements or are members of relevant industry associations: e.g., JPMA (Japan), Medicines Australia, etc.

2. Definitions

2.1 Patient Organisation (PO)

A not-for-profit legal person or entity (including umbrella organisations to which it belongs), mainly composed of patients and/or caregivers, that represents and/or supports the needs of patients and/or caregivers, and whose business address, place of incorporation, or primary place of operation is in Europe or another country covered by this disclosure.

Whenever possible, Sobi ensures that each Patient Organisation is referred to in such a way that there is no doubt as to the identity of the organisation benefiting from the Transfer of Value.

2.2 Transfer of Value (ToV)

A Transfer of Value means any direct or indirect transfer of value, whether in cash, in kind, or otherwise, made in connection with the development and commercialisation of prescription medicines. For Patient Organisations, ToVs include:

Category	Description	Examples
Financial Contributions	Direct monetary support provided to Patient Organisations	Donations, charitable contributions, educational grants, unrestricted grants
Sponsorship	Financial or in-kind support for events, meetings, or activities organised by Patient Organisations	Event sponsorship, meeting support, conference sponsorship, speaker sponsorship
Fees for Contracted Collaborations/Services	Payments for services rendered by Patient Organisations under a written agreement	Consultancy services, advisory services, patient insight gathering, patient advocacy services
In-Kind Contributions	Non-monetary support where the value can be meaningfully quantified	Venue hire, catering, audio-visual equipment, translation services
Non-Financial Support	Non-monetary support that cannot be assigned a meaningful monetary value	Provision of expertise, secondment of personnel

2.3 Direct vs. Indirect Transfers of Value

- **Direct ToV:** Transfers of Value made directly by Sobi to a Patient Organisation
- **Indirect ToV:** Transfers of Value made by Sobi through an intermediary (third party) on behalf of Sobi, where the Patient Organisation can be clearly identified as the beneficiary

- **Cross-Border ToV:** Transfers of Value made by a Sobi affiliate in one country to a Patient Organisation located in another country. Cross-border ToVs are disclosed in the country where the Patient Organisation's headquarters is located.
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3. Reporting Period and Timing

3.1 Reporting Period

The reporting period covers a full calendar year (1 January to 31 December) immediately preceding the year of publication. ToVs are handled according to the **cash basis principle**; a specific ToV is registered when the payment is made or the benefit is conferred.

3.2 Timing of Disclosure

In accordance with EFPIA requirements:

- Disclosures are published **within 6 months** after the end of the relevant Reporting Period (i.e., no later than **30 June** of the following year)
 - Disclosed information remains in the **public domain for a minimum of 3 years** after initial publication
 - Sobi maintains internal records of disclosures for a minimum of **5 years** after the end of the relevant Reporting Period
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4. Geographical Scope

4.1 European Countries (EFPIA Member Association Countries)

Sobi discloses ToVs to Patient Organisations in all European countries where EFPIA Member Associations' National Codes apply and where Sobi has business operations or has made ToVs.

4.2 Non-European Countries

For non-EFPIA countries, Sobi makes its best efforts to collect and disclose direct ToVs made by Sobi affiliates.

4.3 Affiliate Coverage

ToVs disclosed include those made by all Sobi subsidiaries and affiliates providing support to Patient Organisations. Each affiliate that provides support to a Patient Organisation is reported as a "funding entity" throughout the disclosure report and is accountable for the disclosure of the corresponding ToV.

5. Patient Organisations Covered

5.1 Inclusion Criteria

The disclosure includes all Patient Organisations to which Sobi provides:

- Financial support (donations, grants, sponsorships)
- Significant indirect or non-financial support
- Contracted services

To be included in the disclosure, a Patient Organisation must:

- Be a not-for-profit legal entity
- Be mainly composed of patients and/or caregivers
- Represent and/or support the needs of patients and/or caregivers
- Have its business address, place of incorporation, or primary place of operation in a country covered by this disclosure

5.2 Exclusion Criteria

The following are **not** included in this disclosure:

- For-profit entities
- Individual patients not representing a Patient Organisation
- General charitable organisations not primarily focused on patient representation or support

6. What Is Disclosed and What Is Not

6.1 Disclosed Information

For each Patient Organisation receiving support or providing contracted services, Sobi discloses:

For Support (Donations, Grants, Sponsorships):

- Name of the Patient Organisation
- Monetary value of financial support and invoiced costs (in local currency)
- Non-monetary benefit received when non-financial support cannot be assigned a meaningful monetary value
- Description of the nature of support or services provided

For Contracted Services:

- Name of the Patient Organisation
- Total amount paid per Patient Organisation over the Reporting Period (in local currency)
- Description of the nature of services provided that is sufficiently complete to enable the average reader to form an understanding of the nature of the support or the arrangement without the necessity to divulge confidential information.

7. Data Collection and Verification Process

7.1 Data Capture

Sobi has established internal systems and processes to ensure accurate and complete capture of all ToVs to Patient Organisations:

- ToVs are captured through Sobi's financial and contract management systems
- Each Sobi affiliate is responsible for capturing ToVs made to Patient Organisations and validating the accuracy of the data
- A centralised reporting solution consolidates ToVs across affiliates, ensuring consistency and enabling cross-border allocation

7.2 Data Validation

Before publication, ToV data undergoes a multi-level validation process:

1. **Local Affiliate Review:** Each affiliate reviews and validates its ToV data for accuracy and completeness
2. **Central Consolidation:** Data is consolidated centrally to ensure cross-border ToVs are appropriately allocated and duplications are eliminated

7.3 Record Retention

Sobi maintains relevant records of all disclosures for a minimum of 5 years after the end of the relevant Reporting Period, in compliance with EFPIA requirements and applicable local regulations.

8. Currency and Exchange Rates

8.1 Reporting Currency

ToVs are reported in **local currency** (i.e., the currency of the country where the Patient Organisation is located).

8.2 Currency Conversion

Where a ToV is made in a currency different from the local currency of the Patient Organisation's country:

- The ToV amount is converted to the local currency prior to publication
- Sobi applies [standard corporate exchange rates / exchange rates as of the date of payment / average exchange rates for the Reporting Period] for currency conversion

9. Corrections and Updates Policy

9.1 Post-Publication Corrections

Sobi is committed to ensuring the accuracy of disclosed information. If errors or omissions are identified after publication:

- Corrections will be made as soon as practicable
- Material corrections will be documented and the corrected disclosure republished
- Sobi commits to resolving disputes and republishing corrected data within 30 days of receiving notification of a dispute

9.2 Refunds and Credit Notes

- If Sobi processes a refund equivalent to an initial payment made to a Patient Organisation, neither transaction will be recorded since no actual value was transferred
 - If a refund is issued for a payment made in a year already published, the refunded amount will be subtracted from the Patient Organisation's total disclosed ToV in the upcoming year
 - If a Patient Organisation received no payment in the succeeding year, the disclosure report may display a negative value for that organisation
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10. Publication

Disclosure Platforms

All interactions with Patient Organisations are made public through:

- **Sobi Global Website:** www.sobi.com
 - **Country-specific Sobi websites:** Where required by local codes or laws
 - **Centralised Industry Platforms:** In certain countries (e.g., [list countries with central platforms, such as Belgium, UK, Sweden, etc.]), data is disclosed via centralised platforms operated by national industry associations
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11. Contact Information

For questions or concerns regarding this Methodological Note or Sobi's disclosure of Transfers of Value to Patient Organisations, please contact:

Sobi Transparency Office / Compliance Department

Website: www.sobi.com

This Methodological Note is reviewed and updated annually in conjunction with the publication of the ToV report to reflect the latest reporting methodology and any changes in applicable codes or regulations.

