

# UCB Patient Organisations Methodological Note

## Pursuant to Chapter 5 of the EFPIA Code of Practice

*This note describes the global position from UCB with regards to the EFPIA Code of Practice disclosure requirements to Patient Organisations. It is subject to change in each country affiliate depending on the local laws and requirements of the local industry code*

### INDEX:

- 1. Context**
- 2. Definitions**
- 3. Patient Organisations disclosure**

## 1. Context

Patients, their representatives and their caregivers, medical professionals and organisations can offer invaluable knowledge on patients' needs, behaviour and management of diseases. Engaging with such healthcare stakeholders is therefore essential for UCB and other pharmaceutical companies to improve patient care and treatment and has long been a positive driver for advancements in innovative medicine and patient value creation.

In UCB, we believe that the interest of patients and other stakeholders in the transparency of these interactions is compelling.

We are dedicated to demonstrating complete integrity and honesty in our relationships with healthcare stakeholders, including patient organisations, healthcare professionals and organisations such as hospitals. Those interactions, initiated for proper, scientific reasons, unrelated to any purchases, prescriptions, or distribution of our products by those healthcare professionals or to their position, may be related to transfers of values, whether in kind or in cash.

Such financial relationships should occur without potential conflicts of interest and be fully independent of the clinical decisions. Patients need to know that they can trust their doctor to recommend, prescribe and administer appropriate care and treatments based solely on clinical evidence and experience. UCB recognizes its responsibility in supporting a fair and open partnership and protecting the high standards of integrity that patients, governments and other stakeholders expect.



As an EFPIA Member Company, UCB is dedicated to complying with the disclosure of transfer of value requirements and is ensuring that our policies continue to align with the industry standards in all the countries where we operate. On an annual basis and as from 2016, UCB is making publicly available details of transfers of value made to Patient Organisations during the previous calendar year.

This note describes UCB's general methodology used to prepare the disclosure report of the Patient Organisations in accordance with the EFPIA requirements. It is subject to changes in each country affiliate depending on the local laws and requirements of the local industry code. These variations will be specified in the local methodological notes linked to country reports.

We hope that this enables public scrutiny and understanding of these relationships, and therefore contribute to the trust of stakeholders and patients in the pharmaceutical industry.

## 2. Definitions

According to the EFPIA Code of Practice, a Patient Organisation (PO) is defined as a non-for-profit legal person/entity (including the umbrella organisation to which it belongs), mainly composed of patients and/or caregivers, that represents and/or supports the needs of patients and/or caregivers and which business address, place of incorporation or primary place of operation is in Europe.

A PO representative is a person who is mandated to represent and express the collective views of a PO on a specific issue or disease area.

Transfers of Value (ToV): Direct and indirect ToV, whether in cash, in kind or otherwise, made, whether for promotional purposes or otherwise, in connection with the development and sale of POM exclusively for human use. *Direct ToVs* are those made directly by a Member Company for the benefit of a Recipient. *Indirect ToVs* are those made on behalf of a Member Company for the benefit of a Recipient, or those made through a Third Party and where the Member Company knows or can identify the Recipient that will benefit from the Transfer of Value.

## 3. Patient Organisations disclosure

UCB is committed to operate with the highest ethical standards and to ensure transparency on engagement with Patient Organisations and associated transfers of value.

Every year UCB discloses a list of POs to which it provides financial support and/or significant indirect/non-financial support, or POs engaged to provide contracted services.

Reports will remain available online for a period of three years.

The UCB Patient Organisation disclosure report includes:

- Full Name of Patient Organisation
- Full Address of Patient Organisation
- Brief Description of the Nature of Support Provided
- Financial Support (transfer of money directly to Pat.Org)

- Financial Support for contracted services (transfer of money to Pat.Org. for Ad. Board, Speaker activities etc.)
- Non-financial invoiced Support (transfer of money to 3rd party: e.g. print shop, for benefit of Pat Org.)
- Non-Financial non invoiced Support (short description of benefit in kind for activities organized by Pat. Org. e.g. meeting room at UCB premises)
- Country where project/activity took place or Country where Pat. Org. has main European location