

Code of Practice Between the International Prader-Willi Syndrome Organisation (IPWSO) and the Healthcare Industry

Adopted by IPWSO on 22 February 2021

Introduction

IPWSO's mission is to unite the global Prader-Willi syndrome (PWS) community to collectively find solutions to the challenges of the syndrome and to support and advocate for people with PWS and their families, PWS associations, and professionals who work with people with PWS.

Key to IPWSO's work is cooperative engagement with diverse stakeholders in the interest of people with PWS and their families. These stakeholders will include healthcare industry sources, which are defined as commercial manufacturers of healthcare products, devices and services, including distributors and wholesalers.

This Code, which is based on the guiding principles identified by EURORDIS¹, seeks to guide relations between IPWSO and industry sources and to enable IPWSO to act in a fully democratic, independent and transparent manner, according to the highest standards of good governance.

1.1 Funding of IPWSO activities

IPWSO will only accept funds for activities that are consistent with its mission and objectives. IPWSO will publicly declare its funding sources by means of its annual report and website. This will include identifying the percentage of its funding received from healthcare industry sources and identifying the healthcare industry source that provided the largest amount of funding to IPWSO during each year.

1.2 Core funding

Funds for core IPWSO activities will only be accepted on an unconditional basis. To avoid undue reliance on any particular company, such funds will be balanced and diversified as much as possible to avoid conflicts of interest and guarantee independence.

1.3 Project funding

Funds or sponsorships for projects will only be accepted without any conditions imposed on the design and conduct of the project. IPWSO may decide to publish research findings in academic journals or other external fora. Any other ensuing publications will be the property of IPWSO and findings may not be used or quoted by a funder without the explicit

permission of IPWSO. No information in relation to a project should ever be used to promote the use of any specific product or business of a funder.

1.4 Funding of events

IPWSO may accept funds, sponsorship or assistance in kind for its own events. Funding should ideally come from more than one source, though it is recognised that this will not always be possible.

Sponsors will not be permitted to exercise any control over the programme content or choice of speakers at IPWSO events.

1.5 Funding of communication activities

IPWSO will mention the names of any sponsors supporting its website or electronic materials. Sponsor logo size and the space dedicated to the mention of the company on the website will be modest in size to avoid being perceived as an advertisement.

1.6 Involvement with industry sourced websites, publications or leaflets.

IPWSO will not accept funding for activities aimed at promoting the use of any specific product and/or service. IPWSO may contribute to the production of material that relates to the management of PWS but will endeavour to ensure that no specific product or other treatment can be perceived to be recommended by IPWSO.

2. IPWSO INVOLVEMENT IN HEALTHCARE INDUSTRY ACTIVITIES

IPWSO will reflect on the issues identified below before becoming involved in healthcare industry activities.

2.1 Promotional activities related to approved prescription medicines

IPWSO will endeavour to ensure that none of its activities can be associated with promotional activities by healthcare industry sources. Events involving genuine interaction/cooperation (e.g. satellite symposiums) may take place, provided these are in no way promotional. IPWSO will be mindful of potential conflicts and unintended consequences and strictly adhere to its own independent patient-centred agenda.

IPWSO will avoid the following activities that might be considered promotional and therefore might cause a conflict of interest and be against the law:

- Disseminating unbalanced, non-validated or partial information about a product/service which is produced, marketed or provided by a company, whether it funds IPWSO or not;
- Being quoted in the company's corporate communication in favour of, or against a product;
- Participating as a speaker/ participant in a company event for the launch of a pharmaceutical product;
- Participating in an ad hoc meeting sponsored by a single company to inform patients on their products;
- Agreeing that a company displays/disseminates IPWSO's own materials at the company's exhibition stand at any commercial or trade exhibition or scientific conference;
- Appearing in promotional materials for a certain product of the company (eg. booklets about a specific medicine) or to testify as a consumer of that medicine. Contact information for IPWSO can be included in a separate section.

When working in individual countries IPWSO will investigate what other activities might be considered promotional under national legislation before accepting funding from healthcare industry sources.

2.2 Industry press releases

- IPWSO will be vigilant and refuse to be quoted in industry press releases that relate to a marketed product or a product under development.
- If IPWSO feels the need to communicate to the media about a product, it will issue its own press release which is clearly independent of industry.
- If a company quotes IPWSO's opinion or refers to IPWSO's own communication materials (magazines, publications, web site etc.) without IPWSO's written permission, IPWSO will object to the company and may copy any appropriate body – e.g. a national industry association.

2.3 Training organised by industry or a group of companies

If commercial sponsors offer to provide IPWSO with training and capacity building programmes, either about general themes such as "Diseases and the Media", "Management of a NGO", or on more product related themes such as "Drug Regulatory Process", "Cost/effectiveness studies for pricing and reimbursement", or "How to lobby", IPWSO will

bear in mind that these programmes may influence its way of thinking. IPWSO will consider the following points before deciding whether to participate in such training programmes:

- Is the programme sponsored by several companies, instead of a single one?
- Have patient organisations/representatives been involved in the preparatory phase of the training programme?

Where possible, IPWSO's preference will be to find an equivalent programme run by other NGOs or academic institutions and ask the company to sponsor its participation.

2.4 Participation in conferences or seminars held by industry

- If IPWSO participates in an industry launch/promotion of a product, no photographs must be taken or released without prior authorisation from the person/s involved. For clarity and to avoid future complications, IPWSO will seek to make arrangements in writing before the event.
- If an IPWSO representative participates in an ad hoc meeting sponsored by a single company to inform patients about their products, the IPWSO representative should insist that multiple sources of information from independent third parties are involved to ensure that the information is balanced.

2.5 Guidance for individual compensation

There are several situations where industry may propose honoraria to IPWSO volunteers or staff members:

- Participation in a meeting or conference organised by the company itself;
- Participation in a meeting or conference organised by a third party;
- Reviewing industry materials, leaflets, protocols etc.;
- Consultancy on industry policy, advisory committees etc.

This is current practice for health care professionals. Patient organisations should be considered on an equal basis, and therefore can also receive honoraria for similar circumstances. IPWSO's internal policy on Conflicts of Interest outline how honoraria should be recorded and what to do in the event of a conflict or perceived conflict of interest.

2.6 Involvement in industry-source web sites or other material (DVDs, printed material, etc)

IPWSO will refrain from contributing to industry websites.

2.7 Disease awareness campaigns by industry

Disease awareness campaigns can be considered as an indirect form of advertising in some countries and therefore may be against national legislation.

Before getting involved in such campaigns IPWSO will endeavour to ensure that any such campaign is not only an industry initiative, but responds to a well characterised public health need, that is agreed and supported by the national and/or other relevant public health authorities.

2.7.1 PWS awareness campaigns by IPWSO

When conducting its own awareness campaigns, IPWSO will ensure that any information regarding a commercial product mentioned by it must be based on the Summary of Product Characteristics (SmPC) or another commercially independent and validated source. This information can be made available by IPWSO, provided the following conditions are observed:

- Clear statement of how the information was arrived at;
- Mention of the validated source of information;
- Mention of health professionals / independent experts who have been consulted;
- Identification of the Editorial Board who has control, responsibility and oversight;
- Full disclosure of IPWSO funders.

2.7.2 Industry's editorial responsibility

Commercial organisations wishing to mention the name of IPWSO should seek prior written authorisation from IPWSO.

3. CLINICAL TRIALS

This Code of Practice should be read in conjunction with IPWSO's Policy on Clinical Trials.

ⁱ <https://www.eurordis.org/sites/default/files/thumbnails/0904-PO-Code%20of%20practice.pdf>