

# Toolkit for patients' organisations

**Collaborative initiative to support groups in developing effective relationships with key stakeholders**

## BACKGROUND

**The International Alliance of Patients' Organisations (IAPO), a global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world, worked in partnership with the global pharmaceutical company Novo Nordisk and the independent healthcare communications consultancy Pope Woodhead (PW) to produce a free innovative toolkit for patient organisations (POs).**

## CHALLENGE

POs represent and support patients, their families and carers. They have a key role in raising disease awareness and promoting patient-centred healthcare and are powerful and effective lobbying partners. As healthcare is influenced by multiple stakeholders, patient organisations often need to collaborate effectively with other partners to fulfil their mission. Through these collaborations, they help all healthcare stakeholders to understand patients' perspectives, needs, issues and expectations relating to their health, disease and management.

However to ensure credibility, all collaborations must be clearly defined, ethical, transparent, legally compliant, and maintain the independence and accountability of all parties. Furthermore, internationally, POs vary considerably in structures, roles, remits and resource levels. Many are staffed by volunteers and/or patients who may not have the knowledge, skills or experience to help build their infrastructure or communicate with external partners.

IAPO and Novo Nordisk identified a need for appropriate materials to support POs in developing effective and compliant interactions with the different stakeholder groups.

## SOLUTION

PW was engaged as an independent facilitator, to help identify the needs of the various POs, and to translate these into a user-friendly toolkit with materials that could be adapted at a local level.

In-depth research was carried out to clarify POs' challenges related to working with external stakeholders (including industry) and to identify common practices, existing resources, examples of best practice and specific needs. This helped to define the content of the toolkit, the appropriate terminology, and the tone and level of materials required.

IAPO shared its experience of POs' needs to steer the development and content of the toolkit. While the content was developed by PW, IAPO had full editorial control. Plus, in addition to introducing the toolkit to its member

organisations, IAPO made it available free to all via its website. Novo Nordisk supported and funded the project as part of its ongoing commitment to assist POs.

## RESULTS

The result was a kit called 'Working with partners and stakeholders'. It contains advice, guidance, best practice and links to other sources that support POs in developing effective, long-term relationships with key stakeholders while retaining their independence. Included in this is clear guidance for working with industry stakeholders. The toolkit also provides tips and information to help with some of the challenges that can occur when working with external partners, such as maintaining independence and dealing with public scrutiny.

Additionally, there are materials and templates which can be easily adapted by POs. The content is designed to assist organisations in developing their infrastructure and capabilities, as well as guidance on core skills and activities. Areas covered include raising disease awareness, advocacy, strategic planning, fundraising and effective communication.

The kit is available via IAPO's website in interactive flash format. The font size, colours and layout were carefully selected for the target audience. The visually impaired were also considered as each page can be opened as a PDF document so that computer audio screen readers and screen magnifiers can be used to access the information. IAPO invited member organisations to attend face-to-face training seminars run by PW. In addition, PW provides online training and a support service for anyone with specific queries or issues.

It is already proving very popular; in the first eight weeks following launch, people from 21 countries accessed it via the IAPO website. Furthermore, in the first three weeks of July the toolkit webpage had over 149 hits.

Feedback from users has been positive. The following comment is just one example of the many enthusiastic responses received from POs about the toolkit: "Thank you very much for this wonderful toolkit. It will help us from reinventing the wheel time and again and give us a concrete way forward," which came from a national umbrella PO. Based on this encouraging feedback, an evaluation is planned to determine the level of usage and to identify specific areas for further development.

## The Author

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