



Practical guide

**For PHA Europe
Members**

Building awareness of PAH

A practical guide to maximizing the value of the IPCS survey and *Time to Talk* materials

The International Patient and Carer Survey (IPCS) provides valuable insights into the true burden of Pulmonary Arterial Hypertension (PAH) on both patients and their carers. The *Time to Talk Patient and Carer Pack* has been developed as a direct response to the IPCS findings. It aims to encourage open and honest discussion about the challenges of living with PAH and to make it easier for patients and carers to access the support they need.

The next priority is to raise awareness of the availability of these materials so that as many people as possible can benefit from them. This guide outlines a range of activities you can use to spread the word about the impact and true burden of PAH and encourage uptake of the new tools. The specific details and procedures will vary from country to country and some of the activities may not be relevant or may already have been carried out in your area. Simply select the activities that are most appropriate for your situation.

To get you started, we have included ten initiatives which can be used to promote awareness of the IPCS findings and the *Time to Talk* tools. A simple 'how to guide' for each of the activities can be found in the second half of this pack, with practical, step-by-step instructions, tips for maximizing success and template materials for you to use.

Activities

Media launch

Media one-to-ones

Stakeholder mapping

Patient and carer conferences

Optimizing meeting attendance

Making use of related events

Roundtable meetings with key medical professionals

Webcasts

Lobbying for better care for patients with PAH

Direct emails to membership

Media launch

The IPCS results and the launch of the dialogue tools are excellent news hooks and could be launched to the media in your country, if this has not already taken place.

Develop a press pack comprising a press release, factsheet on PAH and summary of the survey results. You may need to do different versions targeted towards different types of media (templates are included later in this guide). It is important to make the materials as relevant as possible to your local media, for example by including quotes from patients who have used the dialogue tool or healthcare professionals in your country. If possible, these contacts should be available for interview. A good distribution list is also vital so check your contacts carefully.

Media one-to-ones

Target key journalists with the offer of individual briefings with medical experts, patients and carers. This can be an excellent means of building strong relationships with these journalists and can also result in more in-depth feature coverage rather than shorter news items.

Stakeholder mapping

Stakeholders are individuals or organizations that have an interest in, are affected by, or have the potential to influence a particular issue or topic.

Stakeholder mapping consists of carrying out research to determine which stakeholders could be most valuable to you in terms of achieving your objectives, allowing you to focus your efforts and achieve maximum results.

Patient and carer conferences

Use the IPCS findings and the launch of the dialogue tools as the basis for a patient and carer conference in your country. The format could vary from a small, informal gathering to a larger, more sophisticated event with a panel of speakers and a range of workshops.

Invite a local healthcare professional to present the survey findings and to discuss the implications with particular reference to your local situation. Invite attendees to use the dialogue tools and encourage them to discuss their experiences. Invite local media to cover the event and offer interviews with healthcare professionals and/or patients and carers to talk about the impact of PAH.

Optimizing meeting attendance

Attending national meetings or conferences as a patient organization can be costly and time-intensive and so it is important to ensure you make the most out of it. The key is to publicize your attendance as widely as possible and to offer features that will attract the maximum audience to your stand. Possibilities include:

- Offering the *Time to Talk Patient and Carer Pack* as giveaways from your stand
- Running the video version of the dialogue tool on a loop on your stand
- Running the webcast (if appropriate) on a loop on your stand
- Offering visitors the opportunity to fill in the dialogue tool and to discuss the results with a member of your organization and/or a healthcare professional.

Journalists from national and local media are likely to be covering the meeting. Alert them to the fact that you will be attending, ensure that you have press materials available and, if feasible, offer interviews with representatives of your organization, patients or healthcare professionals.

Making use of related events

Resources are limited for all patient organizations so it is important to make the most of every opportunity to make useful contacts or increase awareness about PAH.

Whether you are attending a conference as a delegate or representing your organization as a guest at a press briefing for another organization, there will be opportunities for networking. You should make use of every opportunity to spread the word about your organization and about PAH.

Roundtable meetings with key medical professionals

Roundtable meetings bring together a group of medical professionals (and sometimes other stakeholders) with an interest in a particular topic or issue. Such an event will usually have a clearly defined objective, such as developing a strategy for improving diagnosis, producing a report for publication in a key journal, or developing a consensus statement or set of guidelines.

Webcasts

A webcast is a way of streaming or broadcasting an interview or presentation over the internet. It can be transmitted live, in which case the audience is alerted in advance to the forthcoming event, and can even interact with the presenter. Alternatively, it can be made available 'on demand' so that it can be accessed whenever required.

The IPCS survey results and the launch of the dialogue tools would be ideal topics for a webcast to be made available via your website. This could include a step-by-step guide to using the dialogue tools and an interview with a patient/carer who has used the tool and can explain how it has helped them.

The technology for setting up a webcast is relatively simple and inexpensive and in a later section we will provide further information on how to do this.

Lobbying for better care for patients with PAH

The IPCS findings show that in many countries PAH patients and their carers do not have access to the support and care they need. Where service provision is currently inadequate there is a need to lobby to help provide a more comprehensive standard of care for all PAH patients and their carers.

PAH patient organizations are ideally placed to discuss the issues relating to the disease. Lobbying can vary from small-scale, highly targeted tactics to major, long-term campaigns. Lobbying seldom delivers immediate results but with determination and patience, it can be a powerful driver for change.

Direct emails to membership

Sending out regular email updates to members can help to engage your membership and build an on-going dialogue. Emails can draw attention to news items or media coverage or invite members to participate in media activity or to share their views.

This list is a starting point and we would welcome your comments and feedback on activities you have tried – both positive and negative experiences – and any tips you have for maximizing success. In this way we can build up a database of Best Practice Case Studies. Please contact p.ferrari@phaeurope.org.

Time to **Talk** 

