Patient and carer conferences



Activity description

- Many PAH patients and their carers enjoy meeting to share their experiences
- Conferences provide a good opportunity to present the IPCS findings and the Time to Talk materials

Target audiences

- Your members
- Healthcare professionals with an interest in PAH
- Relevant support groups (e.g. carers' groups)
- Relevant media see full list of relevant media in 'Media launch' section

Key considerations

- Small meetings do not have to be costly and it is possible to ask attendees for a small fee to cover basic costs
- Choose a convenient location with good transport links, which is accessible for people with different levels of ability; e.g. Hotels
- Offer a range of speakers, including healthcare professionals, representatives of your organization, patients and carers
- Potential topics could include:
 - presentation of the IPCS findings
 - what is being done to address the issues raised in your country
- Hold workshops on specific topics and offer attendees the opportunity to use the dialogue tools and to provide feedback
- Offer an **exhibition area** to companies with relevant products/services charge a small fee for this



Key steps

Define the aims of your conference and develop an outline program

Identify a suitable venue and book a date for the event

Approach
potential speakers
and finalise the
program

Post an advance announcement on your website (two to three months before event)

Check number of attendees and confirm all details

Distribute
details of the event
to members and to
other relevant
stakeholders,
including media

Co-ordinate visual materials. Consider recording the event (this can be uploaded to your website after the event)

Send **confirmation** and briefing notes to all speakers

Approach **potential exhibitors**

Produce an
information pack
for attendees.
Include a short
evaluation form
asking for feedback

On the day, ensure that you have plenty of helpers available

Soon after the event, meet with your team to discuss what worked well and what could be improved

Top tips



Keep it simple. You can always build on your initial experiences for future events

Meet with your team regularly and develop checklists to ensure no detail is forgotten

Suppliers such as hotels sometimes offer a **discount** to patient support groups – don't be afraid to ask

