

# Global Patients Congress 2006

## Evaluation report



### **Introduction**

This report includes the main results from a number of evaluation activities undertaken at the 2006 Congress including: Part 1: results from completed delegate evaluation forms (both statistics and comments) and Part 2: recommendations made by all Congress delegates during plenary sessions. These recommendations were the result of two Congress sessions focusing on Networking and Networks and identifying key themes and actions from the Congress.

### **Taking the results of our evaluation forward**

As well as using this report to inform our members and partners about the outcomes from the Congress, its other important role is to ensure IAPO has captured all the important learning from the 2006 Congress and that this is used in our future work. We will ensure that all recommendations and evaluation results are fully considered when we plan the next Congress and will aim to build comments which have wider relevance into our ongoing plans. We have shown in this report where we have already started to do this.

### **Number of respondents**

The Delegate Evaluation was carried out during and immediately after the Global Patients Congress. Evaluation Forms were provided to everyone in their delegate bags and in their Programme. 42 out of total of 177 delegates submitted an evaluation form representing 24% of all delegates. The feedback from the plenary sessions involved all delegates attending that session and therefore a greater number of total delegates, we estimate that 80% of delegates were actively involved in these plenary evaluation activities.

### **Part 1: Results from evaluation forms received**

There follows four graphs detailing: 1.What delegates objectives were for the Congress; 2.How delegates rated different aspects of the Congress; 3.How delegates rated the plenary sessions and finally 4.How delegates rated workshops and roundtables. This is followed by a summary of the comments we received from the evaluation forms. Results show that networking and associated activities are the top reasons why people attend the Congress, that 93% of delegates felt the Congress was good or excellent and that overall 77% of delegates thought the congress sessions were good or excellent.

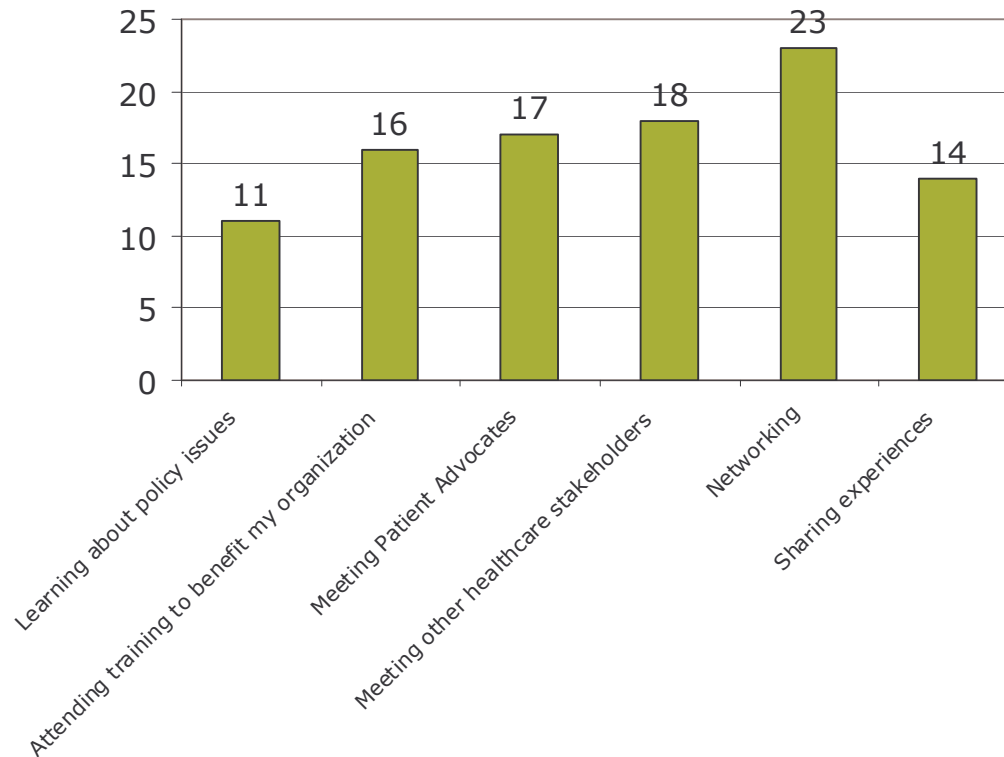
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Figure 1: What were your objectives for attending the Congress?

Percentage (%) of respondents indicating this was one of their objectives

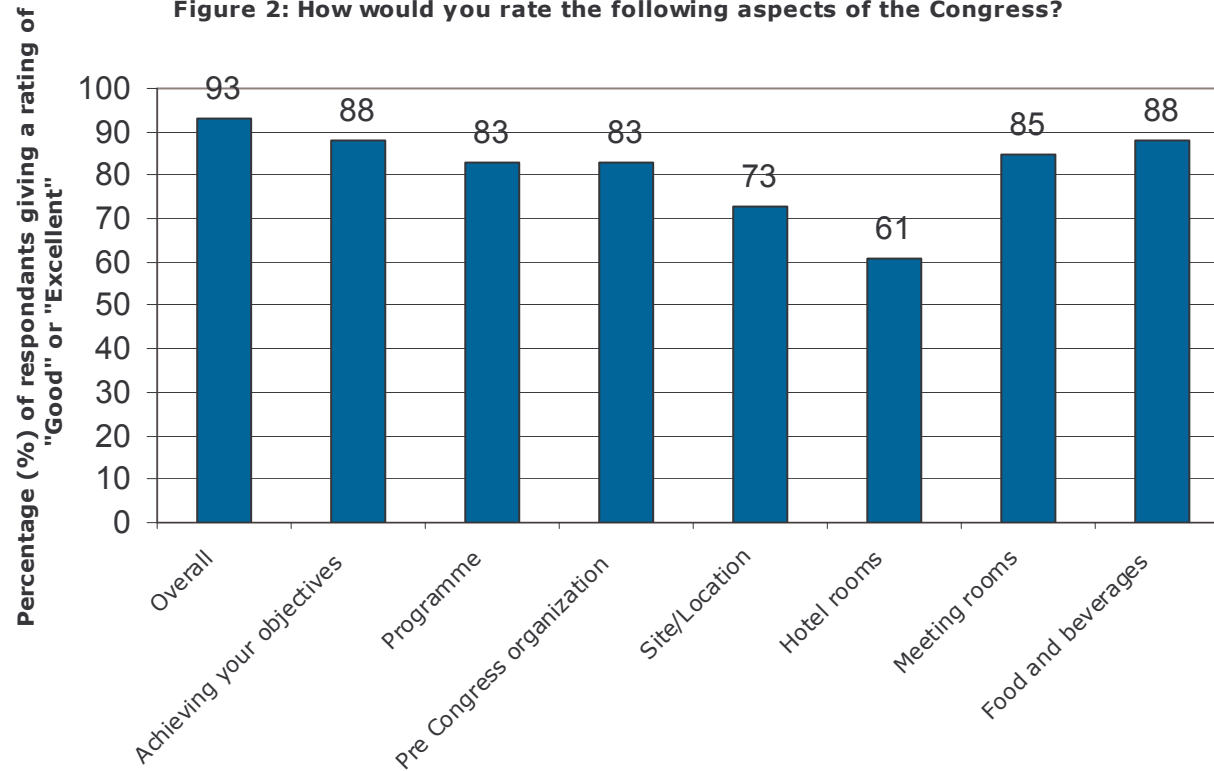


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Figure 2: How would you rate the following aspects of the Congress?

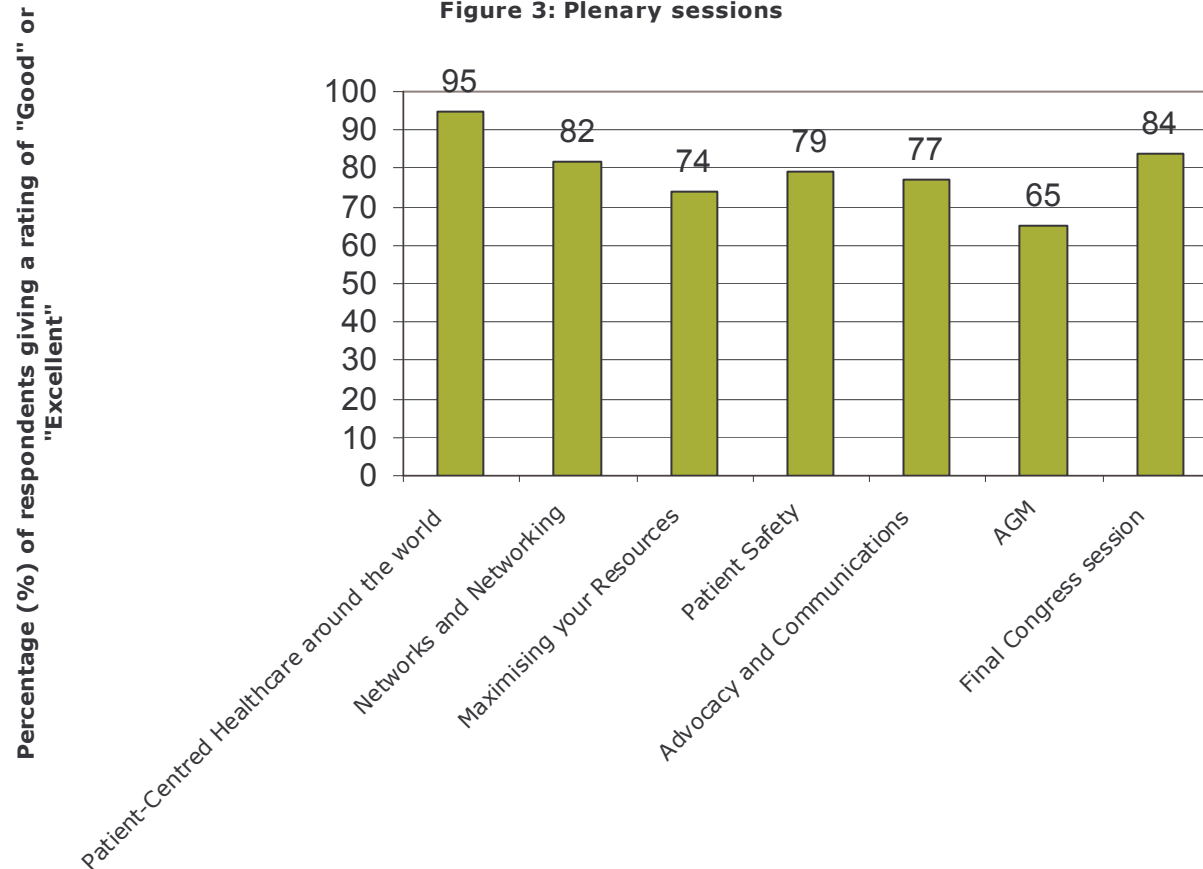


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Figure 3: Plenary sessions

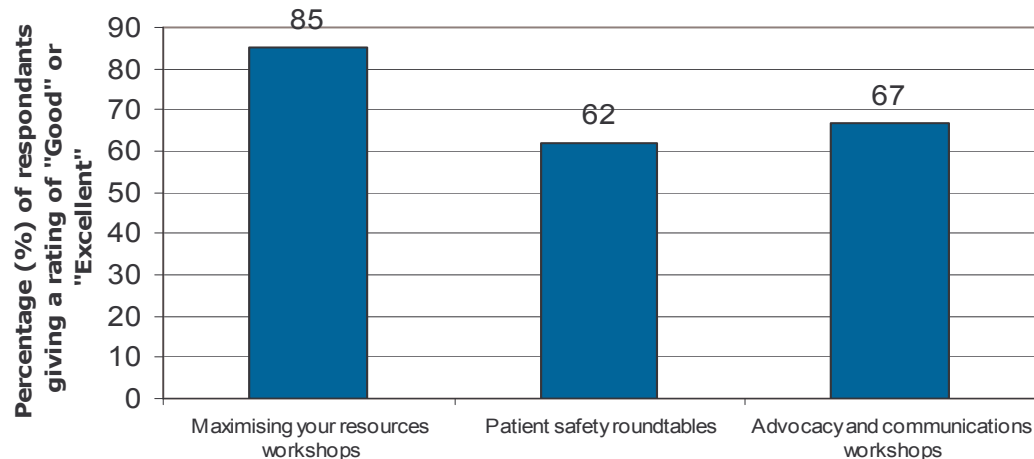


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**Figure 4: Workshops and roundtables**



### A summary of general comments from the evaluation forms:

- **Interpretation / translation:** There was general agreement that interpretation and translation are vital to IAPO's work and specific comments supporting translating the Patient-Centred Healthcare (PCH) Declaration into different languages.
- **Improving networking opportunities:** There were many ideas for improving the networking opportunities at the Congress including more free time during breaks, activities to match people with similar skills / needs with each other and engaging more effectively with local policy makers during the Congress.
- **Debate and reflection:** Some delegates wanted more time for debate and reflection between patients' organizations built into the programme.
- **Media coverage:** Some delegates felt that media coverage of the event was not given sufficient attention.

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All of these comments are being used to inform planning for the next Global Patients Congress. Increasing our media presence is an area of work which IAPO has prioritised within our strategic plan and the Congress will be central to any media strategy developed.

### **Part two: Recommendations from plenary sessions:**

This document sets out recommendations made by delegates at the 2006 Congress during the networking and final sessions. In italics we have included our ideas and commitments to date about how we can take these recommendations forward.

#### **2.1 General**

**“Together we can”** was identified as an important slogan for IAPO members as well as an important reality. Working together we need to identify how we can more effectively change practice towards our ultimate goal of Patient-Centred Healthcare (PCH). *We will ensure that the slogan informs our work on an ongoing basis and that we particularly look at ways we can assist our members to work together and with others effectively.*

**Develop a fund to support underrepresented organizations:** Greater representation from underrepresented regions is important and a fund would assist their attendance. *The bursary fund for the 2006 Congress was a success and IAPO commits to include a bursary for future events.*

**Lots of fantastic ideas:** Establish a contest or award for a project that demonstrates best practice; Develop twinning projects; Workshops that take IAPO policy to members in a local area. *We will make sure that all these ideas are considered and where possible incorporate them into our plans.*

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### 2.2 Patient-Centred Healthcare

**Publicity and awareness of the declaration:** Members suggested a range of actions with the aim of raising awareness of the PCH declaration. These included each nation undertaking a press release or event for the PCH declaration and developing quality posters displaying the 5 PCH principles translated into local languages. *As part of the toolkit we will include a press release which can be adapted by members for use in their region. We aim to have 10 activities in 2006 by IAPO members. We will also develop a project proposal for funding to develop a set of quality posters. IAPO is also working on a translation policy to encourage translation of the Declaration. It has already been translated into French, Bulgarian and Chinese.*

**Increasing our understanding of PCH:** A survey of PCH in each region. *The case studies that IAPO are encouraging members to complete are the first step in this important work.*

**Actions to improve patient-centred care globally:** Members identified a number of specific actions which would lead towards more effective Patient-Centred Healthcare. These included ensuring that patients are on boards of institutions, creating closer and stronger links with healthcare providers to improve the doctor patient relationship, ensuring patients are well informed and ensuring that appropriate international legislation is in place. *A core element of IAPO's work as set out in our mission is to build cross sector alliances. We will work on an ongoing basis to ensure that patients are represented in international institutions, will continue to host events such as the congress where there is an opportunity to share experiences and learning between sectors and will push for patient involvement at all levels. See IAPO policy statement and guidelines on Patient Involvement at [www.patientsorganizations.org/involvement](http://www.patientsorganizations.org/involvement).*

It was also suggested that we work towards a global patient's Bill of Rights – *The IAPO PCH Declaration encompasses many patients' rights and is effectively a Global Bill of Rights focusing on PCH. We will work towards achieving the aims set out in the Declaration before we begin to work towards any other such documents.*

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### 2.3 Networking and Networks

**The benefits of networking** The Congress is an important networking opportunity, and members emphasised the need for a shared common space. Members also raised the importance of maintaining our independence. Grassroots organizations in particular need to be encouraged to become involved in IAPO networks by developing a tool that explains the value of IAPO and its relationship to our local work. *We will look at how we explore and communicate the benefits of networking in our capacity building strategy. When planning the next Congress we will look at how we build in effective networking opportunities.*

**Technology:** We should use the latest technology to improve communications and members asked to be given more time by IAPO to respond to emails. *IAPO are exploring the use of new technologies and also looking at how members can use our existing technological support services such as The Patients' Exchange which includes a Listserv more effectively. We agree that giving as much time as possible to respond to emails is a high priority. Our only restriction is that we are often working within other organizations tight deadlines where this is the case we will make it clear in emails sent.*

**Language:** Participants identified that translation and interpretation are key for the Congress and effective communication. One member stated that an ideal would be interpreting in 4 languages for main sessions and 2 languages for workshops dependant on resources. Emails in more languages would be useful. *IAPO agrees that translation and interpretation is key, the only barrier to providing these services is resources. IAPO commits to including the costs of translation of all key documents and interpretation at the Congress into funding bids and where possible seeking funding solely for this purpose. We will prioritise translation and interpretation into Spanish. Emails in more languages is more challenging, as this requires staff to be fluent in the relevant language. We will explore the feasibility of this in the longer term.*

### 2.4 Maximising your resources

**Streaming:** More streamlining of organizations at similar levels for workshops. *We will build this into future Congress planning.*

**Joint funding:** Facilitate IAPO to explore work on joint fundraising projects between IAPO members and IAPO to co-fund opportunities. *IAPO would like to hear from any member who has a project proposal within the framework of our PCH project.*



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**Piggy backing:** To use resources most effectively we should hold the Congress at a time which coincides with existing gatherings so that participants can obtain maximum use of time at location. *IAPO absolutely agrees with this and will consider this in planning for future events.*

### 2.5 Patient Safety

**Patient Safety Toolkit:** Members asked IAPO to raise global awareness of Patient Safety by developing a toolkit to educate patients. *In 2007/8 we will prioritise seeking funding to take forward this work.*

**Global and regional meetings** to address safety as a whole and deal with regional specific issues. *We will link with the WHO initiative Patients for Patient Safety, ensuring that our members are fully informed about its work, including regional meetings. IAPO will explore regional issues and priorities for potential meetings and safety will be a key consideration.*

**Work with WHO** to put pressure on governments to change patient safety. *As an active member of the WHO World Alliance for Patient Safety – Patients for Patient Safety, we are working towards this on an ongoing basis.*

### 2.6 Advocacy and Communications

**Involvement, participation and dialogue with local groups and the local media** in the city of the Congress is important. It was suggested that it would have been useful to have had a panel of local IAPO member groups at the Congress. *We will consider this in planning for future Congress'.*

**Patient Stories:** For effective advocacy and for the Congress members requested a greater emphasis on the patient story. *We agree and will build into future Congress planning. In our overall work we are also increasing our focus on the patient story. For example gathering PCH case studies to support our Declaration.*

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**Media coverage beyond the standard** Delegates felt that we need to learn from partners and others about effective media coverage for our work. Ideas include having media talking points and contacts, developing links between local media contacts and media back home and helping members build their capacity for media networking. *Increasing the media's awareness of IAPO and its members work is crucial and is a key aim within IAPO's strategic plan. Press activities for the 2006 Congress included pre and post event press releases and a number of other activities. One of the outcomes was coverage in a national Spanish newspaper La Razon. We will work on an ongoing basis to improve our press work – any support and expertise from members would be much appreciated.*

**Enabling members to effectively share information about IAPO's key priorities:** Ideas included providing members with a page of speaking points for the 5 PCH principles, identifying an organization from each nation that has the capacity to spread communications and that can translate key IAPO materials, and using such organizations as a "loud speaker" for IAPO's work. *We will develop talking points for the PCH toolkit as a starting point. We have also considered how we can most effectively support our members in communicating IAPO's vision and mission and aim to identify international spokespeople on particular issues within our membership.*

### Conclusion

IAPO will work to incorporate the feedback we received into all of our work, including towards the next Global Patients Congress. We are delighted that the 2006 Global Patients Congress was a great success but we also want to learn from the areas where we can make improvements for the future. We will be announcing our plans for the next Congress during the Summer 2006.

"We would like to congratulate IAPO for their effort in improving the relationship between patient's associations in the different countries of the world" IAPO member

"The Congress has been a wonderful experience. It is important that recommendations from the last session are implemented. This will have a tremendous effect on patient care worldwide" IAPO member