

## **IHF – IAPO SURVEY - FORMAL ARRANGEMENTS IN HOSPITALS FOR PATIENT INVOLVEMENT**

A survey on “Formal arrangements in hospitals for patient involvement” was sent to IHF Full and Associate Members, as well as members of the International Alliance of Patients’ Organizations (IAPO), at the end of July 2013. The collection and analysis of the questionnaires was realized by the IHF.

The aim of this survey was to sketch out the overall trend of patient involvement in hospitals at the national level. The survey investigated the main objectives of patient involvement in hospitals, the regulations in place for patients’ institutional involvement, the modalities of formal arrangements for patient involvement, the nature of patient representation, and the existence of national documentation on patient involvement.

Completed questionnaires have been submitted by 34 organizations, 17 of which are members of the IHF. Respondents were from the following 27 Countries:

Asia Region: Hong Kong, Indonesia, Israel, Korea, Pakistan, Philippines, Taiwan, Thailand

Africa Region: Cameroon, Nigeria, South Africa,

Americas Region: Argentina, Canada, El Salvador, Guatemala, United States

Europe Region: Austria, Bulgaria, France, Germany, Greece, Hungary, Poland, Switzerland, the Netherlands, United Kingdom

Australasian Region: Australia

From Australia, Israel, Nigeria and South Africa, completed questionnaires were provided by both IHF and IAPO’s members and no discrepancies were found between the answers.

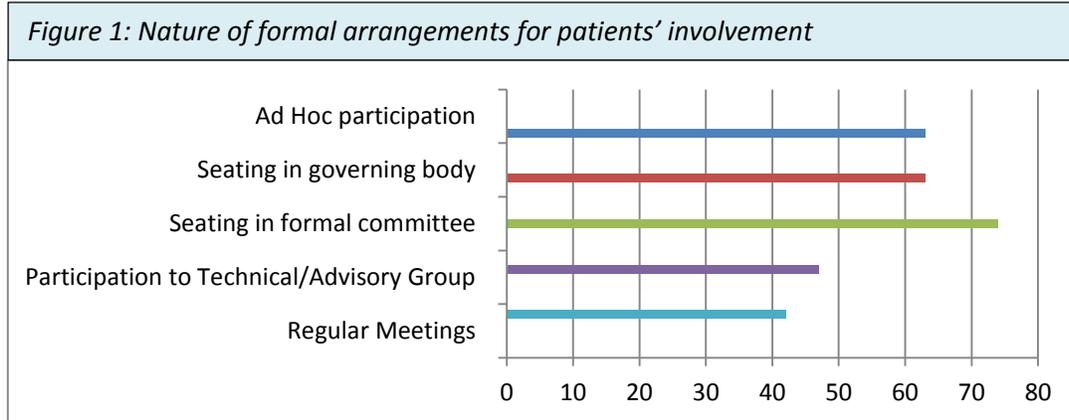
For half of respondents there is no regulation for patients’ institutional involvement in hospitals. For those who responded positively to the question (17 out of 34), the main scope and objectives of the regulations for patient involvement in hospitals are:

- Create a patient-centered health system (24%)
- Collaboration with consumers to improve the quality of healthcare (29%)
- Patient involvement in the hospital board and /or in specific committees (e.g., patient support group, quality of service, patient safety, etc.) (41%)
- Improve patients’ consciousness (24%)
- Improve patients’ participation to the decision (e.g., involvement in treatment decision, right to be informed, free choice of doctor, etc.) (12%)

Of the 34 organizations surveyed, 15 reported having formal arrangements for patients’ involvement. Respondents had the possibility to select between multiple answers regarding the number of modalities of formal arrangement they have. The organizations have anywhere between one and five modalities of formal arrangement:

- One modality (5 organizations)
- Two modalities (7 organizations)
- Three modalities (3 organizations)
- Four modalities (none)
- Five modalities (6 organizations)

The chart below shows the nature of the formal arrangements:



As can be seen in the chart, respondents answered that the principal formal arrangements are:

- Seating in formal committee (74 %)
- Ad Hoc participation (63 %)
- Seating in governing body (63 %)

In eight countries (Argentina, Australia, France, Hong Kong, Philippines, South Africa, Thailand and USA) patients can participate in technical and/or advisory groups. Additionally, in Australia, France, Hong Kong, Taiwan, Thailand, The Netherlands and USA respondents said that they have regular meetings as a formal modality for patient involvement.

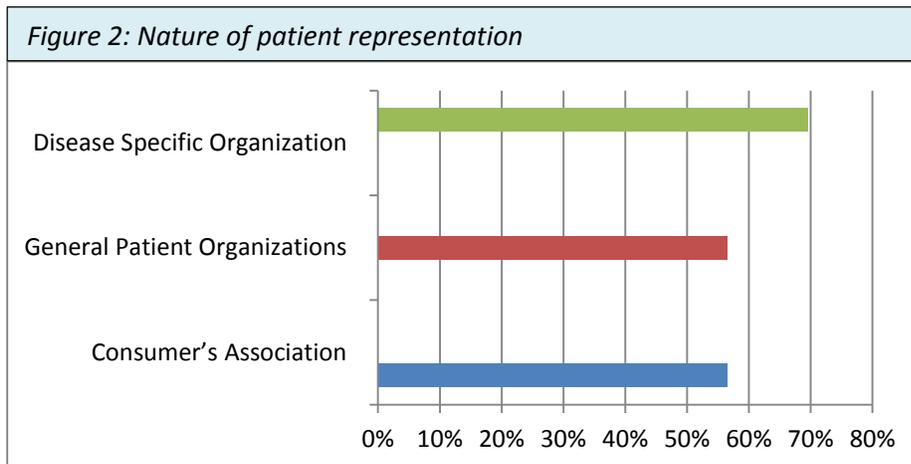
Respondents also highlighted the following additional formal arrangements:

- Patient counseling (both inside and outside the hospital)
- Patient advocacy
- Guardianship legislation
- NGOs
- Representatives of the communities
- Volunteers

Of the 26 respondents, nine indicated that solely designated people represent patients. Six respondents reported having three or more organizations that represent patients, and four organizations reported having both designated people and three or more organizations to represent patients. In Indonesia patients are represented by two organizations. The Philippines was the only country to report representing its patients through designated people and two organizations.

In some specific contexts such as South Africa, the representative can be nominated by the hospital or the province government. In Argentina and Hong Kong there are several patients' organizations/groups representing patients. In Israel there are several NGOs, each representing a different healthcare fields and all collaborate under the umbrella of the Association for Patient's Rights. In Germany the representative is appointed by the Federal Government or by the Government of the Regional States. Peoples from the community are appointed in Nigeria while in the United States anyone can represent patients.

The nature of patient representation is as follows:



In both Cameroon and South Africa, patient representation is also provided by community representatives. In Austria there are patient advocacy organizations that are involved in conceptual and planning activities for the healthcare system on a high level and in political decision-making. In Poland patients' representatives are appointed by the funding organization of the hospital.

In more than 75% of countries there are opportunities for patient involvement when no formal arrangement is in place. The nature of involvement can be as follows:

- Meetings of patients' organizations
- Patients' rights groups
- Complaint tools (boxes, hotlines, etc.)
- Customer feedback systems (survey, etc.)
- Voluntary work
- Informational/educational activities, campaigns and conferences
- Involvement in specific organizations/groups (e.g., consumer organization, public complaints committees)
- Ad Hoc participation

From the above list, the two most frequent modalities of patient involvement are:

- Informational/educational activities, campaigns and conferences at 17%
- Involvement in specific organizations/groups at 22%.

Respondents shared the following resources for national documentation on patient involvement:

- Australia:
  - <http://www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf>
  - <http://hcca.org.au>
  - <http://www.actmhcn.org.au>
  - <http://www.carersact.org.au>
  - <http://www.health.act.gov.au/consumer-information/consumer-involvement>
  - <https://www.chf.org.au>

- Hong Kong: [www.ha.org.hk](http://www.ha.org.hk) (information on composition of Public Complaints Committee, Report on Patient Satisfaction Survey 2010, and minutes of various committees involving patient representatives are available)
- Israel: <http://www.cancer.org.il/template/default.aspx?PageId=6195>
- Netherlands: Agreement on Financing a Client Advisory Board
- Philippines: DOH Technical Advisory Council
- Switzerland:  
[http://www.ejpd.admin.ch/content/ejpd/en/home/themen/gesellschaft/ref\\_gesetzgebung/ref\\_abgeschlossene\\_projekte0.html](http://www.ejpd.admin.ch/content/ejpd/en/home/themen/gesellschaft/ref_gesetzgebung/ref_abgeschlossene_projekte0.html)
- USA: <http://www.aha.org/advocacy-issues/communicatingpts/pt-care-partnership.shtml>