

**IAPO Forum at the United Nations in New York
in collaboration with the U.N. NGO Health Committee
30 March 2007, United Nations, New York, USA**

**A Meeting on Patient-Centred Healthcare:
Aligning Healthcare Systems with Patients' Needs.**

**International Alliance of Patients' Organizations (IAPO) presents
Declaration on Patient-Centred Healthcare**

Representatives of IAPO member organizations from around the world, United Nations NGO Health Committee members, healthcare professionals, academics, pharma representatives and other stakeholders converged on the United Nations in New York on 30 March 2007 for a day-long landmark meeting. The meeting successfully raised awareness of Patient-Centred Healthcare at an international level, generated considerable support for the patient-led IAPO Declaration on Patient-Centred Healthcare and produced a number of recommendations for future action. Delegates attending this top conference included International Painful Bladder Foundation Chairman Jane Meijlink.



What is IAPO?

The International Alliance of Patients' Organizations (www.patientsorganizations.org) is a unique global alliance representing patients of all nationalities and from all disease areas and promoting patient-centred healthcare around the world. IAPO members are patients' organizations working at international, regional, national and local levels to represent and support patients (any person with a chronic disease, illness, syndrome, impairment or disability), their families and carers.

Patients must have a voice

The purpose of this meeting at the United Nations was to discuss many aspects of the international issues that affect patient organizations and to present and sign the IAPO Declaration on Patient-Centred Healthcare. An important aim was also to focus attention on

the vital need for patients to have a voice in the global healthcare system.



A wide range of speakers came together from different international and professional backgrounds, led by patient representatives, to discuss the meaning and application of patient-centred healthcare on a global level. They addressed an audience of participants comprising healthcare policymakers, professionals and patient organization representatives, to further understanding and support for the drive to put patients at the centre of healthcare systems.

The Declaration

The IAPO Declaration outlines the key principles of patient-centred healthcare as agreed upon by a consortium of leading international patients' organizations. During the meeting, delegates formally signed and endorsed the Declaration as the defining document for patient-centred healthcare principles. The Declaration can be found on the IAPO website at: <http://www.patientsorganizations.org:80/declaration>. At the bottom of the text on the IAPO website, you will find a pdf file of the Declaration and a Word file for patient organizations to sign the declaration.

“Chronic diseases currently account for almost half of the global burden of disease, and health systems in world regions cannot cope if they continue to focus on the disease rather than the patient. This declaration helps to universally define this important issue and gives voice to patient concerns,” explained Albert van der Zeijden, Chair of IAPO and United Nations NGO Health Committee Representative.



Speakers from around the world

The landmark meeting at the United Nations was chaired by Paul Rompani, deputy chief executive of the Multiple Sclerosis International Federation (MSIF). The meeting was split into six sessions:

- I. What is Patient-Centred Healthcare.
- II. Patient-Centred Healthcare around the world
- III. Patient-centred healthcare principles
- IV. Benefits and challenges of patient-centred healthcare
- V. Patient-centred healthcare models
- VI. Together we can... Identifying next steps

Perceptions of healthcare survey

Stephen McMahon, Chairman of the Irish Patients Association, presented a 2006 survey that revealed perceptions of healthcare among patient organization members in 10 EU Member States, Canada and Nigeria and demonstrated a need for patient-centred healthcare and universal terms to define its parameters. Around 98% of respondents agreed that “because timing is so important in the prevention of disease, access to the most effective medicine is essential.” Furthermore, 95% of the members participating in the survey demanded a right to participate as partners in making healthcare decisions.

“When patients are passive subject of healthcare provision rather than partners in its delivery, providers are not able to deliver the quality of care that patients need”, explained Myrl Weinberg, IAPO’s Chair Elect. “Therefore, patients should be involved in setting the healthcare, and this meeting will help set an international health agenda for patients around the world.”

What is Patient-Centred Healthcare (PCH)?

Health systems in all world regions are under pressure and cannot cope if they continue to focus on diseases rather than patients. They require the involvement of individual patient who adhere to their treatments, make behavioural changes and self-manage. Patient-centred healthcare may be the most cost-effective way to improve health outcomes for patients.

IAPO believes that patient-centred healthcare must be based on the following five principles:

1. Respect
2. Choice and empowerment
3. Patient involvement in health policy
4. Access and support
5. Information.

More detailed information may be found on the IAPO website:

<http://www.patientsorganizations.org/pchreview>

Patient-Centred Healthcare in Africa still a dream

Regina Namata Kamoga, Country Manager in Uganda for Community Health and Information Network (CHAIN) and IAPO board member, explained that patient-centred healthcare is only a dream in Africa where patients die by the minute of preventable diseases. Patients in her country have to pay for healthcare, but less than 30% of the population earns more than a dollar a day. Literacy is a huge problem and they have been experimenting with videos to teach healthcare to the many people who cannot read or write. Patients, particularly those from rural communities feel afraid and intimidated by doctors and don't dare to ask any questions. They have a long way to go in Africa to achieve anything resembling patient-centred healthcare.



Patient Safety



Hussain Jafri (Alzheimers' Pakistan and IAPO board member) spoke on the Patients for Patient Safety movement, and told delegates that in Pakistan patients have to lie on dirty beds and are given dirty water to drink. He explained that while a patient's right to be treated may be honoured, the way in which they are treated is not being considered. He believes that partnership around the world can help improve situations like these. Further information about Patient Safety campaigns is given at the end of this report.

Memorable quotes from speakers during the conference include:

- PCH can perhaps best be summed up by the slogan: **“Nothing about us, without us”**.
- We should not forget that patients are voters!
- There should be a team approach with collaboration between family and healthcare providers.
- Decisions should be clinically-based and not government-driven.
- A strong doctor/patient relationship should be an essential element.
- The patient is the key person!
- We need a **World Patients' Rights Day!**

A full report on the conference is being prepared by IAPO and will be available on the IAPO website: www.patientsorganizations.org

Patient Safety Campaigns

The World Health Organization (WHO) World Alliance for Patient Safety was launched in October 2004. Further information is available on:

<http://www.who.int/patientsafety/about/en/index.html>

The first Global Patient Safety Challenge, launched in 2005-2006, was: Clean Care is Safer Care.

The five elements of the Global Patient Safety Challenge are:

- Blood safety
- Injection and immunization safety
- Safe Clinical procedures
- Safe water and sanitation in healthcare
- Hand hygiene

At any time, over 1.4 million people worldwide are suffering from infection acquired in hospital. The risk of healthcare-associated infection in developing countries is 2 to 20 times higher than in developed countries. The World Alliance for Patient Safety and its technical partners have developed low-cost strategies that help reduce healthcare-associated infection.

The second Global Patient Safety Challenge, launched in January 2007 is: Safe Surgery Saves Lives. The initial stages of this second Challenge will focus on:

- Clean surgery
- Safe anaesthesia
- Trained providers
- Surgical resources
- Monitoring and quality assurance mechanisms

3rd IAPO Global Patients' Congress 2008

The 3rd IAPO Global Patients' Congress 2008 will be held in February 2008 in Budapest, Hungary. The main theme of this event will be IAPO's vision of patient-centred healthcare worldwide with a special focus on ensuring patient involvement in all levels of decision-making in order to align healthcare systems with patients' needs. Access to health, patient information and patient safety will also be central to the programme

Photos: Enrique Silver and Jane Meijlink

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