International Alliance of Patients' Organizations
A global voice for patients

IAPO Member Case Study

Promoting Patient-Centred Healthcare in the Western Pacific: the Experience of the Alliance for Patients' Mutual Help Organizations

Introduction

This case study describes the work of the Alliance for Patients' Mutual Help Organizations (APMHO or the Alliance) to promote patient-centred healthcare in the Western Pacific region using key International Alliance of Patients' Organizations (IAPO) publications and highlights the key achievements of the Alliance.

Background

The Alliance, founded in 1993, is an alliance of patient groups which aims to provide a united voice for patients and people with disabilities in Hong Kong. It was founded in response to the Hong Kong government's 1992 White Paper on health, a policy paper which set out the government's plans for healthcare and rehabilitation services. Through the Alliance, patient groups were able to articulate the needs of patients and how the paper could address these needs. The Alliance has now grown to a network of 42 patients' organizations crossing a variety of disease areas and, through its membership, represents 40,000 patients.

Patient-centred healthcare: a revolutionary concept

The Alliance became a member of IAPO in 2005. The following year, IAPO launched its Declaration on Patient-Centred Healthcare at IAPO's 2nd Global Patients Congress held in Spain in 2006. Delegates from the Alliance attended the Congress and recognized that, to patients in Hong Kong and China, patient-centred healthcare was a revolutionary concept. Upon returning to Hong Kong, the Alliance decided to promote patient-centred healthcare and translated the Declaration into both traditional and simplified Chinese. Following the Congress, the Alliance began to spread the message of patient-centred healthcare in the mass media and began to identify the direction and strategy of their policy and advocacy work. Since 2006, the Alliance has been promoting the concept of patient-centred healthcare to governments, healthcare service providers, industry and media.

> The Alliance have advocated for the government and major public healthcare providers to accept patient representatives' participation at all levels of decision-making processes, from policy formulation and planning through to implementation and review. They have attended seminars and conferences to introduce and promote patient-centred healthcare.

Advocating for Patient-Centred Healthcare

In December 2007, a patient-centred healthcare conference was held in Hong Kong with the support of the World Health Organization (WHO). IAPO's Chief Executive Officer, Jo Groves, gave a key note presentation. The conference launched the Centre for Systems for Health People and Patient-Centred Healthcare Initiative, which is working to develop healthcare research and advocacy in Hong Kong. Patients, healthcare managers, healthcare providers, academics and the general public came together to discuss how to promote people and patient-centred healthcare.

In 2008, the Alliance presented its achievements at IAPO's 3rd Global Patients Congress in Hungary. KP Tsang, of the Executive Committee of the Alliance, was elected to the Governing Board of IAPO in the same year.

In 2009, KP gave a presentation at the patients' workshop, *Improving Patient-Centred Healthcare in the Philippines*, on the following topics: the concepts and principles of patient-centred healthcare; the importance of patient engagement; the importance of cross-sector alliances with stakeholders and partners; and on the vision and mission of IAPO and its activities as part of the global patient movement. KP also spoke about the policy and advocacy work carried out by the Alliance. Following this workshop, the patient groups took steps towards organizing a coalition in the Philippines and agreed to participate in policy discussions through the Department of Health and other organizations.

▶ The Alliance changed its constitution to reflect the vision and mission of IAPO. The Alliance now aims to: enhance networks of patients' organizations; build the capacity of patient groups; collaborate with all healthcare stakeholders to achieve patient-centred healthcare; and to participate in the national, regional and international healthcare community and patients' movements.

In November 2010, the Alliance launched a new resource for patient groups in the Western Pacific region, the i-patient website. This is the first of its kind in the region and provides an opportunity for patients to exchange their ideas, opinions and experiences with people in Hong Kong and the Western Pacific. The i-patient website is user-friendly and caters to the different needs of patients. It is both interactive and multilingual, with the content in English, traditional Chinese and simplified Chinese. The website has copies of the IAPO Policy Statement on Patient Involvement and the IAPO Policy Statement on Patient Information. Through the interactive platform of the website, the Alliance hopes to achieve patient empowerment through enhanced partnerships between patients and their families and healthcare professionals in the Western Pacific Region as well as the rest of the world.

Throughout this process, the IAPO Declaration on Patient-Centred Healthcare has been a particularly useful tool in explaining the concept and principles of patient-centred healthcare. Recently, the IAPO 2010–2014 Strategic Plan has been useful in helping the Alliance in guiding its future development.

IAPO's publications have provided the Alliance with guidelines on how to put into practice the concepts of patient-centred healthcare, patient involvement and patient information in a local and regional context.

Outcomes and successes

Through its advocacy work, the Alliance has achieved greater patient involvement in decision-making processes. Patient representatives are now sitting on advisory committees of the government and on the steering committees of a number of hospitals. Currently, KP sits on the Primary Care Working Group in the Food and Health Bureau in Hong Kong and is on the steering committee for Electronic Health Record (EHR) sharing. This has resulted in patient opinion being considered on stop smoking policy; the provision of vaccinations to children; and regulations on pharmaceutical products.

One specific example of the impact of the patient voice is when a government hospital authority tried to use a version of a drug that is used to treat colon cancer and age-related macular degeneration (AMD). This particular drug was cheaper than its branded counterpart, but studies have not proven its safety and it is not accepted by drug regulators as an effective medicine for AMD. The Alliance, with the support of healthcare professionals and patients' organizations, spent a year lobbying the government, the health authorities and the universities citing their reasons against the use of this drug on safety grounds. As a result of these efforts, the hospital authority has now dropped plans to use the drug and will use the registered drug.

Another Alliance success came after a government review on healthcare financing in 2010. The review proposed a voluntary medical insurance scheme to supplement the current healthcare system. Patient groups were unhappy with some of the proposals and concerned that there was no incentive for patients with a chronic illness to join. This was because the insurance plan did not include outpatient care and certain examinations, such as Magnetic Resonance Imaging (MRI) scans, as well as outpatient treatment such as chemotherapy and renal dialysis. The Alliance collected patient opinions and comments on the proposals and submitted these to the government. They stated that some aspects of the proposals were unfair to patients with a chronic illness and that these

treatments are not optional but an integral part of the patient's treatment and should be covered in the insurance plan. Following the submission of the Alliance's response, the government is now looking at the responses of patient groups and those of professional bodies and considering a way forward.

Challenges

Although the Alliance has been successful in achieving greater patient engagement, there is still an issue of building the capacity of patients. Most patients do not have an adequate level of health literacy, are unaware of how healthcare systems operate and need training to enable them to engage meaningfully with the healthcare sector. Another challenge is that patient engagement in Hong Kong is not always meaningful. Although patients are increasingly getting involved, for example through working groups and sitting on committees, this has yet to be institutionalised to ensure that patients are involved at all levels of the decision-making process. The Alliance is continuing to advocate for patient engagement to become part of the framework of organizations and to ensure that patients have the opportunity for their opinions to be taken into consideration and necessary action taken.

Next steps

Looking forward, the Alliance would like to recruit more patients' organizations into its membership; train patient leaders; and build the capacity of existing groups. They are continuing to advocate to the government and hospital authorities for meaningful patient engagement that is both genuine and sustainable.

How can IAPO further support this work?

In the Western Pacific region, patients' organizations are not yet well established. In the future, IAPO can further support the region by providing support for delegates to attend Congress and through regional events. This would enable more patients to participate in these activities and come back with the knowledge to do more in their relevant field.

Further reading

- IAPO 2010–2014 Strategic Plan
- IAPO Declaration on Patient-Centred Healthcare
- IAPO's Global Patients Congress
- IAPO Policy Statement on Patient Information
- IAPO Policy Statement on Patient Involvement
- i-patient website
- Alliance for Patients' Mutual Help Organizations website

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