

Working Together to Raise the Patient Voice in the Western Pacific and South-East Asia

Manila, Philippines  12–14 October 2011





Organized by the International Alliance of Patients' Organizations (IAPO)

With our thanks

The IAPO Governing Board and staff team would like to thank everyone who gave their support to this event. In particular, we would like to thank Maria Fatima Lorenzo and colleagues from the Philippine Alliance of Patient Organizations (PAPO) for collaborating on the organization of the local meeting and their overall support for IAPO's Regional Programme in Manila.

We would also like to extend a great debt of thanks to Dr Madeline de Rosas-Valera, World Health Organization Western Pacific Regional Office, and her colleagues who gave invaluable input and support to the Regional Programme.

We would like to thank and acknowledge the sponsors of the event, GlaxoSmithKline, Lilly USA LLC, the Medtronic Foundation, Pfizer and the Pharmaceutical Researchers and Manufacturers of America (PhRMA).

Finally, we would like to thank IAPO members and all participants and speakers for their commitment, contributions and engagement in the event. Special thanks to IAPO members and the Governing Board who took part in the Planning Committee to develop the event. It was a great privilege to learn more about your important work and to work with you.

Event materials

Presentations and agendas from the event are available online: www.patientsorganizations.org/westernpacific

© June 2012 IAPO. All rights reserved.

IAPO is registered as an Association in The Netherlands. Registration Number: 30201854

This publication is the property of IAPO and no part may be reproduced without its prior permission.

Opinions expressed by participants are their own and not necessarily those of IAPO.

Contents



Introduction and Aims of the Report	2
Outcomes and Next Steps	3
Healthcare Issues in the Western Pacific and South-East Asia: the Perspective of Patients' Organizations	6
From Local to Global: Raising the Patient Voice in Communities and Worldwide	9
Partnership and Collaboration: Working Together to Raise the Patient Voice in the Western Pacific and South-East Asia Regions	12
Building Cross-Sector Partnerships to Meet Patients' Needs in Asia-Pacific	16
Media Activities	19
Useful Resources	21
Regional Programme Participants	22



Introduction and Aims of the Report



From 12–14 October 2011, IAPO held a series of events in Manila, Philippines, in coordination with the World Health Organization (WHO). The aims of this Regional Programme were to strengthen the voice of patients in the Western Pacific and South-East Asia regions and to highlight the value of patient engagement to healthcare stakeholders. These events brought together 21 representatives from patients' organizations from ten countries in the regions.¹ Below is a summary of the events that took place as part of IAPO's Regional Programme:

Event	Aims of the event	Who attended?
Local patient group meeting: From Local to Global: Raising the Patient Voice in Communities and Worldwide	To strengthen networks and identify opportunities for collaboration at the national, regional and international levels	<ul style="list-style-type: none">• 16 patients' organizations from across the Philippines
Patient group workshop: Partnerships and Collaboration: Working to Raise the Patient Voice in the Western Pacific and South-East Asia	To support the development of a network of patients' organizations in the region and raise the patient voice on key issues in the region and to strengthen the contribution of the patient voice from the region in international healthcare policy	<ul style="list-style-type: none">• 21 patients' organizations from ten countries across the Western Pacific and South-East Asia
Multi-stakeholder seminar: Building Cross-Sector Partnerships to Meet Patients' Needs in Asia-Pacific	To bring together a wide range of healthcare stakeholders to discuss two pressing healthcare issues: non-communicable diseases and patient safety	<ul style="list-style-type: none">• 16 patients' organizations from across the Philippines• 21 patients' organizations from ten countries across the Western Pacific and South-East Asia• Multi-stakeholders including healthcare professionals, government representatives, academics and industry representatives

The aims of this report are:

- To provide a summary of the events in Manila and to promote understanding of the need for patient-centred healthcare
- To share useful information and resources to support participants in their continued work to promote patient-centred healthcare
- To outline the outcomes of the events and intentions for future action

We look forward to our continued work with colleagues in the Western Pacific and South-East Asia to improve patient engagement in decision-making, to strengthen healthcare systems in order to address patients' needs.

¹ Australia, Hong Kong, India, Japan, Malaysia, New Zealand, Philippines, Sri Lanka, Taiwan and Thailand.

Outcomes and Next Steps



Through these events, patients' organizations had the opportunity to network with like-minded patient advocates and other key stakeholders in health. Participants identified the need for a unified patient voice, evidence-based activities, the sharing of models and resources, media activities, training, and recognition of the role of patients' organizations throughout the healthcare sector.

Participants identified a range of potential follow-up activities as well as future actions, including:



- Working collaboratively to increase the profile of the patient-centred healthcare agenda and make it relevant to all key stakeholders
- Developing resources such as an advocacy toolkit, training programmes and a regional newsletter
- Sharing best practice such as successful communications and fundraising models
- Holding regional workshops (on patient safety and/or advocacy)
- Developing a mentoring or twinning programme to share skills and expertise

“Through these events, patients' organizations had the opportunity to network with like-minded patient advocates and other key stakeholders in health”

Next Steps for IAPO

This event was IAPO's first Regional Programme in the Western Pacific and South-East Asia and was a great opportunity for all involved. Over the coming years IAPO will support the capacity building of patients' organizations and patient networks at the regional level, in turn strengthening the global voice on patient-centred healthcare. IAPO will work with members to develop action plans to meet these aims.



Next Steps for Patients' Organizations Participants

The patients' organizations who attended these events have indicated that they will be taking forward their new learning and networks in a wide range of ways.

"I will start an advocacy working group."

Ken Hanioka, Health and Global Policy Institute

"I will contact healthcare stakeholders and invite them to seminars and conferences where their groups can contribute their experiences and share their views and opinions."

Lulu C Bravo, Confederation of Meningitis Organisations (CoMO)

"We would like to get together and push the agenda of patient safety and we would like to share and learn from other organizations regarding the pursuit of patient-centred healthcare."

Anantha Naik Nagappa, Association of Community Pharmacists of India

"I will work to help develop a network and programme for the region."

Mitch Messer, Health Consumers' Council Inc. (Western Australia)

Of the 19 organizations that completed evaluation forms:

- All respondents said the workshop contributed to their understanding of patient-centred healthcare and what this means in a regional context
- All respondents intended to take action after the workshop, including sharing what they have learnt inside their organizations and more widely through reports, presentations and workshops, applying for IAPO membership and declaring patient-centred healthcare. All respondents expressed a commitment to work more collaboratively within the region



Patients' Organization Participant Case Study

Maria Fatima Lorenzo, Philippine Alliance of Patient Organizations (PAPO)



I was invited to attend and partner with IAPO for their Regional Programme as I had previously met with Governing Board Member Kin-Ping Tsang. Following discussions with Kin-Ping in 2009 we decided to create a network of patients' organizations in the Philippines and the Philippine Alliance of Patient Organizations (PAPO) was born.

As a young organization, this event was an excellent opportunity for us to network with other patients' organizations and learn the best ways to develop our alliance. It was also useful for us to learn more about issues such as patient safety and how patients' organizations can use social media. Hearing the multi-stakeholder perspective was also invaluable.

During the sessions I most enjoyed the open space exercise, which gave us the opportunity to get advice from other organizations on how to develop our organization.

Since the event we have been able to use the important information we gained to take considerable steps to develop our organization and become more sustainable. We have opened a bank account, registered the organization, held our first assembly with our members and are partnering with the Asian Foundation on a programme to increase the inclusion of people with disabilities in the election process. We have been able to engage with local mayors and chief executives and have increased the involvement of patients in health insurance schemes.

Because of the contacts we made at IAPO's events we have been invited to a number of workshops and conferences on behalf of the World Health Organization (WHO) and the Department of Health. We have also been invited to be part of the WHO Patient Safety Curriculum, which has enabled us to go and talk about patient involvement to a number of different healthcare stakeholders and discuss how the medical community can engage with patients. We are being increasingly acknowledged as the group for patient involvement.

As an organization we are increasing our membership. Our membership has gone up from five to ten patient group members, many of these being contacts made at the workshop and local patient group meetings. Each of these organizations has about 5,000 members, which means that slowly but surely we have a much stronger voice. //



Healthcare Issues in the Western Pacific and South-East Asia: the Perspective of Patients' Organizations



Introduction

Ahead of the Regional Programme, a consultation was undertaken with patients' organizations in the region to investigate what issues they face. The results confirmed that despite differences in healthcare contexts and culture, patients' organizations across the region face similar healthcare issues and challenges and are undertaking similar activities to address these issues.

Healthcare Issues Affecting Patients' Organizations

Access to healthcare

This was an issue that affected most organizations and included access to basic healthcare as well as access to innovative medicines. The problem was compounded

for patients with complex and chronic conditions. One organization cited that their disease area, chronic pain, was not recognised as a chronic disease and that this had led to *"inadequate pain management services and understanding of the issue at primary healthcare level"*. Patients' organizations expressed concern that access to healthcare was not timely, with patients not receiving diagnosis or information about the disease quickly enough. To resolve this, they felt that *"it is essential that patients receive the right care by the right person in the right setting"*, and that all patients had access to high-quality, safe and patient-centred services.

Patient support

Patients need support, particularly to enable them to engage in healthcare reform and policy development processes. Patients' organizations felt that patient involvement is not yet widespread and needs to be imbedded in all levels of the healthcare system. One suggestion was to widen health literacy initiatives for patients *"to ensure active participation in their own healthcare"*.

Healthcare system structure

Patients' organizations reported that chronic diseases such as diabetes and heart disease are not being addressed adequately because healthcare systems are emphasising acute care rather than chronic and life-long conditions, with the approach being a *"predominantly medical model rather than a social model"*. Patient information, healthcare financing and a shortage of healthcare workers were also identified as challenges to healthcare systems. Respondents felt that there needs to be a more joined-up approach to healthcare services and that new technologies, such as e-health initiatives, could pave the way to improved healthcare systems.

Activities and Successes

Campaigns

The most common activity that patients' organizations have been undertaking is campaigning, particularly where there is low awareness of a disease area. These campaigns have had some notable successes, with one campaign resulting in faster diagnosis and higher quality of care for patients. Others had been undertaking media campaigns and events. These have resulted in *"increased profile and recognition of the importance of patient engagement and involvement in health reform and policy development"*, as well as strengthening the patient voice.



Services for patients

Patients' organizations provide a wide range of services for patients, such as telephone helpline services, support groups, counselling and email services. This work has improved patients' knowledge and resulted in better care for patients. Others have been providing capacity building services such as training and support to patients and members to help them to better engage with healthcare policy-making processes. By providing these services, more patients have been enabled to become more effective advocates who now have the ability to engage with healthcare stakeholders. One member, as a result of their efforts, now has skilled representatives on more than 50 committees across the healthcare system.

Policy and lobbying

Patients' organizations have been undertaking a wide range of activities with external stakeholders to improve healthcare for patients. They have been calling for more strategic partnerships between stakeholders and patients, promoting patient perspectives and lobbying governments to increase funding to healthcare services. Others have had direct involvement in the development of national policy, and have increased patient involvement by placing patients on national and local committees that work on healthcare issues. Through lobbying, patients' organizations in the regions have brought about change to a wide range of government policies, including stopping spending cuts to healthcare services. Others cited patient recommendations being included in policy areas such as vaccinations, smoking cessation, access to innovative medicines and healthcare reform. Other organizations have been involved in shaping a patient-centred approach in local and national quality and safety frameworks for healthcare.

Challenges

Patient involvement is not a priority

Patients' organizations felt that, in spite of recent advances, getting stakeholders to recognise the importance of involving patients in healthcare policy processes is still an ongoing challenge, with many stakeholders not regarding patient involvement as a priority. They also felt that patient involvement was not yet institutionalised, with decision-makers 'cherry picking' who they want to engage with. Patients' organizations felt that there needed to be more formal structures to ensure that the way in which stakeholders work with patients' organizations is structured and transparent.

Capacity of patients' organizations

Patients' organizations reported that having sufficient capacity is a challenge. Patients' organizations require training and support to enable them to engage with decision-making processes and need further capacity to deliver services to patients. One member felt that as the profile of their organization has grown, there has been increased pressure to respond to policy consultations and requests from the media yet it is essential to maintain day-to-day services for patients. Patients' organizations do not want to miss valuable opportunities to engage with stakeholders yet they do not always have the capacity to respond to all requests. One member felt that it was difficult to be considered an equal partner with healthcare stakeholders when the difference in resources and capacity is so large. Another member felt that they were unable to reach out to vulnerable communities due to their limited capacity.

Funding

Another challenge that hindered the capacity of patients' organizations was funding. They expressed that their workload was increasing, whilst overall budgets are remaining stable, putting pressure on organizations and preventing them from fully achieving their objectives.

Conclusions

Patients' organizations from across the Western Pacific and South-East Asia face common issues and are undertaking similar activities to address these issues. Access to healthcare is the key issue facing patient groups in the Western Pacific and South-East Asia regions and patients' organizations are working to raise awareness and to ensure patients are involved in decision-making. Patients' organizations in the regions have had great successes in bringing about changes to healthcare systems; however, funding and capacity limitations hinder them from achieving all their objectives. There is the additional challenge of ensuring that patients are involved in all aspects of healthcare and that healthcare systems continue to evolve to meet patients' needs. As one member stated: *"The mind-set amongst bureaucrats and health professionals is changing, however, there is still an emphasis on acute care, rather than chronic and life-long conditions, and on cure rather than prevention."*

From Local to Global: Raising the Patient Voice in Communities and Worldwide



IAPO and PAPO Patient Group Meeting, 12 October 2011

On the morning of 12 October 2011, IAPO and the Philippine Alliance of Patient Organizations (PAPO) hosted 16 patients' organizations from the Metro Manila area for a meeting entitled *'From local to global: raising the patient voice in communities and worldwide'*. The meeting explored the relationships between the work of patients' organizations at the international, regional, national and local levels.

The meeting began with three short plenary presentations from Jo Groves, IAPO CEO, on the global patients' voice, Kin-Ping Tsang, IAPO Governing Board Member and IAPO's lead for the Western Pacific region, on the work of patients' organizations regionally in the Western Pacific and Maria Fatima Lorenzo on the patient voice in the Philippines and the work of PAPO. This was followed by a facilitated discussion focused on identifying common healthcare concerns for patients in the Philippines and the possible outcomes of being connected as a network of patients' organizations.

"We share common concerns with other patient groups not just locally but internationally as well."

Maria Lourdes Formalejo, Hemophilia Association of the Philippines for Love and Service (HAPLOS)

Outcomes

Participants discussed their national healthcare issues, describing how the costs of healthcare are too high and patients with chronic conditions often have difficulty in accessing treatment regularly. Participants stated that patients require empowerment through education and information and, whilst patients' organizations can provide some of this, they need support and recognition in order to have an impact. The need for patient involvement in policy-making and the recognition of the patient as an important healthcare stakeholder was described as key to improving healthcare in the Philippines. Participants identified the top three healthcare issues in the Philippines as being:

1. Access to healthcare
2. Recognition of patients in policy-making
3. Lack of education

In a discussion on the value of being connected as a network of patients' organizations, a participant expressed the many benefits this presented which include:

- Sharing materials and best practices rather than reinventing the wheel
- A united and stronger voice with which to advocate
- Increasing credibility and having support which enables patient representatives to realise that *"we are not alone"*



"Networking is key to strengthening advocacy."

Leilani E Eusebio, I Can Serve Foundation

Participants felt that networks such as IAPO and PAPO provide a platform through which to work together and learn from each other, whilst also providing capacity building and advocacy tools and expertise. A participant described that working with PAPO is *"a partnership of sharing information"* and can provide vital recognition, information and support to the important work of patients' organizations throughout the Philippines.

"Overall it was a very educational, eye-opening and life-changing experience."

Cecilia Christine Manuel, Scleroderma Society of the Philippines

The important work of patients' organizations provides a fundamental contribution to the global patients' voice and by working together with national and regional organizations we can ensure that patients are recognised as partners in the healthcare decisions which affect their lives. The challenges of local patients' organizations are multifaceted as they endeavour to gain government recognition for their work whilst still building community and local provisions and support for the patients who they serve.

Next Steps

Participants expressed their commitment to work together on common issues and support each other in their work. PAPO plans to capture the momentum created at this meeting and build on the outcomes identified to bring Philippine patients' organizations together in a strong and active network that will lead towards the empowerment of Filipino patients. The organizations will consider how they can continue to share best practices and resources, undertake joint advocacy on common issues, and network and learn from each other. IAPO will continue to work with PAPO to ensure that the Filipino patient voice is represented at the international level, that they are supported through IAPO's resources and information, and that they share their expertise and experiences as part of our global network.

"PAPO's existence is nice to know."

Christopher L Malco, Yellow Warriors Society Philippines

"The event was very inspirational, it energizes our own mission and vision."

Maria Lourdes Formalejo, Hemophilia Association of the Philippines for Love and Service (HAPLOS)



Patients' Organization Participant Case Study

Orajitt Bumrungkulswat, Heart to Heart Foundation

IAPO invited my organization, the Heart to Heart Foundation, a patient group based in Thailand, to apply to attend the event. The application was accepted and I attended this event on behalf of the foundation.

Following the Regional Programme I have a much clearer understanding of the meaning of patient-centred healthcare. This event has contributed much in my understanding, especially the good practices from other organizations in the region. IAPO has helped to develop my understanding on how to communicate and network with patients' organizations and how to collaborate with stakeholders. The IAPO *Working with Partners and Stakeholders Toolkit* is very useful and I can apply many of the tools to my own work.

The group discussions were the most useful for me, particularly the last session, where my group discussed working as a network with other organizations to further our advocacy work. We discussed the possibility of setting up an advocacy working group comprising of experts, professionals, patients and volunteers to undertake advocacy training courses for healthcare stakeholders. From these training courses, expert patient advocacy champions could emerge.

Since this event I have been continuing my work to educate the public on how to care for their health and how to prevent and control chronic diseases such as cancer and heart diseases.

In November 2011, I will be speaking at a conference being held in Bangkok entitled '*Moving Towards Universal Health Coverage: Health Financing Matters*' on the topic '*voice of the people*'. This event is a great opportunity to advocate for greater patient involvement. I will be talking about how governments can support participants in the healthcare system and how they can strengthen networks with patients' organizations.

Since attending the event I have also organized a study visit to the Alliance for Patients' Mutual Help Organizations (of which IAPO Governing Board Member Kin-Ping Tsang is the Chairperson). Twenty-six people from different patients' organizations will visit Hong Kong for four days in February 2012 where we will learn more about patient-centred healthcare. This will include a visit to a local hospital and is an excellent opportunity to learn from other organizations.

Overall, the meeting was an excellent opportunity to better understand patient-centred healthcare and to meet with and share information with other patients' organizations in the region. Thank you very much, IAPO, for providing me with this opportunity!



Partnership and Collaboration: Working Together to Raise the Patient Voice in the Western Pacific and South-East Asia Regions

IAPO Regional Patient Group Workshop, 12–14 October 2011

On 12–14 October 2011, 21 patients' organizations from the Western Pacific and South-East Asia regions participated in an interactive workshop entitled *'Partnership and collaboration: working together to raise the patient voice in the Western Pacific and South-East Asia regions'*. The aims of the workshop were to:

- Develop understanding on the common issues faced by patients in the regions
- Build networks and increase understanding of patient-centred healthcare
- Develop action plans for follow-on advocacy and partnership work

Participants were welcomed to the event on the evening of 12 October, where they introduced their organizations and shared their expectations for the workshop. The patients' organizations looked forward to the discussions ahead and the opportunity to share and learn experiences and consider the common healthcare issues for the patients who they represent.



On 13 October the workshop opened with plenaries from Durhane Wong-Rieger, IAPO's Chair, Jo Groves, and Kin-Ping Tsang. Kin-Ping outlined the regional variances in healthcare access and delivery across the regions which show that, whilst there are disparities between countries, all face challenges in ensuring patients have access to safe, quality and appropriate healthcare that is equitable and affordable.

"[The workshop] has strengthened my resolve that it takes a village to raise a child. We can't do it alone. We need our friends in the region and in IAPO to make it happen. We share common health issue problems despite our geographical and sociocultural differences."

Maria Fatima Lorenzo, Philippine Alliance of Patient Organizations (PAPO)

Participants considered the difference which patient-centred healthcare would make to the patients they work with, identifying major challenges to achieving patient-centred healthcare and possible solutions. They highlighted challenges relating to a lack of information and awareness for patients and healthcare providers, patient-medical professional relationships, healthcare system funding structures and inequity and disparities in access to quality healthcare. Participants agreed that patient-centred approaches were needed to address these challenges and should include: patient education, collaboration and partnerships between all stakeholders, patient empowerment, improved communications between all stakeholders and the involvement of patients and communities in the

allocation of resources. A need for a change in healthcare cultures and a stronger patient voice were identified as being important to enabling patient-centred healthcare in the Asia-Pacific region. It is not just a patient voice, but a patient voice which is heard and acted upon within healthcare systems, which is required to enable meaningful change. Participants called for patients' organizations to be better supported and recognised by policymakers in the important work that they do.

"The ability to talk to others who have the same issues is great."

David Rawlings, AccessAustralia

The next day participants considered the potential of media and communications in their work, explored advocacy strategies and began action planning. Presentations on global, regional and national advocacy work were shared by IAPO, Dr Madeleine de Rosas-Valera, Technical Officer (Patient Safety), World Health Organization (WHO), Stephanie Newell, Patients for Patient Safety Champion, Australia, and representatives of IAPO member the Health Care Consumers' Association of the ACT from Australia. Participants stressed the importance of patients' organizations working together and across the sector to change regional and national policies for the benefit of patients.

"We can work together with other member groups bilaterally and as a regional consortium to achieve common goals."

Russell McGowan, Health Care Consumers' Association of the ACT, Australia

A participant-led, discussion-based activity drew out the main themes to emerge from the event as:

- Patient education
- Inequitable access to healthcare
- Encouraging healthcare providers to be more patient-centred
- Patient involvement in decision-making
- Raising awareness of patient-centred healthcare
- Empowering patients' organizations





Participants identified the need for a unified patients' voice, evidence-based activities, media activities, training and recognition of the role of patients' organizations throughout the healthcare sector. Participants also discussed strategies in regards to each of these issues. The workshop was rounded up with a group action planning session in which participants drew on their discussions to draft action plans for projects which they could take forward as an Asia-Pacific network of patients' organizations. The workshop was closed by Durhane Wong-Rieger and Kin-Ping Tsang, who reflected on the inspiring contributions which participants had made to the workshop over the two days and remarked on the possibilities that had been raised on working together to strengthen the patient voice in the region.

"Fantastic! Best international meeting I have attended."

Dr H B Tamitegama, Lanka Alzheimer's Foundation, Sri Lanka

"This event has contributed much in my understanding in order to learn and adapt my work, especially the good practices from other organizations in the region."

Orajitt Bumrungruskulswat, Heart to Heart Foundation, Thailand

The workshop was rounded up with a group action planning session in which participants drew on their discussions to draft action plans for projects which they could take forward as an Asia-Pacific network of patients' organizations //





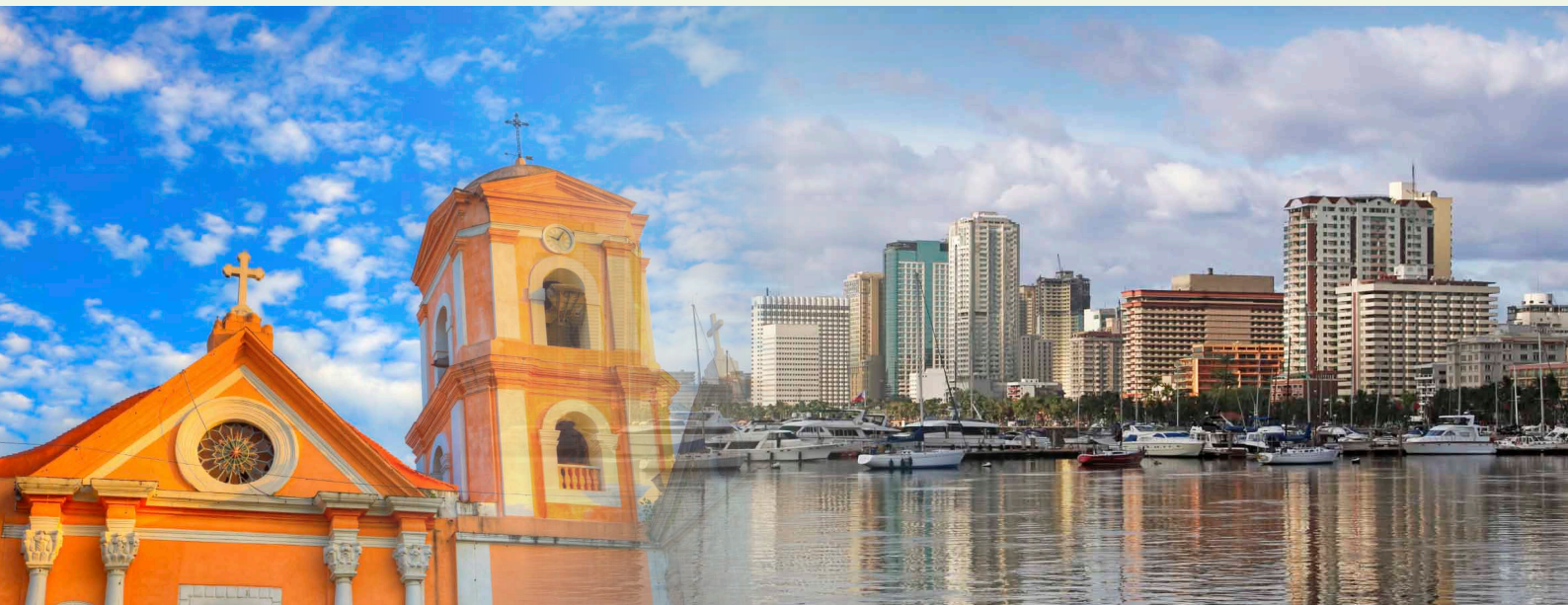
Patients' Organization Participant Case Study

Dr H B (Tami) Tamitegama, Lanka Alzheimer's Foundation, Sri Lanka

// As a fairly new member to IAPO this is the first time I have met with a group of professionals with an interest in looking at the patient as a human being. I felt nurtured and felt like the other stakeholders were very enthusiastic.

I found the sessions where we interacted on individual work assignments of most use, it was a great learning experience to hear about other people's work and how they have worked to meet shared challenges.

These events have enabled me to think more about how we can better support dementia patients. The learnings have been very useful and I have shared these with my colleagues and our constituents. Moving forward, I am very much looking forward to further developing my skills and having further discussions at the 5th Global Patients Congress in March 2012. //





Building Cross-Sector Partnerships to Meet Patients' Needs in Asia-Pacific



IAPO Seminar, 13 October 2011

Patients' needs in the Asia-Pacific region will only be met if there are effective cross-sector partnerships between healthcare stakeholders. To stimulate information exchange and dialogue, IAPO convened a seminar with a range of stakeholders from across the healthcare system including representatives from: patients' organizations, healthcare professional associations, the Department of Health, the healthcare industry and academia.

The seminar, held in coordination with the World Health Organization (WHO), was comprised of two sessions and provided an opportunity to share information and initiatives and to discuss and debate two current challenges for patients and all those involved in healthcare in the Asia-Pacific region: non-communicable diseases (NCDs) and patient safety.

Panel 1: Non-communicable diseases

NCDs are having an increasingly negative impact on the health and socio-economic development of people throughout the region. Chaired by John Forman, Executive Director, New Zealand Organization for Rare Disorders (NZORD), the first panel session featured presentations from a range of stakeholders on the challenges posed by NCDs and the role of patients in addressing them.

Speakers:

- Dr H B Tamitegama, President, Lanka Alzheimer's Foundation, Sri Lanka
- Dr Reynaldo Lesaca, Clinical Psychiatrist, Philippines
- Dr Tony Dans, University of the Philippines College of Medicine
- Dr Paulyn Jean B Rosell-Ubial, Assistant Secretary of Health, Department of Health, Philippines

The first three speakers highlighted many important issues to be considered when tackling NCDs, including:

- The impact of poverty and socioeconomic factors on the prevalence of NCDs
- The need for a range of interventions from legislation to community actions to combat these conditions, including meaningful government support and leadership for community action to flourish
- The importance of including the patient voice in decision-making in a meaningful and comprehensive way
- The importance of joined up, multi-disciplinary teams that are sensitised to the needs of patients
- How patients can be more formally engaged in policy-making, who they need to talk to and how to raise their issues



The final speech was made by Assistant Secretary of Health, Dr Paulyn J Rosell-Ubial, Department of Health, Philippines. The Assistant Secretary spoke of the recognition of the role of civil society and patients' organizations as partners in healthcare within the Department of Health. She stressed that there was a desire to support patients' organizations more but that resources were a challenge. Likewise, the Department of Health was looking at further ways to formalise the involvement of communities in policy-making. The Assistant Secretary described some of the other healthcare reforms taking place to address NCDs and acknowledged that there was work still to be done.

Panel 2: Patient safety

The second panel session focused on patient safety. This session was chaired by Stephen McMahon, IAPO Governing Board Member and Chair of the Irish Patients Association.

Speakers:

- Leonila M Ocampo, RPh, MS, President of the Philippine Pharmacists Association, Inc
- Linda Buhat, Assistant Director, Nursing Services, Philippine Heart Center
- Kin-Ping Tsang, IAPO Governing Board Member and Chair of the Alliance of Patient Mutual Help Organizations, Hong Kong

Key points from the presentations included:

- The need to recognise the importance of tackling patient safety issues in partnership with patients and other healthcare providers
- The experience of patients is a key factor in making patient safety improvements but it is not always easy to convince other stakeholders of the need to capture that experience
- Patient safety is dependent on strong systems within healthcare facilities to prevent patient safety incidents occurring through, for example, fostering a culture of safety
- Small, but well thought out, interventions could mean the difference between ensuring safety and an incident occurring, for example, small alterations to a patients environment to minimise risks of accidents

Key outcomes

Throughout the seminar, a recurring theme was that **patients should be the local leaders of a whole of society approach to tackling healthcare challenges**. Participants felt strongly that their work in addressing healthcare challenges and delivering essential support to patients is not afforded the significance it deserves. In the Western Pacific and South-East Asia regions, patients' organizations are providing services that range from supporting patients in managing their conditions and providing education, to advocating for change, and yet many are not recognised formally by the healthcare system. Their sustainability depends on obtaining this recognition and being included as an integral component of the system.



Patients' Organization Participant Case Study

David Rawlings, AccessAustralia

// The Regional Programme provided excellent networking opportunities and it was great to find out more about what other patients' organizations in the region were doing. It was really valuable to be able to share success stories and to find out that, despite different cultures and healthcare contexts, groups at the meeting shared a lot in common. I also had the opportunity to share my 20 years of experience of patient advocacy with younger patients' organizations in the Western Pacific who are at the beginning of their journey.

The session on social media run by IAPO was very useful. We already use social media at AccessAustralia, but it was interesting to get another perspective from IAPO, who have a lot more expertise in this area. I have definitely taken away some useful ideas to take forward.

The final session was great because, after receiving a lot of information over the couple of days, we were able to sit down and come up with tangible outcomes. Our group discussed the potential to develop a newsletter for the Asia-Pacific region. The aims of the newsletter are to continue the conversation on a regular basis, learn from each other, identify regional issues, provide support on projects addressing regional issues and share resources.

Since the Regional Programme, one of my actions has been to keep in touch with the Australian organizations who attended. I have also been in touch with some of the Philippines organizations, and continued to share my experiences with them.

I am also looking to implement a social media strategy based on what I learnt from the session on social media at the Regional Programme.

Lastly, I have been working with participants from my group and with IAPO to develop the Asia-Pacific newsletter. I am taking the lead in the development of the newsletter and will be responsible for coordinating and editing the newsletter. I am putting together a project plan and my next action following the development of the action plan will be to develop the first edition of the Asia-Pacific newsletter.

The ability to talk to others who have the same issues is great, and knowing that we are all experiencing similar challenges, regardless of differences in culture. Great job guys! //

Media Activities



In the lead-up to, during and after the Regional Programme, IAPO used a variety of methods to share key outcomes and messages.


As well as sending out a media alert and press release, Facebook and Twitter were used extensively to communicate with delegates and other interested parties. This meant that instant updates could be given on discussions and that photographs, presentations and documentation could be shared widely.


A number of patients' organizations and other groups shared information about the workshop in their newsletters, on their websites and in other communications including:


- **Confederation of Meningitis Organisations:** <http://comoonline.org/news-and-activities/2011/10/12/working-together-to-raise-the-patient-voice-in-the-western-pacif/>
- **Retina International:** www.retina-international.org/news-events/press/?id=556
- **Australian Pain Management Association:** www.painmanagement.org.au/content/asia-pacific-regional-meeting-patient-organisations
- **eCancer News:** <http://ecancer.org/news/2057>
- **Patient Safety Foundation, Poland:** www.patientsafety.ntx.pl/index.php?p=news&id=60
- **Consumers Health Forum, Australia:** www.chf.org.au/pdfs/csh/csh-2011-6.html


Using Twitter the hashtag **#IAPOWesternPacific** was created, which meant that every time somebody mentioned the events the discussions could be tracked and shared with networks across the globe. Comments included:

- 🐦 "Thanks for the tweets! Almost feels like I'm there, only without the humidity!"
Darlene Cox, Health Care Consumers' Association of the ACT (HCCA), Australia
- 🐦 "...excellent seminar on building cross-sector partnerships to meet patient needs."
Health Consumers Alliance of South Australia
- 🐦 "Great comment @ #IAPOWesternPacific – no patient involvement in health systems is like trying to put icing on when there's no cake."
Mitch Messer, Health Consumers' Council (WA) Inc, Australia
- 🐦 **IAPO Governing Board Member KP Tsang** comments on patient safety: "The most expensive drug is the unsafe drug."

 **Linda Buhat:** "Trust is a key part of caring and healing and open communication is essential to maintaining trust."

 **Dr Dans** on #NCDs: "We need to identify leaders in each country and convince them to become health advocates and ensure the intentions of #UNSummit are realised."

 "70 million Asians a year pushed across the poverty line by #NCDs."

 #IAPOWesternPacific patient advocates: "Doctor knows best has been replaced by the economist knows best... but really the patients know best."

Using Facebook we were able to instantly upload photographs from the events and share media alerts and press releases with a wider audience.



www.facebook.com/internationalallianceofpatientsorganizations



www.twitter.com/IAPOtweets

Additionally, IAPO also developed and published a press release, '*Patients are the local leaders of healthcare*':
www.patientsorganizations.org/showarticle.pl?id=1371

Useful Resources



IAPO has a number of resources which can be used to promote patient-centred healthcare in the Western Pacific and South-East Asia regions. All of these resources can be found on IAPO's website.

IAPO Declaration on Patient-Centred Healthcare

www.patientsorganizations.org/declaration

This Declaration outlines five principles essential for patient-centred healthcare. The five principles are: respect; choice and empowerment; patient involvement in health policy; access and support; and information.

IAPO Policy Statement and Guidelines on Patient Involvement

www.patientsorganizations.org/involvement

IAPO's Policy Statement on Patient Involvement outlines IAPO's position on the need to involve patients in all levels of healthcare policy decision-making. The Guidelines can be used as a checklist to involve and engage patients and patients' organizations in an appropriate and meaningful way.

IAPO Policy Statement and Guidelines on Health Literacy

www.patientsorganizations.org/healthliteracy

Low health literacy affects a person's ability to make informed decisions about their health. IAPO's policy statement calls on stakeholders to extensively review the existing health-related information they produce and the way in which this is communicated.

IAPO Policy Statement on Patient Information

www.patientsorganizations.org/information

IAPO's Policy Statement on Patient Information calls on all stakeholders involved in communicating information to patients to ensure that they involve patients and

patients' organizations in all information-related policy and delivery decisions.

IAPO Toolkit: Working with Partners and Stakeholders

www.patientsorganizations.org/partnersandstakeholders

This online toolkit outlines how patients' organizations can work effectively with a range of partners and stakeholders. Areas covered include raising disease awareness, advocacy, strategic planning, fundraising and effective communication.

IAPO Statement on Non-communicable Diseases

www.patientsorganizations.org/NCDstatement

IAPO's statement released during the UN Summit on Non-communicable Diseases in September 2011, calls on countries to include a number of specific actions in their strategies to prevent and control non-communicable diseases (NCDs).

Addressing Global Patient Safety Issues: An Advocacy Toolkit for Patients' Organizations

www.patientsorganizations.org/patientsafety

This toolkit provides the means for patients and patients' organizations to engage in the provision of healthcare and contribute to a quality and safe healthcare system, and a reduction in harm to patients.

IAPO Western Pacific

www.patientsorganizations.org/westernpacific

An outline of the events that took place during the Regional Programme, along with presentation slides.



Regional Programme Participants

Twenty-one patients' organizations attended the Regional Programme in Manila, Philippines, from ten countries across the Western Pacific and South-East Asia regions. Thirteen of these organizations were IAPO members and eight were patients' organizations invited to attend the events.

Australia

AccessAustralia

AccessAustralia is a consumer-based, independent, non-profit organization committed to being a national voice in promoting the well-being and welfare of infertile people of all ages, through representation in the general community and in the medical, scientific and political arenas. AccessAustralia's goal is to establish alliances with infertility patient associations around the world, to raise global awareness of our collective needs and to challenge the cultural taboos surrounding the experience of infertility.

Australian Pain Management Association

The Australian Pain Management Association Inc. (APMA) was established by people with chronic pain. Their mission is 'To enhance the wellbeing of all Australians living with persistent pain through supported self-efficacy'. APMA's work is centred on providing support, options, information and advocacy for people with persistent/chronic pain in Australia. APMA advocates for recognition of persistent (chronic) pain as a disease in its own right and for better health and community services for people with ongoing pain, and believes pain management is a human healthcare right.

Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. CHF member organizations reach thousands of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective. CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.

Health Consumers Alliance of South Australia

The Health Consumers Alliance (HCA) is the peak body for health consumers in South Australia. As an independent alliance of health consumers and health consumer organisations, we work together with our members to achieve our vision of wellbeing through health for all South Australians. Reflecting the consumer perspective, HCA promotes a holistic and integrated approach to health and wellbeing. As a fundamental aspect of health, mental health is a key focus within HCA. HCA's vision is 'Wellbeing through health for all South Australians'. HCA's mission is 'To provide a respected and informed consumer voice to influence the development of quality health services'.

Health Care Consumers' Association of the ACT

The Health Care Consumers' Association of the ACT (HCCA) is the principal health consumer advocacy organisation in the ACT. It has supported and developed health consumer perspectives and policy in the ACT for over 30 years. HCCA is a body through which health care consumers can participate in policy, planning and service decisions that affect their health. HCCA works to improve the quality and availability of health services, supports consumers to identify shared priorities about health, and represents these views to the ACT Government. The organisation is the peak consumer organisation in the ACT, advocating for the inclusion of consumers on health boards and planning structures.

Health Consumers' Council Inc. (Western Australia)

The Health Consumers' Council was set up as an independent patient group who would bring a different and unique perspective to matters of health and policy. The Health Consumers' Council comments publicly on all matters to do with health. The purpose of the Council is to raise awareness of and advocate for health consumers rights in Western Australia. Their vision is to be an independent, authoritative and effective voice of and for health consumers in Western Australia.

Hong Kong

Alliance for Patients' Mutual Help Organizations

The Alliance for Patients' Mutual Help Organizations, 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. The objectives of the Alliance are to encourage and escalate the spirit of mutual help; to promote communication among patients with their families and friends and to support patients as they adjust to living with their illness; to undertake advocacy to improve care of chronic patients and raise public awareness; and to strive for the welfare and legal rights for patients.

Retina Hong Kong

Retina Hong Kong (formerly known as "Hong Kong Retinitis Pigmentosa Society") was formed in March, 1995 by a group of people suffering from Inherited Retinal Degenerative Diseases (IRDD) with the genuine support of some medical practitioners, optometrists, geneticists, scientific researchers and warm-hearted individuals. Their aim is to support people with IRDD.

India

Association of Community Pharmacists of India

Association of Community Pharmacists of India is a patient-centred organization in India made-up of all persons engaged in, interested in or connected with community pharmacy. Their objectives include; elevating and establishing a standard of competence for community pharmacy; develop and promote standards of education and training for community pharmacy; developing and promoting short-term informal training programmes for individuals interested in community pharmacy; and to serve as a forum for exchange of ideas and experiences, and collection and dissemination of information in general community pharmacy.

Japan

Health and Global Policy Institute

Since establishment, Health and Global Policy Institute has been working to help citizens shape health policies by generating policy options, and to bring stakeholders together as a non-partisan think-tank. Their mission is to improve the civic mind and individuals' well-being, and to foster a sustainable healthy community by shaping ideas and values, reaching out to global needs, and catalyzing society for impact. The Health and Global Policy Institute promote a Global Citizen Nation by building a society for people with various backgrounds and different values. We aim to achieve a sustainable, healthy, and more prosperous world.

Malaysia

Malaysian Rare Disorders Society

Malaysian Rare Disorders Society (MRDS) was established in 2004 as a support group for individuals with rare disorders. Currently MRDS have 49 members/families with a range of 27 rare disorders. Their objective is to focus in providing support and to be a resource centre for their members. MRDS organize fundraising projects to support their cause, promote awareness on rare disorders and supports training and research for medical genetic professionals. MRDS work in alliance with agencies and organizations in achieving these objectives. They hope to represent the voice of our members, to advocate and empower them to attain a better quality of life.

New Zealand

New Zealand Organisation for Rare Disorders

New Zealand Organisation for Rare Disorders (NZORD) is a registered Charitable Trust set up in 2000, following a conference of over 30 rare disease support groups. NZORD now has a network of 147 support groups. NZORD's mission is to support and

improve the level of organisation and information among patients and families affected by rare disorders; to promote research and education that will identify rare disorders early and ensure the best clinical care for the patient and best social support for the family; and to build partnerships of patients/families, clinicians, researchers, government and industry, that accelerate the research effort towards control and cure of rare disorders.

Philippines

Balikatang Thalassaemia Association

Balikatang Thalassaemia Association (Ba-THa) was founded in 1993 with the aim to promote public awareness of thalassemia while at the same time continuously educating its members regarding the basic and latest updates in the management of this hereditary blood disorder. Their major areas of concern include the need for accessible and affordable thalassemia screening programs for communities, accessibility of safe blood products for transfusion dependent patients and affordability of life saving iron chelating medications for the treatment of iron overload.

Confederation of Meningitis Organisations

The Confederation of Meningitis Organisations Inc (CoMO) brings together patient groups and child health organisations from all over the world who are working towards the elimination of meningitis and its related septicaemia and who support those touched by these diseases. CoMO was founded in September 2004, at the close of a World Conference of Meningitis Organisations. The mission of CoMO is to assist its members to be sustainable, identifiable and influential sources for information and support services for those people affected by meningitis in their countries and regions while being united globally in their endeavors through their membership of CoMO.

Hemophilia Association of the Philippines for Love and Service Foundation

Hemophilia Association of the Philippines for Love and Service Foundation (HAPLOS) is the first ever lay-support group for Filipinos with hemophilia. Its members are people with hemophilia, their families and caregivers, advocates, medical and paramedical practitioners who have an interest in hemophilia. HAPLOS seeks to improve the quality of life of people with hemophilia by providing programs that enable them to become physically active, mentally sharp, socially involved, emotionally healthy, spiritually strong and build a community that can support each other and grow to help each other. Its mission is to foster the care, management and better understanding of hemophilia by making available support, treatment and basic education to people with hemophilia and their families.

Philippine Alliance of Patient Organizations

In 2009 patient groups in the Philippines realised the need for a national coalition and following an event on patient-centred healthcare that year, they formed the Philippine Alliance of Patient Organizations (PAPO). PAPO's vision is one where Filipino patients are health advocates, have access to universal healthcare and allied services, live independently in an inclusive environment and enjoy equal opportunities, while pro-actively participating in nation building. The mission of the coalition is to be a strong and active network of patient groups that will lead towards the empowerment of Filipino patients, to advocate for their rights by providing a venue for networking and capacity building and to enable patients to become productive members of society.

Yellow Warriors Society Philippines

The Yellow Warriors Society Philippines is the nationwide, community-based, voluntary health organization dedicated to promote a healthy and productive society by fighting hepatitis B and C as a major health problem in the Philippines by preventing hepatitis B and C, crushing all forms of discrimination upon hepatitis B and C carriers, and diminishing suffering from it through advocacy, research, education, and service. Their work includes patient education, advocacy for healthy living, reducing stigma and discrimination, support and counselling for those affected by hepatitis, advocacy for free and low cost screening and treatment, and the promotion of research and clinical studies on hepatitis and related diseases.

Sri Lanka

Lanka Alzheimer's Foundation

Lanka Alzheimer's Foundation (LAF) is an approved charity and registered volunteer based community organization. LAF's mission is, 'To do all that is possible to improve the quality of life of those with Alzheimer's and related disorders (dementia) and support their families and carers to cope with the challenges generated by those conditions and provide sustainable information and practical modalities to those reaching their senior years, to maintain the rigors of healthy living and commit to stay engaged throughout those years'. LAF serves a growing population of seniors, through the establishment of their Dementia Services and Information Centre; mobile services; communications with seniors organisations; and initiating relevant professional training and research.

Taiwan

Taiwan Healthcare Reform Foundation

The Taiwan Healthcare Reform Foundation (THRF) is an independent, non-governmental organization that aims to improve the healthcare quality and patient's rights in Taiwan. THRF work to address various healthcare concerns in Taiwan through advocacy, public education, and publications. Their mission is to promote a high quality, fair, and just healthcare system in Taiwan. THRF's goals are to push for a transparent, accountable healthcare system; promote healthcare safety and patient's rights; encourage the public to participate in healthcare reform; advocate for the fair and just distribution of healthcare resources; and to cooperate with the public to supervise the healthcare environment.

Thailand

Heart to Heart Foundation

The Heart to Heart Foundation (HHF) was established to bring together patients with chronic diseases that require high-cost treatments, such as cancer, heart diseases and kidney diseases, in order to provide them with the ability for self-care and care for fellow patients for improved quality of life. HHF also provide help to healthcare providers as volunteers in order to reduce their work load, and to improve the healthcare system and humanize healthcare. HHF's mission includes the promotion and implementation of friendship support activities for quality of life improvement, based on familial and social compassion.

Patients' Hope Givers Club

Patients Hope Givers Club comprises of several patient support groups in Thailand. Their mission is to offer moral support to patients; promote knowledge on healthcare to patients and caregivers; advocate for patients' rights and access to healthcare; and represent the interests of patients and caregivers.



703 The Chandlery, 50 Westminster Bridge Road, London SE1 7QY, United Kingdom
Tel: +44 20 7721 7508 Fax: +44 20 7721 7596 Email: info@patientsorganizations.org
www.patientsorganizations.org