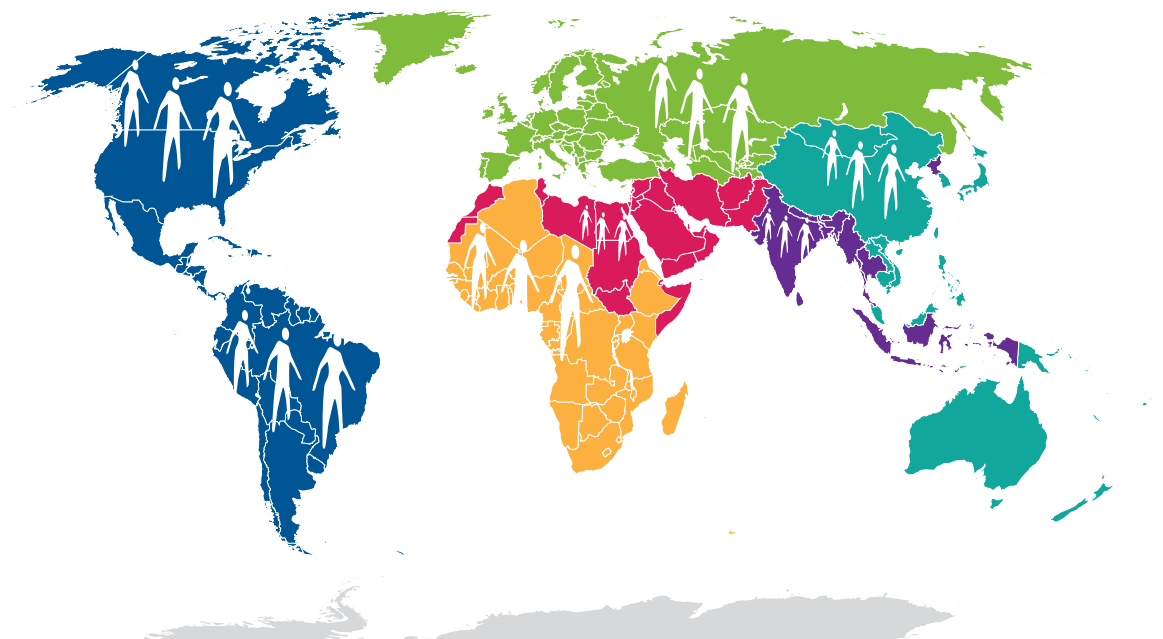


IAPO World Health Assembly Mentor Programme 2011–2012

Report and Guidelines for Patients' Organizations





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Foreword from IAPO Chair



I am delighted to share with you the report and guidelines from IAPO's 2011–2012 World Health Assembly Mentor Programme, held in Geneva, Switzerland, in May 2011 and then delivered remotely in the year that followed.

More than ever, patients' organizations have opportunities to bring the patients' voice to healthcare policy debates at a national, regional and international level on key issues, and this means they must also have the knowledge and skills to develop positions on global health issues. In 2011, we further developed our IAPO member support programme by undertaking an

initiative to mentor seven patient advocates from IAPO member organizations in different world regions through the processes of the World Health Organization (WHO) and its decision-making forum, the World Health Assembly (WHA). This provided a focused opportunity to develop and support these members' strategic approaches to their advocacy work whilst also enabling IAPO to consolidate its advocacy tools for members and provide guidelines for the wider membership. These are included here.

We believe there has never been a more fortuitous time to be a patient advocate. From the United Nations and the World Health Organization to national Ministries of Health to local healthcare providers, patient-centred healthcare and patient engagement are no longer 'nice to have' ideas but truly drive healthcare mandates, programmes and initiatives. IAPO continually strives to support patients' organizations throughout the world to play an effective role at the healthcare decision-making table, and this Mentor Programme was an initiative which enhanced the advocacy work of its participants. It also provides information to patients' organizations worldwide through this report and guidelines.

We would like to thank the participants for their commitment and dedication, which were essential to making the programme a success. We also thank the experts who contributed enormously to the programme, including: Ilona Kickbusch, Director, Global Health Programme, Graduate Institute for International and Development Studies, Geneva; Dr Ashley Bloomfield, Partnerships Adviser, Noncommunicable Diseases and Mental Health Cluster, WHO; Alex Ross, Director, Partnerships and UN Reform, Director-General's Office, WHO; and Marc Wortmann, Executive Director, Alzheimer's Disease International. We thank Anna Lee, Programme Officer, Patients for Patient Safety (PPFS), WHO Patient Safety, for her support during the development of these guidelines. We would like to acknowledge the programme sponsor, the Medtronic Foundation, for their financial support and commitment over the years.

We look forward to our continued work with you to ensure patients throughout the world are at the centre of healthcare. We hope that you find this report and the guidelines useful as you work toward making patient-centred healthcare a reality in your setting.

A handwritten signature in dark ink, appearing to read 'Durhane Wong-Rieger'.

Durhane Wong-Rieger
Chair, International Alliance of Patients' Organizations

Introduction



In 2011 and 2012 the International Alliance of Patients' Organizations (IAPO) ran a World Health Assembly Mentor Programme, which aimed to provide participants with an understanding of the World Health Organization (WHO) and the World Health Assembly (WHA), including relevant issues, activities and processes. Seven patient advocates from five IAPO member organizations participated in the programme, which began with a three-day event to coincide with the 64th WHA in Geneva, Switzerland, in May 2011 and continued remotely for one year.

The Mentor Programme offered participants expertise on working with WHO and Ministries of Health at an international, regional and national level and explored approaches to partnerships and advocacy. Participants were supported in the development of action plans for their time at the WHA and the year that followed this, with goals which supported the mission of their organization and IAPO's mission to build patient-centred healthcare.

This report and guidelines were developed by gathering and consolidating information from IAPO's Mentor Programme, WHO's website, other IAPO materials and knowledge, and from the experiences of IAPO's members. It aims to capture the experiences of IAPO members participating in the programme and provide a resource for all patients' organizations. This publication has two sections: 1) a report of the Mentor Programme; 2) guidelines to assist patients' organizations to understand the role of WHO and the different ways they can engage with WHO.

IAPO and WHO

As part of its Strategic Plan 2010–2014, IAPO aims to facilitate the engagement of patient representatives in WHO activities and decision-making processes. IAPO has worked with WHO in an official capacity since 2007. IAPO is a member of the core steering group for the WHO Patients for Patient Safety (PFPS) programme and it is through this work that IAPO has official relations with WHO. Through their extensive collaborations IAPO has gained insight into the engagement of patients' organizations in WHO's work as well as the valuable contributions that patients can make to WHO.

IAPO works with patients' organizations around the world that often want to know more about the work of WHO and how this relates to their own objectives, but are uncertain about where to start and how to navigate WHO's structure. IAPO's Mentor Programme aimed to address this uncertainty and share information with patients' organizations more widely through this report and guidelines.

"I learned that the people we are talking to are not always the right people. I found out more about the different diseases. Also that you can contact the WHO and find out who the right people are."

Leigh-Ann Bailie, Patient Health Alliance of Non-Governmental Organisations

WHA Mentor Programme Report

To deepen participants' understanding of WHO, the purpose and processes of the World Health Assembly (WHA), and to assist participants in developing their strategic approach to engaging with WHO and their Ministries of Health, the Mentor Programme had three core components:

1) Knowledge Transfer; 2) Action Plans; and 3) Progress Support.



Knowledge Transfer

Information on WHO's purpose, including how it functions, was shared through seminars and workshops held during the 64th WHA. This information was built on in the year that followed via teleconference, email and an online forum. Through the Mentor Programme, participants met with a range of healthcare experts, including representatives from WHO, who shared insight on WHO's activities, particularly in the areas of patient safety, non-communicable diseases (NCDs) and patient engagement. The programme included an introduction to WHO and the WHA, presented by Dr Ashley Bloomfield, Partnerships Adviser, Noncommunicable Diseases and Mental Health Cluster, and Alex Ross, Director, Partnerships and UN Reform, Director-General's Office, WHO. Participants learnt about the structure and role of WHO, as well as acquiring specific information about the WHA agenda and opportunities to get involved during and following the WHA.

The programme explored how to work with WHO, with examples from IAPO's collaborations with WHO and those of IAPO members. Participants were guided through the benefits of working with WHO and the importance of international, regional and national levels of engagement. IAPO member Alzheimer's Disease International (ADI) gave participants an insight into ADI's work with WHO and the key factors in achieving a successful collaboration. One programme participant said that prior to the Mentor Programme they had considered WHO to be a "vast, unknowable machine", and were not sure of how they could engage. Meeting representatives from the WHO helped participants to understand the organization with invaluable insider knowledge.

"We have also made contact with other NGOs – this was very useful as we gained information from many different countries and we discovered new solutions from them."

Anna Sliwinska and Andrzej Bauman, Polish Diabetes Association

Networking with other patient advocates and sharing experience and best practices were reported as being invaluable components of the programme. All participants highlighted that their knowledge increased through the programme and that they valued hearing about the strategies employed by other patients' organizations, in particular, how they have overcome challenges.

"Meeting and networking with other NGOs and hearing about their stories gives me the strength to keep on, as it provides confirmation that we are moving in the right direction and are not working alone."

Anastasiia Gavrilo, Stop Hepatitis, Ukraine

Action Plans

Mentor Programme participants were assisted in the development of a WHA action plan. The plan set out how they could work with WHO and/or Member States to address an issue in their work and what they could offer to the collaboration. Participants developed aims that were either at the international, regional or national level. These focused on a range of areas of healthcare which included diabetes, incontinence and patient safety. They then attended the WHA to work on their action plans with support from IAPO. Action plans were revisited at the end of the event to make any adjustments which participants felt would be necessary after meeting delegates and policy-makers.

An aim of the programme was to provide the opportunity to meet country delegations at the WHA. In preparation, participants considered advocacy and communications strategies to strengthen the engagement of their organization in policy-making. They discussed tactics used to engage in policy debates at the international, regional and national levels and how to raise the voice of their organization in such debates. Activities in the action plans included:

- Collaborations with other civil society stakeholders working in health to build a strong patient voice on shared issues and agendas
- Partnerships with international groups working on health development to improve health outcomes in low-income countries in their region
- Raising awareness of a condition amongst local populations to raise its importance on political agendas

All participants reported that the Mentor Programme had contributed to their advocacy strategies and met or exceeded their expectations.

"It was a great experience. I had the opportunity to understand who I needed to engage with at the international level. I have developed the knowledge of how to move forward in our action plans. I have also gained knowledge on patient safety, patient engagement, how patient groups can engage with WHO and other possible areas of involvement such as dementia."

Antoinette Zahra, World Federation of Incontinent Patients

All participants advanced or completed the actions they intended to in the programme and felt confident that they had gained the skills and knowledge needed to achieve the objectives outlined in their action plans. Participants reported that they felt more confident in recommending a patient-centred healthcare system and that they saw the value of working more collaboratively. As a result, some participants are now more active in European advocacy groups and are networking with other civil society stakeholders in population health, including disease-specific non-governmental organizations (NGOs).

"We have more confidence in recommending a more patient-centred healthcare system based on international movements in this direction, and a greater understanding of the way in which focusing on the impact of social determinants of health can potentially improve health outcomes for populations."

Russell McGowan, Health Care Consumers Association of the Australian Capital Territories



Progress Support

IAPO supported participants throughout the programme, offering guidance, facilitating discussion and sharing information. Participants implemented their action plans with support from IAPO, who provided advice where required and monitored the progress of the achievement of their objectives.

Participants benefited from quarterly group teleconferences during the year, in which they shared progress on their action plans, asked questions and heard policy updates from IAPO and fellow participants. This was supported by an online discussion forum, where participants could continue discussions, post updates and ask questions on an ongoing basis. These discussions provided valuable interaction to these members and facilitated the exchange of learning and experience.

Through the programme, participants have significantly increased their engagement with policy-makers as a result of their activities. Participant successes have included a range of meetings and activities with their country delegation, which have increased communications and contact with national Ministries of Health and other healthcare policy-makers.

After the programme, participants continued to engage with their country delegations and/or key stakeholders from European and global organizations. One participant informed IAPO that they are in “regular dialogue with [their] Chief Medical Officer and the Chief Executive of [their] Health Department, especially around patient safety and quality issues”. This participant had also been in contact with a representative from WHO regarding patient safety and has met their member state delegation and the head of the UN in their country. This activity resulted in increased communication and regular contact with their Ministry of Health and other relevant policy-makers. Another participant was invited to join a Ministry of Health committee where patients’ organizations and other civil society groups sit, which helps to ensure a patient voice in their national health policy.

“We appreciated listening to other participants’ experiences and problems; we loved the fact we could ask the IAPO staff any questions we had and we valued their advice. We didn’t expect the programme would be so helpful.”

Andrzej Bauman and Anna Sliwinska, Polish Diabetes Association



Case Study: WHA Mentor Programme Participants

Andrzej Bauman and Anna Sliwinska,
Polish Diabetes Association

We applied to participate in IAPO's World Health Assembly (WHA) Mentor Programme because we believe that WHO is *the* organization to work with as far as health issues are concerned. We were delighted that our application was accepted.

The Mentor Programme was a unique opportunity. In particular, attending sessions of the WHA was very important and interesting to us and helped to deepen our understanding of issues at the global level and how they affect the patients we represent. We made contact with other NGOs, which was very useful as this gave us information from many different countries and we discovered new solutions to the issues we are facing. We expected to be taken to the WHA, however we didn't expect to receive so much training and this was of great benefit to our organization. The session on the IAPO [Working with Partners and Stakeholders Toolkit](#) gave us useful tools and insight into maximising our partnerships which we will definitely use. When making our point in our advocacy work, we use information from WHO to support our position, which we did not really do before. We also learned that the WHO can be much more patient-friendly than we expected.

Following the Mentor Programme, we have celebrated the 30th anniversary of the Polish Diabetes Association. As part of the celebrations, we held an educational conference which was very successful, as it was an opportunity to meet with doctors to discuss issues that were a concern

to patients with diabetes and find joint solutions. Education on diabetes has always been a priority to us and one way we have been improving diabetes education has been through our Diabetes School. We have opened 150 of these schools in small towns and villages across Poland. The Diabetes Schools hold events once a month which include a test on diabetes knowledge at the end of the day. Family doctors are increasingly supporting this project and becoming interested in the programme, with many requesting the diabetes training. Through these Diabetes Schools, we are aiming for an 80% improvement in diabetes education nationally.

Since the Mentor Programme, there has been an election in Poland with a new government and Minister of Health. The Ministry of Health has set up a committee which patient groups and other civil society groups sit on. Andrzej was invited to sit on this committee, which is an excellent opportunity to provide a patient perspective on diabetes in government. The new government has more of an interest in diabetes, and this is reflected in the increased media coverage of diabetes. We have also had more support for World Diabetes Day and this may well be due to the UN High Level Meeting on NCDs which took place in September 2011. We have written to the new Minister of Health, highlighting the importance of the summit and the political declaration on NCDs, emphasising that diabetes is now recognised by the UN and WHO as a global disease.

We are very grateful to have had the opportunity to participate in the WHA Mentor Programme. We could never have imagined attending the WHA, and having the opportunity was very important to our organization and the patients we represent. We have benefited from hearing the experiences of other participants and we appreciated receiving the valuable support, advice and guidance of IAPO staff. We didn't expect the programme would be so broad and helpful to the strategic development of our organization.





WHA Mentor Programme Guidelines

IAPO's Mentor Programme highlighted a common need for guidelines on how to engage with the World Health Organization (WHO). Following the end of the programme in May 2012, the information and knowledge shared during the programme was consolidated and used to create these guidelines for all patients' organizations. The guidelines aim to assist patients' organizations to:

- Understand the role of WHO
- Understand why the WHA takes place
- Consider the potential benefits of working with WHO
- Identify who to work with in WHO
- Understand the different ways to engage with WHO

About WHO

WHO is an agency of the United Nations (UN), based in Geneva, Switzerland. WHO was established on 7 April 1948, a date that is now celebrated as World Health Day. Over the last 60 years, WHO has been working towards its objective of "the attainment by all people of the highest possible level of health".¹ WHO is the decision-making body which defines global health issues and creates policies which impact on regional decision-making and national health systems around the world. WHO is an important partner for many patients' organizations because of its pivotal role in global health.

What is the role of WHO?

The core functions of WHO are to:

- Provide leadership and engage in partnerships to address international health issues
- Support and promote health research and its dissemination
- Produce health guidelines and standards
- Develop ethical and evidence-based policy options
- Provide technical support to enable countries to address public health issues
- Monitor and assesses health trends

WHO forms policies which impact on health systems around the world. Through WHO's coordination, national governments work together to address global health issues, including international responses to infectious diseases such as malaria, tuberculosis and HIV/AIDS. WHO promotes the use of evidence-based tools and standards to help countries define their health policies and supports research programmes to help identify public health priorities. It has supported a number of international campaigns, including efforts to reduce the burden of NCDs, as well as providing technical support to countries on such issues. WHO is also responsible for the World Health Report, a leading international publication on health, and the World Health Survey.

¹ WHO (1946). Constitution of the World Health Organization. Accessed at: <http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf>



How is WHO structured and governed?

WHO's membership is made up of 194 countries, known as Member States, and two Associate Members. They meet every year in May at the World Health Assembly (WHA), the decision-making body of WHO. WHO is overseen by a Director-General who is elected every five years by the Health Assembly. Their work is supported by the 34 Members of the Executive Board who are elected by the Health Assembly and meet twice a year in January and May. The main function of the Board is to put into effect the decisions and policies of the Health Assembly. WHO employs a secretariat of over 8,000 people from all over the world, who work for WHO in 147 country offices, six regional offices and at the headquarters in Geneva, Switzerland.²

The World Health Assembly

The World Health Assembly (WHA) is the decision-making body of WHO and is attended by delegations from all WHO Member States. The WHA focuses on a specific health agenda prepared by the Executive Board and its main functions are to determine the policies of WHO, to appoint the Director-General, supervise financial policies, and review and approve the proposed programme budget. The WHA is held annually in Geneva, Switzerland.³

Enhancing partnerships

WHO has a commitment to working collaboratively, stating that: "Only through new ways of working and innovative partnerships can we make a difference and achieve our goals."⁴ WHO works with a range of partners, including UN agencies, donors, non-governmental organizations, WHO collaborating centres and the private sector, and it is under the category of non-governmental organizations that patients' organizations are recognised (assuming that they are non-governmental).

The WHO's Declaration of Alma-Ata in 1978 identified primary healthcare as the key to addressing global health needs through guiding values and principles. Principle IV of the WHO Alma-Ata Declaration states that: "The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare."⁵

² WHO (2012). Governance. Accessed at: www.who.int/governance/en/index.html

³ WHO (2012). World Health Assembly. Accessed at: www.who.int/mediacentre/events/governance/wha/en/index.html

⁴ WHO (2007). Working for health, an introduction to the World Health Organization. Accessed at: www.who.int/about/brochure_en.pdf

⁵ WHO (1978). Declaration of Alma-Ata – Principle IV

WHO and Patients' Organizations

How can patients' organizations benefit from working with WHO?

WHO's pivotal role in global health, as well as its extensive expertise, makes it a powerful ally for patients' organizations. By working in partnership with WHO, patients' organizations can:

- Raise awareness of a health issue
- Provide and gain technical expertise in guidelines and practices
- Develop research statistics and an evidence-base to support advocacy campaigns
- Build understanding and support for a patient-centred approach to healthcare within WHO

Joint activities between patients' organizations and WHO are wide and variable, ranging from gaining recognition for a global health issue to producing a joint publication at international level, to involvement in a prevention or treatment programme at country or regional level.

The recognition by WHO of a healthcare issue as global can be instrumental in gaining the visibility and support which your organization needs to achieve its mission. When a healthcare issue is recognised by WHO through the adoption of a resolution at the WHA, Member States have agreed to and made a commitment to this resolution. This can provide your organization with vital support where it is an issue of relevance to your organization's mission. Your organization can stress to national governments commitments made at WHO and outline the invaluable contribution which you can bring to fulfilling these commitments and defining a national strategy.

Recent resolutions adopted on NCDs and viral hepatitis have created global recognition for these diseases and built momentum to help prevent and manage these diseases throughout the world. They have provided a platform for further engagement between WHO and Member States with patients' organizations for joint action to tackle these issues.

What can WHO gain from working with patients' organizations?

Patient experiences make an invaluable contribution to global policies and the implementation of these policies within countries. WHO can benefit from working with patients' organizations in a number of ways, including:

- Ensuring that policies reflect patient and care giver needs, preferences and capabilities
- Filling the evidence gap on how health works best for people in middle- and low-income countries
- Advocating for WHO standards, e.g. the Patient Safety 'Clean Your Hands' campaign⁶
- Identifying how to measure and monitor effective patient participation and engagement for health globally
- Utilising established networks and communication channels which have been created to engage all healthcare stakeholders and communities

⁶ WHO (2012). Clean Care is Safer Care. Accessed at: www.who.int/gpsc/5may/slcyh_2012/en/index.html



How can patients' organizations engage with WHO?

Patients' organizations are an essential partner in ensuring that technical programmes, as well as policies, meet the needs of the people that they are intended to serve. Joint action can be extremely effective in:

- Generating and disseminating research
- Implementing best practice guidelines and checklists
- Creating ethical and evidence-based policy
- Building capacity to meet healthcare needs within countries
- Monitoring and assessing health trends

WHO has made a commitment to working with non-governmental organizations (NGOs), however, the civil society space is very crowded. In order to make your organization a key partner in WHO's work, you need to demonstrate the value you can bring to WHO's work.

Five tips to help your organization stand out:

1. Demonstrate a mutual aim
2. Show the contribution you can make
3. Highlight your strengths
4. Demonstrate why you are best placed to help achieve the mutual aim
5. Show who you represent and how

How Can You Work with WHO?

There are a number of different ways in which civil society can engage with WHO:



- At the international, regional and national levels
- Through formal and informal partnerships
- In policy or technical activities
- Through umbrella organizations in official relations

The department and programme which your organization aims to work with will depend on your mission and the aim of your work with WHO. Your strategy may involve different activities in order to meet different areas of your mission. For example, IAPO works with different departments within WHO in order to strengthen the global patient voice. However, begin in a targeted way with clear aims. IAPO's work with WHO began with a close partnership with the Patients for Patient Safety (PPPS) programme. You will need to develop relationships with individuals at WHO that work in your area of interest.

Once you have identified that your organization could better fulfil its objectives by working with WHO and have a clear sense of what you would like to achieve, you need to identify the correct person/people in WHO to speak to. You may want to develop contacts with a programme operating on a disease-specific or system-wide issue, or you may simply want to strengthen your networks at the national or regional level. Whichever channel is most appropriate for your organization, it is important to demonstrate that you represent a significant proportion of patients and to demonstrate the significance of your work and the value of a partnership.

Work through an international organization

Patients' organizations working at regional and national levels can engage with WHO through membership of an umbrella organization in official relations with WHO, such as IAPO. NGOs affiliated to international NGOs in official relations with WHO are, by definition, in official relations with WHO regional offices and they can work with regional and national WHO offices on strategies to meet the needs of patients at the country level. WHO may also establish working relations with regional or national NGOs affiliated to international NGOs that are not in official relations with WHO.

Official relations with WHO

WHO only recognises one category of formal relations with NGOs and this is known as official relations. All other contact, including working relations, is categorised as informal which can still be long-term and beneficial. Establishing official relations with WHO is an evolving process with several stages that usually takes two or more years.

1. The first stage is to build a relationship with a programme through exchanging information and reciprocal participation in meetings
2. The next is to identify joint activities which utilise the expertise of the NGO
3. These collaborations are then agreed in writing with details of the activities involved, which may result in a period of working relations
4. After two years the organization can apply for admission into official relations with WHO

NGOs must meet WHO's criteria for admission into official relations which includes representing a substantial proportion of people globally in the relevant area of interest. In exceptional circumstances, national organizations are considered for admission into official relations 'subject to the recommendations of the WHO Regional Director and the Member State involved'.⁷

IAPO and IAPO members in official relations with WHO

IAPO has worked with WHO since 2001 when IAPO was invited to be involved in the development of the WHO publication 'Adherence to long-term therapies: Evidence for action in 2001/2002'. Following this, IAPO worked with WHO on a number of other activities and in 2005 was invited to be part of the core steering group for Patients for Patients Safety (PPFS). In 2007, IAPO was granted official relations status in recognition of IAPO's work with WHO through PPFS.

IAPO has developed the scope of its work with WHO which now includes NCDs, health systems and research amongst others. IAPO brings the patient perspective to WHO's work and also connects WHO to a wide range of patients' organizations across the globe. A number of IAPO's disease-specific member organizations have also worked with WHO at an international level. These include the World Hepatitis Alliance, Alzheimer's Disease International (ADI), the International Diabetes Federation (IDF), the Multiple Sclerosis International Federation, the Thalassaemia International Federation (TIF) and the World Federation of Hemophilia (WFH). All of these members have undertaken mutually supportive projects with WHO which have had a significant impact in advancing the work of their organization.

ADI is in official relations with WHO and has worked with them on a number of projects, including a joint publication, 'Dementia: a public health priority', a comprehensive global report on the impact of dementia. The report demonstrated the economic and social impacts of dementia worldwide and raises awareness of the disease. Working together, ADI and WHO are able to broaden their expertise and build a comprehensive evidence base which benefits the aims of both ADI and WHO. ADI brings the patient voice to this work, ensuring that it is relevant to the needs of the patients they represent.

"Working with WHO makes clear that our cause is important and that countries can now ask for their support. The joint report calls for action from governments and gives them a framework that they can use to identify areas for policy."

Marc Wortmann, Executive Director, Alzheimer's Disease International

WHO and MSIF undertook a major collaborative effort to determine the global epidemiology of multiple sclerosis (MS) and the availability of resources to provide services to people with MS, surveying 112 countries, representing 87.8% of the world population, to produce the publication 'Atlas, Multiple Sclerosis Resources in the World, 2008'.

⁷ WHO (2012). Accessed at: www.who.int/civilsociety/relations/principles/en/

Work with WHO Headquarters

It may be the case that your objectives will be best met by working with WHO at the international level through its headquarters in Geneva, Switzerland. At first, it can be hard to think about where to start. There are many departments, many working on similar areas in slightly different contexts, and it is not always obvious where to make your first approach. The many departments of WHO are organized into clusters, each headed up by an Assistant Director General. IAPO works closely with the Innovation, Information, Evidence and Research cluster through the Patients for Patient Safety programme and has ongoing dialogue with other clusters to support its policy work on NCDs and counterfeit medicines, amongst others.

Clusters

WHO's programme work is organised into clusters as follows:

Noncommunicable Disease and Mental Health (NMF)

(Includes: Chronic Disease and Health Promotion, Mental Health and Substance Abuse and Nutrition for Health Development)

Health Security and Environment (HSE)

(Includes: Public Health and Environment, Global Alert and Response and International Health Regulations Coordination)

Health Action in Crises (HAC)

(Includes: Strategy, Policy and Resource Management, Country Focus and Emergency Preparedness and Institutional Readiness)

Innovation, Information, Evidence and Research (IER)

(Includes: Patient Safety programme, Ethics, Equity, Trade and Human Rights, and Research Policy and Cooperation)

General Management (GMG)

(Includes: Finance, Partnerships and human Resources Management)

HIV/AIDS, TB, Malaria and Neglected Tropical Diseases (HTM)

(Includes: Control of Neglected Tropical Diseases, Global Malaria Programme and HIV/AIDS)

Health Systems and Services (HSS)

(Includes: Essential Health Technologies, Health Policy Development and Services and Medicines Policy, Essential Drugs and Traditional Medicine)

Family and Community Health (FCH)

(Includes: Ageing and Life Course, Gender, Women and Health, and Maternal, Newborn, Child and Adolescent Health)

NB: These clusters can change and up-to-date information on current clusters can be found on WHO's website at: www.who.int/entity/en/

The Civil Society Initiative

Aside from getting in touch with a relevant department, you can approach WHO through the Civil Society Initiative, which is run out of the Partnerships Department. The Civil Society Initiative can help you explore the possibility of mutually beneficial exchanges at the global or regional level. This can be done by writing to them at civilsociety@who.int or at:

Partnerships General Management
World Health Organization
Avenue Appia 20
1211 Geneva 27
Switzerland

The department asks that you send a short note on how your organization considers its work relates to WHO's priorities, and include the required supporting documents. This information will be shared with relevant technical departments, the Civil Society Initiative Office or, where relevant, regional offices. This and more information can be found at:

www.who.int/civilsociety/relations/en/

Get Member State support

The support of national delegations is critical to the work of many patients' organizations, particularly where the ultimate aim of working with WHO is to ensure that decisions made at the global level are implemented at the national level. National Ministries of Health put WHO policy into practice and through their support your advocacy efforts can be more effective. It may also be difficult to get your message or idea onto WHO's agenda without a Member State backing it. Therefore, it is essential that any campaign finds the support or backing of one or more supportive Member States. Highlight that your message is representative of a significant number of people and demonstrate the evidence for why your health issue requires attention and the value which your partnership can bring. IAPO member the World Hepatitis Alliance gained vital Member State support in their campaign to gain global recognition of viral hepatitis. Read more about this initiative in the IAPO case study on page 19 and available online: www.patientsorganizations.org/casestudies



WHO Regional and Country Offices

If you would like to contact WHO at the national or regional level, you can find contact details on the regional and country pages of the WHO website at:

www.who.int/countries

Using the contact details you find, you can write to your local WHO representative and introduce your organization, invite them to come and see your work or outline what your organization is doing on a particular topic of focus for WHO. It is important to remember that WHO's representation and areas of work differ greatly from country to country, as does the role they have in individual countries. A quick way to identify WHO's priorities in your country and see where you may have a common interest is to look at the programme areas they are working on. These can often be found on the country office website under 'Areas of work' or 'Programmes'. In some cases, your country may not have its own website but you can often find pages on the regional websites that contain the same information.



You will find that there are many topics that WHO works on and many ways you can interact. If your main goal is to advocate for some action that WHO should take, you will develop a different relationship than if you become a partner in delivering a programme or undertaking a project. It may even be the case that you provide funding for a particular activity. Whatever form your work with WHO takes, it is important to be flexible and remember that you are working with a large organization that may be unable to take decisions as quickly as your organization. Nevertheless, it is important to remain firm on your own objectives and not compromise your own goals by being too flexible. As a large United Nations agency, initial expectations of WHO are often very high and it is important to be realistic about what working in partnership with WHO can achieve. However, as the global focus on NCDs has demonstrated, WHO is a powerful ally in raising awareness on an issue and effecting change.

Working with a regional office

WHO's Member States are grouped into six regions (see page 21). The work of each region is governed by a regional office that coordinates activities and addresses health issues in the region. Each country within a region sends a delegation to their annual Regional Committee which takes place between August and October each year to formulate regional policies and programmes and supervise the activities of the regional office. Wherever possible, IAPO attends the Regional Committee Meetings. Like the WHA, the Regional Committee elects a Regional Director for a five-year term. The regional offices have a high level of autonomy, with Regional Directors holding responsibility for WHO activities within their region, including overseeing the work of country offices. The work of WHO within each region will depend on the priorities identified by the Regional Committee. The regional offices bring issues to the WHA that they feel should have global attention. Often Member States, through their regions, will bring resolutions to the WHA.

- Regional Office for Africa (AFRO), with headquarters in Brazzaville, Republic of Congo
- Regional Office for the Americas (AMRO), with headquarters in Washington, DC, USA
[Better known as the Pan American Health Organization (PAHO)]
- Regional Office for Europe (EURO), with headquarters in Copenhagen, Denmark
- Regional Office for South-East Asia (SEARO), with headquarters in New Delhi, India
- Regional Office for the Eastern Mediterranean (EMRO), with headquarters in Cairo, Egypt
- Regional Office for Western Pacific (WPRO), with headquarters in Manila, Philippines

IAPO member Alzheimer's Pakistan has worked very actively with WHO at country, regional and headquarters levels. In 2005, Hussain Jafri, Secretary General of Alzheimer's Pakistan, was selected as a Patients For Patient Safety (PPFS) Champion that ultimately led to the development of the Pakistan Patients Safety Initiative (PPSI), a group of patients advocates who work together with the aim to promote patient safety in Pakistan. Through IAPO, Alzheimer's Pakistan has also attended EMRO Regional Committee meetings and World Health Assemblies and has made several interventions on a number of issues including patient-centred healthcare. WHO EMRO office is currently developing a Patient Safety Friendly Hospital Initiative Improvement Toolkit for the EMRO region. This toolkit is being developed to assist in the improvement of the level of patient safety in healthcare facilities and Hussain, in his role as a PPFS Champion, has been asked to write a chapter in this toolkit on patient-centredness.

Working with a Regional Committee

Similar to the World Health Assembly, each of WHO's regional offices holds a Regional Committee every year. These committees are open to the public and are a good way to follow what the regional health priorities are. It is likely that your country representative will be attending and often you will get the opportunity to meet them and introduce yourself. If your organization has official relations status with WHO, then you will be able to make an intervention on relevant topics. If you are based in the Pan American Health Organization Region (PAHO), it is possible to establish official relations with the regional office rather than with WHO Headquarters. This opens up the opportunity to make interventions at the PAHO Regional Committees and work more closely with relevant departments in your region.



Working with a country office

WHO has 147 country offices which support their host country to develop policy which promotes sustainable health development as well as providing technical support. The work of WHO's country offices includes providing guidance, building up local relationships to implement technical cooperation, standards and agreements, and ensuring that public health measures are coordinated and in place. The priorities for country offices are set out in a biennial collaborative agreement between WHO's regional office and the host country. The office implements the agreement in collaboration with the relevant national institutions and international partner agencies.⁸

At the country level, IAPO member the Community Health and Information Network (CHAIN) has worked with the Uganda WHO Country Office on community patient safety projects. CHAIN, along with the Ugandan Alliance of Patients' Organizations, built this relationship through frequent communications with the Country Office directly and through mutual contacts. One important link was a contact from the WHO Headquarters in Geneva who visited Uganda when they were working on the project, 'Implementation research for the control of infectious diseases of poverty'. Regina Namata Kamoga of CHAIN took part in this initiative and wrote a chapter of the report. During this project CHAIN accompanied the WHO representative to the Country Office in order to meet the Country Representative and from this point shared regular information on their work. Regina Namata Kamoga is also a WHO PFPS Champion and this role, to promote patient safety in Uganda, has strengthened CHAIN's links with the Ugandan Ministry of Health as well as the WHO Country Office. A letter from IAPO introducing IAPO members in Uganda to the Country Office also strengthened their relationship with WHO at the country level. As a result, WHO now regularly communicates with and participates in CHAIN's activities.

"What is key to forming a relationship with your WHO Country Office is to be persistent and inform them about your activities at every opportunity through invitations to events and sending reports. Once links are established, always keep in touch."

Regina Namata Kamoga, Country Manager, Community Health and Information Network (CHAIN)



⁸ WHO (2012), WHO Country Office. Accessed at: www.euro.who.int/en/where-we-work/member-states/kyrgyzstan/who-country-office



IAPO Member Case Study: The World Hepatitis Alliance

In 2010 the World Hepatitis Alliance (the Alliance) as a member of IAPO made an intervention at WHO's Sixty-third World Health Assembly (WHA). The intervention was to support the first ever resolution on viral hepatitis which was subsequently adopted. As a coalition of advocacy groups, the World Hepatitis Alliance is a global voice for the 500 million people worldwide living with chronic viral hepatitis. Through better awareness, prevention, care, support and access to treatment, their ultimate goal is to work with governments to eradicate these diseases.

Establishing World Hepatitis Day, 2007

In 2007, hepatitis patients' organizations from around the world decided to establish an unofficial World Hepatitis Day on 19 May of each year. Following sustained efforts to get countries worldwide to recognise the day, the Alliance realised that in order to have viral hepatitis recognized as a major global health issue, they would need to get official recognition of the day from WHO and that this would require the assembly to adopt a resolution.

The World Health Assembly and the resolution, 2010

Following sustained lobbying and a postponement in 2009, four Member States proposed a resolution to the assembly. At the January 2010 Executive Board meeting, the World Hepatitis Alliance, facilitated by IAPO, made an intervention under the agenda item 'viral hepatitis'. A new resolution was agreed and ready for consideration by the WHA in May 2010.

"Addressing the Executive Board meeting, with the advice and support of IAPO, was a big step forward and helped to achieve the viral hepatitis resolution and raise the profile of the World Hepatitis Alliance with country delegations and with WHO."

Charles Gore, President, World Hepatitis Alliance

At the sixty-third WHA the Alliance made an intervention to support the resolution on viral hepatitis. Addressing the assembly as a patient and on behalf of IAPO, the World Hepatitis Alliance and the 500 million people infected with chronic viral hepatitis B and C, the Alliance stressed the urgent need to address viral hepatitis. The resolution was adopted; it acknowledges the seriousness of viral hepatitis as a global public health issue, establishes an official World Hepatitis Day on 28 July each year and requires WHO to develop a global strategy for hepatitis prevention and control.

Achieving Official Relations, 2012

In 2012, the World Hepatitis Alliance attended the Executive Board Meeting, as part of IAPO's delegation, where their official relations status with WHO was confirmed. This status recognises the work of the World Hepatitis Alliance with WHO to implement the resolution on viral hepatitis to prevent new infections and provide support to the millions of people living with viral hepatitis worldwide. Working with their members, with IAPO, WHO, Member States and other key experts has been crucial to the World Hepatitis Alliance's success.

What Next?

We hope that this report and guidelines have given you an insight into how WHO works with patients' organizations and the benefits of these collaborations, as well as how and why they are established. As participants in the Mentor Programme found, the journey of working with WHO, as with any relationship, can be a long one with mutual benefits. Having an action plan to guide this journey helps you to identify small goals towards achieving your mission, which include gaining important partner and technical expertise to support your work. The mission of your organization may not require direct work or contact with WHO, so you may consider engaging with WHO through an umbrella patients' organization such as IAPO and benefiting from the global support and representation that this provides. It is only through the collaboration of all healthcare stakeholders that we can improve healthcare systems. This requires the patient at the centre of decision-making as the most important stakeholder in healthcare. With 193 Member States around the table at the WHO, how can you ensure that your voice is heard?

"When proving our point, we use the WHO argument, which we did not really use before."

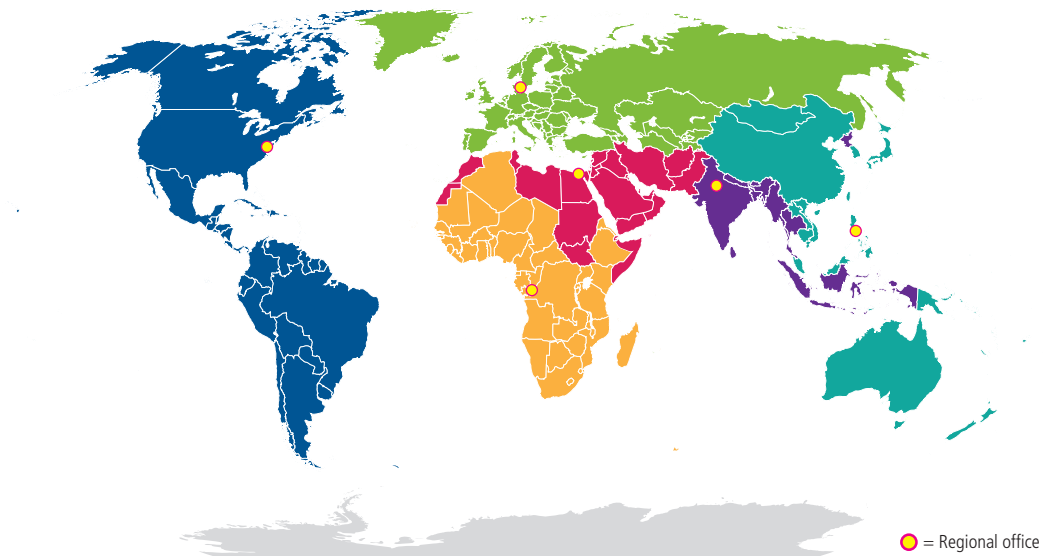
Anna Sliwinska and Andrzej Bauman, Polish Diabetes Association

Opportunities to engage with WHO through IAPO:

1. Apply to be a member of IAPO
2. Apply to attend related capacity building events
3. Gain information on Patients for Patient Safety and how to get involved
4. Participate in IAPO policy briefings
5. Participate in the Global Patients Congress
6. Respond to IAPO member consultations
7. Sign up for IAPO's newsletter to receive regular updates
8. Submit an application to IAPO to attend a WHO regional committee meeting

For further advice, support and information, email IAPO at:
membership@patientsorganizations.org

WHO Regions



Africa | Brazzaville, Congo | www.afro.who.int

Algeria	Eritrea	Niger
Angola	Gabon	Nigeria
Benin	Gambia	Rwanda
Botswana	Ghana	Sao Tome & Principe
Burkina Faso	Guinea	Senegal
Burundi	Guinée-Bissau	Seychelles
Cameroon	Kenya	Sierra Leone
Cape Verde	Lesotho	South Africa
Central African Rep.	Liberia	Swaziland
Chad	Madagascar	Togo
Comoros	Malawi	Uganda
Congo	Mali	United Republic of Tanzania
Cote d'Ivoire	Mauritania	Zambia
Dem. Rep. of Congo	Mauritius	Zimbabwe
Equatorial Guinea	Mozambique	
Ethiopia	Namibia	

Americas | Washington DC, USA | www.paho.org

Anguilla	Colombia	Montserrat
Antigua & Barbuda	Costa Rica	Netherland Antilles
Argentina	Cuba	Nicaragua
Aruba	Dominica	Panama
Bahamas	Dominican Republic	Paraguay
Barbados	Ecuador	Peru
Belize	El Salvador	Puerto Rico
Bermuda	French Guiana	Saint Kitts & Nevis
Bolivarian Republic of Venezuela	Grenada	Saint Lucia
Bolivia	Guadeloupe	Saint Vincent & the Grenadines
Brazil	Guatemala	Suriname
British Virgin Islands (UK)	Guyana	Trinidad & Tobago
Canada	Haiti	Turks & Caicos
Cayman Islands	Jamaica	United States of America
Chile	Martinique	Uruguay
	Mexico	

Eastern Med | Cairo, Egypt | www.emro.who.int

Afghanistan	Lebanon	Somalia
Bahrain	Libya	South Sudan
Djibouti	Morocco	Sudan
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Europe | Copenhagen, Denmark | www.euro.who.int

Albania	Hungary	Russian Federation
Andorra	Iceland	San Marino
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Azerbaijan	Italy	Slovenia
Belarus	Kazakhstan	Spain
Belgium	Kyrgyzstan	Sweden
Bosnia & Herzegovina	Latvia	Switzerland
Bulgaria	Lithuania	Tajikistan
Croatia	Luxembourg	The former Yugoslav Republic of Macedonia
Cyprus	Malta	Turkey
Czech Republic	Monaco	Turkmenistan
Denmark	Montenegro	Ukraine
Estonia	Netherlands	United Kingdom
Finland	Norway	Uzbekistan
France	Poland	
Georgia	Portugal	
Germany	Republic of Moldova	
Greece	Romania	

South-East Asia | New Delhi, India | www.searo.who.int

Bangladesh	India	Nepal
Bhutan	Indonesia	Sri Lanka
Democratic People's Republic of Korea	Maldives	Thailand
	Myanmar	Timor-Leste

Western Pacific | Manila, Philippines | www.wpro.who.int

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Australia	Malaysia	Philippines
Brunei Darussalam	Marshall Islands	Pitcairn Islands (UK)
Cambodia	Micronesia, Federated States of	Republic of Korea
China	Mongolia	Samoa
Cook Islands	Nauru	Singapore
Fiji	New Caledonia (France)	Solomon Islands
French Polynesia (France)	New Zealand	Tokelau (New Zealand)
Guam (USA)	Niue	Tonga
Hong Kong (China)	Northern Mariana Islands, Commonwealth of the	Tuvalu
Japan	Palau	Vanuatu
Kiribati		Vietnam
Lao People's Dem. Rep.		Wallis & Futuna



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