

Patient Solidarity Day

2013 Evaluation Report



Introduction

The International Alliance of Patients' Organizations (IAPO)

IAPO is a unique global alliance representing patients of all nationalities, across all disease areas and promoting patient-centred healthcare around the world. Our members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. IAPO's vision is that patients throughout the world are at the centre of healthcare, and our mission is to help build patient-centred healthcare worldwide.

Patient Solidarity Day

Patient Solidarity Day (PSD) was an initiative started by the Morris Moses Foundation (MMF), a close affiliate with several of IAPO's African members, in Kenya in 2011. The Day aimed to honour patients and highlight the need for patients to be part of healthcare systems. The IAPO African Regional Steering Committee, made up of members elected from around the continent, felt that raising awareness about patient-centred healthcare was critical in Africa, and on hearing about the PSD initiative, agreed that engaging with such an initiative would be beneficial for IAPO and its members. In 2012, PSD was celebrated in Kenya by the MMF, as well as in Uganda by IAPO member, Community Health and Information Network (CHAIN Uganda).

***'Patient-centred healthcare means that patients, their families and communities are viewed and treated as human beings and not diseases, ailments and disabilities.'* (Regional Society for Blood Transfusion Kenya)**

The theme for PSD 2013 was a call to "improve lives through patient-centred healthcare". Through this thematic focus, PSD aimed to raise awareness of the role of patients' organizations in ensuring healthcare systems meet the needs of the communities they serve and the right of patients to be fully informed to make effective healthcare decisions. This is particularly important in Africa, where healthcare systems face complex problems, often neglecting the needs of the patient. PSD 2013 saw broad engagement across Africa, with IAPO members from 10 countries across the continent celebrating and supporting the event. Our members worked hard to make the Day successful in raising awareness of the importance of patient-centred healthcare and we congratulate them for their dedication to prioritise patients across Africa.

Key achievements in 2013:

- 10 countries and 17 IAPO members held awareness raising events across Africa
- Four IAPO members had government representatives present at their events
- A representative of the Ministry of Public Health signed the IAPO Declaration on Patient-Centred Healthcare in Cameroon
- Members held a diverse range of activities and events, including free health screenings, providing basic healthcare to communities, multi-stakeholder seminars, to awareness workshops
- Strong social media engagement and awareness building globally
- Representatives from seven member organizations participated in the PSD Steering Committee, providing valuable insight and input

Official PSD partners included the World Health Organization (WHO) Regional Office for Africa, the International Council of Nurses, African Pharmaceutical Forum, World Medical Association, and the International Federation of Medical Students Associations and the International Hospital Federation.

Objectives:

- Bring together patients across disease areas to share knowledge and experience
- Raise awareness of patient-centred healthcare across Africa
- Communicate a strong, unified voice from IAPO members in Africa
- Improve patient-provider relations
- Increase access to patient information
- Increase health literacy on safe medicines/ safe use of medicines
- Build cross-sector alliances

A PSD Steering Committee, consisting of IAPO members from across the continent, helped draft the principles and theme for the Day, with 30 October selected as the day of action. The Committee provided contextual knowledge on healthcare issues across Africa and valuable input into the overall strategy. This was a great opportunity for members to actively engage in IAPO's work. IAPO provided support and capacity building tools to its members and helped promote PSD and engage a wider audience. A comprehensive Toolkit outlining important messaging and possible outreach activities for the day was developed along with other supporting materials for members to assist with planning their activities and key messaging. Members were encouraged to develop messages and activities suitable for their local contextual issues. All materials were available online, and were sent to participating members, with active support provided by the IAPO Secretariat. A dedicated PSD website provided a one-stop resource site for all PSD related information and was available to all members: www.patientsolidarityday.org

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IAPO also maintained a prominent online presence on various social media platforms to help highlight activities, particularly focusing on active Twitter and Facebook engagement. A film showcasing the Day and its core principles was freely available online, helping to raise awareness.

Overview of 2013 activities

Patient Solidarity Day is a day to come together, unite and speak with one voice. It recognises that regardless of disease, religion or nationality, we all share common problems. (CHAIN Uganda)

On 30 October 2013, activities were held by IAPO member organizations in 10 countries across the continent in Cameroon, Ghana, Kenya, Liberia, Malawi, Nigeria, South Africa, Uganda, Zambia and Zimbabwe. Activities highlighted the need for increased awareness of patients' rights in Africa, and made a call to address the complex, critical healthcare issues evident on the continent. Details of each country's activities are included in Annex One of this report.

Examples of key messaging used by members

- *A patient-centred approach should guide all programmes in the health sector. The patient should be the focus of everything in the health sector. Health services exist because of patients; they should therefore be involved in decision-making and implementation. (ShareGhana)*
- *A combination of preventative services, quality treatments and the safe use of medicines will help to strengthen the evidence base for cost-effective management strategies of communicable and non-communicable diseases. (National Care Centre, Uganda)*
- *Patients must be at the centre, in control of their health. Testing for both infectious and non-communicable diseases must be of paramount priority. Safe use of medicine by patients is essential and governments to focus on prevention than treatment. (Sickle Cell Association of Uganda)*

Publicity

PSD had good media coverage, particularly online through various social media platforms, which helped to show that this Day is growing in support and international recognition. A list of media links is included in Annex Two of this report. Promotion of PSD was done via a number of social media platforms, including on Facebook, Twitter, and LinkedIn, as well as IAPO's newsletter and website.

Social media coverage increased steadily with Facebook followers increasing by 18% and Twitter by 31% in just over a month, with over 130 views of the PSD film.

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All of these platforms provided multiple outlets to highlight IAPO and member activities for PSD and provide background information on patient-centred healthcare and healthcare issues in Africa. PSD also promoted the IAPO Declaration on Patient-Centred Healthcare, and helped encourage people to sign up to the online version. IAPO launched a PSD 2013 Film on YouTube in the run up to the event, visually highlighted the key messages and the work of IAPO members.

Evaluation

IAPO conducted an evaluation survey with member organizations who participated in the initiative. This report is based on survey responses, as well as activity reports submitted by members, and includes analysis done by the IAPO Secretariat. The majority of members were very engaged and highlighted successes and challenges of their PSD engagement and provided constructive feedback for future planning, however a few did not communicate about their achievements or activities.

We felt rewarded that we could impact lives, as the people were generally in dire need of the healthcare services - many of the patients who accessed care on that day were hardly able to afford the care which was rendered free and they were very grateful. The programme was indeed impactful and the people expressed gratitude. The greatest lesson we learnt though is that, with determination, focus and planning, anything can be achievable. (LiveWell Initiative, Nigeria)

Successes:

Members who responded to the evaluation survey felt that PSD was a positive endeavour. Most respondents felt the initiative successfully achieved its objectives by highlighting the key issues.

- **Raised awareness:** PSD activities and engagement were deemed positive as members felt they increased awareness of patient-centred healthcare. Most countries and communities were not aware of the importance of these issues before PSD, as this is not a common issue discussed in Africa and remains largely unknown. Therefore many felt that PSD was successful in engaging people on the need to prioritise patient engagement. Many organizations secured media coverage which was useful to highlight their work and the key messages; a positive impact for all involved.
- **Increased health literacy and community engagement:** PSD provided a beneficial opportunity for dialogue on healthcare issues within local communities who participated in activities on the day. Members felt it was a good initiative to highlight the value of patient-centred perspectives, and activities focused on engaging local groups and families on these issues. PSD was deemed successful as members were able to directly impact and help communities they engaged with, and that through their activities, many of which included free health screenings and services, they could make a tangible difference in people's lives.
- **Communicated a strong, united patient voice:** PSD helped to establish a united voice for IAPO members around the continent on the need to recognise patients as important stakeholders in

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healthcare delivery. The promotion and signing of the IAPO Declaration also helped to highlight the issues to members of government and other leading stakeholders.

- **Built cross-sector alliances:** Members felt that the Day was useful to help highlight and promote the key messages, and provide an opportunity to engage in discussions on these topics with a variety of stakeholders, particularly policy makers and government officials. It encouraged organizations to initiate and establish collaborations with alternative partners and stakeholders. Many felt they had previously struggled to engage with governments or other role players in the health sector, but through PSD, they were more successful in having government representatives engaged, interested in the topic and present at events.

The unified voice of patients was heard by the key stakeholder, the Government, through the Ministry of Health representatives at the event. A platform for patients' voices was created and patients raised their concerns. (Bethesda Zambia)

Challenges:

- **Funding and capacity:** Many organizations expressed difficulty in getting sponsorship and funding for their outreach activities and struggled to find sufficient external funding. This was reportedly due to a number of reasons, including limited internal capacity to dedicate time or staff to fundraising activities. Many reported that due to limited staff capacity, finding extra time to plan and implement activities was difficult, due to completing with core organizational commitments.
- **Participation rates:** Some partners reported that it was challenging to get people participating in activities as PSD was held on a weekday when most people have work or prior commitments that take up their time. It was proposed that the date be reassessed as to whether there was a better possible time to maximise participation and sufficient time for engagement.
- **Regional connectivity:** Certain members felt that increased integrated planning and dialogue at both regional and national levels for PSD would assist to facilitate stronger regional network building and a united patient's voice. IAPO could play a central role in facilitating more networking and sharing between with members and other stakeholders.
- **Partner engagement:** Several respondents found getting support from other stakeholders, such as WHO offices and government ministries was challenging and will need to be strengthened in future. IAPO could assist in partner engagement such as writing letters of endorsements to help promote greater support from key stakeholders.

[Our activities helped create] increased awareness about the objectives of Patient Solidarity Day [with] community members and patients understanding Patient-Centred Healthcare; improved collaboration between patient organizations and health care providers; the number of participating organizations increased, and the numbers of participating service-providers increased. (National Care Centre, Uganda)

Future considerations

- **Increased fundraising capacity and opportunities:** Both IAPO and its members have limited funds, so there is a need to assess how IAPO is able to better support members' outreach and how members will promote PSD. IAPO can assist members by providing capacity building tools to strengthen funding proposal writing, letters of support and endorsement for when members approach funders and supporting organizations, and potentially drafting a list of possible funding organizations members can approach. It is recommended that members have at least 3-4 months in the build up to their events to allow for sufficient out planning time to engage funders and communities and partners they intend to address.
- **Strengthen stakeholder engagement:** It was considered important by members that focus should be on providing a space for patients to discuss their issues, and it was felt that this should be a priority focus for future PSD activities. Very seldom do patients have access to such platforms to voice concerns so this would be key to empowering them and amplifying their voice. Governments, as the lead national level decision-makers need to be further engaged in highlighting the importance of patient-centred healthcare. Members felt there was a need to involve a wider range of stakeholders to bring in diverse perspectives, and raise awareness about the importance of patient-centred healthcare. There is a role for IAPO to facilitate increased engagement of a range of stakeholder groups, particularly other patient groups and healthcare professionals.
- **Increased media attention:** Many members felt that emphasis should be placed on attracting more media attention to PSD activities and principles. Increased media would provide an opportunity to amplify patient voices and highlight the core issues. There is great potential to grow the online presence and audience, as it is a relatively simple, time-efficient way to get increased awareness.

Conclusion

Given the success of PSD 2013, IAPO aims to increase member engagement throughout the global alliance to participate, support and promote PSD. IAPO's role in PSD is to be the main broker in bringing together members and a range of stakeholders to highlight the leading issues of patient-centred healthcare. IAPO will facilitate increased connectivity and networking between members in the alliance, as well as closer working between both regional and global stakeholders. IAPO will focus on broadening engagement in all regions to get more members involved in PSD and in creating increased awareness of the key issues. Simultaneously, IAPO will continue engagement with members who held PSD activities in 2013, and encourage them to repeat activities in 2014. Social media will play a key role in increasing people's awareness of the core principles of patient-centred healthcare. IAPO will assess members capacity building needs and how best to support them. Planning for 2014 activities and outreach will begin early to allow sufficient time for members to prepare.

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Annex one: IAPO member activities

- **Cameroon:** Action for Humane Hospitals distributed flyers on the importance of patient-centred healthcare to inform the public about these issues. They also held a press conference about the Day and its importance, which was covered by local media, including a television show dedicated to youth engagement. A representative of the Ministry of Public Health signed the IAPO Declaration on Patient-Centred Healthcare; a significant gesture to support the importance of this day.
- **Ghana:** Multiple stakeholders, including Government representatives, came together in an event organised in partnership with a number of local patients' organizations, including IAPO members ShareGhana and Mental Health Society Ghana. The event highlighted the importance of patient-centred healthcare, with over 150 people in attendance. Free health screenings provided quality health care to vulnerable groups. The event also inaugurated a new patients' organizations network, Patients Alliance of Ghana in Engagement (PAGE), bringing together a diverse range of patient groups to strengthen the patients' voice in Ghana.
- **Kenya:** PSD events were organized by a multi-stakeholder national committee, which included representatives from the Ministry of Health, WHO Kenya Country Office and patient organizations. The primary organizers were the Morris Moses Foundation, a close affiliate of IAPO's and the founder of PSD. Various events were held including a march to Kenyatta National Hospital in Nairobi; the largest referral hospital in East and Central Africa. Free community health screenings were held offering access to basic medical services and information, donations and care packages were delivered to patients, and key representatives gave speeches on the importance of patient-centred healthcare.
IAPO member, Africa Psoriasis Organization, held a workshop at the Kenya Methodist University to educate students about the condition and highlight patients' needs.
The Regional Society of Blood Transfusion Kenya, another IAPO member also showed solidarity on the Day.
- **Liberia:** IAPO member Liberian United Youth for Community Safety and Development (LUYCD) engaged their networks and partners to support PSD, aiming to how solidarity and implement programmes focusing on health literacy for the disadvantaged throughout the country.
- **Malawi:** IAPO member Global Health Mobilisation gathered patient organizations, government officials and communities together to share experiences of health system delivery in Chikhwawa district. The Patient and Community Welfare Foundation, also an IAPO member, held a seminar to call for governments to adopt patient-centred approaches to healthcare. The event also had theatre, dance and drama to engage the audience in the key messages.
- **Nigeria:** A number of IAPO members active in different regions throughout Nigeria participated in PSD.
LiveWell Initiative (LWI) held a large community health outreach programme with free health screenings and access to information and treatment for the community. LWI were also the winners

of the PSD photo competition, with a moving image of a mother and her twins accessing health services.

PLAN Health Advocacy and Development Foundation held numerous events including a special television programme on patient-centred healthcare as well as a community symposium, highlighting the issues.

The Community Development Alliance, in collaboration with other patient organizations hosted community health screenings, awareness campaigns through public media as provision of key healthcare information to educate communities.

The Network of People living with HIV/AIDS in Nigeria (NEPWHAN) held community dialogues to discuss the quality of healthcare services available in Nigeria. They also held a multi-stakeholder meeting with key players working on HIV/AIDS in the country, to review the quality of anti-retrovirals.

- **Uganda:** Activities on the Day were organized by the Ugandan Alliance of Patients Organizations, which includes a number of IAPO members, the Community Health and Information Network, Uganda (CHAIN), The AIDS Support Organisation (TASO), National Care Centre and Sickle Cell Uganda. UAPO held a health camp, providing free health services for local communities, including HIV/AIDS counselling and testing. They had presentations on the importance of empowering patients and leading health issues, as well as speeches by the Ministry of Health and other stakeholders in the sector. Patient testimonies were shared, with theatre used to promote the key messages of improving lives through patient-centred healthcare.
- **South Africa:** The South African Depression and Anxiety Group linked their support of PSD with World Mental Health Day on 10 October, continuing their awareness raising and engagement activities over two weeks. They performed a number of activities around the country, including a government engagement day at Parliament to raise awareness of mental health and how there is a clear need for further support of mentally ill patients.
- **Zambia:** IAPO members Bethesda Zambia and Advocacy on Human Development held awareness campaigns to educate communities and engage different stakeholders.

Annex two: Select media coverage

1. Agence d'information d'afrique central/ Information Agency for the Central African Republic: 'Health: First Regional Day of Solidarity patients' <http://www.adiac-congo.com/content/sante-premiere-journee-regionale-de-solidarite-des-malades>
2. Breast Cancer Foundation of Egypt: <http://www.ameinfo.com/blog/company-news/b/bcfe/bcfe-in-collaboration-with-iapo-celebrate-patient-solidarity-day-2013/>
3. Business Ghana: 'NGO Advocates Patient-centred Healthcare' http://www.businessghana.com/portal/news/index.php?op=getNews&news_cat_id=&id=192168

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4. Community Health and Information Network, Uganda:
<https://www.facebook.com/pages/Community-Health-and-Information-Network/223315461088203>
5. European Federation of Pharmaceutical Industries and Associations:
<http://efpia.eu/blog/106/51/Patient-Solidarity-Day-Reminds-of-Need-for-Patient-Centred-Healthcare> and <http://efpia.eu/newsletters/24/118/31-October-2013>
6. Ghana News Agency: 'NGO Advocates Patient-centred Healthcare'
<http://www.ghananewsagency.org/health/ngo-advocates-patient-centred-healthcare--66647>
7. International Hospital Federation: 'Patient Solidarity Day; Calling for patient-centred care in Africa':
<http://ihfnews.org/2013/11/01/patient-solidarity-day-calling-for-patient-centered-care-in-africa/>
8. Online news source, Drugs.com: 'IAPO Patient Solidarity Day Film to Launch'
<http://www.drugs.com/news/iapo-patient-solidarity-day-film-launch-48484.html>
9. Pharma Live: <http://www.pharmalive.com/iapo-patient-solidarity-day-film-to-launch>
10. World Innovation Summit for Health 2013: 'Partnering with Patients, Families and Communities for Health: A Global Imperative' Report <http://www.wish-qatar.org/app/media/387>