



Patient Solidarity Day
One voice. United. Universal.

6 December 2014

**Member toolkit
and planner**

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Introduction

On **6 December 2014**, patients in countries across the world will come together to celebrate Patient Solidarity Day. This is a unique opportunity for patients' organizations to stand together in the call for universal health coverage, and equal access for all.

To enable as many people as possible to benefit from Patient Solidarity Day, we need your help. This toolkit is designed to give guidance on how you can celebrate and promote this important day. The toolkit provides you with a range of helpful ideas that can be adapted by you to use in your own campaigns.

There are different levels of engagement that you can consider. This toolkit provides some suggested activities along with suggested paragraphs of literature for marketing purposes that can be adapted according to your organization's needs and capacity. We encourage you to use the platforms and messaging outlined here to engage your members and encourage them to spread the word, either on the day itself or any convenient day close to it, to support the call for universal health coverage for all.

Patient Solidarity Day is an opportunity to raise awareness of, and support for, patient-centred healthcare. We know that patient-centred healthcare will significantly improve health systems and most importantly improve patients' journeys so that they have a better quality of life. This is a critical time for us to ensure that the patient voice is central to the achievement of universal health coverage.

Jo Groves, Chief Executive Officer, IAPO

Contents

Background information	4
History	4
Universal health coverage	5
Ideas for showing your support	6
Little gestures to start a wave...	6
Thinking of making a bigger splash?	6
Using the symbol	7
Using the logo	7
Using the interlocking fingers gesture	7
Using social networks	8
Sharing personal stories using social media	8
Engaging the media	9
Writing and issuing press releases	9
Ideas for catching media attention	10
Speaking on radio and television talk shows	10
Lobbying government	11
Running events	12
Key messages	13
Key messages about IAPO	13
Key phrases about Patient Solidarity Day	14
Available materials	15
Links for further information	16

Background information

History

Patient Solidarity Day was initiated by the Morris Moses Foundation, a close affiliate of IAPO, in Kenya in 2011. The initiative was aligned with IAPO's vision and mission; to put patients throughout the world at the centre of healthcare. IAPO members felt the importance of engaging in the day. In 2012, the day was celebrated in Kenya by the Morris Moses Foundation, as well as in Uganda by IAPO member Community Health and Information Network (CHAIN Uganda), along with support and solidarity from other IAPO members.

2013 saw a dramatic increase in solidarity and activities on the day. Members across the African continent held a diverse range of activities to show their support for Patient Solidarity Day. This year we are going global and 2014 will be our biggest year yet! Many IAPO members from around the world have expressed how important the Patient Solidarity Day issues are for them, and how relevant raising awareness will be for their countries and regions. We hope that all IAPO members, supporters and like-minded organizations highlight the important issues for patient-centred healthcare, and the need for all patients to access equitable, high quality and affordable healthcare.

Patient Solidarity Day is a day to come together, unite and speak with one voice. It recognizes that regardless of disease, religion or nationality, we all share common problems. It's a day to share, and learn best practices for disease prevention and management. It's a day to show love and care for those in pain and give hope. Patient Solidarity Day brings into focus the need to put the patient at the centre to improve healthcare outcomes. Patient-centred healthcare improves the quality and safety of healthcare services and ultimately improves quality of life.

IAPO member from Uganda

2014 theme

High quality, equitable and affordable healthcare; nothing more than a dream for so many people around the world. This needs to change. We have all been a patient at some point in our lives, or cared for one. It's time to stand together in solidarity to call for truly patient-centred healthcare. Every person, every patient is equal and all have the right to access the healthcare they need, when they need it. We need to unite to ensure that all people, across the world, have fair and impartial access to quality healthcare. IAPO and its members are calling for universal health coverage for all.

The theme for Patient Solidarity Day in 2014 aims to continue IAPO's priority issue this year; a focus on universal health coverage and raising awareness about patient-centred

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healthcare. It will continue work that was initiated at the 6th Global Patients Congress earlier in the year, and continued through other work, including interventions made at several World Health Organization regional meetings.

What is universal health coverage?

Universal health coverage was identified as a key issue for our members in the pre-Congress consultation, therefore Patient Solidarity Day is an important vehicle to continue to raise awareness around about these important issues. Drafted by IAPO members themselves, the core principles of universal health coverage include:

- **Patient-centred:** all stakeholders need to work together to ensure that health systems prioritise and meet the needs of patients, their families and carers.
- **Accessibility:** universal health coverage must ensure that all patients can access health services they require.
- **Equity:** all people, regardless of age, gender, race, disease or condition, and economic circumstances must have equitable access to healthcare.
- **Quality:** care must be of high quality at all levels and stages of healthcare.
- **Empowerment:** patients must be actively involved in all levels of healthcare decision-making.
- **Collaboration:** improved access to healthcare for all is only possible with the collaboration of all stakeholders, including patients.
- **Value of healthcare:** it is essential to place priority on the value, not the cost of providing access to high quality, equitable and affordable healthcare for all.
- **Accountability:** health systems must be accountable to the patients they serve, as accountability and transparency are vital to ensuring safe, effective healthcare.

We hope that you will use these member-created Principles in your advocacy and join the call for equal, safe, equitable access to the necessary healthcare for all patients around the world.

Ideas for showing your support

We appreciate that your time and efforts are already stretched, so we have put together a list of ideas to help you show your support using as much or as little time and resources as you can spare. You don't need lots of money to make a large impact and to show your solidarity. All of the ideas below are given in more detail later on in the toolkit, please refer to the contents page on page 3 for more information.

Little gestures to start a wave...

- Use the symbol: Upload a photo of yourself and/or your team performing the "interlocking fingers" gesture or the PSD logo to your social media networks.
- Send letters to the Ministry of Health in your country, WHO regional offices, health system providers, local clinics and health professional bodies, calling for patient-centred healthcare and universal health coverage.
- Use your social media networks to spread the word - follow and share news on **Twitter**, **Facebook** and **miituu** (see p.7). Use the hashtag **#PSD2014** and **@PatientSolidDay** to join the conversation.
- Highlight Patient Solidarity Day in your organization's newsletter or events pages on your website.
- Create a safe space, either online or offline, for patients to discuss their issues, needs and what solidarity means to them.
- Talk to your local/national media about the day and the issues that patient groups face, and how to work towards universal health coverage.

Thinking of making a bigger splash?

- Hold a march around your local area to raise awareness and promote discussion on how to strengthen the patient's voice in healthcare systems.
- Run a cultural event such as hosting a play, theatre, dance or concert with your local groups and networks.
- Distribute flyers on Patient Solidarity Day to your local communities, government, health service providers and any other health professionals to engage them and raise awareness.
- Ask a well-known patient or celebrity from your region or country to support your event or champion/endorse the day, to increase the media and public attention.
- Hold behavioural change or health literacy workshops. These can offer free health screenings: engage with communities about prevention methods, awareness of conditions and patients' organizations support opportunities.
- Visit your local hospital to meet with patients and health professionals and discuss the importance of patient-centred healthcare and universal health coverage with them.

Using the symbol

Using the logo

You can place the logo everywhere you can think of! Examples of where you could show it include:

- Your website
- Your newsletter
- Your email signature
- Onto stickers for placing around your office or on other promotional materials at your events
- Turn it into badges to wear everywhere you go
- Put it onto a car sticker and spread the word even when you are stuck in traffic!
- Make it into t-shirts for your team to wear at your events

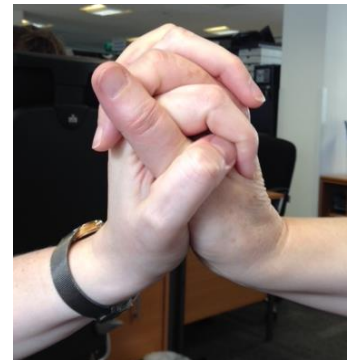


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Just please remember that, for the symbol to become recognisable, it needs to be used in the same way everywhere it is placed. Before you print it or place it online, **please make sure that you are using the official logos. These are available on the website to download: <http://iapo.org.uk/how-use-logo>**

Using the interlocking figures gesture

You can show your solidarity simply by taking a photo of yourself, such as this one as an example, making the interlocking fingers gesture and sending it around your online networks. It's a fun and simple way to show how much you care about patient-centred healthcare and showing your support. Don't forget to add the #PSD2014 hashtag and @PatientSolidDay on **Twitter** and **Facebook** so that we can see it!



Use the IAPO Declaration on Patient-Centred Healthcare as a key resource!

Invite your members and stakeholders to sign-up online:

ipetitions.com/petition/patient-centred-healthcare

www.patientsolidarityday.org

Using social networks



- **Use Twitter to post short updates** and to receive a live feed of current news and events; you can also post photos, films, and share what's happening now. Add #PSD2014 and @PatientSolDay to your posts so that your comments appear on our page and can be easily found by other people celebrating Patient Solidarity Day. Make sure you follow us at @PatientSolDay to follow news and activities.



- **Post longer messages on Facebook** to share stories, news, photos and information about your events and activities. Try and add a photo to your Facebook post whenever possible as it will attract more attention to your post. Be sure to post your updates on <http://www.facebook.com/patientsolidarityday> as well as your own page. Create an event on Facebook to send invitations to your Patient Solidarity Day celebration and raise awareness. Like our page!



- **Join and create discussions in the Patient Solidarity Day LinkedIn group:** LinkedIn is a social networking site aimed at professionals that you can use to build your professional network of connections. LinkedIn groups are useful for discussions on a particular sector or subject.
<http://www.linkedin.com/groups/Patient-Solidarity-Day-5061834>

We want to hear your voice! Tell us your story and record your video here:

http://bit.ly/IAPO_PSD

Or download the IAPO miituu Apple App:

<https://itunes.apple.com/gb/app/iapo/id830604924?mt=8>

Sharing personal stories using social media

Sharing personal stories, or testimonials about your experience as a patient, family member or carer can help people to understand the problem, how patient-centred healthcare provides a solution and what patients' organizations can do to facilitate that solution. Personal stories are a powerful way of explaining why the issue is important and what it means in reality. Define your story; keep it short, poignant and with key messages on patient-centred healthcare. Share it with your colleagues and contacts through social media as above, or in a dedicated area of your website. Share the testimonials and stories of you or your members in your Patient Solidarity Day campaign either online or offline with key partners, other stakeholders or the media.

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Engaging the media

A great way to engage all audiences in Patient Solidarity Day is through your local media. We encourage you to build relationships with relevant influential journalists to help generate coverage of your Patient Solidarity Day activities. This also will help to increase your organization's profile and highlight your great work. You can develop your own media outreach programmes at either national or local levels by using press releases with key messaging (see page 12), social media hashtags and sample social media updates (as noted on page 7), and highlighting your activities.

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.

IAPO member in Zambia

Writing and issuing press releases

When writing and issuing press releases to media, including press and broadcast platforms, it is useful to have the **IAPO Principles on Universal Health Coverage** as well as the **IAPO Declaration on Patient-Centred Healthcare** as a resource and reference. This can help you compare and contrast your country's policies on patient-centred healthcare with those of other countries in your region, using an international definition as a key reference. Link your objectives with government priorities and topical issues that are currently in the news. For example, you may have statistics that demonstrate a lack of access to healthcare. These are useful to create media interest. All efforts to engage the media need to begin with a clear statement and answer the following five questions to define the story:

- **Who** is central to the story?
- **What** is the news you want to report? (Think about the aim for your story when answering this question)
- **Why** has it happened and what will the consequences be?
- **When** did it happen?
- **Where** did it happen?

Remember that a press release must offer new information or a different angle or event, to be considered news. You must offer journalists a clear opinion and an additional insight to increase your chances of them covering your story. It is also often a good idea to announce collaborations with other organizations and launch joint media campaigns to

highlight both of your efforts. An example press release is available for you on the [website](#) to use and adapt when reaching out to your local press and media.

It is important to use personal patient stories in your media engagement. Stories telling the experiences and realities of patients help to strengthen your advocacy by giving it a personal and human angle. **Use personal stories to move hearts, and data and figures to move minds.**

Ideas for catching media attention:

- Organize an educational event or public meeting with government representatives, key medical experts and patients, and invite media to cover the event.
- Issue a joint press release with your government or with the WHO Country Office in your country, or with other patients' organizations, to celebrate national action through Patient Solidarity Day.
- Approach a politician with an interest in the issue to write an article/offer to write it for them, then approach a health, policy, news-focussed publication or blog to publish the article.
- Get a champion to support your cause and highlight your activities! A famous person, well-known patient, or celebrity from your region or country would help to bring increased media and public attention to your event, and to Patient Solidarity Day.



Collaborate!

Partnering with other patients' and health organizations that would like to build patient-centred healthcare can increase the impact of your campaign, and support you with the distribution of press releases and social media updates. These can help to strengthen your engagement with the government, as a coalition with a united voice has more impact. IAPO's toolkit, "Working with partners and stakeholders" offers guidance for patients' organizations on how to develop partnerships with stakeholders while retaining independence.

<http://iapo.org.uk/working-partners-and-stakeholders-toolkit>

Speaking on radio and television talk shows

Sharing your personal story will help others understand why the day is important. Practice your interview technique and be prepared. When you are being interviewed by a journalist, it is often easier to start with the conclusion because those can provide the introduction to the story. This applies in two ways: the way you tell the story and how you respond to questions. It is important to acknowledge the question but then to move on to what you want to say by 'bridging' your response. To do this, you will need to find a word, phrase or

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idea in the question to use as a link. Prepare your story with your key messages in phrases so that you are ready to put this across in your responses.

Patient-centred healthcare means that I am adequately informed and fully involved in the management of my health condition.

IAPO Member from Ghana

Lobbying government

Below is a checklist to consider when writing to government bodies, campaign groups and other important and relevant stakeholders.

a) Identify key role players

Getting your messages heard by the right people is essential to successfully influence policy. Important partners to target may include: Health Ministry representatives, Government officials, campaign groups, academics and journalists.

b) Set up a meeting

It is important to set up a meeting with your local government to ensure your voice is heard. Partner with other patients' organizations and send a joint letter to introduce your organizations and request a meeting.

c) Call on your government to support and sign on to the Principles of Universal Health Coverage and sign the IAPO Declaration on Patient-Centred Healthcare

The involvement of patients who can access treatment, are equipped to manage their conditions and make behavioural changes, are at the heart of a patient-centred approach. This commitment can be demonstrated by signing-up to the **Principles of Universal Health Coverage** and moving towards achieving this, as well as using the **IAPO Declaration on Patient-Centred Healthcare**; either online or print this out and take it with you when you meet.

Patient-centred healthcare to me means respect for patients and family's values, their expressed needs, time and feedback. It also means clear and reliable communication from the healthcare provider to enhance the proper use of the treatment provided, ensure comfort and to minimise confusion. The patient voice and opinions should be heard and considered at all levels of healthcare decision-making.

IAPO Member from Uganda

Running events

You can organize many different types of events, on as large or small a scale as you wish. Here are some tips to consider when planning your event.

- **Plan!** Consider what partners/stakeholders you need to involve, what advocacy tools and messages you want to highlight, what communications you will be using, and what resources you will need.
- **Create materials for awareness.** Create and disseminate flyers to raise awareness and invite people to your celebration. Use the information on Patient Solidarity Day in this toolkit or on the website to create such materials to distribute to your partners and networks. The [website](#) has an example flyer for you to use.
- **Partner** with appropriate organizations to help to organize or sponsor the event. For example, get local sports stores, magazines and teams involved in a sporting event or music stores, clubs, or shopping centres in an entertainment event to help support you and raise the funds available. They can help by organizing fundraising activities and sharing the Patient Solidarity Day key messages in their internal and external communications.
- **Keep it simple!** Use the events you are already planning to highlight the core issues of Patient Solidarity Day and get your networks involved!
- Doing something simple, like wearing the same **colour t-shirts** in a group, is a great way to create a wave and raise awareness and get attention.
- Promote the event by **talking to the media** – use the guide in this toolkit on p.8 for more information on how to engage with the media.
- Decorate your event venue with banners carrying the Patient Solidarity Day **logo and slogan** – One Voice. United. Universal.
- **Get champions!** Use any local or national celebrity contacts to endorse the event, to support the day and highlight the importance of the issues, as they can draw significant crowds and attract media attention.
- Record the event, if possible, for use in your **social media** campaigns and for distributing to your networks and partners to highlight your great work.

Key messages

It is very important that any literature or materials you create or use about Patient Solidarity Day have a unified theme and message. IAPO has a bank of literature that you are welcome to use, and you can create your own of course, though we ask you to bear in mind the key messages about IAPO and about Patient Solidarity Day as listed below.

Key messages about IAPO

- IAPO is the only global alliance representing patients of all nationalities, across all disease areas and promoting patient-centred healthcare worldwide.
- IAPO's Full Members are patients' organizations working at the local, national, regional and international levels to represent and support patients, their families and carers.
- IAPO's Associate Members are health-related, non-profit organizations working towards ensuring patient-centred healthcare.
- IAPO has over 240 members that span over 65 countries and disease areas, representing an estimated 365 million patients worldwide.

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.

IAPO Member from Ghana

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.

IAPO Member from Uganda

- IAPO's vision is that patients throughout the world are at the centre of healthcare.
- IAPO is committed to building cross-sector alliances and working collaboratively with all healthcare stakeholders, including medical and health professionals, policy-makers, academics, researchers and industry representatives.
- IAPO joins its members on Patient Solidarity Day to raise awareness of patient-centred healthcare throughout the world and to increase support for the involvement of patients in the design and delivery of healthcare.

Key phrases about Patient Solidarity Day

- “High quality, equitable and affordable healthcare; nothing more than a dream for so many people around the world. This needs to change.”
- “We have all been a patient at some point in our lives, or cared for one. It’s time to stand together in solidarity to call for truly patient-centred healthcare.”
- “One voice. United. Universal.”
- “Every person, every patient is equal and all have the right to access the healthcare they need, when they need it.”

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 healthcare providers; the number of participating organizations increased, and the numbers of participating service-providers increased.

IAPO Member from Uganda

Patient-centred healthcare means that patients, their families and communities are viewed and treated as human beings and not diseases, ailments and disabilities. This means ensuring that the physical, psychological, spiritual, diagnostic and treatment needs of patients and their families are comprehensively provided.

IAPO Member from Kenya

Available materials

There are a range of materials that IAPO has developed to help you with your engagement and activities. Please download these items from our [website](#):

- IAPO Declaration on Patient-Centred Healthcare
- IAPO Principles on Universal Healthcare Coverage
- Patient Solidarity Day newsletter examples: for including in your newsletter before the Day/ your event, on the Day itself, and after the event
- Patient Solidarity Day web banners and logos
- Example letters to send to the WHO country and regional offices
- Example press release to amend and send to your media contacts

Adding your own information

Where appropriate, we recommend you localise the materials by using facts and figures from your country and your own spokespeople. Develop your own messages based on the theme, and link the core issues of increased access and a need for patient-centred healthcare directly to your specific context and country issues. Include examples from your country about why these issues are important and should be highlighted. These will make your materials more interesting to your networks and local media.

Translations

We recommend you translate the Patient Solidarity Day example materials on the website into any local languages to better reach everyone in your community and broaden the engagement with your networks. If you do translate the materials, please ensure that translations remain true to the original content and meaning of the text. IAPO publications, such as the Declaration are copyright, so we do require an official request from you if you wish to translate our information, as we need to check the translations.

Help us bring Patient Solidarity Day to a wider audience! Please let us know if you have translated any of the materials so we can distribute them to the alliance. Contact megan@iapo.org.uk if you are interested in doing a translation.

Use of quotations for your messaging and materials

Throughout this toolkit, you will find quotations that can be used in your communications. These quotes can be used in internal (eg: newsletters) and external communications (eg: press releases or media alerts). Please note that quotations are to be used verbatim, without edits and must be attributed fully. The quotations can be translated into your local language, however, please ensure that the quotations remain true to their original content and meaning.

Links for further information

- Visit the website for all to download and use:
<http://www.patientsolidarityday.org>
- See 'Frequently Asked Questions' about Patient Solidarity Day for all information about the day: <http://iapo.org.uk/faqs>
- Keep up with news and events by following @PatientSolDay on Twitter:
<https://twitter.com/PatientSolDay>
- 'Like' the Patient Solidarity Page on Facebook:
<https://www.facebook.com/PatientSolidarityDay>
- Share your story on our miituu video wall: http://bit.ly/IAPO_PSD

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.

IAPO member, LiveWell Initiative, Nigeria





6 December 2014
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**Thank you for your support of
Patient Solidarity Day!**

Send us your news!

Please keep IAPO up to date with your plans and progress on Patient Solidarity Day, particularly any media coverage.

We look forward to hearing about your successes!

Email your updates to megan@iapo.org.uk