

Healthcare is a human right Patient Solidarity Day

Member handbook and planner 2015

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Introduction

On 5 December 2015, patients from across the world will come together to celebrate Patient Solidarity Day. This is a unique opportunity for patients, patients' groups and others to stand together and proclaim that healthcare is a human right – without exception - which must be reflected at every level of healthcare.

We need your support

We need your help to make this happen. With your support, we can raise greater awareness, change perspectives and improve the lives of patients across the globe. Please support the Day as much as you can.

This guide

This guide is designed to help everyone support the Day. It provides both big and small ideas for activities and events, plenty of background information, a range of resources and lots of marketing materials you can adapt to make the most of Patient Solidarity Day.

Please use the platforms and messaging outlined here to engage with your community and encourage them to spread the word, either on the day itself or any convenient day close to it.

Find out more

Visit www.patientsolidarityday.org for an online version of this guide and more.

"Patient Solidarity Day is an opportunity to remind everyone that healthcare is a human right. By respecting this, we can improve health systems and services for patients around the world. This is a critical time for us to ensure that the patient voice is central to the achievement of universal health coverage."

- Kawaldip Sehmi, IAPO CEO



1: What you need to know

2015 theme: Healthcare is a human right

"We should all have access to the healthcare we need: good quality, affordable care without fear of discrimination. This is our human right.

The World Health Organization (WHO) states that every person has 'the right to the highest attainable standard of health'. Decision-makers in every country and continent are obliged to make this happen: to respect, protect and fulfil the rights of patients.²

This Patient Solidarity Day we call on individuals, organizations and institutions to agree that healthcare is a human right for all – without exception – which must be reflected at every level of care. Systems should be designed and services delivered to meet the needs of patients.

We call on everyone to stand together on 5 December to raise awareness under this banner, to change the perspectives of others and to improve the lives of patients around the world."

IAPO's seven universal health coverage principles provide a starting point for recognising healthcare as a human right.

¹ Human Rights-Based Approach to Health, WHO. ² A Human Rights-Based Approach to Health, Office of the High Commissioner for Human Rights.

Additional information

The theme of Patient Solidarity Day this year – healthcare is a human right – is built upon a number of international laws which protect the rights of people around the world. There is substance behind the messaging: healthcare decision-makers are obliged by law to respect the rights of patients.

These laws are part the International Human Rights Framework, a body of international law monitored by UN agencies that most Member States have approved in more than ten international treaties. You can find out more about human rights and healthcare on the 'human rights-based approach to healthcare' page on the IAPO website.

What is universal health coverage?

Universal health coverage can be described as affordable, high-quality and accessible healthcare for everyone. The following core principles of universal health coverage have been agreed by IAPO members.



Principles on:

Universal Health Coverage

Every person across the globe has the right to access the healthcare they need. Health systems must be designed and services delivered to meet the needs of patients. Patients must be the first consideration.

The International Alliance of Patients' Organizations (IAPO) has worked with its members to develop the following principles on universal health coverage from a patient perspective.



We believe these principles need to be at the heart of health systems and we call on all governments and stakeholders to put them into practice. These principles can help achieve universal health coverage: affordable, high-quality and accessible healthcare for everyone.

1) Accessibility

All patients have the right to access the healthcare that they need, when they need it.

2) Patient-centredness and equity

All people, regardless of disease or condition; age, gender, race or ethnic background; sexual orientation; geographic location; socio-cultural background, economic or legal status, must have fair and impartial access to quality healthcare.

3) Choice and empowerment

All patients have the right to know about the healthcare services that are available. Patients must be able to be meaningfully involved in healthcare decision-making in a variety of ways at the local, national, regional and global level.

4) Quality

It is not enough for all patients to have access to healthcare. Provision needs to be safe, of the highest attainable standard and include a commitment to learning and improvement. Patients need to define what constitutes quality in healthcare.

5) Partnership and collaboration

Patients have a moral and ethical right to play a meaningful role at all levels; in health and in other areas that can have an impact on health and wellbeing.

6) Sustainability and the value of healthcare

All stakeholders need to recognise the value of healthcare when considering investing in universal health coverage.

7) Accountability and transparency

Accountability and transparency are vital to delivering safe, effective and affordable healthcare. All stakeholders need to be held accountable on commitments they have made to implement universal health coverage, and be accountable to the patients that they serve.

The International Alliance of Patients' Organizations (IAPO) is a unique global alliance representing patients of all nationalities. Everything we do is focused on promoting patient-centred healthcare. We do this by being the global voice for people who suffer from any disease, disability, illness, impairment or syndrome, and by being the focal point for local, national, regional and international patients' organizations.

Find out more about IAPO and the principles at: www.iapo.org.uk/UHC

Key messages

About Patient Solidarity Day

- 1) Healthcare is a human right.
- 2) We should all have access to the healthcare we need.
- 3) Good quality, affordable care without fear of discrimination. This is our human right.
- **4)** Decision-makers should respect, protect and fulfil the rights of patients.
- **5)** Systems should be designed and services delivered to meet the needs of patients.

About IAPO

- **1)** IAPO is the only global alliance representing patients of all nationalities, across all disease areas and promoting patient-centred healthcare worldwide.
- **2)** IAPO has over 250 members that span over 65 countries and disease areas, representing an estimated 365 million patients worldwide.
- **3)** IAPO's vision is that patients throughout the world are at the centre of healthcare.
- **4)** IAPO is committed to building cross-sector alliances and working collaboratively with all healthcare stakeholders, including medical and health professionals, policymakers, academics, researchers and industry representatives.
- **5)** IAPO joins its members on Patient Solidarity Day to raise awareness of the rights of patients and patient-centred healthcare throughout the world.

History of Patient Solidarity Day

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.

In 2014, Patient Solidarity Day was a global event for the first time. 80 organizations from 32 countries took part. The theme was universal health coverage and many people raised awareness in different ways. Activities included awareness walks, hospital visits, free health screenings, debates, meeting health ministers, writing articles and much more! We hope 2015 will make the biggest splash yet.

"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. 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





2: How to show your support

Ideas and activities

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. Please refer to the contents page (page 2) for more information. Please be creative and carry out ideas not listed here too!

Smaller ideas	
Use your social media networks to spread the word - follow and share news on Twitter and Facebook. Use the hashtag #PSD2015 and @PatientSolDay to join the conversation.	Send letters to the Ministry of Health in your country, WHO regional offices, health system providers, local clinics and health professional bodies, calling for healthcare as a human right and universal health coverage.
Highlight Patient Solidarity Day in your organization's newsletter or events pages on your website.	Talk to your local/national media about the day and the issues that patient groups face, and how to work towards universal health coverage.
Create a safe space, either online or offline, for patients to discuss their issues, needs and what solidarity means to them.	

Bigger ideas	
Raise awareness with PSD fliers, posters, stickers or t-shirts among your local communities, government, health service providers and any other health professionals.	Hold behavioural change or health literacy workshops. Practically demonstrate healthcare as a human right with free health screenings, engage with communities about prevention methods, awareness of conditions and more.
Run a cultural event such as a play, theatre, dance or concert with your local groups and networks.	Host a poster competition to engage young people.
Hold a march or a walk around your local area to raise awareness and promote discussion.	Hold a press conference.

Bigger ideas (continued)	
Deliver letters and petitions to decision-makers calling for a commitment to healthcare as a human right and universal health coverage.	Distribute health and patient information to members of the public.
Ask a well-known patient or celebrity from your region or country to support your event or endorse the day, to increase the media and public attention.	Visit your local hospital to meet with patients and health professionals.
Hold health and community engagement workshops, offering opportunities for patients to speak about their conditions and needs.	

Using the logo

You can place the logo everywhere you can think of, such as:

- 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 events



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/psd2015-resources-logos



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 #PSD2015 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 to add a photo to your Facebook post whenever possible as it will attract more attention. 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!



We want to hear from you. Please let us know what you are planning for the Day, what you do and how it went. Email our Communications Officer at ian@iapo.org.uk





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 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 4-6), social media hashtags and sample social media updates, and highlighting your activities.

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 (page 5) (and the IAPO Declaration on Patient-Centred Healthcare) as a resource and reference. This can help you compare and contrast your country's policies 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. 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 real patient stories in your media engagement. Stories telling the experiences 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

Host an educational event or public meeting with government representatives, key medical experts and patients. 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 or offer to write it for them. Approach a health, policy, news-focussed publication or blog to publish the article.

Ask 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.

Don't forget to collaborate! Partnering with other patients', health and human rights organizations 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 have 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 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.



Lobbying decision-makers

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

1) Identify key 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.

2) 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 organizations and send a joint letter to introduce yourself and request a meeting.

3) Call on your government to endorse the Principles of Universal Health Coverage and 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 endorsing the Principles of Universal Health Coverage and moving towards achieving this, as well as using the IAPO Declaration on Patient-Centred Healthcare.





Top tips for 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.

Tips for running events	
Plan! Consider what partners or 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.	Use 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.
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, local sports stores, magazines, music stores, clubs, or shopping centres can 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!	Decorate your event venue with banners carrying the Patient Solidarity Day logo and slogan.
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.	Record the event, if possible, for use in your social media campaigns and for distributing to your networks, partners and the media to highlight your great work.



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 article example
- Patient Solidarity Day web banners and logos
- Example letters to send to decision-makers
- Example press release
- Patient Solidarity Day poster
- Patient Solidarity Day flyer

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 messages based on the theme, and link them to your specific context and country issues. Include examples from your country about why these issues are important and should be highlighted.

Translations

We recommend you translate the Patient Solidarity Day example materials into local languages to better reach everyone in your community and broaden the engagement with your networks. 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 a notification from you if you wish to translate our information.

Final comments

Thank you for your support of Patient Solidarity Day!

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 ian@iapo.org.uk

