



Leave no-one behind

Patient Solidarity Day

Member handbook and planner 2016

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Introduction

On Saturday 3 December 2016, 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 in our claim that patient-centred universal health coverage is essential and that no-one can be left behind.

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 2016 is an opportunity for patients around the world to come together and unite in a call for a patient-centred universal health coverage, as promised by 194 heads of state in September 2015. The Day is a reminder of the global voice that we have as patients and how we must use it to hold stakeholders to account.”

“To be genuinely patient-centred, universal health coverage must involve everyone and be based on healthcare that is universally accessible, affordable and of high quality. It is with this in mind that we must act to ensure that no-one is left behind by 2030.”

Jolanta Bilinska, IAPO Chair



1: The Theme

‘Leave no-one behind: Sustainable patient-centred universal health coverage for all by 2030’

“Achieve universal health coverage (UHC), including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all”. (SDG 3.8)

This Patient Solidarity Day (PSD), Saturday 3 December 2016, we call on our members, organizations, institutions, and stakeholders to support the call for UHC for all. Sustainable, patient-centred UHC is going to need significant efforts and firm commitment over the next 14 years from the key actors in the healthcare system: governments, the pharmaceutical industry, healthcare providers, and patients' organizations.

Patient-centred UHC means that everyone, including our patient organizations and their members, receive the health services they need without suffering financial hardship when accessing them. The full spectrum of essential, safe and quality health services should be covered including health promotion, prevention and treatment, rehabilitation and palliative care.

A patient who has access to UHC can be kept healthy and fit enough to participate in the social, economic, cultural and educational development of their country.

In September 2015, the 194 Member States of the United Nations agreed to develop and put in place practical actions and national frameworks to achieve this and other targets, as part of the 2030 Agenda for Sustainable Development (Resolution A/RES/70/1).

Only if all countries and stakeholders work together in close collaboration will it be possible to ensure that no-one is left behind. This year's PSD presents an opportunity to promote accountability and transparency in healthcare by holding all stakeholders accountable on commitments they have made to achieve UHC in all countries, as set out in Principle 7 of IAPO's Principles on Universal Health Coverage.

Finally, this year's PSD presents a way of re-launching and further strengthening the key message that those who took part in PSD 2015 so strongly voiced last year: healthcare is a human right. UHC is a high-quality, effective, and fair means to promote the right to health to which every person is entitled: leave no-one behind.

Additional information on the theme

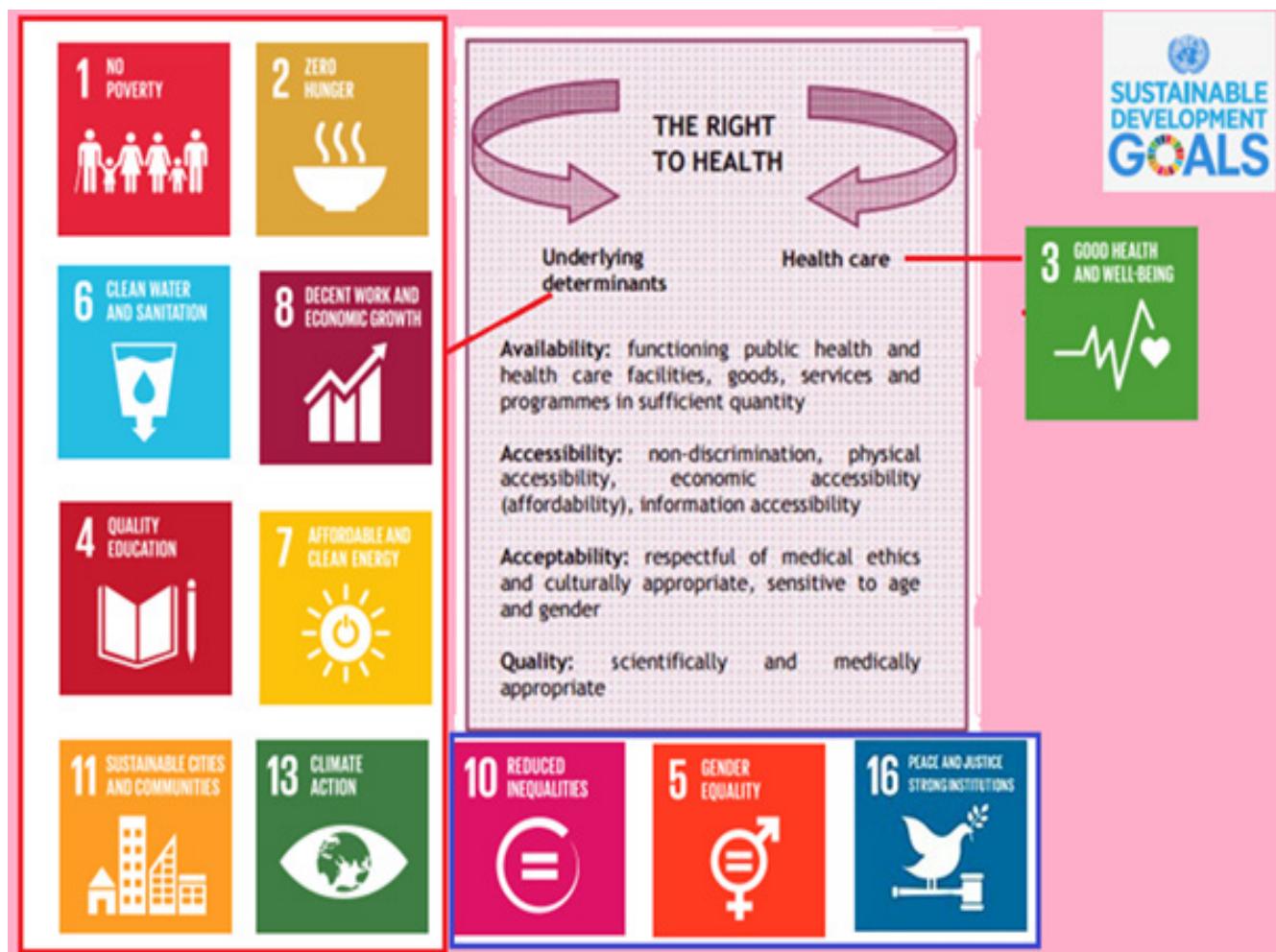
The PSD 2016 theme – Leave no-one behind – builds on the 2030 Agenda for Sustainable Development (Resolution A/RES/70/1), which was adopted by the United Nations General Assembly on 25 September 2015. The Agenda comprises of 17 Goals and 169 Targets. Goal 3 aims to ensure healthy lives and promote well-being for all at all ages. UHC (Target 3.8) represents one of the pillars on which Goal 3 builds.

The 17 goals are closely interconnected. As clearly stated by the United Nations, “The key to success on one will involve tackling issues more commonly associated with another”.

The theme was chosen in a vote by IAPO’s members.

What is universal health coverage?

Universal health coverage can be described as affordable, high-quality and accessible healthcare for everyone. The following page includes the core principles of universal health coverage, which 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.



International Alliance of
Patients' Organizations
A global voice for patients

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.

Declaration on: Patient-Centred Healthcare

Health systems in all world regions are under pressure and cannot cope if they continue to focus on diseases rather than patients; they require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage. Patient-centred healthcare may be the most cost-effective way to improve health outcomes for patients.

To us, the International Alliance of Patients' Organizations (IAPO), the essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective. By promoting greater patient responsibility and optimal usage, patient-centred healthcare leads to improved health outcomes, quality of life and optimal value for healthcare investment.



1. Respect

Patients and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.

2. Choice and empowerment

Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

3. Patient involvement in health policy

Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives. See IAPO's Policy Statement at: www.iapo.org.uk/patient-involvement

4. Access and support

Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that all patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.

5. Information

Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture. See IAPO's Policy Statement at www.iapo.org.uk/patient-information-and-health-literacy

To achieve patient-centred healthcare at every level in every community, the International Alliance of Patients' Organizations is calling for the support and collaboration of policy-makers, health professionals, service providers, and health-related industries to endorse these Five Principles and to make them the centre of their policies and practice. We call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

Key messages

Patient Solidarity Day 2016

- Leave no-one behind.
- UHC is only truly patient-centred when health services are universally accessible, affordable, and of high quality.
- UN member states to take responsibility for implementing robust national frameworks and appropriate measures to achieve patient-centred UHC.
- Collaborative decision-making, based on genuine patient involvement, is key to ensuring no-one is left behind.
- Healthcare stakeholders to be held accountable for their commitments to achieve UHC

About IAPO

- IAPO is a unique global alliance promoting patient-centred healthcare worldwide.
- IAPO has 276 members that span over 71 countries and 51 disease areas.
- IAPO's vision is to see patients throughout the world at the centre of healthcare.
- IAPO is committed to building cross-sector alliances and ensuring that patients play an active role in decision-making processes in healthcare by working collaboratively with key 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 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. In 2015, engagement of patient communities was even stronger, with 108 organizations supporting the Day. The theme was health as a human right 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 2016 will make the biggest splash yet.



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. Patient-centred healthcare can be promoted and supported in multiple ways. It is up to you to choose the ones that you feel can have the strongest impact. You don't need lots of money to make a large impact and to show your solidarity. Be creative and think of ideas not listed here too!

Events ideas	
<ul style="list-style-type: none">• Hold health and community engagement workshops, offering opportunities for patients to speak about their conditions and needs.	<ul style="list-style-type: none">• Hold behavioural change or health literacy workshops. Highlight the importance of patient-centred universal health coverage with free health screenings, engage with communities about prevention methods, awareness of conditions and more.
<ul style="list-style-type: none">• Run a cultural event such as a play, theatre, dance or concert with your local groups and networks.	<ul style="list-style-type: none">• Hold a march or a walk around your local area to raise awareness and promote discussion.
<ul style="list-style-type: none">• Host a poster competition to engage young people.	
Communications ideas	
<ul style="list-style-type: none">• Raise awareness on UHC with PSD fliers, posters, stickers or t-shirts among your local communities, government, health service providers and any other health professionals.	<ul style="list-style-type: none">• “Be the news!” Talk to your local/national media about the day and the issues that patient groups face, and how to work together towards universal health coverage.
<ul style="list-style-type: none">• Use your social media networks to spread the word - follow and share news on Twitter and Facebook. Use the hashtag #PSD2016 and @PatientSolDay to join and enhance the conversation.	<ul style="list-style-type: none">• Promote key messages by matching them with the chosen medium to get to the target audiences.
<ul style="list-style-type: none">• Hold a press conference.	<ul style="list-style-type: none">• Highlight Patient Solidarity Day in your organization's newsletter or events pages on your website.



Campaigning, advocacy	awareness ideas
<ul style="list-style-type: none"> Identify decision-makers and target key players linked to healthcare, such as doctors, nurses, health professionals and teachers who have a strong collective voice in health policy-making through their associations and industry representative bodies. 	<ul style="list-style-type: none"> Distribute health and patient information to members of the public.
<ul style="list-style-type: none"> Create and deliver petitions and letters to decision-makers calling for a commitment to leaving no-one behind and universal health coverage. 	<ul style="list-style-type: none"> Create a safe space, either online or offline, for patients to discuss their issues, needs and what patient-centred universal health coverage means to them.
<ul style="list-style-type: none"> Visit your local hospital to meet with patients and health professionals. 	<ul style="list-style-type: none"> 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.
<ul style="list-style-type: none"> Send letters to the Ministry of Health in your country, WHO regional offices, health system providers, local clinics and health professional bodies, calling on them to abide by the commitments they made, deliver patient-centred UHC, and ensure no-one is left behind. 	

Suggested timeline: A few key dates...

Mid October – early November: Start thinking about possible activities

Early November: Tell IAPO what you are planning

Early - mid November: Contact your supporters to promote your activities (local and regional WHO offices, Ministry of Health, other stakeholders)

Mid – late November: Build up a drumbeat of activity on social media in the lead up to Saturday 3 December

Saturday 3 December: Patient Solidarity Day!

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



Leave no-one behind
Patient Solidarity Day

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 #PSD2016 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!



This year for the first time we are using Thunderclap to get across the message of Patient Solidarity Day. Thunderclap is a crowdspeaking tool that enables us to share and amplify a message. By joining the PSD2016 Thunderclap, you and many others will be able to share a message at exactly the same time, resulting in a stronger voice. Please sign up to our Thunderclap by [clicking here](#).

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 Membership Engagement and Policy Officer at victoria@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 4-8), 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 and the [IAPO Declaration on Patient-Centred Healthcare](#) (page 6 and 7) 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-focused 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

Governments and stakeholders agreed to implement robust frameworks to achieve patient-centred UHC. If these stakeholders are to be held accountable for delivering UHC, it is crucial for patients to develop adequate knowledge as to the most effective ways to reach out to them and call on them to stick to their commitments.

1) Identify key decision-makers

Getting your messages heard by the right people is essential to successfully influence policy. Also, the healthcare system is composed of many, important players, including professionals, health ministry representatives, industry representatives, government officials, academics and the media. Knowing where the decision-making power lies and who the crucial actors are in the various fields is key to holding stakeholders to account for supporting patient-centred healthcare.

2) Approach decision makers

It is important to identify the best methods of engagement depending on the actor that you want to approach. Ensure that the actions that you take are appropriately tailored on the characteristics of the partner or entity to whom you want to speak. Carefully selecting forms of engagement that are fit-for-purpose can do a lot to make your voice stronger and better heard from those who have the power to make UHC become reality. Where possible, partner with other organizations and plan joint activities to ensure that different patient communities come together and speak with one, strong voice.

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	
<ul style="list-style-type: none">• 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.	<ul style="list-style-type: none">• 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.
<ul style="list-style-type: none">• 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.	<ul style="list-style-type: none">• 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.
<ul style="list-style-type: none">• Keep it simple. Use the events you are already planning to highlight the core issues of Patient Solidarity Day and get your networks involved!	<ul style="list-style-type: none">• Decorate your event venue with banners carrying the Patient Solidarity Day logo and slogan.
<ul style="list-style-type: none">• 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.	<ul style="list-style-type: none">• 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.

We currently have translations of the Principles of Universal Health Coverage and the Declaration on Patient-Centred Healthcare in English, Spanish, Arabic and Mandarin. We thank three of our members for their help in translating our Arabic and Mandarin documents.

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 victoria@iapo.org.uk and pirlita@iapo.org.uk

"Patient Solidarity Day is an opportunity for patients around the world to unite and be the voice of many patients that need treatments that the health systems in their countries do not cover."

- IAPO member from Chile

"Patient Solidarity Day offers an opportunity to look at all illnesses, to show love and compassion for our fellow patients, weakened physically or psychologically. In several African countries including my own, patients are considered clients that pay medical care without having the right to examine the quality of care. With a focus on healthcare centered on the patient, Patient Solidarity Day is an important advocacy point which should ultimately put the patient before, during and after public health policies."

- IAPO member from Cameroon