



**International Alliance of
Patients' Organizations**

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International Alliance of Patients' Organizations

2024 Activities Report



2024: A YEAR OF CONTINUED IMPACT AND CELEBRATION

In 2024, IAPO continued its work in collaboration, advocacy, and innovation to advance patient-centred healthcare globally. This milestone year marked our [25th anniversary](#) – a moment to reflect on the journey that has shaped our alliance and honour a quarter century of championing patients' voices worldwide.

This report highlights our main activities in 2024 organized according to the [IAPO Strategic Plan 2022-2024](#).



Strategy Goal 1: EMPOWER

Empower members with cutting- edge knowledge and advocacy skills to enhance the reach, efficacy, and impact of our membership in bringing about a Patient-Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC).

- ◆ In 2024, IAPO proudly celebrated its [25th anniversary](#), reflecting on the quarter century journey we have been on as an alliance championing patient-centred healthcare globally. To mark this milestone, we launched our [new impact strategy](#) to guide our efforts through 2025 and beyond. This includes an updated vision and mission, as well as IAPO's new FACE – a strategic framework standing for Facilitation, Advocacy, Collaboration and Empowerment.
 - **Vision:**
A world where health systems are shaped by the unique needs and preferences of the people and communities they represent.
 - **Mission:**
Mobilise and support patient organisations around the world, empowering them to play an active role in decision-making processes shaping the global health landscape.
 - **FACE strategic framework:**
Facilitation
Advocacy
Collaboration
Empowerment
- ◆ As part of our **25th anniversary celebrations**, we also launched a special 4-episode web series titled [‘IAPO Turns 25’](#) spotlighting the voices of our global membership. Each of the 4 episodes featured members exploring a pillar of our new FACE framework and sharing what these pillars mean to them and their communities.
- ◆ We celebrated [Patient Solidarity Day \(PSD\)](#) on 9 December 2024 under the theme ‘The Power of Community’, which highlighted the collective strength of the IAPO patient organisation community built over the last 25 years. PSD 2024 showcased this community as a powerful testament to what can be achieved when patient organisations come together to take control of their journeys, amplify their voices, and advocate for healthcare systems that prioritise the needs of patients and communities.
 - To mark PSD 2024, IAPO members contributed with video testimonials, sharing their perspectives on the strengths of the global patient organisation community. These insights were brought together as [a special playlist on IAPO's YouTube channel](#), showcasing diverse and compelling interpretations of this concept from different regions around the world.

- ◆ Through the [Personalised Cancer Care Alliance \(PCC Alliance\)](#), IAPO hosted a [capacity-building workshop](#) in **Morocco**, bringing together 18 patient advocates from the country. The workshop served as a platform for exchanging ideas, forging collaborations, and laying the groundwork for initiatives aimed at integrating the personalised approach to cancer care in Morocco.
- ◆ Additionally, through the **PCC Alliance**, we hosted a **second regional capacity-building workshop in Dubai** for cancer patient organisations from countries of the Gulf Confederation (GCC), where we also had the participation of the WHO Office for the Eastern Mediterranean Region. The workshop culminated in a collaborative roadmap translating the action points agreed by the group to advance personalised cancer care.
- ◆ As part of IAPO's efforts to advance social participation in healthcare, we co-hosted a webinar with the Civil Society Engagement Mechanism for UHC2030 (CSEM) and Frontline Aids, titled ["What's next? Follow-up on the resolution on social participation for universal health coverage: Translating global commitments into national action"](#). The webinar was a moment for participants to share valuable insights, lessons learned, and strategies for sustaining political support for social participation at both global and national levels.
- ◆ As a member of the World Skin Health Coalition, IAPO joined the ["Not Just My Skin" campaign](#): a collaborative effort to raise global awareness about the significant impact of skin diseases and conditions on patients, people with lived experience and communities. The campaign addressed the urgent need for timely diagnosis, access to care and affordable treatment, and mental health support for people with skin conditions, advocating for the prioritisation of these critical issues by health policy leaders worldwide. The campaign was a massive success and acted as a spark that ignited a global movement to act for better and more equitable skin healthcare.



- ◆ As part of our involvement in the Global Patient Think Tank (GPTT), a group of patient representatives from across the globe convened by Roche, **IAPO co-created and launched the [UHC Compass](#)**. The compass was designed by patients, for patients, to support local leaders and communities in advancing decision-making and progress toward universal health coverage (UHC) on the ground. In addition to providing accessible knowledge on UHC, the UHC Compass offers self-assessment resources and case studies to help patient organisations develop their capabilities in playing an active role in decision-making processes in health.
- ◆ As a founding and steering committee member of the **[African Medicines Agency Treaty Alliance \(AMATA\)](#)**, IAPO together with its partners finalised the **AMATA Toolkit**. This toolkit aims to support AMATA members and their networks in advocating for the operationalisation of the African Medicine Agency, a continental regulatory body which will ensure timely access to quality medicines that are safe and effective for all patients in Africa.
- ◆ IAPO joined global health stakeholders in celebrating the annual **[World Patient Safety Day](#)** (WPSD), a WHO-led initiative observed yearly on 17 September. Through the 2024 theme of "Improving diagnosis for patient safety," we actively promoted the campaign among our members and wider network, raising awareness about the critical importance of correct and timely diagnosis in ensuring patient safety and improving health outcomes.
 - As part of the global celebration of WPSD 2024, IAPO joined a webinar panel hosted by **[Joint Commission International](#)**, titled "**Diagnostic Safety: The Multidisciplinary Approach**". Representing the patient perspective, we highlighted the importance of a patient-centred, collaborative approach to diagnostic safety underscoring how multidisciplinary cooperation is essential to achieving accurate and timely diagnoses that protect and empower patients.
 - IAPO also marked WPSD 2024 by **co-creating a global social media campaign** in collaboration with GS1 Healthcare, the European Association of Hospital Pharmacists (EAHP), the International Hospital Federation (IHF), and the International Society for Quality in Health Care (ISQua). This joint effort aimed to raise awareness and promote patient safety worldwide, reinforcing the importance of coordinated action across the healthcare community.
- ◆ IAPO participated in the **PEOF Virtual Session ["Catalyzing Change: Using the WHO Resolution on Social Participation in health to achieve real patient-driven impact,"](#)** where we discussed how patient voices can shape more inclusive health policies and systems for universal health coverage. The session was a unique opportunity to co-create actionable plans to advance the WHO resolution on social participation and drive meaningful change in health systems worldwide.
- ◆ We advanced the **[Patient Academy](#)** website by collaborating on additional modules, involving patients in creating videos, and fostering engagement through social media awareness posts. The vision of the Patient Academy is to create communities of empowered patients who take ownership of the management of their medical condition through customized health information.

- ◆ We launched a **new toolkit** on biosimilar medicines, titled **[“Toolkit to Become an Informed Patient: Deciphering the World of Biosimilar Medicines.”](#)** This toolkit was created to empower and equip patient organisations with essential insights into the science, regulatory landscape, and benefits of biosimilars.
- ◆ We launched an **AI-based application** called **[EczemaLess App](#)**, aiming to support patients in tracking and managing Atopic Dermatitis. The app also assists patients in setting up a care routine and tracking trigger factors, as well as providing insights and educational videos to raise awareness about this condition.



Strategy Goal 2: DRIVE RESEARCH

Co-create evidence in support of healthcare that is PC, PP and a UHC that strengthens patient involvement in clinical research and global health institutes.

- ◆ IAPO conducted the [Unmet Patient Needs Research](#), where we co-designed a survey with IAPO members to gather valuable insights about unmet health-related needs from the perspective of patients and people with lived experience. The research project deliverables consist of a comprehensive analytical report and a set of advocacy briefs to be launched in 2025.
- ◆ We launched the report of our commissioned research project ["Improving Breast Cancer in the Middle East and Africa"](#) at an online panel discussion where we highlighted its key findings and potential as an advocacy tool featuring the involvement of patient representatives.
- ◆ We continued our support to the [international research project EOLinPlace](#) both as part of the [Patient Advisory Group](#) and as the project's patient representative. Through IAPO board member Flavia Kyomukama, we participated in the work retreat advising and contributing to the development of the International Classification of Dying Places. This project is hosted by the University of Coimbra and is the largest study of international time trends in place of death and the first showing a rise of home deaths in the COVID-19 pandemic across countries.
- ◆ IAPO also continued to participate as a member of the **BMJ Group International Patient and Public Advisory Panel**, advising within the different working groups, including the ones on Patient Safety and Healthcare Sustainability.



Strategy Goal 3: **SHAPE LAW, POLICY, STANDARDS**

Apply the empowered patient community and evidence created to shape the institutional, law, policy, practice, and standards framework for healthcare that is PC, PP and a UHC at global, regional, and national levels.

- ◆ As part of our role as a Non-State Actor in official relations with the WHO, we developed and submitted our final report on the **IAPO-WHO Triennial Collaboration Plan (2022-2024)** for review by the WHO Executive Board, as well as our **new plan for the next three years of the collaboration (2025-2027)**. Both the final report and the **IAPO-WHO Triennial Collaboration Plan (2025-2027)** were approved and our status as Non-State Actor in official relations with the WHO was renewed for the next three years.
- ◆ We participated in the [World Patient Safety Day 2024 Global Consultation 'Improving diagnostic safety and implementing the Global Patient Safety Action Plan 2021-2030'](#), to discuss the strategies for enhancing diagnostic processes and reducing diagnostic errors and reflecting on the progress and challenges in implementing the Global Patient Safety Action Plan 2021-2030. On the occasion, we joined working groups and integrated the panel "How stakeholders can accelerate the implementation of the Global Patient Safety Action Plan" as representatives of patient and civil society organisations.
- ◆ In collaboration with The Synergist, we jointly hosted the [side event "Leveraging patient organisations as key partners in the delivery of Universal Health Coverage"](#) on the side-lines of the 77th World Health Assembly (WHA77) in Geneva. The event brought together 80 participants and discussed the importance of social participation in the delivery of universal health coverage, highlighting patient organisations' fundamental role in shaping patient-centred health systems.
- ◆ As a member of the Global Self-Care Coalition, IAPO participated in the [1st Global Self-Care Summit](#), titled 'Self-Care in Action: Empowering Health and Well-Being', on the side-lines of WHA77 in Geneva. The event highlighted the relevance of self-care in achieving global health goals, including the health-related SDG targets, universal health coverage, NCD prevention and control, and improving access and quality of primary health care.
- ◆ IAPO joined the speaker panel of the side event "[Uniting Voices for Action on Women Cancer in the Eastern Mediterranean Region](#)", promoted by the NCD Alliance on the side-lines of WHA77. This session catalysed efforts around women's cancers in the region and galvanized the EMR political commitment in ensuring women's cancer remains a central focus on the agenda of the upcoming UN High-Level Meeting on Non-communicable Diseases in 2025.
- ◆ IAPO delivered statements at the WHO Regional Committee meetings as follows:

- In August 2024, IAPO delivered a [statement](#) on **Agenda item 18.1 of the 74th Session of WHO Regional Committee for Africa**. In alignment with the resolution on social participation for universal health coverage, health, and well-being, IAPO urged Member States from the African region to fully commit to its implementation. We also joined the **African Medicines Agency Treaty Alliance (AMATA)**, in delivering a statement at the same regional meeting calling upon the African Union Member States who have not yet ratified the African Medicines Agency Treaty to do so urgently, to enable the operationalization of a strong continental regulatory system with the ultimate objective of improving public health, patient safety and the quality of life for all people in Africa.
 - In October 2024, IAPO delivered a [statement](#) on **Agenda item 8.2 of the 77th Session of the WHO Regional Committee for South-East Asia**. IAPO's statement urged Member States to fully commit to the resolution on social participation for universal health coverage, health, and well-being, stressing that engaging patients, communities, and people with lived experience in policy design and implementation is key to accelerating progress toward safe, quality, equitable, and people-centred healthcare policies across South-East Asia.
 - In October 2024, IAPO delivered a [statement](#) on **Agenda item 9 of the 74th Session of the WHO Regional Committee for Europe**. IAPO's statement called on Member States to commit fully to the resolution on social participation for universal health coverage, health, and well-being, emphasising that involving patients, communities, and people with lived experience in policy design and implementation is essential to advancing safe, quality, equitable, and people-centred healthcare policies throughout Europe.
- ◆ IAPO co-authored an [editorial for the BMJ in July](#), highlighting the resolution on social participation for universal health coverage, health and well-being. Titled "**World leaders unite to embed social participation in health systems**" and published in the BMJ's patient-led issue "**Patient Partnership: Time for patients to have a seat at every table**," the editorial delves into the critical role of social participation as a pressing need and fundamental right in health policy design and practices while discussing strategies to amplify the patient voice across all levels of healthcare systems.
- ◆ As a founding partner of the [International Consensus Framework for Ethical Collaboration](#), IAPO attended a roundtable meeting in May to mark the **10th Anniversary of the Framework**. At the meeting, partners discussed the importance and timeliness of these principles in building ethical and trustful partnerships aimed at delivering greater patient benefits. An outcome of this session was the agreement to review the framework, modernise its language and introduce a fifth principle on upholding the responsible use of health data and technology.
- ◆ To further celebrate the [10th Anniversary of the International Consensus Framework for Ethical Collaboration](#) as well as **Global Ethics Day**, IAPO joined other founding partners including International Council of Nurses (ICN), International Federation of Pharmaceutical Manufacturers

and Associations (IFPMA), International Pharmaceutical Federation (FIP), and World Medical Association (WMA), [in publishing a joint op-ed](#), where we reflected on progress made under the Framework over the last decade and announced our commitment to ensuring it is fit-for-purpose to address unfolding new realities, including the impact of new innovations on patients' lives.

- ◆ IAPO joined a coalition of patient groups, informal carers (Eurocarers), and palliative care professionals from the International Association for Hospice and Palliative Care (IAHPC) and the International Children's Palliative Care Network (ICPCN) in issuing [a statement on home support for patients with advanced diseases and their families](#). The statement urged governments to enhance home support for patients with advanced diseases and their families who prefer to receive care and pass away at home whenever feasible. This call came in response to findings from the [EOLinPlace](#) research project, the largest study to date on international time trends in place of death, where IAPO serves as the patient representative and participates in the Patient Advisory Group.
- ◆ IAPO continued to be part of the [Global Patient Think Tank \(GPTT\)](#), a diverse group of patient community representatives from across the globe, convened by Roche. The GPTT has come together to ensure the patient community voice is integrated into the global movement for universal health coverage, including policy discussion, inclusion into national design, governance and implementation, and at the primary healthcare level.
- ◆ IAPO spoke at the [6th Global Ministerial Summit on Patient Safety in Chile](#), a platform that plays a vital role in driving forward the patient safety agenda, shaping policies, and catalysing action to ensure safer and more effective healthcare delivery worldwide.
- ◆ As a founding member of the African Medicines Agency Treaty Alliance (AMATA), IAPO joined the alliance in publishing a [statement during the 37th African Union Summit](#), in February 2024. The statement urged Member States to expedite the ratification and operationalisation of the African Medicines Agency Treaty to ensure timely access to quality medicines for all patients in Africa.
- ◆ In response to the revision of the **Declaration of Helsinki**, which has long stood as a foundational text in medical research ethics, shaping the ethical principles that govern human participation in clinical research, IAPO – through our board member Prof. Lara Bloom – published an [article](#) to contextualise the history of the Declaration, analyse the implications of its latest revision, and emphasize the need for patient centricity in research ethics.
- ◆ IAPO continued to be a member of the [WHO Civil Society Commission \(CSO\)](#) and applied to join the **working group "CSO engagement strategy"**, which together with the WHO Secretariat will co-develop the **WHO Civil Society Engagement Strategy 2025-2028**.



IAPO's Annual General Meeting

We held our Annual General Meeting in December 2024, where we celebrated IAPO's 25th anniversary by unveiling our new impact strategy for 2025 and beyond and introducing our new FACE framework designed to guide our efforts in empowering patient organisations to drive meaningful change globally. We also unveiled our new brand identity as a first step in our rebranding process which will culminate in the launch of a new website. We also launched a special four-episode web series titled ['IAPO Turns 25'](#) featuring our global membership. We also announced the newly elected and re-elected Governing Board Members.



Communications

Newsletter & mailing

IAPO maintained its newsletter subscription of over 12,000 subscribers, who receive our announcements, campaigns and monthly newsletter covering all IAPO-related news and updates, including initiatives such as our congresses, member activities, advocacy news and information. We also added to the newsletter a section on relevant updates about the World Health Organization (WHO), including new policy documents and guidelines, important dates and advocacy campaigns. We also used several mailing campaigns to disseminate and promote important IAPO initiatives and events throughout the year.

X (formerly Twitter)

The IAPO secretariat continued to operate the following X accounts: [@IAPOvoice](#), [@PatientSolidarityDay](#), [@AfricanAmata](#), [@PCCAlliance](#).

Facebook

We continued to operate the following Facebook accounts: [IAPOvoice](#), [International Alliance of Patients' Organizations](#), [Patient Solidarity Day](#), [Personalised Cancer Care Alliance](#).

LinkedIn

IAPO also continued to operate the following LinkedIn accounts: [International Alliance of Patients' Organizations](#), [African Medicines Agency Treaty Alliance \(AMATA\)](#), [Personalised Cancer Care Alliance](#).

YouTube

We continued to operate IAPO's YouTube channel – [@IAPOPatientVoice](#) – which is currently composed of 235 videos.

Website



www.iapo.org.uk

IAPO's website continues to be the main source of information for all IAPO's activities, initiatives and events, as well as an important promotion and dissemination channel.

UHC Compass landing page



www.tinyurl.com/uhccompass

In 2024, IAPO co-created and launched the **UHC Compass**, an evolving resource to support local leaders and communities in advancing decision-making and progress toward universal health coverage in their countries. The UHC compass can be accessed as a stand-alone landing page or through the IAPO website.

Rebranding

As part of our celebrations to mark IAPO's 25th Anniversary in 2024, we developed and launched a new logo as the starting point of our wider rebranding, which will culminate in the launch of our new website in 2025.

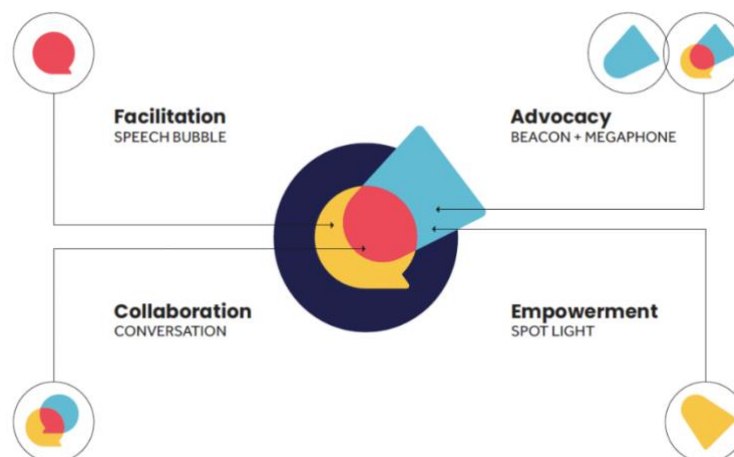
Besides marking the anniversary, a new branding system was needed for several reasons. The old logo had an outdated design with limited colour palette and unclear figures, was not accessible whenever applied to different backgrounds, and ultimately did not link with the IAPO's impact strategy for 2025 and beyond.

The new logo combines the concepts of 'communicate' through the yellow speech bubble, 'empower' through the blue beacon. Both shapes combined result in the multi-colour megaphone standing for the concept of 'amplify'. Altogether, our new icon translates IAPO's support and mobilisation to our IAPO membership and the wider global patient organisation community.

Below are some of the different uses of our new logo when applied against a white background:



Here are the links between the new logo concept and IAPO's FACE framework:



Thank You

The International Alliance of Patients' Organizations is registered in England and Wales as charity n° 1155577 and company limited by guarantee n° 08495711.

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