

From Pilots to Practice: Leveraging the PCCA Position Paper 2.0 for Regional Impact

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PCCA Position Paper 2.0 Workshop Report



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Organized by: IAPO
in partnership with :
WHO EMRO, MSD

1 Background and Context

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1.1 About IAPO

IAPO is the global alliance representing patients of all nations across all disease areas and promoting patient-centred healthcare across the world. IAPO, a Non-State Actor in official relations with the World Health Organisation (WHO), has almost 300 member organisations from 71 countries representing 54 disease areas.

1.2 About PCCA

Launched in 2022 by IAPO, the [PCC Alliance](#) is an alliance of cancer patients, carers and representatives of patient organisations from within the WHO Eastern Mediterranean and selected countries from WHO Africa and Europe set up to advance health literacy in cancer, advocacy skills and education on personalised cancer care.

The initiative is built on the Five Ps framework: Predictive, Preventative, Participatory, Personalised, and Pre-emptive care. This framework aims to improve patient health outcomes and experiences whilst supporting health systems to deliver quality healthcare in an effective, accessible and compassionate way.

The PCCA journey began in 2022, with four webinars, followed by the launch of the original Position Paper in October of the same year, which established the foundational framework for personalised cancer care advocacy in the region. A World Health Assembly side event in Geneva in May 2023 and a roundtable in Egypt in October 2023 built momentum. The Morocco pilot was launched in January 2024, followed by the Gulf Cooperation Council (GCC) Pilot in partnership with the Gulf Federation for Cancer Control (GFFCC) in November 2024 and the establishment of the Gender Working Group (GWG) in July 2025.

Position Paper 2.0 represents the evolution of this work, incorporating real-world evidence from three strategic pilots: one at country-level (Morocco), one at regional-level (GCC), and one focused on gender equity (GWG). Anchored in lived experience and community needs, serving as a stepping stone towards regional transformation in personalised cancer care.



2 Executive Summary

The PCCA Position Paper 2.0 Workshop was held as a side event to the 11th IAPO Global Patient Congress. Bringing together patient advocates, healthcare professionals, and international partners, the workshop was convened to transform Position Paper 2.0 into strategic action.

The workshop pre-launched the Position Paper, completed a month earlier, in order to extract key learnings from its three chapters (Morocco, GCC, and GWG) and establish clear pathways for implementation.

It also highlighted the opportunity to align with IAPO's 2026 Regional Hubs initiative and the WHO framework for meaningful engagement of people with lived experience. Through these alignments, patient organisations can influence policy at all levels.

The core outcome was an actionable roadmap integrating lived experience across all advocacy levels, with renewed commitment to fostering collaboration across the region.

The workshop demonstrated that when patient organisations unite with clear priorities and strategic partnerships, they can accelerate progress from theoretical discussions to tangible community impact.

The agreements and accountability frameworks established in Manila provide the foundations for sustained, scalable and systemic change that meaningfully engages patients in the decisions that affect every aspect of their care journey.

3 Workshop

3.1 Objectives

The workshop was designed with four core objectives:

- Review and discuss key learnings from three chapters
- Co-create implementation roadmap for local, national, and regional levels
- Establish accountability framework for material usage
- Foster collaboration across Morocco, the GCC, and the GWG

3.2 Participants

Moderator:

- Dr Sawsan Al Madhi
Advocacy Advisor, CEO, AlignEfficient Health Consultancies (Dubai.London)

Morocco Chapter:

- Mohamed Belkadi - Cancer: We are All Concerned
- Hajar Gdader - NABD-BC2
- Hajar El Khoudari - AMAL Association

GCC Chapter:

- Majed Mohammed - FOCP UAE
- Dr Safana Alsaïdi - Oman Breast Cancer Society
- Dr Wafa Ajour - Bahrain Cancer Society

GWG Chapter:

- Dr Zehra AlHilali - Eastern Mediterranean NCD Alliance, Bahrain
- Dr Reem Al-Ajloun - King Hussein Cancer Foundation, Jordan/Pan Arab Breast Cancer League

International:

- Dani Mothci - CEO, IAPO
- Rachel Githinji - Partnerships Lead, IAPO

Technical Support:

- Dr Heba Al Sawahli - WHO EMRO Consultant

Pharmaceutical Partner:

- Claire Lebled - MSD EEMEA Regional Director Patient Innovation & Engagement

Unable to attend:

- Ikram Esseghir - NABD-BC2, Morocco chapter and GWG
- Ms Bahija Gouimi - AMAL founder, hosted Morocco workshop
- Dr Khaled Al Saleh - Gulf Federation and GCC
- Dr Al-Fouad Bin Abdul Rahman and Saudi representatives
- Dr Ibtihal Fadhil - NCD Alliance EMRO Chairwoman
- Dr Hessa Alshaheen - Kuwait, GWG member

3.3 Agenda Overview

The workshop was structured to move strategically from sharing knowledge to practical implementation based on the key learnings of Position Paper 2.0.

Morning session

- Welcome remarks
- Recap of the PCCA and Position Paper 2.0
- Pre-launch of the three chapters (Morocco, GCC, Gender Working Group)
- Overview of IAPO's 2026 direction and regional hubs initiative.

Midday session

Roundtable discussion addressing two crucial questions:

- How can Position Paper 2.0 serve as an advocacy tool at national, regional and global levels?
- How can IAPO's support be leveraged?

Afternoon session:

- Workshop 1: Accountability and Commitment Pathways
- Workshop 2: Roadmap Building
- Conclusions and reflections



4 Opening Remarks

Dr Sawsan Al Madhi opened the workshop by congratulating participants for their work on the Position Paper, and thanking IAPO and MSD for their ongoing support. She presented the objectives of the workshop in the run-up to the paper's official launch, whose date will be announced by IAPO.

She outlined the workshop's agenda and goals: to review the three chapters, discuss key learnings, and determine how the chapters would be used. The focus would be on co-creating a roadmap for their implementation at local, national and regional levels, exploring scalability and synergies, and establishing accountability and next steps.

Dr Sawsan summarised the purpose of the first Position Paper in 2022, the pilots and the creation of the second Position Paper. Underlining the importance of cross-country collaboration, She highlighted the landmark establishment of the GWG in 2025 and its crucial role in exploring solutions to gender-based challenges in cancer care at the regional level.

She concluded by reminding participants of the Five Ps framework at the heart of the initiative, placing particular emphasis on the participatory pillar for capacity building.

“We had such a rich experience working in parallel with Morocco, the GCC and the GWG and we've seen an incremental advancement. The dots connect in everything.” – **Dr Sawsan Al Madhi**

Acknowledging the support of IAPO and MSD, Dr Sawsan then introduced Dani Mothci, CEO of IAPO.

Dani Mothci explained the synergies between IAPO and PCCA, reiterating the importance of unity. She asserted how PCCA was created to mobilise stakeholders around personalised care in EMRO and Africa, and provided an overview of the Morocco and GCC pilots and workshops, their outputs, and how they can and must shape priorities in advancing personalised cancer care.

“It's important that we meet in person to get to another level, recognise the work completed and agree on how to move forward together.” – **Dani Mothci**

Dr Sawsan invited all workshop participants to introduce themselves, and paid tribute to those unable to attend and their vital work.



5 Chapter Presentations and Key Learnings

Dr Sawsan invited representatives from the three chapters to present the trajectory and key findings from their respective pilots.

5.1 Morocco Chapter: National Pilot

Morocco was selected for the Group B (middle income) country pilot, launched in January 2024 in Marrakech.

Mohamed Belkadi (Cancer: We are All Concerned), Hajar Gdader (NABD-BC2), and Hajar El Khoudari (AMAL Association) presented the journey and outcomes of this national pilot.

Process

Morocco entered a new phase in its personalised cancer care journey in January 2024, with this national pilot, which unwaveringly demonstrates how patient-led civil society can drive personalised cancer care forward.

The pilot followed a systematic process: mobilisation of cancer patient organisations in collaboration with the Association des Malades Atteints de Leucémies (AMAL); a two-part assessment covering the Five Ps framework and patient organisations' assets; and a national capacity-building workshop in Marrakech with 12 cancer patient organisations from all regions of Morocco.

The organisations participated fully in the subsequent process, receiving ongoing post-workshop support to develop personalised roadmaps that turn the Five Ps framework into practical action. By October 2024, more than 90% had begun implementing their action plans.

A major output from the pilot was the National Advocacy Priority List reflecting these organisations' shared priorities in early detection, treatment access, patient

support, and health system strengthening. The government was engaged in September 2024 through the WHO EMRO workshop, and formal meetings were established with the Moroccan Ministry of Health.

“We progressed from patient organisations ready to speak in January 2024 to governments ready to listen by October 2024.” – **Hajar Gdader**

Achievements

The national pilot identified several critical success factors:

In Morocco, survivor-led advocacy and patient stories have proved to be powerful tools to reduce stigma and encourage others to seek early screening and support.

Women from grassroots communities have been elevated to become national advocates, representing Morocco at regional and global levels.

Cross-coordination among patient organisations has strengthened their collective voice, whilst local ownership remains crucial. The WHO's May 2024 lived experience resolution created valuable political momentum for deeper patient engagement.

“Associations are often founded by survivors, who understand that we are not dealing with doctors, we are dealing with patients.” – **Hajar El Khoudari**

Success stories

Moroccan organisations demonstrate the impact of coordinated advocacy

- **Cancer: We are All Concerned** champions survivor-led awareness and stigma reduction initiatives
- **NABD-BC2** has developed a digital resource platform for patient organisations, gaining WHO EMRO recognition
- **Badr Association** addresses rural access challenges through transport solutions and screening programmes

“Partnership, capacity, and community... that's how we're building a national PCO network through Cancer, We Are All Concerned.” – **Mohammed Belkadi**

Core challenges

Morocco faces ongoing challenges including linguistic barriers with four languages spoken in the country, clear socio-economic disparities, and cultural barriers that affect how cancer is discussed and addressed in communities.

“Only those playing the drum can feel its tension, only those with lived experience can explain what they need.” – **Hajar Gdader**

Key takeaways

The Morocco experience has demonstrated that advocacy becomes exponentially more impactful when grounded in real-world evidence and the meaningful engagement of people with lived experience. Cultural sensitivity and community trust are essential foundations, while regular continuity meetings sustain political traction.

Partnerships, training and support are the building blocks for a national network of patient organisations that can speak with one voice whilst maintaining their individual identities and strengths.

The Morocco model is highly replicable for other Group B countries seeking to strengthen patient advocacy.

“Morocco is now a role model of what unity can do.” – **Dr Sawsan Al Madhi**

5.2 Gulf Cooperation Council Chapter: Regional Pilot

The GCC chapter represents a regional pilot coordinated across six Gulf countries: Saudi Arabia, UAE, Qatar, Kuwait, Bahrain, and Oman. It demonstrates how patient organisations can work collectively across borders whilst simultaneously addressing country-specific priorities.

The initiative grew from plans to conduct a Group A (high-income) national pilot in Saudi Arabia. This evolved into harnessing the opportunity to explore synergies and develop a scalable regional model.

Majed Mohammed (Friends of Cancer Patients, UAE) shared the journey and outcomes of the regional PCCA Group A pilot conducted across the GCC countries.



Process

The regional pilot kicked off at a two-day capacity-building workshop in Dubai in November 2024.

Opportunities and needs regarding how to meaningfully engage patients throughout their process were identified, setting the stage for stronger alignment and collaboration across the GCC.

“Let’s set our sights on Gulf Cancer Week in February 2026 as a prime opportunity for further collaboration.” – **Dr Sawsan Al Madhi**

Achievements

The GCC pilot established a unified Gulf roadmap aligning personalised care priorities across the six countries through collaborative planning. It serves as a strategic framework structured into national and regional actions.

At the national level, patient organisations are empowered to address localised priorities.

Regional actions focus on fostering GCC-wide initiatives and partnerships with key stakeholders to drive cohesive efforts.

The initiative strengthened relationships with WHO EMRO and the EM- NCD Alliance, and identified shared regional advocacy priorities: awareness, early detection, genomic access, psychological integration, and moving towards shared standards.

“There is a keen focus on including digital advocacy, psychological support and establishing a unified policy language in the region.” – **Majed Mohammed**

Success stories

Various best practices across the Gulf have been identified as models for regional and international replication.

- **UAE's Pink Caravan:** Mobile early detection units bringing more than 150,000 screenings to communities
- **Saudi Arabia's Tafaul Programme:** Reaching over 6,500 patients through expanded screening
- **Qatar's Digital Platform:** Wayyakum platform providing digital access to 50,000+ healthcare workers



- **Kuwait's Makeen Initiative:** Psychosocial support and prevention through community-based and sports programmes

“While in the early stages, many GCC countries are exploring digital advocacy tools and AI for future-ready cancer interventions” – **Majed Mohammed**

Core challenges

The pilot revealed that the Gulf region faces unique challenges with its large expatriate communities. Engagement strategies must address language barriers and create volunteer pathways that are accessible to diverse populations.

Key takeaways

The GCC chapter identified four strategic focus areas for 2025 and beyond:

Cross-border collaboration: Increasing system readiness and resilience through shared learning and resources

Meaningful patient engagement: Shifting patient organisations from service providers to strategic partners for shaping policy in health system planning.

Digital advocacy: Leveraging digital tools and AI for future-ready cancer interventions.

Psychological care: Integrating mental health support as a core component of personalised cancer care

“These shared priorities provide us with clear direction for joint efforts across the region.” – **Majed Mohammed**

5.3 Gender Working Group Chapter: Equity in the Spotlight

The GWG chapter takes a thematic approach, focusing specifically on gender equity issues in cancer care across the Eastern Mediterranean region.

Context

The GWG was established in 2025 building on IAPO-IHE Swedish Institute research across nine MENA countries. The research identified common challenges across the region: late detection, lack of screening programmes, and poor health literacy; gaps in diagnostics including limited infrastructure, high out-of-pocket costs, and no BRCA testing; limited access to treatment with shortages of specialists, lack of psychosocial support, and reimbursement barriers. Underlying these are profound social issues of shame, stigma and silence.

“There is massive social stigma: that men will leave, they will remarry.”

– Dr Safana Alsaïdi

A striking finding is that EMRO breast cancer median age is 40 years, ten years earlier than the global average. Women in the region face cancer during peak fertile years, with profound implications for themselves, their families and communities. They often encounter compounded challenges including stigma, oncofertility issues, and access inequality.

Process

The GWG builds on the Five Ps framework and the IAPO-IHE report findings. It amplifies women's lived experiences as evidence, focusing on five critical areas:

1. Fertility preservation: Addressing oncofertility needs before and during treatment
2. Stigma reduction: Confronting social and cultural barriers to care-seeking
3. Mental health: Integrating psychological support throughout the cancer journey
4. Survivorship: Addressing long-term needs beyond initial treatment
5. Equity in access: Ensuring all women can access needed care regardless of location or economic status

Success stories

The GWG chapter highlights best practices from across the region.

- Pan Arab Breast Cancer Alliance: Leading early detection initiatives across multiple countries

- Makeen Initiative: Providing comprehensive psychosocial care models
- MENA HPV Coalition: Advancing awareness and prevention through gender-neutral vaccination

Core challenges

Despite progress, the region faces persistent challenges that require ongoing action: late diagnosis remains common; cancer registries are limited and often lack sex-disaggregated data; financial barriers prevent many women from accessing needed care; under-addressed cancers such as ovarian and endometrial cancers receive insufficient attention.

“Cancer is a year-round issue, not just for October.” – Dr Reem Al-Ajloun

Learning from other regions

The GWG chapter also examines Brazil's national cancer control policy as a potential model for the region. However, governance challenges mean that even when policies exist, implementation doesn't always trickle down to communities. Survivor initiatives often bridge these gaps, demonstrating the critical role of patient organisations in making policies a reality.



Key takeaways

The GWG chapter puts forward six concrete recommendations:

1. Establish sex-disaggregated cancer registries to enable targeted interventions
2. Include oncofertility preservation in Universal Health Coverage packages
3. Normalise immediate reconstruction and psychosocial support as standard care components
4. Integrate palliative and hospice care as core services, not optional add-ons
5. Fund survivor-led awareness programmes that can address stigma from positions of credibility
6. Align HPV vaccination programmes with WHO goals, including gender-neutral approaches

IAPO's Strategic Direction for 2026

Dr Sawsan invited Dani Mothci, CEO of IAPO, to present an overview of the organisation's objectives for 2026.

Dani highlighted several opportunities for integrating PCCA work into IAPO's global patient advocacy efforts.

Regional Hubs Initiative

IAPO is launching a new Regional Hubs model in 2026 to bridge the gap between online communications and ground-level activities. The hubs will provide regional contact points, support WHO engagement, and enable more responsive support to patient organisations. This model creates a framework for sustained engagement beyond individual projects.

“I have a feeling the Gulf will be the first IAPO hub.” – **Dr Sawsan Al Madhi**

RISE Programme

The IAPO Resource and Innovation Sharing Exchange (RISE) Programme will serve as a virtual resource-sharing hub with an annual award ceremony recognising excellence in patient advocacy and innovation.



Leadership Academy

IAPO will launch a one-year Leadership Academy training programme featuring four online workshops and a face-to-face masterclass, building capacity for current and emerging patient organisation leaders.

Global Initiatives

Two key global initiatives were highlighted:

- **SPARCLE:** Focused on amplifying patient involvement in research and development and innovation
- **UHC Compass:** A digitalised resource specifically designed for patient organisations to navigate Universal Health Coverage advocacy

“My wish is that one day, IAPO won't have to exist, but for now, we do.”

– **Dani Mothci**

The Patient Charter and Policy Brief

Dani invited all workshop participants to endorse the IAPO Patient Charter online, share it with their networks, and provide feedback. IAPO is also launching a policy brief and framework on social participation, overseen by a committee, with a call for applications from IAPO members.

WHO Collaboration

IAPO has established a three-year formal partnership with WHO, enabling non-state actor access to WHO platforms through IAPO's unique membership status. This is particularly significant as it creates a gateway for patient organisations to contribute to WHO processes. Regional hubs will support this work.

“We must attend WHO meetings and bring patient voices to these discussions.”

– **Dani Mothci**

Position Paper 2.0 Launch

The full PCCA Position Paper 2.0, will be launched online in 2026.

Workshop participants will be invited to formally launch their respective chapters.

The connection between the GWG and the regional hubs will make the insights and recommendations available to the broader advocacy community.

“The PCCA was created specifically to mobilise stakeholders around personalised care in EMRO and Africa.” – **Dani Mothci**

Implementation Framework: Multi-Level Strategy

Dr Sawsan opened the midday roundtable discussion by inviting participants to discuss two critical questions:

- How can Position Paper 2.0 serve as an advocacy tool at national, regional and global levels?
- How can IAPO's support be leveraged?

Participants actively explored how to use the other chapters in their own advocacy work, where to partner, and how to reach key stakeholders including schools, academia and Ministries of Health.

The resulting framework recognises that different levels require different approaches, whilst all must be connected for maximum impact.

7.1 Local Implementation

Local implementation must focus on community engagement, grassroots mobilisation, and building the foundation for broader advocacy efforts.

Audience segmentation

Communication must be tailored and targeted. Communities will receive different content to healthcare providers or policymakers, to ensure messages resonate with each stakeholder group's specific interests and concerns.

Audiovisual testimonials

Creating libraries of patient testimonials in original languages with subtitles will leverage powerful lived experience without the need to bring survivors to every event, making advocacy more sustainable, accessible, and authentic.

Customisable toolkit

Local organisations need flexible resources: images, social media components, workshop guidance, and interactive elements that can be adapted to specific community contexts and cultural settings.

Community engagement models

Two successful models emerged from the discussion:

- **Jordan's youth engagement:** Approaching youth clubs, religious groups, and universities to reach young people where they already gather
- **Morocco's advocacy champions:** Training 30 champions selected from 900 candidates to serve as multipliers in their communities

“We're blending ongoing mental and psychological support with structured training, to prepare people to become future advocacy champions in their communities.” – **Mohammed Belkadi**

Healthcare provider training

Survivors who are also healthcare providers can share how their own patient experience changed their professional practice. This bridges the traditional gap between providers and patients whilst underlining the value of patient-centred care.

“Connecting with healthcare providers is crucial. Many have their own lived experience with cancer and understanding how that shapes their empathy and communication can move us from historical mistrust to a more human, collaborative relationship.” – **Dr Safana Alsaidi**



Youth engagement

Young people represent a largely untapped resource for cancer advocacy. However, legal and policy frameworks for youth volunteering are often inadequate.

“Schools and universities are a forgotten resource we need to harness at the local level.” – **Majed Mohammed**

Interactive social media platforms including TikTok and Instagram offer opportunities for innovative campaigns. Jordan's 'pink drink' model using QR codes exemplifies how traditional awareness can be enhanced through digital innovation. Morocco is developing a policy brief to regulate youth engagement and create safe, productive pathways for young volunteers

“Youth is there and wants to be engaged. The issue is the framework of how we engage them.” – **Hajar Gdader**

7.2 National Implementation

National implementation must focus on engaging government institutions, shaping policy, and creating systemic change.

Ministry of Health engagement

Engagement occurs through National Cancer Control programmes and NCD task forces. Position Paper 2.0 can be leveraged in formal dialogues, presented during parliamentary hearings, and used as a reference in national media campaigns during awareness weeks.

“There are many health inequities and chronic diseases are not prioritised in national frameworks, so we must use lived experience to advocate for better coverage, for better care.” – **Dr Wafa Ajoor**

Media strategy

Two approaches to media emerged from discussion:

1. Reactive: Responding to immediate media requests (recognising that media often won't schedule a week ahead and requires immediate action)
2. Proactive: Systematically training media professionals to create their own content, building long-term relationships and consistent messaging

“We started awareness work almost 20 years ago. Change will not come within one or two years. People still say, 'we didn't know this information.’”

– **Dr Wafa Ajoor**

Psychosocial support models

The discussion highlighted two active best practices that can be replicated:

- Bahrain's Counselling: One-to-one family sessions (1-2 hours) with WhatsApp follow-up, providing ongoing support
- Kuwait's Makeen Initiative: A comprehensive model for psychosocial integration

Stigma reduction

There is a need for umbrella campaigns that normalise cancer before diagnosis occurs, rather than only communicating during crisis moments. This shifts the narrative from fear to preparedness.

7.3 Regional Implementation

Regional implementation must leverage cross-border collaboration, shared resources, and collective voices to advance issues that transcend national boundaries.

Platforms and channels

Rather than creating new structures, existing platforms provide resource-sharing opportunities that can amplify impact:



- EM-NCD Alliance (open membership model)
- Gulf Federation for Cancer Control (GFFCC)
- MENA HPV Coalition
- WHO EMRO Regional Office

“For the first time, lived-experience advocates joined the Eastern Mediterranean Regional Committee meeting. We need their voices at the table every year.”

– Dr Heba Al Sawahli

Regional mentorship programmes

Peer-to-peer learning within the region enables organisations to learn from neighbours facing similar challenges. Morocco's collective voice model, where 12 organisations unified their advocacy, serves as a replicable structure for other countries within the region.

“Communication creates networks, which enable interventions.”

– Dr Reem Al-Ajloun

Data and evidence

Regional-specific data is essential for targeted, evidence-based advocacy. Better cancer registries with sex-disaggregated data would enable more effective interventions.

Arab Alliance for Breast Cancer Control

Opportunities exist to feature lived experiences from different countries and backgrounds, applying chapter findings and recommendations across the Arab region.

7.4 Global and International Implementation

Global implementation must connect regional work to international frameworks, funding streams, and policy platforms.

Multi-sectoral engagement

Cancer affects every aspect of life and society. Cancer advocacy must extend beyond health ministries to engage transportation, labour, social development, and youth ministries.

“It's essential to engage governments so this work becomes formal and sustainable.” – Mohammed Belkadi

Value proposition

Civil society organisations are increasingly valued for filling ministry gaps, bringing additional resources and funding, and accessing influential networks that governments may not reach directly.

IAPO membership benefits

IAPO membership provides international platform access and connectivity to global patient advocacy networks, funding opportunities, and policy discussions.

“We can't achieve meaningful engagement alone. We work with people to understand their challenges and how to take this forward. We have to do it together.” – Dr Zehra AlHilali

8 Specific Regional Actions for 2026

Building on IAPO's WHO partnership and the Hub for Lived Experience outlined in Section 6, participants identified concrete actions needed to ensure patient voices are embedded in regional policy processes.

8.1 WHO EMR Committee Meeting

Concrete actions are needed in the lead-up to the WHO Eastern Mediterranean Region (EMR) Regional Committee Meeting in Cairo, in October 2026.

- Reserve agenda time for lived experience statements
- Nominate annual advocates to participate
- Contribute to the breast cancer roadmap following the Cairo Call to Action



These actions will establish precedent and expectations for ongoing patient engagement.

“We don’t need to reinvent the wheel, we need to leverage existing avenues and channels.” – **Dr Heba Al Sawahli**

8.2 Engagement Strategy

Regional work should be complemented by national-level engagement to ensure implementation reaches communities. This principle of working within existing structures increases efficiency and sustainability whilst reducing fragmentation.

Long-term policy work must be balanced with visible short-term wins that maintain momentum and engagement.

“What creates this sense of community is making direct connections with the right people and seeing immediate impact. Laborious policy work with ministries and bureaucracy can cause people to lose direction.” – **Dr Zehra AlHilali**

Priority Roadmap and Accountability Framework

The afternoon session opened with an intensive workshop to establish clear priorities and accountability mechanisms that can drive progress beyond the event itself.

9.1 Priority Goals

Three main goals were identified and defined.

Goal 1: Policy dialogues with lived experience

Build mechanisms to access and elevate lived experience within WHO platforms and other policy forums. Ensure lived experience is the thread connecting all three chapters, not a tokenistic add-on.



Goal 2: Communication and network-building

Develop customised messaging toolkits for different stakeholders, ensuring accessibility through infographics derived from full reports. Establish a bi-annual or quarterly newsletter as a consistent touchpoint, maintaining connection between intensive activities and enabling a bottom-up approach.

Goal 3: Celebrate Patient Voices Annually

Establish a dedicated day for celebrating patient voices, potentially linked to Patient Safety Day (17 September). Create a regional webinar model featuring survivors across the region, building visibility and shared identity.

“There is not one participatory step, every step we take should be participatory.”

– **Mohammed Belkadi**

9.2 Country and Regional-Specific Actions

Priority actions for each country and region were pinpointed.

Morocco

Advocating for Universal Health Coverage system improvements and reimbursement policy changes, identifying cross-disease area synergies to strengthen collective advocacy, and building city-specific partnerships to extend reach beyond major urban centres.

Oman

National collaboration through coordination of organisation presidents will strengthen collective voice. Joining the EM-NCD Alliance opens access to regional networks. Regional twinning, particularly partnership with Qatar, enables peer learning and resource sharing.

Jordan

Immediate actions include team orientation to align on goals and approaches, convening a national stakeholder workshop with Ministry of Health participation, presenting the Gender Working Group charter to national audiences, and hosting a regional workshop with the Arab Alliance for Breast Cancer Control.

GCC

Critical priorities include ensuring participatory representation across all six countries, not just the most active voices, and addressing communication gaps that can exclude smaller organisations or those with fewer resources.

9.3 Accountability Mechanisms

Participants agreed on where and how they plan to use the new chapters in policy dialogues, media engagement, capacity-building activities, and other contexts. The workshop established a plan to create accountability tools including a commitments matrix tracking who will do what by when, and regular follow-up communications to maintain momentum.

10 From Dialogue to Action

10.1 Key Success Factors

The workshop identified five critical success factors: unity across constituencies, with Morocco, GCC, and GWG creating stronger advocacy together; lived experience as core, not optional; leveraging existing platforms rather than creating new structures; bottom-up engagement, recognising that communication creates networks which enable interventions; and multi-level simultaneous action at grassroots, health provider, and policy levels.

“This workshop showed real progress. The discussions were strong, the priorities are clear, and the work is already moving forward.” – **Claire Lebled**

10.2 Next Steps

Key partnerships

Participants identified several key partnerships to leverage for implementation

WHO: Framework development is underway for 2025, with emphasis on engaging country offices beyond the regional level to ensure grassroots impact.

MSD: Confirmed alignment with the roadmap, supporting meaningful engagement programmes including the Advocacy Champion programme, with 2026 initiatives already in planning.

Ministries of Health: Partnership with Ministries of Health and stakeholders in women's health and cancer will be essential to include diverse lived experiences across private and public healthcare systems and different governorates.

Existing programmes: The Advocacy Champion Programme (Implemented in Egypt, Saudi Arabia, and Iraq), the recently launched Youth Network, and NCD Diaries (available in written, audiovisual, and podcast formats) provide established platforms for amplifying impact.

“With breast cancer now firmly on the regional agenda after the Cairo Call to Action, we need lived-experience advocates to help turn that commitment into action through nominations for the regional committee and contributions to the breast cancer roadmap.” – **Dr Heba Al Sawahli**



Immediate actions

Participants identified eight priority actions to undertake in the short to mid-term:

1. Identify gaps and develop joint action plans across chapters and countries
2. WHO to develop and share Hub framework with all stakeholders
3. Distribute detailed workshop summary to all stakeholders for transparency and accountability
4. Consider online meeting for broader stakeholder engagement beyond those who attended Manila
5. Begin network identification for local and regional expansion
6. Prepare clear asks for WHO Regional Committee October 2026
7. Develop toolkit and newsletter plans with clear timelines for delivery
8. Plan Jordan national and regional workshops to maintain momentum

"Advocates need to understand the legal framework and learn how to navigate it wisely, how to write, lobby, and push effectively for action." – Mohammed Belkadi

10.3 Long-Term Vision

Position Paper 2.0 provides concrete evidence that patient organisations can drive change when united, strategic, and resilient. The long-term vision for its implementation extends beyond cancer advocacy to system transformation: transform theoretical discussions into concrete action creating real ground-level change; make lived experience advocates' presence at WHO Regional Committee meetings standard practice, and; create a sustainable model replicable across other disease areas and regions.

The PCCA workshop gave rise to a cohesive regional strategy. The accountability frameworks and roadmap established provide clear pathways forward, while the

partnerships affirmed will help to consolidate resources and support. The collective commitment of patient organisations, technical partners, and funders creates a solid foundation for sustained, scalable impact.

"It is crucial to ensure that we continue to do what we do and do better."

– Dani Mothci

11. Final Reflections

Dr Sawsan Al Madhi and Dani Mothci closed the workshop by thanking all participants and reiterating that Position Paper 2.0 is not merely a document but a movement. The three chapters represent lived proof that change is possible when patients lead, partners support, and systems listen.

The challenge now is to maintain momentum, hold each other accountable, and ensure that the roadmap created in Manila becomes the reality experienced in communities across the Eastern Mediterranean region and beyond.

The session concluded with powerful reflections on the sense of belonging, togetherness, and the transformational potential of bringing diverse stakeholders together. Participants expressed gratitude for the mutual trust and the shift from theoretical discussions to concrete, actionable plans that will create tangible change.

"It's encouraging to see things becoming real on the ground. This isn't just talk anymore. I'm hopeful that next year we'll be shaping policy."

– Dr Sawsan Al Madhi



Roundtable Dialogue

*Local Level:

- Audio-visual Testimonials. (Targeted / thematic).
- Toolkit Development for PCC. (Building on the Chapter's themes).
- + Guidance on how to implement on local level / Workshops.

*National Level:

- Formalize & Strengthen memberships structure + Communication mechanisms.
- Integrate & represent collective voice towards PCC within National platforms conferences & related events. (Regional)
- Advocating for the inclusion of Sex-disaggregated / oncofertility messaging.

*Regional level:

- NCDA-EMR + GFFCC + HPV Conit-1017
- Arab League + WHO-EMRO
- ① Regional Data-specific
- Regional Mentorship programs.

Accountability platforms

- 1- Regional networks.
- 2- Legal frameworks in Country.
 - ↳ Municipal
 - ↳ City-based / inside NGOs
- 3- Setting short Medium term goals.
- 4- Engagement with the government.
 - ↳ National Plans (Revise)
- 5- Synergies with other disease areas.
 - ↳ build on successes.
- 6- Leverage existing regional Coalitions. i.e. EM NCD Alliance Youth network

Ad
Info
G-plan

Survivor-led advocacy

- ① what's happening? Situational analysis.
- ② Find survivors and caregivers!
- ③ Build capacities to tell stories.
- ④ Communicate stories through platforms
 - ↳ Digital
 - ↳ In-person
- ⑤ Link & other opportunities.
- ⑥ Culture & Context consideration.
- ⑦ Stakeholder mapping

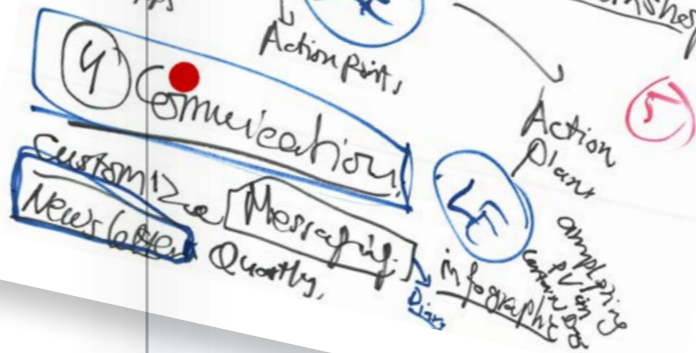
Advocacy champion program

Timeline →

Policy dialogue
① IAPO HUB



③ National & Regional workshop





Report prepared by



Workshop date: 18 November 2025

Location: Shangri-La Hotel, Manila, Philippines

Organised by: IAPO

In partnership with: WHO EMRO, MSD