

# **Strengthening Patient Advocacy in South Asia: Aligning Regional Action with the WHO Global Patient Safety Action Plan 2021–2030**

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## **Highlights**

- South Asia records some of the world’s highest rates of healthcare associated preventable harms due to poor quality of healthcare, highlighting the urgent need for strengthening patient safety and advocacy.
- Despite global and regional commitments under the WHO Global Patient Safety Action Plan (2021-2030) and Regional Strategy for Patient Safety (2016-2025) by WHO SEARO, patient advocacy remains an underdeveloped issue in South Asia’s health system.
- This policy brief calls for the establishment of a regional advocacy network such as South Asian Patient Safety and Advocacy Network (SAPSAN) to institutionalize patient advocacy, unify regional priorities and align national actions with global patient safety frameworks.
- A cohesive regional framework would help to bridge the existing governance gaps, empower patients within and across borders, and embed their voices at the heart of South Asia’s health reform agenda.

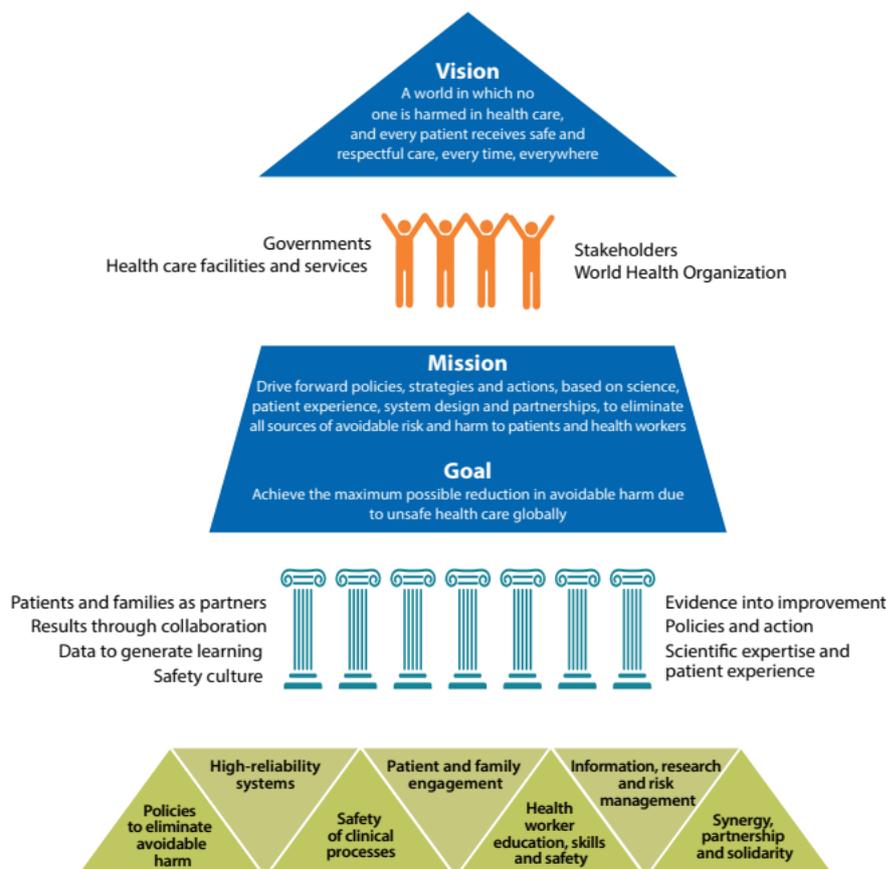
## **Context and Background**

Poor quality healthcare remains a major cause of preventable harm worldwide. Evidence from a comprehensive systematic review and meta-analysis by Panagioti et al. (2019) revealed that approximately 6% of patients experienced healthcare associated preventable harm, of which 12% led to severe harm and even deaths. According to the World Health Organization (WHO, 2023a), more than 134 million adverse events occur annually in hospitals across low- and middle-income countries (LMICs), leading to around 2.6 million deaths. The burden is so acute in LMICs that approximately 4 out of every 100 individuals die due to unsafe healthcare practices (Slawomirski & Klazinga, 2022). South Asia, for instance, records the highest per capita death rates due to poor quality of care (Kruk et al., 2018). These findings underscore the urgent need to strengthen the healthcare quality and safety standards, especially in resource-poor settings.

In response to the global burden of unsafe care, the WHO (2021) introduced the Global Patient Safety Action Plan (GPSAP), 2021-2030, which outlines seven strategic objectives, to improve patient safety worldwide. Strategic objective 4 explicitly mentioned engaging and empowering patients and families to support healthcare safety practice. Recommended strategies to achieve the objective include co-designing healthcare initiatives with patients, involving patient

advocates, educating patients, encouraging open communication on adverse outcomes, and so on. The action plan urges all countries to implement these strategies, to foster a culture of trust, transparency, and partnership in the healthcare system, ultimately improving patient outcomes and reducing preventable harm.

Though WHO provides a global guidance to ensure patient safety, its potential impact will be greatest when tailored to the needs of the regional context where resources are limited and challenges are significant. South Asia, home to nearly two billion people (World Bank, 2025), unfortunately the health systems of which face chronic workforce shortages, weak regulation, and low public trust (Naher et al., 2020). In fact, Asian patients and caregivers were found reluctant to voice their concerns or report healthcare associated harm (Alabdullah & Karwowski, 2024). Patient Advocacy Groups (PAGs) in this context might be crucial to develop more patient-centric, accountable, transparent and quality healthcare where the patient’s voice will be heard and addressed properly throughout the healthcare system and governance (WHO, 2023b; The Lancet Regional Health Southeast Asia, 2024). PAGs are contributing as vital stakeholders in various healthcare systems of Global North to maintain a safe, transparent and an accountable atmosphere in clinical practice (Baker et al., 2024). However, the South Asian countries are still lagging behind integrating PAGs in their healthcare system. Strengthening patient advocacy in this region can therefore become a powerful lever to ensure accountability, transparency and quality care across the region.



Figure

1: Overview of GPSAP (Source: WHO Global Patient Safety Action Plan)

## **Global to regional: A loophole in the system of South Asia**

Regions such as Europe, America, and parts of Africa and Southeast Asia have already developed mechanisms to integrate patient's voice and participation at the core of health governance through patient advocates. For instance, in Europe, a well-structured model of patient engagement was established through the European Patients' Forum (EPF, 2021) and European Patient Advocacy Groups (ePAGs) that operate in collaboration with the European Reference Network (ERN). These networks play vital roles in involving the European patient community in policymaking (European Reference Network ITHACA, 2022). In Africa, the Patient-Centered Care Movement Africa (PaCeM-Afro) has begun integrating patient voices into national and regional governance processes, bridging the gap between community-level engagement and ministerial decision-making to bring sustainable changes in the quality of healthcare (Muganzi et al., 2024). Similarly, in Southeast Asia, Singapore offers a notable model of institutionalized patient engagement through the SingHealth Patient Advocacy Network (SPAN) to amplify the voice of patients within Singapore's largest public healthcare cluster, SingHealth (Sim-Devadas et al., 2022).

In contrast, patient advocacy remains an underdeveloped and less commonly discussed issue within the national healthcare governance of South Asia due to the absence of collective mechanism to translate GPSAP commitments into regional or national practice. Though WHO South-East Asia Regional Office (SEARO) developed a Regional Strategy for Patient Safety (2016-2025), it clearly overlooked the role of patient advocacy, and the patients remained as beneficiaries rather than being recognized as active stakeholders towards shaping a safe, inclusive, and sustainable healthcare system (WHO, 2016). Meanwhile, the existing cooperation under the South Asian Association for Regional Cooperation (SAARC Secretariat, 2020) and the Bay of Bengal Initiative for Multi-Sectoral Technical and Economic Cooperation (BIMSTEC, 2023) continues to focus primarily on communicable diseases, environment and climate changes, paying insufficient attention to patient safety and advocacy as strategic priorities.

This gap highlights the urgent need for regional cooperation and innovation to draw inspiration from the successful models like Europe's collaborative networks or Singapore's institutionalized frameworks, to ensure that South Asian health systems integrate patient engagement as a formal pillar of safety and governance.

## **Insight from South Asia's emerging patient advocacy landscape**

The author conducted a scoping review as part of the MSc thesis to explore the role of patient advocacy groups towards safe healthcare practice in South Asian countries (Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan and Sri Lanka). The findings revealed that the region is not without patient advocacy, rather a home to diverse groups that support patients in ways that a formal health system often cannot. From Afghanistan's family health action groups that support maternal and neonatal health (Samuels, Ancker, & Khan, 2015); to

patient advocacy groups from CanKids (2021-2022) in India supporting cancer-affected children; and several other support groups that help patients with Scleroderma (Scleroderma India Trust, 2021), Psoriasis (Dakshama Health & Education, 2022), HIV/AIDS (Lhak-Sam [BNP+], 2019–2020), mental health issues (KOSHISH, 2023) etc. However, these groups mostly operate at the grassroots level and sometimes remain invisible in the health system. They do advocacy for the patient communities who fall through the cracks of the formal healthcare system and don't know exactly where to seek help, how to make decisions about the treatment continuation, or how to rehabilitate themselves after the treatment.

Despite lacking any formal recognition within the health system, these groups consistently promote patient rights, education, and empowerment that align with strategic objective 4 of WHO's GPSAP. Their activities mostly revolve around enhancing health literacy, guidance during medical procedures, financial support, raising awareness for disease prevention and health promotion, which clearly highlights their patient-centered approach. Some groups even have well-organized structures with clear vision and collaboration with government bodies, healthcare providers, and NGOs.

Building upon this foundation, it is high time to utilize their opportunities and scale up these grassroots-level efforts into a more formal patient advocacy structure and embed their role in the existing national health governance. However, the review also identified some key challenges: donor dependency; weak healthcare infrastructure (poor referral mechanisms, limited facilities, limited trained personnel, etc.); systemic challenges (fragmented health system, lack of intersectoral coordination, fragmented policy implementation system, etc.).

### **Proposed actions:**

The challenges identified from the review could be converted into meaningful opportunities by taking strategic actions such as:

- ***Establishing regional advocacy network:*** Create a South Asian Patient Safety and Advocacy Network (SAPSAN) under the health cluster of SAARC or BIMSTEC and unite all the national ministries, professional bodies, health advocates. Integrating WHO-SEARO's technical expertise within this network would be valuable to harmonizing regional needs, policies and best practices, enabling accountability between institutions and communities, thereby advancing the patient advocacy agenda across South Asia.
- ***Developing regional standards and indicators:*** Promote and fund more interdisciplinary and cross-border research work on this topic to generate context-specific evidence. This outcome will help to guide the development of regional standards and measurable indicators to assess the progress and policy impact.
- ***Building capacity and leadership:*** Strengthen the competencies of patient advocates, healthcare providers, regulatory bodies through regional academic institutions, fellowship programs or digital learning hubs to foster patient-centred healthcare. The International Federation of Medical Students' Association (IFMSA) and national

student bodies could also be valuable collaborators to foster youth-led advocacy and nurture the next-generation of patient advocates.

- ***Ensuring sustainable financing:*** Secure long-term funding through public-private partnerships and integrating patient advocacy into national and regional health budget to ensure autonomy and sustainability of their advocacy efforts. Also, integrate patient rights charters in national health policies.
- ***Embedding patient representation:*** Institutionalize patient representation to amplify the voice of the patient's needs in SAARC/BIMSTEC health ministerial dialogues, policy development forums and technical working groups. Also, convene annual regional advocacy summits to share case studies, data and country progress reports.
- ***Advanced digital actions:*** Harness the power of digital innovations, such as developing app or AI-enabled platform to connect patients across borders to exchange their experiences, foster mutual learnings and amplify their collective voice. Complement this with the creation of health literacy toolkits for patients in their local languages and interactive dashboards for the governments and stakeholders to track the progress towards achieving WHO GPSAP targets.
- ***Strengthening cross-border patient advocacy:*** Since patients increasingly travel across the other South Asian countries to seek better healthcare services, the regional network (e.g., SAPSAN) should also include mechanisms to protect and support the right and safety of the patients throughout their transnational care journey. It could include developing shared guidelines regarding patient information, treatment protocol, continuity of care, compensation for adverse events occurring abroad, etc. Embedding such measures might safeguard patient rights beyond their national boundaries and ensure that advocacy efforts extend to transnational care journeys by fostering trust, accountability and consistent safety standards across South Asia.

Through these mechanisms, South Asia could evolve from isolated and fragmented advocacy efforts to a more coordinated, regional, system-wide movement that would be well-aligned with the WHO's GPSAP to place patients at the heart of safety and health governance. Leveraging regional organizations and networks can function as building blocks for global governance innovation, enabling the translation of UN norms on patient safety and advocacy into context-specific, inclusive and accountable practice.

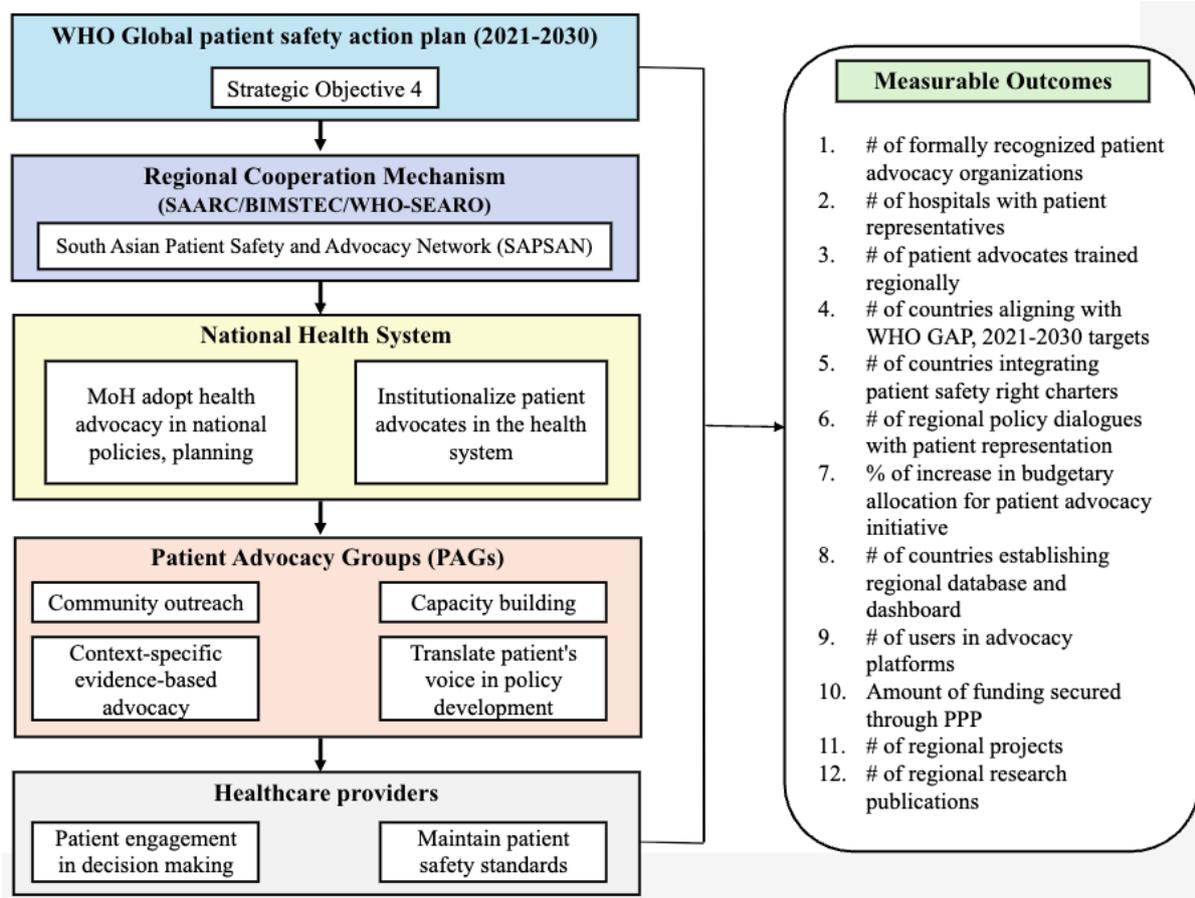


Figure 2: A hypothetical model of integrating patient advocacy into South Asia's health ecosystem

## Conclusion

The health system of South Asia stands on the verge of entering a decisive phase of reformation for the sake of patient safety. The voice of the patients has long been unheard, ignored by the decision makers, but the growing demand for equity, accountability, and transparency makes it imperative to place patients at the core of decision-making. Without a clear, dedicated, and structured regionally coordinated framework, such initiatives might remain fragmented and episodic.

Integrating patient advocacy into national patient safety agendas and regional cooperation mechanisms offers a practical, sustainable path forward, aligning with WHO's GPSAP and turning patient experience into measurable action towards patient safety. By doing so, regional cooperations will not only just act as a delivery platform for health system reforms, but also a catalyst for strengthening the accountability and legitimacy of multilateral health governance across the region. Grounding governance reforms through lived experiences will always remind us that every patient's story is not just feedback, it's a call to action.

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