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| --- | --- | --- | --- | --- |
|  | **Brazil** | **Indonesia** | **South Africa** | **Nigeria** |
| **HEALTHCARE (HC) SYSTEM** |
| **Funding of Care (in-patient)** | UHC via Unified Health System (Sistema Único de Saúde, SUS), private health insurance, out-of-pocket | National Social Insurance – Jaminan Kesehatan Nasional: 80% of population Out of Pocket: 12% of populationPrivate Health Insurance: 8% of population | In 2015, 48.3% of HC expenditure was from public, 49.8% from private sources, and 1.9% was from donors(1). Public (80% of population) and private (20% of population) system run separately (services, resources, treatment facilities and health technologies)(2) 62% of HC expense is hospital cost. | * Out of pocket for most people
* HMOs for employees of big organizations
* National Health Insurance for govern-ment workers and some tax-payers (< 5 percent)(3)
* Only 1.5% of the population have private health Insurance
 |
| **Funding of Care (out-patient)** | Same as in-patient | Same as in-patient | Same as in-patient | Same as in-patient |
| **Government priority areas for health** | * non-transmissible chronic diseases,
* women’s health,
* elderly’s health,
* indigenous people’s health,
* mother child healthcare
* neglected diseases –, rare diseases)
* (tropical) infectious diseases
* Environment and work health, (4).
 | Non-communicable diseases, mental health | * HIV / AIDS (90/90/90 targets of the Joint United Nations Programme on HIV and AIDS),
* maternal/child health,
* tuberculosis,
* rising burden of noncommunicable diseases
 | * Malaria
* maternal and child health
* infectious disease
* NCDs
 |
| **Government priorities for HC** | * UHC, equity,
* Quality improvement,
* HTA, health technology and innovation analysis, health economy and management
* Improvement of health outcomes in specific disease/health areas (neglected diseases – (tropical) infectious diseases, rare diseases)
* health work management and education, health programs and policies,
* Pharmaceutical assistance, post-incorporation into the UHC/SUS health technology analysis,
 | Universal Health Coverage and Coverage expansion | * Promote health, prevent disease and reduce its burden.(5)
* Progress towards UHC through the development of the National Health Insurance scheme
* Re-engineer primary healthcare; and expanding school health services.
* Improve health facility planning by implementing norms and standards.
* Improve financial management.
 | * Universal Health Coverage
* Improvement of health outcomes in specific disease / health areas
 |
| **PATIENT AND PUBLIC INVOLVEMENT (PPI) OR ADVOCACY** |
| **Representation of the interests of patients (and their carers) in the country** | Interests of patients and their healthcare partners are well represented via the tripartite National Health Council (NHC that represents patients and healthcare partners, health professionals and the industrial sector in health), as well as various patient associations and advocacy groups, as NGOs. | Patient organizations, patient advocacy groups are established in selected disease areas  | Over the past 2 decades, patient advocacy and activist groups are gaining influence and playing an increasing important role in HC system, particularly NCD related groups. Key policy issue which currently attract the input of the PPI is the Presidential Health Compact, Comments and public hearings for NHI, Essential Drug List Committee (through influencing stakeholders), and the current review of the Prescribed Minimum Benefits for Medical Schemes, a pre curser to baskets of care for NHI implementation | Not broadly considered except for some disease-based support groups formed by HIV patients |
| **Disease areas or health-related subjects with current PPI** | All via the NHC and respective patient associations and advocacy groups. | Oncology (Breast cancer, Thalassemia), Diabetes, Stroke, Cardiovascular, Hemodialysis, Psoriasis, Tuberculosis, Autism | HIV/AIDSTuberculosis CancerNCDsMental HealthAccess to treatmentUse is TRIPS in relation to IPNational Health Insurance BillPresidential Health Compact – multi stakeholder social compact addressing crisis in the health system | Diabetes, HIV/AIDS, Immunization and vaccination, and malaria |
| **Other important advocates for patients who influence HC decision-making** | * The Evangelical Parties at federal, state and municipal levels of legislative system.
* Print and mainstream media, as well as social media actors and institutions
 | Religious communities: * MUI - Indonesian Ulema Council: general disease area – requiring halal medicine for patients (halal bill published in 2019)
* Hijabersmom community: religious community for veiled Muslim mothers
* Church community: each Catholic Church has health working group. Each diocese or bishopric has a doctor committee who decide treatment for the Catholic member

Consumer association:* YKI - Consumer association: general disease area

Family:* Family members are often involved in the patient’s treatment options (uncle, aunt, parents, kids, grandkids).
 | Labour UnionsCivil society groupings linked to government and HIV – e.g. SANAC (https://sanac.org.za/) | Non-Governmental organizations |
| **How are patient organizations or advocates involved?** | * Formally involved via the NHC
* Patient associations and advocacy groups lobby (mostly) for or against certain types of health technology incorporation into the public national health system (SUS)
* Litigation / judicial pathway: patients and NGOs going to Chamber of Deputies and Senate to appeal for the incorporation of new technologies and draw social & political attention to their diseases.
 | Patient organizations and advocates participate informally in the decision making. | * Involvement in public comment and legislative public consultation.
* Most PAG provide some sort of service that is not provided by government (education, health promotion, Medical and Psychosocial services, subsidies of health professional salaries).
* Input into NCD policy development.
* The public health system uses primary healthcare workers and community-based carers
 | * Formal and informal roles in representing the interests of the group.
* Help in information dissemination
 |
| **Involvement of members of ‘the Public’**  | Always via the NHC | none | National Health Insurance (NHI) BillPatient Charter states that a member of the public can complain or lodge a dispute in relation to service delivery or access to treatment in both public and private healthcare system. However, these processes are laborious and not well advertised. | * Information dissemination,
* Provision of sources for surveys and opinion sampling,
* Stakeholders consultation,
* Public hearing at National Assembly
 |
| **Examples, where patient advocates have influenced any type of healthcare decisions** | * Rare diseases’ representatives are usually lobbying alongside researchers and the industry for stem-cell RCTs to be conducted in Brazil (it is forbidden by law)
* Some Evangelical citizens lobby against the legalization of abortion procedures at the public national health system.
 | * Sildenafil: listing in the national health formulary (indirect influence of PAG through medical association) – only for pulmonary hypertension indication
* Trastuzumab: listing in the national health formulary (indirect influence of PAG through medical association)
* Hemodialysis: listing in the national health formulary (indirect influence of PAG through medical association)
 | * NHI draft bill.
* Access to HIV/AIDs medicine
* Update of the National Cancer Registry
* Access to care for Haemophilia
* Advocating for the reimbursement of Rheumatoid Arthritis biological amongst private funder
* Highlighting of the mistreatment of mental health patients by government
* Reimbursement for cancer, rare disease treatment for individual patients
* Palliative, Breast, cervical and prostate cancer polices
* Health Market Inquiry
* Ministerial Advisory Committee for Cancer
* NCD, cancer and genetic national strategies
* Tobacco Framework
 | HIV/AIDS |
| **Most likely decision processes for relevant PPI** | They are relevant for all the above-mentioned decision-making processes | Currently participation of PPI in decision process only informal – and only in reimbursement decision | * Healthcare policies
* Access related decisions – through advocacy and activism efforts
* Reimbursement decisions (post – overturning a decision)
 | * Healthcare policies,
* Access related conditions,
* Reimbursement decisions
* Coverage decisions
 |
| **Other important stakeholders (support, inhibiting) in relation to PPI** | The legislation that supports the institutionalization of the NHC (other socially representative entities and organizations of civil society) have been dissolved after the current president took place in administration | * Government/policy makers
* Pharmaceuticals/medical device manufacturers
* Insurance company
* Medical association
* Consumer association
 | * Competition (tensions) for resources between PAGs within or between disease areas (HIV and NCDs)
* Private Medical Schemes
* Legislative complexities; resources for PPI
* Very limited pathways for PPI
 | * Traditional rulers (Local chiefs who run public health programs),
* Donors: NGO’s who provide support to hospitals (training, medicines etc.)
* Foreign Partners: Other Countries initiatives to support HC in Nigeria
 |
| **HEALTHCARE DECISION MAKING** |
| **Existence of Health Technology Assessment (HTA)**  | Several HTA Agencies exist, but the MoH of Brazil HTA Agency called CONITEC sets main standards for HTA in Brazil. Decisions are made at monthly multi-representative plenary meetings based on clinical effectiveness, economic evaluation, budget impact and, after public consultation (through which the plenary members can verify people’s preferences and attitudes regarding the technologies for the diseases they experience and/or manage [for health professionals and decision-makers] within both public and private national health system), the CONITEC members ratify and/or rectify their recommendation that will be consider by the Secretariat of Science, Technology and Strategic Inputs of the Ministry of Health of Brazil. Decisions can either be appealed (and then a public meeting may be called by the Secretariat) and/or the Secretariat’s decision will be published in the Official Diary of the Union (and on CONITEC’s website). | HTA committee currently operates under the MoH. No information is publicly available. | * Pharmacoeconomic Guidelines in South Africa (PGSA)(6)
* Regulations on a transparent medicines pricing apply only to the private sector; coordinated by a Pricing Committee of the NDOH including the determination of a medicine’s “therapeutic value”(7,8)
* In the state the EDL committee take into account in its decision on whether to incorporate a medicine on the EDL, the principles of efficiency, safety and effectiveness are although the methodology used to assess, and the assessment is not made public(9).
 | HTA is not existing in Nigeria.  |
| **… or if not, how are decisions made?** |  |  |  | Decisions are made through stakeholder consultation such as the National Council on Health (NCH) |
| **Technologies with HTA (in-patient)** | Pharmaceuticals, medical devices/diagnostics, clinical interventions, programs and guidelines. | HTA assessment applied for: (1) New health technology to be reimbursed, (2) current reimbursed health technology which absorbed high healthcare budget | High cost medications Essential Drug List |  |
| **Technologies with HTA (out-patient)** | Same as in-patient | Same as in-patient | Same as in-patient |  |
| **Most important challenges for HTA or evidence-based health technology decision making** | * Meaningful social engagement with the HTA processes, as well as top-down actual implementation of the health technologies at state/municipal and institutional levels, as directed by the respective sections within the different Secretariats of the MoH
* Litigation processes (judicialization / adjudication of medicine), as strategies to enforce social engagement in HTA by the agency (CONITEC)
 | * Resources (human resource capacity and capability, research funding)
* Transparency framework
 | * Lack of knowledge and skills
* Political will – lobbying
* Small group of experts
* Divided pricing structure and process (state vs private)
* Corruption
 |  |
| **PPI Influence on Market Authorization** | Decision maker is ANVISA.Potential for patient involvement: Public hearings or consultations, Sectorial dialogues, Public grants, Directed queries,Guide review queries, ICH regional queries | For medicines: BPOM (Badan Pengawasan Obat dan Makanan – Local FDA); no PPIFor devices: MoH; no PPI |  | * Institutions regulate the market and give authorization to companies:
	+ National Agency for Food and Drug Administration (NAFDAC)
	+ Pharmacists’ Council of Nigeria (PCN)
	+ Ministry of Health
* Patients can influence via Market surveys and case reporting
 |
| **PPI Influence on Listing** | ./. | MoH; informal patient influence on listing of drugs and medical devices | * EDL committee do not have a process by which qualitative input, as most PPI input would be, to include in assessing a health technology.
 |  |
| **PPI Influence on Coverage** | Decision maker: CONITECPPI influence via public consultation, NHC representative participation at the CONITEC’s monthly plenary meetings, and appeals to the Secretariat’s decision before formal publication at the ‘Official Diary of the Union’ – if appeals are accepted, the Secretariat receives representatives from the population to hear their plead(s) and decide upon it. | MoH; informal patient influence on coverage of drugs and medical devices | Through advocacy |  |
| **PPI Influence on Pricing** | ./. | MoH and LKPP (Ministry of Health and National Tender Agency); no patient influence | Pricing committee has no process to include PPI |  |

Abbreviations:

CONITEC (National Committee for the Incorporation of Health Technologies into SUS, Comissão Nacional de Incorporação de Tecnologias ao SUS), HC (Healthcare), HTA (Health Technology Assessment), MoH (Ministry of Health), NCD (Non Communicable Diseases), NHC (National Health Council), NGO (Non-governmental Organization), PAG (Patient Advocacy Group), SUS (Sistema Único de Saúde), UHC (Universal Health Coverage), TB (Tuberculosis), TRIPS (Agreement on Trade-Related Aspects of Intellectual Property Rights; by World Trade Organization)

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