# PATIENT POWER

## What it takes for patient associations to help shape public policy

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# Executive Summary

In developed countries it is generally accepted that the perspective of patients should be incorporated into the healthcare decision-making process. As pointed out in a 2008 World Health Organisation (WHO) policy brief, patients can play a distinct role in protecting their health, choosing appropriate treatments for episodes of ill health and managing chronic disease. Engaging patients can improve overall healthcare outcomes and patient satisfaction as well as being beneficial from a cost point of view.[1] In other words, patients can provide an essential assessment of current health services based on first-hand experience and are able to express fairly reliable accounts of the likely effect that changes in healthcare policy could have on these services.

Currently, the primary conduits for patients' views are patient organisations, which act as interest groups informing policymakers on areas of concern for their patients. Often this policy role can be secondary to an organisation's core function, for example, providing support and advice to patients and their caregivers or conducting research into disease. Yet in recent years, patient organisations, particularly in the developed world, have grown to appreciate the influence that changes in policy can have on the patients whom they support and the diseases that they address. In many ways, the growth of patient organisations is akin to the rise, size, and influence of consumer groups more generally and the restructuring of government policymaking to accommodate their respective viewpoints.

This paper seeks to understand the environment in which patient associations emerge and play an active part in healthcare policy making, both theoretically and in practice, in a number of emerging markets.

The first half of the paper identifies and examines the optimal group characteristics and external environment in which patient organisations develop and take part in the policy making process. It seeks to analyse patient organisations that have emerged around the following disease areas: HIV/AIDS, oncology, and rare diseases. Globally, patient associations in these disease areas have contributed substantially to healthcare policies within their respective diseases in recent years. However, not all patient organisations contribute to healthcare policies, either by choice or by lack of certain internal factors. For the purposes of this paper, observations are made in terms of the scope, scale, and structure of those organisations that participate in shaping healthcare policies. In addition to these internal factors this paper identifies five external enabling factors, which together create an environment in which the views of patients are incorporated into the creation of healthcare policies. These external factors are:

1. Acknowledgement of patients' rights
2. Presence of multiple organisations and patient support activities

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[1] Coulter, A. *et al* (2008). "Where are the patients in decision-making about their own care?", *WHO European Ministerial Conference on Health Systems: 'Health Systems. Health and Wealth,'* WHO Regional Office for Europe, Copenhagen, DK, p. 1.

3. Existence of cultural awareness and recognition of patient organisations
4. Opportunity for patients and/or patient organisations to provide input to healthcare policies
5. Inclusion of patients' viewpoints in healthcare policies

The second half of the paper examines the existence of these factors in seven key emerging and growth markets: Argentina, Brazil, China, India, Mexico, Russia, and Thailand. Together these countries represent a cross-section of emerging and growth markets from across the world and a variety of political and healthcare systems. Each country is analysed based on the five external factors. This is followed by a number of policy recommendations to improve the strength of the patient voice in the creation and application of healthcare policies in each respective country.

Overall, Brazil and Thailand have the most conducive environments compared to the five other countries examined. Russia has a formal structure in place to incorporate patients' viewpoints, however is deficient in ensuring patient organisations' seat at the table and has not enshrined patients' rights into legislation. Argentina, China, India and Mexico were found to have deficiencies in their environments and being the least conducive to the inclusion of the patient voice in health policy.

Based on these findings, the paper makes the following three recommendations:

Governments should confirm rights of assembly (e.g. patient organisations's right to exist and meet) and freedom of speech (e.g. right to constructively criticize healthcare policies). A Patients' Bill of Rights, although not necessary, would be helpful in formally establishing the rights and roles of patients, patient organisations, and, in terms of responsibilities, the government. Of course, to be most effective the declaration should be legally binding and enforceable.

There must be a cultural awareness and recognition of patient organisations. Patient organisations provide first-hand knowledge of a broad spectrum of patients, who can provide helpful insights into healthcare policies. While public support of specific disease days promotes awareness of these groups, formal recognition through transparent government-NGO partnerships brings credibility to both the patient organisations and the government in the eyes of the public.

There has to exist a formal mechanism for patient input into the policy process. Although the other external factors need to be in place, if there is no formal structure for incorporating patients' viewpoints, it is highly unlikely that healthcare policies will reflect their perspectives. However, as seen in Brazil, Russia, and Thailand, establishing a formal process for patient input does not guarantee the incorporation of those viewpoints into the final healthcare policy. Therefore, patient representatives may need to establish monitoring to ensure their viewpoints are actually incorporated in the resulting policies.

# Section 1: Introduction

In developed countries it is generally accepted that the perspective of patients should be incorporated into the healthcare decision-making process. As Coulter et al (2008) pointed out in a World Health Organisation (WHO) policy brief, patients can play a distinct role in protecting their health, choosing appropriate treatments for episodes of ill health and managing chronic disease.[2] Engaging patients can improve overall healthcare outcomes, patient satisfaction and be beneficial from a cost point of view. In other words, patients can provide an essential assessment of current health services based on first-hand experience and are able to express fairly reliable accounts of the likely effect that changes in health policy could have on these services. Modern healthcare is often provided in a rather fragmented manner with a number of specialists and healthcare professionals caring for a patient and involved in treatment. Under these circumstances patients are often the only ones who experience and take part in all aspects of treatment and the treatment cycle. Consequently, the patient's view should be an integral part of the policymaking process and policy decisions.[3]

### 1.1 The role and types of patient organisations that contribute to healthcare policies

Currently, the primary conduits for patients' views are patient organisations, which act as interest groups and inform policymakers on areas of concern for their patients. Often this policy role can be secondary to an organisation's core function, for example providing support and advice to patients and their caregivers or conducting research into disease. Yet in recent years, patient organisations, particularly in the developed world, have grown to appreciate the influence that changes in policy can have on the patients whom they support and the diseases that they address. In many ways, the growth of patient organisations is akin to the rise, size, and influence of consumer groups more generally and the restructuring of government policymaking to accommodate a broad range of viewpoints.

However, not all patient organisations contribute to healthcare policies, either by choice or by lack of certain internal factors. For the purposes of this paper, observations are made in terms of the scope, scale, and structure of those organisations that participate in shaping healthcare policies.[4] In terms of scope, diseases in which patient organisations have made substantial contributions in healthcare policies are HIV/AIDS[5], oncology (particularly the breast cancer movement)[6], and, more recently, rare disease groups[7]. Consequently, they are used as models when searching for external factors which

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[2] Coulter, A. *et al* (2008), p. 1.

[3] Perrin, JM. *et al* (2011). "Evidence-Based Practice and Health Advocacy Organizations", *Journal of the American Medical Association*, 306(13), p. 1443; authors' reply pp. 1444-5.

[4] Durstine, A. and Leitman, E. (2009). "Building a Latin American cancer patient advocacy movement: Latin American cancer NGO regional overview", *Salud Publica Mexico* 51(2), pp. s319-22.

[5] The aids2031 Consortium (2011). *AIDS: Taking a Long-Term View*, Upper Saddle River, New Jersey, USA: Pearson Education, Inc., pp. 63-96.

[6] Kasper, A.S. and Ferguson, S.J. (2002). *Breast Cancer Society Shapes an Epidemic*. Hampshire, UK: Palgrave Macmillan, pp. 325-354.

[7] Dunkle, M. *et al* (2010). "Advocacy Groups and Their Role in Rare Diseases Research", *Advances in Experimental Medicine and Biology* 686 (Rare Diseases Epidemiology), pp. 515-25.

empower patient organisations to contribute to healthcare policies. Concerning scale, patient associations who contribute to healthcare policies share the following characteristics: large capacity, research support, and regional or international reach.[8] Looking at structure, organisations that appear to have the most credibility in influencing policymakers are those that can demonstrate patient and/or caregiver input in their policy contributions and work.[9]

It is important to note here the distinction between individual patient associations and “umbrella” organisations that pull together the resources of several groups and act much like a trade association. These umbrella organisations (such as the European-based rare disease organisation EURORDIS) perform activities like health policy contributions on behalf of their members, who either cannot undertake such tasks due to lack of capacity or do not wish to because they prefer to maintain their primary focus on patient services, for example. These umbrella organisations also represent a critical mass of patients through the organisations’ member groups and, therefore, may provide a stronger voice than any of the individual constituent groups. Consequently, since they are an extension of their member groups and hold credibility based on representing these groups, this paper will consider umbrella organisations and their health policy contributions as part of the activities performed by individual groups within their respective disease community.

### 1.2 External factors that enable patient organisations to contribute to healthcare policies

The incorporation of patient viewpoints into policymaking does not occur in a vacuum. In addition to the above described internal factors there are a number of external factors which, if in place, enable patient organisations to contribute to healthcare policies. This paper delineates which of these external factors – in combination – provide the optimal situation for the views of patients to be incorporated into the creation of healthcare policies. These external factors are as follows:

1. Acknowledgement of patients’ rights: considers a country’s approach to issues, such as the right to assembly, the right to representation, the existence of a patient’s bill of rights, and informed consent.[10]
2. Presence of multiple organisations and patient support activities: considers the critical mass and number of patient organisations and activities that support a stronger patient voice in a given health system.[11]
3. Existence of cultural awareness and recognition of patient organisations: considers the institutional acceptance and attitudes towards patient associations, like national recognition of

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[8] Daft, R.L. *et al* (2010). *Organization Theory and Design,* Andover, UK: Cengage Learning, p. 94-232.

[9] National Health Service Institute for Innovation and Improvement (2008). Quality and Service Improvement Tools: Patient Perspectives, http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/patient_perspectives.html (Accessed October 2012). See also Casseb, M. (2011). *Action Guide for Patient Organizations in Health Technology Assessment – HTA*, São Paulo-SP, BR: SEI Consultoria, pp. 18, 43-46.

[10] Coulter, A. (2008), pp. 9-13.

[11] International Alliance of Patients’ Organizations “Working with Partners and Stakeholders Toolkit” Media/Toolkits webpage: http://www.patientsorganizations.org/iapo_media/Toolkits/current/iapo_toolkit.html (Accessed October 2012).

patient organisations' events (e.g., specific disease awareness day) and other government–patient group partnerships.[12]

4. Opportunity for patients and/or patient organisations to provide input to healthcare policies: considers a country's formal incorporation of patients' viewpoints into its healthcare system and the health policy process in terms of access to treatment and care, and health technology assessments, for example.[13]
5. Inclusion of patients' viewpoints in healthcare policies: considers the results of the successful empowerment and inclusion of patients' viewpoints into the health system and health policy process. In addition to looking at the inclusion of patients' viewpoints, the paper will also consider patients' level of general approval of existing and new healthcare policies through opinion surveys.[14]

This paper then examines the existence of these factors in seven key emerging and growth markets: Argentina, Brazil, China, India, Mexico, Russia, and Thailand. Together these countries represent a cross-section of emerging and growth markets from across the world and a variety of political and healthcare systems. Each country is analysed based on the five external factors, followed by a number of policy recommendations to improve the strength of the patient voice in the creation and application of healthcare policies.

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[12] Westphal, M.F. *et al* (2000). "Public Health Policies and Advocacy in Latin America: Chances and Environment to Support These Policies", *Promotion & Education* 7 (4), pp. 29-32.

[13] Coulter A. (2008), pp. 1-14.

[14] Houÿez F. *et al* (2011). "Health Technology Assessment and patients' rights: Assess versus access?" *Pharmaceuticals Policy and Law* 13, pp. 169-176.

# Section 2: Types of Patient Organisations that Contribute to Healthcare Policies

Patient organisations play a vital role in communicating the views of patients on healthcare policy issues.[15] However, not all patient organisations participate in the policy arena – either by choice or due to a lack of certain internal factors. Consequently, it is important to discuss briefly some of these primary internal factors in order to identify the types of patient organisations that will serve as a reference point when analysing the external factors, which enable these groups to contribute to healthcare policies. The paper frames this discussion in terms of an organisation's scope, scale, and structure.[16]

## 2.1 Scope

This paper examines patient organisations that have emerged around the following disease areas: HIV/AIDS, oncology, and rare diseases. Patient associations in these disease areas have contributed substantially to healthcare policies in recent years. Their success in changing the healthcare landscape to address the needs of their members and of patients affected by these diseases suggest they provide good models for understanding which external factors empower patient organisations to contribute to healthcare policies.

One of the greatest success stories in recent years has been the HIV/AIDS movement, which has made significant contributions to the fight against HIV/AIDS. For instance, in the US, the gay community played an integral part in mobilizing and spreading awareness of the disease as a first line of prevention. In other parts of the world local groups and patient organisations have also played a key role. For example, in Uganda civil society action contributed to lowering HIV infection rates. Examples of patient associations include the AIDS Service Organization (ASO), an international web-based tool that links HIV/AIDS patients to local groups providing a wide range of community-based services, including combined HIV prevention, intervention, treatment, care and support services, and advocacy.[17]

In terms of oncology, the paper will examine several types of patient cancer organisations but will focus on one of the most prominent movements: the breast cancer advocacy campaign. The breast cancer awareness campaign has created a brand through the pink ribbon which brings the existence of breast cancer and its issues to the attention of the general public and of policymakers more specifically.[18] For example, the Argentine group, *Movimiento Ayuda Cancer de Mama Argentina* (Argentine Movement to Support Breast Cancer), which is a founding member of the Latin American

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[15] Wyke, A. (2012). "The Voice and Impact of Patients in the Formation of Healthcare Policy", London:PatientView, presentation at GHSC meeting.

[16] Durstine, A. (2009), pp. s319-22.

[17] AIDS Service Organization (ASO), http://www.asofinder.com/default.aspx (Accessed October 2012)

[18] Kasper, A.S. and Ferguson, S.J. (2002), pp. 89-152, 213-244, 303-354.

Union Against Cancer in Women, has received formal recognition from the Buenos Aires city legislature and the Argentine Ministry of Health's National Cancer Institute for its contributions to improving the lives of breast cancer patients and their caregivers. Through the efforts of the organisation's founder and other breast cancer survivors, breast cancer prevention and control programmes have been set up in several provinces around the country.[19]

Although rare disease groups have made policy headway in their own rights, much of the policy movement has been amalgamated into two umbrella groups: the US based National Organization for Rare Disorders (NORD) and its European counterpart, EURORDIS.[20] These two groups and other rare disease patient associations have been very influential and contributed to a number of new policy developments and initiatives including: the 1983 US Orphan Drug Act; increased cooperation and links between patient associations and government research and medical regulatory authorities; increased patient group involvement in orphan drug development through research support, the facilitation of patient registries; and patient advocacy with regard to access to treatments.[21]

## 2.2 Scale

One of the internal factors the above models have in common, either as individual organisations or collectively under the representation of an umbrella organisation, is their scale, which includes a large capacity, research activities, and regional or international reach. These elements of scale support the groups' contribution to healthcare policies.

The capacity of patient organisations can best be described in terms of the organisation's or group's growth. Most patient associations follow a growth pattern that can be generalised into three phases: early stage, interim or advanced stage, and maturity.[22] Mostly, the closer to maturity, the larger the organisation's capacity and the more likely it is to participate in healthcare policymaking:

1. In the early phases, groups are usually created by an individual or small collective group of people who are directly affected by the disease and want to address a specific aspect/gap in the handling of their disease. This can include support functions or access to treatment or issues relating to the financing of treatment and living with a disease
2. As groups move to an interim or more advanced stage, their capacity allows them to expand their services, allowing them to address additional gaps in their particular scope, for example, counselling, transportation, financial assistance, and research, amongst others.
3. In the mature phase, the capacity built is advanced enough that groups are able to focus on broader, systematic issues that require engagement with policymakers. Such issues can

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[19] *Movimiento Ayuda Cáncer De Mama* Argentina webpages: http://www.macma.org.ar/ (Accessed October 2012).

[20] National Organization for Rare Disorders webpages: http://www.rarediseases.org/ (Accessed October 2012) and EURORDIS webpages: http://www.eurordis.org/ (Accessed October 2012).

[21] Dunkle, M. *et al* (2010), pp. 515-25.

[22] Umbrella groups follow a different cycle that depends on numerous items, such as scope, membership, scale of existing patient groups, amongst others.

> range from research funding, marketing and regulatory approval times, reimbursement for treatments, to lack of specialised professional expertise or services. However, even mature patient associations will often depend on umbrella organisations to address policy concerns and to engage directly with policy makers. Some groups do this by choice, because they want to focus on core services, while others do so because of capacity limitations.

Research activities – whether done directly by the patient organisation or, for example, by funding through a grant – also develop the scale of the groups. Research pushes patient associations to improve their health literacy and encourages them to be attuned to and contribute to healthcare policies. For example, the Multiple Sclerosis Society United Kingdom (MSS UK) "makes long-term investments to find out about the cause of MS and works towards a cure, as well as research into symptom relief and services to make a difference in the here and now."[23] The group is one of the largest charitable funders of MS research in the UK and actively campaigns and lobbies policymakers.[24]

Growing from a national to a regional or international organisation increases the reputation and influence of patient associations, including in the healthcare policy arena. For example, the American Cancer Society (ACS) has been recognised by the WHO through the Pan American Health Organization as having "demonstrated regional and international expertise as a capacity-builder, coalition creator, and advocacy enabler". [25] As a result, the ACS has developed a reputation as a leader in cancer control and access to policymakers in a number of countries.[26] Other examples of organisations that contribute to healthcare policies due to their regional/international focus/membership are umbrella groups such as EURORDIS and Genetic Alliance UK. EURORDIS advocates for patients suffering from rare diseases at both the EU and national level.[27] The Genetic Alliance UK, an umbrella group for over 150 patient organisations representing patients affected by genetic conditions, advocates and campaigns both in the UK and at the EU level.[28]

### 2.3 Structure

Since policymakers are often most interested in the first-hand experiences of patients, it is important to examine where the patient voice is incorporated in the structure of the patient group. Although many groups begin with a patient(s)'s or caregiver(s)'s close involvement, as organisations grow, they can often lose the controlling voice of the patient as professionals take over the management of an organisation's activities. There are several ways to maintain the direct decision-making power or involvement of patients: the founding patient still has a key decision-making role in the organisation as

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[23] Multiple Sclerosis Society webpages: http://www.mssociety.org.uk/ (Accessed October 2012).

[24] Ibid.

[25] Pan American Health Organization (2008). *Fact sheet: Cancer organizations active in Latin America and the Caribbean (LAC),* Plan of Action for Cancer Prevention & Control: Cancer Stakeholders Meeting, Washington, D.C., retrieved from http://www.paho.org/English/AD/DPC/NC/pcc-fact-sheet-orgs.pdf (Accessed October 2012).

[26] American Cancer Society webpages: http://www.cancer.org (Accessed October 2012).

[27] EURORDIS webpages. http://www.eurordis.org/ (Accessed October 2012)

[28] Genetic Alliance UK webpages: http://www.geneticalliance.org.uk/ (Accessed October 2012).

chairperson or chief operating officer, for example; patients/caregivers sit on the board or hold management positions; and/or patients/caregivers are solicited for their input via conferences, surveys, or policy committees.

For example, the US-based Multiple Myeloma Research Foundation (MMRF) and the Multiple Myeloma Research Consortium (MMRC) are led by a multiple myeloma patient, Kathy Giusti.[29] Similarly, the UK-based Terrence Higgins Trust (THT) is the result of the efforts of Mr Higgins' friends and family following his death from HIV/AIDS. The Trust is now one of the UK's leading voices on HIV and related issues and a number of its board and management are current HIV patients.[30] Much like the Terrence Higgins Trust, the Leukemia & Lymphoma Society (LLS) was born out of a family's grief following the death of a teenage son, who succumbed to leukemia in 1944. According to the LLS website, it is now "the world's largest voluntary health agency dedicated to blood cancer".[31]

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[29] Multiple Myeloma Research Foundation webpage: http://www.themmrf.org/ (Accessed October 2012).
[30] Terrence Higgins Trust webpages: www.tht.org.uk (Accessed October 2012).
[31] Leukemia & Lymphoma Society webpage: www.lls.org (Accessed October 2012).

# Section 3: Environmental Factors that Enable Patient Organisations to Contribute to Healthcare Policies

Patient associations' organisational attributes are not the only factors that facilitate their contribution to healthcare policies. Certain external factors need to be in place as well in order to maximize the opportunity for patient views to be incorporated into healthcare policies.[32] This paper uses five external enabling factors to frame the discussion and analysis:

1. Acknowledgement of patients' rights;
2. Presence of multiple organisations and patient support activities;
3. Existence of cultural awareness and recognition of patient organisations;
4. Opportunity for patients and/or patient organisations to provide input to healthcare policies; and
5. Inclusion of the patient view in healthcare.[33]

### 3.1 Acknowledgement of patients' rights

The acknowledgement of patients' rights is representative of a country's approach to issues such as the right to congregate, the right to representation, patients' bill of rights, and informed consent.[34] These rights are reflected in countries' constitutions, laws, and/or regulations and form the basis of formal recognition of individuals and organisations who can represent and communicate the issues associated with a particular disease through first-hand experience.

### 3.2 Presence of multiple organisations and patient support activities

The presence of multiple organisations and patient support activities are indicative of a critical mass that supports a stronger patient voice in the healthcare system.[35] Keeping in mind the organisational factors described in the previous section, the paper examines the existence of multiple patient associations and the patient services offered to analyse whether there exists a powerful enough voice to communicate patients' viewpoints to healthcare policymakers.

### 3.3 Existence of cultural awareness and recognition of patient organisations

The existence of cultural awareness and recognition of patient organisations relies on institutional acceptance and attitudes towards patient associations. Government-NGOs partnerships are one of

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[32] Wyke, A. (2012), PatientView presentation.

[33] International Alliance of Patients' Organizations (2007). "What is Patient-Centered Healthcare?: A review of Definitions and Principles", http://www.patientsorganizations.org/attach.pl/547/494/IAPO%20Patient-Centred%20Healthcare%20Review%202nd%20edition.pdf (Accessed October 2012).

[34] Coulter A. et al (2008), p. 9-10.

[35] See: International Alliance of Patients' Organizations ("Working with Partners and Stakeholders Toolkit" and Dolan, P. (2007). "More Than Sympathy: Patients Find Collective Voice for Advocacy", *American Medical News*, retrieved from http://www.ama-assn.org/amednews/2007/08/06/bisa0806.htm (Accessed October 2007).

the most visible forms demonstrating public support and acceptance of patients' concerns and their representatives. This factor also includes whether or not there is a national recognition of patient organisations' events, such as specific disease awareness days, and, more generally, how patient associations are treated and viewed in society as a whole.

### 3.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

The opportunity for patients and/or patient organisations to provide input to healthcare policies is reflected in a country's formal incorporation of patients' viewpoints into its healthcare system.[36] A number of mainly OECD countries have begun establishing laws and regulations requiring national health institutions put in place at least a consultative relationship with patients and/or patient organisations. In some instances health authorities have gone further and actually provided real power and authority to patients and/or their representatives.[37]

### 3.5 Inclusion of patients' viewpoints in healthcare policies

The inclusion of patients' viewpoints in healthcare policies or, at least, patients' general approval of healthcare policies are increasingly viewed as important elements of a successful health system.[38] Ideally, as patients' viewpoints are incorporated into the development of healthcare policies, the resulting policies and their application should reflect their voice. The gap between public expectations and patients' experience can be seen in the existence of unfavourable practices towards patients and patients' dissatisfaction with the healthcare system as documented by, for example, patient surveys.

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[36] See: Coulter A. *et al* (2008), pp. 1-14 and Wu, A.W. *et al* (2010). "Adding the Patient Perspective to Comparative Effectiveness Research", *Health Affairs* 29(10), pp. 1863-1871.

[37] Garcia Burgos, J. (2011). "The Importance of Patient Input for the Work of European Medicines Agency", European Medicines Agency, presentation at EMSP Annual Youth Congress, retrieved from http://www.emsp.org/attachments/article/140/The%20importance%20of%20patient%20input%20for%20the%20work%20of%20the%20EMA,%20Juan%20Garcia%20Burgos.pdf (Accessed October 2012). Bundesministerium für Gesundheit (DE) webpages: http://www.bmg.bund.de/krankenversicherung/arzneimittelversorgung/arzneimittelmarktneuordnungsgesetz-amnog/das-gesetz-zu-neuordnung-des-arzneimittelmarktes-amnog.html (AMNOG), http://www.bmg.bund.de/krankenversicherung/arzneimittelversorgung/arzneimittelmarktneuordnungsgesetz-amnog/glossar-zum-amnog.html (G-BA and IQWiG) (Accessed October 2012). National Health Service (UK) webpages: http://services.parliament.uk/bills/2010-11/healthandsocialcare.html (Health and Social Care Act 2012), http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/patient_and_public_involvement.jsp (National Institute for Health and Clinical Excellence), and http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/patient_perspectives.html (Accessed October 2012). Department of Health and Human Services (USA) webpages: http://www.healthcare.gov/law/index.html (Agency for Healthcare Research and Affordable Healthcare Act) and http://www.fda.gov/ForConsumers/byAudience/ForPatientAdvocates/default.htm (Food and Drug Administration Patient Network) (Accessed October 2012).

[38] Coulter, A. and Jenkinson, C. (2005). "European Patients' Views on the Responsiveness of Health Systems and Healthcare Providers", *European Journal of Public Health* 15(4), pp. 355-360.

# Section 4: Patient Organisations' Contribution to Healthcare Policies in Key Emerging and Growth Markets

The external factors described in Section 3 provide the optimal environment for the patient's voice to influence healthcare policies. The combination of these factors serves as a point of comparison to analyse the gaps between the proposed optimal environment for the incorporation of patients' views in healthcare policies within seven key emerging and growth markets. These key markets are: Argentina, Brazil, China, India, Mexico, Russia, and Thailand.

## 4.1 Argentina

Argentina's healthcare system is composed of three principle sectors: a public sector, financed through taxes; a social security sector, financed through obligatory insurance schemes called *obras sociales*; and a private sector, financed through voluntary pre-paid insurance plans. Although all three sectors are overseen by the Ministry of Health and Social Action (MSAS), the public sector is highly decentralised to the provincial level (and even the local township in the case of primary care), leaving the federal Ministry of Health with a limited role in national health policy.[39]

The largest minority of patients (47%) are uninsured and rely on public sector healthcare services provided primarily at the provincial and municipal level. The remainder of the population is either covered through the *obras sociales* (about 45%) or private insurance (about 8%).[40]

Argentina spent 8.1% of GDP on healthcare in 2010 according to World Bank figures.[41] In 2010 public sector spending constituted 55% of total healthcare expenditure.[42] However, only a small proportion of these public funds came from the central government.[43]

### 4.1.1 Acknowledgement of patients' rights

Argentina indirectly recognises the rights of its patients through the general declaration of citizens' rights via its constitution, which states: "All the inhabitants of the Nation are entitled to the following rights, in accordance with the laws that regulate their exercise, namely: to work and perform any lawful industry…to petition the authorities…to publish their ideas through the press without previous censorship…to associate for useful purposes…to teach and to learn."[44]

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[39] Cavagnero, E. *et al* (2010). "A National Social Health Insurance Plan for Argentina: Stimulating Its Financial Feasibility", World Health Organization, pp. 3-9, retrieved from http://www.who.int/health_financing/documents/dp_e_10_04-shi_arg.pdf (Accessed October 2012).

[40] Penchaszadeh, V. *et al* (2010). "The health system in Argentina: an unequal struggle between equity and the market." *Italian Journal of Public Health,* Year 8, Vol. 7, No. 4, pp. 355-356.

[41] World Bank, Health expenditure, total (% of GDP), (Accessed December 2012)

[42] Ibid. Health expenditure, public (% of total health expenditure)

[43] Cavagnero, E. *et al* (2006). "Health Financing in Argentina: An Empiral Study of Healthcare Expenditure and Utilization", *Innovation in Health Financing* Working Paper Series, Fundación Mexicana para la Salud, A.C., p. 8. Cavagnero, E. *et al* (2010), p. 5.

[44] Argentine Constitution retrieved from http://www.senado.gov.ar/web/interes/constitucion/english.php (Accessed October 2012).

The right to health is not explicitly included in the constitution but medical care and access to healthcare is recognised in the constitution and through Argentina being a signatory to a number of international treaties including the Universal Declaration of Human Rights and the Covenant on Economic Social and Cultural Rights.[45]

The country does directly protect patients' rights in terms of informed consent forms, which are required and must be signed in the presence of a third party witness.[46]

### 4.1.2 Presence of multiple organisations and patient support activities

A number of patient organisations exist in Argentina, offering a variety of services. Examples of groups include *Asociación Síndrome de Down de la República Argentina* (Down Syndrome Association of the Republic of Argentina), *Fundación Argentina Pro-Ayuda al Niño con Sida* (Argentine Foundation to Help Children with AIDS), and *Liga Argentina De Lucha Contra el Cancer* (Argentine League for the Fight Against Cancer).[47] Below is an outline of these patient associations with a more comprehensive list of other patient associations provided in the footnotes below.

*Asociación Síndrome de Down de la República Argentina* is an association of parents of children with Down syndrome. The group's mission is to work towards the full integration of patients with Down syndrome into society. The group has three main programmes: information, assistance, and promotion. Activities under the information programme include the facilitation and attendance of events and conferences on Down syndrome, the publication of newsletters and articles, and interaction with healthcare professionals and the media. The group's assistance programme includes facilitating support groups, providing hotlines for questions, and hosting social events. Promotional activities include the pursuit of legislative initiatives and engagement with policymakers as well as campaigning for broader integration of patients into society.[48]

*Fundación Argentina Pro-Ayuda al Niño con Sida's* mission is to help children with HIV/AIDS as well as those children born to parents with HIV/AIDS. In addition to defending the rights of children and

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[45] Penchaszadeh, V. *et al* (2010), p. 352.

[46] Argentine National Administration of Drugs, Foods and Medical Devices Regulation 6677/10 (2010), retrieved from http://www.anmat.gov.ar/Comunicados/Dispo_6677-10_en.pdf (Accessed October 2012).

[47] Additional Argentine patient groups include the following: *Asociación de Talasemia Argentina* (Argentine Association of Thalassemia): http://www.talasemia-argentina.org.ar/; *Asociación Leucemia Mieloide Argentina* (Argentine Association of Myeloid Leukemia): http://www.asociacionalma.org.ar/; *Asociación por los Derechos de las Personas con Cancer* (Association for the Rights of People with Cancer): http://www.sosten.org.ar/; *Ayuda Pacientes con Enfermedad Hipofisaria* (Help for Patients with Pituitary Disease): http://www.apehi.org/default.htm; *Fundación Apostar a la Vida* (Betting on Life Foundation): http://www.apostaralavida.org.ar/ ; *Fundación Argentina de Mieloma* (Argentina Myeloma Foundation): http://www.mieloma.org.ar/; *Fundación Argentina de Talasemia* (Argentina Foundation of Thalassemia): http://www.fundatal.org.ar/ and http://fundatal.wordpress.com/; *Fundación Atención Comunitaria Integral al Paciente* Oncológico (Foundation for Comprehensive Community Care for Cancer Patients): http://www.fundacionaciapo.org.ar/sedes.asp ; *Fundación Natalí Dafne Flexer* (Natali Dafne Flexer Foundation): http://www.fundacionflexer.org; Linfomas *Argentina* (Lymphomas Argentina): http://www.linfomasargentina.org ; *Movimiento Ayuda Cancer de Mama Argentina* (Argentine Movement to Support Breast Cancer): http://www.macma.org.ar/ FUCA (Fundación Cáncer) www.fuca.org.ar; (All websites accessed October 2012).

[48] *Asociación Síndrome de Down de la República Argentina* webpages: http://www.asdra.org.ar/index.php/home/mision-vision-valores-principios-y-objetivos (Accessed October 2012).

adolescents living with HIV/AIDS the organisation provides support services, education through workshops, legal services, hospital referrals and monitoring activities.[49]

*Liga Argentina De Lucha Contra el Cancer* is a civil society group dedicated to furthering education and prevention of breast, gynaecological, colon, skin, lung, and urological cancers. The group has 100 offices throughout Argentina and provides health education, early detection services, counselling and active engagement with health policymakers.[50]

### 4.1.3 Existence of cultural awareness and recognition of patient organisations

Patient organisations are permitted and in some cases even partner with local governments in promoting disease awareness days, such as International AIDS, Rare Disease, and World Cancer days. However, the development of partnerships between the government and NGOs is a relatively new phenomenon.[51]

Patient organisations receive funding from individuals, corporations, and the public sector.[52] The majority of income is derived from fees and charges for services. The non-profit sector in Argentina, like other Latin American countries, relies heavily on fees for its funding as public sector support is relatively limited.[53] This is particularly pronounced in the healthcare sector.

### 4.1.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

Despite the public, formal acknowledgment of patient rights, the government places low importance on the role of patient participation, patient-provider consensus on treatment goals, and specific strategies designed to meet the goals and to improve patient outcomes. For example, patient organisations, such as the International Community of Women living with HIV/AIDS, have voiced strong opposition to the lack of government action on introducing bioequivalence testing for so-called *similares*. *Similares* are a third class of regulatory approved drugs on the market in most Latin American countries which are not required to be tested for bioequivalence but which are frequently promoted even by government officials as being generics. While some major Latin American markets, such as Brazil, have introduced new requirements for *similares* to undergo bioequivalence testing, Argentina has not.[54]

### 4.1.5 Inclusion of patients' viewpoints in healthcare policies

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[49] *Fundación Argentina Pro-Ayuda al Niño con Sida* webpages: www.ayudaalninioconsida.org.ar (Accessed October 2012).

[50] *Liga Argentina De Lucha Contra el Cancer* webpages: http://www.lalcec.org.ar/quienessomos.html (Accessed October 2012).

[51] For details see: The Eckman Foundation (2007). "A Cooperative Effort by the NGO Committee on Ageing and Global Action on Aging", retrieved from http://www.globalaging.org/agingwatch/events/ngos/Argentina.pdf (Accessed October 2012); UNICEF (2009). "Summary Results Matrix: Government of ARGENTINA –UNICEF Country Programmeme, 2010-2014", retrieved from http://www.unicef.org/about/execboard/files/Argentina_CPD_Matrix_by_Focus_Areas_v.5_6_09__BvH_.pdf (Accessed October 2012); and Roitter, M. *et al* (1999). "Argentina", *Global Civil Society: Dimensions of the Nonprofit Sector*, Baltimore, USA: Johns Hopkins Center for Civil Society Studies, pp. 373-392.

[52] Roitter, M. *et al* (1999), pp. 383-388.

[53] Ibid. p. 386.

[54] Torstensson, D. and Pugatch, M. (2010). *Keeping Medicines Safe: A Study of the Regulations Guiding the Approval of Medicines in Emerging Markets*. Stockholm Network, pp. 38-39.

As described above, the healthcare system in Argentina remains fragmented. Almost half of the population remains uninsured and has limited access to medical services. Moreover, since the 1990s there has been a sharp increase in healthcare related litigation. Patients and groups representing patients have increasingly turned to the courts for the perceived poor quality and lack of access to medical services. Of note are examples in which patient associations have sued the Argentinian state. For instance, in the late 1990s a number of NGOs (including the *Asociación Benghalensis* a patient organisation supporting the wellbeing of HIV/AIDS patients) successfully sued the government for not supplying HIV/AIDS drugs to public hospitals.[55]

### 4.2 Brazil

The healthcare system in Brazil includes public, private and nonprofit providers. Patients access these providers through public and private plans. The public system of care, *Sistema Único de Saúd*e (SUS), provides services free at the point of use. Close to three-quarters of Brazilians access healthcare through the SUS system with the remaining 25% having private medical insurance.[56]

While the federal government, via the Brazilian Ministry of Health, sets national health policy, the day-to-day running of the SUS has largely been delegated from the federal level to states and municipalities, which manage and administer local health services. This has led to a wide variety in how national health policies are implemented and health services are delivered.

Total expenditure on health as a percentage of GDP has steadily increased during the 2000s from a total expenditure of 7.2% of GDP in 2000 to 9% of GDP in 2010.[57] The majority of this spending is through the public sector and comes from general taxation, payroll contributions and specific taxes such as the Provisional Contribution on Financial Transactions.[58]

#### 4.2.1 Acknowledgement of patients' rights

The constitution of Brazil both implicitly and explicitly protects the rights of patients. Implicitly, patients fall under the individual and collective rights and duties that include freedom of expression.[59] Explicitly, the 1988 Brazilian constitution recognised health as a citizen's right, supported by the introduction of the national health service, the SUS.[60] The 1988 constitution and Consumers' Defense

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[55] Abramovich, V. and Pautassi, L. (2008). "Judicial Activism in the Argentine Health System: Recent Trends", *Health and Human Rights* 10 (2), retrieved from http://www.hhrjournal.org/index.php/hhr/article/viewArticle/81/166 (Accessed October 2012).

[56] Deloitte (2011), *2011 Survey of Healthcare Consumers in Brazil Key Findings, Strategic Implications*, Deloitte Center for Health Solutions Washington, D.C.

[57] WHO, Global Health Observatory Data Repository, Total expenditure on health as a percentage of gross domestic product, (Accessed November 2012)

[58] Almeida, C. et al (2011), "The Brazilian health system: history, advances, and challenges", *Lancet* 2011; 377: 1778–97, p. 1787.

[59] Brazilian Constitution, retrieved from http://www.wipo.int/wipolex/en/details.jsp?id=11795 (Accessed October 2012).

[60] Almeida, C. *et al* (2011).

Code also provide for informed consent.[61] Finally, Brazil is a signatory to a number of major international human rights treaties.[62]

### 4.2.2 Presence of multiple organisations and patient support activities

A number of patient associations and organisations exist in Brazil offering a variety of programmes and services. Examples of groups include *Associação Brasileira de Combate ao Câncer Infantil e Adulto* (Brazilian Association against Cancers Affecting Children and Adults), *Associação Brasileira de Esclerose Múltipla* (Multiple Sclerosis Association of Brazil), *Associação Brasileira Interdisciplinar de AIDS* (Brazilian Interdisciplinary AIDS Association), and *Instituto Oncoguia*.[63] Below is an outline of these patient associations with a more comprehensive list of other groups provided in the footnotes below.

*Associação Brasileira de Combate ao Câncer Infantil e Adulto's* provides both concrete services for cancer patients as well as broader educational and advocacy activities on behalf of cancer patients more generally. Medical and support services for cancer patients include supply and purchase of cancer drugs, hospital transportation, support services in the form of legal advice and accommodation. The group actively engages with local and national health institutions, and policymakers as well as the public more broadly through awareness campaigns.[64]

*Associação Brasileira de Esclerose Múltipla* is one of the largest patient associations in Brazil. The group campaigns on behalf of Multiple Schlerosis patients and seeks to raise awareness about the disease both with the general public as well as policymakers and health professionals. In addition to public campaigning and awareness-raising activities, the group offers direct medical and rehabilitative services in the form of neuro-rehabilitation, physiotherapy, speech therapy and occupational therapy.[65]

Founded in the late 1980s, *Associação Brasileira Interdisciplinar de AIDS'* mission is to raise awareness about HIV/AIDS and improve access to treatment and services for patients suffering from the disease. The group actively monitors public policy in Brazil and internationally and has played a

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[61] Marteleto Godinho, A. *et al* (2010). "Informed Consent: The Understanding of Lawyers and Courts", *Revista Brasileira de Anestesiologia* 60(2), pp. 207-214.

[62] Geneva Academy of International Humanitarian Law and Human Rights, "Brazil", *Rule of Law in Armed Conflicts Project*, retrieved from http://www.geneva-academy.ch/RULAC/international_treaties.php?id_state=34 (Accessed October 2012).

[63] Additional Brazilian patient groups include the following: *Associação Brasileira de Esclerose Tuberos* (Brazilian Association of Sclerosis Tumors): http://abet.org.br/; *Associação Brasileira de Linfoma e Leucemia* (Brazilian Association of Lymphoma and Leukemia): http://www.abrale.org.br/index2.php; *Associação Brasileira de Portadores de Câncer* (Brazilian Association of Patients with Cancer): http://www.amucc.com.br/; *Associação Brasileira de Talassemia* (Brazilian Association of Thalassemia): http://www.abrasta.org.br/default; *Espaço Saúde* (Health Area): http://www.espacosaude.org.br/site/sobre-nos/historico; *Federação Brasileira de Instituições Filantrópicas de Apoio á Saúde da Mama* (Brazilian Federation of Philanthropic Institutions to Support Breast Health): http://www.femama.org.br/novo/index.php; *Federação Nacional das Associações de Doenças* (National Federation of Associations of Diseases): http://fenafal.wordpress.com/; *Grupo de Estudos Doenças Raras* (Rare Disease Study Group): http://gedr2008.blogspot.com/; *Instituto Canguru* (Kangaroo Institute): http://www.institutocanguru.org.br/index.html; *Instituto Espaço de Vida* (Life Area Institute): http://www.espacodevida.org.br/index.php; International Myeloma Foundation Latin America www.mielomabrasil.org; (All websites accessed October 2012).

[64] *Associação Brasileira de Combate ao Câncer Infantil e Adulto* webpages: http://www.abraccia.org.br (Accessed October 2012).

[65] *Associação Brasileira de Esclerose Múltipla* webpages: http://www.abem.org.br/index.php?option=com_content&view=article&id=96&Itemid=124 (Accessed October 2012).

role in developing new health programmes on HIV/AIDS. In addition to its work in public policy, the group conducts workshops, seminars and other forms of awareness and public education activities.[66]

The *Instituto Oncoguia* represents patients and seeks to ensure patient rights and access to cancer treatment and high quality information. The group hosts a major information forum through its website and publishes information manuals and guides through the website. The group also takes part in Brazilian public policy by actively engaging federal government ministers and officials including the Ministry of Health. In 2011 the group campaigned and lobbied the Minister of Health for changes to health legislation introducing coverage of anticancer orals in health plans.[67]

### 4.2.3 Existence of cultural awareness and recognition of patient organisations

The Brazilian government supports NGOs, including those representing patients. For example, the municipal health secretariat of Ribeirão Preto partnered with *Associação Brasileira de Combate ao Câncer Infantil e Adulto* for a breast-feeding campaign, which sought to encourage women to breastfeed their newborns in order to decrease the risk of breast cancer.[68] The government also recognises and supports the efforts of patient organisations by promoting disease awareness days, such as International AIDS Day, Rare Disease Day, and World Cancer Day.

Patient organisations receive funding from individuals, corporations and the government. Patient associations and other non-profits are allowed to function independently from government. As in Argentina, government funding of non-profits, including patients groups, is relatively limited.[69]

### 4.2.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

Patients in Brazil have the opportunity for input via several avenues, most notably through mandatory representations at all levels of health policy through boards of health and health councils. The 1988 constitution introduced social management councils with direct responsibilities for formulating and approving social policies and, most importantly, the approval of budgets allocated by the federal government.[70] These health councils number in the thousands and are composed of representatives of health service users, health workers and management. The constitution mandates that 50% of representatives on health councils are *usúarios* i.e. users of the health service such as patient associations and NGOs. The remaining 50% of the council is evenly split between health workers and representatives of management.[71] Of note is that this representation and patient voice reaches all the way to the top of healthcare policymaking to the National Health Council (CNS). The CNS is a

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[66] *Associação Brasileira Interdisciplinar de AIDS* webpages: http://www.abiaids.org.br/a_abia/quemsomos.aspx?lang=pt&fg=Quem%20Somos (Accessed October 2012).

[67] See website and specific pages including: "Conheça Nosso Trabalho" and "Audiência com Alexandre Padilha, Ministro da Saúde" http://www.oncoguia.org.br/home/ (Accessed January 2013)

[68] *Associação Brasileira de Combate ao Câncer Infantil e Adulto,* "Servicos" webpage.

[69] Johns Hopkins Center for Civil Society Studies (2010). "Nonprofit Organizations in Brazil: A Pilot Satellite Account with International Comparisons 2002", *Handbook on Nonprofit Institutions in the System of National Accounts,* United Nations, pp. 17-21.

[70] Andrea Cornwall (2007), *Deliberating Democracy: Scenes from a Brazilian Municipal Health Council*, IDS Working Paper 292, University of Sussex, p. 7.

[71] Ibid.

separate federal agency under the Ministry of health responsible for approval of the federal health budget and four-yearly National Health Plan.[72]

4.2.5 Inclusion of patients' viewpoints in healthcare policies

Although patients participate in the development of healthcare policies, there is some debate as to how their viewpoints are being incorporated actively into the healthcare system. For example, patient surveys reveal a relatively high level of dissatisfaction with many aspects of the healthcare system. For example, a 2003 study found that for outpatient care, patients were unhappy with long waiting times, and with regard to hospitalization, the lack of freedom to choose physician was at the top of patients' concerns.  This study also found that users of the SUS had a lower degree of user satisfaction than non-SUS patients.[73] A more recent, 2011, survey by Deloitte found that only 8% of those surveyed gave the Brazilian health system a favourable grade.[74] Instead, 57% of respondents gave the system an unfavourable grade with 31% of the sample saying the system was a failure.

### 4.3 China

Until the 1980s, Chinese healthcare was modeled on a Soviet style, highly-centralised system of free care at the point of use. During the opening up of the Chinese economy in the 1980s and 1990s public expenditure on healthcare was drastically reduced. In 2008 the health system was again fundamentally reformed as part of the Chinese government's wider economic stimulus. A universal system of health insurance was introduced and over $130 billion invested in upgrading public healthcare facilities. As part of this national effort, China also established an essential drugs list. Since 2009 further reform efforts have been started which aim to increase access and equity in the system as well as to improve the quality of medical services provided.[75] Central government drives the reform effort with implementation taking place at the provincial and local level.[76]

In 2010 total expenditure on healthcare as a percentage of GDP was 5.1%.[77] This is a small rise from a decade earlier when total spending stood at 4.6%. Public expenditure constitutes over 50% of total healthcare spending with the remaining 50% private, primarily out-of-pocket, spending.[78] The private insurance market is still undeveloped and only constitutes a small percentage of private health spending (6.9%) and an even smaller percentage of total spending.[79]

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[72] Ministerio de Saude (Ministry of Health), Conselho Nacional de Saude (CNS), http://conselho.saude.gov.br/apresentacao/apresentacao.htm (Accessed January 2013)

[73] Luna, C.F. (2005). "Healthcare users' satisfaction in Brazil, 2003", *Cad Saude Publica* 21, pp. 109-118.

[74] Deloitte (2011)

[75] Ulrich, J. *et al* (2011). "Medicine for the Masses – China's Healthcare Reform: Progress and Future Steps", *Hands-On China Report*, Shanghai: J.P. Morgan, p. 1.

[76] Le Deu, F. *et al* (2012). "Healthcare in China: 'Entering uncharted waters'", *China Healthcare,* Shanghai: McKinsey & Company, pp. 6-8.

[77] World Bank, Health expenditure, total (% of GDP), http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS?page=2 (Accessed November 2012)

[78] World Health Organization, Table of Indicators, China, retrieved from http://apps.who.int/nha/database/StandardReport.aspx?ID=REP_WEB_MINI_TEMPLATE_WEB_VERSION&COUNTRYKEY=84008 (Accessed October 2012).

[79] Ibid.

### 4.3.1 Acknowledgement of patients' rights

According to China's constitution, citizens enjoy freedom of speech, of the press, of assembly, of association, of procession and of demonstration.[80] However, freedom of organisation and congregation are still limited in China with many restrictions in place on the founding and running of civil society groups.[81] With regard to patient associations, they face a number of specific challenges. Many patients still do not have access to healthcare and are not aware of their rights. Likewise, although China has put in place legislation on the rights of patients there are still inconsistencies in terms of legal jurisdiction and exceptions. There are also difficulties in organising patient associations and facilitating communication between patients. Finally, many patients face discrimination from the authorities.[82] For example, HIV/AIDS patients and patient associations reportedly face harassment and in some cases poor access to treatment, particularly in more remote rural areas.[83]

### 4.3.2 Presence of multiple organisations and patient support activities

Given the difficulties in establishing and managing a non-profit NGO in China, there are not a huge number of patient associations and many groups active in China are based outside the mainland. The below paragraphs will provide details on some of the groups that do exist and the work they do.

The Chi Heng Foundation is a Hong Kong based nonprofit providing support and educational services for children and orphans directly suffering from HIV/AIDS or with a parent with the disease. Geographically the group focuses primarily on rural areas in central China. The foundation provides funding and support for keeping children in school and providing them with an education in their home village. Currently over 9,000 children are being supported by the Foundation. In addition to educational support the Foundation also provides counselling, vocational training and wider community self-help support. The group works with local medical centres and hospitals on HIV testing and disease surveillance including the Shenzhen Center for Disease Control.[84]

The China-Dolls Care and Support Association aims to increase understanding and awareness of rare diseases and patients with rare diseases. It is a patient advocacy group primarily intended to help and represent sufferers of osteogenesis imperfecta ("brittle bone disease").[85] The group was founded in the late 2000s by Yi'ou Wang, herself a sufferer of brittle bone disease. Currently, the organisation reaches approximately 3,000 patients the majority of which suffer from osteogenesis imperfecta. The group campaigns for increased recognition and support for sufferers of rare diseases, including

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[80] Chinese Constitution, retrieved from http://www.cecc.gov/pages/newLaws/constitutionENG.php (Accessed October 2012).

[81] International Center for Not-for-Profit Law (2012), *NGO Law Monitor: China*, http://www.icnl.org/research/monitor/china.html (Accessed January 2013)

[82] International Alliance of Patients' Organizations (2008). "To Safeguard Patient Rights in China", retrieved from http://www.patientsorganizations.org/showarticle.pl?id=848 (Accessed October 2012).

[83] Avert Report, "HIV & AIDS in China", retrieved from http://www.avert.org/aidschina.htm (Accessed October 2012).

[84] Chi Heng Foundation webpages: http://www.chfaidsorphans.com/index.php (Accessed October 2012).

[85] YJ Zhang et al, "China's first rare-disease registry is under development", *The Lancet*, Volume 378, Issue 9793, Pages 769 - 770, 27 August 2011. See also: "China Doll Charity Offers Hope to Brittle Bone Sufferers", June 11 2009, CRIEnglish.com, http://english.cri.cn/7146/2009/11/06/1361s527341.htm (Accessed January 2013)

legislation on rare diseases. In 2010 the group founded the first rare-disease database with the aim of recruiting patients and furthering clinical research in China.[86]

The New Sunshine Charity Foundation's[87] mission is to provide support and services to leukemia patients and their families. Z Lie, himself a chronic myelogenous Leukemia patient, founded the group in 2002. The group's programmes include: a bone marrow donor registry, patient information and support services, health education campaigns, financial support to patients, a patient helpline, professional training and research support, as well as policy advocacy.[88]

### 4.3.3 Existence of cultural awareness and recognition of patient organisations

The government does promote disease awareness days, such as Rare Disease, World Cancer, and World AIDS days. In the case of HIV/AIDS, awareness campaigns have had an impact on increasing government support and recognition of the disease and of patients suffering from it.[89]

Although heavily regulated, it is worth noting that patient organisations operating in China do receive funding from individuals, corporations, and foreign governments outside of China. For example, the Chi Heng Foundation receives funding from businesses such as Accor, Farrington American Express Travel, and PizzaExpress, foundations, including The Clinton Foundation and The Global Fund as well as international institutions like the United Nations.[90]

### 4.3.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

There is no apparent formal process of incorporating patients' viewpoints in healthcare policies and given China's decentralised healthcare system, it is challenging for patients and patient organisations to influence healthcare policies on a national level. The Chinese healthcare system is still grappling with the challenges of providing universal coverage and healthcare to residents in both rural and urban areas.

Furthermore, there are cultural challenges in ensuring that the voice of the consumer/citizen – whether as an individual consumer of healthcare or through a patient group – is recognized. Bloom et al (2008) sum up the challenge: "The role of civil society organisations, representing the professions

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[86] Ibid

[87] Previously the Sunshine Volunteers Association

[88] CML Advocates Network, "China: New Sunshine Charity Foundation" webpage: http://www.cmladvocates.net/index.php?option=com_content&view=article&id=137:china-shanghai-roots-a-shoots-cml-home-of-hope&catid=20:asia-pacific (Accessed October 2012) and Liu, Z. "Belief, Hope and Love Can Make a Miracle", presentation retrieved from http://www.worldmarrow.org/fileadmin/Committees/ASIA/Asian%20Sunshine.pdf (Accessed October 2012).

[89] China.org.cn (2006). "China Encourages NGO's Participation in Fight Against AIDS", retrieved from http://china.org.cn/english/2006/Mar/162981.htm (Accessed October 2012) and Avert Report webpage. Voice of America (2011). "China Marks World Aids Day", retrieved from http://www.voanews.com/content/china-marks-world-aids-day-134818793/148940.html (Accessed October 2012).

[90] Chi Heng Foundation "Our Partners" webpage: http://www.chfaidsorphans.com/staticpage.php?id=49 (Accessed October 2012).

or the public, is very underdeveloped, and the degree to which schemes can be influenced to reflect the interests of their beneficiaries is uncertain."[91]

### 4.3.5 Inclusion of patients' viewpoints in healthcare policies

Chu et al (2009) report on patient satisfaction in China via data collected from household interview surveys and the China National Health Services Survey. [92] Their study suggests that there has been a sharp drop in patient satisfaction with the Chinese healthcare system from the late 1990s to the mid-2000s. In 1997 both rural and urban patients had a satisfaction rating of over 50%. By 2003 this had declined by 10% for rural residents and close to 15% for urban residents. Patients often cited cost as the main reason for dissatisfaction with Chinese healthcare.

A more recent study by Shen and Tang (2010) also shows how Chinese patients are often dissatisfied with their healthcare.[93] Through a survey of urban residents the researchers found that higher income and better educated patients were often less satisfied than poorer patients. Higher income patients also tended to focus more on the quality, or lack thereof, of a medical service or product purchased. Poorer patients, on the other hand, were more concerned with the overall cost.

Together these surveys suggest that China's healthcare system faces significant challenges in establishing not only basic levels of coverage and access, but also of improving quality and standards.

## 4.4 India

India's system of healthcare is highly fragmented with services being provided and paid for at both the central and state level of government. The majority of Indians do not have health insurance and have limited access to health and medical services. Only about 20% of the population have health insurance with the remainder relying either on private providers and out-of-pocket (OOP) payment or the public health system. The majority of those inured reside in urban areas with the vast majority of rural Indians uninsured.[94]

Both at the state and central level government has taken steps to improve access to healthcare. The central government, for example, launched the National Rural Health Mission (NRHM) in 2005 as an initiative to expand access to healthcare in largely rural areas. Similarly, the central government has recently announced plans to provide generic drugs free of charge through government clinics and hospitals focusing primarily on rural areas. This scheme builds on existing state level efforts,

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[91] Bloom, G. (2008). "Regulating Healthcare Markets In China And India", *Health Affairs* 27(4), p. 962.

[92] Chu, A. *et al* (2009). "A Study on Patient Satisfaction in China", *Harmonizing Health and Economics,* presented at International Health Economics Association Congress, retrieved from http://ihea2009.abstractbook.org/presentation/201/ (Accessed October 2012).

[93] Shen, Q. and Tang, L. (2010). "Patient Preferences, Concerns, and Satisfaction with Providers before the Chinese Urban Health System Reform: A Social Groups Analysis", Stanford University Walter H. Shorenstein Asia-Pacific Research Center Asia Health Policy Programme Working Paper 17, pp. 3-11.

[94] World Bank, "World Bank Support for the Health Sector in India", April 2010, http://www.worldbank.org/en/news/2010/04/06/worldbank-india-health-support (Accessed January 2013)

particularly in Tamil Nadu and Rajasthan; the former has had a similar programme in place since the late 1990s.

In terms of expenditure, overall India spends less on healthcare than many other emerging economies. In 2010 total expenditure on health as a percentage of GDP stood at 4.1%.[95] This is actually a drop from levels seen a decade earlier in the late 1990s and early 2000s. In 2000 total spending stood at 4.6% and in 2001 at 4.8%.[96] Although rising, the public share of this is still relatively low at 29.2% in 2010.[97] Rates of Out-Of-Pocket (OOP) spending are also considerably higher than in other countries. In 2010, OOP spending accounted for virtually all private spending at 86.4%.[98] The lack of health insurance and high rate of OOP spending has resulted in health expenditure being a leading cause of indebtedness and poverty.

### 4.4.1 Acknowledgement of patients' rights

India's constitution guarantees all citizens the right to assemble peacefully and the right to form associations and unions.[99] Patient's rights are not formally recognized at the central or state level. The Indian government has discussed introducing a patient charter – most recently in 2011 – in conjunction with other healthcare reforms. However, it does not appear that this has materialised.[100] India did adopt the "Patients' Charter for tuberculosis care" – an initiative developed by an NGO and the WHO – in December 2012.[101] However, no timeline for the implementation of this charter has been offered.

### 4.4.2 Presence of multiple organisations and patient support

India has a multitude of patient organisations; examples include AIDS Awareness Group, Alzheimer's and Related Disorders Society of India, and Cancer Patients Aid Association.

The AIDS Awareness Group provides a wide variety of services not only to HIV/AIDS patients but more generally to communities and people in need. The group's main activities include: conducting HIV/AIDS education and awareness campaigns; HIV/AIDs testing and counselling; general health and nutritional counselling including anemia correction through iron supplementation; legal aid to prisoners; literacy programmes; financial services through micro-finance and credit programmes; as well as professional training in counselling.[102]

The Alzheimer's and Related Disorders Society (ARDSI) of India is a national non-profit seeking to raise awareness and recognition of patients suffering from dementia and Alzheimer's disease. The

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[95] World Bank, Health expenditure, total (% of GDP), India. (Accessed January 2013)

[96] Ibid.

[97] Ibid, Health expenditure, public (% of total health expenditure)

[98] Ibid. Out-of-pocket health expenditure (% of private expenditure on health)

[99] Indian Constitution, retrieved from http://india.gov.in/govt/documents/english/coi_part_full.pdf (Accessed October 2012).

[100] *The Times of India*, "Patients' charter of rights in the offing", October 2 2011, http://timesofindia.indiatimes.com/india/Patients-charter-of-rights-in-the-offing/articleshow/10200799.cms (Accessed January 2013)

[101] Vaccine News Daily, "India adopts TB patient charter", December 12 2012, http://vaccinenewsdaily.com/medical_countermeasures/321103-india-adopts-tb-patient-charter/ (Accessed January 2013)

[102] AIDS Awareness Group webpages: http://www.aagindia.org/index.php (Accessed October 2012).

group campaigns actively and organises conferences, workshops and seminars. It engages with government and has as one of its main objectives the Indian Government's recognition of dementia as a disability as well as greater funding for patients suffering from the disease. The group has a number of care centres throughout India offering care to dementia and Alzheimer's patients. In addition, ARDSI also offers educational courses in elderly care as well as support groups and counselling. Finally, the group also supports research on the prevalence of dementia in rural and urban India.[103]

Founded in 1969 the Cancer Patients Aid Association (CPAA) provides support and services to cancer patients across India and even in neighbouring countries such as Nepal, Bhutan and Bangladesh. The CPAA activities include: patient care such as counselling, advice and support throughout a treatment cycle; financial assistance; rehabilitation and jobs training for cancer patients through the CPAA Rehabilitation Centre; awareness and education including early detection and screening services; liaison and support services for the obtaining of cancer specific insurance; and advocacy.[104]

### 4.4.3 Existence of cultural awareness and recognition of patient organisations

The Indian Government recognises and supports the efforts of patient organisations by promoting disease awareness days, such as International AIDS Day, Rare Disease Day, and World Cancer Day. It is also actively promoting ways to partner with and fund NGOs, for example through its NGO Partnership System. This service encourages all "Voluntary Organisations" and NGOs to sign up and register their details "to bring about greater partnership between government and [the] voluntary sector and foster better transparency, efficiency and accountability".[105]

### 4.4.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

India does not presently provide a formal structure for patient input into healthcare policies. This has been discussed and suggestions have been put forward of introducing a patients' charter but currently no charter is in effect. The fragmented nature of healthcare provision with the vast majority of the population being uninsured and the under-developed state of the health system makes it difficult to see how the voices of patients can be effectively included in healthcare policy.

For instance, India's fragmented health system is matched by an equally fragmented regulatory structure. Responsibility, oversight and monitoring of health providers is divided between state, central and professional organisations.[106] This has led to large variations in both the quality of care provided and a dearth of effective remedies for patients with grievances and/or complaints about their care.

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[103] Alzheimer's and Related Disorders Society of India webpages: http://www.alzheimer.org.in/vision.php (Accessed October 2012).

[104] Cancer Patients Aid Association webpages: http://www.cpaaindia.org/aboutus/index.htm (Accessed October 2012).

[105] Planning Commission, Government of India, NGO Partnership System webpages: http://ngo.india.gov.in/auth/default.php (Accessed October 2012). For details of the Indian Government's partnership with NGOs on HIV/AIDS see Mozumder, S. and Nora, E. (2007). "HIV/AIDS in India", The World Bank, retrieved from http://siteresources.worldbank.org/INTSAREGTOPHIVAIDS/Resources/HIV-AIDS-brief-Aug07-IN.pdf (Accessed October 2012).

[106] Bloom, G. (2008), p. 957-962.

For instance, non-institutional care remains largely unregulated.[107] The Medical Council of India (which, among other things, has responsibility for recognizing medical qualifications and addressing non-institutional care grievances) is limited in the type of medical misconduct cases it can hear as well as the type of punishment it can issue.[108]

There are also legal uncertainties in the current system. For example, with regard to Indian common law interpretation of patient consent, there are no clear precedents, particularly in relation to emergency care leaving both patients and health professionals vulnerable.[109]

#### 4.4.5 Inclusion of patients' viewpoints in healthcare policies

Given the immense challenges of access and cost, patients show a surprisingly high degree of satisfaction with many key aspects of Indian healthcare delivery. For example, a 2009 survey of patients using government health facilities in one of India's largest states, Uttar Pradesh, found that patients showed high levels of satisfaction with the medical examination and communication with their physician.[110] Nevertheless, the same study also found that patients were highly dissatisfied with pharmaceutical prescribing and related services.[111]

Similarly, a 2001 survey of patients in district and area hospitals found that while overall patients had relatively high levels of satisfaction they also had misgivings about the quality of care and competency of doctors and health professionals.[112]

### 4.5 Mexico

Mexico's healthcare system has undergone significant changes over the past decade. Starting in the early 2000s the system was fundamentally reformed to increase coverage and access to medical care. In 2003 the System of Social Protection in Health (SSPH) was introduced. Under one of its programmes, the *Seguro Popular*, uninsured Mexicans were offered access to a public insurance scheme. So far the reform has been successful in achieving coverage of over 50 million previously uninsured Mexicans.[113] In terms of overall structure, Mexico has several vertically integrated public insurers/providers for different parts of the population (social security, low-income, unemployed/self-employed). Health policy is quite fragmented and authority and responsibility is divided between federal and state bodies.

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[107] Ibid.

[108] Ibid.

[109] Nandimath, O. (2009), p. 346.

[110] Kumari, R (2009) et al, "Study on Patient Satisfaction in the Government Allopathic Health Facilities of Lucknow District, India", *Indian J Community Med*, 2009 January; 34(1): 35–42

[111] Ibid.

[112] Mahapatra, P. et al (2001), "A Patient Satisfaction Survey in Public Hospitals", *Journal of the Academy of Hospital Administration*, Vol. 13, No. 2 (2001-07 - 2001-12),

[113] Knaul, F. *et al* (2012). "The Quest for Universal Health Coverage: Achieving Social Protection for All in Mexico", *The Lancet* 380, pp. 1259-1262.

Mexico has one of the lowest rates of health expenditure in the OECD. In 2010 total expenditure on healthcare was 6.2% of GDP, 3.3% lower than the 2010 OECD average of 9.5%.[114] Mexico also has the highest rate of OOP spending in the OECD at 49% of total expenditure.[115]

### 4.5.1 Acknowledgement of patients' rights

Mexico's constitution protects and ensures basic rights of assembly, association and freedom of speech.[116] In addition, the 1983 constitution also recognised the right to health. However, until the reforms of the 2000s this was an unrealised right with many Mexicans uninsured and access to healthcare limited. As well as increasing insurance coverage the reform effort of the past decade has also sought to understand the views of patients which are included in regular surveys of patient satisfaction. The Ministry of Health is by law obliged to conduct surveys of users of the Seguro Popular plan.[117]

Some Mexican states have also recognised patients' rights in official patient charters. For example, the State of Mexico has a 10-point list of patients' rights that includes access to care, complete information, informed consent, access to a second opinion as well as the right to be treated with respect and dignity.[118]

### 4.5.2 Presence of multiple organisations and patient support

A number of patient organisations exist in Mexico, offering a variety of programmes and services. Examples include *Asociación Mexicana de Esclerosis Múltiple* (Mexican Association of Multiple Sclerosis), *Asociación Mexicana de Leucemia y GIST* (Mexican Association of Leukemia and GIST), *Cáncer de Mama Tómatelo a Pecho* (Breast Cancer, Take It to Heart) and *Asociación ALE IAP*.[119] Below is an outline of these patient associations with a more comprehensive list of other groups provided in the footnotes below.

The *Asociación Mexicana de Esclerosis Múltiple* is a patient group founded and managed by MS patients. The group currently provides medical, support and therapeutic services to MS sufferers. Specific services include: group and individual counselling and psychological therapy; physiotherapy; and a patient call centre. The group has as one of its founding missions to help MS patients become

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[114] OECD Stat 2012.

[115] Ibid.

[116] Mexican Constitution, retrieved from http://www.oas.org/juridico/mla/en/mex/en_mex-int-text-const.pdf (Accessed October 2012).

[117] Knaul (2012), p. 1270.

[118] State Government of Mexico, "Carta de Derechos de los Pacientes", http://salud.edomex.gob.mx/ccamem/cartapacientes.htm (Accessed January 2013)

[119] Additional Mexican patient groups include the following: *Asociación ALE* (ALE Association): http://www.quierodonar.com.mx/web/; *Asociación de Acromegalia* (Association of Acromegaly): http://www.acromegalicos.org/; *Asociación de Salud y Bienestar Social de la Mujer y su Familia* (Association of Health and Wealfare of Women and their Families): http://www.asbis.org.mx/index.html; *Asociación Mexicana Contra el Cáncer de Mama A.C.* (Mexican Association Against Breast Cancer): http://www.cimab.org/index.html; *Asociación Mexicana de Esclerosis Tuberosa* (Mexican Association of Sclerosis Tumors): http://www.amet.org.mx/; *Asociación Mexicana de Lucha Contra el Cáncer A.C.* (Mexican Association of the Fight Against Cancer): http://www.amlcc.org/; *Fundación GIST México* (GIST Foundation Mexico): http://www.fundaciongist.org/pages/home; *MPS JAJAX A.C.* (MPS JAJAX): http://mpsjajax.com/; *Niños de Hierro* (Kids of Iron): http://www.ninosdehierro.org/; *Proyecto Pide un Deseo México* (Make a Wish Project Mexico): http://iap.pideundeseo.org/ *Red Contra el Cáncer* (Red Against Cancer): http://www.redcontraelcancer.org.mx/red/index.html; Fundación Mexicana para la Planeación Familiar, *www.mexfam.org.mx/* (All websites accessed October 2012).

more financially independent and currently employs a number of patients within its administration and as support staff.[120]

Founded in 2006, *the Asociación Mexicana de Leucemia y GIST's* mission is to support patients with leukemia and intestinal and stomach cancer and improve the quality of life of cancer survivors. The group works closely with cancer patients, organising and hosting meetings, information sharing sessions and counselling.[121]

Founded by Dr Felicia Marie Knaul after her experience of breast cancer, *Cáncer de Mama Tómatelo a Pecho* seeks to reduce and eliminate breast cancer mortality through prevention, early detection and improved treatment. The group has a number of programmes and activities including public education, supporting research and development, awareness raising and engagement with policymakers and health professionals. Sample projects and initiatives supported include the development of an existing cancer registry in the State of Jalisco as well as more generally developing new and innovative strategies for the early detection, prevention and treatment of cancer. The Mexican federal Government, through the National Commission for Social Protection in Health (CNPSS), supports the latter project.[122]

*Asociación ALE IAP* is a patient group dedicated to the promotion of organ donation. Founded by the families of a child whose organs were donated after his death the group seeks to raise awareness of the need for greater organ donations in Mexico and raise the funds and necessary expertise for facilitating organ transplantation. The group has established a number of initiatives including educational and awareness raising; fund raising; a donor data base; a programme to improve hospital infrastructure; active engagement with Mexican health officials to make existing health legislation more practical and amenable to donations; grants for health professionals specialising in organ transplants; and financial assistance and support for low income patients.[123]

In addition to these groups, the umbrella patient group *Red de Accesso* (Access Network) represents and advocates on behalf of Mexican patients suffering from chronic diseases.[124] Significantly, the group is dedicated to public policy advocacy and improving access to and the availability of health services to patients suffering from chronic disease.

### 4.5.3 Existence of cultural awareness and recognition of patient organisations

The Mexican government recognises and supports the efforts of patient organisations by promoting disease awareness days, such as International AIDS Day, Rare Disease Day, and World Cancer Day.

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[120] *Asociación Mexicana de Esclerosis Múltiple* webpages: http://www.amemiap.org.mx/default.asp (Accessed October 2012).

[121] *Asociación Mexicana de Leucemia y GIST* webpages: http://ameleg.org.mx/ (Accessed October 2012).

[122] *Cáncer de Mama Tómatelo a Pecho* webpages: http://tomateloapecho.org.mx/ (Accessed October 2012).

[123] See ALE, "What we do?", http://www.quierodonar.com.mx/en/quehacemos.htm (Accessed January 2013)

[124] *Red de Accesso*, "¿Quiénes somos?", http://reddeacceso.org/conocenos/ (Accessed January 2013)

In addition, the government supports and partners with NGOs, including those representing patients and has begun developing partnerships with NGOs to address specific health concerns, such as HIV/AIDS and breast cancer. As described above with regards to the *Cáncer de Mama Tómatelo a Pecho* a number of patient associations work closely with the Mexican federal and state governments.

### 4.5.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

Currently there does not appear to be in place a formal or direct mechanism for incorporating patients' views into policymaking. The health system's fragmentation, with responsibilities and authority divided between the federal and state level, would suggest that patient input should take place at all levels of government. However, using concept mapping techniques studies have found – see for instance Becerril et al (2011) – that most policy stakeholders outside of federal decision-makers gave healthcare policy a low ranking.[125] Given this and the fact that the federal government is the primary funder and most healthcare policy emanates from the federal level, it would seem that patients' viewpoints would be best incorporated on the federal level.

Currently, a primary source for healthcare policy recommendations is the National Institute of Public Health (INSP), which was formed in 1987 through the merger of the School of Public Health, the Population Health Research Center, and the Infectious Disease Research Center.[126] The INSP conducts public health research, education including graduate training, as well as a wide variety of services to all levels of the Mexican government and community groups. It was heavily involved in the development of more effective cervical cancer programmes as well as public health policies relating to tobacco.[127] As part of its mission the INSP also conducts national, regional surveys on the Mexican health system and offers support and technical consulting to community groups and indirectly provides a bridge between community and patient associations and healthcare policy making.

In addition, as explained above, a number of patient associations work together with both the federal and state governments in developing health policy on an *ad hoc*, project by project basis.

### 4.5.5 Inclusion of patients' viewpoints in healthcare policies

Although the creation of the SSPH and the *Seguro Popular* have made many improvements to the Mexican healthcare system, there still exist several pertinent challenges that would benefit from patients' insights. Large variations in the quality of service persist and out-of-pocket spending, while falling, remains very high compared to other OECD countries.[128]

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[125] Becerril, V. *et al* (2011). "Mapping of Health System Functions to Strengthen Priority Programmes: The Case of Maternal Health in Mexico", *BMC Public Health* 11(164), p. 7.

[126] National Institute of Public Health, "INSP Overview", http://www.insp.mx/insp-overview/education.html (January 2013)

[127] Cooper, K. and Magaña-Valladares, L. (2011). "The National Institute of Public Health: Shaping Public Policy to Advance Population Health in Mexico", *Public Health Reviews* 33(1), p. 333.

[128] Knaul, F. *et al*(2012), p. 1271.

## 4.6 Russia

Prior to 1991 Russian healthcare was highly centralised and the Ministry of Health, in effect, regulated, managed and oversaw healthcare throughout the Soviet Union. In 1991 the healthcare system was decentralised and now works on three distinct levels: the federal, regional (oblast-level) and municipal (rayon-level).[129] In addition, there is a large "parallel" system of healthcare through various other federal departments and ministries. This accounts for roughly 15% of all outpatient facilities and 6% of inpatient facilities.[130] Mandatory health insurance was introduced in 1993 but implementation has been relatively limited. Financing remains problematic and private sector insurance third party payers have yet to emerge in all regions.[131]

An ambitious health reform effort was launched in the mid-2000s which sought to expand coverage and access to medical services. As part of this reform effort a number of initiatives have been created targeting specific areas of healthcare such as preventative care, access to new technologies and improvement to ante- and post-natal care. [132]

Total expenditure on healthcare is rather low in comparison with the OECD average, at 5.1% of GDP for 2010.[133] Public expenditure on health is also relatively low. For 2008 this amounted to an estimated 3.6% of GDP.[134]

### 4.6.1 Acknowledgement of patients' rights

Russia's constitution provides basic rights with regard to freedom of activity, public association as well as the right to health protection and medical care.[135] Russian law does not include a specific or separate piece of legislation on patients' rights. However, there are a number of rights which are reasonably well defined in other relevant pieces of legislation. For example, the Protection of Citizens health law (no. 5487, 22 July 1993) defines a number of patient rights including choice of physician, right to a second opinion and informed consent.[136]

There have been efforts by patient and civil society groups to launch independent patient charters. For example, the All-Russian Congress of Patients (an umbrella group representing patients from across Russia and different disease categories) in 2010 adopted a "Declaration on the Rights of Patients". This declaration proposes several rights, including the right to preventive treatment, access

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[129] Tragakes, E. and Lessof, S. (2003), "Russian Federation", *Healthcare systems in Transition*, European Observatory on Health Systems and Policies, pp. 28-9.

[130] Ibid. p. 38.

[131] Ibid. p. 41.

[132] OECD (2012). *OECD Reviews of Health Systems: Russian Federation 2012*, OECD Publishing, p. 61. Link to document: http://dx.doi.org/10.1787/9789264168091-en (Accessed October 2012).

[133] World Bank, Health expenditure, total (% of GDP), Russia

[134] The World Bank in Russia, (2009), p. 15.

[135] Russian Constitution, retrieved from http://www.constitution.ru/en/10003000-03.htm (Accessed October 2012).

[136] Popovich, L. *et al* (2011), pp. 63-64.

to medical care, protection of privacy and confidential information, safety, the right to voice complaints, and having relatives present during hospitalisation.[137]

### 4.6.2 Presence of multiple organisations and patient support

A plethora of patient organisations exists in Russia, offering a variety of programmes and services. Examples of groups include AIDS Infoshare, Moscow Cancer Society, and the All-Russian Public Organisation of Disabled People with Multiple Sclerosis.

AIDS Infoshare seeks to limit the spread and social harm caused by HIV/AIDS. It accomplishes its mission through creating and publishing educational materials; facilitating training sessions, seminars, and conferences; conducting scientific research; offering financial support; providing capacity-building expertise for NGOs, activists, governmental institutions, and federal agencies; and leading communication efforts between communities, civil society, and government institutions. The group works across Russia and its best practice prevention programmes for commercial sex workers have been introduced in a number of regions.[138]

The Moscow Cancer Relief Society is a patient group founded by and for patients, their families and physicians. The Society works through education and advocacy to spread information about cancer and the issue of early detection and screening programmes. The group also provides support services for cancer patients and their families. Finally, the Society actively works to introduce and spread the concept of palliative care within Russia for instance through the Moscow Home Care Hospice for children.[139]

The All-Russian Public Organisation of Disabled People with Multiple Sclerosis (ARMSS) is a non-profit organisation founded in 2001 with the goal of supporting and advocating on behalf of MS patients and their families. It consists of a number of local or regional MS groups. Unlike many other patient associations, ARMSS focuses on public policy and health policy related to MS patients. The group engages policymakers and health institutions in Russia directly with the view of improving access to medical services for MS patients and raising the quality of these services. ARMSS also works together with pharmaceutical manufacturers to ensure the production and supply of drugs and medical equipment. The ARMSS employs MS patients both at the central level and locally through its member groups.

### 4.6.3 Existence of cultural awareness and recognition of patient organisations

The Russian government recognises and supports efforts of patient organisations by promoting disease awareness days, such as International AIDS Day, Rare Disease Day, and World Cancer Day.

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[137] Declaration on the Rights of Patients in Russia, retrieved from http://www.patients.ru/index.php?option=com_content&view=category&layout=blog&id=6&Itemid=12 (Accessed October 2012).

[138] AIDS Infoshare webpages: http://www.infoshare.ru/globus/ (Accessed October 2012).

[139] Moscow Cancer Relief Society homepage: http://www.vsem-mirom.narod.ru/mop/index1.htm (Accessed October 2012).

In terms of independent actions by patient associations, the All-Russian Alliance of Patients held the first congress of patients and patient organisations in Moscow in May 2010 with the goal of developing a common strategy for patient rights protection and a declaration of patient rights in Russia (described above). Over 100 organisations attended the meeting including patient associations, disabled groups, scientific organisations, medical associations, insurance companies, state authorities and others.[140]

There are examples of the Russian government directly collaborating with NGOs and partially funding their programmes and activities. However, a recently enacted federal law will make it more burdensome for local NGOs to receive foreign funding.[141] The federal law "Introducing Amendments to Certain Legislative Acts of the Russian Federation Regarding the Regulation of Activities of Non-commercial Organizations Performing the Function of Foreign Agents" will require all non-commercial organisations (NCOs) to register with a specially authorised governmental body prior receiving any foreign donations or funding if they intend to conduct political activities. These groups will be labelled by the government as "NCOs carrying functions of a foreign agent."[142]

### 4.6.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

Patient organisations are legally guaranteed the right to contribute to Russian healthcare policy. Specifically, the 2005 Federal Law on Public Chamber and Decree on the Procedure for Establishing Councils Attached to Federal Ministries, Agencies, and Services established two health policy advisory councils on which patients and patients groups have places reserved. The councils are attached respectively to the Ministry of Health and *Rospotrebnadzor* (the Federal Consumer Rights Protection and Human Wellbeing Surveillance Service).[143] These councils have the power to make policy recommendations, however, these recommendations are advisory and non-binding on the respective agency.

### 4.6.5 Inclusion of patients' viewpoints in healthcare policies

Patient surveys paint a mixed picture of Russian healthcare. For example in the 2011 National Health and Wellness Survey administered by Kantar Health (a healthcare consultancy) only 25% of urban Russians surveyed expressed confidence in their physicians.[144] Similarly, and reflecting the challenges with the quality of medicines in Russia, a survey by Synovate (a market research firm)

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[140] Popovich, L. *et al* (2011), p. 39.

[141] Russian Federal Law on Prevention of the Spread in the Russian Federation of the Disease caused by the Human Immunodeficiency Virus (HIV-Infection), retrieved from http://www.hsph.harvard.edu/population/aids/russianfed.aids.95.pdf (Accessed October 2012).

[142] The International Center for Not-for-Profit Law (2012). *NGO Law Monitor: Russia*, retrieved from http://www.icnl.org/research/monitor/russia.pdf (Accessed October 2012).

[143] Popovich, L. *et al* (2011), p. 65.

[144] Kantar Health (2012), "Russian Patients Have Poor Relationships with Their Doctors", June 12 2012, http://www.kantarhealth.com/news-events/news-article/2012/06/12/russian-patients-have-poor-relationships-with-their-doctors (Accessed January 2013)

found that over two-thirds of Russians preferred alternative or natural medicines rather than chemical based drugs.[145]

## 4.7 Thailand

The Thai health system is fragmented with responsibilities divided between central and local governments and public and private service providers. Insurance coverage is provided through social security insurance for private sector employees; civil service or public administration coverage for government employees and their dependents; and universal coverage for all individuals not covered by the public or private plans.[146]

Access to healthcare and universal healthcare coverage was mandated in both the 1997 constitution as well as in 2002 healthcare legislation. The latter introduced a tax-funded health insurance scheme, the Universal Coverage System (UC). The UC allowed patients to see a health professional (doctor or hospital) for a flat fee of Thai Baht130. This fee was later abolished and this type of service is now provided free of charge.[147] UC covers around three-quarters of the population, with the remainder covered by the civil service or social health insurance schemes.

Thailand spends quite a small proportion of its national income on health. In 2010 total expenditure on health as a percentage of GDP was 3.9%.[148] Healthcare spending has largely remained unchanged and has grown only moderately over the last decade from 3.4% of GDP in 2000 to its current level. The majority of this expenditure comes from the public sector which in 2010 made up 75% of total health spending.[149]

### 4.7.1 Acknowledgement of patients' rights

Thailand acknowledges the rights of patients in four ways. First, the Thai constitution allows for freedom of assembly as well as universal access to healthcare.[150] Second, in the mid to late 2000s Thailand structurally reformed its health system policy process, introducing an annual National Health Assembly (NHA), a number of administrative rules as well as primary and secondary legislation on both the formulation of health policy as well as actual policy.[151] Both the National Health Statute and annual assemblies aim to improve and increase public participation in health policy. Specifically, they target civil society, NGOs and other representative groups at the local and national level. The resolutions of the NHA are non-binding but play a prominent role in shaping Thai health policy and

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[145] Synovate (date not specified), "Global healthcare survey reveals rise of 'patient power'", http://www.marketresearchworld.net/index.php?option=com_content&task=view&id=2050&Itemid=77 (Accessed January 2013)

[146] Lindelow, M. *et al* (2012). "Government Spending and Central-Local Relations in Thailand's Health Sector", *Health, Nutrition and Population* Discussion Paper, Washington, DC, USA: The World Bank 71887, pp. 15-26.

[147] General Electric, "Health of Nations", Thailand, http://www.healthofnations.com/countries/profile/thailand (Accessed January 2013)

[148] World Bank, Health expenditure, total (% of GDP), Thailand

[149] Ibid. Health expenditure, public (% of total health expenditure), Thailand

[150] Thai Constitution, retrieved from http://www.nhrc.or.th/2012/wb/img_contentpage_attachment/474_file_name_7532.pdf (Accessed October 2012).

[151] National Health Commission Office of Thailand, "Health Statute" and "Health Assembly", http://en.nationalhealth.or.th/ (Accessed January 2013)

influencing government.[152] Finally, Thailand has in place a Declaration of Patient's Rights, which states that patients are entitled to receive full medical services from their medical practitioner regardless of their status, race, nationality, religion, social standing, political affiliation, sex, age or the nature of their illness. Although not an official piece of legislation, the 1998 Declaration was supported by all Thai professional medical councils and the Ministry of Health through the Council for Registration of Medical Practice.[153] Other rights include the right of consent, information about treatment as well as a right to confidentiality.

### 4.7.2 Presence of multiple organisations and patient support

Numerous patient organisations exist in Thailand, offering a variety of programmes including: the Bangkok Breast Cancer Support Group, the Camillian Social Center Rayong, and the Thai CML Patient Group.

The Bangkok Breast Cancer Support Group is a volunteer group composed of expats living and working in the greater Bangkok region. The group is dedicated to supporting women with breast cancer and is based at the Queen Sirikit Center for Breast Cancer at the Chulalongkorn Hospital in Bangkok. In addition to support services, the group actively campaigns to raise awareness for early screening and detection programmes. The group also facilitates diagnostic ultrasound and mammogram testing. Out-reach activities include lectures and seminars at universities, schools women's clubs and workplaces.[154]

Founded in 1989 by health professionals, patients and their families the Thalassemia Foundation of Thailand acts on multiple fronts to raise awareness of the disease as well as improve healthcare policies and research. For its outreach and public education activities, the group has organised a Thalassemia Club with over 4,500 members through which it holds annual meetings and conferences. The Foundation also distributes literature on the disease across Thailand and works with the Thai Ministry of Public Health training paramedical personnel. In terms of public policy, the group actively engages the Thai government and other health stakeholders (including pharmaceutical companies) to, among other things, increase access to drugs and treatment. Finally, the Foundation has an active research agenda both funding and conducting research. For example, they are leading a pilot project on the prevention of and control of Thalassemia in Pathalung Province, in southern Thailand.[155]

The Thai CML Patient Group seeks to educate patients, their families and the public on chronic myeloid leukaemia. The group provides support services to patients as well as counselling sessions

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[152] Rasanathan, K et al (2010), "Innovation and participation for healthy public policy: the first National Health Assembly in Thailand", *Health Expectations*, WHO

[153] Chiang Mai University, Faculty of Medicine, "Declaration of PATIENT'S RIGHTS", http://www.medicine.cmu.ac.th/research/ethics/patient_right_eng.htm (October 2012) See also Y Teerawattananon et al (2003), "Health sector regulation in Thailand: recent progress and the future agenda", *Health Policy*, 63 (2003) pp. 323-338, p. 336

[154] Bangkok Breast Cancer Support Group webpages: http://www.bangkokbreastcancer.com/index (Accessed October 2012).

[155] Thalassemia Foundation of Thailand, http://www.thalassemia.or.th/our_found.html (Accessed January 2013)

for patients and caregivers. Through annual seminars and group meetings the group has a formalised structure of raising awareness and recognition of the disease and CML patients.[156]

### 4.7.3 Existence of cultural awareness and recognition of patient organisations

The Thai government recognises and supports the efforts of patient organisations by promoting disease awareness days, such as International AIDS Day, Rare Disease Day, and World Cancer Day.

The Thai government also recognises patient organisations on legislative and regulatory fronts. As explained above, civil society groups (including patient organisations) play an active role in the development of national health policy through both the annual NHA and the local assemblies leading up to this meeting. Furthermore, other legislation, such as the Social Welfare Promotion Act, requires relevant governmental agencies and committees to promote the participation of NGOs and civil society groups in the formulation of social welfare policy.[157]

### 4.7.4 Opportunity for patients and/or patient organisations to provide input to healthcare policies

Patients in Thailand have a clearly defined and legally mandated role to play in the formulation of health policy at the most senior levels of government. In addition to their contributions at the local and national level, through the health assemblies, patients are also required by the National Health Act to take part in the National Health Commission (NHC).

Founded in 2007 the NHC sets national health policy and proposes required legislation; reviews national health policy; and advises the Thai government and relevant ministers on health policy. Most importantly civil society groups (including patient associations) are mandated a share of thirteen seats on the NHC. The NHC is chaired by Thailand’s Prime Minister or Deputy Prime Minister with up to five additional ministers members of the Commission. The NHC does not publish the members of the Commission, so it is unclear whether a patient organisation currently holds a seat on the NHC.[158]

### 4.7.5 Inclusion of patients’ viewpoints in healthcare policies

Given the limited public information about members of the NHC, it is difficult to determine whether patients’ viewpoints are directly incorporated into healthcare policies. What is clear is that the Thai government has established a formal structure that gives patients and patient organisations an opportunity to voice their opinions about healthcare policies and that it regards healthcare policy as something created and implemented by several stakeholders in addition to the government.[159]

With regards to overall levels of patient satisfaction with Thai healthcare, patient surveys suggest that levels of satisfaction vary depending on the type of provider and whether the patient is receiving in- or

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[156] Thai CML Patient Group webpages: http://www.thaicml.com/patient/index.php (Accessed October 2012).

[157] The International Programme of the Charity Commission, “NGO Regulation Network”, Thailand http://www.ngoregnet.org/country_information_by_region/Asia_and_Oceania/Thailand.asp (Accessed November 2012)

[158] National Health Commission Office of Thailand About Us webpage: http://en.nationalhealth.or.th/Organizational_Structure#NHC (Accessed October 2012).

[159] National Health Commission Office of Thailand Health Public Policy webpage: http://en.nationalhealth.or.th/Health_Public_Policy (Accessed October 2012).

out-patient treatment. A 1999 survey of patients in Bangkok found that most patients were satisfied with their treatment and services provided but that results varied between type of patient and institution.[160] For example, concerning in-patient care, patients in public hospitals showed higher levels of satisfaction than private for-profit hospitals. The reverse was true for out-patient care. Significantly, this survey found that patients accessing healthcare through social security based coverage were consistently less satisfied with their treatment then patients with other forms of coverage.

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[160] Tangcharoensathien, V. et al (1999), "Patient satisfaction in Bangkok: the impact of hospital ownership and patient payment status", *International Journal for Quality in Healthcare* 1999; Volume 11, Number 4: pp. 309–317.

# Section 5: Conclusions and Policy Recommendations

## 5.1 Conclusions

The incorporation of patient viewpoints into the policy process does not occur in a vacuum but depends upon certain external factors that enable patient organisations to contribute to it. The countries examined in this paper all display some of these external factors. All seven countries contain within their constitution some form of right to assemble (Factor 1). All of them, except for China, also have multiple organisations and patient support activities that would be indicative of a critical mass leading towards a stronger patient voice in the healthcare system (Factor 2). There is also the existence of a cultural awareness and recognition of patient organisations and the work that they do to promote their respective diseases and work to support those affected by them (Factor 3), although it may not always be supported by governments. However, none of the countries demonstrated concretely how patients' viewpoints were, and are, incorporated into their respective healthcare policies. In this respect all the health systems examined contain deficiencies that could be improved in order to obtain a better patient satisfaction rating by increasing patients' power in policymaking process. (Factor 5).

The key, differentiating external factor is the opportunity for patients and/or patient organisations to provide input into healthcare policies. Based on the establishment of a formal structure to incorporate patients' viewpoints, Brazil, Russia, and Thailand are the only countries out of the seven analysed that provide this fourth enabling factor. However, out of those three countries, Russia is the one that has not explicitly legislated patients' rights and is the most ambivalent about the actual input of patients' viewpoints into its formalised structure (Factor 4).

Overall, Brazil and Thailand have the most conducive environments compared to the five other countries examined. Russia has a formal structure in place to incorporate patients' viewpoints, however is deficient in ensuring patient organisations' seat at the table and has not enshrined patients' rights into legislation. Argentina, China, India and Mexico were found to have deficiencies in their environments and being the least conducive to the inclusion of the patient voice in health policy.

## 5.2 Policy Recommendations

First, governments should confirm rights of assembly (e.g. patient associations right to exist and meet) and freedom of speech (e.g. their right to constructively criticise healthcare policies). A Patients' Bill of Rights, although not necessary, would be helpful in formally establishing the rights and roles of patients, patient organisations, and, in terms of responsibilities, the government. Of course to be most effective, the declaration should be legally binding and enforceable.

Second, there must be a cultural awareness and recognition of patient organisations. Patient organisations provide first-hand knowledge of a broad spectrum of patients, who can provide helpful insights into healthcare policies. While public support of specific disease days promotes awareness of these groups, formal recognition through transparent government-NGO partnerships brings credibility to both the patient organisations and the government in the eyes of the public.

Third, there has to exist a formal mechanism for patient input into the policy process. Although the other external factors need to be in place, if there is no formal structure for incorporating patients' viewpoints, it is highly unlikely that healthcare policies will reflect their perspectives. However, as seen in the examples of Brazil, Russia, and Thailand, establishing a formal process for patient input does not guarantee the incorporation of those viewpoints in the final healthcare policy. Therefore, it is recommended that patient representatives establish some form of monitoring power to ensure their viewpoints are actually incorporated in the end result.

The evidence collected in this paper, along with the conclusions and the policy recommendations aim to give governments, policymakers, and members of civil society a broad and effective tool in thinking about how to effectively incorporate patients' viewpoints in healthcare policies with the ultimate aim of improving healthcare outcomes and patient satisfaction rates for all.

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