

The Patient Movement in Numbers —a Focus on Brazil

October 2024



Contents



About Brazilian Patient Groups

33 Brazilian patient groups describe their roles in Brazil's healthcare system. They detail the challenges facing Brazilian patient groups, and point to the support they need to complete their goals.

Source: Brazil-specific findings from the October 2024 PatientView report, *'Patients in Action'*.



About Pharma Partnerships in Brazil

121 Brazilian patient groups describe what they think of pharma. They identify the strategic interventions they wish pharma to implement in Brazil, to improve patient-group relations.

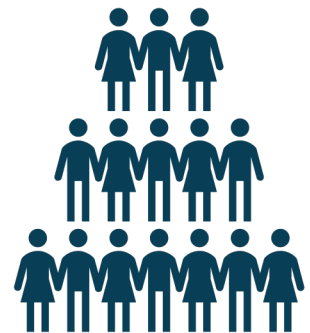
Source: Brazil-specific findings from the most-recent edition (that of 2023/24) of PatientView's annual report, *'The Corporate Reputation of Pharma—from a Patient Perspective'*.

▼ *Introduction: PatientView*

- PatientView is a research, publishing, and consultancy group, created out of a belief that the views of patients should be considered in all important healthcare decisions.
- PatientView has an extensive reach of 40,000 patient groups worldwide (drawn from across most therapy areas, and from almost every country).
- PatientView amplifies the powerful voice of patient groups, and works to ensure that their insights are heard by the pharmaceutical industry, and by other major healthcare stakeholders—all with the aim of enacting meaningful, positive change.

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- Patient groups possess a unique understanding of the needs of patients, and represent the collated voice of patients.
- Patient groups have taken on an increasingly significant role in healthcare—from policy and advocacy, through to the direct provision of services to patients.
- Despite having a growing influence on the shaping of healthcare, patient groups are often misunderstood—seen primarily as patient-support networks, rather than as key contributors to healthcare decision-making and advocacy.



▼ *About the 2024 'Patients in Action' data*



About Brazilian Patient Groups

Brazil-specific findings from the October 2024 PatientView report, *'Patients in Action'*.

33 Brazilian patient groups describe their roles in Brazil's healthcare system.

They detail the challenges facing them, and point to the support they need to complete their goals.

PatientView's research in *'Patients in Action'* has the following aims:

- Determine the roles that patient groups hold within healthcare systems.
- Understand how patient groups believe they are perceived by other healthcare stakeholders.
- Map the activities of patient groups.
- Discover the types of support that patient groups need to receive, if they are to fulfil their goals, and improve patient outcomes.



Methodology behind 'Patients in Action'

- A '*Patients in Action*' questionnaire, aimed at patient groups, was designed by PatientView, in collaboration with healthcare professionals, patient groups, and pharma companies.
- This '*Patients in Action*' questionnaire was run, June to August 2024.
- The survey attracted responses from **1,144** patient groups (drawn from **83** countries, and from **65** broad specialties).
- **33 patient groups from Brazil responded to '*Patients in Action*'**.
- These 33 Brazilian patient groups estimated that they were in contact with (and represented the interests of) approximately **300,000** Brazilian patients during 2024.

About the 2024 study and its analysis

PatientView's 2024 'Patients in Action' questionnaire to patient groups was designed in collaboration with healthcare professionals, patient organisations, and pharma companies. Six key indicators were created to measure the activities and challenges of patient groups, as follows:



Being a vital stakeholder in healthcare: the extent to which patient groups perceive themselves as essential to their healthcare systems, and why.



Having an impact on healthcare: the extent to which patient groups believe their organisations can influence important aspects of healthcare policymaking, provision, education, and research.



Being respected and listened to: the extent to which other stakeholders consider patient groups essential to healthcare systems.



Working with other healthcare stakeholders: looking at whether other healthcare stakeholders provide support for the work of patient groups.



The barriers faced by patient groups: what barriers prevent patient groups from fully participating in healthcare systems.



The services patient groups provide patients: the services that patient groups provide to patients (and whether patient groups carry out policy-related activities).

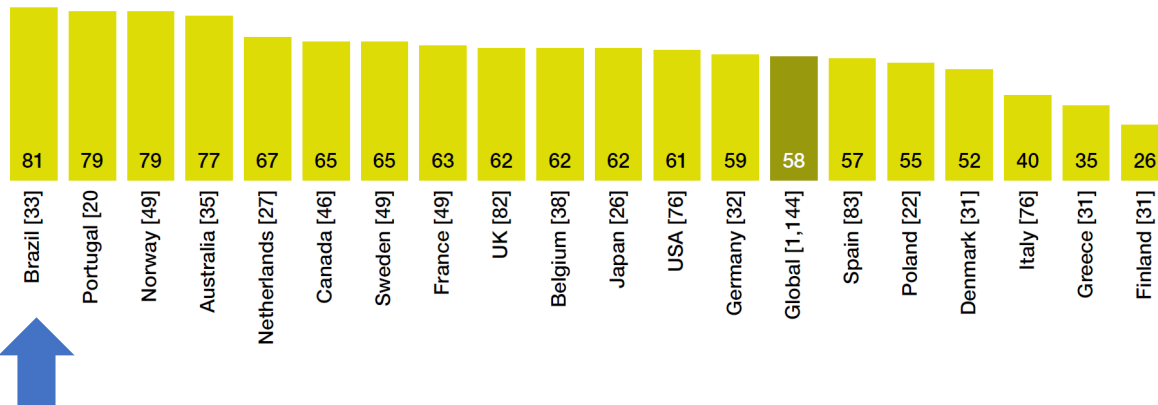
Executive Summary: *‘Patients in Action’, Brazil*

- Patient groups from Brazil are the **most likely** (out of patient groups from the 19 countries analysed in ‘Patients in Action’) to consider themselves **essential healthcare stakeholders** in their country.
- Patient groups from Brazil consider themselves the **most influential** (out of patient groups from the 19 countries examined in details) in **providing patient information, patient education, and education for healthcare practitioners** in their country.
- However, patient groups from Brazil also feel themselves the **least influential** among the 19 countries on **drug reimbursement** in their country.
- Brazilian patient groups provide more **telephone services to patients, and support for patients in economic hardship**, than patient groups in any of the 19 featured countries.
- Most of the respondent patient groups from Brazil cite **lack of Brazilian patient access to medicines, and lack of Brazilian patient-group funding**, as **chief barriers** to Brazilian patient groups’ participation in their country’s healthcare system.

Being a *vital stakeholder* in healthcare

Patient groups from Brazil are the **most likely** (out of patient groups from the 19 countries analysed in detail in *'Patients in Action'*) to consider themselves **essential healthcare stakeholders** in their country.

Percentage saying "Yes" Ordered high to low



Brazilian patient groups explain why they are essential to their healthcare system

Thematic analysis of commentaries

Theme	% of total comments
Guiding policy development, advocacy activities	20%
Providing healthcare	15%
Participating in regulatory, HTA, and insurer decisions	15%
Supporting individual patients and carers	10%
Improving self care, and health literacy	10%
Raising awareness of disease, and its impact	10%
Improving access to care and treatments	5%
Improving care pathways, guidelines, and services	5%
Researching new treatments, and disease insights	5%
HCP education and engagement	5%
Involvement in research	2%
Advocating for equitable access for treatments	0%
Other	0%



Guiding policy development; and instituting advocacy activities

Establishing (and strengthening) relationships with policymakers—to gain an overall commitment to resources.

Implementing effective advocacy strategies for patient and caregiver communities, and engaging with key decisionmakers.

Services that Brazilian patient groups provide to patients

‘Patients in Action’ data show that Brazilian patient groups provide a **wide range of services** to the Brazilian patients with whom they are familiar.

Rankings for Brazilian patient groups (out of patient groups from 19 countries) for the following elements of **service provision to patients**:

- ▶ **1st** for provision of telephone services to patients in their country.
- ▶ **1st** for supporting patients in economic hardship in their country.
- ▶ **4th** for delivering care and treatment to patients in their country.



91%

host telephone
helplines



73%

arrange peer-to-peer
support groups



72%

support patients in
economic hardship



68%

offer healthcare
advice



52%

deliver treatment
and care



31%

support drug-treatment
clinical trials



34%

undertake healthcare
research

Policy / advocacy activities of Brazilian patient groups

‘Patients in Action’ data show that Brazilian patient groups engage in many **policy and advocacy activities** aimed at furthering the interests of Brazilian patients.

Rankings for Brazilian patient groups (out of patient groups from 19 countries) for the following **policy and advocacy activities**:

- ▶ **3rd** for representing patients’ interests to regulatory authorities in their country.
- ▶ **4th** for advocating for better patient access to treatments in their country.
- ▶ **4th** for advocating for better patient care in their country.

% respondents choosing option

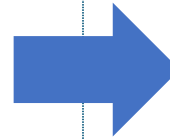
Countries ordered alphabetically.

	Raising awareness of patient/carer needs	Advocating for better patient care	Advocating for better access to medicines	Representing patients’ interests to drug-regulatory authorities
Global [1,144]	88	90	77	67
Australia [35]	100	100	97	85
Belgium [38]	87	87	62	60
Brazil [33]	88	97	88	84
Canada [46]	96	98	93	89
Denmark [31]	87	94	78	71
Finland [31]	73	84	62	59
France [49]	79	81	57	51
Germany [32]	81	97	50	73
Greece [31]	97	100	93	70
Italy [76]	83	80	69	60
Japan [26]	80	76	72	64
Netherlands [27]	96	88	76	56
Norway [49]	85	90	77	69
Poland [22]	95	100	83	74
Portugal [20]	85	90	68	58
Spain [83]	81	87	62	70
Sweden [49]	82	90	72	52
UK [82]	96	95	83	57
USA [76]	95	95	83	63

*Brazilian patient groups' influence on **healthcare policymaking***

The **percentage** of Brazilian patient groups which think that they influence the following aspects of Brazilian **healthcare policymaking**:

- **71%** feel able to influence the **drug-approvals process** in Brazil.
- **64%** feel able to influence Brazilian **government healthcare policymaking**.
- **44%** feel able to influence **drug reimbursement** in Brazil.



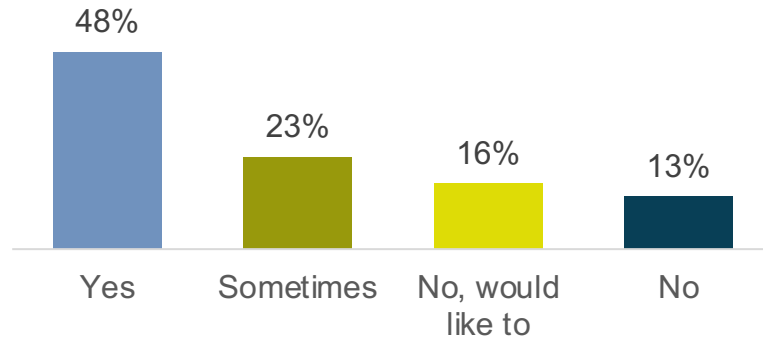
Rankings for Brazilian patient groups (out of patient groups from 19 countries) for influence upon the following elements of **healthcare policymaking**:

- **3rd** for influencing their country's **drug approvals**.
- **5th** for influencing their country's **government healthcare policymaking**.
- **11th** for influencing their country's **drug reimbursement**.

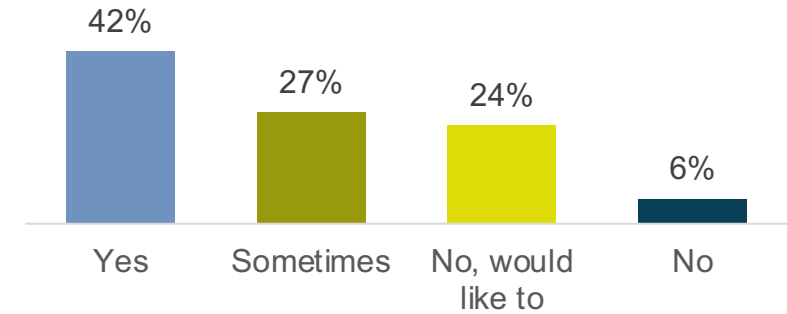
Brazilian patient groups' influence on healthcare policymaking

Percentage of respondent Brazilian patient groups

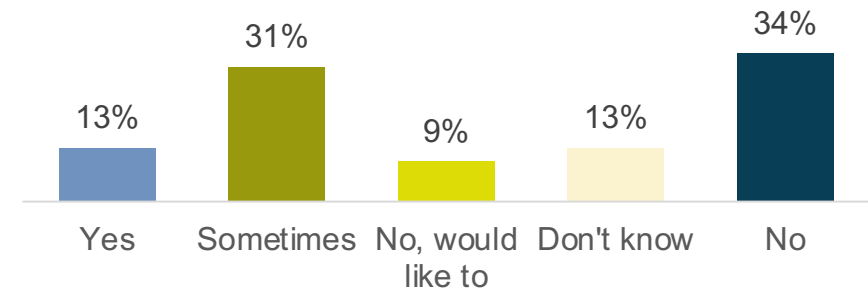
Do you influence government healthcare policymaking?



Do you influence drug approvals?



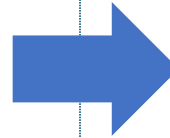
Do you influence drug reimbursement?



*Brazilian patient groups' influence on **healthcare provision***

The **percentage** of Brazilian patient groups which think that they influence **healthcare provision** in Brazil:

- **85%** feel that they influence **patients' access to medicines** in Brazil.
- **64%** feel that they influence **healthcare provision** in Brazil.



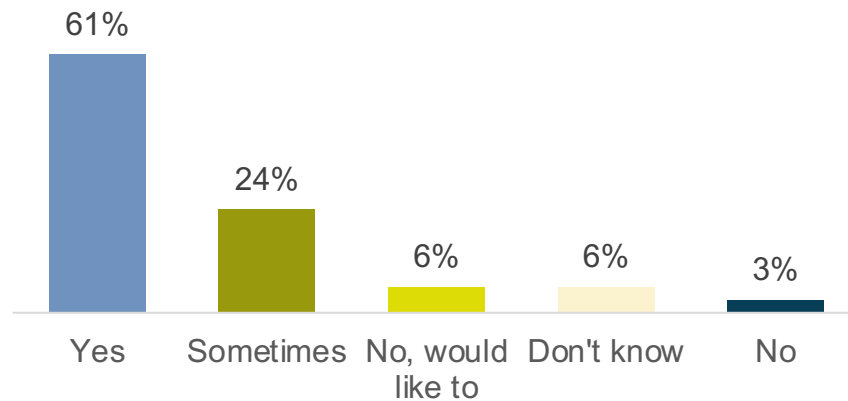
Rankings for Brazilian patient groups (out of patient groups from 19 countries) for influence upon **healthcare provision**:

- **1st** for influencing **patient access to medicines** in their country.
- **16th** for influencing **healthcare provision** in their country.

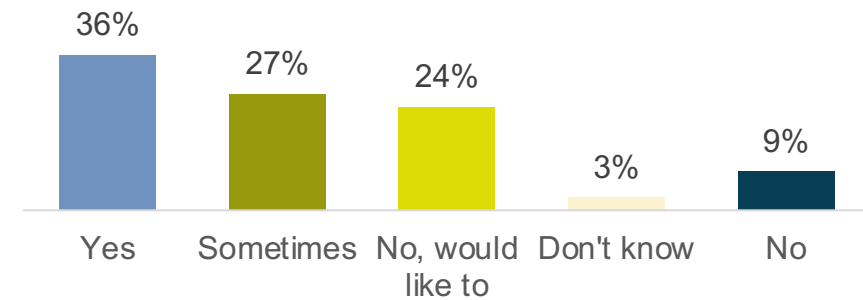
Brazilian patient groups' influence on healthcare provision

Percentage of respondent Brazilian patient groups

Do you influence patients' access to healthcare?



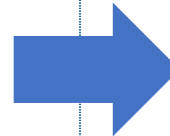
Do you influence healthcare provision?



▶ *Brazilian patient groups' influence on **health education***

The **percentage** of Brazilian patient groups which think that they influence the following aspects of **health education** in Brazil:

- **97%** feel that they influence **patient information** in Brazil.
- **91%** feel that they influence **patient education** in Brazil.
- **85%** feel that they influence the **education of healthcare professionals** in Brazil.



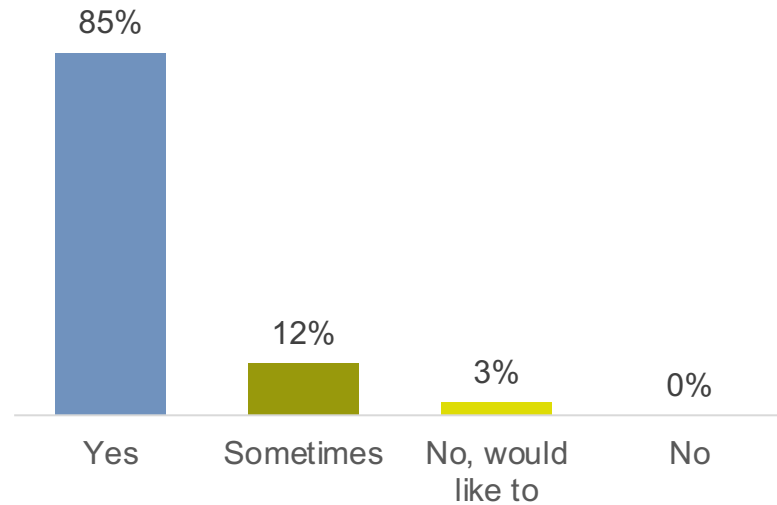
Rankings for Brazilian patient groups (out of patient groups from 19 countries) for influence upon the following elements of **health education**:

- **= 1st** (alongside Italy) for influence upon **patient information** in their country.
- **= 10th** (alongside Germany) for influence upon **patient education** in their country.
- **4th** for influence upon the **education of healthcare professionals** in their country.

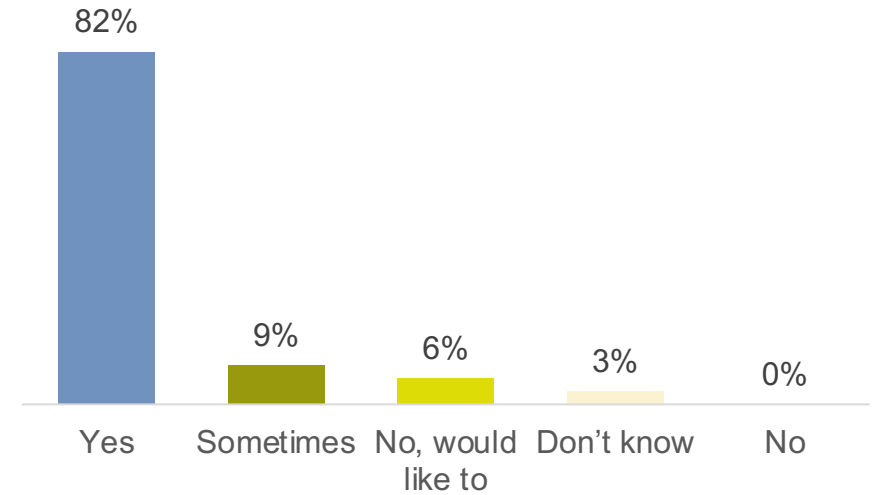
Brazilian patient groups' influence on *health education*

Percentage of respondent Brazilian patient groups

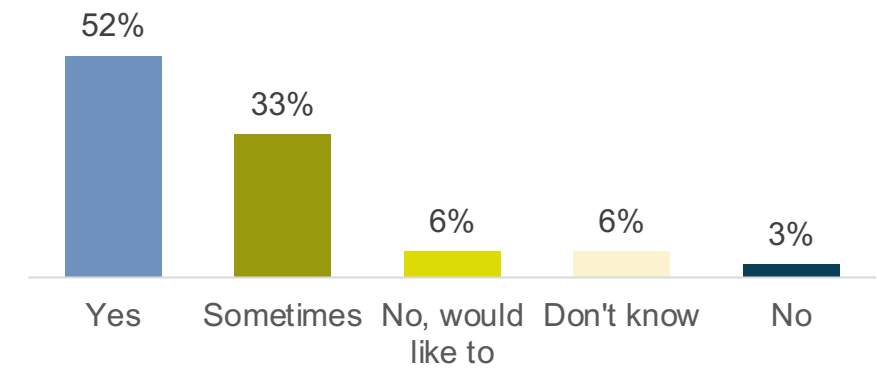
Do you influence patient information?



Do you influence patient education?



Do you influence education of healthcare professionals?





Being respected, and listened to

The vast majority of Brazilian patient groups believe that they are respected, and listened to, by other healthcare stakeholders within their country (at least some of the time).

Brazilian patient groups **rank 1st** (out of patient groups from 19 countries) for being considered by the following healthcare stakeholders in their country as **essential to the national healthcare system**:

- Health Technology Assessment (HTA) authorities.
- Local-government healthcare committees.
- The media.
- Pharmacists.

Percentage saying “Yes” or “Sometimes”



Working with other healthcare stakeholders

The vast majority of Brazilian patient groups believe that they are **supported by other healthcare stakeholders** in their country.

Two exceptions are:

- medical-device companies, and
- health insurers.

Even though only 40% of Brazilian patient groups report getting support from the two types of healthcare stakeholders noted below, Brazilian patient groups **rank 1st** (out of patient groups from 19 countries) for **receiving support** from them:

- Drug regulatory authorities.
- Health Technology Assessment (HTA) authorities.

Percentage saying “Yes” or “Sometimes”



Support needed by Brazilian patient groups

Brazilian patient groups provide ‘*Patients in Action*’ with 64 commentaries on the **types of the support** they require to improve patient outcomes in Brazil, and to achieve their goals.

The commentaries fall into 10 categories—most common being a call for improvements in:

- access to care, pathways, and quality.

II. The types of support that Brazilian patient groups need from other healthcare stakeholders to enable them to achieve their goals

Theme #	Theme	% of total comments
10	Improve access to care, pathways, and quality	26%
2	Capacity building, expertise, and training	21%
14	Improve HCP education	15%
6	Enable networking and engagement with stakeholders	8%
12	Support patient-group goals and co-working	8%
3	Raise disease awareness, prevalence, and burden	6%
11	Improve patient and caregiver experience	6%
13	Enable patient engagement in research	6%
1	Finance and resourcing	3%
8	Enable and improve patient-group delivery of services	2%
4	Address stigma	0%
5	Address inequity	0%
7	Raise patient-group profile and reputation	0%
9	Improve integration of patient group into health systems	0%
15	Support patient-group advocacy	0%
	Other	0%

▼ *Support needed by Brazilian patient groups*

Thematic analysis of commentaries



“Desenvolvimento de protocolos; colaboração no desenvolvimento e padronização de protocolos de atendimento e tratamento, garantindo uma abordagem consistente e eficaz.”

—National rare-disease patient group

“Atender em centros de referência específicos da doença.”

—Regional cystic-fibrosis patient group

“Equipar pelo menos 10 importantes cidades das 5 regiões brasileiras com aparelhos de função pulmonar completa (pletismógrafo).”

—National rare-disease patient group

“Parceria das secretarias Estadual e Municipal nas ações e atividades que são desenvolvidas diariamente pela instituição.”

—Local HIV/AIDS patient group





Brazilian Patient Groups' Views of Pharma

Brazil-specific findings from the most-recent edition (that of 2023/24) of PatientView's annual report, *'The Corporate Reputation of Pharma—from a Patient Perspective'*.

121 Brazilian patient groups describe what they think of pharma.

They identify the strategic interventions they wish pharma to implement, to improve patient-group relations in Brazil.



About the 2024 'Corporate Reputation of Pharma' data

Few studies explore the opinions of patient groups worldwide on whether pharma companies **meet the expectations** of patients and patient groups (and, if not, how might the industry, and individual pharma companies, improve).

PatientView's annual *'Corporate Reputation of Pharma'* survey gives health campaigners and patient-advocacy groups (PAGs) an opportunity to comment on, and assess, the pharma industry's performance.

Each year, the results of the survey help support company efforts to strengthen their ties with patient groups.



Methodology behind 'Corporate Reputation'

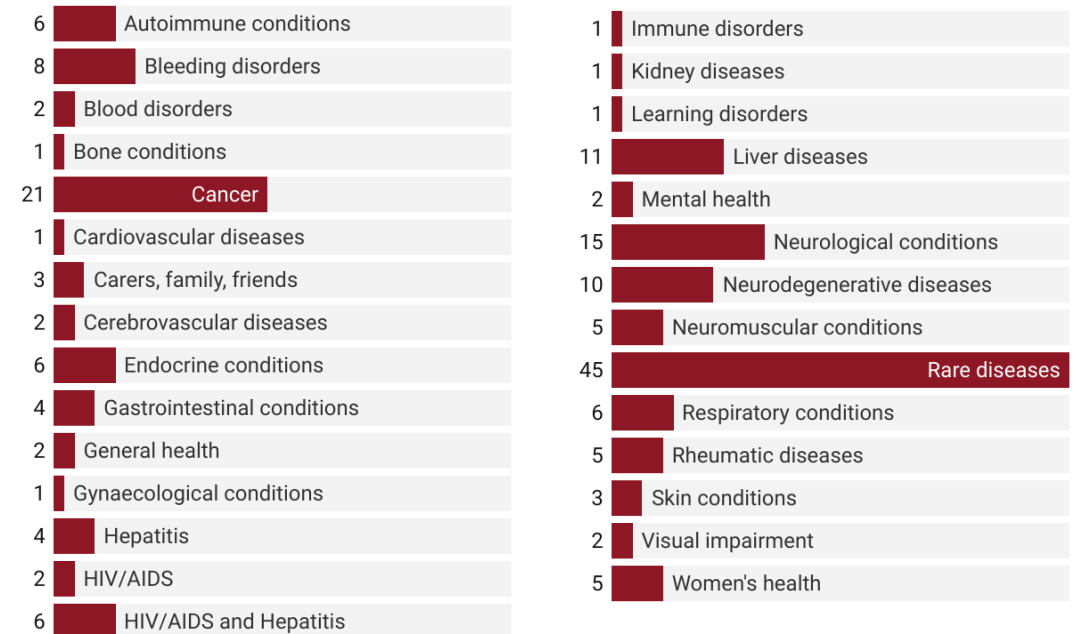
PatientView's annual online 'Corporate Reputation of Pharma' survey, conducted between November-February, measures various aspects of pharma's performance at corporate reputation—always from a patient perspective.

During the course of the survey's 13-year history, pharma companies and patient groups alike have contributed to the design of the survey questionnaire. The survey questionnaire is divided into two sections, to assess ...

- ▶ Firstly, the performance of the [pharma industry \(as a whole\)](#) at activities important to patients and patient groups.
- ▶ Secondly, Brazilian patient-group [advice on how pharma can improve its corporate reputation](#)—from the perspective of patients.

Speciality profile of the 131 Brazilian patient groups which responded to the online 2023 'Corporate Reputation of Pharma' survey

Percentage of total





Executive Summary: Brazilian patient groups on pharma

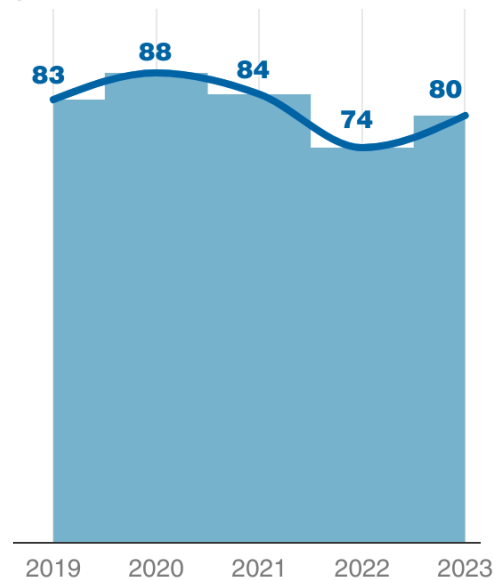
- The **reputation of pharma** among patient groups in Brazil is **high**—with **80%** of Brazilian patient groups stating that the pharma industry has an “Excellent” or “Good” corporate reputation. That reputation has been maintained over several years.
- In 2023, the majority of Brazilian patient groups believe pharma “Excellent” or “Good” at **most** of the activities of importance to Brazilian patients and patient groups:
 - Patient centricity.
 - Patient information.
 - Patient safety.
 - Innovation.
 - Providing products of benefit to patients.
 - Integrity.
 - Patient-group relations.
- However, in 2023, the majority of Brazilian patient groups **do not** believe pharma to be “Excellent” or “Good” at the following five activities of importance to Brazilian patients and patient groups:
 - Transparency.
 - Providing services ‘beyond the pill’.
 - Having fair pricing policies.
 - Engaging patients in R&D.
 - Improving patient access to medicines.

▼ *Industry-wide results*

The corporate reputation of the pharma industry, 2019-2023—according to Brazilian patient groups

% of respondent Brazilian patient groups, per year, stating “Excellent” or “Good”

Number of respondent Brazilian patient groups, 2023, N = 121

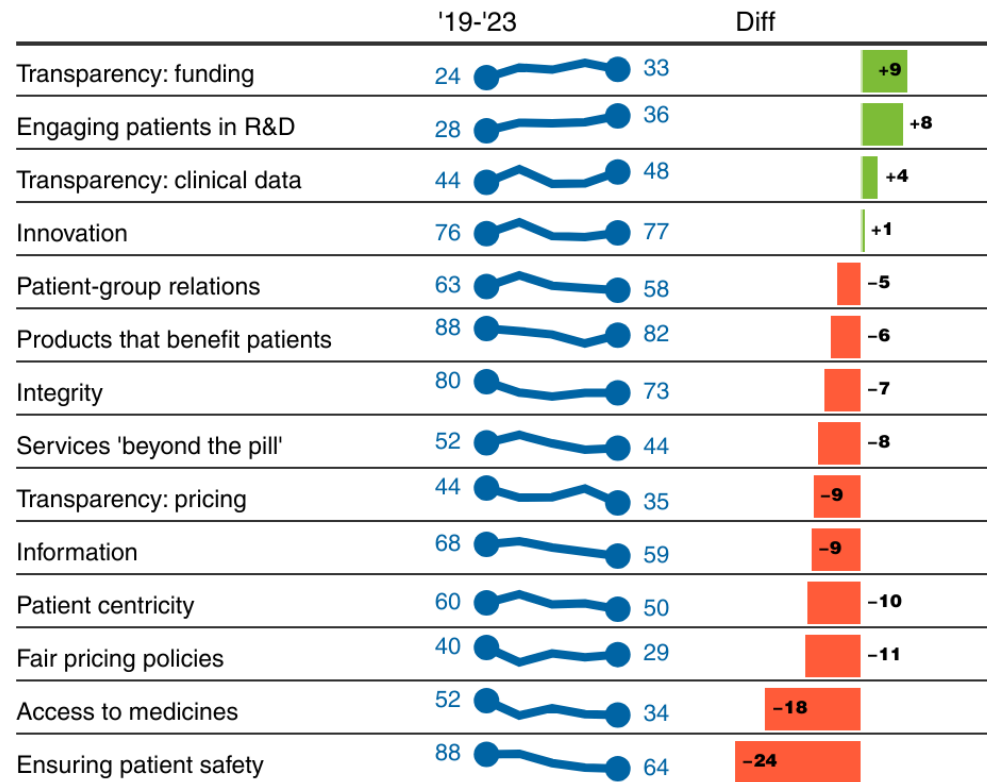


Percentage of respondent Brazilian patient groups stating that the pharma industry was “Excellent” or “Good” at activities of importance to Brazilian patients and patient groups, 2023 v. 2022

	2023	Versus 2022
Patient centricity	50	-9
Information	59	-3
Ensuring patient safety	64	-2
Innovation	77	+3
Products that benefit patients	82	+7
Transparency: pricing	35	-9
Transparency: clinical data	48	+4
Transparency: funding	33	-8
Integrity	73	±0
Patient-group relations	58	-2
Services 'beyond the pill'	44	+3
Fair pricing policies	29	+4
Engaging patients in R&D	36	+4
Access to medicines	34	-1

Industry-wide results

Percentage of respondent Brazilian patient groups stating that the pharma industry was “Excellent” or “Good” at activities of importance to Brazilian patients and patient groups, 2019-2023



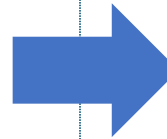
Brazilian patient groups have rated the pharma industry highly for corporate reputation over the past five years.

However, Brazilian patient groups mark the pharma industry down significantly for its performance at some activities of importance to Brazilian patients and patient groups—notably ...

- patient safety,
- access to medicines, and
- fair pricing policies.

▼ *'Moving Forward':
Strategic priorities for pharma*

- A thematic analysis of Brazilian patient groups' qualitative feedback, advising on strategic direction for pharma in Brazil —ranked and defined.
- 121 Brazilian patient groups provide 630 comments on how pharma might improve in Brazil.
- 19% of the commentaries from respondent Brazilian patient groups emphasise that the priority for pharma companies in Brazil should be **patient access to medicines**.



Brazilian patient groups highlight the indicators of corporate reputation at which the pharma industry most needs to improve in Brazil

Thematic analysis of commentaries

Indicator of corporate reputation	% of total comments
Access to medicines	19%
Patient-group relations	14%
Transparency	14%
Patient information	12%
Engaging patient in R&D	9%
Services 'beyond the pill'	8%
Products of benefit to patients	7%
Patient centricity	6%
Integrity	6%
Patient safety	4%

‘Moving Forward’: Strategic priorities for pharma

- As mentioned on the previous slide, 19% of the commentaries from respondent Brazilian patient groups emphasise that the priority for pharma companies in Brazil should be **patient access to medicines**.
- Of these 19%: 21% recommend that pharma focus on **improving pathways, and the patient experience**.

Brazilian patient groups propose key strategic changes that they believe pharma in Brazil needs to make to improve corporate reputation

Thematic analysis of commentaries

What Brazilian patient groups mean by: “improve patient access to medicine”	% of total comments
Improve pathways, and the patient experience	21%
Improve the speed/quality of HTA, and approvals	18%
Enable affordable pricing	18%
Ensure greater equity in access to medicines (overview)	15%
Build local links	13%
Address inequities of access	10%
Help gather evidence to support equity of access	3%
Avoid taking any anti-competitive actions	3%

‘Moving Forward’: Strategic priorities for pharma



Improve pathways, and the patient experience

- Work with healthcare systems at national, and local, levels—to augment the overall experience that patients (and caregivers) have in reliably accessing, and using, treatment.
- Help healthcare systems to develop, and to improve, treatment pathways (and identify critical gaps in local delivery).



Improve the speed/quality of HTA, and approvals

Retain high standards of pharmacovigilance, while accelerating HTA, insurer, payor, and regulatory approvals.

Helping to keep patient views and priorities at the centre of the approvals process. For example:

- Balancing company investment in local clinical research, and in market-access solutions, between high-, medium-, and low-income countries.
- Demonstrating to regulators how patients have been involved in R&D, and in commercialisation decisions—from identifying priority unmet needs, onwards.
- Involving all stakeholders early on in the research process, with the aim of enabling speedier approvals.



Enable affordable pricing

- Focus on affordability throughout the development and commercialisation of a treatment, to help make treatments more affordable for healthcare systems, insurers, or individual patients.
- Be open to drug-pricing reforms, and to innovative pricing models requested by patient groups and healthcare systems.



Ensure greater equity in access to medicines (overview)

- Take equitable access into account in management decisions about pipeline, portfolio, and brand lifecycle—to help healthcare systems achieve their aims to improve patient equity of access to treatments.



Build local links

- Extend relationships to more countries outside of the company’s existing most-profitable markets. For example, enable faster acceptance of a treatment in a country, by involving that country at the research stage.
- Deepen local links within existing core markets (for example, leverage local relationships), to help quantify and address inequity of access to treatments between local geographic areas.

‘Moving Forward’: Strategic priorities for pharma



Address inequities of access

- Globally, take action to rebalance access to treatments between high-, medium-, and low-income countries.
- Within countries, identify actions to support patients’ access to treatments (including, for example, financial Patient Assistance Programs).



Help gather evidence to support equity of access

Work with patient groups (and other healthcare stakeholders) to help prove the scale of health inequities for specific diseases. For example:

- Support registries (and other sources), to demonstrate the scale of the divergence between disease prevalence and treatment delivery.
- Identify the gaps between, on the one hand, clinical pathways, guidelines, and standards, and, on the other hand, what local patients actually receive.
- Map the regional/local patterns of access within a country.
- Identify the personal factors that contribute to patients’ inequity of treatment access—such as age, ethnicity, gender, location, and socioeconomic status.



Avoid taking any anti-competitive actions

- Attempt to increase the scale, and the quality, of appropriate collaboration between companies, and also between the industry and other stakeholders—both for the collective interest of patients.
- Evaluate commercial and competitive decisions on the basis of any perceived harm that they may have on patients. For example, perceptions of:
 - Hindering new entrants by ‘evergreening’ patents.
 - Withholding licenses unreasonably.
 - Focusing brand extensions on protecting brands, and on price rises—rather than on addressing genuine unmet needs.
 - Withdrawing less-profitable treatments, despite their being depended upon by communities of patients—particularly if no immediate alternative treatment is available to those patients.
 - Halting clinical research for commercial (rather than clinical) reasons.
 - Focusing treatment launches onto the most-profitable markets—thereby denying access by many other countries.

▼ *‘Moving Forward’:
Strategic priorities for pharma*



“Temos conhecimento de pacientes que fazem uso de medicação e os programas oferecidos. A farmacêutica não tem nenhum suporte efetivo ao paciente. Do que adianta tomar uma medicação de milhares de reais e não ser acompanhado com serviços de saúde regulamente, e morrer afogado em secreção?”

—Local neurological-conditions patient group

“Programas de acesso precoce e compassivo: implementar programas de acesso precoce para fornecer terapias inovadoras a pacientes que não têm opções de tratamento disponíveis. Isso demonstra um compromisso em atender às necessidades urgentes dos pacientes.”

—Regional cystic-fibrosis patient group

“Entrar em acordo com o governo na questão de preços, praticando valores iguais aos que apresentam em outros países, para que se possa ter acesso por esse meio, já que não é possível de outra forma.”

—National rare-disease patient group



Please do not hesitate to contact us, should you have further questions, or wish to access the report



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