



## WHAT 2,500+ PATIENT GROUPS SAY ABOUT PHARMA IN 2024

*Global edition [14<sup>th</sup>]*

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- ▶ Survey of 2,546 patient groups worldwide, conducted December 2024 to March 2025.
- ▶ The respondent patient groups actively supported over 41 million patients during the past year.
- ▶ 46 companies are featured in the survey—11 are new to the survey (and included on the suggestion of patient groups). The 11 new companies tend to be smaller biotechs which focus their innovatory activities on rare diseases, rather than on creating traditional blockbusters (companies in blue, below, are the new additions). The full list of 46 companies:

• AbbVie • Amgen • **Alnylam Pharmaceuticals** • **Angelini Pharma** • Astellas Pharma • AstraZeneca • Bayer  
• Biogen • BioMarin • Boehringer Ingelheim • Bristol Myers Squibb • Chiesi Farmaceutici • **Crinetics Pharmaceuticals** • CSL Behring • Daiichi Sankyo • Eisai • **Esteve Healthcare** • Eli Lilly • **Exelixis**  
• Gilead Sciences • GSK • **Incyte** • Ipsen • Johnson & Johnson Innovative Medicine • **Jazz Pharmaceuticals**  
• LEO Pharma • Lundbeck • Merck & Co/MSD • Merck KGaA • Novartis • Novo Nordisk • Otsuka • Pfizer  
• PTC Therapeutics • **Recordati** • **Regeneron** • Roche/Genentech/Chugai • Sanofi • Sarepta Therapeutics  
• Servier • **Sobi** • Takeda • UCB • Vertex • **Viatris** • ViiV Healthcare

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### Why pharma needs to work closely and efficiently with patient groups

PatientView has recently documented the activities and opinions of patient groups in its *Patients in Action* study, published October 2024. The study captured one of the largest and most diverse datasets of its kind, and the findings illustrate the evolving relationship between patient groups and other healthcare stakeholders (including the pharmaceutical industry). The findings show clearly that patient groups can now be considered core health actors in national healthcare settings—entities with views respected by most (perhaps even all) healthcare stakeholders.

Patient groups across the world are expanding their roles in advocacy, healthcare-service delivery, patient education, and medical research—a context which creates an imperative for the pharmaceutical sector, since regulatory bodies increasingly expect evidence of patient engagement throughout the product lifecycle. Patient groups possess a depth of insight that can unlock connection to both HTA and to market access, provide critical feedback on treatment tolerability, and help design appropriate communications to target patient populations. These capabilities are not peripheral; they are vital to every aspect of pharma's R&D.

### What patient groups seek from pharma, but are not currently getting

Patient groups (*Patients in Action*) also emphasise that the most-valuable contributions they receive from partners (including the pharmaceutical industry) are additional forms of support beyond just financial grants.

2,193 of the 2,546 patient groups responding to PatientView's latest 'Corporate Reputation of Pharma' survey, that of 2024, stated a working relationship with at least one pharmaceutical company—86% of the whole respondent body. The next chart summaries the types of working relationships that 2024's respondent patient groups said they have with their pharma partners. Seemingly, pharma's investment priorities with patient groups are still oriented more towards one-off outputs, rather than longer-term partnerships designed to build patient-group capacity and capability—relationships that should improve patient-group interactions with the rest of the world of healthcare.

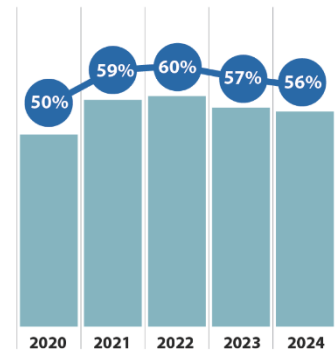
### The types of relationships that respondent patient groups have with pharma companies, 2024

—% of total respondents

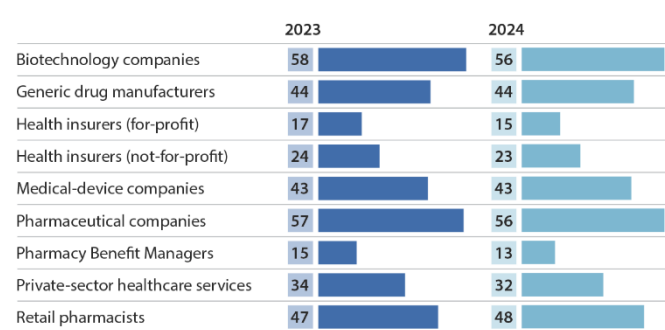


The data in the next set of charts show that patient-group attitudes toward the pharmaceutical industry are, following a reputational gain during the Covid-19 pandemic, more negative than in 2022. Although pharmaceutical companies show signs of improvement in being transparent about their funding of healthcare stakeholders, a large majority of 2024's respondent patient groups still believe that pharma is just "fair" (or even "poor") at being transparent about the pricing of products.

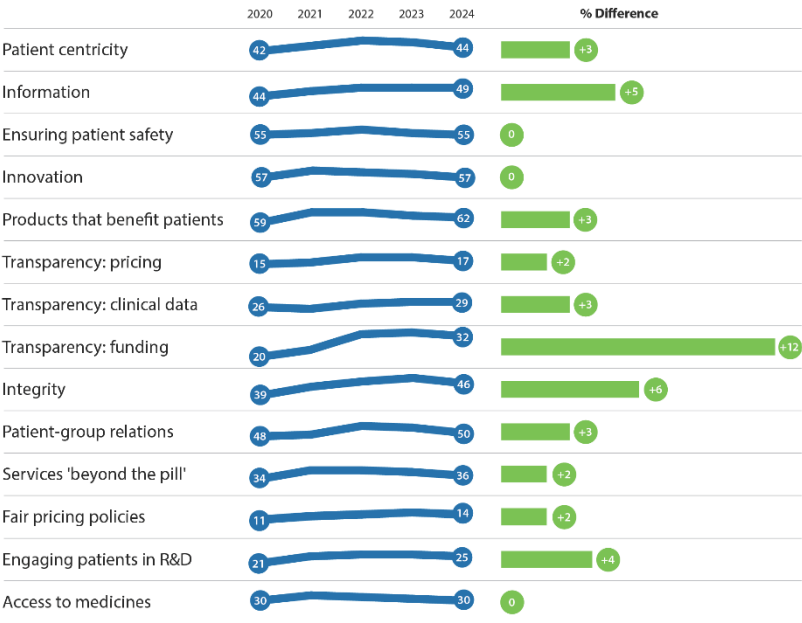
The corporate reputation of the pharma industry, according to respondent patient groups, 2020-2024  
% of respondent patient groups, per year, stating "Excellent" or "Good"



The corporate reputation of the pharma industry, compared with that of other healthcare sectors, 2024 v. 2023—according to respondent patient groups  
% of respondent patient groups, per year, stating "Excellent" or "Good"



How good or bad the pharma industry was at carrying out specific activities, 2020-2024  
% of respondent patient groups stating "Excellent" or "Good"



Pharma’s global reputation is only likely to improve when the industry continues to grow its understanding of the benefits that patient groups wish to attain from corporate partnerships. Patient groups are vocal in what they want to see from pharma, and regulators and policymakers are taking note. If the pharmaceutical industry is to continue to advance healthcare, it needs to do more than just consult patients and patient groups; it needs to build strategies and activities with them.

Individual company results

ALL COMPANIES

The top-three global rankings 2024 (out of all 46 companies)—as assessed by respondent patient groups [familiar](#) with the company:

- ▶ ViiV Healthcare, 1st
- ▶ Roche, 2nd
- ▶ Gilead Sciences, 3rd

The top-three rankings in 2024 (out of 45 companies)—as assessed by respondent patient groups [working](#) with the company:

- ▶ ViiV Healthcare, 1st
- ▶ Sobi, 2nd
- ▶ Lundbeck, 3rd

BIG PHARMA

The top-three global rankings in 2024 (out of 15 'big-pharma' companies)—as assessed by respondent patient groups [familiar](#) with the company:

- ▶ Roche, 1st
- ▶ Gilead Sciences, 2nd
- ▶ Novartis, 3rd

The top-three global rankings in 2024 (out of 15 'big-pharma' companies)—as assessed by respondent patient groups [working](#) with the company:

- ▶ Gilead Sciences, 1st
- ▶ Roche, 2nd
- ▶ Boehringer Ingelheim, 3rd

The companies rising the most in the [upper](#) rankings (out of all 46 companies), 2024 v. the previous year, 2023 —as assessed by respondent patient groups [familiar](#) with the company

Familiar with

Lundbeck	+12	<div></div>
Servier	+10	<div></div>
UCB	+6	<div></div>
Chiesi	+4	<div></div>
Boehringer Ingelheim	+3	<div></div>
PTC Therapeutics	+3	<div></div>
CSL Behring	+3	<div></div>
Ipsen	+3	<div></div>
Roche	+1	<div></div>
Merck KGaA	+1	<div></div>

The companies rising the most in the [upper](#) rankings (out of all 45 companies), 2024 v. the previous year, 2023, as assessed by respondent patient groups [working](#) with the company

Worked with

Chiesi	+10	<div></div>
Lundbeck	+4	<div></div>
Ipsen	+4	<div></div>
Servier	+3	<div></div>
PTC Therapeutics	+2	<div></div>
Novo Nordisk	+2	<div></div>
Boehringer Ingelheim	+1	<div></div>

## A few of the quotations from 2024's respondent patient groups



*"We believe that the industry is distant from patients. Access and work programs with patients, understanding their journeys, and enabling access to treatment management and information, would be ideal, and a great step forward. Outside of clinical studies, the industry does not understand patients' daily reality during their journeys. And, finally, we understand that the industry's active participation in the associations, which experience the reality of patients seeking help beyond hospitals and clinics, would be extremely important, because more than merely offering technology and quality products, we would strive to provide information, quality of life, and monitoring of the patient's journey."*

### Local breast-cancer patient group, Brazil

*"Involving patients and patient associations in the drug-and treatment-development process is essential to meet their expectations. In 2025, pharmaceutical companies can promote patient engagement in various ways:*

- *Partnerships and co-operation: partnerships with patient associations, clinicians, and researchers help to collect diverse perspectives, and better understand patients' needs. Such co-operation can lead to significant innovations and better solutions.*
- *Education and awareness: informing patient associations of treatment options and scientific progress is crucial to an enlightened decision-making process. Pharmaceutical companies can develop educational programmes and awareness campaigns to help patient associations better understand their condition and available treatments.*
- *Improving healthcare access: making healthcare more accessible is an essential aspect of the patient-centred approach. In 2025, pharmaceutical companies can implement various initiatives to improve healthcare accessibility."*

### Regional respiratory-conditions patient group, Canada

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In the separate supplement accompanying this 'Corporate Reputation of Pharma 2024/25' report, five companies offer their views on the importance of patient groups to them and how they manage partnerships with these groups.. PatientView would like to offer its thanks to these five companies: Boehringer Ingelheim; Gilead Sciences; Novartis; Servier; and ViiV Healthcare.

Finally, PatientView would like to thank the 2,546 patient groups that gave up their time to respond to the latest 'Corporate Reputation of Pharma' survey. 2024/2025's respondent patient groups evaluation of the pharma industry, and their experiences on whether the industry (and individual pharma companies) meet their needs and expectations, should help the industry gain valuable insights into improvement.

END OF PRESS RELEASE

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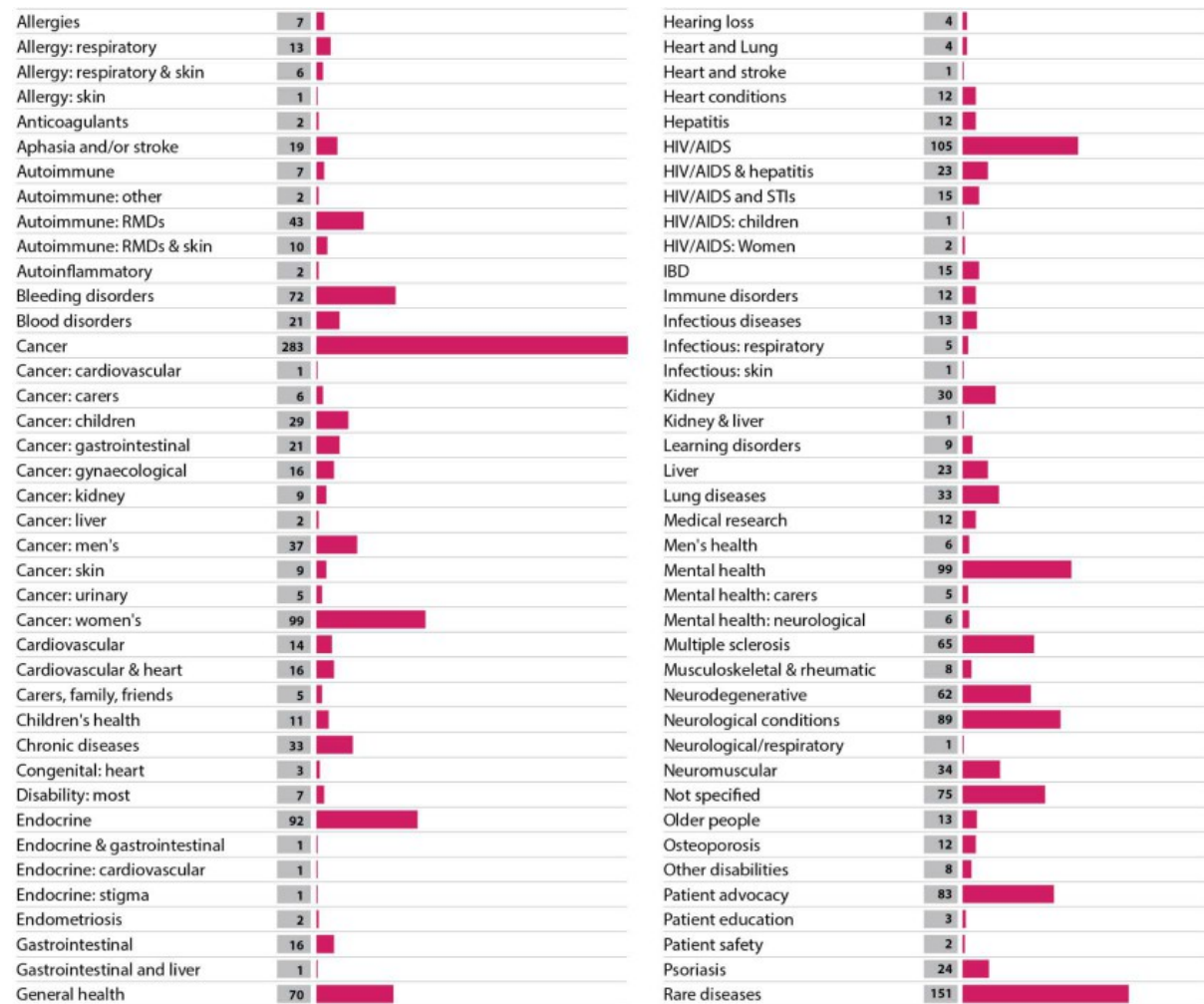
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## APPENDIX to this press release: PROFILE OF 2024's RESPONDENT PATIENT GROUPS

### Therapeutic areas of respondent patient groups

Number of respondent patient groups, N = 2,546

*Respondent patient groups may fall into more than one category of specialty*



*Continued on next page*

Rare diseases: autoinflammatory	1	
Rare diseases: gastrointestinal	1	
Rare: autoimmune	1	
Rare: blood disorders	11	
Rare: bone	11	
Rare: Cardiovascular	3	
Rare: children	5	
Rare: circulatory	1	
Rare: endocrine	27	
Rare: heart	3	
Rare: immune	6	
Rare: kidney	2	
Rare: liver	1	
Rare: neurodegenerative	23	
Rare: neurological	32	
Rare: neuromuscular	32	
Rare: patient advocacy	1	
Rare: respiratory	60	
Rare: skin	7	
Rare: visual	8	
Reproductive health	7	
Respiratory	35	
Rheumatic	61	
Rheumatic: bone	4	
Scleroderma	17	
Sickle cell	5	
Skin conditions	33	
Thrombosis	2	
Thyroid: eye disease	1	
Transplant: heart	2	
Transplant: heart and lung	2	
Transplant: kidney	3	
Transplant: liver	4	
Transplants	8	
Urinary	3	
Vasculitis	3	
Visual impairment	35	
Visual impairment: children	1	
Women's health	10	

## Country headquarters of respondent patient groups

Number of respondent patient groups, N = 2,546

