

# 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/Chuqai Sanofi Sarepta Therapeutics
- Servier Sobi Takeda UCB Vertex Viatris ViiV Healthcare

## 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

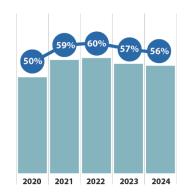
—% of total respondents

%
63
52
44
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37
37
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1

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"



	2023	2024
Biotechnology companies	58	56
Generic drug manufacturers	44	44
Health insurers (for-profit)	17	15
Health insurers (not-for-profit)	24	23
Medical-device companies	43	43
Pharmaceutical companies	57	56
Pharmacy Benefit Managers	15	13
Private-sector healthcare services	34	32
Retail pharmacists	47	48

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 <u>familiar</u> 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 <u>upper</u> rankings (out of all 46 companies), 2024 v. the previous year, 2023 —as assessed by respondent patient groups <u>familiar</u> with the company

# Familiar with Lundbeck +12 Servier +10 UCB +6 Chiesi +4 Boehringer Ingelheim +3 PTC Therapeutics +3 CSL Behring +3 Ipsen +3 Roche +1 Merck KGaA +1

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

Worked with		
Chiesi	+10	
Lundbeck	+4	
lpsen	+4	
Servier	+3	
PTC Therapeutics	+2	
Novo Nordisk	+2	
Boehringer Ingelheim	+1	

## 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

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

## Therapeutic areas of respondent patient groups

Number of respondent patient groups, N = 2,546Respondent patient groups may fall into more than one category of specialty

Allergies	7	Hearing loss	4
Allergy: respiratory	13	Heart and Lung	4
Allergy: respiratory & skin	6	Heart and stroke	1
Allergy: skin	1	Heart conditions	12
Anticoagulants	2	Hepatitis	12
Aphasia and/or stroke	19	HIV/AIDS	105
Autoimmune	7	HIV/AIDS & hepatitis	23
Autoimmune: other	2	HIV/AIDS and STIs	15
Autoimmune: RMDs	43	HIV/AIDS: children	1
Autoimmune: RMDs & skin	10	HIV/AIDS: Women	2
Autoinflammatory	2	IBD	15
Bleeding disorders	72	Immune disorders	12
Blood disorders	21	Infectious diseases	13
Cancer	283	Infectious: respiratory	5
Cancer: cardiovascular	1	Infectious: skin	1
Cancer: carers	6	Kidney	30
Cancer: children	29	Kidney & liver	1
Cancer: gastrointestinal	21	Learning disorders	9
Cancer: gynaecological	16	Liver	23
Cancer: kidney	9	Lung diseases	33
Cancer: liver	2	Medical research	12
Cancer: men's	37	Men's health	6
Cancer: skin	9	Mental health	99
Cancer: urinary	5	Mental health: carers	5
Cancer: women's	99	Mental health: neurological	6
Cardiovascular	14	Multiple sclerosis	65
Cardiovascular & heart	16	Musculoskeletal & rheumatic	8
Carers, family, friends	5	Neurodegenerative	62
Children's health	11	Neurological conditions	89
Chronic diseases	33	Neurological/respiratory	1
Congenital: heart	3	Neuromuscular	34
Disability: most	7	Not specified	75
Endocrine	92	Older people	13
Endocrine & gastrointestinal	1	Osteoporosis	12
Endocrine: cardiovascular	1	Other disabilities	8
Endocrine: stigma	1	Patient advocacy	83
Endometriosis	2	Patient education	3
Gastrointestinal	16	Patient safety	2
Gastrointestinal and liver	1	Psoriasis	24
General health	70	Rare diseases	151

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

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Albania	3	
Algeria	1	
Argentina	35	
Australia	60	
Austria	35	
Bahrain	1	
Belgium	73	
Benin	1	
Bosnia and Herzegovina	1	
Brazil	81	
Bulgaria	8	
Cameroon	1	
Canada	131	
Chile	6	
China	53	
Colombia	31	
Costa Rica	17	
Croatia	17	
Cyprus	9	
Czech Republic	9	_
Democratic Republic of the Congo	2	_
Denmark	50	•
Dominican Republic	4	
Ecuador	3	
Egypt	5	-
El Salvador	3	•
Ethiopia	1	•
Finland	31	<u> </u>
France	97	
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Georgia Germany	137	
Ghana	1	
Greece		·
	49	
Guatemala	8	-
Honduras	4	_
Hong Kong	15	_
Hungary	24	_
India	21	
Iraq	1	<u> </u>
Ireland	33	
Israel	16	
Italy	144	
Ivory Coast	1	<u> </u>
Japan	71	
Jordan	1	
Kenya	7	
Korea	30	
Kosovo	1	
Latvia	4	
Lebanon	2	

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