



WHAT 518 RARE-DISEASE PATIENT GROUPS SAY ABOUT PHARMA IN 2024

Rare-disease edition [12th]

**PRESS RELEASE EMBARGOED until
Tuesday, 23rd September 2025, 6 am GMT**

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London, 23rd September 2025

- These rare-disease findings are based on the results of the 2024 'Corporate Reputation of Pharma' survey of patient groups worldwide, conducted by PatientView, December 2024 to March 2025, and answered by 518 rare-disease patient groups.
- The 518-respondent rare-disease patient groups actively served and supported some 2.8 million patients with rare diseases during the past year.
- 32 pharma companies are featured in the rare-disease results to this 2024 'Corporate Reputation' survey. Eleven new pharma companies were added for the 2024 survey. Five of the 11 new companies are represented in this 2024 rare-disease analysis [blue font, below]. The full list of the 32 featured companies is as follows:

• AbbVie • **Alnylam** • Amgen • Astellas Pharma • AstraZeneca • Bayer • Biogen • BioMarin • Boehringer Ingelheim • Bristol Myers Squibb • Chiesi Farmaceutici • CSL • Eli Lilly • GSK • Ipsen • J&J Innovative Medicine • Merck & Co • Merck KGaA • Novartis • Novo Nordisk • Pfizer • PTC Therapeutics • **Recordati** • **Regeneron** • Roche • Sanofi • Sarepta Therapeutics • **Sobi** • Takeda • UCB • Vertex • **Viatis**.

Why pharma needs to work closely and efficiently with rare-disease patient groups

At the end of 2024, PatientView documented the activities of patient groups, and their contributions to healthcare systems worldwide, in a study entitled *Patients in Action*. The study also captured the evolving relationship between patient groups and other healthcare stakeholders (including the pharmaceutical industry).

For the *Patients in Action* study, data were gathered from 1,144 patient groups globally (including 157 rare-disease patient groups). The findings from the study show that rare-disease patient groups are now considered core health influencers, with views respected by most, if not all, healthcare stakeholders. Whether operating internationally, regionally, nationally, or locally, rare-disease patient groups are seen from the study results to be taking on expanded roles in advocacy, healthcare provision, patient education, and medical research. This context creates an imperative for the pharmaceutical sector, since regulatory bodies increasingly expect evidence of patient engagement throughout the product lifecycle.

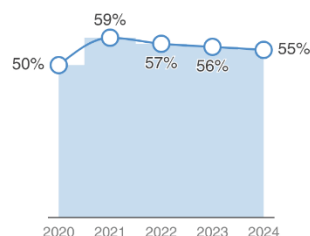
Rare-disease patient groups see the pharma industry's corporate reputation declining slightly since its peak in 2021

PatientView defines a good corporate reputation for a pharma company as that company meeting patient-group priorities. When pharma companies address patient-group priorities, their reputations improve.

The rare-disease patient groups responding to the 2024 'Corporate Reputation of Pharma' survey consider the corporate reputation of the pharma industry as a whole to have slipped marginally since peaking in 2021 (during the Covid pandemic)—when as many as 59% of the rare-disease patient groups responding to the 'Corporate Reputation' survey of that year rated pharma's reputation as "Excellent" or "Good". In 2024, 55% of the respondent rare-disease patient groups rated pharma's reputation as "Excellent" or "Good".

The corporate reputation of the pharma industry, 2020-2024
—according to respondent rare-disease patient groups

% of respondent rare-disease 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 rare-disease patient groups stating "Excellent" or "Good"

The corporate reputation of the pharma industry, compared with that of other healthcare sectors, 2024 v. 2023—according to respondent rare-disease patient groups

% of respondent rare-disease patient groups, per year, stating "Excellent" or "Good"

	2024	2023
Biotechnology companies	59	62
Generic drug manufacturers	40	39
Health insurers (for-profit)	14	12
Health insurers (not-for-profit)	22	22
Medical-device companies	40	37
Pharmaceutical companies	55	56
Pharmacy Benefit Managers	13	14
Private-sector healthcare services	32	30
Retail pharmacists	42	41

	2020 — 2024	Diff
Patient centricity	42 — 46	+4
Information	47 — 50	+3
Ensuring patient safety	52 — 58	+6
Innovation	51 — 57	+6
Products that benefit patients	53 — 61	+8
Transparency: pricing	17 — 16	-1
Transparency: clinical data	28 — 32	+4
Transparency: funding	22 — 32	+10
Integrity	41 — 49	+8
Patient-group relations	48 — 54	+6
Services 'beyond the pill'	36 — 42	+6
Fair pricing policies	9 — 14	+5
Engaging patients in R&D	26 — 28	+3
Access to medicines	28 — 32	+3

Over half of the rare-disease patient groups responding to the 2024 'Corporate Reputation' survey believe the September 2025

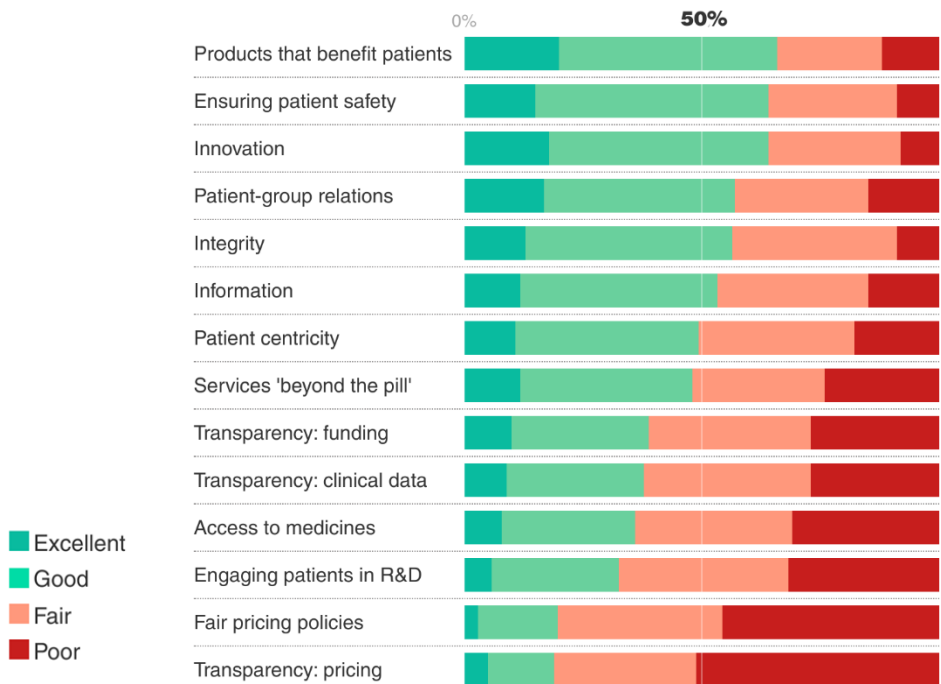
pharma industry to be successful at a number of activities important to patient groups, including:

- providing products of benefit to patients;
- patient safety;
- innovation;
- patient-group relations; and
- the provision of patient information.

However, 2024’s respondent rare-disease patient groups also regard the industry as just “Fair”, or even “Poor”, at a number of other activities of importance to rare-disease patients and patient groups [see chart, below]—particularly the industry’s approach to pricing policies. On the other hand, respondent rare-disease patient groups do also report improvements in most of these latter activities since 2020.

How good or bad the pharma industry was at carrying out specific activities of importance to rare-disease patients and patient groups, 2024

% of respondent rare-disease patient groups [excluding those answering “Do not know”]. N = 518



Feedback from 2024’s respondent rare-disease patient groups outlines dissatisfactions about the quality of their partnerships with pharma companies.

“Be close to patient representatives, and be transparent about products. Work in partnership, to achieve results, so that patients truly have quality of life—and don’t just look for profit. The company must focus on the patient.”
National rare-disease patient group, Brazil

“Pharmaceutical companies should prioritize genuine patient engagement, by incorporating patient voices into drug development, increasing transparency in pricing and access, expanding support programs for rare, and chronic-disease, communities, and streamlining clinical-trial participation, to ensure diverse and inclusive representation.”
National rare-diseases patient group, USA

Corporate reputation in rare diseases for individual pharma companies, 2024

Featured pharma companies were ranked by 2024’s respondent rare-disease patient groups for 10 indicators of corporate reputation [see Appendix]. Rankings at overall corporate reputation for the top-three pharma companies are shown below.

ALL COMPANIES

The top-three rankings for overall corporate reputation in rare diseases, 2024 (out of all 32 companies)
—as assessed by respondent rare-disease patient groups [familiar](#) with the company:

- ▶ Sobi, 1st
- ▶ Roche, 2nd
- ▶ BioMarin, 3rd

The top-three rankings for overall corporate reputation in rare diseases, 2024 (out of 31 companies)
—as assessed by respondent rare-disease patient groups [working](#) with the company:

- ▶ Sobi, 1st
- ▶ Roche, 2nd
- ▶ UCB, 3rd

BIG PHARMA

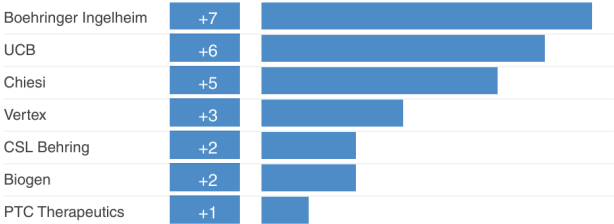
The top-three rankings for overall corporate reputation in rare diseases, 2024 (out of 14 ‘big-pharma’ companies)
—as assessed by respondent rare-disease patient groups [familiar](#) with the company:

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

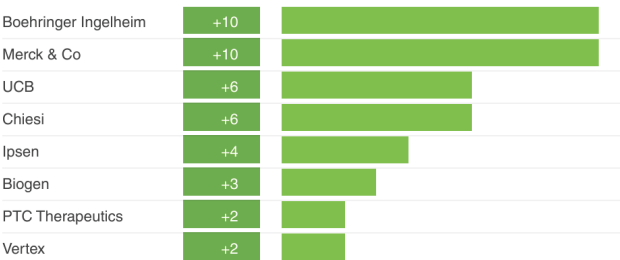
The top-three rankings for overall corporate reputation in rare diseases, 2024 (out of 13 ‘big-pharma’ companies)
—as assessed by respondent rare-disease patient groups [working](#) with the company:

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

Risers in the [upper](#) rankings:
The companies rising the most for corporate reputation in rare diseases (out of all 32 companies), 2024 v. the previous year, 2023
—as assessed by respondent rare-disease patient groups [familiar](#) with the company



Risers in the [upper](#) rankings:
The companies rising the most for corporate reputation in rare diseases (out of 31 companies), 2024 v. the previous year, 2023
—as assessed by respondent rare-disease patient groups [working](#) with the company



PatientView would like to thank the 518 rare-disease patient groups that gave up their time to respond to the 2024 'Corporate Reputation of Pharma' survey. Their evaluation of the pharma industry, and their experiences of whether the industry (and individual pharma companies) meet their needs and expectations, should help the industry gain valuable insights into improvement.

The Appendix below lists: the 10 indicators of corporate reputation; the numbers of 2024's respondent rare-disease patient groups that stated a working relationship with any of the 32 featured pharma companies; plus the countries of domicile, and the specialties, of the 518 respondent rare-disease patient groups.

END OF PRESS RELEASE

For further information, please contact Alex Wyke, PatientView CEO, on the email address at the top of this press release.

APPENDIX to this press release:

10 indicators of corporate reputation—as defined by patient groups



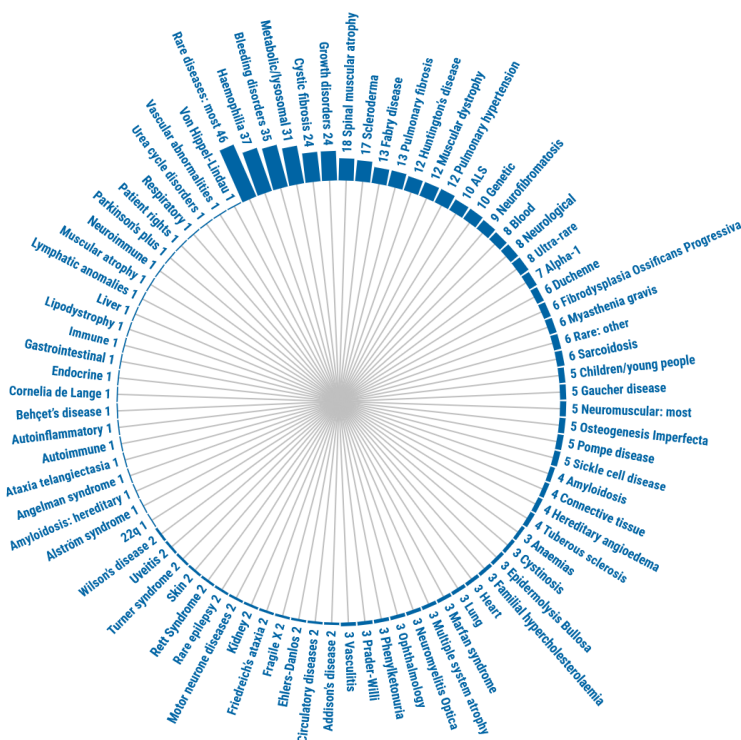
Respondent rare-disease patient groups working with pharma, 2024

Total number of 2024's respondent rare-disease patient groups = 518

AbbVie	23	Merck & Co	34
Alnylam	22	Merck KGaA	17
Amgen	55	Novartis	102
Astellas	16	Novo Nordisk	88
AstraZeneca	95	Pfizer	153
Bayer	70	PTC	45
Biogen	61	Recordati	27
BioMarin	109	Regeneron	18
Boehringer Ingelheim	56	Roche	185
Bristol Myers Squibb	16	Sanofi	138
Chiesi	56	Sarepta	21
CSL	79	Sobi	56
Eli Lilly	13	Takeda	147
GSK	38	UCB	22
Ipsen	22	Vertex	38
J&J Innovative Medicine	49	Viartis	16

Therapeutic areas of all respondent rare-disease patient groups, 2024

Total number of 2024's respondent rare-disease patient groups = 518



Country headquarters of all respondent rare-disease patient groups, 2025

