

WHAT 339 NEUROLOGY PATIENT GROUPS SAY ABOUT PHARMA IN 2023-24

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Overview

PatientView is pleased to publish 'The Corporate Reputation of Pharma—from the Perspective of Neurology Patient Groups, 2023' (the 11th neurology edition in the annual 'Corporate Reputation' series). The 2023 neurology review contains the results of a November 2023 to late-February 2024 survey, answered by 339 neurology patient groups.

2023's 339 respondent neurology patient groups are drawn from multiple neurological therapy areas—the largest representation being 62 respondent multiple-sclerosis patient groups (note that PatientView is also publishing a separate report dedicated solely to 2023's multiple-sclerosis results). The 339 stated that, collectively, and around the world, they had actively supported and served just over 3 million patients with neurological conditions. A profile of the respondent neurology patient groups can be found at the end of this press release.

Continue reading, for details about ...

- ▶ The headline industry-wide neurology results of the 2023 survey.
- ▶ The performance at corporate reputation of the top pharma companies included in the 2023 neurology analysis.

Companies featured in the neurology edition of the 2023 survey results
22 companies are included in the neurology edition of the 2023 'Corporate Reputation of Pharma' survey results. The companies were selected on the following criteria: size of revenue; or on request by companies or patient groups:

• AbbVie • Amgen (including Horizon Therapeutics) • AstraZeneca • Bayer • Biogen • Bristol Myers Squibb • Chiesi Farmaceutici (including Amyrt Pharma) • Eisai • Eli Lilly • GSK • Ipsen • Janssen (known as Johnson & Johnson Innovative Medicine from late 2023 onwards) • Lundbeck • Merck KGaA / EMD Serono • Novartis • Pfizer • PTC Therapeutics • Roche / Genentech / Chugai • Sanofi • Sarepta Therapeutics • Takeda • UCB.

SUMMARY OF RESULTS

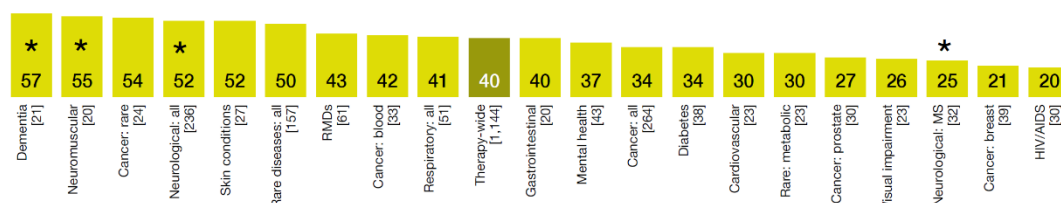
Issues influencing the opinions of neurology patient groups in 2023

A separate study by PatientView, entitled ‘*Patients in Action*’, published in October 2024, has explored how patient groups (including those specialising in neurological conditions) view their roles in their country’s healthcare sector.¹ PatientView compared the results from neurology patient groups responding to the 2024 ‘*Patients in Action*’ survey with the results from respondent peers across 19 other disease areas—allowing patient-group responses from any therapy area to be put into context.

Some 75% of the neurology patient groups responding to the ‘*Patients in Action*’ survey believed that pharma sees them as an essential healthcare stakeholder (at least some of the time). However, only half thought that they could exert influence on drug research and drug development (clinical trials, and real-world evidence generation)—compared with 69% of blood-cancer patient groups, and 70% of cardiovascular-conditions patient groups, saying the same.

One reason why neurology patient groups may feel less influential over pharma activities than other types of patient groups is that most neurology patient groups (52%) believe investment into treating disorders of the nervous system to be inadequate. Equivalent percentages for neurology patient groups specialising in dementia, and neuromuscular conditions, are 57% and 55%, respectively (the highest percentages from patient groups of any therapeutic area). The one exception was patient groups specialising in multiple sclerosis, for which the equivalent figure was just 25%. When the respondent neurology patient groups were asked what kinds of support they needed to fulfil their goals, top of the list were improvements in: access to care; patient pathways; and the quality of care.

Percentage of types of respondent patient groups pointing to a lack of research investment in their therapy area, 2024



Source: ‘*Patients in Action*’, PatientView, 2024

Work by the World Health Organization supports these PatientView findings. Member states at the World Health Assembly in 2022 adopted an ‘*Inter-sectoral Global Action Plan*’ (IGAP) on epilepsy (and other neurological disorders), 2022-2031, putting forward “an ambitious scope to address the long-standing neglect of neurological disorders”.²

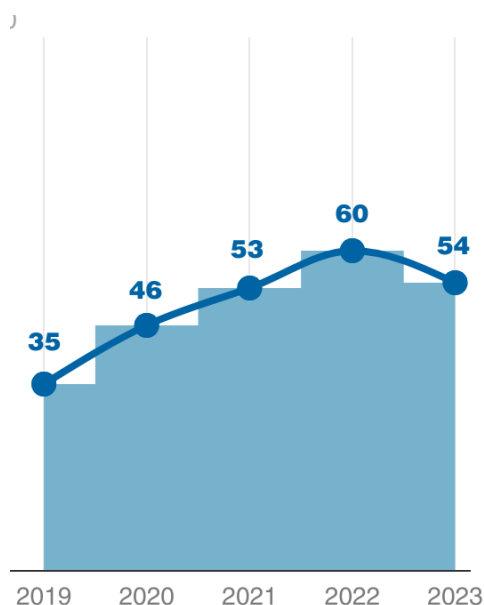
¹ ‘*Patients in Action: Understanding, and Supporting, the Roles Played by Patient Groups in Healthcare*’, PatientView, October 2024.

² ‘*Global, regional, and national burden of disorders affecting the nervous system, 1990-2021: a systematic analysis for the ‘Global Burden of Disease Study’, 2021.*

INDUSTRY-WIDE NEUROLOGY RESULTS:

54% of the 339 neurology patient groups responding to the 2023 ‘Corporate Reputation of Pharma’ survey rated the pharma industry’s reputation “Excellent” or “Good” (slightly lower than 2023’s therapy-wide figure of 57%). The majority of 2023’s respondent neurology patient groups were positive in their rating of pharma’s performance at two important activities: ‘providing products of benefit to patients’, and ‘innovation’—56% and 55%, respectively, describing the industry’s effectiveness at these as “Excellent” or “Good”. However, 2023’s equivalent therapy-wide figures were higher, at 63% and 59%.

The corporate reputation of the pharma industry, 2019-2023—according to neurology patient groups
Percentage of respondent neurology patient groups, per year, stating “Excellent” or “Good”



How good or bad the pharma industry was at carrying out specific activities in the field of neurology, 2023 v. 2022
% of respondent neurology patient groups, per year, stating “Excellent” or “Good”

	2023	Versus 2022
Patient centricity	42	+1
Information	42	-2
Ensuring patient safety	53	+2
Innovation	55	-2
Products that benefit patients	56	-6
Transparency: pricing	16	±0
Transparency: clinical data	23	-4
Transparency: funding	29	-2
Integrity	47	+3
Patient-group relations	51	+6
Services 'beyond the pill'	32	+3
Fair pricing policies	11	+3
Engaging patients in R&D	24	+3
Access to medicines	28	+4

Moving Forward: advice from neurology patient groups on how pharma can improve

The 339 neurology patient groups responding to the 2023 ‘Corporate Reputation of Pharma’ survey provided 791 commentaries on how pharma could improve. A thematic analysis of this qualitative feedback generates advice on strategic direction for pharma companies that focus on neurological conditions.

The table below indicates the percentage of the commentaries dedicated to each of the ten indicators of corporate reputation. The highest percentage of commentaries from respondent neurology patient groups on any single indicator of corporate reputation, 16%, emphasised that pharma should improve its patient-group relations.

Thematic analysis of neurology patient-group commentaries

Neurology patient groups highlight the indicators of corporate reputation at which the pharma industry most needs to improve.

INDICATOR #	CORPORATE REPUTATION INDICATOR	% OF TOTAL COMMENTS
1	Patient centricity	6%
2	Patient information	13%
3	Patient safety	6%
4	Products of benefit to patients	7%
5	Transparency	12%
6	Integrity	7%
7	Patient-group relations	16%
8	Services 'beyond the pill'	7%
9	Engaging patients in R&D	10%
10	Access to medicines	16%

What do patient groups mean when they say “improve patient-group relations”?

Chiefly, they mean that ...

- Companies need to have an efficient process to map (and select) patient groups with which to work.
- The relationship that companies build with their patient-group partners needs to be long term.
- Companies wishing to work with patient groups should be able to demonstrate good governance to potential partners. And ...
- Companies should work at developing direct insight into the real, lived experience of individual patients—in this case, patients with a neurological condition.



“By being honest in their dealings with me—and by developing [a] relationship with us, an advocacy group that represents 3.4 million Australians.”

—National neurological-conditions patient group, Australia

“I think that they should build a closer relationship with patients and patient associations, in order to gain an insight into their needs. The pharmaceutical industry has not yet grasped the fact that patients now make a choice to use a particular medicine. When they refuse to use a certain medicine, they switch to another.”

—Regional neurological-conditions patient group, Brazil

“Involvement from the start. Clear agreements in place about expectations, and remuneration for time.”

—National neurological-conditions patient group, UK

FINDINGS FOR INDIVIDUAL COMPANIES, 2023 v. 2022

The ten indicators used to measure companies' corporate reputation, from a patient perspective



The top-three rankings for corporate reputation in the field of neurological conditions in 2023 (out of all 22 companies)—as assessed by respondent neurology patient groups **familiar** with the company:

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

The top-three rankings for corporate reputation in the field of neurological conditions in 2023 (out of 19 companies)—as assessed by respondent neurology patient groups **working** with the company:

- ▶ 1st, Roche
- ▶ 2nd, UCB
- ▶ = 3rd, Novartis
- ▶ = 3rd, Sanofi.

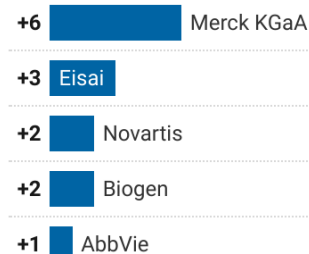
The top-three rankings for corporate reputation in the field of neurological conditions in 2023 (out of 12 'big-pharma' companies)—as assessed by respondent neurology patient groups **familiar** with the company:

- ▶ 1st, Roche
- ▶ 2nd, Novartis
- ▶ 3rd, Sanofi

The top-three rankings for corporate reputation in the field of neurological conditions in 2023 (out of 12 'big-pharma' companies)—as assessed by respondent neurology patient groups **working** with the company:

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The companies rising the most in the **upper** rankings for corporate reputation in the field of neurological conditions, 2023 v. 2022 (out of all 22 companies)—as assessed by respondent neurology patient groups **familiar** with the company



The companies rising the most in the **upper** rankings for corporate reputation in the field of neurological conditions, 2023 v. 2022 (out of 19 companies)—as assessed by respondent neurology patient groups **working** with the company



Finally, PatientView would like to thank the 339 neurology patient groups that gave up their **time to respond to the 2023 'Corporate Reputation of Pharma' survey.**

The respondent neurology patient groups feel that the sharing of their evaluation and experiences on whether the pharma industry (and individual pharma companies) meets patient needs and expectations will help the industry gain valuable insights into improvement.

Because the 22 pharma companies featured in the 2023 'Corporate Reputation of Pharma' neurology edition are currently building strategies around patients, the respondent feedback provided by the survey results can influence company models and approaches, enabling closer alignment with patient needs and perspectives.

For further information on this report, please use contact details below.

END OF PRESS RELEASE

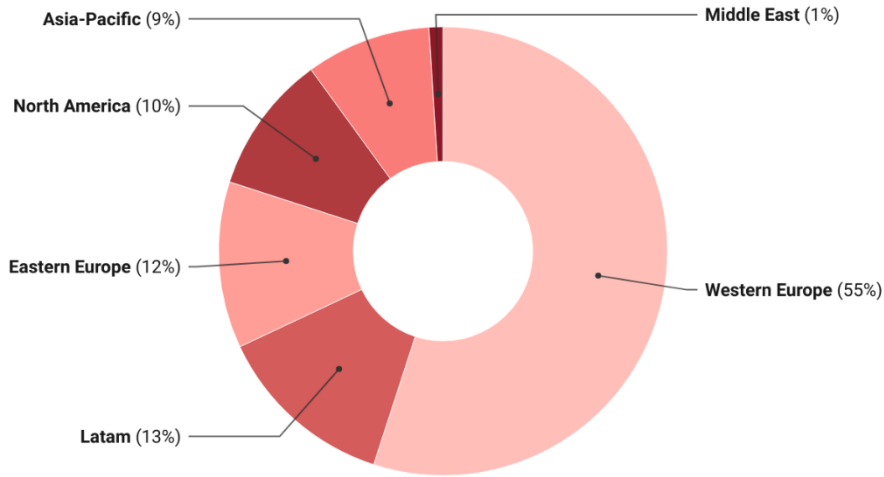
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Appendices

Profile of respondent neurology patient groups, 2023—by geographic region of headquarters
Percentage of respondent neurology patient groups



Profile of respondent neurology patient groups, 2023—by specialty
Number of respondent neurology patient groups

