

## How PatientView measures pharma's corporate reputation from a patient perspective

PatientView's annual 'Corporate Reputation of Pharma' survey measures various aspects of pharma's performance—all from a patient and patient-group perspective.

The survey is financially independent (funded solely by PatientView) and offers respondent patient groups full anonymity (if they wish). The survey results, therefore, are highly likely to reflect honest, true, respondent feedback.

In this latest survey:

☑ The question on Covid-19 that featured in the 2020 and 2021 'Corporate Reputation' surveys has been removed for the 2022 survey.

☑ The Covid-19 pandemic threw into sharp relief existing long-term global (and even national) inequities facing patients who wish to gain **access to medicines**. So, the 2022 survey includes a new indicator on access to medicines (with 'equitable access' defined as 'access for more patients').

## The 10 indicators by which patient groups assess pharma's corporate reputation, 2022



NEUROLOGY edition

# WHAT 286 NEUROLOGY PATIENT GROUPS SAY ABOUT PHARMA IN 2022— The Patient Perspective

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London, October 16<sup>th</sup> 2023

In the last report resulting from PatientView's 2022 'Corporate Reputation of Pharma' survey, we are today publishing the results of feedback received from neurological patient groups (the 10th neurology edition in the annual 'Corporate Reputation' series). Between November 2022-February 2023, the survey collected the opinions of 286 neurology patient groups on the performance of the pharmaceutical industry during 2022.

Patient groups responding to 2022's 'Corporate Reputation of Pharma' survey are uniquely positioned to comment on the pharma industry, and individual pharma companies, as they understand the experiences of patients, and they also network with all other stakeholders in the healthcare system.

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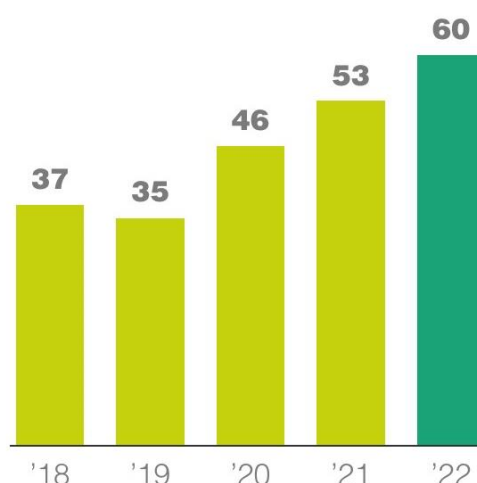
▶ **The headline neurology results of the 2022 survey.**

▶ **The 21 pharma companies included in the 2022 neurology analysis.**

# NEUROLOGY RESULTS

## ► The corporate reputation of the pharma industry, according to respondent neurology patient groups, 2018-2022

% of respondent neurology patient groups, per year, stating "Excellent" or "Good"



### ► Industry wide

The pharma industry has steadily improved its corporate reputation among neurology patient groups over the past five years:

- In 2019, only 35% of respondent neurology patient groups rated pharma's corporate reputation as "Excellent" or "Good." By 2022, the figure saying the same had reached 60%.
- 2022's respondent neurology patient groups are most positive about the industry's ability to provide products beneficial to neurology patients—with 62% describing the industry's performance here as "Excellent" or "Good" (versus 47% saying the same in 2018).

However, the pharma industry scored lower in 2022 for other activities important to respondent neurology patient groups:

- Only 27% of 2022's respondent neurology patient groups see pharma as "Excellent" or "Good" at sharing clinical data.
- Just 21% state the same about the industry's engagement of patients in its R&D processes.
- Only 15% of 2022's respondent neurology patient groups regard pharma as "Excellent" or "Good" at having transparent pricing policies.
- And just 8% think the industry "Excellent" or "Good" at having fair pricing policies.

### Key issues

Breakthrough advances in neurological research have become imperative, since neurological diseases impact heavily on patients, carers, and healthcare systems alike. According to the World Health Organization's 'Global Burden of Disease' study (2019), neurological disorders are the leading cause of physical and cognitive disability across the globe, affecting approximately 15% of the population worldwide.<sup>1</sup> The WHO study also noted year-on-year increases in the number of people

### ► How good or bad the pharma industry was at carrying out specific activities, neurology, 2022

% of respondent neurology patient groups stating "Excellent" or "Good"

Figures just for 2022	
Products that benefit patients	62
Innovation	57
Ensuring patient safety	51
Patient-group relations	45
Information	43
Integrity	43
Patient centricity	41
Transparency: funding	31
Services 'beyond the pill'	29
Transparency: clinical data	27
Access to medicines	24
Engaging patients in R&D	21
Transparency: pricing	15
Fair pricing policies	8

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9945815/>

affected with neurological conditions, with the biggest rises being seen for dementias and Parkinson's disease—due to growing populations and ageing societies.<sup>2</sup> Yet research in the area of neurological conditions has been made challenging by the complexity of the disease progression, and the difficulties that drug treatments find in passing through the blood-brain barrier. Research in the field of neurology has been littered with disappointments.<sup>3</sup>

However, progress has been made possible in the past few years thanks to a new, heightened understanding of neurological diseases by science. The US Food and Drug Administration (FDA) has approved an increasing number of neurodegenerative treatments (the peak annual total, eight, being during 2020-2021). The FDA states that the majority of these approvals are for the treatment of multiple sclerosis and Parkinson's. Additionally, the agency has approved several treatments for rare neurological diseases (such as ALS and SMA).<sup>4</sup>

Rather than standing by on the side lines of neurological research, patients with a neurological condition, and neurological patient groups, are eager to engage in pharma's neurological R&D, and have been playing an active part in promoting research in the field. Yet, the neurological results of the 2022 'Corporate Reputation' survey indicate that most pharma companies with a neurological portfolio have yet to embrace patients and patient groups in their neurology R&D. Nor, according to 2022's respondent neurology patient groups, does the industry actively share its neurology clinical-trial data with neurology patient groups.



These sentiments were underscored in the feedback provided by 2022's respondent neurology patient groups:

“Vi må inkluderes fra innspill- og idéstadiet, ikke bare som forskningskaniner i kliniske studier.”

[“We must be included from the input and ideas stage—not just as ‘lab rats’ in clinical studies.”]

—**National neuromuscular-conditions patient group, Norway**

“Holding patient-and-carer focus groups. Talking to patient-representative groups. Using the healthcare professionals to understand the main issues affecting people with a particular condition.”

—**National neurological-conditions patient group, UK**

“Include patient organizations in determining protocols, and in inclusion-and-exclusion criteria. Also, help in determining clinical-trial sites' requirements, to ease the burden of entering the study.”

—**International migraine/headache patient group, USA**

### ► Individual company results

The 21 companies assessed in the neurology element of the 2022 'Corporate Reputation of Pharma' survey were:

• AbbVie • AstraZeneca • Bayer • Biogen • Bristol Myers Squibb • Eisai • Eli Lilly • GSK • Horizon Therapeutics • Ipsen • Janssen • Lundbeck • Merck KGaA/EMD Serono • Novartis • Pfizer • PTC Therapeutics • Roche/Genentech/Chugai • Sanofi • Sarepta Therapeutics • Takeda • UCB

<sup>2</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9745318/>

<sup>3</sup> <https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/trc2.12330>; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8676526/>

<sup>4</sup> <https://www.belfercenter.org/publication/understanding-how-policy-affects-neurodegenerative-disease-drug-development>

## The three companies ranking top for corporate reputation in the field of neurology, 2022

### Out of all 21 companies

→ As assessed by respondent neurology patient groups *familiar* with the company

**1st: Roche**  
**2nd: UCB**  
**3rd: Lundbeck**

### Out of 18 companies

→ As assessed by respondent neurology patient groups *working* with the company

**1st: Roche**  
**2nd: Horizon Therapeutics**  
**3rd: Takeda**

### Out of 11 'big-pharma' companies

→ As assessed by respondent neurology patient groups *familiar* with the company

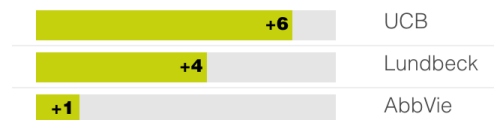
**1st: Roche**  
**2nd: Novartis**  
**3rd: Sanofi**

### Out of 11 'big-pharma' companies

→ As assessed by respondent neurology patient groups *working* with the company

**1st: Roche**  
**2nd: AstraZeneca**  
**3rd: Novartis**

▶ The companies rising the most in the upper part of the neurology rankings (out of all 21 companies), 2021 to 2022, as assessed by respondent neurology patient groups *familiar* with the company



▶ The companies rising the most in the upper part of the neurology rankings (out of 18 companies), 2021 to 2022, as assessed by respondent neurology patient groups *working* with the company



Note: PatientView has also undertaken a separate analysis of 2022's 'Corporate Reputation' neurology results in the field of one specific neurological condition—multiple sclerosis. Of the 9 companies assessed for corporate reputation in this multiple-sclerosis analysis, Roche was found to rank 1st for overall corporate reputation in the field of multiple sclerosis in 2022, as assessed both by MS patient groups *familiar*, and by those *working*, with the company.

The 9 companies included in 2022's multiple-sclerosis analyses were:

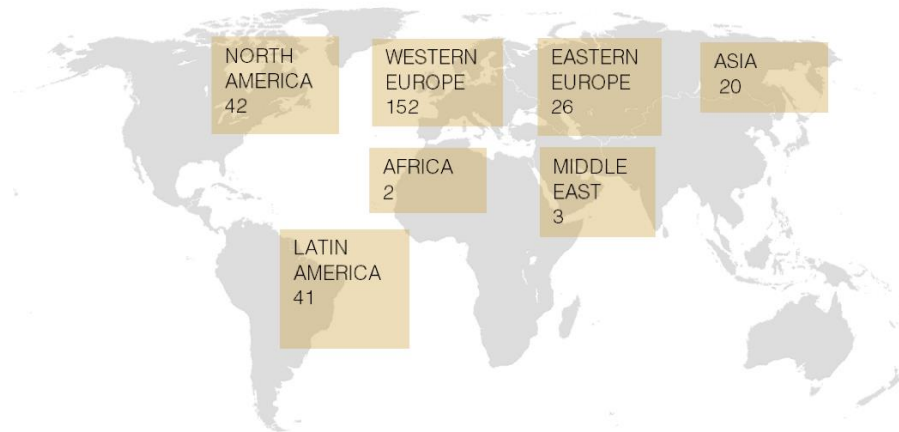
• Bayer • Biogen • Bristol Myers Squibb • Janssen • Merck KGaA/EMD Sero • Novartis • Pfizer • Roche/Genentech/Chugai • Sanofi

# PROFILES OF RESPONDENTS

286 neurology patient groups responded to the neurology element of the 2022 ‘Corporate Reputation of Pharma’ survey. The respondent neurology patient groups stated that they had reached out to approximately some 3.5 million patients with neurology conditions during 2022.

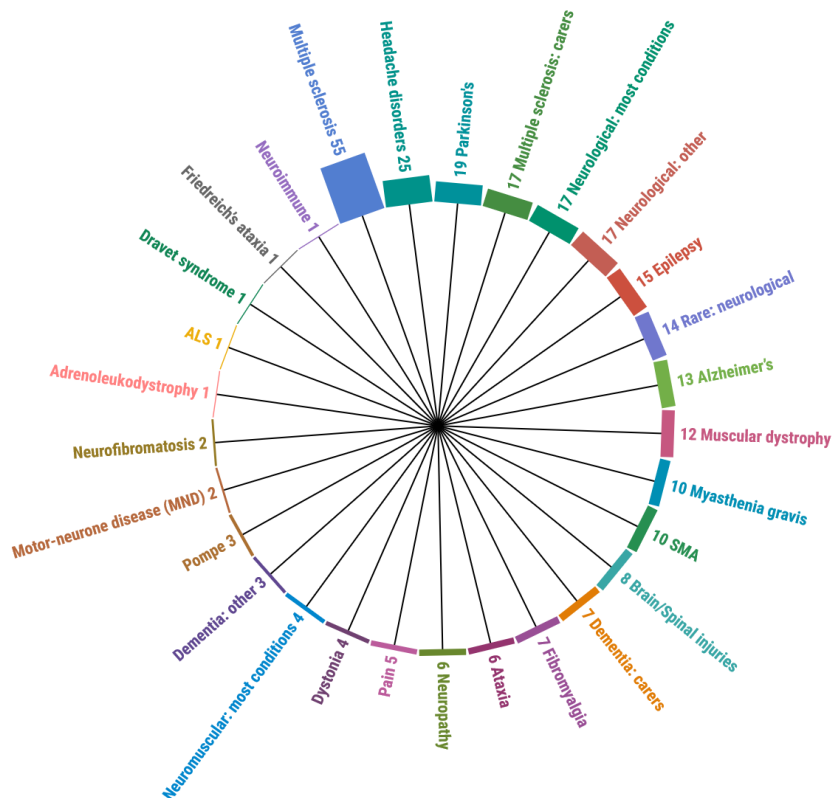
► **Regional headquarters of 2022’s respondent neurology patient groups**

Number of respondent neurology patient groups



► **Specialities of 2022’s respondent neurology patient groups**

Number of respondent neurology patient groups



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**Finally, PatientView would like to thank the 286 neurology patient groups that gave up their time to respond to the 2022 ‘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 many of the 21 pharma companies featured in the neurology element of the 2022 ‘Corporate Reputation of Pharma’ survey 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 neurology report, please use contact details at the head of the press release (or below).

**END OF PRESS RELEASE**

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