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

RARE-DISEASE edition

WHAT 426 RARE-DISEASE PATIENT GROUPS SAY ABOUT PHARMA IN 2022—The Patient Perspective

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PatientView is today publishing the rare-disease results of the latest 'Corporate Reputation of Pharma' survey, (the 4th rare-disease edition in the annual 'Corporate Reputation' series). Between November 2022-February 2023, the survey collected the opinions of 426 rare-disease 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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RARE-DISEASE RESULTS

Industry wide

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

- In 2018, only 33% of rare-disease patient groups rated the industry's corporate reputation as "Excellent" or "Good." By 2022, the figure saying the same had reached 57%.
- 2022's respondent rare-disease patient groups are most positive about the industry's ability to provide products beneficial to rare-disease patients—with 63% describing the industry's performance here as "Excellent" or "Good" (versus 51% saying the same in 2018).

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

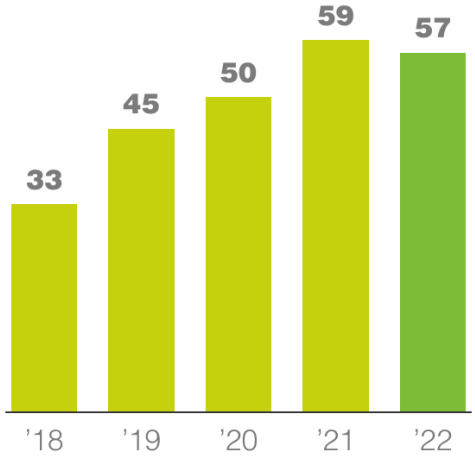
- Only 11% of 2022's respondent rare-disease patient groups see pharma as "Excellent" or "Good" at having fair pricing policies.
- And just 32% state the same about the industry's ability to help rare-disease patients gain access to medicines.

Key issues

By 2022, most larger pharma companies had come to invest over 50% of their R&D budgets in rare diseases.[1] Companies have been galvanised by scientific breakthroughs in rare-disease biotechnology, and also by the potential that artificial intelligence (AI) offers to rare-disease research.[2] According to industry data, 700 rare-disease medicines were moving through the biopharma pipeline in 2022, with gene therapy one of the key research platforms.[3]

The corporate reputation of the pharma industry, according to respondent rare-disease patient groups, 2018-2022

% 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, rare disease, 2022

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

Figures just for 2022	
Products that benefit patients	63
Innovation	58
Ensuring patient safety	56
Patient-group relations	55
Information	47
Patient centricity	45
Integrity	44
Services 'beyond the pill'	39
Access to medicines	32
Transparency: funding	29
Engaging patients in R&D	28
Transparency: clinical data	28
Transparency: pricing	18
Fair pricing policies	11

[1] https://www.fiercebiotech.com/biotech/top-10-pharma-rd-budgets-2022
[2] https://healthcare-digital.com/technology-and-ai/rare-disease-day-bruce-bloom-of-healx-on-technology-ai
[3] https://www.pharmavoice.com/news/rare-disease-market-orphan-drug-pharma/642983/

However, as any rare-disease patient community is, by definition, small in number, output from rare-disease R&D always bears a hefty price tag. The latest gene therapy for haemophilia B, for instance, was approved in the US in November 2022 at a price of approximately $3.5 million (comprising a one-off treatment per patient)—making it the most-expensive drug in the world, and effectively putting the therapy beyond the budgets of most healthcare systems, and out of reach of patients[4] (even when bearing in mind that the costs of the existing management of haemophilia B are also very high).

Large cross-stakeholder collaborations, such as the US-based Accelerating Medicines Partnership (AMC)'s Bespoke Gene Therapy Consortium (BGTC)[5], are examining ways of streamlining, and reducing the costs of, rare-disease R&D. In the meantime, however, rare-disease patients, while encouraged by the rapid pace of innovation, remain disappointed by their inability to benefit from important breakthroughs (as many of the respondents to this 2022 survey noted).

Rare-disease patient groups responding to the 2022 'Corporate Reputation' survey provided considerable written feedback, frequently commenting on the difficulty of balancing the need for new rare-disease products with the challenge of delivering them at prices affordable to patients and healthcare systems (yet remaining attractive enough to encourage industry to keep innovating). For example:

"Engage a wider cross section of the 'rare-diseases' community/groups, and be prepared to invest in novel drugs that benefit even the smallest rare-disease populations. They deserve access to drugs and therapeutics—and, in fact, proportionally have 'higher need'."
—National rare-disease patient group, Australia

"Acompañar más allá de la venta de los medicamentos. Con los medicamentos no aprobados en Chile, somos los padres los que tenemos que movernos y conocer el proceso para importar medicamentos, no se ve mucho acompañamiento del laboratorio."

["Assist beyond the sale of the medicines. In the case of medicines not approved in Chile, we parents are the ones who have to take action, and learn about the process to import medicines. There isn't much assistance from the company."]
—National rare-disease patient group, Chile

"Price adjustments for poorer countries."
—National rare-disease patient group, South Africa

Individual company results

The 34 companies assessed in the rare-disease element of the 2022 'Corporate Reputation of Pharma' survey were:

• AbbVie • Amgen • Astellas • AstraZeneca • Bayer • Biogen • Biomarin • Boehringer Ingelheim • Bristol Myers Squibb • Chiesi Farmaceutici • CSL Behring • Daiichi Sankyo • Eli Lilly • Gilead Sciences • Grifols • GSK • Horizon Therapeutics • Ipsen • Janssen • Lundbeck • Merck & Co/MSD • Merck KGaA/EMD Serono • Novartis • Novo Nordisk • Octapharma • Otsuka • Pfizer • PTC Therapeutics • Roche/Chugai/Genentech • Sanofi • Sarepta Therapeutics • Takeda • UCB • Vertex

* Merck & Co is known as MSD outside of Canada and the USA.
* Roche is known as Genentech in the USA, and as Chugai in Japan.

[4] https://edition.cnn.com/2022/11/23/health/hemophilia-drug-hemgenix/index.html
[5] https://www.nih.gov/research-training/accelerating-medicines-partnership-amp/bespoke-gene-therapy-consortium

The three companies ranking top for corporate reputation in the field of rare diseases, 2022

Out of all 34 companies

➔ As assessed by respondent rare-disease patient groups *familiar* with the company

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

Out of 31 companies

➔ As assessed by respondent rare-disease patient groups *working* with the company

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

Out of 15 'big-pharma' companies

➔ As assessed by respondent rare-disease patient groups *familiar* with the company

1st: Roche
2nd: Takeda
3rd: Pfizer

Out of 15 'big-pharma' companies

➔ As assessed by respondent rare-disease patient groups *working* with the company

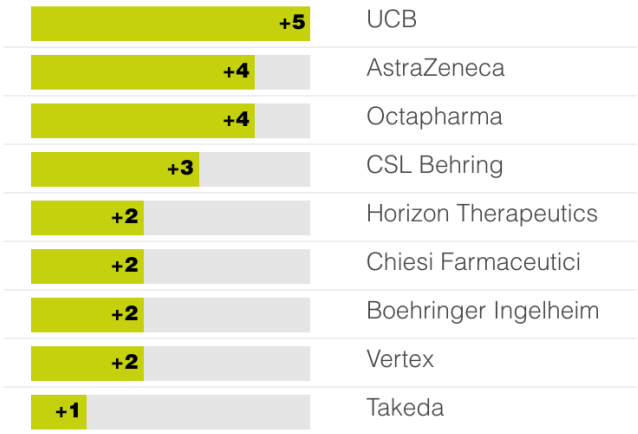
1st: Roche
2nd: Takeda
3rd: Boehringer Ingelheim

Note: A separate analyses was undertaken examining the views of patient groups with a focus on bleeding disorders. 10 companies were included. Roche ranked 1st as assessed both by bleeding-disorder patient groups familiar with and which worked with the company.

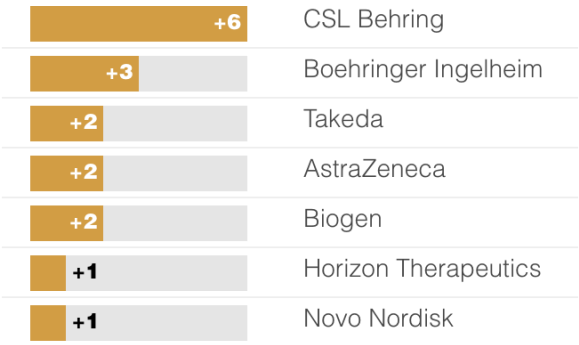
The companies included in the bleeding disorder analyses were as follows:

• Bayer • Biomarin • Boehringer Ingelheim • CSL Behring• Daiichi Sankyo • Eli Lilly • Gilead Sciences • Grifols • Novo Nordisk • Octapharma • Pfizer • Roche/Chugai/Genentech • Sanofi • Takeda.

The companies rising the most in the upper part of the rare-disease rankings (out of all 34 companies), 2021 to 2022, as assessed by respondent rare-disease patient groups familiar with the company



The companies rising the most in the upper part of the rare-disease rankings (out of 31 companies), 2021 to 2022, as assessed by respondent rare-disease patient groups working with the company

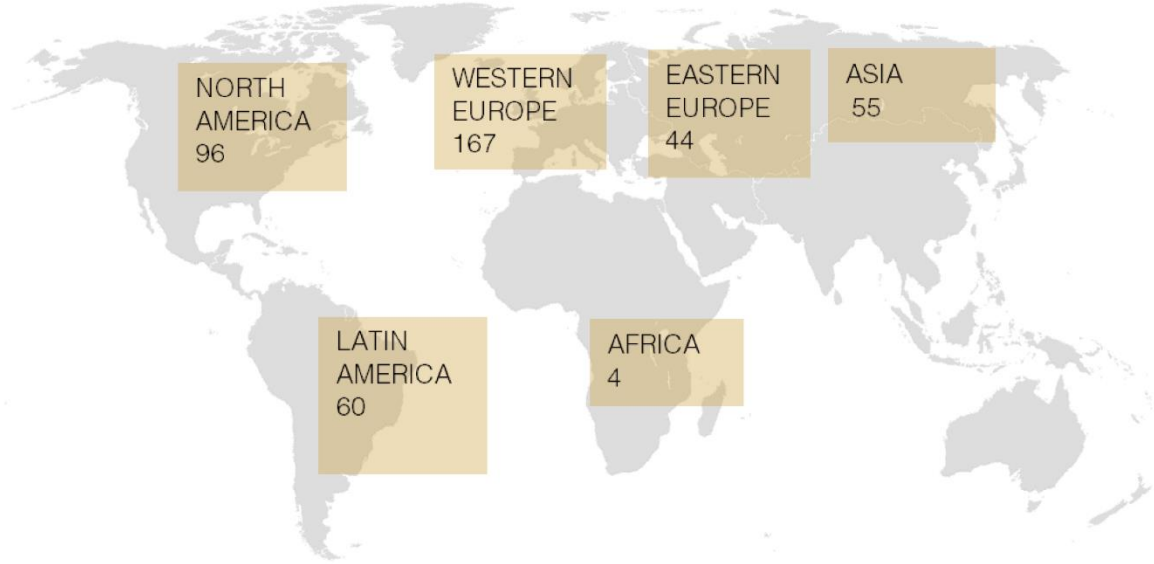


PROFILES OF RESPONDENTS

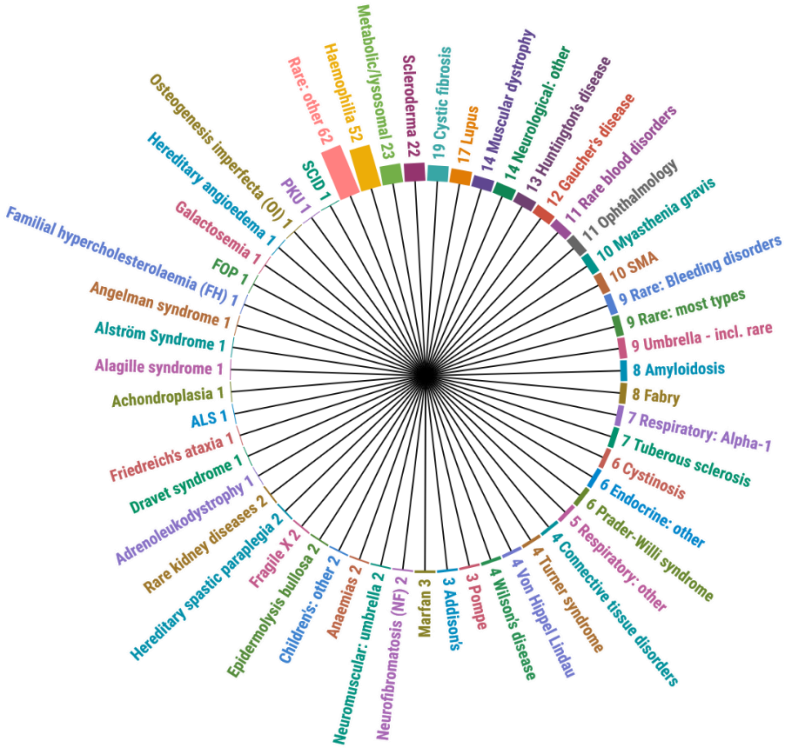
426 rare-disease patient groups responded to the rare-disease element of the 2022 'Corporate Reputation of Pharma' survey.

The respondent rare-disease patient groups stated that they had reached out to approximately some 3.3 million patients with rare disease during 2022.

Regional headquarters of 2022's respondent rare-disease patient groups
Number of respondent rare-disease patient groups



Specialities of 2022's respondent rare-disease patient groups
Number of respondent rare-disease patient groups



Finally, PatientView would like to thank the 426 rare-disease patient groups that gave up their time to respond to the 2022 'Corporate Reputation of Pharma' survey.

The respondent rare-disease 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 34 pharma companies featured in the rare-disease 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 rare-disease report, please use contact details at the head of the press release (or below).

END OF PRESS RELEASE

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