



RARE-DISEASE EDITION: THE CORPORATE REPUTATION OF PHARMA IN 2021

The Patient Perspective—Rare-disease edition

The views of 303 rare-disease patient groups

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PatientView is today publishing the results of its latest 'Corporate Reputation of Pharma' survey—rare-disease edition, now in its 3rd year, and two years into the Covid-19 pandemic. Between November 2021-February 2022, the survey collected the opinions of 303 rare-disease patient groups on the performance of the pharmaceutical industry during 2021, including 56 patient groups focused on bleeding disorders.

Patient groups—and rare-disease patient groups especially—possess a deep and unique understanding of the patients they represent and can express the collated views of these patients. Patient-group perspectives have become increasingly important to regulators that demand patient input into trial design and conduct (as well as into the evaluation of clinical outcomes). At the same time, many patient groups are also familiar with the complexities of the pharmaceutical industry's business. From their vantage point, therefore, patient groups are both able to assess pharma, and to recommend ways in which companies can improve—all from a patient perspective.

Continue reading for details on:

- ▶ **How PatientView measures pharma's corporate reputation from a patient perspective;**
- ▶ **The companies included in the 2021 rare-disease analysis;**
- ▶ **The headline results of the 2021 survey, from the perspective of rare-disease patient groups; and**
- ▶ **The profiles of 2021's respondent rare-disease patient groups.**

Contents and tables can be downloaded [here](#)

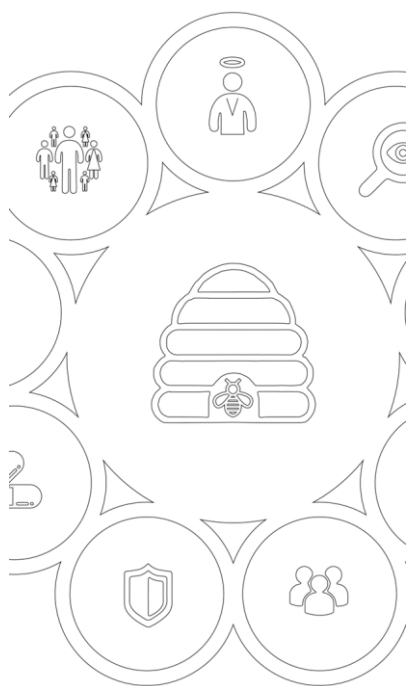
PatientView, press release, October 2022

METHODOLOGY

PatientView’s annual online ‘Corporate Reputation of Pharma’ survey measures various aspects of pharma’s performance—all from a patient and patient-group perspective. The survey’s questions to respondent patient groups fall into two areas:

- (1) The performance of the **pharma industry as a whole**, compared to other healthcare industries, —and for various activities of importance to patients.
- (2) The performance of **individual pharma companies** (32 in total in the rare-disease edition of the 2021 survey results). Companies are assessed by respondent patient groups for their performance across nine indicators of corporate reputation. A new, 10th indicator was added to the previous year’s survey (that of 2020), looking at companies’ support to patients during the Covid-19 pandemic. This indicator was retained in the 2021 survey *[see chart below]*.

Chart 1: The nine indicators that measure pharma’s corporate reputation, from a patient perspective, plus a 10th indicator on patient support during the Covid-19 pandemic



Each indicator measures which three companies were “Best” in 2021 at the following:

1. Supporting patients during the Covid-19 pandemic *[first added in the 2020 survey]*.
2. Having an effective patient-centred strategy.
3. Providing high-quality information for patients.
4. Ensuring patient safety.
5. Providing products of most benefit to patients.
6. Being transparent on ...
 - (i) Pricing;
 - (ii) Clinical data; and
 - (iii) The funding of external stakeholders.
7. Acting with integrity.
8. Quality of relationships with patient groups.
9. Providing services ‘beyond the pill’.
10. Engaging patients in ...
 - (i) Research; and
 - (ii) Development



The 32 companies included in the rare-disease arm of the 2021 ‘Corporate Reputation of Pharma’ analyses: AbbVie | Amgen | Astellas Pharma | AstraZeneca | Bayer | Biogen | Boehringer Ingelheim | Bristol Myers Squibb | Chiesi Farmaceutici | CSL Behring | Eli Lilly | Gilead Sciences | Grifols | GSK | Horizon Therapeutics | Ipsen | Janssen | Lundbeck | Merck & Co/MSD | Merck KGaA/EMD Serono | Mylan | Novartis | Novo Nordisk | Octapharma | Pfizer | Roche/Genentech/Chugai | Sandoz | Sanofi | Takeda | Teva | UCB | Vertex.

Chart 2: The number of respondent rare-disease patient groups familiar, or working, with the companies listed above [<https://bit.ly/3CemOp6>].

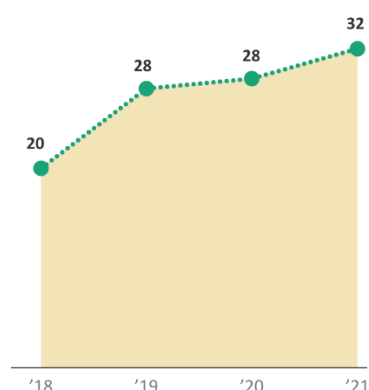
Click here to read more about PatientView’s [methodology for the ‘Corporate Reputation of Pharma’ 2021 \(published 2022\)](#).

SUMMARY OF RESULTS

Several factors have created an escalation in pharma’s R&D efforts to develop drugs that can play a more vital role in the lives of patients with a rare disease. Key among such factors are:

- ▶ Breakthroughs in genetics and genomics;
- ▶ Regulatory legislation offering incentives to develop drugs for people with rare diseases (known as ‘orphan-drug legislation’); and, finally
- ▶ The development of new consortia to address the challenges of building a clinical evidence base for small populations of rare-disease patients.

Chart 3: The numbers of pharma companies familiar to rare-disease patient groups, 2018-2021
(Number of pharma companies with which rare-disease patient groups responding to the ‘Corporate Reputation’ survey, per year, are familiar)



One indication of the greater involvement of pharma in rare diseases is the finding that the 303 rare-disease patient groups responding to the 2021 ‘Corporate Reputation’ survey were familiar with as many as 32 pharma companies—a far-higher figure than the 20 reported by 2018’s rare-disease respondents [see chart 3].

The rare-disease patient movement has been quick to recognise the power of collectivism when asserting itself with policymakers and other healthcare stakeholders. For this reason, gathering insights from all types of rare-disease patient groups is vital in understanding their needs, and how they perceive that pharma can best work with them.

FINDINGS AT INDUSTRY LEVEL

According to respondent rare-disease patient groups, **the pharma-industry’s corporate reputation has risen steadily since 2018**, when just 33% of rare-disease respondents assessed pharma’s corporate reputation as “Excellent” or “Good”. In 2021, the equivalent figure was 59%—the same as the global average for 2021 [see chart on previous page]. 2021’s rare-disease patient groups ranked pharma 2nd for corporate reputation out of a list of nine healthcare stakeholders (biotechnology came first).

Positive about pharma’s R&D

The 2021 survey results clearly show the value placed by rare-disease patient groups on pharma’s development of new drugs; 64% of them judged the pharma industry “Excellent” or “Good” at being innovative—a significant rise from 2018, when only 38% of respondent rare-disease patient groups felt the same way. Similarly, 68% of 2021’s respondent rare-disease patient groups saw pharma as “Excellent” or “Good” at making high-quality products of value to patients with a rare disease—an increase on the 51% recorded in 2018.

Even so, feedback received from 2021’s respondent rare-disease patient groups indicate that they believe pharma could do still more—an expectation driven by the statistics of rare diseases. Taken together, rare diseases affect 6% of the world’s population. Yet only 5% of the estimated total of 7,000 known rare diseases presently have satisfactory treatments.

https://www.ucl.ac.uk/pharmacy/sites/pharmacy/files/vf_embargoed_medicines_for_the_few_and_the_many_may_18.pdf

Moreover, while respondent rare-disease patient groups are positive about pharma's R&D, they are less happy about pharma's levels of engaging rare-disease patients and patient groups in R&D processes. **Only 32% of 2021's respondent rare-disease patient groups felt pharma to be "Excellent" or "Good" at bringing patients into research.**

Fair pricing and transparency remain key issues

Providing expensive drugs to small patient populations requires innovative models and cross-stakeholder involvement. Yet **only 15% of 2021's respondent rare-disease patient groups rated pharma "Excellent" or "Good" at fair-pricing policies. Again, just 14% thought pharma "Excellent" or "Good" at being transparent on pricing.** These figures are not dissimilar to those from 2021's respondent patient groups of other disease areas but do emphasise the need for additional reflection by pharma on the issue of pricing in the field of rare disease—not least because pricing underpins the trust vital to effective pharma/patient-group relations.

Moving forward

The 303 rare-disease patient groups responding to the 2021 'Corporate Reputation' survey provided a significant amount of direction to pharma companies which wish to work effectively with them. Rare-disease patient groups clearly demonstrate support for the science and innovation that pharma undertakes. That said, the scope for improvement by the industry is great—from patient engagement in R&D, to fair pricing and transparency.



"Even more focus on what patients' real needs are, that is making treatment patient friendly; for instance, helping to make at-home therapy available in Belgium. Lowering their prices, so that all orphan drugs get the chance to be brought to the Belgian market."

COMPANY RANKINGS – ALL RARE-DISEASES

▶ **The top-three pharma companies** out of 32 companies, ranked for their overall corporate reputation in 2021, assessed by respondent **rare-disease patient groups familiar with the company**: **Roche**, 1st | **Pfizer**, 2nd | **Horizon Therapeutics**, 3rd.

▶ **The top-three pharma companies** out of 18 companies, ranked for their overall corporate reputation in 2021, assessed by respondent **rare-disease patient groups working with the company**: **Roche**, 1st | **Pfizer**, 2nd | **Horizon Therapeutics**, 3rd.

▶ **The top-three 'big-pharma' companies** out of 13 companies, ranked for their overall corporate reputation in 2021, assessed by respondent **rare-disease patient groups familiar with the company**: **Roche**, 1st | **Pfizer**, 2nd | **Takeda**, 3rd.

▶ **The top-three pharma companies** out of 8 companies, ranked for their overall corporate reputation in 2021, assessed by respondent **rare-disease patient groups working with the company**: **Roche**, 1st | **Pfizer**, 2nd | **Sanofi**, 3rd.

▶ **The companies rising the most in the rankings, 2020 to 2021, as assessed by respondent rare-disease patient groups familiar with the company**, can be seen in the chart below.

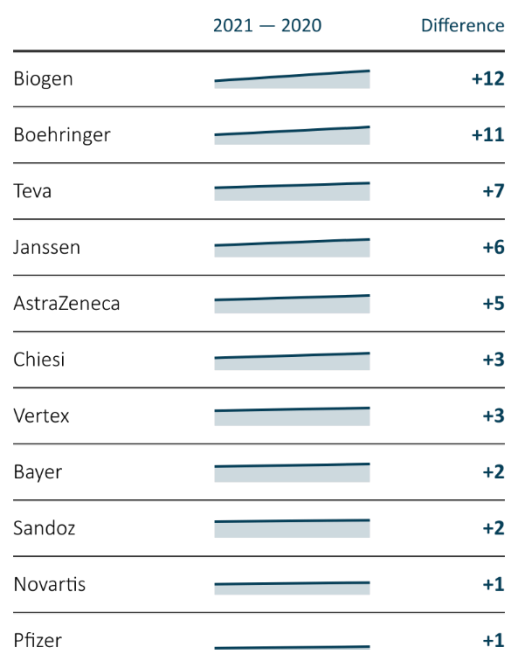


Chart 4: Companies rising the most in the rankings for overall corporate reputation in rare diseases, 2020 to 2021, as assessed by respondent rare-disease patient groups familiar with the company

Listed high to low, top to bottom

COMPANY RANKINGS – FOR BLEEDING DISORDERS

The 9 companies included in the bleeding-disorders arm of the 2021 ‘Corporate Reputation of Pharma’ analyses: Bayer | CSL Behring | Grifols | Novo Nordisk | Octapharma | Pfizer | Roche | Sanofi | Takeda

Chart 5: The number of respondent bleeding-disorders patient groups familiar, or working, with the 9 companies listed above [\[https://bit.ly/3SowH9x\]](https://bit.ly/3SowH9x).

THE VIEWS OF 56 BLEEDING-DISORDERS PATIENT GROUPS FAMILIAR WITH THE COMPANY

► **The top-three pharma companies out of 9 companies**, ranked for their overall corporate reputation in 2021, assessed by respondent patient groups familiar with the company:

Roche, 1st | Pfizer, 2nd | Novo Nordisk, 3rd

THE VIEWS OF 45 BLEEDING-DISORDERS PATIENT GROUPS WORKING WITH THE COMPANY

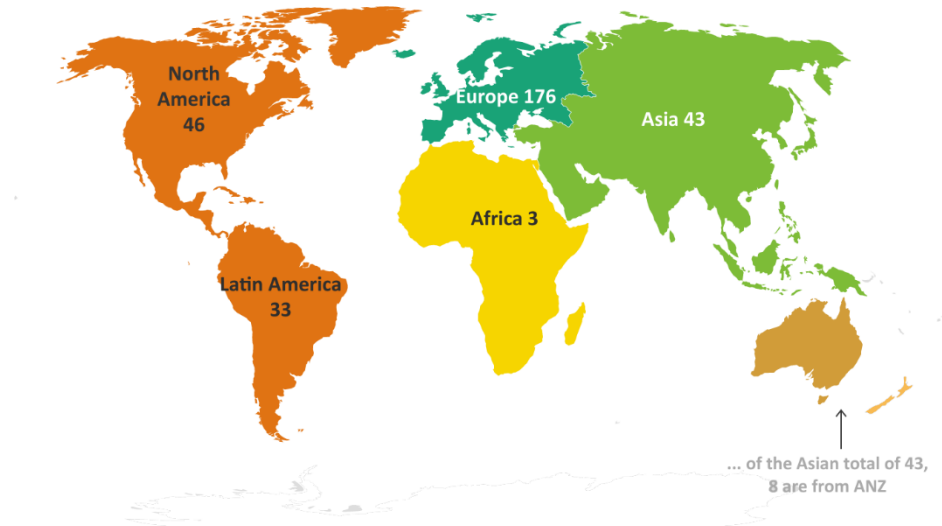
► **The top-three pharma companies out of 9 companies**, ranked for their overall corporate reputation in 2021, assessed by respondent patient groups working with the company:

Roche, 1st | Pfizer, 2nd | Sanofi, 3rd

PROFILE OF RESPONDENTS

2021's 303 respondent rare-disease patient groups specialised in **more than 40 different types of rare-disease**.

Chart 6: Geographic location of respondent rare-disease patient groups, 2021



PatientView would like to thank the 303 rare-disease patient groups who gave up their time to respond to the 'Corporate Reputation of Pharma' survey 2021 (published 2022).

For further information on this report, please use contact details at the head of the press release.

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