



## 'The Corporate Reputation of Pharma in 2020 during the Covid-19 Pandemic — the Perspective of Rare-Disease Patient Groups'

The results of an independent survey of 230 rare-disease patient groups in 2020. Collectively, these patient groups reached out to 109,600 patients with rare diseases during 2020. The respondent rare-disease patient groups commented on 29 companies, selecting those with the “Best” corporate reputation in 2020, and assessing which were “Best” at tackling Covid-19 during 2020.

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## SUMMARY OF FINDINGS

### **London, September 22nd 2021**

*Patient groups responding to 2020's 'Corporate Reputation of Pharma' survey are uniquely positioned to comment on the pharma industry's performance during the pandemic, as patient organisations not only understand the perceptions of patients, but are also the only stakeholder to network with ALL other stakeholders in the healthcare system. For this reason, PatientView collected (November 2020 to February 2021) the opinions of 230 rare-disease patient groups on the performance of the pharmaceutical industry during the Covid-19 pandemic of 2020.*

### **Rare-disease patient-group perspectives on pharma during the Covid-19 pandemic**

#### **2020 INDUSTRY-WIDE FINDINGS IN THE FIELD OF RARE DISEASES**

- **The pharma industry's effectiveness at tackling Covid-19, 2020.** 62% of 2020's respondent rare-disease patient groups judged the industry's actions in tackling Covid-19 to be “Very effective” or “Effective” during 2020 (the same figure as 2020's 62% average from patient groups therapy wide). In a separate analysis looking solely at the responses of 49 bleeding-disorders patient groups, 57% thought the industry's actions in tackling Covid-19 to be “Very effective” or “Effective” during 2020.
- **The pharma industry's corporate reputation, 2020.** 50% of 2020's respondent rare-disease patient groups stated that the pharmaceutical industry had an “Excellent” or “Good” corporate reputation (higher than both the 45% given by rare-disease patient groups responding in 2019, and by the 33% given in 2018). However, not all of 2020's respondent rare-disease patient groups shared the same opinion. Although a high percentage of respondent bleeding-disorders patient groups—57%— thought the pharmaceutical industry's corporate reputation to be “Excellent” or “Good” in 2020, this figure was significantly lower than the 65% from bleeding-disorders patient groups responding in 2019.

## THE 2020 RANKINGS OF INDIVIDUAL PHARMA COMPANIES WORKING IN THE FIELD OF RARE DISEASES

Two sets of rankings are provided in the 2020 rare-disease analyses: (1.) according to 230 rare-disease patient groups assessing the corporate reputation of 29 pharma companies; and (2.) according to 49 bleeding-disorders patient groups assessing 9 pharma companies that hold a portfolio in bleeding disorders.

### Response to Covid-19, 2020

1. **Out of 29 pharma companies, according to 230 rare-disease patient groups:** The three pharma companies voted “Best” in 2020 for supporting patients with rare diseases during Covid-19 were: **1st, Roche/Genentech | 2nd, Takeda/Shire | and, 3rd, Pfizer**—as assessed by respondent rare-disease patient groups familiar with the company.
2. **Out of 9 pharma companies with a portfolio in bleeding disorders, according to 49 bleeding-disorders patient groups:** The three pharma companies voted “Best” in 2020 for supporting patients with bleeding disorders during Covid-19 were: **1st, Roche/Genentech | 2nd, Novo Nordisk | and, 3rd, Takeda/Shire**—as assessed by respondent bleeding-disorders patient groups familiar with the company.

### Overall corporate reputation in 2020

1. **Out of 29 pharma companies, according to 230 rare-disease patient groups:** The three pharma companies voted “Best” for overall corporate reputation in 2020 were: **1st, Roche/Genentech | 2nd, Takeda/Shire | and, 3rd, Pfizer**—as assessed by respondent rare-disease patient groups familiar with the company.
2. **Out of 9 pharma companies with a portfolio in bleeding disorders, according to 49 bleeding-disorders patient groups:** The three pharma companies voted “Best” in 2020 for overall corporate reputation in 2020 were: **1st, Roche/Genentech | 2nd, Takeda/Shire | and, 3rd, Novo Nordisk**—as assessed by respondent bleeding-disorders patient groups familiar with the company.

The commentaries supplied to PatientView by 2020’s respondent rare-disease patient groups made clear that their opinions on pharma companies in 2020 were primarily influenced by company responses to Covid-19—whether that be the development and production of vaccines, or other efforts by companies to support patients with rare diseases during lockdown.

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## ABOUT THE 2020 ‘CORPORATE REPUTATION’ SURVEY

### A survey of 230 rare-disease patient groups

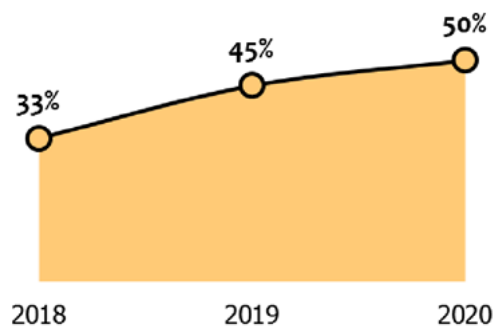
- **When?** The survey was conducted November 2020-February 2021, when key events of the pandemic will have influenced the opinions of respondent rare-disease patient groups.
- **The questionnaire?** Pharma was assessed across a wide range of its activities important to patients and patient groups, including a new indicator for 2020—pharma’s effectiveness at tackling Covid-19.
- **Companies assessed?** 29 companies were included in the 2020 rare-disease analyses: AbbVie | Amgen | Astellas Pharma | AstraZeneca | Bayer | Biogen | Boehringer Ingelheim | Bristol Myers Squibb | Chiesi Farmaceutici | CSL Behring | Eli Lilly | Gilead Sciences | Grifols | Ipsen | Janssen | Merck & Co/MSD | Merck KGaA/EMD Serono | Mylan | Novartis | Novo Nordisk | Octapharma | Pfizer | Roche/Genentech | Sandoz | Sanofi | Takeda/Shire | Teva | UCB | Vertex.

- **How were the companies assessed?** The indicators used to measure a company's corporate reputation: **1.** Covid-19 response [*new for the 2020 survey*] | **2.** Patient centricity | **3.** Patient information | **4.** Patient safety | **5.** High-quality products | **6.i.** Transparency: pricing | **6.ii.** Transparency: clinical-trial data | **6.iii.** Transparency: funding of external stakeholders | **7.** Integrity | **8.** Quality of relationships with patient groups | **9.** Providing services 'beyond the pill' | **10.i.** Engaging patients in research | **10.ii.** Engaging patients in development.

## 1. THE PHARMA INDUSTRY'S CORPORATE REPUTATION AMONG RARE-DISEASE PATIENT GROUPS, 2020

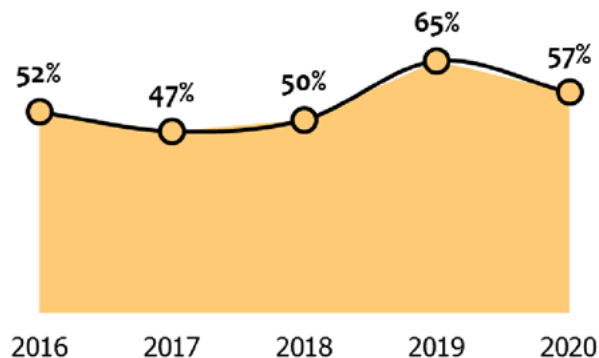
PatientView has collated data on the opinions of rare-disease patient groups since 2018, and historic data on pharma's corporate reputation, as assessed by them, can be seen in Chart 1. The majority (50%) of 2020's respondent rare-disease patient groups stated that the pharma industry had an "Excellent" or "Good" corporate reputation in 2020—higher than in the previous two years.

**Chart 1: The pharma industry's corporate reputation among rare-disease patient groups has steadily increased since 2018** (Percentage of respondent rare-disease patient groups per year stating that the pharmaceutical industry has an "Excellent" or "Good" corporate reputation)



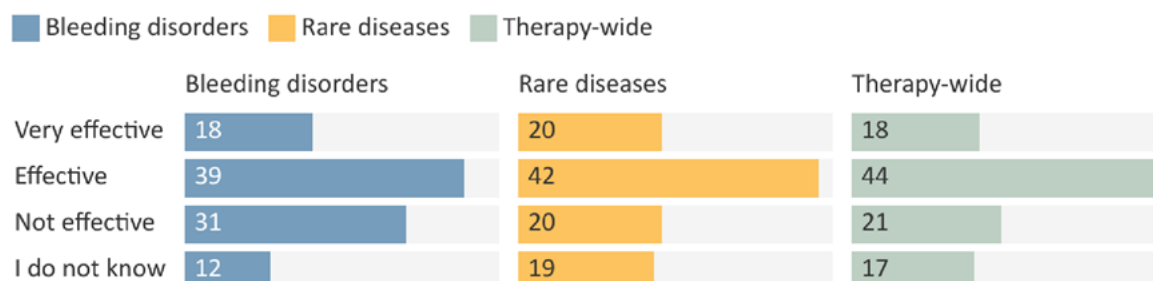
However, the opinions of rare-disease patient groups clearly vary. PatientView has collated data on the opinions of bleeding-disorders patient groups since 2016, and historic data on pharma's corporate reputation, as assessed by these latter patient groups, can be seen in Chart 2. For bleeding-disorders patient groups, the industry's corporate reputation fell from a 2019 high of 65% to 57% in 2020.

**Chart 2: The pharma industry's corporate reputation among bleeding-disorders patient groups fell between 2020 and 2019** (Percentage of respondent bleeding-disorders patient groups per year stating that the pharmaceutical industry has an "Excellent" or "Good" corporate reputation)



## 2. THE PHARMA INDUSTRY’S SUPPORT OF PATIENTS DURING THE COVID-19 PANDEMIC, 2020

**Chart 3: Percentage of respondent patient groups which thought the pharma industry “Very effective” or “Effective” at supporting patients during the Covid-19 pandemic of 2020: Bleeding disorders v. rare diseases v. therapy-wide**



62% of 2020’s respondent rare-disease patient groups, and 57% of bleeding-disorders patient groups, judged the industry’s response to Covid-19 to be “Very effective” or “Effective.” The average from patient groups across all therapy areas was 62% in 2020.

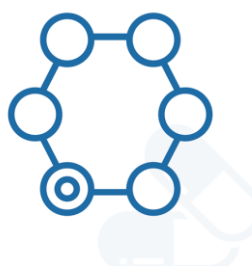
The fact that the majority of respondent rare-disease patient groups (including bleeding-disorders patient groups) were positive about how pharma handled the pandemic in part explains why most of these patient groups also assessed the pharmaceutical industry positively in 2020 for its key R&D activities.

### Key activities performed well by pharma in 2020

The majority of 2020’s respondent rare-disease patient groups and bleeding-disorders patient groups endorsed the pharma industry’s capabilities at two of its key activities:

- 53% of 2020’s respondent rare-disease patient groups stated that the pharma industry was “Excellent” or “Good” at **creating products of benefit to patients** (58% of respondent bleeding-disorders patient groups stated the same).
- 51% of 2020’s respondent rare-disease patient groups described the industry as “Excellent” or “Good” at **innovation** (50% of respondent bleeding-disorders patient groups stated the same).

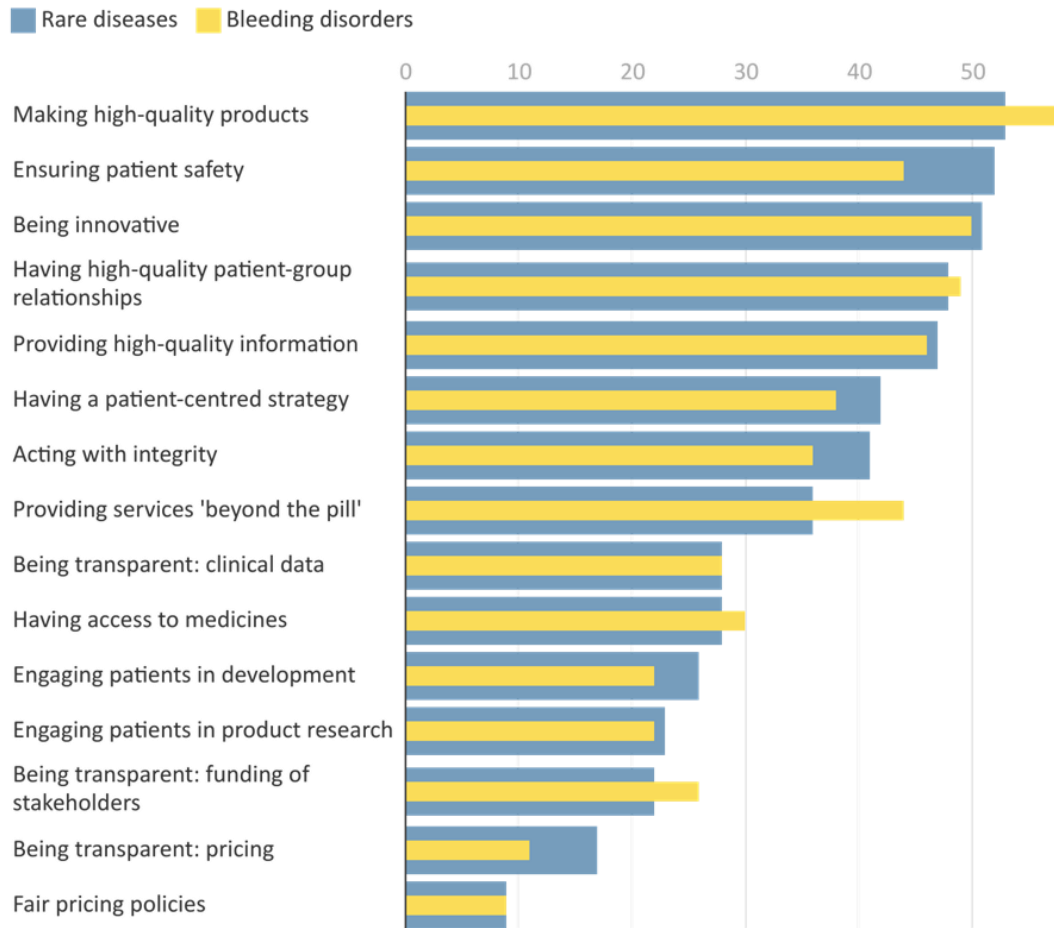
## 3. WHERE PHARMA NEEDS TO IMPROVE



Although 2020’s respondent rare-disease patient groups acknowledged the pharma industry’s capabilities in R&D in 2020, the majority also believed pharma to be either “Fair” or “Poor” (or they “Did not know”) at other key activities of importance to patients— including pharma’s **provision of patient information** (notably information related to the interaction of Covid-19 and patients’ customary treatments). 47% of 2020’s respondent rare-disease patient groups, and 46% of respondent bleeding-disorders patient groups, stated that the pharma industry was “Excellent” or “Good” at providing high-quality patient information.

For data on pharma’s performance at activities of importance to patients, from the perspective of rare-disease (and bleeding-disorders) patient groups, see Chart 4.

**Chart 4. How good or bad the pharmaceutical industry was (from the perspective of respondent patient groups in rare diseases v. bleeding disorders) at carrying out specific activities—all of which influence the industry’s corporate standing with patients and patient groups (Percentage of respondent patient groups stating “Excellent” or “Good”)**



**On patient information**

“Rasch und verständlich über die Auswirkungen von Covid-19 auf die spezifische Krankheit informieren.”  
 (“Provide rapid and understandable information about the impacts of Covid-19 on the specific disorder.”)

—National bleeding-disorders patient group, Switzerland

“Si se trata de una compañía involucrada en el desarrollo de vacunas, ofrecer información a la asociación sobre las vacunas e incluir en sus estudios perfiles de pacientes con las enfermedades que representa la asociación.” (“If it is a company involved in vaccine development, offer information to the patient group about the vaccines, and include in their studies profiles of patients with the diseases that the patient group represents.”)

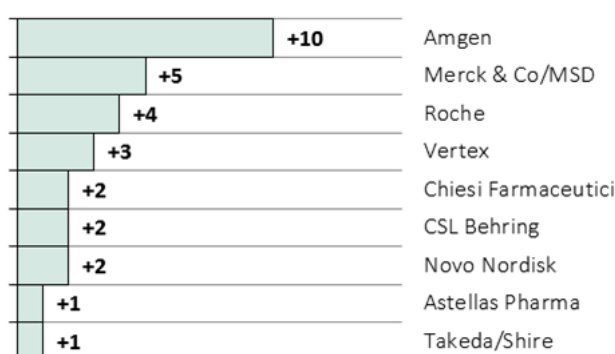
—National rare-diseases patient group, Spain

### 3. 2020'S RANKINGS OF INDIVIDUAL PHARMA COMPANIES THAT WORK IN THE FIELD OF RARE DISEASES

The companies voted "Best" for Covid-19 response by rare-disease patient groups in 2020, and "Best" for overall corporate reputation in the field of rare diseases, in 2020, can be found in the summary at the beginning of this press release (as well as the rankings of companies according to bleeding-disorders patient groups). Other success stories included ...

**Amgen** jumped 10 places in ranking for overall corporate reputation in the field of rare diseases in 2020, as assessed by respondent rare-disease patient groups *familiar* with the company. Amgen ranked overall 13th in 2020 out of 29 pharma companies.

**Companies showing an increase in overall rankings in the PatientView 'Corporate Reputation of Pharma' rare-disease league tables, 2019-2020**  
(As assessed by respondent rare-disease patient groups *familiar* with the company)



### PROFILE OF 2020'S 230 RESPONDENT RARE-DISEASE PATIENT GROUPS

Of the 230 respondent patient groups ...

- 16% held an international geographic remit.
- 67% were national patient groups.
- 11% were large regional.
- 6% local.
- 65% worked/partnered with at least one pharmaceutical company.
- The 230 respondent rare-disease patient groups were headquartered in 53 different countries.



*For further information on this 2020 rare-disease 'Corporate Reputation' report, please use contact details at the head of the press release.*

~END OF PRESS RELEASE~

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