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WHAT 372 US PATIENT GROUPS SAY ABOUT PHARMA IN 2024

USA edition [13th]

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- 2024 'Corporate Reputation of Pharma' survey of patient groups worldwide, conducted December 2024 to March 2025, and answered by 372 US patient groups.
- The 372 respondent US patient groups actively supported over 13 million US patients during the past year.
- 40 companies are featured in the results to this 2024 'Corporate Reputation of Pharma' survey—six are new to the survey (and included on the suggestion of patient groups). The six new companies tend to be smaller biotechs, focusing their innovatory activities on rare diseases, rather than on creating traditional blockbusters [companies in blue, below, are the new additions]. The full list of 40 companies:
- AbbVie Amgen Astellas Pharma AstraZeneca Bayer Biogen BioMarin Boehringer Ingelheim
- Bristol Myers Squibb Chiesi Farmaceutici CSL Behring Daiichi Sankyo Eisai Eli Lilly Exelixis
- Gilead Sciences GSK Incyte Ipsen Johnson & Johnson Innovative Medicine (J&JIM)
- Jazz Pharmaceuticals
 Lundbeck
 Merck & Co
 Merck KGaA/EMD Serono
 Novartis
 Novo Nordisk
- Otsuka Pfizer PTC Therapeutics Regeneron Roche/Genentech Sanofi Sarepta Therapeutics
- Servier Sobi Takeda UCB Vertex Viatris ViiV Healthcare

Why pharma needs to work closely and efficiently with US patient groups

PatientView conducted an October 2024 survey, entitled *Patients in Action*, to document the activities and opinions of US patient groups (results to be published as an online dashboard, June/July 2025). The study captured one of the largest, and most-diverse, datasets of its kind, with the findings illustrating the evolving relationship between US patient groups and other healthcare stakeholders (including the pharmaceutical industry). The *Patients in Action* study results show clearly that US patient groups can now be considered core health actors in a national healthcare setting—entities with views respected by most (perhaps even all) healthcare stakeholders.

Patients in Action has found that US patient groups are expanding their roles in advocacy, healthcare-service delivery, patient education, and medical research. The latter activity, in particular, creates an imperative for the pharmaceutical sector, since regulatory bodies increasingly expect evidence of patient engagement throughout the product lifecycle. US patient groups are well placed to help here. They possess a depth of insight that can unlock connection to HTA and to market access, provide critical feedback on treatment tolerability, and allow for the design of appropriate communications to target patient populations. These capabilities are not peripheral; they are vital to every aspect of pharma's R&D.

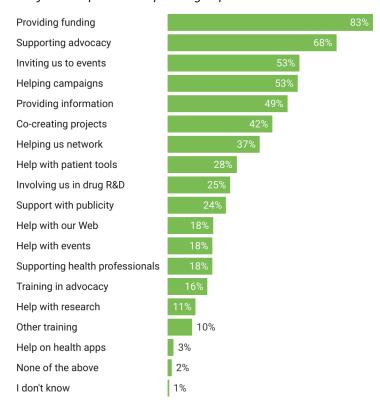
What US patient groups seek from pharma, but are not currently getting

US patient groups responding to the 2024 'Corporate Reputation of Pharma' survey emphasise that the most-valuable contributions they receive from partners (including the pharmaceutical industry) are additional forms of support—beyond just financial grants.

359 (or 97%) of 2024's 372 respondent US patient groups reported having a working relationship with at least one pharmaceutical company. However, findings from this 'Corporate Reputation' survey also highlight a disconnect between the forms of support that patient groups in the US seek from pharma, and the assistance they actually receive.

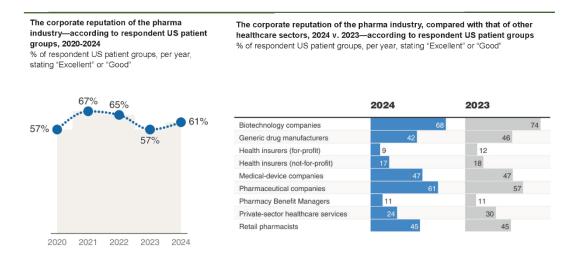
While financial contributions from pharma to US patient groups remain common (83% of 2024's respondent US patient groups mention benefiting from such support), far fewer US patient groups gain deeper, strategic engagement with pharma companies. Only 37% of 2024's respondent US patient groups say that they receive assistance from pharma in networking, or in building meaningful relationships with other essential healthcare stakeholders. And just 25% can claim active involvement in pharma's R&D processes—an area in which patient groups can provide substantial value.

The types of relationships that respondent US patient groups have with pharma companies, 2024 —% of total respondent US patient groups



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Some 61% of the 372 US patient groups responding to the 2024 'Corporate Reputation' survey saw the pharma industry as having an "Excellent" or "Good" corporate reputation in 2024 (up on the 57% of 2023). But, despite this overall increase, 2024's respondent US patient groups marked the industry down for most of its activities of importance to US patients. The equivalent results back in 2020 were better for pharma [see charts below], suggesting a decline in the pharma industry's ability to meet the needs of US patient groups (the definition of a good corporate reputation).



How good or bad the pharma industry was at carrying out specific activities of importance to patients in the US, 2020-2024 % of respondent US patient groups stating "Excellent" or "Good"

| | 2020 — 2024 Diff | |
|--------------------------------|------------------|-----|
| Patient centricity | 60 • 50 | -10 |
| Information | 62 62 57 | -5 |
| Ensuring patient safety | 78 64 | -14 |
| Innovation | 72 63 | -9 |
| Products that benefit patients | 81 • 77 | -4 |
| Transparency: pricing | 18 • 18 | +1 |
| Transparency: clinical data | 44 • 38 | -7 |
| Transparency: funding | 32 • 32 | ±0 |
| Integrity | 64 • 49 | -15 |
| Patient-group relations | 68 • 60 | -8 |
| Services 'beyond the pill' | 48 • 46 | -2 |
| Fair pricing policies | 14 • 12 | -2 |
| Engaging patients in R&D | 44 • 37 | -7 |
| Access to medicines | 47 • 43 | -4 |

"

"Pharma companies need to move beyond buzzwords and make patient centricity a measurable reality. This means actively engaging with patients—not just as end users of treatments, but as partners in drug development, access, and education. Companies should prioritize transparency in pricing, clinical trials, and real-world outcomes, while ensuring diverse patient voices are engaged in the process. True patient centricity means listening, acting on feedback, and making healthcare solutions that are affordable, accessible, and driven by real patient needs—not just corporate priorities."

National patient-advocacy patient group, USA

Results at corporate reputation for individual pharma companies, USA, 2024

ALL COMPANIES The top-three rankings in the USA, 2024 (out of all 40 companies)—as assessed by respondent US patient groups <u>familiar</u> with the company:

- ViiV Healthcare, 1st
- Servier, 2nd
- Amgen, 3rd

The top-three rankings in the USA, 2024 (out of 36 companies)—as assessed by respondent US patient groups <u>working</u> with the company:

- ViiV Healthcare, 1st
- Servier, 2nd
- Amgen, 3rd

The companies rising the most in the <u>upper</u> rankings (out of all 40 companies), 2024 v. the previous year, 2023—as assessed by respondent US patient groups <u>familiar</u> with the company **BIG PHARMA**

The top-three rankings in the USA, 2024 (out of 15 'big-pharma' companies) —as assessed by respondent US patient groups <u>familiar</u> with the company:

- Amgen, 1st
- Roche/Genentech, 2nd
- Pfizer, 3rd

The top-three rankings in the USA, 2024 (out of 15 'big-pharma' companies) —as assessed by respondent US patient groups <u>working</u> with the company:

- Amgen, 1st
- Roche/Genentech, 2nd
- ▶ Gilead Sciences, =3rd
- ▶ Pfizer, =3rd

Familiar with

| PTC Therapeutics | +13 | |
|----------------------|-----|--|
| Boehringer Ingelheim | +12 | |
| Novartis | +6 | |
| Vertex | +6 | |
| Sanofi | +5 | |
| Lundbeck | +3 | |
| Daiichi Sankyo | +2 | |
| ViiV Healthcare | +1 | |
| AstraZeneca | +1 | |
| UCB | +1 | |

The companies rising the most in the <u>upper</u> rankings (out of all 36 companies), 2024 v. the previous year, 2023—as assessed by respondent US patient groups <u>working</u> with the company

Worked with

| Boehringer Ingelheim | +10 | |
|----------------------|-----|--|
| Novartis | +10 | |
| Daiichi Sankyo | +7 | |
| UCB | +5 | |
| Lundbeck | +4 | |
| Vertex | +4 | |
| Sanofi | +3 | |
| Amgen | +1 | |
| Eli Lilly | +1 | |

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PatientView would like to thank the 372 US patient groups that gave up their time to respond to the 2024 'Corporate Reputation of Pharma' survey. Their evaluation of the pharma industry, and their experiences on whether the industry (and individual pharma companies) meet their needs and expectations, should help the industry gain valuable insights into improvement.

END OF PRESS RELEASE

APPENDIX to this press release: PROFILE OF 2024's RESPONDENT US PATIENT GROUPS

Therapeutic areas of respondent US patient groups

Number of respondent US patient groups, N = 372 Respondent US patient groups may fall into more than one category of specialty

| Rare diseases | 00.000 |
|----------------------------------|------------------------------|
| are diseases | |
| leurological conditions 18 | Neuromuscular conditions |
| leurodegenerative diseases 30 | Not specified |
| IV/AIDS 23 | Allergic conditions |
| Respiratory conditions | Heart conditions |
| Patient advocacy | Infectious diseases |
| utoimmune 19 | Medical research |
| iver diseases 18 | Older people 3 |
| /lental health 18 | Cardiovascular diseases |
| Vomen's health 16 | Immune disorders |
| Rheumatic diseases | Patient education |
| General health 13 | Transplants |
| Children's health | Autoimmune conditions |
| /len's health 11 | Circulatory conditions |
| Bastrointestinal conditions | Hearing loss |
| /isual impairment | Other circulatory conditions |
| Bleeding disorders | Other disabilities |
| lepatitis B | Urinary conditions |
| Skin conditions | |
| Blood disorders | |
| Carers, family, friends 6 | |
| ndocrine conditions | |
| Chronic diseases in general 5 | |
| Gynaecological conditions 5 | |
| (idney diseases | |