

NEW PATIENTVIEW TOOLKIT: 'PHARMA, ESG, AND PATIENT GROUPS'

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In 2025, the EU introduced a mandatory requirement *entitled the 'Double Materiality Assessment (DMA)'*—an obligation on companies to measure and report their ESG [Environmental, Social and Governance]¹ impact on their stakeholders. Other countries (including Australia, Canada, Japan, Singapore, and the UK) may follow the trend, and adopt similar legal requirements.²

Patients and patient groups are one of pharma's key stakeholders. So, the question must be: How can pharma introduce patient-group perceptions into assessments of its corporate ESG activities? To address this question: PatientView has produced a new toolkit that should go some way to help pharma companies define and standardise the measurement of their ESG impact on patients (and *patients'* representative patient groups).

About PatientView's new ESG toolkit

PatientView is now in its 3rd year of research into assessing patient perspectives of pharma's ESG activities. This latest toolkit seeks to quantify, for the first time, patient opinions on the ESG practices of:

- a.) The pharma industry as a whole; and
- b.) 15 'big-pharma' companies³ currently holding a detailed ESG agenda (some smaller pharma companies are also clearly active in the ESG arena).

PatientView created the toolkit after developing a patient-group questionnaire, drawing on previous PatientView research as an evidence base, together with input from several pharma companies. The questionnaire was used in an October-November 2024 survey, collecting the responses of

701 patient groups worldwide, from 74 countries, in 201 specialties.

The resulting insights into patient-group priorities for corporate ESG has allowed a set of 8 indicators to be formulated to measure pharma-company effectiveness at ESG (from a patient perspective). These 8 indicators should go some way to defining and standardising how pharma can measure its impact on patient society.

The 15 big pharma companies reviewed are:

- AbbVie • Amgen • AstraZeneca
- Boehringer Ingelheim • Bristol Myers Squibb
- Eli Lilly • Gilead Sciences • GSK
- J&J Innovative Medicine (formerly Janssen)
- Merck & Co/MSD • Novartis • Pfizer
- Roche/Genentech/Chugai • Sanofi • Takeda.

¹ Environmental, Social and Governance (ESG) was a term first introduced in 2004 by the United Nations, to encourage companies to consider issues of sustainability in their investment decisions. Since then, the concept of 'Socially Responsible Investing (SRI)' emerged as a way for investors to align their portfolios with ESG values, compelling more and more companies, including pharma, to adopt in-house ESG strategies.

² <https://www.sustainalytics.com/esg-research/resource/investors-esg-blog/get-ready-to-hear-the-term-double-materiality-what-it-means-for-investors>

³ Although only 15 'big-pharma' companies are included in the analysis for this PatientView toolkit, respondent patient groups also reported on the effectiveness of another 25 pharma companies' ESG strategies. The additional 25 are:

• Astellas Pharma • Bayer • Biogen • BioMarin • Chiesi Farmaceutici • CSL Behring • Daiichi Sankyo • Eisai • Grünenthal • Ipsen • LEO Pharma • Lundbeck • Menarini • Merck KGaA/EMD Serono • Novo Nordisk • Octapharma • Otsuka • Pierre Fabre • PTC Therapeutics • Sarepta • Servier • Sobi • UCB • Vertex • ViiV Healthcare. Any of these companies wishing to know their scores and position on the ranking table can write to PatientView at report@patient-view.com, to get their results.

Key findings

■ PHARMA COMPANIES INDUSTRY WIDE

- ▶ **Growing interest in ESG among a diverse body of patient groups.** The 701 respondent patient groups form a self-selected sample interested in the subject of ESG. The large number (and the various types) of patient groups participating in this PatientView ESG study suggests that the topic of ESG matters to many patient groups in general [see end of press release for a profile of the 701 respondent patient groups].
- ▶ **However, the USA is a particular case.** Distinct attitudes to the integrity of ESG in Western Europe and the USA meant that fewer US patient groups responded to this ESG survey than usually do to other PatientView research. The USA has seen a recent rise in anti-ESG sentiment⁴.
- ▶ **A significant majority of the 701 respondent patient groups reported that all three fields (E, S, and G) were important to them**—but, particularly, the fields most relevant to pharma's impact on society. Over half of the respondent patient groups said that they “always” or “sometimes” bear in mind pharma's ESG activities when deciding whether to partner with a pharmaceutical company.

How important to your patient organisation are the following, 2024?

Percentage of total responses

		Important	Not important – might be in future	Not important	Not relevant	Do not know
E	The impact a pharmaceutical company has on the environment	67%	18%	4%	7%	5%
S	The impact a pharmaceutical company has on society	94%	3%	1%	1%	2%
G	A pharmaceutical company's standards of corporate governance	88%	5%	2%	1%	3%

When deciding with which pharmaceutical company your organisation would like to form a relationship, do you take into consideration any of the following, 2024?

Percentage of total responses

		Always	Sometimes	No – but plan to	No	Not relevant	Don't work with pharma	Do not know
E	A company's efforts to... Protect the environment	30%	28%	8%	13%	9%	5%	7%
S	A company's efforts to... Address social, or society-wide, issues	62%	21%	3%	4%	3%	5%	4%
G	Ensure effective corporate governance	52%	21%	4%	7%	5%	5%	7%

⁴ <https://www.eiu.com/n/anti-esg-sentiment-in-the-us-weakens-esg-markets/>

■ INDIVIDUAL PHARMA COMPANIES

The 15 ‘big-pharma’ companies included in the research were assessed by respondent patient groups, according to 8 indicators:



PatientView provides two sets of company-specific results:

1. The 15 companies' rankings for the eight indicators of ESG—as assessed by respondent patient groups **familiar** with each company (plus each companies' overall 'familiar-with' ranking).
2. The 15 companies' rankings for the eight indicators of ESG—as assessed by respondent patient groups **working** with each company (plus each companies' overall 'working-with' ranking).

Note:

Rankings based on scores calculated to three decimal places; ordered high to low.

AstraZeneca includes Alexion.

Janssen was renamed Johnson & Johnson Innovative Medicine (J&JIM) in late-2023.

Roche is known as Genentech in the USA, and as Chugai in Japan.

The top-three overall rankings among 'big pharma' for being "Best" at ESG from patient perspective, 2024 (out of all 15 companies)—as assessed by respondent patient groups **familiar** with the company:

- **1st**, Roche
- **2nd**, Gilead Sciences
- **3rd**, Johnson & Johnson Innovative Medicine (J&JIM)

The top-three overall rankings among 'big pharma' for being "Best" at ESG from patient perspective, 2024 (out of all 15 companies)—as assessed by respondent patient groups **working** with the company:

- **1st**, Gilead Sciences
- **2nd**, Roche
- **3rd**, AstraZeneca

■ HOW PHARMA CAN IMPROVE ITS ENGAGEMENT WITH PATIENT GROUPS ON THE SUBJECT OF ESG

A pharma company may be generally compliant with ESG standards. But, unless the patient or patient-group stakeholder sees personal benefit from the company's actions on ESG, those company actions might not translate into a positive ESG assessment of the company from the stakeholder.

Many (of course, not all) pharma companies limit their exchanges with patient groups to a focus on the subject of the treatments the companies offer. Patient groups, though, continue to believe that all pharma companies should extend their remit much further—for example, into helping boost patient access to care and pathways; into improving the quality of the services the companies provide; and into addressing health inequities⁵. Such categories fall well within patient-group understanding of what the goals of company ESG interventions should be.

Of the 701 patient groups responding to the PatientView ESG survey, 368 offered 424 commentaries and priorities on the types of support that patient groups would like from pharma to help them engage more effectively with pharma companies' ESG activities. The commentaries are thematically analysed in the toolkit, and fall into two clear areas for action [example feedback is provided immediately below].

Pharma interventions needed

% of all commentaries

I. Developing pharma/patient-group relations in the context of ESG	43%
Create and maintain relations	10%
Build closer contact	24%
Co-design relevant measures	9%
II. Issues of importance to patient-groups around pharma's ESG agendas	54%
Demonstrate practical action	31%
Use clear and targeted communication	17%
Focus on treatment and care	6%

A small number (14) of the 368 respondent patient groups offering comments *on pharma's ESG* practices felt that the topic of pharma-company ESG was not relevant to them (nor to the patient communities they support)—either out of principle, or due to lack of patient-group resources, or because the patient groups do not work with pharma.

⁵ Patients in Action, Part II, PatientView, October 2024

Enable transparent 2-way communication and effective involvement	<p>“For pharmaceutical companies working with multiple sclerosis, it is crucial to have:</p> <ol style="list-style-type: none">1) Transparency – to communicate clearly their ESG initiatives and how they impact patients.2) Education – to provide information about the disease and sustainable practices via workshops and educational materials.3) Dialogue – to create channels to listen to patients’ concerns about treatment and sustainability.4) Collaboration – to work with patient support organisations to understand their needs better.” <p>National multiple-sclerosis patient group, Brazil</p>
Acknowledge patient-groups’ own work in ESG	<p>“Our group is very in tune with matters of ESG. Proof of this is that we have an ESG Rating certificate that assesses our activity. Advice: factor the efforts we make towards sustainability into their assessments and compare this with other groups.”</p> <p>National RMD patient group, Spain</p>
Improve the local healthcare landscape	<p>“Pharma companies should approach ESG in Ethiopia by embedding social responsibility, sustainability, and patient-centered care into their strategies, ensuring that their actions positively impact the local healthcare landscape, while building trust with patient communities.”</p> <p>Regional bleeding-disorders patient group, Ethiopia</p>

Finally, PatientView would like to thank the 701 patient groups that gave up their time to respond to the survey on pharma and ESG.

We hope that the ESG toolkit’s analyses will go some way to establishing a mechanism for pharma to measure patients’ and patient-groups’ views on pharma’s ESG activities (and the impact that the ESG activities have on these stakeholders).

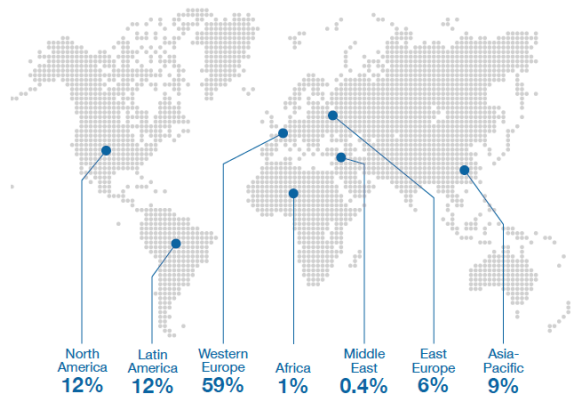
For further information on the ESG toolkit, please use contact details at the beginning of this press release.

END OF PRESS RELEASE

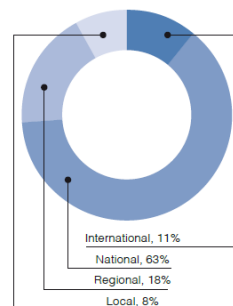
Appendix: Profile of the 701 respondent patient groups

Regional/country headquarters of respondent patient groups

Percentage and number of respondents, N= 701
One respondent did not specify their country headquarters

**Geographic reach of respondent patient groups**

Percentage of respondent patient groups, N=701
One respondent did not specify their geographic reach

**Specialties of respondent patient groups, 2024**

Number of respondents, N= 701
Respondent patient groups may fall into more than one category of specialty

Main therapeutic categories: Percentage of respondent patient groups

	%		%
Allergic conditions	1.4	Medical research	0.6
Autoinflammatory diseases	0.3	Men's health	2.4
Bleeding disorders	2.3	Mental health	3.9
Blood disorders	1.1	Musculoskeletal conditions	0.7
Bone conditions	1.9	Neurological conditions	13.1
Cancer	20.5	Neurodegenerative diseases	6.9
Cardiovascular diseases	1.1	Neuromuscular conditions	1.9
Carers, family, friends	1.0	Older people	0.6
Cerebrovascular diseases	1.0	Other autoimmune conditions	1.4
Children's health	1.9	Other circulatory conditions	0.1
Chronic diseases in general	0.6	Other disabilities	0.1
Endocrine conditions	5.5	Patient advocacy	1.4
Gastrointestinal conditions	2.7	Patient education	0.9
General health	3.0	Patient safety	0.1
Gynaecological conditions	0.7	Rare diseases	20.1
Hearing loss	0.3	Reproductive health	0.3
Heart conditions	2.0	Respiratory conditions	6.9
Hepatitis	1.1	Rheumatic diseases	6.2
HIV/AIDS	4.9	Skin conditions	3.9
Immune disorders	0.9	Spinal disorders	0.1
Infectious diseases	0.7	Transplants	1.4
Kidney diseases	3.0	Urinary conditions	0.9
Learning disorders	0.4	Visual impairment	2.3
Liver diseases	1.9	Women's health	5.0