The pharmaceutical industry:
A global survey of patient groups
Part 1
Patient groups’ perspectives on the pharmaceutical industry: a global survey

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Patient groups’ perspectives on the pharmaceutical industry

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The health advocacy movement, which includes patient groups, has been expanding rapidly throughout the world (with perhaps the biggest growth in numbers of NGOs occurring in Europe). Patient groups are now accepted as part of the healthcare landscape. They help shape policy, act as watchdogs, defining appropriate healthcare infrastructure, and fight on behalf of their constituencies for access to affordable medicines.

Pharmaceutical companies have always seen patient groups as one among many mechanisms for expanding their commercial impact. Yet, with these two healthcare stakeholders sharing a common desire to improve the delivery, quality and effectiveness of medicines, the idea that patient groups and pharma companies should seek to build relationships with each other may not be as inappropriate as some commentators believe.

The process of developing pharma/patient group relationships that are both tangible and ethical can be fraught with difficulties, however—not least because both sides do not always fully understand one another.

The drug industry has several well-known major failings. For instance, pharmaceuticals do not always lead to equitable health among populations. The high prices of certain medicines mean that some patients inevitably have to do without them.

Similarly, excessive marketing and promoting of medicines can result in an over-consumption of pills, which can be dangerous for patients.

Pharma R&D also stands accused of focusing on the needs of richer nations, while ignoring diseases endemic in poorer countries.
Patient groups that liaise with pharma can have their reputations tarnished by indirect linkage to these undesirable trends.

As governments and the public place ever greater emphasis on corporate ethics, reputation and accountability, pharmaceutical companies have come under continued pressure to disclose any active relationships they may have with non-corporate entities (such as doctors and patient organisations) that could influence the sales of medicines.

Issues of transparency which have been around for years continue to reach the headlines. An October 2008 article written by Jeremy Laurance, and appearing on the front page of the UK newspaper The Independent, stated: “Patient groups that have been among the most vocal in spearheading attacks on the UK’s National Institute for Clinical Excellence (NICE) over its decisions to restrict the National Health Service’s access to drugs depend, for up to half of their income, on drug companies. Details of this income are often undisclosed.”

HSCNews International pointed out in a previous issue [‘Latest data on the global patient movement’, issue 44/45, August/September 2008, pp 24-25] that some parts of the pharmaceutical industry are being more open than ever before about their associations with patient organisations. Noteworthy is GlaxoSmithKline, which now publishes on the GSK website details of the company’s donations to patient groups—including the amount given, and its proportion of the NGO’s total revenue.

Another pioneer is the Swedish pharmaceutical trade organisation, Läkemedelsindustriföreningens Service AB, which, as part of a programme called The Price of Credibility, publishes financial data on virtually all of its member companies’ relationships with Swedish patient groups.

Yet, even if pharma is taking strides in the direction of transparency, the industry continues not to consult with the patient community in any significant way. Few pharma companies reach out to patient groups to ask their advice on how to improve the image of pharma-patient group relationships.

What proportion of your income do you draw from pharma companies in an average year?

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What patient groups say about contact with pharma

GROUPS WITH NO (OR LITTLE) CONTACT WITH PHARMA

The Advocacy Initiative Network of Maine is a US local mental health organisation. It does not draw any income from pharma companies, as it does not want to be accused of promoting pharma interests.

“We were contacted by one company that wanted to get information out about their drug. We met with her once, and that was the end of it.”

A personal response from a member of a US group that does not draw any income from pharma.

“I have, on one or two occasions, been asked by pharmaceutical companies for my opinion about how they market weight-loss drugs. I have uniformly explained that their entire business model for such drugs is steeped in prejudice, and, as such, is wholly unconscionable, and unrecuperable by any means.”

Voz Pro Salud Mental DF is a Mexican national mental health organisation that obtains a small proportion of its income from pharma.

“They do not understand our work, and do not see us as professionals. We had good support once, but just from one pharmaceutical company.”

GROUPS WITH REGULAR CONTACT WITH PHARMA

The National Nieman Pick Disease Foundation is a US national metabolic and degenerative neuromuscular organisation. The group receives a small proportion of its income from pharma. Its annual national medical conference is funded by Genzyme.

“We are in the process of finding a cure, and, right now, our pharmacy contact is with companies that have products designed to help with the ailments associated with the disease process. Each child has different ailments, and thus the contact can be wide ranging.”

A personal response from a representative of a US national disability organisation not funded by pharma.

“They [pharma] just see power in doctors and media companies that do not know, most of the time, what a psychiatric illness is, or the way we live, feel, and handle the illness through life.”

The Defeat Diabetes Foundation is a US national diabetes organisation that does not draw income from pharma.

“People with diabetes are often dependent upon insulin or other oral medications to maintain their glucose control, so we keep up to date on the latest drug trials and new diabetes-related drugs that come into the marketplace.”

Gunter Feick is the chair of Bundesverband Prostatakrebse Selbsthilfe e. V. (BPS), a German national prostate cancer advocacy organisation that receives a small or tiny proportion of its income from pharma. The group notes that it only accepts funds from private, public, or government sources if the money is provided unconditionally, with no intent to influence the goals or practises of the BPS.

“It is in the best interest of prostate cancer patients to communicate with pharmaceutical companies to:
1. Learn about new developments.
2. Provide information on patient observations and expectations.
3. Enhance prostate cancer research.”
About the respondents to this *HSCNews International* survey on patient group perspectives of the pharmaceutical industry

» A total of 384 groups from 49 countries completed the short questionnaire of six open-ended questions. The US, with 86 respondent groups, generated the highest single response rate.

» A wide array of disease conditions are represented among the respondents.

» 30% of respondent groups report deriving some portion of their income from pharma.

» 57% receive no pharma funding—either because they choose not to, or because pharma is uninterested in funding them.

» 58% have regular or occasional contact with pharma. Being in contact with pharma is not the same as taking money from pharma, however. Many groups meet repeatedly with pharma companies to discuss the latest drug developments in their disease area. Others only come across pharma executives at conferences. 29% of the respondent body has no contact with pharma. Some in this latter category say that they would like to have contact with pharma.

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This issue of *HSCNews* reports on the results of a global survey that seeks to find out what patient groups currently think of the pharmaceutical industry.

<table>
<thead>
<tr>
<th>How often does your organisation make contact with pharma companies?</th>
<th>% of responses</th>
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The respondent groups differ in the types of relationship they have with pharma. Some, for instance, keep regular contact with the industry. Others have no contact at all.

Some are dependent on pharmaceutical companies for large sections of their income. Others take no money from the industry.

**About the study**

This survey was completely independent, and was funded only by PatientView, the publisher of *HSCNews International*.

Part I of the study focuses on patient groups’ opinions on the following subjects ...
• Pharmaceutical companies’ trustworthiness (including their ability to manage conflicts of interest and adverse news about their products).
• Pharma’s record of innovation.
• Whether pharma provides effective support to patients who take their products.
• How pharma’s agenda affects patients.
• The transparency standards and quality of pharma’s relationships with patient groups.

The study looks at whether groups in close contact with the industry have different attitudes to it than their peers uninvolved with any pharma companies.

Issue 46 concludes with the results of a request to the respondent groups to individually assess a number of the world’s leading pharma companies (though only if each patient group felt familiar enough with each company to be able to offer a competent opinion). The patient groups assessed pharma companies on four criteria: each company’s trustworthiness; its ability to handle relationships with patient groups; its ability to supply patient information; and its understanding of patients’ needs. Listed in tables are the ten companies voted by the patient groups as best performers in each of the four criteria.

The second part of the study results

The study also produced a huge range of advice from the respondent patient groups on how the pharmaceutical industry could offer greater non-financial support to health advocates. These results will be published in HSCNews International, issue 47 (expected late December 2008).
Between October and November 2008, *Health and Social Campaigners’ News International* conducted a global survey of patient groups. The study aimed to discover respondents’ latest views on the subject of the pharmaceutical industry. The survey received 384 responses from 49 countries, with a broad range of disease areas represented. Respondent groups could be (approximately) divided evenly between those that do, and those that do not, maintain some sort of relationship with pharmaceutical companies.

The survey has found that patient groups’ views of pharmaceutical companies are complex, and influenced by the fact that these organisations’ main goal is protecting the interests of their constituency (who may often be sick, and are sometimes poor, and are therefore among society’s weaker members). The study shows that patient groups share little empathy with the world of commerce. The majority of the groups have difficulty understanding how an industry dedicated to making profit can also claim to hold at heart the interests of the vulnerable sick. These preconceptions impact profoundly on patient groups’ views of all aspects of pharma activities. The industry’s profit levels, plus the high prices of some of its drugs, cloud almost every aspect of the patient groups’ thinking on pharma.

**Pharmaceutical companies’ trustworthiness in light of vested interests**

~ Just 37% of the total number of respondent groups say that they believe pharma companies are good (or better than good) at being trustworthy. Only one quarter think that pharma companies are good (or better than good) at managing conflicts of interest. 39% regard pharma companies as good (or better than good) at managing adverse news about their products.

~ The groups in regular contact with the industry hold more mixed attitudes. 60% of these groups consider pharmaceutical companies as good (or better than good) at being trustworthy. However, just 46% of the same set of groups are confident that the companies do a good (or better than good) job at managing conflicts of interest. Only 44% indicate that the companies are good (or better than good) at managing adverse news.
Pharma’s drug pricing policies

~ This survey has found drug prices to be the most divisive issue between patient groups and the pharmaceutical industry. Up to 73% of the respondent groups think that pharma’s pricing policies benefit only the industry itself. One of the most frequent comments received by the survey is that respondent patient groups want pharma companies to reduce the prices of products, making them more affordable to a wider population of patients. Respondents emphasise in note after note that they really do not understand why pharma companies cannot be more altruistic. The Council on Size and Weight Discrimination, a US national organisation that draws no income from pharma, is doubtful about the prospects for change:

“Business needs to make money for its owners and stockholders, and the financial stakes are very high.”

Pharma’s marketing to doctors

~ 57% of the respondent patient groups believe that the marketing efforts made to doctors by pharmaceutical companies are for the sole benefit of pharma. Even 47% of the groups in regular contact with pharma think the same way. Comments received by the survey indicate that the respondents see pharma as too focused on marketing to doctors, who themselves are perceived by the groups as vehicles for bolstering pharmaceutical company revenues.

Pharma’s record of innovation

~ Patient organisations have traditionally been supportive of pharmaceutical innovation. This survey, though, finds that such backing, while still present, may be waning, due to pharma’s reluctance to take more notice of what patients actually want from innovation (including products that better suit personal needs). The Canadian Arthritis Patient Alliance (CAPA), a national organisation that takes funding from pharma, offers an example of overlooked patients’ needs:

“Pharma is getting better at innovating to meet patients’ needs. But a great deal of improvement is possible. Innovating to meet patients’ needs requires engagement between a patient group (such as an inflammatory arthritis group) and pharma, to identify those needs. Two examples of existing needs are pre-loaded syringes and spring-loaded syringes for drug administration.”

As a result, only 44% of all respondents estimate pharma companies to be good (or better than good) at innovating to meet patients’ needs. On the other hand, around 60% of the groups in regular contact with pharmaceutical companies are convinced that industry’s record on innovation to meet patients’ needs is good (or better than good).
Pharma’s ability to help patients comply with treatment
~ The majority, or 67%, of respondents believe that pharma’s record is no better than fair, poor, or bad in improving patient compliance (an exception are diabetes and neurological groups, which are more impressed with pharma in this regard). The equivalent figure for groups in regular contact with pharma is, at 55%, also quite high. One possibility here may be that the health advocacy community’s relative distrust of pharma is among the factors impairing the industry’s ability to improve patient compliance.

Patient information and patient safety
~ The pharmaceutical industry wins plaudits from the majority of respondent patient groups in two of its activities: supplying patient information, and ensuring that products are safe. A few groups, however, suspect that the only reason pharma excels in these areas is that it is obliged to follow government regulations which demand companies act responsibly. A number of the respondents feel that pharma could do still more if it wanted to, particularly in the surveillance of medicines after they are launched on the market.

A more positive outlook for the future
~ Respondents appear to believe that pharmaceutical companies, despite their failings, are trying to improve relationships with patient groups and their standing in the health advocacy community. Some respondent patient groups explain why they rated highly certain companies (such as those listed below). In brief, they observe, pharma companies are best remembered and respected for actions that have a tangible and positive effect on patients—whether this is via the supply of valuable information, or through the quality of innovation, or a generally positive approach to patient wellbeing. As one Australian mental health group insists:

“Patients’ needs are for more than just medication.”

| Pharma companies voted by patient organisations as the best performers in four criteria |
|-----------------------------------------------|-----------------------------------------------|
| Trustworthiness                               | Johnson & Johnson                             |
| Handling relationships with patient groups    | Novartis                                      |
| Supplying patient information                 | Pfizer                                        |
| Understanding patients’ needs                 | Pfizer                                        |
Only a minority of the 384 groups responding to the survey believe that pharmaceutical companies are good (or better than good) at being trustworthy. Even among the respondents that take money from pharma, only just under half regard pharma companies as good (or better than good) at being trustworthy. However, the equivalent figure for groups in regular contact with pharma is slightly higher, at 61%. Respondents give the following sets of reasons why trust in pharma is not greater.
Pharma is overly focused on doctors, not patients
Patient groups think that the industry continues to see medical professionals as the most important of the healthcare stakeholders—mainly because of the influence the latter can exert collectively on the growth of pharma company revenues. ‘Arvan’, an Estonian national multiple sclerosis group that does not receive any of its income from pharma, notes:

“Speaking about the last four years, pharma companies have given no information to, made no propositions to, or had any contacts with, our patient organisation, Arvan. They work only with doctors.”

A member of an anonymous US local mental health organisation that does not draw any income from pharma relates:

“I never met a drug rep who wanted to speak to me, as an advocate (or as a patient). They only want to speak to the doctor, who can prescribe their meds, and make them money.

An allergy group from Pakistan which does not get any income from pharma believes that a distinction can be made between home-grown and overseas companies:

“We have found national or local pharmaceutical companies to be more patient-conscious—as compared to multi-nationals, which are more commercially minded.”

The high prices of some medicines
Some prices seem unjustified to the respondent groups in the light of marginal improvements in therapeutic value. A representative from a German kidney donor group thinks that the prices of drugs exceed what is reasonable:

“Unfortunately, the companies’ profits govern all actions. Prices are far too high for me among too many products—especially new pharmaceuticals.”

Similarly, an anonymous representative of a local US group that does not draw any money from pharma declares:

“In my opinion, pharmaceutical companies are more interested in making money off a patient’s misfortune, particularly cancer patients. The amount of money they charge for almost any drug associated with cancer is ridiculous. Therefore, cancer patients

Pharma trustworthiness: key findings
✓ Out of a total of 384 respondent groups, 37% say that pharma companies are good (or better than good) at being trustworthy. Around the same number, 34%, think that pharma companies are poor or bad at being trustworthy, while 31% indicate that the companies are fair at being trustworthy.

✓ Among patient organisations that take funding from the drug industry, levels of confidence in pharma’s trustworthiness are slightly higher—but not by a great margin. Almost half (49%) of these latter groups describe pharma companies as good (or better than good) at being trustworthy. But a significant minority of the pharma-funded groups, 34%, think that pharma companies are poor or bad at being trustworthy. A further 31% assess the companies as only fair at being trustworthy.

✓ As many as 61% of the 77 patient groups that have regular contact with pharmaceutical companies declare pharmaceutical companies to be good (or better than good) at trustworthiness.
very often do not have good options for treatment. I associate pharmaceutical companies with greed (just like all the rest of corporate America).”

A local asthma group from the Czech Republic that receives a moderate amount of its income from the drug industry maintains that pharmaceutical companies do not consider people’s welfare to be their primary interest:

“The impression is that big pharmaceutical companies are just running after their enormous incomes, without any real interest in people.”

The point is endorsed by many others, including a member of an Irish diabetes group, who states:

“The companies place financial gain at the head of their objectives.”

The Costa Rican branch of an anonymous global organisation that draws a large proportion of its income from pharma describes the industry’s efforts to help patients as:

“Sometimes, it is more for the money, than thinking of their real needs.”

A South African national disability group which takes a small or tiny proportion of its income from pharma considers that because “the public mainly sees the pharmaceutical industry’s huge profits”, public opinion remains focused on this aspect of pharma company operations, rather than on the good that the industry brings to society in general. In fact, high prices for medicines that only offer the most incremental of extra benefits (if any) may explain why the public is so focused on the industry’s profits.

**Trustworthiness and ethical standards**

A representative of a Danish mental health organisation argues that even when pharmaceutical companies agree with advocacy groups to run mutual endeavours for non-profit motives, the former do not always uphold their side of the agreement:

“Our meetings are friendly. But the outcome is not impressive. I don’t think our policy of integrity has any influence.”

A number of groups comment on the variation in ethical standards between one pharma company and another. One Venezuelan national HIV/AIDS organisation that gets a number of small travel and subsistence grants from pharma believes that the industry’s behaviour is largely above board. The group says of its

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**Pharmaceutical companies’ general ability to manage conflicts of interest: key findings**

- Out of a total of 369 respondent groups that answered this question, only one quarter judge pharma companies to be good (or better than good) at managing conflicts of interest; 41% think the industry to be poor or bad in this area.

- A slightly larger percentage of the groups that receive funds from the industry (36%) say that pharmaceutical companies are good (or better than good) at managing conflicts of interest. 28% of the pharma-funded groups think the industry to be poor or bad here.

- 62% that have regular contact with pharma perceive companies as good (or better than good) at being trustworthy. Only 46% of the groups in regular contact, though, report that pharma companies are good (or better than good) at managing conflicts of interest.
relationships with the industry:

“On average, it is a ‘fair’ deal, even though some companies do stand out from others. We have not yet had to deal with a corporation that could be rated as having poor or bad practices.”

Conflict of interest

The Encyclopaedia Britannica defines the phrase ‘conflict of interest’ as a public or corporate official’s conflict between private interests and public responsibility.

In principle, pharma’s interests should be aligned with those of the public. Both sides want good medicines, and the more money that pharmaceutical companies generate from medicines, the more the industry should be able to reinvest in R&D for the good of all. But making money has not always proved to be associated with patients’ interests (one example often cited is the industry’s reluctance to produce products for third-world diseases).

The majority of patient organisations in this survey are unsure whether pharma companies do a good job at managing conflicts of interest.
One Australian local mental health group that does not draw income from pharma regards any relationship between profit-making and non-profit-making organisations as bound to generate conflicts of interest:

“There is an inherent conflict of interest for pharma to have relationships with patient groups (even if pharma works diligently to minimise the conflict of interest).”

A US national group that wishes to remain anonymous, and which receives a moderate amount of its income from pharma, accuses companies of breaching due-diligence rules:

“Pharmaceutical companies break the rules and encourage conflicts of interest, and we all suffer for it.”

For the most part, though, respondents complain not about what pharmaceutical companies do, but what they do not do—selflessly donate to altruistic healthcare-related causes. The Colorado Cross-Disability Coalition, a US local organisation that receives a small or tiny proportion of its income from pharma, asks:

“Why not give to advocacy groups, as long as it is a free gift, and not a quid pro quo? There would be nothing to be ashamed of on the part of the company or the advocacy organisation.”
Managing adverse news about product

The past decade has witnessed the withdrawal on safety grounds of a number of high-profile drugs. During this period, some pharma companies were accused of holding back bad news about their products, thereby endangering the public's wellbeing.

As a consequence, regulators of medicines have become far more fastidious in demanding that pharma demonstrate that the benefits of its products truly outweigh the risks.

Patient groups, too, have become more cautious about unequivocally embracing pharma products. Some presume that companies fail to own up to all of the adverse effects of their products, or seek to bury facts within unnecessarily complex terminology. One Canadian national neurological organisation that wishes to be anonymous, and which derives a small or tiny amount of its income from pharma, sums up the attitude:

“While companies provide information, it is not always fulsome, and adverse news is handled in a legalistic manner.”

The Health Global Access Project (Health GAP), a US HIV/AIDS organisation with a global reach that does not, on principle, take any money from pharma, agrees:

“They [pharmaceutical companies] frequently hide or misrepresent clinical findings that question the safety or efficacy of their products.”

An anonymous US national organisation that specialises in aspects of clinical research, and which does not draw any income from pharmaceutical companies, adds:

“What to say! Pharmaceutical companies make drugs that save lives and decrease suffering. If they would only be content with these amazing accomplishments ... Yet the companies continually and consistently shoot themselves in the foot by so-called off-label promotion, and by obfuscation of adverse drug reactions.”
Despite the new opportunities afforded to medical research by biotechnologies, material sciences, and the digitisation of various media, the past decade has seen the numbers of novel products emerging from pharmaceutical companies remain low. The situation seems unlikely to change for at least another decade. Valuable new products have been developed, but not in sufficient quantities to support the multinational industries involved in their design. Patient organisations have traditionally been highly supportive of pharmaceutical innovation. This survey finds that such support may be waning.

How good do you think pharma companies (in general) are at innovating to meet patients' needs?

The pattern of responses for US and non-US groups is similar.
Many patient groups still applaud the efforts of pharma. One US national group representing the interests of people with a congenital condition, and which gets a moderate amount of income from pharma, attests:

“We are very grateful for the innovations provided by pharma companies to help alleviate the suffering of our disease community. Their research and support is invaluable.”

Others, however, appear to be losing faith in pharma’s ability to innovate to meet patients’ needs. An anonymous Canadian local mental health organisation notes:

“It costs pharma money to improve some medications. So I think they just sometimes leave them alone, when they could be trying to reduce medication side-effects, for instance.”

Respondents blame a lack of appropriate innovation on the profit motive, which forces the industry to concentrate on diseases that afflict large numbers of patients in well-funded healthcare systems. The strategy sidelines other conditions, including rare diseases, and (as mentioned) those that affect mainly third-world nations.

An anonymous US branch of a global organisation that does not receive income from pharma advises:

“Very few pharma companies work with our disease, as it is rare. We get many of our treatments from other plasma-cell diseases, such as multiple myeloma.”

Similarly affected is America’s Baby Cancer Foundation, a national group that gets no income from pharma:

“The industry does too little to address R&D for new drugs that would cure pediatric cancer because the market segment’s return on investment is ‘too small’.”

The Chronic Illness Alliance, an Australian national group that takes no income from pharma, sums up:

“Companies innovate to patients’ needs if it is competitively useful for them. They don’t do it for any altruistic reason.”

Pharmaceutical companies’ general ability to innovate to meet patients’ needs

- Of the 342 groups answering this question, only 44% think that pharma companies are good (or better than good) at innovating to meet patients’ needs.
- Half of the groups in receipt of pharma funds see pharma as good (or better than good) at innovating to meet patients’ needs. The other half declare that pharmaceutical companies are either fair (30%) or poor/bad (20%) at innovation.
- The groups in regular contact with pharma are more convinced by pharma’s record of innovation. 62% of them submit that pharma is good (or better than good) at innovating to meet patients’ needs.
The majority of the 366 groups answering this question believe that pharmaceutical companies are good (or better than good) at providing patient information and ensuring that drugs are safe. However, these same groups are less positive about the ability of pharmaceutical companies to help patients comply with treatments, or to enable patients to get access to medicines, or to tailor their products or services to suit the needs of individual patients.

**How good do you think pharma companies (in general) are at the following activities?**

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<thead>
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<td>Providing patient information</td>
<td>Fair</td>
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<td>Ensuring that drugs are safe</td>
<td>Poor or bad</td>
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<tr>
<td>Helping patients access medicines</td>
<td>Poor or bad</td>
</tr>
<tr>
<td>Supporting patient compliance</td>
<td>Poor or bad</td>
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<tr>
<td>Personalising products/services</td>
<td>Poor or bad</td>
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Patient groups’ attitudes to the pharmaceutical industry

Pharmaceutical companies’ ability to support patients

61% of the 366 groups answering this question consider pharma companies good (or better than good) at providing patients with information. 56% regard the industry as good or better than good at ensuring that drugs are safe.

The majority of the 366 respondents also believe that pharma companies are only fair, poor, or bad at helping patients get access to medicines (59%), supporting patient compliance (67%), and personalising pharma products and services to suit patients’ individual needs (76%).

77% of the groups in regular contact with pharma affirm that pharma companies are good (or better than good) at providing patient information, while 72% see the industry as good (or better than good) at ensuring drug safety. Just over half (51%) believe that pharmaceutical companies are good (or better than good) at helping patients get access to medicines.

However, the majority of the in-contact groups also think that pharmaceutical companies are only fair, poor, or bad at supporting patient compliance (55%), and at personalising pharma products and services to suit patients’ individual needs (68%).

Patient information

Most patient groups generally welcome the information provided to patients by pharma. Indeed, one Australian herpes support group which takes a small proportion of its income from pharma believes that information from the industry ought be circulated more widely, and that doctors are acting as a brake:

“Pharmaceutical companies do have good information available for patients about living with herpes. Unfortunately, this often does not reach patients, as doctors do not refer them to the information—either through ignorance of it themselves, lack of confidence in the pharma companies, or uninterest in patients’ emotional wellbeing.”

Attitudes toward pharma-generated patient information do, however, vary from country to country. Only 48% of groups from New Zealand, for instance, specify that pharmaceutical companies are good (or better than good) at providing patient information. The remaining New Zealand respondents look on pharma as either fair (29%), or poor/bad (24%) at providing patient information.

In New Zealand, pharma companies are permitted to advertise directly to patients—a practice that has been criticised in the country as unethical. One group, which wishes to remain anonymous, insists:

“The profit-focused behaviour of pharma companies directly undercuts all of the above activities. The only ‘information’ that these companies want you to know is to entice you to buy.”

American groups exhibit a greater tolerance towards direct-to-consumer advertising (DTCA). Almost 60% of the US groups in this survey remark that pharma is good or better than good at supplying patient information.
How good do you think pharma companies (in general) are at providing patient information?

<table>
<thead>
<tr>
<th>Country</th>
<th>% of respondents saying good (or better than good)</th>
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<td>Canada (99)</td>
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<td>57</td>
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<tr>
<td>New Zealand (33)</td>
<td>48</td>
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information. A spokesperson for a US disability group also reports that as many commercials by law firms suing pharma for dangerous drugs appear on US television as pharma commercials.

Outside New Zealand and the US, the supply of patient information is heavily regulated, and pharmaceutical companies are forbidden to undertake DTCA. The regulations afford the public some degree of protection on the quality of the data provided. As one anonymous Australian local mental health group that takes no money from pharma explains:

“Many of these issues are imposed on pharmaceutical companies by codes of conduct and regulation of the industry. Pharma must list contraindications of drugs, adverse reactions, efficacy, etc. They must provide accurate patient information. There is no choice.”

In the rest of the world, the majority of respondents believe that pharmaceutical companies are good (or better than good) at supplying patients with information. The only reservations seem to centre on the readability of the information. As the Advocacy Initiative Network of Maine, a US local mental health organisation that does not take funding from pharma, emphasises:

“They [pharmaceutical companies] provide the patient information, but not always in a manner that can be understood by the patient.”

The same failing is raised by a Canadian local older people’s health-promotion group that does not receive funds from pharma:

“After discussions with my clients, it was found that the enclosed information on new and or existing medication is too wordy, the print size is unacceptable for seniors with decreasing eye sight, and it becomes confusing to the point that it is not read at all.”

[Editor: complexity of language in pharma-provided patient information may sometimes be the fault of regulations governing patient information.]

**Patient safety**

Most respondents to this survey (even groups with no links to the industry) believe that pharmaceutical companies do a good job at
ensuring drug safety. The Canadian Arthritis Patient Alliance (CAPA) provides an illustration of the types of efforts made by pharma:

“Pharma have a patient safety programme that urges knowledge about prescribed medications and the conditions for which they are taken, and have published a downloadable booklet that makes it easy to collect and keep all such information in one place.”

But, despite the general approbation, some participants’ comments highlight specific safety issues about which respondents feel pharmaceutical companies are being opaque. A South African local group that obtains no funds from pharma is not satisfied with the industry’s record in publishing the results of clinical trials:

“One hopes that they try to ensure that drugs are safe. But, obviously, they are not always honest with the clinical trial results.”

The CAPA agrees:

“Making results available—negative and positive—is not a strong point, even now.”

Others argue that pharmaceutical companies are well regarded on aspects of patient safety simply because the law obliges them to be strong in this area. The Schizophrenia Fellowship of NSW, an Australian state-wide group that receives a small amount of income from pharma, comments:

“Australia has a process for the registration, approval, and funding of medications which also requires patient information and safety
A Canadian national organisation that wishes to remain anonymous, and which does not get income from pharma, is opposed to pharma running its own product safety testing:

“Drug safety should be monitored closely by a government agency. To leave that to the pharmas is to invite the fox to guard the henhouse.”

And while, as mentioned on the previous page, the CAPA approves of some pharma activities on the patient safety agenda, the organisation also describes an important limitation in the way that patient safety tests are conducted—tests can have little relevance to a medicine’s application in real life:

“Generally, it’s a mixed bag. Pharma conducts clinical trials, and the amount of resulting overall information about real-world application is limited. We support post-market surveillance, and believe it is imperative for patient safety.”
How good are pharmaceutical companies at helping patients comply with treatments?

% of respondents saying good (or better than good).

(Right-hand figures are total numbers of respondents replying from each country/disease subject area.)

<table>
<thead>
<tr>
<th>Country</th>
<th>Neurological</th>
<th>Diabetes</th>
<th>Rare</th>
<th>Mental health</th>
<th>Cancer</th>
</tr>
</thead>
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<td>New Zealand (21)</td>
<td>24</td>
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</tbody>
</table>

Patient access to medicines

Only a minority of the respondent patient groups think that pharma is good at helping patients get access to medicines. But, when companies are successful at supporting patient efforts to get the right prescription medicines, the groups seem appreciative (even though the industry also benefits in the form of increased sales). Comments include:

“It is seen as benefiting the pharmaceutical company to help patients access medicines. Some work has been done in patient group work with body-mind-life programme.”
—Anonymous Australian local mental health organisation that does not draw any income from pharma.

“They have helped many patients get access to incredibly expensive drugs, and have covered all costs not covered to date.”
—Anonymous Canadian national respiratory organisation that receives a small or tiny part of its income from pharma.

“Some companies have better patient-assistance programmes than others, but, overall, they are quite helpful to low-income families.”
—Anonymous US national congenital organisation that receives a moderate proportion of its income from pharma.

Nonetheless, the general consensus among groups replying to this survey is that pharma could do a lot more to increase patients’ access to medicines—particularly through price reductions. Graciela B. Cámara Cáceres, President of Ingenium Morelos AC, a Mexican national mental health organisation that draws some income from pharma, declares:

“There is no help in reducing prices. It is very difficult for families to support the treatment of their love ones.”

In some instances, patients may require a medicine for a purpose beyond a drug’s approved scope (off-label usage). Doctors can
legally prescribe a drug for whatever intent they like (provided they take responsibility for their actions). Gunter Feick, chair of Bundesverband Prostatakrebs Selbshilfe e.V. (BPS), a German national prostate cancer advocacy organisation that takes a small or tiny proportion of its income from pharma, thinks that the industry could help here:

“Off-label and compassionate-use programmes should be offered more frequently.”

Patient compliance

Compliance occurs when patients adhere to instructions for taking their medication. Compliance is necessary to obtain the optimal effects of treatment. Non-compliance with treatment recommendations has become a major health issue.

Half of the respondent groups that represent the interests of people with two particular disease areas—diabetes and neurological conditions—maintain that pharmaceutical companies are good (or better than good) at helping patients comply with treatments.

To avoid drug side-effects and even premature death, people with diabetes must comply with their treatment regimens. Over the years, pharmaceutical companies that specialise in diabetes, together with medical professionals, have developed programmes to enable patients to self-manage their medications and improve their compliance.

People with neurological conditions are also vulnerable, as their dementia or other symptoms can hinder their compliance to treatment. Yet, when taken properly, medicines for neurological conditions can have a profound impact on the quality of life of such patients. For these reasons, pharma (in conjunction with health professionals) has developed compliance tools that provide simple instructions, and has pushed the idea of regular medication reviews and the increasing involvement of carers.

The majority (67%) of the survey’s respondents outside these two disease areas, however, indicate that the pharmaceutical industry’s record on compliance is only fair to poor. A US national respiratory organisation that wishes to remain anonymous, and which draws a significant (though declining) amount of its income from pharma, blames the situation on low levels of patient trust in the industry:

“Many patients do not turn to pharma companies for education due to lack of trust. They call us for education and advocacy-related concerns. Unfortunately, pharma is providing fewer dollars to support those efforts.”

Restrictions in the communications possible between companies and patients may also explain why patient groups think that pharma companies are, on the whole, not good at helping patients be compliant. An anonymous US national rare disease organisation that draws a significant amount of its income from pharma argues that doctors, therefore, not industry, must shoulder the responsibility for boosting patient compliance:

“Pharma companies are limited with regard to compliance to treatment. The patient-physician relationship is important for compliance. Greater efforts to educate physicians about compliance issues would benefit not only patients, but pharma and physicians as well.”
### Personalising products/services

Only one quarter of the survey’s respondents believe that pharmaceutical companies are good (or better than good) at personalising products and services for individual patients—although views on this subject vary across disease areas. Groups representing the interests of patients with cancer or mental health problems see their constituencies as among the worst served. Cancer Voices NSW, an Australian state-based cancer organisation that draws no income from pharma, stresses that the expense involved in developing personalised therapies make them unattractive to the pharmaceutical industry:

“In the cancer area, drugs often take the approach of ‘one size fits all’. We are advocating for much more personalised treatment, using pharmacogenomics, genetic profiling of cancers, and targeted therapies. This will not increase the revenues of pharma—so, there is a challenge for us all here.”

<table>
<thead>
<tr>
<th>Disease Subject Area</th>
<th>% of Respondents Saying Good (or ‘Better than Good’)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rare</td>
<td>50%</td>
</tr>
<tr>
<td>Neurological</td>
<td>44%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>44%</td>
</tr>
<tr>
<td>Cancer</td>
<td>18%</td>
</tr>
<tr>
<td>Mental health</td>
<td>13%</td>
</tr>
</tbody>
</table>

(Right-hand figures are total numbers of respondents replying from each disease subject area.)

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**How good are pharmaceutical companies at personalising products and services for individual patients?**

% of respondents saying good (or ‘better than good’).

(Right-hand figures are total numbers of respondents replying from each disease subject area.)
Activities benefiting pharma

The pricing policies of pharmaceutical companies stand out as the most contentious of the issues referred to by the survey’s respondents. Industry has conducted high-profile campaigns that defend drug prices on the basis of the significant investment required by R&D. For the most part, though, patient groups seem unimpressed by the argument.

Do you or your organisation think that the following pharmaceutical company activities benefit patients or pharma, or both?

% of total responses of 366 groups

- Pricing policies
- Marketing activities to doctors
- Efforts to get drugs reimbursed
- Post-marketing surveillance (PMS)
- Disease-awareness campaigns

... continued on page 32
Who benefits?

✔ Of the 366 respondent groups answering this question, 73% consider that pharma's pricing policies only benefit the industry. 57% of these groups believe that pharmaceutical companies' marketing efforts to doctors also act to the sole benefit of pharma.

✔ The majority of respondent patient groups (60%) think that other aspects of pharma activities (including efforts to get drugs reimbursed, post-marketing surveillance, and disease-awareness campaigns) generate benefits for patients and industry alike. One exception is that half of the respondents from the UK maintain that pharmaceutical company moves to get drugs reimbursed by the country's national health service (NHS) only benefit pharma.

Do you or your organisation think that the following pharmaceutical company activities benefit patients or pharma, or both?

% of responses from the 74 groups answering the question that are in regular contact with pharma.

- Pricing policies
- Marketing activities to doctors
- Efforts to get drugs reimbursed
- Post-marketing surveillance (PMS)
- Disease-awareness campaigns

- ☐ Benefits patients
- ☐ Only benefits pharma
- ☐ Benefits both
Do you or your organisation think that the following pharma company activities benefit patients or pharma, or both?

% of respondents saying “only benefits pharma”. The larger the number, the less benefit to patients.

(The single numbers in each title category [eg. “Rare, 10"] are the total number of respondents replying from that country/disease subject area.)

<table>
<thead>
<tr>
<th></th>
<th>Australia (27)</th>
<th>Canada (69)</th>
<th>Ireland (21)</th>
<th>New Zealand (21)</th>
<th>UK (11)</th>
<th>USA (107)</th>
<th>Cancer (20)</th>
<th>Diabetes (16)</th>
<th>Mental health (31)</th>
<th>Neurological (19)</th>
<th>Rare (10)</th>
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<td>Marketing to doctors</td>
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</tbody>
</table>

... continued from page 30

As Acción Solidaria, a Venezuelan national HIV/AIDS organisation that takes a small or tiny proportion of its income from pharma, observes:

“Even though we understand the need to recover the costs of years of research, we believe that some corporations have been indifferent to people’s needs in some resource-poor settings. The necessity for a balance is absolutely necessary.”

Feelings on the subject of pricing can run high among groups, as a comment from MS Forbundet i Sog og Fjordane, a Norwegian national multiple sclerosis organisation that does not draw income from pharma, illustrates:
Comments like this are the exception among the respondents, not the rule …

“Pharmaceutical companies are businesses. They know that they need to keep patients happy to make money, so they make changes to benefit patients, expecting to then increase business.”

—Anonymous Irish local organisation that specialises in paediatric physical disability, and which does not draw any income from pharma.

“It’s all about money, and it only benefits pharma.”

The Chronic Illness Alliance advises that some current prices can deny poorer patients access to medicines:

“If citizens were reliant on pharma pricing policies, most drugs would be unaffordable.”

The anonymous US national rare disease organisation mentioned on page 28 is one respondent that attributes high drug prices to influences beyond just pharma alone:

“Pharma pricing policies are compounded by US insurance-company policies (including pricing, lifetime caps, etc). This makes the burden greater on patients—especially patients with rare diseases.”

Marketing strategies of pharmaceutical companies come under fire for much the same reasons as pricing policies. Marketing is perceived by 57% of the respondents to entail unnecessary expense, and to only benefit pharma. An Irish national neurological organisation that draws a small or tiny proportion of its income from pharma wonders whether drug prices are inflated by having to subsidise large advertising and marketing budgets, rather than just R&D:

“The cost of drugs is extremely high. I would like to see what percentage of their budgets go towards advertising and entertainment.”

One anonymous Australian local mental health organisation that does not draw income from pharma warns that vigorous marketing can sometimes lead to inappropriate prescribing:

“Marketing efforts can benefit both, but undue pressure on doctors might cause them to push new products onto their patients, when older medications were working well, and change is not necessarily going to benefit the patient.”

An anonymous New Zealand local liver group that does not draw income from pharma agrees:

“We personally want medicines prescribed that work, with the least side affects, rather than the cheapest, or most pushed.”

Mutually beneficial activity

60% of the survey’s respondent patient groups see advantages for patients in the efforts made by pharma across three subject areas: getting drugs reimbursed; pharma surveillance of medicines after they have been sold; and pharma campaigns to raise awareness of the social and economic ramifications of specific diseases on society.

Caveats do exist, though. In the case of post-marketing surveillance (PMS), the
consensus among respondents appears to be that levels of PMS could be stepped up. Two cancer groups explain:

“We see little evidence that pharma surveys the safety of products after drug approval.”
—Cancer Voices NSW.

“Not enough pharmas do phase-IV clinical trials (post-approval studies). So I’m not sure how patients benefit. If they’re doing these studies, we aren’t hearing about them.”
—Anonymous US regional cancer organisation that receives a moderate proportion of its income from pharma.

Groups caution, too, that disease-awareness campaigns should not become a surrogate form of product promotion, which, in effect, prompts patients to ask doctors for medicines they do not need. The US Health Global Access Project submits that:

“Some disease-awareness campaigns and some marketing efforts contain some useful information. But the information is frequently presented in a product-promoting context.”
Only one third of the 326 groups answering this question feel that pharmaceutical companies are good (or better than good) at being transparent about their relationships with patient groups. The equivalent figure among the 162 respondent groups that take some funding from industry is 43%. Among the 74 groups in regular contact with pharma, the figure is 53%.

How good do you think pharma companies (in general) are at being transparent about their relationships with patient groups?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Total answering this question (326)</th>
<th>No funds from pharma (204)</th>
<th>Some funding from pharma (162)</th>
<th>Regular contact with pharma (74)</th>
</tr>
</thead>
<tbody>
<tr>
<td>9%</td>
<td>2</td>
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<td>3</td>
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<td>12%</td>
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<td>42%</td>
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<tr>
<td>76%</td>
<td>22</td>
<td>22</td>
<td>22</td>
<td>17</td>
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HSCNews International, issue 46
A few of the respondent groups advise that levels of transparency about relationships between pharma and patient groups have greatly improved in recent years. One anonymous UK national continence group that draws a significant proportion of its income from pharma describes its ongoing relationship with the industry in positive terms, and refers to joint activities undertaken that advantage patients:

“We work in joint partnership with industry. Pharmas help take out our patient-led information into clinics throughout the UK (as we cannot afford distribution services like ‘waiting room service’). We undertake patient reviews, and research and share results learned (where appropriate, reasonable, and in accordance with data protection) to improve and enhance the patient experience via medication or at service level.”

An anonymous UK national cancer group that draws a significant proportion of its income from pharma says of the industry:

“There is sometimes exceptional behaviour in giving access to innovative new medicines on compassionate grounds.”

An anonymous US local public health organisation that specialises in disease prevention and health promotion, and which does not draw income from pharma, praises the work of GSK and Pfizer:

“In Iowa, GlaxoSmithKline and Pfizer have done a great job in organising coalitions to promote prevention over a period of time, and especially before the Iowa caucuses.”

Testimony like the above, however, is scarce among respondents. The comments received indicate that pharma falls short in three areas of relationship building:

1. **Insufficient engagement of patient partners in the relationship**

   The anonymous US national respiratory organisation mentioned on page 28 remarks:

   “They seek relationships with patient groups. However, typically, they are interested only in funding public-awareness campaigns that raise their visibility—rather than learning from us, and supporting efforts to make a lasting impact on people’s lives.”

   Tom Kujawski, Vice-President for Development at the US National Association of People With AIDS (NAPWA) reflects that pharma (which supplies a moderate proportion of the organisation’s income) should take greater trouble to engage with local community programmes:

   “A true partnership requires transparency, and the full engagement of each partner’s resources. I believe that pharma would benefit by greater pharma staff investment in national and local ASOs [AIDS Service Organisations] programming, volunteerism, and truly leveraging additional in-kind support for programmes.”

2. **Lack of continuity in maintaining relationships**

   The National Association for Continence, a US organisation that receives a moderate proportion of its income from pharma, believes that pharmaceutical companies can sometimes allow relationships with patient groups to lapse prematurely:

   “Pharma companies will initiate relationships with patient groups, but not always be conscious of the need to maintain those relationships.”

   The same organisation reports that relationships can be soured by
LHC-Västra Götaland, a Swedish local hepatitis organisation that does not receive funding from pharma, believes that pharmaceutical companies should never form relationships with patient groups:

“We don’t think that patient groups should have relationships with pharmaceutical companies. Their economical interest, not our wellbeing, is in focus in any such relationship.”

unprofessional companies hired by pharma to act as intermediaries between themselves and patient groups:

“I don’t doubt the intentions of pharma companies. However, sometimes the agencies and ‘go betweens’ they hire to represent them are less than transparent, and staffed with immature, even mismanaged individuals. Their behaviour reflects poorly on the industry.”

3. Industry cherrypicks its partners and worthy causes get ignored

Numerous groups (including the following four) point out that the selective nature of pharma’s approaches to patient groups results in many organisations being overlooked:

“All attempts to receive support from companies—despite our members’ heavy reliance on medicines—have failed.”
—anonymous Australian regional group that does not draw any income from pharma.

“I feel that unless your organisation is large enough, the pharmaceutical companies will not have anything to do with you.”
—Lupus Society of Manitoba; a Canadian state-wide organisation that does not draw any income from pharma

“We wish to be more often surveyed, consulted, and supported by pharma, offering medication to parents who seek our support about ADHD/ADD.”
—Association PANDA Lanaudière Nord; a Canadian local organisation that does not draw any income from pharma

“This disease [Nieman Pick disease] is a rare orphaned-class disease. As a result, the many pharmaceutical companies we have contacted for either public awareness or support funding have either not responded, or had no interest. If a member of their family had this disease, there would be interest. This disease robs children of their childhood and parents are faced with losing their child to a disease that has no known cure. Our foundation is trying, along with other lipid-storage disease groups, to let people know that metabolic disease can affect any family—it knows no boundaries. But the majority of companies out there will only help if support or research affects a majority of people.”
—US National Nieman Pick Disease Foundation; draws a small or tiny proportion of income from pharma.
Around 100 of the respondent groups describe themselves as familiar enough with one or more of the world’s leading pharmaceutical companies to vote on company performance across four criteria: ability to understand patients’ needs; aptitude at supplying patient information; handling relationships with patient groups; and trustworthiness. Companies voted into the top ten performers in each of the four categories are listed in tables on the next four pages. The four companies receiving the highest number of votes in each of the four categories are gathered together in the small table in the ‘Key Findings’ section, page 13.

Some of the organisations responding to the survey argue that a number of pharmaceutical companies are, despite a poor previous record, trying to improve their standing in the healthcare advocacy community, and their relationships with patient groups. The groups remark on why they rate certain companies more highly than others. In brief, they say, pharma is best remembered and respected when its actions prove to have a tangible and positive effect on patients—whether through the supply of valuable information, or via high-quality innovation, or as the result of an interest in patient wellbeing. As one Australian mental health group reflects: “Patients’ needs are for more than just medication.”

The following are among comments that offer favourable impressions of companies:

✔ “Novartis was the only company sending a rep out to a mental health NGO I work with, to answer directly questions re product safety, and to offer information.”

✔ “As an asthmatic patient myself, I actually have most of my medicaments from Glaxo. I know that my doctor is informed by this company very regularly, and, due to this, I have been given all the new medicaments coming to the Czech Republic—to my full satisfaction.”

✔ “We are very aware that Novartis originated a drug that is a major symptom-control agent for carcinoid patients, and greatly improves our quality of life—for a bit price.”

✔ “Johnson & Johnson does so many good products that are family- and health-friendly that they are a household word for health. Other companies would do better if they would work on being more preventative in their outlook.”
The ten pharmaceutical companies ranked highest by patient groups for their levels of trustworthiness

% of groups saying good (or better than good) [excluding groups unfamiliar with the company].

<table>
<thead>
<tr>
<th>Total number of respondents offering an opinion on this company</th>
<th>% of the left-hand column saying “good (or better than good)”</th>
<th>Rank of company</th>
</tr>
</thead>
<tbody>
<tr>
<td>Johnson &amp; Johnson (157)</td>
<td>68</td>
<td>1st</td>
</tr>
<tr>
<td>Pfizer (175)</td>
<td>67</td>
<td>2nd</td>
</tr>
<tr>
<td>Novartis (144)</td>
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</tr>
<tr>
<td>GSK (139)</td>
<td>65</td>
<td>= 3rd</td>
</tr>
<tr>
<td>Merck &amp; Co (126)</td>
<td>63</td>
<td>5th</td>
</tr>
<tr>
<td>AstraZeneca (123)</td>
<td>61</td>
<td>= 6th</td>
</tr>
<tr>
<td>Eli Lilly (145)</td>
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<tr>
<td>Abbott (107)</td>
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<td>= 8th</td>
</tr>
<tr>
<td>Bristol-Myers Squibb (107)</td>
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<td>= 8th</td>
</tr>
<tr>
<td>Roche (123)</td>
<td>60</td>
<td>= 8th</td>
</tr>
</tbody>
</table>

211 respondents replied to this question.

A proportion of respondents did not feel familiar enough with each company to offer an opinion on it. As is obvious from the above chart, this proportion of respondents varies from company to company.
The ten pharmaceutical companies ranked highest by patient groups for their ability to handle relationships with patient groups

% of groups saying good (or better than good) [excluding groups unfamiliar with the company].

<table>
<thead>
<tr>
<th>Company</th>
<th>Total number of respondents offering an opinion on this company</th>
<th>% of the left-hand column saying “good (or better than good)”</th>
<th>Rank of company</th>
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</thead>
<tbody>
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<td>Novartis</td>
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<td>Pfizer</td>
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<td>Johnson &amp; Johnson</td>
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<td>52</td>
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</tr>
<tr>
<td>Eli Lilly</td>
<td>(127)</td>
<td>50</td>
<td>= 5th</td>
</tr>
<tr>
<td>Merck &amp; Co</td>
<td>(107)</td>
<td>50</td>
<td>= 5th</td>
</tr>
<tr>
<td>Roche</td>
<td>(107)</td>
<td>50</td>
<td>= 5th</td>
</tr>
<tr>
<td>AstraZeneca</td>
<td>(118)</td>
<td>47</td>
<td>8th</td>
</tr>
<tr>
<td>Sanofi-Aventis</td>
<td>(94)</td>
<td>44</td>
<td>9th</td>
</tr>
<tr>
<td>Abbott</td>
<td>(93)</td>
<td>43</td>
<td>10th</td>
</tr>
</tbody>
</table>

211 respondents replied to this question.

A proportion of respondents did not feel familiar enough with each company to offer an opinion on it. As is obvious from the above chart, this proportion of respondents varies from company to company.
The ten pharmaceutical companies ranked highest by patient groups for their ability to supply patient information

% of groups saying good (or better than good) [excluding groups unfamiliar with the company].

<table>
<thead>
<tr>
<th>Company</th>
<th>Total number of respondents offering an opinion on this company</th>
<th>% of the left-hand column saying “good (or better than good)”</th>
<th>Rank of company</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pfizer</td>
<td>(164)</td>
<td>68</td>
<td>1st</td>
</tr>
<tr>
<td>Novartis</td>
<td>(132)</td>
<td>67</td>
<td>2nd</td>
</tr>
<tr>
<td>Merck &amp; Co</td>
<td>(116)</td>
<td>66</td>
<td>3rd</td>
</tr>
<tr>
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<td>(91)</td>
<td>63</td>
<td>4th</td>
</tr>
<tr>
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<td>(139)</td>
<td>62</td>
<td>5th</td>
</tr>
<tr>
<td>Roche</td>
<td>(119)</td>
<td>61</td>
<td>6th</td>
</tr>
<tr>
<td>Abbott</td>
<td>(115)</td>
<td>60</td>
<td>7th</td>
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<tr>
<td>AstraZeneca</td>
<td>(130)</td>
<td>59</td>
<td>= 8th</td>
</tr>
<tr>
<td>GSK</td>
<td>(132)</td>
<td>59</td>
<td>= 8th</td>
</tr>
<tr>
<td>Sanofi-Aventis</td>
<td>(97)</td>
<td>56</td>
<td>10th</td>
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The ten pharmaceutical companies ranked highest by patient groups for their ability to understand patients’ needs
%

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—THEIR HOPES, THEIR FEARS, AND THEIR PLANS FOR THE FUTURE

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