BETTER TOGETHER

Why pharma companies and patient organizations need to collaborate differently to deliver better patient experiences.
Over the last several years, we have been exploring the role of patient services in the care continuum. Here is what we’ve learned:

76% of patients believe pharmaceutical companies have a responsibility to provide services that complement their products.¹

<1 in 5 patients are aware of the services that pharmaceutical companies offer.²

85% of companies are raising their investment in patient-centric capabilities over the next 18 months.³

Only 40% of healthcare professionals are very aware of patient services.⁴

In this, our most recent patient services survey, we wanted to understand the role of patient advocacy groups in the services spectrum. To capture that story, we asked 4,000 patients with one of three specific conditions—Migraine, Rheumatoid Arthritis or Chronic Lymphocytic Leukemia (CLL)—from the US, UK, France and Germany to share their experiences with services offered by patient organizations versus services offered by pharmaceutical companies and other healthcare players.

Our survey revealed that all patients, regardless of their country or disease state, highly value services from patient organizations. In addition, they prefer to use services offered by patient organizations over those offered by pharma companies. We also found that patients today perceive pharma companies as having the lowest understanding of their emotional, financial and other needs related to their condition among payers, providers, pharmacies and patient organizations.

These findings and more revealed many opportunities for pharma companies to collaborate with patient organizations. In fact, the vast majority of patients believe that pharma and patient organizations should be working together to create a more seamless experience for them.

This collaboration becomes more important as New Science—the combination of the best in science and health technology, such as digital biomarkers and treatment delivery systems drives—is expected to drive 54% of the industry’s revenue by 2022.⁵

If pharma companies wish to establish more meaningful relationships with patients—ones that enable them to provide much more personalized care and treatment—then patient organizations are clearly one way to do that.
KEY FINDING 1:
Patients prefer services from patient organizations.

Across all the types of services we queried, patients prefer to use services from patient organizations over those from pharmaceutical companies. This isn’t necessarily surprising for areas like emotional support or access to community support groups (where patient organizations are the number one choice), but perhaps more surprising that patients choose patient organizations over pharma companies for information on therapies and clinical trials.

In fact, patients place almost as much reliance on patient organizations for information on therapies and clinical trials as they do on their doctors. Just 15% of patients we surveyed turn to pharma companies for this information and support (See Figure 1).

Figure 1. In terms of helping you manage and recover from your condition, whose services would you prefer to use for each overall area?

- Information on therapies and clinical trials
  - Pharmaceutical company: 14%
  - Health insurer: 16%
  - Pharmacy: 15%
  - Patient organization: 20%
  - Doctor / Physician: 22%

- Support through technology
  - Pharmaceutical company: 10%
  - Health insurer: 15%
  - Pharmacy: 14%
  - Patient organization: 23%
  - Doctor / Physician: 16%

- Managing your condition
  - Pharmaceutical company: 9%
  - Health insurer: 15%
  - Pharmacy: 14%
  - Patient organization: 37%
  - Doctor / Physician: 11%

- Community / patient support groups
  - Pharmaceutical company: 8%
  - Health insurer: 13%
  - Pharmacy: 13%
  - Patient organization: 34%
  - Doctor / Physician: 16%

- Emotional support
  - Pharmaceutical company: 8%
  - Health insurer: 34%
  - Pharmacy: 13%
  - Patient organization: 13%
  - Doctor / Physician: 8%
This has significant implications to the traditional selling model for pharma which is still primarily centered around sales reps visiting doctors, with much less focus on structured engagement with patient organizations. Pharma should be taking a closer look at how they can build relationships with these influencing organizations to help patients make better, more informed decisions.

I think that patients are not aware that pharma companies are providing these type of services because their primary contact is the patient organization.

— Cancer Patient Organization, General Manager, USA.

Patients’ preferences for the services provided by patient organizations may also be triggered by their willingness to share information about their health. We found that patients are more willing to talk to patient organizations about the daily impact of their condition (56%). While pharma ranked the lowest among all players in the healthcare system, nearly half (49%) of all the patients surveyed expressed their willingness to share this information with pharma in return for better care. Across the countries surveyed, patients in the UK are the most willing to share their data with pharmaceutical companies (54%) and German patients are the least likely (38%) (See Figure 2).

Nevertheless, the research highlights a big opportunity for pharma companies to gain easier access to patient insights by developing closer relationships with patient organizations in relevant clinical areas. That could prove to be an easier, quicker way to access patient data compared to having to coordinate data gathering across across a broader, more complex network of other providers and healthcare professionals.
I think it’s far more appropriate for patients to engage with the patient organizations because we’re unbiased. We can give very clear evidence-based support and information and that will help the patient better self-manage their condition.

—Arthritis Patient Organization, Deputy CEO, UK.

In Europe, patients use healthcare providers, payers, patient organizations, pharmacies and pharma companies evenly. This indicates an opportunity for pharma companies to take a thoughtful stance on what service areas they wish to own.

Why Patient Organizations?

Patients say that they trust the information they get from patient organizations and find them easy to engage with. But that’s not all. The opportunity to interact with other patients in their situation is a key factor. Over half say they have a great experience most of the time while engaging with their preferred patient organization.

Which of the following are the top reasons that influenced you the most in choosing to liaise and communicate with this particular patient organization?

- 59% I have greater trust in information being provided.
- 55% It is easy to engage with this organization.
- 56% I can engage with other patients in my situation.
- 53% I have great experiences most of the time I engage with this organization.
KEY FINDING 2: Pharma ranks low in understanding patients’ emotional, financial and other needs.

Whatever their condition, patients’ needs and concerns extend beyond just their clinical considerations. There is often a pronounced financial and emotional impact on their day-to-day lives and wellbeing.

Yet, less than half (47%) of the patients we surveyed said that pharma companies understand their emotional, financial and other needs related to their condition. In fact, patients rate pharma companies lower on this than doctor/physicians, payers, pharmacies and patient organizations. The biggest gap we see is in the US, where 67% of patients say patient organizations understand their needs compared to just 48% who say the same for pharma (See Figure 3).

Figure 3. How well do you believe each of the following organizations understand your emotional, financial, and other needs related to daily activities affected by your health condition?

<table>
<thead>
<tr>
<th>Organization</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor/Physician</td>
<td>68%</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>61%</td>
</tr>
<tr>
<td>Patient organizations</td>
<td>58%</td>
</tr>
<tr>
<td>Health insurer/Payer (including government)</td>
<td>51%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>47%</td>
</tr>
</tbody>
</table>

Patients sensing that pharma companies don’t understand their needs aligns with the perceptions that pharma companies have of themselves. Our survey of 60 pharma CMOs/commercial leads revealed that nearly half said that they don’t really have a good understanding of what patients want or expect from them.6
Pharma companies understanding of patients could be improved by having more patient interaction, doing market research, voice mobility because there are many people at pharma companies who haven’t met the patients personally, but they work for them. The pharma companies say that’s changing.

—Cancer Patient Organization, Head of Business Development, UK.

Understanding Your Patients

One thing is clear: patients want MORE emotional support. Over half (54%) of patients worldwide said their condition has a daily emotional impact on them (See Figure 4). And that proportion rises to 72% in the US. Many also experience financial concerns, with the highest proportion of patients expressing those worries in the US. In European markets that provide greater state-funded healthcare support, a far lower proportion say they experience daily emotional and financial impacts. Patients in France and Germany expressing the lowest levels of day-to-day concern.

Figure 4. What is the emotional and financial impact of your condition per day?

Only half the patients with the conditions included in our survey feel that they get what they require to stay positive in managing their condition—and even fewer feel they receive the necessary support to address their lifestyle and emotional needs. This was the number one factor deterring them from having the best experience when managing their condition.
KEY FINDING 3:
Patient organizations are winning in patient engagement.

Not only do patients prefer to use services from patient organizations over pharma, but they also engage with them with greater frequency. Fifty-two percent of patients engage with patient organizations monthly compared to 35% for pharma companies.

In fact, 1 in 5 patients we surveyed who are involved with patient organizations in the US and UK say they never interact with pharma companies. Here we find some variances across disease states. CLL patients are least likely to engage with pharma companies (31%), while chronic migraine sufferers engage the most on a monthly basis (45%).

Future intentions present an even greater divergence. Over half (54%) globally said that they’re going to engage with patient organizations more in the future—compared with only 35% who say they’ll have more contact with pharma companies (see Figure 5). This gap is even more pronounced in the US where 61% say they will increase their engagement with patient organizations versus just 27% saying they will do so with pharma companies.

Figure 5. How do you think your engagement with the following organizations will change over the next two years?

For some conditions, only a tiny minority say that they plan to increase engagement with pharma companies. For example, just 6% of US patients with CLL say they’ll do this, significantly lower than the 29% of CLL patients across all the countries surveyed.
Patients Engage On- and Off-line

Patients engage with patient organizations via digital channels the most. Whether they’re seeking to understand ways to manage their condition, searching for information on the latest therapies to reach the market or seeking emotional support, patient organizations’ websites are their first choice.

However, they also have high levels of in person or “live” engagement. A remarkable 72% call to talk to someone on the phone and over 50% attend in person events. This gives patient organizations a high level of interaction with patients where they are able to garner a much deeper and richer sense of what patients are experiencing. So it isn’t just that they are interacting more often with patients, they are also getting first-hand insight into what needs they have that are not being met through existing services.

How do you engage with the services offered by this organization, if used?

- **88%** I access content online via the organization’s website.
- **78%** I receive content via email.
- **71%** I call to talk to a person.
- **58%** I attend in-person events hosted by this organization.
IMPLICATIONS
WHAT DOES THIS MEAN FOR PHARMA COMPANIES?

Through closer collaboration with leading patient organizations, pharma companies can...

**Gain a deeper understanding of the patient’s individual needs through earlier, more personal and frequent engagement.**

More than one out of every three patients we surveyed told us that by collaborating with patient organizations, pharma companies would understand their needs better and they would increase their level of interaction with pharma. US patients were especially emphatic here: almost half (47%) of them said it would increase their level of interaction.

What could result from an improved level of collaboration between patient organizations and pharmaceutical companies?

- **37%**
  Pharma would better understand my needs and the needs of other patients with my condition.

- **34%**
  It would increase my level of interaction with the pharmaceutical company.
Pharma companies could also engage with patients much earlier in the treatment lifecycle as a result. Half of all patients we survey said they engage with patient organizations before their treatment begins—at either first sign of symptoms or after diagnosis but before treatment begins (see Figure 6).

The timing could not be more perfect for many reasons. First, patients already told us in one of our previous surveys that pre-diagnosis/treatment is the period where most (65%) experience the greatest frustration. Second, this survey revealed that patient organizations play an extremely important role when it comes to information on therapies and clinical trials – nearly on par with healthcare providers. Collaboration with patient organizations would give pharma companies earlier access to the patient before he or she makes their decisions about which treatment to pursue. This would empower patients to give them the most accurate information to make the most informed decision on the treatment best suited to their individual situation.

**Figure 6. At which stage in the experience of managing your condition have you predominantly used these services offered by the patient organization?**
We know that patients want more help and guidance before they begin treatment for a disease. We also know that 4 out of 5 patients are not aware of the services that are available from pharma to help them along their care journeys.\(^6\)

If pharma companies embrace closer collaboration with patient organizations, they can make great strides in closing these gaps in support and awareness. Eighty-four percent of patients believe that pharma companies should be working more closely with patient organizations to help create a seamless patient experience (rising to 89% of patients in the US). In fact, they want pharma companies and patient organizations to work together more than they do with any of the other healthcare entities (see Figure 7).

"The benefit of patient organizations working with pharma companies for the patient would be easier access to treatment, improved patient experience and easier access to information on patients’ condition and treatments."

—Cancer Patient Organization, Senior Director Corporate Relations, USA.

Figure 7. Do you believe patient organizations should be working more closely with each of the following organizations to help create a seamless patient experience?

<table>
<thead>
<tr>
<th>Organization</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pharmaceutical companies</td>
<td>84%</td>
</tr>
<tr>
<td>Doctor/Physician</td>
<td>82%</td>
</tr>
<tr>
<td>Health insurer/Payer (including government)</td>
<td>80%</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>78%</td>
</tr>
<tr>
<td>Employer</td>
<td>69%</td>
</tr>
</tbody>
</table>

Total
We all know the healthcare environment is not easy to navigate with so many different players. Patients want it to be easier—they need it to be easier, especially when dealing with the emotional and financial burdens involved in managing their disease. They want pharma and patient organizations to work together to help them solve these gaps and challenges in their care.

And they are clear on the areas where they need the most help. Staying positive and having the right support system in place is the greatest factor detracting patients from having a good experience. Patients also shared that the solutions and services currently offered are not covering what is needed to most effectively manage their condition on a daily basis.

Which of the following factors detract from you having the best experience when managing your condition?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>50%</td>
<td>I don’t always have a positive support system to remind me to help me best manage my health.</td>
</tr>
<tr>
<td>43%</td>
<td>Solutions and services offered do not cover my full daily needs related to managing my condition.</td>
</tr>
<tr>
<td>40%</td>
<td>The need to provide the same information to different organizations or organizations having different information.</td>
</tr>
<tr>
<td>35%</td>
<td>Lack of a single point of contact that can work across the different organizations that provide services or support.</td>
</tr>
<tr>
<td>33%</td>
<td>Lack of clear and easy-to-understand information about my diagnosis or treatments I’m taking.</td>
</tr>
</tbody>
</table>

Think about how pharma companies could carve out a very special place in the market if they come at their services strategy with these critical unmet needs as part of their calling card. What if they brought a solution that solves these key issues that patients are grappling with...not just the medication that treats the disease. What if they did what patients want—coordinated with patient organizations to bring this solution to them cohesively, versus potentially competing with them and adding complexity to the system.
New measures of patient value

Let’s think beyond just creating a more seamless experience for patients today. How can partnering with patient organizations create the potential to build entirely new patient experiences?

What if pharma shifted its view of patient organizations from a policy and advocacy standpoint and approached the relationship in terms of what they could collectively do to improve patient care and their health outcomes? Instead of thinking of limitations bound by regulatory, think of uncharted partnerships that use data, analytics, and real-life insights to create a care experiences that more precisely meet the needs of patients.

In many cases, patient organizations play the unique role of aggregator of information, people and treatments. They are patients go-to, trusted place to get counsel about the realm of treatment and care possibilities and options. There is untapped opportunity for pharma companies to work with patient organizations to find unbiased areas that don’t involve a direct or implied endorsement. For example, exploring new ways to provide integrated services, clinical trial set up and recruitment, and services that address people’s non-clinical needs including the social determinants of health.

One recent example is Allergan collaborating with The American Migraine Foundation on Frames of Mind, an interactive campaign to promote the awareness on the impact migraines can have on patients’ everyday living where patients submit original artwork depicting how migraine symptoms affect them.

UCB recently worked with Parkinson’s UK to carry out two patient engagement workshops—one looking at outcome measures and another looking at the design of a clinical trial. They found that the researchers had been looking at helping with tremor or bladder problems but what patients really wanted was help slowing down the progress of the disease.
### Leading Patient Organizations

More than 50% of survey respondents listed the below patient organizations as the one they interact with the most.

<table>
<thead>
<tr>
<th>Migraine</th>
<th>Rheumatoid Arthritis</th>
<th>CLL</th>
</tr>
</thead>
</table>
| **USA**  | American Migraine Foundation  
Migraine Support (Facebook Site)  
Migraine Research Foundation | Arthritis Foundation  
Rheumatoid Arthritis Support Group (Facebook Site)  
Rheumatoid Arthritis Support Network | Association of Cancer Online Resources  
Association of Community Cancer Centers  
American Society of Clinical Oncology |
| **UK**   | The Migrain Trust UK | Arthritis Care  
National Rheumatoid Arthritis Society | Leukaemia CARE  
Macmillan Cancer Support  
CLL Support Association |
| **France** | Association France Migrain  
Club Migraine et Céphalées | Association Française des Polyarthritiques et des rhumatismes inflammatoires chroniques (AFRic)  
Association Française de Lutte Anti-Rhumatismale (A.F.L.A.R.) | L'Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström (SILLC)  
Association Laurette Fugain  
France federation Leucemie espoir |
| **Germany** | Die Deutsche Migräne- und Kopfschmerzgesellschaft e.V. (DMKG) | Deutsche Rheuma-Liga Bundesverband e.V.  
Deutsche Gesellschaft für Rheumatologie (DGRh) | Deutsche Leukämie- und Lymphomhilfe e.V. |

### About the Survey

The results shown in this report are based on a major quantified international study executed by Coleman Parkes Research during February and April 2019. 4,000 patients suffering from Migraine (1,115), Rheumatoid Arthritis (1,115) and Chronic Lymphocytic Leukaemia (1,181) took part in the survey with an equal split of patients across the US, the UK, France and Germany. Patients were asked a series of detailed questions about their experiences with their condition as well as details about their most preferred patient organization with which they have the most regular contact. All data was collected under the strict rules of the Market Research Society and controls were used to generate a representative sample by age of respondent, type of patient organization used as well as overall therapeutic condition. A series of six supplementary qualitative 30-minute interviews were undertaken with the leading patient organizations established through the research, which looked in more detail at the relationship between the patient organization and the pharmaceutical companies, and how this relationship benefits the patient. Opinions on some of the key findings from the quantitative research were also discussed with the patient organizations to understand the context and if the findings fit with their experiences of working with patients and pharmaceutical companies.
Sources
1 Great Expectations: Why Pharma Companies Can’t Ignore Patient Services, 2014 Accenture research.
2 Patient services: Pharma’s best kept secret, 2015 Accenture research.
6 Pharma CMO/CEO, 2019 Accenture research.
7 Patient services: Pharma’s best kept secret, 2015 Accenture research.
8 Patient services: Pharma’s best kept secret, 2015 Accenture research.

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Website: www.accenture.com/lifesciencesblog

Contact Us
KEENA PATEL
Accenture Life Sciences, Managing Director, Patient Services
keena.b.patel@accenture.com

EVA WIEDENHÖFT
Accenture Life Sciences, Managing Director, European Lead – Patient Services
eva.wiedenhoeft@accenture.com

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