

Partnering with patient groups

Developing mutually beneficial relationships between industry and patient representative bodies

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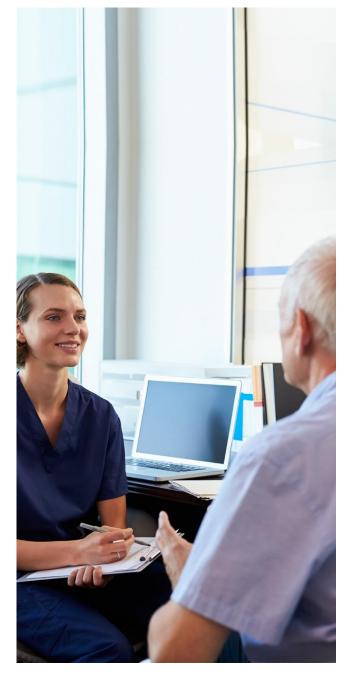
KPMG UK

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Customer experience is one of the main focuses for businesses in every sector. Many life sciences firms are looking to patient groups to inject that true customer focus into their strategy. The successful ones are carefully crafting their methods of engagement – but the aim is always optimising patient outcomes to drive efficiency and create a compelling case to payers.

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The big idea



Patient groups are increasingly well equipped to partner with pharmaceutical companies in a way that can improve patient outcomes – and refine business models. In successful partnerships, both sides agree on the type of activity they are collaborating on; have a clear idea of their respective roles; and build strong lines of communication, often using a trusted third party.

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Patient group activities across the value chain

Patient associations are increasingly well-connected internally, and sophisticated in their lobbying efforts. That has boosted their value to the healthcare and life sciences industries as partners, and helped all three develop shared objectives and activities. Gone are the days of cursory interactions or straightforward information dissemination. In fact we see a huge range of opportunities for co-operation across five dimensions – from supporting public awareness and patient support, through to clinician interactions and even financial advice.

Monitoring/ prevention	Diagnos	sis	Preparation and referral		Treatmer recove			Monitoring/ management
Public awareness	Clinician awareness Patient information and advice		Clinician reviews Disease information and advice for patients Patient-clinician understanding		Reimbursement dossier input Lifestyle counselling Legal advice Financial advice Lobbying government Pastoral support			
Example 1 Patient information and advice (UK) EDS UK, a charity that supports those with ehlers danlos syndrome (EDS), convenes a Medical Advisory Panel of specialists who work in different fields related to EDS symptoms. The Panel informs the charity, who in turn inform the EDS				ns fo not ularly	 working together, the groups can draw senior political figures to attend, giving all the groups a level of visibility and influence 			
The Panel informs th	e charity, ne EDS	some if doc Abou	something that happens regularly if doctors are unfamiliar with HS. About 50% of the patients advised win their appeal. ^(b)					

Indicative patient group activities

Notes: (a) EDS UK website: https://www.ehlers-danlos.org/about-us/medical-advisory-panel/(accessed Nov. 2016) (b) KPMG interview with head of Solidarité Verneuil (Mar. 2016)

(c) KPMG interview with head of Dermatology & Venereology at Stadtisches Klinikum Dessau (Feb. 2016)

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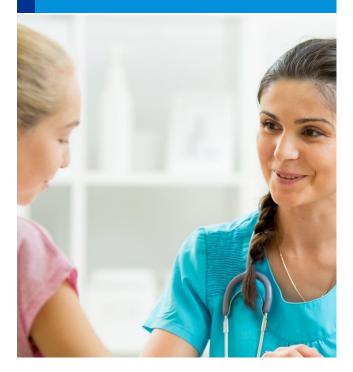
"What's in it for us?"

Working with patient groups is primarily about patient support, better health outcomes and fine-tuning corporate engagement. But there are hard-nosed business benefits, too.

Companies in partnership with patient associations can not only improve their present offerings, but also develop approaches to meet a changing market landscape – one where they're obliged to shift from a product-only offering to one that addresses the wider patient experience (see the article on value-based pricing). And there are plenty of other benefits:

- Understand patient needs to tailor provision.
 Patients often speak more openly to peers than to medical or life sciences professionals about areas such as lifestyle choices and adherence. This feedback is hugely valuable if a level of distrust has arisen with intermediaries. It means field data can yield more accurate results in many cases.
- Turn patients into advocates not to boost sales, as such, but around adherence and lifestyle choices.
 Patients often take advice from their peers more readily than from professionals.
- Better communication. Regular and transparent interactions build trust and negate any misunderstandings that might result in poorer patient outcomes. It can also defuse stereotyping, either of patient attitudes or business approaches.
- Lobbying. Many companies lack either the resources or the credibility (in the sense of being seen as unbiased) to influence policy, especially around therapy promotion. Patient groups help ensure their disease and its attendant issues are recognised by the medical profession, the public and government. They can promote awareness to improve patient outcomes.

Those companies that invest the time and effort to consider how to partner effectively with patient groups can find that they fundamentally alter their strategic thinking and behaviours for the better – for example, restructuring the way they run their clinical trials, in response to feedback on what patients wish to gain from these. Such a move benefits both parties, improving patient satisfaction and recruitment rates. Over time, such interactions can become embedded in company culture, making the following collaborations easier and more effective still.



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Establishing or supercharging a partnership

Whether a business is looking to make first contact with a patient group or make the most of an existing relationship, there are three key factors to weigh up: the type of activity involved; how the pharmaceutical company or medical centre engages; and how the patient group is involved (see case study box, overleaf).

Type of activity

The key question is: where are the gaps in the disease area? For example, those representing well-recognised diseases might be less interested in profile-raising activities than those dealing with rare or under-diagnosed conditions – where limited clinician awareness might cause delays in diagnosis. Or in countries with limited or no government health cover, there is scope to provide patients with advice on insurance that's less relevant for, say, patients in a system such as the NHS.

Identifying gaps in knowledge, information or support allows companies to create a long-list of possible interventions that can then be dovetailed with their objectives to create a short-list of activities that address both patients' and company objectives.

The company or medical centre's involvement

Will they provide straight financial support to patient groups? Or undertake an activity themselves in conjunction with the group? What are the options to work through a trusted third party? What about a blend of those options?

Mode of patient group involvement

An evaluation of the optimal extent and nature of the patient group's involvement at the outset helps provide

clarity on roles and responsibilities. There's no 'right' answer. For example, in partnering on research, the patient group could act in any of the roles outlined in the diagram at the bottom of this page.^(d)Similarly, a patient group can simply provide 'the face' of an awareness campaign organised by the company – or develop and execute the whole programme, with suggestions from their partner.

For both sides, a number of factors should be considered, including:

- Company resources. An organisation where, for example, a staff member has experience of teaching patients is better equipped to support an awareness event; but one with strong cash flow more easily offers to pay for professional presenters.
- Patient group capabilities. Don't double-up on existing expertise. A group with proven project management skills, say, won't need support coorganising an event, but might welcome funding.
- Patient group appetite. Some groups may be enthusiastic about having hands-on support; others may prefer funding for independently developed activities. Third-parties can act as a liaison in cases where one side is reluctant to work directly with the other.

The final decision on how, and how much, each side engages relies on clear dialogue. Regular communication – before and throughout any partnership – ensures both parties are satisfied with their roles, and that these shift appropriately in response to changing requirements.



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Case study: AbbVie and HS Danmark

AbbVie partnered with a Danish patient association, Patientforeningen HS Danmark, to raise awareness of the disease and to support and empower HS patients.^(e)

Type of activity

HS is an under-recognised dermatological condition, with patients often waiting several years before receiving diagnosis or treatment. Patients are often embarrassed of the unpleasant symptoms, and unaware that they signify a disease, and so present late to clinicians. Even when they do, clinicians are often unfamiliar with the condition and unable to diagnose, or refer correctly. Given the delay that this results in, it was felt that an awareness campaign was an important and needed activity.

Mode of engagement

Given the skills within the patient association, and the fact that they worked closely with a facilitator at Roskilde hospital who supported them with content development, AbbVie provided financial support to HS Danmark, to allow the latter to develop a nationwide multimedia HS awareness campaign. The programme was titled 'Shh!', to signify the silence and the taboo surrounding HS. Key elements of the programme included:

- A photo brochure with information about HS for the general public.
- Bespoke information brochures targeting key groups, such as HS sufferers' employers, relatives, teachers, and social workers and healthcare professionals.

"I saw two patients who didn't know that they had this disease till they saw [the Shh! campaign"] on TV. And I don't see many of the HS patients. "

PhD student, Roskilde Hospital

 A Twitter campaign with an associated hashtag, whereby contributors used the tag with a picture of themselves, to raise awareness of HS.

Benefits

Several members of the staff at Roskillde hospital reported that the campaign raised the profile of the disease, encouraging undiagnosed patients to come forward. This meant that they could be treated at an earlier stage than they might otherwise have been, thereby limiting disease progression, scarring, and the need for surgery.

Note: Case study developed from KPMG interview with former head of HS Danmark, and patient support staff at Roskilde Sygehus, Roskilde, Denmark (Mar. 2016)

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KPMG's Strategy Group works with private, public and not-for-profit organisations to develop and implement strategy from 'Innovation to Results' helping clients achieve their goals and objectives. KPMG's Strategy professionals develop insights and ideas to help address organisational challenges such as growth, operating strategy, cost, deals and transformation.

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