

# Pharma-Patient Engagement: insights from patient opinion leaders

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## Abstracts

Patients and Pharma want the same thing, but for different reasons. Patients want access, support and information about the latest drugs while Pharma needs market access for sales and profits that will to fund more research. So, they are natural bedfellows....?

Patient pressure and influence across the range of Pharma's activities is growing. While Patient Advocacy Groups are well established, there is a new breed of patient, empowered by the digital revolution, and with access to a wide-range of clinical and health data. These advocates share information and experiences with fellow patients, are informed about their condition, keen to take an informed part in their diagnosis and treatment, and are no longer willing to abdicate decision-making to health professionals.

Collectively, they have political weight, independence and a high social profile: so what do patients want – and expect – from Pharma?

## Talking the talk

For its part, Pharma speaks the language of patient-centricity but doesn't always deliver. Bound by regulations in many countries limiting what can, and cannot, be communicated to patients or put in the public domain, industry has struggled to square demands for more openness with regulatory regimes that actively limit its ability to communicate with end-user customers. That could be a generous interpretation: perhaps getting too close to patients presents unacceptable risk to reputation, independence, and the prevailing business model.

Whatever Pharma does, it will meet with concern that when profit is part of the health

equation, then its motives can be questioned. The funding of patient groups and related patient focused initiatives leaves Pharma open to the accusation that by encouraging “pester power” and patient pressure on health payers and Health-Technology Assessment bodies, it can achieve what it is unable to do through normal regulatory channels: encourage reimbursement and product uptake while driving sales.

### **Time to catch up**

With the community and voice the internet has given patients, demand for information and dialogue is developing rapidly. The industry’s response – whether by choice or regulatory burden – has not. If the common aims of patients and Pharma are to be truly mutually beneficial, the industry has to up its patient–relations game.

### **Essential insight in this new report: Pharma-Patient Engagement**

This closely argued and concise management report from FirstWord combines keen market observations with the insights of leading players in patients groups. It presents a compelling analysis of the issues and examines key drivers such as:

Understanding patient needs and which support services mean most to them

How patient groups and industry can best collaborate to achieve common goals

Understanding which digital communication channels work best, and what pitfalls to avoid

What industry can do to counter the often cynical light it is seen in

How engaging with patient groups can lead to better clinical-research design and outcomes

The need to take a positive, open role in the patient information debate and assess the benefits of getting it right

For senior management, marketing and communication executives, this report is a timely reminder that industry must do more to harness and engage with the rapidly growing power of the patient.

## Insights from the report

Jan Geissler

Cancer survivor, patient advocate and Director of the European Patients Academy on Therapeutic Innovation (EUPATI)“Provide the patient groups with independent funding to do what patients really need, instead of doing your own programmes and failing on their compliance, restrictions and barriers. Rather than spending so much money on these kinds of single-sponsor awareness programmes, why doesn't industry set up a fund to support organizations with core funding, removing any suspicion of undue influence?”

Eric Low

Chief Executive, Myeloma UK“I would say from this point onwards, pharma should expect to see much more feedback and much more pressure from patient-driven social media platforms, patient groups, around what they do, how they act, their models, their pricing and so on, and as a result will be forced to become more transparent and to justify things much more than they have been in the past.”

Andrew Schorr

Patient advocate and founder of Patient Power LLC“We patients want to have the keys to the car. We patients want to be in control of our own destiny with the pharmaceutical industry, with hospitals – with physicians truly being our consultants in an adult-to-adult relationship, not a parent/child relationship.”

Lizzie Graham

Director of Fundraising and Global Communications, the European Parkinson's Disease Association“It's always better to have support from as many companies as possible. Otherwise, the perception is that you're in the pocket of one company.”

## Experts Interviewed

Ilaria Passarani, head of the Food and Health Department, European Consumer Organisation (BEUC)

Andrew Schorr, patient advocate and founder of Patient Power LLC

Lizzie Graham, Director of Fundraising and Global Communications, the European Parkinson's Disease Association (EPDA)

Jan Geissler, patient advocate and Director of the European Patients Academy on Therapeutic Innovation (EUPATI)

Drew Lindon, Head of Policy and Campaigns, Prostate Cancer UK

Eric Low, Chief Executive, Myeloma UK

Michael Seres, patient advocate

## **Pharma-Patient Engagement**

Use this report to:

Understand how the patient/Pharma relationship will be critical in the future

Define what patients expect from Pharma

Know how social media is changing the face of patient power and communication

Capitalise on the benefits of working effectively with patient groups for common aims

Communicate key data and information effectively in a controlling regulatory environment

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