

What do Patients want from Pharma? The Real Patient-Centric Perspective

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Abstracts

What do Patients want from Pharma?

How can pharma leverage patient insights to deliver the support they want?

Is patient centricity coming of age? The patient voice is becoming increasingly influential and patient groups are looking to pharma for practical and sustained support. But what services do patients want, how do they want them delivered, how do they see their role and what are the commercial and research benefits for industry? As healthcare systems migrate to a pay-for-performance model, the patient/pharma relationship can be a win-win, but only if companies learn from patients and embed a patient centric approach across their organisation.

For a real patient-centric perspective turn to What do Patients want from Pharma 2017? In this revealing report, 12 US and EU patient experts representing a wide-range of patient views identify the critical support services that would really drive better clinical trial recruitment/design, promote the development of more effective medicines, and improve patient adherence and outcomes.

Report Features

Unique and candid insights from US and EU patient advocacy experts

Key actionable insights for how pharma can listen to and learn from patients to deliver more effective clinical research, better products, and improve patient engagement, adherence and outcomes

Figure: Ten principles of patient centricity: Astra Zeneca's view

Figure: The challenges and benefits of adopting a patient centric model

Figure: Patient tools and services provided by pharma

Figure: Top 10 patient services driving above average business impact

Figure: Recent innovative patient initiatives and services from companies such as Roche, UCB, AbbVie, Novartis and Takeda

Figure: Key stages in a patient support framework

Figure: Framework for patient and family engagement in health

Figure: The US HIPPA Act

Figure: The percentage of companies investing/expected to invest in patient services -- 2016 versus 2018

Figure: Opportunities for patient involvement in drug R&D

Insight: Key tips on clinical trial recruitment and retention – a patient advocate's view

Insight: Key tips on developing patient centric materials – a patient advocate's view

Case Study: The EUPATI project

Case Study: Acromegaly: The role of the patient advocate

Case Study: Online clinical trial guide from Eli Lilly

Case Study: The EU Patients' and Consumers Working Party

Case Study: The Patient-Centred Outcomes Research Project

SWOT analysis of the patient/pharma relationship and its future

Key Benefits:

Understand how patient groups see their role developing across pharma's business interests

Identify the critical services and support that patients want from pharma

Appreciate the challenges of distributing health education to all patients and propose solutions

Benefit from the early patient involvement in the drug development process.

Know which digital technologies and services are revolutionising pharma/patient communications

Plan organisational changes to ensure the whole company is working to a patient centric agenda

Understand the US and EU regulatory frameworks that govern – and sometimes impede – pharma's patient communications

Key Questions Answered by This Report:

Expanding role: In what areas is patient input now essential and what are the benefits of getting this engagement right?

Getting the message out: Research indicates that only 1 in 5 patients are aware of available support services – what can you do to address this deficit?

Point of Contact: Why is having a single liaison point in pharma important to patients and what are the operational implications for companies?

Early Clinical Engagement: What are the benefits to pharma of engaging with patients early in the drug development process?

Digital future: Digital technology is driving patient support services – but what

technologies and techniques are delivering real benefits?

Country variables: National health service provision along with social and cultural attitudes affect patient needs and responses – how can pharm meet these diverse challenges?

Regulatory burden: What are the current regulations governing pharma/patient communications and is it time for a fundamental rethink?

Expert Views

Each patient advocacy expert has been carefully selected for their practical experience and detailed current knowledge of the pressures and opportunities in the patient/pharm relationship. They represent a wide-range of disease specific and pan-regional views across Europe and the US.

Carmen Gonzalez: Government Affairs y Patient Advocacy, Relaciones con Pacientes Corporate Affairs, Spain

Denis Hogan: Executive Director, European Alliance for Personalised Medicine, UK

Dr Antonio Ciaglia: Policy Manager, International Alliance of Patients' Organizations, UK

Gary Petersen: Patient Advocate and Founder, Myeloma Survival, USA

Ines Alves: Patient Advocate and Founding Board Member EUPATI, Portugal and European Reference Networks - Patient representative in the Rare Bone Diseases Group

Jenny Sharpe: Patient and advocate, Muscular Dystrophy UK, UK

Jenny Ahlstrom: President, Founder, Multiple Myeloma Patient and Board Member, USA

Jess Bateman: Patient and Research Advocacy at American Urological Association, USA

Jill Sisco: Patient Advocate, President of the Acromegaly Community, USA

Peggy Gibson Carroll: Managing Partner, Patient Alliances, USA

Tamás Bereczky: Patient Advocate, EUPATI, Germany Communications
Advisor of the European AIDS Treatment Group

Wendy Booker: Patient Advocacy Consultant, Keynote and Motivational
Speaker, USA

4 Key Quotes

“There are many restrictions between pharmaceutical companies and patients and we need to work together to change the rules. We need to break some intricate old boundaries to improve communication.” Ines Alves Patient Advocate and Founding Board Member EUPATI, Portugal

“Pharma have created a lot of programmes, but patients aren't aware of them. Pharma need to figure out the best channel to ensure that patients are aware of all the resources that are available, whether that is through the advocacy channel, websites, or physicians and nurses, to get these resources into the patients' hands. Everyone could benefit from programmes that are more visible through the nurse, physician or the advocacy groups to connect with patients and caregivers.” Peggy Gibson Carroll Managing Partner, Patient Alliances

“Patient advocates can help pharma guide companies and clinical research organisations to the right patient populations and we can relay the unmet needs to pharma and translate clinical information into lay people's language. This benefits both parties; it saves lives as patients get access to essential medicines and patient groups grow as they get better at their jobs. Patient groups can also act as mediators between companies and regulators or vice versa.” Tamás Bereczky, EUPATI, Germany Communications Advisor of the European AIDS Treatment Group

“It is important that we integrate the patient perspective at the earliest stage when treatments are being developed at a research level, as well as the clinical trial stages. When a clinical trial finishes and if the treatment has a beneficial effect on certain patients, then these patients should get access to the same type of treatment. The

whole ethical issue surrounding placebos needs to be looked at; there must be a better way to do trials in a more patient-centric manner.” Denis Hogan, Executive Director, European Alliance for Personalised Medicine

Content Highlights

Executive summary

Research objectives and methodology

Patient centricity

Key insights

What is patient centricity?

What are the perceived benefits of adopting a patient centric model?

Where are we regarding the adoption of patient centric business models?

What are the main barriers of adopting a patient centric model?

How patients currently interact with pharma

Key insights

What do patient-centric services entail?

What modalities are popular?

Recent innovative patient services/initiatives

How do companies promote these programmes?

How do companies implement these programmes?

Patient Support Frameworks

Patient Engagement

Engagement with PAOs

Financial influence on PAOs

Patient partnerships

Patient led educational meetings

Problems and potential solutions in designing and implementing patient centric services

Key insights:

A multichannel approach is required

Communicating with online communities

Pharma need to increase the visibility of services

Health literacy and disease awareness needs to be improved

Patient services vary by country and disease area

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Key Insights

Regulatory and legislative hurdles

The HIPAA Act

Pharma Codes of Conduct

Trust and transparency between patients and pharma

The quality of information and language differences

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Key insights

New services will be driven by patient outcomes

Patient partnerships will play a central role

Technology driven offerings will increase level of engagement and patient support

What pharma needs from patients

Key insights

Greater regulatory support for patient participation

Greater patient involvement during the R&D process

Increased patient involvement in clinical trial design and endpoints

Patients can assist with identification and recruitment

Patients can help pharma better understand their preferences relevant content

Patients can assist in the development of marketing materials and product packaging

What patients need from pharma

Key insights

Patients need tangible information about clinical trial enrolment

Pharma need to improve communication to patients during trials

Pharma needs to disseminate fair, trustworthy information

Pharma needs patients to be active participants to drive actionable outcomes

Patient wish list for pharma

SWOT Analysis

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