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Patient Engagement in Orphan Drugs

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Abstracts

Why is the patient voice critical to orphan drug success?

Patient input is critical to an orphan drug’s success, but how and when should you engage and what trends and drivers are shaping their involvement? From understanding the patient journey through better clinical trial design to post-launch support initiatives, patients are essential and knowledgeable partners for Pharma.

Informed by the insights of patient advocates and pharma, this valuable expert views report illustrates the exceptional value patient insights bring to the orphan drug development process.

“It's really important to engage with patients because they know more about their disease than anybody else.”

Tony Hall

Co Founder of Findacure

Answering key questions:

Understanding disease: How can pharma benefit from a deeper understanding of rare diseases through the patients’ experience?

Clinical trials: When should pharma engage with patients to ensure better clinical research outcomes?

Engagement – but who? How can pharma effectively engage with multiple patient advocacy groups who are often pursuing different agendas?

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What do patients want? What do patients with rare diseases want from pharma and how should industry provide information and support?

Supporting value? Can patients play an active role in supporting value claims and influencing regulatory outcomes and pricing/reimbursement decisions?

International challenge: What are the communication and clinical research challenges when an orphan disease patient pool is widely-dispersed across many countries?

With this report you will be able to:

Identify the new CDx approaches and evaluate their benefits.

Understand how and where they will impact the market and review the challenges they must overcome.

Assess the activities, policies and partnerships of CDx-progressive pharma companies.

Understand how financial and reimbursement models need to change to reflect the real value of CDx.

Learn how advanced CDx can radically improve clinical trial research and outcomes.

Formulate strategies that encourage physicians to use approved CDx.

Identify the therapy areas and conditions where next generation CDx will make an impact.

Grasp the growing importance of research consortia in the identification of biomarkers.

Key Topics Explored:

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Pharma must engage with patient groups – but which ones? A review of patient organisations and advocacy groups in 17 countries for Duchenne Muscular Dystrophy illustrates the communication challenges for pharma in accessing rare disease patient populations.

Several patient organisations are working with both pharma and regulators, and often bridge the gap between the two. This facilitates discussion around unmet needs and the importance of new orphan drugs for the rare disease patients.

Outreach is no longer a one-way street, with some patient groups tracking research and actively reaching out to companies that offer something promising.

The trend of patients with rare diseases having a significant impact on the market is expected to continue through funding of new research, creating scientific programmes and even developing drugs. Pharma needs to work alongside these pioneers to support and optimise their activities.

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All respondents met FirstWord's stringent screening criteria, and were compensated for participating. To encourage frank and forthright responses, their names have been withheld.

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