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Payer attitudes to Orphan Drug pricing

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Abstracts

Payer Attitudes to Orphan Drug Funding

The explosion of orphan drugs across Europe and the US is pushing healthcare finances towards breaking point according to payers. Requests for orphan drug designation have reached unprecedented levels and the high cost of these specialist treatments is swallowing up a larger and larger share of the drug funding pot. Payers are not happy and clearly something needs to give. But what?

Payer Attitudes to Orphan Drug Funding gives budget-holders a voice. In this report, senior payers from the US and EU5 (France, Germany, Italy, Spain UK) offer insight into the pressures they face and share their ideas about how the current crisis could be addressed.

Discover on this page

The executive summary, taken directly from the report, presents key findings from the research

Research objectives and methodologies employed to produce the report

Detailed report contents

Key themes covered in the report

What you will learn from the report

Executive Summary

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Rising interest in orphan drug development

The number of requests for orphan drug designation submitted to the FDA has more than doubled since 2012, and more orphan drugs are reaching the market. Coupled with the trend for high prices, this has led to year-on-year growth in the orphan drugs market outstripping the wider pharmaceutical market. Orphan drug spending now accounts for more than 16 percent of total prescription drug spending.

Pricing is based on what the market will bear

Pharma companies have traditionally justified high prices for orphan drugs because of the cost of development and the need to make a return on investment despite a small number of patients. Payers have tolerated this, but the rising number of treatable rare diseases is placing pressure on resources and the current situation is considered unsustainable.

Payers want fair pricing for orphan drugs

Payers suggest that pharma companies need to more effectively assess the factors dictating the price of orphan drugs. Factors such as the level of innovation and the real cost of development, the size of the patient population that would be eligible for treatment, and the clinical benefits of a drug. Payers indicate a need for a comparative analysis of the overall financial impact of the disease state in terms of the resources used currently, against the resources that will be used with the new drug.

Payers want early engagement from pharma

Payers believe that early engagement with pharma companies regarding orphan drugs in development will help to improve planning, and lower costs as a result. For example, if payers are able to explain their data requirements at a stage when these can influence trial design, this will likely expedite patient access following regulatory approval.

Stakeholder collaboration to increase patient access

Payers highlight several opportunities for collaboration between pharma companies, payers, government, academia, physicians and patients that would be helpful to support patient access. These include information sharing and education, working together to

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share risk and make orphan drugs more affordable, developing accurate diagnostics to speed reimbursement decisions, and government/university funding for R&D to share the cost of development, thereby reducing pharma's need for high prices.

Research Methodology and Objectives

At a time when payers are questioning the high cost of orphan drugs, expecting more evidence of value, and grappling with tight budgets, this report gives food for thought on how to ensure they are happy and that patients continue to get access to new orphan drugs.

Key questions explored in this report include:

How are pricing decisions made for orphan drugs? Does this differ to non-orphan drugs?

What factors affect how much payers are willing to pay for orphan drugs?

What should pharma consider when pricing orphan drugs?

What key assessment criteria determine funding/reimbursement of an orphan drug?

If the number of eligible patients for an orphan drug increases, should this affect pricing?

Is value-based pricing or conditional reimbursement a way forward for orphan drugs?

When should pharma companies engage with payers on potential new orphan drugs?

How can stakeholders work together to increase patient access to orphan drugs?

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Value-based pricing and conditional reimbursement

Collaboration on orphan drug development funding

More reasons to buy this report

For orphan drugs, the pricing issue isn't new – but concern about affordability has reached a whole new level and payers clearly expect the industry to take action. The inexorable tide of 'big ticket' orphan drugs has created an unstainable situation that simply can't be ignored. The development of innovative new orphan drugs has to be paid for somehow; however, there are a host of alternative approaches that could help to address the issues and still give pharma the freedom to continue innovating. Collaboration is the key to a workable solution and that requires all parties to come to the table

This report will enable you to

Understand how orphan drugs are priced in different countries and the cost implications.

Find out why payers believe some high prices are acceptable, and some are not.

Explore the concept of 'fairness' and understand the key factors that prompt concern from payers.

Gain detailed insight into funding and reimbursement decision-making for orphan drugs.

Understand more about the impact of real world data post launch.

Be inspired with new ideas for collaboration and issue resolution across the orphan drugs market.

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