

# **Availability of orphan medicines varies between European countries**

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Credit: Raija Törrönen

There are differences in the availability of orphan medicines between different European countries, a new study from the University of Eastern Finland shows.

Orphan medicines are [pharmaceutical products](#) developed specifically for the treatment, prevention or diagnostics of rare diseases. Rare diseases are life-threatening or permanently disabling [medical conditions](#), and they affect some 30 million people in Europe and more than 300,000 people in Finland alone. People suffering from a [rare disease](#) do not always have access to the medicines they need. Factors limiting the availability of orphan medicines include them not entering the markets or their [financial burden](#) on the patient or society being too high.

The study focused on the availability and distribution channels of ten orphan medicines used in [outpatient care](#) in 24 European countries. On average, five of the ten medicines were available on the markets, but there was variation between the countries. All ten medicines were available only in three countries: the Netherlands, Malta and Poland. Five to nine medicines were available in ten countries: Austria, Finland, Germany, Iceland, Italy, Norway, Slovakia, Spain, Sweden and the United Kingdom. Four countries, namely Latvia, Lithuania, Turkey and Belarus, did not have any of the medicines studied available.

Typically, rare medicines were dispensed to patients at pharmacies. Other dispensaries, such as hospitals or health centres, were also quite commonly used. When orphan medicines were dispensed to patients at pharmacies, a part of the price was often paid by the patient, whereas hospitals and health centres typically dispensed the [medicine](#) free of charge.

The study also explored whether the European countries studied had implemented policies to regulate decisions relating to the pricing and reimbursement of rare medicines specifically. Typically, no policies applicable to rare medicines alone were in place; instead, decisions on rare medicines were made on the same grounds as decisions on other medicines. However, 13 countries reported some type of a special arrangement. In Latvia and Russia, for example, rare medicines come under a separate budget, and countries such as Spain, Lithuania and Hungary have set special conditions on the reimbursability of rare medicines.

The study was carried out in April 2016 via a survey sent to the members of a network of authorities dealing with pharmaceutical product pricing and reimbursement in Europe, and 24 countries responded. The study was funded by the Social Insurance Institution of Finland, Kela, and the University of Eastern Finland.

**More information:** Kati Sarnola et al. Policies and availability of orphan medicines in outpatient care in 24 European countries, *European Journal of Clinical Pharmacology* (2018). [DOI: 10.1007/s00228-018-2457-x](https://doi.org/10.1007/s00228-018-2457-x)

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