

# PRESS RELEASE

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### Ethics Council calls for a fairer care for people with rare diseases

In its Ad Hoc Recommendation published today, the German Ethics Council draws attention to the specific vulnerability of people with rare diseases. The Council calls for a number of measures to protect affected people from inadequate care. The goal must be the fair consideration of their needs in clinical research and healthcare.

Anyone in Germany who is one of the four million or so people with a rare disease is often confronted with a variety of problems. Ranging from the wrong or delayed diagnosis to psychological stress due to isolation or poor care when specialist facilities are lacking or difficult to reach - the interests of those affected are often not adequately acknowledged.

At the same time, there is broad consensus that a society based on solidarity must provide all of its members with a fair chance of adequate treatment in the event of illness, regardless of whether it is a common or a rare disease. The Ethics Council therefore considers it an urgent necessity to improve the medical care of people with rare diseases and to promote their opportunities for participation.

As a first step, the poor healthcare situation of people with rare diseases should be countered by improved education, training and further education within the health professions. Medical students, physicians and members of other health professions should be made aware of the specific problems in the diagnostics, treatment and prevention of rare diseases. In addition, patients need access to specific and age-appropriate training programmes which should be understood as part of the overall therapeutic concept and, as such, covered by the responsible bodies for healthcare financing. The Ethics Council also recommends to establish and adequately finance certified centres for rare diseases on a nationwide scale. These centres should enable multi-professional care and assume a guiding role in the healthcare system for those affected. Due to the small number of people affected, clinical research on rare diseases must also be connected across national borders. In general, research to improve the diagnosis, therapy and prevention of rare diseases should be strengthened and also involve patients in the development and, if necessary, decisions about prioritisation of publicly funded research projects.

Self-help groups or patient organisations of people with rare diseases have a wealth of experience that should be used to improve diagnosis, treatment and prevention. In view of the particular problems of those affected, the Ethics Council advocates organising the healthcare system in a way that enables self-help. Patient registries are particularly important for rare diseases to gain even better evidence after the approval of new drugs. They also enable the

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concentration and more efficient use of locally available knowledge and the better networking of specialists and those affected. In the opinion of the Ethics Council, it is important to ensure that such registries are subject to external quality assurance and are neither managed by a single physician nor by a single pharmaceutical company.

The complete Ad Hoc Recommendation can be accessed at <https://www.ethikrat.org/fileadmin/Publikationen/Ad-hoc-Empfehlungen/englisch/recommendation-the-challenges-of-providing-care-for-rare-diseases.pdf>.