

EUROPEAN CALL FOR PROPOSALS: IDENTIFICATION OF UNMET NEEDS VIA THE NEED PROJECT

Health conditions or diseases for which there is no effective treatment, those for which the treatment has numerous side effects, or those diagnosed late... all these realities lead to unmet health-related needs. To guide health policy and healthcare innovation in the right direction, it is essential to identify these unmet needs and to consider them both from the perspective of the patient and that of society.

The Belgian Health Care Knowledge Centre (KCE) and Sciensano have launched a joint project called "NEED" (Needs Examination, Evaluation, and Dissemination) which aims to identify unmet patient and societal needs for a specific health condition. In order to select the conditions to be studied they are launching a call for proposal of a health condition or disease. The proposals should describe which unmet needs deserve to be analysed.

This call for proposals is an initial step in the creation of a list of health conditions or diseases with potentially high unmet needs in Europe.

The ultimate aim of the project is to develop a European database containing scientific evidence on unmet needs in different types of health conditions. This database could be used by policy-makers, researchers, healthcare providers, etc. to guide, for example, policy decisions likely to improve patients' quality of life, investment decisions in the development of new treatments, or treatment choices.

You will notice that some of the questions will ask whether you can provide quantitative data (numbers), which would be valuable additional information. Wherever possible, please provide us with data at the European level or for one or more European countries, specifying the source. Data stored within a patient organisation's internal documents can also be cited as an information source. Providing quantitative data is optional and can be omitted if you do not have access to such information.

If you do not have information on certain aspects of the health condition, please state so (e.g. write "I don't know"). However, the more information you provide, the better we will be able to assess the unmet needs related to the health condition.

Affiliation(s) of the person submitting the health condition proposal

All proposals will be assessed anonymously. This information will be used to inform you about the results of the call for proposals.

- First name:
- Last name:
- Email address:
- Country of residence:
- This call for proposals is intended for institutions/individuals with no commercial interests. Please indicate your affiliation(s)/role(s):
 - Patient
 - Patient organisation
 - Informal caregiver
 - Researcher
 - Healthcare professional
 - Policy maker
 - Citizen
 - Other (please specify) : _____

Information about the proposed health condition

1. Name the health condition (**which can be a disease, a disorder, or a syndrome**).



Disease groups and non-specific health conditions (e.g. cancer, falls, low back disorder, neck disorder, or prostate problems), **symptoms**, and **health conditions with no diagnosis** will be excluded, because they do not allow to identify the relevant patients and their specific needs.

2. Is the health problem considered a rare disease? (a condition is considered to be rare if it affects less than 1 in 2000 persons")
 - Yes
 - No
 - I don't know

3. Briefly describe the health condition (e.g. affected organs/body parts, symptoms, causes, typical age of onset).

4. Why do you think that this health condition is particularly relevant for the NEED call for proposals?

For example, does the health condition have an important impact on patients' quality of life or on their life expectancy? Is it a very frequent health condition? Is the treatment/management of the condition very burdensome or not very effective? Does the health condition have an important economic impact on patients and/or on society? Does the health condition specifically affect a vulnerable group of the population?

You can also mention any other reason for which you believe that the health condition is relevant for the NEED call for proposals.

Impact of the health condition on patients' quality of life

We are interested in the impact of the health problem on patients' quality of life **despite the current management of disease**.

5. Describe the impact of the health condition (if any) on different aspects of patients' quality of life **despite the current management of disease**.

If you have access to quantitative data on the impact of the health condition on the different aspects of patients' quality of life, please provide these data, their sources, and to which European country/ies the data apply.

Aspects of quality of life include, for example, pain/discomfort, mental health (e.g. emotions, anxiety, worry, depression), mobility (e.g. ability to walk, move, or practice a physical activity), self-care (e.g. ability to wash, dress, maintain personal hygiene, and eat/drink), and usual activities (e.g. work, study, housework, family, or leisure activities).

Impact of the health condition on patients' life expectancy

This section is about the impact of the health condition on patients' life expectancy, **given current management of disease**. Life expectancy is the average period that a person may expect to live.

6. Describe the impact of the health condition on patients' **overall life expectancy**. If you have access to quantitative data on the impact of the health condition on life expectancy, on **disease-specific mortality** or **case-fatality**, please provide these data, their sources and to which European country/ies the data apply.

7. If you have additional comments related to the impact of the health condition on life expectancy, please share them here.

Frequency of the health condition

8. Describe **how often** the health condition occurs in the general population. If you have access to quantitative data on the **frequency** of the health condition (prevalence and/or incidence), please provide these data, their sources and to which European country/ies the data apply.
9. If you have additional comments related to the frequency of the health condition, please share them here.

Accessibility, effectiveness, and burden of the overall management of the health condition

The overall management of the health condition covers the combination of interventions prescribed or carried out by healthcare professionals to either cure a health condition, ease symptoms, or prevent complications. This can include medicines, surgery, psychological therapy, or other clinical interventions (e.g. physiotherapy).

10. Describe the **management of the health condition**, including for example medication, surgery, psychological therapies or other clinical interventions. Please provide the information sources and to which European country/ies the information applies.
11. Describe **any problems related to the accessibility of health interventions performed as part of the current management** of the health condition. Accessibility can be defined as the ease of access to healthcare services, both physically and in terms of cost, time and availability of healthcare services and availability of qualified staff.

If you have access to quantitative data on the problems related to the accessibility of current management of the health condition, please provide us with these data, their sources and to which European country/ies the data apply.

12. Briefly describe **the effectiveness of the current management strategy/ies of the health condition**, including the effectiveness of medication, surgery, psychological therapies or other clinical interventions. If you have access to quantitative data on the effectiveness of the current management of the health condition, please provide these data and their sources.
13. Indicate if, overall, the management of the health condition is burdensome:

*For example, the management of the health condition can be burdensome due to its **side-effects**, its **administration route** (e.g. oral, injection), its high **frequency of use**, and/or the **logistics** of receiving it (e.g. having to go to a specific hospital, having to store treatment in a fridge).*

- Very burdensome
- A little burdensome
- Not burdensome
- I don't know

14. Describe **in what way** the management of the health condition can be burdensome. If you have access to that information, please provide the information sources used. (*Only appears if "very burdensome" or "a little burdensome" is selected*)
15. If you have additional comments related to the accessibility, effectiveness and/or burden of the management of the health condition, please share them here.



Financial and economic impact of the health condition

This section is about the financial and economic impact of the health condition, which includes the impact on patients, carers, the healthcare system and on the wider society.

16. Describe the financial impact of the health condition on **patients**. If you have access to quantitative data on the financial impact of the health condition on patients, please provide these data, their sources and to which European country/ies the data apply.

The financial impact on patients can include costs of treatment as a whole, costs of consultations, costs of hospitalisations, costs of transport to receive care, costs of additional childcare, reductions in household income, and interruptions to education.

17. Describe the economic impact of the health condition on **society**. If you have access to quantitative data on the economic impact of the health condition on society, please provide these data, their sources and to which European country/ies the data apply.

The economic impact on society can include costs on the healthcare system, productivity losses, and costs for informal carers.

18. If you have additional comments related to the financial and/or economic impact of the health condition, please share them here.

Impact of the health condition on vulnerable populations

19. Does the health problem affect any **vulnerable population(s)** in a different way? If so, please specify which one(s) and describe how they are affected (for example in terms of the impact of the health condition on quality of life and life expectancy, the frequency of the health condition, the effectiveness and burden of the management of the health condition, and/or the financial or economic impact of the health condition).

If you also have access to quantitative data on how the health problem affects **vulnerable population(s)**, please provide these data, their sources and to which European country/ies the data apply.

20. If you have additional comments related to the impact of the health condition on **vulnerable population(s)**, please share them here.

Thank you for taking the time to complete this form and for helping to identify unmet health-related needs.

Your proposal will be evaluated according to a specific procedure by the researchers of the NEED team. You will be notified by email of the final selection of health conditions for the NEED research programme.

If you have any questions or require further clarification, please contact: info@kce.fgov.be.

To stay informed about the progress of the NEED project, we invite you to subscribe to the NEED newsletter on our website: <https://health-needs.eu/index.php/en/>