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## A framework for assessing unmet health-related needs

Thanks to the tremendous medical and scientific progress made in recent decades, a growing number of health issues can now be treated more effectively than ever. However, many needs remain not or insufficiently met by the current offer of products and services. To better target the areas which should be prioritised for research on solutions to address unmet needs, the first necessary step is to identify and assess these unmet needs. Which diseases remain underserved? What do people living with these conditions need most and foremost? What is the societal burden of a given health problem? These are the crucial questions addressed by NEED, a large-scale project run by the Belgian Health Care Knowledge Centre (KCE) and the Belgian institute for public health Sciensano, in collaboration with several other Belgian public institutions. In this new study, the research team presents a scientific framework for assessing unmet patient and societal needs, which should ultimately allow all healthcare and healthcare innovation stakeholders to better take them into account when making decisions or setting priorities.

Providing the best possible support to people facing health problems is indisputably a major objective for all stakeholders involved in the healthcare sector. However, some conditions attract more attention than others, e.g. because they affect a large number of people or are amenable to relatively straightforward solutions. When medical innovation started to accelerate a few decades ago, looking first and foremost for the low-hanging fruit was a logical choice both from an economic and from a medical and societal point of view. Nowadays, this low-hanging fruit has largely been picked, and more and more effort is needed to achieve increasingly small progress. "Innovation" is often concentrated in areas that have already been well explored, particularly those which involve a large number of patients or where the financial risks are relatively limited. A lot of new health interventions offer, at best, marginal added value for patients and society, which is an inefficient use of public and private resources.

## European awareness

The current model, driven largely by economic considerations, has reached its limits. The time has come for (representatives of) society to regain control of innovation, investments and, more broadly, policy decisions in the healthcare sector and to direct it towards areas where they can generate the greatest added value: those where there are still major needs at the level of individual patients (e.g. because there are no treatments at all for their condition) or at the level of society (e.g. because the condition continues to affect a very large number of people and has major repercussions in terms of productivity, impact on informal caregivers, etc.).

Fortunately, decision-makers are becoming well aware of this need for change, to the extent that unmet needs are one of the main focuses of the Belgian EU Presidency health programme.

## A large-scale project

The NEED (Needs Examination, Evaluation, and Dissemination) initiative aims at supporting the transition towards a needs-driven health and innovation strategy, by creating a research infrastructure that coordinates unmet needs research, which will feed into a European evidence database accessible to all, where scientific information concerning health-related unmet patient and societal needs will be gathered

for a large number of health conditions. The information will be presented so as to make it easy to assess which needs are being met or not, and thus to inform the choices made by decision-makers and healthcare stakeholders.

Because resources for unmet need research are limited, the first necessary step will be to identify the health conditions for which unmet needs remain significant (e.g. on the basis of information from existing sources but also of calls for proposals) and to decide which of them should be prioritised for in-depth unmet needs research. Next, it will be necessary to gather concrete data on the unmet needs that remain for each of these health conditions (using analyses of the scientific literature, surveys, etc.). These data will be used to populate the database.

## What is the purpose of the new KCE-Sciensano study?

The new tool developed by the KCE and Sciensano, the “unmet needs assessment framework”, will serve as a template to collect the necessary data in a scientific, structured and harmonised way. To give as complete a picture as possible of the unmet needs associated with a given health condition, the research team identified 23 criteria, each measured by one or more indicator(s) (see box for a few examples). For each indicator, the framework also mentions the most appropriate sources of information: scientific literature, expert opinion, surveys, individual interviews with patients, etc.

It is important to emphasise that these criteria and indicators cover both the needs of patients, and those of society, but also the anticipated future needs. They also have a broad scope, looking at both the direct and indirect impact of the disease on individual and collective health, the need for healthcare and health services it generates and its social implications (such as its impact on interpersonal relationships, studies, work or income, the environmental impact of its treatment, etc.). Medical or therapeutic needs are in that sense only one aspect of health-related needs. The framework assesses the unmet health-related needs in their current context, taking into account the existing offer of care and other services.

### Some examples of criteria and their indicators

Criterion: impact on patients' physical health

Indicators:

- Perceived burden of physical symptoms
- Onset or worsening of pain or discomfort

Criterion: impact on education

Indicator: number of years of education lost due to illness

Criterion: environmental impact of the standard of care

Indicators:

- Greenhouse gas emissions related to the standard of care
- Hazardous waste related to the standard of care
- Use of natural resources and raw materials related to the standard of care

## A promising tool

In theory, the NEED assessment framework is designed to assess the unmet needs associated with any health condition. The research team experimentally tested it on two conditions, Crohn's disease (a chronic inflammatory bowel disease) and malignant melanoma (skin cancer). A further study confirmed that the framework can also be used in the context of rare diseases, provided that certain attention points are taken into account. Future experience will allow to refine the tool over time.

Will the NEED initiative and the philosophy behind it convince Belgian and European stakeholders involved in health policy and innovation? It is certainly generating a great deal of enthusiasm: 16 EU Member States have already expressed their explicit support to the project. Unmet needs will also be the topic of a European conference organised mid-April by the Belgian Presidency of the Council of the European Union. Hopefully, sufficient resources will be made available to enable in-depth scientific research into as many diseases as possible.

Belgian Health Care Knowledge Centre  
Administrative Centre Botanique, Doorbuilding (10th floor)  
Boulevard du Jardin Botanique 55  
1000 Brussels  
Belgium  
+32 2 287 33 88  
<http://kce.fgov.be>

Gudrun Briat  
Scientific communication  
+32 475 274 115  
[press@kce.fgov.be](mailto:press@kce.fgov.be)