



## International Advisory Committee Meeting

11 June 2024, Brussels, Belgium

### **NEED: Needs Examination, Evaluation and Dissemination**

*“Identifying patient and societal needs for a more needs-driven innovation and policy in healthcare.”*

### **FLASH REPORT**

The second international advisory committee meeting was set up to discuss the progress of the NEED project.

#### **1. State of the art: where are we? (Irina Cleemput, KCE Scientific Director; NEED Coordinator)**

This presentation outlined the various activities undertaken since November 2023 as part of the NEED project, including conferences and publications. One of the highlights was the high-level conference held on April 17-18 2024, as well as the publication of the first four reports related to the project and several related publications like the [NEED brochure](#) and fact sheets for the case study on [Crohn's disease](#) and the case study on [Melanoma](#).

#### **2. Validation of the NEED assessment framework with Delphi survey at EU level. (Laurence Kohn, KCE; Rani Claerman, Sciensano)**

This session covered the methods, process and results of the Delphi survey conducted to validate the NEED framework at EU level. Twenty-seven experts participated in the first round, and 26 in the second, representing 17 different countries. A consensus was reached on most of the criteria and indicators, which were subsequently included in the NEED framework. Additionally, the simplified NEED framework was introduced.

#### **3. Identification of Patient and Societal Unmet Needs associated with Crohn's and melanoma: application of the NEED assessment framework. (Claudia Schönborn, KCE)**

In this presentation, we discussed the application of the NEED framework to melanoma and Crohn's disease. For Crohn's disease: while there have been improvements in diagnostic accuracy and a wider range of surgery-sparing treatments, Crohn's remains a chronic, early-onset disease with a significant impact on quality of life. The incidence and healthcare costs are still expected to rise, treatment effectiveness is lacking, and the disease is not preventable. With respect to melanoma: significant advances have been made over the last few decades in melanoma detection, new treatments for advanced disease, and primary prevention. However, melanoma still causes significant anxiety, and advanced disease and rare types remain fatal for many.

#### **4. Experience with the application of the NEED approach/assessment framework. (Isabelle Huys, KULeuven)**

The KUL presented their experience in applying the NEED approach. For example, we can draw on their experience with using the questionnaire for conducting the online survey. They proposed several



highly relevant adaptations, such as reducing the length of the questionnaire and modifying certain questions to make them clearer for the participants.

#### **5. Presentation of the NEED database. (Robby De Pauw, Sciensano; NEED Coordinator)**

The development of the NEED database was presented, drawing inspiration from the Belgian Burden of Disease (BeBOD) and the Global Burden of Disease (GBD) study. The structure of the database, along with a preliminary version, was showcased. Various implementation barriers were discussed, such as missing data for certain indicators and the need to develop a method for the critical appraisal of health-related unmet needs. Additionally, the automation of survey data analysis was highlighted as a necessary area for further development.

#### **6. Identification and selection of the health conditions with potential high unmet health-related needs. (Muriel Levy, KCE)**

This presentation focused on steps 1A, 1B, and 2 of the NEED 4-step implementation model, specifically the identification of health conditions with potentially high unmet needs, their prioritisation, and selection for the NEED research program. For step 1A, the identification of health conditions was based on the BeBOD database. In step 1B, a public call for proposals was launched in Belgium between January and March 2024. Steps 1A and 1B resulted in the identification of 117 health conditions with potentially high unmet needs in Belgium. The prioritisation and selection phase is currently underway and is expected to be completed in the first part of summer 2024.

#### **7. Experience with the identification and application of approaches on unmet need reporting for innovation policy purposes. (Oliver Bujok, InnoVance GmbH on behalf of German Research Ministry (BMBF))**

InnoVance presented their initiative on unmet need reporting for innovation policy purposes. The goals of this initiative are to evaluate the Burden of Disease (BoD) as a suitable measure for identifying unmet needs relevant to population health through an extensive literature review, to test hypotheses based on BoD data, and to establish a survey grounded in the Global Burden of Disease (GBD) data. This survey aims to estimate the current medical care gap, assess mortality and morbidity associated with these gaps, project future medical care gaps, allocate these gaps across the health continuum, and investigate disease-specific medical care gaps. By achieving these objectives, the initiative seeks to provide a clear understanding of unmet medical needs and their implications for population health, thereby informing and guiding innovation policies.

#### **8. Discussion on possible collaboration for the next case studies and application for funding. (Charline Maertens de Noordhout, KCE; NEED Principal Investigator)**

Several discussion questions regarding the sustainability of NEED ended the meeting. The discussion focused on the strategy to quickly complete the NEED database. For example, the proposed strategies included conducting case studies based on the simplified version of the NEED assessment framework and allowing external researchers to contribute to the NEED database. Additionally, the discussion covered how collaborations could be developed within the framework of the project.