

SHORT REPORT

HOW TO IDENTIFY PATIENT NEEDS?



SHORT REPORT

HOW TO IDENTIFY PATIENT NEEDS?

CHARLINE MAERTENS DE NOORDHOUT, JENS DETOLLENAERE, CÉLIA PRIMUS-DE JONG, LAURENCE KOHN, BRECHT DEVLEESSCHAUWER,
RANA CHARAFEDDINE, IRINA CLEEMPUT



■ SHORT REPORT

TABLE OF CONTENTS

■	SHORT REPORT	1
1	INTRODUCTION	4
1.1	EVOLVING TOWARDS A NEEDS-DRIVEN HEALTHCARE POLICY	4
1.2	THE UNMET MEDICAL NEED PROCEDURE	4
1.3	THE VARIOUS DIMENSIONS OF THE NEED CONCEPT	5
1.4	OBJECTIVE AND RESEARCH QUESTIONS.....	6
1.5	METHODOLOGICAL APPROACH	6
2	METHODS AND TOOLS FOR IDENTIFYING PATIENT NEEDS.....	7
2.1	QUANTITATIVE APPROACH	7
2.1.1	Disability-Adjusted Life Year (DALY)	7
2.1.2	Camberwell Assessment of Need (CAN).....	8
2.1.3	Nottingham Health Needs Assessment (NHNA).....	8
2.1.4	Needs and Provision Complexity Scale (NPCS).....	8
2.1.5	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan survey.....	9
2.1.6	Common points for all quantitative methodologies	9
2.2	QUALITATIVE APPROACH	10
2.3	MIXED APPROACHES	11
2.4	ADDITIONAL APPROACHES	11
2.5	CONCLUSION.....	11
3	POTENTIAL DATA SOURCES FOR IDENTIFYING HEALTH CONDITIONS WITH THE HIGHEST NEEDS	12
3.1	SELECTED DATABASES	13



3.1.1	The Health Interview Survey (HIS)	13
3.1.2	The Belgian Burden of Disease study(BeBOD)	13
3.1.3	The list from the NIHDI's Unmet Medical Need programme.....	14
3.1.4	The SHARE survey (Belgium).....	14
3.1.5	The Global Burden of Disease Study	14
3.2	COMPILED LIST	17
4	DEVELOPMENT OF A GENERIC QUESTIONNAIRE FOR MEASURING PATIENT NEEDS	20
4.1	DEVELOPMENT OF THE GENERIC QUESTIONNAIRE.....	20
4.2	PILOT STUDY	21
4.2.1	Online survey	21
4.2.2	Qualitative research	21
4.3	LESSONS FROM THE DELPHI PROCEDURE AND PILOT STUDY	21
4.3.1	Generic questionnaire	21
4.3.2	Qualitative research: online forum and interviews	23
5	A METHODOLOGY FOR IDENTIFYING PATIENT NEEDS IN BELGIUM	24
5.1	HOW CAN THE DATA BE USED?	24
5.2	A SEVEN STEP MODEL	25
5.2.1	Step 1	27
5.2.2	Step 2	27
5.2.3	Step 3	27
5.2.4	Step 4	27
5.2.5	Step 5	28
5.2.6	Step 6	28
5.2.7	Step 7	28



5.3	WHAT RESOURCES ARE REQUIRED TO IMPLEMENT THIS APPROACH?	29
6	CONCLUSION	30
■	RECOMMENDATIONS	31
■	REFERENCES	34



1 INTRODUCTION

1.1 Evolving towards a needs-driven healthcare policy

European and Belgian policymakers have been adopting measures to make healthcare policy more needs-driven for several decades, particularly in the field of pharmaceuticals. At the regulatory level, compassionate use and medical needs programmes were set up at the Federal Agency for Medicines and Health Products (FAMHP)^a, and procedures for conditional marketing authorisations, granting specific status to orphan drugs and special schemes to support the registration of pharmaceutical products targeting high unmet medical needs (PRIME) were developed at the European Medicines Agency (EMA). In addition, drug reimbursement agencies have established programmes to provide early temporary reimbursement for "promising" drugs to cater for high unmet medical needs. In Belgium, this is referred to as the "Unmet Medical Need" procedure^b. This procedure was introduced by the National Institute for Health and Disability Insurance (NIHDI) in 2014. The current study stems from continued reflection on how to improve the unmet medical need procedure.

1.2 The Unmet Medical Need procedure

The aim of the Unmet Medical Need procedure is to give critically ill patients expedited access to promising, innovative medicines which have not yet obtained marketing authorisation (MA). It regulates the early temporary reimbursement of medicines, pending their official authorisation and potential definitive reimbursement. However, this procedure only applies to serious conditions that appear on a list drawn up on an annual basis by the NIHDI's General Council, on the advice of the "Advisory Committee on Temporary Reimbursement for the use of a medicinal product"

(CATT/CAIT). This committee is also responsible for determining the relative priority of the conditions that appear on the list^c.

Detailed proposals must be submitted in order to add a health condition to the list. Only the NIHDI (more specifically, the College of Medical Directors), the Minister(s) of Social Affairs and Public Health, or pharmaceutical companies can submit proposals. The application procedure is not open to patients and patient associations. As a result, the majority of applications currently come from pharmaceutical companies that have a new drug in the pipeline and regard this route as an opportunity to claim early temporary reimbursement prior to obtaining MA. The Unmet Medical Need procedure therefore remains largely **supply-driven** (i.e. driven by medicines that will shortly be available on the market), **rather than demand-driven** (i.e. driven by patient needs). The original intention, however, was to create a system that would respond better to (high) patient needs.

Back to the original project. An immediate solution would, of course, be to also extend the submission of indications to patients and healthcare providers, as recommended in [KCE-report 272](#). However, it would arguably be more equitable to entrust an (existing or new) body with collecting data on the needs of patients with conditions that have potential for inclusion on the list, and to subsequently prioritise these. This should be an independent body in order to ensure that all health conditions are eligible for inclusion on the list, instead of only those for which patient advocates exist. This collection must be performed (at least partially) in a **standardised** way to ensure that data related to, at times, extremely diverse conditions can be compared and prioritised.

^a https://www.famhp.be/en/human_use/medicines/medicines/research_development/compassionate_use_medical_need

^b Dutch: https://www.inami.fgov.be/nl/themas/kost-terugbetaling/door-zieken_fonds/geneesmiddel-gezondheidsproduct/terugbetalen/Paginas/unmet-medical-need.aspx

French: <https://www.inami.fgov.be/fr/themes/cout-remboursement/par-mutualite/medicament-produits-sante/remboursement/Pages/unmet-medical-need.aspx>

^c This priority exercise is performed using a multi-criteria decision analysis (MCDA), based on previous work by the KCE([KCE report 272](#)).



If our health system is to satisfy unmet patient needs, then identifying these needs should ideally be the starting point for *all* reimbursement decisions (for drugs, technology, medical devices etc.). This would also allow more scope for creativity in finding solutions for patients' unmet needs than just the products provided by the industry. Imagine a scenario, for example, in which patients with heart failure wearing a pacemaker are concerned about the functioning of their device. In this case, the identified need would be to reduce that fear, which would have an impact on their quality of life. The reimbursement of a telemonitoring system could present a technological solution to meet this need. Other options could also be considered, such as regular follow-ups by their GP or psychological support. If the reimbursement decision for these solutions were based on patient needs, it could consider not only the price and efficacy of the various options, but also the degree of need (e.g. severity of suffering as a result of this fear).

It would therefore be best to transpose **the conceptual exercise undertaken by the KCE in the context of the Unmet Medical Need procedure to all reimbursement decision-making processes.**

1.3 The various dimensions of the need concept

The "unmet need" concept has an **individual dimension**, linked to the patient, and a **societal dimension**:

- **therapeutic need** refers to individual patients' need for a treatment (or other care solution) that improves their quality of life, expected lifespan or general health;
- **societal need** refers to needs of the society as a whole, such as the need for a treatment for a very common health problem, or the need for a less expensive (but equally effective) treatment to replace a costly existing treatment for a particular condition, in order to reduce its impact on the healthcare budget. If a new drug can significantly reduce government spending on a particular health condition (because it prevents hospitalisation or lifelong disability for example), then it will meet the societal need to allocate resources more efficiently (achieving the same result with fewer resources, or improved results with the same resources).

A condition can be included on the Unmet Medical Need list due to its individual or societal impact, or both. These two dimensions are difficult to merge into a single concept by virtue of constituting two entirely different perspectives. The criteria for therapeutic need are generally relevant for the patient, while the criteria for societal need may be less important for individual patients, though significant for society. That is why the KCE's report 272 also recommends drawing up two separate priority lists. That way, a new treatment can qualify for the Unmet Medical Need programme due to its high ranking in the therapeutic needs list, in the societal needs list, or both.

This study arises from two independent, yet very similar requests that were submitted to KCE by two separate bodies. The Flemish umbrella association of patient organisations, the **Vlaams Patiëntenplatform (VPP)**, asked KCE (i) to explore the possibility of authorising other stakeholders to submit proposals for the list of unmet medical needs and (ii) to develop a **scientifically based methodology to identify patient-reported unmet medical needs** that could be harnessed as scientifically based information when performing the Unmet Medical Need procedure. The NIHDI's **Observatory for Chronic Diseases** asked KCE to investigate how patient needs could be identified in a feasible and scientifically valid manner and used in a broader framework, beyond the Unmet Medical Need procedure (e.g. also in the context of integrated care for the chronically ill).

Initially, the study therefore focused exclusively on measuring therapeutic patient needs, i.e. the need for (enhanced) treatment or care from the perspective of the individual patients. The advisory committee that was established for this study (see 1.5) subsequently asked for the concept of "patient need" to be extended to other more general health-related needs of individual patients, such as the need for information and support etc. We consequently use the generic term "patient needs" throughout this document.



1.4 Objective and research questions

The aim of this project is to develop a viable scientifically based methodology for the **identification of patient needs** in order to evolve towards a more needs-driven healthcare system. The application of this methodology should lead to meaningful, scientifically based input for **decision processes pertaining to MA, processes that assess the (added) value of health interventions, such as Health Technology Assessments (HTA), and the NIHDI's reimbursement decisions**. The information should allow decision-makers to assess (1) whether a new treatment addresses self-reported patient needs and (2) to what extent it meets these needs (or targets other outcomes that may be of secondary importance for patients, but are used by companies to claim 'added therapeutic value').

In addition, the proposed methodology should provide input for the creation of **a list of patient needs** to enable manufacturers or scientists (from industry and academia) to focus their efforts on those conditions where patient needs are highest. The ultimate goal is to create a **more needs-driven healthcare system**. Other stakeholders, such as patient organisations, health insurance funds and healthcare providers, might also benefit from detailed information on patient needs when it comes to developing, shaping or improving their activities.

The methodology should be:

- sufficiently **generic** to allow general applicability to a wide range of health conditions, stages and severities and to the entire population in all its diversity;
- founded on tools and approaches that are based on **scientific evidence** and guarantee that the various patient populations are treated in the same objective way;
- **practically feasible**;
- capable of being embedded into a **structural approach** for identifying patient needs;

- **implementable** with a reasonable investment of resources, so as to maximise its applicability.

Four research questions have been formulated to achieve these objectives:

1. Which methods for identifying patient needs have been described in the literature, and which validated instruments have been used and applied in practice (in Belgium or abroad)?
2. Which existing data sources are available to prioritise health conditions for the identification of patient needs?
3. What method could be developed to identify patient needs in Belgium, based on the insights from research questions 1 and 2?
4. What are the requirements, in terms of human resources, qualifications and time, to allow for a systematic identification of patient needs in diverse patient populations?

1.5 Methodological approach

This study was conducted in several phases:

- A pragmatic literature review (including grey literature) was performed to identify different approaches (qualitative, quantitative and mixed) to measure patient needs, as well as tools used and dimensions considered.
- An overview was made of possible data sources that could be used either to identify patient needs or to identify health conditions with a potential high burden for patients.
- A generic questionnaire was designed using input from the literature review to measure patient needs and to serve as a basis for an in-depth qualitative assessment of patient needs in specific conditions. The questionnaire was submitted to a Delphi panel of patient representatives who assessed whether the questions were relevant and clear.



- A pilot study was conducted in a specific patient population (patients with long COVID) to test the feasibility and appropriateness of the generic questionnaire, followed by a qualitative study (online forum and in-depth interviews) to further explore the needs raised. The generic questionnaire was subsequently improved using lessons learned from the pilot study.
- We examined the advantages and disadvantages of the two qualitative approaches used in the pilot study and the value of combining both in a patient needs study.

An advisory committee supported the research team throughout the project. This committee comprised patient representatives and healthcare users (the Dutch-speaking umbrella association of patient organisations (VPP), the French-speaking umbrella association of patient organisations *Ligue des Usagers des Services de Santé* (LUSS), the umbrella association of patient organisations for rare diseases (RaDiOrg) and the health insurance funds), the Observatory for Chronic Diseases (which is part of the NIHDl) and researchers with experience in research into patient needs. The committee was regularly consulted on all aspects of the project (“embedded consultation”).

2 METHODS AND TOOLS FOR IDENTIFYING PATIENT NEEDS

A pragmatic literature review was undertaken to identify methods to measure health-related patient needs. Both the strategy and details of the literature review can be found in the English-language scientific report. This document only covers the key points.

2.1 Quantitative approach

The majority of the publications included describe quantitative approaches to measure patient needs for a wide variety of health conditions. In total, we identified 30 instruments, which are described in detail in chapter 5 of the [scientific report](#) (their psychometric properties in terms of content validity, structure and internal consistency can be found in appendix 1.2.). These tools were used to develop the generic questionnaire. Below are some examples of commonly used instruments.

2.1.1 Disability-Adjusted Life Year (DALY)

The DALY measure is often used to assess the severity of a condition (and by extension, its therapeutic needs). It is a summary measure of the effect (or burden) of a health problem on the population or the individual, expressed as the number of years of healthy life lost due to disease, disability or premature death. DALYs are calculated as the sum of *Years of Life Lost* (YLL) and *Years Lived with Disability* or *Years Lost due to Disability* (YLD).

The DALYs used for patient needs estimates are typically derived from the *Global Burden of Disease* (GBD) study, which is coordinated by the *Institute for Health Metrics and Evaluation* (IHME) at the University of Washington.¹ The GBD (2017) contains 38 billion estimates for 359 diseases and injuries, and 84 risk factors in 195 countries and regions.



Example of the implementation of DALYs in the Netherlands

Van Lier et al. calculated the national burden of disease estimates for a set of 32 infectious diseases in the Netherlands for the period 2007-2011.² The following conditions were included in the study: sexually transmitted infections (e.g. chlamydia, gonorrhoea, hepatitis B), vaccine-preventable conditions (e.g. diphtheria, invasive meningococcal infection, measles, rubella, tetanus), food-related diseases (e.g. campylobacteriosis, hepatitis A, salmonellosis, toxoplasmosis), and respiratory diseases (e.g. influenza, legionellosis, tuberculosis).

The DALY approach in this study focuses on all health outcomes that can be causally attributed to one of these specific pathogens and considers the potential long-term consequences. It permits improved estimation of the (future) health benefits associated with the prevention of infections.

2.1.2 *Camberwell Assessment of Need (CAN)*

The CAN is a family of questionnaires that was developed by King's College London in 1994.³ The questionnaires are used to identify the needs of patients diagnosed with a serious or long-term mental health problem (e.g. CANE (*CAN for the Elderly*)). Additional versions of the CAN have been developed around the world. The needs are measured within 22 CAN domains (each domain contains several items): accommodation, food, home care, self care, daily activities, physical health, psychotic symptoms, information on condition and treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, childcare, basic education, telephone, transportation, money and financial benefits. Each item is rated on a three-point scale.

Example of the implementation of CANE in Germany

Stein et al. used the CANE assessment tool to study met and unmet needs and their association with depression in elderly people in Germany.⁴ They did this using structured telephone interviews among a sample of 845 respondents aged 75 years or over and not suffering from comprehension problems or dementia.

The results of this study indicated that the majority of unmet needs fell under the CANE domains related to memory, physical health, mobility, vision/hearing/communication and continence.

2.1.3 *Nottingham Health Needs Assessment (NHNA)*

The NHNA questionnaire is specifically designed to assess the health needs of cardiac patients.^{5, 6} The questions relate to demographic data, employment, mobility and transport, access to local healthcare facilities, information needs and concerns, availability of carers, current health care, accommodation, education, leisure and social facilities. The list contains 49 items across five domains: physical needs (8 items), satisfaction (11 items), information needs (7 items), societal needs (12 items) and concerns (8 items). These items can be rated on a five-point scale.

2.1.4 *Needs and Provision Complexity Scale (NPCS)*

The NPCS tool measures unmet medical needs in patients with long-term neurological disorders and comprises two parts.^{7, 8} The first part ("*needs*") focuses on healthcare needs and support services, while the second part ("*gets*") assesses the extent to which the service meets these needs. In the original version, both parts were designed for completion by healthcare providers. A later patient-report version of the NPCS-gets was subsequently developed. The NPCS can be used at the population level to identify gaps in health service provision, as well as at individual patient level to monitor needs and provision along the care pathway over time.



Example of the implementation of NPCS in Norway

In 2017, the EQ-5D-3L questionnaire was used to assess the health-related quality of life for patients with Huntington's disease. The NPCS tool was subsequently used to measure unmet healthcare and social support needs.^{d7} The results showed a peak in unmet needs in stage III of the disease, while levels of unmet needs were lowest for patients in stage I and II. Patients in stage IV and V showed a constant level of unmet needs, which were higher than those in stage I and II, but lower compared to stage III. A negative relationship was also identified between the number of unmet needs and health-related quality of life.

2.1.5 Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan survey

The CAHPS Survey (US) assesses commercial and Medicaid healthcare programmes from the beneficiaries' perspective.¹⁰ It comprises two surveys for adults (one for commercial programmes and one for Medicaid) and two surveys for children. The survey comprises four parts: getting needed care, getting care quickly, how well doctors communicate, and health plan and customer service information. The respondents can rate these items on a four-point scale.

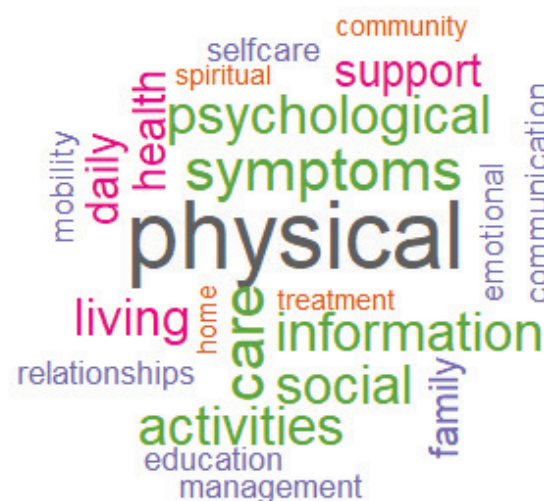
The CAHPS survey also asks respondents to rate their healthcare experiences over the past 6 months with their personal physician, the specialist they saw most often, the healthcare received from all physicians and other healthcare providers, and their health plan in general. The experiences are scored on a scale from 0 to 10.

2.1.6 Common points for all quantitative methodologies

The majority of quantitative methodologies are intended to measure patient needs in specific patient groups (e.g. patients with cancer, mental health

problems etc.); it is therefore difficult to generalise them. Nevertheless, certain domains feature in multiple methodologies. We used the word cloud method to visualise the most frequently cited domains. Figure 1 displays the domains that featured in at least three methodologies.

Figure 1 – Visualisation of the most frequently cited domains in quantitative methods for measuring patient needs



Note: The size and colour of the words are proportional to the frequency of their occurrence in the quantitative instruments.

The following key dimensions were identified:

- Physical dimension: referring to physical needs and the demand for relief from physical symptoms (e.g. pain);

and anxiety/depression. Each dimension has three levels of severity: no problems, some problems, serious problems.⁹

^d The EQ-5D-3L is a generic questionnaire for measuring health-related quality of life in five dimensions: mobility, self-care, daily activities, pain/discomfort



- Psychological dimension: referring to psychological support to deal with emotional problems related to the health condition;
- Autonomy dimension: referring to needs concerning daily living and self-care;
- Social dimension: referring to needs related to social interaction with the community or family and building relationships. This dimension also entails the need for appropriate information and the ability to communicate;
- Accessibility dimension: referring to needs of transportation to access care or activities, waiting lists, financial accessibility;
- Spiritual dimension: referring to needs concerning spiritual issues related to the (diagnosis of the) condition, such as fulfilment, moral contexts or religious beliefs.

These dimensions overlap with the needs of chronic patients identified in previous KCE research^e.^{11, 12} However, a number of dimensions that are not listed above may be relevant for certain patient groups or health conditions. For example, a housing dimension may be particularly relevant when assessing the needs of patients with certain physical disabilities.

2.2 Qualitative approach

We identified only four publications in which patient needs were measured using qualitative techniques. Three of these made use of individual, in-depth interviews with patients or caregivers, one of which also validated the results of the individual interviews with group discussions (nominal groups). The fourth study described a method in which the needs of ethnic minority patients are measured via focus groups.

Example of the implementation of individual in-depth interviews in the US

Schroedl et al.¹³ conducted in-depth, semi-structured, one-on-one interviews with 20 patients admitted to a Chicago medical centre for acute exacerbation of chronic obstructive pulmonary disease (COPD). The interview guide was developed in collaboration with two pneumologists and a clinical psychologist with expertise in qualitative research:

Discussion area 1: experience of living with a lung disease

Can you tell me what is wrong with your lungs?

Can you describe a typical day living with your lung disease?

Discussion area 2: symptoms

Which symptoms do you find most bothersome?

How do you make yourself feel better?

Discussion area 3: social life and relationships

Does your lung disease prevent you from doing the things you enjoy? In what way?

Discussion area 4: end-of-life

^e KCE Report 115 <https://kce.fgov.be/nl/publication/report/organisatie-van-palliatieve-zorg-in-belgi%C3%AB> ; KCE Report 190 : <https://kce.fgov.be/nl/publication/report/position-paper-organisatie-van-zorg-voor-chronisch-zieken-in-belgi%C3%AB>



Do you feel your doctors have provided you with all the information you need to understand your disease?

Six main themes emerged from the qualitative analysis:

- Understanding the disease: most participants correctly identified their diagnosis and recognised their symptoms worsening over time. Only half of the participants understood their disease severity and prognosis.
- Symptoms: breathlessness was universal and severe.
- Physical limitations: the disease prevented participation in activities.
- Emotional distress: depressive symptoms and/or anxiety were present amongst most participants.
- Social isolation: most participants identified social limitations and felt confined to their home.
- Concerns about the future: half of the participants expressed fear about their future.

2.3 Mixed approaches

The researchers identified six studies in which quantitative, qualitative and/or systematic literature reviews were triangulated in various combinations. The combination of various methodologies presents an opportunity to examine the needs of patients from different perspectives and to explore certain facets of these needs in greater depth.

2.4 Additional approaches

Two other very interesting approaches were also examined. However, these were deemed too demanding in terms of the human and financial resources required for routine application and were consequently not selected. These comprised the *James Lind Alliance Priority Setting Partnerships* and the participatory approach of the *Flemish Patient Platform (VPP)* – see paragraph 5.2.5.2 in the [scientific report](#).

2.5 Conclusion

In our opinion, the blended approach, in which quantitative (surveys) and qualitative techniques (interviews, focus groups etc.) are combined and supported by a preliminary review of the scientific literature, appears to be the most comprehensive and promising approach for gaining a full understanding of self-reported patient needs. It enables us to question the multiple health-related dimensions that affect patients' lives. We therefore used this approach to develop our methodology (see chapter 5).



3 POTENTIAL DATA SOURCES FOR IDENTIFYING HEALTH CONDITIONS WITH THE HIGHEST NEEDS

In this chapter, we endeavour to ascertain whether it would be possible to make a rough, preliminary selection of conditions associated with high patient needs, based on the data available in existing databases. We examined various national and international data sources,^f focusing primarily on those with quantitative *Health-Related Quality of Life* (HRQoL) indicators or sources that combined HRQoL with survival rates, disease duration and/or prevalence. Indeed, these indicators give a good indication of the severity of health loss associated with an illness or disability.

By quality of life indicators we mean either intrinsic quality of life indicators (e.g. EQ-5D-5L⁹), or a *summary measure of population health* (SMPH) with an HRQoL component (e.g. *Quality-Adjusted Life Years* (QALY); *Disability-Adjusted Life Years* (DALY, see section 2.1.1); *Years Lived with Disability* (YLD, see Box 1). SMPHs are indicators of disease burden combining various health dimensions (mortality and morbidity, which may or may not be combined with disease duration and/or prevalence). The scientific report explains how these various scores are calculated and interpreted.

^f A prerequisite was that these databases are updated on a regular basis and intended for perpetual use.

Box 1 – QALY – DALY – YLD

QALYs (*Quality-Adjusted Life Years*): a measure of the burden of disease that combines the impact of a health problem (or of an intervention) on survival (measured in life years) and on perceived quality of life. QALYs are commonly used in economic evaluations of health programs. One QALY equates to one year in perfect health.

The sum of the number of QALYs lost at the population level as the result of a health problem is strongly determined by the prevalence of that health problem. However, high prevalence is not necessarily a good indicator of therapeutic needs. A classification based on lost QALYs at the population level will therefore provide results that are very different to a classification based on the number of QALYs lost per patient, or based on the loss of health-related quality of life. For example, less common diseases, such as macular degeneration or Parkinson's disease, will rank quite low based on the total number of QALYs lost, whilst their impact on the patients' quality of life (and thus potentially their level of patient needs) is extremely high.

DALYs (*Disability-Adjusted Life Years*): DALYs are calculated by adding the *Years of Life Lost* (YLL) to the *Years Lived with Disability* (YLD) (see section 2.1.1).

YLD (*Years Lived with Disability*): YLDs are calculated by multiplying the prevalence of a health problem by the weight of the loss of quality of life caused by that health problem (*Disability Weight* - DW). A disability weight of 0 equates to perfect health and a disability weight of 1 equates to death.

⁹ EQ-5D-5L is an instrument for measuring health-related quality of life using five dimensions: mobility, self-care, daily activities, pain/discomfort and anxiety/depression (5D). Each dimension has five degrees of severity (5L).



3.1 Selected databases

We ultimately selected **four data sources/national initiatives** (the Health Interview Survey (HIS), the Belgian Burden Of Disease study, the NIHDl's Unmet Medical Needs list, SHARE) and **an international data source** (the Global Burden of Disease study). The main strengths and weaknesses of these four data sources are summarised in Table 1.

3.1.1 The Health Interview Survey (HIS)

The *Health Interview Survey* (HIS) has been in existence since 1997 and is repeated by Sciensano every 4 to 5 years. The survey is conducted via face-to-face interviews and a self-completed paper-based questionnaire for more sensitive topics. Its main objectives are to assess the health status of the population and identify important conditions, as well as the determinants and behaviours that can influence them.

The HIS covers eight domains (health and quality of life, lifestyle, knowledge and practices concerning prevention, mental health and well-being, use of health services, health and society, and dental health). Most of the results are freely available via various publications and reports collated on a website and via an interactive online analysis tool ^h.

Since 2013, the HIS includes a section devoted to health-related quality of life (HRQoL) in the form of the EQ-5D-5L questionnaire⁹ which comprises five dimensions (5D): mobility, self-care, usual activities, pain/discomfort and anxiety/depression, and five severity levels per dimension (5L). The resulting scores can be used to calculate QALYs.

The last data collection from the HIS was conducted in 2018 and performed on 11 611 participants who were over 15 years of age and representative of the Belgian population.¹⁴ In this latest edition, the loss of HRQoL was primarily attributed to cardiovascular diseases, age-related problems and mental disorders. The loss of QALYs was primarily related to health

problems associated with a sedentary lifestyle: lower back pain, osteoarthritis, neck pain, depression and arterial hypertension. The first two columns in Table 2 clearly show the differences between the ranking of conditions (in descending order of importance) according to the loss of QALYs at the population level or according to the loss of HRQoL at the patient level.

3.1.2 The Belgian Burden of Disease study(BeBOD)

In 2016, Sciensano launched the Belgian National Burden of Disease (BeBOD) study, the aim of which is to establish a coherent framework for routinely quantifying the burden of disease in Belgium. The results pertaining to the burden of cancer in 2018 are now available.^{15, 16}

Two types of SMPH were calculated in order to estimate the burden of cancer: the number of years lived with a disability (YLD) and the number of YLDs per case. The prevalence estimates are based solely on incidence data from the Belgian Cancer Registry (BCR), which contains all cancers registered in Belgium. The quality of life parameters used in the BeBOD estimates are derived from the literature.

In 2018, all cancers combined resulted in 68 806 YLDs in the Belgian population, with prostate cancer, malignant skin tumours, breast cancer, colorectal cancer and bladder cancer topping the list (see section 6.1.4 (Table 10) in the [scientific report](#))ⁱ. These results can largely be attributed to the high prevalence of these cancers in Belgium. If we examine the impact of cancer per patient (i.e. based on the number of YLDs per case), the ranking is very different. In this scenario, mesothelioma comes top of the list (see Table 2). This relatively rare cancer has a major impact on patients' HRQoL.

The burden of cancer results can be explored in more depth via an interactive platform^j.

^h <https://hisia.wiv-isp.be/SitePages/Home.aspx>

ⁱ On 8 November, 2021, Sciensano updated the estimates for the burden of cancer in Belgium for 2018. According to these new estimates, prostate

cancer, breast cancer, colorectal cancer, malignant skin tumours and cancer of the trachea/bronchus/lung now top the list.

^j <https://burden.sciensano.be/shiny/cancer/>



3.1.3 The list from the NIHDI's Unmet Medical Need programme.

The NIHDI's *Unmet Medical Need* procedure, which came into effect in 2016, is intended for pharmaceutical products that have not yet obtained marketing authorisation but which treat a major unmet medical need. The program provides temporary financial compensation for such products, provided that the condition they treat is on the list of unmet medical needs drawn up by the NIHDI on an annual basis (see section 1.2). In 2021, the NIHDI Unmet Medical Need list contained 75 conditions. Of these COVID-19, glioblastoma and amyotrophic lateral sclerosis were assigned the highest scores (i.e. the most unmet medical needs) (see Table 2). Cancers accounted for half of the conditions on the list (53.3%).

3.1.4 The SHARE survey (Belgium)

SHARE (Survey of Health, Ageing and Retirement in Europe) is an interview-based survey that covers the majority of the European Union, including Belgium, and contains a wealth of information: health variables, physical measures and biomarkers, psychological variables, economic variables and social support variables, as well as information pertaining to social media. SHARE's target population comprises all individuals aged 50 and over at the time of sampling and their partners (where applicable).

SHARE uses the CASP-12 (*Control Autonomy Self-Completion Pleasure*, 12 items) quality of life measure, which has been specially developed for older individuals. It comprises a self-completed questionnaire with four dimensions: autonomy, control, self-realisation and pleasure.^{17, 18} Respondents are asked to indicate how often they experience certain feelings and situations on a four-point scale, ranging from "never" to "often." The resulting scores are subsequently classified under four quality of life levels: very high, high, moderate or low.

To date, SHARE has conducted 8 data collections (2004, 2007, 2009, 2011, 2013, 2015, 2017 and 2020 (focussing on COVID-19)) 3 additional collections are planned for 2024. In 2017, 4 902 patients were enrolled in the SHARE study for Belgium. Their mean age was 67.5 years and 55.7% were female. The three conditions that have the greatest impact on quality of life are cancer, hypercholesterolemia and hypertension (see Table 2).

3.1.5 The Global Burden of Disease Study

The Global Burden of Disease (GBD) studies commenced in the early 1990s. They present an important set of comparative findings on the impact of different diseases, injuries and risk factors on population health.¹⁹

We collected the 2017 Global Burden of Disease estimates for Belgium, with a focus on the YLD and DALY measurements. Prior to that year, estimates were available for 293 health conditions in Belgium. When we examine the number of YLDs per case, "other" neurological disorders (i.e. *excluding* Alzheimer's disease/dementia, Parkinson's disease, epilepsy, multiple sclerosis, amyotrophic lateral sclerosis (ALS) and other motor neuron diseases, migraine and tension headache), schizophrenia and totally drug-resistant tuberculosis associated with HIV/AIDS, top the list (see Table 2).

Box 2 – The Special Solidarity Fund (SSF)

In Belgium, only medicines authorised by the European Medicines Agency (EMA) or the Federal Agency for Medicines and Health Products (FAMHP) are eligible for reimbursement, *and* only in relation to the health indications for which they have received this authorisation. There are, however, exceptions, either via the aforementioned Unmet Medical Need procedure or via the Special Solidarity Fund (SSF). In both programmes, a committee decides on potential reimbursement; more specifically per cohort of patients in the Unmet Medical Need programme and on an individual basis in the BSF programme.

The SSF is authorised to process reimbursement requests outside the authorised indications. The following criteria must be met in order to be eligible: rare disease, threatening vital functions, no therapeutic alternative and scientific evidence of efficacy/added value. It does not include any quality of life indicators.

Some diseases are extremely rare. For that reason, we were not given access to the precise indications of reimbursed medicines on grounds of data protection. However, an overall analysis of the numbers shows that many of these agents are used to treat cancers or neurodegenerative diseases. It is therefore challenging to use this data to identify patients



with significant unmet medical needs. This is regrettable, as this data source has clear potential value for the analysis of therapeutic needs.

Table 1 – Data sources selected for this study, strengths and weaknesses

Source	Main strengths	Main weaknesses
The Health Interview Survey (HIS)	<ul style="list-style-type: none">• Representative of the Belgian population• Large sample size• Includes HRQoL estimates for 38 different health conditions	<ul style="list-style-type: none">• Self-reported data• Limited number of assessed (common) health conditions; exclusion of rare conditions• Population under 15 years of age excluded from questions on disease frequency
The Belgian Burden of Disease study (BeBOD)	<ul style="list-style-type: none">• Includes YLD estimates• Incidence data extracted from the Belgian Cancer Registry	<ul style="list-style-type: none">• Cancer data only; currently no YLD estimates for other conditions
The NIHDI's Unmet Medical Need programme	<ul style="list-style-type: none">• List of 75 estimated conditions• Scores attributed according to (amongst other criteria) the impact on the patients' quality of life.	<ul style="list-style-type: none">• Scores attributed by experts
SHARE	<ul style="list-style-type: none">• Includes HRQoL indicator (CASP-12)	<ul style="list-style-type: none">• Self-reported data• Limited to people over 50 years of age
The Global Burden of Disease study	<ul style="list-style-type: none">• SMPH available for a large range of conditions• Facilitates comparison across countries	<ul style="list-style-type: none">• Estimates largely based on data from other countries



Table 2 illustrates the differences in ranking according to the chosen parameter for measuring the loss of quality of life.

Table 2 – Top 5 health conditions, ranked according to burden of disease, per data source

HIS 2018 QALYs lost (population level)	HIS 2018 Loss of HRQoL (individual level)	BeBOD 2018 YLD per case	RIZIV Unmet Medical Needs list 2021	SHARE 2017 CASP-12	GBD 2017 YLD per case
Low back disorder	Myocardial infarction	Mesothelioma	Corona Virus Disease 2019 (COVID-19)	Cancer	Other neurological disorders*
Osteoarthritis	Stroke (or consequences)	Unknown primary site cancer	Newly diagnosed glioblastoma	Hypercholesterolemia	Schizophrenia
Neck disorder	Serious gloom or depression	Prostate cancer	Amyotrophic Lateral Sclerosis	High blood pressure or hypertension	HIV/AIDS - Extensively drug-resistant Tuberculosis
High cholesterol level in blood	Urinary incontinence	Bladder cancer	Acute graft versus host disease	Other fractures	HIV/AIDS - Multidrug- resistant Tuberculosis without extensive drug resistance
Serious gloom or depression	Narrowing of blood vessels in belly or leg	Urinary organs, nos cancer	Locally advanced or metastatic cholangiocarcinoma with a fibroblast growth factor receptor 2 (FGFR2) fusion or other rearrangement	Osteoarthritis/other rheumatism	HIV/AIDS - Drug- susceptible Tuberculosis

*Neurological disorders other than Alzheimer's disease and other dementias, Parkinson's disease, epilepsy, multiple sclerosis, motor neuron disease, migraine and tension-type headache, §Drug use disorders other than alcohol, opioid, cocaine, amphetamine or cannabis use disorders.



3.2 Compiled list

Based on the results and information from the five selected data sources, we compiled a list of conditions for which the burden of disease is highest, and may therefore be associated with the highest patient needs.

The specific characteristics of each data source made it impossible to conduct a direct comparison. In addition, we selected multiple classification options for a number of these sources (for HIS, for example, we selected the ranking based on loss of QALYs, and the ranking based on loss of HRQoL). As mentioned above, indicators such as QALYs, YLD and DALYs are strongly influenced by the prevalence of the respective conditions when used at the population level. They may therefore be useful in assessing healthcare needs at the population level, but not for evaluating individual patient needs. However, measures such as loss of HRQoL, number of YLD/QALY/DALY *per case*, the 'subjective' scores from SHARE and the NIHDI's Unmet Medical Needs list, primarily focus on these individual needs. Both types of measures are therefore relevant for the policymaker.

We consequently made an arbitrary choice to select the top 20 health conditions (16 for the SHARE study) from each data source, which resulted in a total of 176 conditions. After deleting duplicates and vaguely-defined health conditions (e.g. 'other cardiovascular conditions'), 99 conditions remained. These are listed in alphabetical order in Table 3. The way in which the various databases were compiled also gave rise to a significant degree of variation in the level of detail in the pathology descriptions. Cancers account for the biggest share (37 out of 99 conditions), followed by 9 neurological disorders, 8 acute diseases and 6 psychiatric disorders.

Table 3 – List of 99 health conditions with potentially high patient needs in Belgium, in alphabetical order

Health condition
Acid Sphingomyelinase Deficiency
Acute graft versus host disease
Age-related and other hearing loss
Allergy
Alzheimer's disease and other dementias
Amyloid light chain amyloidosis
Amyotrophic Lateral Sclerosis
Anxiety disorders
Appendicitis
Asthma
Bipolar disorder
Bladder cancer
Brain and nervous system cancer
Breast cancer
Cataracts
Cervix uteri cancer
Chronic bronchitis, COPD or emphysema
Chronic cystitis
Chronic fatigue for a period of at least 3 months in the past 12 months
Chronic kidney disease
Colon and rectum cancer
Corona Virus Disease 2019 (COVID-19)
Corpus uteri cancer
Diabetes
Diabetic retinopathy



Disorder of the larger or the small bowel
Duchenne muscular dystrophy
Edentulism and severe tooth loss
Epilepsy
Extensively drug-resistant tuberculosis
Female genital organs, nos cancer
Hemolytic disease and other neonatal jaundice
High blood pressure
High cholesterol level in blood
Hip fracture or femoral fracture
HIV/AIDS - Drug-susceptible Tuberculosis
HIV/AIDS - Extensively drug-resistant Tuberculosis
HIV/AIDS - Multidrug-resistant Tuberculosis without extensive drug resistance
Hypopharynx cancer
Intracerebral hemorrhage
Ischemic heart disease
Ischemic stroke
Larynx cancer
(Acute lymphoblastic) Leukemia cancer
Lip and oral cavity cancer
Lip, oral cavity and pharynx, nos cancer
Liver and intrahepatic bile ducts cancer
Locally advanced or metastatic solid tumours related to NTRK gene fusion in adult and paediatric patients
Locally advanced or metastatic cholangiocarcinoma with a fibroblast growth factor receptor 2 (FGFR2) fusion or other rearrangement
Lower respiratory infections
Macula degeneration
Malignant melanoma of skin cancer

Malignant neoplasms of skin cancer
Maternal obstructed labor and uterine rupture
(Malignant Pleural) Mesothelioma cancer (L2)
Metastatic non-small cell lung cancer (NSCLC) with high, low or no PD-L1 (1L) expression
Metastatic uveal melanoma
Migraine
Multidrug-resistant tuberculosis without extensive drug resistance
Multiple sclerosis
Myelodysplastic syndromes
Myocardial infarction
Narrowing of blood vessels in belly or leg
Neonatal sepsis and other neonatal infections
Neural tube defects
Neuronal ceroid-lipofuscinosis type 2 (CLN2)
Newly diagnosed glioblastoma
Oesophagus cancer
Opioid use disorders
Osteoarthritis
Osteoporosis
Ovary cancer
Pancreas cancer (BRCA+ or not)
Paralytic ileus and intestinal obstruction
Parkinson's disease
Prostate cancer
Psoriasis
Pyriform sinus cancer
Recurrent Glioblastoma



Recurrent and/or metastasized squamous cell carcinoma of the head and neck (SCCHN) with progression or after platinum-based chemotherapy
Retroperitoneum and peritoneum cancer
Rheumatoid arthritis
Schizophrenia
Selective and early debridement of deep burns in children
Self-harm by other specified means*
Serious gloom or depression
Serious heart disease (except myocardial)
Stomach cancer
Stomach ulcer
Stones in the kidney
Stroke (or consequences)
Thyroid gland cancer
Tracheal, bronchus and lung cancer
Treatment of ≥3 lines of HER2-positive metastatic breast cancer (HER2+ mBC) after failure of trastuzumab emtansin (T-DM1)
Ureter cancer
Urinary incontinence
Urinary organs, nos cancer
Uterus, nos cancer
Vascular intestinal disorders

nos =not otherwise specified.

^k PROMs (*patient-reported outcome measures*) are instruments for measuring patient-reported health outcomes; they measure how the patient assesses his/her health.

A key finding from this part of the study is that very few national data sources contain HRQoL indicators. Those sources that do, use heterogeneous indicators. This makes it difficult to compare the impact of the various conditions. Nevertheless, the importance of these types of indicators no longer needs to be demonstrated: they are powerful tools for determining health priorities. Although a number of national initiatives are in place (e.g. the BeBOD study), Belgium is lagging behind other European countries where these types of indicators are already well implemented (e.g. in the Netherlands). KCE has already recommended incorporating the use of PROMs^k and PREMs^l into the Belgium quality assurance policy in a previous report^m. A number of ongoing projects, such as the OECD's PaRIS project, can also help to promote the integration of PROMs and PREMs into existing databases.

A key finding from the analysis of the databases is that conditions for which there is a high therapeutic need are generally more likely to rank high on the list of unmet patient needs than conditions for which effective treatments are already available. This implies that, pending the development of such treatments, the "other" patient needs, e.g. non-therapeutic needs, assume greater importance in ensuring high-quality, patient-driven care. This underlines the importance of asking patients about these needs (by means of a survey and/or qualitative research), in addition to establishing therapeutic needs based on existing databases.

Another key observation is that the needs of individual patients can differ greatly within the same pathology.

^l PREMs (*patient-reported experience measures*) are instruments for measuring patient-reported experiences; they gauge the patient's experience of the care process.

^m See KCE report 303: <https://kce.fgov.be/en/use-of-patient-reported-outcome-and-experience-measures-in-patient-care-and-policy>



4 DEVELOPMENT OF A GENERIC QUESTIONNAIRE FOR MEASURING PATIENT NEEDS

This chapter describes the development process of a generic questionnaire for measuring patient needs. The questionnaire is regarded as a canvas for future, more condition-specific, patient needs questionnaires.

An interim version of the generic questionnaire was tested in a pilot study in patients with long COVID (see section 4.2.). Detailed information pertaining to the development of the generic questionnaire and the pilot study can be found in chapters 7 and 8 of the scientific report.

4.1 Development of the generic questionnaire

A preliminary version of the generic questionnaire was drawn up based on relevant input from the literature review. This preliminary version included seven dimensions (see chapter 7 of the [scientific report](#)). To evaluate and test the relevance, clarity and completeness of the questionnaire, we consulted patient representatives (from LUSS, VPP, RaDiOrg, health insurance funds, the Observatory for Chronic Diseases and individual patient associations) during a 2-round Delphi panel.

Based on feedback from the Delphi panel, a number of dimensions and items in the questionnaire were modified (simplification of certain formulations, addition of examples to make it easier to understand etc.) and others merged. The second version of the questionnaire included the following 12 sections:

1. **Confidentiality of data and informed consent:** legal information + statement of informed consent.
2. **General information:** respondents' demographic characteristics in terms of gender, age and education level, as well as their status (patient or proxy).
3. **General health:** respondents' evaluation of their health prior to the onset of their health problem and at the present time. This assessment is based on the five dimensions of the EQ-5D-5L and a visual analogue scale.
4. **Other conditions:** specification of any co-morbidities.
5. **Symptoms (physical and psychological) related to the condition studied:** list of 44 symptoms with the option of adding more.
6. **Healthcare usage:** healthcare providers consulted and satisfaction levels with each of them.
7. **Treatments and care for the condition studied:** open field in which respondents can list the various treatments received and indicate their level of satisfaction per treatment.
8. **Treatment discomfort:** questions pertaining to the burden of treatment, with an open field in which the respondent can specify the side effects they have experienced.
9. **Accessibility of care:** lack of access to care and reasons why.
10. **Accessibility of information pertaining to the condition studied:** degree of satisfaction with the information received in relation to the condition.
11. **Financial repercussions:** financial repercussions related to the condition studied, with an open field in which the respondent can describe any repercussions.
12. **Support network:** need for assistance during day-to-day activities and relational needs.

Points 7 and 8 and points 6 and 9 were merged at the end of the pilot study (see section 4.2). The results of the Delphi procedure and the interim versions of the questionnaire are described in detail in chapter 7 of the scientific report.



4.2 Pilot Study

We chose to conduct a pilot study on a specific patient population in order to determine whether our methodological approach was able to identify patient needs in a real-life situation. We opted for patients suffering from long COVID, as the KCE had already received a study request on this subject. The potential population was also large enough to further refine the generic questionnaire and adopt qualitative approaches for a more in-depth study of patient needs (i.e. an online forum and in-depth interviews).

4.2.1 Online survey

We added a paragraph on acute episodes of COVID-19 to the generic questionnaire for the specific long COVID theme: how and by whom was the diagnosis made? Did it involve hospitalisation? (In which department? For how long?). As anticipated, some questions were adapted to the specifics of the “long COVID” health problem.

The recruitment of participants was conducted via various communication channels (KCE website, email campaigns, patient associations, long COVID patient groups on social media and general media). Patient association umbrella organisations (LUSS and VPP) and health insurance funds also assisted in participant recruitment. The questionnaire was posted online via Limesurvey on 27 January, 2021, with a closing date of 14 February, 2021.

A total of 1 320 completed questionnaires were selected for analysis. The majority of respondents (74.8%) were women. There was also a relatively large proportion of people with a high level of education (55.9%), and 82% had paid employment prior to their acute COVID-19 episode.

4.2.2 Qualitative research

At the end of the questionnaire, participants were asked whether they were willing to participate in one of the two parts of the qualitative study (only one choice possible). In total, 167 survey participants (12.7%) were willing to participate in the forum, of which 101 effectively did so. The majority of forum participants were women (77.3%) and had a high level of education (40.3%). Thirty-three in-depth interviews were also conducted; again, the majority of participants were women (20 out of 33).

Additional participant information in the various phases of this pilot study and the analysis of the responses pertaining to long COVID can be found in KCE Report 344 on long COVID.^{n,20}

4.3 Lessons from the Delphi procedure and pilot study

4.3.1 Generic questionnaire

The Delphi procedure and pilot study enabled us to draw some interesting conclusions pertaining to the use of the generic questionnaire.

Sufficient information on the condition under investigation must be compiled before a specific questionnaire can be drawn up.

Sufficient knowledge about the condition under investigation, including its symptoms and treatments, is essential for composing a questionnaire that assesses the needs of patients with a particular health problem. This information can be sourced via literature reviews and/or discussions with the patients involved (ideally via a patient association, as they usually have collective knowledge on patient experiences) and/or healthcare professionals with expertise in the problem concerned.

ⁿ KCE Report 344: <https://kce.fgov.be/nl/behoeften-en-opvolging-van-pati%C3%ABnten-met-langdurige-covid>



The option of having the questionnaire completed by a proxy on behalf of the patient should be provided.

Some populations or conditions cannot be studied if the option of completion by a proxy is not provided. The questionnaire should therefore provide this option, as well as clear instructions on how to complete the survey in that scenario. These instructions can be formulated as follows: *"The person you represent is not in a position to make an informed decision to participate in the study at this time. By ticking this box, you are participating in this study based on their likely willingness to participate. Please answer all questions as if you were that person. For most questions, you can indicate 'I don't know' if you don't know how the person would respond."*

The following specific instructions must also be provided for children and minors: *"By ticking this box, you confirm that you are acting in accordance with the presumed wishes of the other parent of the minor you are representing. You commit to informing the other parent as soon as possible."*

These instructions are aimed at mitigating potential weaknesses of assessments by proxy. We are aware that these weaknesses cannot be overcome entirely, but consider it more important to be able to assess all types of conditions and patient populations than to obtain completely unbiased responses.

The generic questionnaire should be adapted to each health problem examined

The generic questionnaire is not intended to be used 'as is'; rather it should serve as a basic template for drawing up a specific questionnaire for each health problem examined. It must **always** be adapted accordingly. Some examples of necessary modifications:

- The question pertaining to the patient's health prior to and following the onset of the problem is normally not relevant for congenital disorders.
- The question pertaining to the treatment(s) received and the respondent's satisfaction with these treatment(s) can be supplemented with a question pertaining to the needs and expectations of patients who are, for whatever reason, not currently receiving treatment. They could be asked, for example, what type of treatment they would like (e.g. pain medication, rehabilitation sessions etc.).

- All questions pertaining to the health problem being studied should be made condition-specific. In many cases, this is relatively straightforward (replacing 'your condition' in the general formulation by the name of the condition under consideration).

The format of the questionnaire should be adapted to the patient population

The format chosen for the questionnaire is another important element, as it determines the participation of patients in the survey and might give rise to a selection bias. If an online format is chosen for the questionnaire (as in our pilot study), there is then a risk that it might not reach populations who do not have easy access to the internet, either by choice/lifestyle or because of their precarious situation. Age is also an important factor in this.

The survey should be widely disseminated

Reaching the target group is often presumed more difficult in the absence of a patient association. However, our experience was that participant recruitment can be achieved using multiple means of communication (press conference, social media such as Facebook, contact with patient association umbrella organisations). Our experience was arguably influenced by the fact that long COVID was receiving significant media attention at the time. However, even if less common conditions require additional effort, we believe that drawing on umbrella organisations of patient associations, health insurance funds and healthcare providers remains an effective solution.

The questions should be clear and unambiguous

The Delphi procedure showed that some questions were ambiguous or open to interpretation. A number of open questions (e.g. the existence of comorbidities) were therefore replaced by a non-exhaustive list of possible answers (with the option of selecting one or more answers).

The response options should be easy for the researchers to use

Response options should be chosen in such a way that they can be readily exploited/analysed by the researchers without subjective interpretation. This can be achieved using a **non-exhaustive list of response options**. This methodology offers several advantages, including ease of use for the patient



(who need not cite difficult terminology) and ease of analysis for the researchers. However, an excessively lengthy questionnaire should be avoided, as this can discourage respondents and cause drop-out.

Although **open fields** are often useful for collecting information that the researchers had not considered, we recommend to limit the number of open fields as much as possible. Open fields complicate the analysis (require recoding, which entails a risk of misinterpretation by the recoding party). We believe that providing the "other" response option is sufficient for indicating that a number of other points require further investigation in the qualitative research part. The main problems related to open fields in the pilot study were responses that were either too brief to enable a valid interpretation, or responses that contained more information than was requested, sometimes related to upcoming questions.

The challenge is therefore to strike the right balance between offering predefined response options and allowing the respondents sufficient freedom of input.

4.3.2 *Qualitative research: online forum and interviews*

Our evaluation demonstrated that online forums and interviews are appropriate techniques for better identifying precise patient needs. However, each technique has its limitations, requirements, advantages and disadvantages, which vary according to the population involved, the health problem examined and the resources allocated to the research. Forums are useful for promoting interaction between participants for example. However, they are less suited to topics in which a certain degree of consensus already exists, because there tends to be little controversy amongst the participants in this type of scenario and consequently less rich discussions that have an added value compared to the online survey.

Our experiences from the pilot study have led to the following conclusions:

- A significant amount of information pertaining to patient needs can be identified via an online forum;
- The majority of forum participants appreciated this approach;
- The needs identified via the forum and individual interviews were largely the same. In contrast, the nature of the information obtained via the two data collection techniques differed:
 - the interviews provided a more complete picture, with more contextual responses, but only for half the needs,
 - the forum generated a greater diversity of information pertaining to needs and more suggestions for improving patient situations. This can likely be attributed to the larger number of respondents. Unfortunately, not all ideas could be clarified. This was due to a lack of interaction during the forum and the fact that respondents did not answer all the moderator's questions;
- A number of specific points pertaining to the use of an online forum were put forward:
 - It is essential to clearly formulate the objectives and the way in which the forum will be run from the outset, so as to avoid patient frustration;
 - The skills of the moderators and their affinity with the methodology are important (moderation, mediation, qualitative research). For the medical aspects, a minimal knowledge of the condition under investigation is desirable; if not, the moderator should be able to contact someone who has this knowledge. An affinity for written communication is essential;
 - User-friendliness and potential for interaction must be considered when selecting the forum platform;
 - Ideally, any issues or concerns should be discussed promptly among the moderators and research team;



- A period of approximately 3 weeks must be provided for the data collection, with prior communication on the planned publication of new topics;
- We recommend requesting that participants log in at least once every 3 days;
- Moderation requires 2 to 3 hours per day, spread over several short periods throughout the day;
- In the case of long COVID, the invitation to participate in a qualitative research project, following the completion of an online survey, attracted relatively more highly educated and/or more severely affected patients. In terms of participation in the various data collection techniques, the forum appeared to attract people who were less affected by the disease than those in the individual interviews.

We can conclude that our pilot study provides the necessary reassurance that an approach using a generic questionnaire adapted to the condition being investigated (based on a literature review and patient input), followed by qualitative research with a limited sample of the participants in the survey, is the most effective way to assess the needs of patients with a specific condition in a sufficiently nuanced manner. The next chapter takes a closer look at a structured implementation model based on this approach.

5 A METHODOLOGY FOR IDENTIFYING PATIENT NEEDS IN BELGIUM

It is unrealistic to expect individual patients, citizens or health professionals to perform extensive in-depth quantitative and qualitative research on patient needs for the purpose of creating an *evidence-based* list of patient needs. It appears more appropriate to assign this responsibility to a scientific organisation that has and/or can attract people with the right skills to design and conduct (or coordinate) the studies required to collect the evidence on patient needs. There are two possible scenarios: either mandate an existing organisation with a new mission or establish a new body. The approach proposed in this chapter is independent of the scenario that is eventually chosen. We therefore refer simply to "the body responsible for patient needs identification".

5.1 How can the data be used?

The main objective of the body responsible for patient needs identification will be to collect detailed data pertaining to patients' needs in relation to various conditions and subsequently supply this data to stakeholders who require it to carry out their mission. We are unable to provide an exhaustive overview of all potential stakeholders and how they can utilise this information in practice, but have highlighted a number of concrete examples below:

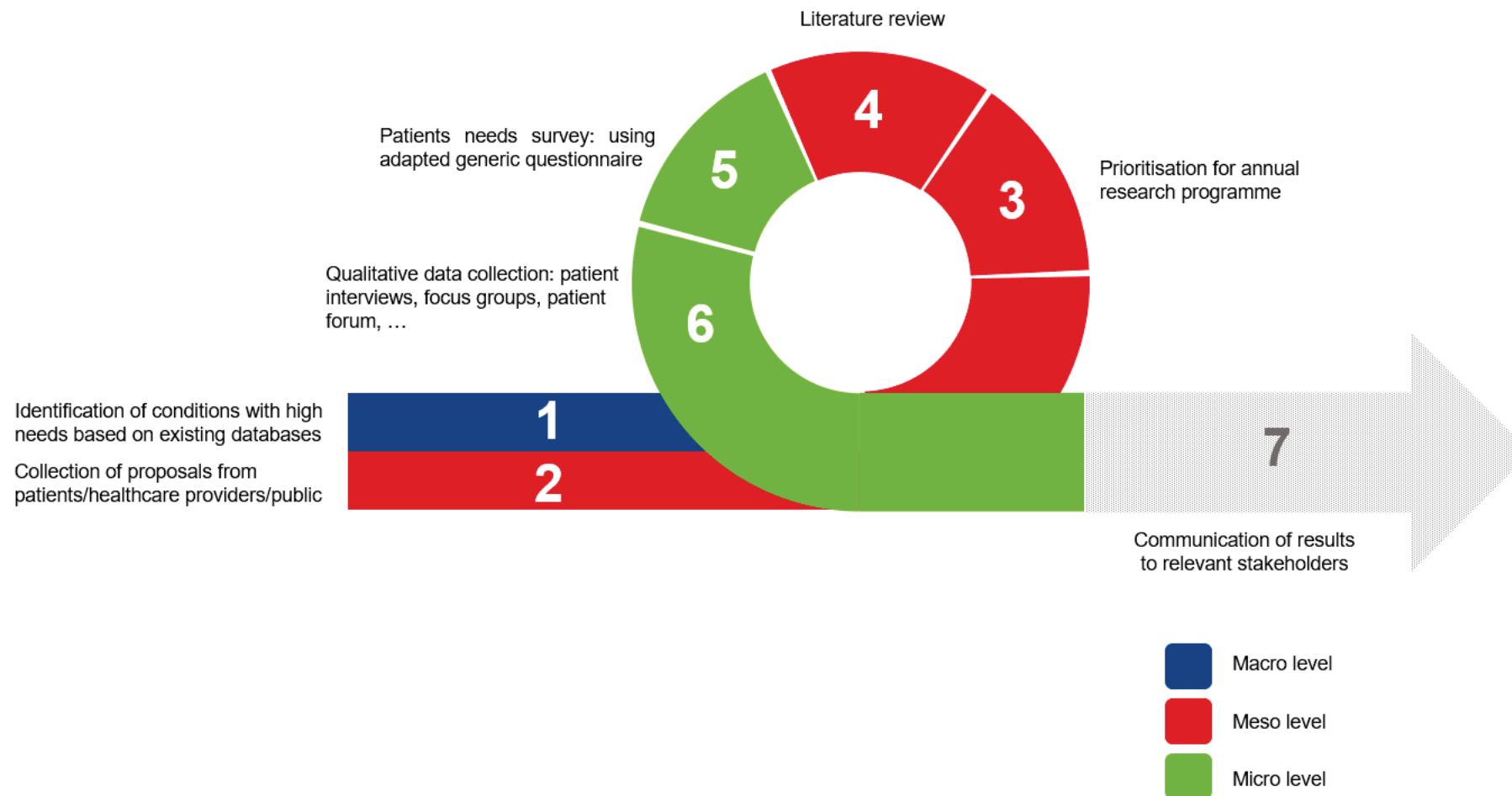
- The NIHDI could incorporate this information into its *Unmet Medical Need* programme, and also more generally into all reimbursement decisions for medical products and healthcare services;
- Researchers, industry and research funding agencies can use this type of information to target the development of new interventions or treatments that address patients' key needs;
- Healthcare providers can use this information in their daily practice to prompt them to discuss matters with patients they might otherwise not have considered;
- Health insurance funds and patient associations can use the patient needs data in the information and education they provide for patients



and/or the public, as well as in their communication with those responsible for healthcare policy. For example, patients that participated in the long COVID pilot study indicated that the lack of information pertaining to their health condition was a major issue. They felt that their health problem was unrecognised and that they repeatedly had to justify being ill.

5.2 A seven step model

To determine patient needs, we propose a global model comprising 7 steps divided over 3 levels.

**Figure 2 – Model for identifying patient needs in Belgium**



5.2.1 Step 1

The first step is to **identify conditions** that require in-depth data collection in order to identify specific patient needs. This step is necessary given that the resources for conducting patient needs studies are obviously limited. The selection should at least be partly based on **Belgian data sources**, such as the Health Survey (HIS), the NIHDI's Unmet medical needs list, the Belgian Burden of Disease database and SHARE, as well as the Belgian estimates from the Global Burden of Disease study. Despite the limitations of each of these databases, they can provide a first rough indication of those (groups of) conditions that have a major impact on HRQoL (see Chapter 3). This step should not exclusively focus on population indicators, which are often heavily determined by the prevalence of the health problem in question, but rather strike a balance between conditions with a high individual impact and conditions with a high impact at the population level. The NIHDI's Special Solidarity Fund, the Federal Agency for Medicines and Health Products (FAMHP) and the European Medicines Agency (EMA) should also be involved in the prioritisation of the disease groups, as these bodies possess essential information and expertise pertaining to the unmet medical needs of patients. In the future, other relevant Belgian databases, currently still under construction, should also be taken into account.

5.2.2 Step 2

Step 2 involves inviting **patients or patient associations, healthcare providers and the general public to submit proposals** for conditions that they believe should be considered. Proposals can also relate to a specific symptom that may occur in several underlying conditions, rather than a specific condition. For instance e.g. hemiplegia (semi-sided paralysis)), thereby expanding the scope from a purely disease-oriented approach to a condition-oriented approach.

The importance of this step lies in overcoming the limitations of the databases studied in step 1, i.e. the heterogeneity of the quality of life indicators used, and the heterogeneity in terms of the accuracy in determining these conditions. Proposals can be submitted for the conditions defined in step 1 or for other conditions. The latter option should be left open,

particularly for rare conditions, emerging conditions, or conditions for which a patient association does not currently exist.

5.2.3 Step 3

Step 3 involves the **selection of specific health conditions** for the **annual programme run by the body responsible for patient needs identification**. The selection should be based on an initial *long list* compiled from the results of steps 1 and 2, via a selection procedure based on explicit criteria and ethical considerations (e.g. so as not to disadvantage patients with less prevalent conditions).

The body responsible for patient needs identification should develop a procedure for the selection of conditions for inclusion in the annual programme, specifying the selection criteria and the methods for evaluating and ranking the proposals. This process should be repeated on an annual basis, with subjects not selected for one year being reconsidered the following year.

5.2.4 Step 4

Step 4 involves performing a **literature review** for each of the conditions selected in order to (1) identify existing scientific data on patient needs and the burden of disease, (2) collect information on available treatments and their efficacy, and (3) collect input for the required modifications to the generic questionnaire (see step 5). It is essential that both researchers and decision-makers are sufficiently and accurately informed about the condition, its treatments or its management strategies, and about any gaps in the scientific evidence related to this condition, so as to be able to take informed decisions. This information is also crucial for understanding and interpreting patient needs. However, the relevance of the information collected for the Belgian context (availability of certain treatments, different standards of care, etc.) has to be taken into account.

Specific Belgian initiatives could also provide useful information in this step. For example, the ongoing PaRIS project (OECD) focusing on PROMs and PREMs of chronic patients in primary healthcare (results for Belgium



expected by the end of 2022) or the *Flemish Patient Platform* (VPP) project on the innovation needs of chronic patients.²¹

The body responsible for patient needs identification will need to prepare a process note for the consultation of literature databases (which ones to search, how to summarise the scientific information collected, how to translate this into modifications to the generic questionnaire in step 5).

5.2.5 Step 5

Step 5 involves **the collection of data from Belgian patients** (or proxies if patients are unable to express themselves) via a survey. In this study, we developed a **generic questionnaire** for this type of data collection. This questionnaire should be regarded as a template that needs to be adapted to the specific health problem under investigation, based on the literature review in step 4 and the discussions with patients and healthcare providers. Specific needs that are not included in the generic questionnaire can consequently be taken into account. Specific questions pertaining to these needs can be added to the questionnaire. However, we do not recommend adding an excessive number of questions or changing the wording of questions, as this can compromise the validity and feasibility of the survey. The aim of this approach is to use a similar questionnaire for various health conditions and populations, to ensure equal treatment of different populations and minimise bias introduced by the researchers when conducting a survey on patients' needs. If more in-depth information is required (e.g. in order to be able to better translate the findings of the patient needs study into concrete (policy) measures or actions, this should then be included in the qualitative part of the research. The method for completing the questionnaire (online, paper-based, self-completion or with the help of a third party) must also be carefully considered, for instance to ensure that the full target population is reached, including patients with limited digital literacy, and patients who do not receive healthcare.

The body responsible for patient needs identification will need to prepare a process note on how the generic questionnaire should be adapted to the patient population (who should review the questionnaire, guidance on patient involvement in this step, whether pre-testing and pilot testing is required and by how many people etc.), how to recruit patients (supported by all relevant actors in the study domain, including the social and associative sector), and how to collect the data, etc.

5.2.6 Step 6

Step 6 **explores the patient needs identified in the survey in more detail** using **qualitative research techniques** (individual interviews, focus groups, online forums etc.). The choice of technique will depend on the patient population, their preferences and abilities. It can be helpful to involve healthcare providers and informal caregivers in this step, particularly if they experience considerable needs themselves due to a patient's condition or if the patients have limited ability to express themselves.

The body responsible for patient needs identification will need to prepare a process note on the qualitative research (choice of technique, methods for involving patients and/or healthcare providers etc.). The KCE process note on patient involvement can serve as a source of inspiration in this regard.^o

5.2.7 Step 7

Step 7 involves **the communication of results to the relevant stakeholders**. It is up to them whether to make use of the information supplied. Relevant stakeholders include the health authorities, NIHDl, health insurance funds, patient associations, healthcare providers, research funding agencies, the pharmaceutical and the medical device industry etc. Regional organisations could also use the results to improve their policies and activities.

^o <https://kce.fgov.be/nl/procesnota-voor-het-betrekken-van-pati%C3%ABnten-bij-kce-projecten>



For an adequate use of the data in reimbursement decisions of the NIHDI, it is necessary that evidence-based indicators of patient needs are included in the reimbursement request file of a health intervention, as well as proof of the effect of the intervention on these indicators. This requires the systematic collection of data on patient needs indicators, including in clinical trials.

The body responsible for patient needs identification will need to prepare a process note on the communication of the study results to the various stakeholders. This process note should describe the role of specific stakeholders in the dissemination of the results.

5.3 What resources are required to implement this approach?

The pilot project revealed that the following people should ideally be involved in conducting the patient needs assessment:

- experts in **quantitative research** (and in particular data analysts) to analyse the data from existing databases and the responses to the patient surveys;
- experts in **qualitative research** (interview techniques, oral moderation (focus groups) and written moderation (online forums)) and experts in sociological research for the interpretation and contextualisation of qualitative research data;
- medical, paramedical and public health experts, to help interpret the results of the database analyses, the responses in the survey's open fields and the literature review, and to contribute to the modification of the generic questionnaire;
- experts in scientific literature review;
- a communication expert responsible for disseminating the survey to all potential participants and (actively) communicating the results to the stakeholders;
- support staff for the organisation of the survey (including IT-related aspects), sending the invitations (and reminders), and liaison with those involved in the interviews/focus groups;
- financial resources for, for instance, complimentary gifts for survey participants, licenses for online tools and possible outsourcing.

A programme manager is required for the management of the body responsible for patient needs identification. The programme manager organises and plans the annual programme and is also responsible for launching the call for proposals. It is also important to involve patients and/or their representatives throughout the process, as well as healthcare providers and other stakeholders. This requires time and resources, both from the body responsible for patient needs identification and from the stakeholders involved.



6 CONCLUSION

This study proposes a methodology to identify the needs of patients with conditions that carry a high individual and societal burden. Implementing this methodology facilitates a more needs- or demand-driven healthcare provision and healthcare policy. Numerous federal level initiatives already exist with intentions in this direction, such as the FAMHP's compassionate use and medical need programmes, the NIHDI's Unmet Medical Need program, the Special Solidarity Fund (see Box 2) and the Observatory for Chronic Diseases. However, these initiatives often lack the scientifically based data needed to fully exploit their potential. Our proposal is designed to contribute to a more evidence-based, needs-driven decision-making process in Belgium. By incorporating patient needs into reimbursement decisions, the NIHDI and the Minister of Health can improve efficiency in the healthcare sector: the greater the focus on high patient needs, the higher the potential gains in patients' health or quality of life.

Patient centricity is a core value of the Belgian healthcare system; by giving it a more solid scientific foundation, its quality will only improve. We

anticipate this to have an impact on various levels of society: a decrease in the population's disease burden, a decrease in costs (related to healthcare, replacement incomes etc.), lower pressure on social security, improved (re)integration into the labour market, and a reduced burden for informal caregivers etc. We are also convinced that the identification of patient needs in the way we propose will not only serve the FAMHP and NIHDI, but also many other stakeholders, both at the policy and operational level, and both nationally and internationally.

This includes the European Medicines Agency, which launched the PRIME program to stimulate the development of new medicines for unmet medical needs by providing companies with enhanced support for marketing authorisation applications, and by accelerating the assessment of new products targeting high patient needs. In this context, the science-based assessment of unmet patient needs, as proposed in this study, certainly has its place. Collaboration with other countries in order to research a larger number of conditions in a larger number of patients could also have a huge impact, particularly for rare diseases.



■ RECOMMENDATIONS^p

Evidence-based needs-driven decision making in healthcare takes patient needs into account in reimbursement decisions, R&D activities, (para)medical research, treatments, information campaigns, etc. It improves both the quality and efficiency of healthcare: the more the focus is on the high patient needs, the higher the possible gains in patients' health or quality of life and hence the better the outcomes for a given amount of resources. Patient-centredness is also an important value in the Belgian healthcare system and is considered to be a component of high quality healthcare.

To promote evidence-based demand-driven decision making we recommend:

RECOMMENDATION 1:

To the minister of Public Health and Social Affairs

- 1.1. Encourage and promote needs-based health policies, where needs are identified through scientific approaches;
- 1.2. To give a mandate to a scientific and independent organisation to set up a programme for the identification of patient needs and explore possible international collaborations for this activity.
- 1.3. To support the method proposed in this report when mandating this organisation and provide the necessary financial resources for it, taking into account the required competencies for carrying out patient needs studies.

RECOMMENDATION 2:

To the Federal Public Service Health, Food Chain Safety and Environment

- 2.1 To define policy priorities in the domain of "patient-related themes" based on the evidence from patient needs studies.

^p The KCE is solely responsible for the recommendations.

**RECOMMENDATION 3:**

To the European Medicines Agency (EMA) and the Federal Agency for Medicines and Health Products (FAMHP)

- 3.1 To use the results of patient needs studies in the evaluation of medicines for which accelerated market access is requested.

RECOMMENDATION 4:

To the bodies within the NIHDI involved in the evaluation of the reimbursement of treatments or other health care interventions

- 4.1 To take the results of patient needs studies into account when assessing and appraising reimbursement requests for treatments and other health interventions. Meeting important patient needs and proving this scientifically should be a condition for reimbursement.

RECOMMENDATION 5:

To the NIHDI bodies involved in the Unmet Medical Need programme (General Council, Advisory Committee on Temporary Reimbursement of Medicinal Products (CATT/CAIT), College of Physicians-Directors)

- 5.1 To use the results of patient needs studies in the evaluation and ranking of proposals for the list of unmet medical needs besides the information provided by medical experts and/or pharmaceutical companies.
- 5.2 To use information on the most important patient needs and the expected impact of the proposed treatment on these needs in the evaluation of cohort requests from pharmaceutical companies who ask for temporary reimbursement in the context of the unmet medical need programme.

**RECOMMENDATION 6**

To patient representatives, the observatory for chronic diseases and the sickness funds

- 6.1 To actively participate in patient needs studies by submitting proposals to the responsible organisation and promote awareness of these initiatives among patients, including those who are not represented by patient organisations.
- 6.2 To support the patient needs studies through procedures of stakeholder involvement.
- 6.3 To use the results of the patient needs studies in prioritising activities directed at specific patient groups and possibly other stakeholders.

RECOMMENDATION 7:

To healthcare providers

- 7.1 To use the results of the patient needs studies in their daily practice to improve the quality of care and patient experience.

RECOMMENDATION 8:

To scientists, research funders and industry

- 8.1 To align research and development of new health interventions with the main needs of patients.

RECOMMENDATION 9:

To Sciensano, the Cancer Registry and other health database owners

- 9.1 To promote and engage in initiatives to collect data on the burden of diseases at a national and individual level, using epidemiological indicators integrating prevalence, mortality, morbidity, duration and impact on quality of life of conditions, diseases or risk factors.



■ REFERENCES

1. Institute for Health Metrics and Evaluation (IHME), Global Burden of Disease Study. Washington.
2. van Lier, A., et al., Disease Burden of 32 Infectious Diseases in the Netherlands, 2007-2011. PLoS ONE Electronic Resource, 2016. 11(4): p. e0153106.
3. Slade, M., et al., Adult Camberwell Assessment of Need (CAN). 1999: Royal College of Psychiatrists.
4. Stein, J., et al., Unmet health care needs in old age and their association with depression - results of a population-representative survey. Journal of Affective Disorders, 2019. 245: p. 998-1006.
5. Asadi-Lari, M., C. Packman, and D. Gray, Unmet health needs in patients with coronary heart disease: implications and potential for improvement in caring services. Health and Quality of Life Outcomes, 2003. 1(1): p. 26.
6. Asadi-Lari, M., C. Packman, and D. Gray, Psychometric properties of a new health needs analysis tool designed for cardiac patients. Public Health, 2005. 119(7): p. 590-98.
7. van Walsem, M.R., et al., Health-related quality of life and unmet healthcare needs in Huntington's disease. Health & Quality of Life Outcomes, 2017. 15(1): p. 6.
8. Aragón Aragón, M.J., M. Chalkly, and M. Goddard, Defining and measuring unmet need to guide healthcare funding: identifying and filling the gap, C.f.H. Economics, Editor. 2017, University of York: York.
9. EuroQol, EQ-5D. 2020: The Netherlands.
10. Agency for Healthcare Research and Quality, CAHPS Health Plan Survey: methodology. 2019, Agency for Healthcare Research and Quality: Rockville.
11. Keirse, E., et al., Organisation of palliative care in Belgium. 2009, Belgian Health Care Knowledge Centre (KCE): Brussels.



12. Paulus, D., K. Van den Heede, and R. Mertens, Position paper: organisation of care for chronic patients in Belgium. 2012, Belgian Health Care Knowledge Centre (KCE): Brussels.
13. Schroedl, C.J., et al., A qualitative study of unmet healthcare needs in chronic obstructive pulmonary disease. A potential role for specialist palliative care? *Annals of the American Thoracic Society*, 2014. 11(9): p. 1433-8.
14. Charafeddine R, Braekman E, and Van der Heyden J, Enquête de santé 2018 : Qualité de vie liée à la santé. 2018, Sciensano: Brussels, Belgium.
15. Devleesschauwer, B., Country Report: the Belgian National Burden of Disease Study 2020. *European Journal of Public Health*, 2018. 28(suppl_4): p. cky213. 830.
16. Gorasso, V., et al., The non-fatal burden of cancer in Belgium, 2004–2018. 2021.
17. Hyde, M., et al., A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). *Aging & mental health*, 2003. 7(3): p. 186-194.
18. Wiggins, R.D., et al., The evaluation of a self-enumerated scale of quality of life (CASP-19) in the context of research on ageing: A combination of exploratory and confirmatory approaches. *Social Indicators Research*, 2008. 89(1): p. 61-77.
19. Murray, C.J., A.D. Lopez, and W.H. Organization, The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020: summary. 1996: World Health Organization.
20. Castanares-Zapatero, D., et al., Long COVID: Pathophysiology – epidemiology and patient needs, in KCE Reports. 2021, Belgian Health Care Knowledge Centre (KCE): Brussels.
21. Becher, K., et al., Een patiëntgedreven innovatie-agenda. 2014, Vlaams Patiëntenplatform.



COLOPHON

Title:	How to identify patient needs? - Short report
Authors:	Charline Maertens de Noordhout (KCE), Jens Detollenaere (KCE), Célia Primus-de Jong (KCE), Laurence Kohn (KCE), Brecht Devleesschauwer (Sciensano), Rana Charafeddine (Sciensano), Irina Cleemput (KCE)
Project facilitator:	Nathalie Swartenbroekx (KCE)
Project coordinator and Senior supervisor:	Irina Cleemput (KCE)
Reviewers	Diego Castanares (KCE), Marijke Eyssen (KCE), Mélanie Lefèvre (KCE)
Advisory committee:	Ann Ceuppens (Onafhankelijke Ziekenfondsen), Sabine Corachan (LUSS – Ligue des Usagers des Services de Santé), Françoise De Wolf (Solidaris), Siska Germonpré (Socialistische Mutualiteit), Wies Kestens (Onafhankelijke Ziekenfondsen), Anneleen Lintermans (VPP - Vlaams Patiëntenplatform), Murielle Lona (ML-OZ – Mutualités Libres-Onafhankelijke Ziekenfondsen), Karen Mullié (Observatorium Chronische Ziekten), Betty Ryckaert (Observatorium Chronische Ziekten), Katlijn Sanctorum (RaDiOrg – Rare Diseases organisation Belgium), Else Tambuyzer (VPP), Marijke Van Duynslaeger (Socialistische Mutualiteit), Anne Van Meerbeeck (VPP), Lisa Van Wilder (UGent), Rebekka Verniest (CM), Ilse Weeghmans (VPP)
Stakeholders:	Michael Berntgen (EMA – European Medicines Agency), Robrecht De Schreye (Sciensano), Charles Denonne (FAGG – AFMPS - Federaal agentschap voor geneesmiddelen en gezondheidsproducten – Agence fédérale des médicaments et des produits de santé), Stefanie Devos (BeMedTec), Martine Dewitte (RIZIV – INAMI - Rijksinstituut voor ziekte- en invaliditeitsverzekering – Institut national d'assurance maladie-invalidité), Wim Penninckx (FAGG), Sander Roosens (RIZIV – INAMI), Maelle Van De Walle (Sciensano), René Westhovens (RIZIV – INAMI), Harun Yaras (SPF Santé Publique – FOD Volksgezondheid)
External validators:	Pauline Boeckxstaens (UGent), Juanita Haagsma (Erasmus Universiteit Rotterdam, the Netherlands), Olivier Schmitz (UCL - Université catholique de Louvain)
Acknowledgements:	Jef Adriaenssens (KCE), Finaba Berete (Sciensano), Jan Bogaerts (EORTC), Nicolas Bouckaert (KCE), Cécile Camberlin (KCE), Carl Devos (KCE), Stephan Devriese (KCE), Martine Dewitte (RIZIV – INAMI), Kris Doggen (Sciensano), Dimitri Mortelmans (University of Antwerp), Caroline Obyn (KCE), Johan Van der Heyden (Sciensano), Carine Van de Voorde (KCE), Amélie Van Vyve (Sciensano), Leen Verleye (KCE), all people who contributed to the KCE project on long COVID and by doing so to the pilot study for this project.
Reported interests:	'All experts and stakeholders consulted within this report were selected because of their involvement in the topic of Patient needs. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report'



Layout:

Ine Verhulst

Disclaimer:

- The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.
- Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.
- Finally, this report has been approved by common assent by the Executive Board.
- Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.

Publication date: 13 January 2022

Domain: Health Services Research (HSR)

MeSH: Needs assessment, Research Design, Surveys and Questionnaires, Qualitative Research

NLM Classification: W84.3

Language: English

Format: Adobe® PDF™ (A4)

Legal depot: D/2021/10.273/50

ISSN: 2466-6459

Copyright: KCE reports are published under a “by/nc/nd” Creative Commons Licence
<http://kce.fgov.be/content/about-copyrights-for-kce-publications>.



How to refer to this document?

Maertens de Noordhout C, Detollenaere J, Primus-de Jong C, Kohn L, Devleeschauwer B, Charafeddine R, Cleemput I. How to identify patient needs? - Short report. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2021. KCE Reports 348C. D/2021/10.273/50.

This document is available on the website of the Belgian Health Care Knowledge Centre.