

## KCE, a key actor in cancer care

S. Stordeur, RN, PhD<sup>1</sup>, K. Rondia, MD<sup>1</sup>, J. Vlayen, MD<sup>1</sup>, R. Mertens, MD<sup>1</sup>

**This article presents an overview of the work of the Belgian Health Care Knowledge Centre in the field of cancer.**

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### Introduction

The Belgian Health Care Knowledge Centre (KCE - the acronym KCE incorporates the abbreviations of its name in both Dutch (Kenniscentrum) and French (Centre d'Expertise)) was set up in 2002 to conduct scientific analyses and research to advise policymakers on decisions relating to healthcare and health insurance. KCE is not involved in the decision-making or implementation process itself. Instead, its role is to identify and shed light on the best possible solutions, in the context of an accessible, high-quality healthcare system with due regard for growing demand and budgetary constraints. KCE is annually financed by the RIZIV/INAMI (75%), the Ministry of Health (12.5%) and the Ministry of Social Affairs (12.5%). The 2015 budget was €9 000 000.

Thanks to the multidisciplinary nature of its team, KCE is able to address divergent research questions from a medical, economic, social, legal and ethical angle.

KCE research focuses on four main domains:

- Developing and adjusting clinical practice guidelines to the most recent scientific findings (Good Clinical Practice).
- Evaluating medical technologies and medicinal products (Health Technology Assessment).
- Investigating the optimal means of organising and funding healthcare (Health Services Research).
- A fourth, transversal axis, is the development of methodological processes based on validated work

methods. These manuals are made available to all researchers working in the domain of healthcare and public health. Very recently, a fifth task was added: the coordination of a publicly funded clinical trial programme.

Over the years, KCE has become a key player in the field of oncology. In fact, cancer is the most frequently studied topic among over 250 KCE reports to date.

Each year, KCE draws up its research agenda on the basis of priority themes. These themes are chosen following consultation with all partners in the Health Research System (composed of the National Institute for Health and Disability Insurance (RIZIV/INAMI), FPS Public Health, the Scientific Institute of Public Health (WIV/ISP), the Superior Health Council and KCE).

The Executive Board of KCE is composed of representatives of the government and the main Belgian healthcare and health insurance stakeholders. All reports are discussed at Executive Board level and their policy recommendations are voted on. Board decisions are taken with a majority vote.

### Conflicts of interest

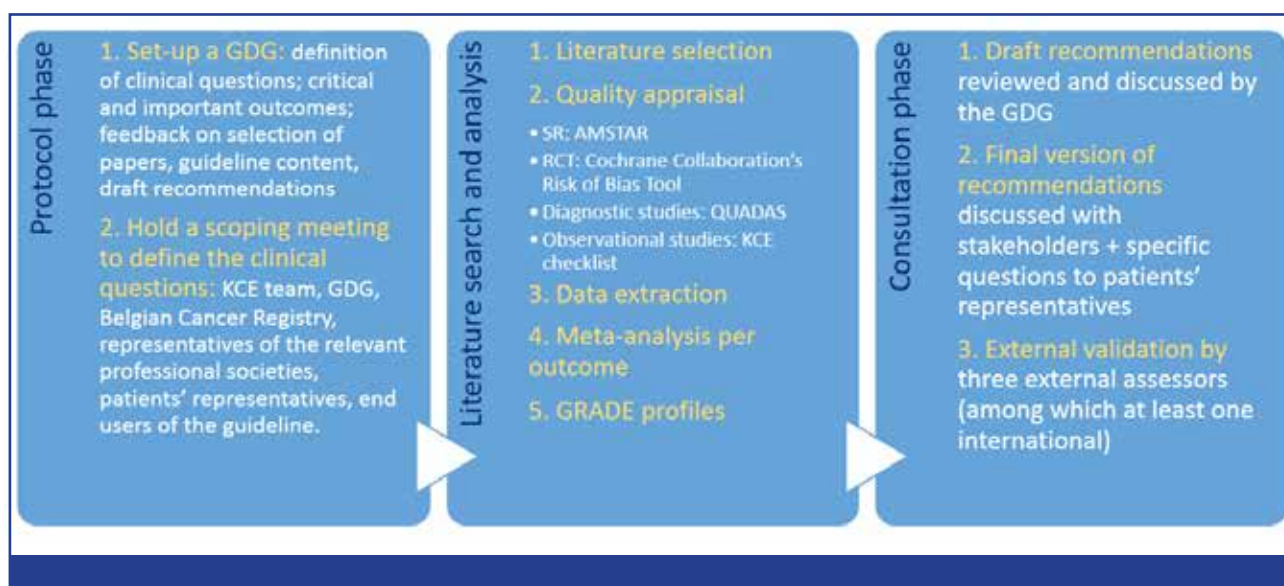
KCE staff members are not permitted to engage in professional activities outside of KCE that may give rise to a conflict of interest. All external contributors to the reports are required to sign a conflict of interest statement, which can be found on the imprint page of the relevant reports.

<sup>1</sup>Belgian Health Care Knowledge Centre (KCE), Brussels, Belgium.

Please send all correspondence to: K. Rondia, MD, Administrative Centre Botanique, Doorbuilding (10th floor), Boulevard du Jardin Botanique 55, 1000 Brussels, Belgium, tel: +32 2 287 33 88, email: Karin.Rondia@kce.fgov.be.

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**Figure 1.** Clinical guidelines methodology at KCE.  
 AMSTAR: A Measurement Tool to Assess Systematic Reviews.  
 QUADAS: Quality Assessment of Diagnostic Accuracy Studies.

## Clinical guidelines

The first category of research that is of interest to oncologists is clinical guidelines. The number of guidelines that are developed by KCE has steadily been increasing over the last couple of years. Each year, the oncological topics to be studied are determined in collaboration with the Belgian College of Oncology.

Historically, this collaboration started in 2006 with the development of the first national guidelines on the diagnosis and treatment of colorectal and testicular cancer.<sup>1,2</sup> At the same time, a framework for a multidisciplinary handbook on oncology for the diagnosis and treatment of cancer was developed.<sup>1</sup> Since then, a wide range of other guidelines have been developed: oesophageal and gastric, pancreatic, cervical, colon, prostate, breast, lung, head & neck, bladder, and very recently renal cancer.<sup>3-14</sup> More are underway, i.e. one on ovarian cancer. The KCE processes also foresee that the relevance of an update would be annually assessed by the authors for each published guideline. Decisions are made on the basis of new scientific publications on a specific topic (e.g. Cochrane reviews, RCTs on medications or interventions). Potential interest for groups of health practitioners is also considered in this process. This appraisal leads to a decision on whether or not to update a guideline – or specific parts of it – to ensure the recommendations stay in line with the latest

scientific developments.

In parallel with the guidelines, KCE and the Belgian Cancer Registry started an ambitious project of quality monitoring. The PROCARE initiative (PROject on CANcer of the REctum) was launched in 2004 by a multidisciplinary group of clinicians, who were concerned by the large diagnostic and therapeutic variability of the rectal cancer treatment in Belgian hospitals. KCE offered its methodological expertise to this profession-driven initiative; this collaboration resulted in an innovative monitoring of the quality of care for rectal cancer patients. The PROCARE working group elaborated a set of quality indicators allowing feedbacks and benchmarking in terms of outcomes and processes.<sup>15-17</sup> After twelve successful years, the PROCARE project was ended on the 31<sup>st</sup> of December, 2014.<sup>18</sup>

KCE also formulated recommendations to set up a quality system for oncology in Belgium.<sup>19</sup> To date, quality indicators were developed for the following cancer types: breast, testicular, oesophageal and gastric cancer.<sup>20-22</sup> Indicators for lung cancer, head & neck cancer and ovarian cancer will be developed in the next months and years. This essential work on quality indicators and monitoring should not necessarily be limited to the field of oncology.<sup>12</sup> However, oncology is an ideal domain for this kind of pioneering initiative. For the benefit of the patients, this will hopefully encourage clinicians to enter into a virtuous circle towards quality and evaluation in their daily practice.

## No ivory tower

From the very beginning, KCE guidelines were developed in collaboration with clinicians and representatives of the concerned professional organisations. Their involvement is essential to transpose the findings from the international literature into practical and concrete recommendations tailored to the Belgian context. Therefore, all working groups – named Guideline Development Groups (GDG) – include at least a dozen active healthcare professionals, physicians and paramedics, to achieve the best match with the reality of daily practice. As a consequence, our recommendations are really intended for use by multidisciplinary care teams, which lead to better care, especially for complex cancers. Collaborators from prestigious scientific institutions are more and more willing to work with KCE experts to develop clinical guidelines and to challenge their knowledge and methodological expertise (e.g. Dutch Cochrane Centre: KCE reports 143, 227, 256; Integraal Kankercentrum Nederland: KCE report 168; Ottawa Health Research Institute: KCE reports 228, 248; National Clinical Guideline Centre: KCE reports 193, 203, 248).<sup>5,11,12,23-27</sup>

## Include the patients' point of view

Like every person involved in healthcare, KCE is also becoming increasingly susceptible to the point of view of the patients. Therefore, quality of life and patient-related outcomes play an essential role in the guideline development process. Patient associations and charitable institutions who defend their interests (Kom op tegen Kanker, Fondation Contre le Cancer-Stichting Tegen Kanker and others more focused on specific patient groups) are regularly invited to participate in the discussions. But providing good quality care is not sufficient. Involving the patients in their treatment and informing them about the pros and cons of every choice also has become a key element in (almost) every guideline.

Another approach to include the patients' point of view was given shape in KCE's project on supportive care. Supportive care is mentioned in all oncological guidelines, but is generally not focused on one type of cancer. KCE treated the subject transversally and developed a series of three reports based on a thorough review of the existing evidence, thereby stressing the importance of physical exercise during oncological treatment, management of adverse effects, and management of pain.<sup>28-30</sup> These projects were a good

example of an interactive approach with patients: not only was this guideline drawn up in collaboration with clinicians and representatives of patient organisations, it was also discussed with groups of patients with first-hand experience of the disease. This original approach led to recommendations highlighting the patients' ability to assess their own pain, and giving them a central role in tackling it, with the help of the necessary information.

## Screening

Informing the patient about cancer screening in a correct and understandable way is even more crucial. In addition to the classical literature studies about the benefits and drawbacks of breast cancer screening before the age of 50 or after 70, and to a guideline on the identification of women with increased risk for breast cancer, KCE did research on the best way to inform the public on screening questions.<sup>31-33</sup> In this respect, a series of messages on breast cancer screening for 'ordinary women' were developed. These messages were adapted to the age of the target population (40-49, 50-59, 60-69, and 70-79 years old).<sup>34</sup> Similarly, a decision aid was developed for general practitioners, to help them inform patients correctly and objectively about prostate cancer screening with a PSA test.<sup>35</sup> Four guidelines for the identification and referral of persons with an increased risk of hereditary cancer have also been published. They cover (hereditary) colorectal cancers, breast cancers, endocrine cancers and a range of malignant syndromes with a dermatological component.<sup>36-39</sup> These guidelines were developed in collaboration with oncologists and geneticists, and are circulated through the website of the Belgian Society of Human Genetics ([www.beshg.be](http://www.beshg.be)).

## Health Technology Assessment (HTA)

According to the definition from the European Network for Health Technology Assessment, (EUNETHTA - <http://www.eunethta.eu/about-us/faq>), a Health Technology Assessment (HTA) study is: "a multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased, robust manner. Its aim is to inform the formulation of safe, effective, health policies that are patient focused and seek to achieve best value. Despite its policy goals, HTA must always be firmly rooted in research and the scientific method". In other words, the mission of KCE is to check – by means of thorough

literature surveys – whether a new product or a new technology is safe, effective and efficient. ‘Efficient’ means that the health benefit is proportional to its costs.

KCE has conducted several HTA studies on a number of oncological topics related to cancer diagnosis and treatment. For instance, the RIZIV/INAMI requested KCE to evaluate gene expression profiling (GEP) and immunohistochemistry (IHC) tests for breast cancer.<sup>40</sup>

At that moment, there were no randomised trials published in the literature, but it was urgent to define the reimbursement options for these tests. Therefore, KCE assessed the clinical effectiveness and cost-effectiveness on the basis of the available evidence on the analytical and clinical validity and on the clinical utility of selected GEP and IHC tests. Budgetary impact scenarios were also presented.

Next generation sequencing (NGS) gene panels for targeted therapy in (haemato)-oncology is another HTA review done by KCE, this time in collaboration with the Belgian Cancer Centre.<sup>41</sup> The aim of the project was to define the indications for NGS panel testing and the required characteristics of such panels (composition with level of clinical utility, technical specifications, informed consent and reporting specifications, quality assurance, etc.) for their implementation in routine clinical care, as an alternative to the currently accepted single gene markers. This implied an assessment of the added value of NGS panel tests compared to current practices, as well as an appraisal of the diagnostic accuracy of the companion test and its impact on the cost-effectiveness of the treatment.

KCE was also involved in the proactive research – from an HTA point of view – of several ground-breaking or promising techniques such as innovative radiotherapy techniques (stereotactic body radiation therapy, accelerated partial breast irradiation, intraoperative radiotherapy), IMRT, hadron therapy, robot-assisted surgery, Positron Emission Tomography (PET) or HIFU for prostate cancer.<sup>8,42-48</sup> Some of them are now routinely used.

Cancer screening campaigns also deserve a careful assessment of their cost-efficiency balance. Back in 2006, KCE evaluated whether, and under which conditions, screening for colorectal cancer could be an effective and cost-effective method to reduce the burden of this disease in Belgium. It also identified the areas of uncertainty for which specific additional data were necessary before implementing the program in Belgium.<sup>49</sup> In 2014, KCE investigated the opportunity to use

HPV-testing instead of cytological tests for the screening of cervix cancer.<sup>50</sup> It was concluded that HPV screening was cost saving and more clinically effective than cytological screening above the age of 30. It also highlighted the excessive number of colposcopies performed by Belgian practitioners and the lack of quality control programmes for the interpretation of cervical cytology specimens.

## Health Services Research (HSR)

What is the best way to organise and finance a health care service? How do we keep this service affordable and accessible? How does this comply with the objectives of Belgian health care? KCE tries to find answers to these questions in the Health Services Research (HSR) domain.

One of the landmark studies was the report about the organisation of care for adults with rare cancers and cancers with a complex diagnosis and/or treatment.<sup>51</sup> This report was very controversial due to the impressive differences in survival depending on the treated number of patients and the experience of the oncological and surgical staff. This was the case for testicular, breast, oesophageal and gastric cancers.<sup>20-22</sup> As it did in 2013 for upper gastro-intestinal cancers, KCE advised to centralise care for rare and complex cancers to a limited number of reference centres having the necessary experience, skills and infrastructure, but collaborating in a shared care model with the ‘peripheral’ centres. In such a model, the reference centre is responsible for the diagnostic confirmation, the elaboration of the treatment plan and the complex parts of the treatment (for instance complex surgery or radiotherapy). The peripheral centre would be responsible for the implementation of the other aspects of the care plan, in particular the less complex elements of the treatment or the follow-up. Service Level Agreements (SLA) between the centres, dealing with patient referral/back referral and patient follow-up are an essential element of the shared care network. This should avoid undue delays and redundant investigations. Today, the European RareCare Network project has acknowledged the KCE recommendations as a gold standard for recommendations at a European level.

In 2014, KCE published a study about ‘Ten years of multidisciplinary team meetings (MDT) in oncology’.<sup>52</sup> Its conclusion was that there is a consensus in the medical community about the fact that these meetings improve the quality of cancer care. However, it is now



## Key messages for clinical practice

1. KCE (Belgian Health Care Knowledge centre) develops clinical guidelines in collaboration with the Belgian College of Oncology. These guidelines are elaborated following a very rigorous multidisciplinary methodology and with much attention for stakeholder involvement.
2. KCE and the Belgian Cancer Registry started an ambitious project of quality monitoring through sets of quality indicators allowing feedbacks and benchmarking in terms of outcomes and processes. This work will hopefully prompt clinicians to enter a virtuous circle towards quality and evaluation in their daily practice.
3. KCE has been conducting several HTA studies on a number of topics related to cancer diagnosis and treatment. The purpose of these studies is to check – by means of thorough literature reviews – whether a new product or a new technology is safe, effective and cost-effective.
4. The third field of research of the KCE is Health Services Research. In a recently published study, it advises to centralise care for rare and complex cancers in a limited number of reference centres having the necessary experience, skills and infrastructure at their disposal, but operating in a shared care model with the ‘peripheral’ centres.

time to focus more on quality. This should be done by paying attention to the presence of key actors, without whom the meeting should preferably not take place, by strengthening technical support when needed (to display imaging and/or pathology results), and by ensuring that MDT meetings gather specialists with real expertise in the management of the cancers to be discussed. Although these meetings are in general very technical, KCE insisted on a patient-centred and not only on a disease-centred approach. It also recommended several urgent legislative, logistic and administrative improvements.

Another relevant trend in oncology is the growing interest for home-based care solutions, including the so-called Hospital at Home. Several innovative projects already exist in Belgium, to provide chemotherapy and/or supportive care to cancer patients in their familiar environment. KCE analysed the current situation to see whether our country was ready to organise that type of care on a larger scale.<sup>53</sup> The answer was “no, but it is worth trying”. On this basis, the Minister of Health decided to launch a call for projects which is now running, and which will open new avenues on the future role and limits of the hospital for the care of cancer patients.

Also in the domain of hospital care organisation and financing, KCE investigated the strengths and weaknesses of the current Belgian hospital financing system and lined out a conceptual framework featuring seven-

teen major orientations for the future.<sup>54</sup>

## Conclusion

Since its creation, KCE has contributed to important evolutions in the ‘culture’ of high quality care in our country. It has helped our healthcare system to follow a number of important international trends: from expert opinion-based to evidence-based decision making; from home-brew studies to international collaborations; from heavy, all-encompassing guidelines to collections of regularly updated recommendations; from treating everything everywhere to shared care around centres of excellence. These are the actual conditions to deliver the quality to which the patient is entitled in the second decade of the 21<sup>st</sup> century.

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