



Original article

# Reference centres for adults with rare and complex cancers – Policy recommendations to improve the organisation of care in Belgium

## *Centres de référence pour adultes ayant un cancer rare ou complexe. Recommandations politiques pour améliorer l'organisation des soins en Belgique*

S. Stordeur\*, F. Vrijens, R. Leroy

Belgian Health care Knowledge Centre, 55, boulevard du Jardin-Botanique, 1000 Brussels, Belgium

Received 6 November 2014; accepted 9 November 2015

Available online 30 December 2015

### Abstract

**Background.** – Rare and/or complex cancers call for a very specific expertise and adequate infrastructure. In Belgium, every hospital with a programme in oncology can deliver care for adults with rare and/or complex cancer types, without having demonstrated a specific know-how to adequately manage these patients. Therefore, the Minister of Health ordered a scenario for the organisation of care for adults with rare and/or complex cancers, taking into account the current Belgian situation and relevant foreign experience.

**Methods.** – Combined methods were used in this study: a literature review, the consultation of stakeholders, in depth discussions in 14 multidisciplinary groups leading to concrete proposals for several rare/complex cancers and the consultation of a panel of expert pathologists.

**Results.** – The core recommendation is the set-up of shared care networks around reference centres, with multidisciplinary teams of recognised expertise in specific rare/complex cancers. The definition of minimum caseloads for hospitals and medical specialists, the evaluation of the quality of care, a model of diagnostic confirmation and the set-up of a national portal website which provides information on rare and/or complex cancers and reference centres are highly recommended.

**Conclusion.** – It is no longer practicable, efficient or ethical that every hospital or every practitioner continues to offer care for every rare/complex cancer. Improving the quality of rare/complex cancer care requires to concentrate expertise and sophisticated infrastructure in reference centres. Furthermore, the formation of networks between reference centres and peripheral centres will allow a delivery of care combining expertise and proximity. The next step is the translation of the recommendations into policy decisions. It is very well realised that this will take some courage and that a certain degree of resistance will have to be surmounted, but eventually, the best interest of the patient should prevail.

© 2015 Elsevier Masson SAS. All rights reserved.

**Keywords:** Rare diseases; Oncology service; Hospital; Cancer care facilities; Centralized hospital services; Referral and consultation

### Résumé

**Position du problème.** – Les cancers rares et/ou complexes exigent une expertise et une infrastructure adéquates. En Belgique, tout hôpital avec un programme en oncologie peut délivrer des soins pour les adultes souffrant de cancers rares et/ou complexes, sans avoir démontré un savoir-faire spécifique pour soigner correctement ces patients. Par conséquent, la ministre de la Santé a mandaté les auteurs pour proposer un scénario d'organisation des soins pour les patients adultes atteints d'un cancer rare ou d'un cancer exigeant des soins complexes tenant compte de la situation actuelle en Belgique et des expériences pertinentes conduites à l'étranger.

**Méthodes.** – Cette étude a combiné plusieurs approches : une revue de la littérature, la consultation des parties prenantes, des discussions approfondies au sein de 14 groupes multidisciplinaires et la consultation d'experts en anatomopathologie.

**Résultats.** – La principale recommandation porte sur la mise en place de réseaux de soins partagés autour de centres de référence, dotés d'équipes multidisciplinaires combinant une expertise clinique et technique reconnue dans la prise en charge de cancers rares/complexes spécifiques. Des recommandations complémentaires portent sur la définition de volumes minimaux d'activité pour les centres de référence et

\* Corresponding author.

E-mail address: [Sabine.Stordeur@kce.fgov.be](mailto:Sabine.Stordeur@kce.fgov.be) (S. Stordeur), [France.Vrijens@kce.fgov.be](mailto:France.Vrijens@kce.fgov.be) (F. Vrijens), [Roos.Leroy@kce.fgov.be](mailto:Roos.Leroy@kce.fgov.be) (R. Leroy).

pour les médecins spécialistes, l'évaluation de la qualité des soins, un modèle de confirmation du diagnostic anatomopathologique et la mise en place d'un portail Internet national fournissant des informations actualisées sur les cancers rares et les centres de référence à divers utilisateurs.

*Conclusion.* – Il n'est désormais plus acceptable, efficient ou éthique que chaque hôpital ni que chaque praticien continue d'offrir des soins pour chaque cancer rare/complexé. Améliorer la qualité des soins pour les cancers rares/complexés nécessite de concentrer l'expertise et les infrastructures sophistiquées dans des centres de référence. De plus, la formation de réseaux entre centres de référence et centres périphériques (modèle de soins partagé) permettra de délivrer des soins en combinant expertise et proximité. L'étape suivante consistera à traduire les recommandations en décisions politiques. Des résistances devront être surmontées mais la primauté de l'intérêt du patient est à ce prix.

© 2015 Elsevier Masson SAS. Tous droits réservés.

*Mots clés :* Maladies rares ; Services d'oncologie ; Hôpital ; Services hospitaliers centralisés ; Référencement et consultation

## 1. Rare and/or complex cancers: a challenge to clinical practice and organisation of care

When a cancer affects yearly less than 6 new patients per 100,000 inhabitants, it is called rare. This threshold is based on a European definition (RARECARE) [1]. Rare cancers present a challenge to clinical practice: they are often diagnosed late or misdiagnosed [2], and evidence-based clinical guidelines are seldom, if ever, available [3]. In addition, some cancer types may require a complex diagnostic work-up, a complex treatment requiring subspecialised professionals and/or expensive equipment, or occur during particular circumstances (e.g. pregnancy). These so-called “complex” cancers like the rare cancers are an important policy concern for public health in Europe [2].

The recent European directive 2011/24/EU on the application of patients' rights in cross-border health care urges Member States to identify reference centres and to create networks throughout Europe. The European Commission was mandated to define the criteria for reference networks and health centres involved in the networks. These criteria have to ensure that reference networks concentrate the required knowledge and expertise, follow a multidisciplinary and collaborative approach, and pursue activities in research and training. For rare diseases, national networks have been successfully implemented in several countries (Italy, France, the Czech Republic, Belgium and Malta) [4]. Also, in the fields of critical and complex conditions (e.g. transplants, burns, trauma and stroke care), similar strategies are envisaged [4]. In cancer care, a few European countries (e.g. the Netherlands [5], Denmark [6], France [7] and the United Kingdom [8]) have already adopted a differentiated model for the organisation of highly specialised cancer care, by referring adults with rare cancers to reference centres (also called centres of excellence).

In Belgium, no strategic vision for rare and/or complex cancer care has been developed so far. Therefore, the Minister of Health and Social Affairs ordered a scenario for the organisation of care for adults with rare and/or complex cancers, taking into account the current Belgian situation and relevant foreign experiences [9]. The results of this study should guide Belgian policy makers in the improvement of rare and/or complex cancer care.

## 2. Cancer care in Belgium

On average, 62,000 new cancers are diagnosed in the Belgian adult population each year. Among them, 4000 adults are diagnosed with a rare cancer (7%) [10]. The majority of rare cancer types affects less than 100 patients a year in Belgium, and in many cases less than 30 patients [10].

In the Belgian law, two types of oncology centres are defined: those for basic oncological care (with focus on diagnosis and less complex treatments) and those with full oncology care programmes (that offer more advanced diagnostic options as well as various therapeutic possibilities). So far, only one specialised care programme (i.e. for breast cancer) has been installed. As a result, any Belgian hospital can treat any patient with any type of cancer, also any type of rare and/or complex cancer.

Several reports of the Belgian Healthcare Knowledge Centre, in close collaboration with the Belgian Cancer Registry, illustrated the dispersion of care in Belgium, both for common and for rare cancers (colon cancer [11], lung cancer [11], pancreatic cancer [11], testis cancer [12], breast cancer [13], oesophageal cancer [14] and gastric cancer [14]). Likewise, a recent report covering the Flemish Region (the Northern part of Belgium) showed a very large spread in the management of patients with rare cancers, such as cancer of the salivary glands, anal canal cancer, lip cancer, nasopharyngeal cancer, vaginal and vulvar cancer [15]. They all confirm that most of the 119 Belgian acute hospitals treat patients with rare and/or complex cancers, many of them treating very few patients per year, sometimes only one patient a year or even less. In this way, most hospitals lack the essential level of expertise to diagnose and treat these patients adequately.

There is now a sufficient number of international high-quality studies, covering a large panel of interventions, which convincingly demonstrate an improved short- and long-term outcome when complex procedures are performed in high-volume hospitals [16–18]. In Belgium, similar results were obtained [11,13,14]. Fundamentally, the challenge boils down to the acquisition and maintenance of complex skills, which require a minimum caseload of patients.

Another shortcoming in Belgium is that there is neither funding of nor a legal basis for the practice of second opinion in

Download English Version:

<https://daneshyari.com/en/article/3830978>

Download Persian Version:

<https://daneshyari.com/article/3830978>

[Daneshyari.com](https://daneshyari.com)