THE BELGIAN INVENTORY OF CANCER CARE & CONTROL POLICIES

A state-of-play for 2023

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EXECUTIVE SUMMARY

This inventory compiles the latest publicly available data on the burden of cancer and cancer care control policies in Belgium, spanning prevention, early detection and screening, diagnosis, treatment, care organisation, quality of care and survivorship. It also details crosscutting topics such as patient centeredness and the reduction of inequalities in cancer care. Policies, including legal statues and mandates, that frame each part of cancer control activities, as well as the actors involved in each stage are also detailed in each of the inventory's chapters. An analysis of gaps and needs was conducted for each of the thematic areas in cancer control. These analyses were based on a non-systematic review of grey and peer-reviewed literature, and were complimented by multi-stakeholder discussions with members of the Cancer Centre's EBCP Belgian Mirror Groups (1).

Four in 100 Belgians are living with cancer. Crude cancer incidence per 100,000 is higher in Belgium than the EU-15 average, both for men and women. Although the **preventable mortality** rate has been decreasing since 2000**, Belgium ranks poorly at the European level (14th out of 15)**. Between 30-50% of cancers are preventable (2), which represents approximately between 22 500 and 37 500 cases of cancer prevented each year in Belgium. Given this high burden and opportunity to reduce the impact on Belgian society, **prevention is of upmost importance in cancer control.** Much work has been done on primary prevention, including law at federal level of tobacco and alcohol sale, as well as wider HPV vaccination programmes, and regional level health literacy and education. Yet, challenges remain. The impact of primary prevention measures conducted at the regional and community level is less clear. While there are many projects on vaccination, healthy environments, and nutrition/obesity, at Sciensano, at the federal level, very few projects directly look at health literacy on cancer, or individual behaviours related to lifestyle behaviour and cancer.

Belgium has developed screening programmes organised at the regional level for breast, cervical and colorectal cancer. There are still deep regional disparities in screening and lower participation in screening programmes than desired. As such, it is essential to understand what barriers may hinder the uptake and maintenance of healthy lifestyle choices and uptake of screening programmes. Necessary attention should be put on understanding the impact of differences between programmes, while a considering the need for harmonized and consistent monitoring, evaluation and follow-up of results, and to ensure all screening programmes follow the same evidence-base.

The precision oncology approach is currently at the heart of innovations in cancer diagnosis and is the result of significant advances in the "omics" technologies (such as genomics, transcriptomics, proteomics, and metabolomics). Based on rapid advances in biotechnology, including massively parallel sequencing or next generation sequencing (NGS), novel biomarkers and targeted drugs are being developed. It is a real challenge to implement a systematic and comprehensive evaluation of these new approaches to give to the physician and the healthcare system the level of confidence needed for optimal diagnostic and treatment decisions (3). Of note, during the COVID-19 pandemic, decline and incomplete recovery in cancer diagnoses was observed in Belgium as reported here which could pose a threat for the health system in the coming years (4).

The future of oncology in Belgium is likely to be shaped by a combination of technological advancements, increased collaboration and integration, and a focus on patient-cantered care. The exact plans for the organization of oncology in Belgium may change over time, but it is clear that the goal of providing high quality, effective, and compassionate care to patients will continue to be a top priority. Centralisation of care by types of procedures or tumours has shown to contribute to quality of oncological care programmes. In Belgium, while there are professional organisations and networks of hospitals, they are not officially organised. Efforts to establish comprehensive cancer centres (CCCs) are an important step to improving this. However, this alone may not be sufficient to improve continuity of care.

An important aspect will be supporting patients in their care journey, which will include understanding what support (information and technical) they will need, and how they can best access this information.

In Belgium in 2020, there were **62 basic oncology care programs (PSBO) and 84 oncology care programs**. Centralisation of care by types of procedures or tumours has shown to contribute to quality of oncological care programmes. CCCs are not formally recognised in Belgium. The decision-making process for medical treatments is changing from a purely biological paradigm to one that prioritizes the needs, values, and preferences of the patient in addition to the relevant medical data. A tailored approach is crucial in many medical fields, but it is especially important in oncology because treatments may have a significant impact on patients' quality of life, often for a long time. There is a need to improve access for cancer patients to the innovative treatment approaches, like autologous cell therapy and radiotherapy.

Cancer care does not end after treatment. **Survivorship is a key element of cancer care**, but often treated as an afterthought. While survival rates in Belgium are comparable or better than other EU countries, in 2021, only 55.6% of cancer survivors having completed their treatment report that their needs are sufficiently taken into account. Belgium does not currently have any guidelines on survivorship, as are found in other countries. A lack of evidence in many areas of survivorship require more research efforts and knowledge exchange. There is often scarce attention given to survivorship in the projects addressing the organization of cancer care. Leaving it aside creates a missed opportunity to integrate survivorship care in standardized care pathways. In Belgium, the ongoing SPADIS project seeks to understand and improve the social participation of individuals living with chronic disease, including cancer. Its outcomes will lend to the ongoing creation of the *Belgian Oncological Handbook on Supportive Care.*

It is likely that the future of oncology in Belgium will continue to place a strong emphasis on patient-centred care. This will involve prioritizing patient needs, preferences, and experiences, and working to ensure that patients receive care that is both effective and compassionate. Nevertheless, a continuous dialogue between patients, citizens and policy makers is required to ensure ethical and socially appropriate cancer control starting with prevention, and across diagnostics, care and survivorship.

In Belgium, there are inequalities in screening, diagnosis, access to treatment and survivorship. However, the ECIR does not provide a full picture of the why behind these inequalities. The European Cancer Inequalities Registry (ECIR) is a new tool that helps monitors inequalities in cancer care across Europe, as part of Europe's Beating Cancer Plan. However, the tool also does not provide for sub-national analysis, an important factor in Belgium, where there are regional disparities. Such, gaps in evidence create a barrier for efficient decision-making thereby undermining principles of equity. These differences may lead to a higher burden of cancer on already marginalised and vulnerable groups. National and regional registries need to be able to collect, store and link data on cancer prevention, diagnosis, treatment, care and care organization, as well as survivorship to identify inequalities and their determinants.

In Belgium Fundamental, Translation and Clinical Research in being conducted on cancer care by various actors. Currently there are over 982 clinical trials related to cancer ongoing in Belgium. The Belgian Cancer Research Alliance is already working to develop research networks within the Belgian landscape. Networks at the European level will also be important, for both access to European funding, and to ensure experiences and knowledge are shared across comparable settings. Such networks should be a focus moving forward. Recruitment remains a challenge for clinical trials in Belgium. Leveraging the EBCP Mirror groups, and like participative approaches to calls and research funding will be important, both to strengthen chances to secure funding and in order to foster a participative approach in cancer research.

Sciensano's Cancer Centre was responsible for the desk research underpinning this inventory. External agencies and partners were not solicited for additional input or data at this stage. Information gaps could be particularly acute relative to activities occurring at the regional and/or local levels for which annual reports are not always available.

In the future, complimenting this initial desk review with qualitative and participative components will be necessary in order to depict a more complete picture of cancer care activities and strategies, and to strengthen the understanding on informal actors working in and around cancer care. This document is intended as a living document, for which regular updates could be foreseen.

List of Abbreviations

	English term	Dutch term	French term
AIDS	Acquired immunodeficiency syndrome	-	-
AIM – IMA	-	InterMutualistisch Agentschap	Agence InterMutualiste
ATMPs	Advanced therapy medicinal products	-	-
AVIQ	-	-	Agence pour une Vie de Qualité
AZ	-	Algemeen Ziekenhuis	-
AZG	Agency for Care and Health	Agentschap Zorg en Gezondheid	-
BARO	Belgian Association for Radio-Oncology	-	-
BCR	Belgian Cancer Registry	Stichting Kankerregister	Fondation Registre du Cancer
BeCRA	Belgian Cancer Research Alliance	-	-
BELAC	Belgian Accredication Organisation	Belgische Accreditatie-instelling	l'Organisme belge d'Accréditation
BeSTRO	Belgian Society of Radiotherapy and Oncology	-	-
BHS	Belgian Haematology Society	-	-
BHSPO	Belgian Society for Paediatric Haemato-Oncology	Belgische vereniging van kinderoncologen	Société Belge d'Hématologie et d'Oncologie Pédiatrique
BSMO	Belgian Society for Medical Oncology	-	-
CAYA	Children Adolescents & Young Adults	-	-
CCCs	Comprehensive Cancer Centres	-	-
CCR	-	-	Centre Communautaire de Référence pour le dépistage des cancers
CHI	Cédric Hèle Instituut	-	-
CvKO	-	Centrum voor Kankeropsporing	-
COCOM	Common Community Commission	Gemeenschappelijke Gemeenschapscommissie	Commission communautaire commune
COCOF	French Community Commission	-	Commission communautaire française de la Région de Bruxelles-Capitale
MOC/COM	Multidisciplinary Oncological Consultation	-	Consultation Oncologique Multidisiplinaire
ComPerMed	Commission on Personalised Medicine	-	-
CPO	Centre for Psycho-Oncology	-	-
CRM/CTG	Commission for the Reimbursement of Medicines	Commissie Tegemoetkoming Geneesmiddelen	Commission de remboursement des médicaments
EBCP	Europe's Beating Cancer Plan	Europees kankerbestrijdingsplan	Plan européen pour vaincre le cancer
EC	European Comission	-	-
ECAC	European Code Against Cancer	-	-
ERNs	European network of reference centers	Europese referentienetwerken	Réseaux européens de référence
ETA	Early Temporary Authorisation	-	-
EU-MS	Member States of the European Union	-	-
FAMHP / FAGG / AFMPS	Federal Agency for Medicines and Health Products	Organisatie Federaal agentschap voor geneesmiddelen en gezondheidsproducten	Agence Fédérale des Médicaments et des Produits de Santé
FPS	Federal Public service	-	-
HPV	Human papillomavirus	-	-

HNSCC	Head and neck squamous cell carcinoma	-	-
HSPA	Health system performance assessment	-	-
INAMI-RIZIV	National Institute for Health and Disability Insurance	Rijksinstituut voor ziekte- en invaliditeitsverzekering	Assurance soins de santé et indemnités
iFOBT	Immunological test for occult blood in the stool	-	-
JA	Joint Action	-	-
KCE	Federal Centre of Expertise for Health Care		
MSM	Men Who Have Sex with Men	-	-
NCCN	National Comprehensive Cancer Network	-	-
NCD	Noncommunicable diseases	-	-
NGS	Next Generation Sequencing	-	-
OECD	Organisation for Economic Co-operation and Development	-	-
OECI	European Organization of Cancer Institutes	-	-
P4P	Pay for Performance	-	-
PREMs	Patient Reported Experience Measures	-	-
PROMs	Patient Reported Outcome Measures	-	-
PSA	Prostate-specific antigen	-	-
PSBO	Basic oncology care programs	-	Programme de soins (de base) en oncologie
PSI	Integrated care projects	-	Programme de soins intégrés
PSO	Oncological Care Programmes	-	Programme de Soins en Oncologie
RBSLM	Royal Belgian Society of Laboratory Medicine	Koninklijke Belgische Vereniging voor Laboratoriumgeneeskunde	Société Royale Belge de Médecine de Laboratoire
R.D	Royal Decree	-	-
SCP	Survivorship care pathway	-	-
SD	Socio-demographic	-	-
SDG	Sustainable Development Goals	-	-
SE	Socio-economic	-	-
SHC	Superior Health Council	-	-
SIO	-	-	Société des Infirmiers en Oncologie
SME	Small and medium-sized enterprises	-	-
STIs	Sexually transmitted infections	-	-
VVRO	-	Vereniging Verpleegkundigen Radiotherapie en Oncologie	-
ULB	-	-	Université Libre de Bruxelles
UZ	-	Universitaire Ziekenhuizen	-
YLDs	Years lived with disability	-	-
WHO	World Health Organization	-	Organisation mondiale de la santé

TABLE OF CONTENTSDDD

1. Introduction

Cancer is a broad family of diseases that involve abnormal cell growth with the potential to invade or spread to other parts of the body. It is one of the most important disease groups in terms of premature mortality, ill health, and healthcare expenditure. Cancer can be caused by inherited genetic traits, but the vast majority is due to genetic mutations occasioned by carcinogenic agents related to lifestyle, and metabolic or environmental factors.

Cancer is one of the five major societal challenges the European Commission identified. Current projection is that, without strong action, the incidence will increase by a fifth by 2040, representing over 3 million cases in Europe. Across Europe, the possibility of receiving a timely cancer diagnosis and of surviving the disease differs considerably because of inequalities in preventive policies, access to state-of-the art diagnostics and treatments, and experienced care.

The WHO promotes creation and implementation of national cancer control plans, programmes and policies, that are harmonized with other NCD prevention and control strategies (5). Cancer prevention and control is related to the Sustainable Development Goal 3.4; reducing premature mortality from non-communicable diseases by one third, through prevention, treatment and promotion of mental health and well-being (6). Cancers related to Hepatitis and HPV are covered by the SDG Goal 3.3, "*By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and* ***combat hepatitis****, water-borne diseases and other communicable diseases*." While primary prevention related to health lifestyle promotion is underlined in SDG 3.5, "*Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol.*"

The European Commission (EC) has launched two major initiatives to tackle cancer: 1) **Europe's Beating Cancer Plan (EBCP)** and 2) the **Mission on Cancer**.

1) The **EBCP** is a policy-driven initiative that sets out actions to support, coordinate or complement Member States' efforts at every stage of the disease. The EBCP launched in 2021 will be implemented using the whole range of EC funding instruments, with a total of €4 billion being earmarked for actions addressing cancer, including €1.25 billion from the EU4Health programme, plus financial support through the Horizon Europe Framework Programme for Research and Innovation and the Digital Europe programme.

2) Along with the EBCP, the **Mission on Cancer** is a research-driven initiative outlined with the input of citizens, **patients** and Member States' stakeholders. The Mission on Cancer aims to improve the survival and quality of life of cancer patients and substantially reduce the cancer burden in the EU through research.

The EBCP aims to bring large benefits to EU-MS health care systems and cancer patients. Nonetheless, given the current breadth of EU calls in the cancer field, there is a need for a coordinated response from stakeholders in Belgium. To better target, those investments that will most benefit cancer patients and the Belgian health care system requires an understanding of cancer control activities in Belgium. It is also for this reason that this inventory has been prepared.

Another reason for the development of this inventory is that the last Belgian National Cancer Plan was developed in 2009 and evaluated in 2012 (7). Since then, several new initiatives were implemented between 2015 and 2019, such as the advancement of molecular oncology diagnostics (e.g., next generation sequencing), as well as concentration of care policies to improve quality for some rare illnesses, and initiatives to aid cancer sufferers' professional reintegration. The last state-of-play of the Cancer Plan implementation was prepared in 2015.

This report provides the latest publicly available figures on the burden of cancer in Belgium and a state of play of cancer control activities in Belgium. This inventory covers different areas of the cancer continuum spanning prevention, diagnosis, treatment, care and care organisation, quality of life and survivorship. In each thematic area, we provide definitions and terminology and a context to the thematic areas in Belgium; a problem statement, outlining the major challenges in a given thematic areas; public agencies and actors involved to understand who in Belgium is implicated in each thematic area; underlying legislation and mandates to detail what frames cancer care in each thematic area; a description of current programmes and activities; and we close with an analysis of the remaining needs and gaps in each thematic area.

2. Objectives & Methodology

2.1. OBJECTIVES

The objective of this cancer inventory was to provide an overview of current cancer control policies and interventions in Belgium starting with prevention, across the patient pathway, and survivorship. We have also considered crosscutting issues such as patient centeredness and the reduction of inequalities in cancer care. More specifically, the inventory:

I. Brings together evidence from desk research on existing cancer control policies and interventions at federal, regional and local level in Belgium
II. Maps the relevant actors, legal statutes and mandates related to each part of the patient pathway.
III. Underlines best practices for cancer care whenever possible, in link with possible gaps and areas for improvement.

While the inventory has been conducted to provide an overview of these policies, actors and intervention to inform decision-makers in Belgium, it can also serve as a baseline for the forthcoming evaluation of the EBCP's implementation uptake in EU Member States.

2.2. METHODOLOGICAL APPROACH

The inventory was conducted through a non-systematic review of both grey and peer-reviewed literature examining cancer care and control in the Belgian health system. Epidemiological indicators were collected from sources responsible for routine data collection, including the Belgian Cancer Registry, Healthy Belgium, and IMA-AIM.

The main data source for analysis of current activities was the Belgian Cancer Barometer from 2021 and Healthy Belgium data reporting, as well as the OECD Country Cancer Profile for Belgium from 2023. Actors were mapped using existing Sciensano database, and snowball sampling[1]. The list of routinely available indicators to report on the burden of cancer in Belgium, and health service use from the Cancer Registry and the IMA-AIM Atlas are available in the annex.

For a more granular identification of the actors at federal, regional and local level, a stakeholder mapping exercise was conducted in parallel to this inventory. It allowed us to identify the main actors involved in the different elements of the patient pathway. We have identified 392 institutions as shown below.

Actor Type	Count
Public institutes at the national, regional and local level	41
Non-for profits (including charities and patient associations),	189
Industry	46

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[1] Please see Annex for detailed stakeholder mapping methodology

Healthcare services (whether public or private, including hospital networks)	77
Universities and research	38

By region, there were 167 actors operating at the federal or European level, 43 in the Flemish region, and 12 in the Wallonia region, 15 in the Wallonia-Brussels federation, 41 in the Brussels-Capital region, and 113 operating in different provinces across Belgium. A more detail description of the each of the actors involved across the patient pathway, can be found in each of the following chapters in subsequent sections.

An analysis of gaps and needs was also conducted for each of the thematic areas in cancer care and control. These analyses were based on a non-systematic review of grey and peer-reviewed literature, and were complimented by multi-stakeholder discussions with members of the Cancer Centre's EBCP Belgian Mirror Groups (1). These seven thematic working groups are composed of actors representing Belgian policy organisations, professional groups, patient associations and scientific researchers, and industry, and act in an advisory capacity. A more detailed analysis of these groups discussions have been documented in each groups policy brief, which can be found in the annexes.

2.3. LIMITATIONS

The review that was conducted was non-systematic, and did not involve any triangulation or enriching techniques with stakeholders. This could lead to omission or inclusion biases. In particular, the results and existing challenges identified in the report below are not exhaustive and draws solely on desk research.

Data were collected by researchers from Sciensano's Cancer Centre and reviewed internally; external agencies and partners were not solicited for additional input. Information gaps could be particularly acute relative to activities occurring at the regional and/or local levels for which annual reports are not always available. For example, the list of indicators available in annex is not necessarily exhaustive and would benefit from a validity check with the data curating agencies.

It should also be noted that data on cancer from 2020-22, relative to early detection and screening, diagnosis, as well as treatment, and survivorship outcomes may have been affected by the COVID-19 pandemic (8). The most recent data has been used, but data from prior to the pandemic has also been leveraged.

Complementing this initial desk review with qualitative and participative components will be necessary in the future. This is in order to depict a more complete picture of cancer care activities and strategies, and to strengthen the understanding on informal actors working in and around cancer care.

3. Overview of the Burden of Cancer in Belgium

3.1. MONITORING BURDEN OF CANCER

In Belgium, the performance of cancer care is measured through a variety of metrics. These help healthcare providers, policymakers, and other stakeholders to evaluate the quality of care and make improvements where needed. Some of the key metrics used to measure cancer performance in Belgium include:

- **Cancer incidence and mortality rates:** These metrics measure the number of new cancer cases and deaths due to cancer in a given population.

- **Screening participation:** These metrics measure the participation of target age group in the regionally organised screening programmes in Belgium.

- **Treatment outcomes**: This metric measures the effectiveness of cancer treatments, including survival rates, response rates, and disease-free survival rates.

- **Patient satisfaction:** This metric, which may be measured qualitatively, measures the level of satisfaction of cancer patients with the care they receive, including the quality of medical services, communication with healthcare providers, and the patient experience.

- **Access to care**: This metric measures the accessibility of cancer care services, including wait times, availability of specialized services, and geographic or financial barriers to care.

- **Resource utilization**: This metric measure the use of healthcare resources, including hospital stays, diagnostic tests, and treatments, and the costs associated with cancer care.

- **Quality of life**: This metric measures the impact of cancer and its treatments on a patient's overall quality of life, including physical, emotional, and social well-being.

These metrics are regularly collected and analysed by healthcare providers and government agencies in Belgium, at various levels, and the results are used to inform policies and initiatives aimed at improving cancer care and outcomes. The actors at different levels and their responsibilities are explained in the subsection sections below. The healthcare system also uses these metrics to evaluate and compare the performance of different providers and facilities, and to identify areas for improvement.

The Belgian Cancer Registry collects data on cancer cases in Belgium. The Belgian Cancer Registry is nationally representative and exhaustive. It collects and records both clinical and pathological data. The recording of data is done using the *International Classification of Diseases for Oncology*. Incidence figures include crude and age-standardized incidence rates. These rates are calculated and published yearly by the Cancer Registry.

3.2. CANCER INCIDENCE

Crude cancer incidence per 100,000 is higher in Belgium than the EU-15 average, both for men and women (9). Compared to the countries with the lowest incidence rates, the incidence per 100,000 in Belgium is 35% higher among men and 46% higher among women. In 2020, 68,782 new diagnoses of cancer (excluding non-melanoma skin cancer) were registered, including 36,840 new cases in men and 31,942 new cases in women.

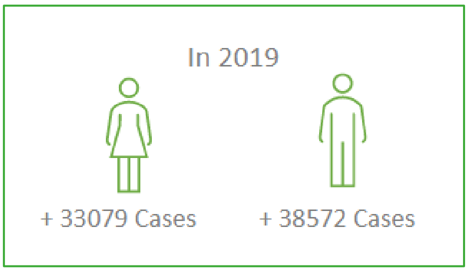


Figure 1: New cases of cancer in Belgium in Women & Men in 2020

In Belgium, the crude incidence rate has increased between 2006 and 2019 in both men and women. When adjusted for age, the incidence rate increased from 371 per 100,000 to 402 per 100,000 in women, while it has decreased from 508 per 100,000 to 495 per 100,000 in men (10).

In men, crude incidence rates are highest in Flanders followed by Wallonia, and Brussels presents lower rates. In women, crude rates are similar in Wallonia and Flanders, with lower rates in Brussels. Age-adjusted incidence rates are highest in Wallonia in both genders, incidence rates in Flanders fall below the national average in both genders.

Between 2006 and 2019, crude incidence rates of cancer increased for both men and women in Flanders and Wallonia. In Brussels, however, a decreasing trend is observed. In men, age-adjusted incidence rates were more or less stable in Wallonia and Brussels, while slightly decreasing in Flanders. In women, age-adjusted incidence rates increased in Flanders and Wallonia, while staying stable in Brussels (10).

Cancer incidence shows a clear association with age, with the highest incidence rate in the 80-84 age group. Before the age of 55, cancers are more commonly diagnosed among women, while in the older age groups, cancer diagnoses become more common among men. The general patient population who are diagnosed with cancer also includes young people with cancer. These are the "AYA" or adolescents and young adults with cancer. These represent nearly 2% of all cancer diagnoses, meaning nearly 1,700 young people between the ages of 16 and 35 which are diagnosed with cancer (11).

3.2.1. Site-Specific Cancer Incidence

In 2019, prostate cancer and breast cancer were the most frequently diagnosed cancers among men and women, respectively. The age-adjusted incidence of breast cancer in women is stable, while the age-adjusted incidence of prostate cancer has decreased in men between 2006 and 2014, but has slightly increased since then.

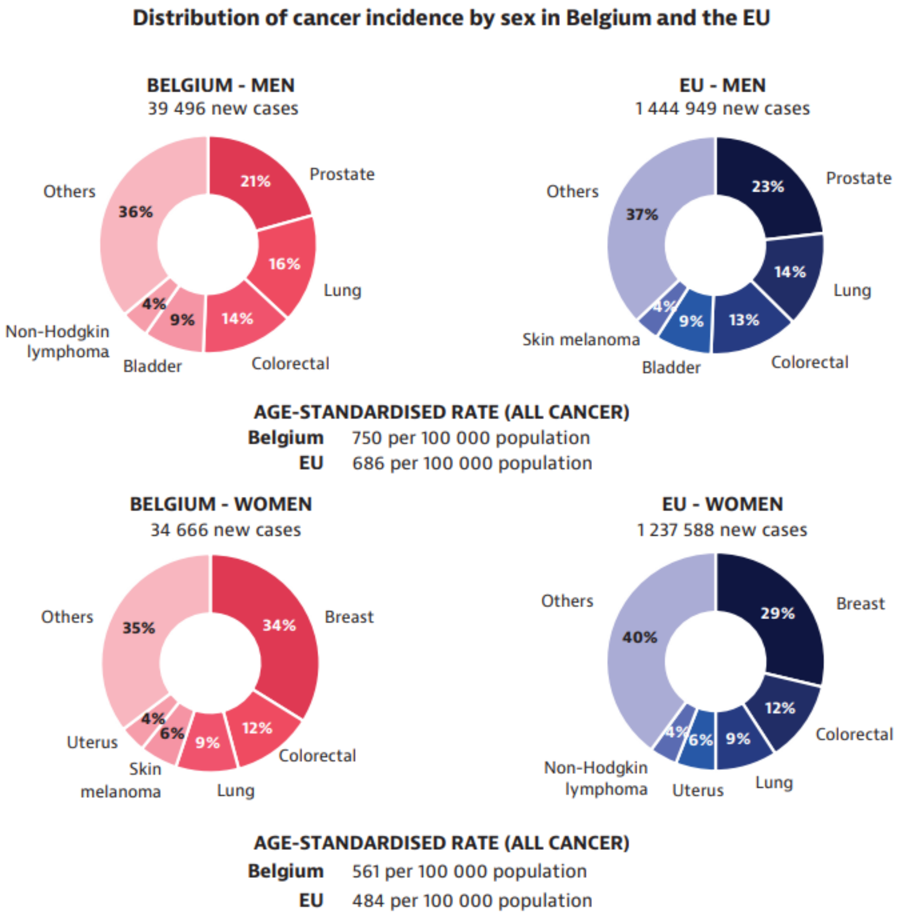


Figure 2: Distribution of cancer cases in Belgium and the EU by sex in 2021. Source OECD (9).

Lung cancer is the second most frequent cancer in men, and since 2018, also the second most frequent diagnosed cancer in women. The age-adjusted incidence of lung cancer has gone up with 63% between 2006 and 2019 in women, it decreased by 16% in men.

Colorectal cancer diagnoses remained stable between 2006 and 2019 in both men and women, and showed a peak in 2014, when a colorectal cancer screening program was introduced in Flanders.

The incidence of melanoma is increasing in both genders. In men, the age-adjusted incidence has increased by 130% between 2006 and 2019 while it has increased by 100% in women, ranking melanoma 4th among the most frequently diagnosed cancers in women since 2010, ahead of cervical cancer. A more active screening can have played some role in the apparent increase of incidence, but most probably does not account for the entire change.

3.3. CANCER PREVALENCE

Cancer prevalence is a function of cancer incidence and survival, and the latter may be very different from one cancer to another. Lung cancer, for instance, has a low survival rate that few survivors will be alive at a given moment, despite the high incidence. On the other hand, prostate and breast cancer both have high incidence and survival rates, explaining their predominance in prevalence estimates.

According to Healthy Belgium, 4 in 100 Belgians are living with cancer. This represents 472,360 persons living with cancer (including non-melanoma skin cancer) in 2020; this number included 240,462 men and 231,898 women. The crude and age-adjusted prevalence per 100,000 was highest in the Flemish Region.

Prostate cancer was the most prevalent cancer type among men (71,647 cases, or 1.3% of the total male population in Belgium). Among women, breast cancer was the most prevalent cancer type (87,789 cases, or 1.5% of the total female population in Belgium). Another 49,227 Belgians were alive by the end of 2020 after having been diagnosed with colon cancer in the past 10 years.

3.4. CANCER MORTALITY AND SURVIVAL RATES

3.4.1. Cancer Mortality

Cancer mortality per capita is among the lowest in the EU. Each year, around 26 000 people in Belgium die from cancer of any kind; 14 000 men and 12 000 women. It is the second leading cause of death among adults after diseases of the circulatory system (9).

The highest mortality rates in 2019 were from lung (52 deaths per 100 000 population), colorectal (23 per 100 000), breast (18 per 100 000) and pancreatic (16 per 100 000) cancers. Between 2011 and 2019, cancer deaths per capita decreased by 15 % from 268 to 229 per 100 000 population – a rate among the lowest in the EU. Belgium experienced decreases in per capita mortality between 2011 and 2019 for all the 10 deadliest cancers except liver cancer, which increased by 4 %, and oesophageal cancer, which increased by 9%.

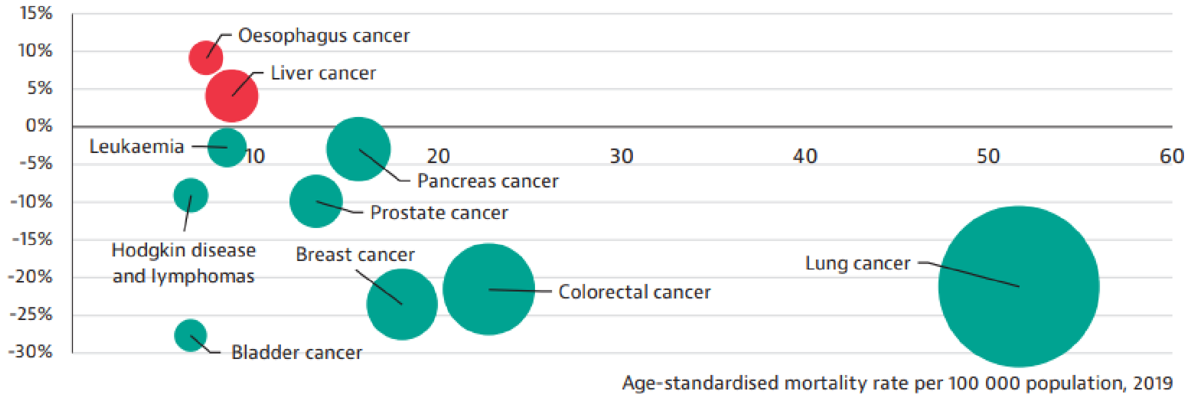


Figure 3: Change in cancer mortality 2011-19. Lung and colorectal cancer were the most important contributors to mortality. Source Eurostat 2021, taken from OECD Country Cancer Profile, Belgium 2023

Although the **preventable mortality** rate has been decreasing since 2000**, Belgium ranks poorly at the European level (14th out of 15)**, with 56.1 age-standardised preventable death per 100 000 inhabitants in 2015. Preventable mortality is much **higher for men than for women** (sex ratio: 1.8), this ratio is comparable in all three regions.

In men (aged under 75 years), the primary causes of death potentially preventable through health policies are lung cancer, cardiac diseases and suicide. In women (aged under 75 years), the **primary causes of preventable mortality are lung cancer, breast cancer** and cardiac diseases. Amenable mortality is higher in men than in women in Belgium (sex ratio: 1.37) and these differences between sexes are most marked in Wallonia (1.52) compared with Brussels (1.41) and Flanders (1.27) (12).

3.4.2. Relative survival rates

The 5-year relative survival rate following breast or colorectal cancer are indicators that can provide an idea about the overall effectiveness of the health system. Firstly, these two types of cancer can be screened at an early stage and are targeted by screening programmes organised at the regional level. Secondly, treatments for these cancers are effective and scientifically well established. The survival rates for these two cancers may therefore reflect good progress in public health procedures (increased population awareness, better screening programmes) as well as high treatment effectiveness.

3.4.3. Relative survival rates following breast cancer

Belgium has a 5-year breast cancer survival rate that is slightly better than the average for European countries (Belgium: 86.4% and EU-13: 86.2% for 2010–2014) (13). The 5-year relative survival rate after a breast cancer diagnosis was 92.4% for patients diagnosed in 2017.

This survival rate strongly depends, however, on the stage of the disease at the time of diagnosis: for an early-stage diagnosis (stage I (39% of cases for the 2004-2012 period) or stage II (35% of cases)), the 5-year survival rate is similar to that of the general population. For the group of women diagnosed at stage III (12% of cases), a marked increase in the 5-year survival rate can be observed (from 72.0% in 2004 to 77.3% in 2012). Lastly, for women diagnosed at stage IV (6% of cases), the 5-year survival rate reached 32.5%. An improvement in survival can be observed over time, from 32.2% in 2004 to 34.6% in 2012. No regional differences were observed for breast cancer.

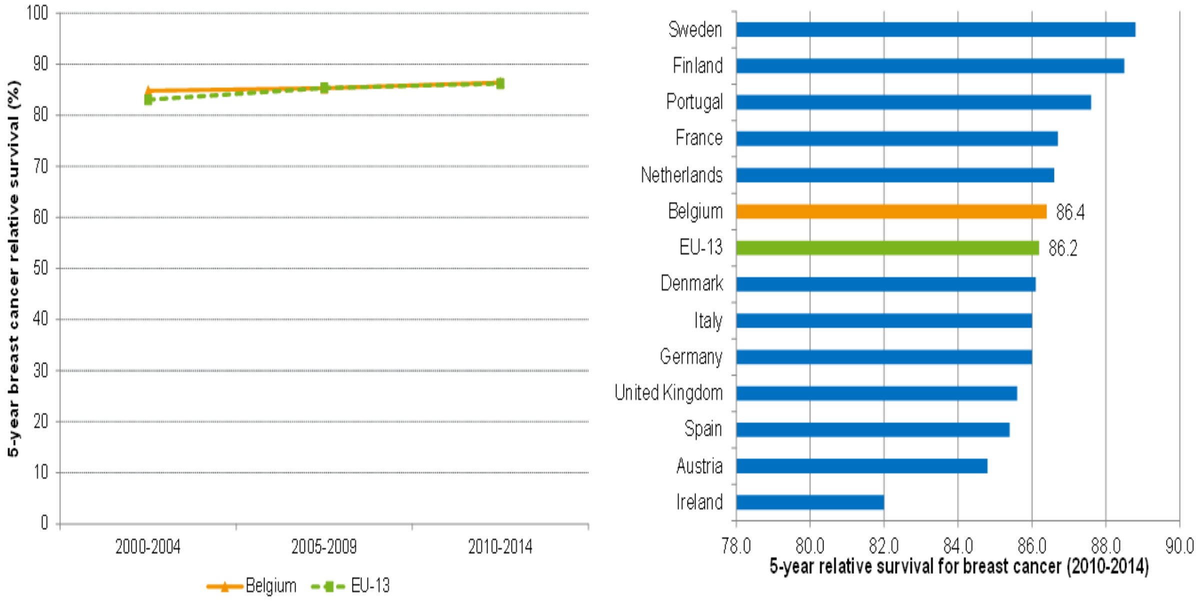


Figure 4: Five-year relative survival for breast cancer: international comparison (percentage, 2000-2014). Data source OECD Country Report 2018 (14)

3.4.4. Relative survival rate following colorectal cancer

The 5-year relative survival rate following a colorectal cancer diagnosis is 71.9% for patients whose diagnosis was issued in 2017, which represents an improvement compared to those who were diagnosed in 2004 (63.7%).

As with breast cancer, the survival rate following colorectal cancer is strongly influenced by the stage of the disease at the time of diagnosis, but colorectal cancer is often diagnosed at a more advanced stage (II or III), hence the difference in prognosis between these two types of cancer.

The 5-year relative survival rate is slightly lower in Brussels and in Wallonia, but these figures require further analysis (taking into account possible differences in patient populations) before any conclusions may be drawn about differences in quality of care.

Compared to the average for European countries, Belgium has remarkable five-year relative survival rates for colorectal cancer. Five-year relative survival rate for colorectal cancer is significantly higher than the average EU-15 (Belgium: 67.8% and EU-15: 63.3% for 2010–2014). Recent initiatives include the Evidence-Based Practice plan and a pilot project on integrated care to improve the quality of care are described (15).

Finally, there are notable social inequalities in cancer survival rates as reported (16). Differences in cancer survival according to social economic status are most pronounced for head and neck, female breast, and colorectal cancer.

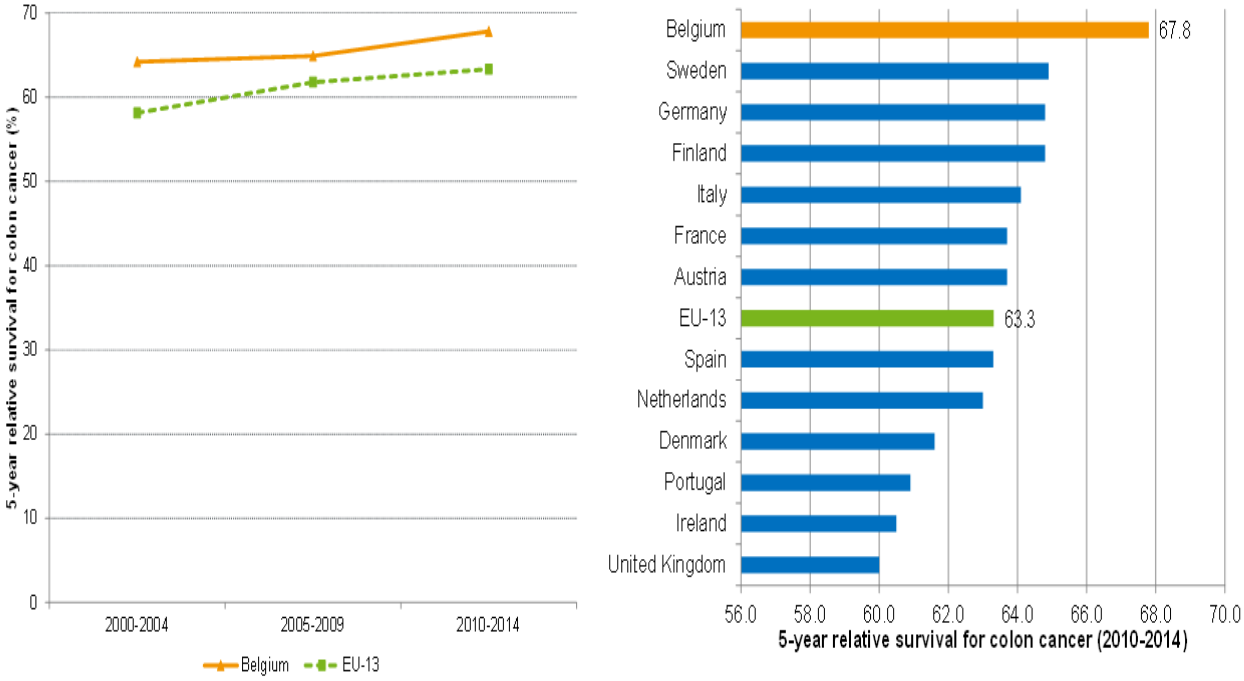


Figure 5: 5 year relative survival for colon cancer, comparison with European Countries (2000-2014), percentage, Source OECD 2018

CANCER CONTROL ACTIVITIES IN BELGIUM

The healthcare system strives to prevent disease in the general population, and provide patients with access to the latest treatments and technologies to help them manage their condition and improve their quality of life.

4. Prevention

4.1. DEFINITION & TERMINOLOGY

Prevention is usually defined in four levels (17):

1. **Primordial Prevention:** risk factor reduction targeted towards an entire population through a focus on social and environmental conditions. Such measures typically are promoted through laws and national policy**.** This type of prevention targets the underlying societal drivers of a disease.

2. **Primary Prevention**: — Primary prevention consists of measures aimed at a susceptible population or individual. The purpose of primary prevention is to prevent a disease from ever occurring. Thus, its target population is healthy individuals. It commonly institutes activities that limit risk exposure or increase the immunity of individuals at risk to prevent a disease from progressing in a susceptible individual to subclinical disease. Measures such as vaccinations, altering risky behaviours (poor eating habits, tobacco use), and banning substances known to be associated with a disease or health condition.

3. **Secondary Prevention**: Secondary prevention emphasizes early disease detection, and its target is healthy-appearing individuals with subclinical forms of the disease. This includes screening to identify diseases in the earliest stages, before the onset of signs and symptoms, through measures such as mammography and regular blood pressure testing. Secondary prevention is covered in the section *Early Detection & Screening.*

4. **Tertiary Prevention:** Targets both clinical management of the disease and outcomes from the disease. This includes managing disease post diagnosis to slow or stop disease progression through measures such as chemotherapy, rehabilitation, and screening for complications. Tertiary prevention is covered in the sections on *Care Organisation* and *Survivorship.*

4.2. PROBLEM STATEMENT

Between 30-50% of cancers are preventable (2), which, given the cancer incidence in Belgium, would represent approximately between 22 500 and 37 500 cases of cancer prevented each year in Belgium. Preventing cancers does not only reduce the costs and burden on the health system, but improves the quality of life for individuals and their families. The European Code Against Cancer (ECAC) lists 12 actions that individuals could take, if capable and motivated, that would reduce the mortality of cancer in Europe by half (18).

Such actions relate to not smoking or keeping home environments and workplaces smoke free, taking action to be physically fit, have a healthy diet and maintain a healthy body weight, as well as items reducing alcohol intake, and avoiding too much sun and using protection when exposed (18). While these points are all upheld by the latest scientific evidence, their implementation depends on the knowledge, motivation and capability of individuals (19). As such, it is essential to understand what barriers may hinder the uptake and maintenance of such barriers, as well as what may facilitate them.

4.3. PUBLIC AGENCIES & ACTORS INVOLVED

In Belgium, responsibility for cancer prevention is predominantly shared among several organizations and government agencies as shown in the table below (20). Beyond public intuitions, Non-for-Profits and For-Profit organisations play a role in the prevention of cancer (see annex – Stakeholder mapping for a detailed list).

Institute	Responsibilities
FPS Public Health (SPF Santé Publique/FOD Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu)	Coordination of prevention policies. Controls the legislation on alcohol and tobacco, as well as legislation for regulating advertising for harmful foods and alcohol. Legislation related to taxing harmful substances to promote behaviour change are also determined at the Federal Level.
FPS Employment, Labour and Social Dialogue	Protect workers against chemical agents in general and against carcinogens (including asbestos) and mutagens.
Kind en Gezin (Flandres) Office de la Naissance et de l'Enfance (Fédération Wallonie Bruxelles)	For maintaining the health of young children in general, including prevention.

Since the 6th State Reform, the regions are responsible for health promotion, health education, prevention care, including vaccination (21). They are also responsible for the funds related to the prevention of substance abuse, screening campaigns, nutrition plans, initiatives regarding oral health in schools and tobacco cessation programmes.

Region	Responsibility
Brussels-Capital Region	Competent for providing primary care, reception-centres, home based-care, and assistance to older people and people with disabilities, care homes for older people in Brussels (Iriscare, 2019). Additionally, the Flemish Community Commission (VGC), the French Community Belgium Commission (COCOF) and the Joint Community Commission (COCOM) have competencies in well-being and health in the region of Brussels-Capital.
Flemish Region	Flemish Care and Health (AZG) is the Flemish agency regulating and supporting public health initiatives. They implement

	prevention policy in Flanders through multi-year management contracts with partner organizations and organizations working in the field. At the local level in Flanders, the loco-regional health consultations and organizations support the implementation of the Flemish health prevention policy.
Walloon Region	AVIQ is responsible for major policies related to well-being and health, support for older people, disability and family allowance. They are responsible for the implementation of the health prevention policy in French-speaking Belgium. Often, other organisations in the French-speaking community are subsidized to carry out various tasks related to health promotion and primary prevention.
German Community	The agency for Autonomous Life (Dienststelle für ein Selbstbestimmtes Leben) informs, advises and assists citizens in a dependency situation due to age, or physical or mental disability (see (Ostbelgien, 2019c) for details). The German-speaking community collaborates with the Community Reference Centre for Cancer Screening for breast cancer and colorectal cancer.

4.4. LEGAL STATUTES AND MANDATES

In Belgium, cancer prevention is organized through a combination of public health initiatives, by public institutes, non-for-profits, as well as individual efforts. Mandates and legislation exist at the federal and can differ somewhat at the regional level.

At the federal level, and since 2010, several health policies have been initiated in Belgium to improve the health of the Belgian population. These include a ban on smoking in closed public places (22), the Royal Decree to promote the use of Nutri-scores for the food industry (23) and the elaboration of a law proposal on prohibiting alcohol sales (except beer and wine) to people under 18 years old in 2019 (24).

Measures were also taken by the Federal Authorities to promote better nutrition. In 2016, they concluded a covenant with representatives of the food companies (Healthy Food Agreement) to promote healthy choices for the consumer by changing the composition, labelling or portions of certain food products (25). In 2018, taxes on soft drinks were almost doubled. Furthermore, a legal framework was adopted for a Nutri-Score label on food. The logo aims to better inform the public about the nutritional value of foodstuffs. Food producers or distributors who opt for its use must comply with the legislation (23). Then in October 2019, food-based dietary guidelines were published by the Superior Health Council (24). Additionally, since 2019, Federal rules prohibit the sale of tobacco products to those under 18 years and from 2020, there is standardised packaging for all tobacco products. Proposals are underway to ban all smoking advertising and to address the regional differences in prohibiting smoking in cars with a minor present (currently applied for minors under 16 years in the Flemish region and for under 18 years in the Walloon region).

The specific policies underpinning each of the regional and community activities are listed below:

- **Brussels-Capital Region**: Following the sixth State Reform, Iriscare was created in 2017. There is also a Brussels Health Plan – Growing up and living in good health (26).

- **Flemish Region**: The policy framework for the organisation of preventive health care in the Flemish community was first described in the decree of 21 November 2003 (27). Targets on the following topics have been developed: healthier living, suicide prevention, cancer screening and vaccination.

- **Federation Brussels-Wallonia (Francophone Communities)**: In a political agreement following the sixth State Reform, the French-speaking parties decided to transfer most of the public health policy competences from the French Community to the Walloon Region and the French Community Commission (or COCOF). The Walloon Government decided to simplify the proceedings and create a single Walloon agency in 2016, **AVIQ**. The agency produced a decree in 2019 on prevention and health promotion introducing several new units including, centres of scientific expertise in health promotion, local health promotion centres (*Centre Local de Promotion de la Santé*), centres for preventative medicine to pilot programmes.

- **Germany Community**: Expert opinions from the Council for Health Promotion (Beirat für Gesundheitsförderung) were used by the Government to define the global concept of health promotion, consisting of a structural level (improving infrastructure, health promotion networks and coordination between health care organisations) and an individual level (age-specific information and self-responsibility) (28)

Additionally**, joint measures have been taken** to reduce tobacco and alcohol consumption upholding cross-cutting principles of health in all policies and health equity (21). In 2016, the Inter-ministerial Conference on Public Health, composed of the Federal State and federated entities, made an agreement on a specific set of prevention policies, including on the cancer related themes of nutrition, tobacco, alcohol, sexual health, oral health, vaccinations, as well as cervical cancer screening, breast cancer screening and colorectal cancer screening (29).

4.5. PROGRAMMES & ACTIVITIES

4.5.1. Behavioural Factors

Behavioural risk factors play an important role in the cancer morbidity and mortality in Belgium, this relates to tobacco consumption, healthy diets and exercise, vaccination, as well as safe sex, as well as health seeking behaviour (20,30). In Belgium, the main sources of data on lifestyle and behaviours are the health examination survey and the health interview surveys. The latest Belgian Health Survey (HIS) was conducted in 2018. The HIS collects information on a wide range of health topics: physical and mental health, lifestyle, and use of health care and preventive services, perception of the physical and social environment, amongst others. As consequence, the study examines trends in different health domains and in health inequalities, and to compares the Belgian results with those of the other EU Member States. Information on health status, lifestyle, health care and socio-demographic characteristics was collected from a representative sample of 11,611 residents of Belgium. The 7th Health Survey will start in January 2023 (31).

The Belgian government and various organizations promote healthy lifestyles and behaviours that can reduce the risk of cancer, as outlined below:

- **In Flanders,** the health conferences consist of representatives of the Flemish government, experts, target groups and local health networks (Logos). Fifteen Logos lead the health promotion work at district level. They are composed of existing local initiatives and structures, and are meant to include all health and welfare workers (32). For support of its health promotional activities, the Flemish government appeals to the Flemish Institute for Healthy Living (before 2017 known as the Flemish Institute of Health Promotion and Sickness Prevention). With advice, ready-made packages and training, the institute supports professionals and their organisations in the health sector, schools, workplaces and local governments. It focuses on mental health, healthy eating, physical activity and reducing tobacco use, and it supports the Logos.

- **The Walloon government** has defined health objectives in the Walloon Plan for Prevention and for Health Promotion (2018–2030) (33).

- **In the Brussels region** a strategic plan for health promotion 2018–2022 of the Brussels French-speaking government has been created (34).

- **The German speaking community** has set focus is on the following topics on health literacy, nutrition, physical activity, mental health, substance abuse, vaccinations, environment and health and dental health in the domains of prevention. In addition, over the next years, health promotion will be focused on the socially disadvantaged population (28).

There has been a decrease in the percentage of daily smokers over the past 15 years. A stagnation in preventable mortality in women may be attributed to increased lung cancer mortality in women, who smoke more than in the past (12). There has been a slight decrease in the consumption of sugar-sweetened beverages since 2004, in addition to and a decrease of the prevalence of alcohol consumption since 2013 (35).

Nonetheless, the majority of these indices have increased for marginalized groups, such as low with lower educational levels, and lower socio-economic status (36). It should be noted that as all these indicators are based on self-reported behaviour, they are subject to response bias, particularly acquiescence, where the participants respond by reporting the behaviour they think they should have.

4.5.2. Vaccination

Another behavioural element for cancer prevention is related to vaccination. This includes both HPV vaccination for cervical cancer, as well as Hepatitis vaccination. While HPV vaccination which is organised by region, and is slightly above the EU average, there remain important gaps, particularly in boys and men, who also transmit the virus and can develop subsequent cancer, and girls and women outside the targeted age group (37).

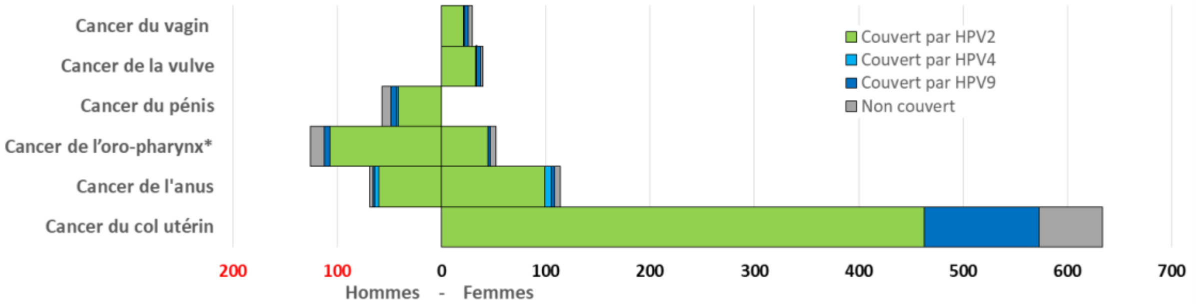


Figure 6: Estimation of the number of cancers attributable to HPV in Belgium, by sex and type of vaccine received (37)

HPV vaccination was first recommended in 2007 by the Superior Health Council (SHC) for girls aged 10-13 years to prevent cervical cancer. French and Flemish communities have extended the HPV vaccination to boys as of the start of the new school year in September 2019.

In Belgium, the HPV vaccination is currently recommended for:

- All adolescents aged 9-14 years-old, including girls and boys, with a 2-dose schedule (0, 6 months).
- Women and men aged 15 to 26-years-old, as a catch-up vaccination with a 3-dose schedule (zero, 1 or 2, 6 months). Vaccination may then be proposed by the general practitioner on an individual basis (whether the patient is sexually active or not).
- MSM should be proposed HPV vaccination up to 26 years old, given their higher risk of infection.
- Immunocompromised patients (transplanted and HIV positive patients), for which a 3-dose schedule is recommended, preferably with Gardasil (37).

Both the Flemish Region and the Federation Wallonia-Brussels propose free vaccination in schools for adolescents between the ages of 12-14, with an additional catch-up program for young girls in Wallonia. Despite the aforementioned recommendations, outside of this school-based program, INAMI-RIZI only reimburses the costs of the vaccine for young girls aged 12-18 years (38). One vaccine dose in Belgian costs approximately 134 euros, which may pose a significant financial barrier for some individuals for who vaccination is recommended but not covered by the current reimbursement.

4.6. GAPS & NEEDS

Belgium ranks poorly in preventable mortality compared to countries that have similar spending on public health and healthcare in the European region (9). While policies for primordial prevention have been put into place at the federal level (e.g., for tobacco and alcohol sale), the impact of primary prevention measures conducted at the regional and community level is less clear. There is a degree of fragmentation of prevention and health promotion activities supported by the numerous non-for-profits and federal, regional and local level. Further investments in the evaluation of prevention programmes would be beneficial as well as exploring what are the determinants for the successful transfer or scale-up of interventions across regions.

Given the small geographic spread of Belgium, and the decentralised responsibility of prevention and health promotion, it is likely that a person may be exposed to various, and possibly conflicting prevention and health promotion intervention. At the federal level, it is essential to better understand the current strategies and indicators at the regional levels, while also assessing the impact of the various strategies on population and individual levels of behaviour change.

There is also a need for more evidence on the link between healthy lifestyles and cancer in Belgium, including the related motivation, capabilities and opportunities of individuals experience that would facilitate them to engage in health positive behaviour change to prevent cancer (19). We would suggest that an area for potential development in the future to fill this gap would be developing novel ways to measure potential for behaviour change. This would support regional levels developing more targeted and risk based prevention and behaviour change strategies. Particular attention must be paid to marginalised and vulnerable groups, and barriers to health positive behaviour change for cancer prevention in these groups is a necessary area to study further.

Addressing the behavioural and social determinants of health is a worthwhile investment for health systems, which is also supported by the EBCP in which nearly a quarter of the actions and call for projects are directly or indirectly related to primary prevention and behaviour. Currently, in Belgium while there are many projects on vaccination, healthy environments, and nutrition/obesity, at Sciensano and at the federal level very few projects directly look at health literacy for cancer, or individual behaviours related to lifestyle behaviour and cancer (see annex for list of Sciensano projects related to primary prevention). Further work on inequalities and cancer health behaviour would also be beneficial.

5. Early Detection and Screening

5.1. DEFINITIONS & TERMINOLOGY

Cancer **screening** is an examination aimed at detecting cancer (at an early stage) in people who have no symptoms and who seem to be in good health. This is very different from **diagnosis**, which is an examination (sometimes the same) performed in a person who shows symptoms (a 'lump' in the breast, blood in the faeces) and in whom cancer is *suspected.* The purpose of screening is to reduce the overall mortality of the type of cancer concerned *in the entire population*, while early diagnosis is aimed at treating, and if possible extending the life of, *the individual* who is being tested. Screening is considered **secondary prevention.**

5.2. PROBLEM STATEMENT

In general, the early detection of cancer in Belgium is organized to ensure that patients receive timely and accurate diagnoses, and that they are able to access appropriate and effective treatments as soon as possible. Because screening concerns people who are, in principle, in good health, it is very important that the examination does not carry an excessively high risk, which would counter-balance the expected benefit at the overall population level. Therefore, tests that involve a certain degree of risk, even minimal cannot be used in the general population as long as there is no evidence that these examinations can help reduce the mortality rate in this population.

Participation in all screening programmes in Belgium is lower than the recommended levels (see sub section *Programmes & Activities* for reported participation). Large disparities exist between groups between and within regional levels (39). Yet, there are almost no recent studies developing an understanding of why there is such low participation in screening programmes.

5.3. PUBLIC INSTITUTES & ACTORS INVOLVED

The organisation of cancer screening programmes is both a regional and a national responsibility in Belgium. The Flemish, Walloon and Brussels authorities are responsible for the implementation and coordination of screening programmes and do so with the help of mandated expertise centres (40).

At the federal level, the following actors and institutes are involved.

Institute	Responsibilities
Federal Agency for Medicines and Health Products (FAMHP)	Responsible for promoting public health initiatives in Belgium, including cancer screening and early detection programs. These initiatives typically involve the distribution of information and resources to healthcare providers, patients, and the public, and are designed to raise awareness about the importance of early detection and encourage patients to undergo regular cancer screenings.
INAMI-RIZIV	Responsible for determining the tests that are performed, the reimbursement level and the frequency at which these screening tests are reimbursed.
Belgian Cancer Registry (BCR)	Registers all new cancer diagnoses and all test results from breast, colon and cervical samples. It links these data to data from screening programmes and to data on the reimbursement of screening costs from the *Agence InterMutualiste* (AIM). All these data are centralised at the BCR. Based on these data, the BCR draws up exclusion lists that allow for more targeted invitations to the target population according to certain criteria and provides information on follow-up and allows for a fail-safe mechanism, and can provide awareness lists.

The regional actors responsible for the implementation of screening programmes are as follows:

Institute	Responsibilities
Centrum voor Kankeropsporing (CvKO) - Flanders	The Cancer Screening Centre is the centre of expertise in Flanders for population screening for cancer. They are responsible for carrying out and coordinating these population-based screening programmes organised by the Flemish government. They monitor international developments and conduct scientific research, as well as raise awareness on screening programmes in the general population(41).
Centre Communautaire de Référence pour le dépistage des cancers (CCR) - Wallonia	Responsible for managing the breast and colorectal cancer screening programmes in Wallonia. The mission concerns the awareness raising of the target groups, the information/training of the actors, and the implementation of the operating procedures and the evaluation of the programmes.
BruPrev – Brussels	BruPrev is an ASBL that organises the screening programmes in the Brussels-Capital Region and is financed by the Joint Community Commission (COCOM), the French Community Commission and the Flemish Community (COCOF) (42).

5.4. LEGAL STATUTES AND MANDATES

The sixth state reform in which Flanders, Wallonia, and Brussels-Capital region, as well as the Flemish speaking, French speaking, and German speaking communities were granted constitutive autonomy also had a considerable impact on the responsibilities related to health, including on prevention (21). In 2014, following the reform, competencies were transferred to the regional entities. In this reform, all preventative care, including for children, as well as health education, health promotion, anti-addiction programmes, vaccination and screening programmes were transferred to the federated entities at the regional level.

The Federal State remains responsible for reimbursements in the health system. The Federal Government's commitments to population-based cancer screening programmes were formulated in the Memorandum of Understanding on Prevention (43). Thus, at the federal level, funding is provided for screening tests (apart from the colorectal screening test, Colotest) and subsequent diagnoses. The Federal Government is responsible for quality control of the laboratories and (radiological) services involved whereas the organisation of cancer screening programmes is also a regional competence.

5.5. PROGRAMMES & ACTIVITIES

Early detection of cancer in Belgium is organized through a combination of public health initiatives, screening programs, and patient education. Belgium has screening program for several types of cancer, including breast, cervical, colorectal, and prostate cancer. These programs involve regular testing, such as mammograms, pap smears, as well as faecal occult blood tests to detect early signs of cancer.

While the programmes are decided at a regional level, there are some common guidelines:

- **Breast cancer screening:** Women over the age of 50 are encouraged to undergo mammograms every two years to screen for breast cancer. Women at higher risk of breast cancer, such as those with a family history of the disease, may need to start screening at an earlier age or undergo screenings that are more frequent. Preventive care indicators include the percentage of women receiving a breast cancer screening test (44).

- **Cervical cancer screening:** Women between the ages of 25 and 64 should be screened every 3 years, on their own initiative or on the initiative of their doctor (45).

- **Colorectal cancer screening**: Adults over the age of 50 are encouraged to undergo regular faecal occult blood tests and/or colonoscopies to screen for colorectal cancer.

- **Prostate cancer screening**: There is no organised screening programme in Belgium. However, men over the age of 50 are encouraged to undergo regular prostate-specific antigen (PSA) tests to screen for prostate cancer.

It is important to note that these guidelines may change over time, and that individual screening recommendations may vary depending on a patient's medical history and other factors. Patients are encouraged to discuss their screening needs with their healthcare provider, and to work with them to determine the best screening schedule for their individual needs.

5.5.1. Breast Cancer Screening

Breast cancer is the most common type of female cancer, and the main cause of death by cancer in women (approximately 20% of all deaths due to cancer in women). Since the beginning of the 2000s, there has been a **national breast cancer screening programme** in Belgium for women aged 50 to 69 years. In this age group, each woman is invited every 2 years, to participate in this programme in an approved radiology/sinology department, free of charge. The mammograms are performed in the framework of an organised programme that follows a standardised procedure defined by European quality standards. **In Flanders there are 160 certified centres for mammograms, 77 in Wallonia and 34 in Brussels** (46)**.**

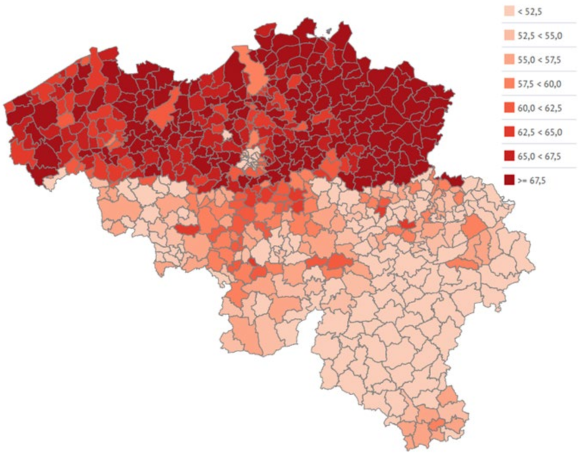


Figure 7: Total coverage of breast cancer screening in women 50-69 years old, by municipality (2016). Source IMA-AIM

In practice, it is also possible for women to be screened outside of the organised programme, using therefore the “diagnostic” path for screening purposes. This type of screening (called ‘opportunistic breast cancer screening’) generally consists in a clinical examination by a specialist, a mammography exam, and often an ultrasound exam. This more expensive examination is not done by invitation, but at the individual’s own initiative. There is no evidence to demonstrate that it is more efficient than organised screening, particularly since it is not standardised and not subject to quality controls. It is reimbursed by INAMI/RIZIV as a diagnostic test.

The recommended screening coverage by international standards is 75% of women in the target group. In Belgium, the total coverage of women (organised screening + opportunistic mammography exams) reached 61.7% in 2016. The highest rate was in Flanders (67.4%), compared to Wallonia (53.9%) and Brussels (52.9%). The total coverage rate was higher for younger women within the relevant age group (50-69 years). On an international scale, **total coverage remains lower than the EU-15 average** (44).

Coverage for the **organised screening programme has been stagnating at country level around 33%**, with major differences between regions. It has increased in Flanders (from 7.5% in 2001 to 50.7% in 2016), has reached a plateau around 10% in Brussels since 2007, and has even slightly decreased in Wallonia, where it was only 6.8%.

For both organised screening and total coverage, **the most vulnerable women at the socio-economical level is lower than the rest of the population** (24.9% versus 34.3% for the screening programme and 48.1% versus 65.1% for total coverage) (44).

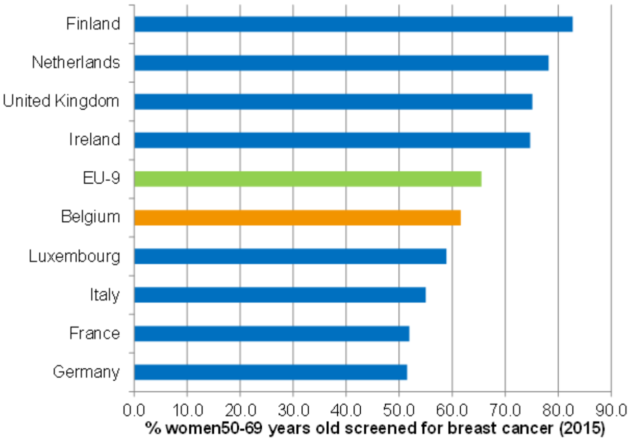


Figure 8- Coverage of breast cancer screening: international comparison (2015). Source OECD Country Data 2018.

5.5.2. Cervical Cancer Screening

In Belgium, cervical cancer affects approximately 64% women per year. Only 60% of them will survive their illness (47). In young women aged 25 to 44, however, it is the fourth most common cancer. Screening allows a 90% reduction in the incidence and mortality linked to this cancer. Coverage of cervical screening is currently around 60 % in Belgium, with marginal differences between the different communities, despite the fact that organisational modalities are different (48).

In Flanders, there is an official screening program. Women between the ages of 25 and 64 receive an invitation letter if they have not been screened in the last 3 years, on their own initiative or on the initiative of their doctor. In Wallonia, there is no official program but there are awareness campaigns and a pilot project has been launched (45). The pilot program invites women between the ages of 25-64 in the cities of Charleroi, Liège and Namur for screenings. In Brussels, there is no organised screening program for cervical cancer; however, cervical cancer screenings are reimbursed every 3 years for all women between the ages of 20 and 65.

On March 4, 2022, the consortium of Walloon hospitals (the University Hospital Centre of Liège, the Sambre and Meuse Regional Hospital Centre, and the Grand Hospital of Charleroi) responsible for the implementation of the screening program organized in Wallonia, launched an awareness campaign for cervical cancer screening in the Walloon and Brussels-Capital regions (49).

5.5.3. Colorectal Cancer Screening

Early and systematic screening campaigns for colorectal cancer are aimed at men and women from the age of 50. The different regions of our country therefore organize this screening, which you can undergo every two years if you belong to this target group. The screening for colorectal cancer within the population (which differs according to the region) targets men and women presenting neither symptom(s) suggestive of this cancer, nor significantly increased risk of developing it. The screening can be carried out at home using a test based on the search for occult blood in the stool sample. This is the iFOBT (immunological test for occult blood in the stool).

The EU recommends 65% of targeted population be screened for colorectal cancer. All regions in Belgium are below the recommended coverage. However, Flanders, with 64% coverage (opportunists screening + screening programmes), is close to the target (39). In Brussels the proportion is much lower at 28%, with only 10% responding to the invitation for an organised screening, which is a decrease from 2020 figures of 13% (46).

In Flanders, colorectal cancer screening has been organised since 2013. The target is all people living in Flanders between the ages of 50-74. Every two years these individuals receive a formal invitation letter, along with a self-testing kit, an information brochure, and instructions on how to use the kit. The sample, once taken, can be sent for free to any laboratory in the region.

In Wallonia, colorectal cancer screening has been carried out since 2009. It includes all people between the ages of 50-74. In additional to the regional health authorities, another nine institutes are involved. A letter of invitation is sent every two years, after which the individual may order a self-test kit from their general practitioner.

In Brussels, colorectal cancer screening has been available since 2002. Until 2018, it was the responsibility of the CCR from Wallonia. Since 2018, it is the responsibility of the *Féderation Wallonie-Bruxelles* (FWB). The FWB has been running a pilot since 2018 called *Colotest*, under which people aged 50-74 receive an email every two years, which they can exchange at any pharmacy in the region for a testing-kit. These testing kits are sent to Wallonia's CCR laboratories, who are then responsible for the testing of the samples.

5.6. GAPS & NEEDS

5.6.1. Coordination of Actors

While the Communities, Regions and the Federal Government engage in cooperative activities, for example through the *Inter-cabinet Working Group,* experts who participated the Belgian Cancer Barometer working groups, believe there is room for improvement (39,50). As we can see from the sections above, there is significant differences in the screening strategies and programmes between the different regions.

5.6.2. Efficiency in Screening

The participation in screening programmes is heterogeneous across Belgium. There are also a high number of individuals participating in screening that do not belong to the target group. This results in overuse of practitioners' time, and expenditures with lower return.

Several novel screening approaches that may also be used to improve the participation in screening programmes. For example, stratified screening, testing for HPV prior to promoting cervical cancer screening, and investing in personal breast cancer screenings. Feasibility studies may be considered to understand the possibilities for pilot programmes.

5.6.3. Understanding Knowledge, Perceptions and Behaviour on Screening Participation

Overall screening uptake is close to the EU average, but regional, educational and socioeconomic inequalities persist. Participation in screening programmes for most cancers is below the recommended levels for EU countries (9). Further efforts are needed to encourage participation in screening programmes. However, without understanding the understanding, perception and behaviour related to screening in Belgium. It will be impossible to develop programmes to improve participation. Necessary attention should be put on understanding the impact of differences between programmes, while a considering the need for harmonized and consistent monitoring, evaluation and follow-up of results, and to ensure all screening programmes follow the same evidence-base.

While studies have been done in neighbouring countries, such as France and Holland, on perception, knowledge and decision-making processes related to participation in screening programmes, few similar studies have been conducted in Belgium (51–57). Moreover socio cultural norms and values evolve in time, which would call for a more regular surveillance of the determinants of participation in organised and opportunistic screenings in Belgium and it's regions – in particular in vulnerable populations. Existing inequalities in participation in screening programmes should be examined, as well as the role of health professionals in decisions on screening. This calls for stronger development of behavioural sciences in cancer care in Belgium.

6. Diagnosis

6.1. DEFINITION & TERMS

Diagnosis is the first step in the treatment planning process, which may include tests such as biopsies, imaging studies, and blood tests. The specific tests used for cancer diagnosis can vary depending on the type of cancer and the patient's symptoms, but typically include:

- **Imaging tests**: Imaging tests, such as X-rays, CT scans, MRI scans, and PET scans, are used to create images of the inside of the body and help detect changes that may be indicative of cancer.

- **Laboratory tests**: Laboratory tests, such as blood tests and urine tests can be used to detect markers in the body that may indicate the presence of cancer.

- **Biopsy procedures:** Biopsy procedures, such as tissue biopsies and bone marrow biopsies, are used to remove a small sample of tissue from the body for examination under a microscope. Biopsy results can help confirm a cancer diagnosis and provide important information about the type and stage of the cancer.

The results of these tests are used to determine the type and stage of the cancer, as well as to identify any potential risk factors.

6.2. PROBLEM STATEMENT

6.2.1. Uptake of Innovations

The precision oncology approach is currently at the heart of innovations in cancer and is the result of significant advances in the “omics” technologies (such as genomics, transcriptomics, proteomics, and metabolomics). It’s advancement is based on rapid advances in biotechnology, including massive parallel sequencing or next generation sequencing (NGS), novel biomarkers and targeted drugs are being developed (3).

However, it remains a challenge to implement a systematic and comprehensive evaluation of these new approaches. This, in turn affects the level of confidence in the novel approaches that can be shared with the physician and use in the healthcare system for diagnosis and treatment decisions.

Structural obstacles that exist are related to: to costs, standardization (e.g. of data interpretation, treatment decision, reporting), quality standards, regulation (e.g. of clinical development, authorisation procedures, reimbursement, access), organisation (e.g. of lab consortium, establishment of Molecular Tumour Board, governance and planning of innovative clinical trials), and having adequate IT and analytical infrastructures (e.g. data collection platforms, decision support tools, knowledge platforms and the use of AI).

6.3. ACTORS & INSTITUTIONS INVOLVED

Organisation	Responsibilities
Commission de l’ Anatomie Pathologique (Commission of Pathological Anatomy)	The Royal Decree of 5 December 2011 concerning the approval of pathological anatomy laboratories lists the quality requirements that a pathological anatomy laboratory must meet in order to be approved by the Minister responsible for Public Health. This Accreditation Order delegates the responsibility of drafting the Practical Guidelines to the Commission of Pathological Anatomy, who is responsible for helping laboratories to establish their own quality manual (58).

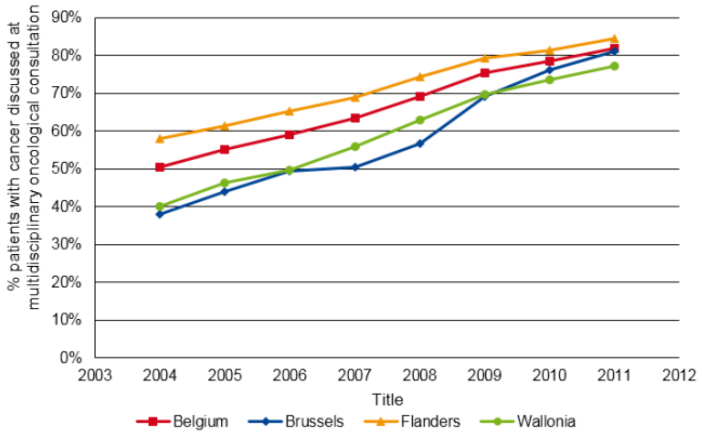
Royal Belgian Society of Laboratory Medicine (RBSLM)	The RBSLM was created in 2014 as a merging of the former Royal Belgian Society of Clinical Chemistry (created in 1958) and the Belgian Society of Clinical Biology. Amongst other aims, they represent the Belgian clinical chemistry and laboratory medicine within the International and European Associations of Laboratory Medicine.
College of Oncology	The College of Oncology was established by the Royal Decree on cancer care programmes of 2003 (59) and is, in a broad sense, responsible for monitoring the quality of cancer care in Belgium. Various working groups work on different thematic areas. Such as the working group 'oncology manual and clinical practice guidelines'. This group deals with the preparation and revision of clinical guidelines, per tumour type. In addition, the College also serves as an advisory body to the Minister of Social Affairs & Public Health and maintains links with many organisations active in oncology in Belgium. It has the particularity of being a multidisciplinary College (60).
Belgian Society for Paediatric Haemato-Oncology (BSPHO)	BEPHO unites the recognized Belgian centres in paediatric haemato-oncology and their professionals to share expertise and knowledge to improve treatment and patient care in childhood cancer.
The Personalised Medicine Commission (ComPerMed)	The commission was created in 2015 by Sciensano's Cancer Centre and the Centre acts as a governance body on the development of precision medicine. The commission is composed of members Belgian's cancer and scientific communities. Their objective is to develop technical guidelines to facilitate quality assurance for the molecular tests, define which molecular biomarkers (DNA) must, as a minimum, be analysed by NGS for each type of tumour (solid and haematological), and to create, for each type of tumour, good clinical practices in the form of a workflow showing the various molecular tests to be carried out in routine clinical practice.
The Belgian Accredication Organisation (BELAC)	Amongst other activities BELAC is responsible for the accreditation of different laboratories working in diagnostics and treatment (61).

6.4. LEGAL STATUTES & MANDATES

6.4.1. Multidisciplinary Oncology Consultation (MOC)

In Belgium, the multidisciplinary approach is mandatory and formally regulated since 2003 (62,63). The purpose of the MDT meetings is to develop a strategic plan already at diagnosis – based on the interpretation of the tests results and imaging conducted (62)(ref).

In Belgium, the “multidisciplinary oncology consult” (MOC) exists as a specific, legally regulated and mandatory type of MDTM. It includes a financial incentive for participating physicians, since 2003 managed by the National Institute for Health and Disability Insurance (NIHDI) (64).



Source: Belgian Cancer Registry data linked to data of the Intermutualistic Agency

Figure 9: Percentage of patients diagnosed with an invasive cancer and discussed at a MDT meeting by year of incidence

The MOC is legally described as a single consultation per individual patient, as for organisational convenience these are clustered in a collective meeting for several patients at stake, generally per tumour group.

A MOC is requested in writing by the general practitioner or by the attending specialist doctor (excluding the doctor specializing in pathological anatomy, clinical biology or radio-diagnosis).

The coordinating doctor can certify three MOC services: a "first MOC", an "additional MOC", in a hospital other than that of the first MOC and on referral, and finally a "Follow-up MOC" or "Follow-up MOC ".

The first MOC (art. 11, p. 4-7) is organized in the context of the diagnosis and treatment of a new oncological condition, with the exception of uncomplicated squamous cell or basal cell epidermal carcinoma. The multidisciplinary team of healthcare professionals, including oncologists, surgeons, radiation therapists, and other specialists, will meet to discuss the diagnosis best course of treatment for the patient. This team will take into account the patient's overall health, the type and stage of the cancer, and any other factors that may affect the patient's ability to tolerate treatment.

6.4.2. Testing Laboratories

BELAC has published recent updates on the accreditation certifications and scope of accreditation for testing laboratories, proficiency of testing providers, calibration laboratories, and reference material producers. The reason for the revision is the entry into force of the law of 22 April 2019 on the quality of healthcare practice (61).

Two elements that include cancer care are 1.1. BELAC 2-405 MED REV 2-2021, specific provisions for the accreditation of medical laboratories authorized by the minister of health, and 1.2. BELAC 2-405 NGS REV 3-2021, specific provisions for the accreditation of medical laboratory preforming Next Generation Sequencing for haematological and solid tumours (61).

High performance NGS warrants investments in infrastructure and technology, trained laboratory staff and in IT that can be mutualized in a network structure. The NGS network establishment is part of the general reform of the hospital care landscape in Belgium. All NGS testing activities in oncology are concentrated in 10 networks of laboratories and hospitals. NIHDI conventions have been established with each of them. This convention covers 115 hospitals and 30 laboratories; the list is available from the RIZIV/INAMI Health Insurance Agency website.

6.5. PROGRAMMES & ACTIVITIES

6.5.1. Diagnostic Approaches

The Belgian Cancer Registry records all diagnostic tests conducted in Belgium. In 2020, there were 68, 782 cases of cancer that were diagnosed in the country (10). Different forms of testing are used in Belgium including:

- **Imaging**: CT scans, MRI, nuclear scan, bone scan, PET scan, ultra sound, X-rays
- **Laboratory**: blood chemistry tests, complete blood counts, cytogenetic analysis, immunophenotyping, spectrum cytology, tumour marker tests, urinalysis, urine cytology, liquid biopsy,
- **Biopsy**: endoscopy, surgery, or through needle withdrawal

In general, it is difficult to obtain an exhaustive overview of all tests invoiced to the health insurance which are linked (or not) to a positive cancer diagnosis (65). The nomenclature for these tests could not be included in this inventory. Data may be available at institutional level but are not routinely reported.

Of note, during the COVID-19 pandemic, decline and incomplete recovery in cancer diagnoses was observed in Belgium as reported here which could pose a threat for the health system in the coming years (4).

6.5.2. Next Generation Sequencing

In 2015, following a HTA/feasibility analysis, major stakeholders in Belgium, including representatives of public bodies active in healthcare, patient associations and health insurance funds, endorsed NGS as a treatment option. Following this, the results of the analysis were translated into a Roadbook that describes the major actions to be taken to introduce NGS in clinical settings. This road book entitled "Introduction of Next-Generation Sequencing in routine diagnostics in oncology and haemato-oncology in Belgium" and was officially approved by the Ministry of Social Affairs and Health in 2016. The road book includes 1°) a description of the governance structure of the intervention, 2°) the major technical and logistic actions to be undertaken including an allocated budget, and 3°) a number of awareness raising initiatives for health professionals and patient/citizens (66).

Following this, a multidisciplinary team of experts was created in 2016, called 'Commission of Personalized Medicine' or 'ComPerMed' (composed of a scientific board and a management board). The mission of ComPerMed is to provide evidence-based advice to policymakers on the relevance of introducing innovative solutions in personalized medicine, with a major focus on 'omics' technologies. The ComPerMed works closely together with another novel advisory body, the so-called Platform CDx of the NIHD (The Commission for Reimbursement of Medicines and the Technical Medical Council).

The governance body has implemented guidelines for NGS use in oncology and haemato-oncology, as well as developing criteria for NGS use in oncology and haemato-oncology, as well as focus group on genetic testing with citizen participation, research on clinical trials and precision medicine, in addition to work on understanding informed consent in the context of NGS, amongst other projects. The management board of ComPerMed decides on a specific work-plan once per year (67).

Network	Roles & Responsibilities
NGS networks	Innovative Next Generation Sequencing (NGS) technique makes it possible to rapidly determine the sequences of a set of genes simultaneously. A pilot study (2019-2022) aims to introduce this technology into our healthcare system. Within this framework, NGS networks of hospitals and laboratories that have signed an agreement with the RIZIV can benefit from a higher reimbursement for molecular diagnostic tests in oncology and haemato-oncology carried out by NGS (68) .

The NGS Roadbook implementation was evaluated in 2021. The all-inclusive cost for a NGS panel test limited to DNA alterations of direct clinical utility varies by platform, and the maximum number of NGS panel tests per year for Belgium is 7000–10,000. Implementation of benchmarking trials in clinical settings/ laboratories, and launch of a national External Quality Assessment for NGS use in (haemato-) oncology Quality of Laboratory Dpt., Sciensano 7 EQA benchmarks were conducted in 16-20 participating laboratories from 2017 to 2021 (69). The reports include the evaluation criteria and outcomes from each of the laboratories.

6.5.3. AI and Imaging

Belgium is participating in several projects aiming to leverage AI to improve the use of diagnostic imagine tests. For example, the Cancer Images infrastructure (EUCAIM) project aims to establish and upgrade a technical infrastructure necessary to connect national cancer image data sources (including Belgium) to the federated European cancer image data infrastructure. This will facilitate the training and validation of AI algorithms and prediction models of outcomes using the cancer imaging data available in the infrastructure, and ensure their trustworthiness. The EUCAIM initiative originates from an unprecedented body of work and expertise of the "AI for Health Imaging" Network (AI4HI), which consists of institutions involved in large EU-funded projects on big data and AI in cancer imaging (CHAIMELEON, EUCANIMAGE, INCISIVE, ProCancer-I, PRIMAGE; coordinated by HULAFE, UB, MAG, FORTH and HULAFE, respectively).

The European Cancer Imaging Initiative will highlight how medical images can be accessed, used and pooled in Belgium while strengthening the ethical questions on, trust in, and security of personal data protection in full compliance with EU values and rules. EUCAIM is one of the flagships of Europe's Beating Cancer Plan (EBCP). It will take important steps towards the European Health Data Space (EHDS) and align with EBCP. The Cancer Image Europe Platform is unique because it will foster the transition from research into clinical practice.

6.5.4. Genomics Data Infrastructure for Diagnostics

Federated search and data access procedures for both research and diagnosis purposes will lead to groundbreaking insights and continued findings into the role genomics can play in healthcare. Belgium, is participating in the Genomics Data Infrastructure (GDI) project, contributes to this. The GDI project builds on the outputs of the Beyond 1 Million Genomes (B1MG) and the Genome of Europe projects and is realizing the ambition of the 1+ Million Genomes (1+MG) initiative. Through the GDI European project context, a federated national and local secure data environment for genomic data will be established in Belgium (i.e., the Belgian ELIXIR hub). Belgium will also start generating its own national genomics database (cf. Belgian Genome Biobank project). At the EU level, secure cross-border access to genomic and related health data for European citizens will be established.

6.6. GAPS & NEEDS

6.6.1. NGS testing

The cost of Next Generation Sequencing (NGS) in Belgium for cancer can vary depending on a number of factors, including the type of NGS test being performed, the type of cancer being tested, and the patient's insurance coverage. On average, NGS tests for cancer in Belgium can cost anywhere from a few hundred to several thousand euros. The cost will also depend on whether the test is covered by the patient's insurance or whether the patient is paying for it out-of-pocket. In some cases, the cost of NGS testing may be covered by the patient's insurance, but in other cases, patients may need to pay for it out-of-pocket. This creates inequalities in accessing NGS as part of a patient’s cancer treatment

In the NGS Roadbook evaluation, the ComPerMed experts indicated that in terms of data sharing, they would like for a core set of NGS metrics to be reported by clinically relevant subgroups (sex, age) (71 %), and reported internationally (64 %). Moreover, the NGS data registered on Healthdata are not augmented with clinical information and/or outcomes and this is a limitation. Issues with the registration of standardized and interpreted patient reports are a crucial point for improving the quality and use of NGS data for decision-making. A clinical trial, “*The Belgian Molecular Profiling Program of Metastatic Cancer for Clinical Decision and Treatment Assignment*”, is underway to evaluate what is needed to capture follow up of NGS testing.

6.6.2. Using AI to Enhance Diagnostics

Artificial Intelligence (AI) in health is already a reality (70). Healthcare providers have embedded AI technology into their workflows and the decision-making processes, including in diagnostics, which has already brought improvements for patients, healthcare professionals themselves, healthcare stakeholders, and society. However, the full benefits of AI in health will only be realized if key challenges are addressed, in particular those related to:

- Data access
- Regulatory and technical matters (e.g., definition of common requirements and establishment of best practices)
- Legal and ethical matters
- Ethical aspects (e.g.,. guidelines for trustworthy AI)
- Interpretation *“black-box”* challenges. For example, how to define of AI-specific reporting guidelines for evaluation of quality and comparison of diagnostic accuracy between studies.

7. Care Organisation

7.1. DEFINITIONS & TERMINOLOGY

Quality of care, and quality of the health services offered within a health system, consist in elements such as : **effectiveness, efficiency, safety, and patient centeredness**, **integrated care***,* as well as **continuity of care** beyond one episode of the disease (71).

These elements can be defined as:

- **Effectiveness**: The degree to which the desired outcomes are achieved through evidence-based healthcare for all people who may receive a benefit*. Indicators* are generally results based reported by the patient (**Patient Reported Outcomes – PROMS**), reported rates of undesirable effects, and any sentinel reporting on errors in medical care. In Belgium, there are indicators of effectiveness of the global health system, as well as the different levels, including primary care, secondary care, and tertiary.

- **Efficiency**: The degree to which appropriate care, that is adapted to patient needs and scientific knowledge.

- **Safety**: The provision of care that does not harm the patient. We do not detail this element of quality of care in detail in this report, as are no specific indices currently collected. In Belgium, there are no cancer-specific indicators for safety, but general indicators such as complications following surgery, as well as hospital acquired infections, are collected.

- **Integrated Care:** Integrated care seeks to better coordinate health and social care around the individual's needs with a commitment to improve the quality of care and overcome fragmented care through ongoing co-productive partnership.

- **Continuity of Care**: The provision of care to a patient in which care is organised in a way that there is no interruption, whether in time or between actors, so that the patient is care for throughout the entirety of their illness. *Indicators* are related to the continuity of information, relationship with the general practitioner, link between the hospital and 1st line care, and coordination of care between different care providers.

Quality of care does not only have as a goal to improve health, but also to empower patients in mastering their own situation. Quality will also have an impact on the perceived acceptability of the care within a health system, and thus having an impact on the accessibility. Given the multifaceted nature of quality of care, and its impact on other elements of the health system, it is essential to have adequate measures to monitor and evaluate quality of care; from the infrastructures available, to the patient experience. In this section, we will focus primarily on the aspects of continuity of care and patient-centeredness in quality of care.

7.2. PROBLEM STATEMENT

7.2.1. Fragmentation vs. Comprehensive Cancer Care & Networks of Expertise

Efforts to establish comprehensive cancer centres (CCCs) are an important step to improving organisation and integration of cancer care, and as consequence, quality of care. CCCs not only provide innovative treatments and opportunities to link patients with clinical trials, they also promote multidisciplinary and continuous care for patients, while also place a strong focus on professionals and patient education (72). In some countries, such as Italy, oncological networks are formally organised as to better coordinate the organisation of care. In Belgium they remain informally organised and not framed by mandates or law (73).

The breast cancer clinics are the only example of such a specialised cancer care programme for adult cancer patients in Belgium. A recent study by KCE showed that patients being treated at non-accredited breast cancer clinics had 30-50% more risk of dying, and that mortality 5 years following treatment was 12% higher for these patients (74). Another study from KCE concerning head and neck tumours, demonstrated great diversity in the treatment depending on the hospital chosen by the patient. Among the 99 hospitals where patients were interviewed for the study, half of the hospitals sometimes treat less than four patients per year for this head and neck tumours. Nearly a quarter of these hospitals treat less than two patients a year (74). In order to ensure good quality treatment for cancer patients, it is advisable to treat them in reference centres. Similarly, it has also been observed that in Belgium 14 types of rare cancers are considered by 14 different working groups. Through this proxy indicator it could be stated that the need for centres of reference for these cancers has not yet been met (75).

7.3. PUBLIC INSTITUTIONS & ACTORS INVOLVED

Many of the other actors working in care organisation are similar to those working in diagnosis and treatment, although their roles may be different. For example, INAMI-RIZIV are heavily involved in the decision on reimbursements of care beyond just treatment and diagnostics. KCE is also involved, studying the effectiveness or access to care. As such, for efficiency, we have copied the same actors here, and made minor adjustments where necessary.

Organisation	Responsibilities
National Institute for Health and Disability Insurance (RIZIV/INAMI)	Is responsible for the reimbursement of medical costs related to cancer in Belgium. The RIZIV/INAMI covers the costs of supportive care for patients with cancer, for example physiotherapy, nutritionists, coaches on sexual health, psychologist, and rehabilitative care, such as plastic surgeons for reconstructive surgery following treatment.
College of Oncology	The College was stablished by the Royal Decree. on cancer care programmes of 2003and is, in a broad sense, responsible for monitoring the quality of cancer care in Belgium (59). In addition, the College also serves as an advisory body to the Minister of Public Health and maintains links with many organisations active in oncology in Belgium.
KCE	The semi-governmental institution, KCE (Belgian Care Knowledge Centre) is conducting research on care organisation, particularly on the effectiveness, efficiency, access and quality of care (76).
Ministry of Social Affairs and Public Health (SPF)	During the implementation of the last cancer plan, (2008-10) SPF was responsible for several actions including the oncological care programmes and the financing of multidisciplinary care teams. Following the hospital reform SPF, has put in place superregional care networks, by which they help coordinate care between the regional and national levels, including for cancer patients.
Vereniging Verpleegkundigen Radiotherapie en Oncologie (VVRO)	In Flanders, VVRO supports nurses working in cancer care (including treatment). The do so by promoting the exchange of knowledge nationally and internationally, offering training and refresher courses, facilitating the collaboration with institutions/organizations that train nurses, and acting as an interlocutor in important national developments regarding the oncology discipline.
Belgian Society for Medical Oncology (BSMO)	The society was founded in 1977 with the aim of obtaining recognition of medical oncology as a medical speciality. Other objectives were to ensure established training and improved care for cancer patients. Today, this professional association of Belgian medical oncologists is mainly concerned with (1) organising educational activities to promote the professional skills of members, (2) facilitating communication between members and with other disciplines and researchers active in cancer, (3) preparing a framework for the implementation of clinical and translational studies,

	and (4) advocating for high quality care without any form of discrimination.
Société des Infirmiers en Oncologie (SIO)[2]	It represents nurses from French-speaking communities with regard to their legal status and training. The SIO is also concerned with increasing knowledge about psychosocial support for patients, their relatives and health professionals. It also promotes multidisciplinary collaboration and the dissemination of the latest scientific and ethical knowledge in oncology
Centre for Psycho-Oncology[3] **(CPO) and the Cédric Hèle Instituut**[4] **(CHI)**	They both organise communication training in the field of oncology. Several colleges and universities, as well as AXXON organise specific training for physiotherapists regarding the care of cancer patients (77).

7.4. LEGAL STATUTES AND MANDATES

Since, the Royal Decree of 25 April 2003: "*The College of physicians holds a specific role in assessing the quality of care. The decree states that: 'an oncological care programme, in order to maintain accreditation, must collaborate in the internal and external evaluation of medical activity'* (...)". Internal evaluations are carried out in very different ways in each programme, which have great freedom in deciding whether to share the results of these evaluations.

There are several Royal Decrees that set out the standards of cancer care, treatment programmes, and their accreditation.

Under Belgian law hospital services can be accredited as (59):

- **'Care programme** for basic oncology care' that focuses mainly on diagnosis and less complex treatment. In January 2017, 83 out of 204 acute hospital sites had a care programme for basic oncology care (**42 in Flanders, 10 in Brussels, and 31 in Wallonia**; source: FOD Volksgezondheid - SPF Santé Publique) (78)

- **'Oncology care programme'** that has to offer more advanced diagnostic options as well as various therapeutic possibilities. The number of care programmes that can be developed is not limited. In January 2017, 76 out of 204 acute hospital sites had an oncology care programme (**49 in Flanders, 9 in Brussels, and 18 in Wallonia**; source: FOD Volksgezondheid - SPF Santé Publique). It should also be noted that no hospital site had both an oncology care programme and a care programme for basic oncology care.

- In **addition, the law allows the development of 'specialised care programmes'** for patients with cancers that need a complex multidisciplinary approach and/or extremely specialised expertise and/or that are very rare. It also states that specific care programmes should be developed for children younger than 16 years old with an oncological illness that requires specific modalities from a diagnostic and/or therapeutic perspective. The breast cancer clinics are the only example of such a specialised care programme for adult cancer patients. One of the licensing norms that breast cancer clinics should meet is a norm on the minimal annual volume. There is a clear guidance at the EU level that there should be at least 150 women with breast cancer treated per centre and at least 50 operations per surgeon. The Belgian legislator adopted this threshold but allowed a transition period with a lower threshold. At present, it is not known what the annual volume of the breast cancer clinics 'in transition' is, and more importantly, it is not known how many breast cancer patients are still being treated outside the licensed centres.

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[2] https://sioncologie.be/

[3] https://www.psycho-oncologie.be/formation/formation-initiale-a-la-communication/

[4] www.chicom.be/evenementen/chi-opleiding-afstand-en-nabijheid-communicatie-oncologie-5-daagse

Since 2002, the European Organization of Cancer Institutes (OECI) offers an accreditation program, on a voluntary basis. Centres wishing to do so can follow this program during which, if they meet the quality criteria, they will be accredited as an integrated multidisciplinary centre for cancer care and research. Of the 39 centres currently accredited, three are located in Belgium Institut Jules Bordet, UZ Brussel and AZ Groeninge) (79).

A further Royal Decree in 2014 set the standards to which the specialised care programme in care programme and the satellite care programme in paediatric haemato-oncology care programme must meet to be accredited (80). With regards to paediatric haemato-oncology, although there is no formal (legal) decision, oncological treatments for paediatric patients (0-19 years), representing about 340 children (0-14 years) and 180 adolescents (15-19 years) per year, is concentrated in 8 centres (81).

Breast cancer clinics are the only example of such a specialised care programme for adult cancer patients. The amendment of the Royal Decree of 26/04/2007 (already amended on 07/06/2012) concerning the standards that the specialised oncological care programme for breast cancer must meet to be accredited

7.5. PROGRAMMES & ACTIVITIES

In Belgium, cancer care is organized through a combination of public and private healthcare systems. The public healthcare system provides medical services to all citizens and is funded through taxes and social security contributions. This includes access to specialized cancer centres and oncologists. The private healthcare system is composed of private clinics and hospitals that offer medical services for a fee. The care programs are organized in a multidisciplinary and transversal way (82). This means that there is collaboration between multiple healthcare providers and multiple disciplines, across hospital boundaries and between different healthcare settings. Current care programs in Belgium are specialized. They focus on groups of patients who present with a specific pathology (e.g. heart problems) or on an organizational or functional aspect of an institution (e.g. emergency management).

7.5.1. Care Programs & Networks

In Belgium in 2020, there were **62 basic oncology care programs (PSBO) and 84 oncology care programs**. Centralisation of care by types of procedures or tumours has shown to contribute to quality of oncological care programmes. In Belgium, while there are professional organisations and networks of hospitals, they are not officially organised (75). In addition, there are several professional networks related to oncological care. They are formally organized through Colleges, Federations or Associations, or sometimes several as for radiotherapy, for which there is both. These professional networks support their members in providing the best care for their patients, including after treatment to ensure they are provided with health information and support

European projects in which Belgium is participating, such as CRANE (JA on EU Networks of Comprehensive Cancer Centres) (83), the 'EU Cancer Treatment Capacity and Capability Mapping' and JANE (Joint Action on European Networks of Expertise (84), will support EU States setting up CCC and networks of expertise to improve comprehensive care and continuity of care for cancer patients. This will help to map and share the different capacities and expertise available in the European Union, and support the building of comprehensive care and knowledge sharing on treatment across the EU. These initiatives will be important considering the work on comprehensive care in Belgium; however, concerted efforts in Belgium will need to be made to improve comprehensive care for the specific context of Belgium.

7.5.2. Care Coverage

In Belgium, medical insurance is obligatory, and only 1% of the population is not covered. Coverage is use as an indicator to measure the accessibility to care. These coverage rates do not include those individuals who are not affiliated to a medical insurance provider (*mutuelles* or *sickness funds*). In 2014, INAMI published a White Book on access to care for vulnerable groups, and identified those that needed special attention. Given the lack of legal framework on their access to care. Included were migrants without papers, who can benefit from urgent medical aid (10-20% benefited from this in 2013), but cannot subscribe to an insurance provider. The report also highlighted that while organisations such as the Red Cross and Fedasil provide covered first line medical services at their reception centres, there was a gap in continuity of care and information, much of the latter being lost through lack of a centralised information system.

7.5.3. Healthcare Workforce

An international survey sought to identify the number of oncology workers (85). Based on 2015 data, it was reported that for Belgium, the rate of new patients per oncologist was 307. This figure is higher than the European average (based on 26 of the 27 Member States) of 238 (21).

According to the 2019 report of the Cellule Planification de l'Offre des Professions des Soins de Santé (Planning Unit for the Supply of Health Care Professions), the number of medical specialists entitled to practice medical oncology as of December 31, 2019 was 304 (171 men and 133 women) (85). In Belgium in 2020, 3,147 nurses specialized in oncology and 44 physicians specialized in haematology and paediatric oncology (32 men and 12 women).

7.5.4. Continuity of Care

For cancer, the main tool for continuity of care in cancer is the multidisciplinary oncological consultation (MOC). The coordinating physician can certify three MOC services: a first MOC, an additional MOC in a hospital other than that of the first MOC and on referral, and finally a follow-up MOC. After the first MOC, a "long-term consultation" is planned for the GP or treating specialist to discuss the result with the patient (86). There has been a systematic increase for MOCs since their introduction. According to INAMI, there are 83,715 MOC registered on average per year.

Continuity care in Belgium is measured by evaluating the proportion of all cancer patients benefiting from a multidisciplinary oncological consultation. In 2015, this was about 86%, which is higher that preceding years and regional disparities were also reduced. Continuity is also measured through delay in care. In 2013, 38% of patients in Belgium had to wait three or more weeks to see a specialist. This leads to delays in diagnosis and treatment; a lack of vertical continuity of care. While this delay in follow-up was reduced from previous years, it remains an important number, and indication of challenges faced in continuity of care.

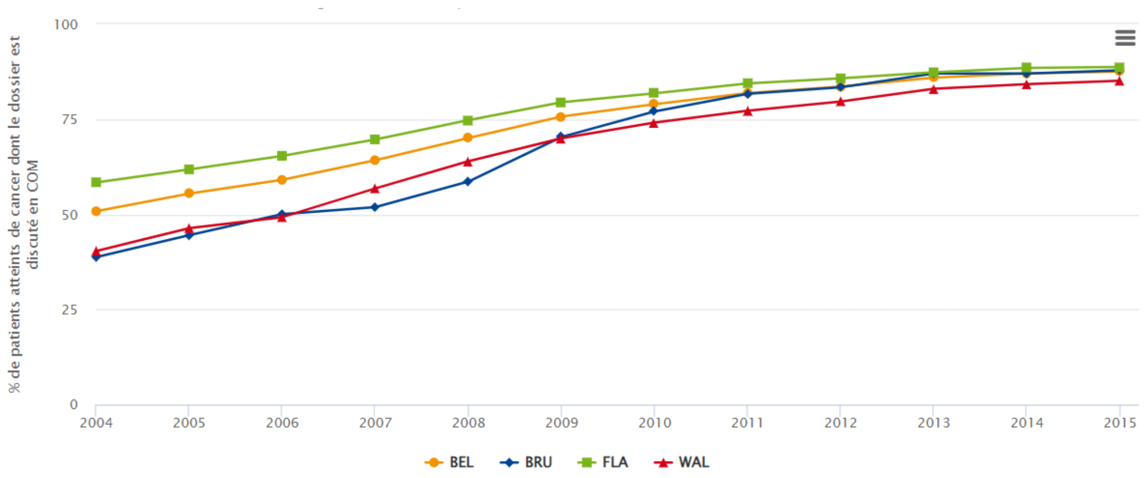

Figure 10: Proportion of cancer patients benefiting from a multidisciplinary oncological consultation. Data source, Belgian Cancer Registry and IMA-AIM.

7.5.5. Integrated Care

Integrated care plays an important role in the provision of quality services provided to cancer patients. Integrated care seeks to better coordinate health and social care around the individual's needs with a commitment to improve the quality of care and overcome fragmented care through ongoing co-productive partnership (13,87).

Many hospitals in Belgium have specialized departments dedicated to the care of cancer patients, including radiation oncology departments, surgical oncology departments, and medical oncology departments, among others. These departments provide a range of services, from diagnostic testing and treatments, palliative care, as well as rehabilitation services (78).

However, in 2011 KCE published a report highlighting the fragmented nature of Belgium's healthcare system, particularly with chronic disease. Following this, a plan was approved by SPF Public Health to improve the integration of care. The goal of this plan is to improve the experience of patients and informal carers, improve the efficient use of resources to ensure the sustainability of healthcare services, reduce inequalities in access and quality of care, as well as improved the work satisfaction of healthcare providers.

Related to this plan, 11 pilots were launched in 2018, 5 in Flanders, five in Wallonia, and 1 in Brussels, covering 2.52 million residents. The pilot ended in June 2020. On July 11, 2022, the INAMI Insurance Committee validated a new stage for integrated care in Belgium. In this context, a transition period was granted for a period of 2 years to the 12 integrated care projects (PSI) (locations can be found here) as well as to the 19 alternative care projects for frail elderly people, and 33 for mental health patients (88). This transition period makes it possible to specify the framework for the structural implementation of integrated care in Belgium and serves as a basis for the future inter-federal integrated care plan.

7.5.6. Effectiveness

The **measurement of the effectiveness of care is limited in Belgium**, mainly because of the lack of being able to evaluate the results reported by the patients (PROM), even if certain initiatives are under development (13). In Belgium, PROMs are generally not collected centrally (except at local level). A recent report by the KCE identified obstacles and factors favouring the development of PROM initiatives in Belgium. These obstacles include difficulties in centralising the collection of PROMs, issues in the coherence between questionnaires if the data collection is not centralised, difficulties patients face in completing questionnaire, and most importantly, gaps in the routine application of PROMs in clinical practice, which could be exacerbated by the lack of support of use at PROMs at the managerial level (89).

30-day and 90-day mortality rates after surgery for colorectal cancer can also be used as indicators of effectiveness of quality of care. For the period 2011-2015, 30556 patients were diagnosed with colon cancer, 80% of whom underwent surgery. The average postoperative mortality for this period is down compared to previous periods, with 3.9% at 30 days and 6.7% at 90 days. Flanders has overall better results (3.3% at 30 days and 5.7% at 90 days) than Wallonia (4.9% at 30

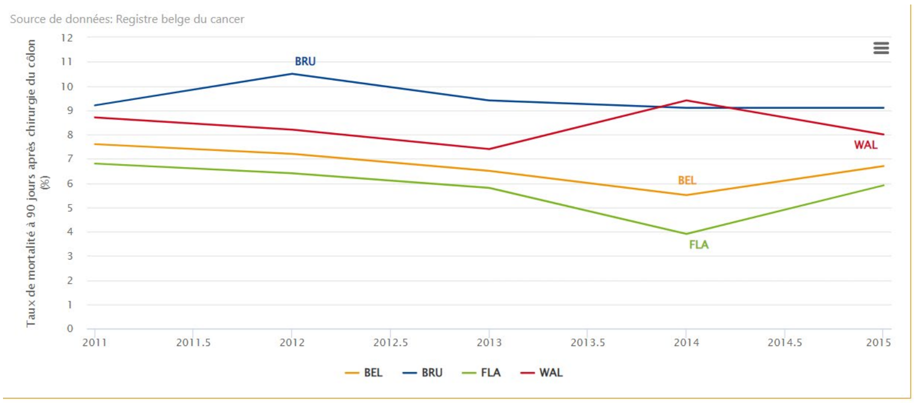

Figure 11: Mortality rate 90 days following surgery for the treatment of colon cancer. Source, Belgian Cancer Registry.

days and 8.3% at 90 days) and Brussels (5.4 % at 30 days and 9.5% at 90 days).

For the period 2011-2015, 12,138 patients were diagnosed with rectal cancer, 70% of whom underwent surgery. The average postoperative mortality for this period is relatively stable, with respectively 2.1% and 4.2% at 30 and 90 days. Flanders has overall better results (1.7% at 30 days and 3.6% at 90 days) than Wallonia (3.0% at 30 days and 5.3% at 90 days) and Brussels (3.2 % at 30 days and 4.8% at 90 days)

Effectiveness for cancer can also be measured through survivorship. For cancer care, the quality of acute care is measured through survival of colorectal and breast cancer after five years (in percentage of all cancer patients), as well as mortality after 30 and 90 days of colorectal or rectal cancer surgery. Avoidable mortality due to the health system and public health policies is also measured, but this measure includes avoidable mortality from other diseases, in addition to cancer. **Belgium ranks as one of the best in Europe for 5 year survivorship for colon cancer, and for breast cancer survivorship is comparable to the average of EU-13, as of 2014** (14).

7.5.6.1. Efficiency

For efficiency, we can use inappropriateness of breast cancer screening as a proxy. First, we observe that rate of participation in organized screening programs is low (as discussed in the section *Early Detection & Screening*). Second, there is a significant proportion of who are women being screened who do not belong to the targeted age group. A third of women aged 41 to 49 have performed screening mammogram, whereas the target population is women aged 50 to 69. In Flanders, the screening outside the target group makes up 26% of women screened, while in Brussels in makes up 47% of women screened, and in Brussels, this is as high as 49%, in 2019. This points to inefficiencies in the organisation of care (90).

We can also measure the challenges with efficiency through the variation of cancer care. In Belgium there are significant variations in the care provided based on gender, social status, as well as geography, which point to inefficient levels of care. For example, the rate of participation in cancer screening (breast cancer, cancer of the cervix) is around 30% lower among individuals not benefiting from reimbursement (91).

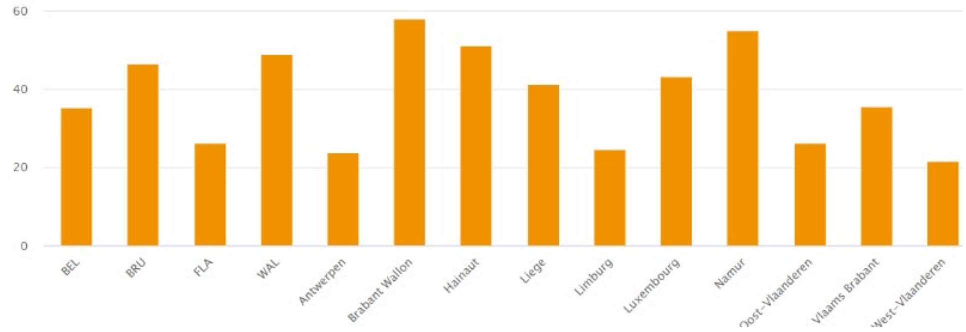

Figure 12: Proportion of women between 41-49 completing a mammogram by province (percentage)

The variability in the delay between diagnosis and treatment can also be used to evaluate efficiency. A 2019 BCR study assessed the quality of diagnosis and stage reported in patients diagnosed between 2009 and 2014 with head and neck squamous cell carcinoma (HNSCC) and the variability in Belgian hospitals. One of the indicators used was the time interval between the confirmation of the diagnosis and the start of curative treatment. The average time interval was 32 days. For surgery, the delay was shorter (24 days) and for radiotherapy, the delay was 36 days. It also appeared that when patients were treated in the hospital where the diagnosis was received, the interval was even shorter (26 days), compared to 37 days when treated in another hospital. In general, there is a large variability between the different centres in Belgium (from 0 to 50 days). Although in comparison with other European countries, these delays seem acceptable, it is desirable to work on the reasons for these delays in order to limit them.

7.5.6.2. CAYA

Young cancer patients are frequently the exception rather than the rule in an adult oncology unit due to their rarity. They have little in common with other cancer patients who are much older and in a different stage of life, and they have limited possibility of connecting with people from their generation who are also battling the disease, with whom they could find some common ground. Belgium is investing in care teams for young cancer patients, the “AYA” (Adolescents and Young Adults). In these AYA care teams, an AYA coach, a psychologist and a social worker are available and provide psychosocial support to the AYAs (92).

Kom-op Tegen Kanker launched another movement for CAYA care. This movement brings together teenagers and young adults with cancer (target group), care providers involved and Kom op Tegen Kanker. Its main objective is to define how care may be better suited to the age of these patients – inside and outside hospitals – from way to improve their quality of life. The management of oncology of young people with cancer is not optimal. A text aimed at defining what that care should be composed of was developed in 2018 in consultation with a working group. A journey of care has been drawn up and a reflection group within of which adolescents and young adults with cancer can also express their ideas and their opinions was created. This care pathway is currently being tested in a pilot project at UZ Gent and in three other hospitals in Ghent. The aim is to determine if this course of care can apply to everyone and to test innovative care for adolescents and young people adults with cancer, for the benefit of patients and nursing staff, in order to be able to administer properly the necessary care. A learning network has also been put in place in Flanders in 2020 under the impetus of Kom op Tegen Kanker. This network brings together (currently) thirteen hospitals that are committed to developing an age-specific management of these patients.

Interviewing 21 specialists working within oncology from the hospitals of UZ Gent, AZ Jan Palfijn, AZ St. Lucas and AZ Maria Middelares, key criteria were identified for the optimisation of AYA care. This included the development of a fertility clinic referral pathway for all AYA patients and the awareness of potential clinical trial enrolment. Furthermore, these specialists required the AYA-MOC to be time sensitive and to optimise current multidisciplinary team communications tools, rather than introduce entirely new ones. As a result of this consultation, an AYA template was designed that can be inserted into the pre-existing MOC template, which included fertility clinic and clinical trial referral sections (93).

7.6. GAPS & NEEDS

7.6.1. Continuity of Care

The recent study by KCE showed that patients being treated at non-accredited breast cancer clinics had 30-50% more risk of dying, and that mortality 5 years following treatment was 12% higher for these patients (74). The study clearly highlights the gaps in comprehensive care in Belgium, and the poorer outcomes faced by patients. We can also observe that in Belgium 14 types of rare cancers are considered by 14 different working groups. Through this proxy indicator it could be stated that the need for centres of reference for these cancers has not yet been met (75).

Efforts to establish comprehensive cancer centres (CCCs) are an important step to improving this. However, this alone may not be sufficient to improve continuity of care. An important aspect will be supporting patients in their care journey, which will include understanding what support (information and technical) they will need, and how they can best access this information. The development of a patient portal for information, as well as development of tools to support patients and practitioners in their interactions and relationship around care will be essential.

7.6.2. Monitoring care performance

In general, the difficulties encountered in measuring certain indicators highlight the lack of available data specifically related to oncology care (94). For example, in terms of supportive care and patient involvement in care. Indeed, very little specific nomenclature exists to identify the care received by oncology patients throughout the care pathway.

A more in–depth examination of key players, activities, networks (informal and formal), and the interest of these groups is warranted. A first step could be to meet with the regional level, to understand what data is available and what it may indicate regarding the quality and impact of their activities on cancer care and control in Belgium. A second step would be to discuss possible sharing or harmonization of data collection in order to develop a more comprehensive picture of the extent of cancer prevention activities in Belgium, Generating indicators that provide visibility on the quality of care for the most vulnerable is also necessary. To this end, we would suggest running a scoping review on existing evaluation frameworks of cancer care performance to determine what might be most relevant in the Belgian context.

7.6.3. PROMs to Measure Effectiveness

Disease-specific patient organisations support patients and their families by better understanding their disease and by helping them navigate and use the healthcare system. In this way, patients are more engaged in their care process, receive better support and have both better health outcomes and higher satisfaction of their treatment. The contribution of patient support groups, or peer-to-peer education, and other activities organised by Non-for-Profits related to care are not considered in the inventory of cancer care activities, nor is the quality of these activities, nor their perceptions by patients included. This inclusion of such activities in the overall monitoring of quality of cancer care in Belgian could be envision by leveraging more participative approaches to evaluation (75).

The concept of participation and empowerment at the individual level is also highly important for the development of the relation between patient and care provider (71). Empowerment can facilitate the provider being responsible to rather than for the patient, implying a transition of power relations between patient and provider. When this relationship is successful, it can facilitate the patient in making decision adapted to and in support of his or her own health, based on the best information available, which can in turn promote responsive and adapted care, as well as overall quality of care.

Measures of effectiveness from the patient perspectives are limited. While there are several standalone projects seeking to increase the use of PROMS, including in cancer care monitoring, this is still not a systematic practice in Belgium (13). Moving forward this gap should be addressed, and actors should be facilitated in including these measures in their work.

Methods for measuring this aspect of quality of care are still emerging and are the subject of extensive research. It is about acknowledging the patient’s needs wishes and preferences. It concerns the quality of communication with the healthcare professional (which implies a number of skills on the professional’s part, such as listening, the ability to provide explanations, courtesy), and about involving patients and their close relatives in their care (giving them the option of managing their own care and making informed decisions about their treatment options). Measuring the aforementioned elements and determining whether care is focused on the patient represents a challenge.

8. Treatment

The following section details cancer treatment in Belgium. While some elements of cancer treatment overlap with cancer care organisation, we have tried to delineate them by focusing in this section on treatment options (radiotherapy, chemotherapy and surgery), including innovative treatments, reimbursement of these treatments, the guidelines that frame the standards and quality of clinical treatment, as well as the role of the MOC in cancer treatment.

8.1. DEFINITIONS & TERMS

In general, the process of cancer diagnosis in Belgium involves close collaboration between healthcare providers, including oncologists, radiologists, pathologists, and other specialists, who work together to ensure that patients receive a thorough and accurate diagnosis.

Then**, based on the results of the diagnostic evaluation and the recommendations of the multidisciplinary team,** the patient and their healthcare team will work together to **develop a personalized treatment plan**. This may include **surgery, radiation therapy, chemotherapy**, or a **combination of these treatments**. The treatment plan will also take into account the patient's goals, preferences, and any potential side effects of the treatments.

Before starting treatment, patients will receive education and support to help them understand their diagnosis and the treatment options available to them. They will also have the opportunity to ask questions and discuss any concerns they may have with their healthcare team. Patients are encouraged to discuss their symptoms and concerns with their healthcare provider, and to work with them to develop a personalized plan for diagnosis and treatment.

8.1.1. A Novel Paradigm: Targeted Therapies & Precision Medicine

Personalized medicine, often used interchangeably with Precision Medicine, is becoming increasingly available in Belgium as an approach to treat cancer. Personalized medicine is a medical approach that tailors treatment to the individual characteristics of each patient, including their genetic makeup, lifestyle, and medical history. This approach is designed to improve treatment outcomes and reduce the risk of side effects. It is ‘a medical model using the characteristics of individuals’ phenotypes and genotypes (e.g. molecular profiling, medical imaging, and lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time’. In Belgium, patients may undergo genetic testing to identify specific mutations in their cancer cells, which can help guide their treatment.

Companion diagnostics are tests that are used in conjunction with specific treatments to determine whether a patient is likely to benefit from that treatment. In Belgium, companion diagnostics are used to match patients with the treatments that are most likely to be effective for them.

Immunotherapy is a **type of personalized medicine that harnesses the power of a patient's immune system to fight cancer**. In Belgium, patients with certain types of cancer may be eligible for immunotherapy, which is designed to target their specific type of cancer and improve their treatment outcomes.

8.2. PROBLEM STATEMENT

8.2.1. Access to Innovative Treatment

Recent years have brought increasing opportunity for patients’ treatment plans through the development of precision medicine initiatives. However, there is a need to improve access for cancer patients to innovative treatment approaches, such as autologous cell therapy and radiotherapy. There is also a need to continue to invest in developing innovative treatment strategies through clinical trials.

Another challenge is the lack of adequate funding and structural organization of precision oncology initiatives. This hampers the further development of and access to innovative cancer diagnostics and treatments in the Belgian health care system. Relative to the possibility to leverage the technology currently available, there is a gap in a standardized and structured reporting platform that would enable linking real world data, which would allow researchers to examine the link between diagnostic data, biomarkers, and therapy outcomes with artificial intelligence algorithms (ref), thereby improving the accuracy and reliability of the technology.

8.3. ACTORS & PUBLIC INSTITUTIONS INVOLVED

In Belgium, there are several actors at the national level involved in diagnostics and treatment.

Organisation	Responsibilities
Ministry of Social Affairs and Public Health (SPF)	SPF is responsible for setting out the reimbursement procedures, as decreed under the law of July 14 1994. They will work with the Ministry of Economic Affairs, who will set the maximum pricing.
National Institute for Health and Disability Insurance (RIZIV/INAMI)	RIZIV/INAMI is responsible for the reimbursement of medical costs for cancer treatment in Belgium. RIZIV/INAMI covers the costs of cancer treatments such as chemotherapy, radiotherapy, surgery, and other supportive care for patients with cancer. They are also the formally responsible party for HTA, assessments that are usually conducted by KCE. Within the organisation, there are the Bodies of Compensation Service (Les organes du Service des indemnités/ De organen van de Dienst voor uitkeringen). The Director General is responsible for the day-to-day management of the Compensation Service. Various bodies are involved in the management of the compensation process. Some of these bodies have decision-making powers; others have only an advisory function. Three management committees manage the benefits component of the health care and benefits insurance. There is a Management Committee for employed and unemployed workers, a Management Committee for self-employed workers, and a Management Committee for miners. The Benefits Service also has two advisory bodies, the Technical-Medical Council and the Technical Sickness Board (95). The Technical Health Insurance Board (Technische ziekenfondsraad) examines the conditions under which benefits may be paid and the issues surrounding them, including for cancer patients. Beyond, making recommendations and proposals to the Management Committees and the Disability Medical Board, the Technical-Medical Council (Technisch Geneeskundige Raad), examines problems encountered by doctors (both advisory doctors of the health insurance funds and our doctors-inspectors) in evaluating incapacity for work draws up guidelines with a view to a qualitative medical evaluation of incapacity for work (96). The Advisory Committee on Temporary Allowance for the Use of a Drug (CATT) is also an important body within RIZIV/INAMI. They formulate cohort proposals under the Unmet Medical Need project, and provides advice on the unmet medical needs and on the individual cases tied to the cohort decisions(97).

RIZIV/INAMI Commission of Medicines Reimbursement (Commission de Remboursement des Médicaments/ Commissie Tegemoetkoming Geneesmiddelen)	Working under the auspices of RIZIV/INAMI, the Commission for the Reimbursement of Medicines (CRM) acts as an advisory body to the Minister of Social Affairs with regard to the reimbursement of pharmaceutical specialties. It proposes changes to the list of reimbursable pharmaceutical specialties. For example: ➢ Admission of new proprietary medicines ➢ Modification of the conditions of reimbursement of existing proprietary medicinal products ➢ Deletion from the list of existing pharmaceutical specialties. ➢ At the request of the Minister of Social Affairs, it gives advice on policy aspects relating to the reimbursement of pharmaceutical specialties. It proposes interpretative rules to the Insurance Committee concerning the reimbursement of pharmaceutical specialties.
Federal Agency for Medicines and Health Products (FAMHP),	The FAMHP responsible for evaluating and authorizing the use of drugs and medical devices in the country (98).The FAMHP evaluates cancer medications based on their safety, efficacy, and quality, and determines whether they can be used in Belgium. This process involves a thorough review of clinical trial data, as well as other relevant information, to ensure that the medications meet the standards for safety and efficacy set by the agency. Once a cancer medication has been approved by the FAMHP, it can be prescribed by healthcare providers and dispensed by pharmacies in Belgium. The FAMHP also monitors the safety of cancer medications once they are on the market and may take action to restrict or withdraw their use if new safety concerns are identified
Sickness Funds (Mutualités/Mutualiteiten)	The main role of sickness funds in Belgium is to provide partial reimbursement of medical and health costs and to provide a financial supplement in the event of incapacity for work. This is called compulsory insurance. It is regulated by law and is identical for all mutual insurance companies (99).
KCE	The semi-governmental institution, KCE (Belgian Care Knowledge Centre) is responsible for the Health Care Technology Assessments (HTA), and provide healthcare recommendations for reimbursements to INAMI/RIZIV based on these assessments (100).
Belgian Society of Medical Oncology (BESMO)	The Belgian Society of Medical Oncology (BSMO) is the professional association of the Belgian medical oncologists, an officially recognized specialty. Main aims include: the Organization of educational activities that strengthen the professional skills of the members; Facilitate communication between the members and with other cancer specialties and researchers; Establish a framework to conduct joint clinical and translational studies; Advocate access to high quality cancer care without social or other discrimination.

Several professional organisations and networks also exist that contribute to the capacity building, training and exchanges between professionals working across cancer types and different treatment elements. The aim of these organisations is to ensure quality care for cancer patients by bringing health professionals together and supporting them. They exchange knowledge on a national and international level, offer training, and serve as a contact point for discussions on new developments in oncology. These organisations are formally organised through Colleges, Federations or Associations, or sometimes several, as for radiotherapy, for which there is the College of Radiotherapy, but also the ABRO-BVRO Association, the Belgian Haematology Society (BHS) or even the Belgian Society for Paediatric Haemato-Oncology (BSPHO). For an exhaustive list, please see the stakeholder mapping in the annexes.

8.3.1.1. Informal Networks

Several informal network contribute to the organisation of cancer treatment in Belgium.

Network	Description
Iridium network	Iridium is a highly specialised radiotherapy network based on a multidisciplinary approach. This network makes possible a structured collaboration between different doctors from different hospitals in the Greater Antwerp and Waasland region. With its 8 partner hospitals, the Iridium network is the largest radiotherapy network in Belgium (101).
Iris Network - Cancéropôle	The Iris Network is a network of hospitals in the Brussels region. Cancéropôle is the integration of the oncological care offered by the hospitals of the Iris network, including Jules Bordet, and the Brugmann University Hospital, and ULB Érasme (102).
NETwerk:	Is the Flemish hospital network for neuroendocrine tumours (103)(ref).
Tripartite collaboration for medical haemato-oncology	The collaboration offers local and quality care to patients in the north of Charleroi and the south of Walloon Brabant (104).

Other hospital networks exist in both Wallonia, Flanders and Brussels (105). However, these networks are do not specifically deal with oncological treatment and care.

In 2016, the creation of a 'rare disease function' within the Belgian university hospitals was implemented in order to promote a multidisciplinary approach to the diagnosis and treatment of rare diseases. Patients with rare or undiagnosed diseases can be referred to a hospital with expertise in a rare disease (106).

8.4. LEGAL STATUTES AND MANDATES

The College of Oncology was established by the Royal Decree (R.D.) on cancer care programmes of 2003 (59). Since 2007, a R.D. the standards to which the coordinating programme of specialized cancer care and the specialised breast cancer care programme must meet in order to be accredited (107).

Belgian legislation contains provisions on licensing standards for radiotherapy departments and equipment. In addition, programming standards establish the maximum number of radiotherapy departments. The Belgian legislator provided a law regulating care for oncology patients via ‘the care programme for oncology care’.

The general framework for reimbursement and use of medicine products can in the Belgian Law dating from March 25 1964 (108). The Compulsory Health Care and Benefits Insurance Act set on 14 July 1994 (and updated in 2021), sets the law for obligatory health insurance and related indemnities (109). In the following paragraphs, we will concentrate on the legal statues and mandates that may relate to novel treatments and use of such innovative treatments in the context of cancer care.

The Royal Decree amending the Royal Decree of 22 May 2014 details the procedures, time limits and conditions under which the compulsory health care and benefits insurance intervenes in the cost of radiopharmaceuticals in order to introduce the list of cost of radio-pharmaceutical products in order to introduce the list of reimbursable radio-pharmaceutical products (110). In addition, since 15 July 2019, the INAMI-RIZIV will only reimburse operations performed a centre for complex oesophageal surgery (10 centres) or in a hospital with which a cooperation agreement is concluded (111).

Compassionate cases concern medicines for which no marketing authorisation has yet been granted. For “compassionate use” of new medicines, Belgium has adopted European guidance (Article 83 of European Regulation 726/2004). With new legislation in 2014 (adaptation of article 6 of the law of 25

March 1964 on medicinal products and articles 106-109 of the Royal Decree of 14 December 2006 on medicinal products), Belgium implemented the European Regulation on compassionate use. At the same time, Belgium has taken the opportunity to create a broader legal framework, notably by also allowing "emergency medical programmes" in addition to compassionate use.

Early Temporary Authorisation (ETA) can also be given in exceptional cases, so that patients may access innovative treatment before it is authorized. For these cases, pharmaceutical companies may apply to the Federal Agency for Medicines and Health Products (FAMHP), to obtain an ETA. If the authorization is granted, the company must offer the treatment free of charge to the patient. The ETA continues until the medication is available on the market and authorized.

Some innovative medicines may be subject to an intervention even before registration, when they treat a serious or life-threatening disease and there is no therapeutic alternative. This procedure is called "Unmet Medical Need", and allows innovative medicines to be accessed more quickly. The Royal Decree of May 2014 (112) and the Belgian Law on “accessibility” from February 2014 (113), have determine the legal framework for such validation. The list of these medications is determined by INAMI/RIZIV every year (114).

Such “Unmet Medical Need Requests” can be made, by cohort, by the company responsible for the medication, and the Ministry of Health and Social Affairs can input a request. The request is made to the College of Doctors-Directors. Their general practitioner or treating doctor makes the request.

8.5. PROGRAMMES & ACTIVITIES

The College of Oncology determines the quality level in cancer care and organises external evaluation in all areas of the oncology care programmes (basic care programme and care programme). There is a Handbook of Oncology and Clinical Practice Guidelines, published in 2006 (115), in addition to various directives on clinical practices, as well as directives for cancer treatment by site, that are published in collaboration with the Federal Centre of Expertise for Health Care (KCE) (116).

Several hospitals in Belgium specialize in the treatment of different types of cancers. These centres are equipped with advanced medical technology and staffed by experienced oncologists, radiologists, and other specialists. Their primary care physician or specialist usually refers patients to these centres, and the treatment plan is developed in collaboration with the patient, their family, and the healthcare team.

Hospital services in Belgium are accredited. Each department within a hospital must be approved and meet specific standards, for example with regard to (117):

- Minimum bed capacity and occupancy rate
- Technical equipment
- Medical, paramedical and nursing staff
- Activity level

The “oncology” treatment program focuses on cancer patients. Patients are cared for in a holistic way, paying the necessary attention to prevention, diagnosis, treatment and palliative care. In oncology, there are the following care programs: “basic oncology care”, “oncology” and “breast cancer”. This care program is largely focused on consultation between care providers around the individual patient.

8.5.1. Oncological Treatment

In 2019, a survey was carried out by the Belgian Scientific Organisation for Oncological Radiation (BeSTRO) in which the following numbers of active radiotherapists-oncologists were identified: **98 in the Flemish Community, 79 in the French Community and 49 residents in 35 units**. There are therefore 226 **active radiotherapists**, which is **less than what is reported by the 2019 report of the Commission for the planning of medical supply**, which reports 254 practitioners, of which 144 are women.

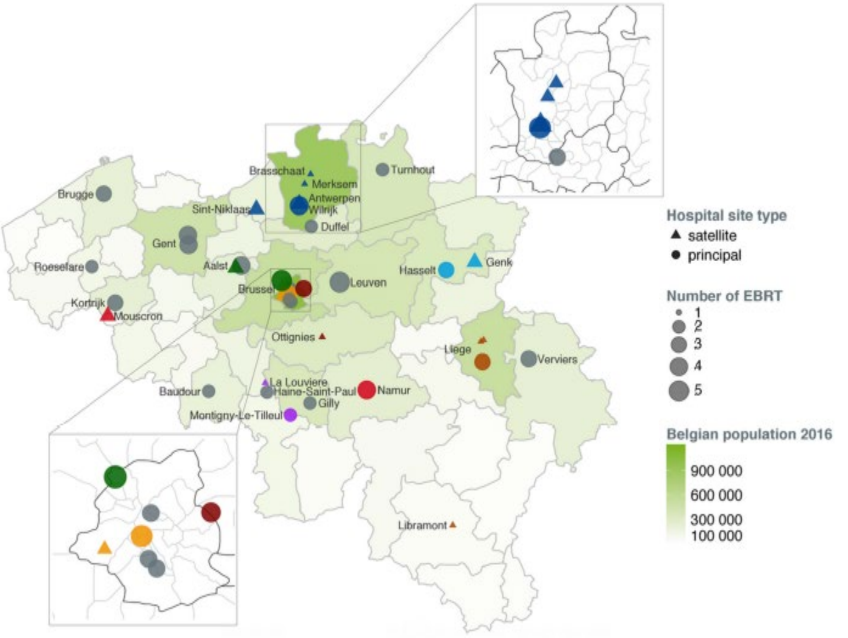

Figure 13: Concentration of radiotherapy treatment by population density. Source KCE report 239.

Conventions that currently exist for specific cancer sites. For example, for complex surgery of the pancreas and oesophageal, describe a good way to work and should be expanded. In December 2018, the RIZIV introduced a text of convention for centres that perform complex pancreas surgery, with the aim of improving the aiming to improve the quality of care. The BCR is in charge of collecting additional data through which an evaluation will be carried out. As of 1 January 2020, 15 centres had signed this agreement (118).

Since 2016, a number of measures have already been implemented in the framework of the hospital landscape reform (75,119). As of 2020, 25 loco-regional hospital networks grouping all acute hospitals have been created, with a distinction between general care provided by all hospitals, specialised care not provided in every hospital within the network (implying referral agreements), and supra-regional care provided in a limited number of reference hospitals. As of July 2019, 10 reference centres for oesophageal cancer surgery and 15 for pancreas cancer surgery have been implemented.

8.5.2. Treatment Guidelines

Both the KCE and the College of Oncology have responsibilities for developing clinical guidelines, but have limited budgets to implement them (13). For the same reason, monitoring the use of guidelines is problematic. The development and monitoring of guidelines and care pathways require adequate resources and the political will to implement them.

Ebpracticenet is a digital database bringing together all clinical practice guides and other evidence-based information materials for Belgian healthcare providers (120). On this online platform, all clinical practice guides (guidelines), recommendations, critical discussions of articles, brochures for patients, measuring instruments and audio-visual tools that are scientifically substantiated can be found.

Guidelines and standardized care pathways are closely linked. An essential aspect when considering these two points is the willingness of policy makers to build an "all-in" plan for patients. The development and monitoring of guidelines and care pathways are linked and require adequate resources and the political will to implement them.

8.5.3. **Multidisciplinary Approaches in Treatment**

In Belgium, multidisciplinary oncological teams are used to facilitate a holistic approach to treatment. These MOC are first present during the diagnosis of a cancer patient, and will continue through to patient's treatment and follow-up of the overall care.

As such, MOC is discussed in both the diagnosis and treatment sections of this document. MOC meetings also called Multidisciplinary Team Meetings (MDMT), can be described as an alliance of all medical and healthcare professionals related to a specific tumour disease, whose approach to cancer care is guided by their willingness to agree on evidence- based clinical decisions and to coordinate the delivery of care at all stages of the process, encouraging patients in turn to take an active role in their care (121).

Figure 14: Proportion of cancer patients (percentage) reporting no contact throughout treatment with different medical and paramedical professionals. Source Belgium Barometer 2021

The percentage of patients discussed at MOC has increased since it was legalised in 2003, with already 9 out of 10 patients being discussed at least one MOC. A KCE report found that the delays in the first MOC meeting by cancer type were MOC meeting was performed within 2 to 3 weeks after the incidence date[5] for 50% of the patients (within 5 weeks for 75% of the patients). However, for some cancers such as for breast cancer, rectum and soft tissue sarcoma, this delay was within 4 weeks after incidence for 50% patients (within 6 to 9 weeks for 75% patients). For malignant melanoma and prostate cancer, the first MOC meeting was performed within 6 weeks for 50% of patients and within 12 weeks after incidence for 75% of patients (62).

In the 2021 Belgian Cancer Barometer data collection, while over 71% of patients reported that needs were met, over a third to two-thirds of patients reported also never having contact with various types of carers (see Figure 14). Notably this included an oncological coach or care coordinator (34% report no contact), psychologists (37% report no contact), physiotherapists (40% report no contact), nursing care at home (45% report no contact), dietician (58% report no contact), social workers (67% report no contact) (75). This calls into question the effectiveness of multidisciplinary treatment offered to patients, as well as the information patients have on the type of care available to them.

8.5.4. **Innovative Treatments**

Understanding the genomic mechanisms of sensitivity to targeted anticancer therapies may improve patient selection, response to therapy, and rational treatment designs. In the last years, much progress has been made toward improving the overall prognosis of patients with metastatic cancer. The identification of activated pathways involved in the pathophysiology of carcinogenesis, metastasis, and drug resistance, as well as the emergence of technologies enabling tumour molecular analysis and the continuous development of targeted therapies have stimulated research focusing on the optimal use of targeted agents (122).

PRECISION is an initiative from the Belgian Society of Medical Oncology (BSMO) in collaboration with several stakeholders, encompassing four programs that aim to boost genomic and clinical knowledge with the ultimate goal to offer patients with metastatic solid tumours molecularly guided treatments. The

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[5] Ideally, date of first histological or cytological confirmation of this malignancy

PRECISION 1 study has led to the creation of a clinic-genomic database. The Belgian Approach for Local Laboratory Extensive Tumour Testing (BALLETT) and GeNeo studies will increase the number of patients with advanced cancer that have comprehensive genotyping of their cancer. The PRECISION 2 project consists of investigator-initiated phase II studies aiming to provide access to a targeted drug for patients whose tumours harbour actionable mutations in case the matched drug is not available through reimbursement or clinical trials in Belgium (122).

8.5.5. HTA & Decisions on Reimbursements

Current legislation defines a unique system of conditional reimbursement for emerging medical implants and devices (e.g., registration in category 5 of article 35 of the medical nomenclature). Although this legislation presents many opportunities for the coverage of potentially innovative implants, for which there is little formal evidence of their efficacy and safety under field conditions, the agreements made under category 5 suffer from several shortcomings. The most important of these is the lack of an established research structure that prevents scientific evaluation at the end of the agreement of the effectiveness under field conditions, the cost-effectiveness, ethical and organisational issues relating to the new implant (100).

Experts from the pharmaceutical policy department at the INAMI-RIZIV conduct the HTA of pharmaceutical products and make recommendations for reimbursement. These are based on the efficacy, safety, applicability, ease of use, and place in practice and need, cost, budget impact as well as on therapeutic benefit compared to existing alternatives in Belgium. If an added value is recognized, cost-effectiveness plays a role in the proposal of reimbursement (123).

Conclusions of the HTA and recommendations (including for price) are presented to a panel of stakeholders independent from INAMI-RIZIV (health care providers, academics, health insurers). This body – Commission for the Reimbursement of Medicines – adopts reports and makes final recommendations to the Minister of Social Affairs. The Minister of Social Affairs takes the final decision, sometimes deviating from the advices of the Commission.

8.5.6. Palliative Care

In 2018, there was 1.7 palliative care services per 100 000 inhabitants, which is above the European median (0.8/100 000 inhabitants) (124). According to the last HSPA report, the accessibility of palliative care has improved: more than half (53.4%) of all individuals with terminal cancer received palliative care in 2015, which represents an increase compared with 2008 (48.0%) (13).

8.6. GAPS & NEEDS

The future of oncology in Belgium is likely to be shaped by a combination of technological advancements, increased collaboration and integration, and a focus on patient-cantered care. The exact plans for the organization of oncology in Belgium may change over time, but it is clear that the goal of providing high quality, effective, and compassionate care to patients will continue to be a top priority.

Technological advancements that are likely to play a major role in the future of oncology in Belgium. For example, the use of artificial intelligence and machine learning to improve diagnosis and treatment planning, as well as the use of advanced imaging and minimally invasive surgical techniques, are likely to become more widespread. Similarly, there is a growing trend towards personalized medicine in oncology, and it is likely that this will continue to be a major focus in the future.

8.6.1. Development of Innovative Treatments

Innovative cell therapy that is academically-developed, patients must be given access in a timely, safe and affordable way (125). To achieve this, several changes must occur. First, academic centres should be supported in the establishment of a (national) academic cell therapy development knowledge platform and in the development of sufficient competence in academic centres involved in point-of-care manufacture to ensure legal and regulatory compliance.

Second, collaboration on GMP manufacturing of cell therapy and greater collaboration between academic centres in setting up larger clinical trials (nationally and internationally) are needed. This all requires early dialogue on clinical development between academics and healthcare authorities (regulators and payers). Early dialogue should be a standard part of the protocol development for academic clinical trials and organisations such as, RIZIV/INAMI, KCE (on a Belgian level) and EMA (on a European level) should have clear and affordable procedures for this.

Third, in the regulatory domain, communication and collaboration between FAGG/AFMPS and academic centres should increase the accessibility and transparency of authorisation procedures for academics. In addition, decision-makers must consider a parallel trajectory for academic development and authorisation of cell therapy.

8.6.2. Equitable Access to Innovative Treatments

With technological advancements, questions of equitable access will remain important. Having objectives at the federal that clearly express the need for equitable access, as well as accompanying indicators to measure this will be important. Adaption of indicators measuring patient-centeredness in the Belgian health system will also need to be adjusted to consider the way patients are included in discussions on their treatment, particularly those with advanced technology.

To improve access to innovative radiotherapy, a structured approach to Coverage with Evidence Development (CED) should also be developed. This requires both financial support and support from the Belgian Cancer Registry and RIZIV/INAMI for evaluating the current international knowledge on and use of CED for innovation in (radiation) oncology and evaluating how to define the radiotherapy interventions that would benefit from a CED program. Critical building blocks (e.g. needs, tasks, stakeholders, outcomes) of a radiotherapy CED program in Belgium should be defined and a structure and template for deploying CED should be developed. Setting-up and initiating data collection, performing the first appraisal of a CED program and assessing critical determinants for successful deployment of CED in radiation oncology is needed for the evaluation of a CED program.

9. Survivorship

9.1. DEFINITIONS & TERMINOLOGY

In Belgium, cancer survivorship is organized through a combination of medical care, rehabilitation services, and support programs. The goal of cancer survivorship programs is to help patients transition from active treatment to long-term follow-up care, and to provide them with the resources and support they need to live with and beyond cancer (126).

Medical care: After completing cancer treatment, patients typically continue to receive medical follow-up care from their oncologist or primary care physician. This may include regular check-ups, monitoring for any signs of cancer recurrence, and management of any late or long-term effects of treatment.

Rehabilitation services: Many cancer survivors experience physical, emotional, and psychological side effects from their treatment. In Belgium, patients can access rehabilitation services, such as **physiotherapy, occupational therapy, and psychological support**, to help manage these side effects and improve their quality of life.

Social Support programs: Cancer survivors in Belgium may also access support programs, such as support groups and counselling services, to help them cope with their diagnosis and treatment. These programs provide a supportive and safe environment for patients to share their experiences and to connect with others who have gone through similar experiences.

Sexual and fertility support programs: Some cancers and their treatments may pose a threat or harm to both intimate and sexual relations, as well as fertility. Programmes exist in Belgium to support individuals and loved ones on matters related to sexual relations and fertility, such as freezing of eggs or sperm, or fertility consultations.

Research and innovation: Many institutions and universities are working to better understand the long-term effects of cancer treatment and to develop new and better treatments for cancer survivors.

9.2. PROBLEM STATEMENT

Survivorship has often taken a back seat to other elements in the patient pathway. Treatment toxicities, physiological and psychosocial (late) effects, overconsumption of drugs and drug interactions, management of comorbidities, etc., should be at the heart of survivorship initiatives at the EU level.

A lack of evidence in many areas of survivorship require more research efforts and knowledge exchange. Second, there is often scarce attention given to survivorship in the projects addressing the organization of cancer care. Leaving it aside creates a missed opportunity to integrate survivorship care in standardized care pathways. This is of tremendous importance, because the criteria and indicators being developed (e.g. for the certification of comprehensive centres) will leave survivorship care and rehabilitation out of the scope of the type of care that such centres should deliver.

9.3. PUBLIC ACTORS & INSTITUTIONS INVOLVED

INAMI-RIZIV are responsible for the decisions on reimbursement of medical acts or services for patients surviving cancer. For example, the decision to reimburse urgent psychological care for patients, or the limit of 60 visits for physiotherapists for rehabilitation are taken by this institution, as are decision on the reimbursement of oncological freezing of eggs and sperm to protect fertility .

While the SPF Santé Publique will work with health system actors, SPF Emploi is also an important actor when discussing survivorship. SPF Emploi will set the norms for return to work, and rehabilitation for survivors returning to work. In a similar vein, for survivors returning to education, the education ministries in the region will play a role in establishing the norms, as well as the possibilities for distance learning or support during and after illness.

A plethora of Non-for-profit actors and support programs exist. This include peer-to-peer support groups for cancer patients and survivors, peer groups for informal carers' support, as well as organisations providing healthcare services. The latter are often linked to hospitals with registered oncological care programmes; For example, a pet-therapy centre, Samson Villa, linked to the University Hospital UZ Brussels. Other organisations such Wellbeing Homes, organised by the Cancer Foundation, fill gaps left by the system, to support survivors return to work. The decentralised and local nature of many of these non-for-profits may mean that monitoring and evaluation of the quality and impact of their activities is not incorporated into the regular health system monitoring performed at the regional or national levels.

9.4. LEGAL STATUTES AND MANDATES

There are currently no legal or clinical frameworks organising survivorship in Belgium, whether for patients or for professionals (126). However, the Royal Decree of 1991 establishing the nomenclature of rehabilitation services for certain patients, or the definition of a care pathway for diabetic patients, the physiological, psychosocial and professional rehabilitation of cancer patients could serve in the future as a legal and clinical framework for survivorship. Similarly, the Royal Decrees that set the standards for the basic and breast cancer care programmes could be used as an example for frameworks to be expanded to include the needs of patients in terms of follow-up and support care.

The law on the right to forgiveness has been in force since 1 February 2020 (127). It introduces a 'right to be forgotten' into insurance legislation, which aims to make it easier for people who have recovered from cancer to take out standard outstanding-balance insurance. This law applies not only to outstanding balance insurance taken out to cover a mortgage loan for the acquisition or conversion of a single home, but also to outstanding balance insurance taken out to cover a business loan.

9.4.1. Re-Education & Rehabilitation

The 2003 Royal Decree setting standards for Oncological Care Programmes (*Programmes Soins Oncologique, PSO*) states that: "*In hospitals, the care programme should also be able to call on a specialist doctor with experience in pain management in pain management, a physiotherapist and a dietician*". However, no specific reference or role for re-education is made, except for breast clinics. If physiotherapy is conducted for survivorship reasons the general practitioner prescribes it, and INAMI foresees 60 sessions covered by medical insurance.

9.4.2. Psycho-social & Psychological Care

The Royal Decree from 2003 on Oncological Care Programmes provides for the presence of a clinical psychologist, a psychiatrist and a social worker. However, the role of these actors in the long term is neither specified nor guaranteed, which has an impact of the quality of care and survivorship. The articles on social and psychological care state the following:

- **Art. 5** *For psychosocial support, the basic oncology care programme in the hospital must be able to call on a multidisciplinary psychosocial support team consisting of a clinical psychologist, a social worker or a public health nurse and a psychiatrist. They should be able to follow the patient throughout the treatment. For the above-mentioned competences, the members of the multidisciplinary team who also perform the palliative function in the hospital may be called upon.*
- **Art. 18**. *The oncology care programme must be able to call on a psychosocial support team within the hospital, consisting of a clinical psychologist, a social worker or a nurse with a degree in public health, and a doctor specialising in psychiatry, to provide psychosocial support to patients. The team must be able to follow the patient throughout the treatment. For the above-mentioned expert assessments, the members of the multidisciplinary team responsible for the palliative function in the hospital may be called upon.*

9.4.3. Professional Reinsertion

The most recent measure in the field of vocational rehabilitation is the reintegration plan (128). However, no specific measures exist for the occupational reintegration of workers with cancer.

9.5. PROGRAMMES & ACTIVITIES

9.5.1. Guidelines on Survivorship

In 2017, under the framework of the Joint Action CanCon, EU experts worked together at the development of evidence-based recommendations for the integration of cancer survivorship and rehabilitation in national cancer control programs.[1] The five key recommendations were:

- Cancer survivors' follow-up, late effect management and tertiary prevention needs to be **anticipated, personalized and implemented** into care pathways, with active participation of survivors and relatives;
- Improvement of **early detection of patients' needs and their access to rehabilitation**, psychosocial and palliative care services is required;
- An **integrated and multi-professional care approach** with a coordination of community care providers and services are needed to implement a survivorship care plan that enhances patient's self-management and quality of life;
- For **children, adolescents and young adults** survivors, late health and psychosocial effects of cancer and its treatments need to be anticipated and addressed;
- More **research** in the area of survivorship is needed to provide data on **late effects**, as well as the impact and **cost-effectiveness of supportive care, rehabilitation, palliative and psychosocial care interventions**.

However, Belgium does not currently have any guidelines on survivorship, as are found in other countries. For example, in Canada, a country with a similar decentralised health system like Belgium, a framework for survivorship research was establish to improve continuity and coordination of care for cancer survivors, following studies highlighting the fragmented nature of survivorship care (129). The framework, built in a participatory manner, aims to promote clinical research that with transition into translational research and changes in available infrastructure to enable high quality care after treatment. In the United States of America, the National Comprehensive Cancer Network (NCCN), which includes guidelines for patients, professionals, as well as continued learning events for professionals on themes related to survivorship (130). The guideline includes general principles on survivorship and care, as well as sections on late and long-term effects of cancer, both physiological and psychological, as well as preventative health following cancer treatment (e.g., healthy lifestyles, immunization, physical activity, nutrition and weight). The project BeONCoSup will aim to develop similar guidelines for Belgium (discussed below).

While survival rates in Belgium are comparable or better than other EU countries, in 2021, only 55.6% of cancer survivors having completed their treatment report that their needs are sufficiently taken into account, compared to 14% who do not feel their needs are taken into account and 25% who do not have an opinion (30,126). This may point to a gap in the support offered to survivors, despite clinical treatment and tertiary prevention following treatment being of high quality.

The 2021 Belgian Cancer Barometer expert groups highlighted that this dissatisfaction is not due to the recommended survivorship care being available within the Belgian system, but rather a lack of understanding of where, what services are available, and who provides them (inventory). In addition, a lack of coordination between these different actors, and a lack of organisation was reported as negatively affecting the quality of care following end of treatment.

9.5.2. Professional Reinsertion

According to the results of the population cohort study conducted in 2019, five years after diagnosis, 69% of surviving patients have returned to work, 48% of them being employed full-time. However, only 35% of patients going on disability (12 months or more off work), return after 5 years (131,132). However, with a lack of specific nomenclature for oncological reinsertion and rehabilitation there are difficulties in evaluating, at population level, the types of care and support survivors receive.

The European Commission will encourage support to Member States in promoting new or upgraded skills programmes to help (ex) patients return to the labour market, with possible funding from the European Social Fund Plus. In 2022, the Commission launched a new study on the return to work of (ex-) cancer patients, mapping national employment and social protection policies and identifying remaining barriers and challenges, which could also have positive effects on the work on professional reinsertion in Belgium.

- The RENTREE project (supported by Kom Op Tegen Kanker and VDAB), active in Brussels and Flanders, supported the reintegration of 560 patients into the labour market between 2017 and 2020.

- The PRINK project has for two years (2016-2017) informed and supported patients of the GZA Ziekenhuis with funding from the Cancer Foundation.

- The non-profit organisation "Work & Cancer" offers support to employees and employers to facilitate reintegration

- www.kankerenwerk.be: a website available in Dutch, which gives advice to (SME) employers who are faced with an employee with cancer.

Think Pink and Pink Ribbon have a page on the website dedicated to informing patients in order to help them in their professional reintegration (133).

9.5.3. Social & Psychological Support

In the last Cancer Plan (2009), particular healthcare staff trained in psycho-social support were envisioned for oncological care programmes (7). Between 2012 and 2016, the number of these workers (FTE) remained stable at 330 nurses, 330 psychologists and 165 social workers. While, Belgium experienced decreases in per capita mortality between 2011 and 2019 for all the 10 deadliest cancers except liver cancer, the age-standardized non-fatal burden of cancer increased from 2004 to 2019 by 6 % for incidence-based years lived with disability (YLDs) and by 3 % for prevalence-based YLDs (9). As such, this stabilization of number psychosocial care for increasing number of people experiencing cancer could lead to a lack of services and support.

9.5.4. Continuing Care after Treatment

Under the auspices of Europe's Beating Cancer Plan (EBCP), grants have been opened and awarded for a "Cancer Survivor Smart Card". The smart card, in the form of an interoperable portable eCard or app, will store certain information related to the monitoring and follow-up of the survivor, including the survivor's clinical history and follow-up.

The smart card will allow connection with the health professionals responsible for the individual's follow-up, including the survivor's general practitioner, to improve healthcare provider and survivor communication on the survivor's worries, questions and other matters of relevance to improve the survivor's quality of life. The action will involve patients' groups and health and social care providers, in order to apply a participatory and co-creative approach to help with the development of the tool, and to coach a group of ‘card-users’ to pilot the smart card’s usage once it has been developed, in preparation for the wider application phase (134).

9.5.5. Social Participation after Cancer

In Belgium, the ongoing SPADIS project seeks to understand and improve the social participation of individuals living with chronic disease, including cancer. The project will measure the association between disability and social participation, develop and implement tools to collect patients' perspective on their social participation, and assess the impact of contextual characteristics, related to health care and social security systems. This will include better understanding the association between disability and social participation, and on patient-reported outcomes and experiences (135). The results from this work should lend to the development of BeONCoSup (Belgian Handbook for Oncological Supportive Care) (136).

9.6. GAPS & NEEDS

While Belgium does not currently have any underlying framework organising survivorship, whether for patients or professionals, other countries have constructed guidelines to organise such care and ensure a continuity of quality of care after treatment. It is important care and prevention continue following treatment. In this regard, it is also necessary to consider the continuity of communication. It may be important for the future to think about the creation of a communication platform between hospital care and frontline care in order to ensure that all patients have a comprehensive and optimal care. The first step is to involve GPs and nurses more and better in long-term management. The second is to organise an electronic alert system, for example, monitoring to record parameters that identify needs and to link these results to a nursing service or the creation of a national cancer survivorship portal, with the objective to improve the ‘information and communication’ among professionals and patients.

Furthermore, in terms of resources, there are many disparities between insurances, particularly in relation to short stays for revalidation. There is therefore a need to harmonise short stays so that all patients are equal in terms of access to rehabilitation services. (Onco) psychology services are not systematically recorded by INAMI. As such, is difficult to assess the proportion of oncology patients who have benefited from the support offered, which consists of coverage of first line mental health care, including for those under 18 and those over 65 years of age. This is a huge limit for monitoring and evaluation of psychosocial aspects of oncological care and survivorship. If one wants to investigate this field, one currently has to go through the medical records, which, for medical records, which, for psychological care, presents important ethical and privacy issues to be privacy issues that need to be resolved beforehand.

During the evaluation of the last National Cancer Plan (2009), approximately 40% of patients stated that they needed psychosocial support and 15% acutely, but only 30% of those who need it explicitly request it. If not requested, the care is not provided, leaving a gap in the psychological and social support care for patients and survivors (7). The development of a generic cancer survivorship care pathway (SCP) and the setup of a recovery convention, recommending the development of a common care trajectory-ensuring equal and high-quality survivorship care for all cancer patients, may address this.

As outlined in the Belgian Cancer Barometer, considering developing a standard care package may support better integration of professionals in building understanding of post treatment care, and clear communication tools. A standard package of care would include a clear definition of the roles and competences of health professionals in oncology follow-up care and an inventory of the resources and care offers available at local level (with oncological expertise and experience). It could be complimented by development of "oncology networks for follow-up care" at local level to ensure that patients and health professionals know where to go when needed.

Additionally, a recent study showed that poor survival outcomes for cancer were associated with lower socio-economic status, there is little understanding of socio-economic impact of cancer prevention, screening and diagnosis (16,135). It may be beneficial to study this in order to better to support professional reintegration and social support following treatment.

10. Cross-Cutting Cancer Control Themes

10.1. PATIENT CENTEREDNESS

10.1.1. Context

The decision-making process for medical treatments is changing from a purely biological paradigm to one that prioritizes the needs, values, and preferences of the patient in addition to the relevant medical data. A tailored approach is crucial in many medical fields, but it is especially important in oncology because treatments may have a significant impact on patients' quality of life, often for a long time.

Patient centeredness refers to the provision of care that is responsive and adaptive to the needs, preferences, and values of the patient, and that these guide the clinical care. This type of care is closer to a partnership between the healthcare professional and the patient (and his/her close relatives) than to a paternalistic relationship. It requires good communication, listening, thought, and exchange between the patient and the caregiver.

According to the BCB2021 survey, 71% of cancer patients felt that their needs were taken into account during treatment (75). Furthermore, 60.5% of them reported that they felt involved in their treatment choices and 69% that their personal feelings were taken into account. This still leaves a third of patients that feel that their needs and personal considerations were not integrated into their care.

Experts in the field also report patients and their relatives are not explicitly mentioned in different elements of the patient pathway, particularly in the aspects of treatment. While PREMs have been integrated into over 90% of surgical services other elements of the care pathway, particularly for oncological treatment, do not systematically report on PREMs nor PROMs.

For patients to be able to actively participate in their care pathway, they need to be sufficiently and correctly informed. While they currently may receive many brochures during their hospital stay or visits to practitioners, but the content varies greatly from one institution to another. There leaves a gap in centralized information system that would allow patients and informal care providers to make informed decisions and be empowered (94).

10.1.2. Legal Statutes & Actors Involved

Based on the stakeholder mapping exercise we conducted, we identified approximately 80 patient organisations. For a full list and description of this mapping, please see the stakeholder mapping in the annexes.

In Belgian law there exists a framework on the quality of healthcare services, published in May 2019 (137). The law outlies the responsibilities of the practitioner, particularly in knowing the limits of their expertise, and the responsibilities to refer patients to appropriate colleagues, should they be unable to provide adapted care. The law also lays out the responsibility of the Ministry of Public Health, Food Safety and the Environment, in being permitted to conduct audits on quality of care, whether following a complaint or for routine inspection (13).

10.1.3. Programmes & Activities

The federal authorities started a Pay for Performance (P4P) programme for general hospitals in 2018 with a section dedicated to patient experience measurement (PREMs); this programme is part of the hospital financing amounts to 6 million EUR. More PROMs and PREMs are included in the P4P of hospitals in the future.

In Belgium, there are several initiatives relating to PREMS in hospitals. For example, the ASPE project (Expectations and Satisfaction of Patients and their Entourage), initiated by a private consultancy company PREMs in Brussels and Walloon hospitals. 17 **hospitals representing more than 40 sites participate freely**. The project supports hospitals in the application of good statistical methodology, standardized measures and provides comparative analyses relating to patient satisfaction and their experience. The project also identifies "good practices" and priorities for action to ensure patient satisfaction. In 2018, 94% of registered hospitals (96/102) had organized PREM in the surgical services (138).

For hospitals in Flanders, there is the patient survey which models questionnaires as part of the Flemish Indicators Initiative (VIP) (139). Hospitals can use these questionnaires and record the results, on a voluntary basis and large parts of Flemish hospitals do so.

In KCE's 2019 Health System Performance Analyses report, two new indirect measures for patient involvement in treatment choice were added (13). In a similar move towards strengthening patient involvement, new guidelines recommend actively involving patients in the choice of treatment in the case of prostate or testicular cancer. It implies that for cancer with low risk of progression, active surveillance (instead of chemotherapy/radiotherapy) should be proposed and discussed with the patient. The choice of taking an active surveillance strategy can only be made with the patient's full agreement and total cooperation (140).

As mentioned in the section on *Care Organisation,* the development of PROMs and PREMs in other initiatives have been announced, such as the SPADIS Social Participation and Employment of People Living with Chronic Conditions and Disabilities) project by Sciensano.

10.1.3.1. Whole-of-Society Approach

It is likely that the future of oncology in Belgium will continue to place a strong emphasis on patient-centred care. This will involve prioritizing patient needs, preferences, and experiences, and working to ensure that patients receive care that is both effective and compassionate. Nevertheless, a continuous dialogue between patients, citizens and policy makers is required to ensure ethical and socially appropriate cancer control starting with prevention, and across diagnostics, care and survivorship.

Rights and preferences can only be respected if they are well understood, preferably by cancer type. Bottom-up approaches to understand rights and preferences also help avoid technology driven conversations, in which rights and preferences of citizens may be lost. In order to achieve this, we must consider **building a governance framework based on citizen's values**. For example, in France, citizens are actively involved every 7 years in a fundamental review of the law on Bioethics and policy makers need to respond to their input in open parliamentary sessions (141).

In this light, more focus on participative approaches to health policy and participative approaches to monitoring should be considered. As suggested in the Belgian Cancer Barometer, a broad study of PROMs and PREMs would desirable, as would be developing a deeper understanding patients' needs and expectations, as well as an understanding of their experience of the care pathway (50).

In many national and international funding programs, including the EBCP and the EU4Health programme, patient and citizen engagement is considered as an important part of new projects. This is a step in the right direction, but it needs to be complemented by a sustainable strategy to involve patients and citizens structurally and continuously. This is particularly true as cancer concerns the entire population; all individuals are susceptible to cancer, and the entire population is affected by screening, vaccination and prevention programs.

Moreover, cancer care is a societal challenge that touches upon many sensitive topics such as reimbursement of expensive drugs, the use of genomic information, nudging for behaviour change, surveillance, and data protection, merging therapeutics and research and even the very definition of what it means to live a good or healthy life. Such challenging topics require the engagement of patients and citizens.

Patient and citizen engagement is essential to prevent ‘shadowboxing’ between health professionals, policy makers and targeted populations. When concepts like privacy, consent, control, health, risk, care, survivorship, dignity, etc. mean something different to each of these parties, it is possible for everyone to fully intend to respect each other’s rights and preferences and do the exact opposite. Each stakeholder has by definition a different perspective and will have a different view on priorities, gaps and best practices. Without a continuous dialogue, perspectives may not align; this way we would revert back to 20th century strategies, like unidirectional awareness-raising campaigns, persuasion and top-down behaviour change campaigns that do not work for a 21st century public.

10.2. CANCER INEQUALITIES

10.2.1.1. Measuring Inequalities in EU Member States

The European Cancer Inequalities Registry (ECIR) is a new tool that helps monitors inequalities in cancer care across Europe, as part of Europe’s Beating Cancer Plan. It examines data on inequalities in urbanisation, education, diet, sex, income, age across the thematic areas of prevention, early detection, diagnosis and treatment, quality of life. Additionally, epidemiological measures of cancer burden are included (ref). The data sources are numerous, including European Cancer Information System, Eurostat, European Environmental Agency, the Global Cancer Observatory, OECD State of Health, amongst others. This tool could be a valuable source of information to better understand how inequalities influence the access to, quality of, and outcomes of cancer care in Belgium.

However, the ECIR does not provide a full picture of the why behind these inequalities. For example, why those that are of lower socio-economic status in Belgium are have lower participation in cervical smears. The tool also does not provide for sub-national analysis, an important factor in Belgium, where there are large regional disparities (see section *Screening*). Gaps in evidence create a barrier for efficient decision-making thereby undermining principles of equity. These differences may lead to a higher burden of cancer on already marginalised and vulnerable groups.

National and regional registries need to be able to collect, store and link data on cancer prevention, diagnosis, treatment, care and care organization, as well as survivorship to identify inequalities and their determinants. If such registries and data collection are defined at the European level (e.g. ECIR), then it is important that these can be tailored to be fit for purpose at national and regional levels. Such data and dashboards would also facilitate patient organisations in addressing these inequalities through their work, alongside other health system actors.

10.2.1.2. Inequalities in Screening

According to the KCE report 313C, there are significant socio-economic inequalities in access to healthcare in Belgium (13). Based on the data that were available for the 2019 report, we were able to conclude that people in more disadvantaged social groups had higher financial barriers to use healthcare services, a **lower participation rate in cancer screening programmes**. Among people with a low level of education, unmet needs are four times greater than among those with a high level of education (142). The report also points to problems with waiting times for a specialist appointment. However, no specific survey or analysis concerning access to cancer care has been carried out.

10.2.1.3. Inequalities in Access to Care

Among people with a low level of education, unmet need is four times higher than among those with a high level of education (13). The report also points to problems with waiting times for an appointment with a specialist. However, no specific survey or analysis of access to cancer care based on different socio-economic status, or other group factors, has been conducted.

10.2.1.4. Inequalities in Survivorship

It was only recently in 2021, that the first study investigating the association between SE and SD factors and cancer survival at the individual-level in Belgium was conducted. The study found that lower socio-economic status resulted in poorer survival of cancer in almost all high-burden cancers in Belgium. The association was most pronounced for colon, breast, head, and neck cancers. For patients diagnosed with rectal, lung, pancreatic, and stomach cancer, survival was lower for patients with low income. No association between survival and income was found for ovarian cancer (16). Lower SE status could be associated with lifestyle habits (such as smoking for stress, poor living conditions, and poor diets) that negatively affect health. While Belgium has health insurance, many services require you pay at point of care, which could alter the optimal and timely use of healthcare services. Similarly, high SE status individuals may have access to more costly and innovative treatments, not yet covered by health insurance.

10.2.1.5. Vulnerable Populations

Socio-economic inequalities in healthcare use may arise from a variety of causes. In addition to the health status of individuals, and related to this the need for health care use, other factors can also have an impact, such as socio-economic (SE) status (education level, income, employment status), availability of services, lifestyle, health insurance coverage (mandatory or supplementary).

There is now ample evidence that socioeconomic status, as well as socio-demographic (SD) characteristics have an impact on healthcare and health outcomes, including cancer (143,144). Although with cancer, there may be differences given variation in tumours (environmental factors), as well as inequalities in prognosis (12,16,145).

In Belgium, previous studies have largely focused on differences in socio-economic status on cancer morbidity and survivorship (146). To our knowledge, no studies have been conducted on the impact of both SE factors on screening, diagnosis or treatment; similarly, no studies on the impact of SD factors on inequalities are available. For example, while there has been improvement in some of the indicators related to healthy lifestyle, this is not the case for marginalised and vulnerable groups. For example, daily smoking is higher among Belgians with very low incomes (25%), relative to those with high incomes (11%), with 1 in 4 people with low incomes smoking, compared to 1 in 10 of those with high incomes (36). Similarly, those with higher income or more education also are more likely to eat more fruits and vegetables, as well as engage in more physical activities.

The latest population based cohort data on social inequalities related to cancer survival are from 2021. Rosskamp *et al* report lower income, unemployment, and living alone were all associated with worse cancer survival. These associations were most pronounced for certain lifestyle-related cancer types (e.g., head and neck cancers) and those with good to moderate prognosis (e.g., colorectal and female breast cancer) (16).

11. Cancer Research

11.1. DEFINITION & TERMINOLOGY

Several types of research can be applied to the field cancer:

Fundamental Research: The main objective of fundamental research is to produce knowledge in relation to natural phenomena. In life and health sciences, the particular focus is on deciphering the mechanisms of life, and understanding not just the functioning of the human body, but also that of organisms and any other entity with which it interacts (147).

Clinical Research: Clinical research is medical research involving people. There are two types, observational studies and clinical trials.

Observational studies observe people in normal settings. Researchers gather information, group volunteers according to broad characteristics, and compare changes over time.

Clinical trials research studies are performed in people that are aimed at evaluating a medical, surgical, or behavioural intervention. They are the primary way that researchers find out if a new treatment, like a new drug or diet or medical device (for example, a pacemaker) is safe and effective in people (148).

Translational Research: Translational research seeks to produce more meaningful, applicable results that directly benefit human health. The goal of translational research is to translate (move) basic science discoveries more quickly and efficiently into practice (149).

11.2. PROBLEM STATEMENT

Like in any other country, there are several challenges to cancer research in Belgium. Some of these challenges include:

- **Funding**: Despite Belgium's strong research infrastructure, funding for cancer research is always a challenge. This is due to the high costs of research and the limited availability of funding from public and private sources.
- **Collaboration**: There can be a lack of coordination and collaboration between different institutions and researchers in Belgium, which can hinder progress in cancer research. Greater collaboration and sharing of resources could help overcome this challenge. fragmentation of cancer research prevents an exhaustive overview of research activities
- **Access to patients and data**: Access to patient populations and clinical data is critical for cancer research, but there can be barriers to accessing this information due to privacy concerns and regulatory requirements.
- **Recruitment of patients for clinical trials**: Recruitment of patients for clinical trials is often challenging, particularly for rare cancer types or for patients who live far from the research institutions.
- **Regulatory environment:** Regulatory requirements and ethical standards can also pose a challenge for cancer research in Belgium, particularly in terms of obtaining necessary approvals and ensuring compliance with relevant regulations.

11.3. PROGRAMMES & ACTIVITIES

11.3.1. Belgian Cancer Research Alliance

BeCRA coordinated by Sciensano is a public consortium supported by researchers, research organisations and public stakeholders in the Belgian Cancer Research domain at large in line with the scope set out in the ’Europe’s Beating Cancer Plan ‘ (EBCP). BeCRA was launched in 2023 and currently includes various partners. The initiative aims to position Belgium, and in particular, its research institutes, optimally at the EU level, especially with respect to the many research initiatives launched in the EBCP within the EU4Health program, the Mission on Cancer and the Digital Europe program. BeCRA partners collaborate across cancer research activities linked to the EBCP to ensure optimal use of upcoming investment and sustain excellence in the Belgian cancer research. BeCRA partners also agree to share their expertise and infrastructures for the purpose of the challenges invoked by the EBCP.

11.3.2. UNCAN.eu

UNderstand CANcer is a European initiative, proposed by the Mission Board and the European Beating Cancer Plan, aiming at achieving a new milestone in cancer prevention and treatment. Sciensano is involved in the 15-month coordination and support action “4.UNCAN.eu” which will result in a strategic agenda to launch UNCAN.eu (150).

Under the umbrella of UNCAN.eu and in the context of the General Data Protection Regulation, high-quality cancer research data generated by experimental model analysis and collected from longitudinal follow-up from cancer patients will be shared and integrated within a Federated Cancer Research data hub. This information will be used to address scientific and medical gaps in cancer prevention, early diagnosis, treatment and survivorship through innovative, cross-border and trans-disciplinary research programmes. Belgium is responsible for Work Package 4 on Patients and European Citizens in cancer research.

11.3.3. ECHoS: Establishing of Cancer Mission Hubs: Networks and Synergies

ECHoS is a consortium gathering more than 57 organisations distributed across 26 countries. Its aims to guarantee a successful implementation of the Cancer Mission (151).
The objectives of ECHoS include:

- Promoting the creation of the National Cancer Mission Hubs (NCMHs) in member states and associated states
- Establishing a network to support advance Cancer Mission across Europe, which involves developing pilot models for the Cancer Mission subareas (prevention, early detection and treatment, quality of life and survivorship), stimulating engagement with relevant stakeholders and ensuring effective citizen engagement.
- Building synergies to implement the Cancer Mission with other European initiatives towards a “Cancer in all” approach.
- Laying out the foundation for European network of NCMHs by developing a business continuity and operations model framework

Sciensano is responsible for work package 5, which involves the development of Future EU network of National Cancer Mission HUBs – Design Study.

11.3.4. Clinical Trials

There are currently 984 registered ongoing clinical trials in Belgium. 278 ongoing clinical trials are looking at rare diseases. Given the complexity of using the clinical trials search engine, we provided at this stage an overall summary of the ongoing clinical trials registered in Belgium (152).

Below, is a descriptive summary of the retrieved clinical trials.

Clinical trial Phase	Number of ongoing studies
Phase 1	113
Phase 2	476
Phase 3	514
Phase 4	44

Number of ongoing clinical trials in Belgium per clinical trial phase

Age category	Number of ongoing clinical trials
CAYA*	112
Adult	948
Elderly	873

*CAYA include preterm new born infants, new born, toddler, infant, children, adolescent, under 18

11.4. GAPS & NEEDS

BeCRA is already working to develop research networks within the Belgian landscape. Networks at the European level will also be important, for both access to European funding, but also to build on experiences and knowledge being generated in other, possibly comparable settings. Such networks should be a focus moving forward.

Recruitment remains a challenge for clinical trials in Belgium. To improve the recruitment of individual partnerships between research groups and university hospitals may be considered. Other comparable decentralised health systems such as Canada have also included indicators in their Cancer Plan Evaluation on clinical trial enrolment as a proxy indicator of success of research involving clinical trials related to cancer.

Leveraging the EBCP Mirror groups, and like participative approaches to calls and research funding will be important. First, to strengthen Belgian research actors' chances to secure funding. Second, the participative approaches and inclusion of professional organisations, patient organisations, public agencies including sickness funds, as well as Non-for-profits should be promoted to ensure that research projects are meeting needs in the field.

12. Conclusion

In a context in which the EBCP challenges Member States to develop a long-term strategy against cancer, this inventory compiles evidence across the cancer patient pathway, and touches upon transversal issues such as patient-centeredness and inequalities in care. This document sheds light on information gaps that need to be filled, and actions that could be considered for future investments in Belgium and where participation in large EU work programmes may contribute.

There is currently no Cancer Plan in Belgium or specific objectives to report on cancer prevention and care. As consequence, reporting systematically on activities, in addition to measuring changes (improvements or degradations) in what care is available and accessible is challenging - without such an approach the exercise remains descriptive, and causality between actions taken, resources spent, and changes in indicators is limited.

This document is intended to be used as a live document, for which annual updates could be foreseen. Novel methods for automating the inventory process could also be relevant in particular given current developments towards the European Health Data Space. In particular and give

Nonetheless, this inventory does not paint a complete picture of the cancer policy and activity landscape in Belgium. We hope this inventory of current activities could be improved though qualitative input from the field as opposed to only desk research. The exercise we have conducted could be put in place on a routine basis, to lay the foundation for a more comprehensive monitoring of cancer control in BE over time. In the near future, we would like to conduct demi structured interviews with key stakeholders to triangulate the information gathered here, and for a deeper understanding their mission and activities, while assessing data availability to support of any future monitoring and evaluation activities.

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14. Annexes

14.1. STAKEHOLDER MAPPING

The following documents outline the methodology for the initial steps of the cancer actor stakeholder mapping (completed), as well as the subsequent steps proposed. The second subsection summarizes the stakeholders that have been identified through the stakeholder mapping.

14.1.1. Methodology

Stakeholder Mapping
Methdology January

14.1.2. Descriptive Mapping Results

Stakeholder mapping - Guide to use

Stakeholder mapping Descriptive Results Ca

14.2. ONGOING SCIENSANO PROJECTS

The following documents list the different ongoing projects related to cancer, by thematic group, that are currently ongoing at Sciensano.

Sciensano Projects Prevention

Sciensano Projects Screening

Sciensano Projects Diagnosis Treatment

Sciensano Projects Survivorship

Sciensano Projects Care Organisation

14.3. POLICY BRIEF BY EBCP THEMATIC WORKING GROUP

Cancer is one of the main public health challenges in Europe and the second leading cause of mortality in EU countries. While over 40 % of cases are preventable, 3.9 million people in the EU are diagnosed each year, and 1.9 million deaths are cancer-related. In Belgium, cancer mortality is among the lowest in the EU, this represents 26 299 cancer-related deaths and a significant loss for families and for society at-large. The burden of cancer has increased substantially over the past 15 years. In Belgium, there were 68782 new diagnoses of cancer in 2020. For men, prostate cancer is the most common, constituting one fourth of new diagnoses in Belgium (26%), followed by lung 15%, and colorectal 11% cancer. For women, breast cancer constitutes 33% of new diagnoses followed by colorectal 10%, and lung 10% cancer. Every year, about 520 children and adolescents (0-19 years) are diagnosed with a malignancy, representing 1% of all diagnoses.

There have been considerable investments in developing cancer control guidelines and recommendations. Belgium adopted a national cancer plan in 2009 and in 2012; a first evaluation of the implementation of the measures of the Cancer Plan took place. Five areas for improvement were identified: transmural care (i.e. coordination between the outpatient and inpatient sectors), socio-professional reintegration of cancer survivors, blood banks, quality of care, and personalized medicine. During the 2015-2019 period, several new actions were adopted, including the development of molecular diagnosis in oncology, concentration of care and measures facilitating the professional reintegration of cancer patients. As of 2022, further actions are envisaged on improving access to cancer care, further development of expertise centres and addressing the needs of children and young adults with cancer.

The European Commission (EC) has recently launched two major initiatives: 1) Europe's Beating Cancer Plan (EBCP) and 2) the Mission on Cancer with the aim to save 3.000.000 lives by 2030.

With a total of €4 billion being earmarked for actions addressing cancer, the EBCP is a policy-driven initiative running from 2021-2027. It sets out actions to support, coordinate or supplement Member States' efforts at every stage of the disease: from prevention, early detection, diagnosis and treatment, to an improved quality of life for cancer patients and survivors. Along with the EBCP, the Mission on Cancer is a research-driven initiative to improve the survival and quality of life of cancer patients and substantially reduce the cancer burden in the EU. Given the current breadth of EU calls in the cancer field (including €1.25 billion from the EU4Health programme, plus financial support through the Horizon Europe Framework Programme for Research and Innovation and the Digital Europe programme), there is a need for a coordinated response from Belgium bringing the relevant stakeholders to work together.

The Federal Minister of Health - Minister Frank Vandenbroucke has appointed the Cancer Centre to coordinate and monitor the implementation of the EBCP in Belgium. This will be done in close collaboration with his services - the Cabinet, the FPS Health, and the National Insurance and Health Disabilities Institute (RIZIV-INAMI).

The initiative referred to as the Belgian EBCP Mirror Group was launched in October 2021. This stakeholder platform involves Belgian representatives of federal/regional health agencies, universities, professional societies, patient/citizen organisations and industry. It consists in over 400 members and organised in 10 TWGs serving in an advisory capacity. Members of the Belgian EBCP Mirror Group meet on a regular basis to review the EC’s proposals most relevant to address cancer needs and challenges in Belgium, stimulate participation in these calls, and to propose relevant topics for action. The expected results are:

- better alignment of Belgium's cancer policy aims, and field activities with EBCP
- systematic identification of funding opportunities for cancer research, care and control
- optimized allocation of resources in a competitive and complex tendering environment
- Uptake of interventions that reduce the cancer burden, and improve the care, survival, and quality of life of patients in Belgium.
- strengthened collaborations amongst national cancer stakeholders and EU counterparts

The objective of the following policy brief sis to outline the major activities and initiatives related to cancer from prevention, to survivorship, including care organisation and patient and citizen engagement. We then present an analysis and detail the remaining gaps and their consequences, and conclude with key recommendations to be taken by policy and decision-makers to improve the status quo.

These briefs detail the key activities, persistent gaps, and recommendations were written in a participative manner, through group meetings with the Belgian-EBCP Mirror Groups. The working groups each currently consists of more than 50 members, with representatives from patient organizations, NGOs, hospitals, industry, professional organizations, research institutes, registries and universities.

Online meetings were organised by each of the Mirror Group leaders to discuss their thematic topic, the current related activities in Belgium, related EU calls for funding and Belgium's participation. During these expert discussions, the status quo, needs, and priorities in the field of cancer. These needs and priorities presented in these brief are an outcome of these discussions and based on the various experiences of members in the Belgian field. The Mirror Group leads and members of the Cancer Centre's, Monitoring and Evaluation Team have distilled the outcomes of the meetings.

Some of these briefs are in draft format, and as we are preparing them for peer-reviewed publication, they must remain confidential.

PolicyBrief Prevention Early Detection
Policy Brief Diagnosis Treatment
Policy Brief Artificial Intelligence
Policy Brief Survivorship
Policy Brief CAYA
Policy Brief Patient Citizen Engagement
Policy Brief Care Organisation

Please note that the policy brief on cancer research is forthcoming and will be shared later.

14.4. DATA SOURCES & INDICATORS

This two documents detail the data available from the Belgian Cancer Registry and IMA-AIM.

Indicators BCR
Indicators AIM-MIA