EVALUATION OF THE CANCER PLAN 2008-2010:

RESULTS 2011

Prof. Dr. Elke Van Hoof
Dr. Eline Remue
Dr. ir. Liesbeth Lenaerts
Ellen De Wandeler
Benoit Mores
Jelle Goolaerts

February 2012
Consignment number: D/2012/2505/14
Authors: Liesbeth Lenaerts, Eline Remue, Liesbet Van Eycken, Renée Otter and Elke Van Hoof.


Copyright statement
This work is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 2.0. This means that the work may be distributed/copied/transmitted, as long as the names of the authors are indicated (1), the work cannot be used for commercial purposes (2) and the work cannot be altered (3). Visit http://creativecommons.org/licenses/by-nc-sa/2.0/legalcode to view a copy of the license.

External evaluators:
Renée Otter (NKP monitor Nederland), Milena Sant, Michel Coleman

Acknowledgements:
The Belgian Cancer Centre would like to thank the Belgian Cancer Registry, which supplied on demand and in collaboration with the Belgian Cancer Centre, figures and numbers on cancer incidence, mortality and survival in Belgium. The data and results presented in this evaluation were obtained from various sources which are responsible for their results used as scientific evidence. All data and results used were checked with the sources concerned, including the FPS Public Health (through Paul Van den Meerssche and Saskia Van Den Bogaert), the KCE (through Raf Mertens, Jo Robays and Dominique Paulus), the Belgian Cancer Registry (through Liesbet Van Eycken), the Marrow Donor Programme Belgium Registry (through Anne Vanhonsebrouck, Etienne Baudoux), the NIHDI (through Vera Beeken Carl Cauwenbergh, Joos Tielemans), the Belgian Health Interview Survey (through Jean Tafforeau), the Brussels Capital Region (through Murielle Deguerry; review of action 1), the Flemish Agency for Care and Health (through Karen Colaert) and the OECD (through Vladimir Stevanovic and Rie Fujisawa).

Remark:
The numbers of cancer incidence in Belgium are complete up till the end of 2009. Figures and tables presenting numbers on survival and mortality only refer to the period up till 2008.
TABLE OF CONTENTS

INTRODUCTION ................................................................. 7

DOMAIN 1: PREVENTION AND SCREENING ................................................................. 9

ACTION 1: REIMBURSEMENT OF CONSULTATIONS TO QUIT SMOKING ................................................................. 9

A1.1. Scientific data on indicators ................................................................................. 9
A1.1.1. Causal relationship between smoking and cancer development ......................... 9
A1.1.2. Prevalence of smokers in Belgium ........................................................................ 9
A1.1.3. Trends in lung cancer by gender over the last 10 years ........................................... 13
A1.1.4. Trends in other smoking-related cancers by gender over the last 10 years .............. 14
A1.1.5. Impact of educational level on the association between smoking and mortality ........ 14

A1.2. Indicators reflecting a specific action of the cancer plan ...................................... 14
A1.2.1. Anti-tobacco policies in Belgium ........................................................................... 14
A1.2.2. Controls on compliance to the tobacco legislation .................................................. 15
A1.2.3. Visits to the smoking cessation specialist to give up smoking ............................... 18

ACTION 2: DETECTION AND COUNSELING OF PERSONS AT RISK WITH A GENETIC PREDISPOSITION TO DEVELOP CANCER ................................................................. 20

A2.1. Scientific data on indicators ................................................................................. 20
A2.1.1. Proportion of cancer patients that develop cancer due to a genetic predisposition .... 20
A2.1.2. Incidence of second tumours ............................................................................... 20

A2.2. Indicators reflecting a specific action of the cancer plan ...................................... 22

ACTION 3: EXTENSION OF THE AGE RANGE FOR VACCINATION AGAINST HPV FOR GIRLS FROM 12 TO 18 YEARS ................................................................................................................................. 22

A3.1. Scientific data on indicators ................................................................................. 22
A3.1.1. Causal relationship between cervical cancer and human papillomavirus infection .... 22

A3.2. Indicators reflecting a specific action of the cancer plan ...................................... 23
A3.2.1. Coverage of HPV vaccination ............................................................................... 23

ACTION 4: IMPROVE DETECTION AND EARLY DIAGNOSIS OF BREAST CANCER ................................................................. 25

A4.1. Scientific data on indicators ................................................................................. 25
A4.1.1. Coverage of breast cancer screening ....................................................................... 25
A4.1.2. Breast cancer incidence, mortality and survival ....................................................... 27

A4.2. Indicators reflecting a specific action of the cancer plan ...................................... 31
A4.2.1. Breast cancer screening and follow-up examinations .............................................. 31

ACTION 5: SYSTEMATIC SCREENING OF CERVICAL CANCER ......................................................................................... 33

A5.1. Scientific data on indicators ................................................................................. 33
A5.1.1. Coverage of cervical cancer screening ................................................................. 33
A5.1.2. Cervical cancer incidence, mortality and survival ................................................... 34

A5.2. Indicators reflecting a specific action of the cancer plan ...................................... 38

ACTION 6: CONSULTATION TO PREVENT HEALTH RISKS ......................................................................................... 38

A6.1. Scientific data on indicators ................................................................................. 38
A6.1.1. Causal relationship between a healthy lifestyle and developing cancer ................. 38
A6.1.2. Trends in proportion of the population adopting a healthy lifestyle ......................... 39

A6.2. Indicators reflecting a specific action of the cancer plan ...................................... 43
ACTION 34: IMPROVE DETECTION AND EARLY DIAGNOSIS OF COLORECTAL CANCER

A34.1. Scientific data on indicators
A34.1.1. Risk factors for colorectal cancer
A34.1.2. Colorectal cancer incidence, mortality and survival

A34.2. Indicators reflecting a specific action of the cancer plan
A34.2.1. Coverage of colorectal screening

ACTION 7: SPECIFIC SUPPORT FOR THE PATIENT WHEN THEIR DIAGNOSIS IS COMMUNICATED

A7.1. Scientific data on indicators
A7.2. Indicators reflecting a specific action of the cancer plan

ACTION 8: REASSESSMENT OF THE MOC

A8.1. Indicators reflecting a specific action of the cancer plan
A8.1.2. Trend over time in the number of MOCs
A8.1.2. Participation of physicians in the MOC
A8.1.3. Proportion of cancer patients discussed in a MOC

ACTION 9: INTRODUCTION OF CARE PATHWAYS FOR CANCER PATIENTS

A9.1. Scientific data on indicators
A9.2. Indicators reflecting a specific action of the cancer plan
A9.2.1. Involvement of General Practitioners in cancer treatment
A9.2.2. Development of guidelines and day care trajectories

ACTION 10: ENSURING PSYCHOSOCIAL SUPPORT IN THE ONCOLOGICAL CARE PROGRAMMES

A10.1. Scientific data
A10.2. Indicators reflecting a specific action of the cancer plan
A10.2.1. Financing of additional personnel for the acknowledged oncologic care programme
A10.2.2. Communications training for psychologists

ACTION 11: FINANCING A DATA MANAGER IN THE ONCOLOGICAL CARE PROGRAMMES

A11.1. Scientific data on indicators
A11.1.1. Trends in numbers of data managers
A11.1.2. Percentage of overlap between cancer notifications from the laboratories and from the hospitals
A11.2. Indicators reflecting a specific action of the cancer plan

ACTION 12: DEFINITION AND FINANCING OF PAEDIATRIC ONCOLOGICAL CARE PROGRAMME

A12.1. Scientific data on indicators
A12.1.1. Incidence, mortality and relative survival
A12.1.2. Follow-up of children who survived cancer
A12.2. Indicators reflecting a specific action of the cancer plan

ACTION 13: TREATMENT OF RARE CANCERS

A13.1. Scientific data on indicators
A13.1.1. Association between volume and outcome of rare cancers
A13.2. Indicators reflecting a specific action of the cancer plan
ACTION 14: CERTIFICATION OF THE ONCOLOGICAL NURSE TITLE ..................................................... 79
A14.1. Indicators reflecting a specific action of the cancer plan ..................................................... 79

ACTION 15: IMPROVEMENT OF THE COVERAGE PROVIDED BY THE COMPULSORY HEALTH
INSURANCE OF CANCER MEDICINES ................................................................................................. 80
A15.1. Scientific data on indicators .................................................................................................. 80
A15.1.1. Performance of cancer care .................................................................................................. 80
A15.2. Indicators reflecting a specific action of the cancer plan ..................................................... 83

ACTION 16: SUPPORT OF RADIOTherapy AND ONCOLOGICAL IMAGING ........................................ 83
A16.1. Indicators reflecting a specific action of the cancer plan ..................................................... 83
A16.1.1. Quality .................................................................................................................................. 84
A16.1.2. Programming ........................................................................................................................ 84
A16.1.3. Numbers on devices in Belgium ......................................................................................... 85
A16.1.4. Numbers on recognised physicians in radiotherapy in Belgium ....................................... 88

ACTION 17: STRUCTURAL SUPPORT OF TISSUE BANKS FOR CELL THERAPY AND UNITS FOR CELL
THERAPY WITH HAEMATOPOIETIC STEM CELLS AND UMBILICAL CORD BLOOD ....................... 88
A17.1. Scientific data on indicators .................................................................................................. 88
A17.1.1. Number of Belgian cancer patients receiving a transplant from a donor abroad .................. 89
A17.1.2. Number of foreign cancer patients receiving a transplant from a Belgian donor ................ 89
A17.1.3. Number of cancer patients needing a transplant who do not find a match ...................... 90
A17.2. Indicators reflecting a specific action of the cancer plan ..................................................... 90

ACTION 18: IMPROVEMENT OF THE REIMBURSEMENT OF ADDITIONAL COSTS RELATED TO CANCER
THERAPY .......................................................................................................................................... 91
A18.1. Scientific data on indicators .................................................................................................. 91
A18.1.1. Cost of cancer ....................................................................................................................... 91
A18.2. Indicators reflecting a specific action of the cancer plan ..................................................... 92

ACTION 19: FUNCTIONAL REHABILITATION OF THE CANCER PATIENT IN REMISSION ...................... 94
A19.1. Scientific data on indicators .................................................................................................. 94
A19.2. Indicators reflecting a specific action of the cancer plan ..................................................... 95

ACTION 20: DETERMINING THE REQUIREMENTS FOR RECOGNISING A DISABILITY CAUSED BY
CANCER TREATMENT ....................................................................................................................... 95
A20.1. Scientific data on indicators .................................................................................................. 95
A20.2. Indicators reflecting a specific action of the cancer plan ..................................................... 95

ACTION 21-22: SUPPORT TO PARENTS OF CHILDREN WITH CANCER AND ACCESS TO PSYCHOSOCIAL
SUPPORt OR PARtICIPATION IN SELF-HELP GROUPS ........................................................................ 96
A21-22.1 Scientific data on indicators ............................................................................................... 96
A21-22.2. Indicators reflecting a specific action of the cancer plan .................................................. 96

ACTION 23: STRUCTURAL FINANCING OF THE CHAIN OF PAEDIATRIC CARE “CONTINUED CARE FOR
CHILDREN” ....................................................................................................................................... 97
A23.1. Indicators reflecting a specific action of the cancer plan ..................................................... 97

ACTION 24: SUPPORT OF PILOT PROJECTS IN CLINICAL ONCO-GERIATRICS ..................................... 98
A24.1. Scientific data on indicators .................................................................................................. 98
A24.1.1. Incidence of cancer in patients older than 70 years of age .................................................. 98
A24.1.2. Types of cancer in patients older than 70 years ................................................................. 99
A24.1.3. Tumour stage at diagnosis for geriatric oncpatients .......................................................... 100

A24.2. Indicators reflecting a specific action of the cancer plan ...................................................... 102

ACTION 25: ENSURE THE AVAILABILITY OF PALLIATIVE CARE FOR CANCER PATIENTS .......... 103

A25.1. Scientific data on indicators ..................................................................................................... 103
A25.1.1. Organisation of palliative care in Belgium ............................................................................ 103
A25.1.2. European guidelines .............................................................................................................. 105

A25.2. Indicators reflecting a specific action of the cancer plan ...................................................... 105

ACTION 26: INITIATIVES IN TALKS WITH THE AUTHORISED FEDERAL MINISTERS ..................... 106

A26.1. Scientific data on indicators ..................................................................................................... 106
A26.2. Indicators reflecting a specific action of the cancer plan ...................................................... 107
A26.2.1. Reconciliation of chronic diseases with professional commitments .................................... 107
A26.2.2. Simplification of the donation procedure ............................................................................. 108

DOMAIN 3: RESEARCH, INNOVATION AND EVALUATION .......................................................... 109

ACTION 27: ESTABLISHING A TUMOUR BANK ............................................................................... 109
A27.1. Indicators reflecting a specific action of the cancer plan ...................................................... 109

ACTION 28: STRUCTURAL FINANCING OF THE COORDINATION OF TRANSLATIONAL RESEARCH IN HOSPITALS .......................................................... 112
A28.1. Indicators reflecting a specific action of the cancer plan ...................................................... 112

ACTION 29: SUPPORT OF TRANSLATIONAL RESEARCH ................................................................ 112
A29.1. Scientific data on indicators ..................................................................................................... 112
A29.2. Indicators reflecting a specific action of the cancer plan ...................................................... 113

ACTION 30: APPLICATION OF HADRON THERAPY IN BELGIUM .................................................. 113
A30.1. Scientific data on indicators ..................................................................................................... 113
A30.2. Indicators reflecting a specific action of the cancer plan ...................................................... 113
A30.2.1. Feasibility study ..................................................................................................................... 113
A30.2.2. Reimbursement of hadron treatment abroad ...................................................................... 114

ACTION 31: REINFORCE THE FOUNDATION OF THE CANCER REGISTER .................................... 114
A31.1. Scientific data on indicators ..................................................................................................... 114
A31.2. Indicators reflecting a specific action of the cancer plan ...................................................... 116

ACTION 32: BELGIAN CANCER CENTRE ...................................................................................... 118
A32.1. Indicators reflecting a specific action of the cancer plan ...................................................... 118

References ..................................................................................................................................... 120

APPENDIX 1: List of abbreviations .................................................................................................. 128

APPENDIX 2: Lexicon ...................................................................................................................... 130
INTRODUCTION

Launched in 2008, the first Belgian Cancer Plan 2008-2010 featured 32 actions divided into three domains that were put forward in order to improve cancer control, to ultimately reduce the number of cancer cases and deaths, and to improve the quality of life of cancer patients in Belgium. The evaluation of this Cancer Plan is a critical main component in organising and managing cancer control and should help identify key successes and failures, while enabling policy makers in Belgium to better determine the most appropriate strategies of cancer control.

This document entitled ‘Evaluation of the Cancer Plan 2008-2010: Results 2011’, describes the objectives of the Cancer Plan 2008-2010 and presents what was achieved during this period, with the aim of assessing the implementation of the Cancer Plan 2008-2010 as well as the impact of actions specified in the Belgian Cancer Plan. One must note that the initiative on nutrition that was added to the Cancer Plan 2008-2010 during 2011 will not be discussed. This report is divided into three chapters or ‘domains’, covering prevention and screening, care for patients, and research, innovation and evaluation in which individual initiatives are presented.

The scientific setting is depicted for every action, followed by an update of its implementation that is measured using a set of indicators. The selection process of these indicators is described in documents 2 and 3 mentioned below. A number of selected indicators could however not be used for the evaluation of the Cancer Plan 2008-2010 because data with regard to these indicators were not yet available within the proposed time frame. The data and results presented in this evaluation were obtained from various sources responsible for the results used as scientific evidence. All data and results used have been checked with the sources concerned. It is to be noted that data from the National Institute for Health and Disability Insurance (NIHDI) were registered on the reimbursement date and not on the date of the medical intervention itself. There is a delay of about two months.

The design of the evaluation of the Cancer Plan 2008-2010 was carried out in six consecutive phases, each phase being described in one of the following documents:

2. Evaluation of the Cancer Plan 2008-2010: Literature review
All these documents can be obtained from our website (www.ekanker.be) or by e-mail (BelgiancancerCentre@wiv-isp.be).
DOMAIN 1: PREVENTION AND SCREENING

ACTION 1: REIMBURSEMENT OF CONSULTATIONS TO QUIT SMOKING

A1.1. SCIENTIFIC DATA ON INDICATORS

A1.1.1. Causal relationship between smoking and cancer development

Currently, there is indisputable evidence for a causal association between cigarette smoking and cancer. In fact, worldwide, tobacco exposure in all its forms is the most important lifestyle risk factor for cancer, being responsible for 31% and 6% of all cancer deaths in middle-aged men and women, respectively [1].

Cigarette smoke contains at least 80 known mutagenic carcinogens, including arsenic, cadmium, ammonia, formaldehyde and benzopyrene, each of which has a separate mechanism for causing cancer. In addition, cigarette smoke is a powerful carcinogen and a source of oxidative stress [2]. Tobacco smoking is recognised as the main cause of lung cancer. Tobacco smoking also increases the risk of cancer to the oral cavity, nasal cavities and nasal sinuses, pharynx, larynx, oesophagus (squamous cell carcinoma and adenocarcinoma), pancreas, liver, urinary bladder and renal pelvis, stomach, kidney (renal cell carcinoma), uterine cervix and myeloid leukaemia [3].

Moreover, there is some hazard to non-smokers being exposed to passive tobacco smoke, which has been classified by the International Agency for Research on Cancer (IARC) as a type I carcinogen in humans [4]. A particular type of involuntary smoking is related to smoking during pregnancy. The use of tobacco products by pregnant women hinders the blood flow to the placenta, which reduces the amount of nutrients that reaches the baby. As a consequence, smoking during pregnancy is associated with miscarriage, stillbirth, lower birth weight and sudden infant death syndrome, among others [3].

A1.1.2. Prevalence of smokers in Belgium

Based on information from the Belgian Health Interview Survey (HIS) [5], the percentage of smokers in Belgium dropped from 30% (1997), 29% (2001) and 28% (2004) to 25% in 2008 (Figure 1A). Adjusted for gender and age, this linear decrease was statistically significant. The percentage of daily smokers was about 24-25% from 1997 to 2004, but showed a significant decline in 2008 (Figure 1B).
Figure 1. Percentage of the Belgian population aged 15 years or more that (A) is currently smoking and (B) smokes daily, sorted by year and region. Adopted from [5].

Figure 1 also shows that, adjusted for gender and age, the proportion of smokers and daily smokers in Belgium in 2008 was significantly lower in the Flemish Region than in the Walloon Region.

With regard to the smoking behaviour of pregnant women, the trends are less positive. Figures from l’Office de la naissance et de l’enfance reveal that the proportion of women in Wallonia that smoke during pregnancy remained stable or even increased during the period 2006 to 2009 ([6], Figure 2).
For the Flemish Region, there is no such corresponding data available. A recent survey carried out in the period May 2008 to April 2009 by Steunpunt Welzijn, Volksgezondheid en Gezin showed that almost half of the number of women quitted smoking when becoming pregnant (the prevalence dropping from 22.7% to 12.3%) [7]. However, still 16.6% and 14.2% of children were exposed to tobacco, respectively during or following pregnancy, through their mothers who where either actively or passively smoking. Birth weight, birth length and head circumference of these babies were significantly smaller compared to babies that were not exposed to tobacco during pregnancy. Smoking behaviour before, during and after pregnancy seemed to depend strongly on socio-economic factors, with smoking prevalence being the highest among women who are socio-economically the weakest.

Using data from the four successive HIS carried out in Belgium in 1997, 2001, 2004 and 2008, Charafedine et al. also demonstrated a persistent social pattern of current smoking for Belgian males and females [8]. A faster drop in smoking rates was noted among the highly educated groups as compared to the lower educated ones (Figure 3). The prevalence of smoking actually increased among women with a low level of education. The disadvantage in smoking trends among the lower educated did not, however, induce a change of inequalities on the absolute level, which may be due to the general decreasing pattern in smoking, and especially the reduction in the size of the lower educated groups.
Contrary to the above-mentioned decrease in the numbers of smokers (as reported by the Belgian HIS), the IPSOS study performed in 2009 upon request of the Foundation against Cancer showed an increase in the percentage of daily smokers from 2002 to 2009 ([9], data not shown). On the other hand, at the European level decreasing trends in smoking behaviour have been noted ([10], Figure 4).
Another indication for the decreasing number of smokers is the observation that the cigarette sales in Belgium was falling from 2004 to 2009 [11]. Most likely, the decrease in the period 2008-2009 was at least in part due to the financial crisis, since the sales of tobacco is increasing slightly in 2010. In contrast with cigarettes, the sales of tobacco show more ups and downs and reached almost the same high level in 2010 as observed about 15 years ago.

**A1.1.3. Trends in lung cancer by gender over the last 10 years**

According to the data from the Belgian Cancer Registry (BCR), there has been a significant decrease in lung cancer incidence in males in the Flemish Region from 1999 to 2009. However, in females, the incidence showed a significant increase, especially among those aged 50 years and older. Since there is a time lag of about 20 years between smoking and lung cancer incidence [12-15], the increase among women might be explained by their increased smoking habits over the last decades. For Belgium, the Brussels-Capital Region and Wallonia, no trend analyses were available since data for these regions were only deemed complete from 2004 onwards.
A1.1.4. Trends in other smoking-related cancers by gender over the last 10 years

Trends with regard to the incidence of and mortality from other smoking-related cancers (such as cancer of the oesophagus, stomach, liver, pancreas, cervix, kidney and bladder) for the period 1999-2008 (Flemish Region) or 2004-2008 (rest of Belgium) can be consulted in [16].

A1.1.5. Impact of educational level on the association between smoking and mortality

Based on smoking-related information extracted from the Belgium HIS of 1997 and 2001, and a mortality follow-up of the survey respondents until the end of 2010, Charafeddine et al. investigated whether the level of education changed the association between smoking and mortality [17]. Their findings supported the hypothesis that educational attainment does not substantially influence the association between smoking and mortality, which is in line with previous studies carried out in England and the United States.

A1.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

A1.2.1. Anti-tobacco policies in Belgium
During the last 20 years, governments at the national and international level are more aware of the detrimental effects of smoking on (public) health, which has led to an increased number of measures and initiatives to control the use of tobacco. Figure 6 (next page) shows a timeline of the Belgian legislation regarding tobacco use since the first law of 1977 on the protection of consumers of food and other articles. For a detailed overview, refer to Documentatiemap Roken [11].

**A1.2.2. Controls on compliance to the tobacco legislation**

With the introduction of a general smoking ban in bars and restaurants on 1 July 2011, a milestone in the smoking legislation has been reached. If obeyed, smoking restrictions might diminish the health risk by reducing the involuntary exposure to smoke [18]. This makes appropriate controls on the compliance to the entire tobacco legislation an imperative. These controls are carried out by teams of inspectors of the Federal Public Service (FPS) Public Health and the FASFC (Federal Agency for the Safety of the Food Chain), which were reinforced by the Cancer Plan in September 2008 by six additional auditors. The mission of these FPS inspections encompasses several aspects (http://www.health.belgium.be):

- Prohibition of smoking in public buildings
- Prohibition of selling tobacco products to young people under the age of 16
- Prohibition of advertising on tobacco products
- Management of vending machines of tobacco products
- Regulations on labelling tobacco products

The FASFC is responsible specifically for the controls on compliance to the smoking ban in restaurants whereas the FPS Public Health controls the compliance to the smoking ban in bars. Table 1 shows the number of controls on compliance to the tobacco legislation by the inspectors of the FPS Public Health and FASFC. In the period January to June 2011, the inspectors registered 52.3% violations of smoking legislation in bars. Following the introduction of the unambiguous, general smoking ban on 1 July 2011, only 10% non-conformities during regular control events were recorded in the period July-December 2011. In particular, in the period November-December 2011 the percentage of non-conformities was higher than in the period September-October 2011 due to an increased number of complaints received at the Contact Centre of the FPS Public Health at the end of 2011 together with a more dynamic follow-up of these complaints. Also, following specific controls performed at night subsequent to complaints received at the Contact Centre of the FPS Public Health, violation rates increased up to 25% (personal communication Paul Van den Meerssche). For restaurants, the legislation did not change, and a similar violation rate was observed in the first and second semester of 2011.

<table>
<thead>
<tr>
<th>YEAR</th>
<th>FPS</th>
<th>FASFC</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>18,300</td>
<td>2,535</td>
</tr>
<tr>
<td>2007</td>
<td>18,000</td>
<td>11,979</td>
</tr>
<tr>
<td>2008</td>
<td>18,600</td>
<td>5,290</td>
</tr>
<tr>
<td>2009</td>
<td>19,800</td>
<td>11,738</td>
</tr>
<tr>
<td>2010</td>
<td>25,500</td>
<td>12,769</td>
</tr>
<tr>
<td>2011</td>
<td>24,250</td>
<td>10,381</td>
</tr>
</tbody>
</table>

**Table 1.** Overview of controls on compliance to tobacco legislation by the FPS Public Health and FASFC. The controls carried out by the FPS Public Health and FASFC inspectors concern inspections in restaurants and bars.
Figure 6. Timeline of Belgian legislation regarding tobacco use. RD, Royal Decree.
**A1.2.3. Visits to the smoking cessation specialist to give up smoking**

Since giving up smoking is difficult the Cancer Plan includes a number of initiatives to encourage efforts to stop smoking [19]. For smokers who want to give up smoking, since 1 October 2009 the Cancer Plan provides a fixed reimbursement of consultations at a medical doctor or a smoking cessation specialist\(^1\). Every two years, a smoker can have eight visits that will be reimbursed: €30 for the first session (at least 45 minutes) and €20 for a maximum of seven subsequent sessions (at least 30 minutes). Pregnant women who visit a smoking cessation specialist or a medical doctor benefit from a forfeit of €30 for each session (maximum eight sessions).

Since the introduction of this specific measure until the end of 2011, a total of 62,929 sessions at the smoking cessation specialist or a medical doctor were registered (including first and follow-up sessions and sessions of pregnant women).

Figure 7 and Figure 8 illustrate that every year a growing number of smokers are seeking help to quit smoking at a smoking cessation specialist or a medical doctor. Based on the numbers of first sessions, it can be deduced that the number of smokers who made use of this financial compensation were 763 in 2009, 9,262 in 2010 and 12,500 in 2011.

Since there is no distinction between first sessions and follow-up sessions for pregnant women, we cannot analyse how many pregnant women got help to quit smoking from a smoking cessation specialist or a medical doctor.

Not considering the sessions for pregnant women, this means that from October 2009 until June 2011 a total of 16,489 smokers went at least once to a smoking cessation specialist or a medical doctor. This represents 0.61% of the target population, assuming that 25%\(^2\) of the population were smokers on 1 January 2010.

---

\(^1\) called 'tabakoloog/tabacologue' in Belgium

\(^2\) As determined by the Health Interview Survey of 2008.
Based on these figures, the NIHDI concluded that this initiative seems to be more effective than previous efforts to encourage people to quit smoking, which were limited to pregnant women and their partners. A possible explanation could be a greater access to support for tobacco withdrawal by the medical doctor or recognised smoking cessation specialists.

Since the launch of the reimbursements until 30 June 2011, there were 1.7 follow-up sessions for each initial session. In other words, a smoker visited their smoking cessation specialist about 2.7 times. It is still unclear whether this is sufficient and whether the smoker stopped smoking or they abandoned their efforts to quit smoking. A recent meta-analysis indicates that the addition of further follow-up to a minimal intervention had a slightly larger estimated effect on cessation rates compared to a single visit to the physician. This effect might be larger when provided to smokers in high risk groups [20].

For an in-depth analysis of the provider, the patient and the outcome of the quitting smoking support, data on their profiles and follow-up is needed.

To sustain caregivers in assisting smokers in the process of giving up smoking, the Cancer Plan also provides training to become a smoking cessation specialist. Organising this training was assigned to Fonds des Affections Respiratoires (FARES) for Wallonia and Vlaamse vereniging voor Respiratoire Gezondheidszorg en Tuberculosebestrijding (VRGT) for Flanders. During this one-year training, participants acquire the skills to guide and support smokers who want to quit. Table 2 summarises the number of participants for both institutions for two sequential school years, since these trainings were funded by the Cancer Plan in September 2009.

<table>
<thead>
<tr>
<th>Year</th>
<th>FARES</th>
<th>VRGT</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009-2010</td>
<td>55</td>
<td>24</td>
<td>79</td>
</tr>
<tr>
<td>2010-2011</td>
<td>56</td>
<td>59</td>
<td>115</td>
</tr>
<tr>
<td>TOTAL</td>
<td>111</td>
<td>83</td>
<td>194</td>
</tr>
</tbody>
</table>

Table 2. Number of participants to the training smoking cessation specialist at FARES and VRGT per year that financing was provided.
Assuming that 25%³ of the Belgian population older than 15 years of age smokes, this means that there is now one trained smoking cessation specialist for every 14,175 smokers.

Besides the Cancer Plan, there are also other initiatives to encourage the cessation of smoking, such as ‘Tabakstoplijn/Ligne Tabacstop’ mentioned on tobacco products, Centres d’aide aux fumeurs (CAF), support groups, projects financed by the ‘Fonds ter bestrijding van het tabaksgebruik/Fonds de lutte contre le tabagisme’, and more.

**ACTION 2: DETECTION AND COUNSELING OF PERSONS AT RISK WITH A GENETIC PREDISPOSITION TO DEVELOP CANCER**

**A2.1. SCIENTIFIC DATA ON INDICATORS**

Cancer incidence increases with age. However, people with a genetic predisposition have a higher risk of developing cancer at an early age compared to those developing sporadic cancer [21]. The proportion of patients having a genetic predisposition is discussed in A2.1.1. Among these patients, those that survive cancer have also a somewhat higher risk of developing a second tumour within the first ten years. This is discussed in A2.1.2. Remark that the development of a second tumour can also occur in patients without a genetic predisposition as a result of factors related to the treatment of the first tumour [22].

**A2.1.1. Proportion of cancer patients that develop cancer due to a genetic predisposition**

Today, a growing proportion of 5% to 10% of all cancers develops in individuals who have inherited a genetic mutation conferring them heightened susceptibility to specific cancers [21]. The past 20 years, many cancer susceptibility genes have been identified. As a consequence, in oncology, genetic testing is being used more and more often to identify individuals with germline mutations predisposing them to hereditary cancers [23]. Risk assessment by genetic testing is offered mainly for several well-defined, hereditary malignant diseases caused by germline mutations with high penetrance and can enable targeted preventative treatments. (High penetrance refers to the great likelihood that a tumour will be diagnosed during a patient’s lifetime because of the respective germline mutation.) An extensive list of syndromes of cancer predisposition and their associated genes can be consulted in [21]. Hereditary breast cancer and ovarian cancer, prostate cancer and colorectal cancer (see also below) are among the major inherited cancer syndromes [21].

As mentioned above, hereditary cancer syndromes are associated with an earlier age of onset compared with sporadic cancers. In this regard, the BCR calculated the number of Belgian patients younger than 50 years of age diagnosed with cancer in 2009 at 7,302. In particular, the number of these patients that developed breast, ovarian and colorectal cancer between 1999 and 2009 is shown in Table 3.

**A2.1.2. Incidence of second tumours**

As indicated, cancer survivors have a somewhat higher risk of developing a second tumour within ten years, which is partly due to genetic factors, but can also be due to factors related to the treatment of the first tumour [22]. To illustrate this, the BCR calculated the number of second tumours in Belgian patients, younger than 60 years of age, following an earlier diagnosis of breast, colorectal or ovarian cancer between 1999 and 2009 in the Flemish Region. Patients were followed until the end of 2009. The average interval between the first and the second tumour, the type of second tumour

---

³As determined by the Health Interview Survey of 2008.
and the average length of the observation period for these patients are shown in Table 3. In order to compare, corresponding results are also shown for patients aged 60 years or above (except for type of the second tumour).

<table>
<thead>
<tr>
<th></th>
<th>BREAST</th>
<th>COLORECTAL</th>
<th>OVARY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENTS &lt;50 Y</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total N° of patients</td>
<td>13,444</td>
<td>2,641</td>
<td>860</td>
</tr>
<tr>
<td><strong>PATIENTS &lt;60 Y</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total N° of patients</td>
<td>27,608</td>
<td>8,338</td>
<td>1,981</td>
</tr>
<tr>
<td>N° (and percentage) of patients with 2\textsuperscript{nd} tumour</td>
<td>1,568 (5.68%)</td>
<td>406 (4.87%)</td>
<td>103 (5.20%)</td>
</tr>
<tr>
<td>Mean interval between 1\textsuperscript{st} and 2\textsuperscript{nd} tumour</td>
<td>31.6 months</td>
<td>31.2 months</td>
<td>26.0 months</td>
</tr>
<tr>
<td>Mean observation period</td>
<td>59.6 months</td>
<td>47.8 months</td>
<td>51.9 months</td>
</tr>
<tr>
<td><strong>Type of second tumour</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Head &amp; neck</th>
<th>Digestive organs</th>
<th>Respiratory organs</th>
<th>Bones, articular cartilage &amp; soft tissue</th>
<th>Malignant melanoma</th>
<th>Mesenchymal</th>
<th>Breast</th>
<th>Female genital organs</th>
<th>Urinary tract</th>
<th>Eye &amp; CNS</th>
<th>Thyroid &amp; other endocrine glands</th>
<th>Hematologic tumours (incl MDS, MPD)</th>
<th>Unknown primary and ill defined sites</th>
<th>Unknown primary and ill defined sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>58.7%</td>
<td>9.4%</td>
<td>6.5%</td>
<td>3.4%</td>
<td>1.2%</td>
<td>0.7%</td>
<td>2.8%</td>
<td>1.1%</td>
<td>0.1%</td>
<td>1.2%</td>
<td>4.9%</td>
<td>0.1%</td>
<td>1.2%</td>
<td></td>
</tr>
<tr>
<td><strong>PATIENTS ≥ 60 Y</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total N° of patients</td>
<td>29,423</td>
<td>37,648</td>
<td>3,807</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N° (and percentage) of patients with 2\textsuperscript{nd} tumour</td>
<td>2,324 (7.9%)</td>
<td>2,941 (7.8%)</td>
<td>175 (4.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean interval between 1\textsuperscript{st} and 2\textsuperscript{nd} tumour</td>
<td>25.4 months</td>
<td>25.7 months</td>
<td>19.1 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean observation period</td>
<td>50.1 months</td>
<td>37.1 months</td>
<td>30.6 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Number of patients (aged 15 years or older) diagnosed with breast (females only), colorectal or ovarian cancer before the age of 50 years, or with a second tumour after being diagnosed with breast (females only), colorectal or ovarian cancer below or above the age of 60 years in Flanders, incidence years 1999-2009 (numbers provided by the BCR).
22

**A2.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

The Cancer Plan wants to provide support for people with a genetic predisposition to develop cancer by reimbursing the costs of genetic testing to detect genetic defects. As a result, the nomenclature concerning human genetics is under review. The work group ‘Clinical biology’ of the Medical Technical Board has elaborated a proposal for these new nomenclature codes in human genetics, which was approved in September 2011. The National Commission of Physicians and Sickness Funds accepted the proposal on 7 November 2011. The implementation of these reimbursements awaits the approval of the convention regarding genetic counselling. The objective of this convention is to re-evaluate genetic consultations by raising the fees of physicians with an expertise in genetics accordingly. During the discussions, it became clear that the paramedic framework also needed to be reinforced. An extended proposal was finalised in November 2011 in close collaboration with the centres for human genetics. As mentioned before, this proposal awaits approval of the institutions responsible within the NIHDI.

In a joint effort with the Rare Diseases Plan, DNA tests performed abroad will also be reimbursed in the near future. This initiative wants to support people with a rare genetic defect for which no specialised lab capable of analysing these malignancies is present in Belgium. Currently, such a reimbursement is only done if the patient travels abroad and the test is reimbursed in the country of their destination. This initiative is included in the proposal concerning the re-evaluation of genetic counselling and should probably be approved during 2012.

Finally, the Cancer Plan would like to make the specialism of genetics more attractive to professionals by eliminating the financial barriers for patients with a potential genetic predisposition.

**ACTION 3: EXTENSION OF THE AGE RANGE FOR VACCINATION AGAINST HPV FOR GIRLS FROM 12 TO 18 YEARS**

**A3.1. SCIENTIFIC DATA ON INDICATORS**

**A3.1.1. Causal relationship between cervical cancer and human papillomavirus infection**

Human papillomavirus (HPV) is one of the most common sexually transmitted infections, with a high prevalence in sexually active adolescents and young adults, and is the primary risk factor for cervical cancer. In most cases, HPV infection is cleared by immunological intervention without ever developing clinically recognised manifestations. The progression of HPV infection into invasive cervical cancer depends, among others, on the HPV type. There are over 100 strains of HPV, and approximately 40 infect the anogenital epithelium. The majority of HPV-associated diseases is caused by four HPV types: the low-risk types HPV 6 and 11 are associated with about 90% of genital warts and low-grade cervical abnormalities, and the high-risk HPV types 16 and 18 both account for approximately 70% of all high-grade cervical intraepithelial neoplasia (CIN) or dysplasia and invasive cervical cancer, causing significant morbidity and, in the case of cervical cancer, mortality (for extensive reviews, see [24;25]).

Although current screening methods have proven to be effective in reducing cervical cancer incidence and associated mortality rates, these rates vary greatly within population subgroups, with ethnic minority and low-income women significantly more likely to be diagnosed with cervical cancer and to die from the disease (see also below). Therefore, identifying HPV as the causal agent in nearly all cases of cervical cancer and the availability of an effective prophylactic vaccine may further reduce the cervical cancer disease burden.
Currently, there are two licensed prophylactic HPV vaccines: (i) Gardasil®, produced by Merck and Co and approved by the European Medicines Agency (EMA) in 2006, which protects against HPV types 6, 11, 16 and 18, and (ii) Cervarix®, produced by GlaxoSmithKline and approved by the EMA in 2007, which protects against types 16 and 18. Phase III trials demonstrated that the vaccines protect against CIN and adenocarcinoma in situ (AIS) associated with the targeted HPV types under the condition that subjects were not infected with one or more vaccine types at baseline [26]. Modest cross-protection to closely related high-risk types HPV 31, 33, 45 was found with the bivalent vaccine (Cervarix®) and also to some extent with the quadrivalent vaccine (Gardasil®). However, today there is no concrete information available on long-term (>10 years) efficiency of the vaccines and the necessity of a booster.

In order to be prophylactic, both vaccines need to be administered before the individual is exposed to the HPV types covered by the vaccine [27]. In Belgium, a survey among school-aged children from East and West Flanders revealed that the mean age for the first sexual contact is 15.5 years [28], therefore, vaccination at an age of 12 to 14 years, just before the initiation of sexual contact or at childhood age seems like an obvious strategy. On the other hand, females of 15 to 26 years old (those most at risk of exposure) may represent a ‘catch-up’ population for vaccination. However, higher antibody responses are observed when vaccinated at the age of 9 to 15 compared to the age of 16 to 26.

A3.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

A3.2.1. Coverage of HPV vaccination

In 2007 the Belgian Superior Health Council (SHC) recommended that organised (i.e. school-based) HPV vaccination should be offered each year to a one-year birth cohort of girls aged 10, 11, 12 or 13 years (http://www.health.belgium.be). From September 2010 onwards, school-based HPV vaccination was introduced in Flanders for girls aged 12 years. Until then, the initiative to be vaccinated was taken by the girls, their families or the physicians (general practitioners/paediatricians/gynaecologists).

Opportunistic reimbursed vaccination

According to data from the NIHDI during the period 2006 to 2011, the coverage reached by opportunistic reimbursed vaccination in Belgium was moderate and the trend was decreasing. In particular, the coverage of 12 to 13 year-old girls, which represent the main target group, reached by opportunistic vaccination, was low ([29], Figure 9).
Figure 9. Number HPV vaccines sold (IMS – bars) and reimbursed (NIHDI – lines) per month in Belgium, for the period 2006-2011. (Taken from [29]).

Lefevere et al. analysed the HPV vaccination initiation in Flanders during the first 2.5 years after the vaccines were introduced in the Belgian market and before the HPV vaccines were offered free of charge through the school-based vaccination system [30]. Vaccination uptake was found to be affected by both individual and organisational factors, with substantially lower uptake among girls from lower socio-economic backgrounds, a substantially higher probability of vaccination initiation among older girls than younger girls, a higher vaccination coverage among girls whose mother was participating in cervical cancer screening, and an increased vaccination coverage following campaigns using personal letters [30;31].

Thanks to the Cancer Plan, the reimbursement of the HPV vaccine was extended to girls up to 18 years old, starting on 1 December 2008 (Figure 9), meaning that the cost for girls of this age group decreased from €412 to €33 (€11 per dose). Before this, reimbursement was limited to girls aged 12-15 years. Analysis of the registration data on HPV vaccination (Farmanet) from November 2007 until December 2010 by the NIHDI reveals that about 45% of the targeted population has received at least one dose of the HPV vaccine. In the same period, 35% of the targeted population received all 3 doses. With regard to girls younger than 15 years, 24% of them got at least 1 dose of the HPV vaccine, whereas 15% of them completed the vaccination scheme.

**Organised vaccination**

In September 2010, the first organised vaccination campaign was started in the Flemish Region for girls aged 12 to 13 years, or born in 1998, with the Gardasil® vaccine. Before the start of the programme a leaflet was made to be used in schools with a link to an informative website (http://www.zorg-en-gezondheid.be/HPV). The vaccination was mainly school-based (90% of vaccinations was performed through School Health Services (SHS, Centra voor Leerlingenbegeleiding (CLB)), whereas general practitioners and paediatricians contributed for 10% [32]. The coverage in this first year of organised vaccination was substantially higher (about 85%-90%) than that obtained through opportunistic vaccination, at a cost of about six times less (Table 4).
Table 4. Number of vaccinations per birth cohort, as registered by Vaccinnet from September 2010 till June 2011, for the first (HPV1), second (HPV2) or third (HPV3) dose. The number of HPV1, HPV2, and HPV3 vaccinations given by the SHS (CLB) is shown separately. Data collection for HPV3 is still incomplete (Data source: [32]).

Remark that the relative number of registrations within girls born in 1996 (and part of those born in 1997) is higher than within girls born in 1998. Presumably, a part of the first group of girls has already passed first year of secondary school. However, since no link can be made with school level, this hypothesis can not be verified. The data of the girls born in 1998 probably best reflect the true vaccination rate of the target group.

No data are yet available from the French Community as the school-based HPV vaccination was only introduced during the school year 2011-2012. Starting September 2011, the Cervarix® vaccine will be freely available for girls in their second year of secondary school. Three doses will be administered with a minimum interval of six months between the first and the last dose. An information leaflet will be distributed to these girls and their parents to notify them about this new inclusion in the school-based vaccination programme. More information can be found on http://www.sante.cfwb.be.

**ACTION 4: IMPROVE DETECTION AND EARLY DIAGNOSIS OF BREAST CANCER**

**A4.1. SCIENTIFIC DATA ON INDICATORS**

**A4.1.1. Coverage of breast cancer screening**

Breast cancer is the most frequent cancer and accounts for the largest number of cancer-related deaths in women in Europe [33]. Although there is some debate about the association between mammography screening and breast cancer mortality [34;35], the scientific majority agrees that there is sufficient evidence that screening for breast cancer with a mammography can reduce mortality from this disease, at least in women aged 50 years and over [3;36]. In 1985, the first ‘Europe against Cancer’ programme encouraged extending systematic population-based screening throughout Europe with the goal of reducing breast cancer mortality through early detection of cancer, prior to developing more life-threatening advanced stages. To be efficacious, a minimum screening participation rate of 70% was recommended [36]. In 1989, a breast screening network (European Breast Screening Network) was established by the first pilot projects for breast cancer screening co-funded by the EAC programme. Four years later, the European Parliament set out fundamental principles of best practice in early detection of cancer in its Council Recommendation, which represented a shared commitment by the EU member states to implement organised screening programmes [37].

Based on the European guidelines, a national biannual screening programme was established in Flanders in 2001, and one year later in Brussels and Wallonia for women 50-69 years old, registered
for health insurance and with a record at the national population register. The most recent report of the Intermutualistic Agency (IMA), which pools information from all social health insurance companies in Belgium, revealed that coverage in Belgium is growing ([38], Figure 10). In 1999-2000, before the onset of the organised screening programme, 38% of women aged between 50 and 69 underwent a diagnostic mammography, and around 2005 this proportion had increased to about 56%. In 2006-2007, the total coverage, including screening as well as diagnostic mammography, approached 61%, half of which was performed in the context of the organised breast screening programme. The proportion of women undergoing a mammography was comparable in the three regions. However, in Flanders about two thirds of screening examinations were done as part of the organised programme, compared to one sixth in Brussels and Wallonia.

![Figure 10.](image)

Figure 10. (A) Coverage of screening mammography and (B) total coverage, including screening as well as diagnostic mammography, by district. (Taken from [38]).

Whether women were participating in organised screening programmes seemed to correspond to the practice of having a spontaneous mammography before the onset of the national screening programme [38]. Concurrently, breast screening programmes had the largest encouraging effect on
older women and women who were weaker socio-economically. However, participation rates within the latter group remained 23% lower compared to the rest of Belgian women. Further investigation by IMA into the reasons of non-participation in breast cancer screening programmes in Belgium is currently being carried out.

A4.1.2. Breast cancer incidence, mortality and survival

Incidence
Breast cancer is the most common cancer among females in Belgium (BCR). For Belgian women, the risk of being diagnosed with the disease before the age of 75 years is about 11%. In 2009, 9,596 diagnoses of invasive breast cancer were made in Belgium, with the highest incidence rates in Wallonia and the Brussels-Capital Region. In 2008, Belgium ranked first for the age-standardised incidence rate (WSR) in Europe, which was explained by a combination of factors, such as low fertility indices and high use of hormonal replacement therapy, coinciding with screening effects [39].

Data from breast cancer screening in Flanders during the period 2003-2009 showed that the proportion of in situ tumours was larger within the group of screen detected breast tumours compared with the interval cancers and the cancers in non-screened patients (BCR, Figure 11). Carcinoma in situ of the breast is a precursor of invasive breast cancer and progression towards invasive disease should be avoided. Through screening, invasive tumours were diagnosed at an earlier stage, ensuring a better prognosis (Figure 11). [Since it is not known whether the tumours in the non-screened patients were diagnosed by opportunistic screening or after clinical symptoms occurred, breast cancer in this group might be diagnosed at a higher stage.] In the screen-detected cancers, a percentage of 83.4% of invasive tumours was obtained, indicating that the European desired standard level of 80-90% was met [36].

![Distribution of stages among breast cancer detection groups in Flanders](image)

**Figure 11.** Distribution of stages among breast cancer detection groups in Flanders. Data source: BCR data linked to Heracles 2003-2009 (= Breast cancer screening in Flanders).

When monitoring the incidence of preinvasive and invasive breast cancer over an 11-year period (1999-2009) in Flemish women, the incidence of carcinoma in situ significantly increased (estimated annual percentage change (EAPC) = 4.0% (p=0.01)). The incidence of pT1 tumours exclusively
increased in the age group 50-69 years until 2003 and decreased thereafter (BCR, Figure 12C). This evolution was attributed to the combined influence of setting up the screening programmes in 2001 and the administration of hormonal replacement therapy at menopausal age in the early 2000s. Once its negative impact became clear, hormonal replacement therapy was no longer extensively used in clinical practice, contributing to the decrease in incidence from 2003 onwards. In the other age groups, the incidence of pT1 tumours remained stable over time (Figure 12B and D). The pT2 tumours were the most frequently observed tumours in women of 70 years and older, and significantly increased during the 11-year period (EAPC = 2.2% [p=0.001]). A significant decrease was observed for pT2 in the age group 50-69 years (EAPC = -1.7% [p = 0.01], and no significant trend was observed in the age group 0-49 years. For pT3 tumours, no significant trend was observed in any age group (Figure 12). For pT4 tumours, however, a significant decrease was noted in all age groups.

Figure 12. Trends for breast cancer by pT in Flemish women for the age group (A) all ages (B) 0-49 years (C) 50-69 years and (D) 70+ years. WSR, World age-standardised incidence rate; pT1: tumour ≤ 2 cm across; pT2: 2cm < tumour ≤ 5 cm across; pT3: tumour > 5cm across; pT4: tumour of any size growing in the chest wall or skin (incl. inflammatory breast cancer) (BCR). To be continued.
Mortality

With about a 20% mortality rate (representing 2,329 deaths), death from breast cancer was the most frequent cause of death by cancer among Belgian females in 2008 (BCR). As for incidence, in 2008 Belgium also ranked first for breast cancer mortality when compared to other European countries. Renard et al. analysed breast cancer mortality data from 1954 to 2006 and found that mortality increased until the late 1980s to then decrease in all regions and in all age groups younger than 70 ([39], Figure 13). The period of increase (1954-1986) was attributed to an increase in incidence, whereas the subsequent decline in mortality (after 1986) most probably corresponded to an improvement in survival rather than a decrease in incidence, as many risk factors of incidence continued to increase until the end of the century. Since the decline in breast cancer mortality started before the implementation of nationwide breast cancer screening and had reached unscreened age groups, the relative contribution of screening to the mortality decline observed since 1986 was supposed to be low. The decrease in mortality rates in older women was observed later than in the other age groups, suggesting less efficient treatment schemes in this age group (Figure 13).
Relative survival

Unless otherwise stated, survival results in this document are expressed by the relative survival, which corresponds to the ratio of the observed survival in a group of cancer patients to the survival that would be expected for a group in the general population with the same age as the patients at diagnosis. Relative survival is a good estimate for the disease specific survival. The expected survival rate is based upon age-specific mortality rates (life tables).

According to survival data from the BCR for women diagnosed with invasive cancer between 2004 and 2008, the survival rate for stage I invasive cancer was close to 100% (Table 5). Patients diagnosed with stage II or III invasive breast cancer still had more than a 70% chance of survival after five years. Even if disseminated towards distant organs, breast cancer, when compared to other cancer types, is not fatal at five years for a substantial percentage of patients (around 30%). Five-year relative rates were lower in women older than 70 years compared to those aged between 0-69 years, which was, at least in part, explained by the prevalence of more advanced stages in the oldest age group.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>All Stages</th>
<th>Stage I</th>
<th>Stage II</th>
<th>Stage III</th>
<th>Stage IV</th>
<th>Stage X</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-49 year</td>
<td>92%</td>
<td>99%</td>
<td>94%</td>
<td>80%</td>
<td>41%</td>
<td>86%</td>
</tr>
<tr>
<td>50-69 year</td>
<td>91%</td>
<td>99%</td>
<td>94%</td>
<td>78%</td>
<td>31%</td>
<td>81%</td>
</tr>
<tr>
<td>70+ year</td>
<td>79%</td>
<td>100%</td>
<td>90%</td>
<td>64%</td>
<td>23%</td>
<td>58%</td>
</tr>
<tr>
<td>All Ages</td>
<td>88%</td>
<td>100%</td>
<td>93%</td>
<td>74%</td>
<td>29%</td>
<td>73%</td>
</tr>
</tbody>
</table>

Table 5. Five-year relative survival rates for females with invasive breast cancer diagnosed between 2004 and 2008 in Belgium (BCR).
A4.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

A4.2.1. Breast cancer screening and follow-up examinations

One of the initiatives of the Cancer Plan is to improve the quality of the screening for breast cancer. Therefore, quality criteria for mammographies in both a diagnostic and screening context should be the same\(^4\). The proposal of the Technical Medical Council (TMC) describes modifications to the regulations related to mammographies. A refund of mammographies will only be made when the equipment used is approved according to the European guidelines [36]. The proposal was approved on 18 May 2010 by the TMC, but still needs to be discussed by the National Commission of Physicians and Sickness Funds (NIHDI).

The Communities are responsible for the quality audits of the mammography devices held twice a year, in close collaboration with the Federal Agency for Nuclear Control (FANC).

To meet the demands of the Minister of Health in providing free follow-up examinations in case an anomaly is found in the mammography and free screening for women at high risk, the nomenclature concerning breast cancer screening needed to be revised. The revision had to consider the opinion of several organisations and experts who were invited to discuss the proposal in the Medical Imaging work group. A distinction was made between women without symptoms and normal risk, women without symptoms but with a high-risk profile, and finally women with symptoms. The proposal describes the conditions to be met for the reimbursement of mammographies and ultrasounds in each separate risk group. Ultrasounds are free for women with a deviating mammography. The inter-cabinet Cancer work group of September 2010, comprised of representatives of the NIHDI, the Communities and the reference centres, discussed the proposal. A roundtable was organised in September 2011 to take into account every different point of view, which will continue in early 2012.

The definition of the risk profile could still be adapted according to the recently published report of the Belgian Health Care Knowledge centre (KCE) [40]. This study identifies several groups of women who are considered at high risk for developing a breast tumour, for instance familial prevalence, radiation of the upper body at a young age, elevated breast density, etc. An overview of these risk factors for developing breast cancer is given in Table 6. The report advises that for women at high risk a more in depth assessment is done by experienced and qualified persons, followed with an information supply and discussion with the patient. Who or which health structures can be considered as sufficiently qualified still needs to be determined. A flow chart on recommendations for screening per risk group is shown in Figure 14. The report also advises not to use ultrasound screening in a population-based screening programme since the recall rate and number of false positives is too high and the additional cancer detection rate is minimal [40].

\(^4\)For example, in the Flemish organised breast screening programme, a procedure for a daily, weekly, half-yearly and yearly physical and technical check-up is included (Flemish Government Decree 16 March 2012). Also medical and radiological check-ups are performed. In addition, for digital devices a permission request has to be addressed to the Flemish work group ‘Bevolkingsonderzoek naar borstkanker’.
A. FAMILY HISTORY

Average risk
- Maximum 1 first-degree or second-degree relative diagnosed with breast cancer at older age than 40 years

Raised risk (i.e. a 10-year risk at age 40-49 of 3-8%, or a lifetime risk of 17-30%)
- 1 first-degree relative diagnosed with breast cancer at age younger than 40 years
- 2 first-degree or second-degree relatives diagnosed with breast cancer at an average age of 50 years or older
- 3 first-degree or second-degree relatives diagnosed with breast cancer at an average age of 60 years or older

High risk (i.e. a 10-year risk at age 40-49 of >8%, or a lifetime risk of >30%)
- 2 first-degree or second-degree relatives diagnosed with breast cancer at an average age younger than 50 years (at least 1 must be a first-degree relative)
- 3 first-degree or second-degree relatives diagnosed with breast cancer at an average age of 60 years (at least 1 must be a first-degree relative)
- 4 relatives diagnosed with breast cancer at any age (at least 1 must be a first-degree relative)
- Jewish ancestry
- One of the following is present in the family history:
  - Bilateral breast cancer;
  - Male breast cancer;
  - Sarcoma in a relative younger than 45 years of age;
  - Glioma of childhood adrenal cortical carcinomas;
  - Complicated patterns of multiple cancers at young age;
  - Very strong paternal history (4 relatives diagnosed at an age of 60 years or younger on the father’s side of the family)

B. OTHER RISK FACTORS

- Persons with a past history of mantle irradiation for Hodgkin lymphoma should be considered at high risk
- Women with very dense breast tissue (BIRADS 4) could be considered as raised risk (life-time risk ± 17%)
- Lobular and ductal atypical hyperplasia should be considered as high risk
- Other risk factors such as BIRADS 3, obesity, alcohol intake, hormone replacement therapy, early menarche, nulliparity, oral contraceptives, or exogenous hormones (such as Diethylstilbestrol or DES) should be used only as an element integrated in comprehensive risk models as they are only moderately or modestly associated with breast cancer

Table 6. Risk factors identifying women at risk for breast cancer. Taken from [40].
Figure 14. Flow chart on recommendations for screening per risk group (Taken from [40]). Remark, for women at proven high risk for breast cancer, yearly MRI and mammography is recommended from the age of 30 years onwards or starting five years before the age of the youngest diagnosed family member with breast cancer.

Another action addresses the invasive diagnostic examinations related to breast cancer screening. The TMC agreed to reimburse four new medical acts for breast punctures, including the devices used. The National Commission of Physicians and Sickness Funds approved these additions, which were inaugurated on 1 November 2011 (Royal Decree of 1 September 2011).

The KCE investigated the effects of a potential extension of the current target group for screening to women of 40 to 49 years old [41]. The researchers concluded that this would have more downsides than benefits since the risk of dying from breast cancer in this age group is relatively low. Systematic screening of these women could prevent 24 deaths by breast cancer annually, but could initiate 40 additional cancers and 16 deaths caused by the radiation of mammographies. Likewise, the KCE did not advise to extend the target group to 70 to 74 year old women, since there is evidence that this has only modest effect on the number of life years saved, and it may even lead to a loss of quality of life [42].

ACTION 5: SYSTEMATIC SCREENING OF CERVICAL CANCER

A5.1. SCIENTIFIC DATA ON INDICATORS

A5.1.1. Coverage of cervical cancer screening

Among all malignant tumours, cervical cancer is the one that can be most effectively controlled by a well-organised cytological screening. Since the progression of cervical cancer, from a precursor lesion into an invasive stage, is a multi-step process and may take as long as 10 to 20 years, and since timely
diagnosis by cervical cytological examination and adequate treatment of precursor lesions can diminish cervical cancer incidence up to 80%, cervical cancer seems to be an ideal candidate for screening [43]. In 2003, the Council of Europe recommended the implementation of population-based cervical cancer screening to women of the target population, aged 25 to 64, with three to five-year intervals, in all EU Member States according to the European guidelines [44,45]. To be efficacious, a minimum screening participation rate of 85% was recommended [46]. Although cervical cytology still is the cornerstone of cervical cancer prevention programmes in Europe, new perspectives for other screening technologies are developing rapidly. According to a report of Arbyn et al., testing for HPV was found to be superior in predicting cervical cancer than a cervical smear test. In agreement with the current situation in the Netherlands, introduction of HPV-based screening should also be considered in Belgium [29].

In Belgium, current screening practices are essentially opportunistic. In their recent report, Arbyn et al. analysed individual patient records on cervical screening, collected by the IMA during the period 2002-2006 and found that the screening coverage was comparable throughout the different regions and, overall, had increased by 2% from 2000 onwards, reaching 61% in 2006 ([47], Figure 15). The one-year and three-year screening coverage seemed to peak in the age group of 25 to 34 years. Remarkably, in the whole Belgian target population, women with a special increased reimbursement status for health care displayed a lower coverage (40%) than women not having this benefit (64%). In general, there was a tremendous overuse of cervical smears since the amount of smears taken was theoretically sufficient to cover more than 100% of the target population over a time span of three years. The excess use of cervical smears was the highest in the age group of 25 to 34 years. In 2006, these figures implied that each screened woman received 1.88 smears over a three-year period.

Figure 15. Trend of three-year coverage for cervical cancer screening among women 25 to 64 years old, evaluated in the years 1998, 2000, 2004 and 2006, (Belgium, 1996-2006). Observed values: green circles; fitted values: red line (linear regression) (Taken from [47]).

A5.1.2. Cervical cancer incidence, mortality and survival

Incidence and mortality

According to records of the BCR in 2009, cervical cancer was the eleventh most frequent tumour in Belgium with 612 Belgian women being diagnosed with invasive cervical cancer (Table 7). Death due
to cervical cancer was rather low (186, i.e. 1.6%, women died from the disease in 2008), putting cervical cancer in 17th position of all cancer deaths in Belgium in 2008. When comparing data from 2004 and 2009, an increasing incidence rate could be observed for carcinoma in situ between 2004 (31.8/100,000 person years) and 2009 (39.2/100,000 person years) (Table 7). A slight decrease in invasive cancers could be observed for this time period.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Invasive Cervical Cancer</td>
<td>653 8.5</td>
<td>189 2.0</td>
<td>640 8.2</td>
<td>186 1.8</td>
</tr>
<tr>
<td>CIN3 / Carcinoma in situ</td>
<td>1,826 31.8</td>
<td>-</td>
<td>2,150 38.0</td>
<td>-</td>
</tr>
</tbody>
</table>


Compared to other European countries in 2008, Belgium had an average position with regard to incidence and mortality of cervical cancer ([48], Figure 16).

Data from the BCR also revealed that in 2009, preinvasive lesions were detected more often than invasive cervical cancers in patients younger than 65 years of age (Figure 17). This was not the case for older women, in whom invasive lesions outnumbered the preinvasive stages.
Figure 17. Incidence of cervical cancer by stage and age group in Belgium in 2009. Only cancers with known stages (In Situ, I-IV) are taken into account; cancers with an unknown stage make up 0 to 23% of all cancers (known and unknown stages together) per age group (BCR).

When monitoring the incidence of preinvasive and invasive cervical cancer over a period of 11 years (1999-2009) in Flemish women, it was shown that for women younger than 65 years of age, the incidence of pre-invasive lesions was increasing over these years, especially for women aged between 25 and 64 years of age (Figure 18B and C). In the same time period, incidence rates for invasive cervical cancers for all ages showed a significant decrease for stage II tumours (EAPC = -5.3% [p = 0.02]) and stage III tumours (EAPC = -3.9% [p = 0.01]) (Figure 18A). No significant trends were observed in the age group of 65 years and older (Figure 18D), except for stage II tumours that showed a significant decrease (EAPC = -4.4% [p = .01]).
Figure 18. Trends for cervical cancer by stage in Flemish women for the age group (A) all ages (B) 0-24 years (C) 25-64 years and (D) 65+ years. WSR, World age-standardised incidence rate (BCR).
Relative survival
Data from the BCR showed that the five-year relative survival rate for patients with cervical cancer diagnosed in Belgium between 2004 and 2008 was 70% for all patients combined (Table 8). In line with other cancer types, five-year relative survival for cervical cancer was lower for older patients (65+ years) than for younger ones (Table 8). This observation was partly attributed to the stage distribution, showing more advanced stage diseases in elderly women (Figure 17). However, also within stages, lower survival rates could be noted for women of 65 years and older as compared to younger patients (Table 8). Five-year relative survival of stage I invasive cervical cancer, which is the most frequently occurring stage, was around 90%. From stage II onwards, five-year relative survival rates dropped rapidly, ranging from 64% for stage II to 17% for stage IV disease (Table 8).

<table>
<thead>
<tr>
<th>Age Group</th>
<th>All Stages</th>
<th>Stage I</th>
<th>Stage II</th>
<th>Stage III</th>
<th>Stage IV</th>
<th>Stage X</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-24</td>
<td>89%</td>
<td>88%</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>25-64</td>
<td>78%</td>
<td>94%</td>
<td>67%</td>
<td>60%</td>
<td>24%</td>
<td>75%</td>
</tr>
<tr>
<td>65+</td>
<td>44%</td>
<td>82%</td>
<td>56%</td>
<td>38%</td>
<td>6%</td>
<td>36%</td>
</tr>
<tr>
<td>All Ages</td>
<td>70%</td>
<td>92%</td>
<td>64%</td>
<td>54%</td>
<td>17%</td>
<td>65%</td>
</tr>
</tbody>
</table>

Table 8. Five-year relative survival rates for females with cervical cancer diagnosed between 2004 and 2008 in Belgium. NA, calculation of relative survival was not possible because of low numbers (BCR).

A5.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN
Based on European recommendations, the organisation of a systematic campaign to detect cervical cancer with a smear every three years for women between 25 and 64 years old was approved in March 2009. On 28 September 2009, the agreement on prevention was signed, offering a framework for co-financing of the federal government of prevention programmes organised by the Communities. This agreement will be extended to enable further campaign funding in 2012. In Flanders, the implementation of a population-based screening programme for cervical cancer is planned in 2013. The target population is set to women aged 25 to 65 years old living in Flanders. Cervical cytology with a three-year interval is the preferred screening test, but transition to HPV-testing is taken into account in the set-up of the screening programme. The practical organisation of this programme is being prepared in 2012. A cytobhistopatholo-register, called Cervibase, is already implemented to certify the quality control, monitoring and evaluation of the population-based screening programme.

Until now, no screening programme for cervical cancer has been developed in the French Region.

ACTION 6: CONSULTATION TO PREVENT HEALTH RISKS
A6.1. SCIENTIFIC DATA ON INDICATORS
A6.1.1. Causal relationship between a healthy lifestyle and developing cancer
In 2007, the World Cancer Research Fund and the American Institute for Cancer Research published their report on the correlation between food, nutrition, physical activity and cancer prevention [2]. Their exhaustive analysis was based on 20 independently commissioned and conducted systematic
reviews of the literature published up to 2006. Conclusions with regard to physical activity and the consumption of fruit, vegetables, alcohol and soft drinks are listed below.

- Since the early 1990s evidence has continued to accumulate showing that regular, sustained physical activity protects against colon cancer and female hormone-related cancers, independently of other factors such as body fatness.
- Findings from cohort studies conducted since the mid-1990s showed that the overall evidence of vegetables or fruits protecting against cancer was somewhat less impressive. The strongest evidence was found for non-starchy vegetables and fruits, demonstrating a potentially protective effect against cancers of the mouth, larynx, pharynx, oesophagus, and stomach. Fruits and allium vegetables were also shown as likely to protect against lung and stomach cancer, respectively.
- Alcoholic drinks were found to be a cause of cancers of the mouth, pharynx, and larynx, the oesophagus, the colorectum in men, the breast, and probably liver cancer and colorectal cancer in women. It is unlikely that alcoholic drinks have a substantial adverse effect on the risk of kidney cancer.
- With regard to soft drinks and fruit juices, the evidence was also too limited in amount, consistency, or quality to draw any conclusions about a correlation between consuming fruit juices or soft drinks and the occurrence of any type of cancer. In addition, there was limited evidence suggesting that sugars are a cause of colorectal cancer.
- Smoking is also an important lifestyle risk factor for the development of cancer, but this has already been addressed in section A1.1.

When interested in the incidence of the above-mentioned types of cancer (oesophagus, stomach, liver, lung, breast, colon and rectum) in Belgium for the period 1999-2008 (Flemish Region) or 2004-2008 (rest of Belgium), the reader is referred to Cancer Incidence in Belgium [16].

A6.1.2. Trends in proportion of the population adopting a healthy lifestyle

Physical activity
The most recent Belgian HIS revealed that the percentage of the Belgian population with an elevated health risk due to a lack of physical activity during leisure time had been stable from 1997 (33%) to 2001 (34%) and from 2004 (25%) to 2008 (26%) ([5], Figure 19A). The drop noticed between 2001 and 2004 was explained by a modification in 2004 in the way surveys were taken. In addition, the proportion of people that were doing moderate or intense physical exercises at least 30 minutes a day had not increased between 2004 (36%) and 2008 (38%). However, a significant increase was seen in the percentage of people doing physical activity at least once a week (Figure 19B).
The level of physical activity is also reflected in the degree of overweight and obesity, the latter being a risk factor for a range of chronic diseases (including major cancers such as breast and colorectal cancer [49]). An analysis of obesity within Organisation for Economic Co-operation and Development (OECD) and non-OECD countries, carried out by the OECD in collaboration with the WHO, showed that Belgium is doing slightly better than average with regard to the prevalence of overweight as well as obesity ([50], Figure 20). However, in 2008 still 54% and 13% of Belgian men and 40% and 14% of women had issues with overweight and obesity, respectively.
Alcohol consumption

Analysis by the Belgian HIS of the percentage of the Belgian population that had been consuming alcohol during the last 12 months demonstrated that, following adjustment for age and gender, numbers had been stable in all Belgian regions during the period 1997-2008 [5]. The percentage of people who were drinking alcohol daily showed a significant increase from 8% (1997), to 9% (2001 and 2004) and to 12% in 2008. On the other hand, the average alcohol consumption per week, as well as the percentage of overconsumption had reduced significantly in 2008 compared to 2004 and 2001, adjusting for age and gender. According to OECD records, which analysed the trends in alcohol consumption during the period 1980 to 2009, a decrease of 28% was noted for Belgium ([10], Figure 21).
Consumption of fruit and vegetables

According to the Belgian HIS, the percentage of people eating fruit has been growing considerably since 2001 and 2004 (circa 50%) to 64% in 2008 (Figure 22A). Similarly, the daily consumption of vegetables increased from 74% (in 2004) to 85% (in 2008) ([5], Figure 22B).
A6.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

A6.2.1. Number of people that have had a consult to prevent health risks

A healthy lifestyle contributes to an overall better health condition. To increase the awareness of the impact of one’s decision and lifestyle habits, and to detect potential health risks early, the NIHDI introduced a new medical act for a free preventive health check-up.

This check-up is aimed at people between 45 and 75 years of age with a global medical file (GMF). They can use this free preventive survey once a year during the test phase from 1 April 2011 until 31 December 2012. In 2012 the duration of this initiative was prolonged with 1 year. After this trial, the results of this system will be analysed and evaluated.

In practice, the general practitioner will evaluate their patient through an age-related checklist containing several criteria related to lifestyle, the cardiovascular system, screenings, vaccinations, etc.
In the period from 1 April 2011 to 31 December 2011, 159,052 preventive check-ups were registered (data from NIHDI). It is too soon in the implementation to evaluate this initiative accurately. To approximate the proportion of the target population that has already been reached, we applied the available data of the population rate and the registration of GMFs of 2009.

In 2009, about 43% of the total Belgian population had a GMF. For further calculations, we assume that this percentage is similar for 2011 and that a GMF is independent of age. This means that 1,690,458 people between the ages of 45 and 75 have a GMF. Taking into account the number of registered preventive check-ups, about 9.41% of the target population was reached within the first nine months of this measure.

The evaluation planned after the test phase was finalised and will provide a better impression of the exact coverage and the impact of this initiative.

**ADDITIONAL ACTION (34): IMPROVE DETECTION AND EARLY DIAGNOSIS OF COLORECTAL CANCER**

**A34.1. SCIENTIFIC DATA ON INDICATORS**

**A34.1.1. Risk factors for colorectal cancer**

Colorectal cancer mostly begins as a precancerous polyp that develops into a colorectal tumor following the adenoma-carcinoma sequence [51]. It occurs in individuals with acquired or inherited genetic predisposition who are exposed to a range of risk factors. Five percent of colorectal cancer cases are associated with major genetic predisposition syndromes such as familial adenomatous polyposis or hereditary non-polyposis colorectal cancer (Lynch syndrome). An overview of major genes, for which mutations are correlated with colorectal cancer, is given in Table 9.

<table>
<thead>
<tr>
<th>Gene(s)</th>
<th>Syndrome</th>
<th>Inheritance</th>
<th>Lifetime CRC risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>APC</td>
<td>FAP</td>
<td>Autosomal dominant</td>
<td>100%</td>
</tr>
<tr>
<td>APC</td>
<td>AFAP</td>
<td>Autosomal dominant</td>
<td>69%</td>
</tr>
<tr>
<td>MUTYH</td>
<td>MAP</td>
<td>Autosomal recessive</td>
<td>80%</td>
</tr>
<tr>
<td>MLH1, MSH2, MSH6, PMS2, TACSTD1 (EpCAM)</td>
<td>LS</td>
<td>Autosomal dominant</td>
<td>80%</td>
</tr>
<tr>
<td>STK11</td>
<td>PJS</td>
<td>Autosomal dominant</td>
<td>39%</td>
</tr>
<tr>
<td>SMAD4 (DPC4), BMP1A</td>
<td>JPS</td>
<td>Autosomal dominant</td>
<td>39%</td>
</tr>
<tr>
<td>PTEN</td>
<td>CS</td>
<td>Autosomal dominant</td>
<td>rare</td>
</tr>
</tbody>
</table>

*Table 9. Major colorectal genes and syndromes. FAP, familial adenomatous polyposis; AFAP, attenuated FAP; MAP, MUTYH-associated polyposis; LS, Lynch syndrome; PJS, Peutz-Jeghers syndrome; JPS, juvenile polyposis syndrome; CS, Cowden syndrome (Taken from [52]).*

Another 20-25% of cases occur in patients with a family history of colorectal cancer or colorectal polyps, suggesting a contribution for shared genes and environment [52]. The majority of colorectal cancers (approximately 70%), however, occur in individuals without a significant hereditary risk. As already mentioned, the presence of colorectal polyps is associated with an increased risk of developing colorectal cancer and this risk increases as the size of the polyps increases [51]. Also, a considerable risk of developing colorectal cancer is associated with the presence inflammatory bowel diseases, such as ulcerative colitis [53]. Recently, smoking was recognised as a risk factor [54]. Energy consumption also influences colorectal cancer risk, with obesity increasing risk and exercise reducing risk [2]. Yet, the strongest environmental risk for colorectal cancer is dietary. Consuming fat, alcohol and red meat is associated with an increased risk, while fresh fruit and vegetables and dietary fibre
could be protective [2;55-57]. Finally, the risk of developing colorectal cancer increases with advanced age (see below).

### A34.1.2. Colorectal cancer incidence, mortality and survival

#### Incidence and mortality

In 2009 colorectal cancers were the second and third most frequently occurring types of cancer in Belgian females (14% of total incidence, with 3,715 females being diagnosed) and males (14% of total incidence, with 4,515 males being diagnosed), respectively (BCR). Looking at colon and rectum cancer separately, colon cancer was diagnosed more frequently, with almost 9% of all cancer diagnosis in 2009. The incidence of rectal cancer was lower and counted for approximately 30% of all colorectal cancers. Comparing the incidence rate of Belgium with other European countries, Belgium ranked average for colorectal cancer in 2008 [33].

With regard to mortality, colorectal cancer was the third cause of cancer death in females (12%) and the second in males (10%) in 2008. Mortality from colon cancer was predominant and accounted for about 10% of all cancer deaths. Again, in 2008 Belgium took an average position with regard to mortality from colorectal cancer in Europe [33].

Table 10 summarizes incidence and mortality numbers for colon and rectal cancer in Belgian males and females in 2008.

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Incidence</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>3,085</td>
<td>1,728</td>
</tr>
<tr>
<td>Females</td>
<td>2,798</td>
<td>1,173</td>
</tr>
<tr>
<td>Rectal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>1,430</td>
<td>277</td>
</tr>
<tr>
<td>Females</td>
<td>917</td>
<td>202</td>
</tr>
</tbody>
</table>

**Table 10.** Colon and rectal cancer: incidence and mortality in Belgium, in 2008. WSR: age-standardised rate, using the World Standard Population (n/100,000 person years) (BCR).

When looking at the division of colon cancer stages within the different age groups, the majority of patients (i.e. 72% of males and 74% of females) diagnosed with colon cancer in 2009 was 65 years or older (Figure 23). The incidence rate of this age group was three (males) to four (females) times higher than the incidence for patients between 50 and 64 years of age, and 16 (females) to 20 (males) times higher than the incidence for patients between 35 to 49 years of age. The risk of colon cancer was also slightly higher in males than in females (male/female ratio is 0.9, 1.2 and 1.1 for the age groups 35-49, 50-64 and 65+, respectively). Of all colon cancers with a known stage, most were diagnosed in stages II or III.

For rectal cancer a comparable picture was seen. The majority of patients (i.e. 65% of males and 68% of females) diagnosed with rectal cancer in 2009 were 65 years or older (Figure 24). The incidence rate in this group was more than 2 times higher than this for the age group 50-64 years of age and about 13 times higher than for the age group 35-49 years of age. Rectal cancer was also diagnosed more frequently in males than in females in all age groups (male to female ratio is 1.3, 1.9 and 1.5 for the age groups 35-49, 50-64 and 65+, respectively). For both sexes and all age groups, it appears that of all cancers with a known stage, most are diagnosed in stages II or III. Following the introduction of
an organised screening programme (see below), an increase in the detection of early stage cases is expected and, consequently, a reduction in the proportion of late stage diseases [58].

Figure 23. Incidence of colon cancer by stage and age group in Belgian (A) males and (B) females in 2009. Only cancers with known stages (I-IV) are taken into account; cancers with an unknown stage make up (A) 11 to 13% and (B) 9 to 11% of all cancers (known and unknown stages together) per age group (BCR).
Figure 24. Incidence of rectal cancer by stage and age group in Belgian (A) males and (B) females in 2009. Only cancers with known stages (I-IV) are taken into account; cancers with an unknown stage make up (A) 10 to 11% and (B) 9 to 16% of all cancers (known and unknown stages together) per age group (BCR).

When monitoring trends over an 11-year period (1999-2009) in Flanders, it is clear that the incidence of colon cancer increased during this period. All patients combined, a significant increase was observed in males (EAPC: 1.52% [p < 0.01]) and females (EAPC: 1.56% [p < 0.01]). The incidence rate by stage for all ages combined indicated a significant increase in stage I (males: EAPC: 5.89% [p < 0.01], females: EAPC: 5.33% [p < 0.01]), in stage III in males (EAPC: 3.05% [p < 0.01]) and in stage IV in females (EAPC: 2.36% [p < 0.01]). In the meantime, stage II colon cancers in males decreased significantly (EAPC: -3.07% [p < 0.01]). This evolution is possibly due to stage migration via enhanced diagnostic work-up.

For rectal cancer, when looking at all age groups combined, no significant increase is observed in Flanders during the period 1999 to 2009. When looking at the incidence rate by stage, a significant increase was noticed in stage I (males: EAPC: 3.44% [p < 0.01], females: EAPC: 4.33% [p = 0.01]) and in females in stage III (EAPC: 1.57% [p = 0.02]). On the other hand, a significant drop was observed in males for stage II (EAPC: -3.07% [p < 0.01]).
Relative survival
Data from the BCR showed that the five-year relative survival rate for patients with colon and rectal cancer diagnosed in Belgium between 2004 and 2008 was comparable for patients between 35-49 years and 50-64 years (Table 11 and Table 12, respectively). Patients 65 years and older had a lower five-year survival rate, reflecting at least partly the negative influence of comorbidity in this age group. Another possible explanation could be that treatment for older patients might conform less to good clinical practice guidelines or less optimally performed guidelines. Similar to other cancer types, survival rates for colon cancer were inversely related to disease stage. For stages I-III, five-year relative survival remained higher than 60% in both sexes. Once metastatic, the relative five-year survival rate for this disease dropped to less than 20%.

### Five-year relative survival for colon cancer

<table>
<thead>
<tr>
<th>Ages</th>
<th>All Stages</th>
<th>Stage I</th>
<th>Stage II</th>
<th>Stage III</th>
<th>Stage IV</th>
<th>Stage X</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-49</td>
<td>69%</td>
<td>96%</td>
<td>92%</td>
<td>71%</td>
<td>22%</td>
<td>75%</td>
</tr>
<tr>
<td>50-64</td>
<td>67%</td>
<td>91%</td>
<td>93%</td>
<td>72%</td>
<td>19%</td>
<td>64%</td>
</tr>
<tr>
<td>65+</td>
<td>60%</td>
<td>91%</td>
<td>83%</td>
<td>57%</td>
<td>12%</td>
<td>48%</td>
</tr>
<tr>
<td>All Ages</td>
<td>62%</td>
<td>92%</td>
<td>86%</td>
<td>62%</td>
<td>15%</td>
<td>55%</td>
</tr>
</tbody>
</table>

### Five-year relative survival for rectal cancer

<table>
<thead>
<tr>
<th>Ages</th>
<th>All Stages</th>
<th>Stage I</th>
<th>Stage II</th>
<th>Stage III</th>
<th>Stage IV</th>
<th>Stage X</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-49</td>
<td>72%</td>
<td>98%</td>
<td>80%</td>
<td>74%</td>
<td>21%</td>
<td>73%</td>
</tr>
<tr>
<td>50-64</td>
<td>70%</td>
<td>95%</td>
<td>84%</td>
<td>75%</td>
<td>26%</td>
<td>58%</td>
</tr>
<tr>
<td>65+</td>
<td>60%</td>
<td>92%</td>
<td>74%</td>
<td>62%</td>
<td>13%</td>
<td>46%</td>
</tr>
<tr>
<td>All Ages</td>
<td>64%</td>
<td>93%</td>
<td>77%</td>
<td>67%</td>
<td>18%</td>
<td>45%</td>
</tr>
</tbody>
</table>

### Table 11. Five-year relative survival rates for males and females with colon cancer diagnosed between 2004 and 2008 in Belgium (BCR).

### Table 12. Five year relative survival rates for males and females with rectal cancer diagnosed between 2004 and 2008 in Belgium (BCR).

A34.2. Indicators reflecting a specific action of the Cancer Plan

A34.2.1. Coverage of colorectal screening
The identification of a well-determined premalignant lesion, the adenomatous polyp, together with the good survival rate associated with early detection, makes colorectal cancer an ideal candidate for screening. There is indeed evidence that screening of average-risk individuals can result in cancer
prevention and in reduction of mortality by early detection and removal of cancer precursor lesions (reviewed in [59]). Faecal occult blood testing (FOBT) and flexible sigmoidoscopy are the two colorectal screening methods which have been tested in randomised trials and which have been shown to reduce colorectal mortality. The European Code against Cancer therefore recommended a population-based approach for colorectal screening [37;45]. According to the European recommendations 95% of the target group should be invited in order to maximise screening impact. A minimum of 45% of invitees should be examined, but it was recommended to aim for a rate of at least 65% [60].

The Interministerial Conference Public Health of 8 December 2008 permitted an asymmetric approach, which allowed for a different set-up in the prevention of colorectal screening in the French, German-speaking and Flemish Communities. Co-financing of these programmes was made possible by the agreement on prevention, which was signed on 28 September 2009. Since the design of the prevention of colorectal cancer in the Communities is different, both programmes will be discussed separately.

In March 2009 the French and German-speaking Communities started a colorectal cancer screening programme for people between 50 and 74 years of age. Between 1 March 2009 and 28 February 2011, 1,141,565 invitations were sent to encourage people in Wallonia and Brussels Capital to consult their GP in order to participate in the screening programme. An information sheet was also included in the mailing. Based on the risk profile of the patient, the GP decided whether the guaiac FOBT (gFOBT) (moderate risk) or a colonoscopy (high risk) was the most appropriate. The patients could do the gFOBT at home by taking samples of three consecutive stools, which were sent to the ‘Centre de Gestion’ for analysis. If the test was negative (i.e. no traces of blood found), they would be invited again in two years. If the test was positive, patients would be referred for a colonoscopy; when it was negative, the patient would be invited to participate in the screening again in five years. Patients with a positive colonoscopy would receive the appropriate treatment and would no longer take part in the screening programme. The workflow of the screening set-up is illustrated in Figure 25. The GP has a central role in the information, allocation to the right screening branch and feedback and follow-up of the participants. At the end of 2010, 5,107 GPs were involved in the set-up and elaboration of the screening programme, corresponding to about 70% of all GPs active in the Brussels Capital Region and Wallonia (http://www.sante.cfwb.be).
Of the 1,141,565 invitations that were sent between 1 March 2009 and 28 February 2011, 42,055 people responded. Another 36,697 people participated spontaneously in the programme. Among the participants, 74,757 were at moderate risk and 3,995 were at high risk.

Figure 26 summarises the main results of patient screening with a moderate risk. Of the 74,757 gFOBTs, 2.9% turned out to be positive. These positive tested patients were advised to have a colonoscopy. Among the 1,716 colonoscopies, more than half of them did not show any clinical problem. Adenomas and advanced adenomas were detected in respectively 16.6% and 20.3% of the
colonoscopies, while 148 colorectal cancers were diagnosed corresponding to 8.6% of the colonoscopies. The detection rate was 8.4‰ for adenomas and 2‰ for cancers. These results are in line with the performance indicators defined in the European guidelines for quality assurance in colorectal cancer screening and diagnosis.

![Figure 26](http://www.cancerintestin.be).

In the high-risk screening arm, participants were referred to have a colonoscopy immediately (without prior gFOBT). The results of 2,635 patients out of 3,995 participants were collected (66.0%) and showed 97 advanced adenomas in 87 patients and a tumour in 22 patients. They showed 536 adenomas (20.3%), 224 advanced adenomas (8.5%) and 43 cancers (1.6%)

Several actions were introduced to improve the participation rate and organisation of the screening programme in general: questionnaires over the phone and focus groups were organised to shed light on reasons for non-participation, how the screening could be made easier for participants and how to involve all social groups.

In Flanders, a small-scale screening trial was set up in 2009 in three communities in the Antwerp region to explore the feasibility and the best conditions to organise a community-wide campaign. A sufficient participation rate is a key factor in determining the efficiency of the programme at the population level.

People between 50 and 74 years of age with a normal risk were invited to take a stool sample for colorectal cancer screening. Two methods of inviting were compared: one group was asked to
Contact their GP to obtain the stool sample kit; the other group received the kit together with the letter, an information leaflet, a reply form and instructions for sampling. If people did not respond, a reminder letter was sent 6 to 8 weeks later. Participants took a sample of their stool on their own and sent it for analysis to the lab. The result of the test was sent first to the GP within 10 working days after receiving the sample. In case of faecal blood traces, the GP would recommend their patient have a colonoscopy. The design of this trial is illustrated in Figure 27 [61].

---

5 The cost of the colonoscopies was not included in the set-up of the screening trial. Patients had to pay for it themselves.
In this design, the immunological FOBT (iFOBT) was preferred above the gFOBT. With this test, one sample is sufficient (instead of three for gFOBT) and there are no dietary restrictions. Moreover, Van Rossum et al. confirmed that a higher participation rate could be achieved when comparing iFOBT to gFOBT [62]. Out of the 18,541 eligible people, 8,219 sent in a sample (44.3%) of which 5.3% tested positive (see Figure 28). In the end, the presence of an adenoma or carcinoma was confirmed in 0.9% of the target population.

An invitation by mail with direct access to the sampling kit resulted in a higher participation (64.3%) compared to the group who was invited to see their GP to obtain the kit (24.8%). As a comparison, the first screening round of breast cancer in Flanders in 2002-2003 had a participation rate of 33% [63].

To know how the participants experienced the screening procedure and to identify the reasons for not participating, questionnaires were sent to 2,000 participants and 1,600 non-participants. The response rate was 69.3% in the participatory group and 43.2% in the non-participatory group. Despite all information campaigns, it seems that the main reasons not to take part in the screening is still that people feel healthy, have no complaints and do not feel the urge and need to screen for a disease they believe they do not have. A so-called ‘stool taboo’ is not a key reason for non-participation.
Overall, the researchers concluded that a population-wide screening programme by means of an iFOBT test is feasible in Flanders. They stress the importance of the involvement of GPs for information, motivation and follow-up of their patients. As well, they stress that linking to the data of the Belgian Cancer Registry and a register for colonoscopies is critical for the proper evaluation of the impact of screening programmes. For more recommendations on the implementation of a population-wide organised screening on colorectal cancer, visit http://www.dikkedarmkanker.be.

The expertise and recommendations of this trial will be used to set up a population-based screening programme for colorectal cancer in Flanders in 2014. The target population will be men and women between 50 and 74 years of age living in Flanders. This will involve more than 1,900,000 people. The invitations will be sent over a period of two years. Similar to the trial, the iFOBT test is preferred for this screening. In the mean time, the practical organisation of this programme is being planned.
ACTION 7: SPECIFIC SUPPORT FOR THE PATIENT WHEN THEIR DIAGNOSIS IS COMMUNICATED

A7.1. SCIENTIFIC DATA ON INDICATORS

The diagnosis of cancer and its treatment is a stressful event that generates fears, uncertainty, distress and psychosocial needs. Between 10 and 50% of cancer patients experience high levels of distress [64]. Untreated, distress may have long-term detrimental consequences on patients’ compliance with treatment, survival, desire for hastened death, and the quality of life of both patients and their relatives. Studies have shown the positive impact of different psychological interventions on cancer patients’ distress, compliance and pain, and underlined the importance of detecting distress early in the course of the disease [65]. In fact, the physicians’ communication during the first consultation was shown to be related to a better long-term adjustment [66]. Ineffective physician-patient communication skills led to psychological distress, including increased anxiety and depression and poorer psychological adjustment to cancer. Unfortunately, oncologists often fail to recognise distress in their patients and tend to underestimate the level of distress experienced. It also seems that patients are sometimes reluctant to disclose their psychological concerns spontaneously, and leave the initiative of discussing these topics to their physician. Merckaert et al. recently investigated cancer patients’ desire for psychosocial support from professionals in 10 Belgian hospitals and found that one female cancer patient out of four and one male cancer patient out of 10 wanted psychological support [67]. Moreover, their results emphasised the need to screen not only for cancer patients’ distress but also for their desire for psychological support in order to implement psychological interventions according to patients’ needs and desires.

A7.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

The notification of a severe disease is a traumatic experience. When announced, the patient is confused and actually does not hear what the physician is saying. Patients testify that communication is often inappropriate and call for a more humane approach. Since communication and the way of communicating are key aspects of a trustworthy relationship between a physician and a patient, the Cancer Plan also turned its attention to the moment when the diagnosis is announced and how the message is delivered.

The NIHDI introduced a new medical act for a long-term consultation during which time the physician informs the patient extensively about their disease, potential additional examinations and the treatment plan that is discussed during the MOC. This consultation has been reimbursed since 1 November 2010 and can be charged by either the GP or the specialist on the condition that a MOC has taken place. The number of such consultations during Nov-Dec 2010 and in 2011 are depicted in Figure 29 for GPs as well as for specialists.
The vast majority of patients are informed about the diagnosis by their specialist as seen in Figure 30.

For an in-depth evaluation of the impact of this opportunity to devote more time to explaining the condition of the patient, questionnaires to appraise the satisfaction of both patients and physicians should be organised.

The Cancer Plan also aims at introducing training opportunities for physicians, nurses and paramedics (such as social workers, physiotherapists, etc.) who are active in the field of cancer care in order to develop their communication skills when dealing with cancer patients and their relatives. In 2009, a group of 29 experts developed a curriculum for a communications course for health workers. The first proposal is aimed at physicians and caregivers in hospitals who have contact with cancer patients. The second proposal is discussed in more detail in Action 10 and is aimed at psychologists who work in an oncology unit.
The Cédric Hèle Institute and the Centre de Psycho-Oncologie organise these trainings. In 2010, more than 300 health workers enrolled into the programme: in the Cédric Hèle Institute 44% of the 156 trainees were physicians, while 56% were nurses and paramedics. In the Centre de Psycho-Oncologie, physicians made up 7% of the 150 enrolments, nurses 75% and paramedics 17%. In 2011, 18% of the 154 subscribers in the Cédric Hèle Institute were physicians, 53% were nurses and the remaining 29% were other caregivers. In the Centre de Psycho-Oncologie, 2% of 168 trainees were physicians, compared to 97% nurses and 1% paramedics.

To provide the same level of quality in the counselling of each patient, several hospitals elaborated procedures for psychologists and nurses who announce the diagnosis and support patients in dealing with their disease. In France, a protocol was designed to meet the wishes and expectations of each patient about the information they need and when they need it, taking into account the time a patient needs to process all the information. This procedure is not only focused on the diagnosis, but also applied to the entire disease process, for example, in case of a relapse or when the treatment seems ineffective. The Belgian Ministry of Health intends to develop a similar protocol. The College of Oncology and Radiotherapy was asked to elaborate a standard procedure to announce bad news that should support the caregiver without concessions in an individualised approach. Based on their proposals, the Cancer Centre developed several recommendations to implement such a protocol. The FPS of Public Health will eventually propose concrete actions.

**ACTION 8: REASSESSMENT OF THE MOC**

**A8.1. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

Multidisciplinary oncologic consults (MOCs) are part of standard cancer care in many countries such as the UK, Australia, US, and Canada. To evaluate the impact of MOCs on physician practice patterns and patient outcomes, Wright et al. conducted a review of the evidence on MOCs, published between 1960 and 2005 [68]. Although the evidence is limited, all relevant studies concluded that a multidisciplinary setting resulted in positive patient outcomes in terms of diagnosis and/or treatment planning, survival, patient satisfaction, and clinician satisfaction in terms of communication and cooperation.

Since 2003, Belgian patients with a new cancer diagnosis should be discussed in a MOC. The refunding of the MOC and the norms for recognition of the oncological care programmes were published in Royal Decrees (Royal Decree of 25 November 2002 and of 21 March 2003). From that moment on, hospitals were obliged to register every diagnosis of cancer, irrespective of whether or not the diagnosis was discussed during a MOC.

During the MOC, physicians from different disciplines discuss the patient’s diagnosis, treatment options and which strategy of treatment will be proposed to the patient. To receive financial compensation for a MOC, physicians are obliged to complete a registry form including patient, tumour and treatment characteristics. The Cancer Registry uses this standardised form to achieve a complete registration of cancer in Belgium.

**A8.1.2. TREND OVER TIME IN THE NUMBER OF MOCs**

Figures from the NIHDI show a rapid increase in the number of patients diagnosed with cancer that were discussed in a MOC since its formal launch in 2003. While 16,375 cancer patients were
discussed in a MOC in 2003, the number had more than tripled in 2005 (54,301 cancer patients). A further increase was noted from 2007 onwards. One of the reasons for this growth could be the retrospective follow-up discussion about patients with existing tumours that was possible temporarily after publishing the follow-up registration form at the end of 2006.

The number of patients with a cancer diagnosis discussed in a MOC further increased from 2009 till 2011 (Figure 31). The most recent rise of MOCs could probably and partially be explained by the introduction of the Cancer Plan in 2008 and the financial support for a data manager that was given by the government as of 2009 (Royal Decree of 20 September 2009). The assignment of a data manager should result in a reduction of the administrative burden of physicians, which is often given as a reason for not completing the MOC registration form (see also Action 11). Moreover, additional financial support for personnel in oncological care programmes according to the number of registered MOCs (as defined in the Royal Decree of 20 September 2009, see also Action 10) may have added to the increase in the number of MOCs since 2008.

Figure 31. Number of booked MOCs from 2003 — 2011. *= starting on 01-02-2003. RD, Royal Decree (Data source: numbers from NIHDI processed by the Cancer Centre).

In November 2010, The Cancer Plan added two new nomenclature codes: one for a follow-up MOC and an additional MOC when a patient is referred to another hospital. The code that already existed was further specified as ‘first MOC’, which is mandatory for every new cancer case. The follow-up MOC is exclusively used in case there is an objective necessity to reconsider the former diagnosis or adapt the therapeutical plan and/or if a new irradiation cycle of the same target area within 12 months of the first cycle. The additional MOC can only be charged if a consensus was not reached for a definitive diagnosis and treatment during the first MOC. In this case, the additional MOC should be organised in another hospital. Table 13 shows the number of MOCs registered at the NIHDI for each type of MOC.
**Table 13.** Number of booked MOCs per type in Nov-Dec 2010 and in 2011 (Data source: NIHDI). Remark: since the nomenclature of the first MOC already existed before the follow-up and additional MOC were introduced, the number of first MOCs in Nov-Dec 2010 still contains MOCs executed in ‘the old system’.

<table>
<thead>
<tr>
<th>Type of MOC</th>
<th>Nov-Dec 2010</th>
<th>Nov-Dec 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>First MOC</td>
<td>16,610</td>
<td>72,452</td>
</tr>
<tr>
<td>Follow-up MOC</td>
<td>279</td>
<td>25,760</td>
</tr>
<tr>
<td>Additional MOC</td>
<td>3</td>
<td>484</td>
</tr>
</tbody>
</table>

A8.1.2. Participation of physicians in the MOC

A MOC should involve at least 4 and maximum 6 physicians of different specialities. One of them needs to coordinate the meeting and provide a written report on the diagnosis and treatment. The coordinating physician can charge one of the three MOC nomenclature codes, while the other physicians use the code for participation in the MOC or the code for participation by a physician who does not belong to the hospital staff.

An increase over time in the number of registered participations to the MOC can also be noted in Figure 32, both for physicians from the hospital staff, as for physicians not belonging to the staff of the hospital where the MOC was organised, the latter including both physicians of other hospitals as well as GPs. Efforts to encourage the participation of GPs to the MOC are described in Action 9.

Figure 32. Time evolution of participation to the MOC by physicians of the hospital staff (orange, left Y axis) or by physician not belonging to the hospital staff (green, right Y axis). Data source: numbers from the NIHDI being processed by the Cancer Centre.

Medical oncologists/haematologists are entitled to an additional fee by charging the code. For this purpose, two additional codes were created in March 2010, one for participation to the MOC, the other can be attested when this specialist is coordinating the MOC. Figure 33 shows a gradual increase of the number of additional honoraria for medical oncologists/haematologists.

---

6At least one of them has to have experience in oncologic surgery or is specialised in medical oncology or radiotherapy-oncology, clinical haematology or paediatric haematology and oncology.

7Royal Decree of 24 September 2010 and interpretation rule published in the Belgian State gazette on 26 April 2012.

8This designation is used to refer to ‘the physician-specialist in medical oncology, or with the particular title in clinical haematology, or in paediatric haematology and oncology’.
Figure 33. Number of additional honoraria charged by an oncologist/haematologist for participating in (orange) or coordinating (green) a MOC. The year 2010 includes March to December. (Data source: numbers from the NIHDI processed by the Cancer Centre).

A8.1.3. Proportion of cancer patients discussed in a MOC

An increase in the proportion of patients with cancer discussed in a MOC (from 63.0% in 2007 to 68.8% in 2008) can be observed when using linked data on tumour characteristics from the BCR and health insurance data from the IMA. Patients with breast cancer (84.4%) were most often discussed, followed by patients diagnosed with mesothelioma (75.6%) and cancers of the female genital organs (76.4%). Patients with cancer of the respiratory and digestive tract and head and neck cancer were also frequently discussed. The lowest proportions (<60%) discussed in a MOC were patients with bone and soft tissue sarcoma, malignant melanoma, thyroid and prostate cancer, and hematologic tumours and primary site unknown tumours. Tumour stage (I to IV) did not seem to have an influence on the proportion of patients discussed in a MOC for colorectal, larynx, lung, breast and testicular cancer (Figure 34). By contrast, patients with cancer of an unknown stage (X) were less often discussed in a MOC based on these results.
Figure 34. Proportion of cancer patients discussed in a MOC by stage in Belgium in 2007 (blue bars) and in 2008 (red bars), for patients with (A) colon cancer, (B) rectum cancer, (C) larynx cancer, (D) lung cancer, (E) breast cancer and (F) testicular cancer (BCR).

ACTION 9: INTRODUCTION OF CARE PATHWAYS FOR CANCER PATIENTS

A9.1. SCIENTIFIC DATA ON INDICATORS

A9.1.1. Overview of guidelines

In collaboration with the KCE, the College of Oncology developed national clinical practice guidelines to be used primarily by physicians and other health care providers, in order to support care for cancer patients. These guidelines were developed by adapting existing national and international guidelines to the Belgian context by using the formal adaptation methodology, developed by the
ADAPTE group. Some of these clinical practice guidelines were developed by a multidisciplinary
guideline development group without the methodological support of the KCE.

At present, for 21% of tumour types a clinical practice guideline is developed. An overview of current national clinical practice guidelines for the treatment of these different types of cancers is given in Table 14. The date of an eventual update is mentioned between brackets. The full text of these guidelines can be consulted on the website of the College of Oncology (http://www.collegeoncologie.be/EN/Guidelines/). The current guidelines support the treatment of about 54% of cancer patients.

### ALREADY PUBLISHED GUIDELINES

<table>
<thead>
<tr>
<th>TUMOUR SITE</th>
<th>FIRST PUBLICATION DATE OF GUIDELINES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain Tumours (neuro-oncology)</td>
<td>2008</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>2012</td>
</tr>
<tr>
<td>Colon Cancer</td>
<td>2004 (will be updated in 2012)</td>
</tr>
<tr>
<td>Gastric Cancer (incl. gastric lymphoma, GIST)</td>
<td>2012</td>
</tr>
<tr>
<td>Gynaecological Cancers</td>
<td></td>
</tr>
<tr>
<td>Cervical Cancer</td>
<td>2011</td>
</tr>
<tr>
<td>Endometrial Cancer</td>
<td>2010</td>
</tr>
<tr>
<td>Gynaecological Sarcomas</td>
<td>2010</td>
</tr>
<tr>
<td>Ovarian Cancer</td>
<td>2010</td>
</tr>
<tr>
<td>Vulvar-vaginal Cancer</td>
<td>2010</td>
</tr>
<tr>
<td>Melanoma</td>
<td>2007</td>
</tr>
<tr>
<td>Oesophageal Cancer</td>
<td>2012</td>
</tr>
<tr>
<td>Pancreatic Cancer</td>
<td>2009</td>
</tr>
<tr>
<td>Rectal Cancer</td>
<td>2004</td>
</tr>
<tr>
<td>Testicular Cancer</td>
<td>2010</td>
</tr>
<tr>
<td>Non-Small-Cell Lung Carcinoma</td>
<td>2006 (will be updated in 2012)</td>
</tr>
</tbody>
</table>

### PLANNED PUBLICATIONS

<table>
<thead>
<tr>
<th>TITLE</th>
<th>RESULTS EXPECTED IN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of care for oesophageal and stomach cancer</td>
<td>Guidelines: May 2012</td>
</tr>
<tr>
<td>Thyroid cancer: diagnosis and treatment</td>
<td>Quality indicators: Dec 2012</td>
</tr>
<tr>
<td>Practice guideline for the management of localised prostate cancer</td>
<td>May 2012</td>
</tr>
<tr>
<td>Practice guideline for the supportive treatment of cancer patients</td>
<td>Dec 2012</td>
</tr>
<tr>
<td>Organisation of the care of rare tumours and tumours with a complex treatment</td>
<td>Oct 2012</td>
</tr>
<tr>
<td>Innovative radiotherapeutic techniques</td>
<td>May 2013</td>
</tr>
<tr>
<td>Guideline for the management of colon cancer</td>
<td>Mar 2013 (update 2012)</td>
</tr>
<tr>
<td>Practice guideline for the management of lung cancer</td>
<td>Dec 2013</td>
</tr>
<tr>
<td>Practice guideline for the management of head and neck tumours</td>
<td>Dec 2013</td>
</tr>
</tbody>
</table>


### A9.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

#### A9.2.1. Involvement of General Practitioners in cancer treatment

It is very important that the patient’s GP is involved during the cancer treatment. The guidelines listed above were created in order to increase the involvement of the GP during the care process. Participation of the GP to the MOC may bring important additional information about the patient.
However, the rate of participation of GPs to the MOC is rather low. Particularly in an urban setting, GPs are rarely present at the MOC of their patients. This absence is probably due to several aspects like the time of the MOCs, required mobilisation or high workload.

As of 27 July 2009, two pilot projects were introduced to stimulate the participation of GPs to the MOC.

The first project in collaboration with AZ Maria Middelaars Gent intends to increase the participation rate of GPs to the MOC by providing means of communications such as videoconferencing. This project was started on 15 September 2009 and was evaluated one year later on participation and the quality of information exchange (compared to physical presence). During that time period, 200 GPs took part in the MOC: 70 through videoconferencing and 130 were physically present, representing an increase of about 22% as compared to the number of participating GPs (163) before the introduction of the pilot.

The second project in collaboration with the GZA (‘Gasthuis Zusters Antwerpen’) and the ZNA (‘Ziekenhuis Netwerk Antwerpen’) implemented a system for bidirectional electronic data exchange that aims at defining the relevant data, elaborate the technical details and refine the procedure. Intermediate evaluations after six months revealed that 62 (17%) of the 356 electronic dossiers were completed successfully. These preliminary results showed that the success rate (17%) was lower than expected, but that this way of communicating was a valuable tool to promote interactivity of GPs with intramural care process, which in turn is beneficial for the patient. Further investigation is needed to elucidate the obstructing factors. Attention should be paid to a uniform IT procedure and to inform GPs about these possibilities.

**A9.2.2. Development of guidelines and day care trajectories**

To enable hospitals to follow-up the innovations in oncology and the multitude of therapeutic options, care programmes were launched, supervised by the College of Oncology. They are responsible for evaluating the quality of care, developing guidelines and drafting guidelines on care trajectories. Work groups, including representatives of the care centres, were set up to define standards and guidelines for several types of cancer. Including representatives from universities and regional hospitals willing to collaborate increases the chance that the manuals will actually be implemented.

The Royal Decree of 21 March 2003 describes the specific standards a care programme in oncology or a care programme for basic care in oncology should meet. In the beginning of 2012, 106 centres, divided over 171 locations in Belgium, had an acknowledged care programme in oncology and/or a basic oncological care programme (Figure 35).
Figure 35. Geographic distribution of the 106 Belgian centres with an oncological care programme and/or a programme for basic care in oncology. Dots indicate the presence of minimal one (basic) oncological care program (Data source: FPS Public Health).

The KCE report 152, published in April 2011, investigates the implementation of an umbrella quality system through indicators in Belgium [69]. A system to monitor the quality of care could substantially contribute to constantly improving the quality of care in oncology. Essential elements of such a system are a clear definition of the objectives, the role of each party involved, development of guidelines and related quality indicators, efficient data collection, correct analysis and interpretation of the data, opportunities to provide feedback and adjust practices through corrective actions.

The start of care trajectories in oncology awaits the evaluation of the initial projects of care trajectories for renal failure and diabetes launched in 2009. The results of these pilots are expected in the spring of 2013.

In the mean time, the KCE will continue to define care trajectories for cancer patients (see Table 14). In their report published in 2010, the KCE reviewed their 3 pilot studies (on quality indicators for rectal, breast and testicular cancer) and formulated recommendations to set up a quality system for oncology in Belgium [69]. They stated that the necessary elements and know-how seem to be present in Belgium, but need to be structured to allow the operationalisation of a quality system for oncology.

**ACTION 10: ENSURING PSYCHOSOCIAL SUPPORT IN THE ONCOLOGICAL CARE PROGRAMMES**

**A10.1. SCIENTIFIC DATA ON INDICATORS**

As mentioned above (see Action 7), diagnosing of cancer and its treatment have far-reaching consequences for the patient and their relatives. Patients not only experience physical pain, but also suffer from emotional, social, spiritual and existential problems, also called distress. Although many
cancer patients, together with their relatives and the primary oncological care, are able to cope with these experiences, about 25-50% of patients should be referred to special psychosocial care because of their high levels of distress (projected to the most recent numbers of Belgium cancer incidences in 2009, this would mean that about 15,000 to 30,000 of patients would have suffered severely from distress). However, only 10% of all cancer patients appeal for psychosocial support from professionals [70]. As pointed out in Action 7, the major reason for this is that physicians and other health care workers fail to recognize distress in their patients and tend to underestimate the level of distress experienced. In addition, patients often hesitate to reveal their psychological worries, or are not aware of the opportunities for psychological support offered by the hospital. As a consequence, a number of patients do not receive the professional support they need, which in turn results in a lower quality of life, low satisfaction with the obtained medical care, poor compliance with their treatment and the application of additional medical care, associated with higher medical costs.

Besides the diagnosed individual, the closest relatives of the patient also experience the demands and contingencies of cancer during the early stages of diagnosis and treatment as well as during the ongoing illness experience. The effect of cancer on the psychological well-being of the partner could result in increased risks of several psychiatric disorders related to stressful life events. Support programmes for the family, as well as the patient, are clearly indicated.

**A10.2. Indicator reflecting a specific action of the Cancer Plan**

**A10.2.1. Financing of additional personnel for the acknowledged oncologic care programme**

The multidisciplinarity of the team of health workers is an essential aspect of the care for cancer patients. Such a team can guarantee a holistic support of the patient at any point of time during their treatment (during the announcement of the diagnosis, for questions about social facilities, the announcement of a relapse, for questions about dying) and can also tackle the desperation of the patient and their relatives. This support should also be available even when the patient already left the hospital.

To achieve the best possible care for each cancer patient, the Cancer Plan finances additional nurses, social assistants and psychologists in hospitals that are accredited for their oncologic care programme. The number of financed Full Time Equivalents (FTEs) is based on the number of MOCs carried out at the hospital two years previous. One FTE nurse and one psychologist are allocated for every 250 MOCs, one FTE social assistant is assigned to the hospital per 500 MOCs. Figure 36 illustrates the number of financed FTEs for each professional category from 2009 to 2011. The number of financed nurses, psychologists and social assistants per 100,000 new cancer cases in Belgium in 2009 is depicted in Figure 37. Due to the steep rise in the number of MOCs (see above) and the budgetary limits, the calculation of this financing will be evaluated.
When estimating the ratio between the numbers of nurses, psychologists and social assistants financed on the one hand, and the number of cancer patients, their partners and children on the other hand in Belgium in 2009\(^9\), the following approximations can be made: in 2009 there was one additional nurse and one psychologist financed for every 283 cancer patients, for about 116 partners of cancer patients, and for about 136 children of cancer patients. In the same year, there was one social assistant financed for every 563 cancer patients, corresponding to about 231 partners and 270 children.

A10.2.2. Communications training for psychologists

\(^9\)Based on cancer incidence in Belgium in 2009; the number of nurses, psychologists and social assistants in 2009 and data from StatBel on 1 January 2010 (containing data till the end of 2009).
Similar to what is organised for physicians and care givers, communications training is also provided to psychologists working within a department acknowledged for its oncologic care programme. A biennial programme is organised by the Cédric Hèle Institute in Flanders and a two-year course is given every year by the Centre de Psycho-Oncologie in Wallonia. As of September 2010, respectively 35 and 25 students can register for this course.

In 2010, one of the 35 participants at the Cédric Hèle Institute dropped out early; at the Centre de Psycho-Oncologie 20 of the 25 financed participants finished the first year of the curriculum and will continue the second year (1 participant participated without the financial support of the Cancer Plan). In 2011 26 new students registered for the next two-year during course; 5 of them were not financially supported by the Cancer Plan. Assuming that about 10% of students drops out during the course, the psychologists trained by the Cédric Hèle Institute and the Centre de Psycho-Oncologie represent 10% of the psychologists financed. Note that the Cédric Hèle Institute already coached 37% of the currently trained psychologists before the onset of the Cancer Plan 2008-2010.

On 25 November 2011, the Cédric Hèle Institute organised a symposium that was attended by 190 participants (http://www.cedric-heleinstituut.be). The Dutch translation of the American manual with guidelines in psychooncology was presented here. Later, a French edition will also be published.

**ACTION 11: FINANCING A DATA MANAGER IN THE ONCOLOGICAL CARE PROGRAMMES**

**A11.1. SCIENTIFIC DATA ON INDICATORS**

**A11.1.1. Trends in numbers of data managers**

As of 1 July, 2008 hospitals are refunded to employ a data manager, depending on the number of registered MOCs (Royal Decree of 20 September 2009). To be refunded by the government, data managers must follow a training organised by the BCR. Before 1 July 2008 a number of hospitals already employed data managers, but training was on a voluntary basis.

At the end of 2011, the number of trained data managers varied between 0 and 63 per hospital (data BCR). Nineteen of the oncologic care programmes had no trained data managers. The reason for this variation is partly explained by the way in which cancer registration in the oncological care centre is organised: most of the hospitals centralise the registration activities and need less trained personnel; some centres organise the cancer registration within the different clinical departments and need more people to be trained. This does not necessary mean that all these data managers are still active in cancer registration. At present, there is no information available on the turn-over in this function or on the other tasks these employers perform. It is clear from daily contacts with data managers that their role and profile vary greatly between centres. Moreover, there is no formal monitoring system for the quality and quantity of cancer registrations (audit system) treated by the data managers. Figure 38 depicts the number of trained data managers since the year 2000, together with the evolution of the number of booked MOCs (the latter has already been shown in Figure 31).
A11.1.2. Percentage of overlap between cancer notifications from the laboratories and from the hospitals

As mentioned above, through the clinical network hospitals have to register all new cancer diagnoses with the BCR, irrespective of the diagnosis being discussed during a MOC. Concurrently, pathological anatomy laboratories encode their received specimens and annually transfer every pre-malignant and malignant diagnosis to the BCR. Subsequently, the BCR can link the individual tumour records from clinical sources and pathological anatomy laboratories by means of the unique patient identifier. Linkage of data from different sources and source types ensures the completeness and reliability of the information.

Data of the BCR, combining delivery of cancer notifications by the clinical and the pathological network obtained in 2009, revealed that only 80.9% of new cancer diagnoses were reported to the BCR via the clinical network (Table 15, sum of clinical and pathological network and clinical network only) implying that a significant proportion of 19.1% cancer cases were registered through the pathological network only. The proportion of new cancer cases reported by the clinical network was best for breast cancer and lowest for cancers with unknown primary or ill-defined cancer sites. The proportion of malignant melanoma was also low, but it can be assumed that some of these patients were treated in a private dermatology practice and were therefore only reported to the BCR by the pathologists. Prostatic cancer, the most frequent cancer in males, remained also underreported by the clinical network.
An evolution of the overlap between the clinical and pathological network between 2005 and 2009 (as shown in Table 16 for breast and prostate cancer) demonstrates that notifications via the pathological network only decreased slowly until 2008 and dropped significantly in 2009.

<table>
<thead>
<tr>
<th>Localisation</th>
<th>Total</th>
<th>Clinical and pathological network</th>
<th>Clinical network only</th>
<th>Pathological network only</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Head &amp; neck</td>
<td>2,574</td>
<td>2,061</td>
<td>80.1</td>
<td>140</td>
</tr>
<tr>
<td>Digestive organs</td>
<td>13,217</td>
<td>9,672</td>
<td>73.2</td>
<td>1,122</td>
</tr>
<tr>
<td>Respiratory organs</td>
<td>7,645</td>
<td>5,467</td>
<td>71.5</td>
<td>973</td>
</tr>
<tr>
<td>Bones, articular cartilage, soft tissue &amp; Kaposi Sarcoma</td>
<td>606</td>
<td>375</td>
<td>61.9</td>
<td>57</td>
</tr>
<tr>
<td>Malignant melanoma</td>
<td>1,912</td>
<td>989</td>
<td>51.7</td>
<td>270</td>
</tr>
<tr>
<td>Mesothelioma</td>
<td>232</td>
<td>166</td>
<td>71.6</td>
<td>27</td>
</tr>
<tr>
<td>Breast</td>
<td>9,695</td>
<td>8,457</td>
<td>87.2</td>
<td>277</td>
</tr>
<tr>
<td>Female genital organs</td>
<td>3,146</td>
<td>2,486</td>
<td>79.0</td>
<td>188</td>
</tr>
<tr>
<td>Prostate</td>
<td>8,681</td>
<td>6,032</td>
<td>69.5</td>
<td>317</td>
</tr>
<tr>
<td>Other male genital organs</td>
<td>400</td>
<td>316</td>
<td>79.0</td>
<td>21</td>
</tr>
<tr>
<td>Urinary tract</td>
<td>4,053</td>
<td>2,727</td>
<td>67.3</td>
<td>318</td>
</tr>
<tr>
<td>Eye &amp; central nervous system</td>
<td>977</td>
<td>673</td>
<td>68.9</td>
<td>185</td>
</tr>
<tr>
<td>Thyroid &amp; other endocrine glands</td>
<td>952</td>
<td>623</td>
<td>65.4</td>
<td>86</td>
</tr>
<tr>
<td>Hematologic tumours (incl MDS,MPD)</td>
<td>5,574</td>
<td>2,571</td>
<td>46.1</td>
<td>1,896</td>
</tr>
<tr>
<td>Unknown primary and ill defined sites</td>
<td>959</td>
<td>401</td>
<td>41.8</td>
<td>134</td>
</tr>
<tr>
<td>All tumours, excl. non-melanoma</td>
<td>60,572</td>
<td>43,001</td>
<td>71.0</td>
<td>6,006</td>
</tr>
</tbody>
</table>

Table 15. Number of Tumours Registered via the Clinical versus the Pathological Network, 2009. MDS, Myelodysplastic syndromes; MPD, Myeloproliferative diseases (BCR).

An evolution of the overlap between the clinical and pathological network between 2005 and 2009 (as shown in Table 16 for breast and prostate cancer) demonstrates that notifications via the pathological network only decreased slowly until 2008 and dropped significantly in 2009.

<table>
<thead>
<tr>
<th>Incidence year</th>
<th>Total</th>
<th>Clinical and pathological network</th>
<th>Clinical network only</th>
<th>Pathological network only</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>BREAST CANCER</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>9,480</td>
<td>7,357</td>
<td>77.6</td>
<td>324</td>
</tr>
<tr>
<td>2006</td>
<td>9,562</td>
<td>7,732</td>
<td>80.9</td>
<td>202</td>
</tr>
<tr>
<td>2007</td>
<td>9,775</td>
<td>8,305</td>
<td>85.0</td>
<td>191</td>
</tr>
<tr>
<td>2008</td>
<td>9,769</td>
<td>8,249</td>
<td>84.4</td>
<td>166</td>
</tr>
<tr>
<td>2009</td>
<td>9,695</td>
<td>8,457</td>
<td>87.2</td>
<td>277</td>
</tr>
<tr>
<td>PROSTATE CANCER</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>9,721</td>
<td>4,981</td>
<td>51.2</td>
<td>528</td>
</tr>
<tr>
<td>2006</td>
<td>9,275</td>
<td>5,278</td>
<td>56.9</td>
<td>311</td>
</tr>
<tr>
<td>2007</td>
<td>8,980</td>
<td>5,527</td>
<td>61.5</td>
<td>300</td>
</tr>
<tr>
<td>2008</td>
<td>8,837</td>
<td>5,619</td>
<td>63.6</td>
<td>286</td>
</tr>
<tr>
<td>2009</td>
<td>8,681</td>
<td>6,032</td>
<td>69.5</td>
<td>317</td>
</tr>
</tbody>
</table>

Table 16. Numbers of tumours registered via the clinical versus the pathological network for breast cancer and prostate cancer. Data source: BCR.
However, at present there is no complete registration of new cancer diagnoses by the clinical network which is necessary for a complete and qualitative cancer registry. Data managers play a crucial role in achieving this goal.

**A11.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

To evaluate the cancer care accurately, proper registration is mandatory. As already mentioned before, the Cancer Plan finances 1 FTE data manager per 1,000 MOCs (based on the number of registered MOCs of two years before) within the oncologic care programmes since 2008. Data managers need to register all cancer cases and follow-up on the correct implementation of the recommendations of the oncologic manual and on compliance to the treatment plan that is discussed during the MOC. Since their work is indispensable for reliable data within the Cancer Registry, they should follow a mandatory course on proper registration which is organised by the Belgian Cancer Registry. Note that also data managers not financed by the Cancer Plan are allowed to attend this training. Figure 39 depicts the number of data managers financed by the Cancer Plan a year, from 2009 to 2011, together with the number of data managers that have been trained by the BCR since 2000.

![Graph showing number of trained and financed data managers from 2000 to 2011](image)

**Figure 39.** Number of trained data managers (source: BCR) and data managers financed by the Cancer Plan per year, from 2009 to 2011 (Source: FPS Public Health). Data were processed by the Cancer Centre.

**ACTION 12: DEFINITION AND FINANCING OF A PAEDIATRIC ONCOLOGICAL CARE PROGRAMME**

**A12.1. SCIENTIFIC DATA ON INDICATORS**

**A12.1.1. Incidence, mortality and relative survival**

**Incidence of paediatric tumours**

Cancer is a rare disease in children (0-14 years). In Belgium, every year about 320 children are diagnosed with cancer (BCR). In 2009, childhood cancer comprised less than 1% of the total cancer burden in Belgium. All sites combined, more boys (59%) than girls (42%) were diagnosed with cancer. In the period 2004 to 2009 about 1.4% of children developed a second tumour. Children develop different types of cancers than adults. According to international standards, these tumours are
reported following the ICCC-3 classification [71]. In the period 2004-2009, leukaemias were the most frequent malignancies in children, followed by brain tumours and lymphomas (Table 17). The Automated Childhood Cancer Information System (ACCI S) project, which evaluated trends of cancer incidence and survival in Europe, showed an annual increase of 1.1% in childhood cancer incidence between 1970 and 1999 [72]. Due to the low number of new diagnoses, it is not possible to draw conclusions on trends based on the Belgian cancer incidence data only. In 2008, the incidence rates for childhood cancer in Belgium were comparable with the incidence rates of other European countries (Figure 40).

![Figure 40. Childhood Cancer (both sexes): comparison of Age-Standardised Incidence Rates (WSR), 2008. (BCR).](image-url)
### Table 17. Childhood cancer: incidence by sex, age group (0-5, 5-10, +10 years) and histological type in Belgium, 2004-2009. CR, crude (all ages) incidence rate (N/1,000,000 person years); WSR: age standardised incidence rates, using the World Standard Population (N/1,000,000 person years); CRI, cumulative risk 0-14 years (%). (BCR).
Mortality
Little information is available on mortality from paediatric cancers in Belgium. Official numbers from the FPS Economy, SME, Self-employed and Energy pointed to 41 cancer deaths among Belgian children (aged 0-14 years) in 2008 (http://economie.fgov.be/nl/modules/publications/statistiques/bevolking/Doodsoorzaen.jsp).

Observed survival in comparison to Europe
According to data from the BCR the five-year observed survival rate for children diagnosed with cancer in Belgium in the period 2004 to 2008 was 85% (Table 18). There were significant differences between the different subtypes. For instance, the survival rates for lymphoid leukaemia (Ia), which is the most frequent leukaemia variant in children, had a prognosis that was almost twice as high as the survival rates for acute myeloid leukaemia (Ib).

<table>
<thead>
<tr>
<th>Childhood Cancer: Observed Survival</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICCC-3</td>
<td>5 year OS</td>
<td>5 year OS</td>
</tr>
<tr>
<td>I Leukaemia, myeloproliferative and myelodysplastic diseases</td>
<td>82%</td>
<td>85%</td>
</tr>
<tr>
<td>Ia Lymphoid Leukaemia</td>
<td>87%</td>
<td>90%</td>
</tr>
<tr>
<td>Ib Acute non-lymphocytic leukaemia</td>
<td>42%</td>
<td>60%</td>
</tr>
<tr>
<td>II Lymphomas and reticuloendothelial neoplasms</td>
<td>95%</td>
<td>93%</td>
</tr>
<tr>
<td>III CNS and miscellaneous intracranial and intraspinal neoplasms</td>
<td>82%</td>
<td>77%</td>
</tr>
<tr>
<td>IIIa Ependymoma</td>
<td>83%</td>
<td>80%</td>
</tr>
<tr>
<td>IIIb Astrocytoma</td>
<td>82%</td>
<td>78%</td>
</tr>
<tr>
<td>IIIc-Illc Other</td>
<td>83%</td>
<td>73%</td>
</tr>
<tr>
<td>Total (I-XII)</td>
<td>84%</td>
<td>85%</td>
</tr>
</tbody>
</table>

Table 18. Childhood cancer: observed survival (OS) in Belgium (BCR).

No direct comparison with recent European data can be made. However, in the most recent period of the ACCIS analysis (1988–1997), the observed overall five-year survival rate among all childhood cancer patients was 72% [73]. According to the same ACCIS project, overall five-year survival increased greatly during the last 30 years of the past century: from 44% for children diagnosed in the 1970s, to 64% when diagnosed in the 1980s and 74% for children diagnosed in the 1990s [72].

A12.1.2. Follow-up of children who survived cancer
Due to substantial improvements in survival after treatment for malignant disease in childhood, the number of long-term survivors of all ages is increasing. Unfortunately, there is clear evidence that these survivors are at risk for adverse health-related long-term sequelae associated with their cancer and its treatment: it is estimated that approximately 60% of survivors will have one or more treatment or disease related late effects, with over 30% of these being classified as moderate or severe [74]. Besides the risk of developing late adverse effects from treatment, the most important health and quality of life concerns for survivors include the need for appropriate health education, potential impairment of psychosocial function (as many as 30% of survivors are said to develop significant psychosocial late effects), and assistance with important practical and financial issues such as employment and insurance (e.g. health insurance or life insurance). Therefore, follow-up for life is
recommended to facilitate timely diagnosis and appropriate management of incipient or established late adverse effect in order to reduce the frequency of severe complications and morbidity, and the effects on health services. How this long-term follow-up care should be designed and delivered remains the subject of ongoing discussion. An extensive review of current models of care can be found in the following publications: [74-76].

A12.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

The Cancer Plan also includes specific measures for the treatment and care of children with cancer. They should strengthen the support to families of children with cancer, organise and finance a care programme in paediatric oncology based on international guidelines, create a network and guarantee the further specialisation of the current seven centres for paediatric oncology (see Table 19). They should all be given the specialised personnel they need. These goals will be achieved by the acknowledgement of the centres currently active in paediatric oncology as unique centres of reference, financial support of collaboration between these centres, the realisation of a specific care programme and by introducing two additional FTEs in paramedic support for each centre. In the end, this should result in a specialised treatment of high quality for every child diagnosed with cancer.

<table>
<thead>
<tr>
<th>BELGIAN HOSPITALS WITH A PAEDIATRIC ONCOLOGIC UNIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>UZ Gent</td>
</tr>
<tr>
<td>UZ Leuven</td>
</tr>
<tr>
<td>UCL St-Luc</td>
</tr>
<tr>
<td>ZNA</td>
</tr>
<tr>
<td>Hôpital Universitaire des Enfants Reine Fabiola</td>
</tr>
<tr>
<td>UZ Brussel</td>
</tr>
<tr>
<td>SUHOPL: collaboration between CHC-Espérance, CHR-La Citadelle and CHU Liège</td>
</tr>
</tbody>
</table>

Table 19. Centres with paediatric oncology activity in Belgium in 2011 (Data source: FPS Public Health).

Figure 41 shows the number of new cancer cases in 2010 in each of the seven Belgian centres with paediatric oncology activity, as reported to the BCR. These figures also include a number of malignant tumours that are not listed in cancer incidence statistics.
Experts from the centres elaborated an analysis of the needs and identified criteria to obtain a qualitative treatment and framework. It became clear that a differentiation based on the level of activity is essential for elaborating quality criteria.

A Royal Decree is prepared based on the proposal of this work group describing recommendations for standards leading towards acknowledgements and staff. In anticipation of structural financing of recognised care programmes, the Cancer Plan finances the centres for paediatric oncology, which concerns five specialised and two satellite centres (Table 19).

This arrangement also mentions establishing a scientific team to coordinate the research between the acknowledged care programmes for paediatric oncology. Financing one FTE and 15% of physicians for the follow-up of clinical research within the programmes is defined in an agreement between the Belgian Society of Paediatric Haematology Oncology (BSPHO) and the BCR.

Additionally, as of 1 July 2008, two extra employees were financed per centre for paramedic support. The BSPHO announced the publication of a joint manual containing guidelines for the care and treatment of children with cancer. These standard protocols are also available from the BSPHO website.

**ACTION 13: TREATMENT OF RARE CANCERS**

**A13.1. Scientific data on indicators**

Recently, the Surveillance of Rare Cancers in Europe (RARECARE) project developed a definition of rare cancers. They defined rare cancers as cancers with an incidence lower than six per 100,000 a year, which corresponds to less than 30,000 cases a year in Europe [77]. If this definition is applied to the Belgian cancer incidence data of 2009, it appears that a total of 188 types of cancer can be considered as rare (based on combinations of topographical and morphological characteristics, as defined by the International Classification of Diseases for Oncology, ICD-O). Looking at the incidence rates in 2009, the number of new cases per year was 8,401, or 14% of all cancer diagnoses during that year. RARECARE also estimated the number of rare cancers in Europe between 1995 and 2002 (using a more fine-grained classification than the one based on ICD-10), and ended up with an annual incidence rate of all rare cancers of 108 per 100,000, corresponding to 541,000 new diagnoses annually, or 22% of all cancer diagnoses [77].

According to the RARECARE study, on average patients with rare cancers were younger than those with more common cancers (Figure 42A), and the relative survival rate was worse for patients suffering from a rare cancer (five-year relative survival rate 47%) than from a common cancer (five-year relative survival 65%) (Figure 42B). It was suggested that this poorer survival rate was not attributed to a higher stage at diagnosis, but was the result of less effective treatment options for rare cancers compared to common cancers. No numbers on survival of rare cancer in Belgium are currently available.
Since rare cancers are often inadequately diagnosed and treated due to lack of knowledge or clinical expertise, RARECARE suggested improving the quality of care by establishing centres of excellence for rare cancers as well as international collaborative groups throughout the European Union to achieve the necessary organisational structure, critical mass and patients for carrying out clinical trials and developing alternative study designs and methodological approaches to clinical experimentation [77].

**A13.1.1. Association between volume and outcome of rare cancers**

A number of rare cancers were subject to recent KCE studies. In their report on the association between volume and the outcome of surgical procedures [78], the KCE used Belgian administrative data from 2004 to analyse the relationship between the number of procedures performed per hospital or surgeon as well as the outcome variable mortality for two rare cancers, namely oesophageal and pancreatic cancer. For pancreas cancer surgery, the results of the KCE study were in line with findings from the literature, demonstrating that results were better in high volume centres. Although not statistically significant, patients treated in hospitals performing less than 11 interventions a year had a higher two-year mortality rate than patients operated in hospitals.
performing at least 11 interventions a year (Table 20). Likewise, patients operated by surgeons performing less than six interventions a year had a significantly higher risk of mortality than patients operated by surgeons performing at least six interventions a year. Therefore, the KCE recommended centralising the expertise in a limited number of centres by establishing an annual minimum threshold of pancreatectomies. For oesophageal cancer surgery, the KCE data did not find an inverse relationship between the volume of centres and a two-year mortality rate, whereas an inverse association, although not statistically significant, was found between the volume of surgeons and a two-year mortality rate. Since there is a clear consensus in scientific literature concerning the inverse relationship between hospital as well as surgeon volume and mortality for oesophageal cancer surgery, the KCE advised to re-investigate the volume-outcome relationship for oesophagectomies for cancer on recent data from at least two consecutive years. This study is currently on going, using incidence data from the period 2004-2008, and results will be available in December 2012.
With regard to testicular cancer, another rare cancer for which a relationship between volume and outcome has been suggested in the scientific literature, a volume-outcome analysis is not yet performed with Belgian data. However, in their report on quality indicators for testicular cancer [79], the KCE concluded that the dispersion of care and the resulting low annual number of patients with testicular cancer in many Belgian centres raised questions about the organisation of care for these patients and the need to centralise this care in a limited number of centres.

Besides the number of procedures performed per hospital or surgeon, the presence of a dedicated multidisciplinary team may also be important in determining the outcome of rare cancers [80]. Concerning the above mentioned issues, the KCE is planning a study aimed at establishing the threshold to define rare cancers and cancers requiring complex treatment, and to investigate the optimal organisation of care for rare cancers in Belgium.

### A13.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

A study to delineate the quantitative and qualitative criteria for the treatment of rare cancers is assigned to the KCE. The results are expected in May 2013 and should provide an answer to the following questions:

- Is the current standard of 400 cases a year in Belgium useful in defining rare cancers?

---

**Table 20.** Results of the analyses on the volume-outcome relationship for two rare cancer surgery procedures (based on data from 2004; numbers taken from [78]). aThe threshold used for oesophagectomies for hospitals and surgeons was six interventions a year; the threshold for pancreatectomies for hospitals and surgeons was 11 and six interventions a year, respectively. bnot statistically significant. CI, confidence interval; OR, Odds ratio. The incidence numbers of oesophagus and pancreatic cancer in women in Belgium meet the RARECARE definition of rare cancers (i.e. lower than 6 per 100,000 a year). The incidence numbers in men vary between 7.35 and 8.06/100,000 a year for oesophagus cancer and between 5.93 and 7.15/100,000 a year for pancreatic cancer (Source: BCR, data from 2005 till 2009).
- Which competences are present in Belgium to treat rare tumours and which ones are needed?
- Which standards are necessary for appropriate care of patients with a rare cancer, based on scientific guidelines on an international level?

For this investigation, the KCE will cooperate with the BCR and the College of Oncology. The latter already formulated advice concerning the quantitative and qualitative criteria.

**ACTION 14: CERTIFICATION OF THE ONCOLOGICAL NURSE TITLE**

**A14.1. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

Nurses can play a pivotal role during the diagnosis process as well as in the care and support of cancer patients. Since this requires additional specific knowledge, nurses who successfully complete a course of a minimum of 450 hours to specialise in oncology can obtain the title of oncology nurse. The Ministerial Decree of 28 January 2009 states the conditions for the certification of this title. The number of certifications of oncology nurses is listed in Table 21 for the Flemish and French Communities.

<table>
<thead>
<tr>
<th>YEAR</th>
<th>FLEMISH COMMUNITY</th>
<th>FRENCH COMMUNITY</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>7</td>
<td>51</td>
<td>58</td>
</tr>
<tr>
<td>2010</td>
<td>268</td>
<td>221</td>
<td>489</td>
</tr>
<tr>
<td>2011</td>
<td>374</td>
<td>245</td>
<td>619</td>
</tr>
<tr>
<td>TOTAL</td>
<td>649</td>
<td>517</td>
<td>1,166</td>
</tr>
</tbody>
</table>

*Table 21. Number of certified oncology nurses from 2009 to 2011 in the Flemish and French Communities. Data source: FPS Public Health.*

![Figure 43](chart.png)

*Figure 43. Number of certified oncology nurses from 2009 to 2011 in the Flemish and French Communities. The blue line depicts the total number of certifications a year (Data source: numbers from the FPS Public Health processed by the Cancer Centre).*

Not only nurses with a further specialisation in oncology are active in cancer care. According to the Hospital Statistics of 2011, hospitals reported a total of 3,148 nurses that are actively involved in oncological services. Figure 44 shows the proportion of nurses per type of degree that are working in cancer care. Nurses with an additional training in oncology represent 27% of the total nursing staff.
Taking into account the most recent cancer incidence numbers in Belgium, there are about 5,180 nurses for every 100,000 new cancer patients compared to 1,390 nurses with a specialised training in oncology.

**ACTION 15: IMPROVEMENT OF THE COVERAGE PROVIDED BY THE COMPULSORY HEALTH INSURANCE OF CANCER MEDICINES**

**A15.1. SCIENTIFIC DATA ON INDICATORS**

**A15.1.1. Performance of cancer care**

In a recent study, the OECD explored the performance of systems of cancer care and the correlation with the differences in cancer survival in OECD countries (a schematic overview of the different systems of cancer care in the OECD countries can be found in Table 22). The preliminary findings demonstrated that about half of the differences in cancer survival were explained by the countries’ resources, such as total national expenditure on health, investment in innovative cancer drugs and technology, and available human resources and infrastructure, and about one third by process quality [81]. A strong association was found between survival and investment in innovative drugs for breast, cervical and colorectal cancers, and to a lesser extent for lung cancer. In fact, the availability of innovative cancer drugs (the number in clinical use) appeared to be a more important explanatory variable than providing drugs free of charge.
<table>
<thead>
<tr>
<th>Completely free with some restrictions</th>
<th>More financial access for cancer patients</th>
<th>Same financial access as other patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Czech Republic, England, France, Greece, Italy, Netherlands, Scotland, Slovak Republic, Slovenia, Spain and Turkey</td>
<td>Free access</td>
<td>Support for drug and other costs</td>
</tr>
<tr>
<td></td>
<td>Free access</td>
<td>Belgium, Denmark, Malta, Norway, Poland, Portugal and Sweden</td>
</tr>
<tr>
<td></td>
<td>More financial access for patients with high medical costs</td>
<td>Australia, Belgium, Chile, Denmark, Finland, Germany, Iceland, Ireland, Israel, Japan, Korea, Latvia, Norway and Switzerland</td>
</tr>
<tr>
<td></td>
<td>More financial access for patients with low incomes</td>
<td>Australia, Belgium, Chile, Cyprus, Hungary, Ireland, Italy, Japan, Korea, Latvia, Portugal and Singapore</td>
</tr>
<tr>
<td></td>
<td>Financial support for travel costs</td>
<td>Australia, Belgium, Finland, Hungary, Latvia, Luxembourg and Norway</td>
</tr>
</tbody>
</table>

Table 22. Systems of cancer care across OECD countries. Taken from [81].

Although a number of new cancer drugs have been authorised over time, the speed with which these drugs become available to patients differed across countries as shown in Figure 45. Generally, countries granting faster authorisation of innovative cancer drugs also allowed their clinical use earlier than the other countries. The results from the OECD investigations concur with a previous report on the access of cancer patients in countries throughout the world to new innovative cancer drugs [82]. The latter study indicated that an increase in the number of available drugs was associated with an increase in both the one-year and five-year survival rates.
In the context of the Belgian EU presidency in 2010, a study was performed to analyse the optimisation of the access to innovative medicines within the European Union [83]. At present, member states have to take into account Directive 89/105/EEC of 21 December 1988 in deciding whether or not to reimburse the cost of (innovative) medicinal products. The explicit assessment of cost-effectiveness and budgetary impact is however not mandatory at the EU level, and remains the responsibility of the individual member states. The results of the evaluation processes in the different countries depend on the context, agency processes, ability to engage in price negotiation, and even differences in social values. There is thus an urgent need for better guidelines for budget impact analyses and for making these mandatory.

Also, innovative medicines are generally launched in markets where the companies can get a high price for them, and are launched in other markets later at comparable prices. This makes it difficult for low income countries to have affordable access to medicines. It remains to be examined if adjustments or price-differentiation, merely on Gross Domestic Product, will suffice, and should they not, which other criteria could be considered. Alternatively, innovative pharmaceutical drugs could be considered as a social insurance service, hence not requiring the rules of the EU internal market.

From the above it was concluded that a pan-European, coordinated assessment of both relative effectiveness and medical need at the EU level (including ethical and social considerations) should be envisaged and assigned to the EMA, Health Technology Assessment and competent bodies together. Local assessment of medical need, supplementary ethical and social aspects, cost-effectiveness, and budget impact should remain the responsibility of the member states.
A15.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

Since 2008 more than 70 new indications for cancer medication have been reimbursed. The efforts for these reimbursements are a work in progress. An overview of medication reimbursed by the NIHDI can be found in the Monitoring Of Reimbursement Significant Expenses (MORSE) report of the NIHDI (http://www.riziv.fgov.be/drug/nl/statistics-scientific-information/report/index.htm).

An NIHDI report on the monitoring of reimbursement of significant expenses shows that oncolytics contribute to the drug expenditure in hospitals to a large extent. For example, in 2009, €272.6 million was spent on oncolytics, corresponding to about 22.4% of the total drug expenses of the NIHDI. Detailed analysis shows that the increase in expenditure is largely attributable to a limited number of molecules (19 molecules represent 90% of the expenditures). The molecule responsible for the highest cost is trastuzumab (HERCEPTIN®), which main use is to treat aggressive HER-positive metastatic and adjuvant breast cancer (17% of the expenses in oncolytics). Other molecules with an important contribution to the costs are docetacel (TAXOTERE®) and rituximab (MABHERA®) (http://www.riziv.be/drug/nl/statistics-scientific-information/report/index.htm).

A collaboration between the NIHDI and the Federal Agency for Medicines and Health Products (FAMHP) analysed the differences between Belgium and the neighbouring countries regarding the pace, rates and conditions for reimbursement of cancer treatments, resulting in proposals to enable quick access to medications for the ‘unmet medical needs’. A work group consisting of the NIHDI, the FAMHP and Parliament was asked to formulate concrete recommendations. They initiated a new initiative for a quicker reimbursement of particular pharmaceuticals and therapies out of indication. It takes a very long time before an innovative treatment can be sold and is approved for reimbursement. During the research phase, only a minority of patients has access to this treatment by participating in clinical trials or by medical emergency programmes, or compassionate use. Accessibility to new treatments should be improved by shortening the time to approve reimbursement.

This initiative was proposed within the framework of the Fund for Rare Diseases and Orphan Medicines, and was inspired by the French ‘ATU model’ (Autorisation Temporaire d’Utilisation). This mechanism allows specified groups of patients to benefit from a temporary right to take advantage of new treatments before they are officially sold. All partners involved are discussing a proposal for a law and Royal Decree.

Not all indications are covered by the mandatory health insurance. These patients can rely on a reimbursement from the Particular Solidarity Fund of the NIHDI. One such indication is breast cancer in men, for example.

ACTION 16: SUPPORT OF RADIOTHERAPY AND MEDICAL IMAGING

A16.1. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

Radiotherapy is mainly focused on cancer treatments and represents one of the main used treatment plans (about 40% of cancer patients in Belgium are given radiotherapy, i.e. about 24,000 patients). The major objectives of the Cancer Plan regarding radiotherapy and oncological imaging are to guarantee the quality and a sufficient availability of diagnostic and therapeutic equipment in balance with the needs of the population. Coverage by the mandatory health insurance should guarantee accessibility to these technologies for every patient.
A16.1.1. Quality

Due to a series of incidents in radiotherapy within Europe, a work group was established to discuss possible initiatives that could increase the quality and lower the risk of accidents. Based on their proposals, the College of Radiotherapy and the FANC organised a pilot project for quality control within the radiotherapy services in Belgium. The project includes the progressive introduction of a monitoring system of the quality of radiotherapy and the elaboration of an internal system for registering and analysing incidents in radiotherapy services. There are three main cornerstones for improving quality:

The first one is recruiting quality managers specifically devoted to the radiotherapy services included. They are responsible for implementing the quality management system, placing its description into a quality manual and for the correct registration of incidents. Five centres benefited from funds to develop a comprehensive quality assurance program in 2010 (Jessa Ziekenhuis, Hasselt; AZ Turnhout, Turnhout; Clinique et Maternité Sainte-Elisabeth, Namur; CHU Sart Tilman; Liège; Centre Pelzer La Tourelle, Verviers). These five centres have been audited by the college of radiotherapy in 2011. In 2011, five additional radiotherapy centres received the same budget to develop their quality assurance program (UZA-ZNA, Antwerp; H-Hart Ziekenhuis, Roeselare; J Bordet, Brussel; UZ Gasthuisberg, Leuven; AZ Sint-Augustinus, Wilrijk). They will be audited in 2012. Each year the project will add five additional services until all 25 centres of radiotherapy in Belgium are included in 2015 (personal communication with P. Scalliet, Chairman of the Radiation Oncology Department at St. Luc University Hospital of the Catholic University of Louvain, Belgium).

Secondly, BELdART will carry out dosimetrical and mechanical checks of all the photon and electron beams with the financial support of the FANC. The results of these audits will be treated in strict confidence and will be validated before communicating to the participating centres (http://nutec.xios.be/index.php/nl/projecten/emr-dosimetrie/beldart).

Next to the mandatory notification of significant events that might threaten the safety or health of patients, a national database will be created for the voluntary registration of incidents and near-incidents, to be managed by the College of Radiotherapy. In doing so, local expertise could benefit the entire sector by sharing this information.

The FPS Public Health will follow up the evolution of these projects through steering committees. Later on, audits will be organised, and a quality label for radiotherapeutic services will be launched by the FANC and the College of Radiotherapy.

A16.1.2. Programming

The College of Radiotherapy is charged with surveying the current use of radiotherapy services. They formulated recommendations concerning the programming and criteria for the certification of these services. They concluded that the introduction of satellite services would involve a duplication of the infrastructure that will be more expensive than expanding current services. Moreover, an increase in services might jeopardise the quality of care since the minimum activity level will not be reached. The results of a new KCE study on innovative techniques in radiotherapy are expected in March 2013.

The consultation between the different stakeholders and experts regarding the possible programming of a certain amount of PET scans in Belgium was introduced in 2011 under supervision of the FPS Public Health. They will take into account the KCE report 110 regarding PET in Belgium [84].
The Budget of Financial Resources will procure the required financial input for the renewal of equipment or the acquisition of new devices in relation to the needs of patients. This budget also guarantees the introduction of so-called techniques of high conformation (IMRT, IGRT, ART, Stereotaxy).

A16.1.3. Numbers on devices in Belgium

Radiotherapeutic devices

Figure 46A summarises the number of LINACs installed in Belgium and its regions during the period 1989 to 2011. When we take into account the number of hospitals in each region, we see that hospitals in the Brussels Capital Region possess the most radiotherapeutic devices (Figure 46B). A similar situation can be seen when the number of devices per 1,000,000 residents is calculated: again, more devices are available per inhabitant in the Brussels Capital Region (Figure 46C).
Figure 46. Number of LINAC devices installed during the period 1989 to 2011 (A) per region; (B) per hospital per region and (C) per 1,000,000 residents per region. Remark that the number of installed LINACs does not necessary reflect the actual number of devices in Belgium and its regions since old LINACs are regularly replaced by new ones. (Data source: numbers on installed LINACs were obtained from the BELdART audit via XIOS Hogeschool Limburg; numbers on hospitals in Belgium were obtained from the hospital statistics 2010, FPS Public Health and population numbers on 1 January 2010 were retrieved from StatBel of FPS Economics processed by the Cancer Centre).

Medical imaging
Table 23 summarises the number of CT, PET and MRI scanners for Belgium and each region in 2010. Again, when we take into account the number of hospitals in each region, we see that hospitals in the Brussels Capital Region possess the most imaging devices, except for CT scanners (Figure 47A). A similar situation can be seen when the number of devices per 1,000,000 residents is calculated: again, more devices are available per inhabitant in the Brussels Capital Region (Figure 47B). According to the recent Health at a Glance report of the OECD, Belgium has less CT and MRI scans per million inhabitants than the OECD average (being 22.8 CT scans and 11.0 MRI scans per million residents, respectively) [10].

<table>
<thead>
<tr>
<th>Hospital sites</th>
<th>CT scanners</th>
<th>PET scanners</th>
<th>MRI scanners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brussels Capital Region</td>
<td>26</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td>Flemish Region</td>
<td>105</td>
<td>68</td>
<td>13</td>
</tr>
<tr>
<td>Walloon Region</td>
<td>64</td>
<td>55</td>
<td>8</td>
</tr>
<tr>
<td>BELGIUM</td>
<td>195</td>
<td>144</td>
<td>28</td>
</tr>
</tbody>
</table>


Figure 47. Number of CT, PET, and MRI devices (A) per hospital site per region and (C) per 1,000,000 residents per region in 2010 (Data source: numbers from the hospital statistics 2010, FPS Public Health processed by the Cancer Centre).
A16.1.4. Numbers on recognised physicians in radiotherapy in Belgium

According to the annual reports of the NIHDI (http://www.riziv.be/presentation/nl/publications/annual-report/index.htm), the number of recognised physicians active in radiotherapy has been increasing annually the past ten years. Figure 48 shows the number of acknowledged physicians active in radiotherapy from 2005 to 2010, together with the ratio of active radiotherapists over every 100,000 new cancer patients for the period 2005 to 2009.

![Graph showing number of acknowledged physicians active in radiotherapy from 2005 to 2010 and ratio of active radiotherapists per 100,000 new cancer cases needing radiotherapy.]

**Figure 48.** Total number of recognised physicians active in radiotherapy from 2005 to 2010 and number of acknowledged active radiotherapists per 100,000 new cancer cases needing radiotherapy from 2005 to 2009 in Belgium (Data source: numbers from the annual reports of the NIHDI, and cancer incidence numbers from the BCR processed by the Cancer Centre, assuming that about 40% of cancer patients in Belgium are given radiotherapy).

ACTION 17: STRUCTURAL SUPPORT OF TISSUE BANKS FOR CELL THERAPY AND UNITS FOR CELL THERAPY WITH HAEMATOPOIETIC STEM CELLS AND UMBILICAL CORD BLOOD

A17.1. Scientific data on indicators

In 1989, the Marrow Donor Program Belgium (MDPB) was set up in collaboration with the Belgian Red Cross in order to coordinate search activities for patients needing unrelated stem cell transplantation. Figures from the MDPB-Registry (MDPB-R) indicate that the number of Belgian patients receiving an allogenic stem cell transplant from an unrelated donor has been growing strongly from 50 to 60 transplantations in 2000 to about 200 transplantations in 2010 [85]. The majority of these patients (90-95%) are diagnosed with a haematologic malignancy (such as leukaemia and lymphoma), whereas non-malignant diseases (such as other blood diseases and metabolic disorders) represent a minority of the indications (respectively 2-4% and 0-4% of
transplantations) (personal communication Anne Vanhonsebrouck, MDPB-R, based on numbers from the period 2005-2009). In recent years, the number of Belgian stem cell donations has decreased due to the higher age of the donors and poor quality of HLA typing. In 2008 the MDPB and the Belgian Red Cross launched a national five-year recruitment campaign to revitalise the registering of candidate stem cell donors. It was decided to prolong this campaign after 2013.

A17.1.1. Number of Belgian cancer patients receiving a transplant from a donor abroad

Due to the relatively lower quality of HLA typing in Belgian donors (see above), the number of Belgian patients receiving a transplant from a donor abroad has been increasing over the last decade (Figure 49). In fact, in recent years, more than 95% of patients were transplanted with an international donor. Since 2011, the effects of the recruitment campaign are becoming visible, resulting in a higher number of Belgian donors with a better quality of HLA typing, eligible for stem cell transplantation to Belgian patients.

![Figure 49. Percentage of Belgian patients transplanted with a Belgian donor or a donor abroad. Data source: MDPB.](image)

A17.1.2. Number of foreign cancer patients receiving a transplant from a Belgian donor

Since 2000, the number of Belgian stem cell donors (of peripheral blood stem cells (PBSC) and stem cells from bone marrow (BM)) eligible for transplantation to a patient abroad was decreasing, with the lowest level being reached in 2010 (Figure 50). Together with the increase in Belgian donors for Belgian patients in 2011 (see above), the use of Belgian donor stem cells for foreign patients also increased.
A17.1.3. Number of cancer patients needing a transplant who do not find a match

Analysis of the numbers of the MDPB-R revealed that in 2008 and 2009, respectively 2.6% and 2.3% of all Belgian patients waiting for a stem cell transplantation did not find a suitable donor or CBU (personal communication Anne Vanhonsebrouck, MDPB-R). Assuming that about 90-95% of these patients are suffering from malignant disease (see above), this means that about 2.4% and 2.1% of cancer patients needing a transplant did not find a match in 2008 and 2009, respectively.

A17.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

For a number of years, banks for haematopoietic stem cells and umbilical cords are certified at several hospitals, and they may participate in a large international network. For many patients with leukaemia or severe blood diseases, these cell banks represent hope for a cure. Their own blood cells are destroyed by heavy chemotherapy and they need a transplantation of compatible haematopoietic stem cells that are kept at these cell banks. Certification requires proper management, and very strict quality criteria need to be met. The stem cells can be derived from the patient (autologous stem cells) for stem cell transplantation or from compatible family members (allogeneic stem cells).

Although these banks are increasingly important, they were not structurally funded. For this reason, the Cancer Plan started up structural support for tissue banks and units for cell therapy by financing a databank manager, a quality coordinator, technicians and a lump sum for storage and general costs. As of 2011, 13 recognised hospitals receive this structural funding to manage their tissue banks with haematopoietic stem cells. Five of them also have a bank with umbilical cord blood units. The human resources are divided as shown in Table 24.

<table>
<thead>
<tr>
<th>HAEMATOPOIETIC STEM CELLS ONLY</th>
<th>HAEMATOPOIETIC STEM CELLS + UMBILICAL BLOOD UNITS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician Manager</td>
<td>0.2 FTE</td>
</tr>
<tr>
<td>Technician</td>
<td>1 FTE</td>
</tr>
</tbody>
</table>

Figure 50. Number of foreign patients receiving a transplant from a Belgian donor. PBSC: peripheral blood stem cells; BM: stem cells from bone marrow; CBU: cord blood units. PBSC and BM are sourced from donors in registries; stem cells from umbilical cord blood are collected post partum. Data source: MDPB.
Table 24. Number of funded FTEs for cell banks with haematopoietic stem cells only and cell banks with both haematopoietic stem cells and umbilical blood. Data source: FPS Public Health.

<table>
<thead>
<tr>
<th>Position</th>
<th>FTE</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality Coordinator</td>
<td>1 FTE</td>
<td>1 FTE</td>
</tr>
<tr>
<td>Data Manager</td>
<td>0.5 FTE</td>
<td>1 FTE</td>
</tr>
<tr>
<td>Forfeit</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Total funding per bank</td>
<td>€ 208,480</td>
<td>€ 351,720</td>
</tr>
</tbody>
</table>

Having an EBMT certification (European group for blood and marrow transplantation) and a FAMHP accreditation is a prerequisite for the haematopoietic stem cell banks to receive structural support from Cancer Plan. Tissue banks with umbilical cord blood units need to be FACT-NETCORD\textsuperscript{10} and FAMHP accredited before they receive structural support from the Cancer Plan.

**ACTION 18: IMPROVEMENT OF THE REIMBURSEMENT OF ADDITIONAL COSTS RELATED TO CANCER THERAPY**

**A18.1. SCIENTIFIC DATA ON INDICATORS**

**A18.1.1. Cost of cancer**

Many cancer patients are worried when facing medical and non-medical costs following the diagnosis of cancer. For some patients, the significant impact of these costs on their income even leads to substantial financial problems. In Belgium, a number of different insurance, benefit and reimbursement mechanisms exist, such as the compulsory health and disability insurance (NHI/HDI), OMNIO, third party payment, MAF (maximum invoice), Flemish care insurance, etc. Two recent studies investigated the reasons why having these health insurances is no guarantee that cancer patients will be protected from major, life-changing expenses.

An analysis of data from patients relying on financial support from the Cancer Fund of the Flemish League against Cancer (VLK) during the period 2007-2010 revealed that the percentage of singles with financial problems doubles from 22 to 43% when facing medical and non-medical costs due to cancer and its treatment [86]. Similarly, 17% of couples without children are dealing with financial shortcomings when not taking into account medical and non-medical costs, whereas this percentage increases to 35% when these costs are included. One must note that this analysis was not based on a representative sample, as people relying on financial support from the Cancer Fund already have a low income as well as relative high costs. Also, data on lump sum compensations from the health insurances were not taken into account.

In the study of Pacolet et al., medical costs obtained between 2008 and 2010 were analysed using the data bank of the Christian Sickness Fund [87]. A subdivision was made into the following phases: prediagnostic, acute, chronic and terminal phase.

- Within the prediagnostic phase (i.e. during the three months preceding the diagnosis), the average cancer patient spent about €130 a month on medical costs. The medical surpluses due to cancer and its treatment rose to almost 300% of medical costs spent by the control group.
- During the acute phase (i.e. the first six months following the diagnosis), about €212 a month was spent on medical costs. The medical surpluses due to cancer and its treatment rose to almost 600% of medical costs spent by the control group.

\textsuperscript{10}International NetCord Foundation is a non-profit association of umbilical cord blood banks whose members comprise the largest source of high-quality cord blood grafts for patients in need of hematopoietic stem cell transplantation. FACT is the international accrediting body in charge with CB bank inspection and accreditation.
During the chronic phase (i.e. the period between six and twenty-four months following the diagnosis) medical costs were lower. The patient was confronted with an average net cost of €46.5 euro a month, which resulted in an incremental cost of €15 compared to the control group (€30 a month).

In the terminal phase (i.e. two months before death): In the period from day -60 till -30 before death, the patient had a net average cost of €154.3 a month; in the period from 30 till day 1 before death, the average decreased to €116.7 a month. In the last month before death, 73% of patient costs were lowered by means of insurance, benefit and reimbursement mechanisms.

No large differences were noted between the different regions in Belgium, except for Brussels where there were significant surpluses, which could be explained by the potential absence of homecare in Brussels.

Pacolet et al. also performed a pilot study, analysing the non-medical costs of cancer patients. Non-medical costs of these patients were €212 a month on average, and mainly resulted from loss of income. For retired people with a low income, these non-medical costs could lead to financial problems. Important costs included non-reimbursed medication and costs of paramedics (accounting for €63 a month) and hospital insurance (€31 a month).

In 2009 the Plan Chronic Diseases was launched. The programme ‘Priority to Chronic Diseases’ aims at improving the accessibility and quality of care for chronically ill patients. In particular, the programme focuses on the recognition of patients with a chronic disease, the enhancement of the accessibility to information together with the simplification of administrative procedures, enhanced accessibility of medical care, improved integration of patients and a permanent reflection on policies on chronic diseases.

A18.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

Cancer patients are often confronted with additional expenses as well as the costs for curative or palliative treatments. The Cancer Plan foresees three different additional costs: stem prostheses for laryngectomised patients, hair implants for people who lost their hair due to the treatment, and implants for women who underwent the amputation of one or two breasts.

From 1 November 2009 the safety margin of a stem implant was reimbursed (€49.07). Since such an implant and the kit for its maintenance needs to be replaced several times a year and the expenses for the delivery margin are high, the mandatory health insurance will also reimburse the delivery margin and the accessories of a stem implant. Figure 51 shows the registered reimbursement from November 2009 to the end of 2011.

---

11More information can be found on http://www.laurette-onkelinx.be/articles_docs/20110330_-_SVZ_Prioriteit_aan_de_chronisch_zieken.pdf
Figure 51. Number of reimbursements of the delivery margin of stem implants from 2009 (Nov-Dec) to 2011 (Data source: numbers from the NIHDI processed by the Cancer Centre).

People who lose their hair due to a cancer treatment receive a lump sum. This amount was re-evaluated from 1 February 2009 as follows:

- People who became completely bald, but whose hair will recover receive €180 (instead of €120): see Figure 52
- People displaying permanent hair loss due to radiotherapy receive a lump sum of €270 (instead of €180): see Figure 53.

A renewal of these lump sums can only be done two years after the first application.

Figure 52. Number of lump sums for hair prostheses for people who lost their hair temporarily due to radiotherapy or chemotherapy from 2006 to 2011 (Data source: numbers from the NIHDI processed by the Cancer Centre).
A better reimbursement of breast reconstructions, including those involving the most recent techniques, was introduced on 1 December 2008 as described in the Royal Decree of 18 September 2008. As from 1 January 2009, two additional measures entered into force:

- Introduction of reimbursement for external breast prostheses in case of unilateral agenesis (Royal Decree of 14 October 2008). Previously, reimbursement was restricted to internal prostheses only.
- Introduction of reimbursement for two external breast prostheses after amputation of the second breast. Due to this initiative, only one application is needed for both prostheses as the period for renewal coincides.

**ACTION 19: FUNCTIONAL REHABILITATION OF THE CANCER PATIENT IN REMISSION**

**A19.1. SCIENTIFIC DATA ON INDICATORS**

As a consequence of cancer and its treatment, cancer survivors often experience increased fatigue, decreased physical activity, and a reduction in quality of life. In addition, survivors tend to be less active than people not diagnosed with cancer. Recent investigations have demonstrated possible physiological and psychological benefits of physical exercise in cancer survivors resulting in alleviation of cancer sequelae and enhanced returning to the health status patients had before treatment. Most of the studies performed to day focused on breast cancer. Vanderstraeten et al. recently presented an overview of randomized controlled trials that examined the effects of physical exercise on physical fitness, fatigue and quality of life in breast cancer patients during and after treatment [88]. It appeared that resistance exercise training merely affected muscle strength and muscle mass, whereas aerobic exercises increased peak oxygen uptake and resulted in decreased fatigue. Both training programs eventually led to an improvement in the quality of life. At a European level, the needs of cancer survivors are currently addressed within the European Cancer Health Indicator Project (EUROCHIP) by defining a list of indicators on cancer rehabilitation in collaboration with patient associations (http://www.tumori.net/eurochip/). A recent estimation of the proportion of cured patients among European cancer patients diagnosed between 1988 and 1999 revealed that 21% to 47% of men and 38% to 59% of women belonged to this category [89]. When we project these percentages onto the number of Belgian cancer incidences in 2009, this would mean that 6,878 to 15,394 men and 10,571 to 16,413 women were cured in 2009.
**A19.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

After terminating an aggressive cancer therapy, patients are confronted with severe physical, psychological and/or neuro-cognitive problems. There is a need at that time point for an integrated rehabilitation programme following the treatment. Moreover, these patients desire assistance to reintegrate into society and be able to pursue a qualitative life.

The Cancer Plan aimed at starting up pilot projects to determine which kind of care programme regarding multidisciplinary rehabilitation is needed for the reintegration of cured cancer patients. Ideally, such a reintegration should already be prepared during the active treatment in close deliberation with the patient and the relevant caregivers.

A project to enhance the quality of life and the reintegration of women with breast cancer by physical training and management of their lifestyle was launched in November 2010. A manual was developed for both patients and caregivers. In the next stages of the project, the efficacy of the programme, as described in the manual, will be investigated in seven hospitals, which will later be expanded to 15 hospitals.

**ACTION 20: DETERMINING THE REQUIREMENTS FOR RECOGNISING A DISABILITY CAUSED BY CANCER TREATMENT**

**A20.1. SCIENTIFIC DATA ON INDICATORS**

Patients with cancer and disease-free survivors often experience a number of problems, such as fatigue, cognitive dysfunction, depression, sexuality problems, etc. due to cancer and its treatment. The impact of these effects on the patients’ functioning is reflected by the degree of employment among survivors. A recent overview of papers published between 2000 and 2009 revealed that 40% of patients remained at or returned to work six months following the diagnosis. The mean duration of absence from work was 151 days. Factors significantly associated with a greater likelihood of being employed or returning to work were perceived employer accommodation, flexible working arrangements, counselling, training and rehabilitation services, younger age and cancer sites of younger individuals, higher levels of education, male gender, less physical symptoms, lower length of sick leave and continuity of care [90]. Return to work did however not imply a return to the status before the diagnosis: following cancer treatment a reduction of up to 26% was found in physical and mental work ability.

**A20.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

Not all cancer patients are able to reintegrate and take up the life they had before the cancer diagnosis. For patients suffering from disability caused by their illness or the treatment, Social Security provides income replacement allowances, integration allowances or allowances for help to the elderly (+65y). Several criteria (related to nationality, age, place of residence, age, etc) need to be met in order to be entitled to these allowances. The amount of the allowance depends on the particular family situation and the level of disability and loss of self-reliance.

The Cancer Plan wants to accelerate the application procedure for disabled cancer patients, including people having chemotherapy or radiotherapy, people with a fast evolving condition with negative perspective in the short term and for terminal patients receiving palliative care.

Priority is given to cancer patients, by judging their applications merely on the dossier itself, rather than inviting the patients to undergo any additional medical examination.
The modification of the procedure was published in the Royal Decree of 19 May 2008 and entered into effect on 1 January 2008. Despite the improved procedure, not all priority dossiers can be treated as such because of the massive inflow of applications that should be evaluated as a priority. As a consequence, the service responsible cannot devote time to registering the applications, so a detailed follow-up and evaluation is not yet possible.

**ACTION 21-22: SUPPORT FOR PARENTS OF CHILDREN WITH CANCER AND ACCESS TO PSYCHOSOCIAL SUPPORT OR PARTICIPATION IN SELF-HELP GROUPS**

**A21-22.1 Scientific data on indicators**

Following diagnosis of childhood cancer, the many treatment procedures and their associated side effects, such as hair loss, weight gain, mood swings, susceptibility to infections, fatigue, nausea, potential impairment of education and psychosocial function, not only impact the quality of life of the child with cancer, but also of the whole family. In addition, families have to adapt to the unpredictable and uncontrollable course of cancer treatment [91]. Childhood cancer thus causes considerable distress to parents, which may however ease up with time, possibly as the perceived risk of relapse declines. Wakefield et al. recently reviewed the psychosocial impact of treatment completion on parents. Their findings demonstrated that while parents celebrate treatment completion, there is an unmet need for continued psychosocial support specifically targeting parents' risk perceptions, physical and emotional fatigue, social isolation and parenting concerns post-treatment [92].

**A21-22.2. Indicators reflecting a specific action of the Cancer Plan**

Several parents of sick children, especially those not living near a hospital, have transport problems between home, work and the hospital, and the associated loss of time. Parents of children diagnosed with cancer often feel the urge to express their emotional burden and distress caused by the disease and potential loss of their child. Psychological care is not only needed during hospitalisation, but also definitely needed when the patient is back home.

The Cancer Plan is not blind to the requests of these parents and wants to support them by enabling them to spend time with their child or to take time to recover, strengthen and become capable again of taking care of their children. Patients and their relatives should have access to psychological guidance (individual or in group) and to support groups. These initiatives are strongly focused on improving their quality of life despite the difficulties.

A call for projects was launched on 12 June 2008 to finance specific projects to support parents and children with cancer and to psychosocial support of all cancer patients. Some 50 out of 58 projects submitted by hospitals were selected and have been financed since 1 January 2009. The projects aim at different target groups: cancer patients themselves (both children and adults) and their families (children, parents and partners). The subsidised projects can be globally divided into three main categories: arrangement of a meeting space, organisation of support groups and more specific projects such as individual support of the relatives of patients in relapse or foreign patients, organising school visits to sick children, further optimisation of multidisciplinary support, research projects, etc.

The projects were launched in 2009, but a period of two years seemed insufficient to finalise and evaluate them properly, so the financing was continued in 2011. The FPS Public Health through
steering committees ensured the follow-up and an evaluation report was requested in November 2011. Based on these reports, the added value of this specific support for patients and their relatives will be analysed to formulate recommendations in order to implement concrete initiatives in hospitals.

In January 2012, a new call for projects was launched with four main motives: first, the organisation of contact opportunities between fellow patients; secondly, the establishment of spaces to psychologically support children and grandchildren of cancer patients or their partners; third, innovative approaches of psychosocial support; and lastly, the establishment of a scientific team to evaluate the organisational model of the pilots. Selected projects will be financed from 1 July 2012 till 1 July 2015.

**ACTION 23: STRUCTURAL FINANCING OF THE CHAIN OF PAEDIATRIC CARE “CONTINUED CARE FOR CHILDREN”**

**A23.1. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

To guarantee the continued care for children with cancer, the FPS Public Health finances five liaison teams Table 25. The conditions for recognition of these teams are described in the Royal Decree of 15 November 2010. The creation of the liaison function is intended for young patients (-16 year) suffering from a severe chronic pathology. These teams ensure the continuous care and treatment of these patients when they are hospitalised as well as after hospitalisation when care is still needed in their home environment. The treatment may be of a curative, palliative or terminal nature. The minimum team consists of:

- 50% physician, specialised in paediatrics with expertise in pain control
- 4 x 100% nurses of which at least one has a specialisation in paediatrics and neonatology
- 50% psychologist
- 50% person for the administration

One physician and one nurse should be permanently on call.

Their tasks can be summarised as follows:

- Encouraging the communication between the hospital team and the primary care
- Ensuring the continuity of the treatment in the hospital when the patient leaves the hospital and receives care at home, or vice versa
- Providing information about team functions
- Providing advice on the liaison team to the management of the hospital.

These teams can be organised by hospitals with a minimum limit of activity of 50 new patients a year younger than 16 years old with severe pathologies requiring a complex treatment (also including non-oncologic diseases).

**BELGIAN HOSPITALS WITH A PAEDIATRIC LIAISON TEAM**

| UZ Gent          |
| UZ Leuven       |
| CHR de la Citadelle |
| Cliniques Universitaires St-Luc |
| Hôpital Universitaire des Enfants Reine Fabiola |

*Table 25. Data source: FPS Public Health.*
ACTION 24: SUPPORT OF PILOT PROJECTS IN CLINICAL ONCO-GERIATRICS

A24.1. SCIENTIFIC DATA ON INDICATORS

A24.1.1. Incidence of cancer in patients older than 70 years of age

Currently about 13% of the Belgian population is 70 years of age or older. By the year 2020, the total number of inhabitants in the age group 70+ will rise by approximately 200,000 people, resulting in an increase in the need of specialised oncological care for patients in this age group (Table 26).

<table>
<thead>
<tr>
<th>Belgium</th>
<th>2010</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group 0-69</td>
<td>9,418,881</td>
<td>9,771,634</td>
<td>9,957,224</td>
</tr>
<tr>
<td>Age group 70+</td>
<td>1,388,515</td>
<td>1,428,122</td>
<td>1,581,108</td>
</tr>
<tr>
<td>Total</td>
<td>10,807,396</td>
<td>11,199,756</td>
<td>11,538,332</td>
</tr>
</tbody>
</table>


Data from the BCR with regard to the incidence of invasive cancers in patients 70 years and older in the Flemish Region revealed an increase in the total number of new diagnoses with 36% between 1999 and 2009 (Figure 54). The age standardised incidence over the same period showed only a small increase (EAPC = 0.6% \[p=0.02\]), indicating that the main reason for the increase in the number of new diagnoses was due to ageing.

In 2009, the BCR registered 27,424 new diagnoses of cancer in Belgian patients in the age group 70+ (45.3% of the total number of new cancer diagnoses). Due to the ageing of the population, the absolute number is expected to rise with about 4,000 new diagnoses a year from 2009 to 2020. More specifically, the proportion of patients aged 85 years and older is supposed to increase from 6.8% in 2009 to 8.4% in 2020 (Figure 55). The slight decrease in the relative proportion of invasive cancers in patients aged 70 years and older that is expected in 2020 compared to 2008 can be explained by a
shift in the proportions of people aged 75 to 79 years old compared to those aged 60 to 69 years old. Indeed, in 2020 there will be a decrease in the number of people aged 75 to 79 years old (due to the decrease in the number of births during World War II) whereas the number of people aged 60 to 69 years will increase (due to the baby boom in the period after World War II). In addition, cancers in both age groups contribute for a large part to the incidence numbers of invasive cancers, explaining the distribution of these cancers as depicted in Figure 55.

![Figure 55. Distribution of invasive cancers by age (A) in 2009 and (B) in 2020, according to a prognosis by the BCR.](image)

**A24.1.2. Types of cancer in patients older than 70 years**

The most frequent tumours in elderly people in Belgium in 2009 were prostate cancer in males and breast cancer in females (Figure 56). The frequency of colorectal cancers, which are the third and second most frequent tumours in men and women respectively, was higher in people aged 70 years and older than in the general population.
A24.1.3. Tumour stage at diagnosis for geriatric oncopatients

According to the EUROCare II study on survival of elderly cancer patients in Europe, the survival probabilities of the elderly are worse as compared to younger adults, due to a variety of factors including differences in the nature of the tumours, weaker general condition, comorbidity and the usage of less aggressive (and therefore less efficient) therapies [93]. In general, elderly patients have a large survival disadvantage, particularly one year after diagnosis and if they are women. An important factor in the prognosis is the difference in stage distribution at the time of diagnosis. As shown in Figure 57 for breast and colorectal cancer in Belgian patients diagnosed in 2009, elderly patients are more often diagnosed in prognostically less favourable stages. Moreover, with age, an increase can be observed in the proportion of diagnoses without information on the stage (Figure 58).
Figure 57. Incidence of breast and colorectal cancer by stage and age group in Belgium in 2009. (A) Breast cancer in females, (B) colorectal cancer in females and (C) colorectal cancer in males. Only cancers with known...
stages (I-IV) are taken into account; cancers with an unknown stage make up (A) 7 to 13%, for (B) 12% and for (C) 11 to 12% of all cancers (known and unknown stages together) per age group (BCR).

![Proportion of breast tumours with unknown stage](image1)

![Proportion of colorectal tumours with unknown stage](image2)

**Figure 58.** Proportion of tumours with unknown stage in Belgium in 2009. (A) Breast cancer and (B) colorectal cancer (BCR).

**A24.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

Health care should be ready for the increased needs in oncological care adapted to the elderly due to the aging population. Therefore, instruments for geriatric evaluation should be defined and validated, recommendations should be formulated for the care of older patients, and the composition of the most suitable multidisciplinary teams for this specific care should be specified. In doing so, caring for older cancer patients can be optimised and specialised teams in clinical onco-geriatrics can be established. To achieve these goals, a call for projects was launched in June 2008 to care programmes in oncological geriatrics. Fifteen out of 27 projects submitted by the hospitals were selected and financed for one year (2009-2010). The funding of 14 of these projects was continued in 2011. Based on the evaluation reports requested in November 2011, the contribution of these projects to the well-being of the elder cancer patients and their relatives will be assessed and recommendations for implementation will be defined.
In January 2012, a new call for projects was launched with two main motives: first, the establishment of a scientific team to evaluate the organisational model of the pilots; second, optimal approach of onco-geriatric patients by implementing an organisational model within onco-geriatrics where collaboration between the medical oncologist and the geriatric is crucial. Selected projects will be financed from 1 July 2012 till 1 July 2015.

**ACTION 25: ENSURE THE AVAILABILITY OF PALLIATIVE CARE FOR CANCER PATIENTS**

**A25.1. SCIENTIFIC DATA ON INDICATORS**

**A25.1.1. Organisation of palliative care in Belgium**

In 2009, the KCE performed an extensive study of the organisation of palliative care in Belgium by means of a systematic literature review, an analysis of the prevalence of palliative care and of the perception and experience of general practitioners with palliative care in Belgium. In addition, a pilot study was performed to estimate costs [94]. A summary of the KCE findings is given below.

- **Definition and needs of a palliative patient**
  
  From the literature it was clear that there is no consensus on the definition of a palliative patient, although the importance of including the patient’s status and needs in the definition (as advised by the WHO) was emphasized. The current policy in Belgium relies on a definition based on the patient’s prognosis. However, the literature and surveys clearly show that life prognosis does not identify patients with palliative care needs since prognosis is often inaccurate, especially when long and in the case of diseases other than cancer. In accordance to the WHO’s definition, Belgian GPs generally labelled a patient as ‘palliative’ according to the additional care they needed. The KCE study suggested to use their designation, i.e. ‘a patient suffering from an incurable, progressive, life-threatening disease, with no chance of obtaining remission or stabilization or restraining of this illness’ to redefine the patient with palliative care needs. This assessment implies a judgment by the usual main caregiver in cooperation with an experienced team, in order to enhance the accuracy of the assessment.

  Information and social support are two domains where patients have important and frequently unmet needs, especially for activities of daily living. This is particularly true for the patients with a long life prognosis (dementia, chronic failure, respiratory disease). The fulfilment of these needs would give them an opportunity to live as long as possible within their familiar environment.

- **Palliative care models**
  
  The literature review of the KCE also analysed different palliative care models in the scientific literature. Most models under study were either home settings or transmural care models. The content of the care models was heterogeneous and no evidence was found to demonstrate the superiority of any model in terms of better outcomes. Though, transmural care models ensured a continuity of care between settings, particularly in the case of transfers during the last weeks of life. In addition, the literature reviews did highlight a gap in studies on informal caregivers. Nonetheless, all palliative care models either at home or in transmural settings heavily rely on their availability and competences. The KCE study therefore suggested to specifically target them in order to answer their needs and to give them an appropriate support in order to prevent situations of exhaustion.

- **Prevalence in Belgium**
An estimate was made of the population of patients that were potential candidates for palliative care in Belgium in 2008, independently of their prognosis and of the care they received. Between 10,000 and 20,000 patients in Belgium were considered as being palliative according to their health care professionals, whereas only 400 beds are available in palliative care units. There is thus a growing need for care givers that can provide the best palliative care for patients, staying either at home or in home replacement settings.

One out of 10 GPs seemed to have referred to palliative care services at home in 2008. A recent study of the Christian Sickness Funds also found that less than half of the patients who died at home benefited from the ‘lump sum’ and one fifth of the demands occurred during the last week of life (http://www.mc.be/cm-tridion/fr/135/Resources/mc_info_235_fin_vie_tcm183-56800.pdf). In hospital, professionals considered a referral to the palliative care team for less than half of the patients, less often for patients who were older and/or with a non-cancerous disease. Belgium also has structures that facilitate patient care at home with mobile teams and continuity of first-line care, although the efficiency of these systems is hindered by missing liaisons between health care settings and lack of multidisciplinarity.

**Perception of general practitioners and hospital health professionals**

The KCE also analysed the patients’ expectations with regard to palliative care and preferred place of death, and found that most patients died where they wanted to die, when the main caregiver knew about these wishes. Most palliative patients preferred to die at home or in home replacement settings (e.g. nursing home). According to a recent study on the end-of-life care and circumstances of death in patients dying as a result of cancer in Belgium 34% of deaths occurred at home and 29% at the hospital [95]. In 43% of cases end-of-life treatment preferences were known.

The KCE study further revealed that hospital physicians and GPs ignored patients’ wishes concerning the treatment options in about one quarter of cases, pointing to the importance of optimal communication between the lines of care in order to identify the patient’s expectations. The web based survey however showed that many GPs, particularly those without any training in palliative care, feel uncomfortable communicating with patients. The situation might be even more difficult for specialists as communication and palliative care are less frequently included in their training. In this regard, the KCE study underlined the importance of training of all caregivers in palliative care. Furthermore, continuing medical education afterwards was recommended, in order to keep up with the latest developments in palliative care.

In home and home replacement settings, the treatment options planned by the health professionals were mostly followed during the following weeks. The definition of the treatment’s goal was essential for the treatment decision-making but the physicians pointed out the grey area between curative and palliative care as well as the potential evolution in the patient’s wishes, again emphasising the significance of an accurate definition of palliative care.

The second field where patients had important and frequently unmet needs was the social support, especially for daily activities. The fulfilment of these needs would give to terminally ill patients an opportunity to live as long as possible within their familiar environment.

**Pilot study: costs of palliative care for patients**

The KCE pilot study on the costs of palliative care revealed that, in the home setting, the most salient point was the total costs paid by the patient and the high variability recorded within this small sample. Median monthly costs were higher than €1,500, three times as much as the lump sum paid by the NIHD1. A part of this sum might be reimbursed later, although medical fees only represented a
limited proportion of the budget. Informal care (loss of income), support from social services and nourishment were the most costly items. Cost calculations in hospital acute wards showed that a patient identified as a patient with palliative care had lower costs than a patient who is not yet identified as a patient with palliative care. The costs difference was explained by higher NIHDI charges in the absence of palliative intervention. Therefore, the question arose as to whether the interventions administered within ‘classical (acute) care’ settings are appropriate for patients at the end of life while other terminal patients benefit from palliative interventions with fewer procedures. Costs were highest in palliative care units, probably resulting from higher staffing levels. Costs calculation in nursing homes pointed to the definite role of hospitalisations and further highlighted the role of palliative care in decreasing hospitalization costs: patients without palliative care had higher costs than residents with palliative care, due to the higher hospitalization costs in the first group.

**A25.1.2. European guidelines**

In 2003, the Council of Europe published their recommendations for new standards in palliative care provision across EU member states. The report highlighted the need for structured programmes of education, training and research [96].

Recently, the European Association for Palliative Care also presented its white paper, including recommendations for a common European terminology and presenting standards and norms for hospice and palliative care in Europe with regard to structural quality for the provision of palliative care with inpatient and outpatient services in different settings [97;98]. Among others, the white paper addresses the definition and terminology of palliative care and hospice care, common values and philosophies (such as the relationship between patient and health care professionals and the preservation and enhancement of quality of life), the availability and continuity of care, the preferred place of care as well as types of services and the staff in these services.

**A25.2. Indicators reflecting a specific action of the Cancer Plan**

Palliative care should be considered more broadly than merely as end-of-life care. Palliative care starts when the treatment does not provide any perspective towards recovery or curing which is much earlier than the final weeks or months of a patients’ life. Subsequently, the number of palliative teams should be high enough to meet their needs, as well in their home environment as well as in institutions.

The Cancer Plan is actively sustaining the organisation of palliative care since the majority of ‘palliative patients’ are cancer patients.

Together with the Federations of Palliative Care, the KCE published in October 2009 a study investigating the needs in the organisation of palliative care in Belgium ([94], see above). A work group was created with representatives of the Federale Evaluatiecel Palliatieve Zorg/Cellule Fédérale d’évaluation des soins palliatifs and the NIHDI to discuss the improvements needed in the organisation of palliative care. The Federale Evaluatiecel Palliatieve Zorg/Cellule Fédérale d’évaluation des soins palliatifs has to present a report illustrating the needs of palliative care every two years. The conclusions of their meetings during 2011 will be finalised in the spring of 2012. Previous reports can be consulted on http://www.health.belgium.be. They include the debate regarding the definition of ‘the palliative patient’, the concordance of the definition with the current regulations, continuity of care, registration issues and programming beds in the palliative care unit.
The Cancer Plan also pays special attention to the provision of palliative care in nursing homes. Therefore, nursing homes are allowed a reinforcement of the staff by 10% FTE for every 30 heavily dependent patients since 1 July 2008. Patients who are not hospitalised, but prefer homecare at the end of their life are financially supported: several lump sums may be requested to pay for specialised care at home. Palliative homecare can relieve the family of a terminal patient, especially when they continue their job. In this context, the lump sum for palliative home care was evaluated again and increased by 15% (from €512.44 to €589.31). In 2012 this sum was set at €621.15. This lump sum is exclusively for patients with an irreversible condition and a negative evolution whose death is expected in the short-term. They are in need of permanent care and support in their home environment. The lump sum is paid for one month, but can be extended for an additional month if the patient still meets the conditions for this lump sum. It can also be combined with the lump sum for care, incontinence and the ‘PVS-lump sum’.

Figure 59 shows the number of registered forfeits from 2006 to 2011.

![Figure 59. Number of registered lump sums for palliative home care from 2006 to 2011 (Data source: numbers from the NIHDI being processed by the Cancer Centre).](image)

Because of the highly demanding nature of palliative care, institutions other than hospitals or nursing homes are needed to provide palliative day care. This also offers a solution for short treatments like punctures or parenteral feeding. Specific standards for these specialised centres are being developed.

**ACTION 26: INITIATIVES IN CONSULTATION WITH THE AUTHORISED FEDERAL MINISTERS**

**A26.1. SCIENTIFIC DATA ON INDICATORS**

Health can be influenced by policies in other sectors and in turn, health has important effects on the realisation of the goals in other sectors, such as economic wealth. A model of the factors, also called determinants, which are found to have the most significant influence on health, is presented in Figure 60. In 2006, the European Observatory on Health Systems and Policies presented its strategy ‘Health in All Policies’ to help strengthen the link between health and other policies. In their book ‘Health in All Policies: Prospects and potentials’ the effects on health across all policies such as agriculture, education, the environment, fiscal policies, housing, and transport were addressed [99].

12This lump sum is meant for patients with a persistent vegetative status.
The ultimate goal is to improve health all while contributing to the well-being and wealth of nations through structures, mechanisms and actions planned and managed mainly by sectors other than health.

![Figure 60. The determinants of health (adopted from [99]).](image)

**A26.2. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

A cancer diagnosis does not exclusively affect health; it has also an impact on other aspects of daily life, which is why the Cancer Plan also includes initiatives that require the collaboration of other ministries.

**A26.2.1. Reconciliation of chronic diseases with professional commitments**

One of the items that the Cancer Plan would like to improve is the combination of a cancer treatment with a professional career, both for patients and their parents. Currently, people who are absent from work on a regular basis due to a planned medical treatment, such as chemotherapy, have to rely on the general rules of incapacity:

- Although all treatments are planned in advance, every new period of treatment requires a new declaration of incapacity
- The entitlement of a guaranteed salary depends on the statute and length of service of the employee. However, in case of a relapse due to the same cause of the first absence, the employer does not have to pay the guaranteed salary any more and the employer depends on the NIHDI allowance.
- The length of the treatment may cause invalidity of the patient and even additional problems: administration difficulties, serious loss of income, etc.

Together with the Minister of Labour, the possibility of a specific system for sick leave and allowances for patients with a chronic disease will be discussed to improve their current financial and administrative situation.

A work group, organised by the NIHDI in the scope of the Plan Chronic Diseases, edited a proposal describing criteria to identify the status of ‘chronic diseased’. The creation of a legal basis and concrete technical elaboration has been delayed.

For the parents of a child diagnosed with cancer or a chronic disease, it is often difficult to combine caring for their child with their professional commitments. A prolongation of the current period of
the leave for medical assistance could enable the parent to devote more time to caring for their child without being confronted with loss of income. The potential modifications of the conditions for leave for medical assistance was discussed during a first meeting with the Minister of Labour in November 2010, but has also been delayed since then.

The self-employed can rely on the system of ‘substituting entrepreneurs’ to be replaced in their professional activities up to 30 days a year. Replacements longer than 30 days are only allowed in case of incapacity, invalidity or maternity leave. Since January 2011, these exceptions are extended by palliative leave and leave for assistance to or care for a severely sick child. This addition makes it possible for the self-employed to fully devote their time to their sick child without great financial deficit.

A26.2.2. Simplification of the donation procedure

In the fight against cancer, there is an important role for associations in the support of scientific research and in the provision of information and social support for sick people. Their activities are often heavily dependent on donations and bequests from citizens. Therefore, the government should encourage this generosity by enabling these people to deduct taxes from their donations or bequests to recognised associations.

The procedure regarding tax-deductible donations was simplified and modified in deliberation with the Ministry of Finances. Due to the index, the minimum amount eligible to deduct taxes increased from €30 to €40.
ACTION 27: ESTABLISHING A TUMOUR BANK

A27.1. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN

In recent years, several Belgian hospitals, mainly university hospitals, established tumour banks for the collection and preservation of frozen tumour samples derived from biopsies or resections. These biobanks are crucial for research, especially translational research and research for new pharmaceuticals. To guarantee the biological quality and appropriate use of the samples, correct management, standard registration and procedures for freezing and preservation are indispensable.

In 2007 the first Belgian biobank network was created, gathering together oncologists and pathologists from five university hospitals. With the launch of the Cancer Plan in 2008, one of the goals was to extend this biobank project to all the major Belgian university hospitals in order to create a Belgian virtual tumour bank. The subsequent Royal Decree of 20 September 2009 indicated the conditions for hospitals to be financed in this initiative. Funded tumour banks receive a lump sum to cover the costs of 1 FTE manager, 1 FTE technician and general costs for staff, security, etc. Ten percent of this sum is returned to the BCR to cover the management of the virtual tumour bank. During 2010 this led to an extension of the network to 11 hospitals, among which all major Belgian university hospitals (Figure 61).
The aim of the Belgian virtual tumour bank is to register the data of the tumour samples, which are stored in the local biobanks of the individual hospitals, in a central database that is hosted by the BCR. One of the major assets of the virtual tumour bank model is the use of the national registry number as a unique patient identification number by the BCR, which allows future linkage with relevant clinical and longitudinal data. This linkage not only allows performing the necessary quality controls and adding extra clinical information, but also creates the possibility of retrieving extra information of potential scientific interest, even years after the sample is taken from the donor (personal communication Jimmy Van den Eynden, BCR). These linkage procedures to retrieve extra information are always subject to an authorisation request to the privacy commission. After removing all the identifying variables, this central database is made accessible to research groups through a virtual catalogue, allowing researchers to perform queries on the available data and find samples of interest. This ultimately facilitates the identification of new diagnostic and prognostic biomarkers and the development of new cancer therapies. The concept and the dataflow of the Belgian virtual tumour bank are depicted in Figure 62. Additional information on the Belgian tumour bank can be found on http://www.virtualtumourbank.be.
Figure 62. Dataflow within the Belgian virtual tumour bank. The dataflow assumes the presence of three different databases and datasets: (i) the local database of every single local biobank. Data from this local database are sent to the central database; (ii) The central database is the database used by the BCR to centralise the data, publish data in the anonymous database, perform quality controls and add clinical TNM (cTNM) values and (iii) the anonymous database, which is extracted from the central database, after removal of all the identifying variables (i.e. SSIN number, biopsy number and birth date). BVT, Belgian virtual tumour bank; BVTc, catalogue module of BVT; BVTr, registration module of BVT. Adopted from http://www.virtualtumourbank.be.

In 2010 the Flemish government committed to providing the financial stimulus for the creation of a centralised biobank in Flanders. To this end, the Centre for Medical Innovation (CMI) was established with the financial support of the Flemish Financing Fund for Debt Reduction and One-off Investment and the IWT (the government agency for Innovation by Science and Technology). The CMI links the Flemish universities, the university hospitals, pharmaceutical and biotech industries and the Flemish Government to jointly develop translational research, based on high quality biobanks. The CMI is currently setting up this Flemish Biobank and its IT infrastructure, linking the five biobanks that are associated to the four university hospitals and the University of Hasselt. In addition, four Clinical Research Centres will be set up within the for university hospitals (UZ Ghent, UZ Leuven, UZ Brussels and UZ Antwerp). Additional information can be found on http://www.cmi-vzw.be.
**ACTION 28: STRUCTURAL FINANCING OF THE COORDINATION OF TRANSLATIONAL RESEARCH IN HOSPITALS**

**A28.1. INDICATORS REFLECTING A SPECIFIC ACTION OF THE CANCER PLAN**

Clinical oncological research is based on fundamental research in the lab and aims at discovering new diagnostic methods and treatment strategies. The greatest challenge of translational research is to translate the scientific findings into therapeutic applications as quickly as possible. Patients have much hope in scientific research investigating the origins of cancer, new therapies for more efficient treatment, possible reasons for failure of treatment, etc.

University and hospitals certified for their oncological care programme, and disposing of extensive experience in translational research are structurally financed by the Cancer Plan since 2009. Out of nine applications, seven hospitals met the criteria for funding of coordination cells for translational research. This financing covers one physician-coordinator for translational research within the hospital, one FTE secretary for administration and logistics and one FTE data manager.

The physician-coordinator needs to have research and clinical experience. Besides the continuation of this work, they have several specific responsibilities:

- Coordinate the translational research within the hospital
- Bridge the gap between physicians, patients and investigators by integrating discoveries in the lab into clinical studies and patient care and vice versa by transmitting the questions of physicians to researchers in the lab
- Be an intermediary between academic labs and pharmaceutical industry to set up close collaborations
- Guarantee that the medical community, inside and outside the hospital, is aware of the results of the research done

Through this initiative, patients will benefit from new technologies and the results of discoveries in the lab more quickly.

**ACTION 29: SUPPORT OF TRANSLATIONAL RESEARCH**

**A29.1. SCIENTIFIC DATA ON INDICATORS**

The application of findings derived in basic science to the development of new understanding of disease mechanisms, diagnoses, and therapeutics in humans is known as translational research. Within the field of cancer research, recent advances in understanding cancer biology are now being translated into improvements in diagnosis and treatment of cancer. However, a faster and more efficient translation of these basic research findings into the development of clinical applications relies on a strong collaboration between basic and clinical scientists, industries as well as governments. Therefore, investment in translation research is a major determining factor for future medicine. In Belgium, an overview of public and private cancer research funding (based on a draft formulated in the context of European Partnership Action Against Cancer (EPAAC) WP 8 Cooperation and Coordination in European Cancer, http://www.epaac.eu/cooperation-and-coordination-in-cancer-research) revealed that a total of €56,301,236 was spent on cancer research in 2010 (an approximation as numbers from the private sector were not complete because of confidentiality issues. Also, numbers from cancer research projects funded by the FWO in 2010 were not included in the analysis). With regard to translational research in the field of cancer research, a major source of funding comes from the Cancer Plan: a total number of €22,202,600 was provided for funding
Actions 17, 27, 28, 29 and 30 in 2010. These investments are therefore indispensable for progress in translational cancer research.

**A29.2. Indicators reflecting a specific action of the Cancer Plan**

In June 2008 a call for projects in translational research in oncology was launched. An independent international jury read the 61 transmitted research projects. As of 1 January 2009, 25 projects received funding.

The subjects of these projects are very heterogeneous but can be divided into three main groups: genetic characteristics, identification or validation of biomarkers and the implementation of techniques for functional imaging. A wide array of tumours is subject of investigation: leukaemia, neuroblastoma, breast tumours, lung, cervical or colorectal, and cancer during pregnancy.

In January 2012, a new call for projects was launched within the field of translational research. These new projects should ideally lead to improved diagnostic performance, an enhanced prediction of the prognosis of cancer patients, an improved insight into the reasons of treatment failure of particular patient groups and/or a better prediction of success rates of cancer therapies. Selected projects will be financed from 1 July 2012 till 1 July 2015.

**Action 30: Application of Hadron Therapy in Belgium**

**A30.1. Scientific data on indicators**

Particle therapy is an emerging technique in radiotherapy. Protons and carbon ions have been used for treating many different solid cancers, and worldwide several new centres with large accelerators are under construction. Due to their physical and radiobiological properties, hadron therapy allows to obtain a more precise treatment of the tumour, leading to a reduction of normal tissue damage and/or improvement of local disease control in cancer treatment [100]. Indeed, more precise tumour treatment allows dose escalation to tumours that might benefit from it, such as intra-ocular melanoma or chondroma of the spine. On the other hand, reduction of normal tissue damage might be of particular interest to prevent late complications, for example in children treated with irradiation. However, debate continues on the cost-benefit ratio of this technique, that is, on whether the high costs of accelerators and beam delivery in particle therapy are justified by a clear clinical advantage. In 2007, a feasibility study by the KCE did not support building a Belgian hadron therapy centre due the absence of sufficient scientific evidence for clinical efficacy [101]. A recent review analysing current clinical results in the field worldwide [100], also stated that in many cases, the clinical data are still not sufficient to draw firm conclusion on the clinical effectiveness of particle-based therapy, especially due to the lack of Phase III trials. However, the present clinical results support the rationale for this therapy. The Belgian Nuclear Research Centre (SCK•CEN), the Belgian Foundation against Cancer as well as various Belgian universities involved in applied clinical research have recently created a Belgian Hadron Therapy Consortium (BHTC). This consortium is involved in the preparation of a two-year feasibility study of a Belgian hadron therapy project (see below).

**A30.2. Indicators reflecting a specific action of the Cancer Plan**

**A30.2.1. Feasibility study**

In May 2011, the BHTC elaborated a proposal to study in several phases the establishment of a hadron therapy centre in Belgium. Items of research are its eligibility, added value, public benefits, defining its activities, organisation and financing. The contract for the execution of this investigation was approved and signed in July 2011 and is valid until 31 December 2012. The FPS Public Health
provides a close follow-up of the evolutions. A first phase focuses on the collection of scientific evidence that may or may not justify the development of such a technology in Belgium. The results of this phase should be ready in March 2012. Currently, the Walloon government is also looking into the financing and establishment of a hadron therapy centre in Wallonia.

**A30.2.2. Reimbursement of hadron treatment abroad**

In cooperation with the existing European centres for hadron therapy, the reimbursement of the treatment and the transportation costs for cancer patients needing hadron therapy will be reinforced. In 2009 the NIHDI finalised a standard procedure for reimbursement of hadron therapy abroad for cancer patients. The proposal describes the conditions for treatment, the procedures for application and evaluation of the scientific report, the fees and financial rules for reimbursement. Implementation of this initiative is expected in 2012. In the mean time, patients in need of hadron therapy can still be reimbursed by the Particular Solidarity Fund of the NIHDI.

**ACTION 31: REINFORCE THE FOUNDATION OF THE CANCER REGISTRY**

**A31.1. Scientific data on indicators**

Cancer registration is a basic instrument for following up cancer, and aims at the following two objectives:

i. Contributing to the public health by following up changes in prevention and prognosis (epidemiology) of cancer and evaluating large-scale interventions such as screening, also as regards the following objective. To do so, standard methods from the epidemiology are used to estimate incident, survival and prevalence.

ii. Contributing to the oncological field by studying access and variation in quality of care and the results, including the perspective of the patient and cause-specific death figures. The methods used to research the quality of care also relate to the interpretation of the context and providing regular feedback to the doctors involved.

There are many kinds of cancer registrations; its content is determined by their objective. A differentiation is made between:

- Population-based (PBCR) versus hospital-based cancer registration (HBCR)
- National versus regional cancer registration
- General and/or illness-specific cancer registration

The difference between HBCR and PBCR (see Table 27) is mainly based on the fact that the HBCR is much more focused on the institute itself and the PBCR more on society as a whole.

<table>
<thead>
<tr>
<th><strong>Characteristics</strong></th>
<th><strong>HBCR</strong></th>
<th><strong>PBCR</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>First goal</td>
<td>Cancer patient in the hospital</td>
<td>Cancer in society</td>
</tr>
<tr>
<td>Indicators cancer</td>
<td>Number of diagnoses a year</td>
<td>Cancer incident</td>
</tr>
<tr>
<td>dimensions</td>
<td>Division of cancer types in percentages</td>
<td>Cancer prevalence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Survival of cancer</td>
</tr>
<tr>
<td>Cancer care</td>
<td>Active follow-up, contact patient-</td>
<td>Trends in cancer incidence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Trends in cancer survival</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Indirect follow-up via the hospital</td>
</tr>
</tbody>
</table>
medical doctor

Time trends in stage and underlying ratios

Length and quality of survival in relation to type of cancer, stage and treatment

Research: treatment
Participation in clinical trials
Provides the basis for (im)possibilities for clinical trials

Research: prevention
Participate in case control studies
Provides a basis for clinical research

Develop and evaluate classifications
Identify rare cancers
Identify groups of rare cancers

Health services
Support quality of cancer care
Support planning of care
Support effectiveness of preventive measures

Support hospital planning
Contribute to educating professionals
Contribute to educating professionals and public health

Table 27. Characteristics of population-based (PBCR) and hospital-based (HBCR) cancer registries

A cancer registry based on the population must collect definite and relevant population-based data about the risk and prognosis of cancer and at least analyse, clarify and report about them. It is important to take into account previous and current changes in cancer-causing exposures (already known or derived from other sources), detection, classification and treatment details.

The aim is to improve:

i. Public health by:
   - Following up trends in cancer incidence, prevalence and survival (mortality is mainly measured by a statistics firm, in close collaboration with the Cancer Registry) and studying the link between cancer and various factors and circumstances.
   - Encouraging and simplifying epidemiological research on the etiological aspects of cancer and on the link between cancer and other illnesses.
   - Comparing with other Registries and performing research on the differences of the impact of cancer in different regions or countries.
   - Following up the effectiveness of screening programmes for cancer.
   - Evaluating measures for preventing cancer.
   - Evaluating care needs and requirements.
   - Evaluating end-of life treatment
   - Contributing to feasibility analyses
   - Monitoring and evaluating the effects of a national and regional cancer policy.

ii. Quality of care by:
   - Providing extensive data to people in charge of programmes in order to plan services.
   - Following up the carrying out of guidelines.
   - Evaluating quality indicators and giving feedback to the developers of guidelines.
   - Examining the effectiveness of (new, often specific and expensive) drugs within the population: Phase IV studies.
   - Following up the development of cancer and patient treatment, as regards complications, progression and survival.
   - Following up the local cancer services.
- Provide professionals with clinically relevant indicators.
- Following up on the long term, as cancer is a chronic illness
- Following up the effects of survival.
- Supporting research into previous diagnoses, better treatments and better care for cancer patients on the long term.
- Providing transparent information in collaboration with the hospitals/caregivers to patients and the population, as for access to qualitative cancer services.
- Providing data for health policy in oncology.

**A31.2. Indicators reflecting a specific action of the cancer plan**

**1950-2005**

In the 1950s, the Belgian cancer registration relied on the data obtained by health insurance companies from attending physicians in hospitals. Back then the health insurances considered cancer as a social illness with specific reimbursement regulations.

In 1983 a National Cancer Registry (NKR) was set up by the former ‘Belgisch Werk tegen Kanker’ in collaboration with the health insurances. The National Cancer Registry collected the data from all the health insurances. Registration was done on an entirely voluntary basis. An evaluation of the databank showed that the results could not be considered as representative for Belgium because much information from hospitals was missing and the quality of the information was also insufficient [102]. Due to this, the use of these data in a scientific context was extremely limited or even nonexistent. Belgian data was internationally not accepted or published by the IARC (WHO) ‘Cancer Incidence in Five Continents’

As a response to this, at the end of the 1980s various new initiatives for cancer registration were set up, mainly in Flanders, such as the Antwerp [103] and Limburg Cancer Registry [104]. All new initiatives as well as the existing circuit of doctors, specialists and insurers were bundled in a registration network which was mainly subsidised by the Federal and Flemish governments as of 1994 until half way 2005. The bundling of means and forces within a network resulted in international recognition of Flanders.

In 2001 the data for Flanders was listed for the first time in the international publication ‘Cancer Incidence in Five Continents’ [105]; the most recent publication in this book dates back to 2007 [106].

**2005-2011**

At the same time, European guidelines were pressing for the foundation, organisation and establishment of proper national cancer registrations. In June 2005 the national cancer registration was reborn following the foundation of a new organisation called ‘Cancer Registry Association’. By setting up this new organisation, all governments, authorised for ‘health’ matters, committed themselves to accomplishing a national cancer registration. An Administrative Council and an Advisory Committee constitute the executive institutions of the Cancer Registry (http://www.kankerregister.org). The entirety of the registration was put forward as the first and foremost objective. Flanders took a leading as it already had a well-built registration network. In Wallonia and in the Brussels-Capital Region building up the network was realised in the working years 2006-2008. As of the incidence year 2004 there is an almost 100% coverage for the Belgian territory.
During these years the Cancer Registry strived to improve both the quantity and the quality of the data and to keep the time between the incidence year and the publication delay as short as possible.

The Cancer Registry was given an additional, important mission in setting up and managing a database of cytohistopathological data for tumours that are eligible for preventive measures (cervical, colorectal and breast). The Cancer Registry was called up for the analysis and calculation of quality indicators within the scope of screening.

From various directions more attention was also being paid to retrospective and prospective registration studies with regard to the quality of care. These studies are mainly performed in the context of the evaluation and improvement of the quality of care (and reduction of treatment variability) and/or the limitation of the increasing costs in a responsible way (see the Procare project). Most of these studies are performed by associations of scientific physicians, the KCE, the College of Radiotherapy or the NIHDI, in collaboration with the Cancer Registry.

The Private Cancer Registry Association was founded on 28 June 2005 by the Federal government, the communities and insurers. As of July 2005 the Association guarantees the collection of data as well as the quality control, processing, analysis, encoding, storing and protection of cancer registration data.

Following the integration of Article 39 ‘Cancer Registry in the Health Act 2006 (‘Law of 13 December 2006 with diverse provisions regarding health’), the Cancer Registry was given a legal basis for the first time. By January 2005 the Commission for the Protection of the Privacy had approved the content.

A milestone was the approval to use of the social insurance identification number in cancer registration. Article 39 entered into force in December 2008 by a Royal Decree that anticipated the creation of a foundation of public utility, which implied that the Private Foundation needed to be transformed.

On 30 March 2009 (BS 02022010) the document was turned into a foundation of public utility at the notary’s office. On 9 October 2009 the Minister of Social Affairs and Public Health approved the statutes (MB published in the BS on 28 October 2009). The Cancer Registry Foundation was then officially a Foundation of Public Utility.

The flow of data for the national registration is clearly described in the same Article 39 of this Act. On the one hand the flow of data is based on the legal obligation of every care programme to report all cases of cancer, regardless of they have been discussed in a multidisciplinary oncological consult. On the other hand a parallel circuit is run with all services for pathological anatomy and with the services for haematology/clinical biology. With this article the Cancer Registry also received the legal basis for making links to nomenclature, socio-economic and geographical (geocode) data from insurers.

The change on 19 May 2010 of the RD No. 78 of 10 November 1967 on the carrying out of health care professions (‘Act on various provisions regarding health’) and the protocol agreement of 28 September 2009 between the Federal government and the governments meant in Articles 128,
130 and 135 of the Constitution regarding prevention (BS 29102009) give the Cancer Registry an additional and important mission in setting up and managing a database of cytohistopathological data for tumours that are eligible for preventive measures (cervical, colorectal and breast).

Objectives and accomplishments of the Cancer Registry Foundation for 2006-2010

- Complete cancer registration (level of coverage)
- Promote the quality of cancer registration data to increase its use by various partners
- Publication of complete incidence numbers
- Reduce publication delay (time between incident reports)
- Achieve 100% electronic data sharing
- Switch from a single-user application (back-end for the registry) to a multi-user system, adapted to the safety precautions
- Setting up a link between cancer registration data and the nomenclature from insurers
- Expand the registration with project-specific registrations, collaboration with scientific physician organisations, NIHDI, eHealth, etc.
- Starting a cyto-pathology registry for early cancer detection (population screening)
- Participating in European and international projects on cancer registration

ACTION 32: BELGIAN CANCER CENTRE

A32.1. Indicators reflecting a specific action of the Cancer Plan

The Cancer Centre was founded on 1 September 2008 through an agreement between the Institute of Public Health (IPH) and the NIHDI. This settlement was extended until 31 December 2012.

The Cancer Centre represents an autonomous department within the IPH. The multidisciplinary team currently consists of seven colleagues who guarantee continuous support for cancer control in Belgium. The centre is responsible for the permanent evaluation of the Cancer Plan and provides advice and recommendations based on this evaluation. Moreover, the centre organises consultations on a large scale with representatives of the field to centralise all pertinent and necessary expertise relevant to developing recommendations.

The evaluation of the actions of the Cancer Plan and the cancer policy was elaborated in 2011. As well, a portal site was developed, providing information for the field.

In accordance with the indicators proposed by the OECD to assess the performance of cancer care systems [107], the following indicators were put forward to evaluate the performance of the Cancer Centre and whether the support for governance of cancer care was ensured.
<table>
<thead>
<tr>
<th>Indicator</th>
<th>Goal achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introducing a comprehensive national cancer control plan</td>
<td>+</td>
</tr>
<tr>
<td>Setting up cancer-specific targets</td>
<td>In progress</td>
</tr>
<tr>
<td>Making additional funding available to achieve these specific targets</td>
<td>+</td>
</tr>
<tr>
<td>Assigning the lead person/or organisation to oversee the implementation</td>
<td>+</td>
</tr>
<tr>
<td>Putting quality assurance mechanisms in place for cancer care</td>
<td>±</td>
</tr>
<tr>
<td>Coordinating care and developing networks for service delivery</td>
<td>+</td>
</tr>
<tr>
<td>Identifying key milestones and timeframes</td>
<td>+</td>
</tr>
<tr>
<td>Monitoring the progress</td>
<td>+</td>
</tr>
<tr>
<td>Make someone responsible if targets are not met</td>
<td>+</td>
</tr>
</tbody>
</table>

Table 28. Indicators used to assess the performance of the Cancer Centre
References


17 Charafeddine R, Van Oyen H, Demarest S: Does the association between smoking and mortality differ by socioeconomic status? Social Science and Medicine 2012;in press.


123


47 Arbyn M, Simoens C, Fabri V: Analysis of individual health insurance data pertaining to pap smears, colposcopies, biopsies and surgery on the uterine cervix (Belgium, 2002-2006); Public health and surveillance, 2010.


62 van Rossum LG, van Rijn AF, Laheij RJ, van Oijen MG, Fockens P, van Krieken HH, Verbeek AL, Jansen JB, Dekker E: Random comparison of guaiac and immunochemical fecal


102 Haustermans K, Van Oyen H: Kankerregistratie in Vlaanderen: Inventarisatie van de bestaande registers en voorstel voor een uniform kankerregistratiesysteem; IHE, 1996.

103 AKR AK: Kankerregistratie in de provincie Antwerpen incidentiejaar 2004; 2008.


## APPENDIX 1: List of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACCIS</td>
<td>Automated Childhood Cancer Information System</td>
</tr>
<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
</tr>
<tr>
<td>AIS</td>
<td>Adenocarcinoma <em>in situ</em></td>
</tr>
<tr>
<td>ATU</td>
<td>Autorisation Temporaire d’Utilisation</td>
</tr>
<tr>
<td>BCR</td>
<td>Belgian Cancer Registry</td>
</tr>
<tr>
<td>BM</td>
<td>Bone marrow</td>
</tr>
<tr>
<td>BSPHO</td>
<td>Belgian Society of Paediatric Haematology Oncology</td>
</tr>
<tr>
<td>CBU</td>
<td>Cord blood units</td>
</tr>
<tr>
<td>CAF</td>
<td>Centres d’Aide aux Fumeurs</td>
</tr>
<tr>
<td>CIN</td>
<td>Cervical Intraepithelial Neoplasia</td>
</tr>
<tr>
<td>CMI</td>
<td>Centre for Medical Innovation</td>
</tr>
<tr>
<td>CT</td>
<td>Computed tomography</td>
</tr>
<tr>
<td>EAPC</td>
<td>Estimated annual percentage change</td>
</tr>
<tr>
<td>EBMT</td>
<td>European group for Blood and Marrow Transplantation</td>
</tr>
<tr>
<td>EUROCHIP</td>
<td>European Cancer Health Indicator Project</td>
</tr>
<tr>
<td>EMA</td>
<td>European Medicines Agency</td>
</tr>
<tr>
<td>EPAAC</td>
<td>European Partnership Action against Cancer</td>
</tr>
<tr>
<td>FANC</td>
<td>Federal Agency for Nuclear Control</td>
</tr>
<tr>
<td>FASFC</td>
<td>Federal Agency for the Safety of the Food Chain</td>
</tr>
<tr>
<td>FAMHP</td>
<td>Federal Agency for Medicines and Health Products</td>
</tr>
<tr>
<td>FARES</td>
<td>Fonds des Affections Respiratoires</td>
</tr>
<tr>
<td>FOBT</td>
<td>Faecal occult blood test</td>
</tr>
<tr>
<td>FTE</td>
<td>Full Time Equivalent</td>
</tr>
<tr>
<td>gFOBT</td>
<td>Guaiac faecal occult blood test</td>
</tr>
<tr>
<td>GMF</td>
<td>Global medical file</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>HBCR</td>
<td>Hospital-based cancer registry</td>
</tr>
<tr>
<td>HIS</td>
<td>Health Interview Survey</td>
</tr>
<tr>
<td>HPV</td>
<td>Human papillomavirus</td>
</tr>
<tr>
<td>IARC</td>
<td>International Agency for Research on Cancer</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases (10th edition)</td>
</tr>
<tr>
<td>ICD-O</td>
<td>International Classification of Diseases for Oncology</td>
</tr>
<tr>
<td>iFOBT</td>
<td>Immunochemical faecal occult blood test</td>
</tr>
<tr>
<td>IMA</td>
<td>Intermutualistic Agency</td>
</tr>
<tr>
<td>IPH</td>
<td>Institute of Public Health (Wetenschappelijk Instituut voor Volksgezondheid/Institut Scientifique de Santé Publique)</td>
</tr>
<tr>
<td>KCE</td>
<td>Belgian Health Care Knowledge Centre (Federaal Kenniscentrum voor de Gezondheidszorg/Centre Fédéral d’Expertise des Soins de Santé)</td>
</tr>
<tr>
<td>LINA</td>
<td>Linear particle accelerator</td>
</tr>
<tr>
<td>MDPB</td>
<td>Marrow Donor Program Belgium</td>
</tr>
<tr>
<td>MDPB-R</td>
<td>Marrow Donor Program Belgium Registry</td>
</tr>
<tr>
<td>MDS</td>
<td>Myelodisplastic syndromes</td>
</tr>
<tr>
<td>MOC</td>
<td>Multidisciplinary oncologic consult</td>
</tr>
</tbody>
</table>
MPD: Myeloproliferative diseases
MRI: Magnetic resonance imaging
NIHDI: National Institute for Health and Disability Insurance (RIZIV/INAMI)
OECD: Organisation for Economic Co-operation and Development
OIVO/CROIC: Onderzoeks- en Informatiecentrum van de Verbruikersorganisatie/Centre de Recherche et d’information des Organisations de Consommateurs
PBCR: Population-based cancer registry
PBSC: Peripheral blood stem cell
PET: Positron emission tomography
SHC: Belgian Superior Health Council (Hoge Gezondheidsraad/ Conseil Supérieur de la Santé)
SHS: School Health Services (CLB, Centrum voor Leerlingenbegeleiding)
SWGV: Steunpunt Welzijn, Volksgezondheid en Gezin
TMC: Technical Medical Council
VLK: Flemish League against Cancer (Vlaamse Liga tegen Kanker)
VRGT: Vlaamse vereniging voor Respiratoire Gezondheidszorg en Tuberculosebestrijding
WHO: World Health Organization
WSR: World age-standardised incidence rate
## APPENDIX 2: Lexicon

**Age-standardised Incidence Rate/WSR**
An age-standardised rate is a summary measure. It is the rate that a population would have if it had a standard age structure. Standardisation is necessary when comparing several populations that differ with respect to age structure, because age has a powerful influence on the risk of cancer. The most frequently used standard population is the World standard population. The calculated incidence rate is then called the World Standardised incidence Rate.

**Cancer incidence in Belgium**
The number of new cancer cases arising in a given period in a specified population. The Belgian population is defined as all residents having an official address in Belgium. Incidence can be expressed as an absolute number of cases per year or as a rate per 100,000 persons per year.

**Carcinoma in situ**
Pre-invasive cancer: an early form of cancer that is defined by the absence of invasion of tumour cells into the surrounding tissue, usually before penetration through the basement membrane.

**Cumulative risk (CRi)**
Cumulative risk is the probability of individuals getting the disease before a certain age (e.g. 75 year), expressed as a percentage during a specified period. For cancer, it is expressed as the proportion of newborn children who would be expected to develop a particular cancer before the age of 75, if they had the rates of cancer observed in the period, in the absence of competing causes. Like the age-standardised rate, it permits comparisons between populations of different age structures.

**Crude incidence rate (CR)**
For a specific tumour and population, the crude rate is calculated by dividing the number of cases observed during a given time period by the corresponding number of people in the population at risk. The crude rate is expressed as the number of cases per 100,000 person years.

**Date of incidence**
Date of first microscopic verification

**EAPC**
The estimated annual percentage change is used to describe the magnitude of change in the trend on fitting a simple regression model to the log of the age-standardized rate. It is the average annual rate of change in the age-standardized rate over the time period selected.

**Observed survival**
The proportion of cases surviving a certain number of years after diagnosis, irrespective of the cause of death

**Person years**
The total number of the "population at risk" for every year under study (risk duration) is expressed as person years. The population at risk is the part of a population that is susceptible to develop a specific cancer. It is defined on the basis of demographic data, such as place of residence, sex, age group, etc.

**Relative survival**
An estimate for the disease-specific survival.
| TNM | Staging system for describing the anatomical extent of malignant tumours on the assessment of three components  
|     | - T-category: the extent of the tumour  
|     | - N-category: the absence or presence and the extent of regional lymph node metastasis  
|     | - M-category: the absence or presence of distant metastasis  
|     | Categories are converted to stages corresponding to progression of the disease, i.e., 0, I, II, III, IV and X (=unknown).  
| cTNM | The clinical TNM represents the extent by which the cancer has spread, based on all of the available information obtained before surgery (to remove the tumour).  
| pTNM | The pathological TNM represents the extent by which the cancer has spread after resection of the tumour. |