# National Cancer Plan <sup>3 days to debate</sup> 30 visits on the field

30 concrete actions

Address by Laurette Onkelinx, Minister of Social Affairs and Public Health

10 March 2008

**Résidence** Palace

### IMPORTANT

The practical initiatives described here are only one element of the Cancer Plan 2008-2010. During the year we will be adding joint initiatives supported by the Communities, the Regions and the Federal authorities.

Indeed, given the importance - in particular of the Communities - as regards information, prevention and screening, any decisions that are taken must be the result of the full agreement of all the bodies involved.

Here are a few examples:

- 1. On 11 March, the Inter-Ministerial Health Conference will consider a draft **National Alcohol Action Plan** and joint actions to combat **smoking**.
- 2. The **National Health Food Plan** (*Plan National Nutrition Santé*), which falls within the scope of joint competence, was launched in 2006 and will be implemented until 2010. In addition, following the survey of the eating habits of Belgians aged over 15 years that was conducted in 2004, a survey of the eating habits of under-15s is expected to be launched in 2009.
- 3. On 12 March, the Interministerial Conference on Environment and Health (CIMES) will adopt as part of its plans for 2008 a project entitled **cancer of children and the environment**. A working group made up of university experts will focus on the problem of cancer cases among children caused by environmental factors. It is expected that their findings will be submitted in 2009.
- 4. Furthermore, the **systematic vaccination and screening programs** can be carried out only with the agreement of the Federal authorities and of the Communities. Negotiations are currently under way (for example, the papillomavirus vaccine and colorectal cancer screening).

### **BUDGET FRAMEWORK**

At the recent conclave for the 2008 budget, the Government gave its approval to a multi-annual allocation of EUR 380 million to cover 2008-2010.

Each of the actions presented below has undergone a budgetary assessment that will be confirmed at a later date.

We have included here only the amounts reserved for calls for projects, particularly in the field of translational research.

Finally, it goes without saying that the measures of this Cancer Plan will comply with the procedures for routine consultation within the INAMI, the National Hospital Council, etc.

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prevention and screening

### Action 1 : Refund of consultations geared towards the cessation of tobacco use

### Objective

A substantial increase in the means at our disposal to prevent smoking and to help smokers kick the habit, along with robust measures to combat smoking, have enabled countries like Belgium to do more to curb the use of tobacco products.

Smoking is addictive, and we must lend our support to every effort undertaken to help people stop, among other things through medical and psychological means.

### Action

- 1. Refund for all smokers of a lump sum of EUR 30 for the first tobacco weaning consultation with a smoking cessation specialist.
- 2. Thereafter, refund of a lump sum of EUR 20 per consultation, with a maximum of 8 consultations. For pregnant women, the refund will be EUR 30.
- 3. Within the framework of a general tightening of inspections and additional inspections with the support of the AFSCA, the services of the Public Health Ministry will be responsible for carrying out targeted inspections to ensure compliance with the "tobacco" laws.

### Implementation: 2008

### Towards a tobacco-free society

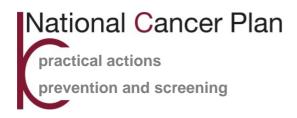
 The World Health Organisation (WHO) estimates that no fewer than 40% of cancers could be prevented through efficient prevention strategies.

Nonetheless, smoking remains very widespread: there is fairly unanimous agreement among experts that smoking is responsible for 25 to 30% of all cancers, including in particular lung and throat cancers.

Passive smoking is a real problem, especially for children. On this basis, the ban on smoking in public places (administrations, stations, airports, etc.) was decreed and confirmed by a law passed in 2006. The legislation on the banning of smoking in the workplace came into force on 1 January 2006, and on 1 January 2007 a ban was introduced on smoking in hospitality venues.

As promised, these laws will be evaluated before they are extended to include a ban on smoking in bars and a ban on the placing of vending machines for tobacco products. With the agreement of the Public Health Committee of the Chamber, this evaluation will be carried out in Parliament.

 It has been found that increasing the price of tobacco does much to deter smokers, and a further price increase for 2008 was decided at the last budgetary conclave.



# Action 2 : Screening and care of persons at risk of being genetically predisposed to cancer

### Objective

Too few members of the public and professionals are aware of the risks of genetic predisposition to cancer. However, it is now estimated that 5 to 10% of some cancers can be predicted on the basis of a genetic anomaly.

In many cases, awareness of this risk can allow monitoring measures to be set in place aimed at the prevention of the onset of cancer or early detection.

Around 10,000 people consult a geneticist in Belgium every year. These tests are carried out in the 8 human genetics centres in Belgium. Although a study by the *Centre fédéral d'expertise* on health care shows that the average number of genetic tests carried out in Belgium following a genetic consultation is around two times higher than in neighbouring countries, these tests are still too infrequently carried out to detect a genetic predisposition to cancer.

### Action

- 1. Refund of several new very inexpensive genetic cancer predisposition tests such as the detection of BRCA1/2 mutation (breast and ovarian cancer) and mutations of hereditary forms of cancer of the colon.
- 2. A specific increase in the fees for genetic consultations charged by geneticists should be considered within the framework of the 2009 *Médicomut* Agreement. This increase in fees is designed to make the work of geneticists a more appealing speciality, given that there is reported to be a shortage of such specialists in Belgium. From the current figure of EUR 30, the maximum fee for a consultation could be increased to EUR 150, without changing the amount to be paid by the patient.

Implementation: 2008-2009

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Action 3: Extending the age group for vaccination against papillomavirus to young girls aged between 12 and 18 years (instead of between 12 and 15 today)

### Objective

Optimum prevention for young women against the risk of human papillomavirus (HPV), which can lead to cervical cancer, in line with the scientific recommendations on the use of this vaccine.

### Action

Extension of the age group that benefits from a refund of the vaccine against the human papillomavirus (HPV). The current age group (12-15 years) will be extended to include all young persons aged between 12 and 18 years, which in practice means for them that the cost of vaccination will be reduced from around EUR 412 to EUR 31.

### Implementation: 2008

### Drastically reducing the number of cases of cervical cancer

A consultation process is currently under way with the Communities aimed at setting in place a systematic vaccination program that would include all categories of young girls.

practical actions prevention and screening

### Action 4: Improved screening and early diagnosis of breast cancer

### Objective

Apply the same quality level to the two screening systems, i.e. the mammotest and diagnostic mammography. Prevent competition between the two systems and optimise their use and efficiency. Increase women's participation to improve the detection rate of breast cancer.

### Action

1. Ensure the same level of quality control for the equipment used to carry out diagnostic mammography and mammotests. Organise an official inspection twice a year for analog and digital devices. Ensure systematic recording of individual screenings.

### Implementation: 2009-2010

2. For patients who tested positive on the mammotest, free examinations such as ultrasound, MRI and/or puncture.

### Implementation: 2008

3. The cost of complete breast examinations (ultrasound and mammography) will be refunded in full for women with a high risk of breast cancer with a medical prescription and a proven risk (family history, genetic risks, etc.)

Implementation: 2008

practical actions

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### Action 5: Systematic cervical cancer screening program

### Objective

Improve screening for cervical cancer in accordance with the international scientific recommendations.

### Action

In consultation with the Communities, detection of cervical cancer at an early stage, in connection with the human papillomavirus (HPV):

- 1. Program of systematic screening for cervical cancer for women aged between 25 and 64 years with a cervical smear every three years.
- 2. Higher refund for additional tests (colposcopy, HPV test) if the smear is positive.
- 3. Inclusion of the recording of the results of screening in the data of the Cancer Registry.

### Implementation: 2009

practical actions prevention and screening

### Action 6: Consultation for the prevention of health risks

### Objective

Assign to general practitioners a pivotal role as regards information on cancer and the prevention of the risk of cancer. This measure may also encourage the populations concerned to undergo the mammotest and facilitate the detection of hereditary cancer risks.

### Action

1. Free access to a preventive check-up with a general practitioner every 3 years from the age of 25 years for patients who have a general medical record.

More specifically, the idea is to include in the general medical record (*dossier médical global*, or DMG) a module designed to collect data based on this periodic health risk check-up. This information will be gathered in the course of a special lengthy consultation for which the fees will be accordingly increased on the basis of an anamnesis protocol that will be drawn up in consultation with the medical corps. This examination will concern adults aged 25 years and over.

2. Training of general practitioners: within the framework of the accreditation of doctors, points will be awarded for participation in an in-service training module focusing on the prevention of health risks. Doctors will be required to follow this training course in order to be accredited.

**Implementation**: 1 January 2009: the measure will be included in the 2009 budget of compulsory health insurance, and the arrangements will be coordinated within the framework of the negotiations concerning the 2009-2010 Medico-Mutualist Agreement.

### The importance of involving general practitioners in prevention

One of the main ideas that came out of the round table on "prevention and information" is the importance of close cooperation between the public authorities and first-line care for effective prevention of health risks. In particular, it is important to encourage the systematic screening of health risks by general practitioners:

- Continuing training of doctors in the prevention and detection of health risks and the recognition of symptoms;

- Through GPs we can reach socio-economically fragile populations;

- Use of "general medical record" computer software, in particular to facilitate the detection of persons/groups at risk (list the indicators for prevention, scientific evidence, linkage with existing databases, vaccinations, screening, etc.).

This recognition of the role of the general practitioner in the prevention policy must be accompanied by measures to foster awareness of their mission.

practical actions

patient care, treatment and support

### Action 7: Specific support for patients when diagnosed with cancer

### Objective

Create the best possible conditions in which to inform patients of the diagnosis of their illness, not only when they are first told that they have cancer but also when they are informed of a recurrence of the illness. Provide the patient and his/her next of kin with information, care and support and ensure better coordination between the medical team and the general practitioner.

### Action

- Creation of a new item in the nomenclature for a long consultation that gives the doctor time to break the news to the patient. An appropriate time will be allocated for consultations involving children.
- Training of professionals to communicate with the patient and next of kin.
- Creation of a diagnosis announcement protocol drawn up by a group of experts and a patients' association to foster teamwork with continuous interaction among the various healthcare actors.

### Implementation: 2008-2009

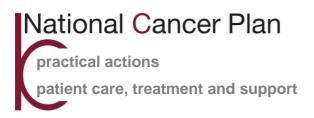
## For a more sensitive approach that takes more account of the needs of patients when they are informed of the diagnosis

The announcement of a serious illness is always a traumatic experience for patients. The diagnosis of cancer conjures up images of death, long and arduous treatment, a sense of disorientation and insecurity about the future. In short, this announcement is bound to cause patients great distress, and they will be quite overwhelmed and unable to hear what the doctor says during the consultation.

Patients' associations have said that the arrangements and the way in which diagnostic information is transmitted is often inadequate. When the doctor announces the diagnosis, how this is done will determine the relationship of trust between the patient and his/her doctor. This will have an impact on the patient's attitude to the illness, the treatment, follow-up, etc.

The patient goes through various psychological phases during which his/her need for information and guidance will vary: requests for explanation about the illness, details of the treatment, an opportunity to talk and listen, etc. The patient will need time to understand and to take in and come to terms with the diagnosis of cancer. Patient organisations highlight the fact that doctors do not sufficiently understand the emotional impact of the announcement.

As regards the announcement of the diagnosis and information on the illness, various hospitals are setting in place procedures for the announcement of diagnoses with the help of a psychologist or a nurse. They are devising ways to provide patients with the needed support and information.



While the process must be individualised, the announcement made to the patient that he/she has cancer should, as far as possible, follow a standard protocol for sensitive communication, whereby the patient must be given the necessary time to take in the information. France has developed an announcement protocol which was put together to respect the patient's desire for information and to give him/her the necessary time to take it in. Interprofessional coordination and the training of doctors in communication skills (importance of non-verbal language, etc.) are also key objectives of the protocol.

The process involves 4 specific stages:

- A medical stage during which the doctor breaks the news to the patient of the diagnosis and proposes a therapeutic strategy (that will be confirmed in writing) for a personalised program of care defined by the multidisciplinary team;
- A care stage which will take the form of a period of paramedical consultation immediately after the medical consultation (counselling and information on the services offered by associations and the social services, referral to a psychologist, etc.);
- 3. Access to a team involved in support care (social worker, psychologist); and
- 4. A stage of coordination with the general practitioner (communication between the hospital team and the doctor); this is essential to guarantee continuity and quality of care.

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### Action 8: Promotion of multidisciplinary oncological consultation

### Objective

Multidisciplinary oncological consultations have been designed to improve the quality of care given to cancer patients. These sessions are also important as sources of information for the databases of the Cancer Registry. In order to provide all new cancer patients with the best possible care and to ensure that as much data as possible are recorded, these consultations will be made compulsory. As a corollary, the fee for these consultations will be increased.

### Action

- Multidisciplinary oncological consultations (MOCs) will be compulsory for all new cancer cases.
- A 5% increase in the fees for MOCs is planned.

### Implementation: 2009

# Ensure systematic consultation with the doctors involved in the case concerning therapeutic decisions

All new cancer patients will be given a multidisciplinary consultation (MOC) and a "personalised program of care", based on a care strategy defined according to the specific type and stage of the cancer. Within this framework, the fee for multidisciplinary oncological consultations will be increased, and each patient will have privileged medical contact subject to the identification of a reference physician.

In addition to the reference specialist, the participation of general practitioners in the cancer care process is very important. In consultation with the INAMI and the Public Health Ministry, discussions will soon get under way to determine the role and position of GPs within the cancer care network and, of course, the remuneration for their services.

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### Action 9: Creation of care plans for cancer patients

### Objective

Arrange for new cancer patients, in addition to multidisciplinary consultations (MOCs), a "personalised program of care" based on care strategies defined according to the type of cancer.

### Action

In addition to the reference specialist, the participation of general practitioners in the cancer care process is very important. In consultation with the INAMI, discussions will soon get under way to determine the role and position of GPs within the cancer care network and, of course, the remuneration for their services.

It is essential to stress the importance of the involvement of general practitioners in their patient's treatment plan in various ways:

- give information on the treatment parameters
- develop skills through regular training
- give general practitioners a greater role in monitoring the patient after treatment in hospital.

**Implementation**: Creation of a working group of the National Medico-Mutualist Commission by next April, with a request to frame practical proposals for the 2009-2010 Medico-Mutualist Agreement.

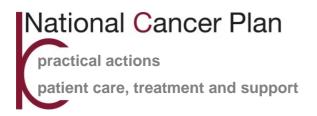
### Develop guidelines and devise day care strategies

To enable hospitals to keep pace with innovations in the field of oncology and the tremendous increase in therapy options, care programs are being placed under the supervision of the College of Oncology. This body is responsible, among other things, for assessing the quality of care provided, developing guidelines and drawing up manuals outlining the different care strategies.

Consensus has therefore been reached within the College to propose manuals for the different general care strategies according to the type of cancer.

Based on the outline proposed in the manuals, it is up to the care centres to get involved in the working groups set up to define the standards and guidelines for the different types of cancer.

Ideally, these working groups should involve the representatives of the university and regional hospitals that are willing to work together. The manuals will therefore be more likely to be used on the ground, especially at the level of the procedures for referral to a particular centre.



In order to enable the College of Oncology at that point to carry out its responsibilities as regards the monitoring of the quality of care (compliance with guidelines, international standards and the latest scientific data), it is essential to set up a structure that is sufficiently flexible to allow the guidelines to be rapidly adapted, to develop quality control mechanisms to ensure the efficiency of care and to deploy the human and financial resources required to achieve these goals.

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# Action 10: Nursing and psychosocial support for patients within the framework of cancer care programs

### Objective

Support patients through the funding of suitable multidisciplinary teams.

To enable these teams to support the patients and their next of kin, in particular when the diagnosis is announced, with regard to the social issues connected with the illness, the announcement of a recurrence, doubts and concerns relating to death and the concerns and distress of the next of kin. This work will be carried out within the framework of multidisciplinary cooperation in order to guarantee high-quality care.

The support and care measures may be continued if a person wishes, including when the patient has returned home.

### Action

Funding of nurses, social workers and psychologists in hospitals with an approved cancer care program based on the number of patients for whom a compulsory multidisciplinary oncological consultation (MOC) has been arranged.

Evaluation: social workers: 120 FTEs, nurses: 240 FTEs, psychologists: 240 FTEs.

### Implementation: 2009

### A more sensitive approach that takes more account of the needs of patients

Faced with the overwhelming emotional and relational upheavals connected with the illness and the concerns that it brings, the patient and his next of kin must deal with a whole host of difficult situations: the announcement of the diagnosis, the need for major medical examinations and treatments, the interruption of normal activities, etc., and the need to review plans for the future. These relational upheavals (bearing in mind that support, assistance and protection are accompanied by feelings of guilt, helplessness and insecurity) inevitably disrupt the life of the family and of the couple: psychological distress, marital and sexual problems and social problems (friends, etc.).

Many studies have revealed that that a high percentage of cancer patients have high levels of distress. Similarly, caring for a cancer patient can cause considerable emotional distress to the next of kin. Additionally, in many cases they do not receive the support and information they need.

Some patients' associations have also highlighted the fact that patients and their next of kin face difficulties when it comes to communicating and interacting with the medical team. In addition to this emotional and psychological turmoil and the arduous treatments and hospitalisations, there are the difficulties caused by the interruption of professional activities or the loss of work, resulting in financial difficulties (loss of income).

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This situation compounds the difficulties resulting from the often high cost of the different treatments and the consequences of these treatments (physiotherapy sessions, psychological support, aesthetic treatments, etc.).

It has also been reported that problems that are not dealt with will affect the patient's quality of life, treatment compliance, morbidity and mortality. All this will have an impact on the cost of health care and will increase the number and duration of stays in hospital.

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Action 11: Funding of a data manager within the framework of the cancer care programs

### Objective

Improve the quality of care by ensuring the recording and evaluation of compliance with the recommendations of hospitals' oncology manuals.

### Action

Funding of data managers within the framework of the cancer care programs. They will be responsible for recording the data concerning cases of cancer and for assessing compliance with the decisions of the multidisciplinary oncological consultations and of the recommendations of the oncology manual.

### Implementation: 1 July 2008

## A dynamic evaluation process to optimise the quality of patient care and the functioning of the cancer care programs

Evaluation requires not only reliable recording of new cases of cancer diagnosed in hospitals but also the review of the medical records to ensure that the decisions taken during the multidisciplinary oncological consultation have been followed or to analyse why they were not.

This assessment will also provide a means of checking that the (re)referral of patients between hospitals was carried out properly, in particular between hospitals with a basic oncological care program when required by the type of pathology. These internal assessments will serve to review practices, improve behaviour among peers and foster multidisciplinarity principles.

Reports must be drawn up and submitted to the College of Oncology. Proper recording of cases is also essential to ensure a reliable cancer registry. Data managers will be trained in the recording of cases of cancer through the Cancer Registry. Funding will be provided on this basis.

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### Action 12: Definition and funding of a paediatric cancer care program

### Objective

It is essential to support the 8 reference paediatric oncology centres and to create a specific care program in paediatric oncology to further improve the quality of care for children with cancer.

### Action

- 1. Recognition of the 8 existing paediatric oncology centres as unique reference centres for the treatment of paediatric cancer.
- 2. Financial support for synergies among the paediatric oncology centres to improve the quality of care and the specialisation of each of the centres.
- 3. In consultation with the 8 centres, creation of a paediatric oncology care program, taking into account its funding needs.
- 4. Funding from 2009 aimed at supporting 2 FTEs to provide paramedical assistance in the eight paediatric oncology centres, in consultation with the latter. This should also help strengthen the link between the day hospital and the home environment.

### Implementation: 2008-2009

### Special efforts to help children suffering from cancer

For children, the Cancer Plan will in time also include:

- greater support for the families of children with cancer
- the creation and funding of the paediatric oncology care program (fortunately, paediatric cancers are rare: all the basic care guidelines for this type of cancer are defined at an international level)
- networking and specialisation of the 8 existing paediatric oncology centres. These centres must each have the necessary specialised staff.

practical actions

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### Action 13: Care for rare tumours

### Objective

Setting a qualitative and quantitative threshold for the care and treatment of rare tumours.

### Action

Launch of a study by the *Centre Fédéral d'Expertise des Soins de Santé* (Belgian Healthcare Knowledge Center, or KCE) to define the qualitative and quantitative criteria for the treatment of rare tumours.

The KCE will answer questions such as:

- Is the current standard of 400 cases per year to define a rare tumour in Belgium a correct figure?
- What skills are available in Belgium to care for rare tumours?
- What are the quantitative and qualitative standards for optimum care based on the international scientific guidelines?

Implementation: The KCE will be asked to include this study in the schedule for 2008.

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Action 14: Recognition of oncology nurses

### Objective

Like other therapeutic fields, oncology is blighted by a staff shortage. In addition, oncology is a field that requires fully-qualified nurses who are specially trained to care for cancer patients.

The current shortage of nurses is damaging because several studies have shown that there is a positive correlation between, on the one hand, a higher number of nurses on the staff and, on the other hand, lower mortality among patients and a reduction in the number of medical complications.

As is the case with oncologists, there is a need to recognise oncology nurses.

### Action

Before the end of the first quarter of 2008, the royal decree defining the criteria for the granting of the title of oncology nurse will undergo the necessary consultation procedures with a view to being enacted.

Implementation: 2008

practical actions

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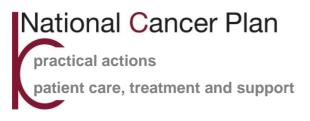
### Action 15: Improved cover for cancer treatments by compulsory health insurance

### Objective

Making effective anticancer treatments rapidly available and accessible.

### Action

- 1. Based on the recommendations of the oncologists who penned the White Paper, refund of certain medications according to the "Article 56" procedure which is designed to test the cost control of refunds and the real added value offered to patients. The proposed refund indications will be validated by the EMEA, and these medications will be issued by a limited number of cancer centres based on qualitative criteria:
  - AVASTIN 400 mg for the treatment of colon cancer with hepatic generalisation to reduce metastases with a view to surgery, issued as first-line treatment (at the same time as the first course of chemotherapy) or as second-line treatment (after the first course of chemotherapy has failed).
  - BUSULFAN IV (Busulfex): This drug, which is in the form of a powder-based syrup for children and tablets for adults, is already refunded. It combats leukemia when total body irradiation is not recommended. It is refunded everywhere in Europe except in Belgium in its intravenous injectable form because the cost of this Galenic form is 90 times more expensive than tablets. However, it offers some definite advantages in terms of side effects.
  - RITUXIMAB (Mabthera): This drug is used to combat certain forms of lymphoma, with or without chemotherapy. In terms of side effects, it can replace certain chemotherapeutic agents for the treatment of some of these lymphomas, but it is much more expensive. The proposal is to bring this product into line with the criteria recommended by the EMEA for refund.
- 2. Give men access to cancer drugs that are currently refunded only for women suffering from breast cancer: a procedure to extend the refund criteria will shortly be submitted to the Medicines Reimbursement Commission.
- 3. Since 1 March, FASLODEX (€458.97 for a pre-filled syringe containing 5 ml of product) is 100% refunded by compulsory health care insurance. It is one of the drugs that combats breast cancer in certain indications.
- 4. The INAMI and the Federal Agency for Medicines will be responsible for carrying out an analysis of the causes of differences in the speed of refund and the price and conditions of cancer treatments between Belgium and neighbouring countries.



On this basis, they will be asked to frame recommendations aimed at improving the situation in Belgium, particularly with regard to the drugs that are specially designed for the treatment of paediatric cancers.

Implementation: In compliance with the procedures, by November 2008 at the latest.

### **Development**

In today's world, rapid access to oncology treatments is a particularly acute problem because of the added value of the new cancer drugs. Considerable effort has been undertaken in Belgium to reduce the duration of the procedure to 180 days, as recommended at European level.

The new cancer drugs are very expensive, with prices ranging from EUR 30,000 to EUR 60,000 per year per patient, and these innovations often offer real added value in response to a medical need and/or in terms of efficacy and tolerance.

The possible limitation of access to these new molecules may become a major public health issue. It is therefore necessary to decide on the basis of accurate information how much society is prepared to spend on these initiatives.

practical actions

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### Action 16: Support for radiotherapy and oncological imaging

### Objective

Ensure the sufficient availability and quality of diagnostic and therapeutic equipment for oncological radiotherapy and imaging to cater for the needs of the population and to guarantee accessibility to all through compulsory health insurance cover.

### Action

1. Quality control of all devices

The devices used for the diagnosis and monitoring of cancers (MRI, scanners, PET scans, etc.) and for radiotherapy will be evaluated in relation to objective needs within the framework of the fight against cancer and, if necessary, adapted accordingly. In particular, as promptly as possible the KCE will be asked to examine the final consensus reached on 1 February 2008 by the Standing Committee of the Belgian Society of Nuclear Medicine on PET scanning in Belgium.

- 2. New programming if this is deemed to be appropriate.
- 3. Funding within the framework of the Budget des Moyens Financier (Financial Resource Budget, or BMF). Adequate funding will be provided according to need to replace these machines or to purchase additional machines. The budget must also make provision for the introduction of high-conformation techniques (IMRT, IGRT, ART, stereotaxy).

**Implementation**: 2008-2009. The multi-annual investment program must be planned and budgeted from 2009.

### Ensure access to medical technologies for the diagnosis and treatment of cancer

One of the major challenges in the years ahead will be to make all the therapies that have been recognised as efficient by clinical research available to caregivers and patients according to proper conditions of access. The refund of cancer drugs is of course important, but scientific progress also affects the other disciplines involved in the treatment of cancer. Innovative techniques are also being developed in surgery and in radiotherapy.

In radiotherapy, we can mention the example of hadrontherapy and innovations in the field of safety, equipment and IT. The quality of radiotherapy depends not only on the expertise available but also on the modernisation and timely replacement of equipment and machines. Access to medical technologies for all presupposes that proper attention is given to the need to make proper use of every euro that is invested to buy and use the equipment, which means that a number of efficient tools must be used to assess their usefulness:

- Health technology assessment: before any refund is made by compulsory health insurers for a new medical technique or technology, its actual added value for the care of patients should be scientifically verified.



- Independent and regular evaluation of requirements as regards specific devices (MRI, PET, etc.); for example, is it necessary to increase the use of PET scans for the diagnosis of cancer and, consequently, increase the number of devices that are currently approved (13 in all)?
- Development of Evidence Based Medicine and the good practice recommendations for the use of the different technologies that are available.

practical actions

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# Action 17: Structural support for cell therapy banks and units for hematopoietic stem cells and cord blood

### Objective

Hematopoietic stem cells and cord blood banks have been approved for a number of years in several hospitals across the country. These banks form part of vast international networks.

They are a source of great hope of a cure for patients (children and adults) who suffer from leukaemia or serious blood disorders. These patients must be given heavy chemotherapy treatments to remove their blood lines, which must then be restored by a graft of hematopoietic stem cells which are stored in these banks and which come from compatible donors.

These banks must be properly managed and must meet strict quality criteria to be approved at Belgian and international level and thus guarantee the biological quality of the stock of samples. The grafts which are stored there may come from the patient himself/herself through autografts or may come from donors. They can then be used for Belgian or foreign patients.

Prior to storage but also prior to clinical use, these cells must undergo various processes (separation, amplification of cells, purges, etc.) in cell therapy units which, among other things, render them more compatible for the recipient.

These banks and cell therapy units are currently not receiving funding, but they constantly need more infrastructures and quality control processes because of their professionalisation and the growing number of grafts that they store.

### Action

Fundamental structural support for hospital-based banks and cell therapy units that store hematopoietic stem cells and cord blood: bank manager, quality coordinator and laboratory technician and funds for storage tanks and for operation.

Implementation: 1 July 2008

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### Action 18: Improved refund for certain costs associated with cancer treatments

### Objective

In addition to the actual curative or palliative cancer treatments, patients are sometimes confronted with often high extra costs.

A case in point concerns patients who have had a laryngectomy: the current accumulation of medical expenses not covered by insurance and operating margins of hospital pharmacists that the patient is required to pay during the year for a tracheal cannula, maintenance kits for their laryngectomy, phonatory implants or home nursing care represent a heavy financial burden.

This is the case for patients who lose their hair following treatment.

This is also the case for people who have to have a mastectomy.

### 1. For patients who have had a laryngectomy

- Refund from 2009 of the security margin for phonatory implants (€49.07).
- In view of the need to change at regular intervals the phonatory implant (2 or 3 times a year) and the laryngectomy maintenance kit (4 or 5 times a year) and the high operating margins, covering the operating margins through compulsory health insurance.

### Implementation: 2009

### 2. For patients who lose their hair following cancer treatment

Increase by 50% the two current lumpsum payments:

- The lumpsum payment will increase from EUR 120 to EUR 180 for people who suffer total baldness following treatment.
- The lumpsum payment will increase from EUR 180 to EUR 270 for people who suffer cicatricial alopecia caused by radiotherapy.

### Implementation: 2008

### 3. For patients who have to have a mastectomy

The total budget set by the 2008 Medico-Mutualist Agreement to improve the current refund for breast reconstructions is EUR 601,000.

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### Action 19: Developing functional rehabilitation of cancer patients in remission

### Objective

Following aggressive cancer treatments that have resulted either in a cure or in a long period of remission, patients experience considerable physical, mental or neurocognitive problems. They then need not only an integrated program of rehabilitation in the weeks and months following the end of treatment but also assistance with reintegration into society to help them return to a full quality of life.

### Action

The implementation of pilot projects designed to create the type of multidisciplinary rehabilitation program that is essential for the social reintegration of patients who have been cured or who are in a period of remission.

The rehabilitation and social reintegration of patients after treatment must be prepared during the active phase of the treatment, not only with the cooperation of all the caregivers but also in consultation with the patient himself/herself as an active partner of the health care team. Ideally, this should be part of a cancer care program.

A call for projects will be made.

### Implementation: 2009-2010

A budget of EUR 1.2 million has been earmarked.

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# Action 20: Setting the conditions for the recognition of post-treatment handicaps of cancer patients

### Objective

The objective of the measure is to set up a system to ensure the accelerated processing of benefit claims by handicapped persons, who may include:

- patients who are undergoing chemotherapy or radiotherapy, with or without surgery;
- patients who have a rapidly progressing condition with a poor short-term survival prognosis;
- or patients who are terminally ill and on palliative care.

### Action

Procedures for the accelerated processing of benefit claims by handicapped persons.

Claims for benefits by these handicapped patients will be processed according to a priority procedure. To this end, the administration will make privileged use of medical expertise on the basis of medical records.

The benefits concerned by the measure are income replacement benefits, integration benefits and benefits for assistance to the elderly. In addition to the conditions as regards age, nationality, residence and income, receipt of these benefits depends on the loss of earning capacity of the person (as regards income replacement benefits) and the loss of autonomy (as regards integration benefits and benefits for assistance to the elderly).

The measure thus directly concerns numerous claims submitted by persons suffering from cancer.

### Implementation: 2008

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### Action 21: Support for parents of children with cancer

### Objective

To allow parents who have a child who is suffering from cancer to receive assistance and support either to be with their children (parents' house close to the hospital where their child is staying) or to have a short break to recharge their batteries so that they can have the energy to take care of their child.

### Action

Within the framework of a call for projects: to fund specific projects that provide support and help for parents and children who are dealing with an illness, such as a "respite home", the aim being to allow children to get out of hospital for a few weeks (4 weeks a year) or to give parents a short break.

### Implementation: 2008-2009

A budget of EUR 6 million has been earmarked.

# For a society managing the needs of the parents to recharge their batteries while they are taking care of a sick child

- Some parents, especially those who do not live near a hospital, face difficulties because of the problem of travelling and the time spent going to visit their child. There are a number of solutions and projects that are designed to enable parents to live in a house intended for the parents of sick children and to give them a better quality of life despite the difficulties that they have to cope with as a result of the illness and the suffering caused by the illness.
- Parents who have a sick child express the need for somewhere to recharge their batteries and to devote time to activities that do not necessarily revolve around the child, the illness or the problems associated with the illness.

Basically, these parents need some time, perhaps a week or a few days, for themselves or for the other members of the family.

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# Action 22: Access to psychological support or participation in counselling groups or support activities

### Objective

To allow people who have been diagnosed with cancer and their families to receive psychological support either individually or in a group (counselling group, etc.) and especially when the patient leaves hospital and finds himself alone or alone with his family. There is a need for places to meet, talk and listen.

Parents of children suffering from cancer often need to express all the emotional burden and the psychological distress that is caused by caring for a sick child and facing the possibility of the loss of a child. It is a time of intense solitude and distress when they need a lot of support to avoid even more serious psychological or psychopathological disorders.

### Action

Within the framework of a call for projects: funding for psychological support or patient care projects (adults, teenagers or children) and/or for families of patients, either within hospitals or projects supported by associations who assist patients and families of patients with cancer.

### Implementation: 2008-2009

A budget of EUR 2 million has been earmarked.

practical actions

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Action 23: Structural funding of paediatric care networks - "ongoing care for children"

### Objective

To structurally finance an inter-university liaison team made up of at least 3 nurses and, according to need, the services of a paediatrician, a psychologist, a physiotherapist and a secretary.

The task of the inter-university liaison team is to make arrangements for patients between 0 and 18 years of age suffering from illnesses with a reserved prognosis (in most cases fatal) -regardless of their illness and place of residence - to return home and remain there. This program of care continues until the patient dies at home, and it includes bereavement support. The liaison team constitutes the link between the hospital and the home environment and is responsible for guaranteeing continuity of care and the overall management of the care of seriously sick children at home.

### Action

Between 2004 and 2007, seven multidisciplinary liaison teams (4 Flemish-speaking and 3 French-speaking) had an agreement with the Public Health Ministry to fund this "ongoing care" for children in the palliative care phase.

The average annual cost of funding this type of multidisciplinary liaison team was €53,200 over the period 2004-2007.

Double the annual budget of these 7 teams to bolster their capacity for action.

Implementation: 2008-2009

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### Action 24: Support for pilot projects in the field of clinical geriatric oncology

### Objective

The ageing of the population observed in recent decades will increase the need for cancer care tailored to this population. In the light of this trend, it is essential to define and validate tools for geriatric assessment, to develop specific recommendations for the care of elderly patients and to clearly identify the composition of the multidisciplinary teams that are best suited to take care of them.

### Action

Call for pilot geriatric oncology projects for hospitals aimed at optimising the care of elderly patients suffering from tumours with a view to creating units specialising in clinical geriatric oncology.

Within the framework of inter-hospital cooperation, these projects will:

- validate and adapt tools to evaluate the geriatric care of elderly patients suffering from cancer in order to predict those who will benefit the most from certain treatments and what types of treatment they will be able to tolerate;
- define the best type of multidisciplinary management of this type of patient according to their own needs;
- conduct clinical trials on treatment strategies tailored to elderly patients.

### Implementation: 2008

# Development: the need to support pilot projects in the field of clinical geriatric oncology

Elderly persons (65 years and over) currently account for around 17% of the Belgian population. One person in 5 will have reached that age by the year 2020, and this figure will be more than one in 4 by the year 2050. It is expected that the effects of the ageing population will be felt until the middle of the century.

The incidence of cancer increases steadily with age. Around two-thirds of women and three-quarters of men are 60 years old or more when they are diagnosed with cancer. The chance of survival of elderly patients is lower than that of younger adults. This is due not only to various factors such as differences in the stage of the disease at the time of diagnosis, differences in the nature of the tumour and the greater fragility of elderly patients (partly because of comorbidities), but also to the use of therapies that are less aggressive and therefore less effective.

Support for pilot projects in the field of clinical geriatric oncology is essential if in future we are to create units specialising in geriatric oncology in hospitals and as a result to cope with the increasing number of cancer patients taken into care in this age group in view of the ageing of the population.

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### Action 25: Improving the provision of palliative care for cancer patients

### Objective

If there is no effective treatment that offers the patient a chance of remission or complete cure, the patient should be referred to palliative care units. Palliative care starts well before the last few weeks or months of life, by which time curative care has lost its *raison d'etre*. Around half of cancer patients need palliative care according to this wide-ranging definition. This means that there must be sufficient health care teams, both at home and in the hospital.

### Action

The development of palliative care, 80% of which is for cancer patients, will be actively supported in various ways:

- 1. More resources for palliative care: a study by the KCE is under way to identify objective needs.
- 2. Program to reinforce the infrastructure for palliative care in rest and nursing homes, funded by the compulsory health care insurance budget.
- 3. Within the framework of home-based end of life palliative care, the current lump sum cover must be increased to ensure better home care in order to offer some relief to the families of patients, especially when members of the family must continue to work. It is proposed that in 2009 the lump sum payment given to patients at the end of their life will be increased by 15%.
- 4. Development of more palliative care structures which are neither hospitals nor rest homes: palliative day care centres are also a solution for short-term treatments such as drain punctures, parenteral feeding, etc.

### Implementation:

- 1. The results of the study will be available in April 2009.
- 2. 2008
- 3. 2009
- 4. 2010 on the basis of the results of the KCE study

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# Action 26: Actions to be taken in consultation with the ministers competent at Federal level

### Objective

A consultation exercise will be conducted with the Ministers of Employment and the Selfemployed to consider ways to make essential improvements as regards the reconciliation of the professional life of patients and parents and the management of cancer. There will also be consultations with the Minister of Finance on the deductibility of donations to associations involved in the fight against cancer and patient care.

### 1. Improving ways to reconcile the patient's professional life and cancer

At the present time, people who have to be regularly absent from work because of a scheduled medical treatment (e.g. chemotherapy) come under the general arrangements that apply in the case of disability:

- At each new phase of the treatment, they must once again declare that they are unable to work (even though the treatment program is known).

- At the time of the first absence and, subsequently, if the time spent back at work between the two treatments exceeds 14 days (a period referred to as the "relapse"), the employer must pay the guaranteed wage and the workers are imposed one day's waiting time.

- The duration of the treatment can result in these persons being defined as disabled.

For the persons concerned, this situation therefore has serious consequences: administrative complexity, considerable financial losses, etc.

To guarantee a better financial situation, it would be good to have a special system of sick leave and compensation for chronically ill patients who are following treatments (e.g. chemotherapy) and who have to take time off regularly.

### 2. Improving ways to reconcile the parent's professional life and cancer

It would be interesting to review the current duration of leave for medical assistance to allow the parents of children suffering from serious illnesses such as cancer to be able to take care of their child for an extended period of time without losing too much income.

### 3. Procedure for easier and tailored tax deductibility of donations

In the fight against cancer, the voluntary sector plays a leading role, in terms not only of support for research but also of information/prevention and social assistance for patients. The work of associations depends mainly on the generosity of citizens and the extent to which the state is prepared to encourage this generosity by offering tax deductions for donations and bequests made to approved associations.

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### Action 27: Creating a tumour bank

### Objective

Create a virtual inter-university tumour bank to promote translational research and to create a network of cooperation among the academic institutions, general hospitals and the various concerned industrial partners who engage in research activities in Belgium (pharmaceutical companies, biotechnology firms, diagnostics agencies, etc.).

### Action

Structural funding:

- Tumour banks of university hospitals or partners of universities that already have a tumour bank with an annual subsidy of €300,000 and that can finance:
  - a tumour bank manager responsible for the recording and storage of samples and data as well as the proper use of this material
  - a laboratory technician responsible for collecting, preparing and freezing tumours and extracting nucleic acids for storage
  - freezers and storage tanks and security of the premises
  - the operating costs of the infrastructure (IT, liquid nitrogen, reagents, transport of samples, etc.)
- Infrastructure for the inter-university virtual tumour bank consisting essentially of the sharing of local databases and the standardisation of the processes:
  - a manager of the virtual tumour bank
  - administrative and logistical support
  - computer hardware and arrangements for security

Implementation: 2008. A budget of EUR 3 million per year has been earmarked.

### Development

Several hospitals around the country (mainly university hospitals) have set up tumour banks, i.e. banks that collect and store frozen samples of tumours taken from patients in the course of biopsies or surgical resection. At the present time, these structures are mainly funded through sponsoring.

The tumour banks are an essential tool for research, in particular translational research and research into new drugs which are important sources of partnership with the pharmaceutical industry. They also provide a means of going back to analyse a sample of a tumour taken from a given patient to carry out additional analyses in the light of new discoveries (for example, in the event of a relapse, an analysis to identify the presence of a new biological marker that is predictive of a given treatment that was not known at the time of the first diagnosis) and thus to help improve patient care. National Cancer Plan practical actions research, innovative technology and evaluation

Proper management of these banks and standardised recording of the medical data accompanying each sample, as well as procedures for freezing and storage, are essential to guarantee the biological quality of the samples and correct use of this material.

The creation of a virtual tumour bank that pools the databases of the different tumour banks would enable researchers to share this information, gain access to a greater number of samples and thus get results much more rapidly within the framework of cooperation initiatives.

Cooperation agreements should be concluded between the university tumour banks and the general hospitals to provide a means of collecting and storing as many samples of tumours as possible.

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# Action 28: Structural funding for the coordination of translational research in hospitals

### Objective

To allow patients to benefit as rapidly as possible from the results of laboratory discoveries and new technologies thanks to structural funding of the coordination of translational research.

### Action

Structural funding of translational research coordination units, including:

- a doctor responsible for coordinating translational research in the hospital
- a secretarial FTE responsible for giving the coordinating doctors administrative and logistical support
- a data manager FTE responsible for providing assistance in the encoding of data.

### Conditions

This funding will be granted to hospitals that are approved for a program of cancer care and have funding for new technologies (B4) and that have already demonstrated expertise and a clinical and translational research infrastructure in the field of functional imaging and molecular biology (genomics or proteomics). The evaluation of this expertise will be based on the impact of scientific publications in the field, the number of clinical studies in cancer research, existing scientific collaborations at national and international level, the existence of a partnership with the pharmaceutical industry and the composition of the existing team, existing resources, etc.

The medical coordinator of translational research must have experience of research and at least 5 years of clinical experience and must be involved in mixed clinical and research activities and:

- coordinate translational research within the hospital
- act as an intermediary between clinicians from the hospital, patients and laboratory
  researchers in order, firstly, to incorporate the discoveries made in the laboratory in
  clinical research studies and the care of patients as quickly as possible and, secondly,
  to transmit to the laboratory researchers the questions that the clinicians consider that
  the laboratory should investigate
- act as a relay for the academic laboratories and the pharmaceutical industry and in the field of new technologies in order to carry out studies in close cooperation
- act as a relay for doctors from other hospitals so that all patients might potentially benefit from these discoveries and the new diagnostic and therapeutic strategies resulting therefrom
- provide the medical community with information both inside and outside the hospital on the results of the research carried out.

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### Development

Structural funding of coordination of translational research in hospitals through "clinician/researcher" doctors and logistics support structures (secretariat and data manager).

The hope for cancer patients is research: understanding the causes of cancer and the reasons for the failure of treatments and detecting ways to treat cancer more effectively. Clinical cancer research aims to explore new diagnostic methods and new treatment strategies within the framework of patient care. The results depend on fundamental laboratory research. The first priority of translational research into cancer is to transfer scientific discoveries as quickly as possible to therapeutic applications that benefit patients.

It is in this area that it is essential to ensure a genuine continuum from the laboratory to the patient's bedside by involving doctors, scientists and patients and by enabling as many patients as possible to benefit from the results of these discoveries.

Implementation: 2008

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### Action 29: Support for translational research

### Definition

Translational research is the link between fundamental research and clinical research. This is often summed up by the "lab to bedside" concept. Translational research creates a continuum between fundamental research and patient care that is designed to allow cancer patients to benefit as quickly as possible from the latest scientific discoveries. The research currently focuses mainly on molecular markers and new technologies to predict a particular sensitivity of a tumour to a given treatment and thus help individualise treatments.

The scientific knowledge that comes from fundamental cancer research is becoming increasingly sophisticated with regard to the mechanisms underpinning the occurrence of cancers, the biological factors that account for the prognosis of patients and the efficacy of treatments. This brings about a change in therapeutic modalities with a switch from conventional cancer treatments that are toxic to all the cells (whether they be cancer cells or normal cells) to treatments that increasingly target diseased cells based on their molecular or genomic profile or their behaviour in functional imaging.

### What fields will be concerned?

<u>Molecular biology</u> (genomics and proteomics) permits the identification of genes and of the proteins responsible for cancerous transformation of cells and uncontrolled cell growth. Thanks to these new technologies, doctors know more about the genetic alterations involved in the cancers of their patients. They are able to be more precise about the classification of tumours, better predict the prognosis of their patients and individualise treatments, offering less aggressive treatments to patients with a good prognosis who do not need them.

<u>Pharmacogenomics</u> is the study of the interaction between the genetic profile of an individual and his/her organism's response to drugs. In certain cases, pharmacogenomics tells the doctor in advance whether it would be advisable to administer a treatment (a drug) or if it would serve no purpose because the genome of the person in question is not appropriate. In the latter case, useless and costly treatments can be avoided in favour of alternative treatments.

<u>Metabolic and functional imaging</u> (via MRI, PET scan, etc.) provides a means of exploring the functioning of tissues and evaluating the characteristics of cancers and of their environment: physiological (vascularisation, oxygenation, cell density, etc.), metabolic (incorporation or accumulation of substances during cell division) and molecular (identification of specific cells). This evaluation is potentially useful when it comes to making therapeutic choices and taking quick decisions in response to a treatment. This means that patients can be spared inefficacious and toxic treatments even before this information can be obtained from the current conventional methods based on response evaluation.

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### Objective

Support for research into defining *a priori* the most effective cancer treatments according to the characteristics of each patient, with a threefold objective:

- 1. to reduce the aggressiveness of the treatment for the patient as much as possible;
- 2. to maximise the patient's chances of a cure or periods of remission;
- 3. to control more effectively the costs of compulsory health insurance and the costs to be borne by the patient.

To develop the existing translational research infrastructures in the field of oncology in order to ensure enhanced individualisation of treatments for cancer patients and to rationalise health care expenditure. The aim of translational research is to help the doctor not only predict the chances of success of the treatments envisaged for each patient but also to spare him/her aggressive treatments that will not improve his/her state of health.

The main objectives of this type of research include identifying the types of treatment that will be most effective for a given patient, targeting sub-populations of patients who will benefit most from a certain drug and avoiding unnecessary toxic treatments for patients who do not really need them. This type of research plays an essential role in the field of public health not only by controlling costs but also by benefiting patients by avoiding costly and unnecessary examinations.

This research is costly and currently under-funded, but it is also too fragmented in Belgium and in other countries, leading to a dispersion of resources. Therefore, this type of research must be supported within the framework of cooperation dynamics.

### Action

A call for translational research projects in oncology will be made for hospitals that have been approved for a program of cancer care and that receive funding for the new technologies (B4). These projects are designed to ensure better targeting of therapies and the identification of new diagnostic and therapeutic targets.

In particular, these projects will be evaluated according to the following parameters:

- originality of the project
- integration of the research/care continuum
- innovative nature of the proposed approach
- prospects for application and development strategy
- level of excellence and expertise of the managers and teams involved in the project
- complementarity of the different teams involved in the project
- positioning of the project in the future national context.

### Implementation: 2008

A budget of EUR 15 million has been earmarked. The subsidies awarded can also be used for the purchase of equipment or for operating costs (salaries, reagents and sundry equipment). Specific projects focusing on research into child cancer will be included.

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### Action 30: Using hadrontherapy in Belgium

### Objective

Creation of a hadrontherapy centre in Belgium that will provide patients with care and advance research.

In the meantime, the refund of hadrontherapy treatments given abroad should be maintained to guarantee that Belgian patients who need this treatment have access to it.

### Action

Two practical initiatives are planned:

- 1. the launch of a feasibility study for the construction and operation of a hadrontherapy centre in Belgium. This study will be entrusted:
  - either to the private foundation referred to as the "Belgian Hadrontherapy Centre Project", provided it includes all Belgian universities and provided the support committee for this study includes representatives of the public authorities concerned;
  - or to an ad hoc inter-university centre.
- 2. initiatives aimed at increasing the refund of care and travelling expenses for cancer patients requiring hadrontherapy cooperation with the existing European hadrontherapy centres pending the possible creation of a centre in Belgium.

### Implementation: 2008/2009

### Hadrontherapy

There are currently only around twenty centres in the world that use this type of treatment. The results have been promising, although hadrontherapy is still considered an experimental treatment that has benefited a limited number of patients. This new form of radiotherapy is in the initial phase of clinical development.

Numerous studies are under way to validate its best indications. In the medico-scientific jargon, the term used in this context is "clinical translational research". This means that results are studied at the same time in order to gain better understanding and to evaluate the results in terms of the biological anti-tumour effects of this new form of treatment.

Conventional radiotherapy is also rapidly developing. Increasingly sophisticated devices and techniques are coming on stream that optimise irradiation and reduce side effects.

Nevertheless, hadrontherapy remains the only available alternative for most tumours that are resistant to conventional radiotherapy.

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Our country has an excellent reputation in the field of radiotherapy. In the university centres, new techniques are rapidly being developed and made available for clinical practice. In other words, Belgium has a recognised role in the benchmarking of these treatments.

The creation of the infrastructure, buildings and equipment would cost EUR 100 million. The operational costs needed to cover the period of clinical research and startup for such a centre (to be spread over a period of around 5 years) would cost approximately 50 million euros.

To treat a total of around 1,000 patients a year, the cost would be around EUR 25,000 per patient, including operating expenses and depreciation. By way of comparison, the cost of treating a patient with the latest-generation chemotherapy is roughly the same.

The hadrontherapy centre will not only generate costs, but it will also make substantial savings. A local relapse or occurrence of metastases of a cancer that has previously been treated not only causes human suffering, but it also results in high costs for the administration of a new treatment. The costs generated by the treatment of the side-effects of radiotherapy on sensitive tissues (the "toxic phenomena") can also be reduced thanks to hadrontherapy.

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### Action 31: Consolidating the Cancer Registry Foundation

### Objective

- 1. To remove the legal, material and financial obstacles in the way of the proper functioning of the Cancer Registry Foundation.
- 2. To extend the nature and type of data available to the Cancer Registry in order to be able to make a better analysis of the situation of cancer in our country.

### Actions

- 1. Creation by Royal Decree of the Cancer Registry Foundation as a recognised body:
- 2. Creation of a consultative committee of users of the data of the Cancer Registry Foundation
- 3. Structural funding for the Cancer Registry Foundation:

### Implementation: 2008-2009

A budget of EUR 1 million has been earmarked.

### Better understanding the development of the disease

Consolidating the Cancer Registry Foundation so that it can have free rein to collect and analyse all the data relating to cancer in our country.

It is very important to record all the data that are useful for efficacious prevention:

- recording vaccinations, the results of cervical smears, mammotests and biopsies and linking them to the Cancer Registry
- analysing the data geographically in order to interpret local phenomena, to determine potential risk factors and to give patients better information
- identifying the sources of data that can usefully and feasibly be linked to the Cancer Registry, such as data on behaviour (smoking) or on the patient's environment
- in all the aspects of this policy geared towards the recording of multifactorial data, constantly taking steps to comply with the legislation on respect for privacy
- strengthening the human resources of the Foundation in terms of descriptive and analytical epidemiology.

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### Action 32: Creation of a Cancer Reference Centre

### Objective

To coordinate and unite all the stakeholders in the fight against cancer. A Reference Cancer Centre will be set up within the Scientific Institute of Public Health (ISSP), the Belgian Healthcare Knowledge Center (KCE) or another public institution.

A study of the comparative advantages of one or other option will be conducted without delay.

The missions of this centre will be perfectly coordinated with and complementary to the different organisations involved in the fight against cancer and the support structures of the Plan that are already present (KCE, ISSP, IMA, AFM, INAMI, the Cancer Registry, the College of Oncology, the College of Radiotherapy, etc.), as well as with the federate bodies.

The Reference Cancer Centre will involve researchers, healthcare professionals, representatives of healthcare establishments and patient representatives very closely in this initiative in order to facilitate the implementation of the Cancer Plan.

The Cancer Plan will be accompanied from the outset by an evaluation mechanism. It will publish an annual review of the results achieved within the framework of the Cancer Plan.

### Action

Creation of a Reference Cancer Centre.

The tasks of the Centre will be:

- to collect, analyse and encourage the necessary expertise to improve the fight against cancer
- to coordinate, support and strengthen the efforts of all the actors concerned (oncologists, hematologists, radiotherapists, surgeons, nurses, psychologists, radiologists, nuclear medicine physicians, etc.)
- to evaluate the efforts undertaken in Belgium to fight cancer; collection and analysis of the data required for this purpose
- to promote cooperation and exchange of information among the different authorities, public services, institutions, organisations, universities, hospitals, research centres and companies involved in the fight against cancer
- to develop, monitor and evaluate best practices and guidelines for prevention, screening, diagnosis, treatments, the organisation of care, research, palliative care,

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reintegration and management of patients and their entourage in Belgium.

- Follow-up and transposition of European and international guidelines, recommendations and initiatives
- Coordination, evaluation and optimisation of programs, structures and care strategies in the field of cancer
- Inventorising, coordinating and promoting academic, translational and evaluative research in cancerology
- Analysing the efficiency, added value and optimum use of new therapeutic and technological developments and providing the authorities with relevant advice
- Supporting and promoting the training and coaching of health professionals and cancer researchers
- Informing the population, health care professionals and the competent authorities
- Preparing the 2011-2015 Cancer Plan

Implementation: 2008-2009