Efficiency and sustainability in innovative patient centred cancer care

Vision document All.Can Belgium

14/03/2019

All.Can is a multi-stakeholder platform established to create political and public engagement on the need to improve the efficiency in cancer care. To do this, it focuses on what matters most to patients and makes sure resources are targeted towards achieving these outcomes. All publications from the group reflect consensus of the members, who hold full editorial control.

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BELGIUM

Changing cancer
care together

All.Can

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Introducing All.Can

Ensuring sustainability in health care is an ongoing challenge. Waste and inefficiency within the system not only generate financial costs. Lost time, cancelled appointments and unnecessary processes also decrease patients' quality of life.

The All.Can initiative was created to tackle waste and inefficiency in cancer care by improving outcomes in cancer care for patients. All.Can is a multi-stakeholder platform working to mobilise the international cancer care community. The aim is to achieve more sustainable, efficient, innovative and patient-centred cancer care. All.Can brings together patient and care representatives, health care professionals, health experts, health economists, policymakers and industry representatives who are committed to this objective.

To achieve its goals, All.Can focuses on four key areas[1]:

1. Across all aspects of cancer care we must ensure that we are focusing on what matters most to patients. We do so by including patients and their representatives in all aspects of cancer care planning, delivery and evaluation, and consequently **put patients at the heart of cancer policy.**
2. **Invest in data** in the form of real-world data collection to capture variations in use of care and patient-relevant outcomes. We also need better linkages between health information systems and big data analytics to guide a continuous cycle of improvement, help target care more effectively, and support technological and service innovation.
3. **Create greater accountability** through measurement and public reporting of outcomes, outcomes-based reimbursement, and built-in mechanisms to systematically identify and remove inefficiencies in cancer care.
4. **Focus political will** to drive efficiency measures and strategic reinvestment across the entire cancer care pathway.

Introducing All.Can Belgium

Although cancer occurs worldwide, where a person lives largely determines both whether the person will develop cancer and his or her treatment prospects.[2] This is largely dependent on the health care system of the specific country and its policy on cancer treatment. Therefore, each country has to adapt All.Can's key areas to its own system and formulate its own goals.

Specifically, All.Can Belgium is a national chapter of the international All.Can initiative. Our work reflects the global vision and mission of changing cancer care together.

All.Can Belgium has five main goals:

1. Align stakeholders on a joint vision on cancer care and create stakeholder support for this vision
2. Initiate and realise projects to deliver the vision
3. Propose solutions that contribute to more efficient and innovative cancer care across the whole patient pathway
4. Proactively provide input to the policy debate
5. Create societal support for the vision.

About this vision document

Why?

The quality of cancer care in Belgium, as measured by five-year survival for treatable cancers such as breast cancer, cervical cancer and colorectal cancer, is better than the EU average.3 However, cancer remains one of the most common causes of death. Incidence and prevalence of cancer have been rising along with an ageing population and more effective treatment solutions.[4] 3% of the Belgian population was affected by cancer between 2004 and 2013.[5] The challenge to improve cancer care and ensure sustainable cancer care remains high on the policy agenda.

This paper reflects on the Belgian needs in relation to efficiency and innovation in cancer care. It is based on a unique multistakeholder approach. Furthermore, it brings ideas and suggestions to policymakers and aims to inspire everyone concerned with better cancer care. Finally, this analysis will help to define priority projects for All.Can Belgium. Using the content of this report is encouraged while mentioning the source.

Who?

The policy note reflects the views and opinions of All.Can Belgium. Co-authors of the report are: Ahmad Awada (Institut Jules Bordet), Ann Ceuppens (Mutualités Libres/Onafhankelijke Ziekenfondsen), Pia Cox (Pink Ribbon), Ri De Ridder (Health expert), Gilles Poncé (Bristol-Myers Squibb Belgium), Ann Rogiers (CHU Brugmann), Ine Somers (Member Federal Parliament), Marc Van den Bulcke (Sciensano (Kankercentrum)), Didier Vander Steichel (Fondation contre le Cancer / Stichting tegen Kanker), Dominique Vandijck (UHasselt/UGent), Jan van Meerbeeck (UZA), Brecht Vanneste (MSD Belgium), Stephanie Devisscher (Secretariat All.Can Belgium/hict).

We are grateful for the expert contributions received from other key stakeholders in cancer care.

How to read?

This vision document is made up of two chapters. In the first chapter we define the concept of efficiency and innovation in cancer care in order to clarify the focus of All.Can Belgium. The second part focuses on key issues and challenges in the Belgian cancer care system. Reflecting the integrated approach of All.Can Belgium it offers ideas to improve cancer care all along the patient journey.

Defining efficiency and innovation

As effectiveness, efficiency and innovation are at the heart of the All.Can initiative, we start by defining these concepts.

An **effective cancer care system** is a system that is able to reach the best possible health outcomes. Health outcomes can vary from practical output measures (e.g. participation in screenings) through intermediate results (e.g. satisfaction of patients, stages of diagnosed cancers) towards long-term, sustainable impacts such as higher survival rates or better quality of life for cancer survivors. Effectiveness also relates to the ability to reach predefined objectives of cancer care in a national and international context.

Efficiency of cancer care is concerned with the relation between resources utilised in cancer care (costs, labour, capital) and the health outcomes reached. Efficiency is thus the ability to produce the outcomes with a minimal amount of resource inputs or to maximise the health outcomes given a certain amount of resources.[1] All.Can Belgium will focus on waste reduction and efficiency gains.

All.Can Belgium believes that **innovation** in all its forms can contribute significantly to greater efficiency in cancer care. Innovation can lead to a reduction of variety in cancer care, to the reduction of wasted time and resources, to increased

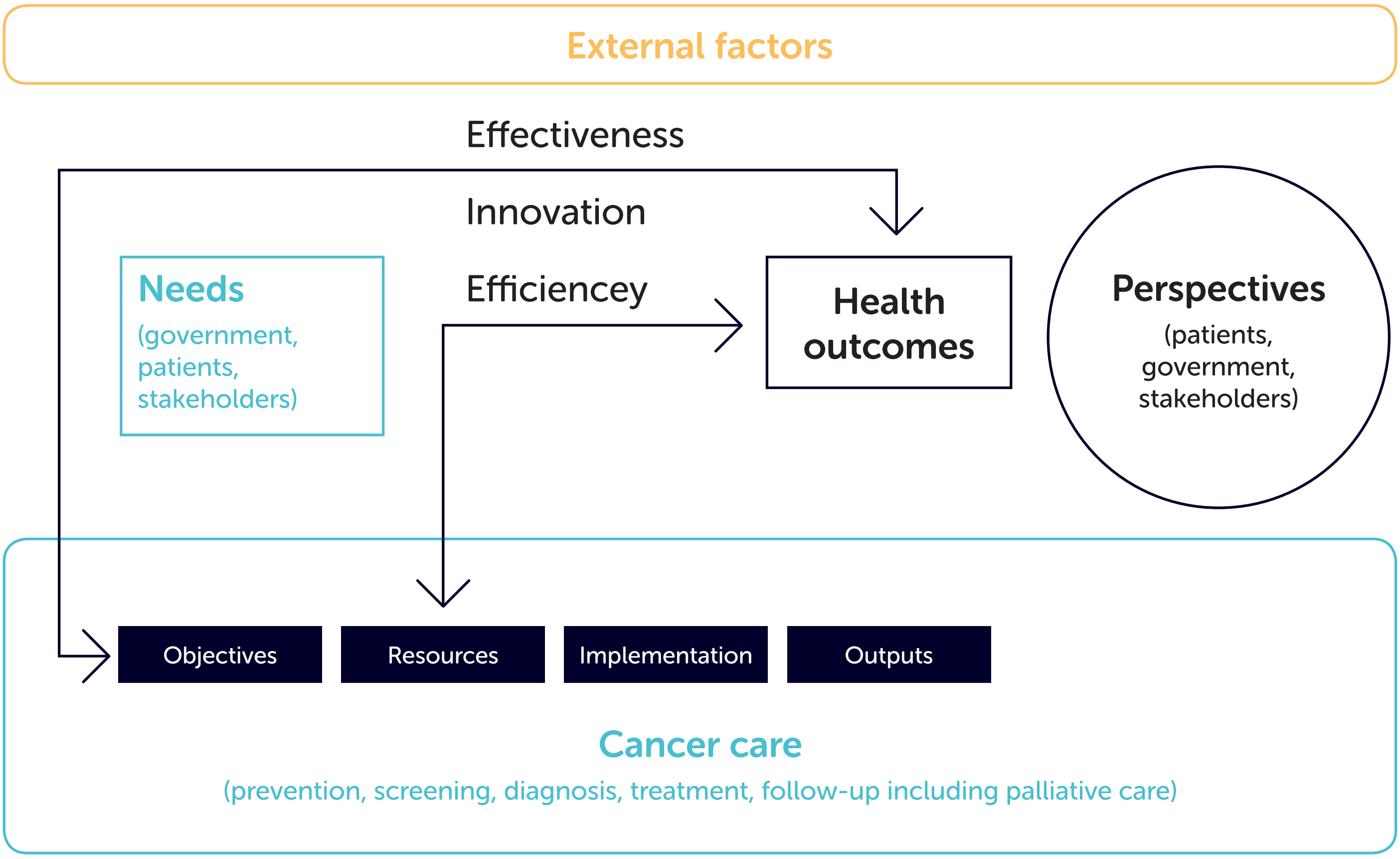

Figure 1 Factors influencing health outcomes in cancer care. Scheme of the elements of the cancer care system in relation to effectiveness, efficiency and innovation.

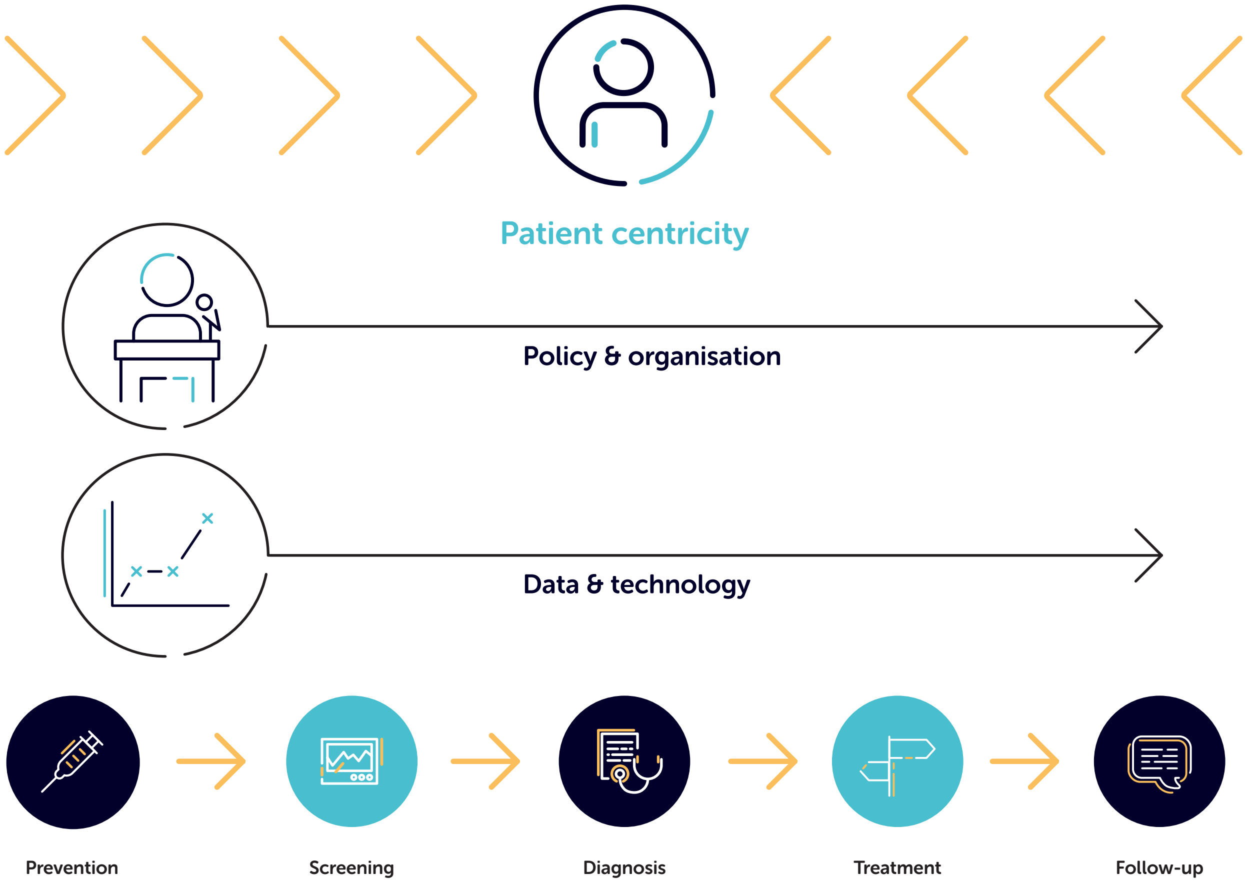

Figure 2 Focus points of All.Can Belgium. General recommendations include the centricity of patients, organisation of policy structures and the usage of data and technology in cancer care. More specific recommendations focus on the patient journey.

patient safety and to better health outcomes.[6] All of these aspects can contribute to a better quality of life for the patients and more sustainable cancer care.

The concept of innovation is here used in a broad sense. It is about changing and improving the way things are done in cancer care, finding better ways to include the patient perspective and listen to patient needs, improving the collaboration between first and second line care professionals, stimulating the use of the latest digital technologies for data collection and data analysis, enhancing research and development, making sure that innovative diagnostics and treatments are available to all patients that need them, and much more.

Figure 1 illustrates the relation between the different elements of the cancer care system and effectiveness, efficiency and innovation.

Key issues and ideas for Belgium

The discussion with the members of All.Can Belgium and other key stakeholders, and the exploration of good practices and literature, has led to a list of key issues, ideas and recommendations. We focus on increasing efficiency, reducing waste and inefficiency, and ultimately protecting the financial sustainability of high-quality cancer care taking into account the priorities of Belgian citizens (patient centricity).

Some recommendations are general and relate to patient centricity, data & technology, and policy & organisation (Figure 2). We present more specific recommendations along the patient journey starting with prevention of cancer, the screening of the population (at risk), followed by the diagnosis phase, before entering the treatment stage and ending with the follow-up phase including the end of life care.

On the following pages we will describe and clarify these focus points in more detail.

GOOD PRACTICE

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The Choosing Wisely Campaign

This initiative of the ABIM Foundation seeks to advance a national dialogue on avoiding unnecessary medical tests, treatments and procedures.

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http://www.choosingwisely.org/

> Across all aspects of cancer care we must ensure that we are focusing on what matters most to patients

Patient centricity

Although patient centricity is a leading paradigm in national cancer policy, it is not yet integrated in all health care levels. Studies have shown that patient well-being during treatment has a positive effect on patients' quality of life and clinical outcomes.[7,8] Thus, cancer care should be patient-centred. Across the cancer care continuum, we should ensure that we are focusing on what matters most to patients. This can be achieved in two key ways: by emphasizing the importance of the patient's quality of life and by considering patient preferences.

Patient centricity also means that we include patients and their representatives in all aspects of the cancer care system from cancer research, policy development, planning and delivery to evaluation. Delivery considers all steps in the patient journey including prevention, screening & diagnosis, cure, care, follow-up and end of life care. Patient representatives, patient organisations, patient education initiatives (e.g. Eupati[9]) and civil society initiatives (e.g. KBS[10]) are key partners in this field.

Patient navigation can be improved by better informing patients and their relatives. Information available for patients should reveal what information they need, where to find it as a central starting point, and who can help them with this. Examples include the patient navigator pilot by the Anticancer Fund, navigators in the Netherlands and Canada, and the Choosing Wisely Campaign in the US. Mining techniques can be used to find the latest data and keep information in online tools up-to-date with minimal human effort. In addition, online information and personal guidance should be combined.

Proximity of care is needed by patients, but on the other hand, centralisation of cancer services in special centres could bring many advantages. An interesting idea is to organise cancer care around the patient, and not the patient around the care. This can be reflected in the design and architecture of new hospitals and cancer care centres.

More specific suggestions include:

- Guarantee patient-centred communication and decision-taking so that patients feel well informed and supported – and this should include the individual network of family and care givers. Aim for an empowering approach towards patients that avoids a paternalistic approach so that patients can actively participate and have a say in their treatment.

- Ensure a sufficient health literacy level to deal with this information through health literacy initiatives regarding cancer and cancer care. Create the right attitude somewhere between denial and obsession. Provide a continuum of information and education through the entire life of the patient.

- Reduce the gap between the hospital, first-line care givers and home so that patients feel more reassured and connected. The technologies are available, but they should become more integrated in the health care system for different patient groups (adoption of innovation). Specific examples are: create the possibility to talk, Skype or chat with a cancer nurse or onco coach. Use applications that, for example, enable daily registration of weight or other parameters or provide patients with guidance on medication.

- Enable sufficient support during sickness leave and inform about sickness benefits, rights and obligations. Ensure that patients receive good information about the consequences of illness and about available support (including financial support by social services), home care, private insurance benefits and general health insurance benefits. Help with administration and application if necessary.

- Develop a common understanding about quality of life and what it means for patients, especially during their treatment and afterwards

- Improve the efficiency of the collection and the transparent reporting of patient-relevant outcomes and experiences **(PROM's and PREM's)** data. Increase knowledge on what PROM's and PREM's are, and how they should be used.

Policy and organisation

In recent years, there is a trend in cancer care away from disease-focused management towards a patient-centred approach. The implementation of this shift requires optimal coordination among health practitioners, policymakers and patients. The absence of clarity in the health care system leads to poor understanding and communication and hampers the organisation of cancer care.

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European Partnership for Action Against Cancer (EPAAC)

Addresses multidisciplinary care from a policy perspective in order to define the core elements that all tumour-based multi-disciplinary teams (MDTs) should include.

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https://www.ncbi.nlm.nih.gov/pubmed/24321260)

More specific suggestions include:

- The national cancer plan 2008[11] received much credit for creating a comprehensive and actionable plan for cancer care in Belgium. It was created in a collaborative way by means of stakeholder consultation and took into account the recommendations formulated in the white paper prepared by Belgian oncology experts.[12] Considering the positive and long-term impact of the national cancer plan as well as the challenges for cancer care ahead of us – efficiency, innovation and sustainability – we believe there is a need to stimulate a new momentum. As a minimum we suggest to create a national **cancer care vision** (Road-map) on what effective, efficient, innovative and sustainable cancer care would look like, what the guiding principles are and the steps to be taken to reach this vision.

  - This vision should be developed in dialogue with care givers, patient advocacy groups and other stakeholders. It should take into account the results and lessons learned from the first national cancer plan, trends and forecasts, and a performance analysis of the Belgian

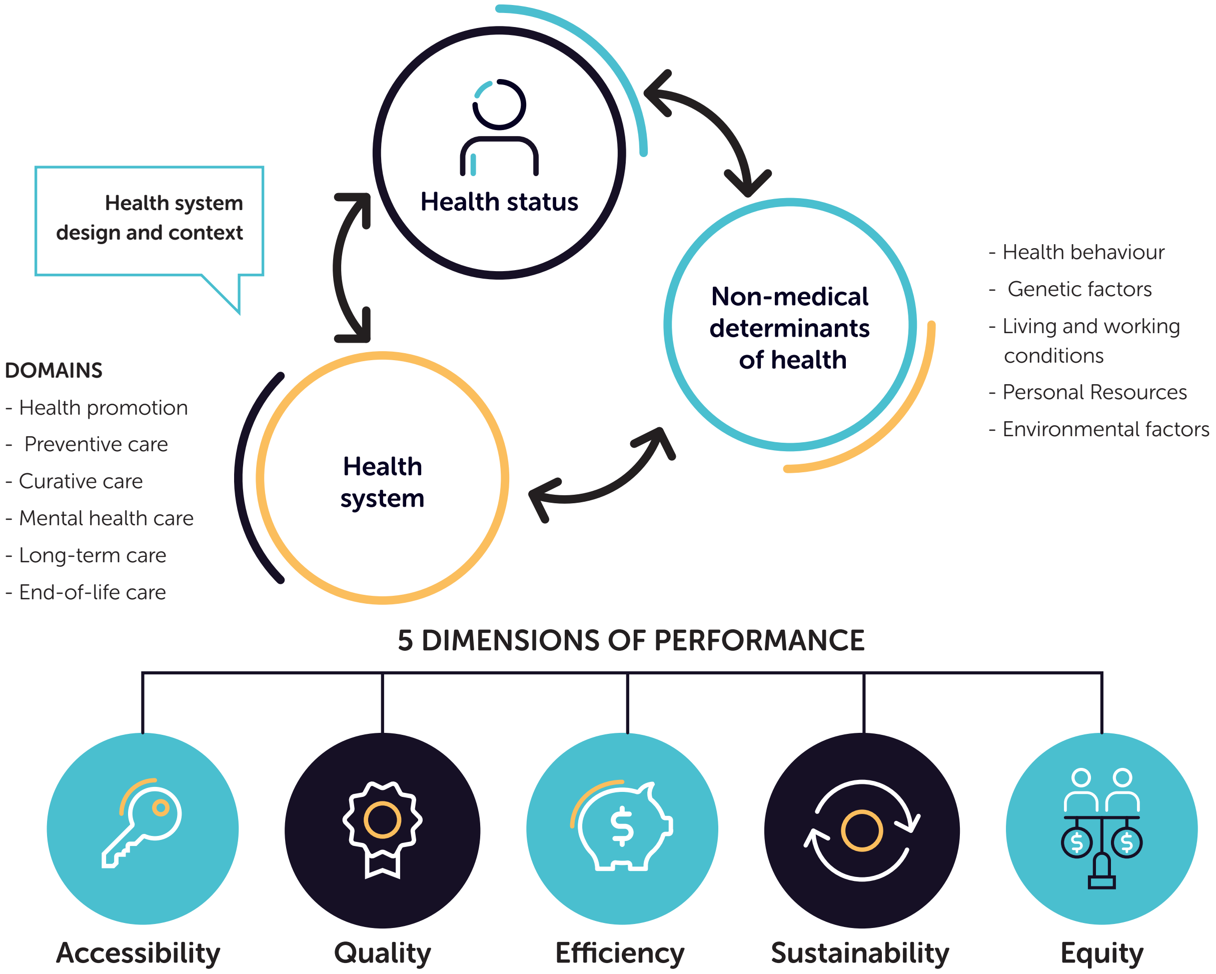

Figure 3 Conceptual framework to evaluate the performance of the Belgian health care system. Adapted from KCE report 259C.

cancer care system (see below). It should include ambitious targets, such as KPI's on prevention, treatment and care goals, MTD (Multi-Disciplinary Team) functioning and a clear distribution of responsibilities.

- Ensure regular **monitoring and evaluation** of cancer care policies by installing and maintaining a steering committee or a national cancer commission. Examples of such an approach include the NHS England strategy 2015-2020 for achieving world-class cancer outcomes with annual progress reports, and the annual plans by Cancer centre (Kankercentrum) for implementing the actions of the National Cancer Plan.[13]

- **Organisational mapping:** Provide information on who does what in the Belgian cancer care system in a clear way for a large audience. Make it relevant for patients and the other cancer care stakeholders. Reflect on the different models and how existing structures can be improved. Simplify where possible.

- **Coordinate policy actions** with regional governments and establish an even stronger regional and national coordination of Belgian cancer care. Overcome barriers (potentially) created by division of competences across different policy levels.

- Analyse the **performance of the Belgian cancer care system** in an international and forward-looking perspective, e.g. by using the concept developed by KCE for performance measurement of the Belgian health care system illustrated in figure 3.[14] Include the functioning and performance of the organisational structure of cancer care. Also highlight what goes well and where Belgium outperforms, e.g. in the area of clinical trials.

- Make room for **innovation in policymaking.** Favour evidence-based and needs-based policymaking supported by scientific research, policy research and stakeholder consultation. The patient perspective and needs should be included.

  - Incorporate lessons learned from policy pilot projects in health care, e.g. regarding eHealth, integrated care, hospital at home, projects in the regions or in hospital (networks). Several of them are relevant to cancer care.

  - Introduce innovative funding and allocation of budgets for cancer care. Compare efficiency and effectiveness of different approaches. Budgeting across different silos (policy areas, budget posts) is needed where appropriate as gains in one area can help alleviate higher costs in another area. This can apply to different areas such as financing of care in hospitals and at home, better diagnosis to ensure a higher likelihood of positive results of treatments, reimbursement of medical costs and medication. Examples include: move towards an integrated approval and pricing system based on dialogue between government, medical industry and society throughout the lifecycle of a medicine (not just during the market access phase)[15]; pay for performance financing models; and a system of annuities.

- Find new and better ways to organise the **(institutional) dialogue** between stakeholders where needed.

- Learn from international cancer initiatives, WHO, OECD, etc. and initiatives in other countries. Ensure the active participation of Belgian stakeholders in international initiatives.

- Discuss the **involvement of the government** concerning the public interest. Should it ensure timely uptake of improvements that bring savings and advantages to patients, as seen for Herceptin? How to provide better data provision taking into account privacy issues (e.g. what data should be made accessible for public interest)? What is the government's role as gatekeeper of correct information for all, including patients, relatives, employers and care professionals?

Finally, we need **highly skilled and competent health care professionals** (in a broad sense) in order to be ready for technological and digital innovations, and to maintain the highest standard in cancer care.

- Where necessary, reinforce participation in European reference networks or create national reference networks. Focus on knowledge sharing. We may need more specialised cancer centres dedicated to care, research and training. Examples include: Institut Jules Bordet and French cancer centres[16].

- Check how initial education or continued education/ training for health care professionals (e.g. new skills, knowledge, professions) can be stimulated. For instance, through closer collaboration with technological companies for traineeships, revising curricula or creating new programmes responding to new professions. The latter could include medical information officers, data managers, onco coaches, cancer nurses, care coordinators and innovation managers.

- Optimise caregivers' daily practices to reduce waiting times. Clarify the role of health nurses. Allow specialised nurses to help oncologists in their tasks. Improve specialisation, also for cancer care at home (e.g. home nurses and paramedics).

> Belgian policymakers should develop a new cross-functional cancer roadmap with a vision on sustainable and innovative cancer care

Data and technology

Today, the **amount and diversity of new technologies** seems to be exploding. Technology can help to improve efficiency in cancer care, but many questions remain on the selection of the right technology, the costs of it and the adoption and mainstreaming of technologies by health care professionals (tools for diagnosis, simulation, preparation of surgery, etc.[17]), patients (personal health apps, communication apps, health data access) and public authorities (registration, exchange and use of data).

Negative results in preclinical studies mainly remain unpublished and preclinical data is often irreproducible, leading to unnecessary repetition and cost. However, the reliability of preclinical cancer studies needs to be improved to ensure a smoother translation to clinical trials.[18] In addition, evidence-based policymaking requires an adequate **cancer data system** to process all the information.[19]

More and more data are available, but they are sometimes fragmented across different sources, not easily accessible or unexploited for policy and research purposes such as clinical records or clinical trial data. Silo thinking is a source of waste as data are not optimally shared. Therefore, further enhancing the Belgian cancer data system will be necessary. However, it should be integrated and aligned with the overall health care data system. The cancer data system should have data of its own and data sourced from elsewhere in the health data system. The Belgian Cancer Registry, internationally recognised for its work, can play a central role in the further development as reference centre for cancer data as shown in a pilot on registration of innovative radiotherapy.[20] The 'ultimate' cancer data set will combine data from different sources.

In addition to a national cancer road map, we also suggest elaborating a **Digital Cancer Agenda** that identifies the needs, possibilities, budget implications and priority actions in relation to digital technologies. We refer to technologies used for the prevention, diagnosis, provision of care, communication with patients, registration and analysis of data, detection of patterns and trends, forecasting, etc. This agenda can be connected to existing plans such as the eHealth plan and could aim to set up or continue a range of pilot projects in this field.

More specific suggestions include:

- Make an overview of the available data: **mapping** of cancer data, from for instance Kankerregister, health surveys, quality indicators, financial data and costs of cancer care. Also determine the data needed for a performant cancer data system and plan how to close the possible data gaps. Pay attention to the data needs for rare cancer types, given the small number of patients and the lack of clinical data. Other important aspects are the possibility to map regional or local variations, the availability of time series, the comparability with international data and the time the data becomes outdated and requires updates.

- Hospitals, sick funds and other organisations possess a lot of useful data. Make this relevant data more accessible and disclosed for public purposes.

- An example of good **incentives for better data registration** and sharing: the budget for the Multidisciplinary Oncology Consult (MOC) is related to data registration; thorax-oncologists register in a EU database in order to obtain accreditation. However, this information is not available for analysis by for example Kankerregister.

- Create a **data framework** describing what kind of data from hospitals, patient files, etc. should be made available for scientific and policy research. Ideally, cancer data should be accessible for oncologists, hospitals, policymakers and researchers for medical benchmarking, efficiency and quality optimisation. At the same time, clear conditions need to be fulfilled to respect ethical and data privacy regulations.

- Improve **longitudinal follow-up** of patients (real-world data). Explore the possibilities of patient panel data, which might include working with voluntary patient panels. Patient-driven initiatives exist, especially for rare diseases where patients form a community and create their own databases. Examples are databases developed by FAPA and Fondation 101 Génomes.[21] Better integrate personalised medicine in **clinical trials** so that real-world data is better reflected in clinical studies. In addition, we need to continue to invest in fundamental cancer research and secure Belgium's position as a major hub for clinical trial roll-out in cancer as this brings new opportunities for (seriously) ill patients. Subsequent to performance of clinical trials in Belgium, patients need to be informed about the possibility to participate in these clinical studies. Finally, the collected data from preclinical and clinical studies need to be used optimally.

- Encourage common IT standards for all health care applications.

- GDPR is important but can create a barrier to new research, access to vital data, sharing of data and timeliness of information provision. It also increases the costs. Thus, apply privacy legislation less strictly if possible, especially as patients are more willing to give data if they can improve their own treatment and/or those of others (cf. patient-driven registers).

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Systematic Anti-Cancer Therapy (SACT)

This project ensures mandatory reporting of cancer outcomes and prescribed treatments at every NHS hospital in England (National Health Service).

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https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5606292/

Clinical Mandates

A call to clinical researchers who are active as clinicians in a Belgian university hospital and who want to dedicate 50% of their time to fundamental, translational or clinical research at one of the seven Belgian universities. Stichting tegen Kanker commits to pay 50% of the salary of these postdoctoral/physician-specialists for a period of 5 to 10 years.

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https://www.kanker.be/mandates-basic-translational-oncology-research-year-2018

Prevention

About **a third of all cancers can be prevented,** according to World Health Organization estimates. According to KCE, there is a need to bring preventive care more in line with international health targets.[14]

Preventive care also includes **vaccinations**. Vaccination against Hepatitis-B prevents against liver cancer. Vaccination against HPV not only reduces the risk of cervical cancer but also reduces the incidence of several other types of cancers for women and men.

A number of important **lifestyle-related factors** strongly affect individuals' risk of cancer. Many of the actions and lifestyle changes needed to reduce the risk of cancer would also prevent other serious disease states, such as cardiovascular disease and lung disease. This would in turn lead to better treatment for the cancer when diagnosed.[22] Therefore it is recommended to intensify information campaigns and health promotion actions regarding smoking, alcohol, excess sun exposure, overweight and a sedentary lifestyle, and health and safety at work.

GOOD PRACTICE

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The association between health literacy and cancer-related attitudes, behaviours and knowledge

Adults with low health literacy were more likely to avoid physician visits, more fatalistic about cancer, had less familiarity and knowledge about common cancer screening tests, and were less likely to seek health information from sources other than physicians.

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https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3815140/

More specific suggestions include:

- Individuals are responsible for their lifestyle, however not all responsibility lies with the individual. There is a **shared responsibility** between citizens, industry (e.g. healthier food products) and policymakers (right incentives). This creates a need for motivation techniques to stimulate people in a positive way to adjust their behaviour: "Health in all policies" (nudging). Examples include: colour codes on food, behavioural economics, taxation on tobacco, credits for insurance for people following a healthy lifestyle (see policies in the USA).

- Actions at the level of community: "cancer-friendly town", via information sessions, lectures, events, and so on.

- Primary care: key role for general practitioners and caregivers. Example: engaging "public health nurses" (see England) who take preventive measures, provide information sharing and coach the patient in a healthy lifestyle.

- Genome sequencing can be used as primary prevention.

- The vaccination coverage rates should be optimised in all Belgian regions, and expanding vaccination against HPV to boys could be considered. This will require a solid registration system and a set of clear targets.

Screening

Adequate **screening** for cancer requires that we reach the actual population at risk in an efficient way that will contribute to detection of cancer at an early stage. Currently, participation in breast, colon and cervical population-based screening programmes is sub-optimal. Screening both suffers from under- and over-participation since it is difficult to find the right balance.[14]

There may be a great variation in participation among different profiles of patients. Other potential causes of inefficiency are low quality tests, tests delivering false positives, follow-up of screenings and the complex coordination between the regions and the federal level (as illustrated in figure 4, which represents the organogram and process flow of the population-based screening programme for breast cancer in Flanders).

More specific suggestions include:

- Screening for different types of cancer (e.g. lung cancer) should be considered when they are **evidence-based.**
- Targeted screening based on risk: the better the risk population is targeted, the more efficiently resources can be used.
- Stratified screening (group of individuals with higher risk, e.g. family) as a step in the process towards personalised screening of individuals.
- Different strategies of breast screening, based on the individual risk profile of each woman, could be considered (see European study MyPeBS[23]).
- Consider an improvement of the practical organisation of screening, for instance by optimising the design, content and language of the invitation letter, and/or the combination of online and offline communication.
- Analyse if screening can be made more cost-effective by for instance combining it with prevention and raising awareness.

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PRIAS (Prostate cancer research)

This project encourages doctors in 17 countries to keep low-risk prostate cancer patients under active surveillance and avoid starting unnecessary active treatment.

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http://www.erspc.org/prostate-cancer/active-surveillance/

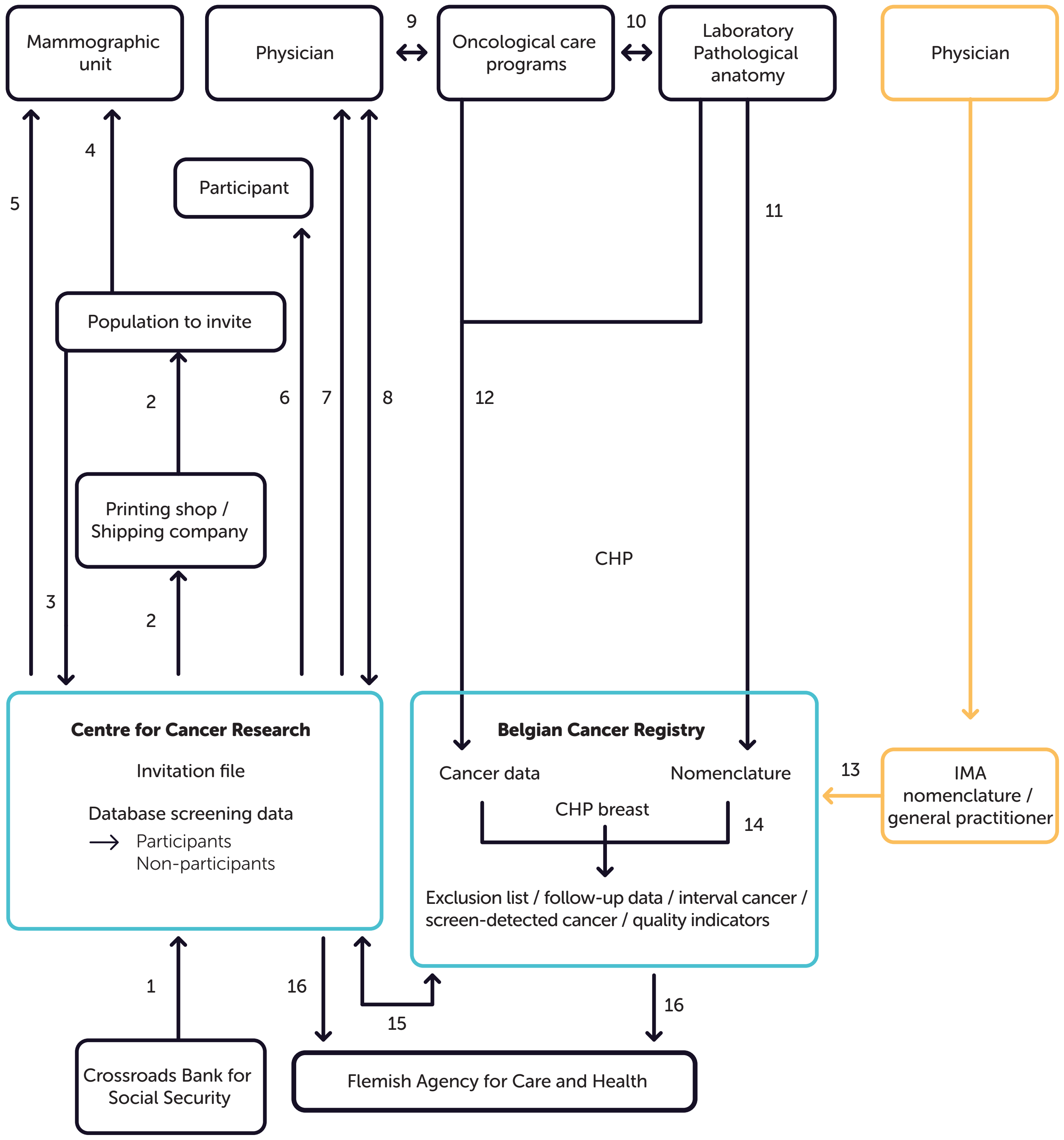

Figure 4 Organisation and evaluation of population-screening in breast cancer. Adapted from the Centre for Cancer Research (Centrum voor Kankeropsporing).

Diagnosis

In terms of **diagnosing cancer,** the key question is if cancer is diagnosed accurately and in time. Late diagnosis should be avoided since it significantly decreases the chance of survival.[24] From the perspective of the patients, the key questions are if patients receive all relevant information, and in what way and if they can really understand what is explained to them (type of cancer, stage of cancer, treatment options and consequences, risks and uncertainties). There is a great need for accessible, correct and validated information for patients, as was mentioned before.

> We believe in prevent rather than cure by the "Health in all policies" principle

GOOD PRACTICE

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The Danish cancer pathway for patients with serious non-specific symptoms and signs of cancer

A cross-sectional study of patient characteristics and cancer probability (NSSC-CPP).

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https://www.ncbi.nlm.nih.gov/pubmed/25990247

More specific suggestions include:

- Analyse if GPs have sufficient knowledge of symptoms for diagnosing cancer and if the referral occurs quickly and adequately to the right specialist and/or cancer centre.
- Examine if official guidelines, protocols and regulations are sufficiently implemented in the daily practice of health care suppliers.
- Further analyse how well-informed patients are about the understanding of their diagnosis and how they can be encouraged to come back after the first screening or diagnosis. As an example, up to 30% of people with an abnormal test result in colon cancer do not go to a second examination, which significantly impacts the later cost of treatment and survival rate.[25]
- Innovative technologies are available or in development. However, it is unclear if the current market access system is adequate to guarantee these technologies are used where they are needed (e.g. in regard to timely update of the reimbursement system).
- From diagnosis to treatment: We should aim for effective and efficient diagnosis, and avoid over-diagnosis as this can lead to over-treatment. "Watch and wait" can be a good approach (e.g. prostate cancer), as can be NGS testing in an early phase.

Treatment

Side-effects of cancer treatment can have a significant impact on patient quality of life and outcome of the treatment itself.[26] In addition, wrong treatments lead to unnecessary costs for society. As a consequence, in regard to the treatment of cancer patients, the following questions are central. Do patients receive the best possible care from the appropriate specialists and care givers during all stages of cancer at the right time and with the least possible adverse effects, and in the right place? Is care adapted to each patient's needs and does it consider medical health outcomes and non-medical aspects including quality of life aspects? Are patient preferences and priorities taken into account? As was mentioned before, do they receive accessible, correct, complete and validated information regarding their treatment?

Do regulatory evaluation and approval frameworks ensure timely access to innovation? Are decisions based on comprehensive assessments of benefits and costs? Do we have the right financial incentives for all stakeholders in cancer care?

More specific suggestions include:

- **Selectivity** in type of treatment is a delicate but promising approach to avoid waste in cancer treatment: most cancer medication only works for a strictly defined population, making 'general treatment' inefficient. Focus on stratified and precision medicine in combination with a holistic view on the treatment of patients (personalised medicine). An example includes the Next Gen Sequencing pilot study by RIZIV and Kankercentrum (Sciensano).[27]

- Efficiency gains can be found in faster implementation of less costly treatment methods.

- The **place of treatment** is another point of discussion for two reasons:

    - Not every hospital should perform every treatment; some treatments should be centralised. Consider the recognition of reference centres for the treatment of every type of cancer, based on the model of the breast clinics. Currently 119 hospitals are allowed to treat rare and complex cancers, resulting in sub-optimal treatments.

    - In the future, cancer care may take place more often outside the traditional hospital setting. Consider different possibilities with their advantages, disadvantages and challenges. Different options are to be found in integrated care models, hospital at home initiatives and care hotels.

- Consider more centralised investments where possible, e.g. central location for preparation of medication.

- It is important to secure a **reasonable growth in cancer care spending.** In Belgium, cancer represents 17.5% of the total disease burden.[28] The relative share of total health care expenditures spent on all cancers combined was estimated at 4% (2009).[29] The Flemish Cancer League (VLK) estimates that if the total cost of treatment continues to rise as it currently does, the total cost for the government will go up from 2.5 to 5 billion euros. This is 20% of the total budget of the health insurance.[30]

    - Historically, cancer spending was not in relation to the burden of the disease. Budget allocation in relation to the burden of the disease should be considered.

    - Securing a broad and fast access for the Belgian cancer patient to new innovative treatments while keeping cancer treatment financially sustainable and accessible for all patients. In order to grant the necessary access to the newest cancer innovations and to safeguard the sustainability of the health care budget, we will have to take into consideration new financing models as there are pay-for-performance, multi-indication pricing.

    - Identify unmet medical needs and see how they can be addressed. Here, international collaborations are important.[31]

> We recommend multistakeholder dialogue as a constructive and effective way of mobilising the cancer care community

GOOD PRACTICE

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PROCHE (Programme d'Optimisation du circuit Chimiothérapie)

An innovative oncology monitoring programme designed to reduce patient waiting time and chemotherapy wastage, ultimately improving patient care.

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https://www.ncbi.nlm.nih.gov/pubmed/23021062

Guidelines on the management of rectal cancer

KCE report 260CS responded to the following questions: What medical imaging technique should be used for optimal staging? Can local resection or transanal endoscopic microsurgical resection be performed instead of radical resection without compromising the outcome in rectal cancer patients? This guideline is intended to be used by all care providers involved in the management of patients with rectal cancer, including general practitioners, oncologists, gastroenterologists, surgeons, radiologists, pathologists and nurses. It should also be of interest to patients and their families, hospital managers and policymakers.

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https://kce.fgov.be/sites/default/files/atoms/files/KCE_260Cs_Managementrectumcancer_0.pdf

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http://procare.kankerregister.be

- Increasing the efficiency of implementing therapies and care protocols and making sure that the optimal treatments are used for each patient. Benchmarking of costs and outcomes across cancer centres can lead to better results (see collaboration for oncology data in Europe (CODE).[31]

- Adverse effects are underestimated or taboo and should be anticipated and addressed in a professional and adequate way.

- Find the right balance between cancer therapy with possible adverse side-effects and quality of life. Regularly, cancer therapy can or should be limited in function of quality of life.[32]

- The treatment of cancer has become teamwork which creates new challenges.[33,34]

- Further strengthen the multidisciplinary approach in cancer care in the multidisciplinary teams and multidisciplinary onco-consult (MOC) including oncologists, cancer nurses, onco-psychologists, onco-coaches, social workers, data managers, nutritionists and physical therapists. Continue or even raise funding. Moreover, make more effort to include general practitioners in the MOC.

- Is it possible to give the first-line health professionals such as general practitioners, home nurses and household assistance a more central role in cancer care, starting by improving communication and information exchange between the hospital team and the patients and his/her carers at home? Special training programmes can support this.

Follow-up

After the treatment phase, patients arrive in a phase of medical follow-up. In addition to the actual procedure of follow-ups, this phase in their life can be very difficult considering the many insecurities patients face including the possible recurrence of the cancer. Thus it is important that patients receive appropriate support following their active treatment to resume active lives.

More specific suggestions include:

- Efficiency in the **medical follow-up** of cancer patients. Include best practice in protocols/clinical pathways informing, for example, what scans and tests to use in which circumstances, what are useful or not, and useful combinations. In order to reduce costs, it is important to consider what kind of medical follow-up is needed and by whom it should be performed (first line or second line).
    - There will be greater need of **post-cancer support** because there will be more cancer survivors across different age groups. Rehabilitation, revalidation, reintegration at work, physical activity, and social and psychological psychosocial support should be key in a patient-centred approach.
    - Resources for rehabilitation should be dimensioned so that all patients may be offered relevant efforts in accordance with the existing healthcare programmes.
    - Improve the psychosocial support for patients and their family and friends, for example through securing access to contact nurses/patient navigators, psychologists and social workers.
    - Enable more research to examine which rehabilitation efforts are the most relevant for different patient groups, and what are the barriers and success factors to resume active life and return to work. An example of an initiative for patients focusing on resuming work is Vie & Cancer[35].
    - Living as a former cancer patient should not cause additional financial burdens, e.g. when requesting a loan. In 2017, France introduced a "droit à l'oubli" to make loans accessible for cancer patients.[35] In September 2018 it was announced that this right to be forgotten will also be introduced in Belgium.[37] In addition there is a procedure to make the debt insurance required for a mortgage more accessible for (former) cancer patients.[38]

GOOD PRACTICE

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Prink project

Tailor-made support during reintegration into work after cancer (Iridium Kankernetwerk).

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http://www.iridiumkankernetwerk.be/Nieuws/page.aspx/1011?xf_catId=13&xf_itemId=224

Moovcare™

Medical software device used to detect cancer relapse or complications during the follow-up of lung cancer patients at high risk of relapse.

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http://www.sivan-innovation.com/moovcare

German Prospective Study

Effectiveness of a 10-week physical exercise intervention to significantly improve psychosocial well-being, individual body image, and physical fitness among breast cancer patients.

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https://www.ncbi.nlm.nih.gov/pubmed/21577030

Conclusions

Impressive **progress** has been made in the field of cancer care leading both to better treatment of cancer patients and to higher survival rates. At the same time, more people are diagnosed with cancer each year. Together, this leads to an increasing demand for **better cancer care** beyond cancer treatment.

Patients have an active role to play in the development and delivery of cancer care. In addition, **innovations** in oncology are becoming rapidly available with more to come such as predictive diagnosing, the use of biomarkers, precision and personalized medication, gene and cell therapy (advanced therapeutic medicine), high tech surgery and radiotherapy, big data and real-world data, virtual reality or augmented reality supported tools, patient at home care, and others.

At the same time there is uncertainty how the health care system can keep up with this evolution. Questions on the financial **sustainability,** accessibility and patient centricity of the health care system are commonly voiced in the cancer care policy debate.

One of the ways forward is to create more efficiency in the cancer care system. All.Can Belgium aims for the better use and allocation of available resources in cancer care. **Together with all stakeholders** we should identify and **reduce waste,** seek how to achieve more with the time and money available, and address unmet needs. We believe innovation is a powerful instrument in creating greater efficiency and improving patient outcomes.

In this document, All.Can Belgium has presented its vision, ideas and recommendations for such an approach. It marks the beginning of the All.Can Belgium work programme.

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