BELGIAN CANCER BAROMETER 2020

Methodology for the working groups

This project is conducted at the initiative and under the funding of the Belgian Cancer Foundation, in close collaboration with the Belgian Cancer Center, the Belgian Cancer Registry and the College of Oncology

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1 INTRODUCTION

The Belgian Cancer Barometer 2020 (BCB2020) is a project commissioned and funded by the Belgian Foundation Against Cancer. The Belgian Cancer Centre of Sciensano is the project coordinator and works in close collaboration with the Belgian Cancer Registry and the College of Oncology. Although not a member of the Steering Committee, the Belgian Healthcare Knowledge Centre (KCE) is also involved in supporting the working groups with existing evidence collected by the KCE on economic evaluation.

The BCB 2020 aims to provide a **political and epidemiological state-of-play** of cancer control in Belgium. The remaining challenges for patients, professionals and policy-makers will be identified and recommendations on how to overcome these challenges will be made.

The BCB2020 will encompass five domains, also purpose of the five BCB2020 working groups:

- Health Promotion and Primary Prevention
- Screening and Early Detection
- Diagnosis and Treatment
- Survivorship and Rehabilitation
- Palliative care

Four transversal topics will structure each domain:

- Epidemiological and political state-of-play
- Resources and costs
- Research and innovation
- Access/ equity/ quality

The inclusion of **patient perception** is key in identifying remaining challenges in cancer control in Belgium within the BCB2020. In providing an epidemiological and political state-of-play, an evidence-based approach (scientific justification) will be used and international comparisons will be made (European level).

In addition to patients, other relevant stakeholders will be surveyed/ questioned on their perspectives concerning the previously stated domains and on their views on (remaining) challenges and possible recommendations.

During three preliminary meetings and five preparatory meetings with members of the Steering Committee, the framework and objectives of the project have been discussed and agreed on. Following a close look at the scientifc literature and Belgian regulatory frameworks, the Steering Committee decided to focus on three aspects: an epidemiological and political state of play for each domain; the capture of the perspective of patients, relatives and the general public and, the formulation of recommendations to improve cancer control in Belgium (including the identification of needs for future research).

Within a bit less than one year, experts (also including patients and informal caregivers?)/ experienced professionals in relevant fields of study/work will be invited to participate in working groups organized by domains and by topics within these domains.
As for the final result of the project, a comprehensive report will be written mainly targetting policy-makers but also the general public as the reading audience.

2 KEY QUESTIONS TO BE ANSWERED IN THE FIVE WORKING GROUPS

2.1 Epidemiological and political state of play

Each working group will start with a list of indicators that could be used to conduct an epidemiological and/ or political state of play of the domain. The first objective would be to select those that are the most relevant for the Belgian context; the second objective is to identify those for which data can be easily obtained. For the others, it will be recommended to organize efforts in the future for measuring them.

A second important aspect concerns the existing (legal/ regulatory) frameworks. The working group will be presented with the identified frameworks and participants will be asked to:

- possibly complete the list of frameworks
- discuss their evaluation or need of evaluation (what, when and by whom)
- discuss the gaps in the regulatory frameworks, i.e. how to improve/ expand their content

2.2 Address the issues

From July 2020 until September 2020 the BCB2020 steering committee has worked on the identification of the main issues to be addressed for each domain by the working groups. This selection has been made on the basis of a careful literature review, the screening of the Belgian legislation and based on the available “grey” material[1].

If the working groups identify any additional crucial issues which were not yet mentionned or identified, these can still be included.

The dicussion will be guided by specific questions that are presented herebelow in the section 3.2.

After each working session, the moderator will draft detailed minutes of the session.

2.3 Formulate recommendations

Based on the state of play and the discussions, the working groups will formulate recommendations aiming to:

- fill the gaps in the regulatory framework(s)
- ensure a relevant and comprehensive epidemiological state of play
- list the needs for further investigations (and which type)
- improve the quality of care and/ or the quality of life of patients and relatives.

3 CONTENT OF THE FIVE WORKING GROUPS

3.1 Practicalities

The working group sessions will start in the week of the 20th of October and should present their final output by January the 31st. A minimum of three working sessions for each group has to be organized. The final output of each working group will be a report including the minutes of each sessions and presenting a conclusions and a series of recommendations. To ensure the coherence and quality of the recommendations, the working groups have to provide, for each recommendations the following information:

- a clear statement (max 2 sentences)
- the (regulatory) framework(s) to which the recommendation relates to

[1] Websites of institutions, reports, etc.

- the rationale/ justification: which problem(s) does the recommendation address?
- the added value/ anticipated effects/ (if possible the number of people affected)
- consider the resources that will be required

3.2 Description of the working groups

3.2.1 HEALTH PROMOTION AND PRIMARY PREVENTION

A lot of efforts have been made to identify the **risk factors at the individual level**. In order to implement evidence-based strategies, the ECL and the IARC developed the European Code Against Cancer (ECAC)[2]. The twelve recommendations of this guide will be used as a basis to (1) assess the awareness of the population about the main cancer-related risk factors and (2) choose those for which actions need to be taken.

WG1.1 Health Literacy and Knowledge

Epidemiological state-of-play

- What is measured in Belgium and what should be measured in Belgium
  - On risk factors presented by the ECAC
  - On perceptions regarding the risk factors
- How often should measurements take place?
- Are there inequalities measured in Belgium?
  - If so, what determinants of inequalities can be identified?

Knowledge on risk factors and their relation to cancer

- How can public awareness on risk factors related to cancer be increased?
- Where/how could interventions to increase health literacy and knowledge on risk factors for cancer be implemented?
  - In primary care settings? (GPs?)
  - In schools targetting AYAs and children? (Teachers, CLB/PSE, etc. ?)
  - By regional organizations for health promotion and/or primary prevention? (VIGL, AVIQ, LOGOs, ONE/K&G, etc. ?)
  - In the work environment?

[2] https://cancer-code-europe.iarc.fr/index.php/en/

WG1.2 Federal Initiatives & Frameworks

State-of-play

- What policy initiatives or frameworks exist in regard to health promotion and primary prevention at the federal level of government?
    - *Federale Voedings- en Gezondheidsplan (incl. convenant evenwichtige voeding)*
    - *Nutri-score*
    - *Voedselconsumptiepeiling (2014-2015, next survey: 2024)*
    - *The Belgian National Strategy for Well-being at work 2016-2020.*

Current federal policy instruments include: *setting product standards, labeling, health warnings, taxation and pricing policy, advertising and supply regulations, accreditation and funding of organizations.*

- How are existing initiatives monitored and evaluated?
    - Level of achievement and implementation
    - Frequency of monitoring and evaluation
    - Is there a cyclical process of quality improvement of initiatives driven by monitoring and evaluation?

- Health In All Policies/Economy of Well-Being; what about Belgium? .
    - How could the Health in All Policies/Economy of well-being approaches be implemented in national/regional policies?
        - Has this already been implemented in an efficient and effective way?
            - If not, what needs to be done to achieve this? What would be the obstacles and how could they be overcome?

WG1.3 Regional prerogatives, iniatives and cooperation

State-of-play of the protocol agreement (2016)

- Has the protocol agreement yielded the intended results?
    - Did initiatives on different levels of government strenghten each other's policies?
    - Was goal-setting used? And was goal setting coordinated across different levels of government?
    - Were indicators widely developed and implemented? Was the use of indicators coordinated across different levels of government?
- How is the follow-up organized? Are measures described in the protocol agreement adequately monitored/evaluated/adjusted?

State-of-play of regional initiatives (incorporated in the protocol agreement)

- What policy initiatives or frameworks exist in regard to health promotion and primary prevention at the regional levels of government?

- Does the protocol agreement include all aspects of primary prevention and health promotion mentioned in the ECAC recommendations?
- How are existing initiatives monitored and evaluated?
    - Level of achievement and implementation
    - Frequency of monitoring and evaluation
    - Is there a cyclical process of quality improvement of initiatives driven by monitoring and evaluation?

3.2.2 CANCER SCREENING & EARLY DETECTION

WG2.1 Working group: Perception and participation

State-of-play on cancer screening Belgium

- Do **participation rates** comply with international recommendations?
- Are participation rates adequately assessed in Belgium?
- Do participation rate assessments in Belgium accurately differentiate between opportunistic screening and participation in organized screening programs?
- Can **inequalities in participation** be identified in Belgium?
    - demographic determinants, regional inequalities?

Perception of screening among the population and the target groups

- Have **perceptions of screening** among the population and target groups been measured? How could such a measurement be carried out in the three regions?
    - Can inequalities in perceptions be identified?; if so, what determinants for inequalities can be identified? (socio-demographic, regional inequalities?)
- What **evidence-based interventions** could strenghten participation rates and decrease rates of opportunistic screening?
    - Communication strategies ?
    - What initiatives, excluding communication strategies, can increase participation rates and decrease opportunistic screening?

Perception and role of health professionals

- Have perceptions of screening among health professionals been measured? If not, how could such a measurement be carried out in the three regions?
    - GPs, gynecologists, gastroenterologists, radiologists
- What evidence-based interventions aimed at health professionals could decrease rates of opportunistic screening?

WG2.2 ORGANIZATION OF SCREENING PROGRAMS

Monitoring, evaluation and quality improvement of screening programs

- Do Belgian organizational structures adhere to European guidelines? (e.g. *European Guide on Quality Improvement in Comprehensive Cancer Control*)
- Is there annual reporting of activities and results of screening programs for screening programs to stakeholders and the general public in each region?
- What aspects of cancer screening programs are being monitored and evaluated and by which organizations
- Is there a cyclical process involving monitoring, evaluation and quality improvement that is efficient and effective in improving the quality of screening programs?
- What role do HTAs play in quality improvement of screening programs (e.g. cost-effectiveness studies, validity of new tests, redefinition of target groups, etc.)?
    - Is there a need to improve the contribution of HTAs to screening programs and decrease delays between HTA findings and changes in screening policies?; if so, how could this be done and what would be the obstacles?
    - Is there a need for more frequent HTAs? Is there adequate funding?

Impact of COVID-19

- What lessons can be learnt from the COVID-19 crisis?
    - How resilient is/has been our health care system?
    - What needs to be put in place in order to prevent the reoccurence of having to put on hold screening programs in future health crises (or other detrimental consequences of COVID on screening programs)?

WG2.3 Innovation, future screening programs and research

Information systems

- Can an expansion of current systems improve the quality of cancer screening programs?
- Possibility of linking HPV vaccination records to cervical cancer screening programs (for research purposes)
- Linkage of socio-economic determinants to screening program participation and/or results to help map out socio-economic inequalities (and inform decision making)

Research, innovation and future screening programs

- Is research and innovation adequately encouraged by responsible governments? If not, how could this be achieved?
  More specifically, the following subjects can be addressed:
    - High risk stratification in breast cancer screening (MyPeBS-pilot study)
    - Lung cancer screening

- Prostate cancer screening
- Genetic screening and counseling
- Melanoma screening (EUROMELANOMA)

HPV testing

- What barriers can be identified that delayed the adaptation of the Flemish cervical cancer screening program and the introduction of the Brussels and Wallonian cervical cancer screening programs?
  - How can those barriers be overcome?
- How do we encourage policy-makers to more actively pursue the implementation of HPV testing in cervical cancer screening programs in Belgium?

3.2.3 DIAGNOSTIC AND TREATMENT

WG3.1 Communication and Coordination

Reference centers and Cancer Networks

- Have existing cancer networks been evaluated?
- How could the expansion of networks contribute to quality improvement in cancer care?
  - What obstacles can be identified that complicate the expansion of cancer networks?
  - How can those obstacles be overcome?
- Reference centers
  - What obstacles can be identified in steps toward the expansion of reference centers? Based on steps taken in the last years in, for example, pancreas cancer surgery.
  - What benefits does the existence of reference centers offer in Belgium?
  - Should diagnostics and treatments for rare/neglected cancers increasingly take place in reference centers?
    - Which rare/neglected cancers are already treated exclusively in reference centers?
    - What would be the obstacles for expanding this list of rare/neglected cancers and how could they be overcome?

Home care

- How is home care organized in Belgium?
- Who is responsible for the follow-up (and quality) at home? Are there clear descriptions of roles and responsibilities?

- What obstacles can be identified that impede the expansion of home care opportunities for patients? ; How can those osbatcles be overcome?

Multidisciplinarity

- Are there clear frameworks describing the roles and responsibilities of multidisciplinary team members in (basic) oncological care programmes?
  - *The Royal Decree (2003) doesn't provide a clear desciption of the roles and responsibilities of coordinators in cancer care. This had led to inefficiency in the use of funds allocated for the role of coordinator. Furthermore, a large heterogeneity of the way in which the function of coordinator is carried out exists in Belgium.*

Shared-decision making / person-centredness / comprehensibility of information

- How can person-centeredness be encouraged by policy-makers?
- How can shared-decision making be encouraged by policy-makers?

WG3.2 Monitoring and Evaluation and Quality Improvement

Internal and external quality assessments (as foreseen by the Royal Decree 2003)

- What is already being assessed by hospitals and by the governments?
  - What could/should be further assessed?
    Example:
    - Overtreatment and overdiagnosis (how could this be assessed?)
    - Acces and equity in cancer care specifically, rather than acces and equity in the Belgian health care system in general.
- How is this organized?
- Is there a need for a system that:
  - provides for broader data linkage possibilities, and;
  - includes an independent structure that assesses data and performs external evaluations, and;
  - that enables policy-makers to tie measures/consequences to evaluations (e.g. pay-for-performance)?

Guidelines and standardized care pathways

- Guidelines
  - Which organizations are involved in the development of guidelines? (Are there adequate resources to ensure frequent updates of guidelines?)
  - How is the montoring of the use of the guidelines organized?
- Standardized Care Pathways

- What are the possible benefits to the implementation of standardized care pathways in a Belgian context?
- What are possible obstacles in the implementation of standardized care pathways in Belgium?

Guidelines and standardized care pathways are strongly interrelated. The construction of standardized care pathways depends on the guidelines. Adaptations of guidelines therefore require adaptations of standardized care pathways. One of the critical aspects in addressing these topics constitues the willingsness of policy-makers to construct an "all-inclusive" plan with adequate funding and structural capacity.

PREMs and PROMs

- Would the implementation of standardized PREMs and PROMs provide benefits for cancer care (policy-making) in Belgium?
- What obstacles can be identified in the implementation of PREMs and PROMs?
  - How could those obstacles be overcome?
  - Do we have a good organizational structure that would allow for the implementation of standardized PREMs and PROMs assessments?
    - Would PREMs and PROMs assessments need to be registered and if so, where would it need to be registered?

WG 3.3 Research & Innovation

Research & Innovation

- What research is being conducted in Belgium (proportion of fundamental vs. clinical vs. translational research)?
  - Is it possible to construct an overview of all cancer-related research that is being carried out in Belgium? ; What would be the obstacles in doing so? How could they be overcome?
- Which policy-measures would allow for the possibility of organizing large national clinical trials in which all cancer centers in Belgium participate? Such endeavours would bolster the already high quality of research in Belgium. As of yet, this seems not feasible in Belgium even though neighbouring countries are able to organize such trials (e.g. the Netherlands).

Personalized/stratified medicine

Although personalized/stratified medicine encompasses much more than Next Generation Sequencing (NGS), the BCB2020 can focus on the *NGS: Roadbook Personalized Medicine (Sciensano, 2015).*

- State-of-play on the actions described in the roadbook
- What future steps are important for the further inclusion of NGS in cancer care?
- What obstacles have been identified in the proceedings surrounding the implementation of NGS?
  - How can those obstacles be overcome?

Reimbursement of innovative therapies

How do the below mentioned topics relate to/affect the reimbursement of innovative therapies; which obstacles can be identified that inhibit their contribution to facilitating reimbursements of innovative therapies:

- Health Technology Assessments (HTAs)
- Horizon Scanning Systems (HSS)
- BeNeLuxA collaboration

3.2.4 BCB2020_WG4 SURVIVORSHIP AND REHABILITATION

The BCB2020 defines survivors as : "all patients diagnosed with cancer, who are still alive and have completed primary therapy".

WG4.1 Medical follow-up

Surveillance and management of side effects

- Surveillance for cancer spread, recurrence, or second cancers
- Management of side effects (fertility, urinary dysfunction, cardiopathy, neuropathy, etc.); including the occurrence and management of comorbidities

Tertiary prevention (Prevention of recurrent and new cancers, and of other late effects)

Nutrition: do survivors have access to nutrionary support?; is this accessible for all survivors (and reimbursed)?

- Do guidelines exist?
- How can this be further integrated into survivorship care and rehabilitation?

Physical activity

- Do survivors receive support and guidance to physical activity?; Is this accessible for all survivors?
- Do guidelines exist?
- How can this be further interated into survivorship care and rehabilitation?

Stress management: does the current care as usual allow support to coping?, i.e. to help patients and relatives to (psychologically and socially) face the disease

Assements and evaluation

- What measurement instruments exist that assess the needs of survivors?
- How often do these assessments take place?
- Is medical follow-up adequately based on assessed needs of survivors?
- Are PROMs and PREMs organized for cancer survivors? To which extent could they be (systematically) registererd?

WG4.2 Psychosocial Care

Psychological care available for all survivors and relatives? (has it been evaluated?)

- Do (Belgian) **guidelines** exist for (onco)-psychological care for survivors?
- Is the provided psychological care based on (frequently) assessed needs or quality of life (QoL)? ; which needs/QoL **assessment** instruments exist/ are frequently used in Belgium?
- How is psychological care organized for survivors and relatives of children and AYAs? Has it been evaluated?

Social care

- Do guidelines exist that address social care for survivors?
    - How are survivors reintegrated into the **work environment**? What is needed to further facilitate the return to work? ; How can self-employed workers be supported in returning to work?
- Is acces to **insurance and mortgage** ensured for all survivors?
    - What shortcomings or obstacles can be identified in the availability of acces to insurance and mortgage for survivors? ; What is needed to address these shortcomings formally organized or obstacles?
- Is adequate support offered to survivors with **remaining disabilities** in regard to social-reintegration?
    - What shortcomings or obstacles can be identified in the social-reintegration support offered to survivors with remaining disabilities?
    - What is needed to address these shortcomings or obstacles?

WG4.3 Survivorship care delivery

Organization of survivorship care

How is **homecare** for survivors organized in Belgium?

- Is home care accessible for all survivors? (what are the obstacles?; how can we overcome these obstacles?)
- Does available home care encompass a comprehensive and integrated approach to survivorship care and rehabilitation?

Infrastructure and insurance coverage

- What does the insurance coverage of survivorship care and rehabilitation look like? i.e. does the existing insurance cover a comprehensive and integrated approach to survivorship care and rehabilitation (including **extramural** settings); is there a need for financing of service ‘packages’?
- What role can sickness funds play in the insurance of survivorship care?

Monitoring and evaluation

- How is survivorship care monitored and evaluated in Belgium? What is registered?; Is there a cyclical process of monitoring, evaluation and quality improvement?

- If not, how could this be organized in Belgium? ; Which instruments are available for policy makers to encourage quality improvement in survivorship care (based on monitoring and evaluation of services)?

(Personalized) after care plan

- Does surivorship in Belgium make use of a (personalized) after care plan?
  - If not, how could this be encouraged/organized? What would be the obstacles and how could they be overcome?
- Is survivorship care in Belgium based on **shared care models**?
  - If not, how could this be encouraged/organized? ; What would be the obstacles and how could they be overcome?
- **Self management** (includes relatives)/ empowerment
  - Is self-management or empowerement (also for relatives) encouraged in Belgium? Is it considered and used as a best practice?
- Coordination and communication with **primary care**
  - Is there a clear framework that describes the role of GPs as coordinators of survivorship care?

Research

- Is research adequately performed/funded in Belgium in regard to the below mentioned topics? Content and quality of the follow-up:
  - Cost-effectiveness studies
  - Mechanisms of late effects
  - Long term survivors of childhood cnacers
  - Determinants of inequalities
  - Management of comorbiditie

Education and training of health professionals

- Are the health professionals adequately educated to provide with an all-inclusive survivorship care to cancer survivors?

3.2.5 PALLIATIVE CARE

WG5.1 Comprehensive palliative care

Comprehensive approach to palliative care

- Does the approach to palliative care in Belgium address all needs of palliative patients? Does it include symptom, distress and functional status management (e.g. pain, dyspnea, fatigue, sleep disturbance, mood, nausea, constipation) as well as physiological care needs, psychological/emotional/spiritual care needs and social care needs.
  - If not, how could this be facilitated/encouraged?
  - What obstacles can be identified to do so and how can they be overcome?
- Is the provided palliative care based on (frequent) needs assessments?
  - What instruments are used to assess the needs?; is there wide-spread use of specific needs assessment instruments?

        - If not, how could systematic use of one instrument be beneficial for palliative care in Belgium, and how could this be facilitated in Belgium?
- How are comobordities/multiple chronic conditions managed in palliative care services in Belgium?
    - Do guidelines exist to address the complexity of care in palliative cancer patients that are diagnosed with comorbidities/multiple chronic conditions?
- Is euthanasia accessible for all palliative care patients that meet the legal requirements?

Early referrals and advanced care planning (ACP)

- Is ACP systematically used in palliative care in Belgium?
    - If not, would its implementation be beneficial for the quality of palliative care in Belgium?; how can this be facilitated/encouraged? ; what are the obstacles and how could they be overcome?
- At which phase of the cancer care pathway are patients generally referred to palliative care in Belgium?
    - What obstacles can be identified that delay the referral to palliative care? How could they be overcome?
    - Did the PICT instrument yield the intended results?

Patient, Health professional and general public perceptions and knowledge on palliative care

- Have the perceptions of patients, health professionals and the general public been previously assessed (specifically in regard to early referrals and ACP)?
    - Could increased awareness on the benefits of early referrals in these groups be beneficial to palliative care in Belgium?
    - What could be identified as obstacles in increasing awareness in these groups? How could those obstacles be addressed?
    - Do intercultural beliefs and norms affect perceptions on palliative care in Belgium?
        - If so, what role can intercultural mediation play in increasing awareness of palliative care in different cultural groups?
        - How could we improve the wide-spread use of intercultural mediation and the competences needed to do so in the relevant professions?
    - Acces to euthanasia

WG5.2 EVALUATION, MONITORING AND QUALITY IMPROVEMENT

Evaluation and monitoring

- How is the quality of palliative care services monitored in Belgium? Which structures/organizations are responsible? Is there a cyclical process of monitoring, evaluation and quality improvement?
    - At which level(s) does this occur? (Hospitals, networks, federations, regional governments, federal government, etc.)
        - If inadequate, how can policy-makers strenghten monitoring, evaluation and quality improvements? ; What policy-instruments could be used to do so?

- What is registered in Belgium in regard to palliative care services?
    - What indicators are used to assess the quality of palliative care services in Brussels, Wallonia and Flanders? (e.g. QPAC indicators in Flanders)
        - Do these indicators include PREMs and PROMs?
    - Is there systematic use of one set of indicators at a regional and/or national level?
        - If not, how could this be facilitated/encouraged, and what would be the benefits for the quality of palliative care in Belgium?

- How is euthanasia in palliative care patients registered and how is the quality of euthanasia monitored?
  - Which quality indicators are used?

Guidelines and research

- Do the pallialine/palliaguide guidelines encompass all aspects of palliative care in Belgium?
  - If not, how can the incorporation of more aspects be encouraged/facilitated?
- Are the pallialine/palliaguide guidelines updated with enough regularity?
  - If not, how can this be achieved? What would be the obstacles and how could they be overcome?
- Is research conducted and funded adequetaly to guide quality improvement in palliative care? (e.g. cost-effectiveness studies; inequalities in palliative care; management of comorbidities/multiple chronic conditions)

WG5.3 SETTINGS, FUNDING AND CAPACITY FOR PALLIATIVE CARE

Funding and capacity

- Does government funding meet the requirements of the palliative care sector?
  - If not, how could more detailed frameworks enhance the efficiency of allocated funds and what could such frameworks look like?
- Is there a need for a broad revision of the financing of the palliative care sector and what would this look like?
  - If necessary, what would be the obstacles in doing so? And how could these obstacles be overcome?
- In regard to health professionals involved in the palliative care sector, do the legal staff requirements reflect the human resources needs?

Settings for palliative care

- Which institutions/structural aspects of palliative care are lacking in Belgium?
  - What is required to meet the demands for such institutions or aspects?
- A frequently cited “institutional void” in Belgium concerns middle care.
  - What has been done to explore the possible incorporation of medium/middle care in the palliative care sector in Belgium? ; how could this be integrated in the palliative care landscape in Belgium? ; what would be the obstacles and how could they be overcome?