POLICY BRIEF

Is Belgium ready for Cancer Survivorship ?

Alhtough one can recognize the many services, initiatives and professional's readiness in Belgium for cancer survivorship, the lack of organization, coordination and monitoring compromise its quality and sustainability.

This policy brief identifies gaps and recommendations for actionable implementation of survivorship care (programs) in Belgium.

The first Policy brief focused on mapping the actions of the EBCP related to survivorship care, checking the alignment with Belgian initiatives and identifying remaining gaps[1]. As most of these EU projects are in progress[2], this second brief will explore the readiness of Belgium to develop and implement survivorship care (programs). A strong emphasis is put on sustainable opportunities for moving towards quality and comprehensive survivorship care in Belgium, ensuring equity among patients. For the purpose of this brief, survivorship care is defined as the care needed by the patients on remission and relatives from the end of the active treatment onward.

In Belgium legal and clinical frameworks for such type of care is still lacking. After completion of treatment, the relative intensive support provided by the oncological care program (OCP) team suddenly evaporates.

A successful implementation of survivorship care would ensure maintaining and improving QoL of patients and families but also reducing social and health-related inequalities among cancer patients (a.o. differences in health outcomes, access to care and exposure to risk factors)[3] and support the sustainability of the healthcare and social security systems[4], especially if efficient stratification of patients is applied[5,6].

Methodology

The method used for discussing the current readiness of Belgium to implement survivorship care, has been to start from existing models for which consensus among international experts have been sought and reached. We then compare to the current practice in Belgium and look for opportunity to reach the objectives prescribed by these models. Three works and publications have been selected and are the basis of this brief:

1. the IOM Report 'Lost in translation'[7] and
2. the related Quality Cancer Survivorship Care Framework[8] and
3. the ESMO consensus paper[9].

KEYWORDS
Cancer survivorship
Quality of life
Patient-reported measures

GAPS & RECOMMENDATIONS

State of play: what does survivorship care implementation require?

Survivorship, including psychological care and socio-professional support

Based on the precursors publications, four essential pillars for survivorship care can be identified[9]:

1. the **prevention** of recurrent and new cancers, and of late effects;
2. the **surveillance** for cancer spread, recurrence, or second cancers, the assessment of medical and psychosocial late effects;
3. the **intervention** for consequences of cancer and its treatment, and
4. the **coordination** between specialists and primary care providers to ensure that all of the survivor's health needs are met.

In practice, and given the relatively good adherence to clinical practice guidelines, the first two pillars (prevention and surveillance) are generally well implemented within OCPs[10] although **wide variation** exist in how medical and psychosocial late effects are assessed and managed. Regarding the third and fourth pillar (intervention and coordination), current data don't allow the drawing of a clear state of play on interventions provided to survivors neither on the coordination with primary care at the national level. The IOM stresses that psychosocial services should be provided as a part of the oncological services, but referrals to specialists in psycho-oncology or other professionals may be necessary when the level of distress is high.

Importantly, given the lack of a framework for the provision of (long-term) survivorship care in Belgium, these interventions are currently at the discretion of the clinics, with important variations in practices observed.
Different models for the provision of survivorship care have been developed and several have shown effectiveness[11].

For example, the **shared-care model**[12] which could support functional communication and coordination between different healthcare actors, at different levels of care, but also with social security institutions. This would also particularly facilitate a successful implementation of psychosocial support and socio-professional (re)integration. However, further research is needed to establish the cost-effectiveness of such a model and adapt it to the specific Belgian healthcare and social security contexts[13].

Regarding **socio-professional (re)-integration**, it should be addressed from diagnosis onwards although remaining the responsibility of social security institutions. Early discussions about work can enable workplace adaptations and arrangements, combined with targeted physical, psychological, and vocational support[14].

To allow the development of legal and clinical frameworks for survivorship care, evidence are still needed. The table 1, based on the *Quality of Cancer Survivorship Care Framework,* presents the domains and indicators that could form a comprehensive framework for a regular monitoring and measurement of cancer survivorship care quality and QoL of cancer survivors, including health economy considerations. The table also identifies the currently available sources of data and opportunities for patient-reported measurement (PRM).

In its 2022 report on integrated care, the Federal Knowledge Centre for Health Care (KCE) highlighted that fragmented clinical, epidemiological, and financial databases hinder comprehensive monitoring and evaluation efforts based on existing data sources[15]. Furthermore, the impossibility to evaluate rehabilitation programs for breast cancer in Belgium is illustrated by these important limitations in terms of data availability[16].

A survey sent out on behalf of BSMO Supportive Care Working Group (2021) found that out of 30 institutions 50% have inpatient supportive care units[17]. But the extent to which these services are actually used by cancer patients and their efficiency, is unknown.

Even though there is a need to improve the recording of survivorship care an QoL data, a limitation due to the workload that it represents will be inevitable. Therefore, **involving patients in the reporting** process should be considered, presenting several advantages.

Patient-reported measurements

The table 1 suggests the dimensions for which the patient perspective should be gathered (PRM column), in order to inform the healthcare and social security systems about their performance.

Besides administrative and clinical data, patient-reported measurements (PRMs) are crucial to ensure a patient-centred assessment of the care. A 2020 publication of the main EU cancer societies stated that the PRMs are key instruments to ensure quality of care. "*a cornerstone of research should be to investigate the impact of intervention on endpoints that are patient oriented (…) There is a pressing need for the development and incorporation of patient reported outcomes/measures (PROs/PROMs), and research on quality of life and survivorship.*"

Efforts in that direction have been undertaken, among which the SPADIS project[a] of Sciensano and the PROOF project from VIKZ, KUL and BCR[b]. Although paving the way, these projects currently partially reflect and assess the needs that survivors are confronted with. These first attempts reveal that the implementation and integration of the PRMs in healthcare settings represent an important technical challenge.

Table 1. Domains of Cancer Survivorship and related indicators

Domain	Sub-domain	Indicators
Cancer and its treatment	Prevention and Surveillance for Recurrence and New Cancers	Assessment of risk predisposition including family history
		Referral and receipt of recommended genetics evaluation
		Recommendation for adjuvant and/or risk-reducing strategies
		Assessment of adherence with recommended adjuvant and/or risk-reducing strategies
		Clinical surveillance visits recommended and completed
		Laboratory surveillance testing recommended and completed per guidelines
		Imaging surveillance recommended and completed per guidelines
Context of healthcare delivery	Clinical structure	Type of health-care delivery environment (e.g., primary care office, oncology office, survivorship clinic, academic medical center/community-based hospital, urban/rural)
		Status of cancer survivorship providers' education and/or training
		Availability of needed specialty care (e.g., cardiology, nephrology, endocrinology)
		Availability of needed health-care professionals (e.g., psychology, nutrition, social work, physical therapy, sexual health)
		Access to care enabled (e.g., availability of appointments, financial counseling, navigators)
		Availability and functionality of health information systems (e.g., electronic medical records, tele-health)
		Opportunities for research participation offered
	Communication / Decision making	Information/education provided and understanding assessed while taking into account health literacy (e.g., survivorship care plan may serve as a tool)
		Assessment of self-management skills and support and/or advice provided
		Advance care planning discussion and/or documentation
		Discussion of sensitive topics (e.g., sexual activity, continence, end-of-life care)
		Cancer care team involves family members or friends in discussions
		Involvement in shared decision making (e.g., assessment of risk perception, values, decision support)
		Respectful communication with patient
		Care consistent with patients' goals of care
	Care coordination	Discussion with patient about care planning, documentation, and sharing with patient and care team (e.g., survivorship care plan as tool)
		Evidence of communication between oncology specialists and primary care providers
		Evidence of communication between other health-care professionals, oncology team, and primary care providers
		Providers aware of important information about patient's medical history and/or ongoing care
		Patient and cancer care team office talked about all prescription medications the patient was taking
	Patient / Caregiver experience	Satisfaction with provider and/or health care delivery setting
		Perceived timely access to care
		Perceived access to services
		Timely follow-up with patient/caregiver to give test results

Wat is the problem and/or at stake?

There is no formal framework for survivorship care in Belgium, impeding its proper organization and delivery, but also the quality assessment[19].Most cancer-related legal and clinical basis very briefly address or evade the issue. The R.D of 2003 for example foresees the presence (i.e. availability) of a multi-disciplinary team (MDT) for psychosocial care in OCPs, which in practice, is not sufficient to translate into a long-term follow-up care. One could look for underlying reasons: lower levels of scientific evidence for supportive and integrative care and the concerns of related costs for the society.

The financial impact of cancer is often taken lightly in publicly funded universal health system. In Belgium, one out of four women affected by breast cancer are often struggling with financial hardship[20]. Across Europe, Belgian patients are found to reported significantly high financial stress scores compared to other countries[21]. This has been observed in using savings and cutting down spending on luxury, leisure and basic goods as well as delaying or avoiding additional treatment related expenses. Such double penalty does not contribute to foster any patient's well-being.

Survivorship programs could tackle it in the big picture. Little information is known about the cost-effectiveness of these programs as their success is challenging to measure against outcome from a comparison group, and depends on its model of organization[22]. The scarce economic evaluations in the field have been focusing on assessing the cost-effectiveness of long term's surveillance of recurrences[23], while survivorship programs encompass a variety of interventions which should also be investigated in order to assess their impact in terms of healthcare and social security expenditures. **Investing in supportive interventions upfront would alleviate out-of-pocket costs, employment absenteeism, lost household productivity and informal caregiving time** which weight on our Belgian social security system.

What is Belgium doing currently to address this issue?

Most initiatives in Belgium are coming from the civil society or professional and scientific societies. In the last decade, inspired by the movement of respite homes and the Anglo-Saxon recovery model for patients with mental health disorders, more than thirty walk-in centres have emerged in the three regions of the country[24], where devoted civilians, professionals and integrative therapists, mostly on a voluntary basis, support patients and their family to cope with the side effects of cancer and its treatment[25].

The Belgian Society of Medical Oncology (BSMO) Task Force on Survivorship launched a study on Emotional Freedom Techniques (EFT) for self-reported Cancer-Related Cognitive Impairment (sr-CRCI) ; and in the absence of governmental support, several hospitals have independently started to establish survivorship and/or integrative medicine clinics to better respond to the long-term needs of their patients.

One should recognize the support from the Belgian government having charged the Cancer Centre of Sciensano, in 2023, of developing a supporting tool for professionals in order to improve the provision of supportive care. This mandate translated into the development of the eHandbook for Supportive Care . Although not accompanied by adequate resources, this showed the recognition of a need on the field.

However, the BeOncosup initiative, while supporting professionals in their referral, doesn't solve the resource problem. The efforts (time and human resources) needed to identify, measure the needs and then find the right support is still missing an adequate momentum in the care pathway/healthcare system.

Policy recommendations

The ambition of this policy brief was to assess the readiness of Belgium for the implementation of survivorship care. Comprehensive models have been used as a starting point for the reflection and for which opportunities or barriers have been identified.

- **Develop and Implement and operational framework, including communication, coordination and practice guidelines.**
  Dedicated resources for the long-term follow-up of cancer patients need to be foreseen in the framework of a **long-term care plan**. This plan has to be designed based on the screening of patient's individual needs and ensure efficient coordination of the care.

- **Develop and Implement a Monitoring & Evaluation Framework for long-term QoL and Participation, including the use of PRMs and health economics.**

Although these two large recommendations can be the purpose of a series of actions run in parallel, they need to be understood as parts of a cyclic process, allowing for evidence-based decisions for both healthcare professionals and policy decision-makers.

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