SUPPORTIVE CANCER CARE IN BELGIUM: UPDATES & COLLABORATIONS

Report

Date: 03.06.2025
Venue: Eurostation 1, Ernest Blérot, Room Storck, 1070 Anderlecht
Attendees: 65

Symposium summary:

The symposium was dedicated to the presentation of the latest developments in the BeONCOsup initiative and to explore collaborations. The first project of this initiative is the Belgian eHandbook for (Hemato-)Oncological Supportive Care which helps professionals in finding available supporting care services to which they can refer their patients.

Topics addressed

- Latest developments in the BeONCOsup initiative: eHandbook, SPADIS.
- Key initiatives and projects for improving supportive care
- Launching The Belgian eHandbook for (Hemato)-Oncological Supportive Care
- Insights from international experts in the field of supportive cancer care
- Stakeholder involvement : interactive workshops

The workshops on stakeholder involvement yielded some important points for future discussion:

- More actionable and less fragmented efforts for awareness-raising regarding supportive care in cancer
- Need for greater harmonization across projects and a stronger emphasis on patient experience in shaping tools and services for supportive care.
- Absence of reimbursement frameworks for supportive care and lack of formal recognition. Contrasts with other countries, where supportive care pathways are institutionalized and data-supported, were highlighted.
- Need for more centralised and coordinated information on the projects to engage stakeholders
- Need for incentives, clear roles, or feedback loops, otherwise stakeholder involvement risks becoming symbolic.

Content table

1. General introduction

Christian Léonard (General Director of Sciensano) reflected on the real 'why' for supportive care, stating that supportive care must be provided not only for strategic or utilitarian outcomes, but because it is our **moral duty**. We are called to **help, protect, and support vulnerable people**, such as cancer patients, out of compassion and respect for their **human dignity**. We should act not because the care is effective or efficient, but simply because it is the **right thing to do**. Of course, to **secure funding** and implement care, we may need to **demonstrate effectiveness or efficiency** but these are strategies, not the true reasons. Let us never confuse our **justification** with our **motivation**. The heart of the matter is **humanity**.

2. Supportive care for cancer patients: An overview of key initiatives and projects

2.1 The Beoncosup initiative

During her presentation, **Régine** introduced the **BeONCOsup initiative**, a framework that brings together multiple projects at both national and European level, all centered on supportive care and survivorship for cancer patients. The initiative plays a crucial role in aligning the efforts of the Supportive Care & Organisation Unit of Sciensano, ensuring coherence, strategic coordination, and optimal use of stakeholder engagement and available resources. A key driver behind the creation of BeONCOsup is the significant disparity in access to supportive care services among cancer patients.

The main objective of the initiative is to **facilitate the development and uptake of the different projects for the practice in Belgium.** Additionally, BeONCOsup aims to coordinate the gathering and exchange of knowledge and expertise, ultimately supporting improvement in the field of supportive care and survivorship. An overview of the different projects of the BeONCOsup initiative can be found in the slides attached to the email.

2.2 SPADIS

During his presentation, **Maxim** gave insights into the **SPADIS project**, which aims to better understand and measure how people with cancer and other chronic conditions are able to participate in society. This includes, for example, returning to work or broadly being socially active. In the SPADIS project, existing administrative data in Belgium are used to measure labour market transitions after diagnosis, and a patient-reported outcome and experience measurement tool is being developed to collect patients' own views and experiences, capturing relevant aspects of social participation, such as physical, mental, and environmental factors. The next steps are the expert validation and the dissemination of the tool. Currently, professionals are invited to review the instrument (see QR code below)

You can participate in the first phase of the expert validation by completing the survey which is active right now !

2.3 The Belgian Cancer Inventory

During her presentation**, Gabrielle** gave an update on the **Belgian Cancer Inventory**. The purpose of the Inventory is to provide a routine monitoring of Belgian policies in the context of the European Beating Cancer Plan (EBCP) and Mission on Cancer. The Inventory includes **5 thematic areas** :

- Prevention & Detection
- Diagnosis
- Treatment & care organisation
- Quality of life & Survivorship
- Children & AYA

Each thematic area contains 15-20 indicators which will be used to monitor input, implementation, output or outcomes of identified policy objectives. Zooming in on the **indicators for survivorship, monitoring faces significant gaps,** a substantial portion of available data is held at the oncological care program level and is not population-based, which hinders a comprehensive monitoring at the population level. Specifically for survivorship data, there are current shortcomings in monitoring the patient experience throughout the entire care continuum, especially after treatment. Data issues range from being unavailable to inaccessible. While plans exist for some data collection efforts, nothing concrete is in the pipeline for others. The most common data hosts are the Belgian Cancer Registry (BCR), RIZIV-INAMI and IMA-AIM. Additionally, regional hosts manage data for specific thematic areas. The involvement of various data hosts leads to higher costs and time delays, impacting the sustainability and timeliness of the entire data inventory process.

2.4 AYA & Pediatric care

During her presentation, **Hélène** introduced initiatives targeting the pediatric and AYA (Adolescent and Young Adult) populations. Significant efforts have been made in integrating supportive care for these groups, supported by funding from the previous Cancer Plan. Since 2017, the **Pediatric Late Effects Database**, developed in collaboration with the Belgian Cancer Registry (BCR), has contributed to better understanding and managing the long-term consequences of cancer treatment in young patients. Caroline Piette of the Cancer Center is currently **investigating local initiatives to**

improve transition from paediatric to adult wards and the opportunity for medical and psycho-social long-term follow-up consultations in these populations. The Cancer Centre of Sciensano is also **coordinating** the **development of clinical guidelines** aiming to integrate supportive care into standard practice. This approach seeks to ensure equal access to optimized care for all patients.

In her presentation, Hélène further talked about the role of the Cancer Centre for the AYA convention. The **Cancer Centre plays a central role in advancing care for adolescents and young adults (AYAs) with cancer**. Several initiatives are being carried out in collaboration with national (RIZIV-INAMI, University of Antwerp, Belgian Board of Oncology) and international partners (JANE 2 partners):

- Assessment of the implementation of the AYA Convention
- Coordination of the project group to implement the AYA convention
- Development of Clinical Guidelines
- Establishment of a Network of Expertise through JANE 2, aiming to develop dedicated programs tailored to this specific age group.

3. The Belgian eHandbook for (Hemato)-Oncological Supportive Care

3.1 Insights into the eHandbook

Sofie presented the project on The Belgian eHandbook for (Hemato)-Oncological Supportive Care (BeONCOsup), also known as the **BeONCOsup webtool**. An important rationale for this project is the **lack of an overview** of available supportive care services, which makes it challenging for professionals to guide patients effectively toward the support that is available and out there.

The eHandbook is a **practical webtool developed to help professionals** in finding available supportive care services. Its main goal is to facilitate referral to the existing support. The tool is structured around the needs of the patients (identified through literature and Thematic Working Groups) and is available in Dutch and French, with an English version potentially in development. Importantly, this tool is **not limited to oncologists**—it is equally valuable for **non-clinicians**, **first-line caregivers**, **general practitioners**, and anyone engaged in guiding patients through their cancer journey.

The tool offers an overview (mapping) of **available supportive care services**, along with an overview per need of evidence-based **interventions**, **tools**, **guidelines**, and **general information**. The eHandbook also includes accessible resources (e.g. flyers, brochures, podcasts etc.) that professionals can easily share with patients and families. These materials are printable, making them ideal for use during consultations or follow-up discussions. It should be stressed that the eHandbook **is not a decision supporting tool nor a clinical guideline**. The rationale for developing this tool specifically for professionals lies in the need to address a common concern among healthcare providers: the difficulty in locating and navigating available supportive care services. Also, the information mapped in the eHandbook is mostly adapted to professionals.

In what followed in the presentation, some project results were discussed, and insights into the eHandbook were provided. For now, the first version of the eHandbook contains information for the following needs :

- Cancer-related fatigue; Cancer-related cognitive impairment; Physical activity; Sexuality; Psychological needs; Return-to-work

The primary focus of the tool is on **long-term supportive care**—particularly addressing the needs that arise when patients have less frequent contact with their clinical team. During this phase, patients may still face physical, emotional, social, or practical challenges that require coordinated support. In a later stage the tool will also focus more on information regarding the acute needs.

In the last part of the presentation future plans and remaining challenges for developing the eHandbook were discussed. The challenges were identified while having discussion with stakeholders. There is a clear need for a **decision-supporting tool**. Additionally, support is needed for the **identification and management of symptom clusters**. In the future there should be linked a **screening or monitoring tool** to the eHandbook that assess patient needs and symptoms in real time. Another important step is the **integration of the eHandbook with digital platforms and interfaces** that professionals already use in their daily practice, to streamline its accessibility and relevance.

The link to the eHandbook can be found here :
https://beoncosup.sciensano.be/

When applying for the first time, your application will be reviewed by our team. You will receive a response within one to two days, after which you will be able to log in.

3.2 The eHandbook: professionals engagement, the example of Return-to-work

During **Joke De Schepper's** presentation, the focus was on the involvement of professionals and experts in the development of the Return to Work (RTW) chapter of the eHandbook. The main goal was to validate the content by including experts from the field, such as VDAB, RIZIV, and health insurance funds and to ensure the information is accessible and useful for professionals by testing the eHandbook with them. Professionals and experts were involved in two key phases: first, a needs-based working group in 2023, which helped shape the content; and later, in May 2024, (1) a simulation session with professionals to test the eHandbook and (2) an expert validation session to refine the info and materials. By working closely with the professionals (end-users), several challenges emerged: limited knowledge of RTW legislation, fragmented responsibilities across institutions, the absence of clear guidelines for professionals to support the RTW of their patients, and the difficulty of staying up to date with legislative changes. Expert support helped address these issues by identifying reliable resources, relevant institutions, key experts, and applicable legislation—enabling the team to provide accurate information and facilitate correct referrals.

3.3 The eHandbook: professionals engagement, the example of psychological support

Séverine presented, in the context of the eHandbook, the topic of professional involvement, using the need for psychological care as an example. The main objectives of involving professionals and experts are to validate the content of the eHandbook and to map professionals with experience or expertise in oncopsychology. The process to achieve these objectives is structured in three steps: mapping professionals and experts, engaging in content discussions, and conducting testing and validation of the eHandbook. However, some challenges remain, particularly in terms of engagement, lack of clarity, and limited resources.

4. Improving supportive care for cancer patients: Insights from an international expert

Florence discussed cognitive disorders linked to cancer and its treatments, highlighting that these issues—once called “chemobrain”—are now recognized as broader “cancerbrain” effects, not limited to chemotherapy. Important research began in France and spread across Europe, aiming to understand and support patients facing these cognitive challenges.

A key study from the “**Les Sentinelles**” breast cancer network showed 75% of 1,610 patients reported cognitive complaints, often tied to fatigue or psychosocial stress. While only 20–30% showed measurable impairments, many still struggled long-term, especially after chemo or hormone therapy. Notably, 72% wanted cognitive or psychological support, and access to physical activity.Research explored biological causes like inflammation and aging, leading to a unique model in Normandy combining animal studies and neuroimaging. This evolved into the national “**Cancer & Cognition**” platform and later expanded through international partnerships and the **ICCTF consortium**.

Florence also introduced the **IPAAC project**, which created expert-backed guidelines to help healthcare providers manage cognitive effects in cancer care. She concluded by emphasizing the need for continued research and collaboration to improve support and care quality.

5. Improving supportive care for cancer patients: The Colpach Centre Experience

Joachim introduced the Centre de Réhabilitation du Château de Colpach. The centre operated by the Luxembourg Red Cross, is a national **reference hospital specializing in post-oncological and physical rehabilitation.** The **services are structured according to Luxembourg’s hospital law**, which classifies rehabilitation into four categories: geriatric rehabilitation, functional rehabilitation.

The center offers both **inpatient and outpatient care**.The care is **organized around five pillars**: daily medical and nursing support, a modern technical platform for rehabilitation, psychological and social support, interdisciplinary therapeutic education, and access to complementary and wellness care.

Conventional therapies at Colpach include physiotherapy, occupational therapy, speech therapy, dietetics, and psychological support. Patients are monitored 24/7, and return-to-work planning is actively incorporated. **Specialized medical support** is available for a range of conditions. **Complementary therapies**—such as art therapy, dance therapy, sophrology, massage, EMDR, and hypnosis—are also integrated to promote mental well-being and enhance the rehabilitation process. Therapeutic education and support for behavioral change are key elements in helping patients regain autonomy in their daily lives.

The **rehabilitation process is clearly structured and includes several key phases**: pre-admission screening, interdisciplinary intake evaluations, weekly progress reviews, and a final discharge evaluation, which includes planning for post-hospital care and transition to community-based services. Throughout this journey, patients are encouraged to co-define their care goals and participate actively in decision-making. The approach is aligned with the WHO’s International Classification of Functioning (ICF) model.

In terms of **organization**, the center functions as part of a larger network, with 22 outpatient facilities and multiple coordinated services that support patients before, during, and after their stay.

Looking to the future, the center is actively expanding its services. Projects include the development of home-based rehabilitation through the HELP network, the integration of digital rehabilitation platforms like Ergokit, and the creation of specialized care pathways for conditions such as lymphoedema, neuropathic pain, and hospital-specific medication management.

6. Workshops

During the symposium, workshops were organised around **stakeholder involvement**. The objective of the workshops was to **encourage stakeholders to reflect on and share their experiences with projects and initiatives related to supportive care** for cancer patients, particularly those led or coordinated by Sciensano. The sessions aimed to understand participants' level of awareness and how well-informed they feel about these initiatives. Additionally, the discussions explored perceptions of the relevance, impact, and collaborative value of these projects in their professional settings. The insights gathered are instrumental in identifying gaps, improving communication strategies, and fostering stronger engagement with stakeholders across the healthcare landscape.

1. Awareness

Some participants reported limited or lack of awareness with Sciensano’s supportive care initiatives prior to the symposium. While some were aware of specific projects, others lacked a clear overview of the Cancer Centre activities, especially among professionals without coordinating role or duties. There was also a recurring sense of confusion around how Belgian, European, and Sciensano-led efforts intersect. One participant described this experience as *“trying to piece together puzzle parts between BE, EU, and Sciensano projects,”* while another noted, *“we’ve lost the overview—different colleagues follow different topics, and themes get repeated across meetings.”*

Internal communication within institutions, and between the Cancer Centre of Sciensano and external partners, was perceived as fragmented or inconsistent. Several noted the challenge of keeping track of overlapping projects, often leading to confusion about roles, responsibilities, and progress. Participants reported also on the lack of visibility on the role of the Cancer Centre: *“Even within our hospital, many don’t realize Sciensano works on cancer. Nurses were surprised—‘Oh, they do that too?’”*

To address this, participants recommended:

- The introduction of **concise newsletters** with links to key updates.
- Online platforms to **centralize information—**but only if paired with active communication strategies. As one attendee explained, *"People won't go looking on platforms without being prompted—newsletters should pull them in."*
- **Short webinars** to improve visibility and engagement.
- Sharing updates through **professional networks and scientific societies** to enhance reach.
- Clear **mapping of projects and contact persons,** to support navigation and involvement. Some also highlighted the value of an online platform for accessing information, though noted this should be complemented with more proactive communication to prompt engagement.

Overall, participants agreed that awareness-raising efforts need to be **less fragmented and more actionable**, with information tailored to both insiders and newcomers.

2. Relevance

The projects and tools presented were generally considered relevant and aligned with the needs of healthcare professionals. However, stakeholders expressed concern that many of these tools are more oriented toward professionals than patients, with limited visibility or accessibility for the latter. Given time constraints in oncology consultations, participants stressed the importance of developing patient-oriented communication tools or care coordinators (professionals) who can help bridge this gap.

There were diverging views on giving patients direct access to tools like the eHandbook. While some saw value in increasing transparency, others warned that the content may not be appropriate for self-navigation (whitout guidance) and could lead to unsupervised care decision-making. One participant cautioned: "*It's not about shopping for services—it's about guided access*."

There was strong support for greater use of PROMs and PREMs, but concerns were raised over the fragmented and unstandardized implementation. Stakeholders called for **harmonization across projects and a more prominent role for patient experience in shaping tools and services**.

Financial and **structural barriers to supportive care** were also discussed. The lack of reimbursement frameworks and **absence of formal recognition** were identified as major obstacles. Comparisons were drawn with other countries (e.g., France and the UK), where more supportive care pathways are institutionalized and data-supported. A suggestion was made to replicate past successes in palliative care by creating formal platforms and public mandates to legitimize and structure supportive care at the national level. Another participant underlined the need to adapt care trajectories to specific cancer types, stating: *"A prostate cancer patient has different challenges—like sexual dysfunction—that need tailored indicators. One-size-fits-all tools won't work."* Others stressed that while clinical input is vital, **patient experience and quality of life deserve equal weight** in developing guidance and tools.

3. Involvement

The degree of involvement in supportive care projects varied widely across participants. Some were long-time collaborators; others had only recently joined and were unsure how to engage meaningfully. The lack of clarity about roles and pathways to involvement emerged as a recurring theme. Participants recommended:

- Creating smaller, thematic working groups for more focused collaboration. *"One working group per topic—bring all relevant subgroups together. It would also boost internal* *knowledge."*

- Appointing institutional contact points to help identify and mobilize relevant actors.
- Expanding beyond the usual stakeholders to include regional hospitals and first-line providers, who often feel excluded from national-level initiatives.
- It was also noted that many professionals face time and resource limitations, and that participation needs to be better recognized and supported, possibly through structured funding mechanisms.

Several participants noted that without **incentives, clear roles, or feedback loops**, stakeholder engagement risks becoming symbolic. Funding and recognition mechanisms were seen as essential to move from consultation to co-creation.

4. Synergies & Impact

Though time constraints limited in-depth discussion of this theme during the workshop, several key points emerged from participant comments and written feedback. Stakeholders emphasized the need to:

- Align projects around sustainable goals and develop practical tools for everyday clinical use.
- Improve the usability and accessibility of results and materials, including dissemination methods.
- Support psychosocial care services, such as walk-in centers, with greater visibility and resource allocation.
- Sciensano was also encouraged to play a stronger coordinating role, helping to filter, consolidate, and prioritize efforts across the diverse field of supportive care. As one participant put it: "*We need filtration—someone to identify what's impactful so we can commit fully, not spread ourselves thin*." Sciensano was seen as well positioned to play that coordinating and streamlining role.
- Stakeholders saw value in clearer structures and standardized indicators, ideally differentiated by cancer type, to ensure that tools and services are truly aligned with patients' needs and clinical realities.
- Several participants pointed to the need for guidelines tailored by cancer type, especially where quality of life indicators differ substantially. Concerns were raised that current efforts risk becoming too general or "top-down," missing the nuances of individual patient experiences. One comment noted that political targets may overshadow genuine patient needs: *"Quality indicators become political benchmarks—not tools for better care."*

7. CONTACT INFORMATION & WEBPAGES

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Webpages :

- BeONCOsup : https://www.sciensano.be/en/projects/belgian-handbook-oncological-supportive-care
- SPADIS : https://www.sciensano.be/en/projects/measuring-social-participation-among-people-living-chronic-diseases
- Belgian Cancer Inventory : https://www.sciensano.be/en/projects/belgian-cancer-inventory
- JANE 2 (EU project) : https://jane-2.eu/
- EUnetCCC (eu project) : https://www.sciensano.be/en/projects/european-network-comprehensive-cancer-centre

eHandbook link
- https://beoncosup.sciensano.be/nl or https://beoncosup.sciensano.be/fr