

22 MARCH 2024

Supportive cancer care in Belgium :
State of play and future directions.

15:30 | Eurostation
20:00 | 1, Ernest Blérot
Room Storck

BeONCOsup
 sciensano

WELCOME AND INTRODUCTION



Marc Van den Bulcke
Head of service Cancer
Centre - Sciensano

WELCOME AND INTRODUCTION



Anouk Waeytens
Cabinet of Minister of Social
Affairs and Public Health

KEYNOTE SPEECH PROFESSIONAL

Supportive cancer care - Survivorship: where are we now?



Prof. Dr. Jean Klastersky
Cancer Supportive Care Task
Force

Slides cannot be shared

KEYNOTE SPEECH PROFESSIONAL

Supportive cancer care - Survivorship: where are we now?



Dr. Florence Van Ryckeghem
Cancer Survivorship Task Force



Supportive cancer care in Belgium

BeONCsup: **Survivorship**

22/03/2024 – sciensano

Florence Van Ryckeghem, medical oncologist AZ Glorieux-AZ Groeninge
BSMO Survivorship Task Force and Supportive Care Task Force

Definition

Future anticancer therapies can be part of it

Survivorship is not survivorship without **quality of life**

The focus on **health and wellbeing** and the **psychological, physical and socio-economical problems** that influence people after the end of cancer treatment. It is about people who are **free of sickness**, people who receive a **maintenance therapy**, people who receive a **treatment to diminish the risk of relapse** and people with residual disease and few symptoms who receive **chronic treatment**. Survivorship contains issues that are related to **follow-up**, management of **late side effects** of treatment, preventing and monitoring for relapse and **improving quality of life** and of **psychosocial and emotional health**. A **key aspect** is to **regain** as much as possible the important aspects **of life before cancer** and finding **new ways** to move forward in a satisfied way.

Unique for every individual

Caregivers, family and friends are also part of survivorship

Some facts

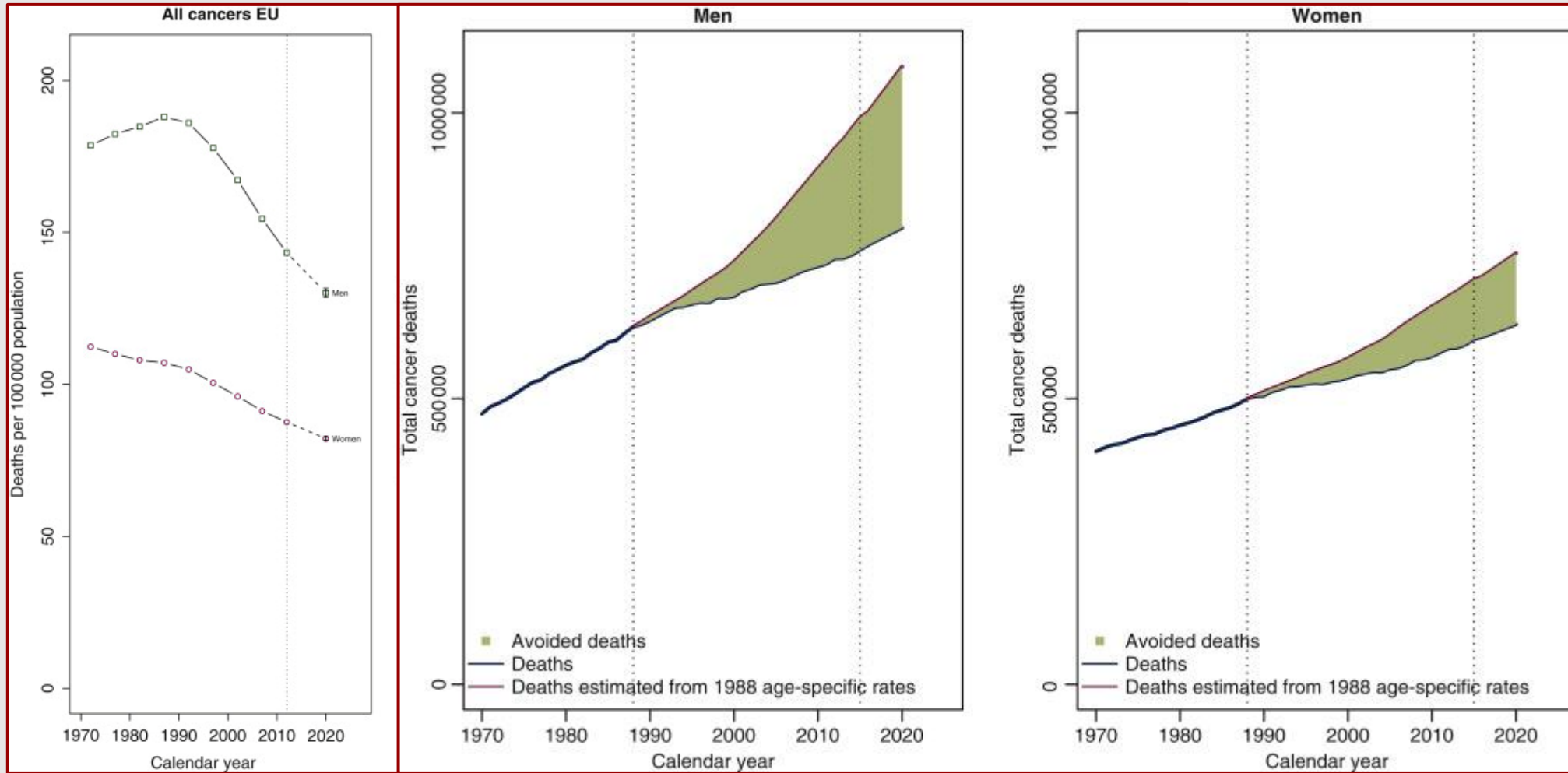
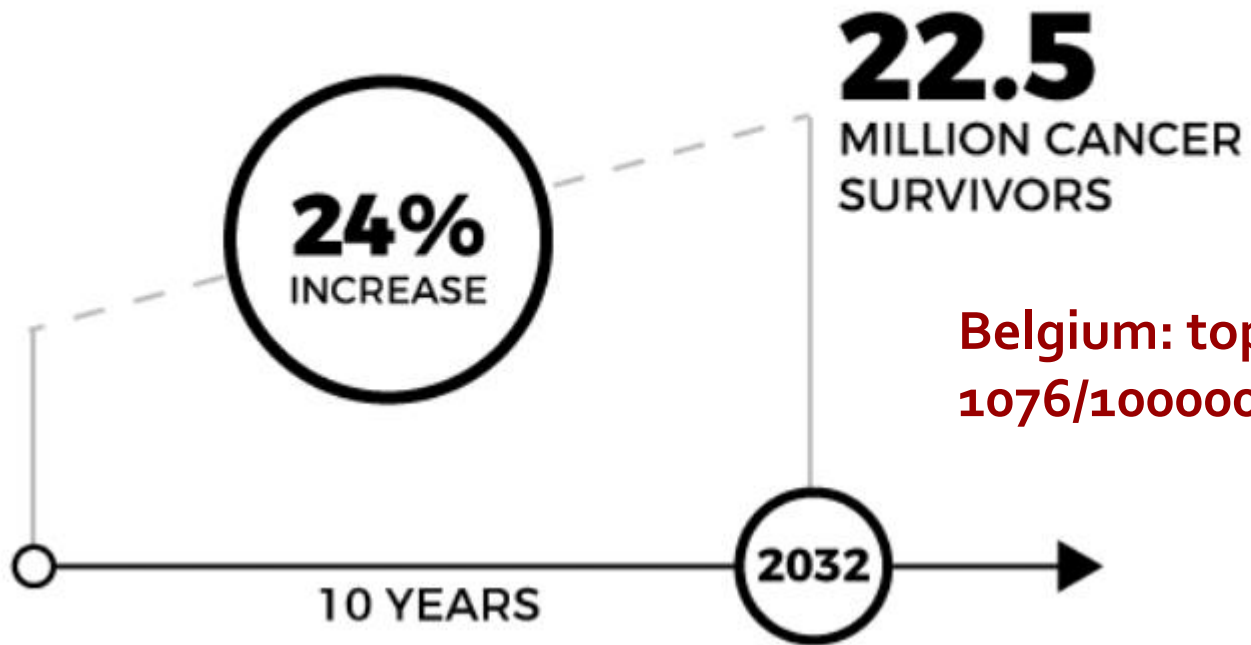


Table 7 – 1-, 3-, and 5-year unadjusted observed and relative survival for patients diagnosed with non-metastatic* IBC who had surgery

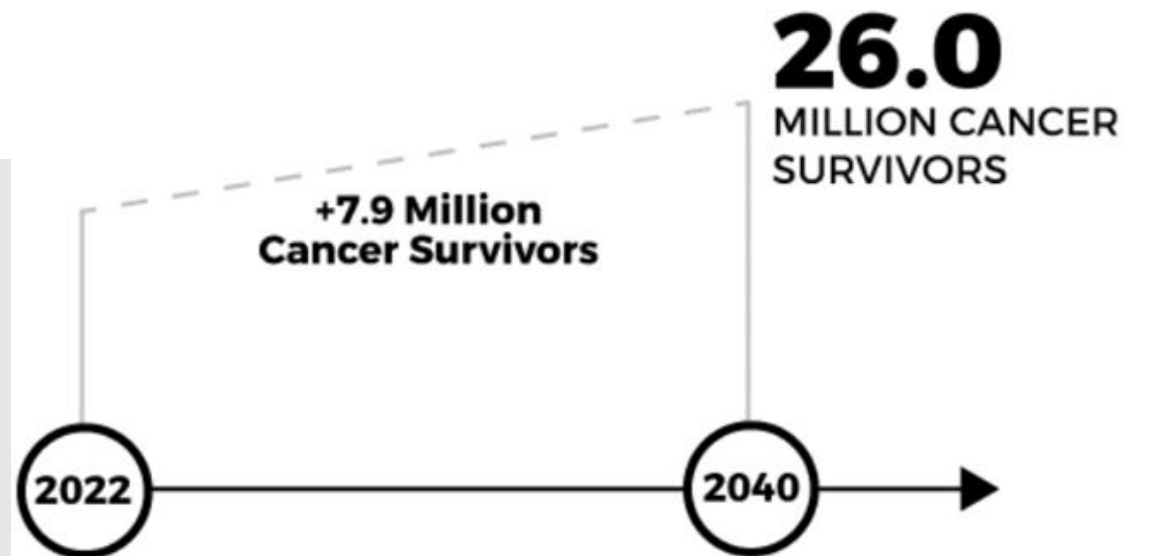
Characteristics	N at risk	Unadjusted observed survival (%, 95% CI)			Unadjusted relative survival (%, 95% CI)		
		1-year	3-year	5-year	1-year	3-year	5-year
Overall	33 000	99.0 [98.9, 99.1]	95.3 [95.1, 95.5]	91.1 [90.7, 91.4]	100.4 [100.3, 100.5]	100.0 [99.8, 100.3]	99.5 [99.1, 99.8]

IBC: invasive breast cancer
Source: BCR-IMA

Documenten bureaublad



Belgium: top 10 worldwide number of survivors
1076/100000 inwoners





Care in survivorship has to involve:

1. **Regular controls** for early detection of relapse and screening for other tumours
1. Monitoring of **long term consequences** of cancer, including psychosocial, physical and immunological consequences
1. **Prevention** and detection of late consequences of cancer and its treatment
1. Evaluation and management of **cancer related symptoms** with appropriate referral for the correct approach

Care in survivorship has to involve:

1. **Coordination** of care between **1ste line** and **2de line** with role delegation of care
1. **Information** about aftercare
1. **Encouraging** of healthy **lifestyle measures**
1. **Reintegration worklife** tailored to the patient



Is the patient free of disease?

- Is the patient free of side effects?
- Are the consequences acceptable, in regards to quality of life?
- Is he/she physically fit?
- Is the patient satisfied?
- Are the family members and caregivers satisfied?
- Is it possible to lead a 'normal' life?

- **Patient Reported Outcomes!**



SURVIVORSHIP ASSESSMENT (Patient Version)

Please answer the following questions:

Survivorship Concerns	Survivorship Care Survey
Cardiac Health	1. Do you have shortness of breath or chest pain after physical activities (eg, climbing stairs) or exercise? Yes/No 2. Do you have shortness of breath when lying flat, wake up at night needing to get air, or have persistent leg swelling? Yes/No
Anxiety, Depression, Trauma, and Distress	3. In the past two weeks, have you been bothered more than half the days by little interest or pleasure in doing things? Yes/No 4. In the past two weeks, have you been bothered more than half the days by feeling down, depressed, or hopeless? Yes/No 5. Has stress, worry, anger, fear of recurrence, or distress about effects of cancer treatment interfered with your life? Yes/No
Cognitive Function	6. Do you have difficulties with multitasking or paying attention? Yes/No 7. Do you have difficulties with remembering things? Yes/No 8. Does your thinking seem slow? Yes/No
Fatigue	9. Do you feel persistent fatigue despite a good night's sleep? Yes/No 10. Does fatigue interfere with your usual activities? Yes/No 11. How would you rate your fatigue on a scale of 0 (none) to 10 (extreme) over the past week? 0–10
Lymphedema	12. Since your cancer treatment, have you had any swelling, fatigue, heaviness, or fullness on the same side as your treatment that has not gone away? Yes/No
Pain	13. Have you had any pain in the past week? Yes/No 14. How would you rate your pain on a scale of 0 (none) to 10 (extreme) over the past week? 0–10
Hormone-Related Symptoms	15. Have you been bothered by hot flashes/night sweats? Yes/No 16. Have you been bothered by other hormone-related symptoms (ex, vaginal dryness, erectile dysfunction, urinary incontinence)? Yes/No
Sexual Health	17. Do you have any concerns regarding your sexual function, sexual activity, sexual relationships, or sex life? Yes/No 18. Are these concerns causing you distress? Yes/No
Fertility	19. Do you have concerns about fertility or family planning? Yes/No
Sleep Disorder	20. Are you having problems falling asleep, staying asleep, or waking up too early? Yes/No 21. Are you experiencing excessive sleepiness (ie, sleepiness or falling asleep in inappropriate situations or sleeping more during a 24-hour period than in the past)? Yes/No 22. Have you been told that you snore frequently or that you stop breathing during sleep? Yes/No
Healthy Lifestyle	23. Do you engage in regular physical activity or exercise, such as brisk walking, jogging, weight/resistance training, bicycling, swimming, etc.? Yes/No ▶ 23a. If you answered "Yes," how often? 24. Excluding white potatoes, do you eat at least 2½ cups of fruits and/or vegetables each day? Yes/No 25. Do you have concerns about your weight? Yes/No 26. Do you take vitamins or other supplements? Yes/No
Immunizations and Infections	27. Have you received your flu vaccine this flu season? Yes/No 28. Are you up to date on your vaccines? Yes/No/Don't know
Employment/ Return to Work	29. Do you have concerns about how cancer and/or cancer therapy has affected your ability to work? Yes/No

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

[Footnotes](#)
[\(SURV-A 2 of 2\)](#)

SURV-A
1 OF 2

Support in dealing with a new reality: who/what can help?

- Personal journal, map hospital, emotion workbook
- Family/friends/caregivers
- (Onco)psychologist
- Caretakers involved in treatment and follow-up (medical oncologist, general physician, at home nurse, oncocoach, (breast) nurse, social services, dietician, physiotherapist, palliative care team,...
- Supportive care plan
- Patient organisations, open houses

Patient organisations Belgium

- Local: Sabel, Toekan
- vzw Think Blue Vlaanderen (prostaatkanker)
- Think Pink (borstkanker)
- SmakSmak vzw (mondkanker)
- Prostaatlijn vzw
- Contactgroep GIST
- NET & MEN Kanker België
- Pancreas Vlaanderen vzw
- Patiëntenvereniging MelanoomPunt
- Werkgroep Hersentumoren
- Gynca's
- Borstkanker Vlaanderen
- La Vie en Rose (cancer de sein)
- ...

Other important aspects

- Changes in family and relationships
- Becoming pregnant/fertility after cancer
- New hobbies and interests
- Finances and insurance **“The right to be forgotten”**
- Resuming work duties <https://www.rentree.eu/>



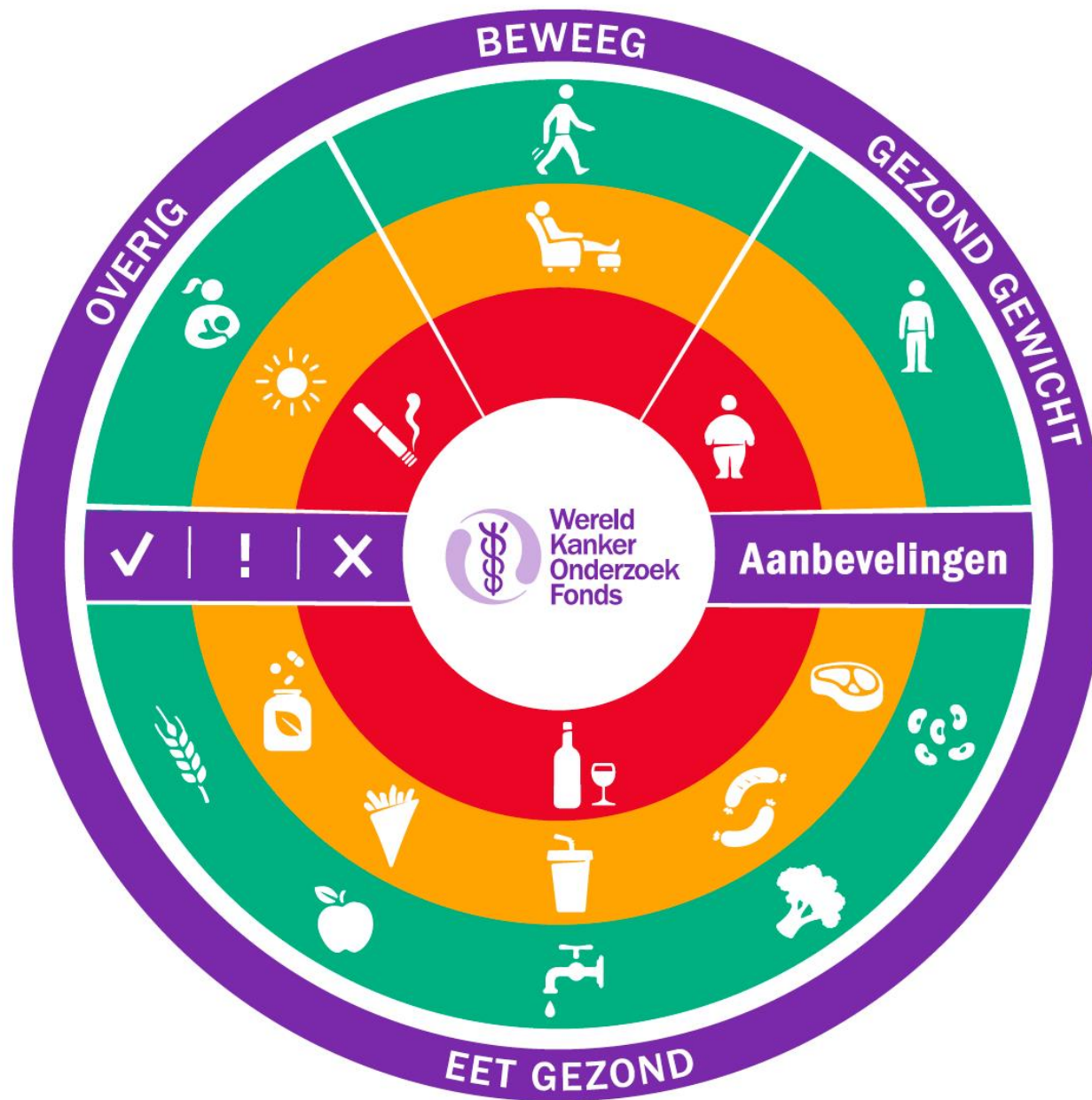
Tips for patients

- Daring to **lean on a network**, whether or not created with the help of professionals
- Trying to maintain a “**flow**”: focus on the here and now, moment by moment. Tomorrow is another day.
- To not be afraid of **asking questions**; questions help the care team gain insight in this specific person
- Finding a **motto** or perspective that motivates to go on
- Remembering that **each trajectory is different**

Prevention of a new or recurring cancer

- Regular clinical visits
- Screening tests
- Exams, blood work
- Hereditary tests

Preventive health: lifestyle advice



Symptoms as a consequence of cancer and/or its treatment

Sexual dysfunction

Nausea and/or vomiting

Hormonal problems

Pain

Peripheral neuropathy



Fatigue and/or insomnia

Eye problems

Skin, mucosal, teeth problems

Osteoporosis

Depression, anxiety, fear for recurrence

Infertility, amenorrhea, menopause

Cognitive dysfunction

Lymphoedema

Cardiovascular problems

Urological, gastro-intestinal, lung problems

Peripheral neuropathy

- Frequent side effect, until years after treatment
- Prevention: mostly dose adjustments!



ESMO GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

ANNALS OF ONCOLOGY
driving innovation in oncology

SPECIAL ARTICLE

**Systemic anticancer therapy-induced peripheral and central neurotoxicity:
ESMO—EONS—EANO Clinical Practice Guidelines for diagnosis, prevention,
treatment and follow-up[☆]**











B. Jordan¹, A. Margulies², F. Cardoso³, G. Cavaletti⁴, H. S. Haugnes^{5,6}, P. Jahn⁷, E. Le Rhun^{8,9,10,11}, M. Preusser¹², F. Scotté¹³,
M. J. B. Taphoorn¹⁴ & K. Jordan¹⁵, on behalf of the ESMO Guidelines Committee^{*}, the EONS Education Working Group^{*} and
the EANO Guideline Committee^{*}

ESMO GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

EUROPEAN ONCOLOGY NURSING SOCIETY



EANO EUROPEAN ASSOCIATION
OF NEURO-ONCOLOGY

Jordan B. et al., Ann Oncol. 2020; 31(10):1306-1319

Intervention	LoE/GoR	„Translated“ Recommendation
Duloxetine	I, B	
Venlafaxine	II, C	
Pregabalin	II, C	
Amitriptyline	II, C	
Tramadol	II, C	
Strong opioids	II, C	
Nortriptyline	II, D	
Gabapentin	II, D	
Lamotrigine	II, E	 

LoE: Level of Evidence,
GoR: Grade of Recommendation

Jordan B et al. Ann Oncol. 2020;
31(10):1306-1319

Intervention	LoE/GoR	„Translated“ Recommendation
Topical menthol*, low concentrated ¹	III, B	
Capsaicin Patch, 8 % ²	III, C	

LoE: Level of Evidence, GoR: Grade of Recommendation

*1 % menthol (levomenthol) in aqueous cream¹

¹Fallon, M. T. (2015). Support Care Cancer 23:2769-2777; ²Anand, P. (2019) J Pain Res 12: 2039-2052;
Jordan B et al. Ann Oncol. 2020; 31(10):1306-1319

Fatigue







SPECIAL ARTICLE

Cancer-related fatigue: ESMO Clinical Practice Guidelines for diagnosis and treatment[†]

A. Fabi¹, R. Bhargava², S. Fatigoni³, M. Guglielmo⁴, M. Horneber⁵, F. Roila³, J. Weis⁶, K. Jordan⁷ & C. I. Ripamonti⁴, on behalf of the ESMO Guidelines Committee*

Therapeutic approaches:

- Therapy of accompanying factors (depression, anemia, ...)
- Physical activity [I, B] 
- Cognitive behavioural therapy [II, B] 
- Mindfulness-based stress reduction [II, C] 
- Yoga [II, C] 
- No consensus: Acupuncture, mistletoe extract, wisconsin ginseng
- Pharmacological intervention ...next slide

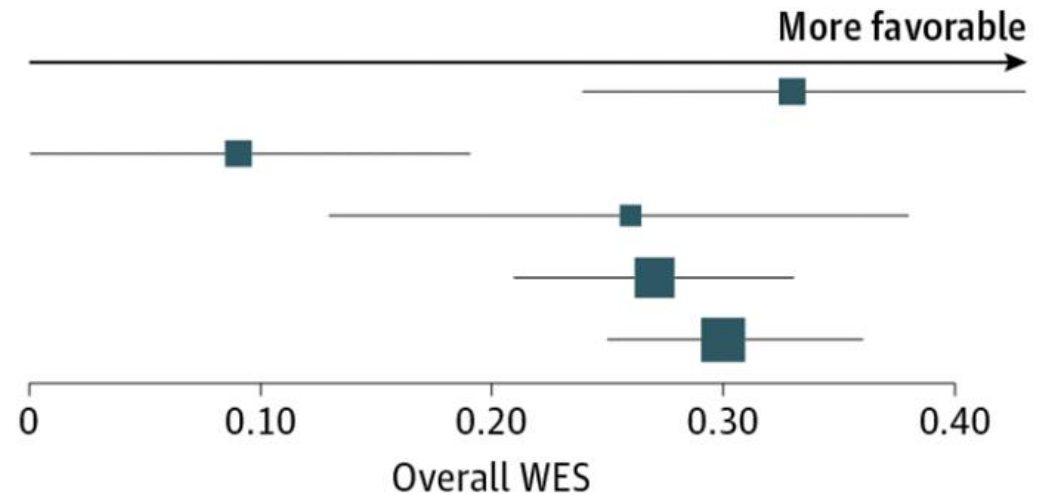


Fatigue – Physical exercise

More effective than drug intervention

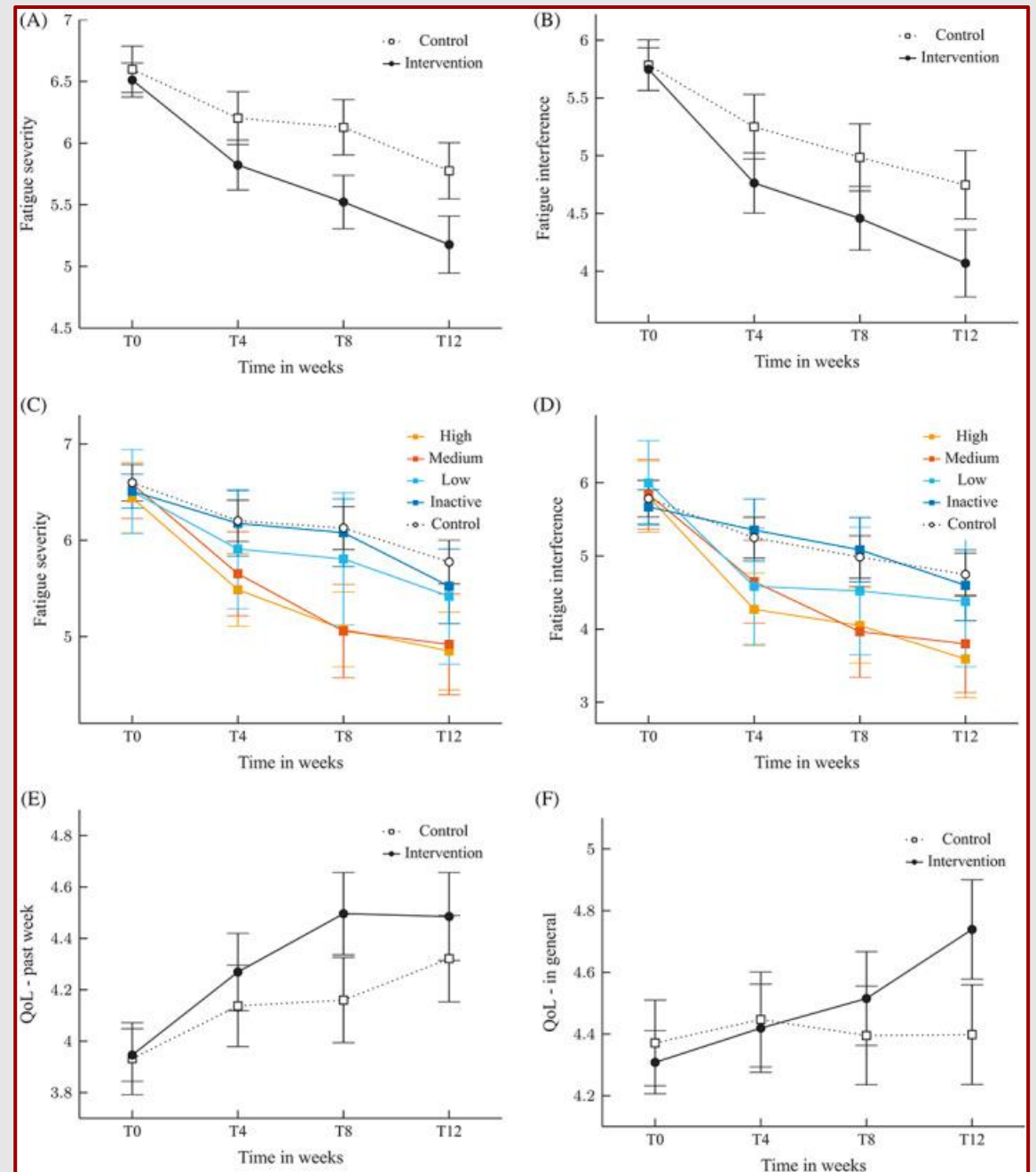


Intervention	No. of Effect Sizes	WES	SE	(95% CI)
All	127	0.33	0.05	(0.24-0.43)
Pharmaceutical	14	0.09	0.05	(0.00-0.19)
Exercise plus psychological	10	0.26	0.07	(0.13-0.38)
Psychological	34	0.27	0.05	(0.21-0.33)
Exercise	69	0.30	0.03	(0.25-0.36)




Physical exercise of moderate intensity and aerobic and functional resistance exercise are recommended in patients with CRF [I, B].

Beating cancer-related fatigue
 with the **Untire** mobile app:
 Results from a waiting-list
 randomized controlled trial



Cardiac Follow-up

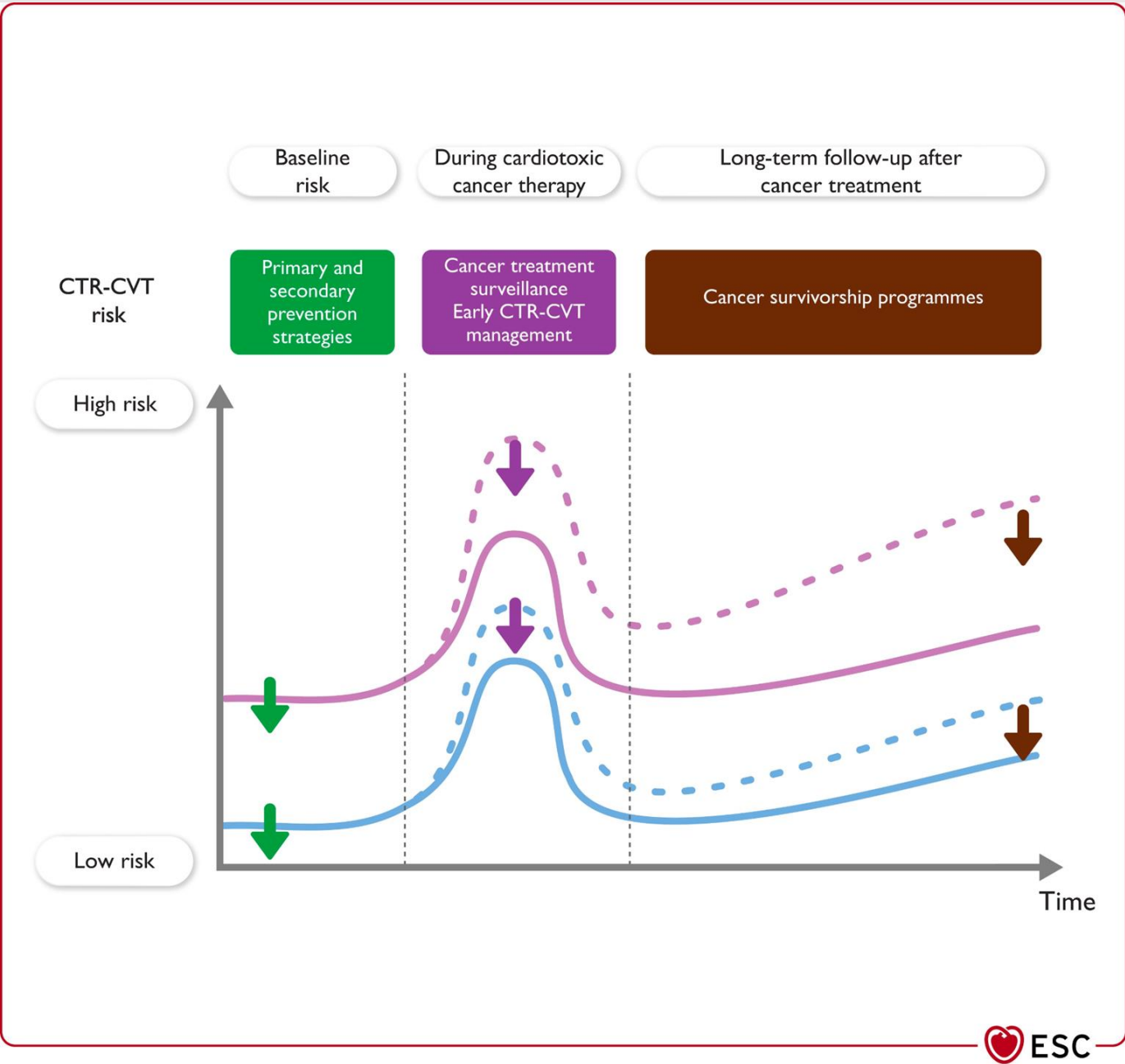
2022 ESC Guidelines on cardio-oncology developed in collaboration with the European Hematology Association (EHA), the European Society for Therapeutic Radiology and Oncology (ESTRO) and the International Cardio-Oncology Society (IC-OS): Developed by the task force on cardio-oncology of the European Society of Cardiology (ESC) 

[Alexander R Lyon](#) ✉, [Teresa López-Fernández](#) ✉, [Liam S Couch](#), [Riccardo Asteggiano](#), [Marianne C Aznar](#), [Jutta Bergler-Klein](#), [Giuseppe Boriani](#), [Daniela Cardinale](#), [Raul Cordoba](#), [Bernard Cosyns](#) ... [Show more](#)

[Author Notes](#)

European Heart Journal, Volume 43, Issue 41, 1 November 2022, Pages 4229–4361,
<https://doi.org/10.1093/eurheartj/ehac244>

Published: 26 August 2022



Personal aftercare compass

- Each person receives a survivorship checklist, care plan and summary of treatment
- Role of telehealth?
- Role of transition moment/consultation multidisciplinary
- Has to be feasible in the own environment



Table 2. Findings regarding efficacy of telemedicine in post-treatment survivorship care, for outcomes included in >2 systematic reviews

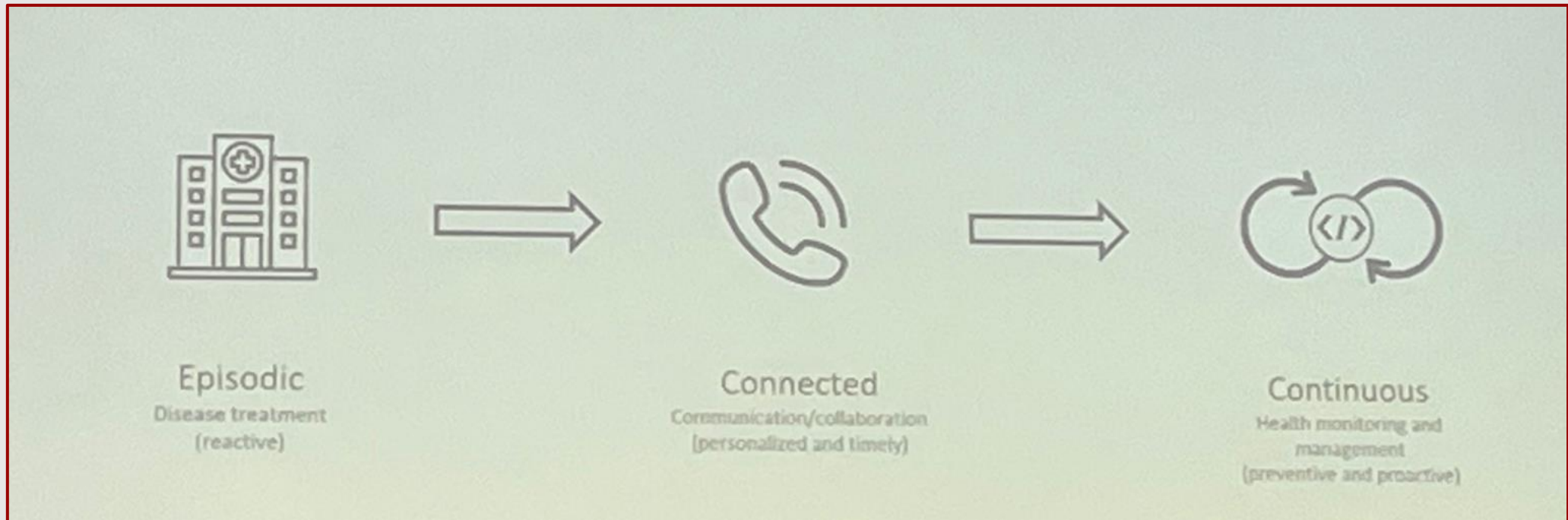
Outcome	Finding	N SRs	N primary Studies	Overlap	Intervention designs	SR Refs
Domain 2: Surveillance and management of physical effects						
Physical symptom burden	+	6	6	14%	Web, phone	24,25,37,40,42,48
Physical functioning	+	5	6	16%	Web, wearables	24,29,36,40,42
Fatigue	+	18	31	35%	Web, phone, mobile app	11,24-26,29,30,31,36-40,42,44,47-50
Sleep quality	+	6	5	40%	Web, mobile app	25,29,38-40,49
Sexual function	+	3	6	16%	Web, phone	31,40,45
Cognitive functioning	+	6	11	9%	Web, mobile app	24,25,37,40,42,48
Pain	-	5	5	40%	Web, phone	25,28,29,40,44
Domain 3: Surveillance and management of psychosocial effects						
Motivation	+	2	2	0%	Wearables	24,48
Stress	+	4	4	25%	Web, mobile app	37,40,48,49
Fear of recurrence	+	4	3	66%	Web, app	27,40,48,49
Social and emotional functioning	+	4	5	20%	Web, app	26,44,47,48
Self-efficacy	+	4	9	11%	Web, app, phone	11,27,40,48
Quality of life	+	15	47	45%	Web, app, phone	11,23-25,27,36-39,42,44,45,47-49
Body image	+	2	2	50%	Web	40,45
Mood	NC	4	5	20%	Web, phone	28,29,36,38
Distress	NC	9	15	13%	Web, app, phone	24,27,29,30,31,34,42,48,49
Depression	NC	18	21	52%	Web, app, phone	23-30,34,37-41,47-50
Anxiety	NC	9	15	46%	Web, app, phone	25,29,30,31,37,38,40,41,48
Domain 5: Health promotion and disease prevention						
Physical activity	+	15	34	47%	Web, app, phone, wearables	12,24,29,32,33,35-40,42,47-49
Body weight	+	7			Web, app, phone, wearables	29,36-38,40,42,49
Diet quality	+	4	10	20%	Web, app, phone, wearables	33,38,39,42
Smoking	NC	4	3	66%	Web	33,36,37,47
Alcohol	NC	3	2	50%	Web, phone	33,36,37

N, number; NC, Non-convincing findings; Refs, references; SR, systematic review.

+Statistically significant improvement in outcome with telemedicine intervention (more than two-thirds of systematic reviews concluding an overall significant effect).

-Telemedicine intervention had no significant effect on outcome (more than two-thirds of systematic reviews concluding non-significant finding).

Telehealth, always combined with real life contact



Integrative oncology

A patient-centered, evidence-informed field of cancer care that utilizes mind and body practices, natural products, and/or lifestyle modifications from different traditions alongside conventional cancer treatments. Integrative oncology aims to optimize health, quality of life, and clinical outcomes across the cancer care continuum and to empower people to prevent cancer and become active participants before, during, and beyond cancer treatment.

Music therapy, meditations, yoga, massage, acupuncture,...

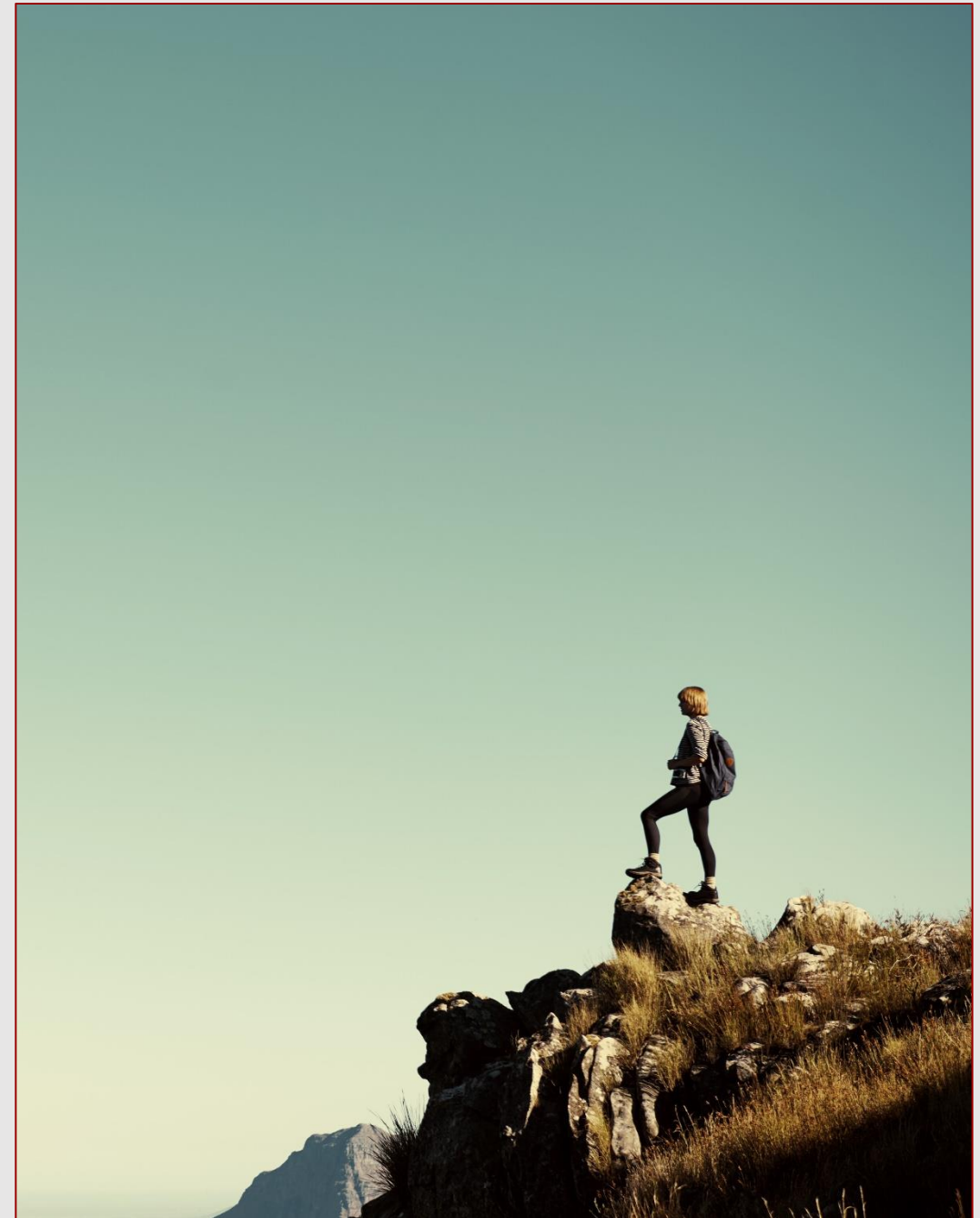
Greenlee et al. Clinical practice guidelines on the evidence-based use of integrative therapies during and following breast cancer treatment. 2017 May 6;67(3):194-232. doi: 10.3322/caac.21397

Challenges

- identifying the exact **needs**
- need for a **landscape review** of who and what services are available
- access to **evidence-based integrative care** in survivorship
- raise **awareness**
- **equality** across Europe

ACTIONS

- Clinical practice guidelines and/or general recommendations for medical professionals, patients; further development and implementation
- Development Network of Survivorship Experts, University and Non-University driven
- Specialized working groups
- Organisation of supportive care- survivorship in Belgium and Europe Development of integrative survivorship care programme
- Efforts to promote research



Take Home messages

- strong increase in number of cancers survivors in expected
- awareness about survivorship is critical: Public awareness and advocacy/policy actions
- contains issues that are related to **follow-up**, management of **late side effects** of treatment, preventing and monitoring for relapse and **improving quality of life** and of **psychosocial and emotional health**: Integrative and holistic approach
- coordination of care is important



Together we move mountains
Thank you for your attention

PATIENT PERSPECTIVES ON SUPPORTIVE CANCER CARE



Kayla Rifaâd

Qui suis-je ?

- **Diagnostiquée** [officiellement], le 8 juin 2022 en Australie,
=> *Après une obtention d'un P.V.T.*
=> *rapatriée le 9 juin en Belgique.*
- **LEUCEMIE** lymphoblastique de type T avec lymphome au médiastin et thrombose cérébrale

=> ***Avec complications : hémorragie cérébrale et EPILEPSIE avec aphasie. Hématome sous-dural.***
- **Greffée** de la moelle osseuse en novembre 2022
- **Cohabitante**

Pendant mon traitement

Difficultés

- Complications : pertes cognitives
- Hôpitaux ≠
- Flou / oubli
- Peur - mort
- Isolement - solitude
- Manque de sommeil
- Douleurs
- Nourriture
- Gestion administratif : proche-aidant seul

Besoins

- Aides complémentaires : assimiler le changement
- De structure, stabilité
- De Comprendre
- De parler des croyances
- De contacts /!\
- De se reposer, dormir
- De soins agréables
- De m'alimenter
- D'accompagnement social adapté

Qui m'accompagne ?

- Équipe soignante :
 - infirmiers
 - infirmiers : bien-être
 - médecins
- Proches-aidants
- Psychologue (*)
- Kinésithérapeute
- Logothérapeute
- Ergothérapeute
- diététicienne
- Personne Morale

Le positif

MA* psychologue

Personne de Lien pour m'accompagner et répondre à mes besoins, demandes et difficultés.

(-) Le négatif : Social

- Difficultés pour **proche-aidante/ cohabitante**
 - Surcharge émotionnelle, STRESS
 - Entre son travail temps plein et les visites
 - L'administratif (Qui ? Où ? Quand ?)
 - Les Finances (Quelles aides? Public/privé !)
 - Fatigue +++
- A.S. De l'hôpital dirigeant mais n'aident pas.
- A.S. Extérieur, non formés et adaptés à l'accompagnement du cancer (et/ou handicap) (ici, nous parlont du CPAS)

Et la rémission ?

Difficultés

- Proches-aidants
Fatigués+, déni, burn-out, conflit.
- Difficultés à passer à autre chose
- Difficultés à me reposer, dormir, à équilibrer mes journées

Besoins

- De suivi psychologique pour les P-A.
*=> P-A à bout ! /!\ **Tabou***
- De suivi psychologique : assimiler le parcours, comprendre et faire le deuil.
- D'accompagnement pour le gestion du quotidien :
cf. Madame fatigue

Trop de charges mentales ?!

- Difficultés

- Gestion de la Peur : d'être seule, récurrence, lâcher-prise, la mort,...
- Gestion des émotions
- Gestion du stress
- Gestion de l'anxiété : handicap, travail, capacités ?

- Besoins

- D'être rassurée, présence et de soutien, de suivi, d'accompagnement, ...

- Gestion de la fatigue

- **BESOIN DE REPOS !!!**

Mon cas : June après-cancer

Difficultés

- Administratif – financier-
logement.
- Vie sociale :
Immunodéprimée, salle
d'attente, transports,
contacts sociaux
- Gynécologie :
ménopause, traitement,
hormones, douleur,
Infertilité et deuil,
Sexualité, libido, couple

Besoins

- D'aide pour à la
(Re)construction.
=> calme, step by step.
- Sortir de l'isolement et
Manque de structures
adaptés aux jeunes
et/ou immunodéprimés
- Besoin d'un suivi adapté
au vécu et écoute active

Ma conclusion

- L'accompagnement médical hématologique pendant et après : parfait
- L'accompagnement psychologique au service hématologique : parfait
=> **mais** besoin de plus d'accompagnement psychologique de PROFESSIONNELS* pour l'après. Vulnérabilité !
- L'accompagnement social : à totalement améliorer en général
=> *manque de coordination, de communication entre les services, personnels non adaptés au public concerné, manque de formation, temps d'attente énorme*
« *L'administratif vole les dernières forces restantes au patient* »

- Quand le handicap se lie au cancer ?
Entre fatigue du cancer, de la greffe, de la paperasse ET épilepsie :
=> fatigue, crises, repos, SURVIE, fatigue, crises, ...
- Manque de structures pour les adolescents et jeunes adultes après le traitement - hospitalisation.

Suggestions pour les jeunes ?

- Créer une équipe spécifique avec des **référents** pour les jeunes à l'hôpital avec :
=> Un médecin référent, Un infirmier référent, Un psychologue référent, Un assistant social référent (par jour, semaine, mois, cf. Aus)
- Un expert-Patient pour soutenir l'équipe médicale ET le patient malade.
- Une structure – base officielle de jour et/ou de nuit pour une réadaptation progressive à la vie active et professionnelle dans chaque région.

Des suggestions, en général ?

- Un document complet donné, **directement à l'entrée**, expliquant les premières démarches à suivre, lors de l'hospitalisation et/ou diagnostic.
- Avoir des assistants sociaux en première ligne, à l'hôpital qui **communique directement** avec les services adéquats !
- Créer **UNE** base de données pour la BELGIQUE qui regroupent toutes les infos au bon déroulement du traitement et de l'après-cancer avec :
 - Une liste des structures avec des professionnels qui peuvent concrètement aider.
 - Une liste d'associations adaptées à la maladie

PATIENT PERSPECTIVES ON SUPPORTIVE CANCER CARE



Marieke Colpaert

Juli/Julliet 2020:
Diagnose/diagnostic
DCIS

November /
novembre 2020:
start/début
chemo

Sept 2021:
Vervolgoperatie
(proces nog
steeds niet
afgerond) /
Opération de
suivi (processus
toujours en
cours)

Oktober 2020: bilaterale
mastectomie en
reconstructie DIEP flap.
Tumor stadium 1 /
Octobre 2020 :
mastectomie bilatérale et
reconstruction par
lambeau DIEP. Stade de la
tumeur 1

April 2021: start
oncorevalidatie
/ Avril 2021 :
début de la
revalidation
oncologique

Supportive Care

‘Oei, en mogen wij dan ook niet meer vrijen?’

‘ Et on n'a pas le droit de faire l'amour non plus ? ‘

Supportive care:

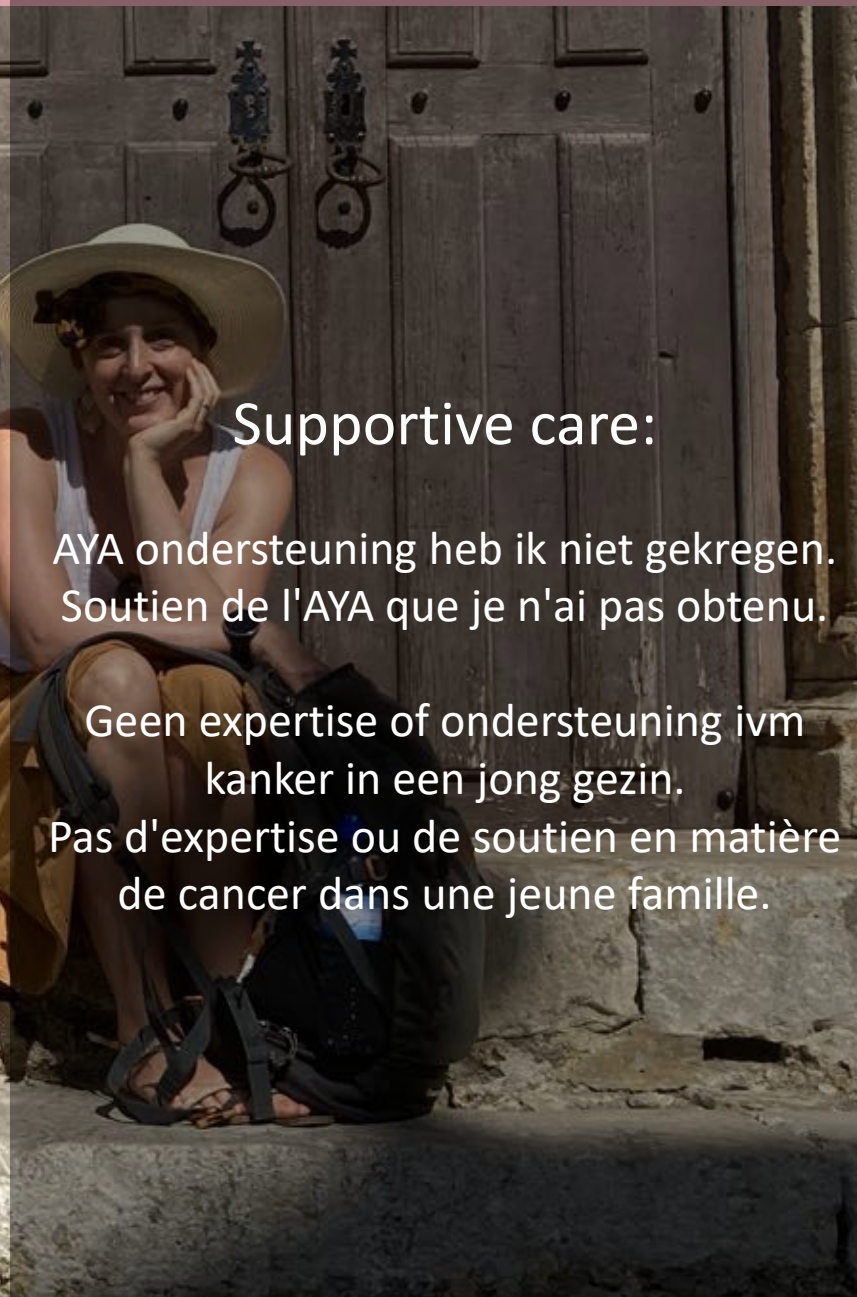
Meer informatie bij aanvang van het proces over gevolgen op vlak van seksualiteit en lichaam / Plus d'informations au début du processus sur la sexualité et les implications corporelles

Voordien consultaties bij psycholoog die toevallig ook seksuoloog was (partnertherapie zorgde voor een sterke basis) / Avant cela, des consultations avec un psychologue qui était également sexologue (la thérapie de couple a constitué une base solide).



Supportive Care:

Begeleid sporten tijdens chemotherapie dankzij testproject Sterkker onderweg van AZ Groeninge / Sports encadrés pendant la chimiothérapie grâce au projet test Sterkker onderweg de AZ Groeninge.



Supportive care:

AYA ondersteuning heb ik niet gekregen.
Soutien de l'AYA que je n'ai pas obtenu.

Geen expertise of ondersteuning ivm
kanker in een jong gezin.
Pas d'expertise ou de soutien en matière
de cancer dans une jeune famille.

Survivorship Care

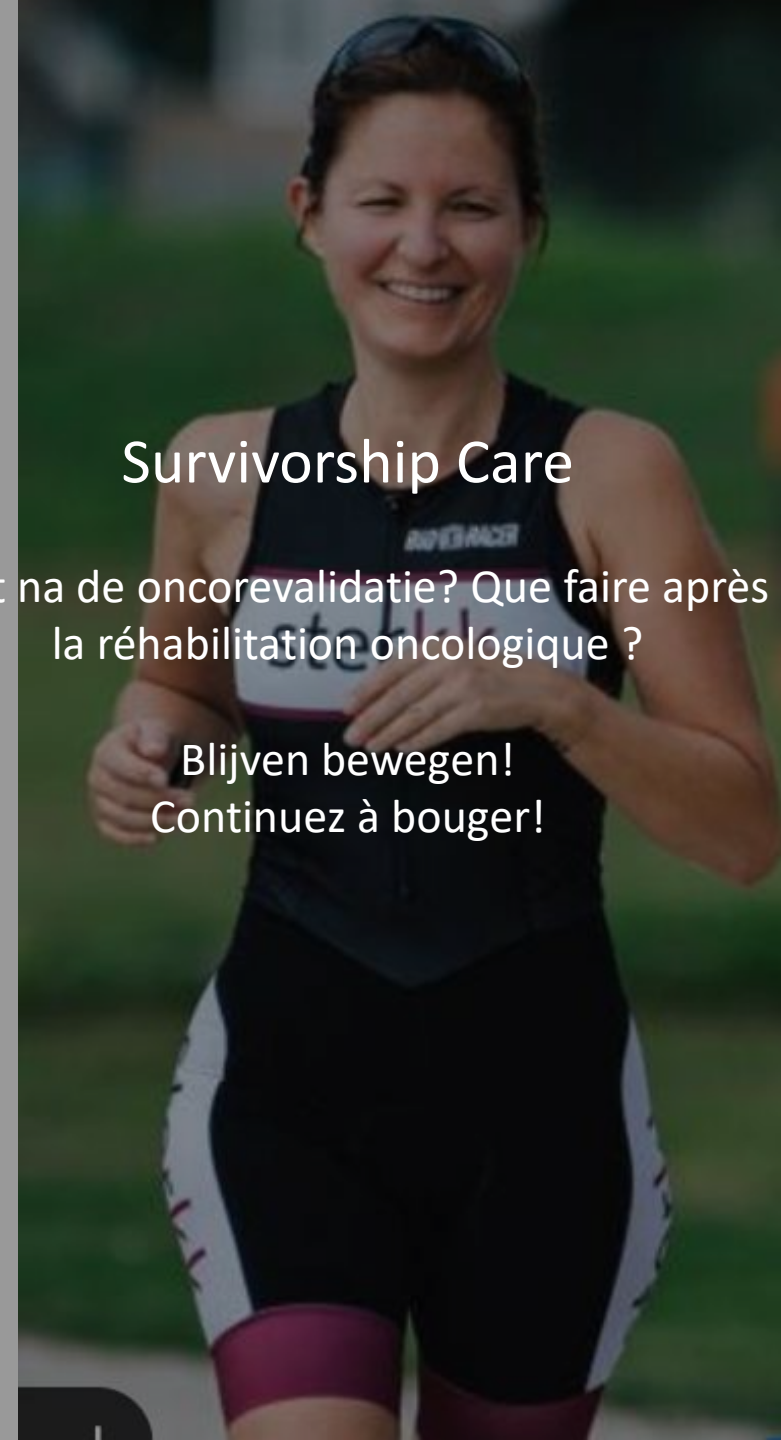
TEAM NEXT



Survivorship Care

Wat na de oncorevalidatie? Que faire après la réhabilitation oncologique ?

Blijven bewegen!
Continuez à bouger!



RUST



MEDITATIE



Survivorship Care:

Oncorevalidatie geeft veel aandacht aan het fysiek herstel.

La réadaptation oncologique accorde beaucoup d'attention à la récupération physique.

Maar wat met het mentaal herstel?

MBSR cursus

Mais que faire du recouvrement mental ?

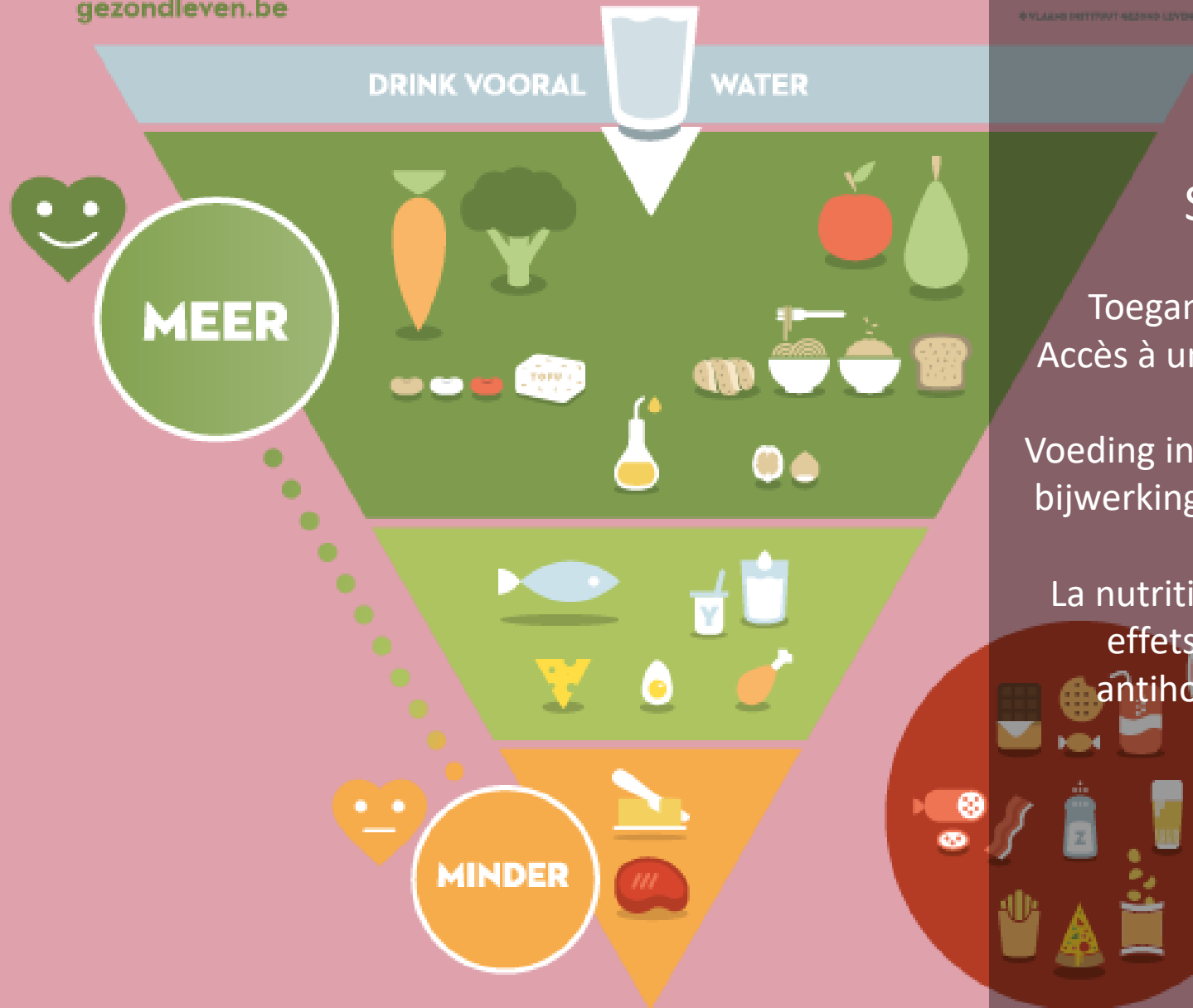
Cours MBSR

VOEDINGSDRIEHOEK

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LEVEN

gezondleven.be

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Survivorship care

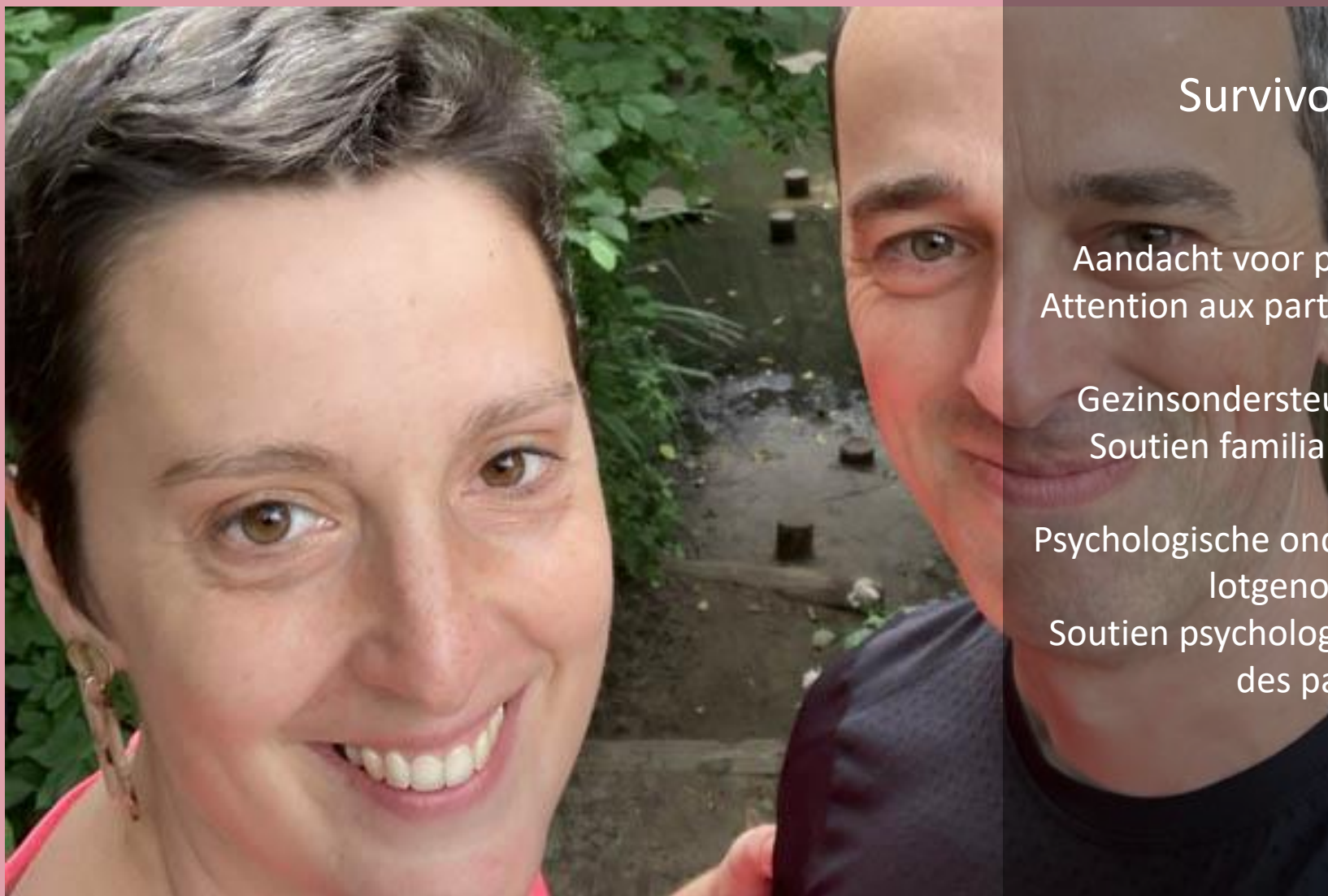
Toegang tot diëtist of leefstijlcoach
Accès à un diététicien ou un coach de vie

Voeding in combinatie met sport maakt de
bijwerkingen van antihormonale therapie
draaglijker.

La nutrition combinée au sport rend les
effets secondaires de la thérapie
antihormonale plus supportables.



ZO WEINIG
MISTALIK



Survivorship care

Aandacht voor partners en kinderen
Attention aux partenaires et aux enfants

Gezinsondersteuning tijdens proces
Soutien familial pendant le procès

Psychologische ondersteuning en contact
lotgenoten nadien.

Soutien psychologique et contacts avec
des pairs après.



Op de
tast

Marieke Colpaert &
Marlies Meersman

Seksualiteit na kanker

Survivorship care:

"Op de tast is het eerste werk over vrouwelijke seksualiteit na kanker dat zo veel kennis bundelt. Een schat aan informatie voor elke vrouw."
Sileny Han, gynaecoloog en oncoloog,
UZ Leuven

"Op de tast est le premier ouvrage sur la sexualité féminine après un cancer à rassembler autant de connaissances. Une mine d'informations pour chaque femme. "
Sileny Han, gynécologue et oncologue,
UZ Leuven

Komt er een intimiteitskliniek?

Survivorship care:

Nazorgconsultatie van 1u

Consultation de suivi d'une durée de 1
heure

Oncologisch seksuoloog gratis consulten

Sexologue en oncologie consultations
gratuites

Y aura-t-il une clinique de l'intimité ?

Multidisciplinaire aanpak in
intimiteitskliniek

Approche multidisciplinaire dans la
clinique de l'intimité

Bedankt voor jullie
aandacht / Merci de votre
attention

www.mariekecolpaert.be

BELGIAN HANDBOOK FOR (HEMATO)- ONCOLOGICAL SUPPORTIVE CARE



Sofie Theys

Cancer Centre – Sciensano

Supportive care & organization unit

Context of the project

- More people are **surviving cancer** due to better treatments
- **End 2020, 472.360 people** were still alive who had been diagnosed with cancer between 2011 and 2020
- Yet, **not all cancer patients have equal access** to support after treatment (during follow-up)
- **Lack of knowledge** among the professionals on available supportive care and specific oncology services for cancer patients (during follow-up)



Key objectives of the project



! Need for a systematic and quality approach

! Fill the gap of who can be referred to whom and for what?

→ Developing an **innovative tool** (webtool) that provides a reliable and **up-to-date overview of providers and services** offering supportive care for the **needs** of (hemato-) **oncological patients** in Belgium.

→ Also:

- Supporting professionals **to detect and assess the care needs** of cancer patients and their relatives by providing an inventory of available guidelines, screening and assessment tools.
- **Supporting patients and relatives with (low health literacy)** by including relevant resources that helps them in understanding their supportive cancer care needs.
- From the development process, identify **gaps** in the supportive cancer care.

Impact



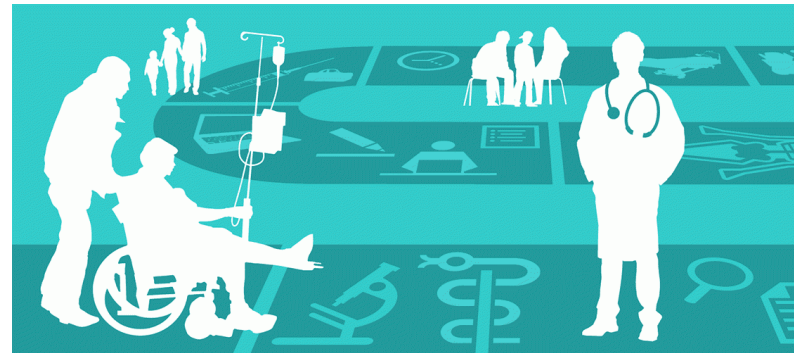
- **Impact:**

- Potential to **improve referral and (equal) access** to supportive care for cancer patients.
- Improved referral could **decrease the unnecessary costs** related to the non-management of patient's needs (at early phase).
- Opportunity to detect **gaps** in supportive care provision, leading to recommendations to better address patients' needs, encouraging structural approach and funding of organisation and research in supportive cancer care.

Phase 1 (January 2023 – March 2024) : Developing the structure and preliminary content of the tool

- **Step 1/4:** Establishment of **5 working groups** for 5 domains : (1) medical follow-up, (2) (onco)psychosocial support, (3) palliative support, (4) socio-professional (re)integration and (5) social support
 - **Objective:** prioritise the needs to be discussed in the following thematic working groups and to be included in the tool

! NEEDS-BASED APPROACH



Methods phase 1

Phase 1

Phase 2

Phase 3

Needs-based thematic working group sessions (2023):

Medical follow-up	(Onco)psychosocial support	Palliative support	Socio-professional support	Social support
Fertility, sexual functioning and hormonal-related symptoms (26/05)	Body image/sexuality and intimacy (9/06)	Psychosocial, emotional and relational needs (16/06)	Return to work (17/11)	Social, administrative, legal, and financial care (24/11)
Sleep and cancer-related fatigue (27/06)	Anxieties, distress, existential wellbeing, family wellbeing, interpersonal relationships (22/09)	Respite care, end-of life care and proactive care planning (20/09)		
Cognitive impairment and pain (6/10)				
Hearing, voice, vision problems and oral health (cancelled)				
Healthy lifestyle/prevention (7/11)				

Methods phase 1

Phase 1

Phase 2

Phase 3

Phase 1 (January 2023 – March 2024) : Developing the structure and preliminary content of the tool

- **Step 2/4** : Needs-based thematic working group sessions with professionals, patient organisations, patient experts to discuss :
 - Support that can be provided for the specific needs
 - Professionals and services/institutions that patients can be referred to
 - Guidelines and measurement tools
 - Gaps in the supportive care



Methods phase 1

Phase 1

Phase 2

Phase 3

Phase 1 (January 2023 – March 2024) : Developing the structure and preliminary content of the tool

- **Step 3/4** : Further development list of needs (long-term needs, late effects) + prioritization of needs for the first version of the tool:
 - Feedback round with experts, professionals and patient experts/patient organisations
 - Final version list of needs, including prioritised needs.
- **Step 4/4** : Development of the structure of the tool (webtool) together with SC-ICT services :
 - Based on input from the thematic working group sessions
 - Preliminary example of the tool: [see screenshots added to the report of the event](#)

Results phase 1



- **Preliminary results (phase 1):**

- The healthcare system already offers supportive care for most of the discussed needs, but gaps were identified :
 - **Information** on supportive care providers and services is currently **fragmented**
 - Lack of a clear framework for **follow-up on psychosocial and other needs** for cancer patients (survivors)
 - Lack of a **formal supportive care – survivorship model**
 - **Lack of a policy on supportive care during and after treatment**
 - Inequality in access to supportive care (e.g. oncodietitians) amongst others due to **differences in reimbursement** by health insurers
 - Also some lack of **need-specific offer** (e.g. nutritional support, sexuality);
 - > in phase 2 of the project continuing to gather more information on need-specific gaps

Results phase 1

- **Preliminary results (phase 1):**

- Identified 5 general **guidelines** on supportive cancer care (1 for Belgium in development),
→ In Belgium almost no guidelines for specific needs available
- For each of the needs we identified **tools for identification + assessment**
→ *to be validated with experts in phase 2*
- a first **overview of support for many needs and the professionals and institutions** that can provide the support
→ *further developed in phase 2*
- we gathered some **brochures, websites** etc. that could be helpful for professionals to support patients with low health literacy
→ *we will continue this during phase 2*

Phase 2 (January 2023 – **continuous** activity) : **Developing the content**

- Possible organisation of working group sessions for **specific patient groups** e.g. children, adolescents and young adults, older cancer patients, etc.
 - *working together with the AYA unit of the Cancer Centre*
- Surveys, focus groups and interviews with patients, professionals, experts etc. to **explore in depth the results of phase 1**
 - *methodology used will depend on the specific needs*
 - Mapping supportive care for the different needs + all the professionals and institutions providing the supportive care
 - Guidelines and identification/assessment tools for the needs
 - Relevant sources for patients with low health literacy
 - Gaps in the support

Methods phase 3

Phase 1

Phase 2

Phase 3

Phase 3: Building the electronic database

- Contacting (professional or umbrella) organisations for the contact details of professionals and institutions.
- > *HB foresees referral to existing mappings and databases (e.g. Chi, StK, AVIQ, KOTK, etc.)*
- Obtaining legal/juridical advice for personal data sharing
- Set up agreements (criteria, data sharing, update data, etc.) with the suppliers of information

Challenges



- ❖ Mapping the available supportive cancer care in Belgium outside structures/organizations
- ❖ Keeping the tool up-to-date
- > *HB foresees referral to existing mappings and databases (e.g. Chi, StK, AVIQ, KOTK, etc.)*
- ❖ Data-sharing (GDPR) consents to be collected
- ❖ Set up agreements (criteria, update data, etc.) with professional and umbrella organisations

THE BELGIAN NETWORK FOR SUPPORTIVE CARE (BELNETSUP)

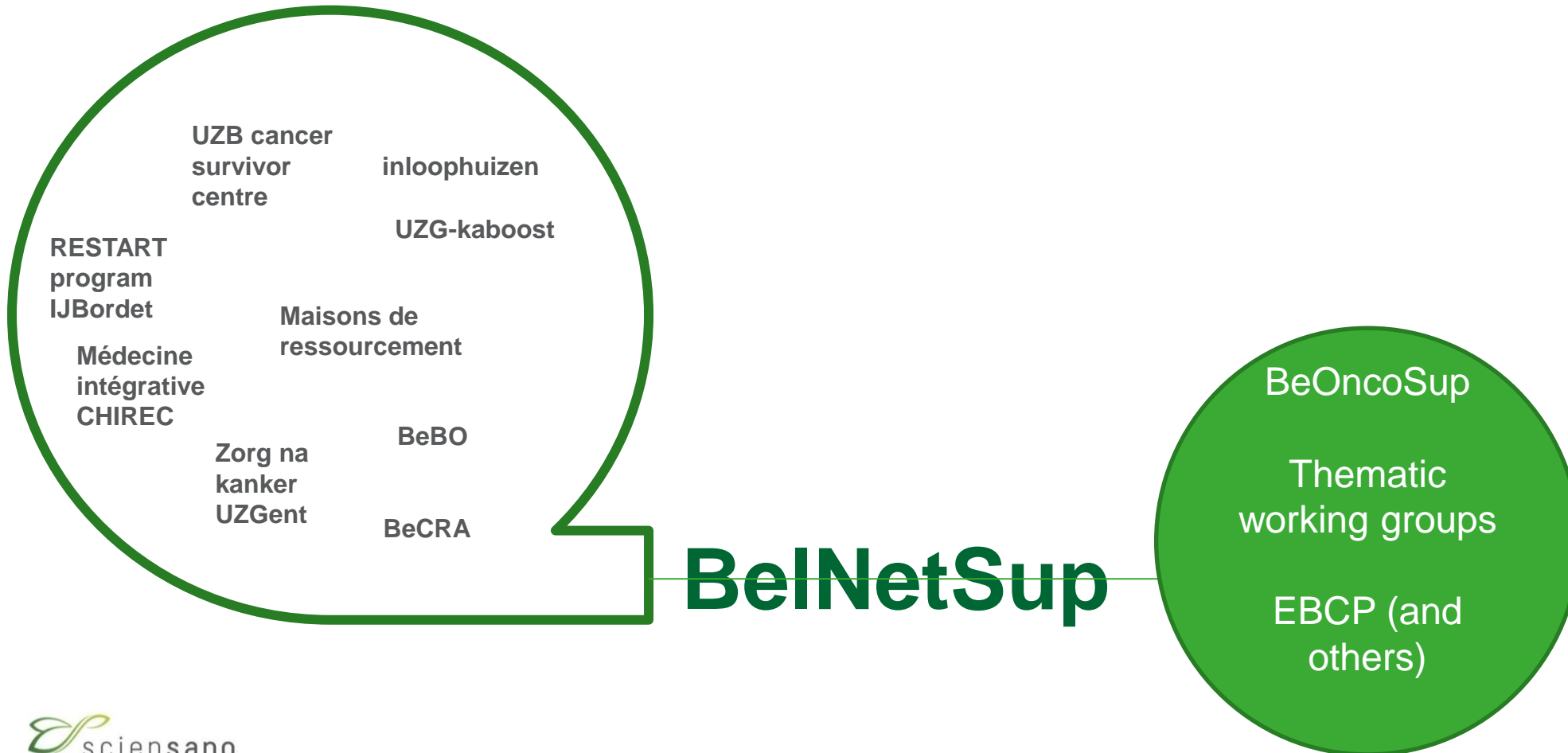


Régine Kiasuwa Mbengi, Pol&Soc, MPH, PhD
Cancer Centre - Sciensano
Supportive care & organization unit

BeINetSup: rationale

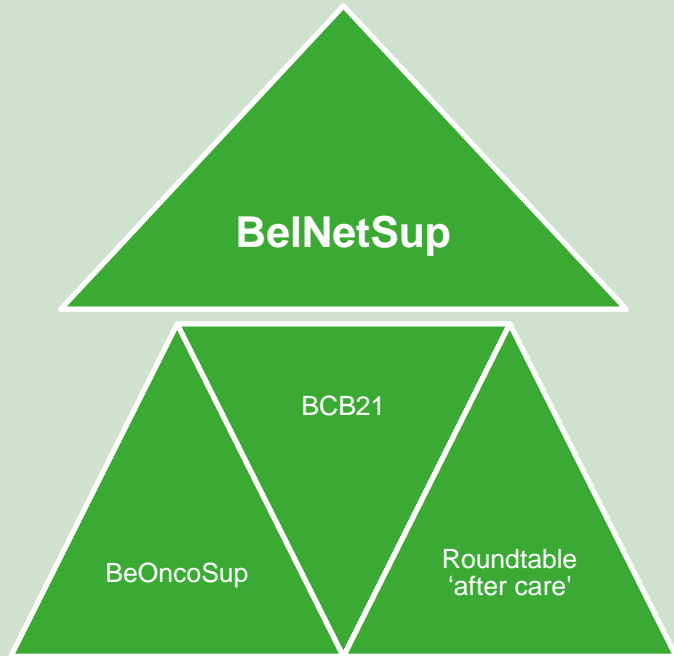


- Many (multidisciplinary) initiatives



BeINetSup: where to start?

Framework (bottom-up)

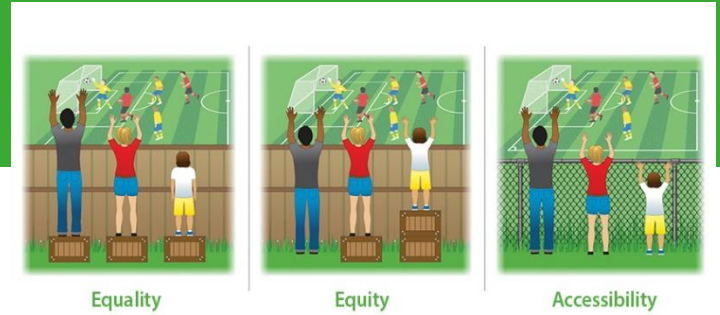


- Inter-federal plan for integrated care
- EBCP
- MASCC

Key building stones

- ❖ OBJECTIVES & MISSIONS
- ❖ STRUCTURE
- ❖ STAKEHOLDERS

BeINetSup: objectives & missions



- ❖ Ensure **accessibility**
- ❖ Enhanced **coordination & cooperation** -> **multidisciplinary**
- ❖ Knowledge and **(best)practices sharing** and capacity-building
- ❖ **Stimulate (collaborative) research and innovation**

PROPOSAL!!!

BeINetSup: objectives & missions

- ❖ Ensure **accessibility**
- ❖ Enhanced **coordination & cooperation** (multidisciplinary)
- ❖ Knowledge and **(best)practices sharing** and capacity-building
- ❖ **Stimulate (collaborative) research and innovation**

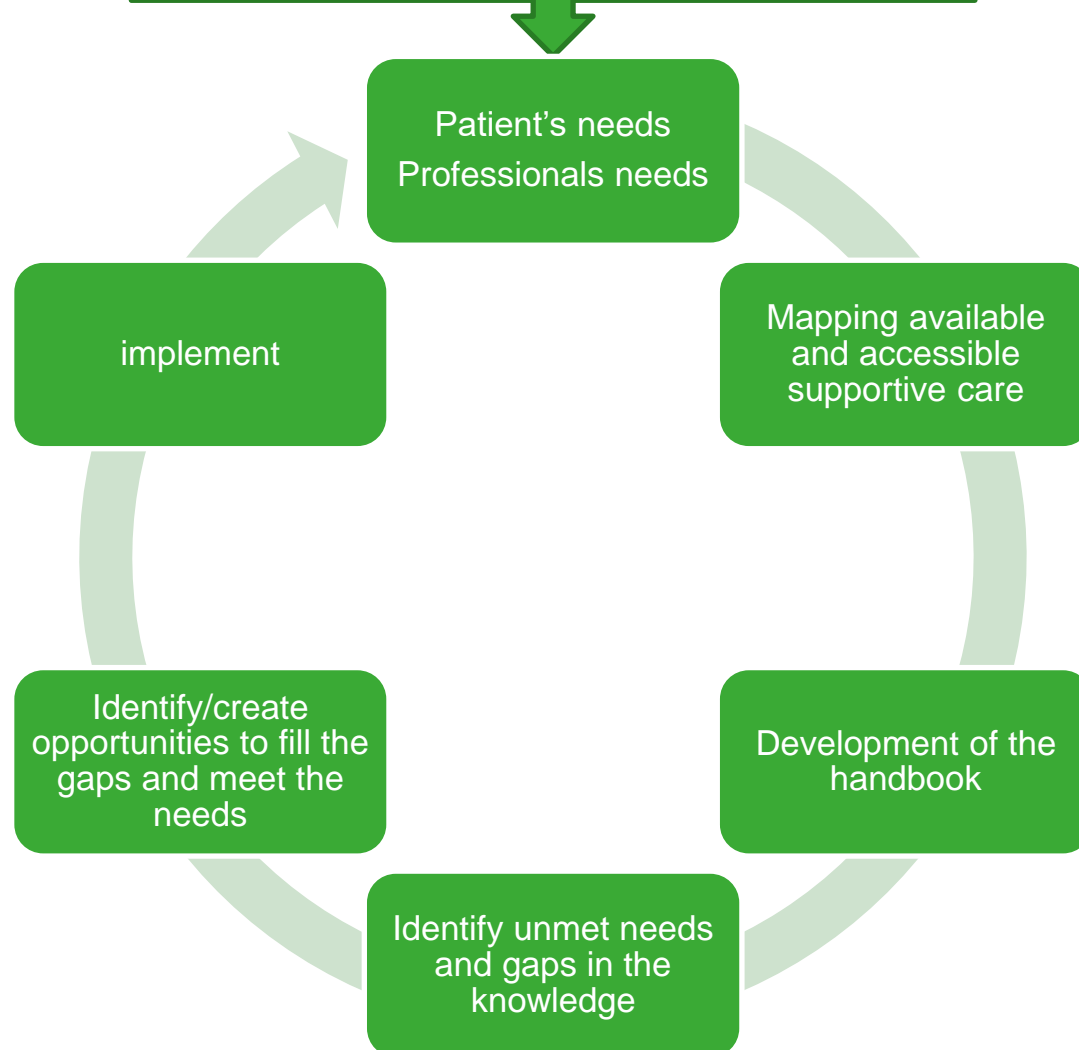


Operationalisation of the missions (?)

- Needs-based and multidisciplinary approach
- As pragmatic as possible -> continuous development of the handbook and related material

BeINetSup: objectives & missions

Operationalisation of the missions (?)



BeINetSup: members

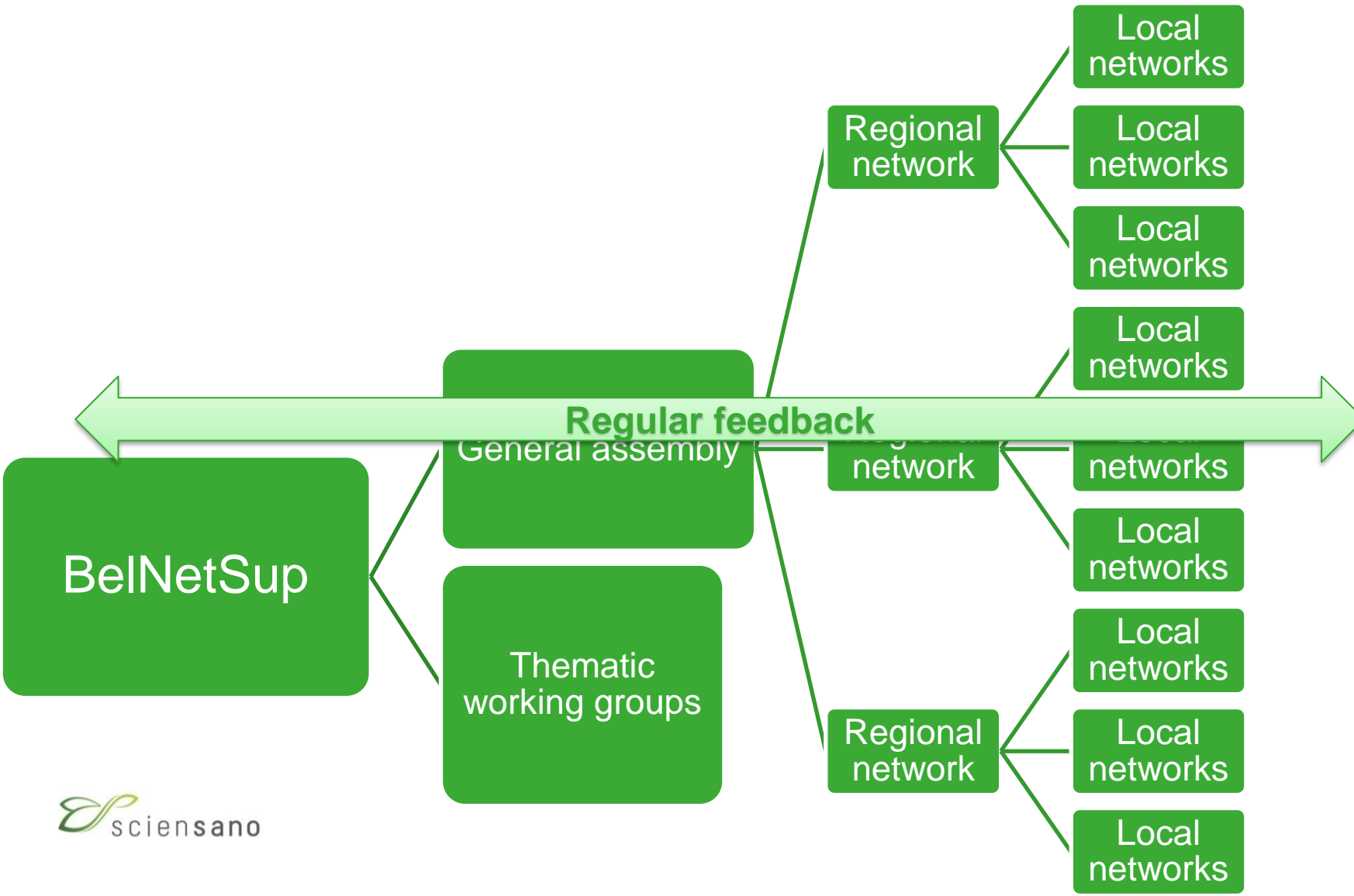
REPRESENTATIVENESS:

- ❖ Good geographical coverage
- ❖ Multidisciplinary group (with thematic WGs, to be defined)
- ❖ Integrated approach

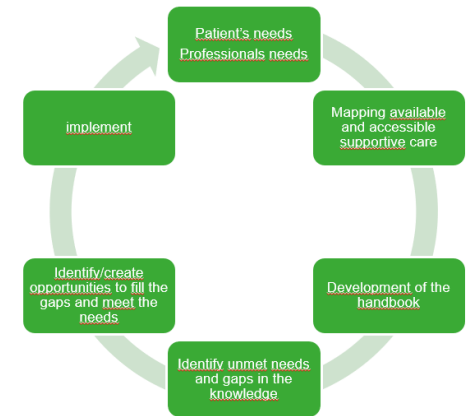
PROFILE OF MEMBERS:

- ❖ Healthcare professionals and organizations/ societies
- ❖ Healthcare centres (ie. 86 OCPs)
- ❖ Scientific societies and relevant research groups (e.g. health economy; AI; ...)
- ❖ NGOs, charities
- ❖ Patient organizations

BelNetSup: structure



The structure should serve the process...



BeNetSup: support & framework



MASCC's affiliate program strengthens our relationships with national associations of supportive care in cancer around the world. These partnerships help promote supportive care at the local level, tailored to each nation's particular needs, resources, and context.

Joining MASCC's affiliate program can help grow your membership, expand your reach, amplify your messages, and increase the profile of supportive care in cancer in your country. If you belong to a national-level organization focused on supportive care in cancer, contact our office at mascc.office@mascc.org for more information about becoming a MASCC affiliate.

If there's currently no national-level supportive care organization in your country, why not start one? Contact our office at mascc.office@mascc.org for information on getting started.

BeINetSup: support & framework for development

Early 2025: two joint actions will start

Joint Actions are collaborative projects involving several EU and associated countries with the objective to address key EU health policy priorities, for example, by sharing, testing and refining successful tools, methods and approaches.

	Joint Action Network of Expertise (JANE2)	Joint Action EU Network of Comprehensive Cancer Centres (EUnetCCC)
Target group(s)	centres of expertise, highly-specialized centres, research institutions, etc.	Certified and potentially future CCCs
Be partners involved in survivorship WPs	SC (co-leader of WP3) 6 partners: IJ Bordet, St Luc, UZ Gent, UZL, UZA, VUB	Sciensano (co-leader of 8.2.7) Second round of calls (+/- 2026)

BeINetSup: support & framework

❖ JA EuNetCCC

*The primary objective of the EU CCC network is to create a cohesive and integrated consortium of CCCs across Europe to ensure that all patients, regardless of their location, have access to high-quality care. This network will also serve as **a platform for collaboration, allowing centres to share best practices, resources, and knowledge.** Such collaboration is essential in promoting research, integrating the latest findings into clinical care, and ensuring that patients benefit from the most effective treatments available.*

BeNetSup: support & framework

❖ JA EuNetCCC

WP8 Network activities

Task 8.2 Develop and implement specific cooperation activities

Sub-task 8.2.7 Introduce comprehensive cancer survivorship programs in all EU CCCs.

*This subtask focuses on **creating and implementing comprehensive survivorship programs** across EU CCCs to address the varied needs of cancer survivors:*

CCC Role Definition: *Outline CCCs' roles in survivorship programs (services coordination and integration)*

Knowledge Exchange: *Set up forums for CCCs to share survivorship care best practices and innovations*

Program Customization: *Develop survivorship programs tailored to different age groups*

Strategic Partnerships: *Collaborate to align programs with wider initiatives (incl. training)*

Program Dissemination: *Share JANE2's harmonized survivorship care plans and organize twinning opportunities for specialized programs like elderly care, sports, art therapy, and support in psychology and nutrition*

BeINetSup: support & framework

Joint Action Networks of Expertise

The Joint Action on Networks of Expertise (JANE-2) is aimed at creating seven EU networks of a new kind, named “Networks of Expertise” (NoEs), in the cancer area, and allowing them to start fulfilling their Mission:

- a) producing, or supporting, clinical practice guidelines and/or general recommendations for medical professionals, patients, the public;
- b) raising public awareness and carrying out advocacy/policy actions;
- c) developing healthcare organization models;
- d) developing educational initiatives/tools for medical professionals and patients
- e) undertaking efforts to promote research;
- f) developing quality criteria for accreditation/endorsement mechanisms;
- g) engaging patients and the public;
- h) others.

BeINetSup: support & framework

Joint Action Networks of Expertise

TASK 1. NoE organigram, governance and synergies

UZL, IJB

TASK 2. Landscape analysis on current survivorship care across Europe

UZL

UZA, IJB

TASK 3. Development of integrative survivorship care programme

VUB, UZG, IJB

UZL

TASK 4. Capacity-building programme on integrative cancer survivorship care

UZG, IJB,

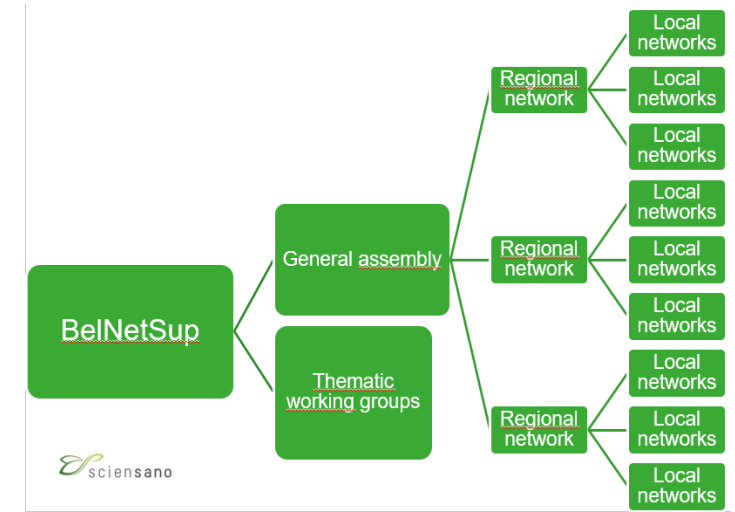
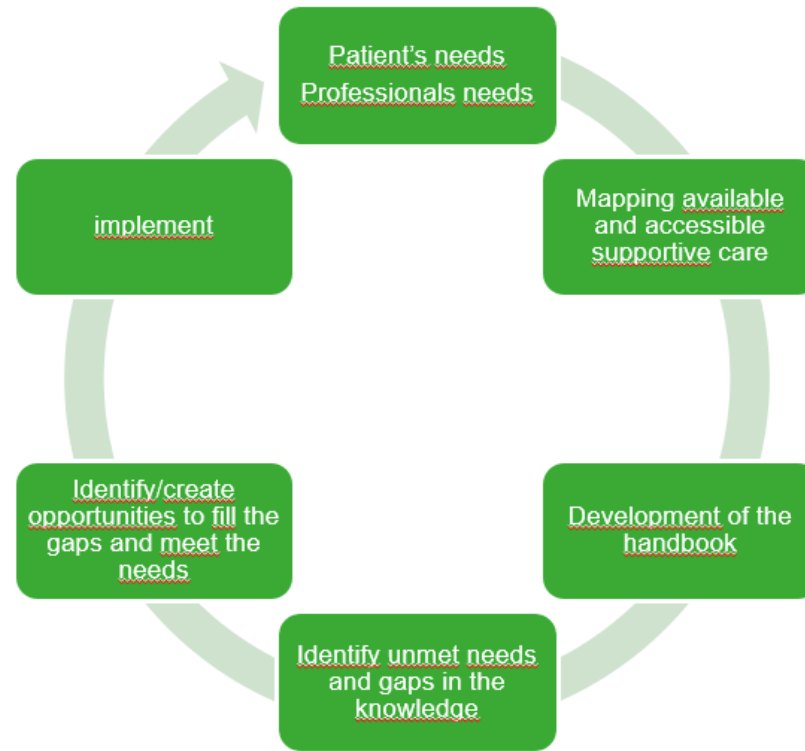
UZL

TASK 5. Implementation of cancer survivorship care programmes

UZL, UZG, IJB

TASK 6. Evaluation of cancer survivorship program, scaling-up, dissemination and sustainability

UGENT, UZL, IJB



Equality



Equity



Accessibility

Contact

Régine Kiasuwa Mbengi • BeONCOsup@sciensano.be • +32 2 642 5765

Sofie Theys • BeONCOsup@sciensano.be • +32 2 642 5889

RECEPTION



During reception : presentation of Belgian initiatives regarding oncological supportive care



Ann De Zitter (Axxon)

Andrea Cornez and Jerome Van Lindth (Bao Academy)

Juliette Berguet (Baob Brussels)

Nathalie Deleu and Isabelle Paelinck (Oncobulle)

Régine Simonis and Alexandra Paye (Oncocoon)

Nathalie Vanlaer (UZ Brussel - CHU Brugmann))

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



An Lebacqz

Expert Care and Support at Stichting tegen Kanker/ Fondation contre le Cancer. She focuses her efforts on the cancer care homes and patient empowerment

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



Dr. Bernard Willemart (Espace bien-être l'Essentiel – Namur)

Head of the Department of Onco-Hematology, Radiotherapy and Nuclear Medicine at the Sainte-Elisabeth site of the Centre Hospitalier Universitaire (CHU) UCL Namur. He is also in charge of the wellness centre Espace Bien-être l'Essentiel, created exclusively for cancer patients and their families.

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



Dr. Christel Fontaine (BSMO taksforce Supportive Care - Survivorship)

Medical oncologist working at the UZ Brussel for 30 years. At the beginning of her career she treated all types of cancers, but is now mainly focused on the care of breast cancer, sarcomas and supportive care. In 2018 together with Prof. Klastersky, she created the Belgian Society of Medical Oncology (BSMO) supportive care task force and organized in 2023 the fifth post MASCC meeting

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



Prof. Dr. Dirk Van Gestel (Belgium Board of Oncology)

Medical Director of Oncology and Academic Director of the Radiotherapy department at the Institut Jules Bordet, Hôpital Universitaire de Bruxelles (H.U.B.). He is also professor Radiation-Oncology at the ULB. Dirk is president of the Belgian Board of Oncology and the Belgian Hadron Group, secretary of the Belgian Society of Cancer Research, member of ESTRO, BeSTRO, BARO, college of Radiotherapy, Flemish task group Head and Neck Cancer, different EORTC Groups (ao HNC group), European Head and Neck Society (EHNS), etc.

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



Michiel Daem (University hospital UZ Ghent)

Clinical nurse specialist at the Cancer Centre of Ghent University Hospital. In recent years, he has been responsible for the follow-up and supervision of neuro-oncology patients. He is also committed to optimising care for cancer survivors at the hospital. Michiel is active on the boards of BANO, CHI and VVRO.

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



Hans Neefs (Kom Op Tegen Kanker)

Researcher and policy advisor for Kom op tegen Kanker, a cancer NGO in Flanders. His topics of interest are survivorship care, psychosocial care, AYA (Adolescents and Young Adults with Cancer) care, transmural care and healthcare professional-patient communication.

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



Magali Mertens (ASBL Travail et cancer)

Her mission revolves around harmonising illness and working with RESILIENCE, as a coach, author, consultant and trainer. Her motivation is to INSPIRE everyone to focus on their abilities to create a more inclusive work environment, essential for a healthy business.

ROUNDTABLE

State of play and future directions for supportive cancer care and survivorship in Belgium



An Lebacqz (Stichting tegen Kanker/Fondation contre le Cancer)

Bernard Willemart (Espace bien-être l'Essentiel - Namur)

Christel Fontaine (BSMO taksforce Supportive Care - Survivorship)

Dirk Van Gestel (Belgium Board of Oncology)

Michiel Daem (Universitair Ziekenhuis Gent)

Hans Neefs (Kom Op Tegen Kanker)

Magali Mertens (ASBL Travail et cancer)

CLOSING REMARKS



Karin De Ridder

Scientific Director Epidemiology and
Public Health - Sciensano

‘Health literacy’: What’s in a word...

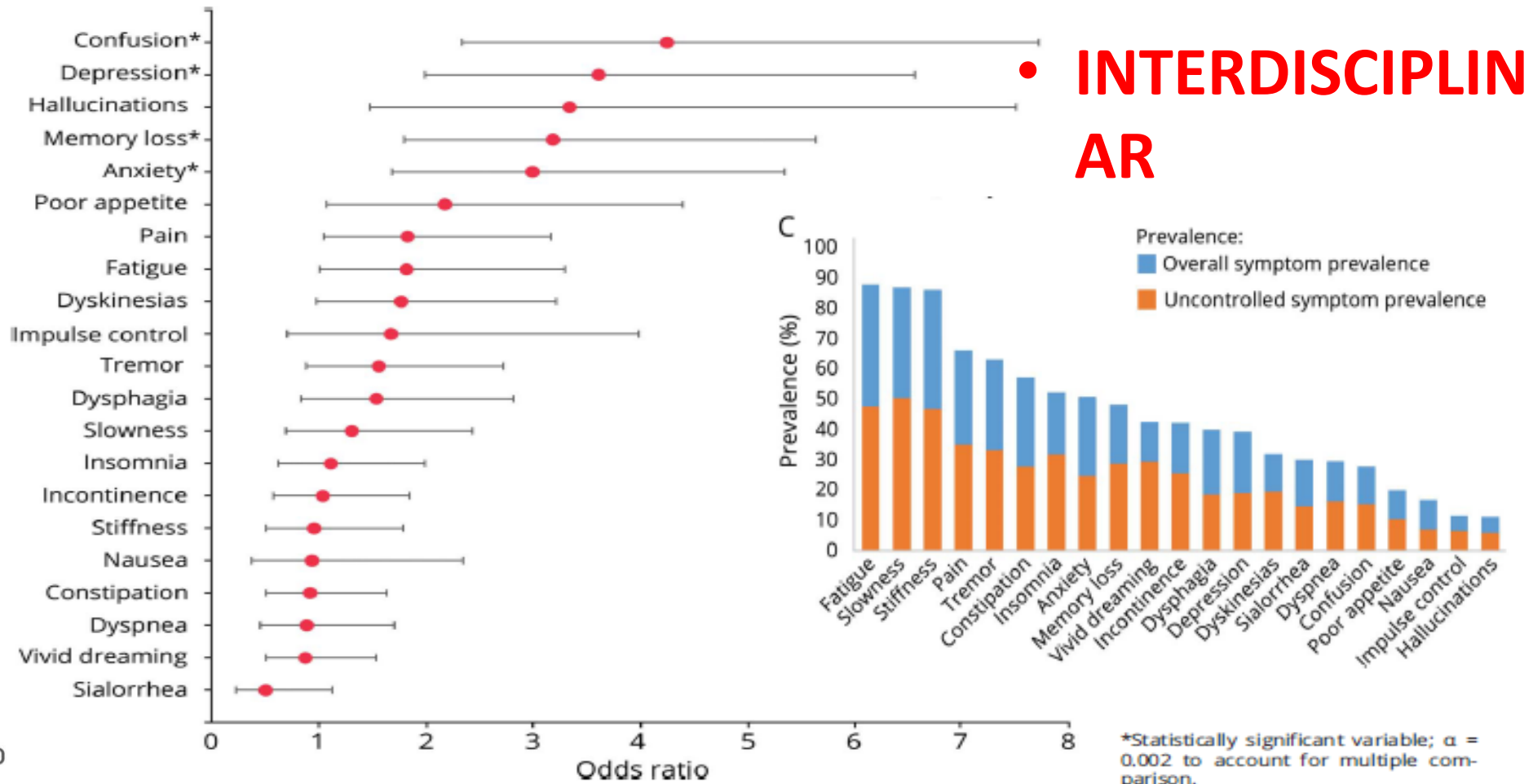


- Term more positively perceived (by patients and caregivers)
- Popularization of this alternative term? Beyond cancer...
- ‘general road maps’ based on clinical state and trajectory → proactive planning
- Systematised? Nomenclature? Care plans?

The terms supportive and palliative care – analyses of their prevalence and use: quasi-systematic review. Sobocki et al. Palliat Med Pract 2021; 15,: 248-253

The importance of an integrated medical follow up... for quality of life

Figure 2 Odds ratios of each uncontrolled symptom predicting poor quality of life in independent regression models



Psychosocial support...from the start

- Not patient with disease BUT **family with disease**
- Patient-centered care - emotional, spiritual, social struggles?
early and routinely screening (guidelines?)
- Care giver/partner/family support

- Planning future (by the patient & their family)
→ need for 'general road map'

TRANSDISCIPLINAR



.....empowerment

Acute medicine \neq chronic disease medicine \rightarrow caring attitude

'Empowerment begins when you feel heard, seen, respected and recognised.'

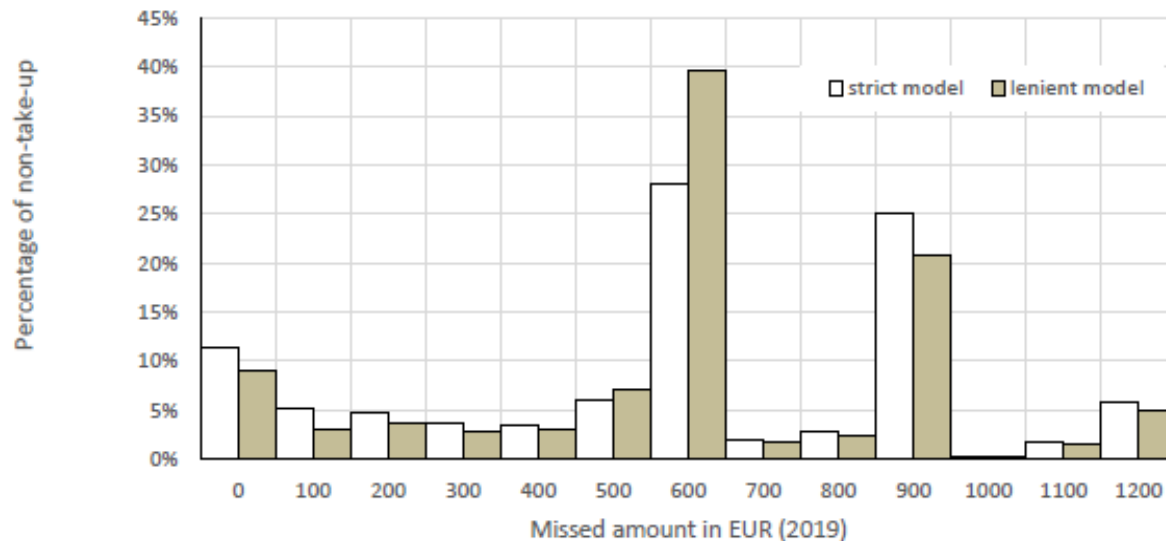
Manu Keirse



\rightarrow 'RAINBOW' model of integrated care:
normative (cultural) and functional (technical) enablers in the system?

Access to social care...

Figure 11. Percentage of persons with non-take-up by “missed” amount of benefit (%), active population (18-64 years), 2019



Source: TAKE Survey, TAKEMOD mixed model, own calculations.

- Increased Reimbursement for Health Care (18-64 yrs old): ‘those in paid employment have a relatively high probability of non-take-up (about 64%), while also accounting for a about half of all those not taking up IR’
- Take. Reducing poverty through improving take up of social policies (BRAIN-be)

→ Which professionals and services/institutions are central?
→ What are the ‘system’ gaps?

Self-Manager of our health

a **proactive and universal** support to people with long-term physical and mental health conditions to build **knowledge, skills and confidence and to live well** with their health condition:

Normative:

Shared decision making?

Plan?

Enabling choice?

Technical:

Community-based support?

Supported self-management?

intensive and integrated approaches to empowering people with more **complex needs to have greater choice and control over the care they receive.**



Contact

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THANK YOU!

Contact

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Sofie Theys • BeONCOsup@sciensano.be • +32 2 642 5889