

How to include the specific needs of AYA in cancer care

pictures: <https://www.uzleuven.be/nl/jong-en-kanker>



Hello!



Johan De Munter

Cancer Nurse manager Cancer
Center
University Hospital Ghent, Belgium



EONS Past President
European Oncology Nursing Society



SIOP Europe AYA Committee
& The European Network for
TYA with Cancer (ENTYAC)



Co-chair AYA steering
Committee, AYA movement, BE



Board member Majin Huis



Once Upon a Time ... in 2003

- I met Ben, 16y... diagnosed with a brain tumor.
- No idea how to handle this situation...
- No idea where to find support...
- After some time transferred to a University hospital.
- Lost in transition (patient & healthcare professionals)



“I MAY NOT TELL YOU, I MAY NOT SHOW YOU, BUT I HAD CANCER“



Not shared
(read on my
file &
Googled)

Only parents
were informed

Unaware of
treatment steps

Treatment decisions
→ mainly medical
team & sometimes
shared with carers

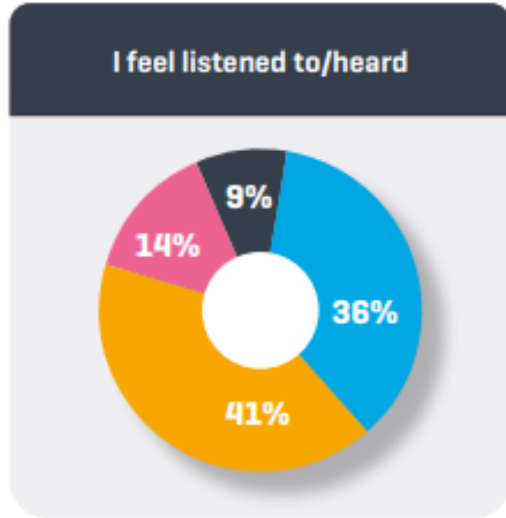
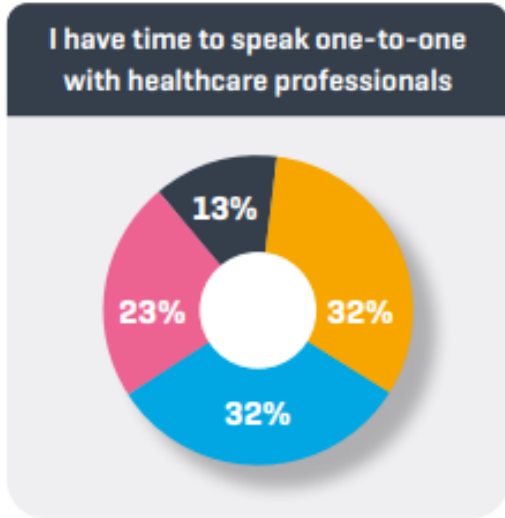
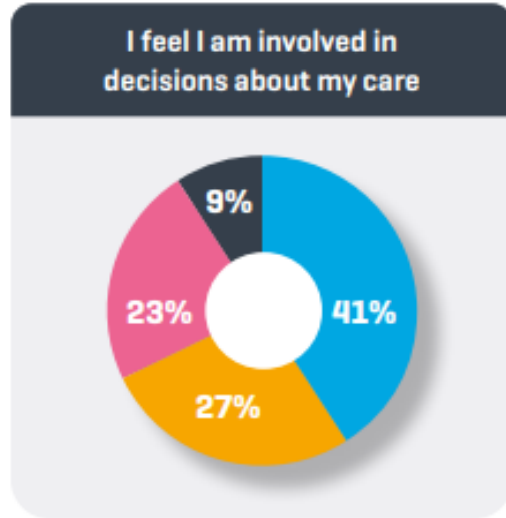
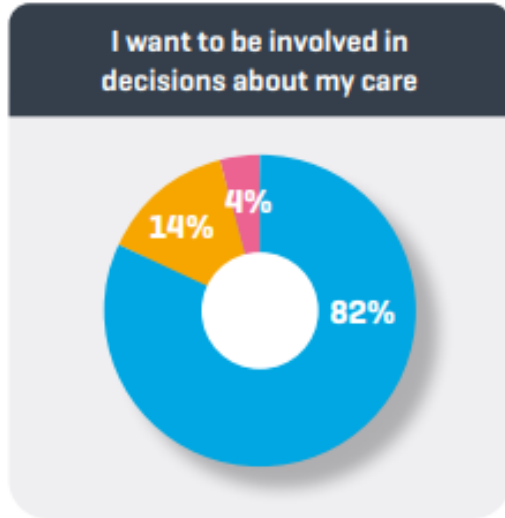
Unaware of
late effects
& follow-up

What is that?!



AYA experiences

Never Rarely Sometimes Often Always







22 November 1990, Teenage Cancer Trust's first specialist cancer unit at the Middlesex Hospital in London

"We never dreamed back then in the early 90s that Teenage Cancer Trust would become what it is today. We had no great vision of the future at that stage, but just wanted to do something that would make things better for young people experiencing the great burden of cancer diagnosis and treatment."

Myrna



The global burden of Adolescent & Young Adult cancer

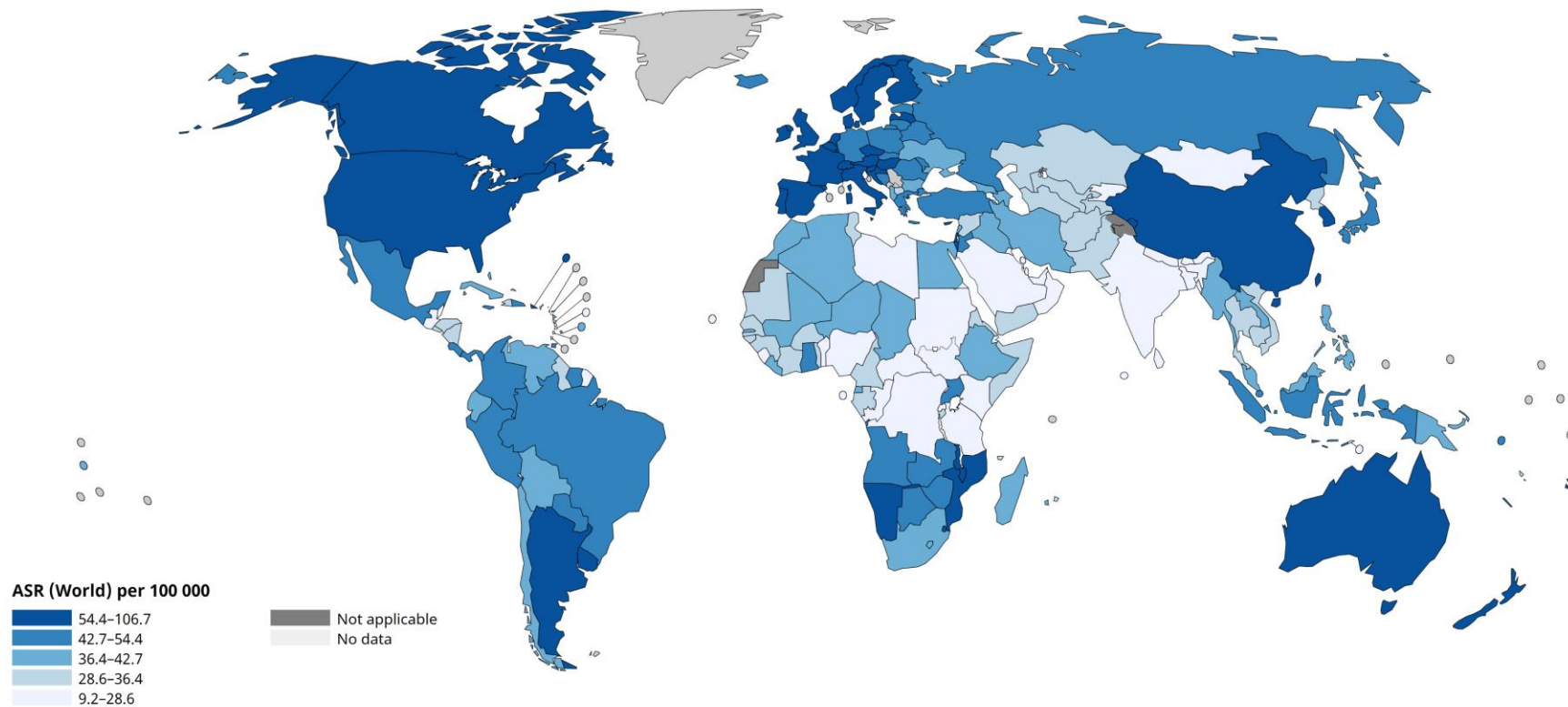
In 2021 → 1.19 million incident cancer cases & 396 000 deaths due to cancer among people aged 15–39 years worldwide

A	Absolute DALYs, millions (95% UI)	Global rank	High SDI rank	High-middle SDI rank	Middle SDI rank	Low-middle SDI rank	Low SDI rank
Mental disorders	56.5 (41.0-74.8)	1	1	1	1	1	1
Self-harm and interpersonal violence	40.5 (37.8-43.4)	2	6	3	4	2	4
Musculoskeletal disorders	39.4 (27.3-52.6)	3	2	2	2	6	13
Other non-communicable diseases	37.5 (27.3-51.8)	4	4	4	5	3	5
Transport injuries	35.7 (32.1-38.7)	5	7	5	3	4	7
Neurological disorders	30.5 (10.8-60.4)	6	5	7	7	9	10
Cardiovascular diseases	29.8 (27.6-32.1)	7	11	8	6	5	9
Unintentional injuries	29.7 (25.9-34.3)	8	8	6	8	8	12
Respiratory infections and tuberculosis	24.3 (21.6-27.1)	9	17	13	11	7	2
Adolescent and young adult cancers	23.5 (21.9-25.2)	10	9	9	9	13	15
HIV/AIDS and sexually transmitted infections	23.3 (18.3-30.4)	11	19	16	10	11	3
Substance use disorders	19.8 (15.3-25.0)	12	3	10	15	19	22
Digestive diseases	19.3 (17.1-22.1)	13	13	12	12	10	14
Maternal and neonatal disorders	18.4 (16.3-20.6)	14	15	17	16	12	6
Skin and subcutaneous diseases	15.5 (10.1-23.1)	15	10	11	13	17	19
Diabetes and kidney diseases	13.2 (11.4-15.2)	16	14	15	14	16	18
Enteric infections	12.0 (8.74-16.5)	17	20	20	21	14	11
Neglected tropical diseases and malaria	10.8 (7.65-14.6)	18	22	21	20	18	8
Nutritional deficiencies	10.3 (6.95-14.5)	19	18	19	19	15	16
Sense organ diseases	10.1 (6.52-14.8)	20	16	14	17	20	21
Chronic respiratory diseases	9.04 (7.59-10.8)	21	12	18	18	21	20
Other infectious diseases	6.57 (5.89-7.34)	22	21	22	22	22	17

B	Absolute deaths (95% UI)	Global rank	High SDI rank	High-middle SDI rank	Middle SDI rank	Low-middle SDI rank	Low SDI rank
Self-harm and interpersonal violence	599 000 (559 000-641 000)	1	1	1	2	1	3
Transport injuries	505 000 (451 000-550 000)	2	2	2	1	3	5
Cardiovascular diseases	456 000 (420 000-494 000)	3	5	4	3	2	6
Adolescent and young adult cancers	396 000 (370 000-425 000)	4	4	3	4	7	8
HIV/AIDS and sexually transmitted infections	357 000 (271 000-480 000)	5	13	7	5	5	2
Respiratory infections and tuberculosis	321 000 (292 000-354 000)	6	11	8	7	4	1
Unintentional injuries	321 000 (285 000-351 000)	7	6	5	6	6	10
Digestive diseases	245 000 (224 000-267 000)	8	7	6	8	8	9
Maternal and neonatal disorders	161 000 (140 000-184 000)	9	16	15	11	9	4
Enteric infections	140 000 (93 600-207 000)	10	17	16	12	10	7
Diabetes and kidney diseases	127 000 (117 000-138 000)	11	9	10	9	11	13
Substance use disorders	95 100 (88 300-102 000)	12	3	9	16	17	18
Neglected tropical diseases and malaria	93 600 (54 000-152 000)	13	21	17	14	13	11
Other infectious diseases	87 600 (78 400-98 700)	14	14	14	13	12	12
Other non-communicable diseases	82 800 (74 100-92 900)	15	8	11	10	14	14
Chronic respiratory diseases	58 000 (52 500-64 100)	16	12	13	15	15	15
Neurological disorders	51 700 (47 100-57 700)	17	10	12	17	16	16
Nutritional deficiencies	12 200 (10 500-14 200)	18	19	20	19	18	17
Musculoskeletal disorders	11 100 (9 000-13 300)	19	15	18	18	19	19
Skin and subcutaneous diseases	4 940 (3 450-5 740)	20	18	19	20	20	20
Mental disorders	1 990 (176-257)	21	20	21	21	21	21

The global burden of Adolescent & Young Adult cancer

Age-Standardized Rate (World) per 100 000, Incidence, Both sexes, age [15-39], in 2022
All cancers

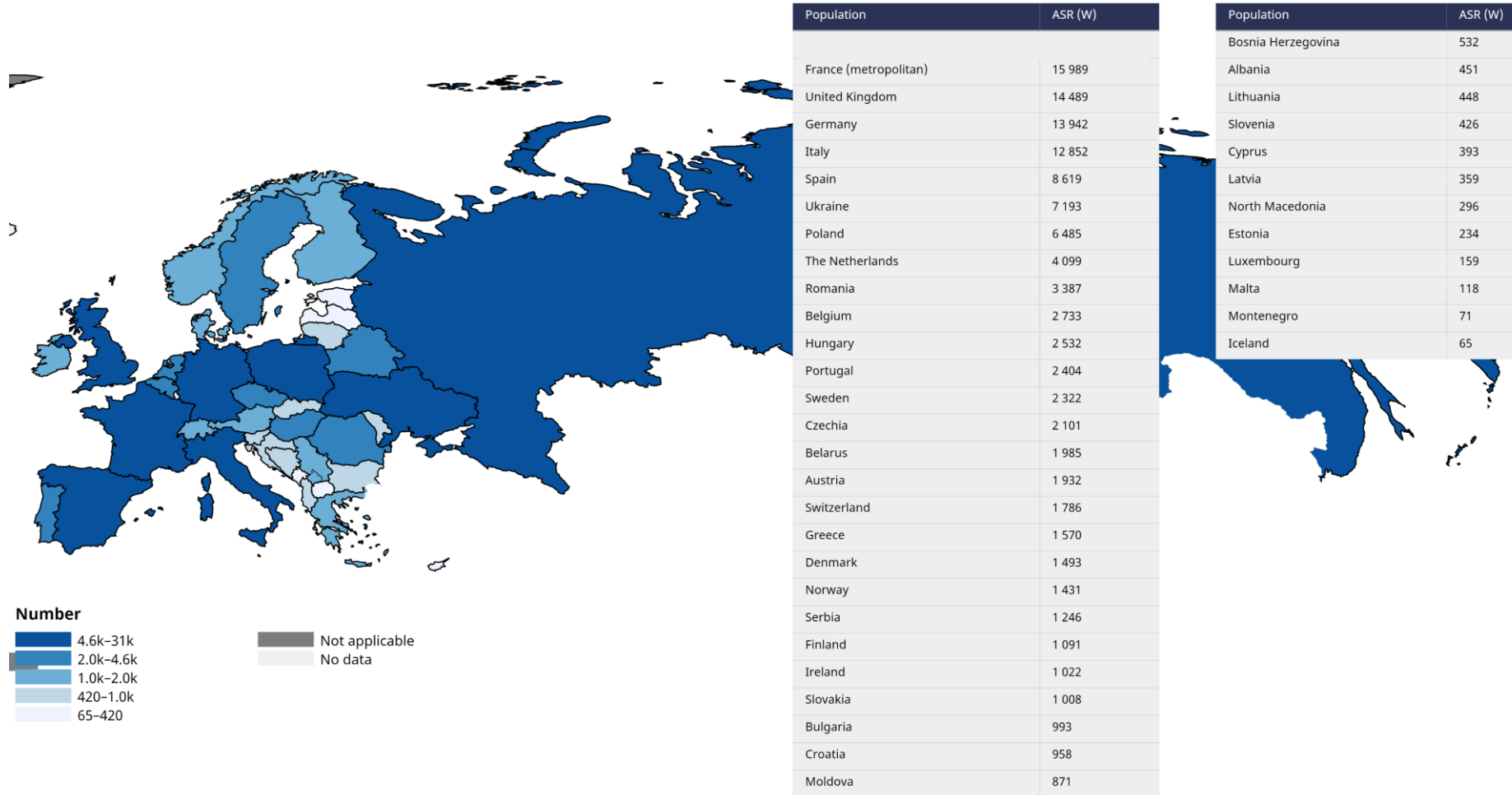


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Cancer TODAY | IARC
<https://gco.iarc.who.int/today>
Data version: Globocan 2022 - 08.02.2024
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Absolute numbers, Incidence, Both sexes, age [15-39], in 2022

All cancers



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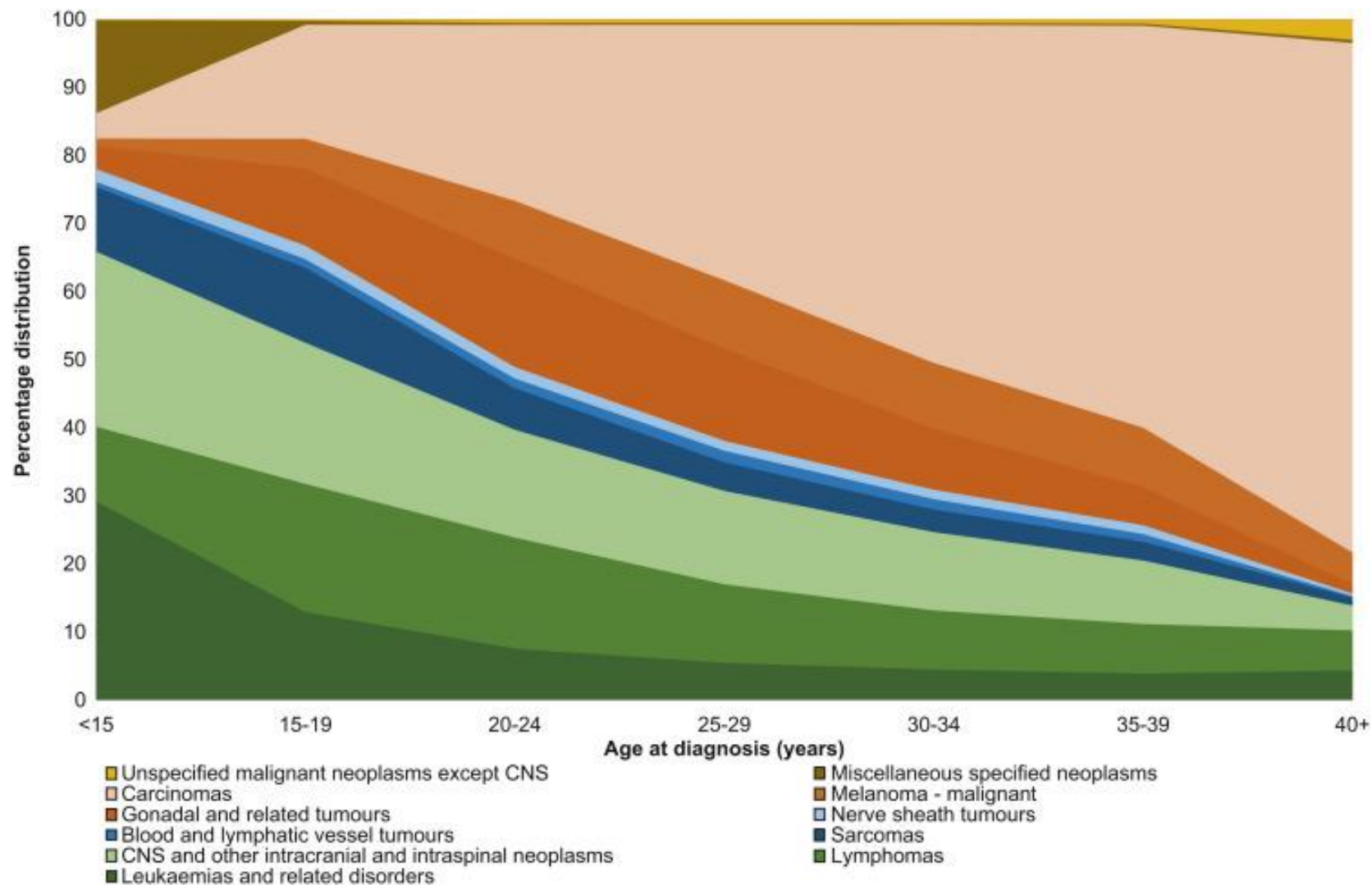


A. Trama, D. Stark, I. Bozovic-Spasojevic, N. Gaspar, F. Peccatori, A. Toss, A. Bernasconi, P. Quarello, K. Scheinemann, S. Jezdic, A. Blondeel, G. Mountzios, S. Bielack, E. Saloustros, A. Ferrari, Cancer burden in adolescents and young adults in Europe, ESMO Open, Volume 8, Issue 1, 2023, 100744, ISSN 2059-7029, <https://doi.org/10.1016/j.esmoop.2022.100744>.

Data from the European Cancer Information System (ECIS) for the EU-27 countries

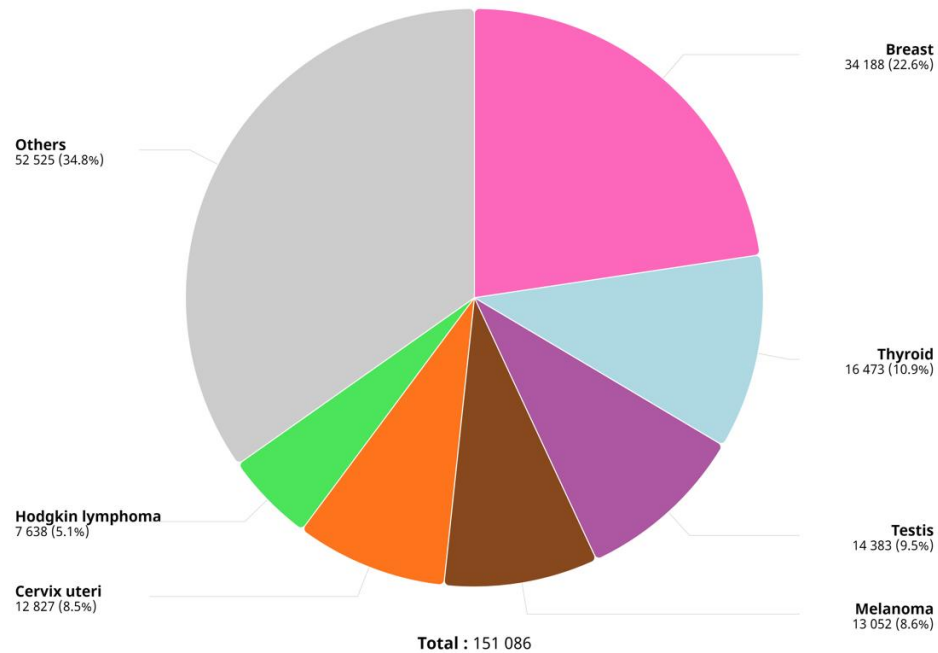
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Distribution of AYA cancer

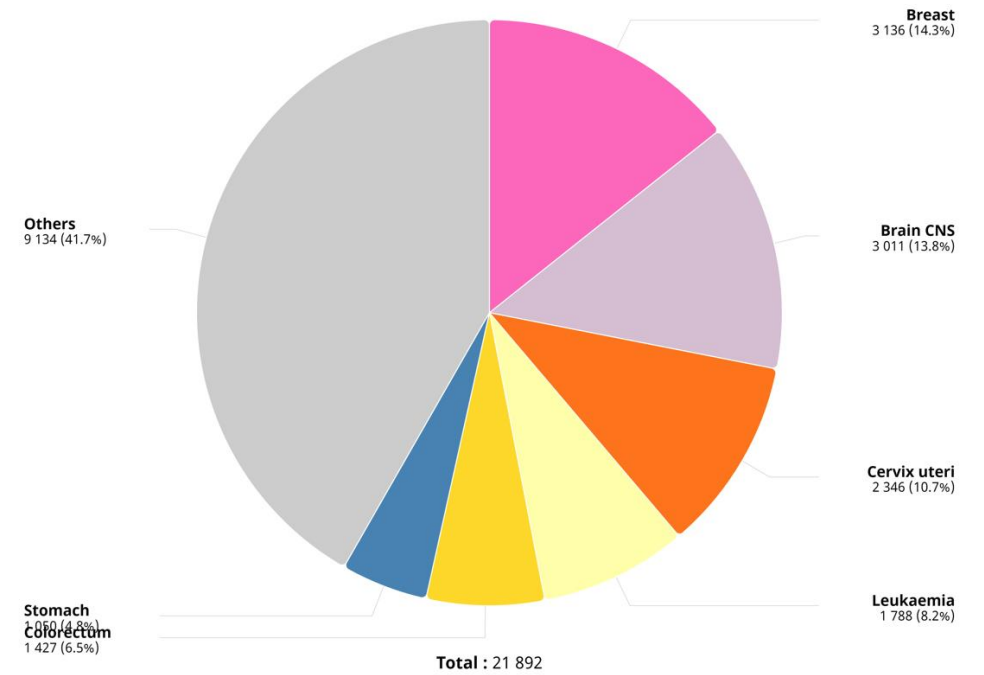


AYA cancer in Europe

Absolute numbers, Incidence, Both sexes, age [15-39], in 2022
Europe

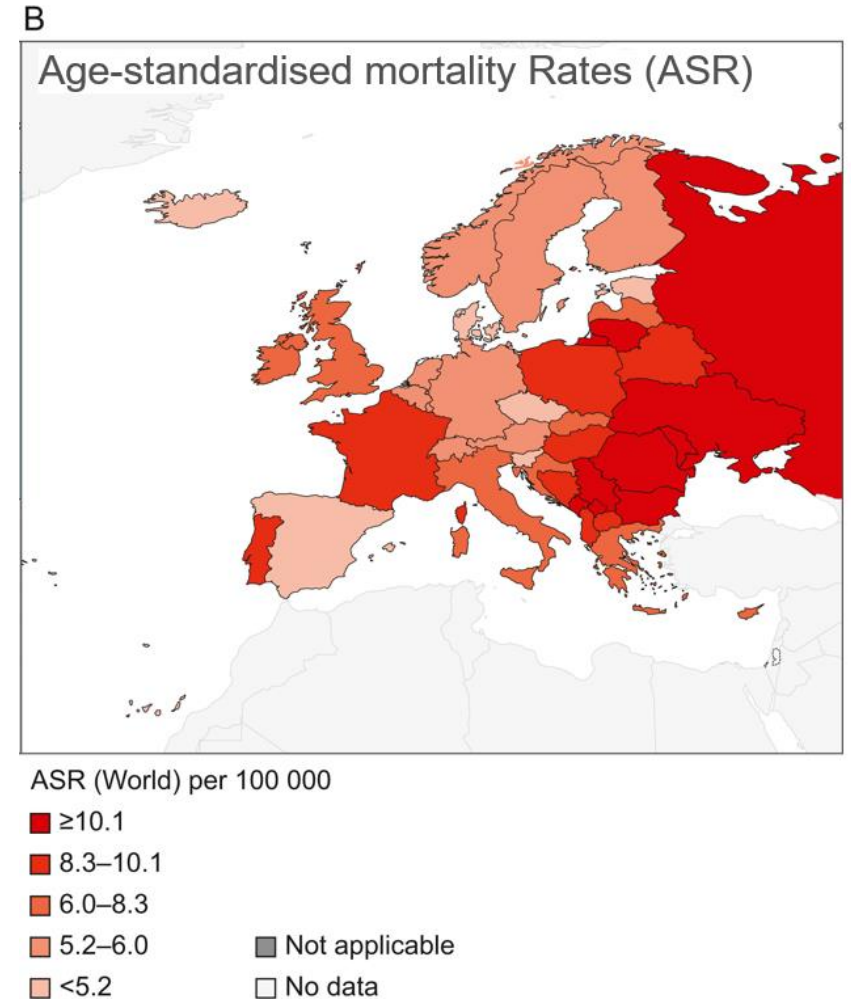


Absolute numbers, Mortality, Both sexes, age [15-39], in 2022
Europe



AYA cancer in Europe

- ▶ AYA cancer = rare cancer
- ▶ Differences in AYA cancer incidence and mortality exist within European countries.
- ▶ Mortality rates low for most cancers with the exception of cancers of the CNS & leukaemia

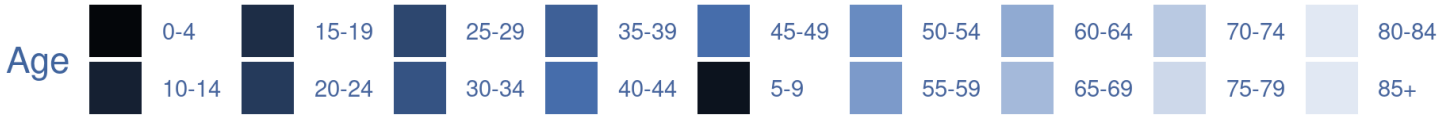
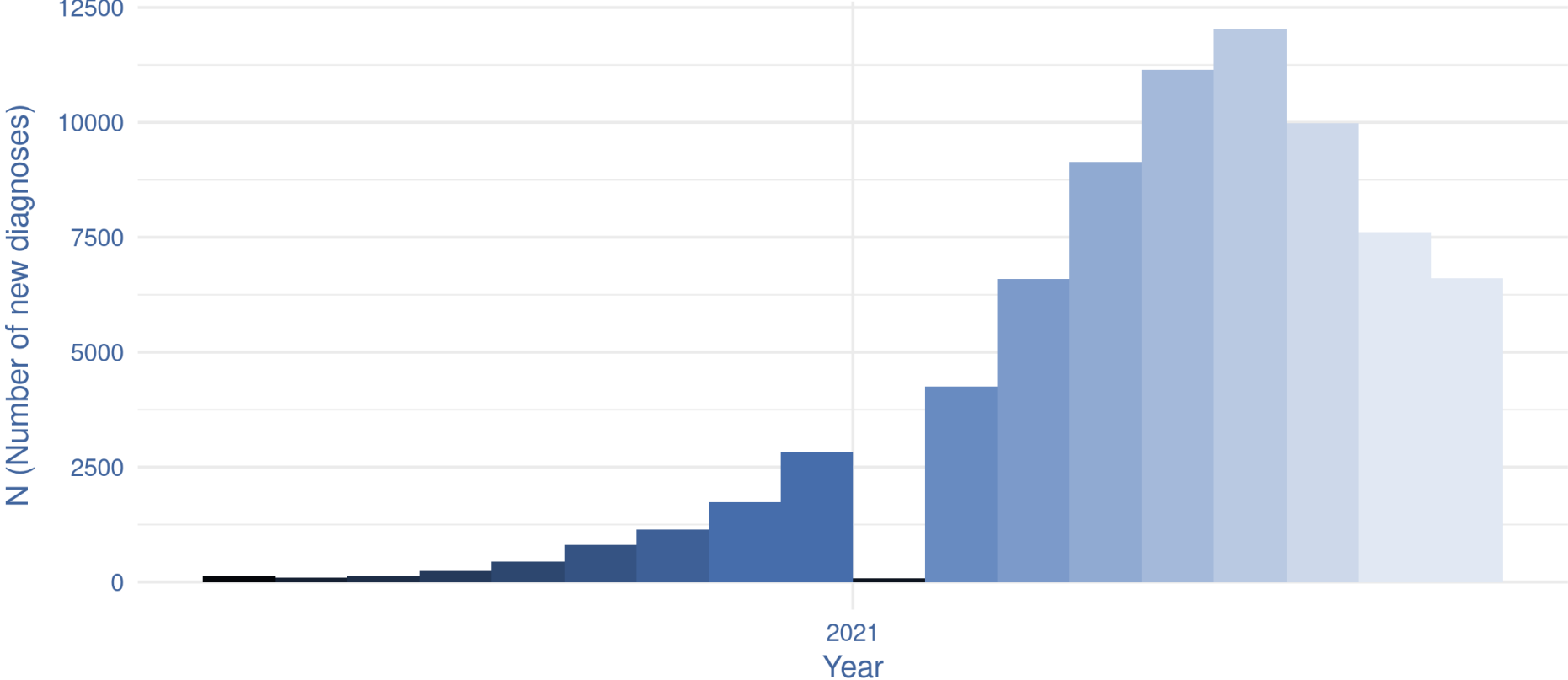


EPIDEMIOLOGY

Incidence by year & age (Number of new diagnoses)

Sex: Males and Females **Region:** Belgium **Cancer:** All cancers (excl. non-melanoma skin)

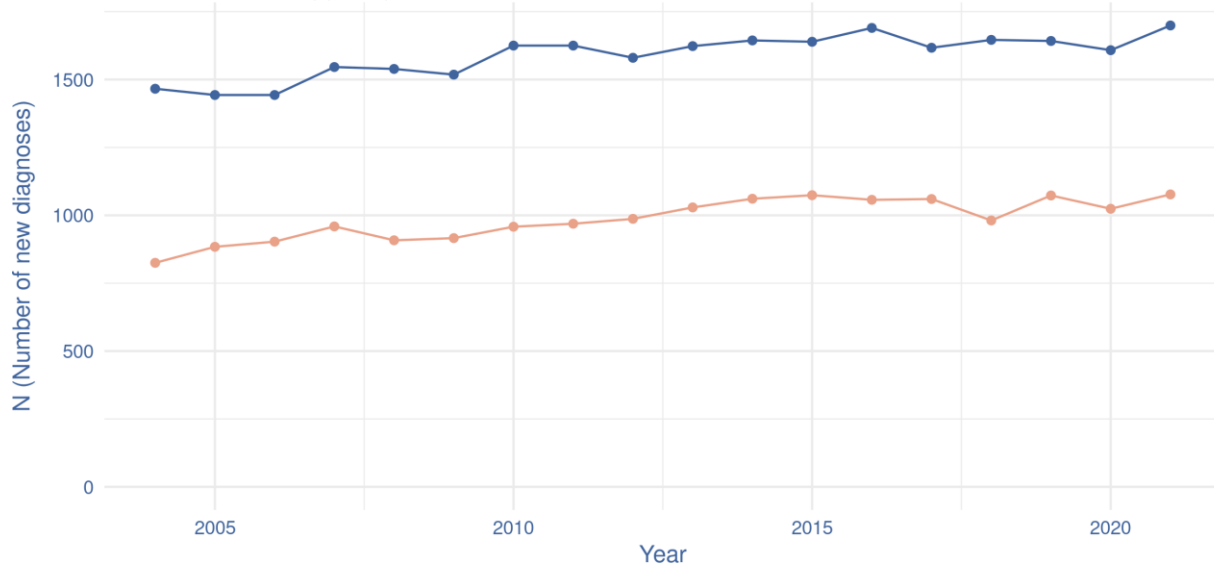
Source: Belgian Cancer Registry (05-2024)



Incidence by year & sex (Number of new diagnoses)

Age: 15-39 Region: Belgium Cancer: All cancers (excl. non-melanoma skin)

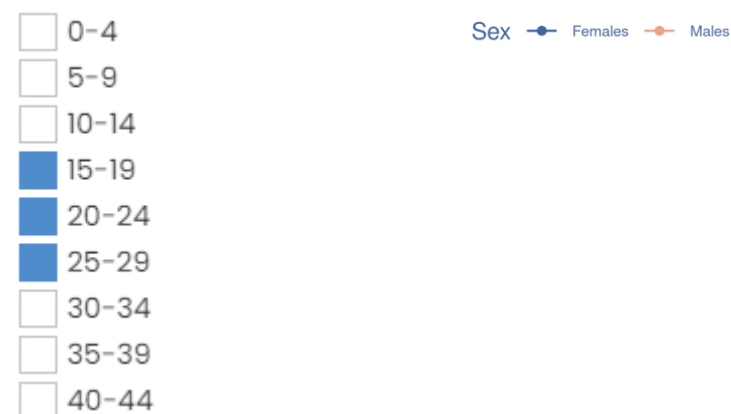
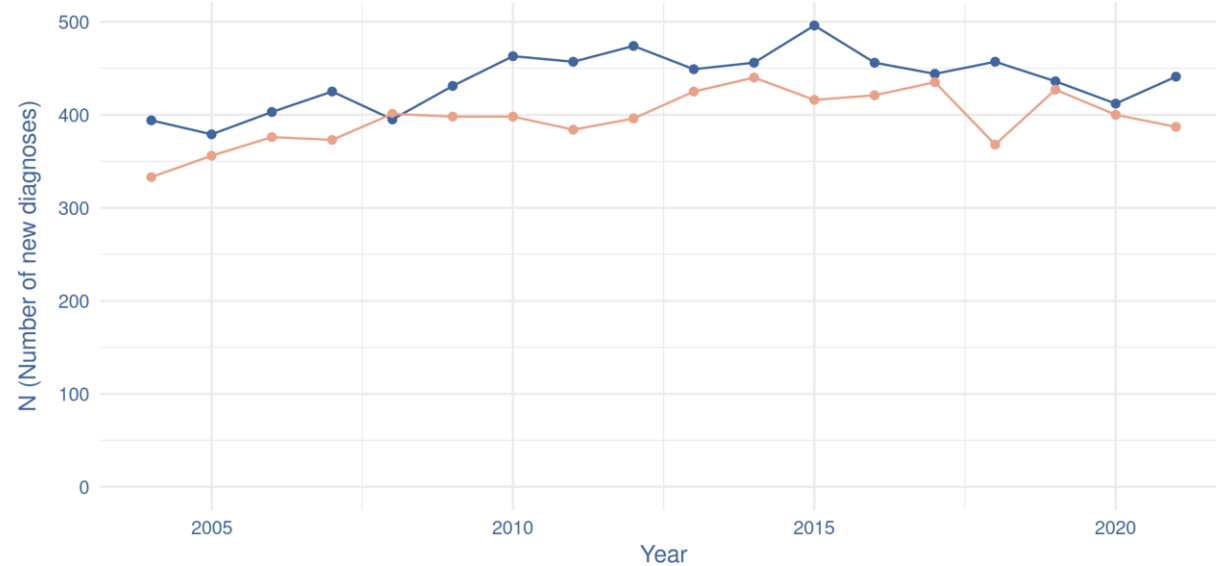
Source: Belgian Cancer Registry (05-2024)



Incidence by year & sex (Number of new diagnoses)

Age: 15-29 Region: Belgium Cancer: All cancers (excl. non-melanoma skin)

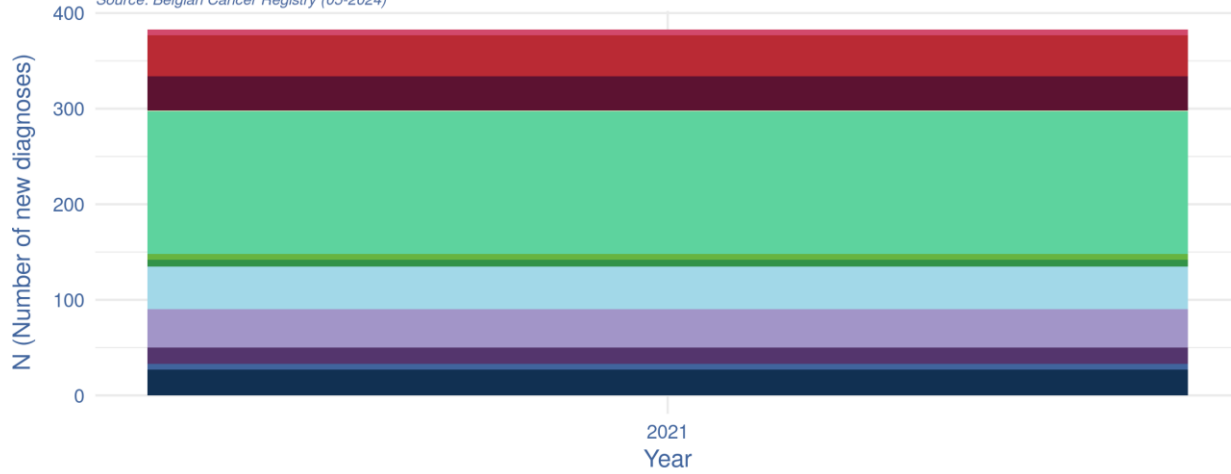
Source: Belgian Cancer Registry (05-2024)



Incidence by year & cancer (Number of new diagnoses)

Sex: Males and Females Age: 15-24 Region: Belgium

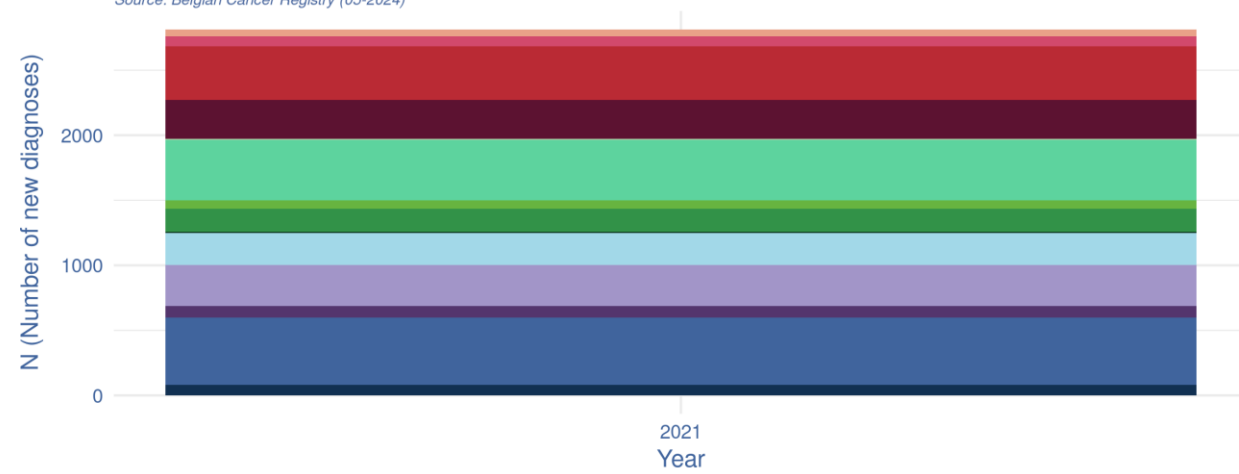
Source: Belgian Cancer Registry (05-2024)



Incidence by year & cancer (Number of new diagnoses)

Sex: Males and Females Age: 15-39 Region: Belgium

Source: Belgian Cancer Registry (05-2024)



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The International Charter of Rights for Young People with Cancer

Shree Rajani,¹ Andrew J. Young, PhD,² Devon A. McGoldrick, MPH,³
David L. Pearce,⁴ and Sarah M. Sharaf⁵

The International Charter of Rights for Young People with Cancer is a global internet-based initiative set up by five charities from across the world. They are calling on the international community to recognize that access to quality cancer care is a right, not a privilege, and to improve the services and support that young people diagnosed with cancer receive, regardless of geographical location.

The International Charter of Rights for Young People with Cancer

The International Charter of Rights for Young People with Cancer

Shree Rajani,¹ Andrew J. Young, PhD,² Devon A. McGoldrick, MPH,³
David L. Pearce,⁴ and Sarah M. Sharaf⁵

1. Receive **education** about cancer and its **prevention**, including **early detection**
2. **Be taken seriously** when seeking medical attention and receive the earliest possible **diagnosis and speedy referral for suspected cancer**
3. Have **access to suitably qualified multi-disciplinary medical specialists** with significant experience in treating cancer in this age group
4. **Information about and reasonable access to clinical trials and treatment** that has been clinically trialled with people in their age group
5. Receive **age-appropriate support** including, but not limited to, psychosocial, community and palliative support services
6. **Empowerment in making decisions** supported by full and detailed explanation of all treatment options and long-term effects of the disease enabling them to actively influence their care
7. **Fertility preservation**, as well as information and counselling concerning short-term and long-term effects of cancer and treatment which affect fertility
8. Have **access to specialised treatment and services in age-appropriate facilities alongside their peers**
9. **Financial and practical support** to minimise the burden of the disease during treatment
10. **Elimination of all forms of discrimination**, during and beyond treatment, in education, vocation and insurance, or in the community

The International Charter of Rights for Young People with Cancer is a global internet-based initiative set up by five charities from across the world. They are calling on the international community to recognize that access to quality cancer care is a right, not a privilege, and to improve the services and support that young people diagnosed with cancer receive, regardless of geographical location.

Introduction

CANCER IS A SIGNIFICANT ISSUE worldwide. In 2008, there were 12.7 million new cancer diagnoses worldwide, with nearly 21.4 million new cases annually predicted by 2030.¹

The International Charter of Rights for Young People with Cancer (www.cancercharter.org) is a global initiative set up by five charities from across the world—Teenage Cancer Trust in the United Kingdom, CanTeen Australia, CanTeen New Zealand, and LIVESTRONG and SeventyK in the United States. The term and age range used varies by organization and country, but each organization recognizes the needs of young people diagnosed with cancer and understands that this age group's cancers, symptoms, side effects, and psychosocial needs differ from those of children or older adults. The goal of each organization individually and collectively is to raise awareness of cancer patients that fall between the standard pediatric and young adult groups and to increase access to care and cancer care for these patients worldwide.

The Founding Charities

Teenage Cancer Trust

Teenage Cancer Trust (www.teenagecancertrust.org) is a United Kingdom-based charity dedicated to improving the quality of life and survival chances for teenagers and young people (TYAs, aged 13–24) with cancer. The charity receives no government funding and relies on voluntary donations to design, build, equip, and staff specialist teenage cancer units within National Health Service (NHS) hospitals. Because

young people often feel isolated during their treatment, Teenage Cancer Trust units are not like ordinary cancer wards—they are bright and vibrant and equipped with televisions, pool tables, music, and comfortable furniture. As well as creating a home-away-from-home atmosphere, they allow young people to be treated alongside others their age so that they can support each other. In addition to the specialist units, Teenage Cancer Trust also funds a number of services all with the same goal—to help young people fight cancer. These include clinical and research staff, an education program for schools, family support networks, and an annual conference for young cancer patients.

CanTeen Australia

CanTeen (www.canteen.org.au) is the Australian Organisation for Young People Living with Cancer. The touchstone of CanTeen is the belief that young people, through meeting and talking with one another, are better able to cope with the uncertainties of a cancer diagnosis. CanTeen's mission is to support, develop, and empower young people living with cancer. This is accomplished by providing a high-quality Australia-wide peer-support network of adolescents and young adults (AYAs, aged 12–24) living with cancer who share experiences, have fun, offer resources, and promote understanding, well-being, and leadership.

CanTeen is managing the implementation of a US\$30 million Youth Cancer Fund to establish age-specialized youth cancer centers and services throughout Australia, in partnership with the Sony Foundation Australia and the Australian government, and with the support of health professionals (through the

¹Teenage Cancer Trust, London, United Kingdom.

²CanTeen Australia, Sydney, Australia.

³LIVESTRONG, Austin, Texas.

⁴CanTeen New Zealand, Auckland, New Zealand.

⁵SeventyK, Laguna Beach, California.

A blueprint for age-specific care for adolescents with cancer in Flanders!



AGE in AYA cancer care

2021

Healthcare professionals survey about Adolescents and Young Adults (AYA) with Cancer

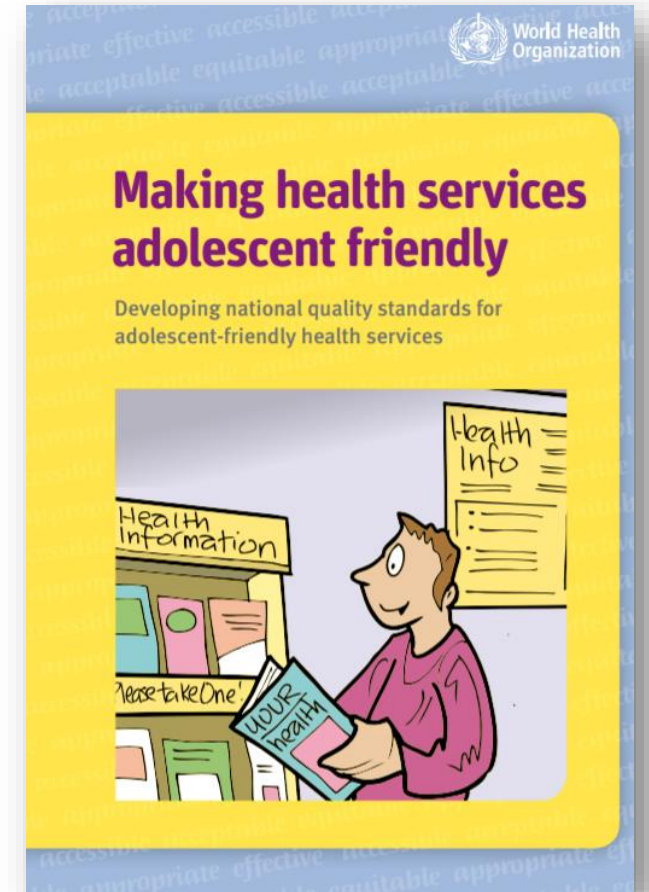


9. Indicate the lower age that is included in AYA where you work:
10. Indicate the upper age that is included in AYA where you work:
11. What age range would you find ideal?

AGE in AYA cancer care

- ▶ WHO definition of adolescence = 10-19 years!

Country or region	Age range of AYAO	Details
Australia	15-25	Widely accepted in jurisdictions and AYA services Australia-wide
USA	15-29	Generally what's used when talking in terms of clinical epidemiology (as a result of the 2006 Surveillance, Epidemiology and End Results (SEER) program report ¹ , a very prominent statistical reference in the field of AYAO)
	15-39	Generally what's used when talking in terms of a wider agenda for AYAO
Canada	15-29	Has followed the example of SEER
Europe BE: 16 -35 y NL: 18-35 y	13-24	The UK has developed AYAO services (through the Teenage Cancer Trust) around this age group
	15-24	Used by European members of EURO CARE (EUROpean CAncer REgistry-based study on survival and CARE of cancer patients)



The World Health Organisation. The second decade: improving adolescent health and development. The World Health Organisation, document WHO/FRH/ADH/98.18; Geneva, CH; 2001 & https://www.who.int/maternal_child_adolescent/documents/adolescent_friendly_services/en/

Bleyer A, O'Leary M, Barr R, Ries LAG (eds). Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD; 2006.

What should the age range be for AYA oncology? J Adolesc Young Adult Oncol. 2011;1(1):3-10.

AGE in AYA cancer care



<https://www.opeigenbenen.nu>

- ▶ **No universally accepted limits** defining the age range of AYA cancer.
- ▶ **Older patients in paediatric care** ⇔ **young patients in adult care!**

Adolescents → unique group?!

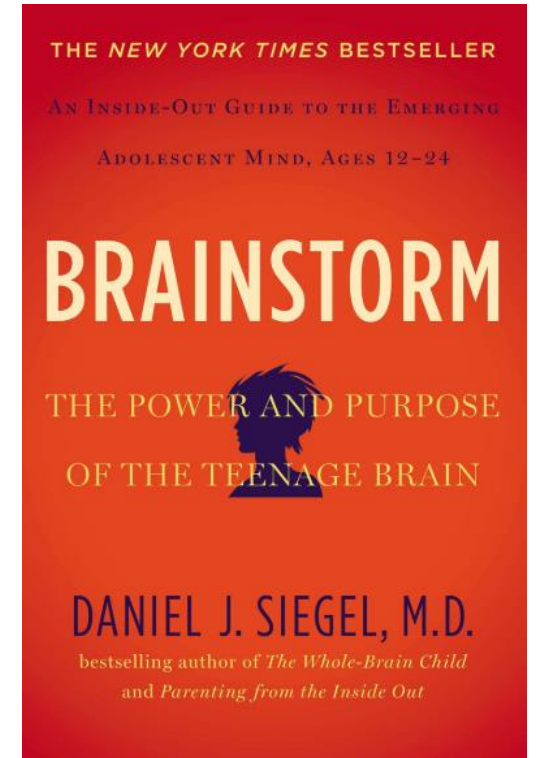
Adolescence

=

elements of biological growth

+

elements of growth in taking a position in society.



AYAs → unique group?!

- ▶ **Use age as demarcation of target group!?**

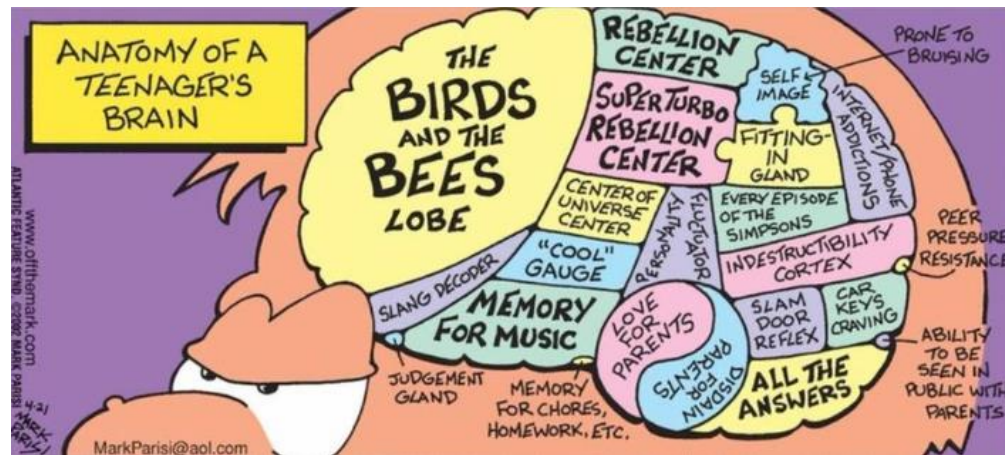
- ▶ BUT:

- Our biological development does not stop at 18!

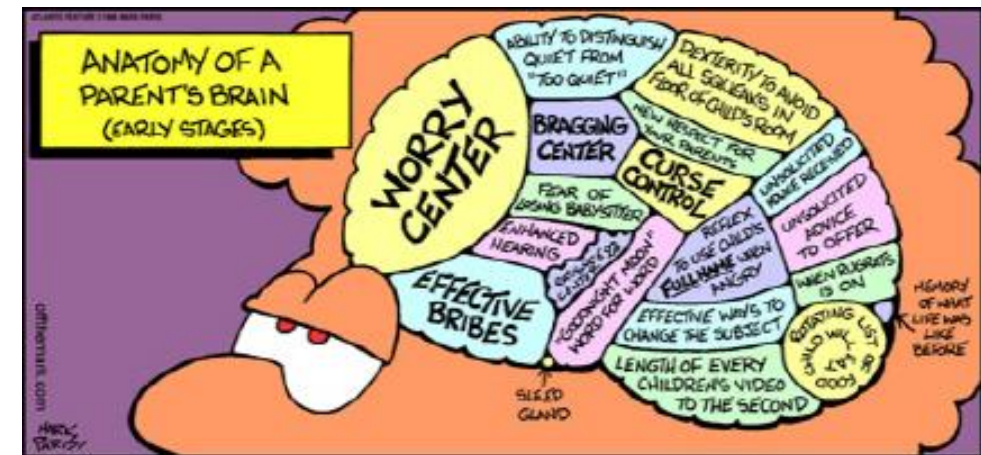
- Times are changing → graduating later, timing start professional activity, getting married, having children, ...

- Legislation! 18y → rights & duties

Adolescents



Parents, siblings, peers, ...



Two universal changes take place during adolescence:

- ▶ Physical & emotional Changes!
- ▶ Pushes away from parents, socializes more with peers & trying to do things in new/other ways. → AYAs are in the process of developing their own thoughts and perceptions of the world, forming new relationships and pushing boundaries.
- ▶ There is often a desire to challenge the rules set by their seniors, and experiment with risk-taking behaviours.

Listening to young people's concerns



Discussing difficult issues

Advocating for young people



Using familiar language yet remaining professional

Communicate by...

Current therapies and side effects specific to young people



Impact of cancer on psychological development



Developmental issues of emerging adulthood

Know about...

STUDY FINDINGS AND LEARNING

Honest and respectful

Please be...

Humorous

Committed to caring for young people



Friendly and approachable



Be skilful in...

Identifying the impact of disease on young people's lives

Excellent clinical skills

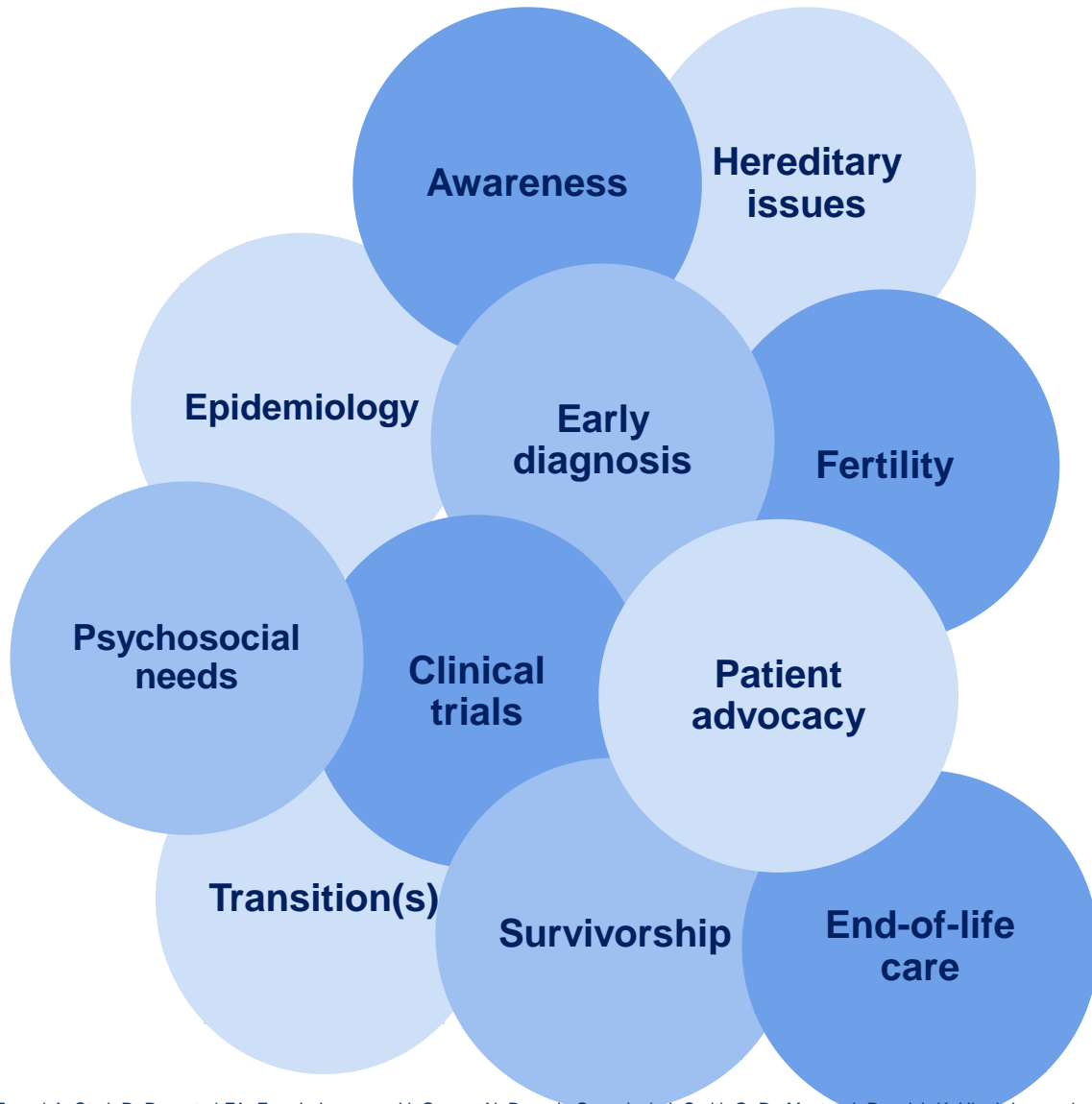


Partnership working



Patient-centred care

Current challenges in AYA care



REVIEW

Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE)

A. Ferrari^{1*†‡}, D. Stark^{2*†‡}, F. A. Peccatori³, L. Fern⁴, V. Laurence⁵, N. Gaspar⁶, I. Bozovic-Spasojevic⁷, O. Smith⁸, J. De Munter⁹, K. Derwich¹⁰, L. Hjorth¹¹, W. T. A. van der Graaf¹², L. Soanes¹³, S. Jezdic¹⁴, A. Blondeel¹⁵, S. Bielack¹⁶, J.-Y. Douillard¹⁴, G. Mountzios¹⁷ & E. Saloustros^{18†}

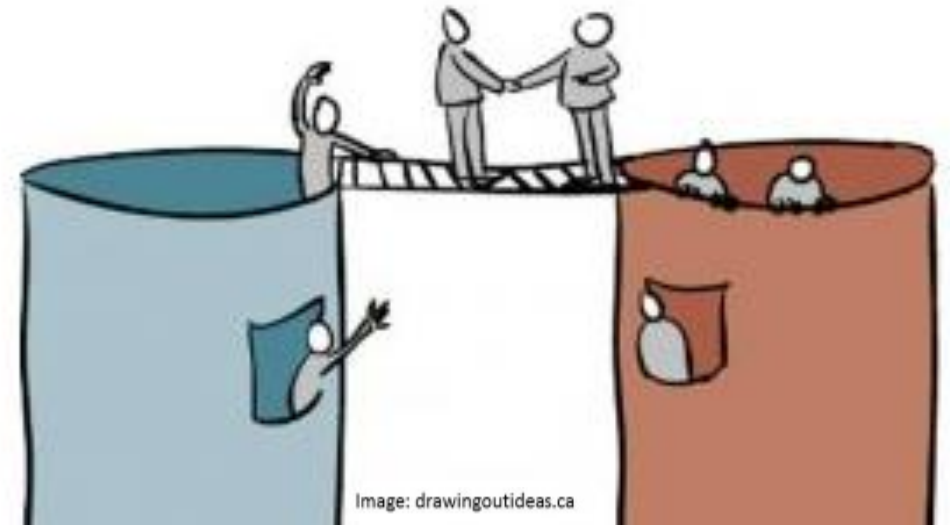
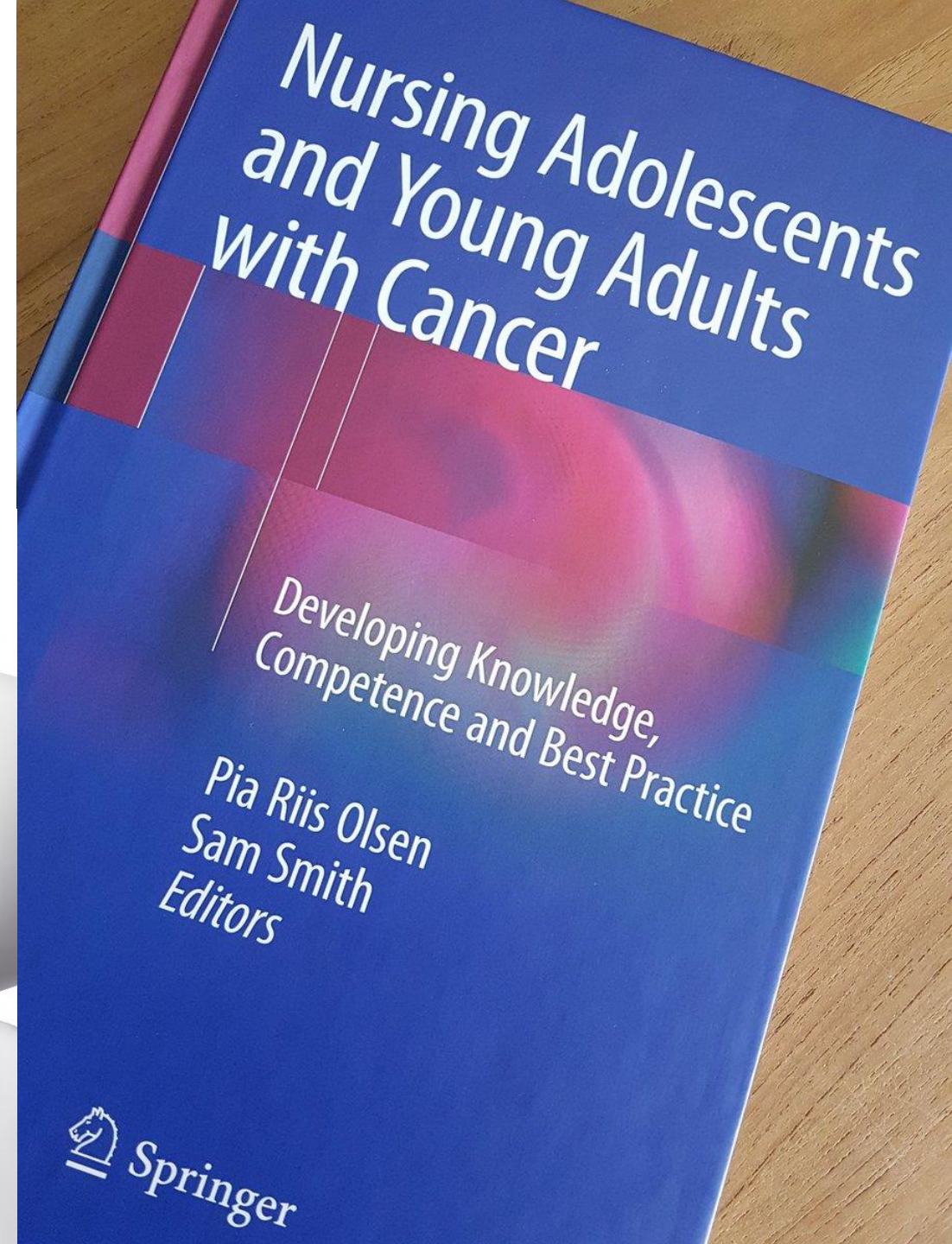


Image: drawingoutideas.ca

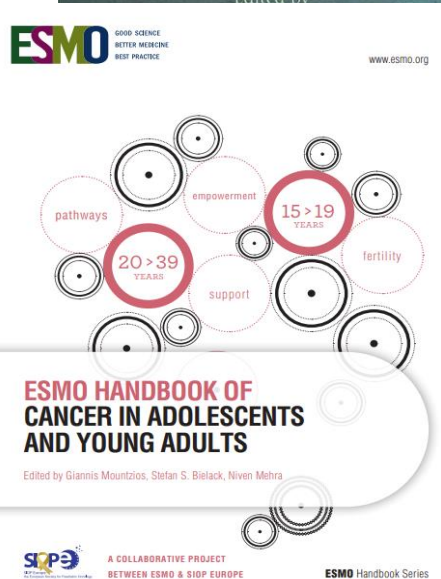
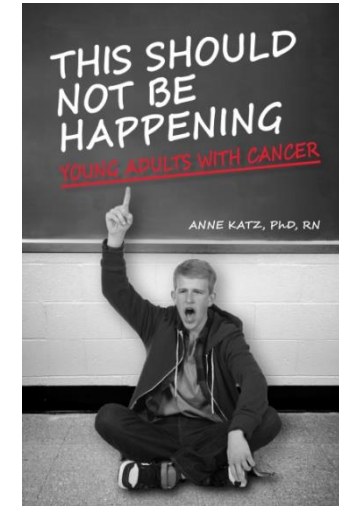
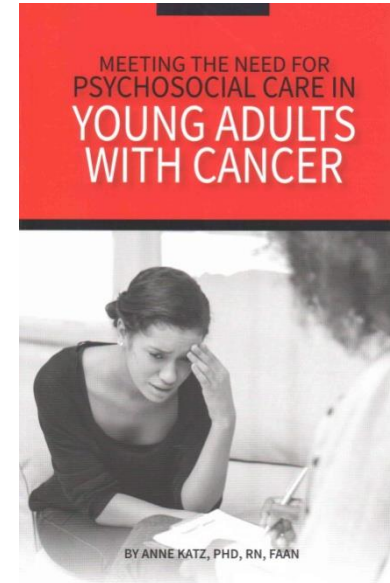
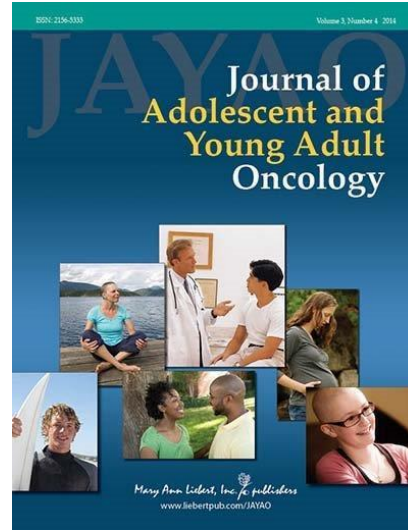
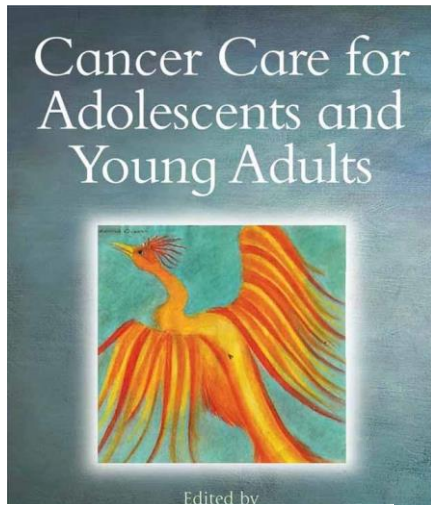
Knowledge about...

- ▶ **Education & training of Healthcare professionals**

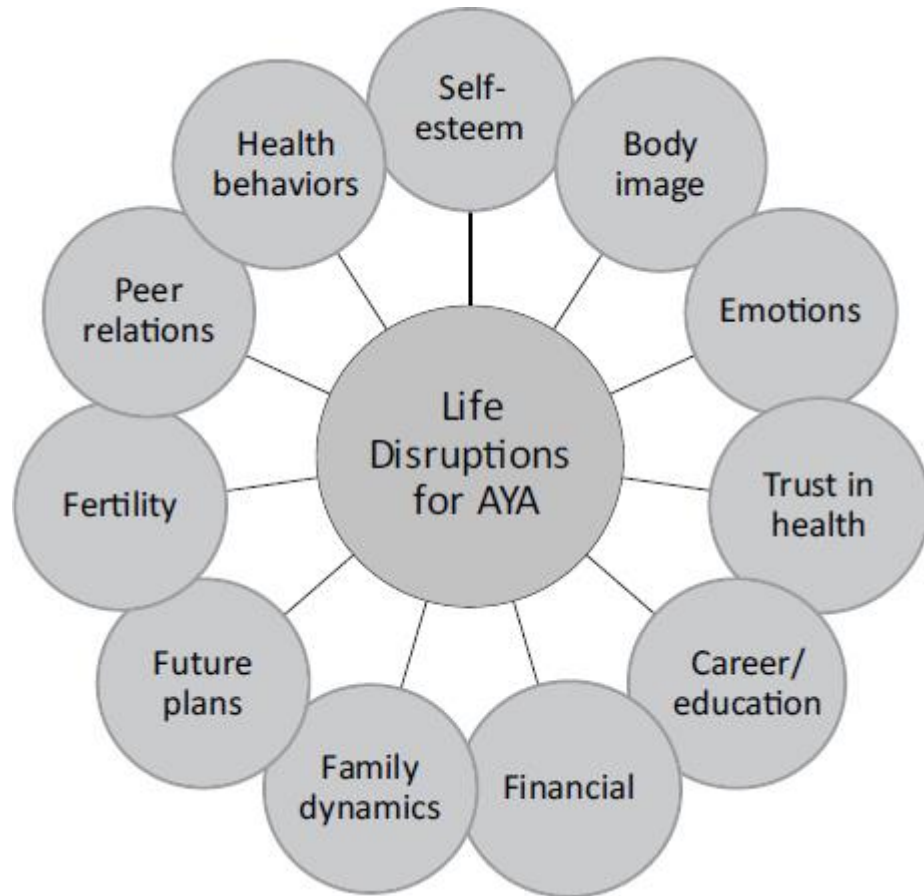
TRAINING

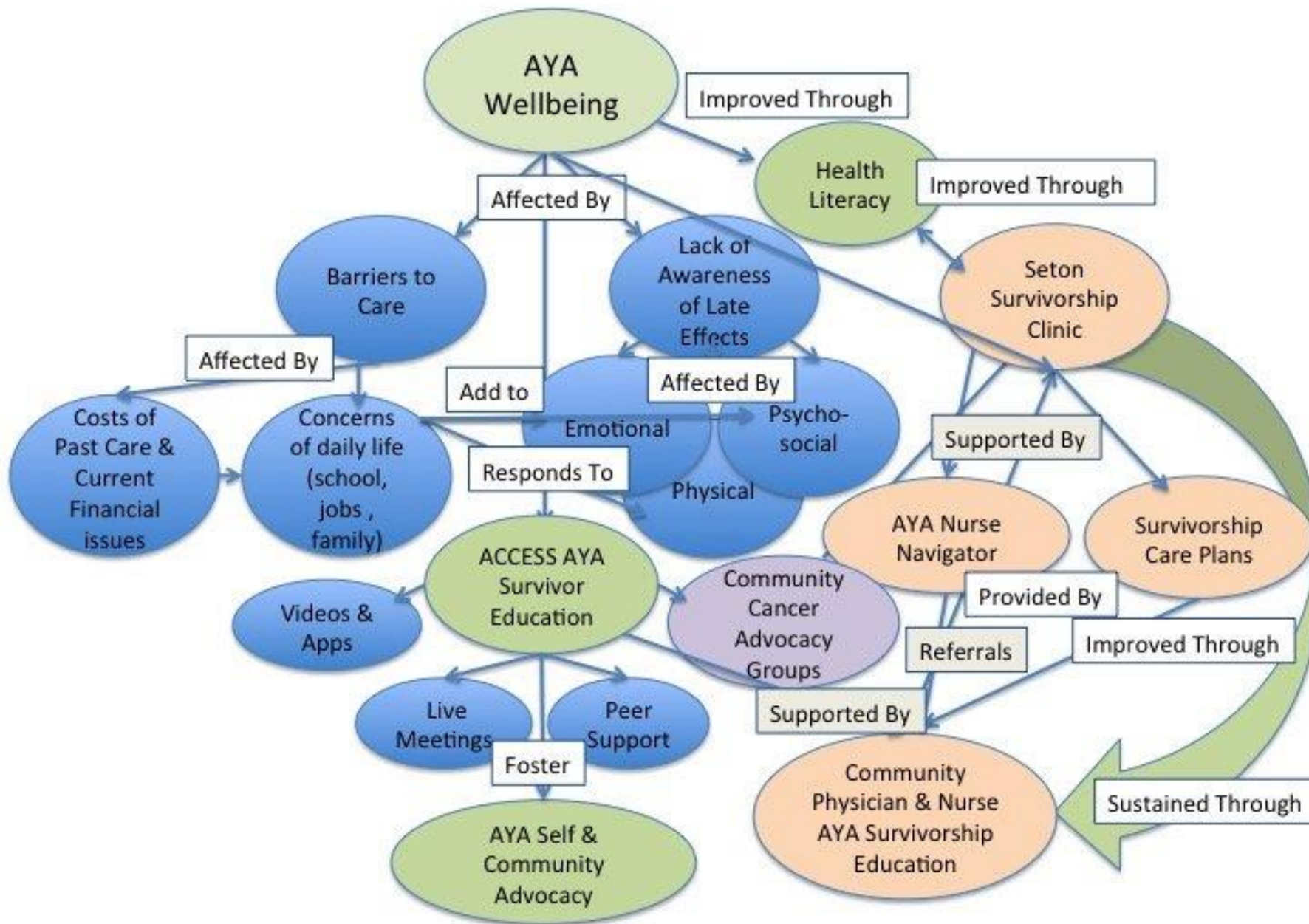


Knowledge about...



Knowledge about the AYA with cancer





AYA communication - Why make the connection?



- ▶ **Improve the results of AYAs experience** through this connection.
- ▶ Improving caregivers' ability to connect with and maintain AYAs is **essential for identifying and addressing AYAs' psychosocial needs.**
- ▶ Connectedness can help **reduce the anxiety/stress experience(s) during & after treatment.**

LACK OF COMMUNICATION LEADS TO...

- ▶ **Not** aware of the side effects being experienced
- ▶ **Not** aware of developmental delays or possible changes in cognitive function
- ▶ **Not** aware of late effects: cardiac problems & pulmonary function
- ▶ **Not** prepared for the emotional and psychological problems: anxiety, isolation, PTSD, grief and guilt, body image, fear of relapse, concerns around relationships, having a family later etc.



Some of the learnings from hospitalisation period...



- ▶ As a patient my needs, concerns and preferences are not paramount / important.
- ▶ Decisions regarding myself and my health are not to be taken by me.
- ▶ My health is not my responsibility.

Impact of effective and ineffective communication





HOW TO INVOLVE US? THE AYA PERSPECTIVE

- 1 SAFE ENVIRONMENT
- 2 IS IT THE RIGHT PERSON? / ARE CARERS NEEDED?
- 3 ARE YOU THE RIGHT PERSON TO TALK TO THE PATIENT? MAYBE SOMEONE ELSE FROM THE TEAM?
- 4 GIVE THE IMPRESSION THAT YOU HAVE TIME & ARE NOT IN A HURRY
PROVIDE THE OPPORTUNITY FOR THE PATIENT TO SHARE THEIR STORY
- 5 LANGUAGE: TRANSLATOR, NO MEDICAL JARGON
- 6 USE DIGITAL HEALTH / INSTANT MESSENGERS
- 7 MAINTAIN STRONG CONNECTIONS & BE COMMITTED
- 8 ASK FOR FEEDBACK
- 9 ENSURE CONTINUITY IN CARE

How do we want to be involved in our care!



AYAs WANT TO:

- ▶ Be **heard & listened** to
- ▶ Be **involved in decisions** about our care
- ▶ Receive **information & support** → treatment / clinical trials, pain management, mental health, side effects & late effects, nutrition and physical activity, sexual health & fertility, financial aspects
- ▶ Be **assisted in identifying ways to manage** hair loss, weight gain / loss, loss of limbs or organs and scars
- ▶ Be allowed **to live somehow a normal life** in which partners & friends are allowed to be by our side
- ▶ Avoid being abandoned / left without **information during transition & follow-up**
- ▶ **Be equipped to manage** our physical and mental health, the side effects, the late effects and our overall care by ourselves when you are not there

Needs Assessment!

▶ Periodic needs assessment (at pivotal moments)

- ▶ Home
- ▶ Education
- ▶ Activities
- ▶ Drinking/drugs
- ▶ Sexual activity
- ▶ Safety
- ▶ Suicide
- ▶ Social media

Revised 04/21/2015

CONFIDENTIAL

ADOLESCENT HEALTH HISTORY CONSULTATION

This information is **CONFIDENTIAL**. Its purpose is to help your doctor give you better care. We request that you fill out the form completely, but you may skip any question that you do not wish to answer.

NAME _____ DATE _____

First Middle Initial Last

BIRTHDATE _____ AGE _____ Name you like to be called _____

1. Why did you come to the clinic today? _____

MEDICAL HISTORY

2. Are you allergic to any medicines? YES NO

If Yes: Name of Medicine _____

3. Are you taking any medicines now? YES NO

If Yes: Name of Medicine _____

4. Were you born prematurely or did you have any serious problems as an infant? YES NO

5. Do you have any chronic health conditions? YES NO

Condition _____

6. Have you ever been hospitalized? YES NO

Have you had any serious problem:

If YES to any _____

DATE _____

7. Have you _____

When did the problem started:

No _____

Age _____

AYA-kompas
Adolescents & Young Adult 16-25 jaar

Dit AYA-kompas maakt duidelijk wat jou op dit moment bezig houdt. Het is een hulpmiddel voor zorgverleners om een beeld te krijgen van wie je bent, waar je tegengestelde noden en verwachtingen worden afgestemd. Je zorgverlener zal het AYA-kompas gebruiken in een persoonlijk gesprek. Sommige thema's vind je misschien minder relevant, je kunt er ook de thema's weghalen die niet in je richting van het gesprek en jouw zorgkompas bepalen.

Fysiek Welzijn
Energiepeil
Lichamelijke klachten
Sleep

Gedachten en gevoelens
Positieve gevoelens
Negatieve gevoelens
Drukvoelingsproblemen
Psychosociale ondersteuning

Geloof, zingeving en cultuur
Cultuur
Geloof
Zingeving

Interesses en vrije tijd
Interesses en hobby's
Vrije tijd

Intimiteit en seks
Intimiteit
Seks
Vrijwillig

Levensstijl
Beweging
Spart
Alcohol
Drugs
Roken
Engagement en voeding

UZ GENT
Ziekenhuis Universitair Ziekenhuis Ghent

Today

Click on an area

Worry & Anxiety

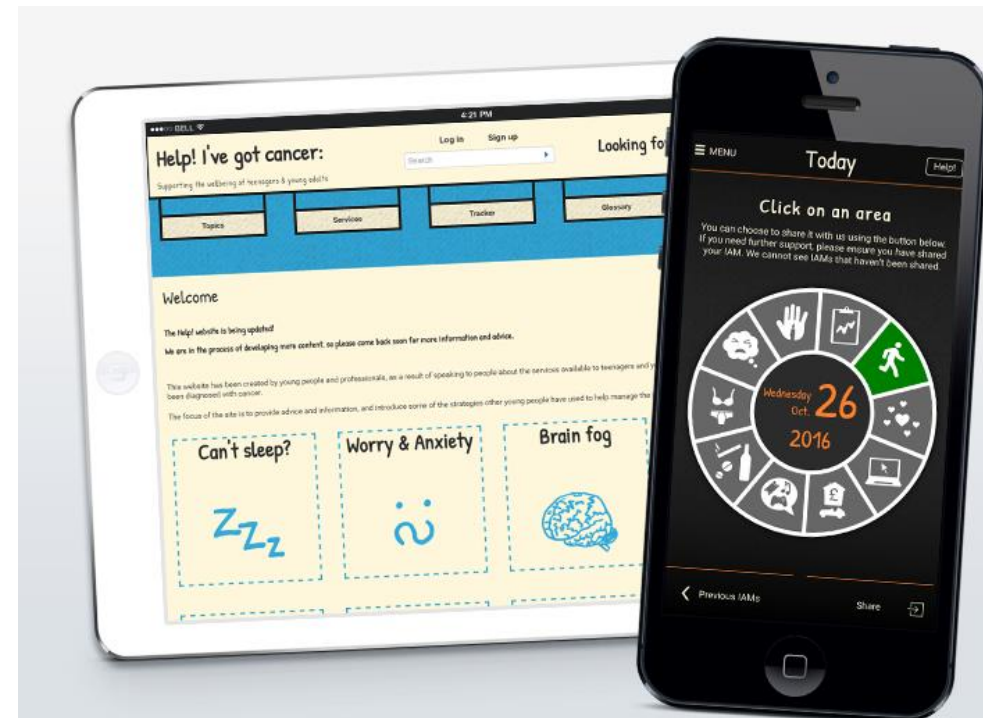
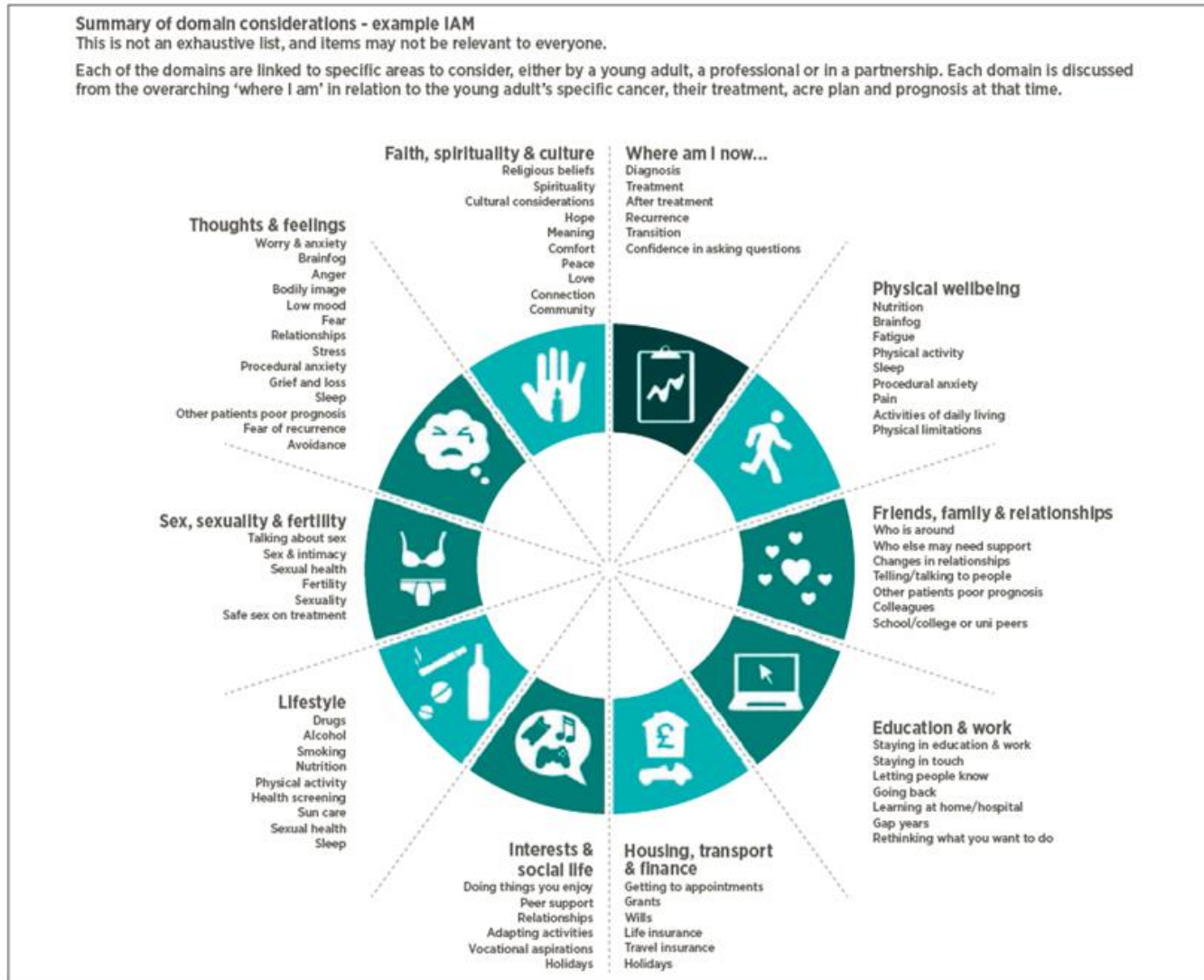
Brain fog

Don't sleep?

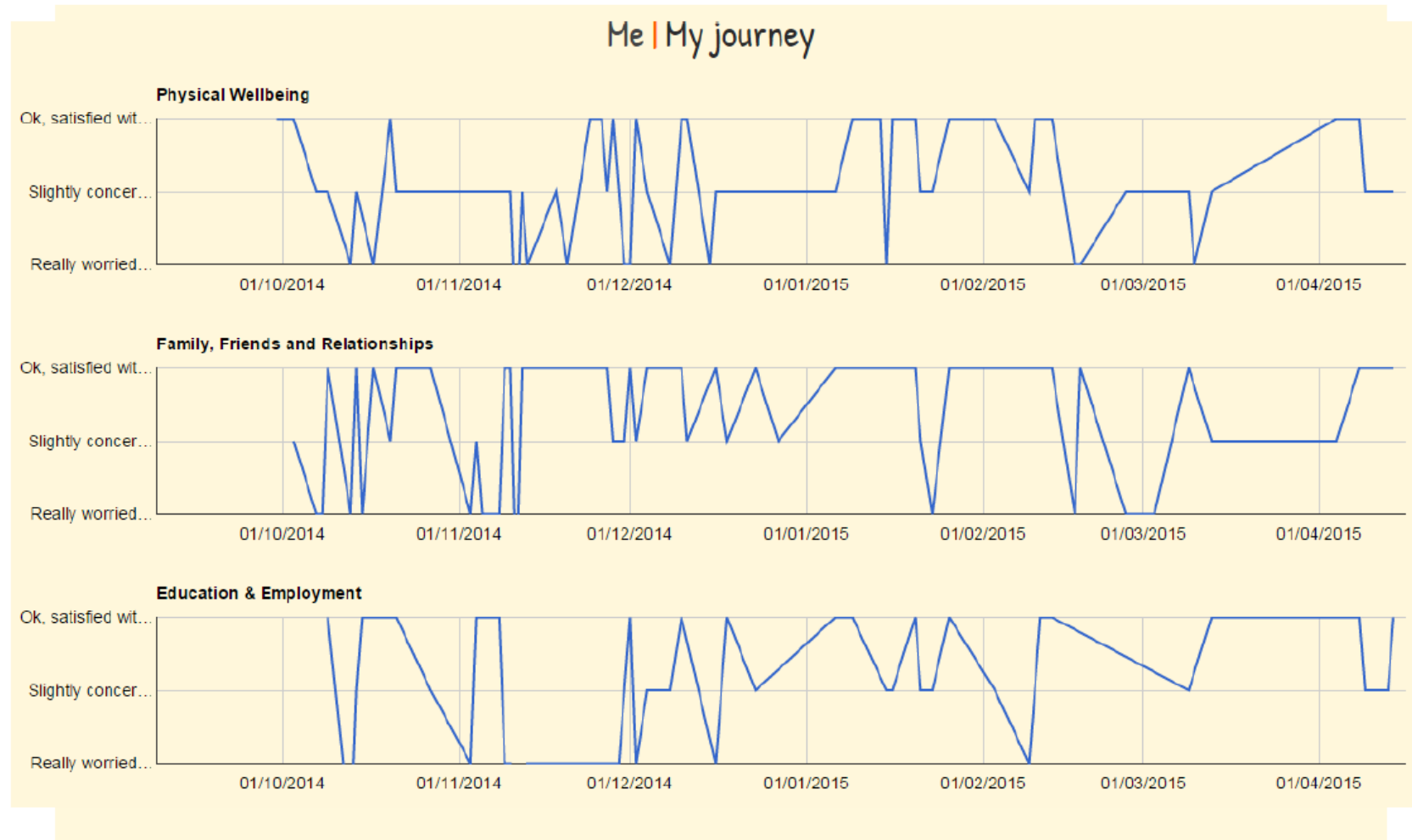
26

20%

The I.A.M – Integrated Assessment Mapping



The I.A.M – Integrated Assessment Mapping



AYA-kompas

Adolescents & Young Adult 16-35 jaar

Dit AYA-kompas maakt duidelijk wat jou op dit moment bezig houdt. Het is een hulp voor zorgverleners om een beeld te krijgen van wie jij bent, waar je tegenaan loopt en wat je belangrijk vindt. Zo kan de zorg beter op jouw specifieke noden en verwachtingen worden afgestemd. Je zorgverlener zal het AYA-kompas gebruiken in een persoonlijk gesprek. Sommige thema's vind je misschien minder relevant. Je bent vrij om op de thema's wel of niet in te gaan. Jij staat aan het roer! Met het AYA-kompas bepaal jij de richting van het gesprek en stuur je jouw zorg.

Het AYA-Kompas werd ontwikkeld
i.k.v. het AYACare@Gent project,
met de steun van Kom op tegen Kanker.
Meer info vind je op www.care4aya.be



NAAM

DATUM

NOTA'S

Hiervoor wil ik een individueel gesprek met de zorgverlener.
Hier wil ik vandaag zeker over praten.

Duid hier aan
in welke mate
het thema je
bezig houdt.

Fysiek Welzijn

Energieniveau	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Lichamelijke klachten	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Slaap	<input type="radio"/>	<input type="radio"/>	<input type="text"/>

Gedachten en gevoelens

Positieve gevoelens	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Negatieve gevoelens	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Durven praten over wat me bezig houdt	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Psychosociale ondersteuning	<input type="radio"/>	<input type="radio"/>	<input type="text"/>

Geloof, zingeving en cultuur

Cultuur	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Gewoontes en tradities	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Spiritualiteit en religie	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Zingeving	<input type="radio"/>	<input type="radio"/>	<input type="text"/>

Interesses en vrije tijd

Interesses en hobby's	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Vrije tijd	<input type="radio"/>	<input type="radio"/>	<input type="text"/>

Intimiteit en seks

Intimiteit	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Seks	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Veilig vrijen	<input type="radio"/>	<input type="radio"/>	<input type="text"/>

Levensstijl

Beweging	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Sport	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Alcohol	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Drugs	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Roken	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Eetgedrag en voeding	<input type="radio"/>	<input type="radio"/>	<input type="text"/>

AYA communication – How to make the connection?

Core communication skills	AYA specific communication skills
<p>Establishing rapport</p> <p>Speak directly to the patient, acknowledge their supporters but keep the patient at the center of care</p>	<p>Take an active interest in the AYA's life beyond their cancer experience. It may vary for different ages: in younger AYAs this could be school/college/hobbies/interests and in older AYAs, career/family</p> <p>Keep trying to engage with AYAs where disengagement or passive aggression is a barrier to effective communication</p> <p>For younger AYAs be mindful to not talk to them as if they are a child and to not patronize them</p>
<p>Navigating the conversation</p> <p>Be vigilant for verbal and nonverbal cues Acknowledge and explore patient concerns</p>	<p>AYAs may not utilize cues in the same way as other age groups. Nonverbal cues are more common than verbal—be alert for them</p> <p>Spend time alone with the AYA to discuss sensitive topics</p> <p>Once rapport is established, humor may be a useful tool to build the professional relationship</p>
<p>Information giving and shared decision-making</p> <p>Use language that the patient can understand Explore the patient's agenda and priorities Assess the patient's wishes for the amount of information they want to receive, and their level of involvement in decision-making Be honest, do not withhold information</p>	<p>AYAs, depending on their age, may bring different types of supporter (e.g., parent vs. partner) who may have different agendas/needs</p> <p>Use scans, laboratory results, and diagrams, where available, as communication aids</p> <p>Contextualize information to the AYA's life</p> <p>Check the AYA's understanding; for younger AYAs, parents may be able to frame information in a way which is easier for the AYA to process</p> <p>Revisit an AYA's preferences for information giving and decision-making periodically</p>
<p>Facilitating engagement in LTFU</p> <p>Address barriers to attendance Encourage self-management, be opportunistic with health promotion education</p>	<p>For AYAs treated in pediatrics where information may have been directed toward parents, it is important to establish the AYA's "starting point":</p> <ul style="list-style-type: none"> Understanding of diagnosis Treatment received, and Potential late effects <p>Assess the AYA's developmental, emotional, and mental health. This may be facilitated by the use of a psychosocial assessment tool</p> <p>Bridge information gaps based on the AYA's starting point. Use this opportunity to emphasize the importance/need for LTFU</p> <p>Explain the rationale behind tests in LTFU</p> <p>Written treatment summaries are useful to support verbal communication</p>

In an Ideal world scenario...

“CANCER IS DARK, BUT THE RELATIONSHIP WITH THE HCPs CAN BE THE GUIDING LIGHT”

SPEAKING SKILLS

- Timing.
- Tone.
- Environment.
- Ask if they want to talk about x?
- Patient only or carers needed?

ADAPTABILITY

- You both come from different families & have different beliefs, backgrounds & communication styles.
- Adjust & adapt → to speak the same language.

BODY LANGUAGE

- Be aware of your body language.
- Recognise your patient's body language.
- Use warm non-verbal communication.

LISTENING SKILLS

- Listening is not just the process of mechano-electrical transduction done by the hair cells.
- Understanding & empathy.

PATIENCE

- Patient deals with a difficult situation & may need more time for processing.

**DESPITE BEING
SURROUNDED BY PEOPLE, I
FEEL SO ALONE.**



DISTANCE ISN'T A LIMITATION, LACK OF COMMUNICATION IS - HOW TO IDENTIFY & RESPOND TO THE UNIQUE NEEDS, VALUES AND PREFERENCES OF AYAs?

INITIATE / AVAILABILITY



- Would you like us to talk about ...?

TALK / OPEN-ENDED QW_s



- How are you feeling today?
- How have you been lately?

EXPLAIN (AGAIN)



- In other words, this would mean ...
- To put it another way ...
- To be more specific ...

ADDRESS MISUNDERSTANDINGS



- How do you feel about what we discussed?
- What do you expect will happen next?

A LITTLE CHAT CAN GO A LONG WAY

VALUES & OTHER INFORMATION



VALIDATE



SHARED DECISION / RESPONSIBILITY



YOUR AVAILABILITY



FOLLOW-UP



- I'd like to hear more about ...
- How did you come to the decision about this particular treatment?
- I can see you are upset when / about...
- If I get it right, you would want ...
- There is option A and option B, which one do you prefer?
- How are you managing with your pain?
- If unclear / you need me, just come / call between ...
- How often would you like us to meet?

AYA communication – How to make the connection → in the digital divide?

- ▶ **Provide access** to the internet during hospitalisation to **encourage** young people's usual day to day connectivity using social media.
- ▶ **Guide** young people to **reputable and approved sources** of online cancer information.
- ▶ Help **educate and support** young people to **gain the digital literacy and safety skills** to manage privacy and personal disclosure online.
- ▶ **Healthcare professionals should be mindful of their own online behaviour so that professional boundaries with young people are maintained.**
- ▶ **Encourage young people to talk about their online experiences** as part of normal everyday conversation with parents and carers. This will encourage early discussion of anything they encounter that upsets them.

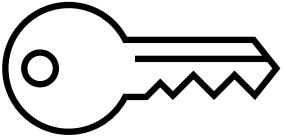
“The impact of digital technologies can have both positive and negative aspects, which should be taken account of by healthcare professionals.”



Handling Online healthcare professional-Patient Boundaries

	Situation	Recommendation	Example
Active patient	personal Facebook page & you receive a friend request from pt	Consider declining the request	“I have a personal policy not to connect with patients or their family through SoMe”
Former patient	request from a patient you treated for cancer in the past	No formal pt-HCP relationship exists, it may be acceptable to accept the request	Accept or decline like in first example
Connected and active patient	One of your current Facebook friends is diagnosed with cancer and he is now under your care as a patient	a formal patient-HCP relationship exists	“I’d prefer to discuss your care off line and make an ...”
Patient, not in your practice	A person on SoMe who follows your professional profile sends a tweet to you asking what screening tests you would recommend	Avoid giving specific medical advice but feel free to share reputable online resources	“There is good information on..., and I recommend that you take contact with your treatment team...”

AYA & prevention – How to make the connection

Co-Creating = 





EUROPEAN CODE AGAINST CANCER

12 ways to reduce your cancer risk

- 1 Do not smoke. Do not use any form of tobacco.
- 2 Make your home smoke free. Support smoke-free policies in your workplace.
- 3 Take action to be a healthy body weight.
- 4 Be physically active in everyday life. Limit the time you spend sitting.
- 5 Have a healthy diet:
 - Eat plenty of whole grains, pulses, vegetables and fruits.
 - Limit high-calorie foods (foods high in sugar or fat) and avoid sugary drinks.
 - Avoid processed meat; limit red meat and foods high in salt.
- 6 If you drink alcohol of any type, limit your intake. Not drinking alcohol is better for cancer prevention.
- 7 Avoid too much sun, especially for children. Use sun protection. Do not use sunbeds.
- 8 In the workplace, protect yourself against cancer-causing substances by following health and safety instructions.
- 9 Find out if you are exposed to radiation from naturally high radon levels in your home. Take action to reduce high radon levels.
- 10 For women:
 - Breastfeeding reduces cancer risk. If you can, breastfeed your baby.
 - Hormone replacement therapy (HRT) increases the risk of certain cancers. Limit use of HRT.
- 11 Ensure your children take part in vaccination programmes for:
 - Hepatitis B (for newborns)
 - Human papillomavirus (HPV) (for girls).
- 12 Take part in organized cancer screening programmes for:
 - Bowel cancer (men and women)
 - Breast cancer (women)
 - Cervical cancer (women).

The European Code Against Cancer focuses on actions that individual citizens can take to help prevent cancer. Successful cancer prevention requires these individual actions to be supported by governmental policies and actions.

Find out more about the European Code Against Cancer at: <http://cancer-code-europe.iarc.fr>

This project is co-financed by the European Union and coordinated by the specialized cancer agency of the World Health Organization, the International Agency for Research on Cancer.

International Agency for Research on Cancer



AYA cancer & Awareness



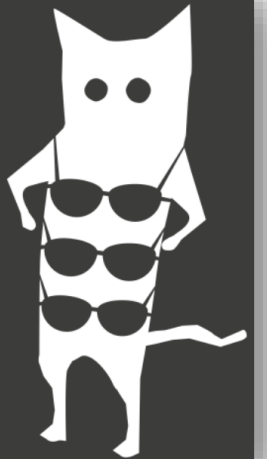
Cancer Awareness in Teenagers and Young People Society (CATS)



CHECKED YOUR BOOBS LATELY?

Breast cancer is much more common in older women but younger women can still get it. Make sure you check your boobs regularly, as when caught early breast cancer can be much easier to treat. It's best to check once a month - try and do it at the same point in your menstrual cycle each month. Look for:

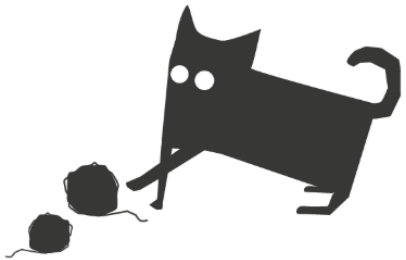
- A change in the shape or size of the breast
- Changes in the look or feel of the skin
- Any unexplained or persistent pain
- A lump in the breast or armpit
- Changes in skin texture (puckering or dimpling)
- Nipple changes (discharge or inversion)



LET'S HAVE A LOOK AT THOSE BALLS.

Testicular cancer is the most common cancer in males between the ages of 15 and 24, so make sure you check your balls regularly - it might be easier to check them while in the shower or bath. Look for:

- A lump or swelling in one testicle (even if there is no pain)
- A change in the shape or size of the testicles



AYA cancer & fertility

In some centres, the practice of discussing fertility with AYAs diagnosed with cancer & referring them for assisted reproductive assessment is routine. However, many young people report feeling that:

- ▶ they were not, or were inadequately, advised of the risk or their options for preserving fertility → **health professionals' failure to discuss risks to fertility**
- ▶ the decision about whether to pursue fertility preservation or not was made for them
- ▶ they were not given enough time to discuss the concerns
- ▶ they did not fully understand the ramifications of the decision



AYA cancer & sexuality

CANCER & SEX

Everything **oncology professionals** should discuss with their patients but maybe were afraid to start...

ECL PATIENT SUPPORT WORKING GROUP

https://www.europeancancerleagues.org/wp-content/uploads/ECL-Cancer-and-Sexuality-Leaflet-HCP_September-2020.pdf

CANCER & SEX

Everything you wanted to know about your **sexual health** but were afraid to ask.

ECL PATIENT SUPPORT WORKING GROUP

https://www.europeancancerleagues.org/wp-content/uploads/ECL-Cancer-and-Sexuality-Leaflet-Patients_September-2020.pdf

**CHEMO =
CONDOM**

**LET'S TALK
ABOUT SEX**

AYA & parents



AYA & parents

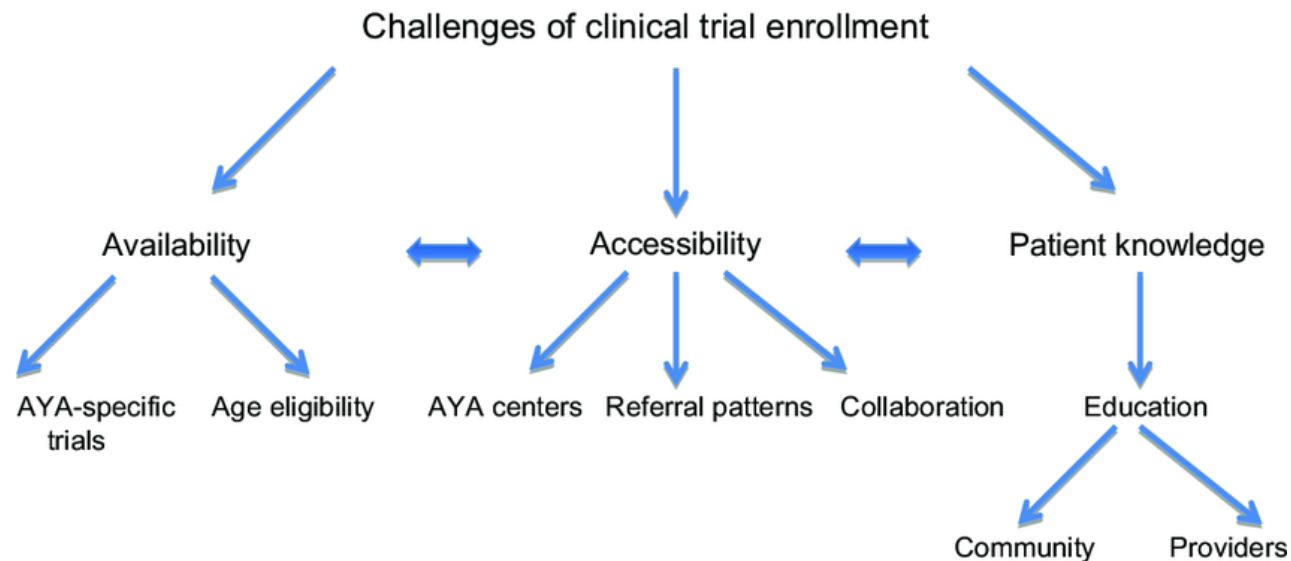
Central themes that can be discussed with the parents of AYAs:

- I want **to take care**, I want to be there for my child
- **Manager** - managing (from spokesperson to advocate)
- How to **Balance** in relationship with my child/partner/other children/social network
- **Self-care**: how do I take care of myself?
- The **Future**: how do I see the future?

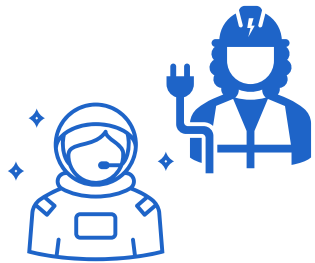


AYA cancer & treatment

- ▶ Different treatment strategy needed?
 - ▶ Few clinical trials specifically for AYAs & participation is mostly low!!!



AYA cancer & treatment

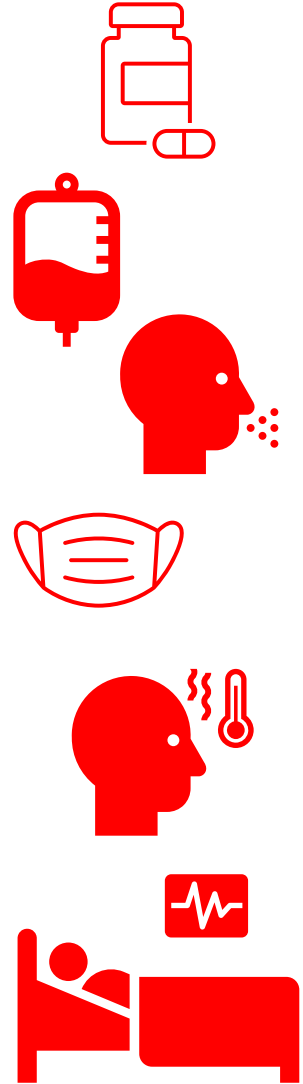


independence

dependency

Type of treatment	Potential toxicities of treatment		
	Short-term	Intermediate	Long-term (beyond 5 years after treatment)
Surgery	Infertility Infections	Lymphoedema	Endocrine dysfunction Infertility
Chemotherapy	Pain Fatigue Mucositis Nausea Infection Myelosuppression High-frequency hearing loss Amenorrhoea	Premature ovarian failure	Second cancer Endocrine dysfunction Cardiovascular diseases Infertility Low bone mineral density (osteopaenia and osteoporosis) Avascular necrosis Renal damage Neurocognitive deficits Peripheral and central neuropathy Hearing loss
Radiotherapy	Fatigue Mild skin reactions Mucositis Nausea Intestinal discomfort Infertility	Premature ovarian failure Intestinal fibrosis Enteritis	Second cancer in radiation field Endocrine dysfunction Cardiovascular diseases Infertility Low bone mineral density (osteopaenia and osteoporosis) Avascular necrosis Renal damage Intestinal fibrosis Enteritis Neurocognitive deficits (radiation to brain)
Bone-marrow transplantation <i>For treatment of haematological malignancies</i>	Toxicities as mentioned for chemotherapy and radiotherapy	Toxicities as mentioned for chemotherapy and radiotherapy	Toxicities as mentioned for chemotherapy and radiotherapy Graft-versus-host disease Chronic immunosuppression
Anti-oestrogen therapy <i>For treatment of oestrogen-positive breast cancer</i>	Hot flashes Vaginal dryness Mood changes Weight gain	Depression	Cardiovascular diseases

Note: The specific details of treatment such as type of chemotherapy, dosage, type of radiotherapy, number of fractions, combination of treatments, genetic predisposition and general health condition of the survivor are all essential determinants for the risk for treatment-related side effects.



AYA cancer & treatment



Transition

TYAC best practice statement for health professionals

Authors:
Caroline Langford
David Wright
in association with
the TYAC service
development group

Approved by TYAC Board:
Dr David Hobin, Chair

Final Version



- ▶ Collaboration with paediatric & adult cancer care services
 - ▶ Which treatment protocol is best for the AYA?
 - ▶ Transition from paediatric to adult care!

Consequences of a Care Gap!

New healthcare problems!

More symptomatic problems!

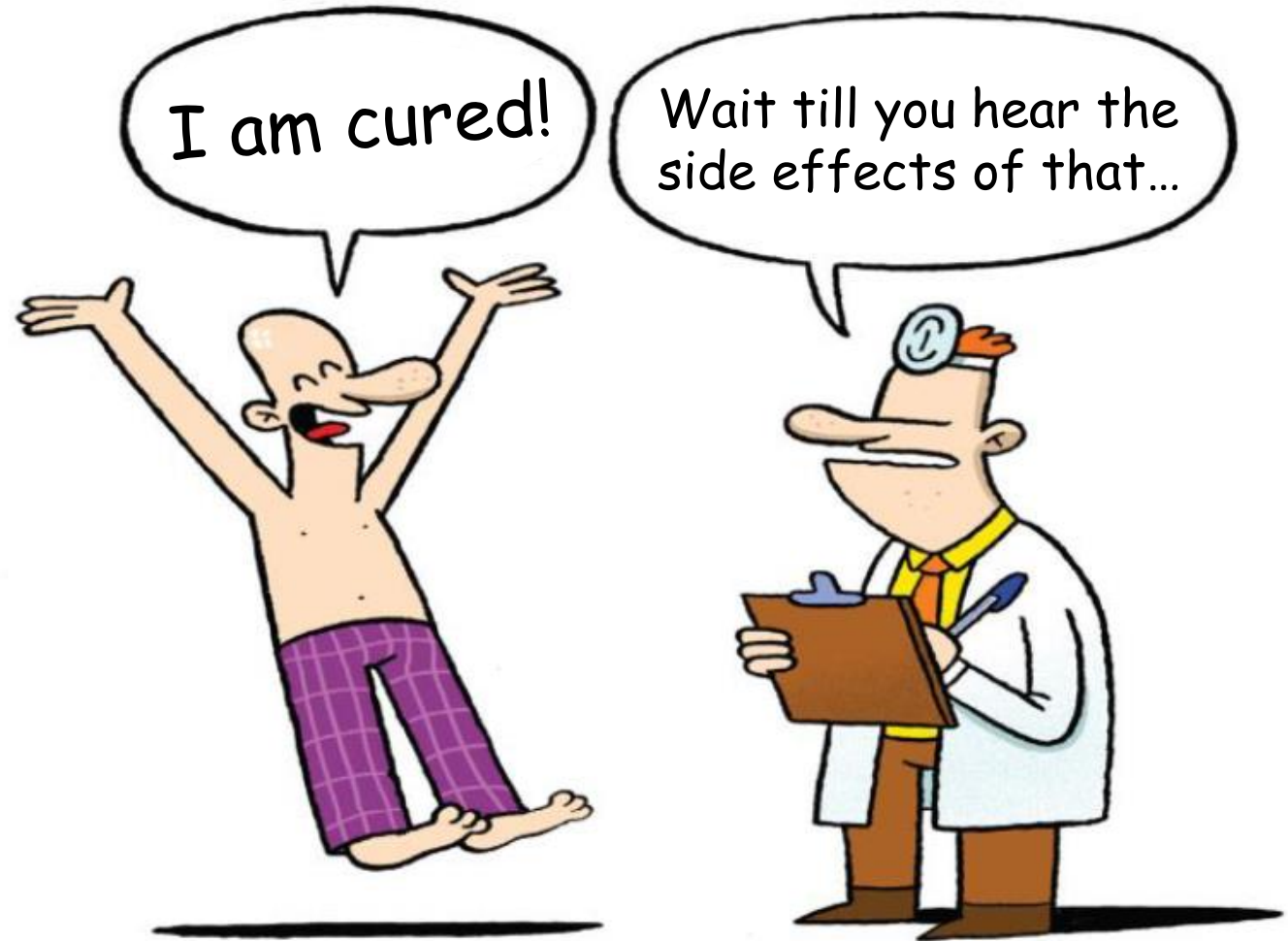
3x more chance of urgent interventions!

More hospital admissions!



AYA Survivorship

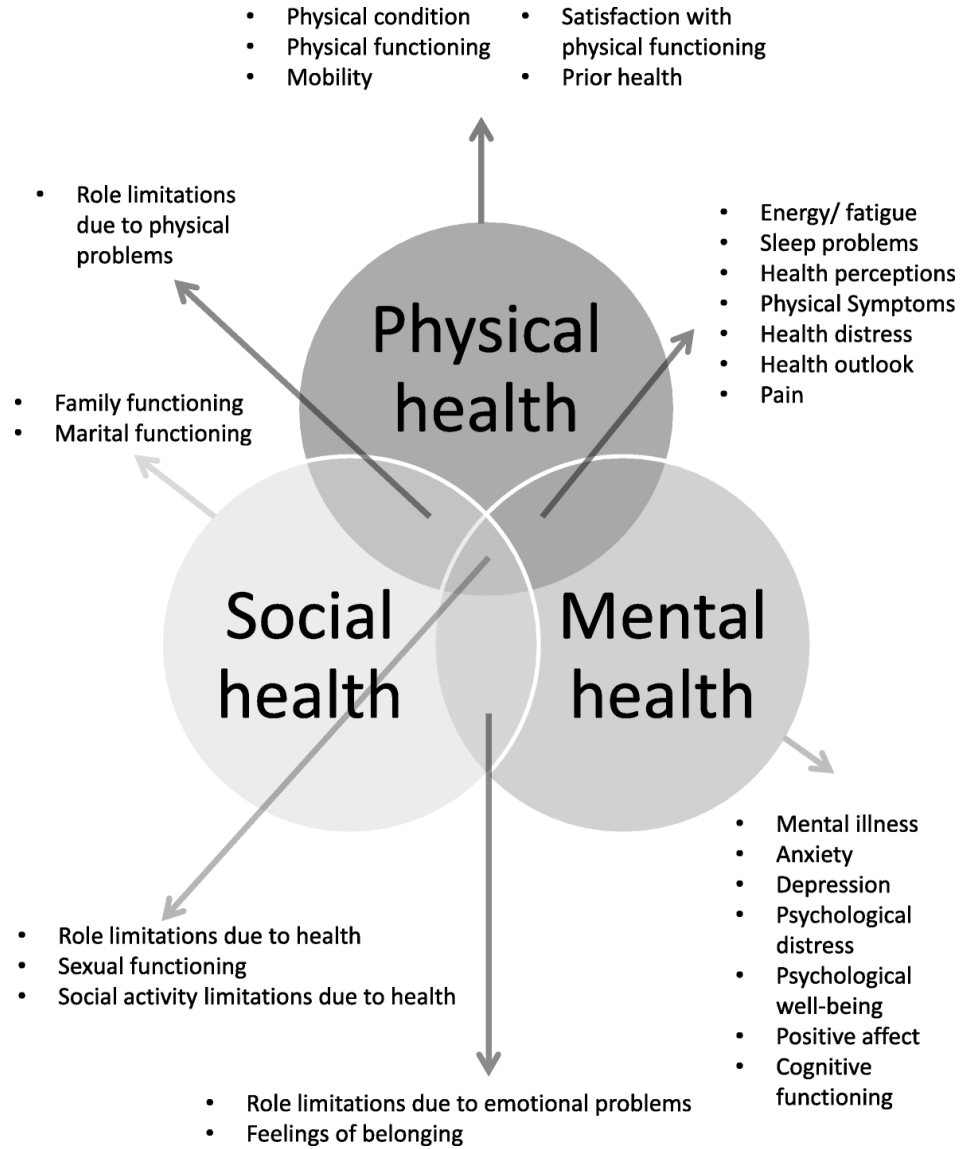
- ▶ Conceptually a time when **late effects are more common** than relapse!
- ▶ A **new set of fears** - tensions between the impact of cancer & wanting to put cancer behind you.



LECTRR

Bye Bye treatment...but...

- Planned but... uncertainties!
- Re-integration into the 'new normal'?
- Still recovering!
- Loss of medical & care support (safety)!
- Concerns about relapse!

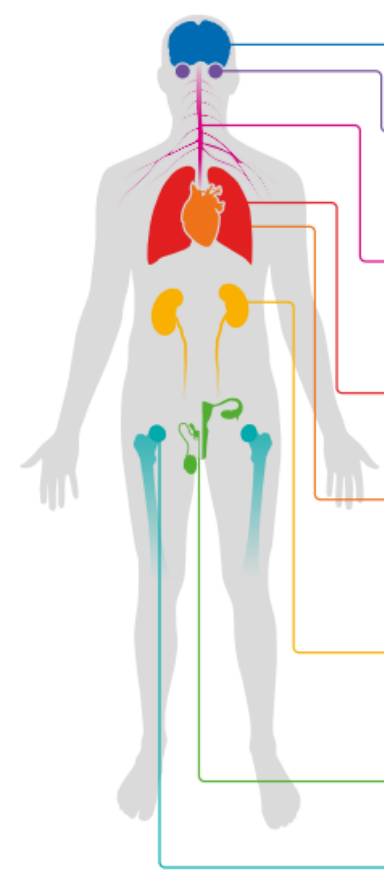


Managing long term side effects of chemotherapy

Teenagers and young adults (TYA) who survive cancer treatment can have a range of side effects later in life. If it is known which chemotherapeutic agents were used, the "Principal causative drugs" column can guide monitoring and management. Factors that further increase the risk of complications from chemotherapy are listed in the "risk groups" section.

thebmj Read the full article online <http://bmj.co/chemfx>

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Side Effect	Principal causative drugs							Risk groups	Managing those at risk					
	Alkylating agents	Antimetabolites	Antitumor antibiotics	Topo II inhibitors ²	Endocrine	Targeted	Immunomodulatory		Baseline	Consider	Encourage	Consider referral to		
Loss of executive function								Concurrent cranial RT ³	Baseline MMSE ⁴	Repeat if symptoms	Consider: Neurorehabilitation, Psychotropic drugs	Encourage communication with school/ university/ place of work	Consider referral to: Social worker, Psychologist, Occupational therapist	
Memory loss														
Cataract								Concurrent RT ³	Funduscopy	Every year	Refer to ophthalmology if symptoms			
Peripheral neuropathy									Neurological examination	Every year for first 3 years	After this, reassess if symptoms change			
Tinnitus								Smoking	Baseline audiological assessment	Repeat if symptoms	Refer to ENT specialist if changes	Consider: Hearing aid, Speech therapy, Assessment of reversible causes	Offer advice: Against smoking, Respiratory specialist review before anaesthesia or SCUBA diving	
Deafness														
Raynaud's phenomenon									Warm gloves in winter		Calcium channel blockers			
Pulmonary fibrosis								Smoking, Younger, HD ¹ , Exposure to high O ₂ concentration, Renal dysfunction	Baseline tests: Chest radiograph, Lung function	Respiratory examination	Every year	Vaccinations: Influenza, Pneumococcal		
Ventricular failure								CVS risks: Smoking, Diabetes, High cholesterol; Mediastinal RT ³ , High dose, Time since chemo; Pregnancy	Encourage early presentation	Cardiac disease may occur at much younger ages in people who have had chemotherapy	MUGA ⁵ /echocardiogram	Consider ECG and blood pressure	Every year	
Coronary artery disease														
Hypertension														
Chronic kidney disease								Prior renal dysfunction, Diabetes	Blood pressure	Every year	Urinalysis	Every year	Baseline urea and electrolytes	Repeat if symptoms or signs of renal failure
Haemorrhagic cystitis								Concurrent RT ³ to urinary tract	Encourage self reporting	Advise patient to report potential symptoms	Refer to renal specialist if deterioration in symptoms or results			
Renal tract malignancy														
Infertility								Older age at time of treatment, RT ³ to gonadal region, Higher cumulative doses	Fertility preservation	Refer all TYA ⁶ undergoing chemotherapy to fertility preservation services	Baseline bloods: Men (Testosterone, LH, FSH), Women (Oestradiol)	Hormone replacement	Mammogram, Breast MRI	Every year from 8 years after RT / age 25 (whichever is later)
Primary hypogonadism														
Necrosis of femoral head								Concurrent RT ³	Clinical examination	Every year	Refer for MRI if clinical suspicion			
Second malignant neoplasm								High dose, RT ³ , t-AML survivors, Autologous stem cell transplant	Full blood count for t-AML survivors	Every year	After thoracic radiotherapy	Enhanced breast cancer surveillance		
Psychosocial problems								CNS tumour, Hearing loss, Female, Younger, Cranial RT ³ , Learning difficulties, Lower SEG ⁷	Psychosocial assessment	Every year	Support groups, Psychology referral, Counselling	Screen for underlying depression, Rule out reversible causes, Advise short bursts of exercise	Antidepressants, Anxiolytics, Assess impact on family members and carers	
Fatigue								Depression						
Osteoporosis								Smoking	Bone density scan	Every year	Calcium and vitamin D according to results	Rule out hypogonadism		

¹HD = High dose ²Topoisomerase II inhibitors ³RT = radiotherapy ⁴Mini Mental State Examination ⁵Multigated acquisition scan ⁶SEG = socio-economic grouping ⁷TYA = teenagers and young adults



Navigating Life During and After a Blood Cancer Diagnosis: A Workbook for Parents, Children and Adolescents

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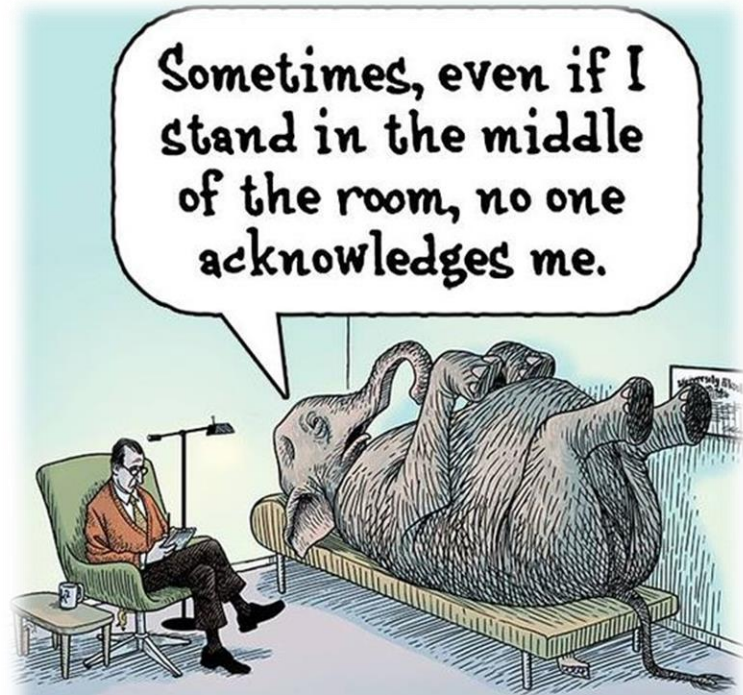


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Navigating Life During and After a Blood Cancer Diagnosis: A Workbook for Young Adults

FACING DEATH AND TALKING ABOUT IT



WHEN YOUR
BROTHER OR
SISTER DIES

Current challenges in AYA care

Open Access Published: April 07, 2021 - DOI: <https://doi.org/10.1016/j.esmoop.2021.100096>

The definition of the minimal essential requirements for AYA centres

This WG appreciates that there are some specific criteria and required facilities that a centre—whether it is in a paediatric or adult oncology department—must fulfil in order to treat AYA with cancer:

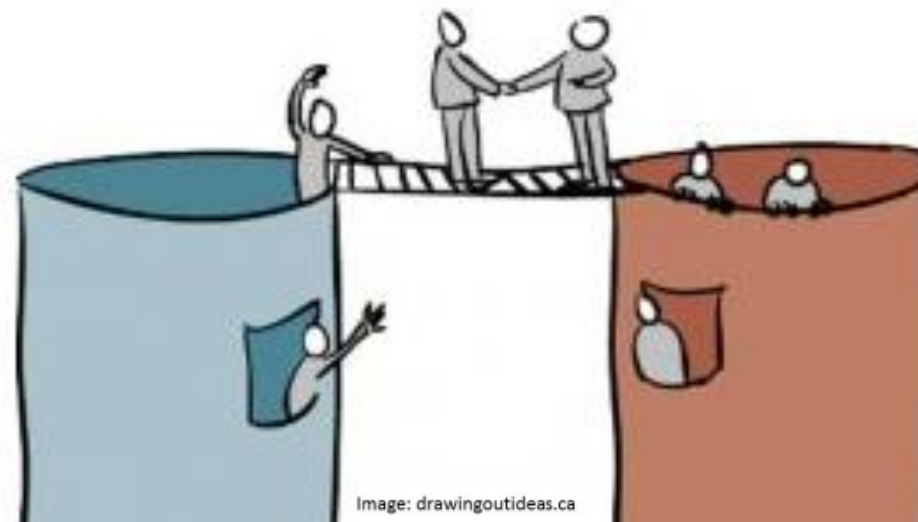
- A sufficient MDT, as defined earlier, to hold routine and structured case discussion meetings.^{4,5,20,55}
- Clinical trial availability in AYA cancers.³
- Flexibility in terms of age eligibility for access to treatment and care.
- Disease expertise resources for the whole variety of tumour types seen in the AYA population. This frequently requires active paediatric and adult membership via a complete AYA MDT, distinct from the adult (<https://www.oeci.eu/>) or children's (<https://paedcan.ern-net.eu/>) models of comprehensive cancer centres.
- Age-appropriate psychosocial support and an adequate age-specific environment designed around AYA needs, for example, access to peers and siblings, provision of social/arts activities, education, etc.⁶¹⁻⁶⁴
- Fertility preservation programmes.⁶⁵⁻⁶⁷
- Late effect/survivorship clinics and primary health care engagement.⁶⁸⁻⁷⁰
- Transition programmes (from childhood to AYA or adult services).⁷¹
- Genetic counselling and access to genetic testing for hereditary cancer syndromes.
- Age-specific palliative care services, including regular age-specific training for the staff.⁷²
- Sustainable programmes for AYA, with strong referral pathways⁷³ and standards of care from the clinical, patient and health care authorities' position, both acutely and in survivorship care.



REVIEW

Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE)

A. Ferrari^{1*††}, D. Stark^{2*††}, F. A. Peccatori³, L. Fern⁴, V. Laurence⁵, N. Gaspar⁶, I. Bozovic-Spasojevic⁷, O. Smith⁸, J. De Munter⁹, K. Derwich¹⁰, L. Hjorth¹¹, W. T. A. van der Graaf¹², L. Soanes¹³, S. Jezdic¹⁴, A. Blondeel¹⁵, S. Bielack¹⁶, J.-Y. Douillard¹⁴, G. Mountzios¹⁷ & E. Saloustros^{18†}





Tailoring care for AYA cancer through national regulation of AYA reference teams

- ▶ National Project Group → healthcare regulators, cancer services, reference centres and AYA with lived experiences → develop national AYA policy.

Six hospitals endorse the following five priorities in AYA care:

- ▶ Early diagnosis
- ▶ Early referral to reproductive medicine
- ▶ Early genetic testing
- ▶ Priority on Clinical studies
- ▶ Psychosocial support

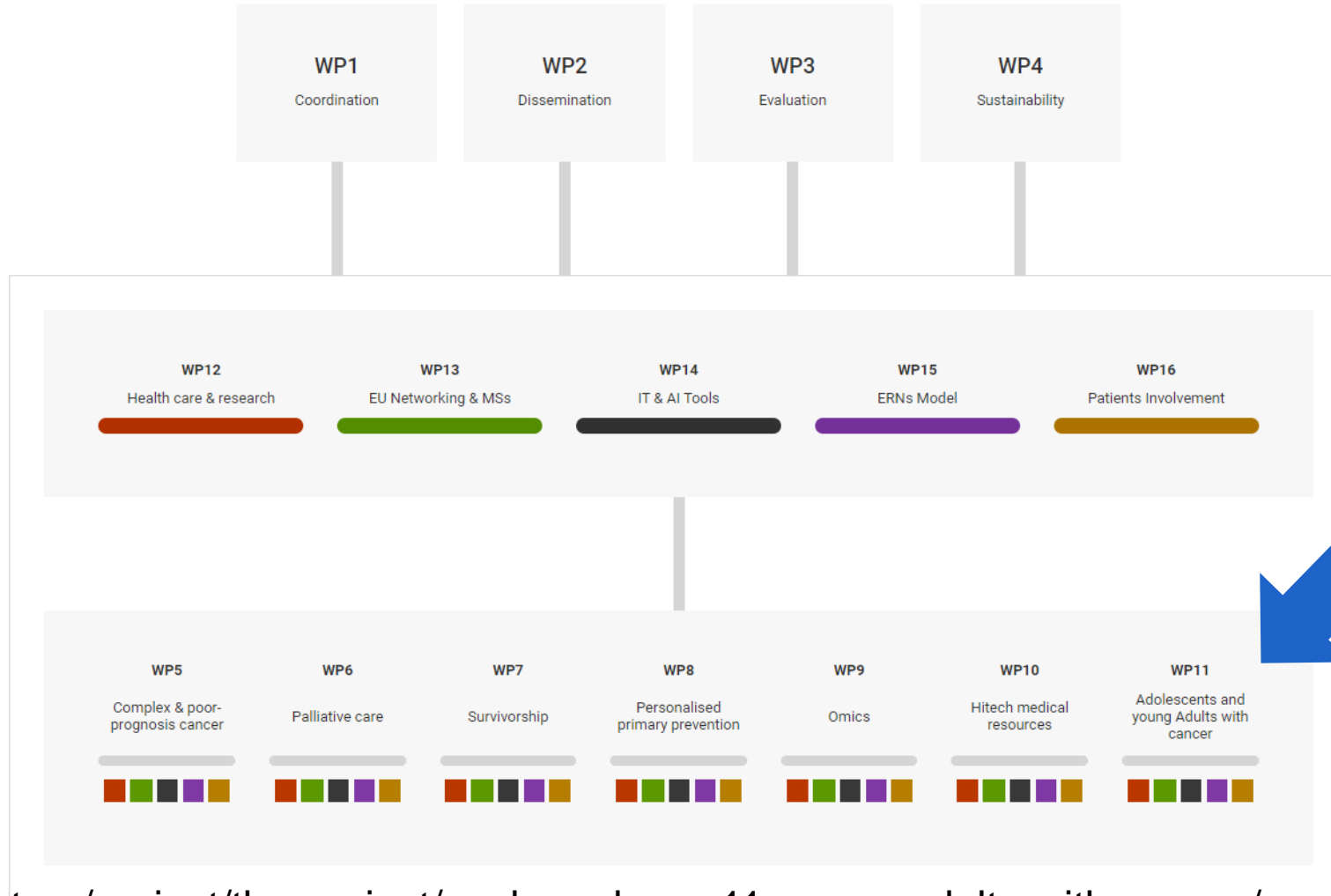


Europe's Beating Cancer Plan

objectives are

- The development of a **Core Outcome Set** (COS) for AYAs with cancer.
- The **implementation** of the COS in five national healthcare systems **across Europe**, with participating centers in France, Italy, the Netherlands, Poland and the United Kingdom, and the establishment of national infrastructures for outcome data management and clinical decision-making and a pan-European ecosystem that also welcomes future European countries.
- The **dissemination of outcomes and facilitation of interactions between national and pan-European stakeholders to develop data-driven analysis tools** to process and present relevant outcomes, establish feedback loops for AYA cancer patients and the healthcare systems, and improve the reporting and assessment of outputs towards policy-makers.

Shaping the EU Networks of Expertise on cancer!





EU-CAYAS-NET Project Outcomes



EU – CAYAS – NET project

Peer Visits: An In-Depth Look

GENERAL REPORT

AYA PEER VISITS

Italy – Belgium – Netherlands



<https://beatcancer.eu/>

https://www.youthcancereurope.org/wp-content/uploads/2023/11/general_information_aya_care_document.pdf



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GHENT UNIVERSITY HOSPITAL

GHENT, BELGIUM: JULY 12-16, 2023

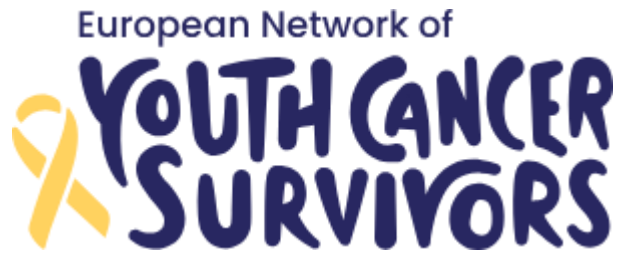
STRENGTHS

- There is an AYA-dedicated team that also conducts research, [Geen titel]
- The AYA care is very structured, and there is a large involvement of NGOs, supplementing the clinical care, resulting in a very good relationship between formal and informal care aspects,
- AYAs are included in the design of their spaces and services,
- The hospital provides AYA-specific training to the healthcare professionals,
- Availability of clear guidelines for AYA care,
- The Transition into long-term/post-treatment care is seamless and organized.

WEAKNESSES

- A lot of the initiatives depend on private/grant/award funding, which makes AYA services hard to sustain.
- Services are holistic and include multidisciplinary teams but feel scattered as they are only sometimes present in the same ward, wing, or even hospital building.
- The focus is slightly more geared towards AYAs younger than 25 years; the need remains to include older AYAs.
- Lack of staff for the number of patients
- Lack of systematic support for diverse needs such as LGBTQ and migrant populations





<https://beatcancer.eu/>

The European Network of Youth Cancer Survivors Launches Its Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe



<https://beatcancer.eu/wp-content/uploads/2024/04/EDI-Policy-Recommendations.pdf>

