



MAKESENSECAMPAIGN

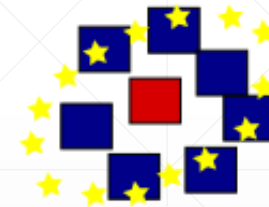


**EUROPEAN
CANCER
PATIENT
COALITION**

“Nothing about us without us!”



ALLIANCE OF LIBERALS AND
DEMOCRATS FOR EUROPE >>



EHNS
European Head
&
Neck Society

WELCOME

MEP Lieve Wierinck

Alliance of Liberals and Democrats for Europe (ALDE, Belgium)



Introductory remarks and ECPC involvement in supporting survivorship of head and neck cancer patients

Jana Pelouchova

ECPC Board Member



European Cancer Patient Coalition

- ECPC is the largest European cancer patients' umbrella organisation.
- Representing more than 400 organisations in 46 EU and non-EU countries.
- **ECPC's mission:**
 - Empower European cancer patients
 - Foster co-operation among cancer patients' organisations through joint activities
 - Fight against Europe of disparities
 - Have an active role in shaping European and national healthcare policies
 - Increase cancer research



MAKESENSECAMPAIGN

- For several years ECPC has partnered with the European Head and Neck Society (EHNS) to deliver the Make Sense Campaign, with this year's theme:

Supporting Survivorship

We aim at:

- ✓ Raising awareness of head and neck cancer
- ✓ Improving patients' outcomes
- ✓ Moving head and neck cancer up the European healthcare agenda

Why did ECPC decide to get involved?

- The Make Sense Campaign is a unique and exciting initiative addressing still very much unserved type of cancer
- Head and neck cancers are the 6th most common in Europe with more than 150,000 new patients diagnosed every year
- There is still little awareness of head and neck cancer, and patient outcomes remain very poor
- For patients diagnosed in the early stages of the disease, there is 80–90% survival rate – **strong reason to fight!**
- Head and neck include some of the rare cancers, which ECPC strongly represents

Working Group on Rare Cancers (WGRC)



ECPC counts on the **expertise** and **collaboration of rare cancer patient organisations** all over Europe to continuously represent the rare cancer patient community.

- ECPC **has established** the WGRC operating in parallel with the Joint Action on Rare Cancers (JARC), in order to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, are contributing to the activities of the Joint Action: **currently the WGRC hosts 65 member organisations.**
- JARC is shaping its efforts around the European Reference Networks (ERNs).

WE STRONGLY ENCOURAGE HEAD & NECK COMMUNITY TO CONNECT WITH US!

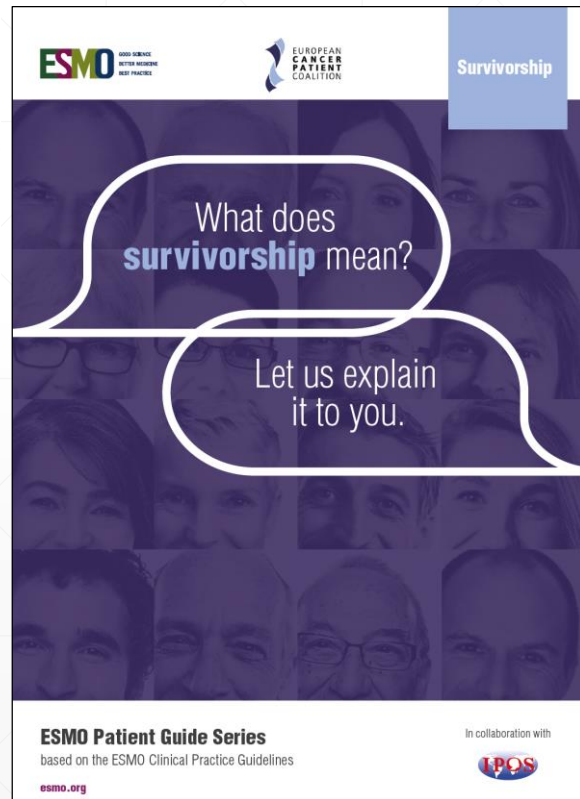
Cancer Survivorship

- Although approximately 25% of deaths in Europe are caused by cancer, the patients recovering from this disease are not given due attention.
- Key to survivorship is to regain, as far as possible, the important aspects of your life before cancer, and to find new pathways to a satisfactory life going forward.
- The European Union has recognised the need to invest resources in meeting cancer patients' needs, partly due to the efforts made by the European Cancer Patient Coalition in cancer patient advocacy.

ECPC's activities in the field of cancer survivorship

Patient Guide on Survivorship

Created by: **ESMO and ECPC** in collaboration with **International Psycho-Oncology Society (IPOS)**



- **Aimed at:** (1) post treatment cancer survivors having no disease after treatment, or (2) continue to receive treatment to reduce the risk of relapse, and (3) people with well controlled disease and few symptoms, who receive treatment to manage cancer as a chronic disease.
- **Why?:** To regain (1) the important aspects of a patients' life before cancer, and (2) to find new pathways to a satisfactory life going forward.

Thank you

 info@ecpc.org

 [@cancereu](https://twitter.com/cancereu)

 [European Cancer Patient Coalition](https://www.facebook.com/EuropeanCancerPatientCoalition)

Life after diagnosis: My journey

Patients' testimonies:

- **Anke Steinbacher, Germany**
- **Magali Mertens, Vie&Cancer, Belgium**

Moderator: Dr Lydia Makaroff, ECPC Director





MAKE SENSE CAMPAIGN



EHNS

www.ehns.org

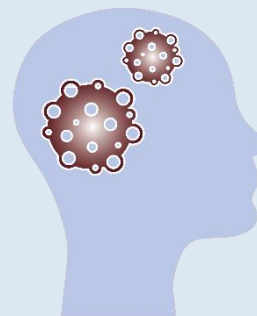
European Head and Neck Society

MAKESENSECAMPAIGN

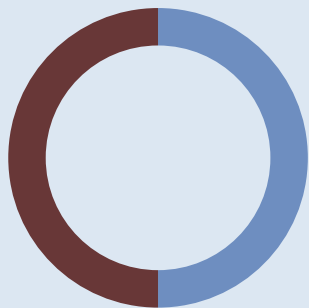
Why Was the EHNS Formed?



Globally, approximately **686,000** people are diagnosed with **HEAD AND NECK** cancer each year...



Yet, **77%** of people **don't even know** what **HEAD AND NECK CANCER** is.



...Of these, **HALF** will not be alive after **5 years.**



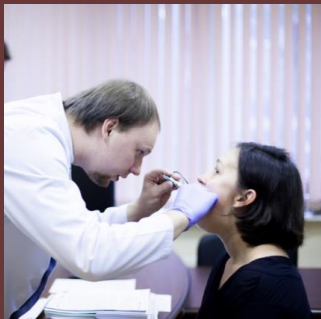
By driving **AWARENESS**, and encouraging **earlier diagnosis and treatment** we can **SAVE LIVES.**



Our Campaign has reached over **5 million** people



303,000+ educational leaflets distributed



36,500+ patients screened in 529 clinics across Europe



4 meetings held at European Parliament

www.makesensecampaign.eu



MAKESENSECAMPAIGN

Need for Early Diagnosis & Treatment





Early Diagnosis and Treatment

A person who
SMOKES
WILL BE

15 times **more**
LIKELY



TO DEVELOP

HEAD & NECK
cancer than a
NON-SMOKER



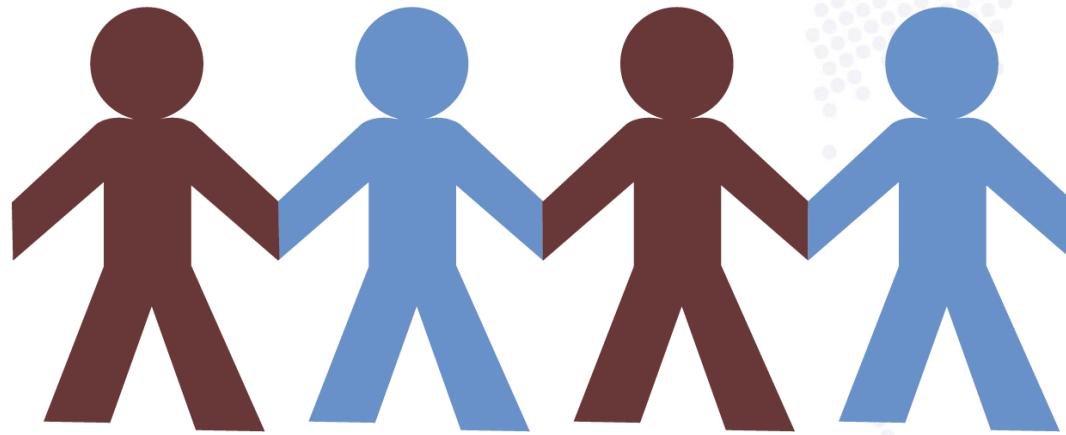
ALCOHOL
— plus —
TOBACCO

INCREASES the risk further

85%
of **Head & Neck**
CANCERS
are linked to
tobacco
USE



Supporting Survivorship



Current gaps in care

THEN

Mortality rates were high
Little awareness and often
diagnosed too late
Inconsistent approaches
Care post survival rarely
needed



NOW

Survival rates on the
increase
MDT approach vital but
inconsistent
Earlier diagnosis on the
rise
Critical need for guideline
driven, standardised care

As survivorship rates continue to rise.....

An MDT approach
must be maintained
as the impact of the
treatment itself
can have life-altering
implications



MAKESENSECAMPAIGN

A Survivor's Story



Magali, Belgium

My name is Magali, I am 36 and consider myself an idealistic dreamer, whose glass is always half full. I love to get lost in a good novel, meditating, swimming and running, all of which allow me to be truly mindful and in tune with myself. Long chats with my girlfriends over a good glass of wine and laughing with the ones I love, centres me.

How did you feel when you were diagnosed with cancer?

I was diagnosed with Stage IV salivary gland cancer (with bone infiltration) when I was 30 and pregnant with my first child. I still cannot describe what it felt like when I was diagnosed; it was like a tsunami, devastating and impossible.

The delivery of my diagnosis was a trauma I had to work really hard to overcome, even after treatment. I had a poor prognosis, and the doctor spent just three minutes talking to me. I was standing there, pregnant, crying, still not really knowing if it was actually cancer or just a risk of cancer. I am now dedicated to educating young healthcare professionals on how to deliver news to patients at such a crucial and distressing time with empathy and patience.



“The first time I saw my face in the mirror I almost fainted and couldn't speak. The pain was almost unbearable.”

Anke, Germany

My name is Anke, and I am a 52-year-old full-time working mother of two teenage boys, living in Munich. Our family spends a great deal of free time outdoors enjoying activities such as running, hiking, mountain biking, camping, canoeing and skiing; I also enjoy yoga. One of my favourite things is Oktoberfest, and we are lucky to live just 200m from where it is held each year.

How did you feel when you were diagnosed with cancer?

When I was diagnosed with human papilloma virus-related tonsil cancer I could not believe it. I heard the words and a part of me knew it was true; however, the other part of me thought this must be a mistake.

I've always led a healthy lifestyle, eating healthy, organic food, almost no sugar, no meat, lots of vegetables, limited dairy and almost no alcohol. I used to smoke, but only a few cigarettes here and there.

After diagnosis, I really struggled to understand how I could get cancer; it felt impossible. The only thing I could think of was how unfair it was. I went through the typical Kubler-Ross model, which is more commonly known as the five stages of grief. First I experienced shock, followed by anger, and then at my lowest point, depression.



“I really struggled to understand how I could get cancer; it felt impossible.”

If you remember one thing from today...

**WE need to develop unified guidelines for the
care of head and neck cancer patients across
Europe**

Prevention and survivorship: European Union initiatives on head and neck cancers

Antoni Montserrat Moliner

Senior Expert for Cancer and Rare Diseases, Directorate of Public Health, European Commission

Rehabilitation and Survivorship care in Head and Neck Cancer Patients

The ESMO-ECPC Guide on Survivorship

Dr Stefan Rauh
CHEM, Esch, LU

ESMO Practising Oncologists' Working group,
ESMO Public Policy Committee, ext. member

Conflict of interest

- No disclosures to declare



What does
survivorship mean?

Let us explain
it to you.

..who is a cancer survivor?

- Only someone who has been **cured** from cancer?
- Also someone who lives in a **long** remission (without evidence of remaining disease)? (how long is long??)
- Also someone with remaining but stable and **quiescent** cancer (without treatment)?
- Also someone under **maintenance treatment**? Even though going on for years??....
- Only after 2 years of follow-up??

Cancer survivor according to **wikipedia**

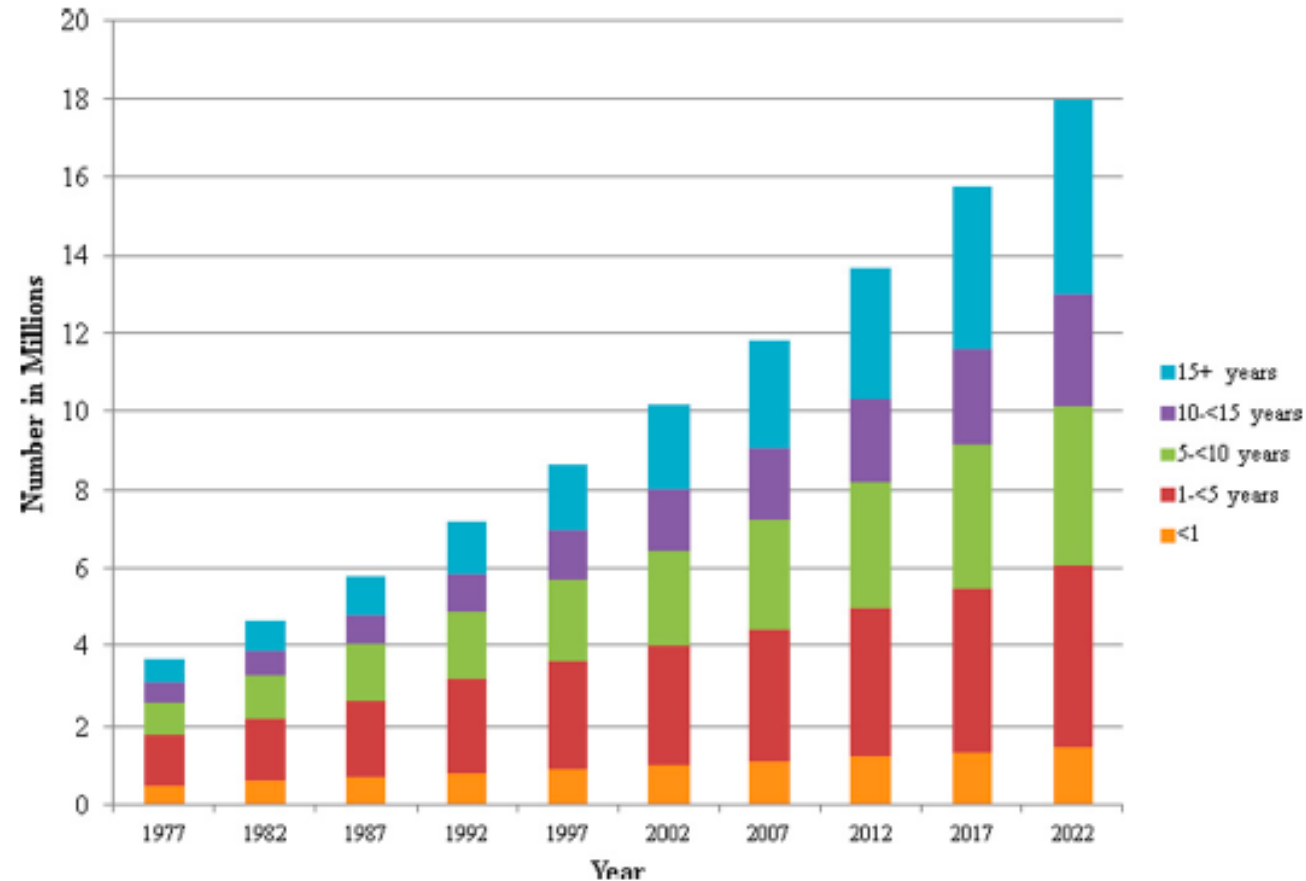
A **cancer survivor** is a person with [cancer](#) [of any type who is still living.](#)

[Whether a person becomes a survivor at the time of diagnosis or after completing treatment, whether people who are actively dying are considered survivors, and whether healthy friends and family members of the cancer patient are also considered survivors, varies from group to group.](#) (NCI and NCCS definitions similar)

Our survivorship- definition (ESMO/ECPC guide)

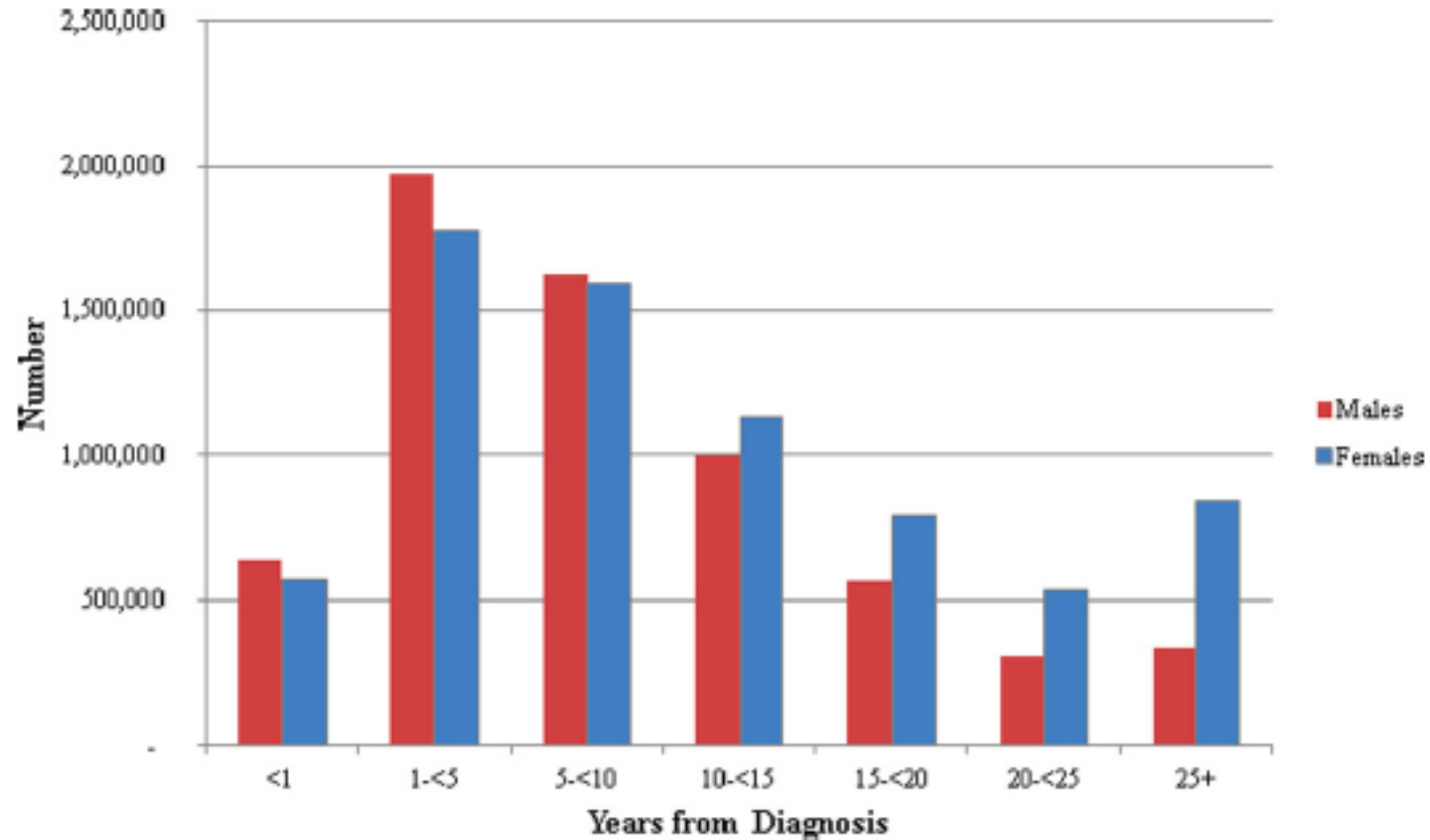
- Focuses on health and the physical, psychological, social and economic issues affecting people after their primary treatment of cancer
- Encompasses
 - « people having no disease after having finished their treatment »
 - « ..to receive treatment to reduce the risk of their cancer coming back » (i.e. adjuvant hormonal treatment in breast cancer)
 - « patients ... who receive treatment to manage cancer as a chronic disease « (i.e. metastatic breast cancer or Chronic Myeloid Leukemia))

Cancer survivors – rising!



Estimated and projected number of cancer survivors in the United States from 1977–2022 by years since diagnosis.

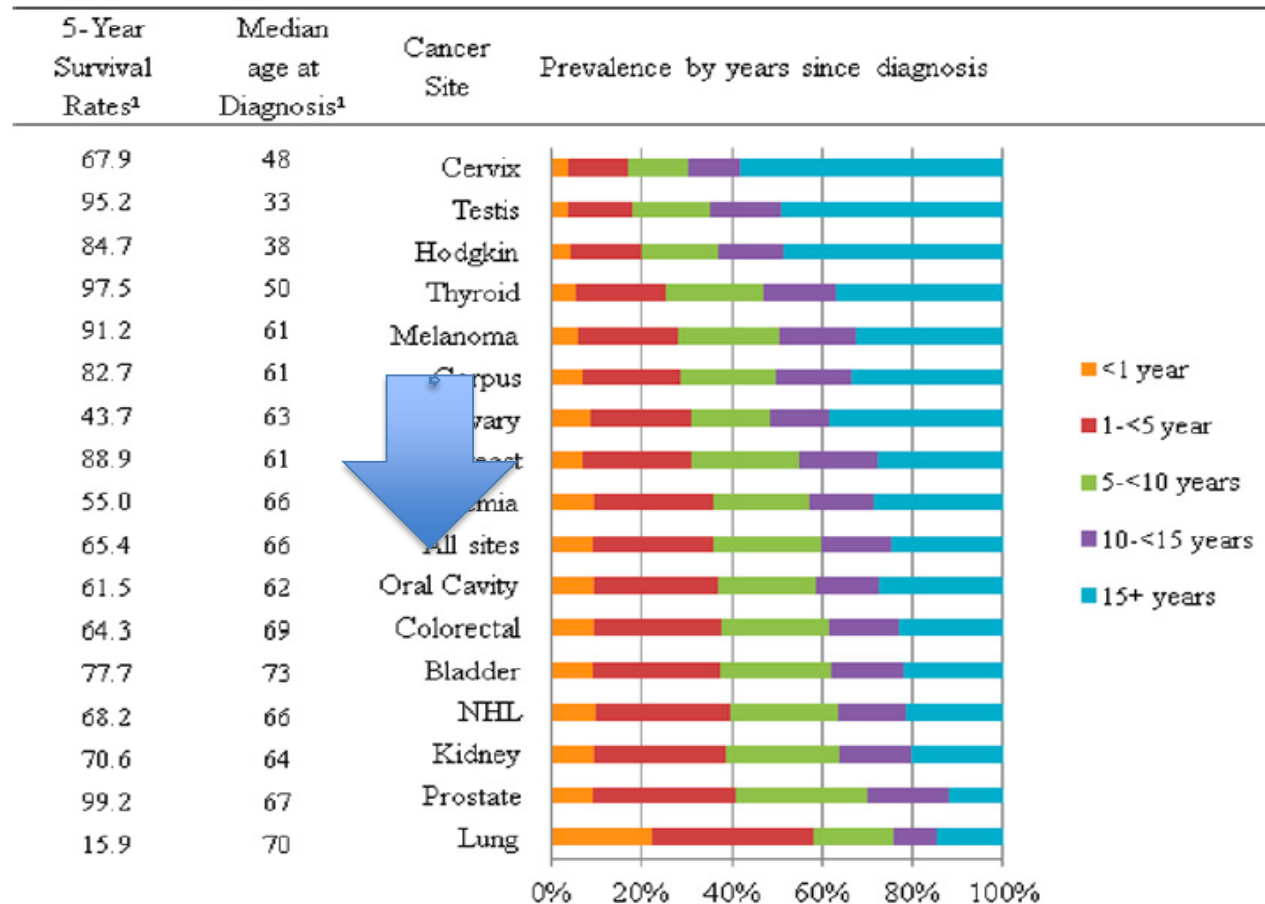
Follow-up : 25 years and more



Estimated number of cancer survivors in the United States as of January 1, 2012 by time since diagnosis and sex.

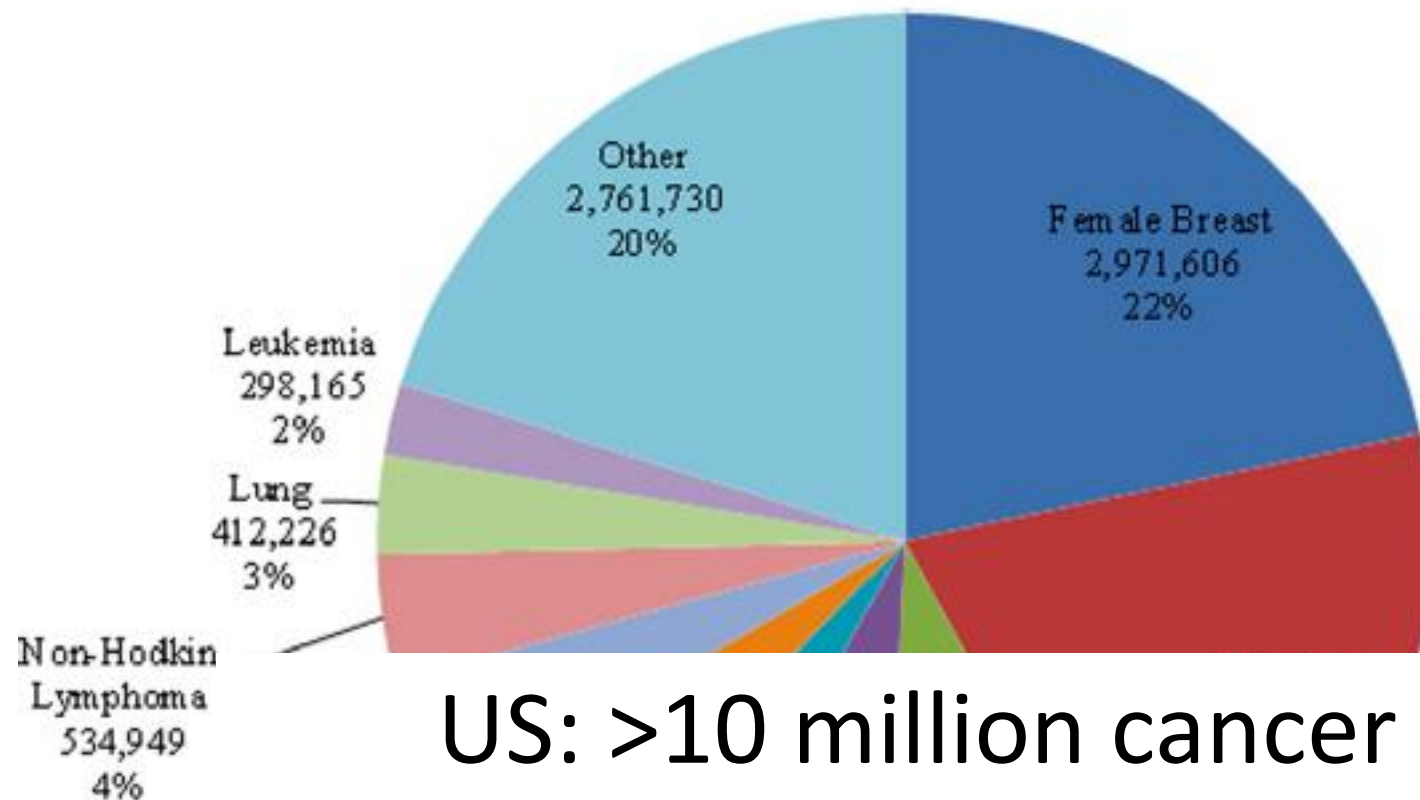
De Moor et al : Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care ; [Cancer Epidemiol Biomarkers Prev. 2013 Apr; 22\(4\): 561-570.](#)

Survivorship varies by cancer type (and overall mortality factors)

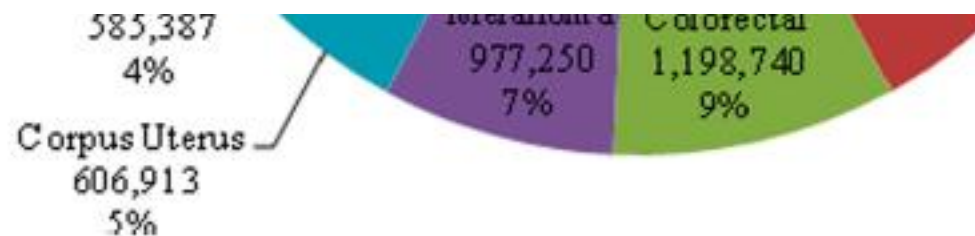


¹Howlader N, Noone A, Krapcho M, Neyman N, Aminou R, Waldron W, Altekruse SF, Kosary CL, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Eisner MP, Lewis DR, Chen HS, Feuer EJ, Cronin KA. SEER Cancer Statistics Review, 1975-2009 (Vintage 2009 Populations). Bethesda, MD: National Cancer Institute based on November 2011 SEER data submission, posted to the SEER web site, April 2012.

Estimated number of cancer survivors in the United States as of January 1, 2012 by cancer site and years from diagnosis.



US: >10 million cancer survivors in 2012



Estimated number of cancer survivors in the United States as of January 1, 2012 by cancer site.

De Moor et al : Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care ; [Cancer Epidemiol Biomarkers Prev. 2013 Apr; 22\(4\): 561-570.](#)

What does **survivorship** mean?

Approaching the needs of
patients in a curable or chronic
disease state

it to you.

Target: patients subject to survivorship care

- All cancer patients having absolved their first active anti cancer



A day in my life consulting a cancer survivor in 1999

- Happy to see my patients survive as responders to treatment
- Establish follow-up plans for medical exams (mammographies, ct- scans, endoscopies) , often in a « copy-paste » 3 monthly style (due to the lack of evidence based guidelines)
- Deal more and more with other diseases (i.e. diabetes, etc..) as the follow-up continues (or refer for any of these to the GP)
- Refer to a psychologist in case of anxiety or reactional depression problems

Survivorship care is a lot more

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Survivorship care is a lot more

- Personalised follow-up plan including secondary prevention features
- Trying to rehabilitate: getting body and mind back in shape
- Coping with ongoing disease and treatment related side effects and sequelae
- Coping with compliance in maintenance treatments
- Trying to re conciliate : social life, both within the family and in the community
- Trying to re integrate : workplace, financial burdens
- dealing with uncertainty : how long will remain a cancer survivor

REHABILITATION is the 1st important step of survivorship care

Support in coping with the new reality - Who can help me?

1. Cancer rehabilitation

Cancer **rehabilitation** is one of the first important steps in survivorship. Cancer and its treatment produce a multi-dimensional impact on patients' lives, affecting the physical, sensorial, cognitive, psychological, family, social and spiritual functional levels. **Rehabilitation** is part of cancer care, and has been recognised as a cancer patient's need and right along with cancer treatment. It is a way to minimise the impact and **side-effects** of cancer and cancer treatment at the many affected levels, to help patients in optimising their quality of life and in recovering the normalcy in their lives.

Rehabilitation programmes may be proposed as an outpatient programme, mostly provided by specialised **caregivers**, or carried out in specialised clinics. Their goal, is to help people recover many psychological and physical aspects of their lives and to remain as productive and independent as possible. **Rehabilitation** is valuable for everyone who is recovering from cancer treatment, those living with cancer and their families in:

- Improving physical and psychological strength to help offset any limitations caused by cancer or cancer treatment.
- Regaining good physical condition in order to return to everyday life.
- Improving self-management to reduce stress, improve sleep, improve emotional balance and well-being.
- Regaining self-confidence.
- Becoming more independent and less reliant on **caregivers**.
- Learning to manage possible **side-effects** from **chemotherapy**, **hormonal therapy**, **targeted therapies**, **immunotherapy** and/or **radiotherapy** to minimise the effect of these side-effects on everyday life.
- Learning how to have a balanced diet, good nutrition and preserving or achieving healthy weight.
- Learning how to manage sexual life.
- Learning how to preserve **fertility**.
- Reducing the number of **hospitalisations**.

Rehabilitation programmes will vary in content, extent and form, depending on availability and choice. They may be proposed even when you have already returned to work, or in a block before you do so. Most will be outpatient-based and some may be proposed through a medical inpatient institution.

Ask your doctor and **caregiver** about **rehabilitation** options available to you. A rehabilitation programme targeting your specific needs can be organised by the health **caregivers** in cooperation with the **social workers** and the patient and family.

Frequent problems of patients after curative treatment of head and neck cancer

- Xerostomia: dryness of the mouth
- Loss of taste (smelling) sensation
- Loss of teeth, destruction of jaw
- Dysphagia: troubles swallowing
- Voice disorders
- Respiratory difficulties
- Lymphoedema : swelling of head and neck
- Malnutrition
- Neck and shoulder pain disorders
- Chronic pain
- Difficulties in tracheostoma management
- disfiguration

In addition:

- Frequent secondary cancers: need for tight follow-up
- Frequent poor healthy life style including high incidence of smoking / alcohol consumption
- Frequently co morbidities due to tobacco consumption, alcohol
- Poor self image
- Low income may hamper restoration efforts (i.e. dental care, ...)
- Prolonged treatment and recovery time often lead to work loss and difficulties to re integrate

Survivorship care for H&NC patients: a multi disciplinary challenge



- Multidisciplinary team:
 - Oncologist
 - Head & Neck Specialist
 - Orthodontist
 - Orthophonist
 - Pain specialist
 - Nurses
 - Physiotherapist
 - Nutritionist
 - Psychologist
 - Social worker
 - Addictologist
 -

Individualizing survivorship care: the ESMO ECPC Survivorship Checklist

Background information	
Family history of cancer	YES / NO
Genetic/hereditary risk factor, predisposing conditions:	
Genetic counselling	YES / NO
Genetic testing results:	
Fertility: cryopreservation	YES / NO
Diagnosis	
Cancer type and location	
Date of diagnosis (year):	
Stage:	<input type="checkbox"/> I <input type="checkbox"/> II <input type="checkbox"/> III <input type="checkbox"/> IV <input type="checkbox"/> NOT APPLICABLE
Method of diagnosis:	
+ Imaging tests	YES / NO
+ Laboratory tests	YES / NO
+ Biopsy	YES / NO
+ Site of biopsy	

Treatment	
Surgery	YES / NO
Surgical location, findings:	
Surgery date:	
Radiation therapy	YES / NO
Surgery date:	
Radiation area:	
<input type="checkbox"/> Chest <input type="checkbox"/> Abdomen <input type="checkbox"/> Pelvic area	
<input type="checkbox"/> Head and Neck <input type="checkbox"/> Testis <input type="checkbox"/> Breast and Axilla	
<input type="checkbox"/> Other area (i.e. extremities)	
Systemic therapy (Chemotherapy, hormonal therapy, immunotherapy, targeted therapies)	YES / NO
Type of therapy:	
<input type="checkbox"/> Chemotherapy <input type="checkbox"/> Hormonal therapy	
<input type="checkbox"/> Targeted therapies <input type="checkbox"/> Immunotherapy	
<input type="checkbox"/> Combination	

Name of drug	Therapy start date	Therapy end date

and treatment summary

Background information	YES	NO	Treatment	YES	NO
Family history of cancer	<input type="checkbox"/>	<input type="checkbox"/>	Surgery	<input type="checkbox"/>	<input type="checkbox"/>
Genetic/hereditary risk factor, predisposing conditions:			Surgical location, findings:		
Genetic counselling	<input type="checkbox"/>	<input type="checkbox"/>	Surgery date:		
Genetic testing results:			Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>
Fertility: cryopreservation	<input type="checkbox"/>	<input type="checkbox"/>	Surgery date:		
Diagnosis			Radiation area:		
Cancer type and location			<input type="checkbox"/> Chest <input type="checkbox"/> Abdomen <input type="checkbox"/> Pelvic area		
Date of diagnosis (year):			<input type="checkbox"/> Head and Neck <input type="checkbox"/> Testis <input type="checkbox"/> Breast and Axilla		
Stage:	<input type="checkbox"/> I <input type="checkbox"/> II <input type="checkbox"/> III <input type="checkbox"/> IV <input type="checkbox"/> NOT APPLICABLE		<input type="checkbox"/> Other area (i.e. extremities)		
Method of diagnosis:			Systemic therapy (Chemotherapy, hormonal therapy, immunotherapy, targeted therapies)		
+ Imaging tests	<input type="checkbox"/>	<input type="checkbox"/>	Type of therapy:		
+ Laboratory tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Chemotherapy <input type="checkbox"/> Hormonal therapy		
+ Biopsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Targeted therapies <input type="checkbox"/> Immunotherapy		
+ Site of biopsy			<input type="checkbox"/> Combination		

Name of drug	Therapy start date	Therapy end date

Symptoms and side-effects during therapy

Fatigue	<input type="checkbox"/>	Nausea and Vomiting	<input type="checkbox"/>	Pain and peripheral neuropathy	<input type="checkbox"/>
Sleep disorders	<input type="checkbox"/>	Skin and soft tissue problems	<input type="checkbox"/>	Loss of appetite	<input type="checkbox"/>
Heart problems	<input type="checkbox"/>	Change in weight	<input type="checkbox"/>	Change in mood or depression	<input type="checkbox"/>
Lung problems	<input type="checkbox"/>	Difficulties with breathing	<input type="checkbox"/>	Memory or concentration loss	<input type="checkbox"/>
Low red blood cell count (anaemia)	<input type="checkbox"/>	Low white blood cell count	<input type="checkbox"/>	Infections	<input type="checkbox"/>

...needed

- **Awareness among all stakeholders concerning ReHab and Survivoship**
- Empowerment of patients
- Evidence based ReHab programmes (research)
- Individualized ReHab and Survivorship tracks

THANK YOU FOR YOUR ATTENTION !

Prevention and survivorship: European Union initiatives on head and neck cancers



Antoni Montserrat Moliner

Senior Expert for Cancer and Rare Diseases, Directorate of Public Health, European Commission



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DISCUSSION

