

SOPRAVVIVENZA DOPO TUMORE DIAGNOSTICATO IN ETÀ PEDIATRICA

→ Sopravvivenza globale a 5 anni: 80%.

→ In aumento il numero di pazienti lungosopravvivenenti dopo tumore diagnosticato in età pediatrica.

→ Nell'anno 2000 **1 su 900** giovani adulti di età compresa tra 16 e 34 anni sarà un "sopravvivenente di tumore trattato in età pediatrica"

Meadows AT, 1993: American Cancer Society Workshop on Children with Cancer and Long-term Survival

→ "Valutando la sopravvivenza globale e l'incidenza di patologia tumorale nei bambini e giovani adulti si prevede che **1 su 450** individui giovani adulti sarà un lungosopravvivenente da tumore insorto in età pediatrica".

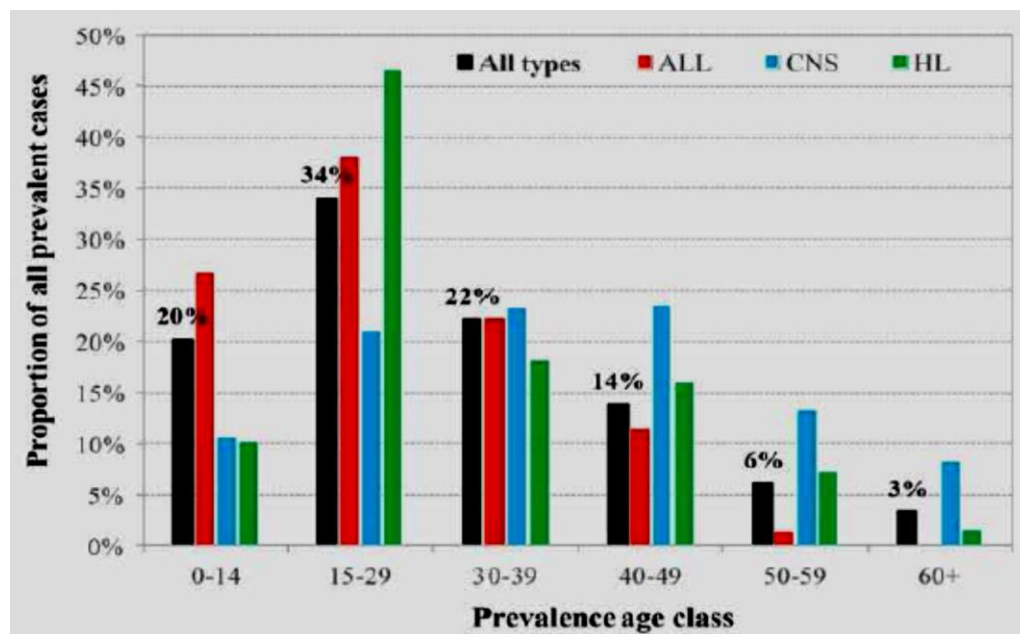
Meadows AT, JCO 2006

Attualmente in Europa: 300-500.000 **lungo-sopravvivenenti**

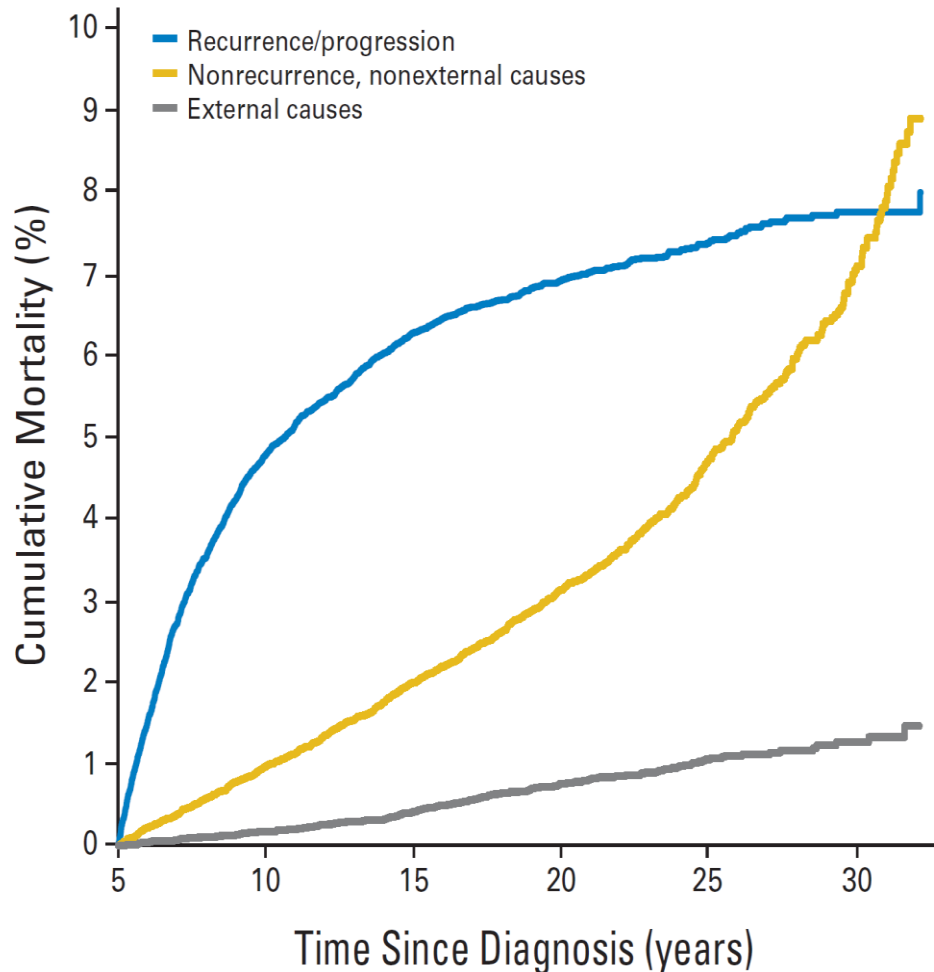
Vassal et al, PBC 2014

An estimate of the number of people in Italy living after a childhood cancer

Cancer type	Sex	Prevalent cases
All types	Both	44,135
	Males	23,687
	Females	20,448



Late Mortality Among 5-Year Survivors of Childhood Cancer: A Summary From the Childhood Cancer Survivor Study (n=20,483; diagnosi 1970-1986)



Mortalità a 30 anni: 18.1%

Cause di mortalità tardiva:

- recidiva di malattia 58%
- tossicità tardiva: 34.7%
- cause esterne 7.3%

• **SMN**: SMR 15.2

(> se pazienti radiotrattati e/o esposti ad alchilanti e/o epipodofillotossine)

• **Eventi cardiaci**: SMR 7

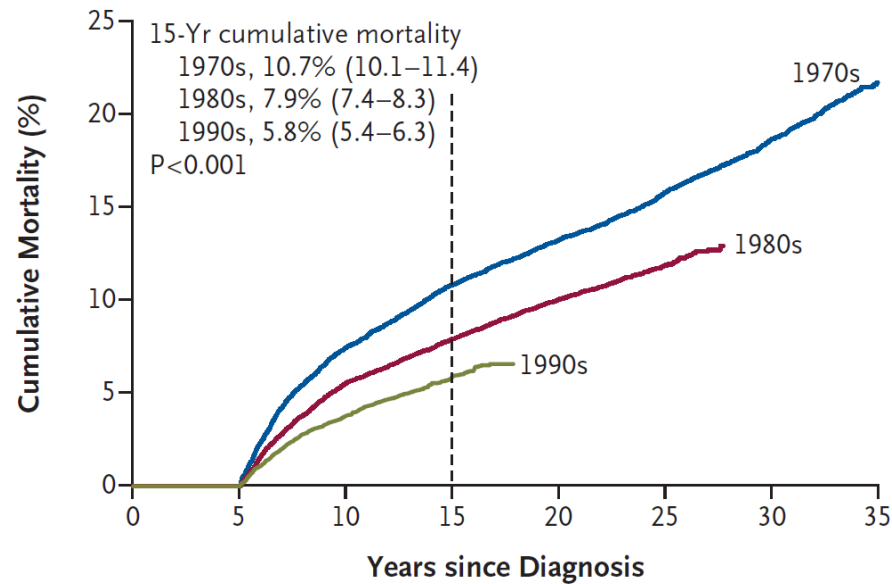
(> se pazienti radiotrattati localmente e/o esposti ad antracicline)

• **Malattia polmonare**: SMR 8.8

Reduction in Late Mortality among 5-Year Survivors of Childhood Cancer

n=34,033; diagnosi 1970-1999

A Death from Any Cause

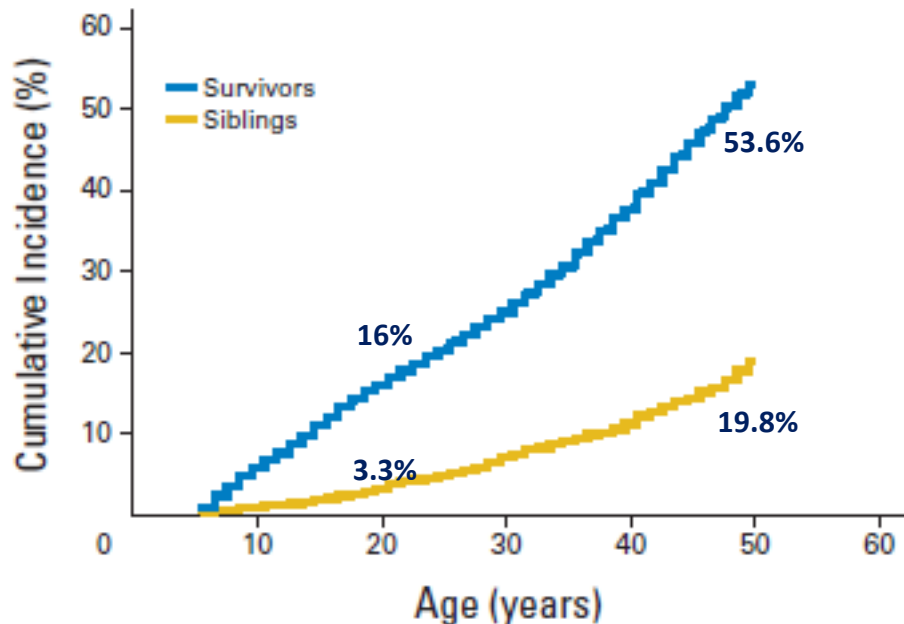


Aging and Risk of Severe, Disabling, Life-Threatening, and Fatal Events in the Childhood Cancer Survivor Study

14390 long term survivors vs 4031 siblings

Età mediana all'ultimo follow up: 31 anni.

Mediana di follow up di 24,5 anni



I lungosopravvivenenti presentano una maggiore incidenza di complicanze severe, a prognosi infausta e fatali.

Score in accordo con il CTCAE:

Grado 1: lieve

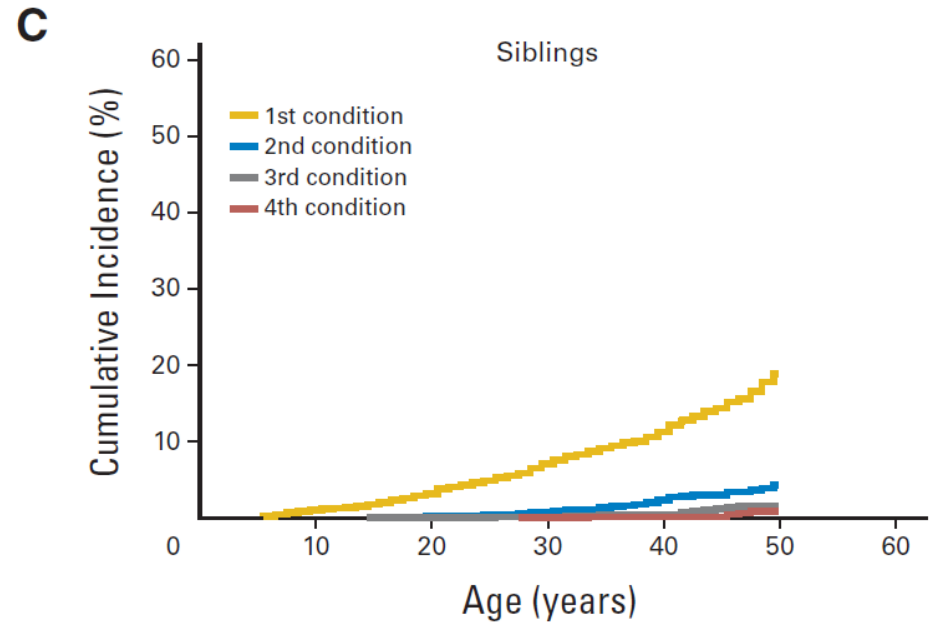
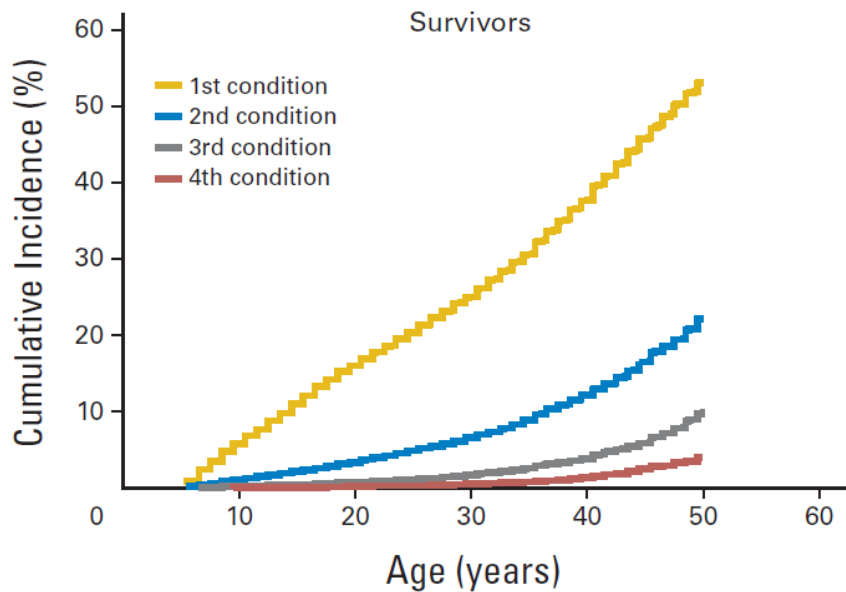
Grado 2: moderato

Grado 3: severo

Grado 4: disabilitante o a rischio di vita

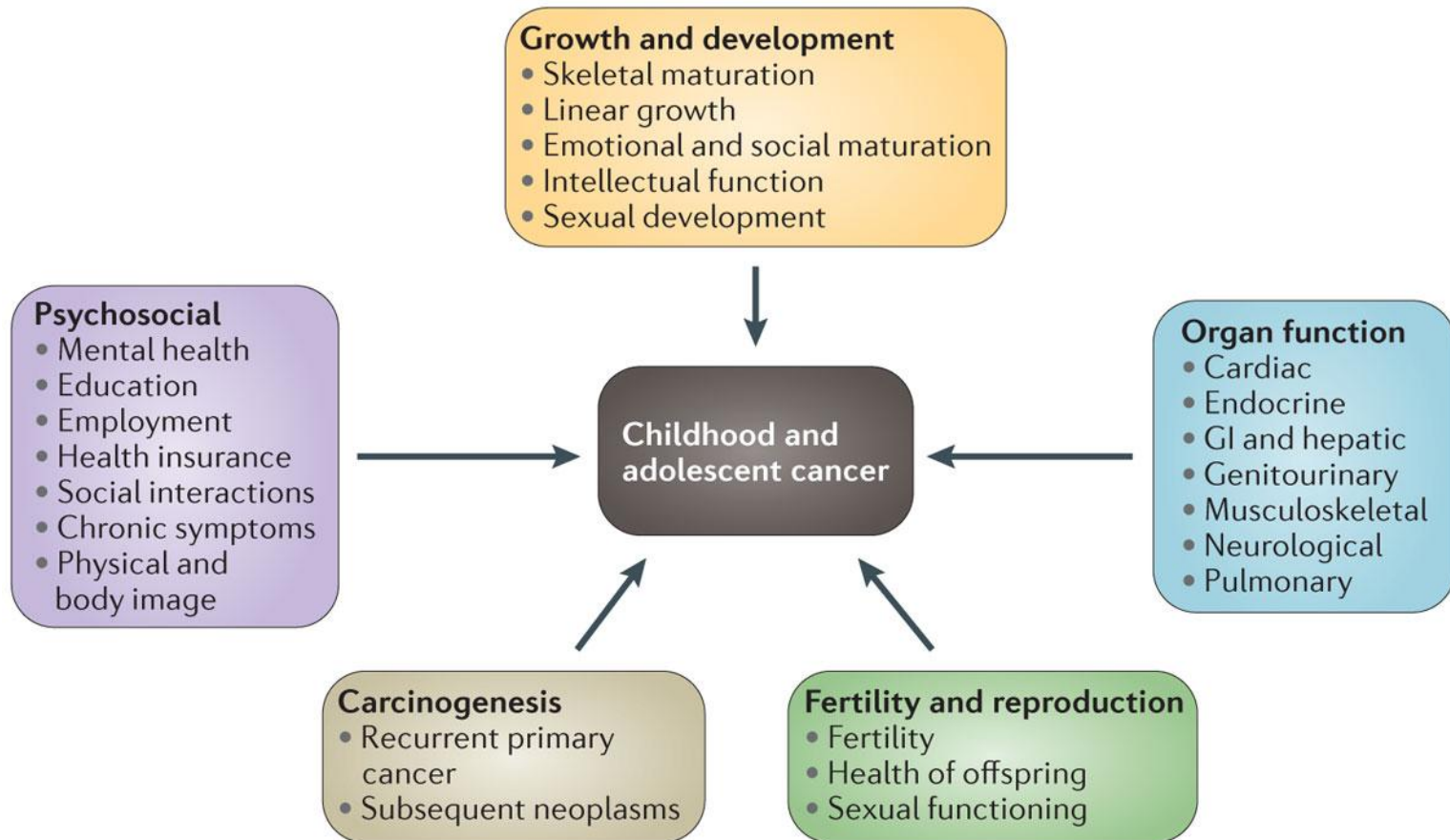
Grado 5: fatale

Aging and Risk of Severe, Disabling, Life-Threatening, and Fatal Events in the Childhood Cancer Survivor Study



- 2/3 dei lungosopravvivenenti presenta almeno una alterazione cronica dello stato di salute
- 1/4 presenta una condizione severa o a rischio di vita

Survivors of childhood and adolescent cancer: life-long risks and responsibilities



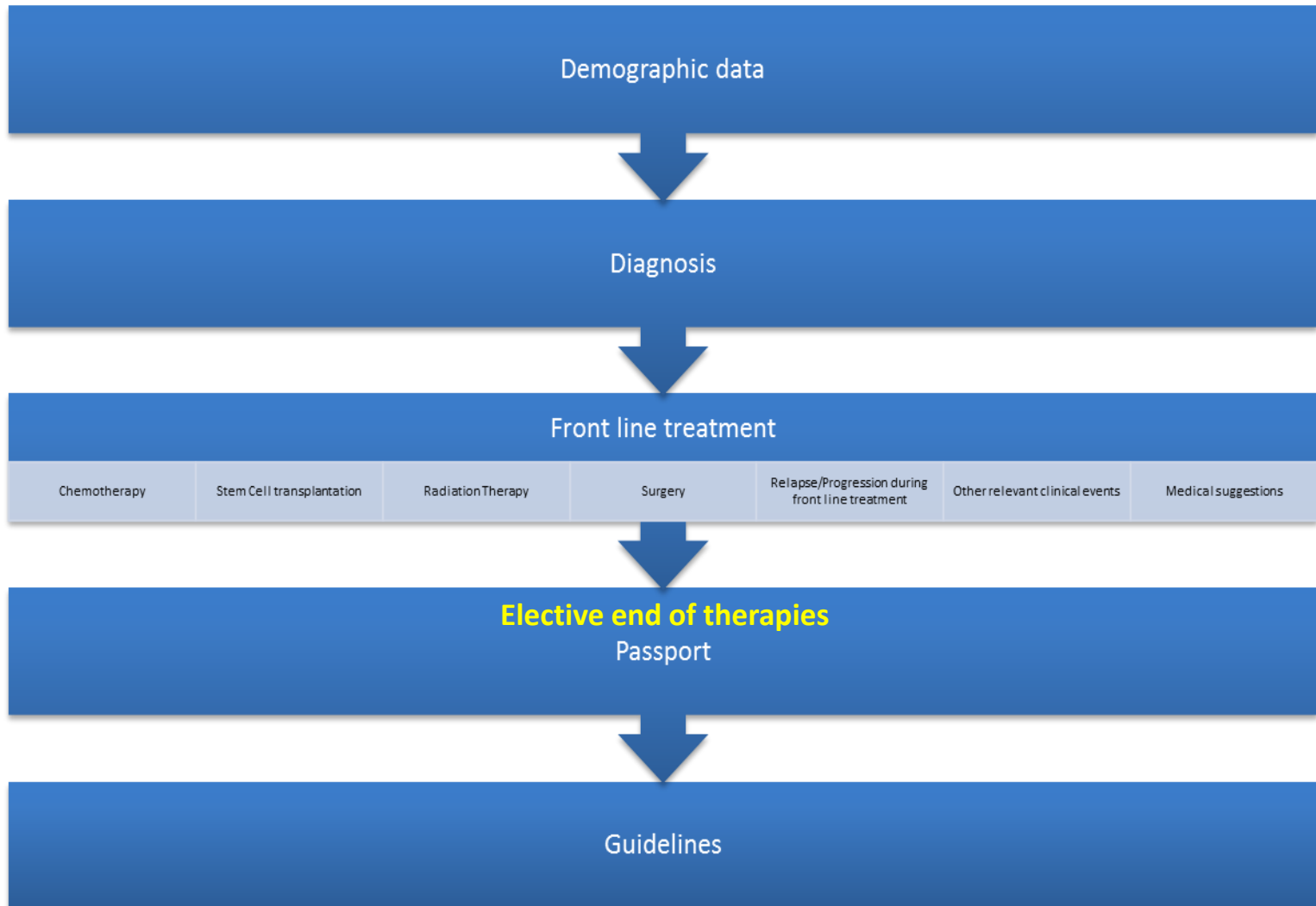


- L'obiettivo strategico è quello di fare in modo che in Europa ogni lungosopravvivenente da un tumore in età pediatrica o adolescenziale riceva un'assistenza ottimale a lungo termine.
- Il Passaporto è un documento disponibile su carta o in formato elettronico che viene dato a tutti i soggetti che hanno raggiunto la fine elettiva delle cure.



- Storia di malattia con i dati anagrafici del soggetto, le specifiche sul tipo e categoria di rischio del tumore, le dosi cumulative di farmaci e o radioterapia ricevute, così come gli interventi chirurgici maggiori e/o eventuali complicanze avvenute durante il trattamento.*
- Linee guida per un follow-up a lungo termine per monitorare, diagnosticare precocemente e possibilmente prevenire eventuali effetti a distanza dei trattamenti utilizzati per il trattamento del tumore stesso.*

General outline of the survivorship passport



Demographic data



Diagnosis



Front line treatment

Chemotherapy	Stem Cell transplantation	Radiation Therapy	Surgery	Relapse/Progression during front line treatment	Other relevant clinical events	Medical suggestions
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Relapse/ SMN after first elective end of treatment

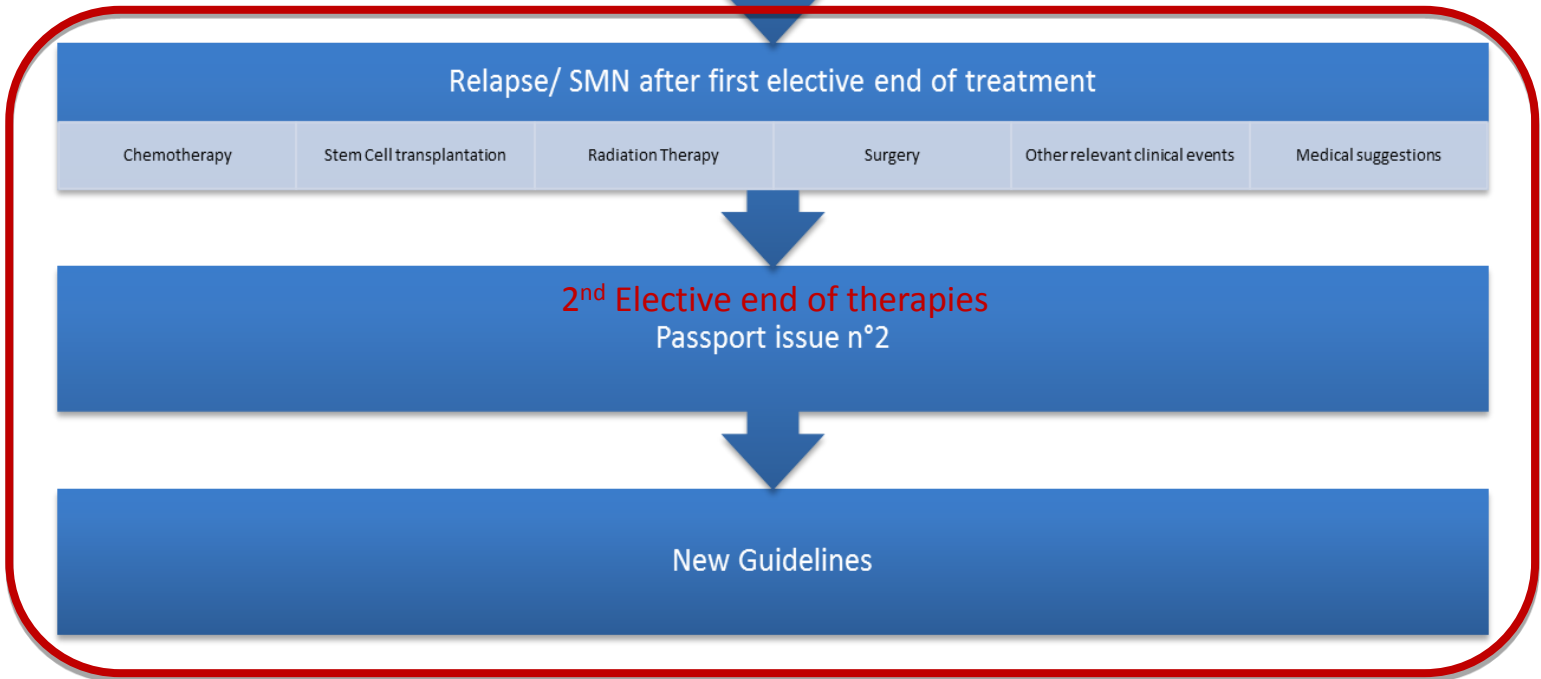
Chemotherapy	Stem Cell transplantation	Radiation Therapy	Surgery	Other relevant clinical events	Medical suggestions
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2nd Elective end of therapies
Passport issue n°2



New Guidelines



Summary of cancer treatment

SUMMARY OF CANCER TREATMENT

"This Survivorship Passport is a short summary extracted from the information reported in the medical record. It describes the disease and its clinical course as well the treatments you received. This document does not replace the medical record that is always available at our center."

JANINE DOE

Passport Number: IT12016021871

PERSONAL DATA

Date of birth	02/10/1998	Sex	Female
CHAMPAGNY-EN-VANOISE, RHÔNE-ALPES, FRANCE			
Identification Document type	NANTTRI	Number	12244
Contact belonging to	Survivor		
Email	jde@gmail.com		

FIRST TUMOR

DIAGNOSIS

Date of diagnosis	01/01/2004
Institution	Gaslini Hospital
Diagnosis	Nephroblastoma, NOS
Site	Kidney, NOS
Laterality	Right

OTHER DISEASES

Hereditary Cancer Predisposition Syndrome or medical condition cancer associated	No
Other medical conditions, not cancer associated	No

FRONT LINE TREATMENT

The treatment has been executed following	Trial/Protocol: EPSSG	
Group/Arm/Randomization	C	
Summary of major treatments	Chemotherapy	Yes
	Stem Cell transplantation	Yes
	Radiotherapy	Yes
	Major Surgery	Yes
Progression/relapse during frontline treatment	Yes	
Date of first elective end of treatment	02/12/2004	

STEM CELL TRANSPLANTATION

CLINICAL COURSE

N. 1	
Type of donor	Sibling parent
GVHD prophylaxis	Yes
GVHD Acute	Yes, Grade: 2
GVHD Chronic	No
Blood type before transplant	A (Rh +)
Blood type after transplant	A (Rh +)
Date of end of immunosuppressive treatment after HSCT	30/12/2004

MAJOR SURGERY

CLINICAL COURSE

N. 1	
Surgery description	total nefrectomy
Shunt application	Yes (Removed)
Amputation	Yes
Prosthesis	Yes (External)
N. 1	
Type of event	Relapse
Type	Local

Guidelines selection and passport

Passport date **17/09/2015**

On the basis of the treatments received by the patient, the system proposes the following guidelines. If you consider a different level of risk, you can change the guidelines to be delivered to the patient.

Breast Cancer Screening

Colour*

[Download Guideline](#)

Cardiomyopathy Screening

Colour*

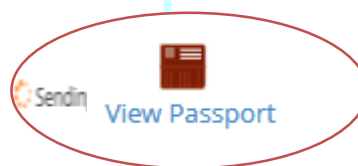
[Download Guideline](#)

Female Gonadal Toxicity Surveillance

Colour*

[Download Guideline](#)

Notes



Il follow up può essere modificato dal medico che compila il passaporto



Guidelines selection and passport

CLINICAL COURSE			
Start date	2004	End date	2005
CLASSIC/TRADITIONAL ANTINEOPLASTIC AGENTS			
Drug name		Total cumulative dose	Measure unit
Doxorubicin		4000	mg/m2
Ifosfamide		500	mg/m2
Intrathecal injections	No		
OTHER ANTINEOPLASTIC AGENTS			
Hormones	No		
Immunotherapy	No		
OTHER TREATMENTS			
Other treatments	No		

Because of the treatment you have had we have listed the tests recommended for you. This advice is because a few people who had the same treatment as you have developed problems which we hope can be picked up at an early and treatable stage.



Breast Cancer Screening

We think that you need to have regular breast cancer screening.



Cardiomyopathy Screening

We think that it is reasonable to consider having regular checks on how y

Data are updated to the date of issue of the passport or the date of the last clinical examination

Recommendations are reported in the patient summary, with different color according to the level of risk



Passport issued by Riccardo Haupt
Institution Gaslini Hospital
Date of issue 16/11/2015



Personalized guidelines

Personalized guidelines can be printed or downloaded (pdf format).

Some cancer treatments can affect the heart.

Problems can arise even several years after you have completed your treatment.

Symptoms of heart failure can include:

- Feeling short of breath (breathless), especially during activities such as walking up stairs, and when lying flat at night. However, breathlessness may also be due to other conditions such as lung problems, or being unfit or overweight
- Increasing fatigue (extreme tiredness)
- Palpitations
- Dizziness or loss of consciousness
- Swollen ankles

The heart is a large muscle that pumps blood around your body to deliver oxygen and nutrients and carry away carbon dioxide and waste products (see figure).

The blood is pumped into the body through two large "pipes", big vessels called the aorta and the pulmonary artery, and returns to the heart through two other large vessels: the superior vena cava and the inferior vena cava.

The heart is divided into four chambers. The collecting chambers, called the right and left where blood goes into the heart. There are two pumping chambers, called the right and left that pump blood out of the heart.

Cardiomyopathy Screening

www.slope.eu
www.pancare.eu
www.ighg.org

1 Superior vena cava	8 Aorta
2 Right pulmonary artery	9 Left pulmonary artery
3 Right pulmonary veins	6 Left pulmonary veins
4 Inferior vena cava	7 Coronary arteries

Name of the survivor and passport number

Cardiomyopathy Screening

WHAT DO I NEED TO KNOW?

for survivors of childhood cancer

Name **JANINE DOE**

Passport nr. **IT2016021871**

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Multi-language translation

Patients can display and print their documents in different languages

The image shows three overlapping documents representing the Survivorship Passport in different languages: German (left), English (middle), and Italian (right). Each document features the 'Survivorship Passport' logo and various patient information sections.

Il paziente potrà accedere al proprio passaporto che potrà anche essere tradotto in diverse lingue

RIEPILOGO DEL TRATTAMENTO DEL CANCRO

Questo "Passaporto del 'guarito'" ("Passaporto del fine cura") è un breve riassunto estratto dai dati documentati in cartella clinica. Descrive la malattia di base e i trattamenti ricevuti per la sua cura. Questo documento non sostituisce la cartella clinica che è comunque sempre a disposizione presso il nostro centro, in caso di necessità.

Marie DOE Passaporto numero: IT12015092121

DATI PERSONALI			
Data di nascita	15/07/1993	Sesso	Femmina
Città di residenza	LONDON, ENGLAND, UNITED KINGDOM		
Tipo di documento identificativo	Carta d'identità	Numero	UK120101277
Contatto appartenente a	Lungo-sopravvivente		
E-mail	john.doe@example.com		

PRIMO TUMORE

DIAGNOSI	
Data di diagnosi	07/02/2007
Istituto	Test Sistema
Alto rischio	No

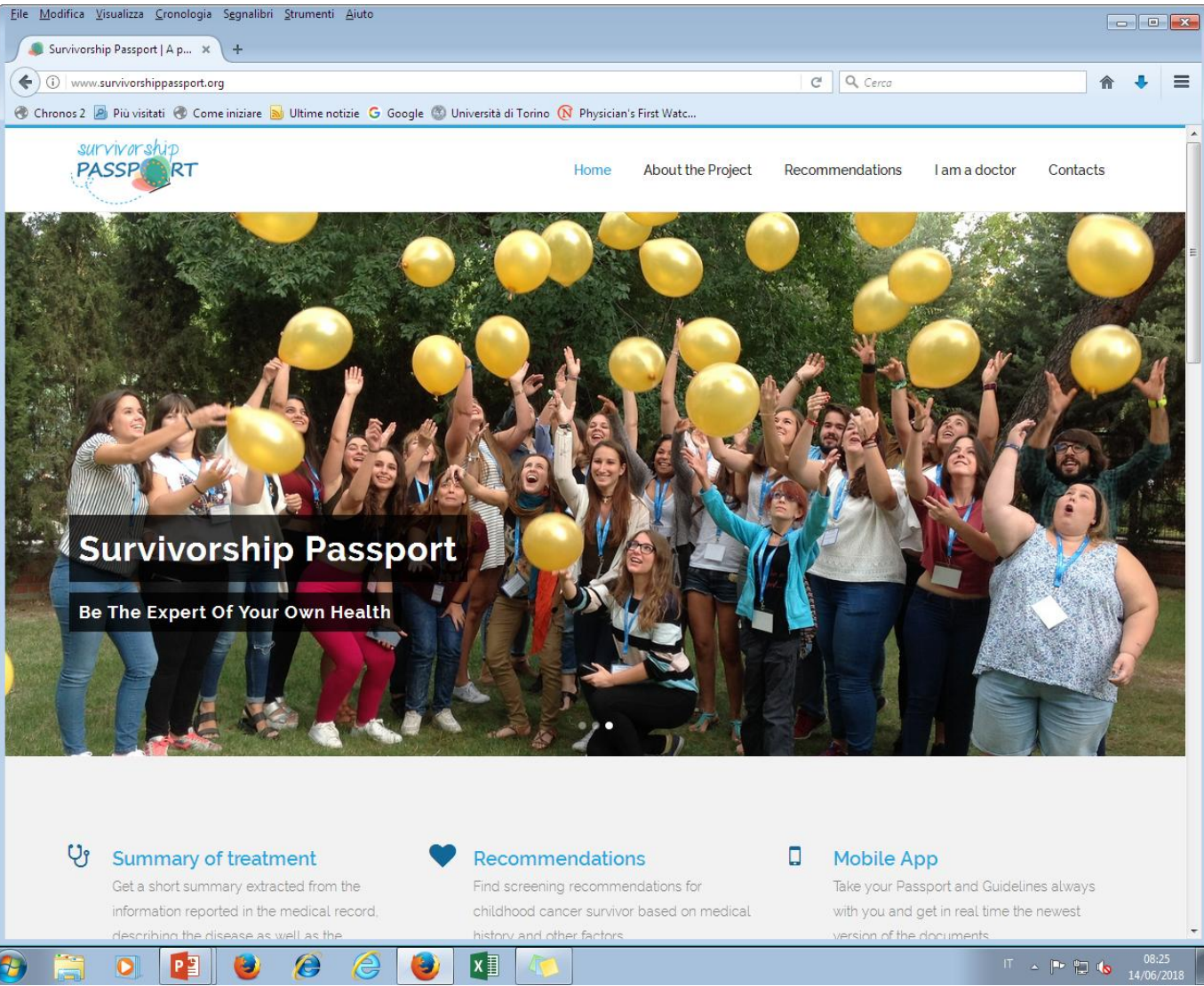
ALTRE MALATTIE

Sindromi genetiche predisponenti	No
Altri quadri clinici, associati al tumore	No
Altri quadri clinici, non associati al tumore	No

TRATTAMENTO DI PRIMA LINEA

Il trattamento è stato eseguito secondo	Linee guida	
Lista delle principali terapie	Chemoterapia	SI
	Trapianto di cellule staminali	SI
	Radioterapia	SI
	Chirurgia	SI

Progressione/recidiva durante il trattamento di prima linea SI



Il passaporto verrà compilato, validato e consegnato al paziente a 2 anni dall'off therapy.