

ECPC: Cancer Survivorship: Current Challenges and EORTC Perspectives

ECPC 9 June 2018

Françoise Meunier, MD, PhD, FRCP

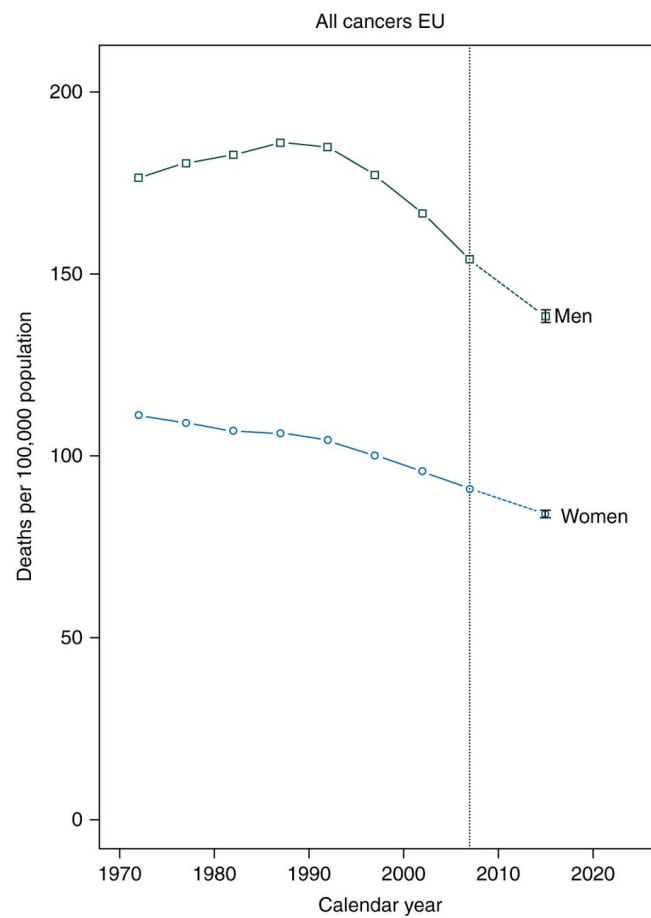
Director Special Projects, EORTC

Brussels, Belgium

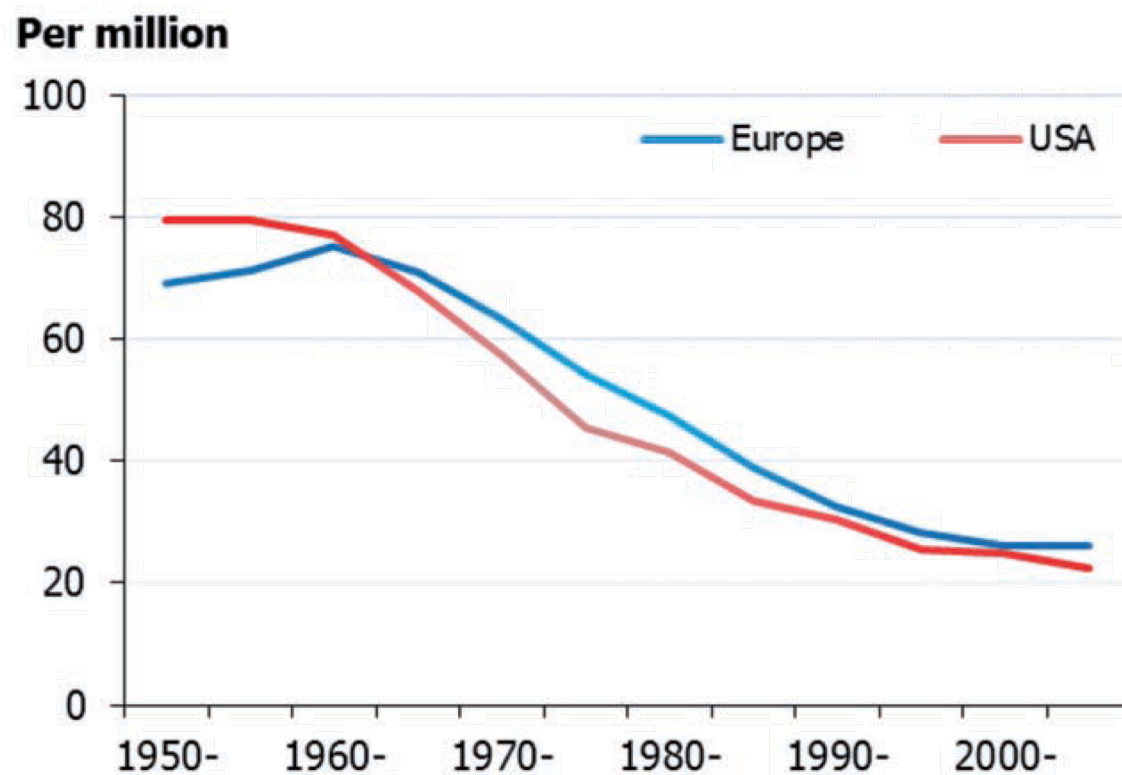
Cancer is here to stay



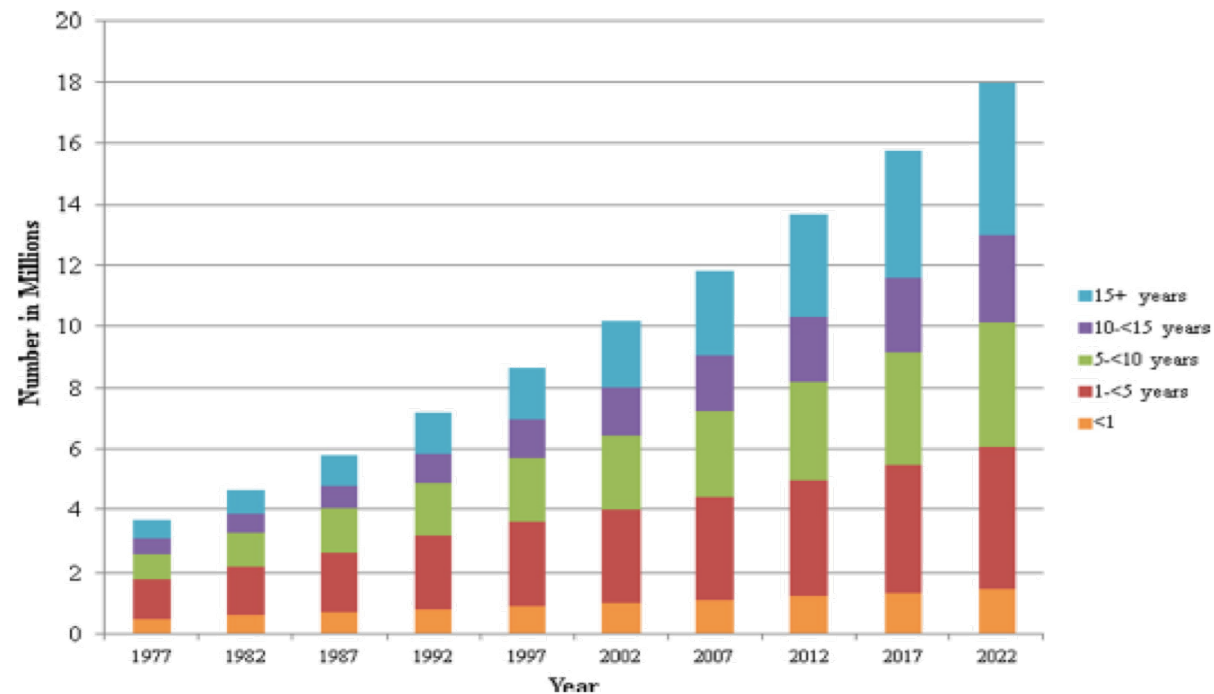
Decreased Cancer mortality in Europe



Childhood Cancer Mortality



US:>10 million cancer survivors in 2012



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

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.](#)

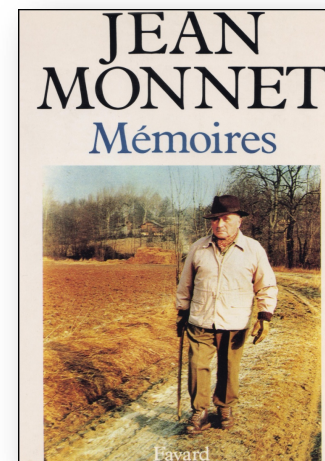
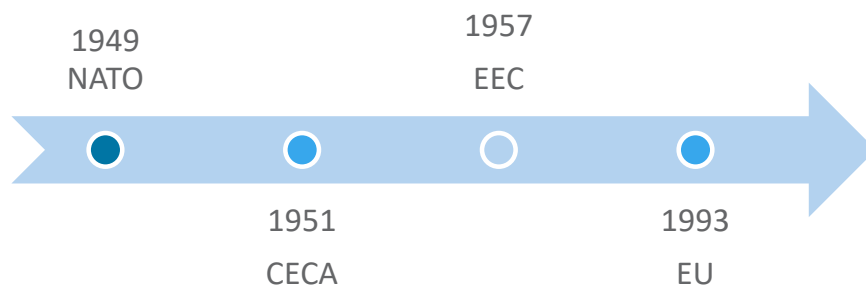
Long term survival (%)

	1970	2017
• Testis cancer	0	95
• Leukaemia in children	10	90
• Breast cancer	40	90
• Hodgkin's disease	10	90
• Colon cancer	30	65
• Bone cancer	5	60
• Leukaemia in adults	10	55
• Non-small cell lung cancer	10	20
• Pancreas	5	10

OF MICE AND MEN: THINGS ARE MUCH MORE DIFFICULT IN MEN

Professor Henri Tagnon

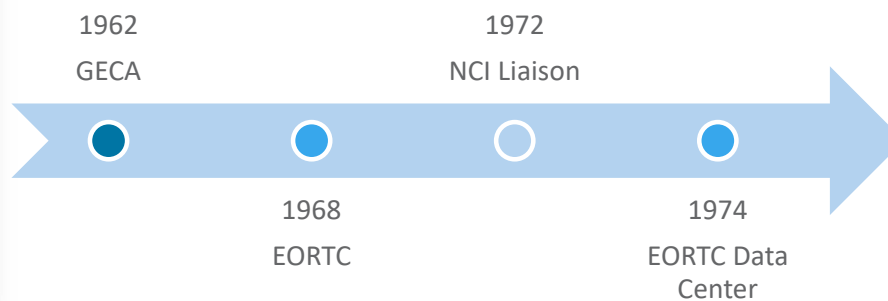
European visionaries



1888 - 1979



1911 - 2000



EORTC by the numbers (2017)

A world-class network	An expert HQ	Unique output
<ul style="list-style-type: none">• > 5,500 collaborators• 930 institutions• 27 countries• 21 groups & task-forces• 120 collaborative groups	<ul style="list-style-type: none">• 214 employees• > 198,000 patients in database• > 25,000 patients in follow-up	<ul style="list-style-type: none">• 15 new studies open to patient entry in 2017• 53 ongoing studies• 25 studies in protocol outline development• 19 studies in protocol development• 9 studies in regulatory activation• Working on \approx 203 studies

EORTC Patients Accrual

Accrual of screened patients in EORTC clinical studies from 2007 to 2017: 48341 patients

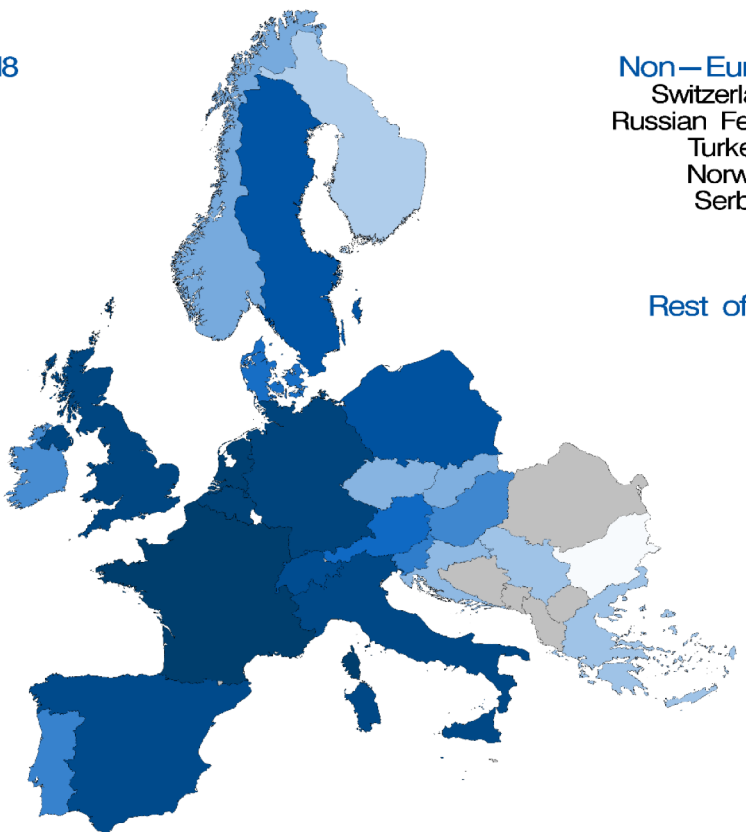
European Union: 43418

France: 10403
 Netherlands: 9067
 Belgium: 5628
 Germany: 5185
 United Kingdom: 4174
 Italy: 3362
 Spain: 2486
 Poland: 507
 Sweden: 459
 Austria: 364
 Denmark: 314
 Slovenia: 261
 Portugal: 228
 Hungary: 224
 Ireland: 222
 Slovakia: 96
 Czech Republic: 91
 Croatia: 86
 Greece: 66
 Estonia: 62
 Finland: 48
 Cyprus: 36
 Latvia: 30
 Lithuania: 16
 Bulgaria: 2
 Luxembourg: 1

Non—European Union: 1591

Switzerland: 1206
 Russian Federation: 117
 Turkey: 105
 Norway: 97
 Serbia: 66

Rest of the world: 3332



Cancer Clinical Research

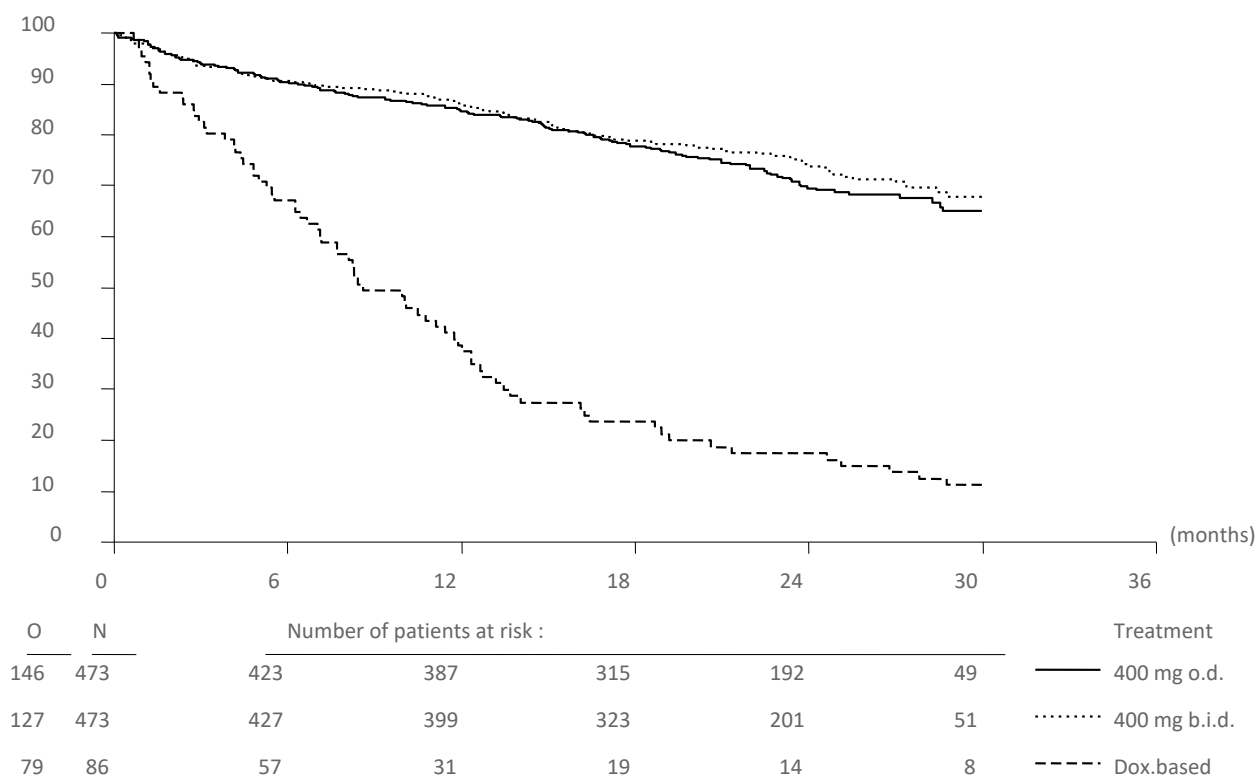
- 2 types of clinical trials

Drug
Development

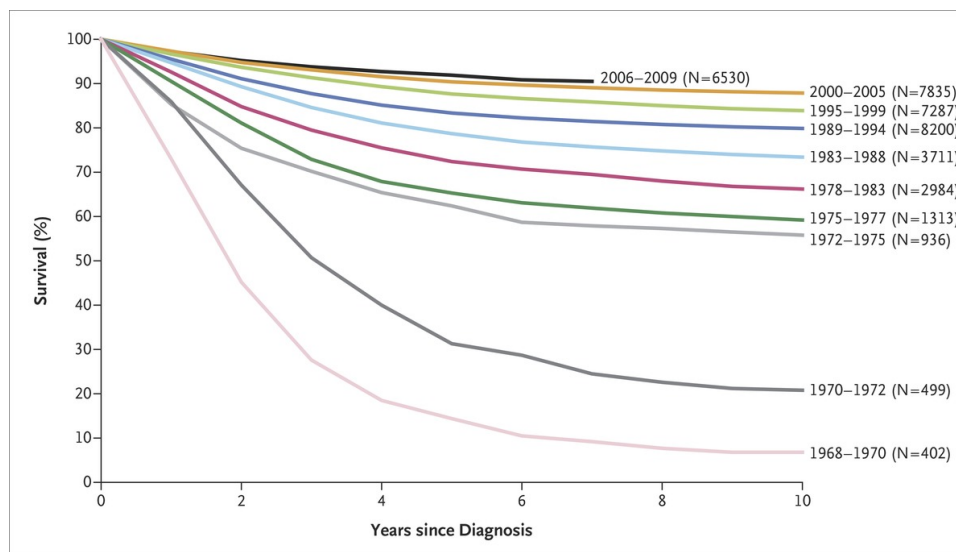
Therapeutic
strategies:
Multidisciplinary
approach

- Role of independent evaluation and increasing complexity – the importance of investigator driven clinical trials

Glivec study in GIST overall survival



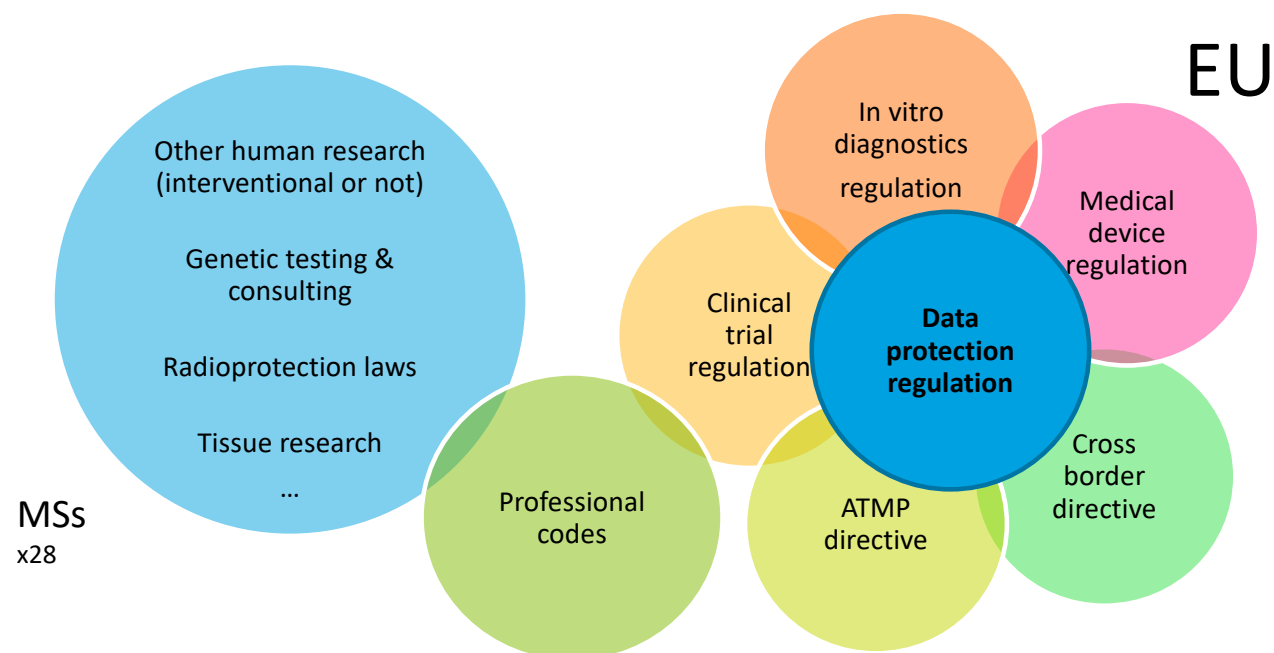
Overall survival according to treatment period



Children with Acute Lymphoblastic Leukemia (ALL)
Enrolled in Children's Cancer Group (CCG) and Children's Oncology Group (COG) Clinical Trials

Hunger, NEJM, 2015

Regulatory framework in Europe: a major bottleneck



⇒ *Streamline - Simplify - Harmonize*

Europe must build an integrated and harmonized legal and ethical framework to foster relevant international cancer clinical research

The Way Forward?



Streamline - Simplify – Harmonize

Building a bright future together requires
Wisdom - Courage – Vision and Trust

“COLLABORATE OR DIE”

(Steve Arlington – PwC)



Contents lists available at ScienceDirect

Journal of Cancer Policy

journal homepage: www.elsevier.com/locate/jcpc

Diverging EU health regulations: The urgent need for co ordination and convergence

Anastassia Negrouk^a, Denis Lacombe^b, Françoise Meunier^{b,*}

^a International Policy Office, EORTC, Belgium

^b EORTC, Belgium

ARTICLE INFO

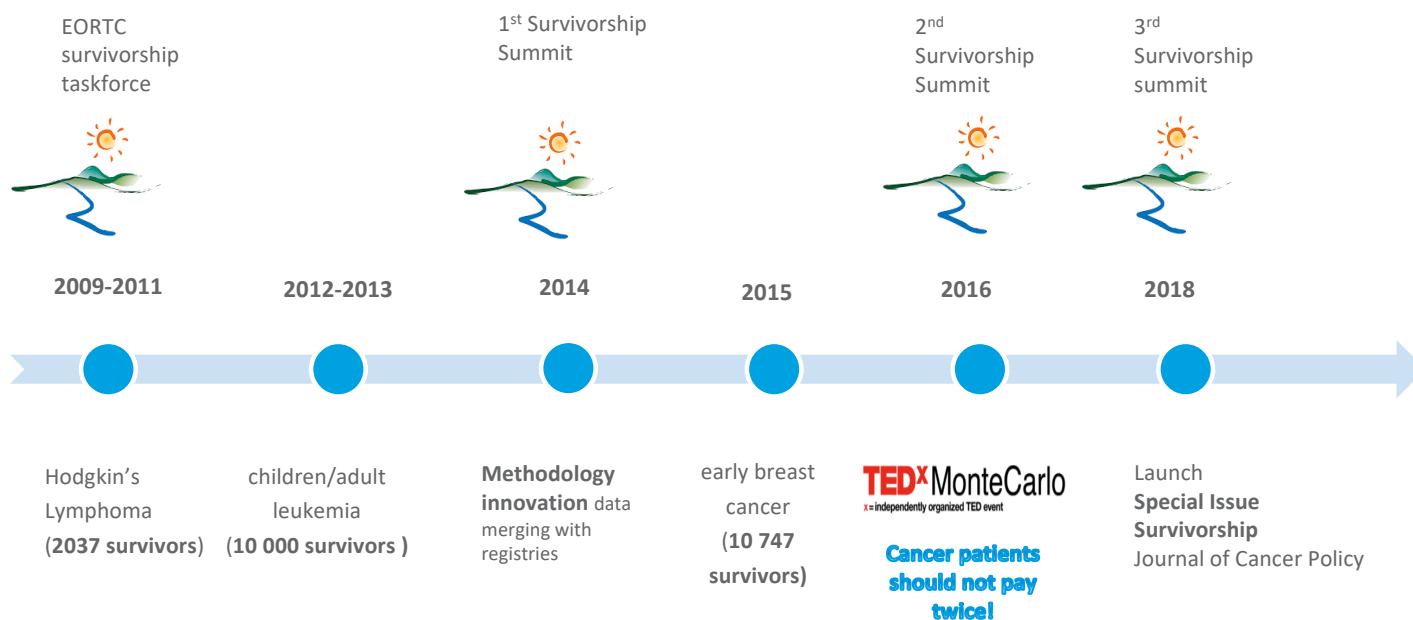
Keywords:

European competitiveness
Regulatory framework
Innovative clinical research
Pan-European legislation

ABSTRACT

At the time of mayor breakthroughs in knowledge of molecular biology leading to change in design and conduct of innovative clinical research, there is a clear need for optimal co-operation at the EU level as well as with each Member States. The current legal framework for health research is developed and revised by several DGs dealing with clinical trials, data protection, in-vitro diagnostic tests and biomarkers. Also medical devices and advanced therapy directive / regulation have to be taken into consideration, all within a single trial/study. Such fragmentation of legal framework and national laws lead to several inconsistencies, wasting time and scarce resources of everyone, whether academic or pharmaceutical industry, and all involved parties are facing the

EORTC Survivorship achievements



EORTC Cancer Survivorship research program

- Fellowship on legal issues
- Fellowship on epidemiology research
- The YOU infrastructure
- Publications :
 - Reports from summits
 - Special issues:
(Journal of Cancer Policy)
- “cancer Survivorship : an innovative era for research and the need for cross-border collaboration”.

Long-term data collection

Cancer
Free



Problem
Free



..who is a cancer survivor?

- 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....
- ...

ALL OF THE ABOVE

S. Rauh, EORTC Cancer Survivorship Summit, 2018

Survivorship issues

Physical/Medical

- e.g., pain, fatigue, memory problems, lymphedema, infertility, sexual impairment, amputations, secondary malignancies, cardiovascular, pulmonary, renal disease, neuro/muscular impairments etc

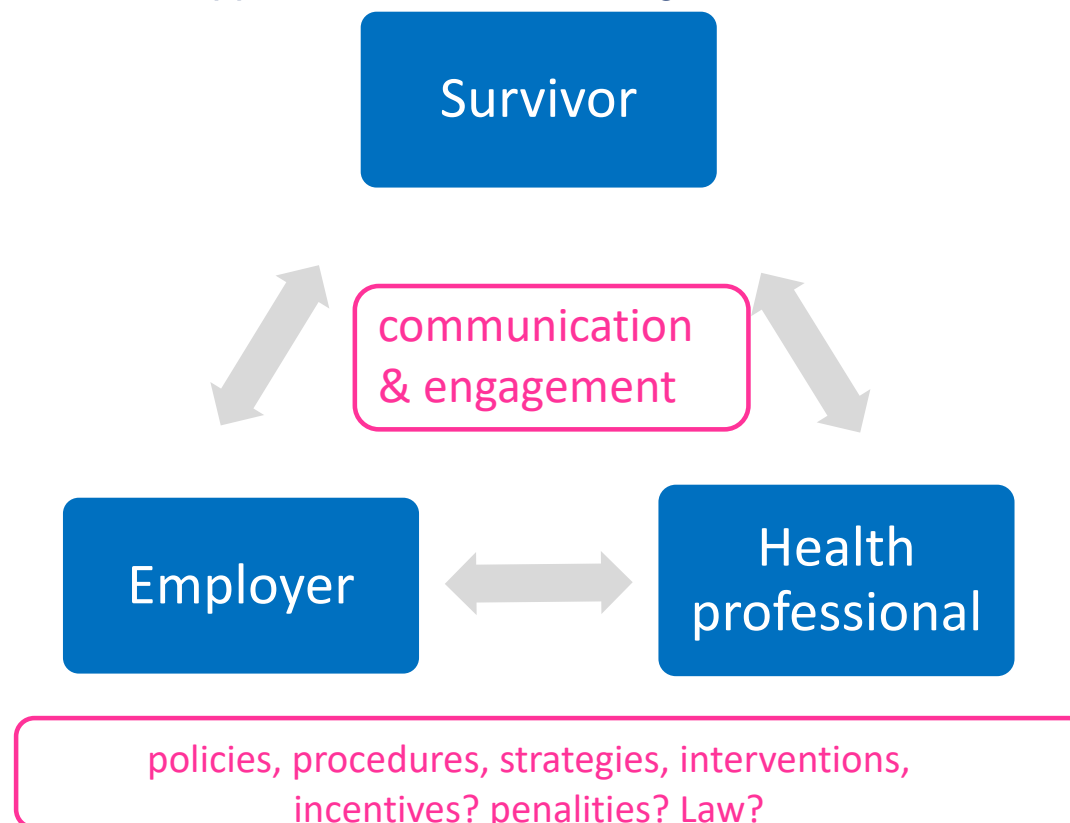
Psychological

- e.g., depression, anxiety, uncertainty, isolation, altered body image

Societal

- e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, mortgage, return to school, financial burden

What's needed to support work access among survivors?



L. Sharp, EORTC Cancer Survivorship Summit, 2018

Long Term Survival Study : fertility among survivors of ALL (EORTC trials)

- Most survivors who tried to have children, succeeded(75% of females, 72% of males)
- However, the average number of children per female seemed to be lower than in the general population
- Incidence of birth defects and medical abortions was low, both among female survivors and the partners of the male survivors

C. Piette & al

A long-term clinical research infrastructure within EORTC

The YOU (Your Outcome Updates)

Aim

- To build the capacity to answer long-term questions, cross-tumor, cross country
- To provide the platform and legal framework to collect high quality long-term follow-up data for patients in EORTC or EORTC supported clinical trials

The RIGHT to be forgotten!

The right to be forgotten: a change in access to insurance and loans after childhood cancer?

30 years after cancer

1/3 experienced difficulties buying a home...

1/10 for small amount of personal loan...

Dumas A., et al. (2017), The right to be forgotten: a change in access to insurance and loans after childhood cancer?, J Cancer Surviv, 1932-2267: 1-7



New French Law Feb 2016

Belgian Partyka Law

- In Belgium the law "Partyka – Lalieux" come into force on 1st January 2015.
- The objective is to facilitate access to credit life insurance policy in relation to mortgages for those who have a history of disability and serious or chronic illness.
- The law opens also the possibility to appeal the insurer's decision to a committee called "Bureau de suivi de la tarification".
- The committee consists of representatives of insurance companies, patients and consumer organisations. Through this law, it would also be possible to appeal a refusal or a premium that is 75% above the cost of the basic premium.

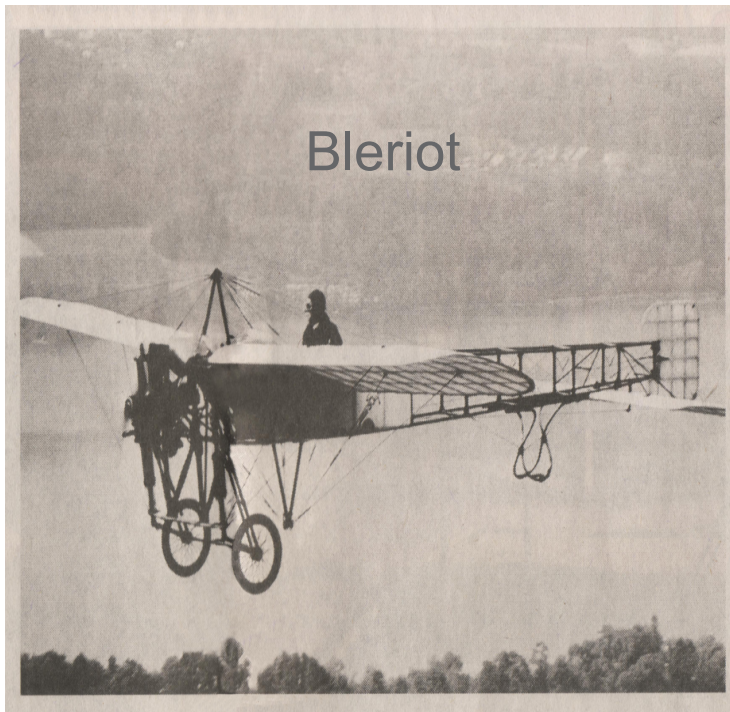
Conclusions

- Survivorship is a rapidly growing issue - and this is great !!!
- Awareness of physical issues in survivorship care has still to rise , more evidence to be gained –and shared with our patients
- Interventions should follow an established common track , then individualized « made-to fit»
- I (the oncologist) can't do it all myself ... : need for multi-disciplinarity and organizing workflows
- Patient empowerment : facilitator and catalyst!

S.Rauh, EORTC Cancer Survivorship summit, 2018

From the Channel to the Moon

1909



1969



Thank you