

ECPC: Cancer Survivorship: Current Challenges and EORTC Perspectives

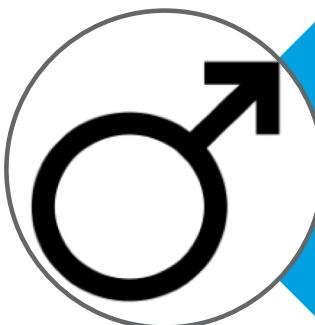
ECPC 9 June 2018

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Director Special Projects, EORTC

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Cancer is here to stay

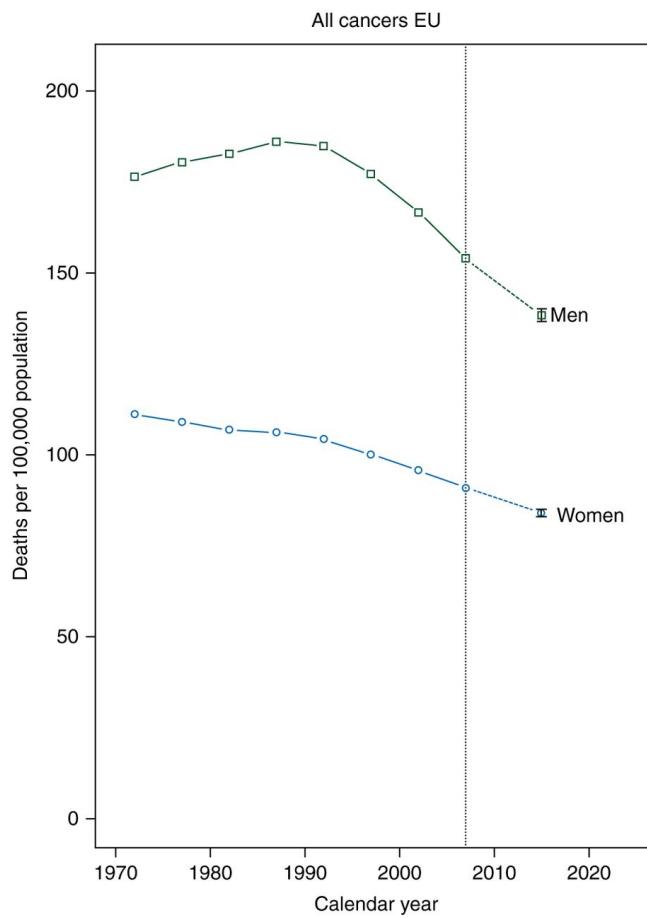


1 man
in 3

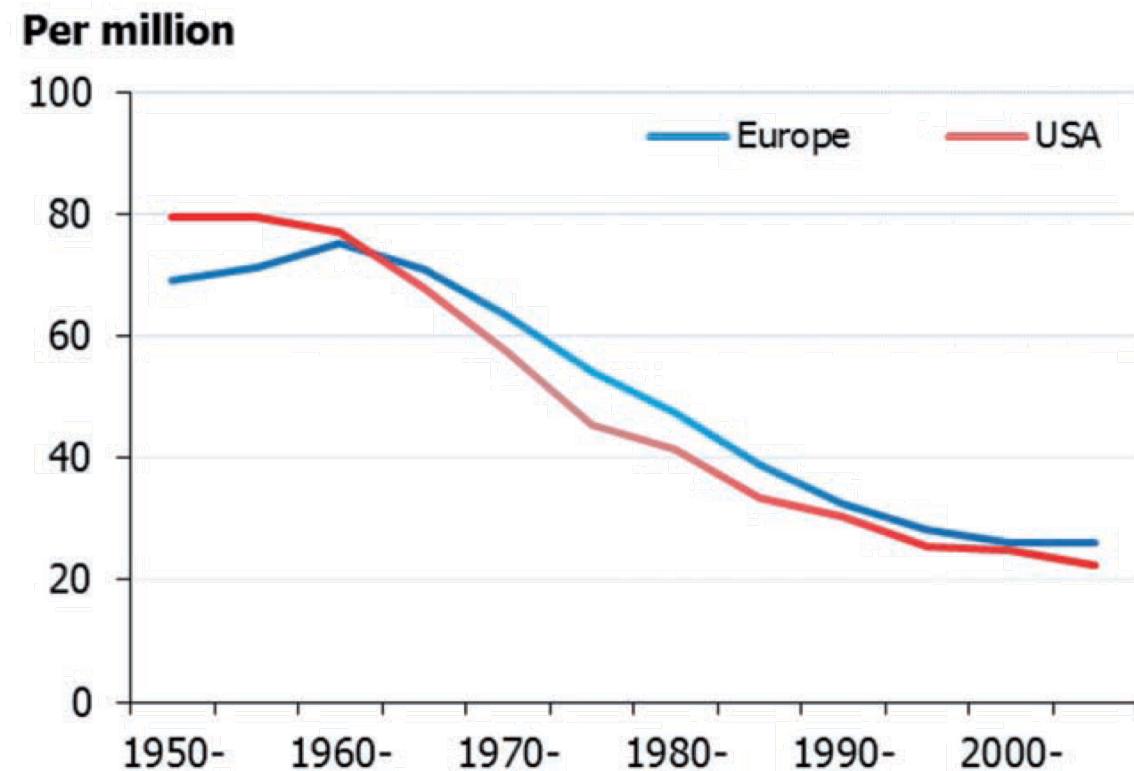


1 woman
in 4

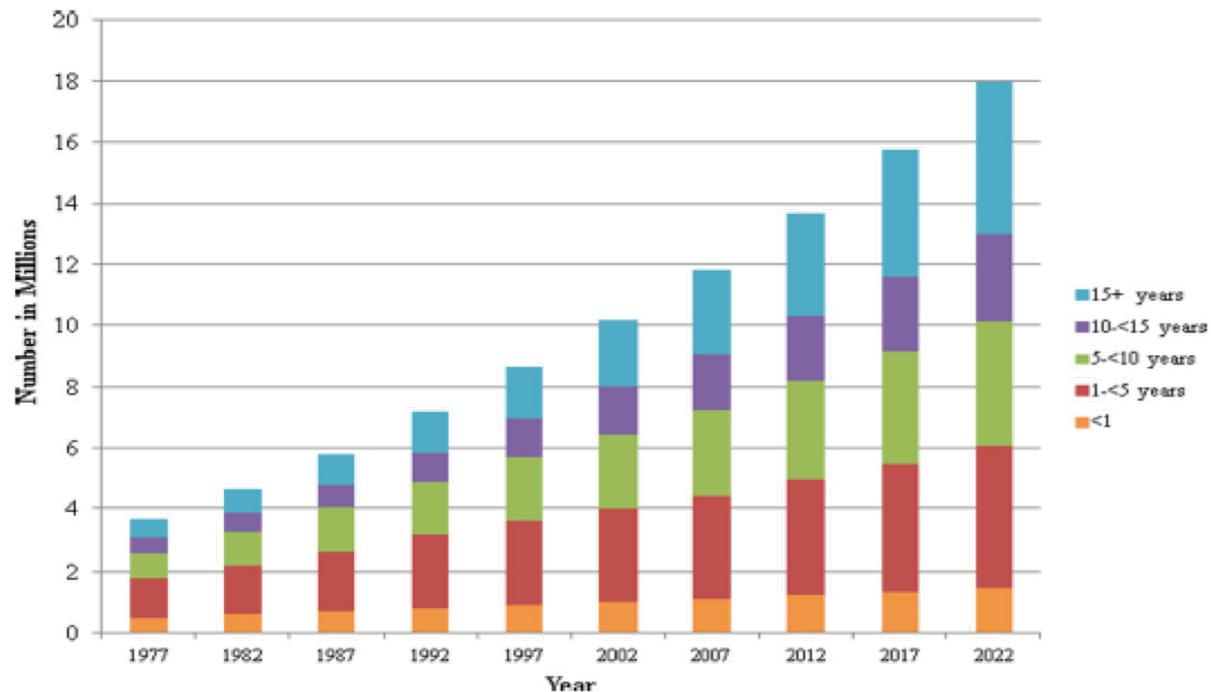
Decreased Cancer mortality in Europe



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.](https://doi.org/10.1158/0748-2041.CEP-12-0431)

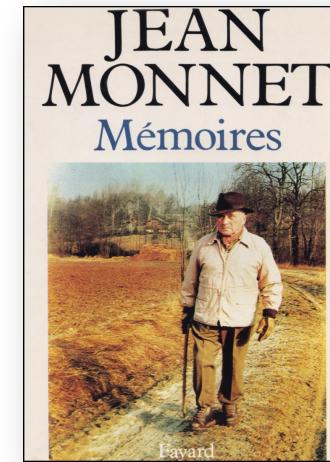
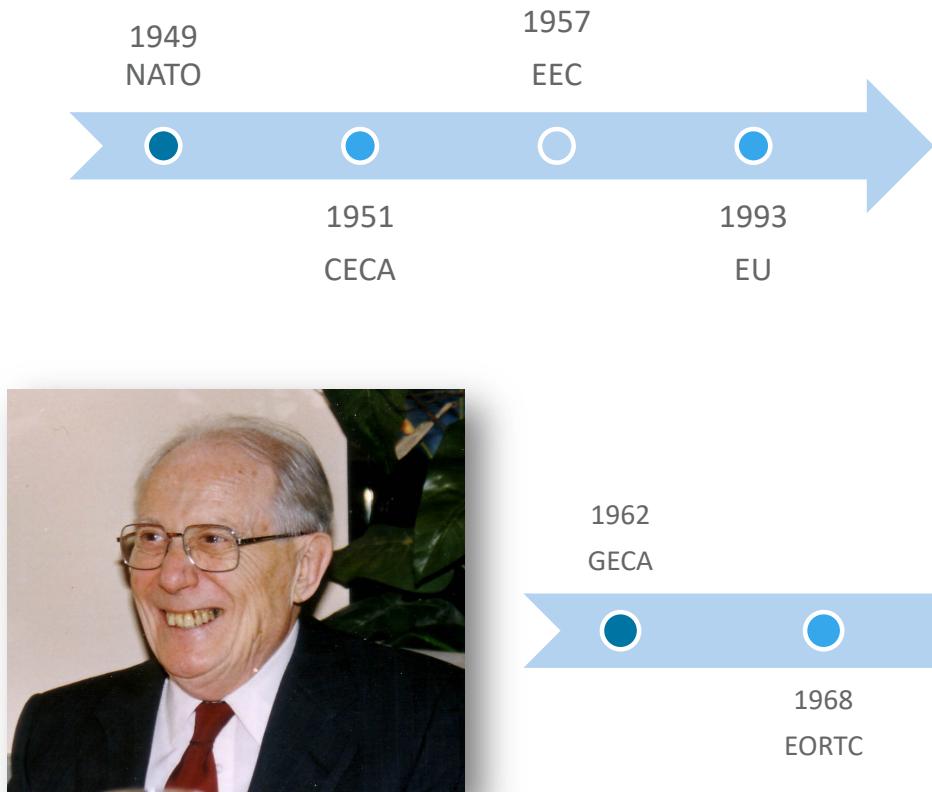
Long term survival (%)

	<u>1970</u>	<u>2017</u>
• 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

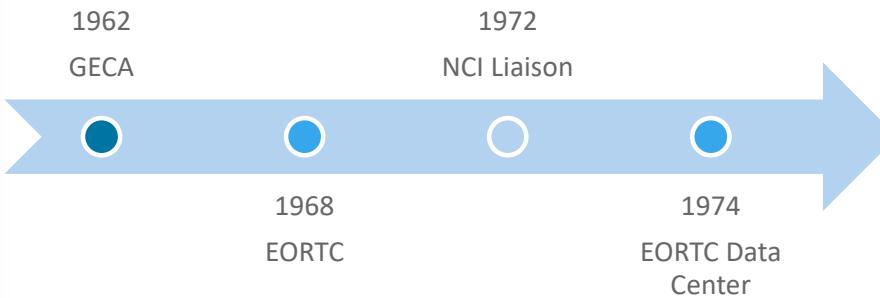
OF MICE AND MEN: THINGS ARE MUCH MORE DIFFICULT IN MEN

Professor Henri Tagnon

European visionaries



1888 - 1979



EORTC by the numbers (2017)

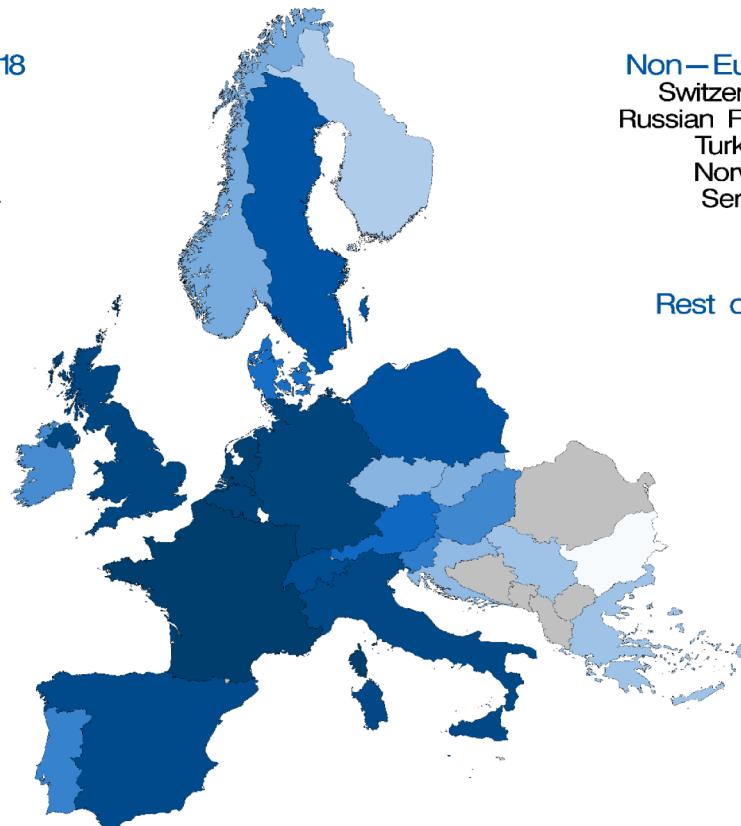
A world-class network	An expert HQ	Unique output
<ul style="list-style-type: none"> • > 5,500 collaborators • 930 institutions • 27 countries • 21 groups & task-forces • 120 collaborative groups 	<ul style="list-style-type: none"> • 214 employees • > 198,000 patients in database • > 25,000 patients in 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 ≈ 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

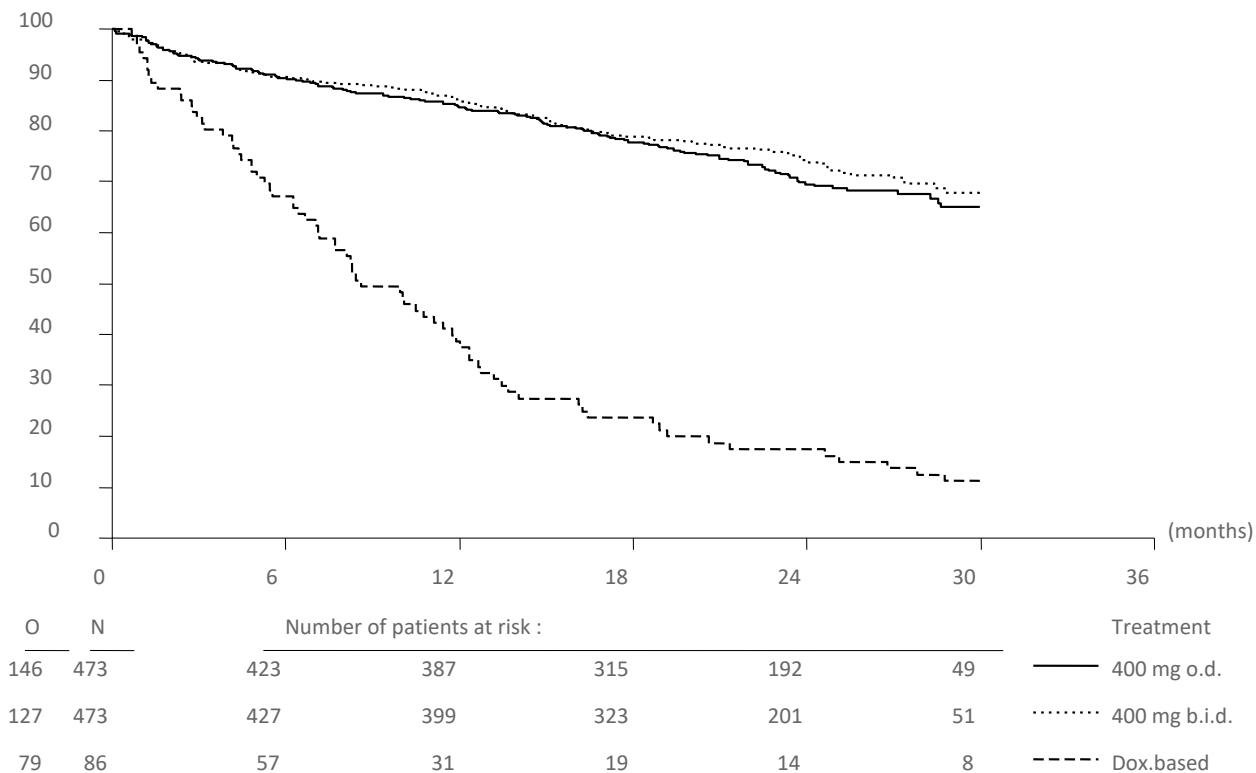
- 2 types of clinical trials

Drug
Development

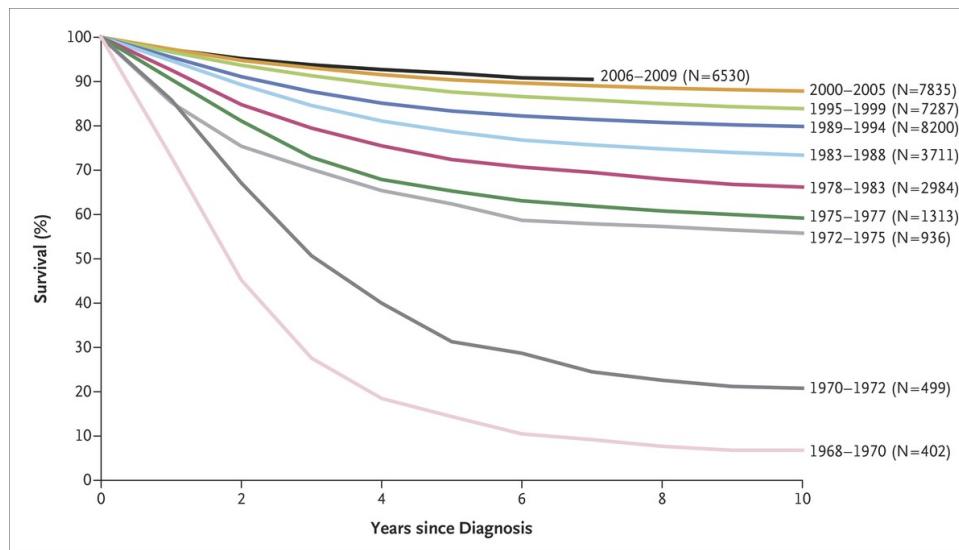
Therapeutic
strategies:
Multidisciplinary
approach

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

Glivec study in GIST overall survival



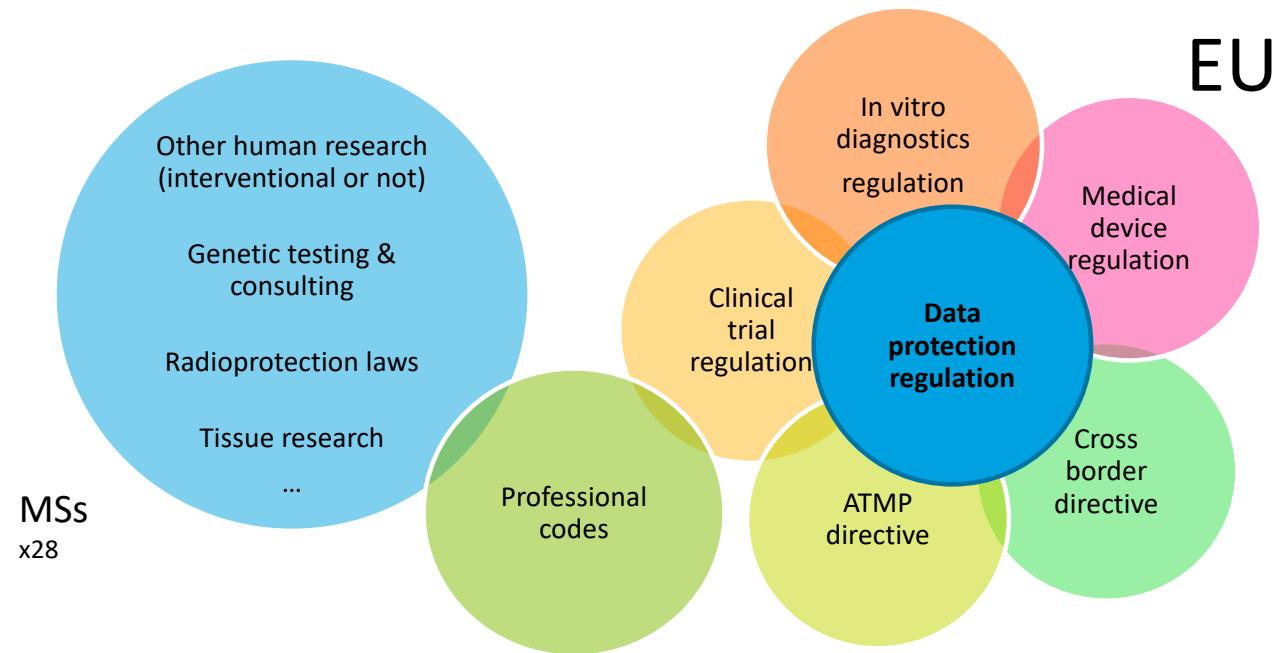
Overall survival according to treatment period



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)

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

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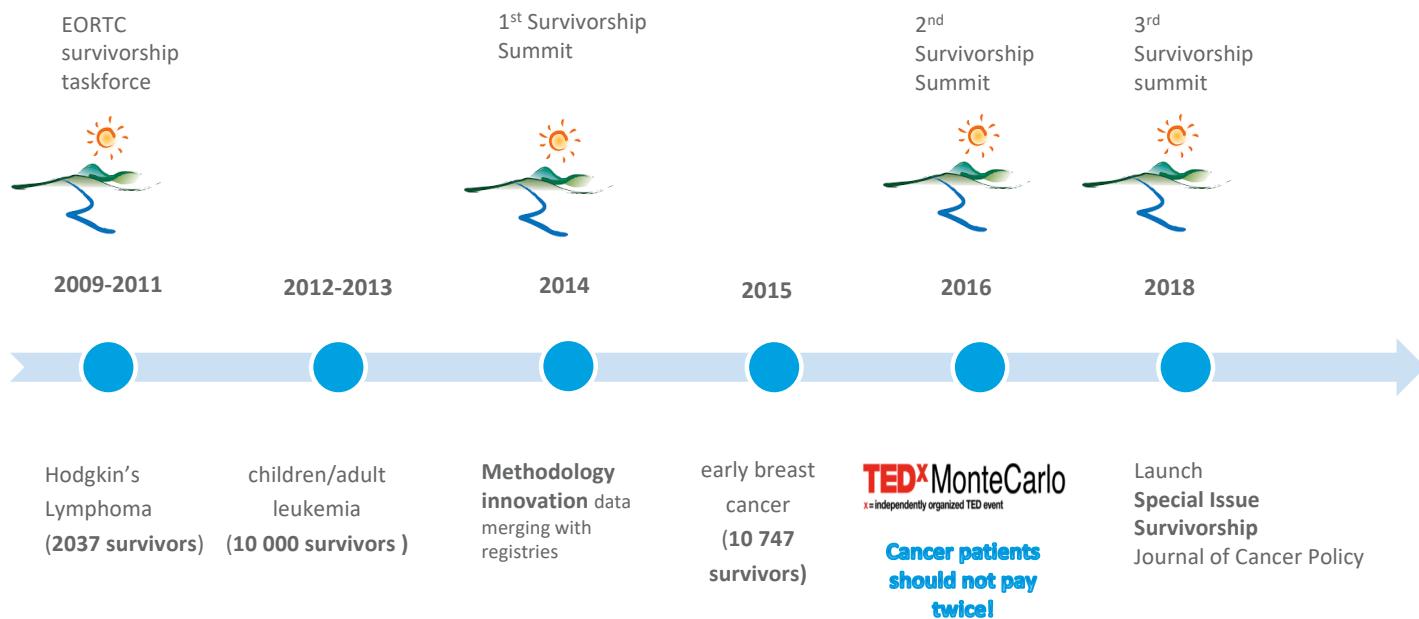
Keywords:

European competitiveness
Regulatory framework
Innovative clinical research
PanEuropean legislation

ABSTRACT

At the time of major 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 companies 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 **maintainance 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

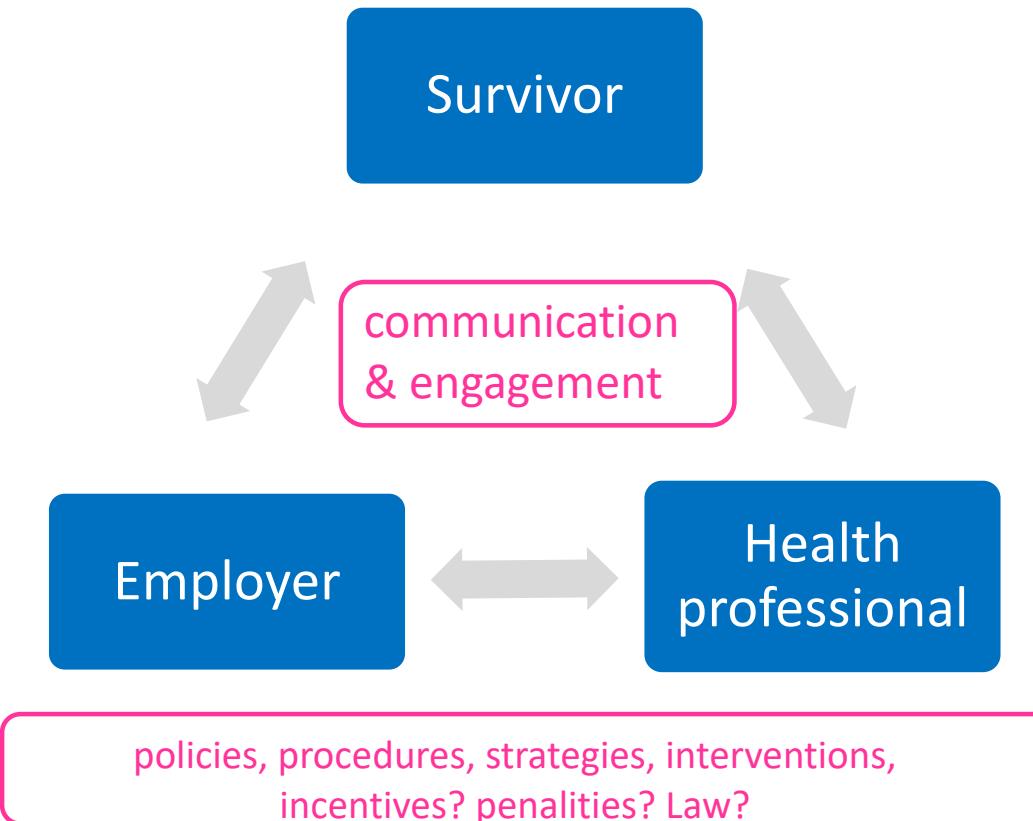
Psychological

- 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?



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.

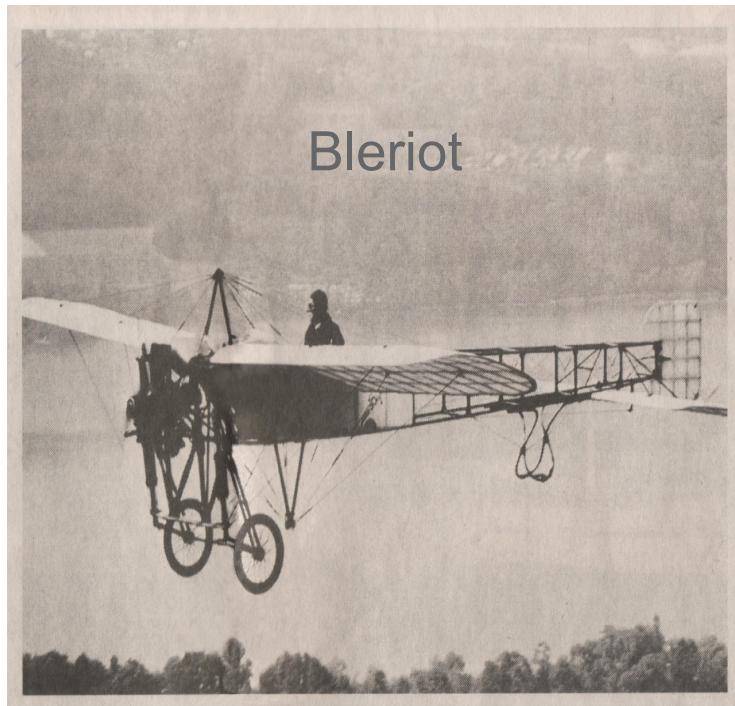
Conclusions

- 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