“Cancer survivors should not pay twice”

The EORTC Survivorship Task Force

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CANCER IS HERE TO STAY

1 man in 3
1 woman in 4
## Long term survival (%)

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>1970</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Testis cancer</td>
<td>0</td>
<td>95</td>
</tr>
<tr>
<td>Leukaemia in children</td>
<td>10</td>
<td>90</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>40</td>
<td>90</td>
</tr>
<tr>
<td>Hodgkin’s disease</td>
<td>10</td>
<td>90</td>
</tr>
<tr>
<td>Colon cancer</td>
<td>30</td>
<td>65</td>
</tr>
<tr>
<td>Bone cancer</td>
<td>5</td>
<td>60</td>
</tr>
<tr>
<td>Leukaemia in adults</td>
<td>10</td>
<td>55</td>
</tr>
<tr>
<td>Non-small cell lung cancer</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Pancreas</td>
<td>5</td>
<td>10</td>
</tr>
</tbody>
</table>
Decreased Cancer mortality in Europe

Survivorship Summits

Survive and thrive. Help us address these issues.

The future of cancer therapy
EORTC survivorship achievements
data collection, analysis on >20,000 trial patients, millions of control population in Europe with 40 years of follow-up

EORTC survivorship Task Force

2009-2011

2037 long-term survivors of Hodgkin’s Lymphoma diagnosed 1964-2004


2012-13

Update survival and QoL of 5000 survivors of leukemia diagnosed 1986-2008

2014

Methodology innovation data linkage with population-based registries to compare survival and QoL of trial and non-trial population of 5714 patients of Hodgkin’s Lymphoma diagnosed 1986-2004

2015

Outcome after recurrence of 10747 early breast cancer survivors diagnosed 1986-2010

2016

Collaboration with European Commission Joint Research Center-European Network of Cancer Registries

Consortium of experts tackle societal issues in EU

The future of cancer therapy
SAVE THE DATE

3rd EORTC Cancer Survivorship Summit

1 - 2 March 2018
Brussels, Belgium
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
Long-term data collection

Cancer Free ≠ Problem Free
The EORTC Research Project

YOU protocol

Your Outcome Updates
Aim

- Building the capacity to answer long-term questions, preferably cross tumors
- Providing the platform and legal framework to collect high quality long-term follow-up data for patients treated in EORTC studies
Information of interest for cancer survivors

- **Medical Data**
  - survival, second primary cancers, relapse, other late adverse effects (e.g. cardiovascular events), etc.

- **Psychosocial Data**
  - Fatigue, distress, fear of recurrence, fertility, parenthood, relationship etc.

- **Social Economic Data**
  - Work participation, access to insurance, loan and mortgage etc.
Data Sources

- **Requisite**
  - EORTC databases (1964-)

- **Innovative models of partnerships**
  - Cancer Registries (national, ENCR, RareCareNet)
  - Investigators/institutions
  - Patient self-reported information (e.g. QoL survivorship module and patient-reported outcomes)
  - General Practitioners, in some European countries
  - Other (administrative DB, reimbursement & insurance data etc...)
Proposed cross-tumor long-term survivorship models

Trial
Trial
Trial

YOU* infrastructure

Lymphoma, Sarcoma, testicular, young BC...
YOU Fertility
YOU Fatigue
Young cancer patients: <65 yrs
YOU societal

Cancer diagnosis
5 years after initial anticancer treatment

* Your Outcome Update (EORTC platform for cancer survivors)
Future perspectives
European cooperation

Dream – Reality - Necessity

- 1898: Radium
- 1947: DNA
- 1953: Helsinki
- 1964: EU Data Protection Directive
- 1995: EU CTD
- 2001: Human Genome
- 2003: NGS
- 2005: EU CTR
- 2014: Data Privacy debate ongoing

1898, 40s, Nuremberg, Nitrogen mustard

The future of cancer therapy
Comparativeness effectiveness research (CER) as the BRIDGE

Evidence-based drug development
- basic medical research (effective anticancer compound)
- phase I-III clinical trials
- regulatory approval

Evidence-based Care Provision
- patients' preference/affordability of the society
- options for therapeutic strategies
- drugs available on the market

EOR TC

The future of cancer therapy
From the Channel to the Moon

1909 Bleriot

1969 JULY 20, 1969

The future of cancer therapy
THANK YOU