



Survivor's perspective: Quality of Life and Long-term Follow-up

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Facts and numbers

- Overall 5-year survival rate: 80% in developed countries
- Better treatments and supportive care, only possible by research
- Estimated 300-500,000 CCS in Europe
- Another 10-12,000 new CCS each year
- This has a price: late effects
- Negative impact on quality of life





Quality of Life

- Quality of life: general well-being of individuals, in this case CCS
- Medical late effects:
 - Heart failure
 - Failure of the kidneys
 - Reduced fertility / infertility
 - Chronic fatigue
 - Secondary cancer
- Psychosocial late effects
 - Self-esteem
 - Education
 - Work
 - Social network





Long-term follow-up care

- Prevent and treat late effects
- End-of-treatment summary is fundamental
- Inequalities across Europe
- Every survivor should have the right to receive such end-of-treatment summary to have good long-term follow-up care





Longterm follow-up studies

- 15-20-30 years?
- Connect treatment burden to actual long-term outcomes
- Data protection: to do long-term follow-up studies, secondary use of data where no specific consent has previously been provided is required
 - DPR: Explicit and specific consent
- Consequence: multiple requests and reminders, because a consent is necessary





Survivors' perspective

- Survivors deem it not to be reasonable to re-contact them systematically
- Broader consent (i.e. one-time consent)
 - One-time consent at 18 could be an option
 - Donation of data, without much extra burden
- Voluntariness at risk
- Survivors want to live a normal life, to the degree possible
- Psychological need to “move on”





The Survivorship Passport

- Developed by ENCCA and PanCare
 - Prototype with big potential
- The Survivorship Passport provides a condensed end-of-treatment summary:
 - Risks related to treatment burden (surgery, radiotherapy, chemotherapy)
- It is in my view important that the patient gets better control on his/her data, think of eHealth
- Prototype
- It aims to harmonize the follow-up care
 - Homogeneous criteria and evidence-based guidelines





To conclude

- End-of-treatment summary is fundamental for follow-up care
- In long-term observational studies secondary use of data is required
- Secondary consent is necessary
- Survivors do not want to be overwhelmed with consents
- Balance between right to privacy and right to health
- A one-time consent (at the age of 18) is preferred by survivors



Thanks for your attention!



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