

Cancer registries and administrative databases to study the effects of cancer in AYA cancer survivors



**TYPE
STATUS**

Guidance for implementation
Fully implemented and ongoing in Italy and Spain
Piloted in Norway

**LAST
UPDATE**

January 2022

ITALY • NATIONAL
Cancer survivorship

PROBLEM & OBJECTIVE

PROBLEM Long-term outcomes in adolescent and young adult (AYA) cancer survivors are extrapolated from survivors of childhood cancer, despite the differences between AYAs and children (e.g., biology, physiology, clinical outcomes of cancer).

OBJECTIVE We aim to define a population-based cohort of AYA cancer survivors to study the cancer effects. This will help develop follow-up plans for survivors, increasing the likelihood for early diagnosis of cancer-induced morbidities.

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KEY COMPONENTS / STEPS

- Identification of AYA as a fragile and poorly studied population.
- Involvement of CR and connection with administrative DB.
- Evaluation (content and quality) of the administrative DB.
- Estimation of the late effects of cancer.
- Discussion of the results with relevant stakeholders.

KEY CONTEXTUAL FACTORS

Four pre-requisites have been identified:

- Availability of population-based cancer registries (CRs), national registry of deaths, clinical discharge records together with additional relevant databases (eg, outpatients DB, drug DB, census, socio-economic DB etc.).
- Availability of clear rules on the mandate of the CRs regarding links to the administrative database and/or rules for requesting authorization to access the administrative database.
- Cancer registries with a good understanding of the information included in administrative databases and their quality problems.
- Availability of adequate financial support for CRs.

MAIN IMPACTS / ADDED VALUE

- We showed that exploiting already available data sources, it is possible, with a limited effort, to study late effects occurring in cancer survivors.
- Our analyses have highlighted that AYA cancer survivors face persistent risks for a broad range of diseases. AYA cancer survivors face many life transitions in terms of education, employment, social relations, and family formation. Late effects could thus have far more physical and social consequences for AYA than for older adults.
- Our findings, underscore the need for strict evidence-based and personalised follow-up plans for survivors, to prevent chronic cancer-induced conditions and minimise the burden of follow-up examinations.

LESSONS LEARNED

- The role of CRs should be strengthened and widened.
- Collaboration with several experts including clinicians, computer scientists, statisticians, cancer registration experts and owners of administrative databases should be promoted.
- Innovative methods to ensure interoperability of the different dataset within and across countries should be developed.
- A common understanding of the legal framework to ensure data integration should be promoted.
- Quality checks of integrated data sources should be standardized.
- IT infrastructure should be updated.

REFERENCES & DOCUMENTATION

- Bernasconi A, et al. Adolescent and Young Adult Cancer Survivors: Design and Characteristics of the First Nationwide Population-Based Cohort in Italy. *J Adolesc Young Adult Oncol.* 2020 Oct;9(5):586–593. doi: 10.1089/jayao.2019.0170.
- Trama A, et al. Excess risk of subsequent malignant neoplasms in adolescent and young adult cancer survivors: Results from the first Italian population-based cohort. *Cancer.* 2021 Sep 28. doi: 10.1002/cncr.33931.
- <https://www.ipaac.eu/res/file/outputs/wp7/piloting-registries-data-integration-cancer-survivorship-adolescents-young-adults.pdf>

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