Preliminary results from the Italian Adolescents and Young Adults cancer survivor's cohort

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OBJECTIVES **Adolescents and young adults (AYAs) with cancer** are less studied than other age classes. In the last decades their survival is improving and, by consequence, the number of **AYA survivors**, but still little is known about late effects of first primary cancer arisen in this age class.

In Italy, the project **"Adolescents and young adults with cancer in Italy" (Ada)** has developed the first **population-based cohort of AYAs cancer survivors**. The aim of this cohort is **to estimate the burden of late effects in AYA survivors** focusing on **excess risk of second primary cancers, hospitalizations and mortality**.

METHODS The cohort was established retrospectively using an **incident-based design**. Each Cancer Registry (CR) was asked to identify incident cases with **first cancer diagnosis between 15-39 years** in the entire incidence period covered by the CR and to link these patients to all their subsequent tumors and to all data sources available in the CR. **Survivors** were identified centrally by INT **as patients alive at least 5 years after first cancer diagnosis**.

Tumors were classified using an ad hoc classification, ICD-O-3 based, adapted by *Trama et. Al, Lancet Oncol 2016*, to better define tumors in this age class.

RESULTS **34** out of the 57 Italian population-based and specialized **CRs** participate to the cohort, covering around **43% of the Italian population**.

Data on 88,156 incident cases **(incidence period: 1976-2015)** were collected, 66,054 of them are survivors. AYA incident cases are followed up **for on average 9.5 years** since cancer diagnosis, with **maximum follow-up time 40 years**.

Figure 1. Data sources linked in the database

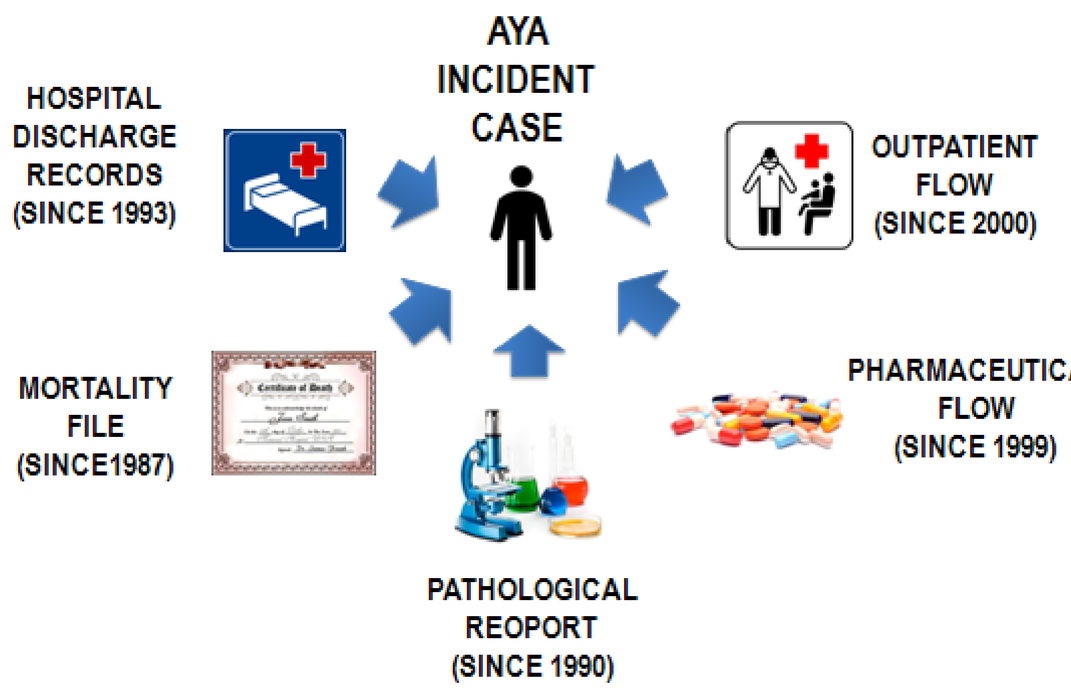
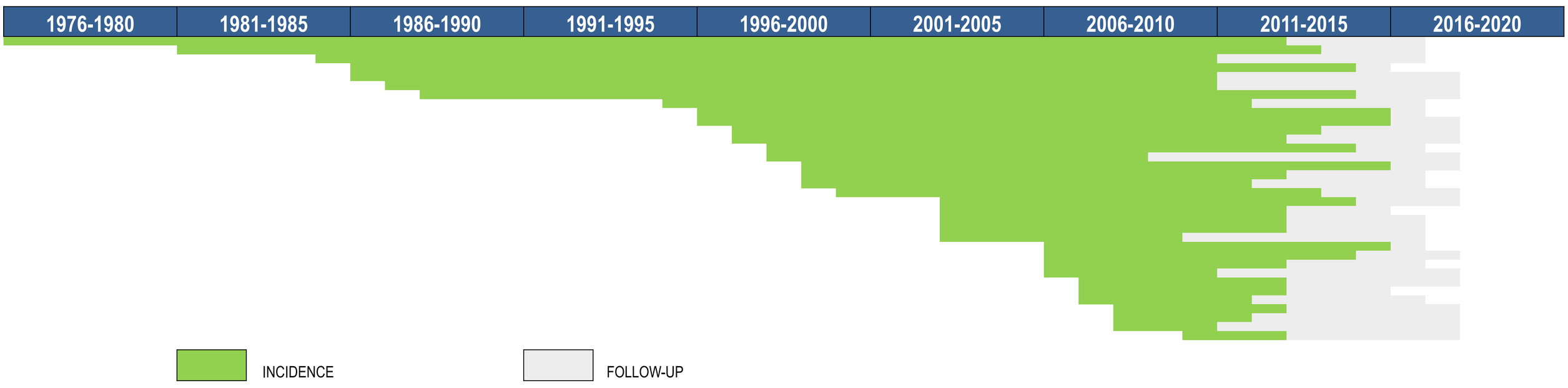


Table 1. Distribution of AYAs by first primary tumor

	INCIDENT CASES	SURVIVORS
BREAST	13,738	10,785
LYMPHOMAS	12,567	9,761
THYROID AND OTHER ENDOCRINE GLANDS	12,254	10,512
MALIGNANT MELANOMAS	9,120	7,598
GERM CELL AND THROPHOBLASTIC TUMOURS	7,645	6,464
DIGESTIVE ORGANS	5,609	2,776
LEUKEMIAS	4,711	3,046
FEMALE GENITAL TRACT	4,591	3,457
URINARY TRACT	3,817	3,184
SOFT TISSUE AND OTHER EXTRAOSSEOUS SARCOMAS	3,573	2,421
TUMOURS OF THE CNS	2,555	1,321
HEAD & NECK	1,764	1,253
NOT BETTER CLASSIFIED	1,597	919
THYMUS	1,382	862
LUNG AND TRACHEA	1,330	460
MALIGNANT BONE TUMORS	969	591
MALE GENITAL TRACT	490	375
MESOTHELIOMAS	108	34
GIST	91	76
NEUROBLASTOMA	90	50
ADNEXAL SKIN TUMORS	71	59
EYE	52	35
RETROPERITONEUM AND PERITONEUM	32	15
ALL CLASSIFIED CASES	**88,156**	**66,054**

Figure 2. Incidence and follow-up period coverd by italian CRs participating to Ada cohort



CONCLUSIONS **Tumors in AYAs are rare** and **late effects of first primary cancers may take a long time** to develop, that's why population-based CRs are the best data source available to study them. In CRs, however, **some important information's on risk factors are missing** (i.e. treatment, socio-economic factors).

Methods to overcome this limit are being studied through different prospective, for example **linkage with clinical records** but also, whenever linkage is difficult, **new artificial intelligence techniques** to avoid it. In Europe, **iPAAC Joint Action** is developing similar cohorts also in **GRELL Countries** such as **PORTUGAL** and **SPAIN** (Granada and Basque Country) exploring the chance to link new administrative data sources like Census.