



FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI



European
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ENCR
European Network
of Cancer Registries

Linkages between cancer registries and administrative data to study late effects in cancer survivors

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Cancer survivors

Patients alive 5-years after cancer diagnosis

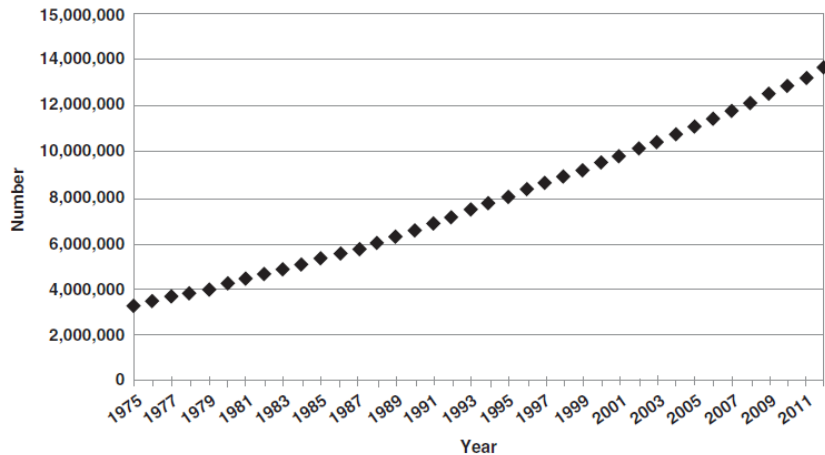
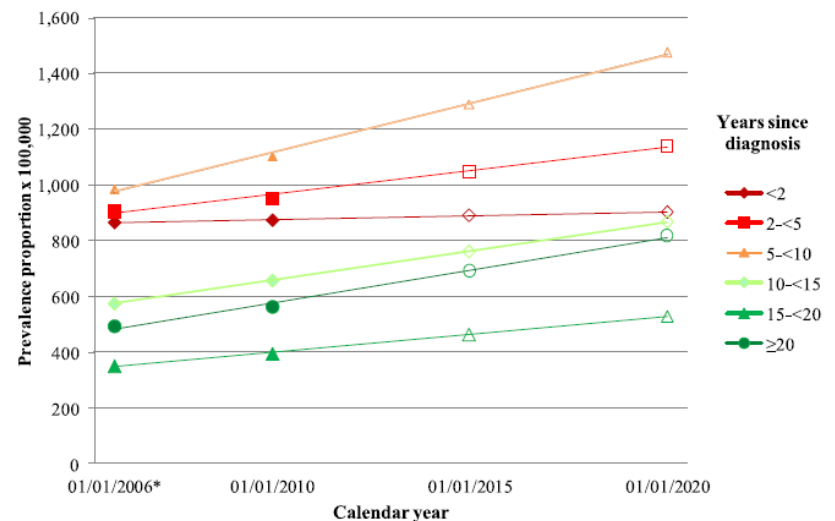
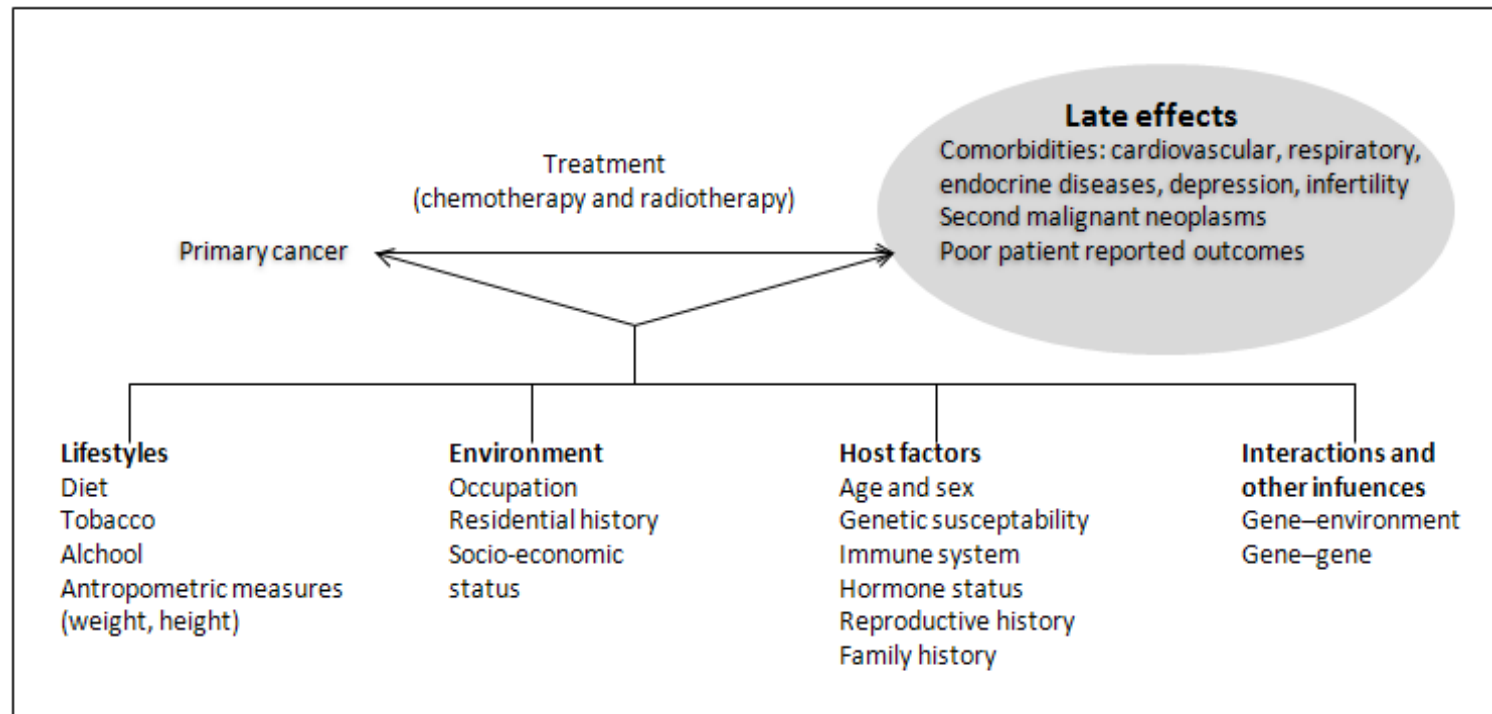


Figure 1: Estimated number of cancer survivors in the United States from 1975 to 2012¹

Figure 2: Complete cancer prevalence (proportions) in Italy from 2006 to 2020 by years since diagnosis²



Risk factors for multiple late effects



Secondary Malignant Neoplasms Following Radiotherapy for Primary Cancer in Children and Young Adults

Richard W. Harbron,^{1,2} Richard G. Feltbower,³ Adam Glaser,⁴ John Lilley,⁵ and Mark S. Pearce²

Cardiac Mortality Among 200 000 Five-Year Survivors of Cancer Diagnosed at 15 to 39 Years of Age

The Teenage and Young Adult Cancer Survivor Study

Subsequent hospitalisation experience of 5-year survivors of childhood, adolescent, and young adult cancer in Scotland: a population based, retrospective cohort study

D H Brewster^{*,1,2}, D Clark¹, L Hopkins¹, J Bauer¹, S H Wild², A B Edgar³ and W H Wallace³

Cardiovascular morbidity in long-term survivors of early-onset cancer: A population-based study

A.E. Kero¹, L.S. Järvelä¹, M. Arola², N. Malila³, L.M. Madanat-Harjuoja³, J. Matomäki¹ and P.M. Lähteenmäki¹

Increased Risk of Second Malignant Neoplasms in Adolescents and Young Adults With Cancer

Jean S. Lee, MD¹; Steven G. DuBois, MD¹; Peter F. Coccia, MD²; Archie Bleyer, MD³; Rebecca L. Olin, MD⁴; and Robert E. Goldsby, MD¹



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Ada project

*“Adolescents and young adults with cancer in Italy.
How to ensure access to the best care and quality of survival”*



AYA SURVIVORS COHORT

To estimate **the burden of late effects in AYA**
cancer survivors

To study the **association between treatments**
received and late effects

WHY AYAs?

- Less studied than other age classes
- Have a long life expectation to develop late effects

Data sources available to CRs



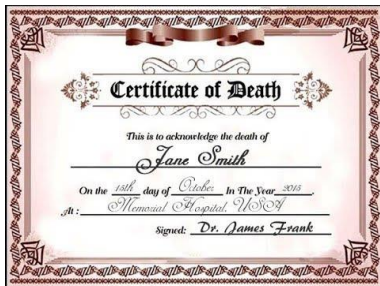
**HOSPITAL
DISCHARGE
RECORDS**



**CANCER
REGISTRY DATA**



**OUTPATIENT
SPECIALIST
FLOW**



**MORTALITY
FILE**

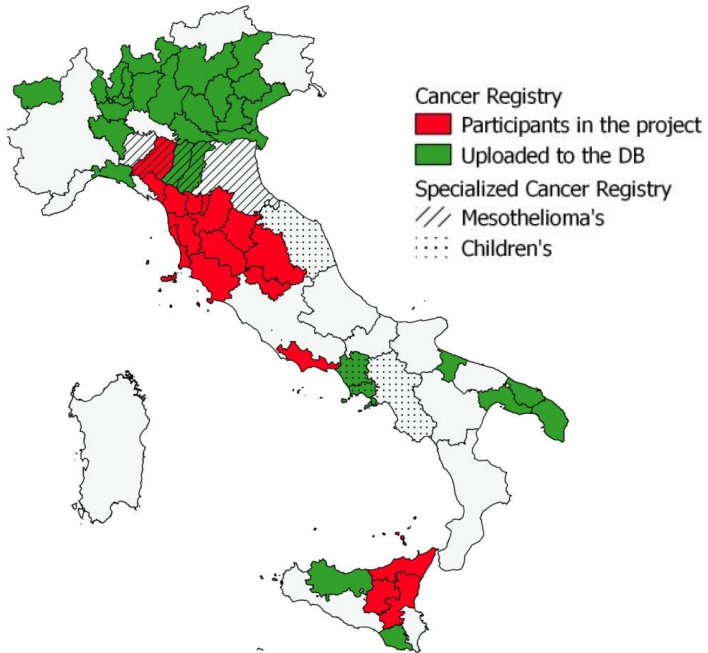
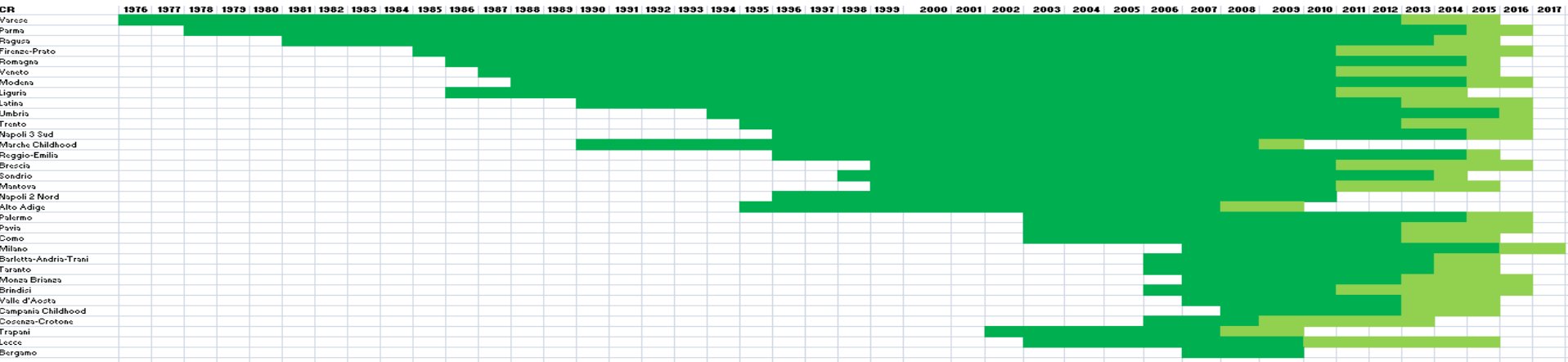


**PHARMACEUTICAL
FLOW**



PATHOLOGICAL REPORT

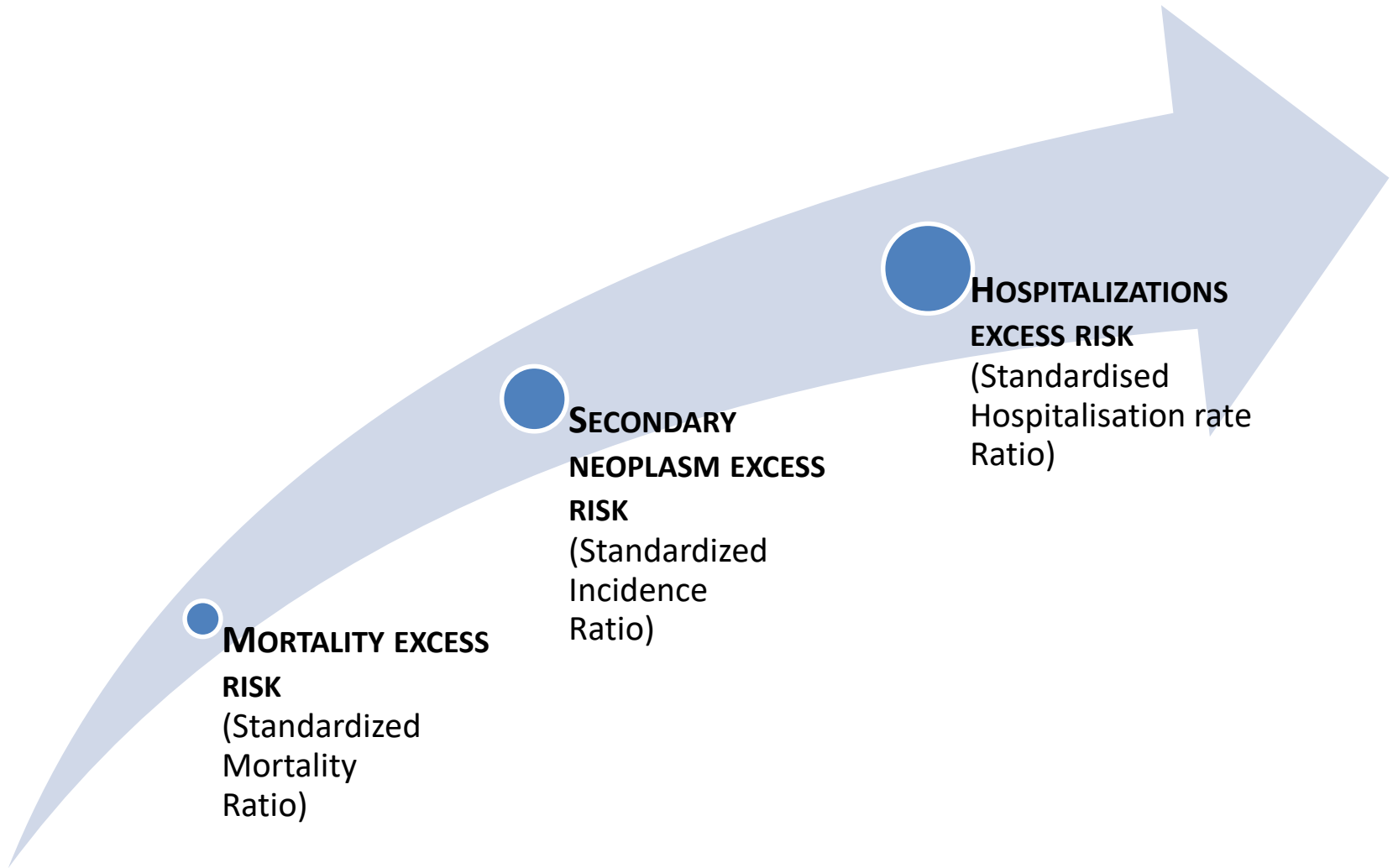
The Cohort



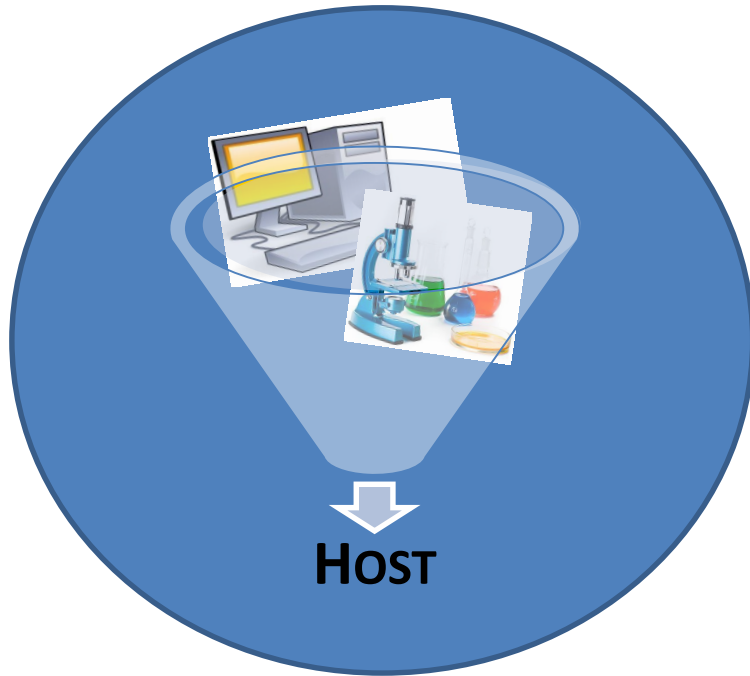
71 444 incident cases
from 1976 to 2012

54.972 survivors

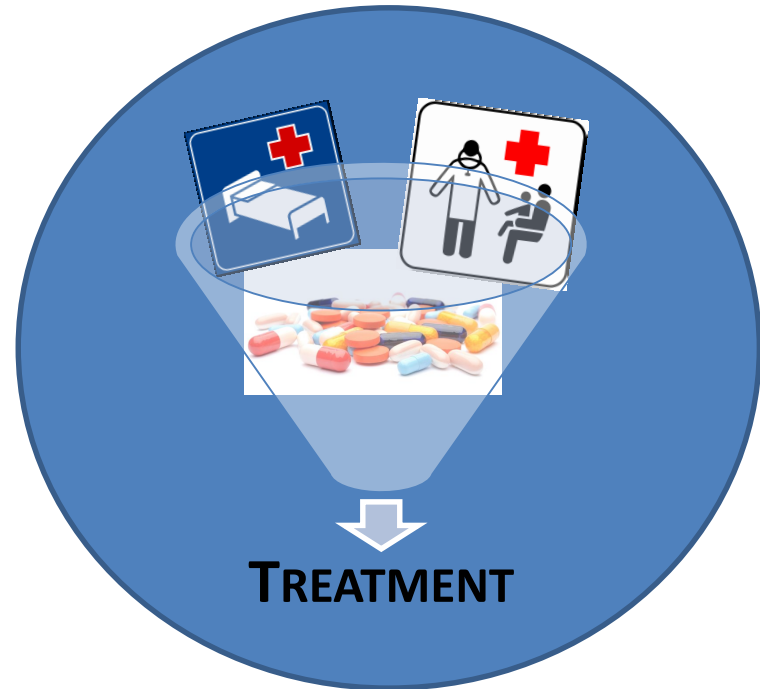
Analysis



To study association



LIFESTYLE?



ENVIROMENT?

Experience of data linkage

Social outcomes in adult survivors of childhood cancer compared to the general population: linkage of a cohort with population registers

Anna Font-Gonzalez^{1*}†, Elizabeth (Lieke) Feijen¹†, Elske Sieswerda¹, Eline van Dulmen-den Broeder², Martha Grootenhuis³, Helena Maurice-Stam³, Huib Caron¹, Marie-Louise Essink-Bot⁴, Helena van der Pal^{1,5}, Ronald Geskus⁶ and Leontien Kremer¹

Psychological distress, optimism and general health in breast cancer survivors: a data linkage study using the Scottish Health Survey

Janni Leung^{1,2,3} • Iain Atherton⁴ • Richard G. Kyle⁴ • Gill Hubbard⁵ • Deirdre McLaughlin¹

Economic Independence in Survivors of Cancer Diagnosed at a Young Age: A Norwegian National Cohort Study

Maria W. Gunnes, MD^{1,2}; Rolv Terje Lie, PhD^{1,3}; Tone Bjørge, PhD, MD^{1,4}; Astri Syse, PhD⁵; Ellen Ruud, PhD, MD^{6,7}; Finn Wesenberg, PhD, MD^{4,6,7}; and Dag Moster, PhD, MD^{1,2,3}

23 SOPRAVVIVENZA DEI PAZIENTI ONCOLOGICI PER SCOLARITÀ

Vincenzo Coviello¹, Francesco Cuccaro¹, Antonio Chieti¹, Simona Carone², Claudia Galluzzo², Lucia Bisceglia³

27 SPERIMENTAZIONE DELLA VALUTAZIONE DELLO STATO DI SALUTE E DEI FATTORI COMPORTAMENTALI DELLE PERSONE CON TUMORE

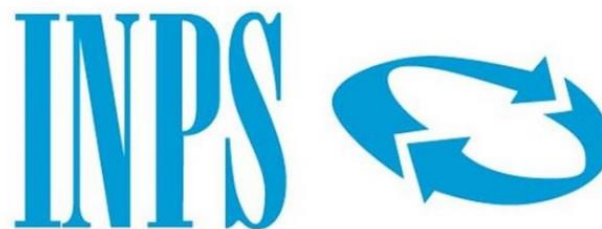
Giuliano Carrozzi¹, Letizia Sampaolo², Lara Bolognesi³, Claudia Cirilli¹, Katia Valla¹, Vincenzo Amendola¹

Linkable sources in Italy



INAIL

ISTITUTO NAZIONALE PER L'ASSICURAZIONE
CONTRO GLI INFORTUNI SUL LAVORO



Limitations

Data sources already available	New data sources
Data quality	Ownership of data and access rules
Lack of informations	Privacy legislation
Data collected for different aims	Anonymous records
	Difficulties in linkage procedure

For sample sources
Number of linkable cases

The way forward: iPAAC



IPAAC JA - WP 7 – Task 7.4

Piloting integration of data on long-term follow up of cancer survivors

A Trama

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Thank you for this opportunity!

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