



**iPAAC**  
INNOVATIVE PARTNERSHIP  
FOR ACTION AGAINST CANCER

# WP 7 Cancer Information and Registries

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CANCON recommendations pointed to

- **Comprehensive Cancer Care**

Better coordination from primary to palliative care and long term follow up  
Better integration of health data flows in order to cover the whole clinical pathway and to measure the performance of cancer care services

- **Cancer survivorship care plans**

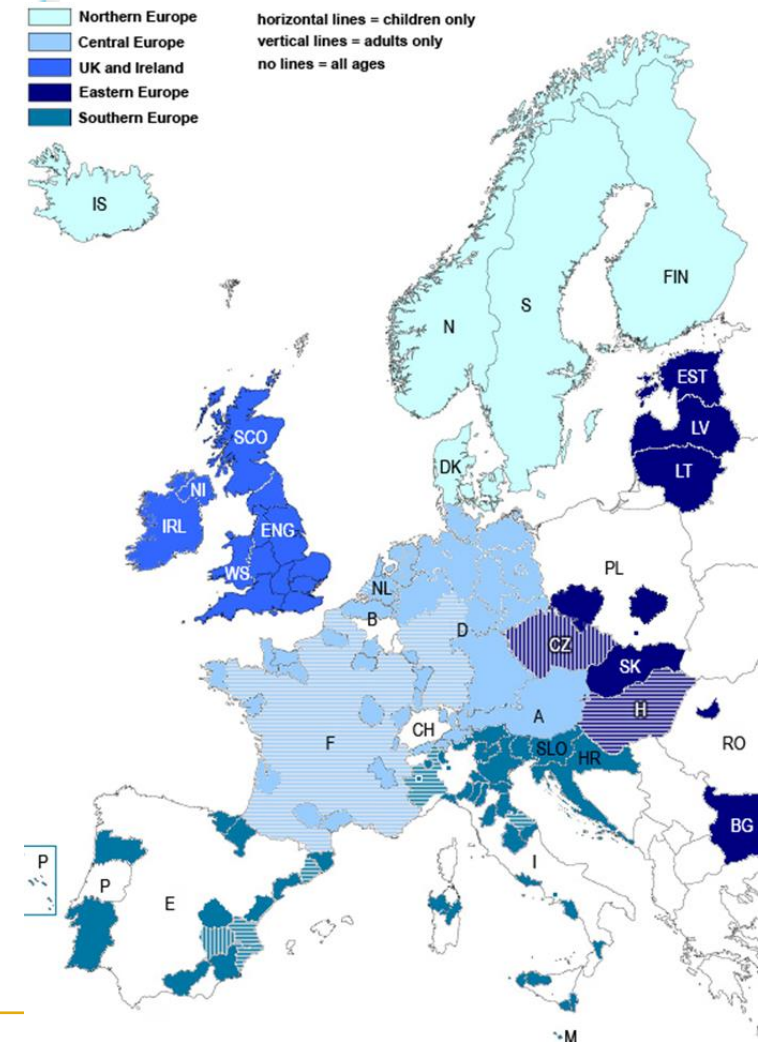
Collecting data on clinical follow up and quality of life of cancer survivors at the population level to improve survivorship and prevent late effects



**Need to enhance cancer information systems** at national/regional scale

# CANCER REGISTRIES: A KEY INFORMATION SYSTEM FOR CCC

- Un-biased, accurate, representative data. Indispensable for epidemiological research, cancer plans, quality of care assessment
- Integration with other health data to collect clinical information on the entire pathway of care **is still a challenge**
- Room to improve the potential of CR in most MS and to strengthen their support to address clinically relevant issues



## Actions to enhance population-based cancer information systems to better support evidence-based comprehensive cancer care

### 1. To advance current registries datasets

Piloting the integration with *clinical and administrative electronic data* in order to derive key indicators on cancer care pathway and costs

### 2. To expand information available from current registries datasets

Promoting the use of more informative epidemiological indicators on cancer prevalence at European MS level

# 1. ADVANCING REGISTRIES DATASETS

Task 1 **Mapping key administrative and clinical data sources**  
to integrate registries data

## Task2

Pilot study to  
integrate data on  
**cancer pathways**

## Task3

Pilot study to  
integrate data on  
**cancer costs**

## Task 4

Pilot to integrate  
data on **long term**  
**follow up of**  
**cancer survivors**

## Task 5

ICT model piloting a  
national cancer care  
information system by  
**integrating multiple**  
**data sources**

# TASK 1: MAPPING KEY DATA SOURCES



- Mapping **informs pilot data collection** performed in Tasks 2-5
- Mapping the clinical/administrative data sources eligible for linkage with cancer registries data across the EU
  - ownership, data quality and standardisation, legal and privacy issues
- Data on the whole cancer trajectory (comorbidity, stage, disease progression, treatment, late/adverse effects, second tumours) and on direct cancer care costs

## How

- Review of the pertinent scientific literature
- Focus groups involving iPAAC partners (experts/registries) to select relevant indicators and validated information available in health/administrative data
- Survey among cancer registries of participating MS



# TASK 2: CANCER CARE PATHWAYS

- Pilot study to test feasibility of linking individual registries data with administrative and health data in order to :
  - 1) describe the complete pathway of cancer patients, from diagnosis to terminal care or complete rehabilitation
  - 2) assess the adherence of treatments to standard guidelines

## How

- Representative cohorts of individual patients' data from participating registries for selected frequent cancers (e.g. breast, colon, lung, melanoma, ...)
- Cancer and country-specific procedures
- Validated indicators of quality and appropriateness of care → WP-10
- Relying on European High Resolution studies (<http://www.hrstudies.eu>) ongoing in 13 EU countries

# TASK 3: CANCER COSTS

- Pilot study to estimate direct costs related to care pathways through individual linkage of registry data with administrative health reimbursement records
  - Cost profiles of cancer survivors by disease phase and care pathway

## HOW

- Cohorts of prevalent cases identified by participating registries
- Direct cancer related costs from hospital admissions, outpatients records, drugs prescriptions
- Extending to other EU countries the procedures applied in Italy in the framework of the EPICOST project



# TASK 4: LONG TERM FOLLOW UP

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- Piloting integration of administrative and clinical data sources with individual registries data to assess long term clinical follow up (late and adverse events)
  1. Focus on Adolescents and Young Adults (AYAs, age 15-39 at diagnosis)
  2. Model to establish longitudinal population-based cohorts of AYA survivors

## HOW

- Cohorts of AYA survivors identified by participating registries
- **Outcomes:** excess risk of second cancers, mortality, specific diseases (heart, kidney, liver,..)

# TASK 5: ICT MODEL

- Piloting a comprehensive Information and Communication Technology (ICT) model to derive a *national cancer care information system* by longitudinal integration of multiple data sources:
  1. Standard population based cancer registries - epidemiology
  2. Health care records from participating providers
  3. Administrative data on cancer management and costs

## HOW

- Model developed in Czech Republic and based on previous outcomes from CANCON (pilot model of CCCN)
- Addressing legal background, data protection and access to relevant data
- Model to support CCCNs (real time control) and national bodies to get control on entire care pathway including long-term surveillance (disease management)

# WP-7 OBJECTIVES

## 1. ADVANCING REGISTRIES DATASETS

Task 1 **Mapping key data sources** to integrate registries data

Task2 Pilot study to integrate data on **cancer pathways**

Task3 Pilot study to integrate data on **cancer costs**

Task 4 Pilot study on **long term follow up of cancer survivors**

Task 5 Piloting **integration of multiple data sources** ICT model

## 2. EXPANDING INFORMATION AVAILABLE FROM CURRENT REGISTRIES DATASETS

### Task 6

Promoting informative **epidemiological indicators on cancer prevalence** by country and region in Europe

# TASK 6: CANCER PREVALENCE IN EU

- Cancer survivors are a frail growing population
- Quantifying their health care needs is of increasing importance to assist CCC and decision-making processes, whilst prevalence data are sparsely available in EU at MS level \*
- Indicators on cancer survivors can be derived at MS level **by using current registries datasets** so as to strengthen their support to evidence-based cancer control in Europe
  - i) total prevalence and prevalence by disease duration
  - ii) prevalence by phase of care (initial, terminal, intermediate)
  - iii) prevalence of cured/uncured patients, cure fraction and time to cure
  - iv) life expectancy of cancer survivors

\* Population based data available from IARC GLOBOCAN are limited to 5-y prevalence

# TASK 6: CANCER PREVALENCE IN EU



- This activity relies on the [EUROCARE-6](#) dataset, the widest collaborative study on cancer survival/prevalence in Europe
- Data were harmonised and quality checked in collaboration with JRC and European Network of Cancer Registries (ENCR)
- The use of more informative indicators on cancer prevalence will be promoted in collaboration with national/European stakeholders
- Comprehensive and comparable indicators on cancer prevalence can contribute to feed the European Cancer Information System (ECIS) web-site



# WP-7 OBJECTIVES

## 1. ADVANCING REGISTRIES DATASETS

**Task 1** Mapping key data sources  
to integrate registries data

**Task2** Pilot  
study on  
cancer  
pathways

**Task3** Pilot  
study on  
cancer costs

**Task 4** Pilot  
on long term  
follow up of  
cancer  
survivors

**Task 5**  
Piloting  
integration  
of data  
sources in a  
ICT model

## 2. EXPANDING INFORMATION DERIVED FROM CURRENT REGISTRIES DATASETS

**Task 6**

Deriving  
epidemiological  
cancer prevalence  
and risk

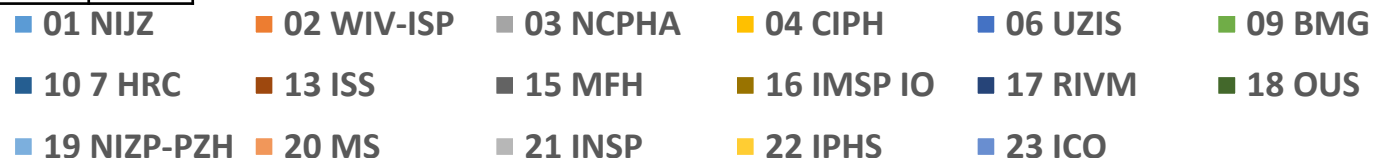
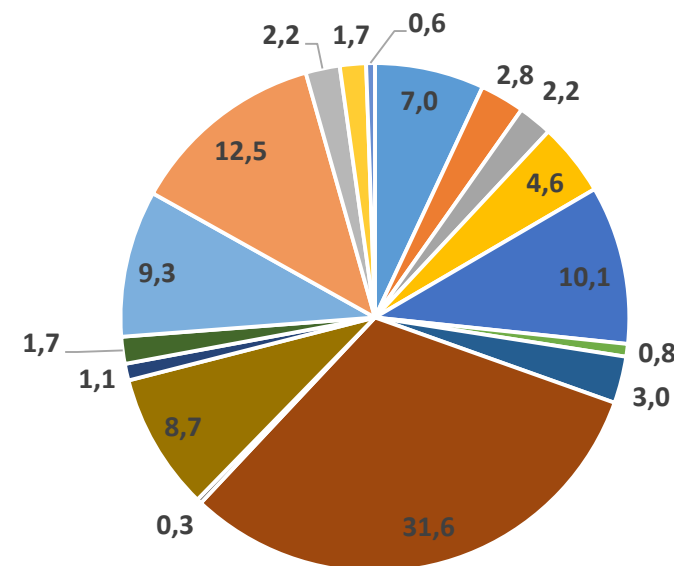
**Task 7 Road Map**

Recommendations and strategy for  
implementation for policy makers

# WP-7 PARTNERSHIP: 17 COUNTRIES

Applicants Nr	1	2	3	4	6	9	10	13	15
Applicants Acronym	NIJZ (OIL)	WIV-ISP	NCP HA	CIPH	UZIS	BMG	7HR C	ISS (MoH)	MFH
Country	SI	BE	BG	HR	CZ	DE	GR	IT	MT
Person month per applicant	13.8	5.6	4.3	9.2	20	1.6	5.9	62.6	0.6
Tasks	1,2,4	3,6	1,6	3,5,6	1,5	3,4	2	all	1
Applicants Nr	16	17	18	19	20	21	22	23	
Applicants Acronym	IMSP IO	RIVM	OUS	NIZP -PZH	MS	INSP	IPHS	ICO	
Country	MD	NL	NO	PL	PT	RO	RS	ES	
Person month per applicant	17.3	2.1	3.4	18.5	24.8	4.3	3.3	1.1	
Tasks	1,5	1,2,3, 4,6	4,6	1,2,3, 4,6	3,4	2,6	1,5	2,4,6	

## Staff effort per applicant (%)



# ITALIAN PARTNERSHIP IN WP7 AND IPAAC

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- MoH (AE ISS) WP 4,5,7,10
- ISS Third Parties
  1. AUSL-RE, Reggio Emilia, WP 7,8
  2. CRO, Aviano, WP 7,9
  3. INT Milan, WP 7,8,10
  4. IOV, Padua, WP 5,6
  5. ISPO, Florence WP 5,7,10
  6. LA SAPIENZA, Rome WP 4,5,10
  7. UCSC, Rome WP 6
  8. UNIVERSITY of FOGGIA , Foggia WP 7





# WP7 DELIVERABLES: ROAD MAP

Deliverable Number	Deliverable Name	Leading applicant acronym	Content specification	Dissemination level	Delivery month
D7	Roadmap on Implementation and Sustainability of Cancer Control Actions in the field of cancer information and registries	ISS	The conclusions, results of the WP activities will be integrated into a roadmap instrument for sustainable implementation of actions in cancer control in the EU.	PU	36

## Milestones to be reached

- M 7.1 Workshops to discuss results of the survey and to agree on protocols of pilot studies and prevalence study – tasks 1-6, M 12
- M 7.2 Pilot data sources integration and data collection completed by the CRs - tasks 2-4, M 18
- M 7.3 Workshops to agree on results of pilot studies and of prevalence study – task 1-6, M 28

# WP7 MEETINGS SCHEDULES

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1. M 2: kick-off meeting
  - Milan (INT) 31 May 2018 (communication this week)
2. M12: workshops to discuss results of the survey and to agree on protocols of pilot studies and prevalence study
  - Rome (ISS) April 2019
3. M 28 Workshops to agree on results of pilot studies – tasks 1-5 and prevalence study – task 6,
  - Milan (INT) September 2020

# COLLABORATING PARTNERS AND STAKEHOLDERS

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- **Cancer registries**
  - Single registries adhering to pilot studies
  - ENCR – European Network of Cancer Registries
  - AIRTUM, CIBERESP, Italian Spanish Associations of Cancer Registries
- **JRC - Joint Research Center in Ispra (IT)**  
Results (ECIS) and methods dissemination
- **Experts**  
University of Rome Tor Vergata, Italian National Research Council
- **OEI** – Organization of European Cancer Institutes
- **ECPC** – European Cancer Patients Coalition



# WP7: RISKS AND CONTINGENCY PLAN

Identified Risk	tasks	Contingency planning
Pilot studies: lack of engagement of cancer registries (CRs)	tasks 1-4	Communication and involvement in data collection protocol to minimise registries effort to retrieve data. Recruitment of additional registries further to those already committed to implement the pilots.
Pilot studies: Problems in linking different data sources	tasks 1-5	Restrict number of variables for linkage. Assessing the feasibility of linkage/data retrieval is one of the objectives 'per se'.
Resistance of health care providers to integrate data in a comprehensive health care record	task 5	Communications and involvement in value guide and user guide (data – IT standards, etc) to facilitate the work of IT specialists in hospitals
Prevalence study - Issues in applying statistical models to specific cancer sub-types or prognostic variables	task 6	Alternative models performance assessment. Estimations limited to wider groups or less specific prognostic classes



# Thanks for your attention

