



JA PreventNCD

Joint Action Prevent Non-Communicable Diseases

Preparing the questionnaire (*subtasks 8.4.1-2-3*)

**JA PreventNCD T8.3 & T8.4 Meeting
Rome, Tuesday 5th November 2024**

Tania Lopez
National Institute of Health



Co-funded by
The European Union

AIMS of this presentation



- Introducing the *Questionnaire* as the tool through which the activities of subtasks 8.4.1-2-3 are realised
- Giving an overview on *some items and definitions crucial* for the application of the methodologies proposed in the task 8.4 activities
- Identifying one expert per participating Country/AEs interested to join the establishing working group



Internal Deliverables (ID) and Milestones (IM):



JA PreventNCD

ID/IM number	ID/IM description	Month
IM8.4.1/2/3	Questionnaire for mapping available data for estimating cancer costs indicators sent to the participating countries	M15 (31 March 2025)
ID8.4.1/2/3	Interim report on the questionnaire for mapping available data for estimating cancer costs indicators in the European countries	M20 (31 August 2025)



Co-funded by
The European Union

Questionnaire Main Objective



To evaluate the **feasibility** of implementing
in the specific Country's contest,
methodologies and procedures
to monitor the impact of NCDs
in terms of **access** to health care services and corresponding
expenditures,
along the **entire disease pathway**



Key Aspects/Highlights



Questionnaire will be focused on:

1. **Cancer** as the cross-cutting theme of this JA
2. Information retrieved by Health data sources accessible for the Cancer Registry (*Cancer Registry-centric approach*)
3. **Population-based** data, linkable **at individual level**
4. Monitoring intended as **computing costs concerning services accessed by the cancer patient**, from diagnosis to possible recovery or end of life



Questionnaire structure



The design of the questionnaire will reflect the distribution of activities in the 3 subtasks:

Subtask 8.3.1: Mapping of available data for estimating patterns of care and costs of NCDs: this step consists in the mapping of the health care data sources containing information on access to health care services and corresponding costs across Europe

→ **SECTION 1:** *Mapping of available data source for estimating patterns of care and costs of NCDs*

Subtask 8.4.2: Identification of healthcare cost components: in this step the definition of cost types (direct, indirect, social, informal) and related measurement techniques are identified and described.

→ **SECTION 2 :** *Estimating Cost of healthcare services provision*

Subtask 8.4.3 Definition of standards and framework for collecting, linking and selecting health care access and costs of cancer patients, taking into account ownership, data quality and standardization, legislative background in member states

→ **SECTION 3 :** *Legal framework for data protection and exchanging*



SECTION 1: Mapping of available data source for estimating patterns of care and costs of NCDs



JA PreventNCD

Mapping National Health information system by Public funding perspectives

Questions investigating:

- who **provides** healthcare services (national, local, regional providers; public or private)
- who **funds** the health system (publicly or privately; tax-funded or insurance scheme)
- population, benefits and cost **coverage**

Possible Answer for *ITALY*:

The structure of the Italian National Health System (NHS) relies primarily on general taxation and operates as a regionally organized public service.

Its principles are rooted in universal coverage, unrestricted access, freedom to choose, pluralism in service provision, and fairness.

Some benefits are excluded from public coverage (eg dental care, psychotherapy).



SECTION 1: Mapping of available data source for estimating patterns of care and costs of NCDs



JA PreventNCD

Mapping Data sources by Cancer Registries perspective.

Questions investigating:

- Data sources **eligible for individual linkage** with Cancer registries' data
- Availability of data for the services accessed by patient and relative costs, along the **entire pathway of care**, from diagnosis to possible recovery or end of life.

Possible Answer for *ITALY*:

Data flows eligible for record linkage, routinary collected :

- Hospitalization
- Outpatients Services
- Drugs Prescriptions
- Hospital Drugs

Data flows eligible for record linkage, **NOT** routinary collected

- Hospice
- Emergency Room
- Local Residential Care
- Integrated Home Care
- Medical Devices
- Community Hospital (CH) and Rehabilitation units (RU)



SECTION 2: Estimating Cost of healthcare services provision- preliminary key definitions

Which costs measuring?

- directly used in treating the patient → DIRECT COSTS
- Transportation, time spent by family members in providing home care → OTHER DIRECT NON-HEALTH CARE COSTS
- Typically cost of productivity loss → INDIRECT COSTS

How measuring costs?

- Summing up all the medical expenses incurred during disease pattern of care
- Summing up only diagnosis specific expenditures
- Measuring the incremental cost

Where retrieving cost?

- Reimbursement claims by local providers to NHS
- Data recorded by Insurances

SECTION 2: Estimating Cost of healthcare services provision



JA PreventNCD

Definition of healthcare Direct cost components and costing methodology

Questions investigating:

- Definition of **cost attribution criteria**, such as case-based per time-period (eg in primary care), per diagnosis, per area, per provider; itemised per service or per individual good (e.g. for pharmaceuticals)
- **Costing methodologies**
- **International Classification system** used to code treatment and procedures

Possible Answer for *ITALY*:

*In Italian health system the universal coverage allows to evaluate the economic burden of cancer care through the reimbursement claimed by the health services providers to the National Health System for the expenses incurred in diagnosis and treatment of oncological patient (**DIRECT COST**).*

Direct Costs are classified per health care service/ setting

*Procedures and treatments are coded according the **international classification systems** available*



Co-funded by
The European Union

SECTION 2: Estimating Cost of healthcare services provision- a Case study for ITALY



Example of the information used to monitor cost and patterns of care for cancer patient **in the Italian healthcare information system**

- **CASE-STUDY:**

Describing patterns of care and corresponding expenditures, incurred by a patient diagnosed with colon cancer along the first year after diagnosis (*initial phase of care*)

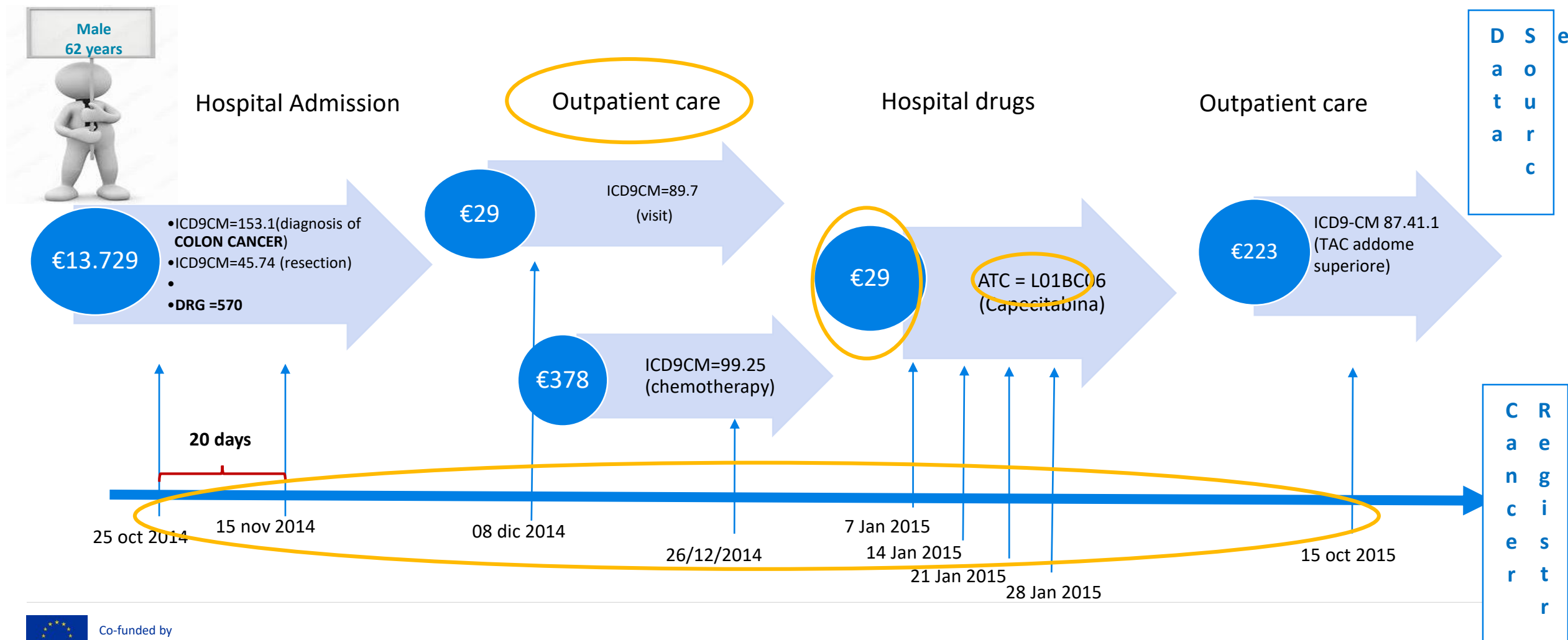


CASE STUDY

Temporal window: one year after diagnosis



JA PreventNCD



Co-funded by
The European Union

SECTION 3: Legal framework for data protection and exchanging



JA PreventNCD

Definition of standards and framework for collecting, linking and selecting health care access and costs of cancer patients.

Questions investigating:

- interoperability among Cancer Registry and health or administrative data sources (data quality and standardization)
- legal context for data exchanging
- data protection regulation

Possible Answer for ITALY:

Ministry of Health coordinate the New Health Information System infrastructure (NSIS) which collect a minimum information data set required to monitoring of HCS, from the main administrative health data sources.

The collection and reporting of health data are governed by the GDPR (General Data Protection Regulation), which ensures the protection of patient privacy.

Italian CRs are legally permitted to link the registry personal record data with health or administrative data sources, according to their mission/mandate or for specific purposes (eg. research project).



Co-funded by
The European Union

What we expect from this recognition



JA PreventNCD

- The completion of the questionnaire by all the participants to task 8.4!!
- To gather all the information needed to **draw the health information system the Cancer Registry can access to** and so to be able to feed the report required as internal deliverable!
- **To open a discussion about the coordinates within which to move into each regulatory system** to apply the methodology proposed for monitoring treatments and costs.
- **To share a set of definitions** useful to give a comprehensive reading of the cancer treatment costs comparison
- **To assess the feasibility for each participant** to join the pilots activities



Co-funded by
The European Union

Next steps



JA PreventNCD

1. Set up a working group to get feedback on the questions proposed, before the release* → 1 on line meeting between January and February 2025
2. Live simulation of filling in the questionnaire, around the release deadline → 1 on line meeting by the middle of March 2025
3. Release of the questionnaire → by the end of March 2025
4. Collection of the answers* → deadline on 30 May 2025
5. Drafting of the interim report (D8.4.1/2/3) → by the end of August 2025

** It is warmly recommended to involve in activities 1. and 3. personnel from Cancer Registry, at least one participant per country*



Co-funded by
The European Union



JA PreventNCD

Joint Action Prevent Non-Communicable Diseases

Thank you for the attention

question, comment and

candidature for the Working Group, are welcome

tania.lopez@iss.it

daniela.pierannunzio@iss.it



Co-funded by
The European Union