# EUROPEAN CURRICULUM VITAE FORMAT





### PERSONAL INFORMATION

Name ANNALISA TRAMA (AT)

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Nationality Italian

#### **WORK EXPERIENCE**

• Dates (from - to)

• Name and address of employer

• Type of business or sector

· Occupation or position held

· Main activities and responsibilities

May 2009 - to date

Fondazione IRCCS Istituto Nazionale dei Tumori, Milano (INT)

Research Institute (public)

Senior Researcher

Research activities focused on rare cancers at European and national level.

**RARECARE** (Surveillance of Rare Cancers in Europe; 2007-2010) aimed at defining rare cancers, proposing a list of rare cancers and at improving the quality of rare cancers registration. **RITA-2** (Rare Cancers in Italy: surveillance and evaluation of the access to diagnosis and treatment; 2011-2014) aimed at updating rare cancers epidemiological data in Italy, studying rare cancers patterns of care and at assessing the feasibility of evaluating the impact of the national clinical network for rare cancers using the Italian network of CRs.

**RARECAREnet** (*Information network on rare cancers*; 2012-2016) aimed at updating epidemiological indicators for rare cancers in Europe, identifying centres of expertise for rare cancers; developing clinical practice guidelines for rare cancers and developing and disseminating information for patients with rare cancers.

**LUME** (Mesothelioma survivors in Italy: what is contributing to long term survival?; 2013-2015) aimed at describing the patterns of care for malignant pleural mesothelioma (MPM); studying the clinical and biological characteristics of MPM long term survivors (alive >3 years from diagnosis); proposing new criteria for staging patients on the basis of computed tomography and Positron Emission Tomography.

**JARC** (*Joint Action on Rare cancers; 2016-2019*) aimed at optimizing the process of creation of the European Reference Networks (ERNs), by providing them with operational solutions and professional guidance in the areas of quality of care, research and innovation, education, clinical practice guidelines development and epidemiology. AT was Co-Pl.

Improving treatment strategies in Thymic Epithelial Tumors: a TYME collaborative effort (2017-2020). The project had two main studies: a clinical trial (study 1) and a translational, descriptive study including genomic, transcriptomic, proteomic and metabolomic analyses, the collection of clinical information and of Patients Reported Outcomes in a shared clinical database.

**STARTER** (*STarting an Adult Rare Tumor European Registry; 2020-2023*). This project aimed at developing a clinical, hospital-based, registry for the European Reference Network (ERN) on Rare Adult Cancers (EURACAN) which is focusing on 10 out of the 12 families of rare cancers and include about 70 health care providers across 18 European Member States. AT was PI.

**RARITY** (Register rAre adult solid canceRs In iTalY; August 2020-December 2021). This project aimed at initiating the Italian part of the EURACAN registry, exploiting and strengthening Alliance Against Cancer (ACC). AT was PI.

**BlueBerry** (Co-creating a Blueprint for Building a sustainable, effective and scalable EURACAN Rare cancer RegistrY; 2022-2023). The project aims to address organizational, legal, financial and practical challenges undermining the functioning of the EURACAN registry. AT was Co-Pl.

**IDEA4RC** (Intelligent Ecosystem to improve the governance, the sharing, and the re-use of health Data for Rare Cancers; September 2022- September 2026). The project leverages on EURACAN's wealth of data, on one side, and on emerging interoperability technologies and AI approaches for distributed data integration, federated analysis, and knowledge extraction from existing structured (e.g., EHRs, e-CRFs, Registries) and unstructured (e.g., clinician notes, image reports, pathology reports) health data on the other side, to improve the delivery of care, facilitate patients' information and advance clinical and epidemiological research in rare cancers. AT is the PI of the project. Horizon 2020-funded project.

**EURACAN** registry (2022-2028). AT is the coordinator of the registry of EURACAN. She is responsible for the registry set up and scale up across EURACAN health care providers and rare cancer families. She is the coordinator of the Steering Committee of the EURACAN registry aimed at promoting the registry and monitoring data quality and data access request. The registry is supported by the EURACAN grant.

AT contributed to **X-eHealth** (Exchanging electronic Health records in a common framework) with the specific objective to develop patient summary functional specifications for rare cancers to account for the European Health Network (eHN) Guidelines. AT contributed to **SELNET** (Sarcoma as a model to improve diagnosis and clinical care of rare tumours through a European and Latin American multidisciplinary network) with the specific objectives to define criteria for identifying sarcoma expert centre and support the definition on national network on sarcomas.

### Research activities on children and on adolescent and young adult cancers

Ada (Adolescents and young adults with cancer in Italy. How to ensure access to the best care and quality of survival; 2016-2019) aimed at 1) identifying health care organisation-related factors contributing to explain the lower survival of adolescents compared with children with the same disease and 2) developing a cohort of adolescent and young adult (AYA- 15-39 years old) cancer survivors to study the disease patterns and to identify causes of late effects in AYA cancer survivors. AT was the PI.

**iPAAC Joint Action** (innovative partnership for action against cancer; 2018-2020) aimed at developing innovative approaches to advances in cancer control. AT was involved in work package 7 focusing on cancer information and registries. AT was responsible of the study aimed at integrating CRs dataset with administrative database to study long term morbidity in AYA cancer survivors in Norway, Portugal and Spain.

**Rosanna** (pRedicting cardiOvascular diSeAses iN adolescent and young breast caNcer pAtients; 2021-2025). The project aims to define predictive models and biomarkers-based risk stratification to support a tailored follow-up for AYA breast cancer survivors at risk for cardiovascular diseases. AT is the PI of the project.

The Italian Cancer Institute for AYA (L'Istituto Nazionale dei Tumori di Milano per gli Adolescenti ed i Giovani Adulti con Tumore) (2022-2026). The project aims to increase knowledge on cancers arising in AYA to improve survival and quality of life of survivors. AT is Co-PI

**JANE** (*Joint Action on Network of Expertise*; 2022-2024). AT is the Co-PI pf the Action and the co-lead of the work package aiming at developing a European network of Expertise on AYA.

**JANE-2** (2025-2028). AT is the Co-PI pf the Action and the co-lead of the work package aiming at developing a European network of Expertise on AYA.

**JAPreventNCD** (Joint Action Prevent Non-Communicable Diseases; 2024-2027). AT is the lead of a pilot study aiming at developing and validating Al-based model for predicting late cardiovascular diseases in AYA breast cancer survivors.

## Research activities on cancer epidemiology

**Prostate cancer survival patients in Italy** (2010-2012) aimed at understanding whether the wide within country variability and overtime survival trends were due to early diagnosis, or to the availability of more effective therapies.

**FABIO** (*Valutazione dell'utilizzo di farmaci biologici nel paziente oncologico biological drugs in Oncology*; 2016-2019) coordinated by the Healthcare Research and Pharmacoepidemiology Unit of the Bicocca University/Milan aimed at using administrative database to study the use of biological drugs in the real-world setting.

**BD2Decide** (*Big Data and Models for Personalized Head and Neck Cancer Decision Support;* 2015-2019). The main objectives of the project were to build and validate an integrated head and neck cancer clinical decision support tool, linking together patient-specific multi-parameter characteristics from clinical, pathologic, transcriptomic, and imaging data. In addition, population-based clinical, epidemiological and environmental data were considered in graphical visualization tools.

**BD4QoL** (Big Data Models and Intelligent tools for Quality of Life monitoring and participatory empowerment of head and neck cancer survivors; 2019-2014). AT is responsible together with

Piedmont Region Public Health Observatory to develop and integrate occupational and health DB already available in Italy (INAIL and INPS DB monitoring employees and work-related injuries and disease; Ministry of Health clinical discharge records DB and Italian Office of Statistics mortality DB) to assess the long-term impact of head and neck cancer treatment on employment and salary changes. DG Research-funded project.

**CARÉ** (CAncRo E covid-19; 2020-2021). This project aimed to assess the impact of SARS-CoV-2 on cancer patients. AT was the PI of the project. Institutional Strategic Research Priority Line 4-funded project.

AT is Section editor (epidemiology area) of Tumori Journal and reviewers of several epidemiological scientific journal.

AT is a member of the Steering Committee and Board of the ERN EURACAN.

AT is one of the scientific directors of EUROCARE, the epidemiological study monitoring cancer survival across Europe.

AT is a member of the Steering Committee of TYME, the Italian collaborative network on rare thoracic cancers.

AT is member of the Steering Committee of EUSICA, the European collaborative group on sinonasal cancers.

AT is the coordinator of the Italian cohort of Adolescent and young adults cancer survivors.

• Dates (from - to)

2008- to 2019

· Name and address of employer

Università degli Studi di Roma Tre (University of Roma 3)

• Type of business or sector

Research Institute

Occupation or position held

Teaching position

• Main activities and responsibilities

Teaching position - annual course in Public Health

• Dates (from - to)

September 2006 - April 2009

· Name and address of employer

Italian National Institute of Health - National Centre for Rare Diseases

• Type of business or sector

Research Institute

· Occupation or position held

Senior researcher

· Main activities and responsibilities

- Development of a post marketing surveillance system for orphan drugs.

### **European projects**

National level activities

**TEDDY** (Task force in Europe for Drug Development in the Young).

**E-Rare** project aiming at strengthening the collaboration in the field of research for rare diseases among 9 European Countries.

**EUROPLAN** (European project for rare diseases national plan development).

AT was Member of the European rare diseases task force and its working groups on registry and indicators.

• Dates (from - to)

January 2004 September 2006

· Name and address of employer

UNAIDS Kenya country Office (Gigiri Complex, Nairobi)

• Type of business or sector

**United Nations** 

Occupation or position held

Program officer of the Joint United Nation Programme on HIV and AIDS.

Officer in charge of the Kenya UNAIDS country office from April to September 2006

· Main activities and responsibilities

### **Activities within the UN**

- development of the United Nations Implementation Support Plans for country response to HIV and AIDS
- collaboration with UN agencies for mainstreaming HIV and AIDS in their activities

### Activities outside the UN to support the Kenya HIV and AIDS response

National AIDS Control Council (NACC):

- Monitoring and Evaluation working group.
- National response coordination
- Contribution to the development of the Kenya global funds proposals
- Support to civil society officer for the coordination of civil society activities

National HIV/AIDS and STD Control Programme (NASCOP) – Kenya Ministry of Health:

- member of the antiretroviral drugs (ARV) task force
- member of the paediatric ARV steering committee

• Dates (from – to) September 2002- December 2003

• Name and address of employer Italian National Institute of Health (Istituto Superiore di Sanità)

• Type of business or sector Research Institute

Occupation or position held
 Researcher

• Main activities and responsibilities Research activities on health service management.

• Dates (from – to) October 1999 – September 2001

• Name and address of employer Public Health Department, "La Sapienza University", Rome

Type of business or sector
 Research Institute

Occupation or position held
 Researcher

Main activities and responsibilities
 Research activities on health education, cancer risk factors, hospital infectious.

### **EDUCATION AND TRAINING**

• Dates (from – to) 2004-2006

• Name and type of organisation University "La Sapienza" – Rome providing education and training

 Principal subjects/occupational skills covered
 Public health, epidemiology, monitoring and evaluation, health planning, health service research

• Title of qualification awarded PhD in Public Health

• Dates (from – to) 1999-2003

Name and type of organisation University "La Sapienza" – Rome providing education and training

• Principal subjects/occupational skills covered Epidemiology, statistics, health education, environmental health, microbiology, prevention, health care planning

Title of qualification awarded
 Post graduate certificate in Public Health

• Dates (from – to) 2001-2002

Name and type of organisation London School of Hygiene and Tropical Medicine providing education and training

Principal subjects/occupational
 Epidemiology, health economics, health planning, qualitative research

Title of qualification awarded Master's in health services/system research (health economics)

• Dates (from – to) 1993-1999

• Name and type of organisation University "La Sapienza", Rome providing education and training

Principal subjects/occupational
 Basic science and clinics

**TECHNICAL SKILLS** 

AND COMPETENCES

• Title of qualification awarded Degree in "medicine and surgery" (cum laude)

SOCIAL SKILLS

AND COMPETENCES

ORGANISATIONAL SKILLS

Good team working. Used to work in multidisciplinary team and in different socio-economic and multi-cultural context.

Great experience in project planning, management and coordination including administrative and

AND COMPETENCES

financial provisions. Great experience in direct management of research teams in complex institutions and indirect leadership in multifaceted setting.

Proficient computer user. Comfortable with MS Windows platform as well as Macintosh. Experienced in using the Microsoft Office package and in the use of statistical software e.g. STATA. Experienced in using the Internet and handling web-based literature searches