

## **European curriculum vitae**

# EUROPEAN CURRICULUM VITAE FORMAT



## PERSONAL INFORMATION

Name

**ANNALISA TRAMA (AT)**

## 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 2009-2021; from June 2021, Head of Unit

### **Unit management**

The Evaluative Epidemiology Unit has nine staff members, collaborates with two external project managers and currently supports a PhD student.

Prior to her appointment as unit manager, AT contributed to, and is now responsible for, defining the unit's strategic direction, defining research priorities aligned with the overall goals of the National Cancer Institute.

AT leads and motivates the unit's staff, providing guidance and support, fostering a collaborative work environment, and offering training and development opportunities for researchers and research support staff to enhance their skills and knowledge. AT manages the unit's budget, equipment, and other resources. AT identifies opportunities for innovation and development within the research unit because she believes in and fosters a culture of continuous improvement.

The unit is involved in and/or coordinates several projects, and AT oversees the planning, execution, and timely completion of research projects, ensuring they are carried out in compliance with ethical guidelines and relevant regulations, and within budget. AT also ensures that research results are effectively communicated through appropriate channels (e.g., publications, presentations, policy events, etc.). AT builds and maintains relationships with key stakeholders, including other researchers, collaborators, and funding agencies.

**AT research activities focused on cancer epidemiology with a special focus on rare cancers and cancers in adolescents and young adults (AYAs) and on clinical and data networks implementation.**

Since 2020, AT is the coordinator of the registry of the European Reference Network (ERN) on rare adult solid cancers (EURACAN). She is responsible for the registry set up and scale up across EURACAN health care providers and rare cancer families. Coordination of the registry includes management of governance, legal aspects, privacy, technical infrastructure, data collection and quality control, and analysis of research proposals. To ensure the registry's continued operation and expansion, AT coordinates and supervises a data manager, two statisticians, a data scientist, a technician, and collaborates with an external IT company. She is the coordinator of the Steering Committee of the EURACAN registry. The registry is supported by EURACAN funding and additional funds raised by AT through projects including: **BlueBerry** (Co-creating a Blueprint for Building a sustainable, effective and scalable EURACAN Rare cancer Registry; 2022-2023) aimed at addressing organizational, legal, financial and practical challenges undermining the functioning of the EURACAN registry. AT was the Co-PI of the project. KWF, Dutch Cancer Society-funded project. **RARITY** (Register rAre adult solid cancerRs 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) expert centres. AT was the PI of the project. Italian Ministry of Health-funded project. **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.

AT began her career at INT contributing to the **RARECARE** project, which provided the definition of rare cancer. She subsequently served as Co-PI of the **RARECAREnet** project, which updated epidemiological data on rare cancers in Europe and defined the criteria for defining centres of expertise for rare cancers. She also had the honour of being Co-PI of **JARC**, the first Joint Action on Rare Cancers.

**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. AT: 1) was the PI of the study on data quality in rare cancers registration (38 population-based cancer registries [CRs] from 13 European countries involved) and 2) contributed to the dissemination activities and to the scientific and financial reports. DG Sante-funded project. A similar project was run in Italy named **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. AT was: 1) the co-PI of the project (including 5 Italian partners); 2) the PI of the study on the patterns of care (10 Italian CRs involved from different geographic areas) and 3) responsible for the collaboration between the Italian national clinical network for rare cancers and the Italian CRs. Italian Ministry of health-funded project. **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. AT was the Co-PI of the project comprising 9 associated partners from 9 European countries and 10 collaborating partners and the co-PI of the epidemiological studies. DG Sante-funded project. **JARC** (*Joint Action on Rare cancers*; 2016-2019) aimed at optimizing the process of creation of the 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 the co-PI of the project (34 associated partners from 18 European Member States) and the co-PI of the work package on the epidemiology of rare cancers including models for assessing the ERN impact at population level. Consumers, Health, Agriculture and Food Executive Agency (CHAFEA)-funded project. AT contributed also 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.

AT has aimed to exploit and understand the potential of different types of data (CRs, administrative datasets etc.) as reflected in some of the projects she has been involved in. **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. AT was responsible of the epidemiological data and contributed to the discussion on population-based data integration. DG Research-funded project. **BD4QoL** (*Big Data Models and Intelligent tools for Quality of Life monitoring and participatory empowerment of head and neck cancer survivors*; 2019-2024). 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. **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. AT overviewed the design of the studies undertaken. (AIFA)-funded project. **CARE** (*CAnRo E covid-19*; 2020-2021). This project aimed to assess the impact of SARS-CoV-2 on cancer patients based on the Lombardy region administrative data flows. AT was the PI of the project. Institutional Strategic Research Priority Line 4-funded project

Based on data integration, AT has developed the first and only **Italian cohort of adolescents and young adults** (15-39 years at cancer diagnosis) **cancer survivors** based on the linkage of CR data with administrative datasets. This was possible thanks to Ada project funded by INT. **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 cancer survivors to study the disease patterns and to identify causes of late effects in AYA cancer survivors. AT was the PI of the project. INT-institutional grant. The Italian experience was scaled up in the **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 CRs. 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. AT developed AYA cancer survivor cohorts in Basque Country, Slovenia and Norway. (CHAFFA)-funded project. Furthermore, with the **Rosanna** (pRedicting cardiOvascular diSeAses in adolescent and young breast caNcer pAtients; 2021-2025) project, AT aimed to integrate clinical and CRs data using AI-based approach. Rosanna 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. Associazione Italiana per la Ricerca sul Cancro/Italiana Association for cancer research (AIRC)-funded project. This experience was also expanded in the **JAPreventNCD** (Joint Action Prevent Non-Communicable Diseases; 2024-2027). AT is the lead of a pilot study aiming at developing and validating AI-based model for predicting late cardiovascular diseases in AYA breast cancer survivors in different countries including Belgium, Denmark, Estonia and Norway. Finally, AT leveraged the Italian cohort of AYA cancer survivors contributing to different EU projects. **Strong-AYA**. The project aims to define a set of outcome indicators for AYAs with cancers and a data ecosystem to collect and utilize them. AT is coordinating data collection activities at INT and is responsible for data collection through CRs. **PredictAYA**. The project aims to study reproductive problems in young adult cancer survivors. AT is responsible for several tasks, including defining the epidemiological context and studying the long-term effects of assisted reproductive technologies using cohorts of young adult cancer survivors from five different European countries.

Regarding the activities on networking, AT was and is deeply involved in launching networks of expertise on cancers via 2 joint actions. **JANE** (Joint Action on Network of Expertise; 2022-2024) aimed at defining 7 network of expertise (NoEs) on cancers. AT was the Co-PI of the Action and the co-lead of the work package aiming at developing a European network of Expertise on AYA with cancers. JANE included 16 countries and 36 partners. **JANE-2** (2025-2028) is currently working to launch the 7 NoEs. JANE-2 includes 124 partners from 32 countries (budget €40 millions). In addition to managing the day-to-day coordination of the various activities (with the support of a project manager and a consulting firm), AT supports policy discussions, coordination between the seven networks, coordination with relevant projects, and coordination with Member States. AT also co-coordinates the NoE for AYAs with cancer. Finally, across the seven NoEs, AT facilitates discussions on the data the networks need, which the networks can produce, also with a view to European health data space (EHDS).

Finally, for years, the unit has coordinated the EURO CARE project, together with the Italian National Institute of Public Health (ISS), which collects and analyses data from over 100 CRs across Europe. Since 2022, AT has been a member of the scientific secretariat responsible for the EURO CARE's strategic direction and coordination. In recent years, AT has promoted and coordinated a series of articles on AYA with cancers published in the European Journal of Cancer and contributed to the working group on survival promoted by the Joint Research Centre to promote the European Cancer Information System. AT helped define the new EURO CARE call for data collection. The context of CRs is evolving to adapt to EHDS. To ensure the registries' full participation in this new vision, in 2024 AT contributed to and drafted the Joint Action (Cancer Watch), for which she holds significant responsibilities in terms of expertise in survival analysis and governance of complex data systems.

AT has established collaboration with:

- Patients' associations at European (i.e. EURACAN e-Patient Advocacy Group) and national level (i.e. she is in the steering committee of the working group of the Federazione Italiana Delle Associazioni Di Volontariato In Oncologia on rare cancers).
- East Asia CRs of Japan, Republic of Korea and Taiwan in the framework of the initiative launched by the European Society of Medical Oncology, Rare Cancers Asia. She is currently coordinating the epidemiological project RARECAREnet Asia aiming at comparing rare cancers burden in Europe and Asia.

- Experts from Canada and the USA and was part of the group revising the AYA tumours classification (A System for Classifying Cancers Diagnosed in Adolescents and Young Adults. In press in Cancer).

AT has been an expert of the International Rare Diseases Research Consortium (IRDiRC) Task Force 'Chrysalis' aimed at identifying key criteria that would make rare diseases research more attractive to industry for research and development (1 year from Q3 2020- Q4 2021). Finally, she served as coordinator of the Institutional Strategic Research Priority Line 3 on rare cancers and complexity in oncology (including frailty population such as children and elderly and palliative care).

AT is the coordinator of the Italian AYA cancer survivor cohort.

AT is in the Steering Committee of EURACAN and other networks: EUSICA (European Network for Sinonasal Cancer Research) and TYME (Italian network for thymic malignancies).

AT is in the scientific secretariat and Steering Committee of EURO CARE.

AT is one of the 3 co-chairs of the Organisation for Economic Co-operation and Development (OECD) Data Free Flow with Trust (DFFT) Expert Group on Cross Border Health Data Sharing.

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- Main activities and responsibilities

2008- to 2019

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

Research Institute

Teaching position

**Teaching position – annual course in Public Health**

- Dates (from – to)
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- Main activities and responsibilities

September 2006 – April 2009

Italian National Institute of Health - National Centre for Rare Diseases

Research Institute

Senior researcher

**National level activities**

- Development of a post marketing surveillance system for orphan drugs: national registry of orphan drugs; contribution to the development of the rare diseases national registry; implementation of training courses on orphan drugs for patients' associations; scientific support for rare diseases patients' associations.

**European projects**

**TEDDY** (Task force in Europe for Drug Development in the Young). AT was responsible for: 1) the survey on availability of orphan drugs in European Member States; 2) the treatment satisfaction questionnaire for identifying therapeutic un-met needs in children medicine; 3) bibliographic review on the status of clinical trials in children and contributed to the development of methodological recommendations on clinical trials tailored to rare diseases and children.

**E-Rare** project aiming at strengthening the collaboration in the field of research for rare diseases among 9 European Countries. AT main activities: survey on available rare diseases research programmes in EU, identification of areas of collaboration among Member States, launching of translational call for proposals for EU projects on rare diseases.

**EUROPLAN** (European project for rare diseases national plan development). AT was 1) coordinator of the project and 2) leader of the task aimed at identifying best practices for addressing rare diseases.

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

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- Main activities and responsibilities

January 2004 September 2006

UNAIDS Kenya country Office (Gigiri Complex, Nairobi)

United Nations

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

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

**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

	<ul style="list-style-type: none"> <li>– member of the UN learning team on HIV and AIDS</li> </ul>
	<b>Activities outside the UN to support the Kenya HIV and AIDS response</b>
	<i>National AIDS Control Council (NACC):</i>
	<ul style="list-style-type: none"> <li>– Monitoring and Evaluation working group.</li> <li>– National response coordination</li> <li>– Contribution to the development of the Kenya global funds proposals</li> <li>– Support to civil society officer for the coordination of civil society activities</li> </ul>
	<i>National HIV/AIDS and STD Control Programme (NASCOP) – Kenya Ministry of Health:</i>
	<ul style="list-style-type: none"> <li>– member of the antiretroviral drugs (ARV) task force</li> <li>– member of the paediatric ARV steering committee</li> </ul>
<ul style="list-style-type: none"> <li>• Dates (from – to)</li> </ul>	September 2002- December 2003
<ul style="list-style-type: none"> <li>• Name and address of employer</li> </ul>	Italian National Institute of Health (Istituto Superiore di Sanità)
<ul style="list-style-type: none"> <li>• Type of business or sector</li> </ul>	Research Institute
<ul style="list-style-type: none"> <li>• Occupation or position held</li> </ul>	Researcher
<ul style="list-style-type: none"> <li>• Main activities and responsibilities</li> </ul>	<b>Research activities on health service management.</b>
<ul style="list-style-type: none"> <li>• Dates (from – to)</li> </ul>	October 1999 – September 2001
<ul style="list-style-type: none"> <li>• Name and address of employer</li> </ul>	Public Health Department, “La Sapienza University”, Rome
<ul style="list-style-type: none"> <li>• Type of business or sector</li> </ul>	Research Institute
<ul style="list-style-type: none"> <li>• Occupation or position held</li> </ul>	Researcher
<ul style="list-style-type: none"> <li>• Main activities and responsibilities</li> </ul>	<b>Research activities on health education, cancer risk factors, hospital infectious.</b>
<b>EDUCATION AND TRAINING</b>	
<ul style="list-style-type: none"> <li>• Dates (from – to)</li> </ul>	2004-2006
<ul style="list-style-type: none"> <li>• Name and type of organisation providing education and training</li> </ul>	University “La Sapienza”– Rome
<ul style="list-style-type: none"> <li>• Principal subjects/occupational skills covered</li> </ul>	Public health, epidemiology, monitoring and evaluation, health planning, health service research
<ul style="list-style-type: none"> <li>• Title of qualification awarded</li> </ul>	<b>PhD in Public Health</b>
<ul style="list-style-type: none"> <li>• Dates (from – to)</li> </ul>	1999-2003
<ul style="list-style-type: none"> <li>• Name and type of organisation providing education and training</li> </ul>	University “La Sapienza”– Rome
<ul style="list-style-type: none"> <li>• Principal subjects/occupational skills covered</li> </ul>	Epidemiology, statistics, health education, environmental health, microbiology, prevention, health care planning.
<ul style="list-style-type: none"> <li>• Title of qualification awarded</li> </ul>	<b>Post graduate certificate in Public Health</b>
<ul style="list-style-type: none"> <li>• Dates (from – to)</li> </ul>	2001-2002
<ul style="list-style-type: none"> <li>• Name and type of organisation providing education and training</li> </ul>	London School of Hygiene and Tropical Medicine
<ul style="list-style-type: none"> <li>• Principal subjects/occupational skills covered</li> </ul>	Epidemiology, health economics, health planning, qualitative research
<ul style="list-style-type: none"> <li>• Title of qualification awarded</li> </ul>	<b>Master’s in health services/system research (health economics)</b>
<ul style="list-style-type: none"> <li>• Dates (from – to)</li> </ul>	1993-1999
<ul style="list-style-type: none"> <li>• Name and type of organisation providing education and training</li> </ul>	University “La Sapienza”, Rome
<ul style="list-style-type: none"> <li>• Principal subjects/occupational skills covered</li> </ul>	Basic science and clinics
<ul style="list-style-type: none"> <li>• Title of qualification awarded</li> </ul>	<b>Degree in “medicine and surgery” (cum laude)</b>
<b>PERSONAL SKILLS AND COMPETENCES</b>	
MOTHER TONGUE	ITALIAN

OTHER LANGUAGES

- Reading skills
- Writing skills
- Verbal skills

**ENGLISH**

EXCELLENT

GOOD

EXCELLENT

SOCIAL SKILLS  
AND COMPETENCES

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

ORGANISATIONAL SKILLS  
AND COMPETENCES

Great experience in project planning, management and coordination including administrative and financial provisions. Great experience in direct management of research teams in complex institutions and indirect leadership in multifaceted setting.

TECHNICAL SKILLS  
AND COMPETENCES

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

DRIVING LICENCE(S)

Italian