

La cura del cancro. Implicazioni etiche, sociali ed economiche

Firenze, 13 aprile 2018

Rete europea della Ricerca: Come esserci?

Giovanni Nicoletti |

Ministero della salute | Segretariato Generale

National Focal Point EU Health Programme 2014-2020

TITOLO XIV - SANITÀ PUBBLICA - ART. 168 (EXART. 128 DEL TCE)

1. Nella definizione e nell'attuazione di tutte le politiche ed attività dell'Unione è garantito un livello elevato di protezione della salute umana. L'azione dell'Unione, che completa le politiche nazionali, si indirizza al miglioramento della sanità pubblica, alla prevenzione delle malattie e affezioni e all'eliminazione delle fonti di pericolo per la salute fisica e mentale. Tale azione comprende la lotta contro i grandi flagelli, favorendo la ricerca sulle loro cause, la loro propagazione e la loro prevenzione, nonché l'informazione e l'educazione in materia sanitaria, nonché la sorveglianza, l'allarme e la lotta contro gravi minacce per la salute a carattere transfrontaliero. L'Unione completa l'azione degli Stati membri volta a ridurre gli effetti nocivi per la salute umana derivanti dall'uso di stupefacenti, comprese l'informazione e la prevenzione.
2. L'Unione incoraggia la cooperazione tra gli Stati membri nei settori di cui al presente articolo e, ove necessario, appoggia la loro azione. In particolare incoraggia la cooperazione tra gli Stati membri per migliorare la complementarietà dei loro servizi sanitari nelle regioni di frontiera. Gli Stati membri coordinano tra loro, in collegamento con la Commissione, le rispettive politiche ed i rispettivi programmi nei settori di cui al paragrafo 1. La Commissione può prendere, in stretto contatto con gli Stati membri, ogni iniziativa utile a promuovere detto coordinamento, in particolare iniziative finalizzate alla definizione di orientamenti e indicatori, all'organizzazione di scambi delle migliori pratiche e alla preparazione di elementi necessari per il controllo e la valutazione periodici. Il Parlamento europeo è pienamente informato.
3. L'Unione e gli Stati membri favoriscono la cooperazione con i paesi terzi e con le organizzazioni internazionali competenti in materia di sanità pubblica.
4. In deroga all'articolo 2, paragrafo 5, e all'articolo 6, lettera a), e in conformità dell'articolo 4, paragrafo 2, lettera k), il Parlamento europeo e il Consiglio, deliberando secondo la procedura legislativa ordinaria e previa consultazione del Comitato economico e sociale e del Comitato delle regioni, contribuiscono alla realizzazione degli obiettivi previsti dal presente articolo, adottando, per affrontare i problemi comuni di sicurezza:
 - a) misure che fissino parametri elevati di qualità e sicurezza degli organi e sostanze di origine umana, del sangue e degli emoderivati; tali misure non ostano a che gli Stati membri mantengano o introducano misure protettive più rigorose;
 - b) misure nei settori veterinario e fitosanitario il cui obiettivo primario sia la protezione della sanità pubblica;
 - c) misure che fissino parametri elevati di qualità e sicurezza dei medicinali e dei dispositivi di impiego medico.
5. Il Parlamento europeo e il Consiglio, deliberando secondo la procedura legislativa ordinaria e previa consultazione del Comitato economico e sociale e del Comitato delle regioni, possono anche adottare misure di incentivazione per proteggere e migliorare la salute umana, in particolare per lottare contro i grandi flagelli che si propagano oltre frontiera, misure concernenti la sorveglianza, l'allarme e la lotta contro gravi minacce per la salute a carattere transfrontaliero, e misure il cui obiettivo diretto sia la protezione della sanità pubblica in relazione al tabacco e all'abuso di alcol, ad esclusione di qualsiasi armonizzazione delle disposizioni legislative e regolamentari degli Stati membri.
6. Il Consiglio, su proposta della Commissione, può altresì adottare raccomandazioni per i fini stabiliti dal presente articolo.
7. L'azione dell'Unione rispetta le responsabilità degli Stati membri per la definizione della loro politica sanitaria e per l'organizzazione e la fornitura di servizi sanitari e di assistenza medica. Le responsabilità degli Stati membri includono la gestione dei servizi sanitari e dell'assistenza medica e l'assegnazione delle risorse loro destinate. Le misure di cui al paragrafo 4, lettera a) non pregiudicano le disposizioni nazionali sulla donazione e l'impiego medico di organi e sangue.

TITOLO XIV - SANITÀ PUBBLICA - ART. 168 (EXART.152DEL TCE)

5. Il Parlamento europeo e il Consiglio, deliberando secondo la procedura legislativa ordinaria e previa consultazione del Comitato economico e sociale e del Comitato delle regioni, possono anche adottare **MISURE DI INCENTIVAZIONE** per proteggere e migliorare la salute umana, in particolare per lottare contro i grandi flagelli che si propagano oltre frontiera, misure concernenti la sorveglianza, l'allarme e la lotta contro gravi minacce per la salute a carattere transfrontaliero, e misure il cui obiettivo diretto sia la protezione della sanità pubblica.

EMPLOYMENT, SOCIAL POLICY, HEALTH AND CONSUMER AFFAIRS **OTHER**

"30 years of EU action against cancer" ceremony – Assessment of the successes achieved and debate on future action to be taken

15-09-2015



On the 30th anniversary of the first action taken in the fight against cancer, an official ceremony, entitled "30 years of EU action against cancer" and organised jointly by the European Commission and the Luxembourg Presidency of the Council of the EU, was held in Luxembourg on 15 September 2015. This event, attended by the Minister for Health, **Lydia Mutsch**, and the European Commissioner for Health and Food Safety, **Vytenis Andriukaitis**, provided an opportunity for numerous invited specialists to assess the successes achieved and to debate the future action to be taken within this context.

During a press conference organised ahead of the meeting, Lydia Mutsch pointed out that, since the European Council's decision to launch a programme of community action against cancer in 1985, the fight against this disease had become "a priority for European public health policy". This decision "has added a new dimension to the fight" and created "a stronger link between Europe and the concerns of its citizens", she said.

According to the Minister, the recorded successes in this area show that, even if health remains a national responsibility for each Member State, "it is evident that joint European action can create considerable added value by confronting the major challenges for health in a more efficient way". Regarding this matter, Lydia Mutsch referred specifically to the sharing of information and the exchange of best practices and experience which were sparked by this decision, of which Luxembourg was "a keen supporter". "Common European action and a joint approach can, in effect, help to avoid ineffective action or the duplication of roles. It can also encourage better use of available resources", she added.



© Ministerium für Gesundheit

From left to right: Vytenis Andriukaitis, European Commissioner responsible for Health and Food Safety; and Lydia Mutsch, Minister of Health

The "Europe against Cancer" programme was initiated in 1985 by the European Council of Heads of State and Government, and a Committee of Cancer Experts was set up to advise on this European initiative. In February 1986, the Committee adopted at its first meeting in Paris an opinion describing the main lines of a comprehensive programme. That opinion led to the elaboration by the European Commission of a first 1987-1989 action plan. In December 1989, the Heads of State and Government praised the achievements of this first action plan and expressed their satisfaction on the launch of a second plan for the period 1990-1994.

The objective of the second cancer action plan was to develop information on prevention of cancer and possible methods of early detection and treatment.



European
Commission

EU HEALTH ACTIONS AND PROGRAMMES

AIDS
Prevention &
communicable
diseases

Injuries
prevention

Drug
prevention

Health
Monitoring

Cancer

Rare diseases

Pollution
related
diseases

Health
Promotion,
Information,
Education &
training

1998 - 2002



- Community action in the field of health 2003-2007

EUR 312
million



- 2nd Community action in the field of health 2008-2013

EUR 321,5
million



- 3rd Union action in the field of health 2014-2020

EUR 449,4
million

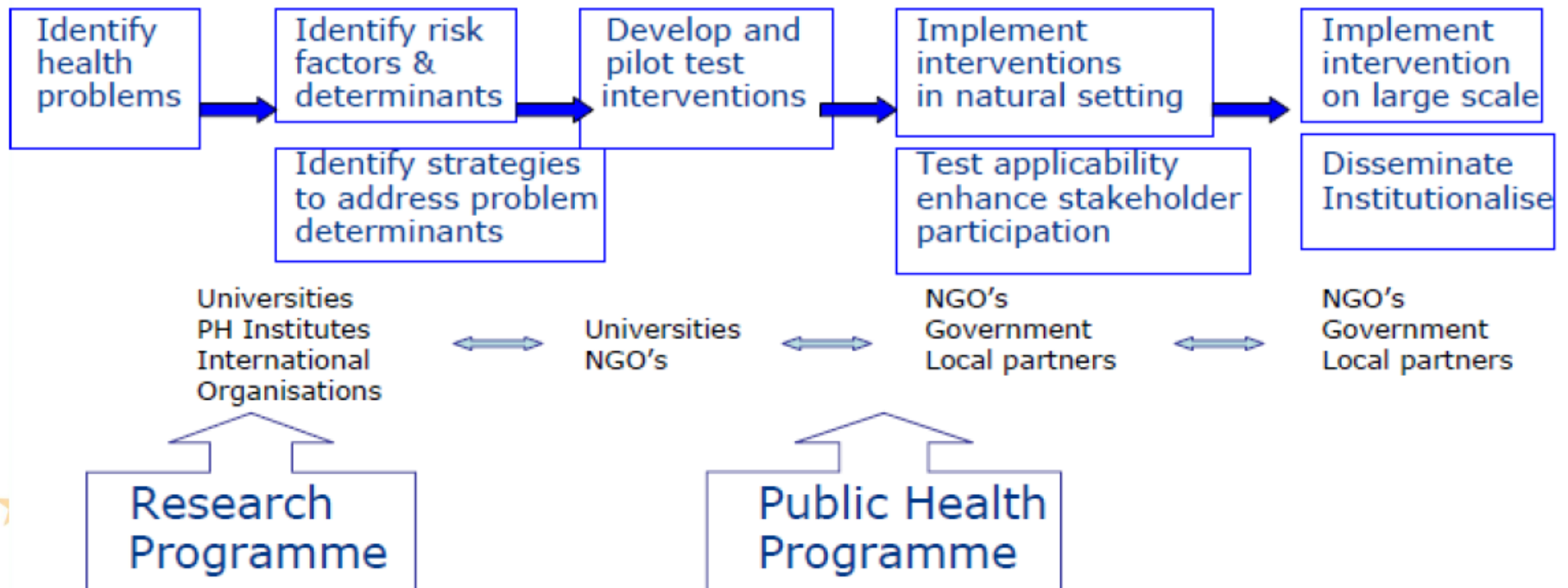
1993-2002	<p>8 different Action Programmes (health promotion, cancer, drug dependence, AIDS and other communicable diseases, health monitoring, rare diseases, accidents and injuries, pollution-related diseases)</p>
2003-2008 € 353,8 Mio.	<p>Community Action Programme for Public Health</p> <ul style="list-style-type: none"> •Health Information •Health Threats •Health Determinants
2008-2013 € 321,5 Mio.	<p>2nd Programme of Community Action in the field of Health</p> <ul style="list-style-type: none"> •Health Security and Safety •Health Promotion and Health Inequality •Health Information
2014-2020 € 449,4 Million	<p>3rd Programme of Community Action in the field of Health</p> <ul style="list-style-type: none"> •Promote health, prevent diseases and foster supportive environments for health lifestyles •Protect citizens from serious cross-border health threats •Facilitate access to better and safer healthcare for Union Citizens •Contribute to innovative, efficient and sustainable Health Systems

Research projects

Development projects

Implementation projects

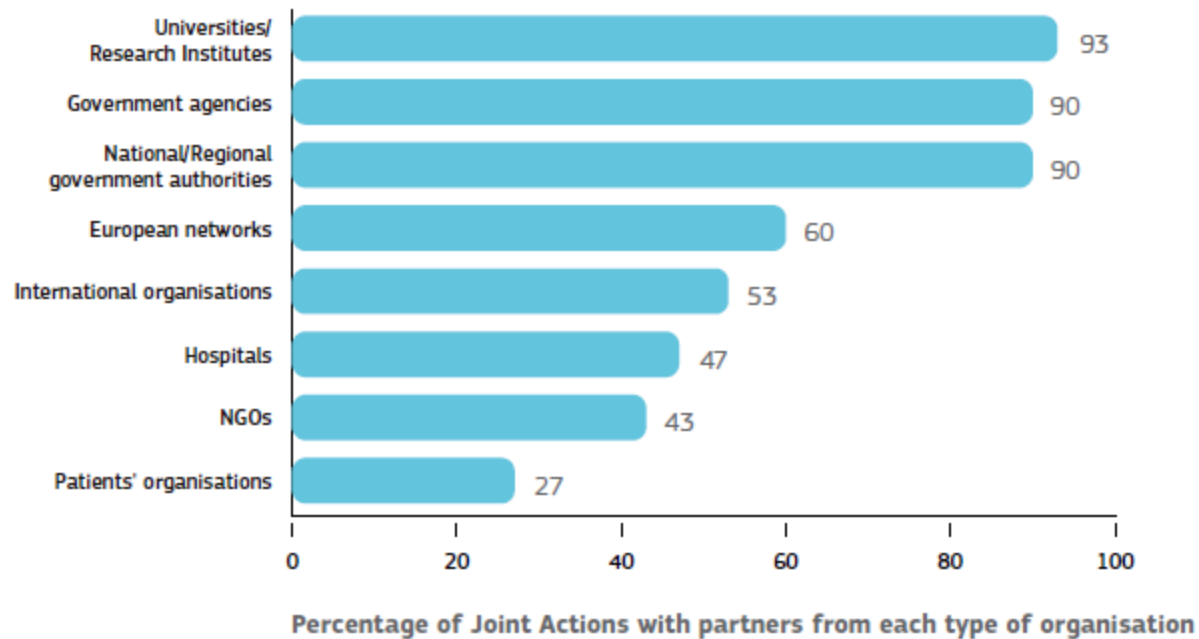
Execution projects



JOINT ACTIONS

- Joint Actions (JAs) are projects intended to develop different policy solutions for EU Member States. Ideally, they should provide general or generic solutions for as many as possible
- They are established between the European Commission and a coordinating institution from one of the member states who assembles a consortium of partners interested in developing the proposed framework.
- Financing is provided both by CHAFEA as well as by the (interested) Member States

Figure 13: Types of organisations participating in Joint Actions 2008-2013 as associated and collaborating partners





- Health Promotion & Prevention
- Screening & Early Diagnosis
- Healthcare
- Cooperation & Coordination In Cancer Research
- Cancer Data And Information
- National Cancer Plans
- Open Forum
- Steering Committee
- Final Deliverables

The European Partnership for Action Against Cancer (EPAAC) was launched in 2009, after the European Commission published its Communication on Action Against Cancer: European Partnership.

The specificity of the Partnership is that it brings together the efforts of different stakeholders into a joint response to prevent and control cancer. In its initial phase, until early 2014, the work of the Partnership will be taken forward through a Joint Action (cofinanced by the EU Health Programme). The National Institute of Public Health in Slovenia has assumed the role of leader of the EPAAC Joint Action, which encompasses 36 associated partners from across Europe and over 100 collaborating partners.

See the [EPAAC GANTT chart](#) with all of the latest updates on project milestones and deliverables!

Latest News

Final EPAAC Deliverables

EPAAC Videos

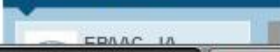
The EPAAC Story: European Collaboration for the Health of Citizens



I'm a Fan of Life Campaign with Olympic Alpine Ski Champion Tina Maze



Latest tweets



CANCON

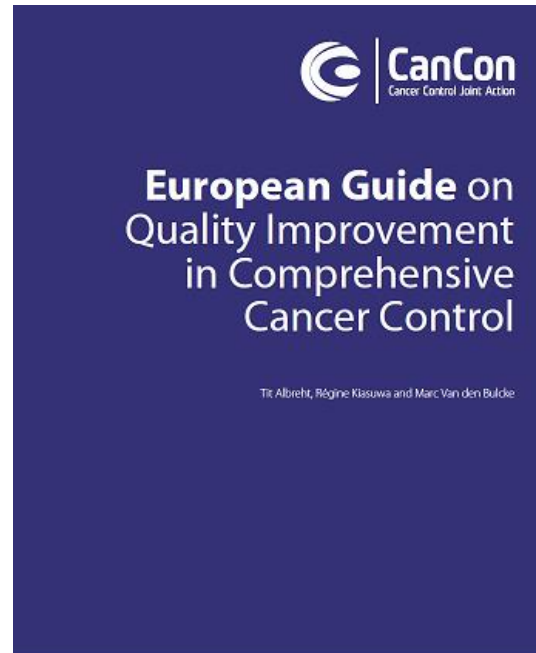
- CANCON is the Joint Action – European Guide on Quality Improvement in Comprehensive Cancer Control
- 3 year duration
- 24 February 2014 – 23 February 2017
- 27 Associated Partners
- Over 100 Collaborating Partners



CanCon
Cancer Control
Joint Action

GENERAL OBJECTIVE

- General Objective of CANCON:



GENERAL OBJECTIVE

The Guide aims to contribute to improvements in overall cancer control through:

- quality based cancer screening programmes,
- better integration of cancer care,
- community-based cancer care approaches,
- providing concerted efforts in all aspects of survivorship, including palliative care

KEY CONCEPTUAL THEMES - CCCNS

- Extensive discussion, elaboration and agreement on the **definition of a CCCN**
- Providing for a **framework for an integration of services** in a Comprehensive Cancer Control Network
- **Successful pilot implementation of a Comprehensive Cancer Care Network** in the Czech Republic
- Exploring the potential in several EU member states (e.g. Italy, Hungary, UK, Germany), though with different triggers and roles of stakeholders

SECOND OBJECTIVE

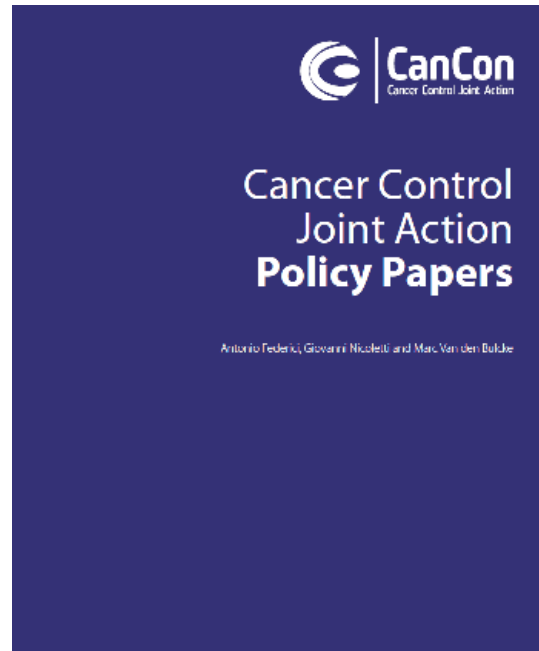
- Member State Platform – discussion of key cancer control topics, delivering policy papers to be used by Member States

MEMBER STATE PLATFORM

- 5 topics selected with core working groups for each, regular Member State Platform meetings (*left – Milan, 9.2014, right- Rome, 11.2015*)



POLICY PAPERS



POLICY PAPERS

Impact Evaluation System to Assess Prevention Outcomes

Common European Objectives for National Cancer Control Plans

Public Health Genomics in Cancer

Enhancing the Value of Cancer Care Through a More Appropriate Use of Healthcare Interventions

Tackling Social Inequalities in Cancer Prevention and Control for the European Population

DELIVERABLES

- Both Guide and Policy Papers are available for download at the official CANCON website.

Download at www.cancercontrol.eu or
request hard copies at cancer.control@nijz.si

Innovative partnership for action against cancer (iPAAC)

General objectives

To develop innovative approaches to advances in cancer control with further developments in:

- *cancer prevention,*
- *use of genomics in cancer control*
- *cancer information and registries*
- *improvements and challenges in cancer care*
- *mapping of innovative cancer treatments*
- *governance of integrated cancer control, including a new analysis of National Cancer Control Plans (NCCPs)*

Innovative partnership for action against cancer (iPAAC)

Main Deliverable

Roadmap on Implementation and Sustainability of Cancer Control Actions, to support MS in implementation of iPAAC and CANCON recommendations

The Roadmap will act as the central pillar of the JA, integrating the diverse topic areas, providing synergies between the topics, ensuring consideration of transversal issues for all topics and acting as the central comprehensive deliverable, integrating all the JA outputs. A variety of methods will be used to fulfill the general and specific objectives including pilot studies, working groups, expert panels, literature review and surveys.

A governmental board will be in place to ensure that implementation and sustainability in national contexts are duly considered for each topic area.

Innovative partnership for action against cancer (iPAAC)

WP1 Coordination - NIJZ (SLO)

WP2 Dissemination - UZIS (CZR)

WP3 Evaluation CIPH (CRO)

WP4 Integration in National Policies and Sustainability WIV-ISP (BEL)

WP5 Cancer Prevention – THL (FIN)

WP6 Genomics in Cancer Control and Care WIV-ISP (BEL)

WP7 Cancer Information and Registries ISS (ITA)

WP8 Challenges in Cancer Care ICO (SPA)

WP9 Innovative Therapies in Cancer - INCA (FRA)

WP10 Governance tegrated/Comprehensive Cancer Care BMG (GER)

<http://jointactionrarecancers.eu/>

jointactionrarecancers.eu



goog



1.

Improving epidemiological surveillance of rare cancers in the EU

2.

Identifying standards of care for all families of rare cancers to ensure sharing of best practices and equality of care for rare cancers across Europe, particularly through clinical networking

3.

Improving the implementation at local level and within ERNs of clinical practice guidelines on rare cancers

4.

Promoting integration of translational research innovations into rare cancer care

5.

Improving education on rare cancers for medical and non medical experts to ameliorate management of rare cancers and to improve rare cancer patients' empowerment in the EU

6.

Identifying core strategies to incorporate in National cancer plans and Rare disease plans to address the specific needs of rare cancers across EU MSs



Anno 2017: 49 IRCCS

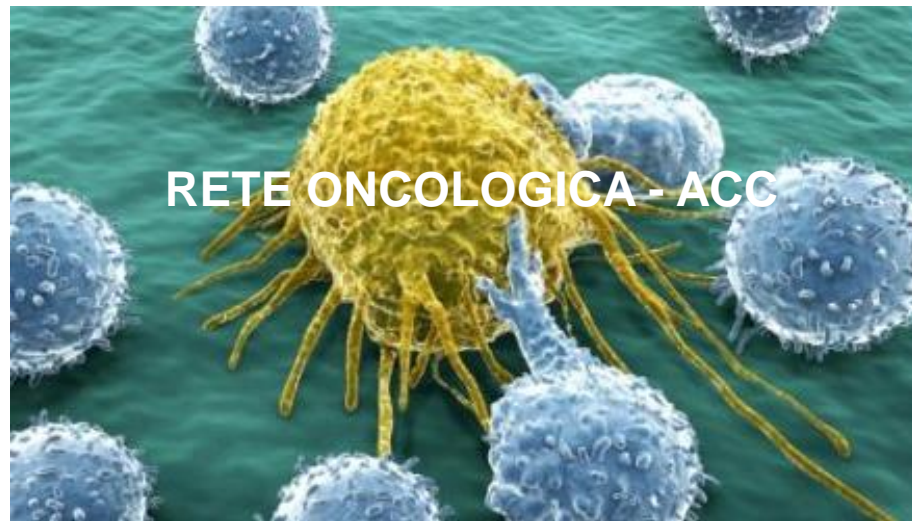
IRCCS N° RICERCATORI	10.172
IRCCS - N° Pubblicazioni Scientifiche (*)	11.857 + 583 pubblicazioni
IRCCS – Totale IF Normalizzato (*)	50.984 +3.187 (6,55%)
IRCCS – N° Ricoveri Anni	710.312



- Dermatologia
- Neurologia e Psichiatria
- Politematici
- Gastroenterologia
- Oncologia
- Riabilitazione neuromotoria e malattie professionali
- Geriatria
- Ortopedi
- Patologie cardiovascolari
- Malattie genetiche ed eredo-familiari
- Pediatria
- Malattie infettive



RETE NEUROSCIENZE



RETE ONCOLOGICA - ACC



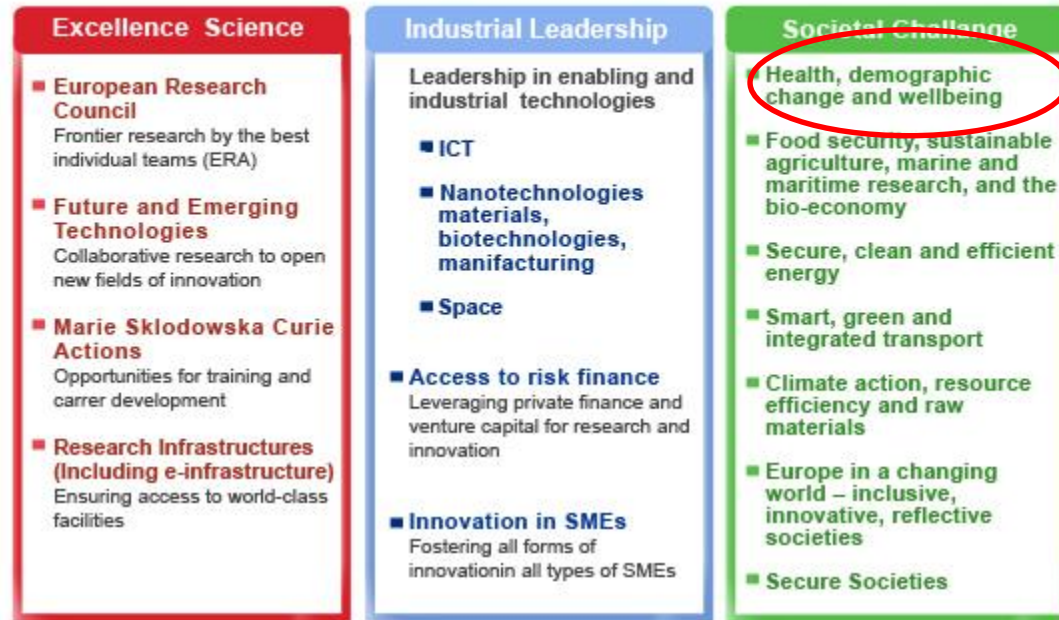
RETE CARDIOVASCOLARE

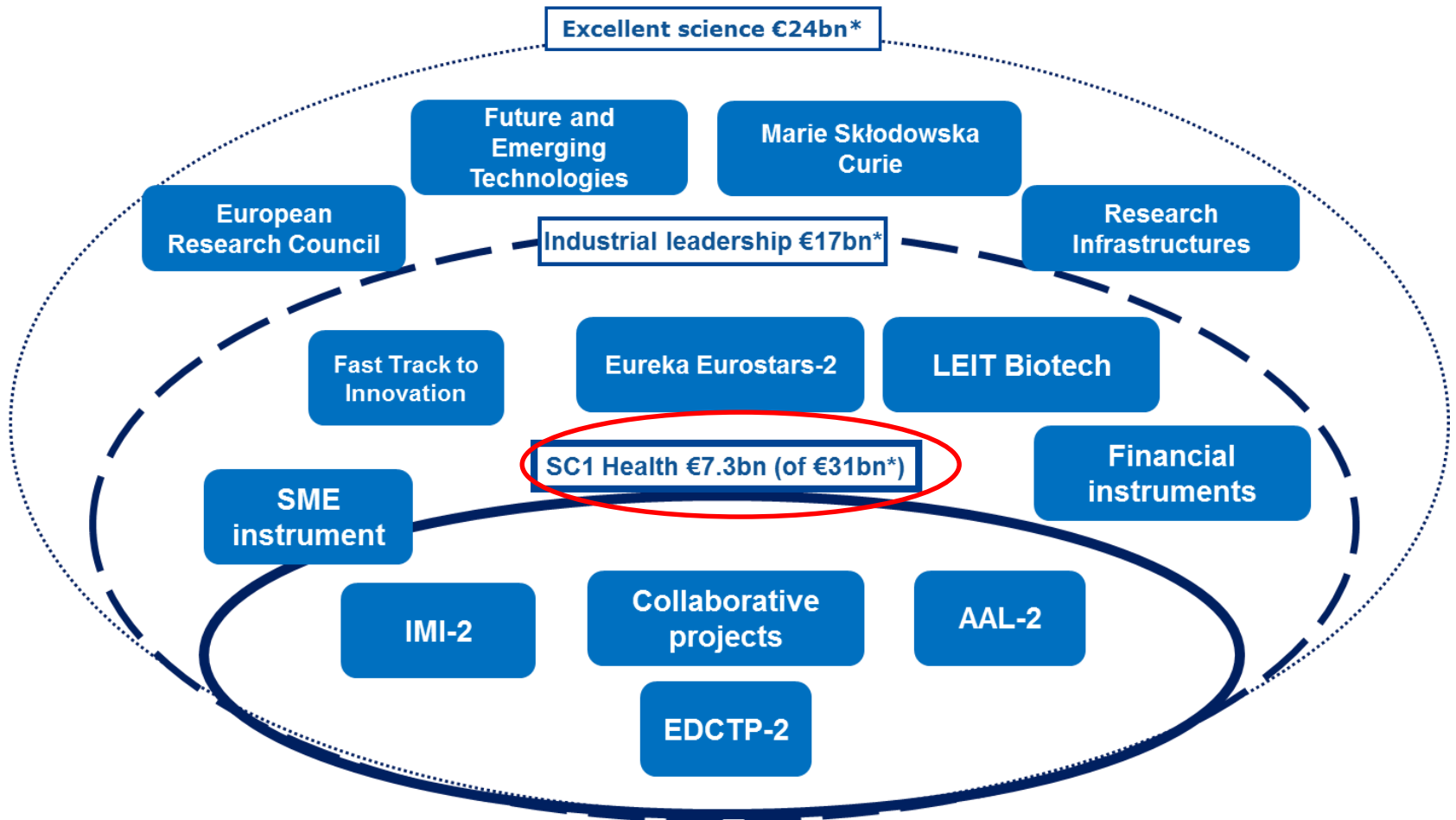


RETE AGING

RETE SALUTE DELL'ETÀ EVOLUTA

Horizon 2020: tre Pilastrì e cinque Programmi trasversali





* Figure to be updated following EFSI investments in 2016-2017 and FP7 recovery in 2016



ERA-NET Cofund

Combinare gli impegni nazionali nella ricerca al fine di utilizzare al meglio le preziose risorse pubbliche di ricerca e sviluppo (R&S) dell'Europa

- **ERA-NET Cofund**

strumento disegnato per sostenere gli Stati Membri e Associati nella preparazione di partenariati pubblico-privati, nella costituzione di reti e nel disegno, implementazione e coordinamento di attività congiunte comprendenti un bando di ricerca trans-nazionale co-finanziato dalla Unione europea (cofunded call).

L'obiettivo delle ERA-NET è di contribuire a migliorare la sinergia tra i programmi nazionali di ricerca degli Stati Membri e Associati ed il programma Quadro. In particolare le ERA-NET consentono la creazione di network di soggetti pubblici nazionali a geometria variabile che attuano programmi di R&S in determinate aree tematiche attraverso il lancio di bandi congiunti o comuni inviti a presentare proposte

COLLABORATIVE PROJECTS che vedono impegnato il Ministero della salute

Tema 'Neuro'	ERA-Net JPco-fuND (Joint Programming on Neurodegenerative Disease (JPND)) ERANet NEURON
Tema 'Cardio'	ERA-Net on CardioVascular Disease (ERA-CVD)
Tema 'Malattie infettive'	Joint Programming Initiative on AntiMicrobial Resistance (JPI AMR) III
	ERA-Net Infect-ERA
Tema 'Malattie Rare'	ERA-Net E-Rare 3 EJP-Cofund on rare diseases research
Tema 'Paesi Latino-Americani'	ERA-Net for Latin American and Caribbean States (ERANet-LAC) II
Tema 'Technology and nanomedicine'	ERA-Net EURONANOMED 3
'System Medicine'	ERA-Net on Collaboration on System Medicine (ERA-CoSysMed)
Tema 'Healthy Aging – invecchiamento'	Active and Assisted Living (AAL-2)
Tema 'Oncologia'	ERA-Net TRANSCAN-2
Tema 'sociale': parità di genere e dell'integrazione di genere in R&I	GENDER NET-Plus
'Personalized Medicine'	IC PERMED (CSA) ERANET PerMed
Tema 'Bio-monitoraggio'	Human Bio Monitoring 4 (HBM4EU)
Tema 'Clinical Trial'	ERA-Net on CLINICAL TRIALS & TRANSLATIONAL RESEARCH
Tema 'Servizi e Sistemi sanitari'	Joint Research Unit "TO REACH"
Tema 'emergenza in salute pubblica'	GLOPID

<http://www.transcanfp7.eu/>



The image shows a browser window displaying the homepage of the Transcan-2 website. The browser's address bar shows the URL www.transcanfp7.eu. The website's navigation menu includes links for HOME, NEWS, ABOUT, CALLS, FOR RESEARCHERS, and PUBLICATIONS. The main banner features the Transcan-2 logo, which consists of a blue wave with yellow stars, and the text "TRANSCAN-2 ERA-NET: Aligning national/regional translational cancer research programmes and activities". Below the banner, the heading "Welcome to TRANSCAN-2" is displayed, followed by a date stamp "Pages 13 July 2016 Hits: 6298". The main content area contains a paragraph describing the project: "The ERA-NET: Aligning national/regional translational cancer research programmes and activities - TRANSCAN-2 is a five-year project (2015-2019) funded by the European Commission under the EU framework programme Horizon2020 (Grant Agreement no. 643638). It is the continuation of the previous ERA-NET on translational cancer research TRANSCAN, funded under the FP7 from 2011 to 2014." On the right side of the page, there is a "Reserved Area" button and a "TRANSCAN-2 News" section with a "CLOSED CALL" announcement for the "Fourth Joint Transnational Call 2017 (JTC 2017)".

Transcan-2

HOME NEWS ABOUT CALLS FOR RESEARCHERS PUBLICATIONS

TRANSCAN-2

ERA-NET: Aligning national/regional translational cancer research programmes and activities

TRANSCAN-2

Welcome to TRANSCAN-2

Pages 13 July 2016 Hits: 6298

The **ERA-NET: Aligning national/regional translational cancer research programmes and activities - TRANSCAN-2** is a five-year project (2015-2019) funded by the European Commission under the EU framework programme **Horizon2020 (Grant Agreement no. 643638)**.

It is the continuation of the previous ERA-NET on translational cancer research TRANSCAN, funded under the FP7 from 2011 to 2014.

Reserved Area

TRANSCAN-2 News

CLOSED CALL

Fourth Joint Transnational Call 2017 (JTC 2017)

What are ERNs?

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources.

Need for a coherent strategy – from bench to bedside



- More efficiently bring the results of research and innovation to the patient
- Programme to implement a research and innovation pipeline, from bench to bedside
- Integrative programme linking major EU and national initiatives – R&D, research infrastructures, registries
- **Bridging** to ERNs to help implementing research results and taking lessons learned from the clinic back to the bench

ERN on adult cancers (solid tumours) (ERN EURACAN)



More than **300 rare cancers** have been identified. ERN EURACAN covers all rare adult solid tumour cancers, grouping them into 10 domains corresponding to the RARECARE classification and ICD10. The management of rare cancers poses significant diagnostic challenges, sometimes with major consequences for patients' quality of life and outcome. Inappropriate management of these patients may also result in an increased risk of relapse, and risk of death.



The network aims to reach all EU countries within 5 years and develop a referral system to ensure at least 75% of patients are treated in a EURACAN centre.

ERN EURACAN is sharing best practice tools and establishing reference centres for rare cancers. It is also establishing regularly updated diagnostic and therapeutic clinical practice guidelines. The network aims to reach all EU countries within 5 years and develop a referral system to ensure at least 75% of patients are treated in a EURACAN centre. It seeks to improve patient survival, produce communication tools in all languages for patients and physicians, and develop multinational databases and tumour banks.

The ERN builds on pre-existing clinical and research networks that have successfully conducted clinical trials through the European Organisation for Research and Treatment of Cancer (EORTC), and established guidelines through EORTC and the European Society for Medical Oncology (ESMO). It also benefits from the work of networks formed by the European Neuroendocrine Tumour Society (ENETS) and Connective Tissues Cancer Network (ConTicaneT), as well as several EU research projects.

NETWORK COORDINATOR

Professor Jean-Yves Blay
Centre Léon Bérard, Lyon, France

ERN on haematological diseases (EuroBloodNet)



Haematological diseases involve abnormalities of blood and bone marrow cells, lymphoid organs and coagulation factors, and almost all of them are rare. They can be subdivided into six categories: rare red blood cell defects; bone marrow failure; rare coagulation disorders; haemochromatosis and other rare genetic disorders of iron synthesis; myeloid malignancies; and lymphoid malignancies.

Diagnosis of rare haematological diseases (RHDs) requires considerable clinical expertise and access to a broad range of laboratory services and imaging technologies. These tests allow precise disease classification according to WHO criteria using international scoring systems and, where possible, biomarkers.

Given these requirements and the fact that some RHDs are very rare, diagnosis is frequently overlooked or delayed, especially in elderly patients. Treatment is also often difficult due to the specialised infrastructures and teams required and the difficulty accessing specific treatments such as allogenic stem cell transplantation or coagulation factors.

Preventive programmes are in place in some countries for certain conditions, but there is an urgent need for harmonisation in the field of screening.

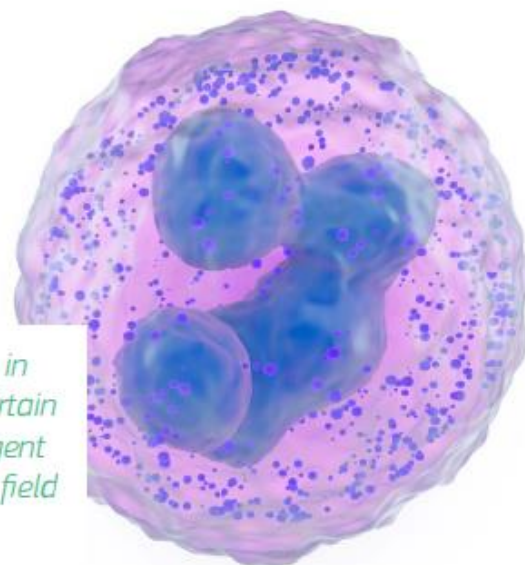
Preventive programmes are in place in some countries for certain conditions, but there is an urgent need for harmonisation in the field of screening.

EuroBloodNet, with the experience gained thanks to the EU-funded European Network for Rare and Congenital Anaemias (ENERCA) and the European Haematology Association (EHA), will seek: to improve access to healthcare for RHD patients; to promote guidelines and best practice; to improve training and knowledge-sharing; to offer clinical advice where

national expertise is scarce; and to increase the number of clinical trials in the field.

NETWORK COORDINATOR

Professor Pierre Fenaux
*Assistance Publique-Hôpitaux de Paris,
Hôpital Saint-Louis, France*



ERN on paediatric cancer (haemato-oncology) (ERN PaedCan)



Paediatric cancer is rare and comes in multiple subtypes. With 20 000 children newly diagnosed with cancer across Europe and 6 000 paediatric cancer patients dying each year, it remains the leading cause of death from disease for children older than 1 year of age.

Average survival rates have improved in recent decades; for some conditions the progress has been dramatic, while for others the outcomes remain very poor.

Significant inequalities in survival rates are also a challenge in Europe, with worse outcomes in Eastern Europe.

ERN PaedCan is working to improve access to high-quality healthcare for children with cancer whose conditions require specialist expertise and tools not widely available due to low case volumes and a lack of resources. It builds on previous EU-funded projects ENCCA, PanCare and ExPO-r-Net. ERN PaedCan is building a roadmap of specialist centres to



*A paediatric oncology
tumour board network will be
implemented using IT tools to
share expertise and advice.*

help improve their visibility to healthcare providers and patients. A paediatric oncology tumour board network will be implemented using IT tools to share expertise and advice.

The network aims to increase childhood cancer survival and quality of life by fostering cooperation, research and training, with the ultimate goal of reducing current inequalities in childhood cancer survival and healthcare capabilities in EU Member States.

NETWORK COORDINATOR

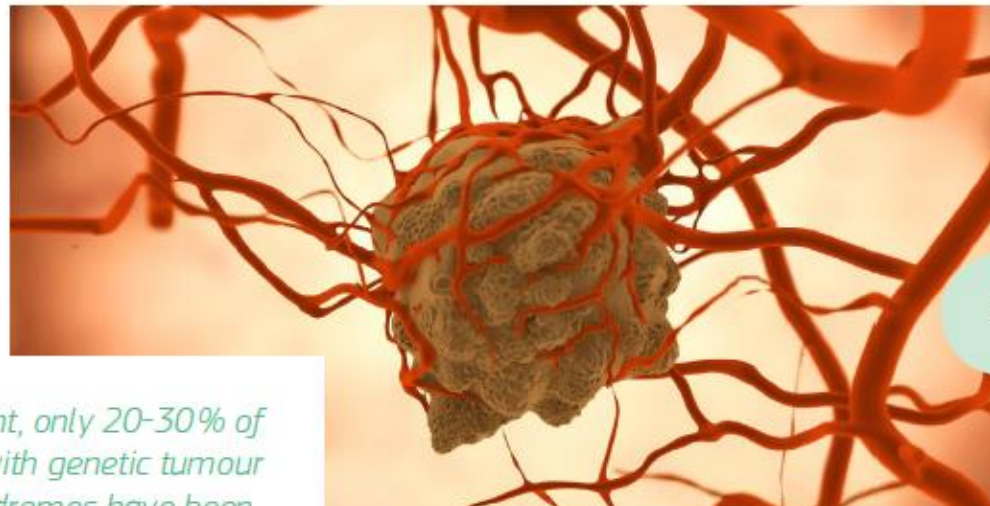
Professor Ruth Ladenstein
St. Anna Kinderspital & St. Anna
Kinderkrebsforschung, Austria

ERN on genetic tumour risk syndromes (ERN GENTURIS)



Genetic tumour risk syndromes are disorders in which inherited genetic mutations strongly predispose individuals to the development of tumours. The lifetime risk of cancer can be as high as 100%. While there is considerable diversity in the organ systems that may be affected, individuals affected by these conditions share similar challenges: delay in diagnosis, lack of prevention for patients and healthy relatives, and therapeutic mismanagement. At present, only 20-30% of people with genetic tumour risk syndromes have been diagnosed.

ERN GENTURIS is working to improve identification of these syndromes, minimise variation in clinical outcomes, design and implement guidelines, develop registries and biobanks, support research, and empower patients. The network will educate the public and healthcare professionals, and foster the sharing of best practice across Europe. Access to multidisciplinary care will be improved, with new models and standards for sharing and discussing complex cases. The network is enhancing the quality and interpretation of genetic testing,



At present, only 20-30% of people with genetic tumour risk syndromes have been diagnosed.

and increasing patient participation in clinical research programmes.

ERN GENTURIS will cooperate with other ERNs to improve the care of patients with genetic tumour risk syndromes who develop conditions that fall within the expertise of another network.

NETWORK COORDINATOR

Prof. Nicoline Hoogerbrugge
Radboud University Medical
Center Nijmegen, The Netherlands

<https://webgate.ec.europa.eu/hpf/>

Legal Notice

Support/Help

Login

English (en)



European
Commission

EU Health Policy Platform

A discussion platform on health issues

Home

About us

IT Platform

Face-to-face meetings

About you



Health-EU Newsletter: "National Contact Points geared up to answer cross-border healthcare questions"

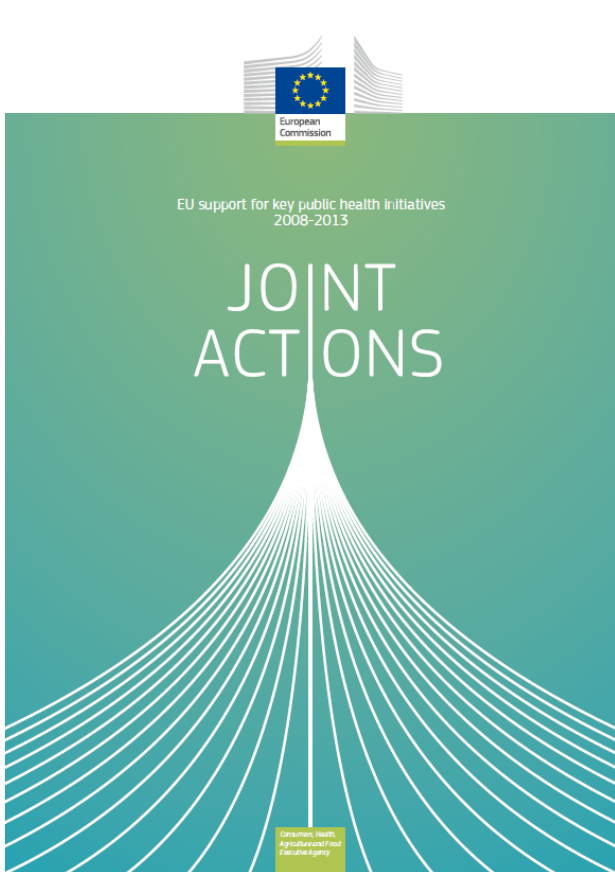
Editorial by by Xavier Prats Monné
Director-General of DG Health and Food
Safety European Commission

[http://ec.europa.eu/health/newsletter/165/
newsletter_en.htm](http://ec.europa.eu/health/newsletter/165/newsletter_en.htm)





European
Commission



http://ec.europa.eu/chafea/documents/health/leaflet/chafea-joint-action-2015_en.pdf

Consumers,
Health And Food
Executive Agency

GRAZIE PER L'ATTENZIONE