The new EU Agenda on Cancer and the role of the European Reference Network EURACAN

J-Y Blay
EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.

EURACAN
Rare Adult Solid Cancers

G1 Sarcoma
G2 Rare GYN
G3 GU
G4 NET
G5 Digestive tract
G6 Endocrine
G7 Head & neck
G8 Thoracic
G9 Skin & soft tissue melanoma

Co-funded by the EU
CONQUERING CANCER: MISSION POSSIBLE
Interim report of the Mission Board for Cancer

Mission on Cancer:
By 2030, more than 3 million lives saved, living longer and better

Prevent what is preventable
Optimise diagnostics and treatment
Support quality of life

Ensure equitable access

Understand
By 2030, more than 3 million lives saved, living longer and better

Understand cancer

Prevent the preventable

Optimise diagnostics and treatment

Support quality of life

Ensure equitable access

Support EU-wide network of Comprehensive Cancer Infrastructures

Policy support: Cancer Health Equity

Capacity building: European Cancer Patient Digital Centre

Support Action: Transform cancer culture

Capacity building to accelerate innovation and use of new technology

R&I: UNCAN research infrastructure for large scale studies

R&I: Identify cancer risk factors

R&I: paediatric cancers

R&I: early diagnostics + minimally invasive treatments

R&I to enhance personalised medicine

R&I + policy support to improve cancer prevention

R&I + policy support to improve quality of life

R&I: transform cancer culture

Support Action: Transform cancer culture

Figure 2. Relationships between Mission’s goal, areas of action and recommended actions
Recommendation 10: Set up a network of Comprehensive Cancer Infrastructures within and across all EU Member States to increase quality of research and care
Connective tissue
Female genital organs and placenta
Male genital organs, and of the urinary tract
Neuroendocrine system
Digestive tract
Endocrine organs
Head and neck
Thorax
Skin and eye melanoma
Brain, spinal cords
2017
- 66 full members across 17 Member states

2020
- 9 APS across 7 Member States

2021
- 42 new members

Geographical spreading of the Consortium all over Europe.

AUSTRIA (Graz)
BELGIUM (Antwerp, Brussels, Leuven, Liège)
CROATIA (Zagreb, Sestre)
CZECH REPUBLIC (Brno, Prague,)
DENMARK (Aarhus)
ESTONIA (Tallinn, Tartu)
FINLAND (Turku)
FRANCE (Lyon, Paris, Villejuif)
GERMANY (Berlin, Essen, Mannheim, Hamburg-Eppendorf, Marburg, Würzburg)
HUNGARY (Budapest)
ITALY (Aviano, Bologna, Candidoli, Firenze, Genoa, Melodia, Milan, Naples, Roma, Siena, Torino, Treviso)
LATVIA (Riga)
LITHUANIA (Kaunas)
LUXEMBOURG (Luxembourg)
NETHERLANDS (Amsterdam, Leiden, Maastricht, Nijmegen, Rotterdam, Groningen)
MALTA (Mater Dei)
NORWAY (Oslo)
POLAND (Warsaw)
PORTUGAL (Coimbra, Lisboa, Porto)
SWEDEN (Karolinska, Uppsala)
SPAIN (Barcelona, Sevilla)
SLOVENIA (Ljubljana)
UNITED KINGDOM (Coventry, London, Oxford, Sheffield)

Designed by Yohan Fayet (Centre Léon Bérard, Lyon, France)
ASSOCIATE PARTNERS
**AFFILIATED PARTNERS**

**Associated National Centres approved**

**Austria**
- Centre for bone and soft tissue tumors – Graz

**Croatia**
- University Hospital centre - Zagreb
- Sestre University Hospital centre - Zagreb

**Cyprus**
- Bank of Cyprus oncology centre in collaboration with the Karaiskakio Foundation

**Estonia**
- North Estonia Medical Centre
- University Hospital - Taru

**Latvia**
- East clinical University Hospital - Riga

**National Coordination hub approved**

**Luxembourg**
- Hospital Centre

**Malta**
- Mater dei Hospital -
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Recommendation 1: Launch UNCAN.eu – a European Initiative to Understand Cancer

Despite tremendous progress in deciphering the genetic and biological basis of cancer, our understanding of the molecular processes at the cancer cell level and the interactions of the tumour and its host is still very limited. This holds in particular for cancers for which understanding is lacking and rare cancers. The potential for increasing our understanding in this area is demonstrated by the significant benefit obtained through targeted therapies and host immune activation against some tumours. Recent technological developments and European collaborations provide an excellent opportunity for realising this potential through obtaining a comprehensive and dynamic view of how certain cancers initiate, develop and spread in the context of the host.

This requires a new level of investment in innovative research, including high-potential/high-risk projects. Therefore, the Mission Board proposes a Europe-wide platform, UNCAN.eu, utilising relevant research infrastructure and investing in the development of new models and technologies interrogating the interactions of cancers and their host. UNCAN.eu would encompass relevant stakeholders and enable integration of innovative models and technologies with longitudinal patient data, samples and biomarkers for identification and translation to patients. UNCAN.eu would provide breakthroughs in understanding how cancers initiate, develop and spread in the context of the host and thereby provide a basis for saving millions of European citizens’ lives in synergy with actions related to recommendations 2-6 and 11-12 of this Draft Mission outline as well as actions related to the Europe’s Beating Cancer Plan and other EU Research and Innovation Missions (see Annex I).
Mutational landscape and significance across 12 major cancer types

TP53 loss creates therapeutic vulnerability in colorectal cancer

Comprehensive genomic characterizes human glioblastoma genes and core pathways

Comprehensive molecular characterization of gastric adenocarcinoma
## Ordered incidences of sarcomas and connective tissue tumors in NETSARC & published clinical trials

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<tr>
<td>Undifferentiated sarcoma</td>
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<tr>
<td>Trichoblastic fibrosarcoma</td>
<td>40</td>
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<tr>
<td>Liposarcoma</td>
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<tr>
<td>Undifferentiated sarcoma</td>
<td>40</td>
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<tr>
<td>Trichoblastic fibrosarcoma</td>
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<tr>
<td>Liposarcoma</td>
<td>40</td>
<td>0,400</td>
<td>0,400</td>
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<td></td>
</tr>
</tbody>
</table>
Recommendation 2: Develop an EU-wide research programme to identify (poly-)genic risk scores

This action aims to assess the individual cancer risk with refined algorithms based on newly identified polygenic risk scores (PRS). Based on an increased understanding of individual cancer risks, education activities and counselling could be improved.

Recommendation 3: Support the development and implementation of effective cancer prevention strategies and policies within Member States and the EU

Preventing cancers calls for effective policy underpinned by excellent research. The Mission Board proposes to establish a research programme to identify effective cancer prevention strategies and methods to provide up-to-date knowledge to EU institutions and countries for designing and implementing effective cancer prevention measures at EU- and national level, tailored to local needs and conditions. Initial areas of research would focus on alcohol, food and sugar sweetened beverages and tobacco consumption, as well as commercial determinants of health. These would be supplemented with research on exposures to workplace carcinogens, including emerging causes of cancer, air pollution, interactions of behavioural risk factors and comorbidities, as well as prevention strategies along the entire cancer continuum.
Prevention and understanding aetiology

• Not our first mission

• But an opportunity to do that on rare cancers through registries and biological studies

• Support from EJP RD needed!
Recommendation 4: Optimise existing screening programmes and develop novel approaches for screening and early detection

Recommendation 6: Develop an EU-wide research programme on early diagnostic and minimally invasive treatment technologies
EURACAN General Assembly
Board of all HCP full members and associate/affiliated partners

Decisions for key questions

Steering Committee
EURACAN Coordinator
domain leaders
1 representative per country not already represented
Task force leaders
Patient Advocacy representatives

Scientific Advisory Group
6 independant Experts
Outside/inside EU
Rare/Frequent cancers/diseases

Decisions for daily management

Domains (Clinical action)

- G1 Sarcoma
- G2 Rare GYN
- G3 Rare GU
- G4 NET
- G5 Rare GI
- G6 Endocrine
- G7 Rare H&N
- G8 Rare Thoracic
- G9 Rare Skin
- G10 Rare Brain

Transversal Task forces

- Guidelines
- Research
- Training/Education
- Funding/sustainability plan
- Communication with PAGs
- Dissemination
- Quality Control
- Diagnosis

EURACAN Governance June 2020
Sarcomas, in collaboration with the ESMO, development of the ESMO-EURACAN guidelines: Gastrointestinal stromal tumours, Soft tissue and visceral sarcomas

ESMO-PaedCan-EURACAN Bone Sarcomas guidelines

Medulloblastomas: in collaboration with EANO, development of clinical practice guidelines for diagnosis, treatment, and follow-up of post-pubertal and adult patients with medulloblastoma.

Pleural Mesotheliomas: EURACAN/IASLC Proposals for Updating the Histologic Classification of: Towards a More Multidisciplinary Approach

Peritoneal malignancies: in collaboration with PSOGI & RENAPE development of guidelines on pseudomyxomas & peritoneal mesotheliomas

In collaboration with the ESMO development of the following ESMO EURACAN guidelines are on-going: Mesothelioma; Penile cancer; Biliary cancer; Testicular cancer; Eye melanoma, Merkel Cell carcinoma.
Introduction

Those ESMO-EURACAN Clinical Practice Guidelines cover STTs (Soft Tissue sarcomas).

In general, the same principles apply to children and adults for those tumors.

- Multidisciplinary approach by sarcoma expert in a Multi-disciplinary Team is mandatory in all cases.
- Management of STTs should be carried out in reference centers for sarcomas and/or within reference networks.

see page on reference networks and centres

Referral of all patients with a lesion suspected to be a sarcoma would be recommended.
Domains also work on developing patient brochures on their respective diseases to be disseminated in centres across Europe.

- **Endocrine tumours**
  - Refractory thyroïd
  - Adrenal cancers

- **Gynae tumours:**
  - Ovarian Sex Cord-Stromal Tumours (oSCST)
  - Gestational Trophoblastic Disease
  - Malignant ovarian Germ Cell tumors
  - Granulosa tumour
  - Rare Cervical cancers

- **Digestive tract**
  - Biliary tract
  - Peritoneal
  - Anal cancers

These brochures will be translated using both the e translation tool and a review will be performed by each member state in its own language.
In the framework of EURACAN and the JARC, ESO implemented new e-sessions on Rare Adult Solid Cancers on an annual basis with the ultimate goal to strengthen the educational coverage of a group of cancers which may be neglected in spite of their collective incidence.

The European school of Oncology in collaboration with the University of Milan, has also launched a series of **Post-graduate Courses** for an international audience of clinical oncologists interested in advancing their knowledge and skills on rare adult solid cancers.

*University post-graduate course - clinical oncology*

The video-recorded lessons of these two courses are available on the e-learning website [www.eso.net](http://www.eso.net)

**Preceptorships:** clinical update on Rare Adult Solid Cancers

**e-learning sessions (live)**

The recorded sessions are available on [www.e-eso.net](http://www.e-eso.net)
Recommendation 9: Achieve Cancer Health Equity in the EU across the continuum of the disease
Histological discordances

Histological reviews registered in 2010: 14% of major discordances (341 cases)
Cost of the treatments assessed for the initial diagnosis: €2,186,816 vs. final diagnosis: €1,060,174
Histological reviews/molecular biology result in a cost saving of more than €1,000,000

Lionel Perrier, ISPOR 19th, Canada, June 2014
LRFS & OS: incident patient population

Operated
- In NETSARC, N=9910 (38.5%)
- Outside NETSARC or no data, N=15901 (61.5%)
The Clinical Patient Management System (CPMS) is the secure web-based application provided by the EC to support ERNs in the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders. https://cpms.ern-net.eu/login/

Physicians can ask for their patient case to be reviewed by expert registered on the platform either by organizing ‘virtual’ advisory boards of medical specialists across different disciplines or by uploading patient clinical data, images or virtual slides to get a second opinion on a management or review of a diagnosis.

The goal is to have clinical and biological patient data to travel and not patients.
The CPMS/ERNs are not accessible directly to patient, however, with a patient's consent and in accordance with the rules of their national health system, a patient's information can be uploaded on the platform and referred to the relevant ERN member by their healthcare provider.

- Physicians from ERNs
- Physicians from outside the network, from the EU/EEA can also access the CPMS as guests
EURACAN CPMS ACCESS PROCEDURE  Http://137.74.172.63/euracan/decisiontree/home

Guide to the CPMS

Are you a healthcare professional*?  

Yes  No

*A healthcare professional is, according to the Article 3(f) of Directive 2011/24/EU on the application of patients’ rights in cross-border healthcare: “a doctor of medicine, a nurse responsible for general care, a dental practitioner, a midwife or a pharmacist within the meaning of Directive 2005/36/EC, or another professional exercising activities in the healthcare sector which are restricted to a regulated profession, as defined in Article 3(b)(a) of Directive 2005/36/EC, or a person considered to be a health professional according to the legislation in the Member State of treatment.”
You are a healthcare professional

Let's see if there is a national network covering the disease you are concerned about in your country.

Please choose the country you are working in:

Austria  France  Malta  Sweden
Belgium  Germany  Netherlands  United Kingdom
Bulgaria  Greece  Norway  Another country
Croatia  Hungary  Poland
Cyprus  Ireland  Portugal
Czech Republic  Italy  Romania
Denmark  Latvia  Slovak Republic
Estonia  Lithuania  Slovenia
Finland  Luxembourg  Spain
You are working in France

Please choose the rare cancer you are concerned about.

- Sarcoma
- Male genital organs and urinary tract
- Digestive tract
- Head and neck
- Skin and eye melanoma
- Female genital organs and placenta
- Neuroendocrine system
- Endocrine
- Thorax
- Brain and spinal cord
Rare cancer of connective tissue

Please contact the following network for the management of your patient.

NetSarc+

NetSarc is the French clinical reference network for soft tissue and visceral sarcomas, implemented in 2010 and approved by the INCa in 2019 (28 centers).

https://expertisesarcome.org/centres-experts-par-region/

CLCC Léon Bérard 28 rue Laennec
69373 LYON CEDEX 8 France

Jean-Yves BLAY (Coordinator)
+33478782757
STATER (3 YEARS)

EURACAN REGISTRY
(WILL STAY… )
EURACAN Registry tumours included

1. Pediatric cancers
2. Haematologic rare neoplasms
3. Sarcomas
4. Rare thoracic cancers
5. Neuroendocrine tumours
6. Head & neck cancers
7. Central nervous system tumours
8. Rare female genital cancers
9. Rare urological and male genital tumours
10. Endocrine gland tumours
11. Digestive rare cancers
12. Rare skin cancers & non-cutaneous melanoma
EURACAN Registry health care providers involved

Open to Not EURACAN health care providers
• Develop the IT infrastructure
• Define the rare cancer family in major need of a registry
• Discuss the objectives of the registry per each rare cancer family
• Address legal and ethical issues for data collection and data sharing
• Develop the EURACAN registry governance
EURACAN REGISTRY

Federated model
EURACAN registry
Federated Learning Analysis
Recommendation 5: Advance and implement personalised medicine approaches for all cancer patients in Europe

Personalised medicine offers the promise of maximally effective therapies with minimal harm, both for patients and society. While considerable efforts are being made (e.g. ERA PerMed\textsuperscript{31}, ICPeMed\textsuperscript{32}), many cancer patients still do not benefit from personalised medicine approaches. This recommendation aims to advance, scale, implement and optimise current personalised medicine approaches for cancer, deepening our understanding of cancer complexity, i.e. the role of the host, the impact of the outer environment on cancer initiation, and the evolution of cancer over time, to increase the number of patients for whom effective personalised approaches can be found.

As increased precision in cancer management will rely on large datasets for
**Recommendation 7:** Develop an EU-wide research programme and policy support to improve the quality of life of cancer patients and survivors, family members and carers, and all persons with an increased risk of cancer.

**Recommendation 8:** Create a European Cancer Patient Digital Centre where cancer patients and survivors can deposit and share their data for personalised care.

Best treatment is key, post treatment & tertiary prevention should be in our focus.
Recommendation 11: Childhood cancers and cancers in adolescents and young adults: cure more and cure better

Recommendation 12: Accelerate innovation and implementation of new technologies and create Oncology-focused Living Labs to conquer cancer
1843-Arcagen
Status Euracan Network 2020-10
**ARCAGEN RECRUITMENT STATUS**

<table>
<thead>
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<th>STATUS</th>
<th>08-Jan</th>
<th>30-Sep</th>
<th>Evolution</th>
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<tbody>
<tr>
<td># of registered patients</td>
<td>99</td>
<td>453</td>
<td>358%</td>
</tr>
<tr>
<td># of eligible patients</td>
<td>45</td>
<td>310</td>
<td>589%</td>
</tr>
<tr>
<td># of Patients pending</td>
<td>50</td>
<td>112</td>
<td>124%</td>
</tr>
<tr>
<td># of not eligible patients</td>
<td>8</td>
<td>31</td>
<td>288%</td>
</tr>
</tbody>
</table>

- **Recruitment from 28 investigators from 12 countries**
- **40-50 patients / month since end of May**
Molecular reports generated: 301
  - F1 Liquid: 26%
  - F1 Heme: 2%
  - F1 CDx: 57%

TAT: 3 to 5 weeks

F1 Liquid CDx to replace F1 Liquid in Q4 2020
Upcoming Cohort adaptation:
- Domain 1
- Domain 2
- Domain 4
- Domain 5 \[ Under discussion \]
- Domain 10

Protocol amendment targeted for Dec 2020
• Publication on retrospective part:
  • Global publication submitted/in review - ESMO Open
  • Poster for ENA (24-25 Oct)
  • Specific GYN publication under preparation

• Communication on prospective part
  • Discussion with NCCJ (Japan), for possible collaboration around Arcagen,
  • A possibility could be to propose a co-analysis of some rare cancer subtypes common in Arcagen and Japanese cohort

• General communication plan - 2021
Collection of clinical data from cancer patients harboring an actionable fusions (NTRK and others)

To describe the survival rate of this population in real-life practice, according to overall survival (OS)
Real world European registry of rare actionable fusions

- At least 41 centers in 11 countries
  - Up to 250-500 patients
  - EHR data and quality of life questionnaire (QLQC30)
  - 2 years inclusion - 2 years follow up
  - Opening in Europe: Q1 2021

Regulatory submission in France

➔ Feedback expected this month
➔ Immediate opening of French centers

Contractualization with a CRO for regulatory submissions

**Aixial**: in charge of regulatory submission to ECs (in countries other than France)
➔ will contact center to obtain missing information for the submission (e.g. CV of the PI)
➔ is not in charge of establishing contracts. **Contracts will be established between participating centers and CLB.**
➔ CLB remains your contact for all questions
If your did not receive the feasibility questionnaire or the newsletter, and/or if you would like to participate, please do not hesitate to contact us!

CONTACT

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Project Manager
julien.BOLLARD@lyon.unicancer.fr

Alexandra BIETTE
Clinical Research Associate
alexandra.BIETTE@lyon.unicancer.fr

Thank you!
Recommendation 13: Transform cancer culture, communication and capacity building
COMMUNICATION & DISSEMINATION

New EURACAN website

website Newsletter

ECP

ECP Newsletter
ONLINE EVENT

5TH ESO-ESMO-RCE
CLINICAL UPDATE ON RARE ADULT SOLID CANCERS

PRE-RECORDED SESSIONS:
from 1 December 2020

LIVE SESSIONS:
16-17 January 2021

Chairs: J.Y. Blay, FR - P.G. Casali, IT - R.A. Stahel,

REGISTRATION FOR THE EVENT IS FREE BUT MANDATORY.
FURTHER INFORMATION AVAILABLE AT WWW.ESO.NET AND WWW.E-ESO.NET

Held in collaboration with
In partnership with
Conclusions

• ERN are key to the objectives of the mission cancer

• Prevention(s)
• In depth biological understanding of these cancers (genomics, immunology...)
• Early detection
• QoL
• Big data