



DigiCore

**Summary of activities
2022**

DIGICORE is a pan-European research network built to accelerate the Implementation of precision oncology in Europe.

DIGICORE promotes and equips cancer centres in their use of routine electronic health records (EHR) and molecular diagnostic information (MDX) for trial automation, real world outcomes research, digital diagnostics and quality of care management.

The ultimate goal is to shape a digital research infrastructure based on digital interoperability between its members. Network membership supports them to improve data quality and completeness, develop new data sources and tools, share digital best practices and promote novel, digitally enabled research methods.

DIGICORE is set-up as a European Economic Interest Grouping which is Headquartered in Belgium at the Fondation Universitaire and includes 34 prominent European cancer centres, two cancer networks, UNICANCER and Alleanza Contro il Cancro, and two commercial partners allied in this challenge.

DIGICORE with its own budget, supports strategic projects and training activities closely linked with its objectives and mandate. It is also involved in several European actions as part of the European Cancer Mission of Horizon Europe and of Europe's Beating Cancer Plan.

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PARTICIPATION IN EUROPEAN COMMISSION ACTIONS

IDEA4RC – Intelligent ecosystem to improve the governance, sharing and the re-use of health data for rare cancers – HORIZON-HLTH-2021-TOOL-06

The main objective of IDEA4RC is to establish a Data Space for rare cancers (RC) that will make it possible to re-use the existing multisource health data (cancer registry data, national registries, data from biobanks etc.) across European healthcare systems leveraging emerging interoperability technologies and AI approaches.

The realised “Rare Cancer Data Ecosystem” is expected to improve the quality and the organisation of RC patients care, and to increase knowledge on rare cancers advancing health research, so that all patients have equal access to high quality specialist care.

The project approach will be experienced in the framework of the European reference network for rare adult solid cancers (EURACAN). DIGICORE is asked to participate to the creation of the Data Space with its experience on the internal DigiONE project.

CAN-HEAL – Building the EU cancer and health genomics platform – EU4H-2021-JA

Genomics plays an emerging role in clinical and public health research. Cancer is strongly driven by genomic modifications, and wide-profiling of these modifications with new technological approaches has become a major asset for (early) diagnosis, prognosis and therapy in regard to personalised medicine.

The CAN.HEAL consortium recognises that prevention, diagnosis and treatment should be approached in a concerted way for optimal benefit of patients and citizens.

The CAN.HEAL clinical arm, responding to the ‘Cancer Diagnostic and Treatment for All’, will focus on applying ‘next generation sequencing’ technology and identify implementation paths in order to:

- extend the application of genetic profiling of patients and tumour cells to allow harmonized data interpretation and facilitated treatment decisions,
- apply the same or similar diagnostic and therapeutic approaches to patients with comparable cancer profiles across the EU;
- take up the molecular tumour profiling biomarkers that estimate cancer predisposition to allow better counselling of family members regarding cancer risk.

In the arm on ‘Genomics for Public Health’, the application of novel insights on estimating cancer risks in healthy populations by polygenic risk score analysis within population wide interventions as well as strategies of remote genetic counselling and telegenetics will be further developed.

Finally, CAN.HEAL wishes to set the framework for integrating and aligning the Genome of Europe biobanking initiative into public health genomics for cancer.

EUonQoL – Quality of life in oncology: measuring what matters for cancer patients and survivors in Europe – HORIZON-MISS-2021-CANCER-02

EUonQoL aims to develop, pilot and validate the EUonQoL-Kit, a patient-driven, unified system for the assessment of quality of life (QoL) based on evaluations and preferences of cancer patients and survivors.

The EUonQoL-Kit will be developed from a patient perspective, administered digitally, available in the EU27 and Associated countries languages, and applicable in future, periodic surveys to contribute to the EU's Cancer Mission.

At the core of the EUonQoL there is the adoption of a multistakeholder, co-design methodology, engaging patient representatives, healthcare professionals, administrators, policymakers, and citizens in all project related activities.

This review will be used in the context of the co-design consensus with stakeholders' and patients' preferences to identify gaps and establish all QoL dimensions that are relevant from the perspectives of patients, clinicians, and society.

A multidisciplinary researcher panel, composed by the most talented experts, will develop the EUonQoL-Kit that will be validated in a pilot survey using digital data collection within month 24 of the project.

A total of 4,000 cancer patients and survivors will be enrolled through a network of EU cancer centres. An analysis of factors potentially impacting on cancer patients and survivors QoL, will also be performed.

Implementation and exploitation strategies, as well as the linkage with other Cancer Mission projects and actions will be explored to develop future periodic surveys.

EUonQoL is composed by research institutions, cancer centres, as well as scientific, professional, and patient representative organisations, all with extensive experience and robust scientific background in the development of self-report QoL measures.

This partnership fuels the ambition of EUonQoL to translate QoL information into future changes in cancer care policy and clinical practice.

DIGICORE leads the WP5: Digital tools for data collection.

CCI4EU – Strengthening research capacities of comprehensive cancer infrastructure – HORIZON-MISS-2022-CANCER-01-02

There is a large variability among (and within) MSs in the presence, functioning and performance of Comprehensive Cancer Infrastructures (CCIs).

CCI4EU solution: this Coordination and Support Action (CSA) will support MSs and ACs in improving or developing their existing or future CCIs, focussing on developing their research innovation and digital-related capacities and their integration with cancer care. A tailored Capacity Building (CB) programme should achieve that 90% of cancer patients are treated in CCIs by 2030.

CCI4EU's main objective is to improve or develop existing or future (CCIs).

This will be achieved within 3 years, through the following specific objectives:

1. To finalize a standardised matrix of cancer research/care performance indicators, and a CCI Maturity Model (CCI MM), to be used to analyse the maturity of CCIs across the EU.
2. To map the maturity of CCIs across all EU MSs according to the agreed matrix of cancer research/care performance indicators; thereby clustering CCIs according to maturity.
3. To plan a CB programme tailored to each identified CCI, and further customising tailored interventions (in agreement with the relevant public authorities), giving precedence to those MSs and ACs with absence of, or a low maturity of, CCIs.
4. To identify and coach CB subject experts to deliver the onsite tailored interventions ('Deep Dives') and for online lectures and 3 F2F regional conferences.
5. To execute the CB programme, covering all EU MSs and ACs at various levels of tailored intervention (all having access to online interventions, and some having onsite interventions according to a co-creation model¹, reporting on the impact and recommended sustainable follow-up actions for each CCI site.
6. To disseminate and communicate to the relevant stakeholders (i.e., research and healthcare professional, policymakers, citizens including patients, patients' associations, and informal caregivers) the CB lessons learned and best practices, to further exploit the CB beyond the project.

DIGICORE will be involved in all training activities related to its expertise in data storage and retrieval and dissemination actions.

DIGICORE SELF-SUPPORTED PROJECTS

Platinum Technology Fund

DigiONE, the cancer network supported by the Platinum Technology Fund, will create a federated digital research network that links routine, high quality clinical data with routine molecular data information from 6 large cancer centres in 6 countries that were selected in 2022 following an open call and a selection performed by an independent Leadership Advisory Board.

The underlying digital infrastructure provides a minimal description of every patient's cancer diagnosis, biomarkers, treatment and outcomes in near real time relying on a **Minimal Essential Description of Cancer (MEDOC)** consensus built upon consensus and aligned with international standards. It provides a minimal description of cancer from diagnosis to outcome, and includes all major research inclusion/exclusion criteria, to create a unique resource for high-quality RWE and care quality management.

An open innovation programme leveraging interoperability technologies (OMOP) improving primary data capture with NLP or Natural Language processing solutions. New research services will follow with high quality structured real-world data (RWD) from routine cancer care with privacy-preserving data analytics (federated AI) addressing some urgent clinical research questions that require scale.

Currently, stakeholders and researchers of **DigiONE** are working on infrastructure-related solutions to support federated data sharing approaches to make the data, models, or digital objects smart in their original silos.

For further information on the DigiONE Oncology Network for Europe please [click here](#).

IDEAL4RWE Leadership Training 2022-2023

Equipping the real-world evidence research leaders of the future Outcomes research has never been more important in healthcare, and in particular in cancer care. Survival variation across countries is well documented through epidemiological registries, but the identification of actionable solutions is more challenging. Clinical trials remain of central importance but are rarely possible at a scale to address all questions of risk, prognosis, treatment and personalised care. These restrictions on research are reflected in the European Cancer Mission priorities and the funding programmes to support them.

The efficient and scalable generation of evidence derived from existing data within routine electronic medical records (real-world evidence (RWE)) has a key role to play in highlighting and driving changes in clinical practice. But there is a critical skills gap - a lack of clinical researchers with the skills to scale digital methods into care systems and so transform care quality management internationally. To equip young research leaders with the skills they will need to drive RWE research in the future, including accessing funding, we have developed the IDEAL4RWE Programme, designed based on years of academic and commercial experience in delivering outcomes research in cancer.

The IDEAL4RWE training programme combines:

- an overview of the opportunities, challenges and practice of RWE in cancer;
- technical skills to realise “the art of the possible”, including novel study designs and technologies;
- strengths and weaknesses of RWE study design;
- effective hypothesis generation and preparation of funding proposals;
- research leadership skills, including self-awareness, forming teams across diverse functions and geographies, influencing systems and managing projects and budgets.

Programme includes development of a collaborative RWE research proposal with course participants from other European countries, competitive application for IDEAL4RWE funds to complete your analysis and delivery of your study protocol with the guidance of research leaders in a Scientific Advisory Board (including submission of an academic poster to a 2023 clinical conference).

EVENTS IN 2022

Connect to Win, DIGICORE's annual meeting, provided a forum where attendees met in-person over two days to discuss important issues in cancer care and get updated on the Grouping's running activities.

As a result, the event is a friendly interaction between DIGICORE Members, potential partners from European Cancer Centres and industry stakeholders, all brought together by a common goal: developing and implementing a European research network to accelerate the standardisation of precision oncology.

Every year, Connect to Win is supported by a DIGICORE Member. In 2022 the event was organised by the **Fondazione Istituto Nazionale dei Tumori of Milan**, and was held in Milan on November 8th - 9th with an attendance of more than 120 delegates from 18 countries and more than 45 cancer centres.

More information at: [Connect to Win 2022](#).

OTHER EVENTS IN PERSON

Advances in Clinical Development in Oncology Pre-ESMO 2022

Live Symposium & Livestreamed Webinar Paris, France September 9th

Digicore IDEAL4RWE Leadership Development Retreat

Institut Curie, Paris, September 17th–19th 2022

WEBINARS

Outcome Research Programme and Funding Opportunities - Virtual Seminar March 15th

IDEAL4RWE - Introductory Seminar April 19th

IDEAL4RWE Training Programme - Virtual Seminar May 12th

IDEAL4RWE Training Programme - Virtual Seminar May 24th

The Platinum Technology Fund - Introductory Seminar May 24th

The Platinum Technology Fund - Virtual Seminar June 9th

IDEAL4RWE Training Programme - Virtual Seminar June 10th

The Platinum Technology Fund - Virtual Seminar June 14th

The Platinum Technology Fund - Virtual Seminar June 16th

The Platinum Technology Fund - Virtual Seminar June 21st

Ideal4RWE - Virtual Webinar September 6th

Ideal4RWE - Seminar October 4th

Ideal4RWE - Seminar October 20th

Ideal4RWE - Seminar November 23rd

TRAINING FOR IDEAL4RWE LEADERSHIP DEVELOPMENT ACTION LEARNING SETS

ALS group 1

Tue 11 October 2022, 17:30 – 19:30 BST
Wed 2 November 2022, 17:30 – 19:30 GMT
Thu 1 December 2022, 17:30 – 19:30 GMT

ALS group 2

Fri 14 October 2022, 17:30 – 19:30 BST
Tue 15 November 2022, 17:30 – 19:30 GMT
Tue 13 December 2022, 17:30 – 19:30 GMT

ALS group 3

Tue 18 October 2022, 17:30 – 19:30 BST
Wed 16 November 2022, 17:30 – 19:30 GMT
Wed 14 December 2022, 17:30 – 19:30 GMT

ALS group 4

Thu 27 October 2022, 17:30 – 19:30 BST
Thu 10 November 2022, 17:30 – 19:30 GMT
Thu 8 December 2022, 17:30 – 19:30 GMT

COMMUNICATION AND DISSEMINATION

All DIGICORE information and news are published on the website digicore-cancer.eu and are disseminated through the monthly newsletter sent via Mailchimp to a subscriber list of about 1500 researchers, clinicians, stakeholders.

DIGICORE is active on social media with pages on LinkedIn, Twitter and Facebook.

Membership 2022

The membership in 2022 increased from 22 Members in 2021 to 38 Members.

2 new Full Members

Oslo University Hospital (OUH)
Fundacion Jimenez Diaz University Hospital

14 new Associate Members

Centre de Lutte Contre le Cancer Jean
Cliniques Universitaire Saint-Luc
Maastricht Comprehensive Cancer Center
Sestre Milosrdnice University Hospital Centre
South Texas Accelerated Research Therapeutics, LLC
Tartu University Hospital
TAYS Cancer Centre Tampere University Hospital
The University Court of the University of Edinburgh
Trinity St. James's Cancer Institute
Vision Zero Cancer
INT Fondazione Pascale
Istituto Oncologico Veneto IRCCS - IOV
National Cancer Institute
The Leeds Teaching Hospitals NHS Trust

To see the entire membership go to:

Full Members/Founders

<https://digicore-cancer.eu/Page.aspx?name=MEMBS>

Associate Members

https://digicore-cancer.eu/Page.aspx?name=ASS_MEMBS