



Joint Action on Networks of Expertise

Deliverable number. D2.3

Title: JANE Final Meeting Report

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DOCUMENT INFORMATION

Author(s)	Vasiliki Pletsa, Evgenia Kouli
Deliverable lead partner	NHRF
Contributing partner(s)	INT
Work Package	WP2
Task	T2.3
Deliverable type	R-Document, report
Due delivery date	September 30, 2024
Actual delivery	October 17, 2024
Dissemination level	Public
Annex version	1

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1. Introduction

The final event of the Joint Action on Networks of Expertise (JANE) was held in Brussels on 24th-25th September 2024, with the in-person participation of more than 120 project members, policymakers and stakeholders. The aim of the meeting was to discuss progress made in shaping the seven networks of expertise on cancer (NoEs), present the challenges experienced by European networks, as described in greater detail in the Consortium's Green Paper entitled, "Health networking on cancer in the European Union", and introduce the follow-up project JANE-2.

The final meeting was widely communicated through the JANE website, the Agora Network of EU Health Policy Platform (EUHPP) – Agora Network, and the recently created JANE profiles on social media (X and LinkedIn). Members of the European Parliament and other key stakeholders, including academic associations and patient advocacy groups, were individually invited to take part in the two events.

The aim of NoEs is to establish a new kind of functional network and their contribution in enlarging networking is expected to be of great importance for European health care and policy. Therefore, JANE has prepared the groundwork for these NoEs while JANE-2 will meet the challenge to actually build and implement them.

2. JANE Final Stakeholder Meeting

The Final Stakeholder Meeting of JANE (*agenda attached*) opened with a welcome address from Dr. Giovanni Nicoletti, of the Italian Ministry of Health, who described the work being done by JANE as being crucial for healthcare at both EU and national level, stressing that, "if CRaNE (the Joint Action on establishing a European Network of Comprehensive Cancer Centres) is the 'hardware', JANE will provide the 'software'".

Thereafter, Paolo Casali, Coordinator of JANE and JANE-2, introduced the ambitious vision of JANE: the creation of seven transversal Networks of Expertise (NoEs) on Cancer. The complexity of establishing and implementing these networks at EU level will require the support and collaboration of all 121 entities from the 29 European countries participating in JANE-2, as well as collaboration with competent authorities, affiliated entities, Action Grant recipients, and collaborative stakeholders. JANE's successor, JANE-2 will be translating this vision into reality over the next 4 years.



Consequently, the leaders of the seven Networks of Expertise of JANE, namely NoE on Complex and Poor Prognosis Cancers, Personalized Primary and Secondary Cancer Prevention, Survivorship, Palliative Care, Adolescents and Young Adults with Cancer, Omics Technologies, Hi-Tech Medical Resources, presented the outcome of their work and outlined the ambitious scope, impact, synergies and challenges foreseen by each network to be created in the context of JANE2. The leaders of the Transversal Task Forces (Integration between health care and research, Integration between EU networking and Member States, Integration between IT infrastructures and AI tools, the ERN model, Patient involvement) also presented the outcome of their work and the challenges identified during the two years of JANE's implementation.

JANE's NoEs on cancer must be shaped in collaboration with all EU projects, Joint Actions and initiatives which could directly or indirectly impact their function and effectiveness. With this in mind, the first day of the final meeting of JANE concluded with two roundtables. One addressed issues of networking synergies and challenges, including a thorough discussion on synergies involving representatives from the Joint Action on establishing a European Network of Comprehensive Cancer Centers (CRaNE - to be followed up by JA

EUNetCCC), the European Initiative to Understand Cancer (UNCAN.eu), and the European Reference Network on Rare Adult Solid Cancers (EURACAN). JANE-2 is expected to take these discussions forward and implement synergies over the next four years.

In the second roundtable, the discussion on current and future challenges was focused on the JANE Green paper (*submitted to ESMO Open for publication*) which identifies 13 main challenges. NoEs, as conceived by the JANE community in close partnership with most European stakeholders, hold the promise of creating a new way of providing high-quality care to all patients with cancer in the EU, in most cancer care areas. Moreover, they could serve as a pilot for care delivery within and across disease areas at national and EU level. The aim of the JANE Green paper is to foster discussion within the oncology community, meet the main challenges and create effective and sustainable NoEs on cancer at European level. Issues such as governance, sustainability, evaluation, dissemination and communication, and patient involvement were thoroughly discussed among the participants during the roundtable.

3. JANE European Parliament Meeting



The two-day Final Meeting of the Joint Action on Networks of Expertise (JANE) culminated in the European Parliament on September 25th (*agenda attached*). The event was hosted by MEP Vlad Voiculescu and supported by MEPs Vytenis Andriukaitis, Paulo do Nascimento Cabral and Stine

Bosse. It brought together stakeholders from the oncology community, national health authorities, as well as representatives from the European Commission. The aim of the meeting was to introduce the seven Networks of Expertise to the new legislature of the European Parliament, as well as to present JANE's Policy Document (*attached*), highlighting the challenges that need to be overcome in establishing and implementing these NoEs. All participants agreed that the JANE concept overall and the work done so far are in full compliance with EU4Health Programme 2021-2027 and Europe's Beating Cancer Plan. Reference was made by MEP Vlad Voiculescu to the recent launch of "Personalised cancer medicine," a Joint Action (JA) expected to complement and work hand in hand with all current EU4Health JAs on cancer.



4. Conclusions

- In the context of JANE, significant progress towards the shaping of the Networks of Expertise (NoEs) on cancer was made; the networks established a crosstalk with a significant number of players of the oncology community, beyond the Consortium, at national and European level and defined the criteria for NoE implementation.
- Key networking challenges such as governance, sustainability, evaluation, dissemination, communication, and patient involvement were identified and discussed in the JANE Green paper. Progress and outcomes were efficiently communicated to the oncology community and wider audiences while the Consortium initiated a collaboration with main EU networks in this field.
- JANE's NoEs on cancer must be established in collaboration with all EU projects, Joint Actions and initiatives that could directly or indirectly impact their function and effectiveness.
- The support of policymakers at both EU and national levels will leverage JANE's effort to create effective NoEs providing cancer care of high quality to all those affected by cancer in the EU.
- JANE-2 will address all these issues over the next 4 years through the enlargement of the Consortium, involvement of additional key players and stakeholders, in collaboration with all relevant EU4Health initiatives to maximize the benefits for European patients.

Revision History

Version no.	Date of Issue	Author(s)	Brief Description of Change
1.0	17.10.2024	Vasiliki Pletsa, Evgenia Kouli	
2.0	25.10.2024	Joanne Fleming Malvika Vyas	

The EU Joint Action on Networks of Expertise (JANE) Final Stakeholder Meeting

24th September 2024

Thon Hotel EU
Wetstraat/Rue de la Loi 75, 1040 Brussels



Agenda

Time Topic

10.00 *Welcome coffee*

10.30 G. Nicoletti (Ministry of Health, Italy)

Welcome

10.45 P.G. Casali (INT)

Paving the way towards the European Networks of Expertise (JANE-JANE-2)

Interactive discussion on the Networks of Expertise (NoE)

Moderators: P-G. Casali, A. Trama

11.00 NoE on Complex and Poor Prognosis Cancers
(introduction: I Ługowska, MSCI, K Corbishley, SoS)

11.30 NoE on Personalised Primary and Secondary Cancer Prevention
(introduction: D Nicoară, IOCN, PM Mæhle, OUS)

12.00 NoE on Survivorship
(introduction: P Rutkowski, MSCI, A Morales La Madrid, HSJD, R Kiasuwa Mbengi, Sciensano)

12.30 NoE on Palliative Care (introduction: S Kaasa, OUS, M Jensen Hjermstad, OUS, J González-Barboteo, ICO)

13.00 *Lunch*

14.00 NoE on Adolescents and Young Adults with Cancer
(introduction: A Ferrari, INT, S Provenzano, INT)

14.30 NoE on Omics Technologies
(introduction: H Antoine-Poirel, M Van Den Bulcke, Sciensano)

15.00 NoE on Hi-Tech Medical Resources
(introduction: JY Blay, Unicancer, V Hancock, Unicancer, K J Gehl, ZEALCO)

15.30 *Coffee break*

16.00 Roundtable Discussion: Networking Synergies

M Van den Bulcke, CraNE/EUnetCCC, JY Blay EURACAN, A Piris UNCAN

16.45 Roundtable Discussion: Networking Challenges

A Fullaondo, Biosistemak; S Berrocoso, Biosistemak; D Nicoară, IOCN;
E Hovig, OUS; JY Blay, Unicancer; W Van Hoof, Sciensano; V Pletsa, NHRF;
Mario Šekerija, CIPH

18.00 Wrap up

18.30 *End of the Day and Welcome cocktail*

Networks of Expertise: An Ambitious Vision for Tackling Healthcare at EU level

Joint Action on Networks of Expertise on Cancer
an EU funded Joint Action

25 September 2024

European Parliament, Brussels
Room: SPAAK 5B1
Time: 10am – 12pm

Hosted by:
MEP Vlad Voiculescu



Fondazione IRCCS
Istituto Nazionale dei Tumori



Sistema Socio Sanitario
Regione
Lombardia



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Agenda

Time	Topic	Speaker	Affiliation
10'	Welcome	MEP Vlad Voiculescu	Member of the European Parliament
		MEP Vytenis Andriukaitis	Member of the European Parliament
		MEP Paulo do Nascimento Cabral	Member of the European Parliament
10'	Introduction to the Joint Action on Networks of Expertise of JANE	Paolo G. Casali	Coordinator, Joint Action on Networks of Expertise 1 and 2
10'	European Commission Perspective	Matthias Schuppe	Directorate General for Health and Food Safety (DG SANTE), European Commission
30'	Speed-date with the 7 Networks of Expertise:	Moderated by: Paolo G. Casali and Annalisa Trama	Fondazione IRCCS Istituto Nazionale dei Tumori, Italy
	1) Complex and Poor Prognosis Cancers	Iwona Lugowska	Maria Sklodowska-Curie National Research Institute of Oncology, Poland
	2) Palliative Care	Stein Kaasa	Oslo University Hospital, Norway
	3) Survivorship	Piotr Rutkowski	Maria Sklodowska-Curie National Research Institute of Oncology, Poland
	4) Personalised Primary and Secondary Cancer Prevention	Delia Nicoară	The Oncology Institute "Prof. Dr. Ion Chiricuță", Cluj-Napoca, Romania
	5) Omics Technologies	Hélène Antoine-Poirel	Sciensano, Belgium
	6) Hi-Tech Medical Resources	Julie Gehl	Region Zealand – Zealand University Hospital, Denmark
	7) Adolescents and Young Adults with Cancer	Andrea Ferrari	Fondazione IRCCS Istituto Nazionale dei Tumori, Italy
10'	Synergies with EUnetCCC (Comprehensive Cancer Centres) and European Reference Networks	Thomas Dubois	Coordinator, Joint Action European Network of Comprehensive Cancer Centres (EUnetCCC)
		Jean-Yves Blay	Coordinator, European Reference Network on Rare Adult Solid Cancers (EURACAN)
15'	Open Questions on Health Networking: What do we Need to Create Successful Health Networks at EU Level?	Paolo G. Casali	Coordinator, Joint Action on Networks of Expertise 1 and 2
30'	Interactive Discussion - Q&A	All	
5'	Conclusion	MEP Vlad Voiculescu	Member of the European Parliament

**Networks of Expertise:
An Ambitious Vision
for Tackling Healthcare at EU level**

Joint Action on Networks of Expertise on Cancer
an EU funded Joint Action



Networks of Expertise: An Ambitious Vision for Tackling Healthcare at EU level

Joint Action on Networks of Expertise on Cancer an EU funded Joint Action

Cancer, a challenging group of diseases, is expected to have a 77 percent increase in new cases by 2050. In the European Union, cancer cases are estimated to reach 3.7 million by 2045.¹ Overall, the population of people living with cancer is rising faster than the advancements in science, aimed at treating the group of diseases. This implies that the focus of healthcare services over the coming years will be on delivering care to the population, in the best way possible.

Europe's Beating Cancer Plan (EBCP) anticipated this rise in cases and became the first initiative in the EU to tackle a specific disease, cancer, at the supranational level. It brought together Member States and the European institutions to jointly work together on an area that is a national competence: health.

The Beating Cancer Plan was launched on February 3rd, 2021, the eve of World Cancer Day, and since then it has given rise to 32 key actions and 10 flagship initiatives – addressing the entire continuum of cancer care.

The ambitious Joint Action on Networks of Expertise (JANE), and its seven new networks of expertise based on the concept of **health networking**, was created upon a request from the European Commission in the context of Europe's Beating Cancer Plan.

What are Joint Actions?

Joint Actions are collaborative projects involving several EU and associated countries with the objective to address key EU health policy priorities – **areas that are both high on the agenda nationally (Member States) and at the EU level.** These direct grants under the EU4Health and Third Health Programmes are implemented by a consortium of national public health authorities nominated by EU countries and involve the non-profit sector, academia and governments/national authorities.



¹ International Agency for Research on Cancer. *Global Cancer Observatory – Cancer Tomorrow*. Accessed 27 August 2024

Health Networks in Cancer: What are they?

Health networks may be defined as networks involving a form of regular collaboration, at a distance, amongst healthcare professionals focusing on items pertaining to the mission of the network². To date, health networking at the EU level has only been attempted via the Cross-Border Healthcare Directive, through the creation of European Reference Networks (ERNs) focusing on rare diseases and rare cancers. Building on the ERN model, the **Joint Action on Networks of Expertise (JANE)** will be shaping **seven new transversal health networks** in oncology, that will transform the way cancer care will be delivered at EU level. These Networks of Expertise (NoE) will be the first of their kind as they will focus on transversal aspects of the disease (as opposed to the ERNs that were focusing on a specific disease). In addition to JANE, a parallel Joint Action is working towards the creation of a European Network of Comprehensive Cancer Centres (CCCs) that will aim to ensure timely and qualitative care provision to cancer patients.



² Casali, P., et al., Health networking on cancer in the European Union: a “green paper” by the EU Joint Action on Networks of Expertise (JANE) – Submitted for publication (September 2024)

The Joint Action on Networks of Expertise (JANE)

JANE is an ambitious Joint Action, stemming from Europe's Beating Cancer Plan (EBCP), that aims to shape seven new Networks of Expertise in the area of oncology, focusing on: 1) complex and poor prognosis cancers; 2) palliative care; 3) survivorship; 4) personalised primary and secondary cancer prevention; 5) omics technologies; 6) hi-tech medical resources; 7) adolescents and young adults (AYA) with cancer.

These Networks of Expertise will be the first of their kind and will aim to provide the highest standard of care within the EU - to its citizens and inhabitants - in the area of oncology. If this model works, they can also serve as a pilot for new disease areas or delivering care in general.



JANE's 7 Networks of Expertise (NoE)

Network of Expertise (NoE) Vision

NoE on Complex and Poor Prognosis Cancers	Empowering hope, extending life: a world where poor prognosis cancer no longer steals futures and equal access to care prevails throughout Europe
NoE on Palliative Care	Establishing a sustainable NoE in palliative care that supports the integration of palliative care into routine cancer care, thereby ensuring that evidence-based PC is available according to patient needs in all EU MSs
NoE on Survivorship	Supporting the integration of evidence-based approaches to cancer survivorship into routine care and to ensure equitable access across EU MSs
NoE on Personalised Primary and Secondary Cancer Prevention	Advancing individualized strategies to prevent disease by integrating genetic, lifestyle and environmental factors into tailored healthcare approaches
NoE on Omics Technologies	Supporting the integration of innovative omics technologies into the standard of care at the different steps of cancer management in a sound and sustainable manner, achieving equitable access to these services for all EU citizens
NoE on Hi-Tech Medical Resources	Providing equal access across Europe to hi-tech medical resources
NoE on Adolescents and Young Adults with Cancer	Becoming the network where collaboration between paediatric and adult cancer services will be strengthened to face the gap of AYA patient survival across EU Member States

JANE 1: 36 partners from 15 Member States and 1 Associated Country (2022 – 2024)

JANE-2: 121 partners from 25 Member States and 4 Associated Countries (estimated 2024 – 2028)



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Networks of Expertise:
An Ambitious Vision
for Tackling Healthcare at EU level



Why is this **Important for the EU?**

The European Union (EU) is working towards cementing an EU Health Union. A Union that will focus on the mutual agreement of Member States and the European Union, on an area that is currently a national competence. Currently, this Health Union has been tested in the context of serious cross-border threats (i.e. the COVID-19 pandemic) and to an extent via the Cross-Border Healthcare Directive (i.e., the ERNs on rare diseases and rare cancers). The collaboration between Member States and the European Commission has shown us the benefits of cooperation at supranational level.

However, in order to have a strong supranational collaboration in an area that is a national competence, health, Member States and the European Union need to pilot their collaboration in specific areas pertaining to health and healthcare, outside the area of serious cross-border threats and other exceptions.

JANE's seven new Networks of Expertise in oncology, shaped over the next four years, involving the cooperation of 29 European countries, national authorities and key stakeholders, may provide a concrete example in the context of the EU Health Union.

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NETWORKS OF EXPERTISE
ON CANCER

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Networks of Expertise:
An Ambitious Vision
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Challenges to Address Over the Next 4 Years – 2024 - 2028

Despite the ambitious nature of the seven Networks of Expertise, the JANE community is also acutely aware of the challenges that health networks have faced at EU level. If these seven visionary Networks of Expertise are to be shaped effectively, the health, and more specifically, oncology community, with the support of all policymakers needs to work together to address critical open issues³ such as:

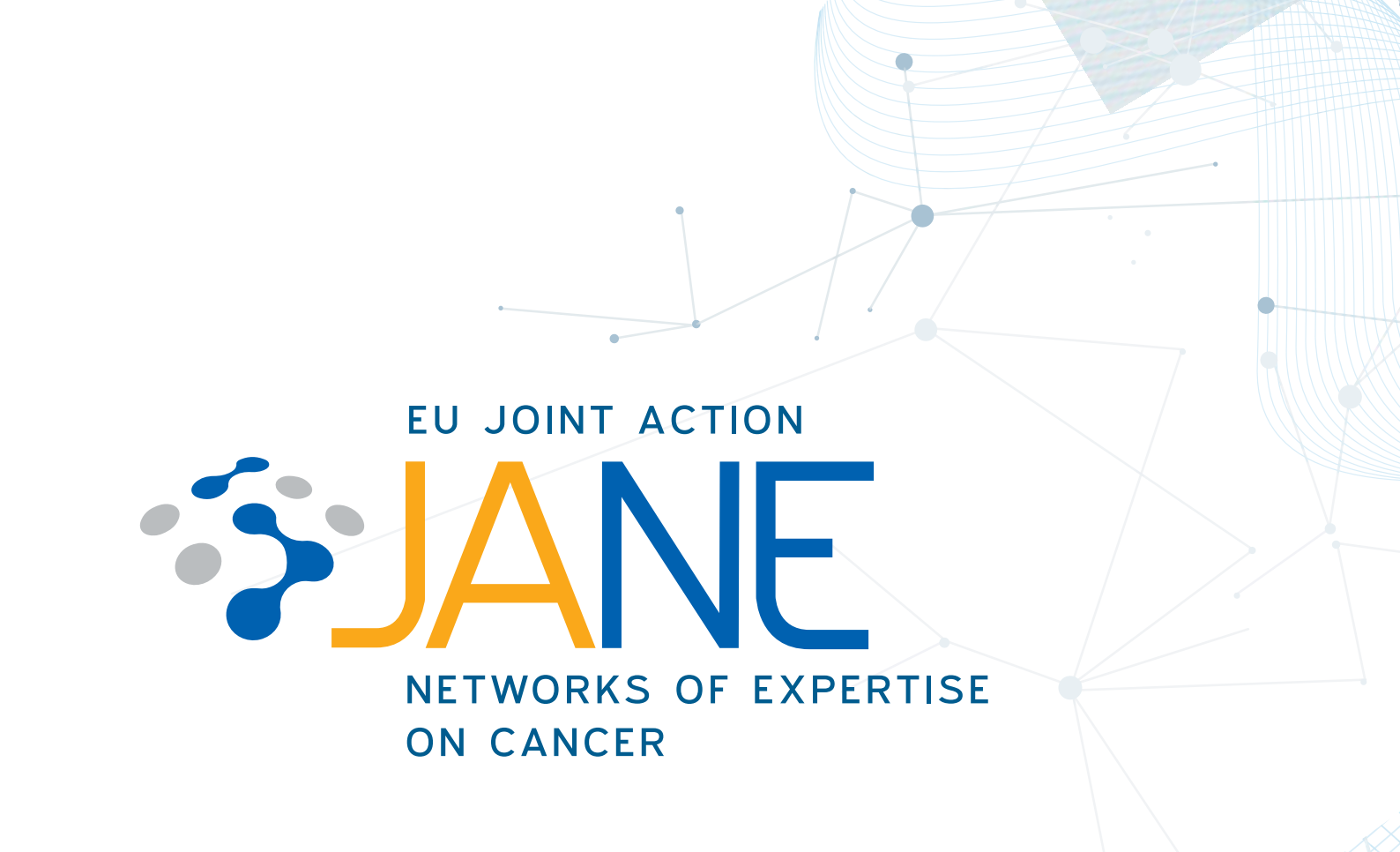


- 1 How can we study and innovate the concept of health networking?
- 2 What areas are better suited for health networking at EU level?
- 3 What degree of cooperation and harmonisation should be required of EU Member States to best exploit health networking and give rise to European networks of national/regional networks?
- 4 How can the idea of subsidiarity be best interpreted to support health networking in the context of EU Treaties, which basically do not include health?
- 5 How should the concept of a “network of networks”, i.e., the national/regional network counterparts to the European networks, be developed?
- 6 How should EU health networks be funded and with what degree of cooperation between the EU and national levels?
- 7 How can a system of EU networks integrated with national networks be best organized and funded, e.g., should the costs be split between the EU and Member States?
- 8 Should EU health networks be shaped as legal entities or could they give rise to secondary legal entities, also with a view to fundraising?
- 9 How should health networks be best shaped to advance cancer research?
- 10 How should the EU regulatory system be updated to exploit such impulse to health networks, in view of the EU General Data Protection Regulation and the new EU Health Data Space?
- 11 How can artificial intelligence be exploited today within health networks and to what extent will it be able to overcome challenges such as the current lack of interoperability of electronic health records and the language barrier across the EU?
- 12 How should health networks involve patients and their groups, with regard to their formal role within EU health networks?
- 13 Within health networks, which are the areas where patients and their groups should be best involved, e.g., production of clinical practice guidelines, the design of investigator-driven clinical trials, EU regulatory decisions on medicines and devices, health service data governance, identification of unmet needs?

These critical issues are addressed in greater detail in a Green Paper authored by the Joint Action on Networks of Expertise, entitled *Health networking on cancer in the European Union: a “green paper”*.⁴

³ Casali, P., et al., Health networking on cancer in the European Union: a “green paper” by the EU Joint Action on Networks of Expertise (JANE) – Submitted for publication (September 2024)

⁴ Ibid.



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NETWORKS OF EXPERTISE
ON CANCER



Shaping the EU Networks
of Expertise on Cancer

WWW.JANE-PROJECT.EU

For more information, please contact
the Coordination Team at:

Jane_Coordination@istitutotumori.mi.it

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