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ON CANCER

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Blueprint: Recommendations for the Implementation of a Sustainable Network of Expertise on Complex and Poor Prognosis Cancer

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LIST OF ABBREVIATIONS

Abbreviation	Definition
AI	Artificial Intelligence
CCC	Comprehensive Cancer Centre
CCI	Comprehensive Cancer Infrastructure
CCCN	Comprehensive Cancer Care Networks
CPE	Cancer Patients Europe
CraNE	Joint Action on Network of Comprehensive Cancer Centres
CSA	Coordination and Support Action
ECHoS	European Network of National Cancer Mission Hubs
ERN	European Reference Network
EORTC	European Organisation for. Research and Treatment of Cancer
ESMO	European Society for Medical Oncology
ESO	European School of Oncology
EU	European Union
EURACAN	European Reference Network on Rare Adult Cancers
GDPR	General Data Protection Regulation
INCA	French National Cancer Institute
INT	Instituto Nationale dei Tumori
IPAAC	Innovative Partnership for Action Against Cancer
JA	Joint Action
M	Milestone
MS	Member State
MTB	Molecular Tumour Board
NoE	Network of Expertise
OECI	Organisation of European Cancer Institutes
PAG	Patient Organisation Groups
PPC	Poor Prognosis and Complex Cancers
PRIME-ROSE	Precision Cancer Medicine Repurposing System Using Pragmatic Clinical Trials
R&D	Research and Development
RWE	Real-World Evidence

SAB	Scientific Advisory Board
SC	Steering Committee
WP	Work Package

RECIPIENTS OF THIS DOCUMENT

This document is addressed to the whole JANE consortium. It is an official deliverable for the project and shall be delivered to the European Commission and appointed experts.

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1. Executive Summary

Key findings

Given the rising incidence trends and low survival rates, Poor Prognosis Cancers (PPC), defined as those with a 5-year overall survival below 30%, such as pancreatic and lung cancer, pose emerging health challenges (1). The development of a Network of Expertise (NoE) for PPC aims to create a dynamic ecosystem that transforms cancer research, diagnosis, treatment, and patient care. This report serves as the final deliverable for WP5, dedicated to establishing the NoE for PPC as part of the European Joint Action on Networks of Expertise (JANE), detailing the progress made over two years regarding its vision, objectives, and the range of services necessary to manage these cancers.

The NoE will integrate multidisciplinary expertise across oncology, molecular biology, clinical medicine, and patient advocacy to foster a collaborative environment that promotes innovation and shared learning. It also defines an effective organisational structure and governance model, with a focus on patient-centred care, the engagement of key stakeholders, and expertise within the European cancer landscape to build a sustainable network. The strategies presented here will guide the implementation of the NoE for Poor Prognosis Cancers in the next phase of the JANE (JANE-2), ensuring a coordinated effort to improve outcomes for patients across Europe.

Recommendation

Developing a roadmap for establishing and expanding NoE for PPC is crucial. This NoE PPC should aim to address the needs of patients with poor prognosis cancers and implement an action plan to enhance survival rates at a good quality of life by:

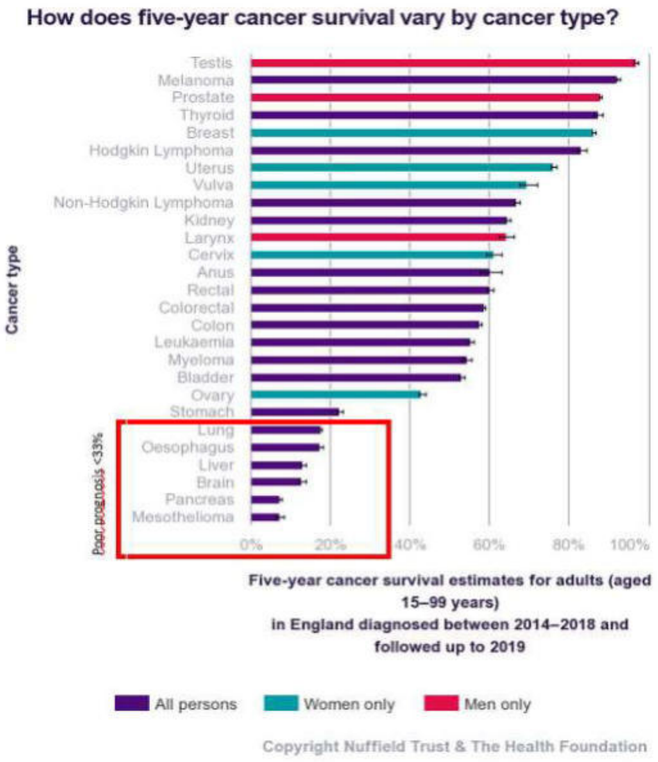
1. supporting the development and implementation of clinical guidelines/pathways in all phases of the disease, including prevention, early diagnosis and treatment, symptom management and palliative care to promote high-quality cancer care
2. promoting novel translational research programs to foster high-tech solutions and innovation in PPC
3. collaborating with policymakers to dissolve cancer inequalities in Europe and increase/facilitate access to innovation for individuals with PPC
4. educating and involving the community, stakeholders and patient advocacy groups in PPC actions, and assisting them in the wide dissemination of relevant information about PPC
5. developing a roadmap for further NoE addressing public health priorities for PPC patients as well as continuing activities of NoE for pancreatic cancer released in May 2023 as a JANE WP5 action.
6. ensuring effective NoE PPC governance, dissemination, evaluation, and sustainability
7. addressing the possible synergies between various work packages of future JANE2, other CSA/JA, scientific societies, and stakeholders.

2. Introduction

Cancers continue to challenge the medical community with their diverse manifestations and varying responses to treatment. Among the myriad challenges that oncology faces, PPC stands out as a particular one. These cancers, characterised by limitations in early detection, aggressive behaviour, rapid onset of metastases, and limited treatment options, pose a significant threat to patients' lives and well-being. The conventional approach to cancer research and treatment often falls short in addressing the peculiar complexities of PPC. In response, the concept of establishing the "Network of Expertise for Poor Prognosis Cancers, NoE PPC" has emerged as a promising initiative for patients and the community. This comprehensive report explores the rationale and significance of the NoE PPC and outlines its objectives, scope, roadmap, and potential challenges.

Background and Context

PPCs represent a subset of malignant neoplastic diseases whose complex biological and clinical features are associated to limited therapeutic options leading to an unfavourable clinical course and poor overall survival. Clinically, these cancers often present at advanced stages, with a high symptomatic burden due to a propensity for early metastases to distant organs.



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One of the aims of the Innovative Partnership for Action Against Cancer (iPAAC) was to tackle "poor prognosis cancers" by developing new key indicators to assess clinical cancer pathways and health-related costs, with a focus on pancreatic cancer, as an example. The IPAAC project was collaborative and forward-thinking and started building a bridge between diverse stakeholders, including healthcare professionals, researchers, patient advocates, policymakers, and other organisations, to drive innovative solutions in the fight against cancer (2). In the Bratislava Statement, it was acknowledged that the increase in survival of patients with poor prognosis cancers underscores the importance of collaborative research, improved access to care, and enhanced advocacy efforts. Per the definition established by IPAAC and acknowledged by the WP5 experts, poor prognosis cancers are those where the 3- and 5-year patient overall survival rate is below 30%. (3). The diagnosis of PPC carries profound clinical implications for patients, caregivers, and healthcare providers.

Treatment decisions necessitate careful consideration of potential benefits, risks, and anticipated outcomes. The management of these malignancies often demands a multidisciplinary approach, with experts from various specialities to devise personalised treatment regimens. These malignancies often harbour genetic alterations that disrupt critical cellular pathways regulating cell growth, proliferation, apoptosis, and DNA repair. These genetic alterations may lead to therapeutic resistance, making tumours refractory to conventional treatments such as chemotherapy or radiation therapy.

The current therapeutic landscape for PPC is often characterised by a lack of effective treatment modalities, leading to suboptimal outcomes for patients. Conventional chemotherapy and radiation therapy may provide temporary relief, but the development of resistance frequently hinders long-term success. The rapid emergence of treatment resistance further undermines the efficacy of therapeutic interventions, resulting in a compromised quality of life for affected individuals and a heightened burden on healthcare systems. As a result, there is an urgency to explore innovative approaches, especially for lung, pancreas, stomach, central nervous system, or liver cancers, which fall under the category of PPC [Fig. 1] (4).

Rationale and Significance of a Network of Expertise

The NoE PPC represents a paradigm shift in how to most efficiently approach the diagnosis, treatment, research, education, and policy decision-making in this group of cancer patients. It recognises that a single discipline or institution alone cannot adequately address the multifaceted challenges. Instead, a collaborative, multi-stakeholder, interdisciplinary and interinstitutional effort that brings together experts from diverse fields is essential for making substantial strides and improving patient outcomes.

The significance of such a network lies in its ability to foster a synergistic exchange of knowledge, ideas, and technologies. By transcending traditional silos, experts from oncology, radiology, genetics, immunology, bioinformatics, and other relevant fields can collaborate to unravel the phenomena driving poor prognosis cancers. This collaborative environment not only enhances our understanding of these diseases but also accelerates the transition of scientific discoveries into clinical applications, along with the appropriate community empowerment and delivery of care.

3. Methodology

The methodology for establishing and operating the WP5 NoE PPC (Fig 2) was designed to ensure a comprehensive, systematic, and collaborative approach to achieving the network's objectives. The following steps outline the key components of the methodology.

FIGURE 2 WP5 METHODOLOGY

The first step was to **Establish the framework for NoE**. The representatives of Consortium Members with expertise with PPC and representatives of scientific organisations and patients were invited. To define the scope and operational concept of NoE, we performed:

- **Needs Assessment to define the scope of NoE PCC -** A thorough needs assessment was conducted to identify the gaps and challenges in the current management of poor prognosis cancers. An extensive literature review has been done, and the following priorities were defined: enhance patient care, advance research, empower knowledge, raise awareness, and advocate for change in policy and strategy building based on measurable impact. The final decision was made after consultations with healthcare professionals, researchers, and patients during the online and in-person meetings (Annex 7). Additionally, building the bridge between WP5 PPC and ongoing initiatives was critical. One of them was initiated during the French EU presidency in 2022 by the French National Cancer Institute (INCa). There was consensus about building a multidisciplinary group that gathers expertise, professionals from different specialisations, PAGs, and societies or institutions representing European healthcare systems.

- **Establishment of Network Model and Governance -** The methodology for establishing this organisation involves several key steps. Firstly, a comprehensive organisational structure was designed, defining roles and responsibilities for network members, including leadership positions and task/domain leaders. Next, a governance framework was established to coordinate activities, monitor progress, and ensure adherence to standards and protocols. We proposed to take advantage of the existing network models, and therefore, we followed the EURACAN concept. The rare cancers, regardless of their survival rate, will be a topic of interest of EURACAN, and the remaining cancer types with a 5-year survival rate below 30% will be a part of NoE PCC.

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- **Engagement -** WP5 decided to address NoE PPC activities for final users such as HCP/CCC and other medical professionals (together to work on the quality of care and treatment outcomes), researchers (together accelerate a deeper understanding of cancer biology, the development of more effective anti-cancer therapies and diagnostic as well as IT) PAGs, Medical Societies/Organisation, and policymakers/stakeholders. Regular meetings were organised to foster collaboration and ensure all relevant perspectives were considered.

- **Use case -** The group decided to run a use case as a pilot NoE dedicated to pancreatic cancer since the 5-year overall survival in this group is around 12% (6). There is a need to increase the quality of care and better understand tumour biology, enabling the introduction of diagnosis and treatment pathways, innovative therapies, and exploring possibilities of personalised prevention and early detection.

- **Survey to define the future directions of the network -** A survey was developed to gather data on the future perspectives of NoE, and a specific subsection was dedicated to a cost-benefit analysis. This survey targeted a diverse group of respondents, including clinicians, patients, educators, and policymakers, to ensure a comprehensive understanding of the PPC landscape. The participants of JANE1 and JANE2 were invited. Data collection involved gathering information from diverse sources, including patient feedback and experts' opinions.

- **Implementation plan -** This plan outlines the specific objectives, actions, timelines, and resources required to establish further NoEs and operate the NoE PPC effectively in the future. By following this methodology, the NoE PPC aims to create a robust, interdisciplinary network that drives innovation and improves outcomes for patients with poor prognosis cancers. A detailed implementation plan was developed in the JANE2 proposal submitted in January 2024.

4. Understanding NoE for PPC

The establishment of the NoE PPC is driven by a comprehensive set of objectives that collectively aim to transform the landscape of cancer care, research, and treatment. These objectives are rooted in recognising that the multidimensional challenges posed by PPCs demand a collaborative and interdisciplinary approach to achieve meaningful advancements. At the heart of the NoE PPC is the promotion of seamless collaboration among experts from diverse fields, affecting a shift in strategy at the European and member-state levels.

We developed the list of experts involved in the WP5 PPC (Annex 2 - M5.1), which is still open to individual experts, scientific societies, and institutions who are interested in collaboratively working to achieve the project goals and define the NoE scope (Annex 3 – M5.2)

Vision Statement

Empowering Hope, Extending Life: A World Where Poor Prognosis Cancer No Longer Steals Futures and Equal Access to Care Prevails Throughout Europe.

Mission Statement

Building on successful EU networking models such as EURACAN, the mission of NoE PPC is to enhance healthcare through improved diagnostic and treatment management, knowledge sharing, and fostering communication among patients, organisations, institutions, and authorities involved in PPCs. Through personalised treatment strategies, cutting-edge research, and robust networking opportunities, we aim to enhance patient care, advance research, empower knowledge, raise awareness about poor prognosis cancers, advocate for policy change, and develop a strategic roadmap for future efforts through collaborative endeavours.

Central to the network's objectives is the recognition of patients as active participants in their care journey. The network prioritises patient-centric care, addressing not only the physical aspects of the disease but also the psychosocial and emotional well-being of patients. Placing patients at the centre of the network's efforts ensures that research, diagnosis, and treatment decisions are tailored to individual needs, values, and preferences. Engaging patients as active partners fosters shared decision-making and empowers them to participate actively in their care journey. Improving the quality of care and treatment outcomes relies on clear, interdisciplinary clinical practice guidelines developed by international and national societies. It is essential to introduce indicators of quality of care.

By dismantling traditional disciplinary boundaries, NoE PPC aims to create a dynamic research environment where collective insights lead to breakthroughs in understanding poor prognosis cancers. The network's collaborative efforts are designed to accelerate the translation of personalised treatment strategies from the research bench to the clinical bedside, providing patients with more effective and tailored interventions and enhancing therapeutic efficacy. NoE PPC is positioned to promote and support research initiatives focused on PPCs, with the goal of advancing understanding, treatment options, and breakthroughs in these challenging malignancies.

One of the network's critical objectives is to gather expertise for developing cutting-edge tools for early and accurate detection of aggressive malignancies. Through interdisciplinary collaboration, the network seeks to integrate advanced technologies, molecular profiling, and data analytics to identify characteristic markers for early detection of PPCs. Therefore, collaboration within JANE – WP Omics and WP High Tech is essential. Implementing NGS testing as a routine practice, followed by MTB for precise diagnostics, is potentially crucial for initiating targeted therapies and improving patient survival rates.

The network aims to bridge the gap between basic research and clinical practice, expediting the transition of groundbreaking discoveries into real-world applications. The goal is to optimise clinical trial design for innovative therapies, ensuring that promising interventions are rigorously evaluated and swiftly integrated into standard care protocols.

Emphasising continuous education and professional development fosters a culture of learning within the network. Workshops, seminars, webinars, and mentorship opportunities enable members to stay updated on emerging trends, share expertise, and refine their skills. Continuous learning enhances collective knowledge and promotes a culture of excellence. Education and knowledge sharing are vital for the comprehensive management of PPCs. Equipping healthcare professionals, researchers, patients, and caregivers with the necessary expertise empowers them to deliver high-quality care and support throughout the cancer journey. Collaborative networks that facilitate the dissemination of research findings, treatment approaches, and best practices are essential for providing current and effective care. Education is a critical tool for patients and their caregivers, guided by dedicated healthcare professionals and driven by cutting-edge research.

Finally, healthcare organisations, professional societies, and policymakers must prioritise research and development (R&D), regularly update clinical practice guidelines, and implement practical actions for patients in each Member State. Promoting the adoption of NoE PPC deliverables in healthcare policies can reduce heterogeneity in diagnostics and treatment approaches, ensuring consistent, high-quality care and innovation for patients with PPCs in Europe. Policies and initiatives that improve access to specialised care and increase research funding are crucial components of this advocacy effort.

Based on the "Political Declaration and List of Actions Against Cancer" (5) prepared by INCA and NoE PPC experts, three concrete actions have been identified:

1. Shift research proposals towards "high risk, high gain" and establish research programs with a high translational agenda.
2. Provide a framework to facilitate data sharing in advance of projects for mutual benefit.
3. Ensure the best available care by enhancing the quality and speed of delivery (e.g., time to diagnosis, time to treatment) and implementing guidelines for early access to novel therapies.

The Political Declaration and List of Actions Against Cancer were released in Paris during the French Presidency, with the first results presented in Stockholm during the Swedish Presidency (Annex 8).

Ecosystem for implementation

It is essential to integrate several key elements to build and manage a successful NoE PPC. Promoting international collaboration allows for sharing knowledge, resources, and expertise on a global scale, ultimately advancing our understanding of and ability to address the unique challenges posed by PPCs. Facilitating interdisciplinary collaboration and support services to address the patients' multifaced needs will help.

Creating use cases focused on specific patient groups will enhance the network's effectiveness. These will represent the future PPC-specific "domains" of the NoE, thus organized in a network of networks. Each subnetwork requires inspirational and goal-oriented leadership, as well as exploration of critical elements, emphasising their significance in shaping the network's transformative potential. Therefore, the starting point was initiated as a use case for pancreatic cancer since it is an emerging clinical issue in oncology. It was also selected based on the deliverables provided by IPAAC, which proposed putting a set of standards on early diagnosis, guidelines, and education into practice.

Regular meetings were organised to foster collaboration and ensure all relevant perspectives were considered. (Annex 7 – meetings/activities). Additionally, as a part of the implementation, in April 2022, the NoE for Pancreatic Cancer was established under the leadership of Mathis Lohr and the following areas of interest were defined:

- Quality of Care (leader Michel Ducreaux-coordinator the ESMO CPG for pancreatic cancer),
- Research and Innovation (leader Marta Mańczuk MSCI),
- Policy and citizen engagement (leader Joseph Borras – IPAAC leader),
- Education (leader - Dorota Dudek-Godeau – IPAAC partner),
- Patients Advocacy Group – Pie ro Rivizzigno (Codice Viola).

Based on the experiences of the pilot Network of Expertise (NoE) dedicated to pancreatic cancer, a roadmap for future NoEs can be developed for other cancer types that meet the criteria of poor prognosis and represent the most challenging clinical indications.

To enhance effectiveness and raise awareness about PPCs, we have undertaken targeted communication efforts. We have informed the community and disseminated our actions through various initiatives, including:

- Conference on "Cancer, Equality, and Europe's Beating Cancer Plan" - A Swedish Presidency event organised by the Swedish Comprehensive Cancer Centers and the Swedish Cancer Society, held on 09 May 2023, at Karolinska University Hospital (Annex 8 Swedish Presidency Flyer).
- CRANE Stakeholder Forum and Workshops – Paris, 2023.
- OECI Oncology Days Dedicated Session for EU4Health JA – Paris, 2023.
- CRANE Stakeholder Forum and Workshops – Oslo, 2023.
- High-Level Stakeholders Conference: Networking on "Tackling the Implementation Gap: SWOT" – Madrid, 2023.
- OECI Oncology Days Dedicated Session for EU4Health JA – Helsinki, 2024.
- NoE JA Event at the European Parliament – Brussels, 2024.

Endorsement Criteria for Partners and Organisation

Our commitment to collaboration is integral to the success of the Network of Expertise for NoE PPC . We prioritise the following elements to ensure effective partnerships and organisational synergy:

- **Leadership and Influence**: The network should include individuals who have demonstrated leadership in the field of solid tumours. This element can be evidenced by positions held in professional societies, editorial roles in scientific journals, or involvement in policy-making organisations related to solid tumours.
- **Clinical Excellence**: The network should include members with significant experience treating patients with solid tumours and a track record of providing high-quality care. This element can be evaluated based on patient outcomes, institutional reputation, and peer recommendations.

- **Research Contributions**: The network members should have a history of active research contributions in the study of solid tumours. This element can be demonstrated through peer-reviewed journal publications, clinical trials, preclinical study participation, or scientific conference presentations.
- **Funding and Resources**: The network should have access to adequate funding and resources to support its activities. This element can include grants, institutional support, or collaborations with industry partners.

Given the complexities involved in establishing uniform endorsement criteria for expertise in PPC (Annex 5 – M5.4), the WP5 team has agreed that each Member State would independently identify its experts, hospitals, societies and PAGs and other research centres to participate in the NoE PPC. This approach ensures that the network integrates a diverse range of specialists and institutions while accommodating the unique needs and priorities of each Member State.

Consortium members with expertise in PPC joined the WP5. Between them were oncologists, oncological surgeons, molecular biologists, scientists, patient advocates, and policymakers. In January, under preparation of the proposal of JANE 2, the consortium members enlarged to more than 60 institutions from each MS. Therefore, the expertise of health care providers (centre selection) was identified and endorsed at the national level. (Annex 6 - M5.5).

Future activities and plan for implementation

To examine NoE's future priorities, activities, and deliverables, we analysed data from surveys realised for this purpose. We analysed and identified key trends, gaps, and areas for improvement. The survey findings were compiled into a comprehensive report and presented to the WP5 PPC group, ensuring that the insights and recommendations were thoroughly vetted and refined. The survey's main findings highlighted the need for robust policy support to facilitate rapid innovations and improvements in cancer care. There is a strong emphasis on enhancing collaborative efforts and adopting innovative solutions for PPCs. We defined critical gaps and list of future actions of NoE (M5.6) as below:

Critical gaps	Prioritisation and activities for future NoE
Limited accessibility of new treatment advances like immunotherapies and targeted therapies. Inequalities in the integration of scientific developments in diagnostic methods (e.g. integration of AI in radiology, use of liquid tumour biopsy, and other genomic technologies). Room for improvement in early symptom identification and tailored screening. Missing registries enabling monitoring of quality of care and survival	Multidisciplinary care approaches and patient pathways as a part of the cancer infrastructure. Enhancing drug availability and usage, especially based on genomic biomarkers. Programs for early diagnosis, innovative screening, and vaccination therapies. Establishing a data-driven approach enabling monitoring of quality of care and survival NoE for PPC prioritises activities for poor-prognosis cancers: pancreatic cancer (con't), lung cancers, and for other indications based on research and roadmaps.
National databases and biobanks are essential for supporting clinical trials, research, and cooperative research projects from bench to bedside.	Strengthen collaboration between research groups and develop a database about ongoing research projects. Drug development programs for innovative therapies, including patient involvement in research.

The need for early diagnostic tools and focus on developing risk stratification and public education to detect cancer early. Address gaps in international trial participation, regulatory hurdles, and the need for more academic research.	Improvement of early cancer detection technologies. Focus on reducing bureaucracy and protecting time for research in clinical personnel.
Continuous medical education and standardised care practices through interactive training sessions covering new diagnostic and screening techniques, molecular biology and genomics for targeted therapies, therapies and their complications and integration of palliative care at early-stage metastatic disease.	Workshops on clinical trial design. Forming cross-disciplinary teams and mentorship programs. Training on emerging technologies like AI, telemedicine, and advanced imaging, and incubators for healthcare innovations focused on poor prognosis cancers. Enhancing communication and management skills and implementing nationwide awareness of PPCs.
Highlight the needs of management of PPCs endorsed by the EU Emphasise the limitation in adherence to guidelines. Address the MDT/MTB management for patient diagnostics and care in accredited centers. Discuss the challenges of GDPR and data sharing, especially the need for reforms that balance privacy with research and treatment needs. Identify gaps in economic support for research and discrepancies in reimbursement policies across countries.	Building relationships with regulatory bodies to streamline approval processes. Provide support for navigating regulatory processes for new cancer treatments. Advocating for policies and partnerships to facilitate innovation adoption. Conducting cost-benefit analyses to showcase new treatment benefits. Built infrastructure to monitor the effects of intervention.

To deliver and implement prioritised activities, the consortium members were enlarged to more than 60 institutions from each MS, and therefore, the expertise of healthcare providers (centre selection) was identified and endorsed at the national level (Milestone 5.5).

Indicators of efficacy and cost-efficiency

The NoE PPC is pivotal in advancing the scientific understanding of these complex and challenging clinical situations. A primary benefit of the network lies in its ability to bridge the gap between laboratory research and clinical practice. The patient-centric approach ensures that NoE is aligned with individual needs and values. The network serves as a hub for knowledge dissemination and education, fostering the exchange of insights through conferences, seminars, publications, and online platforms, and enables experts to stay informed about the latest advancements, trends, and breakthroughs in the field of PPCs, driving continuous learning and improvement.

However, to maximise the impact of the NoE PPC, a comprehensive cost-effectiveness analysis using health economics methodologies is needed. Current efforts are limited by significant challenges, such as the lack of granular, high-quality data from multiple sources, including medical records, treatment costs, and patient outcomes across different countries and institutions. The difficulty in accessing comprehensive data from various stakeholders, such as healthcare providers and institutions, further complicates this analysis. To address these gaps in future, a cost-effectiveness analysis will benefit if the following additions will be in place:

- **Enhanced Data Collection and Integration** across different national and institutional settings to create a centralised data repository that aggregates information on costs, treatments, and patient outcomes, ensuring consistency and comparability after employing data-sharing agreements as collaborative partnerships with stakeholders, hospitals, research institutions, and pharmaceutical companies.
- **Usage of Advanced Analytical Techniques** by utilising artificial intelligence (AI) to analyse complex datasets and identify patterns of different interventions across diverse settings.
- **Comparative Effectiveness Research** to evaluate and compare the costs and outcomes of various treatment modalities, programs, and initiatives across different healthcare systems.

By incorporating these elements, future cost-effectiveness analyses of the NoE PPC can be significantly improved, leading to more informed decision-making and better allocation of resources to optimise patient outcomes.

5. Network structure and detailed activities

The NoE PPC is a structured platform for experts to collaborate, ensuring that interactions are purposeful, goal-oriented, and aligned with objectives and can lead to discoveries, innovative solutions, and novel approaches to challenges. The preliminary governance structure was submitted as MS5.3 (Annex 4), and, during further discussion, evaluated as follows.

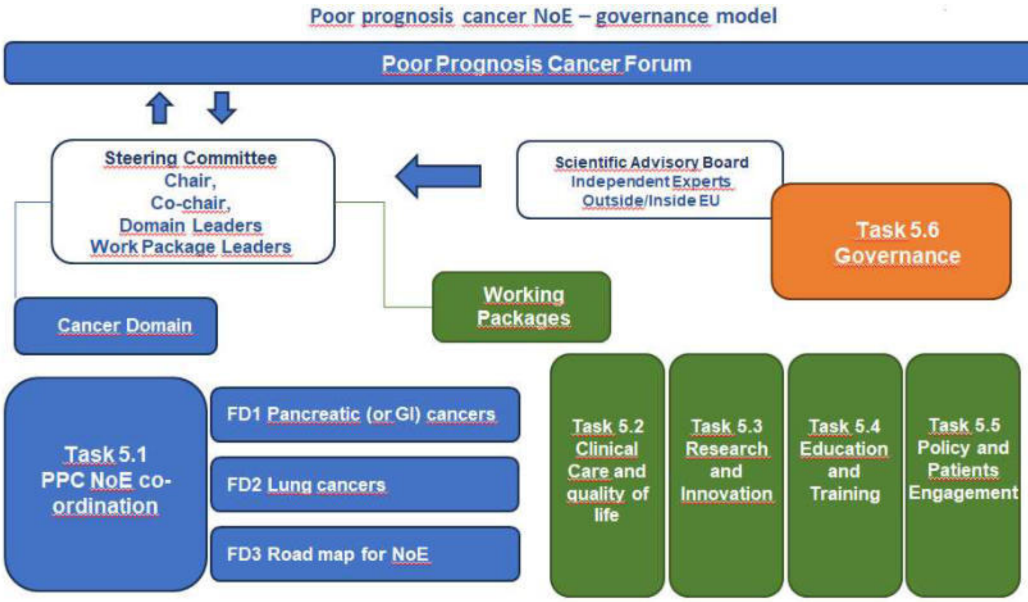

FIGURE 3 WP5 GOVERNANCE MODEL

Steering Committee

We propose establishing a diverse and interdisciplinary steering committee to oversee the activities of NoE PPC. The SC should include a multidisciplinary team, patients' representatives, and relevant stakeholders. The SC will play a crucial role in providing guidance, strategic direction, and oversight needed to effectively address the challenges associated with PPC. Regular meetings are planned to discuss progress, challenges, and decisions (at least twice yearly).

Tasks and Domain

Specialised domains are formed to streamline the management of diverse WP5 components and address quality of care, research & innovation, education, and policy. Each domain focuses on its designated tasks to ensure comprehensive coverage. These are listed below.

Task Clinical Care & Quality of Life will provide expertise on the best practices for patients with PPC, focusing on optimising the quality of care and their quality of life. The major challenges are overcoming late diagnosis and improving access to the best available care and innovative therapies. Task focus on supporting the PPC NoE in developing recommendations for implementing diagnostic-therapeutic guidelines, pathways, consensus statements, and informative do's-and-don'ts factsheets for prevention, early diagnosis, therapy and early access to supportive/palliative care for PPC and on establishing cooperation with CCCC/N structures to facilitate the assessment of the impact on outcomes, the definition of care quality indicators.

Task Research & Innovation will identify challenges, advancements, and gaps in PPC's. Nowadays, precision oncology is a reality, and therefore, patients with PPC should take advantage of this therapeutic strategy. The integration of omics technologies into EU healthcare systems is still not equally accessible to all cancer patients across Europe, nor are high-tech resources such as innovative radiology, surgery, nuclear medicine, or cellular therapy. Beyond genomics, the integration of transcriptomics, proteomics, methylomics, metabolomics or even epigenomics, lipidomics and radiomics needs to be accelerated for adequate clinical decisions in primary, secondary, as well as diagnosis and therapy. PPCs are relevant pilots, allowing us to test the feasibility and added value of omics and their integration via AI in patients' care. The main objective of this Task is to assess the feasibility and provide guidelines for implementing innovative omics & other high-tech medical resources in patient management. This Task will be undergone with JANE WPs 6&7 (omics and high tech). All pilots' designs will actively engage patients' groups. The training dimension will also be covered.

Task Education & Training aims to develop and implement a comprehensive education and training program focused on enhancing the knowledge and skills of healthcare professionals within European healthcare systems in the management of PPC. Recognising the unique challenges posed by PPC, this initiative seeks to empower healthcare providers with cutting-edge information, evidence-based practices, and advanced skills necessary for delivering optimal care to patients facing these challenging conditions. To define training and education need assessment through literature review, then a Delphi consensus study will be organised to set core competencies for PPC to create educational materials with online modules and organise workshops/ webinars to facilitate hands-on training and interactive learning experiences and to develop a framework for online training modules and resources delivery. This framework would function as a centralised hub tailored to allow healthcare professionals to access educational materials, participate in webinars, and engage in collaborative discussions. It will prioritise user-friendliness, accessibility, and interactivity within the content.

Task Policy & Patient Engagement will promote a systematic survey of health policy interventions or strategies deployed in each member state to promote positive discrimination in cancer care for patients with poor prognosis cancers. The patient engagement domain will focus on assessing how NoE Centers deploy patient engagement strategies for both direct care and organisational design and governance. Leveraging the information obtained from these two approaches, a catalogue of policy initiatives and patient engagement strategies will be made publicly available to support MS and affiliate centres in the selection of policy alternatives to improve national healthcare outcomes and improve patient engagement. Building upon current best practices on patient engagement identified within the NoE centres, we propose the development of educational materials and supportive literature to foster the dissemination of these practices across the network. The expertise will be selected based on the endorsement criteria. Collaboration with patient organisations, non-governmental organisations, and national policymakers is critical for making clinically relevant and patient-centred decisions and their effective implementation.

Task PPC NoE coordination (Cancers Domain) dedicated to the overall establishment and support of NoEs that are dealing with selected PPC – continue action for pancreatic patients and release NoE for lung cancer , and develop of a roadmap for future NoEs based on the experiences gained from the pancreatic and lung cancer groups. The activities of the NoE on Poor Prognosis Cancers will include defining and agreeing on guidelines, recommendations and patient information packages. The first step in these activities will be to define NoE needs, map existing guidelines, and set up a legal framework for collaborating with scientific societies and patient advocacy groups. These strategic decisions will be made by the Steering Committee and NoE partners.

Task Governance for NoE effective management is vital for optimising collaboration, streamlining communication, and ensuring that experts' collective knowledge and skills are harnessed efficiently towards common goals. The Coordination Task aims to manage the progress of project activities with timely achievement of milestones and deliverables within planned resources. The Task focuses on the dissemination targeted approach designed to engage professionals, patients, and key stakeholders involved in PPC effectively, evaluation to gauge its efficiency and sustainability, which focuses on establishing the sustainability strategy of the NoE addressing key factors such as resource allocation, funding mechanisms, scalability, EU collaborations, implementation of achievements at country level.

Supporting Bodies

Poor Prognosis Cancer General Assembly serves as a central platform for collaboration, knowledge sharing, and expertise exchange within the NoE PPCof NoE and plays a critical role in providing oversight, guidance, and direction to the organisation, ensuring that its efforts are effective, transparent, and aligned with its mission and goals.

Scientific Advisory Board (SAB) is a multidisciplinary team of leading experts in oncology, pathology, genomics, and health economics, also outside the JANE Consortium. The SAB provides strategic guidance and oversight to ensure the network's research and clinical initiatives align with the latest scientific advancements and best practices. It plays a key role in evaluating new research proposals, fostering collaborations, and facilitating the translation of laboratory findings into clinical applications.

6. Sustainability

Adequate financial and non-financial resources are essential for sustaining the network's operations over the long term. Securing diverse funding sources—such as collaborative grants, partnerships with the private and public sectors, leveraging institutional support, and optimising resource allocation—are critical to ensuring the network's long-term viability. A sustainable approach empowers the network to execute initiatives, drive innovation, and continue making impactful contributions to the field of poor prognosis cancers.

Establishing robust metrics to measure the network's impact is vital to support sustainability. This action should include regularly assessing key outcomes, achievements, cost-effectiveness, and member satisfaction, providing valuable insights into the network's performance and guiding strategic decision-making.

Additionally, these metrics can help demonstrate the value and impact of the network's work to stakeholders, thereby attracting further support and engagement.

Furthermore, fostering a collaborative culture is crucial to the network's success and sustainability. Promoting open communication among members and creating structured opportunities for collaboration helps build a productive and inclusive environment. By encouraging members to actively contribute insights, share knowledge, and participate in joint initiatives, the network can enhance its collective expertise and drive meaningful advancements, particularly during the PPC Forum.

Lastly, building strategic partnerships with external organisations, including academic institutions, research bodies, patient advocacy groups, and industry partners, can amplify the network's reach and resource base. Such collaborations can open new avenues for funding, innovation, and impact, reinforcing the network's sustainability in the long term.

7. Interplay with MS, networks and EU patients

The NoE PPC is designed to work synergistically with Member States, other NoEs, existing EU initiatives (e.g., EUonCCC, ECHOS, UNCAN), patients across the European Union, and societies involved in cancer care and research (OECI, ECO, ESMO, EORTC, ESSO). This collaborative approach ensures a cohesive and integrated strategy for tackling poor prognosis cancers.

Member States: Each participating Member State plays a vital role in the network by contributing local expertise, resources, and data. Member States are encouraged to align their national cancer strategies with the network's objectives, facilitating cross-border collaboration and standardisation of care. This cooperation enhances the overall effectiveness of the network and supports the implementation of best practices across different healthcare systems.

Networks: The NoE PPC interacts with other NoEs (e.g., Omics, Hi-tech Medical Resources, Palliative Care, Survivorship, AYA). This interplay fosters information exchange, coordinated research efforts, and shared resources. Additionally, collaboration with EUonCCC leverages existing knowledge, avoids duplication of efforts and amplifies the impact of collective research and clinical advancements. This relationship ensures that the network remains at the forefront of cancer care and research while providing patients' access to the latest therapies and innovations.

EU Patients: Engaging with patients across the EU is central to the NoE PPC's mission. Patient involvement is sought to ensure that the network's initiatives are patient-centred and address the real-world needs of those affected by poor prognosis cancers. This approach helps to tailor the network's activities to better serve the diverse patient population across the EU.

Organisations and Societies: Collaboration with key organisations and societies, such as the OECI, ECO, ESMO, EORTC, and ESSO, is crucial to the NoE PPC's strategy. These organisations provide a platform for exchanging best practices, develop clinical guidelines, and innovative research findings. Their involvement strengthens the network's ability to implement cutting-edge cancer care solutions and foster a unified approach to tackling poor prognosis cancers. Engaging these societies also enhances advocacy efforts, increases visibility for research findings, and facilitates the adoption of new standards of care across Europe.

8. Challenges and Solutions

The concept of the Network of Expertise for Poor Prognosis Cancers (NoE PPC) holds immense promise for advancing the fight against these challenging malignancies. However, this ambitious approach faces several limitations. Understanding and addressing these limitations is crucial for developing a realistic and effective strategy to tackle the complex challenges encountered in real-world settings. Key challenges and their potential solutions are outlined below:

Resource Constraints. Establishing and maintaining the NoE PPC requires substantial resources, including financial support, access to cutting-edge technologies, and dedicated human capital. Limited funding or inadequate access to state-of-the-art facilities could hinder the network's ability to conduct comprehensive research and implement ambitious projects.
Solution: Actively pursue diverse funding sources, including grants, public-private partnerships, and philanthropic contributions where possible. Foster synergies with other European NoEs and initiative to enhance information exchange, coordinated research efforts, and resource sharing. These collaborations can maximise the efficient use of resources and expand the network's capacity.

Lack of Legal Entity. The absence of a formal legal entity for the NoE can complicate the network's ability to enter contracts, manage funds, and establish formal collaborations. This limitation can hinder operational efficiency and legal accountability.
Solution: Establish a formal legal entity, such as a non-profit organisation or consortium, to provide a clear legal framework for the network's operations. This entity can handle contractual agreements, manage finances, and facilitate formal partnerships. Engaging legal and financial experts to guide the establishment and governance of this entity will ensure compliance and operational effectiveness.

Lack of Access to Data for Monitoring Quality of Life and Network Performance. Monitoring the quality of life of patients and assessing the performance of the network is challenging due to limited access to comprehensive and up-to-date data. This gap can affect the network's ability to measure impact and make informed decisions.
Solution: To take advantage of EU initiatives related to data collection. Advocate for policies that enhance data accessibility and integration across healthcare systems, ensuring that relevant data is available for assessing patient outcomes and network effectiveness.

Inequalities in care in the EU. Ensuring equitable access to the network's benefits is crucial to avoid health disparities and biases in outcomes.
Solution: Prioritise inclusive policies and practices. Collaborate with local organisations and healthcare providers to reach underserved populations and address disparities in care access across different EU regions.

Evolving Scientific Landscape. The field of oncology is marked by rapid scientific advancements, with new discoveries and technologies emerging frequently. Keeping pace with these developments and integrating evolving insights into clinical practice requires continuous vigilance and adaptability.
Solution: Establish dedicated activities to monitor scientific trends and technological innovations and organise regular training and workshops to ensure network members stay updated and adaptable.

Tackling Clinical Translation Hurdles. Translating laboratory findings into clinical practice can be challenging due to complexities such as clinical trials bureaucracy, which can cause delays in applying breakthroughs.
Solution: Foster partnerships with regulatory bodies and industry to expedite approvals. Develop a robust patient engagement strategy to facilitate the implementation of breakthroughs and reduce delays.

Interdisciplinary Challenges. The network's strength lies in its ability to integrate expertise from diverse fields. However, this interdisciplinary collaboration may face challenges, such as differing research priorities and organisational goals, which can impact smooth cooperation.
Solution: Facilitate regular interdisciplinary workshops, create collaborative platforms, and establish clear communication channels among members to enhance cooperation.

Collaboration and Community Integration. Collaborative efforts within the network may encounter dilemmas related to authorship, intellectual property, and the fair distribution of credit for discoveries. These issues can affect open collaboration and trust among stakeholders.

9. Conclusion

The NoE PPC represents a collaborative effort to improve outcomes for patients with challenging cancer types across the European Union. By leveraging the combined strengths of Member States, other Networks of Expertise, EU initiatives, patient communities, and key organisations involved in cancer care and research, the network promotes a cohesive and integrated strategy for addressing poor prognosis cancers.

Through these efforts, the NoE PPC aims to drive significant advancements in research, clinical practice, and policy, ultimately enhancing the quality of life and care for all patients affected by these cancers. Additionally, this approach is strengthened through synergies with other Coordinating and Support Actions (CSA), Joint Actions (JA) projects, scientific societies, and relevant stakeholders. These collaborative efforts will ensure the alignment of activities, priorities, and deliverables, culminating in a comprehensive report for MS5.6, which reflects the network's achievements and strategic goals.

10. References

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6. https://pancan.org/news/five-year-pancreatic-cancer-survival-rate-increases-to-12/

11. Annex

Annex 1

Partners involved in JA JANE WP5.

Annex 2

Milestone 5.1 List of Experts (attached)

Annex 3

Milestone 5.2 Definition of the aims and specific objectives of the NoE (attached)

Annex 4

Milestone 5.3 Governance structure (attached)

Annex 5

Milestone 5.4 Endorsement criteria (attached)

Annex 6

Milestone 5.5 Site selection (attached)

Annex 7

Meetings/Activities

Annex 8

Swedish Presidency flyer (attached)

Annex 9

Survey (attached)

Annex 10

Milestone 5.6 (in the report pages 14-15)

Annex 1

Partners involved in JA JANE WP5.

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Belgium	Sciensano
Czech Republic	University Hospital Motol
Luxembourg	INC Centre Hospitalier de Luxembourg – HPB Surgeon
Portugal	Institute of Oncology Porto
Poland	NIZP-PZH MSCI – WP5 Leader
France	INCa Euracan Gustave Roussy Unicancer
Sweden	Karolinska Institute
Italy	INT-IRCCS University of Palermo CNAO Pierro Rivizzigno – Patient Organisation
Greece	NUKA NHRF
Norway	Oslo University Hospital
Spain	IDIVAL Hospital Universitatrio Marques de Valdecilla Kronikgune ICO

Annex 2

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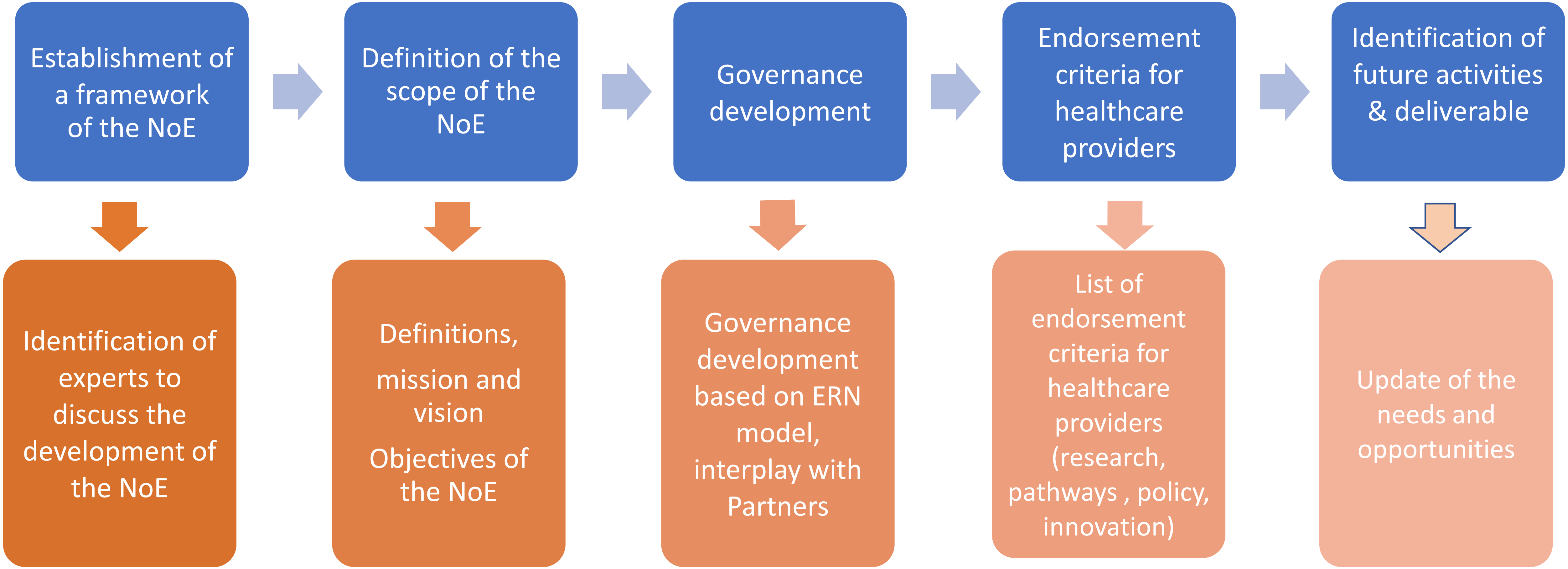
Joint Action JANE

WP 5 Complex & poor-prognosis cancer

Prof. Iwona Lugowska, MD PhD

WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)



Establishment of a framework of the NoE

Identification of experts to discuss the development of the NoE

Definition of the scope of the NoE

Definitions,

mission and vision

Objectives of the NoE

Governance development

Governance development based on ERN model, interplay with Partners

Endorsement criteria for healthcare providers

List of endorsement criteria for healthcare providers (research, pathways , policy, innovation)

Identification of future activities & deliverable

Update of the needs and opportunities

WP 5 Deliverable

Report with the scope and expected activities of the NoE, its governance, sustainability, indicators of efficacy and cost/efficacy evaluation criteria, interplay with MSs, other EU networks, CCCs, patients.

WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)

Establishment of a framework of the NoE

Identification of experts to discuss the development of the NoE

The aim of this task will be to scope and bring together experts and relevant stakeholders to be involved in the NoE(s), starting from

- a discussion about which are the complex and poor-prognosis cancers that deserve a NoE and

- what type of network is most advantageous and effective.

In this NoE, representatives of health-care providers, ePAGs, ERNs, MS and other EU initiatives may be involved.

Leader: MSCI
Partners: TTF4, TTF5 IOL, OOI, NKUA, Sciensano, INCa, IRST, CNAO, IOV, KG, IDIVAL, ICO, Junta Andalucia

Task 5.1. Milestone
List of experts (M3)

WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)

Establishment of a framework of the NoE

Identification of experts to discuss the development of the NoE

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Task 5.1. Milestone
List of experts (M3)

The steps to achieve these goals

1. **discussion on the definition of what type of cancer or oncological condition has a poor prognosis and prioritise them based on clinical needs.**
2. **establishing the model network: NoE for D5-GI (pancreatic cancers)** starting with
    a. mapping of existing resources and expertise across Europe, which will be experts in the field and European or international scientific societies, national networks, tertiary care providers, patient organisations and their advocates (PAG), member states representatives and public health experts.
    b. Discussion about Tasks of NoE D5 GI: pancreatic cancer
    c. Defining Task leaders
3. **Scale up the model NoE for other poor prognosis cancers and prepare endorsement criteria for further NoEs PPC.**

WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)

Definition of the scope of the NoE

Definitions,

mission and vision

Objectives of the NoE

The main objectives will include the identification **of tools and strategies which might improve the quality of care and reduce inequalities across the EU** in complex and poor prognosis cancers.

We should focus on

- Clinical care & pathways (guidelines)
- Innovation and research
- Policy and Implementation
- Education and PAG cooperation.

Task 5.2. Milestone
List of objectives (M6)

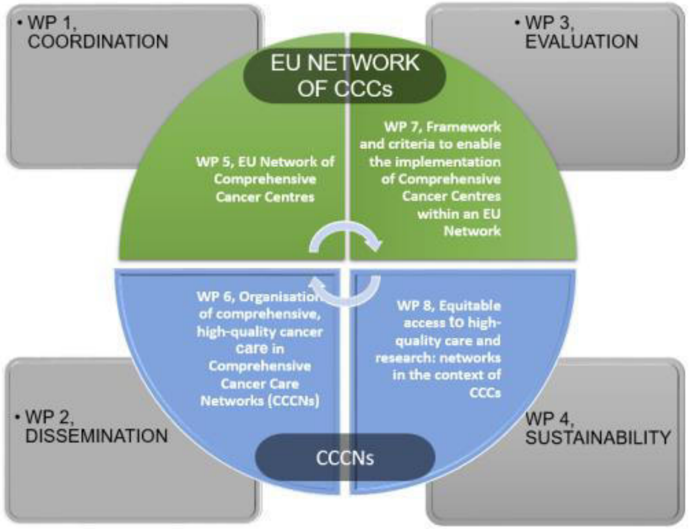
WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)

EU4Health Programme (EU4H)

Application Form

Technical Description (Part B) –

CraNE Joint Action



RÉPUBLIQUE FRANÇAISE
Liberté Égalité Fraternité

INSTITUT NATIONAL DU CANCER

European 2022 CANCER MEETING

UE FRANCE22

DÉCLARATION POLITIQUE
ET LISTE DES ACTIONS CONTRE LE CANCER
RECOMMANDÉES PAR UN PANEL DE PARTIES PRENANTES EUROPÉENNES

POLITICAL DECLARATION
AND LIST OF ACTIONS AGAINST CANCER
RECOMMENDED BY A PANEL OF EUROPEAN STAKEHOLDERS

LEADING INITIATIVE 4: Make research the priority to radically switch approaches to poor prognosis cancer: call for "High risk High gain"[54] proposals at European level. Simultaneously, set up clinical research programs, with high translational research agenda.

LEADING INITIATIVE 5: Provide a framework and tools to enable the engagement of health professionals and researchers to share their data in advance of projects, in order to better understand barriers and benefits from each other's progress.

LEADING INITIATIVE 6: Ensure the best available care is provided by increasing quality and speed of delivery, for the patient as an individual (time to diagnosis, time to treatment initiation) and for the patient population as a whole (implementation of guidelines, early access to innovative drugs and new therapies in surgery and radiotherapy).

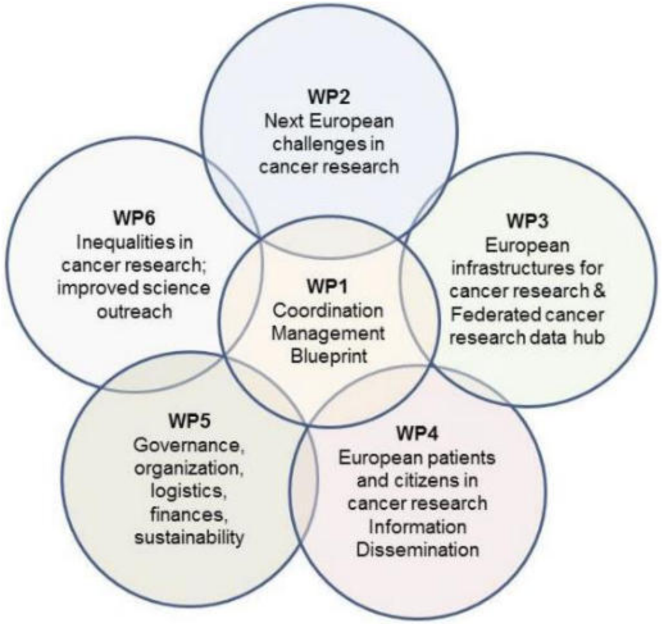
Call: HORIZON-MISS-2021-UNCAN-01
(Preparing UNCAN.eu, a European initiative to understand cancer)

Topic: HORIZON-MISS-2021-UNCAN-01-01

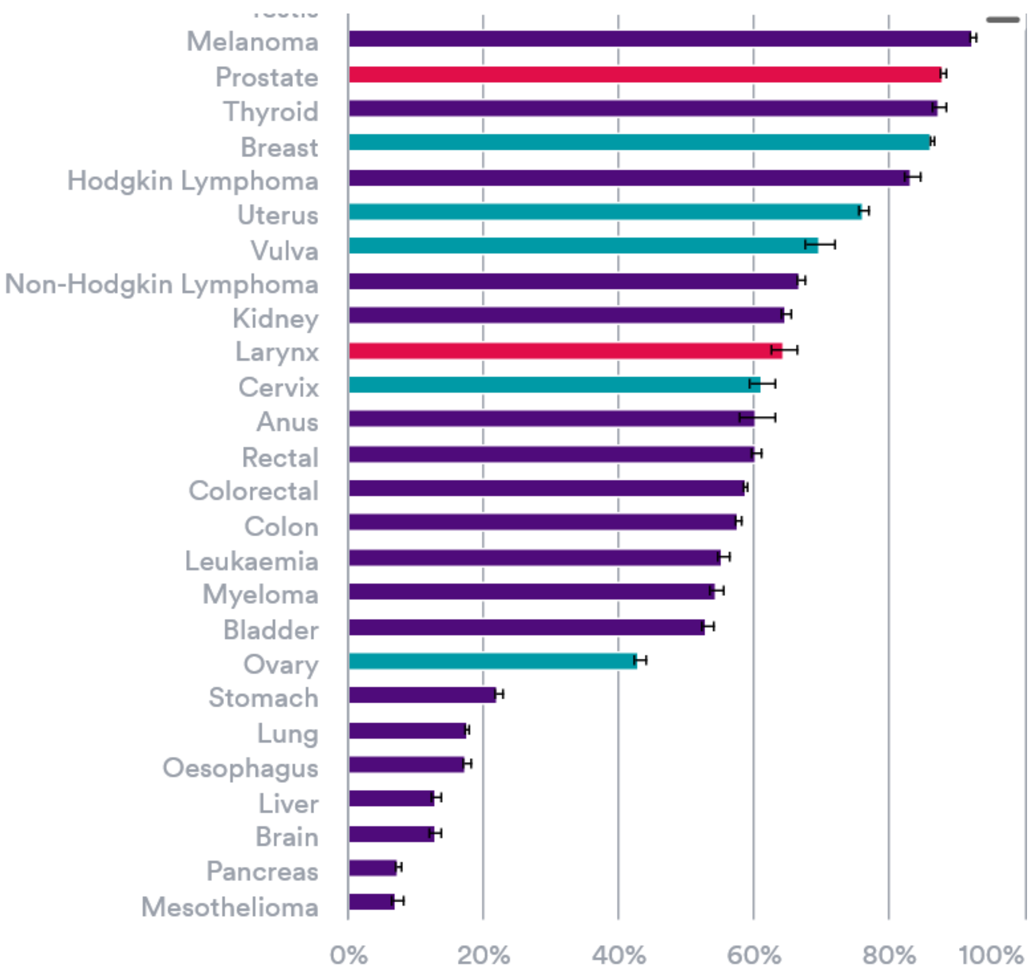
Type of Action: HORIZON-CSA

Proposal number: 101069496

Proposal acronym: 4.UNCAN.eu



WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)



Five-year cancer survival estimates for adults (aged 15–99 years)
in England diagnosed between 2014–2018 and

INCA/IPAAC defined a poor prognosis for cancers whose survival rate at the time of discovery is estimated to be below 33% after five years.

05 JAN 2023 – INCA: The proposal is to have more broad definition of PPC which should be based on:

- 5-year survival rate below 33% (stomach, CNS, gall bladder and bile ducts, lung, liver, esophageal cancer, pancreatic, pleural mesothelioma).
- clinical situations (metastatic disease, resistant tumors, specific cancers subtypes eg. triple negative breast cancer)
- molecular subtypes (if the literature is available)

The definition should be broad enough to guarantee that sufficient data is available.

Mission of NoE – PPC

It is essential to develop at a ***European level fundamental, translational and clinical research*** *to build new treatment paradigms that* ***could radically transform the prognosis of these cancers****.*

- The mission of NoE – PPC, based on its network of experts of a multidisciplinary team, is to improve knowledge, research, healthcare as diagnosis and treatment management, and communication for all patients, authorities and institutions involved in poor prognosis cancers defined as:

1) to critically evaluate existing models of current and future EU networking

- The EURACAN model of organ domains will be adapted with a need to perform a mapping of existing resources for selected PPC such as clinical expertise, EU consortium and research groups, PAGs, and other JA activities. The four fields of interest will be addressed: education, patients care, research and innovation and policy

1) to prepare recommendations to launch the new networks of expertise for one or more complex & poor-prognosis cancer(s).

- The pilot network for pancreatic cancer with is organised, and we will propose it as a model for further networks dedicated to PPC

WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)

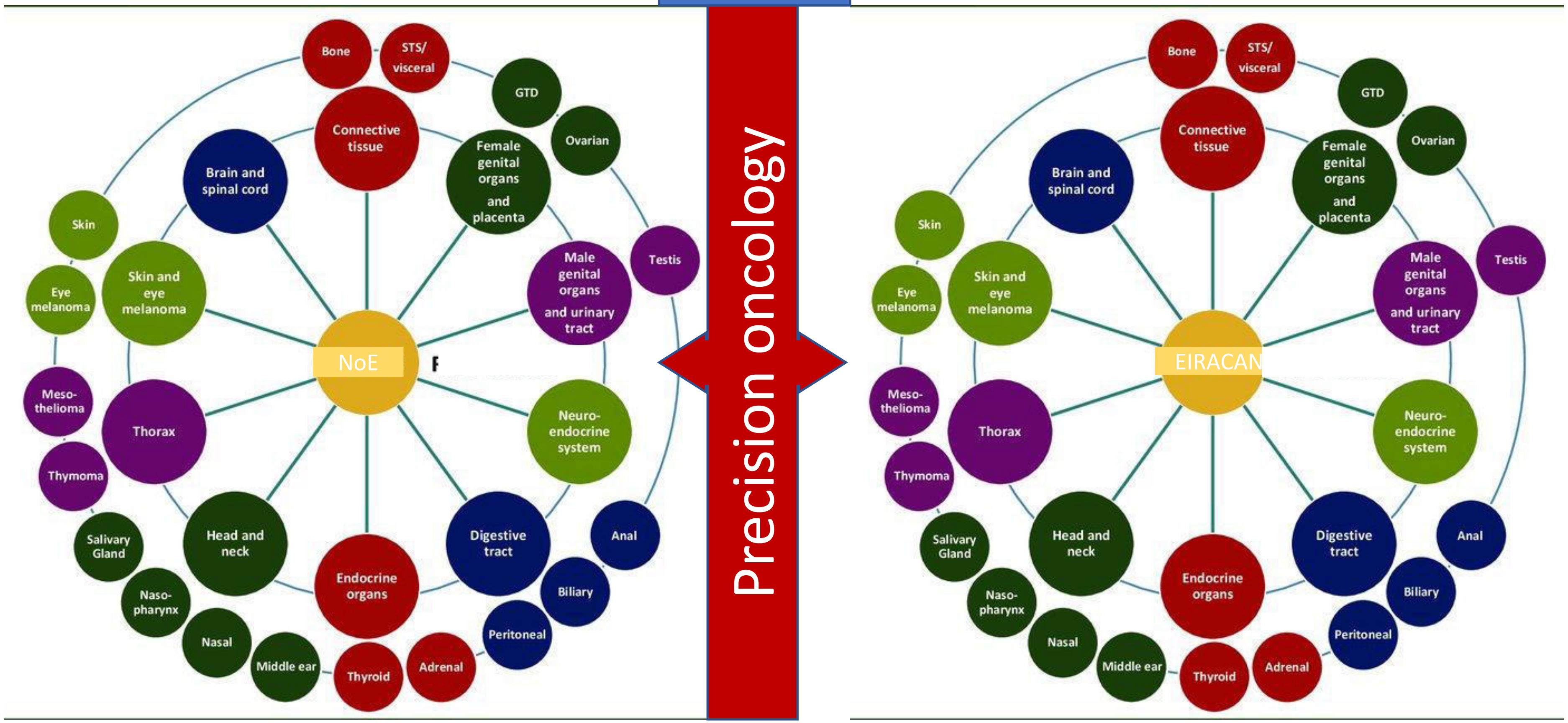
Governance development

Governance development based on ERN model, interplay with Partners

Network for poor prognosis cancers

RWE

Reference Network on Rare Adult Cancers



Task. 5.3 Milestone

Final document describing the governance of the NoE available on the JANE website (M12)

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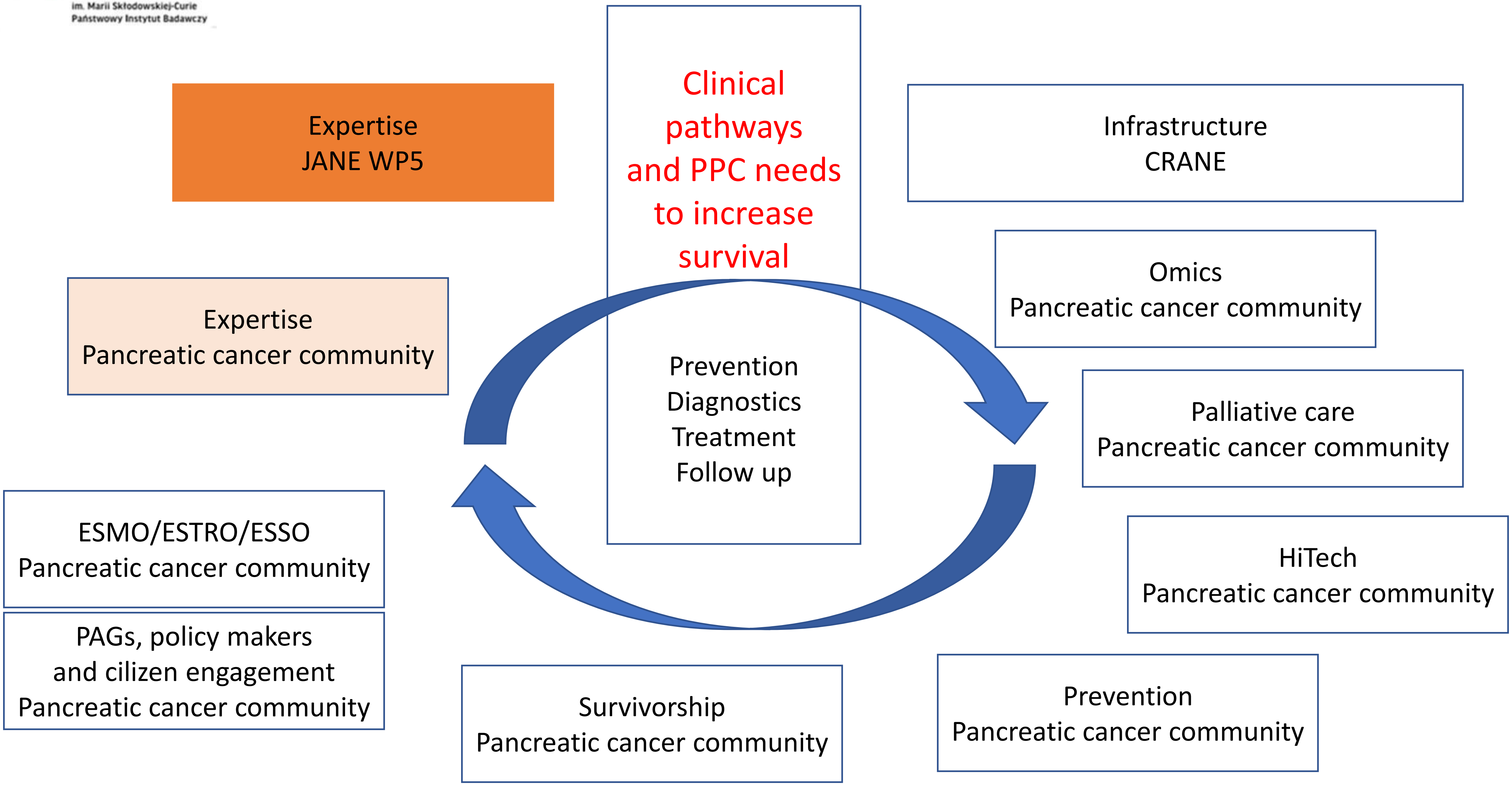
WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)



Expertise
JANE WP5

Clinical pathways and PPC needs to increase survival

Infrastructure
CRANE

Omics
Pancreatic cancer community

Expertise
Pancreatic cancer community

Prevention
Diagnostics
Treatment
Follow up

Palliative care
Pancreatic cancer community

ESMO/ESTRO/ESSO
Pancreatic cancer community

HiTech
Pancreatic cancer community

PAGs, policy makers
and cilizen engagement
Pancreatic cancer community

Survivorship
Pancreatic cancer community

Prevention
Pancreatic cancer community

The specific objectives of NoE PPC

- to provide recommendations and educate the community about poor prognosis cancers, to implement clinical pathways assuring the high quality of care and leverage cancer inequalities in Europe, also by developing and continuously reviewing cancer outcomes, and based on the results, to define further public health priorities for the NoE PPC (integration with oncological Societies, other JA)
- to implement "roadmaps" from referrals to experts, to promote optimised care, to increase and facilitate access to innovation for people with poor prognosis cancers (integration with CRANE)
- to initiate and promote novel translational research programmes (integration with research consortium, 4 UNCAN etc)
- to proactively involve patient advocacy groups to support people with poor prognosis cancers and assist them in the wide dissemination of relevant information about these diseases using educational tools, collaborative networks, and other means (integration with PAGs and policy)

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WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)

Endorsement criteria for healthcare providers and centeres selection

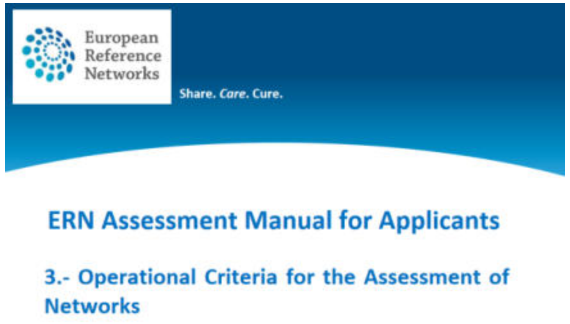
List of endorsement criteria for healthcare providers (research, pathways , policy, innovation)

The expert working group will need to agree on required endorsement criteria for centres' selection, focusing on the expertise on poor-prognosis cancers.

This may include general quality criteria, literature and expert opinion.

The application modalities for joining the NoE will also be defined, critically evaluating the ERN experience.

An expression of interest call will be launched. Applicant sites will be selected according to preestablished criteria (T5.4) and depending on the availability of an endorsement provided by the national authorities.

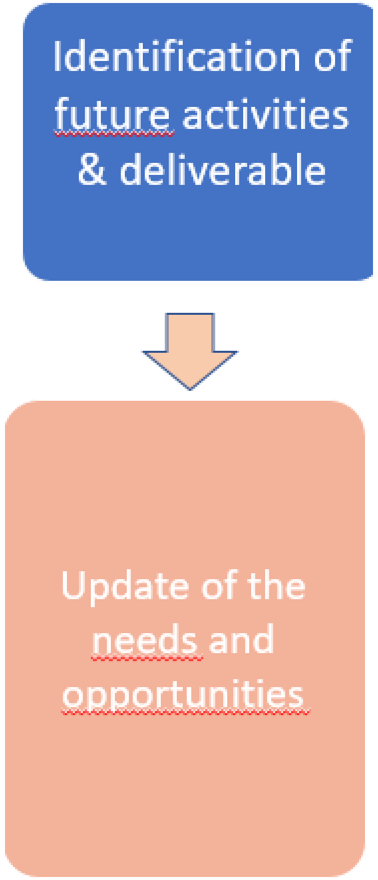

European Reference Networks
Share. Care. Cure.

ERN Assessment Manual for Applicants

3.- Operational Criteria for the Assessment of Networks

Task. 5.4 and 5.5 Milestones
Identification of the endorsement criteria for participant centres available on the JANE web-site (M14)
Documentations of the expression of interest (M18)

WP5 Network for Expertise to tackle with poor prognosis cancers (PPC)


Identification of future activities & deliverable

Update of the needs and opportunities

This task will provide a detailed definition of the activities carried out by the NoE, and of the deliverables.

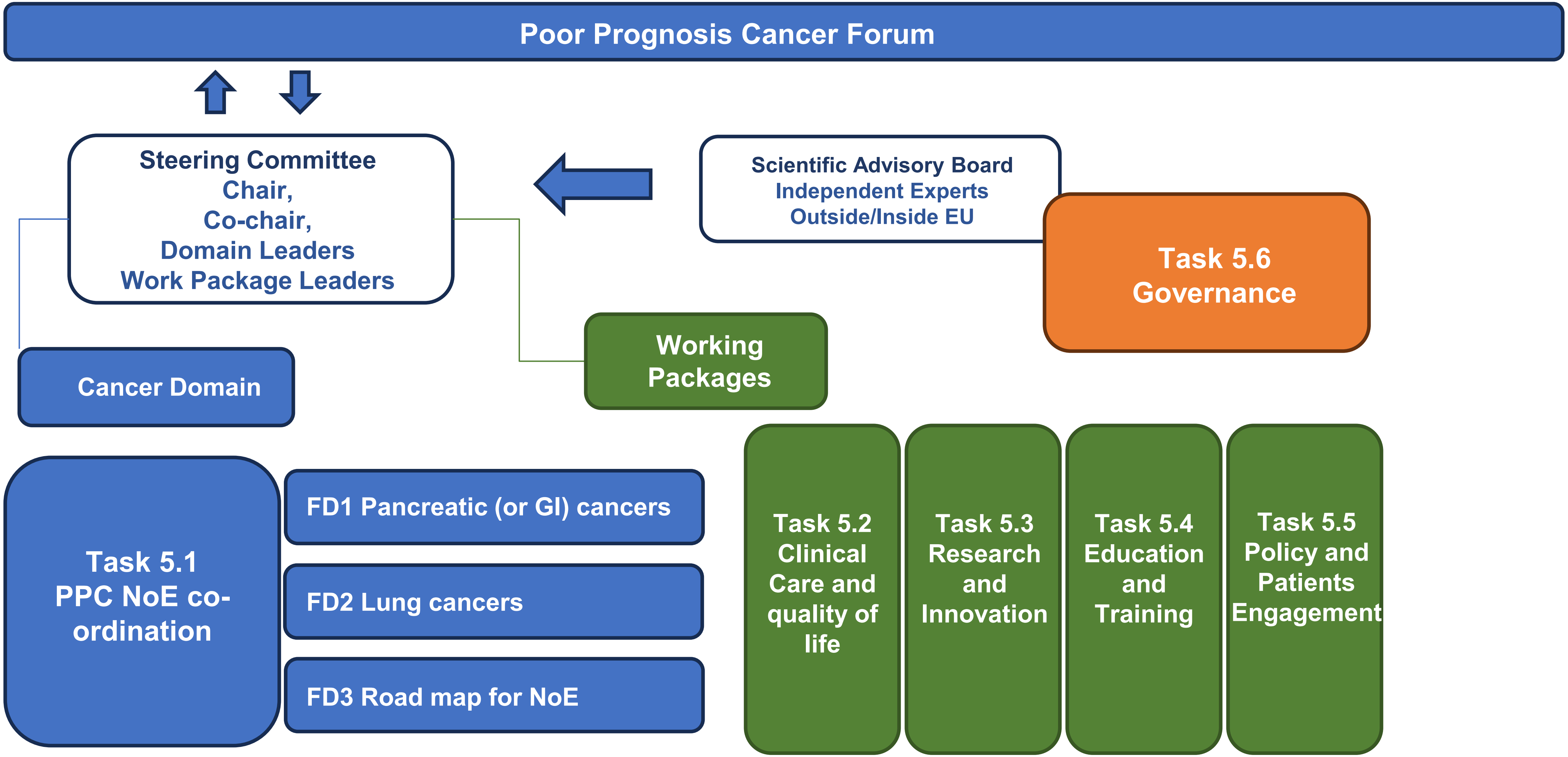
Regular updates needed (based on RWE and literature)

WP5 realisation
1. Mailing list
2. Monthly basis TC
3. Common repository

WP5 Deliverable Report with the scope and expected activities of the NoE, its governance, sustainability, indicators of efficacy and cost/efficacy evaluation criteria, interplay with MSs, other EU networks, CCCs, patients.

Task. 5.6 Milestone
Description of activities, priorities and deliverables of the NoE (M22)

Poor prognosis cancer NoE – governance model



Poor Prognosis Cancer Forum

Steering Committee
Chair,
Co-chair,
Domain Leaders
Work Package Leaders

Scientific Advisory Board
Independent Experts
Outside/Inside EU

Task 5.6
Governance

Working Packages

Cancer Domain

Task 5.1
PPC NoE co-ordination

FD1 Pancreatic (or GI) cancers

FD2 Lung cancers

FD3 Road map for NoE

Task 5.2
Clinical Care and quality of life

Task 5.3
Research and Innovation

Task 5.4
Education and Training

Task 5.5
Policy and Patients Engagement

Annex 6 - Endorsement criteria

NoE	Objectives	Activities	Final user	Final target (general)	Final target (specific)	Full partners					Collaborators
						Type of Full partners	EU scope	National scope	No per country	Criteria	
Poor prognosis cancer	Increase survival,Improve the quality of care and reduce inequalities across the EU in complex and poor prognosis cancers	1. **Enhance Patient Care:** Provide comprehensive, patient-centred care that addresses the physical, and psychological needs of patients and their families throughout their journey	HCP/CCC medical professionals and researchers, PAGs, Medical Societies/Organisation, and policymakers/stakeholders	Achieve increase in overall survival rates and quality of life in complex and poor prognosis cancers at equal level in each MS (done by focus groups per cacner type eg pancreatic cancer NoE)	improvement of the quality of care and treatment outcomes for patients diagnosed with PPC	1.Representative experts on PPC from accredited CCI who meet endorsement criteria and are involved in interdisciplinary clinical practice guidelines	Representatives from CCI with expertise in care of PPC (national influence and international experience), preferably involved additionally in Medical Societies/Organisations (eg ESMO, UEG, ESSO, ESTRO, OECI)		at least 1 per country; based on geographical spread, diversity in the provision of care, research, policy, education and strategy building (up to 50 participants in focus group dedicated to defined poor progrnosis population)	General criteria: alignment with network goals, objectives and values; involvement in guidelines development, changing practice research and involvement in policy-making processes, leadership skills; capability and resources for actively participating in NoE activities, representing national and international groups. Experts: leadership position, top qualifications (board certification, advanced degrees, track record of excellence of clinical and research fields), endorsement from CCI/international organisations, ability to impact on the decisions making process, the organization of cancer care, research and education at the MS level Healthcare providers: track record of clinical excellence with high-quality patient care outcomes, strong reputation within its speciality areas, clinical resources (state-of-the-art equipment, specialized facilities, skilled healthcare workforce), relevant specializations align with the expertise of the NoE, history of research and innovation, accreditations and certifications, ethical conduct, diversity in workforce and patient population, commitment to quality improvement, patient data protection, and clinical training and education programmes. Organisations: interest in collaboration, knowledge sharing and research initiatives, access to valuable data, resources or tools that can enhance the NoE aims, Quality of Network/Organisation governance and decision making that supports society's voice and interests, Ethical and Legal compliance and long-term viability.	Other NoE and JA representatives, patient advocates, governmental bodies (eg. MoH, MoS), and non-governmental organizations, industry, medical societies, HTA, epidemiology and pub-lic health organizations, academic/Research Institutions, educational institutions. Representatives other research project on PPC (eg UNCAN)
		2. **Advance Research:** Drive innovative research to uncover breakthroughs in the early detection, treatment, and prevention of poor prognosis cancers.			to accelerate a deeper understanding of cancer biology, the development of more effective anti-cancer therapies and diagnostics	2. Researchers from accredited CCI, who meet endorsment criteria , societies, and institutions involved in changing practice research	Representatives from CCI with expertise in research of PPC (national influence and international experience), preferably involved additionally in Medical Societies/Organisations (eg EORTC, OECI), Medical Research Agencies, Reaserch Institutes or international research project dedicated to PPC				
		3. **Empower Knowledge and Raise Awareness:** Foster collaboration among healthcare professionals, researchers, stakeholders and patient advocates to share knowledge and best practices and raise public awareness about poor prognosis cancers			raise awareness of the disease among the public to improve early detection	3.Charities and Non-Profits Organizations, PAGs, CCCs, Health Educators, Social Media and Health Bloggers/Vlogers	Representatives from CCI with expertise in education/dissemination/PR of PPC (national influence and international experience), preferably involved additionally in educational Medical Societies/Organisations (eg ESO, PAGs)				
		4**. Advocate for Change in Policy**: Advocate for policy changes, increased funding, and improved access to cutting-edge therapies and treatments to reduce the burden of poor prognosis cancers on individuals and society. Offer a network of support services, including counselling, financial assistance, and emotional support, to patients and families facing the challenges of poor prognosis cancer.			improvement of timely access to treatment as well as reduce inequalities in access to cancer treatments and healthcare services across EU member states	4. Cancer Networks, Healthcare Management Professionals, Governments and Public Health Organisations, PAGs and Industry (including Pharmaceutical Companies	Representatives from CCI with expertise in policy/stakeholder engagement of PPC (national influence and international experience), preferably involved in influential organisation on policy making(eg ECO, OECI, PAGs)	Ministry of Health, National Cancer Institution, National cancer registry, National Health Fund			
		5. **Strategy building based on measurable impact**: Continuously assess and measure our impact on improving the outcomes and quality of life for those affected by poor prognosis cancers and establishment of the future strategy through collaborative efforts guided by Real-World Evidence (RWE). (Other domains)			development of KPI to measure the impact	5. Representatives from International organizations and associations focused on cancer care and research	Representatives from CCI with expertise in strategy buiding of PPC (national influence and international experience)	National Cancer Registries representatives, National Public Health Institutes			

Annex 7

Meetings/Activities

12/12/22 (online)

- Identifying experts for PPC NoE and definition of Complex and poor prognosis cancer (PPC

24/01/23 (online)

- Debate on the definition and scope of the PPC NoE
- Use the Euracan Model as a benchmark for PPC structure)

30/03/23 (online)

- Building pilot NoE on Pancreatic Cancer
- The framework of the PPC NoE

24/04/23 (online)

- Pancreatic Cancer NoE kick-off meeting
- Main objectives of the Pancratic NoE
- Collaboration with other WP's

06/07/23 (online)

- Pancreatic Endorsement criteria for education

13/07/23 (online)

- Pancreatic Endorsement criteria for research

20/07/23 (online)

- Pancreatic Endorsement criteria for patient care

27/07/23 (online)

- Pancreatic Endorsement criteria for policy

27/11/23 (online)

- Synergies with leveraging ongoing EU actions and projects
- Future JA JANE2 structure
- Identification of CA and AE for JA JANE2

21/12/23 (online)

- Presenting the objectives of JANE in light of the continuation in JANE2
- Task division in JANE2
- Preparation of JANE2 tasks description

11/01/24 (online)

- Overview of the objectives of JANE2
- Presentation of the structure of WP5

17/01/24 (online)

- Discussion on the tasks of the focus groups

22/01/24 (in person in Milan)

- Presentation of PPC NoE in JANE2

29/01/24 (online)

- Objectives of the JANE2
- Overview of JANE and its MS
- Collaboration with other EU projects
- Overview of future Tasks of JANE2

07/02/24 (online)

- Final description meeting with Task Leaders

09/02/24 (online)

- Pancreatic Domain meeting

14/02/24 (online)

- Presentation on the final structure of WP5 for JANE2
- Description of Tasks of WP5 for JANE2
- Request of specifying involvement of the participants in each Task – excel provided

13/03/24 (online)

- Pancreatic Domain meeting
- 1st meeting with new Pancreatic Domain Leader – Maximilian Kordes

26/03/24 (online)

- Overview of MS for JANE and Deliverables
- Survey for identifying future activities and deliverables

13/05/24 (online)

- Discussing the task of assessing the availability of clinical trials for PPC in Europe

28/05/24 (online)

- Survey conducted and completed
- Pancreatic Domain NoE summary from the last meeting
- JANE2 proposal update
- Summary from the meeting of assessing the availability of clinical trials for PPC in Europe

30/07/24 (online)

- Focus on the final report, which serves the role of Deliverable for WP5

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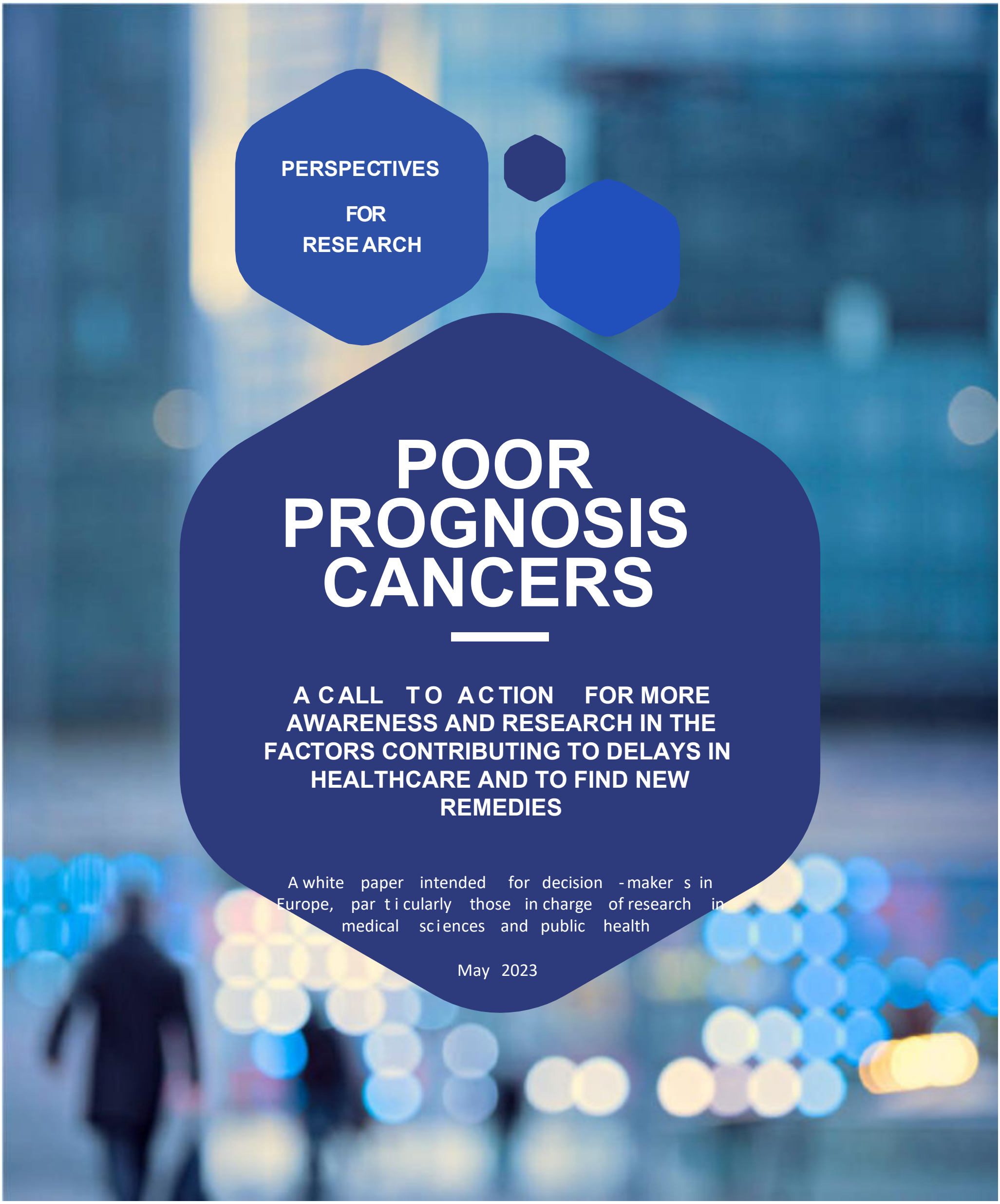


PERSPECTIVES

FOR
RESEARCH

POOR PROGNOSIS CANCERS

A CALL TO ACTION FOR MORE AWARENESS AND RESEARCH IN THE FACTORS CONTRIBUTING TO DELAYS IN HEALTHCARE AND TO FIND NEW REMEDIES

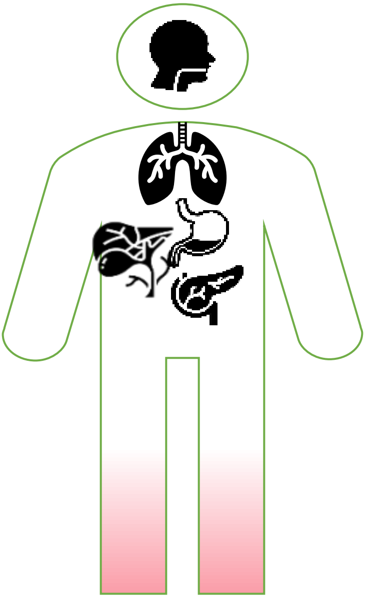
A white paper intended for decision-makers in Europe, particularly those in charge of research in medical sciences and public health

May 2023

Karolinska Institutet
KAROLINSKA UNIVERSITY HOSPITAL

Karolinska Comprehensive Cancer Center

POOR PROGNOSIS CANCERS



FRANCE22 EU2022.CZ

Europe’s battle against Cancer

INTRODUCTION

During the French EU presidency in 2022, the French National Cancer Institute (INCa) gathered experts from all of Europe to work on a “Political Declaration – and list of actions against cancer”[1]. As one of four major actions, “**Poor Prognosis Cancers**” were identified to be of most pressing need of attention. These cancers are defined by a ratio of mortality over incidence (M/I) of > 0.9 – in other words **less than 10% of patients with these cancers survive**[2] or less than 30% 5-year survival rate. Some of these cancers also qualify as “neglected cancers”, a “definition based on literature data and population-based indicators (such as M/I)”[2]. Poor prognosis cancers are primarily those of the upper gastrointestinal tract, especially **cancers of the pancreas, bile ducts and liver** (HPB) while neglected cancers list pancreatic cancer and ovarian cancer on top[2,3].

The political declaration[1] identified three concrete and specific actions:

1) Switch research proposal towards “high risk high gain” and set up research programs with high translational agenda.
2) Provide a framework of tools to enable data sharing in advance of projects for mutual benefit.
3) Ensure the best available care is provided by increasing the quality and speed of delivery (time to diagnosis, time to treatment) as well as implementation of guidelines and early access to novel therapies.

In pursuit of these action points, the working group « Poor Prognosis Cancers » (members at the end of this document) has started to collect the scientific evidence to describe the delay to diagnosis and delay to start of therapy and to demonstrate the inequality amongst different tumor diagnosis groups and across Europe. The working group consists of oncologists of different specialties, nurses, and patient representatives.

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[1] POLITICAL DECLARATION AND LIST OF ACTIONS AGAINST CANCER RECOMMENDED BY A PANEL OF EUROPEAN STAKEHOLDERS. In: Breton T, Ifrah N, editors. 2022 European Meetings of the French National Cancer Institute. Paris.

[2] IPAAC. Innovative Partnership for Action Against Cancer. 2022. www.ipaac.eu/

[3] Michl P, Löhr M, et al. UEG position paper on pancreatic cancer. Bringing pancreatic cancer to the 21st century: Prevent, detect, and treat the disease earlier and better. *United European Gastroenterol J* 2021; 9(7): 860-71.

POOR PROGNOSIS CANCER - DEFINITION

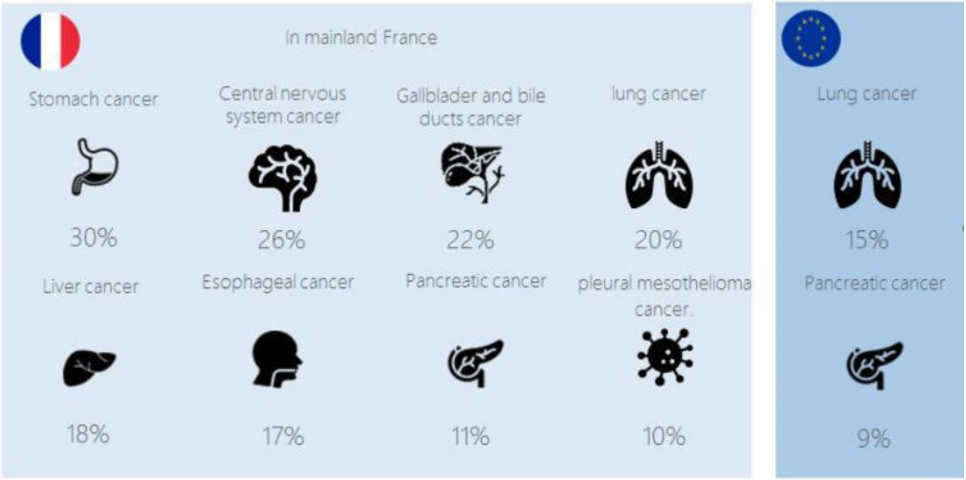
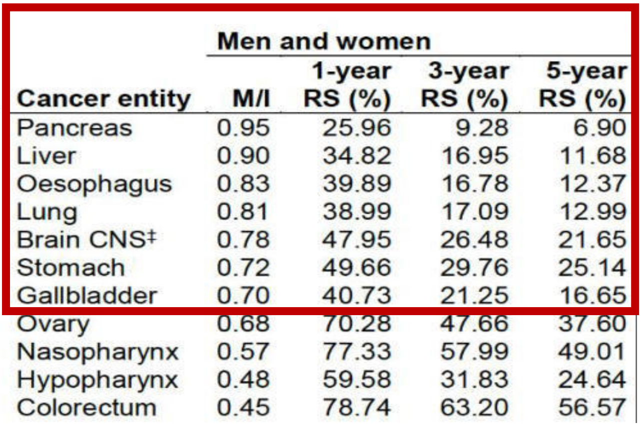


Fig. 1 : Poor prognosis cancers are defined by a 5-year survival rate of >30%

POOR PROGNOSIS CANCER - DEFINITION



	Men and women			
Cancer entity	M/I	1-year RS (%)	3-year RS (%)	5-year RS (%)
Pancreas	0.95	25.96	9.28	6.90
Liver	0.90	34.82	16.95	11.68
Oesophagus	0.83	39.89	16.78	12.37
Lung	0.81	38.99	17.09	12.99
Brain CNS‡	0.78	47.95	26.48	21.65
Stomach	0.72	49.66	29.76	25.14
Gallbladder	0.70	40.73	21.25	16.65
Ovary	0.68	70.28	47.66	37.60
Nasopharynx	0.57	77.33	57.99	49.01
Hypopharynx	0.48	59.58	31.83	24.64
Colorectum	0.45	78.74	63.20	56.57

Fig. 2: Mortality to incidence (M/I) in relation to survival[4]

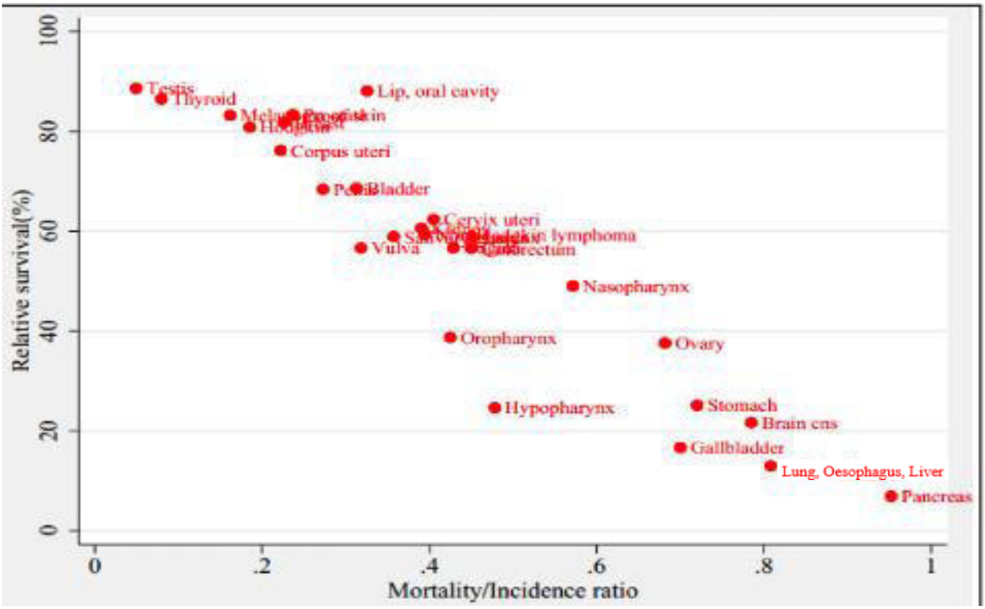


Fig. 3: Mortality to incidence (M/I) in relation to 5-year survival[4]

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[4] Data from IPAAC. Innovative Partnership for Action Against Cancer. 2022. www.ipaac.eu/

POOR PROGNOSIS CANCER - PERSPECTIVES

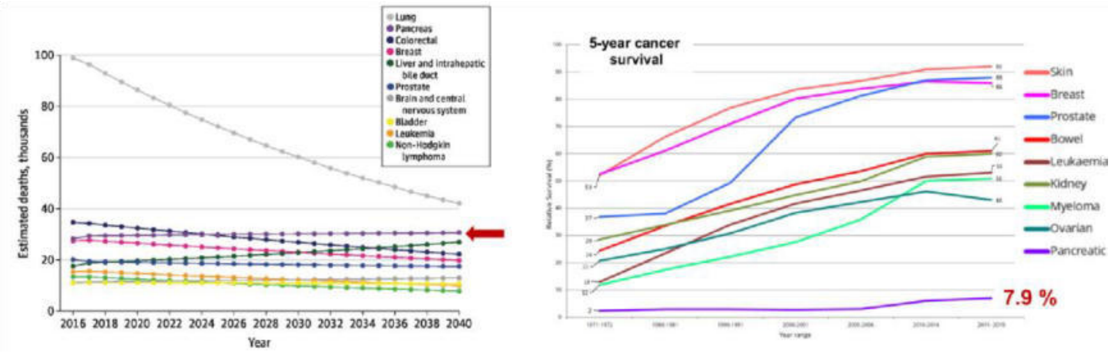

Fig. 4: Estimated cancer-related deaths (left) and 5-year survival rates right) for the major cancers.

The incidence of Pancreatic Cancer as one example for a Poor Prognosis Cancer is rising and the 5-year survival rate remains very low[5].

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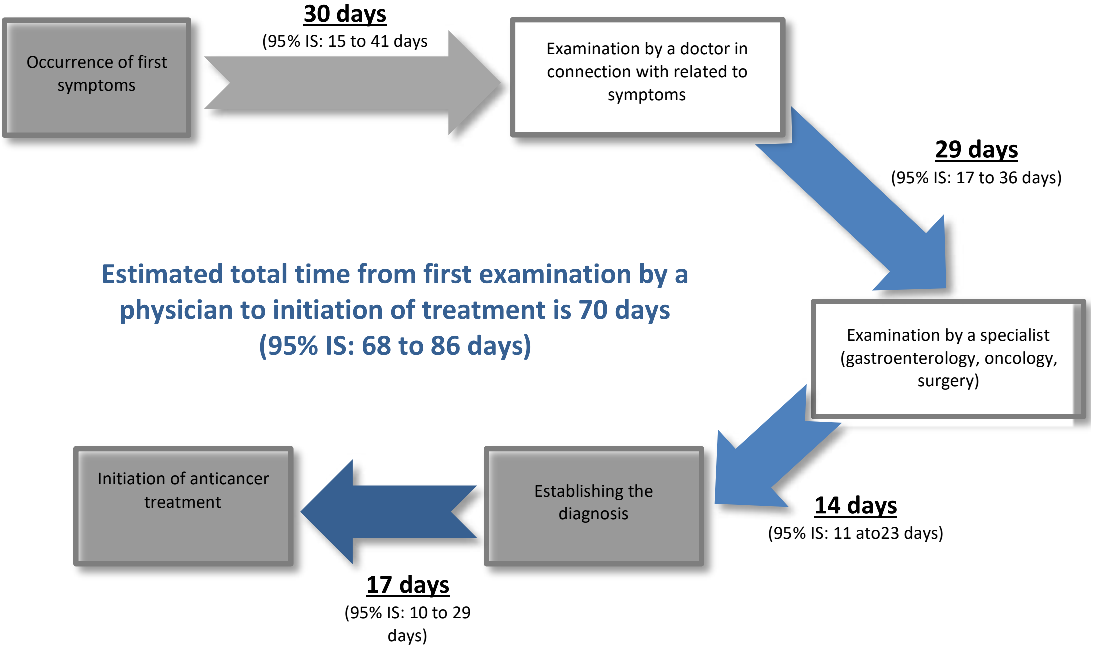
[5] Data from IPAAC. Innovative Partnership for Action Against Cancer. 2022. www.ipaac.eu/

POOR PROGNOSIS CANCER - DELAYS



Occurrence of first symptoms

30 days
(95% IS: 15 to 41 days

Examination by a doctor in connection with related to symptoms

29 days
(95% IS: 17 to 36 days)

Examination by a specialist (gastroenterology, oncology, surgery)

14 days
(95% IS: 11 ato23 days)

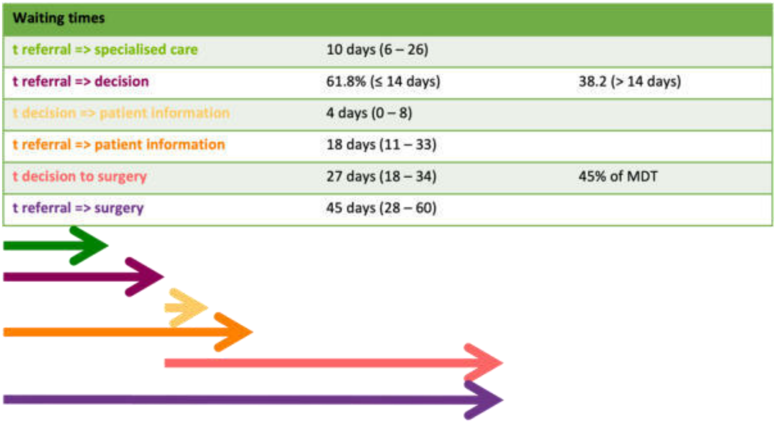
Establishing the diagnosis

17 days
(95% IS: 10 to 29 days)

Initiation of anticancer treatment

Estimated total time from first examination by a physician to initiation of treatment is 70 days (95% IS: 68 to 86 days)

Fig. 4: Delays from symptoms to diagnosis and treatment with Pancreatic Cancer as one example from a Czech Republic Center (Masaryk MemorialCancer Institute)



Waiting times		
t referral => specialised care	10 days (6 – 26)	
t referral => decision	61.8% (≤ 14 days)	38.2 (> 14 days)
t decision => patient information	4 days (0 – 8)	
t referral => patient information	18 days (11 – 33)	
t decision to surgery	27 days (18 – 34)	45% of MDT
t referral => surgery	45 days (28 – 60)	

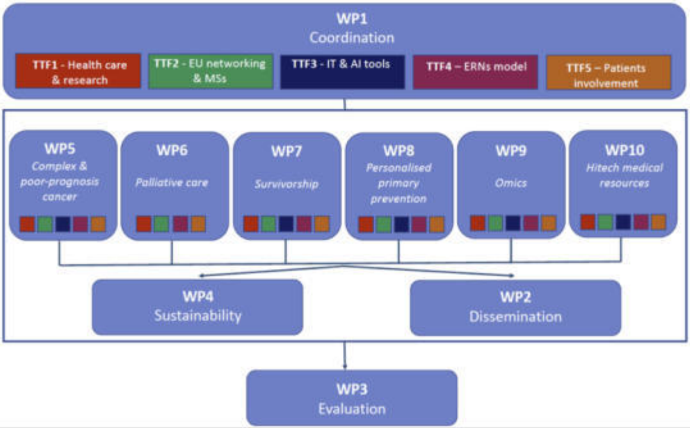
Fig. 5: Delays from symptoms to diagnosis and treatment with Pancreatic Cancer as one example from Sweden (National database)

CALL FOR ACTION
FOR THE EUROPEAN UNION

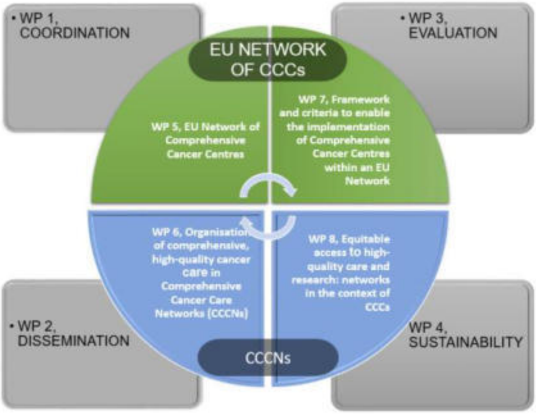
KEY TAKEAWAYS

- **Raise AWARENESS for Poor Prognosis Cancer**
- **Issue specific calls for Research Projects**
- **Keep the Poor Prognosis Cancers on the European Agenda (next Trio)**

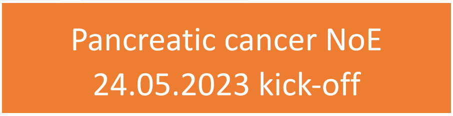
The EU has been working to tackle cancer for decades to save and prolong lives. The progress in cancer research, the implementation of new diagnostics technologies and personalised medicine in clinical practice is a breakthrough in oncology, however growing challenges in patients with poor prognoses need urgent, further investments. One of the flagship initiatives of Mission Cancer and Europe's Beating Cancer Plan (EBCP) is the establishment by 2025 of the European Union (EU) Network linking Expertise with the recognised National Comprehensive Cancer Centres (CCCs) in every Member State (MS), to facilitate the uptake of quality-assured diagnosis and treatment, including training, research, and clinical trials across



the Union. The ongoing Joint Actions (JAs) on European Networks of Expertise (JANE) and Network of Comprehensive Cancer Centres: Preparatory activities on the creation of National Comprehensive Cancer Centres and EU Networking (CRANE) support the flagship initiative of EBCP objective to deliver higher-quality care and implements the EU4Health Programme's general objective of improving and fostering health in the Union (Article 3, point (a)) through the specific objectives defined in Article 4, points (a) and (g) of Regulation (EU) 2021/522.



The goals of JA JANE WP5 is to establish together with CRANE a NoE dedicated to one complex/poor prognosis cancer to increase the efficacy of treatments and quality of care, reduce inequality across the EU, boost basic/preclinical research and the use of innovative technologies, promote education, clinical practice guidelines and multidisciplinary care development, as well as epidemiological surveillance. The specific objectives include the definition of the scope of the NoE, potential partners and its governance, and indicators of efficacy. Because pancreatic cancer has a poor prognosis with increasing incidence and requires early diagnosis and recommended treatment in centres of expertise (with assess to clinical trials), the Pancreatic Cancer NoE is a model of networking for future.



By joining efforts across Europe with medical practitioners, stakeholders and Member States, the EU initiatives aim to provide a better understanding of cancer, allow for earlier diagnosis and optimisation of treatment and improve cancer patients' quality of life during and beyond their cancer treatment, also considering all synergies.

CALL FOR ACTION

FOR THE NATIONAL HEALTHCARE SYSTEMS AND RESEARCH

// KEY TAKEAWAYS

- **Early access to diagnosis and clinical pathways**
- **Identify the « roadblocks » in the existing pathways (SVF)**
- **If needed, reorganise care/pathways**
- **Special calls for translational and clinical projects forcing national collaboration**

Pancreatic cancer is the most representative example of the poor prognosis cancer group. Although there is a limited number of therapeutic strategies to improve outcomes, their effectiveness could be expanded if changes in health services organization are implemented across EU countries.

The Bratislava statement developed within the framework of iPAAC Joint Action, supported by relevant scientific societies and patient organizations as well as other stakeholders, clearly acknowledged the relevance of an optimal model of cancer based on the following key points:

- Implement a policy of organizing cancer services based on reference centers of expertise with specialized multidisciplinary teams at the core of clinical decision making.

- Build clinical services at all levels of the healthcare system through a network approach, by including primary care, palliative care (eg, home care) and survivorship care, among others, in the organizational framework.

- This network model should support the continuity of care, the circulation of knowledge and integration of professionals. Non reference hospitals will continue to play a role in the clinical management and care of these patients in some parts of their treatment and follow up and coordination among the network is essential.

- Capitalize the opportunities offered by reference centers for developing, accumulating, and applying expertise.

- Develop indicators of quality of cancer care and keep registries.

- Evaluation of the process and outcomes of the model should be monitored continuously and be the background to improve the quality of care.

- Research and training are an integral component of a model of cancer care aimed at progressing in cancer care.

This proposal involves a need to reorganize pancreatic cancer care in many countries of Europe. In fact, a difference in policies of concentration of surgical services has been observed, which is an opportunity to converge in this policy in the coming future within the framework of EBCP.

The major key points that this reorganization requires could be summarized in the following:

- **Early access** to **diagnosis** and to **clinical pathway** that links non-reference and reference hospitals in a **network** of high-quality cancer care.

- **Implement** a system of **reference hospitals** that should centralize the key components of the active treatment in pancreatic cancer patients.
- Treatment decision making should be carried out within a **specialized multidisciplinary team**, with all major therapeutic strategies available and precision oncology tools, if required.
- **Intervals** of the process of care aimed at assessing **early access** to high quality cancer care **outcomes of care** should be monitored.
- **Patients** should be actively involved in their care, and they should receive clear and understandable explanation of their process of care along the clinical pathway.

Health policy should be oriented to apply what we know is effective to improve the quality of care. This is the major challenge that we need to cope in order to improve our health services in this poor prognosis cancer, jointly with the investment on research and training.

References:

- Prades J, Arnold D, Brunner T et al. Bratislava statement: Consensus recommendations for improving pancreatic cancer care. ESMO Open 2020; 5:e001051.

- Coll-Ortega C, Prades J, Manchon-Walsh P, Borras JM. Centralisation of surgery for complex cancer diseases: A scoping review of the evidence base on pancreatic cancer. J Cancer Policy; 2022; 32: 100334

POOR PROGNOSIS CANCER

AIMS FOR THE WORK GROUP

// KEY TAKEAWAYS

- Analyse and report the scientific evidence underlying the disparity across Europe and within the member states
- Analyse and report the delays in « time to diagnosis » and « time to treatment »
- Investigate whether the delays are responsible for the negative impact on survival

Following the "POLITICAL DECLARATION AND LIST OF ACTIONS AGAINST CANCER RECOMMENDED BY A PANEL OF EUROPEAN STAKEHOLDERS" [6] written as part of « European cancer meetings 2022 » and set up by the French National Institute of Cancer (INCa), it has been decided to address accelerating care pathways for patients with poor prognosis cancer. (according to the Action 14 : "define common European objectives and indicators for rapid entry into pathways").

For that purpose, a working group which is authorised by the organizations behind the individual members (e.g. ESMO, INCa, UEG) has been created with 25 experts in different cancer fields from 13 countries (France, Spain, Sweden, Czech Republic, Germany, Greece, Poland, Belgium, Norway, Italy, Austria, Denmark, Portugal) as well as ESMO.

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[6] POLITICAL DECLARATION AND LIST OF ACTIONS AGAINST CANCER RECOMMENDED BY A PANEL OF EUROPEAN STAKEHOLDERS. In: Breton T, Ifrah N, editors. 2022 European Meetings of the French National Cancer Institute. Paris.

A first workshop has been held in Paris (13/09/2022) to precise the scope and the methodology. The group agreed on actions to be conducted:

- Writing an authoritative review regarding the impact on prognosis of delaying steps of diagnosis or treatment;
- Based on a systematic literature review and on a pragmatic approach (immediate availability of data), defining common indicators to monitor quality and performance in this field of delay management.

Thereafter, the participants of the working group met several times online to define the scope and a common methodology to conduct the literature review: concrete definition of poor prognosis cancer, cancer types, steps of the pathway which should be addressed first.

Based on a preliminary work on definitions and literature queries, a selection of 408 abstracts of manuscripts from international peer-reviewed journals have been analysed by at least 2 to 3 experts. Finally 95 have been considered as relevant to be reviewed in detail by 2 experts for lung cancers and mesothelioma (26), pancreatic cancers (23), central nervous system tumours (23), liver, gallbladder and biliary duct cancers (9), oesophagus and gastric cancers (3), acute myeloid leukemias/myelodysplastic syndrome (7) , several cancer types (4) as well as 29 other manuscripts which could be useful for discussion.

This extensive review has been a strong and scientific support to write this call to action in addition to a systematic review which will be both submitted to ESMO Open.

The activities of this working group are in line with and 'feeds' the work package 5 of the European Joint Action JANE which aims to shape a new European Network of expertise for complex and poor prognosis cancer. Indeed, some experts participate to both initiatives. This future network of expertise ensures a perfect way to implement in the different European Member states the recommendations raised by the working group created in February 2022 during the French EU Presidency.

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JA JANE WP5 Poor Prognosis Cancer PPC Network of Expertise - future scope

This survey is part of the EU4Health Programme (EU4H), which stands for Joint Action on European Network of Expertise, or JA JANE.
The JA JANE1 and JA JANE2 Teams developed this survey within Work Package WP5, Complex and Poor Prognosis Cancer (PPC).

Aim of the Survey

Creating a structured questionnaire aims to present yourself and identify strengths, opportunities for collaboration, knowledge gaps, and needs for further research or resource allocation of JANE PPC Network of Expertise (NoE).

The questionnaire will help gather insights on future directions for PPC care, policy, education, and research, identify shared priorities and inspire initiatives that leverage the network's collective knowledge for maximum impact. Based on the responses, we will plan a strategy to support high-quality care and innovation and lead collaborative efforts to improve outcomes for PPC patients in the future JA JANE PPC NoE.

***Definitions used in the context of this survey**.*

Definition of Poor Prognosis Cancer based on common Consensus JANE1 meeting is defined as:
A poor prognosis for cancers whose survival rate at the time of discovery is estimated to be below 33% at five years.

* Wymagane

1. Information on Personal Data Protection

1

Participation in the JA JANE project is inextricably linked with the processing of personal data.

Therefore, we inform you that:

- The administrator of your personal data contained in the survey will be Maria. Sklodowska – Curie National Research Institute of Oncology, ul. W.K.Roentgena 5, 02-781 Warsaw, Poland (MSCI).

- MSCI has appointed The Data Protection Officer that can be contacted via e-mail iod@nio.gov.pl

- Providing the data contained in the survey is necessary to participate in it. MSCI will process them based on your consent (in accordance with Article 6 sec. 1. (a) of the GDPR*).

- Your personal data, including telephone number and e-mail address, may be made available to other participants of the JA JANE project

- Your personal data will be processed until the end of 2028 or until you withdraw your consent.

- You have the right to: access the content of your personal data, the right to rectify, delete or limit processing, the right to object to their processing, the right to withdraw consent at any time without affecting the lawfulness of the processing carried out on the basis of consent before withdrawing it.

- You have the right to lodge a complaint with the President of the Office for Personal Data Protection (Polish abbreviation: PUODO), if you consider that the processing of your personal data by the Administrator violates the provisions of the GDPR*.

* Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation)

I consent to processing at the Maria. Sklodowska – Curie National Research Institute of Oncology my personal data contained in this survey in order to carry out tasks in the JA JANE program. *

○ I agree

2. Respondent Information

2

Name and title
*

3

Affiliation *

4

Contact information (e-mail) *

5

Contact information (phone number) *

6

Area(s) of expertise (e.g. medical oncology, surgical oncology, research, stakeholder representative, patient advocacy) *

7

ORCID number (if available)

8

Area of interest within JANE *

☐ PPC

☐ Pancreatic

☐ Lung

☐ Other* - you can elaborate on this option in point 9

9

Please elaborate here if you have chosen "other" in point 8.

10

Please enter all of the research projects you are involved in the PPC field, including the project title, ref—number, description of tasks you are involved in, website, etc. *

11

Key accomplishments in the field related to PPC. *

DEFINITION OF THE SCOPE OF THE NoE

12

Do you agree with the Vision Statement of NoE?

Empowering Hope, Extending Life: A World Where Poor Prognosis Cancer No Longer Steals Futures and Equal Access to Care Prevails Throughout Europe. *

○ Yes

○ No

13

Do you agree with Mission Statement of NoE:

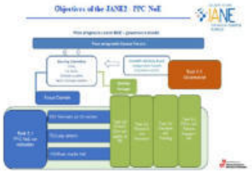
To improve healthcare as diagnosis and treatment management, knowledge sharing, fostering research and communication between patients, organisations, institutions and authorities involved in poor prognosis cancers, by adopting the best models of EU networking *

○ Yes

○ No

14

Do you agree with the Governance structure? *



○ Yes

○ No

CARE

15

Based on your experience, define critical gaps in care that need significant progress in diagnosis and treatment. *

16

What areas related to care should be prioritised in your region, country, or Europe? *

17

What initiatives could the network undertake to foster collaboration and knowledge sharing among professionals working in this field? *

18

How can the network support the development and rapid adoption of innovations in care? *

RESEARCH

19

Based on your experience, define critical gaps in research that need significant progress in diagnosis and treatment. *

20

What areas related to research should be prioritised in your region, country, or Europe? *

21

What initiatives could the network undertake to foster collaboration and knowledge sharing among professionals working in this field? *

22

How can the network support the development and rapid adoption of innovations in research? *

POLICY

23

Based on your experience, define critical gaps in policy that need significant progress in diagnosis and treatment. *

24

What areas related to policy should be prioritised in your region, country, or Europe? *

25

What initiatives could the network undertake to foster collaboration and knowledge sharing among professionals working in this field? *

26

How can the network support the development and rapid adoption of innovations in policy? *

EDUCATION

27

Are there specific areas where the network could provide educational resources or training programs to improve the skills of professionals involved in PPC, especially remaining pancreatic cancer care and lung cancer care? *

28

What should be the mode of educational activity deliverables? *

☐ e-learnings modules

☐ webinars and virtuals workshops

☐ discussion forums and platforms

☐ field trips and on-site visits

☐ internships and co-op placement

☐ printed materials

☐ exsams and quizes

☐ written asigments

☐ coaching programms

☐ presentations

☐ other* please describe in point number 29

29

Please elaborate here if you have chosen "other" in point 28 *

30

What initiatives could enhance patient engagement and community awareness about PPC, its treatment options, and the importance of early detection? *

NETWORK OF EXPERTISE

31

From your perspective, what should be the strategic priorities for the JA JANE1 and JANE2 PPC Networks of Expertise over the next five years to maximise their impact on PPC treatment outcomes? *

32

What is necessary to make the PPC NoE sustainable? *

33

Please propose the indicators of efficacy evaluation of the PPC NoE. *

34

Please propose a cost-efficacy evaluation within the PPC NoE. *