Joint Action on Networks of Expertise

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Final evaluation report

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ABBREVIATIONS

AB: Advisory Board

AE: Associated Entities

AYA: Adolescent and young adult

BBMRI-ERIC: Biobanking and BioMolecular Resources Research Infrastructure - European Research Infrastructure Consortium

BENs: Beneficiaries

CANCON: European Guide on Quality Improvement in Comprehensive Cancer Control

CCC: Comprehensive Care Centre

CCI4EU: Comprehensive Cancer Infrastructure for the European Union

CIPH: Croatian Institute for Public Health

CNCR: Croatian National Cancer Registry

CraNE: Network of Comprehensive Cancer Centres: Preparatory activities on the creation of National Comprehensive Cancer Centres and EU Networking

DG RTD: Directorate-General for Research and Innovation

DG SANTE: Directorate-General for Health and Food Safety

EC: European Commission

ECHoS: Establishing of Cancer Mission Hubs: Networks and Synergies

ECO: European Cancer Organisation

ECRIN: European Clinical Research Infrastructure Network

EOSC4Cancer: European Open Science Cloud for Cancer

EPAAC: European Partnership for Action Against Cancer

ERN: European Reference Network

ESFRI: European Strategy Forum on Research Infrastructures

ESSO: European Society of Surgical Oncology

ESTRO: European Society for Radiotherapy & Oncology

EU: European Union

EUCAIM: European Federation for Cancer Images

EUnetCCC: European Network of Comprehensive Cancer Centres

EURACAN: European Reference Network for rare adult solid cancers

GDPR: General Data Protection Regulation

HaDEA: European Health and Digital Executive Agency

HCSs: Healthcare systems

INT: Fondazione IRCCS Istituto Nazionale dei Tumori

iPAAC: Innovative Partnership for Action Against Cancer

IT: Information Technology

JA: Joint Action

JA eCAN: EU Joint Action on strengthening eHealth including telemedicine and remote monitoring for health care systems for cancer prevention and care

JANE: Joint Action on Networks of Expertise

JARC: Joint Action on Rare Cancers

MS: Member State

NoE: Network of Expertise

OECI: Organisation of European Cancer Institutes

OUS: Oslo University Hospital

PAG: Patient Advocacy Group

PanCare: A European network focused on improving the care of childhood and adolescent cancer survivors.

PC: Palliative Care

PCCP: Patient Centred Care Pathways

PDT: Prevention, Diagnosis and Treatment

POC: Proof of Concept

PPC: Poor Prognosis Cancer

PROMs: Patient Reported Outcome Measures

PROSPERO: International prospective register of systematic reviews

SC: Steering Committee

SIOPE: European Society for Paediatric Oncology

SMUHC: School of Medicine, University of Zagreb

TTF: Transversal Task Force

WP: Work Package

CONTENTS

1 EXECUTIVE SUMMARY

Joint Action on Network of Expertise (JANE) is a project co-funded by the EU4Health Programme of the European Union and the participating national Competent Authorities and Affiliated Entities. It builds upon the previous Joint Actions on cancer control (iPAAC, JARC, CANCON and EPAAC) and its deliverables and recommendations. Cancer control is still a great public health challenge in the European Union, and the general objective of the JANE JA was to set the foundation for establishment of Networks of Expertise in the cancer field.

The project's core goals were twofold: firstly, to prepare all necessary steps for launching the Networks of Expertise (NoEs), and secondly, to critically evaluate current EU networking models to optimize future operations. After the definition of the project objectives, a decision towards initiating a JANE2 project was established, so some of the project goals and procedures were amended. The NoEs are designed to focus on integrating research, advanced technologies, and patient care while promoting sustainability and collaboration across Member States. The project's management goal was to establish the groundwork for the creation of seven Networks of Expertise in the following domains: personalized primary prevention, survivorship, palliative care, "omic" technologies, hi-tech medical resources, one or more complex and poor-prognosis cancer(s) and adolescents and young adults with cancer.

The aim of this report is to provide a comprehensive overview of the achievements and results of the JANE project, emphasising how they serve as a cornerstone for the forthcoming JANE 2 initiative. It also addresses the challenges and obstacles encountered during the project implementation. Furthermore, the report provides a summary of the qualitative analysis of the surveys which measured participant's satisfaction with the meeting organisation, level of cooperation and the progress of project activities and it provides summaries of Advisory Board meetings, the description of the Green Paper on the Networks of Expertise produced in the Action, as well as a description of transition towards JANE2.

Significant progress has been made in defining the scope, governance, and sustainability strategies for each NoE. Various work packages have addressed different aspects of the project, from dissemination and evaluation to sustainability; core work packages dealing with specific NoEs and transversal task forces connecting different aspects of the project.

JANE has also emphasized the importance of patient involvement and the development of tools for empowering patients and ensuring their perspectives are integrated into cancer care networks. Despite challenges such as coordination across diverse stakeholders and Member States, the project has laid a strong foundation for the forthcoming JANE 2 initiative, which will formally launch the NoEs and further enhance cancer care across Europe.

2 JANE OBJECTIVES

JANE represents a significant collaborative effort across EU Member States. The initiative aims to establish seven new NoEs that will focus on critical areas within cancer care. The project had two primary objectives. The first (1) was to prepare everything needed to launch the NoEs, from defining their missions and objectives, studying their design and working out selection criteria for participants, to providing all items to set up calls for expressions of interest. The second (2) was to critically evaluate existing models of current EU networking, research infrastructures and platforms, future networking among comprehensive cancer centres, as well as technologically relevant aspects for optimal functioning of networking in general, in order to properly shape the new NoEs.

The seven NoEs will concentrate on several key areas of cancer care. These include personalised primary prevention, survivorship, palliative care, omic technologies, high-tech medical resources, complex and poor-prognosis cancers, and the specific needs of adolescents and young adults aged 15-39 who are diagnosed with cancer. In terms of operational structure, each NoE was assigned a specific Work Package. Additionally, five Transversal Task Forces, along with another work package, had operated across all Work Packages. These task forces addressed crucial aspects such as the integration of EU networking with Member States, the incorporation of information technology infrastructures and artificial intelligence, the integration of healthcare and research, the European Reference Networks (ERN) model, patient involvement, and sustainability.

To ensure transparency and maximise its impact, JANE shared findings and consensus from the Task Forces with the European oncology community and Member States. This was achieved through the preparation of the Green Paper and the organisation of a dedicated European conference. Ultimately, JANE aims to establish highly effective NoEs that build on existing EU networking experiences and drive solutions created by the European oncology community. By fostering expertise, knowledge sharing, and innovation, JANE seeks to improve outcomes and enhance the quality of life for individuals affected by cancer across Europe.

3 WORK PACKAGES

One Work Package was allocated to each Network of Expertise. Five Transversal Task Forces were established to work transversally across all WPs (Table 1 shows the deliverables of all the WPs). The themes of the transversal task forces were: integration between the EU network and the Member States, integration between information technology infrastructures (including the use of artificial intelligence tools), integration between healthcare and research, the ERN model and patient involvement. The following section provides a brief overview of the achievements of the WPs.

Table 1: Work Package Deliverables

Deliverable	Work Package	Due Date (month)
D1.1 Mid-term report	WP1	14
D1.2 18-month report	WP1	20
D2.1 Project website	WP2	3
D2.2 Dissemination strategy plan	WP2	6
D2.3 Final conference report	WP2	24
D3.1 Evaluation strategy	WP3	8
D3.2 Final evaluation report	WP3	24
D4.1 Policy recommendations on sustainability	WP4	24
D5.1 NoE on complex and poor prognosis cancers	WP5	24
D6.1 Palliative care NoE	WP6	24
D7.1 NoE dedicated to survivorship	WP7	24
D8.1 Personalised Primary Prevention NoE	WP8	24
D9.1 Omics NoE	WP9	23
D10.1 Hi-tech NoE	WP10	24
D11.1 Adolescents and young adults with cancer NoE	WP11	24
D12.1 Recommendations for effective and efficient organization and management of research efforts	WP12	24
D13.1 Recommendation to support national healthcare systems interconnection with EU networking	WP13	24
D14.1 Recommendations to integrate local IT infrastructures for European cancer networking	WP14	24
D15.1 Recommendations to improve EU cancer care networking in general and specifically for the new NoEs	WP15	24
D16.1 Toolkit for patient empowerment and engagement in different contexts and for different subjects	WP16	24

3.1 Work package WP1 – Project Management and Coordination

Objectives

1. To manage the action and to make sure that it is implemented as planned.

2. To ensure coordination with other relevant JA (eg, CRANE, JA on telemedicine).

Achievements

A coordination team was set up at INT, consisting of a coordinator, a project manager and a financial officer. This team took on the critical responsibility of overseeing the day-to-day operations, ensuring that the project ran smoothly and that all partners and WP leaders were supported. One of the key tasks of WP1 was to provide editorial, financial and administrative support to the WP and TTF leaders, manage the project finances, monitor financial reports and ensure accurate financial reporting to HaDEA.

Moreover, WP1 formed the Steering Committee (SC), composed of the leaders of both the Work Package (WP) and the Transversal Task Force (TTF). The SC oversees the work of the project, reviews reports and manages quality control, with a focus on maintaining the project schedule and organising workshops and conferences.

To facilitate coordination and communication across the consortium, three General Assembly meetings have been held (two in person in Milano and Barcelona, and one on-line), and the final conference was held in Brussels in September 2024. These meetings provided a forum for discussing roles and collaboration within the project, sharing progress and planning future actions. In addition to the General Assembly, individual meetings were held with WP and TTF leaders to discuss the planning of the NoE and the strategy for the TTFs. Meetings were also held with key scientific societies, including ECO, ESTRO and ESSO, to explore potential collaborations.

JANE has also established several important collaborations. These include a partnership with the Joint Action CraNE and CCI4EU as well as a collaboration with JA eCAN focusing on teleconsultation and telemonitoring. A meeting was also held with DG SANTE, DG RTD and HaDEA to discuss the alignment and synergies between JANE, CraNE, CCI4EU and ECHoS.

To ensure that project progress remained on track, WP1 relied on a system of monitoring and reporting in which the leaders of each WP and TTF were required to submit detailed reports every six months, documenting objectives, tasks completed, challenges encountered and proposed next steps. This structured approach enabled the Coordination Team to keep abreast of developments, anticipate potential risks and take corrective action where necessary.

In conclusion, the WP1 project management strategy relied on close collaboration, regular meetings, structured reporting and clear communication channels to ensure the effective implementation of the JANE Joint Action. Therefore, WP1 made significant contributions to project management, quality assurance and monitoring.

3.2 Work package WP2 – Dissemination

Objectives

To disseminate JANE activities through multiple channels and strategies

To raise awareness within the medical community and patient advocacy groups on NoEs that will be developed through JANE

To contribute to the launch of calls for expressions of interest of potential participants in NoEs

Achievements

A dedicated JA website has been launched (**Deliverable D2.1)**, featuring key documents, policy papers and recommendations from the JANE WPs and TTFs, organised into thematic sections. Moreover, the website clearly presents goals, ambitions, work packages and JANE partners and provides regular news updates, including significant meetings and events.

A document including stakeholder analysis was produced to inform and tailor messages to three main audiences: health professionals, patients and the public, and policy makers.

WP2 created a dissemination strategy plan which includes the following: (1) Mapping and analysing the content and audiences of JANE WPs, creating a roadmap for communicating key issues; (2) Updating network surveys to refine communication channels and content to engage relevant European networks and groups; (3) Focus on sustainability and knowledge transfer of key JA findings and recommendations, using a communication map linking WP reports with online updates on the JANE portal.

Overall, the launch of the dedicated JA website and the development of a comprehensive dissemination strategy represent a major step forward in the JANE project's efforts to improve communication and stakeholder engagement. WP2 has laid a strong foundation for effective knowledge transfer and meaningful collaboration by addressing the needs of diverse audiences and focusing on sustainability. The final stakeholder conference has further consolidated these efforts and made an important towards the project's findings and recommendations driving further progress in European cancer networking in the scope of JANE2.

3.3 Work package WP3 – Evaluation

Objectives

To verify if the project is being implemented as planned and reaches the objectives.

Achievements

The project conducted evaluations of four critical meetings, ensuring that each event was carefully assessed to measure its effectiveness and alignment with the project's objectives. Four meetings were evaluated: (1) JANE Kick-off Meeting; (2) JANE 1st Policy Dialogue; (3) JANE WP & TTF Leaders Meeting; (4) JANE Plenary Meeting. These evaluations provided important insights into the progress and effectiveness of these meetings. A summary of the evaluation results can be found in section 6 of this report. Additionally, the WP3 collaborated with WP4 on designing the surveys for the needs of the Sustainability Work Package.

In addition to the evaluation of the meetings, an important part of the evaluation of the project is the external evaluation of the Advisory Board. Advisory Board meetings took place on 14 September 2023 and 5 July 2024. The minutes of both meetings were documented and made available for reference. Summaries of both meetings can be found in section 5 of this report.

The agenda of the first meeting focused on evaluation activities, including a presentation on the development of the evaluation strategy, an overview of the ongoing work on the interim report, and lessons learned from JARC regarding the timing and completion of the report. In addition, the meeting reviewed the progress of WP1 and WP4 and discussed issues such as ensuring a seamless transition between different Joint Actions, proposals for engaging non-health partners, an overview of informal meetings with Policy Board members, and planning for upcoming Policy Dialogue and Stakeholder Forum meetings.

The agenda of the second meeting included reviewing key points from the core WPs and TTFs, gathering feedback for the final evaluation report, and discussing both the interim evaluation report and the final evaluation questionnaire. In addition, the meeting explored how the findings and lessons learned from the JANE1 project could be used to support the development of the subsequent JANE2 project.

WP3 had also prepared the **Interim Evaluation Report**, which focused on the progress of product delivery and was completed, delivered and accepted by the project coordinators. This report served as a critical checkpoint to assess the ongoing activities of the project and ensure that they were on track to meet the defined objectives.

The project produced two key deliverables that were integral to the evaluation process. The first was the Evaluation Strategy, which was completed in Month 8 (M8). This document defined the evaluation strategy by identifying indicators for each of the objectives of the Joint Action. It was provided in a paper version in English. The second deliverable is this Final Evaluation Report, completed in Month 24 (M24). This report summarises the achievements and results of JANE and how these achievements lay the foundations for JANE 2, as well as the difficulties encountered during project implementation.

In conclusion, the project undertook thorough evaluations of key meetings and the Advisory Board to assess their effectiveness and alignment with project objectives. These evaluations, together with the interim and final evaluation reports and the product evaluation provided valuable insights into the project's progress and challenges.

3.4 Work package WP4 – Sustainability

Objectives

Ensure that the established NoEs assemble the best knowledge, skills and facilities available in Europe.

Support NoEs' creation by focusing on strategies to guarantee their sustainability and aligning them with European and national policies.

Contribute to the improvement of EU health care cancer networks ensuring a long-term sustainable model for NoEs.

Generate policy recommendations and guidance to facilitate the sustainability of NoEs, possibly extending also to other health care networks in the EU.

Achievements

WP4 developed a reference framework for the analysis of European cancer networks, organisations and societies. Using this framework, WP4 partners and JANE NoE leaders identified 62 potential reference entities for a sustainability model, which were later narrowed down to 15 priority organisations through an online survey. Biosistemak then undertook and reviewed detailed analyses of these organisations, which informed the 'Sustainability Strategy of NoEs', identifying essential components such as management, infrastructure, strategic alliances, services and legal considerations.

In addition to the underlying analysis, WP4 has established a dedicated Policy Board composed of policy makers and representatives from national cancer centres and public health organisations. This board provided essential strategic guidance and ensured that the work was aligned with both EU and national policies. WP4 also developed a Stakeholder Matrix, which includes representatives from different sectors, including healthcare, patient organisations, research and academia. This inclusive approach ensured that all relevant perspectives were considered and encouraged engagement and valuable input from the broadest range of stakeholders.

A key component of the WP4 strategy was the organisation and facilitation of two policy dialogues and a stakeholder forum. These meetings provided platforms for deliberative discussions, allowing participants to share best practices and work towards consensus on the sustainability of NoEs. Key issues explored during these sessions included building alliances, ensuring alignment with EU and national policies, addressing regulatory and funding challenges, and promoting patient engagement. In addition, WP4 reached out to different groups, organised bilateral meetings, attended international events and participated in knowledge exchange initiatives.

Building on the work mentioned above, WP4 formulated a first set of recommendations aimed at improving the governance, strategic planning, service delivery, communication, ethical considerations and funding models within the NoEs.

Finally, dissemination of the findings and recommendations of WP4 was another important step. By sharing reports, giving presentations and attending conferences, WP4 ensured that its valuable insights reached the appropriate stakeholders across the cancer care community.

In summary, WP4's extensive efforts in analysing key cancer organisations, engaging diverse stakeholders and developing strategic recommendations have laid the groundwork for ensuring the long-term sustainability of the NoEs.

3.5 Work package WP5 – Complex and poor prognosis cancers

Objectives

The goal of WP5 will be to establish at least 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. Since some poor-prognosis cancers fall within cancers which are already covered, at least in part, by existing ERNs (namely, EURACAN), a discussion with stakeholders will be held to decide whether some poor-prognosis cancers may be added to EURACAN's domains already in place (with regard to head & neck cancers).

The specific objectives include the definition of: - the scope of the NoE - the activities of the NoE - potential partners - governance - sustainability - indicators of efficacy and cost/efficacy - interplay with MSs, networks, CCCs, EU patients.

Achievements

WP5 conducted a thorough needs assessment to identify the gaps and challenges in the current management of PPCs. This assessment included extensive consultation with a wide range of stakeholders, including healthcare professionals, researchers, patients and caregivers, to ensure a comprehensive understanding of the existing landscape. The experts, in collaboration with the Institut National du Cancer, defined poor prognosis cancers as those with a 5-year survival rate below 33%. In addition, the concept of the PPC NoE, based on the EURACAN domain model, was proposed and accepted by the consortium. It comprises four domains: clinical care, research and innovation, education and training, and policy and patient advocacy.

Furthermore, a pilot NoE on pancreatic cancer was initiated, in which existing pancreatic cancer models and initiatives in poor prognosis cancers were evaluated by the leaders of WP4 and WP5. The pilot provided invaluable insights and a tangible foundation on which to build future NoEs.

In addition to these achievements, a two-step endorsement process was established for partners not included in the JANE2 proposal: applicants submit a narrative application matching their capabilities to the endorsement criteria, followed by a presentation to the PPC Executive Board. Approximately 69 institutions from 27 countries nominated experts for JA JANE2.

It is also worth noting that WP5 developed and carried out a survey to collect data on future perspectives and a cost-benefit analysis. This survey reached a diverse group of respondents, including clinicians, patients, educators and policy makers, and provided valuable insights into the future direction of cancer care for PPCs. The results of this survey were presented to the Poor Prognosis Cancer Group. They highlighted the need for greater collaboration and innovation in cancer care, particularly for PPCs.

Finally, WP5 developed a detailed implementation plan for a JANE2 Joint Action proposal. This plan outlined the objectives, actions, timelines and resources required for the establishment and operation of future NoEs, providing a clear path for the further development of expertise in PPC care.

To conclude, the efforts of WP5 have significantly advanced the understanding and management of poor prognosis cancers by identifying key gaps, initiating a pilot NoE and fostering collaboration between different stakeholders. The development of an endorsement process and a comprehensive implementation plan for JANE2 laid a solid foundation for future NoEs, thus ensuring continued progress in PPC care.

3.6 Work package WP6 – Palliative Care

Objectives

The overall objective of WP6 is to establish a sustainable, high profile NoE on palliative care, to support the integration of evidence-based palliative care into routine cancer care and to ensure equitable access to palliative care across EU MSs.

The specific objectives will include the definition of: - the scope of the NoE on palliative care - its activities - its potential partners - its governance - its sustainability beyond 2 years. incl. proof of evidence - its indicators of efficacy and its cost/efficacy constraints - its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients.

Achievements

WP6 completed a thorough scoping of palliative and cancer care networks across Europe. To ensure broad representation, experts, clinicians and stakeholders from different geographical areas and levels of care were brought together to form a sustainable and trusted NoE. By establishing that PC should be integrated across the cancer care continuum, WP6 ensured its recognition as a fundamental component of care. To achieve this, the work was divided into five groups: content, indicators, implementation, development of PCCPs and relevant competencies. These groups worked together to define the role of PC, ensuring that it is considered from the point of diagnosis, through treatment and beyond.

A major focus of WP6 was to promote the integration of PC into mainstream cancer care and to emphasise patient-centred care pathways (PCCPs) that are aligned with both treatment and palliative care guidelines. These pathways were designed to be dynamic and adaptable, tailored to the individual needs and preferences of each patient. The potential of digitalised care pathways was also recognised as a way to improve coordination and information sharing between healthcare providers.

To establish measurable progress in the integration of PC, WP6 undertook an extensive literature review and identified key indicators of success. The results highlighted the lack of widely accepted indicators and the challenges of translating research findings into clinical practice. Despite these hurdles, WP6 provided valuable insights into practical indicators such as early palliative interventions, the use of patient-reported outcome measures (PROMs), multidisciplinary consultations, and improved communication across healthcare settings.

In addition to identifying indicators, WP6 focused on developing strategies for implementing effective palliative care in different healthcare systems. By examining the influence of organisational culture, leadership, resource allocation and stakeholder engagement, WP6 provided a nuanced understanding of the complexities surrounding PC integration.

WP6 also developed clear endorsement criteria to maintain the relevance of the network and established a governance structure to oversee its activities. Furthermore, communication strategies and plans for collaboration with existing networks and organisations were developed to ensure that the NoE would remain active and influential beyond the JANE project.

In summary, WP6's comprehensive approach not only identified key challenges but also provided a roadmap for future efforts. Its work has laid a strong foundation on which JANE2 can build to ensure that palliative care becomes a more integrated and effective part of cancer care across Europe.

3.7 Work package WP7 – Survivorship

Objectives

The overall objective of WP7 is to establish a sustainable, high-profile NoE on survivorship and cured patients to support the integration of evidence-based approaches to cancer survivorship into routine care and to ensure equitable access across EU MSs, also driving the identification of all relevant issues pertaining to the increased survival of cancer patients and possible solutions.

The specific objectives will include the definition of: - the scope of the NoE on survivorship - its activities - its potential partners - its governance - its sustainability - the indicators of efficacy and its cost/efficacy constraints - its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients.

Achievements

WP7 conducted a survey of its members to understand the current state of survivorship care organisation in different EU countries. This survey assessed the use of formal survivorship care plans, the types of plans used, and existing survivorship services, helping to identify areas for improvement and potential best practices.

Moreover, a questionnaire prepared by the WP leader identified potential partners such as CCCs, networks and societies that would benefit from participating in the project. In addition, larger organisations such as ESMO, SIOPE, OECI, PanCare and ECO were contacted for closer collaboration.

Leading experts were identified for four key aspects of survivorship (the definition of survivorship provided by ESMO was endorsed by WP7 members): cancer-related issues, adverse events, psychological distress and social aspects.

Endorsement criteria for healthcare providers and other institutions were developed. These criteria include factors such as multidisciplinary care, coordination with local healthcare professionals, patient involvement, educational programmes, accessibility of information, use of survivorship care plans, data collection and adherence to guidelines.

WP7 has proposed a detailed governance structure for the NoE, which outlines the organisational framework, the responsibilities and the decision-making processes of the NoE. This structure includes a Steering Committee responsible for overall strategic direction, decision-making and oversight of NoE activities, and subcommittees focused on specific areas such as clinical care, research and innovation, education and training, and policy. In addition, a Scientific Advisory Board will provide independent scientific guidance and expertise.

Finally, WP7 outlined the deliverables of the NoE which aim to achieve comprehensive and coordinated care for cancer survivors. These include comprehensive guidelines covering different aspects of survivorship care, such as education and training programmes for healthcare professionals, patients and the public; patient resources such as survivorship care plans and information materials; data collection and research to monitor the effectiveness of survivorship care; and advocacy for policy changes to improve survivorship care at national and EU level.

In summary, WP7 has laid the foundations for a robust NoE that aims for a comprehensive and coordinated approach to cancer survivorship care in Europe. It has established key partnerships, defined endorsement criteria, proposed a robust governance structure, and created a framework that prioritises multidisciplinary care, patient involvement and evidence-based practice.

3.8 Work package WP8 – Personalised primary prevention

Objectives

The overall objective of WP8 is to establish a NoE to promote the implementation of personalised primary prevention at a community level.

The specific objectives will include the definition of: - the scope of the NoE on personalized primary prevention - its activities - its potential partners - its governance - its sustainability - its indicators of efficacy and its cost/efficacy constraints - its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients

Achievements

WP8 conducted a comprehensive needs assessment and gap analysis which enabled the development of a conceptual framework for personalised primary prevention. Given the crucial role of GPs in the delivery of prevention services, WP8 put a strong emphasis on exploring their perspectives on this matter.

Moreover, WP8 reviewed and updated the criteria for participation and identification of participants in the future Personalised Primary Prevention Network, which will bring together health centres, experts and providers to collaborate on advancing prevention strategies. The criteria ensure that participants have expertise, experience, and a strong professional reputation. Moreover, collaboration, innovation, and adaptability are key qualities expected from participants, alongside compliance with legal and ethical standards like GDPR.

WP8 also created a comprehensive governance framework for the NoE which includes roles, responsibilities and decision-making processes within the network. Key thematic areas and operational requirements for the network have been identified. Four thematic domains - lifestyle factors, biomarkers, genetics and omics, and psychosocial behaviour - and seven operational groups were established: (1) coordination and management; (2) dissemination and communication; (3) evaluation; (4) policy and public engagement; (5) research, data management and biobanking; (6) education and training; (7) clinical practice guidelines and decision support tools.

Furthermore, WP8 ensured that the NoE on Personalised Cancer Prevention included broad representation and fostered collaboration across sectors. The governance structure includes input from different stakeholders, such as healthcare providers, patient advocacy groups, national coordinators, scientific advisors and experts from different fields.

WP8 also established mechanisms to disseminate knowledge and influence policy. Dedicated operational groups focus on communication, public engagement and policy development, ensuring that the network's research and findings are translated into practical clinical guidelines and policy recommendations.

In conclusion, the efforts of WP8 culminated in the creation of a robust and collaborative governance framework that emphasises expertise, innovation and compliance. By fostering broad representation and establishing mechanisms to influence policy and practice, WP8 has laid a solid foundation for the NoE on personalised primary prevention.

3.9 Work package WP9 – Omics Network of Expertise for cancer

Objectives

This WP will focus on the development of a NoE fostering the integration of omic technologies into the EU healthcare systems (HCSs) to ameliorate prevention, diagnosis and treatment of cancer. Indeed, cancer is to be considered as a disease that should be prevented, early/timely diagnosed and treated appropriately within a continuum (the PDT cycle).

The specific objectives will include the definition of: - the scope of the omics technologies "as is" and "to be" - the tasks and roles of an NoE 'omics' - the integration of omics NoE in the European/global omics ecosystem - the omics NoE governance structure - its sustainability - its indicators of efficacy and its cost/efficacy constraints its relationship with MSs, other EU and national networks, patients and citizen

Achievements

WP9 conducted a thorough literature review on omics technologies in cancer care, as well as consultations on six specific use cases where omics technologies are expected to play a critical role. To ensure high quality service provision, WP9 developed endorsement criteria for expert participants, categorising them on the basis of thirteen criteria, including their volume of activity, infrastructure, expertise, quality management and integration into care.

WP9 also assessed the Technology Readiness Level of different omics technologies, noting that while genomics is well established, other areas such as transcriptomics and multi-omics are still emerging and require further research. Furthermore, WP9 proposed a detailed organisational and governance structure for the NoE, drawing on successful existing models such as ERN EURACAN.

During the project, collaboration was a key priority for WP9. The team actively collaborated with other JANE work packages, in particular WP10 and WP5. To gather different perspectives and ensure broad representation, WP9 organised meetings and discussions with a wide range of experts and stakeholders, including key organisations such as ELIXIR, BBMRI-ERIC, ECRIN, ESFRI and ESMO. Moreover, WP9 identified key stakeholders - including other NoEs, ERNs, scientific societies, initiatives such as ELIXIR and private sector partners - to effectively integrate the NoE into the wider EU cancer landscape.

In summary, WP9 envisioned a NoE that not only supports healthcare providers, but also addresses unmet needs in the field, streamlines complex procedures and improves interoperability between different systems.

3.10 Work package WP10 – Hi-tech medical resources

Objectives

The overall objective of WP10 is to establish a NoE on emerging/innovative and/or privileged technologies in the cancer area to ensure optimal coverage of patient needs throughout the EU. Such technologies include biotherapies and advanced therapies, innovative surgical procedures, complex radiation equipment (e.g. hadron therapy), innovative therapeutic nuclear medicine solutions, interventional radiology techniques, early phase clinical research centres dedicated to first in-human studies and the like. Overall, this NoE will ensure a link with the network of CCCs to progressively promote equitable access to these advanced technologies in the EU and MS.

The specific objectives will include the definition of: - the scope of the NoE on hi-tech medical resources - its activities - its potential partners - its governance - its sustainability - its indicators of efficacy and its cost/efficacy constraints - its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients.

Achievements

WP participants defined the scope of the NoE, focusing on five sub-groups of high-tech medical resources and identifying three additional sub-groups for future consideration. The objectives and principles of the NoE were established, prioritising the most urgent and promising resources due to the rapid evolution of the field.

One of the more technical aspects of WP10's work was to define the seven key areas of expertise within the NoE. Based on consultations with experts and careful consideration of technological advances, seven priority subgroups or "domains" were validated, which are likely to form "sub-networks": (1) nuclear medicine; (2) radiomics; (3) innovative radiotherapies; (4) innovative surgery; (5) physical methods of ablation; (6) cell therapies; (7) ex-vivo testing of agents.

Another achievement was the establishment of endorsement criteria to ensure the quality and inclusiveness of the NoE. These 13 criteria, developed in collaboration with WP9, focused on various factors such as volume of activity, infrastructure, expertise and accessibility.

In addition to defining the scope of the NoE and the endorsement criteria, WP10 also developed a comprehensive blueprint for the NoE. This blueprint included a detailed organisational structure, a governance model, a clear division of labour between stakeholders and potential areas of collaboration with other European stakeholders. Furthermore, WP10's significantly expanded the network. Originally comprising seven member states, WP10 extended its reach to 17 countries plus Ukraine in preparation for JANE-2. The network now includes 53 partner organisations and nearly 200 experts in seven key areas of expertise.

Therefore, WP10 has laid a strong foundation for the NoE on High-tech Medical Resources, setting it on a path towards sustainability and growth. Its work highlights the importance of continued collaboration, especially as the NoE moves into its next phase with JANE-2. Looking to the future, WP10 also laid the groundwork for the continuation of the NoE into JANE-2. It outlined future tasks, including governance, advocacy, infrastructure support, education, training, dissemination and sustainability. Furthermore, WP10 identified key stakeholders in each area of expertise to ensure that the network continues to evolve and remain relevant as healthcare challenges change and new technologies emerge.

3.11 Work package WP11 – Adolescents and young adults with cancer

Objectives

The overall objective of WP11 is to establish a NoE on young adults to ensure special challenges of this population are adequately addressed throughout the EU. Such challenges include unique epidemiology, specific tumor biology, insufficient awareness of cancer in this population, diagnostic delay, limited inclusion in clinical trials, psychosocial needs etc. Overall, this WP will ensure a link with the Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) on adolescent and young adults with cancer.

The specific objectives will include the definition of: which NoE to establish considering the discrepancies between adolescents on one side and young adults with cancer the scope of the NoE/s the activities the potential partners the governance the sustainability the relationship with MSs, other EU and national networks including the ERN

Achievements

The NoE on adolescent and young adult (AYA) cancer addressed the specific needs of adolescents and young adults with cancer by identifying the type and number of NoEs needed for care and research. Key tasks included identifying participants from Member States, scientific societies and patient organisations, and defining eligibility criteria for their selection. A call for expressions of interest was launched to involve relevant stakeholders.

WP11 successfully formed a core group of key players from European AYA cancer projects. The team focused on refining the NoE objectives and addressing national versus EU level issues. The revised objectives are: (1) develop AYA-specific programmes, (2) develop clinical recommendations on AYA issues, (3) promote AYA cancer research, (4) raise awareness of AYA cancer, (5) monitor AYA cancer epidemiology, (6) define and promote AYA education, and (7) support patient and public engagement.

Participation in the NoE will be guided by clear endorsement criteria to ensure its relevance and effectiveness. For instance, WP11 sets a European scope as the primary criterion, meaning that participants, including healthcare providers, scientific societies and research groups, must demonstrate involvement in EU projects or collaborative initiatives. For healthcare centres, additional criteria include a national mandate or leadership role in AYA cancer care, proven competence in AYA-specific issues, and involvement in national programmes or research. WP11 placed particular emphasis on including both paediatric and adult cancer centres to bridge the gap in care, and also gave priority to centres from EU Member States that do not have dedicated AYA programmes.

To ensure the long-term success of the NoE, WP11 has established a robust governance framework. A dedicated task force is responsible for defining the structure of the network, outlining roles and responsibilities, and establishing links between experts and stakeholders. Collaboration with other relevant NoEs, is a key aspect of the governance strategy. WP11 also plans to expand the network, ensure patient representation and raise awareness of the. In addition, a specific task force is focused on developing a sustainability strategy, addressing funding mechanisms, resource allocation and EU collaborations, all of which are critical to ensuring the network's impact at the national level.

In conclusion, WP11 has demonstrated a deep understanding of the unique challenges faced by the AYA patient population. The foundation laid by WP11 is critical to the operational success of the NoE, which is likely to lead to significant improvements in the quality of life and care of AYAs with cancer across Europe.

3.12 Work package WP12 – TTF1 - Integration between health care and research

Objectives

Mapping current challenges in the integration between healthcare and research in the perception of clinical researchers and physicians.

Analysing existing opportunities to conduct large low-cost clinical trials and to generate real-world evidence through networking.

Improving the coordination of research by providing effective and efficient mechanisms by means of the new NoEs.

Widening participation in research and improve the efficiency of research.

Achievements

Biosistemak has developed and reviewed a search strategy for WP12, including a desktop search and literature review. Preliminary results from the desktop search were analysed and the literature review protocol was published in PROSPERO under the reference: 'Challenges in the Integration between Health Care and Research in the Cancer Field: A systematic review [CRD42024520574]'.

WP12 was also involved in Establishing clinical research networks with the aim to define mechanisms for establishing clinical research networks by investigating research platforms, funding opportunities and NoE assessment tools.

3.13 Work package WP13 – TTF2 - Integration between EU networking and Member States

Objectives

The big challenge ahead is to establish specific solutions for each Member State, sticking to general principles while considering all those features which are unique to Member States' health systems vis-a-vis the specificities of each NoE on the other. This TTF will focus on all solutions potentially able to improve the interplay between national health systems, including their possible networking facilities, and the EU networking systems, such as the new NoEs, the new network of CCCs, existing ERNs.

Achievements

The team has identified key similarities and differences between Member States' health systems, providing the basis for tailor-made, principled solutions. Efforts included mapping existing solutions within the JANE project to identify effective policy implementation and strengthen links between Member States, building on the knowledge and insights gained from the project.

A research study was carried out to address cancer-related challenges, systemic issues and country-specific differences in 16 countries, including Italy, France, Romania and others. This comparative documentation has been instrumental in improving decision-making processes and supporting the creation of effective NoEs. This activity explores the challenges of health networking within the EU, focusing on legal and policy barriers, and aims to improve understanding and propose solutions for better integration and collaboration.

3.14 Work package WP14 – TTF3 - Integration between IT infrastructures and AI tools

Objectives

This TTF will focus on the objective to contribute to the improvement of EU health care networking on cancer with regard to the challenges of integrating local IT infrastructures with IT tools for European cancer networking and to exploit the use of AI.

Achievements

The TTF3 team has recruited 12 experts in AI, data and IT, expanding its network to include additional European cancer AI experts. Besides recircuiting experts, TTF3 has mapped key EU initiatives focused on improving IT and cancer data integration. Through collaborations with the ELIXIR Cancer Data Community, the 1+ Million Genomes initiative, the EOSC4Cancer project, EUCAIM and the BiGPicture Imaging Consortium, the team has gained insights into the latest AI infrastructure solutions that are driving advances in cancer research, diagnostics and data sharing across Europe.

Moreover, IT and data sharing survey was conducted in 75 cancer care and research institutions across Europe. The survey assessed data sharing capabilities and identified addressable gaps in infrastructure and regulatory frameworks that need improvement in order to enhance scientific and clinical data sharing.

Finally, TTF3 has advanced the evaluation of IT systems for improved interoperability, particularly in genomic and imaging data, with a focus on secure data sharing and federated data solutions. These solutions allow institutions to analyse and share insights from patient data without centralising or transferring sensitive information, thereby preserving patient privacy and enhancing data security.

TTF3's recruitment of AI and data experts, coupled with its collaboration with leading EU initiatives, has significantly improved the integration of advanced technologies in cancer research. Efforts to evaluate IT systems and improve data sharing infrastructure have addressed critical gaps and paved the way for secure and effective data management in the field, ultimately driving progress in cancer diagnosis and treatment.

3.15 Work package WP15 – TTF4 - The ERN model

Objectives

This TTF will assess current rare cancer ERNs' functioning, with a view to identify problems, challenges and solutions with regard to EU networking, in order to suggest improvement strategies for EU cancer care networking in general and specifically for the new NoEs, in collaboration with the other TTFs plus the WP on Sustainability. The specific topics dealt with by each of the latter will be individually assessed.

Achievements

Through four online meetings, WP15 explored how the experience of ERNs, particularly EURACAN, could inform the development of future NoEs. The focus was on understanding the differences and complementarities between ERNs and NoEs.

WP15 identified significant challenges to the effectiveness of cancer care networking. Budgetary constraints, inconsistent involvement of Member States and limited effectiveness of the Clinical Patient Management System were among the most pressing issues. The assessment also revealed difficulties in maintaining engagement with different stakeholders, administrative burdens and a lack of a legal framework for collaboration with industry. The barriers to cross-border healthcare, coupled with the inadequate resources available to healthcare professionals, added to the challenges.

Seven main recommendations for future NoEs were created: (1) Invite all ERNs to participate in the various NoEs, even if they do not express initial interest; (2) Provide funding mechanisms to support connections between ERNs, EURACAN, and future NoEs. Utilize existing guidelines and develop new ones where needed, alongside creating informational materials and teaching courses); (3) Improve access to NoEs within JANE 2 for rare cancer patients, both nationally and internationally; (4) Facilitate cross-border healthcare for diagnosis, participation in multi-disciplinary teams, and treatment; (5) Establish a streamlined governance structure for NoEs; (6) Collaborate with the European Health Data Space to create registries; (7) Regularly measure and publish the activities of NoEs, along with the interactions between NoEs and ERNs.

WP15's evaluation of ERNs, with a focus on EURACAN, underscores the critical need to address systemic challenges in cancer care networking. WP15 has identified key areas for improvement and developed solutions that, if implemented, could significantly improve the strategies for the networking of cancer care in the EU in general, but also for the NoEs.

3.16 Work package WP16 – TTF5 - Patient Involvement

Objectives

This TTF will focus on developing strategies to improve patient empowerment and engagement through European health care cancer networking. The goal will be to develop a toolkit for different methods of patient and citizen engagement that can be tailored to specific contexts and to build on existing national and European patient organization networks for the implementation of the tools

Achievements

WP16 developed a **patient involvement toolkit** to support networks of expertise. The toolkit focuses on maximising the benefits of patient involvement, addressing potential challenges and providing practical guidance on how to effectively involve patients in different aspects of cancer care. The intended impact of the toolkit is significant. It is designed to directly support the implementation of patient involvement activities within various work packages of the JANE2 project. In addition, WP16 envisions the toolkit as a dynamic resource that will be continuously updated with experiences and insights from patient involvement initiatives in different NoEs. This approach will ensure that the toolkit remains relevant and effective, ultimately contributing to more meaningful and effective patient involvement in cancer care.

To develop the toolkit, WP16 relied on a multidisciplinary and collaborative effort, with a strong emphasis on incorporating the input and perspectives of patients and patient organisations. To this end, WP16 established a working group of national and European cancer patient representatives to support the activities of the TTF and ensure broad representation within the project. In addition, the WP16 team conducted 14 interviews with patient organisations to gain insight into best practices, real-world experiences, effective methods of engaging patients and potential challenges. A workshop was also organised in Brussels, bringing together 35 patient organisations. The workshop facilitated discussions on patient involvement, in particular on legitimacy and funding, as well as on how patient organisations should be involved and how to support patient involvement.

While input from patients and organisations was prioritised, WP16 also conducted desk research to explore specific projects and experiences mentioned by participants, as well as to draw on relevant academic literature on patient involvement. This research complemented the findings from the interviews and workshop, thus contributing to a well-rounded and robust toolkit.

In conclusion, the development of the patient involvement toolkit represents a major step forward in the integration of patient perspectives into cancer care networks. By focusing on practical guidance and continuous updates, the toolkit will improve patient involvement across different JANE2 work packages. The extensive input from patient representatives and organisations will ensure that the toolkit is both relevant and effective in promoting more meaningful patient involvement in cancer care.

4 CHALLENGES ENCOUNTERED

This section provides an overview of the challenges and issues encountered by various work packages throughout the project.

Work Package 2 (Dissemination) encountered difficulties due to the size and complexity of the consortium, which made it difficult to gather input and reach consensus on the design of the website. This led to delays in the website development and delivery schedule. To overcome this, a special meeting was held to finalise decisions on the website design.

Work Package 3 (Evaluation) struggled with low survey response rates. To address this challenge, QR codes linking to the survey were included at the end of presentations to encourage more participants to participate.

In **Work Package 4 (Sustainability)**, the team encountered several problems, including difficulties in recruiting representatives from all participating Member States to the Policy Board and in attracting policy makers. In addition, some members of the Policy Board left after the first Policy Dialogue. Suggested solutions included extending the final nomination deadline for Policy Board members, allowing for changes in representation throughout the project and possibly broadening the profile of members. Challenges were also encountered in nominating representatives for the Stakeholder Matrix, leading to the suggestion of allowing more members to be involved throughout the project. In addition, some partners with allocated contributions were not actively involved, leading to the Contributing Authorities taking on additional responsibilities to ensure progress.

Work Package 5 (Complex and Poor Prognosis Cancers) faced challenges in defining eligibility criteria for individuals, healthcare providers, and societies that were not overly restrictive. Encouraging collaboration across Member States was identified as a critical aspect of overcoming these challenges.

Work Package 6 (Palliative Care) initially planned to use surveys to identify potential participating centres. However, the call and application for JANE-2 led to a revised approach. Recruitment and engagement of sites became a collaborative effort involving multiple work packages and the coordination team, with a particular focus on sites directly involved in Work Package 6. In addition, unforeseen circumstances prevented some participants from completing their agreed tasks. In order to ensure the timely completion of the report, the Work Package Leader (OUS) took on a larger role in three working groups.

Work Package 9 (Omics Network of Expertise for Cancer) encountered difficulties in defining the scope of the NoE and its interactions with ERNs until each NoE clarified its scope and objectives.

Work Package 11 (Adolescents and Young Adults with Cancer) experienced delays in reaching a common understanding of the objectives regarding the interaction between the national and EU levels. As a result, discussions on endorsement criteria were postponed in order to prioritise the NoE deliverables.

Work Package 12 (Integration Between Health Care and Research) experienced delays in gathering input for the desktop search due to the summer months, which pushed the final input to early 2024. In addition, securing the active participation of all partners proved challenging due to the demanding nature of the tasks. To mitigate this, additional steps, such as a desktop search, were built into the methodology to encourage greater participation.

Work Package 14 (Integration Between IT Infrastructures and AI Tools) struggled to achieve full participation of the assigned members. Only around 12 members were consistently involved in meetings, follow-up and communication.

Work Package 15 (The ERN Model) encountered obstacles in focusing on the challenges faced by ERNs due to the need to first clarify the differences between NoEs and ERNs. A clear understanding of the scope and objectives of each NoE was necessary to understand their added value and interactions with cancer ERNs.

Finally, **WP16 (Patient Involvement)** dealt with several challenges, including potential conflicts between different patient organisations and difficulties in communication and coordination with WPs 4-9. To address these issues, the team planned to draw on the experience of previous projects, devote considerable time to building trust, and address any issues that arose in depth. Regular meetings with representatives from Work Packages 4-9 were also planned to ensure effective communication and maximise implementation of the toolkit.

In **summary**, the project has sometimes faced significant hurdles - including delays, coordination difficulties and uneven participation. However, practical steps were taken to address these issues. By organising special meetings, extending deadlines and revising strategies, the project was kept on track. Given the experience of JANE, which illustrates the complexity of managing large-scale, multinational initiatives, recommendations for JANE 2 would be to focus on even tighter coordination and more active stakeholder participation with defined guidelines and deadlines from the start of the Action.

5 Advisory Board Meetings

2.1 Summary of the 1st JA JANE Advisory Board meeting

1st JA JANE Advisory Board meeting was held online on September 14th, 2023. The meeting focused on the structure and progress of WP1, evaluation activities in WP3, sustainability efforts in WP4 and insights from the previous Joint Action, Joint Action on Rare Cancers (JARC).

WP1 presented procedural organisation focused on ensuring a seamless transition between Joint Actions. The emphasis was put on avoiding overlaps and defining clear responsibilities in order to prevent any confusion or duplication of efforts when the project moves from one phase to another. In addition, the consideration was given to include non-healthcare partners, such as patient advocacy groups and professional societies, in NoEs.

WP3 presented evaluation activities which encompassed the development of an Evaluation Strategy and the production of an Interim report. Although the evaluation strategy was not fully completed, it was presented during the meeting and it was mentioned that the remaining work would be completed and made available to the Advisory Forum members in a timely manner. With regards to the Interim report, WP3 stated that the work is ongoing and that it should be completed by the end of November 2023.

WP4 shared their progress on the generation of policy recommendations and sustainability efforts. Moreover, WP4 has been actively involved in informal meetings with Policy Board members, the organization of a Policy Dialogue meeting, and planning for a Stakeholder Forum in October and November.

Finally, Advisory Board opened further discussion regarding the evaluation activities and shared some lessons from previous experience in JARC. For instance, the Board emphasised the importance of effective scheduling, allocating sufficient time for report finalization following Advisory Committee meetings, and maintaining regular contact with work package leaders. The subsequent discussion revolved around the workload considerations for Advisory Board members, the specific project aspects to be evaluated, the methods for evaluation, and the proposed timeline. The emphasis was placed on evaluating project quality, its value to patients, and the relevance of the outcomes.

Overall, the meeting underscored the need for a clear mission in light of a new JA, avoiding overlaps between JAs, the inclusion of non-healthcare partners in NoEs, and the role of the Advisory Board in evaluating project outcomes.

2.2 Summary of the 2nd JA JANE Advisory Board meeting

2nd JA JANE Advisory Board meeting was held online on July 5th, 2024. The main aim was to update the Advisory Board on the progress of the JANE JA, including achievements across various work packages and the content of the final evaluation report and questionnaire.

Annalisa Trama (INT) discussed significant changes in JANE coordination under WP1, highlighting the shift from JANE 1 to JANE 2 and the preparation of a Green Paper to document project activities. Paolo G. Casali (INT) added that the Green Paper should address key EU healthcare networking issues, such as governance, funding, patient involvement, and sustainability.

In WP3, Mario Šekerija reported that most of the milestones had been completed, with the exception of the final evaluation questionnaire, which was still in draft form. He presented the interim evaluation report, noting positive results and identifying areas for improvement, such as time management and clearer communication of project activities. The discussion also focused on the design and timing of the final evaluation questionnaire.

Sarah Berrocoso Cascallana (Biosistemak) led the discussion on WP4's sustainability strategy for NoEs, focusing on governance, strategic planning, stakeholder engagement and the outcomes of the Policy Dialogue and Stakeholder Forum meetings. The importance of facilitating research, national collaborations and dissemination strategies was emphasised.

Sakari Karjalainen expressed satisfaction with the project's progress but questioned the feasibility of an external evaluation at this stage. Annalisa and Paolo then discussed the legal and operational challenges of launching and sustaining NoEs.

Iva Kirac (SMUHC, Zagreb) provided an overview of Croatia's involvement in EU-funded cancer projects. She presented ongoing initiatives like Cancer Care Beacon, CCI4EU, and EUonQoL, which address disparities, integrate cancer infrastructures, and improve quality of life assessments.

Finally, Annalisa and Paolo provided updates on JANE2, discussing inclusivity, operational structures, and sustainable business models to ensure long-term viability. The meeting concluded with Sakari expressing optimism about progress and stressing the importance of sustainability. Mario outlined pending matters related to the final evaluation and suggested further communication via email.

6 SURVEY RESULTS AND FINAL EVALUATION QUESTIONNAIRE

The process evaluation measures the day-to-day strengths and weaknesses of the operational part of the project. Short surveys were conducted immediately after the meetings to measure participants' satisfaction with the organisation of the meetings, the level of cooperation and the progress of project activities. The evaluation team used LimeSurvey (www.limesurvey.org) as a tool for creating surveys. Initially, the evaluation of the meetings was done through a personalised link to the survey that was sent to each participant by email, while at later meetings a QR code that led directly to the survey was provided on the spot.

The surveys covered issues such as the clarity of the topics discussed, the time organisation and management of the meeting, whether the meeting was useful in terms of both networking and activity planning, and suggestions for the future. The surveys used a mixed methods approach. They included both qualitative (e.g. open-ended questions) and quantitative data. Qualitative data included open-ended questions, the purpose of which was to gain deeper insights, discover unforeseen issues and collect suggestions for improvement, which are critical for evaluation. Quantitative data was collected through the use of questions that offered response options on a scale. Coding and grouping were used for qualitative data analysis. For quantitative analysis, basic statistical approaches such as frequencies and means were used (see also Evaluation strategy).

During the first half of the Joint Action, five meeting evaluation surveys were carried out during the Kick-off Meeting, the Policy Dialogue Meeting, the WP and TTF Leaders' Meeting, the Plenary Meeting and the Stakeholders' Forum. The average response rate of the evaluated meetings included in this Report is 40%, ranging from 24% (the Policy Dialogue meeting) to 67% (WP and TTF leader meeting). See Chart 1 on page 35 for illustration of the response rates for each survey.

The results of the surveys revealed a general sense of satisfaction among participants. The meetings were praised for their inclusive nature, adherence to agendas and opportunities for participation. However, a consistent theme emerged, indicating the need for improvement in a number of key areas. In particular, participants expressed a desire for better time management to make meetings more efficient. Most importantly, there was a notable call for greater clarity in the definition and communication of project activities and objectives. Therefore, future meetings should prioritise better time management and a clearer definition and communication of project activities and objectives. The next subsection focuses on analysing the results of the Final Evaluation Questionnaire that was presented to the participant of the final JANE conference held in Brussels on September 24th, 2024.

Final Evaluation Questionnaire

The results of the **questionnaire** provide valuable insights into the functioning of the JANE project, focusing on three key areas: processes, outputs and outcomes. There were 40 received responses altogether.

Feedback on the JANE project **processes** were largely positive. The majority of respondents were satisfied with the way the project was managed and coordinated. Most participants suggested that the project had strong organisational capacity, ensuring that tasks were carried out efficiently and effectively. Communication between project partners was also seen as clear and timely. Many respondents considered that all stakeholders were well informed. Furthermore, respondents widely acknowledged that the views of all partners were considered in shaping and adjusting the project objectives. The results also suggest that the consensus-building mechanisms within the JANE project were highly effective, and that efforts to reach agreement on critical issues were well managed and properly followed up.

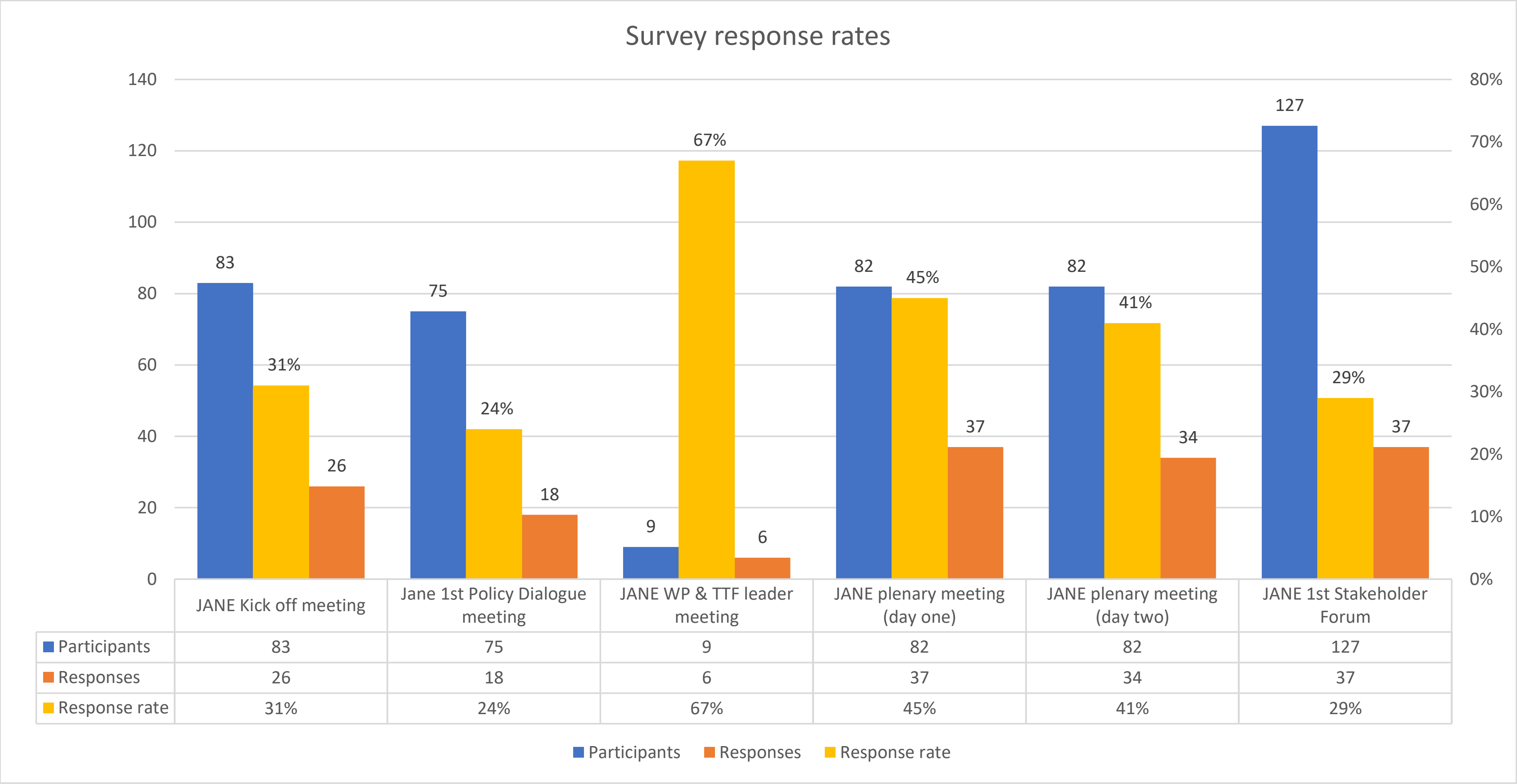
In terms of **outputs**, the results show significant progress, particularly in preparing for future NoEs. The majority of respondents agreed that the groundwork for the NoEs had been successfully laid. This is a crucial achievement, as the success of the NoEs largely depends on the preparatory work done during the JANE project. In addition, most respondents felt that both the objectives and the activities of the NoEs were clearly outlined and well defined. Regarding the evaluation of existing EU networking models, it has received somewhat mixed feedback from respondents. While many agreed that the evaluation had been successful, a significant number of participants were neutral and a minority were negative. Similarly, there was some uncertainty around the issue of potential overlap between the NoEs and other EU networks. While many agreed that these overlaps had been addressed, a proportion of respondents remained unsure or disagreed, indicating a need for further clarification.

Regarding **outcomes**, the survey results are overwhelmingly positive. Respondents expressed strong confidence that future NoEs will add significant value to EU oncology networks, particularly in supporting the objectives of the European Plan to Beat Cancer. Moreover, respondents gave positive feedback on the use of the Green Paper format as a dissemination tool. This approach was seen as an appropriate means of sharing findings and stimulating further discussion on the challenges facing European networks.

Finally, a minority of participants responded to the **open questions**. Firstly, participants suggested involving additional partners in JANE2, such as partners from Eastern Europe, independent cancer advocacy groups like the Association of European Cancer Leagues and scientific societies. Secondly, respondents emphasised the need for clear governance frameworks for each NoE and better coordination with other EU cancer networks such as EUnetCCC and ERNs. There was also a call for a greater focus on poor prognosis cancers. Furthermore, participants noted the need for increased dissemination activities, the uneven progress and level of achievement of different NoEs, and the need for prevention to collaborate with other sectors.

In summary, the survey results paint a positive picture of the JANE project. The processes were perceived as well organised, inclusive and collaborative. The outputs, in particular the groundwork for future NoEs, are promising, despite some reservations regarding the evaluation of EU networking models. Finally, the outcomes are expected to be highly impactful, with the project expected to significantly strengthen EU oncology networks and support key initiatives such as Europe's Beating Cancer Plan.

Chart 1. Response rate for each survey



	JANE Kick off meeting	Jane 1st Policy Dialogue meeting	JANE WP & TTF leader meeting	JANE plenary meeting (day one)	JANE plenary meeting (day two)	JANE 1st Stakeholder Forum
🟦 Participants	83	75	9	82	82	127
🟧 Responses	26	18	6	37	34	37
🟨 Response rate	31%	24%	67%	45%	41%	29%

7 GREEN PAPER

The EU's 'Beating Cancer' plan envisaged the expansion of the existing European Reference Networks for rare cancers through the creation of new health networks. These include a network of comprehensive cancer centres and several NoEs focusing on areas such as poor prognosis cancers, palliative care, survivorship, personalised prevention, omic technologies, advanced medical resources and cancers in adolescents and young adults. To support the development of these NoEs, experts from the EU Joint Action have produced the Green Paper, which looks at the potential and challenges of health networking in the EU, particularly in cancer care. It highlights the benefits of networking, such as improving access to high quality care, fostering collaboration in research and education, and improving cost-effectiveness by exploiting economies of scale. However, a key issue is the lack of research on the effectiveness and cost-effectiveness of different network models, which makes it difficult to design and implement new networks.

The paper raises a number of critical questions, grouped around five key themes:

1. Research and good practice on health networks in the EU: How can research on health networks be further developed to better guide the design and implementation of networks? What are the most effective models for addressing specific cancer care needs?

2. EU integration and national sovereignty: How can Member States cooperate in health networking while respecting national sovereignty? How can the concept of "networks of networks" be effectively implemented?

3. Funding and sustainability: Who should fund these networks and how can their cost-effectiveness be demonstrated? Should these networks be set up as legal entities to enable independent fundraising?

4. Integration between health and research: How can health networks be future-proofed and integrated with clinical, translational and health services research, including securing funding in a changing environment? In addition, how can the regulatory environment be adapted to support data sharing and research within health networks, while ensuring patient privacy? Can AI help overcome data interoperability issues?

5. Patient involvement: How can patient advocacy groups be more formally involved in shaping EU health networks, and how can their perspectives be effectively integrated into network activities?

In summary, the paper emphasises the transformative potential of NoEs and other EU health networks for the improvement of cancer care. However, it also identifies significant challenges that require open discussion and collaboration between stakeholders in order to realise the full potential of the networks. To this end, the green paper will facilitate discussion within the oncology community and contribute to the development of the best possible NoEs, thereby improving health networking in Europe.

The paper has been submitted for publication in a scientific journal.

8 BRIDGE BETWEEN JANE AND JANE 2

8.1 Brief overview of JANE 2

The JANE 2 project is part of an EU initiative to create specialised NoEs to improve cancer care across Europe. It follows on from the ongoing JANE project, which laid the foundations for these networks. The new phase, called JANE 2, will formally establish seven NoEs in key areas of cancer care, guided by the EU's Beating Cancer Plan. These areas include:

1. Complex and hard-to-treat cancers
2. Palliative care
3. Survivorship
4. Personalized cancer prevention
5. Advanced medical technologies (omics)
6. High-tech medical resources
7. Care for adolescents and young adults with cancer

Each NoE will focus on one of these critical areas, with the aim of working together to improve cancer treatment and care in all EU countries. The project will also work to develop clinical guidelines, raise awareness, improve healthcare models, educate both health professionals and patients, promote research and engage the public.

8.2 JANE as a foundation for JANE 2

The JANE project has achieved a number of significant milestones that provide a solid foundation for the forthcoming JANE 2 initiative. These achievements not only lay the groundwork for the continuation of the effort, but also ensure a smooth transition from JANE to JANE2.

One of the most significant achievements of the JANE project has been the careful development of a framework for each of the seven proposed NoEs in cancer care. Focusing on critical areas such as personalised primary prevention, survivorship, palliative care, omic technologies and complex cancers, each NoE was carefully designed with a detailed scope and objectives. Work packages for each NoE outlined not only potential partners, but also governance structures, sustainability plans and indicators of effectiveness. By providing a clear and strategic direction for each NoE, JANE has ensured that these networks are well prepared for implementation in JANE 2. This preparatory work acts as a blueprint that will guide the NoEs through their early stages, providing them with a robust structure that is crucial for long-term success.

Another critical area where JANE has excelled is in the identification and engagement of key stakeholders across Europe. The project's success in this area is particularly noteworthy given the complexity of coordinating such a wide range of participants from diverse backgrounds. Through extensive scoping and recruitment efforts, JANE identified leading experts, potential participating centres and relevant stakeholders for each NoE. The development of specific endorsement criteria should further ensure that the most qualified and relevant individuals and institutions are brought into the fold. This careful selection process is essential to ensure that the NoEs are not only staffed with the best talent, but also connected to the right networks, which will be critical to their success in JANE 2.

JANE also placed a strong emphasis on sustainability, recognising that the long-term success of NoEs will depend on their ability to survive beyond the initial project funding. JANE dedicated a specific work package to the analysis of existing cancer networks and the development of sustainability strategies. By mapping and analysing 15 existing cancer networks, JANE was able to identify the key factors contributing to their sustainability. These findings were then used to formulate policy recommendations and strategies aimed at ensuring that the NoEs established under JANE 2 receive the necessary support to continue to function effectively in the long term. This emphasis on sustainability is a crucial element in ensuring that the benefits of JANE and JANE 2 are felt long after the projects have officially ended.

Collaboration was another area where JANE made significant progress. Recognising that the complex challenges of cancer care require a coordinated effort, JANE has worked to foster links with other relevant EU initiatives and stakeholders. In particular, the project established collaborative partnerships with the JA CraNE, JA eCAN and CCI4EU. These partnerships aimed to align the work of these initiatives with that of JANE, creating synergies that maximised the impact of all the projects involved. By integrating the efforts of these different initiatives, JANE has not only increased its own impact, but has also contributed to a more cohesive and effective European strategy for cancer care. This collaboration will be essential in JANE 2 as the project seeks to operationalise the NoEs and integrate them into the wider European oncology landscape.

In addition, dissemination has been a key priority throughout the JANE project. Recognising the importance of broad support, JANE implemented a multi-faceted dissemination strategy designed to reach a wide audience, including the medical community, patient advocacy groups and policy makers. A dedicated website and various other dissemination channels such as newsletters, conferences and meetings were used to ensure that the project's activities were widely known and understood. This outreach has not only helped to build support for the NoEs, but has also laid the foundations for their successful implementation in JANE 2. Going forward, JANE 2 will build on these efforts with an updated dissemination strategy plan designed to maximise resources and ensure that the NoEs continue to receive high visibility and engagement.

The above achievements of JANE provide a strong foundation for JANE 2 in several important ways. First, the detailed planning and preparation activities carried out in JANE ensure a seamless transition to the implementation phase of the NoEs in JANE 2. With a well-defined framework already in place, the NoEs are able to move quickly from planning to action. Second, the strong network of partners and stakeholders established during JANE will facilitate effective collaboration in the operationalisation of the NoEs. This network, built on trust and shared goals, will be instrumental in overcoming the challenges that will inevitably arise during the implementation phase. In addition, JANE's emphasis on sustainability increases the likelihood that the NoEs will have a long-term impact and continue to function effectively well beyond the JANE 2 project.

The lessons learned from JANE, particularly in terms of stakeholder engagement, collaboration and sustainability, will be invaluable as JANE 2 seeks to take these NoEs from concept to reality.

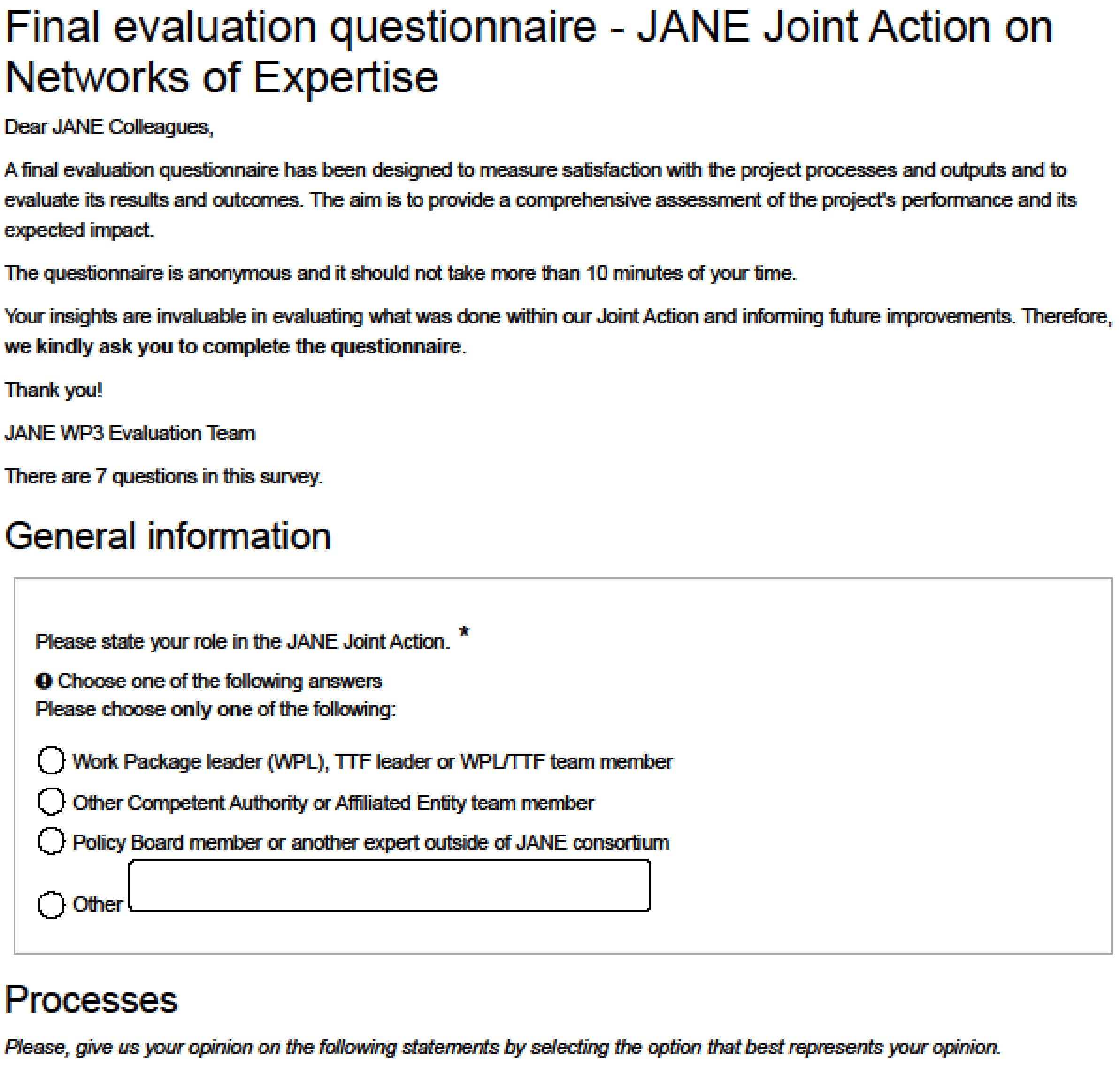
9 CONCLUSION

The JANE project is a major EU initiative to establish seven NoEs to improve cancer care across Europe. The main objective of the project was to lay the groundwork for these NoEs by addressing critical areas such as personalised prevention, survivorship, palliative care, omic technologies and complex cancers. Despite some challenges in coordinating such a large and complex project, particularly in ensuring the consistent participation of all Member States and the introduction of the idea for JANE 2 during the project, JANE has been successful in developing a comprehensive framework for each NoE.

This framework, which includes the scope, objectives, potential partners, governance structures, sustainability plans and indicators of effectiveness for each network, provides a robust blueprint for the implementation phase in JANE 2. The careful identification and engagement of key stakeholders, including experts, participating centres and relevant organisations across Europe is another major achievement of JANE. By setting clear endorsement criteria, the project ensured the participation of the most qualified individuals and institutions, fostering a strong network that is crucial to the success of JANE 2.

Looking ahead, there is optimism for the success of JANE 2, which will formally launch the seven NoEs and build on the foundations laid by JANE. The experience, networks and lessons learned, particularly in terms of stakeholder engagement, collaboration and sustainability, will be instrumental in enabling JANE 2 to operationalise the NoEs and integrate them into the wider European oncology landscape. Ultimately, JANE and JANE 2 have the potential to significantly improve cancer care and the lives of people affected by cancer across Europe.

10 ANNEX 1: FINAL EVALUATION QUESTIONNAIRE



Final evaluation questionnaire - JANE Joint Action on Networks of Expertise

Dear JANE Colleagues,

A final evaluation questionnaire has been designed to measure satisfaction with the project processes and outputs and to evaluate its results and outcomes. The aim is to provide a comprehensive assessment of the project's performance and its expected impact.

The questionnaire is anonymous and it should not take more than 10 minutes of your time.

Your insights are invaluable in evaluating what was done within our Joint Action and informing future improvements. Therefore, **we kindly ask you to complete the questionnaire.**

Thank you!

JANE WP3 Evaluation Team

There are 7 questions in this survey.

General information

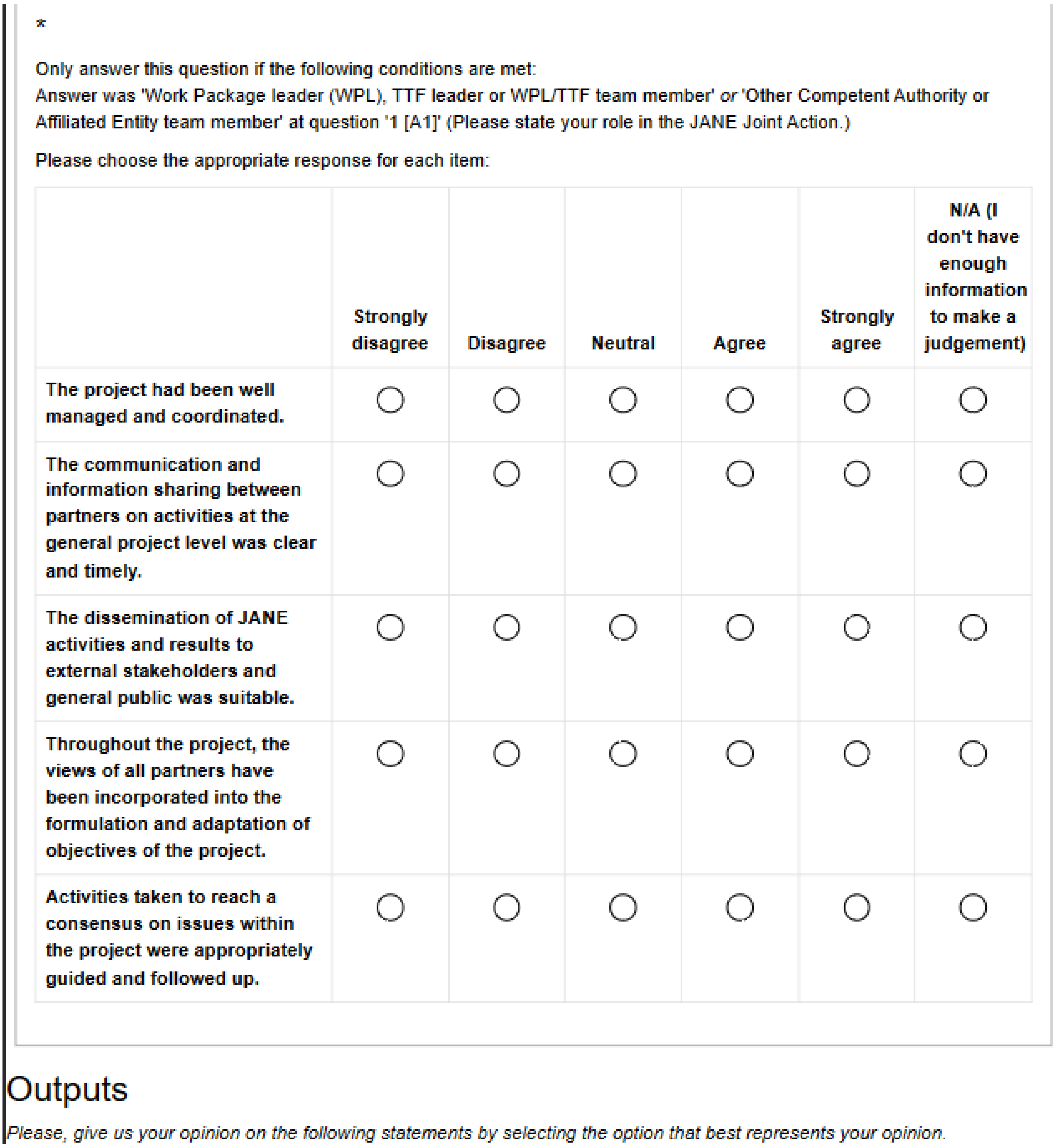
Please state your role in the JANE Joint Action. *

❶ Choose one of the following answers
Please choose **only one** of the following:

○ Work Package leader (WPL), TTF leader or WPL/TTF team member
○ Other Competent Authority or Affiliated Entity team member
○ Policy Board member or another expert outside of JANE consortium
○ Other ☐

Processes

Please, give us your opinion on the following statements by selecting the option that best represents your opinion.



*

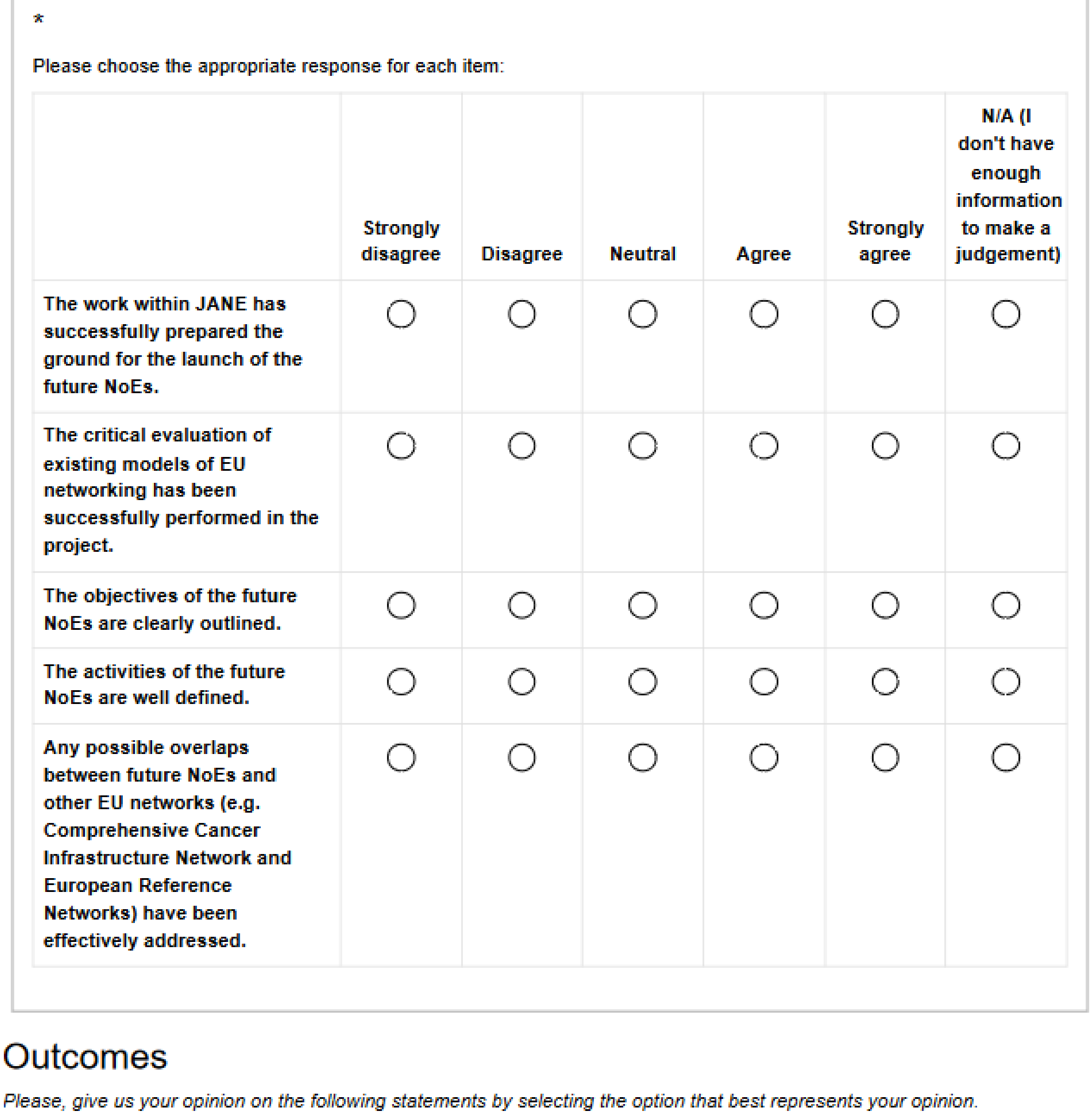
Only answer this question if the following conditions are met:
Answer was 'Work Package leader (WPL), TTF leader or WPL/TTF team member' *or* 'Other Competent Authority or Affiliated Entity team member' at question '1 [A1]' (Please state your role in the JANE Joint Action.)

Please choose the appropriate response for each item:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	N/A (I don't have enough information to make a judgement)
The project had been well managed and coordinated.	○	○	○	○	○	○
The communication and information sharing between partners on activities at the general project level was clear and timely.	○	○	○	○	○	○
The dissemination of JANE activities and results to external stakeholders and general public was suitable.	○	○	○	○	○	○
Throughout the project, the views of all partners have been incorporated into the formulation and adaptation of objectives of the project.	○	○	○	○	○	○
Activities taken to reach a consensus on issues within the project were appropriately guided and followed up.	○	○	○	○	○	○

Outputs

Please, give us your opinion on the following statements by selecting the option that best represents your opinion.



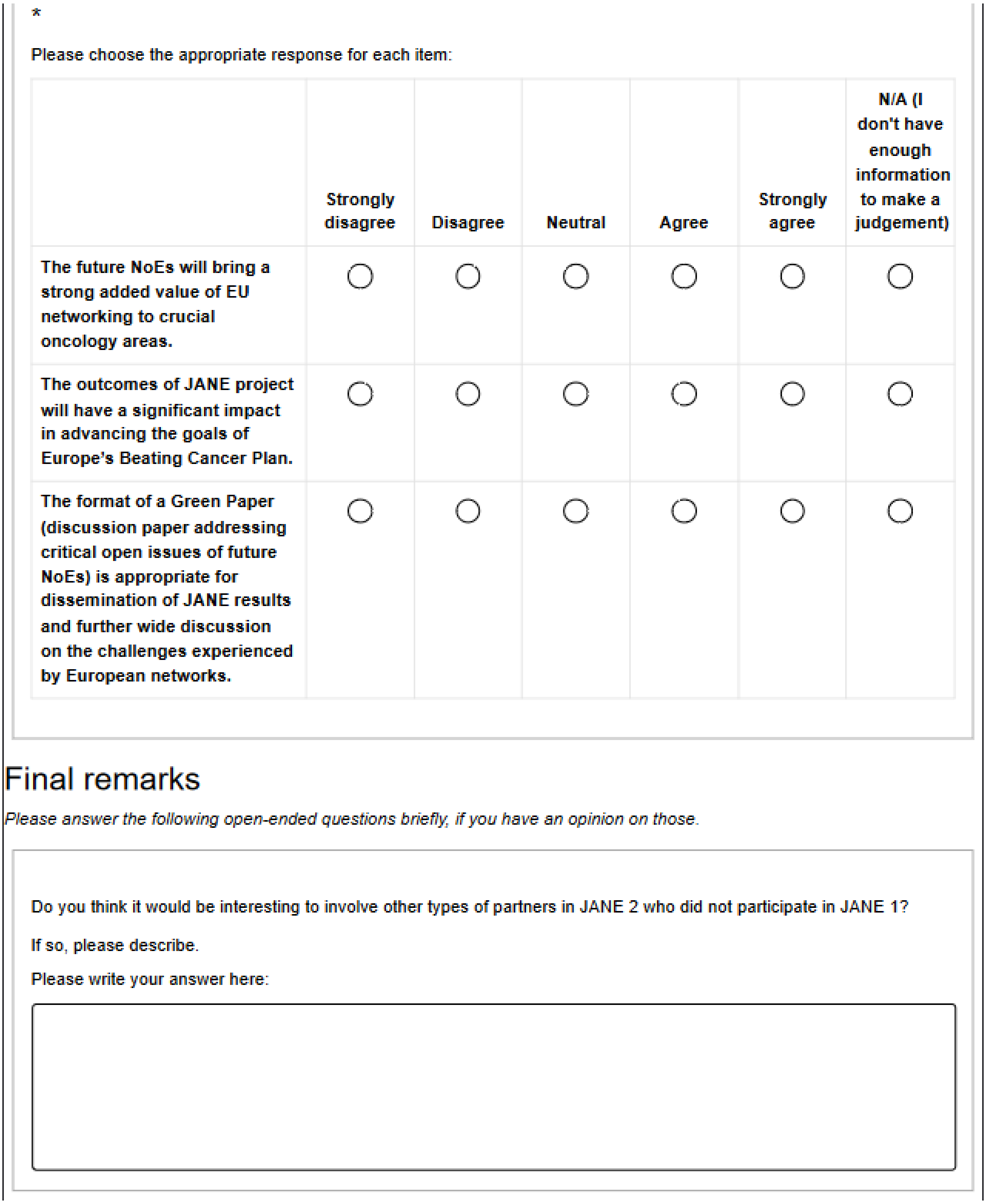
*

Please choose the appropriate response for each item:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	N/A (I don't have enough information to make a judgement)
The work within JANE has successfully prepared the ground for the launch of the future NoEs.	○	○	○	○	○	○
The critical evaluation of existing models of EU networking has been successfully performed in the project.	○	○	○	○	○	○
The objectives of the future NoEs are clearly outlined.	○	○	○	○	○	○
The activities of the future NoEs are well defined.	○	○	○	○	○	○
Any possible overlaps between future NoEs and other EU networks (e.g. Comprehensive Cancer Infrastructure Network and European Reference Networks) have been effectively addressed.	○	○	○	○	○	○

Outcomes

Please, give us your opinion on the following statements by selecting the option that best represents your opinion.



*

Please choose the appropriate response for each item:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	N/A (I don't have enough information to make a judgement)
The future NoEs will bring a strong added value of EU networking to crucial oncology areas.	○	○	○	○	○	○
The outcomes of JANE project will have a significant impact in advancing the goals of Europe's Beating Cancer Plan.	○	○	○	○	○	○
The format of a Green Paper (discussion paper addressing critical open issues of future NoEs) is appropriate for dissemination of JANE results and further wide discussion on the challenges experienced by European networks.	○	○	○	○	○	○

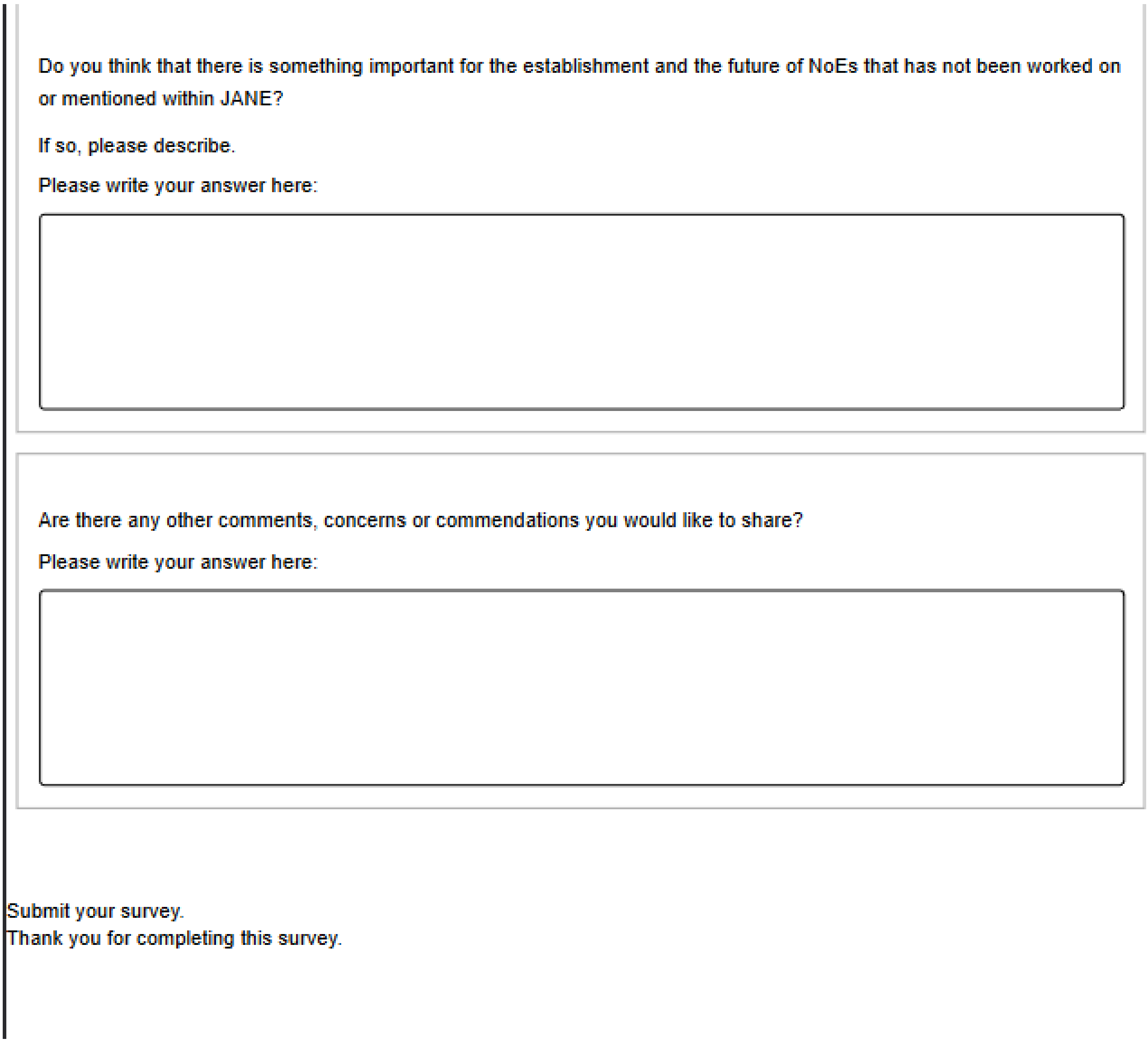
Final remarks

Please answer the following open-ended questions briefly, if you have an opinion on those.

Do you think it would be interesting to involve other types of partners in JANE 2 who did not participate in JANE 1?

If so, please describe.

Please write your answer here:



Do you think that there is something important for the establishment and the future of NoEs that has not been worked on or mentioned within JANE?

If so, please describe.

Please write your answer here:

Are there any other comments, concerns or commendations you would like to share?

Please write your answer here:

Submit your survey.
Thank you for completing this survey.