



Joint Action on Networks of Expertise

Deliverable number 6.1, month 24

Implementation of a sustainable Network of Expertise on Palliative Care in Europe (JANE WP6)

DOCUMENT INFORMATION

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Deliverable lead partner	OUS
Contributing partner(s)	CRUK, RM, INT, FINC, PEHR, UMGH, DGS, LiU, SoS, ICO, SAS, UNAV, AU, CUB, AOH, OIL, AUH, NKUA, NCI
Work Package	WP6
Task	Palliative care
Deliverable type	Report
Due delivery date	30/09/2024
Actual delivery date	30/09/2024
Dissemination level	Public
Annex version	2

Deliverable 6.1 is part of the Joint Action "JANE", GA 101075328, which has received co-funding from the European Union under the EU4Health programme



DISTRIBUTION LIST

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REVISION HISTORY

Version	Date of Issue	Author(s)	Brief description of changes
1.0	18/06/2024	Marianne J Hjermsstad (OUS)	First draft
1.1	24/06/2024	Jesus Gonzales Barboteo (ICO)	First revision
1.1	24/06/2024	Carlos Centeno (UNAV)	First revision
1.1	26/06/2024	Anna Reyners (UMHG)	First revision
1.1	26/06/2024	Ursula Scheibling (SoS)	First revision
1.1	28/06/2024	Augusto Caraceni INT	
1.1	01/07/2024	Johann Ahn (CUB)	First revision
1.1	01/07/2024	Emanuel Gouveia (DGS)	First revision
1.1	01/07/2024	Stein Kaasa (OUS)	First revision
1.1	04/07/2024	Jayne Wood (RM)	First revision
1.1	04/07/2024	Joanne Droney (RM)	First revision
1.1	04/07/2024	Andrew Tweddle (RM)	First revision
1.1	05/07/2024	Line Foss (OUS)	First revision
1.1.	07/07/2024	Radu Dragomir/Dana Nagy (Oncohelp)	First revision
1.2	08/07/2024	Marianne J Hjermsstad (OUS)	Second draft
1.3	23/1/2024	Marianne J Hjermsstad (OUS)	Final revision

LIST OF ABBREVIATIONS

Abbreviation	Definition
ASCO	American Society of Clinical Oncology
CCCs	Comprehensive Cancer Centers
DC	Designated Center
dPCPs	Digitalized Patient Care Pathways
EAPC	European Association for Palliative Care
EduPALL	European Palliative Care Educational Program
EHCP	European Health Care Providers
EMRs	Electronic Medical Records
ER	Emergency Room
ESMO	European Society for Medical Oncology
ESMO DC	ESMO Designated Centre
HC	Health Care
HCP	Health Care Provider
MSs	Member States
NoE	Networks of Expertise
PC	Palliative Care
PCP	Patient Care Pathways
PROMs	Patient Reported Outcome Measures
PUME4	Palliative Care Education Initiative
QoL	Quality of Life
RCT	Randomized Controlled Trial
RESPACC 3	Responsive Palliative Care Education
WG	Working Group
WHO	World Health Organization

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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

The aim of WP6, the NoE on Palliative care, is to build the conceptual framework with expert networking, and an agreed-upon content that is necessary and instrumental to establish a sustainable NoE in Palliative Care (PC). This is necessary to support the integration of evidence-based PC into routine cancer care and to ensure equitable access to palliative care across EU Member states (MSs). This would include better access to diagnosis, treatment, rehabilitation, palliative care, and support to survivorship – in other words improve the quality of care during the entire cancer journey. An underlying, but poorly communicated premise, is that PC should be needs-based, not time-based. Hence, it is not a question of “if” PC should become an inherent part early into oncology, but “how”(1).

The WHO recognition and recommendation that the 3-level PC expertise of primary, secondary, and tertiary care defined as specialized PC services, is necessary for implementation in all health care systems contributes to the conceptual framework of JANE (2). Notably, it highlights that specialised, hospital-based PC is not relevant to the majority of patients, but that the PC principles of listening to the patients’ own reports, adopting a situational evaluation, and promote shared decision-making should be applied in any clinical encounter. This calls for a shift in mind-sets and the organisation of work, be it inside or outside of hospital, pertaining to daily routines, change of attitudes and clear communication and willingness from management and stakeholders to acknowledge PC as an important part of cancer care. This applies to all health care levels, local, regional, national and involves key influential stakeholders within the medical field, politicians, and professional organisations with ESMO and EAPC as examples. To prepare a sustainable NoE in PC, our work in JANE has focused on five areas: *content, indicators, implementation, the pathway methodology* and *education/competence* and recruitment of multiprofessional European health care providers (HCP) and stakeholders.

This report provides information about the NoE's governance structure and recommendations to develop a sustainable NoE in PC. It underlines the unmet needs and proposes the use of standardized care patient-centred pathways and multidisciplinary teams to promote integration of oncology and PC and coordinate the activities of professionals. To succeed, changes at all organisational levels are pivotal.

2 Introduction

The burden imposed by cancer it is set to exponentially increase, and in 2020, cancer was the second leading cause of death globally. Thanks to innovative technologies and the rapid development of new therapies for effective anticancer treatments, cure rates will continue to improve, and more patients will live longer with cancer. This represents an increasing demand for palliative, supportive and end-of-life care.

To meet this challenge there is a need for a new approach to the organisation and provision of PC that also benefits families, communities, and health systems. The ‘holy grail’ in cancer care is the delivery of patient-centred care that meets the patients’ needs and preferences and facilitates shared decision-making and caregiver involvement. As stated in a call for action put forth by the European Cancer Control Joint Action (<https://cancercontrol.eu/archived/>), the gold standard of care consists of a combination of patient- and tumour-centred approaches. Robust evidence from randomised controlled trials documents that the integration of patient-centred care as a part of standard oncology care results in better patient and caregiver outcomes. Results show reduced symptom burden, better symptom management, increased patient and caregiver satisfaction with care, less psychological distress, and better quality of life (QoL). These factors

increase the tolerance to anticancer treatments, may prolong survival time and have been reported as being cost-effective (3,4).

The aim of the NoE in Palliative care is to define the content of PC, emphasise its place as a key element of modern cancer care and propose an organisation to succeed in establishing a *sustainable* NoE. The NoE must be perceived as relevant to the multiple health care levels in which PC is or should be provided, be it at the macro (organisation), meso (team) and micro (individual) levels within the European health care systems. We postulate that a well-structured NoE using a Network-in-Network model may prove efficient in placing evidence-based patient-centred PC into routine cancer care. PC must be available at the primary, secondary, and tertiary health care levels for those in need. Taken together, this might facilitate access to PC for more people.

The specific activities of JANE in WP6 have focused on the scope of PC in today's European cancer care, how to define what constitutes PC, why it is needed in general cancer care and how to liaise with relevant bodies, stakeholders, and networks, including MSs, other EU and national networks, CCCs and diverse organisations. as sustainability is a known challenge for new NoEs. This presupposes a firm governance, defining the proof of concept, and organisational adaptations to ensure efficient, patient-centred, and cost-effective delivery of care, based on adequate competence and education.

3 Methodology used (i.e., to design the NoE)

The work to organise, design and develop the NoE has been conducted in phases, both hierarchical and in parallel. The first activities consisted of frequent overall JANE meetings within the entire consortium to gain information of the overall organisation, goals, and expectations from the JANE coordination team to setting the WP structure and inform the planning of working methods. An important activity from early on was approaching and recruiting collaborators and stakeholders, some already nominated in the DoA and other JANE WPs and to ensure a wide European spread. The PC leads at OUS have an extensive international network in oncology, PC, and other scientific disciplines and organisations. These were contacted as important resources, given their experience and expertise in policy, health care organisation, and oncology/PC.

The meeting structure was set shortly after project initiation. Based on our experience from other large-scale projects, a working group (WG) organisation was established to cover essential areas in the conceptualisation and definition of PC, with emphasis on integration between general oncology and PC to increase the awareness, understanding and access to PC. Each WG had a lead, some also a co-lead. Overall meetings were held approximately once a month with specific WG meetings in between.

The focus of the five WGs of WP6 are,

- WG1. The content of PC
- WG2. Indicators of successful integration of PC in routine cancer care
- WG3. Palliative care implementation
- WG4. Development of patient-centred care pathways
- WG5. Ensuring competence in PC in the different EU countries.

WP6 consisted of health care professionals from Denmark, Estonia, Finland, Germany, Italy, Norway, Portugal, Romania, Spain, Sweden, and UK, with people from Lithuania and Greece (JANE2) sitting in.

3.1 WG1. The content of PC

Palliative care was originally focused on the care of dying patients, usually within stand-alone hospices or community care settings. However, the remit of PC has expanded and grown in response to an increased acknowledgement of its benefits and value for all patients with a high symptom burden and life-limiting or life-threatening illness (5). Clinical trials have demonstrated improved patient outcomes of PC throughout patients' illness, from as early as diagnosis, alongside their anti-cancer treatment (3).

PC involves early and systematic identification of need by use of PROMs (Patient Reported Outcome Measures), comprehensive clinical assessments and multi-disciplinary, individualized management of physical, psychosocial, and social needs, aiming to improve the symptom burden, functioning and QoL of patients and families, all recommended in the ESMO and ASCO clinical practice guidelines. PC is now recognised a core component of cancer care, this notwithstanding, still not integrated in routine European cancer care, and frequently perceived as end-of life care only (4).

Although care for patients who are dying remains a key element, PC is now offered to a wider cohort of patients in recognition of their specific needs. Patients living with "treatable but not curable" cancers, benefit from proactive identification and management of symptoms, which makes possible anticancer treatment. A systematic PC approach also supports better QoL and lower symptom burden in patients undergoing many of the novel systemic cancer treatments despite significant uncertainty in terms of prognosis and survival. These aspects also apply to patients and staff in intensive care settings.

PC is delivered across the spectrum of settings, from specialist PC hospital units to hospices and patients' homes. Outpatient PC clinics, whether stand alone or embedded within oncology clinics, are increasingly utilised to offer proactive PC to initiate immediate interventions whilst maintaining longer lasting benefits in terms of coping, communication, and prognostic awareness. The principles of PC should be practiced by all HCPs given the increasing demands in the coming years. The delivery of a PC service that is integrated with oncology services is reliant on at least three key resources. (4, 6)

- a trained workforce, meaning that the HCPs' competence should correspond with the level of specialised PC that is necessary according to needs and delivered in the actual context,
- recognition and acceptance of PC as a core service, at local, national, and international levels with a normalisation of its role in promoting integration and reduce inequity in access and availability,
- population-level access to essential medications used for the symptom alleviation is crucial and used by WHO to measure access and delivery of PC. Unfortunately, commercial determinants have caused a lack of access to morphine for thousands of people over the years. (7)

The misconception that PC is synonymous to end-of-life care must be eradicated, as it serves as barrier for integration. Public dissemination activities and guidance may serve as valuable resources in spreading the understanding of the benefits of early PC. This warrants an agreement on the content and availability of PC resources, with clear definitions, albeit flexible, given the heterogeneity of services around Europe.

To summarize, a PC resource analysis requires to challenge care fragmentation, a plan for integration, identifying different providers defined by standardized criteria, and a systematic assessment of needs.

3.2 WG 2. Indicators of PC integration into oncology

A systematic monitoring of the degree of integration of PC into oncology warrants reliable indicators for both international and local use. WG2 has conducted an unsystematic literature scoping to identify relevant indicators of successful integration of PC in oncology to pave a common ground for further work in JANE2. An important source from onset was the Lancet Oncology Commission (4) results which included a proposed list of indicators, the importance thereof and recommendations for some degree of standardization combined with adaptations to national and local health care organisations and systems. The scoping review in PubMed/Medline identified works by the Hui/Bruera group in the US (8), ESMO reports (9), a Delphi survey on common indicators (10) and the European status in the EAPC Atlas of Palliative Care in Europe, 2019. (11)

Our work and contact networking, knowledge, group members' experience and discussions with partners around Europe makes it clear that there are no universal indicators of the quality of PC cancer care at the moment. This is despite the substantial body of patient-centred care evidence, that is readily available and consolidated in widespread local, national, and international clinical practice guidelines i.e., the European Commission, WHO, ESMO, ASCO and national documents. However, these recommendations have not translated into clinical oncology practice, not at an institutional level, nor at an individual care level. Once again this underlines the challenges of translating evidence into clinical practice, emphasises the need for organisational changes in care delivery models to improve.

The ESMO Designated Centres (DC) Accreditation Programme has played a prominent role by setting standards for provision of highly integrated oncology and PC services. To qualify for the ESMO-DC accreditation, a list of 13 qualitative criteria related to program infrastructure, clinical processes, education, and research is used for evaluation. Examples of criteria are a PC inpatient consultation team, interdisciplinary palliative care team, referral to PC (>6months), routine symptom screening, proportion of patients with 2(+) ER visits in last 30 days of life, continuing education in PC, routine rotation in PC for oncology fellows. Quantitative measures like this may have implications for patients, healthcare professionals, hospital administrators, policy makers and researchers in terms of hospital selection, program development, quality improvement, resource allocation, and benchmarking.

The WG2 discussions pointed to several empirical indicators that arose from clinical practice and experience. Examples are establishment of specific early palliative intervention programs with routines for needs-based rather than time-based referrals, prioritisation of symptom control with PROMs, shared decision-making, advance care planning, access to multidisciplinary consultations, inpatient and outpatient access to PC resources during the entire disease trajectory, and structured communication between tertiary hospital settings and community care facilities.

Referrals to PC should come from all cancer related disciplines, medical, surgical oncology, and radiation oncology, haematology, gynaecology. Members of the PC teams should participate regularly in tumour committee meetings. There should be resident training programs within the institution's PC services, joint participation of the different cancer related treatment disciplines in research and in the development of anticancer clinical guidelines. Statistics on PC referrals, consultations (physical/digital/phone) number of patients receiving both anticancer treatment and PC, and extramural follow-up should be in place. Further, statistics on place of death, use of PC resources in specific patients populations, access to and use of acute care/emergency services resources at the end-of-life at population levels at the end-of-life.

3.3 WG3. Strategies for implementation of PC into oncology

A traditional assumption has been that convincing evidence-based research results would suffice to an uptake in practice. The perpetual siloing of disciplines and expertise within health care, however, has repeatedly demonstrated the pivotal role of a firm leadership in the organisational settings and contexts to succeed with sustainable changes in health care systems, practices, and workflow. Further, the role and influence of stakeholders must be acknowledged pertaining to national policies, political and organisational bodies, and diverse regional and local health care authorities, including hospital managers. As fundamental barriers to change exist at all organisational levels, these must be encountered and solved in different ways.

Figure 1. Factors to consider regarding implementation.



Figure 1 shows crucial factors related to implementation that apply to integration of PC and oncology.

Even if the macro-level mostly concerns institutions and policies and the meso-level focuses more on groups, they are both strongly related to organisational factors. Each organisation or group has its unique culture, hierarchy, processes, and structures that must be acknowledged, approached, and engaged for a successful integration of PC and oncology. This

represents an innovation and may as such be perceived as threat to the existing organisation and structure.

Crucially, the introduction of a new initiative hinges on leadership support and a shared recognition of its necessity. A strategic vision not only fosters motivation among potential adopters but also aligns divergent agendas, ensuring a unified goal among all stakeholders. This consensus on the intervention's potential to enhance patient care quality and safety is vital. Despite convincing research evidence from RCTs, numerous barriers come into play, heavily influenced by commercial interests favouring anticancer treatment. Medical and technological developments are driven by the medical industry and encouraged by mass media, thereby supporting a societal demand for cure. This could be counterbalanced with a stronger strategic investment in terms of leadership, policies, benchmarking, and an extension from the sole focus on cure to include quality care. For an initiative to gain traction, it must be backed by adequate organisational resources, i.e., financial, equipment and personnel. The role of competence must not be underscored, as new insights, understanding and perspectives arise from education and training. Lectures on PC as part of medical and nursing curricula, also in specialist training is vital, supplemented by clinical rotations in PC clinics to internalise the contribution of PC to cancer care quality.

Table 1. Relevant clinical factors to make PC an inherent part of oncology

What	How
Adherence to national standards	Adaptations for local usefulness, level of care Explicit goals for PC patient-centred treatment Action plans based on GAP-analysis of provided PC, regardless of anticancer treatment Timely evaluation and adjustments
Adequate organisational resources	Involve management Budget planning and timely reviews
Follow-up of adherence	Regular audit of adherence to agreed-upon standards of care/indicators
PROMs	Systematic use, management, and routine follow-up as part of care plans
Multiprofessional collaboration	MDT meetings Patient-centred joint team meetings with oncology and PC members
E compensation	Financial incentives for PC services

From a practical, clinical point of view, some of the main implementation barriers are: The HCP and public perception of PC being end-of-life care, short length-of-stay in PC units, low concordance between health care levels regarding follow-up, and unsystematic, if any, PC care-plans and shared decision-making. PC implementation

trials do not correspond with real-life, and seldom bring about changes.

3.4 WG4. Patient-centred pathways

The perceived utility and benefits of implementing PC principles rely on the care organisation, and how this accommodates the needs of patients and caregivers. We propose the development of patient-care pathways (PCPs) adapted from the European Pathway Association <https://e-p-a.org/> and recommended by a Lancet Commission (doi: 10.1016/S1470-2045(18)30415-7) as the most efficient method to ensure and visualize these factors, for patients, caregivers, and HCPs alike. Pathways are evidence-based, multidisciplinary healthcare management plans used to organise the care to promote consistency, efficacy, and coordination of the HCP activities. Clinical pathways are structured multidisciplinary care plans used by health services to detail essential steps in the care of patients with a specific clinical problem. They aim to link evidence to practice and optimise clinical outcomes whilst maximising clinical efficiency through a coordination of the HCP activities. In other words; providing the right competence to the right patient at the right place at the right time.

The care and interventions of the PCPs should be based on evidence-based care guidelines and tailored to the individual patients, their needs, and preferences at any given point in time. Importantly, quality care also relies on the use of PROMs referring to instruments that measure patients' perceived and experienced symptoms, such as pain, fatigue, nutrition, sleep disturbances, psychosocial needs, also including preferences and satisfaction with the delivery of health care. Shared decision-making and family involvement are part of this. Thus, the PCPs should be dynamic and amenable to rapid adaptations to provide predictable care trajectories for all involved, facilitated by digitalized PCPs (dPCPs) for immediate transfer of patient registrations. These systems may be fully integrated with the EMRs, but also developed as stand-alone solutions, that can still be easily accessed by HCPs. The latter is relevant to JANE2, given the diversity of cancer care provision and organisation in the MSs. A prerequisite for the PCPs' utility, is easy access to patient data, clinical and self-reported at the HCPs' working stations, and secure channels for transfer of personally identifiable information.

The PCP principles should be implemented in any health care context regardless of the actual clinical level of the PC provision and treatment. In other words, these principles are applicable both in primary health care and highly specialised hospital-based cancer care and PC alike. Following this, objective indicators of good

clinical PC can be organised in pathways that fit with the level of care and the needs of the patient and family, be it home-based, at local hospitals or in specialist hospital-based PC units. The decision-making processes should enable the "allocative" efficiency of the care model accounting for flexibility according to needs. (4).

3.5 WG5 Education and competence in PC

Today's demographic development calls for a stronger focus in the education in PC. Increased educational efforts are necessary to ensure that both basic and PC specialist skills, including relevant knowledge, attitudes, beliefs, and values are in place in the conduct of work.

The World Health Organization (WHO) framework measures the PC development at a national level, with one of the indicators being the presence of educational programs for healthcare professionals in PC. The pertinent questions to ask are what kinds of medical competence, be it general or specialised, are needed at the different care levels, and how can the necessary levels of competence be achieved? Further, to be recognised as an integral part of general oncology, it is pertinent to ask if palliative medicine should be a medical specialty. The forthcoming complex panorama of an increasing cancer incidence, a rapidly growing elderly population also having comorbid conditions and the strong focus and anticancer treatment and cure, lends support to this.

The basic PC competencies at an institutional level include understanding the issues of life-threatening illness and the need to apply the basic principles of PC, i.e., early identification and relevant management of the physical, psychological, social, and spiritual needs of patients and family by PROMs. Competence also pertains to an interdisciplinary approach to patients and families in which the different medical, nursing, and other HCPs are responsible according to their clinical expertise and professional competence. The requirements are multifaceted, requiring communication skills and experience with bereavement support and shared decision-making processes.

According to ESMO, PC educational programmes are particularly heterogeneous among European countries. There are formal educational programmes, e.g., postgraduate diplomas, masters, specialist training, undergraduate programs, PC curricula in medical/nursing schools) and "online" educational resources such as PAHO – Virtual course on fundamentals of PC, EduPALL: European PC program for undergraduate medical students.

Despite the tremendous evolvement in PC research in the last two decades, a number of important challenges remain: the poor uptake in clinical care exemplified by the unsystematic use and follow-up of PROMs despite robust and convincing evidence, the disproportionate funding of PC research and strong momentum of research on anticancer treatment and cure leading to low publicity and prioritization at international congresses and the low proportion of chairs, and the limited numbers of academics in research and education at universities. The latter also leads to an insufficient number of HCPs with adequate competences and practical skills. The RESPACC3 framework measuring clinical research competence at an institutional level (12), the PUME4 programme for enhancing PC education in medical schools and the recent COST Action on Palliative Care Education are important educational initiatives.

3.6 Major stages of development

3.6.1 Stakeholder involvement

Engagement of key stakeholders is essential for integration of PC alongside anticancer treatment. WP6 stakeholders represent health care policy-makers and managers at different health care levels, academic chairs from educational institutions and programmes, members of professional, patient, and lay organisations, multiprofessional HCPs within and outside of cancer care, and patients and caregivers. Importantly, the understanding of the role of PC amongst oncologist and other physicians colleagues needs to be explored with direct teaching and training as main tools to foster strong relationships. This may inform a model with informed implementation strategies with joint actions by organisations the medical industry, politicians, EU, and HCPs. Also, the national anchoring in JANE2 serves as a main contributor.

The influence of mass media should not be downplayed. Their unilateral focus on cure and new medications that are only relevant for a very small proportion of patients is at the expense of the focus on QoL and living well with or beyond cancer. Death and dying attract little attention compared to new promising anticancer treatments, but also draw the focus away from the benefits of integrating PC. Education of the public and dissemination activities are crucial.

3.6.2 Timing

The work in JANE has progressed as planned from onset, with tasks and report delivered on time. Recruitment and collaboration with participants representing various health care professions and stakeholders in different fields have been fruitful. With the approval of JANE2 in mind, we have been able to pave the route towards an extension of the scope and ambitions of making PC an integral part of routine oncology.

3.6.3 Consent and approval

In WP6, there were no activities involving any personal information requiring informed consent or other forms for approval. As mentioned above, national level anchoring was mandatory in JANE. The planned pilot studies in JANE2 will adhere to national and international guidelines for preservation of personal data.

3.7 Scope of the NoE

The WP6 working group have focused on the main features of the PC, i.e., providing better and equitable access to PC to all patient who need this, regardless of age, sex, nationality, cancer stage, prognosis, and the course of treatment. A shift in today's recognition and provision of PC will improve the care quality during the entire cancer journey. Notably, a better understanding of what PC entails, an improvement in education of HCPs (and patients) and a stronger focus on competence and relevant research are fundamental to the integration and recognition of evidence-based PC into routine cancer care.

To ensure universal access to PC according to patients' needs, robust indicators are necessary for continuous quality assurance and benchmarking. Our approach is that the use of the basic principles underlying PC should be present at all health care levels, primary, secondary, and tertiary, and guarantee continuity

between acute hospital care and community care. Hence, the five WP6 working groups have focused on essential factors to succeed with this, the content of PC, indicators, implementation, patient-centred pathways, and education/competence.

To disseminate a common understanding of the obvious benefits of PC and patient-centred care alongside anticancer treatment among health care professionals, the public and stakeholders is crucial to attain both attitudinal, organisational and political changes. Connecting and liaising across professional boundaries are necessary for effectiveness and efficacy, workwise and economically.

3.7.1 Governance of the NoE

As the primary focus of WP6 in JANE was to pave the route for establishing a sustainable NoE in Palliative Care (PC), the governance structure was relatively simple, coordinated and led by OUS. Regular WP6 meetings were held with both with the task leads specifically and all participants, depending on the focus and themes. These meetings focused on exchange of relevant information on the cancer care organisation and PC integration, nationally, regionally and locally, also including the level of basic and specialist PC educational programmes in the different partner countries. Memorandum of understanding and proof of concept (PoC) were discussed and defined. When JANE2 became a reality, the expertise, resources, and interest to participate among the JANE participants were thoroughly mapped and combined with agile recruitment processes by the OUS team to extend. These activities were also embarked on by the WP6 members.

The governance of WP6 in JANE2 implies a larger, multilevel and more network-based structure. A steering committee should be established for each WP. The Core Management Group is led by OUS and INT. The responsibilities are to oversee the overall management of the WP, resolve issues, ensure alignment with the overall JANE2 objectives and the tasks and progress of WP6. Further, the work consists of ensuring synergies across tasks and other WPs, by building a framework for continuity beyond the project's duration. Supporting task leads and co-leads is an orchestral activity to consolidate the Network-in-Network, activities that go across health care levels and involve collaboration with experts, collaborators, different health care organizations and stakeholders. These activities were part of the WP6 management conducted by OUS in JANE, meaning that the basis for a firm leadership has been settled

The governance of JANE is the responsibility of the WP6 leads at OUS and concerns recruitment of influential participants and stakeholders, management of the WP6 activities, establishing efficient and transparent strategies for coordination and communication in this NoE. Herein lies the responsibility to pave the route for a sustainable and wider NoE in JANE2, applying the Network-in-Network structure.

OUS is the lead of the WP6 on Palliative care together with our co-lead from IT, Milan. The WP lead structure further encompasses the 4 task leads from Denmark (T1), Norway (T2), Estonia (T3) and Portugal (T4), forming the core group. A somewhat wider group, also includes the co-leads for these tasks, representing Austria, the Netherlands, Hungary and Spain. The wide geographic spread, the experience and interest in PC of the leads coupled with the extent of their national networks were the main factors looked for in the recruitment processes. We regard this as main facilitators for establishing a Network-in-Network structure

We plan for regular smaller and larger meeting keeping a tight schedule, to build contact and set the structure. There will be monthly digital meetings (some physical) between the WP6 leads/co-leads and partners the WG coordinators to discuss the WG tasks and the resulting recommendations for a sustainable

PC NoE. Each WG has 5-8 members and other WP6 participants have occasionally joined the meetings as well.

As the endorsement of the JANE NoE was not through a formal accreditation process initiated by the European Commission, as in the European Reference Networks (ERNs), the Endorsement Criteria were set by the individual NoE. We regard the content, scope and summaries acquired during the work of the five WGs as our Endorsement Criteria, described in report.

3.7.2 Endorsement criteria for NoE participants

National anchoring was a prerequisite for participation in JANE. The WP6 participants represent different professional categories reflecting differences in cultures, organisation and content of PC services, degree of specialisation, professional education and/or experience and positions as advocates and stakeholders in an international context. Our endorsement criteria have been reported previously and their definitions reflect the overall WP6 objectives.

The following criteria applied to JANE and are regarded instrumental to develop a sustainable NoE

- **Full partners:** Centres, institutions, organisations, committing to take part in the NoE
- **Collaborators.** In JANE 1, these participants were representatives whose expertise and role in their respective fields will benefit the conduct and influence of the NoE, internationally and nationally. They have provided support and been consulted intermittently for advice on the NoE development, preparation of reports and in relation to the JANE2 preparations.

To fulfil the NoE aims, improving access to PC and integrate PC in routine cancer care, the PC NoE should include

- Representatives from cancer centres with expertise in PC. They should have clinical, leadership and management experience in PC and its integration in cancer care. Accredited experts on PC, One (at least) representative from comprehensive cancer centres (CCC), ESMO designated centres (ESMO DC) and Centres with OECI accreditation
- Leadership anchoring, hospital and institutional level managers, policy makers, government endorsement
- The NoE should aim to have at least one representative from each country in the EU (geographical diversity). If deemed necessary, more than 1 representative per country is desirable to account for heterogeneity in PC provision and development

National influence: prove capability or resources for forming and representing national groups, by reaching to other centres, institutions and existing organisations or bodies in PC. Experience from the development of national PC guidelines.

- Links to patients and caregivers, i.e., involvement of patients, patient representatives and voluntary organizations, and collaboration with advocacy groups.
- Links to national and international PC organizations and institutions and with the public healthcare.
- Representatives from international organizations and associations focused on cancer care and research
- Representatives from centres and institutions that provide care and support the delivery of PC (Charities, Hospices, primary healthcare professionals).

Most full partners and collaborators in JANE have confirmed their participation in JANE2, representing more than 20 European countries. These are mostly Affiliated Entities (AEs) acting as Task leads or Collaborators, all with predefined contribution levels (high, low, observer).

3.7.3 Network's organisation

Given the complexity of the network's objectives and the need to include expertise from different fields, we established the structure with the five WGs at onset to direct the focus on areas and tasks that we regard as pivotal to improve European PC provision and organisation. Each of the WGs has a coordinator, some also a co-chair.

As the endorsement of the JANE NoE was not through a formal accreditation process initiated by the European Commission, as in the European Reference Networks (ERNs), the Endorsement Criteria were set by the individual NoE. We regard the content, scope and summaries acquired during the work of the five WGs as our Endorsement Criteria, described in report.

3.7.4 Services provided by the NoE

The mission of WP6 in JANE was to pave the ground to establish a sustainable NoE in PC that would collaborate and liaise with existing European networks, organisations, and collaboratives to gain momentum for PC as an inherent part of European cancer care. The identified areas of work; content, indicators, implementation, pathways, and education are overarching and pivotal pillars for quality care which requires pan-European cooperation. The network and the vast expertise possessed by the many stakeholders representing different clinical, management and academic knowledge supplemented by experienced health care policy makers are important resources for a functional and relevant NoE.

The services we envisage to provide through the NoE on palliative care take on different forms, formats, and extents and are directed at different organisational levels (health politicians, health care management levels industry, professional organizations), educational levels (basic, graduate/post-graduate, specialist programs) and levels of health care provision (primary, secondary, tertiary). The underlying premise is that the basic principles of palliative and patient-centred are present in all patient/HCP encounters according to patients' needs. These should follow clinical practice guidelines, case management programs, evidence-based guidelines for referral, communication transfer and indicators for monitoring adherence, that will be developed and provided in WP6.

3.7.5 Synergies with the NoE

The proposed Network-on-Network structure in JANE2 might be a facilitator for the collaboration with the MSs. As the organisation of health care is nationally based, a direct influence in terms of policy and regulations is out of scope. Hence, it will be necessary provide services in terms of clinical practice guidelines, clinical case discussions, medical education, and mutual research efforts. For NoEs like the one on PC that is not focusing on a specific cancer diagnosis, collaborative efforts with other NoEs is important. Examples are the NoEs on Poor prognosis cancer and Survivorship care that WP6 has already contacted. Other relevant networks and groups are CRANE and the ERNs.

3.7.6 Collaborating stakeholders of the NoE

Collaboration with stakeholders, interest groups, professional organisations, management, and politicians at multiple levels is important part to any networks, to ensure sustainability. Further, with stakeholders being involved in decision-making processes, the messages and / or initiatives are likely to become more influential. For WP6 and PC this is pivotal, given the dominating focus on cure in European oncology. To close the existing abyss between tumour-centred and patient-centred care, both PC and oncology need to adapt -a matter of attitudes, education, policies, and dissemination of the abundant evidence about the benefits of early PC. Stakeholder influence is one of many initiatives to be enhanced. WP6 has already recruited some stakeholders i.e., in education and health policies.

4 Recommendations for JANE2

The experience gained in JANE will be carried forward to JANE2 as it constitutes a basis for further work, with the overall goal of making PC available to European patients according to needs. To reduce the present organisational gap in PC access, we have decided to merge two of the JANE WGs (WG1 Content/WG2 implementation) into one, Task1, called *Content, understanding, organisation* as these areas are highly tied. Further, the combination will complement the services provided by the ERNs that focus on centres directly providing health care to specific groups of cancer patients, and the CCINs that engage tertiary care providers. The pathway task (Task2) will build on our experience from Norway and the Netherlands, and embark on digitalisation, albeit not with a full-scale integration with the hospital administrative and clinical systems. The education and competence task (Task3) will primarily focus on physician, nursing and related professional educations and curricula, at different educational levels. Task4 aims to develop a more comprehensive set of indicators to improve the quality of PC at the different health care levels and all countries. Literature reviews and thorough mapping with pilot studies will be performed by all tasks, supplemented by a Delphi process in Task 4. The set of indicators will be revised with extensions and abbreviations for use at different health care levels. Taken together, we think that these activities represent a relevant working model to close the evidence and practice gaps in the existing abyss between general oncology and PC. As our thinking is not specifically innovative by nature, we aim to collaborate and liaise with scientific societies, patient/caregiver organisations and other stakeholders to optimise chances of closing the apparent gaps in PC provision.

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