



**Expression of Interest of the Network of Expertise on Palliative Care**

Project no. 101075328

Task 6.5

**Version 01**

**WP6:** Palliative Care.

## 1. Objectives for the Expression of interest in Palliative Care

A pivotal activity to succeed in establishing a sustainable and influential Network of Expertise (NoE) in Palliative Care (PC) is the preparation of relevant activities to launch an NoE that is perceived as useful and relevant to improve the integration of the basic principles of palliative care into routine cancer care. Experienced persons i.e., experts, managers, and stakeholders as well as different entities represent important expertise and influence at various policy, management, and clinical levels. These act both formally and informally as opinion leaders, stakeholders, and end users. Hence, the activities related to the Expression of interest must be directed to and include representatives from all these groups.

### 1.1. Participation and recruitment of WP6 members

The following three actions have been applied in WP6 to recruit participants to and promote participation in an NoE on PC.

- **Reaching out to our clinical and research networks within PC, informing about JANE in general and WP6 in particular:** With our more than three-decade long research and clinical activities at a Pan-European level, our network of professional clinicians and stakeholders is large.
- **Establishing contact with new potential liaisons in other JANE WPs and TTFs:** JANE meetings represent a suitable arena for promoting WP6 and emphasizing the importance of PC integration, as well as opting for synergies across WPs
- **Advocating about the NoE in PC at international meetings, symposia, and conferences.** Professional meetings are highly relevant arenas to reach out to potential representatives whose expertise and role in their respective fields will benefit and contribute to the NoE. They will provide support and/or be consulted “periodically” (i.e., once a year, once every 6 months...).

### 1.2. Setting up the WP6 organisation to ensure sustainability beyond project duration

Sustainability is a prerequisite for a functional NoE, if not, the NoE will not function as intended. In these first two years of Jane, the aim of the NoE is not to get directly involved in clinical activities, but to act as a network for advice, networking with other clinical entities, and to provide an easier access to other NoEs, expert advice, special centres, and research initiatives. In this respect and within the 2-year time-frame, we have decided to concentrate our activities around defining and describing important clinical features of what constitutes PC and how its basic principles can be implemented into routine cancer care, at all health care levels. Thus, we have established 5 working groups, each covering central elements of palliative care.

#### 1.2.1. The five working groups of the NoE in PC

As the aim of the JANE WPs is to prepare what is needed to launch NoEs in the pre-defined domains, several actions are necessary. First and foremost, there is a need to define the need for the different WPs in today's cancer care, the related objectives, and their missions. Further, the methods to achieve this must be clarified, and relevant and influential participants must be selected. Last, but not least

the selected criteria for the work within the WPs and the recommendations related to the actual establishment of the forthcoming NoEs must be summarized for the EU commission.

To comply with these tasks, we have defined five working groups that we think constitute the main pillars of Palliative Care (Table 1). These have been explained in more detailed in *Task 5.4, Endorsement Criteria of WP6*. Importantly, the composition and content of the work that will come from these five groups enhances the understanding of what PC is, its benefits, the importance of integrating PC and routine cancer care, and points to the importance of including PC in the educational curricula for health care providers. Taken together, the final WP6 report will offer a better understanding of what PC represents and its place in modern cancer care.

The established working groups are:

- WG1. Defining the content of palliative care
- WG 2. Establishing indicators of successful integration of palliative care in routine cancer care
- WG 3. Palliative care implementation
- WG 4. Development of patient-centred care pathways
- WG 5. Ensuring competence in palliative care in the different EU countries

**Table 1. The WP6 working groups**

Working group	Definition of the content of PC	List of indicators	Implementation Science	Development of PCCP	Ensure Relevant Competence in PC
Coordinator	Jayne Wood (RM)	Emanuel Gouveia (PDG)	Ursula Scheibling (Palliativa kliniken Västerås)/Kathrin Cresswell (UEDIN)	Marianne Hjermstad (OUS)	Mari Lohmus (NEMC)/Amaia Urrizola (OUS)
Participants	The Royal Marsden	Instituto Català d'Oncologia	The Royal Marsden	Instituto Català d'Oncologia	Sistema Andaluz de Salud
	Jayne Wood, Andrew Tweddle, Joanne Droney	Jesús González North Estonia Medical Center Mari Lohmus	Jayne Wood, Andrew Tweddle, Joanne Droney	Jesús González University Medical Hospital Groningen Anna Reyners	Miguel Giraldez, Alberto Moreno, José Núñez, Carlos Miguez
	Fondazione IRCCS Istituto Nazionale dei Tumori	University Medical Centre Groningen	Cancer Research UK Edinburgh Centre	Sunstone Oncology and Palliative care center	Programa Nacional para as Doenças Oncológicas - Direção-Geral da Saúde
	Augusto Caraceni, Giacomo Massa	Anna Reyners	Marie Fallon, Kathrin Cresswell	Liisa Sailas	Nuno Sousa, Emanuel Gouveia
	Sunstone Oncology and Palliative care center	Programa Nacional para as Doenças Oncológicas - Direção-Geral da Saúde	Sistema Andaluz de Salud	Charité Centrum (CC) für Tumormedizin	North Estonia Medical Center
	Liisa Sailas	Nuno Sousa Emanuel Gouveia	Miguel Giraldez, Alberto Moreno, José Núñez Carlos Miguez	Johann Ahn	Mari Lohmus
			Charité Centrum (CC) für Tumormedizin	Oncohelp	Oslo University Hospital
		Marit Karlsson	Johann Ahn	Radu Dragomir Dana Nagy Aarhus Universitetshospital og Syddansk Universitet Anni Raynsbæk Jensen	Amaia Urrizola

All but one group have had their initial meetings, while the defined task from the WP6 management is to plan the work related to the separate WG tasks, as well as internal and external liaisons. A short summary of the organisation and PC pathways at each site is to be presented to all in an overall WP6 meeting in December 2023.

All groups will summarize their specific work and recommendations in the form of a short report (appr. 1,000 words) by August 2024. These summaries will be condensed in a comprehensive report that constitutes the final deliverable of WP6, describing the palliative care content, organisation, and pathway to optimize PC integration to the best of patients. As emphasized in the DoA, this deliverable will point to:

- scope of the NoE
- expected activities and partners governance
- sustainability
- capacity of participating centres to perform as required
- indicators of efficacy and cost/efficacy evaluation criteria
- interplay with MSs, other EU networks, CCCs, patients

According to the DoA, WP6 should undertake a pilot study at each centre to scope all PC and integration related activities, coupled with numerical statistics on patient flow, referrals, and overall treatment related issues etc. In this context, it is important to remember that the aim of the current 2-year JANE project is not to create the NoEs as per se, but to shape them to move forward with the implementation of the actual NoEs.

This is crucial as we have now learned that the JANE2 call has been launched with a potential time frame of 4 years (2024-2028). Hence, we have decided not to move forward with this task, as the centres that are now participating in JANE, may not necessarily participate in JANE 2, and several other centres will join the PC NoE. This makes a larger, more focused pilot study highly relevant.

### 1.2.2. Recruiting working group participants

The current participants of WP6 represent a relatively broad range of professionals working in general cancer care, specialized or general PC, researchers in PC, oncology, and patient-centered care, economics, also including managerial responsibilities. The initial recruitment of group participants were performed by reaching out to PC collaborators that we had known and collaborated with for many years, professionals who were members of national or international PC organisations and among those who participated in the writing of the JANE application. Further, we aimed at a wide European geographical distribution. In addition to this, the liaison between WP6 and other WPs is relatively strong, as meeting invitations and initiatives are frequently shared. During the first steering committee and

## 2. Dissemination activities in WP6

Most of our dissemination activities constitute of internal and external meetings in professional settings within oncology and palliative care, presentations at conferences and smaller seminars, and direct contact with present and potentially new collaborators.

### 2.1. Meetings and information/dissemination activities in JANE, as per December 2023

Table 2 lists the meetings and dissemination activities performed by WP6 members

Table 2. Meetings and dissemination activities

Date	"With whom"
07.12.22	ESMO - Nicola Latino
09.01.23	Professors møte
10.01	1st WP6
01.02	Initial expert recruitment
06.02	Anne reynners (Netherlands)
06.02	Others (Charité, Liisa Sailas, Mari Lohmus)
07.02	Romania (Radu and Dana)
08.02	2nd WP6
22.02	CRANE (Per Magnus/Ingrid)
06.03	First meeting with ECO
10.03	ECPC-FAVO
14.03	EAPC
30.03	3rd WP6
11.04	Jesus González (ICO)
21.04	
24.04	Presentation JANE in KLB
04.05	4th WP6
09.05	JANE presentation in ECO
06.06	5th WP6
12.06	CRANE (Per Magnus/Ingrid OUS)
15.06	OEI short presentation of JANE (Cinzia B. on behalf of Stein Kaasa)
Jul-23	WP6: meeting of all working groups coordinators
01.09	JANE information and recruitment of Swedish centre
07.09	6th WP6 meeting
18.09	JANE/CRANE EU Commission
18.09	JANE/CRANE, Norwegian Directorate of Health
21.09	CRANE (Per Magnus/Ingrid)
26.09	JANE information and recruitment of one Danish centre
25.10	JANE information and recruitment of 2nd Swedish centre
15.11	JANE1 &2 information to Danish centre
Jan-Oct 23	3 meetings with WP5
Jan-Oct 23	2 meetings with TTF5 (2-3 meetings)

### 3. The upcoming JANE2, recruiting participants

As we have just learned that the call for JANE2 has been launched, we foresee a somewhat higher activity when it comes to approaching centres and participants. Given the fact that JANE2 will have a much closer collaboration with the CCCs, CRANE and other EU initiatives as well as other European

networks in cancer, we expect that a different policy will be relevant in recruiting centres. Further, the nomination of Competent Authorities in each country and national entities affiliated to these Competent Authorities, the entire recruitment process will change, and probably be handled at another level than in the current JANE project.