EU JOINT ACTION JANE

Endorsement Criteria of the Network of Expertise on Palliative Care

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Task T6.4

Version 05

WP6: Palliative Care.

1. Considerations for the endorsement criteria

In order to fulfil the overreaching objectives established for the Network of Expertise (NoE) on Palliative Care (PC), the present endorsement criteria will cover all the important stakeholders that will play an important role, and whose joint effort will “ensure/facilitate” the completion of those objectives.

1.1. Participating roles

For the participation of the NoE on PC we distinguish two “different roles”.

- **Full partners:** Those centres, institutions, organisations, and individuals that will be part of the network, “fully devoted” to its activities.
- **Collaborators**. These would be 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. Network’s organisation

Given the complexity of the network’s objectives and the need to count with expertise from different fields, we propose the following structure to ensure the efficiency of the network.

The network should be structured into 5 working groups that will cover different task and deliverables to fulfil the aims and objectives. In this regard, we envision the creation of 5 working groups with a specific focus on:

- 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.

Each of the working groups will have a chair or coordinator. We propose regular/monthly meetings between the WG coordinators and the management chair(s) of the network. Each WG will rely on the collaboration from different partners and collaborators, who will report to their coordinators, and in turn, the coordinators will communicate the directions and conclusions from the meetings with the management chair. Every 3-6 months “plenary” meetings will take place with all the partners of the network.

2. Endorsement criteria ("Full partners")

To fulfil the NoE aims, ensuring access to PC and the integration of PC in routine cancer care, the NoE would need:

- Accredited experts on PC.
- 1 representative from comprehensive cancer centres (CCC).
- Stakeholders who can influence their organization and care provision of CCCs.
- Links to patients and caregivers.
- Representatives from the National PC organisations.
- Representatives from centres and institutions that provide care and support the delivery of PC (Charities, Hospices, primary healthcare professionals).
- Representatives from International organizations and associations focused on (or ~~that~~ include) cancer care and research.

The experts of JANE WP 6 have agreed on the following criteria:

2.1. Accredited experts on Palliative Care

Representatives from cancer centers with expertise in PC. They should have clinical, leadership and management experience in PC and its integration in cancer care. The NoE should aim to have at least **one** representative **from each country** in the EU. If deemed necessary, more than 1 representative per country is desirable to account for:

- Geographically spread countries.
- Diversity in the provision of health care.

The prioritised centres should have:

- Accreditation of their experience on PC and its integration with Oncology:
    - ESMO designated centres (ESMO DC).
    - Centres with OECI accreditation.
- Involvement in development of national PC guidelines.
- 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.
- International experience and future international presence.
- The involvement of patients, patient representatives and voluntary organizations, and collaboration with advocacy groups.
- Centers that belong to or have links with the public healthcare.
- Links to national and international PC organizations and institutions.

For countries that are not accredited centres on PC, the representatives should have:

- Experience from clinical PC
- Experience in systematic use of patient reported outcome measures (PROMs).
- Experience in the provision of PC at earlier stages of cancer, not only as end-of-life (EOL) care.
- Be knowledgeable of the status of PC in their country and the barriers to the access to PC and its integration.
- Links to national and international PC organizations and institutions.

The centers participating in the NoE will need to be nominated as a competent authority for each member state.

2.2. 1 representative from CCC

One of the steps to ensure equitable access to PC is that all CCCs provide PC to their patients. In this regard, we envision that the NoE should count with a representative from the future NoE on CCCs.

- This representative should gather knowledge regarding the status of PC delivery in the different CCCs included in the network of CCCs, and the provision of cancer care in the different centres.

2.3. Stakeholders that can impact the organization and care provision of CCCs/individual centres.

- **Representatives from CCC** with influence or contact with stakeholders that can impact the organization of cancer care of their institution such as:
    - Hospital administrators and managers.
    - Policy makers and government representatives.
- These representatives should come from both **CCC** that deliver PC and does that currently do not offer PC.

2.4. Links to patients and caregivers

To ensure that the actions of the NoE would benefit and be of most interest to patients, the NoE will need direct links to them to learn their needs and priorities. These should include representatives from existing patient representatives’ organisations and advocacy groups at the national and international level (i.e.: FAVO, ELLOK, ECPC, etc.).

These links and collaborations should be of a bidirectional nature. In the one hand, they will represent the patient’s best interest in the NoE. On the other hand, they will contribute to disseminating what is PC and what are the basic principles underlying PC that should be integrated into routine cancer care.

2.5. Representatives from the national PC organisations.

The NoE should aim to count with a representative from each of the national PC organisations of the different EU countries. They can provide a clearer picture of the national status of PC in each of their countries and reach out to the different national centres. Furthermore, they could contribute to dissemination.

2.6. Stakeholders that can provide care and support for the delivery of PC.

Since PC is also provided outside cancer centres, the NoE should have representatives from:

- Charities involved in and promoting PC (McMillan, Help the Hospices, AECC…).
- Hospices
- Clinicians from primary healthcare: GP and/or nurses who deliver clinical PC.
    - They should have national influence: prove capability or resources for forming and representing national groups.
    - They should have international experience and future presence in the international agenda.

  - Involvement in national guidelines development.

This collaboration could help improving the transition between the hospital-based and community care.

2.7. Representatives from International organizations and associations focused on (or that include) cancer care.

Including representatives from existing associations and organizations that focus on improving cancer care would avoid overlap and duplication of tasks. In addition, it would help addressing existing gaps, and enhance collaboration. In this regard, representatives from the following should be considered:

- ESTRO
- EAPC
- ESMO
- MASCC
- OECI
- ECO
- …

In addition, institutions and organizations focused on research on PC, should be included:

- PRC: European palliative care research centre.
- ATLANTES global observatory of palliative care
- Palzon, Dutch PC research group
- European Pain Federation
- European Oncology Nursing Society
- International PsychoOncology Society (IPOS)
- …

3. Endorsement Criteria (Collaborators)

In this subsection, we refer to experts and representatives who can play an important role and contribute "periodically" to the NoE, but who will not be full partners.

3.1. Links to Ministry of Health and EU commission

Collaboration with national representatives from the Ministry of Health/Public health institutes in each country is important to strengthen the local, national and international influence of the NoE. Moreover, establishing links with a representative from the EU commission could help when calling for funding to address the identified needs in PC provision and organisation.

As of today, these links will be established through the Policy Board of JANE. We believe it to be of the utmost importance that the connections with the different NoEs continue beyond the duration of the present JA.

3.2. Implementation science experts

To succeed with the implementation of PC in routine clinical cancer care the contribution from experts within Implementation Science is desirable. They will not be "full members/partners" of the NoE.

3.3. University representatives

Representative stakeholders from universities with influence on the structure and content of education and training at the graduate and undergraduate levels may be contacted with the primary objective being to improve the education and training of PC in the different curricula. This may improve the future graduates' understanding of the unmet needs for basic and more specialised PC for thereby impacting clinical cancer care, and applies to diverse professionals, e.g., medicine, nursing, psychology, social work).