COST
EUROPEAN COOPERATION
IN SCIENCE & TECHNOLOGY

Brussels, 12 May 2023

COST 037/23

DECISION

Subject: Memorandum of Understanding for the implementation of the COST Action "COllaboratively DEveloped culturallY Appropriate and inclusive Assessment tool for Palliative Care EDUcation" (CODE-YAA@PC-EDU) CA22127

The COST Member Countries will find attached the Memorandum of Understanding for the COST Action COllaboratively DEveloped culturallY Appropriate and inclusive Assessment tool for Palliative Care EDUcation approved by the Committee of Senior Officials through written procedure on 12 May 2023.

Funded by
the European Union

MEMORANDUM OF UNDERSTANDING

For the implementation of a COST Action designated as

COST Action CA22127
COLLABORATIVELY DEVELOPED CULTURALLY APPROPRIATE AND INCLUSIVE ASSESSMENT TOOL FOR PALLIATIVE CARE EDUCATION (CODE-YAA@PC-EDU)

The COST Members through the present Memorandum of Understanding (MoU) wish to undertake joint activities of mutual interest and declare their common intention to participate in the COST Action, referred to above and described in the Technical Annex of this MoU.

The Action will be carried out in accordance with the set of COST Implementation Rules approved by the Committee of Senior Officials (CSO), or any document amending or replacing them.

The main aim and objective of the Action is to set quality indicators to establish a gold standard for high quality education and training in palliative care, with a focus on primary health care, which is considered the most sustainable and cost-effective model for palliative care delivery. This will be achieved through the specific objectives detailed in the Technical Annex.

The present MoU enters into force on the date of the approval of the COST Action by the CSO.

OVERVIEW

Summary

All health systems across the WHO European Region should prepare to respond to the age-related increase in deaths from chronic diseases, by focusing on integration and boosting of palliative care education. The CODE-YAA@PC-EDU COST Action will set quality indicators to establish a gold standard for high-quality education and training in palliative care. CODE-YAA@PC-EDU aims to measure, explore, and promote access to palliative care education and training in the WHO Euro-region, focusing mainly on primary health care, which is considered the most sustainable and cost-effective model for palliative care delivery. CODE-YAA@PC-EDU will develop and provide a new culturally and ethically appropriate inclusive evidence-based self-assessment tool, CODE-YAA, to inform leadership priorities and evidence-based decision-making related to palliative care education and training. CODE-YAA@PC-EDU is composed of three Pan-European; interdisciplinary; geographical, age and gender balanced; open and inclusive; and excellence-driven working groups: FIRE, TORCH, and THUNDER. CODE-YAA@PC-EDU will provide networking opportunities and activities for researchers and innovators to strengthen Europe's capacity to the scientific, technological, and societal challenge of ensuring access to palliative care education and training. CODE-YAA@PC-EDU will capitalise on other EU-funded projects on ethics, research ethics, and palliative care. The CODE-YAA indicators will have a long-lasting impact in Europe and beyond. CODE-YAA@PC-EDU will coordinate joint efforts to seek ways to improve palliative care education and accelerate knowledge transfer into ethically sound practices that can be shared across Europe to reduce the societal and economic burden and harmful experiences caused by people experiencing unnecessary health-related suffering.

Areas of Expertise Relevant for the Action	**Keywords**
● Health Sciences: Health services, health care research ● Philosophy, Ethics and Religion: Ethics and morality, social ethics ● Educational sciences: Education: training, pedagogy, didactics ● Sociology: Population dynamics, demography	● education and training ● quality assessment indicators ● capacity building ● palliative care

Specific Objectives

To achieve the main objective described in this MoU, the following specific objectives shall be accomplished:

Research Coordination

- Defining the Quality indicators for Palliative Care education for the CODE-YAA.
- Translation of CODE-YAA tool and language diversity.
- Testing the CODE-YAA tool.
- Analysing the data for scientific and public dissemination.

Capacity Building

- Enhance advocacy and policy skills of young researchers, palliative care practitioners and allied professionals, to integrate quality palliative care into primary health care.
- Showcase innovative teaching methods to COST ITC members through CODE-YAA missions.
- Foster partnerships between mentors from the FIRE and THUNDER Group and mentees from the TORCH Group, to support each other by forming bilateral partnerships.
- Develop, transform, and empower leaders from the WHO European Region to advance palliative care

education, training, and practice internationally and to address present and future challenges in the field.

- Foster clinical and research ethics competencies and practices among all members of the network.
- Encourage the scientific and public dissemination for advocacy and best practice.
- Promote the uptake of the results of the CODE-YAA to relevant policy-makers and member states.

TECHNICAL ANNEX

1. S&T EXCELLENCE

1.1. SOUNDNESS OF THE CHALLENGE

1.1.1. DESCRIPTION OF THE STATE OF THE ART

The World Health Organisation (WHO) defines palliative care as an approach that improves the quality of life of patients (adults and children) and their caregivers who are facing problems associated with life-limiting illness. Palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial and/or spiritual. It offers a support system to help patients live as meaningfully as possible until death and provides structures to support patients' caregivers. This includes addressing practical and psycho-social needs and providing bereavement counselling. Palliative care is explicitly recognised as a human right. According to the WHO, Palliative care should be provided at all levels of care through person-centred and integrated health services that pay special attention to the specific needs, values, and preferences of individuals. Evidence supporting investment in palliative care shows that it is effective in reducing suffering for patients and families, and it is cost-effective for integrated health care systems. Prior to COVID-19, projections outlined that by 2060 an estimated 48 million people will die each year with serious health-related suffering (47% of all deaths globally), and 83% of these deaths will occur in low- and middle-income countries. In higher and upper-middle-income countries, prolonged and more 'care-intensive deaths' are predicted due to age-related frailty, multi-morbidity, and compromised mental ill-health, requiring more palliative care support. Together with the United Nations, the WHO promotes and facilitates activities to improve palliative care around the world. Sustainable Development Goals (SDG) 3 "Ensure healthy lives and promote well-being for all at all ages" and 10 "Reduce inequality within and among countries" of the United Nations Sustainable Development Group call on member states to 'combat inequalities and discrimination that often underlie the barriers people face in accessing healthcare and other services. Focusing on palliative care, these SDGs call for palliative care strategies, including enabling access to palliative care education, to reach the 48 million people worldwide each year who will need this type of support/care. If recent mortality trends continue as predicted, more people will need palliative care by 2040. As noted in the European Declaration on Palliative Care (2020), an evidence-based declaration with recommendations resulting from two EU-funded projects, IMPACT and Euro-IMPACT, all health systems should prepare to adapt to the age-related increase in deaths from chronic diseases, by focusing on the integration and boosting of palliative care across the health and social care workforce. The global health community has the responsibility and the opportunity to improve the quality of life of people living and dying with serious health-related suffering, by recognising it as a public health priority and by supporting initiatives to tackle it.

The goal of this COST Action is to set quality indicators to establish a gold standard for high-quality education and training in palliative care. CODE-YAA@PC-EDU aims to measure, explore, and promote access to palliative care education and training in the WHO Euro-region, focusing mainly on primary health care, which is considered the most sustainable and cost-effective model for palliative care delivery.

Funded by
the European Union

1.1.2. DESCRIPTION OF THE CHALLENGE (MAIN AIM)

Palliative care is a universally applicable philosophy and approach in healthcare. In practice, this means accepting cultural and social pluralism and respecting the needs and value-based preferences and choices of patients and caregivers. This makes teaching palliative care a very special endeavour, which requires culturally appropriate and inclusive curricula, particular skill-grade-mix, and innovative teaching strategies. European curricula recommendations currently exist for undergraduate medical, nursing, psychology, and social work education as well as for postgraduate training in medicine. Such regularly updated recommendations are essential to influence national policy makers and other key stakeholders of the importance of palliative care education. In practise, such curricula recommendations need to be culturally appropriate or adjusted according to national regulations, healthcare systems' ability to make palliative care accessible, and societal needs.

Educational recommendations and quality assessment criteria validated by high-level non-governmental organisations, governments or professional bodies are critical to advancing palliative care education. The model proposed by the WHO (2021) highlights six essential components needed for optimal palliative care provision for people experiencing serious health related suffering. One of these is the education and training of all healthcare professionals and volunteers who provide palliative care. According to the WHO, the quality indicators for palliative care education are the proportion of formal education in: (1) undergraduate medical studies, (2) undergraduate nursing studies, and (3) specialisation in palliative care for medical doctors. The latter seriously undermines the role and contribution of nurses and allied healthcare professionals because patient care relies on nursing, and other health and social care professionals in the delivery of palliative care services. To meet the values and address the needs of people with serious illnesses and their caregivers, countries need more interprofessional and interdisciplinary resources than those identified for clinical medicine.

Access to palliative care education is key. It is paramount to ensure that all healthcare professionals are able to provide an integrated and holistic palliative care approach, as well as a generalist palliative care provision for all those who need it. To ensure access to pain relief, physicians, nurses, health, social, and psychological care workers need to be trained in the core principles (which are commensurate with good quality care generally) and to overcome their misconceptions and those of the society around caring for patients with life-limiting illnesses. Even in countries with limited resources, training and education in palliative care can have a profound effect and even influence change in government policies in a bottom-up process. The general public, law enforcement and government agencies also need to be educated about pain relief, symptom control medications and the overall importance of palliative care. Governments' interest in palliative care results from its societal impact. It is necessary to enact policies and guidelines that also provide opportunities for better education and training in palliative care.

Most students in clinical disciplines do not feel prepared to provide family care and address ethical challenges at the end of life. In a recent study from the United Kingdom that focused on undergraduate medical education, six indicators were proposed to measure the effectiveness of palliative care education. These six indicators could be used to develop frameworks to evaluate effectiveness across wider international programmes. The indicators were: (1) mandatory introduction of palliative care into the undergraduate curriculum; (2) a specific number of hours proposed for teaching in a structured and meaningful standardised curriculum; (3) the introduction of mandatory assessment of palliative care as part of the undergraduate curriculum; (4) the introduction of a palliative care teaching programme in hospitals to support newly trained physicians; (5) the availability of a senior staff member with sufficient knowledge in palliative care to support newly trained physicians; and (6) the integration of an academic department of palliative care in each medical school. The evaluation of these indicators is needed. Data collected in 23 low- and middle-income countries in Europe show that there are challenges related to poor access to pain relief, lack of political commitment, policies and guidelines, sustainable funding models, human resources and workforce, leadership in palliative care and quality palliative care education. To achieve quality palliative care education, distance learning and exchange programmes, training programmes for educators balancing theory and practice, and the selection of appropriate teaching methods and follow-up strategies are needed. Existing recommendations and competency frameworks are considered useful. Yet, the resolution of issues related to global and regional (cultural) challenges, professional and/or multidisciplinary training, professions to be included, number of competency levels and number of hours allocated to palliative care training is still pending.

Learning to care for people with life-limiting health-related suffering is an essential competency for all professionals engaged in health and social care, regardless of the field in which they work. That is why the goal of this COST Action is to set quality indicators for high quality education and training in palliative care.

1.2. PROGRESS BEYOND THE STATE-OF-THE-ART

1.2.1. APPROACH TO THE CHALLENGE AND PROGRESS BEYOND THE STATE OF THE ART

Alongside demographic changes, such as people living longer, the incidence, prevalence, and mortality of chronic illnesses are rising worldwide, with an increase in long-term conditions, fragility, vulnerability, and multi-morbidities. Healthcare services will therefore need to adapt to provide appropriate services for changing populations, and this will require more resources, including palliative and end-of-life care.

Current models of palliative care provision must adapt to these projected changes, and a greater focus on non-specialist health professional education is needed. In this COST Action, special attention is given to the issues of interdisciplinary, community, diversity, and intersectoral collaboration to foster educational collaboration and provide training in palliative care to all non-specialists from different backgrounds. Three working groups were created: FIRE, who will provide long-existing networks, expertise and leadership; TORCH, who will provide innovation in communication and public outreach; and THUNDER, whose main objective is to encourage participation and collaboration with the global audience. Together, these three working groups collectively will develop, test, implement, and disseminate a tool for positive change in palliative care education. Key to this COST Action is the development of a culturally and ethically appropriate inclusive evidence-based self-assessment tool – the CODE-YAA. This is an online resource for anyone wishing either to develop initial education and training in palliative care or to assess gaps to strengthen their existing education and training in palliative care. It is a self-assessment tool that can be used by a range of stakeholders, including governments of member states, clinicians, educators, researchers, policy makers and health services users. Open dialogue and discussion are encouraged by asking stakeholders to consider: (i) where they are now in relation to palliative care education and training, (ii) where they want to be in the future, and (iii) what actions they need to take to achieve this. These questions are asked in relation to a range of issues: palliative care provision, initial education and training of health and social care professionals, access to programmes, curricula (general, theory, practise), academic faculty, resources, clinical learning, and regulation of education. The CODE-YAA tool includes a response section to summarise the discussions and a section with links to useful resources.

CODE-YAA is intended for use within countries across all disciplines, sectors and services that provide palliative care. It has a great potential as a benchmarking tool.

1.2.2. OBJECTIVES

1.2.2.1. Research Coordination Objectives

Objective 1. Defining the Quality indicators for Palliative Care education for the CODE-YAA. The aim of this activity in this COST Action is to identify and agree on a set of quality indicators for palliative care education and training. An online Delphi technique will be used. The Delphi technique is often used to find and develop consensus in palliative care where evidence is limited. Online Delphi studies involve (1) identification of a research problem, (2) preparation of a literature review, (3) development of a questionnaire with indicators. There are iterative rounds of online questionnaires in which experts are asked to anonymously rate or rank statements, individual and group feedback between rounds, consensus building and summary of results. Defining and agreeing on a set of quality indicators for palliative care education and training is important to address issues related to the development and description of the status of palliative care education at a country level. We address the following research question: What are essential quality indicators for palliative care education and training? A three-round Delphi study is proposed to identify preliminary consensus on the pre-identified indicators and to generate additional statements (Round 1), to identify consensus (Round 2), and to evaluate the shortlisted items determining the essential competencies based on the level of consensus reached

(Round 3). Three rounds are considered sufficient to achieve a successful outcome. If the results and open questions suggest otherwise, a fourth round will be considered.

The quality assessment tool CODE-YAA will be tested in practice in a two-day Dissemination Conference involving the entire CODE-YAA@PC-EDU network. This conference is for all Action MC Observers, Working Group Members as well as ad hoc participants. This conference is to gather feedback on the content, test the usability, and understand the process of using CODE-YAA. During this conference, all participants will be provided with (i) a guide and glossary to translate the CODE-YAA into their native language, and (ii) instructions to initiate a two-stage workshop at least once in their country.

Objective 2. Translation of CODE-YAA tool and language diversity. For on-site testing, the CODE-YAA will be translated into COST Action members' official languages. The emphasis is on a high-quality and culturally adapted translation that reflects the meaning of the original text and is appropriately worded, error-free, and coherent. To assess the translation's quality of expression, people responsible for the translation process will use the cognitive interviewing/think-aloud method. This will be continued until the translation is coherent. Final steps include checking for any grammatical or spelling mistakes and if everything has been handled consistently. This activity contributes to the development of the vocabulary of palliative care in each Member State, which is necessary for each discipline. Given that workshops and data collection (see Objectives 3 & 4) will be undertaken in the national language of each participating country and the final reporting of the data and project will be in English, we propose innovative approaches that favour collaboration and group consensus to manage linguistic diversity. A glossary of key terms will be developed in English and confirmed or adapted to the host language through a process of consensus validation between members of Code-YAA team and the national centre. Other documents and tools (e.g., codebook for data analysis) will initially be prepared in English and sense-checked with the local team to ensure equivalence and understanding. For quantitative measures, validated tools in the host language will be used wherever possible. Qualitative data will be collected and analysed in the host language and core themes translated into English. Clarification of understanding and confirmation of core themes will be managed through a consensus process between the local centre and the project team.

Objective 3. Testing the CODE-YAA tool. For field testing, all participants will organise a half-day virtual country wide workshop to investigate:

- Whether the process of using the CODE-YAA is acceptable and useful?
- Whether the CODE-YAA could improve the ability of health and social care professionals and users of palliative care services to have open discussions about strengthening initial palliative care education and training in the country?

The virtual workshop, which supports a geographically broad participation within each participant country, will identify the areas of palliative care where teaching and training need to be improved locally. At the same time, the workshop will elicit whether participants have knowledge and experiences for a broader implementation of palliative care education and training that can be used as inspiring case studies or examples in the CODE-YAA glossary. The workshop will be facilitated by a moderator, who is a member from the FIRE group. An observer from the TORCH group will take brief notes on the discussions, the quality of participants' engagement, and their suggestions. Depending on organisational cultures, the online workshops can be conducted in interprofessional or mono-professional groups of 5 to 10 people, consisting of clinicians, educators, academics, policy makers, students, patient representatives or/and other key stakeholders. The discussions can be conducted in English as well as in the participants' mother tongue. Language will be adapted according to the preferences of the participants. Participation in the workshops will follow existing ethics guidelines to ensure ethically sound procedures. Hence, all participants in the workshops and online evaluations will be informed, in writing, beforehand. Participation is voluntary and attending the workshop will be taken as a sign of participants' consent. Withdrawing participation will be granted at any time in the process.

Each group will be asked to go through CODE-YAA, discuss the questions from CODE-YAA and record the answers, which will then be transcribed, translated and uploaded to the project management tool for thematic and network analysis (Objective 4). The Nominal Group Technique, a structured method to obtain information on a topic of interest in the context of a cross-cutting activity, will be used to get and set priorities without pressuring participants to reach consensus or stay in the group for the long term.

The findings of national workshops are intended to be used both as an agenda for improving palliative care education at the local level and as a framework for wider COST Action activities.

Objective 4. Analysing the data for scientific and public dissemination. This objective will select the predictors of benchmarking for developing palliative care education and training, which will be presented for implementation across the European region. The transcriptions of the country-level workshops will be analysed using Thematic Analysis and Social Network Analysis. The Social Network Analyses will be conducted with the InraNodus software. In order to analyse textual outcomes across the COST Action activities, including the transcripts of all virtual meetings, a mixed approach of qualitative and quantitative methods for text mining analysis will be conducted in R (a statistical software programme). The virtual meetings will be recorded and transcribed using a specific Artificial Intelligence text recognition software, which allows creating meeting memos that can be used for bite-size dissemination as well as various reporting activities.

1.2.2.2. Capacity-building Objectives

Objective 1. Enhance advocacy and policy skills of young researchers, palliative care practitioners and allied professionals, to integrate quality palliative care into primary health care. A series of virtual courses will start in the second year and are an important component of capacity-building and dissemination under the CODE-YAA@PC-EDU action. These virtual meetings are offered to enhance the advocacy and policy skills of young researchers, palliative care practitioners and allied professionals, to integrate quality palliative care into primary health care as part of universal health coverage within each country, and to improve access to palliative care services. The media, advocacy and policy courses consist of several modules organised as a series of virtual meetings. The aim of these courses is to further build and strengthen the palliative care education network, giving people from different disciplines a forum to discuss palliative care and share ideas. This will help those involved to 'light their TORCH' to illuminate how to develop and sustain palliative care education, CODE- YAA@PC-EDU network and accelerate global, national, and grass root advocacy and influencing policy making. Participants will learn to use various media channels, such as podcasts, vlogs, public talks, posters, policy papers to make a permanent change in public perception of palliative care. The latter will be encouraged by Scientific and Public Influencer award nominations each year.

Objective 2. Showcase innovative teaching methods to COST ITC members through CODE-YAA missions. These short-term scientific missions are specifically aimed at the capacity-building of COST inclusiveness target countries (ITC). However, non-ITC countries with limited or no palliative care training and education structures may also apply for this fast-track action. CODE-YAA is to be completed prior to a consultation requested by organisations or countries seeking support or advice from an external advisory body, such as the CODE-YAA @PC-EDU Collaborative Network. An (inter)national team will be formed to conduct 2-to 3-day visits to present innovative teaching strategies. Short-term scientific missions may also take place in HOST countries as part of dissemination conferences. In this case, members from ITC countries may receive a travel allowance to participate in these missions. Anyone participating in this action can submit a proposal for a short-term mission grant and, if plausible, carry out these missions as agreed. However, the proposal must include evaluation strategies to measure the feasibility and impact of such missions. CODE-YAA missions will allow inviting relevant stakeholders, so they can be involved early on.

Objective 3. Foster partnerships between mentors from the FIRE and THUNDER Group and mentees from the TORCH Group, to support each other by forming bilateral partnerships. The aim of the mentoring programme is to foster partnerships between mentors from the FIRE and THUNDER Group and mentees from the TORCH Group, who support each other by forming bilateral partnerships. Each mentor and mentee (young researchers, young clinicians, and innovators) should agree on their specific contribution (e.g., mentors supporting their mentees in acquiring new scientific, ethical, clinical, communication, or management competencies or helping to pave the way for the involvement of workshop participants). Partners who have agreed to act as mentors are expected to establish and agree on a programme for engagement and exchange emails or arrange virtual meetings with mentees in line with this. The Action MC members will lay out the conditions for mentors to apply for a short-term visit of mentees (VM grantee) to the mentor's HOST organisation. The main purpose of CODE-YAA Mentorship Program is to enhance research ethics and integrity, support the scientific dissemination of results, such as the completion of manuscripts for submission to national and international journals. Mentor and mentee groups are encouraged to plan joint events with other similar partnerships. A mentor can invite several mentees to visit at the same time. CODE-YAA Partnerships should foster respect, trust, and inclusivity both between mentor and mentee and within the network.

Objective 4. Develop, transform, and empower leaders from the WHO European Region to advance palliative care education, training, and practice internationally and to address present and future challenges in the field. The aim of the CODE-YAA TORCH Empowering Leadership Education Programme is to develop, transform, and empower leaders from the WHO European Region with the necessary competencies in empowering leadership, management, health policy and evaluation to advance palliative care education, training, and practice internationally and to address present and future challenges in the field. Effective palliative care leaders will be able to envision, transform, and culturally align services to meet the needs of patients, families, teams, organisations, and external stakeholders. The Empowering Leadership Education Programme will be organised as a summer school. It will be built bringing together four theoretical perspectives of empowering leadership with a strong international empirical foundation: (i) the rational goal model; (ii) the internal process model; (iii) the human relations model; and (iv) the open systems model. This interdisciplinary Empowering Leadership Education Programme will prepare junior leaders with a solid foundation in eight key areas of empowering leadership in palliative care: Transforming Clinicians, Researchers, Educators, and Managers into Leaders; Health Policies and Healthcare Systems; Diagnosing and Changing Organisational Culture; Strategic and Operational Planning; Development of Empowering Leadership Competencies; Ethics and Decision-Making in Palliative Care; Improving Quality and The Value of Palliative Care; and Empowering and Leading Effective Teams.

Objective 5. Foster clinical and research ethics competencies and practices among all members of the network. The aim of the CODE-YAA Ethics Programme in Palliative Care is to foster clinical and research ethics competencies and practices among all members of the network (FIRE, TORCH, and THUNDER), including young palliative care researchers and clinicians from the WHO European Region. This programme will be organised as a summer school. It will promote partnerships between mentors from the FIRE and THUNDER Group and mentees from the TORCH Group, who will support each other in the development of ethical competencies and practices in palliative care. The Ethics Programme in Palliative Care is rooted in the field of bioethics, which is a broad interdisciplinary field of inquiry that brings together different disciplines to address the ethical questions and problems raised by the scientific and technological developments in Health and Natural Sciences, Engineering, Social Sciences and Humanities. This programme will unite the different disciplines, perspectives, and worldviews represented within the network and beyond to address issues within palliative care, research, and education. Topics will focus on:

- Ethics in Palliative Care: Concepts and foundations
- Bioethics, Biolaw and Ethics in Palliative Care
- Bioethics and Biolaw in the European Union and in the Council of Europe
- Ethical Principles and Values applied to Palliative Care
- Applying Bioethics and its Methodology to Palliative Care Clinical Practice, Research, and Education.

The programme will capitalise on the activities, results and impact of other EU-funded projects on ethics, research ethics, and palliative care.

Objective 6. Encourage the scientific and public dissemination for advocacy and best practice. The current translation gap that hinders the provision of palliative care in primary care is partly due to ineffective public dissemination and a lack of public awareness. The overall dissemination agenda of this COST action will be based on the theory of multiple streams, which states that policies move forward when three streams - "the problem", "the potential solution" and "political and public opinion" - come together to enforce policy change. To reach all relevant stakeholders: patients and caregivers, clinicians, researchers, and policy makers, this COST Action will include news media, social media, policy briefs, one-to-one meetings, workshops and seminars in its dissemination plan. All messages will be framed to better resonate with the target audience. In particular, dissemination of research findings to non-scientists will be improved by using messages that are worded in a way that evokes emotion and interest and demonstrates the benefits (stories, visual and video abstracts).

Objective 7. Promote the uptake of the results of the CODE-YAA to relevant policy-makers and member states. The final capacity building objective is to develop a summary research protocol to study the CODE-YAA impact and the wider effects of this Cost Action. The protocol will address the relevance of the evaluation, its usefulness and the commitment of policy makers and member states using these findings as well as its potential use for advocacy and policy making. The evaluability assessment will also discuss the timing of the impact evaluation, not too early or late, to make sure that the impact evaluation will be meaningful.

2. NETWORKING EXCELLENCE

2.1. ADDED VALUE OF NETWORKING IN S&T EXCELLENCE

2.1.1. ADDED VALUE IN RELATION TO EXISTING EFFORTS AT EUROPEAN AND/OR INTERNATIONAL LEVEL

The network will make it possible to identify the basic / common elements of education and training in palliative care across cultures and countries. These elements can be used to improve palliative care education and services in all Member states. The added value of this COST Action network is four-fold:

1) Ensuring that Member States are equipped with the collaboratively developed culturally appropriate and inclusive assessment tool for palliative care education. This will enable the setting of a gold standard for education and training in palliative care to minimise health-related suffering and to optimise access to palliative care as primary care;
2) Identifying ways to improve access to palliative care education to prevent, minimise and resolve health-related suffering and optimise emotional, social and spiritual outcomes for patients and carers;
3) Accelerating the translation of this knowledge into best practise that can be disseminated across Europe and globally to reduce the societal and economic burden and harmful experiences caused by people experiencing unnecessary health-related suffering; and
4) Rejuvenating and sustaining the network of academics, clinicians, researchers, policy makers and grassroots stakeholders focused on advancing palliative care education and training worldwide.

Ultimately, the CODE-YAA @PC-EDU Action will work towards an ideal universal gold standard of palliative care education and training to prevent or at least minimise health-related suffering and optimise access to palliative care as a primary care service.

2.2. ADDED VALUE OF NETWORKING IN IMPACT

2.2.1. SECURING THE CRITICAL MASS, EXPERTISE AND GEOGRAPHICAL BALANCE WITHIN THE COST MEMBERS AND BEYOND

This COST Action is based on the long-standing cooperation and connections of the people who belong to the group FIRE. All participants in the group FIRE are active in different capacities; for instance, as clinicians and researchers with experience in the policy field and as academics involved in palliative care education and training. People in the FIRE group represent the national and international palliative care community and participate in the implementation of the coordination and management elements that fully support this action. Previous collaborations of this group have been strengthened through numerous ERASMUS+, FP7, H2020, and Horizon Europe funding programmes. Furthermore, between the members of the FIRE group there are many bilateral activities in the field of education and training that are solely based on ‘informal’ agreement and voluntary work. Many FIRE group members are authors of relevant policy and white papers. All participants in the FIRE group are in a position to facilitate access to relevant policy actors who may be invited to participate in this COST Action at a later stage or as ad hoc members. Members of this Action are advisory to scientific expert committees of various organisations and contribute to the initiatives of the European Council, the European Union and the United Nations. Since 2016, the FIRE group has focused on collaborating with COST Inclusiveness Target Countries. This work has shown that some of these Member states have very advanced palliative care education and training structures compared to high and middle-income countries in Europe. The existing collaboration and exchange are a strength of this Cost Action, which has enabled a strong interdisciplinary, multi-professional, and multi-sectoral core group to be formed, capable of implementing this action.

2.2.2. INVOLVEMENT OF STAKEHOLDERS

It is expected that the early involvement of stakeholders in research and evaluation processes through virtual nationwide workshops will improve dissemination of scientific results. The CODE-YAA network supports its work through its membership across all Europe and beyond, by organising regular online meetings and events to build on the work done during the lifetime of the Action, and through ongoing public and scientific dissemination of the network's work. Most of the members of the network of this Action have been partners in many large EU-funded studies focusing on knowledge transfer and stakeholder engagement.

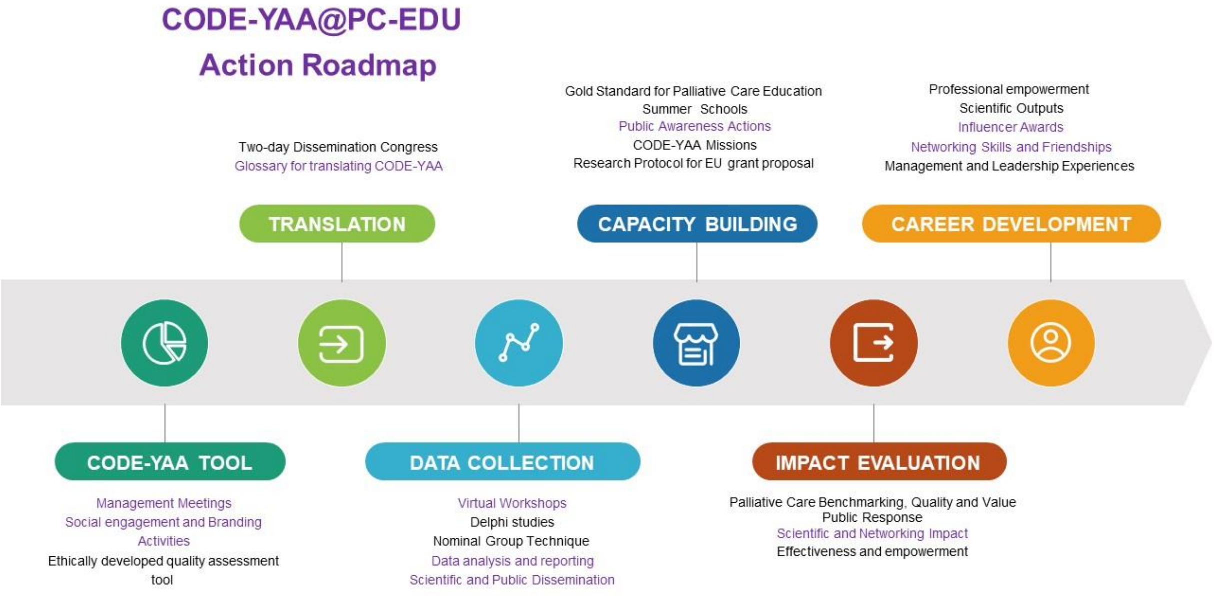
3. IMPACT

3.1. IMPACT TO SCIENCE, SOCIETY AND COMPETITIVENESS, AND POTENTIAL FOR INNOVATION/BREAK-THROUGHS

3.1.1. SCIENTIFIC, TECHNOLOGICAL, AND/OR SOCIOECONOMIC IMPACTS (INCLUDING POTENTIAL INNOVATIONS AND/OR BREAKTHROUGHS)

The CODE-YAA indicators will be used to set the focus for making a long-lasting impact in Europe and beyond. Current knowledge about developments in palliative care education and training are systematically collected. Nevertheless, country-level studies show severe inaccuracies in the available data and methodologies used. CODE-YAA shall become a valuable resource for national agencies as a gold standard for data collection and evaluation. It will help Member States to develop palliative care in line with the WHO Resolution: Strengthening Palliative Care (2014), help gather more accurate data and ethically sound evidence to make informed decisions on how to improve access to palliative care education and training for all health professionals, which has been one of the biggest barriers to access to palliative care for all who need it. Palliative care can significantly reduce health care expenditure. Early consultation of palliative care leads to greater cost reductions than consultation in the last week of life. For some diseases and clinical syndromes, such as multi-morbidity, chronic progressive diseases with long disease courses, and diseases with complex symptoms, more palliative care support is needed.

Figure 1. CODE-YAA@PC_EDU Action Roadmap.



In terms of socio-economic impact, this COST Action is expected to (1) coordinate joint efforts to seek ways to improve access to palliative care education to prevent, minimise and resolve health-related suffering and optimise emotional, social and spiritual outcomes for patients and carers, and (2) accelerate the translation of this knowledge into ethically sound practises that can be shared across Europe to reduce the societal and economic burden and harmful experiences caused by people experiencing unnecessary health-related suffering.

All our Activities and Programmes will be evaluated. For example, the CODE-YA TOURCH Empowering Leadership Education Programme incorporates an Empowering Leadership Competency Assessment Instrument (LIDERA©) that has been validated by members of the FIRE group. The instrument will assess participants' (members of the TORCH group) competencies and empowering leadership roles within four dimensions: (i) leading people; (ii) leading change; (iii) leading activities; and (iv) leading results.

3.2. MEASURES TO MAXIMISE IMPACT

3.2.1. KNOWLEDGE CREATION, TRANSFER OF KNOWLEDGE AND CAREER DEVELOPMENT

The goal of this COST Action is to set quality indicators to establish a gold standard for high-quality education and training in palliative care. Accordingly, the CODE-YAA @PC-EDU Action aims to measure, explore and promote access to palliative care education and training in the WHO Euro-region focusing mainly on primary health care, which is considered the most sustainable and cost-effective model for palliative care delivery.

This Cost Action will work towards an ideal, universal 'gold standard' of palliative care education and training, to minimise health-related suffering and optimise access to palliative care as a primary care service.

- CODE-YAA Tool is intended for use within countries across all disciplines, sectors and services that provide palliative care. It has great potential as a benchmarking tool.
- CODE-YAA Tool is a free online resource for anyone wishing to develop initial education and training in palliative care or to assess gaps to strengthen their existing education and training in palliative care.
- CODE-YAA Tool can be used by a range of stakeholders, including governments of member states, clinicians, educators, researchers, policy makers and health services users to encourage open dialogue and discussions.
- Translating the CODE-YAA Tool contributes to the development of the vocabulary of palliative care in each Member State, which strengthens the discipline.
- The CODE-YAA@PC-EDU Action will summarise and disseminate the predictors of best practise for the development of palliative care education and training in primary care.

The transfer of knowledge of CODE-YAA@PC-EDU Action is evidence-based.

The current Palliative Care Education and Training Network (Group FIRE) actively seeks to mobilise a new generation of clinicians and academics to train, foster policymaking and advocate for palliative care. The CODE-YAA@PC-EDU campaign offers all participants a wide range of training and capacity building programmes, as well as one-to-one mentoring. The young academics and clinicians (TORCH group) participating in this action will have the opportunity to attend:

1) the CODE-YAA Advocacy & Policy Training;
2) the CODE-YAA Empowering Leadership Education Programme;
3) the CODE-YAA Ethics Programme in Palliative Care; and/or
4) the CODE-YAA Mentorship Programme.

All members of the TORCH group take on leadership roles in specific action groups. At the end of this networking action, they will all have enhanced skills in ethics, leadership and advocacy, scientific dissemination, and policymaking, as well as enhanced skills in branding and public dissemination. Management, methodological and networking skills are enhanced along with a number of significant scientific outputs: presentations, posters, journal articles. Hereby, FIRE group mentorship will guarantee high scientific quality and enable TORCH group members leading roles in the dissemination process. Participants become established members and leaders of an interprofessional Europe-wide network of experts to enforce policy change, education, public awareness of palliative care, and palliative care benchmarking, quality and value.

3.2.2. PLAN FOR DISSEMINATION AND/OR EXPLOITATION AND DIALOGUE WITH THE GENERAL PUBLIC OR POLICY

As uptake is rarely spontaneous, a special CODE-YAA action group will develop a public and scientific dissemination plan early in the process for branding, printing and presenting, agency and evaluation. All these activities are honoured with the CODE-YAA annual influencer award in public engagement and scientific dissemination. Social Engagement and Branding. The first step is to brand the CODE-YAA@PC-EDU Action on social media (website and social media accounts). All participants are encouraged to contact the public affairs or communications office at their institution to produce evidence based high-quality social engagement products, such as vlogs and podcasts. This liaison will enhance dissemination through the public media. To reinforce the message of the CODE-YAA@PC-EDU Action, newsfeed on the project website will be set up for bite-sized dissemination of various activities. Media, advocacy, and policy training will provide skills and understanding of different streams to move forward to enforce policy change. Vlogs and Podcasts will share peoples' experiences with palliative care, death and dying to make health care consumers understand the importance of palliative care, which will be used to shape and influence policy. The Culture, Language and Diversity Working Group will be responsible for multilingual messaging and content accuracy and respect for global diversity.

To support and strengthen research flow and impact, scientists, clinicians and stakeholders are invited to join the THUNDER group, whose main objective is to encourage participation and collaboration with the global audience. For scientific dissemination, this COST Action will follow the principles of open science, which should increase the impact of the research. At least two joint special issues on education and training in palliative care will be initiated and published. This means (i) proposing the curation of a virtual issue on palliative care education and (ii) a special issue on palliative care education and the future of palliative care by TORCH group members under FIRE group supervision. Topic-specific journal issues will make it easier for readers to find the relevant information. The publication of preprints is encouraged. In addition to presenting scientific results at national and international conferences, the dissemination plan will include participation in science festivals, science slams and lectures streamed via social media. At the 'agency' level, the scientific progress of the CODE-YAA@PC-EDU action is expected to provide a new tool to inform leadership priorities and evidence-based decision-making related to palliative care education and training. Impact and quality indicators will be used to monitor and measure the impact of public and scientific dissemination. Dissemination strategies will be based on the evaluation results.

4. IMPLEMENTATION

4.1. COHERENCE AND EFFECTIVENESS OF THE WORK PLAN

4.1.1. DESCRIPTION OF WORKING GROUPS, TASKS AND ACTIVITIES

This COST Action is composed of three working groups: FIRE, TORCH, and THUNDER. All three groups are to advance and promote the work and activities performed within this COST Action. Group FIRE consists of Action MC Members and observers who represent and benefit their national community and pro-actively participate in the implementation of coordination and management decisions in this Action. The Group FIRE has the task of proposing and analysing the quality indicators, evaluating the responses, and reaching an expert consensus in the Delphi process.

The FIRE group will provide regular virtual mentoring to all members of the TORCH working group throughout the process, focusing on activities and exchanges that can foster capacity-building and empowering leadership competencies, as well as methodological, ethical, and intercultural communication competencies, especially for young researchers. After setting up an online self-assessment tool, the TORCH group will be invited to translate and test the CODE-YAA tool in the field and present the results at the dissemination conference. Younger researchers from the FIRE group are seen as experts on diversity and intersectional challenges in present and future communities. This knowledge will be incorporated into the discussion guide for all users of the CODE-YAA.

Figure 2. CODE-YAA Working groups.

FIRE
- F=inalize CODE-YAA tool
- I=nternational meetings
- R=eport
- E=xpert mentorship

TORCH
- T=raining
- O=btaining data
- R=esearch
- C=ollaborative publications
- H=eterogeneity

THUNDER
- T=ool dissemination
- H=elp to understand
- N=avigation
- D=efine challenges
- E=xpertise sharing
- R=ecognition

All observers of the COST ACTION as well as ad hoc participants are invited to participate in the THUNDER group. Their task is to give feedback, and disseminate, making the CODE-YAA tool known and accessible globally. At the other end, the members of the THUNDER group will integrate the knowledge gained from this Action into local policy, government, and NGO reports in order to improve access to palliative care education and training.

In line with the principles of COST Action, specific action groups or working groups will be initiated and agreed to increase the quality, awareness, visibility, and impact of this COST Action. The six working groups dedicated to specific scientific and capacity building objectives and action-based deliverables. These working groups are:

1. Gold Standard Working Group
2. Culture, Language and Diversity Working Group
3. Research Coordination, Methods & Impact Analysis Working Group
4. Capacity Building, Leadership and Ethics Working Group
5. Global Policy and Advocacy Working Group
6. Communication and Dissemination Working Group

All working groups involve members of the FIRE, TOURCH and THUNDER groups. The leadership role in these groups will be distributed among the members of FIRE, TORCH and THUNDER groups. There is considerable overlap in their activities, which should encourage active exchange between and across these task-oriented groups. The FIRE group will ensure that the three groups link the specific actions to achieve better results and greater impact across the scientific and capacity building objectives, COST network and beyond.

Gold Standard	**Culture, Language and Diversity**	**Research Coordination, Methods & Impact Analysis**	**Capacity Building, Leadership and Ethics**	**Global Policy and Advocacy**	**Communication and Dissemination**
Defining the Quality indicators for Palliative Care Education Testing the CODE-YAA tool	Translation of CODE-YAA tool Preparing the glossary for translation CODE-YAA missions to showcase innovative teaching methods	Analysing the data for scientific and public dissemination Promote the uptake of the results of the CODE-YAA to relevant policy-makers and member states	CODE-YAA Empowering Leadership Education Programme The CODE-YAA Ethics Programme in Palliative Care CODE-YAA Mentorship Program	CODE-YAA Advocacy & Policy Training Scientific and public dissemination for advocacy and best practice	Calls & Actions Stakeholder communication Dissemination congresses

Table 1. The scientific and capacity building objectives of working groups.

4.1.2. DESCRIPTION OF DELIVERABLES AND TIMEFRAME

The expected outputs of CODE-YAA@PC-EDU Action are summarised in the table below. These actions-based deliverables are expected to be finalised by months 12, 24, 36, and 48.

Month 12	Month 24	Month 36	Month 48
Completion of interactive website and social media diffusion links. CODE-YAA and quality indicators set completed as reference document. Scoping, planning and process for influencer award programme defined and completed.	Final series of podcasts and Vlogs as tools for best practice implemented. Translation guide for CODE-YAA with glossary completed and ready for implementation. CODE-YAA tool finalised and freely accessible.	Country-level reports finalised and published. Interim report on the impact of CODE-YAA and statement of future actions.	Influencer award programme implemented. CODE-YAA Action Report on education, palliative care in public health and sustainable development.

Table 2. The expected outputs of CODE-YAA@PC-EDU Action.

4.1.3. RISK ANALYSIS AND CONTINGENCY PLANS

International exchange programmes and networking activities are perceived as enriching, but involve high out of pocket expenditure, which can become a major problem for all participants in this Cost ACTION. As palliative care education and training development is critically underfunded, human rights, including the right to autonomy, bodily integrity, equality, and protection from inhuman or degrading treatment, cannot be fulfilled in the WHO European region. Without significant investment in the training of palliative care practitioners and future leaders, the expected growth of palliative care could come to a stop. Sufficient financial support to promote the development of palliative care education and training is paramount. Cost-effectiveness and financial management are integral part of the COST Action management. Dedicated scientific and capacity-building objectives include and are not limited to: facilitation of the Main Proposer; Coordination of Actions including budget control. Interim and final STSM reports will also serve as external quality assessment and financial evaluation.

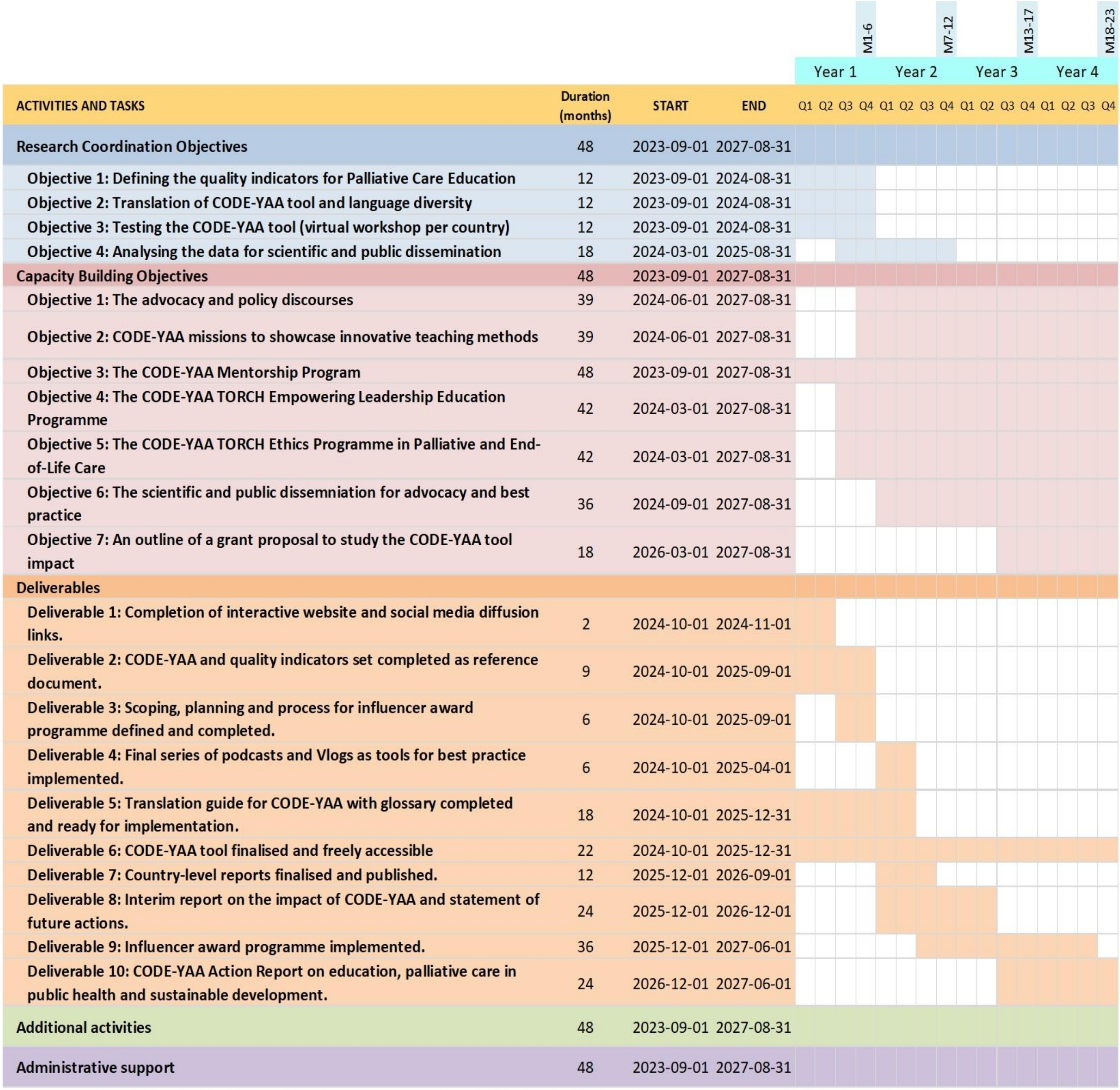
Essentially risk management and contingency planning is the responsibility of the Main Proposer and the Communication and Dissemination Working Group members. Together, they will supervise project risk management and contingency. Should they foresee or experience a risk situation, they will undertake appropriate steps to mitigate this, if necessary, by involving the rest of the Working Groups and/or Action participants. Should a risk escalate, they will contact the Project Officer for further discussion and advice. The Main Proposer will constantly monitor the project activities in relation to the contractual work plan and will identify any quality issues, delays and/or risks. During the kick off meeting the Communication and Dissemination Working Group will present: (1) Quality Management, (2) Risk Management, and (3) Contingency Management Plans; these will be updated in the SMST reports. The STSM are to be delivered as outputs annually. Corrective actions will be adopted if needed.

Efficient use of financial and time resources is key to the management strategy of the CODE-YAA@PC-EDU Action. All participating countries are represented by senior professionals in education, academic and clinical work and leadership, all with wide experience and, importantly, a motivation to improve the status quo (The FIRE Group). Their rich background will provide high quality efficient input to the content creation in a short time span. To build on this, each participant country will be represented by young academics and clinicians (The TOURCH group), whose career will benefit from all national and international COST Action outputs and activities. Together with global advisors (The THUNDER group), they will design, produce and validate CODE-YAA Tool content and its deployment. The same principle is applied to the dissemination group of partners. Online meeting solutions are used to cost efficiently support communication inside the consortium whenever possible. Minimal subcontracting costs are foreseen. All materials will be produced and shared electronically. Participants have agreed to deliver their workload with an equal distribution of activities for the design, co-creation, testing, finalisation and dissemination of CODE-YAA@PC-EDU outputs.

4.1.4. GANTT DIAGRAM

The following Gantt Diagram shows CODE-YAA@PC-EDU objectives and deliverables displayed against time.

Figure 3. CODE-YAA@PC-EDU activities and timeline.



							M1-6				M7-12				M13-17				M18-23
				Year 1				Year 2				Year 3				Year 4			
ACTIVITIES AND TASKS	Duration (months)	START	END	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Research Coordination Objectives	48	2023-09-01	2027-08-31	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Objective 1: Defining the quality indicators for Palliative Care Education	12	2023-09-01	2024-08-31	■	■	■	■												
Objective 2: Translation of CODE-YAA tool and language diversity	12	2023-09-01	2024-08-31	■	■	■	■												
Objective 3: Testing the CODE-YAA tool (virtual workshop per country)	12	2023-09-01	2024-08-31	■	■	■	■												
Objective 4: Analysing the data for scientific and public dissemination	18	2024-03-01	2025-08-31			■	■	■	■	■	■								
Capacity Building Objectives	48	2023-09-01	2027-08-31	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Objective 1: The advocacy and policy discourses	39	2024-06-01	2027-08-31				■	■	■	■	■	■	■	■	■	■	■	■	■
Objective 2: CODE-YAA missions to showcase innovative teaching methods	39	2024-06-01	2027-08-31				■	■	■	■	■	■	■	■	■	■	■	■	■
Objective 3: The CODE-YAA Mentorship Program	48	2023-09-01	2027-08-31	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Objective 4: The CODE-YAA TORCH Empowering Leadership Education Programme	42	2024-03-01	2027-08-31			■	■	■	■	■	■	■	■	■	■	■	■	■	■
Objective 5: The CODE-YAA TORCH Ethics Programme in Palliative and End-of-Life Care	42	2024-03-01	2027-08-31			■	■	■	■	■	■	■	■	■	■	■	■	■	■
Objective 6: The scientific and public dissemniation for advocacy and best practice	36	2024-09-01	2027-08-31					■	■	■	■	■	■	■	■	■	■	■	■
Objective 7: An outline of a grant proposal to study the CODE-YAA tool impact	18	2026-03-01	2027-08-31											■	■	■	■	■	■
Deliverables				■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Deliverable 1: Completion of interactive website and social media diffusion links.	2	2024-10-01	2024-11-01	■	■														
Deliverable 2: CODE-YAA and quality indicators set completed as reference document.	9	2024-10-01	2025-09-01	■	■	■	■												
Deliverable 3: Scoping, planning and process for influencer award programme defined and completed.	6	2024-10-01	2025-09-01			■	■												
Deliverable 4: Final series of podcasts and Vlogs as tools for best practice implemented.	6	2024-10-01	2025-04-01					■	■										
Deliverable 5: Translation guide for CODE-YAA with glossary completed and ready for implementation.	18	2024-10-01	2025-12-31	■	■	■	■	■	■										
Deliverable 6: CODE-YAA tool finalised and freely accessible	22	2024-10-01	2025-12-31	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Deliverable 7: Country-level reports finalised and published.	12	2025-12-01	2026-09-01					■	■	■									
Deliverable 8: Interim report on the impact of CODE-YAA and statement of future actions.	24	2025-12-01	2026-12-01					■	■	■	■	■	■						
Deliverable 9: Influencer award programme implemented.	36	2025-12-01	2027-06-01							■	■	■	■	■	■	■	■	■	
Deliverable 10: CODE-YAA Action Report on education, palliative care in public health and sustainable development.	24	2026-12-01	2027-06-01											■	■	■	■	■	■
Additional activities	48	2023-09-01	2027-08-31	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Administrative support	48	2023-09-01	2027-08-31	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■