

TECHNICAL ANNEX

1. S&T EXCELLENCE

1.1. SOUNDNESS OF THE CHALLENGE

The increasing population of Europe coupled with the ageing demographics in many European countries means that the overall number of people with dementia is likely to continue to increase significantly. In 2018, 11 million Europeans lived with dementia (1.6% of the European population). In 2050, it is estimated this figure will have almost doubled to 19 million or 3% of the European population¹.

There is currently no effective treatment for the neurodegeneration of dementia, i.e. it is not yet possible to halt or reverse the cognitive decline caused by dementia². Some treatments may temporarily slow down disease progression, but none provide any lasting effect.³ Consequently, care is the most important health intervention for supporting people with dementia and their caregivers and promoting their quality of life.

However, there are profound ethical difficulties involved in caring for people with dementia.^{4 5} The gradual loss of their cognitive abilities complicates retainment of autonomy and agency, and causes a number of ethical care dilemmas, including: balancing safety with freedom; deciding what is in the best interest of the person with dementia; and recognising that the needs of the person with dementia may sometimes conflict with the needs of others, e.g. those of relatives, other residents at care facilities or the like, who also deserve consideration.

Legal frameworks and professional guidelines are helpful in guiding practice and decision-making, but they call for interpretation and application with regards to specific situations and thus cannot provide precise answers to particular ethical problems.⁵

1.1.1. DESCRIPTION OF THE STATE OF THE ART

To address ethical challenges in dementia care, a growing body of ethical research has emerged and several initiatives have been implemented. The research on ethics in dementia focuses on what interests people with dementia have,⁶ research ethics and dementia,⁷ advance directives, advance care planning⁸, and autonomy and personhood,⁹ assistive technologies¹⁰, dignity¹¹ and end-of-life decisions.¹²

Important policy initiatives have also been implemented to address the ethical challenges in dementia care. In 2008, the need for ethical discussion of dilemmas in dementia care was taken up by the European Commission's Alzheimer's initiative. A common reflection on dementia ethics was highlighted as one of the priority areas for European collaboration. It was agreed that greater collaboration on dementia ethics will lead to better ethical practices among people living with dementia and their carers; both formal and informal. In 2009, a network on ethics in dementia was therefore created thanks to initial funding (EUR 60,000) from the German Health Ministry and operation grants of the European Commission. The network, operated by Alzheimer Europe, published ethical reports on various topics, but was discontinued after some years when both the initial funding and the later operation grants expired.¹³

The British Nuffield Council on Bioethics has also addressed ethical issues in dementia and proposed policy recommendations. More than a decade ago, in 2009, the council published a report on dementia ethics in response to the increasing prevalence of dementia in the UK. The report concluded that both formal and informal caregivers for people with dementia needed more support in tackling the ethical

problems they meet on a day-to-day basis than is currently provided. To this end, it presented a new framework aimed at helping people with dementia and their caregivers¹⁴. Over the years, organisations, like national Alzheimer and dementia associations, National Health Authorities, and academic institutes, such as the Hastings Center, have published papers, analyses and strategy plans on ethical issues in dementia, such as end-of-life decisions, informed consent, etc.¹⁵

In addition, some existing dementia research networks and capacity building organizations occasionally address ethical issues in dementia care, e.g. Interdem, a pan-European network of researchers examining psychosocial interventions in dementia¹⁶; and Alzheimer's Disease International, a capacity building organization helping existing and emerging Alzheimer and dementia associations to develop and strengthen their organisations¹⁷. None of them, however, provide systematic development of tools to support ethical decision-making in various European dementia care settings

In general, there is little homogeneity and uniformity within the European system of care as to how to address ethical problems in dementia care, and much of the existing efforts in terms of implementation of country-specific-strategies are centred in non-Central and Eastern European Countries. At present, countries like Slovakia, Romania, Poland, Lithuania, Latvia, Hungary, Estonia, Croatia and Bulgaria do not have dementia plans available¹⁸.

Thus, an unmet need remains for an active network that mobilizes European researchers and stakeholders to research and develop an agile culture and context-sensitive framework to deal with ethical issues in European dementia care. Because of this unmet need, caregivers lack tools and a skill set to make uniform, reflective, ethical care decisions and recommendations across healthcare systems and nations.¹⁹⁻²¹ To be effective in meeting this need and differ from existing networks and institutions, a network would need to have the following scope and structure:

- An exclusive focus on ethical challenges in dementia
- A broad bottom-up approach to mobilizing a heterogeneous group of stakeholders, including formal caregivers, e.g. leaders of homecare services and nursing homes, and informal caregivers, people with dementia, NGOs, policy decision-makers, industry and researchers.
- A strong focus on ensuring representation of Central and Eastern European Countries (CEECs)
- Application of advancements in dementia research and ethical theory to day-to-day dementia care in a broad European healthcare context

This COST Action on Ethics in Dementia (EDEM) will meet such a scope and structure. More broadly, the network will improve the quality and homogeneity of dementia care across Europe, including the quality of care in CEECs, among which only a few countries currently have specific dementia strategies.

1.1.2. DESCRIPTION OF THE CHALLENGE (MAIN AIM)

The main aim of the Ethics in Dementia (EDEM) Action is to promote ethical dementia care beyond the current state of affairs:

EDEM will work (1) to promote dignity, autonomy, and quality of life for people with dementia; (2) to reduce burnout and moral distress among formal and informal caregivers for people with dementia, and (3) to improve the quality and homogeneity of dementia care across Europe, by fostering international collaboration in the field of dementia and ethics, including CEECs. The main COST Action aim is operationalized in objectives centered on:

- **Mapping:** Exploring ethical problems in dementia care in different European contexts and settings and mapping principles and values relevant to addressing these problems within an ethical framework.
- **Development:** Providing a proposal for a European framework for ethics in dementia care in the form of a practical catalogue of principles and values.
- **Recommendations:** Developing policy recommendations on integration of this framework into European healthcare systems and facilities.
- **Education:** Developing an EDEM educational toolkit that helps caregivers of people with dementia make better ethical decisions. The toolkit will be applicable formal caregivers, and equally useful for informal caregivers either at home or in their contact with nursing homes or other institutional settings.
- **European collaboration:** Facilitating long-term work-relations and promoting European research in ethics in dementia among Early Career Investigators (ECI), senior researchers and stakeholders more generally. This is a horizontal objective overarching all other objectives.

1.2. PROGRESS BEYOND THE STATE OF THE ART

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

The Action will achieve its aim through an innovative bottom-up citizen science approach where caregivers, people with dementia, academics and representatives from care facilities, the dementia technology industry and health policy decision-makers, as well as applied and theoretical scientists, will identify key challenges and propose recommendations on how to solve them. This approach has the potential to change current practice through activities based on ethical theory and perceived needs in dementia care. It comprises the following three elements:

- **Stakeholder involvement:** With the citizen science approach, EDEM will involve a multiplicity of stakeholders from different countries and sectors in the process of identifying and analysing the key ethical dilemmas in dementia care. The bottom-up involvement will include formal and informal caregivers, healthcare professionals, health policy decision-makers and representatives from the dementia technology industry. This will ensure identification of the most significant ethical dilemmas and proposals for how to address them, grounded in both theory and practice.
- **State-of-the art research:** The network will engage top researchers within the field to analyse and discuss which principles and values should be included in an ethical framework in order to address the most burning issues in **dementia** care.
- **Change:** The Action will focus on changing the practice of dementia care in two respects: 1) by developing policy recommendations on important values and principles to take into consideration in dementia care: 2) by creating an EDEM educational toolkit for caregivers across Europe on how to address ethical dilemmas, either at home or in specific institutional, cultural and care settings like nursing homes, adult day care centres etc.

EDEM will thus provide a comprehensive and innovative stakeholder informed understanding and analysis of ethical dilemmas, a proposal for a practical framework for addressing these dilemmas as well as policy recommendations and toolkits for training caregivers in how to tackle them either at home or in specific institutional, cultural and healthcare settings.

The strong emphasis on intercountry and cross-sectional stakeholder involvement in the network combined with high-level research will ensure that the network results in innovative outcomes that match previously unmet needs. Moreover, EDEM's focus on recommendations, implementation, education

and change warrants creation of a practical ethical framework and educational tools applicable to specific and culturally diverse healthcare settings.

1.2.2. OBJECTIVES

1.2.2.1 Research Coordination Objectives

The COST Action comprises the following research coordination objectives (RCOs):

- **RCO1. Mapping:** establishing a coherent scientific overview of existing efforts to tackle ethical dilemmas in dementia care in Europe through both a narrative overview of the scientific literature on ethical dilemmas in dementia care and of existing ethical frameworks, i.e. a synthesis of published literature on the topic, describing the current state-of-art, as well as a stakeholder informed mapping and assessment of existing ethical frameworks, e.g. national dementia plans and strategies or guidelines (see 4.1.1, WG1).
- **RCO2. Development:** developing a proposal for a practical European ethical framework that will support formal and informal caregivers in making ethical decisions in dementia care.
- **RCO3. Recommendations:** designing policy recommendations on how to implement the proposal for a practical ethical framework in concrete European cultural contexts and healthcare settings.
- **RCO4. Education:** developing an EDEM educational toolkit that can be integrated into the curriculum of formal caregivers of people with dementia, and which will be equally useful for informal carers (see 4.1.1, WG3).

1.2.2.2 Capacity-building Objectives

The COST Action comprises the following capacity-building objectives (CBOs):

- **CBO1. Common research agenda:** providing a milieu for advancement in knowledge exchange and the creation of a common relevant research agenda on ethics in dementia across the network and Europe in general.
- **CBO2. Bottom-up involvement of stakeholders:** promoting a bottom-up stakeholder involvement and facilitating interdisciplinary collaboration among research institutions, patient associations (NGOs), small and medium-sized dementia technology enterprises (SMEs), care facilities, municipalities and health political institutions. The Action will establish targeted workshops on ethics in dementia and incorporate an action research methodology, pursuing change and understanding at the same time, thus achieving the RCOs of this Action (see. 4.1.1. WG2). This will create opportunities for research institutions, industry, NGOs, healthcare and health political institutions to collaborate on identifying and solving real needs in dementia care.
- **CBO3. Inter-country collaboration:** creating partnerships between research-intensive and less research-intensive nations in Europe, i.e. COST Inclusiveness Target Countries (ITCs).
- **CBO4. Career development:** 1) facilitating career progression, with a specific focus on gender balance and Early Career Investigators, by coordinating short-term scientific missions (STSMs) and facilitating partnerships among PhD students and postdocs and promoting research funding, e.g. Marie Skłodowska-Curie fellowships.
- **CBO5. Empowerment:** incorporating people with dementia's experiences and understanding of the various ethical dilemmas into the Action, by establishing local dialogues with people with dementia.
- **CBO6. Education:** bridging academic, educational and stakeholder expertise to develop innovative approaches to train student nurses and formal caregivers in participating countries.
- **CBO7. Networking:** gaining the support of and joining forces with existing networks, organisations and stakeholders like Alzheimer Europe, Interdem and Alzheimer's Disease

International – as well as medical (neurologists, geriatrician, psychiatrists, general practitioners) nursing and social workers and care organisations in Europe, both at the national and international level.

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

EDEM differs in scope and organisation from existing networks and institutions like Alzheimer Europe, Alzheimer’s Disease International, Interdem, The Hastings Center, or The Nuffield Council on Bioethics.

The scope of EDEM is different from initiatives like Interdem, Alzheimer Europe and Alzheimer’s Disease International, as it focuses exclusively on ethical issues in dementia care and not pharmaceutical, biomedical research and innovation or psychosocial interventions in dementia care²². The practical change-oriented focus of EDEM also sets it apart from both the Hastings Center and the Nuffield Council on Bioethics. EDEM therefore provides a valuable complement to existing efforts in the field.

EDEM also differs in its organisation. The EDEM network will be openly accessible and actively encourage stakeholders to partake in network activities. It will also be a cardinal point of the network for employing interdisciplinary approaches to ethics in dementia care, by establishing close dialogue between various fields of research and dementia care. This Action will thus add value in relation to existing efforts by encouraging stakeholder involvement, providing an educational toolkit for formal and informal caregivers and promoting incorporation of practice experiences in dementia care into research.

In sum, the network both differs from and supplements the work of existing networks and institutions, and will seek to foster collaboration with these networks and institutions to enable knowledge exchange and cross-fertilisation.

2.2. ADDED VALUE OF NETWORKING IN IMPACT

2.2.1. SECURING THE CRITICAL MASS AND EXPERTISE

The COST Action will bring together researchers and key stakeholders from dementia care and ethics from across Europe. It will focus on learning and sharing best practices and experiences across borders, both national and local, and draw on research methods across disciplines.

At the preparation stage of EDEM, an initial critical mass of academic profiles required for reaching RCO1 (Mapping) will be secured, including researchers within dementia ethics, nursing, sociology, cognitive psychology, psychiatry, gerontology and medicine. In addition, the Action has secured broad geographical representation: from Northern, Western, Eastern and Southern European countries; a significant number of early career investigators; and will ensure gender balance. This diverse and inclusive participation will ensure bidirectional transfer of practical interventions, institutional policies and state-of-the-art research methods. This will enable mutual learning across cultures, societies, and healthcare systems.

To unite the critical academic expertise with that of European practice, and in order to secure the critical mass of non-academic stakeholders from, e.g. healthcare facilities, administration and the industry,

the current network will promote further growth of the consortium, by reaching out to relevant stakeholders in the respective countries of the Action (see. 2.2.2). The networks and knowledge of the Action will be utilised to identify additional relevant participants in a snowballing and purposive sampling process, i.e. a process in which Action Members will employ individual networks and judgment when recruiting new Action members.

This COST Action already has, at the proposal stage, several proposers in contact with the care sector, who are thus accustomed to recruiting persons with dementia and formal or informal carers, through ongoing collaboration with the care sector in the respective contexts of the Action Members.

In addition, a dedicated part of WG2 will ensure that strong collaboration and knowledge transfer with the non-academic stakeholders of the Action will be established. The network will thereby function both as a platform for academic discussion of ethical dilemmas, and actively engage non-scientific stakeholders or experts in dementia care, since they, as representatives from the affected target groups, possess privileged insights into dementia.

The Action will actively encourage new members, representing gaps, both in terms of geography, knowledge and expertise, to participate in the Action on the Action's webpage.

2.2.2. INVOLVEMENT OF STAKEHOLDERS

The Action is designed following a bottom-up approach, and consequently has a strong focus on involving relevant stakeholders other than academic researchers working within the field in all phases of the project. Key stakeholders include:

- People with dementia
- Informal caregivers: relatives and other non-professional carers
- Formal caregivers, typically health and social care professionals and direct care workers
- Small and medium-sized enterprises specialised in dementia care, including dementia technology
- Representatives from care facilities (both public and private)
- Local or governmental bodies of oversight and policy
- Relevant patient associations and NGOs within the field

To ensure a balanced representation of all main interests, views and opinions on ethics in dementia care, the Action will apply a three-string approach to stakeholder engagement²³:

- First, the Action will make use of a continuous process of purposive sampling to involve key stakeholders already known to members of EDEM. These stakeholders will be classified according to an interest-influence matrix along two dimensions; interest in the subject at hand, and influence in the processes involved, thereby allowing the identification of key stakeholders that should be targeted, and ensuring that the different voices are represented. Identified stakeholders will be invited by mail and personal contact.
- Secondly, the Action will use the snowball method to further include relevant stakeholders. Proposers will reach out to stakeholders known to them in their respective countries and these will in turn assist in reaching out to other relevant stakeholders, ensuring that informal caregivers also have a say. Stakeholders that have been identified will be invited by mail and personal contact.
- Thirdly, EDEM will make use of open calls. The Action will invite stakeholders to join the network on its website, as well as on proposers' websites, and Action members will be encouraged to post open calls on social media like LinkedIn and Twitter.

The Action will, moreover, promote ongoing stakeholder engagement and involvement by organising the exchange of ideas and needs by the following means:

- Organising scientific meetings and workshops with relevant stakeholders to achieve insight into their perspectives and accommodate needs.
- Establishing a dialogue with public and private care providers and other relevant stakeholders to continuously test the importance of identified dilemmas and ethical principles with practice.
- Collaborating with and creating awareness of the Action among relevant national and international NGOs and interest groups within the field.
- Establishing a network stakeholder advisory board (cf. section 3.2.2 – the plan for dissemination, exploitation and dialogue with the general public or policy).

The abovementioned approach will be operationalised into a detailed stakeholder engagement plan as part of WG2 (see 4.1.1 WG2).

2.2.3. MUTUAL BENEFITS OF THE INVOLVEMENT OF SECONDARY PROPOSERS FROM NEAR NEIGHBOUR OR INTERNATIONAL PARTNER COUNTRIES OR INTERNATIONAL ORGANISATIONS

This Action does not intend to include secondary proposers from non-COST countries. However, international collaboration will be part of the stakeholder engagement plan of EDEM.

3. IMPACT

3.1. IMPACT TO SCIENCE, SOCIETY AND COMPETITIVENESS, AND POTENTIAL FOR INNOVATION/BREAKTHROUGHS

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

This Action aims to promote ethical dementia care by identifying ethical problems in dementia care in different European contexts and settings, and fostering broad knowledge exchange across the network and Europe in general.

Advances in both dementia ethics research and improvements in quality and homogeneity of dementia care across Europe are essential in promoting dignity, autonomy and quality of life for people with dementia across Europe.

The Action is expected to have the following *short- and long-term* impact within the Action's aims:

SHORT-TERM IMPACT

- **Improved awareness.** The Action creates awareness about ethical issues in dementia care and promotes the dignity, autonomy and quality of life of people with dementia, especially among participating nursing homes.
- **Better care.** The Action provides formal and informal caregivers with innovative tools to assist them in their everyday work. This will create better workflows at participating nursing homes and better in-home care among several informal caregivers.
- **Improved working environment.** The action will lead to an improved work environment at participating nursing homes. This will reduce burnout and moral distress among informal and formal caregivers.

- **Policy agenda-setting.** The Action will help put dementia care and ethics on the political agenda in several European countries.
- **Improved European research collaboration.** The Action will be a strong force in advancing the European research agenda on ethics in dementia care, as the EDEM network will facilitate research collaboration across countries.

LONG-TERM IMPACT

- **Improved ethical focus at nursing homes.** The Action's tool-kit has more broadly been integrated into the operation of a number of nursing homes across Europe. As a consequence, the dignity, autonomy and quality of life of people with dementia at these nursing homes has improved.
- **Improved care-competences.** Innovative tools for tackling ethical dilemmas in dementia care, i.e. nursing home care and home-based care, have been developed and implemented in the curricula of informal and formal caregivers across Europe.
- **Reduced burnout and distress.** Fewer informal and formal caregivers experience burnout and moral distress and the general work environment at adult daycare centres, nursing homes etc. has improved
- **Fewer sick days.** Better work environments at care facilities and quality of life among people with dementia lead to fewer sick days among personnel and ensure more efficiently run care facilities.
- **Policy impact.** The ethical framework and white paper of the Action has become part of the health policy agenda in several European countries.
- **Scientific development.** The network has grown and become established. A vibrant research agenda and a solid research collaboration on ethics in health have been established. New projects and research goals have been designed and young researchers have been recruited to the field.

3.2. MEASURES TO MAXIMISE IMPACT

3.2.1. KNOWLEDGE CREATION, TRANSFER OF KNOWLEDGE AND CAREER DEVELOPMENT

The Action will be led by a Management Committee (MC) which will consist of MC Coordinators from participating countries and Working Groups (WGs). The MC will oversee that a plan for knowledge creation, transfer and career development will be established and adequately implemented throughout the Action. The MC will meet once a year, during which measures to maximise scientific and practical impact, e.g. coordination of activities, scientific meetings or possible cooperation, will be discussed and tasks within respective WGs distributed.

Knowledge creation: EDEM will provide a narrative overview of scientific literature on ethical dilemmas in dementia care and of existing ethical frameworks, and generate new perspectives on ethical dilemmas in dementia and how to manage them. This will generate new research ideas, a new framework for understanding ethical issues in dementia care, policy recommendations on how to manage them and new partnerships, both within and outside the Action. The interdisciplinary expertise of the network will identify and seek to close existing knowledge gaps, in establishing cross border and bottom-up collaborations in dementia care.

Knowledge transfer: The Action is based on a citizen science approach. Hence, it requires that all stakeholders, including scholars, policy decision-makers and caregivers, are a part of all phases of the network to identify and analyze central dilemmas, design recommendations and develop a toolkit for educating formal caregivers and supporting informal caregivers. This integration of sectors and of theory

and practice in the structure of the network secures future knowledge transfer between sectors and between theory and practice. Not only will this approach enhance the quality of the outputs of the network and its impact; it will also promote practical and policy uptake of the project results for the benefit of people with dementia and caregivers across Europe. To promote this political uptake, the Action will seek to contribute to public consultation exercises by local Government Departments, correspond directly with local MPs and Peers and in general opportunistically engage in debates and campaigns.

Career development: The aim is to maximise individual potential among network members through relevant training. All training will be delivered within an equity framework to ensure equal access to opportunities for learning, regardless of gender and other personal characteristics and circumstances. As the Action is based on both research and practice, the career development approach has two focus areas:

- Academia – engage young researchers and provide them with the opportunity to improve their research skills through an approach that pays attention to both theory and practice.
- Non-academia – engage informal and formal caregivers and provide them with novel skills and practices that are founded in research.

A senior member of the network will have designated responsibility for designing and monitoring this aspect of the overall activity, and will ensure it is an agenda item at all relevant network meetings. Each network member will consider their potential contribution to these in terms of specialist training reflecting their areas of expertise for individual activities. The person in charge of career development will be entitled to encourage, promote, and help plan research visits and workshops among members.

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

The dissemination plan of the Action will be developed according to the Guidelines for the communication, dissemination and exploitation of COST Action results and outcomes. The Action's dissemination strategy will be managed by the Action's Communication Manager, reporting to the Management Committee (MC). All Action participants contribute to the dissemination and communication of the Action. At the onset of the Action, the MC will appoint the Communication Manager as well as a Communications Officer for each Action member country. Communication Officers will encourage local level dissemination to all relevant stakeholders, e.g., policy decision-makers, the industry, NGOs, and nursing homes.

The Action will disseminate its results via appropriate recipient-oriented outlets to maximise the impact among stakeholders. Since each of the general public and policy decision-makers must be approached differently according to their interests and affiliations, the Action will apply multiple communication tools and strategies, which will be specified in the final dissemination plan of the Action. Hence the main scope of dissemination and exploitation is dual, and each part is of equal importance:

- Policy outreach: The Action targets the EDEM policy recommendations to relevant policy makers in each Action Member Country, and to as many relevant European NGOs, industries, and media as possible.
- Communication with the public: Dissemination and dialogue with the general public. The main public stakeholders include people with dementia, informal and formal caregivers, nursing homes, health professionals, NGOs and citizens.

The Action will make use of the following three communication channels to reach its public and policy stakeholders:

- Website directed at policy and public stakeholders
- Communication to policy decision-makers
- Communication to the public

Website: At the onset of the Action, a dedicated COST Action website will be set up, acting as the Action's main dissemination outlet and tool for dialogue. Content will be posted on the website as the Action progresses. It will comprise a primary site in English with general information for all stakeholders, and secondary sites in native languages for each participating country. The Actions Communication Manager will be responsible for maintaining the primary site and from each participating country a local Communication Officer will be responsible for maintaining their specific country site.

At the main site, news on the start-up, process and results of the network will be announced. This news will include:

- Start-up: A presentation of the COST Action, its objectives and Working Groups (WGs) as well as WG managers and other officials
- Ongoing activities: E.g. reports on STSMs' activities, information and news on relevant symposia and conferences, publications and events and an interactive platform for Action members, e.g. in SharePoint format
- Network results: These will include the developed ethical framework, a white paper with policy recommendations, the toolkit for formal and informal caregivers, publications etc.

At secondary sites, country representatives will be able to communicate with national stakeholders and the general public. Here they can post news that may only be relevant to their country, engage with national policy stakeholders and inform the public stakeholders about network activities, including announcements of national workshops and events.

Communication to policy decision-makers: The Communication Manager and the local Communication Officers will ensure targeted communication to policy stakeholders. This includes developing strategies for contributing to public consultation exercises by local Government Departments, corresponding directly with local MPs and Peers and opportunistically engaging in societal health policy debates and campaigns²⁴.

Communication to the public: This channel will be directed at engaging public stakeholders, including dementia interest groups and patient organisations through, for example, the following exploitation and dissemination activities:

- Establishing a presence on professional social media networks such as LinkedIn and Twitter
- Online content, e.g. YouTube videos
- Communicating and presenting the Action's activities and results via national outlets
- Publishing content in non-scientific outlets, e.g. dementia communities on Facebook, newspaper articles, trade magazines, (e.g. patient organisation newsletters and membership magazines) or local/national TV spots and other appropriate social media.
- Presenting the Action's activities and results at relevant conferences and seminars.
- Hosting inclusive stakeholder workshops throughout the Action.

WG5 will be designated to coordinate Communication and Dissemination oversight and will be led by the Action Communication Manager and attended by the Communication Officers, representatives from all WGs and relevant dementia care stakeholders.

4. IMPLEMENTATION

4.1. COHERENCE AND EFFECTIVENESS OF THE WORKPLAN

4.1.1. DESCRIPTION OF WORKING GROUPS, TASKS AND ACTIVITIES

EDEM will be organised in accordance with the COST Action structure described in the SESA Guidelines. It will consist of a management committee (MC) of the Action responsible for supervising the appropriate use of funds, coordinating activities, expanding the network, knowledge creation, transfer of knowledge and career development and managing results. The MC consists of up to two representatives of each COST Full Member that has accepted the Memorandum of Understanding. The Action will also include a number of positions assigned with the responsibility for promoting keyfocus areas in the Action. These positions include:

- A dissemination and outreach manager
- An early-stage research manager
- An equal opportunities manager

To engage key stakeholders, the Action will also consider setting up an advisory board consisting of relevant NGOs, industry and policy decision-makers, e.g. representatives from Interdem, Alzheimer Europe, national health authorities etc. The advisory board will function as a sparring partner on implementation strategy, communication strategy, design of outlets etc.

The EDEM objectives will be achieved through 5 Working Groups (WGs). All members of the Action will be encouraged to join two or more of the WGs, corresponding to their know-how and scientific interests. The tasks of the WGs will foster mutual knowledge of one another and move toward attaining the common aim of the Action. WG 1 and 2 will run consecutively and merge into WG3 when the deliverables of the WGs have been delivered.

Working Group 1	Mapping of existing efforts to manage ethical dilemmas in dementia care in scientific literature and ethical frameworks
<p>Description: The objective of this WG is to map existing <i>ethical frameworks</i> focused on ethical dilemmas in dementia care, as well as relevant <i>scientific literature</i> and <i>grey literature</i> dealing with ethical issues in dementia care. Findings will be discussed among WG members at regular WG meetings. The WG will result in a state-of-the-art narrative overview of relevant literature and frameworks, which WG 3 can draw on in its work towards developing a practical European ethical framework for dementia care and recommendations on how to implement it.</p>	

Tasks

T1.1: Narrative overview of scientific literature on ethical dilemmas in dementia care and of existing ethical frameworks. The WG manager, with relevant members of the WG, will coordinate the search of literature in relevant databases such as PubMed, CINAHL, ResearchGate etc., as well as grey literature accessed through searches and the snowball method. Narrative overviews focus on creating a quick overview of existing literature. They are far less demanding to carry out than, for example, systematic reviews. The aim of the narrative overview is to provide a thorough but rapid understanding of the existing literature on the subject that can inform the process of developing a proposal for a practical ethical framework on how to deal with ethical dilemmas in dementia care²⁵.

T1.2: Assessment of existing ethical frameworks dealing with ethical dilemmas in dementia care. The aim of this task is to evaluate existing ethical frameworks, identified in the narrative overview, focused on dementia care, in order to determine which components to integrate into the proposal EDEM plans to develop. The assessment will be coordinated by the WG manager and take place at the consecutive meetings in WG1.

T1.3: Synthesise and analyse findings from T1.1 and T1.2 to assess ethical principles and frameworks, including to which extent principles and frameworks have been implemented and their resulting impact.

Combined, T1.1, T1.2 and T1.3 will constitute an inventory which WG3 can draw on in developing a proposal for a practical European framework and recommendations on how to implement it.

Activities:

- Members of the WG will meet twice a year for the duration of the WG.
- At one of the first meetings, a research plan (research design and timetable) for conducting the narrative overview and assessment of existing ethical frameworks will be developed.
- The WG will comprise three scientific workshops (SWS) and include their results in WG meetings: SWS1 focuses on delineating the design of, and assigning responsibilities for writing, the narrative overview. SWS2 focuses on discussing a first draft of the narrative overview. SWS3 focuses on assessing ethical frameworks identified through the narrative overview.
- The WG will initiate two STSMs that will link Early Career Investigators and senior researchers in discussions of relevant ethical principles and precedent European frameworks.
- The WG will disseminate its findings to WG3 and WG4. This will enable them to incorporate the findings in developing a practical European framework and recommendations for how to implement it.

Milestones

M1.1: Pre-startup WG meeting with appointment of WG1 Chair, roles and structure. (ITC members will be encouraged to assume a leadership position as WG Leader or STSM Coordinator) (Y1Q1) M1.2:

Development of research plan (Y1Q1)

M1.3: Narrative overview of relevant scientific literature (Y1Q2-Y3Q2)

M1.4: Assessment of existing ethical frameworks (Y1Q2-Y3Q2)

M1.5: Advertise, engage & establish 2 STSMs (one each under M1.3 and M1.4) (Y2Q1, Y2Q3)

M1.6: Bi-annual WG meetings (Y1Q2, Y1Q4, Y2Q2, Y2Q4, Y3Q2)

M1.7: Three scientific workshops analysing findings from M1.3 and M1.4. (Y1Q2, Y1Q4, Y2Q2)

M1.8: Annual and final reports of WG progress (Y1Q4, Y2Q4, Y3Q2)

Deliverables

D1.1: A narrative overview of the scientific literature on ethical principles in dementia care

D1.2: An assessment of existing ethical frameworks dealing with ethical dilemmas in dementia care

D1.3: 2 Summary reports or publications based on STSM activities

Working Group 2	Mapping of perceived ethical dilemmas in dementia care
<p>Description: The objective of WG2 is to incorporate perspectives from relevant stakeholders into the process of developing a practical European ethical framework and recommendations on implementation. The WG will promote stakeholder involvement and facilitate interdisciplinary collaboration among research institutions, patient associations, industry, political institutions, caregivers and people with dementia. The WG will inform and qualify discussions and design of tools with real-life experiences, and hence enhance the practical appropriateness of the deliverables of the Action.</p>	
<p><i>Tasks</i></p> <p>T2.1: Developing an appropriate stakeholder engagement plan.</p> <p>T2.2: Mapping practice needs by</p> <ul style="list-style-type: none"> • Arranging workshops with stakeholders, e.g. people with dementia, formal and informal caregivers, patient organisations, industry, health policy decision-makers etc. • Identifying practical and educational needs among relevant stakeholders <p>T2.3: Empowering people with dementia by incorporating their experiences and understanding of the various ethical dilemmas into the Action, by establishing local dialogues with people with dementia</p> <p>T2.4: Transferring the knowledge produced that WG3 can draw on in developing a practical European framework and recommendations for how to implement it.</p>	
<p><i>Activities</i></p> <ul style="list-style-type: none"> • Members of the WG will meet twice a year for the duration of the WG. One of the first meetings will focus on designing a plan for involving relevant stakeholders in all participating countries (see 2.2.2 for recruitment strategies). • Representatives from each country participating in the WG will conduct 1-3 workshops and/or a number of interviews with relevant stakeholders, e.g. from local NGOs, health professionals, health authorities etc. The data collection will be conducted prior to WG2 meetings, to inform the WG on practice needs and perspectives in different countries. The workshops will be conducted in accordance with “the theory of change workshop methodology”²⁶. In this type of workshop, the participants identify the main stakeholders that might influence or have an interest in the desired impact. The participants then engage in backward mapping and identify the short- and medium-term outcomes that can lead to the desired impact. The result is represented using the ‘roadmap to change’ – a map that shows the various rigorously and consequentially structured outcomes and the preconditions for them. Interviews will be informal in character but use a semi-structured interview guide to explore practice needs and perspectives. <p>The combination of these initiatives will promote stakeholder involvement in the Action and produce data for a white paper on practice needs and submission of an intercountry journal editorial or commentary.</p>	

Working Group 3	Development of ethical framework and policy recommendations
<p>Description: The objective of WG3 is to synthesise results from WG1 and WG2 and create a proposal for an integrated practical European ethical framework and recommendations on how to implement it in different cultural healthcare settings.</p>	
<p><i>Tasks</i></p> <p>T3.1: Synthesise results from WG1 and WG2.</p> <p>T3.2: Develop a proposal for a practical ethical framework on how to deal with ethical dilemmas in dementia care based on knowledge from WG1 and WG2.</p> <p>T3.3: Develop policy recommendations on how to implement the developed ethical framework in individual European healthcare systems.</p>	
<p><i>Activities</i></p>	

- Members of the WG will meet twice a year for the duration of the WG
- The WG will conduct two scientific workshops, drawing on insights from WG1 and WG2
- WG3 will organise two STSMs with specific emphasis on young researchers, hence encouraging agility and career progression for ECIs.

Milestones

M3.1: Pre-startup WG meeting with appointment of WG3 Chair, roles and structure. (ITC members will be encouraged to assume a leadership position as WG Leader or STSM Coordinator) (Y3Q2)

M3.2: Bi-annual WG meetings. (Y3Q3, Y4Q1, Y4Q3)

M3.3: Two STSMs connecting professionals and academics on the issues of European ethical recommendations for dementia care. (Y3Q4, Y4Q3)

M3.4: Two scientific workshops (with international participation) discussing ethics in dementia. (Y3Q3, Y4Q1)

M3.5: Develop a proposal for a practical European framework on how to deal with ethical dilemmas in dementia care (Y3Q3-Y4Q4)

M3.6: Develop recommendations on how to implement the ethical framework in individual European healthcare systems. (Y3Q3-Y4Q4)

M3.7: Annual and final reporting of WG progress. (Y3Q4, Y4Q4)

Deliverables

D3.1: A proposal for a practical European framework on how to deal with ethical dilemmas in dementia care, published on the Action website

D3.2 Recommendations on how to implement the ethical framework in individual European healthcare systems, published on the Action website

D3.3: Two summary reports or publication based on STSMs activities

Working Group 4	Education
Description: The objective of WG4 is to develop an EDEM educational toolkit that enables formal and informal caregivers to incorporate ethical perspectives and concepts in their care of people with dementia.	
<i>Tasks</i>	
<p>T4.1: Develop an EDEM educational toolkit that can be integrated into the curriculum of formal caregivers of people with dementia and provide support for informal caregivers when face with ethical issues.</p> <p>The toolkit will be uploaded to and made accessible on the EDEM website.</p>	
<i>Activities</i>	
<ul style="list-style-type: none"> • Members of the WG will meet annually for the first two years and subsequently bi-annually for the remainder of the duration of the WG. • Representatives of the WG will be present at two WG2 workshops with formal and informal caregivers, gathering information about educational and support needs. 	
<i>Milestones</i>	
M4.1: Annual/bi-annual WG meetings (Y1Q2, Y2Q2, Y3Q2, Y3Q4, Y4Q2, Y4Q4)	
M4.2: Two attendances at WG2 workshops with formal caregivers to people with dementia in countries participating in the network (this will be done within the established WG2 stakeholder contacts) (Y1Q3, Y2Q1)	
M4.3: Annual and final reporting of WG progress (Y1Q4, Y2Q4, Y3Q4, Y4Q4)	
<i>Deliverables</i>	
D4.1: EDEM educational toolkit that can be integrated into the curriculum of formal caregivers of people with dementia and provide support for informal caregivers.	

Working Group 5	Exploitation and dissemination
<p>Description: The objective of WG5 is in part to communicate and disseminate scientific information via publication outlets, aimed at a general public, and in part to present policy makers with key outcomes of EDEM's work, hence maximising the outreach of EDEM's work for the benefit of dementia care stakeholders. EDEM will encourage and help Open Access publishing.</p>	
<p><i>Task</i></p> <p>T5.1: Promote joint dissemination and communication of knowledge and experiences of EDEM. T5.2: Ensure continuous dissemination and exploitation of information from EDEM via accessible, user-friendly websites, as well as social media outlets, including the following:</p> <ul style="list-style-type: none"> • Develop an interactive website available to the public, with a reserved file sharing platform for Action members. • Establish an advisory board of relevant representatives from various patient organisations in Action member countries. 	
<p><i>Activities</i></p> <ul style="list-style-type: none"> • Members of the WG will meet once a year and coordinate efforts. • Representatives from WG5 will be available to assist strategic dissemination and communication for other WGs. 	
<p><i>Milestones</i></p> <p>M5.1: Pre-startup WG meeting (Y1Q1) M5.2: Launch of website (Y1Q2) M5.3: Annual WG meetings (Y1Q3, Y2Q3, Y3Q3, Y4Q3) M5.4: Gather representatives from relevant patient organisations in Action member countries to EDEM Advisory Board. (Y1Q2-Y1Q4) M5.5: Annual dissemination of Action results, newsletters, communicated by all participants, including the EDEM Advisory Board, via their respective channels. (Y1Q4, Y2Q4, Y3Q4, Y4Q4)</p>	
<p><i>Deliverables</i></p> <p>D5.1: A COST Action website D5.2: Annual dissemination and communication of the Action in all participating countries D5.4: A fully updated website with Action material, e.g. practical ethical framework, recommendations for implementation and the educational toolkit on ethical dilemmas in dementia care</p>	

4.1.2. DESCRIPTION OF DELIVERABLES AND TIMEFRAME

#	Title of deliverable	Variety	Deadline
D1.1	Narrative overview of scientific literature and frameworks on ethical principles in dementia care	Publication (e.g. journal paper or commentary)	Y3Q2
D1.2	An assessment of existing ethical frameworks dealing with ethical dilemmas in dementia care.	Publication (e.g. journal paper or commentary)	Y3Q2
D1.3	Two Summary reports based on STSM activities	Publication (Action website)	Y2Q1, Y2Q3
D2.1	Stakeholder engagement plan for how to precisely involve the stakeholders in the Action	Action Strategy	Y1Q1

D2.2	White paper on practice needs	Publication (editorial or commentary)	Y3Q2
D2.3	Submission of a scientific paper on perceived ethical dilemmas in dementia care	Publication (submission)	Y3Q2
D3.1	Proposal for a practical European framework on how to deal with ethical dilemmas in dementia care, published on the Action website	Publication (Action website and possibly journal paper, letter or editorial)	Y4Q4
D3.2	Recommendations on how to implement the ethical framework in individual European healthcare systems	Publication (Action website)	Y4Q4
D3.3	Two summary reports based on STSM activities	Publication (Action website)	Y3Q4, Y4Q2
D4.1	EDEM educational toolkit that can be integrated into the curriculum of formal caregivers of people with dementia and equally helpful for providing support for informal caregivers.	Toolkit (published Action website)	Y4Q4
D5.1	A COST Action website	Dissemination	Y1Q2
D5.2	Annual dissemination of Action in all participating countries.	Dissemination	Y1Q4, Y2Q4, Y3Q4
D5.4	A fully updated website featuring Action material.		Y1Q2-Y4Q4

4.1.3. RISK ANALYSIS AND CONTINGENCY PLANS

The vast majority of the EDEM activities involve little substantial risk, because they utilise firm practices, such as workshops, a narrative overview of scientific literature and scientific and white papers. Moreover, the Action includes a large number of experienced researchers with large individual and institutional networks, some of which have already established cooperation.

However, there are some risks associated with the Action. The following inventory of risks (risk level in parenthesis) includes a description of each risk and the proposed risk mitigation and contingency measures.

	Risk	Mitigation	Response
Scientific risks	Inadequate knowledge flow from WG1 and WG2 to WG3 (low)	The dissemination manager will seek to improve communication between groups.	STSM or scientific workshop might be employed to enhance collaboration and communication.
	The Action does not achieve deliverables or only provides low-quality deliverables (low)	Responsible WGs will be requested to improve the quality of the deliverable.	If critical mass for quality deliverables cannot be obtained within the WG, other WGs will be involved.

Network	Low participation from stakeholders (low)	Action participants, national communication managers and healthcare professionals will recruit stakeholders.	Action dissemination manager will coordinate recruitment procedures.
	Diversity, gender balance and inclusion of ECIs not achieved (medium)	Distinct initiatives will be employed to promote diversity in participation in the activities.	Systematically reaching out to women or other underrepresented groups in science
Management and dissemination	Hold-up in completion of deliverables (medium)	Coordinate efforts between WG leaders and MC to safeguard compliance with the timeframe. Take measures in reassigning deliverables if non-compliance occurs.	A replacement will be allocated to the delayed task.

4.1.4. GANTT DIAGRAM

Activity	Year 1				Year 2				Year 3				Year 4			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
WG1 Mapping of scientific literature and ethical frameworks																
M1.1: Pre-startup WG meeting																
M1.2: Development of research plan																
M1.3: Narrative overview of relevant scientific literature													D1.1			
M1.4: Assessment of existing ethical frameworks													D1.2			
M1.5: STSMs						D1.3	D1.3									
M1.6: Bi-annual WG meetings																
M1.7: Scientific workshops																
M1.8: Annual and final reports																
WG2 Mapping of perceived ethical dilemmas in dementia care																
M2.1: Pre-startup WG meeting	D2.1															
M2.2: Bi-annual WG meetings																
M2.3: Stakeholder workshops																
M2.4: Online dementia platform																
M2.5: Annual and final reports													D2.2			
													D2.3			
WG3 Development and recommendations																
M3.1: Pre-startup WG meeting																
M3.2: Bi-annual WG meetings																
M3.3: STSMs																
M3.4: Scientific workshops																
M3.5: Development of proposal (for ethics framework)																D3.1
M3.6: Development of recommendations (for implementation)																D3.2
M3.7: Annual and final reports																
WG4 Education																
M4.1: Annual/bi-annual WG meetings																
M4.2: Attendance at WG2 workshops																
M4.3: Annual and final reports																D4.1
WG5 Exploitation and Dissemination																
M5.1: Pre-startup WG meeting																
M5.2: Launch of website			D5.1													
M5.3: Bi-annual WG meetings																
M5.4: Gather representatives to EDEM Advisory Board				D5.3												
M5.5: Annual dissemination of Action				D5.2				D5.2					D5.2			D5.4