

# Communication Plan for COST Action CA21137 – Ethics in Dementia (EDEM)



The management Committee (MC) of the COST Action CA21137 “Ethics in Dementia” (EDEM) adopts this Communication Plan. The Plan reflects the Memorandum of Understanding (MoU) in connecting to the aims and objectives of the Action. The Communication Plan, including progress on implementation, will be discussed on a yearly basis by the Action MCs and reviewed or amended when necessary. The Communication plan is developed, updated and its implementation monitored under the overall supervision of the Science Communication Coordinator, in close collaboration with other relevant contributors.

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## 1. SUMMARY

This document describes the dissemination and communication plan for COST Action CA21137 “Ethics in Dementia” (EDEM), including the different tools, channels and means of communication that will be implemented throughout the Action’s duration.

The plan contains the main strategic and operative guide that shall govern the overall Action dissemination and communication activities. These guidelines will help to ensure that relevant information is shared with appropriate audiences on a timely basis by the most effective means. The dissemination activities will be continuously monitored during the Action. The main objective of the communication activities is to raise awareness about the Action activities and disseminate information in a consistent and coherent manner about its results and to maximize its impacts.

The responsibilities of the dissemination and communication activities are organized within the Action according to the MoU. **Work Group 5 is dedicated to Dissemination and Communication of the Action and its results. The Science Communication Coordinator and the Work Group 5 leader coordinate all activities,** in close collaboration with the core group of the Action.

## 2. ACTION DESCRIPTION

The main aim and objective of the EDEM COST Action is to promote ethical care beyond the current state of affairs. Specifically, 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.

In reaching these goals, the EDEM COST Action will apply a bottom-up citizen 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. The following three elements serve as the basis for the approach:

- **Stakeholder involvement**
- **State-of-the-art research**
- **Change generation** – through the development of policy recommendations and by developing an EDEM educational toolkit for caregivers across Europe.

The target groups involved in the communication and dissemination actions will be part of the following categories:

### **Scientific community**

- Research institutes and universities

### **Non-scientific community:**

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- Dementia care stakeholder organizations
- General public
- Policy makers EU/National level/local level
- Media
- Relevant students from universities and high schools

### 3. WORKING GROUP 5

**Working Group 5 is devoted to the dissemination and communication activities of the Action.**

#### WG5 Objectives

The objective of WG5 is in part to communicate and disseminate scientific information via publication outlets, aimed at the general public, and in part to present policy makers with key outcomes of EDEM's work, and hence maximizing the outreach of EDEM's work for the benefit of dementia care stakeholders.

#### WG5 Tasks

**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:

- Develop an interactive website (a comprehensive “**knowledge hub**”) available to the public, with a link to reserved file sharing platforms for Action members.
- Establish an advisory board of relevant representatives from various patient organizations in Action member countries.

#### WG5 Milestones

**M5.1.** 2<sup>nd</sup> year WG meeting (Y2Q1)

**M5.2.** Launch of website (Y1Q2 - finished)

**M5.3.** Annual WG meetings (Y1Q3, Y2Q3, Y3Q3, Y4Q3)

**M5.4.** Gather representatives from relevant patient organizations in Action member countries to EDEM advisory board (Y1Q2-Y4Q4)

**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)

#### WG5 Deliverables

**D5.1.** A COST Action website

**D5.2. Starting in the 2<sup>nd</sup> year of the Action,** annual dissemination and communication of the Action in all participating countries.

**D5.3.** 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.

**D5.4.** Report on activities within the Action (Q16).

## 4. PLAN FOR THE COMMUNICATION OF ACTION RESULTS

Beyond the implementation of the usual means (such as a comprehensive web site, or scientific social networks), special attention will be paid to the methodologies and instruments utilized by members of the Action. Some participants have valuable experience in dissemination and communication activities but acting in collaboration with communication professionals will be encouraged. Further, the use of short video documentaries that will be used while communicating with different target groups will be strongly supported and encouraged. The same means will also be used to facilitate communication and collaboration with stakeholders and policy makers.

COST Action EDEM aims to achieve, within its action duration (4 years), the following communication objectives:

- To manage the communication network of EDEM
- To organize and continuously manage WG5 to verify the content to be communicated and/or disseminated and approve the target groups to be addressed
- To take all necessary actions to communicate the activities and results of the project
- To participate in symposia, workshops, meetings
- To create and continuously enrich a dedicated website for EDEM
- To create, in collaboration with the MC, all necessary communication tools to a visual identity for the Action (logo, ppt, word, pictures, etc.)
- To ensure the proper communication and dissemination of information generated by the project to relevant stakeholders and the general public
- To facilitate communication systems within the on-going Action as well as other relevant COST Actions and professional and civil organizations, in order to promote data sharing related to the focus of the Action

### Communication platforms

#### Website

Our website ([www.ethicsindementia.org](http://www.ethicsindementia.org)) serves as the major communication and dissemination hub, and includes news items and general information on objectives, WGs, and events. It will also hosts the key deliverables of the Action, e.g. it contains the list of papers published and training materials used. Finally, it will serve as the central contact point for all COST Action EDEM participants. The website of the Action also provides a unique portal to the dissemination of research results to the general public and stakeholders.

### Social media

In addition to the website, the Action will have accounts on Twitter and Facebook, to target different groups of stakeholders. Communication via these platforms includes news on recent achievements, upcoming events and opportunities (conferences, workshops, training schools, publications, reports, etc.). In addition, the Action's social media profiles serve as a direct communication platform via live tweets and posts during conferences and MC meetings as needed.

### Plan for visual identity

The WG5 Leader and the Science Communication Coordinator, together with the MC, has already selected, the logo of Action. Additional visual identity items have also been developed and approved to promote COST Action EDEM. The materials available include the logo, word template and powerpoint presentation template (for presentations and posters). However, using these templates will not be mandatory but only recommended.

## 5. PLAN FOR THE DISSEMINATION OF ACTION RESULTS

This Action will be accompanied by the following scientific dissemination tools: journal publications, one or more books, collaborative special issues, conferences, workshops, and schools specifically devoted to the training of young researchers.

Training schools will be organized. The main themes that are currently planned are:

- Ethical theory and principles important to dementia care
- Theory of Person Centered Care and its application to dementia care
- Current issues/changes in ethical theory used to guide health care/dementia care in the EU
- Communication Limitations and ethical questions
- Ethical issues related to the use of AT (Assistive Technology) in dementia care
- Organizing and managing national and trans-national networks/trainings about ethics in dementia care

This Action aims to achieve, within its action duration (4 years), the following dissemination objectives:

- To take all necessary actions to disseminate the activities and results of the Action.
- To disseminate action materials to the widest audience of the general public, to raise awareness around the action topic and create an interest among the audience.
- To increase action awareness via the use of informational and promotional materials (newsletters, flyers, brochures, leaflets etc.) in workshops or conferences in which EDEM will participate.
- To publish a thematic volume with the results of the objective with an integrated comparative view of the different approaches.
- To integrate in a holistic view the different approaches and related results published in peer reviewed publications.
- Publication on best practices/new results particularly oriented to application in health care.
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The Action promotes the Open Science and Open Access approach (e.g., openness, accessibility, adherence to FAIR principles, IPR to Action activities, (expected) results and outputs.

In general, when submitting manuscripts associated with EDEM topics, the authors will acknowledge COST which is very important for the Action success, and obligatory for any form of direct support, and especially for results associated with STSMs. The following sentences, which are in line with COST instructions on acknowledgements, **are highly recommended (but not compulsory)**:

- For works at least partially inspired by exchanges fostered by an Action or benefiting from the coordination provided by an Action, regardless of the number or the status of authors, use the following text: “The author(s) would like to acknowledge the contribution of the COST Action CA21137, supported by COST (European Cooperation in Science and Technology).”
- For works co-authored by at least two Working Group/Management Committee members from at least two different countries participating to the Action: “The author(s) would like to acknowledge networking support by the COST Action CA21137, supported by COST (European Cooperation in Science and Technology).”
- For outputs of Short-Term Scientific Missions: “This work was supported by a STSM Grant from COST Action CA21137, supported by COST (European Cooperation in Science and Technology).”



## 6. RISKS AND MITIGATION MEASURES

<b>DESCRIPTION OF THE RISKS</b>	<b>PROPOSED RISK-MITIGATION MEASURES</b>
Low level of engagement/disengagement of the Action members.	Ensure frequent and equal interaction with all Action members to obtain regular updates.
Low level of awareness about the activities of EDEM from the targeted audiences.	Regular updates on the Actions activities on the EDEM Webpage and Social Media Platforms.
Lack of structure in the communication activities.	Set-up regular editorial meetings with the Core Group members to define the content and schedule of communication activities.
Underuse of the visual templates that advertise the Action (templates and/ or formats of documents, reports, etc.)	These tools are made available on the EDEM website. Their use is much encouraged, but non-compulsory. The Science Communication Manager will monitor their use throughout the Action and will intervene to encourage the use of these tools, where necessary.
Insufficient effort by partners to publicize the Action and its results at National/European level.	The Science Communication Manager will monitor effort at regular intervals.
Lack of interest by stakeholders' groups in the Action	Efforts will be made throughout the lifecycle of the Action through meetings, workshops etc. to engage and interact with stakeholders to prevent or correct such incidences.

## 7. ROLE OF THE PARTNERS

The Science Communication Coordinator, in close cooperation with the Chair and Vice-chair of the COST Action EDEM, will be responsible for the Action dissemination and communication plan, guarantee consistency in the messages delivered and ensure all the targets are successfully reached. **All Action partners will contribute to the implementation of the stakeholder and public engagement strategy and play a key role in networking with stakeholders.**

As defined in MoU, WG5 will lead dissemination and communication activities of the EDEM action. The roles of WG5:

- To manage the communication network of EDEM.
- Organize partners' participations in symposia, workshops, meetings taking place at European level.
- Organize targeted information sessions at non-COST conferences.
- To disseminate all relevant information to the widest audience of the general public to promote greater public engagement and dialogue between the scientists and society.
- To ensure the proper communication and dissemination of the information generated by the action to relevant stakeholders and the general public.

Specifically, the Action participants will themselves be responsible for:

- Creating bridges between the Action and the national/local networks they are involved in;
- Providing input to the content of the Action website, communication materials and mediachannels;
- Translating relevant action documents to national languages;
- Disseminating the activities and results of the Action through to own social media channels;  
Disseminating the activities and results of the Action at events/fairs where they participate.

## 8. ADDENDUM ON STAKEHOLDER INVOLVEMENT

### Stakeholder Engagement Plan for involving stakeholders in Ethics in Dementia (EDEM) COST Action

#### Introduction

The Ethics in Dementia (EDEM) COST Action responds to the challenge of how to address ethical issues in dementia care in a European context. EDEM's primary aim is to alleviate burnout and moral distress or uncertainty amongst both professional and family caregivers, while enhancing dignity, autonomy, and quality of life for people living with dementia. Recognizing the complex nature of ethical care issues and the many stakeholders involved, EDEM seeks to make a meaningful impact on the broader context of dementia care through collaboratively engaging such stakeholders. By actively engaging a diverse set of stakeholders throughout the course of the Action, EDEM will develop a framework, comprising of an organised set of ethical principles and recommendations, as well as an educational toolkit, pertinent to ethical decision-making in dementia.

For more information on Ethics in Dementia (EDEM) COST Action and its objectives and deliverables, read the Project Description MoU.

#### Purpose and Intended Audience

This document serves as an introductory guide to the stakeholder engagement in EDEM and provides an overview of who the various stakeholders are, how we encourage the Action members to engage them, as well as the level of influence we expect the respectively stakeholders to have in the Action. This document is tailored members of the EDEM COST Action, who in the coming years will work toward meeting the primary aim of the Action – a process in which stakeholder engagement is essential.

The document should be considered a living document, which should be guide the decisions pertaining to involving various stakeholders in the action and meeting the objectives and deliverables of the Action.

#### Stakeholder Engagement and Analysisü

EDEM will adopt a broad approach, in terms of stakeholder engagement, to achieve its objectives and deliverables. Throughout the Action we will identify key stakeholders and involve them in the Action. This is accomplished by organising stakeholders on an interest-influence matrix, i.e., classifying stakeholders according to their interest and influence of the Action. In this way, we aim to ensure a balanced representation of all interests, views, and establish an inclusive engagement framework that is sensitive to the varying levels of interest and influence among stakeholders of the Action. The stakeholder analysis and mapping should be viewed as an evolving framework. Therefore, we invite continuous expansion through snowball and purposive sampling of relevant stakeholders known to members of the Action and stakeholders involved in the action.

Stakeholder influence	<i>Low interest/high influence</i>	<i>High interest/high influence</i>
	<ul style="list-style-type: none"> <li>• Entities providing funding for dementia care research and initiatives.</li> <li>• COST association</li> <li>• Media organizations interested in reporting on advancements and challenges in dementia care ethics.</li> </ul>	<ul style="list-style-type: none"> <li>• People with dementia</li> <li>• Academic researchers within related fields of dementia care, nursing, geriatrics and ethics.</li> <li>• Representatives from care facilities (both public and private)</li> <li>• Relevant patient associations and NGOs within the field</li> <li>• Family and non-professional caregivers</li> <li>• Professional caregivers, e.g., health and social care professionals, and direct care workers</li> <li>• Educational Institutions, e.g., schools involved in training healthcare professionals and caregivers.</li> </ul>
	<i>Low interest/low influence</i>	<i>High interest/low influence</i>
	<ul style="list-style-type: none"> <li>• Professionals with expertise in healthcare law, bioethics, and legal considerations in dementia care.</li> </ul>	<ul style="list-style-type: none"> <li>• Local or governmental oversight and policy bodies</li> <li>• Small and medium-sized enterprises specializing in dementia care, including dementia technology.</li> <li>• National and regional health departments responsible for policy and regulation in healthcare.</li> <li>• Larger healthcare organizations or medical centers involved in dementia care.</li> <li>• Associations representing healthcare professionals, caregivers, and other relevant groups.</li> </ul>

Stakeholder interest →

**Stakeholder interest**

In the above interest-influence matrix, we have identified key stakeholders and priority will be given to engaging stakeholders with high interest and high influence in the Action. We will work toward actively engaging these stakeholders as key collaborators throughout the Action. Despite the limited influence of high interest/low influence stakeholders, we also encourage all members of the Action to continuously engage those in their work. In respect to low interest stakeholders, regardless of their influence, they should be periodic engaged, but mainly to ensure minimal disruption of the Action or meeting specific project needs.

**Stakeholder Engagement Approach:**

Stakeholder engagement will be versatile, combining a structured approach, where stakeholder involvement will be discussed at MC meetings, in which ad hoc strategies for engagement will be settled, with decentralized methods in the Working Groups (WG) and WG Subgroups. Strategies include:

- I. Regular discussions on MC meetings to plan stakeholder engagement activities, to gather specific insights in relation to the ongoing work in the Action.ü
- II. Ongoing engagement and continuous dialogue with practice to address real-world challenges, including caregivers, professional and family and schools involved in training healthcare professionals and caregivers.
- III. Partnerships with relevant organisations or NGOs for broader project impact. Here we encourage network leverage for increased collaboration and awareness of the Action.

**This Stakeholder Engagement Plan aligns with project goals, ensuring flexibility, in respect to the needs in the specific WGs and fostering meaningful collaboration in the EDEM project.**