# Minutes of the Management Committee CA21137 Ethics in Dementia (EDEM)

# *Malta, 11th of April 2024*

Date: 11/04/2014, 9.30-12.00

Location: Hybrid (University of Malta, Valletta Campus and online)

Referent: Frederik Schou-Juul

## Welcome to Malta by Anthony Scerri

Anthony warmly welcomed all attendees to Malta, providing essential logistical information and offering a brief overview of Malta's history and the University.

## Brief updates from Sigurd Lauridsen (participating online) and Kate Irving – 30 minutes

**Main achievements last year**

Kate Irving expressed gratitude for the collective efforts of the group and provided updates. Currently, there are 5 Working Groups (WGs) with over 8 subgroups actively engaged in their respective tasks. The total membership stands at 191 individuals. However, several countries, such as Bosnia, Germany, and Latvia, have only one Management Committee (MC) member, and there is a need for additional MC members from various countries, including Finland and Bulgaria.

Last year, a training school was held in Lithuania, and another is planned for this year in Poland.

**Additional funding**

During the meeting, Kate highlights an opportunity for additional funding of the network, approximately €39,000, which must be spent before October. Discussion ensues on how to allocate this funding, with Kate proposing ideas such as a significant Working Group (WG) event, dissemination efforts, or a stakeholder meeting. There is a general agreement that some of the funding may be allocated to a stakeholder meeting, especially pertinent to WG2, given the impracticality of expecting certain stakeholders to contribute without being compensated. Daniel emphasizes the need for meetings with national organizations and other stakeholders, while Sara from COST clarifies that the Management Committee (MC) has the authority to decide how to spend the additional funding, stressing that activities must align with the Action's objectives.

There is also support for organizing a large WG meeting. While nobody initially agrees to host such meeting, Veselin suggests hosting this meeting in Belgrade, combining it with a conference.

Diana proposes allocating funds to actively reach out to countries currently absent from the COST Action, although there's concern about diluting network funding. Sara suggests addressing this aim through dissemination efforts within the existing budget.

No precise decision is made on how to allocate the funding.

**Upcoming plans**

## During the meeting, the following meeting strategies for the upcoming year are decided:

## MC/WG Joint Meeting: Yesim confirms hosting the meeting in Istanbul in September 2025.

## Core Group/Training School: Rodrigo agrees to host the meeting in Barcelona in April/May 2025.

## Sara from COST emphasizes the importance of issuing all invitations for WG meetings, including online ones, through e-COST to track the action's progress. She also notes that budget can also be allocated for online meetings.

## Brief updates on work of the WG1

Rodrigo gives a brief update on the progress of the WG1. He explains that there are currently 124 members from 31 countries, in 5 different groups. For of the subgroups are active (1-4).

**Umbrella Review (Task Force Group 1):**

Anthony provides a comprehensive update on the progress of Task Force Group 1. Currently consisting of 11 members, the group is focused on elucidating ethics issues surrounding the utilization of assistive technology. Over the past year, the team has conducted five meetings to advance their objectives. Employing Rayyan, a systematic review software, they have meticulously removed duplicate references. The initial screening of references involved six members, followed by a secondary screening conducted by Anthony and Adrienne to resolve any conflicting or ambiguous articles. Christian undertook the task of reviewing additional studies, culminating in the identification of 15 relevant reviews. The team is pleased with the steady progress of their work.

**Scoping Review (Task Force Group 2):**

Rodrigo offers insights into the advancements made by Task Force Group 2. The protocol for the scoping review has been successfully published on the Open Science Framework (OSF). Comprehensive searches across five databases have been completed, and all references have been meticulously identified. Moving forward, the team will proceed to the next phase of the study, which involves screening titles and abstracts. To streamline this process, they will leverage COVIDENCE in collaboration with Diana and Thomas from UCN. The anticipated completion date for this phase is April 2025.

**European National Dementia Strategy Study (Task Force Group 3):**

Frederik delivers an overview of Task Force Group 3's work so far. The primary objective of this study is to explore the ethical foundations underlying European National Dementia Strategies and ascertain whether the strategies refer to established ethical frameworks. The forthcoming analysis is scheduled to commence in the spring of 2024 and continue until September 2024. A total of 20 actively engaged members will participate in thematic synthesis, contributing to either the direct analysis of European strategies (phase 1) or the analysis of the analyses of the European strategies (phase 2).

**Review of Legal Documents (Task Force Group 4):**

Task Force Group 4's objective is to identify ethical principles embedded within legal literature. Currently, the group is finalizing revisions to their protocol. Key considerations revolve around determining the methodology for quality assessment and evaluating legal sources. To gauge the feasibility of their proposed search parameters, the team conducted a pilot search, resulting in ongoing deliberations regarding the scope of the review. Among the considerations are suggestions for conducting analyses at the national level, incorporating international sources, and utilizing a checklist for legal documents. Discussions are ongoing to refine the focus of the review and ensure its alignment with the group's objectives.

## Brief updates on work of the WG2

Daniel provides an overview of the WG's overall progress, highlighting its current composition of 109 members representing 27 countries, organized into four sub-groups with diverse focuses on addressing the needs of stakeholders involved in dementia care. The overarching objective is to systematically explore, map, and analyse ethical issues experienced by these stakeholders, culminating in the development of an evidence-based framework to inform the work of WG 3.

**Systematic Review of Qualitative Studies:**

In our systematic review, we aim to delve deep into the qualitative data available to uncover the ethical dilemmas encountered in dementia care by all stakeholders involved. Our search encompasses a wide array of studies, and we've already initiated our exploration with searches in CINAHL and MEDLINE. Moving forward, we'll cast our net wider, targeting six databases, including PsycINFO and SCOPUS, to ensure a comprehensive analysis.

**Comparative Study:**

Our comparative study sets out to explore and contrast how ethical issues manifest across different countries, seeking to understand any variations that may exist. To facilitate this examination, we've developed a standardized interview guide, which we'll translate into various national languages to ensure accessibility. Our study unfolds in two distinct phases: first, a meticulous national-level analysis, followed by a comparative assessment of these findings. Thus far, we've conducted 23 interviews with informal caregivers and 27 with formal caregivers, providing valuable insights into their experiences.

**Case Study:**

In our case study, we're delving into caregivers' understanding of advance directives through an engaging edited volume project. Spearheaded by editors Daniel, Olga, and Veselin, this volume will feature 17 articles, carefully curated to offer both theoretical insights and empirical observations at the national level. As we prepare to solicit contributions from authors, we're excited to see this project take shape, with plans to submit the finalized manuscript to the publisher by early 2025.

**Practice needs of Information and Formal Caregivers:**

Our subgroup is dedicated to understanding the practical needs of both informal and formal caregivers, employing diverse methodologies to achieve this goal. For informal caregivers, we're developing a multinational survey to capture their perspectives comprehensively. Meanwhile, for formal caregivers, we're organizing workshops to engage directly with their insights and experiences. Although the questionnaire for informal caregivers won't undergo validation, it will serve as a valuable tool in shaping our understanding. With our questionnaire slated for finalization by May 2024, we're eager to proceed with the study and seek approval from the Research Ethics Committee.

## Brief updates on work of the WG3

## Bert provides an overview of the WG's progress, emphasizing the primary focus on developing an ethical framework and recommendations for its implementation. Due to the interdependency of WG 3's deliverables on the work of WG 2 and WG 3, substantive progress within the group has been limited, with initial efforts primarily focused on abstract visualizations and preparatory work regarding the content and structure of ethical frameworks.

## Diana proposes establishing a consultant subgroup within the WG to provide constructive feedback on the framework's development, which finds support.

## Brief updates on work of the WG4

Isabel provides a concise overview of the WG's objective and progress, centered on the development of an educational toolkit. While still in its early stages, the group has made headway in defining the toolkit's contents. During a recent meeting, participants engaged in a fruitful brainstorming session, leading to the identification of key components such as differentiation between formal and informal caregivers, defining ethical issues, distinguishing between ethical and clinical matters, and promoting person-centered care and effective communication strategies with individuals with dementia (refer to Isabels presentation for more information).

Future directions include exploring teaching methodologies through a scoping review, with the goal of crafting a comprehensive toolkit, with a potential curriculum, tailored for both formal and informal caregivers.

## Brief updates on work of the WG4

Hilde and Krisztina provide an overview of the communication and dissemination efforts of the Action. While a website has been established, challenges persist in making it more interactive and keeping it up-to-date. It is noted that Lucca diligently posts newsletters on a regular basis. Krisztina emphasizes the need to significantly enhance dissemination activities, envisioning the website as a comprehensive knowledge hub by the end of the Action. WG leaders are encouraged to brainstorm ways to contribute to communication and dissemination efforts.

All WG leaders are requested to designate a specific individual within their WG to oversee communication efforts. This delegated person will be responsible for ensuring effective communication about what is going on within the WG and will work in close collaboration with Hilde and Krisztina. There are no objections to this proposal.

*The MC meeting was adjourned at 12.00*