

Brussels, 12 May 2023

COST 062/23

DECISION

Subject: Memorandum of Understanding for the implementation of the COST Action "Supporting emerging care economy, empowering caregivers to provide safe care at home" (BETTERCARE) CA22152

The COST Member Countries will find attached the Memorandum of Understanding for the COST Action Supporting emerging care economy, empowering caregivers to provide safe care at home approved by the Committee of Senior Officials through written procedure on 12 May 2023.





MEMORANDUM OF UNDERSTANDING

For the implementation of a COST Action designated as

COST Action CA22152 SUPPORTING EMERGING CARE ECONOMY, EMPOWERING CAREGIVERS TO PROVIDE SAFE CARE AT HOME (BETTERCARE)

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 improve prevention of caregivers' errors at home to implement efforts to increase recipients' safety, introducing an open dialogue about consequences of caregiver errors based on a collaboration integrating citizens, end-users, disciplines, approaches. This Action will facilitate discussion, share scientific knowledge, perspectives, and best-practices on prevention of caregivers' errors. 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

The Care Economy is a groundbreaking field due to population aging and the increase of noncommunicable diseases. Ensuring the provision of safety care at home and helping people to stay in their places as much as possible are current challenges. Caregiving at home has increased in the complexity of care and intensity which augmented the risk of making errors impacting on both, recipients' health, and caregivers' wellbeing. In most cases, home care is provided by family members, usually women, which enlarges the gender gap. This Action joints efforts to ensure an error-free care environment at the homes. It introduces an open dialogue and discussion among all stakeholders about the consequences of caregivers' errors based on a cross-national collaboration that integrates citizens, end users, different disciplines, and perspectives. It will be built on existing work and will provide opportunities to re-think national, and international deinstitutionalize policies, assuring the same care safety at home as the one received in residential facilities. To assess available resources to meet the qualification threshold and modify the support net available for the management of risk of caregiving and dispensing medications at home. Citizens Science principles will be adopted to open debates and analyses about educational standards, develop of a guideline and case study based on caregivers' stories, and other materials. Also, to organize and conduct a Training School and Short-Term-Scientific-Mission involving caregivers as ended users and professionals. Health, psychological, social, legal, ethical, and economic issues will be considered and the usability of disruptive technologies as well.

 Areas of Expertise Relevant for the Action Health Sciences: Health services, health care research 	 Keywords home-based care citizen science
	 caregivers qualification standards medical errors

Specific Objectives

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

Research Coordination

• Encouraging discussion of the new care economy meaning by the institutionalization and the development of home care support.

• Increasing stakeholders' awareness on the consequences of unsafe care and implications for the institutionalization policies.

• Further developing the theoretical conceptualisation of the care errors at home and developing a common understanding of its implications.

• Raising general awareness of the impact of errors on caregivers (considering gender differences) and their consequences in psychological, social, legal, ethical, and economic terms.

• Facilitating discussion of the ethical, and organisational gaps while promoting a common understanding of factors underlying the interventions designed to empower caregivers to assure safe care at home.

• Agreeing on what to do after the occurrence of adverse events, sharing knowledge about research evidence and methods to tackle with these unsafe events.

• Paying attention to the situation of women who take on the care of family members while giving up their



personal and professional careers.

• Introducing the qualification range of contents, and standards set for caregivers which should be used to capacitate them to provide safe home care.

Capacity Building

• To lead a debate as a contribution to furthering the wellbeing of caregivers at home as part of the commitment to guarantee optimal care. It encourages changes in health and social services considering its implications for caregivers.

• To bridge management, social, legal, ethical, educational, and care provision expertise to further develop the steps that need to be taken to improve the quality of care delivered.

• To provide a platform to develop an agenda involving relevant stakeholders to promote effective solutions and facilitate discussion of the legal, ethical, social, psychological, economic, and medical issues.

• To create a network for the integration of fragmented initiatives, identifying more effective measures, applying lessons learned and to foster knowledge exchange and dissemination of research results.

• To encourage the development of solutions to support caregivers and reduce errors at home by overcoming the current fragmentation and isolation from the services, including leader experiences in the public and private sectors.



TECHNICAL ANNEX

1. S&T EXCELLENCE

1.1. SOUNDNESS OF THE CHALLENGE

1.1.1. DESCRIPTION OF THE STATE OF THE ART

Self-care and care others are a core component of the human existence. On September 7th, 2022, it was approved a <u>European Care Strategy for Caregivers and Care Receivers</u> (European Commission, 2022) to ensure quality, affordable and accessible care services across the European countries. This strategy pursues to improve the situation for both care receivers and the people caring for them, professionally or informally (relatives), particularly including homecare. <u>Open and transdisciplinary</u> <u>debates and analysis around how to increase the safety of home care</u> when looking for a chronically ill child, adolescent, young or older adult are a must. Therefore, meeting the needs of our modern society, with a special stress in elderhood to respond the demands in Europe.

Autonomous elderhood at home as a priority in Europe. By 2030, the number of people in the world aged 60 years or over is projected to grow up to 1.4 billion and, by 2050, older adults' population will nearly double and reach 2.1 billion humans (United Nation, 2017). Although this is an unprecedented success for humanity, it comes with a challenge: <u>how can welfare states remain to be sustainable and provide health and social care for the whole population?</u> In fact, the accumulation of health risks across the lifespan: disease, injury, medications, and chronic illness, explains the higher disability rates among older people. What is more, those figures will only increase in the coming decades.

Outbreak of care economy. The G20's Tokyo declaration acknowledges the impact of the care economy since 70% of people aged 65 years old or above live in G20 countries. A global strategy has been adopted to reinforce the person-centred care, boost <u>deinstitutionalization</u>, and <u>develop qualified home care support</u>. Given our societal circumstances, <u>new care economy</u> has the potential to boost economy larger than old industries combined. In European countries, significant improvements to provide safer care for patients have been introduced in health care systems seeking to ensure that procedures and treatments are being performed correctly and in a timely and effective way. However, this Action is facing the need for a transference or continuation of those towards a new paradigm, where the attention to health is not only provided in institutions, but also at home environments. This paradigm needs to be set up, standardized in knowledge and services, and accounted with tools to enable it to be feasible.

Citizen science brings all citizens involved. Patient safety is relatively under-represented in Citizen Science, despite the fact that it is a very diverse and promising domain. Citizen Science has a huge potential to contribute to <u>innovative research</u>, and therefore to society (Vohland et al., 2021). A proposal where a community of stakeholders will be dedicated to promoting and developing safety care at home using Citizen Science to foster dialogue is required. Standards and collaboration are needed in COST and non-COST Members Countries.

Caregiver portrait. Caregivers (both professionally or informally) should be prepared to develop their performance and dispense safe care. Despite the above, caring for elders, children and persons with a disability is frequently an unpaid or precarious job, mostly assumed by women (Zarzycki et al., 2022). This task drags their professional development, reports financial insecurity, and has a profound negative physical and psychological impact (Cascella-Carbó et al., 2020). The above mentioned is an economic setback and deepens the <u>gender gap</u>. Caregivers' responsibilities range from laundry and cooking activities to managing and administering medications and healing wounds or pressure ulcers leading to role overload. The previous, existing, and offered training in how performing those activities is scarce, leading to an emotional overload, as they feel responsible for recipients' health preservation (Jadalla et al., 2020 & Palacio et al., 2020). Nowadays, <u>the care provided by caregivers at home is more complex and intense</u>, and that is expected to grow (McKenna et al., 2022). This not only affects the caregiver but also the recipient's health, since caregivers' burden of care or unmet needs affect recipients' mortality rate (Schulz et al., 2020).

Errors in the act of care at home. Most studies with caregivers have focused on analysing the emotional and social burden deriving from caring persons with a dependency situation (Schulz et al.,



2020). Fewer, studies analyse the impact of care performance procedures and medication errors on health status of the recipient, plus caregivers' emotional state after makes a mistake (Look et al., 2018). Although there is some previous literature on how care should be provided at home, information about the unintentional and frequent caring errors and its consequences (e.g., inadequate performance in rehabilitation after hip fracture, pressure ulcers, or infections related to home care develop for patients as result of the lack of hygiene of the caregivers) is scarce. The risk increases when the patient receives care by multiple caregivers. Health literacy and beliefs, understanding of the instructions on how to care for and care complexity are key when providing this error-free care (Glick et al., 2019, Li et al., 2020 & Mira, 2021). 3/4 of patients over 65 years of age suffer at least one medication error per year at home. 1/4 of adverse drug reactions have been associated with medication errors, usually inappropriate use of analgesics, insulin, antihistamines, antitussives, and antimicrobials at home (Look et al., 2018). Despite this topic being of interest for the scientific community, most caregivers are still unaware of the precautions to use medications safely (Alsaeed et al., 2016). Nowadays, caregivers are not receiving a standardized training before providing care, in the best scenarios, they may receive some instructions that usually are incomplete, do not fulfil their individual requirements, nor have a follow-up of their learned safety tips or instructions (Guilabert et al., 2018).

What has been done so far. Some resources such as caregivers' schools, self-help groups, brochures, websites and blogs, multicomponent caregiver apps could educate caregivers on problem-solving practices. These approaches are focused on providing plain information and training on home care through traditional methods, such as passive information reception schemes. Studies focusing on ensuring adequacy, promoting self-efficacy, and avoiding errors are scarce. Furthermore, there is a need of developing tools that satisfy the unmet needs of caregivers in a geographically disperse society (Herur-Raman et al., 2021). Systematically tackling into the cultural gender gap and its impact on the caregiver's experience when errors have occurred has not been analysed, neither its limiting effects. The demand for long-term care requires innovative responses. Caregivers' empowerment on safety and new care economy developments could be reinforced using emerging technologies (Lindeman et al., 2020).

In future, This Action is already seeing caregivers at home facing a complex care, a significant increase in disruptive technologies usage as tools that improve caregivers' qualifications, and instruments for the continuous update of their educational needs (Barteit et al., 2021 & Bracq et al., 2019). Growth of new business opportunities for a sector of the population with lower professional qualifications that can now see a change in their careers, which particularly affects women. Enrichment of bridges between the workers of the healthcare and welfare systems and caregivers, can provide a better care enhancing patient safety environment (Brennan et al., 2013). There is an evident need of discussion across the countries which contents and areas represent a minimum when considering the safety of home care.

1.1.2. DESCRIPTION OF THE CHALLENGE (MAIN AIM)

Isolation of caregivers providing care at home may predispose them to cause avoidable harm, which has a negative impact on the provided healthcare, affects them physically and psychologically, and additionally cause an inadequate manage of risks (Brydon et al., 2021 & Wijma et al., 2018). Moreover, in most scenarios all the above is experienced by women, who in most cases are recipients' relatives with a lack of independence in economic terms.

Caring Errors' existence and experience at home is far more widespread than imagined. This Action will contribute awareness to the current situation, to point out relevant themes around this phenomenon, analysing its impact on patient safety, debating preventative measures and interventions after a care error at home, and gathering potential technological solutions to cope with it (Oh-Park et al., 2021). Legal, ethical, psycho-socio-cultural-economic perspectives will also be included in the debates and analyses. Guidelines and standards that reflect and harmonize the act of care at home are needed. Recipients have to receive the same quality of care in this new home paradigm, or possibly even better, than the care received in residential facilities. It is a citizen duty to join to a discussion where all stakeholders are represented and have a chance to share their needs and beliefs.

The overall aim of this Action is to facilitate discussion and share scientific knowledge, perspectives, and best practices concerning the prevention of caregivers' errors occurring at home to implement joint efforts to increase recipients' safety, and to introduce an open dialogue and discussion among all stakeholders about the consequences of the caregiver errors based on a cross-national collaboration that integrates citizens, end users and different disciplines and approaches.



European The Council's recommendations and directives (2009/C 151/01, 2011/24/EU, 2013/36/EU) and the WHO's guidelines (WHO 2019) have repeatedly stated that patient safety is a core dimension of the qualityof-care provision. From this viewpoint, there are two specific challenges: the design of healthcare systems' connection to caregivers at home to improve their skills regarding their recipients' safety and therefore impact



them in terms of satisfaction by providing higher quality care, <u>evaluation, and discussion around the cost</u> of <u>unsafety environments and the available technology resources</u> that may benefit all the population regardless of their residential areas. This Action encourages reflection and introduces evidence-based interventions facilitating <u>rethinking educational and ethical issues</u> to achieve recipients' safety targets at national and international levels.

Other aims are understanding and describing factors causing care provider errors, implementing a <u>shame-free and safe environmental for speaking-up about errors</u>, taking care of the economic aspect of this new paradigm, and all the ethical issues that may surround the act of care at home. All those matters can reinforce caregivers' commitment to safety, and reduce caring error related experiences. Initiatives and research describing the nature of main medication errors at home in Europe are mostly related with paediatric population or do not cover caring errors. The approaches for caregivers' qualification across the different epochs that their recipient may experience, remain fragmented, location-dependent, and heterogeneous. European countries need to implement a coordinated effort to offer qualifications and support resources to caregivers, common strategies, and disruptive technology alternatives to address the inception of errors, increase awareness and improve recipients' trust in the act of care. All initiatives should be designed considering the Citizen Science paradigm.

Despite some errors, especially medication errors, being widely acknowledged and typified by care providers and clinicians. The conceptualisation of the caregiver errors has not received enough attention, and it is unclear which interventions could be applied. Furthermore, legal, ethical, educational, economic, and social issues in the European context have not been addressed, nor have the roles of stakeholders (citizens, policy makers, jurists, deputies, journalists, patients, caregivers, and healthcare providers) in existing interventions. This phenomenon requires a multidisciplinary answer from various backgrounds that shares knowledge and experiences in a different way. In this respect, the current European literature appears to be fragmented based on work from researchers confined to a single country or to a dual-country context that does not capture the multilevel complexity of this phenomenon. Moreover, since a simple dissemination of policies will not work, there is a need for a comprehensive approach with multiple stakeholders, including general public. <u>A multilevel joint approach with interdisciplinary perspectives is needed to tackle this challenge to develop a framework to improve training for a safer environment in home care.</u>

Furthermore, the consequences for morale and caring capacity with respect to the caregiver error include expecting delaying or omitting certain elements of care as consequence of the event, then it is jeopardising patient safety. There is no discussion from the <u>ethical perspective of either caregivers or patients</u>, or of how institutions must act to preserve the rights of both. There is hardly any dialogue on which new interventions may be accepted by stakeholders. <u>Recipients'</u>, <u>caregivers'</u>, <u>scholars'</u>, <u>policy</u> <u>makers' or citizens' views must be introduced into the debate</u> to identify realistic interventions.



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

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

This Action will for the first time bring together various disciplines (e.g., clinicians, psychologists, lawyers, economists), roles (e.g., recipients, family members, caregivers, education community members) and organisations (e.g., citizens', caregivers', or chronic patients' associations) to discuss standards and create new knowledge from a wide range of perspectives to increase recipients' safety. It will be built on existing work and provide opportunities to rethink locally, nationally, and internationally how to modify training for caregivers, the access to available resources and the support net available to caregivers.

Involving all stakeholders and perspectives in addressing this challenge. There is no standardized track of knowledge to guide people, especially women, if a sudden and unexpected episode requiring care occur in their families. This Action proposes to build a common framework to share knowledge, approaches, attitudes, (unmet) needs, research outcomes, and experiences based on PM² management methodology (PM² version 3.0.1., 2021). Unlike traditional approaches, this Action also invites other stakeholders to participate, such as patients, citizens, and other social agents. This Action will provide a cross-national analysis and bring together colleagues from other Non-COST and COST Member Countries to set common targets and agendas, and build a network to exchange their expertise, experience, good practices, as well as develop solutions.

Empowerment for optimal quality of care demands our attention, and currently there is an increasing interest in redesigning devices, and procedures that affect all ages recipients' and caregivers' commitment to safety. This Action will provide targets for debate and research, proved interventions, and new perspectives from disciplines committed to safety of care at home through better conditions and educational resources that would harmonize qualified and unqualified caregivers.

Rethinking the standards of care for caregivers. The thirteenth program of work (WHO 19-23) grants the opportunity to update the education requirements of the caregiver's situation to consider advancements in patient safety from several perspectives. This Action pursues to move in this direction and provide a framework for collaborative work in Europe that will have an impact beyond our borders.

New requirements of caregivers' qualification and resources to respond to care economy demands. There is a shift from residential facilities towards a home model of care, in where caregivers assume a main role. This Action will discuss the needed skills and contents that have to be provided to persons having to become caregiver at home.

Progressing beyond the state of the art. There is increasing evidence of the need of supporting caregivers in their performance (e.g., high levels of burn out described or physical lesions, increase of complexity affecting recipients' safety). Although there is accumulating work on theorization and description about caring and medication provision by European research groups, it is not clear how to achieve safety standards. There is a pressing need to debate these issues within a multidimensional framework.

In view of the currently fragmented state of work as well as the gaps regarding practical issues in Europe, this COST Action will enable the establishment of an internationally coordinated framework to facilitate debates, materials and highlighted proved interventions at the international levels to increase recipients' safety at home. This Action seeks to reinforce connection while fostering scientific excellence overseas.

1.2.2. OBJECTIVES

1.2.2.1. Research Coordination Objectives

The following figure summarises the main factors underlying the scenario where caregiver errors happen, its direct consequences, and the proposed Research Coordination Objectives (RCO).

1. Encouraging discussion of the <u>new care economy</u> meaning by deinstitutionalization and the development of home care support, considering that errors of care and lack of qualification of caregivers are one of the major focuses of this Action. This debate will be enrichened by international collaboration,



considering among other issues the differences in the role attributes to the family in the care of their loved ones in the European Countries.

2. Increasing stakeholders' awareness on the consequences of unsafe care and implications for <u>deinstitutionalization policies</u>. Caregivers do not usually receive information and training on patient safety concepts, tools, or methods, and least of all about the consequences of mistakes for themselves. There are no international guidelines addressing patient safety education for caregivers assuming care at home and about how to reduce the impact of caregiving errors at home. Proposals for new directives for training and requirements for educational interventions may involve scholars and other stakeholders such as citizens and end users.

3. Further developing the <u>theoretical conceptualisation of the care errors at home</u> and developing a common understanding of its implications. Health and social institutions are witnesses to the emotional reactions of home caregivers when safety events occur. There has been emphasis mainly on the description of the emotional reactions when a safety event occurs and very little debate about the underlying factors with respect to the conceptualisation of this event and the impact of its consequences on patients' rights and the providers' commitment to patient safety.

4. Raising general <u>awareness of the impact of errors on caregivers</u> (considering gender differences) and their consequences in psychological, social, legal, ethical, and economic terms. This objective seeks to establish a more in-depth understanding of the complexities of these issues and facilitate discussion for the subsequent development of proposals to reduce the impact of adverse events on caregivers (e.g., guilt or increasing disaffection with recipients' relatives), considering the characteristics of the COST and Non-COST Member Countries. Debate on the health, psychological, social, economic, legal, and ethical issues regarding healthcare provider errors is not limited to healthcare and welfare institutions. There is increasing evidence about the role of all stakeholders in the definition and achievement of safety goals. International teamwork must reinforce the exchange of data, but also contribute to disseminating effective information, including the general public.

5. Facilitating discussion of the ethical, and organisational gaps while promoting a common understanding of factors underlying the <u>interventions designed to empower caregivers</u> to assure safe care at home. Differences in healthcare workflows, organisational models, or absence of debate about ethical issues are common. Currently, there is very little work investigating aspects involved in home care experience and there is an urgent need for international collaboration in a collective discussion of their implications for quality of care. A multidisciplinary approach is needed in this early stage to capture the multidimensionality of the factors linked to the errors experienced at home. Such goals cannot be achieved without a broad vision involving different disciplines and perspectives.

6. Agreeing on <u>what to do after the occurrence of adverse events</u>, sharing knowledge about research evidence and methods to tackle with these unsafe events. There is a paucity of recipient safety education programs to support and provide resources to caregivers in most healthcare institutions in Europe. Furthermore, the interventions available do not incorporate psychological, legal, social, economic, or ethical perspectives regarding care errors. There is a need to expand the range of methods to elicit data and promote interventions that can grow capacities of caregivers to cope with this challenge. This goal cannot be achieved without international coordination due to the diverse environments, rules, customs, and cultures, consequently less experienced countries can learn from the more advanced ones.

7. <u>Paying attention to the situation of women</u> who take on the care of family members while giving up their personal and professional careers. The gender biases in our societies, since mostly women take on this role, limit their personal and professional development and well-being. Women are many times transparent, and this Action seeks to put it on the spot. Social debate on this issue should be approached considering cultural differences across countries, so their progress can serve as a model for others. Enriching their life quality requires an analysis involving the entire society.

8. <u>Introducing the qualification</u> range of contents, and standards set for caregivers which should be used to capacitate them to provide safe home care. There is hardly any discussion of new metrics that include factors contributing to the avoidance of healthcare provider errors and measures reducing error impact. These new indicators should respond to new requirements for international accreditation



and be designed considering contributions from multiple disciplines, not just nurses' and clinical perspectives.

Workshops, forums, and face-to-face meetings at national and international levels, blog entries, podcast, and reports will contribute to Objectives 1–8, following the work plan. A depository of best practices will contribute to Objectives 6,7,8; scientific reports and publications to 1,4,5,8; proved interventions to 2,7,8; training schools (TS) to 3,4,5,6,7,8; Short-Term Scientific Missions (STSMs) to 2,3,8.

1.2.2.2. Capacity-building Objectives

1. To lead a debate as a contribution to furthering the <u>wellbeing of caregivers</u> at home as part of the commitment to guarantee optimal care. It encourages changes in health and social services considering its implications for caregivers. Transferring theoretical conceptualisation of caregiver errors at home into practice and understanding its consequences. New metrics will be introduced and used to improve quality assurance. Also, promote rationalisation and integration of fragmented initiatives to assess this phenomenon and raise general awareness about its impact on patient safety. Through this objective, this Action will contribute to the sustainable development of the new care economy.

2. To bridge management, social, legal, ethical, educational, and care provision expertise to further develop the steps that need to be taken to improve the quality of care delivered. There is an absence of multidisciplinary work analysing the causes, unmet needs, and consequences of the errors made at home by caregivers. Further efforts sharing knowledge, perspectives, and proposals from different backgrounds and positions can contribute to acknowledge these events. There is a need to encourage the inclusion of the consequences of safety incidents and mistakes in the agenda of the various health, social, legal, and humanistic science fields.

3. To provide a platform to develop an agenda involving relevant stakeholders to promote effective solutions and facilitate discussion of the legal, ethical, social, psychological, economic, and medical issues. A debate about the best way to approach the safe care provision problems that caregivers are facing at home in Europe is practically non-existent. There are fragmented proposals, and no ongoing communication between experts, researchers, safety leaders, and other stakeholders to collectively identify gaps in knowledge and foster coordinated and collaborative actions. It is necessary to put together experiences and perspectives from all stakeholders (caregiver associations, family members, patient associations, professional societies, healthcare institutions, academic institutions, manager associations, scholars, jurists, policymakers) and general public to replace barriers to facilitate an open debate about alternatives. This platform will invite organizations wishing to participate in this Action objectives by endorsing citizen science principles.

4. <u>To create a network</u> for the integration of fragmented initiatives, identifying more effective measures, applying lessons learned and to foster knowledge exchange and dissemination of research results. Isolated teams confined to individual countries conduct much of the research on caring and medication errors at home. However, nature and extent of this phenomenon plus gaps and barriers that persist appear to be consistent across COST and Non-COST Member Countries. This Action can provide more systematic and coordinated work between diverse teams (experienced and less experienced) and should focus attention on its development for future collaboration on and strengthening of the work done on this topic, including once the Action ends.

5. To encourage the <u>development of solutions</u> to support caregivers and reduce errors at home by overcoming the current fragmentation and isolation from the services, including leader experiences in the public and private sectors. There is a relative lack of experience regarding the implementation of practices, guidelines and/or interventions to decrease errors and bad experiences of caregivers at home. Progress beyond state of the art must include the following targets: apply guidelines or proved interventions; develop ethical norms, and teaching protocols; and exchange team expertise to trigger global expertise in the field. The lessons learned from the disruptive technologies solutions designed in other health services can also be applied to reinforce approaches in health systems developing a set of recommendations to be considered meanwhile patients' right being protected.

A description of measures to determine whether the following Capacity-Building Objectives (CBO) are achieved (effectiveness and timely delivery of results) is included in the Implementation section.



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

Although literature about safe practices of the caregivers at home is scarce, there is an increasing number of studies and interventions in Europe. The advancement of work on this topic has been slow and has not captured the increasing complexity of the area, e.g., psychological, legal, social, ethical, or educational issues have been scarcely studied. There are no international projects currently initiated and the collaboration between work teams from different European countries is still in progress.

While the human factor in safety has been considered, this Action complements this approach by drawing attention to an issue that is the least studied and known. Rather than an isolated situation, being a caregiver is a condition that most families will face, not exclusively accompanied by a qualification. Any family at some point will care for a close member and will need tools to be able to handle that.

As clinical, psychological, ethical, social, and educational aspects play a role in the experience of home care, this Action aims at involving different disciplines, perspectives, and stakeholders in this topic. This Action has several objectives in the exchange of knowledge and experience to contribute to the provision of optimal care in the health systems of COST and non-COST Member Countries and abroad. Promoting an economy of care and making homes safe environments.

Health and welfare systems across Europe differ in key aspects but share the same situation when it comes to caregiving errors occurring at home. This Action includes academics, health and social service providers, patients' representatives, carer associations and public officials from 7 different European countries (Central, Eastern, Southern and Western Europe). All will ensure the ability of this Action to reach a comprehensive multi-country understanding of the field and its capacity to propose implemented solutions considering diversity. This network is made up of country teams that have made progress together on this issue, and other country teams that have just started to emerge. In designing the Action, the generational, geographical, experiential, academic, clinical, psychosocial, and legal backgrounds of its members have been considered. The Action will draw on the expertise of professionals developing a position in both clinical and academic contexts, and an ongoing collaboration with national health and social authorities alongside patient and caregivers' platforms. This Action is fully open to other institutions and countries that share these same objectives.

This Action will explore new goals and targets, pursue how to build consensus, and address an impact of home-based care and medication errors on recipients and their caregivers, by rethinking caregivers' programmes, including through changes in society's understanding of homecare. This empowerment of caregivers has already been achieved in some of the COST Member Countries, and its extension would contribute to the successful implementation of safety plans at national and international levels across Europe and beyond.



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 Action includes 14 COST full Member Countries, and one COST Cooperating Member, representants from North, South, East and West Europe are present in this proposal which secures the critical mass needed. The Action guarantees a high rate of inclusion of COST Target Countries and respects a balanced gender distribution in the promotor team and making decisions afterwards. Gender



issues will be considered when using COST tools. Furthermore, this Action will be open to the participation of other COST or Non-COST Member Countries. In terms of the experience, the Network of Proposers already includes members involved in conducting empirical and applied research on patient safety in international collaboration and promoting caregivers' educational programs reinforcing this topic. The Network draw on the expertise of partners from different disciplines who play their role in universities, research institutes, patients' and caregivers' associations or schools, hospitals, and primary care centres, social or professional organisations, and quality and safety agencies at national level.

2.2.2. INVOLVEMENT OF STAKEHOLDERS

The most relevant stakeholders of this Action are caregivers' associations, schools and foundations, professional organisations at national and international levels, care receivers and their representatives, and the general public. This Action endorses the principles of Citizens Science in support to establish decision-making processes. Researchers and academics in medicine, nursing, geriatrics, pharmacy, law, sociology of health, health economics, psychology, and ethics; directors and managers (e.g., working in health and welfare institutions and agencies), lawyers, policy makers, parliamentarians, journalists, staff of governmental bodies (e.g., national quality assurance agencies) will be also involved using COST tools. This Action aims to engage diverse stakeholders through various channels, fostering an understanding of their needs and expectations. We will share innovative solutions to address medication and home care errors and misunderstandings, breaking taboos and alleviating fears. By incorporating different perspectives, disciplines, and experiences, we will overcome barriers and bring successful proposals closer to end users. The involvement of officials at national and international levels will facilitate access to other governmental structures in other countries. They will participate in various joint activities, such as discussions, conferences, workshops, or forums; receive information, education, or training through permanent (e.g., accessing website resources, technical briefings, podcasts) or nonpermanent channels (e.g., workshops, forums, face-to-face and electronic meetings); and exchange ideas with other partners at national and international level using mixed channels (e.g., blogs, CTS).

The Action will bring together participants with a diversity of profiles and experiences from different countries, disciplines, and backgrounds with the aim of forming collaborations and partnerships that will open debates on key issues, enable scientific knowledge and improve approaches, health and social policies and interventions with caregivers. This diversity will promote changes in legal, ethical, care, educational, organizational, professional and/or social contexts by means of debates and meetings in which interventions are shared. A special effort will be made to involve not only caregivers, but citizens, through citizen science, workshops, TS, national or international conferences and discussion forums. During the four years of this Action, other COST and non-COST Member Countries will invite to contribute to some or all the objectives of this Action and to participate in selected activities designed at national or international level. All stakeholders will benefit from having access to the website and blog (including the electronic repository of best practices and proven interventions, annual, scientific, or technical reports, and scientific publications). In addition, they will have access to guidelines, checklists, and other training materials to enhance their approaches to dealing with medication error and care experiences. Social media will be used for discussions with specific groups on some issues, e.g., what changes are needed to modify and generate tools that can help caregivers, what training is needed for caregivers, how to involve caregivers and representatives of patient and caregiver associations in the development of safety practices at home. Regardless caregivers' labour recognition in each country, factors underlying safety problems and burden on the caregiving experience are the same. How these situations are addressed, makes a difference in terms of the consequences, and international collaboration can help to address them.

A stable framework and agenda for discussing, exchanging, and testing new ideas, experiences and interventions is an opportunity to increase the scope of studies, debates, and exchanges, especially encouraging the collaboration of research teams from different countries and regions of the world, thus increasing the quality of current and future research. This Action will facilitate the integration of expert and less expert teams at the European level, and of teams from neighbouring countries in ongoing and future projects to provide an adequate and global response to the challenge of providing home care with safety equivalent to that of other institutional facilities and produce benefits for both caregivers and recipients. This Action will always be open to new institutions and organizations and will include them in the activities planned and in the proposed COST Action to increase inclusiveness.

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)

Innovation	Breakthroughs
- Scientific Impact, this Action will	
 Enhance the quality of European research on home economics of care and patient safety for the dependent people of all ages by bringing together not only professional and non-professional caregivers (end users in this Action) and healthcare professionals but also other social stakeholders such as citizens, patients and caregivers' associations, caregivers' schools, community platforms and policymakers. Increase the level of research on currently neglected aspects, such as the quality and safety of home care (medication errors, pressure ulcers, falls, harm suffered by the caregivers themselves, etc.), the level of training of caregivers, the well-being of the caregiver of the older adult, gender issues, situations of abuse towards care recipients or the role of disruptive technologies in creating safer homes for the caregiver and the care recipient. 	 Turn knowledge into action. Proposed a set of recommendations (<u>Scientific Report I</u>) considering the current state-of-art. Promote international collaborations. Initiation of a <u>minimum of 6 research proposals</u> for continued collaboration beyond the lifetime of this Action and publish a minimum of <u>4 scientific papers</u> published in high impact journals. Involving of a <u>minimum of 8 young researchers</u> (e.g., PhD students) in new projects, retaining talent and increasing the sustainability of the Action
- Health, psychosocial-legal-ethical-economic Impact	t, this Action will
 Bring together various profiles (e.g., professional and non-professional caregivers, clinicians, jurists, managers, citizens, policymakers), backgrounds (e.g., scholars, journalists), and organisations (e.g., citizens', scientific/professionals', caregivers' and patients' associations, and governmental institutions) for the first time. Stimulate ongoing discussions on the impact of policies, legislation, standards, and mechanisms designed to enhance the safety at home of the recipients by promoting a people-centred model and professionalizing the health and dependency care sector from the perspective of aging and the fight against depopulation. Specifically, discuss measures and policies to ensure the quality and safety of care in the home, both for the caregiver and the recipient. 	 Create a <u>common agenda</u> to debate relevant questions concerning legal, ethical, economic, and psychosocial issues related to safe care at home among all stakeholders. Promote changes in current policies (<u>Scientific Reports II and III</u>, that favour the creation of safe homes for the provision of quality care, guaranteeing the professionalization of the sector and mechanisms to prevent and respond to adverse events.
- Educational, this Action will	
 Discuss the creation of specific mechanisms and resources for training home care caregivers of children and adult recipients to ensure care quality and safety. Involve representatives of citizens', patients' and caregivers' associations and caregivers' schools to create expert citizen networks in care that enable the exchange of knowledge and best practices and provide solutions to care-related difficulties that can be a source of error at home. 	- Propose <u>structures, mechanisms, and</u> <u>resources to professionalize</u> the care economy (training for providing safe and quality care at home) based, e.g., on disruptive technologies (Scientific Report IV).
- Technological, this Action will	
- Pay attention to primary prevention approaches, raise awareness and train professional and non-professional caregivers to prevent care errors at home.	- Intervention program to prevent home care errors. <u>A minimum of 15,650 caregivers will participate using developed materials and programmes</u> .



- Discuss the possibilities of applying disruptive technologies to increase training efficiency of professionals and informal caregivers, ensuring recipients receive quality and safe care at home, contributing to the deinstitutionalization of people during old age.

- Improve guidelines for supporting caregivers based on new evidence, also considering gender differences in caregiving, and acute stress responses when errors occurred, and actors involved in caregiving at home.

3.2. MEASURES TO MAXIMISE IMPACT

3.2.1. KNOWLEDGE CREATION, TRANSFER OF KNOWLEDGE AND CAREER DEVELOPMENT

This Action will promote dialogue, co-creation and co-design between the public and private initiatives, citizens', caregivers' and professionals' associations and the academic sector, as well as with national/international agencies and policymakers, thus pooling their attention on how to improve current interventions to ensure the provision of qualified and safe care at home by professional and non-professional caregivers.

Knowledge creation. This will prioritise the analysis of psycho-socio-cultural-economic factors, ethical, and educational issues, and social and health policies since heretofore there have only been fragmented initiatives and limited international research on patient safety at home related to the new care economy. It will create a primary preventive approach, based on developing training materials and standards, a guideline for safety care at home, and new metrics, and a set of recommendations promoting changes in the caregiver's education reducing gender biases, considering the issue of the lack of safe care at home from a multisectoral perspective.

Transfer of knowledge. Participants in this Action are experienced in transferring research results to the health and social care context, which facilitates the transfer of knowledge. TSs, STSMs, and forums have been aimed. Channels to transfer knowledge in a bi-directional way have also been planned as well as mechanisms to share advances (see Implementation).

Career development. This Action encourages the training of professional and non-professional caregivers to strengthen their ability to provide safe care and proactively manage risks at home. Also, a new generation of PhD students will initiate their careers as researchers, seeking technological solutions for each patient safety problems related to errors at home by caregivers.

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

The main methods of dissemination, exploitation, and dialogue in this Action can be classified into permanent and non-permanent communication channels.

Permanent: The website of this Action (training materials for caregivers, including working papers, repository of best care practices, database), blog entries, podcasts, technical and scientific reports, publications, guidelines (including checklists), case studies, training manuals, and news and accessible reports for the public. The website will act as a platform to provide updated information about this Action and other relevant links (such as host reports and other documents produced during this Action), and invite potential new members to join this Action. The website will also support registration in the various aimed activities during the duration of this Action. Expected <u>publications</u> of this Action will include annual and technical reports (8), 4 scientific publications (JCR, Q1 or Q2), guidelines (including checklists), stories involving peers and case studies, training materials and self-learning programmes, and news, links on the website, and blog entries for the public (web monthly visitors increase, 2%).

Non-permanent: Active actions will include an <u>international forum, 7 national workshops</u> (each partner will organize a national workshop throughout the project), and <u>3 training schools</u> with all stakeholders invited to participate. Citizens' and patients' representatives (caregivers' and patients' associations and

- A <u>guideline</u> to tackle with the medication and caring errors at home, including case studies, and checklists.

- Develop <u>new metrics</u> to assess the safety of home care and make decisions on errorfree care policies.



schools), professional organizations, scholars' leaders and policy makers will be invited to participate. In addition, <u>STSMs</u> will enable mobility between partners, particularly caregivers as end users, and PhD students. <u>Media communication and public announcements</u> will be made by participants in this Action to increase dissemination and public attention to the activities of the Action. The implementation of activities at national level in each participating country will require at least two to three <u>online meetings</u> per year. In addition, two <u>online meetings</u> will be held yearly for the international management and coordination of the project (responsibility of Management Committee). Social media will be used to maximise dissemination and debates; particularly geared towards the general public (it is envisaged biweekly question through the blog and the tool offered by Twitter, Instagram, Facebook, META or Tik-Tok, monitored through the Google Analytics and Twitter Analytics tools, which will allow us to better adapt to the audience). All materials and conferences from the workshops and forums will be made available online with the consent of the authors.

The Action's dissemination activities as well as the dialogue with the general public will mainly be implemented by the Working Group 1 (WG; see section 4.1.1), but will require input from the other WGs and, in many cases, from the Management Committee (see section 4.1.3). The latter will participate in exploitation activities. All Action members will be encouraged to participate in dissemination activities, particularly social media ones.

4. IMPLEMENTATION

4.1. COHERENCE AND EFFECTIVENESS OF THE WORK PLAN

4.1.1. DESCRIPTION OF WORKING GROUPS, TASKS AND ACTIVITIES

This Action proposes four working groups (WG) organised as follows:

WG1. NETWORK PROMOTION			
Associated O	RCO1, RCO5, RCO6, CBO3, CBO4.		
Tasks	 Networking, also involving new members; analysis and results promotion in social media. Disseminate and assess implementation and sustainability of aimed objectives. 		
Activities	(1) Schedule workshops, International Forums, and Training Schools. (2) Disseminate reports, guidelines, case studies, training materials, and scientific articles in collaboration with the rest of the WGs. (3) Invite new collaborators from the COST and non-COST Member countries, citizens', patients', caregivers' associations, and schools of caregivers. (4) Monitor and disseminate outcomes and aim at their sustainability beyond the lifetime of the Action. (5) Promote agreements with entities across Europe for the organisation of workshops, forums, and training schools to minimise cost.		
Deliverables	Website and blog (Q2Y1, Q3Y1); International Forums (Q2Y2, Q2Y4); Annual reports (Q4Y1, Q4Y2, Q4Y3, Q4Y4); Meetings (Q1, Q2 and Q3 in each of the four years).		
WG2. REVIEW AND DESCRIPTION OF THE STATE-OF-THE-ART OF SAFE CARE AT HOME			
Associated O	bjectives	RCO1, RCO3, RCO4, RCO5, RCO6, RCO7, RCO8 CBO1, CBO2, CBO5.	
Tasks	(1) Examine evidence regarding errors at home from all perspectives, gaps and factors causing inequities such as gender biases, and proved interventions to address the phenomenon, providing a clearer understanding of it. (2) Refine concepts, methodologies, and new targets for research and further develop evidence-based interventions to reduce errors. (3) Assess feasibility and acceptability of the designed intervention techniques, how they are implemented, and old and new metrics to evaluate the safety of the environment at home.		
Activities	(1) Map and evaluate existing guidelines, educational materials, and other interventions. (2) Facilitate stakeholders' discussions and assess differences between countries.		



Deliverables	Reports (Q3Y1, Q1Y3, Q4Y3, Q2Y4); Training materials (Q1-2Y2); National workshops (Q4Y4); Meetings (Q2Y1, Q1-4Y2, Q2-3Y3, Q1-3-4Y4; Scientific publications (Q4Y1, Q4Y2, Q3-4Y3, Q3Y4).			
WG3. MAKING SAFE HOME-BASED PRACTICES HAPPEN				
Associated Objectives RCO1, RCO2, RCO3, RCO4, RCO5, RCO6, RCO8, CBO4, CBO5.				
Tasks	(1) Explore and discuss feasibility of the designed interventions. (2) Analyse and debate around the former European safety of care standards at home for care providers.			
Activities	(1) Facilitate discussions of professionals' attitudes and skills to address caregiver errors at home phenomenon. (2) Transfer of the proved interventions implementation and promote best practices in COST and non-COST Member countries. (3) Pilot proposed interventions (guidelines, checklists) and educational materials and self-learning programmes. (4) Support caregivers after making errors.			
Deliverables	Standards (Q4Y2, Q1-2Y4); National workshops (Q1Y2-Q4Y4); Training School (Q3Y2, Q2Y3, Q2Y4); STSM (Q3-4Y1, Q1-2Y2, Q3Y3, Q1-2Y4); Guideline (Q1Y3-Q4Y4); Meetings (Q4Y1, Q2Y2, Q1-3Y3, Q1-3-4Y4).			
WG 4. CARE RECEIVERS' SAFETY PIECES FOR THE NEW CARE ECONOMY				
Associated O	bjectives RCO1, RCO4, RCO5, RCO8, CBO1, CBO2, CBO5.			
Tasks	(1) Explore and facilitate discussion of cultural, professional, corporate, educational, and social barriers which intensify caregiver errors' experience. (2) Discuss potential alternatives to overcome these barriers by analysing ethic aspects and attitudes considering national contexts, characters, and traditions. (3) Encourage business opportunities in the care economy for women in the most vulnerable situations by turning them into experts in safe care at home.			
Activities	(1) Promote debate and exchange of experiences concerning the national and international strategies for caring for care providers, as well as examine their impact on the caregivers at home phenomenon, developing activities and programs for future collaborations once this Action ends. (2) Promote the participation of all stakeholders (patients, associations, family members) in debates around status of care providers.			
Deliverables	Reports (Q3Y2-Q4Y4); Meetings (Q4Y1, Q2-4Y2, Q2-3Y3, Q1-3-4Y4); National workshops (Q3Y2-Q4Y4); Best practices/guideline, strategies linking stakeholders (Q3Y2-Q4Y4).			
RCO: (1-8); CBO: (1-5); Q: Quarter (1-4 for each year); Y: Year (1-4)				

The effectiveness of this Action will be monitored biannually through objective measures (such as number of visits, meetings, participants) and subjective measures (such as satisfaction with activities, changes achieved in self-esteem, perceptions of the usefulness of guidelines, or other materials). All information will be shared to ensure correct tracking. The following Table summarises the indicators that have been defined to assess progress in the CBO.

Capacity-Building Objectives (CBOs)	Example of indicators to assess the impact achieved
To enrich qualification of caregivers	Number of participants in the meetings, educational activities aimed, entries to blog, podcasts, and visits to the website.
To bridge management, social, academic, educational, and clinical expertise.	Number of national reports elaborated about standards of care needed to be achieved for safety care at home, and new multidisciplinary research projects on caregivers' function at home reported by participants during aimed activities. Number of PhD students involved in new research projects on this topic. Number of secondments at international level during the Action.
To provide a platform to develop a joint agenda with and for stakeholders.	Number of national and international attendees (including citizens) to workshops, and non-clinical participants in the aimed activities such as self-learning. Successful involvement of all stakeholders.



To create a network to foster knowledge exchange and dissemination of experiences.	Number of participants in the seminars or workshops at the national and international levels, caregivers' school, National Safety Agencies involved, visits to the website, and downloads. Assessment of changes achieved and their sustainability.
To encourage the development of interventions supporting caregivers' actions at home.	Number of new educational programs based on the guidelines and case studies (including PhD programs), health professionals trained to support caregivers, caregivers participating in the TS and STSM. Usefulness of developed materials and workshops to end users.

4.1.2. DESCRIPTION OF DELIVERABLES AND TIMEFRAME

YEAR 1, 2nd quarter: Website of this Action, in all members' languages with general and scientific information, agenda of activities, recent scientific developments, electronic repository of best practices and proven interventions, materials, podcasts, self-learning programmes, documents and reports resulting from this Action. It will also facilitate participation and membership in workshops or other aimed activities and disseminate the results obtained. **3rd quarter**: Blog to exchange news, perspectives, disseminate results and promote discussions using the advantages of blogging to facilitate the active participation of stakeholders identified in this Action. **STSM** involving young researchers and caregivers' representatives, **Technical report** focusing on the conceptualisation of the safe care at home, the importance of coaching and training carers on safety and identifying where carers need to be empowered to safely care for patients in the health and social care system across Europe. **4th quarter: Scientific publication** on the state of the art. **Annual report** including a description of all activities, indicators for monitoring the usefulness and progress of this Action, as well as theoretical and methodological developments.

YEAR 2 National workshops and face-to-face meetings with the aim of exchanging ideas to face the new care economy with all the challenges of including the carer as the main axis of the safe care received by the patient at home. Thus, introducing possible changes in procedures, necessary training for people who are carrying out care work at home and that curricula and health and social organisations incorporate this reality of empowering third parties in the safe care of patients. 1st quarter: Case study (detailed examination of a case considering its clinical, professional, organisational, ethical, social, cultural, and economic aspects and the perspectives of the citizens, the caregiver, the patient, and the professionals), which will be available to all stakeholders and will also be used as material during the workshops and the Training School foreseen in this Action. STSM promoting the exchange of young researchers and caregivers' representatives for exploration of learning solutions (methodologies, tools, and content) to train caregivers for the provision of safe home care. 2nd quarter: International forum including conferences, round tables and seminars involving policy makers, social agenda makers, professional associations and citizens', carers', and patients' associations. 3rd quarter: Training materials to be followed during the activities of the Training School and the self-learning programme. These will provide a set of knowledge to be shared, skills, examples and exercises that will continue to be used after the end of this Action. **TS** focused on studying risk situations for care recipients provided by professional and non-professional caregivers at home and strategies for safe medication management and safe care practices. 4th quarter: Scientific publication focusing on a review of interventions carried out in professionalised sectors, e.g., training situations with disruptive technologies, which can serve as an example or a source of new ideas. STSM promoting the exchange of trainees and PhD students between COST and non-COST Member Countries, with the aim of strengthening future collaboration in this area empowering caregivers to provide safe care at home. Annual report.

YEAR 3. National workshops and face-to-face meetings. 1st quarter: Technical Report focusing on training needs and even adaptations at home to address the provision of safe care in the scheme of the new care economy. Guideline including evidence-based interventions to prevent, support and rehabilitate carers at home after care errors, provide them with tools and be able to manage risks. 2nd quarter: TS focused on learning in other more professionalised sectors (gerontological centres, day centres, home hospitalisation units). In addition, this TS will also include a specific activity for carers from COST and non-COST Member Countries to raise their awareness of the impact of their role providing safety care and to enable them to cope with errors. 3rd quarter: STSM of young researchers and caregivers' representatives to exchange experiences about safe home care. Scientific publication focusing on scientific and technological advances to prevent medication errors at home by caregivers and supporting them when errors occurred. 4th quarter: Discussion and development of standards to reduce the variability of care at home to ensure safe care provision and update qualifications and



educational requirements of caregivers. **Technical report** and **scientific publication** on the existing gaps in the curricula of health and social professions to incorporate tools and strategies to empower caregivers for a safe caring. **Annual report**.

YEAR 4. National workshops and face-to-face meetings. 1st quarter: STSM promoting the exchange of caregivers and PhD students between COST and non-COST Member Countries, aiming to strengthen future collaboration in home care risk management. 2nd quarter: STSM and TS focusing on proven interventions to skill health professionals to become trainers of caregivers improving safety of the care receivers. Technical report focusing on effective interventions to prevent home errors in caregiving (e.g., focusing on new and disruptive technologies). 3rd quarter: Scientific publication focusing on advances from various perspectives and disciplines. Network of future collaborations because of this Action. 4th quarter: Annual report (final).

4.1.3. RISK ANALYSIS AND CONTINGENCY PLANS

The **main and actual risks** have been classified into management (mainly related to governance and cost), operational, and external risks. <u>Proposed risk-mitigation measures</u> (PRMM) are also described.

Lack of coordination. PRMM: The **Management Committee** (MC) will be responsible for ensuring coordination between the participating countries. It will in turn be in direct contact with the **National Representatives** (NRs) who will be responsible for coordinating activities within their country. <u>Unexpected escalation of project costs</u>. PRMM: The MC will be responsible for assuring that the funding is used as aimed and for resolving any problems that may arise in relation to the costs of the project. <u>Specific activities will take longer than expected</u>. PRMM: Rescheduled activities as the project progresses and examine causes to avoid similar problems to occur.

Obstacles to developing intervention mechanisms due to some cultural, legal, and ethical barriers or diversity of systems in the different countries avoiding achieving objectives. PRMM: Creating a multidisciplinary workforce scheme across Europe integrating scholars, social, ethical, and legal leaders, and research teams from an international perspective; setting up innovative formats for the dialogue; involving non-governmental organizations (caregivers' and patients' associations and schools); NRs will be responsible for reporting to MC on legislation, rules, policies, or practices related to the objectives of this Action. Inability to involve all expected stakeholders. PRMM: Partners from each country will strive to involve citizens, caregivers, patients, other stakeholders such as journalists, or industries representatives, and academic, and governmental institutions; it will prioritise involving stakeholders that are not Action members through formal and informal meetings and stressing the opportunity to contribute to long-term advances. Low attendance of activities. PRMM: Spread of responsibility among Action members; alerts (indicators) to detect problems have been included to fine tuning of the activities when needed. Poor implementation of work plans. PRMM: Monitoring the work plan and results of aimed activities bi-yearly; Chair and WGs leaders will be responsible for promptly identifying deviations and potential problems in the execution of the work plan and for responding appropriately. Failure to reach RCOs or CBOs. PRMM: Using indicators to provide information and alerts to detect these potential failures in advance. Lack of updating of website content. PRMM: Bi-weekly revision of the content of the website and blog to ensure their updating and suitability.

<u>Change in regulations, as well as unexpected risks due to external context</u> (e.g., partner drop out). The MC will reassign responsibilities, redefine objectives and seek for new partners and participants. To respond to the mentioned and unexpected risks, this Action will constantly self-monitor its activities (see examples of indicators above) and include the following structures.

The **Management Committee** comprised of representatives from each of the participating countries, will be led by the Chair and the Vice Chair. The MC will act to ensure the strategy, coordination, implementation, allocation, use of funds, intellectual property rights issues, and the management of the Action as detailed in the Rules for COST Actions COST 089/21. The MC will bi-yearly oversee further work based on information collected and reports obtained from WG1, monitoring the milestones achieved and the results obtained. WG1 will provide the MC with all data needed and will implement its decisions. The MC will invite social organizations, caregivers' and patients' representatives, scholars, researchers, managers, policymakers, and professionals from institutions implicated in the targets and objectives to participate once in its meeting. MC will be in constant contact with NRs, who will be responsible for the coordination of activities within their country, collecting data, reporting to MC on



legislation, rules, policies, or practices related to the objectives of this Action, and identifying stakeholder representatives at the national level. They will contribute to assessing and monitoring the successful progress of this Action. This Action will have a NR in each of the participating countries. Multiple encounters may be organised throughout the Action, promoting the role of the NR, which is key to the sustainability of the impact of this Action.



The leader/s of each WG will be responsible for the coordination of activities within their WG and with other WGs to meet the objectives defined in the work plan and will coordinate the submission of outreach materials on the website and blog of the Action. They will also be responsible for collecting and providing data to assess the progress of the Action and give alerts about potential deviations and biases. They will take responsibility for promptly

identifying potential problems in the execution of the work plan of the WG and Action, for taking appropriate measures, and for reporting to the MC whether they require immediate attention. They will meet every quarter, usually via electronic communication.



4.1.4. GANTT DIAGRAM

Each participant will choose, according to their needs and particularities, the moment of realization of the national workshops and face-to-face meetings. The period available for such activities is indicated in peach colour.