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Vanderstichelen, S., De Moortel, D., Nielsen, K. [orcid.org/0000-0001-9685-9570](https://orcid.org/0000-0001-9685-9570) et al. (9 more authors) (2024) Developing and evaluating Compassionate Workplace Programs to promote health and wellbeing around serious illness, dying and loss in the workplace (EU-CoWork): a transdisciplinary, cross-national research project. *Palliative Care and Social Practice*, 18. ISSN 2632-3524

<https://doi.org/10.1177/26323524241281070>

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# Developing and evaluating Compassionate Workplace Programs to promote health and wellbeing around serious illness, dying and loss in the workplace (EU-CoWork): a transdisciplinary, cross-national research project

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## Abstract

**Background:** Most employees will experience serious illness, caregiving, dying and loss (End-of-Life (EoL) experiences) at multiple points throughout their working lives. These experiences impact affected employees but also their colleagues in terms of health and wellbeing, and the workplace as a whole in terms of workplace safety, productivity and labour relations. The impact of EoL experiences on employees means that workplaces are called to play a more active role in providing support for EoL experiences.

**Aim:** To describe how the EU-CoWork (2024–2028) project addresses its main aims to (1) create Compassionate Workplace cultures, practices and policies and improve health and wellbeing for employees dealing with EoL experiences in different national work contexts in Europe; (2) describe and evaluate the process of co-creation and implementation of Compassionate Workplace Programs (CWPs) and how these influence the programs' outcomes.

**Design:** EU-CoWork employs a facilitated and co-creative Developmental Evaluation approach to the development of 12 tailored CWPs across four European countries (Belgium, Austria, Sweden and Greece).

**Methods:** To evaluate the outcomes and processes leading to these outcomes, a mixed-methods Realist Evaluation methodology is applied, formulating and testing Context-Mechanism-Outcomes configurations and combining longitudinal quantitative and qualitative data collections.

**Results:** EU-CoWork will generate evidence to support an expanded model of occupational health and safety risk factors sensitive to the specific challenges related to employees' EoL experiences. In doing so, several challenges will have to be navigated: involving employees with EoL experiences while avoiding overburdening them, avoiding tokenistic engagement, managing power differentials, balancing the need for scientific rigour with the flexibility required in co-creation, reconciling different epistemologies and disciplinary traditions and organisational resistance to change.

**Conclusion:** There are potential long-lasting broader societal impacts through the stimulation of open discourse on EoL topics, the reconciliation of work and care, and changes in gendered work and care patterns.

**Keywords:** Compassionate Workplaces, End-of-Life, occupational health, public health, realist evaluation

Received: 3 June 2024; revised manuscript accepted: 20 August 2024.

*Palliative Care & Social Practice*

2024, Vol. 18: 1–15

DOI: 10.1177/

26323524241281070

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## Background: Rationale and aims of the EU-CoWork project

Serious illness, caregiving, dying and loss are social more than medical experiences, requiring social responses alongside health service interventions.<sup>1</sup> Most people generally encounter these experiences (called End-of-Life (EoL)) and their consequences in the families, homes and communities where they live, the schools where they study and the places they work. Indeed, most employees will experience serious illness, caregiving, death and loss at multiple points throughout their working lives.<sup>2</sup> Estimates suggest a substantial proportion of the workforce is impacted by EoL experiences each year, either as seriously ill themselves, providing informal care to someone in this situation,<sup>3</sup> or experiencing loss of someone close to them.<sup>4</sup> Based on these estimates, in an average workplace of 100 employees, about 15–17 will be family carers each year. Of these, eight will be caring for someone with a serious (chronic or terminal) illness, and nine will be dealing with the loss of a close relative. Additionally, (even) more employees will experience the loss of non-relatives and personal losses, such as miscarriages. A small number will cope with the consequences of serious illness themselves. Studies indicate a large proportion of the adult population have one (e.g. 60% of US adults<sup>5</sup>) or more (42%<sup>5</sup>) chronic conditions and that a large share of people with chronic and serious illnesses (e.g. 25% in the Netherlands<sup>6</sup>) are actively employed.

These experiences impact affected employees but also their colleagues and the workplace as a whole in various possible manners. In addition to their work responsibilities, employees with EoL experiences must carry the burden and worries of providing care to someone with a serious illness or may be exhausted from grief or living with a serious illness themselves. Fatigue and sleep deprivation are in turn risk factors for developing chronic conditions<sup>7</sup> and decrease physical and cognitive reaction and accuracy, increasing the risk for accidents and injury at work.<sup>8</sup> This may result in an increase in absenteeism and increased safety risks due to demanding family and work roles, fatigue and lack of concentration, and also a loss of productivity. For instance, the time demand of family caregiving is estimated to be substantial, with many providing care for more than 10h/week, often for several years, which may increase in time and intensity when providing EoL-related care. Vicente et al.<sup>9</sup> found that 40% of working family carers experience

hindered work ability and 31% face career advancement obstacles. Ekman et al.<sup>10</sup> estimated that informal caregiving costs around 3% of the Swedish GDP (equal to approximately 13 billion EUR/year), with 55% of costs from lost productivity and the rest due to caregiver time, out-of-pocket expenses and lost sleep, which negatively impacts individual health and workplace safety. At workplace level, labour relations and communication can also be affected by these experiences and workplace responses to them. According to Hospice UK<sup>11</sup> estimated 57% of employees experienced bereavement in the past 5 years, but only 17% of managers were comfortable providing support in such situations, while over 75% of younger workers reporting they would consider leaving the workplace if they felt the workplace was unsupportive to EoL situations.

These challenges for workplaces in Europe are predicted to increase for a variety of reasons. First, the workforce is expected to age, with later labour market exit ages.<sup>12</sup> Second, the old-age dependency ratio, that is, the proportion of people 65+ to working-age adults, is rising fast.<sup>13</sup> Third, the number of individuals needing serious illness care or palliative care is projected to rise.<sup>14</sup> These trends mean that substantially higher proportions of employees will cope with serious illness and/or cognitive and functional decline while working, will manage intensive family caregiving responsibilities simultaneously with work, and will deal with bereavement while in the workplace. Furthermore, rapid changes like increased digitalisation in work life leading to less human contact, and changing job demands may leave employees feeling less supported when facing EoL experiences.<sup>15,16</sup>

These impacts of EoL experiences means that workplaces are called to play a more active role in providing support for employees experiencing EoL challenges, with substantial implications for physical and mental health and wellbeing. Despite this recognition, EoL experiences often are still seen as external risk factors beyond the scope of workplace safety, health and employee wellbeing programs. As a result, most workplaces lack strategies to address these disruptive life events.<sup>17</sup> In the emergent literature on ‘Compassionate Communities’ (see Box 1), the development of ‘Compassionate Workplaces’ has been suggested as an appropriate social-ecological health promotion response to the described challenges.<sup>1</sup> The underlying idea of Compassionate Workplaces is that workplaces use

**Box 1.** Compassionate Communities.

Compassionate Communities are multidimensional, whole-systems approaches to improve community circumstances related to serious illness, death, dying and loss.<sup>19</sup> They are 'communities that invest in and promote individual behaviour, group strategies or societal structures or policies that prevent or reduce suffering resulting from experiences of serious (mental or physical) illness, death, dying and loss; actively promote health and wellbeing, community support and empowerment of community members affected by such experiences; and actively acknowledge these experiences as natural parts of daily life'.<sup>1</sup>

participatory approaches<sup>18</sup> to develop policy and actions to improve the work circumstances, health and wellbeing of those directly and indirectly facing EoL experiences. However, while the theoretical concept has been described, and resources and materials are (sometimes freely) available to workplaces, empirical insights on how to cultivate Compassionate Workplaces are largely absent. This creates critical knowledge gaps: we lack guidance about how to design and implement effective Compassionate Workplace Programs (CWPs); there is limited understanding of the specific processes and outcomes that result from such programs; as well as little data about how and why they contribute to change.

The EU-CoWork project was designed as an innovative transdisciplinary, cross-national project to develop, implement and evaluate CWPs and provide an evidence basis for such programs. The overarching project objectives are to (1) create Compassionate Workplace cultures, practices and policies to improve health and wellbeing for employees dealing with EoL experiences in different national and work contexts in Europe, (2) describe and evaluate the process of co-creation and implementation of our CWPs and how these influence the programs' outcomes.

The current article describes how the newly initiated EU-CoWork project (2024–2028) will be implemented to address these objectives. The key questions are: (1) what are the characteristics of a CWP? (2) what is an appropriate approach to develop such programs? and (3) what research designs, frameworks and methods can be used to rigorously evaluate development processes and outcomes of CWPs across a wide variety of national and workplace contexts?

### The EU-CoWork project

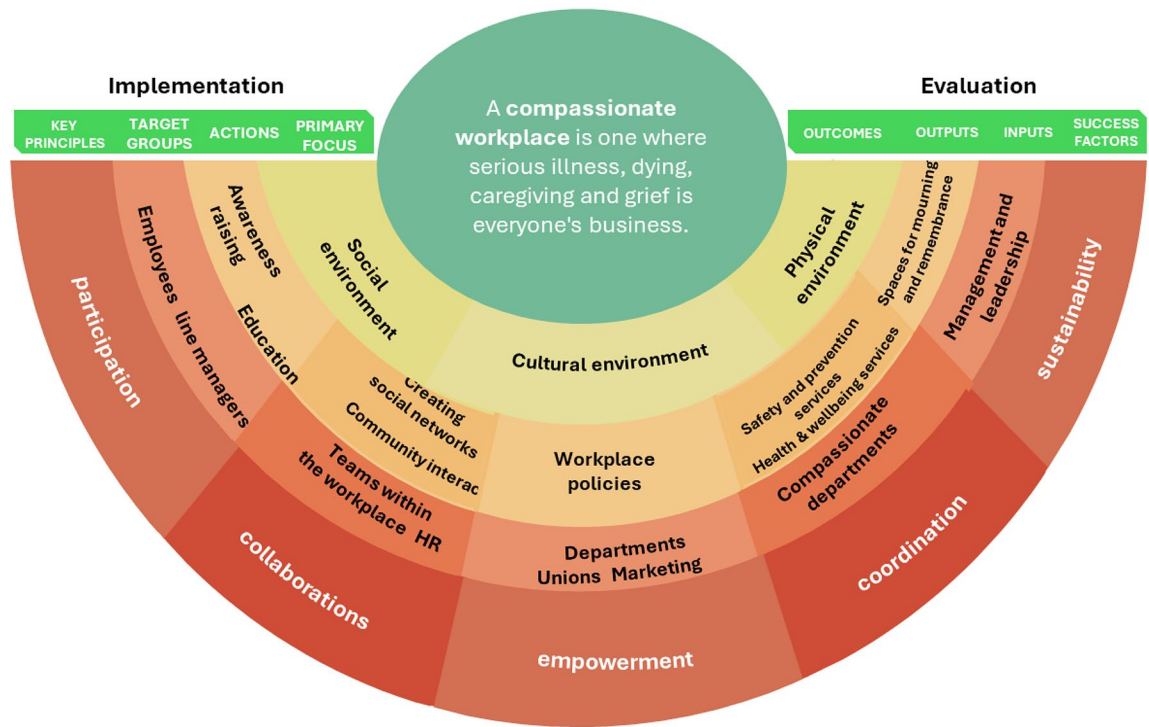
#### *What are characteristics of a CWP: Defining a CWP*

We refer to Compassionate Workplaces as work environments in which workplace leadership (i.e.

management and others in positions with power and mandate for decision-making) and employees develop deliberate policies and actions to support experiences of serious illness, caregiving, dying and loss. This entails a work environment in which members collectively notice, feel and respond to the suffering and pain of other employees. Leadership within the workplace should explicitly commit itself to help by offering support, finding solutions together with others and encouraging employees to support their co-workers with EoL experiences. A Compassionate Workplace is a specific form of Compassionate Community.<sup>1</sup> Based on an understanding of health promotion, a Compassionate Community develops proactive and salutogenic means<sup>20</sup> of dealing with serious illness, loss, dying, death and bereavement in the places in which we live, love and work.<sup>21</sup> It recognises the important impact of community (including within workplaces) and social connectedness on mortality<sup>22</sup> and wellbeing.<sup>23</sup> A Compassionate Workplace thus refers to the working world as a living world that does not ignore issues of vulnerability, finiteness and dependency. By proactively acknowledging and addressing these issues, the world of work also becomes a more humane, health-promoting environment.

In EU-CoWork, we view Compassionate Workplaces as a social ecology approach<sup>24</sup> that aims to make the workplace one where serious illness, dying, caregiving and grief are everyone's business and not an a priori endpoint or a matter exclusively for specialist or wellbeing services, or those directly affected. Figure 1 provides a conceptual illustration of how a CWP operates.

CWPs are developed in accordance with two *key principles*: they must be (1) *participatory*, based on collaboration and trust among involved stakeholders and researchers and they must (2) strive towards *empowerment of workplaces to support employees*. In line with a system-theoretical understanding of workplace development and

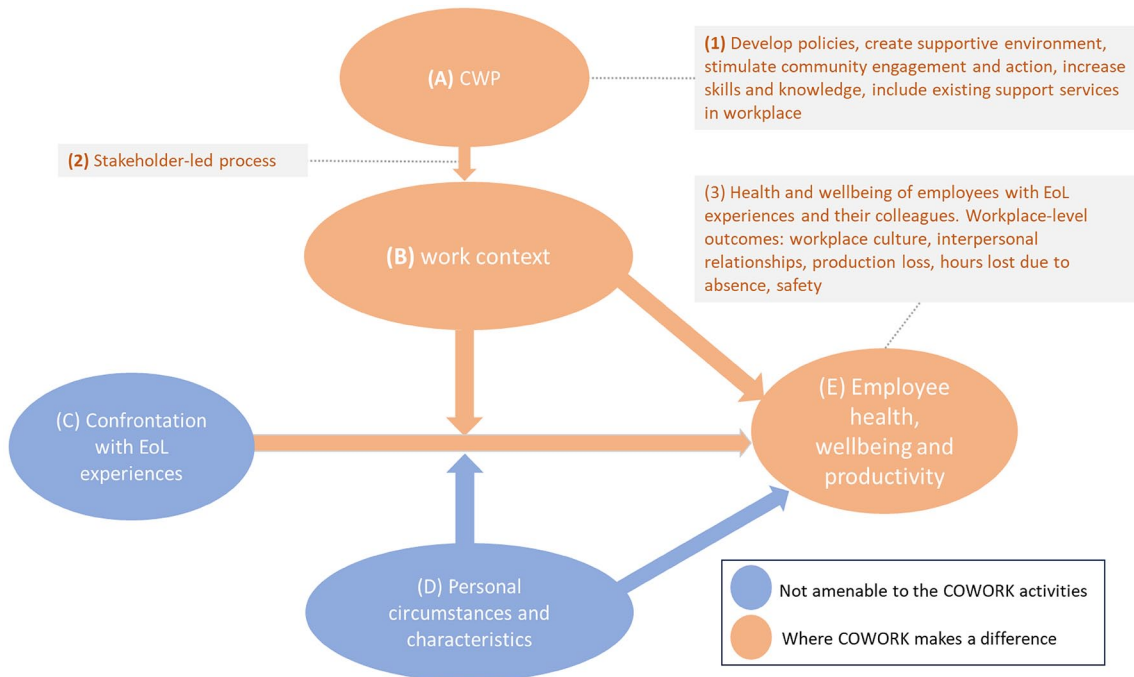


**Figure 1.** Conceptual illustration of a Compassionate Workplace.

the promotion of a caring organisational culture,<sup>25</sup> CWP development will thus NOT entail programs that are implemented by an external agent or organisation together with management or a particular service. Their development will be a facilitated process in which each country will have a dedicated facilitator who will guide and support the project work on, for example, mapping assets and needs, building a plan of action, evaluating the activities and adjusting the activities. Sustainability is an explicit aim, as the CWP should be able to continue and further develop after the study concludes and the facilitators leave the workplace. CWPs work with and for the *different stakeholders* at the workplace. Stakeholders can include employees from different levels, units and/or departments of the organisation (e.g. employees with and without EoL experiences, managers and leaders at different organisational levels, union and safety representatives, HR, marketing, and safety, prevention, health and wellbeing services). CWPs intend to be inclusive of the different employees, structures or departments of the workplace. Working *with* stakeholders means that *activities or actions* are developed jointly and working *for* stakeholders means that these are aimed at raising awareness, enabling questions about care and EoL experiences to be openly

addressed and discussed, educating, improving social connection, developing policies, creating places of solace and stimulating community participation. These activities target a *social, physical and cultural environment* that is supportive of all types of EoL experiences and highlight and potentially address fundamental structural barriers (in terms of policy, social security, etc.), even if they cannot be solved within the workplaces within the duration of the project. The identification of such barriers could serve as inspiration for possible workshops, creating awareness of the broader social context (e.g. compatibility of care and employment) and may act to open dialogue at a policy level.

Figure 2 illustrates the assumed contributions of CWPs, highlighting aspects that we deem amenable to change through the CWPs. The CWPs target the workplace (including work organisation, work content, work and employment conditions and work relations) relying on a stakeholder-led but facilitated process (2) for this. EoL experiences have direct impact on the mental and physical health and wellbeing of those confronted with the experience.<sup>26</sup> But we also consider the indirect impact of employee EoL experiences on colleagues and team as relevant exposure. Through



**Figure 2.** EU-CoWork conceptual basis.

adjustments in work context due to the activities of the CWP, the negative impact of EoL experiences on the health, wellbeing and productivity of these workers can be reduced. As such, a CWP work context can be an important moderator of the detrimental influence of EoL experiences on health, wellbeing and aspects of productivity. Moreover, not only employees and their colleagues confronted with EoL experiences will benefit from the intervention, also employees and workplaces not (yet) confronted with EoL experiences can benefit since a supportive work environment fosters overall wellbeing and safety. This, in turn, enhances productivity and safety, as CWPs also target workplace-level outcomes. In this conceptual model, we also recognise that both EoL situations and means of dealing with them vary based on numerous factors beyond our influence (e.g. personal circumstances and characteristics, structural-political and legal issues at different levels, such as labour laws, care or hospice leave conditions), which might enhance or weaken the positive effects of the CWPs.

#### *Approaches to development and development process of the CWPs*

*Developmental Evaluation as an intervention approach.* Based on the conceptual clarifications, it follows that the development process of CWPs

intrinsically needs to be a co-creative process that aims to reorient settings, thereby creating ongoing change and adaptation, building on existing strengths. CWPs are emerging initiatives that are asset-based, focused on experiential knowledge exchange without prior assumptions about what knowledge is relevant, and strongly based on facilitation and tailoring. This means that traditional approaches to implementation, following clearly defined and predetermined plans and where the focus is on standardisation and implementation fidelity are not appropriate for CWPs. We identified Developmental Evaluation (DE) as a suitable approach. DE was first described by Patton in the mid-1990s as a distinct approach to evaluation with the explicit purpose of helping to develop and shape an innovation, intervention or project that is emergent, complex and dynamic.<sup>27</sup> The focus of DE is on reflection, learning and change to enable projects to adapt to the emerging complex environments in which they are situated.<sup>28</sup> In DE, the plan, action and evaluation run parallel and can influence each other along the way. As such, a DE approach enables the CWPs to adapt quickly to any changes in the environment or to new learnings that emerge, thereby also generating and advancing knowledge about the initiative in the field. In short, DE is highly compatible with the core features of CWPs as described above and is appropriate when working

in complex environments where the route to change is non-linear and cannot easily be predicted beforehand. Rapid evaluation with rapid feedback becomes part of the intervention as data are systematically gathered, interpreted and used to make decisions regarding the development.

The concrete operationalisation of our DE approach implies that in each participating workplace, a *core development group* is established, composed of different relevant stakeholders (representing the different departments and employee categories in the organisation), a Compassionate Workplace facilitator (trained by the project) and an EU-CoWork national researcher. The core development group will be involved in the decision-making process of the CWP, yet for an asset and needs assessment of the workplace strengths, resources and capacities (at the start of the ‘intervention’) all employees (beyond the core development group) should be consulted.

*Characteristics of the CWP development process.* The immediate work context, the broader societal context in which each workplace is embedded (e.g. labour policies, employment conditions, available resources), and workplace organisation will vary strongly between countries, sectors, industries and individual workplaces. As such, our CWPs must be tailored to the context, needs and strengths of each participating workplace. EU-CoWork’s CWP development process therefore distinguishes six core components (standard in every CWP): (1) preparation, (2) asset and needs mapping, (3) the facilitated co-creation of outputs, (4) facilitated knowledge exchange workshops, (5) communities of practice (CoPs)/learning network and (6) use of an inspiration guide. These will contribute to specifically tailored activities in each workplace.

*Core component 1: Preparation:* Upon identification of relevant stakeholders, the core development group will be established. Relevant stakeholders from the workplace will be identified and invited based on having relevant knowledge and experiences that can contribute to the co-creation process, as well as willingness and availability to attend meetings.<sup>29</sup>

*Core component 2: Asset and needs mapping:* For the CWP to be context-driven and tailored to the involved workers, an asset-based and needs-informed approach is taken throughout the CWP

development process. An asset-based approach moves from a problem-based focus to a salutogenic approach,<sup>20</sup> focusing on factors that promote wellbeing and resources that support this. This means that each workplace’s existing strengths, resources and capacities are utilised in a transformative process. First contacts with the workplace include discussions on the co-creation process, and an agreement on the roles and responsibilities.<sup>30</sup> These are done jointly by a facilitator and a researcher using tools such as asset mapping and needs assessment interviews, that will be available to them in a facilitator manual.

*Core component 3: The facilitated co-creation of outputs:* An experienced facilitator assists each workplace in the development of their own CWPs. The facilitator will be experienced in enhancing participation, co-creation methods, guiding adaptation processes, familiar with EoL topics and will have a relevant background, for example, in occupational health or health promotion. The facilitators will receive both initial and continued training and support for the CWP development process through the EU-CoWork project. A CoP is set up to guarantee continued training through ongoing exchange of expertise and experiences.

*Core component 4: Facilitated knowledge exchange workshops:* Given the aim to engage with the workplace community and create momentum for workplace-wide change, the facilitator and the core development group will organise at least two workshops or events with the extended workplace focused on experiential learning and knowledge exchange. Experiential learning is the process of learning through experience, more specifically defined as ‘learning through reflection on doing’. Experiential learning has proven to be an important feature in a variety of formal and informal educational endeavours seeking to increase abilities to deal with EoL situations. One means of implementing experiential learning is through a process of knowledge exchange, that is, sharing of experiences and exchange of ideas leading to action, in a reflective cycle (see Johansson<sup>31</sup>, p. 84). The facilitator will offer guidance and inspiration (including that compiled in an inspiration guide, see core component 6) on possible and appropriate workplace-specific formats to organise these.

*Core component 5: CoP/learning network:* EU-CoWork will facilitate a learning network

across all participating countries developing CWPs (i.e. Belgium, Greece, Austria and Sweden) to which all workplace core development groups are invited to participate and exchange experiences, knowledge and inspiration. This network will convene approximately every 6 months and is expected to help expand knowledge beyond the individual workplaces.

*Core component 6: Inspiration guide:* A compilation of existing resources used in other settings is being developed to serve as an inspiration about a range of potential activities, to support workplaces in deciding about their own activities. The inspiration guide is first and foremost intended as an instrument to encourage the facilitators and the core development group rather than a normative product from which ready-made interventions can be copied and pasted into the workplace. It is important that ideas used from this guide are adapted to the specific context, needs and characteristics of the workplace in question as part of the co-creation process.

*Workplace-specific activities.* The type of activities or interventions that will be decided by the workplaces as part of the CWP development process will be workplace-specific and generated through the six core components described above. The activities are emergent and therefore unpredictable, but will be classified according to six action domains:

1. *Development of policies* (e.g. revising and developing policies that support and foster a culture of openness, experienced support and a stigma-free environment around EoL experiences, workplace agreements that might include legal requirements for flexible working hours, days off and support formats).
2. *Adaptations in the social and physical environment* (e.g. physical space for solace and rituals, awareness-raising moments and awareness-raising communications, community-building activities to strengthening relationships and social participation).
3. *Reorientation of existing wellbeing services within the workplace* (e.g. existing wellbeing-related services, if there are any, integrate the topics of the Compassionate Workplace in their functioning).
4. *Activities to increase skills and self-efficacy* (e.g. how to talk/be supportive in situations of grief; leadership training). A specific

activity will focus on increasing skills to create compassionate leaders and a Compassionate Workplace culture.

5. *Knowledge exchange and support groups* (e.g. creating support groups and buddy systems).
6. *Stimulation of community initiatives* (e.g. spontaneous, self-organised, bottom-up and continuous community activities around the topics).

*Selection of workplaces.* We seek variation in sector, socio-demographic profile of employees as well as workplace size in the workplaces participating in EU-CoWork. Using purposive sampling, we will recruit three workplaces in each of the four implementation countries (Belgium, Austria, Sweden and Greece), that is, 12 in total. Each national team will be responsible for recruitment in their country and will – in a concerted effort, across the four countries – purposively select a heterogeneous theoretical sample of work environments that reflects variation in characteristics based on different industries and sectors, organisational size, type of workplace transition (e.g. degree to which workplaces are engaged in digital and green transitions) and socio-demographic profile of the workforce. Some project partners have existing client bases of workplaces (e.g. the External Service for Prevention and Safety at Work (IDEWE) in Belgium) or are themselves network organisations around care and health promotion (e.g. Sorgenetz in Austria); others will work via their professional networks.

*Identification of appropriate research designs, frameworks and methods to evaluate the development process and outcomes of CWPs*

The immediate work context (Figure 2 – B), the broader societal context in which each workplace is embedded (e.g. labour policies, employment conditions, available resources), and the degree to which work transitions like digitalisation influence workplace organisation can all be expected to vary between countries, sectors, industries and individual workplaces. Moreover, as we established CWPs to be highly participatory, complex, adaptive, multi-stakeholder and dependent on community-specific priorities, a subsequent challenge is to identify research approaches that are commensurate with this.<sup>32</sup> We concur with other scholars who have argued that studying such initiatives requires a shift away from more traditional research designs predicated on linearity and



**Table 1.** Examples of Context-Mechanism-Outcomes (CMO) configurations.

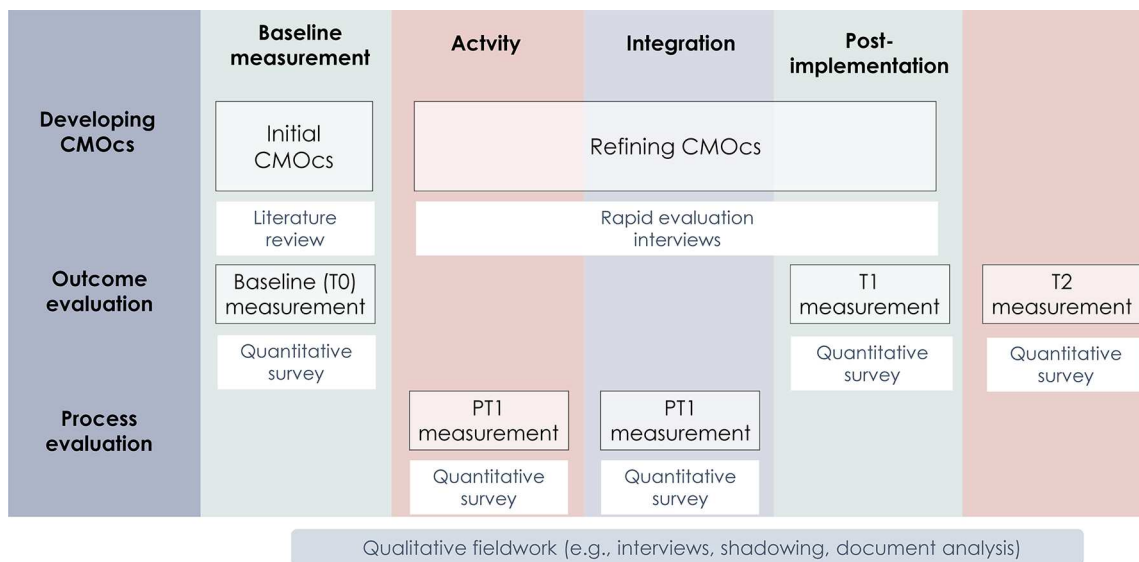
Context	Mechanism	Outcomes
If there is a culture of speaking openly about sensitive issues, . . .	. . . then senior managers will be able to communicate openly with staff about the bereavement of a colleague and employees will openly share their feelings . . .	. . . and as a result employee wellbeing will increase
If there is space for reflection, . . .	. . . then employees will be able to reflect on their situation . . .	. . . and as a result their wellbeing will increase
If company agreements explicitly include issues of care, dying, death and mourning . . .	. . . workers can take care or hospice leave without a guilty conscience . . .	. . . and as a result the workers will have legal security in dealing with care tasks and the care-oriented self-image of the organisation becomes clear

predictability.<sup>33,34</sup> Traditional process evaluation methods focus strongly on elements such as reach, quality of implementation, dose and fidelity and assume a priori determined and linear intervention logics. Traditional paradigms addressing the causality question of what outcomes a program produces tend to also focus on assumptions of linearity and control. The question that presented itself was how to study CWPs with methodological rigour while at the same time remaining true to the principles and philosophies of the programs. We identified a combination of approaches to data collection and data analysis as useful. These include a Realist Evaluation approach<sup>35,36</sup> to construct a program theory and drive the quantitative and qualitative data collection and a broad qualitative data collection to evaluate aspects of impact and contribution.

*Realist evaluation approach for data on process and impact evaluation.* Realist Evaluation is useful to evaluate and understand the impact of the CWPs and the processes leading to these impacts. Realist Evaluation is a recommended approach to evaluate organisational interventions.<sup>36,37</sup> It strives to learn from real-world phenomena, rather than trying to forcibly keep intervention conditions under control, thus enabling an in-depth understanding of the mechanisms of effective interventions in different contexts. This contextualisation is particularly important in different organisational and national settings as existing CWPs cannot be transposed. Realist Evaluation formulates initial programme theories (i.e. in the form of Context-Mechanism-Outcomes configurations (CMOCs)) with relevant stakeholders and tests them to explore the causal

mechanisms that are responsible for creating the impact of the intervention.<sup>37</sup> Examples of CMOCs that could be tested as part of the process evaluation are provided in Table 1. The EU-CoWork consortium will organise several workshops within the consortium to generate initial program theories that will later be refined through the initial contacts and preparatory conversations with the workplaces and throughout the development process. As such, Realist Evaluation aligns well with our participatory approach to the development of the CWPs and can help identify and understand unexpected and unfolding outcomes during the process of continuously developing the program.

For the Realist Evaluation, the project will employ a mixed-methods approach, combining longitudinal quantitative observational surveys with qualitative interviews, focus groups, document extraction (and analysis) and fieldwork. Data collection will follow the five-phase model<sup>38</sup> outlined in Figure 3. Quantitative data for the outcome evaluation will be collected at three timepoints: once at baseline (T0) when the workplaces join the project, once more 2 years later, after the tailored CWPs have been developed and implemented (T1), and one final time at T3 (=T0 + 3 years). Quantitative data for the process evaluation will be collected during implementation (activity and integration phases): once in the first year of joining the project (PT1) and once in the second year of the company's involvement in the project (PT2). Throughout the project, qualitative data will also be collected via fieldwork (e.g. interviews, shadowing, observational notes and document analysis) to contextualise and provide deeper understanding of the process of development and implementation and to provide impulse



**Figure 3.** Overview of the different data collections and phases in EU-CoWork.

for reflection regarding the adaptation of the implementation processes.

*Quantitative data collection for outcome and process evaluation.* Quantitative data will be collected to describe the current state of EoL-related needs and support structures and mechanisms in workplaces across Europe and to develop an understanding of the relationships between employee health and wellbeing, work organisation, workplace culture, employment relationships/conditions and other contextual aspects for employees facing EoL experiences and their colleagues. EU-CoWork will collect quantitative data to generate evidence on the impact of CWP on the mental and physical health and wellbeing of employees facing EoL experiences and their colleagues and on workplace-level outcomes including workplace culture and structural conditions, employee orientation, HR development, interpersonal relationships, production loss, hours lost due to absence and work overload (when substituting a colleague), team dynamics and distribution of work tasks. Finally, quantitative data will also be used to evaluate the economic value and cost-effectiveness of the CWPs and how the CWPs may help prevent financial losses due to confrontations with EoL challenges.

*Qualitative data collection for development adaptation and impact evaluation.* Qualitative data are collected to drive ongoing adaptations to our development processes (in accordance with DE

and to better understand the impact of the tailored CWPs in each workplace and the processes leading to this impact. Qualitative data will also provide insight into the contextual factors facilitating or hindering the implementation of CWPs and the mechanisms of the intervention.<sup>39</sup> Furthermore, qualitative data will be used to explore unexpected changes and ripple effects that are difficult or impossible to measure quantitatively. To this end we will utilise approaches such as the Qualitative Impact Protocol<sup>40</sup> which provides for collecting narrative statements from people within our target population (i.e. our collaborators and stakeholders described previously), and from the target setting (i.e. the workplace) in which we aim to create impact and long-lasting change. These qualitative data enable understanding of what factors contributed to the identified changes and will help us determine causal attribution, as validly and objectively as possible, in relation to the implementation of the CWPs and its consequences (within the limitations of the *real-world context* within which the implementations take place).<sup>41</sup>

*Analysis strategy.* The complexity of the health-promoting conditions of Compassionate Workplaces and the context-specific implementation processes of the 12 workplaces require methodological diversity in data collection and evaluation. Exploratory elements of analysis reflect the contextual conditions; impact analyses support exploration of the individual, organisational and

economic effects; process analyses will address changes over time quantitatively and qualitatively. Through the analytical and interpretative lens of Foucault's dispositive analysis,<sup>42</sup> the heterogeneous data types will be related to each other to capture the contours and implementation conditions of the 'Compassionate Workplaces' dispositive.

### Discussion

EU-CoWork was designed to address the negative impact of EoL experiences on the physical and mental health and wellbeing of employees and workplaces in different national and work contexts in Europe. The project aims to develop an evidence base for and subsequently develop, test and evaluate tailored CWP in an international, transdisciplinary research project. In this effort, we are guided by three questions regarding conceptual delineation, processes of co-creation and development, and adequate research methodology.

In developing our concept of Compassionate Workplaces, tailoring and adaptation to highly variable national, sectoral and workplace contexts proved crucial. This led to a development strategy in keeping with these principles, that is, co-creation and DE as development approaches and the outlining of six core components of a CWP. In considering how to combine scientific rigour with flexible methodologies that can adequately capture complexity, we decided on a Realist Evaluation design, encompassing diverse data collection and analysis strategies.

The EU-CoWork project illustrates both the opportunities for and potential contributions of research into social responses, outside the domain of health services, to address challenges related to serious illness, caregiving, dying and loss. However, taking this route also poses ethical, practical and methodological challenges. Although not exhaustive, we briefly discuss, first, some opportunities and potential contributions, and, second, a number of anticipated challenges.

#### *Opportunities and contributions of the EU-CoWork project*

*New funding avenues.* EU-CoWork was funded under an atypical funding stream for palliative and EoL care-related projects. Public health palliative care research has long argued the

importance of community and non-clinical settings in supporting people faced with the multidimensional challenges of EoL situations.<sup>43,44</sup> However, palliative care and more traditional medical and clinical research-focused funding streams provided limited opportunities (and sometimes understanding) for more social scientific approaches to the study of these challenges. EU-CoWork was funded under an occupational health call (HORIZON-HLTH-2023-ENVHLTH-02-02), illustrating that there can be opportunities for this type of research outside of funding streams 'traditionally' associated with it. Crucial ingredients for its success were first and foremost the interdisciplinary network setting in which social health scientists from palliative care research, labour sociologists, work and organisational psychologists, educational scientists, philosophers and economists were brought together to work on this proposal and its core ideas. Second, and a result of this interdisciplinary network setting, was the cross-fertilisation of ideas, methods, frameworks and epistemologies. This allowed ideas to mature over time and be reviewed in an open environment. Finally, it took courage and optimism, a belief that this original and out-of-the box idea – particularly in view of the call to which it was submitted – was worth investing our time and efforts into and stood a chance to get funded.

*Putting serious illness, caregiving, dying and loss on the occupational health policy agenda.* EU-CoWork is in a prime and strategic position to directly impact the occupational health policy agenda. To this end, the project will generate policy recommendations for occupational policies and practices based on strong scientific evidence generated in several mixed-methods implementation studies. The insights generated through this project will help expand a model of occupational health and safety risk factors sensitive to the specific challenges related to EoL experiences and help managers and policymakers understand how a working population that will increasingly be confronted with these EoL experiences can be better supported by their work environment.

*Achieving long-lasting societal impact.* We expect the development of these Compassionate Workplaces to result in a broader positive impact on society in several ways. First, by stimulating a reduction of burden in terms of human suffering, social exclusion, stigmatisation of the mentally and physically ill and distressed and their families and the resulting economic costs. Second, we

have the chance to contribute to a more open social discourse on issues of serious illness, care experiences, loss, dying, death and mourning, the reconciliation of work and care, and changes in gendered work and care patterns. Workplaces themselves will have the opportunity to become 'Death Literate Organisations',<sup>45</sup> champions in their sector in promoting healthier and more compassionate environments for employees. Third, the knowledge, skills and confidence to support others faced with EoL experiences around us acquired by employees in the workplace may also spill over into the lives of employees beyond work and can spread through communities via informal networks. Finally, EU-CoWork contributes to two key Sustainable Development Goals (SDGs). It promotes positive health and wellbeing across workplaces (SDG3) and fosters inclusive, sustainable and decent work for all (SDG8) by helping workers to balance productivity and mental and physical health.<sup>46</sup>

#### *Challenges of the EU-CoWork project*

In our chosen development and research approaches we anticipate a number of challenges that EU-CoWork's researchers and facilitators will need to carefully navigate.

The first set of challenges concerns the ethical aspects inherent to participatory research and asset-based co-creation. It is both likely and desirable, that people actively facing EoL challenges of illness, caregiving or loss will participate actively in the development of the CWP or the activities planned within them. However, at the same time, it is important to avoid putting unnecessary strain on them, as core assets across the whole project trajectory as they may already struggle with balancing job demands and resources. Tokenistic engagement or participation is also a typical trap for co-creation processes.<sup>47</sup> People with lived EoL experiences need to be assured that they are not merely seen as a diversity checkbox, or as a 'token' for the management within the project, but are instead equal collaborators in the development of solutions. Disappointments may also need to be mitigated as co-creation processes can lead to frustration if participants feel their recommendations are disregarded. The DE co-creation process, which will include input in the development process of various data collections within the workplace, also creates risks for privacy if some aspects (e.g. stories and suggestions) will be difficult to entirely pseudonymise.

A second type of challenge relates to the managing of power differentials between the different workers involved in the development process (e.g. between managers and floor workers and between the workers and the researchers and facilitators).<sup>48</sup> Communication skills and languages within each workplace's co-creative development may differ and present their own challenges. Mindfulness of the researcher's and facilitator's position, how to build trust, and work side by side with the worker will be attention points.<sup>49</sup>

A third type of challenge is methodological. A tension seemingly exists between, on the one hand, the need for rigour in the scientific methods and, on the other, the flexibility, adaptability and unpredictability of the co-creation process. Many research methods that are perceived as rigorous are often too structured and linear to be in keeping with the co-creation procedures (and may even be counterproductive to it).<sup>50,51</sup> What could be the most interesting method for data collection is not always the best method to engage with (sometimes vulnerable) persons in view of the co-creation process. The interdisciplinarity of the EU-CoWork project is a particular strength in handling the necessary balance between rigour and flexibility. However, the collaboration of groups with different research and practice traditions from occupational health, occupational sociology, work psychology, nursing, palliative care, public health, philosophy, economics and management also creates epistemological tensions. One such tension may revolve around how we conceptualise and subsequently measure the success of several co-created – and thereby tailored – interventions when processes and outcomes will differ and no control groups are available. Reconciling these tensions, by balancing different methods of knowing and validating knowledge but also by learning to 'speak the same language', will be a challenge in the management of the project. However, such a challenge also offers opportunities for interdisciplinary methodological innovation.

In addition to the ethical, practical and methodological challenges that researchers and facilitators will have to navigate, they will also need to develop skills and competence for the challenges of dealing with different types of workplace motivations for participating in the project, variability in resources of workplaces or possible organisational resistance. For that reason, EU-CoWork will invest strongly in training of facilitators and

researchers and continued training through a CoP – a community based on shared processes of social learning and idea-sharing through collaboration over extended periods of time.<sup>52</sup>

### Conclusion

The EU-CoWork project represents a novel approach to address the negative impacts of serious illness, caregiving, dying and loss on the health and wellbeing of employees and workplaces in different national and work contexts in Europe. The project will foster and evaluate CWP's through co-creation and rigorous but appropriate evaluation methods. Navigating the ethical, practical and methodological challenges inherent in co-creative development processes will be crucial for the project's success. However, EU-CoWork's broad interdisciplinarity and investment in facilitator and researcher training position it to well address these challenges. The project holds promise for significant scientific and societal impact. It will not only generate evidence-informed guidance for Compassionate Workplace Programs in different contexts but also aspire to contribute to a broader paradigm shift around our societal responses and health promotion strategies around serious illness, caregiving, dying and loss.

### Declarations

*Ethics approval and consent to participate*  
Not applicable.

*Consent for publication*  
Not applicable.

### Author contributions

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### Acknowledgements

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### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by Horizon Europe (Grant No. 101137223) and UK Innovate (Grant No. 10106747). Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the Health and Digital Executive Agency. Neither the European Union nor the granting authority can be held responsible for them.

### Competing interests

The authors declare that there is no conflict of interest.


### Availability of data and materials

Not applicable.

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