Compassionate Communities Centre of Expertise (COCO)

RESEARCHING THE DEVELOPMENT, IMPLEMENTATION AND SUSTAINABILITY, PROCESSES AND OUTCOMES OF COMPASSIONATE COMMUNITY APPROACHES TO SERIOUS ILLNESS, DEATH, DYING AND LOSS

SUPPORTED BY THE VRIJE UNIVERITEIT BRUSSEL (VUB) VIA THE INTERDISCIPLINARY RESEARCH PROGRAMME (IRP)

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Faculty of Social Sciences & Solvay Business School
- Tempus Omnia Revelat (**TOR**)
- Interface Demography (**ID**)

Faculty of Science & Bio-engineering Sciences
- Cosmopolis Centre for Urban Research (**Cosmopolis**)

Faculty of Psychology & Educational Sciences
- Belgian Ageing Studies (**BAST**)
- Clinical and Life Span Psychology (**KLEP**) & Brussels University Consultation Centre (**BRUCC**)
- Work & Organisational Psychology (**WOPS**)
- Brussels Innovation and Learning Diversity (**BILD**)

External document to define the mission, vision, strategy and structure of the COCO Centre of Expertise.

COCO Centre of Expertise
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1. Mission statement

1.1. Serious illness, death, dying and loss as part of life

We are all, at different and various points in our life, confronted with experiences of serious illness, death, dying and loss, regardless of our age, gender, location, or socioeconomic background. It is a fact of life, and as such, we cannot talk about life, without also talking about serious illness (mental and physical), death, dying and loss. These experiences affect our entire social environment, but today appear too often as taboo topics. Serious illness, death, dying and loss are social experiences with a medical component and not medical experiences with a social component. We find ourselves confronted with serious illness, death, dying and loss in our own families, neighbourhoods, workplaces, schools, groups of friends, and leisure communities or associations.

1.2. Creating a more compassionate society…

While the medical-professional sector treats the physical and psychopathological symptoms of serious illness, it is the community that cares for the often-neglected human and social issues that surround serious illness, death, dying and loss: social companionship, quality of life, mental and existential well-being, financial pressure, etc. The Compassionate Communities centre of expertise (COCO) believes that these experiences are part of life and should not be medicalised. COCO wants to create a more compassionate society in which communities have the capacity and know-how to provide care for their members during times of serious illness, death, dying and loss and to take on the social challenges associated with it. This shift in practice will require an even broader cultural shift and relevant expertise is currently lacking on many fronts.

1.3. …through Compassionate Communities

Compassionate Communities are places and environments that recognise "all natural cycles of sickness and health, birth and death, and love and loss that occur every day", in which community members and stakeholders from all sectors of government, the private sector and civil society actively work together to improve the circumstances and experiences of people facing serious illness, caregiving, dying and loss. Compassionate Communities recognise that care for others in these times is not simply a task for health and social services alone but is everyone's responsibility. Compassionate communities are environments that foster social connectivity, civic participation, empowerment, inclusion, respect and dignity. As inspirational practice, it combines social, political and environmental action to impact the influence of the social determinants of serious illness, death, dying and loss on health and wellbeing.

1.4. Aims of COCO as centre of expertise

The overarching mission of COCO is to develop itself into a national and international reference point for academics, practice and policy interested in Compassionate Communities as a model for care in times of serious illness, death and loss. The specific aims of COCO are:

- Build expertise: Conduct fundamental and applied research into the development, implementation, and evaluation of Compassionate Communities; collect existing national and international evidence- and practice-based knowledge, tools and other resources;
- Provide expertise: Disseminate evidence- and practice-based knowledge and resources through knowledge exchange and scientific, societal and educational valorisation aimed at researchers, students, communities, citizens, patients, caregivers and policymakers;
- Build a network: Stimulate and facilitate network-building and collaboration between researchers, communities, societal actors, policymakers, etc.

2. Conceptual groundwork

The definitions of the concepts below are not intended to be exhaustive nor prescriptive. Rather, they are the product of a continuing process of exploration, of new and emerging insights. They are intended to guide us in our research, to reflect our research, but not to define a priori how our research should be conducted. This document is intended to be a living document that will periodically be updated.

2.1. Towards a common understanding of 'Compassion'

2.1.1. Compassion as response to suffering

Compassion can be considered a response to suffering; a response that may be formulated and implemented at the individual (micro) level, the group (meso) level, and the societal (macro) level. Suffering itself may also take many forms and can originate from various experiences and situations throughout life. COCO is interested in particular in the suffering, both physical and mental, that originates from experiences with serious illness, death, dying and loss and the social challenges associated with these experiences.

2.1.2. Compassion as individual attribute (micro level)

Compassion is most often conceptualised as an individual attribute. Strauss et al. (2016) define it **as a cognitive, affective and behavioural process** that consists of **five elements** that refer to both self-compassion and compassion towards others. First, it involves the recognition of suffering. Second, it requires the understanding of the universality of suffering in human experience. Third, it requires an emotional resonance with the person, which is a feeling of empathy for the person suffering and connecting with the distress. Fourth, it entails tolerating uncomfortable feelings that are aroused in response to the suffering person (such as distress, anger and fear), such that the individual remains open to and accepting of the person suffering without judgement. This also means that compassion requires a certain detachment in order to be able to continue to be compassionate. Finally, compassion requires the motivation to act and acting to alleviate suffering. According to Perez-Bret et al. (2016, p. 602) a compassionate act is inherently ethical as "*it should overcome indifference, fear and distress, in an effort to ward off misfortune and hardship.*"

Strauss et al. (2016) provide an extensive description of the differences between compassion and concepts often mistakenly used as synonyms. Compassion requires but is different from *empathy* as the latter does not entail a desire to act or acting to alleviate suffering. It differs from *pity*, as pity assumes an unequal relationship and implies condescension. It differs from *altruism* as altruism has a greater focus on behavioural acts that may be at great personal cost to the person. Lastly, it differs from *kindness* as compassion may not always include kindness in the moment (e.g. tough love) and kindness is not only linked to suffering.

2.1.3. Compassion as a group attribute (meso level)

Inspired by the *Ottawa Charter for Health Promotion* and by *Community Development* approaches, **Compassionate Communities** employ bottom-up health promoting approaches and citizen initiatives to destigmatize caregiving, dying, death, and grieving through social and cultural sectors (e.g. museums, art galleries, media). Compassionate Communities take an active role in the care for people affected by experiences of serious illness, death, dying and loss, and empower community members by building supportive networks, raising awareness and literacy related to end-of-life issues (Karapliagou, Kellehear & Wegleitner, 2018). These community settings can vary and encompass workplaces, schools, neighbourhoods, etc.

2.1.4. Compassion as a societal attribute (macro level)

Compassion implemented at the macro level requires a **structural, systematic and sustainable approach** to providing long-term answers to the social challenges posed by experiences of illness, death, dying, loss and end-of-life care at population level. Compassionate cities, for example, structurally and visibly

embed the themes of (caring in times of) serious illness, death, dying and loss in all sectors of civil society through annually reviewed policy, public events, and incentive schemes.

When combining these frameworks at the macro and meso level, representing bottom-up and top-down approaches, mobilize the contributions of healthcare professionals and the social support of communities to increase our collective capacity for care in times of serious illness, death, dying and loss (Grindrod, 2020).

2.2. Defining Community

Communities are groups, large or small, that share something in common and may vary in scope, size, scale and strength of within-group ties (social relationships). A community can be defined (1) by a **shared location** (geographical communities) or (2) by a **shared interest** (communities of interest). Communities can provide their members with a sense of identity of varying strengths.

Geographical communities can be found at different scales and can encompass smaller scale communities that can be embedded in larger geographical communities. At the micro level, communities can be defined by a street, block, neighbourhood, or school. At the meso level, communities may be defined by a municipality, town or university. At the macro level, communities may be defined by cities, provinces, countries or continents.

Communities of shared interest may take many forms and may be entirely rooted in a geographical community or lack a geographical rooting entirely. They may be workplaces, unions, associations (music, leisure, sports, culture, art…), etc. They may also be online communities, political parties, advocacy groups, patient organizations, salad enthusiasts, etc.

People can be members of various communities at the same time, none, some or all overlapping, each with their own identity. Intersection of shared locations and shared interests can strengthen communities or even give rise to focused niche communities with a strong identity. Similarly, opposing interests or locations can weaken communities and their respective identity.

3. Vision: How to achieve a more compassionate society?

Creating a more compassionate society requires a cultural shift in how we, as individuals and as a society, deal with experiences of serious illness, dying, death, loss and the end of life. To achieve this, the COCO centre of expertise will need to drive (1) innovation, (2) public engagement and co-creation, and (3) shape public discourse.

3.1. Innovation in knowledge and practice

In order to drive this cultural shift, innovative knowledge and practices must be developed, collected, integrated and implemented to formulate new answers and approaches to the challenges outlined above. However, this innovation cannot come from one perspective and discipline alone.

The many ways in which situations of serious illness, death, dying and loss affect us can be considered a "wicked" problem. These are problems that are multidimensional (social, cultural, economic…) and difficult or impossible to 'solve'. They may appear and affect people differently and represent an interconnected cluster of challenges. Such complexity therefore requires an interdisciplinary perspective and integrated whole-systems solutions, involving sociology, psychology, demography, architecture, educational sciences, health sciences and more. Whereas *multi*disciplinarity uses theories and methods from different disciplines and keeps them separate and distinct, *inter*disciplinarity fully integrates them to develop new approaches and insights.

3.2. Citizen engagement and co-creation

Efforts to develop and implement community approaches to the social challenges associated with serious illness, death, dying and loss, should furthermore ensure that they are relevant, feasible and acceptable to those that will be affected by them. COCO therefore adheres to the principles of co-creation and participation through public engagement and Patient Public Involvement (PPI) at all stages – development, production, implementation and evaluation – of each of its individual projects. COCO will function as a facilitator and will share ownership fairly and equally with its stakeholders (the communities and their members).

To connect research and practice at the principal and fundamental level, the centre of expertise emphasises participatory action research (PAR) approaches, which bring together action and reflection, theory and practice (Reason & Bradbury, 2008, p.4) and involve stakeholders (e.g. community members, end-users…) in defining needs and priorities (Bowling, 2009, p.69). COCO will partner with cities, institutions and the societal sectors (e.g. education, employers, banks, healthcare schools, religious institutions), which shape our communities, to develop Living Labs, where knowledge and practices are procedurally generated.

3.3. Shape public discourse

As a centre of expertise, COCO should be a driving force in the public discourse on community approaches to and social challenges related to situations of serious illness, death, dying and loss in the community. The centre of expertise should be a visible and approachable entity for individuals and organisations with questions related to these themes. It should contribute to public opinion and help seek and reach consensus at the policy level.

4. Aims and strategy of COCO

COCO's mission can be divided into **three aims** and mapped onto two important pillars: academic and societal. (See **Table 1**.) These pillars often influence each other, tend to overlap and are sometimes intrinsically inseparable. This is acknowledged and represented by the jagged borders between both pillars in Table 1.

Table 1: COCO's aims mapped onto two pillars: academic and societal.

Academic Pillar ⇔	Societal pillar
Aim 1: Build expertise	
Develop new knowledge: conduct fundamental research into the development, implementation and evaluation of Compassionate Communities.	**Develop practice-based knowledge:** conduct applied research into the development, implementation and evaluation of Compassionate Communities and stimulate the generation of practice-based knowledge in living labs.
Collecting existing knowledge: national and international evidence, tools and other resources.	**Collect existing practice-based knowledge**: available resources and toolkits for practice.
Aim 2: Provide expertise	
Disseminate knowledge: Scientific publications, reports, methodological toolkits, conferences and conference contributions. Offer advice to other research groups and consortia. **Implement knowledge:** integrate the COCO themes and expertise into formal **university/college education**: new courses and curricula.	**Disseminate knowledge:** popular publications, evidence- and practice-based recommendations for policy and practice, offer advice to policymakers, civil society actors, non-profit organisations. **Implement knowledge**: integrate the COCO themes and expertise into informal **community education**, empowering citizens, patients, carers, policymakers and communities by increasing "death literacy."
Aim 3: Build a network	
Develop and maintain an academic platform for **knowledge exchange and collaboration between academic personnel** from various VUB departments and faculties who integrate the themes of Compassionate Communities in particular and care provision in times of serious illness, death, dying, and loss more broadly in their research and education.	Develop and maintain a societal platform to **stimulate and facilitate network-building and collaboration** between communities, civil society actors, policy makers and researchers and to stimulate **Personal and Public Involvement (PPI)** in COCO's research efforts and practice initiatives.

4.1. Aim 1: Build expertise (Academic pillar)

COCO's first aim is to build expertise by (1) **developing new knowledge** and (2) c**ollecting existing knowledge**.

There is a **strong need for a scientific evidence base** to support the development, implementation and evaluation of Compassionate Communities. To fill these gaps, **COCO will conduct and coordinate interdisciplinary fundamental and applied research** into Compassionate Community approaches to serious illness, death, dying and loss and the development and evaluation of Compassionate Community initiatives. COCO will achieve this through fostering new collaborations between academic researchers from different scientific domains and research groups, societal stakeholders from local communities, civil society organisations, companies, schools, healthcare services, etc.

Additionally, **much of the available expertise is currently located outside of Belgium**, with pioneering initiatives being developed and researched in the UK, Australia, India, etc. COCO intends to learn from this existing expertise through **research visits** and by **collecting the available knowledge to expand its knowledge base**.

4.2. Aim 2: Provide expertise (Academic & Societal pillars)

COCO's second aim is to provide expertise by disseminating knowledge and translating this knowledge into usable products for different audiences. The centre of expertise aims to do this in three ways. COCO will (1) **add to the scientific literature** by publishing research findings in international peer-reviewed journals and organising international scientific seminars and conferences (scientific valorisation); (2) **contribute to the public debate and empower communities** by developing and making available tools and resources for practice (societal valorisation); (3) **integrate Compassionate Community approaches** to care, serious illness, death, dying and loss and the conceptualisation of these issues as social challenges **into formal and informal education** (educational valorisation).

4.3. Aim 3: Build a network (Academic & Societal pillars)

COCO's third aim underlies aims 1 and 2 by building a community of interest, through the development of platforms for knowledge exchange and collaboration. Members will be kept up to date of COCO's progress, new insights, new resources and will be invited to all COCO seminars and other opportunities to connect digitally or face-to-face. COCO will first develop and maintain an academic platform for **knowledge exchange and collaboration between VUB academics** who integrate the themes of Compassionate Communities in particular and care provision in times of serious illness, death, dying, and loss more broadly in their research and education. Members will periodically receive news regarding calls, seminars, networking events, etc.

After the establishment of the academic platform, a societal platform will be added to **stimulate and facilitate network-building, idea exchanges and collaboration** between communities, civil society actors, policy makers and researchers and to stimulate **Personal and Public Involvement (PPI)** in COCO's research efforts and practice initiatives. Members will be invited to stakeholder meetings to discuss progress in COCO's research, explore existing and future resource and data needs, and will be kept up to date of new projects and opportunities to connect via a mailing list.

5. COCO Research Agenda

Below we outline a first research agenda for the COCO consortium. It is based on current knowledge gaps in the literature and the strengths and interests of the consortium members. This first agenda will evolve over time and is therefore subject to change.

5.1. Research objectives

COCO has **3 overarching research objectives**:

I. Develop a theoretical framework for Compassionate Communities, including an interdisciplinary research framework, incorporating various theoretical and empirical perspectives from different disciplines relevant to compassionate communities in diverse contexts: university, workplaces, municipalities, neighbourhoods, schools, etc.

II. Develop a methodological toolbox for research into Compassionate Communities: a collection of effective, feasible and useful methods to describe, analyse and evaluate Compassionate Communities in various contexts.

III. Describe, evaluate and evolve outcomes and processes of Compassionate Communities: both the different contexts and mechanisms that lead to changes in dealing with care, illness, death, dying, and loss will be examined.

These research results will be used to develop an evidence-based, user-experienced, user-tested and user-friendly **'roadmap'** and **'toolbox'** for Compassionate Community **development, implementation, and evaluation**.

5.2. Avenues for interdisciplinary research within COCO

Topics to explore in Compassionate Community research are wide ranging and interdisciplinary. Among the consortium members, three main research themes were identified for the centre of expertise to explore and more may be added in the future:

1. **Defining, and measuring compassion**
    - Development of a conceptual model of compassion as individual (micro), group (meso), and structural (macro) approach.
    - How can compassion and compassionate behaviour be stimulated and shaped?
    - What is the role of training, policy and awareness raising and how can their effectiveness be evaluated?
2. **Studying transitions towards and the sustainability of Compassionate Communities**
    - How do community members internalize or make sense of operationalizing new practices?
    - How do community members build and sustain a community of practice around compassionate community interventions?
    - How do community members appraise the ways that new sets of practices affect them and others around them?
    - How do community members reconfigure these practices over time?
    - Exploring social inequality and social determinants of serious illness, death, dying and loss
    - How can communities be (re)oriented to provide a space for serious illness, dying and loss?
    - Shaping compassion: how can art be used as a tool, medium or outcome of compassion?
3. **Compassionate community building in specific contexts**
    a. **Compassionate workplaces**
        - How do serious illness, dying and loss find a place in the work environment?

- What is the role of staff and workplace policy in creating individual and community capacity for care giving?
- Exploring the mediating role of job certainty / precariousness on the impact of drastic life experiences such as serious illness, family caregiving, death and loss.
- Improving the **work-life balance** for informal caregivers and people experiencing grief and loss through **psychological safety** at work. Psychological safety is a belief that one will not be punished or humiliated for speaking up with ideas, questions, concerns or mistakes.
- Exploring representation, diversity and intersectionality in policy on serious illness, family caregiving, dying and loss.

b. **Compassionate housing and (urban) design**
   - How can spatial design in housing contribute to creating compassionate communities?
   - How can housing contribute to creating new opportunities for care provision and build and maintain community ties?
   - How do neighbourhood networks facilitate the support and care for people in situations of serious illness and end-of-life experiences?
   - How is access to such supportive networks and housing circumstances distributed?

c. **Compassionate schools and learning environments**
   - What role do schools and other educational institutions have in stimulating compassion and as channel for processing experiences of serious illness, dying and loss?
   - Exploring health promotion and education as instruments to create options at the end of life
   - Exploring symbolism and meaning making in times of serious illness, dying and loss and the role of art, culture, education and participation in it.
   - Art as an instrument for promoting health and wellbeing at the end of life.
   - Representation, diversity and intersectionality in the public discourse on serious illness, dying and loss.

5.3. Living Labs

COCO will make use of living labs to foster research and social change. Currently 3 living labs are being developed: Compassionate University (VUB) and two Compassionate Cities (Bruges and Herzele).

5.3.1. Compassionate University (VUB)

In November 2019, VUB Chancellor, prof. dr. Caroline Pauwels, and the president of the VUB Board, Eddy Van Gelder, signed a declaration, committing the university to become Europe's first Compassionate University. This initiative is coordinated by a steering group consisting of researchers and representatives from student counselling, communication and IT, HR, and the rectorate and will develop concrete actions and initiatives to foster a more compassionate environment. The Compassionate University actively offers opportunities to VUB researchers and master students to contribute to this environment through on-campus research and by facilitating data collection.

5.3.2. Compassionate Cities

The cities of Bruges (BE) and Herzele (BE) are both developing into Compassionate cities in a large collaboration between VUB researchers (EoLC), the local governments of Bruges and Herzele and a wide range of local civil society stakeholders. Both cities have signed the Compassionate City charter which outlines several efforts a city can make to make itself a warm and caring environment that is sensitive to the challenges surrounding experiences of serious illness, death, dying and loss. These two cities therefore present researchers with numerous opportunities to study and evaluate this ongoing social change process. [See the separate overviews for more details of these Living Labs.]

6. Structure of and roles within COCO

Table 1: Research Teams involved (all VUB teams) in COmpassionate COmmunities centre of expertise (COCO)	
Faculty of Medicine & Pharmacy • End-of-Life Care Research Group (**EOLC**) **Faculty of Social Sciences & Solvay Business School** • Tempus Omnia Revelat (**TOR**) • Interface Demography (**ID**) **Faculty of Science & Bio-engineering Sciences** • Cosmopolis Centre for Urban Research (**Cosmopolis**)	**Faculty of Psychology & Educational Sciences** • Belgian Ageing Studies (**BAST**) • Clinical and Life Span Psychology (**KLEP**) & Brussels University Consultation Centre (**BRUCC**) • Work & Organisational Psychology (**WOPS**) • Brussels Innovation and Learning Diversity (**BILD**)

Table 2: Supervising committee members and roles

Member	Role
Prof. dr. Luc Deliens (EoLC)	Chair and promotor
Prof. dr. Liesbeth De Donder (BAS)	Chair and promotor
Prof. dr. Joachim Cohen (EoLC)	Co-promotor
Prof. dr. Kenneth Chambaere (EoLC)	Co-promotor
Prof. dr. Sarah Dury (BAS)	Co-promotor and scientific coordinator
dr. Steven Vanderstichelen (EoLC)	Scientific coordinator

6.1. COCO supervising committee and consortium

The **COmpassionate COmmunities centre of expertise (COCO)** is an **interdisciplinary research consortium** of 8 research groups across 4 VUB faculties. (See Table 1.) It is led by a supervising committee (see Table 2) consisting of the two leading partners – the End-of-Life Care research group (EoLC) and Belgian Aging Studies (BAS) – and coordinated by two postdoctoral researchers and one valorisation coordinator. (See Figure 2.) The members of the consortium meet twice per year to discuss progress in research, project funding and collaborations. The consortium collaborates to organize two seminars per year open to the wider public.

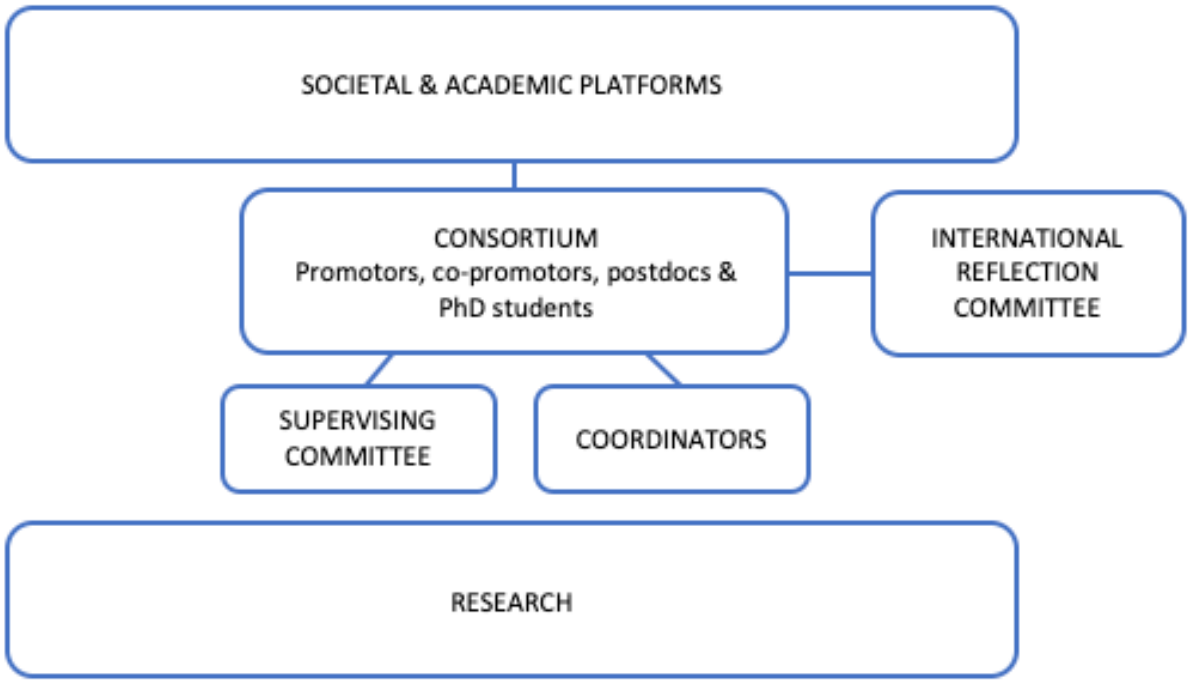

Figure 1: Structure of the Compassionate Communities centre of expertise (COCO)

COCO has 2 **scientific coordinators**, dr. Steven Vanderstichelen (EoLC) and prof. dr. Sarah Dury (BAS). They coordinate and support the generation of scientific knowledge, development of scientific project proposals and scientific valorisation work. They will support and facilitate the interdisciplinary collaboration and knowledge exchange between the COCO members and affiliated members and supervise PhD. students working within the consortium framework.

COCO's **valorisation coordinator** is responsible for gathering national and international, scientific and practical knowledge on Compassionate Communities and for building and maintaining an extensive knowledge repository accessible to the consortium partners and the wider public. The valorisation coordinator will also coordinate the valorisation and dissemination of knowledge within the consortium and within Belgium. Finally, the valorisation coordinator is in charge of general management of and support for COCO, including acquiring funds for valorisation initiatives, internal and external communication (including contact with the media), website management, and building and maintaining a stakeholder network. **COCO currently does not yet have an appointed valorisation coordinator.**

6.2. International scientific reflection committee

COCO is advised yearly by a group of international experts on Public Health Palliative Care and Compassionate Communities. Reflection committee meetings are organized coinciding with international scientific conferences where possible. [Committee to be determined.]

6.3. COCO's stakeholder network

COCO actively pursues citizen and user involvement in its work by maintaining an active and broad network of societal and academic stakeholders. Stakeholders are kept up to date through a mailing list and are actively involved and consulted via frequent network and knowledge exchange events and stakeholder committee meetings. [Stakeholder committee to be determined.]