

Compassionate Communities: Together for Palliative Care

World Hospice and Palliative Care Day Special Lecture 2023



Presented by:

Christopher A. Klinger, PhD

Joachim Cohen, PhD; Professor, Ghent University and Vrije
Universiteit Brussel (Belgium)

Jeffrey B. Moat, CM, Chief Executive Officer, Pallium Canada

Date: November 7th, 2023

Territorial Honouring



Agenda

Welcome

Christopher A. Klinger, PhD

Chair, End-of-Life Issues Theme Team, National Initiative for the Care of the Elderly (NICE)

Research Scientist, Pallium Canada

Assistant Professor (Part-Time), Dr. Joshua Shadd - Pallium Canada Research Hub, McMaster University

The Palliative Care ECHO Project –Update

Jeffrey B. Moat, CM

CEO, Pallium Canada

Special Lecture

Joachim Cohen, PhD

Professor of Public Health and Palliative Care

Question and Answer Session

Please click the Q&A icon and type your question(s) to the speaker(s) there, we will try to get to as many of them as possible.

Award Ceremony

Esme Fuller-Thomson, PhD

Director, Institute for Life Course and Aging, University of Toronto

Welcome and Reminders

- Please introduce yourself in the chat
- Your microphones are muted. There will be time for questions and discussion following the Special Lecture. Please add your questions in the Q&A function.
- Please use the chat function for comments or if you are experiencing technical difficulties.
- This session is being recorded and will be made available via Pallium Canada.



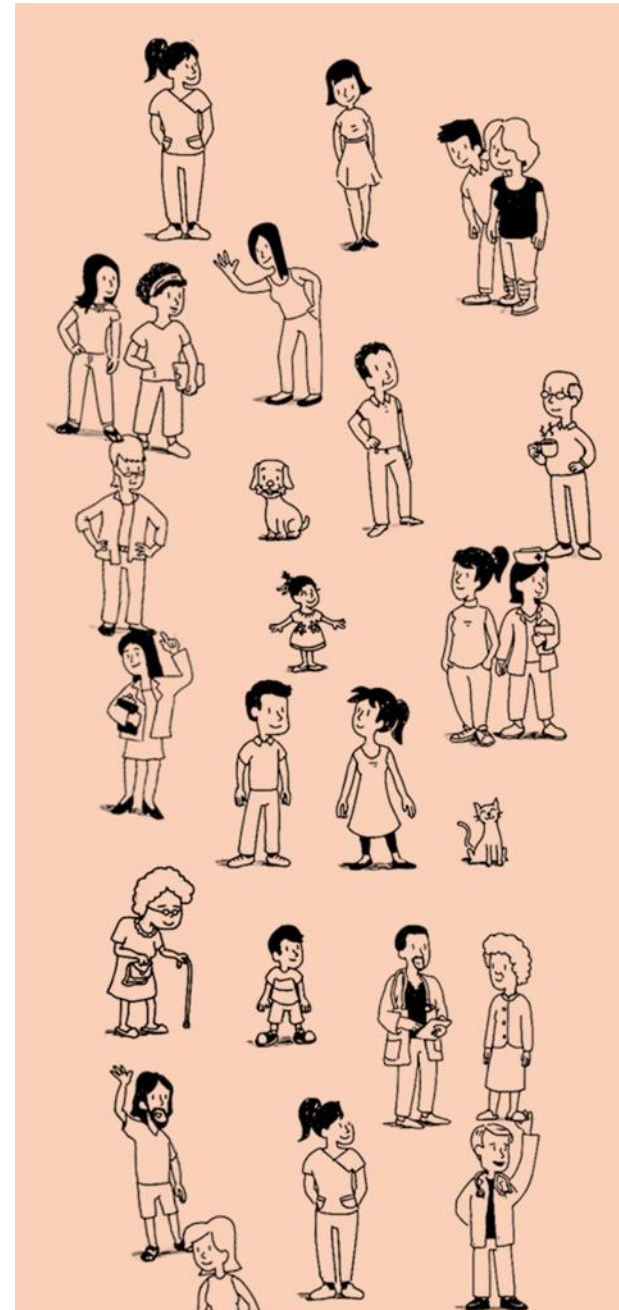
COMPASSIONATE COMMUNITIES
Together for Palliative Care
14 OCTOBER 2023
WORLD HOSPICE & PALLIATIVE CARE DAY

Care Connections Program

A suite of free resources and activities designed to support caregivers.

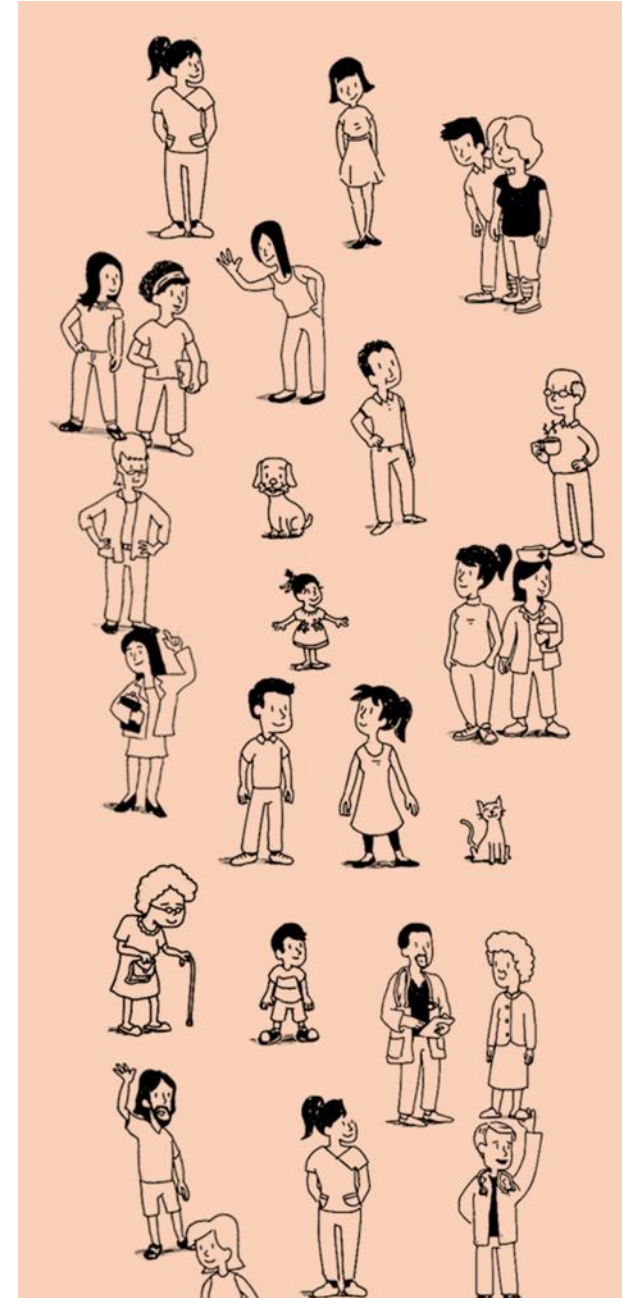
Purpose: Empower Canadians to better support the caregivers in their lives and to help strengthen the important social connections within our communities.

Target audience: All those providing care, and anyone interested in supporting a caregiver.



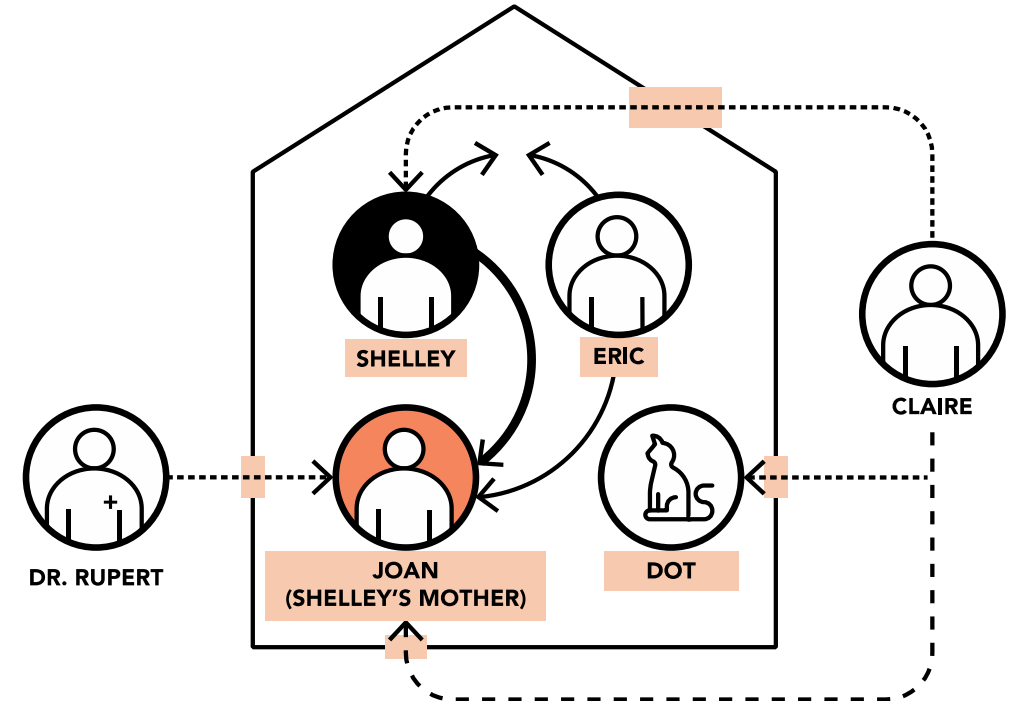
Care Connections Program

- What is included:
 - Atlas CareMap Toolkit
 - Atlas CareMap Community Workshop Toolkit
 - Social Connections in Palliative Care
 - LEAP™ Carers



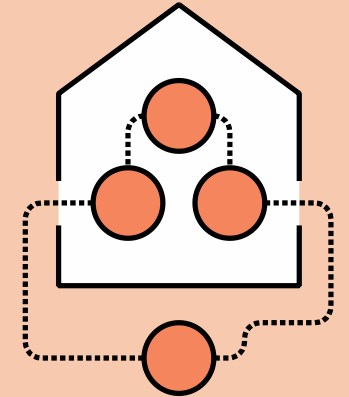
What is a Care Map?

- A Care Map is a simple, visual diagram of the people involved in providing care.
- The map helps to:
 - Strengthen a caregiver's support network.
 - Organize caregiving tasks and activities.
 - Highlight areas where additional support is needed.



Atlas CareMap

- Atlas CareMap Toolkit - Resource for anyone who would like to create a care map. Includes:
 - Guide to create an Atlas CareMap.
 - Sharing with family, friends and health care professionals.
- Atlas CareMap Community Workshop Toolkit - Resource for anyone who would like to run a care map workshop in their community. Includes:
 - PowerPoint presentation for workshop.
 - Templates to promote and invite people.
 - Speaking notes.



Developing and evaluating Compassionate communities

Joachim Cohen

There is an obvious reason for

compassionate communities

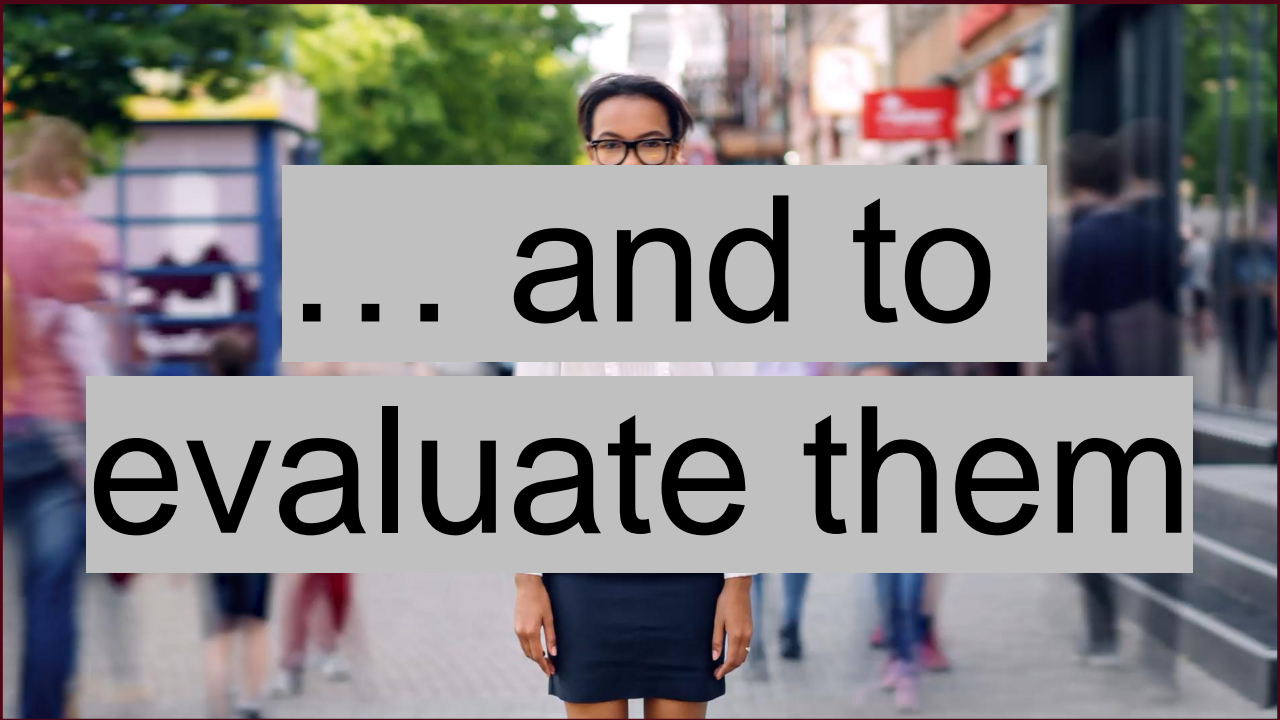


A challenge is how to develop them and where

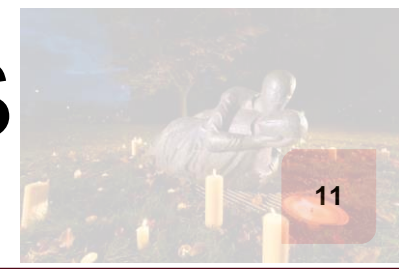


... and to

evaluate them



Examples illustrate opportunities and barriers

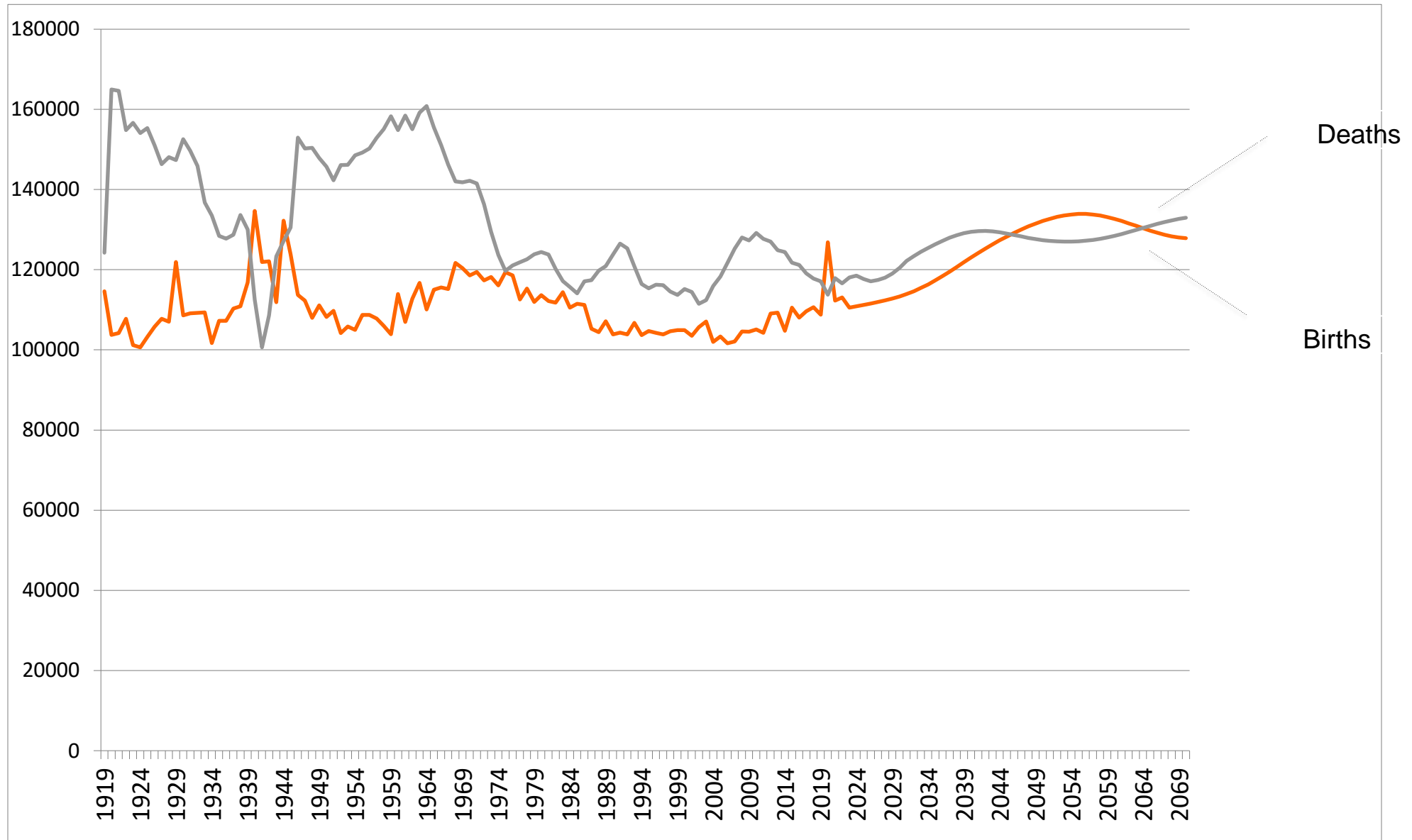


There is an obvious reason for
compassionate communities



+/- 11 mln inhabitants



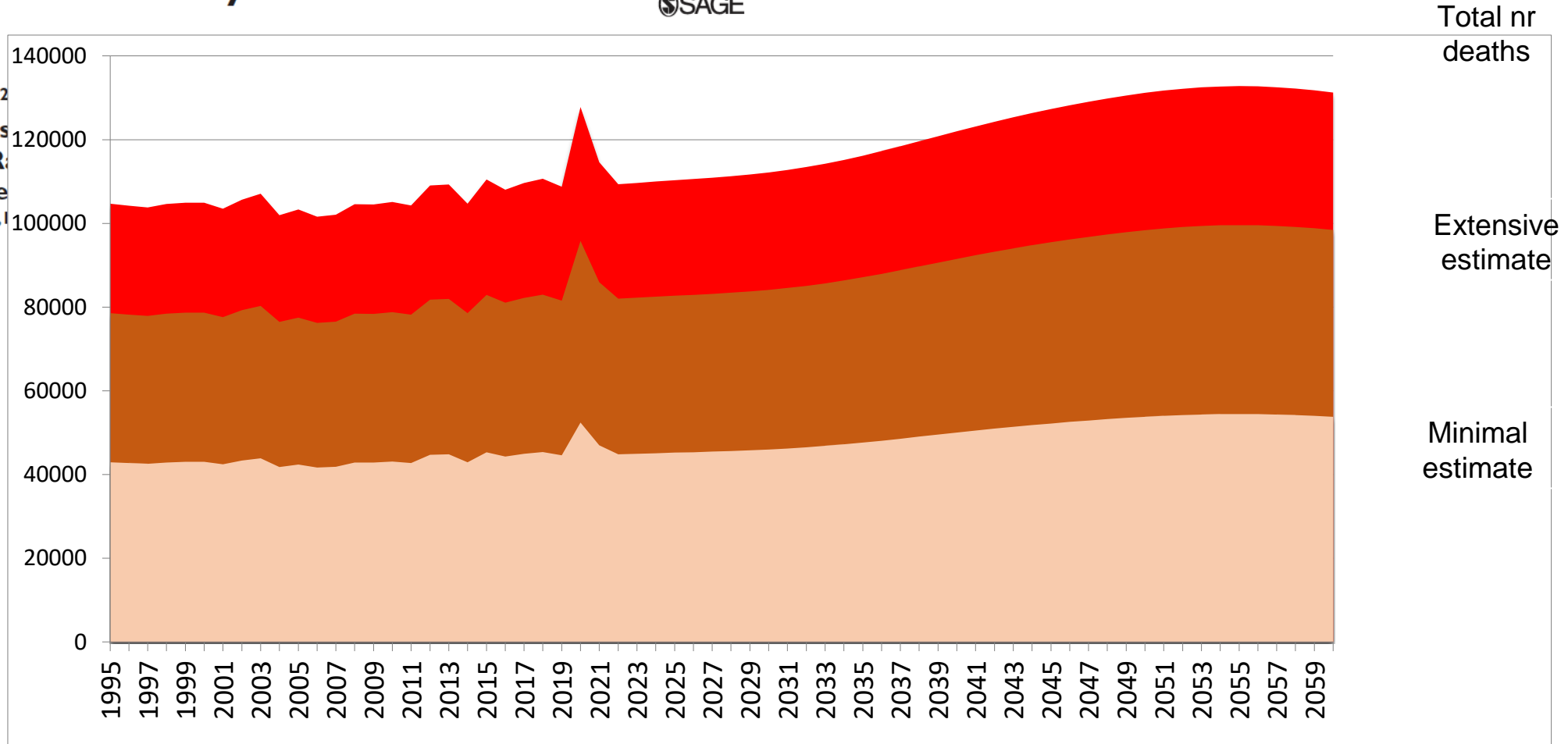


Estimating the need for palliative care at the population level: A cross-national study in 12 countries

Palliative Medicine
1-11
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DOI: 10.1177/0269216316671280
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SAGE

55.000 tot 100.000 deaths every year with preceding palliative care needs (2050-2060)

Lucas Morin^{1,2}
Donna M Wils
Miguel Ruiz-R
YongJoo Rhee
Luc Deliens^{1,4,1}



And family caregivers?

What does the family 'palliative' care giver look like?

Palliative and Supportive Care

cambridge.org/pax

Original Article

Cite this article: Van Goethem V, Dierickx S, Deliens L, De Vleminck A, Lapeire L, Cohen J (2022). Size and characteristics of family caregiving for people with serious illness: A population-based survey. *Palliative and Supportive Care*, 1–10. <https://doi.org/10.1017/S1478951522001079>

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Accepted: 21 July 2022

Key words:

Burden of family caregiving; Family caregivers; Meaningfulness of family caregiving; Population-based cross-sectional survey; Serious illness

Author for correspondence:

Vincent Van Goethem,

Size and characteristics of family caregiving for people with serious illness: A population-based survey

Vincent Van Goethem, M.Sc.^{1,2,3} , Sigrid Dierickx, M.Sc, Ph.D.^{1,2,3},

Luc Deliens, M.Sc, Ph.D.^{1,2,3}, Aline De Vleminck, M.Sc, Ph.D.^{1,3}, Lore Lapeire, M.D.^{1,4}

and Joachim Cohen, M.Sc, Ph.D.^{1,3}

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²Department of Public Health and Primary Care, Ghent University, Ghent, Belgium; ³Department of Family Medicine and Chronic Care, Vrije Universiteit Brussel (VUB), Brussels, Belgium and ⁴Department of Medical Oncology, Ghent University Hospital, Ghent, Belgium

Abstract

Objectives. Family caregivers play a vital role in care for people with serious illness. Reliable population-level information on family caregiving is scarce. We describe the socio-demographic and family caregiving characteristics and experiences of family caregivers of people with serious illness in the adult population.

Method. We performed a secondary analysis of the cross-sectional population-based 19th Social-Cultural Changes survey. A random sample of 2,581 Dutch-speaking people aged 18–95, living in Flanders or Brussels, were contacted for participation in the survey between March and July 2014 using a stratified two-step sample. Differences between groups are

Meer dan 600.000 informal palliative caretivers every year in Belgium

SCV survey 2014; adult population Flanders

7.6%

Family care in past 12 months to person met chronic/terminal illness

= +/- 390.000

every year (→ +/- 670.000 for whole Belgium?)



Every year almost 1 million Belgians experiencing loss close family member



Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States

Ashton M. Verdery^{a,1}, Emily Smith-Greenaway^b, Rachel Margolis^c, and Jonathan Daw^a

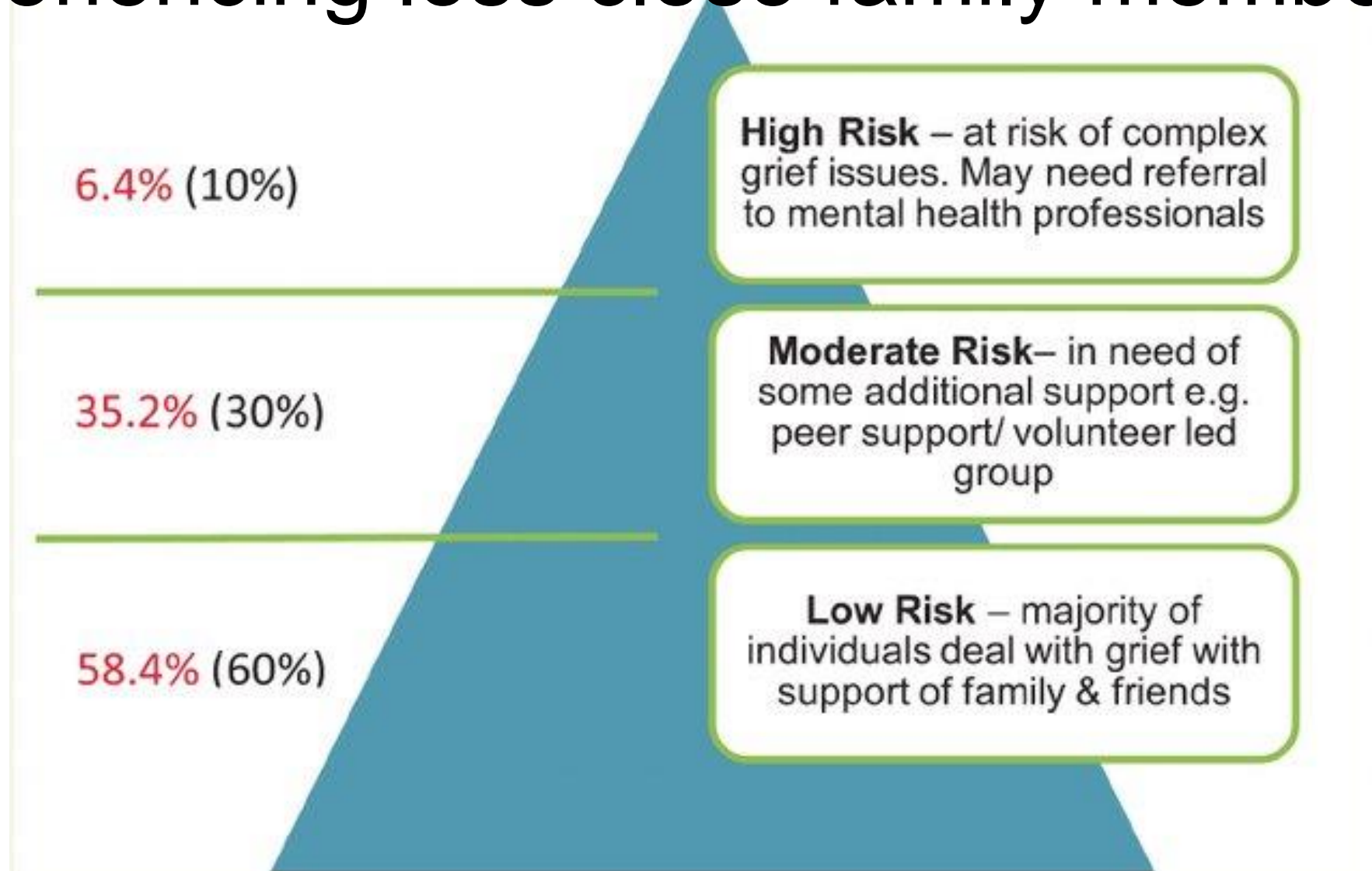
^aDepartment of Sociology and Criminology, Pennsylvania State University, University Park, PA 16802; ^bDepartment of Sociology, University of Southern California, Los Angeles, CA 90089; and ^cDepartment of Sociology, University of Western Ontario, London, ON N6A 5C2, Canada

Edited by Douglas S. Massey, Princeton University, Princeton, NJ, and approved June 19, 2020 (received for review April 18, 2020)

The coronavirus disease 2019 (COVID-19) pandemic has led to a large increase in mortality in the United States and around the world, leaving many grieving the sudden loss of family members. We created an indicator—the COVID-19 bereavement multiplier—that estimates the average number of individuals who will experience the death of a close relative (defined as a grandparent,

grandchildren bereaved. Kin represent some of the most important social ties (4–6). Having a family member recently die is tied to an elevated risk of physical and mental health decline (7–11) and broader adverse implications for individuals' social, economic, and relationship well-being (12–15). Quantifying the average bereavement burden associated with each death can

Every year almost 1 million Belgians experiencing loss close family member





+/- 11 mln inhabitants

every year:

110.000 deaths,
→ 50.000-82.000 with PC
needs;

> 600.000 family carers for
chronic /terminally ill

+/- 1.000.000 experiencing loss
close family member



+/- 38 mln inhabitants

every year:

>300.000 deaths,
→ 120.000-225.000 with PC
needs;

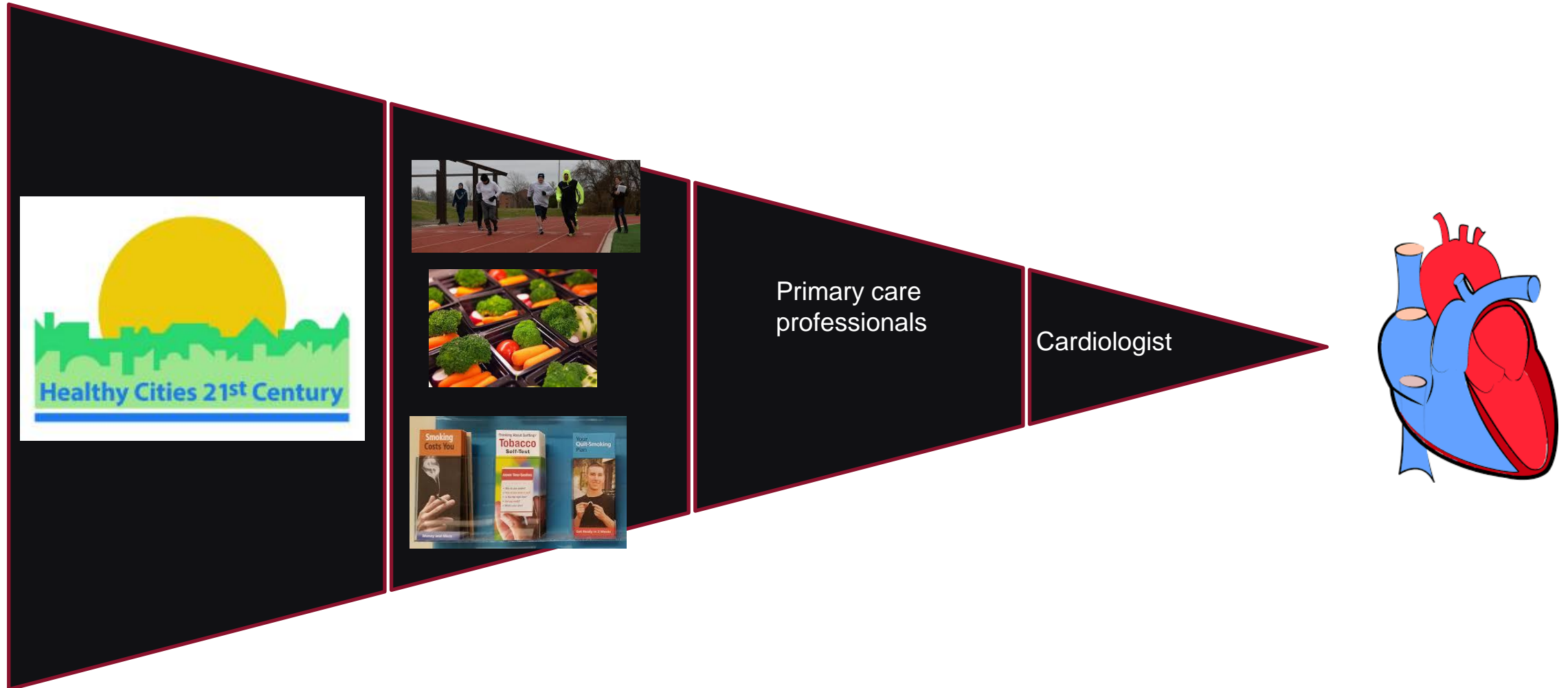
> 1.6 million family carers for
chronic /terminally ill

+/- 2.700.000 experiencing loss
close family member

Our main responses to these challenges



Model for cardiovascular health



My PC algorithm:

IF

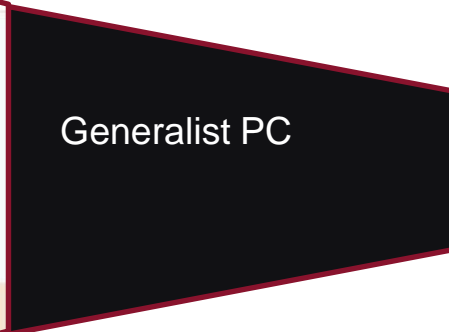
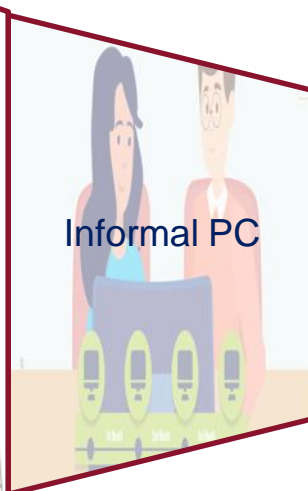
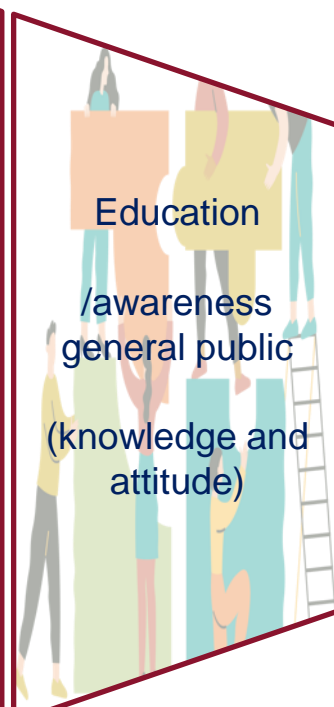
Palliative Care = promoting wellbeing in experiences of serious illness, dying and loss,

Through strategies that include early intervention, harm reduction and prevention

THEN

Broader model/approach is needed to address challenge, including health service AND civic/social responses

Model to address serious illness, end of life, family caregiving and loss



Prevention
Early intervention
Harm reduction

The larger part of our experiences with serious illness, caregiving, dying and loss happen in community contexts

Home (with family and friends)

Schools

Workplaces

Neighborhoods

Cities

...

Experiences of serious illness, caregiving and bereavement happen every day in a university



Death Studies



ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/udst20>

A compassionate university for serious illness, death, and bereavement: Qualitative study of student and staff experiences and support needs

Hanne Bakelants, Filip Van Droogenbroeck, Kenneth Chambaere, Steven Vanderstichelen, Liesbeth De Donder, Luc Deliens, Sara De Gieter, Deborah De Moortel, Joachim Cohen & Sarah Dury

To cite this article: Hanne Bakelants, Filip Van Droogenbroeck, Kenneth Chambaere, Steven Vanderstichelen, Liesbeth De Donder, Luc Deliens, Sara De Gieter, Deborah De Moortel, Joachim Cohen & Sarah Dury (2023): A compassionate university for serious illness, death, and bereavement: Qualitative study of student and staff experiences and support needs, *Death Studies*, DOI: [10.1080/07481187.2023.2233495](https://doi.org/10.1080/07481187.2023.2233495)

To link to this article: <https://doi.org/10.1080/07481187.2023.2233495>



“That you have the practicality to postpone an exam, reschedule a task, that they give the documents that are needed. That’s the main form of support a university could offer. That you don’t have to start looking for 10 documents on 5 sites to be able to postpone 1 deadline.” (S5)

Clear processes and procedures

Flexibility in policy application

“Perhaps like a top sport statute, there could be a statute for family caregivers. That you don’t have to bring in proof from a doctor every time you have to go to the hospital.” (P15)

Support needs

Skills training and awareness raising

“Let’s do a theme week about death with arts, music, or dance so we can share things, things we cannot yet comprehend or put into words, like the overwhelming pain of grief.” (S3)

Proactive support and recognition

“One of my professors last year was lovely, she sent me an e-mail with a poem (...). I felt so supported by this small gesture.” (S4)

University as high-pressure environment

“The university is a stressful work environment because you need to be available to your students and continue with your research and other responsibilities. You may have to cancel classes or need to find a colleague who can take over; however, you are always worried about burdening others. What I wanted to say, is that **I am worried about my potential absence. There is very, very little margin to be missed.**” (P12)

Experiences

Navigating a complex information and support system

“I was so tired because **I was being pushed from pillar to post.** So I thought, I’ll just do the exams and see what happens, if I pass I pass, if I don’t pass I don’t pass. That was a real shame. And in the end, I got an e-mail that I was not even able to apply for a retake because the death did not take place within the exam period itself.” (S19)

Disenfranchised grief

“Apart from digital condolences from my manager, I have felt very little compassion. (...). Only one colleague, besides my supervisor, sent me a warm message during that whole period. **I was devastated.**” (P26)

There is an obvious reason for **compassionate communities**



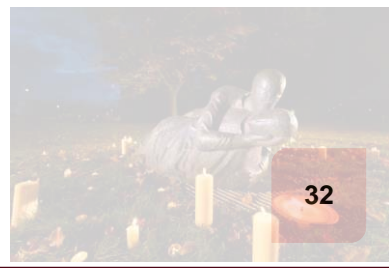
A challenge is how to develop them and where



... and to evaluate them



Examples illustrate opportunities and barriers

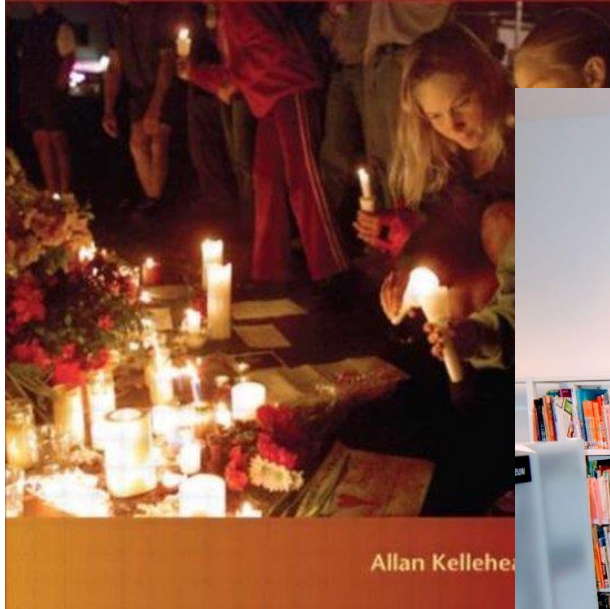


A challenge is how to develop
them and where



Compassionate Cities

Public health and end-of-life care



Compassionate community/city

What?

How?

With whom?

Whereto?



Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide

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2022, Vol. 36(3) 422–442
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DOI: 10.1177/02692163221101
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Bert Quintiens^{1,2*} , Louise D'Eer^{1,2} , Luc Deliens^{1,2},
Lieve Van den Block¹, Kenneth Chambaere^{1,2}, Liesbeth De Donder^{2,3},
Joachim Cohen^{1,2*} and Tinne Smets^{1,2*}

Abstract

Background: Area-Based Compassionate Communities are community public health interventions which focus on the role of community in palliative care provision. They apply a set of actions based on the Ottawa Charter for Health Promotion which increase people's control over their health.

Aim: To review and compare Area-Based Compassionate Communities with respect to their contextual characteristics, development processes and evaluations.

Design: A systematic integrative review with narrative synthesis. Registered in Prospero: CRD42020173406.

Data sources: Five databases (Pubmed, Web of Science, PsycInfo, Embase and Scopus) were consulted, consisting of publications from 1999 onwards. This was supplemented with grey literature and author-provided documentation.

Results: Twenty articles were drawn from the peer reviewed search, three from grey literature and two from author-provided documentation. Notwithstanding the substantial variation in what is reported, all Area-Based Compassionate Communities in focus on multiple action areas of the Ottawa Charter for Health Promotion. Variability in their contextual and development characteristics is high. Only a minority of initiatives have been evaluated and although conclusions are generally positive, evaluation often does not match their aims. Attaining support from policy makers can help in obtaining funding early in the process. Strengthening people's social networks was a recurring community engagement strategy.

Conclusions: While the concept of Area-Based Compassionate Communities is gaining momentum as a new paradigm for the development of palliative care capacity across society, only a handful of initiatives have been described. The lack of formal evaluations and envisaged health benefits indicates a pressing need for rigorous research about ongoing and future initiatives.



Civic engagement in serious illness, death, and loss: A systematic mixed-methods review

Palliative Medicine
1–27
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DOI: 10.1177/02692163221077850
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Louise D'Eer^{1,3} , Bert Quintiens^{1,3} , Lieve Van den Block^{1,3}, Sarah Dury^{2,3},
Luc Deliens^{1,3}, Kenneth Chambaere^{1,3}, Tinne Smets^{1,3*}
and Joachim Cohen^{1,3*}

Abstract

Background: New public health approaches to palliative care such as compassionate communities aim to increase capacity in serious illness, death, and loss by involving civic society. Civic engagement has been described in many domains of health; a description of the characteristics, processes, and impact of the initiatives in palliative care is lacking.

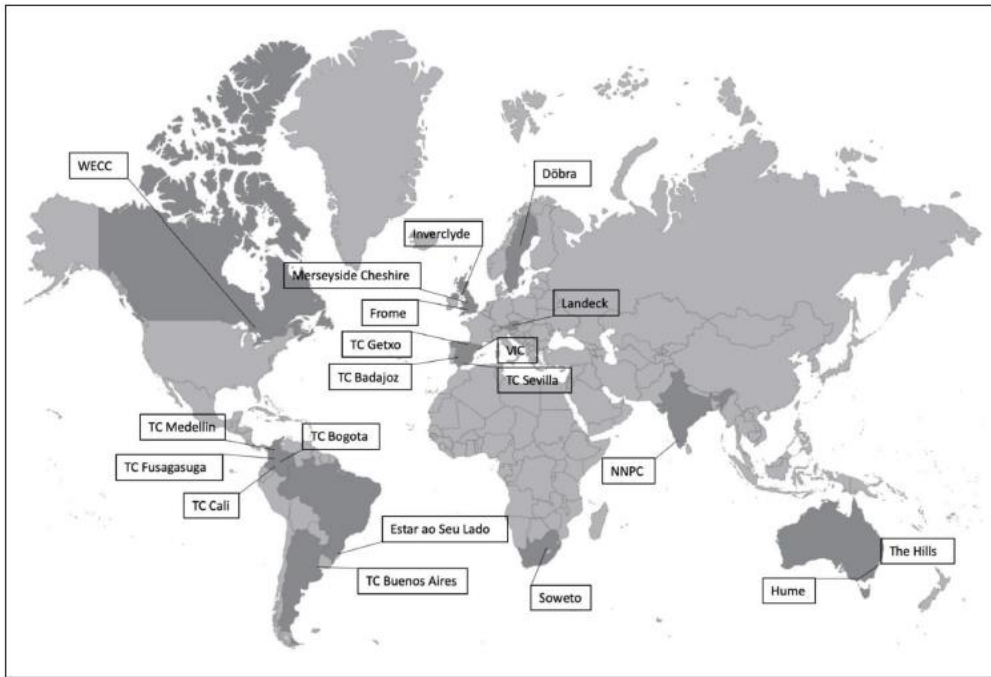
Aim: To systematically describe and compare civic engagement initiatives in palliative care in terms of context, development, impact, and evaluation methods.

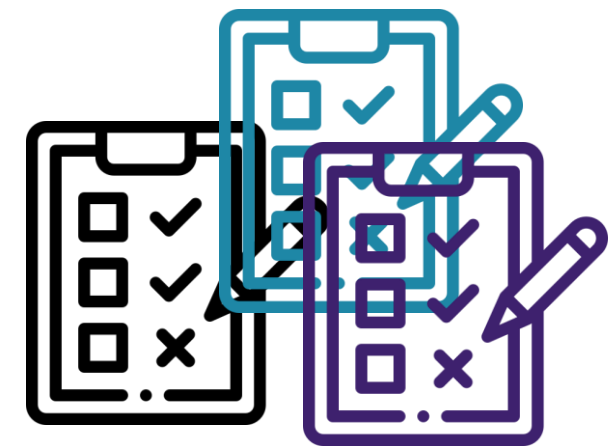
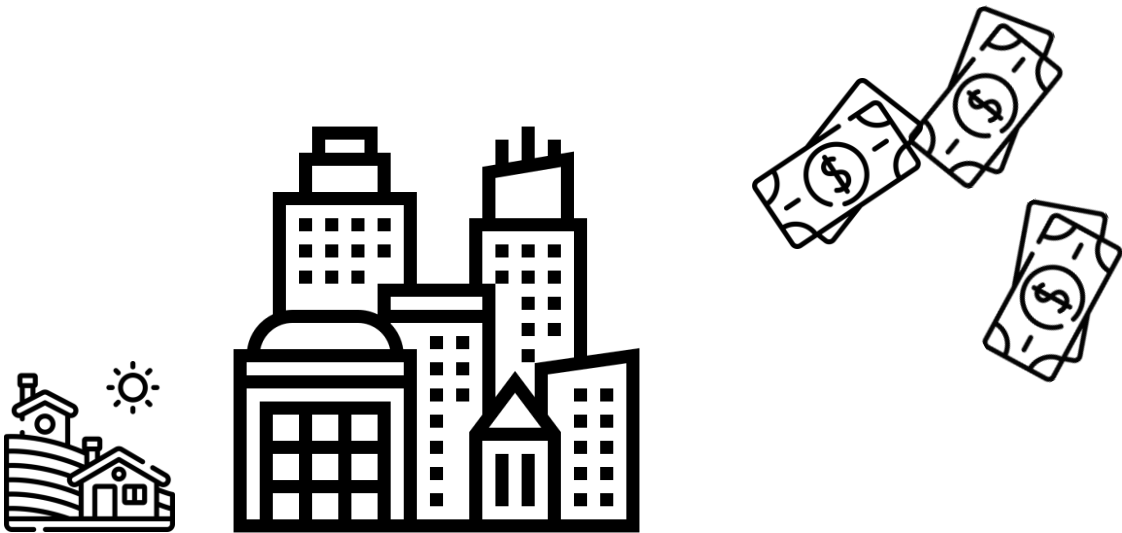
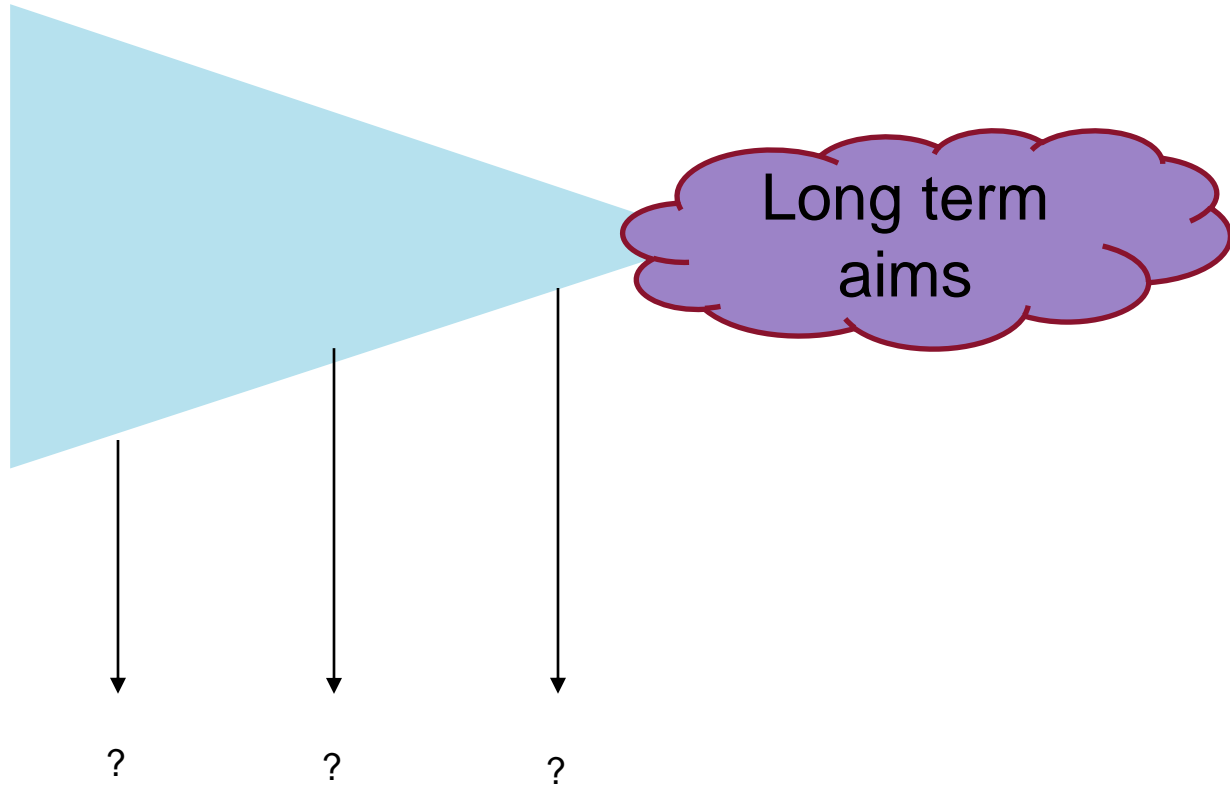
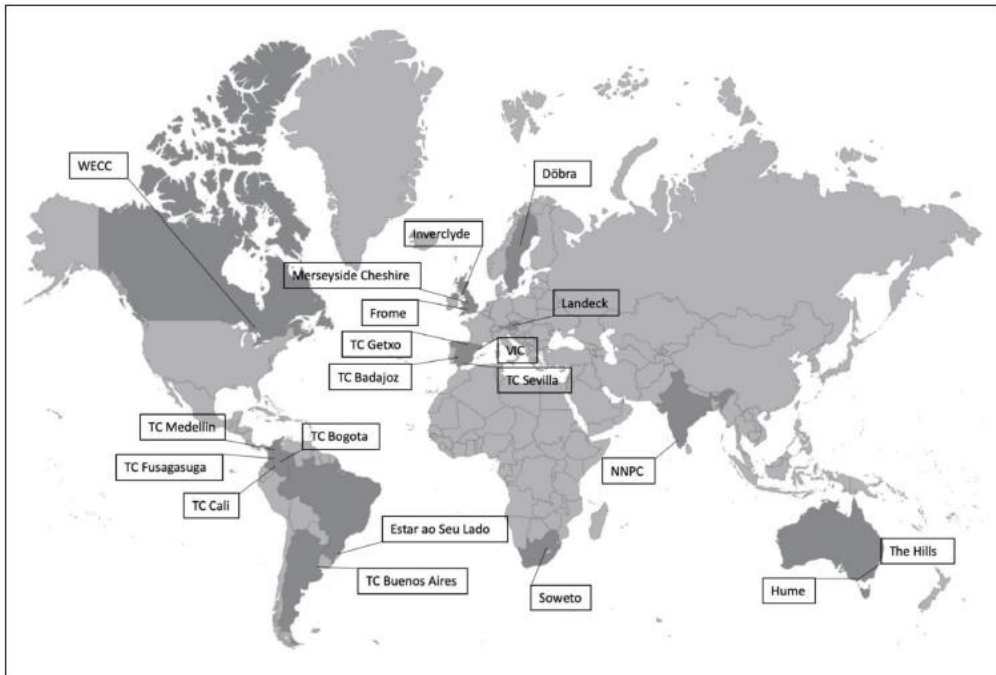
Design: Systematic, mixed-methods review using a convergent integrated synthesis approach. Registered in Prospero: CRD42020180688.

Data sources: Six databases (PubMed, Scopus, Sociological Abstracts, WOS, Embase, PsycINFO) were searched up to November 2021 for publications in English describing civic engagement in serious illness, death, and loss. Additional grey literature was obtained by contacting the first authors. We performed a quality appraisal of the included studies.

Results: We included 23 peer-reviewed and 11 grey literature publications, reporting on nineteen unique civic engagement initiatives, mostly in countries with English as one of the official languages. Initiatives involved the community in their development, often through a community-academic partnership. Activities aimed to connect people with palliative care needs to individuals or resources in the community. There was a variety of evaluation aims, methods, outcomes, and strength of evidence. Information on whether or how to sustain the initiatives was generally lacking.

Conclusions: This is the first review to systematically describe and compare reported civic engagement initiatives in the domain of palliative care. Future studies would benefit from improved evaluation of impact and sustainability.





Implementation

Evaluation

Key principles Target groups Activities/a ctions Primary focus

OUTCOMES OUTPUTS INPUTS SUCCESS FACTORS

A compassionate city is one where serious illness, dying, caregiving and grief is everyone's business. It is a social ecology approach based on principles of participation, empowerment, inclusion, respect and dignity



Characteristics of a compassionate city program

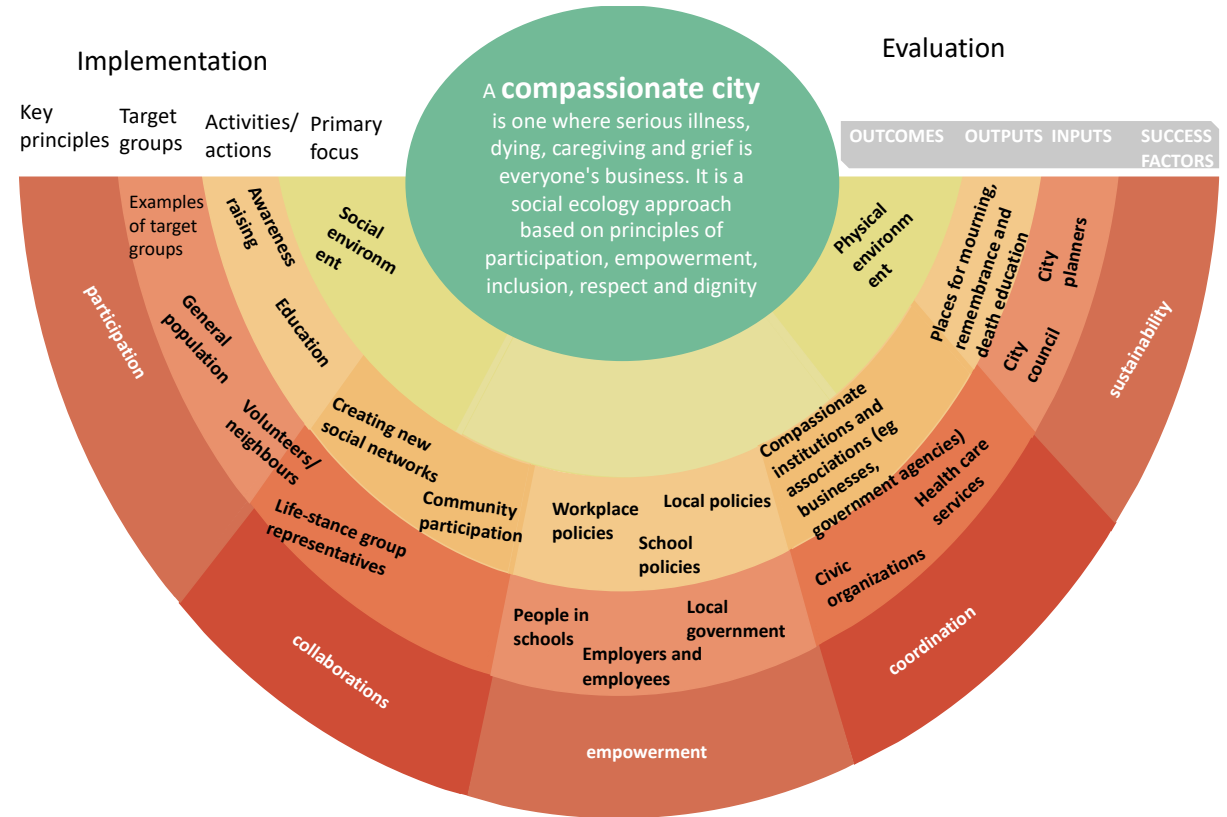
Participation and collaboration

Coordination and Facilitation

Change at different socioecological levels

Sustainability

Complexity and nonlinearity



Bruges



Herzele



Vrije Universiteit Brussel



Bruges

Large city (7th in Belgium)
Urbanized (Historic centre)

119,000 inhabitants

37% single household
31% aged 60 or over

Herzele

Smaller municipality
Semi-Rural (Urban centre)

18,500 inhabitants

29% single household
26% aged 60 or over

Vrije Universiteit Brussel

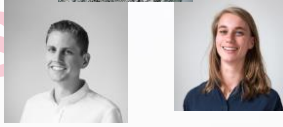
Mid-size university
2 large campuses, 9 Faculties

+/- 20,000 students (4,700
international)
4,000 staff

Research Project



Social change manager (20% FTE)



PhD researchers

Bruges

City:

Council: 2 Aldermen + City Director

Project lead: Team 'Local Social Policies'

Herzele

City:

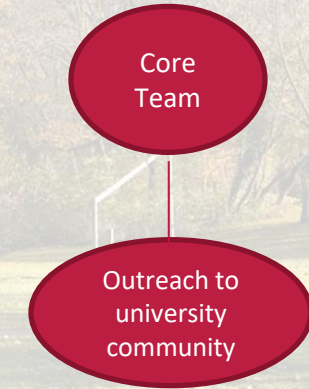
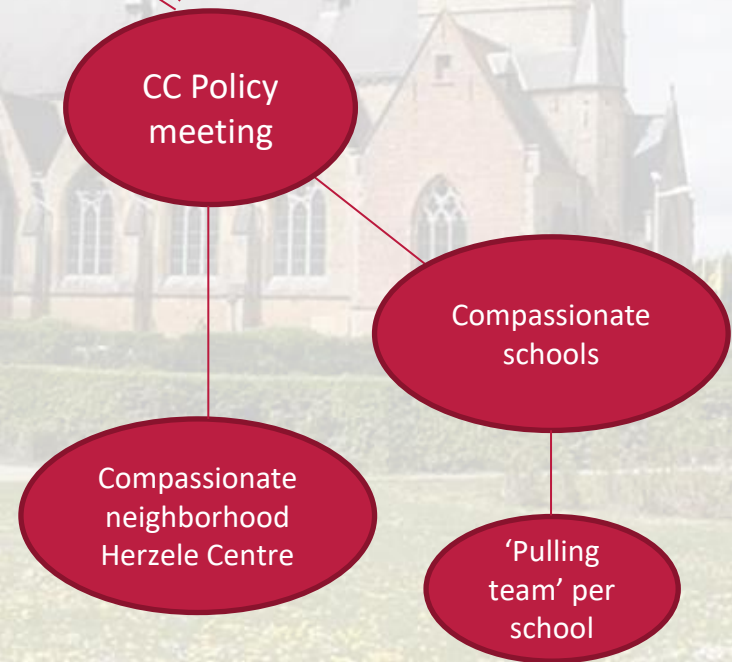
Council: 2 Aldermen + City Director
Project lead: Local Services Center

Vrije Universiteit Brussel



PhD researcher

Chancellor's office, HR, Marketing & Communication, Student Guidance, Academics of COCO



Should hospice or PC services lead this?

PALLIATIVE
MEDICINE

Original Article

Engagement of specialized palliative care services with the general public: A population-level survey in three European countries

Palliative Medicine

1–11

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DOI: [10.1177/02692163221079546](https://doi.org/10.1177/02692163221079546)

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Aline De Vleminck¹ , Sally Paul², Maria Reinius³ , Libby Sallnow^{4,5}, Carol Tishelman^{6,7}  and Joachim Cohen¹ 

Abstract

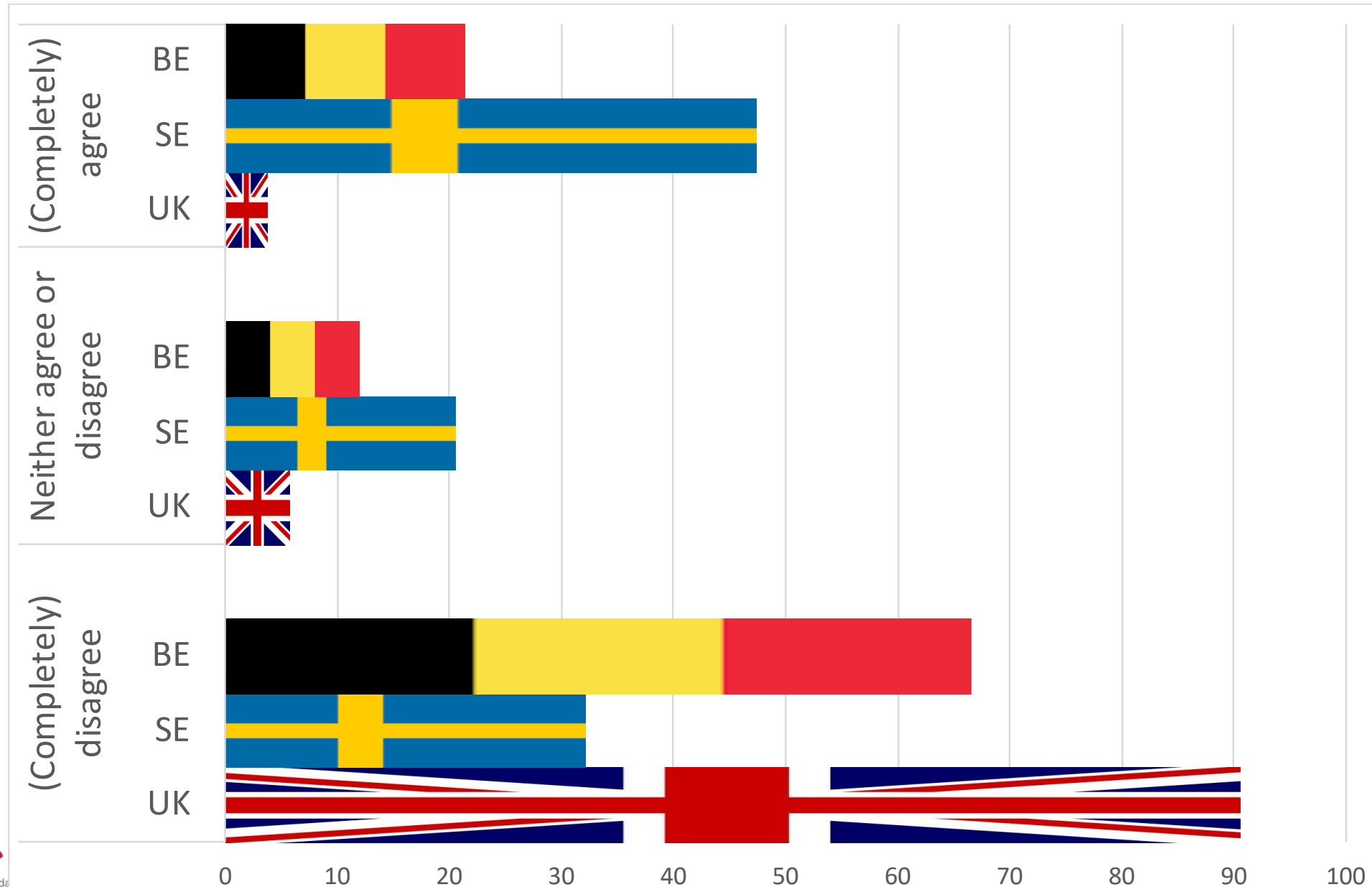
Background: There is growing recognition of a need for community capacity development around serious illness, dying and loss, complementary to strategies focussing on health services. Hitherto, little is known about how and to what extent palliative care services in different countries are adopting these ideas in their practices.

Aim: To examine views towards and actual involvement in community engagement activities as reported by specialized palliative care services in Belgium, Sweden and the UK.

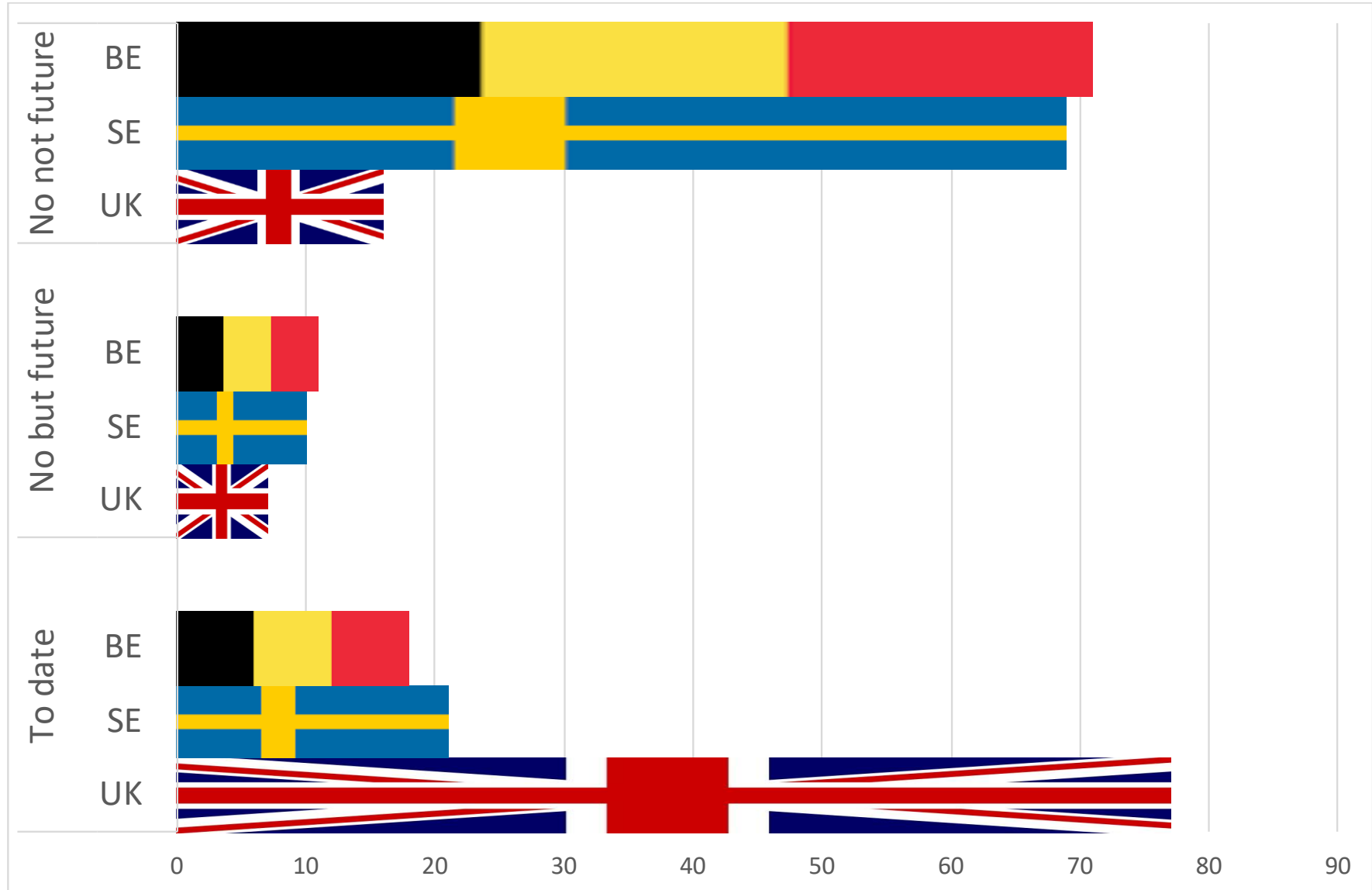
Design, setting, participants: Cross-sectional survey among all eligible specialized palliative care services in Flanders (Belgium) ($n = 50$), Sweden ($n = 129$) and the UK ($n = 245$). Representatives of these services were invited to complete an online questionnaire about their actual activities with the general public and their attitudes regarding such activities.

Results: Response rates were 90% (Belgium), 71% (Sweden) and 49% (UK). UK services more often reported engaging with the general public to develop knowledge and skills through a range of activities (80%–90%) compared to Belgian (31%–71%) and Swedish services (19%–38%). Based on a combination of engagement activities 74% of UK services could be labelled as extending their focus beyond

Focus on bedside care, not general public (%)



Built or helped to build informal end-of-life support or care networks(%)



There is an obvious reason for

compassionate communities



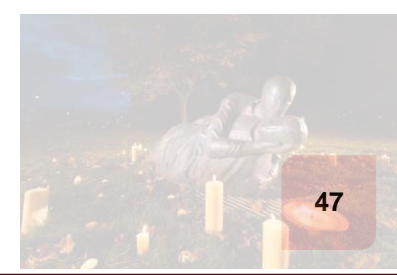
A challenge is how to develop them and where



... and to evaluate them



Examples illustrate opportunities and barriers



A young woman with dark hair and glasses stands in the center of a busy city street. She is wearing a white long-sleeved blouse with a black bow at the neck and a dark, knee-length skirt. The background is filled with blurred figures of people walking, trees, and buildings, suggesting a bustling urban environment. A semi-transparent grey banner is overlaid across the middle of the image, containing the text "... and to evaluate them".

... and to evaluate them

Researching Compassionate Communities: Identifying theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives

Palliative Medicine

1–11

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Hanne Bakelants^{1,2,3} , Steven Vanderstichelen^{1,2} , Kenneth Chambaere^{1,2} ,
Filip Van Droogenbroeck^{2,4} , Liesbeth De Donder^{2,3} , Luc Deliens^{1,2} , Sarah Dury^{2,3*} 
and Joachim Cohen^{1,2*} 

More than 100 frameworks exist, making it difficult to know where to start

Criteria of Compassionate Communities

Characteristics of a compassionate city program

Participation and collaboration

Coordination and Facilitation

Change at different
socioecological levels

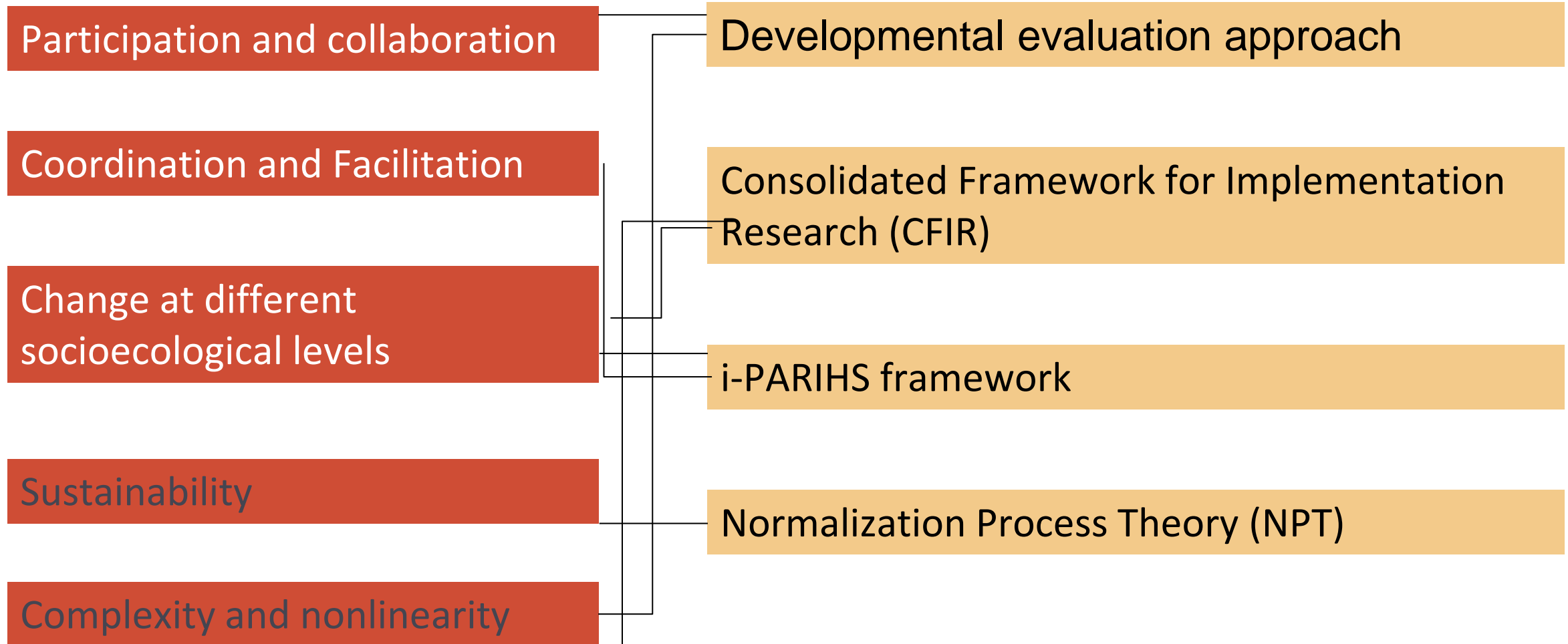
Sustainability

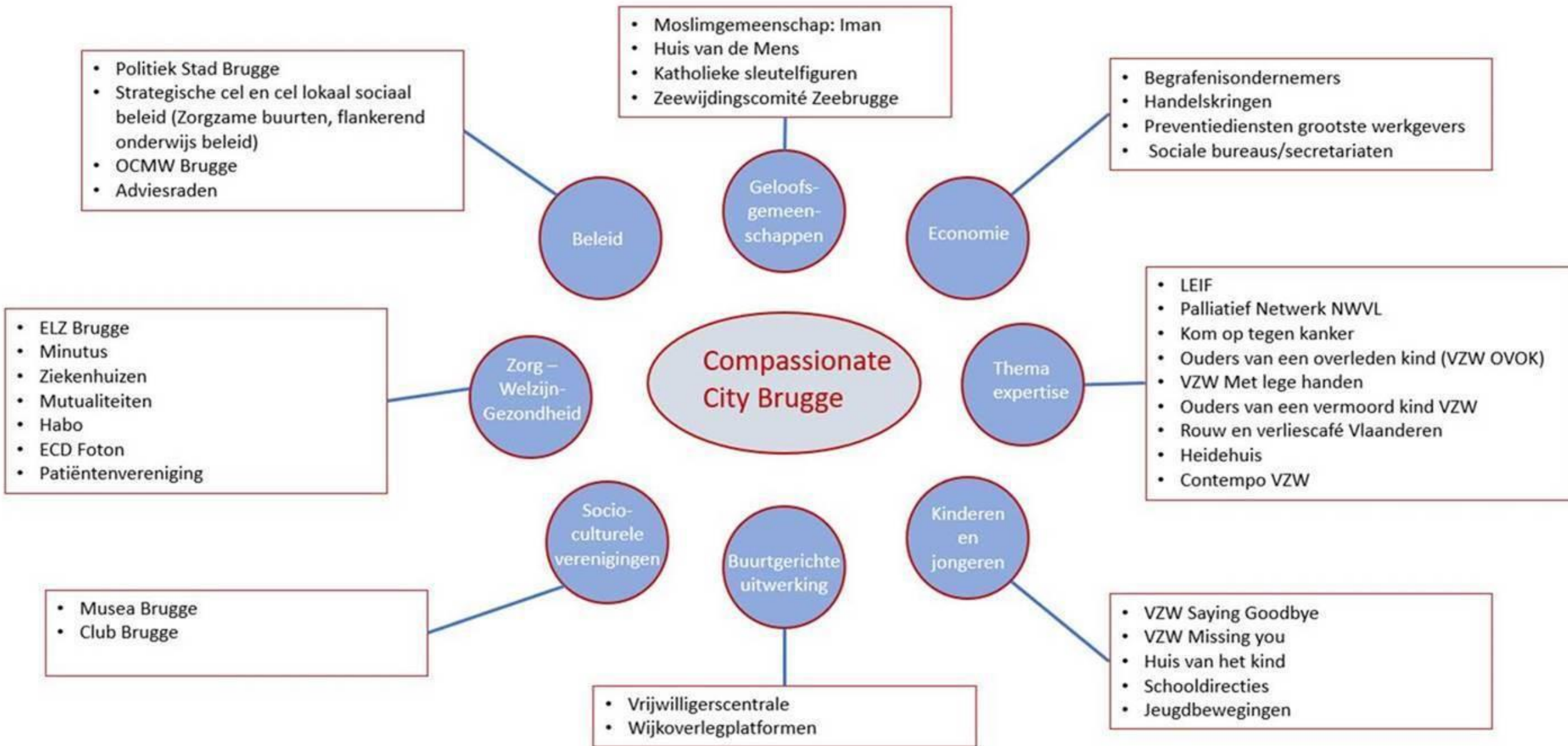
Complexity and nonlinearity

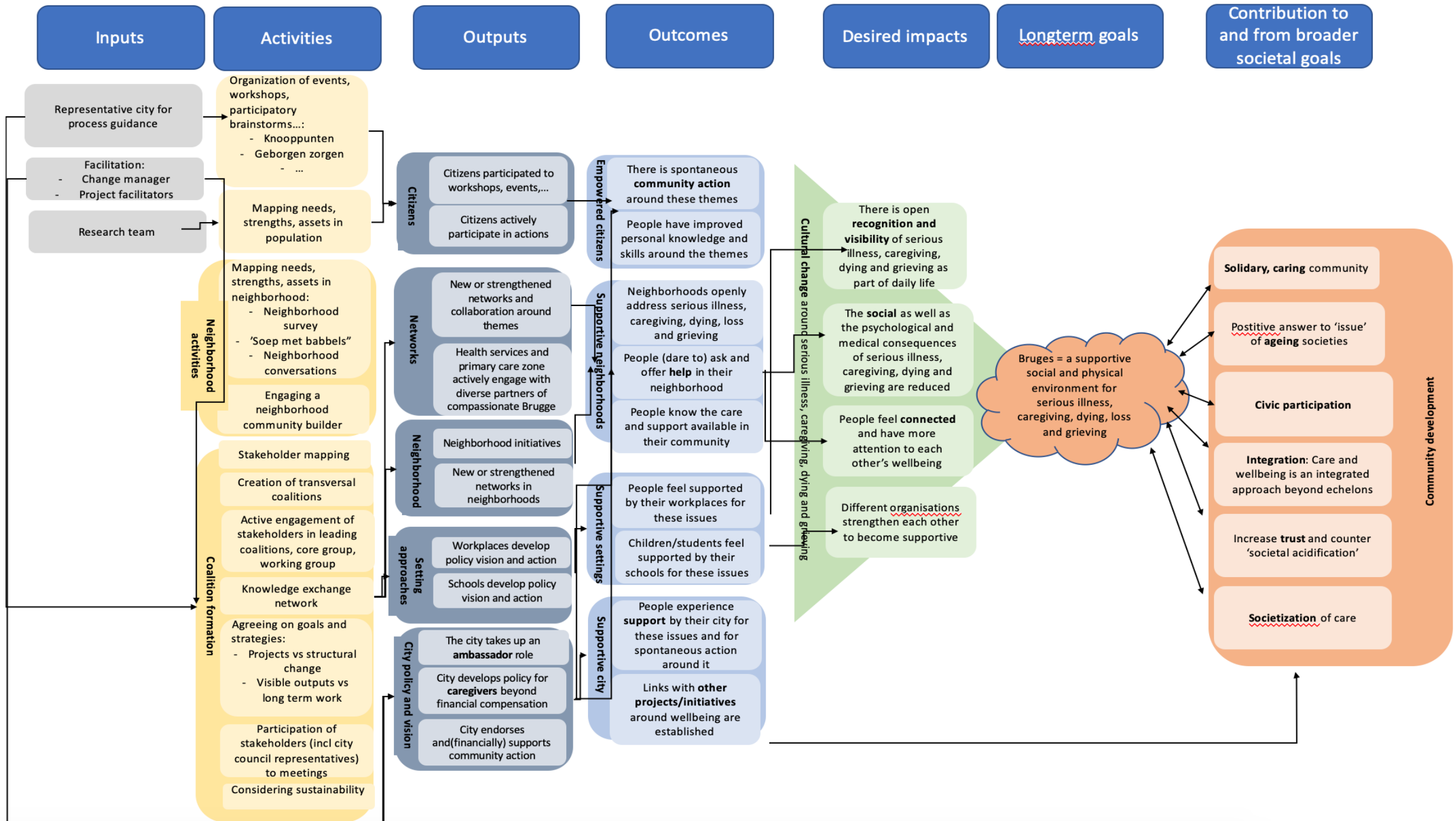
Compassionate cities programs = Complex Adaptive Systems

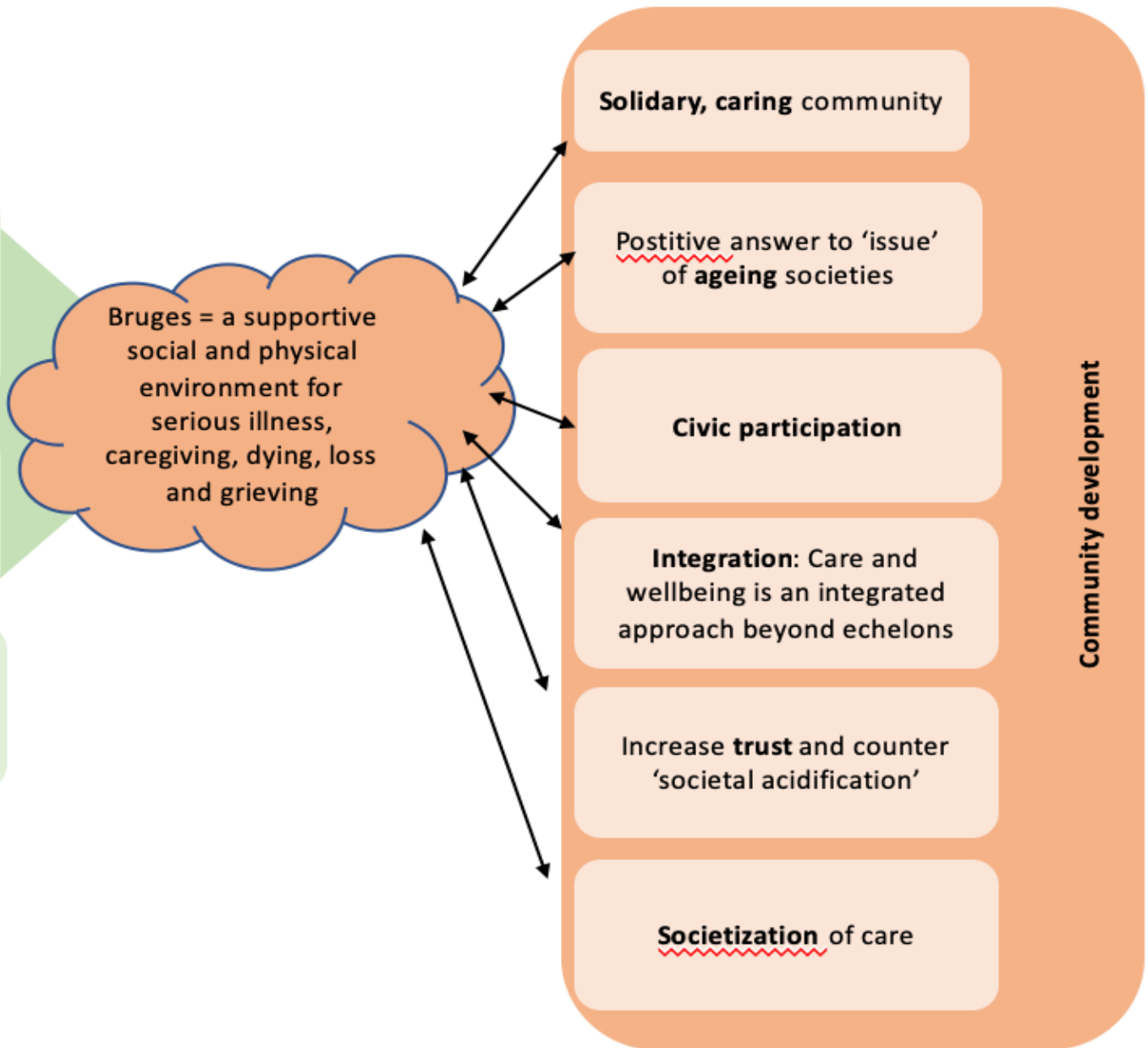
Agents	
Emergence	
Feedback	
Adaptation	
Self-organisation	
Co-evolution	
Non-linearity	

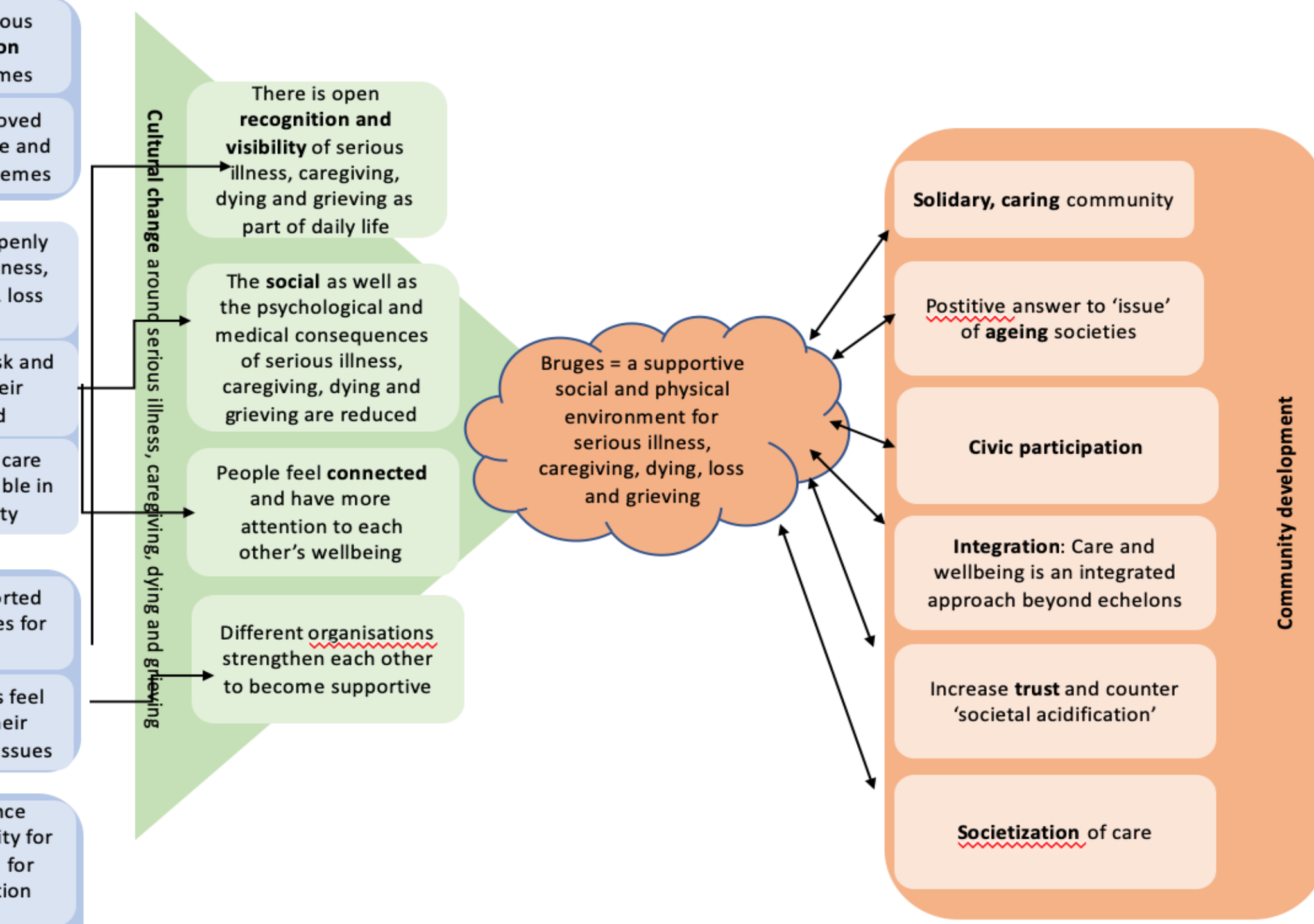
A combination of frameworks and approaches is suitable

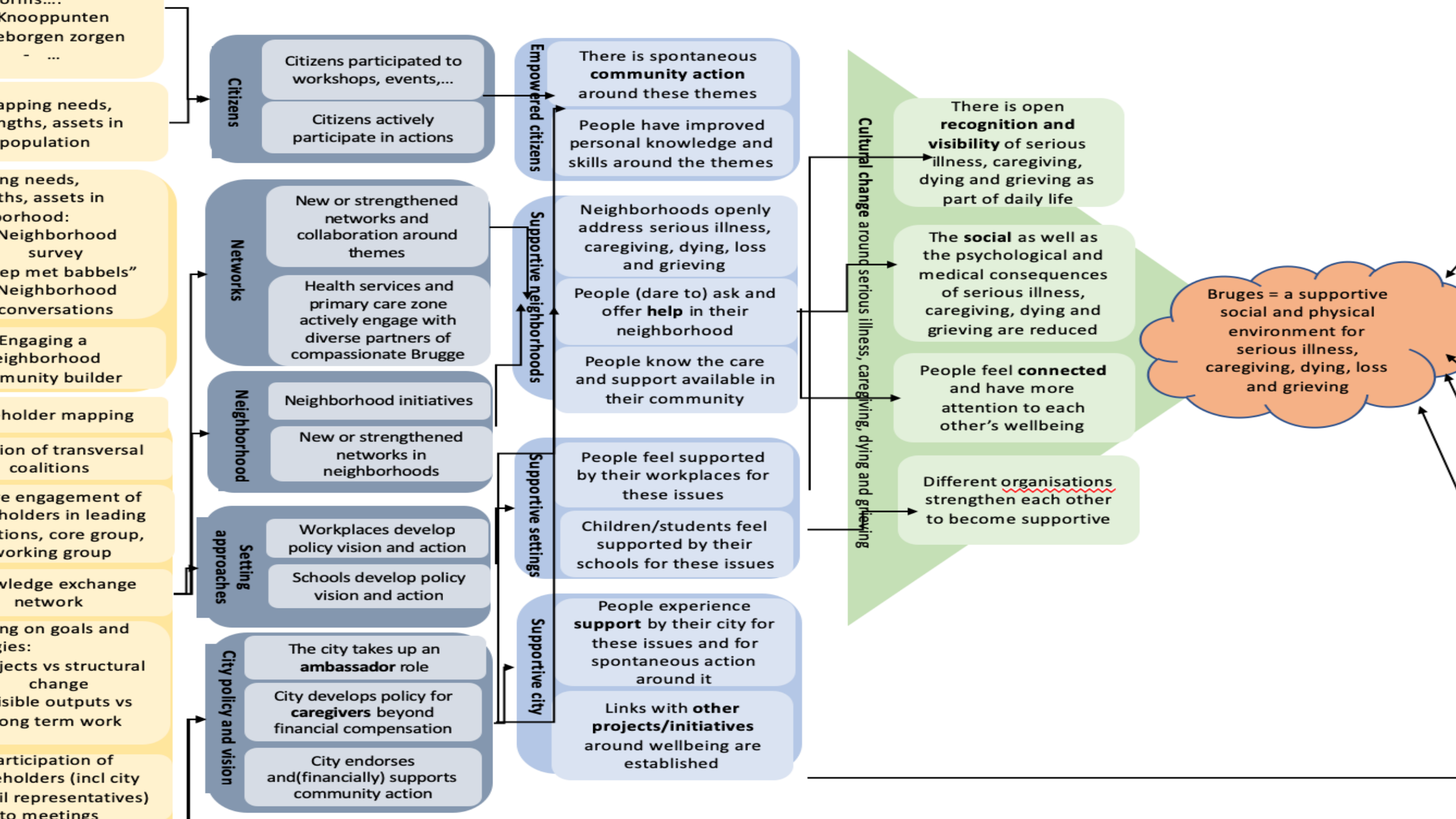


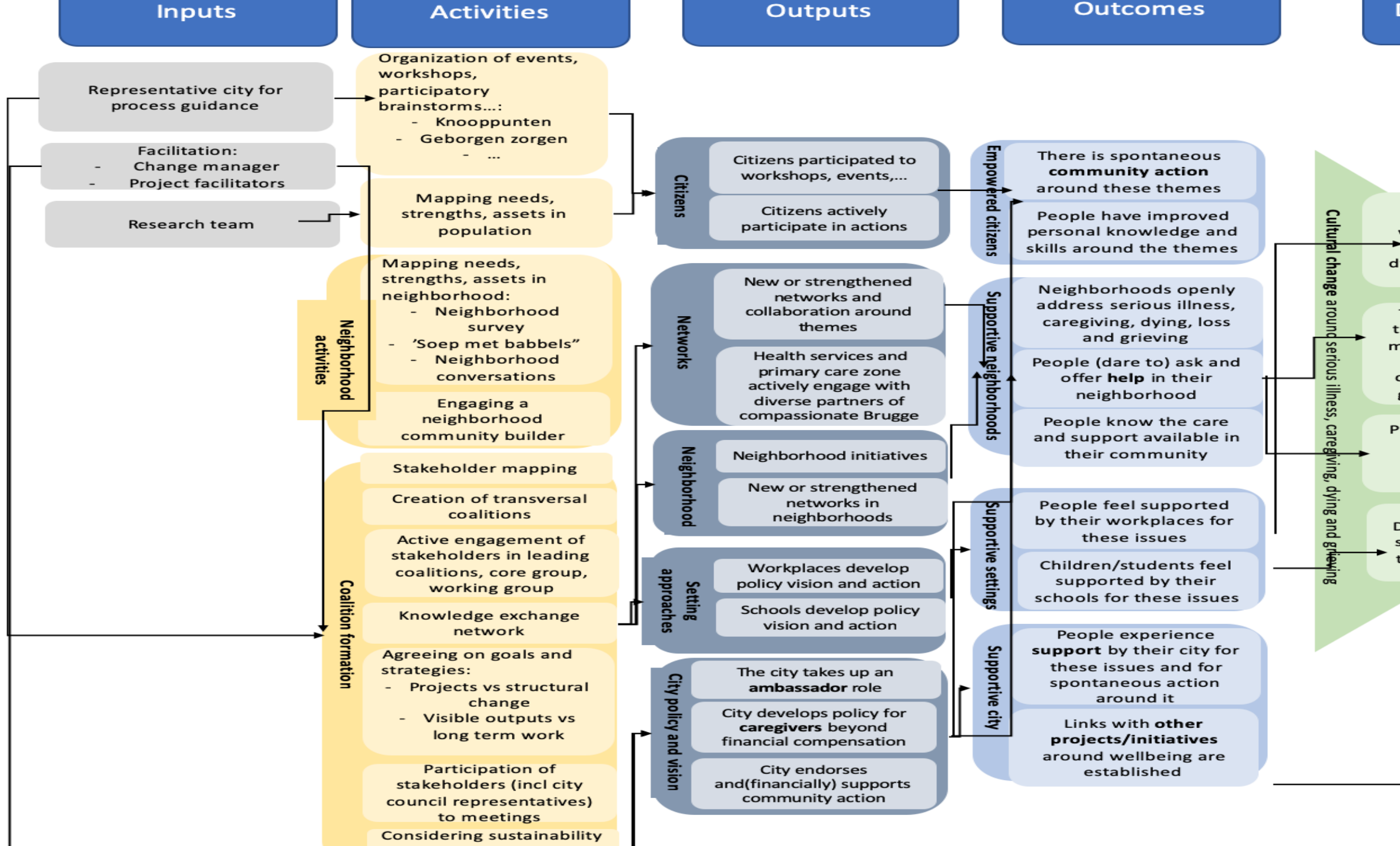












Facilitation

Interviews

Document
analysis

Observations

structured
reports

Inputs

- 1) change manager - city project facilitator - research team
- 2) Access to networks
- 3) Operational <> developing vision

Representative city for process guidance

- Facilitation:
- Change manager
 - Project facilitators

Research team

Barriers

- 1) Shortage of staff and staff turnover on project at city level
- 2) Risk of 'taking over' versus engaging, stimulating...
- 3) Reshuffling priorities due to external context (COVID, electoral pressure, other projects)
- 4) Issues of (perceived) power, ownership, echelons

Coalitions / internal environment

Interviews

Document analysis

Observations

- Creation of new collaborations and networks**
- Knowledge exchange**
- Autonomy for different working groups**
- Linking with other wellbeing projects**

I think we have learned that some things really need be addressed differently.

The fragmentation has become a bit smaller to me.

Coalition formation

- 'Meetings logic'**
- Lack of concrete actions**
- Lower engagement in some working groups**
- Usual suspects problem (missing stakeholders)**
- Evolution to a transversal knowledge exchange network**

Neighborhood survey

Neighborhood conversations

Neighborhood interviews with identified assets

Outputs



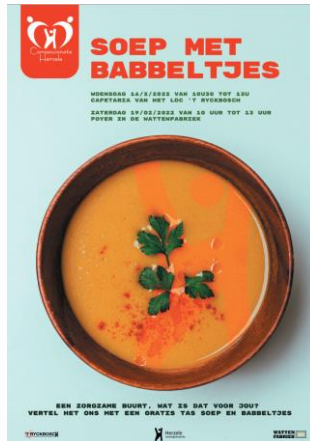
In 1 neighborhood in Bruges and Herzele
Random sample from population register
Obtained N= 714,
about 40% response rate

Mapping needs, strengths, assets in neighborhood:

- Neighborhood survey
- 'Soep met babbels'
- Neighborhood conversations

Neighborhood activities

Engaging a neighborhood community builder



Experienced needs for a change around serious illness, loss, grief

- ✓ Large nr of experiences
- ✓ Need for knowledge exchange and inspiration
- ✓ Referrals: how and to whom?

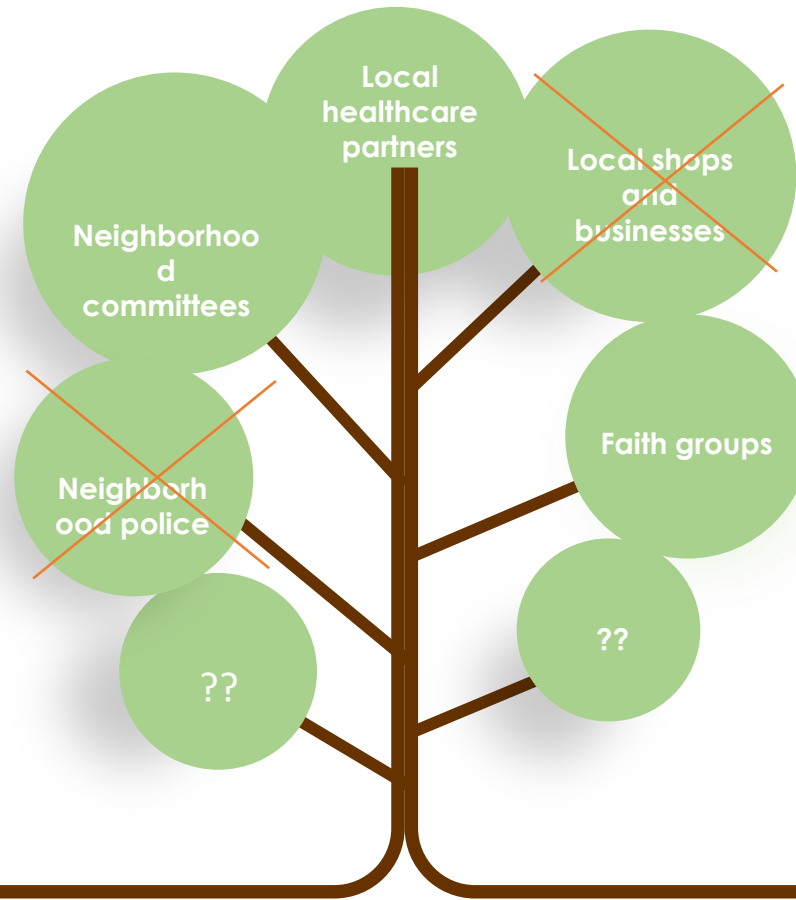
Relative priority?

- ✓ Is it our task to do this?
- ✓ Will I be doing the right thing?
- ✓ I don't always have time for this....
- ✓ Discrepancy between theory and practice: can neighbourhoods solve palliative care challenges?

Designing the innovation?

- ✓ Places of solace
- ✓ Inspiration days
- ✓ ...

- ✓ Identified need for a facilitating (not dictating) neighborhood Community developer as external change agent



Inputs

Activities

Outputs

Representative city for process guidance

Facilitation:
- Change manager
- Project facilitators

Research team

Organization of events, workshops, participatory brainstorms...:
- Knooppunten
- Geborgen zorgen
- ...

Mapping needs, strengths, assets in population

Mapping needs, strengths, assets in neighborhood:
- Neighborhood survey
- "Soep met babbels"
- Neighborhood conversations

Engaging a neighborhood community builder

Stakeholder mapping

Citizens participated to workshops, events,...

Citizens actively participate in actions

New or strengthened networks and collaboration around themes

Health services and primary care zone actively engage with diverse partners of compassionate Brugge

Neighborhood initiatives

New or strengthened

Empowered citizens

Supportive neighborhoods

COMPASSIONATE Buddies



KAN JIJ EEN VERSCHIL MAKEN?

Een Compassionate Buddy luistert naar zijn vrienden en vriendinnen en helpt hen wanneer zij bijvoorbeeld ziek zijn, verdriet hebben, zich niet goed in hun vel voelen...

Lokaal bestuur Herzele is op zoek naar leerlingen uit de Herzeelse scholen die willen groeien tot echte Compassionate Buddies-kampioenen! Daarom organiseren wij een workshop speciaal voor de geïnteresseerde leerlingen!

Inhoud van de workshop

- Nadenken over hoe we gevoelige gesprekken kunnen voeren met andere kinderen;
- Leren om te zien dat tijd samen voor elkaar, een verschil kan maken;
- Welke ondersteuning er kan zijn voor kinderen die zich niet goed voelen, verdrietig voelen;
- Leren praten over verlies, verdriet en doodgaan.

Praktische informatie

- Start: September 2022 (onder voorbehoud)
- Locatie: De Wattenfabriek (onder voorbehoud)
- Wat: 2 sessies van telkens 120 minuten




17-25 SEPTEMBER 2022

KNOOP PUNTEN



www.brugge.be/knooppuntenfestival

STADSFESTIVAL ROND ZORG, VERLIES EN VERBINDING





DARE TO CARE. DARE TO BE COMPASSIONATE.

#COMPASSIONATEVUB

© Felipe Aguirre y Otegui



Join us during **Compassionate Week**
13/11 – 16/11

Seminars, Webinars and Workshops

Words of Comfort, Literature and Art

13/11 Writing Into Grief:
Poetry and Prose Workshop
(NL/ENG)



13/11 Grief Studio
(NL/ENG)

GRIEF EDITION



15/11 Voices of Compassion:
An Evening of Mourning and
Healing @ Pilar (NL/ENG)



16/11 Write a Compassionate
Card!



13-16/11 Compassionate
Library



13/11 Open Les -
Compassionate Communities:
Hoe dood, sterven, en rouw uit
de taboesfeer halen? (NL)



14/11 Webinar - What can
participatory artists and
nurses learn from each other?
(ENG)



14/11 Lezing - Compassion op
de werkvloer (NL)



Come together, remember, and connect

14/11 Compassionate Café @
Bar Pilar (NL/ENG)



14-15/11 Remembrance Tree



15/11 Compassionate Walk
(NL/ENG)



15/11 Online Samenkomst
Lerend Netwerk
Compassionate Scholen (NL)



15/11 Workshop - How can
VUB deal with grief in the
workplace? (NL/ENG)



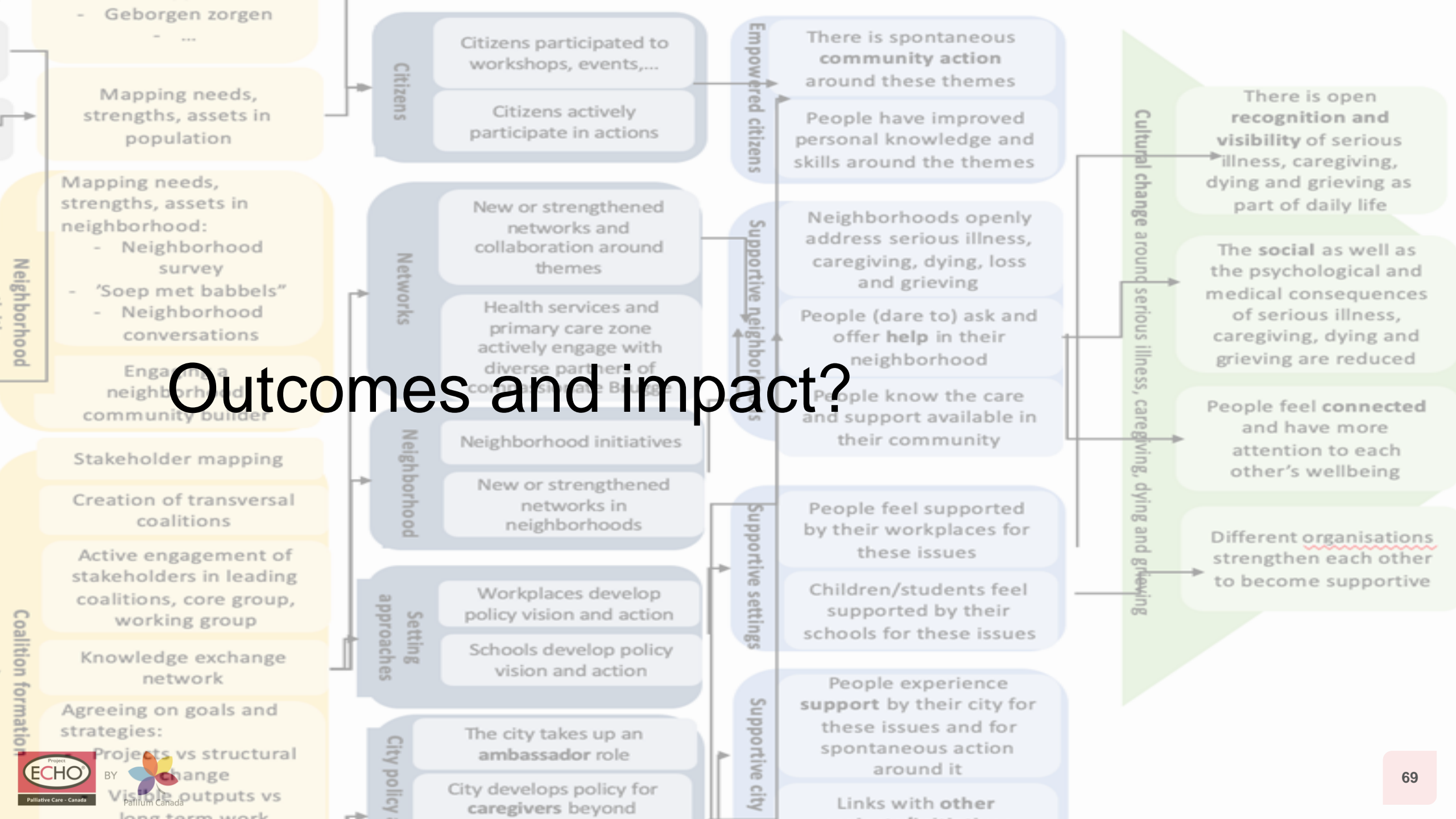
16/11 6th COCO Seminar -
Grieving in Public Places
(ENG)



Before I Die Wall
Before I die I want to
Before I die I want to
Before I die I want to
Before I die I want to
Before I die I want to
Before I die I want to
Before I die I want to
Before I die I want to
Before I die I want to



Outcomes and impact?



Some preliminary outcomes/impacts

Spontaneous action is happening (in schools, in neighborhoods ...)

Neighborhoods have added these topics to their caring neighborhood work, responding to identified need and strengths

Strengthened broader group cohesion (eg schools, workplaces)

Strengthened networks and improved collaboration between organisations → knowledge exchange

Links/integration with other wellbeing projects established

Increased acceptance and awareness

Broader support for compassionate policy and procedures

Creation of champions within some settings

Ripple effects to other communities, localities and organisations

There is an obvious reason for **compassionate communities**



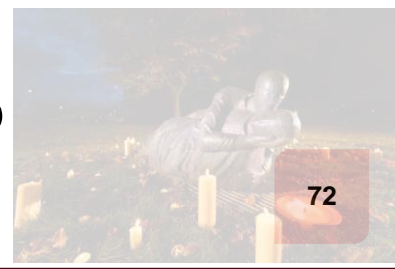
A challenge is how to develop them and where



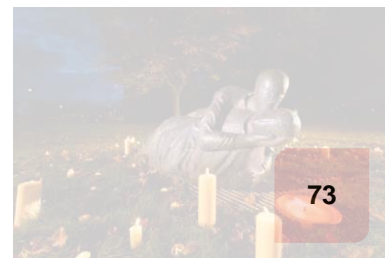
... and to evaluate them



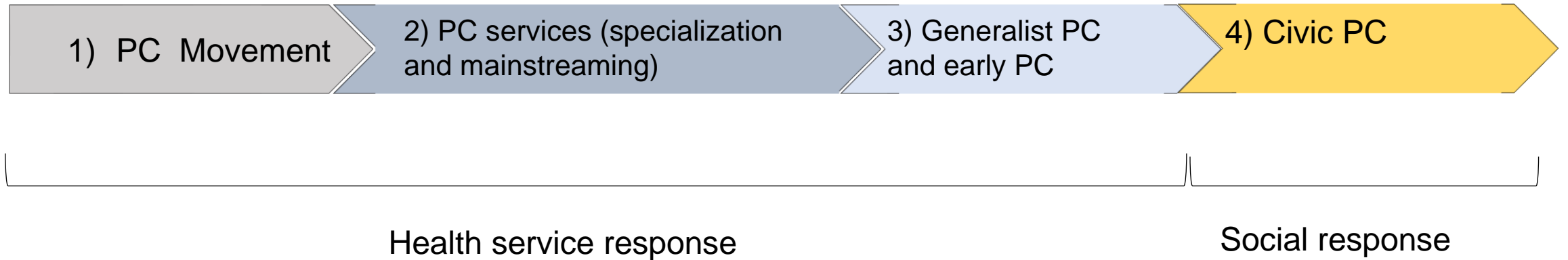
Examples illustrate opportunities and barriers



Examples illustrate opportunities and barriers



The palliative care response to societal challenges of serious illness, dying and loss in 4 stages



There is a range of possible (compassionate community) programs that can address this

Pesut et al. BMC Palliative Care (2018) 17:2
DOI 10.1186/s12904-017-0210-3

BMC

RESEARCH ARTICLE

Volunteer navigators a compassionate early palliative care

Barbara Pesut^{1*}, Wendy Duggleby², Gra
Madeleine Greig⁷ and Kelli Sullivan⁷

Research

Julian Abel, Helen Kingston, A
Alexandra Thomson-Moore and

Reducing emergency a population health comp care and compassionate

Abstract

Background: A compassionate commu
community-based hospice volunteer ca
which volunteers and a nurse partnered
adults living in community. The goal wa
community connections.

Methods: Volunteers received navigatio
visits with clients living with advanced
mentorship. Mixed method evaluation
and other stakeholders.

Results: Seven volunteers were partnere
visits in home or by phone every two to
and facilitating engagement. Although it
the role satisfying and meaningful. Client
regional Western Australia.

Design: Controlled before-a

Methods: A total of 43 compr


period 2020–2022. A comparator population of 172 individuals v
illnesses was randomly selected from usage data from the san

Abstract

Background


Reducing emergency admissions to hospital
has been a cornerstone of healthcare policy.
Little evidence exists to show that systematic
interventions across a population have achieved
this aim. The authors report the impact of a
complex intervention over a 44-month period
in Frome, Somerset, on unplanned admissions
to hospital.

Aim

 Palliative Care & Social Practice

Revis

Developing a compassionate community: a Canadian conceptual model for community capacity development

Mary Lou Kelley 

Abstract: The purpose of this article is to share a Canadian model called *Developing a Compassionate Community (DCC)* in which aging, dying, caregiving, and grieving are everyone's responsibility. The model provides a research-informed practice guide for people who choose to adopt a community capacity development approach to developing a compassionate community. Based on 30 years of Canadian research by the author in rural, urban, First Nations communities, and long-term care homes, the *DCC* model offers a practice theory and practical tool. The model incorporates the principles of community capacity development which are as follows: change is incremental and in phases, but nonlinear and dynamic; the change process takes time; development is essentially about developing people; development builds on existing resources (assets); development cannot be imposed from the outside; and development is ongoing (never-ending). Community capacity development starts with citizens who want to make positive changes in their lives and their community. They become empowered by gaining the knowledge, skills, and resources they need. The community mobilizes around finding solutions rather than discussing problems. Passion propels their action and commitment drives the process. The strategy for change is engaging, empowering, and educating community members to act on their own behalf. It requires mobilizing networks of families, friends, and neighbors across the community, wherever people live, work, or play. Community networks are encouraged to prepare for later life, and for giving and getting help among themselves. This Canadian model offers communities one approach to developing a

*Palliative Care & Social
Practice*

2023, Vol. 17: 1–11

DOI: 10.1177/
26323524231193040

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Developing compassionate communities: some recommendations based on encountered opportunities and barriers

Who leads this matters

Different sources of entry, each with their advantages and disadvantages (city vs health care service vs civil society...)
Reflection about who owns dying and death

Stakeholder coalition building, engagement and participation demand facilitation:

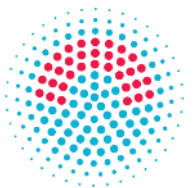
Building on and strengthening existing assets rather than implementing a program
Dynamic process
Tensions about power and mandate emerge throughout
Avoid limitation to the 'usual suspects'
Facilitation is key, needs resourcing (and mandate)
Participation is a core underlying principle (but expert input can meet a desire for best practices and guidance)
Clarity about expectations and co-creation
Invest in group cohesion
Tensions between community-building approach and need for demonstrable and quantifiable change (KPIs)

Social change takes time:

A lot of work/time in finding common ground / collective understanding about aims and road thereto
Change happens slowly (not in 3-4 year period) → long term program rather than project
Change does not happen linearly
One step at a time
Time and mandate (and staff turnover) are a constant challenge

Focus on distal aims but proximal actions

Paralysing effect of 'distal cultural change'
Logic model to link actions to desired outcomes
Connecting existing networks and ongoing initiatives and 'adding our themes' rather than only setting up new structures



8th Public Health Palliative Care
International Conference
brücken bauen
bâtir des ponts
building bridges

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22-25 OCTOBER 2024



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International Conference

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bâtir des ponts
building bridges



ACADEMY

18 – 20 OCTOBER 2024



CONFERENCE

22 – 25 OCTOBER 2024



**CITY FESTIVAL
HIGHLIGHT**

**22 – 25 OCTOBER 2024
24 OCTOBER 2024**



CALL FOR ABSTRACTS: UNTIL 28 JANUARY, 2024



MORE INFORMATION?
WWW.PHPCI2024.ORG

Q&A Session



Award Ceremony





Certificate of Recognition

This award is given to

Dr. Joachim Cohen

for the World Hospice and Palliative Care Day Special Lecture 2023:

Compassionate Communities: Together for Palliative Care

Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat

Thank You



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PALLIATIVE**
CARE DAY

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