PHPCI Conference Bruges

Researching and evaluating compassionate city programs

Joachim Cohen

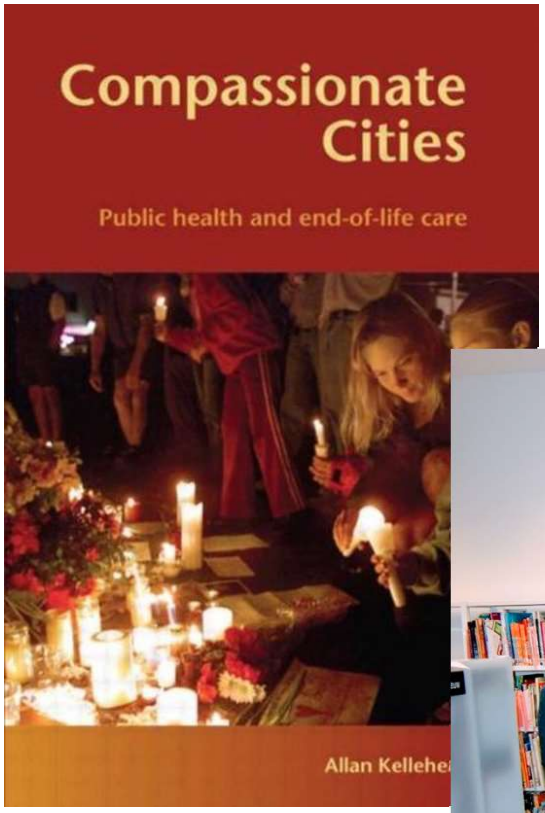
Dinah, eigenlijk moeten we...

Dinah, eigenlijk moeten we...

COMPASSIONATE BRUGGE

VERLIES-VERBINDEN-VERSTERKEN

Compassionate Herzele


Compassionate Cities
Public health and end-of-life care
Allan Kellehe

Compassionate city

What?

How?

With whom?

Whereto?

Review Article

PALLIATIVE MEDICINE

Palliative Medicine
2022, Vol. 36(3) 422–442
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Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide

Bert Quintiens[1,2], Louise D'Eer[1,2], Luc Deliens[1,2], Lieve Van den Block[1], 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 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, develo 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 publi 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-p documentation. Notwithstanding the substantial variation in what is reported, all Area-Based Compassionate Community ini focus on multiple action areas of the Ottawa Charter for Health Promotion. Variability in their contextual and develop characteristics is high. Only a minority of initiatives have been evaluated and although conclusions are generally positive, evaluated often does not match their aims. Attaining support from policy makers can help in obtaining funding early in the 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 c of palliative care capacity across society, only a handful of initiatives have been described. The lack of formal evaluations envisaged health benefits indicates a pressing need for rigorous research about ongoing and future initiatives.

Keywords

Review Article

PALLIATIVE MEDICINE

Palliative Medicine
1–27
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Civic engagement in serious illness, death, and loss: A systematic mixed-methods review

Louise D'Eer[1,3], Bert Quintiens[1,3], Lieve Van den Block[1,3], Sarah Dury[2,3], Luc Deliens[1,3], Kennneth 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.

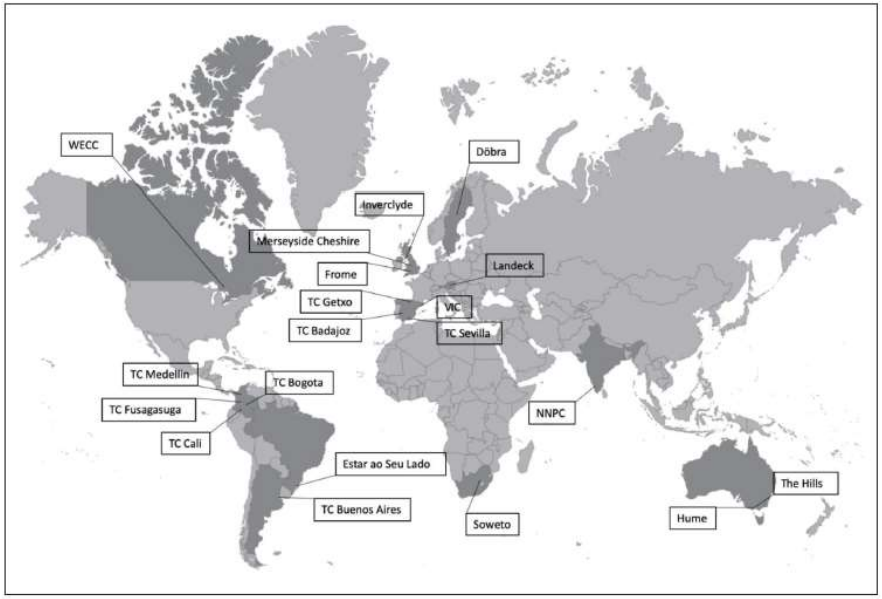
Aim: To systematically describe and compare civic engagement initiatives in palliative care in terms of context, development, impact, and evaluation methods.

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.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TC Sevilla
TC Medellin
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Estar ao Seu Lado
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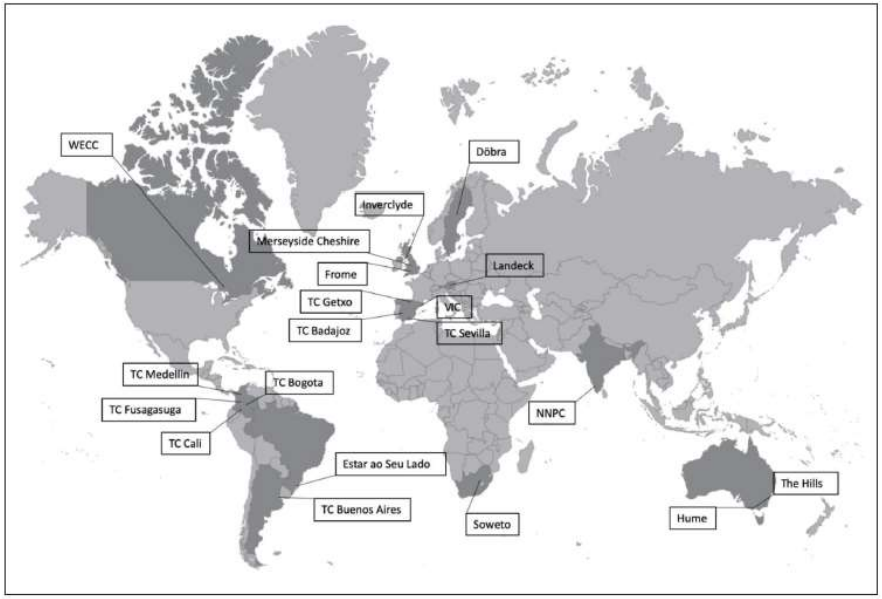
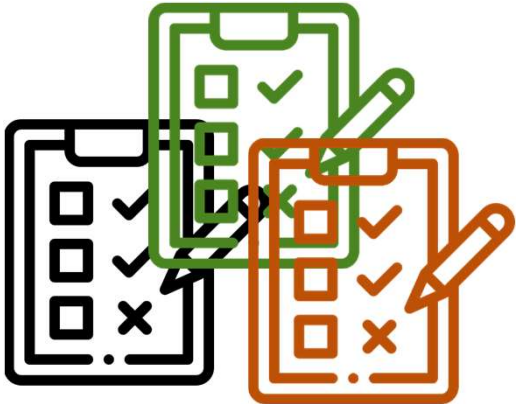
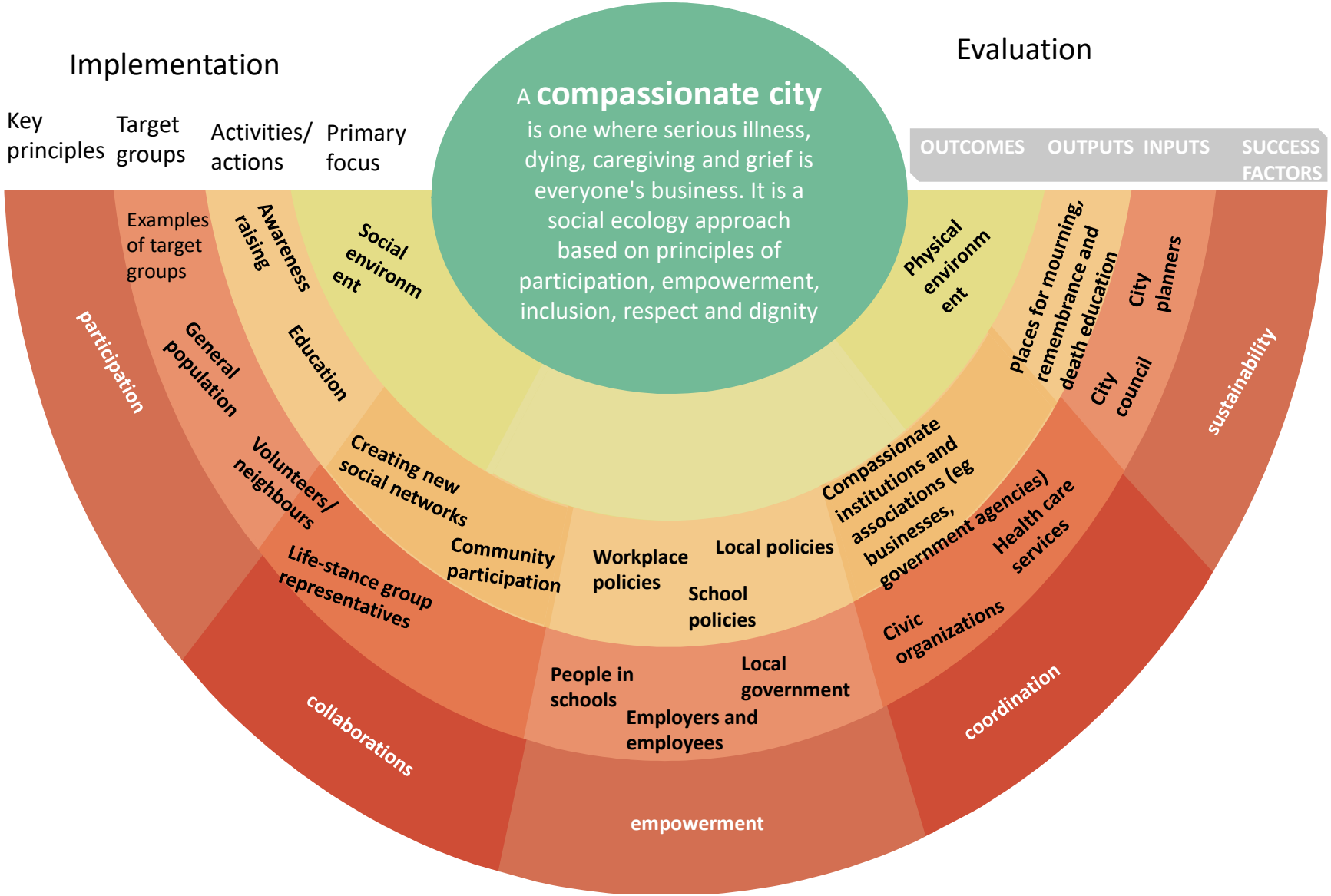
Soweto
Hume



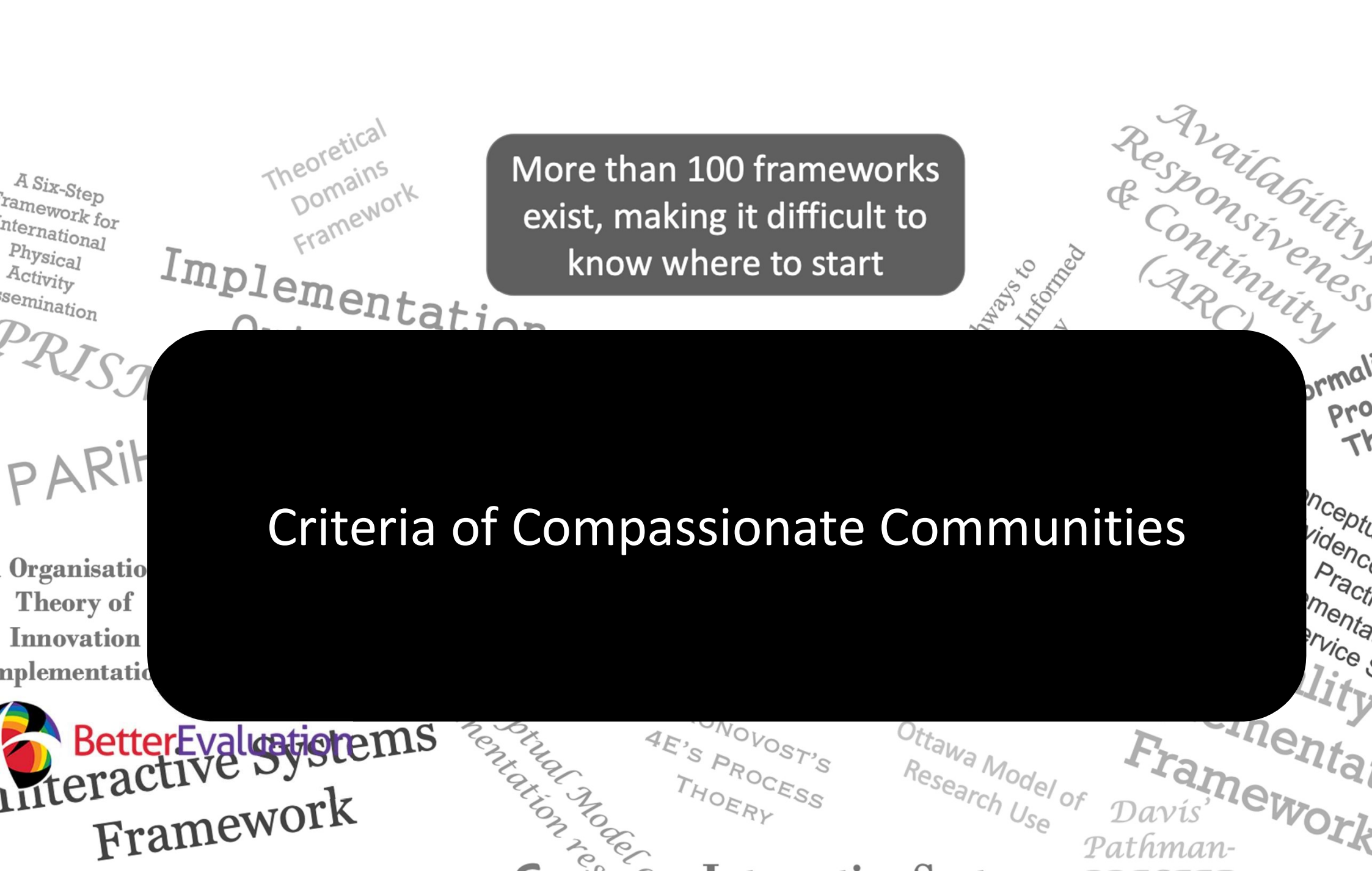
Long term aims

? ? ?




Implementation
Evaluation
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
Key principles
Target groups
Activities/ actions
Primary focus
OUTCOMES
OUTPUTS
INPUTS
SUCCESS FACTORS
Examples of target groups
Awareness raising
Social environment
Physical environment
Places for mourning, remembrance and death education
City planners
City council
participation
General population
Education
sustainability
Volunteers/ neighbours
Creating new social networks
Compassionate institutions and associations (eg businesses, government agencies)
Health care services
Life-stance group representatives
Community participation
Workplace policies
Local policies
School policies
Civic organizations
People in schools
Local government
Employers and employees
collaborations
coordination
empowerment

More than 100 frameworks exist, making it difficult to know where to start
A Six-Step Framework for International Physical Activity
Theoretical Domains Framework
Implementation Outcomes
PRISM
Precede-Proceed Model
PARiHS
Active Implementation Frameworks
Pathways to Evidence-Informed Policy
Availability, Responsiveness & Continuity (ARC)
CFIR
Normali
Pro
Th
Multi-Level Conceptual framework of Organisational Innovation Adoption
Concept
Evidenc
Practi
Implementa
Public Service
CDC DHAP's Research-to-Practice Framework
FAB Model
Organisational Theory of Innovation Implementation
Behaviour Change Wheel
Conceptual Model
Implementation
RE-AIM
IHI Framework for Leadership Improvement
PRONOVOST'S 4E'S PROCESS THOERY
Ottawa Model of Research Use
Quality
Implementa
Framework
Davis'
Pathman-
BetterEvaluation
Interactive Systems Framework

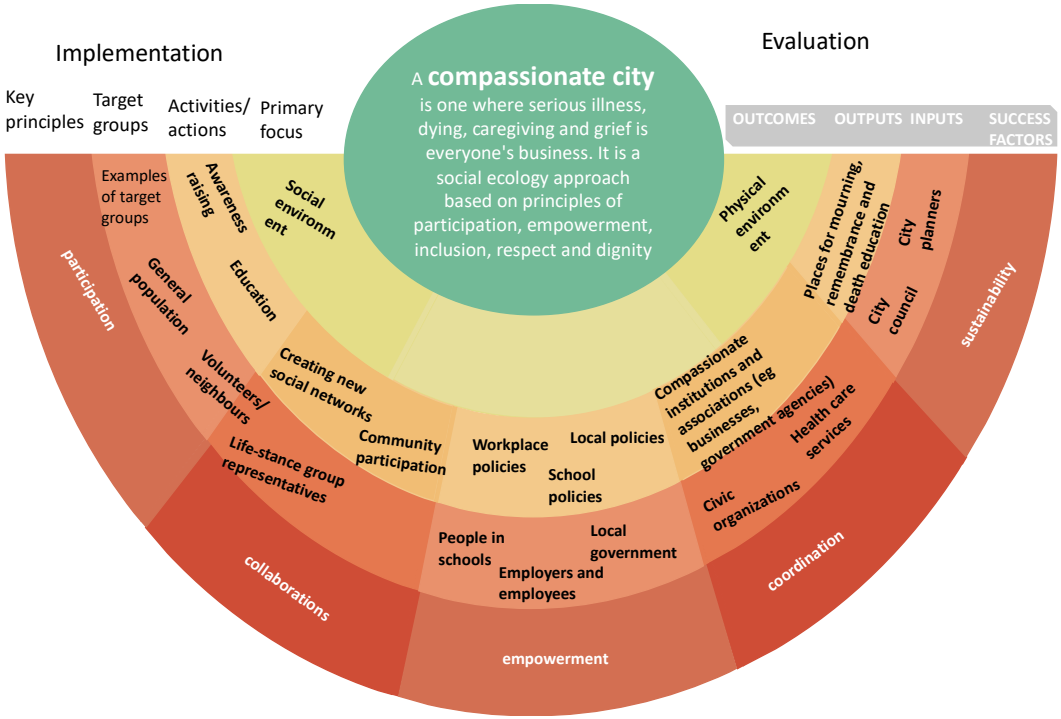


More than 100 frameworks exist, making it difficult to know where to start

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



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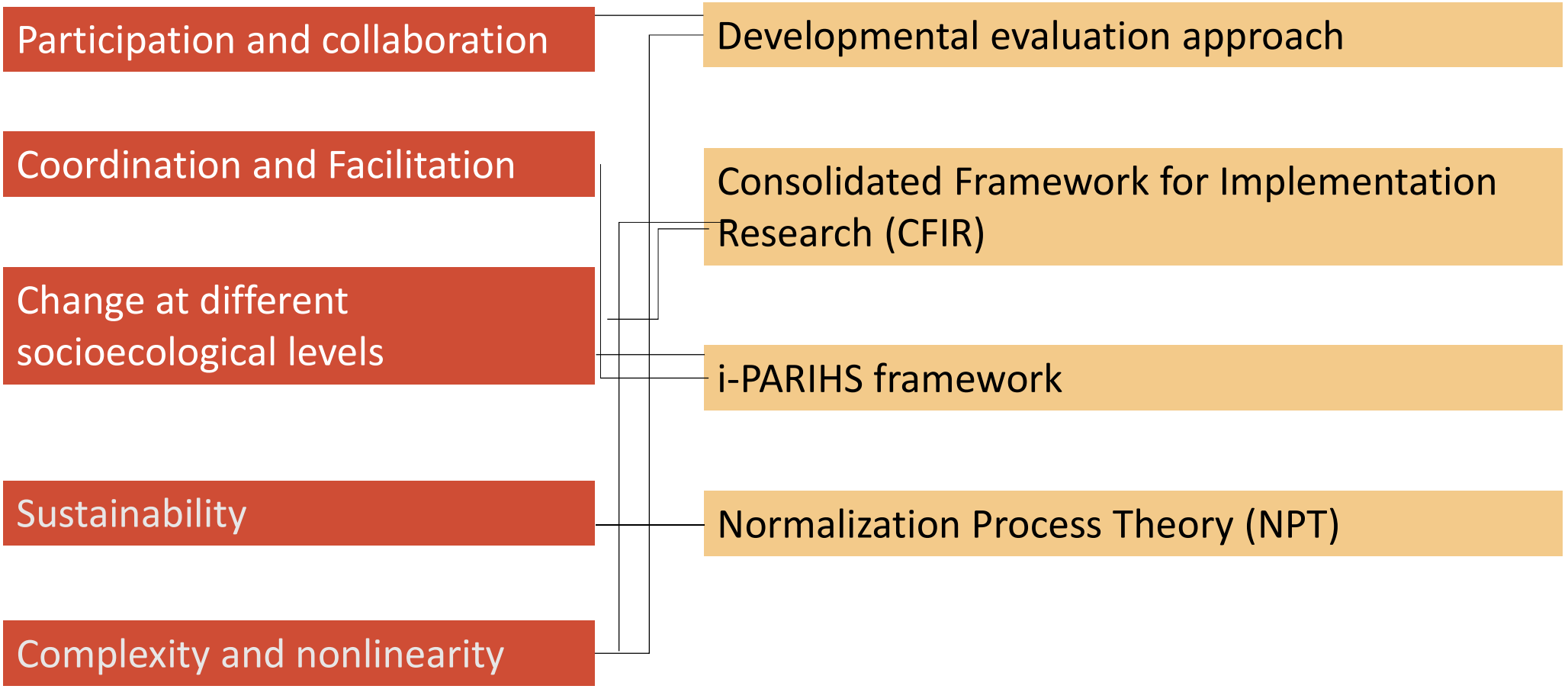
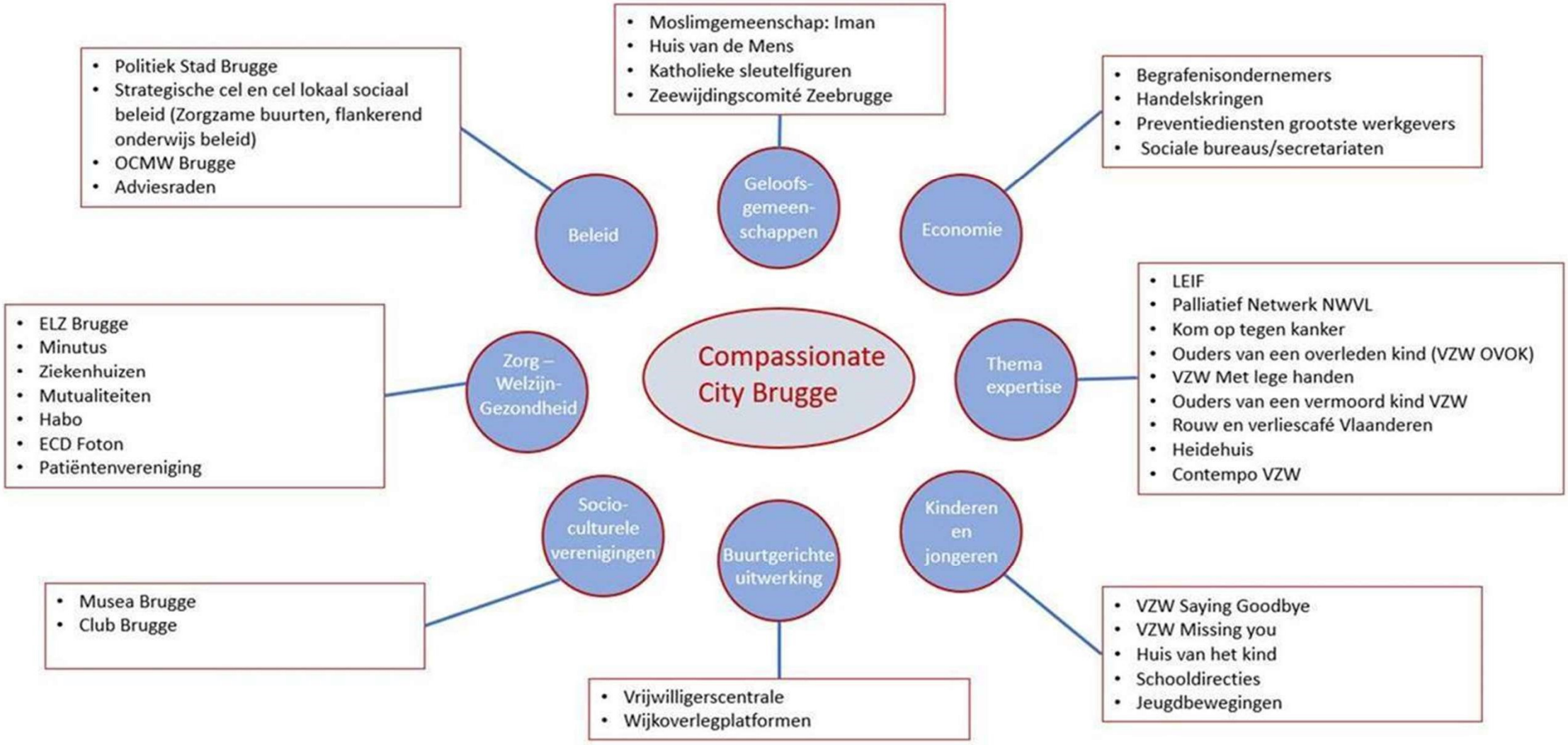
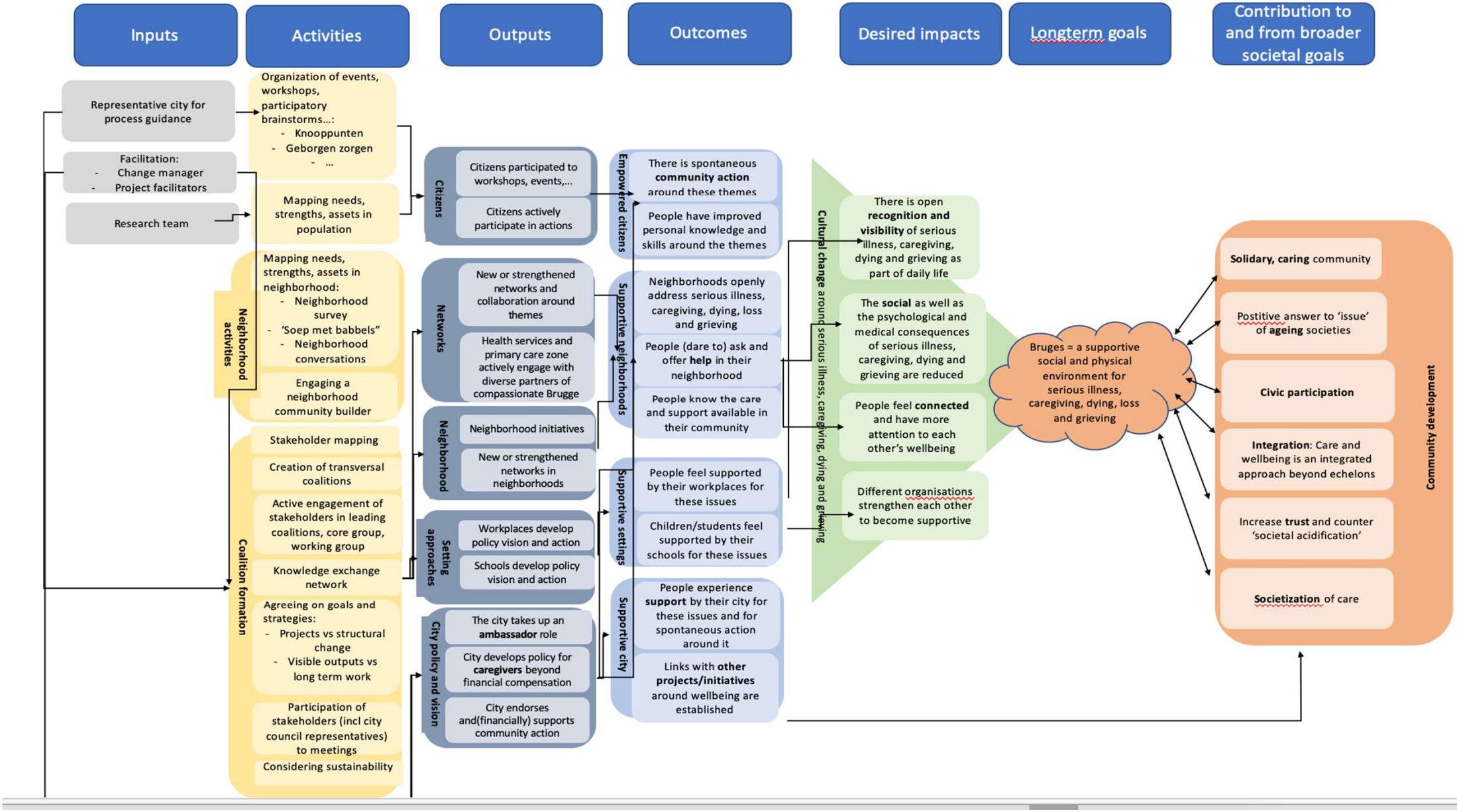
- Complexity and nonlinearity

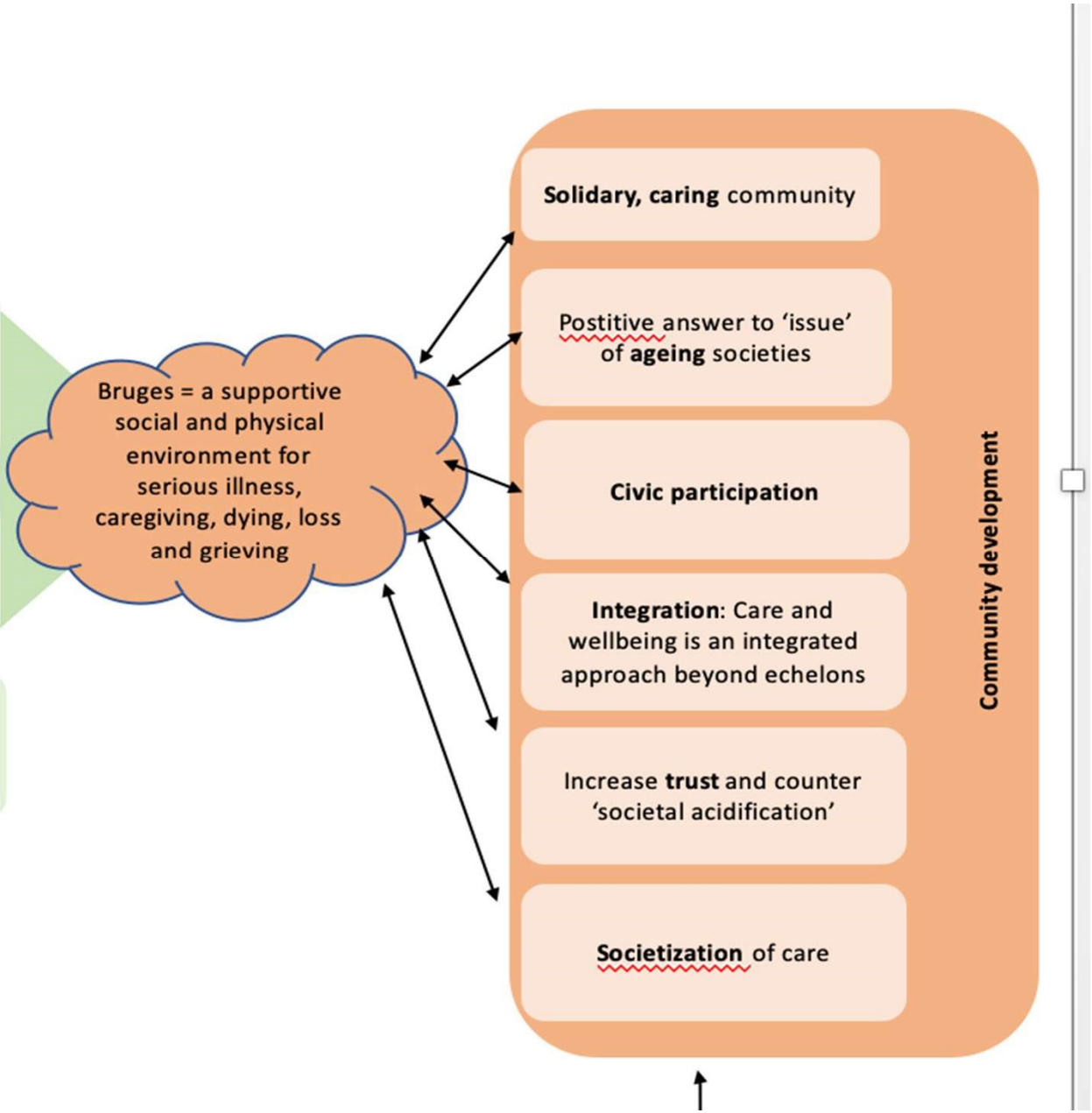
Compassionate cities programs = Complex Adaptive Systems	
Agents	
Emergence	
Feedback	
Adaptation	
Self-organisation	
Co-evolution	
Non-linearity	

A combination of frameworks and approaches is suitable




Compassionate City Brugge
Beleid
Politiek Stad Brugge
Strategische cel en cel lokaal sociaal beleid (Zorgzame buurten, flankerend onderwijs beleid)
OCMW Brugge
Adviesraden
Geloofs-gemeen-schappen
Moslimgemeenschap: Iman
Huis van de Mens
Katholieke sleutelfiguren
Zeewijdingscomité Zeebrugge
Economie
Begrafenisondernemers
Handelskringen
Preventiediensten grootste werkgevers
Sociale bureaus/secretariaten
Zorg – Welzijn-Gezondheid
ELZ Brugge
Minutus
Ziekenhuizen
Mutualiteiten
Habo
ECD Foton
Patiëntenvereniging
Thema expertise
LEIF
Palliatief Netwerk NWVL
Kom op tegen kanker
Ouders van een overleden kind (VZW OVOK)
VZW Met lege handen
Ouders van een vermoord kind VZW
Rouw en verliescafé Vlaanderen
Heidehuis
Contempo VZW
Socio-culturele verenigingen
Musea Brugge
Club Brugge
Buurtgerichte uitwerking
Vrijwilligerscentrale
Wijkoverlegplatformen
Kinderen en jongeren
VZW Saying Goodbye
VZW Missing you
Huis van het kind
Schooldirecties
Jeugdbewegingen


Inputs
Activities
Outputs
Outcomes
Desired impacts
Longterm goals
Contribution to and from broader societal goals
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
Neighborhood activities
Mapping needs, strengths, assets in neighborhood:
- Neighborhood survey
- 'Soep met babbels"
- Neighborhood conversations
Engaging a neighborhood community builder
Coalition formation
Stakeholder mapping
Creation of transversal coalitions
Active engagement of stakeholders in leading coalitions, core group, working group
Knowledge exchange network
Agreeing on goals and strategies:
- Projects vs structural change
- Visible outputs vs long term work
Participation of stakeholders (incl city council representatives) to meetings
Considering sustainability
Citizens
Citizens participated to workshops, events,...
Citizens actively participate in actions
Networks
New or strengthened networks and collaboration around themes
Health services and primary care zone actively engage with diverse partners of compassionate Brugge
Neighborhood
Neighborhood initiatives
New or strengthened networks in neighborhoods
Setting approaches
Workplaces develop policy vision and action
Schools develop policy vision and action
City policy and vision
The city takes up an ambassador role
City develops policy for caregivers beyond financial compensation
City endorses and(financially) supports community action
Empowered citizens
There is spontaneous community action around these themes
People have improved personal knowledge and skills around the themes
Supportive neighborhoods
Neighborhoods openly address serious illness, caregiving, dying, loss and grieving
People (dare to) ask and offer help in their neighborhood
People know the care and support available in their community
Supportive settings
People feel supported by their workplaces for these issues
Children/students feel supported by their schools for these issues
Supportive city
People experience support by their city for these issues and for spontaneous action around it
Links with other projects/initiatives around wellbeing are established
Cultural change around serious illness, caregiving, dying and grieving
There is open recognition and visibility of serious illness, caregiving, dying and grieving as part of daily life
The social as well as the psychological and medical consequences of serious illness, caregiving, dying and grieving are reduced
People feel connected and have more attention to each other's wellbeing
Different organisations strengthen each other to become supportive
Bruges = a supportive social and physical environment for serious illness, caregiving, dying, loss and grieving
Solidary, caring community
Postitive answer to 'issue' of ageing societies
Civic participation
Integration: Care and wellbeing is an integrated approach beyond echelons
Increase trust and counter 'societal acidification'
Societization of care
Community development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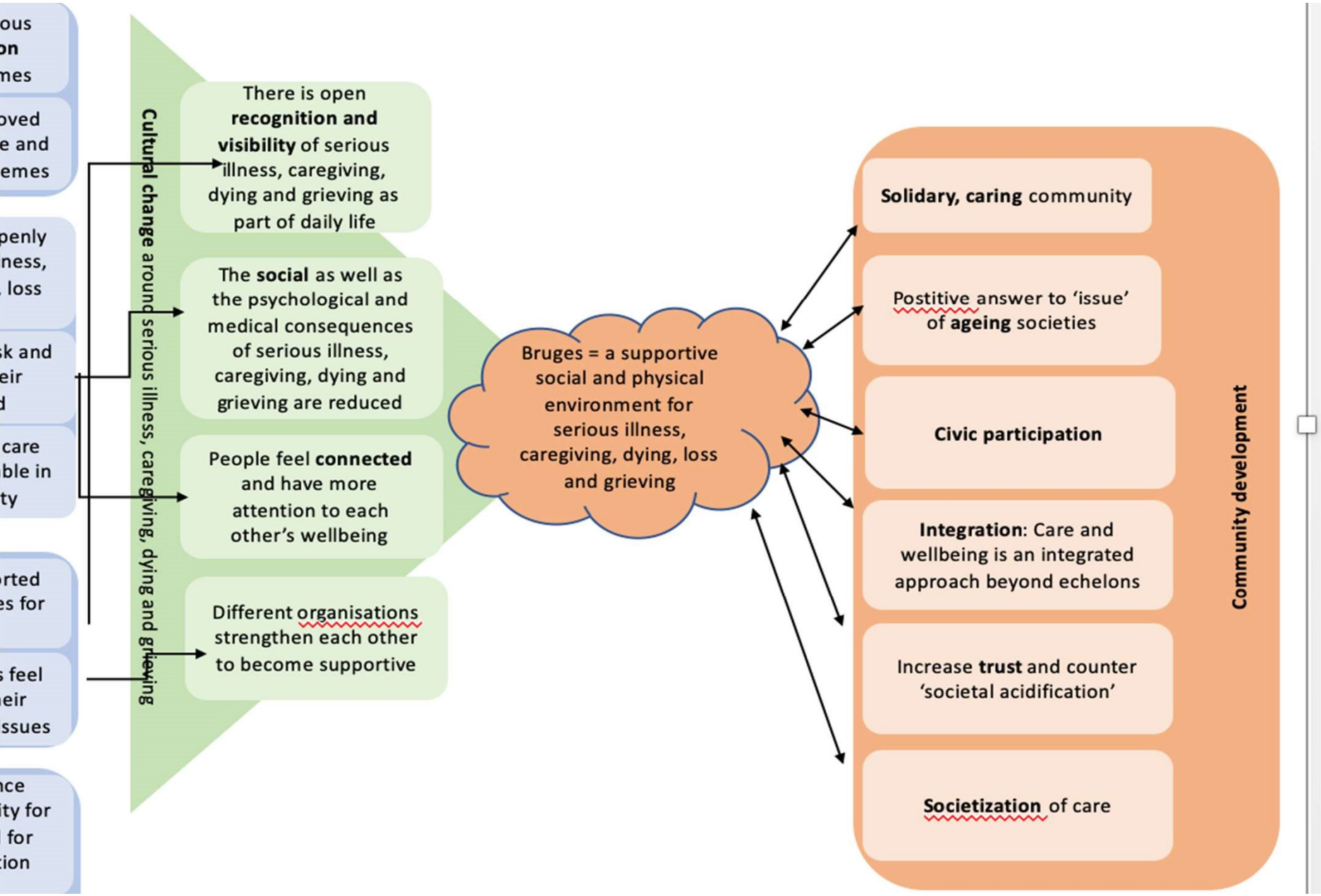
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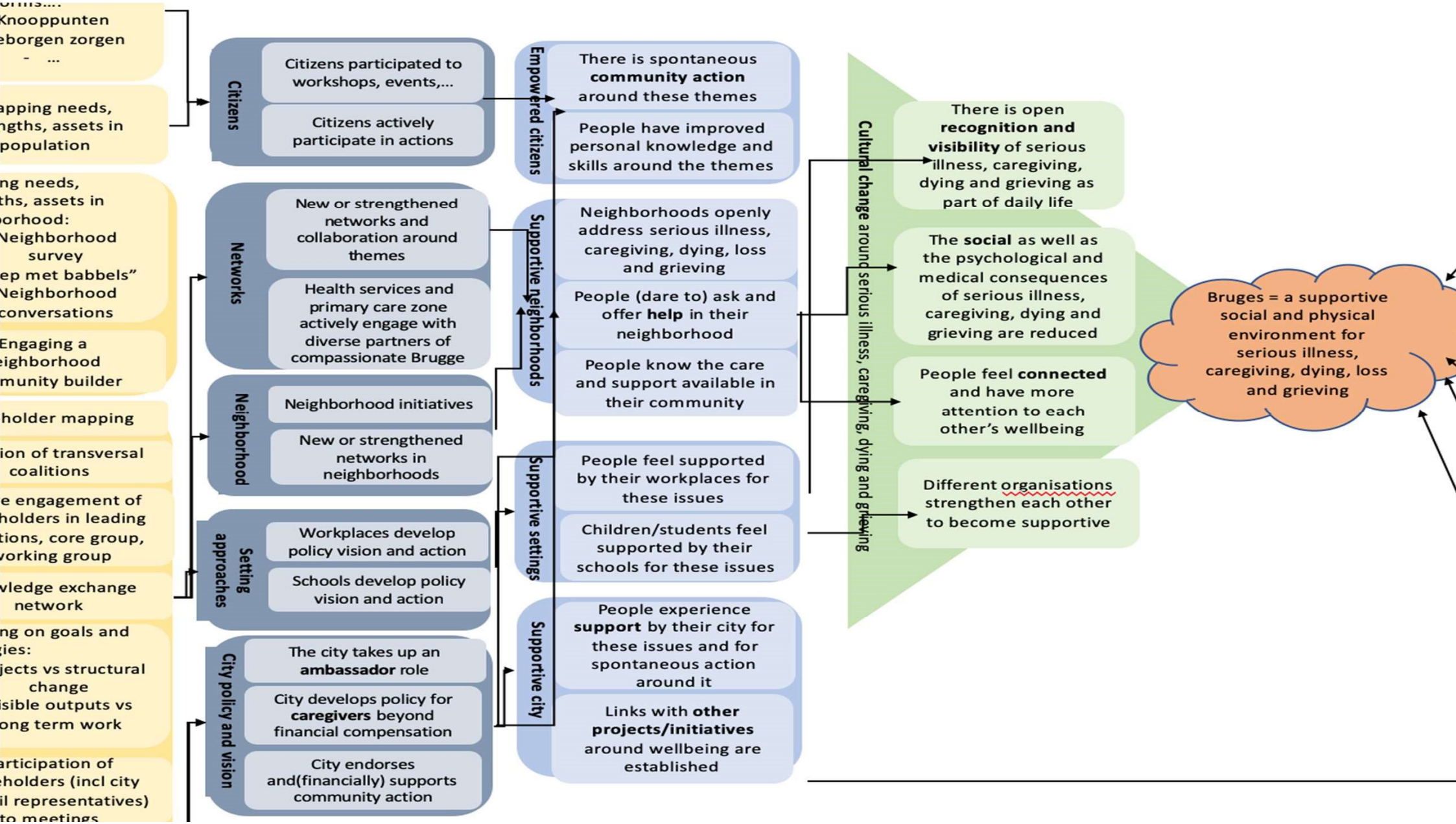
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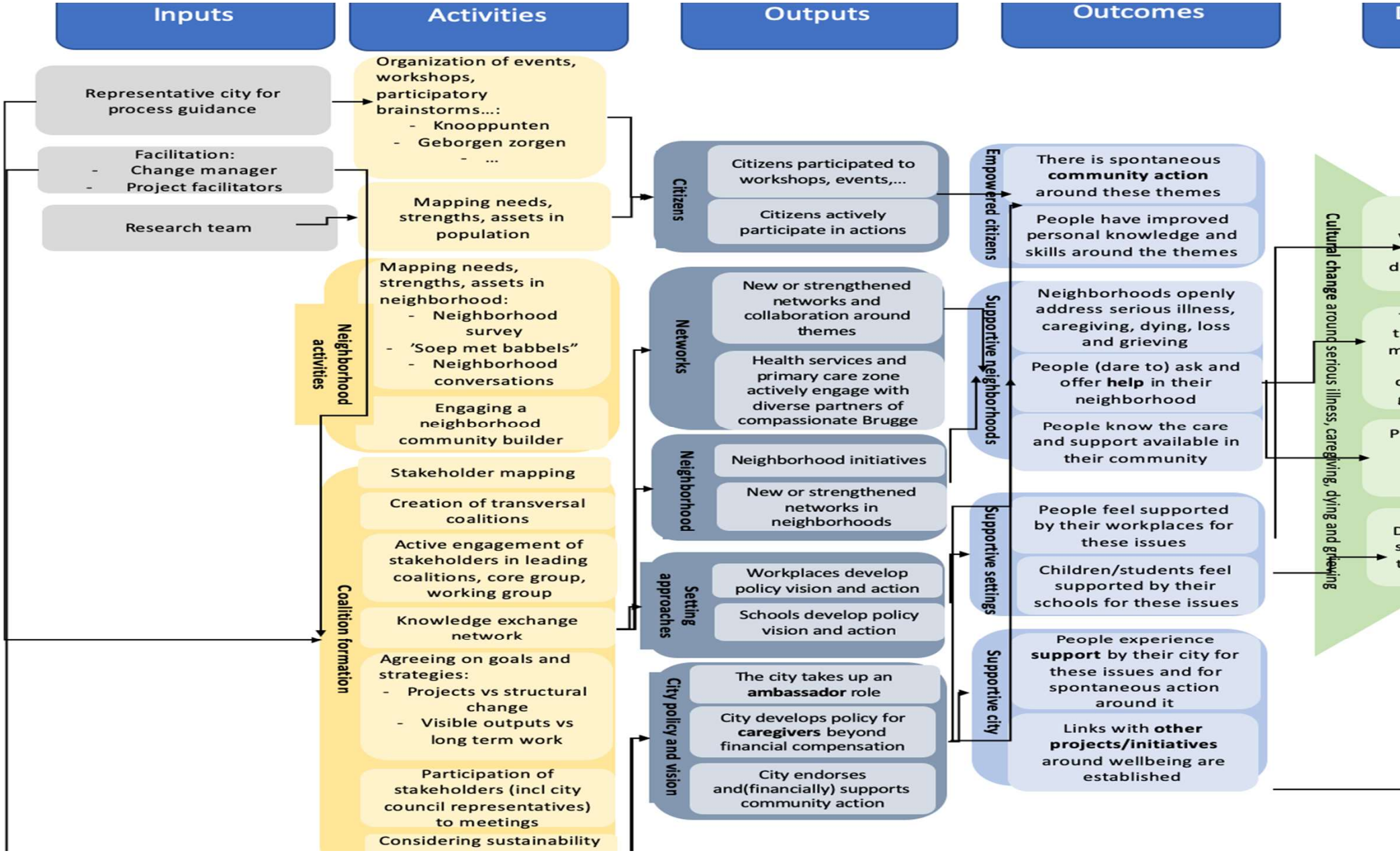
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Cultural change around serious illness, caregiving, dying and grieving

Facilitation

Interviews | Document analysis | Observations | structured reports

Representative city for process guidance

Facilitation:
- Change manager
- Project facilitators

Research team

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

Barriers
1) **Shortage of staff on project at city level**
2) **Risk of 'taking over' versus engaging, stimulating…**
3) **Reshuffling priorities due to external context (COVID, electoral pressure?)**
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

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

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

The fragmentation has become a bit smaller to me.

Population survey

Workshops

In Bruges, Herzele and 2 other 'control' cities
Random sample from population register
Obtained N= 2008,
about 50% response rate

High willingness to support others
Available potential social support
Knowledge palliative care

Mapping needs, strengths, assets in population

Knowing available support
Actions around own EOL
Overall participation in community life
Discomfort with dying of others

Neighborhood survey

Neigborhood conversations

Neigborhood interviews with identified assets

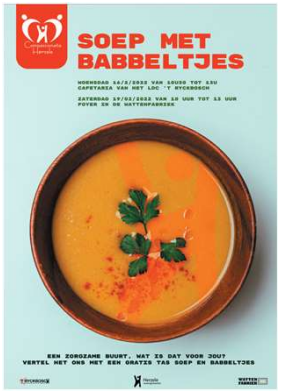
In 1 neighborhood in Bruges and Herzele
Random sample from population register
Obtained N= 714,
about 40% response rate

Neighborhood activities

Mapping needs, strengths, assets in neighborhood:

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

Engaging a neighborhood community builder



Neighborhood activities

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?

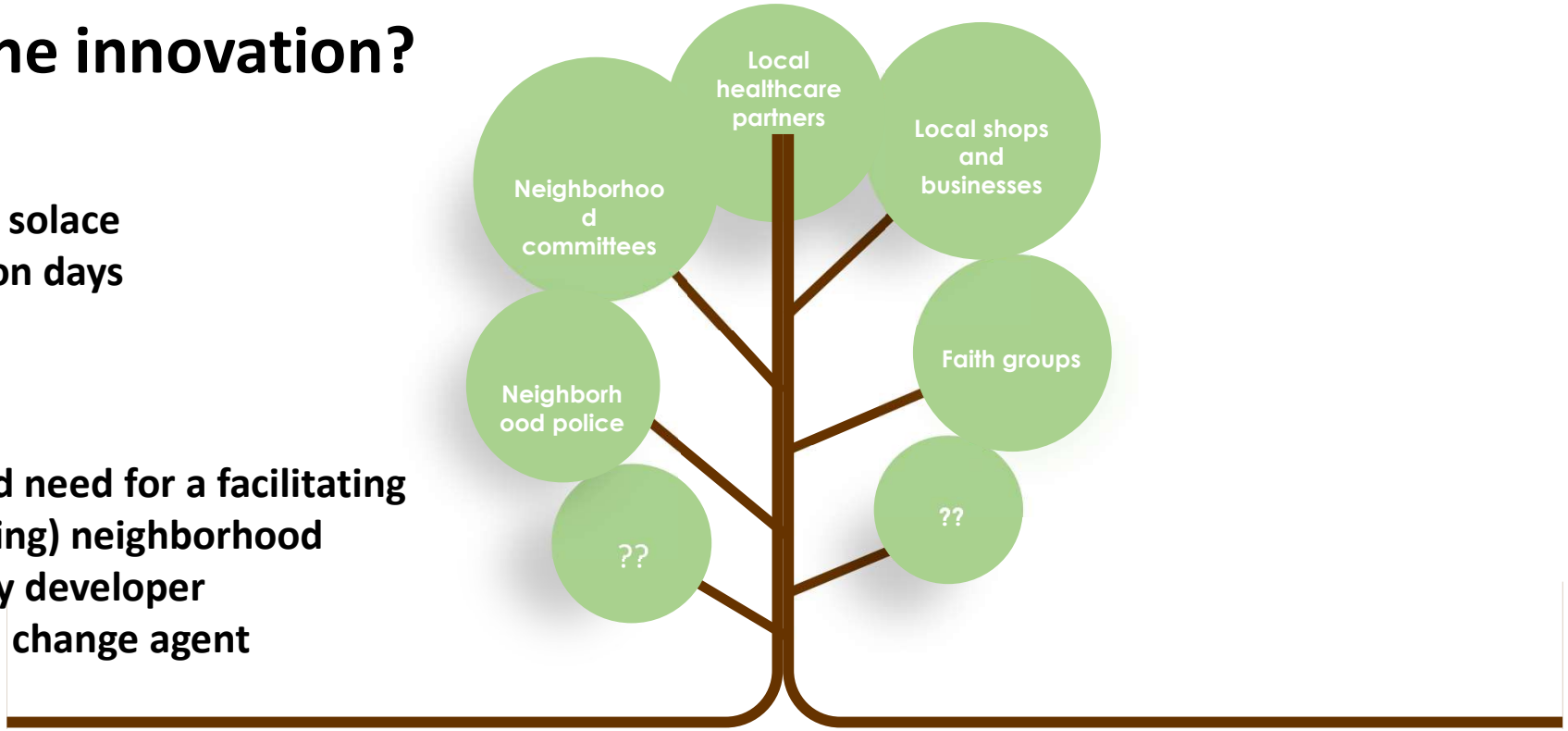
- ✓**Is it our task to do this?**
- ✓ **Will I be doing the right thing?**
- ✓**I don’t always have time for this….**

Neighborhood activities

Designing the innovation?

✓Places of solace
✓Inspiration days

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



Activities

Organization of events, workshops, participatory brainstorms…:

- Knooppunten
- Geborgen zorgen
- …

Outputs

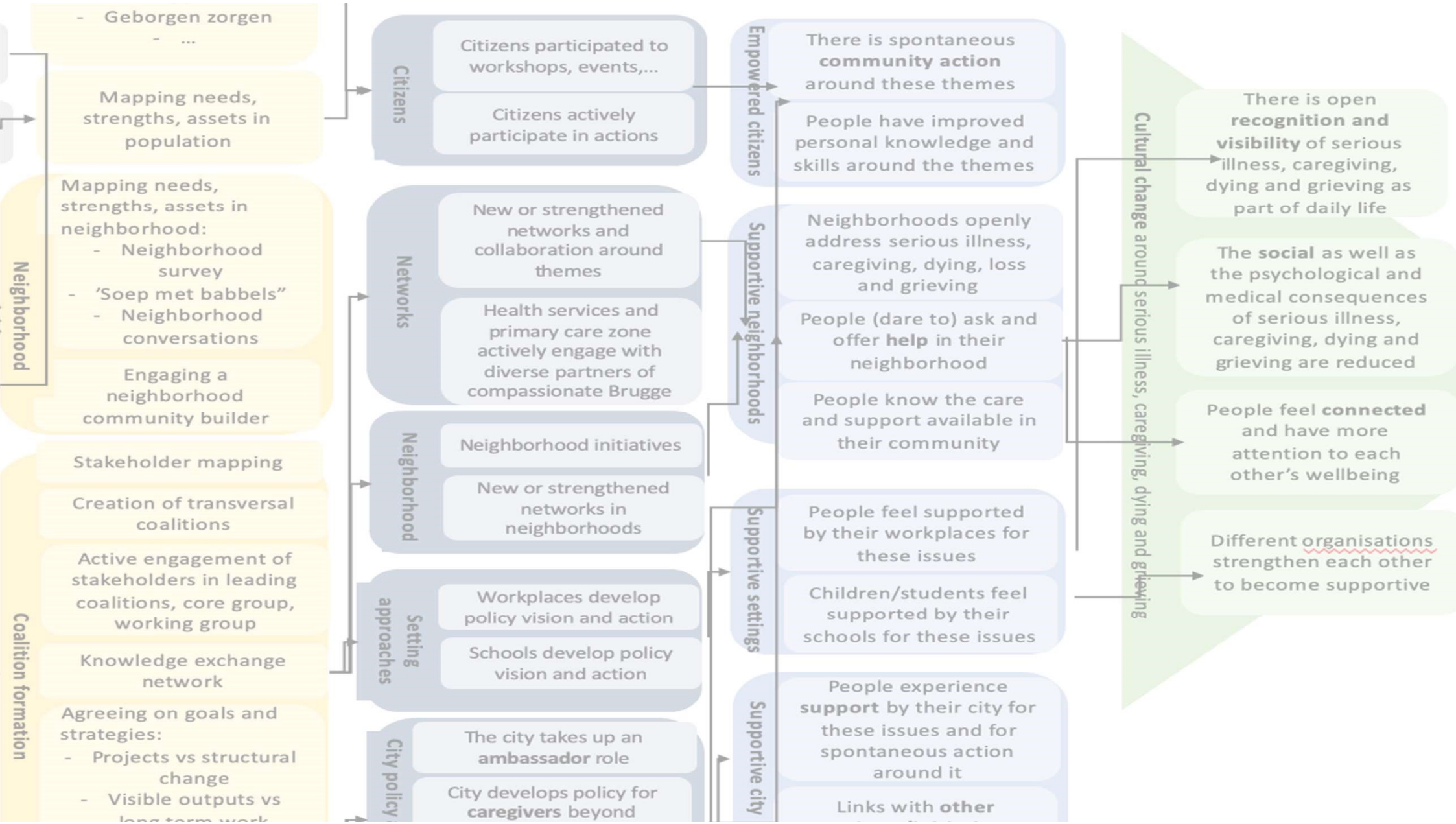
Citizens

- Citizens participated to workshops, events,…
- Citizens actively participate in actions

Quantitative event data

Interviews with organisers

Interviews with participants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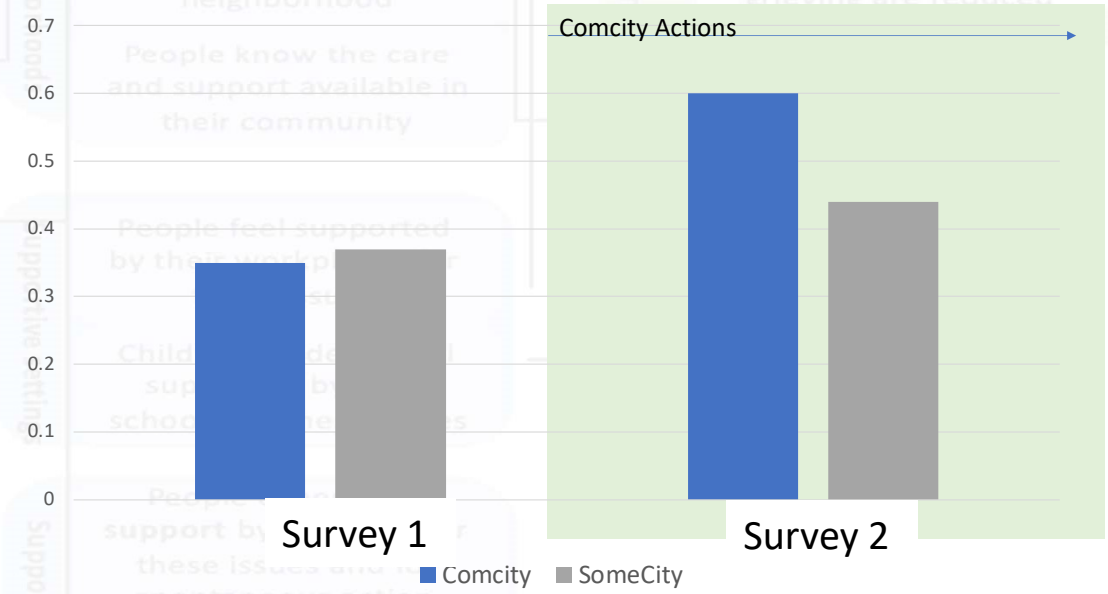
Monitor changes

Flexible process evaluations

Causal attribution

Longitudinal qualitative data from observations and interviews

Repeat survey in all cities and neighborhoods



Monitor changes

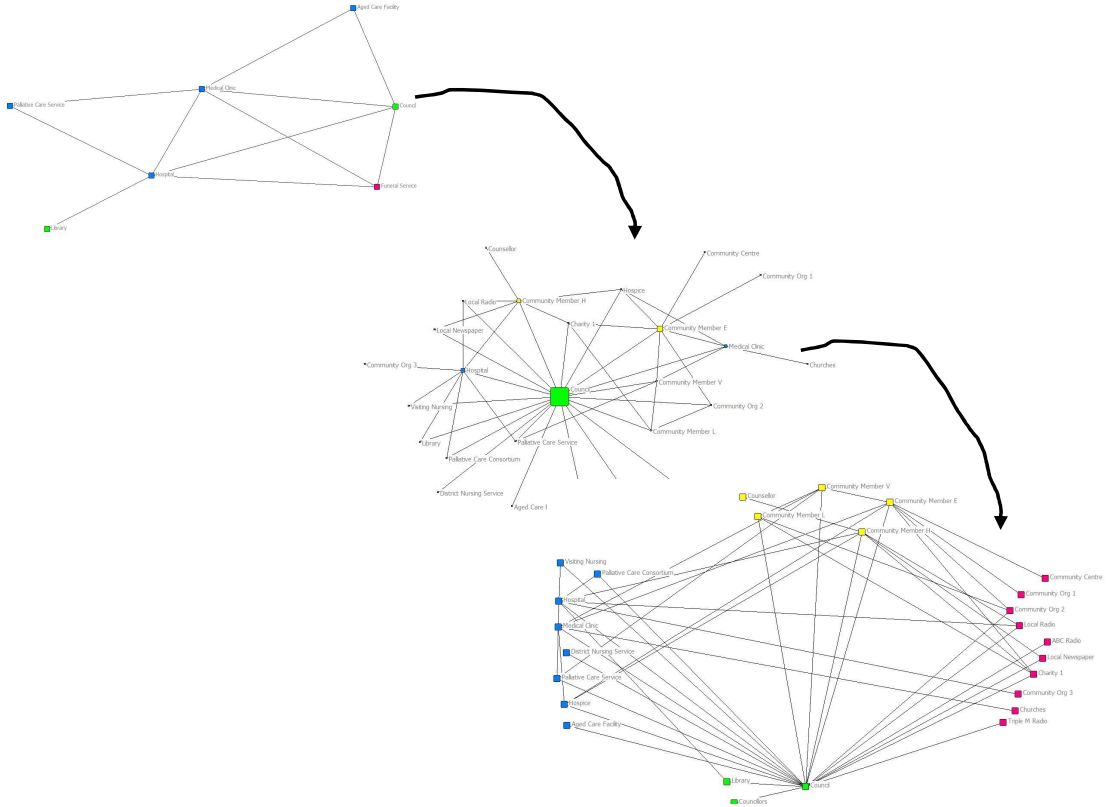
Flexible process evaluations

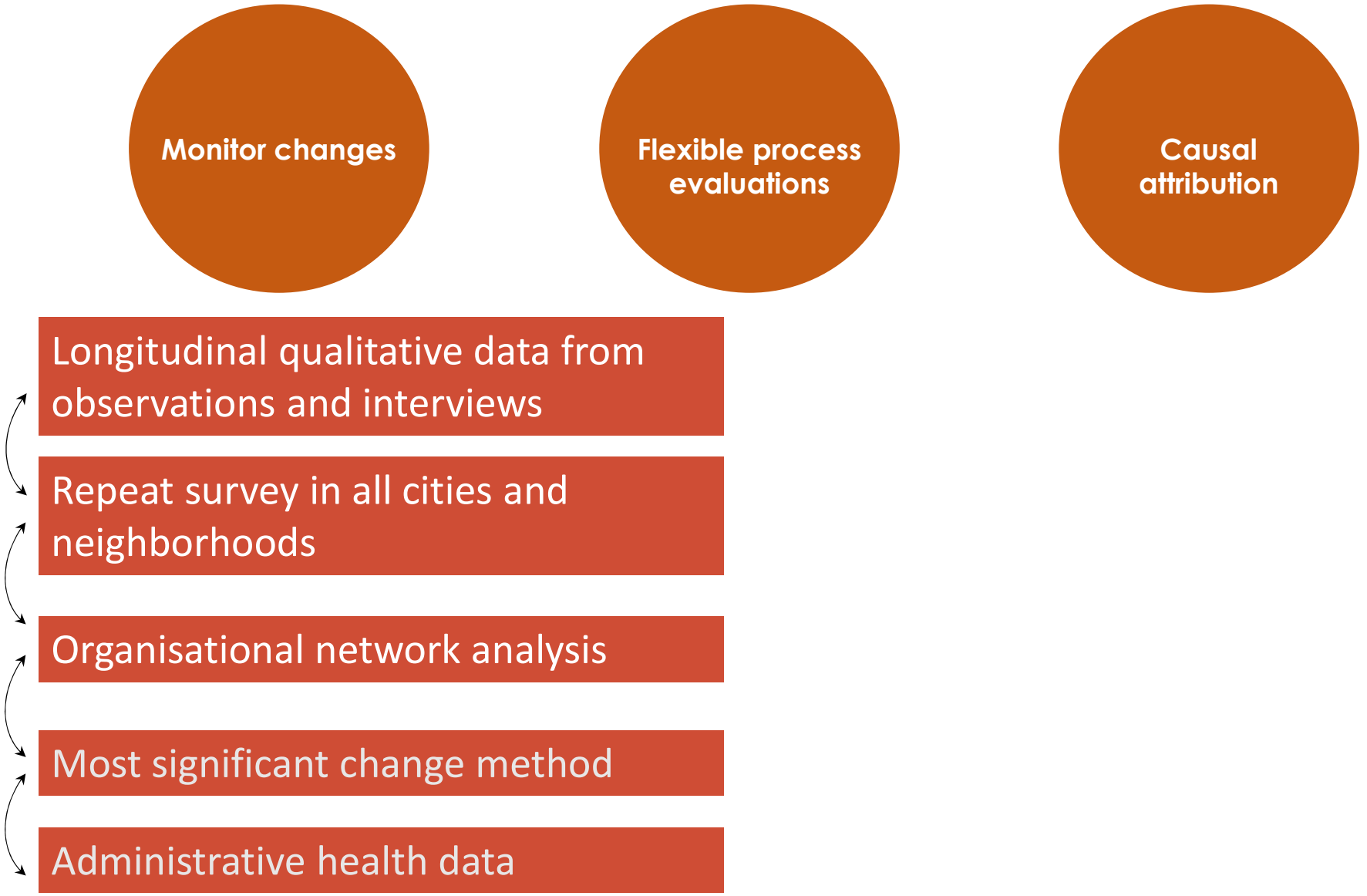
Causal attribution

Longitudinal qualitative data from observations and interviews

Repeat survey in all cities and neighborhoods

Organisational network analysis




Monitor changes
Flexible process evaluations
Causal attribution
Longitudinal qualitative data from observations and interviews
Repeat survey in all cities and neighborhoods
Organisational network analysis
Most significant change method
Administrative health data

A compassionate city program is a complex adaptive system where change happens nonlinearly at different socioecological levels, by different stakeholders through facilitated participation and collaboration

This requires adequate approaches to combine development and evaluation and frameworks to understand different important factors of development and success

The research needs to focus on flexibility, adaptive management, monitoring change, and causal attribution and use different data collection methods and sources thereto