

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

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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 twenty-three peer-reviewed and eleven 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 for support. 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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1 **Key words**

2 Civic engagement, volunteers, community participation, community development, compassionate
3 communities, public health, palliative care, systematic review³

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³ All the concepts are MeSH headings in PubMed, except for 'civic engagement' and 'compassionate communities', for which no MeSH heading exists.

1 **Key statements**

2

3 What is already known?

- 4 • Public health perspectives on palliative care transcend an individual, service-centred
5 interpretation of palliative care, and value community responses such as civic engagement.
- 6 • Previous studies in different domains of health and wellbeing have described the positive
7 impact of civic engagement initiatives, but a systematic description of civic engagement
8 initiatives in palliative care is lacking.

9 What this paper adds

- 10 • All initiatives were initiated after the year 2000, except for one that was initiated in 1995. The
11 year of initiation ranges from 2000 to 2020. Given the fact that we searched for publications in
12 English, a majority of the initiatives are located in countries with English as one of the official
13 languages.
- 14 • All initiatives in this review engaged with the community in their development, most often
15 through a community-academic partnership. Initiatives offered a variety of civic engagement
16 activities generally aiming to provide a link between seriously ill people and their caregivers
17 and other resources in the community.
- 18 • Although we found that all the evaluation studies showed a positive impact; most conducted
19 either a process or an outcome evaluation without including sustainability as one of the
20 evaluation outcomes.

21

22 Implications for practice, theory or policy

- 23 • Considering the variation in quality of the evaluation studies, there is a need to conduct in-
24 depth evaluations measuring both the impact of the civic engagement initiatives and the
25 mechanisms that lead to this impact.
- 26 • Future research should evaluate factors that influence the sustainability of a civic engagement
27 initiative, and should evaluate the influence of embedding the initiative in a compassionate city
28 context on its continuation.

29

1 Background

2 Demographic and epidemiologic trends increasingly confront individuals with the challenges of serious
3 illness, caregiving, dying, loss and bereavement, whether as the person with serious illness, a caregiver,
4 or just as a relative, friend, neighbour, etc.^{1, 2} Palliative care can offer added value in this regard by
5 increasing the quality of life of both the person with serious illness and their informal carers. However,
6 as is discernible from recent discussions in the literature about the definition and branding of palliative
7 care³⁻⁵, the term comes with different interpretations. A common interpretation of palliative care is one
8 that sees it as a formal healthcare service approach aimed at optimising individual care relationships
9 and improving distressing symptoms for patients and those close to them.^{3, 4} Others point to the
10 informal dimension and affirm that palliative care is also provided by friends, family members and the
11 wider community.^{3, 4} In turn, public health perspectives on palliative care insist on the social ecological
12 dimension where palliative care is framed as more than a response to the individual problems and
13 challenges of serious illness by healthcare services or informal caregivers, but includes societal actions
14 designed to improve or promote health and wellbeing around illness, death, dying, loss and
15 bereavement.⁵⁻⁷ Kellehear, for instance, has formulated this in the notion of caring for one another
16 during times of confrontation with serious illness, death, dying, loss or bereavement as a responsibility
17 for everyone.⁸

18 Compassionate communities have grown out of this public health approach and entail *“A community*
19 *of people who are passionate and committed to improving the experiences and well-being of individuals*
20 *who are dealing with a serious health challenge, and those who are caregiving, dying, or grieving.*
21 *Members of a Compassionate Community take an active role in supporting people affected by these*
22 *experiences. This can be done through connecting people to helpful resources, raising awareness about*
23 *life and end of life issues, and building supportive networks in the community (p.1)”*.⁹ However, engaging
24 community members on topics such as serious illness, death and loss can be a challenge. Civic
25 engagement is an important way of engaging people in civil society^{8, 10, 11}, and can be interpreted as
26 collective action undertaken to help improve connections between, or conditions for, people in the
27 community.¹²⁻¹⁴ We interpret civic engagement as an umbrella term for both volunteering and informal
28 caregiving as the context is the community, as it can be both performed from a personal connection
29 with the person receiving support, as is the case in caregiving, or from a broader social interest position,
30 as is often the case in volunteering.¹²⁻¹⁵

31 Previous studies have described the positive impact of such civic engagement initiatives in other
32 domains of health and wellbeing¹⁶⁻²¹, e.g. serving as a bridge between older people and youth^{17, 18}.
33 However, the context, processes, evaluation and impact of civic engagement initiatives in palliative

1 care have not yet been systematically described. Consequently, the aim of the review is to
2 systematically describe and compare the reported initiatives of civic engagement in serious illness,
3 death and loss in terms of the context in which they were initiated, their development and
4 sustainability, whether and how they were evaluated, and their impact. By describing these
5 characteristics, we aim to provide inspiration for current or developing initiatives, for the activities they
6 can undertake, and for ways to sustain and evaluate them.

7 Specific research questions are:

- 8 1) In what context, why and for whom are civic engagement initiatives around serious illness,
9 death and loss initiated?
- 10 2) How are they developed and how are they sustained?
- 11 3) How have they been evaluated, and what is their impact?

12
13

14 **Methods**

15 Protocol and registration

16 A protocol of the review was prospectively registered in Prospero July 5th, 2020. Registration number:
17 CRD42020180688 (<https://www.crd.york.ac.uk/prospero/#recordDetails>). The protocol was edited on
18 March 29th 2021, in order to clarify our focus on civic engagement, instead of the narrower term
19 ‘volunteering’.

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21

21 Review design

22 We conducted a systematic, mixed-methods review of civic engagement initiatives in palliative care
23 reported in peer reviewed literature, following the ‘Methodological guidance for the conduct of mixed-
24 methods systematic reviews’.²² Results were reported following the Preferred Reporting Items for
25 Systematic Reviews and Meta-Analysis (PRISMA).²³

26
27

27 Search strategy

28 Due to the dearth of knowledge on the domain of civic engagement in serious illness, dying and loss,
29 we argue it is a good first step to start from peer reviewed literature to gain a first insight into initiatives
30 that are being researched. Peer reviewed literature in English language publications was searched
31 through six databases: PubMed, Scopus, Sociological Abstracts, Web of Science, Embase and PsycINFO,
32 by using set eligibility criteria. In Scopus, Sociological Abstracts, Web of Science, Embase and PsycINFO
33 a limit was applied to acquire peer reviewed literature only. A search string was developed by the
34 research team in cooperation with a librarian from the VUB library consisting of three main elements
35 and their synonyms: compassionate communities, palliative care and civic engagement. The search
36 string does not include “care” because this term is a too general description of compassionate

1 communities, or a public health palliative care approach. Instead we used the term “caring
2 communities” because it is more specific, and sometimes used as a synonym for compassionate
3 communities. The search string was validated in PubMed (Table 1) and translated to the other
4 databases (Tables and figures, Table 6). No limited timespan for literature was applied in the databases.
5 Literature was searched up to November 2021. We searched the reference list of the included articles
6 for peer reviewed literature on other initiatives. Next, additional grey literature publications (including
7 websites of initiatives) were searched by contacting the first authors of the included articles. We
8 contacted fifteen authors of whom eleven replied after sending a reminder e-mail. For those initiatives
9 we did not have the contact details from the authors or for which the author did not reply, we
10 performed a limited google search in order to include the official website of initiatives. We performed
11 a limited google search for five of the initiatives.

12 **Table 1. Search string PubMed**

13 ("compassionate community"[Title/Abstract] OR "compassionate communities"[Title/Abstract] OR "caring
14 community"[Title/Abstract] OR "compassionate city" OR "compassionate cities" OR "caring communities"[Title/Abstract]
15 OR "new public health approach"[Title/Abstract] OR "public health palliative care"[Title/Abstract] OR "community
16 based"[Title/Abstract] OR "health promoting palliative care"[Title/Abstract] OR "social network approach") AND (volunteer
17 OR volunteers OR volunteering OR voluntary OR "civic engagement" OR "civic society" OR "civil society" OR "neighbor" OR
18 "neighbors" OR "neighbour" OR "neighbours" OR "community connector" OR "community connectors" OR "community
19 initiative" OR "community initiatives" OR "community network" OR "community networks" OR "community group" OR
20 "community groups" OR "community organisation" OR "community organisations" OR "community organization" OR
21 "community organizations" OR "self-help groups" OR "support group" OR "support groups" OR "community participation"
22 OR "community engagement") AND (palliative* OR hospice* OR terminal* OR "end of life" OR bereave*)

23
24 Eligibility criteria

25 Publications were eligible for inclusion if:

- 26 (A) they were written in English, and
27 (B) described one or more civic engagement initiative in which community members identify
28 certain challenges in their community concerning serious illness, death and loss, and
29 (C) decide to mobilise collectively in order to address these issues.

30 Publications were excluded if:

- 31 (D) they reported on public engagement that is essentially service-centred, meaning that the
32 engagement work has the main aim of enhancing the quality or reach of a professional service,
33 and the engagement is described as a formal part of this service.

34
35 Study selection

36 The articles from the database searches were imported into the electronic systematic review program
37 *Rayyan*. Duplicates were removed by the program. The imported peer reviewed literature was first
38 screened on title and abstract. Articles were either given the label ‘included’, ‘excluded’ or ‘maybe’.

1 Articles that were labelled as ‘included’ or ‘maybe’ in the first screening were subjected to a full text
2 screening. In order to be eligible, articles had to meet the three inclusion criteria and not fall within the
3 exclusion criterion. The screening and study selection were independently performed by two
4 researchers (LDEE and BQ). There was an initial disagreement about nineteen articles between the
5 researchers, sixteen of which were resolved. The three remaining disagreements were resolved by an
6 independent screening by a third reviewer (TS). The study selection resulted in twenty-three included
7 publications, reporting on nineteen unique civic engagement initiatives.

8

9 Data extraction

10 Data were extracted from the included peer reviewed and grey literature publications to answer the
11 research questions on their context, development and evaluation. A data extraction form was pilot
12 tested for the identified studies found in PubMed. This resulted in the following variables for which
13 data were extracted from the included publications:

- 14 - Regarding the context of the initiatives : (1) name of the initiative, (2) year of initiation (3) country
15 and continent, (4) reason for initiation, (5) target group.
- 16 - Regarding development of the initiatives: (1) nature of community engagement in the
17 development (i.e. did the community develop the initiative themselves? Or if not, were they
18 informed, consulted or did they collaborate with others partners in the development?), (2)
19 activities of civic engagement, (3) training and support for people participating in civic engagement,
20 (4) continuation (i.e. is the initiative still ongoing at the moment of this publication and if not, what
21 are the reasons for termination), and (5) sustainability recommendations (i.e. recommendations
22 from studies to other initiatives to increase or ensure the continuation of their civic engagement
23 activities).
- 24 - Regarding evaluation of the initiatives: (1) the aim of the evaluation, (2) evaluation design (3), data
25 collection methods, and (4) Impact of the initiative.

26 For each variable, exhaustive data from the article was put directly in the data extraction form (Table
27 3, Table 4 and Table 5). This data was supplemented by the data from the reference list search and
28 from the grey literature search. Data extraction was independently performed by LDEE (entirely) and
29 by BQ for 25% of the publications (five articles).

30

31 Data synthesis & analysis

32 We conducted a convergent integrated approach to synthesise data from qualitative, quantitative and
33 mixed-method studies.²² We produced a descriptive paragraph on each of the included studies,
34 thereby providing textual descriptions not only of the qualitative data but of the quantitative and
35 mixed-method studies as well. Consequently, the author (LDEE) examined the assembled data and

1 grouped this data into categories, based on their similarity in meaning. These categories were reviewed
2 by and discussed together with author B.Q. in order to come to a consensus.

3

4 Quality appraisal

5 We performed a quality appraisal of those civic engagement initiatives that were evaluated in a study.
6 The quality appraisal was conducted using a self-developed tool based on the Mixed Method Appraisal
7 Tool (MMAT)²⁴ (Tables and figures, Table 7). We adapted two screening questions from the MMAT: (1)
8 are there clear research questions or is the aim of the evaluation clear? and (2) does the collected data
9 allow us to answer the research questions or aim?. If one or both of these screening questions was
10 answered negatively, the appraisal was stopped and a score of 0 out of 4 was assigned. If both screening
11 questions could be answered 'yes' the following two self-developed screening questions were
12 answered: (1) are the results adequately derived from the data? (2) is the conclusion sufficiently
13 substantiated by data?, For each question answered 'yes', one point was given. Next, we calculated a
14 total quality score by summing the scores of the individual questions, ranging from 0 to 4, with higher
15 scores indicating better quality. Quality appraisal was entirely performed by LDEE, and by BQ for 25%
16 of the included articles (five articles).

17

18 **Results**

19 Study selection

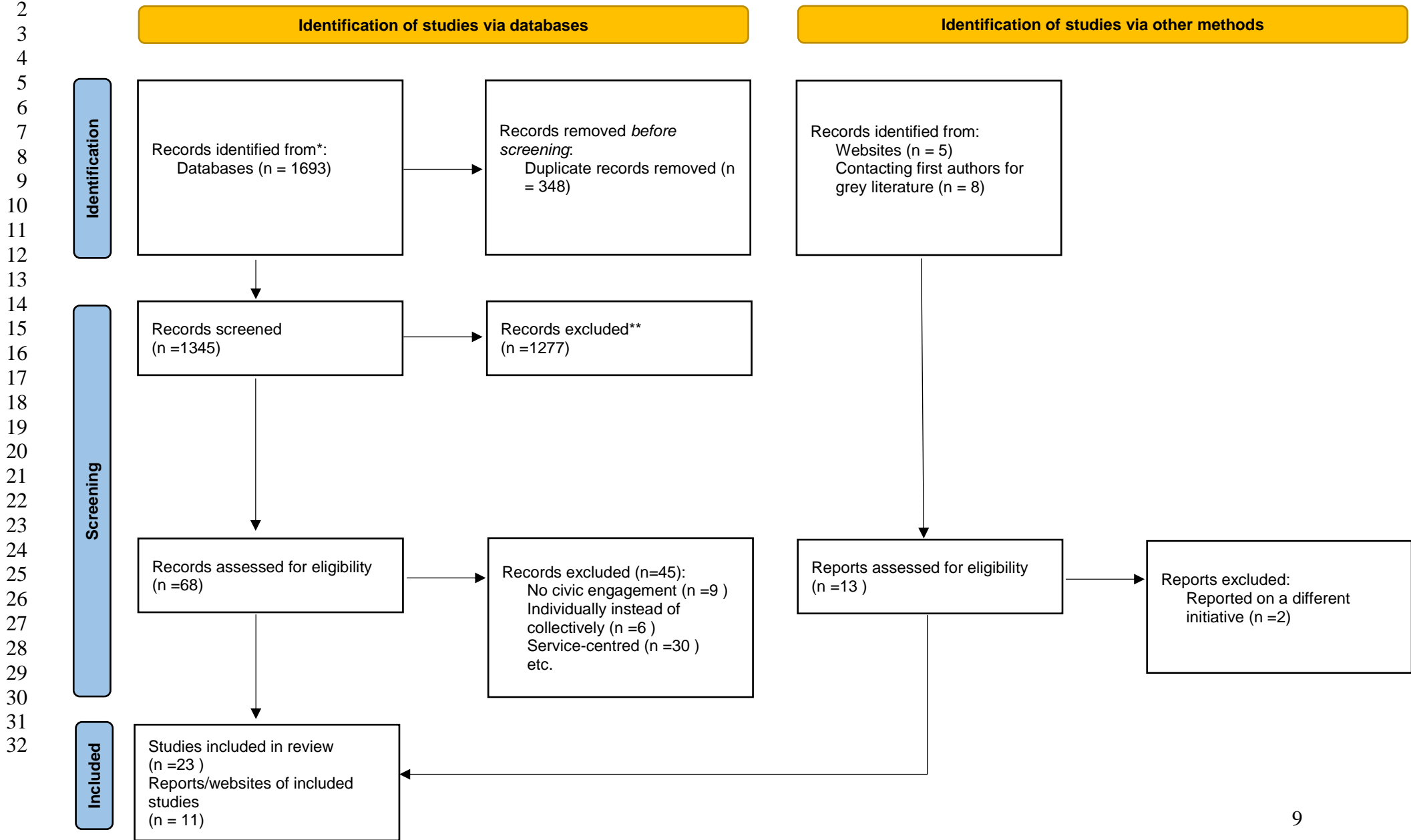
20 The process of study selection is depicted in a PRISMA flow chart²³ (Figure 1). From the twenty-three
21 included publications, we searched the reference lists and found two additional peer reviewed
22 publications that met the eligibility criteria. These two additional articles were not identified through
23 the database search because they focused on one specific serious illness (dementia or cancer) and could
24 therefore not be identified using the general terms (palliative* OR hospice* OR terminal* OR "end of
25 life" OR bereavement*) included in the search string. In the next phase, we included eleven additional
26 grey literature publications by contacting the first authors of each of the articles.

27

28 Results on civic engagement initiatives

29 The twenty-three peer reviewed and eleven grey literature publications reported on nineteen unique
30 civic engagement initiatives, included in table 2, a descriptive overview of the included civic
31 engagement initiatives.

1 Figure 1. PRISMA flowchart of the study identification, screening, eligibility and inclusion process



1 Table 2, descriptive overview of the included civic engagement initiatives

	Name of the initiative	Narrative description of the initiative
I-1	The Good Neighbour Partnership ^{25, 26}	The Good Neighbour Partnership (GNP), is a volunteer-led model of social and practical care/support for community dwelling adults living with advanced life limiting illness in Limerick, Ireland. The role of a Compassionate Community Volunteer is to make the link between a person/family living with palliative care needs at home, and those in their circle of community who are able to offer support. Thereby aiming to enhance “Good Neighbour” capacity within the local community.
I-2	Health Promoting Resource Team in the Hume Region’s Caring Communities Project ²⁷⁻²⁹	The Hume Regional Palliative Care Service in Victoria, Australia sought to implement a health-promotion in palliative care approach through partnerships formed with a range of community groups and service agencies in their region. Following the education phase ten people – nurses, social workers and volunteers formed a regional palliative care health promotion resource team. Over a period of two years they mentored and supported community services and groups, as well as palliative care services, in developing, providing and evaluating local projects that utilised a health promotion approach.
I-3	Walk Each Other Home ³⁰	In 2015, the Okines Community Garden (Okines) in southern Tasmania, Australia, collaborated with the University of Tasmania’s Centre for Rural Health (CRH) to explore how the garden community might provide better support for people at the end-of-life and in bereavement. The garden coordinators and volunteers prompted this partnership
I-4	Bereavement support intervention ³¹	Ten orphaned adolescents living with HIV (ALHIV) aged 18–21 years volunteered to work with a bereavement consultant to develop a bereavement intervention. After receiving training they facilitated a six-session bereavement intervention as peer counsellors, in ten existing ALHIV support groups.
I-5	Home-and Community-Based Care (HCBC) program ³²	Family Health International (FHI), in collaboration with government, local nongovernmental organizations (NGOs), and community organizations, jointly implemented home- and community-based care (HCBC). HCBC includes provision of basic nursing care by trained volunteer caregivers from the community.
I-6	Community Home Based Care CHBC in Mufudzi ³³	Mufudzi, a Christian organisation, adapted a community home-based care (CHBC) approach modelled on pastoral visits of local churches, involving visiting all chronically ill individuals in a neighbourhood to educate them and their families about HIV, offering comfort-oriented basic care as well as emotional and spiritual support, and referral to appropriate health and social services.
I-7	Neighbourhood network in palliative care (NNPC) ^{34, 35}	The first palliative care experiment with community support in Kerala (India) was initiated in 1993 by a nongovernmental organisation. Involvement of the community in the decision making was minimal. In the attempts of overcoming the defects of the earlier model that resulted in the formal initiation of a project known as the Neighbourhood Network in Palliative Care (NNPC). In this program, volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively, with active support from a network of trained professionals
I-8	Sanjeevani ^{36, 37}	Sanjeevani is a community-based palliative care organization in Nadia district, West Bengal (India), that is modelled on the Kerala approach. Sanjeevani was spearheaded by the District Magistrate of Nadia, in collaboration with physicians from the local chapter of the Indian Medical Association, and the Institute of Palliative Medicine (IPM), Kerala. More than 150 volunteers participated in an elaborate train-the-trainer programme. These trainers then spread out to the villages and conducted satellite training, yielding a total of 1000 volunteers to provide community-based palliative care.
I-9	Four-phase capacity-building program ^{38, 39}	The Four-phase capacity-building program is part of the JCECC (Jockey Club End-of-Life Community Care Project), a multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with special emphasis on the interface between social and medical systems. The program entails a holistic capacity-building program for volunteers in community-based end-of-life care, entailing four steps: motivational screening, core competence training, internships, and supervision.
I-10	Gilda’s Club Toronto ^{40, 41}	Gilda’s Club of Toronto is a not-for-profit venue in Ontario, Canada, that serves as a communal meeting place where people living with cancer, as well as their families and friends, can join with others to build physical, social, and emotional support as a supplement to their medical treatment. Gilda’s Club include yoga classes, art therapy, writing classes, and lectures from health care professionals.
I-11	The Hudson and District Hospice Society ^{42, 43}	The study occurred when a group of committed citizens from Hudson began to meet informally to talk about how to improve its hospice care in their community. After a meeting between the small community group and the researcher, a request was made to develop a study while they continued through their community development process. The need for, and interest in hospice care grew, resulting in training volunteers to offer care to those with a life limiting illness which also supported family members.
I-12	N-Care/Nav-Care ⁴⁴⁻⁴⁷	Nav-CARE is a volunteer-led intervention designed to build upon strategic directions in palliative care: a palliative approach to care, a public health/compassionate community approach to care, and enhancing the capacity of volunteerism. Nav-CARE uses specially trained volunteers to provide lay navigation for older persons and family living at home with advanced chronic illness.
I-13	Circles of Care ⁴⁸⁻⁵⁰	Investigators initially recruited and trained 24 lay health advisors who shared information or support with 210 individuals. New volunteers, separate from those who trained as lay health advisors, were recruited from community organizations or the social network of an individual with cancer. Volunteers were trained to do “what

		they like to do, when they can do it, in a coordinated way". Support activities were offered by the volunteers based on their time and willingness to provide specific types of support, and the needs that were expressed on the patient checklist.
I-14	Volunteer Information Provider Program (VIPP) ⁵¹	A Volunteer Information Provider Program (VIPP) was initiated in five rural Missouri counties to help families deal with the strain of caregiving. Starting from two major community-based organizations in rural areas, Cooperative Extension Services and Extension Homemakers Clubs, 63 volunteers shared information with over 1100 caregivers in a 14-month period.
I-15	Chinese-American Coalition for Compassionate Care (CACCC) ^{52, 53}	A group of Chinese-American community activists formed an exploratory group in December of 2005 to establish the CACCC. The coalition identified two projects for the beginning phase of the organization: 1) to provide end-of-life care training for volunteers and caregivers; and 2) to create an enhanced resource database for the Chinese-speaking population. Overall goal is to improve the quality of end of- life care for Chinese Americans.
I-16	Advance Care Planning Community Guides Program ⁵⁴	A community-academic partnership developed an Advance Care Planning Community Guides Program that trained individuals to have community-based advance care planning (ACP) conversations. The ACP Community Guides Program seeks to provide concrete communication skills to train ACP Guides to initiate and facilitate peer-to-peer conversations in the community around ACP.
I-17	Support Teams for Caregivers ⁵⁵	The Support Teams for Caregivers is a dementia caregiver model program that merges an evidence-based intervention, Resources for Enhancing Alzheimer's Caregiver Health (REACH II), with a proven volunteer program, The Support Team Network. The resulting implementation research program is called Support Teams for Caregivers. The support team members are community volunteers who provide practical, emotional, and spiritual support to anyone who is open to receiving help with their situation.
I-18	Care Teams from the Compassionate Project ^{56, 57}	The Support Team model enhances community support for practical, emotional, and spiritual caregiving. Project Compassion's network of community-based Care Teams enhancing community support for patients and families dealing with illness and death, caregiving. A Care Team is a coordinated group of 6-12 volunteers working together to help meet practical, emotional, and spiritual needs. Project Compassion provides education, support, and guidance for Care Teams sponsored by faith communities, organizations and other groups.
I-19	Compassionate Communities Connectors ⁵⁸	Compassionate Communities Connectors is a model of community volunteers who support people living with advanced life limiting illnesses/palliative care needs. Up to 10 Connectors are trained to work with at least 30 families selected by the palliative care service as requiring support. The approach seeks to map and mobilise people's personal networks of care through the Connectors enlisting helpers in the community (Caring Helpers).

1
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1 Characteristics of the context of the initiatives

2 All initiatives were initiated after the year 2000, except for one that was initiated in 1995³³. The year of
3 initiation ranges from 2000 to 2020, with an equal distribution of initiatives being initiated in the first
4 and second decade. Given the fact that we searched for publications in English, a majority of the
5 initiatives are located in countries with English as one of the official languages, except from the
6 initiative in Ethiopia³². We found initiatives in North America⁴⁰⁻⁵⁸(in Canada or in the USA), Oceania²⁷⁻³⁰
7 (Australia and in Europe^{25, 26} (Ireland). Other initiatives are located in Asia³⁴⁻³⁹ (India, Hong Kong) and
8 Africa³¹⁻³³ (Zimbabwe, Ethiopia, and Mozambique). The geographic distribution of the initiatives is
9 depicted on a map (Tables and figures, Figure 2).

10 Reasons for initiation vary. Most cited reasons were to address the complex needs of people in the
11 community with serious illness and/or their caregivers and families^{30, 32, 42, 43, 48-50, 56, 57}, to reduce
12 inequality in access to quality palliative care^{32, 34-37, 48-51, 58}, and for research purposes^{30, 36, 37, 48-50, 58} such
13 as to examine a model of peer support⁴⁸⁻⁵⁰ or to study ways to empower and build capacity for civic
14 engagement in end-of-life care^{38, 39}.

15 Target populations of the initiatives included healthcare providers^{27-29, 52, 53}, all people in the community
16 regardless of their health status^{42, 43, 54}, or people in the community with a serious illness, their family
17 or caregivers^{25, 26, 30-41, 44-53, 55-58}. Some of the initiatives partially focused on people with a specific
18 condition such as HIV and AIDS^{31, 32} or cancer^{36, 37, 40, 41, 48-50}. Others partially focused on adolescents³¹,
19 older people⁴⁴⁻⁴⁷, African-Americans⁴⁸⁻⁵⁰, Chinese-Americans^{52, 53}, bedridden people^{36, 37} or cancer
20 survivors^{40, 41}.

21 Characteristics of the development of the initiatives

22 In all the initiatives, the community was involved in the development process. Twelve out of nineteen
23 were developed from a community-academic partnership^{25-31, 38, 39, 42-51, 54, 55}. In eight of these initiatives,
24 the community led the development and consulted or collaborated with a research team^{25-31, 42-47, 54, 56,}
25 ⁵⁷. In the other four, the community was involved to a limited extent; researchers developed the
26 initiative in consultation or collaboration with community members^{30, 38, 39, 51, 55}. The other seven
27 initiatives were entirely community-owned and were driven and developed by community
28 organisations and/or governments without any input from research^{32, 33, 36, 37, 58}, or by individual
29 community members^{34, 35, 40, 41, 53}.

30 The actions of the initiatives were generally aimed at linking people with care needs to those in the
31 community who could provide help, to professional health care or to other community resources^{32-37,}
32 ^{44-47, 58}. Additionally, activities included identifying the problems of the chronically ill people in their
33 area^{25, 26, 32, 34-37}, providing social and emotional, physical, spiritual, practical or financial support for ill
34 people in the community or those affected^{32, 34-37, 40-42, 44-50, 55-57}.

1 Almost all the initiatives included training for those participating in civic engagement^{25, 26, 30, 32-36, 38, 39, 44-}
2 ^{51, 54-58}. The intensity and content of the training varied per initiative. The content included training on
3 navigation to community resources and how to access them^{44-50, 54, 56-58}, and competencies in providing
4 palliative care and end-of-life care^{25, 26, 31-35, 38, 39}. As well as training, a minority of the initiatives provided
5 ongoing support to those participating in civic engagement^{25-29, 34-39, 44-50, 54, 57, 58}, such as individual
6 feedback opportunities with a mentor or peer-support group meetings^{36, 37, 44-50, 58}.

7 Eight out of nineteen initiatives mentioned continuing their civic engagement activities^{33-35, 40-43, 48-50, 52,}
8 ^{53, 56, 57}. These eight were either entirely developed by the community^{31, 34, 35, 40, 41, 52, 53} or by a
9 community-academic partnership in which the community had made a far-reaching contribution in the
10 development process^{42-47, 56, 57}. Of the remaining initiatives, a majority did not report whether they still
11 existed. The three that explicitly mentioned they had stopped^{25-29, 38, 39}, reported that funding ceased,
12 or the research had been time-limited from the beginning. For the other ten, information was lacking
13 on their intentions regarding sustainability^{30-32, 36, 37, 51, 54, 55, 58}. A majority of studies did make
14 recommendations to other initiatives to increase the sustainability of their civic engagement activities²⁷⁻
15 ^{29, 32, 34, 35, 42, 43, 50-55}. The sustainability recommendations varied, and included ongoing education and
16 mentoring of people participating in civic engagement^{38, 39, 51}, and creating a culture of civic
17 engagement in the community^{44-47, 52, 53}.

18 *Characteristics of the evaluation of the initiatives*

19 An evaluation study was conducted for eighteen^{25, 27, 29-34, 36, 38, 40, 42, 44, 45, 48-50, 55, 58} of the nineteen
20 initiatives. Most of these studies involved a process evaluation^{25,30, 31, 33, 36, 40, 45, 48, 49, 51, 54}; a minority
21 evaluated outcomes^{27,32, 38, 50}, or conducted both a process and outcome evaluation^{44, 55}. The majority
22 of the initiatives were evaluated using qualitative^{27, 30, 31, 33, 36, 40, 42, 46, 49, 54} or mixed method^{25, 32, 44, 45, 48,}
23 ^{51, 52, 58} data collection including interviews, focus groups, observations and surveys. The quality of the
24 evaluation differed between the initiatives. Three received a score of 0 (out of 4)^{34, 44, 51}, as a result of
25 not being able to answer the two screening questions positively. One initiative received a low score of
26 1⁵² as a result of answering negatively to the three follow up questions. Furthermore, most of the
27 initiatives received a score of 2 or 3^{27, 29, 31, 33, 48, 49, 54}. A minority had an evaluation of a very high quality
28 and received a score of 4^{25, 30, 36, 38, 42, 45, 46}.

29 Most of the evaluation studies focused on one particular aspect of the initiative, such the role in
30 healthcare or the voluntary organisations in the development process³⁶. Also the feasibility, acceptance
31 and reach of initiatives^{25, 31, 44, 48, 58} was measured and their preliminary effectiveness on certain
32 outcomes^{27, 29, 32, 40, 50, 55} (e.g. empowered people to provide end-of-life care for older persons in their
33 communities³⁸); there were studies on how an initiative contributes to the health of cancer survivors⁴⁰,
34 on how a community garden might function as a place of end-of-life and bereavement support³⁰, and

1 the contextual factors that helped (e.g. community-based champions) and hindered (e.g. the lack of
2 direction for rural-focussed, community-based planning for hospice care by government) people in
3 their civic engagement activities⁴⁵. Almost all the initiatives demonstrated positive benefits as a result
4 of civic engagement^{27, 29-32, 34, 38, 40, 42, 44-46, 48-52, 54, 55}, including increased understanding and knowledge
5 of dying, loss and of palliative care in the community^{27, 29}. A minority of the studies included the
6 sustainability of the initiative in their results, e.g. if the future is to be one that is sustainable, caution is
7 required as these community groups are working voluntarily, often in addition to their own paid jobs
8 and family responsibilities⁴².

9

1 **Table 3: Characteristics of the context of the reported civic engagement initiatives: RQ 1=** In what context (i.e. year of initiation, country & continent), why (i.e. reason for
 2 initiation & target group) and for who are the reported initiatives initiated?

	Name of the initiative	Year of initiation	Country & continent	Reason for initiation	Target group
I-1	The Good Neighbour Partnership ^{25, 26}	2015	Ireland (Europe)	To navigate people with serious illness to community resources & the other way around	People with serious illness, their caregivers & families
I-2	Health Promoting Resource Team in the Hume Region's Caring Communities Project ²⁷⁻²⁹	2003	Australia (Oceania)	To reduce the growing demands on local (specialist) palliative care services	Local (specialist) palliative care services
I-3	Walk Each Other Home ³⁰	2015	Australia (Oceania)	- To address the complex needs of bereaved people -To examine the therapeutic landscapes of community gardens (research purpose)	bereaved people
I-4	Bereavement support intervention ³¹	Not reported	Zimbabwe (Africa)	To address the complex needs of people with serious illness	Bereaved adolescents living with HIV
I-5	Home-and Community-Based Care (HCBC) program ³²	Not reported	Ethiopia (Africa)	- To address the complex needs of people with serious illness - To reduce inequality in access to palliative care services	People living with HIV and their family members
I-6	Community Home Based Care CHBC in Mufudzi ³³	1995	Mozambique (Africa)	Not reported	People with serious illness
I-7	Neighbourhood network in palliative care (NNPC) ^{34, 35}	2000	India (Asia)	- The need for culturally and socioeconomically appropriate palliative care - To reduce inequality in access to palliative care services	People with serious illness
I-8	Sanjeevani ^{36, 37}	2014	India (Asia)	- To reduce inequality in access to palliative care services - To examine if and how the community form of palliative care in Kerala can be replicated into a new geographic and institutional context (= research purpose)	People with serious illness (partial focus on people with advanced cancer, chronic renal conditions, and people who are chronically bedridden)
I-9	Four-phase capacity-building program ^{38, 39}	2018	Hong Kong (Asia)	To research ways to empower and build capacity for volunteers in end of life care (research purpose)	People with serious illness
I-10	Gilda's Club Toronto ^{40, 41}	2001	Canada (North-America)	Not reported	People with cancer, caregivers, families & friends, cancer survivors
I-11	The Hudson and District Hospice Society ^{42, 43}	Not reported	Canada (North-America)	-To reduce the growing demands on local palliative care services -To address the complex needs of caregivers of people with serious illness	Everyone in need of hospice services in the community
I-12	N-Care/Nav-Care ⁴⁴⁻⁴⁷	2015	Canada (North-America)	To navigate people with serious illness to community resources & the other way around	People with serious illness (partial focus on elderly people)
I-13	Circles of Care ⁴⁸⁻⁵⁰	2005	USA (North-America)	- To reduce inequality in access to qualitative palliative care - To address the complex needs of people with serious illness -To examine the model of peer support (= research purpose)	African-Americans with serious illness (partial focus on advanced cancer)
I-14	Volunteer Information Provider Program (VIPP) ⁵¹	Not reported	USA (North-America)	-To address the complex needs of caregivers of people with serious illness - To reduce inequality in access to palliative care services	Caregivers of elderly people with serious illness
I-15	Chinese-American Coalition for Compassionate Care (CACCC) ^{52, 53}	2005	USA (North-America)	To address the lack of linguistically and culturally appropriate palliative care (information & training)	-Chinese-Americans community regardless of their health status -Health care providers who care for Chinese-American people with serious illness

	Name of the initiative	Year of initiation	Country & continent	Reason for initiation	Target group
I-16	Advance Care Planning Community Guides Program ⁵⁴	2017	USA (North-America)	To address the need for individuals being able to initiate quality advance care planning conversations in their communities	All people in the community regardless of their health status
I-17	Support Teams for Caregivers ⁵⁵	Not reported	USA (North-America)	To provide an evidence-based intervention outside the current models of formal healthcare services (research purpose)	Caregivers of people with Alzheimer's disease or other forms of dementia
I-18	Care Teams from the Compassionate Project ^{56, 57}	2000	USA (North-America)	To address the complex needs of people with serious illness, their families and caregivers	People with serious illness, their caregivers & families
I-19	Compassionate Communities Connectors ⁵⁸	2020	Australia (Oceania)	<ul style="list-style-type: none"> -To reduce inequality in access to palliative care -To address a lack of understanding of palliative care services; -To address the quality of palliative care: poor uptake of Advanced Care Plans; issues with communication, information sharing and poor linkages between agencies; a lack of support for people with a non-cancer diagnosis; and lack of support services for carers and families -To address a scarcity of evaluations of Australian community-led initiatives of practical and social support resulting in improved social connectedness. 	People with serious illness and their caregivers & families

- 1 **Table 4: Characteristics of the development** of the reported civic engagement initiatives: **RQ 2=** How are the reported initiatives developed (i.e. nature of community
 2 engagement in the development, activities of civic engagement, training & support for people participating in civic engagement), and sustained (i.e. is the initiative
 3 continuing, and if not, what is the reason for termination and what are sustainability recommendations)?

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
I-1	Developed from a community-academic partnership: developed from a specialist palliative care service (hospice); supported by research & local community organisations	People participating in civic engagement form groups of 10-15, identify the problems of the chronically ill people in their area and organize appropriate interventions (including medical, social and financial support).	Training: Volunteers receive a 15 hour training programme (on knowledge and skills necessary to provide the Good Neighbour Intervention) after screening and prior to the start of the intervention Support: Support provided by a facilitator	No, research was limited in time	Not reported
I-2	Developed from a community-academic partnership: developed by a palliative care service through partnerships formed with a range of community groups, service agencies, and the university	People participating in civic engagement (selected from a pool of trained service providers and volunteers) mentor and support local communities, community services and palliative care services, in developing, providing and evaluating local projects of health promotion in palliative care	Training: As part of the education phase of the project generalist health professionals (including community health workers), palliative care staff and volunteers are offered education and training on health promoting palliative care (Workshop of 1 day) before starting in the Health Promoting Resource Team . Support: Not reported	No, only funding for 2 years	Capacity building without imposing burdens on the people engaging in the initiative
I-3	Developed from a community-academic partnership: development by a group of community members in collaboration with the University	People participating in civic engagement organised three community events: an information evening for service providers and community members; four conversation sessions; and a one-day workshop	Not reported	Not reported	Not reported
I-4	Developed from a community-academic partnership: developed by researchers together with adolescents living with HIV	People participating in civic engagement (10 adolescents with HIV) are trained as peer grief counsellors and facilitate a bereavement intervention for other adolescents with HIV in 10 pre-existing community-based support groups.	Training: Initiative is developed together with the peer volunteers who are already part of a support group. 1 4-day training of 5 hours is provided in these pre-existing groups to engage peer volunteers in their own grief and build their understanding of grief processes Support: not reported	Not reported	Not reported
I-5	Developed together by the local government, community-based organisation (NGOs & community groups) and an international human development organisation	People participating in civic engagement provide holistic palliative care in the homes and communities of people with HIV and their family members: including provision of basic nursing care, facilitation of access to clinical services, and transfer of basic nursing skills to family members, needs assessments, and financial support through loan groups	Training: A train-the-trainer module focused on comprehensive palliative care, including sexual reproductive health, was given to more than 120 nurse supervisors. They in turn rolled out the training to 60 parasocial community workers and more than 2,100 voluntary caregivers. Support: Not reported	Not reported	Not reported

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
I-6	Developed from two community-based organisations (NGO's)	People participating in civic engagement visit chronically ill individuals in a neighbourhood to educate them and their families about HIV, offering comfort-oriented basic care, emotional and spiritual support, and referral to appropriate health and social services.	Training: Volunteers attended a two-week workshop on CHBC focused on HIV transmission, the signs of AIDS, and how to care for an HIV-positive person at home, often bed bound, before being assigned to 5 to 6 patients. Support: Not reported	Yes	Not reported
I-7	Entirely developed by local communities. The community or group sets up a process to control its own development). Volunteers are recruited from the community.	People participating in civic engagement identify the problems of the chronically ill people in their area and organise appropriate interventions (including medical, social and financial support). And they act as the link between the patient in the community and the professional health care provider	Training: People who can spare at least two hours per week to care for the sick in their area are enrolled in a structured training program (16 hours of interactive theory sessions plus four clinical days under supervision) before they start giving support. Support: Support is provided by a network of trained doctors & nurses)	Yes	Creation of good-quality palliative care' in a context of poverty and ill health should also be in line with efforts at poverty reduction and provision of essential services such as clean drinking water, sanitation, and primary education.
I-8	Developed by the local government (the District Magistrate of Nadia) in collaboration with physicians from local medical association & institute & other stakeholders & NGO's	People participating in civic engagement survey neighbourhoods for chronically ill patients, identify needs & map home-care schedules & maintain regular contact with families), provide support and provide updates to home care teams	Training: After the kick-off meeting awareness camps and training programmes were held in public auditoriums for students, home-makers, teachers, and local social workers wishing to participate in the project. These 'Master trainers' trained other interested volunteers in their own neighbourhoods Support: Participatory monthly review meetings and general meetings where volunteers deliberated on difficulties	Not reported	Not reported
I-9	Developed from a community-academic partnership: Collaboration between academic institutions & community-based organisations e.g. (healthcare services, NGO's, religious affiliations, community centres)	The four-step capacity-building program selects a group of potential people participating in civic engagement with most suitable qualities for end of life care (motivational screening), trains them (core competence training, internships, and in-service supervision), and evaluates the training	Training: Training is part of the four step-program: motivational screening, core competence training, internships, and in-service supervision. It is a 16-hour training course in core competencies and contextual skills in end of life care in community-based settings Support: Individually mentored or in a group	No, research was limited in time	-More meetings for volunteers for sharing experiences, workshops, and volunteer appreciation events to enhance ongoing support -Instruments for evaluating the effectiveness of capacity building for the people participating in the civic engagement
I-10	Entirely developed by community members	People participating in civic engagement are part of a communal meeting place where people living with cancer, as well as their families and friends, can join with others to build physical, social, and emotional support as a supplement to their medical treatment	Not reported	Yes	Not reported
I-11	Developed from a community-academic partnership: Developed by	People participating in civic engagement provide physical, psychological, emotional, spiritual and educational support in a home-like setting for	Not reported	Yes	A strong role for governments to be involved in the planning process of the initiatives

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
	community members in consultation and collaboration with researchers	those in the community facing end-of-life, death or bereavement.			
I-12	Developed from a community-academic partnership: developed by researchers together with stakeholders from government & community-based health care	People participating in civic engagement partner with a nurse partner to visit older persons living at home with advanced chronic illness, provide social support and facilitate connections to resources in the community	Training: Training is part of the Navigation-Care implementation. After screening, volunteers receive a 3-day workshop on navigation. Support: The nurse navigator meets with individual volunteers on an as-needed basis and through group meetings that take place every six weeks	Yes	-Stronger connections with healthcare services. to ensure that volunteers get the referrals and support they require -Supportive culture for volunteers -incorporating the initiative into existing organisational structures
I-13	Developed from a community-academic partnership: developed by researchers together with community-based organisations and a community advisory board	People participating in civic engagement form support teams (6-10) and work together to provide practical, emotional and spiritual support for African Americans facing advanced cancer	Training: Investigators initially recruited and trained 24 lay health advisors who shared information with volunteers (3-hours training on physical, emotional, and spiritual pain and supportive approaches and region-specific information how to access healthcare services) Support: Volunteers meet monthly (for 1 year) to share experiences, barriers and suggestions to improve support. Community project coordinators check in with the support team to address challenges	Yes	-Broad target population (not limited to one type of illness, e.g. cancer), -Stronger connections with healthcare services -Early awareness of the activities of the initiative -A meaningful community-academic partnership
I-14	Developed from a community-academic partnership: developed by researchers, in consultation with people in the community	People participating in civic engagement share information with caregivers to help them deal with stress, communication problems with elderly persons and doctors, misinformation about aging, identifying and accessing appropriate community resources, medicine use, personal care of the patient	Training: Recruitment and training is provided by State Cooperative Extension Services and entails 3 days (7 hours per day) training Support: Not reported	Not reported	Organising the training for volunteers via the volunteer organisation
I-15	Entirely developed by a group of community members	A community coalition of people participating in civic engagement provide training for caregivers and volunteers, developed a speakers bureau and disseminates written materials about to Chinese cancer survivors.	Training: not reported Support: Operational support from the California Coalition for Compassionate Care (CCCC)	Yes	-Strong leadership -Supportive culture for civic engagement -A feeling of shared purpose among the people participating in the initiative
I-16	Developed from community-academic partnership of community members from a specialist palliative care service (i.e., a chaplain, nurse, volunteer coordinator) and academic members (i.e., a geriatrician, a palliative care	The program trains people participating in civic engagement to have community-based advance care planning conversations and is developed with an emphasis on communication skills training	Training: The aim of the program is to develop, test, and evaluate a training for lay individuals to engage in relationship-centred advance care planning conversations (16-hour training in advance care planning conversations, knowledge of advance care planning forms, and strategies for linking advance care planning to the health-care system). Support: The advance care planning program coordinator provides ongoing support	Not reported	Not reported

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
	physician, and a social scientists).				
I-17	Developed from a community-academic partnership: developed by researchers, community only closes gap in human and financial resources	Support Teams for Caregivers is a dementia caregiver model program that merges an evidence-based intervention, Resources for Enhancing Alzheimer's Caregiver Health (REACH II), with a proven volunteer program, The Support Team Network model. People participating in civic engagement provide practical, emotional, and spiritual support. REACH II adds an in-home assessment with target areas	Training Training is part of the program implementation. After recruitment volunteers receive training on building feelings of confidence and self-efficacy for their time spent with caregivers and persons with dementia Support: not reported	Not reported	Incorporating the initiative into existing organisational structures
I-18	Developed from a community-based organisation in collaboration with research	People participating in civic engagement (6-12) work together to help meet practical, emotional, and spiritual needs for all people as they deal with serious illness, death, and grief	Training Training is part of the program implementation. After recruitment volunteers receive training on how to connect to area health resources for cancer care, palliative care, and hospice Support: Project Compassion provides education, support, and guidance	yes	Not reported
I-19	-The South West Compassionate Communities Network (SWCCN) - Initiated from a partnership between the community and the palliative care service in the South West of Western Australia,	Connectors work with patients and families to co-design a plan on how to mobilise their network of Caring Helpers who will be providing the hands-on assistance	Training: Connectors attend a training course of 2-days delivered by content experts. As part of the training, Connectors are provided with a training resource to assist them understand their role and what is expected of them. I Support: The project coordinator will liaise with the Connectors weekly to share their experiences and work through any arising issues.	Pilot project	Not reported

1 **Table 5: Characteristics of the evaluation** of the reported civic engagement initiatives: **RQ3: How have the reported initiatives been evaluated (aim of the**
 2 **evaluation, evaluation design, data collection), and what is their impact?**

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
I-1	To evaluate the feasibility, acceptability & potential effectiveness of the GNP	Phase III Randomised Controlled Trial (RCT)	Mixed method data from interviews with volunteers & receivers, volunteer record/logs, standardised questionnaires for receivers	It is anticipated that the findings from the various elements will provide important insights into the effectiveness, efficacy, utility and acceptability of a unique model of social and practical care for people with life-limiting illness.
I-2	-An overall descriptive evaluation about the sustainability and effectiveness of the Health Promotion Research Team)	A qualitative study	Qualitative data from focus groups, individual interviews & telephone interviews (coordinators, volunteers & funding applicants)	-Participants indicated that the health promoting resource team has been most effective in its task of promoting and supporting community development activities that have increased understanding and knowledge of dying, loss and grief in general, and palliative care in particular, across the region. -Sustainability of the community capacity thus developed has yet to be demonstrated long term; but the authors argue that the reflective thinking, equitable participation and shared knowledge emerging through the local projects are themselves marks of a sustainable community.
I-3	To investigate how a community garden, largely run by volunteers located in a small rural location, might function as a place of end-of-life and bereavement support	Participatory action research/evaluation	Qualitative data from participant observations, semi-structured in dept interviews (receivers), focus group discussions (the project team)	The community garden provides a physical, social and therapeutic space between home, where family and friends provide care for people as they die and grieve, and between formal care sites where health professionals provide the bulk of care.
I-4	To assess the feasibility and acceptability of the bereavement intervention	Process evaluation	Qualitative data from feedback (volunteers & caregivers), participant observations of the delivery and focus groups (volunteers & receivers)	Implementing high-quality grief interventions is critical when responding to the complex realities of ALHIV in sub-Saharan Africa.
I-5	To assess the results and impact of the HCBC program (primarily to collect information about how the program affects the lives of people living with HIV, orphans and vulnerable children)	Outcome evaluation	Mixed method data from in-depth interviews (stakeholders, coordinators & volunteers), focus group discussions (receivers & coordinators), case studies (receivers), limited secondary analysis of existing baseline and service deliveries	The program has been shown to 1) reduce stigma and discrimination of PLHIV and vulnerable children, 2) increase acceptance and use of voluntary testing and counselling for HIV, 3) improve people living with HIV's health and well-being, 4) improve household economic conditions of people living with HIV, orphans and vulnerable children, and other beneficiaries, and 5) increase community support.
I-6	Feasibility study: To consider how it happened that over the course of the scale-up of the initiative, some volunteers felt exploited and ultimately abandoned (and in doing so raising questions about the communities constituted by global health interventions)	Intertwined biography research	Qualitative data from participant observation, semi-structured interviews (interviews)	Mufudzi suffered from a lack of care, as it was granted far more resources than it could successfully utilise in order to carry out national and global priorities. With insufficient training and oversight, the organisation became collateral damage of the scale-up.
I-7	Not reported	Not reported	Not reported	Within less than five years, the NNPC initiatives have resulted in the establishment of 68 community-based palliative care initiatives in northern and mid-Kerala, covering a population of more than 12 million. Also, expansion into "non-traditional" areas in palliative care (e.g. for non-malignant conditions) and active involvement of the local government in palliative care. Given these aspects there is a good potential for sustainability.
I-8	To identify the institutional context that influenced the translation of the Kerala community-based palliative care form to Nadia	In depth case study of the initiative	Qualitative data from previous research findings on the Kerala model, other published sources, interviews (stakeholders, volunteers & nurses), field observations & communication between various actors	The findings contribute to translation studies in healthcare, and particularly to conversations about the transfer or 'roll out' of palliative care interventions from one geographic region to another.

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
I-9	To evaluate the preliminary effectiveness a holistic capacity-building program for volunteers in community-based end of life care (e.g. volunteers' competence in end of life care, awareness of self-care, and death work competence)	A single-group longitudinal design with a pretraining test (T0), post training test (T1), and 6-month follow-up test (T2)	Quantitative data from a questionnaire (volunteers)	The four-phase capacity-building program effectively empowered volunteers to provide end-of-life care for older persons in their communities.
I-10	To explore how Gilda's Club promotes and contributes to healing and health of cancer survivors	Exploratory qualitative evaluation	Qualitative data from semi-structured interviews (receivers)	The findings demonstrate the importance of therapeutic landscapes to cancer survivorship and the contribution of recreation to a holistic understanding of health.
I-11	To describe how a group of citizens in a rural community in Alberta, Canada worked towards meeting their own community's hospice care need; by exploring the factors that both helped (e.g. powerful storytelling) and hindered (e.g. the lack of direction for rural- focussed, community-based planning)	A case study	Qualitative data from focus groups & interviews (stakeholders)	The results reinforce that communities are not simply 'engaged' but are actually leading the way in the planning, and delivering of social and health supports and services. Their story emphasizes the significant lack and neglect of needed healthcare in rural communities and shows, how rural communities continue to do more with less by building on their own resources and capacities. -If the future is to be one that is sustainable, caution is required as these community groups are working voluntarily, often in addition to their own paid jobs and family responsibilities.
I-12	Study 1 -Piloting a community-based volunteer model, and evaluating feasibility Study 2: To describe the contextual factors that influenced the development of Nav-CARE in eight diverse Canadian contexts. Study 3: To explore the key factors that facilitated the sustainability of Nav-CARE in a rural hospice society.	Study 1: Process & outcome evaluation Study 2: Process evaluation Study 3: A qualitative single case study design	Study 1: Mixed method data from volunteer visit logs, volunteer journals, volunteer mentoring sessions, questionnaires (for volunteers, receivers, coordinator & stakeholders), semi-structured interviews (with volunteers, receivers & coordinator) Study 2: Mixed method data from semi-structured individual & group interviews (stakeholders), email, phone correspondence & teleconferences (coordinators), observations (volunteer mentoring sessions & all interactions), volunteer visit logs Study 3: Qualitative data from individual interviews (community stakeholders, the study volunteer coordinator, hospice society coordinator and Nav-CARE volunteers). Meeting notes of volunteer debriefing sessions and meetings with stakeholders	Study 1 Volunteers providing supportive navigation services during the early phase of palliative care is a feasible way to foster a compassionate community approach to care for an aging population. Study 2: This study highlights the importance of community-based champions for the success of volunteer-led initiatives and the critical need for support and mentorship for both volunteers and those who lead them. -New initiatives such as Nav-CARE, need to be accompanied by adequate resources. -This study illustrated the need to think carefully about the language and role of hospice societies as palliative care moves toward a public health approach to care. Study 3: The role of the facilitator, the facilitation processes and the characteristics of the organizational context were important for the sustainability of Nav-CARE. Future research is needed to understand how to assess and enhance an organization's sustainability capacity and the impact of additional facilitator training and mentoring.
I-13	Study 1: Evidence for the feasibility and acceptance of the intervention (by evaluating the reach, adoption and the implementation of to evaluate reach, adoption, and implementation of peer support using Circles of Care support teams. Study 2: -To understand the potential benefits and barriers of support teams Study 3: To evaluate the support teams' ability to improve support, awareness of services, and quality of life for these patients.	Study 1: Process evaluation Study 2: post-intervention qualitative evaluation Study 3: Pre-post outcome evaluation	Study 1: Mixed method data Including surveys (volunteers & receivers), brief interviews (receivers) Study 2: Qualitative data from semi-structured interviews with volunteers, receivers & stakeholders Study 3: Quantitative data from surveys (volunteers & receivers)	Study 1: Support teams are a promising model of peer support for African Americans facing advanced cancer and serious illness, with reach, adoption, and implementation superior to the lay advisor model. This formative initial evaluation provides evidence for feasibility and acceptance. Study 2: There is initial evidence that a support team intervention helps meet the emotional and spiritual needs of African American persons with cancer or other serious illness. Volunteer support teams merit further study as a way to improve quality of life for persons facing serious illness. Study 3: Coordinated volunteer support teams are a promising new model to provide peer support for African Americans facing cancer and other serious illnesses. Further testing in a pragmatic clinical trial is warranted.
I-14	-To review the trainees' experiences of sharing their information with caregivers.	Process evaluation	Mixed method data from debriefing sessions (volunteers), volunteer diaries, volunteer logbooks, daily evaluations, interviews (receivers), feedback & observations (field staff)	VIPP is documented as a successful strategy in reaching and helping rural caregivers.
I-15	-Piloting a training for caregivers and volunteers informal -Gather descriptive feedback of the training for the curriculum committee (i.e. participants' competence in	Post-training evaluation	Mixed method data from telephone interviews (coordinators of sponsoring organisations), written evaluations & follow-up questionnaires (receivers)	As a pilot program undertaken entirely by volunteers and with no organisational financial support, the training has provided a vehicle for improving future training and curriculum planning.

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
	end of life care, their awareness of self-care and their death work competence.			
I-16	-To understand the quality of the communication between trained advance care planning guides and their conversation partner	Qualitative study	Qualitative data from non-participant observations, individual semi-structured interviews (volunteers & receivers)	Trained advance care planning guides could use the model of communication to support advance care planning conversations.
I-17	-To measure the fidelity of the program: the delivery, receipt and enactment of the implementation -To measure the effectiveness of the implementation	Process and outcome evaluation	Quantitative data from questionnaires (volunteers & receivers)	The Support Teams for Caregivers project displays the feasibility of reaching into the community with an evidence-based intervention. Delivering such intervention provides an accessible, needed, and usable tool for family caregivers of dementia patients.
I-18	Not evaluated	/	/	/
I-19	-To Evaluate a training programme for the Compassionate Communities Connectors -To Assess the feasibility, acceptability and preliminary effectiveness of this community model of care.	Non-randomised prospective intervention study with pre/post design	Mixed method data from a questionnaire Baseline (patients and family carers), interviews (patients, family carers and Connectors), a brief questionnaire (Caring Helpers), a focus group (service providers) and social network mapping (patients and family carers)	It is expected that, by the end of the project, the community will have a sustainable pool of trained and experienced people who can work with the palliative care services to attend to the social and practical needs of dying people, improve their social connectedness and reduce the need for unplanned hospital usage.

1

1 Discussion

3 Main findings

4 This review identified nineteen unique civic engagement initiatives concerning serious illness, death
5 and loss, often referred to as ‘compassionate community initiatives’. The identified initiatives are
6 mostly located in countries with English as one of the official languages. Activities performed by
7 community members participating in them included various forms of support, including identifying the
8 problems of the chronically ill people in their area and organising appropriate interventions. In those
9 initiatives that still existed at the time of this review, the community had the lead in the development
10 process. Although sustainability is a common challenge for all the initiatives, none of the evaluation
11 studies focused on sustainability but consisted mostly of either a process or an outcome evaluation,
12 and were often focused on one particular aspect of the initiative, e.g. researching the institutional
13 context in which an it developed³⁶.

15 Civic engagement: blind spot in non-English speaking contexts

16 In 1986 the Charter for Health Promotion was adopted in Ottawa, Canada, in order to give direction to
17 a new public health approach in various domains of health and wellbeing. The translation of this health-
18 promotion approach to the domain of palliative care was first explored by Allan Kellehear in 2000 in an
19 Australian context. Kellehear founded the compassionate city movement, in which geographically
20 defined regions work towards culture change concerning serious illness, death and loss by working
21 together with various stakeholders, including local governments, cultural organisations, health and
22 social care organisations, schools, etc.⁵⁹ In the following years, the compassionate city movement found
23 support mainly in Australia and in the UK where the political welfare system considers volunteering
24 and civic engagement as an essential supplement to the mainly service-driven organisation of palliative
25 care.⁶⁰⁻⁶² We identified nineteen civic engagement initiatives worldwide, almost all in countries with
26 English as one of the official languages. This finding triggers a few critical notes. Firstly, we must note
27 that we only searched for publications in English, thereby excluding those written in other languages.
28 Also, as it often concerns bottom-up initiatives, there is a chance that some are not reported or
29 described in scientific literature – particularly in non-English speaking contexts. Secondly, the civic
30 engagement initiatives we found mainly originated from a bottom-up compassionate community
31 approach instead of a conjuncture of top-down mediations (e.g. creating a supportive policy) and
32 bottom-up approaches (e.g. stimulating community action), as is the case in compassionate cities. This
33 may give the impression that the civic engagement movement is an extension of the Anglo-Saxon
34 compassionate city influence; however, literature shows that some African and Asian regions had
35 already organised themselves into compassionate communities before the concept came into use in

1 Australia and the UK.⁶³ Future research should therefore investigate the potential blind spot of starting
2 compassionate communities in non-English speaking contexts or not published in English, together with
3 the cultural and political aspects that influence the initiation of civic engagement.

4 5 Civic engagement initiatives: commonalities and differences

6 The initiatives that we identified show great variation in their context, development and evaluation,
7 but there are also important commonalities. These include engaging communities in providing a link
8 between a person with palliative care needs and those in their community who are able to offer help⁴⁴⁻
9 ^{47, 58}. This differs from the common service-centred approach that primarily focuses on clinical
10 contributions and treating illness. Rather, compassionate communities apply a salutogenic approach
11 by trying to increase the overall wellbeing of people through health-promotion.⁷ Accordingly, in these
12 initiatives, the community as the core of social interactions provides this social support for people
13 confronted with illness, death and loss. Another important commonality is that most of the initiatives
14 provide training and ongoing support for community members involved in civic engagement. This
15 includes, for instance, individual feedback sessions with a mentor or group sessions with peers^{36, 37, 44-}
16 ^{50, 58}. Although such training and support is widely provided by the initiatives, many of them
17 recommend that it is a recurrent event throughout the entire course of the initiative, in order to
18 increase the chances of sustainability^{38, 39, 44-46}.

19 A lack of information on sustaining civic engagement initiatives

20 Some the evaluation studies mentioned the sustainability of the initiative in their results, e.g. the role
21 of the facilitator and the characteristics of the organisational context are important for the
22 sustainability of the initiative⁶⁴. However, although the evaluation studies measured for instance the
23 feasibility and applicability of the civic engagement activities, the results of these feasibility study were
24 often not discussed in the light of whether or not to continue the initiative, or under which conditions
25 the initiative should continue to exist. The three initiatives that explicitly mentioned they ended^{25-29, 38,}
26 ³⁹, and provided reasons for not continuing, all indicate that funding ceased or research was time-
27 limited from the outset. From this we can tentatively suggest that in community-academic
28 development processes sufficient attention should be paid to empowering the community to continue
29 the initiative when the research ends. Additionally, initiatives should search for alternative funding
30 sources if necessary. As suggested in some of the publications, activities may also be more sustainable
31 if integrated into a context of broader public involvement for encouraging a civic engagement culture
32 in the community^{44-47, 52, 53}. Compassionate city programs have been suggested for the purpose of
33 facilitating and stimulating ongoing community action. Through involvement of stakeholders and
34 endorsement by the city council they provide an overarching structure for community engagement,

1 build public health policy, create supportive environments, enhance personal skills, and reorient health
2 services towards the topics of illness, death, dying, loss and bereavement.⁸ Future research should
3 investigate the influence of embedding civic engagement initiatives in a compassionate city context on
4 their sustainability.

5 The need for a thorough evaluation of civic engagement initiatives

6 Evaluation of civic engagement initiatives remains a challenge. Although all evaluations reported
7 positive outcomes, the results are impossible to compare across the different initiatives as they vary
8 in quality, content and in the way they were studied. Literature suggests that frameworks on how to
9 evaluate civic engagement initiatives in palliative care are needed to build up a robust body of evidence
10 that allows us to increase the overall quality of the evaluation.⁶⁵⁻⁶⁷ Existing guidelines on such complex
11 interventions recommend evaluating both the process of development and the impact of the initiative
12 by using a mixed-method approach to data collection.^{64, 68} Although some of the studies do use mixed
13 method data collection, evaluation is often limited to either the process of development or to specific
14 outcomes. Additionally, the evaluation studies exclusively focus on whether the objectives of the
15 intervention are achieved, rather than providing a clear rationale for the choice of objectives and
16 outcomes. Future research could be ground breaking in sharing experiences not only of measuring the
17 impact of such initiatives but also of better comprehending in which context and through which
18 mechanisms impact can be achieved.

19

20 Strengths & limitations of this review

21 A mixed-methods review is the most suitable design to systematically describe a variety of initiatives in
22 different contexts. Since compassionate community volunteer initiatives often rely on public
23 promotion, additional grey literature on the included initiatives was also searched. By searching and
24 retrieving data from both peer reviewed and grey literature, we were able to provide a more
25 comprehensive description of the initiatives, including the characteristics of their context,
26 development, and evaluation. Due to the dearth of knowledge on the domain of civic engagement in
27 serious illness, dying and loss, we argue it is a good first step to start from peer reviewed literature to
28 gain a first insight into initiatives that are being researched. However, having received only additional
29 grey literature for six of the initiatives by the authors, and by performing only a limited google search
30 for websites of the initiatives, we potentially missed other grey literature documents. An independent
31 grey literature search could have provided us with additional data (e.g. reports, secondary websites,
32 blogs) on the included initiatives, or on initiatives that have not been evaluated and therefore are not
33 published in peer reviewed literature. Consequently, we recommend further research to perform a
34 systematic review of grey literature, in addition to this review. However, since we included peer
35 reviewed publications and additional grey literature, it is not surprising that most of those included

1 have already been evaluated in a study. Due to the fact that we included only publications in English,
2 we are likely to have missed initiatives from non-English speaking countries. Furthermore, by using
3 general terms such as “serious illness” and “bereavement” in our search string, we may have missed
4 articles on one specific serious illness or condition. However, focusing on specific serious illness or
5 condition was not an exclusion criterium in this review. Consequently, we did include articles that
6 beside their general description of palliative care or serious illness also mentioned a specific illness or
7 condition, e.g. dementia or cancer.

8 Conclusion

9 This review identified civic engagement initiatives concerning serious illness, death and loss around the
10 world, initiated in the first and second decades of the 2000s. The initiatives vary considerably but also
11 share some fundamental characteristics. They all draw on community engagement for their
12 development, they aim to connect people with palliative care needs to people or other resources in the
13 community that can address these issues, and have all reported benefits in – albeit often limited –
14 evaluation. The systematic description of the characteristics, strengths and challenges of the initiatives
15 provides a basis for more informed future civic engagement initiatives concerning serious illness, death
16 and loss. Such future initiatives may particularly need to pay attention to their integration into public
17 health policy, the need for a thorough evaluation that provides a rationale for the original choice of
18 objectives and outcomes, and a reflection on sustainability based on the results of their evaluation.
19 Better evaluation of civic engagement initiatives in palliative care could contribute to building a body
20 of evidence, and could allow comparison between initiatives.

21

22 **Declarations**

23

24 Declaration of conflicting interests

25 The authors declare that there is no conflict of interest.

26

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29 Society’, a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic
30 University Leuven, Belgium. This study is supported by a grant from the Research Foundation –
31 Flanders, file number S002219N.

32

33 Research ethics

34 This article does not involve researching human subjects, hence it did not require approval of an Ethics
35 Committee or IRB.

1

2 Data management and sharing

3 Additional data will be made available on request from the corresponding author (LDEE), including all
4 the data extracted and analysed of the included publications.

5

6 Author contributions

7 All authors contributed to the concept of the article, the study design, the interpretation of the data
8 and the data analysis. LDEE and BQ performed the study selection and data extraction. LDEE, and TS
9 drafted the article. The draft was revised by all authors. All authors gave approval for the final version.

10

11

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- 1 Tables & Figures
- 2
- 3

Table 6. Full search string electronic data base

Pubmed			Scopus		
ID#	Searches	Results	ID#	Searches	Results
1	("compassionate communities"[Title/Abstract] OR "compassionate community"[Title/Abstract] OR "compassionate cities"[Title/Abstract] OR "caring communities"[Title/Abstract] OR "caring community"[Title/Abstract] OR "new public health approach"[Title/Abstract] OR "social network approach"[Title/Abstract] OR "community based"[Title/Abstract] OR "health promoting palliative care"[Title/Abstract])		1	TITLE-ABS-KEY ("compassionate communities" OR "compassionate community" OR "compassionate city" OR "caring communities" OR "caring community" OR "new public health approach" OR "social network approach" OR "health promoting palliative care" OR "community based palliative care")	
2	("volunteer"[All fields] OR "volunteers"[All fields] OR "voluntary"[All fields] OR "civil society"[All fields] OR "community"[All fields] OR "neighbors"[All fields] OR "neighbour"[All fields] OR "neighbours"[All fields] OR "community connector"[All fields] OR "community connectors"[All fields] OR "community initiative"[All fields] OR "community initiatives"[All fields] OR "community group"[All fields] OR "community groups"[All fields] OR "community network"[All fields] OR "community networks"[All fields] OR "community organisation" [All fields] OR "community organisations"[All fields] OR "community organization"[All fields] OR "community organizations"[All fields] OR "support group"[All fields] OR "support groups" OR "community participation" OR "community engagement" [All fields])		2	ALL(volunteer OR volunteers OR voluntary OR "civic engagement" OR "civic society" OR "civil society" OR neighbor OR neighbours OR neighbour OR "community connector" OR "community connectors" OR "community group" OR "community groups" OR "community initiative" OR "community initiatives" OR "community network" OR "community networks" OR "community organisation" OR "community organisations" OR "community organization" OR "community organizations" OR "support group" OR "support groups" OR "community participation" OR "community engagement")	
	#1 AND #2	6,796		#1 AND #2	256
3	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*		3	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*	
	Filter: English			Filter	
	#1 AND #2 AND #3	166		#1 AND #2 AND #3	453
Embase			PsychInfo		
ID#	Searches	Results	ID#	Searches	Results
1	(("compassionate community" OR 'compassionate communities' OR 'compassionate city' OR 'compassionate cities' OR 'caring community' OR 'caring communities' OR 'new public health approach' OR 'public health palliative care' OR 'community based' OR 'community-based participatory research' OR 'health promoting palliative care' OR 'social network approach')		1	ab("compassionate community" OR "compassionate city" OR "caring community" OR "new public health approach" OR "public health palliative care" OR "community participation" OR "community engagement" OR "community based" OR "community based participatory research" OR "health promoting palliative care" OR "social network approach")	
2	(volunteer OR volunteers OR volunteering OR voluntary OR 'civic engagement' OR 'civic society' OR 'civil society' OR neighbor OR neighbours OR neighbour OR "community connector" OR "community connectors" OR "community initiative" OR "community initiatives" OR "community network" OR "community networks" OR "community group" OR "community groups" OR "community organisation" OR "community organisations" OR "community organization" OR "community organizations" OR "self-help group" OR "self-help groups" OR "support group" OR "support groups" OR "community participation" OR "community engagement")		2	(volunteer OR voluntary OR volunteering OR "civic engagement" OR "civic society" OR "civil society" OR neighbour OR "community connector" OR "community initiative" OR "community network" OR "community group" OR "community organisation" OR "self-help group" OR "support group" OR "community participation" OR "community engagement")	
	#1 AND #2	30,911		#1 AND #2	5183
3	palliative* OR hospice* OR terminal* OR 'end of life' OR bereave*		3	(palliative* OR hospice* OR terminal* OR "end of life" OR bereave*)	
	Filter: AND [article]/lim AND [embase] AND [english]/lim			Filter: Peer reviewed, English	
	#1 AND #2 AND #3	395		#1 AND #2 AND #3	115
Sociological Abstracts			Web of Science		
ID#	Searches	Results	ID#	Searches	Results
1	ab("compassionate community" OR "compassionate city" OR "caring community" OR "new public health approach" OR "public health palliative care" OR "community based" OR "community based participatory research" OR "health promoting palliative care" OR "social network approach")		1	TI=((compassionate community) OR (compassionate city) OR (caring community) OR (new public health approach) OR (public health palliative care) OR (community based) OR (community-based participatory research) OR (health promoting palliative care) OR (social network approach))	
2	volunteer OR voluntary OR volunteering OR "civic engagement" OR "civic society" OR "civil society" OR neighbour OR "community connector" OR "community initiative" OR "community network" OR "community group" OR "community organisation" OR "self-help group" OR "support group" OR "community participation" OR "community engagement")		2	ALL=(volunteer OR voluntary OR volunteering OR (civic engagement) OR (civic society) OR (civil society) OR neighbor OR neighbour OR (community connector) OR (community initiative) OR (community network) OR (community group) OR (community organisation) OR (community organization) OR (self-help group) OR (support group) OR (community participation) OR (community engagement))	
	#1 AND #2	2,289		#1 AND #2	21,702
3	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*		3	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*	
	Filter: Peer reviewed			Filter: AND LANGUAGE: (English) AND DOCUMENT TYPES: (Article)	
	#1 AND #2 AND #3	125		#1 AND #2 AND #3	439

1 **Table 7. Quality appraisal tool**

2 Instructions: The first two questions are screening questions. If these are answered negatively, further appraisal is not feasible, and automatically answered negatively. If
 3 answered positively, appraisal is continued with 4 sequencing questions. A score on 4 is assigned. As there are 4 questions, every question is 1 point.

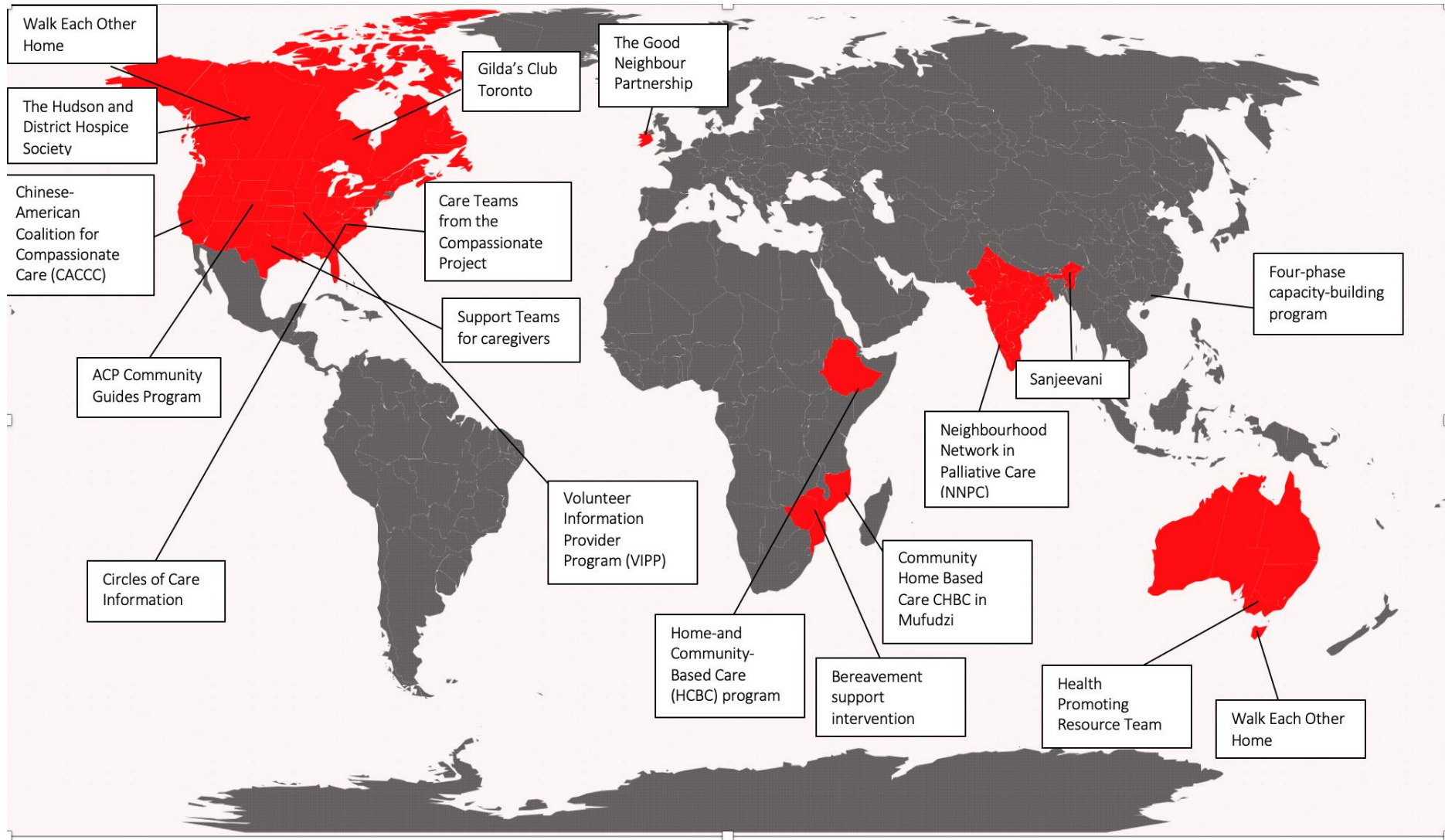
V	Yes	X	No			
	<i>Are there clear RQs or is there a clear evaluation aim?</i>	<i>Do the collected data allow to answer the RQs or aim?</i>	<i>Are the results adequately derived from the data?</i>	<i>Is the conclusion sufficiently substantiated by data?</i>	<i>Score (on 4)</i>	
	V	V	V	V	4	
Health Promoting Resource Team in the Hume Region's Caring Communities Project ²⁵	V	V	V	V	4	
Walk Each Other Home ³⁰	V	V	V	V	4	
Bereavement support intervention ³¹	V	V	X	X	2	
Home-and Community-Based Care (HCBC) program ^{27, 29}	V	V	V	X	3	
Community Home Based Care CHBC in Mufudzi ³³	V	V	V	X	3	
Neighbourhood network in palliative care (NNPC) ³⁴	X	X	X	X	0	
Sanjeevani ³⁶	V	V	V	V	4	
Four-phase capacity-building program ³⁸	V	V	V	V	4	
Gilda's Club Toronto ⁴⁰	V	V	V	V	4	
The Hudson and District Hospice Society ⁴²	V	V	V	V	4	
N-Care/ Nav-Care ⁴⁴	X	X	X	X	0	
N-Care/ Nav-Care ⁴⁵	V	V	V	V	4	
N-Care/Nav-Care ⁴⁶	V	V	V	V	4	
Circles of care ⁴⁸	V	V	V	X	3	
Circles of care ⁴⁹	V	V	V	X	3	
Circles of care ⁵⁰	V	V	V	V	4	
Volunteer Information Provider Program (VIPP) ⁵¹	X	X	X	X	0	
Chinese-American Coalition for Compassionate Care (CACCC) ⁵²	V	X	X	X	1	

	<i>Are there clear RQs or is there a clear evaluation aim?</i>	<i>Do the collected data allow to answer the RQs or aim?</i>	Are the results adequately derived from the data?	Is the conclusion sufficiently substantiated by data?	Score (on 4)
Advance Care Planning Community Guides Program ⁵⁴	V	V	x	X	2

1
2

1 **Figure 2. Geographic distribution of the initiatives**

2



3
4