

Researching Compassionate Communities in Australia:

A short-term longitudinal study.

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THE GROUNDSWELL PROJECT



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Summary

Compassionate Communities and Compassionate Cities are emerging as international strategies for implementing public health palliative care. There is also a growing body of evidence documenting how these concepts can be operationalised, and what happens when they are (Paul & Sallnow, 2013; Barry & Patel, 2013; Wegleitner et al., 2015; Abel et al., 2016; Abel et al., 2018). In this report we present research findings of a nation-wide Compassionate Communities project in Australia over an 18-month period of time, from June 2018 to November 2020.

In 2018, The GroundSwell Project initiated two funded projects with a focus on community development and community-centred care at end of life: *Blue Mountains Compassionate Communities* and the *National Compassionate Communities Practice Forum (NCCF)*¹. These projects encompassed nine diverse geographical communities across Australia and drew heavily on developments in the UK and Europe, in particular the Pathfinders Project and Health Connections Mendip (Abel & Clarke, 2020; Eyres, 2016). The overall aim of the Australian projects was to build upon this international work and tailor it to the Australian context. The hope was that by supporting these nine communities knowledge, stories and ideas about *how to do* Compassionate Communities in Australia would become contagious, enabling more communities to embark upon their own Compassionate Community work.

Researchers from the Caring at End of Life Research Team at Western Sydney University initiated and supported a practice-based research group comprising self-selected representatives (called GoundBreakers), from the 8 NCCF communities, and the lead of the Blue Mountains project. This group functioned as an action learning/research group. Together we reflected upon strategies, barriers and opportunities as well as critical moments in operationalising Compassionate Communities nationally. Additionally, the two GroundSwell community leads², also authors of this report, were interviewed separately across the life of the project.

Compassionate Communities work is relatively new. It is work which seeks to transform how and where we care for each other in times of need. It challenges the dominant medicalised model of caring at end of life. As such, the work, especially at this early stage, is bound to be a site of struggle and a place where people encounter resistance/s to their efforts. What we have captured here, are what Jim Ife (2009) might call *multiple wisdoms from below*: moments across time where the people leading this development on the ground reported on their struggles and successful strategies for change. Overall, we found that these people had clear understandings

¹ GSP changed the name from the *National Compassionate Communities Practice Forum*, to the *National Compassionate Communities Forum* after commencement of the project. For clarity we have also used the new name in this report.

² The community leads for the two projects were employed by The GroundSwell (GSP) project to both lead and facilitate the implementation of the respective projects. They were called 'leads' by GSP and they adopted this language themselves. In this report therefore we have also called them 'leads'.

of, and commitment to, Compassionate Communities and principles of community development. They drew upon this throughout. Their knowledge and commitment were strengths. They believed that change was possible and this belief led to practices of hope, predominantly hope that doing caring, dying, death and grieving differently is possible. What we offer in this report is evidence that this hope is realisable as all of the Compassionate Communities took multiple and diverse actions to build their communities and support each other better in times of need at end of life. Furthermore, they developed collective strategies to overcome resistance. We found that the current dominant forms of evidence and models of leadership remain organisational-centric, which is a strong barrier to the documentation, and hence sharing, of this work. If we are serious about this movement, this research suggests that the leaders of this movement at all levels need to strongly advocate for community and civic-centric evidence, leadership, and knowledge exchange.

Key findings

*Wanderer, your footprints are the path,
and nothing else;
Wanderer, there is no path.
The path is made by walking.*

Antonio Machado (1912) [Proverbios y cantares XXIX (Proverbs and Songs 29)]

Our key findings document the obstacles and barriers that the community leaders across Australia encountered in developing Compassionate Communities and the strategies they developed to continue moving forward with their work – naming, removing, challenging and subverting these obstacles and barriers. The participants in this research were indeed making the path of Compassionate Community development by walking. Our findings capture the steps they took and their tenacity, courage and creativity as they walked this path. Our key findings are summarised below and are discussed in detail from page 28 of this report.

Resistance and struggle

The first 4 themes in this section are strongly interrelated and had a compounding effect on each other.

Questioning Legitimacy. (page 29) Participants questioned their ability, and/or their desire, to undertake leadership roles. They also questioned the work of Compassionate Communities itself. The questioning of legitimacy was equally strong for participants from health, community organisations, or non-aligned workers. People in/from a health setting, most of whom had no previous experience in community development, felt a tension between themselves as members of their community and their professional selves in a health setting. This theme became less apparent over time as participants became familiar with, and confident in, their work and as actions within their communities began taking place.

Coming face to face with Gatekeepers. (page 31) Participants from health backgrounds, those in unpaid community roles, and others in paid community development roles, all came up against Gatekeepers over the course of this project. Gatekeeping is a well-recognised strategy used by those with power and control to maintain the status quo. Consequently, *questioning legitimacy* was felt more strongly by participants. Participants experienced gatekeeping strategies that included obstruction, misinformation, take-over attempts, trivialising, and being disciplined to stay in their place. The people who engaged in gatekeeping behaviours represented a diverse cross-section of this field, including but not limited to, international and

local academics, leading practitioners, medical practitioners, health leaders and local community leaders. This theme also diminished over time.

Compassionate Communities as women's work? (page 34) Participants discussed gendered performances and the impact on the work. There were only a few male participants in community meetings and the overall Compassionate Community work. The issue of gender is a conundrum for the Compassionate Communities movement. Furthermore, the movement risks exploiting unpaid labour and re-inscribing the notion that developing Compassionate Communities and providing *on the ground* caring is women's business/work. Gender was discussed across the time of the project.

The tensions of leadership in community development work. (page 37) At the onset of the project many participants were reluctant leaders. Tensions around leadership are linked to *questioning legitimacy* and perhaps that of *gatekeeping*. Available models of leadership did not meet the needs of the participants. The dominant leader-centric perspective is at odds with the community development perspective of participants which calls for a collective model of leadership. By end of the project this tension was dissolving as community members had begun stepping up, taking action and sharing responsibilities.

What is this thing, Compassionate Communities? (page 39) Community members across Australia, and participants, questioned the meaning and purpose of 'Compassionate Communities.' Participants were anxious that the work be grounded in community need, which may or may not align with the expectation that Compassionate Communities was about end of life. The central tension for participants being: *is this about caring at end of life, or, community compassion more broadly?* Participants actively put the following strategies in place to deal with this tension: (1) facilitating community-specific definitions of Compassionate Communities and the work needed to develop them; (2) shifting the focus from end of life to acts of kindness and compassion; and (3) supporting end of life by developing a 'better' community that focuses on celebrating life. This theme was present across the life of the project.

Exhausting and Exhaustive Expectations. (page 42) The nature of community development work was in itself overwhelming. Multiple expectations from multiple stakeholders, with a limited understanding of community development, or a workplace culture which reflected the dominant health/service provider ethos, added pressure and distress. In particular, the type and nature of evidence being demanded of the participants was problematic. Participants focused on relationship building as the first stage in developing community capacity. However, the time this takes often went unrecognised or unacknowledged. Stakeholders needed answers, roadmaps, toolkits, impact statements and measures of success in a language they understood, often devoid of the humanness and complexity which is the very life blood of Compassionate Communities.

What does it take to do this work? Strategies for success

The community development way: A clear understanding of community development to drive strategies and actions. (page 49) Most of our participants had a solid understanding of community development and were committed to developing Compassionate Communities using the *old* community development way which is

about relationship building and a global vision of self-determination and community-centric values. Community needs drove the strategies of participants as they built support from the ground up. Critical to success was the generation and allocation of formal resources and increasing bonding and bridging ties between community members. They tirelessly built alliances and relationships and stood by *that old grass roots model* [FG4] with the attitude that if it doesn't work, rethink it, learn from it and try again. They made themselves public, wrote submissions, applied for grants and raised funds. They persevered. This was a strength of the work.

Deliberate communications: Using language, being strategic. (page 51) The participants learnt to speak in ways that were inclusive of, and made connections with, everyday folk in their communities *and* service providers, policy makers, local politicians and medical professionals. They were conscious of how the language they adopted shaped their own practices and the practices of others. They had a very clear understanding of the power of language. They learnt (when needed) and used communication strategies which were fluid and dependant on the needs of those being communicated with.

Towards collective leadership: Moving from the 'I' to the 'we'. (page 53) Participants struggled to share leadership with those in their communities who appeared to resist taking responsibility or doing the work that needed to be done. Nevertheless, they persisted with helping their communities to collectivise the work and encouraged them to become self-reliant. This theme became less apparent over the life of the project as the communities moved into the action phase of their work and as leadership became a set of actions rather than a role or position.

Reflective and collegial spaces for people working in precarious places. (page 56) Developing collegial spaces of support, encouragement and knowledge exchange that fostered critical consciousness and solidarity-building was fundamental to supporting participants. Being part of a national forum with a respected not-for-profit organisation was also important. They valued the ability to call upon expertise and support from people who had clear understandings of community development and Compassionate Communities. Being part of an actively supported network meant that they were conscious of being part of something bigger, a movement. The research group meetings contributed to this sense in addition to providing a structured space for people to report on their work, share their knowledge and learn from each other. We also found that, unless these meetings/collegial spaces were promoted as important, people found it difficult to prioritise meeting each other.

Our voices, our stories: Sharing stories of success. (page 60) There was evidence of tangible changes in relationships between formal and informal services and networks. There was also evidence of changes in the way communities came together to care for each other in times of need. Participants reported that these changes could be sustainable as they were becoming woven into the fabric of community life. Despite a relatively short period of time and little or no resourcing, in the final focus group participants enthusiastically recounted the ripple effects of their work permeating their communities as communities became self-organising and self-determined.

Recommendations

- 1. Develop an easy-to-use process of documentation for workers in this field to provide evidence of lived experiences, using stories and narratives as evidence.** There is a danger that Compassionate Community development will become a conservative, rather than a transformative set of practices if new ways of measurement and accounting for this work are not urgently developed. To facilitate the shift away from service-centric systems of measurement to community, or civic-centric, measures we recommend that **appropriate and realistic measures of impact and knowledge production in this field be developed and shared.** Leaders in this field (academics, practitioners, researchers and peak bodies) must **advocate for the value of alternative types of knowledge** as being valid, meaningful and rigorous.
- 2. Develop resources which showcase diverse examples of how the work can be done.** We caution against another 'how to do' set of resources and instead suggest developing and sharing resources of 'how we did'. The issues identified in this report will undoubtedly be, and have been, faced by others. As such, **documenting multiple and different collective strategies to negotiate these issues would be a useful process-based set of resources which would guide and support people while not suggesting a recipe-based approach.** The emerging movement will be more inclusive and coherent if Compassionate Communities are co-defined and designed with the community themselves.
- 3. Support and expect a 'whole of community' response and re-presentation.** Strategies need to be developed which both support and expect a more diverse response across all levels of the community, from local meetings, to leaders and peak bodies in the field. Presently it is still able-bodied women who dominate this work, especially on the ground. Men need to develop and make visible their own cultures of *on the ground* caring and contributing to community capacity - otherwise we risk re-inscribing and continuing the gendered nature of this work. Additionally, **more inclusive strategies, cultures, and ways of working with marginalised and vulnerable groups as equal partners are urgently required to protect against exclusion.**
- 4. Develop and model collective/dispersed leadership:** Representations of leadership currently available, which focus on the heroic individual or the individual who holds power and influence, are not helpful for people doing this work. Instead **collective, or dispersed, leadership exemplars need to be developed, shared and modelled by current leaders** and organisations in this field. It would be useful, and have integrity, if this development were done in partnership with practitioners in this field.

5. It may be useful to **target communities who are already well placed to develop Compassionate Communities**. Although more research is required, we found that certain demographic parameters could be useful signposts for choosing which communities/regions to target. Those attributes were: older than average age group, with more lived experience to draw upon and share with their community; higher levels of volunteer work; having assisted people with disabilities; and a higher than average level of employment. According to the Australian Bureau of Statistics, employed people do more volunteering and caring than those who are unemployed. Interestingly, income levels and religious affiliations do not appear to be predictors of responding to community need.
6. **Funding is urgently needed to provide and maintain a collegial clearinghouse of structured support and resources which is practitioner focussed**. This clearinghouse could be the central access point and repository for: practical resources; colleagues to problem solve with; a place to centralise research evidence; the space from which to develop a network of expertise via conferences, symposia and other opportunities for people to come together to share and develop their practice wisdom; the development of a nationwide community of practice and peer led learning networks and theory development. This clearing house could also enable people to locate their work in the broader socio-political context which would shed light on the obstacles and barriers they will undoubtedly experience. One of the strengths of the participants in this research was their understanding of community development theory, processes and principles. A clearinghouse such as we envisage would facilitate the development of the theory and practice as a dialogic process. An urgent first step is to clarify, and provide concrete examples of, the differences between service delivery, Compassionate Communities and community development.

Background

The new public health agenda in end of life (EOL) care is encapsulated in the public health palliative care (PHPC) movement of which Compassionate Communities and Compassionate Cities are two strategies for operationalising this movement (Karapliagkou & Kellehear, 2014; Kellehear, 2020; Kellehear, 2013; Abel et al., 2013). PHPC is a significant departure from the dominant resource intensive, medicalised, service delivery model of care (Noonan et al., 2016) as it advocates for developing a whole of community approach to aging, dying, caring and loss. As such, it is hoped that dying, caring and grieving will become less medicalised and more socialised, resulting in: a decrease in unnecessary, costly, and stressful hospital admissions; people being less lonely and socially isolated; workplaces, schools and other civic institutions providing support and assistance in times of need and carers being appropriately supported by a combined network of formal and informal carers and services ensuring that they are not overly stressed and burnt out. In short, the vision is that we will all know what to do, how to get help and who to ask for help in times of need and crisis. Dying, caring, and grieving are such times. Good neighbourliness (MacKay, 2018), Compassionate Communities, networks of care then become just the stuff of everyday life.

Such a move towards social and collective responsibility requires a recalibration of health and social services *and* communities and civic organisations (Horsfall et al, 2012 & 2017). For services, the challenge is to work with people in respectful, equal partnerships which promote individual and collective wellbeing and centre stated need. For community, it means taking responsibility to care for each other in times of need and having support structures and systems in place to do so. For both service providers and community there is a need to develop collective death literacy (Noonan et al., 2016).

Most of the research to date in EOL care focuses on non-professional caring as a burden (Fukui et al., 2013; Dumont et al., 2006; ABS, 2009; Hagel et al., 2016; Veloso & Tripodoro, 2016). This reflects a medicalised and individualised orientation where the carer is at risk of harm, needing to be relieved of the burdens associated with such care (Sadler & McKeivitt, 2013). As such, it is problematic to expect community members to take on this burden as informal carers. However, caring at EOL can also be rewarding. It can provide meaning, purpose and a sense of belonging, thus having a positive impact on carers' wellbeing, quality of life and social relations (Horsfall et al., 2017; Ratcliffe et al., 2013) provided there is a network of care-givers comprising partnerships between formal and informal services and ordinary people. As such, adequate structural and civic support is required to develop a whole of community approach to avoid potential exploitation of informal carers, often women, who dominate the unpaid, informal caring field (Milligan et al., 2016).

There is a growing body of evidence showing that carers and dying people with active community networks and structural social and legal supports (via workplaces, schools etc.) experience decreased social isolation and fatigue, improved social support and

increased confidence in asking for help (Horsfall et al., 2013; Sallnow et al., 2016; Hilbers et al., 2018; Abel & Clarke, 2020). If dying, caring and death are to be understood and responded to as social events (Brown & Walter, 2014) where isolation, anxiety and fear are seen as social problems (which can only be fully addressed by a whole of community approach) then we need to understand how the theory and aspirations of Compassionate Communities and Cities can be translated into action, and what happens when they are.

In 2016, building on this growing body of evidence, The GroundSwell Project and Palliative Care Australia organised a national symposium on Compassionate Communities with the stated goal being to stimulate the sector to translate the theory into practice in Australia. This two-day event brought together a number of social, medical and health practitioners, academics and researchers internationally and from across Australia and New Zealand. The symposium created a significant surge in interest and led to the Commonwealth Department of Health commissioning the *Compassionate Communities Feasibility Study*, delivered in 2018. It highlighted a number of projects from across Australia and internationally, noting that the “compassionate communities’ movement has grown and that they are indeed, feasible in Australia” (NOUS Group, 2018, p.3). A number of barriers and challenges were noted. These included issues related to sustainability, concerns from health services about community involvement and the pervasiveness of the medical model. The interface between formal and informal care was also discussed as both a barrier and enabler of community development approaches to end of life care (NOUS Group, 2018). In addition, in 2017, as part of its *Greater Choice for Palliative Care at Home Measure*, the Australian government (Australian Government Department of Health, 2017) released over eight million Australian dollars to Primary Health Networks to implement Compassionate Community strategies which explicitly targeted formal and informal networks of care and caring in place.

For those of us interested in, and committed to, the new public health agenda in palliative care, some of the questions arising for practice are: how do you recognise, value, and upscale already existing material practices (those everyday social relations and interactions that comprise caring for one another in times of need)? How do you identify what else is needed and build community capacity to do the work required? Whose responsibility is it to do these things? How do you avoid the danger that the development of Compassionate Communities and Cities remains professionally led reflecting professional needs and priorities despite the best intentions (Noonan et al 2020; Rosenberg et. al 2020)? And, is locating the Compassionate Communities and Cities strategies best kept within a public health palliative care framework?

These questions can begin to be answered as more initiatives translate the theory and aspirations of Compassionate Communities and Cities into action on the ground. Over the past decade, the UK has led the development of a number of Compassionate Community projects which appear to have had a national impact (see for example: Barry & Patel, 2013; Hartley, 2012; Paul & Sallnow, 2013; Richardson, 2011). Of particular relevance to this research was the National Council for Palliative Care Pathfinders Project (NCPC) and the work of Health Connections Mendip scheme, sometimes called the Frome model (Abel & Clarke, 2020; Eyres, 2016; Abel et al., 2018). For the Pathfinders Project, instead of using a more traditional seed funding model, NCPC resourced a program of support and mentoring to local organisations wanting to develop a public health approach to end of life care. This included the adoption of the Dying Well Community Charter (Eyres, 2016). The fact that there were no central funds available

deliberately encouraged Pathfinder communities to establish working partnerships in order to deliver initiatives. Central project co-ordination was provided by NCCP, along with some expert leadership and evaluation support. The Pathfinders model directly influenced the development of the National Compassionate Communities Forum (NCCF) in Australia where one of the goals was to build upon the Pathfinders project (Eyres, 2016) in the Australian context.

Concurrently the Nepean Blue Mountains Primary Health Network (NBMPHN) established a Key Leaders Group to drive forward key recommendations in the *Caring for People at End of Life* report (Rees et al., 2017). As such, they contacted both the Caring at End of Life Research Team at Western Sydney University and The GroundSwell project with the aim of jointly developing a local program to implement Compassionate Communities in the Blue Mountains. At this early stage they agreed to trial the implementation of both the community connector and health connector models (Health Connections, Mendip, 2018). Primarily funding was provided to employ a community development worker who then became the health connector as this role was established. This project also had an explicit focus on building death literacy (Noonan et. Al, 2016) as a central focus.

Research context

As outlined above, in 2018, the GroundSwell Project launched two industry funded Australian based Compassionate Community projects:

1. The National Compassionate Communities Forum (NCCF) was a two-year project funded by BUPA and influenced by the Pathfinders project in the UK (Eyes, 2016). The overall aim of the NCCF was to invest in the capacity and willingness of community and health leaders to collaborate with and engage their fellow citizens in end of life support with the purpose of effecting change within their communities. The role of the GroundSwell Project was predominantly to work closely with these health and community leaders to support community mobilisation and capacity building. The NCCF was designed to encourage organic grassroots growth of Compassionate Communities across Australia through predominantly a process of community development using community capacity building as the primary means for change. A central question of this project was: what can we learn when these community members are equipped with support, encouragement and research tools in a collaborative network?
2. In 2017, the Nepean Blue Mountains Primary Health Network (NBMPHN) established a Key Leaders Group to drive forward key recommendations in the *Caring for People at End of Life* report (Rees et al., 2017). The first task was to develop a whole-of-community approach to end of life care based on Compassionate Communities, and The GroundSwell Project and Western Sydney University were engaged to begin the Blue Mountains 'Our Compassionate Community' project in early 2018. The broader aim of the project was to develop the overall death literacy of the community, including General Practitioners, and to build networks of support across the region in order to treat the end of a person's life as normal, and enable greater support for more positive and values based options. A focus of this project was to adapt the work of Health Connections Mendip UK (see <https://www.somersetccg.nhs.uk/news/health-connections-mendip-scheme/>) to an end of life context by training community members as community connectors and establishing the role of health connector in a GP practice to assist people in the last year or two of their lives to plan in meaningful ways and foster support in their social networks and local community.

Community development

Both projects were underpinned by a strong ethos of community development work where building the capacity of people to work together and take collective action to address *their* common needs and interests is central (Kellehear, 2005). Any resulting actions are designed to effect change. In this model of community development, community is understood as an interconnected web of relations with already existing strengths which can be built upon (Harrison et al., 2019). The projects we are reporting on here were place-based communities and participants were concerned with

“building common purpose within localities as the best way to understanding and developing human capabilities” (Harrison et al., 2019, p8; see also Bhattacharyya, 2004; Newman & De Zoysa, 1997). Although fundamentally a bottom up, self-determined community driven process, the changes sought were located within community “while at the same time work is done to advocate for organisational, policy and political change to advance social justice and equality” (Wilkinson, 1991, p.240; see also Kenny & Connor 2017). This definition and understanding clearly locates community development as transformative and radical. However, whether or not this is the intent, or understanding, of so-called community development projects in the EOL space is contested, with community engagement and/or community capacity building often being seen as the end goal by service providers and policy makers in particular.

Compassionate Communities

For the purpose of this research, and the two projects reported upon, we define Compassionate Communities as:

communities that develop social networks, social spaces and social conduct that support people through the many hours, days, weeks, months and sometimes years of living with a life-threatening or life-limiting illness, ageing, grief and bereavement, and long-term caregiving... they are seeking ways for how caring responsibilities might be distributed and assigned democratically (Wegleitner et al., 2015, p.xiv).

The GroundSwell Project funded the Caring at End of Life Research Team at Western Sydney University to research these projects. For research purposes, the two projects were combined. The project aimed to explore how Compassionate Communities can be initiated and mobilised, what helps or hinders this process, and what the effect of such work are.

Research aims

1. Identify and document strategies to translate the Compassionate Communities model of end of life care into practice in participating communities across Australia.
2. Develop in-depth understandings of barriers and enablers to translating a Compassionate Communities model into practice.
3. Document and analyse changes in these participating communities, from the community's point of view, which occur as a result of this translation process.
4. Develop understandings of, and provide evidence for, engaging non-medical supports in palliative care at end of life.

The research was approved by Western Sydney Universities Human Research Ethics Committee in May 2018, under approval number H12684.

Methodology and methods



Fig. 1 GroundBreaker communities located around Australia.

Participants and recruitment

The GroundSwell Project (GSP) appointed a community development worker in the role of Compassionate Communities National Lead, whose role was to manage the delivery of the forum project and provide community development mentorship and guidance to the participants. Informed by the Pathfinders process in the UK, GSP invited expressions of interest (EOI) from communities around Australia who self-identified as being actively engaged in furthering the Compassionate Communities model locally. The EOI was an online form submitted via GSP's Compassionate Communities Hub website. People were asked to respond to questions aimed at capturing baseline data about the community demographic: population, geographical location, existing community partnerships and support, as well as a commitment to an initial community meeting and agreement to being part of the research project (see appendix 1). GSP received 30 expressions of interest from a diverse mix of applicants nation-wide, ranging from people and groups who had been practicing this work for years as well as people for whom this was a completely new concept. These 30 applications were shortlisted to 15 using the following exclusion criteria: applications which had not addressed the questions in the EOI; applications from an individual applying rather than a group or community; and Primary Health Networks (PHN's) who had already received government funding to develop Compassionate Communities. The NCCF steering group, comprising of GSP and Western Sydney University (WSU) personnel,

met and analysed the resulting shortlist of 15 applications. The following criteria were applied to choose the final 8 communities from this shortlist:

- Demonstration of solid grasp of the Compassionate Community's concept including an understanding of community development
- Evidence that connections and support from the wider community existed or had been initiated
- The community had not received federal funding to implement Compassionate Communities work
- To show the feasibility of this work across Australia in varying settings, it was important to choose groups that were diverse as follows:
 - Geographical location (national spread)
 - Geographical zone (urban / regional / remote)
 - Population size
 - Led by different sectors (health / community / corporate)
 - Access to budget/support

The 8 groups chosen were termed the 'GroundBreakers' linking the project to the Pathfinders in the UK as well as recognising the forum project was exploring new terrain in the Australian context. These GroundBreaking communities were located in: Dulong, QLD; Ballina, NSW; Newcastle, NSW; Sydney Northern Beaches, NSW; Bundanoon, NSW; Central Coast, TAS; Warrnambool, VIC; and, Bunbury, WA.

Of these 8 communities: 4 were comprised of activated citizens working at a grassroots level; 1 operated from within the health system, to prioritise death literacy and community engagement; and 3 groups hailed from existing not-for-profit organisations already doing some element of Compassionate Communities as part of their core work who were now looking to extend that through the NCCF. Figure 2, below, provides a pictorial representation of the diversity of skills represented by these groups.

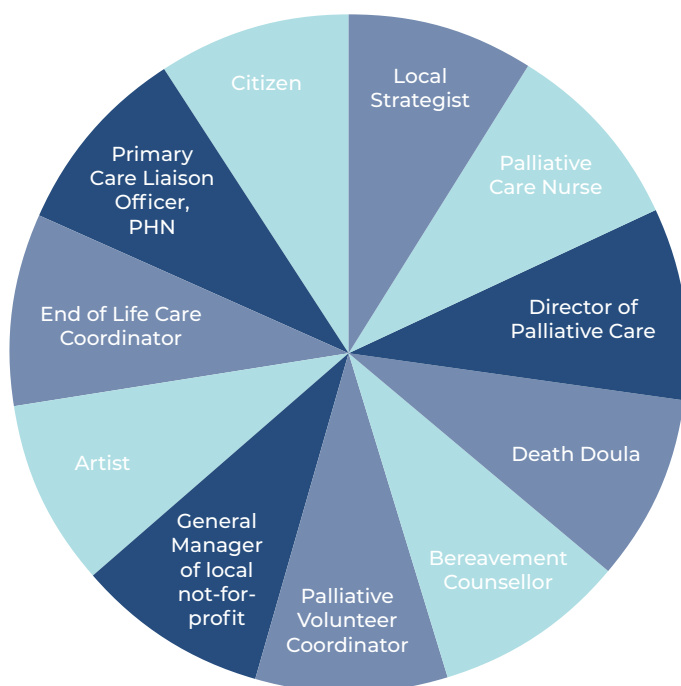


Fig. 2 Roles represented in GroundBreaker groups.

For the Blue Mountains 'Our Compassionate Community' project funded by the NBMPHN, GSP employed a community development worker to establish Compassionate Communities through community development, health professional education and local network building in the region. That project is included in this report as the 9th community. The community development worker will be referred to herein as the NBMPHN lead.

Once the 8 communities and NBMPHN lead had been chosen and had confirmed their intention of being part of the research project, we searched the Australian Bureau of Statistics (ABS) database for any further relevant features of these communities. That data was taken from the 2016 Census (ABS, 2016) using the ABS zones that best represented the size of each community as outlined by them in their EOI (see appendix 1 for geographical zones used for each location).

Population sizes varied greatly between the 9 participating communities and it should be noted that the scale of each community represented below is not necessarily an indication of the reach of Compassionate Community work undertaken in each location. For example, Dulong, QLD at only 564 people, proportionally doesn't appear on this chart in figure 3 below, however their Compassionate Community work extended into other regions of the Sunshine Coast with some community meetings held in towns of up to 10 kilometres away. One group member reportedly drove 100km to join in on a meeting. Likewise, the reach of Bundanoon, NSW and Central Coast, TAS extended further into areas that surround them. While the Compassionate Community work of smaller locations permeated beyond their townships, larger locations represented here did not necessarily have the expansive reach their population size suggests.

Population

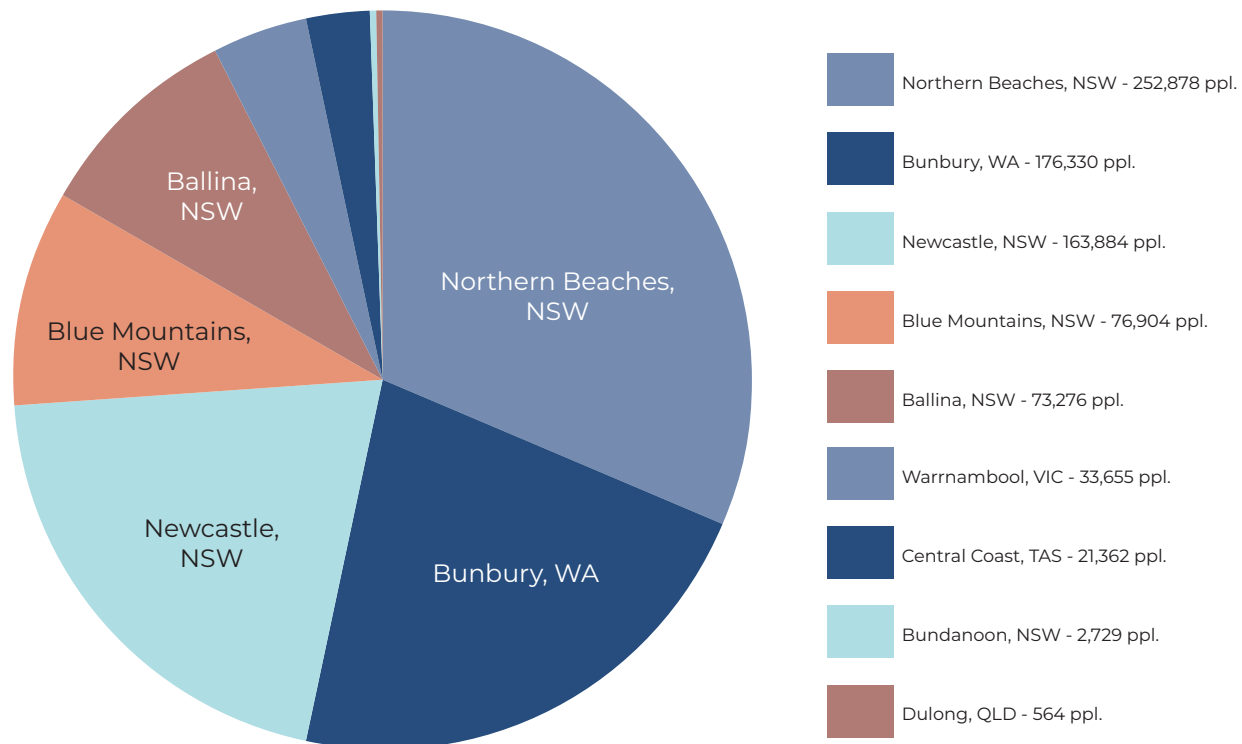


Fig. 3 ABS 2016 census for population size of GroundBreaker communities.

Average Age

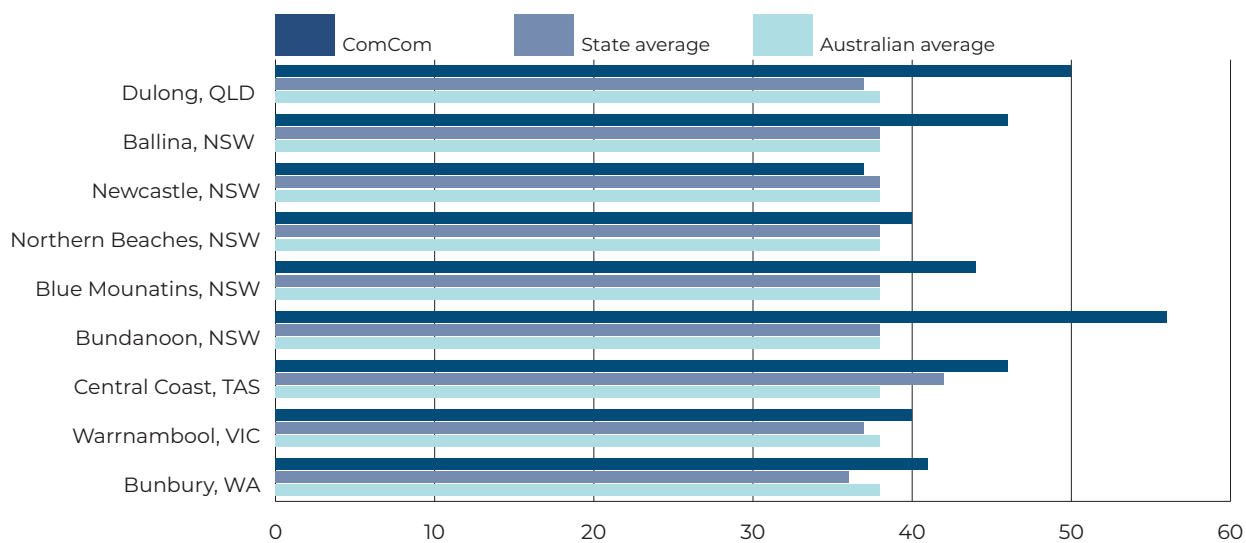


Fig. 4 ABS 2016 census for average age of GroundBreaker communities.

The **average age** of all but one community (Newcastle at 37 years) was above the national average of 38 years of age. Bundanoon had the highest average age at 56 years (see figure 4).

Personal income per week

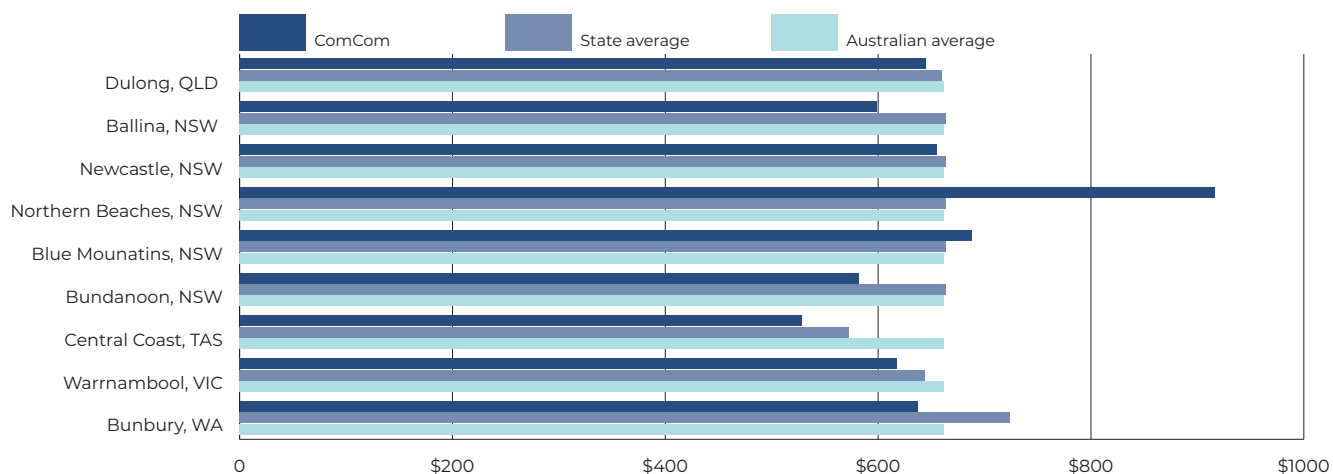


Fig. 5 ABS 2016 census for average personal weekly income of GroundBreaker communities.

The average **personal weekly income** of all but two communities was slightly below the national and state averages. The Northern Beaches reported the highest income at \$916 per week, compared to the national average at \$662 (see figure 5).

Not Working (Unemployed/Retired)

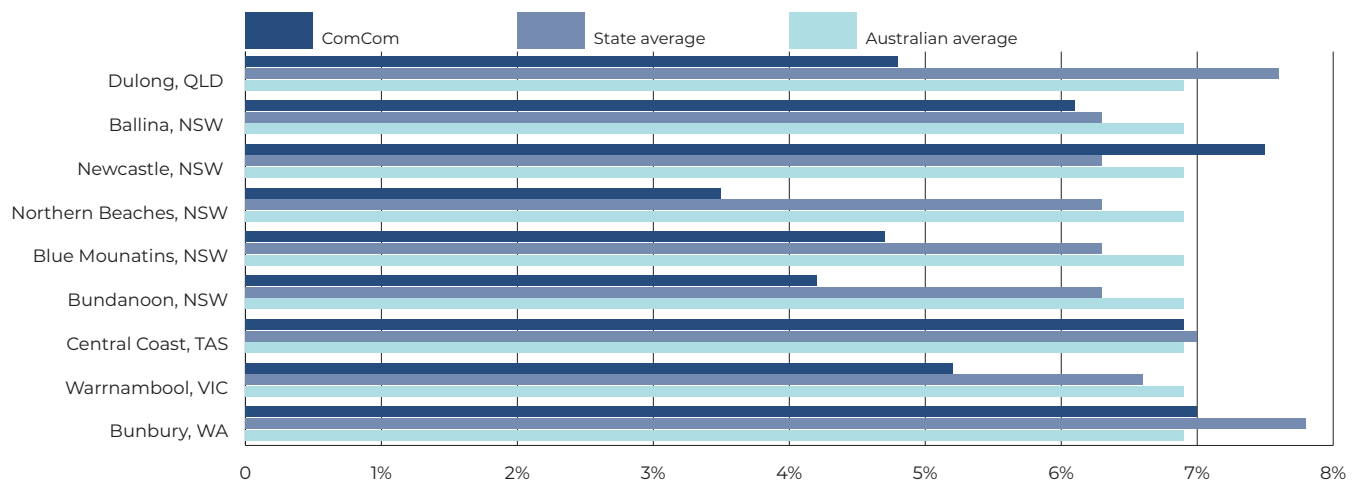


Fig. 6 ABS 2016 census for average percentage of people not working in GroundBreaker communities.

The percentage of people **not working** was generally well below the national and state averages for all communities but Newcastle (see figure 6).

Provided unpaid assistance to a person with a disability (last two weeks)



Fig. 7 ABS 2016 census for average percentage of people who provided unpaid assistance to a person with a disability in GroundBreaker communities.

The percentage of people who **provided unpaid assistance to a person with a disability (in the last two weeks)** was above national and state averages for all communities but one (see figure 7).

Did voluntary work through an organisation or group (last 12 months)

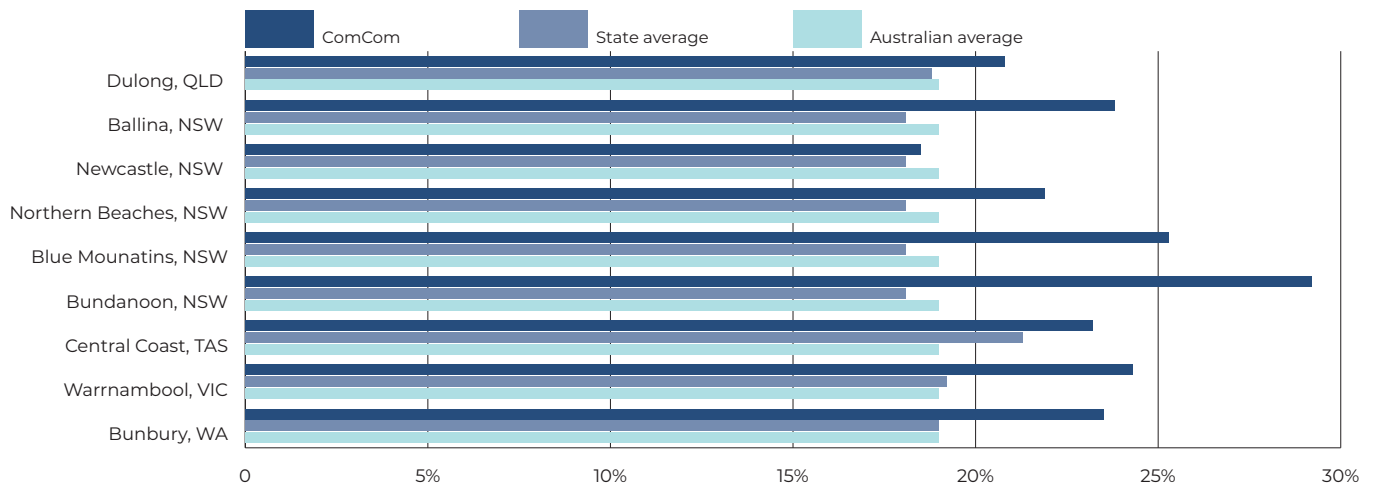


Fig. 8 ABS 2016 census for average percentage of people who did voluntary work through an organisation or group in GroundBreaker communities.

The percentage of people in all 9 communities who **did voluntary work through an organisation or group (in the last 12 months)** was markedly above national and state averages (see figure 8).

No Religion, so described

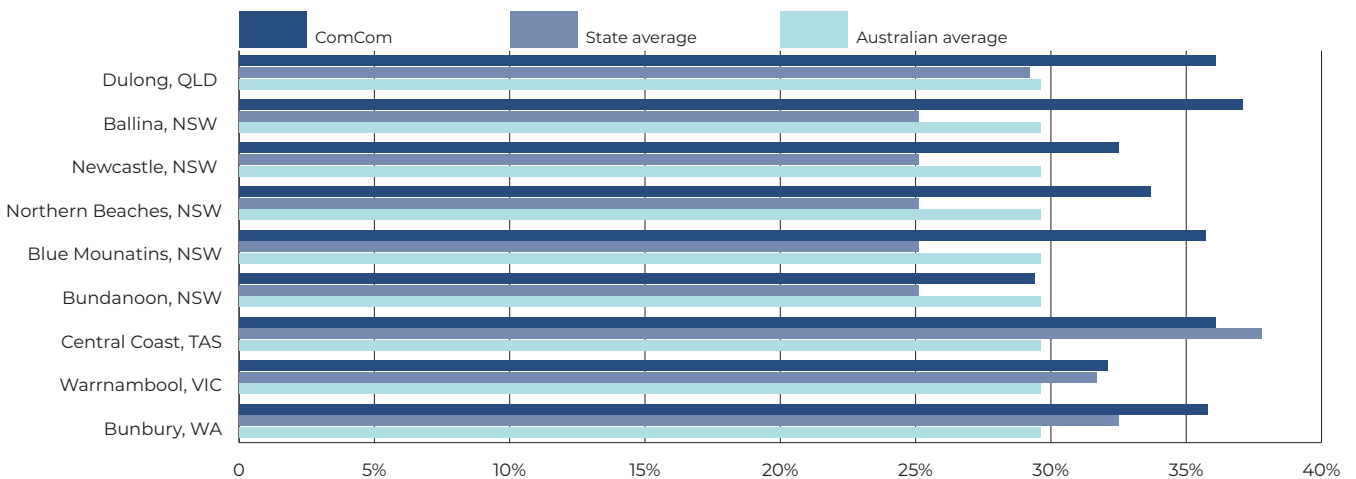


Fig. 9 ABS 2016 census for average percentage of no religion, so described in GroundBreaker communities.

The percentage of people who **did not claim a religious affiliation** was above the national average for all communities except Tasmania where the state's religious affiliation ranked significantly higher than the national average (see figure 9).

This told us that the 9 communities represented in this research were comprised of an older than average age group, with more lived experience to draw upon and share with their community. Volunteer work and assisting a person with a disability also both rated above average. Likewise, people who are employed do more volunteering and caring than those who are unemployed. Interestingly, income levels and religious affiliations do not appear to be predictors of responding to community need. While ostensibly a finding, we have put this information here as it does provide a richer picture of the communities involved in these projects.

The EOI process for the NCCF included information regarding the research component of the project, however from the researcher's point of view it was important that the process of being part of the research was opt-in. As such, care was taken to not tell the NCCF lead which of the GroundBreakers had opted in to the research. After receiving ethics approval, a flyer was distributed to all the GroundBreaker communities by the NCCF lead over email. This flyer explained the project and offered participants the opportunity to opt in by contacting the WSU research assistant (RA) and to ask any questions before they agreed, or not, to participate (see appendix 3). The NBMPHN lead was given the flyer by the researchers and asked to contact the RA if she would also like to participate in the research. Self-selected representatives of each of the 8 communities agreed to be part of the research.

As a result, 3 different groups of participants engaged with the research over the 18-month period from 2018-2019 (see appendix 4 for participant information sheets).

1. Group 1 was the research group [RG] which met via teleconferencing for 2 hours every 3 months, totalling 4 meetings over the course of the project. This group comprised the NBMPHN lead; the GroundBreaker leads, and in 5 of the 8 locations, a community representative as well. This group totalled 16 participants. Although not everybody attended each meeting, there was usually at least 1 representative present from each community.
2. Group 2 was the focus group [FG] participants consisting of 1 representative from each community and the NBMPHN lead. Their self-selection process resulted in all GroundBreaker leads being the focus group participants. Two focus groups were held, one at commencement (June, 2018) and one at the conclusion of the project (October, 2019). This group totalled 9 participants.
3. Group 3 comprised the NCCF lead and the NBMPHN lead. Monthly interviews over 17 months were held either face to face or via video conferencing with the NCCF lead, depending on the requirements of the participant. Ad hoc conversations with the chief investigator (CI), RA or both were offered on an 'as needed' basis to the NBMPHN lead across the life of the research project - approximately 6 meetings were conducted with this lead.



Method

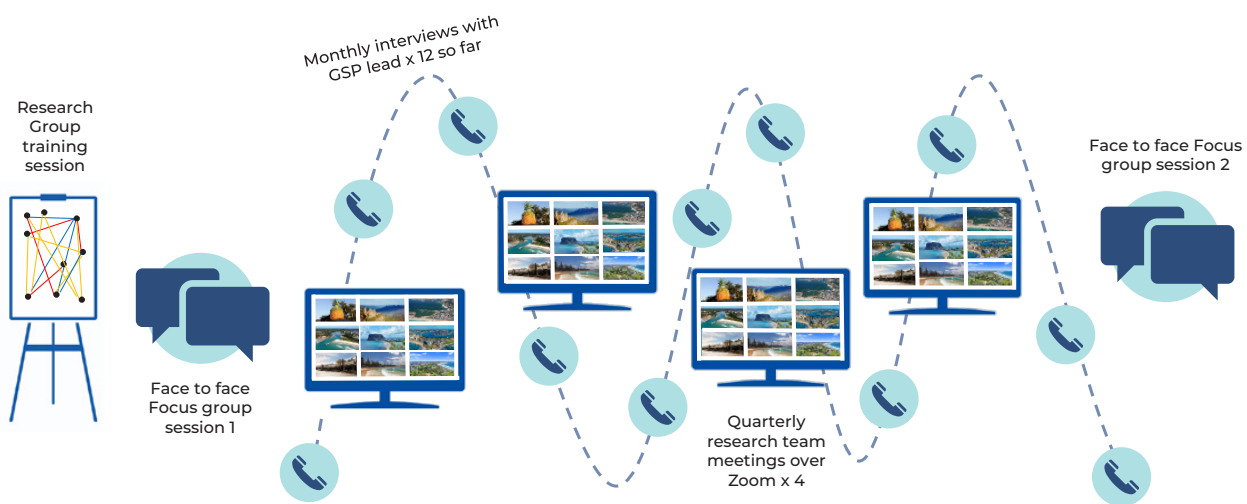


Fig. 10 Visual timeline of research methods used in project.

Procedures

The GroundBreaker community members along with the NBMPHN lead, came together for the first time in June 2018 at the Death Literacy Conference in Sydney. There, the WSU researchers, CI and RA, met with them in two separate groups. Firstly, in a training session with Group 1 and secondly in a focus group with Group 2.

Group 1

Research training session

The 3-hour research training session incorporated the principles of Action learning/research and Appreciative Inquiry (Hennessy & Hughes, 2014; Revans, 1982; Herr & Anderson, 2014). As these participants were the people initiating and developing the work across Australia, the research was designed to support them to do their own research and evaluation. As a nation first initiative of this sort, it was important that evidence was collected along the way so that these initiatives could be up scaled based on the learnings of this pilot. The researchers' role was to provide back-up, support and resources as needed and to ensure that on-going evaluation and research were built into the participants' endeavours. As such, the training session included a selection of possible data collection methods including: social network mapping (Leonard et.al, 2018); photovoice (Sutton-Brown, 2014; Wang & Burris, 1997); forms and

templates; and a general discussion of ideas the participants had to capture evidence of the impact of their work. The aim of this session was to acquaint participants with research methods and methodologies they could comfortably and confidently use to support their work. They were also given a booklet of instructions and guidelines of methods for their ongoing research.

Social network mapping exercise

During this session, Group 1 participated in a social network mapping exercise that mapped the strength of any current relationships they might have with each other. The aim of this was twofold. First, to provide an experiential learning opportunity for one method of creating a network map that they may wish to use in their respective communities. Second, to serve as a pre and post measure of potential relationship building within this Australian wide group. This exercise was repeated via an online version at the conclusion of the research process in January 2020.

Research group meetings

Research group meetings were semi-structured aiming for a balance between researcher driven questions (see appendixes 5) to guide the critical reflections of participants, and, the issues and themes arising from their work in the field. For each meeting, we provided a series of questions based on: themes that had emerged from the previous meeting; feedback from participants via ad hoc email and phone communications; interviews with the NCCF lead; ad hoc phone meetings with the NBMPHN lead; and the research aims of the project.

We encouraged participants to be specific as they spoke about their work. We asked for concrete examples and encouraged participants to explore *how they knew what they knew*. Participants tended to focus on activities and tasks (*the what*). The researchers coached them to delve into the *how's, why's* and *so what's*.

These meetings were limited to 2 hours, with approximately 12 minutes of discussion time was allocated to each community. After the first research meeting, it was evident that the work being discussed was very rich and difficult for participants to capture in the short space of allocated time. We then suggested photovoice as a tool to drive photo informed, or photo elicited, discussions (Sutton-Brown, 2014; Wang & Burris, 1997) as a method to get to the heart of the matter as quickly as possible, without losing this richness. This method was agreed to by the participants who could choose to use it or not for each meeting. Questions were provided via email prior to the meeting and participants were invited to select one or two questions that resonated with them, and, provide up to three photovoice images as a response to the chosen questions. These images could be photographs they'd taken or ones they'd found in a book, magazine or online. Participants were asked to email their images to the RA so she could collate them and distribute to the group prior to the meeting. This method was used for the remaining 3 research group meetings.

After each meeting, a detailed summary of emerging themes and discussion topics was compiled and circulated amongst the participants, often including supporting commentary and observations we'd made either during the meeting or upon initial analysis of the data. The presence of both the CI and RA at these meetings enabled the RA to take detailed notes and make sure the process was being followed. This allowed the CI to concentrate on what participants said while offering feedback on emerging

themes within the meeting. Ad hoc telephone and email support was offered by the RA, including compiling and sharing relevant resources, reading material, and guidance on data collection methods.

Group 2

Focus Groups

In the first of two focus groups with Group 2, the 9 participants were asked to discuss their visions and strategies for building their Compassionate Communities. This group met in a private room at the Death Literacy Conference at Homebush, Sydney in 2017. The second focus group took place 18 months later at the 6th annual International Public Health Palliative Care conference in Leura, Blue Mountains in 2019. Again, this was in a private room. Food and drinks were provided to add a celebratory air to the group as it marked the official end of the project. In the second focus group participants were asked to reflect on key learning's and changes made in their communities over the course of the 18 months (see appendix 6 for questions).

Both focus groups were held over a 2-hour period, but unlike the research group meetings, there was no allocated time frame per community. Discussion was an open forum, with the CI chairing the discussion to ensure members received an opportunity to contribute. Participant attendance and travel to the conferences was paid for by GSP out of the project funds. This enabled all participants to attend in person.

Group 3

Interviews with NCCF lead and the NBMPHN lead

Both researchers met with the NCCF lead on a monthly basis to offer support and a space for critical reflection on the work. This had not been a part of the original project design, but it was soon apparent the NCCF lead required an outlet to discuss and troubleshoot her leadership role. In addition, it provided us, as researchers, a dedicated way to feedback de-identified issues and themes arising from the research group, which would help her in supporting them (see more in methodological findings). Photovoice was also introduced to the lead as a way to drive her reflections and anchor the exploration of her thoughts and ideas. On the whole, these interviews were unstructured and led by the participant. Our role was to respond to issues she brought up, answer questions she had, provide relevant resources where appropriate, and provide critical feedback. In many ways, this role echoes that of a critical companion, where the expectation is for high level work within a highly supportive environment (Titchen, 2004). The NBMPHN lead was part of group's 1 and 2. We also offered her phone or in person support meetings as required/requested. These were driven by the participant's needs at the time and were unstructured. The different methods between the two leads were due to different levels of resourcing of the projects.

Method of analysis

All research meetings and focus groups with Groups 1 and 2 were audio recorded and transcribed verbatim. For the Group 3 interviews and discussions with the NCCF and NBMPHN leads, the RA took detailed notes which she emailed to them soon after each meeting. The data pool for analysis consisted of: verbatim transcripts from Group 1 and Group 2 meetings; the RA's field notes during those and Group 3 meetings; conversations between the RA and participants via email correspondence or phone; and the photovoice images submitted by participants.

The CI and RA used research driven thematic analysis to interrogate the data based on the original project aims, while asking what is emerging from the data. Emergent themes were tested with the greater WSU research team for clarity. The first round of analysis involved the RA's detailed meeting notes, who collated summaries and quotes to capture the key points and themes emerging. In the second round of analysis, the field notes and meeting transcriptions were coded and categorised (Braun & Clarke, 2006). While focusing on the project aims, the CI and RA interrogated the data for themes arising within the kinds of strategies the participants employed, and the types of barriers and enablers they encountered.

The photovoice images were interrogated first by analysing the transcripts and RA's field notes in relation to what participants said about the image and the conversations that took place around them. Next, the photos and accompanying text for each image were coded based on the research questions and themes emerging from the data. We looked for any surprises that enlarged our expectations, however all themes that arose from the photovoice data sat within the existing set of themes from discussions.

Action on the ground – a summary of community activities³

Upon commencement of the two projects³, each community group was asked to host a community forum where community members could come together to discuss the successes and gaps in the end of life sector in their area and identify ways to address the gaps. Each group successfully ran a forum with attendance ranging from 25 people to 130 people. Communities discussed what was important to them along with what they thought was important at end of life. They identified different areas of priority, with differing resources in terms of access to finances, and the ongoing interest and skills of community members. These influenced the different ways each group proceeded. The GroundBreakers/community leads were encouraged to listen to the community when determining what initiatives to work on. The following points highlight some of the key and diverse activities and projects which grew out of these initial forums over the life of the projects.

- Compassionate Community ‘action groups’ or ‘committees’, consisting of 5 to 10 community members, were established and met regularly to steer the direction of the group. Member roles interchanged as the work became more established and new opportunities arose.
- In their communities, Compassionate Community members facilitated discussions on death, dying, grieving, isolation and loneliness, encouraging people to share their stories of loss and of being a carer. They mobilised networks of care by fostering relationships and encouraging people to ask for and accept help.
- New connections, social networks and connectedness were established by actively calling on volunteers to: fill positions in preschools by reading books, playing games and gardening with the children; visit vulnerable and isolated people in the community; form genuine friendships with participants at initiatives; and run end of life planning workshops for community members; a volunteer service was established in one area to regularly phone elderly and isolated community members just to check in and say hello.
- Monthly support cafés started up in 4 of the 9 communities. Along with providing a place for people to connect and access information, for some attendees these groups served to expand their social networks as they connected with members outside the context of the café meet-ups. Most of the café groups had a direct focus on bereavement support where community members drew on their lived experience to equip them with the confidence to hold these groups. One of these 4 communities expanded their monthly meet up by initiating a second monthly meeting at a different location and at a different time in the week in response to community requests for more options to access this initiative. Another group decided to host a weekly support café and share the leadership

³ See page 62 in the report, Critical Moments and Turning Points, which provides more detail and analysis regarding the changes within communities and the sector/s as a result of these activities.

responsibility amongst the group. Regular attendance grew and soon the attendees were sharing in the rostered leadership of the group.

- Educational workshops and seminars included free workshops in response to communities' desire to be better equipped to plan for end of life. Invited speakers covered topics such as: Non-Traditional Funerals; Organising your own funeral; Having a Good Life to the End; Advance Care Planning; Palliative Care; Death Doula services; and Grief and Bereavement.
- In the Blue Mountains, forty-two community members were trained in signposting local end of life services and supports to people in their day to day life. Currently being trailed is the role of a health connector in a General Practice, to assist people in the last year or two of their lives to plan in meaningful ways and foster support in their social networks and local community.⁴
- Partnerships with organisations also provided a series of discussion panels and seminars. Informal gatherings as well as formal committees brought health providers and community members together to share insights and gain knowledge.
- Communities held events for *Dying to Know Day*⁵, which included talks with guests from the end of life sector.
- Australia's first Coffin Club, established for several years through the Tasmanian GroundBreakers (see <https://www.facebook.com/CommunityCoffinClub/>), has inspired some of the other GroundBreaker communities to follow suit, as well as other groups around Australia.
- As part of a new partnership between Tender Funerals⁶ and Social Ventures Australia (see <https://www.socialventures.com.au/sva-quarterly/the-cost-of-dying/>), three GroundBreaker communities have been chosen as locations to scale up their alternative funeral model.
- Groups utilised the practice of bringing art and ritual into some of their initiatives and partnerships that include: art festivals and exhibitions; spoken word poetry; coffin decorating; art making in aged care facilities; picnics and ceremony; a choir, singing to people reaching the end of life; dinner parties and a creative, *From the Brink*⁷ festival focused on end of life.

4 These two initiatives have been modelled on the work at Health Connections Mendip in the UK and have been adapted to an end of life context with their blessing.

5 Annual campaign day of community-run events which encourage conversations about end of life (see <https://www.thegroundswellproject.com>).

6 Community run not for profit funeral provider in Wollongong, NSW.

7 A fringe festival held in the Blue Mountains community as part of the PHPCI conference in October, 2018.



Fig. 11 Rus-Hartland, L. (2018). *Funeral of an old surfer, coffin made by his son, and attended by those he taught to surf* [photograph]. [RG2]⁸

- A centralised place for information accessible to all (such as an online directory of compiled resources to support people at EOL) was highlighted as an important need by most community groups. Many GroundBreakers/community leads had begun either thinking about or compiling these but were met with practical challenges. These included the responsibility of updating this into the future; people wanting to list only health and allied services; and ensuring accessibility to everyone in the community as both a paper based and online resource. This process, for many, involved negotiating the tensions involved in creating a directory that could hold stories and information about 'what people don't know they don't know', i.e., other options to support people at EOL. Such a resource has scope to include information on supports such as: mutual aid and neighbourhood networks; death doulas; non-traditional funerals; and, EOL planning that includes social networks and community values *to complement* the more traditional service provision directories of healthcare providers.
- Lastly, and arguably most importantly, countless cups of tea and coffee were shared with organisations, local councils, community services, aged care services, primary healthcare providers, and interested passionate and willing community members, mostly people with lived experience. This precious time allowed relationships to flourish as people got to know each other and share stories while also exploring what could be possible within a Compassionate Communities framework.

⁸ The images used in this report were submitted by participants as part of using photovoice. They were used as discussion points during research meeting discussions.

Findings: Moments across time

Our findings are organised by themes and sub-themes. These themes appear below chronologically, rather than in order of prevalence or importance. For readers who would like to understand more about the nature and effect of the actual work the participants did before they read the rest of the findings, please refer to page 62 for details of critical moments and activities, as well as evidence of change. One of the benefits of researching over time was our ability to map the process and progress, the ups and downs along the way, and what sustains people doing this work. So, we ended up with not just a moment in time, but moments across time. For example, the theme of *resistance and struggle* was more apparent during meetings at the beginning of the project. Later as communities and groups began taking action, this transformed, for the most part, into understanding *what it takes* to do this work. Importantly all of these themes and sub-themes are interconnected and interrelated. Instead of being discreet units they flow as an over-lapping account of the research, making sense and meaning as they become a whole.

Resistance and struggle

1. Questioning Legitimacy.
2. Coming face to face with Gatekeepers.
3. Compassionate Communities as women's work?
4. The tensions of leadership in community development work.
5. What is this thing, Compassionate Communities?
6. Exhausting and Exhaustive Expectations.
 - Community development work is overwhelming at times.
 - New managerialism: What we measure, and how we measure it, determines what we do – or does it?
 - Being a research participant: What we measure, and how we measure it, determines what we do – or does it?

What does it take to do this work?

1. The community development way: A clear understanding of community development to drive strategies and actions.
2. Deliberate communications: Using language, being strategic.
3. Towards collective leadership: Moving from the 'I' to the 'we'.

4. Reflective and collegial spaces for people working in precarious places.
5. Our voices, our stories: Sharing stories of success.

Resistance and struggle

My hope emerges from those places of struggle where I witness individuals positively transforming their lives and the world around them.

(bell hooks, 2003, p. xiv)

Our main findings highlight strategies of resistance and struggle, regardless of location with/in either health services or in the civic arena and, creative strategies used to capture and document ‘what worked’ in the development of Compassionate Communities across Australia. Like bell hooks though, we use these terms hopefully. It is a practice of hope to believe that doing caring, dying, death and grieving differently, is possible. It is a practice of hope to bring community groups together to act in ways that are different to the norm. And it takes courage. Compassionate Communities work is new. It is work which seeks to transform how and where we care for each other. It challenges the dominant medicalised model of caring at end of life. As such the work, especially at this early stage, is bound to be a site of struggle and a place where people encounter resistance/s to their efforts. In the following section we describe and discuss the nature of such resistance and the struggles encountered by the participants and their Compassionate Community collaborators.

Questioning legitimacy

A prevalent theme in the first focus group and earlier research meetings, we defined as “questioning legitimacy”. Whether it was the participants questioning their own legitimacy and ability to lead their Compassionate Communities, or, health workers and community members questioning, and at times even challenging, their credentials to lead their community groups. A further questioning surrounded the nature of compassionated communities themselves. This theme was recurrent at the start but changed over time as participants became confident in their work and multiple actions began to occur.

By the third research meeting in April 2019, the questioning of their legitimacy had petered out as participants had formed their identities as leaders of their Compassionate Communities. Discussion then focussed on the strategies they had adopted and their shared stories of success. Tensions were still encountered from the demands of the work, the people around them, and the high expectations they had of themselves, however these frustrations were no longer met with self-doubt or insecurity but confidence: *Sometimes you may have one or two silos that will just work with each other and nobody else... So it's nothing new and wonderful but the*



Fig. 12 Elena, I. (n.d.). Silos [photograph]. [RG3]

reason for choosing the silo pic where you can see the blue sky is because that's where we stay focused and that's what we aim for [RG3].⁹

Initially, the leads working within a health setting, with no previous experience in community development, questioned their position to represent the community and felt a conflict of interest between themselves as members of their community and their professional selves in a health setting: *I still feel this major anxiety about health versus community development work [RG2].* This anxiety and being *just a service provider [RG2]* led to people questioning their legitimacy: *One of my concerns is that we may not be viewed as legitimate providers [RG2].* On occasion, this lack of legitimacy was reflected back to various participants by members of their community groups: *They don't do community because they don't understand it. They [health personnel] don't understand community development. They don't understand processes, and in actual fact, what they're trying to develop [FG2].¹⁰*

Unsurprisingly then, for some of the participants who were health personnel they were reluctant leaders in this work:

This should not be led by health people. This was a health event – it shouldn't be a health event [RG2].

On the flip side, community members who were experienced in community development, but lacked experience in health settings, also felt ill-equipped, and reluctant, to take on a lead role in their communities.

I don't have a health background, so that makes me feel quite exposed... There'll be people in the community or naysayers saying well what's she talking about, she's just this... [creative] person you know, what's her bag? [FG1].

⁹ RG signifies the data is from a research group meeting with the number telling you which meeting.

¹⁰ FG signifies the data is from a focus group, either focus group 1 or focus group 2.

Coming face to face with Gatekeepers

Questioning legitimacy was compounded by the various Gatekeepers who acted to keep participants in their place. We use the term Gatekeepers here to mean “those who control access to resources, services and knowledge” (Collyer et al., 2017, p.96). These people are individuals, or groups of individuals, who hold rank and are usually key decision makers in the given field. Participants from health backgrounds, those in unpaid community roles, and others in paid community development roles, all came up against Gatekeepers at some stage over the course of this project. Usually this happened as some sort of milestone was being met or success achieved. The Gatekeeper/s could be other people in the local area also working on developing Compassionate Communities: *'Oh my God! You're going to be competing with us!' is what I heard. And I kind of thought, oh my gosh, does it really matter?* [RG3]. Or other service providers in the community: *I've already been told half a dozen times what I'm not allowed to do, and it's really interesting they don't claim it. They can't do it, they've got no resources to do it, but you can't go into that space because I'm just 'who are you, where do you fit?'* [FG1].

Deliberate strategies of obstruction and misinformation were also used by other workers in the field, on occasion. In one example a prominent worker in one community was repeatedly invited to meetings about the work. They never turned up. Then just as the work was getting media coverage and a particular strategy was about to be launched this person spoke out against the work at local meetings, questioned the legitimacy of the person leading the work, and told people that if they allowed this to continue they were putting vulnerable people in danger. Perhaps most disappointingly, recognised leaders in the Compassionate Communities/cites movement sought to tell people what they should and should not be doing: *We've sort of had feedback from others in the movement that we shouldn't really be doing that. That that's not really ComCom – that's not community development* [RG2].

Gatekeeping is a well-recognised strategy used by those with power and control



Fig. 13 [Photograph of stepping on toes] [RG3]

to retain power and control and to maintain the status quo. Here it is both the performance of a role and a process which both produces, and constrains, possibilities for taking action (Collyer et.al., 2017). Gatekeeping often becomes apparent when the usual taken for granted way of things is being challenged by those seen as outside of the gate, and where change seems both possible and probable. Interestingly in the health field gatekeeping is a function of 'managed care' often exercised by a physician to coordinate and streamline patient care (Liang et.al, 2019). While often promoted as a good thing for patients, the function of the Gatekeeper here is precisely that the person with power and control of a person's health, the physician, retains that power and control. A systematic review (Garrido et al., 2011) of the outcomes of this model of care showed that it has a limited positive impact on patient well-being although it was indicated to save money in the health system. In many ways this is a good metaphor for our use of the term gatekeeping – the function of the Gatekeepers is to protect the system, for the benefit of the system, whether that is the system of health services or the system of knowledge production. The following quote shows this quite well: *It is when people ... don't acknowledge that contribution or someone does the work and then they claim the credit, or they feel that you can't do it as a community group because it's their turf* [RG3]. The research participants here were well aware of this phenomenon, although they did not name it as such. They were also quite clear that it did not serve their interests or the interests of their communities: *If we're going to take each other down that's not going to be very beneficial for anyone* [RG2].



Fig. 14 Lane, J. (n.d.). *The Fearless Girl* [photograph]. [RG3]



Fig. 15 Furuncu, V. (n.d.). *Fearless Girl stares down Charging Bull* [photograph]. [RG3]

During the research meetings, we reassured participants that it can be helpful when difficult questions are asked as a reflection tool to build better practices, but not as a silencing or exclusion tool. There was certainly a place for critical self-reflection but what we are talking about here is different. Being told they were not following the recipe for Compassionate Communities, springs from a Gatekeeping mentality about disciplining and domesticating the participants and leading to the Gatekeepers' retaining control of the Compassionate Community's movement. Furthermore, *'only this type of person can do this work'* is the language of exclusion. We are left asking: In whose interest is it to exclude people? Who gets to be the Gatekeepers? What happened to gratitude?

As with the previous theme of questioning legitimacy, discussions around gatekeeping became less prominent after the third research meeting, when participants moved into sharing their insights, strategies and approaches with more confidence.



Fig. 16 [Promotional photograph for stage play, Perfect Pie] [12.11.18]¹¹

¹¹ The date refers to when the photo was given to the researchers by a participant.



Fig. 17 Psychogios, H. (2018). *Eggs, Sugar, Imposter* [digital collage]. [RG2]¹²

Compassionate Communities as women's work?

A direct impact of Gatekeeping was that some participants felt that they were ill prepared to do the work of Compassionate Communities and that they were imposters. The imposter syndrome is a long-known phenomenon experienced, specifically, by high achieving women setting out on a new venture (Clance & Imes, 1978). Which leads us to talk about gender. A total of 18 community leads/GroundBreakers participated in focus groups, research groups and research training groups. Of those 18, only 1 was male. In the first focus group it was clearly apparent that the people leading this work across Australia were predominantly women. The participants discussed the gendered performances of men and women and how that impacts new movements and the work entailed. They were well aware that Compassionate Communities work was different to the norm, and that it challenged the usual medicalised and patriarchal way of responding to caring, dying death and grieving.

Traditionally men are in positions of authority, specialists, GP's – it's been hard to steer culture away from that in a meaningful way [FG1];

The challenge is not to give it to men, or women who act in masculine ways, to professionalise it and monetise it. Gender plays an important role in being part of movements [FG1].

¹² RA's creative response during the analysis of RG2 data, included in summary provided to participants.



Fig. 18 [Photograph of woman in Groucho Marx glasses] [5.12.18]

They were also aware that in approaching this work differently it was important to recognise and claim the difference, rather than be seduced into feeling ill prepared and apologetic: *We apologise for being heartfelt, when actually that's what drives every single one of us [FG1], and, we're going to face that, we are, we're going to face that. People are going to say it's wishy washy, it's emotional, it's female stuff, it's not you know, facts [FG1].*

Gender was discussed across time. Participants spoke of the gender imbalance in their communities, the scarcity of men taking part in meetings and the work of capacity building and caring, and how often it was women doing this work.

They're all women by the way, which is also interesting in itself. Those 12 women who are really, really into doing something locally. They're just so knowledgeable and wise and connected [RG2];

It was all women who sat at the stalls yesterday [RG3];

So a challenge has been the local council... the looks on their faces when we were talking was just like – it was just the Old Boys Club [RG4].

However, there were exceptions. For example: *Dying to Know Day we had so many men that turned up which was really quite remarkable [RG4].*

The issue of gender is a conundrum for the Compassionate Community's movement and has so far been given scant attention in the literature. If one of the desired outcomes of the movement is to enable a whole of community response at times of need and crisis, then it is fair to say that this response must include women and men. Otherwise the movement risks further exploitation of unpaid labour as well as re-inscribing the notion that caring and community work is women's business (Morgan et al., 2016; Sharma et al., 2016; Swinkels et al., 2019; Wakabayashi, 2006).



Fig. 19 [Digital image of woman in communication] [11.2.19]

Women dominate the unpaid labour market in countries like Australia, spending nearly twice as long as men on unpaid work activities (ABS, 2015). The majority of community and caring work is carried out by women, who represent 7 in every 10 primary carers (ABS, 2018). Similarly, women dominate the so-called caring professions accounting for 84% of workers in community service industries, as compared to 45% of workers in all industries (ABS, 2011). Where men are present, they disproportionately appear in positions of authority, management and decision making (Whittock & Leonard, 2003). The same is true in terms of community workers, mostly women in a poorly paid profession with few systems of support. The movement needs to become more inclusive and demanding of equality and its leaders need to challenge the notion that this work is the domain of women, perhaps led by men. Men need to step up to this, often unpaid, work if indeed it is to become a whole of community response to times of need and crisis.

There is plenty of evidence that men can do it, such as with the Aids epidemic (Munro & Edward, 2008 & 2010), and in our previous research projects men were often primary carers, or members of caring networks for people at the end of their lives (Horsfall et al., 2012 & 2017). There is also plenty of literature referencing the different attitudes and behaviours men adopt to cope with the challenges of caring (Evans & Jones, 2008; Morgan et al., 2016), including strategies adopted to preserve a masculine identity (Lupton, 2000) while performing so called 'women's work' (Calasanti, 2007). It makes sense, then, that if men and women perform caring work differently (McDowell, 2015; Morgan et al., 2016), they might also want to apply different gendered approaches for an all-inclusive Compassionate Community. Men's Sheds are a good example of how a grass roots community movement, led by men, provides a supportive environment for older men to come together to alleviate social isolation and loneliness (AMSA, 2017; Hansji et al., 2015). Although the participants at times considered options that would be more inclusive of men: *Groups are talking about engaging men, more bloke friendly, Friday nights at the surf club, local bowling club...* [RA Field notes 7.8.19], broadening the movement is something men need to take responsibility of themselves, for themselves:

I went to the Men's Shed a couple of weeks ago, I did a talk about Coffin Club – they were interested... Anyway, this guy rings me up and he wants to support his wife to die at home and all the do-it-yourself things... his wife died a couple of days ago. Things didn't really go as he would have liked... what I've since found out is the hospital did things they have never done before and they did it because of the Compassionate Community stuff that their staff had been to. While it's not ideal in our world, what they are doing now is when I get back, we're going to have a conversation about "how do we do this better next time". And in that conversation, there'll be [Jack], there'll be us, there will be the funeral director and there will be a specialist palliative care team. So when that stuff happens, I know that what we're doing makes a difference. It is making a difference [FG2].

In addition to the issue of gender there was some data which questioned the inclusivity of Compassionate Communities' strategies overall: *I have to say that I don't think it's inclusive... I recognised straightaway early in the piece that we had a need of a vulnerable group of people, that grief, isolation, all the things we talk about – happen to these people. It's part of their everyday life but they're not part – they don't turn up to the meetings, they're not part of any of the ComCom stuff... I'm working with a disability group to build their capacity so they can actually join in. I want them to join in ComCom stuff, but we can't get them. They've got practical issues about transport, about all sorts of stuff. They can't participate [FG2].* Other issues about the apparent whiteness and middle classness of the movement were also raised: *Why is it so white middle class? [FG2]* along with the recognition that some of the promoted activities were not inclusive as not everyone is interested in *coffee things [FG2]*. Although this particular issue was not a strong theme, it is worth noting here as a concern as the movement expands and moves forward.

The tensions of leadership in community development work

An early frustration for the participants was the seeming reluctance from community members to take early ownership of the ideas and initiatives that emerged amongst the group. At the beginning the responsibility to follow through on such matters, more often than not fell on the community leads: *We've already got quite a lot of connections, but not strong commitments from people [RG1]*. Extending this sense of responsibility and ownership to the greater group proved challenging.

Tensions around leadership were also linked to the theme of questioning legitimacy and that of Gatekeeping. As a new venture and one clearly challenging some fairly powerful institutions and ways of doing things, performing leadership roles placed people at risk of being ridiculed, challenged, ignored or silenced. It also directly challenged people's beliefs and knowledge about how to do community development: *It should be led by the community. But I'm waiting for that community person to come and do that something [RG2]. I already feel like I have to resign and we haven't started yet, and I'm looking around the table and thinking we need everyone to step down and a whole new group of people to actually take over the project already, because I just think it's way too health focused for my liking [FG1]*.

The theory and available models of leadership are somewhat lacking in meeting the needs of the participants in this project. This is problematic as undoubtedly the

participants were leaders and were chosen to be leaders. However, the dominant leader-centric perspective of one person who has power, influence and control (Kniffin, 2019, p.1) is at odds with the community development perspective of participants which calls for a collective model of leadership (see also pg x of this report for more on this sub theme).



Fig. 20 [Digital image of gnomes gathered around camp fire] [RG3]

Interestingly these tensions became less prominent over the course of the research. By the time of the second focus group, it was evident that community members had begun sharing responsibilities. Perhaps this was because, by then, leadership had also become an activity, not a position (Kniffin, 2019, p.153). The participants were quite joyous and felt a sense of achievement as they spoke about this:

I'm not leading at all. I think they all know what's happening and I don't make any decisions without the rest of the group. If someone wants to do something else, I'll say, 'Well let's ask the rest of the group'. So, I'm by no means leading [FG2];

That was Compassionate Communities in action. Nobody was driving [FG2];

We're not drivers – we're all hanging outside like cats, going, 'Whod!' [FG2].

So perhaps a measure of impact or a milestone in this work is the democratisation of groups that are established to do this work? One of the main aims of community development work is to move from the 'I' to the 'we' (Westoby, 2019) but of course this takes time as group trust is built and people feel able to take on more responsibility. It also takes courage to do so.

What is this thing ... Compassionate Communities? [RG3]

This sub-theme was present across the life of the project. Although the initial invitation to the participants in this project was very clearly located in the end of life field, members of their communities and participants themselves questioned the meaning and purpose of 'Compassionate Communities'. The central tension was: *is this about caring at end of life, or, community compassion more broadly?* Many, although not all, of the participants had an understanding of Compassionate Communities from the literature, or from attending conferences and workshops. This understanding was usually informed by the work of Allan Kellehear, where the work of Compassionate Communities (and Cities) is mostly concerned with caring, dying, death and bereavement (Kellehear, 2005 & 2013).



Fig. 21 Winfield Martin, E. (n.d.). *The Death of Cock Robin* [illustration]. [RG2]

Participants reported that at the beginning stages of their work, when community meetings were happening and groups were working to define the vision and focus of their Compassionate Community, questions and concerns about the term and the focus it implied were commonplace:

I have been reminding the GroundBreakers that they originally signed up for broadening EOL as I'm getting questions about it. The [...] community have expressed interest in more than just EOL – this was also raised at the [...] community meeting [RA field notes 12.11.18].

The term *compassion* could be misleading as community members at times expected a broader focus than just end of life and were at times shocked to encounter the narrower version in community and town hall meetings, although this could easily be addressed by clearly communicating that in this instance Compassionate

Communities is about end of life. Some community members lacked understanding of the concept of Compassionate Communities as something separate to service provision: *I've been to so many community meetings and people tell me, 'But we've got a range of care, we've got services. Are you duplicating what's already there?' [RG1].* One participant informed the research group that a great deal of her early work on this project was defining and explaining the concept: *A lot of the work around Compassionate Communities is just informing people as to what it actually is because it can be very difficult to do – you use the word 'compassionate' and it's so wide-ranging [RG3].* Although this participant found explaining and informing people about Compassionate Communities to be difficult others relished the resulting conversations: *'This is not what I thought it would be. You're talking about death, dying, da da da... I kind of thought that it's what I thought compassion is – not what you were saying it is'. So we had an amazing discussion about that [RG2].*

For others the focus on death was either too narrow:

and she said, 'I don't like – I'm not comfortable with this thing about Compassionate Communities'. She stood up and she said, 'I think there should be compassion overall and I'm just not comfortable. And she didn't come ever again and it triggered a whole lot of other people to respond saying, 'I actually feel the same too' [FG2].

or too challenging:

'Is this just about end-of-life? Well I'm not interested. I'm not working in that space' or 'End-of-life is more for older people', 'End-of-life is not something I want to talk about right now' [RG3].

and some people were highly suspicious:

'Are these people just religious nuts handing out stuff? Is this about church or something?' I did get that recently by the way [RG3].

The participants, while voicing frustration and at times questioning their own beliefs about what compassion means, on the whole were clear about what they were working towards and they actively put strategies in place to deal with this issue. For some the strategy was to ask the community what they believed Compassionate Communities to be about: *So I'm pushing back saying, 'Well you tell me what ComCom's about... All we're doing is facilitating what this group wants [RG2].* Others stopped focussing purely on end of life and: *just went back to kindness and compassion [FG2].* While others recognised that while the focus of the work was end of life, developing Compassionate Communities meant developing a better community and to achieve that they would focus on celebrating life:

*Whereas we're really trying to rebadge that and talk about it as this is a real celebration of life and it's also about recognising that people **do** die at different stages and if we can support people throughout their different stages throughout their own journey of end-of-life, then that makes us better as a community [RG3].*

Some of this lack of clarity is because both compassion and community are very broad terms with little consensus in the literature and the groundwork in this area is new and emerging. Additionally, the strategy of community development focuses on a ground-up process. Although the process is often well described, it is accepted that the work is fluid, unpredictable and often not quite under control. This is compounded by the fact that there is another Compassionate Communities/cites movement, *The Charter For Compassion*, emanating from the United States of America, which does not focus on end of life but rather those things more usually associated with community development and activist work: homelessness; violence; poverty and climate change for example (see their website at: <https://charterforcompassion.org/>). This movement is also international, has been promoting a Compassionate Cities Charter for over 10 years and has a broad set of aims which explicitly challenge the foundations of the current late-capitalist neo-liberal democracies many of us live in. For some of our participants this resonated with their own values and/or politics. At least two of our participants were approached by members of this movement over the course of the project. We are left wondering if there is some strength to be gained by the two movements working more closely together – at the very least formally recognising each other.



Fig. 22 [Digital image of too many cooks] [11.2.19]

Exhausting and exhaustive expectations

Over the course of the project participants experienced an enormous sense of responsibility and high expectations. These expectations were of themselves; of their processes; of others; and, from others. It appeared at times as if there was too much resting on the one person's shoulders. We wondered where these expectations came from. Was it the tension between process and outcome, feelings of lack of control, the lack of resources? Often this work was being done on top of participant's other work, so time was an issue. Was it the weight of the work, or expectations from the organisations people worked for, or the added dynamic of being 'researched' and the subsequent pressure that placed on participants to perform? In reality it was a complex mix of all these factors, which at times led to feelings of overwhelm.

Community development work is overwhelming at times

Look, I've been doing lots of things and I think that's probably why I'm getting tired [RG4].

In the second focus group participants were able to reflect on their experiences over time. For some the nature of community development work, with its focus on process rather than outcome led to feelings of overwhelm: *community development work is never ending, goals are always emerging, so there's never a clear end point [RA field notes 7.8.19]; yeah, it can feel really intangible and amorphous and overwhelming... You know it's a thunderstorm of overwhelm that you feel like you could be working in [FG2].*

In community development work there is a tension between big picture thinking and on the ground detail. The process takes a long time when you are doing the groundwork and it's hard to negotiate moving between working on the ground and holding the vision, or the big ideas over time [RA field notes 19.2.19].



Fig. 23 Fairbank, E. (2019). *Slow and steady* [photograph]. [RG4]

Others experienced a very fast rate of change which was problematic and compounded if doing this work in their own time:

But it comes with pain. It's backbreaking. I hate being the lead of Compassionate Communities... because the pace of change has been big, and not everybody agrees, and our society tends to say 'well let's just cop the shit at [omitted]... and I can't deal with all the other high level stuff... I'm not, whatever [FG2].

The 'I'm not, whatever' statement at the end of this quote perhaps speaks to a lack of recognition, or role status when not paid or in a formal position.

For community development workers, community work is always there demanding their attention. The working hours blur and every interaction with community offers an opportunity to connect, gain insight and network. Participants spoke fondly of the enriching impromptu conversations they'd have with community members at parties and on the street, but while one's identity becomes fused with community work, so too does the tendency to feel personally responsible for things not progressing (Kenny, 2019) as well or as quickly as one had hoped:

Involvement is not something that one can neatly close the door on at 5pm. In fact, for a lot of activists it might be a case of literally opening the door to the home-cum-office-cum action headquarters: papers on the bed, meetings round the kitchen table... Operating in this way means there's no getting away from it. Though all this activity has the potential to enrich our lives, it is this feature of unceasing demands which creates much fuel for burnout (Shields, 1991 as cited in Kenny & Connors, 2017, p431).

Indeed, it's these blurred boundaries combined with the drive to always improve and 'do good' that makes this work relentless, adding to the overwhelm, which if left unchecked can lead to burnout (Kenny & Connors, 2017).

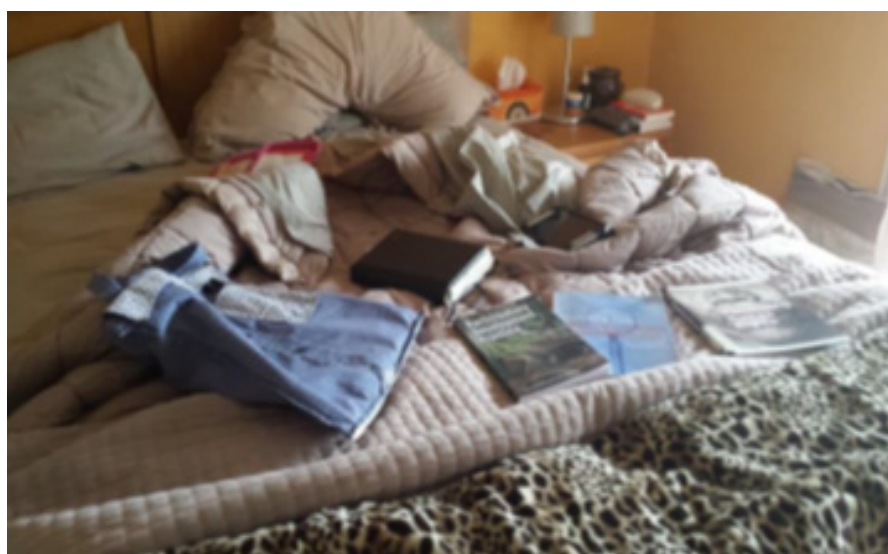


Fig. 24 Hall, G. (2018). *My Books - Seeking Guidance from Theory and Sleeping on it* [photograph]. [RG2]

There was still more to do when I went to bed - reading. Too tired to move the text books off the bed, we woke up around 3.00 am to the sound of a 'thud', the book on Human Rights hit the floor [quote from RG participant].

New managerialism: What we measure, and how we measure it, determines what we do – or does it?

The palliative care nurse ringing me and saying, 'I've done all I can for this person. I need your help now'. That's really big stuff! But it doesn't go into my form [FG2];

Within the current climate, resources are only given under conditions of surveillance and accountability; this is usually in relation to narrowly defined outcomes and indicators that are usually not very meaningful in everyday contexts (Harrison et.al, 2019, p4).

A further, at times exasperating, tension for the participants was the demand to account for their work, in a particular way. This 'accounting' could be from their employer, the community itself, potential and/or actual funders, the researchers or themselves. At the first focus group we were struck by the enormity of what participants believed they were charged with doing:

I think ultimately what we're trying to measure and quantify and prove, is does a Compassionate Community make a difference to someone at their point of need... if it does, then what does it look like and how do we build on it, how do we prove that it makes a difference and how do we resource it? [FG1].

In the quote above there is a yearning to 'prove' that Compassionate Communities work. Given that we have seen from the above that this is an amorphous, open ended process which takes time this emphasis on proof is a huge expectation. This emphasis on proof or quantifiable evidence does not come out of no-where. It is the result of the current 'new managerialist' practices within our health and social care systems, and some may argue in our society as a whole (Harrison et.al, 2019; Higgs & Horsfall, 2014).

New managerialism is imbued with defensive and prescriptive performance management techniques with a focus on audits, risk assessment, performance management, and adherence to rules and regulations. It has led to a pervasive workplace culture of "monitoring and surveillance" (Lees, Meyer, & Rafferty, 2013, p.550).

No-one argued against being accountable or being able to say this is what is working and this is how I know it's working. The difficulty was about 'what counts as data'. The following data quote demonstrates well how the culture of new managerialism and risk management impacts the work of Compassionate Communities:

I wrote like a big 15-page long story and told them all the stories... then for the next stage they gave me [a] form. It's a page. It's really heartbreaking actually... I know that the staff that have made this happen really value the stories, but we've been squeezed into... all they want is numbers [FG2].

In this case the 'they' was the funder. This emphasis on stories was a common theme throughout the research. Participants felt that it was the stories that mattered, that demonstrated impact, that explained what was working and how. In the second focus group this theme arose again leading the facilitator to encourage participants to honour the power of story and to reframe our role as one of educating others to recognise stories as data too:

*The other thing I heard you say is that the stories matter. The stories and the conversations and the shouting across the street is what matters and that's what we have to argue is **impact** We need to educate them, what you're talking about actually is impact [FG2].*

Indeed, overwhelmingly participants felt that the stories of the community, of people working in the end of life space and stories about the work, were what would drive change: *It's the stories that get to the heart and change, change people in the [organisation]. So they can then go and do things differently as well, and so then that starts to ripple out [FG2].* And that if these stories were systematically documented then the evidence for this work would be there: *when you talk about impact that's really powerful stuff and it's only through those stories and the writing of those stories that I think that can be measured [FG2].* However, there was also recognition that people working in the Compassionate Community's field also needed to be able to give the funders, the bureaucrats, the system, what it needs too: *It's not an either/or, it's an 'and'. The 'and' needs to be more inclusive [FG2].*

Although participants readily acknowledged the benefit of privileging stories as evidence, there was a tension in navigating where boundaries lie while collecting this data: *I'm finding it hard to marry the researcher's hat with the community member on the ground, trying to have every day authentic conversations with the researcher's hat in mind [RG2].* Even though this participant was specifically relating to her participation in this project, this internal conflict is certainly a real consideration for community workers as they collect and provide evidence of their work. Rawsthorne and Howard also warn that too much focus on collecting evidence might leave less time to 'develop genuine and full relationships with community members' (2011, p30).

Although the efficacy of stories as evidence was widely endorsed by the participants, there was initial concern from this participant, as to the credibility of stories retold:

I'm also worried about the credibility of the story telling – and we need to better capture those stories, whether it's pictorially, you scribe them or record them somehow because they're just so rich – I mean the stories are unbelievable. People's lives and how they've ended where they are and how they reflect back and what's really helped them at this particular time in their life and what hasn't. So we're verbalising them, we're hearing them second or third hand now – you're hearing it fourth hand. I worry about that not being seen as credible when we talk about this in a year or two years' time when we finish this research [RG2].

Indeed, there must be consideration in maintaining the integrity of these stories, not only for their impact, but to honour the people at the heart of them.



Fig. 25 Rus-Hartland, L. (2018). *Dying at home, tended to by her daughters and nieces* [photograph]. [RG2]

Compassionate Communities work, and community development more broadly, is essentially relational work. It is about building connections and strategic partnerships: between people; between people and organisations; policy makers; and with workers in the health and social care systems. This is a dramatic departure from the predominantly bureaucratic and dollar-driven health and social care systems that emphasise efficiency, cost accountability and practice drivers such as empirical quantitative research which often ignores important local and contextual considerations. In these dominant managerialist systems and cultures with a focus on rules, procedures and accountability the foundations of relationships, and an ethic of care (Gilligan, 1982), such as compassion, generosity and trust are undervalued (Horsfall & Higgs, 2014).

Lathouras et al., (2019) also found that for many, being a part of the social service system and working within managerialised roles, gets in the way of what community development could be doing. We didn't find this as an overall theme from participants although we did note that: *The bureaucratic nature of governance stopped natural organic momentum – but they have achieved great things despite this* [RA field notes 7.8.19]. This is one of the downsides to appreciative inquiry, and perhaps the current iteration of community development work with its focus on what works, or victory narratives. Participants brought up in our third research group meeting – that focusing on what works means we can miss some important elements of the work and we miss spending time developing, understanding and articulating the problem/s which are often about structures/values and systems within society. We agree with this. The focus on what works could be part of the neoliberal discourse itself, and as researcher's dependant on industry funding, we are influenced by this too.

One outcome of this new managerialism is that community development, certainly in Australia, becomes a conservative, or reformist, rather than transformist set of practices (Lathouras et al., 2019). Certainly, this was a tension for many participants who had a solid understanding of community development but were reporting to organisations and structures which did not have such an understanding. These organisations needed answers, roadmaps, toolkits, impact statements and measures of success in a language they understood, often devoid of the humanness and complexity which is the very life blood of Compassionate Communities.

Being a research participant: What we measure, and how we measure it, determines what we do – or does it?

I've felt so duty-bound to try and make something happen because you're being researched and you need to deliver. Whether that's conscious or subconscious

[FG2].

In the first focus group, when participants were asked to discuss their visions and strategies for building their Compassionate Communities, they very clearly told us they didn't know what those visions were as they had not asked their communities yet. The collective group response remained true to the spirit of community development. Their visions were to be driven by the community, they argued in true grass roots fashion: *I think vision is from the community, it has to go to the community so they can lead it. This is what we would like, but it has to come from the community* [FG1]. It immediately became evident to us that we had asked the group a very top down question. This was an important learning in the first stages of the project. The question about vision was one that was included to meet the needs, we believed, of the funding bodies. We had not been aware enough, as researchers, to realise that in asking this question we were inadvertently questioning the validity of community development. As we held positional power and rank as university researchers this was a grave error. As such, it gave rise to an on-going research question about this research *what effect does being part of a project have on the work itself? In what ways do we (as researchers, as funders) work against the heart and spirit of the work itself?* A salutary reminder that no work is truly benevolent (see Spivak, 1994).

Of course, we had hoped to have a positive effect, to provide advice and support to people, to share resources, to provide a forum for people to critically reflect upon their work and to give the work status and respect. We had not paid enough attention to the fact that being part of a project with aims, and questions and ethics and institutional requirements would also shape the work of the participants, perhaps in constraining and counter community development ways.

Understanding barriers and tensions encountered in this work, which is at its heart is about social change work, is key to the process of change. It is, we believe, unethical to promote this work without also having a clear understanding of the difficulties people, groups, communities and organisations might encounter. Naming these, saying “Yes they do exist”, it’s not necessarily easy work – but it is important.

What does it take?

The possibility of creating a more compassionate society may sound farfetched, but attitudes and values change over time, sometimes remarkably quickly (Staudt, 2013, p.1075).

The central question for all practitioners involved in developing community practices for end-of-life-care is how to make Compassionate City (and community) policies real? (Kellehear, 2005:117) [our insert].

People need to know; this is actually not just us... it's happening around the world folks and either step up or get out of the way [FG1].

What does it take? Is borrowed from Fran Peavey, author of *Heart Politics* (1985), community developer and community activist extraordinaire. Much of her work centred on strategic questioning for social change. Her main question was *what will it take?* This is an enabling and strategic question which assumes that there is always something/s that can be done, and that people’s efforts are best placed in working towards what it will take rather than becoming overwhelmed with explanations and reasons why nothing can be done. Follow-up questions include: who can make a difference and how; what are the many and diverse ways you can meet your goals or enact your vision; what supports are needed; and, how can you get others to work on this too (Peavey, 1994)? For this report we borrowed Fran’s main question and changed it to *What does it take* to develop Compassionate Communities?

Although, as discussed earlier in this report, there was some tension in assigning the name Compassionate Communities to the end of life, loss and bereavement space.

The next section speaks to what worked for participants in translating the theory of Compassionate Communities into practice. It also encapsulates what they now believed would work for others in the future.

The community development way: A clear understanding of community development to drive strategies and actions

It was clear very early in the project that participants, on the whole, had a strong understanding of community development: *we're very much a grass roots model and we want to build our Compassionate Communities that way and come from the bottom up... we want it to be really grass roots* [RG1]. Of course, there are many ways to 'do' Compassionate Communities. What is interesting is that most of our participants did it the community development way. And we add they did it the *old* community development way which is about process, a global vision of self-determination and community centric values, not the more recent definition where community development is limited to a professional occupation (Kenny, 2019). This 'way' may have been due to the overall selection process for the participants and was certainly a key attribute of the NCCF lead and the NBMPHN lead.

How participants spoke about community development work was, mostly, reminiscent of the 1980's where community development arguably had its heyday in Western democracies: *the impact is the process it's not the end result* [RA field notes 7.8.19]. We found that participants resisted or re-framed more current terms and practices such as community engagement or capacity building. We wondered if the participants were reimagining and re-radicalising community development practice (see Lathouras et al., 2019) through their work across Australia?

Similar to Gómez-Batiste et al.'s (2018) work, although on a smaller and more diffuse scale, the pulse of their community's needs (Rawsthorne & Howard, 2011) drove participants as they consulted with their communities; explored their values; initiated community planning; brought people together to build connections; and provided the space for people to share stories. Participants purposefully made this process accessible and fun, while avoiding the 'formal stuff'.

One of the first steps in community development work is to organise and mobilise the community. As such, participants built support from the ground up, often one step, one person at a time:

We're garnering support – it's a bit like network selling I call it - every time we speak to someone we then get them to bring a couple of extra people into the fold and then those couple of extra people will bring other people to the fold [RG3].

The participants shared leadership with their communities by mobilising their members to take lead roles; by being liaisons and advocates for them; and inviting them to meetings with local organisations, governments and health departments: *this kind of presentation to a minister... myself and three of our group being invited to a high level meeting with the [state] Government... We got 30 minutes to present and each member of our group had a little bit to say. They stood up – oh it was just amazing! It was so powerful* [RG4].

Critical to the success of their community, was the generation and allocation of formal resources and creating opportunities for increasing bonding and bridging ties (Leonard & Onyx, 2003; Rawsthorne & Howard, 2011) between their community

members: *I am seeing changes in terms of people knowing about each other, people working together, people having conversations with each other – that whole thing – there’s all these different groups but they’ve never spoken to each other. So we’ve been an enabler for some cross-fertilisation, which I think’s helpful. Certainly, people coming to this table together and we’ve had some good meetings between formal and informal groups to explore what the world could look like moving forward [RG3].*

Fig. 26 Ter Haar, K. (n.d.). *Put Learning in the Hands of Students* [photograph]. [RG3]



They drew on the relevant talents of their members and nurtured alliances that gave their members the confidence to support each other and lead initiatives within the community: *some of these new people that have come along are creatives and what they’re adding to the mix is they’ve always been good at cultural change and social change and they’re really good about doing things without very much money or how do you find ways to get money. So we’re learning a lot from them and we’re also learning a lot about how do you have the conversation? You make it fun. So we’re writing some applied theatre skits [RG3], and a health participant: being like a liaison person or an advocate, and part of that – getting our Compassionate Community group to be on our End-of-Life committee in our health district. So they come along to that meeting once a month and they can see evidence of what’s happening in our district – all the good, the bad and everything. And they also – the Compassionate Communities group are a standing agenda item in that meeting, so they can also update the group with what we’re doing out in the community... It’s a good relationship where we can work together. They can see what the problems are and if they want to work towards it, they can but we’re working together which has been really good [RG4].*

The participants sought conversations with key people; partnered with organisations; and found the right people to promote them. Some established alliances with GP’s to foster further community connections. They tirelessly built relationships and stood vehemently by *that old grass roots model if it doesn’t work, rethink it, learn from it*

and try again [FG4]. They persevered: and that's what it is – you just find other ways of doing things when that barrier comes up. You just try another door for something [FG2]. This perseverance often paid off: at the first public hearing we were invited as a witness. I've got to say we didn't exist before and we were invited... that's got to be acknowledgement of what we are [FG2].

They advocated for, and promoted, their Compassionate Communities through social media; local newspapers; media events; and word of mouth. They found it important to develop one-line value statements that defined what their community stood for, and devised scripts to use as guides for members to open up conversations. They built relationships with people; made themselves public; wrote submissions; applied for grants and raised funds. All of this is community development work. All of this was work towards developing Compassionate Communities the community development way. And it is work which takes time:

Taking it slowly is essential, need to let it happen organically not make it work overnight. Give people a chance to invest in change through the slow growth/organic common experience [RA field notes 7.8.19].



Fig. 27 [Photograph of sprouting asparagus] [RG2]

Deliberate communications: Using language, being strategic

Anyone that wants to actually do community work is going to need to know how to pitch it. Isn't that just the forever issue with community development: how to talk about community to rich people who don't give a shit? [RA field notes 5.6.19].

So I actually could only answer things with more questions ... I guess the learning from that was how do I talk about it? [RG2]

In many ways the participants learned to speak both ways. By that we mean that they had to speak in a way that was inclusive of, and made connections with, everyday folk in their communities. At the same time, they also needed to speak, and sometimes

be accountable to, service providers, policy makers, local politicians and medical professionals etc. What is important here is that this was a deliberate strategy of the participants. They were very conscious of how the language they adopted shaped their practices (Rawsthorne & Howard, 2011) and the practices of others. They had a very clear understanding of the power of language. Sometimes this need to speak both ways was exasperating as can be seen in the quote above, but mostly participants were good humoured taking it in their stride: *we didn't even call it committee – we just said the group, we're meeting and whoever wants to join in and wants to do something for this* [RG1].

They found humour in the back and forth's required:

They said straight away 'no meetings.' Now it's really funny isn't it 'cause this is a meeting but it doesn't look or feel like a meeting... and they said 'no coffee meet-ups' but everyone is meeting for coffee [RG3].

The communication strategies they adopted in working with the community were decided by the nature of the groups people were working with:

We don't use PowerPoints. We never use handouts. We try to be exactly the same – I try to be exactly the same as the folks I'm working with, so we just kind of don't do the formal stuff [RG4].

Sometimes this meant that talking about Compassionate Communities themselves was not always the best way forward:

Yeah it's difficult... if it's genuine community development work, and I know people have done this, you adapt the language that best seems to fit that community. So you might have to abandon this idea of Compassionate Communities along the way if it's not the language that the majority are responding to [FG2].

On the other hand, participants were also strategic when they needed to present information differently in order to be heard and taken seriously by funders, or institutions, for example: *measuring impact is not as crucial as describing the process... recognising that what we do has impact, there is a strong impact from our work – it's just wording that in a language that speaks to the funders* [RA field notes 7.8.19].

And: *when I come in with a story to the board I sometimes worry 'is that going to be enough' so I try to make sure I marry it with the data – the metrics that they want* [RG2].

Some participants also found local resources to help them communicate differently: *she's a really savvy business/PR person... and she has taught me a lot about getting communication out there* [RG3].

Towards collective leadership: Moving from the 'I' to the 'we'

We are the right people at the right time doing the right thing I feel... and we step in and we step out. If we have to step out, we step out... Have you ever done TaKeTiNa...You know what that is, you have the circle and the circle's still going and you can step in and you can lie down and you can get up and you can come back in. You can take a break and go out and walk around but then you come back in the circle – we're all still here, have you noticed? We're all still here holding the circle [FG2].

And I can't keep up because we've got that many little groups of people that are meeting and I'll get a message saying, 'We need to talk you'" [RG3].

While Kenny (2019) stresses that community development workers must encourage community members to speak for themselves, rather than adopt the role of 'leader', she acknowledges the difficulties and tensions of not acting as the spokesperson when facilitating the group. As we described earlier, participation in the projects caused people to feel a certain pressure for their communities to perform, which in turn encouraged them to perform leadership roles. They had, after all, been labelled Compassionate Community *leads*. Navigating the nuances between leadership, facilitation, stepping out and stepping in, proved a challenge all round: *they can do it but I'm in the way when I'm leading and it's not sustainable [RG4]*. Leading, did not sit comfortably with most participants but they held the tension that they needed to drive the group forward. When community members began taking their own action, it was met with a sense of relief: *[It's] really exciting because local members of the community are taking a lead role [RG3]* and, *there have been moments when somebody has gone ahead and done something that perhaps I thought I should be doing, I should have control of... and it's just fantastic really. It's just what you want to see. [RG3]*. By the time of the 4th research group meeting participants reported that their "I" identity had finally transformed into the collective "we" of the group identity: *I'm still part of the group but everyone else has really stepped up and it's taken off and I've stepped back. That's been positive [RG4]*. It was a sign of success as collective self-determination began to emerge.

However, there was still some on-going tension regarding individual leadership and collective self-determination. The more dominant and usual forms of leadership were reflected upon as not being the most useful for developing Compassionate Communities: *that's pretty important learning for ComCom... I could see that leadership style isn't the best for the group [RA field notes 6.11.19]*. However, most participants were quietly questioning how much to, or not to, lead the community: *and am I any different to that big hand in that first photo that has their agenda and we might not agree with that agenda but I'm doing much the same thing. I'm leading too much [RG4]*.



Fig. 28 Waters, G. (n.d.). [Digital image of hand leading a crowd]. [RG4]

As was seen in the section the tensions of leadership in community development work many of our participants were hesitant 'leaders' of this work. Some of this hesitancy was due to the nature of community development where the 'correct' role is one of facilitator or mobiliser. However, we suggest an alternative and hopefully more useful way of conceiving leadership in this work. First, leadership, like community, is a set of relational social practices. One *does* leadership, or not, and one can only do leadership in relation to others, so it is also a relational practice. A second reason that the participants may have felt hesitant is that there is little or no language, or framework, of collective leadership yet this is what most participants hoped for and exercised.

The notion of collective (shared or diffuse) leadership can provide a common language and framework that would be useful as it centres on leadership practices and action/s rather than individual people as leaders.

The [c]ollective models align with the "Leadership-as-Practice" movement, which is based on the understanding that "leadership occurs as a practice rather than from the traits or behaviours of individuals" (Raelin, 2016, p.3) ... The theoretical understanding of Leadership-as-Practice and the collective nature of leadership are on the forefront of leadership scholarship and are still emerging (Kniffin, 2019, p.19).

The, also evolving, Compassionate Community practices are then well placed to both contribute to and use these emerging collective models. Within the emerging literature the "phrase 'collective dimensions of leadership' signals the importance of shifting attention from the single 'heroic' leader to the emergent processes and practices that help actors interact, co-construct meaning, and advance a common goal unattainable by themselves" (Opsina & Foldy, 2016, p.1). The focus then becomes one of having a system of decentralised decision making, initiating mobilising and maintaining networks of relationships and distributing authority horizontally (Opsina

& Foldy, 2016; Kniffin, 2019; Bunce & Hendry, 2019). Here roles of leadership are held lightly and people can step into them and out of them as appropriate and needed. Our participants without exception were delighted when this stepping in and out, up and down, eventually began to occur in their communities as can be seen from the data so far. They also set up systems to enable this: [...] *group have a folder of action points, flyers etc, they present at each meeting. Different people take it home, it's not [Susan's] folder. It's a core action group within a wider group* [RA field notes 11.9.19].

In their work in Scotland, Bunce and Hendry (2019) also recommend a new vision and set of practices for leadership in this area and advocate for authentic compassionate leadership and for the development of collective impact through multi-level collaborative leadership. From our research we would also advocate for this as one strategy to ensure that leadership is valued and not sanitised out of Compassionate Community development work. However, it is a certain sort of leadership that should be developed and centred; one where responsibility and authority are shared within and between networks and communities and one where it is the common goal, or vision, and sets of supporting actions which knit the groups, networks and communities together (Kniffin, 2019).



Fig. 29 Leunig, M. (2014). *The Woes of the Whirled* [illustration]. [RG3]

Reflective and collegial spaces for people working in precarious places



Fig. 30 Seuss, Dr. T. (n.d).
[Illustration of The Cat in the Hat
character]. [RG2]¹³

I think it's a multi-faceted, multi-pronged approach and it's great that we have this sort of diversity among the GroundBreakers... it just means we can flesh out what works and what doesn't work. It's a beautiful thing [RG2].

We have borrowed the term 'precarious places' from Lathouras et al. (2019) who, using a participatory action research process, researched with 33 Australian community development workers (see also Westoby et al., 2019). They used the term to describe the position of people employed to do community development work and how, in attempting to re-radicalise community development, workers could be in a precarious place as they were enmeshed in neo-liberalist organisations dogged by managerialist practices. As researchers and advocates for radical community development in their case, and Compassionate Communities in ours, it is salutary reminder that often the people expected to do this work are indeed in a precarious place. Perhaps in this project doubly so as they were working to do community development, already a marginalised practice, to implement Compassionate Communities which deliberately challenges the dominant discourse of medicalised death, dying, caring and grieving. As such it is important that those advocating Compassionate Communities (and/or Cities) galvanise their support behind the frontline workers in this movement, in practice.

We found, as did Lathouras et al. (2019), that enabling conversations that foster critical consciousness and solidarity-building is fundamental. The forum and the research meetings provided places and spaces for this to happen: *useful to kind of have those conversations around so that we can all see how we can support each other [RG3]; having a network and supporting each other in this work is really helpful [FG1]*. Being part of a national forum with a respected not for profit organisation supporting them was also important for participants. This support was either in terms of direct action

¹³ Image researchers included in RG2 summary to participants.

calling upon expertise: *how we as a group move forward, I think has proven to be somewhat challenging. We've actually had [representatives] up from GroundSwell to try to help us with some of that [RG1] or that being part of a supported network was important as participants did not feel alone, they were part of something bigger: They're holding the megaphone and so, they've got our back I think? They're holding events like this [National Death Literacy Conference] you know, it's nice to feel part of a network [FG1].*



Fig. 31
[Photograph of
flock of geese].
[RG3]

In the pre and post social network mapping exercise at the commencement and conclusion of the project, we saw an overall increase in the strength and number of ties and relationships between participants. However, it was not as big a change as we might have hoped for after 18 months' work. Stronger connections were between people who had had physical contact, which suggests more opportunities to be face-to-face would be advantageous. That said, an informal support network did function in the background as the NCCF lead, WSU researchers, and participants themselves provided emotional support, beyond any required practical support. This was mainly through phone and email correspondence, however the NCCF lead also travelled to community locations when she felt it would be helpful to be there in person. This provided a backbone of support throughout the project as different avenues and *reflective and collegial spaces* were available when and if participants needed them. Engagement was more evident amongst participants who developed a familiar rapport through frequent communications, and from participants themselves reaching out for advice or guidance. Concerns for wellbeing along with accolades and reassurances were observed both during research meetings and confidentially through correspondence between participants and researchers.

Another benefit of these reflective spaces which enabled the participants to share their work, the ups and the downs, was that as researchers, we were able to feed

emerging themes back to the NCCF lead to shape their practice and the support offered in the forum. For example:

1. Suggesting a monthly check in between GroundBreakers and the NCCF lead to catch up on their progress and activities, leaving research meetings free for more specific conversations about data and evidence;
2. Scheduling regular check-ins between GroundBreakers and the NCCF lead (via text, phone or Zoom) to offer a supportive structure that doesn't rely on GroundBreakers having to contact the NCCF lead;
3. Suggesting the GroundBreakers draft a report to *take stock* of their progress using data they'd collected;
4. Instilling amongst the GroundBreakers that they have the expert knowledge – *they're in it, they're doing it, they're the experts*;
5. Giving the GroundBreakers permission to not do anything for a while to overcome feelings of overwhelm that the researchers noted towards the end of the first year;
6. Offering validation and reassurance that people know they have done good things. To praise their differences, strengths and diversity;
7. Recognition of concrete things now happening that were not before – overcoming the negativity when GroundBreakers spoke of not having changed people's hearts and minds.

In addition to being collegial spaces for support, encouragement and knowledge exchange, the research group meetings were also designed to support participants in collecting their own data about what was successful, or not. Throughout research meetings we checked in on how participants were finding the data collecting process. We encouraged participants to recognise the kind of evidence that could back up their process and findings, and to reassure them that it was not as daunting as it sounded. In fact, most were doing this instinctively anyway it was just getting used to thinking about it as data and evidence, whether it be attendance forms; notes in journals; or email threads. Most participants though, found it difficult to allocate the time to organise and categorise their data. Others struggled with the notion of collecting 'evidence' from the honest and heartfelt day to day dealings they had in their communities, as though they might have had a hidden agenda.

It's hard to marry the researchers hat with the community member on the ground with the researcher's hat on [RG2].

I do not have a 'research-mind' I find all this SO 'Duh'. It is so much about common sense - ComCom goes back to tribal living, village life. It is how we are MEANT to live! Why research it? Research takes time away from what we can DO and gives into a society I dislike being part of. Yet, I DO understand the need to forge ahead - simply because we live in such a society [RA field notes 16.10.18].

I feel intimidated by the words 'collect data' [RG2].



Fig. 32 Read, N. (2018). *The creative chaos of community* [photograph]. [RG2]

At the same time participants acknowledged how data helped them check in on their integrity as community workers and gave them an evidence base to guide their actions: *[it] supports the activities... the direction we go in next, a cycle of evidence – activity* [RG2]; *we are pulling together all that data and we'll catch up with the group again next week to try to work out what we do next and where we go from here* [RG2].

The notion of precariousness is seen as a defining feature of life in 2020, 'we live in precarious times' has become a truism. One act of hope in the face of this precariousness or uncertainty is for people to work together, to engage and activate 'the citizenry' around particular issues, such as Compassionate Communities/Cities. However, "the ability to engage as a community of citizens is too often thwarted by policies that privilege economic interests over the wellness of those affected" (Cristal et. al, 2020, p.1). One aspect which could be introduced to the reflective spaces we are talking about, is critical reflection on the larger social-political-historical context. This could help people doing this work to understand the forces they are up against in addition to building solidarity and knowledge exchange. As Compassionate Community work is deliberately about relationships, building social ties and collaborate action it flies in the face of the dominant individualistic discourse and therefore the people doing the work are in a precarious position we contend, regardless of their organisational, or non-organisational positions. We need to avoid the frontline workers becoming part of the precariat, a rising class of intentionally marginalised people "set aside with one purpose—to lessen corporate risk with workers absorbing insecurity" (Arnette, 2020, p.1).

In the face of all of this it was heartening to see that in one state (Victoria) two of our participants established the Victoria Compassionate Communities Network, supported by La Trobe university.

Our voices, our stories: Sharing stories of success

Personal stories and social histories of resistance and change... need to be widely shared. Otherwise we are left with the impression... that only extraordinary heroic people can get involved and make a difference

(Marino, 1997, p.128)

We need to critically engage with what counts as knowledge and evidence. We need to reclaim our subjugated knowledge(s) derived from contextualised, thick meanings emerging from our work with communities (Rawsthorne & Howard, 2011, p.141).

Sharing stories of success is an enabler of community development. It can be a deliberate strategy used to encourage others to act, to join the work or to be inspired to start something similar in another place. Stories of success throw out threads of possibility for others to catch and use. They demonstrate that change can happen and focus energy and attention on successful actions and reason for change (Horsfall & Pinn, 1999; Pinn & Horsfall, 2000). This research was deliberately designed to enable participants to share their stories. We directly asked them to focus on what was working and how they knew something was working. Interestingly, when directly asked what was working or what had changed participants were very reticent to claim success. They did not see the changes made in their communities as change, or they did not initially value what had been accomplished: *Thank you very much Debbie. You know I haven't considered that a change but I suppose it is [RG3]*, and: *It's a bit early to tell but I think the change certainly – maybe it's not a change maybe we've just created the space – is people want to talk about this generally. If you create a space and you invite people, they come. They'll talk and they'll share their experiences [RG3]*. This is understandable as the already existing discourses and tools for measurement can negate or trivialise the work they are doing and how they are talking about it. Additionally, the words community and compassion are not highly valued in the end of life space even if they are 'having a moment' (Zaman et al., 2018). So, sharing and researching stories of success is an important strategy for change and sustainability:

I'm just really touched by hearing what everyone says but please don't beat yourself up. I mean I've got to the point where I thought "everything I'd done for the last 18 months was like the pin had been pulled out and



Fig. 33 [Photograph of young girl holding thumbs up] [RG4]

everything was a house of cards". It was all collapsing down. But I actually know that it's not aligned to me and that things are still there and will still happen whether I'll still be part of it or not [FG2].

In our final research group meeting we asked participants to discuss what strategies had worked for them in their Compassionate Communities and to define any critical moments or turning points they could think of. This request was emailed to participants two weeks before the meeting with the hope that people would have had time to reflect on their work in this way. This question was also followed up on in the final focus group where we emphasized 'what has worked' and cultivated a celebratory atmosphere. Additionally, the GroundBreakers presented at the 6th International Public Health Palliative Care conference in October 2019. Two of the researchers were present and took field notes during the presentations. These notes also comprise the data in the following section.

Critical moments or turning points

When discussing critical moments and turning points, some participants acknowledged that when they stepped back from their roles as leaders (for various reasons) that opportunity arose for others in their community to step up, which they did: *it's helped that I have had to go back to my old job in health... so everyone else in the group – like I'm still part of the group but everyone else has really stepped up and it's taken off and I've stepped back* [RG4]. They recognised the importance and the willingness of individuals in their community to share their stories and experiences as critical: *to see two people sit next to each other who both went, 'Oh my God! Their husbands had both died within months of each other. Both had been single mothers of really badly-behaved teenage boys...* [FG2]. They were excited to see things in their communities taking off in their own directions without the need for them to be driving it: *They go, 'We don't want you to come from [town]. We're not interested. We're going to do our own thing'. Stuff's popping up all over the place!* [FG2]. The skill though, is in being able to recognise when it is the right time to step back and in being flexible enough to step back in when and as required.

Organisations, systems and communities beginning to change?

Much of the participant's work had been about navigating barriers, opening doors, doing 'stuff' together, mobilising networks using the media and social media, often stepping outside of their comfort zones and amplifying the pearls of wisdom in the community [CI field notes 14.10.19]. As a result, participants said that service providers and organisations had begun taking an interest in Compassionate Communities with evidence of changing attitudes and practices to embrace 'the com com way': *it's also quite affirming... our first manager... said, 'I can't believe what you guys are now doing'...it's just grown what we do so much* [FG2].

Some of this change had come about due to partnerships with formal service providers: *I think it's good to keep working with them [organisation] actually and I think they are learning... And they keep wanting us to do it* [FG2]. Although it often took quite a long time, many conversations and a great deal of tenacity there was also evidence that the local health sector was beginning to engage with the Compassionate Community's work: *I've got to this point where we have developed really strong relationships with palliative care, with the GP practices – like that's huge. A GP told one of their patients to go to one of the... events the other day and I was like, my job is done* [FG2]. However, the group who reported the most difficulty was the one mainly comprised of health professionals. In this group it was difficult to get a clear vision of Compassionate Communities developed and there was very little community interest or support to do the work of keeping the group going. There was evidence of gatekeeping from

people who worked in the health sector and suggestions of deliberate sabotage [CI field notes 14.10.19].

Participants spoke about new on-going relationships with local aged care facilities: *we've attracted a lot of the staff that work in the local nursing home... they've come to learn from us and surely that's got to feed back into their work practices* [FG2], local government, schools, local Aboriginal services, Churches, service clubs, the state ambulance service and local cemeteries. In one of the communities, relationships between the community, palliative care and the funeral industry were being built as all these groups literally met around a table to see what they could do better [CI field notes 14.10.19]. In an example of developing resilience through adversity one community group had to face a very difficult and very public question about inclusion/exclusion. In response the group developed a strong values statement and set of procedures and processes. As a result of this, the relationship between the group and the health district strengthened as the district came to trust that the community could take ethical and purposeful actions at times of challenge.

There was emerging evidence that the tangible work the participants were doing was becoming valued and that they were increasingly seen as experts: *they now want us to help them build resources and do education for their staff and teach them about death literacy and do a lot of that stuff. But they're also very interested in the social connectivity side of things* [FG2]. In one community, people came from interstate to attend Compassionate Community workshops and in at least two communities' relationships were sought from the local university researchers. In another, the Compassionate Community representatives were key informants to a state government review process. In this way there was evidence

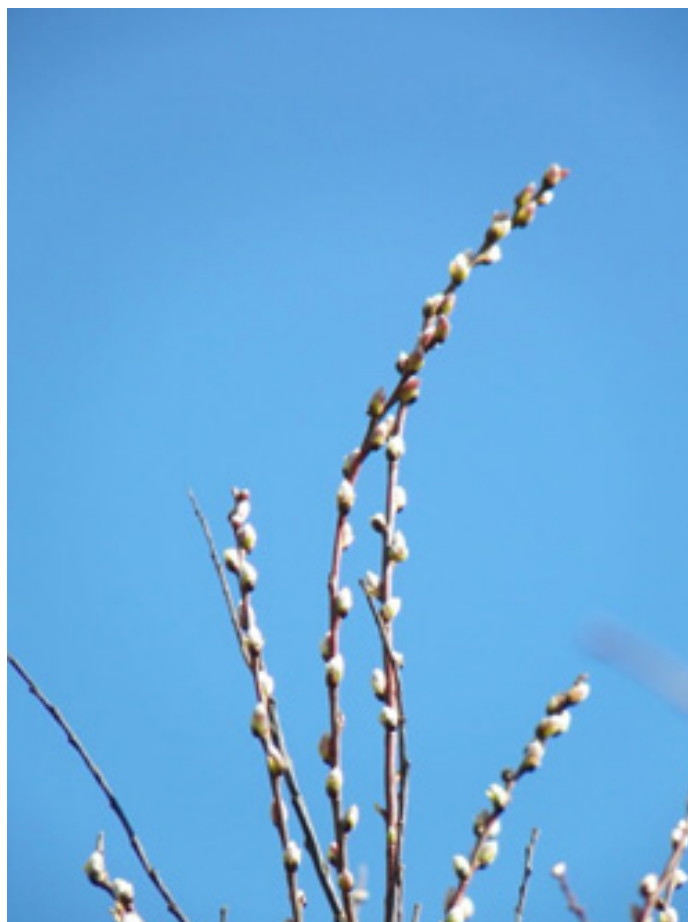


Fig. 34 [Photograph of tree beginning to blossom] [RG4]

that 'the system' was beginning to engage with this work: *it may never happen but the mere fact that they're trying to find a way to make it happen within the system, within the health system is extraordinary* [FG2].¹⁴

In addition to tangible changes in relationships between formal and informal services and networks there was also evidence of changes in the way communities came together to care for each other in times of need: *so watching our community just go, 'Right. Well we did this 12 months ago. We need to do it again'. And seeing it work even better than it worked last time and last time I thought it was awesome and this time I was blown away* [FG2]. People reported that the act of caring built relationships: *getting her as a bereaved mother to come in to help a widow, and that relationship has just blossomed because she knows what's going to happen and so they can help each other* [FG2]. Sometimes unexpected friendships emerged across usual social groupings [CI field notes 14.10.19] as people connected together in their grieving: *socially you would not have put the two together... one helped the other. 'We'll go to a movie together. How about there's a community talk' said the [woman], 'and then we could have a cup of coffee'. By the next one they'd already had their own thing going* [FG2].

Fig. 35 [Photograph of light streaming through crack of door] [RG4]



¹⁴ Two further examples at time of writing: the community lead for the NBMPHN is a member of the Blue Mountains palliative care Covid-19 working group; after a year of conversations and meetings Compassionate Communities Dugong/Sunshine Coast was successful in their EOI to join Tender Funerals Australia.

Despite a relatively short period of time and little or no resourcing in the final focus group participants enthusiastically recounted the ripple on effects of their work permeating their communities. The following quote comprising many voices shows this:

So while it doesn't feel huge, it's satisfying to know that there are ripple effects going on and I think in the space of 18 months that is pretty good... what I keep finding is absolutely everything I'm doing is having this ripple effect. I'm just staggered every week...word of mouth comes back to you. Someone stops you in the street, 'I heard this...random people saying that they know something about something through something that was emailed or someone who was at a group [FG2].

For many it felt as if Compassionate Communities now had a life of its own. The rate of movement and change was at times surprising to participants: *like there's almost a popping – it can happen in different spots – that we don't necessarily have any contact with anymore but it's off doing its own thing [FG2].* This is what the theory of community development says will happen – it is a sign of success when communities become self-organising and self-determined. The trick is to hold one's nerve through the build up until you know: ***We're not it. It is it [FG2].***

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Appendix 1

NCCF EOI Application Questions

When considering if you or your organisation should apply to be one of our GroundBreakers in the Compassionate Communities social movement in Australia, successful applicants will need to answer the questions below:

1. Contact Name, Organisation (if applicable) and contact details.
2. Outline the main reason you would like to be involved in the NCCF program.
3. On a scale of 1-5 please rate your understanding and experience of public health approaches to end of life and compassionate communities programs to support people who are dying, caring and bereaved?
4. Please tell us more details about why you responded in this way to the above question.
5. Describe your community and the current approaches to end of life. (For example, are you a rural, urban or remote community, what is the mix of formal and informal care? Where do people die? What services are available?).
6. What are the key challenges faced by people who are dying and their carers in your local community?
7. What are some of the strengths that exist in the community? (For example, there are local fundraisers for people in need, people tend to help each other, there is bereavement walking group that people use regularly, the local shops support elderly neighbours. Give examples that are not only service delivery related).
8. What are your ideas to build upon or develop if you were to work with The GroundSwell Project as a GroundBreaker community?
9. Who are you already working with and who have you talked to about your ideas? How might you collaborate with other organisations / services / individuals?
10. As part of the EOI for GroundBreakers, you/your organisation are agreeing that you will help organise a community gathering to kick start compassionate communities in your area. Can you tell us who you might invite and if you have access to a community hall or other setting to facilitate this?

Appendix 2

ABS 2016 census geographical zones used for each community location

AUSTRALIAN BUREAU OF STATISTICS - 2016 CENSUS QUICKSTATS			
LOCATION	ZONE	POPULATION	LINK
Dulong, QLD	State Suburb (SCC)	564	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/SSC30896?opendocument
Ballina, NSW	State Electoral Division (SED)	73,276	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/SED10003?opendocument
Newcastle, NSW	Statistical Area - Level 3 (SA3)	163,884	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/11103?opendocument
Northern Beaches, NSW	Statistical Area - Level 4 (SA4)	252,878	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/122?opendocument
Blue Mountains, NSW	Local Government Area (LGA)	76,904	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/LGA10900?opendocument
Bundanoon, NSW	State Suburbs (SSC)	2,729	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/SSC10670?opendocument
Central Coast, TAS	Local Government Area (LGA)	21,362	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/LGA60810?opendocument
Warrnambool, VIC	Local Government Area (LGA)	33,655	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/LGA26730?opendocument
Bunbury, WA	Statistical Area - Level 4 (SA4)	176,330	https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/501?opendocument

Appendix 3

Flyer to partake in research project



Researching the Compassionate Communities Practice Forum

Compassionate Communities is a whole of community approach to end of life care where caring for one another at times of need, loss and/or crisis becomes the task and responsibility of everyone.

Compassionate Communities and compassionate cities are emerging as an international strategy for implementing the public palliative care approach to end of life. However, there is insufficient research on how these concepts might be put into practice, especially within the Australian context. We hope that this 18-month research project will contribute to our knowledge and understandings of how such implementation might be achieved in a cost effective and sustainable way with resulting policy and practice implications.

What's involved?

- Two x 2-3 hour face to face focus group sessions with 1 key player of the eight community groups participating in the Compassionate Communities Practice Forum. The first focus group session will run at the commencement of the project and the second will be held at its completion.
- During the course of the project, 2 hour follow up meetings will take place every 3 months via phone or Zoom teleconferencing. These will include 2 self-selected representatives from each community group and be facilitated by researchers at Western Sydney University.
- To help inform discussions participants will be supported to keep research portfolios which may include: photographs, meeting notes, plans of action, reflections, and critical moments or turning points.
- At the last face to face focus group, the key player/s from each participating community group will be supported by the research team to offer their own final reflection of the past 18 months.

If you are interested in more information about participating in this research, please contact: Helen Psychogios on 02 4736 0083 or h.psychogios@westernsydney.edu.au, or Professor Debbie Horsfall on 02 4736-0093 or d.horsfall@westernsydney.edu.au

Our Researchers



Appendix 4

Participant information sheet for research and focus groups



Participant Information Sheet – General (Extended)

Project Title: *Researching the Compassionate Communities Practice Forum*

Project Summary:

The GroundSwell Project has been funded to establish and support 8 compassionate community GroundBreaker groups across Australia to be part of the National Compassionate Communities Practice Forum. These groups are comprised of a combination of service providers and active community members who have established themselves as a group of people who want to operationalize compassionate communities in their local area.

Researchers from Western Sydney University will also be involved to report on the project, and invite you to participate in a research study being conducted by Professor Debbie Horsfall, Marguerite Kelly, and Helen Psychogios from the School of Social Science and Psychology, at Western Sydney University. Additionally, Kerrie Noonan and Holly Rankin-Smith, from the GroundSwell Project are partner researchers on the project.

The research project will run for the duration of 18 months and will comprise of 2 x 2-3 hour face to face focus groups involving 1 key player from each compassionate community. These face to face focus groups will be held at the beginning and the end of the project. In addition to those, two self-selected representatives from each community will be regular members of a research group which will meet over phone or Zoom teleconference for 2 hours every 3 months on average over the course of the project.

By researching the Compassionate Communities Practice Forum, this project aims to identify and document strategies to translate the compassionate communities model of end of life care into practice; develop in-depth understandings of barriers and enablers to translating a compassionate communities model into practice; analyse changes in the participating communities and develop understandings of, and provide evidence for, engaging non-medical supports in palliative care at end of life.

How is the study being paid for?

The GroundSwell Project received funding for this research from Bupa Health Care and have partnered with Western Sydney University to conduct the research.

RESEARCH GROUP

What will I be asked to do?

You will be asked to participate in regular research meetings every 3 months for the total duration of 18 months. You may choose to collect your own research/data such as photographs, meeting notes, plans of action, reflections, and critical moments or turning points to help inform these meetings. These research meetings will be facilitated by Western Sydney University.

How much of my time will I need to give?

You will need to allocate 2 hours every 3 months for 12 months (total 8 hours).

FOCUS GROUP

What will I be asked to do?

You will be asked to participate in 2 face to face focus groups, one at the commencement of the project and one at the end. At the last focus group, the representative from each participating community group (with the support of the research team) will be asked to offer their own critical reflection on the past 18 months. These focus groups will be facilitated by Western Sydney University.

The first focus group will be held to coincide with the 2018 Death Literacy Conference held in Sydney in June; the second focus group will coincide with the 2019 International Public Health Palliative Care Conference to be held in the Blue Mountains of NSW in October 2019. This has been arranged as we anticipate that the core members from each of the 8 communities will attend both of these conferences. If you cannot attend the conference/focus group but wanted to be part of the focus group/s then alternative arrangements will be made via Zoom teleconferencing.

How much of my time will I need to give?

If you participate in both the first and second focus groups, you will need to allocate a total of 4-6 hours plus travel time.

What benefits will I, and/or the broader community, receive for participating?

The benefits of taking part in this research will be that you have dedicated time to reflect upon your role in the development of a compassionate community. In

addition, you will receive expert advice and input into developing the intervention. We envisage the relationship as supportive and mutually beneficial and hope this research will make a significant contribution to our knowledge and understandings of how operationalising compassionate communities might be achieved in a cost effective and sustainable way with resulting policy and practice implications.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?

We do not anticipate any risks to you as we are only collecting information about operationalising the CCPF and what works or does not work in your local area. We will not be collecting personal information about you or the people you are working with. There is a risk attached to working in groups though as you will be visible to other GroundBreakers. However, we do not anticipate any personal risk from this as both the focus groups and research group meetings are designed to be supportive and facilitate your work. We will also remind all group members at the beginning of each meeting about confidentiality and privacy guidelines. Any data provided to the GroundSwell researchers (Kerrie Noonan and Holly Rankin-Smith) will be de-identified to protect your privacy. If you do feel any discomfort you should immediately contact one of our researchers: Helen Psychogios, Debbie Horsfall or Marguerite Kelly.

How do you intend to publish or disseminate the results?

We will publish and/or present the findings from this research in a variety of forums such as a final report, journal articles, blogs, print media and conference papers. In any publication and/or presentation, information will be provided in such a way that we are talking generally about the CCPF, not specifics relating to you. All information will be de-identified prior to publication.

Will the data and information that I have provided be disposed of?

Please be assured that only the researchers will have access to the raw data you provide. However, your de-identified data may be used in other related projects by the existing research team for an extended period of time. Please note that minimum retention period for data collection is five years post publication. The data and information you have provided will be securely disposed of.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time without giving reason. To withdraw from the study, please inform the researcher that you no longer wish to participate. This can be done in person, by telephone or by email. However, if you have already taken part in a research group meeting we cannot destroy your data.

Can I tell other people about the study?

Yes, you can tell other people about the study. They can contact:

- Helen Psychogios on 02 4736 0083 or h.psychogios@westernsydney.edu.au,
- Professor Debbie Horsfall on 02 4736-0093 or d.horsfall@westernsydney.edu.au,
or
- Marguerite Kelly on 02 4736 0056 or marguerite.kelly@westernsydney.edu.au

What if I require further information?

Please contact Research Assistant Helen Psychogios on 02 4736 0083 or h.psychogios@westernsydney.edu.au should you wish to discuss the research further before deciding whether or not to participate.

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H12684.

Appendix 5

Questions asked in Research Groups

Questions for initial meeting

1. How will you show what you do works or not?
2. What data do you want to collect and why?
3. How we can develop in depth understandings of this process?

Questions for ongoing meetings

1. What is working/has changed in your communities and how do you know/ what evidence do you have?
2. What strategies are you developing?
3. What else do you need support with from us?

Appendix 6

Questions asked in Focus Groups

FG1

1. What is your vision for compassionate communities in your area?
2. What do you hope to achieve?
3. What will you be drawing on in the local area (skills, resources, capacity etc., relationships and connections) to realise your vision?
4. What will the community look like in 18 months?
5. What do you need from GSP to help?
6. What is your priority?
7. How will you engage the compassionate cities charter?

FG2

1. In what ways has the capacity of your community to care for each other at end of life changed?
2. How sustainable are these changes?
3. What differences do you notice in the relationships between formal and informal networks?
4. Has end of life care become more of a public priority in your community/place of working? What evidence do you have to support these claims?
5. How does what you ended up doing match your previous vision?