



Compassionate Neighbours (Hertfordshire Hospices): a qualitative evaluation

Kathryn Almack and Chloe Bennett

Centre for Research in Public Health and Community Care

University of Hertfordshire

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**University of
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Table of Contents

1. Executive summary	2
2. Background to the project	4
3. The evaluation	5
Aims of the evaluation	5
Ethical approval	5
Methods.....	5
Data collected	5
Analysis	7
4. Demographics of the project service users and the catchment area	7
Demographic analysis	7
5. Qualitative Findings	10
Staff	10
Businesses.....	14
Benefits to Community Members.....	16
Benefits to Compassionate Neighbours.....	23
6. Recommendations for future development	25
7. References	28
8. Appendix.....	29

1. Executive summary

This report provides an analysis of a qualitative evaluation of the Compassionate Neighbours project run by Hertfordshire hospices and funded by a grant from the Big Lottery Community Fund, 2019 – 2022. The independent evaluation was commissioned by Garden House Hospice Care and carried out by the University of Hertfordshire, over a six-month period (Nov 2021 to April 2022).

Qualitative data include telephone, online and in person interviews and focus groups interviews with different groups of stakeholders (total = 57), including hospice staff (N = 8), businesses (N=2), Compassionate Neighbours (N = 13) and Community Members (N=34).

The findings illustrate the value of the Compassionate Neighbours Project. This report provides evidence that the project is meeting the aims set out to:

1. Improve wellbeing and quality of life
2. Bring people together through helping patients, family members, carers, and volunteers to reconnect to their communities
3. Reduce feelings of loneliness and isolation
4. Ensure equitable access to services so anyone in need of palliative care can easily access the support they need, at the earliest opportunity

There is further work to be done regarding point 4. In part, our evidence on equity of access to and delivery of the project is limited due to the different ways in which the organisations involved have collected demographic data. **We make recommendations on improving data collection and engaging with a wider diversity of communities in Section 6.**

The Compassionate Neighbours project was developed to deliver one-to-one support for individuals in the community who were feeling lonely, isolated and/or receiving palliative care. **In all conversations with Community Members, being involved in the project has helped them feel less isolated.**

It has also enabled a significant proportion of Community Members to build up confidence to get out and about - going out into their neighbourhoods and attending social gatherings. In the words of one Community Member 'my whole life just changed for the better'.

Community Members also reported ways in which **the project had benefits for their wider relationships such as providing reassurance and/or respite for a partner, spouse, or other family members.** Many mentioned that the project took some burden of care off family members, as they knew their relative had someone visiting or someone looking out for them on a regular basis. Additionally, a visit from a Compassionate Neighbour might allow a spouse or relative time to themselves while a Compassionate Neighbour was visiting.

The Compassionate Neighbours project helps people reduce their reliance on or need for other statutory and voluntary sector services. The benefits cannot be overstated, and examples include:

- A Community Hub providing informal but valued bereavement support, particularly valued as members in the group often had met the partner or spouse of the bereaved person (who would have attended the Hub meetings prior to their death)
- A significant proportion of Community Members reported having regular contact with their Compassionate Neighbour had reduced feelings of depression
- Involvement in the project has been credited by Community Members for being a literal life saver or a lifeline

As the Compassionate Neighbours project has developed, it increasingly echoes the ethos of the Compassionate Communities approach that enable people who are lonely, or living with a life limiting illness, at end of life or following a bereavement to access practical, emotional, and social support provided by volunteers in their local community. It also extends to support people to develop friendships and other supportive links within their community and build confidence, which in turn reduces loneliness and isolation.

Through the Compassionate Neighbours project, the hospices have developed new collaborations with several organisations in their local communities. Examples include using existing community venues and a pub to hold Community Hub meetings – get together for Compassionate Neighbours and Community Members. These meetings can reduce the demand for one-to-one support and staff time in setting up the one-to-one matches between a Compassionate Neighbour and a Community Member. As the demand for the project has grown, the Community Hub meetings are a good development to extend support to more people.

Community Hub meetings could represent an important way forward for the project, with the potential of requiring less intensive staff input and bringing a wider range of benefits to Community Members.

The project has trained large numbers of volunteers to be Compassionate Neighbours; they are increasingly seen as community ambassadors. To further extend the reach of the project, Community Ambassadors could potentially organise further Community Hub type meetings. These appear to work best if organised to run at a regular time each week or fortnight. Listening to those who attended the Hub meetings, it was clear these serve an additional purpose to the one-to-one support provided by matching a Compassionate Neighbour to a Community Member. **The interactive Community Hub spaces help peers to share experiences, both happy and sad. Supporting each other in this way was evidenced to have made a positive difference and enhanced people's well-being.**

The project's collaborations have helped to build important relationships with other organisations and that allows for mutual signposting of service users which benefit a wide pool of people in the community. Further new collaborations such as one underway with a local housing organisation provides an excellent example of sharing knowledge, expertise, and resources. The hospice will share their end-of-life expertise and extend the Compassionate Neighbours project, whilst the housing organisation can share their knowledge on their local community, support services and potentially offer spaces to deliver more community-based groups. Another possibility under investigation will offer similar mutual benefits to both organisations.

This evaluation has shown that the Compassionate Neighbours project offers a space of support, company and shared learning for Compassionate Neighbours, Community Members, and other organisations and businesses. It is a key mechanism that can work alongside people to help them during challenging times, such as at end-of-life, through bereavement or times of isolation and is highly valued by all those involved.

2. Background to the project

Compassionate Communities are becoming a more common approach to end-of-life care with hospices around the world adopting the model to support those with life limiting illnesses and people who have been bereaved by developing a network of support around the person focussed on community, rather than solely on health care (Abel, 2018). The Compassionate Neighbours concept, built on the principles of Compassionate Communities, was developed by St Joseph's Hospice in East London in 2014. The Compassionate Neighbours project was set up in March 2018, by Garden House Hospice and Isabel Hospice. This was in partnership with St Joseph's Hospice and six other hospice adopters thanks to some funding from NESTA.

Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers have since collaboratively developed a Compassionate Neighbours scheme offering practical, emotional, and social support both in a one to one and group environment. Each Compassionate Neighbours project are independent projects supported by their parent hospices. This has been funded by a grant from the Big Lottery Community Fund, 2019 – 2022.

Members of the community who wish to volunteer to be a Compassionate Neighbour are provided with training by hospice staff (and others). They are then 'matched' to be a Compassionate Neighbour for someone referred (or self-referred) to the project, known as Community Members. They are provided with ongoing training and support from hospice staff.

As part of the Compassionate Neighbours scheme, the hospices have developed partnerships with local businesses who offer space, sponsorship, or staff time so that Compassionate Neighbours activities can take place and in return the hospices provide Compassionate Neighbours training and training around death and dying to staff.

The aims of the Compassionate Neighbours projects are to:

- Improve wellbeing and quality of life
- Bring people together through helping patients, family members, carers, and volunteers to reconnect to their communities
- Reduce feelings of loneliness and isolation
- Ensure equitable access to services so anyone in need of palliative care can easily access the support they need, at the earliest opportunity

Building on the learning from the first 2 years of this project, the Compassionate Neighbours Project's (Hertfordshire) focus was on three key areas:

- Continuing the Compassionate Neighbours programme – taking forward learning from the first two years and focussing on supporting the Compassionate Neighbours and Community Members post-lockdown.
- Re-opening and developing the Wellbeing Hub model to offer additional social opportunities in more areas, retaining the hospice input where available/appropriate.
- Developing the Compassionate Communities approach to bereavement and end-of-life care, through events and sessions designed to encourage and equip people to deal with these difficult issues.

3. The evaluation

This evaluation, undertaken by the University of Hertfordshire, took place between November 2021 and April 2022. It follows on from previous progress reports written by Richard Julian (Community Engagement Lead at Garden House Hospice):

- Progress Report – Community Development and Partnership Working, November 2020.
- Year 2 Progress Report – Community Development and Partnership Working, May 2021.

and a report of initial findings of a research project by Sam Murphy, Open University:

- Compassionate Neighbouring in a pandemic, April 2021

Aims of the evaluation

- To evaluate the Compassionate Neighbours scheme run by a collaboration between Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers
- To explore how Compassionate Neighbours has unfolded with a view to make recommendations for the future
- To inform future practice and to inform the development of future partnerships with other community organisations and businesses.

Ethical approval

Approvals were provided by the UH Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (ECDA). Protocol number: HSK/SF/UH/04734. This included working within the confines and restrictions of Covid-19 measures and guidance from UH Ethics Committee with Delegated Authority (ECDA).

Methods

We adopted a mixed method approach using demographic data and virtual and in person interviews and focus groups with multiple groups of stakeholders.

All participants were informed about the purpose of the evaluation and with their consent, the interview / focus group was audio recorded and later transcribed. It was explained that the transcripts would be anonymised, and all participants were assured of confidentiality.

All participants were allocated an anonymised identification number and no quotations are identifiable to participants. Files have been stored securely on password protected files on the University of Hertfordshire network, only accessible to the research team.

Three Compassionate Neighbours were also provided with research skills training to undertake telephone interviews with Community Members. All other interviews and focus groups were carried out by the authors of this report.

Data collected

Demographic data obtained from Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers, including gender, age, ethnicity (where available) and referral location was compared with the demographics of the local areas. All data obtained from the hospices was pseudonymised prior to researchers receiving it and sent in a password protected file. It was then securely stored on the University of Hertfordshire's OneDrive.

Sixteen semi-structured interviews with current Community Members, identified by colleagues at Garden House Hospice, Isabel Hospice and Respite at Home. These interviews were conducted by Compassionate Neighbour volunteers. These volunteers were provided with a two-hour training

session on how to deliver this specific set of semi-structured interview questions and a form to record responses. The authors of this report also recorded a role play interview, which the volunteers found useful. As part of this session, the interview questions and prompts were revised in discussion with the Compassionate Neighbour volunteers. For example, we had included questions about how involvement with the Compassionate Neighbours project had changed Community Members thoughts and feelings around death and dying or led to conversations with family/friends/strangers around death and dying. Compassionate Neighbours did not feel comfortable asking these questions.

All interviews were carried out over the phone and notes taken on a specified form. All notes were returned to the Research Team, anonymised and a participant number allocated to each participant. Topic areas covered included:

- How did Community Members find out about the Compassionate Neighbours project?
- What are the Community Members experiences of having a Community Neighbour?
- Has the Compassionate Neighbours project changed Community Members views of and communication around hospices?
- How has Compassionate Neighbours affected the support circle around the Community Members?
- Have Community Members heard of or attended the well-being hubs/meet-ups? (If yes, what have been their experiences of these meetings? If no, is this something they would like to attend/have more information about?)
- Is there anything that Community Members think that could be improved about the Compassionate Neighbours project?

Semi-structured interviews were carried out with [i] a current business partner and [ii] a potential business partner identified by colleagues at Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers. Topic areas covered included:

- What are partners' current involvement in Compassionate Neighbours?
- What are the enablers and barriers to being involved in Compassionate Neighbours?
- Has Compassionate Neighbours changed partners feelings of and communication around death and dying?
- What would partners like to see in the future from Compassionate Neighbours and their partnership with the hospice?
- What are potential partners current understanding and thoughts of Compassionate Neighbours?
- What are the expectations that potential partners have of a partnership with the hospices as part of Compassionate Neighbours?
- What do potential partners expect the positives and negatives to be of becoming involved in Compassionate Neighbours?
- What would potential partners like to see in the future from Compassionate Neighbours and could anything be changed to increase their interest in becoming partners?

One focus group (N=8 participants) was conducted with staff at Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers. Topic areas covered included:

- What are staff's experiences of setting up and delivering Compassionate Neighbours?
- What has helped and hindered the set up and delivery of Compassionate Neighbours?
- What would staff like to see the future of Compassionate Neighbours to be?

Two focus groups (N=13) were conducted with current Compassionate Neighbours identified by colleagues at Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers. Topic areas covered included:

- What have the volunteers' experiences of Compassionate Neighbours been so far?
- Do volunteers feel they have been supported and able to grow in their role?
- How has Compassionate Neighbours affected the volunteer's wider life?
- How has Compassionate Neighbours affected the volunteer's views and conversations around death and dying?
- What would volunteers like to see the future of Compassionate Neighbours to be?

Two focus groups (N = 18) were conducted in person at the wellbeing hubs delivered by Garden House Hospice Care and Isabel Hospice. These focus groups consisted of both Compassionate Neighbours and Community Members. Topic areas covered included:

- What have volunteers and community members experiences been of Compassionate Neighbours so far?
- How has Compassionate Neighbours affected volunteers and Community Members wider lives?
- How has Compassionate Neighbours affected the volunteers and Community Members views and conversations around death and dying?
- What would volunteers and Community Members like to see the future of Compassionate Neighbours to be?

Analysis

Quantitative data was analysed using a descriptive analytical approach to contextualise the qualitative findings and to assess how the Compassionate Neighbours project has achieved equitable access to services (so anyone in need of palliative care can easily access the support they need, at the earliest opportunity).

The focus group and interview transcripts were designed to address all the aims of the Compassionate Neighbours project. Data were analysed using thematic analysis (Braun and Clarke 2021). This involves systematically working through the transcripts and identifying emerging themes in the text. Initially, the transcripts were coded by one researcher and progressively the codes were integrated into overall themes. A second researcher verified the themes.

4. Demographics of the project service users and the catchment area

Demographic analysis

The demographic analysis is based on data we were able to access about Community Members in the Compassionate Neighbours project. We were able to obtain information about 991 Community Members across the three organisations. We looked at Community Members gender, age and ethnicity. One organisation collected referrer location, which we have included in the analysis. The level and type of data collected varied across the organisations. Comparison data was also obtained from the SHAPE Atlas, covering the following Local Authority areas:

Central Bedfordshire
East Hertfordshire
Welwyn Hatfield

North Hertfordshire
Stevenage
Broxbourne

Gender

Gender was collected by all three organisations. As shown by the table below, females are overrepresented in the Compassionate Neighbours project with 63% of Community Members being female and 37% being male. In the local community 51% of the population are female and 49% are male.

Table 1: Gender of Community Members and the local population

Gender	Local population (%)	Compassionate Neighbours population (%)
Female	51%	63%
Male	49%	37%

Age

We received age data from two of the three organisations in the project. In these organisations, 35.6% of Community Members were 80-89 years old, compared to 5.4% in the local population. Most Community Members were over 60 years old (90.6%), with only 0.4% of people aged under 30. This is shown in the table below.

There was a younger demographic of people volunteering to be Compassionate Neighbours when compared with Community Members, with 23.4% of Compassionate Neighbours under the age of 50. Most Compassionate Neighbours were between the ages of 50 and 79 (73.0%). Only 3.6% were 80 and above.

Table 2: Age of Community Members, Compassionate Neighbours and the local population in percentages

Age range	Local population (%)	Community Members (%)	Compassionate Neighbours (%)
20-29	15.2%	0.4%	2.9%
30-39	18.0%	0.7%	6.1%
40-49	17.8%	2.3%	14.4%
50-59	18.4%	6.1%	23.7%
60-69	13.4%	11.3%	23.0%
70-79	10.6%	23.6%	26.3%
80-89	5.4%	35.6%	3.6%
90+	1.2%	20.1%	0.0%

Ethnicity

Two of the three organisations in the Compassionate Neighbours project recorded ethnicity and this was only fully complete by one organisation. The below tables show the ethnicity recorded in the local population and in the project. The highest recorded ethnicity in both areas was white but there was an overrepresentation of people identifying as white within the Compassionate Neighbours project (96.79%) compared to the local population (91.05%).

Table 3: Ethnicity of the local population

Ethnicity	Local population count	Local population (%)
Asian/Asian British	31,646	3.92%
Black/African/Caribbean/Black British	18,871	2.34%
Mixed/multiple ethnic group	17,582	2.18%
White	734,997	91.05%
Other ethnic group	4,187	0.52%
Total	807,283	100.01%*

*Data sourced directly from the SHAPE Atlas- www.shapeatlas.net

Table 4: Ethnicity of Community Members

Ethnicity	Compassionate Neighbours count	Compassionate Neighbours population (%)
Asian/Asian British-Pakistani	1	0.36%
Black/Black British Caribbean	2	0.71%
Other Asian background	2	0.71%
Other Mixed background	1	0.36%
Other White background	5	1.79%
Prefer not to say	1	0.36%
White and Black Caribbean	2	0.71%
White English/Welsh/ Scottish/Northern Irish/British	266	95.00%
Total	280	100.00%

Referrer

We received referral data from all three organisations. The tables below show the top three referrers at each organisation and the percentage of referrals made by each of these sources. The full list of referral locations can be found in Appendix 1. Referrals came from a total of X organisations.

Table 5 below shows referral location into the project at Isabel Hospice. As can be seen below, for recorded referrals Social Prescribers had made the most referrals into the project. The second and third most common referral locations were from within Isabel Hospice (28%). When combined with other services within the hospice, internal referrals made up 37.1%.

Table 5: Top three referrers of Community Members- Isabel Hospice

Referrer	Percentage (%)
Social prescriber	15.8%
Isabel Hospice - Living Well	14.9%
Isabel Hospice - CNS	13.1%

Table 6 shows the top three referrers into the project at Garden House Hospice Care. Here, the greatest proportion of referrals came from Community Members or their family members (19.1%). This was followed by the Hawthorne Centre at Garden House Hospice Care (15.2%) and Herts Help Hospital and Community Navigation Service (15.0%). When looking at all referrals from within the hospice, they made up 18.8% of the total referrals.

Table 6: Top three referrers of Community Members- Garden House Hospice Care

Referrer	Percentage (%)
Self or family member	19.1%
Garden House Hospice Care - Hawthorne Centre	15.2%
Herts Help Hospital and Community Navigation Service (HCNS)	15.0%

Table 7 shows the top three referrers into the project at Respite at Home Volunteers. Half of referrals came from the Palliative Nurse (50%), followed by the Social Prescriber (15%) and Community Nurse (12%).

Table 7: Top three referrers of Community Members- Respite at Home Volunteers

Referrer	Percentage (%)
Palliative Nurse	50%
Social Prescriber	15%
Community Nurse	12%

The demographic analysis highlights an opportunity for Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers to improve equity of access to the service. Men and people of non-white ethnicities are underrepresented in the data available when compared to the demographics of the local community. A more targeted approach to promoting the project could be a useful way to increase the involvement of people in these groups.

Older adults (60+) represent the majority of Community Members in the project whilst in the local area there is a more even spread of ages. This difference could be attributed to more isolation in later life due to illness, mobility problems, bereavement and retirement. However, loneliness and isolation are prevalent in working age adults so they could still benefit from Compassionate Neighbours. Compassionate Neighbours volunteers represented a younger demographic that was more closely aligned with the local population. Most Compassionate Neighbours were around retirement age (50-79 years); potentially due to peoples changes in circumstance and availability of more time to commit to the project.

The referral data shows differences in where referrals come from between the organisations. At Isabel Hospice and Respite at Home Volunteers, health and social care professionals were the most common referral sources, whereas at Garden House Hospice Care, this was family members or Community Members themselves. The variation in referral location that can be seen in appendix 1 demonstrates the spread of awareness of Compassionate Neighbours in health and social care professionals across the local area. The occurrence of referrals coming from within Garden House Hospice Care and Isabel Hospice highlights the additional support that the project provides to people alongside other services offered by the hospice.

It would be beneficial for all Compassionate Neighbours data to be collected in the same format for ease of organisation and analysis in the future. This would allow project staff to more easily identify gaps in provision and improve equity of access to Compassionate Neighbours.

5. Qualitative Findings

Findings are reported in relation to the four groups of participants interviewed:

- Staff
- Community Members
- Compassionate Neighbours
- Business partners (current and potential)

Staff

Staff are all employed by the hospices or charities and have varying roles across the Compassionate Neighbours project. At a strategic level staff develop partnerships with local organisations and plan the future scope of the project and at a practical level they assist in the day to day running of the project. This includes:

- Following up on referrals to the project

- Recruitment and training of new Compassionate Neighbours
- Setting up matches between Compassionate Neighbours and Community Members
- Provision of ongoing training and support for Compassionate Neighbours.

In this section, we reflect on findings reported by staff but also the views of staff reported by Compassionate Neighbours and Community Members; many of whom reported the importance of the paid staff members in the success of the project and reflected on the myriad of advanced skills individual staff members bring to the project. These skills include interpersonal and communication skills, organisation, planning, and critical thinking skills.

At the initial point of access, it is important for staff to have these skills in working with both Compassionate Neighbours and Community Members. Good interpersonal skills put Community Members and their families' minds at ease when they approach the service and consider inviting a new person into their home. Furthermore, the planning and organisation skills were valued by Community Members as they reported being 'contacted quickly'. Many Compassionate Neighbours commented that the knowledge and support from staff throughout recruitment and training really helped volunteer confidence and motivation and thus, improved volunteer retention. Some commented that this was not the case with other charities they had attempted to volunteer with prior to becoming a Compassionate Neighbour and this key difference of staff input and skills led to them becoming a Compassionate Neighbour.

In forming successful matches, staff use interpersonal and communication skills to understand what it is that Compassionate Neighbours and Community Members want from a match. In a focus group with Compassionate Neighbours there was a feeling that the staff embody the values of the Compassionate Neighbours project through showing compassion to others, and this is what drives successful matches being formed. The warmth and friendliness of staff was discussed in focus groups with hub attendees, as we shall report in more detail in a later section.

Once a match is made, the involvement of staff is light touch, though the necessity for paid staff was clear in interviews and focus groups. Compassionate Neighbours reported feeling reassured in knowing that support was always there for them, and that they had someone to call on, should any challenges arise.



Staff were involved in the delivery of ongoing training for Compassionate Neighbours and brought in external trainers where appropriate. The ability of staff to listen to Compassionate Neighbours needs and apply this to the training schedule is a driver of the continued success of the sessions. Compassionate Neighbours reflected on the range of training they were provided with and valued staff organising external speakers to come to speak at these training sessions.

Box 1: Comments from and about staff

*"She's always there if you want to contact her, but not only that, **she kind of pre-empts as well**. She's absolutely brilliant at keeping in contact, whether it's by email or message."- Compassionate Neighbour*

*"I would say the key thing is, I think what we've all said in a roundabout way is the people that are the managers and supervisors, they're key to- it's almost how good they are matching people, so **they have to be really compassionate, and they really need to be a people person**. Because I think it's key what we're saying... is they just seem to have that gift of knowing who's the right person to visit and then I think it works."- Compassionate Neighbour*

*"At first was a bit wary but when member [staff member] came to visit **she was so lovely and friendly** they felt at ease. May not have felt quite as confident with the project if [staff member] hadn't been as friendly."- Notes from interview with Community Member*

*"In the past, a couple - myself and a couple of my team, have done end of life training and having conversations, but there's still conversations that I think people find a little awkward sometimes. So having this initiative, and obviously speaking to people that really do have that knowledge about those conversations, **it's just going to improve our skillset**."- Business partner*

*"So, the development side and also **equipping of the neighbours**, and all the things that we've seen over the years, rather than staff being the main driver for things, is empowering the neighbours themselves."- Staff member*

*"I would say **Compassionate Neighbours has been the most, brought about and more professional** than, say, [other charity], which is very chuck you in and then don't even bother with you after that, if you know what I mean?"- Compassionate Neighbour*

"If it hadn't have been for you and you [staff members], I would not come. I would never have come. I would never have come."- Community Member

*"Sometimes they [trainers] charge expenses and things, but it's **getting them interested to come to your group** as well."- Compassionate Neighbour*

*"So, I rang up and from ringing up you know the lady was so nice and then **I got a phone call, and you know within the hour** about it and everybody was just really nice and friendly and welcoming and I just thought yeah this is something I can do."- Compassionate Neighbour*

*"You've got those at the top, who really believe in it and want to do it and they're wholeheartedly- **it's not just a job for them it's something that they believe in really wholeheartedly**"- Compassionate Neighbour*

Staff also spend time communicating with professionals and the public outside of the project to promote, improve and expand the project. Through innovative thinking and networking, new collaborations are developing. In an interview with a current business partner, the project is expanding so that it will be delivered in collaboration with a supported housing complex. Here, hospice staff will provide training to the partner around Compassionate Neighbours and conversations around death and dying as well as support the expansion of the Compassionate Neighbours project to the supported housing complex. This collaboration will widen the reach of Compassionate Neighbours. The business partner also voiced hopes that this initiative will increase awareness of the hospice, improve understanding and confidence when talking about death and promote future collaborative working and sharing of resources.

Staff at Garden House Hospice, Isabel Hospice and Respite at Home Volunteers take on multiple tasks in their roles. The staff focus group highlighted the increased pressure they are under to recruit and train more Compassionate Neighbours to keep up with demand.

As the project has grown, the demands on staff have increased. For example, one member of staff spoke about starting with a small cohort of Compassionate Neighbours, which has since expanded from 30 to about 300.

My role was very much around home visits, and matching visits and kind of enjoying that side of things. Now I feel like I'm troubleshooting most of the time. I'm dealing with queries, I'm dealing with people leaving, I'm dealing with matches that haven't worked

Another member of staff commented how her role had changed:

I still do home visits, but I obviously can't do as much because I'm trying to deal with everything else. So that's a big change.

In the focus group with staff, adaptations due to the COVID pandemic were mentioned (further information on the impact of the COVID pandemic available in the Progress Reports, Nov 2020 and May 2021). One impact was what one member of staff referred to as readjusting “our core values”:

the face-to-face connections, the personalised package, if you like, where you go and do that home visit and you do that, then you take the person for a matching visit. And it's all very lovely and personalised, and so forth.

In the longer term, staff reported that it has led to working in a ‘smarter way’.

I've realised I don't need to be involved in every match ... people can make their own introductions ... we have so many volunteers, so many referrals, so many matches, you can't do everything. So, naturally, that probably would have happened anyway because of time, but I think Covid has kind of forced that to happen,

The culture that the staff have built has encouraged Compassionate Neighbours to identify solutions to problems, resulting in one Compassionate Neighbour forming pub meet ups with their Community Member and others which has developed to become a key aspect of the Compassionate Neighbours project. Hospice staff also organised coffee mornings for the Compassionate Neighbours at the hospice. One member of staff noted how this facilitated peer support for the Compassionate Neighbours:

It wasn't just about me answering everything, it was about someone said, oh, I don't know where to take (my Community Member), I'm running out of ideas and another Compassionate Neighbour would go, do you know where I've been? So they would help each other, so it was like a mass group supervision, if you like.

Another response to the expansion of Compassionate Neighbours project, as to think about group settings, such as the community hubs and the social meet-ups. One member of staff reported:

That has worked really, really well for us in the early days, and I think has gone on to help shape the bigger development of it now. That, for me, has been really exciting, actually, because what it's done is it's shifted the responsibility from us, so we can be the broker for the relationship introduction, but actually it shifts it onto the pairs, and then onto being introduced to the community. So it's empowering people to take responsibility for themselves, but also to be connected in their local area.

Another member of staff noted the benefits of this approach:

We link up now with different organisations, to get them on board and equip them, to then take on some of the responsibility and use some of their staff. Whether it's a business, or, for us, it's been the McMullen Brewery chain, where their staff are not necessarily your classic Compassionate Neighbour, but have been trained as a Neighbour, and are aware of the options and being that conduit to link. I really like that equipping other people to do it. So that's more in line with the original vision of the social movement, of us not having to be completely, people completely dependable on us as staff, so things can keep going.

These developments echo the Compassionate Communities ethos. Abel et al., (2021) observe that death, dying, loss and caregiving are events that occur in a community context, with each family and each community having their own meanings and social, understandings of these experiences. They identify the need for reaching out into communities and partnering with them. Staff reported working in partnership with a range of organisations and being able to link people in, which doesn't take up large amounts of staff time but has significant impacts in terms of benefits to Community Members. It can also work well for Compassionate Neighbours. Staff observed that some volunteers don't always want to take on the responsibility of a one-on-one match and having a Community Member become dependent on them. Another role for Compassionate Neighbours is to support Community Members attending social meet-ups; helping the Community Members overcome the barrier of going somewhere new by themselves.

Businesses

The hospices have made links with a number of businesses and organisations in the community. These include the McMullen Brewery chain and the Jim McDonald Centre (a community centre) and Friendship House in Hatfield. As part of the evaluation, we undertook interviews with two businesses. One of these had just become partners to deliver Compassionate Neighbours in the communities they manage. The other has not partnered with Compassionate Neighbours but has referred people into the project and was identified as a potential future business partner.

Current business partner

The current business partner, an employee of a local housing association described how they approached the Garden House Hospice Care to enquire about the project as they identified it as something highly relevant to their residents. From this initial enquiry the partnership developed and

now they are working together for one year to roll out Compassionate Neighbours to 500 of their residents and communities. The housing association reaches 2,500 people of all ages and reflects a clear opportunity to expand the project and encourage new Community Members and Compassionate Neighbours to join. It is hoped that following the initial one-year period the project will be generally self-sufficient. This highlights the value of Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers developing and maintaining links with wider stakeholders in the community.

'I think the hospices run a fabulous community... I've always held them in very high regard, anyway, so when there was this opportunity, there wasn't really a question of why would we not be involved with them?'

Alongside rolling out Compassionate Neighbours in the community, members of the hospice team will deliver training sessions on Compassionate Neighbours and having challenging conversations such as those around death, dying and bereavement to staff within the housing association. During the interview the business partner observed that the staff were already having these conversations but felt that these sessions would improve their skillset and confidence around initiating these conversations. It is expected that workshops around these topic areas will also be delivered to residents in the community. This is a clear example of Compassionate Neighbours meeting one of their current focusses around encouraging and equipping people to deal with issues around bereavement and end-of-life care.

It is hoped that the partnership will also have benefits to both parties outside of the Compassionate Neighbours project. The hospices and housing association both run dementia groups that operate in different ways. The business partner reflected in the interview that the partnership could enable more referrals to better suit the needs of the individual. For residents, now is a key time for additional support to be accessible due to the increased isolation caused by Covid-19. The housing associations social groups are seeing an increase in attendees and have experienced the tragedy of suicide as outlined below:

'Things that are coming to the forefront more, because we are coming out of Covid, we've had a suicide, we've dealt with a couple of attempted suicides around sort of loneliness and isolation, and you can really see the value that this service could potentially bring. And for us to make it bigger with our hospices would be phenomenal.'

The partnership demonstrates good cost effectiveness for both parties and offers the potential for the project to develop the Wellbeing Hub Model. The business partner explained that they have space that could potentially be utilised by the hospices without cost to enable growth in group activities. They also envisage that the current volunteers within the housing association may be able to secure volunteering or paid work at the hospices through the relationships developed by the partnership.

'And this is not really going to cost us hardly any money, but it would bring so much value. It's about the social return on investment, isn't it? It doesn't really cost an awful lot, but it means so much to individuals' lives.'

Potential business partner

The potential business partner that we interviewed was from a community organisation that promotes independent living. Whilst the business had not worked directly with Compassionate Neighbours before, the interviewee explained that they have previously made around 20 referrals into the project in a six month period, noting the wide spread of the project as helpful. As the relationship between the businesses works currently, it is beneficial to both parties for example, the

organisation had referred one lady in particular to Compassionate Neighbours and she accessed one of the Wellbeing Hubs. The interviewee noted that this had a huge impact on her wellbeing and gave her the opportunity to meet people and boost her confidence, which in turn positively impacted her involvement in the exercise programme the business offers. It was noted that feedback on how a Community Member had got on once a part of Compassionate Neighbours would be valued in the future.

During the interview it became apparent that whilst the businesses are not currently in direct contact with each other, there is some overlap in the people they are working with through either long term or palliative conditions, bereavement or isolation. It was also mentioned that staff within the organisation were not confident in having conversations around end-of-life care and bereavement and as such would refer these people on to other services. This highlights an area that the Compassionate Neighbours could partner with this business to support, through training or workshops such as those planned with the current partner.

We all have motivational interviewing and certain aspects of our training, but certainly in terms of bereavement, not so much. Yeah, so we always would refer on.

It's like they're a befriending scheme, but we don't know what they do as like an evaluation process. We don't know how they assign the volunteers in that process. So, yeah, it would be really nice to kind of know, well, if we could go and just observe them and shadow them for a session.

A partnership with this organisation could build staffs confidence to have conversations they may currently find difficult with the potential to reduce the need for outside services. Equally, it could build their confidence in knowing services or organisations specific to end-of-life care that they could signpost to. A more structured partnership with this business could also grow the Compassionate Neighbours knowledge base on services available to Community Members throughout Hertfordshire, thus growing the network of support around the Community Members.

'I guess it would just be really interesting to, as I said, understand a little bit more about what the hospices do, so that we can actually better advise people where to go.'

A key feature of this organisation is the lunch they provide to the community, through meals on wheels or to existing groups in the community. During the interview there was an openness to collaboration and a suggestion that they could provide lunch to one or more of the existing Wellbeing Hubs. This would be at a cost but is subsidised by the council. There is also the opportunity for the organisation to come to one of the Wellbeing Hubs and have a taster session to see if they enjoy the food.

But, certainly, lunch clubs, we could certainly provide lunch clubs.

There is a clear opportunity for future collaborations with new organisations in the local area with an interest being expressed from this interview. It could provide the opportunity to increase the reach of Compassionate Neighbours, improve confidence in talking about end-of-life care and bereavement and expand the current provision of the Wellbeing Hubs.

Benefits to Community Members

Being part of Compassionate Neighbours afforded Community Members benefits to their wellbeing, mental and even physical health, as well as providing support with practical tasks such as shopping.

In addition, Community Members reported the project positively affecting their partner's and families lives.

From our interviews and focus groups, people mentioned a number of sources through which they had found out about the Compassionate Neighbours project. These included:

- GPs
- Social prescriber
- Age UK
- Leaflet through door
- Leaflet in town
- Direct from hospice- through other services or following care of a spouse at the hospice

One Community Member who found out about the project through a leaflet posted through her door reported that her daughter said not to trust someone coming into the house. The daughter had concerned it was a con and made several phone calls to find out more about the project. Another Community Member reported her daughter having similar concerns, worried that a stranger coming to the house might con her mother out of money. For further door to door leafleting, it might be helpful to ensure there is contact information on leaflets specifically highlighted for people (including relatives) to check that this is a genuine scheme and alleviate any concerns.

Community Members often have a visit from a member of staff following the referral and are then matched with a Compassionate Neighbour if they want one to one support and contact. The first point of contact was reported as important by Community Members. For example, one participant said:

At first, I was a bit wary but when (staff member) came to visit she was so lovely, friendly, I felt at ease.

The person who interviewed this Community Member noted that she (the Community Member) said she didn't think she could have met anyone better and that she might not have felt quite as confident with the project if the member of staff hadn't been as nice/friendly.

On the whole, we found that matches had worked well and that is testament to staff skills as noted in the section above. For those Community Members who reported lacking confidence or feeling wary, having someone come to their house who is effectively a stranger could represent a major hurdle to overcome. If not successful, that person might not have the confidence to reach out again. Thus, the first point of contact is clearly important, so that any wariness, concerns and so on are immediately alleviated. That first point of contact might be a leaflet through the door as described above or the first visit in person from a member of staff and/or a Compassionate Neighbour.

Community Members have very individual relationships with their Compassionate Neighbour and our findings suggest that these relationships can vary between support from a volunteer and various levels of friendship. This approach means that Community Members feel they can have conversations with their Compassionate Neighbour that they may not have with family or friends. Community Members spoke about trusting their Compassionate Neighbour and being able to speak to them about things such as family problems.

Community Members reported many benefits to having a Compassionate Neighbour. Examples included:

- Something to look forward to
- Contributing to feeling less isolated
- The opportunity to have someone to talk with and have a laugh
- Friendship
- Gaining confidence to go out

Case Study 1

Alan became involved with the hospice when his wife was diagnosed with a life limiting illness. His wife died at the hospice and at this time Alan was contemplating ending his own life. It was this point Alan was put in touch with members of the Compassionate Neighbours team. They spoke to him, and Alan recalls they reminded him of his wife's courage throughout her illness recalled her concerns: 'what is going to happen to my Alan?'. Alan reported that this conversation reminded him that he needed to continue to make his wife proud.

Alan had no intentions of attending the hub, but the Compassionate Neighbours staff visited him at home and encouraged him to come. Alan now visits the hub weekly and has made new friends there. He has found people who have also been bereaved following a spouse's death and feels able to share his feelings with these friends. He keeps in touch with friends from the group between meetings and has recently booked to go on a cruise with another member of the group. Alan reported that he had previously been reluctant to group meetings because of his hearing impairment. However, he found that staff, volunteers, and other hub members ensure this is not a barrier at the hub.

Alan was concerned that he would not be able to do many of the things his wife had done around the home, for example cooking, washing or finances but has been able to do these things and look after himself with input and support from other hub attendees, volunteers, and the staff.

Case Study 2

Sue was originally referred into Compassionate Neighbours by a nurse, when she confided that she was feeling low and lonely. A member of staff came and matched Sue up with a Compassionate Neighbour. Sue has now been seeing her Compassionate Neighbour for almost four years and they do various things together including going to a coffee shop or the local garden centre. They stay connected throughout the week and regard each other as best friends now. During lockdown Sue was classed as extremely vulnerable; she reported that without her Compassionate Neighbour she would have been very isolated and does not think she would have managed without her. Sue can talk to her Compassionate Neighbour about many things including family problems, and she knows that she will always listen.

Sue decided that she wanted to help somebody in the same way her Compassionate Neighbour has helped her and so she signed up with the project. She is now a Compassionate Neighbour and reports having 'a real laugh together' with the Community Member she has been matched with. Not only this, but Sue also helps run one of the weekly hubs where she is able to meet more people. She has brought her Community Member with her to the hub so that she could take part in one of the activities. If Sue ever has any difficulties or concerns with her Compassionate Neighbour role, she feels like she can talk to any member of the team and is well supported by hospice staff. Sue likens the Compassionate Neighbours community to a family and feels that is has been her lifeline.

Before being involved with Compassionate Neighbours, Sue just assumed the hospice was for dying but now realises they do so much more. She has been able to get involved with exercises, massages, and coffee mornings at the hospice. Sue still gets lonely but her involvement with Compassionate Neighbours has helped so much.



The project's aim reduce feelings of loneliness and isolation is clearly met. In all conversations with Community Members, being involved in the project helped them feel less isolated. Community Members' wellbeing and quality of life is by association also improved. For example, one Community Member said she has experienced depression and used to cry all the time. Having a Compassionate Neighbour has helped her to feel much better and provided essential support when she was diagnosed with cancer. Another Community Member described the project as a 'lifeline'.

Though the Compassionate Neighbours project is not a therapeutic service *per se*, it does allow a space for people to process challenging situations they may be feeling with their peers. Interviewees reported that the benefits experienced through Compassionate Neighbours added value to Community Members' wider life too. Some Community Members felt the project had helped increase their confidence to go out independently again, others reported having more conversations with family at home because the interactions with their Compassionate Neighbour gave them more things to talk about. Another Community Member described how seeing his Compassionate Neighbour had helped their speech improve following his stroke. Some reported that it raised their mood for the rest of the day.

Meeting these aims for Community Members has extended benefits for Community Members' relatives. Community Members described how it reassured their family members to know that somebody was visiting and in other circumstances provided an opportunity for a person's relative to go out or just relax whilst the Compassionate Neighbour was visiting. As noted above, some Community Members were able to talk about family problems with their Compassionate Neighbour, which has the potential to reduce family tensions. Others spoke about not wanting to 'burden' their family members. One member said her daughters had their own busy lives; another's daughter had her own health problems, and several said their family lived some distance away and were reassured that their parent had someone visiting them regularly:

It takes the stress of family knowing there is someone visiting me

It's been very helpful for my family to know there is someone looking out for me

It takes some of the strain of family so it's helpful all round

If I'm happy, then (my daughter) is happy

My daughter really appreciates it

The hub meetings are also beneficial to Community Members. The hubs further meet the project's aim to reduce feelings of loneliness and isolation. For some, their feelings of isolation were further improved through being integrated into a group at the hubs whilst for others one-to-one interaction was sufficient and preferable as they did not like the prospect of participating in a group setting. This demonstrates the need for the project to offer different settings for interaction to enable increased accessibility. One Community Member said that going to the Hub meetings get them out of the house and they liked socialising with more than one person. Another said: No, I wouldn't want someone to particularly come to the house.

The hubs also address the project's aims of improving wellbeing and quality of life. One stark illustration of this is illustrated in the Case study (1) outlined above, where both the support of staff and attending the hub meant that this person no longer felt at the point of ending their own life.

Community Members who attended hub meetings reported that they felt able to share openly at the group; they received reassurance that their feelings were normal and valid from people who had experienced similar things. At one Hub meeting we attended, there were several members who had been bereaved following the death of a spouse:

You know that you can speak openly here, and people will listen and then you'll hear their stories. And it all helps if you've had a bereavement or whatever, it does help.

People who know what you're going through ... always someone to listen

When we're having bad days, and we get a tap on the shoulder, or a rub, so that... Yeah, and it's very, very important to have that

You don't want to burden friends too much with how you're feeling. I feel guilty and I think, no, they've got all their own problems. But coming here ... someone will say, oh yeah, that happened, this is what I feel like sometimes. And you know that other people feel exactly the same, and it's just... it's a hand on your back.

Lots of us have lost our partners. You tend to think, oh, I don't want to sit with a load of lonely people that have lost partners, it's going to be all sad and it's not like that. You realise other people are going through what you're going through and you get laughter.

At this same Hub meeting, there was a conversation about the ways in which bereaved members spoke about their dead partner's belongings. Some still had their partner's clothes and belongings and couldn't face getting rid of things. One member said he still had his wife's false teeth in a cup. There was a lot of laughter and it was clear that members felt reassured that their ways of coping were OK or normal.

A number of people who attended the Hub meetings had originally attended meetings with their spouse and they found additional comfort in being with a group of people who had met their wife or husband prior to their death.

Case study 3

Mary originally attended a hub meeting with her husband, Eric, who was very ill. The couple had become isolated because Mary didn't feel she would leave the house. Her husband didn't want to go anywhere but staff persuaded them to give the hub meeting a go. Mary said her husband was 'dragged here (to the meeting) kicking and screaming' and initially wouldn't talk to anyone: "Then John's wife sort of took him under her wing one meeting ... and all of a sudden, we couldn't stop him talking". Mary said it took about three visits and then Eric understood that he didn't have to be the life and soul of the meeting but he very much found his voice and that he could just be himself. Mary said 'our whole life just changed for the better'. She reported that previously ... "at home, like lots of people, he just sat down in front of the TV" and that she felt they had lost the art of conversation ... "what was there to talk about, if you're not going anywhere?"

Attending the hub meetings gave Eric a 'new lease of life'. Mary continues to attend the hub meetings and values the friendships with people who had known Eric. As she said 'We've all become friends'.



The hubs also meet the aim of bringing people together (through helping patients, family members, carers, and volunteers to reconnect to their communities). Through joining a hub, Community Members find this extends their social support network. Many reported hearing about other groups, clubs or support services from other members of the group, thus further extending their networks within their communities. We witnessed this at one hub meeting we attended where people spoke about other activities they engaged in, which they then recommended to other members.

Box 2: Comments about benefits to Community Members

*Loves connecting and meeting neighbour – “**helped with speech following stroke.**”- Community Member*

*“But you do find that **they talk about things that ... they find difficult to talk about with their families.**”- Compassionate Neighbour*

*“You could turn inwards; you know what I mean? Within yourself. But you've got - **this place brings you out**, and you can converse with different personalities, so it gets you out and about, and back in the world again.”- Community Member*

*“It's a great therapy to come here, it really is. **Better than any pills.**”- Community Member*

*“I suppose the ability to know the way I was dealing with my bereavement, **didn't matter... It doesn't matter, it's how you deal with it, and they understand that, and they listen. They don't give an opinion; they just listen and they are the best.**”- Community Member*

*“It has made me **feel less isolated** especially since going to the hub”- Community Member*

*“And I have with some of the visits, some of the clients we've had, **it has been more for the carer to be able to go out for an hour**, and do some shopping or do some walking, or do some thinking, whatever, quietly on their own.”- Compassionate Neighbour*

***You don't want to burden friends**, your social life too much with how you're feeling. I don't know if anyone else feels that? I feel guilty and I think, no, they've got all their own problems. But coming here, you're just - you've just mentioned something, and someone will say, oh yeah, that happened, this is what I feel like sometimes. **And you know that other people feel exactly the same, and it's just... It's a hand on your back.** - Community Member*

*My wife wouldn't come out at first. But someone at her yoga group told her about this place, and once we'd come, **our whole life just changed for the better.** - Community Member*

*But when he came here, we kept in communication with people and, yeah, **it really did give him an extra lease of life.** - Community Member*

*She comes to me every Wednesday and **we have a chat and go shopping** and all that. - Community Member*

***It has helped me feel less isolated** and my Compassionate Neighbour has been helping me to find out about other groups that run in [town name] so that I get connected for when we move to [town name] in the near future. - Community Member*

Community Members also reported being able to tap into the expertise of others at the hub meetings where they may have otherwise needed support from private or statutory services and rehabilitation from illness. Another benefit of the Hub meetings is that for some, it replaces the need for one-to-one support from a Compassionate Neighbour. If or when the Community Member's

need for one-to-one support reduces, this can free up the Compassionate Neighbours availability to be matched with another new Member. Some Community Members reflected that they had initially begun meeting one-to-one with their Compassionate Neighbour, then with the support of the Compassionate Neighbour they began attending the hubs or group activities in other settings.

This represents the non-medicalised, community focussed approach outlined in the Compassionate Communities principles (Abel, 2018).

Benefits to Compassionate Neighbours

Compassionate Neighbours also experience positive impacts on their wellbeing, improve their knowledge and skills base and expand their social circle through being involved in the project. This further demonstrates that the value of the project. Compassionate Neighbours reported that their relationship with their Community Member worked both ways i.e., with both parties benefiting from their involvement and many becoming friends.

For some, they reported that their involvement in the project had enhanced their lives (in similar ways as reported by Community Members) by providing them with company and reducing their isolation. For one Compassionate Neighbour, their involvement in the project significantly helped them following the death of their spouse. There is a sense of community between the Compassionate Neighbours and for some this has developed into friendship outside of the project. This demonstrates that Compassionate Neighbours is not only increasing the Community Members social resources but that of the Compassionate Neighbours too. The regular meetings as a group facilitated these relationships and offered a space for reassurance and learning.

The Compassionate Neighbours project offers members of the community the opportunity to become involved in something rewarding that makes them feel they have made a difference. Current Compassionate Neighbours explained that being involved in the project changed their perspective on life as they learnt from their Community Member. One Compassionate Neighbour explained that being in this role has helped her understand it is not the material things that matter but those you help around. For others they have enjoyed being involved in new hobbies such as learning new games or going to the pub or coffee shop. This range of experiences reflects the variety and flexibility Compassionate Neighbours experience in their role, allowing them to fit it with their schedule and to their own and the Community Members preferences.

In more practical terms, their involvement in the project has equipped them with knowledge they apply in their role as a Compassionate Neighbour but also in their wider life. Many reported this knowledge developing through training but less formal situations such as conversations with people with varying experiences could also be a way this knowledge develops. Due to one person's increased death literacy developed whilst in the role, they were able to support somebody in their personal life whilst they were navigating end of life care and services and raise concerns when they were unable to access the support they needed. This is a key example of how the learning and experiences through Compassionate Neighbours has diffused into the wider community. Compassionate Neighbours found the initial and ongoing training sessions useful and gave examples such as learning to use a wheelchair correctly and having information on easy-to-use wheelchairs and where to acquire them as useful when with their Community Member. The value gained from delivering the Compassionate Neighbours project impacts society more widely than just those directly involved in the project. Compassionate Neighbours share their new knowledge around end of life and community services with other people in their lives.

Box 3: Comments about benefits to Compassionate Neighbours

*"You can do as much or as little as you want, and **it's incredibly flexible**. You sort the times out with your family, the people that you're visiting, and I do try to stress that."-Compassionate Neighbour*

*"**It does give you a confidence, too**. I have heard, and people have said things to me in my personal life, friends and colleagues have said things about people that they're caring for, or that they know people with life-limiting or life-limiting illnesses. And it is so nice to be able to say to them, that's not right, this, that and the other should have happened."- Compassionate Neighbour*

*"I've visited a few people who were terminally ill, who are right near end of life, who welcomed me into their home to enhance their life, I feel. And **they certainly enhanced mine** and invited me at the worst time of their life into their home, and their care homes after that."- Compassionate Neighbour*

*"I've never looked back and that's **what's got me through losing my wife**."- Compassionate Neighbour*

*"And it's also a **really good network of friends** amongst the Compassionate Neighbours when we get together"- Compassionate Neighbour*

*"We've had air ambulance, we've had all sorts of people, so that we understand different conditions. Because as much as you might think you understand a condition, actually having a speaker come out and explain it to you, has been brilliant, hasn't it? **An hour of your life once a month - it's great**."- Compassionate Neighbour*

*"So, it's a two-way street, and it's as much giving as - **much receiving as giving**, I think."- Compassionate Neighbour*

*"So, I really enjoy it. I enjoyed the training as well... and **I wish I'd done it years ago**, but it's not something you think about sometimes."- Compassionate Neighbour*

*"For me it's changed me completely. **If I hadn't had been doing this I don't know where I'd be by now**, I think I'd be in a right pickle to tell you the truth. So doing this has really got me through what I've gone through."- Compassionate Neighbour*

*"It's changed my way of looking at things as well you know, and **it's really broadened my horizons** and everything."- Compassionate Neighbour*

*"As I'm getting older and I'm retiring and gradually you're perhaps not doing as much it's just great it gets you out and certainly **the courses and things that we're able to access keeps the brain going as well** and it's good to be out there, helping others too."- Compassionate Neighbour*

*"I did this, when I was working, and I used to find it **such a nice relief from a working job** to do something that because I want to."- Compassionate Neighbour*

*"You just get this I don't know this warm feeling inside that you've helped somebody and through that you kind of help yourself. **It makes you appreciate things more on a deeper level**- that the things that we value aren't things, money, and possessions it's how you feel and what you do, the basics and that's it basically it's the basics of human beings, helping each other."- Compassionate Neighbour*

6. Recommendations for future development

1. Improving data on use of services

We were not able to retrieve a full dataset across the two hospices and Respite at Home Volunteers; gender was the only demographic collected by all three organisations. Moving forward, it would be helpful to develop a consistent monitoring protocol to be adopted across the three organisations, which will facilitate a more accurate picture of service reach. This would allow project staff to identify gaps more easily in the provision and equity of access to Compassionate Neighbours.

2. Referrals

From the evaluation interviews and focus groups, people mentioned a number of sources through which they had found out about the Compassionate Neighbours project. These included:

- GPs
- Social prescribers
- Age UK
- Leaflet through door
- Leaflet in town
- Direct from hospice- through other services or following care of a spouse at the hospice

The referral data collected by Respite at Home Volunteers indicates that most referrals come from health and social care professionals.

It would be beneficial for all Compassionate Neighbours referral data to be collected in the same format for ease of organisation and analysis in the future.

Participants in the evaluation felt the project could be publicised more widely (this would need to be considered alongside project capacity) – examples included putting leaflets in libraries and GP surgeries; posters in local shops. Leaflets should have a clear point of contact if a relative wanted to check out the service is genuine – at least two Community Members mentioned relatives' concerns that the service could be a scam – a way of getting into a vulnerable person's house.

3. Improving equitable access to services

From the demographic data available, the analysis highlights an opportunity for Garden House Hospice Care, Isabel Hospice and Respite at Home Volunteers to improve equity of access to the service. Men and people from black ethnic communities are underrepresented in the data available when compared to the demographics of the local community. However, it is worth noting that at the Community Hub meetings the researchers attended, there were more men present than women¹.

¹ We didn't count all attendees at that Community Hub meetings we attended, but of those at those meetings who took part in the two focus groups, there were more men present than women (12 men and 6 women in total)

**No one is hard to reach, just more expensive to reach.
It is important to put more effort and creativity in reaching
these groups. Parnez, 2015**

4. Further Community Engagement

Future outreach initiatives could be targeted to address under-representation of different ethnic communities:

- Consider bringing in a trainer to run a course to increase understanding of different cultures and religions; when you research the culture ahead of time, it is easier to identify ways around specific barriers that you may run into during outreach work
- Target engagement with diverse ethnic and migrant groups to raise awareness of the work of the project. This might include community centres used by ethnic and migrant groups; adult English language schools
- Engage with local faith groups and community leaders in the local area
- Provide culturally sensitive training, support and supervision for Compassionate Neighbours who are interested in learning more about how to support others in their communities

5. Building confidence to talk about death, dying and bereavement

Volunteers (the Compassionate Neighbours) act as a key point to share information and provide support for people. During the focus groups and in the training provided for the Compassionate Neighbours to interview Community Members (as reported above), it became clear that some were more comfortable discussing topics around end of life than others.

We recommend that staff consider developing further training to build people's confidence around having conversations around these topics. This would better equip them should conversations around death and bereavement come up and build their confidence to initiate them in appropriate situations with their Community Member and those in their wider community.

6. Accessibility of hub meeting venues

Some Community Members reported some limitations regarding accessibility of hub meetings – in terms of disabled access but also geographical location and accessibility by public transport. To further improve accessibility, we suggest that the project aims to use that are fully accessible, for example with disabled access toilets, ramps and automatic doors at the entrance. The hubs provide a network of support to those that attend and feedback from interviews was that they wanted the project to be available to as many people as possible. Another suggestion for increasing accessibility is developing a network of volunteer drivers who could provide lifts to the Hub meetings for Community Members (something that already happens but perhaps on a more ad hoc basis).

Other accessibility issues to consider are to identify community venues in areas with higher densities of ethnic minorities; this needs some preparation (see earlier recommendations); getting key figures within the community on board will facilitate word-of-mouth referrals.

7. Developing Community based initiatives

The availability of Compassionate Neighbour volunteers compared to referrals of potential Community Members presented challenges for the project to meet demand. Community initiatives such as the social groups at the pub and the hubs address this problem well. We suggest continuing to link with the wider community and encouraging organic growth through Compassionate Neighbours' or Community Members' existing links with their community. Listening to those who attended the Hub meetings, it was clear these serve an additional purpose to the one-to-one support provided by matching a Compassionate Neighbour to a Community Member. The interactive spaces help peers to share experiences, both happy and sad, and supporting each other in this way really makes a difference to people's well-being.

8. Continue to build partnerships with other local organisations and businesses

The new collaboration with a local housing organisation is an excellent example of sharing knowledge, expertise, and resources. The hospice will share their end-of-life expertise and extend the Compassionate Neighbours project, whilst the housing organisation can share their knowledge on their local community, support services and potentially offer spaces to deliver more community-based groups. The interview with another potential business partner identified ways in which this partner could collaborate more closely with Compassionate Neighbours. This has the potential to help the facilitation of more groups without drawing extensively on hospice staff resources.



7. References

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8. Appendix

Appendix 1. Full list of referral location across Isabel Hospice, Garden House Hospice Care and Respite at Home Volunteers.

Referrer	Count
Adult Care Services	44
Adult Care Services - Serco	1
Age UK	16
Alzheimer's Society	9
Bishops Wellbeing Interconnected Support	1
British Red Cross	2
Broxbourne Alliance PCN	2
Care Coordinator	1
Community Care Officer	1
Community Navigator	5
Community Nurse	3
Compassion Plus Healthcare	4
Compassionate Neighbour	5
Connected Lives	2
Create Community Network	3
Cruse	1
Early Memory Diagnosis and Support Service (EMDASS)	8
East Herts Council	1
Eastern Herts - HCT	1
Frailty Service	4
Frontline	6
Garden House Hospice	1
Garden House Hospice Care - Family Support Team	11
Garden House Hospice Care - Hawthorne Centre	96
Garden House Hospice Care - Hospice At Home	9
Garden House Hospice Care - IPU	3
HandB PCN	1
HCT Neuro Service	1
Hertfordshire Care Trust	13
Hertfordshire County Council	27
Hertfordshire Independent Living	1
Herts Complex Needs Service	1
Herts Help	21
Herts Help Hospital and Community Navigation Service (HCNS)	95
Herts Independent Living Service	6
Herts Partnership Foundation	1
Herts Vision Loss	5
Hertswise	7
Home Group Housing Association	1
Hospice	2
HPFT	2
Integrated Community Respiratory Service (ICRS)	8
Isabel Hospice - CNS	29

Referral location	Count
Isabel Hospice - Family Support	17
Isabel Hospice - IPU	3
Isabel Hospice - Living Well	34
Lister Hospital ENHT	2
Macmillan Braincare Team	1
Mary Barfield House	6
Mental Health Services for Older People	10
MIND	1
Mind in Mid Herts	1
MS Neuro Service	1
MS Nurse	1
MS specialist	1
Neuro nurse	1
New River Health	4
NHDC	1
NHDC - Adult Disability Team	1
NHDC - Integrated Care Team	1
NHDC - Older People Services	3
NHS	16
North Herts NHS Trust	7
Other	27
Palliative Care Nurse	24
Reach Out	1
Reach Out - NHCVS	3
Roseanne House	1
Self or family member	132
Sensory Services	1
Serco	14
Settle	21
Silverline	1
Social Prescriber	39
Specialist Palliative Care	6
Stevenage Borough Council	18
Stroke Association	2
Targeted Intervention	1
Targeted Intervention Service	3
Targeted Intervention Service East	1
Targeted Support	4
Targeted Support Services	4
TIS	1
TIS HCC	1
Waymarks	1
Welhat HCT	1
Welwyn Hatfield Borough Council	1
Total	881