

Nesta/DCMS Centre for Social Action Innovation Fund Phase 2 Evaluation Report Summary Sheet

Grantee Name	St Joseph's Hospice
Programme Name	Compassionate Neighbours
Fund Name	Second Half Fund
Stage of Development	Scaling
Evaluation Partner	McPin Foundation
Date Completed	January 2020
Budget	£28,000

Project Overview

Compassionate Neighbours (CN) is a growing movement of people who support each other to promote compassion in their communities. They provide social and emotional support to people who have a life-limiting illness and are experiencing loneliness or social isolation

The Compassionate Neighbours programme started in 2014 at St Joseph's Hospice in the London Borough of Hackney. Local people (Compassionate Neighbours), are invited to join the project and are trained and supported in their efforts to connect with people in their neighbourhood at risk of loneliness and isolation. The Compassionate Neighbours are then matched with a community member (i.e. a person who is coming to the end of their life), who has indicated an interest in establishing a new relationship. Following matching, the Compassionate Neighbours and the community member begin to meet and decide together how the relationship unfolds. Some Compassionate Neighbours are not matched to a community member but remain involved, supporting the programme in a range of other ways.

In 2017, St Joseph's Hospice received funding from Nesta and DCMS to scale up the Compassionate Neighbours programme. From Autumn 2017 to the Spring of 2019, seven hospices across London, Hertfordshire, Essex and Surrey adopted and developed the Compassionate Neighbours model in their own setting.

Headline Findings

Outcomes for community members:

- **Improved quality of life** - The evaluation showed positive outcomes for community members. Survey data confirmed that most community members (95%) confirmed a

positive impact on their lives on the part of the project. They talked about the project giving them “something to look forward to”, and “turning things around”.

- **Creating new connections and friendships** - When community members were asked about the Compassionate Neighbour they had been matched with, over 90% of community members said they had a good match with their Compassionate Neighbour. The majority (88%) said they felt they had things in common with their Compassionate Neighbours.
- **Being part of the community** - Over half of the community members surveyed (53%) indicated that they had met new people with their Compassionate Neighbour. 47% said the project led to changes in their feelings of connectedness to their local community.

The wider impact:

- There is good evidence from the evaluation that Compassionate Neighbours benefit from being part of this programme too, and that their engagement with the hospice is positive. Compassionate Neighbours relayed how they derived value from the relationships with community members, which they felt were genuine and equal, and how they came to view community members as friends (rather than as someone they 'helped').
- Carers of people living with serious illness found the involvement of a Compassionate Neighbour useful too.
- Hospices benefitted from participating – engaging in new relationships extending their reach and augmenting professional services with those provided by people in the local community. This three-way relationship seems key to the experience of all involved.

Evaluation Approach & Methodology

Aims of the evaluation focused on:

1. The experiences of community members, including the benefits of having a relationship with a Compassionate Neighbour around quality of life, social relationships and the experience of connectivity.
2. The experiences of being a Compassionate Neighbour and any consequences of adopting this role including their comfort around issues of dying, their own social networks, connectivity and support. Also new skills, actions, roles or confidence focused on addressing societal concerns related to serious illness, death or loss as a result of being a Compassionate Neighbour.

The evaluation adopted a mixed-method, co-production approach:

1. Observation - The McPin project team attended and observed different elements of the project (coffee mornings, catch up and development meetings, training)
2. Community Member insights
 - a. A community member survey - 61 completed from a possible 541 members.
 - b. 4 interviews with community members
 - c. 2 interviews with carers of community members
3. Compassionate Neighbour insights
 - a. A survey immediately after training and another 4-6 months after training of 102 Neighbours out of a possible 901
 - b. Survey for 'established' Compassionate Neighbours at St Joseph's hospice
 - c. A selection of informal interviews
4. Stakeholder insights - Interviews with hospice leads and with other staff in strategic positions across the project about their experiences. And a mini-focus group at the end

with staff who had been overseeing the project.

Quantitative

Qualitative

Mixed

Impact Evaluation

Process Evaluation

Economic Evaluation

One-off evaluation

Developing internal
evaluation capacity

Evaluation Implementation Challenges and Limitations

- Gaining access to and collecting information from community members was difficult. Some hospices were reluctant to refer community members or their carers to be interviewed. The evaluators struggled to recruit community members, and this aligns with others' experiences of 'gatekeeping' in research with vulnerable populations. Researchers report difficulties recruiting into a range of studies, partially due to a desire on the part of palliative care staff to protect people approaching the end of life from perceived burdens of research activities. The evaluation team got around this to some degree by using peer evaluators (volunteers) – small in number but highly effective.
- The final dataset represented a small proportion of the total population of Compassionate Neighbours (11%) meaning that this data cannot be seen as representative of Compassionate Neighbours overall and should be treated with caution.
- Data collected from Compassionate Neighbours was collected at coffee mornings or meetings and may have missed the perspectives of people who cannot attend these meetings through work or other commitments.
- The evaluation team received feedback that the questionnaires were too long. Hospice leads with busy schedules may find co-ordinating data collection time-consuming.
- It was not possible to comment on differences between individual hospice sites because the evaluators did not have sufficient time to analyse individual data sets.
- The working group for the evaluation was large in order to be inclusive of all hospices and to include Compassionate Neighbours. However, this at times meant that some processes took longer, and decision making was slowed down.

Key Recommendations and Next Steps

The Compassionate Neighbours team is now considering how it can best scale further and embed the programme into more hospices.

In relation to further evaluation the team has identified the following opportunities:

- There is an opportunity for further analysis of the quantitative and qualitative data collected from the evaluation to uncover deeper insights and understand the Compassionate Neighbour and community members' profiles and experiences.
- Further research could be undertaken to identify the differences in how the model is adapted and adopted and what the outcomes look like across the different hospice sites.
- The team would also like to identify further tools that measure the outcomes identified in this evaluation and how to better capture insights from both Compassionate Neighbours and community members.
- As the programme scales, it will be important that data collection is implemented at the start of the programme as a role for the hospice. Data could then be centrally captured to better measure impact by investing in a Customer Relationship Management system.

Compassionate Neighbours

Evaluation Report 2019

Authors:

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“Compassionate Neighbours changes people’s lives. Long may the project continue to grow, its roots dig deep and become the lifeline it is for all. You cannot put monetary value on this project, if I had to, I would say there is not enough money in the world, it is priceless”

Katherine Anne Cannon, peer evaluator

Acknowledgments

We would like to acknowledge the help of Zaidee O’Dell in coordinating many of the activities of the evaluation across the hospice sites.

We would also like to acknowledge the following people for their help and support at various point of the process through this evaluation:

- | | |
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Introduction

This report offers highlights and recommendations from an evaluation of Compassionate Neighbours^{1,2}, a social action initiative focused on increasing connectivity for people coming to the end of their lives. The term ‘social action’ describes an initiative where people come together to help improve their lives and solve the problems that are important in their communities. It is based on harnessing the skills and passion of citizens, communities and organisations to help tackle long-standing challenges (Cabinet Office 2015 Social action: harnessing the potential).

The programme “Compassionate Neighbours” started in 2014 at St Joseph’s Hospice in the London Borough of Hackney. Local people, invited to join the project, are trained and supported in their efforts to connect with people in their neighbourhood at risk of loneliness and isolation. They are “matched” with a ‘community member’ (i.e. a person who is receiving Hospice Care), who has indicated an interest to establish a new relationship. Following matching, the compassionate neighbour and the community member begin to meet and decide together how this relationship unfolds. Some compassionate neighbours are not matched to a community member but remain involved, supporting the project in a range of other ways.

The origins for the programme are traced to two sources – the work of Allan Kellehear who described a new public health approach to end of life in a seminal book “Compassionate Cities: Public Health and End of Life Care” (2005). Simultaneously, Suresh Kumar, a pioneer doctor in Kerala, India was developing neighbourhood networks in palliative care. Within the network model developed in Kerala, volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively, with active support from a network of trained professionals. Essentially these networks aim to empower local people to look after people who are dying in the community. Inspiration was drawn from both, augmented by community development expertise and hospice care in East London to create the notion of compassionate neighbours.

In 2017 St Joseph’s Hospice received money from Nesta and the Department for Culture, Media and Sport (DCMS) as part of the Second Half Fund to introduce Compassionate Neighbours to other hospices in and around Greater London to scale the programme up. The programme ran between Autumn 2017 and Spring 2019. Over the course of the project seven hospices across London, Hertfordshire, Essex and Surrey applied and were accepted as adopters of Compassionate Neighbours.

Adopter Hospices

- St Christopher’s Hospice, Sydenham
- North London Hospice, XXX
- Princess Alice Hospice, Esher
- Garden House Hospice in Letchworth,
- Isabel Hospice in Welwyn Garden City,
- St Clare Hospice in Harlow
- Greenwich & Bexley Community Hospice, Abbey Wood

Developed by:  **St Joseph’s Hospice** Funded by:  **nesta** 

¹ When Compassionate Neighbours is capitalised it refers to the programme. When individuals working as compassionate neighbours are described the term is decapitalised.
² More information about the Compassionate Neighbours programme can be found at compassionateneighbours.org

This focused on the following activities/outcomes:

1. Creating greater capacity to respond to the needs of people at the end of life
2. Building new skills and confidence around death, dying and loss
3. Establishing valued connections within and between communities to strengthen support available in times of serious illness, declining health and loss
4. Developing stronger links between local hospices, people and communities to increase access and acceptability
5. Generating new knowledge about how best to upscale further in the future

A theory of change was established at the outset. It focuses on the actions of hospices in the roll out of Compassionate Neighbours, the impact and response of Compassionate Neighbours, and also the impact on community members. This evaluation reflects on the amended version in discussion of its findings.

About the evaluation

The McPin Foundation was commissioned by St Joseph's Hospice to conduct an evaluation of the upscale.



Aims of the evaluation focused on:

- The experiences of community members including the benefits of having a relationship with a compassionate neighbour around quality of life, social relationships and the experience of connectivity.
- The experiences of being a compassionate neighbour and any consequences of adopting this role including their comfort around issues of dying, their own social networks, connectivity and support. Also new skills, actions, roles or confidence focused on addressing societal concerns related to serious illness, death or loss as a result of being a compassionate neighbour.

Peer evaluators (volunteers, many of whom themselves were compassionate neighbours) helped collect data from community members and support data entry across the hospices. The reflections of one of the peer evaluators is described in the box below.

Reflection from a peer evaluator

I was a peer evaluator for the Compassionate Neighbours research out of St Christopher's Hospice. I had never done research of this kind before, the only research I had done was part of my undergraduate studies in psychology. I was enthusiastic as I am interested in research, and also in working in bereavement and end of life care. I found the training day very informative and felt confident about the process and what my responsibilities were. However, I was also apprehensive, as I was aware that I was going to have a conversation that required a great deal of empathy and compassion. I made sure in the interviews to follow all the procedures, particularly regarding confidentiality and consent. During the interviews I tried to sit with silence and give space for the community member to speak their mind. I tried to be non-judgmental and open, both in my body language and in my style of speaking. I found the semi-structured interviews easy to use, although there was a little bit of repetition in

some of the questions towards the end of the interviews. I was impressed and moved by the honesty and responsiveness of the community members when discussing their experiences with me, a stranger. After the interviews I felt quite emotional, particularly when I had a good connection with the community member. For me, that is what is important about Compassionate Neighbours, it connects people. It creates community and connections. It helps people to talk, to be there for each other, people who do not know each other and would otherwise not have met. It helps people to talk about death, which helps us to live. It creates new threads through local communities and enables people to help each other. It provides emotional and social support to people who need it, both for the community members but also for the compassionate neighbour. It builds relationships, the cornerstone of communities.

Method

Data collection

The evaluation adopted a mixed-methods, co-production approach. A working group was established to include leads from each of the adopter hospices and compassionate coaches³ to design the evaluation, and the tools required to collect the data. The working group co-produced an evaluation tool for compassionate neighbours and for community members. We worked with the project co-ordinator to bring together individuals from the different hospices involved, and staff from St Joseph's Hospice who had been involved in the development of the project there, and one compassionate coach who had been involved in the roll out.



While membership fluctuated over time, there were 12 people on the working group. The group met five times to discuss how to approach collecting quantitative data from compassionate neighbours and community members. Over a series of meetings, we worked with this group to establish what was important to include in an evaluation tool, and what was important to avoid. Within these meetings we reviewed existing evaluation tools and questionnaires and discussed the pros and cons of these existing options within the context of the Compassionate Neighbours project. The table below provides examples of decisions made as part of the co-design process.

Decisions made by hospice leads and the evaluation team as part of a co-production approach:

Compassionate neighbours would not collect data from community members matched with them, as this may disrupt their relationship

The consensus of the group is that most of these scales used intrusive or medicalised language or were lengthy.

Data would be collected from compassionate neighbours and community members separately (not as matched pairs). We wanted to understand the experiences of all compassionate neighbours, not only those who had been matched.

Data collected from community members should be light touch. Many community members may be unwell, have dementia or may in general be experiencing a decline in their quality of life. Where possible we should not burden community members with repeated attempts to collect data. We eventually settled on an approach that involved a one-off retrospective questionnaire by peer evaluators.

Not to use validated scales. We reviewed validated scales that related to the project aims. Most of these scales were designed to assess wellbeing, quality of life, feelings of belonging.

³ Compassionate coaches are compassionate neighbours with a remit to support adoption by new sites.

A range of information from different sources informed this evaluation:

1. Observation

The McPin project team attended different elements of the project (coffee mornings, catch up and development meetings, training) so that we could see how the project worked 'from the inside'. Notes were made about these experiences.

2. Information from community members

The evaluation team co-produced a short questionnaire for community members with the working group. We asked community members about:

- How they spent their time with their compassionate neighbour
- Whether having a compassionate neighbour had made a difference to them
- How their compassionate neighbour may compare to other types of support they received
- If they felt more connected with their local community as a result of being part of Compassionate Neighbours

Survey data (qualitative and quantitative) were available from 61 community members. The data were collected by peer evaluators. At the time of writing there were 541 community members in the project, meaning that our sample covers 11.3% of the population.

We also conducted four in-depth interviews with community members and two further interviews with carers of community members to hear in their own words a bit more about their life stories, how they had become part of the project and what their experiences had been with the project.

3. Information from compassionate neighbours

A survey (see Appendix A) given to compassionate neighbours immediately after training (Time 1) and 4-6 months following training (Time 2). We also asked compassionate neighbours who had been involved with the project before it was expanded to the other seven hospices to complete a version of this questionnaire once. We have referred to these compassionate neighbours as 'established' compassionate neighbours and report their data as a reference point for the more recent cohort.

The survey focused on:

- Whether compassionate neighbours felt they gained new skills, or confidence in existing skills
- Whether compassionate neighbours felt more confident to talk about living, death and dying
- Whether compassionate neighbours felt an increased sense of belonging in relation to other

compassionate neighbours

- Whether compassionate neighbours felt more connected to their local community as a result of being part of the programme

We only included data from participants who had data from both time points (Time 1 and 2), or where we had data from 'established' compassionate neighbours. In total we received usable data from 102 compassionate neighbours. At the time of writing there were 901 compassionate neighbours in the project, meaning that our data is drawn from just over 11% of the population. It is important to note here that much of the questionnaire data was collected at social gatherings such as coffee mornings and meetings. The evaluation therefore misses perspectives of people who cannot attend these meetings through work or other commitments such as caring responsibilities in this evaluation.

We also conducted a small number of informal interviews with compassionate neighbours where they were asked to 'their story' with the project. We asked compassionate neighbours to tell us about their own story as a compassionate neighbour. We also invited them to talk about the benefits and challenges they experienced through being part of the project.

4. Interviews with key stakeholders and focus group

We conducted interviews with hospice leads and with other staff in strategic positions across the project about their experiences. We also conducted a mini-focus group at the end with staff who had been overseeing the project.

Data analysis

Qualitative data were analysed by reviewing transcripts and audio recordings of interviews to identify important themes to create an analysis framework. We then reviewed transcripts and audio recordings against the framework. Finally, we wrote up the findings and did further exploration of the data for missing themes, finalising important insights through this writing process.

Quantitative data from the compassionate neighbour questionnaires (from all time points: immediately after training, 4-6 months after training and from established compassionate neighbours) were entered into template excel spreadsheets designed by the McPin Foundation within the local hospices. Anonymised datasets were then transferred to the McPin Foundation, where they were cleaned, checked and analysed. We report here a range of descriptive statistics from this data set.



Findings

Understanding the Compassionate Neighbours Project

Our introduction to the project was by speaking to people involved and spending time in the project. We spoke to strategic level staff who were 'rolling it out' to new hospices, management staff at St Joseph's Hospice, compassionate neighbours and people using hospice services themselves.

We learnt how a compassionate neighbour is an individual who is motivated to support people in their local community who may be approaching the end of their lives and who may be socially isolated or lonely. Many (although not all) compassionate neighbours are 'matched' through the project to someone, a community member, who may be elderly or have a life limiting condition, and who may be socially isolated, in their local community.

Compassionate neighbours and community members will then develop a relationship over time. Both the compassionate neighbour and the community member will decide together how this relationship should unfold.

We understood how a core aim is for compassionate neighbours to feel confident to engage and support people in their local community. A second core aim is

for compassionate neighbours to develop confidence in talking about the experience of living, death and dying.

This includes being able to support those that are approaching the end of life and encouraging discussion and understanding about the topic within the wider community.

"If you met somebody and you were at a fair or at a market stall or at a community event and you met someone and you have a chat with them and then you went round to their house for a cup of tea and a friendship developed naturally, in a way, that's the way I see Compassionate Neighbours."

(Hospice lead A)

Compassionate neighbours are trained via an informal, interactive two-day workshop. This focuses on enabling trainee compassionate neighbours to reflect on their own responses to different potential situations. Discussions involve exploring topics such as death and dying and thinking about how to talk about those matters in a sensitive and supportive way and reflecting on personal boundaries.



Many compassionate neighbours are 'matched' with a community member, based on factors such as geographical location, background, personal interests, language and general preferences. Staff are involved in the matching, speaking to community members and compassionate neighbours before introducing them to each other. If both people want to continue with the match they then go on to develop the relationship together through mutual negotiation and agreement.

Compassionate neighbours are also included in community activities at the hospice and beyond. Staff organise informal coffee mornings for compassionate neighbours (who sometimes bring their community member with them). This is a casual activity enabling compassionate neighbours to socialise and participate in group activities, craft activities, etc. Compassionate neighbours are also invited to social events within the hospice (such as a Christmas meal), helping newer compassionate neighbours feel part of the community.

Compassionate neighbours are supported through monthly 'Catch Up and Development' meetings and through speaking to staff. Meetings allows compassionate neighbours to debrief, plan with and learn from each other. Staff are available for compassionate neighbours who may have concerns.

"I've been matched now and I went to [...] meet my community member and you know that people have already been there and if you need anything you just need to contact somebody at the hospice and you know they're there for you which I think is really good."

(Compassionate neighbour #8)

The experience of Community Members

Many of the community members who participated in the evaluation were already receiving care from the hospice and had heard about the project through that route. Others heard about the project through another organisation who had referred them:

"I was in the hospice, and there was a little leaflet on the wall. And I read it, and I thought do you know what? I'd love a compassionate neighbour that sounds brilliant. I wrote [hospice lead] an email, she came to visit me, the next thing I knew [compassionate neighbour] came along to meet me."

(Community member #5)

"I think, believe it or not it was down in the market square. They had a stall out and it was compassionate neighbours. I said oh are you from the hospice? Because I was just started going over to the hospice. And then I met [hospice lead name] from there and she said would you be interested in a compassionate neighbour? [...] That was the time I was needing help and I felt they would help."

(Community member #6)

"I'm a carer of a husband with dementia and I think that we were introduced to Compassionate Neighbours through the Alzheimer's Society, I'm pretty sure. Somebody from [hospice name] then came to see us to see what sort of support they could provide."

(Community member, Carer #2)

Some had recently lost someone close to them and were used to visiting the hospice and familiar with hospice activities. For others, a family member had been matched with a compassionate neighbour who had continued to visit after their family member had died:

"When mum died, I thought that would be the end of it. But [compassionate neighbour] still came to see me... we have a cup of tea and chat. It's something that I could look forward to because when mum died I had a load of stuff that needed to be dealt with."

(Carer of community member #1)

"My husband got cancer and went into [hospice name]. They looked after him very well. And then when it finished, I stayed on, and I went to doodle club... one or two others was there and it's sort of been part and parcel now and I have my neighbour... she lives fairly local to me."

(Community member #3)

Community members and carers explained that for them the hospice connection was an important quality of the project. They trusted the reputation of the local hospice and the relationship of the programme with the hospice made it more appealing:

"I think the hospice has got such a good name and reputation; it immediately gives it a feeling of solidity. Also, the expertise, the people connected to the hospice know what they're doing and have good caring skills let's say. So, you'd think that translates across the compassionate neighbours. I'd say it has done. So, the link to the hospice is important."

(Community member, Carer #2)

"I think the fact that it was connected to the hospice was helpful, because [hospice name] to me is like my second home... when I was really ill and I trust the hospice. So, I kind of figured, if it was something connected to the hospice, then it must have been something good, whereas I mean there's a local cancer group... I haven't had the courage to go there yet, because that's a bit more of the unknown."

(Community member #5)

Improved quality of life

Survey data confirmed that most community members (95%) confirmed a positive impact on their lives on the part of the project. They talked about the project giving them "something to look forward to", and "turning things around". One person described their relationship with their compassionate neighbour as "emotional, nourishing and reliable", another said the impact was "huge, absolutely huge and entirely positive", and another described the project as "a lifeline".



“I got to the point where it seemed my entire life was illness and death. Do you know what I mean? So, I badly needed someone who had a future ... so it wasn't all terminal all the time. We talked about other things, y'know, she told me about her life and we've become friends now, we go out, have meals together and all sorts. [...] She's become another friend and I only have three friends... my support network has become practically non-existent and I didn't have time to set up another one because I was too busy looking after mum. In the hospice, it's not just the people that are dying that need support, it's the people around them.”

(Community member, Carer #1)

Many of the community members described the impact on them in terms that reflected a positive change in their quality of life. When we explored these changes further many of those positive changes arose through the relationships they built with their compassionate neighbour, and the things that having a compassionate neighbour enabled, or re-enabled them to do.

Having a compassionate neighbour also provide respite for carers. Perhaps because it was unintended, this benefit could not always be maximised. One carer, who indicated that the project was beneficial to her in providing a little respite time, mentioned that they would like more time on the part of the compassionate neighbour. However, they went on to say that they were unsure of how much time they could reasonably ask for, and what the rules were around this. This created some uncertainty.

“For me it's absolutely invaluable because it's you know time when I get a break, which is just fantastic, absolutely fantastic, I really need that. So the impact on me has been great, it's been lovely to know that there is somebody who is sort of warm and skilled and very well matched [...] I'd love to have more access to her, but I think there's a restriction of how much time you're allowed. I think it's a couple of hours a fortnight, I'm not really sure. I think

communicating that clearly is important so that the carer knows what kind of respite they can rely on. What I'd love really is a little more compassionate neighbour time.”

(Community member, Carer #2)

Another carer was concerned that community members may feel too unwell to receive visits and make conversation, but may not feel comfortable cancelling visits with their compassionate neighbour (she clarified that she had not experienced this situation herself, but it had been a concern early in the project):

“A lot of people might feel that when someone has come to make the effort to see them, they can't say that [I want you to leave]. It's a bit of a slap in the face. I remember when I was in hospital and lots of people came to see me and to be honest with you I wasn't well enough to see people but people had made the effort to see me...”

(Community member, Carer #1)

New connections and friendships

When we asked community members about the compassionate neighbour they had been matched with, over 90% of community members said they had a good match with their compassionate neighbour. The majority (88%) said they felt they had things in common with their compassionate neighbours. 100% of those who answered said they felt the compassionate neighbour listened to them. Most felt their compassionate neighbour understood what was helpful to them (95%). The vast majority



(93%) felt their relationship with the compassionate neighbour was different to their relationship with other health care professionals where such relationships existed. Over 80% also said their relationship differed to relationships with family members, where they had family.

Community members were positive about their compassionate neighbours, with one community member saying their compassionate neighbour had “enriched their life”. Many felt that their compassionate neighbour was more like a friend to them, one even describing them as their “best friend”. One said that from the beginning, they “had a strong connection, an instant connection [...] the same world view, and share the same values such as religion, family”. Community members described relationships that felt equal and reciprocal, where both parties have control of what is happening, and gain enjoyment out of spending time together.

“As time has gone on, we have obviously got to know each other more... it is a friendship... unlike counselling... which finished after a number of weeks... it's open ended, if both parties want to meet then so be it.”

(Community member #1)

“He's become more of a friend. We ring each other out of hours, that sort of thing. It started off as he came to me, to my convenience obviously, for an hour. And now I can't get rid of the bloody bloke! [laughs]”

(Community member #6)

“They go to photography exhibitions and they go for lunch and they go have walks. Photography is a big love of [community member] and his compassionate neighbour is married I think to a photographer... if I compare it with the medical help that [community member] and I get for his condition which is very clinical. What you get from compassionate neighbours is I feel, is much more humanitarian if you like, and much more emotionally empathetic.”

(Community member, Carer #2)



Compassionate neighbours described a similar relationship. Many compassionate neighbours talked about the relationship with their community member as being a natural, reciprocal friendship that developed over time:

“It's a two-way process, because you are getting something, so it works both ways. I've met two guys, especially [community member], he's my hero. When you get a chance in life to meet certain people like [hospice lead] and a few of the compassionate neighbours, and like [community member] and how they deal with their illness but still got their sense of humour. It just works both ways.”

(Compassionate neighbour #12)

In spending time with some community members, it became apparent to the evaluation team that community members viewed compassionate neighbours as important people in their social world.

For example, one community member showed us an album of family photos during an interview with her. This community member had included photos of herself and her compassionate neighbour in her family album.

For some, there was an important impact to having a compassionate neighbour which involved having someone to talk to about things that may be difficult or frightening. Some found it helpful to speak with their compassionate neighbour about difficult, sensitive topics, which said that they felt they could not have with their family members as they didn't want to upset them. One said they were “not able to express grief for her husband to her family”, as did not want to upset them. It was easier to talk to her compassionate neighbour about her grief.

“There’s certain things you can talk to [family] about and there’s certain things you can’t. With [compassionate neighbour] I can confide... it’s more of a confidant than a friendship. I can go to him if I have a problem, I can ring him. Whereas I wouldn’t ring probably of my own because they’ve got problems... if you’ve got fears and you obviously want to talk about death, y’know whereas the family, you look at their eyes and you know they want to shut off. Whereas with [compassionate neighbour], I feel it’s personal but it’s not, if you understand what I mean. He’s got a life, and I find it easier to talk to him and get a man’s point of view.”

(Community member #6)

A small minority of community members (n=3) told the evaluation team that they did not feel they had the correct match, or that the match had not worked for them. Six community members reported having nothing in common with their compassionate neighbour. One person in this situation reported that despite having few things in common with their compassionate neighbour, they appreciated talking to them about subjects on which they had different opinions. Another community member voiced a similar concern, but for them the lack of commonality caused difficulties and they could not make the relationship work: “He doesn’t show real interest in what I have to say. Goes into his shell and I can’t make him out”.

A couple of people described matches that appeared to dissolve soon after being established. One reported that her compassionate neighbour had started visiting enthusiastically but had missed several appointments before eventually stopping completely. Another person reported that her compassionate neighbour had only visited once before illness and childcare issues had prevented further meetings.

Being part of community

The evaluation considered the degree to which a relationship with a compassionate neighbour impacted on the quality and quantity of the social relationships community members enjoyed, and their feelings of being connected to their local community.

To this end, the evaluation team considered where compassionate neighbours and community members spent their time together. Most community members



(89% of respondents) met their compassionate neighbours at home. In addition to meeting with their compassionate neighbours at home, we also asked community members if they met their compassionate neighbours out of the house. Over half of the community members we spoke with said that they did (57%). At the time of writing, the average length of the relationship with compassionate neighbours was nine months (min=1, max=36 months). Most met with compassionate neighbours weekly (86% of people who responded). Some met more frequently (4%), some met less frequently (5%) or not at all (5%).

Many community members spoke about spending time with their compassionate neighbours through a combination of being at home and going out to do activities. Some of the things that they did outside of the home included: going to the park, going out for coffees and meals, going shopping, going to the theatre, museums, visits to the hospital, going fishing, playing golf, or simply going out for walks. Over one third said that they had been to new places with their compassionate neighbour (38%). One community member described going out with their compassionate neighbour, and how those visits made them feel:

“We have a gone out a few times, went to the cinema once, went to a place called [name of local attraction], and went there a few times. I feel better after having a chat and that, normally it’s a couple of hours. It’s just really relaxed and takes your mind off anything I was worrying about. I just feel happy and positive for them couple of hours and that spreads on for the rest of the day, and the next part of the week... I think of them now as a friend.”

(Community member #2)

For many the ability to “get out more” was of particular value. One person told us that having a compassionate neighbour had enabled him to retain his independence and this was very important to him. Community members have been able to continue with hobbies such as fishing, attended garden centres and National Trust properties. Some explained the difficulties of travelling independently, and how they otherwise relied on friends and family, who worked and had busy lives. Having a compassionate neighbour enabled them to leave the house:

“It’s totally turned my life around. My husband works Monday to Friday and I spend most of my time at home. I’ve got friends but obviously they work, so [compassionate neighbour] kind of like... stable in my life. I know at least once a week that I’m going to get to go out and someone’s going to see me. And for my husband, if I’ve been in out in the week... he’s not then forced to take me out at the weekend. If he has to work, on Saturday and Sunday he just wants to chill, he can because I’ve been out, whereas before [compassionate neighbour] came along, he felt duty-bound to take me out to get me out of the house.”

(Community member #5)

Some spoke of being able to visit places that had become inaccessible as their mobility deteriorated or reconnecting with activities and places that they enjoyed previously. This means that while some community members may not have joined a new social network or community, they were able to retain links with existing networks, communities or places of importance to them. In this sense the project may act to prevent the deterioration of existing connections to the community, rather than support the development of a new one.

As part of the evaluation’s interest in social networks we also asked community members directly about whether they had met any new people through the project. Over half of the community members we spoke to (53%) indicated that they had met new people with their compassionate neighbour. 47% said the project led to changes in their feelings of connectedness to their local community, with one person commenting that it had enabled them to “Meet other compassionate neighbours and community members”.

“I come to the pub every week! I recognise more people now than I did a year ago! They are not only in saying hello in the street anymore. This would have been impossible without you [their compassionate neighbour] coming on the scene.”

(Survey respondent)

While many of the community members spoke to us about going out and connecting with other people or places, some community members were able to do so only rarely, or not at all. Some only met with their compassionate neighbours at home reported being ‘bedbound’ or having limited mobility which made going out difficult. Of the people who said they did not meet their compassionate neighbour, one said they spoke on the phone.

Stronger links with the hospice

For some community members, expanding their social network meant connecting with their local hospice. Community members told us that they met new people by attending events such as the ‘Friday meet up’ where they were able to meet other compassionate neighbours.

Some also told us they had become more familiar with people at their local hospices, and one person told us that they now feel able to “ring the hospice to point me to other services they have”. This person went on to say “I now trust the hospice. I suffer paranoia so this is a big help”.

“I’m yet to meet anyone that’s rude, unsocial... Even going into the hospice, there’s something about the place that is calming. You can just pop in, sit down and have a coffee and people will speak to you - I feel totally at ease. I’ve been bored and just sat in there and had a coffee, chatted to the lady behind the counter, bought some nic-nacs...”

(Community member #1)

“They had a Christmas do at [hospice name] and I went to that. [Compassionate neighbour] came and got me because she had a car.”

(Community member #3)

The experience of Compassionate Neighbours

Being part of the hospice

In developing the compassionate neighbour questionnaire, those involved spoke of the importance to them of feeling part of the community at the hospice. This was borne out in the survey. Over half of the compassionate neighbours had a sense of being part of the hospice after training (53%), increasing to 71% among established compassionate neighbours. In our observations and conversations with compassionate neighbours we did not find an appetite for the project becoming independent of the hospice to which it was attached.

“You have to be prepared to say whether it’s right or not because that’s what they’re there for... A backup. It’s not always easy, y’know, you never know what situation is gonna arise and you gotta have somebody there to talk to, even if just to ask their opinion about something.”

(Compassionate neighbour #7)

Compassionate neighbours said the hospice link was important to them and felt part of the hospice community. Compassionate neighbours attached to some hospices had become involved in other activities within the hospice or used the hospice and as a place to bring their community member to meet other people and to take part in activities. Some compassionate neighbours were using hospice services themselves.

“The reason I was interested was partly because I’m not working because I was diagnosed with secondary breast cancer. It was about that time when I was thinking of different ways in which I wanted to become more involved in something locally. I’m also a patient here... I felt well enough to do something flexible and more local but not well enough to go full time back to work. So it really fulfilled quite a few things about wanting to give something back, community and connections, and something that was flexible and manageable.”

(Compassionate neighbour #2)

For many compassionate neighbours their motivations for joining the project in the first place were strongly affected by a desire to support the hospice. Some had relevant life experiences including caring for a family member who spent time in a hospice. The project could help some make sense of their past or present experiences.

“My father died just over a year ago... I saw the poster for compassionate neighbours and it really hit me because I saw how lonely he [name removed] was at the end of his life. Even though he had family, he didn’t really have many visitors... wouldn’t it be great to help someone who could be really lonely.”

(Compassionate neighbour #6)

“Maybe because I had to handle so much death that I was attracted to it because want to be able to see death and life as a journey as one, as opposed to seeing death as scary, there’s no way out of it. It’s just a weird subject, it’s really strange.”

(Compassionate neighbour #5)

Others wished to repay the kindness of the hospice which had supported their family through the difficult time period:

“So I got involved through [the hospice] because they had looked after my late mother. My mum had been under their palliative care team for many years... and was cared for them until she passed away. We as a family wanted to give something back.”

(Compassionate neighbour #4)



“Basically I lost an aunt who was very close to me in [the hospice]. And I felt like they were so wonderful in there, in terms of her care and for accommodating us family members - I was really impressed. So when it came to January I was like, right, I’m going to give some time back, so I rang the hospice.”

(Compassionate neighbour #11)

New skills and confidence

The evaluation team asked compassionate neighbours to rate their confidence on a series of skills identified as relevant to the role immediately after training, and after 4-6 months in the role. We found that over time people indicated they felt confident in relation to these skills.

- Talking about ‘content close to home’ (meaning content that may resonate closely with their own difficult life experiences: 59% after training, 81% after being in the role)
- More comfortable in other people’s homes (49% after training, 71% after being in the role)
- More ‘imaginative’ (62% after training, 74% after being in the role)
- Less judgemental about other people’s home environments (69% after training, 79% after being in the role).

Compassionate neighbours were invited to discuss how confident they felt talking about the issues of living, dying and death to a range of people including family and friends, other people with whom they may come in contact with as a result of their role as a compassionate neighbour, and their community members. Following training the majority (66%+) of compassionate neighbours felt confident to talk about these issues.

- When we asked compassionate neighbours how confident they felt to talk to people in their local community. There was little difference in confidence between the time of training (63%), and 4-6 months later (65%).
- When we asked how confident compassionate neighbours felt about talking to their community member about these issues, 68% of compassionate neighbours indicated they felt confident immediately after training. There was little difference (70%) after 4-6 months in the role.

- We saw an increase in the number of people who felt confident talking with family and friends after being in the role for 4-6 months (77%) than did immediately after training (69%).

The levels of increased confidence appeared to differ in relation to the audience. In relation to discussions with people they didn’t know, compassionate neighbours reported increased confidence after taking on the role. After training the proportion of those confident to talk about issues of living, dying and death was 56%. This increased to 74% after being in role for 4-6 months.

Compassionate neighbours spoke of the project as a source of purpose, pride and achievement and of how they liked to be known as a compassionate neighbour. They indicated that their identity generated confidence and self-esteem:

“Sometimes I feel, and I know it might sound silly, but as though I am a better person because of what I’m doing, I’ve got more time for other people.”

(Compassionate neighbour #7)

The training offered “tools and the confidence to go out and be themselves and develop a relationship with the community member”.

Compassionate neighbours felt confident and autonomous in establishing their own boundaries, without feeling restricted by confines of the project:

“What I really liked [about the training] was that it allows you the independence to develop the relationship.”

(Compassionate neighbour #2)

“A lot of us that volunteered in cohort one came from nursing, teaching, those sort of areas. Where everything is particularly micromanaged from a health and safety point of view. It took us a while to get our head round that we really aren’t being micromanaged, and I think that is one of the beauties of the project. I love the fact that it is very hands off, and they kind of just put you together and the support is there and the meetings are there, but nobody is in the middle of it with you. I really think that’s the strength of the project.”

(Compassionate neighbour #11)

We heard that the training offered compassionate neighbours space to think through difficult issues, such as their own feelings about death and dying. Some compassionate neighbours in this situation spoke to us of new insights, making a choice not to be matched with a community member at that point in time as they did not feel ready:

“My experience has proved that I just couldn’t use it, because it’s just too raw, it went the other way. That’s how I felt after training. I’m just not ready to deal with somebody dying again... once you’re matched with somebody you’ve got to give them real commitment and time, be there for them and be prepared when they die as well, and I kind of knew I wasn’t ready at that stage.”

(Compassionate neighbour #5)

Whilst compassionate neighbours acknowledged that some of the emotions they encountered could be difficult, they also explained that these difficult emotions could provide an opportunity for growth, or new understanding. One explained to us about being matched with someone she shared a diagnosis with. Both the compassionate neighbour and the community member also had children of a similar age. She spoke movingly of her journey alongside her community member as the community member became increasingly unwell, and later died. She described this experience as emotionally hard, but equally as important to her. She explored with us how that experience had helped her and her family learn more about hospice care and how it had been very helpful to her in helping explain to her own family what may happen to her:

“I learned a huge amount from getting to know [the community member] and her family. Huge amount from the strength of [community member]... In the final stages, I would come visit her on the wards. That was really quite hard, but it was also important to do... It helped me enormously about understanding the hospice and the care here, but in a very positive way, breaking down the barriers of the hospice for my own family, in relation to what’s ahead, in many ways. But in an open way and in a very positive way, for example how [community member] was preparing her family and how they were talking about things was incredibly



supportive in that very difficult thing in how you talk to your children about your illness and the future.”

(Compassionate neighbour #2)

Through our observation work we also spoke to compassionate neighbours who had not been matched with a community member, some of whom had waited a long time. Some of these compassionate neighbours told us that this left them feeling like there was something wrong with them, especially as new cohorts of people we trained and matched as they continued to wait.

Expanded social networks

Some compassionate neighbours told us that they had joined the project in part because they wanted to connect with other like-minded people. They spoke about wanting to connect to others who had a passion to do something positive, or to give back to their local community.

“I think there is a like-mindedness about it... I think it attracts people with the same values to some degree.”

(Compassionate neighbour #5)

“I was becoming very cynical in my old age. It does restore my faith when I see that there are these people out there, not only the ones that are ill, but ones that are not only voluntary like me but also the professionals. You can tell they put so much effort and thought into it. It helped me have a bit more optimism about human beings.”

(Compassionate neighbour #12)

Through the project many opportunities were provided for compassionate neighbours to meet each other; regular coffee mornings and meetings. More than half of survey respondents said that they attended coffee mornings, with a greater attendance on the part of established compassionate neighbours (65% compared with 54%). Two thirds said they contributed to meetings, 77% of new compassionate neighbours and 74% of established compassionate neighbours. Most (88%) reported having made at least one or more new connections with other compassionate neighbours, some reporting over 20 new connections. One compassionate neighbour told us about making connections during training.

“There was only one other man there and I got chatting to him and we had a very similar background... There was a connection made there. Its early stages but I can imagine another level of support there.”

(Compassionate neighbour #6)

We asked compassionate neighbours about the sense of community they experienced in relation to other compassionate neighbours. 64% of recently trained compassionate neighbours indicated they did, increasing to 79% of established compassionate neighbours. However, this varied between sites and cohorts. From our observations, we saw that where meetings or coffee mornings were held in the working week, very few compassionate neighbours who had full time employment attended. Where meetings were held on weekends we saw more people attend and meet with each other.

“The only thing I am disappointed with, the group I did my training with. We haven’t met up and we have only just arranged for dinner, and it’s almost been a year. But quite a few of those people work... those friendships haven’t been able to necessarily blossom.”

(Compassionate neighbour #4)

When we asked about relationships with their community members they described natural, reciprocal friendships developing over time. This impact might expand to the community member’s family, who may also need support.

“We talk about everything. We talk about Brexit, or we talk about anything, I come in and I say hello [Community member]. He just tells me everything that’s going on and stuff with his family and I sit there and say have you thought about doing this? It’s like

having another friend really isn’t it? That you can talk to without judgment as well.”

(Compassionate neighbour #10)

“A lady that was almost a hundred who had lung cancer and other medical problems, and her daughter who was her main carer who was nearly 70... it was immediately apparent to me that it was the daughter that needed the support rather than the community member.”

(Compassionate neighbour #8)

These new networks offered benefits beyond the experience of connectivity alone. Compassionate neighbours were keen to highlight that sometimes their community member wanted or needed to talk to someone other than a carer or family member.

“I think she has actually said to me before when they’ve had issues in the family, she’s sort of off-loaded. That is really helpful for her because everything is emotionally charged. If she has a crisis and she ends up going back into the hospice, they’re all expecting that this could be the time when they have to say goodbye. I’m not quite as emotionally involved, I’m one step back from that, and I wouldn’t be part of that. And so she has said that she finds it valuable to talk.”

(Compassionate neighbour #11)

Just under half of compassionate neighbours indicated that they felt confident in supporting other compassionate neighbours with grief and loss after training (46%), this increased once they had been doing the role for 4-6 months (56%). Only 46% of established compassionate neighbours felt confident. Compassionate neighbours who are in their role for extended periods may experience the loss of people (both community members and compassionate neighbours). The experience of loss may diminish confidence around supporting other people.

Compassionate neighbours spoke to us about the support networks that they formed with each other. Those that had been in the role for 4-6 months ascribed greater support from other compassionate neighbours in the event of grief (79% of respondents) than support available from their friends (65%), family (59%), or hospice staff (77%). They acknowledged support through regular face-to-face meetings, and through social media such as WhatsApp support groups with fellow compassionate neighbours.

“When I messaged them to say that [they] had died, the [hospice lead] was absolutely brilliant. And she messaged regularly... she was adamant that I had to go to the next drop in session. I was able to chat it through with everybody. [...] One of the girls I met on my training course. I see her once a month probably and we support each other really. She’d been great.”

(Compassionate neighbour #8)

We also found that a smaller proportion of established compassionate neighbours reported of being supported by other compassionate neighbours (16%), friends (20%), family (30%), or hospice staff (33%) than did new compassionate neighbours. At the time of the evaluation many new compassionate neighbours joined the project. This influx of new compassionate neighbours may have resulted in more established compassionate neighbours finding it difficult to connect with the compassionate neighbours they knew well. In addition, we observed that established compassionate neighbours were seen to know what they were doing. This respect for their skills and experiences but may have unintended consequences in reducing the amount of support available to them.

Different feelings about death and dying

The evaluation was interested to explore, also, whether becoming a compassionate neighbour resulted in any changes in the way they felt about death and dying. While 69% of compassionate neighbours expected that being a compassionate neighbour would change the way they felt about their own death when asked at training, only 41% of compassionate neighbours indicated that how they felt about their death had changed after 4-6 months in the role. However, 65% of established compassionate neighbours reported that their feelings towards their own death had changed since becoming a compassionate neighbour, suggesting that the way someone feels when thinking about their own death may take time to evolve. Compassionate neighbours offered some explanation about their response and what may have influenced their feelings, or how their feelings had changed. They described how meeting other compassionate neighbours, or spending time with their community member had an impact on how they thought about their own death:

“Meeting people in challenging situations makes me think about how I might be if I were in that situation”

(Compassionate neighbour at Time 2, survey)

“Since knowing my CM I feel much more positive about being independent later in life.”

(Established compassionate neighbour, survey)

“It has re-affirmed the importance of the relationships in my life, the ability to make new friends at any stage of your life.”

(Compassionate neighbour at Time 2, survey)

“It is difficult to put into words. I think that becoming a Compassionate Neighbour has increased my appetite for life!”

(Established compassionate neighbour, survey)

For some thinking about death and dying led to practical action:

“I am accepting of my future demise. I have made a will and told my heir.”

(Established compassionate neighbour, survey)

“I have made a will; paid for my funeral, appointing power of attorney. Making notes about belongings.”

(Established compassionate neighbour, survey)

Some compassionate neighbours told us they now knew about the resources that were available for people at the end of life and the reassurance it offered. Some said they felt less afraid of the end of life.

“I realised that everybody dies but before that you can have respite care in the hospice which releases the stress on your family of trying to cope with a terminal illness.”

(Compassionate neighbour at Time 2, survey)

“Sense of belonging through St Joseph’s Hospice and being able to talk openly about facing death.”

(Established compassionate neighbour, survey)

“The training helped us all address our own anxieties about death and dying - sharing our feelings within the group.”

(Compassionate neighbour at Time 2, survey)

However, for others, the change in how they felt about dying, or becoming ill, was not as straightforward. Some observed that the project could provoke strong emotions, the emotional impact could be difficult to manage. For some who had recently lost a loved one, they found it hard to talk about death and dying.

“I think it’s hard because it’s not for everybody. Its grief isn’t it, they say time heals but it doesn’t - you adjust. That can take as long as it takes.... a couple of things have come up in coffee mornings and I’ve thought oh gosh, that’s really raw, where a couple of people have spoken about similar situations and come from a different place from where we’d hope it have come from. Does it fill in a gap for somebody? It’s hard.”

(Compassionate neighbour #8)

“Lots of preconceptions about dying have been challenged, but not necessarily made easier. Spending time with people with dementia makes you more familiar with the common humanity we all share, whatever our mental state and however outside the social ‘norms’ we operate, but this familiarity does not necessarily make it an ‘easier’ disease to cope with.”

(Established compassionate neighbour, survey)

Promoting societal change

The evaluation sought to explore how compassionate neighbours used their networks to talk about death and dying or contribute to changes in societal views and responses to serious illness. Through the project we heard of many compassionate neighbours taking advantage of the opportunities offered through the broader network provided by the project to engage in outreach. We heard that compassionate neighbours had been involved in street festivals, local markets, farmers markets and other public events. These events and their involvement were important opportunities to engage with the wider community.

We heard from compassionate neighbours that they were comfortable, and often enthusiastic about talking to people they knew, or sometimes people they had just met, about what they did as compassionate neighbours.

“I’m a very shy person... hard to communicate with people. After I did the training, I approach people as a compassionate neighbour, show them my badge... ask if they would like to be matched.”

(Compassionate neighbour #1)

Some suggested the project gave them ‘permission’ to help their neighbour (by which they meant people who lived near to them). This may have been something they were already motivated to do, but did not feel comfortable doing without ‘compassionate neighbour’ status. The project had helped them to embrace this opportunity, part of their initial motivation to sign up in the first place:

“It gives people permission to do it, which is a massive thing I think. A couple of people have said oh I could never do that and I say why? And they say because that’s not a normal thing to do. But I said you’re allowed to talk to people, you’re allowed to smile at them – it’s that sort of thing. It’s almost like a label isn’t it? That will allow you to do that.”

(Compassionate neighbour #8)

Some compassionate neighbours were able to offer examples of where had changed the perspective of another person through conversation. One compassionate neighbour told us that she had spoken to a colleague who was worried about one of her elderly neighbours who lived near her house. After their conversation this colleague decided that she would knock on the door of this person that evening on their way home. A second compassionate neighbour explained to us that becoming a compassionate neighbour had impacts on multiple levels of his life.

He explained that first, it had made him have conversations with his daughters about what he would like to happen at the time of his death, and that these open conversations had resulted in a much more open relationship with them both. Secondly, he had felt that the principles around compassion were very important to some voluntary work he was doing with young people in his local area, and that he had tried to incorporate these in practice.

Finally, he had spoken openly with colleagues and friends in his life about the project, which had opened new conversations about these issues with many people.

Discussion

Reflections on the programme

In our reflections on the programme and our findings as an evaluation team we recognise two key aspects of Compassionate Neighbours. The first is the value placed on the experience of being part of the programme by multiple stakeholders, the second is the unseen complexity of its structures and processes when it is done well.

Our evaluation showed positive outcomes for community members. Few who contributed to this evaluation had bad experiences with their compassionate neighbour. We also confirmed that carers of people living with serious illness find the involvement of a compassionate neighbour useful too. If this is to be maximised then further consideration is required by the programme about its role in supporting carers, what they can expect and whether this relationship extends beyond the life or involvement of the community member. Community members found value in their association with the hospice and amended how they used the hospice to their benefit.

There is good evidence from the evaluation that compassionate neighbours benefit from being part of this programme too, and that their engagement with the hospice is positive also. This is not one way. We believe that hospices benefitted from participating – engaging in new relationships extending their reach and augmenting professional services with those provided by people in the local community. This three-way relationship seems key to the experience of all involved.

That said, enacting this partnership is more complex than we might have thought at the outset. Early in its history the programme identified an important unmet need in people coming to the end of life, even those receiving help from palliative care services. For many people, the experience of dying is a lonely one and this a situation that is increasingly likely when people are older and have been living with illness for a number of years. Compassionate Neighbours facilitates opportunities that allow people to build and maintain relationships over time. While this sounds like a simple idea, relationships between people are never straightforward. As evaluators, we spent over two years with the project, having formal and informal conversations with people involved, collecting quantitative data and observing the project in action.

Our key reflection is that this simple idea requires the thoughtfulness, energy and goodwill of many skilled people. Complex processes of training and matching must occur before compassionate neighbours can build relationships with community members, which in themselves involve delicate interactions.

Training for compassionate neighbours involves a series of workshops and exercises in which new compassionate neighbours get to know each other and discuss how they would deal with different, sometimes challenging, situations. This may involve negotiating sensitive subjects or resolving differences of opinion. Training is designed to help compassionate neighbours make decisions and set boundaries. At its best the training brings together groups of people from a whole range of backgrounds and experiences and there is an added challenge of building connections when there are differences in opinion and approach.

The process of matching compassionate neighbours to community members is complex and potentially time consuming. Project staff spend time getting to know both, attempting to match based on shared interests, personality, sense of humour, or 'fit'. Once a successful match has



been made, compassionate neighbours build relationships with community members who may be different from them and who may be coming to terms with a difficult diagnosis or life event.

We heard from compassionate neighbours how they derived value from these relationships, which they felt were genuine and equal, and how they came to view community members as friends (rather than someone they 'helped'). In building genuine, 'real' relationships we heard that compassionate neighbours often heard or saw emotionally difficult things, and learned how to listen to and process these experiences. Compassionate neighbours are offered opportunities to seek support over time as their role evolves, and they may confront experiences such as death and loss.

Future developments

The origins of the programme can be traced to a small group of people who wanted to redress social isolation and intervene earlier to avoid this in the future. Over time this attracted funding and expanded. Recent developments have resulted in an influx of new compassionate neighbours and new sites in different locations.

Whilst this growth is positive in the eyes of those early participants, expansion can also cause some difficulties. Findings suggested that compassionate neighbours who had been with the programme the longest felt less supported in the scaled-up programme. There are several possible reasons. They may find it harder to connect with each other or seek support from project staff (whose time is divided between more compassionate neighbours). Those who have been with the project for longer are more likely to have seen the health of someone they are close to deteriorate, or experience loss of a community member or other compassionate neighbour they were close to. Over time these compassionate neighbours may have a more realistic view of the challenges of being a compassionate neighbour or may need more support as difficult experiences accumulate over time.

Scaling up allows more people to benefit, but those involved would be foolish not to attend to the challenges identified in the course of this evaluation. The programme relies on people building relationships and supporting one another. This is easier with smaller numbers of people. Relationships are built up through repeated contact over time. This is more difficult to achieve in a larger programme and so adjustments are required accordingly. Holding training over a longer period may allow cohorts to meet more often as an example.



Compassionate neighbours may embrace emotionally difficult situations, but this causes emotional pressure. Finding ways of supporting compassionate neighbours around death and dying is ongoing and can be particularly challenging whilst scaling up, when energies are diverted elsewhere. There appear to be opportunities in which the project could develop support systems organically, including those proposed by compassionate neighbours themselves. For example, compassionate neighbours from one site have suggested they could be matched up to mentor each other and share experiences.

We spoke to several compassionate neighbours who were not matched with a community member, but who were involved in the Compassionate Neighbour community through other activities. However, we often heard that unmatched compassionate neighbours worried that there was something wrong with them, suggesting that they saw the role as being about the 'match'. In contrast we also heard of compassionate neighbours who supported hospice staff to co-ordinate the project itself, through helping with training, running coffee mornings and becoming involved in making new matches. Clarifying the breadth of the compassionate neighbour role description would be helpful.

Our findings and previous research

Our findings add to the (limited) evidence for public health approaches to end of life care. We found that community members enjoyed their relationships with compassionate neighbours, which enabled them to reconnect with places or activities they previously enjoyed. Findings were similar to those of an evaluation into befriending services at end of life, in which patients derived social and psychological benefits from befriending, and that decline in quality of life was mitigated by the presence of skilled befrienders⁹.



Further we found that compassionate neighbours acted with a great deal of agency and autonomy, which, along with the genuine nature of the friendships developed, takes this approach beyond traditional befriending approaches in palliative care and beyond. This finding aligns with another study of the Compassionate Neighbours programme, finding reciprocal relationships between compassionate neighbours and community members, giving control and agency to community members in choosing how they would spend their time with their compassionate neighbours (Sallow, 2018)¹⁰.

Implications for further research

Compassionate neighbours' roles are unlikely to end when community members die, since they may continue to support carers and families. It would be helpful to explore how this 'ongoing' support works. The evaluation did not look at differences between urban (i.e., London) environments against outer-London areas. Many new adopter projects were outside London in areas poorly served by public transport. Exploring implementation challenges in rural areas would be important in understanding how future adopter hospices in rural locations

could be successful. Our findings suggest that the emotional burden of being a compassionate neighbour may be significant and this needs further exploration including research on how to support compassionate neighbours experiencing grief and loss.

Limitations to the research

Collecting information from community members was difficult, as was gaining access to community members. Some hospices were reluctant to refer community members or their carers to be interviewed. We struggled to recruit community members, and this aligns with others' experiences of 'gatekeeping' in research with vulnerable populations. Researchers report difficulties recruiting into a range of studies, partially due to a desire on the part of palliative care staff to protect people approaching the end of life from perceived burdens of research activities¹¹. We got around this to some degree by using peer evaluators – small in number but highly effective. This is a development we invite others in palliative care to consider.

Our final dataset represented a small proportion of the total population of compassionate neighbours (11%). Data collected from compassionate neighbours was

collected at coffee mornings or meetings, and may miss the perspectives of people who cannot attend these meetings through work or other commitments. We also received feedback that the questionnaires were too long. Hospice leads with busy schedules may find co-ordinating data collection time-consuming.

We cannot comment on differences between individual hospice sites because we did not receive enough data from all sites to conduct meaningful analyses.

We were able compare the patterns of data that we received from St Joseph's and the collective of newly adopted hospices. We did not find any differences between them.

Recommendations

The Compassionate Neighbours programme depends on compassionate neighbours' ability to develop and maintain relationships with community members and with each other.

We have the following recommendations to make that focus on this particular aspect of the programme:

1. Hold training over a longer period (i.e. over several occasions rather than in a single chunk of time), giving cohorts of compassionate neighbours more opportunities to build relationships with each other and to reflect on their experiences. This would support the development of peer networks.

2. Offer 'booster' training to existing compassionate neighbours each year.
3. Co-develop support mechanisms with long-term compassionate neighbours, discuss what kind of support would be helpful and decide together on a feasible approach given demands on staff time.
4. Review matches earlier (i.e., after three months) to identify matches that are not working sooner.
5. Explore the benefit of the programme for carers, how carers can be included in compassionate communities, and how compassionate neighbours could employ their skills to help carers.
6. Formalise the negotiation between community members, compassionate neighbours and carers regarding the relationship and any expectations when a match is brokered. Where appropriate, clarify expectations of carers and any other relevant parties.
7. Explore how the contributions of unmatched compassionate neighbours are better recognised. Find ways to share this across the community and with all incoming compassionate neighbours.
8. Ensure some of the support mechanisms (coffee mornings, meetings) are available outside of working hours to make them available to people in full-time employment.



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Appendices

Appendix A: questionnaires for compassionate neighbours

Questionnaire for Compassionate Neighbours at St Joseph's

Information sheet and Instructions for completing this questionnaire

Before answering the questions please make sure you have read the following information and completed a consent form. If you have not been given a consent form then please ask for one.

We are carrying out a survey on behalf of St Joseph's to gather information about the role of Compassionate Neighbours. The evaluation will look at the impact of being a Compassionate Neighbour on individuals as well as on the local community and those who live there.

It is your choice whether to take part or not. If you decide not to take part, this will not affect your relationship with the hospice, or any support or contact with services relating to this work. You can also decide to withdraw at any point, even after signing the consent form – just let us know and we will remove you from the evaluation, again with no negative consequences to you.

We will keep all information that you provide confidential, in line with the all current Data Protection legislation and all data will be securely stored. All data will be kept until all reporting is completed or December 2020, whichever is soonest, at which time it will be destroyed. No identifying information about you will be used in the analysis or reports; we will remove any names from questionnaires should you provide this.

The only circumstances where confidentiality may be broken would be if you reveal that you or someone you know may be at risk of serious harm. We will speak to you about this and then, if necessary, tell the appropriate people.

If you are happy to take part, please complete the consent form. It would be great if you could answer as many questions as possible. If you do not understand a question then please ask for help from a member of the Compassionate Neighbours staff team or contact the research team using the contact details opposite.

For some questions there will be options so please choose the one that most applies to you.

Some questions will also give you the opportunity to add any comments that you feel are relevant – if you run out of space please use an extra sheet of paper and add the question number so that we know what this relates to. To keep all paperwork together question one asks you for your date of birth and initials; this will be used as a unique identifier to ensure anonymity so if you use any additional sheets it would be great if you could add your date of birth and initials on each page.

Once you have finished answering the questions please return the questionnaire to the person who gave it to you. If you have been sent this by post please return in the envelope provided.

Many thanks for agreeing to participate in this important work.

If you have any queries about this please get in contact with Rose at McPin: rosethompson@mcpin.org, or you can call us on 020 7922 7876.

You do not need to give us your name, but if you would like to please add this in the space below:

Your Name (optional): _____

To start with it would be helpful for us to collect a bit of information that will help us to understand more about the kind of people who choose to become a Compassionate Neighbour. We will not be able to use this information to identify you. We will then move on to questions about the role of Compassionate Neighbour.

1. Please can you provide your initials and date of birth so that we can match the response of this questionnaire to your responses to the questionnaire you completed immediately after training (this will NOT identify you in any way other than to use in our confidential evaluation, so anything you say will still be completely anonymous):

Initials: _____

DOB (dd/mm/yyyy): _____ / _____ / _____

2. So that we can record the area in which you live, please can you provide the first part (2, 3 or 4 digits) of your home post code (e.g. AL11, E1, SE26, KT7) _____
 3. How long have you lived in this area? (approximate years) _____
 4. Which Hospice are you connected with as a Compassionate Neighbour? _____
 5. Which gender do you identify with? male female other
- Other Comments: _____
6. How would you describe your ethnicity?

- | | |
|--|---|
| <input type="checkbox"/> White English/ Welsh/ Scottish/ Northern Irish/ British | <input type="checkbox"/> Other Black/Black British background |
| <input type="checkbox"/> White Irish | <input type="checkbox"/> Other Asian background |
| <input type="checkbox"/> White Gypsy or Irish Traveller | <input type="checkbox"/> Asian/ Asian British – Indian |
| <input type="checkbox"/> Other White background | <input type="checkbox"/> Asian/Asian British-Pakistani |
| <input type="checkbox"/> White and Black Caribbean | <input type="checkbox"/> Asian/Asian British – Bangladeshi |
| <input type="checkbox"/> White and Black African | <input type="checkbox"/> Asian/Asian British Chinese |
| <input type="checkbox"/> White and Asian | <input type="checkbox"/> Arab |
| <input type="checkbox"/> Other Mixed background | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Black/ Black British African | <input type="checkbox"/> Not listed |
| <input type="checkbox"/> Black/Black British Caribbean | |

Please give more detail if you would like to: _____

7. How old are you? _____ years

8. What is your religion?

- No religion Buddhist Hindu Sikh
 Christian* Jewish Muslim Other (please specify): _____

*Christian includes C of E, Catholic, Protestant & all other Christian denominations.

9. Please can you list any social, religious or other groups that you are connected/affiliated to/a member of (for example Women's Institute, Church group, Social Club):

10. When did you first train as a Compassionate Neighbour? _____

11. Are you currently matched with a community member? Yes No **If no, go to 11c**

a. If yes, how long have you been matched with your current community member?

b. If yes, how long did you wait after your training to be matched? _____

c. If no, is there anything you would like add about this? _____

12. If you are matched with a community member, approximately how long does it take you to travel to meet with them? (please write NA if not applicable) _____

13. There are many things that people may do as a Compassionate Neighbour. Below is a list of some of the things we know people do.

Can you tell us which ones you do in your role as a Compassionate Neighbour?

	Yes	I am unable to do so due to other commitments	I choose not to do so	No, but I would like to
I spend time with a Community Member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I spend time with people on the wards of my local hospice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I spend time with people who are living in supported accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I spend time with people I know in my community who are coming to the end of their life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I spend time with people I know in my community who I know are lonely or isolated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk with people in my community about living, death and dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	I am unable to do so due to other commitments	I choose not to do so	No, but I would like to
I talk to people in my community about the hospice I am connected to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk with people in my community about the Compassionate Neighbour social movement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I attend coffee mornings with other Compassionate Neighbours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I contribute to discussions during meetings with other Compassionate Neighbours (e.g. PDM's, monthly meet-ups)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am a Compassionate Coach	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other – please provide details: _____				

14. We would like to know about the kind of personal skills you use in your roles as a Compassionate Neighbour. Please complete the following to tell us, how confident you feel in using those skills.

	Not Confident	Some confidence	Confident
Being a good listener	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being accepting or non-judgemental towards different life choices, lifestyles and opinions of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being imaginative (e.g. being able to think of new things to talk about)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Empathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treating people with respect and dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being comfortable in other people's homes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being non-judgemental about other people's home environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking about things that may be emotionally 'close to home' for you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please use this space for anything you would like to add. _____			

15. How confident do you feel about talking about living, death and dying for each of the groups listed below? (for each group, please tick which applies most to you):

Categories of groups or individuals	Not Confident	Some confidence	Confident	NA
With people close to you (e.g. friends or family)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With people in the community you live in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With your Community Member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With other people you may come into contact with as a Compassionate Neighbour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. Since becoming a Compassionate Neighbour do you feel more confident in talking to other people about life, death and dying? Yes No
17. Since becoming a Compassionate Neighbour have you changed the way you feel about your own life and death? Yes No
- a. If yes, can you tell us in what way this has changed? _____

- b. If no, can you tell us in why you think this might be? _____

18. Please can you tell us about anything you find difficult or challenging about your role as a Compassionate Neighbour? _____

19. Is there anything that prevents you attending Compassionate Neighbour meetings or coffee mornings? _____

20. Please can you tell us about anything that you have found disappointing about the Compassionate Neighbour programme? _____

21. Please can you tell us the three best things about your role as a Compassionate Neighbour?

22. Do you feel that you are part of the Compassionate Neighbour community? Yes Somewhat No
23. Do you feel part of the community within the Hospice you are linked to? Yes Somewhat No
24. Have you formed positive relationships with other Compassionate Neighbours? Yes No
 Approximately how many? (please tick below the number that best applies)
 None 1-5 6-10 11-15 16-20 21 or more
25. Have you formed any other new connections or relationships with people other than Compassionate Neighbours since training as a Compassionate Neighbour? Yes No
 Approximately how many (please tick below the number that best applies)?
 None 1-5 6-10 11-15 16-20 21 or more
26. Have you been to any new places since becoming a Compassionate Neighbour? (please list in the space provided)

27. Have you started any new activities or joined any new groups (e.g. social, spiritual or community groups) since becoming a Compassionate Neighbour? Please list in the space provided (you do not have to give the exact name of the group if you do not want to, you can give a brief description of what you do as a group if you prefer)

28. How confident do you feel you would be in supporting another Compassionate Neighbour living through the loss of a Community Member or someone else close to them?
 Not confident Some confidence Confident
 Any comments or examples: _____

29. If you have experienced loss since becoming a Compassionate Neighbour, how supported did you feel?
 (Please tick below the one that most applies from the options below)
 Not at all supported Somewhat supported Very supported
 Who provided this support? (select from below, you may tick more than one)
 Another Compassionate Neighbour A friend (who is not part of the Compassionate Neighbour team)
 Compassionate Neighbour project staff Someone else (please specify)
 A member of my family
 Any comments or examples: _____

30. How confident would you feel about helping others in your community without relying on the support of the Hospice/the Compassionate Neighbour programme (please tick the one which most applies from the options below)?
 Not confident Some confidence Confident
31. The following questions ask about how you feel about different aspects of your life. We would like to know if any of these things have changed over time as you have developed as a Compassionate Neighbour. For each question, please tick the option that best applies and add any related comments in the space below each of these questions.
- | | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| I feel positive about my friendships with others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Any additional comments: _____
_____ | | | | | |
| I feel connected to other people | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Any additional comments: _____
_____ | | | | | |
| If I need advice on a problem related to the Compassionate Neighbours project, I would usually know where to go for help | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Any additional comments: _____
_____ | | | | | |
| My social network consists of lots of people from lots of different backgrounds (e.g. different ages, lifestyles, etc) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Any additional comments: _____
_____ | | | | | |

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I feel positive about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any additional comments: _____					
I feel confident that I can enable people that I may come into contact with in my role as a Compassionate Neighbour to seek a better deal for themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any additional comments: _____					
I feel confident in pushing for a 'better deal' for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any additional comments: _____					
I feel I can make a positive impact on the lives of people in my community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any additional comments: _____					
I feel confident in pursuing the kind of future I would like for myself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any additional comments: _____					
32. If there was one thing that you could change about the Compassionate Neighbours programme what would this be (e.g. matching process, support, time needed, communication)?					

33. Is there anything else you want to tell us that is important about being a Compassionate Neighbour?					

Appendix B: questionnaire for community members

Please can you tick the Yes/No options as you go along and then add comments from your Community Member's responses. Also ensure they have completed the consent form.

This is a guide of questions that can be used in an **informal conversation** with Community Members – depending on who you are speaking to this may need adjusting and you may also find that some questions are answered within others so can be skipped (or you could revisit them for clarification).

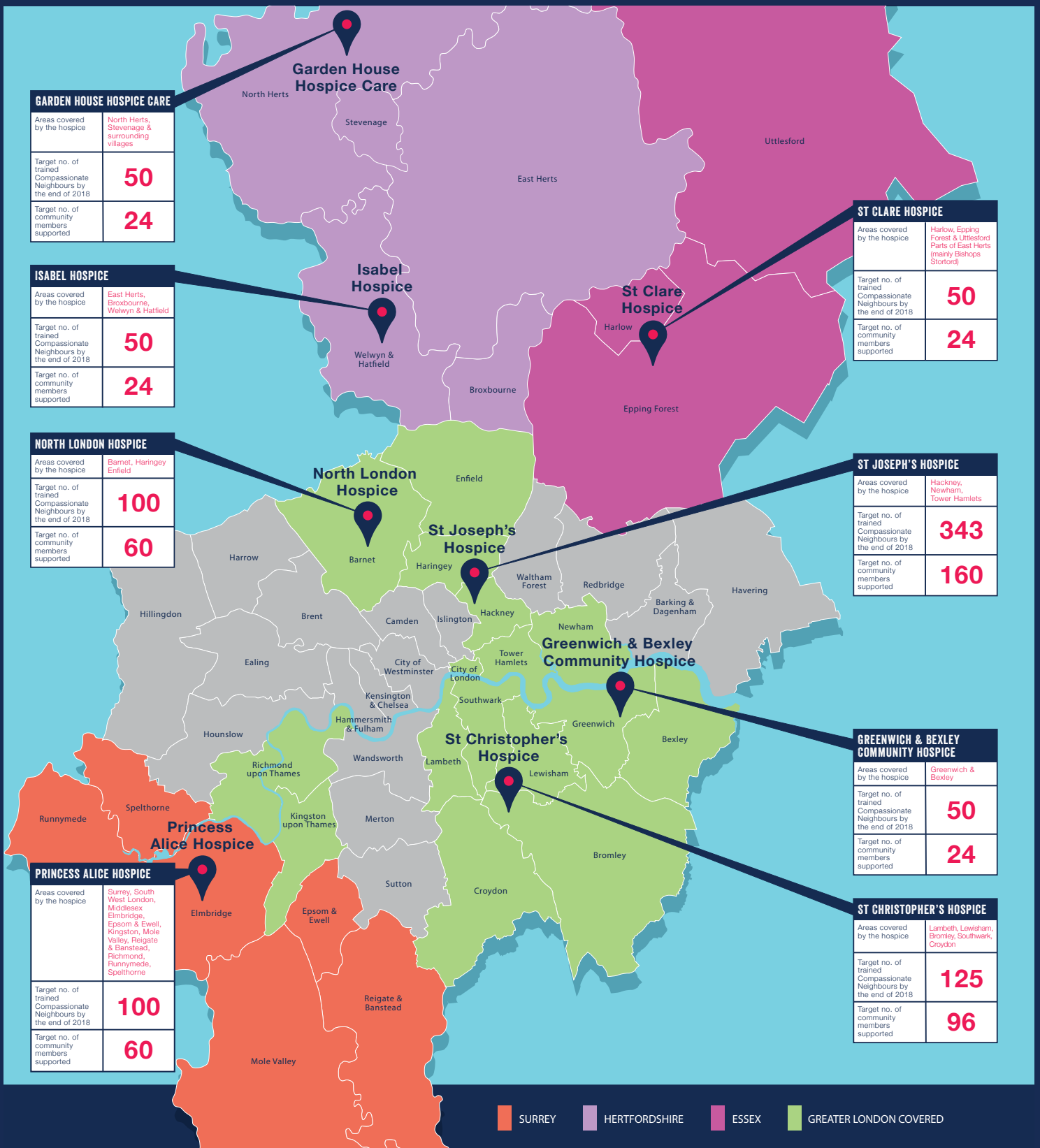
When speaking, rather than keep repeating Compassionate Neighbour use their name.

QUESTIONS

- You've been with your Compassionate Neighbour [NAME] for [_____] months now, is that about right?
- How often do you meet with [COMPASSIONATE NEIGHBOUR NAME]? _____
 - Do they usually come to see you at home? Yes No Sometimes
 - Do you meet or spend time together outside of your home? Yes No Sometimes
 - Where? _____
- Overall, how would you say meeting with [COMPASSIONATE NEIGHBOUR NAME] has been for you? _____
- Do you have any other regular visitors? Yes No
 - Who are they? (can be friends, family, neighbours, professionals) _____
 - What kind of support do they give? _____
 - Do you offer others any kind of support or help? Yes No
Can you tell me about that? _____
- Is the relationship you have with [COMPASSIONATE NEIGHBOUR NAME] any different to the one you have with professionals that come to visit you (e.g. nurse)? Yes No

IF THEY HAVE SAID THEY DO NOT HAVE OR SEE FAMILY SKIP THIS QUESTION

- Is the relationship you have with [COMPASSIONATE NEIGHBOUR NAME] any different to the one you have with your family? Yes No Unsure
- Has [COMPASSIONATE NEIGHBOUR NAME] coming into your life made a difference? Yes No Unsure
Can you say more about this? _____
- Do you feel that [COMPASSIONATE NEIGHBOUR NAME] listens to you? Yes No Sometimes
- Do they understand what you want/what is helpful to you? Yes No Sometimes
- Are there any changes to how connected you feel to what's going on in your local area since meeting with [COMPASSIONATE NEIGHBOUR NAME]? Yes No
 - In what way? _____
 - Any new places that you have found out about or different things that you now do (this might include different parts of their home, accessing other services)? Yes No
 - New people that you have got to know? Yes No
Can you tell us about any of these people? _____
- Did we get the match of you and [COMPASSIONATE NEIGHBOUR NAME] right? Yes No
 - Have you found that you have things in common with your Compassionate Neighbour? Yes No
 - If you were unhappy with your Compassionate Neighbour or any part of the programme would you feel comfortable in speaking to the programme lead about this? Yes No
 - Is there anything about Compassionate Neighbour that you would like to change? Yes No
- Is there anything else that you would like to tell me about how you find meeting with [COMPASSIONATE NEIGHBOUR NAME]? _____



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