

Companions in the Community

Vulnerability and Carbon Monoxide Allowance

November 2024

SGN



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1 Description

Project title	Companions in the Community
Funding GDN(s)	SGN
New/Updated (indicate as appropriate)	New
Date of PEA submission:	November 2024
Project contact name:	Kerry Potter
Project contact email:	Kerry.potter@sgn.co.uk
Total cost (£k)	£759,461
Total VCMA funding required (£k)	£759,461

2 Problem statement

Anyone can experience fuel poverty, but among the groups most vulnerable to the damaging consequence of living in cold housing are older people, those with chronic illnesses or long-term conditions, and people with low or declining incomes. Many people who are terminally ill fall into several, if not all, of these categories.

Terminally ill people are more likely to experience a vicious cycle of fuel poverty. Their deteriorating health means they must spend more to heat their homes sufficiently, which some may struggle to afford due to depleted incomes and the other significant costs associated with their illness. The consequences of living in a cold home can be severe. It can lead to new infections, make existing symptoms flare up or become worse, affect their mental wellbeing and, in the worst cases, even hasten their death.

There is a gap in end-of-life care which means thousands of people in the UK are not getting the care they desperately need. This gap is even bigger for those from marginalised groups and those living in areas of high deprivation. The Care Quality Commission identifies several groups for whom inequality is observed at the end of life (Care Quality Commission, 2016) including people from Black and minority ethnic groups and lesbian, gay, bisexual and transgender people. Further to this, 2 in 5 working age people from ethnic minority communities are dying below the poverty line. Even among those who are not at the end of life, for those in minority ethnic groups the risk of fuel poverty is 18 and 15 percentage points higher in working people and pensioners, respectively, compared with white groups. The difference between these two broad ethnic groups is of a similar magnitude for those in the last 12 months of life. However, this means an alarming 43% of working age people and 27% of pensioners from minority ethnic groups are estimated to be in poverty if they are in the last year of life.

In a recent review, most studies reported that minority ethnic groups are more vulnerable to financial hardship at the end of life than white ethnic groups (Gardiner et al. 2020). Ethnic and cultural differences can influence the progression of advanced disease, illness experiences, attitudes, and access to healthcare (Bischoff et al., 2013), and experiences of and attitudes to palliative care can therefore be affected (Hospice UK, 2021). People from minority ethnic groups may also experience greater difficulties in accessing state benefits and appropriate health-related access to health-related state benefits and services, particularly in older age, when compared with their white peers (Moffatt and Mackintosh, 2009).

We also know that people from these groups are less likely to access Marie Curie services and other palliative care services as evidenced by the insights already captured by Marie Curie's Information and Advice teams and Energy Support Officers. These are due to numerous potential and perceived barriers, such as a lack of cultural and religious sensitivity in how services are delivered, discriminations (and/or fear of it), absence of translation resources, different cultural views regarding the acceptability of openly discussing death, shortages of female doctors for Muslim women and assumptions that family members from ethnically diverse backgrounds will be able and willing to care for relatives at home (Dixon et al, 2015. Op cit).

We recognise this gap in end-of-life care, particularly for people from minoritised communities, the devastating impact it can have and the urgent need for change.

References

1. Dixon et al. 2015. Equity in the Provision of Palliative Care in the UK: Review of Evidence. Personal Social Services Research Unit, London School of Economics and Political Science. Available at: <https://www.pssru.ac.uk/pub/4962.pdf>
2. Gardiner, C., Robinson, J., Connolly, M., Hulme, C., Kang, K., Rowland, C., Larkin, P., Meads, D., Morgan, T., Gott, M., 2020. Equity and the financial costs of informal caregiving in palliative care: A critical debate. *BMC Palliat. Care* 19.,
3. Moffatt, S., Mackintosh, J., 2009. Older peoples experience of proactive welfare rights advice: Qualitative study of a South Asian community. *Ethn. Heal.* 14, 5-25.

3 Scope and objectives

Marie Curie and SGN will proactively target underserved communities to make sure people with a terminal illness can have a warm and safe home by delivering;

- Roadshow events, specifically targeted at reaching underserved communities including ethnic minority groups, LGBTQ+ population and those living in areas of high deprivation. Roadshows will be held in community spaces including libraries, community centres, health centres, GP surgeries, hospital receptions, local Health events, foodbanks/cafes, health and support fayres. At these events Marie Curie Community Engagement and Development Managers will have face to face conversations about fuel poverty, energy support and Marie Curie's end of life services. They'll also distribute materials with additional information about how to access support for people who are experiencing terminal illness and are at risk of fuel poverty. These materials will include translated versions in Romanian, Punjabi and Easy Read to increase accessibility for those who are not confident in communicating in English.
- Face to face workshops for vulnerable people from underserved communities. These events will be hosted in collaboration with partner organisations including: UHS Hospital, The Horizon Centre, The Terrence's Higgins Trust Drop-in centre, Lunch Positive community group, The Lawson Unit, Places of worship and Community Centres. At these workshops Marie Curie Community Engagement and Development Managers will provide personalised, face to face guidance on fuel poverty, energy support and Marie Curie's end of life services. Workshops will focus on building awareness and understanding as well as trust within these communities. Following the workshop Marie Curie staff will refer vulnerable people to other Marie Curie services including Information and Support Energy Support Officers and Community Companions and other organisations within SGN's Safe and Warm Partnership network including National Energy Foundation and local Citizens Advice services.
- Face to face workshops for professionals working in/ with vulnerable people from underserved communities. These will be hosted with partner organisations including those listed above and other charities, community groups. At these workshops Marie Curie Community Engagement and Development Managers will give face to face guidance on fuel poverty, energy support including SGN's Safe and Warm Partnership Network as well as Marie Curie's end of life services, which can be shared with the community.
- Community Companion Service, where trained companion volunteers will be matched with people in their community experiencing terminal illness. Community Companions will develop a relationship with the vulnerable person, supporting them with all aspects of terminal illness including advanced care planning, carer support, emotional support and fuel poverty through 121, in- person visits. They will be trained to identify fuel poverty, they will provide basic energy safeguarding support including CO safety conversations, PSR conversations, support in signing up to PSR and referral to Marie Curie Energy Support Officers. They'll also complete benefits calculations and support vulnerable people to complete benefits applications, increasing the likelihood of that person getting the right support. Community Companions

will also support with any actions recommended following referral to SGN's Safe and Warm Partnership network, for example they may be present during home visits from National Energy Foundation.

4 Why the project is being funded through the VCMA

This project is proposed for funding through the Vulnerability and Carbon Monoxide Allowance (VCMA) which aims to support priority customer groups and those in fuel poverty. This project does this by providing direct support to marginalised and fuel poor people who are struggling to afford to maintain a safe and warm home.

The project delivers against SGN's Vulnerability Strategy, by providing targeted support to households with people with critical illnesses and those communities culturally and or digitally excluding and therefore most at risk of living in fuel poverty based upon their personal circumstances.

This partnership service goes above and beyond our core responsibilities as a Gas Distribution Network and is eligible under the VCMA funding criteria as it will provide energy efficiency advice and carbon monoxide awareness, empowering vulnerable households to use energy safely, efficiently, and affordably.

This partnership aligns to the SGN commitment to deliver support services customers aligned to our four strategic pillars:

1. Services Beyond the Meter
2. **Supporting Priority Customer Groups**
3. Fuel Poverty & Energy Affordability
4. Carbon Monoxide Awareness

This project aligns to strategic pillar 2 with outcomes in 3 and 4.

5 Evidence of stakeholder/customer support

5.1 Marie Curie

Marie Curie's purpose is to create a better end of life for all. We want to see high quality end of life care and support for everybody, but our research and experience has found that profound and persistent inequalities exist, particularly for those who have already encountered unfairness and discrimination throughout their lives.

Research carried out by Marie Curie shows that people from minority ethnic backgrounds are more likely to be experiencing poverty before they reach the end of life, with 27% of pensioners and 42% of working age people from these groups living the last year of their lives below the poverty line. They are therefore likely to be less able to afford the additional costs and income loss brought on by terminal illness, and at particular risk of being below the poverty line as they reach the end of life (Marie Curie Dying in Poverty report, May 2022). Our research also shows the numerous barriers people from minority ethnic backgrounds may face at the end of life, from lack of religious sensitivity to different cultural views around openly discussing death.

Marie Curie has collected feedback from engagement sessions to try to better understand these barriers, with responses ranging from:

"I try and go home to my country for treatment and help, I don't trust or understand the systems here"

"If my family accept help, I feel I will be seen as weak and not doing my duty as a daughter"

"I am worried that if I accept end of life support or help for my family, I will later be asked to pay for it"

There is further Marie Curie research that shows LGBTQ+ people experience inequity in access to healthcare due to discrimination, assumptions made by healthcare professionals and the anticipation of discriminatory behaviour. This is exacerbated for those at the end of life.

One anonymous research participant said:

"I don't want to be shamed for who I am or how I lived. I want to die the way I lived and don't want my life to be erased in any way. Planning for death means, hopefully, I don't lose any agency in death".

Michele's wife Terri was diagnosed with terminal bowel cancer and died at home in March 2020 at home:

"As a gay couple, Teri and I didn't see ourselves represented in healthcare in lots of ways and that does have an effect... People already see barriers in reaching out for help with their grief. Sexuality doesn't need to become an additional barrier to that."

References

1. [h420-dying-in-poverty-5th-pp.pdf \(mariecurie.org.uk\)](https://mariecurie.org.uk/h420-dying-in-poverty-5th-pp.pdf)

5.2 SGNs Vulnerability Steering Group (VSG)

Our VSG has helped us shape our vulnerability strategy and our priorities for GD2 and how best to utilise the VCMA to help those most at risk of living in a cold and unhealthy home. It is with guidance and support from our dedicated VSG that SGN uses data to prioritise and target communities most likely to be living in a cold and unhealthy home, in particular those living with a health condition made worse by living in a cold and damp home.

As we've progressed our portfolio of projects throughout GD2 our strategic steering group reiterated the vital impact we could have by coordinating our activities with others to support those most in need, those most impacted by the cost of living and energy cost crisis. The VSG have recommended that we look to build stronger links with organisations who already are trusted by the community we're looking to support.

In 2024 our strategic steering group re-iterated the vital impact we could have by embedding support services in trusted organisations who can deliver impactful community engagement that addresses the impact of the cost-of-living crisis.

6 Outcomes, associated actions and success criteria

6.1 Outcomes

- Improve awareness of Marie Curie services in underserved communities by providing accessible information and resources to vulnerable people through targeted outreach.
- Increase trust and likelihood of positive action to achieve a warm and safe home through face-to-face personalised energy safeguarding support for vulnerable people from underserved communities.
- Enhance local knowledge of fuel poverty by training Marie Curie staff making them better equipped to support patients, volunteers and others from or linked to underserved communities with enquiries related to utility companies and energy support.
- Support people from underserved communities experiencing terminal illness to sign up to the Priority Services Register helping them achieve greater resilience and peace of mind should they experience a supply interruption or need extra help from their utility companies.
- Ensure terminally ill people from underserved communities have the information they need to be safe at home by having face to face conversations about CO safety.
- Support terminally ill people from underserved communities to access the financial benefits they are entitled to by completing benefits calculations, referring to ESO's or other referral partners from complex checks, and supporting them to complete their application which will in turn increase financial resilience and reduce the risk of fuel poverty.

Recruit and train skilled volunteers to provide support terminally people from underserved communities and by doing so improve wellbeing for terminally ill people from underserved communities by removing some of the fear and stigma around the practical elements of end of life including the complex end of life care system and energy support, allowing people in the last year of their life and those closest to them to focus on what matters the most.

6.2 Success Criteria

SGN and Marie Curie are aiming to deliver the following customer outcomes, which has formed the basis of our social return on investment modelling.

Total customer reach of the programme is targeted to reach 11,100 vulnerable households through community-based events, 1,000 of which will receive personalised support, plus 1,000 professionals from third party organisations who work with/in underserved communities, supporting around 1,800 underserved households, as well as training for 88 staff or volunteers at Marie Curie supporting people at the end of life. This is broken down as:

- Provide in-depth energy support training to 4 Volunteer Service Co-ordinators and 4 Community Engagement and Development managers led by Energy Support Officers
- Recruit and train 80 Community Companions to identify fuel poverty, provide basic energy safeguarding support and onward referral where required
- Provide 11,100 people with face-to-face energy information including PSR and energy safeguarding services such as access to the Cold Weather Payments, Winter Fuel Payments and triage for further energy related enquiries, through roadshow events targeted at underserved communities
- Of those 11,100, provide 1,000 people from underserved communities with personalised energy safeguarding information in face-to-face workshops
- Provide 1,000 professionals from third party organisations who work with/ in underserved communities with energy support information in face-to-face workshops
- Provide 1,800 people referred from third party organisations from underserved communities with personalised energy information through one-to-one support from Community Companions
- Provide 1,800 people from underserved communities with CO safety conversations
- PSR conversations to raise awareness and encourage signups, with a success rate of 1,600 new PSR registrations
- 1,000 benefits calculations completed with support from Community Companions, of which 800 benefits applications will be completed
- Provide 1,650 vulnerable individuals from underserved communities with copies of translated energy resources, signposting to support available such as the PSR, benefits calculator and other energy safeguarding related resources
- Refer vulnerable/terminally ill people from underserved communities who are identified through the project as requiring additional help from energy crisis services via SGN's Safe and Warm Partnership network including National Energy Foundation and local Citizens Advice services.

7 Project partners and third parties involved

- **SGN** - provide funding and ongoing support to deliver successful outcomes for the programme
- **Marie Curie** – lead delivery partner, delivering on Community Companions programme
- **Marie Curie partner organisations including:**
 - The Terence Higgins Trust Brighton
 - Surrey Minority Ethnic Forum (SMEF)
 - St Johns Church, Caterham
 - Actions For Carers Surrey
 - Healthwatch Surrey
 - Tandridge Council (East Surrey)
 - Trussel Trust Caterham
 - Dementia UK (Surrey Branch)
- **We would also explore building new relationships with community organisations such as:**
 - Foodbanks
 - Interfaith Groups
 - Winter Warmer Groups

8 Potential for new learning

Monitoring and evaluation

This partnership has been co-designed by Marie Curie and SGN. The partnership provides access to key services including the PSR, interventions that address fuel poverty and broader safeguarding and wellbeing services to those in need, particularly marginalised client groups.

As we continue to evolve the partnership and progress with the delivery, the following activities will be in place to monitor and evaluate project progress and impacts:

- Quantitative and qualitative customer outcomes
- Feedback questionnaires to ensure that the services are valued by those who use it
- Ongoing referrals from/to partners to ensure that we're delivering outcomes that address both crisis and long-term fuel poverty / health outcomes
- Conversations with Companion volunteers to understand their volunteering experiences, to seek their suggestions for improvement and to identify patterns, trends, and themes.
- Wherever relevant we will ask those accessing the service to complete a short Wellbeing Questionnaire during their first session and at each 3-month review which explores their experiences of the service, what has been most beneficial to them, what could be different and if they think there would be a difference in their health and wellbeing if they had not been accessing the service.
- We will speak with connected professionals to understand their experiences of the service and their professional opinions of the benefits of the service.
- Each month we will review the progress of the support service to share ideas and challenges through individual and organisational partnership case studies.
- Marie Curie will aim to complete an evaluation at the end of the project to evidence impact and SROI.

Marie Curie will also collect the following quantitative data:

- Number of Roadshows hosted
- Number of Workshops hosted
- Number of translated materials shared
- Average number of Companion volunteer sessions provided per person
- Average duration of a Companion volunteer session
- Service activity provided split by service type
- Number of active Companion volunteers
- Number of contacts to Marie Curie's Support Line related to energy and finances in the SGN region
- Number of referrals to SGN's Safe and Warm partnership network
- Number of conversations about the Priority Services Register
- Number of signups to the Priority Services Register
- Number of downloads and print orders for each energy related resource

Learning

We are keen to learn from this project and for successes to be incorporated into ongoing projects that engage communities from marginalised communities to close the gap in end-of-life care.

The monitoring of performance reporting will contain SROI data in line with the measures in this document, and as agreed with SGN, as well as qualitative information about challenges, successes and learnings.

To evidence the impact of this service, the partnership will be managed by an external evaluation company managed by the Impact and Evaluation team at Marie Curie. This evaluation will examine the difference made to service users of both the companion in the community service model and referral to the Energy Support Officers on Marie Curie's Information & Support Line. We will look to evidence impact against outcomes related to improving social isolation and loneliness, improved planning for the future, and the reduced impact of fuel poverty. It will explore enablers and barriers of any improvements in experience and outcomes.

Data sources will include:

- Impact fields and difference questions from the Marie Curie Companions database

- Secondary analysis of service activity data including the number of visits, number of sessions, activities undertaken
- Qualitative interviews with staff, volunteers and service users
- A survey with volunteers about activities completed

We envisage that there will be both an interim and final report, but findings and learnings will be shared as part of regular steering group meetings.

SGN will share the outcomes via stakeholder mechanisms including the SGN Safe and Warm partnership network the GDN Vulnerability Working Group as well as via the VCMA Annual Showcase and VCMA Annual Report.

This project has the potential to be upscaled as a model, working with other GDNs, enabling more underrepresented people to be supported as a result.

9 Scale of VCMA Project and SROI Calculations, including NPV

We and the other Gas Distribution Networks worked with leading social impact research consultancy SIRIO Strategies on the development of the Industry Standard Social Value Framework and supporting GDN Rulebook. We have used that GDN Rulebook to carry out an assessment of the financial and wellbeing outcomes applicable to our services for vulnerable customers incorporated in this partnership. Carrying out an assessment of the predicted outcomes we forecast a positive net Social Return on Investment of £4.46

Social Value Measurement

Total cost*	£740,135.60
Total gross present value	£4,041,995.48
Net Present Value (NPV)	£3,301,859.88
SROI	£4.46

*Accounting for inflationary factors over the term of the project.

10 VCMA Project start and end date

Recruitment for the project will start in October 2024, and the full programme will run to March 2026.

11 Geographic area

The project will take place within the SGN Southern Network, in the below areas:

- Brighton & Hove – with a focus on supporting LGBTQ+ and people living with HIV/AIDS
- Bournemouth – with a focus on supporting people living with high levels of deprivation and poverty
- Surrey – with a targeted focus on high pockets of social deprivation and older generations
- Kent – pockets of people from minority ethnic communities

12 Internal governance and project management evidence

The SROI has been internally assessed by SGN using the GDN rulebook as part of the Industry Standard Social Value Framework, the current partnership scope has been forecast at adding an additional £4.46 for each £1 invested, this will be monitored closely to ensure we adhere to the VCMA governance criteria.

SGN and the project team will meet monthly and quarterly to review outcomes, learn, share best practices, and address any delivery issues.

The PEA has been reviewed and approved by the business lead Kerry Potter and the Director of Customer Services Maureen McIntosh.