

# Results from an analysis of hospice community volunteering



**Author: Dr Ros Scott**  
Voluntary Sector Researcher and Consultant

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# Acknowledgements

We would like to acknowledge thank all those who responded to the survey and interviews. We would also like to acknowledge the contribution and support of the project reference group:

**Carly Attridge**, Head of Volunteering, St Joseph's Hospice, London

**Gillian Austin**, Head of Volunteering, The Hospice of St Francis, Berkhamstead.

**Barbara Gale**, Chief Executive, St Nicholas Hospice, Bury St Edmunds

**Jean Hindmarch**, Projects Director, Hospice UK

**Melanie Hodson**, Information Specialist, Hospice UK

**Katrina MacNamara**, Director of Service Development and Improvement, Together for Short Lives

**Professor Catherine Walshe**, Director of the International Observatory on End of Life Care, Lancaster University

Thank you also to **Amber Morgan**, Programmes Coordinator Hospice UK for her support to the project.

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Published by Hospice UK in May 2019

# Executive summary

## Background

The last few years have seen some very significant changes in hospice volunteering as volunteers have become increasingly involved in the direct support of people with palliative and end of life care (PEOLC) needs in the community, along with their families and carers. In this context volunteers are more empowered, working alone with much less day-to-day supervision from staff. As this area of palliative care continues to grow it is important to understand more about the extent, frameworks and value of community volunteering.

This has prompted a Hospice UK project to explore this area in more depth and to develop an electronic signposting resource built on the experiences of current hospice community volunteering programmes.

## Project aims

The aims of the project were to:

- map the extent of community volunteering activity in hospice organisations
- gather information about the services already in place and identify any barriers to developing such services
- create an electronic resource to help the development of voluntary support in this context.

## Method

A reference group, comprising people with expertise in this field, oversaw the project. A 40 item online questionnaire was developed and circulated to the Hospice UK membership of 225 hospices. This was followed by a small number of semi-structured interviews. Qualitative data were analysed using a framework approach. Quantitative data were used as descriptive statistics to give context.

## Key Findings

### Overview

With a response rate of 54%, 121 hospice organisations completed the survey. This included six children's hospices, the data from which were analysed and reported separately. Findings demonstrated that:

- 70% (n= 80) of adult hospice respondents had community volunteering programmes.
- 9% had more than one such service.
- Of the 35 hospices without a community volunteering service, 21 (60%) wished to develop one.
- 45% offered support to people with PEOLC needs not using hospice services.
- A diverse range of support was offered to people with PEOLC needs and their carers including practical, emotional support.
- The focus of support was mainly companionship, neighbourliness and enablement.

- All except two services had a range of policies in place for community volunteering.
- 63% (n=50) of hospices with existing community volunteering services intended to develop these further by increasing the size and scope or by developing new models of support.
- Two children's hospices supported families in the community caring for a child with a life-limiting/ life-threatening condition, whilst another was using Together we Can<sup>1</sup> resources to develop a pilot project.

### **Type of support offered**

A diverse range of support was provided and of the services that gave this information:

- 75% (n= 72) offered volunteer support to people with PEOLC needs as long as required; 62% (n=60) offered support to families/carers as long as required.
- 25% (n=24) offered time-limited volunteer support to people with PEOLC needs; 38% (n=36) time-limited volunteer support to families and carers.
- 52% (n=52) of services extended volunteer support into bereavement.
- 83% (n=48) of services were staff-led.
- 7% (n=4) identified themselves as volunteer or community-led.

### **Management, service profile and costs**

Only a small number of respondents gave management data. From those who provided this data the findings suggest that:

- The hours of support given by volunteers varied widely.
- Two hours per week was the amount of support most commonly offered but this was generally influenced by individual circumstances and need.
- The number of staff required to run community volunteering services varied between 0.2 and 3 FTE and was most frequently given as 0.6-1 FTE. Other staff were often involved in supporting the service.
- Staff costs varied widely but ranged between £15,000 pa and £80,000 pa.
- The cost of volunteer expenses also varied widely but commonly ranged between £100 pa and £7,000 pa with few volunteers claiming reimbursement.
- The cost of training for volunteers was most frequently under £2,000 pa.

### **Preparation and training and support**

A range of training supervision and support was offered and this included induction to the organisation as well as comprehensive training programmes. Findings suggest that:

- There was broad similarity in the training provided to community volunteers, which covered a wide range of topics.
- There was little difference in the training topic content between staff-led and volunteer or community-led volunteering programmes.
- Community-led volunteering programmes appeared to have a greater emphasis on helping volunteers to build on their inherent skills.

- 63% (n=37) of services included training as part of the volunteer selection process.
- The length of training varied widely.
- All respondents provided support and supervision to community volunteers, including, group, peer and one to one support.

## Benefits and drawbacks

### Benefits

The benefits identified for people with PEOLC needs emerged under three key themes:

- companionship, friendship and relationships
- improved wellbeing
- improved access to services and better care.

Very similar benefits for carers were identified but with the addition of respite care, which was reported most frequently. Benefits for staff and organisations included better understanding of the needs of people with PEOLC needs and their families and a stronger connection to the community.

Four key benefits for volunteers were identified:

- personal development/ experience for employment
- giving back/making a difference
- a sense of purpose and fulfilment
- improved health and wellbeing.

### Drawbacks

Drawbacks emerged under four key themes:

- management (including recruitment, support, training, funding),
- maintaining boundaries
- meeting demand
- managing risk.

## Hospices without community volunteering services

Of the 30% (n=35) of hospice organisations that had no community volunteering service the reasons given most frequently included that they were currently planning or developing a service, or lacked the resources, capacity or ability to support such a service.

## Challenges in developing community volunteering services

A number of organisations had identified a range of challenges in developing community volunteering services including:

- lack of funding
- lack of internal support

- organisational culture and challenges in involving volunteers
- lack of time to develop training and concerns about boundaries.

When asked what would help to develop services, respondents overwhelmingly identified guidance, case studies and examples from hospices experienced in this area.

## Findings from interviews

Interviewees provided more detailed information in response to six key themes:

- The impetus for starting the service and overcoming challenges.
- Inclusion criteria for people to receive volunteer support.
- The possibility of re-referral to the community volunteering service.
- Specific activities that volunteers are not permitted to do and the reasons for this.
- The type of support most often accessed.
- The management of risk.

Reasons given most frequently for the development of community volunteering programmes were to extend the organisation's reach and improve the support provided or being influenced by others already doing this. Challenges were most frequently overcome through engagement with other hospices with experience of community volunteering. Inclusion criteria varied widely and in most cases were geographic or health related.

Although permitted volunteer activities varied by organisation, in almost all circumstances volunteers were not allowed to give personal care or medication. The most frequently requested support by both people with PEOLC needs and their carers was companionship, enabling social connections, and respite for carers. Risk was managed in a variety of ways, including training, supervision and risk assessment.

## Summary and conclusion

The findings provided a wealth of rich data giving valuable insights into hospice community volunteering in the UK. They suggest a significant change in the way in which volunteers are involved with people with PEOLC needs. There appears to be a growing move towards this type of volunteering with a clear interest from those hospices not already involved. It is possible, however, that respondents were drawn from organisations most committed to this type of volunteering, and findings may not necessarily be reflected across the wider Hospice UK membership.

There are clear benefits to people with PEOLC needs, their families and carers, organisations, volunteers and communities. However, challenges also exist in developing such volunteering programmes. The sharing of knowledge and experience by hospices with experience of community volunteering was clearly important in helping others to overcome challenges. Although the minority of community programmes are volunteer or community-led, a number of hospices were keen to move more towards this model. It would appear, therefore, that the proposed Hospice UK community volunteering resource hub is timely.



# Section 1: Overview

## Background

In recent years, volunteers have become increasingly involved in supporting people with palliative and end of life care needs and their families and carers in the community. This support involves a spectrum of volunteering services from those managed by staff, to those led by volunteers. A key change that has emerged from this evolution is the growing empowerment of volunteers, working alone with much less onsite day-to-day supervision from staff than would be usual in inpatient and day care hospice settings. It is important to understand more about this area of hospice volunteering, as hospices see the involvement of volunteers as vital in helping them to address rapidly growing demands for their services.

This has led to the development of a Hospice UK project to explore in more detail volunteering in people's homes, similar to Hospice Neighbours<sup>2</sup> and Compassionate Neighbours<sup>2</sup>. This project has built upon work already undertaken in the children's hospice and palliative care sector by Together for Short Lives, which developed and piloted resources (Together We Can) which support families at home caring for a child with a life-limiting condition.<sup>1</sup>

## Project aims

The aims of the project were to:

- map the extent of community volunteering activity in hospice organisations
- gather information about the services already in place and identify any barriers to developing such services
- create an electronic resource to help the development of voluntary support in this context.

This report summarises the findings from a survey and interviews undertaken to inform the work of this community volunteering project and the subsequent electronic resource.

## Note on definitions and terminology

For the purposes of this project community volunteering is defined as “volunteering undertaken out of the hospice building, directly supporting people with palliative and end of life care needs in their homes.” The survey intentionally did not use the term ‘patient’ but referred to ‘adults with palliative and end of life care needs’. In this report, therefore, the word ‘patient’ is only used in quotes from respondents and the term ‘person/people with PEOLC needs’ is used throughout.

## Method

A 40 item online questionnaire was developed, reviewed by the project reference group, piloted and revised prior to circulation. Comprising multiple choice and open-ended questions, it was circulated to the full membership of Hospice UK: 225 hospices, including 14 combined adult and children's services and 25 children's hospices. Quantitative analysis was undertaken using both the online survey data output and Excel.

Qualitative data were analysed using a framework approach. Quantitative data were used as descriptive statistics to give context to the study.

Semi-structured follow up interviews were undertaken with the cohort respondents who had indicated their willingness to do so (n=48). The purpose of the interviews was to explore themes emerging from the survey. The number of interviews was necessarily limited because of timescales and resources.

Ten semi-structured interviews were undertaken. Participants were initially randomly selected. However, some adjustments were subsequently made to ensure a geographic spread.

## **Introduction to findings**

Responses were received from 121 hospice organisations, giving a good response rate of 54%. Also included in the total number of hospices were six children's services. As the focus of the study was adult hospices, the children's hospice data were extracted and analysed separately, so that the adult data were not skewed. A total of 115 adult hospices were included in the survey analysis.

Examination of children's hospice data found limited information from five of the six hospices. One hospice, however, gave comprehensive data from their community volunteering service for young adults and their families/carers. The data were closely comparable with those from adult hospices. Therefore, in order to protect the anonymity of the organisation, these data are included with the adult hospice data reported. Findings from the remaining five children's hospices are reported in Section 7 of this report.

Of the 115 adult hospice organisations, 80 (70%) indicated that they involved volunteers in supporting adults with palliative and end of life care needs in the community. Indeed 10 organisations (9%) had more than one community volunteering service. Thirty-five (30%) indicated that they did not.

# Section 2: Service provision: hospices with community volunteering services

The survey asked respondents to give details about the extent to which community volunteering support was offered to people who did not use hospice services. They were also asked about the source of referrals, the type and length of support offered to people and to their families and carers.

## Supporting those not using the hospice: numbers and referrals

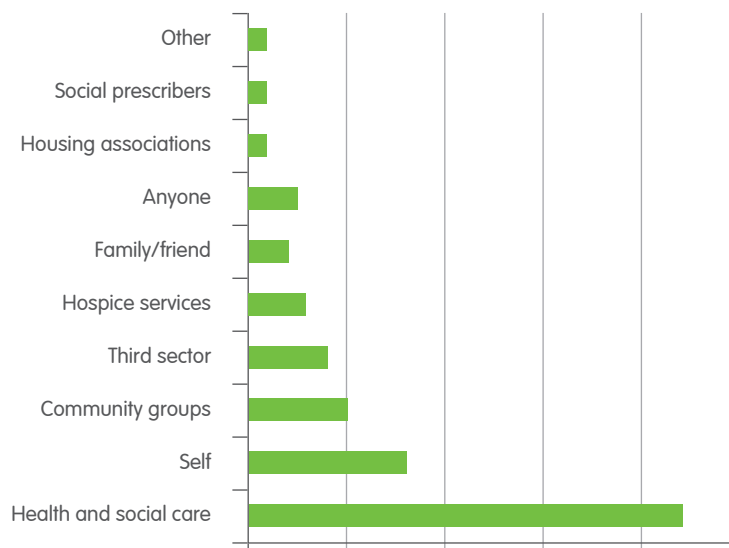
Of those who responded to this question, just under half (45% n=43) offered support to those not using hospice services, whilst 55% (n=53) of services did not.

For those services that extended support to this group, referrals came from three main areas. These comprised:

- **Health and social care** - GPs, hospitals, district nurses, community nursing teams, hospices (including bereavement and advanced care planning services), clinical nurse specialists, occupational therapists, physiotherapists, social workers, mental health services and nursing homes.
- **Other organisations** - community groups, third sector organisations, faith groups, housing associations, social prescribers, community libraries and police.
- **Individuals** - self-referral, family, friends and anyone.

As can be seen in Figure 1 the most common source of referrals are from health and social care and self-referral. One respondent noted that their Hospice Neighbour service could also be part of the local hospital's discharge planning.

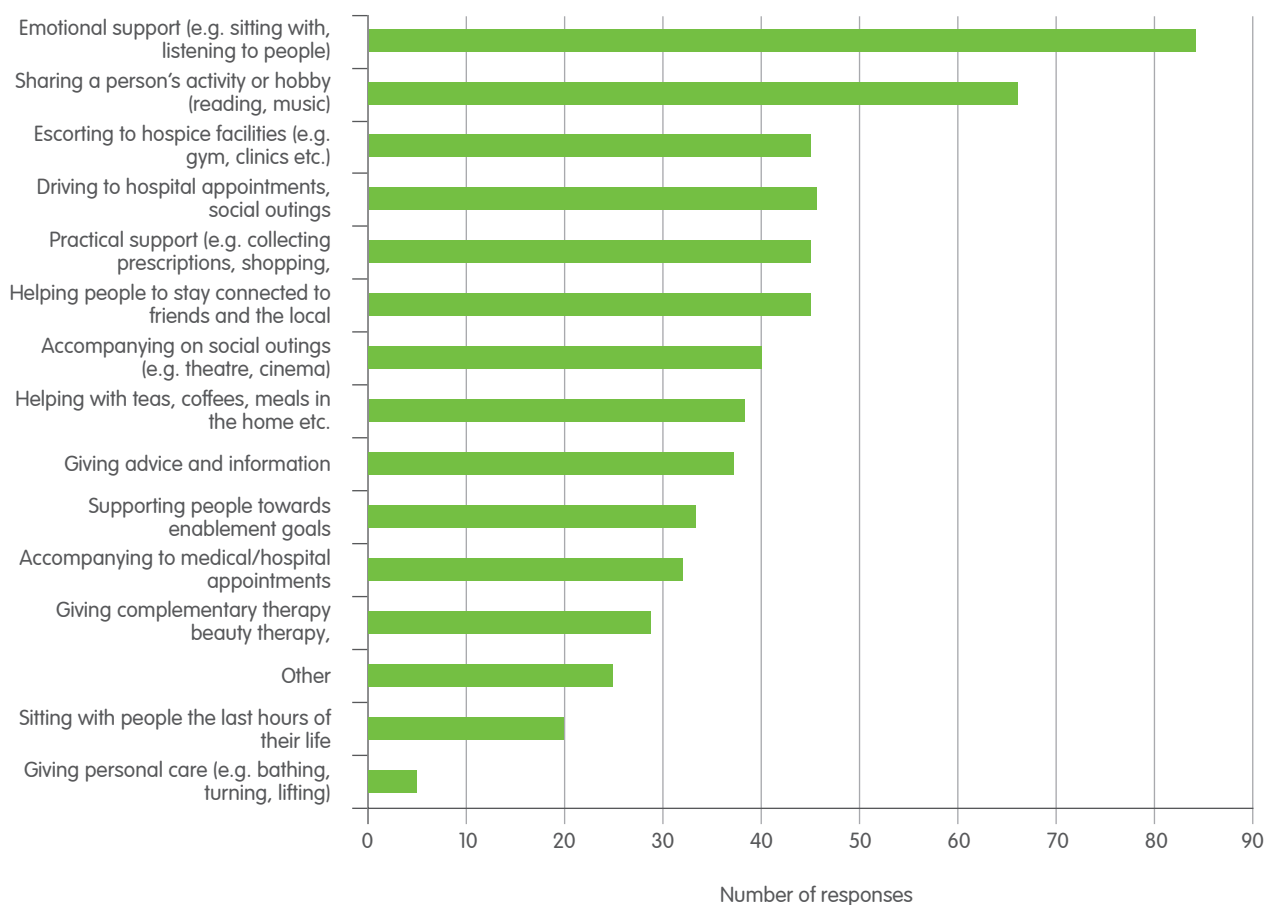
Figure 1: Sources of referrals



## Support offered to people with PEOLC needs

Figure 2 shows the range of support offered by community volunteers as reported by participants. By far the most frequently offered service is the provision of emotional support followed by sharing activities or hobbies. The least common service offered was personal care.

**Figure 2: Volunteer support for adults with PEOLC needs in the community**



### Other support for people with PEOLC needs.

Figure 2 also shows that a number of respondents gave details of 'other' support offered to people with PEOLC needs which had not been included in the multiple-choice categories including:

- company that a neighbour would provide
- support with applications to official bodies such as Department of Work and Pensions or the Office of Public Guardian
- one to one telephone or group support
- helping people to make the transition from hospice to home
- advance care planning
- counselling
- rehabilitation sessions
- practical activities done in partnership with rather than for the person.

Examples provided by respondents included:

“Our Hospice Neighbours will also do light housework (vacuuming, cleaning, ironing, washing clothes) and make light meals for a patient in their homes. They will also provide help with journaling, arranging photo’s, putting together memory boxes and help with technology.”

*(Hospice 89)*

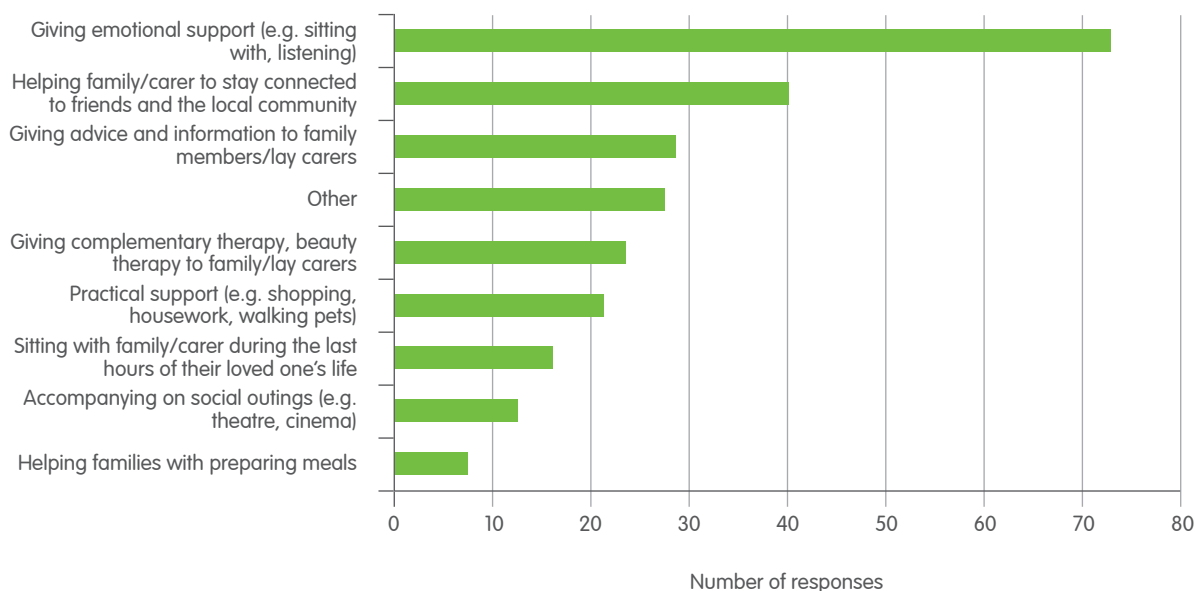
“For some this may be language support or maintaining use of the first language in care settings if access to first language is limited.”

*(Hospice 44)*

## Support offered to families and carers

Once again respondents reported a range of support offered in the community to families and carers as shown in Figure 3. There were similarities to the support offered to people with PEOLC.

**Figure 3: Volunteer support for families/carers**



## Other support offered to families and carers

Figure 3 also shows that a number of respondents gave details of ‘other’ support offered to families and carers which had not been included in the multiple choice categories. Most described this support as offering respite to carers. Such support included:

- helping with benefit applications
- signposting to correct services
- transport for family members

- helping the carer to provide support for rehabilitation and physiotherapy
- pre-bereavement and bereavement support.

Further insights provided by respondents included:

“Part of the X Volunteer’s role is teaching family members practical skills on breathlessness management techniques and demonstrating rehabilitation exercises so that family members can support the patient on their goals safely and confidently.”

*(Hospice 84)*

"We have a bereavement drop in and will encourage people who feel isolated after death to re-engage via coming to the drop in and meeting other bereaved people. This may follow a period of time where the befriender has been visiting them at home first."

*(Hospice 28)*

## Length of support offered to adults with PEOLC needs

In response to this question, of the services that responded 75% (n=72) offered volunteer support for as long as required with 25% (n=24) offering support for a specified length of time only. It was clear that time-limited support was not only determined by a set period, but also by progress against agreed goals, as described by a small number of respondents.

### Time-limited support

Time-limited support was described variously by weeks, visits, months, progress towards goals or for as long as the person met the criteria for support. The type of support offered could also determine the period over which it was given, for example where support was provided to help people through specific stages, or with complementary therapy treatments. Some services included a review of progress and support could be extended according to need. Timescales were wide ranging from six weeks to twelve months. One respondent noted that their community volunteers provided support in the last two weeks of life and another service would provide support indefinitely in certain circumstances. Few respondents stated the frequency of visits but for those that did this was typically for 2-3 hours per week.

### Goal oriented support

One respondent described support being time-limited for people with long-term conditions where goals had been set. Another offered six weeks of goal-oriented rehabilitation.

One individual gave details:

"X Team volunteers offer eight weeks of 1-1.5 hours of support after which a review is carried out to assess progress made towards goals. Additional sessions are offered if the goal is partially achieved or if new goals have been identified".

*(Hospice 84)*

## Length of support offered to families/carers

Respondents were asked to give details regarding the length of support offered to families and carers. Of the services that responded to this question, 62% (n=60) offered the service for as long as required and 38% (n=36) offered the service for a specified length of time only. Five respondents indicated that they did not offer this support. A number of services indicated that the support offered to families was similar in structure and length to that offered to those with PEOLC needs. This included goal-oriented support, time-limited support, and more open-ended support.

### Time-limited support

Once again, time-limited support was expressed in terms of weeks, visits, months, progress towards goals, or for as long as the person met the criteria for support. Most time-limited support for families and carers also included ongoing review and assessment with the possibility for extension as required. Timescales were similar to those for people with PEOLC needs, ranging from six weeks to 12 months. The frequency of support was not given.

Two respondents highlighted that:

"Support is given to the patient predominately, when the patient dies the visits cease, but some volunteers do continue in their own time as friends. Would be sign posted to other support."

*(Hospice 88)*

“We never cut off support, but specialist services, e.g. complementary therapies and counselling, are offered on a time-limited basis, according to need but we are very flexible with the length of that time.”

*(Hospice 15)*

For some services, support to families and carers continued after the death of the person with PEOLC needs.

## **Extending volunteer support into bereavement**

Findings suggest that it is not uncommon for community volunteering support for families and carers to extend into bereavement. In responding to this question, 54% (n=52) offered this care as part of the service, 24% (n=23) did not and 22% (n=21) provided support on an occasional basis. In some cases pre-bereavement support was also offered.

The length of such support varied and ranged from six weeks to 12 months. One service offered support for two years following bereavement. The frequency of support was not reported except by one service that offered a monthly Carer's Drop-in service.

One respondent added:

“We will provide support to families after the person has died for a length of time that is appropriate, then we will try to signpost them to organisations that will be more suitable.”

*(Hospice 68)*



# Section 3: Management, service profile and costs

Respondents were asked in this section of the survey to give details about service management, length of time in existence, number, age, gender of and hours given by volunteers, number of people supported, number of staff required to run the service and a breakdown of costs.

## Management of the community volunteering service

It was clear from responses given that community volunteering services are overwhelmingly staff led (83%, n=48), with volunteers delivering services. Only four services (7%) identified themselves as being volunteer and community-led. Of the six services (10%) which indicated an alternative leadership structure, three would appear to be staff-led. In one instance this was led by paid staff not employed by the hospice.

One respondent described their service as staff, volunteer and community-led whilst another indicated that:

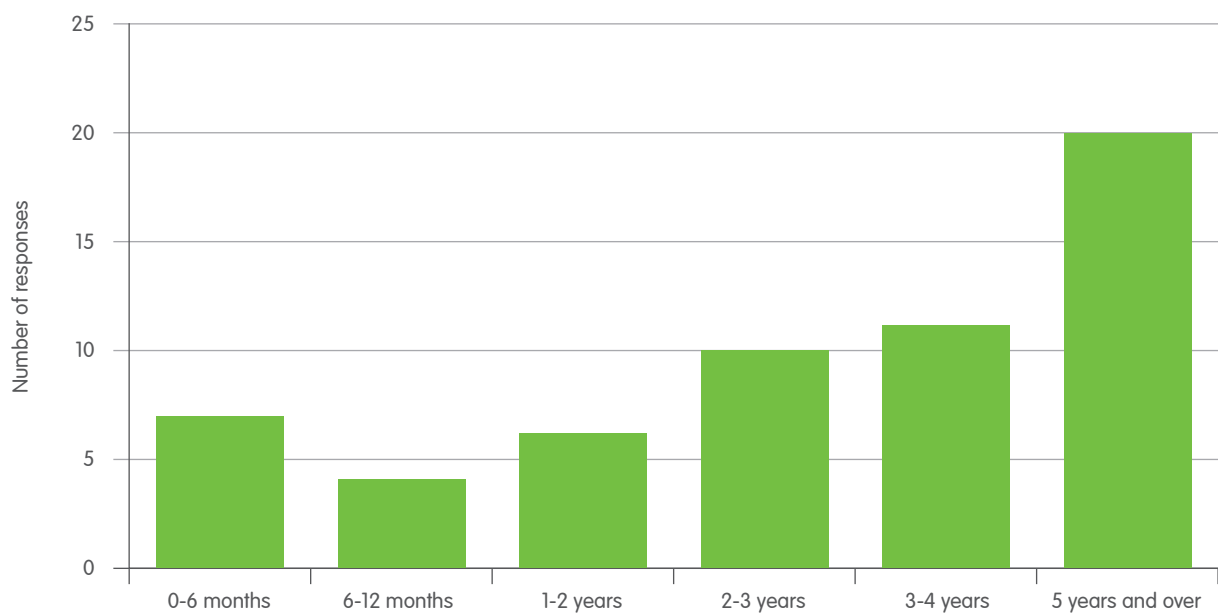
“Whilst we have project staff we see the project as community led, with major stakeholders being our neighbours and community members, as such power is shared.”

(Hospice 84)

## Length of time community volunteering service has been running

As can be seen in Figure 4, just over half of those who responded indicate that community volunteering services had been running for more than three years (n=31), 10 between two and three years, with 17 in existence for less than two years.

Figure 4: Length of time service has been running



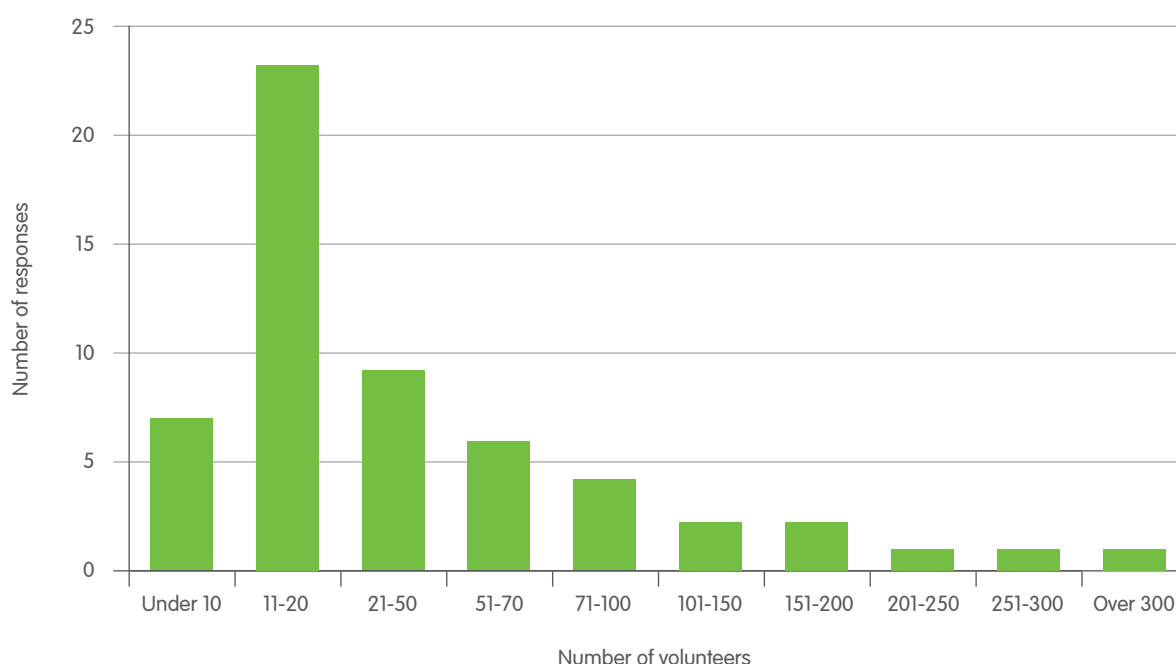


## Profile of volunteers and volunteering

### Number and gender of volunteers

Respondents were asked about the number of volunteers involved in their community volunteering service or services. The responses are shown in Figure 5. The majority of services that responded involved fifty or fewer volunteers.

**Figure 5: Number of volunteers**

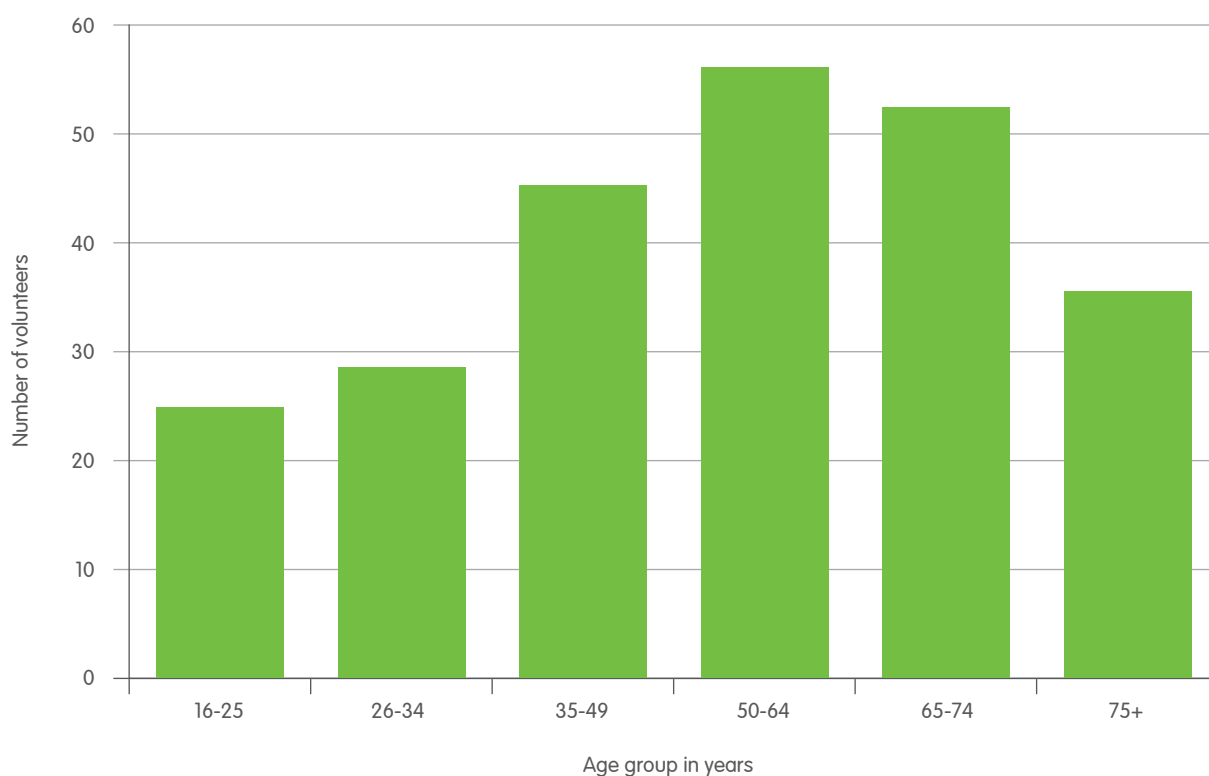


The responses indicated that the majority of volunteers are female, making up 78% (n=1915) of the total number of volunteers stated in this question. Only 22% (n=531) were men.

## Age profile of community volunteers

As shown in Figure 6 the majority of volunteers were aged between 35 and 74 and they are fairly evenly spread across the three age groups in this range. The lowest number of volunteers was to be found in the 16-25 years age range.

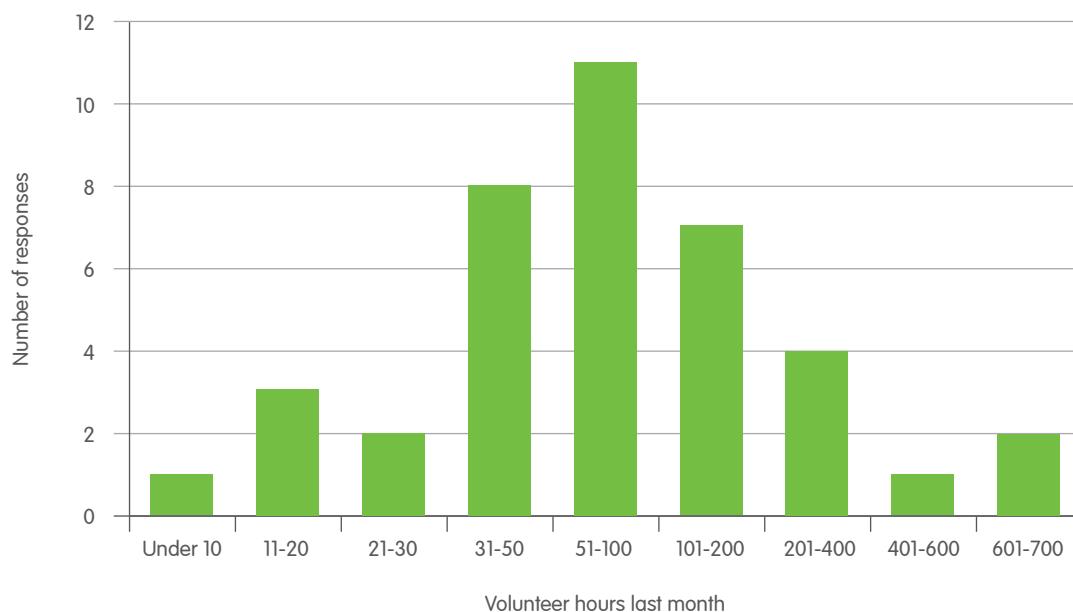
**Figure 6: Age profile of volunteers**



## Volunteer hours given in the last month

The number of hours given by community volunteers in the last month varied widely, as can be seen in Figure 7.

**Figure 7: Community volunteer hours in the last month**



Not all services recorded this data and one stated:

"We don't record hours as the project is fairly light touch but I would say around 100 hours a month."

*(Hospice 98)*

One service gave a breakdown of how their volunteer hours were calculated:

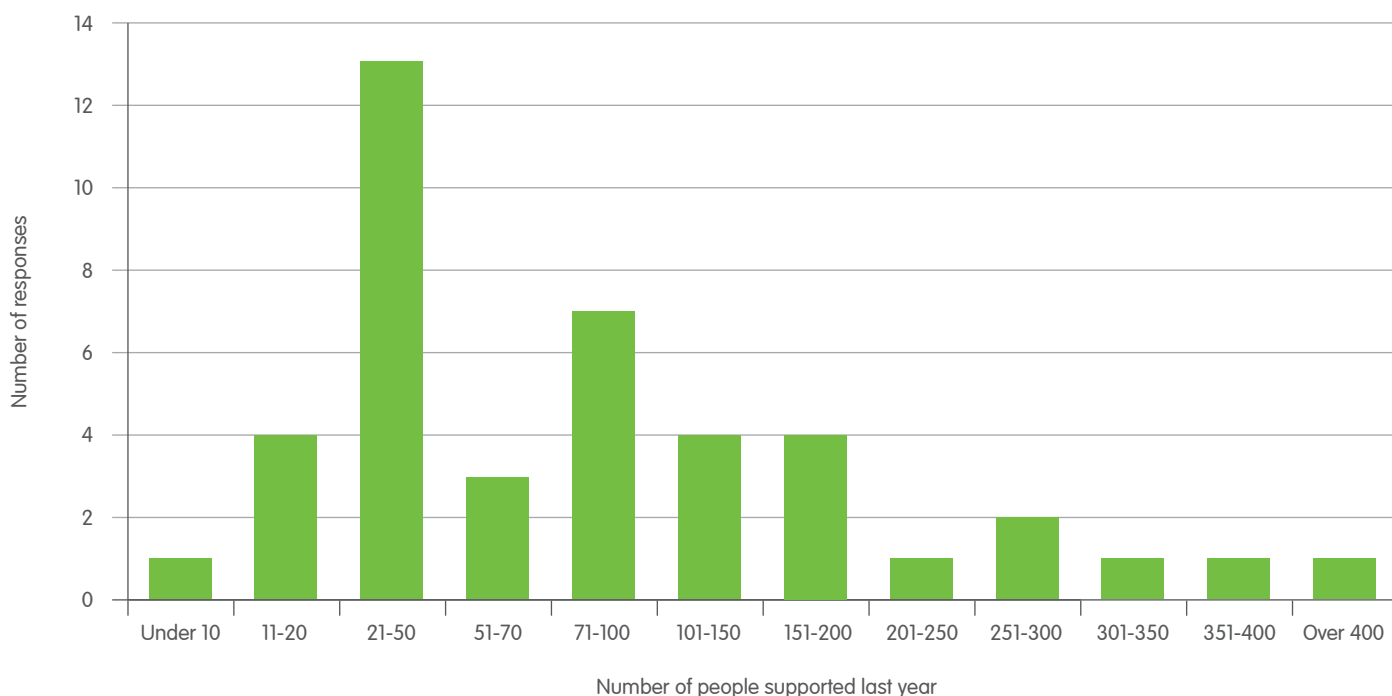
"Approximately 21 hours directly with patient, plus approximately 21 hours of travel to and from patients home, approximately 10 hours of meeting time to get briefed about patient approximately 2.5 hours to attend case sharing and group supervision session."

*(Hospice 84)*

## Number of people supported by community volunteering per year

Only a small number of services completed this question and a number noted that they could not provide this data. Findings, as shown in Figure 8, suggest that in the main, smaller numbers of people tend to be supported by community volunteers. One service quoted a figure of 4,000 people supported but it is unclear whether this related solely to the community volunteering service.

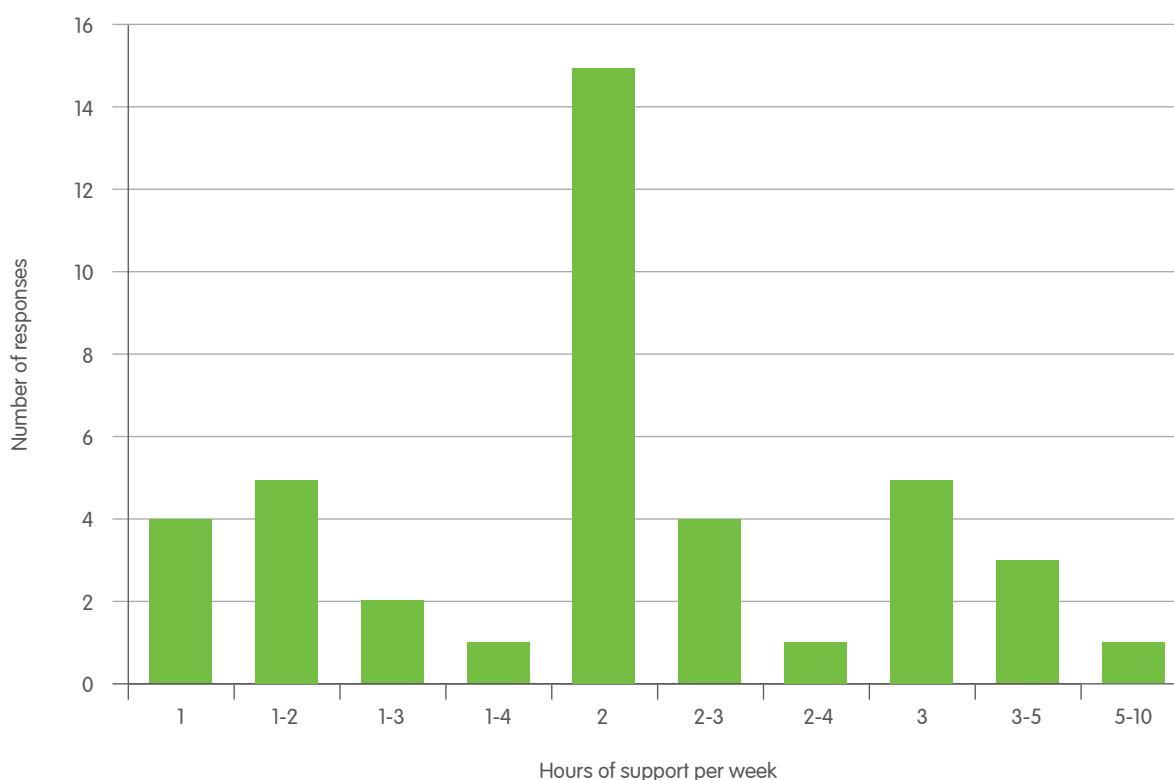
**Figure 8: Number of people supported by community volunteering**



## Hours of support received

Respondents were asked to give details about the number of hours of volunteer support received by people each week. Although this varied, the most typical level of support received was two hours, as shown in Figure 9.

Figure 9: Hours of support received by individuals per week



A number of services did not record this data, and for others the support offered varied depending on need, the person's condition, or the type of support accessed, as highlighted by the following quotes:

"It varies on the type of volunteer support offered - some people access monthly walk and talk support others receive a weekly visit from a hospice neighbour."

*(Hospice 55)*

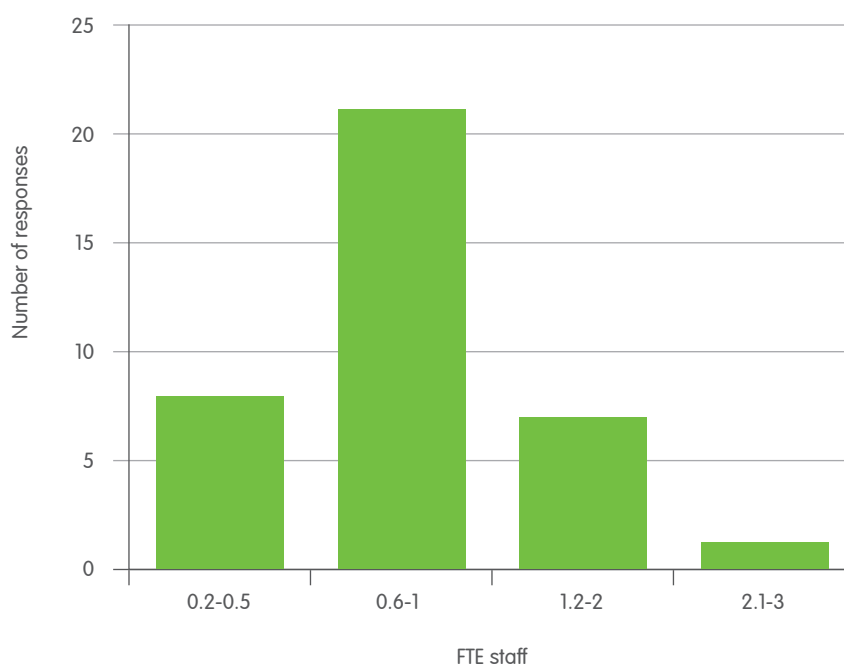
"We suggest an hour a week, but it's up to both people to decide this, we're flexible. Most of our volunteers do more than this, but we don't ask them to report back on visits."

*(Hospice 77)*

## Number of full-time equivalent staff required

Respondents were asked to give details of the number of full-time equivalent (FTE) staff required to run the community volunteering service. Of those that responded, the majority of services indicated that a 0.6-1 FTE member of staff was required to run the service, as shown in Figure 10.

**Figure 10: Number of FTE staff required to run service**



A number of services quoted significantly higher figures, including 12, 16, 22 and 33 FTE staff. As these figures were not consistent with large services, based on information given in Questions 19-21, it may be that these figures quoted relate to the number of staff who are involved in some way with the community volunteers. Additional information was provided by some services:

"10 approximately - but they are not solely running this service, they have volunteers embedded in their teams."

*(Hospice 13)*

"No one person is designated to run the service it falls under our hospice at home team."

*(Hospice 60)*

## Community volunteering service costs per year

This question asked for details of the annual cost of the community volunteering service under four headings:

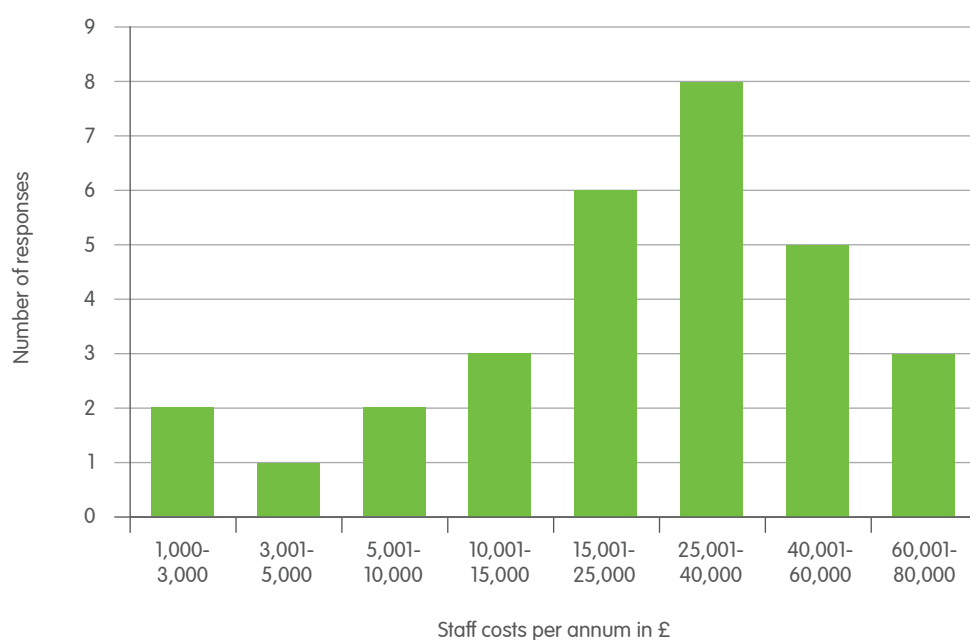
- staff
- volunteer expenses
- volunteer training
- other.

Only a small number of services provided this information.

## Staff Costs

As shown in Figure 11, staff costs vary considerably across the 30 services that responded. For the majority of services the costs were in excess, ranging between £15,000 pa and £80,000 pa.

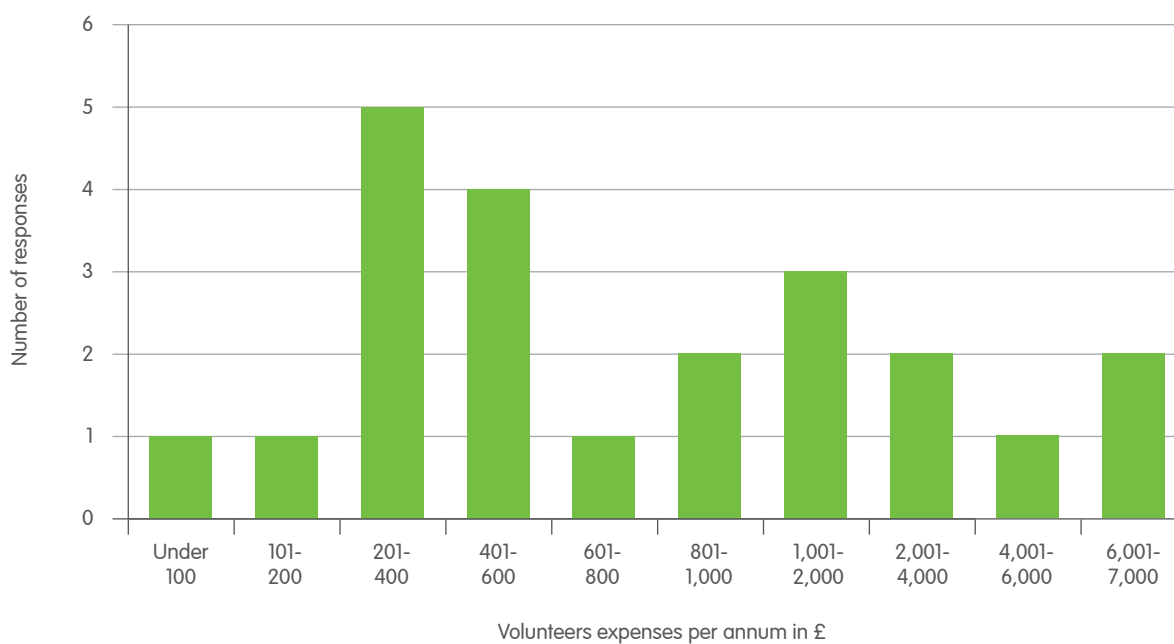
**Figure 11: Staff costs per annum**



## Cost of volunteer expenses

Again, costs varied considerably across the 23 responses, ranging from under £100 to £7,000, as shown in Figure 12. Few volunteers claimed expenses and reimbursement for travel expenses was paid at either 40p or 45p per mile.

**Figure 12: Cost of volunteer expenses per annum**

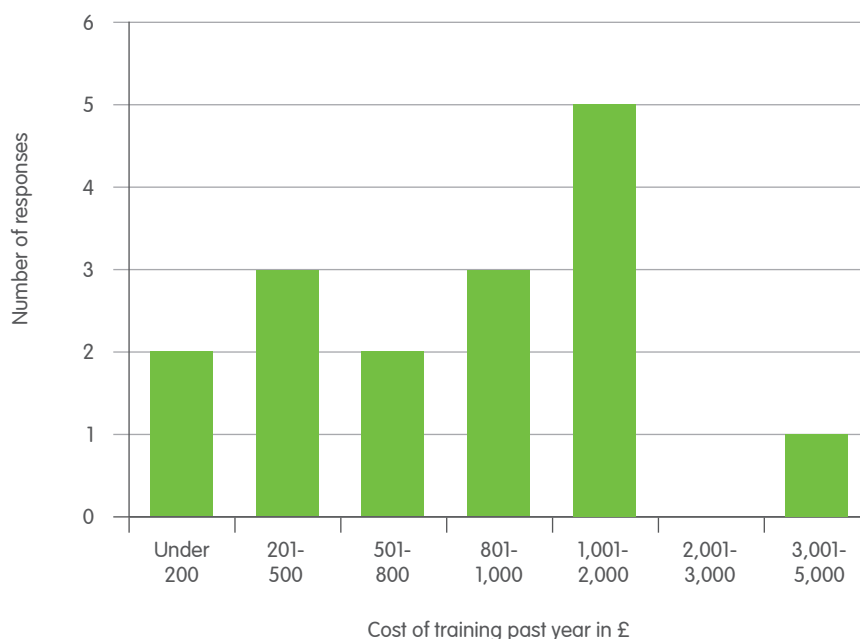




## Cost of volunteer training

The final question in this section explored the cost of volunteer training. As shown in Figure 13, volunteer training costs varied widely across the 21 services that responded but were most commonly under £2,000 per year.

**Figure 13: Costs – volunteer training per annum**



Findings suggest that training costs were often hidden as volunteers accessed internal courses delivered by hospice staff.

## Other costs

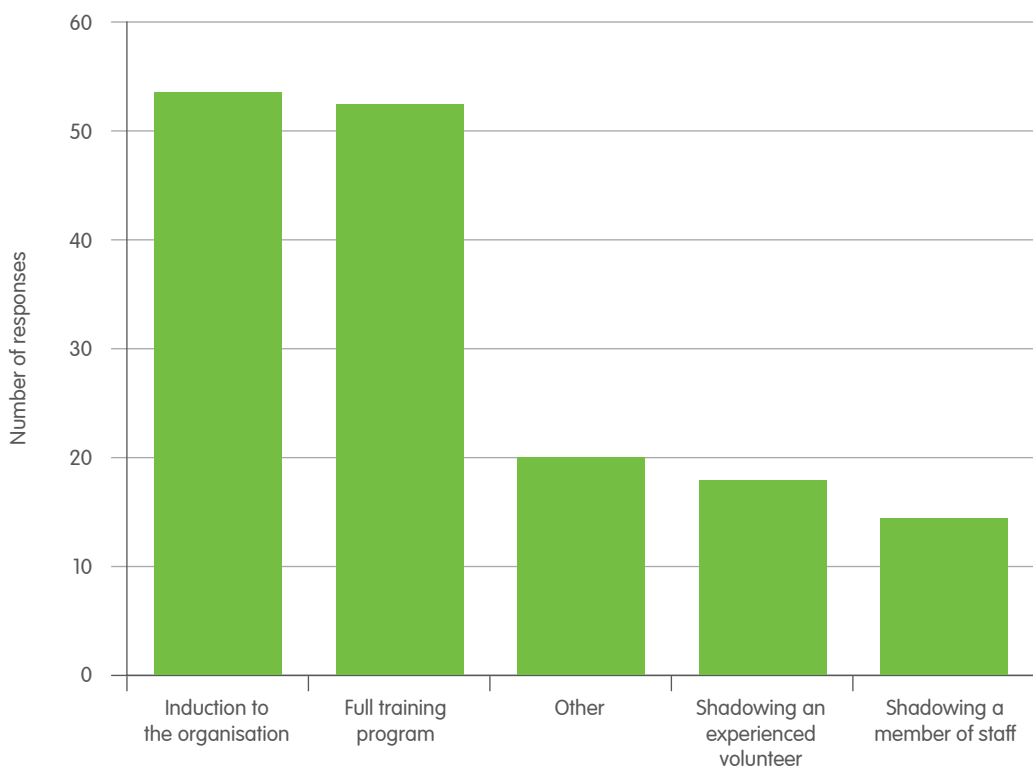
Respondents gave details of additional costs, including £5,000 for outreach and promotion. Others gave examples of associated training costs including administration, badges, photocopying mail and promotional information. One service received a Department of Health grant to run the project.

# Section 4: Preparation and training

## Training type and content

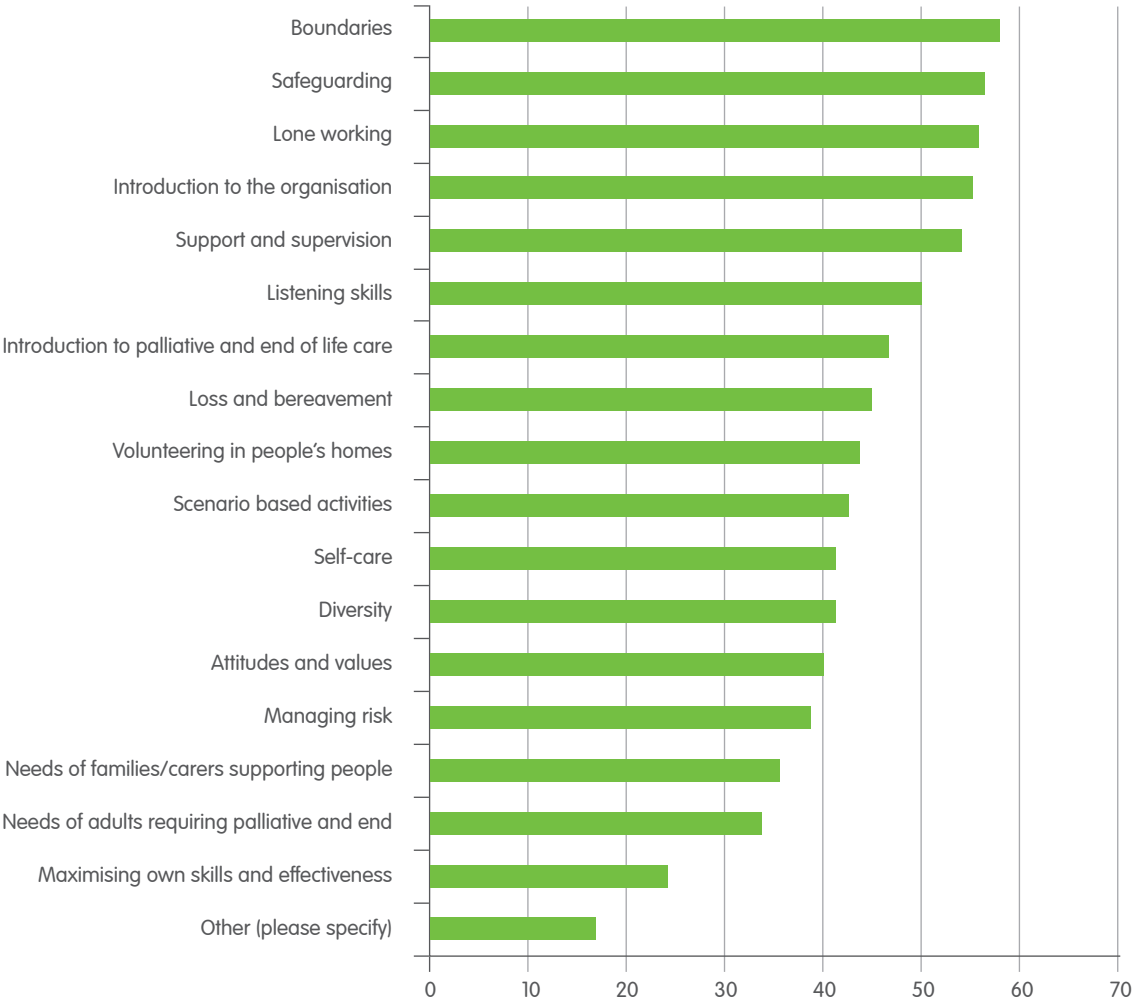
Respondents gave details about the type of training offered to those undertaking community volunteering roles. The majority of services provided both an induction to the organisation and a full training programme, as shown in Figure 14.

Figure 14: Preparation undertaken by community volunteers



Topics covered in community volunteering training programmes were broadly similar, as demonstrated in Figure 15.

**Figure 15: Topics covered in community volunteering training programmes**



**Other training offered**

Respondents gave details of other training offered which had not been included in the multiple-choice categories. This could be broadly grouped into three main areas:

- health and safety/regulatory
- patient care and support
- self-care/personal safety.

Examples of content within each of these groups are given in Table 11 (Appendix 2).

A number of respondents explained their approach to training as outlined in the following quotes:

- “Our training style is based around bringing out the innate qualities that people already within themselves and to build up networks amongst the neighbours.”
- “Confident volunteers who have demonstrated competencies will undertake the role in the community soon after training. Less confident volunteers or those who have not been able to fully demonstrate their

competencies will be offered a role within the hospice in the gym group, where they can support patients in a more supported and supervised way until they feel more confident and have demonstrated all the necessary competencies.”

(Hospice 84)

### Delivery of training

Respondents were asked to identify those who delivered training to community volunteers. A range of staff delivered training in the majority of services including:

- voluntary services staff
- HR team
- learning and development/education staff
- line managers or other staff (including project managers, physiotherapists, occupational therapists, social workers, psychologists, chaplains, bereavement staff and health and safety advisors).

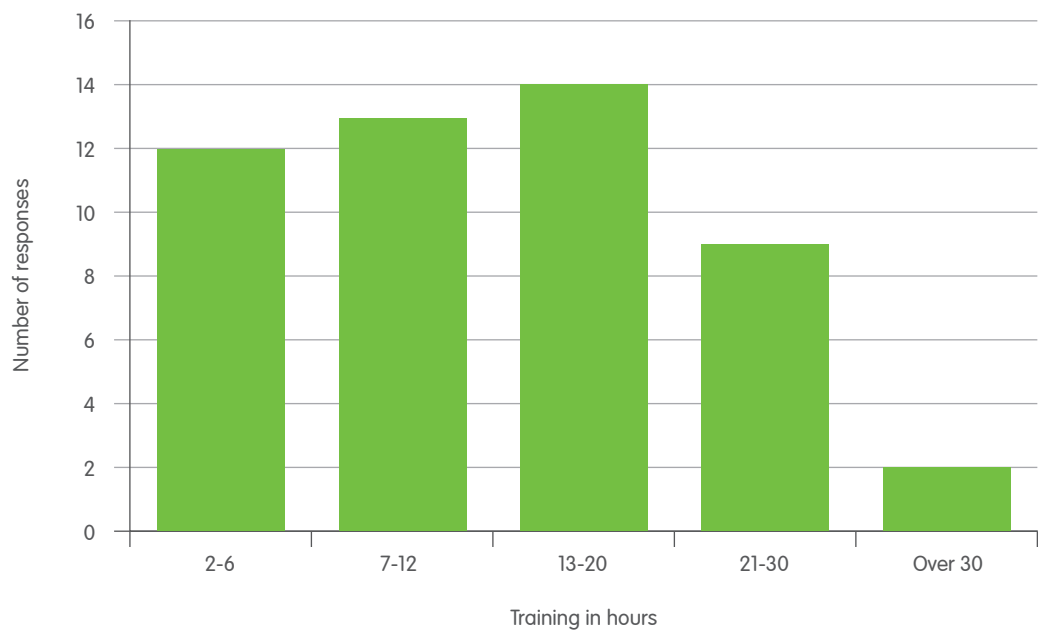
- hospice at home team
- family support team
- community nurse specialist
- befriending staff
- volunteers.

A small number of respondents included eLearning modules, whilst others involved external organisations. One service provided guest sessions on dementia and another indicated that counsellors and therapists were all fully trained before being recruited.

### Training duration and role in selection

There was wide variation in the length of training for community volunteers, as shown in Figure 16, with most services ranging between two and 20 hours. One service reported provided 60 hours of training.

Figure 16: Length of volunteer training in hours



A number of services indicated that initial training was supplemented by ongoing support and training. Additional details provided included:

“Seven hours day training plus online e-learning which can be done off site from home...”

*(Hospice 62)*

“15 hours emotional resilience, seven hours organisational induction, five hours role specific, seven hours shadowing more if required.”

*(Hospice 47)*

“Induction for Advanced Care Planning is 50 hours. Induction for counselling and complementary therapy volunteers is 15 hours. Training for all services is on-going throughout the year.”

*(Hospice 52)*

In response to the question about whether training was part of the selection process, of those that responded, 63% (n=37) included training as part of the volunteer selection process and 37% (n=22) did not.

# Section 5: Policies and support

## Policies in place for community volunteering

Respondents were asked for information on the policies that they had in place for community volunteering. Only two respondents had none. As shown in Figure 17, the most commonly reported policies covered managing risk and lone working, in addition to guidance for community volunteers.

Additional policies identified emerged in two main categories; regulatory and practice, as shown in Table 1.

Figure 17: Policies in place for community volunteering

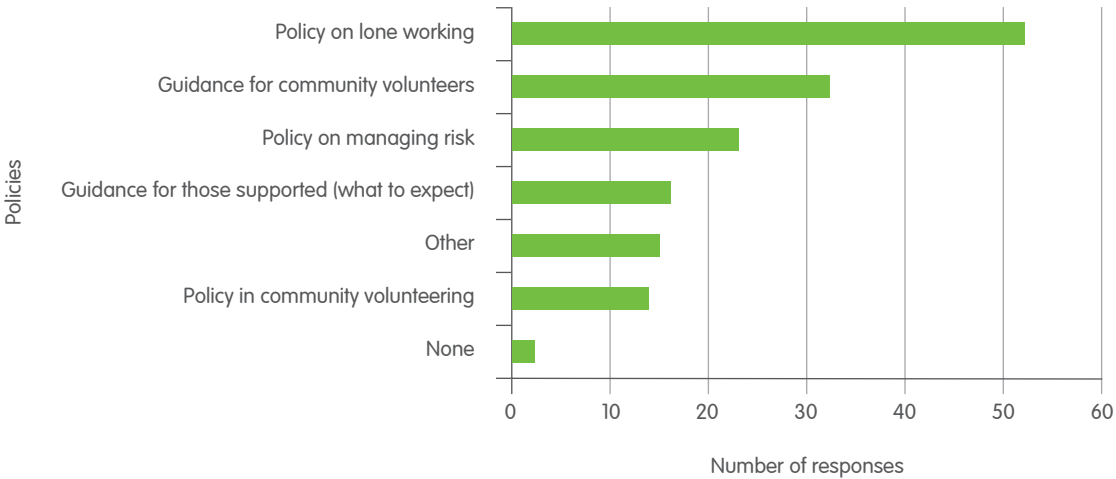


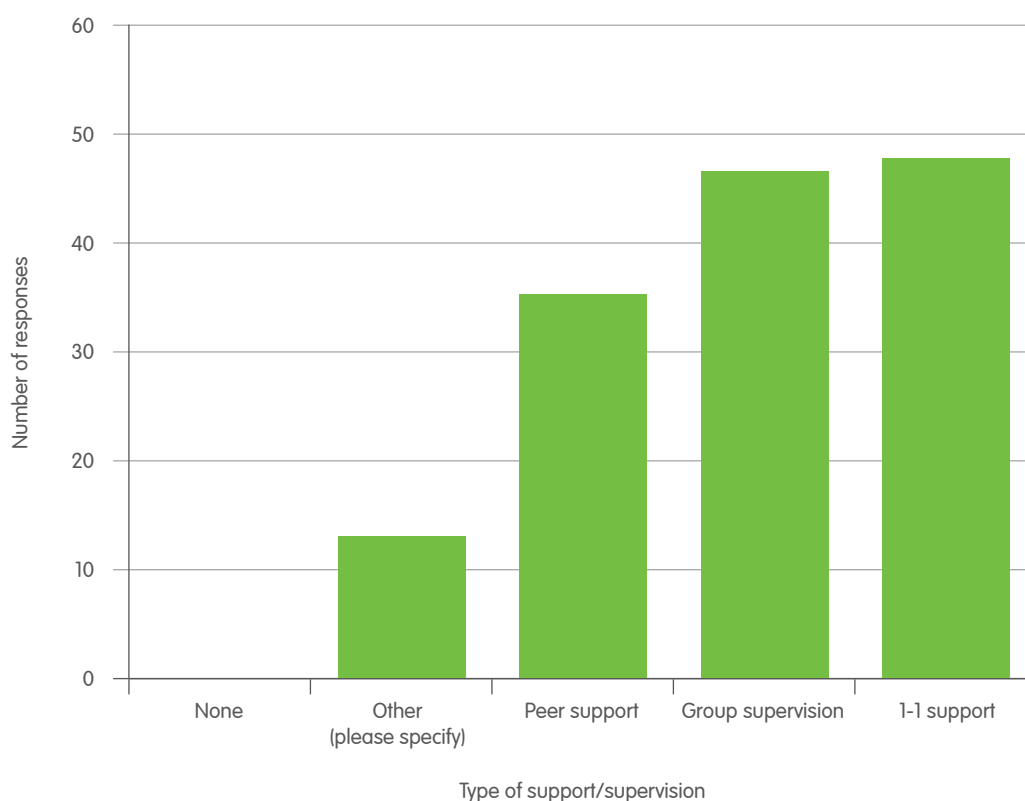
Table 1: Additional policies

Regulatory policies	Practice policies
Confidentiality Policy	Adverse weather contingency plan
Complaints Policy	Emotional and Psychological Support Policy
Consent Policy	Gaining access to a person’s home
Deprivation of Liberty Safeguards Policy	General clinical policies encompassing volunteer work
Equal Opportunities Policy	Referral allocation
Fire Prevention and Safety Policy	Reporting before and after visits
Health and Safety Risk Management Policy	Suicide Prevention Policy
Incident Reporting Policy	Volunteer Policy
Management of Records Policy	Volunteer Handbook
Mental Capacity Policy	Volunteer Code of practice/behaviour
Safeguarding Adults and Children Policy and Procedures	Volunteer Agreement

## Support and supervision for community volunteers

All respondents provided support and supervision to community volunteers. The majority provided this either through group supervision or on an individual basis, as shown in Figure 18. A smaller number of respondents provided peer support opportunities.

**Figure 18: Support and supervision received by community volunteers**



Other support reported included one-to-one support on request, counselling if required, contact after each visit, access to hospice training, regular communication, and open door access to a member of staff. Examples given by respondents included:

*"Afternoon Tea catch up sessions, opportunity to come in for a chat one to one if needed."*

*(Hospice 23)*

*"Bi-monthly community volunteer meetings which is open to all community volunteers."*

*(Hospice 44)*

*"We hold quarterly meetings at the hospice facilitated by myself, the Hospice Neighbour Officer and a member of our education department. Topics are led by the volunteers, but are often as a result of a challenging situation or need for further training/skills. We use this time to do a reflective exercise also. This year we are looking to set up peer groups for the neighbours who live near to each other so they can discuss what they're doing, share experiences and agree on what support they may need. We also offer clinical supervision with a member of our Bereavement Team."*

*(Hospice 89)*

# Section 6: Benefits and drawbacks

## Benefits of community volunteering for people with PEOLC needs

Respondents were asked, from their experience, what they saw as the benefits of community volunteering support to people with palliative and end of life care needs. In order of frequency reported, these were:

1. companionship, friendship and relationships
2. improved wellbeing
3. improved access to services and improved care.

Further details are given in Table 2.

**Table 2: Benefits of community volunteer support - people with PEOLC needs**

1. Companionship, friendship and relationships	2. Improved wellbeing	3. Improved access to services/ Improved care
Providing practical support: help with household tasks, transport to appointments.	Improved confidence.	Ongoing contact with and link to hospice.
Providing social opportunities - taking people out to socialise, keep up with hobbies, engage in local activities.	Increased independence.	Increased level of information for staff – more appropriate care.
Building trusted relationships.	Improved health and mobility.	Helping people to access additional health services.
Someone to talk to out of clinical and family environment.	Learning to live better with illness.	Helping people to access other relevant local services.
Giving people something to look forward to and enjoy.	Learning to manage stress, pain and anxiety.	Improving care, including end of life care and bereavement support.
Helping people to stay connected to or re-connect with the local community.	Distracting people from illness.	Reduction in inappropriate demands for health and social care support by addressing social needs.
Emotional support: companionship and friendship, being with.	Reducing social isolation and loneliness.	
Listening to fears and anxieties.	Enabling to live safely at home.	



Two quotes give more details:

"They really appreciate the fact the volunteer wants to visit them and enjoy the company. Can improve confidence when they can manage out of the house and mix in community. The befriender has time to listen rather than being task focused. Person knows they have time and don't need to be rushing somewhere else."

*(Hospice 71)*

"The gift of time to build trust/relationships and help patients to live well and safely at home. Help to signpost or access further services and information if needed."

*(Hospice 30)*

"To be heard, listened to and the space to reflect and say things they wouldn't be able to say to loved ones. Also to be identified as something other than a medical patient."

*(Hospice 28)*

"Better self-management of their condition and symptoms and understanding of the condition. Support in adopting health and wellbeing positive behaviours. Remaining as independent as possible for as long as possible in their preferred place. Increased motivation and confidence to participate in meaningful activities."

*(Hospice 84)*

"Another suggested that individual support enabled people to work through their diagnosis and prognosis, enabling them to 'die with dignity and live well for as long as they have left'."

*(Hospice 31)*

One respondent shared feedback from their service:

"We have conducted feedback surveys from our patients who tell us that Hospice Neighbours - Helps reduce pressure on family/carer - 90% Improves quality of life at home - 90% Improves quality of relationships at home - 80% Helps the patient spend time on things they enjoy - 83% Reduces fatigue and pain - 73% Increased ability to cope with illness - 66% Feeling socially connected - 83%."

*(Hospice 89)*

## Benefits of community volunteer support for families and carers

In terms of benefits to families and carers, some themes were very similar to those identified for people with PEOLC needs, as shown in Table 3. In order of frequency reported, these were:

1. respite for families and carers
2. companionship, friendship and relationships
3. improved wellbeing
4. improved access to support.

**Table 3: Benefits of community volunteer support for families and carers**

1. Respite for families and carers	2. Companionship, friendship and relationships	3. Improved wellbeing	4. Improved access to support
Help with household tasks - enable families to take a break.	Provide company - companionship and friendship.	Brings some normality to lives of families/carers.	Volunteers provide continuing link with hospice.
Able to take a break from caring knowing person cared for is safe.	Reduces family/carer isolation and loneliness.	Improved self-esteem and wellbeing.	Give family/carers information about local services.
Able to take a break without feeling guilty.	Enables family/carers to remain connected to their friends, social networks.	Enables families/carers to feel less overwhelmed, reduces stress and anxiety.	Help families/carers to access additional services and support.
Reduces carer burnout and family breakdown.	Enables family/carers to feel part of the local community.	Helps families/ carers to understand more about managing the person's condition.	
Improves relationships between carer and those cared for.	Families/carers share anxieties, concerns and fears with someone who is neither family or a health professional.	Enables family/carers to be more confident in their caring role.	
Reassurance for families who live at a distance and cannot visit regularly.	Volunteers can support family/carers in preparing for the future.	Improved self-esteem and wellbeing.	
Benefits people with PEOLC needs by reducing anxiety about their impact on those who care for them.	Continuing support into bereavement.	Enables families/carers to feel less overwhelmed, reduces stress and anxiety.	

Overwhelmingly, respondents identified respite for families and carers as the main benefit of this type of support, which is highlighted by the following quotes:

*"Individuals are able to maintain normal activity and the quality of the relationship with the patient and also other family members is improved."*

*(Hospice 3)*

*"Well trained volunteers enriching their lives, both in terms of the care and company they deliver to the person with dementia, and also the respite that the carer receives strengthening the relationship between the person with dementia and their carer."*

*(Hospice 15)*

Other benefits are highlighted in the following quotes:

"Relief for the family/carer that their loved one isn't on their own in their last hours or lonely at night - many family members live further afield from the patients we support so they can take comfort from the fact there is someone sitting with their loved one."

*(Hospice 57)*

"... to have 2 hours per week to enable maintaining contact with friends/social groups; able to undertake domestic or household tasks; able to have "me time".

*(Hospice 43)*

"To be heard, listened to and the space to reflect and say things they wouldn't be able to say to loved ones. Also continuing support throughout bereavement - normalisation, resolve complicated grief etc."

*(Hospice 28)*

Although reported less frequently, improved wellbeing was also identified as a benefit for families and carers. One respondent described how volunteers enabled carers to develop confidence:

"Better understanding of conditions and self management techniques - feeling enabled to support loved ones confidently and safely to engage in meaningful activities."

*(Hospice 84)*

Benefits for staff and the organisation

Respondents identified a range of benefits from community volunteering in this context. In terms of benefits for staff, two main themes emerged, as detailed in Table 4:

- 1. better understanding of the needs of people with PEOLC needs and their families
- 2. connection to the community.

Table 4: Benefits for staff

1. Better understanding of the needs of people with PEOLC needs and their families	2. Connection to community
Volunteers feed back information and concerns to hospice staff.	Volunteers help staff feel connected to local community.
Staff have greater insight into and understanding of the needs of the person with PEOLC needs and their family or carer	Increased job satisfaction from the positive feedback from the community volunteering service.
Volunteers bring a fresh perspective. Without this feedback important information might stay 'hidden' with staff unaware of the home circumstances.	
Volunteers helped to reduce staff workload and pressure.	

Respondents highlighted some of the benefits to staff in the following quotes:

“Volunteers are often given an insight to a situation at home staff are often not made aware of, again allowing additional care or services being made available that may otherwise have been overlooked.”  
(Hospice 46)

“Volunteers are a valuable source of public engagement and feedback. They broaden diversity and add value and the capacity to deliver more services to more people.”  
(Hospice 52)

Respondents identified three main organisational benefits arising from the involvement of community volunteers. In order of frequency reported, these were:

1. increased service provision for people with PEOLC needs and their families
2. improved quality of services
3. ability to maximise use of staff skills and time.

Further details are given in Table 5.

**Table 5: Benefits to the organisation**

1. Increased service provision for people with PEOLC needs and their families	2. Improved quality of services	3. Ability to maximise use of staff skills and time
Organisation able to extend service provision for people and families thus reaching more people.	Complement staff activity and contributed to the improvement of services.	Volunteers bring “ <i>experience and energy</i> ” to the organisation.
Enable organisation to extend range of different non-clinical support offered in the community.	Greater integrated working, more holistic services and the ability to support people through the discharge process.	Volunteers help staff to manage their time and workload better through sharing the caseload.
Helps to develop new ways of working.	Enabled services to keep in contact with those who have been discharged and to offer earlier palliative care intervention.	Staff have more time, enabling them to maximise their specialist skills in providing care.
Strengthen care and enable services to be tailored to individual need.	More socially inclusive and able to offer services to people who, because of geographic location, would not otherwise be able to access services.	Staff enabled to focus their time on managing more complex cases.
Enable the development of cost-effective services not otherwise affordable.	Improvement in services for people with dementia.	Enable staff to develop new skills.
Organisation able to address unmet social needs of people with PEOLC needs and families and helping to reduce loneliness and “total pain.”		Reduction in number of calls to clinicians from socially isolated people.

Respondents outlined some of the organisational benefits in the following quotes:

“Supports the patient when medical intervention is not required. Less reliance on medical teams for emotional support.”

(Hospice 5)

It has given the “opportunity to develop a ‘Hospice at Home’ programme, staff development in prescribing, connectedness with other local partners, enabling link to hospice care to those unable to travel.”

(Hospice 37)

"Volunteers can assist the organisation in its overall provision of services and support in the community which it would not have the resources to do otherwise."

*(Hospice 108)*

It was noted by one service that they were able to support:

"more referrals for people who wouldn't traditionally access hospice services but who really benefit from earlier referral and from PEOLC when they most need it. A change in attitude towards the hospice from the local community."

*(Hospice 78)*

Another service highlighted improvement in dementia services:

"We are better connected to the growing issue of Dementia, which has improved the services we offer internally and also made us deliver Dementia Friends sessions to staff and volunteers."

*(Hospice 15)*

Staff workload changes were highlighted in the following quote:

"The nurses are able to restructure their workload and concentrate on the more seriously ill patients. The nurses can see how volunteers give continuity throughout difficult times, for patients and families. For the organisation, it has been good to involve volunteers to a higher degree of patient support as this aspect of volunteering work appeals to a wide range of people and those have received hospice care at some point."

*(Hospice 30)*

A further respondent identified the opportunity for the development of staff skills through working with community volunteers:

"Our Hospice Neighbour Officer finds the role - Incredibly rewarding - Helps develop many skills including problem solving, service/people management - Increased collaborative working - Highly inspiring (specifically when volunteer and patient is successfully matched)"

*(Hospice 89)*

Other benefits were summarised by one respondent:

"Community engagement through recruiting local volunteers from various backgrounds with community languages - Raising the profile and awareness of the hospice and its services to a wider audience."

*(Hospice 84)*

## Benefits to volunteers

Respondents identified many benefits to volunteers and these could be grouped under four main headings. In order of frequency reported, these were:

1. personal development/ experience for employments
2. giving back - making a difference
3. sense of purpose and fulfilment
4. improved health and wellbeing.

Further details are given in Table 6.

**Table 6: Benefits to volunteers**

1. Personal and professional development	2. Giving back – making a difference	3. Sense of purpose and fulfilment	4. Improved health and wellbeing
Sharing existing and learning new skills.	Reward in making a difference to people with PEOLC needs and their families.	Volunteers find role a satisfying experience despite the emotional challenges.	Social interaction and inclusion from volunteering.
Learning about palliative care and the individual needs of people with PEOLC needs and families.	Reward from seeing the impact of support.	Fulfilment from the relationships built with people with PEOLC needs and their families.	The opportunity to meet new people and to develop new friendships.
Increased understanding of diversity.	Satisfaction from doing something worthwhile.	Being part of a team.	Reduction in loneliness and stress from volunteering.
Training, ongoing support, supervision and mentoring contributing to development.	Giving something back to the community that has a positive impact.	Gives structure to the day for those who are retired.	Feeling valued and appreciated.
Value to volunteers of continuing to use their professional skills after retirement.	Volunteers' involvement strengthens community engagement.	Volunteers, people with PEOLC needs and families all enjoy the mutual relationships that evolved through community volunteering.	Increased confidence.
Gaining experience for employment - especially within health sector.		By helping others, volunteers could also give meaning to their own experiences of loss.	Volunteers report gaining as much as those supported.
Volunteering of value on CVs and availability of references.			

Respondents summarised the benefits to volunteers in the following quotes:

"Many of our volunteers have reported volunteering in the XX Team has helped them secure paid employment in the health sector and has helped shape carer decisions.

A number of our volunteers have gone on to study medicine, physiotherapy, occupational therapy, psychology or speech and language therapy."

(Hospice 84)

"It enriches their lives. As one put it recently, I find my time spent with XX confusing and hard work, but fulfilling and uplifting."

*(Hospice 15)*

"For many volunteers, being able to visit patients regularly at home and help in such practical and emotional ways has been of great interest and very rewarding. They appreciate the value of the service and enjoy the individual relationships they make... The volunteers know that this collaborative working relationship with staff increases the care for patients with added flexibility and time."

*(Hospice 30)*

One respondent gave details of feedback from their Compassionate Neighbour programme:

"91% of Compassionate Neighbours feel that their quality of life and connectivity has increased because of the project. 78% feel that their social life has improved, 81% feel more confident, 82% are more confident to talk about death, dying and loss, 94% feel an increased sense of wellbeing and feelings of purpose since getting involved in the project and 100% feel that their skills and knowledge have improved."

*(Hospice 84)*

Findings also suggested that volunteers gain much from their involvement. One respondent shared comments from their befrienders which included:

"humbled", "so little for such a lot", "privileged with information shared", "appreciated", "reciprocal" and "befriending .....magical!"

*(Hospice 74)*

This was also echoed in the following quote:

"Community Volunteers have often commented that they feel they benefit greatly from the connections they make; feel humbled and inspired by the resilience and strength in adversity they encounter in the people they support..."

*(Hospice 43)*



## Challenges and drawbacks

Respondents identified a number of challenges and drawbacks, which were grouped into four main areas. In order of frequency reported, these were:

1. management (including recruitment, support, training, funding)
2. maintaining boundaries
3. meeting demand
4. managing risk.

Further details are given in Table 7.

**Table 7: Challenges and drawbacks**

1. Management (including recruitment, support, training, funding)	2. Maintaining boundaries	3. Meeting demand	4. Managing risk
Sourcing adequate funding for services.	Volunteers overstepping boundaries.	The challenges of dealing with fluctuating demand.	Managing remote and lone working.
Difficulty in recruiting appropriate and reliable volunteers.	Volunteers becoming over involved with particular people, particularly when the relationship is long term.	The need to have an adequate number of volunteers to meet the demand from people with PEOLC needs and their families.	Volunteers arriving and leaving safely from people's homes.
The provision of initial and ongoing training and support.	Volunteer capability and ensuring that they fully understood the requirements of the role.	Too few people requiring support resulting in volunteers having nothing to do.	Staff risk averse when considering suitable roles for volunteers.
Finding time for management of community volunteers/ the time taken to support growing numbers of volunteers in these roles.	Impact of maintaining boundaries; significant commitment for staff in monitoring activity and in ensuring adequate support and supervision.	Keeping volunteers engaged and motivated when there were no people to support.	
Ensuring consistency.	Staff concern about maintaining boundaries identified as a barrier to community volunteering.	Recruiting enough people to keep the service going. Managing volunteer retention and turnover and replacing volunteers who cannot continue because of the emotional impact or who leave suddenly.	
Encouraging volunteers to attend regular supervision and additional training.	Selecting the right people to work in roles with limited supervision.	Inconsistency of work-flow from month to month.	
Reliability, flexibility, commitment and availability of volunteers.	Difficult to manage activity in an unsupervised setting when volunteers are keen to do more.	Matching volunteers to the needs of people was identified as a further challenge.	
Coping with holidays and sickness.		Managing inappropriate referrals to the service and the increasing numbers of people with more complex needs.	



**Table 7: Challenges and drawbacks (continued)**

1. Management (including recruitment, support, training, funding)	2. Maintaining boundaries	3. Meeting demand	4. Managing risk
Managing volunteers could leave at any time with little or no notice when their circumstances changed.		Geographical issues – matching suitable volunteers with people with PEOLC needs.	
Sudden changes in the circumstances or condition of people with PEOLC needs causing problems with the scheduling and management of volunteers.		Difficulties that arise when terminally ill people died whilst receiving support from befrienders.	

The different challenges experienced by respondents are highlighted in the following quotes:

“Constant challenge of securing funding - Searching for ongoing, free training opportunities for staff and volunteer development in topics that surround palliative care.”

*(Hospice 84)*

“Difficult to recruit to dementia roles, difficult sometimes to make staff understand the value of the work our community volunteers deliver, and their need for training and support.”

*(Hospice 15)*

“A lot of work can be involved with recruitment of volunteers and not all are reliable once selected and trained. There is a lot of admin involved and the whole process of screening referrals to establish how to best match them can take some time. The positives outweigh the drawbacks in my mind.”

*(Hospice 62)*

“This is very emotionally challenging work and can often bring up issues for people. Maintaining boundaries can be a challenge, people don’t always find it easy to say no to what appears to be a simple request i.e. can you pop and get a pint of milk. This can put volunteers on the spot but these kinds of issues are discussed during their induction training and constantly reviewed in supervision sessions.”

*(Hospice 46)*

“From the time we have been doing this, it is getting staff on side with the project. They can see the benefit but seem to be very concerned around boundaries, safeguarding and letting volunteers ‘loose’ into patients homes.”

*(Hospice 23)*

“As the volunteering manager, the challenge is to keep pace with the needs of the service and be flexible. Induction to the role training has become more regular to accommodate the time volunteers are able to offer.”

*(Hospice 30)*

"The balance between the community and the hospice. The time it takes to form relationships to help grow the project. To truly make the programme community-led rather than hospice-led. The tensions between clinicians around risk and letting go."

*(Hospice 77)*

"Attitudes of the hospice to an influx/invasion of a new 'breed' of volunteer coming to the hospice - can be difficult. Challenges of a non-clinical model of care for clinicians and those who are risk-averse. Hospice tendency to tie projects in knots with bureaucracy and policies! Lack of community connections for a hospice that has been insular previously - takes longer for the project to 'take hold'."

*(Hospice 78)*

In contrast, however, one respondent identified that it was easy to identify issues with boundaries and to address these through supervision and training.

Separately, one respondent commented that what was offered was:

"Gold standard care to the few - risk averse. Not enough people being supported in a low-level way."

*(Hospice 104)*

# Section 7: Hospices without community volunteering services

Respondents from hospices with no community volunteering services were asked to give reasons for this and to identify issues or challenges, which were barriers to this development. They were also asked if they would like to develop such a service and if so what might help them.

## Reasons for not offering a community volunteering service

As previously noted in Section 1, there were 35 hospices with no community volunteering service. Respondents gave a variety of reasons for this and two themes emerged most frequently:

- currently planning or developing a service
- lack of resources, capacity or ability to support a service.

Other reasons cited by a three or fewer respondents included:

- the demand on staff to train and support volunteers
- concerns about risk, health and safety, and safeguarding
- not appropriate to the particular hospice (e.g. hospice is a day care only service; current staff services already offer this support)
- volunteers prefer not to be isolated in people's homes
- volunteering service currently under review to identify needs
- not in current strategy or not a priority.

Respondents were then asked to give details from their experience of the barriers to developing a community volunteering service.

## Challenges in developing community volunteering

A range of challenges were identified and themes highlighted by a number of respondents included:

- lack of resources (time, funding, management, staff and volunteers)
- risk and safety (lone working, safeguarding, risk assessment)
- meeting training needs and supervision
- insurance concerns.

Other themes identified by a small number of hospices (three or fewer) included:

- already services in the area so identifying gaps there
- lack of internal support (lack of understanding of impact on and recognition of work load increase in terms of time and management required; reluctance of clinical staff)
- cultural (NHS culture and challenges in involving volunteers, volunteers not involved in this way)
- developing training (no time or staff resource)
- impact on staff resources
- concerns about boundaries and volunteers overstepping (becoming too close to clients, compassion fatigue)
- recruitment of volunteers

- time taken to develop service (researching needs of people with PEOLC needs and their families, developing partnerships)
- accountability if things go wrong
- identifying a suitable model
- lack of volunteer management expertise.

A total of 21 hospices indicated that they wanted to develop a community volunteering service, with 10 stating that they did not.

## Resources that would help in developing services

The two main areas highlighted by respondents were information and examples of successful services, and resources, including funding and staff.

Overwhelmingly respondents suggested that what would help most would be examples and case studies from other organisations already successfully providing such services. Information identified as being most valuable included:

- guidance, toolkit on how to set up a service
- examples of models, structures, costs
- marketing plans
- management and co-ordination
- volunteer roles
- sample leaflets
- guidelines on supervision and training
- examples of training programmes.

One respondent indicated that it would be helpful to work in partnership with other hospices already providing this service, whilst another suggested the development of an eLearning training programme available to everyone.

Other suggestions included:

- board approval
- consultation with clinical teams
- identifying a need not already being met by others

- evidence of increased need in the future.

Having considered the findings from adult hospices without community volunteering services, the final part of this section gives an overview of the data from children's hospices.

## Children's hospice data

This section reports on the findings from five children's hospices. All indicated that they did not provide community volunteering services as described in the survey.

Two children's hospices offered support to families in the community caring for a child with a life limiting/life threatening condition, one of which had been running for 10 years. One of these two hospices which offered support to families and siblings also gave details of a new pilot project:

*"We are already supporting families in their homes and have started to pilot nursing volunteers in homes (volunteers with clinical experience). We just need the resource to scale it up and I'm hoping that we will get that investment very soon."*

*(Hospice 7)*

One respondent from a hospice without a community volunteering service noted that their nurses and carers currently provided support and that they had concerns about volunteer skills, reliability and continuity. A second indicated that they had not been able to support this previously, and had concerns about how to manage such a service. However, they described how they are planning to develop a community volunteering service:

*"We are currently using the Together We Can' resources to propose a pilot project, with the aim of launching it in September 2018. I am a member of the Community of Practice and value guidance and hearing about experiences from hospices where family support volunteering is being used. Once our pilot is up and running, an opportunity to meet face to face and network with other project leaders would be useful."*

*(Hospice 27)*

# Section 8: Planned development of services

Respondents were asked if they planned to develop their community volunteering service/s and if so how they would do this. Of those who responded to this question, almost all (n=50) intended to develop their service, while six had no plans to do so. A number of approaches to development were described which were grouped under two headings, as shown in Table 8:

1. increasing the size and scope of the service
2. developing new models.

For most respondents, developing their service meant building on current services and increasing the size, recruiting more community volunteers in order to reach more people with PEOLC needs, and addressing growing needs.

**Table 8: Approaches to development of services**

Increasing size and scope of service	Developing new models
Recruiting more volunteers to reach more people.	Moving from matched befriending to Compassionate Neighbours.
Biography service .	Volunteer community rehabilitation support programme.
Carer support groups held in community.	Introducing Namaste.
Home from Hospice service - to help transition.	Introducing telephone befriending.
Pre and post bereavement support.	Exploring involvement of corporate volunteers.
Offer volunteers support earlier in diagnosis.	Improving seamless provision through partnership working (e.g. GP surgeries, community groups, existing services, hospitals).
Development of volunteers to be more hands on.	
Involving volunteers' networks and ideas to develop service.	
Extending to seven days per week.	
Extending to full 24 hour service.	

Examples of approaches to expanding services were highlighted in these quotes:

"We are in the first three months of the project but it is a strategic decision to invest as a hospice in this type of work so that we reach significantly more people and improve PEOLC for more local people than we can 'cope' with our finite hospice building and numbers of nurses."

*(Hospice 78)*

"Growing using connections and ideas from the volunteers. Currently it operates on a small area compared to the hospice's catchment area. This is part of the wider Compassionate Neighbours roll out programme across London and the suburbs."

*(Hospice 77)*

One respondent noted, however, that any development would be based on the availability of funding.

Respondents also gave details of changing models:

"We have also started a Hospital service which is due to go live in a few weeks - we are providing volunteers to sit with patients who are dying so they are not alone in their last hours."

*(Hospice 57)*

"We plan to turn Hospice Neighbours into a three tier, pyramid model. At the 'base', we would like to recruit people to be 'good neighbours' who can support anyone who has a life limiting illness. The second layer would be our existing Hospice Neighbours. The third and smallest layer would be a small group of volunteers, who have had experience of healthcare who will be trained to support patients with more complex needs."

*(Hospice 89)*

"This project will seek to develop our existing Compassionate Communities further by empowering volunteers to create 'Compassionate Hubs' in their own areas. These will be hyper-local versions of the existing project managed by CN Leaders – trained Compassionate Neighbours supported by the CN Team. Suitable venues, such as supported living schemes, individual estates, community centres or local coffee shops, will be identified as a base for these schemes and the CN Team will support the Neighbours to forge a relationship with them."

*(Hospice 84)*

## Additional comments

A number of respondents offered additional comments. A few commented that the survey had been longer and more detailed than expected. Three noted that the survey had been difficult to complete as the data was not always available. In one case this was because the community volunteering service was completely integrated with no separate data. Other respondents highlighted how important community volunteering services were and how proud they were of what they had achieved as highlighted in this quote:

"I am proud of the service we have developed, namely Volunteer Care Navigators. The patients benefit, the nurses benefit and the volunteers enjoy this role immensely. I would recommend this service/care for anyone in need."

*(Hospice 30)*

One respondent commented:

"Thank you for conducting this survey and putting community volunteering on the map in Palliative Care."

*(Hospice 84)*



# Section 9: Findings from interviews

The interviews explored six key themes:

1. The impetus for starting the service and overcoming challenges.
2. Inclusion criteria for people receiving volunteer support.
3. The possibility of re-referral to the community volunteering service.
4. Specific activities that volunteers are not permitted to do and the reasons for this.
5. The type of support most often accessed.
6. The management of risk.

The interviewees represented a variety of community volunteering projects including: a dementia project (n=1), a bereavement service open to all in the community (n=1), support for people with PEOLC needs and their carers (n=1) befriending (n=2), Hospice Neighbours (n=2), Compassionate Neighbours (n=2), both Hospice Neighbours and Compassionate Neighbours (n=1).

## 1. Impetus for starting the service and overcoming challenges

There were a number of common factors that had influenced hospices to develop community volunteering programmes, as outlined in Table 9.

**Table 9: reason for developing services**

To develop/improve support	Influenced by others	Other reasons
Identified need/feedback from people with PEOLC needs about the need for additional support at home.	Inspired by others already doing this and could see the need.	Recognition that the hospice was only seeing the tip of an iceberg and wished to reach a wider group - not traditionally hospice patients.
Scoping exercise identified no available bereavement services in the area and the only support was through GPs or mental health referrals.	Influenced by Alan Kellehear's work on Compassionate Cities and the Demos Report 'Dying for Change'.	A review of the hospice strategy and a desire to foster Compassionate Communities.
Desire to help people live their life, achieve their goals and improve enjoyment of life.	Influenced by Carers Act in Scotland.	Desire to develop volunteering from a traditional hospice model.
Need identified by the counselling team through client assessment for companionship rather than counselling.		Hospice covers very deprived area and load on carers significant.
Identified that carers were not coping and becoming exhausted.		To prevent carer breakdown and strengthen relationship between carer and person with PEOLC needs.
People with PEOLC needs isolated and needing more support/wanting to discuss situation with someone other than family.		To move away from medically driven model of care and develop community engagement work.



Three hospices identified funding and resources as a challenge. This was particularly acute for one that had struggled for several years to find funding to ensure the sustainability of their community volunteering project. As a result, the project remained small, unable to develop to meet demand. Other challenges reported by interviewees reflected these already highlighted in Section 6, Table 7 and included:

- balancing the demand for support with the availability of volunteers
- non-optimal communication with volunteers arising from lack of structure due to limited resources
- staff resistance
- concerns about boundaries and sending volunteers into people's homes
- persuading the organisation of the importance of supervision for community volunteers.

One interviewee described the challenges in more detail:

"I would say that one of the challenges has been around managing the volunteers' frustrations that we haven't been able to grow to meet the need that we know is there... They understand now but it took a while to explain that whilst they are giving their time for free, there needs to be infrastructure in place to support the project and that doesn't happen on its own. There are costs that aren't obvious to people and in particular, employee time as so far everything has been done amongst the rest of people's day to day job."

*(Hospice 98)*

## Overcoming challenges

Where funding challenges existed, no solutions were identified. Hospices had overcome concerns about introducing community volunteering in a number of ways. Three achieved this through seeking advice from

others already experienced with Hospice Neighbours or Compassionate Communities projects. One hospice was also exploring Compassionate Circles. A successful pilot project had also helped to reduce staff concerns about community volunteering for one hospice. Another found that trustee and senior staff support for the project had enabled development. One interviewee spoke of the importance of selling the idea to staff teams internally. In addition their staff had undertaken training from an external befriending organisation and information leaflets were developed for people with PEOLC needs, their families and staff.

## 2. Inclusion criteria for people receiving volunteer support

The majority of hospices required that the person be registered with a GP within the hospice catchment area and/or be receiving some hospice services. One interviewee stated that this was because they lacked the resources to extend support beyond this. For one community dementia service the person also required to be living at home with a carer and have a formal diagnosis of early stage dementia. Other criteria included: the person must have a life-limiting or chronic condition or be over 85 years, the person must be fit enough to undertake their own personal care in addition to being independent and mobile. Two hospices did not require people to be using their services. One interviewee described the assessment process used to establish the person's needs to identify whether or not a volunteer visitor was required. In another organisation volunteers were also allocated to support people with PEOLC needs close to end of life to enable their carer to take a short break from caring.

For one hospice, the extent of their service was informed by their charitable objectives, which stated that people eligible for support were those who had a chronic illness and were isolated.

### 3. Re-referral to the community volunteering service

Most interviewees indicated that re-referral was possible. In some instances this did not apply as the volunteer support was continued until the person died.

One respondent indicated that re-referral for befriending would not be possible as this was goal-oriented and offered for one year only. The aim of befriending was to make people independent, giving them confidence. However, once the befriending relationship was formally ended, clients and volunteers could continue contact on a personal basis. Another interviewee noted that the people with neurological conditions were usually supported over a protracted period of time and they were most likely to be re-referred during the course of their illness.

### 4. Specific activities that volunteers are not permitted to undertake

In almost all cases volunteers were not permitted to give personal care or administer medication. One interviewee noted that moving and handling of people was not permitted. Reasons given by some were that the aim of community volunteering was companionship and the promotion of independence, rather than home help. However, another interviewee noted that the underlying principle of their community volunteering programme was “What would you do for your neighbour?”

One interviewee added that volunteers did not undertake tasks that became regular such as washing or grass cutting and that if these were required people would be signposted to other services that could help.

Volunteers from one Hospice Neighbour project were not permitted to transport people in their own car at present, but it was hoped that this would change and that they would also be enabled to provide personal care in the future.

### 5. Support most often requested

Volunteers offered only one type of support in four hospices and so this question was not applicable. For the other six, social connections and companionship, enabling people to go out, and offering the carer respite from caring were most in demand.

A number of hospices indicated that their community volunteer support continued to evolve and they would consider if and how to respond to any new needs identified. For example, one hospice is considering the development of ad hoc respite support for carers as required.

### 6. Approach to managing risk

The majority of interviewees reported a range of measures in place to manage risk. These included four main areas and are detailed in Table 10:

1. training and supervision
2. risk assessment
3. systems enabling volunteers to check in and out
4. other measures.

One hospice in describing their Hospice and Compassionate Neighbour project indicated that they were increasingly trying to be less risk averse and to enable their volunteers to work more independently. Another described their ‘light touch’ approach to risk management, noting that:

*“volunteers are adults, assessed, trained and trusted.”*

*(Hospice 23)*

Another also indicated that they did not have a checking in and out system and that their Compassionate Neighbour volunteers had a more generic connection with the people they supported:

*“empowering people and making connections - still associated with the hospice but community led”.*

*(Hospice 55)*

**Table 10: Approach to managing risk**

1. Training and supervision	2. Risk assessment	3. Systems enabling volunteers to check in and out	4. Other measures
Specific training on dementia, how it presents, causes of different behaviours.	Consultant Nurse Specialist accompanies Hospice Neighbour on first visit and undertakes risk assessment. Importance of nurse risk assessing as skilled to risk assess complexity of person's condition.	Use of people-safe devices and systems to enable volunteers to check in before and after the visit.	Timing of support. People with dementia can become restless in the evenings and behaviour may deteriorate. Volunteers are not involved in the evenings.
In depth training: lone working, safeguarding, self-care, difficult conversations, guidance in declining gifts and how to deal with concerns.	Risk assessment of home, activity and person to be supported undertaken.	Use of volunteer buddy systems to enable volunteers to check in before and after the visit.	Volunteers do not exchange phone numbers with people they support. All such direct phone contact is done through staff.
Formal and informal group support and supervision reflecting on experiences and challenges helps in identifying risk, managing boundaries and offers learning.	Volunteers are required to read and sign to say that they understand the risk assessment.	Volunteers check in with member of staff who has all visits diarised.	Volunteers only support people known to the hospice.
Peer support - compassionate neighbours keeping in touch with each other.	Risk assessment training provided.		Detailed record-keeping including documentation of concerns.
One-to-one support available as needed.			Ongoing support from referring Admiral Nurse when supporting people with dementia.

## Additional information from interviews

Interviewees were asked if there was any additional information that they wished to give. One interviewee described how their Hospice Neighbour volunteering programme was positioned within the hospice:

“Initially the project was to be based in and run by the care side of the hospice. However, after discussions at senior level and talking to XX hospice (a hospice experienced in doing this) it was decided the project would be based within volunteer services which has enabled the service to become more wide ranging with fewer restrictions.”

*(Hospice 23)*

Another noted that the Compassionate Neighbours programme gave community volunteering credibility with the clinical team. They believed that this type of volunteering can only work if carried out in partnership with other organisations and if it ultimately moves away from the hospice, becoming embedded in the local community. They suggested that hospice involvement should only be temporary.

There was recognition from another interviewee that their service was restricted by very specific criteria and boundaries. In common with others, the interviewee spoke of their desire to move beyond this and to develop a more ‘light touch’ and empowered community volunteering programme. Emphasising this theme, a number of interviewees spoke of their intention to push boundaries and change the hospice culture through community volunteering. One interviewee recognised that community volunteering was more flexible, fitting better with people’s life styles thus opening up volunteering to more people.

# Summary and conclusion

The findings provided a wealth of rich data giving valuable insights into hospice community volunteering in the UK. They suggest a significant change in the way in which volunteers are involved with people with PEOLC needs. There appears to be a growing move towards this type of volunteering with a clear interest from those hospices not already involved. It is possible, however, that respondents were drawn from organisations most committed to this type of volunteering, and findings may not necessarily be reflected across the wider Hospice UK membership.

There are clear benefits to people with PEOLC needs, their families and carers, organisations, volunteers and communities. Community volunteering enables hospices to provide more support, reach out to communities, and in some cases empower community members to support one another. However, challenges also exist in developing such volunteering programmes, including lack of funding and resources, organisational culture, resistance from staff and the management of boundaries and risk. The sharing of knowledge and experience by hospices with experience of community volunteering was clearly important in helping others to overcome challenges. Although the minority of community programmes are volunteer or community led, a number of hospices were keen to move more towards this model. It would appear, therefore, that the proposed Hospice UK community volunteering resource hub is timely.

# Appendix 1

## Survey questionnaire

We invite you to take part in this survey which will help to inform the work of this project. The survey should be completed by the member of staff or volunteer (in volunteer-led projects) who has responsibility for the community volunteering service or project. It should take approximately 30 minutes to complete. If your organisation has more than one project of this type please complete one questionnaire for each service.

The purpose of the survey is to

- map the extent of community volunteering activity in palliative and end of life care
- gather information about the services already in place
- identify any barriers to developing such services.

The information will be used to inform the development of a signposting hub on Hospice UK's website, to resources on community volunteering to offer help and support to organisations that are interested in developing services in this area.

Taking part is optional and you may withdraw from the survey at any time.

Thank you

## About you

1. Please give us the name and postcode of your organisation .....

.....

2. Your job title .....

.....

3. Does your organisation currently have volunteers supporting adults with palliative and end of life care needs in the community, e.g. as compassionate/hospice neighbours/befrienders?

☐ Yes

☐ No

## No service

4. Why does the organisation not have this service? .....

.....

.....

5. What issues or challenges, if any, have you identified that make it difficult to develop this type of service?

.....

.....

6. Would you like to develop a service?

☐ Yes

☐ No

7. What might help you to develop a service? .....

.....

.....

## Service provision

8. Do you offer this service to people who do not currently use hospice services?

☐ Yes

☐ No

If yes, who refers people to this service? .....

.....

.....

9. In your service what type of support do volunteers offer to **adults with palliative and end of life care needs** in the community?<sup>1</sup>

(Please select all that apply)

Based upon and adapted from Burbeck et al (2014) Volunteers in specialist palliative care - A survey of adult services in the UK. Journal of Palliative Medicine 17 (5) 568-574<sup>1</sup>

☐ Emotional support (e.g. sitting with, listening to people)

☐ Sharing a person's activity or hobby (reading, music)

☐ Practical support (e.g. collecting prescriptions, shopping, walking pets)

☐ Accompanying on social outings (e.g. theatre, cinema)

☐ Driving to hospital appointments, social outings

- ☐ Accompanying to medical/hospital appointments
- ☐ Escorting to hospice facilities (e.g. gym, clinics etc.)
- ☐ Helping with teas, coffees, meals in the home etc.
- ☐ Sitting with people the last hours of their life
- ☐ Giving advice and information
- ☐ Giving complementary beauty therapy, hairdressing
- ☐ Giving personal care (e.g. bathing, turning, lifting)
- ☐ Supporting people towards enablement goals
- ☐ Helping people to stay connected to friends and the local community
- ☐ Other: please give as much detail as you can.....
- .....
- .....

10. In your service what type of support do volunteers offer specifically to **families/lay carers** of people with palliative and end of life care needs in the community?<sup>1</sup> (Please select all that apply)

- ☐ Giving emotional support (e.g. sitting with, listening)
- ☐ Practical support (e.g. shopping, housework, walking pets)
- ☐ Accompanying on social outings (e.g. theatre, cinema)
- ☐ Helping families with preparing meals
- ☐ Sitting with family/carer during the last hours of their loved one's life
- ☐ Giving advice and information to family members/lay carers
- ☐ Giving complementary beauty therapy to family/lay carers
- ☐ Helping family/carer to stay connected to friends and the local community
- ☐ Other: please give as much detail as you can.....
- .....
- .....

11. How long is the support offered to **adults with palliative and end of life care needs**?

- ☐ As long as the person needs
- ☐ For a specified length of time only
- ☐ Please give details .....
- .....
- .....



12. How long is the support offered to families/carers?

☐ As long as the family/carer needs

☐ For a specified length of time only

☐ Please give details: .....

.....

.....

13. Does volunteer support to families in the community continue into bereavement?

☐ Yes

☐ No

☐ Occasionally

## Management, service profile and costs

14. Who manages the community volunteering service?

☐ Staff led with volunteers delivering service

☐ Volunteer and community led

☐ Other (please specify) .....

.....

.....

15. How long has the community volunteering service been running?

☐ 0-6 months

☐ 2-3 years

☐ 6 -12 months

☐ 3-4 years

☐ 1-2 years

☐ 5 years and over

16. How many volunteers are involved in this community service?.....

.....

17. How many are

Male.....

Female.....

Other.....

18. What is the age profile of volunteers? (Please give numbers)

- ☐ 16 - 25
- ☐ 26 - 34
- ☐ 35 - 49
- ☐ 50 - 64
- ☐ 65 - 74
- ☐ 75+

19. How many people does this service support per year?.....

20. How many hours of volunteer support do people receive from this service per week? .....

21. How many hours did volunteers give to this service? (in past month).....

22. How many FTE staff are required to run this service? .....

23. What is the cost of the service per annum?

Staff costs .....

Volunteer expenses .....

Volunteer training costs .....

Other .....

## Preparation and training

24. What preparation do volunteers have before undertaking this type of volunteering in the community?  
(Please select all that apply)

- ☐ None
- ☐ Induction to the organisation
- ☐ Full training programme
- ☐ Shadowing a member of staff
- ☐ Shadowing an experienced volunteer
- ☐ Other (please give details).....  
.....  
.....

25. If training is provided who delivers this?.....  
.....  
.....

26. What is the length of training in hours.....

.....

27. Is training part of the volunteer selection process?

☐ Yes

☐ No

28. What topics do you cover in the training for these volunteers? (Please select all that apply)

☐ Introduction to the organisation

☐ Introduction to palliative and end of life care

☐ Needs of adults requiring palliative and end of life care

☐ Needs of families/carers supporting people requiring palliative and end of life care

☐ Listening skills

☐ Loss and bereavement

☐ Maximising own skills and effectiveness

☐ Volunteering in people's homes

☐ Scenario based activities

☐ Diversity

☐ Attitudes and values

☐ Self-care

☐ Boundaries

☐ Safeguarding

☐ Lone working

☐ Managing risk

☐ Support and supervision

☐ Other (please specify) .....

.....

.....

## Policies and Support

29. What policy/procedures do you have specific to volunteers working in in the community? (Please select all that apply)

- ☐ Policy in community volunteering
- ☐ Policy on managing risk
- ☐ Guidance for community volunteers
- ☐ Policy on lone working
- ☐ Guidance for those supported (what to expect)
- ☐ None
- ☐ Other

30. What support/supervision do community volunteers receive? (Please select all that apply)

- ☐ 1-1 Support
- ☐ Group Supervision
- ☐ Peer support
- ☐ Other (please specify) .....
- .....
- .....

## Benefits and Drawbacks

31. From your experience what are the benefits to adults with palliative and end of life care needs who receive support?

.....

.....

32. From your experience what are the benefits to families/carers who receive support?

.....

.....

33. From your experience what are the benefits to staff and the organisation?

.....

.....

34. From your experience what are the benefits to volunteers?

.....

.....

35. From your experience what are the challenges or drawbacks?

.....

.....

**Other information and comments**

36. Do you plan to develop the service?

☐ Yes

☐ No

If yes, please say how.....

.....

.....

37. The results of this survey may be used to develop a signposting hub to resources on community volunteering on Hospice UK’s website.

Would you be willing to share your organisation’s resources with others interested in developing a similar service?

☐ Yes

☐ No

If yes, please give contact details .....

.....

38. Would you be willing to consider providing a case study for the resource?

☐ Yes

☐ No

39. Would you be willing to take part in a follow-up interview about your service?

☐ Yes

☐ No

If yes, please give contact details .....

.....

40. Any other comments? .....

.....

.....

.....

.....

# Appendix 2

**Table 11: Additional training offered**

Health and safety/regulatory	Care of people and support	Self-care/ personal safety
Car safety	Activities of daily living	Emotional resilience
Confidentiality	Anaphylaxis	Managing violence and aggression
Data protection/IT governance	Breathlessness management techniques	Practical advice
Equality and diversity	Complementary therapies	
Fire	Dealing with falls	
Food Hygiene	Dementia awareness	
Health and safety	Mental health	
Infection control	Mobility and rehabilitation in palliative care	
IT governance	Oxygen awareness	
Moving and handling (including people and back care)	Resuscitation	
Slips, trips and falls	Spiritual care	
Transferring people in/out vehicles	Where to signpost to	
Use of wheelchairs		

# References

1. Together for Short Lives (2017). Together We Can. Available from <https://www.togetherforshortlives.org.uk/changing-lives/developing-services/developing-volunteering-services/about/>
2. Hospice Neighbours and Compassionate Neighbours are community led volunteer programmes offering practical support and companionship to people and their families.



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Hospice UK, Hospice House, 34 – 44 Britannia Street, London WC1X 9JG