What is the impact of social action befriending services at the end-of-life?

Evaluation of the End of Life Social Action Fund

June 2016

International Observatory on End of Life Care

Institute for Volunteering Research

Lancaster University

The research team

Principal Investigator:

Dr Catherine Walshe, International Observatory on End-of-life Care (IOELC), Lancaster University

Co-investigators: Professor Sheila Payne, IOELC, Lancaster University

Dr Guillermo Perez Algorta, Division of Health Research, Lancaster University

Nick Ockenden, Institute for Volunteering Research

Dr Nancy Preston, IOELC, Lancaster University

Investigators: Dr Steven Dodd, IOELC, Lancaster University

Matt Hill, Institute for Volunteering Research

Acknowledgements:

With thanks to Dr Evangelia (Evie) Papavasiliou, Research Associate on the project to 15.9.15 and Paul Sharples, Research Intern on the project 11.1.16 – 15.4.16.

The trial element of this study was originally published in BMC Medicine[1].

This evaluation could not have been conducted without the engagement of the participating sites. Their willingness to learn and develop new research skills was invaluable. We are also indebted to the patients, carers and volunteers who gave their time to participate in this research, for some at a time of great challenge in their lives.

Picture acknowledgements:

Front cover pictures with thanks to St Michael's Hospice, St Joseph's Hospice and Hampshire Hospital's Foundation Trust.

The International Observatory on End of Life Care and Institute for Volunteering Research were contracted as part of a competitive process to conduct this evaluation.

Institute for Volunteering Research
NCVO
Society Building
8 All Saints Street
London N1 9RL
www.ivr.org.uk

International Observatory on End of Life Care
Division of Health Research
Faculty of Health and Medicine
Lancaster University
Furness Building
Lancaster LA1 4YT
www.lancaster.ac.uk/ioelc

Key points

This is the first trial of a social action volunteer provided befriending service, and so its findings are important to guide research, policy and practice. The key findings from this study are:

- **More hours of contact with a volunteer appear beneficial.** Increasing contact with volunteers as part of a social action befriending service appears to significantly improve quality of life for people in their last year of life.
- **Outcomes of quality of life, loneliness and perception of social support were improved.** Improvements did not reach statistical significance, but all trends were consistently in favour of the befriending service.
- **Befriending support appears to slow a decline in quality of life at the end of life.** Quality of life was low, and deteriorating, for people referred to the service. This decline was reduced once they were referred.
- **People who were older, had cancer, who live alone and are male may be more likely to benefit.** People with certain characteristics appear to benefit more from befriending services.
- **People enjoyed receiving the befriending service.** People who had experienced a befriender described multiple benefits, mostly social and psychological, from receiving the service.
- **Trained and supported volunteers are able to deliver a high quality befriending service to those in their last year of life.** Services are not resource neutral, and sufficient investment in ongoing training and support is essential.
- **The support that volunteers offer is unique, occupying a position between family/friends and professional care.**

It is recommended that:

Social action volunteer delivered befriending services continue to be developed to provide an important and unique element of high quality end of life care. Evidence from this study can be used to guide how these services are provided and tailored to maximize the likely benefit that people derive.

Service commissioners, funders, service providers and communities consider how they can support the development of these services.

Further research explores how to target these services, and best develop and prepare volunteers, in well designed and powered trials and other robust studies.

Executive Summary

Background:

Providing compassionate and effective support to people at the end of their life should be a core societal imperative. Whilst health and social care professionals are critically important to achieving this aim, the contribution of volunteers and communities should also be recognised. It may be that developing social relationships and networks can buffer the effects of crisis associated with dying, maintain a good quality of life, and provide a framework to support family networks. Traditional family and community networks can be small and fragile because of societal and demographic changes. In response to this a number of providers of end-of-life care have initiated volunteer 'befriending' or 'good neighbour' services. These services generally provide home based support such as companionship, support or information. Whilst there is evidence people at the end of life like and are satisfied with volunteer provided support, outcomes of such care have not been evaluated in well-designed comparative studies. In response to these needs the UK Cabinet Office grant funded a number of social action befriending services in the context of a high quality evaluation. This report details the results of this evaluation.

Aim:

The primary aim of the study is to evaluate the effectiveness of receiving care from a social action volunteer service plus usual care at improving quality of life than usual care alone for adults in the last year of life.

Methods:

Study design: A wait-list controlled trial (with 8 nested qualitative case studies) testing volunteer delivered befriending services across 11 hospice, charity and NHS sites. Participants were randomly allocated to either receive the befriending intervention immediately or after a four week wait.

Services evaluated: The interventions provided by these services shared core elements including regular face to face volunteer provided tailored support including befriending, practical support and signposting.

Participants: were adults estimated to be in their last year of life, with any diagnosis.

Sampling and recruitment: All people referred to the befriending/good neighbour were invited to take part in the study, eligibility assessed, and written consent taken.

Data collected: Data were collected at baseline before randomisation, and then at four week intervals for eight weeks of intervention receipt. Participant completed questionnaires used validated measures to assess quality of life, loneliness and perceptions of social support. Data were collected weekly from each site on the type, frequency and length of volunteer contact with patient participants. Qualitative data collected within eight sites included interviews with patients, carers, staff and volunteers.

Results:

195 people entered the trial, and interviews were conducted across 8 case study sites with volunteers (n=23), staff (n=34), patients (n=24) and family carers (n=3).

People referred to the befriending services were typically older, female, white and living alone. Fewer than half had a diagnosis of cancer. Whilst age and ethnicity of the sample were typical of those accessing end of life care services, the befriending services appear to reach out more to those who live alone or who do not have cancer. Baseline data indicated participants tended to be lonely and with a poor quality of life. 20% of enrolled participants died during the study.

The trial showed that a greater number of hours of volunteer input is likely to be important in improving quality of life. When the amount of input was taken into account a significant effect on the physical domain of quality of life was found. No other significant effects on quality of life, social support, loneliness or use of health and social care services were found, although the trend in the results were all in favour of the intervention. Where the intervention may have an effect is in slowing the rate of decline in quality of life for people receiving the volunteer provided intervention. The effect of the intervention is small, and a larger trial would be required to detect a difference from the outcomes measured.

Qualitative data supported these results, with participants overwhelmingly describing benefit from the volunteer provided befriending services. Patients, informal carers, staff and volunteers reported benefits such as companionship and reductions in negative feelings. These were felt to emerge both from directly discussing concerns, but also from everyday activities and conversations. Volunteers could also act as a link to other professionals, alerting people to obvious changes in condition. Volunteers provided considerable social support, and could form strong bonds with those to whom they provided support.

Benefits were also expressed for carers, as burden was alleviated, and for volunteers who appreciated contributing to others, giving back to society, and reducing their own isolation.

Services provided varied in the way they operationalised support with variability in whether role included taking people outside the home, if practical tasks were undertaken, the informality of the role, and the intensity of support offered. Importance was attached to volunteer selection, training and matching with participants.

Conclusions:

Those who received these services in their last year of life tended to have a low quality of life, were lonely and with high social support needs. Volunteers were able to deliver responsive, safe, effective and appreciated support. Small benefits from these volunteer delivered services were seen in domains of quality of life, loneliness and perceived social support.

Evidence from this study can be used to guide how these services are provided and tailored to maximize the likely benefit that people derive. Service commissioners, funders, service providers and communities should consider how they can support the development of these services.

Contents

		Page
1.	Introduction	8
1.1	Why is this study important?	8
1.2	Why we need to do this study now	9
2.	End-of-life social action (ELSA) research project	10
2.1	Aims of the study	10
2.2	Approach taken in this study	10
2.3	The type of service being provided and evaluated	11
2.4	The process of the study	11
3.	Results	13
3.1	Baseline data	13
3.2	Outcomes of the befriending service: Quality of life	17
3.3	Outcomes of the befriending service: Loneliness, social support and use of health and social care networks	19
3.4	Outcomes of the befriending service: Multilevel modelling of outcome predictors	20
3.5	Outcomes of the befriending service: Qualitative case study data	22
3.6	Outcomes of the befriending service on carers, volunteers and staff	25
3.7	Providing a volunteer delivered befriending service	26
4.	Interpreting the findings	30
4.1	Do volunteer social action services make a difference to people at the end of life?	30
4.2	Do volunteer social action befriending services extend access to end of life care?	31
4.3	Volunteer social action befriending services reach out to those who have a poor quality of life	31
4.4	What type of volunteer provided social action befriending support should be provided?	32
4.5	How should the volunteer social action befriending service be delivered and managed?	34
4.6	Recommendations for research, policy and practice	35
5.	References	36

List of tables

List of figures

List of appendices

List of tables

3.1.1 Numbers of participants in the eight qualitative case studies
3.1.2 Demographic characteristics of those people in the last year of life referred to, and participating in the trial
3.1.3 Baseline data on quality of life, loneliness and social support
3.1.4 Type of contact in existing social network at baseline
3.4.1 Modelling key variables for their influence on study outcomes

List of figures

2.4.1 The overall process of the study
3.1.1 CONSORT diagram of participant flow during the study
3.2.1 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) for physical domain of quality of life.
3.2.2 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) for psychological domain of quality of life
3.2.3 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) for environmental domain of quality of life.
3.2.4 Estimated rate of change from baseline to week 4 (phase 1) and week 4 to 12 weeks follow up (phase 2) for physical domain of quality of life, controlling for site and hours of input
3.2.5 Visit hours received by those in the intervention arm between baseline and week 4 assessment
3.7.1 Theorising the factors that underpinned impact
4.3.1 Comparing ELSA baseline quality of life scores with those from other studies
4.4.1 Dilemmas of the volunteering role
4.5.2 The process of delivering a volunteer provided social action befriending service

Appendices

Technical appendix one	Design and methods of the study
Technical appendix two	Results from the study
Appendix three	Mapping quantitative outcome measures and qualitative interview data
Appendix four	Case study interview topic guides
Appendix five	Case study interview coding framework

1. Introduction

This section introduces the context, and explains the rationale for, the study.

1.1. Why is this study important?

1.1.1. In 2013 over half a million people died in England and Wales, mostly dying from long term conditions such as cancer (29%), circulatory (28%) and respiratory (15%) disease that are known to be life limiting[2]. For deaths that can be anticipated, providing excellent care at the end-of-life that is responsive to need is critically important. Most people want to be cared for as close to home as possible, especially in the last year of life[3]. Patients and family carers express satisfaction with home palliative care services, and these services appear effective in enabling death at home and reducing hospital stays[4-7].

1.1.2. However there is poor understanding about which components of home based interventions provide the highest benefit at the end-of-life[8]. Understanding the impact of these components, in context, is important so that priority is given to developing services in a way known to maximize benefit to patients, carers and the services themselves. These questions are critically important in the current healthcare context: a wider range of people accessing services at the end-of-life; and a policy shift to home care, but often without a commensurate shift in resource from other healthcare sectors[9 10].

1.1.3. A developing aspect within care in the last year of life is the importance of social aspects of care, recognising that compassionate support cannot be the responsibility of health and social care professionals alone and requires a response from the wider community[11 12]. Volunteers are a critical part of many end-of-life care services[13-20]. Family members are satisfied with the services that volunteers provide at the end of life[18], but there is little evidence of their effect on care outcomes.

1.1.4. A recent systematic review assessing the impact of volunteers involved in the direct care of patients and their families at the end of life only found 8 studies, none from the UK. They indicate that volunteer involvement has a positive impact on satisfaction with care and that patients may survive longer with home visits from a volunteer. They conclude that further research is needed to ensure the resource of volunteers in care at the end of life is used appropriately and effectively. Evaluation in well-designed comparative studies is therefore recommended[21].

1.1.5. Alongside a developing interest in the work of volunteers at the end of life is an increasing appreciation of the importance of public health approaches to end-of-life care, recognising the importance of social networks and social capital[22]. Proponents of these approaches argue that a primary focus on bio-medical and physical aspects of end-of-life care ignores the social context within which dying takes place. Social relationships and networks can buffer the effects of crisis associated with dying, provide a framework that may prevent family carer burn out, and demonstrate the importance of supporting social contexts[23-25].

1.1.6. Research demonstrates that individual and community networks and relations of support can be inadequate to meet care needs because networks can be small and fragile, community engagement shifted by caregiving, and where formal care services provide little practical support[23]. Demographic changes such as increased female employment, delayed childbearing, geographical mobility, divorce rates, and longer working lives all potentially impact on the availability of traditional family and neighbourly support. Services are being increasingly developed and invested in to provide such neighbourly support that may be missing, but there is little evidence on the outcomes or effectiveness of such services.

1.2. Why we need to do this study now

1.2.1. Many volunteer delivered 'befriending' or 'good neighbour' social action services are being run or developed to provide support to people in their own homes such as companionship, running errands and providing information. Whilst this feels intuitively helpful, there is no robust evaluation of the outcomes of these services nor understanding of how best to provide such care to maximise their effectiveness. Research is needed to ensure that the resource of volunteers in palliative care is used appropriately, and in a way which effectively improves quality of life and the experience in the last year of life.

1.2.2. Evaluation of interventions such as this in the last year of life in well-designed comparative studies is essential. Many interventions in end-of-life care are not tested using robust designs: this is potentially wasteful of resource and could lead to poorer or unintended outcomes. The sector has learnt from the issues associated with the withdrawal of the Liverpool Care Pathway[26], where a previously widely adopted end-of-life intervention did not have the required evidence base to provide a defence against its critics and appeared to be potentially harmful due to errors and issues with its implementation.

1.2.3 The UK Cabinet Office, recognising both the importance of social action initiatives at the end-of-life, and the need to evaluate them robustly, grant funded a range of organisations to provide volunteer delivered befriending/good neighbour services in the context of a high quality evaluation. This report details the results of this evaluation.

2. End-of-life Social Action (ELSA) research project

This section introduces the ELSA research project, addresses the aims of the study and outlines the approach adopted for its implementation. Full details of the design of the study are found in Technical Appendix One. The trial was originally published as a paper in BMC Medicine[1].

2.1. Aims of the study

2.1.1. The **primary aim** of the study is to evaluate the effectiveness of receiving care from a social action volunteer service plus usual care at improving quality of life than usual care alone for adults in the last year of life.

2.1.2 The **secondary aims** of the study are to:

a) explore whether receiving care from a social action volunteer service plus usual care can reduce the experience of loneliness for adults in the last year of life;
b) assess whether receiving care from a social action volunteer service plus usual care can affect the perception of social support for adults in the last year of life;
c) examine whether informal carers[1] for those receiving care from a social action volunteer service plus usual care experience less carer burden;
d) determine whether receiving care from a social action volunteer service plus usual care can affect participant's use of other health and social care services;
e) identify and explore the factors that influence the impact of social action volunteer services on end-of-life experience

2.2. Approach taken in this study

2.2.1 As the primary aim of this study is to evaluate the effectiveness of social action volunteer befriending/neighbour services at the end-of-life the most appropriate design is a randomised trial. There are few evaluative studies in this area, and this is one of the first trials to be conducted[28 29]. The issues of conducting research at the end-of-life are well known in the field, but nevertheless careful attention has to be paid to such a design to ensure it is both ethical and robust[30-32]. The chosen design is a 'wait-list' trial (also called fast-track or delayed start), considered to address many of the ethical problems of trials at the end-of-life as all participants eventually receive the intervention[33]. In this design all those who participate in the study receive the intervention, but half are randomised to receive this after a previously determined period of time (the 'wait'). The protocol for the study is published[34].

2.2.2 Whilst trials can provide information on whether there has been change in the chosen measured outcomes of interest, they do not enable an understanding of what people think about the service evaluated, whether

[1] Informal carers, for the purposes of this study, are defined as lay people, who may or may not be family members, in a close supportive role sharing in the illness experience of the patient or providing emotional support27. NICE. Improving supportive and palliative care for adults with cancer - the manual. London, 2004.

the outcomes they perceive from the service match the chosen measured outcomes, nor explore what factors influenced such outcomes. To address these issues qualitative case studies were also conducted, with eight of the 11 participating sites acting as a case study site.

2.3. The type of service being provided and evaluated

2.3.1 Eleven sites participated in this study. Nine of them were based within existing Hospice end-of-life care services: St Michaels Hospice (Harrogate); St Joseph's Hospice (London); Herts Neighbours Network (a collaborative project between Peace Hospice, Watford, Hospice of St Francis, Berkhamsted, Hertfordshire Community NHS Trust and Hertfordshire County Council - Health and Community Services); and six hospice sites which are part of the Sue Ryder organisation (Wheatfields, Leeds; Manorlands, Keighley; Thorpe Hall, Peterborough; St John's, Bedford; Leckhampton, Cheltenham; Nettlebed/Duchess of Kent, Reading). One site was a NHS Trust (Hampshire Hospitals NHS Foundation Trust, Basingstoke), and one a charity providing care to those with alcohol and substance use issues (Aquarius, Birmingham). All sites were providing services to those anticipated to be in their last year of life.

2.3.2 Individual sites had a freedom to determine and deliver the social action intervention within the parameters of the tender. The interventions provided by each service shared common elements:

a. The services were provided by trained volunteers rather than paid members of staff. Services were managed and facilitated by paid staff that were responsible for delivering training, allocating volunteers to patient participants, and monitoring the provision of the volunteer service.
b. Volunteer training addressed issues of safety, boundaries and organisational requirements as well as basic communication skills.
c. Volunteer support was tailored to the needs of the individual and offered from a suite of potential options including 'befriending' e.g. sitting with someone to provide companionship, 'practical support' e.g. assisting with household tasks such as dog walking, gardening, picking up prescriptions or other errands, and 'signposting' e.g. providing information on other available services. Volunteer support did not replace any other care provision, but was provided in addition to usual care.
d. Volunteer support was typically provided face to face, in the home, but telephone contact, and meeting outside the home were possible.
e. The frequency and length of contact was individually determined, but was typically a visit once a week for 1-3 hours.

Sites were provided with financial resource from the UK Cabinet Office to implement this intervention which typically enabled staff employment to facilitate and manage the service.

2.4. The process of the study

The overall process of the study is displayed in figure 2.4.1 below.

2.4.1 Participant recruitment for the study commenced 8th June 2015 and completed on the 8th January 2016 following a three month extension due to delays in commencing the study. Prior to commencement all required research ethics and governance approvals were secured from a NHS Research Ethics Committee, Lancaster University and each site, and an appropriate contract put in place.

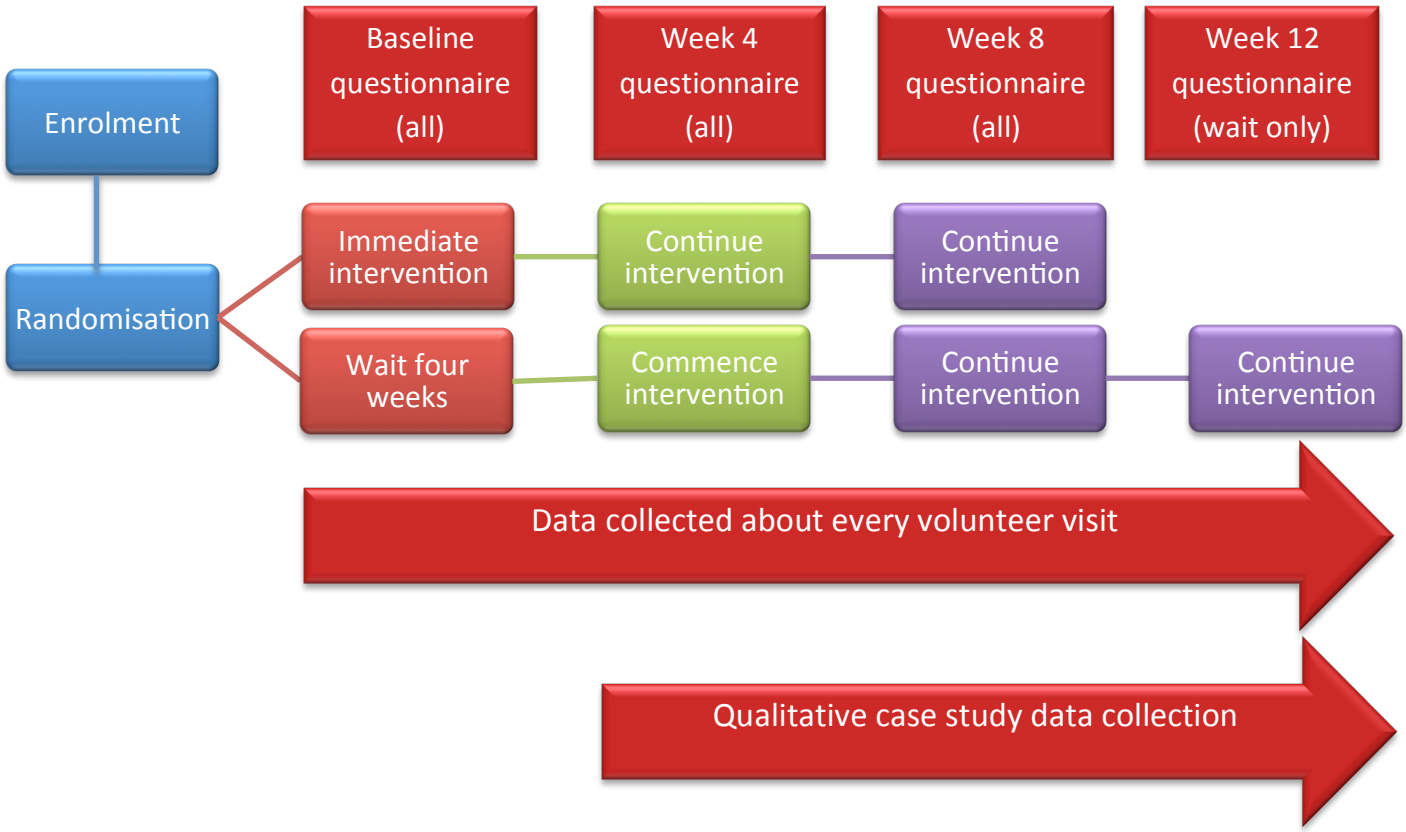


Figure 2.4.1 The overall process of the study

2.4.2 Referrals to the befriending/good neighbour services were received by the sites, and their eligibility to enter the study determined. Written consent was then received from patients to enter the study, baseline data collected, and participants randomly allocated to either receive the study immediately or following a four week wait. Participants were able to pass study details on to a family carer regarding their participation in the study. Data were collected at 4 week intervals for 8 weeks of intervention receipt. The rationale for these data collection intervals was both because the intervention effect needs to be seen rapidly in end-of-life care services, and also drew from experience of other similar research[35 36]. Participants could continue to receive the service once the data collection period had ended.

2.4.3 Eight sites were chosen to participate in qualitative case studies, with variability in geographical location, organisational type and service characteristics. Interviews were conducted with patient, carer, volunteer and staff participants. Staff meetings were observed, and documents about the service and its operation collected.

2.4.4 Participants completed written questionnaires to assess their quality of life (WHO QOL Bref[37]), loneliness (De Jong Gierveld Loneliness Scale[38]), social support (mMOS-SS[39]), carer burden (CBS-EOLC[40]), and social network size, together with demographic details. Data were collected weekly from each site on the type, frequency and length of volunteer contact with patient participants.

3. Results

Findings from the study are presented here. First, baseline data on patient trial participants; second, trial results; third, case study data. Data are given here both on the outcomes of the social action intervention and the factors which affected these outcomes.

3.1. Baseline data

Key messages from baseline data

- The age, gender and diagnosis of those referred were similar to those who participated, indicating that the trial participants were likely to be typical of those referred to befriending services.
- Baseline data were similar for those randomised to each arm of the trial.
- People referred to the befriending services were typically older (but not the oldest old), female, white and living alone.
- Fewer than half of participants had a diagnosis of cancer.
- Participants had scores on quality of life domains and loneliness scales indicating they tended to be lonely and with poor quality of life.

3.1.1 The flow of patient participants into and through the trial component of the study can be found in detail in the CONSORT diagram (figure 3.1.1), and the numbers who participated in the qualitative case studies in table 3.1.1. In summary, 369 people thought to be in the last year of their lives were referred to the 11 participating services. 329 were eligible to enter the study. One hundred and ninety six entered the study, one died before allocation, and 100 were randomly allocated to receive the befriending intervention immediately, and 95 to wait for four weeks. These participants were followed up for either 8 (immediate arm) or 12 (wait arm) weeks, but a number did not complete the study either because they withdrew from the study or they died during the study period. 20% of enrolled participants (39 of 196) died during the study.

3.1.2 There were some missing data where not all study participants provided study data at all time points, common in studies with such ill participants[41]. Few carers entered the study, and their data are given in technical appendix two. As the number of participants was considerably lower than anticipated by the participating services (196/700), there is a lower likelihood of detecting an effect if there is one.

Table 3.1.1 Numbers of participants in the eight qualitative case studies

	Staff	Volunteer	Patient	Carer	TOTAL
St. John's	2	3	1		6
Duchess of Kent	4	2	4		10
Hampshire hospital	5	3	3	1	12
Peace	8	4	3	1	16
Aquarius	3	2	2		7
St. Michael's	4	3	3	1	11
Manorlands	4	3	3		10
Wheatfields	4	4	4		12
TOTAL	34	24	23	3	84

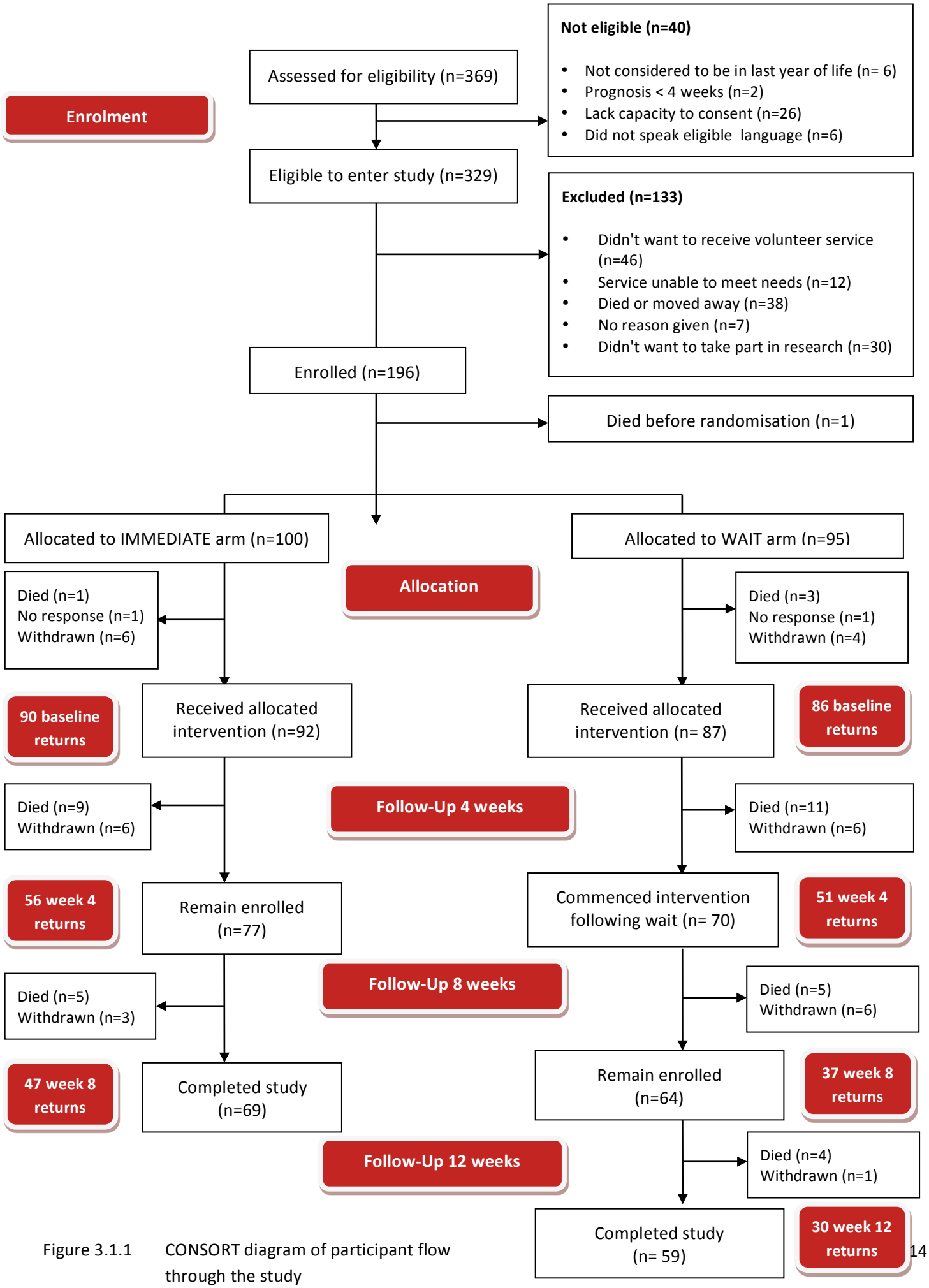


Figure 3.1.1 CONSORT diagram of participant flow through the study

3.1.3 Baseline data at the start of the study were similar for both groups.

Table 3.1.2 Demographic characteristics of those people in the last year of life referred to, and participating in the trial

	Immediate *n* = 92	Wait *n* = 87	Referrals n= 369
Age, Mean ± SD	71.72 ± 12.03	71.91 ± 12.50	73.5 ± 12.9
Gender, Female n (%)	56 (61)	53 (61)	197 (54)
Education, Standard n (%)[a]	62 (76)	54 (70)	
Marital Status, Single n (%)[b]	54 (61)	61 (72)	
Living Status, Living Alone n (%)[c]	47 (53)	54 (64)	
Occupation, Retired n (%)[d]	74 (86)	70 (82)	
Ethnicity, White British n (%)[c]	81 (92)	76 (89)	
Spirituality, Religious n (%)[e]	58 (71)	51 (69)	
Cancer diagnosis n (%)	37 (41)	47 (55)	202 (55)

Note: Number of respondents to each question at baseline [a] n = 159, [b] n = 174, [c] n = 173, [d] n = 171, [e] n = 156.

3.1.4 Baseline data were also collected on the main outcomes of interest: quality of life, loneliness and social support. These data are displayed in table 3.1.3.

Table 3.1.3 Baseline data on quality of life, loneliness and social support

	Immediate arm	Wait arm
Quality of Life, Poor or Very Poor n (%)[a]	38 (44)	37 (44)
Are you dissatisfied with your health? n(%)[b]	62 (70)	65 (76)
Quality of Life, Mean ± SD		
QoL Physical[b]	32.09 ± 15.21	34.95 ± 17.42
QoL Psychological[a]	46.52 ± 19.10	45.74 ± 17.01
QoL Environment[c]	58.75 ± 16.23	57.05 ± 14.76
QoL Social Relationships[d]	55.47 ± 23.26	52.88 ± 26.41
Loneliness, Mean ± SD		
Social Loneliness[e]	1.51 ± 1.21	1.69 ± 1.25
Emotional Loneliness	**1.70 ± 1.11**	**2.12 ± .87**
Total Loneliness Score[f]	**3.17 ± 1.89**	**3.77 ± 1.66**
Social support, Mean ± SD		
mMOSS Instrumental[f]	3.27 ± 1.31	3.00 ± 1.28
mMOSS Emotional[g]	3.25 ± 1.10	3.98 ± 1.09
mMOSS Total[f]	3.27 ± 1.08	3.01 ± 1.07
Number of people in contact with over last 2 weeks, Mean ± SD[h]	4.39 ± 2.41	4.41 ± 2.56
Overall number of contacts (visits, phone calls) over last two weeks, Mean ± SD[j]	39.85 ± 31.03	46.29 ± 45.33

Note: Number of respondents to each question at baseline [a] 172 [b] 175 [c] 173 [d] 161 [e] 160 [f] 162 [g] 164 [h] 168 [j] 165. Numbers in **bold** represent a statistically significant difference between trial arms.

3.1.5 Data on type of contacts participants had at baseline are displayed in table 3.1.4.

Table 3.1.4 Type of contact in existing social network at baseline

Type of contact	Number of contacts	Percentage
Non-Resident Family	284	43.89
Friends and Neighbours	127	19.63
Health care professionals	96	14.84
Social care professionals	66	10.20
Co-resident	44	6.80
Other Professionals	30	4.64
Total	647	100.00

3.2. Outcomes of the befriending service: Quality of life

Key messages from quantitative trial data

- Increasing hours of input may be important; when this was taken into account a significant positive effect on the physical domain of quality of life was found.
- The effect of the intervention appears to be in slowing the rate of decline of quality of life.
- The befriending/neighbour volunteer intervention did not have a significant effect on quality of life, social support or loneliness but the trend in the results is in favour of the intervention.
- Key characteristics affect outcomes including age, diagnosis, living status, gender, number of volunteer contact hours and size of social network.
- The effect of the intervention is small, and a larger trial would be required to detect a difference from the outcomes measured.

3.2.1 Quality of life was measured using the WHO QOL Bref[37] as our primary outcome (this measures physical, psychological, social and environmental domains of quality of life). The rate of change of quality of life was calculated on an intention to treat basis, both for the time from t0 to t1 (phase 1: when the wait-list participants were not receiving an intervention) and from t1 to t3 (phase 2: when all participants were receiving the intervention). This is displayed in figures 3.2.1, 3.2.2 and 3.2.3. These figures show that there is a significant decrease in physical quality of life during the first time period for those in the wait group, a change not observed in those in the immediate arm.

These data are tabulated in the technical appendix for both an intention to treat and per protocol analysis.

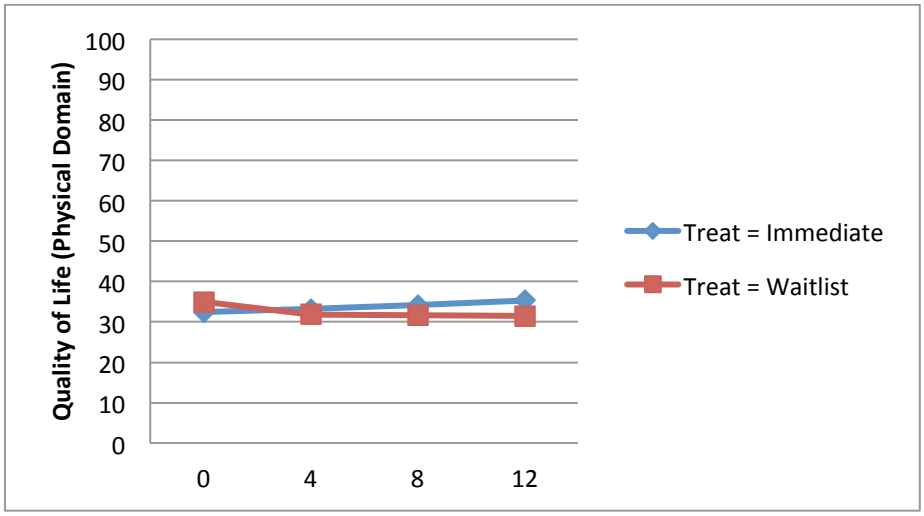


Figure 3.2.1 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) for physical domain of quality of life

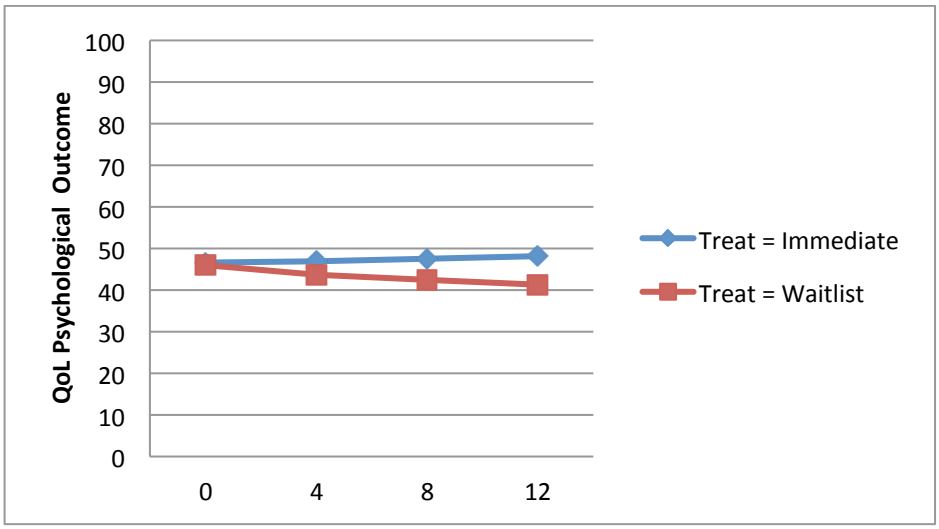


Figure 3.2.2 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) for psychological domain of quality of life

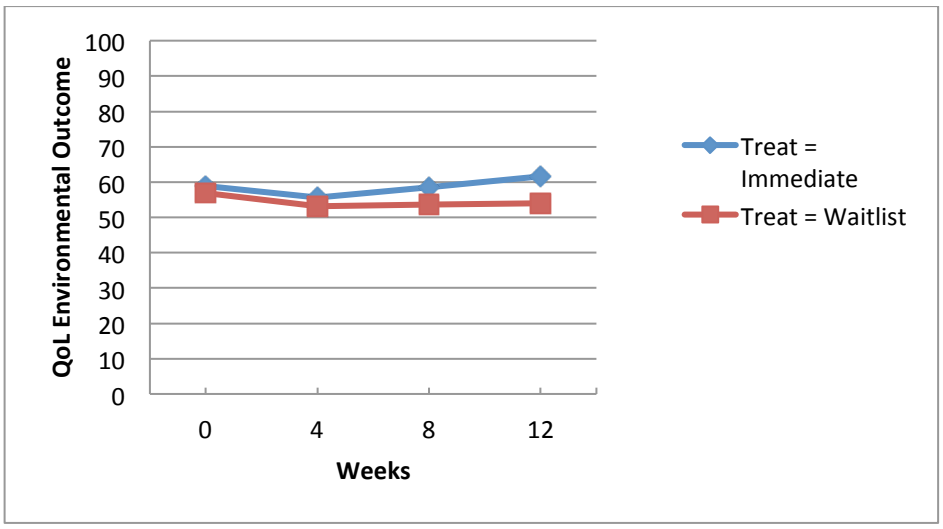


Figure 3.2.3 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) for environmental domain of quality of life

3.2.2 Sensitivity analyses were conducted to take account of the amount of volunteer input people received ("*number of visits*" and "*number of hours of contact*") in the initial four week period. Due to the high correlation observed between both indicators (r=.80), a model was therefore specified using only hours of input and controlling for site. The range of number of visits in the immediate group was 0 to 14, with a mean number of visits of 1.75 (SD = 2.05).

3.2.3 These data taking account of amount of volunteer input received are displayed in figure 3.2.4, and tabulated in the technical appendix. A significant treatment effect was observed when QoL Physical Domain was used as the primary outcome, reflecting the presence of a small effect size (Cohen *d*= .27). This indicates that there is a 'dose' effect whereby the number of hours of volunteer support received makes a difference to the impact of the intervention.

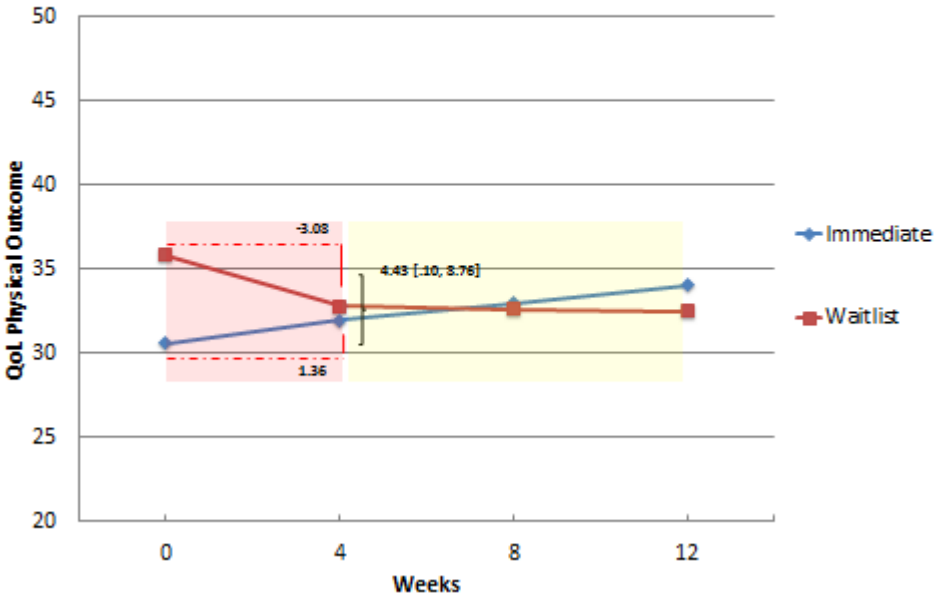


Figure 3.2.4 Estimated rate of change from baseline to week 4 (phase 1) and week 4 to 12 weeks follow up (phase 2) for physical domain of quality of life, controlling for site and hours of input

3.2.4 There was a wide range of hours of input, shown in figure 3.2.5. This effect persisted even when the outlier was removed from the model.

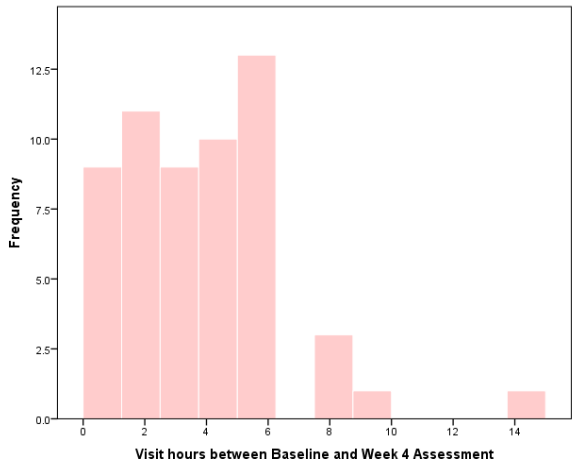


Figure 3.2.5 Visit hours received by those in the intervention arm between baseline and week 4 assessment

3.2.5 Quality of life outcomes, measured using the WHO QOL Bref[37], are also reported in technical appendix two as estimated means and confidence intervals on both an intention to treat and per protocol basis. No significant differences were found on the three domains of quality of life for which we have robust data.

3.3. Outcomes of the befriending service: Loneliness, Social Support and use of health and social care networks

3.3.1 Loneliness (De Jong Gierveld Scale[38]) and Social Support (mMOS-SS[39]) were both assessed as outcomes, and are reported in technical appendix two where treatment effect was evaluated testing the interaction between treatment and time. No significant differences were found for loneliness or social support.

3.3.2 People in the study self-reported their contacts with health and social care professionals at each data collection point. These data are reported in technical appendix two. No significant differences were found between the intervention and wait-list arms over time.

3.4 Outcomes of the befriending service: Multilevel modelling of outcome predictors

3.4.1 Sensitivity analyses were conducted on primary (quality of life) and secondary (loneliness and social support) outcomes of the study after controlling for outcome predictors which emerged from analysis of qualitative case study data. Variables in these models included the treatment condition (which arm of the trial they were in), the effect of research site (to assess if those sites managed by the same organization shared characteristics), gender, age, number of contact hours until week four, social network size at baseline, whether they lived alone, and diagnosis. These data are all reported in detail in technical appendix two, and summarised here in table 3.4.1.

Table 3.4.1 Result summary of sensitivity analyses

OUTCOMES	QOL Physical	QOL Psychological	QOL Environmental	Emotional loneliness	Social loneliness	Instrumental social support	Emotional social support	Total social support	Use of health and social care
PREDICTORS	Higher score = better QOL			Higher score = more loneliness		Higher score = more social support			Higher score = more contact
Intercept									
Treatment Condition, *Immediate*									
Site, *Sue Ryder*									
Gender, *Male*									+
Age		+	+	-	-		+	+	
Number of contact hours, *until week 4*	+								+
Network Size, *at baseline*									+
Living Status, *Living alone*			-	+	+	-	-	-	
Illness condition, *Cancer*	+			-			+		
Time 1, *until week 4*			-						
Treatment Condition x Time 1							+		
Time 2, *after week 4*									
Treatment Condition x Time 2									

Note: + variable associated increase in outcome score. – variable associated with decrease in outcome score.

3.4.2 We observed significant outcome predictors such as age, living status and diagnosis, but also number of contact hours, network size and gender:

a) Being male was associated with worse scores on the QOL physical domain.
b) People with cancer had a significantly higher score on QOL physical domain than those with other diseases.
c) Those who were older had higher scores in the QOL psychological domain.
d) There were similar patterns in the QOL environmental domain where older people tended to have higher scores, those living alone to have lower scores, and the scores are low in the first phase of the study where fewer receive the intervention.
e) Older people and those with cancer were less lonely, but those who live alone were more lonely.
f) Those who were older and with cancer had fewer social support needs than those who were living alone.
g) The more hours of contact people had with a volunteer was associated with an increase in contacts with health and social care professionals.

3.5 Outcomes of the befriending service: Qualitative case study data

Key messages from qualitative case study data

- Study participants overwhelmingly saw benefit in the social action befriending services.
- Patients, informal carers, staff and volunteers reported benefits such as companionship and reduction in negative feelings.
- Volunteers acted as a link to other professionals, alerting people to changes in condition.
- Volunteers provided considerable social support, and could form strong bonds with those to whom they provided support.
- Benefits were expressed for carers, as burden was alleviated, and for volunteers who appreciated contributing to others, giving back to society, and reducing their own isolation.
- Services varied in the way they operationalised support with variability in whether roles included taking people outside the home, if practical tasks were undertaken, the informality of the role, and the intensity of support offered.
- Importance was attached to volunteer selection, training and matching with participants.

3.5.1 Psychological impacts of the social action befriending service

Patients, informal carers, staff and volunteers all reported psychological benefits of the service. These varied from reductions in negative feelings (such as depression or loneliness) to benefits of companionship. The benefits were felt to both emerge directly from discussing anxieties and concerns with the volunteer as well as flowing from everyday activities or conversations that might enhance self-worth and feelings of being cared for.

> With the befriender coming and getting me out, it makes a lot of difference to me because when I'm stuck in here and I don't get out, because I'm not so well or whether it's because of the weather or whatever, I get really depressed and really weepy and if I've got [befriender name] to look forward to, knowing if the weather's fine we can go out and that's it. (Patient)

Patients more commonly reported 'milder' psychological benefits resulting from enjoyment of the company provided as part of the befriending relationship than did staff or volunteers. Impacts were also reported through more practical help where volunteers allowed patients and carers to achieve what would otherwise be difficult for them resulting in them feeling better about their situation e.g. walking the dog, shopping or putting up a Christmas tree.

> Sometimes you can't be bothered or you won't do things and when somebody else comes and you talk to them and you talk between you you realise that you should be doing different things and not just sat and feeling sorry for yourself and things like that, and I feel better when she's gone because I know she's been making an effort with me which I feel is a big thing (Patient)

An illustrative example of this is the benefits for a patient of being able to regularly have her hair cut and styled by her volunteer. This patient benefited psychologically as it allowed her to have her hair cut regularly in the way she had before she became largely housebound. This had an impact on the patient's self-esteem and confidence.

The social action intervention was often reported to have increased patient confidence and motivation. For those patients with anxiety issues or experiencing social isolation, this effect appeared particularly pronounced. Patients explained their growth in confidence or motivation in terms of being "drawn out" of themselves, being given the motivation to do "something positive" and "talking a lot more than I used to do and open up that little bit". In complement to these patient responses, a volunteer suggested that the greatest impact she had on the patient was on the greater sense of hope he had gained. These impacts could be borne simply of social support but could also be linked to the growth in self-esteem from knowing that the befriender was making an effort to visit the patient.

> So, it's a great thing, you know? It's nice that the government are funding things like that because it would save the health service so much money for antidepressants when people don't need them. (Patient)

Psychological impacts could be brought about through a wide range of actions that did not necessarily need to be concerned with end-of-life care. Unusual cases of this included a volunteer helping the patient come to terms with the experience of losing contact with her son. Another example was reassuring a patient that it was okay to use her savings to pay for her own care, rather than pass it on to her children. For maximum impact to be realised it appears the volunteer must remain open to attending to a broad range of stressors.

3.5.2 Physical impacts of the social action befriending service

> I said, "But if we want to get to the root of all the anxieties and the issues that you have in life it's got to start somewhere again. It's unfortunate that the GP you were seeing has left but please just consider going again, starting off a new dialogue". And he's done it. (Volunteer)

Services were not designed to offer direct physical care, however, volunteers were seen to bring about physical impacts indirectly. First, the physical benefits were seen to flow from psychological and social impacts. For example, a staff member described how the daughter of a patient believed that the volunteer regularly researching and discussing her father's football team had prolonged her father's life by providing him with a fixed point of stability and continuity in a time of great change. Second, the volunteer could mitigate some negative physical constraints of the patient including mobility and their ability to undertake the activities of daily living. Third, the volunteer could function as a link to clinical professionals. Through their regular contact with the patient volunteers could monitor their health and, via their coordinator, alert clinical staff to any obvious changes in the condition of the patient.

It was perhaps this last aspect of the relationship through which volunteers could bring about the greatest impacts to patient health. Volunteers understood that it was not their role to contact medical professionals on behalf of the patient and instead passed the relevant information on to the befriending coordinator, who, in turn, could pass the information on to the GP or nurse dealing with the patient. In some cases patients could need encouragement to access health services and benefited when persuaded to do so. One volunteer gave an example of persuading a patient to visit a GP despite the anxieties this provoked in him after his previous GP had moved on.

> For me, it's been tremendous, tremendous.... I actually started to cry because I said, "It's wonderful that somebody can be caring when someone has problems."... It's a wonderful idea, and it should go on forever really. (Carer)

3.5.3 Social Impacts of the social action befriending service

> I could go days without seeing or speaking to anybody[...]. I'd get down sometimes, who doesn't? Maybe I do more than others because my wife died. No prospects at the moment. [...] So I don't feel lonely but I do like company and she is good company. (Patient)

As the primary focus of most roles, volunteers provided considerable social support. The social interaction provided company, everyday chit chat and conviviality for the patients but in some instances the social impacts were more substantial based on closer and deeper social relationships. Where patients were experiencing high levels of loneliness the social impacts were seen to be highest, alleviating a degree of the patient's loneliness and providing them with social support.

As a form of social support, conversation was important to patients, particularly for those with limited contact with others. Interview participants described a range of conversational topics such as family, past work, the weather and physical health. The opportunity for the patient to speak their mind to someone they could trust was especially important. This could be a valuable outlet for patients as they consider their illness. A patient interviewee gave a good example of how important this could be, as the befriending relationship provided an outlet for the patient to discuss concerns about her illness that would otherwise remain "bottled up".

> And I think if you really are really isolated it can have a huge impact because it's partly the company but it's also somebody taking an interest and it's all that kind of self-esteem side of it and feeling valued and cared about as well, I think that can have a huge impact. So it does depend on the situation but for some people it is a huge, huge difference and huge outcome. (Staff)

Wide-ranging conversation was aided by the novelty of the relationship and how little each party initially knew of each other. In some cases this could lead to a deep bond forming quite quickly. For example, in a two month period a patient had grown to see her befriender as her 'best mate'. This was likely to be related to the benefit this patient had drawn from being able to discuss her problems with the volunteer. In her words this was a matter of "being able to talk about my problems freely". Some positive impacts could also be felt in relationships that were characterised by more 'episodic' and 'everyday' interactions (see below).

> I just see it as something that hasn't got an agenda, something that's open. I would imagine it would be, and should be, different for every individual [...] Because you're not there as a medical professional, you're not there as a health support worker, you're not there as a next of kin, you're not, it's almost like that little bit of no man's land, that little bit of lost space in the middle. (Volunteer)

Patients also mentioned pleasure in being able to go out more and access social activities they might otherwise be unable to such as visiting garden centres or coffee shops. Such apparently commonplace or routine activities could be very beneficial to patients.

3.5.4 The different nature of impact across domains

There appears to be a spectrum which represents different dimensions of impact cutting across the different social, psychological and physical domains of impact on patients based on the nature of interaction:

At one extreme are impacts from the service resulting from a continuous relationship which becomes closer and has benefits which persist between volunteer visits and progress as the relationship grows. These impacts are more existential and relate to the patient's sense of self. In contrast, some relationships were characterised by episodic interactions, self-contained from one visit to the next and with the volunteer offering more everyday interaction. The varying nature of impact across these various dimensions is a major finding from the case study interviews. However, the differing forms that the role could take were not necessarily linked to the level of impact experienced by the patient as some more episodic, everyday roles were believed to have profound impacts.

3.6 Outcomes of the befriending service on carers, volunteers and staff

3.6.1 Impact on Carers

There were three primary impacts for carers. First, a clear benefit of the service was the way it could allow carers respite to take time away from caring while the volunteer made their visit. This was described in terms of a "relief" and an alleviation of "burden". Time to themselves could allow the carer to go out on their own, keep their own appointments, run errands, maintain a greater degree of social contact with others or simply relax at home. When the volunteer had won the trust of the carer, they could benefit from sharing their responsibilities with the volunteer. Second, in some cases the carer received direct social and psychological support from the volunteer – sometimes post-bereavement, although this was rare. Third, carers had the "peace of mind" and satisfaction that their relative was receiving support.

3.6.2 Impact on volunteers

The impact on volunteers of engaging as a befriender was overwhelmingly discussed in positive terms. The most important of these were altruistic benefits, meaning the pleasure taken in 'giving something back' or 'feeling useful'. Other reasons given for valuing the role included that participation made volunteers feel more grateful for the good fortune they experienced in their own lives. More specifically, volunteer's own problems seemed less important when compared to those of the patient they were supporting. Finally, the role was also valued for the social benefits it could have for volunteers, which mirrored many of the patient benefits including reduced isolation and loneliness to more everyday social contact. One volunteer stated relief from "being bored most of the time".

> You walk away and you think actually, you know, whatever was not going so well this morning, it does not really matter when you look at what some people have got to put up with and face, you know. So it has done me a lot of good in that respect, to see the strength in other people, how they cope. Yes, definitely. (Volunteer)

3.6.3 Barriers and Facilitators to Achieving Impact

The precise nature of the volunteer role is a crucial underpinning to the success of the service as well as shaping how the service should be delivered most effectively. There is divergent structuring of and conception of the volunteer role both between and within the services.

Asked to comment on what defined a proficient volunteer, or what was distinctive about the volunteer-patient relationship, respondents would often phrase their answer in terms of how the role differed from medical/social care professionals and family members. Compared to medical professionals, this might simply be a question of the length of time volunteers could spend with the patient, allowing them to have different conversations. This was complemented by the way in which the role facilitated discussion of a greater range of subjects because it was not directed towards an immediate goal, creating an opening in which other types of interaction could take place. Unlike the primarily goal-directed or 'instrumental' role of clinical professionals, the success of the volunteer role was partly a question of its open orientation to adapting flexibly to a range of patient needs. Because volunteers were not focused on a narrow and pre-defined set of priorities, they can instead be led by the range of patient needs, responding in a more holistic manner to the patient's requirements.

> The biggest impact I think is them having someone they can talk to that isn't their family because, actually, having to tell your family that you are dying and you are afraid, you end up then being the strong one for them, particularly if you are the mother in that relationship or the father or the husband, you end up taking on a strong role and, actually, you need that outlet to go, 'I'm not okay.' (Staff)

The value of the volunteer role was not only illustrated through reference to clinical professionals and was also positioned in distinction to family members. In this case the distinctive input of the volunteer was partly a consequence of their unfamiliarity with the history of patient and their favourite anecdotes. Unlike the patient's family, this enabled the volunteer to talk through the patient's account of their life with them with genuine interest and surprise.

Another way in which the relationship differed from that with family members was the opportunity it provided for the patient to discuss topics they feared might upset or worry their family. In cases such as these it seems that the relative distance and lack of familiarity between volunteer and carer/patient can mean they are able to discuss sensitive topics. Paradoxically, the advantage of the relationship was based both on the distance of the volunteer from the patient, and the close level of trust in which they were held by the patient. Because the volunteer was more distant than family and close friends the patient could often confide more in them than in those closest to the patient. On the other hand, this was only possible if the patient felt enough trust in the volunteer to confide in them. This type of dynamic could be likened to the combination of distance and trust required in a successful counselling relationship. The success of the relationship in these terms could be particularly significant for patients who feel unable to discuss their fears or worries about death with their closest carers and relatives.

> She's just brought me out of myself. As I say, I don't talk a lot to people. I don't see anybody really to talk to. (Patient)

3.7 Providing a volunteer delivered befriending service

3.7.1 Theorising the factors that underpinned impact

A way of representing the dynamics underpinning the impact of the social action intervention is through a series of spectrums illustrating the differing ways in which the role was conceptualised and practiced.

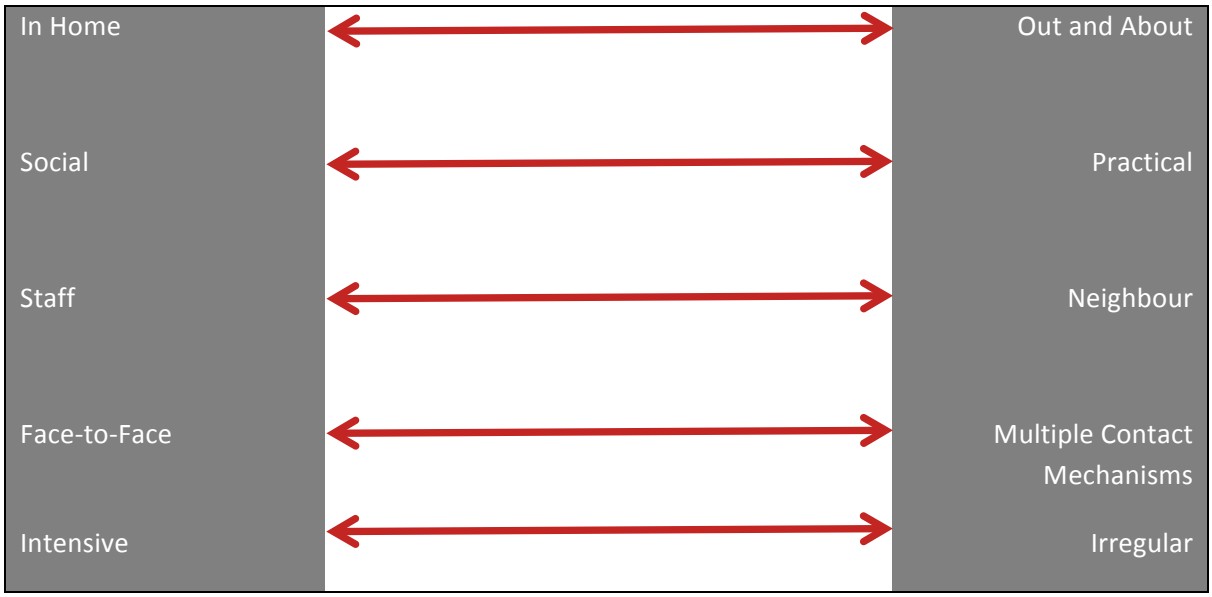


Figure 3.7.1 Theorising the factors that underpinned impact

Home vs out and about: Some roles were restricted to within the patient's home. This suited some patients but there was appetite amongst many to get out and about more and considerable frustration where it was not possible. Where this was seen it could have significant social, psychological and physical impacts allowing patients to undertake activities they wouldn't otherwise be able to.

Social vs Practical: The vast majority of roles were social befriending roles but a number of practical tasks were undertaken including domestic tasks (painting, cleaning, decorating, making food and drinks), dog walking, transport, shopping, advice and helping with medication. Patients generally stressed the importance of the social support provided by volunteers whereas staff also articulated the potentially profound impact of basic practical support.

Staff vs Neighbour: Site staff perceived the role as a marked alternative to staff-delivered, professional care and indeed a number of sites actually called the role "neighbour". To some extent this freer, more informal role had been realised, however, the roles tended to remain subject to a number of restrictions (see 'managing boundaries' below) and in many sites the volunteers were from different communities to the patient receiving the service. The importance of human-to-human neighbourly aspects were stressed by all groups – often distinguished from professional, especially clinical, staff, however, volunteers received substantial training and the role that was seen to need a certain type of person to succeed.

Face to face vs multiple contact mechanisms: The vast majority of contact was face-to-face, which was seen as important for underpinning impact. In most sites contact was limited to face-to-face communication although there were examples of telephone befriending. This tended to be short interactions and seen as a holding contact rather than a replacement for face-to-face contact.

Intensive vs irregular: There was variety in terms of the regularity and length of visits from more than once a week to fortnightly. Regular visits were seen to underpin greater impact. Where volunteers were unable to visit a patient (e.g. due to a holiday) one site gave a temporary match with another volunteer in order to maintain intensive interaction. As well as the above dynamic features of the role the impact and success of the social action intervention was also underpinned by the specific way the service was delivered.

> But the volunteers, they don't have to do this, it's because it's coming from the heart. It's coming from in here. It's they want to help other people and they don't want it for personal gain. (Patient)

3.7.2 Delivering the Service

Patient referrals: The majority of referrals came through existing channels, for example, through the hospice. This was planned in some sites whereas others had the explicit ambition to broaden referral pathways, especially from the community. Part of the challenge was lack of awareness amongst community referrers such as GPs or social workers, however, because they had undertaken considerable awareness raising activity using a variety of tactics, some staff felt that negative perceptions amongst these groups towards both social support services and volunteer-delivered services were the primary barrier to more referrals.

> I think GPs felt it wasn't their responsibility and consultants felt it wasn't their responsibility. (Staff)

Volunteer recruitment: As with patients, a substantial number of volunteers were recruited through existing hospice channels. Partly because of this, volunteers were perceived as reflecting the characteristics of hospice volunteers more widely including being primarily female and older than the general population. Recruitment processes tended to be quite substantial including a written application form and face-to-face interview. There was disagreement over the necessary level of selection of volunteers. Very few felt that specific qualifications were necessary and rather stressed certain personal characteristics such as being caring, having good communication skills and a certain level of emotional skill. In practice the vast majority of those who applied were recruited, however, this was due to the passive selection of only certain types of people coming forward.

> I wouldn't say it could be open to anyone because, you know, you need to want to do it, you need to have the right attitude to do something like that. I definitely wouldn't say carte blanche that anybody could do the role. (Volunteer)

Training: Overall, the training of volunteers appeared to be successful across sites with volunteers generally feeling well prepared for their placements. This satisfaction was seen across sites even though the length of training ranged from one day up to eight days. There were also differences in the extent to which volunteers received general hospice volunteer training and that specific for this role. Some volunteers asked for greater instruction in first aid or dealing with an emergency whereas staff tended to see this as unnecessary for the volunteer role.

Matching of patients with appropriate volunteers: The importance of a good match was stressed through the case studies by patients, volunteers and staff. The matching processes were primarily based on the staff member's professional judgement rather than any systematic procedure. This was possible due to the low number of referrals in many areas although these low numbers restricted the ability to be too selective in the match. Interviewees identified different factors that underpinned a successful match – specific needs (e.g. language or a medical need); practical (e.g. rurality or smoking); personality (e.g. chattiness or extroversion); interests (e.g. football or gardening); and demographic characteristics (e.g. age or gender). The level of matching will likely depend on how the role in structured with more friendly, neighbourly roles requiring substantial matching with it being less critical in more distant, befriending, professional roles. Interviewees in most sites felt matching was worth substantial time and investment but as some matches were unsuccessful it was important to build in a review. For example, one patient felt dissatisfied that the befriender she had been matched with was a lot younger than her and unable to drive. By building in a review staff were made aware of this and could address the patient's concerns by finding another volunteer or working on the existing relationship.

> Yes it is important ... you're working 1-2-1 here, they're going into somebody else's home, there's the element of trust on both parties ... I try to find a volunteer that is a close match to the patient. I then go back, introduce them, we have a chat and they see how they get on with each other. (Staff)

Ongoing support for volunteers: Across all sites the ongoing support and supervision offered to volunteers was substantial including in-role coordination (e.g. scheduling and practicalities); emotional support (e.g. discussing emotions and sometimes sign posting on); role development (e.g. reflecting and sharing good practice and ongoing training) and social support (mixing with other volunteers). This support is undertaken through a range of mechanisms including phone, staff review meetings and group support sessions for volunteers. In addition, most sites had a formal lone working system, which in some cases involved a phone call before and after each visit but a less intensive buddying system with friends and family was used in some sites.

Managing boundaries: Sites had various mechanisms for managing different types of boundaries relating to the role (e.g. what household tasks were allowed or sharing of phone numbers) and emotional boundaries (e.g. volunteers or patients becoming too attached). The role boundaries were set differently in different sites but generally the boundaries were managed more loosely than the perceived rigidity of existing end-of-life volunteering roles. This included greater autonomy for volunteers to coordinate their own activities and shape their precise role. However, managing boundaries remained a substantial aspect of the programme and were stressed at recruitment, discussed at training and managed through ongoing support. There remained many prohibited activities in some areas including not driving with patients, not contacting patients directly, not helping with medication, not undertaking certain household tasks and not contacting the family post-bereavement. Interestingly, many volunteers flouted these rules.

> We've kind of been quite liberal ... it's not so rigid and you have to do this and can't do that, mustn't do this...it's been quite free. So that's quite different to what the other models have been, I would say. (Staff)

4. Interpreting the findings

4.1 Do volunteer social action befriending services make a difference to people at the end of life?

4.1.1 The data from the trial show small but significant effect from the social action befriending/good neighbour intervention on the physical domain of quality of life when the number of hours of volunteer input are taken into account. Most other results reported show a trend in favour of the befriending/good neighbour intervention. We observed a repeated pattern of deteriorating levels of quality of life in the wait group during the first 4 weeks, a decrease not observed in the immediate group, that tends to disappear when all participants receive the intervention. Finally, some of the findings comparing treatment arms at week 4 were close to being statistically significant.

Key findings are:

a) *More contact with a volunteer appears to be beneficial*. Participants who had more hours of contact with the volunteer and/or more frequent contact with a volunteer had improved outcomes, particularly on the physical domain of the quality of life score. The high correlation of hours of input and frequency of contact means it is not possible to determine whether it is more beneficial to visit more frequently or for more hours of input to be provided over a specific time period. The length and frequency of visits participants received might be considered low, and it may be that a more intensive service could be beneficial.

b) *Trends were consistently in favour of the intervention*. There is no evidence that the intervention causes harm, or that 'usual care' is necessarily superior.

c) *The effect of the intervention is likely to be in slowing the rate of decline in quality of life*. People in this study were anticipated to be in their last year of life, and a decline in quality of life was anticipatable over time due to disease progression. No improvement in quality of life was seen during this study, and people who participated tended to have lower quality of life scores than the general public or those in earlier disease stages. What can be seen in these data is that the rate of decline of quality of life slows when the intervention is in place. The befriending/good neighbour intervention therefore seems to have a place in maintaining quality of life or slowing decline, rather than facilitating quality of life improvement.

d) *Participants with certain characteristics may be more likely to benefit*. Our modelling data show that certain participant characteristics may be associated with increased benefit for some outcomes. Those who are older, who have cancer, who live alone and who are male may be more likely to benefit from the befriending/good neighbour intervention.

e) *The qualitative case study data show reported and anticipated benefits*: Described benefits crossed psychological, social and physical domains, and support the trends seen in the quantitative trial data. An example of this is where both the quantitative data suggesting a greater impact for those who live alone is supported by the qualitative data exploring impacts for people who experience social isolation. Whilst living alone does not necessarily equate to isolation[42-45], these data indicate that some targeting of these services to those who may experience loneliness may be worthwhile.

4.1.2 There are a number of possible explanations for the trial not demonstrating a significant effect across more domains:

a) *The trial was underpowered*. As hypothesised in the development of the protocol, and as is observed here, the effect of the intervention is small, and hence a larger number of participants would be needed to detect any significant effect. This current study would only have seen a difference with this intervention if the effect size of the intervention on chosen outcomes were much larger.

b) *The outcomes that were measured in the trial were inappropriate*. This may be the case if the benefits of the intervention were not in the domains of quality of life, loneliness or social support. Little research to date has explored outcomes of such services[46]. These outcome measures were carefully chosen, and other similar studies also explore similar domains[29]. Data reported in technical appendix two also indicate that these outcome measures discriminated well between respondents and showed good psychometric properties. Qualitative data from this study indicate that the self-reported benefits of the services fell within these selected areas of influencing quality of life and wellbeing. It is likely therefore that these were appropriate outcome measures to choose.

c) *There was a 'response shift' effect*. Response shift is the changing internal standards, values and conceptualization of quality of life which occurs in people managing a life-limiting illness[47]. This means that people have a similar perception of their quality of life over time, as they accommodate to deteriorations, which are therefore difficult to measure. There are examples of research where the impact of an intervention was only seen after such a shift was taken into account[48], but more research has been recommended to understand such shifts in the context of end-of-life care research[41].

4.2 Do volunteer social action befriending services extend access to end of life care?

4.2.1 Facilitating equitable access to services at the end of life is challenging. Those who are older, with non-malignant conditions, who are from minority ethnic communities or who are socio-economically disadvantaged are known to use specialist services less at the end of life[49-53]. It may be that those who access volunteer delivered befriending/good neighbour services at the end of life are more representative of those in need than other services.

4.2.2 Data collected from most providers of specialist end-of-life care services annually shows that younger people (aged 64 and under) appear to have disproportionate access to specialist end of life care in all settings, accounting for 13.5% of deaths but always at least 23.8% of people accessing any specialist care. They also found that 76.1% of those accessing community care have a cancer diagnosis, and 71.5% were white[54]. Comparing these national data to the data on those referred to and using the befriending/good neighbour services in this study shows that these services appear successful in reaching out to those who do not have cancer, and possibly therefore could act as an access point to such services for people. It does not appear that the befriending/good neighbour services studied enabled referrals of those from minority ethnic communities, nor those who are older, despite two of the studied services specifically targeting referrals from BME communities.

4.2.3 Over half of those who accessed these services live alone. Whilst data on living status for those using other services is not routinely reported, some research data indicate that in some community end of life care services about 7-12% of patients live alone[55]. Living alone is associated with a higher likelihood of not dying at home[56]. Better meeting the support needs of those who live alone is strongly recommended[57], and it may be that these services are part of that package of care. It cannot be determined from this study whether participants were more likely to die at home or not.

4.3 Volunteer social action befriending services reach out to those who have a poor quality of life

4.3.1 The baseline scores for quality of life and loneliness were compared to reference scores from other studies of the general population and those with similar diseases or health status. Figure 4.3.1 shows the scores across the four domains of the quality of life score (WHO QOL BREF) compared to those reported in studies of good health[58], a Danish population study[59], people with breast cancer[60], MND/ALS[61] and using a hospice service[62]. These data show that the quality of life score appears to discriminate between those who are in

good health or not, and that the participants of the ELSA study show many similarities to those in other studies where the population (end-of-life) would be expected to be similar.

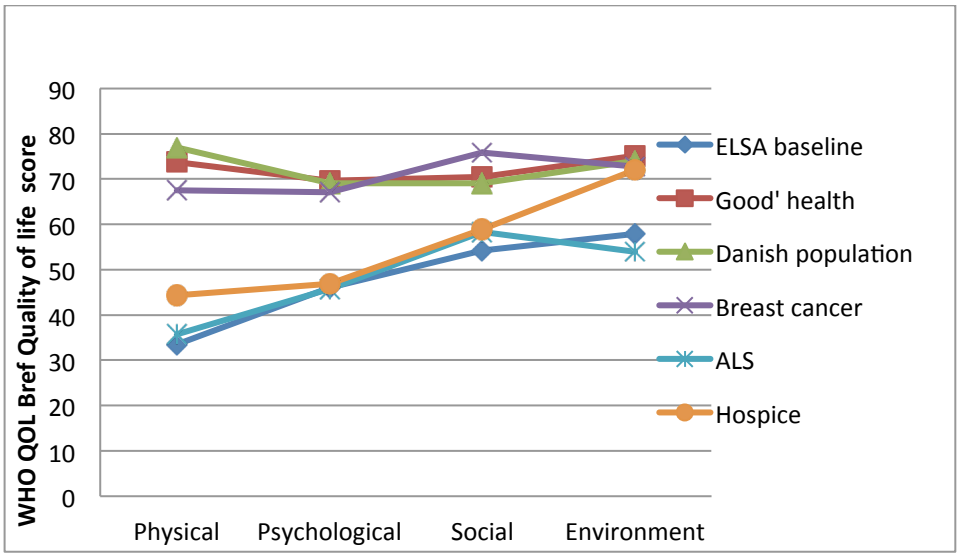


Figure 4.3.1 Comparing ELSA baseline quality of life scores with those from other studies

4.3.2 For the loneliness score (where a score above 2 is considered to demonstrate a degree of loneliness), the mean baseline score in the ELSA study is 3.47, compared to reference scores of 60-70 year olds in France (1.7) and the Netherlands (1.89)[38].

4.3.3 These comparisons show that people referred to these volunteer provided services often had low quality of life, were lonely, and had high social support needs. Indeed a large proportion of those referred died during the study, indicating that they were also physically unwell. These services clearly reach out to those who are in need, and our qualitative data shows that the services are appropriately provided and that people feel well supported. These data indicate that there is little need to be nervous about the use of volunteers to provide such supportive services to people at the end of life, provided that they are well trained and supported in this role.

4.4 What type of volunteer provided social action befriending support should be provided?

4.4.1 Qualitative data from the case studies revealed variability in both the planned way that support was provided to people (for example in planning the frequency and length of contacts), and the way that the support was experienced by people (for example in the type of relationship which developed between the volunteer and patient). Decisions were made about the way the befriending role operated across a number of different spectrums such as place, type of support, role of volunteer, mode of contact and frequency of contact. What is clear from this study is that it supports the body of evidence which stresses the distinctive contribution of volunteers within palliative care through their embodiment of "a unique third culture of care that fuses elements of formal care with the informal visiting of friends and neighbours"[63].

4.4.2 Using the concept of a spectrum as a heuristic, three central dilemmas of the role which emerged from the data are discussed which represent routes through which the benefits of befriending can be brought about.

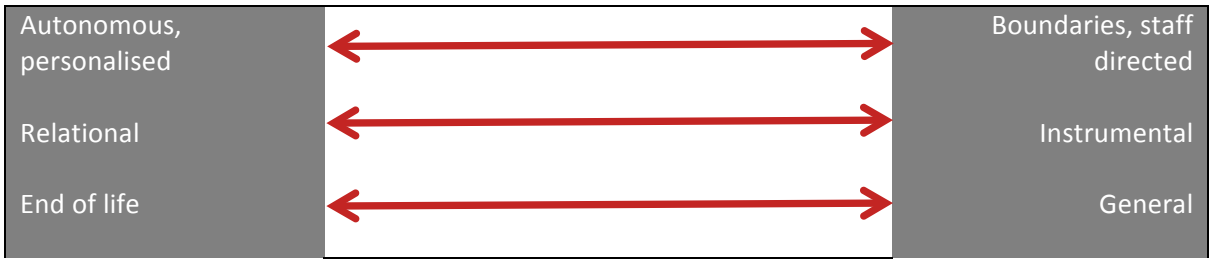


Figure 4.4.1 Dilemmas of the volunteering role

4.4.3 ***Degree of autonomy:*** The first spectrum indicates divergence between two primary ways in which befriending teams could guide their volunteers to act. On the left side, the befriender is given greater autonomy and discretion to support the patient in the way they believe is appropriate, and the role may be more tailored and personalised to the needs of the patient. Some patients reported that impact was higher when they could direct the role. At times there were signs of frustration if the patients could not control when the volunteers came or exactly what role the volunteer undertook such as going out of the home. For example, one patient felt the volunteer was doing what *she* wanted to do and asked to be rematched.

At the other end of the spectrum is a more tightly defined version of the role in which the acceptable duties of the befriender are more narrowly circumscribed by the relevant befriending team. In such cases staff can direct the befriender towards supporting the patient in ways they believe are most likely to deliver benefits to the patient. For example, if staff take the general view that conversation rather than practical support is the element of the role which is likely to help patients the most, they may ask of volunteers that they focus on talking to the patient and do not spend their time on practical tasks. The value of this will depend on the reliability with which the team can know what type of activity delivers the most benefit. A clearer advantage to this version of the role is that it may help to define boundaries for what is acceptable practice for a befriender.

4.4.4 ***Type of impact:*** This concerns the type of impact that is created through the support of the volunteer. On one side there is a version of the role in which the volunteer adopts an instrumental orientation, helping the patient to achieve specific and immediate goals. If the patient is less in need of company and more in need of practical help, the utilitarian and instrumental version of the role may be very beneficial. At the other end of the spectrum is the opposing orientation in which the volunteer is tasked with developing relational, intangible benefits; less with a view to bringing about immediately definable benefits and more with a view to increasing the wellbeing of the patient through conversation. Unlike the more utilitarian orientation, the 'relational' version of the role was seen by patients to be associated with altruistic motivations, distinguishing it from other professional or instrumentally motivated roles. Both types of support may deliver benefits and it is important to know which will better meet the needs of an individual patient, and in what circumstances.

4.4.5 ***Skill level:*** The final spectrum represents a divergence in the level of specialised skill that may be needed to carry out the befriending role. The left hand side represents a version of the role in which the skills required are highly specialised and would not be possessed by a generic befriender. This might be because of the sensitivity needed when talking to someone at the end of life. It also speaks to the need for the befriender to be resilient enough to deal with the death of a patient and robust enough to be strong for the patient if they are in distress. This aspect of the role was borne out in interview data when participants referred to the tact and sensitivity needed when talking to patients. On the other end of the spectrum is a more generalist view of the role which suggests the important attributes required are applicable to befriending volunteers in general. In this view of the role the volunteer offers conversation to the patient as they would if they were befriending any person. This reflects the overriding importance of companionship for many patients. It was borne out in interviews by the view that what was important about the befriending relationship was that it

was “human” or “normal” and not clinical. Although training in end of life issues was seen as essential, the vast majority of befriending roles were general.

4.5 How should the volunteer social action befriending service be delivered and managed?

4.5.1 The data from this study give clear indications on appropriate ways to deliver and manage these volunteer delivered social action befriending services. Many of these key points support recognised good practice[64], and provide stronger evidence for their implementation. The key elements of the process are encapsulated in figure 4.5.2:

Figure 4.5.2 The process of delivering a volunteer provided social action befriending service

4.5.2 Key issues which need consideration when setting up these services are:

a) *Determination of service model:* A number of factors need to be taken into account when determining the service model including the beliefs and values of the organisation and the positioning of the service with reference to other local providers of end-of-life care.
b) *Resource allocation:* Volunteer provided social action services are not resource neutral. Substantial time and costs are associated with provision of support staff, training, monitoring and supportive roles.
c) *Training and support:* Little is currently known about how to train volunteers for such roles[46], although evidence suggests that volunteers do not find these roles unduly stressful[65]. In this study volunteers felt well trained, although different models of training were followed.
d) *Determination of boundaries:* Service boundaries need to be clearly defined, but close attention needs to be paid to flexibility so that services are responsive and not constrained. Volunteers can and did flout

boundaries which they felt to be artificial or not meaningful, and this reflects the positioning of these volunteers in the complex space between service and friend.

e) *Role flexibility:* Volunteer roles should not be unduly constrained, but attention paid to enabling flexible responses to need. Recognition of the distinctive role of the volunteer, clearly differentiated to staff roles, is critical.

4.6 Recommendations for research, policy and practice

4.6.1 Recommendations for research:

a) It is possible for robust research to be ethically conducted in this area. Providers, funders and other stakeholders should support future well designed studies. Site staff proved that they can develop good research skills to enable and conduct such studies.
b) Design areas which could be developed for future studies include the outcome measures chosen and how response shift can be determined, the time points for assessment, especially within a wait-list study, and enabling sufficiently powered studies.
c) The significant predictors of response could be considered candidate moderators of treatment response for future trials.
d) Future research is required which focuses on the outcomes of specific forms of support, in different settings.
e) Future research is required which more explicitly tests different modes of training for these volunteer roles.

4.6.2 Recommendations for policy:

a) Volunteer roles in end-of-life care should be clearly recognised and identified in policy as an important component of care provision.
b) There should be recognition that social action volunteer provided befriending services are not resource neutral, and sufficient financial and other support for these services identified.

4.6.3 Recommendations for practice:

a) Existing volunteer provided services should be examined in the light of these findings to ensure that they are providing care appropriately.
b) Attention should be paid to maximising the amount of volunteer input to service recipients to enhance benefit. If resource is not increased, then it is likely that intensive support to fewer recipients is likely to be more beneficial than allocating volunteer resource over a larger number of patients.
c) Services should be targeted to those who appear to gain the most benefit, especially those who live alone.

5 References

1. Walshe C, Dodd S, Hill M, et al. How effective are volunteers at supporting people in their last year of life? A pragmatic randomised wait-list trial in palliative care (ELSA). *BMC Medicine* 2016;14(1):203. doi: 10.1186/s12916-016-0746-8
2. Office for National Statistics. Deaths in England and Wales, 2013 2013 [Available from: http://www.ons.gov.uk/ons/rel/vsob1/death-reg-sum-tables/2013/info-deaths-2013.html accessed 22.12.14.
3. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *Journal of palliative Medicine* 2000;3(3):287-300.
4. Gomes B, Calanzani N, Curiale V, et al. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews* 2013;6(CD007760.):DOI: 10.1002/14651858.CD007760.pub2.
5. Chitnis XA, Georghiou T, Steventon A, et al. Effect of a home-based end-of-life nursing service on hospital use at the end of life and place of death: a study using administrative data and matched controls. *BMJ Supportive & Palliative Care* 2013;3(4):422-30.
6. Alonso-Babarro A, stray-Mochales J, Dom+¡nguez-Berj+¦n F, et al. The association between in-patient death, utilization of hospital resources and availability of palliative home care for cancer patients. *Palliative Medicine* 2012
7. Shepperd S, Wee B, Straus SE. Hospital at home: home based end of life care. *Cochrane Database of Systematic Reviews* 2011;7(DOI: 10.1002/14651858.CD009231)
8. Higginson IJ, Sarmento VP, Calanzani N, et al. Dying at home ΓÇô is it better: A narrative appraisal of the state of the science. *Palliative Medicine* 2013;27(10):918-24.
9. Murtagh FE, Bausewein C, Verne J, et al. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine* 2013
10. Department of Health. End of life care strategy. Promoting high quality care for all adults at the end of life, 2008.
11. Dempers C, Gott M. Which public health approach to palliative care? An integrative literature review. *Progress in Palliative Care* 2016:1-10. doi: 10.1080/09699260.2016.1189483
12. Sallnow L, Richardson H, Murray SA, et al. The impact of a new public health approach to end-of-life care: A systematic review. *Palliative Medicine* 2016;30(3):200-11. doi: 10.1177/0269216315599869
13. Addington-Hall JM, Karlsen s. A national survey of health professionals and volunteers working in voluntary hospice services in the UK. I. Attitudes to current issues affecting hospices and palliative care. *Palliative Medicine* 2005;19:40-48.
14. Burbeck R, Candy B, Low J, et al. Understanding the role of the volunteer in specialist palliative care: a systematic review and thematic synthesis of qualitative studies. *BMC Palliative Care* 2014;13(3):doi:10.1186/472-684X-13-3.
15. Burbeck R, Low J, Sampson EL, et al. Volunteers in Specialist Palliative Care: A Survey of Adult Services in the United Kingdom. *Journal of palliative Medicine* 2014;17(5):568-74.
16. Chauhan C, Eppard W. Systematic education and utilization of volunteer patient advocates for cancer clinical trial information dissemination at NCCTG community sites. *Journal of Clinical Oncology* 2004;22(14S):1031.
17. Claxton-Oldfield S. Hospice palliative care volunteers: The benefits for patients, family caregivers, and the volunteers. *Palliative & Supportive Care* 2014;FirstView:1-5.
18. Claxton-Oldfield S, Gosselin N, Schmidt-Chamberlain K, et al. A Survey of Family Members' Satisfaction With the Services Provided by Hospice Palliative Care Volunteers. *American Journal of Hospice and Palliative Medicine* 2010;27(3):191-96. doi: 10.1177/1049909109350207
19. Morris S, Wilmot A, Hill M, et al. A narrative literature review of the contribution of volunteers in end-of-life care services. *Palliative Medicine* 2013;27(5):428-36.
20. Woitha K, Hasselaar J, Van Beek K, et al. Volunteers in Palliative Care ΓÇô A Comparison of Seven European Countries: A Descriptive Study. *Pain Practice* 2014:n/a-n/a.

21. Candy B, France R, Low J, et al. Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence. *International Journal of Nursing Studies* (0)
22. Abel J, Walter T, Carey LB, et al. Circles of care: should community development redefine the practice of palliative care? *BMJ Supportive & Palliative Care* 2013;3(4):383-88.
23. Lewis J, DiGiacomo M, Currow D, et al. Social capital in a lower socioeconomic palliative care population: a qualitative investigation of individual, community and civic networks and relations. *BMC Palliative Care* 2014;13(1):30.
24. Lewis JM, DiGiacomo M, Currow D, et al. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. *J Pain Symptom Manage* 2011;42(1):105-18.
25. Lewis JM, DiGiacomo M, Currow D, et al. A social capital framework for palliative care: supporting health and well-being for people with life-limiting illness and their carers through social relations and networks. *J Pain Symptom Manag* 2013;45(1):92-103.
26. Department of Health . More Care, Less Pathway. The Liverpool Care Pathway. Review of the Liverpool Care Pathway. London, 2013.
27. NICE. Improving supportive and palliative care for adults with cancer - the manual. London, 2004.
28. Allen RS, Harris GM, Burgio LD, et al. Can senior volunteers deliver reminiscence and creative activity interventions? Results of the legacy intervention family enactment randomized controlled trial. *J Pain Symptom Manage* 2014;48(4):590-601. doi: 10.1016/j.jpainsymman.2013.11.012 [published Online First: 2014/03/29]
29. McLoughlin K, Rhatigan J, McGilloway S, et al. INSPIRE (INvestigating Social and PractIcal suppoRts at the End of life): Pilot randomised trial of a community social and practical support intervention for adults with life-limiting illness. *BMC Palliat Care* 2015;14(1):65. doi: 10.1186/s12904-015-0060-9 [published Online First: 2015/11/26]
30. Grande GE, Todd CJ. Why are trials in palliative care so difficult? *Palliative Medicine* 2000;14:69-74.
31. Janssens R, Gordijn B. Clinical trials in palliative care: an ethical evaluation. *Patient Education and Counseling* 2000;41:55-62.
32. White C, Hardy J. Gatekeeping from palliative care research trials. *Progress in Palliative Care* 2008;16(4):167-71.
33. Higginson IJ, Booth S. The randomized fast-track trial in palliative care: Role, utility and ethics in the evaluation of interventions in palliative care? *Palliative Medicine* 2011;25(8):741-47.
34. Walshe C, Perez A, G, Dodd SR, et al. Protocol for the End-of-Life Social Action Study (ELSA): A randomised wait-list controlled trial and embedded qualitative case study evaluation assessing the causal impact of social action befriending services on end of life experience. *BMC Palliat Care* 2016 **15**:60 **DOI:** 10.1186/s12904-016-0134-3
35. Greene A, Aranda S, Tieman JJ, et al. Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: Community facilitator pilot. *Palliative Medicine* 2012;26(7):917-23.
36. Molina EH, Nuno-Solinis R, Idioaga GE, et al. Impact of a home-based social welfare program on care for palliative patients in the Basque Country (SAIATU Program). *BMC Palliat Care* 2013;12:3. doi: 10.1186/1472-684x-12-3 [published Online First: 2013/02/01]
37. Skevington SM, Lotfy M, O'Connell KA. The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL Group. *Quality of Life Research* 2004;13:299-310.
38. De Jong Gierveld J, van Tilburg T. The De Jong Gierveld short scales for emotional and social loneliness: tested on data from 7 countries in the UN generations and gender surveys. *European Journal of Ageing* 2010;7(2):121-30.
39. Moser AF, Stuck AE FAU - Silliman R, Silliman RA FAU - Ganz P, et al. The eight-item modified Medical Outcomes Study Social Support Survey: psychometric evaluation showed excellent performance. (1878-5921 (Electronic))
40. Dumont S, Fillion L, Gagnon P, et al. A new tool to assess family caregivers' burden during end of life care. *Journal of Palliative Care* 2008;24(3):151-61.

41. Preston NJ, Fayers P, Walters SJ, et al. Recommendations for managing missing data, attrition and response shift in palliative and end-of-life care research: Part of the MORECare research method guidance on statistical issues. *Palliative Medicine* 2013;27(10):899-907.
42. Gierveld JdJ. A review of loneliness: concept and definitions, determinants and consequences. *Reviews in Clinical Gerentology* 1998;8:73-80.
43. Pennix BWJH, van Tilburg T, Kriegsman DMW, et al. Social network, social support, and loneliness in older persons with different chronic diseases. *Journal of Aging and Health* 1999;11(2):151-68.
44. Stokes JP. The relation of social network and individual difference variables to loneliness. *Journal of Personality and Social Psychology* 1985;48(4):981-90. doi: 10.1037/0022-3514.48.4.981
45. Victor C, Scambler S, Bond J, et al. Being alone in later life: loneliness, social isolation and living alone. *Reviews in Clinical Gerentology* 2000;10:407-17.
46. Pesut B, Hooper B, Lehbauer S, et al. Promoting volunteer capacity in hospice palliative care: a narrative review. *Am J Hosp Palliat Care* 2014;31(1):69-78. doi: 10.1177/1049909112470485 [published Online First: 2013/01/02]
47. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med* 1999;48(11):1507-15. [published Online First: 1999/07/10]
48. Ring L, Höfer S, Heuston F, et al. Response shift masks the treatment impact on patient reported outcomes (PROs): the example of individual quality of life in edentulous patients. *Health and Quality of Life Outcomes* 2005;3(1):1-8. doi: 10.1186/1477-7525-3-55
49. Walshe C, Todd C, Caress A, et al. Patterns of access to community palliative care services: a literature review. *Journal of Pain and Symptom Management* 2009;37(5):884-912.
50. Sleeman KE, Davies JM, Verne J, et al. The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012. *Palliat Med* 2016;30(1):45-53. doi: 10.1177/0269216315585064 [published Online First: 2015/05/21]
51. Gatrell AC, Wood DJ. Variation in geographic access to specialist inpatient hospices in England and Wales. *Health Place* 2012;18(4):832-40. doi: 10.1016/j.healthplace.2012.03.009 [published Online First: 2012/04/24]
52. Ahmed N, Bestall JC, Ahmedzai SH, et al. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine* 2004;18:525-42.
53. Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. *Age and Ageing* 2006;35(5):469-76.
54. National Council for Palliative Care. National Survey of Patient Activity Data for Specialist Palliative Care Services MDS Summary Report for the year 2013-2014. London: National Council for Palliative Care, 2014.
55. Aoun S, Kristjanson LJ, Currow D, et al. Terminally-ill people living alone without a caregiver: an Australian national scoping study of palliative care needs. *Palliative Medicine* 2007;21(1):29-34.
56. Costa V, Earle CC, Esplen MJ, et al. The determinants of home and nursing home death: a systematic review and meta-analysis. *BMC Palliat Care* 2016;15:8. doi: 10.1186/s12904-016-0077-8 [published Online First: 2016/01/23]
57. Aoun SM, Breen LJ, Howting D. The support needs of terminally ill people living alone at home: a narrative review. *Health psychology and behavioral medicine* 2014;2(1):951-69. doi: 10.1080/21642850.2014.933342 [published Online First: 2014/01/01]
58. Hawthorne G, Herrman H, Murphy B. Interpreting the WHOQOL-Brèf: Preliminary Population Norms and Effect Sizes. *Social Indicators Research*;77(1):37-59. doi: 10.1007/s11205-005-5552-1
59. Noerholm V, Groenvold M, Watt T, et al. Quality of life in the Danish general population – normative data and validity of WHOQOL-BREF using Rasch and item response theory models. *Quality of Life Research*;13(2):531-40. doi: 10.1023/B:QURE.0000018485.05372.d6
60. Svensk AC, ÖSter I, Thyme KE, et al. Art therapy improves experienced quality of life among women undergoing treatment for breast cancer: a randomized controlled study. *European Journal of Cancer Care* 2009;18(1):69-77. doi: 10.1111/j.1365-2354.2008.00952.x
61. Lo Coco G, Lo Coco D, Cicero V, et al. Individual and health-related quality of life assessment in amyotrophic lateral sclerosis patients and their caregivers. *Journal of the neurological sciences* 2005;238(1-2):11-7. doi: 10.1016/j.jns.2005.05.018 [published Online First: 2005/08/20]

62. Galfin JM, Watkins ER, Harlow T. A brief guided self-help intervention for psychological distress in palliative care patients: a randomised controlled trial. *Palliat Med* 2012;26(3):197-205. doi: 10.1177/0269216311414757 [published Online First: 2011/08/03]
63. McKee M, Kelley ML, Guirguis-Younger M, et al. It takes a whole community: the contribution of rural hospice volunteers to whole-person palliative care. *J Palliat Care* 2010;26(2):103-11. [published Online First: 2010/08/20]
64. Scott R. Volunteering: vital to our future. How to make the most of volunteering in hospice and palliative care. London: Hospice UK, 2014.
65. Claxton-Oldfield S. Hospice Palliative Care Volunteers: A Review of Commonly Encountered Stressors, How They Cope With them, and Implications for Volunteer Training/Management. *Am J Hosp Palliat Care* 2016;33(2):201-4. doi: 10.1177/1049909115571545 [published Online First: 2015/02/12]
66. Zwarenstein M, Treweek S, Gagnier JJ, et al. Improving the reporting of pragmatic trials: an extension of the CONSORT statement. *BMJ* 2008;337 doi: 10.1136/bmj.a2390
67. Farquhar M, Higginson IJ, Booth S. Fast-track trials in palliative care: an alternative randomized controlled trial design. *J Palliat Med* 2009;12(3):213. doi: 10.1089/jpm.2008.0267 [published Online First: 2009/03/04]
68. Yin RK. Case study research. Design and Method. Third ed. Thousand Oaks: Sage 2003.
69. Walshe C. The evaluation of complex interventions in palliative care: An exploration of the potential of case study research strategies. *Palliative Medicine* 2011;25(8):774-81.
70. Schulz KF, Altman DG, Moher D. CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. *BMJ* 2010;340 doi: 10.1136/bmj.c332
71. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32 item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007;Advanced Acess
72. Bausewein C, Jolley C, Reilly C, et al. Development, effectiveness and cost-effectiveness of a new out-patient Breathlessness Support Service: study protocol of a phase III fast-track randomised controlled trial. *BMC Pulmonary Medicine* 2012;12(1):58.
73. Farquhar MC, Prevost AT, McCrone P, et al. Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial. *BMC Med* 2014;12:194. doi: 10.1186/s12916-014-0194-2 [published Online First: 2014/11/02]
74. Farquhar MC, Prevost AT, McCrone P, et al. The clinical and cost effectiveness of a Breathlessness Intervention Service for patients with advanced non-malignant disease and their informal carers: mixed findings of a mixed method randomised controlled trial. *Trials* 2016;17(1):1-16. doi: 10.1186/s13063-016-1304-6
75. Currow DC, Plummer JL, Kutner JS, et al. Analyzing phase III studies in hospice/palliative care. a solution that sits between intention-to-treat and per protocol analyses: the palliative-modified ITT analysis. *J Pain Symptom Manage* 2012;44(4):595-603. doi: 10.1016/j.jpainsymman.2011.10.028 [published Online First: 2012/07/24]
76. Ritchie J, Lewis J. Qualitative research practice. A guide for social science students and researchers. London: Sage Publications 2003.
77. Walshe C, Chew-Graham C, Todd C, et al. What influences referrals within community palliative care services? A qualitative case study. *Social Science & Medicine* 2008;67(1):137-46.

Appendices

Technical Appendix One: Design and methods of the study

Study Design

This study was a pragmatic, randomised, prospective open wait-list trial and nested qualitative case studies. The trial used a wait-list design to randomly allocate participants on a 1:1 basis to either receive the intervention immediately or after a four week wait[33 66 67]. In-depth qualitative case studies enabled the exploration of participant perceptions of the intervention and its provision, and factors that influence the impact of the intervention[68 69]. This study is reported using the CONSORT recommendations, including the extension for pragmatic trials[66 70], and the COREQ requirements for reporting qualitative studies[71].

Pragmatic trials favour design choices that maximize applicability of results to usual care settings and are tested in a wide range of participants, factors which should enable services to judge if the results of this trial are applicable to their situation and setting. A wait-list approach, where consented participants are allocated to either receive an intervention immediately or after a defined period on a waiting list during which they receive usual care is regarded as more ethically defensible in end-of-life care[33 67 72-74]. A short four week wait was proposed, recognising that interventions need to be effective in a short period where life expectancy is short, and attrition due to illness or death highly anticipated[41].

Participants and setting

Participants in the trial include people anticipated to be in their last year of life and their self-identified informal carer. Additional participants in the qualitative case studies were the volunteers providing care and staff running and managing the services. Inclusion criteria were deliberately broad to include typical participants of such services.

Patient inclusion criteria:

1. Those eligible to be referred to an end-of-life care service determined by the referring organisation/individual. They should be able to answer 'no' to the 'surprise question': 'Would you be surprised if the patient dies within a year?'
2. Able to give informed consent.

Patient exclusion criteria:

1. Age <18 years
2. Those who only understand or speak a language in which our main outcome measure (the WHOQOL-BREF) is unavailable.
3. Those with an anticipated prognosis of < 4 weeks

Family/informal Carer

At inclusion, patient participants were asked to also identify a family member/informal carer to participate in the study. Carers, who may or may not be family members, are defined as lay people in a close supportive role who share in the illness experience of the patient[27] or provide emotional support. Patients who were unable to identify a family member or informal carer at inclusion were not excluded from the study.

1. Identified as a family/informal carer by the patient participating in the trial/qualitative case study
2. Over 18 years
3. Able to give informed consent at the time of the interview

Volunteer/staff inclusion criteria:

1. Involved in provision or management of the service providing the social action befriending service at the chosen case study site.

Setting:

Participating sites were funded to provide care following a competitive tendering process with the UK Cabinet Office as part of an initiative to support social action in England. Selection considerations included their match to the tender, their capacity to deliver the proposed service, and their ability and willingness to contribute to the evaluation of these services. Eleven sites throughout England participated in the study. Ten of the social action volunteer services were provided as part of a wider offering from a local hospice. These included St Joseph's in London, St Michael's in Harrogate, Peace Hospice in Watford, and six hospices which are part of the larger Sue Ryder organisation (Wheatfields in Leeds, Manorlands in Keighley, St John's in Bedford, Thorpe Hall in Peterborough, Nettlebed/Duchess of Kent in Reading, Leckhampton in Cheltenham). One site (Hampshire Hospitals Foundation NHS Trust) provided the service within an NHS Trust, and one (Aquarius in Birmingham) is a charity providing care and services to people with substance abuse issues.

Intervention:

Individual providers of the intervention had a degree of freedom to determine and deliver the social action intervention within the parameters of the tender. This reflects the pragmatic nature of the design, and to facilitate this detailed data were collected on the intervention delivered to each participant to facilitate future recommendations on the intervention. The interventions provided by each service however shared common elements, and were all based on a model of social action:

a) The services were all provided by trained volunteers rather than paid members of staff. Services were managed and facilitated by paid staff who were responsible for delivering training, allocating volunteers to patient participants, and monitoring the provision of the volunteer service.
b) Volunteer training addressed issues of safety, boundaries and organisational requirements as well as basic communication skills.
c) Volunteer support was tailored to the needs of the individual and offered from a suite of potential options including 'befriending' e.g. sitting with someone to provide companionship, 'practical support' e.g. assisting with household tasks such as dog walking, gardening, picking up prescriptions or other errands, and 'signposting' e.g. providing information on other available services. Volunteer support did not replace any other care provision, but was provided in addition to usual care.
d) Volunteer support was typically provided face to face, in the home, but telephone contact, and meeting outside the home was possible.
e) The frequency and length of contact was individually determined, but was typically a visit once a week for 1-3 hours.

Sites were provided with financial resource from the UK Cabinet Office to implement this intervention which typically enabled staff employment to facilitate and manage the service.

Participants continued to receive all usual care during the study, and this could vary considerably across participants depending on diagnosis, stage of illness, and care needs.

Objectives:

The **primary aim** of the study is to evaluate the effectiveness of receiving care from a social action volunteer befriending service plus standard care at improving quality of life as compared to usual care alone for adults in the last year of life.

The **secondary aims** are to:

- explore whether the social action volunteer befriending service reduces loneliness and affects the perception of social support for adults

- examine whether informal carers for those receiving care from a social action volunteer befriending service experience less carer burden
- determine whether receiving care from a social action volunteer befriending service can affect participant's use of other health and social care services
- identify and explore the factors that influence the impact of social action volunteer befriending services on end-of-life experience

Trial outcome measures:

The causal impact of the intervention on each aspect of end-of-life experience examined in this study was measured using a pre-determined set of outcome measurement tools:

- Quality of life (primary outcome measure) was measured using the World Health Organisation Quality of Life (WHOQOL-BREF) Scale, a short validated measure of quality of life and wellbeing, having wide breadth. Our primary outcome will be overall quality of life (single response question), with secondary outcomes the quality of life domains measured by the WHOQO-BREF (social, environmental, psychological and physical domains) [37].
- Loneliness (secondary outcome measure) was measured using the De Jong Gierveld 6-item Loneliness Scale, a short, well-used, reliable and valid measurement instrument for overall, emotional, and social loneliness, chosen for brevity and relevance of the items when mapped onto anticipated outcomes[38].
- Social Support (secondary outcome measure) was measured using the 8-item modified Medical Outcomes Study Social Support Survey (mMOS-SS), a short validated scale covering two domains (emotional and instrumental social support) designed to identify potentially modifiable social support deficits, chosen for brevity and relevance of the items when mapped onto anticipated outcomes [39].
- Carer Burden (secondary outcome measure) was measured using the Caregiver Burden Scale-End-of-life Care (CBS-EOLC), a reliable and valid measurement tool designed to specifically assess family caregivers' burden within the palliative care context, chosen for brevity and relevance of the items when mapped onto anticipated outcomes[40].

Cronbach's Alpha was calculated for these scales at baseline. All scales and subscales scored above 0.7 except for the social relationship sub-scale of the WHO QOL BREF (0.461) and the Total Loneliness Score of the De Jong Gierveld scale (0.374). The social relationship scale is only comprised of three items, and the question about sex might be considered in appropriate, and is an item where much missing data were noted. Whilst the individual loneliness scales had good Alpha values (0.846 and 0.678), the total scale appears to not reflect a single broad construct. Data using the total scale must therefore be treated with caution.

Socio-demographic data (age, gender, disease diagnosis, education, marital status, living status, spirituality and ethnicity) in the form of a self-completed questionnaire was collected from both patients and informal carers at baseline. At baseline and subsequent time points patient participants were asked to indicate the number, type and frequency of contact they have with networks of others (to include social networks and contact with health and social care service providers).

The schedule of data collection is in table a1.

Table a1. ELSA: Schedule of enrollment, interventions, and assessments

	Enrollment	Allocation	Post-allocation		
TIMEPOINT	$-t_1$	0	t_1 *4 weeks*	t_2 *8 weeks*	t_3 *12 weeks*
ENROLMENT:					
Eligibility screen	X				
Informed consent	X				
Baseline data collection	X				
Allocation		X			
PATIENT INTERVENTIONS:					
Immediate Arm			←	→	
Waitlist Arm				←	→
PATIENT ASSESSMENTS:					
Demographic details	X				
QOL, Loneliness, Support Network size/contact	X		X	X	(X)
CARER ASSESSMENTS:					
Demographic details	X				
Carer burden	X		X	X	(X)
SITE DATA:					
Date of volunteer allocation, date of volunteer first visit		X			
Details of each volunteer contact with participant			←	→	

(X) indicates that week 12 data are only collected for those in the wait arm of the trial (8 weeks after commencement of intervention)

Qualitative Case Study data collection:

Single qualitative interviews were conducted with i) patient participants and informal carers both receiving and having waited to receive the intervention to explore their experience of the service, ii) volunteer staff providing the intervention to explore their experience of providing care, motivations, training, and the research study design etc. ; and iii) staff e.g. social action volunteers key manager/coordinator, other responsible stakeholders e.g. chief executive or general manager, clinical care staff etc. to explore organizational culture, history of the programme, selection, training and support of volunteer/ social action team. An interview topic guide was prepared, and iteratively developed through the study (see appendix four). Interviews were audio recorded using encrypted digital recorders, and fully transcribed, transcripts were not returned to participants. Contemporaneous field notes were made. Patient participants were already involved the trial and thus had a degree of understanding of the research process as a whole. All key staff members from case study sites invited to be interviewed. Staff from case study sites identified patients, carers and volunteers to participate in interviews. Immediately prior to interviews researchers introduced themselves and the research project in some detail, gaining additional interview consent. Additional data included non-participant observation of relevant organizational meetings, workload allocation, decision-making activities etc. and collection of documentary data such as service policies, job descriptions and other relevant written materials about the services provided. Qualitative data were collected by SD, MH (both male research associates),

CW (female academic), all are experienced qualitative researchers. Participants had access to information about the positions held by the researchers and their credentials. Some participants had an opportunity to meet some of the team in advance of participating in interviews. Data were collected from staff members and volunteers at the case study sites. Data collection with patients and carers took place in patient's homes. Interviews ranged in length from 11.06 - 94.03 minutes, with a mean length of 37 minutes.

Sample size:

Trial sample size was initially determined pragmatically from the estimate of likely referral numbers (700) to their services over the time period of funded data collection given by included sites. Trial power was estimated using a worst case scenario assuming 5% attrition at primary outcome measure. With 350 or more participants per arm power will exceed .80 to detect difference in change over time corresponding to an effect size of f=.10 (considered a small effect size) between the intervention and wait-list groups. This power model uses alpha = .05, two tailed, and uses a conservative correlation of r = .6 for scores lagged 4 weeks, and r = .5 for 12 weeks.

For the qualitative case studies it was planned that three to six (patients, informal carers and volunteers) and two to three (key managers or co-ordinators) would be invited to interview per case study site. Eight sites were selected from the 11 sites involved in the study comprising a total sample size of 88 - 168 participants.

Randomisation and study procedures:

Referrals to the individual services were managed by the site coordinators, who assessed eligibility and took written consent after potential participants had received information about the service and the study. Information about the study was available to referrers. Site coordinators received standard 'Good Clinical Practice' training and bespoke study training to facilitate this role. Once written informed consent was obtained to participate in the trial, and baseline data collected (freepost return to Lancaster University), patient participants were randomly allocated (1:1 allocation ratio) to either the intervention or the wait-list arm of the trial. Site coordinators contacted a randomisation line at Lancaster University, and the next sequence in the allocation (stored in sequentially numbered sealed opaque envelopes) was revealed. The randomisation sequence was computer generated, with rebalance in the arms after 10 randomisations. Blinding of site staff and patient participants was not possible due to the nature of the intervention. Efforts were made to minimise potential bias. At time of randomisation all patient participants were allocated an alphanumeric study identifier which was then used for all subsequent communications between sites and research staff. Data collected at 4, 8 and 12 weeks were coordinated by Lancaster University and sent postally to patient and carer participants. Data were returned directly to Lancaster University. Participants agreed to the possibility of an interview when they consented to participate in the overall trial and intervention. A sub section of this group was approached to participate in interviews during or after when they had received the intervention

Data analysis:

Exploratory data techniques were used to examine all distributions of outcome variables. Continuous data was summarised using means and standard deviations (SD) where normally distributed and medians and interquartile ranges (IOR) where non-normally distributed. Categorical data were described using frequencies and percentages. Basic exploratory and descriptive statistical test (e.g. t and Chi-square tests) were conducted at the $\alpha = .05$ level of significance. Confidence intervals were reported at the 95% level.

Hierarchical Linear Models (HLM) for primary and secondary outcomes used the full intent-to-treat (ITT) sample over all available assessments. The HLMs compared primary and secondary outcome scores (e.g. WHO QOL Bref) between the immediate and wait-list group. We specified a piecewise model generating two-time predictor variables, setting the intercept at session 0 (baseline), and configuring the slope of the first predictor to index the change from baseline to week 4 (Phase 1). Meanwhile, the second time predictor that was inactive during baseline to week 4, was turned on after week 4 to capture change from week 4 to week12 (Phase 2). Considering the unbalanced design utilised in this study, values for new time predictors matched exact participant evaluations depending on treatment arm (Immediate group: 0, 4 and 8 weeks; waitlist group: 0, 4, 8 and 12 weeks). Restricted

Maximum Likelihood (REML) estimation was used, and fixed slopes and random effect of each time predictor were assessed to determine the most appropriate model. We finally modelled intercepts as random effects to account for correlations among observations at different time points from the same participant.

Basic fixed effects in the HLMs included treatment condition, time, and treatment condition x time interaction. With this last fixed effect, we tested whether there was a significant linear change between treatment groups before and after week 4.

An intention to treat (ITT) analysis was conducted as the most conservative and appropriate test of treatment effects. This minimises type I errors related to different rates of drop out in study arms. It has been argued that the greater number of drop outs due to deterioration or death (unrelated to the intervention) in end-of-life care studies can create a systematic bias away from the true effect, although per protocol analyses can underestimate treatment problems[75]. In this study as well as the ITT analysis we also completed secondary analyses by testing the same HLMs described before with treatment completers. In the immediate arm these are those who received any intervention before 4 weeks, and who returned baseline and week 4 data. In the wait arm these are those who did not receive any intervention before the return of week 4 data.

Test statistics for Hierarchical Linear Models (HLM) were conducted using SPSS version 22.

Case-study evaluation analyses

Data analyses followed a framework analysis approach using a matrix approach informed by the final theory of change. Framework analysis facilitates within and cross case pattern matching and has been used in case studies in palliative and end-of-life care [76 77]. Coding was performed by SD and MH. The final coding tree is in appendix five. Staff participants had an opportunity to meet to discuss emerging analysis. This analysis was integrated with trial data so that an understanding of the factors affecting impact were compared with quantitative impact. Cross case pattern matching followed to identify thematic factors associated with challenges and successes in creating impact. All qualitative analyses were performed using NVivo software.

The trial was prospectively registered. ISRCTN 12929812 http://www.isrctn.com/ISRCTN12929812
Health Research Authority research ethics approval was granted 12.3.15 by NRES Committee Yorkshire & The Humber - South Yorkshire. REC reference 15/YH/0090. IRAS project ID 173058. Site specific approvals were granted by NRES Committee Yorkshire and the Humber – South Yorkshire.

Technical Appendix two: Results from the study

Quality of life was measured using the WHO QOL Bref as our primary outcome. The rate of change of quality of life was calculated on an intention to treat basis, both for the time from t0 to t1 (phase 1: when the wait-list participants were not receiving an intervention) and from t1 to t3 (phase 2: when all participants were receiving the intervention).

Table a2 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2).

Measure	Immediate *b* (95% CI)	Wait *b* (95% CI)	Immediate vs. Wait *b* (95% CI)
QoL Physical Phase 1	.84 [-2.24, 3.92]	**-3.14 [-6.23, -.05]**	3.98 [-.38, 8.34]
Phase 2	.97 [-2.51, 4.47]	-.15 [-2.22, 1.92]	1.12 [-2.93, 5.19]
QoL Psychological Phase 1	.27 [-3.11, 3.66]	-2.32 [-5.77, 1.13]	2.59 [-2.24, 7.43]
Phase 2	.61 [-3.22, 4.44]	-1.21 [-3.49, 1.07]	1.82 [-2.63, 6.28]
QoL Environmental Phase 1	-3.34 [-6.53, -.16]	-3.14 [-6.23, -.05]	.39 [-4.13, 4.91]
Phase 2	2.95 [-.70, 6.61]	.46 [-1.69, 2.61]	2.50 [-1.75, 6.73]

This analysis was repeated, as above, as a per protocol case study analysis, displayed in table a3 showing the same pattern as the ITT analysis presented above.

Table a3 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) – Case Study.

Measure and slope	Immediate *b* (95% CI)	Wait *b* (95% CI)	Immediate vs. Wait *b* (95% CI)
QoL Physical Phase 1	2.01[-1.88, 5.90]	-2.85 [-6.52, .82]	4.86 [-.49, 10.21]
Phase 2	.94 [-3.45, 5.34]	-.59 [-3.00, 1.82]	1.53 [-3.48, 6.55]
QoL Psychological Phase 1	1.52[-2.46, 5.49]	-2.15[-5.97, .67]	3.67 [-1.85, 9.18]
Phase 2	.91 [-3.58, 5.40]	-1.07[-3.56, .41]	1.98 [-3.15, 7.12]
QoL Environmental Phase 1	-2.94[-6.94, .06]	-3.92[-7.72,-.11]	.98 [-4.54, 6.50]
Phase 2	3.18[-1.35, 7.71]	1.13[-1.36, 3.61]	2.06 [-3.11, 7.22]

Table a4 Estimated Rate of Change from Baseline to week 4 (Phase 1) and week 4 to 12 weeks follow ups (Phase 2) – ITT controlling for Site and number of hours before week 4.

Measure and slope	Immediate *b* (95% CI)	Wait *b* (95% CI)	Immediate vs. Wait *b* (95% CI)
QoL Physical Phase 1	1.36 [-1.72, 4.43]	-3.08 [-6.12, -.03]	**4.43 [.10, 8.76]**
Phase 2	1.04 [-2.43, 4.51]	-.15 [-2.19, 1.89]	1.19 [-2.83, 5.22]
QoL Psychological Phase 1	.52 [-2.88, 3.92]	-2.21 [-5.63, 1.19]	2.74 [-2.08, 7.55]
Phase 2	.61 [-3.21, 4.43]	-1.20 [-3.45, 1.05]	1.81 [-2.62, 6.24]
QoL Environmental Phase 1	-3.25 [-6.50, -.009]	-3.65 [-6.87, -.43]	.40 [-4.17, 4.96]
Phase 2	3.32 [-.37, 7.02]	.46 [-1.68, 2.61]	2.86 [-1.41, 7.14]

Quality of life outcomes, measured using the WHO QOL Bref[37], are reported here (table a5) as estimated means and confidence intervals on an intention to treat basis. No significant differences were found on the three domains of quality of life for which we have robust data. A significant difference on estimated means between arms at time points would be seen if the 95% confidence intervals did not overlap. Non-statistically significant differences in favour of the intervention were observed on main outcomes between treatment arms at different points.

Table a5 Estimated Means and 95% Confidence Intervals at each time point for Immediate and Waitlist groups

Measure and time point	Immediate Estimated mean [CI]	Wait Estimated mean [CI]
QoL Physical domain		
Baseline	32.46 [28.99, 35.92]	34.95 [31.40, 38.50]
Week 4	33.29 [29.40, 37.18]	31.81 [27.85, 35.77]
Week 8	34.27 [30.22, 38.31]	31.65 [27.96, 35.35]
Week 12	35.24 [28.77, 41.71]	31.50 [27.02, 35.99]
QoL Psychological domain		
Baseline	46.60 [42.87, 50.33]	46.06 [42.23, 49.90]
Week 4	46.87 [42.68, 51.07]	43.74 [39.44, 48.04]
Week 8	47.49 [43.12, 51.85]	42.53 [38.54, 46.52]
Week 12	48.10 [41.04, 55.15]	41.32 [36.46, 46.17]
QoL Environmental domain		
Baseline	58.95 [55.81, 62.09]	56.88 [53.64, 60.12]
Week 4	55.61 [51.99, 59.23]	53.15 [49.47, 56.83]
Week 8	58.56 [54.74, 62.38]	53.61 [50.25, 56.98]
Week 12	61.52 [54.97, 68.06]	54.07 [49.80, 58.34]

Not all participants received the intervention as planned. Around 2/5 of those in the immediate arm received no volunteer intervention before week 4 assessment, and some in the wait arm received the intervention at or after 4 weeks, but prior to completing their week 4 assessment. To account for this a per-protocol analysis was undertaken of a 'case study' of those who received the intervention and wait as planned (e.g. all those who received at least one visit in the immediate arm in the 4 week period, and those who did not commence the intervention in the wait arm until after they completed a week 4 assessment). These data are in table a6 below. They show the same pattern as the ITT analysis as a trend to favouring the intervention, but are not statistically significant.

Table a6 Estimated Means and 95% Confidence Intervals at each time point for Immediate and Waitlist groups – Per Protocol analysis Case Study

Measure and time point	Immediate	Wait
QoL Physical		
Baseline	32.44 [27.60, 37.29]	35.47 [30.58, 40.35]
Week 4	34.45 [29.26, 39.64]	32.62 [27.55, 37.68]
Week 8	35.40 [30.00, 40.80]	32.03 [27.22, 36.83]
Week 12	36.34 [27.99, 44.69]	31.44 [25.79, 37.08]
QoL Psychological		
Baseline	45.26 [40.14, 50.39]	44.71 [39.56, 49.86]
Week 4	46.87 [42.68, 51.07]	43.74 [39.44, 48.04]
Week 8	46.78 [41.35, 52.21]	42.56 [37.20, 47.92]
Week 12	47.69 [42.02, 53.36]	41.49 [36.40, 46.57]
QoL Environmental		
Baseline	58.23 [54.01, 62.45]	55.75 [51.47, 60.03]
Week 4	55.29 [50.66, 59.91]	51.83 [47.37, 56.30]
Week 8	58.47 [53.60, 63.34]	52.96 [48.81, 57.10]
Week 12	61.65 [53.47, 69.83]	54.08 [48.94, 59.23]

Loneliness as an outcome, measured using the De Jong Gierveld Loneliness Scale are reported here (table a7) as the key interactions of treatment with time. No significant differences were found on the two domains of loneliness.

Table a7 Emotional and Social Loneliness as a main outcome

Variables	Emotional Loneliness b	Emotional loneliness 95% CI	Social Loneliness b	Social Loneliness 95% CI
Intercept	1.71	[1.43, 1.98]	2.08	[1.85, 2.30]
Treatment Condition, *Immediate*	-.20	[-.58, .17]	-.39	[-.71, -.08]#
Phase 1, *until week 4*	.02	[-.29, .32]	.10	[-.17, .37]
Treatment Condition x Time 1	-.08	[-.52, .35]	-.20	[-.58, .18]
Phase 2 *after week 4*	.02	[-.20, .23]	-.04	[-.22, .14]
Treatment Condition x Time 2	.07	[.34, .47]	.22	[-.13, .57]

Note: # Sensitivity analyses controlling for social loneliness at baseline and week 4, didn't show a different result pattern (data upon request).

Perception of social support as an outcome, measured using the mMOSS-SS 8 item scale are reported here (table a8) as the key interactions of treatment plus time. No significant differences were found on the two domains of social support, nor the total social support scale.

Table a8 Social support as a main outcome

Variables	Social Support, Instrumental b	95% CI	Social Support, Emotional b	95% CI	Social Support, Total b	95% CI
Intercept	3.04	[2.75, 3.32]	3.03	[2.80, 3.26]	3.05	[2.81, 3.28]
Treatment Condition, *Immediate*	.23	[-.17, .63]	.16	[-.16, .49]	.19	[-.14, .52]
Phase 1, *until week 4*	.14	[-.10, .38]	-.07	[-.28, .15]	.02	[-.16, .21]
Treatment Condition x Time 1	.02	[-.31, .36]	.19	[-.10, .49]	.13	[-.13, .39]
Phase 2, *after week 4*	-.08	[-.25, .09]	.08	[-.07, .22]	.01	[-.12, .14]
Treatment Condition x Time 2	.03	[-.28, .35]	-.06	[-.35, .22]	-.01	[-.26, .23]

People in the study self-reported their contacts with health and social care professionals at each data collection point. These data are reported in table a9. No significant differences were found between the intervention and wait-list arms over time.

Table a9. Participant use of health and social care – Total number of contacts with health and social care professionals as a main outcome

Variables	*b*	95% CI
Intercept	1.07	[.77, 1.37]
Treatment Condition, *Immediate*	.11	[-.31, .53]
Time 1, *until week 4*	.16	[-.22, .55]
Treatment Condition x Time 1	-.21	[-.75, .34]
Time 2, *after week 4*	.01	[-.27, .29]
Treatment Condition x Time 2	-.11	[-.64, .42]

No variables were found to significantly affect the primary or secondary outcomes of the study in these analyses. Some trends were found in the data and these are highlighted in **bold** in the tables.

Table a10 Physical quality of life as a main outcome

Variables	*b*	95% CI
Intercept	32.79	[13.47, 52.12]
Treatment Condition, *Immediate*	-4.56	[-11.04, 1.93]
Site, *Sue Ryder*	-3.76	[-9.65, 2.14]
Gender, *Male*	-.86	[-6.89, 5.16]
Age	-.01	[-.24, .23]
Number of contact hours, *until week 4*	**1.25**	**[.01, 2.49]**
Network Size, *at baseline*	-.11	[-1.22, 1.01]
Living Status, *Living alone*	1.91	[-3.99, 7.81]
Illness condition, *Cancer*	**7.28**	**[1.60, 12.96]**
Time 1, *until week 4*	-4.73	[-7.94, -1.52]
Treatment Condition x Time 1	3.56	[-.99, 8.11]
Time 2, *after week 4*	.49	[-1.70, 2.67]
Treatment Condition x Time 2	2.85	[-1.39, 7.10]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

There is a trend to the number of contact hours up to week 4 and having cancer having an effect on the physical domain of quality of life.

Table a11. Psychological quality of life as a main outcome.

Variables	*b*	95% CI
Intercept	16.78	[-3.36, 36.92]
Treatment Condition, *Immediate*	2.94	[-3.91, 9.81]
Site, *Sue Ryder*	-3.54	[-9.68, 2.60]
Gender, *Male*	-1.60	[-7.87, 4.67]
Age	**.33**	**[.08, .58]**
Number of contact hours, *until week 4*	.90	[-.39, 2.19]
Network Size, *at baseline*	.51	[-.66, 1.67]
Living Status, *Living alone*	-.02	[-6.16, 6.12]
Illness condition, *Cancer*	5.71	[-.21, 11.63]
Time 1, *until week 4*	-2.63	[-6.52, 1.26]
Treatment Condition x Time 1	1.13	[-4.35, 6.60]
Time 2, *after week 4*	-.48	[-3.09, 2.14]
Treatment Condition x Time 2	3.38	[-1.68, 8.44]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Table a12 Environmental quality of life as a main outcome.

Variables	*b*	95% CI
Intercept	35.34	[19.54, 51.13]
Treatment Condition, *Immediate*	-.14	[-5.56, 5.28]
Site, *Sue Ryder*	-2.52	[-7.31, 2.27]
Gender, *Male*	-1.35	[-6.26, 3.56]
Age	**.34**	**[.15, .53]**
Number of contact hours, *until week 4*	.83	[-.17, 1.84]
Network Size, *at baseline*	-.30	[-1.22, .61]
Living Status, *Living alone*	**-5.48**	**[-10.28, -.69]**
Illness condition, *Cancer*	4.60	[-.03, 9.22]
Time 1, *until week 4*	**-9.41**	**[-8.22, -1.61]**
Treatment Condition x Time 1	2.05	[-2.64, 6.73]

Time 2, *after week 4*	1.47	[-.80, 3.73]
Treatment Condition x Time 2	1.94	[-2.46, 6.34]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Table a13 Emotional Loneliness as a main outcome

Variables	*b*	95% CI
Intercept	3.85	[2.56, 5.13]
Treatment Condition, *Immediate*	-.17	[-.62, .28]
Site, *Sue Ryder*	.30	[-.09, .69]
Gender, *Male*	-.34	[-.74, .06]
Age	**-.03**	**[-.04, -.01]**
Number of contact hours, *until week 4*	.03	[-.06, .11]
Network Size, *at baseline*	-.07	[-.15, .001]
Living Status, *Living alone*	**.44**	**[.04, .83]**
Illness condition, *Cancer*	**-.40**	**[-.78, -.02]**
Time 1, *until week 4*	.15	[-.16, .47]
Treatment Condition x Time 1	-.21	[-.65, .24]
Time 2, *after week 4*	-.03	[-.25, .19]
Treatment Condition x Time 2	.02	[-.39, .43]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Table a14 Social Loneliness as a main outcome.

Variables	*b*	95% CI
Intercept	3.27	[2.27, 4.26]
Treatment Condition, *Immediate*	-.29	[-.66, .07]
Site, *Sue Ryder*	.09	[-.21, .40]
Gender, *Male*	-.10	[-.41, .21]
Age	**-.01**	**[-.02, -.002]**
Number of contact hours, *until week 4*	-.06	[-.13, .001]
Network Size, *at baseline*	-.03	[-.09, .03]
Living Status, *Living alone*	**.33**	**[.03, .64]**
Illness condition, *Cancer*	-.29	[-.58, .006]
Time 1, *until week 4*	.09	[-.20, .39]
Treatment Condition x Time 1	-.16	[-.57, .26]
Time 2, *after week 4*	-.04	[-.25, .17]
Treatment Condition x Time 2	.18	[-.21, .57]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Table a15 Social Support Instrumental as a main outcome.

Variables	*b*	95% CI
Intercept	2.49	[1.07, 3.91]
Treatment Condition, *Immediate*	.04	[-.44, .52]
Site, *Sue Ryder*	-.26	[-.69, .18]
Gender, *Male*	.05	[-.40, .50]
Age	.02	[-.001, .03]
Number of contact hours, *until week 4*	-.04	[-.13, .05]
Network Size, *at baseline*	.04	[-.05, .12]
Living Status, *Living alone*	**-1.16**	**[-1.60, -.73]**
Illness condition, *Cancer*	.09	[-.33, .50]
Time 1, *until week 4*	.17	[-.06, .41]

Treatment Condition x Time 1	.12	[-.21, .45]
Time 2, *after week 4*	-.11	[-.28, .07]
Treatment Condition x Time 2	.04	[-.28, .36]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Table a16 Social Support Emotional as a main outcome.

Variables	*b*	95% CI
Intercept	1.55	[.46, 2.65]
Treatment Condition, *Immediate*	.13	[-.24, .51]
Site, *Sue Ryder*	-.19	[-.52, .15]
Gender, *Male*	.16	[-.19, .50]
Age	**.02**	**[.007, .03]**
Number of contact hours, *until week 4*	-.04	[-.11, .03]
Network Size, *at baseline*	.05	[-.01, .12]
Living Status, *Living alone*	**-.78**	**[-1.11, -.44]**
Illness condition, *Cancer*	**.41**	**[.09, .73]**
Time 1, *until week 4*	-.07	[-.30, .15]
Treatment Condition x Time 1	**.32**	**[.007, .63]**
Time 2, *after week 4*	.10	[-.06, .27]
Treatment Condition x Time 2	-.14	[-.44, .16]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Table a17 Social Support Total as a main outcome.

Variables	*b*	95% CI
Intercept	2.02	[.88, 3.16]
Treatment Condition, *Immediate*	.08	[-.31, .47]
Care Home(?), *Sue Ryder*	-.21	[-.56, .15]
Gender, *Male*	.10	[-.26, .46]
Age	**.02**	**[.005, .03]**
Number of contact hours, *until week 4*	.04	[-.11, .03]
Network Size, *at baseline*	.04	[-.02, .11]
Living Status, *Living alone*	**-.96**	**[-1.31, -.61]**
Illness condition, *Cancer*	.24	[-.09, .58]
Time 1, *until week 4*	.03	[-.16, .22]
Treatment Condition x Time 1	.24	[-.03, .50]
Time 2, *after week 4*	.01	[-.13, .15]
Treatment Condition x Time 2	-.05	[-.31, .20]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Table a17 Participant use of health and social care as a main outcome.

Variables	*b*	95% CI
Intercept	.08	[-1.22, 1.37]
Treatment Condition, *Immediate*	.29	[-.79, .21]
Site, *Sue Ryder*	-.07	[-.46, .31]
Gender, *Male*	**.53**	**[.13, .92]**
Age	.01	[-.01, .02]
Number of contact hours, *until week 4*	**.13**	**[.05, .21]**
Network Size, *at baseline*	**.13**	**[.06, .21]**
Living Status, *Living alone*	-.24	[-.62, .14]
Illness condition, *Cancer*	-.36	[-.74, .01]

Time 1, *until week 4*	.30	[-.13, .73]
Treatment Condition x Time 1	-.39	[-.99, .21]
Time 2, *after week 4*	-.23	[-.55, .08]
Treatment Condition x Time 2	.23	[-.36, .82]

Note: Continuous variables were not centered, preventing a meaningful interpretation of intercept values.

Carer data

Thirty three carers took part in this study, of whom 29 returned complete baseline data. Most were spouses or partners, as seen in table x below. Qualitatively sites indicated the reason for the low enrolment rate was that many patient participants lived alone and did not feel they had a carer to pass the questionnaire on to, or else were concerned about burden.

Table a18. Carer relationship to patient

Relationship to patient	Number	Percentage
Spouse/Partner	21	63.6
Parent	7	21.2
Other relative	3	9.1
Friend or Neighbour	1	3.0
Other	1	3.0
Total	33	100.0

Table a19. Carer burden outcomes

Intervention / Waitlist		Carer burden at baseline	Carer burden week four	Carer burden week eight	Carer burden week twelve
Intervention	N	15	9	8	
	Mean	36.0000	36.6667	34.6250	
	Std. Deviation	12.02379	13.94633	12.55772	
Waitlist	N	14	6	7	4
	Mean	28.1429	29.1667	34.2857	35.7500
	Std. Deviation	10.35417	8.99815	13.06030	14.38460
Total	N	29	15	15	4
	Mean	32.2069	33.6667	34.4667	35.7500
	Std. Deviation	11.74849	12.43076	12.32806	14.38460

Appendix three: Mapping quantitative outcome measures and qualitative interview data

Qualitative data were collected, with open questions asked about the areas of people's lives that they felt the befriending intervention had an impact upon. These data have been mapped onto the questions asked in the pre-selected quantitative measures so readers can determine if the chosen outcome measures address the issues people felt related to the intervention. Qualitative interviews were not routinely scheduled to take place associated with questionnaire completion. Green indicates where qualitative data were offered that maps onto these domains, black where no data were offered.

WHO QOL Bref

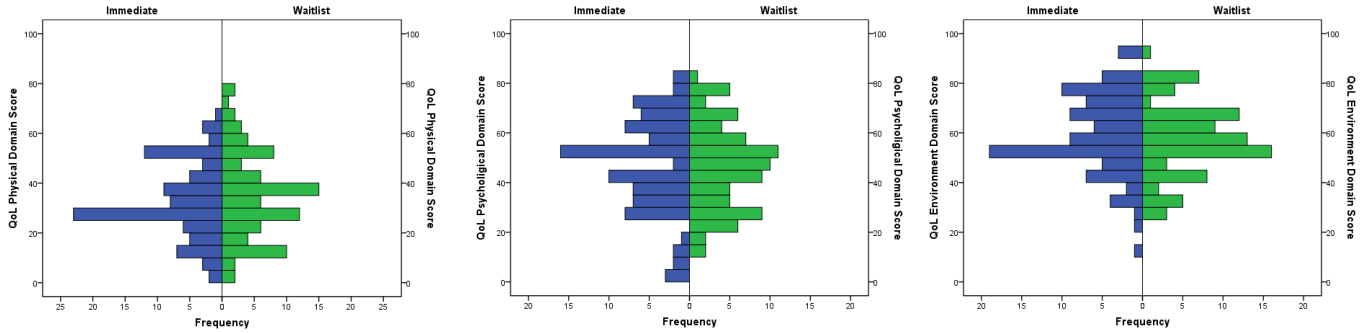
WHO QOL Bref questions and domains	Qualitative data collected that mapped onto the question
How would you rate your quality of life?	
How satisfied are you with your health?	
Domain 1(Physical Health)	
To what extent do you feel that physical pain prevents you from doing what you need to do?	
How much do you need any medical treatment to function in your daily life?	
Do you have enough energy for everyday life?	
How well are you able to get around?	
How satisfied are you with your sleep?	
How satisfied are you with your ability to perform your daily living activities?	
How satisfied are you with your capacity for work?	
Domain 2(Psychological)	
How much do you enjoy life?	
To what extent do you feel your life to be meaningful?	
How well are you able to concentrate?	
Are you able to accept your bodily appearance?	
How satisfied are you with yourself?	
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	
To what extent do you have the opportunity for leisure activities?	
Domain 3(Social Relationships)	
How satisfied are you with your personal relationships?	
How satisfied are you with your sex life?	
How satisfied are you with the support you get from your friends?	
Domain 4(Environment)	
How safe do you feel in your daily life?	
How healthy is your physical environment?	
Have you enough money to meet your needs?	
How available to you is the information that you need in your day-to-day life?	
To what extent do you have the opportunity for leisure activities?	
How satisfied are you with the conditions of your living place?	
How satisfied are you with your access to health services?	
How satisfied are you with your transport?	

De Jong Gierveld Loneliness Scale

Loneliness scale Questions.	Qualitative data collected that mapped onto the question
I experience a general sense of emptiness	
There are plenty of people I can rely on when I have problems	
There are many people I can trust completely	
There are enough people I feel close to	
I miss having people around	
I often feel rejected	

mMOS-SS 8 item questionnaire

mMOS questions. If you needed it, how often is someone available …	Qualitative data collected that mapped onto the question
to help you if you were confined to bed?	
to take you to the doctor if you need it?	
to prepare your meals if you are unable to do it yourself	
to help with daily chores if you are sick	
to have a good time with?	
to turn to for suggestions about how to deal with a personal problem?	
who understands your problems?	
to love and make you feel wanted?	



Figures a 1, 2, 3. Spread of scores on physical, psychological and environmental domains of the WHO QOL Bref at baseline

Completion data on the WHO QOL Bref indicate a good spread of answers indicating that the tool was discriminating between respondents.

Appendix four: Case Study Interview topic guides

The aim is to identify and explore the factors that influence the impact of social action volunteer services on experience in the last year of life. We wished to encourage participants to discuss their views, perception and attitudes in an open way without excluding issues which may be of importance to the study.

Patient interviews

a) Ask the patient to briefly summarise their experience as a patient receiving the volunteering service (this helps to frame the agenda, indicates the level of disclosure and sets the terminology);
b) Explore what support was already available to the patient before they were referred to the social action service and what services they continue to use;
c) Probing events and experience of receiving the social action service i.e.
    a. Could you tell me a bit more about what happened when you were referred?
    b. How were your needs assessed and identified?
    c. What support did the volunteer provide? (We need to know exactly what the nature of the volunteer service is – the frequency, length, how it is coordinated and exactly what the volunteer is doing/ providing. This may differ from the project plan.)
    d. Are they still receiving the service?
    e. If they had to wait to receive the service, was there any impact from waiting?
d) As the rapport builds ask for examples of things that pleased them about the volunteer service and anything that they were less pleased with.
e) Ask explicitly how they think the service could be improved? Then probe around particular issues:
    a. What staff contact have they had as well as volunteers
    b. Boundary issues (e.g. the clarity of volunteer role; the relationship between patient and volunteer)
    c. Do the volunteers need to be more highly selected or trained?
    d. Have they ever been unsure about anything that has happened (e.g. can they do this, can the volunteer do that?)
    e. How are problems dealt with?
f) What have been the biggest impacts of the service? (unprompted at first and then ask around the key areas). In all areas probe around how and why these impacts have come about and explore those factors that have maximized or minimized (enabled or inhibited) these impacts.
    a. Loneliness
    b. Social support
    c. Use of other health and social care services
    d. Carers
    e. Has there been any untoward effect of receiving the service, or any benefits they didn't anticipate?
    f. How is it different from paid staff services?
g) Ask them about their experiences of taking part in the evaluation
h) Anything else?

Carer interviews

a) Ask the carer to briefly summarise their experience as a carer receiving the volunteering service (this helps to frame the agenda, indicates the level of disclosure and sets the terminology);
b) Explore what support was already available to the patient/ them before they were referred to the social action service and what services they both continue to use;
c) Probing events and experience of receiving the social action service i.e.
    a. Could you tell me a bit more about what happened when the patient was referred?
    b. How were the patient's needs assessed and identified?
    c. What support did the volunteer provide? (We need to know exactly what the nature of the volunteer service is – the frequency, length, how it is coordinated and exactly what the volunteer is doing/ providing. This may differ from the project plan.)

    d. Is the patient still receiving the service?
    e. If the patient had to wait to receive the service, was there any impact from waiting?
d) As the rapport builds ask for examples of things that pleased them about the volunteer service and anything that they were less pleased with.
e) Ask explicitly how they think the service could be improved? Then probe around particular issues:
    a. What staff contact have they/ the patient had as well as volunteers
    b. Boundary issues (e.g. the clarity of volunteer role; the relationship between patient and volunteer)
    c. Do the volunteers need to be more highly selected or trained?
    d. Have they ever been unsure about anything that has happened (e.g. can they do this, can the volunteer do that?)
    e. How are problems dealt with?
f) What have been the biggest impacts of the service? (unprompted at first and then ask around the key areas). In all areas probe around how and why these impacts have come about and explore those factors that have maximized or minimized (enabled or inhibited) these impacts.
    a. On them
    b. Patient loneliness
    c. Patient social support
    d. Patient use of other health and social care services
    e. Has there been any untoward effect of receiving the service, or any benefits they didn't anticipate?
    f. How is it different from paid staff services?
g) Ask them about their experiences of taking part in the evaluation
h) Anything else?

Volunteer interviews

a) Ask them to describe their role and the type of support they are providing?
b) Their motivation for volunteering and previous experience in similar volunteering or professional roles?
c) The volunteer journey (probe around all areas for exactly what is involved, successes, challenges and potential improvements)
    a. Recruitment and selection (process, channels, type of volunteers)
    b. Pre-placement induction and training (process, gaps)
    c. How they were matched to the person(s) they are supporting (process, what characteristics? how important is this?)
    d. In-role support and management (initial introduction, formal / ad hoc, 1-2-1 / group, face-to-face / remote)
d) Other management issues (probe around all areas for successes, challenges and potential improvements)
    a. Their views on the balance between the different types of support they are providing (e.g. befriending and practical support) and the relative importance of these different types of support?
    b. Boundary issues (e.g. the clarity of volunteer role; the relationship between patient and volunteer)
    c. Do the volunteers need to be highly selected or trained?
    d. Have they ever been unsure about anything that has happened (e.g. can they do this, can the patient do that?)
    e. How are problems dealt with?
e) What have been the biggest impacts of the service? (unprompted at first and then ask around the key areas). In all areas probe around how and why these impacts have come about and explore those factors that have maximized or minimized (enabled or inhibited) these impacts.
    a. Patient loneliness
    b. Patient social support
    c. Patient use of other health and social care services
    d. Carers
    e. Has there been any untoward effect of receiving the service, or any benefits they didn't anticipate?
    f. How is it different from paid staff services?
f) Ask them about their experiences of taking part in the evaluation

g) Anything else?

Service provider interviews

a) Ask them to describe their role in the project
b) Their organisation's motivation for involvement
c) Ask them to describe the volunteer role and the type of support they are providing?
d) Project start up (this will include transition where there was an existing service)
e) The volunteer journey (probe around all areas for exactly what is involved, successes, challenges and potential improvements)
    a. Recruitment and selection (process, channels, type of volunteers)
    b. Pre-placement induction and training (process, gaps)
    c. How they were matched to the person(s) they are supporting (process, what characteristics? how important is this?)
    d. In-role support and management (initial introduction, formal / ad hoc, 1-2-1 / group, face-to-face / remote)
f) Recruitment of patients
    a. Referral process
    b. Referral channels
    c. Types of patients
g) Other management issues (probe around all areas for successes, challenges and potential improvements)
    a. Their views on the balance between the different types of support the volunteers are providing (e.g. befriending and practical support) and the relative importance of these different types of support?
    b. Boundary issues (e.g. the clarity of volunteer role; the relationship between patient and volunteer)
    c. Do the volunteers need to be highly selected or trained?
    d. Have they ever been unsure about anything that has happened (e.g. can they do this, can the patient do that?)
    e. How are problems dealt with?
h) How is the service integrated with other local service providers in the last year of life?
i) What have been the biggest impacts of the service? (unprompted at first and then ask around the key areas). In all areas probe around how and why these impacts have come about and explore those factors that have maximized or minimized (enabled or inhibited) these impacts.
    a. Patient loneliness
    b. Patient social support
    c. Patient use of other health and social care services (NB: they likely will not know this)
    d. Carers
    e. Has there been any untoward effect of receiving the service, or any benefits they didn't anticipate?
    f. How is it different from paid staff services?
j) Ask them about their experiences of taking part in the evaluation
k) Plans for the future of the service
l) Anything else?

Appendix five: Case Study Interview coding framework

Primary Nodes	Sub Nodes
Successes and challenges of running the service	
	Boundary issues (practical and emotional)
	Relationship between patient and volunteer
	Problems
	Dealing with problems
Service details	
	Volunteer role (exactly what are the volunteers doing)
	Regularity (frequency and length)
	Staff structure
Lone working policy	
	Description (i.e. what exactly is the process)
Volunteer recruitment (successes and challenges throughout)	
	Channels – which have worked best, challenges etc
	Diversity and types of volunteers
	Recruitment and selection process (interview, application, DBS)
	Level of selection (i.e. how selective does the programme need to be)
Pre-placement induction and training (successes and challenges throughout)	
	Description of induction and training (format, content, length, specific vs generic)
	Successes and challenges
Matching process (successes and challenges throughout)	
	Description (e.g. interview with patient and volunteer, formal needs assessment, written forms)
	Successes and challenges
Patient recruitment (successes and challenges throughout)	
	Referral channels (e.g. hospice and non-hospice)
	Diversity and types of patients
	Recruitment process (house visit, phone call etc)
	Eligibility criteria
	Patient Needs
Motivation of Volunteer	
Impact	
	Patient wellbeing
	Patient loneliness
	Patient social support
	Patient use of other health and social care services
	Carers
	Other impacts and benefits
	Negative impacts
	What underpins the impact (e.g. distinctive contribution of volunteers)
	Impact on volunteers [we could use sub nodes here around – personal (e.g. enjoyment, feeling good), social (meeting people), health, employment etc]
Perception of Research	
	Positive
	Negative
Organisational background	
Organisational motivation for applying	

Ongoing support with volunteers (successes and challenges throughout)	
	Communication (e.g. of training events, email and phone calls etc)
	In-role coordination (who decides exactly what happens during the visits
	Emotional support (e.g. post bereavement – individual and group; internal and external etc)
	Role development (developing their practice – individual and group; internal and external etc)
Future of the service (funding, plans etc)	
Anything else	
Patient's pre-existing support and background	
Organisational benefits or learning	

With thanks to the sites who participated in this study