

‘Being with’ or ‘doing for’? How the role of an end-of-life volunteer befriender can impact patient wellbeing: interviews from a multiple qualitative case study (ELSA)

Running title: Volunteer service impact at end of life

Dr Steven Dodd^a Research Associate. 0000-0001-9421-2941

s.r.dodd@lancaster.ac.uk

Dr Matt Hill^{b1}, Research Officer

Nick Ockenden^{b2}, Head of Research

Dr Guillermo Perez Algorta^c Lecturer in Mental Health. 0000-0001-6610-4951

g.perezalgorta@lancaster.ac.uk

Prof. Sheila Payne^a Emeritus Professor of Palliative Care. 0000-0001-6982-9181

s.a.payne@lancaster.ac.uk

Dr Nancy Preston^a Senior Lecturer in Palliative Care. 0000 0003 2659 2342

n.j.preston@lancaster.ac.uk

Prof. Catherine Walshe^{a*} Professor of Palliative Care. 0000-0002-4531-8608

c.walshe@lancaster.ac.uk

* Corresponding Author. International Observatory on End of Life Care, Division of Health Research, Furness Building, Lancaster University, Bailrigg, Lancaster, LA1 4YG. + 44 (0)1524 510124

c.walshe@lancaster.ac.uk

^aInternational Observatory on End of Life Care, Division of Health Research, Furness Building, Lancaster University, Bailrigg, Lancaster, LA1 4YG, UK

^bInstitute for Volunteering Research, NCVO, Society Building, 8 All Saints Street, London, N1 9RL, UK

^cDivision of Health Research, Furness Building, Lancaster University, Bailrigg, Lancaster, LA1 4YG, UK

¹[Present address] Head of Research and Learning, Centre for Youth Impact, 21 Garden Walk, London EC2A 3EQ, UK. matthew.hill@youthimpact.uk

²[Present address] Freelance Researcher, Copenhagen, Denmark.

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Declarations

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Authors contributions: CW conceived the study, was the chief investigator and co-wrote the manuscript. CW, NP, SP, GPA and NO co-wrote the protocol and were involved with the conduct of the study. CW, MH and SD were responsible for study data collection and analysis. GPA was the trial statistician. All authors contributed to and approved the final manuscript. CW is the guarantor.

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Abstract

Purpose: To explore the perspectives of people anticipated to be in their last year of life, family carers, volunteers and staff on the impacts of receiving a volunteer provided befriending service. Patient participants received up to 12 weeks of a volunteer provided befriending intervention. Typically this involved one visit per week from a trained volunteer. Such services complement usual care, and are hoped to enhance quality of life.

Methods: Multiple case study design (n=8). Cases were end-of-life befriending services in home and community settings including UK based hospices (n=6), an acute hospital (n=1) and a charity providing support to those with substance abuse issues (n=1). Data collection incorporated qualitative thematic interviews, observation and documentary analysis. Framework analysis facilitated within and across case pattern matching.

Results: Eighty four people participated across eight sites (cases), including patients (n=23), carers (n=3), volunteers (n=24) and staff (n=34). Interview data are reported here. Two main forms of input were described – ‘being there’ and ‘doing for’. ‘Being there’ encapsulated the importance of companionship and the relational dynamic between volunteer and patient. ‘Doing for’ described the process of meeting social needs such as being able to leave the house with the volunteer. These had impacts on wellbeing with people describing feeling less lonely, isolated, depressed and/or anxious.

Conclusion: Impacts from volunteer befriending or neighbour services may be achieved through volunteers taking a more practical/goal based orientation to their role and/or taking a more relational and emotional orientation. Training of volunteers must equip them to be aware of these differing elements of the role and sensitive to when they may create most impact.

Introduction

Volunteers and the voluntary sector are increasingly seen as critical in the collective effort to address societal challenges in health and social care as an ageing society creates more demand for public services[1]. Volunteers are important in providing services where public spending is under pressure, but also where new solutions are needed to respond to new needs and enrich communities. This approach brings both challenge and opportunity; whilst there are increasing opportunities for volunteers to contribute to care, there are also expectations that the outcomes and user perceptions of such care should be known, and services transparent and accountable[2].

Volunteers are distinctively different from paid providers, with definitions emphasising the free choice to give unpaid time to benefit others[3,4]. Whilst such support was traditionally in non-patient facing roles in many countries, care for those with cancer and at the end of life is an area where volunteers are increasingly being used in patient facing roles [5,6,2,7], especially providing psychosocial care [8-11].

Most volunteering research in cancer and palliative care focuses on the roles of volunteers, their organisation and training, and their experiences, rather than service outcomes or perspectives on care [12,8,13,9]. Studies tend to explore issues such as the volunteer experience [14-16], the nature of their role [17], their interaction with professional staff[18], the ethics of working as a volunteer[19], and the impact on their own health[20]. Satisfaction with services has tended to be explored from the perspective of volunteers or the services they work with rather than those of the people who receive care [21-23]. Benefits to people who receive care are assumed to include improvements in quality of life and enhancement of wellbeing [23,6,9,24]. Other potential impacts include the impact of services on the survival of those at the end of life [25], and whether health service utilisation costs could be reduced[26]. However the voice of people who receive care from volunteers is largely absent from research in this field.

Studies are required which examine the impact of volunteer services within cancer and palliative care on care outcomes, and explore patient perceptions of volunteer service provision and its impact. Our own and other volunteering trials are addressing understanding impact in terms of measurable patient outcomes [27-30], but it is also important to explore patient perspectives on impact and the mechanisms by which this may be achieved.

Methods

Aim

To identify and explore patient, carer, volunteer and service provider perceptions of impact of volunteer befriending services provided to those perceived to be in their last year of life. The focus of this paper is primarily patient perceptions of impact, as these are under-represented in existing literature.

Design

The interviews reported here were collected as part of a large mixed-methods evaluation of volunteer provided befriending services at the end of life (the End of Life Social Action (ELSA) study) [27-29]. The ELSA study included both a wait-list randomised controlled trial and eight qualitative case studies centred on sites providing the service within the trial [31-33]. Qualitative case studies incorporated interviews, observation and documentary analysis, but only interview data are reported here.

Setting

Sites were funded to deliver volunteer provided befriending services to people anticipated to be in their last year of life. Eleven sites throughout England participated, primarily hospices, but also an acute hospital trust and charity providing support to those with alcohol and drug use problems. Key elements of the volunteer provided support intervention include its delivery by trained volunteers who provided care tailored to the needs of the individual offered from a suite of options including befriending, practical support and signposting. Volunteer support was typically provided face to face, one to one, in the home, but telephone contact, and meeting outside the home were possible. The frequency and length of contact was individually determined, but was typically a visit once a week for 1-3 hours.

Sampling and recruitment

Eight sites from the 11 were selected for in-depth qualitative case study work on the basis of size and type of provider organisation and type of befriending service offered. The case is defined as the provision of the end-of-life befriending service within a defined locality by a provider organisation. Data were collected in 2015-16.

Case study participants were patients, family carers, volunteer befrienders and staff. Potential patient participants were those who had already consented to be part of the trial and given permission to be approached about participating in a qualitative interview. Participants in the trial include people anticipated to be in their last year of life and their informal carer (Table one). At trial inclusion, patient participants were asked to also identify a family member/informal carer to participate. Local site coordinators sampled patient trial participants for the qualitative study to maximise variability in age and gender. Where possible volunteer befrienders were those providing care to patients sampled for qualitative interview, but they were also arbitrarily sampled from the pool of all volunteer befrienders. All site staff were invited to participate. All potential participants were provided with information about the study, and written consent taken prior to the interview being conducted, in addition to any existing trial consents. Inclusion criteria were deliberately broad to include typical participants of such services.

< Insert table 1 around here >

Data collection

Single qualitative thematic interviews were conducted with patients, family carers, volunteer befrienders and staff to ascertain experiences and impacts associated with the befriending services. Volunteers and staff reflected on their overall experience, not just associated with patient participants. An interview topic guide was prepared, and iteratively developed through the study. The topic guide is summarised in Table 2.

<Insert Table 2 around here>

Interviews were audio recorded using encrypted digital recorders, and fully transcribed. Transcripts were not returned to participants. Contemporaneous field notes were made. Qualitative data were collected by SD, MH (both male research associates), CW (female academic); all experienced qualitative researchers. Whilst additional data were collected including non-participant observation of organisational meetings and collection of documentary data such as service policies, and job descriptions these are not reported here.

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 - 94 minutes, with a mean length of 37 minutes.

Data analysis

The five steps of framework analysis facilitated within and cross case pattern matching: familiarization; identifying a thematic framework; indexing; charting; and mapping and interpretation [33]. Data displays enabled identification of divergence in responses given by those from different sites and interviewee groups [33,34]. NVivo 11™ was used to manage data. The initial a-priori coding frame mostly mirrored the structure of topic guide used in interviews, developed by SD, MH and inductive elements were added through the study [SD, MH, CW]. Staff participants had an opportunity to meet after data collection was complete to discuss emerging analysis, and this influenced the final framework. Cross case pattern matching followed to identify thematic factors associated with perceptions of impact.

Ethical and funding considerations

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Results

The inputs and impacts of the volunteering service are presented below, as a cross case analysis, with particular attention paid to patient perceptions of changes (impacts) brought about by the presence of the volunteer in the life of the patient and their family/carer, and the views of volunteers and staff on such perceptions and impacts. Table 3 presents data on the number of participants within each case study site. Table 4 characterises the patient participants, compared to the trial participants from which the sample was drawn. Patients selected for qualitative interview shared typical characteristics of those receiving the service, but with a greater proportion of females.

Figure 1 conceptualises the process of impact, demonstrating a temporality to the perception of impact, and dependent on the form of input. The inputs and impacts are described below.

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<Insert table 4 around here>

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'Being with': Relationship building input

An agreeable relationship between patient and volunteer, and a degree of relational chemistry appeared an important prerequisite for impact. In practical terms, the relational aspects of the volunteer visit were apparent in the opportunity provided for conversation. Conversation was the most common object of patient's appreciation:

Chatting generally and exchanging viewpoints and all the rest of it; so that's that. It's convivial. Friendly conversation, which is what the whole thing was intended to be wasn't it? ... It shouldn't be a friendship as though it was contrived; it should just naturally develop as it might in ordinary circumstances. (CAS3/PAT/04)

Conversation could involve 'small talk' about mundane topics, which may act as a distraction from more weighty concerns that might be preoccupying patients. It could also be a welcome change from conversation with family members who might be overly focused on health-related matters. Wide-ranging conversation was aided by the novelty of the relationship and how little each party initially knew of each other. At the other extreme, conversation could also be valuable to patients when it provided the opportunity for them to speak their mind to someone they could trust about sensitive topics. Most typically, this involved speaking about health concerns.

'Doing for': Activity input

Of the activities undertaken by volunteers with patients, the opportunity provided to go out was commonly linked by participants to impact. The impacts promoted through this activity could be particularly pronounced when the volunteer has more time for going out than the patient's family or friends, or when the volunteer can take the patient somewhere they would not otherwise be able to visit:

They [volunteer and patient] found themselves in [supermarket] and it was just before Christmas and they came back, I came back and there was [patient name] with a half assembled, really appropriate looking Christmas tree. At a time when we knew we wouldn't be going anywhere and we knew we would not be visited and felt guilty and unhappy and a little sad at not being able to get the old fashioned things down and put all the lights up. But not wanting it to be an empty, Christmas-free house and it ended up, if anything, a better looking Christmas tree. (CAS6/01/CAR)

Although support to go out was a common component of some services, the impact of this on social support is likely to be particularly high for the subset of patients who would otherwise be unable to go out:

To go out I have got to have somebody with me, I mean when you are getting older it doesn't mean to say you have stopped going out, but if you are injured, then it does stop you going out without ... I have got to have somebody with me, put it like that. (CAS8/01/PAT)

Relationship between input and perceptions of impact

Some impacts, such as those tied up with the opportunity for patient self-expression, appear linked to the relational dynamics between patients and volunteer. In cases where the relationship afforded the opportunity to discuss deeper and more troubling topics, patients reported benefits tied to being able to frankly discuss their thoughts without the fear of worrying family or friends:

If you keep getting bad news thrown at you and then you've got to keep it bottled up. You go for these visits to the hospital, you come back home, and you know that night you're going to be getting text messages and phone calls from everybody, 'How did it go?' and you've got to do your best to keep it bottled in. Well now, to have someone like [volunteer name] ... maybe we meet up the week after, and someone to be able to talk to about it because I keep it to myself. (CAS7/01/PAT)

Unfamiliarity with the volunteer can enable a person to openly speak about problems to somebody they don't know:

Being able to talk about my problems freely to somebody I don't know. They're not like that, well [volunteer name]'s not like that....I open up talking to a person that doesn't know me. I open up and that's it, the floodgate's open, isn't it, and everything comes out. (CAS8/02/PAT)

Conversation could also have other wellbeing impacts, including the benefits for the patient of being able to discuss topics that were overly familiar to their other social contacts. This could be important to the patient, allowing them an opportunity to speak regularly about their life story to someone for whom it is unfamiliar. This could be seen as a chance to put their life in context or see it through a fresh pair of eyes:

And perhaps doesn't want to talk to her family too much about all the past, because they've heard it before. I haven't and I'm quite intrigued. She has some wonderful stories and everybody likes to share a story and to an interested party. (CAS6/01/VOL)

Positive wellbeing effects could emerge both from discussing anxieties and concerns as well as from activities or conversations with the volunteer that enhanced self-worth, often from a greater sense of being cared for due to the volunteer making the effort to contribute their time, energy and interest on a regular basis. 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.

The forms that wellbeing impacts took varied from reductions in negative feelings (such as depression and/or loneliness) to growth in confidence. For people who appeared more socially isolated, an impact of conversation or support to go out was the alleviation of loneliness. Staff members within each site were clear that the befriending service helped some patients to reduce their level of isolation. Where patients were experiencing high levels of loneliness the impacts were perceived to be highest, potentially helping with associated problems such as depression. As a consequence of the service provided, several patients mentioned the relief from loneliness:

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. It's getting out is the main thing for me really. (CAS7/03/PAT)

Though wellbeing impacts were not always spelt out, there were examples in which the impact of the service was made clear, such as motivation to do “something positive” and to do more than sitting down “feeling sorry” for oneself:

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. (CAS8/03/PAT)

Other forms of impact

In addition to the wellbeing impacts promoted by the service, there were other impacts that were promoted by the opportunity to go out, the relationship involved, or the presence of an attentive volunteer. Volunteers were generally encouraged to take a versatile and open approach to befriending, increasing the possibility that impact could be created by responding to need. For example, people were supported to participate in hobbies:

We had one gentleman quite early on who used to paint, but had stopped painting, had not painted for a few years. So his volunteer, she is adorable, she just was asking him about what his hobbies were and things, and he was, she said oh well show me some of your paintings ... And eventually he started painting again, and he got his volunteer painting. (CAS6/02/STA)

Although the befrienders did not directly intervene in the physical health of the patient, the volunteer could function as a link to other professionals. This might involve supporting their client to attend a medical appointment, requiring them to schedule their visit to coincide with the appointment. Volunteers also played a role in observing the health of their client and updating others on any changes they notice. This is not a substitute for contact with clinical staff, but the lay input of the volunteer could be of value given their frequent and regular contact with the patient:

The volunteer goes in one day and notices they've reached crisis point and none of their medications have been taken, the carer has disappeared off and they are not in a good place. That volunteer can call up our specialist services straight away and a clinical nurse specialist can go out or a doctor could go out, or if it was a physio we could get our physio in really quickly. (CAS6/01/STA)

By staying in regular contact with a volunteer, there is the potential that patients with worsening symptoms will access medical services sooner than if they were without the input of the volunteer. This could potentially increase the efficiency of the patient's use of medical resources by enabling them to access services in a timely way.

Discussion

Summary of findings

Wellbeing appears to be facilitated through two forms of volunteer input. First, 'being with' or relationship building enabled the creation of a relational dynamic between patient and volunteer which facilitated open expression. Second, 'doing for' or activity efforts enabled a (re) opening of the patient's world which assisted a sense of participating in a more usual life than previously. These are important impacts on a person's quality of life and wellbeing, enabled by people centred 'small things'.

What this study adds

'Being with' and 'Doing for' are identified in the research of others. Relationship-building is usually considered critical to end-of-life care provision [35], although it may not be a necessary pre-requisite for good psycho-social care [36]. However, the emotional experience of care is critically important to patients and carers [37]. Social capital is recognised to have an impact on health [38,39], and a focus on everyday life known to be an important component of coping well towards the end-of-life [40]. Social networks can strengthen as death nears [41], befriending services may be an important element in both enabling re-engagement with others, and becoming part of a network of care. Our research contributes to this developing understanding of the importance of emotional and social aspects of care.

The evidence on the impact of volunteers on people with cancer or towards the end of life is scant, mostly pointing to satisfaction with services rather than understanding outcomes for those receiving services [42]. Befriending interventions appear to have some benefit on patient wellbeing, but the effect size is small [43,27]. This could be considered surprising, as there is evidence that the presence of social relationships has a direct impact on health and mortality [44,26,45]. Studies of volunteering impact call for a more theoretically informed approach to understanding why volunteers may have an impact, and what outcomes could be anticipated from the input of volunteers [42]. Our study provides qualitative data to inform this discussion, pointing towards the importance of understanding the 'being with' and 'doing for' work of volunteers, and the effects these had on perceptions of wellbeing as impact. The challenge for researchers will be the sensitivity of tools to measure the nuances of these effects in the context of an overall decline in wellbeing and quality of life towards the end of life[27].

This research adds to an understanding of the importance both of person centred responsive care, and that this need not be always professionally provided to have impact. People towards the end of life respond to those who pay attention to need, whether that be, for example, conversations with cleaning staff[46] or the responsiveness of someone unfamiliar with their care needs[36]. What may be distinctively different about the responsiveness of volunteers in both ‘being there’ and ‘doing for’ is that people also responded to the altruism inherent in the volunteer role, in contrast to the roles of professional care providers. This appeared to enhance perceptions of impact, possibly because social expectations of reciprocity and intention were affected by the voluntary role[47].

Much attention has been given recently to concepts of community involvement in, and the importance of public health approaches to, palliative and end of life care[48]. Volunteer befriender services can be seen as part of a response to these calls. Whilst these services could be said to be meeting both personal and population needs [49], the focus is frequently on mobilising networks of care within and across different caring communities of family, friends and the wider community[50]. These findings support the roles of such services in enabling brokerage across ‘holes’ in an individual’s person’s networks[51], whether that be for companionship or practical support, and the impact on people of meeting these non-clinical needs.

Strengths and limitations of the study

This is one of the largest qualitative studies of volunteers providing care towards the end-of-life, and has particular strengths in its focus on the voice of people being supported as well as those of staff or volunteers. Limitations include the data being collected in the context of a trial, participation in which may potentially have influenced people’s views. We also did not recruit family carers in the numbers desired. Selection of patient participants from those within the trial was mediated by service coordinators, to ensure those who were ill or deteriorating were not contacted, and this may have an unknown influence.

Implications for practice, and suggestions for future research

Clinicians can support volunteer provided befriending services, as these appear to have emotional and social benefits which clinical services may struggle to provide. This research identifies the domains these services have influence in, the challenge for future researchers is to identify how to measure impact across these domains to enable targeting of services where resources (e.g. volunteers) may be limited.

Conclusion

Impacts from volunteer befriending or neighbour services may be achieved through volunteers taking a more practical/goal based orientation to their role and/or taking a more relational and emotional orientation based on conversation, sharing stories and expressing feelings. The exact combination and weighting given to both of these aspects of the role must be determined by the needs of the patient and their relationship with the volunteer. Training of volunteers must equip them to be aware of these differing elements of the role and sensitive to when it is necessary to depend on one facet of the role or the other.

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Table 1. Study inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Patient participants	
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.	1. Age <18 years 2. Those who only understand or speak a language in which the main trial outcome measure (the WHOQOL-BREF) is unavailable. 3. Those with an anticipated prognosis of < 4 weeks, estimated by service providers.
Family/Informal carer participants	
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	

Table 2. Interview topic guide

Patient and carer participants	<p>As a qualitative interview this guide was used flexibly, and iteratively developed. Similar questions were asked of patients and carers, flexibly adjusted to explore related issues from their perspectives.</p> <p>Ask the patient/carer to briefly summarise their experience as a patient/carer receiving the volunteering service to help frame the agenda, indicate the level of disclosure and set the terminology;</p> <ul style="list-style-type: none"> a) Explore existing source of support/services; b) Probing events and experience of receiving the social action service i.e. <ul style="list-style-type: none"> 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? d. Are they still receiving the service? e. If they had to wait to receive the service, was there any impact from waiting? c) What may have pleased them about the volunteer service and anything that they were less pleased with. d) How they think the service could be improved? <ul style="list-style-type: none"> 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. Selection and training of volunteers
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	<ul style="list-style-type: none"> d. Have they ever been unsure about anything that has happened e. How are problems dealt with? e) What have been the impacts of the service? How and why these impacts have come about and explore those factors that have maximized or minimized (enabled or inhibited) these impacts. <ul style="list-style-type: none"> 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?
Staff and volunteer participants	<p>As a qualitative interview this guide was used flexibly, and iteratively developed. Similar questions were asked of staff and volunteer participants, flexibly adjusted to explore related issues from their perspectives.</p> <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> a. Recruitment and selection b. Pre-placement induction and training c. How they were matched to the person(s) they are supporting d. In-role support and management d) Other management issues <ul style="list-style-type: none"> a. Their views on the different forms of support to patients. b. Boundary issues c. Do the volunteers need to be highly selected or trained? d. Have they ever been unsure about anything that has happened e. How are problems dealt with? e) What do they think are the impacts of the service? <ul style="list-style-type: none"> a. Patient loneliness b. Patient social support c. Patient use of other health and social care services d. Has there been any untoward effect of receiving the service, or any benefits they didn't anticipate? e. How is it different from paid staff services?

Table 3. Numbers of participants interviewed in the eight qualitative case studies

	Staff (STA)	Volunteer (VOL)	Patient (PAT)	Carer (CAR)	TOTAL
Site 1 (CAS1)	2	3	1		6
Site 2 (CAS2)	4	2	4		10
Site 3 (CAS3)	5	3	3	1	12
Site 4 (CAS4)	8	4	3	1	16
Site 5 (CAS5)	3	2	2		7
Site 6 (CAS6)	4	3	3	1	11
Site 7 (CAS7)	4	3	3		10
Site 8 (CAS8)	4	4	4		12
TOTAL	34	24	23	3	84

The abbreviations STA, VOL, PAT, and CAR are used within the text to identify respondents, and which case study site (CAS) their data were collected within.

Table 4. Characteristics of case study patient participants, compared to all ELSA trial participants overall

Demographics	ELSA Immediate trial arm <i>n</i> = 92	ELSA Wait trial arm <i>n</i> = 87	Participated in case study qualitative interview <i>n</i> =23*
Age, Mean	72	72	74
Gender, Female <i>n</i> (%)	56 (61)	53 (61)	16 (76)
Marital Status, Single <i>n</i> (%)	54 (61)	61 (72)	16 (76)
Living Status, Living Alone <i>n</i> (%)	47 (53)	54 (64)	14 (67)
Occupation, Retired <i>n</i> (%)	74 (86)	70 (82)	16 (76)
Ethnicity, White British <i>n</i> (%)	81 (92)	76 (89)	19 (90)
Cancer diagnosis <i>n</i> (%)	37 (41)	47 (55)	9 (42)

* Demographic data available on 21 participants

Fig.1 The process and timescale of perceived service impacts.

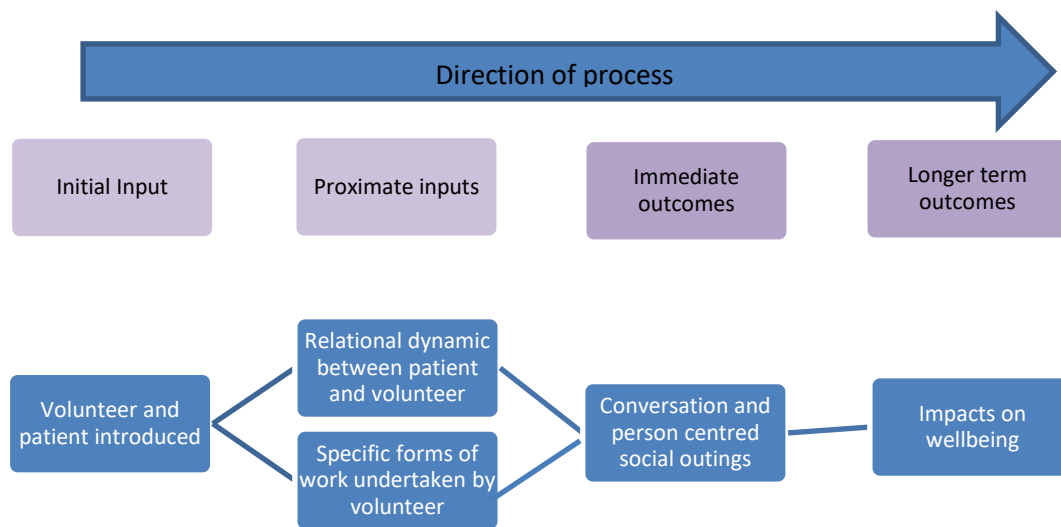


Fig.1 The process and timescale of perceived service impacts.

