

Institution: Lancaster University		
Unit of Assessment: 3, Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Enhancing and expanding the scope, reach and value of volunteers in palliative and end-of-life care		
Period when the underpinning research was undertaken: 2011-2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Catherine Walshe	Professor	2013–present
Sheila Payne	Professor	2006–present
Nancy Preston	Professor	2012–present
Sean Hughes	Lecturer	2013–present
Guillermo Perez Algorta	Lecturer	2015–present
Sara Morris	Senior Research Associate	2006–2018
Evie Papavasiliou	Senior Research Associate	2014–2015
Steven Dodd	Research Associate	2015–16, 2017–19
Period when the claimed impact occurred: 2013-2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Evidence-based practices about the volunteer role within palliative care have been severely lacking. This is important, as palliative care benefits three quarters of those who die. Research by Walshe, Preston and Payne played a leading role in providing an evidence base for volunteer-provided care. Findings from this research determined that there are 1.5 volunteers for each paid palliative care staff member. In addition to establishing the sheer scale of volunteer-provided palliative care, the research was pioneering in its use of high quality, robust methods to enable the identification of best practices and an evidence-based practitioner focused toolkit. This work has enabled adoption of these best practices, facilitated the safe uptake and growth of volunteer roles, promoted widespread distribution of the toolkit amongst a diverse range of beneficiaries, and provided the high-quality research base that UK and European bodies have used to develop volunteer programmes in palliative care.</p>		
2. Underpinning research		
<p>Volunteers provide a substantial proportion of palliative care in the UK, with an associated reduction in hospice costs of approximately 23%, according to Hospice UK. Moreover, demand for these volunteers is increasing – the aim of the NHS Long Term Plan (2019) is to double the number of volunteers over the next 3 years. This requires an accurate and evolving evidence base to identify not only the scale of volunteering in palliative care settings but also novel ways to ensure safe best practice and longevity of the volunteer role. Yet, research concerning volunteers within palliative care has been scarce. To this end, Walshe, Payne and Preston have led a research programme focused on volunteers in palliative care since 2011 to the present day.</p>		
1) Scale and scope of palliative care volunteering		
<p>Lancaster research was the first to establish the scale and scope of direct care volunteering within UK hospices (between 2011 and 2013, [G1]). Research led by Payne took a multifaceted approach that included a national survey of hospices and palliative care services, extensive literature reviews, and in-depth case studies. The research team demonstrated not only the need for high-quality, robust research [R1], but also the sheer scale of volunteering that was in existence – establishing that there are 1.5 volunteers for each single paid member of staff [R2]. The research also targeted volunteering provision [R2, R3] and identified that tensions around ‘managerialism’, where hospices were concerned about managing risk in the roles of volunteers, such as their personal safety and those of the patients for whom they are caring, was a serious barrier to accessing volunteer-provided care.</p>		

2) Value of volunteer-provided care

Through the research an evidence base for the potential value of volunteer-provided care was established. Walshe, Payne and Preston conducted the very first randomised controlled trial of volunteer-provided end-of-life care (between 2014 and 2016, [G2]), commissioned by the Office for Civil Society, Cabinet Office (now DCMS) [ISRCTN Registry: 12929812]. Involving 196 people towards the end of their lives, trained volunteers provided tailored face-to-face befriending support, primarily provided within the home. This trial identified that increased contact with volunteers in the intervention group was associated with a slower rate of deterioration in physical quality of life compared to patients in the control group, and the intervention showed a dose-response effect such that more hours of contact was associated with this slower rate of decline [R4]. Importantly, there were no adverse effects, and participants felt the service was safe and well managed – demonstrating that concerns surrounding risk need not be a barrier to provision. This was supplemented by an in-depth analysis of how volunteers in non-clinical services can provide unique and highly valuable benefits to those experiencing the end of life [R5] – patients said that befriending services impacted quality of life through ‘being with’ (e.g. by providing companionship) and ‘doing for’ (e.g. by aiding different activities).

3) Developing a range of volunteer end-of-life care services

Having demonstrated that volunteers are both valuable and viable as a resource for palliative care, the research team then targeted the need for scaling up and ensuring longevity of a wider range of evidence-based volunteer roles. This was achieved through research that (1) established the feasibility of performing a randomised controlled trial, and recruiting and training a new peer mentor system for patients with advanced cancer (between 2015 and 2018; [G3]), (2) found end-of-life volunteers in non-clinical services enriched relationships and improved mental health through their flexible, responsive approach (between 2017 and 2019; [G4], [R6]), and (3) evaluated the development of a new model for the initiation of novel volunteer-provided services in hospices (between 2016 and 2019; [G5]).

4) Development of evidence-based toolkit

As a direct outcome of [G2], and additionally drawing from work in [G1] and the wider existing evidence base, the research team worked with stakeholders such as hospices, NHS Trusts and volunteers to develop a practitioner and service friendly evidence-based toolkit to guide the future development and provision of end-of-life care volunteering services. The toolkit enables the practical application of the research and is available in print, [as a free PDF download](#), and with an associated promotional video.

3. References to the research

- [R1] **Morris, S.**, Wilmot, A., Hill, M., Ockenden, N., & **Payne, S.** (2013). A narrative literature review of the contribution of volunteers in end of life care services. *Palliative Medicine*, 27(5), 428-436. <https://doi.org/10.1177/0269216312453608> (82 citations Google Scholar, Altmetric score: 24)
- [R2] Burbeck, R., Low, J., Sampson, E.L., Bravery, R., Hill, M., **Morris, S.**, Ockenden, N., **Payne, S.**, Candy, B. (2014). Volunteers in Specialist Palliative Care: A Survey of Adult Services in the United Kingdom. *J Palliat Med*. 2014 May 1; 17(5): 568–574. <https://doi.org/10.1089/jpm.2013.0157> (55 citations Google Scholar, Altmetric score: 42)
- [R3] **Morris, S.**, **Payne, S.**, Ockenden, N., & Hill, M. (2017). Hospice volunteers: bridging the gap to the community? *Health and Social Care in the Community*, 25(6), 1704-1713. <https://doi.org/10.1111/hsc.12232> (35 citations Google Scholar, Altmetric score: 6)
- [R4] **Walshe, C. E.**, **Dodd, S. R.**, Hill, M., Ockenden, N., **Payne, S. A.**, **Preston, N. J.**, & **Perez Algorta, G. D.** (2016). 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*, 14, [203] <https://doi.org/10.1186/s12916-016-0746-8> (24 citations Google scholar, Altmetric score: 70)
- [R5] **Dodd, S. R.**, Hill, M., Ockenden, N., **Perez Algorta, G. D.**, **Payne, S. A.**, **Preston, N. J.**, & **Walshe, C. E.** (2018). '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). *Supportive Care in Cancer*, 26(9), 3163-3172 <https://doi.org/10.1007/s00520-018-4169-2> (23 citations Google Scholar, Altmetric score: 18)

[R6] **Dodd, S., Preston, N., Payne, S., & Walshe, C.** (2020). Exploring a New Model of End-of-Life Care for Older People that Operates in the Space Between the Life World and the Healthcare System: A Qualitative Case Study. *International Journal of Health Policy and Management*, 9(8), 344-351. <https://doi.org/10.15171/ijhpm.2019.138>

Research Grants

[G1] Payne, Morris (2011-2013). *Meeting the specific challenges of involving volunteers in palliative care roles which require direct contact with patients or their families*. Dimpleby Marie Curie Cancer Care Research Fund, GBP137,910.

[G2] Walshe, Payne, Preston, Perez Algorta, Papavasiliou, Dodd (2014-2016). *Evaluation of the End of Life Social Action Projects (ELSA): A waitlist randomized controlled trial with qualitative case studies*. Centre for Social Action, Cabinet Office, GBP123,000.

[G3] Walshe, Perez Algorta (2015-2018). *Peer support to maintain psychological wellbeing in people with advanced cancer: A feasibility study for a Randomised Controlled Trial*. NIHR Research for Patient Benefit (PB-PG-0614-34070), GBP249,767.

[G4] Walshe, Payne, Dodd, Preston (2017-2019). *Understanding the experience of providing and receiving the Age UK Later Life Service. A multiple qualitative case study*. Age UK, GBP41,000.

[G5] Hughes, Walshe (2016-2019). *Using participatory action research to advance hospice care*. Hospice in the Weald, GBP91,284.

4. Details of the impact

Palliative care is needed for around 75% of those who die, or globally around 42 million people a year. Improving the scale, reach and quality of palliative care provision, including through volunteers, therefore, has wide ranging global potential, and could make a substantial difference to the quality of life and death of many of those who die each year. Lancaster research has improved the provision of palliative care in two distinct ways: by increasing the scale and reach of volunteers in palliative and end-of-life care through evidence-based practice, and by forming a high-quality research base that has actively been used for UK-based and European policy around volunteer-provided palliative care.

1) Increasing the scale and reach of volunteers through evidence-based practice

The research has been instrumental in scaling up palliative care volunteer programmes. Helpforce and NHS England used the research to help develop their end-of-life volunteer programme and to provide evidence for funding the programme itself [S1]. As a direct result, in February 2020 Helpforce initiated the establishment of volunteer programmes across 7 hospitals in England, Wales, Scotland, and Northern Ireland, with the ambition of training 200 volunteers to support >1,000 patients (due to the COVID-19 pandemic this programme has been delayed) [S1].

The work also directly addressed and alleviated concerns about risks associated with volunteer-provided services – a crucial part of enabling the ambition within the NHS Long Term Plan to double the number of NHS Volunteers between 2019 and 2021. To this end, NHS England asked Walshe to counter adverse perceptions by writing [a blog](#) for them about volunteering based on the research and to reiterate that when properly managed, volunteer-based services can be both safe and effective [S2]. In relation to this work, the Head of Voluntary Partnership and Volunteering, NHS England and NHS Improvement stated that, “*The research from Lancaster University provides evidence that demonstrates the benefits of volunteers in those settings, and criteria that can be used to assess the characteristics and needs of a safe and effective volunteer scheme. Moreover, the evidence-based toolkit derived from their research is an excellent means to assist designing volunteering schemes*

in a user-friendly and accessible way”. [S2]. In October 2018 the National Council for Voluntary Organisations (NCVO) [published a guide to using the toolkit](#).

This evidence-informed volunteering toolkit has shaped practice and increased access to befriending services. The toolkit was also distributed in print to all 230 hospices and specialist palliative care services in the UK (September 2018), and made available for free download. Between October 2018 and December 2020 the toolkit has been downloaded 505 times, including 32% of downloads coming from 42 non-UK countries [S3(a)]. Data collected at the time of toolkit download shows a diverse range of roles and organisations, including clinicians, service coordinators, educators, and policy makers from public, private and third sector organisations [S3(a)]. The toolkit [video](#) has been viewed 5,600 times between December 2018 and December 2020 [S3(a)]. Toolkit users were asked to feedback how they used the toolkit, what changes have been implemented, and what the outcomes have been so far. Users reported benefits such as better support for families, prioritising how patients (rather than the service) would benefit from volunteer support, new and better ways of organising work and fewer patients dying alone [S3(b)]. One toolkit user stated that, *“The toolkit is something which both myself and our EOLC clinical lead have read and used elements of to help shape how our role looks. Particularly the advice around training, support and supervision has helped us to ensure that we are thinking very carefully about what we are doing and that we have looked at what is already happening and what works”* [S3(b)].

Other examples of the benefits of using the toolkit in practice include the words of a volunteering business partner at Macmillan, who reported in November 2020 that *“We are constantly looking to improve the support we provide to beneficiaries, volunteers and their managers and have used the ELSA toolkit as a reference framework when planning this work”* [S3(c)]. In addition, the Chief Executive of St Michael’s hospice in East Sussex stated in March 2020 that the toolkit, *“takes us beyond traditional community volunteering programmes...to partnerships, community led and initiated projects and diversified roles”* [S4]. In New Zealand, the manager of volunteer and hospitality services at North Haven Hospice stated that the toolkit is being used to plan the future design and delivery of the organisation’s volunteer services [S3(d)].

Many of the hospices that were involved in the original ELSA trial [G2, R4] set up new or expanded volunteering services as part of their involvement in the trial and have subsequently continued to use volunteers as a core part of their volunteering services. Examples include Sue Ryder Duchess of Kent Hospice who reported that a total of 102 volunteers have been supporting a total of 206 patients between March 2016 and March 2020 [S5(a)], and St Michael’s Hospice in Harrogate where a total of 80 volunteers supported 221 clients between April 2019 and March 2020 [S5(b)]. Illustrating the value of volunteers to patients, the Befriending Coordinator for Sue Ryder Wheatfields Hospice stated in May 2020 that *“Volunteers have supported patients to get their affairs in order, write letters to loved ones and sort through belongings. They have accompanied people to appointments. They have taken people out to parks, pubs, cafes, art galleries, shops, cinema’s, to name but few...The feedback from patients and families has been overwhelmingly positive... Volunteers have had special mentions at funerals”* [S5(c)].

2) Provision of a research base to inform UK and European policy

The toolkit provided a practical application of the trial and qualitative research [G2, R4, R5] that has facilitated UK volunteering policy in palliative care. The Government Minister for Care in 2018 said, *“Those who volunteer their own time to support others in this position really do make a difference to their lives and this new online toolkit will make it easier for people to provide this service and offer both practical and emotional support.”* [S6]. The work and toolkit have been discussed with a member of the House of Lords as part of her House of Lords fellowship on palliative care [S7], and the work has also been promoted in a Cabinet Office impact event [S8]. These activities have also helped produce policy that supports carers in the community – the UK Government Office for Civil Society recommended the toolkit in their Government Carers Action Plan 2018–2020 to train

volunteers to conduct home visits and provide non-medical care alongside the support carers provide [S9]. In addition, the research [R2] has also been used by Public Health England in developing [a tool designed to support all Clinical Commissioning Groups](#) across England to make commissioning decisions on end of life services in their areas. Between July 2017 and December 2020, the tool was accessed 3,209 times [S10]. Further to this, greater awareness and uptake of the toolkit within allied health and social care services was facilitated in November 2016 when the [Professional Association for Social Work and Social Workers](#) publicised the ELSA evaluation report on their website.

Additionally, the work continues to support both UK and European volunteer-based care in hospices. The ELSA toolkit is one of Hospice UK's key community volunteering resources [S11]. The research team also supported the European Association of Palliative Care (EAPC) Task Force on Volunteers, where [Walshe's blog on volunteering](#) was one of their top 10 viewed blogs in 2019. Walshe is (and Payne was) part of the steering group of this taskforce, as experts in palliative care volunteering research, which led to the [EAPC Volunteering Charter](#), signed by >3,000 people from 50 different countries. This Charter serves as a formal document for European advocacy of the successful development of volunteering policies for the benefit of patients, families, and the palliative care community, and was presented at the EAPC World Congress in May 2019.

5. Sources to corroborate the impact

[S1] Letter from Helpforce outlining contribution of the research to developing NHS Volunteering, 2020.

[S2] Letter from NHS England outlining contribution of research to promoting safe volunteering, 2020.

[S3] Evidence-based volunteering toolkit data: a) evidence of reach, b) comments from users returned via secure RedCap survey distribution c) email update from volunteering business partner at Macmillan, 2020, d) email update from manager of volunteer & hospitality services at North Haven Hospice, New Zealand, 2021.

[S4] Letter from St Michael's Hospice outlining importance of research in enabling creation of volunteering service, 2020.

[S5] Testimonials from befriending services involved in the original trial: a) Sue Ryder Duchess of Kent Hospice, 20210 b) St Michael's Hospice, Harrogate, 2020 c) Sue Ryder Wheatfields Hospice Peace Hospice, 2020.

[S6] Evidence from Minister for Care, 2018.

[S7] Evidence of meeting with member of the House of Lords, 2018.

[S8] Impact event with stakeholders in social action across the UK hosted by the UK Cabinet Office and involving people providing and using social action services in the NHS, Social Care and charity sectors. The event also involved policymakers and commissioners, 2016.

[S9] The evidence-based volunteering toolkit is recommended in the UK Government [Carers Action Plan 2018-2020](#) in regard to enhancing community engagement, 2018, p.27.

[S10] Email from Public Health England, 2021.

[S11] [Hospice UK link](#) to toolkit in their resources for hospices around volunteering.