

Institution: Lancaster University		
Unit of Assessment: 3, Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Dying well: improving international palliative and end-of-life care		
Period when the underpinning research was undertaken: 2006–2020		
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:
Sheila Payne	Professor	2006–present
Nancy Preston	Professor	2012–present
Katherine Froggatt	Professor	2006–2019
Sean Hughes	Lecturer	2013–present
Period when the claimed impact occurred: 2015–2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact		
<p>Lancaster research has provided significantly greater access to the 40 million people annually who need palliative care but only 14% of whom receive it. Promoting a ‘good death’ not only benefits patients and families by reducing emotional and physical distress but also reduces costly healthcare usage. The research has improved access to palliative care internationally by underpinning the first national palliative care policy in Jordan, informing NICE guidance in England and Wales on end of life care, providing evidence to support the introduction of integrated clinical care for respiratory services and nursing homes in Europe, informing education for more than 12,000 healthcare professionals and patients in 153 countries, and promoting the recognition of palliative care as a human right by the UN Working Group on Ageing through European advocacy networks.</p>		
2. Underpinning research		
<p>Palliative care seeks to improve the quality of life of those facing life-threatening illnesses. It entails prompt, accurate assessment and symptom management and providing caregivers and patients the understanding that death need not be painful or undignified. With an ageing population and an increasing number of care home residents, the development of international palliative care standards is paramount. In recognition of this fact, the World Health Assembly (2014) called for all governments to incorporate palliative care into national health programmes. This requires robust research into palliative care services in both clinical and care home settings to enhance integration.</p> <p>Lancaster University has a long track record of research into palliative and end of life care. Payne and Preston, along with many other colleagues, have been at the forefront of this since 2006 and have built up an extensive body of research on various aspects of the topic. Much of this has been externally funded, with examples since 2013 including Payne and Preston leading a research programme encompassing 5 EU-funded projects in palliative care (<i>InSuP-C</i>, <i>PACE</i>, <i>ACTION</i>, <i>MyPal</i>, and <i>Palliative Sedation</i>) that directly address the integration of quality palliative care with co-existing health and social care systems. Two exemplars are focused on:</p> <p>The EU funded Integrated Palliative Care in Cancer and Other Chronic Conditions (InSuP-C) project (between 2013 and 2016) investigated specialist palliative care across 6 countries (the Netherlands, Germany, Belgium, Spain, Hungary, and England). Payne and Preston served as executive committee members, providing strategic management and leadership across the entire consortium. As part of the InSuP-C project, for the first time an extensive assessment of pre-existing European specialist palliative care was conducted [R1], which led to 16 peer reviewed papers. Three were systematic reviews regarding current guidelines on the integration of palliative care with cancer and non-cancer services, including services for congestive heart failure (CHF) and chronic obstructive pulmonary disorder (COPD); although these diseases are leading causes of death worldwide, the systematic review (assisted by Hughes) results showed that care services for these diseases lack integration with palliative care. This lack of integration was also found for</p>		

cancer and other chronic diseases [R2]. Best practices from up to 6 innovative services were also identified through organisational case studies in 5 of the 6 InSuP-C countries [R3]. The case studies involved in-depth interviews with patients with cancer and chronic diseases, family carers, and healthcare professionals and facilitated the cross-cultural sharing of best practices. InSuP-C identified excellent exemplars where integration of care planning and care delivery has shown innovation, dynamism, and better outcomes for patient and families. Lancaster team led the dissemination of the findings of the InSuP-C project to patients, policy makers, and healthcare professionals through Massive Online Open Courses (MOOCs).

In 2014, the research team aimed to address the need for integrated palliative care in care homes with the [Palliative Care for Older People \(PACE\)](#) EU funded project (between 2014 and 2019). Froggatt and Payne led the mapping of palliative services in care homes across 29 European countries, which provided the first international typology that identified the types of care homes and the systematic factors that support palliative care development within this setting [R4]. The identified care home types included *Type 1* (onsite medical and nursing care), *Type 2* (onsite nursing care only), and *Type 3* (residential, no onsite nursing or medical care), and the identified systematic factors were *macro* (country system level, e.g. policy), *meso* (organisational level, e.g. educational programmes), and *micro* (palliative care provision level, e.g. service activity) factors. For the first time, this new typology allowed for the consistent comparison and assessment of care homes across European countries, revealing that the majority are *Type 2*, and for the identification of clear systemic factors for the improvement of palliative care in care homes in a retrospective survey of n=1,374 deceased residents [R5]. Payne and Froggatt also developed a culturally adapted educational intervention for care home staff (PACE Steps to Success) for country-specific use. The developed resources were tested in a cluster randomised controlled trial of the PACE intervention in 78 nursing homes across 7 European countries (Belgium, Finland, Italy, the Netherlands, Poland, Switzerland, and England), and the results demonstrated improvement in staff knowledge after the intervention [R6].

3. References to the research

[R1] den Herder-van der Eerden, M., Ebenau, A., **Payne, S., Preston, N.**, et al. (2018). Integrated palliative care networks from the perspectives of patients: A cross-sectional explorative study in five European countries. *Palliative Medicine*, 32(6), 1103-1113 <https://doi.org/10.1177/0269216318756812> (9 citations Google Scholar, Altmetric score: 9).

[R2] Siouta, N., Van Beek, K., van der Eerden, M. E., **Preston, N.**, Hasselaar, J. G., **Hughes, S.**, Garralda, E., Centeno, C., Csikos, A., Groot, M., Radbruch, L., **Payne, S.**, & Menten, J. (2016). Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease. *BMC palliative care*, 15, 56. <https://doi.org/10.1186/s12904-016-0130-7> (78 citations Google Scholar, Altmetric score: 12).

[R3] den Herder-van der Eerden, M., van Wijngaarden, J., **Payne, S., Preston, N.**, et al. (2018). Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. *Palliative Medicine*, 32(6):1091-1102. <https://doi.org/10.1177/0269216318758194> (22 citations Google Scholar, Altmetric score: 60).

[R4] **Froggatt K, Payne S**, Morbey H, et al (2017). Palliative Care Development in European Care Homes and Nursing Homes: Application of a Typology of Implementation. *Journal of the American Medical Directors Association*, 18(6), 550.e7-550.e14 <https://doi.org/10.1016/j.jamda.2017.02.016> (46 citations Google Scholar, Altmetric score: 64).

[R5] Baranska I., Kijowska, V., Engels, Y., Finne-Soveri, H., **Froggatt, K.**, Gambassi, G., Teija Hamar, T., Oosterveld-Vlug, M., **Payne, S.**, et al (2020). Perception of the quality of communication with physicians among relatives of dying residents of long-term care facilities in 6 European countries: PACE cross-sectional study. *Journal of the American Medical Directors Association*, 21(3), 331-337. <https://doi.org/10.1016/j.jamda.2019.05.003> (Altmetric score: 19).

[R6] Van den Block L, Honinx E, Pivodic L, Miranda R, Onwuteaka-Philipsen B, van Hout H, Pasman HRW, Oosterveld-Vlug M, Ten Koppel M, Piers R, Van Den Noortgate N, Engels Y, Vernooij-Dassen M, Hockley J, **Froggatt K, Payne S**, et al, for the PACE trial group. (2019). Evaluation of a palliative care program for nursing homes in 7 countries: the PACE Cluster-randomized clinical trial. *JAMA Intern Med* 11;180(2), 1-10. <https://doi.org/10.1001/jamainternmed.2019.5349> (17 citations Google scholar).

4. Details of the impact

The research has had three main impacts: 1) policy development in the UK, and in Jordan (a country that previously did not have any national palliative care policy); 2) improvement of European palliative care in both specialist and care home settings using education developed based on the research; and 3) advocacy that has helped alter views on palliative care as a fundamental human right within the United Nations.

1. Impact through national and international policy development

At a national level, Lancaster palliative care research (including [R2]) was used as evidence in 7 of the 13 evidence reviews used to develop [NICE guideline NG142: 'End of life care for adults: service delivery'](#) [S1]. It aims to ensure that people have access to the care that they want and need in care settings, and is stated by NICE as being designed as a tool for service commissioners and planners, service providers, health and social care practitioners, and adults approaching the end of their life as well as their carers and families.

As a result of InSuP-C highlighting integrated care, Payne took up educational and strategy advisory roles with the WHO Eastern Mediterranean Regional Office for Kuwait (November 2015) and Egypt (November 2016). Building upon her work in these roles, Payne helped pioneer the first national Strategy on Palliative and Home Care in Jordan in 2017. Drawing on the InSuP-C research [R1, R3] Payne provided detailed feedback on Jordanian strategy and implementation plans, and as a result, *The Jordanian Palliative and Home Care Strategic Framework* (2017; English and Arabic) was endorsed and funded by the Jordanian government in 2018 and is currently being implemented nationwide to 10 million people [S2, S3(a)]. The framework provides the policy basis for practice developments informed by the research, for example, the integration of hospital based and home care palliative care provision was incorporated in the subsequent national strategy developed in Jordan. The effect of this is already visible across the country; for example, the number of home care visits for cancer centre patients in Amman doubling from 2,600 patients in 2016 to 5,200 in 2019. Payne in 2017 supported the first sub-speciality training for physicians in palliative care in Jordan [S3(a,b)]. In recognition of the influence of the research in Jordanian policy, the Chairman of the Department of Palliative Care, King Husain Cancer Center said, *"Professor Payne's work on integrated palliative care, especially in highlighting the important of homecare, has not only been extremely helpful to my leadership role in pioneering palliative care services in Jordan, but it has also been instrumental in changing policy and practice with our first Jordanian Palliative and Homecare Strategic Framework which has been adopted and funded by the Jordanian Government"* [S3(a)].

2. Impact through clinical practice improvements via education

The findings of the InSuP-C and PACE projects [R1-R6] have been used to provide education that not only enhances patient and professional understanding of the need for integrated palliative care but also enables change in palliative care practice itself. For example, the InSuP-C recommendations presented during the MOOC [S6] were used by

regional respiratory clinics across Switzerland to develop the first integrated respiratory and palliative care service for patients with end-stage COPD [S4].

InSuP-C has also provided open access to educational resources for specialist palliative services – visits to the [project website](#) totalled 82,423 between June 2013 and December 2020, and an open access e-book based on the InSuP-C findings on the best practices in international integrated palliative care (in English and Spanish; co-edited by Payne) had been downloaded 32,362 times between September 2016 and June 2020 [S5]. Preston also used the findings from the 16 papers from InSuP-C to develop and run MOOCs in 2016, 2017 and 2018. These courses were attended by 9,709 healthcare professionals, policy makers, patients and family members from 153 countries, generating engagement in these countries and among these groups of individuals who are vital to the provision of palliative care [S6]. The impact of the MOOC on practice was assessed by a survey sent out several months after course completion. For participants who provided feedback, numerous positive changes to practice were reported. For example, one participant reported in March 2019, *“I think the most important issue in palliative care at this point is getting all services to understand palliative care, its benefit to the patient and family at end of life, when to implement it and how to introduce it into the treatment plan so it is received in a positive manner. The more all medical professionals understand how palliative care works the better it will help every person at the end of life”* [S6]. Other feedback gathered at the same time provides further evidence in support of the practice benefits that the MOOC enabled, and how practice has been changed in ways congruent with the research evidence. As one participant put it, *“I think the family members and patients aren't as fearful of considering palliative care and that allows them to embrace the concept, which means they avail themselves of the services earlier which is much more beneficial to everyone involved”* [S6].

The work on the PACE project has also impacted European palliative care by providing access to education and evidence-based resources for use in care homes. Following the PACE randomised controlled trial, the PACE Steps to Success Information Pack and Tools was launched in January 2019; the resources guide implementation of palliative care in care homes and were made available for free following cultural adaptation in 7 languages (English, Flemish, Dutch, Polish, Finnish, Italian, and French) [S7]. Further translation and feasibility testing in care homes are currently underway in Japan and Sweden. The PACE Steps to Success resources also underpinned the PACE MOOCs, which were delivered in April 2019 and March 2020 and were attended by 3,115 participants (58% of which were from outside the UK) from 126 countries [S8]. The impact of this MOOC is far reaching and feedback indicates that it is having a substantive effect in changing practices and increasing quality across thousands of services worldwide. Referring to how the knowledge gained through the MOOC benefits patients and clinicians, one participant reported, *“Patients are benefitting, Health care professionals find it easy to work with these new conditions and the business aspects are improving.”* [S8]. These resources are continuing to be used and further educational resources are scheduled for future delivery.

3. Impact through advocacy

A key part of ensuring that palliative care is part of a worldwide agenda is raising awareness of its role in ageing, dementia, and long-term care. To this end, Lancaster's research on the PACE project has helped provide a basis for global advocacy of palliative care. The research team have worked directly with Alzheimer Europe (NGO with 42 membership organisations across Europe) and undertaken extensive engagement with their users and at policy conferences, advocating for palliative care in care homes at EU level using PACE research [S9].

Age Platform have also begun to address palliative care for the first time in their advocacy and policy work with stakeholders as a direct result of their involvement in PACE and have used PACE research [R3-6] [to lobby the United Nations](#). This supported the United Nations Working Group on Ageing to include palliative care as a human right for older people at its Ninth Working Session in July 2018 [S10(a)]. In February 2019 PACE research was again used when the International Association of Hospice and Palliative Care incorporated PACE research as part of their recommendations submitted to the Tenth Working Session of the

United Nations Open-Ended Working Group on Ageing [S10(b)]. Building on this, at the Tenth Working Session in April 2019 [Payne presented oral evidence](#) from PACE research to advocate for integrated palliative care in care homes [S10(c)].

5. Sources to corroborate the impact

[S1] [NICE guideline NG142 evidence reviews](#), 2019.

[S2] The Jordanian Palliative and Home Care Strategic Framework (in English and Arabic), 2017.

[S3] Evidence of policy impact in Jordan: a) Testimonial from the Chairman of the Department of Palliative care at King Hussein Cancer Center, KHCC, 2020 b) [Paper: Gaining Palliative Medicine Subspecialty Recognition and Fellowship Accreditation in Jordan](#), 2020.

[S4] Letter of support from Senior Consultant in Palliative Care from the Oncology Institute of Southern Switzerland and Ente Ospedaliero Cantonale providing evidence that they developed integrated palliative care clinics for COPD based on InSuP-C project results, 2019.

[S5] a) Hasselaar J and Payne S, [Integrated Palliative Care e-book](#), 2016 – available in English and Spanish b) reach data.

[S6] [InSuP-C MOOC](#) 2016,2017,2018: reach data and participant feedback survey.

[S7] [PACE Steps to Success Programme Information Pack and Tools](#) – available in English, Finnish, Flemish, Polish, Italian, Dutch and French, 2019.

[S8] [PACE MOOC](#) 2019, 2020: reach data and participant feedback survey.

[S9] Evidence of engagement with Alzheimer's advocacy organizations and users: a) Testimonial from the Executive Director of Alzheimer Europe, 2020, b) Age Platform and Alzheimer's Europe consultation event schedule, 2017; and c) Age Platform Europe conference agenda, 2018.

[S10] Impact on UN Working Groups on Ageing: a) UN Report of the Open-ended Working Group on Ageing on its ninth working session, 2018; b) IAHPHC submission to OEWGA10 re normative elements to right to palliative care, 2019; c) Letter of support from an Advocacy Officer of the International Association for Hospice and Palliative Care, 2020.