

Institution: University of Liverpool		
Unit of Assessment: UoA 17 Business and Management Studies		
Title of case study: Transforming Palliative and End-of-Life Care Services		
Period when the underpinning research was undertaken: 2014 – present		
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:
Professor Philippa Hunter-Jones	Professor of Marketing	1 st Sept 2005 – present
Dr Lynn Sudbury-Riley	Senior Lecturer in Marketing	1 st August 2012 – present
Dr Ahmed Al-Abdin	Lecturer in Marketing	17 th August 2015 - present
Period when the claimed impact occurred: 2014- present		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>Service and design science research about the experience of vulnerable service users undertaken at the University of Liverpool, has been adapted to the context of palliative and end of life care in the NHS, leading to the design, testing and validation of a new methodology for service improvement, the Trajectory Touchpoint Technique (TTT). A total of 6 hospices and 3 End of Life Care (EOLC) hospital teams including Marie Curie and Macmillan staff have applied the TTT. The TTT work benefits patients, their families, the bereaved and clinicians through care that is better tailored to patient needs, and enables greater service choice and clinical support. It is estimated that palliative and EOLC services have been transformed for approximately 20,000 patients between 2015-2020. Subsequently, the TTT has also been endorsed by Hospice UK supporting their work at Parliamentary level and informing the All Party Parliamentary Group (APPG) inquiry into improving access to hospice and palliative care.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>Hunter-Jones and Sudbury-Riley (since 1997) have developed a particular research expertise in relation to examining and improving the experiences of vulnerable service users, covering a range of service provision and contexts. Using methodologies which include Design Science Research (DSR), they have worked together with Al-Abdin to develop a unique research portfolio, supported by a series of 4 research grants totalling £177,284 and covering two distinct strands of inquiry. The first strand questions the impact of ill-health upon patterns of service consumption, particularly in the case of terminal illness [3.1]. The second strand examines the service needs and experiences of seniors [3.2], informal carers [3.3] and children [3.4]. The key insight of the research was the importance of mapping service user journeys in a systematic, visual way. The Trajectory Touchpoint Technique (TTT) is the resulting mapping tool and its development was the practical manifestation of this insight.</p> <p>In 2015, this research portfolio prompted East Cheshire Hospice (ECH) to commission the team to undertake a service design research project to develop a systematic approach to visualising, recording and improving the palliative and EOLC experience for patients and other stakeholders. The research team appraised the available palliative and EOLC evaluation instruments concluding that most fail to capture overall user experience and how users feel.</p>		

The research team responded by focusing on a full evaluation of psychosocial, spiritual, familial and wider quality-of-life issues in the hospice. Building upon their earlier research [3.2, 3.3, 3.4] and applying DSR to a new context, they identified multiple opportunities for service redesign, innovation, enhanced communication strategies and professional practice in common with palliative care findings, all contributing to an enhanced, personalised patient experience.

Encapsulating these research findings, the team designed, tested and validated a new methodology, TTT [3.5] as an outcome of the research. The TTT facilitates a more granular understanding of changes needed to enhance the palliative and EOLC service user experience, particularly in terms of the mental health and non-clinical aspects of service hitherto ignored, for example communication strategies and accommodation preferences that introduce patient choice and support.

Findings prompted ECH to implement a new Hospice@Home service (2018), later evaluated by the research team. The development and application of the TTT research was detailed in both eHospice [3.6], a practitioner publication, and academic research [3.5]. These publications contain the proof of concept that has enabled additional providers (5 hospices and 3 hospital based palliative and EOLC teams) to engage with the TTT methodology. These service providers included national groups Marie Curie and Macmillan, and both adult and children's hospices. Adult engagement with hospices is often relatively short. In contrast, children and their families may engage, in some cases, over many years.

These collaborations resulted in a substantial research dataset which contributed evidence to Hospice UK's response to the All Party Parliamentary Group (APPG) Inquiry into improving access to hospice and palliative care, along with an invitation to profile the work at Hospice UK's national conference in 2019 (approximately 1000 delegates). Hospice UK is the practitioner organisation representing all UK hospices.

3. References to the research (indicative maximum of six references)

[3.1] Hunter-Jones, P., Sudbury-Riley, L. & Al-Abdin, A. (2019). Making sense of healthcare experiences: An application of story-based medicine. *Advances in Consumer Research* Vol. 47, eds. Rajesh Bagchi, Lauren Block, and Leonard Lee, Duluth, MN : Association for Consumer Research, Pages: 399-402. Available from institution on request.

[3.2] Sudbury-Riley, L. (2018) eHealth Technologies: The faster we go, the more we leave behind? *European Medical Journal Innovations* 2(1), 56-63. Available on request.

[3.3] Hunter-Jones P (2010). Consumer vulnerability and exclusion: a study of carers in the tourism marketplace. *Journal of Marketing Management* Vol 27(1-2): 165-180. Available from institution on request.

[3.4] Rhoden S, Hunter-Jones, P. and Miller, A. (2016) Tourism experiences through the eyes of a child. *Annals of Leisure Research* Vol 19 (Part 3): 424-443. Available from institution on request.

[3.5] Sudbury-Riley, L., Hunter-Jones, P., Al-Abdin, A., Lewin, D. & Naraine, M. (2020). The trajectory touchpoint technique: a deep dive methodology for service innovation. *Journal of Service Research* 23(2) 229-251. Available from institution on request.

[3.6] Hunter-Jones, P. Sudbury-Riley, L. and Al-Abdin, A. (2018) Research uncovers barriers to accessing palliative and hospice care. *eHospice*, 29th October https://ehospice.com/uk_posts/research-uncovers-barriers-to-accessing-palliative-and-hospice-care/

4. Details of the impact (indicative maximum 750 words)

The impact of the Trajectory Touchpoint Technique (TTT) enables care organisations and clinicians to provide emotional and physical comfort for people at, or near, end of life. Working with 6 hospices and 3 palliative care hospital units (circa 20,000 patients in total between 2015-2020), the TTT has resulted in a series of diverse practical steps for organising, resourcing and improving care. These changes have helped clinicians to improve mental health support for patients and families, to further tackle loneliness and low mood, to enhance communication strategies and accommodation preferences by introducing choice and support to service delivery. The research has also informed Hospice UK advocacy strategy at parliamentary level in relation to improving palliative care.

Structural changes improving the provision of palliative and EOLC care were implemented as a consequence of the insights of the research informed TTT. These included a greater involvement of hospice practitioners in GP networks to ensure comprehensive and co-ordinated choice and support is provided to patients [5.1] and new training initiatives for caring professionals. For example, Oakhaven Hospice (Hampshire, UK) enhanced training and reworked communication protocols for hospital clinicians to improve professional standards and practice for patients [5.2]. East Cheshire Hospice (ECH) increased staff training around dementia awareness, heart failure, motor neurone disease and advanced day therapies to be better prepared to support non-cancer patients as raised in the TTT [5.3].

These changes have significantly impacted upon the experiences of palliative and EOLC patients, their families and professional practice enabling healthcare professionals to improve their effectiveness in communicating and delivering services, in turn improving difficult conversations, mental health support and choice at end of life for patients and their families.

Improved Choice and Support for Patients and Bereaved

Dying at Home (Choice): As a direct result of the TTT research, ECH launched a new Hospice@Home service to complement their on-site hospice offering: *'Taking the [TTT] findings (...) a clear concern with dying away from home also emerged. These findings directly influenced our decision to launch our new Hospice at Home service in October 2017'* [5.3].

Hospice@Home represents a *'complementary community service [which] provides care at home, supporting current healthcare professionals, patients and carers to stay at home as long as they can, if that's their choice'* [5.1]. Hospice@home allows community health workers to deliver palliative and EOLC care in home settings, supporting families to care for loved ones in their preferred place of death, in their final days. In the first 5 months, 175 new patients received the service, avoiding over 50 hospital admissions, and enabling practitioners to support the dying wishes of 102 people who attained their preferred place of death [5.1]. To put this research impact in context, the National Survey of Bereaved People (2015) found 81% of people indicate a preference to die at home [5.4, p.14]. In the first two years of the service, an estimated 250 crisis admissions to hospital were avoided [5.1]. The service has also reached *'patients in the community in hard to reach areas'* [5.1].

Commenting on the significance of the service for both those receiving and those delivering it, the Director of Quality and Innovation observes: *"... we have been able to support almost 700 new patients in the 3 years since the service was set up. These are patients that we may not have come into contact with if we hadn't followed your recommendation of looking to provide additional support in the community..."* [5.1].

Patient Support and Experience Away from Home

For patients being cared for in hospices and hospitals, the research enabled a range of service experience improvements. Liverpool Heart and Chest Hospital and Royal Liverpool University Hospital re-allocated private rooms for staff to deliver difficult news to patients and

families in [5.5, 5.6]. ECH provided enhanced technological support, such as phone and internet connectivity, enabling families to keep in touch with their loved ones at all hours [5.3] and extended the availability of bereavement counselling by 250% to support carers/relatives across all services [5.1].

Oakhaven Hospice introduced a bedside companion service with specially trained volunteers stationed in the in-patient unit. Commenting upon the importance of the service, the CEO notes the support for mental wellbeing as a major driver *"They are available to offer conversation or just company if a patient is in need, or low in mood, or if they are socially isolated in some way"* [5.2]. Oakhaven Hospice also re-worked Cardiopulmonary Resuscitation (CPR) information for patients and their families delivering in-house training to support professionals in delivering this patient care [5.7].

Bluebell Wood Children's Hospice (BBWCH), working with 300+ families per annum, in some cases over a number of years, upgraded their facilities enabling terminally ill children to enjoy experiences similar to their peer group eg film nights and revisited their respite care to enable a simple system for accessing short breaks [5.8]. Parent Forum feedback notes *"Parents reported being very happy with the upgraded Family Lounge facilities and equipment (...) it is [now] possible to slot a hoist underneath to transfer a child or young person over to sit next to other family members. This had been an issue with the previous furniture"* [5.9]. They also introduced 'Family Wellbeing Workshops' to reduce social isolation and loneliness with profound effects *"I'm really struggling on my own at the minute (...) I've really learnt some good coping strategies and found the sessions invaluable"* [5.9].

Subsequently, the research team provided written and oral evidence to the All Party Parliamentary Group (APPG) inquiry into improving access to hospice and palliative care. The TTT therefore informed policy-level debate and *'is key in supporting Hospice UK's representation and effectiveness at parliamentary level'* [5.10]. The researchers also presented the TTT at the 2019 Hospice UK conference. The research by the team represented a robust, evidence-based approach that is *'key to maintaining [the sector's] sustainability and success'* [5.10].

5. Sources to corroborate the impact (indicative maximum of 10 references)

5.1 Hospice@Home study (2018-2020) - Corroborating statement from the Director of Quality and Innovation at East Cheshire Hospice (2020), Macclesfield, detailing the introduction of the service as a direct result of the 'Touchpoint Tool' work of Hunter-Jones, Sudbury-Riley and Al-Abdin and the strategic, operational and healthcare improvements which have resulted from the introduction of the new service.

5.2 Oakhaven Hospice study (2016-2019) - Corroborating statement from the Chief Executive of Oakhaven Hospice, Hampshire (2019), detailing the strategic and operational changes which have resulted from the 'Touchpoint Tool' work of Hunter-Jones, Sudbury-Riley and Al-Abdin. These changes are also embedded in Oakhaven's updated 5 year strategy, Fit for the Future. 2019-2024 see mention on pp 3 & 6:
<https://www.oakhavenhospice.co.uk/hospice-reports/>

5.3 East Cheshire Hospice study (2014-2018) - Corroborating statement from the Director of East Cheshire Hospice, Macclesfield (2018), detailing the strategic and operational changes which have resulted from the 'Touchpoint Tool' work of Hunter-Jones, Sudbury-Riley and Al-Abdin including the addition of a new service, Hospice@Home, directly attributable to the earlier 'Touchpoint Tool' study.

5.4 The full reference for the study referred to is: The National Survey of Bereaved People (VOICES) (2015): England 2015.

5.5 Liverpool Heart and Chest NHS Foundation Trust (2018-2020). Board Meeting, January 8th 2019 detailing the findings of the TTT in relation to the need for private space for palliative care patients and their families to receive news, plus Service User Feedback for Liverpool Heart and Chest Action Plan (2020) produced on behalf of the Medical Team.

5.6 The Royal Liverpool and Broadgreen University Hospitals, Liverpool (2015-2020), 'End of Life Care Strategy Group', Minutes of Meeting and Action Notes, October 2018' chaired by the Chief Executive (2018) which include reference to the need for space to be set aside for families receiving difficult news.

5.7 Oakhaven Hospice study (2016-2019) - Corroborating email trail including in-house training to support professionals in improving patient care plus updated Cardiopulmonary Resuscitation (CPR) information for patients and their families.

5.8 Bluebell Wood Children's Hospice study, Sheffield (2018-2020) - Corroborating piece in their 'Newsletter Spring/Summer 2019' detailing the TTT project and the changes introduced in response, see page 18:

https://issuu.com/bluebellwood/docs/february_newsletter_2019_digital

5.9 Bluebell Wood Children's Hospice study, Sheffield (2018-2020) - Parent Forum Minutes corroborating the positive impact on families of facility upgrades made as a direct outcome of the TTT project; Evaluation of the Family Wellbeing Workshops, December 2019, introduced as a direct result of the the 'Touchpoint Tool' work of Hunter-Jones, Sudbury-Riley and Al-Abdin.

5.10 Hospice UK Testimonial Letter (2020) - Head of Research and Clinical Innovation detailing the contribution of the TTT to the work of Hospice UK, the national organisation representing hospices in the UK. Two specific contributions are noted: 1) the contribution of the work to the All Party Parliamentary Group Inquiry into improving access to hospice and palliative care, 2018 and 2) the contribution of the work to Hospice UK annual conference, 2019, with approximately 1,000 delegates in attendance.