

Impact case study (REF3b)

<b>Institution:</b> King's College London
<b>Unit of Assessment:</b> 3. Nursing & Midwifery, and Palliative Care
<b>Title of case study:</b> <b>Significant improvements in respecting and achieving people's preferred place of care and death at the end of their lives</b>
<p><b>1. Short summary of the impact</b></p> <p>King's College London (KCL) research has transformed how people's preferences are respected, supported and achieved at the end of their lives. It has driven policy for end-of-life care in the UK, Europe and Australia, with a cascading impact on clinical practice and training. Our research has helped to reduce institutionalisation at the time of death despite an ageing population. These tremendous economic, sociological and psychological impacts were based on an integrated KCL research programme that identified dying at home as an important and often unmet preference, highlighted barriers that must be overcome, and aids that could help people at the end of life to achieve their preferred place of care and death.</p>
<p><b>2. Underpinning research</b></p> <p><b>KCL researchers analyse the British trends behind where people end their lives:</b> In 1998, Professor Higginson (KCL, 1997-present) led a large KCL investigation of more than 1.3 million cancer deaths in England between 1985-1994 to identify and examine patterns in place of death. Over ten years, the proportion of people who died at home remained fairly stable at ~26%, with some geographical and gender-based variation. For those who did not die at home, the number who died in an NHS hospital or nursing home fell, while the number who died in non-NHS hospitals, nursing homes, hospices and communal establishments increased.[1]</p> <p>Further population-based research found that older people, those living in deprived areas, of a lower socioeconomic status, and from ethnic minorities were less likely to die at home.[2] Patients under the age of 15 were less likely to die at home if they came from a lower social class or lived in an area with a high rate of childhood poverty.[3]</p> <p><b>Original KCL research identifies the gap between preference and reality in place of care and death, and factors affecting place of death:</b> While it was highly advantageous to know where people died, and what influenced the location, we also wanted to investigate where people would like to die when given the choice. In 2000, we showed that most people with advanced cancer would prefer to die at home.[4] Yet despite this preference, in 2004, our study led by Dr. Koffman (KCL, PhD student/researcher/lecturer/senior lecturer 1997-present) found that only half the people who wanted to die at home actually did so.[5]</p> <p><b>Extending KCL-led research to analyse international variation in end-of-life care:</b> In 2006, an international meta-analysis led by Professor Higginson and Dr. Gomes (KCL, MSc student/research assistant/PhD student, 2004-12; research fellow from 2013) analysed which groups were more likely to die at home in over 1.5 million cancer patients across 13 countries. Dying at home was more common among patients who had received intensive home care, lived with relatives, had access to an extended family support network, or had a clearly stated preference to die at home.[6]</p> <p>To get a more complete direct comparison of end-of-life trends, KCL researchers collaborated with the US National Centre for Health Statistics to compare home death rates in London with those in New York for more than 110,000 individuals over 40 years of age. While the overall likelihood of dying at home was similar in both cities, fewer women and those of an older age died at home in London than in New York.[7]</p> <p><b>Our research highlights the healthcare and economic implications of current and future end-of-life trends:</b> In 2008, KCL researchers developed models to predict the impact of place of death decisions on the NHS and other healthcare facilities. Since we already know that the overall number of deaths will increase by almost 20% in the next 20 years, and more people will die at an older age, KCL models predicted that fewer than 1 in 10 people will die at home if current trends continued. This would require a 20% increase in the number of available hospital beds, placing a major burden on existing healthcare infrastructures.[8] The findings of this pioneering set of projections (first in the world) highlighted the need for ongoing efforts to improve the rights of patients at the end of life to die in their place of choice, often in the home</p>

environment.

### 3. References to the research

- 1) **Higginson IJ**, Astin P, Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliat Med* 1998, 12, p353-363. PMID: 9924598. (159 Scopus citations)
- 2) **Higginson IJ**, Jarman B, Astin P, Dolan S. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. *J Public Health Med* 1999, 21, p22-28. PMID: 10321855. (71 Scopus citations)
- 3) **Higginson IJ**, Thompson M. Children and young people who die from cancer: epidemiology and place of death in England (1995-99). *BMJ* 2003, 327(7413), p478-479. PMID: 12946969. (23 Scopus citations)
- 4) **Higginson IJ**, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000, 3(3), p287-300. PMID: 15859670. (300 Scopus citations)
- 5) **Koffman J, Higginson IJ**. Dying to be home? Preferred location of death of first-generation black Caribbean and native-born white patients in the United Kingdom. *J Palliat Med* 2004, 7, p628-636. PMID: 15588353. (17 Scopus citations)
- 6) **Gomes B, Higginson IJ**. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006, 332, p515-521. PMID: 16467346. (283 Scopus citations)
- 7) Decker SL, **Higginson IJ**. A tale of two cities: factors affecting place of cancer death in London and New York. *Eur J Public Health* 2007, 17(3), p285-90. PMID: 17068001. (20 Scopus citations)
- 8) **Gomes B, Higginson IJ**. Where people die (1974-2030): past trends, future projections and implications for care. *Palliat Med* 2008, 22(1), p33-41. PMID: 18216075. (136 Scopus citations)

Since 1996, our KCL research programme into improving the way people's preferences for place of care and death are supported has been awarded over £385,000 in national, international and regional funding. This includes:

- NHS National Research & Development Cancer Programme 2 x 2-year grants (1996-1998) **£80,000**
- South Thames NHS Executive 2-year grant (1997-1999) **£79,792**
- Duke Institute on Care at the End of Life 2-year grant (2001-2002) **£30,581**
- Cicely Saunders International Centre 6-year grant (2002-2008) **£195,000**

### 4. Details of the impact

KCL research showing that most people at the end of life want to be cared for and die at home has influenced healthcare professionals, funding bodies, policy makers and the general public. Such research has promoted the re-orientating of health and social care services to be more sensitive to users' needs, improving the quality of end of life care for people in many countries. This has included the targeting of certain underserved groups in society to improve their access to end-of-life care planning. The adoption by governments of new strategies and programmes, as championed by KCL research, is now enabling more people to die in their preferred place.

#### **Changing awareness and strategy, leading to place of death as a core policy measure:**

Achieving home care and death, if preferred, in advanced illness has become a core part of the Department of Health's (DoH) End of Life Care Strategy. In 2008, KCL researchers were part of a DoH advisory group that produced a report which cites the majority of the above references.[9] Additionally, the National Audit Office used KCL research to highlight the need for home care.[10] As a result, the DoH commissioned the development of the End of Life Care Intelligence Network (ELCIN) to "improve the collection and analysis of information related to the quality, volume and costs of care provided ... to adults approaching the end of life".[11a] Among resources provided is a 2011 ELCIN-commissioned report authored by KCL researchers (and containing the above references) regarding local preferences and place of death in England.

The report concluded that "maximum impact is derived from focusing future investment and service developments in extending and improving care at home and in hospices".[11b] Place of death has become a key measure reported in ELCIN locality and regional profiles. In their

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Mapping Tool, they use the format developed in KCL studies, reporting profiles for local areas.[11c]

### Changing where people die and better meeting their preferences:

Over the past few years the NHS has developed a National End of Life Care Programme to implement the End of Life Care Strategy by “working with health and social care staff, providers, commissioners and third sector organisations across England to improve end of life care for adults”. [12] That adoption of end of life care strategies, as championed by KCL research, is changing where people die, as has been shown in recent KCL analysis of place of death. These found that the trend of a reduction in home deaths is showing a sustained reversal, with increasing numbers of people dying in their place of choice [12a], and a reduction in hospital deaths.[12b] The latter concluded that “the increase in home and hospice deaths suggests that the National End of Life Care Programme has enabled more people to die at their preferred place of death.”

### Shifting the focus of charities, patient-based organisations and funding for care:

As well as government-based health services, several independent organisations and patient-based charities use KCL research on place of care and death.

- The 2012 ‘Independent Palliative Care Funding Review’, an independent report for the Secretary of State for Health, sought to develop a “per-patient funding mechanism (for palliative care)”. This report (which cites Gomes 2008 and Higginson 2009) was based on work commissioned from KCL and its partners. The KCL work was used to project that by 2021 hospital deaths could be reduced by up to 60,000 a year, with a reduction in associated costs, while delivering “optimised provision of services outside the hospital setting”. [13a]
- The King's Fund, an independent charity, cite Gomes 2008 in their 2011 report ‘Issues facing commissioners of end-of-life care’ when discussing how more people dying at an older age in 2030 will “undoubtedly have a significant impact on the level and intensity of provision that is necessary and will require change in the way that services are commissioned”. [13b]
- The National Council for Palliative Care, an umbrella charity, cites KCL research in their reports including ‘Commissioning End of Life Care’, ‘A 2030 Vision’, and ‘Policy Roundup’. [13c]

An independent report [14] into the effect of the KCL work, which involves review of policy documents and interviews with policy experts, shows how the research galvanised action and thinking as exemplified by this quote:

- *“For me one absolute tipping point was in 2011 when I was exposed to the work on preferences compared to actual place of death for particular groups in England. ... It was readable and linked to the strategy (and) ... highlighted the preferences of older people - how they wanted to get into hospice but didn't get into hospice. I was struck by the disparity between my beliefs and this data.” (6(p14, RP6)*
- The review concludes: *“The early Cicely Saunders Institute [KCL] research was one key source of evidence that enabled key figures to embark on public debate and discussion of death and dying in a new way. ... There is no doubt that the work of the Institute was often dominant in the use of evidence over preferences and that this often drove the public debate.”*

### International reach:

KCL research and experts have also been used by international bodies for help in their work. Achieving place of care and death is recommended in the World Health Organisation's 2011 publication ‘Palliative care for older people: Better practices’ aimed at European policy makers. Professor Higginson was selected as Senior Editor on this report and it contains the majority of the KCL references detailed above when discussing this recommendation.[15a] In Portugal, the Calouste Gulbenkian Foundation (a major international charity) is developing a programme of home care support at the end of life in response to KCL work and evidence on people's preferences. In 2011 the Foundation established a formal partnership with the Portuguese Ministry of Health to fund four pilot projects delivering home palliative care.[15b] In Australia, Care Search, a palliative care knowledge network, cites Gomes 2008, when listing “inadequate

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family support and/or community-based palliative care services” as a “limiting factor for patients who wish to die at home”. [15c]

#### **Public reach and Government reach:**

Findings from KCL research received extensive press coverage, most recently of the reversal of trends in place of death, e.g. The Huffington Post [16a] and the Daily Mirror [16b], among others. Recently (8/11/12), the House of Lords debated ‘NHS: Death at Home’ and KCL research was highlighted by both Lord Low of Dalston and Baroness Finlay of Llandaff, to show evidence of the persisting gap between preferences and reality for place of death, and the socially and culturally patterned disparities. [17]

#### **5. Sources to corroborate the contribution, impact or benefit**

##### **9) DoH 2008. End of Life Care Strategy:**

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_086345.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf) and [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_086273.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086273.pdf);

##### **10) 2008 Report from the National Audit Office on end of life care:**

[http://www.nao.org.uk/publications/0708/end\\_of\\_life\\_care.aspx](http://www.nao.org.uk/publications/0708/end_of_life_care.aspx)

##### **11) National End of Life Care Intelligence Network.**

a. Website: <http://www.endoflifecare-intelligence.org.uk/home.aspx>

b. Report: Gomes B, Calanzani N, Higginson IJ. Local preferences and place of death in regions within England 2010. August 2011. [http://www.endoflifecare-intelligence.org.uk/resources/publications/lp\\_and\\_place\\_of\\_death.aspx](http://www.endoflifecare-intelligence.org.uk/resources/publications/lp_and_place_of_death.aspx)

c. End of Life Care Profile Instant Atlas mapping tool: [http://www.endoflifecare-intelligence.org.uk/profiles/la\\_2012/atlas.html](http://www.endoflifecare-intelligence.org.uk/profiles/la_2012/atlas.html)

##### **12) NHS National End of Life Care Programme:** <http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/reversal-of-the-british-trends-in-place-of-death-time-series-analysis-2004-2010.aspx>

a. Gomes B, et al. Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliat Med* 2012;26(2):102-7. Doi: 10.1177/0269216311432329.

b. Gao W, et al. Changing patterns in place of cancer death in England: a population-based study. *PLoS Med*. 2013;10(3):e1001410. Doi: 10.1371/journal.pmed.1001410

##### **13) Independent organisations utilising KCL research**

a. Independent Palliative Care Funding Review. Funding the Right Care and Support for Everyone. 2012:

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_133105.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_133105.pdf)

b. King’s Fund. Issues facing commissioners of end-of-life care. Addicott R, Hiley J. 2011.

[http://www.kingsfund.org.uk/publications/endoflife\\_care.html](http://www.kingsfund.org.uk/publications/endoflife_care.html)

c. National Council for Palliative Care: <http://www.ncpc.org.uk/older-people>

##### **14) Dewar, S. Identifying and achieving preferences for place of care and place of death at the end of life:** [http://www.csi.kcl.ac.uk/files/CSI%20Impact%20Report%20SD010713\\_List.pdf](http://www.csi.kcl.ac.uk/files/CSI%20Impact%20Report%20SD010713_List.pdf)

##### **15) International use of KCL research**

a. World Health Organisation guidance on palliative care. 2011:

[http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0017/143153/e95052.pdf](http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf) (Chapter 3)

b. Portuguese home palliative care press release. 2011: <http://www.theportugalnews.com/cgi-bin/article.pl?id=1108-14>

c. Australian-based CareSearch: Palliative care knowledge network:

<http://www.caresearch.com.au/caresearch/tabid/743/Default.aspx>

##### **16) Press coverage Jan 2012**

a. The Huffington Post: Dying At Home: People With Terminal Illness Moving Away From ‘Institutionalised Death’: [http://www.huffingtonpost.co.uk/2012/01/18/dying-at-home-terminal-illness\\_n\\_1213349.html](http://www.huffingtonpost.co.uk/2012/01/18/dying-at-home-terminal-illness_n_1213349.html)

b. Daily Mirror: Number of people dying at home is rising. Jan 2012:

<http://www.mirror.co.uk/news/technology-science/number-of-people-dying-at-home-is-rising-159558>

##### **17) House of Lords debate on NHS: Death at Home. 2012:** <http://tinyurl.com/p8gzn28> (pgs 1192, 1196-1198)