Institution: King's College London		
Unit of Assessment: 3		
Title of case study: Transforming access to palliative care for underserved groups		
Period when the underpinning research was undertaken: 2000-2019		
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:**
Richard Harding	Professor, Palliative Care and Rehabilitation	2001-present
Irene Higginson	Professor, Director of Cicely Saunders Institute	1996-present
Katherine Sleeman	Professor in Palliative Care	2010-present
Jonathan Koffman	Reader in Palliative Care	1996-present
Catherine Evans	Reader in Palliative Care	2010-present
Clare Ellis-Smith	Lecturer in Palliative Care	2017-present
Period when the claimed impact occurred: 1 August 2013-2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

The WHO estimates that only 10% of those who need palliative care globally actually receive it. King's College London research has underpinned a global shift in how palliative care is considered, defined and delivered. The research has transformed access to person-centred palliative care beyond its origins for advanced cancer in high income countries through (i) identification of underserved groups and inequalities; (ii) development of tools to measure and manage patients' symptoms and concerns; (iii) development and testing of complex interventions to reconfigure care delivery. The research has helped realign regional, national and international policies to improve access to palliative care; improved access to care for ethnically diverse groups in the UK; transformed delivery of quality palliative care in Africa; reoriented Standards of Care for people living with HIV to include person-centred and palliative care; improved identification of symptoms and concerns for people with dementia. Much of this impact has been underpinned by the development of the Palliative Outcome Scale (POS) family of measures: Since the early impact described in our 2014 Impact Case Study, this work has broadened and increased its reach through implementation across diverse diseases, global regions and underserved groups.

2. Underpinning research

The World Health Organisation (WHO) identifies palliative care as an essential health service under Universal Health Coverage. For patients and families facing serious illness, palliative care improves outcomes such as distressing symptoms, and delivers care concordant with preferences such as enabling people to die at home. For health systems, palliative care is a high-value low-cost intervention. Historically palliative care was mainly available for people with cancer and those in high-income countries. King's research has transformed access to palliative care for patients, families and health systems regardless of diagnosis or geographical location, in three steps:

1. Identification of underserved groups and inequities at a population level. Having identified a knowledge gap about palliative care for conditions other than cancer, King's research revealed a high symptom burden for people living and dying with diverse conditions, including dementia, HIV and neurological conditions, and showed that global palliative care needs will escalate over the next decades, especially in low- and middle-income countries **(1)**. We found that people living with HIV nationally and internationally commonly experience high symptom burden and poor clinical outcomes, especially anxiety and pain. We identified the information and communication preferences of people living with HIV in the UK and Africa, and the lack of coverage of palliative care services **(2)**. This led to research on palliative care needs for people with TB **(3)**. For people with long-term neurological conditions (such as motor neurone disease, multiple sclerosis (MS) and Parkinson's disease) King's research identified the palliative care needs of patients and families. We found that multiple, burdensome symptoms are highly prevalent in these groups, that patients and families experience multiple losses, and that care is poorly coordinated. King's research identified widespread and consistent disparities in relation to the receipt of end of life care among Black, Asian and ethnically diverse (BAED) groups, impacting on patient experience and outcomes such as fulfilling preferences for place of care and death **(4)**.

2. Measuring and managing symptom burden and concerns across physical, psychosocial and spiritual domains. This research was underpinned by development and implementation of the King's-led Palliative Outcome Scale (POS) series of measures. The original validated POS, (included in REF2014) was a 10-item measure of physical, emotional, social and spiritual concerns affecting patients living and dying with serious illness and their families. We validated a self-report version for patients with limited literacy in sub-Saharan Africa, and an observational version for staff to use when patients are too ill to self-report. Since 2013, the POS has been culturally adapted and validated in different languages and underserved disease groups (e.g. HIV, renal disease, myeloma, heart failure, dementia, multiple sclerosis, and drug-susceptible and resistant TB). In 2017, the Integrated Palliative Outcome Scale (IPOS) brought together the best features from earlier versions **(5)**.

3. Developing and testing complex interventions to reconfigure care delivery and improve outcomes. POS formed the basis for several complex interventions to improve care and patient wellbeing. King's developed and tested, in a randomised controlled trial, a novel approach to integrate palliative care for people living with HIV in Africa which improved patient-reported outcomes **(6)**. Our further randomised controlled trial found integration of palliative care into neurology to be cost effective (the first cost effectiveness trial in palliative care) **(7)**. For people with dementia, our research found integration of IPOS for Dementia (IPOS-Dem) in routine clinical care improved detection of symptoms and concerns, facilitated communication of care between care staff, family and health professionals, and supported care planning **(8)**.

3. References to the research

1. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, Gomes B, Harding R. (2019). *The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions*. Lancet Glob Health. 7(7):e883-e892. doi: 10.1016/S2214-109X(19)30172-X
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7. Higginson IJ, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. Higginson et al. (2009). *Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial.* JPSM 38(6):816-26. doi: 10.1016/j.jpainsymman.2009.07.002
8. Ellis-Smith C, Higginson IJ, Daveson BA, Henson LA, Evans CJ (2018). *How can a measure improve assessment and management of symptoms and concerns for people with dementia in care homes? A mixed methods feasibility and process evaluation of IPOS-Dem.* PLOS One 11;13(7):e0200240. doi: 10.1371/journal.pone.0200240

4. Details of the impact

King's research has been a major contributor to a global shift in how palliative care is considered, defined and delivered. Our academics were part of a Global Consensus Statement (2019) that redefined palliative care using our research on global projections of palliative care need, ensuring it is provided according to individual needs, with reducing suffering as the main goal of care, across high- middle- and low-income countries **[A]**. Our research on global projections and palliative care for people living with HIV in low- and middle-income countries informed the 2020 World Health Organisation (WHO) Global Atlas of Palliative Care which drives the global effort to improve and monitor access **[A2]**. All United Nations member states are, since 2012, required to provide palliative care under the WHO's Universal Health Coverage goals; King's research has delivered tools and interventions to help implementation and drive change.

King's research helped transform regional, national, and international policies to improve access to palliative care.
1. Regional policy impact – end of life care as a priority for London. King's research played a key role in the decision to include End of Life Care as one of ten priority areas in the 2019 Our Vision for London, a pan-London partnership bringing together the Greater London Authority, Public Health England (PHE), London Councils and the National Health Service (NHS) in London **[B1]**. The Vision seeks to improve health and care outcomes for the 8,900,000 people living across London. It includes a commitment that all Londoners in their last year of life have access to personalised care planning and support that enables them to die in their preferred place. The Clinical Director for End of Life Care, NHSE/I (London region) said: *"I am certain that Dr Koffman and the [King's] CSI team's research evidence played a key role in engaging the London Assembly and ultimately the decision to include End of Life Care as a priority area"* **[B2, B3]**.

2. National policy impact – inclusion of King's research in NICE guidelines. King's RCT of palliative care for people with MS was the first cost-effectiveness trial of a palliative care service in the world, and found palliative care to be cost effective. This evidence was used in NICE guidelines (NG27, 2015) to recommend that inpatient hospital settings should establish multi-disciplinary palliative care teams, in addition to ensuring that people needing end-of-life care are offered both general and specialist palliative care services, according to their needs **[C1,2]**. It also informed NICE guidelines (NG94, 2018), recommending the option of specialist multidisciplinary community-based palliative care for patients in the terminal phase of illness **[C3,4]**. Finally, King's data underpinned PHE's 2017 tool for cost-effective palliative care commissioning **[C5,6]**.

3. International policy impact – inclusion of King's research by World Health Organisation. King's research on palliative care for people with multi-drug resistant tuberculosis was used by the WHO to make recommendations on access to palliative and end of life care for all patients with multidrug resistant TB in their End TB Strategy (2014). This was the first time the strategy promoted access to palliative and end of life care for all patients with multidrug resistant (MDR) TB **[D1]**. King's research informed the associated toolkit **[D2]** and ethics guidance **[D3]** to assist programme managers, policymakers and healthcare staff ensure management of multidrug resistance is based on patient need rather than prognosis. It also informed the companion handbook **[D4]** for public health decision-makers, programme managers and clinical staff. Additionally, the WHO technical report 'Selection and Use of Essential Medicines' (2014) used King's research to highlight that palliative care medicines are needed in conditions other than cancer, namely MDR TB and HIV/AIDS **[D5]**. This report informs the WHO Model List of Essential Medicines, used by at least 154 countries to guide national and institutional lists of essential medications, and the procurement and supply of medicines in the public sector.

King's research has improved how hospices in the voluntary sector provide palliative care to people from ethnically diverse communities across the UK. Our work on inequality of access to palliative care by ethnically diverse groups led Marie Curie, a major end of life care charity, to commission King's researchers to write a report on palliative and end of life care for Black, Asian and ethnically diverse (BAED) groups in the UK **[E1]**. Following its publication (2013), Marie Curie has used the report to launch activities focused on broadening access to palliative and hospice care, and increasing the involvement of service users from BAED communities. This has led to: improved recording of data on ethnicity in clinical services (from 40-60% to 95%); introduced service user feedback to drive service improvements, focusing on access, quality of care and outcomes; better assessment and meeting the communication needs of all service users through the Accessible Communication Policy and regular accessible information audits **[E2,E3]**; led to a new three-year Lottery funded project to develop an evidence base to improve access to services for people from BAED backgrounds **[E4]**; development of a staff learning resource to ensure staff can deliver the highest quality care to terminally ill people and their families and carers from BAED communities. The CEO of Marie Curie said: *"The report has been highly influential, both to our internal discussions and our strategic planning for this as a priority area. The report provided robust evidence for problems we were aware of but unable to quantify and identified issues that had not been previously considered by us. These activities have had a direct impact on the quality of services that we offer to patients and families."* **[E5]**.

King's research has improved palliative care for people living in Africa. Our work to develop, validate and implement the African POS (APOS) was carried out with African partners, drawing on POS with an additional focus on spiritual wellbeing and self-report for people with low literacy. APOS has impacted health care staff and services (enabling them to holistically assess and identify priorities for patients), and patients/caregivers (enabling them to communicate and get help for burdensome symptoms and concerns). APOS is used by services across Africa: a survey in 2020 by the African Palliative Care Association (APCA, a pan-African non-governmental organisation) found 44 services in 9 African countries used APOS, all of whom reported a positive impact on care **[F]**. Use of APOS benefits patients by making the care processes more efficient and effective, by focusing on measurable outcomes. Staff from Makarere/Mulago Palliative Care Unit Uganda said: *"It enabled staff to prioritise and treat the most distressing symptoms and to give the most appropriate interventions"*. Survey respondents described how this happened. APOS helps open communication between health professionals and patients/carers, enabling the latter to *'clearly articulate what their problems are'*. Its use *'brings families on board'* so that they feel *'like part of the care giving team by being involved in every step of care planning'*. Use of APOS has helped staff improve services; one African provider said *"Using a research tool has shown us that we are making a difference in outcomes for patients. (It has) given us reason to continue to improve our service and recognize symptoms we are not doing well on"* **[F]**.

King's research has strengthened palliative and person-centred care for people living with HIV in the UK. For people living with HIV, palliative care needs were previously poorly identified and managed. Since 2007, the British HIV Association (BHIVA) has led on production of the UK's National Standards of Care for People Living with HIV (PLWH). The Standards, which are NICE-approved national guidelines, are critically important to everyone living with HIV in the UK, ensuring joined-up care. In 2018, as a result of King's research, for the first time the updated Standards of Care included both person-centred and palliative care **[G1]**. To ensure meaningful person-centred care, King's research co-developed and tested with patient groups a person-centred outcome measure (POSitive outcomes), which is now included in the Standards of Care as a measurable and auditable outcome, with a target that 90% patients complete it. The Standards of Care also include IPOS to identify palliative care needs among people living with HIV. A patient advocate who works with i-Base and UKCAB (NGOs that advocate for and support people living with HIV) said: *"The research…identified the things that affect the wellbeing of people living with HIV such as pain and other symptoms, and concerns such as housing, poverty, and stigma….This will help bring changes to clinical practice that can benefit all PLWH regardless of ethnicity, gender, sexuality, class, or age"* **[G2]**.

King's work also led to the inclusion, since 2015, of palliative care in the national audit of HIV deaths run by PHE. While initially focused on the 38,600 people living with HIV in London, since November 2019 this has expanded to a National audit to receive data on the 97,650 people living with HIV in the UK. The co-lead for HIV surveillance at PHE said: *"This has enabled us to … better care for those approaching death"* **[G3]**.

King's research has improved the assessment of symptoms and needs in people with dementia. IPOS-Dem was developed by King's from IPOS to incorporate the common symptoms and concerns of older people with multi-morbidities and dementia. IPOS-Dem was developed to be completed by care staff without formal clinical training using acessible language. It underwent cognitive testing to ensure that it is quick to complete, acceptable to care staff, and easy to understand and use. IPOS-Dem addresses an important gap in the comprehensive assessment of symptoms and concerns important to people living with dementia. IPOS-Dem empowers clinical staff to meet the palliative care needs of people with dementia, and monitor response to management strategies. An audit of 11 UK services where IPOS-Dem is used found IPOS-Dem facilitated patient-centred care by increasing awareness of previously unknown problems, and through involving patients and families. It demonstrated the feasibility and benefit of using outcome measures in routine care to support assessment and management **[H1]**. The Dementia Lead Nurse at Trinity Hospice *"Using IPOS-Dem enables an easier and more structured identification of symptoms and problems among people with dementia"* **[H2]**. Since its publication in 2017, teams in Switzerland, Germany, the Netherlands, Taiwan, Japan and Sweden are translating and validating its use in routine care across care settings e.g. care homes, hospitals **[H]**.

Ongoing development of the POS family of measures has had a global reach and impact. Since the REF2014 case study that described the development of POS and its early impact, this work has broadened and increased its reach across diverse disease groups and global regions. An important mechanism to ensure the global impact of POS has been the POS website (www.pos-pal.org), which provides free downloadable versions of the POS, guidance on its use and links to related publications. The website has 14,871 registered users (increased from 1,274 in 2014 REF case study), from 150 countries (increased from 74 in 2014) **[I1]**. In the UK, IPOS is recommended as part of the Palliative Care Clinical Dataset **[I2]**. The renal version of POS (POS-S-Renal) was used to develop a national programme supported by NHS England and the UK Renal Registry to empower patients to take greater control of their health and wellbeing **[I3,4]**. IPOS and IPOS-Dem are incorporated into standards of care internationally **[I5,6]**.

Rapid identification of symptom control needs and management of people with COVID-19. Early in the COVID-19 pandemic it became clear that while palliative care was essential to the Covid response, it was missing from national and international guidelines. Our rapid research provided the first evidence of palliative care needs and response to treatment among people dying with COVID-19, as well as recommendations for the response of palliative care and hospice services to the pandemic. We led a collaboration with the European Lung Foundation to produce factsheets for patients admitted to hospital with COVID-19, and their families **[J1,2]**. These have been translated into 27 languages and downloaded >13,000 times in English and >1,000 times in other languages by patients, family members and hospitals across the NHS and globally. Feedback from patients shows that this resource has improved communication with medical teams, allaying anxiety for patients and families. Health professionals have reflected they have been an invaluable resource to meet information needs in a rapidly changing and stressful situation: *"Having something to give to patients in their language has been so helpful. They can then take their time reading this and come back to us if they have any questions"* **[J3]**.

5. Sources to corroborate the impact

[A] Evidence on global shift in palliative care: WHO consensus statement, Global Atlas policy
[B] Evidence bundle on regional policy impact: London strategic vision, Health Committee report and testimonial from End of Life Care Clinical Director, NHS England / Improvement.
[C] Evidence on national policy impact: NICE guidelines; PHE economic analysis tool, user guide
[D] Evidence on international policy impact: WHO strategy and two implementation guides, companion handbook and technical report on the selection of essential medicines.
[E] Evidence on improving how hospices in the voluntary sector provide palliative care to people from ethnic minorities across the UK: Marie Curie reports, policy, and CEO testimonial.
[F] Independent Report on impact by Olivia Dix.
[G] Evidence on strengthening care for people living with HIV in the UK: BHIVA Standards of Care guideline, patient advocate testimonial, and testimonial from co-lead for HIV Surveillance, PHE.
[H] Evidence on improving assessment in people with dementia: Collaborative audit report, testimonial from Palliative Care and Dementia Nurse Specialist, four translations of IPOS-Dem.
[I] Evidence on the POS measures, global reach and impact: POS download statistics, PHE clinical dataset, UK Renal Registry summary & Think Kidneys report, New York Care Collaborative Standards of Care, New York State Department of Health reporting manual.
[J] Evidence on rapid identification of symptom control needs and management of people with COVID-19: European Lung Foundation factsheets, translated factsheets, report on factsheet use.