Impact template (REF 3a)

Institution: King's College London (KCL)

Unit of assessment: 3. Nursing & Midwifery, and Palliative Care

a. Context and beneficiaries:

Importance in society: Nursing & Midwifery and Palliative Care research tackles concerns that affect everyone in society. Nurses and midwives fulfil a core societal need, and are pivotal in providing health and social care, across the lifespan from health promotion to caring for patients and their families whenever they are affected by disease, disability or the frailty of older age. In palliative care, the focus is on chronic and progressive diseases, complex disabilities, death and dying. There are 53 million deaths per year worldwide; 75% of these have a period of progressive illness and/or disability as their disease becomes incurable. In these phases, palliative care and rehabilitation are needed to enable people to live as well as possible, and to support them and all those who care for them, including in bereavement.

Our multi-professional research, education, public information, support and clinical care strives to identify and raise the profile of patient and family needs, and develop evidence-based solutions to enduring health problems and in the critical phases of life and death. We lead applied health and social care research where findings are critical and directly relevant to policy, clinical practice, patients and families. We produce and advocate for high-quality research to achieve evidence-based impact. We publish major protocols in advance and results in peer-reviewed, high-impact journals. This maintains our attractiveness as collaborators, and the thoroughness and relevance of our research along with our emphasis on person-centred care strengthens our partnerships with patients, families and their carers. As a result the reputation of our research ensures reach and impact with wide ranging beneficiaries.

Our non-academic user groups, collaborators, beneficiaries and audiences include - National and global reach:

- **Health service providers**, clinicians, service managers and directors in hospitals, hospices and community services, both in the National Health Service (NHS) and the voluntary sector.
- **Policy makers** in the UK Department of Health (DoH), NHS England, Public Health England, Monitor, Scottish and Welsh Health and Social Services, the National Institute for Health and Clinical Excellence (NICE) and governments overseas.
- **Inter-governmental organisations** such as the World Health Organisation (WHO) and the European Commission.
- **National/international professional associations** including the UK Royal Colleges (across professions and specialty), European Association for Palliative Care (EAPC), Association for Palliative Medicine (APM), British Society of Rehabilitation Medicine (BSRM).
- **Non-governmental organisations and major charities:** Macmillan Cancer Support, Help the Hospices, National Council for Palliative Care (NCPC), African Palliative Care Association (APCA),The Worldwide Palliative Care Alliance, Bill and Melinda Gates Foundation, The Health Foundation, The King's Fund, Genetic Alliance UK, Cancer Research UK, Diabetes UK,USAID.
- **Individual and umbrella service-user organisations that influence policy** such as the European Cancer Patient Coalition, the National Childbirth Trust and the Neurological Alliance.
- **Industry**, partners in engineering and the fashion industry in developing wound care products.

Policy impact: Our work has impacted NHS frameworks and guidance across the lifespan and at critical junction points, for example:

- **Maternity care**: Bick et al (2002; 2008) demonstrated the issues arising from postnatal morbidity, which informed multiple guidelines: NICE guidelines: routine postnatal care (2006); intra-partum care, antenatal and postnatal mental health (2007); C Section (2011); Maternity Matters (DoH 2007); National Service Framework (2004); Children and Young People's Health Outcomes Framework (2012).
- **UK End of Life Care Strategy** (2008) (population predictions); the Independent Palliative Care Funding Review for England (2011), Australian National Palliative Strategy (2010, Supporting Australians to Live Well at the End of Life).
- **Getting it Right: End of Life Care in Advanced Kidney Disease** (2012): Our seminal study in renal disease – a model for the care needs of multiple morbidity among older people - (*Murtagh*, NDT, 2007:22; 1955-62, 0.23%ile in subject area) shows dialysis does not significantly increase survival for older patients with co-morbidity It led to recognition of

conservative (non-dialytic) kidney management as an alternative care pathway (NHS Kidney Care's End of Life Care in Advanced Kidney Disease: A Framework for Implementation, 2009).

- In recognition of its influence and impact, since 2009, the Cicely Saunders Institute (CSI) has been recognised as a WHO Collaborating Centre – we produce policy guidance with influence across nations and regions; in 2013 this was renewed and extended to more of our activities.

Health and welfare impact: Our work has improved care for patients and families by transforming services, e.g:

- **Clinical tools** to aid robust assessment and outcome evaluation in routine clinical practice and to support service development. These have fed directly into national and international policies.
- For example, **our rehabilitation research** (*Turner-Stokes*) directly led to the development of **a novel costing method, an evaluation system and a set of tools** to measure needs, inputs and outcomes for specialist rehabilitation services in the UK. These tools are incorporated into the national commissioning dataset for specialist rehabilitation services across England, in the UK Rehabilitation Outcomes Collaborative (UKROC) database. The data are used by NHS England and Monitor, to develop tariffs under Payment by Results (PbR) and to underpin commissioning rehabilitation services (http://tinyurl.com/o6c3x8f; http://tinyurl.com/nj8q47d). The approach has helped shape case-mix complexity costings in palliative care.
- **In diabetes care**, our cohort studies have shown the co-morbidity symptoms that result from type 2 diabetes, including cognitive impairment. This resulted in the introduction, in South London, of self-care support for cognitive impairment and diabetes and glycaemic management.

Societal impact: Often the most vulnerable in society miss out on health and social care. Our work has raised their profile, tested solutions and improved access to care in the UK, Europe, Australia, Asia and Africa. In addition to our impact case studies we can provide further examples:

- International surveys of >50,000 nurses across 12 countries demonstrated the relationship between nurse numbers and co-morbidity and mortality in acute settings, and informed the Francis report and the Berwick report (2013) on quality care and patients' safety.
- Older people and those with non-cancer conditions have better access to specialist palliative care. Our work raised the profile of the needs of older people and non-cancer patients leading to policy improvements and attitude changes amongst service-providers. Palliative care service profiles (the NCPC's 'National Survey of Patient Activity Data for Specialist Palliative Care Services', 2011-12) now report 16 - 24% non-cancer patients, when in 2008 it was < 12%.
- The Social Care Workforce Research Unit's research has informed policies in safeguarding children and vulnerable adults, including protection of older people from abuse and harm.
- In many chronic illnesses and complex disabilities, our research has found new ways to improve the experiences and care for people affected by cancer, HIV/AIDS, organ failure, diabetes, gastro-intestinal disease, mental distress and illness, severe brain injury and genetic diseases.

b. Approach to impact: We have developed strategic approaches of wide multi-sector partnership, innovation in research methods, active anticipation of Nursing & Midwifery and Palliative Care needs, and emphasis on both significance and reach. Over this REF period we improved our approaches, based on analysis of our impact and experiences. We achieve reach and significance by combining the following approaches according to context (see figure, page 4):

b.1) Active Patient and Public Engagement (PPE): We have embedded PPE into all our research projects and programmes. This is fundamental within all grant developments:

- We involve patients and public as co-applicants, co-designers of the research, they are the co-creators of interventions and dissemination of the research to aid impact.
- Building on experiences in leading the National Cancer Research Institute (NCRI) Collaborative COMPASS we transformed our partnerships with service users. From 2009-11 COMPASS consumers ran master classes to train staff in patient engagement (http://tinyurl.com/nb2q26z).
- Patients and families were central to planning and designing the Cicely Saunders Institute.
- Service users attend our conferences, discuss research results and co-chair seminars.
- We adapt our PPE to individual patients/families' needs, who can be very ill or disabled.

b.2) Co-design:

- We spearheaded the **reconfiguration of healthcare services based on experience based co-design (EBCD)** (developed originally by *Robert*). This has patients and health professionals working together to redesign service provision. EBCD has been used and evaluated in at least

57 clinical services in eight countries, including the UK, Australasia, North America and Europe. An evaluation of EBCD use (2013) shows over 90% of respondents thought EBCD engaged patients and 78% thought it also engaged staff participation. *Robert* co-developed the NHS and King's Fund EBCD toolkit. This is now a model for other co-design initiatives. The evaluation showed 24 further projects are planned.

- Co-working with industry led to innovative interventions developed for wound care, which resulted in patented products.

b.3) Fostering clinical/academic talent: We have won support for new combined clinical/ academic posts from HEFCE, NIHR and charities. These, and our clinical academic groups in our academic health science centre, the King's Health Partners (KHP), have fostered joint working and increased impact in practice.

b.4) Integration and engagement: Clinicians, policy makers, industry and other non-academic beneficiaries are integral to implementation of our research evidence, locally via KHP and nationally**.** We:

- **Work in an integrated way** with policy makers, clinicians and others from project planning to dissemination. For example, this has led the DoH to use our Rehabilitation Complexity Scale (RCS) to identify complex patients requiring specialist rehabilitation services.
- **Hold consensus-building policy maker/expert events** in many projects to support integration between health and social policy. E.g. an **international conference in the European Parliament** on measures in palliative care (2011); **'Making Research Count' -** a network of universities, local council policy-makers, health and social care services, patients and families set up by our Social Care Workforce Research Unit.

b.5) Resource provision: We provide user-friendly, free, targeted resources appropriate for the audience, culture and language, to aid access (reach) and validity (impact). Our research has identified that clinicians, the public, patients and families from many different contexts need free access to resources. Examples include:

- Information packages on genetic risk communication and genetic testing for families, clinical units, and charities nationally and internationally, which informed EU guidelines on genetic testing of children.
- Our measurement tools are freely downloadable from http://www.csi.kcl.ac.uk/tools.html; the Palliative care Outcome Scale (POS) is freely available at http://pos-pal.org/ in 11 languages.
- We complement virtual dissemination with documents in hard copy. WHO Solid Facts series (now translated into Russian, Italian and Spanish) is described by WHO as one of the most popular resources they have ever produced.

b.6) Engage with social and traditional media as appropriate to increase the awareness and reach of our research:

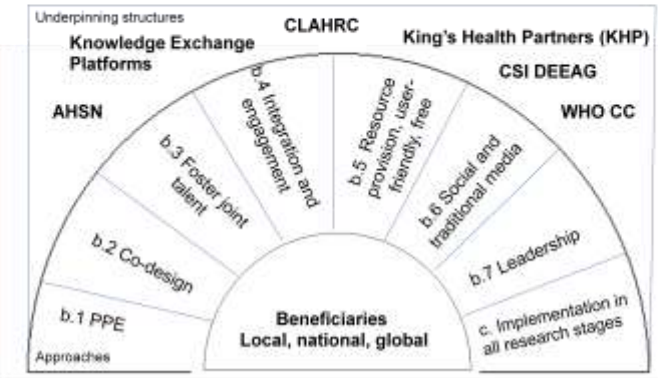
- Social blogs, media platforms, radio and television, Twitter (@CSI_KCL; @scwru; @nursingpolicy) and Facebook (facebook.com/CicelySaundersInstitute facebook.com/KCL/nursing) launched summer 2012 (to share latest updates, alert to news, engage in public discussions).
- Based on this we launched a **YouTube channel** (www.youtube.com/user/CSIKCL) where we upload presentations, discussions and short videos about our work.

b.7) Leadership: All our PIs are board members of, and/or chair, international advisory groups, taskforces, national bodies and professional associations including: WHO; EAPC taskforce; APCA; UK Prime Minister's Commission on Nursing; Prime Minister's Task Force on Nursing; DoH (England) committees; NICE; King's Fund; National Service Frameworks for Long Term Conditions; Children, Adolescents and Maternity; PbR Expert Reference Panel for Rehabilitation; steering group for the Palliative Care Funding Pilots; NHSE's Clinical Reference Group for specialist rehabilitation; End of Life Care Intelligence Network; APM; BSRM.

c) Strategy and plans:

Our strategy for 2013-18 combines the learning from the successes and challenges of our approaches to date and integrates these into new structures to increase the reach and significance of our impact with greater efficiency for our beneficiaries (see figure, page 4):

- Nursing & Midwifery and Palliative Care are partners and theme leads within the new NIHR South London Collaboration for Leadership in Applied Health Research and Care (CLAHRC). The CLAHRC along with the King's Centre for Implementation Science, has dedicated clinical implementation teams and health systems collaboratives that drive research and service change to deliver patient, family, and health care benefit.



Strategy to enhance reach and significance of impact in FNSNM and CSI

- The CLAHRC brings together health, social and voluntary sector services in our relevant themes with Clinical Commissioning Groups and research.
- The new NIHR South London Academic Health Science Network (AHSN), awarded 2013, will aid our local impact, by translating the research into education and service improvement.
- The CSI has recently established a Dissemination, Engagement, Empowerment and Advisory Group (DEEAG), which includes the Chief Executive of the NCPC, the Programme Director of National End-of-Life Care Programme, and the Director of Communications from the Dying Matters Coalition (with 25,000 supporters), lay members, patients, clinicians and students to help steer the ways to improve impact.
- We participate in international, national and local networks and with local clinicians, building on early successes, integrated into the above structure, such as the Knowledge Exchange Forum in palliative care. In nursing & midwifery we have instituted two translation fellows and communities of practice set up in clinical areas interfacing primary and secondary care. We also have a Health Foundation research translation fellowship (2014-16) in maternity care.

In addition we add a **further approach** which we will use increasingly in combination with others:

- Integrate implementation assessment into all research stages and where necessary request funding for this in research grant applications, e.g. examining workforce capacity and training implications of interventions, integrated dissemination and implementation plans. This builds on the findings from our Medical Research Council supported study MORECare.

d. Relationship to the case studies.

We have selected five impact case studies to illustrate the breadth of our research and to highlight our different audiences and combination of approaches to impact (see **b,c**). These range from new approaches directly for improving clinical care (*wound products, outcome measures*), improved delivery of services (*health visiting*, *preferred place of care and death*) and improved access (*to maternal care in developing countries*). The experience gained from these Case Studies has helped inform our future Impact Strategy, outlined in section **c**.

Research Impact	**A)Beneficiaries & Audiences, B)Impact Types**	**Impact approaches used in combination (sub-headings from section b)**
Innovative wound care products	A) Patients, families, carers, clinicians and industry B) Health and welfare, economic and commercial	PPE, co-design, integration, media, leadership
Improved palliative care: Palliative care Outcome Scale	A) Patients, families, carers, clinicians B) Health and welfare, policy, service development, workforce expansion	PPE, co-design, integration, resource provision, media, leadership
Enhanced provision of health visiting services	A) Policy makers, patients, families, primary care and health visiting B) Health and welfare, policy, service development, workforce expansion	PPE, co-design, integration, media, leadership
Achieving people's preferred place of care and death	A) Policy makers, patients, families, primary care and clinical services B) Health, welfare, practitioner, service development, society, economic	PPE, fostering talent, integration, resource provision, media, leadership
Improved access to maternal care in developing countries	A) Health team workers, their patients and government policy makers B) Health and welfare, clinical provision, socio-economic	PPE, co-design, fostering talent, integration, resource provision, leadership