Institution:	**King's College London**
Unit of Assessment:	**2. Public Health, Health Services and Primary Care**
Title of case study:	***King's South London Stroke Register: Informing Innovation in Stroke Care***

1. Summary of the impact

The King's South London Stroke Register is the world's longest running, population-based stroke research register, assessing the incidence of stroke; the acute and long-term needs of stroke patients; and quality of stroke care. The South London Stroke Register provided data and analyses that informed the Parliamentary Public Accounts Committee report on stroke, the National Strategy for Stroke, and contributed to two National Audit Office reports on acute and longer-term stroke care. The latter contributed to a major service reconfiguration in London, which has led to lower mortality and more efficient use of health care resources for stroke. The King's South London Stroke Register provides a platform for designing and evaluating new models of stroke care, including the largest trial of Early Supported Discharge, a cost-effective intervention which is now provided in 66% of hospitals in England, as well as being rolled out internationally.

2. Underpinning research

The South London Stroke Register at King's collects data for stroke incidence and stroke outcomes (including mortality, morbidity and quality of life) in a well-defined multi-ethnic population. The South London Stroke Register is led by Professor Charles Wolfe (King's, 1988 to present), Professor Anthony Rudd (King's, 1990 to present), and Dr Christopher McKevitt (King's, 1994 to present). To date we have collected detailed information from almost 5,000 stroke patients in the Register area, with each patient followed up at 3 months and annually after stroke, for life.

King's stroke research has: 1) measured the incidence of stroke and its immediate and long-term consequences for patients, contributing to understanding needs for services; 2) provided evidence of the effectiveness of Early Supported Discharge and other models of post-stroke care; 3) measured the quality and cost-effectiveness of care; and 4) explored patient and carer perspectives of need and outcome and developed a framework for patient/carer engagement in stroke research and service development in the UK and Europe.

King's research provided epidemiological estimates of the needs for stroke care

From its first key study (Stewart et al., 1999), the South London Stroke Register has continued to report changing patterns in stroke incidence since 1995, with a focus on ethnic variations in risk (Heuschmann et al., 2008). Our research showed that stroke risk and stroke sub-types vary substantially between ethnic groups, with a large proportion of strokes occurring in people with *untreated risk factors* including hypertension with limited improvement in detecting these risk factors over time (Heuschmann et al., 2008). We have used Register data to show that 20-30% of survivors have a poor range of *functional outcomes* (e.g. walking ability) up to ten years after stroke (Wolfe et al. 2011), over half of all stroke patients have *depression* (Ayerbe et al., 2011), and stroke has a substantial long-term impact through *cognitive impairment* (Douiri et al., 2013). We and other research groups have used our epidemiological data to quantify risk of stroke and needs for long term care, as well as to develop interventions to reduce the significantly poor outcomes of stroke survivors.

King's research provided evidence of the effectiveness of Early Supported Discharge

The South London Stroke Register team conducted the first and largest randomised trial to assess the clinical effectiveness of an Early Supported Discharge (ESD) policy (Rudd et al., 1997). This study provided evidence that outcomes following ESD were comparable to conventional hospital and community care, while the length of hospital stay was substantially reduced. King's contributed data and co-authored a meta-analysis that pooled data on the effectiveness of ESD internationally (Langhorne et al., 2005), showing that appropriately resourced ESD services, provided for selected groups of stroke patients, can reduce long-term dependency and admission to institutional care as well as shortening hospital stays. Subsequently, the King's group has reported on the cost-effectiveness of ESD (Saka et al., 2009).

King's researchers led and co-ordinated Europe-wide research on stroke

The team has co-ordinated a programme of collaborative research across the European Union with a focus on explaining variations in incidence (Heuchmann et al. 2009), quality and costs of stroke care in Europe (Grieve et al, 2001) and outcomes (Heuschmann et al., 2011). These studies highlighted the high costs and poor outcomes associated with acute stroke care in the UK, contributing to making the case for more efficient service models that provide higher quality care. They also showed wide variations in quality of stroke care and implementation of evidence-based practice. The studies were the catalyst for research registers being established in other European centres which have enabled on-going comparative research to improve the quality of stoke care.

King's researchers engaged with patients and families to inform stroke research

The King's stroke research programme is informed by an active Stroke Patient and Family Group, established since 2005, with over 20 people participating in 6 research meetings a year, at which research priorities are identified and research methods refined. The group contributed to the development of a national survey of long term need that has informed the Stroke Association's policy on longer term care (McKevitt et al., 2011). The group also produces a research newsletter sent to 1,600 Stroke Register patients twice a year. It has contributed to the national Stroke Research Network strategy for public and patient involvement (PPI) in research and service development and to the European developments in PPI. The group is linked to a social science programme embedded within the Stroke Register; our European Programme has also focused on patient and public engagement well as facilitating patients and carers involvement in designing studies and tools for research and the dissemination of results.

3. References to the research

Grieve, R., et al. (2001) A comparison of the costs and survival of hospital-admitted stroke patients across Europe. *Stroke* **32**:1684-91. doi: 10.1161/01.STR.32.7.1684

Heuschmann, P.U., et al. (2008) Ethnic group disparities in ten-year trends in stroke incidence and vascular risk factors: the South London Stroke Register (SLSR). *Stroke* **39** (8):2204-210. doi: 10.1161/STROKEAHA.107.507285

Heuschmann PU et al. (2009) Incidence of stroke in Europe at the beginning of the 21st century. Stroke. 2009 May;40(5):1557-63. doi: 10.1161/STROKEAHA.108.535088.

Heuschmann PU et al. (2011) Three-month stroke outcome: the European Registers of Stroke (EROS) investigators. Neurology 76:159-65. doi: 10.1212/WNL.0b013e318206ca1e

Langhorne, P., et al. (2005) Early supported discharge services for stroke patients: a meta-analysis of individual patients' data. *Lancet* **365** (9458):501-6. (doi:10.1016/S0140-6736(05)17868-4)

McKevitt, C., et al. (2011) Self-reported long term needs after stroke. *Stroke* **42**:1398-1403**.** doi: 10.1161/STROKEAHA.110.598839

Rudd, A.G., Wolfe, C.D., et al. (1997) Randomised controlled trial to evaluate early discharge scheme for patients with stroke. *BMJ* **315** (7115):1039-44.

Saka, O., et al. (2009) Cost-Effectiveness of Stroke Unit Care Followed by Early Supported Discharge. **Stroke 40**:24-29. doi: 10.1161/STROKEAHA.108.518043

Stewart, J., et al. (1999) Ethnic differences in stroke incidence. The South London Stroke Register. *BMJ* **318**:967-971.

Wolfe, C.D., et al. (2011) Estimates of outcomes up to ten years after stroke: analysis from the prospective South London Stroke Register. *PLoS Med.* **8**(5):e1001033. doi: 10.1371/journal.pmed.1001033

Research Grants

UK Stroke Survivor Needs Survey. Redfern, J., et al. The Stroke Association, 2009: £81K.

Modelling, evaluation and implementing cost effective services to reduce the impact of stroke.

Wolfe, C et al. NIHR Programme Grant for Applied Research, 2008-2013: £1.134m.

Identifying the long-term needs of stroke survivors and modelling implications for innovative services. McKevitt et al. NIHR, Research for Patient Benefit, 2008-2010: £226k.

The South London Stroke Register. Wolfe, C. Department of Health, 2003-2007: £300k.

European variation in stroke interventions from patients, carers, primary, ambulatory, community, and hospital services: its impact on outcomes and costs. Wolfe, C. European Community BIOMED 2 Programme, 1996-1998: £574k.

4. Details of the impact

King's stroke research has had substantial impact through translation into national and local policies for stroke care, leading to improved commissioning and delivery of stroke services. This has contributed to reductions in mortality and cost savings for health services, mainly through transformation of services in cities and the implementation of Early Supported Discharge, the latter also being rolled out internationally. The ultimate beneficiaries of these impacts are patients with stroke, as well as their family members, who benefit from better health, less disability and longer lives. Other stakeholders benefit from our research through high quality evidence to inform policy. Such beneficiaries include the government and non-governmental policy-makers, commissioners and providers of health and social care, and the voluntary sector including the Stroke Association and aphasia charities.

King's research influences national policy for stroke

South London Stroke Register data informed the Department of Health *National Stroke Strategy* on the need for acute and longer term stroke care. King's data informed and were embedded into 'Action on Stroke Services: An Evaluation Toolkit (ASSET) for providers and for commissioners' which is cited as a 'key resource' in Annex B of the National Stroke Strategy. King's was also commissioned by the Department of Health to develop recommendations for the top ten priorities in stroke service research. The South London Stroke Register team was commissioned by the *National Audit Office (NAO)* to write an annex to the report on stroke care (NAO, 2010: 'Progress in improving stroke care'). This utilised King's estimates for risk of stroke, long term outcomes and survival to inform recommendations for stroke care. King's data were used to model cost-effective options for stroke care (NAO, 2010: 'Report on the findings from our modelling of stroke care provision', pages 15-16), informing the Parliamentary Public Accounts Committee (2010) report on the need for a step change in stroke care.

King's research informs major service reconfiguration in London

In response to Lord Darzi's 2007 report 'Healthcare for London: A Framework for Action', South London Stroke Register data on incidence and patient outcomes were used by *Healthcare for London* to develop a Stroke Strategy for London (2008). King's data were specifically employed to estimate the number of people who can be expected to have a stroke and thereby the number of Hyper Acute Stroke Unit (HASU) and Acute Stroke Unit (ASU) beds required in the city, and to develop models of cost effective configurations of services (page 7). Wolfe and Rudd led work streams for the strategy development. The reconfiguration, implemented in 2010, consisted of 8 HASUs and 24 Stroke Units. An evaluation (Hunter et al., 2013) found an estimated 12% reduction in deaths at 90 days, as well as a reduction in the median length of stay, with an estimated cost saving of £811 per patient (2011) in London after the reconfiguration.

King's provides professional leadership and research evidence to inform clinical guidelines

The South London Stroke Register leadership has also been instrumental in improving stroke care nationally. Professor Anthony Rudd from King's has chaired the *Royal College of Physicians' (RCP) Intercollegiate Stroke Working Party* (ISWP) since its inception in 1995. The fourth edition of the Working Party's National Clinical Guideline for Stroke (2012) recommends that Early Supported Discharge should be a component of stroke care. The Guidelines also discuss the unmet needs of stroke patients (following McKevitt et al., 2011 cited above). The RCP's National Sentinel Stroke Audit 2010 recommended that Early Supported Discharge should be made

available in all districts.' (page 11). Early Supported Discharge is now provided by 66% of English hospitals. (RCP Sentinel Audit 2012) and has been implemented internationally (Fisher et al. 2011). Earlier editions of the ICSWP National Stroke Guidelines, which also cite King's stroke research, have been used to inform the 2008 *National Institute of Health and Care Excellence* (NICE) guidelines on stroke and the 2010 Stroke Quality Standard, the latter recommending Early Supported Discharge as a component of the rehabilitation pathway. In a report authored by King's stroke researchers, and using methods developed by King's researchers to estimate the quality of stroke care, data from the RCP National Stroke Audit data for the first 72 hours of stroke care in NHS facilities, demonstrated reduced mortality in hospitals with better organised stroke care (Bray et al., 2013). The work of King's is also influential in the *NHS Improvement* initiative for stroke care. For instance, the ISWP documents are referenced throughout their website and publications, especially in terms of calling for pathways that include Early Supported Discharge.

King's works with voluntary sector and patients to articulate needs

The *Stroke Association* (SA) recently published *'Saving Lives. 20 years of investment in vital stroke research'* that identifies how the research it has funded has led to patient benefit. This report highlights King's research in developing and evaluating Early Supported Discharge. The results of the Stroke Association 2010 Stroke Survivor Needs survey have informed Stroke Association policy, and identified stroke survivor priorities, for areas of research and service development which have not previously been addressed, for example high prevalence of stroke-related fatigue.

5. Sources to corroborate the impact

Department of Health: National Stroke Strategy
'Action on Stroke Services: An Evaluation Toolkit (ASSET) for providers and for commissioners'
Top ten priorities in stroke services research

House of Commons Committee of Public Accounts. Progress in improving stroke care. Twenty-sixth report of Session 2009-10.

NHS Improvement. Stroke Improvement: Early Supported Discharge
NHS London. Healthcare for London: A framework for action. London: NHS, 2009:
National Audit Office (2010). Progress in improving stroke care. Second report. London: National Audit Office. Report on the findings from our modelling of stroke care provision

National Institute for Health and Care Excellence:
National clinical guideline for diagnosis and initial management of acute stroke and transient ischaemic attack (TIA)
Stroke quality standard (stroke rehabilitation pathway recommends Early Supported Discharge)

Royal College of Physicians Intercollegiate Stroke Working Party
National Clinical Guideline for Stroke. Fourth Edition. 2012.
National Sentinel Stroke Audit 2010
Stroke Improvement National Audit Programme:

Published Evidence on Implementation

Bray BD et al. (2013) Associations between the organisation of stroke services, process of care, and mortality in England: prospective cohort study. BMJ **346**:f2827. doi: 10.1136/bmj.f2827.
Fisher RJ et al. (2011) A consensus on stroke: early supported discharge. Stroke **42**:1392-7. doi: 10.1161/STROKEAHA.110.606285
Hunter RM et al. (2013) Impact on clinical and cost outcomes of a centralized approach to acute stroke care in London: a comparative effectiveness before and after model. PLoS One**. 8**:e70420. doi: 10.1371/journal.pone.0070420.

The Stroke Association
Stroke Association (2012) Saving Lives. 20 years of investment in vital stroke research (page 33)
Stroke Association (2010) UK Stroke Survivor Needs Survey