Institution: University of Edinburgh		
Unit of Assessment: 1		
Title of case study: L: Delivery of early integrated palliative care for all patients with advanced illnesses: the development, validation, translation and international adoption of a research-based tool (SPICT)		
Period when the underpinning research was undertaken: 2002 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Roles (e.g. job title)**	**Period(s) employed by submitting HEI:**
Kirsty Boyd	Reader in Palliative Care	2000 – present
Scott Murray	St Columba's Chair of Primary Palliative Care	1990 – present (Emeritus since 2018)
Bruce Mason	Senior Research Fellow	2008 – present
Period when the claimed impact occurred: August 2013 – December 2020		
Is this case study continued from a case study submitted in 2014? N. Although the concept of the SPICT tool was introduced in UoE/UoA1/M, the definitive tool described here has been produced over the subsequent 6 years (2013–2019) based on emerging research findings, expert consensus and evaluation in primary and secondary care in the UK.		

1. Summary of the impact

Underpinning Research: University of Edinburgh (UoE) researchers led an extensive programme of descriptive and intervention studies in early palliative care, providing evidence that suffering and financial problems due to ill-health are preventable from earlier in the illness journey. This led to the development and evaluation of the clinical Supportive and Palliative Care Indicators Tool (SPICT) in community and hospital settings. Using the research-based SPICT indicators and guidance drives effective identification of needs and planning of palliative care.

Significance and Reach of Impact: Scottish legislation now allows earlier access to welfare benefits for people with all advanced illnesses (from 2016), and financial support for family caregivers (from 2018). Scottish, UK, European, Australian, Canadian and World Health Organization policies and guidance all recommend use of the SPICT.

As a result of these policy and legislation changes, more people at the end of life in Scotland, especially those with advanced multi-morbidity, now receive palliative care planning (69% in 2017; 60% in 2014 and 38% in 2011) and do so earlier (on average 6 months earlier in 2017 than in 2014).

2. Underpinning research

The Challenge: Timely identification of needs and care planning for people with declining health due to a range of conditions

People with life-threatening illnesses are known to suffer unnecessarily when they do not receive holistic palliative care to help them live as well as possible until they die. The key challenge is to identify people with diverse illnesses while there is still time to have a significant impact on their quality of life and service use. This was addressed by UoE's Primary Palliative Care Research group (PPCRG) through development and validation of the SPICT from 2014.

Palliative care needs are universal and usually start many months before dying

Early work by the PPCRG had demonstrated the relevance of early integrated palliative care for people with heart and lung disease as well as cancer (UoE/UoA1/M). A pivotal 2002 study contrasted dying of heart failure with dying of lung cancer in the UK [3.1] and showed that all patients and families had unmet physical, social, psychological and spiritual needs and suffered unnecessarily, but people with heart failure received little coordinated care and fewer health, social and palliative care services.

Since 2014, UoE's longitudinal, multi-perspective methods, intervention modelling and feasibility trials have built a convincing evidence base of health-related suffering in people with different illness trajectories: 1) progressive cancers, 2) organ failure (heart, lung and liver), 3) frailty and multimorbidity, and 4) major stroke [3.2, 3.3]. The key finding was that palliative care needs are universal and usually start many months before dying [3.2]. Feasibility trials in organ failure (liver disease, chronic obstructive pulmonary disease and heart disease [3.3]) provided more evidence that palliative care planning from diagnosis is acceptable to people with all serious illnesses, improves care coordination and reduces hospital admissions of low benefit.

Using research to change patient experiences and outcomes: SPICT

Having researched people's needs, illness trajectories and experiences across diverse advanced conditions, the PPCRG next highlighted the adverse consequences of 'prognostic paralysis' (i.e. delayed discussion of end-of-life issues until death is imminent). Boyd addressed the evident lack of an effective tool and process for timely identification of people for palliative care by developing a new clinical tool (SPICT) with educational resources, and by setting up an international network of SPICT Partners (www.spict.org.uk). Identification is based on burden of advanced illness and general markers of declining health indicative of unmet care needs [3.4]. Although the concept was introduced in REF2014, the definitive SPICT tool has been produced over the subsequent 6 years (2013–2019) based on emerging research findings, expert consensus among SPICT Partners, and evaluation in primary and secondary care in the UK and internationally [3.4]. Boyd has supported completion of research-based translation, adaptation and validation of SPICT into 10 other languages with 7 more underway, and for lower-income settings (SPICT-LIS) [e.g. 3.5].

Supporting family carers as well as patients

In 2016, UoE research with family carers of people with advanced illness modelled and evaluated a systematic approach to identify, assess and support carers of people with palliative care needs in primary care. This mixed-method, feasibility study in 4 Scottish general practices led to improvement in carers' welfare and reduced stress and anxiety [3.6], for which the research team won the 2019 National Institute for Health Research (NIHR) award for "the most impactful recent palliative care study" in the NIHR portfolio.

3. References to the research

[3.1] Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. BMJ. 2002; 325:929. doi: 10.1136/bmj.325.7370.929

[3.2] Kendall M, Carduff E, Lloyd A, Kimbell B, Cavers D, Buckingham S, Boyd K, Grant L, Worth A, Pinnock H, Sheikh A, Murray SA. Different Experiences and Goals in Different Advanced Diseases: Comparing Serial Interviews with Patients with Cancer, Organ Failure or Frailty and Their Family and Professional Carers. J Pain Symptom Manage. 2015; 50:216-24. doi: 10.1016/j.jpainsymman.2015.02.017

[3.3] Kimbell B, Murray SA, Byrne H, Baird A, Hayes P, MacGilchrist A, Finucane A, Brookes Young P, O'Carroll R, Weir C, Kendall M, Boyd K. Improving care in the community for people with advanced liver disease: a feasibility study. Palliat Med, 2018; 32:919-29. doi: 10.1177/0269216318760441

[3.4] Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Support Palliat Care 2014; 4: 285-290 doi: 10.1136/bmjspcare-2013-000488

[3.5] Afshar K, Feichtner A, Boyd K, Murray S, Jünger S, Wiese B, Schneider N, Müller-Mundt G. Systematic development and adjustment of the German version of the Supportive and Palliative Care Indicators Tool (SPICT-DE). BMC palliative care. 2018 Feb 17; 17(1):27. Available from, doi: 10.1186/s12904-018-0283-7

[3.6] Carduff E, Jarvis A, Highet G, Finucane A, Kendall M, Harrison N, Greencare J, Murray SA. Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study. BMC Fam Prac, 2016;17:18. doi: 10.1186/s12875-016-0414-

Selected Grants

[3.7] Murray SA, Boyd K, Mason B. Kendall M. Definition and evaluation of models of primary and secondary care collaborative working at the end of life. National Institute for Health Research (NIHR), SDO. 2009–2012. GBP467,000.

[3.8] Denvir M, Murray SA, Boyd K, Weir C. Phase 2 randomised trial of early versus delayed future care planning for patients with advanced heart disease. Marie Curie Cancer Care, 2013–2015. GBP147,074.

4. Details of the impact

Impact on Scottish Government strategy and policy

Timely identification of people with any advanced or life-limiting illness is the first commitment of the Scottish Government Palliative Care Strategy for 2015–2021 [5.1a, b], reflecting the UoE PPCRG's key research finding. This strategy recommends SPICT in primary care settings to identify people for palliative care assessment. The Healthcare Improvement Scotland toolkit for patient identification and anticipatory care highlights the benefits of using SPICT [5.1c]. The Scottish Government lead for palliative care confirms that *"research by the PPCRG, and especially the SPICT, has been instrumental in the successful delivery of palliative care earlier, and to many more people in Scotland"* [5.1d]. The NHS Scotland National Digital Platform, currently under development, will replace the Key Information Summaries (KIS) and include SPICT as a recommended tool to prompt care planning [5.1e].

Impact on Scottish legislation

UoE palliative care research has directly informed 2 key bills passed by the Scottish Government. The first provides more financial support for family caregivers [Carers (Scotland) Act 2016; [5.2a]. The second legislation means people with any advanced progressive condition receive financial support earlier and regardless of diagnosis [Social Security (Scotland) Act 2018; [5.2b]. This Social Security Act was widely reported in mainstream media, for example by the BBC [5.2c]. The Head of Policy & Public Affairs for the UK charity Marie Curie, who campaigned actively for this legislative change, citing UoE research, said; *"This research helped us show MSPs* [Members of the Scottish Parliament] *in the Scottish Parliament that people with terminal conditions in addition to cancer also need a new fair definition of terminal illness*" [5.2d]. All 4 'special rules for terminal illness' in the Act (no minimum period; no requirement for assessment; eligibility from date of application; entitlement to maximum amount) stem directly from UoE research [p.59; 5.2b]. These changes to national benefits are being applied in clinical practice using the SPICT to guide assessment and eligibility [5.2e].

Impact on clinical practice in the UK

Since 2019, Scottish and English General Practitioner (GP) contracts have instructed NHS Primary Care Organisations and GP practices to implement community palliative care for people who need it, and highlight SPICT as a key tool to identify more patients [5.3a, b]. GPs in Scotland now complete electronic KIS to communicate people's care plans to NHS 24, GP out-of-hours services, hospitals and the ambulance service as part of routine care.

Following the widespread practical uptake of the SPICT in Scotland, the number of patients receiving palliative care planning documented in a KIS before they die increased from 38% in 2011 to 60% in 2014 and 69% in 2017. These people also received coordinated care planning much earlier; a median of 10.3 months before dying in 2017 compared with 4.1 months in 2014 [5.3c]. Furthermore, within 3 months of the start of the Covid-19 pandemic, the number of KIS in Scotland rose from 4% of the population to approximately 17%, indicating the extent to which proactive anticipatory care planning is established as essential to good patient care [5.3d].

The Royal College of General Practitioners and Marie Curie published the Daffodil Standards in 2018, defining UK-wide core GP standards for palliative care in advanced, serious illness and end-of-life care. This resource combines policy recommendations with educational resources and is being re-launched in 2020 as part of the COVID-19 response. Standard 2 "Early Identification" refers to key PPCRG research and recommends SPICT [5.4a]. The Royal College of Physicians report "*Talking about Dying*" seeks to offer advice and support for any doctor on holding conversations with patients much earlier after the diagnosis of a progressive or terminal condition and recommends SPICT for patient identification to prompt timely discussions about palliative care [5.4b]. In Scotland, SPICT is being used to identify people who could benefit from the ReSPECT process, which is the Resuscitation Council UK's care-planning process built around a summary of Recommendations for Emergency Care and Treatment for when a person lacks capacity to make or express choices [5.4c].

Impact on global policy and practice internationally

The SPICT has been translated and revalidated into 10 languages (French, German, Spanish, Italian, Portuguese, Dutch, Danish, Swedish, Japanese and Brazilian Portuguese) and at least 7 further translations are in progress to support good practice and train GPs, hospital doctors and other clinicians. 86 SPICT Partners routinely use a version of SPICT in more than 30 countries, and over 4,000 people are on the current SPICT mailing list. SPICT website analytics show that SPICT downloads have been rising steadily since 2014, numbering 128,100 by November 2020.

Since 2014, national bodies and healthcare providers in many countries including Canada [5.5a,b] and Australia [5.5c] have embedded versions of SPICT in their clinical management systems and recommended it as an identification tool to support delivery of systematic, early palliative care and to support care planning in educational resources.

UoE research has been instrumental in developing *"a deeper understanding of illness trajectories and how generalist and specialist palliative care complement each other in primary care settings"* as stated by the President of the European Association of Palliative Care (EAPC) [5.6a]. The information provided via the EAPC Primary Care Toolkit (including use of SPICT) means early identification of palliative care needs in primary care is now national policy in many European countries [5.6b]. In 2018, 9 out of 34 countries reported financial incentives for early identification [5.6c]. The French National Plan for the Development of Palliative and End of Life Care (2015–2018) recommends early identification of patients, involvement of primary care professionals and use of SPICT-FR [5.7a]. In Belgium, a Royal Order recommends use of SPICT-BE to identify palliative patients [5.7b]. The Danish Health Authority issued a guide entitled ''Recommendations for palliative action'', which recommends SPICT-DK for use at the primary level [5.7c].

In addition, 3 key World Health Organization documents (2014, 2017 and 2018), all citing UoE research and specifically the SPICT, state the need to integrate palliative care for patients with all life-threatening illnesses in the community as being a core aspect of primary healthcare [5.8].

5. Sources to corroborate the impact

[5.1] Scottish Government strategy and policy changes:
a. Website Strategic Framework for Action on Palliative and End of Life Care 2016–2020 (2015)
b. Strategic Framework for Action on Palliative and End of Life Care 2016 –2020 (2015)
Evidence Summary for the Framework (referencing 6 UoE publications and the SPICT website)
c. Healthcare Improvement Scotland Palliative Care Toolkit (2018)
d. Testimonial letter from former Palliative Care Lead at Scottish Government 14th Aug 2019
e. Email from NHS Education Scotland confirming inclusion of SPICT in anticipatory care

[5.2] Scottish legislation changed through UoE research evidence:
a. Carers (Scotland) Act 2016 (Sections 7 and 13)
b. Social Security (Scotland) Act 2018 (Section 31(1); Chapter 3)
c. BBC News Article reporting on the Social Security Act (20 April 2018)

d. Testimonial letter from Marie Curie Head of Policy & Public Affairs, Scotland Nov 2018
e. Scottish Government guidance on assessment for terminal illness benefits; March 2020 draft
f. Email from Scottish Government Terminal Illness Policy Manager confirming inclusion of SPICT in assessment guidance, once this is published

[5.3] Integration of SPICT guidance for palliative care planning in UK healthcare delivery:
a. GP contract for Scotland: NHS Circular: PCA(M)(2019)06 regarding the Primary Medical Services Directed Enhanced Services (Scotland) 2019 Palliative Care Scheme
b. GP contract for England and Wales: NHS England. 2019/20 General Medical Services (GMS) contract Quality and Outcomes Framework (QOF)
c. Finucane A, *et al* Electronic care co-ordination systems for people with advanced progressive illness. Br J Gen Pract 2019; doi: 10.3399/bjgp19X707117
d. Blog post by Chair RCGP Scotland, May 2020, citing numbers of patients with KIS between January and May 2020.

[5.4] Recommendations for using SPICT to primary and secondary care doctors in the UK:
a. Daffodil Standards 2018 (Royal College of General Practitioners and Marie Curie)
b. Royal College of Physicians London 2018 Talking about dying report: how to begin honest conversations about what lies ahead
c. Resuscitation Council UK ReSPECT process implementation in Scotland educational poster

[5.5] Implementation of SPICT internationally in service development, education:
a. Screenshot from website introducing Life and Death Matters (British Columbia, Canada) textbook *Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse.* ISBN 13: 9781926923116)
b. Email from author and publisher of the book, confirming inclusion of SPICT in the versions in English and Spanish
c. Inclusion of SPICT as a tool for identification in the Australian Government-sponsored Advance Project for Palliative Care in Primary Healthcare resources (screenshot from website (https://www.theadvanceproject.com.au/) in resources accessed by registered users)

[5.6] Impact on palliative care in Europe through the European Association of Palliative Care:
a. Testimonial letter from President, European Association of Palliative Care, Dec 2018
b. EAPC Primary Care Toolkit (2019)
c. EAPC Atlas of Palliative Care in Europe 2019 (Chapter 9; p.81–84)

[5.7] Recommendations for early identification and care planning in national health policies:
a. French National Plan for the Development of Palliative and End of Life Care 2015 –2018 (p.18)
b. Royal Order setting Belgian criteria for identifying a palliative patient (21 October 2018)
c. Recommendations for palliative action (Danish Health Authority, 2017) (p.11, 15)

[5.8] WHO Policy Documents:
a. WHA 2014 World Health Assembly Resolution 67.19
b. WHO 2018 Integrating Palliative Care and Symptom Relief into Primary Healthcare (referencing 5 UoE publications and UoE video, and acknowledging UoE input on page vi)
c. WHO collaborating Centre 2017. Building Integrated Palliative Care Programs and Services (6 UoE publications and reference to SPICT on page 128; 3 chapters co-authored by Murray)