

# Primary Palliative Care Research Group

Usher Institute of Population Health Sciences & Informatics, The University of Edinburgh

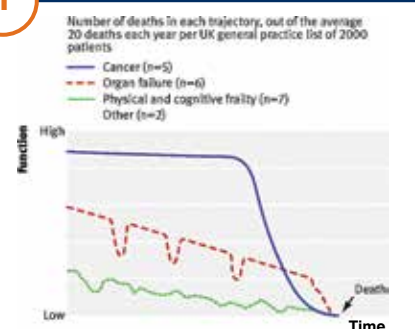


THE UNIVERSITY of EDINBURGH



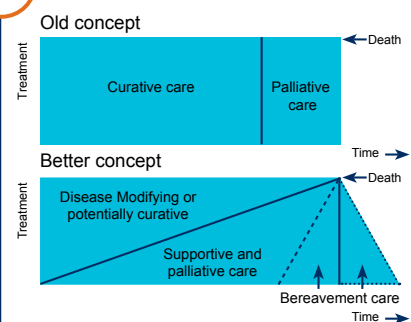
**Palliative care is becoming an urgent priority internationally. How governments respond to this challenge will be a test of the country's development as a civilised nation.**

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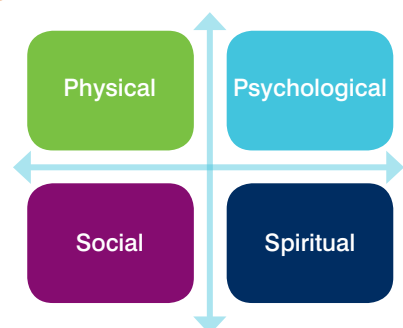
**All illnesses** - according to need, not diagnosis - page 2

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## Recent successes of the Primary Palliative Care Research Group

- Advising WHO on how to best integrate palliative care in primary care internationally
- Published a Toolkit on how to introduce palliative care in primary care nationally [www.eapcnet.eu/LinkClick.aspx?fileticket=QDeFwspXKkA%3D](http://www.eapcnet.eu/LinkClick.aspx?fileticket=QDeFwspXKkA%3D)
- SPICT™ is being widely downloaded from our website and used internationally to identify people for care planning. The Supportive & Palliative Care Indicators Tool <http://www.spict.org.uk/>

## International Primary Palliative Care Network

Scott Murray chairs the International primary palliative care network to encourage research in the community in both the economically developed and poorer countries.

See: [www.ippcn.org/](http://www.ippcn.org/)



Prof. Scott Murray MBE

# 1 All Illnesses

## Liver Disease

### Supportive care in the community for people living with advanced liver disease: a feasibility study

**Funder:** Chief Scientist Office



**Research team:** Barbara Kimbell, Scott Murray, Marilyn Kendall, Kirsty Boyd, Alastair MacGilchrist, Chris Weir, Anne Finucane, Peter Hayes, Ronan O'Carroll, Patricia Brookes-Young, Michael Deighan

Palliative care for patients with liver disease is neglected compared to patients with cancer, and with heart, lung and renal failure. This study tests the feasibility of a supportive care liver nurse specialist to improve the care planning, care coordination and quality of life for patients living with advanced liver disease and their family carers. We will assess how patients, carers and health care professionals feel about the intervention and evaluate its impact on resource use, care coordination processes and quality of life. We will also consider effectiveness, feasibility and potential improvements which will allow us to test this intervention on a larger scale in the future and inform the development of appropriate support for people living with advanced liver disease.

See: [http://www.thelancet.com/pdfs/journals/lancet/](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736%2815%2960191-X.pdf)

[PIIS0140-6736%2815%2960191-X.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736%2815%2960191-X.pdf)

<http://bmjopen.bmj.com/content/5/11/e009241.full.pdf+html>

## Frailty

### Understanding the needs and experiences of frail older people towards the end of life

**Funder:** ESRC PhD awarded 2015



**Dr Anna Lloyd**

**PhD Supervisors:** Scott Murray, Marilyn Kendall, John Starr

Frail older adults are rarely offered palliative care. It remains unclear as to what model of palliative care is appropriate for them. The physical trajectory of frail older people is of a gradual dwindling decline yet how social, psychological and existential needs change over time and relate to physical changes is not understood. This study found patterns of physical, social, psychological

and spiritual experiences that differ from the archetypal trajectories of other groups. In the face of threats to the sense of self, the frail older people valued alternative identities and struggled with the absence of clear causative factors to explain their circumstances.

It may be helpful to encourage a focus of advance planning on addressing the fears of burdening others, of moving to a nursing home or of developing dementia. Such fears were more prevalent than fears of dying. Community health and social care structures and networks appear essential for supporting the end of life needs of frail older people. Understanding the distinct losses and sustaining factors that contribute to the well-being of frail older people is integral for assessing how best to offer care and support. A direct application of the cancer care model may not be helpful.

Paper in press with EJPC

## Major Stroke

### Understanding the experiences and multi-dimensional needs of people with major stroke: a mixed methods study

**Funder:** Chief Scientist Office



**Research team:** Gillian Mead, Scott Murray, Marilyn Kendall, Eileen Cowey, Mark Barber, Christine McAlpine, David Stott

The prognosis of patients with total anterior circulation (TACS) strokes who survive to hospital discharge is as poor as many cancers, yet they are not included in palliative care registers in primary care. We are using serial qualitative interviews, with 30 patients (recruited from Glasgow and Edinburgh), and their informal and health care professionals at 4-8 weeks, 6 months and 12 months after the index stroke, to describe multidimensional illness trajectories, identify unmet care needs and determine whether, and when, a palliative care approach may be appropriate. Our data linkage study of TACS patients admitted to our stroke units (death, pattern and duration of subsequent hospital admissions) will put the qualitative data in context. If, as anticipated, we identify unmet need for palliative care, our data will inform the development and testing of an intervention to provide palliative care to stroke survivors who need it.

## Chronic Obstructive Pulmonary Disease

### What can be done to help and support people living and dying with COPD?

**Funder:** Dunhill Trust

**Research team:** Hilary Pinnock, **Marilyn Kendall**, Susan Buckingham, Ulugbek Nurmatov, Cristina Matthews, Susie Ferguson



People with severe COPD live with disabling symptoms. This project aimed to provide people who had just had a hospital admission with an assessment of their physical, psychological, social and spiritual care needs and to plan actions that might help them cope.

The study is now complete and the first paper published in the npj Primary Care Respiratory Medicine. People appreciated the holistic assessment, though the intervention generated fewer actions than we had expected. This was partly because our intervention overlapped with routine discharge planning, but also because the people with severe COPD had adapted their lifestyles and preferred not to be seen as needing help.

<http://www.nature.com/articles/npjpcrm201520>

## Heart Disease

### A randomised controlled trial of care planning for patients with advanced heart disease (FLAME trial)

**Funder:** Marie Curie Cancer Care



**Research team:** **Gill Highet**, Martin Denvir, Sarah Cudmore, Shirley Robertson, Lisa Donald, Christopher Weir, Kirsty Boyd, Scott Murray

Patients with cancer have better developed palliative care services than people with heart disease. To address this we evaluated a care planning intervention with patients and families. This combined a holistic needs assessment by a cardiologist and cardiology nurse with the creation of a shared future care plan and nurse led care in the community, following a recent unscheduled hospital admission with acute coronary syndrome (ACS) or heart failure (HF). We explored whether such a complex intervention is acceptable to patients, their carers and health professionals, and if it is practical, deliverable and feasible.

The primary outcome measure was quality of life of patients and carers. Patients with a 12 month estimated mortality risk of 20% or greater were randomised to either early (upon discharge) or delayed (after 12 weeks) intervention. 50 patients were enrolled into the study (22% ACS, 68% HF, 10% valvular heart disease). Findings demonstrated that the intervention and outcome measures were acceptable, feasible and deliverable. A multi-centred clinical trial is being planned.

<http://heart.bmj.com/content/early/2015/04/21/heartjnl-2014-306724.full.pdf+html>

## Multimorbidity

### Living with advanced multimorbidity

**Funder:** National Institute for Health Research

**Research Team:** **Bruce Mason**, Kirsty Boyd, Anne Donaldson, Marilyn Kendall, Allison Worth, Scott Murray

In a recent study of patients in Edinburgh, London and Warwick we discovered that most people during their last year of life had multiple needs requiring a range of health and social services. However such patients and their family carers reported these services to be inflexible, unresponsive and poorly coordinated. Family carers played a significant role in managing the care of patients with multimorbidity and often bridged the gaps in professional care coordination. Patients wanted to retain a sense of autonomy and self-control often through limiting their interactions with the health service. Identifying such patients is crucial so that they can receive equitable care appropriate to their multiple needs. Multimorbid patients receive much less palliative care than cancer patients with an equivalent burden of need.

<http://www.ncbi.nlm.nih.gov/pubmed/25023218>



## 2 All Times

### Early identification of people for a Palliative Care approach

#### Anticipatory Care Planning in primary care: an after-death analysis of electronic Key Information Summaries



**Funder:** University of Edinburgh and NHS Lothian

**Research team:** Julia Tapsfield, Carey Lunan, Peter McLoughlin, Hazel McCutcheon, Juliet Spiller, Scott Murray

GPs are caring for increasing numbers of elderly patients approaching end of life with various and often multiple illnesses. Anticipatory Care Planning (ACP) is central to chronic disease management and palliative care, allowing patients, and their family carers, a chance to think about their future, consider what they do or do not want to happen and who may speak on their behalf. ACP needs to be easily started, updated and accessible and electronic Key Information Summaries (KIS) were introduced throughout Scotland in 2013 for this purpose. These electronic records, completed, updated and shared by GPs, are accessible to health care providers including NHS 24, Ambulance services, out of hours GPs, Accident and Emergency and hospitals.

We are undertaking a retrospective study of ten GP practices looking at all patients who died in 2014. Quantitative analysis of deceased's records for KIS completion and the quality of records completed along with review of records to identify which disease trajectory patients died on and their preferred place of care. We will describe how KIS are being used in ACP, discuss how the different disease trajectories impact on ACP, and explore the strong association of ACP with dying outside hospital. We will provide insight into GPs experiences of ACP, identify areas of good practice and make recommendations for improvement. Paper in press with BMJ Supportive & Palliative Care

#### Supportive & Palliative Care Indicators Tool (SPICT™)



**SPICT™ Programme Leads:** Dr Kirsty Boyd and Professor Scott Murray

Timely identification of people who might benefit from supportive and palliative care and coordinated future care planning alongside appropriate management of their underlying illnesses is central to improving care for the growing number of people around the world whose health is deteriorating with one or more advanced illnesses. SPICT™ is being used by health and social care professionals and health care organisations internationally who are members of an expanding online SPICT Community which we are leading. Ongoing evaluation and peer review informs development and review of both the SPICT™ itself and ways to use it more effectively in all primary and secondary care settings. Our website allows users free downloads of SPICT™ and guides to using it in clinical practice and we have collaborating partners across the UK and internationally- Europe, Australia, New Zealand, USA, Canada, S America and Africa. Translations into French, German, Spanish, Dutch and Portuguese are building non-English speaking SPICT communities. SPICT™-App is being developed and our SPICT Partners can share their SPICT related research and development projects online. <http://www.spict.org.uk>

#### Computerised searching of GP records to help identify patients who might benefit from palliative care, irrespective of diagnosis (project 2, 2015-17)



**Funders:** Marie Curie, Edinburgh and Lothians Health Foundation

**Research team:** Bruce Mason, Kirsty Boyd, John Steyn and Scott Murray

These work streams aim to develop and test a method of searching primary care records in routine clinical practice as a tool to improve patient identification for a palliative care approach. The first project, now successfully conducted, was able to identify 0.6% to 1.6% of patients in each practice who were not already on the palliative care register with an agreement rate of 30%-60% among GPs.

The second project, started in February 2015, aims to refine the search and integrate it with pre-existing medical software so that it can be interacted with by GPs during a consultation or as part of a multi-disciplinary team meeting. An innovative year-long trial is planned in up to 10 practices drawing on methods developed for software ethnography in order to test how the search can best support current practices.

<http://www.biomedcentral.com/content/pdf/s12875-015-0312-z.pdf>

### 3 All Dimensions of need

#### Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family caregivers of patients with lung cancer

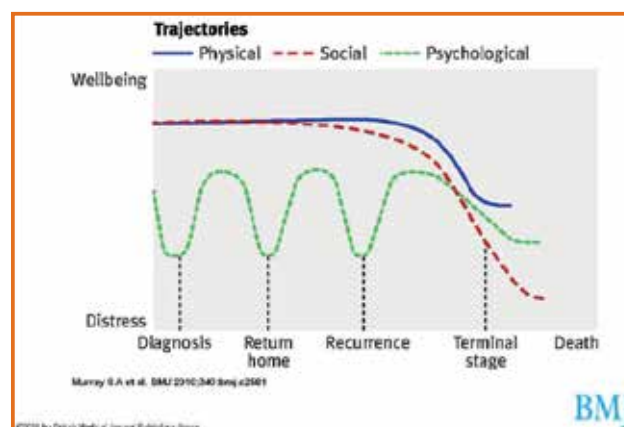
**Funder:** Chief Scientist Office

**Research team:** Scott Murray, Marilyn Kendall, Kirsty Boyd, Liz Grant, Gill Highet, Aziz Sheikh

We explored if family caregivers of patients with lung cancer experience the patterns of social, psychological, and spiritual wellbeing and distress typical of the patient, from diagnosis to death. Secondary analysis of serial qualitative interviews was carried out every three months for up to a year or to bereavement. The findings revealed that carers followed clear patterns of social, psychological, and spiritual wellbeing and distress that mirrored the experiences of those for whom they were caring, with some carers also experiencing deterioration in physical health that impacted on their ability to care.

Certain key time points in the illness tended to be particularly problematic for both carers and patients: at diagnosis, at home after initial treatment, at recurrence, and during the terminal stage.

The multidimensional experience of distress suffered by patients with lung cancer was reflected in the suffering of their carers. Carers need support from diagnosis and not just in the last weeks.

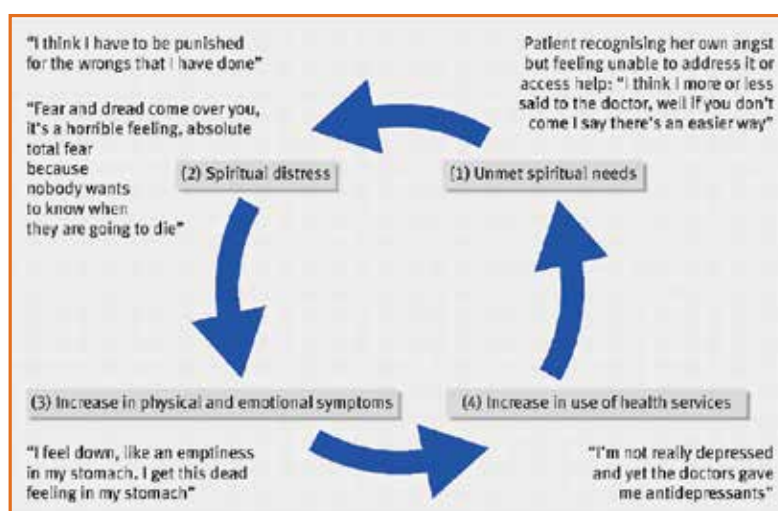


#### Spiritual dimensions of dying in pluralist societies

**Funder:** Chief Scientist Office

**Research Team:** Liz Grant, Scott Murray, Aziz Sheikh, Marilyn Kendall

We mapped spiritual distress across different disease trajectories, identifying triggers of spiritual need in order to understand better the spiritual issues that patients experienced and the times in patients' illness journeys when spiritual care could be of most value. These are at *diagnosis*, at *returning home*, at *disease progression*, and in *the last days*. Many patients identified feelings of emptiness, and loss, a sense of worthlessness and a fear of dying exacerbated by a longing to connect with others including, for many, the sacred. They expressed a desire to be at peace and to make amends and a number looked for religious and social rituals that would help them gain and retain meaning in life, when disease became the predominant concern of the health professionals. For patients spiritual support was often deeply intertwined with empathy and the valuing of the individual.



#### Influencing empathy: A qualitative longitudinal study of medical students' views and experiences



**Funder:** Self-funded

**PhD candidate:** David Jeffrey. **Supervisors:** Marilyn Kendall, Marie Fallon, Michael Ross

This qualitative study uses interpretative phenomenological analysis (IPA) to gain a deeper understanding of the influences on students' empathy as they progress through their training.

## 4 All Settings

### To scope the feasibility of establishing a Care Home Centre of excellence, Innovation, training and research (CHIC)



**Funder:** Burdett Trust for Nursing

**Research team:** Jo Hockley, Scott Murray

Care homes are the largest provider for the 24-hour care of frail older people in the UK. There are currently 18,000 care homes supporting 400,000 older people - three times the number of NHS beds. People over the age of 80yrs old now represent the fastest growing group within the UK population. However, care homes have suffered from an over-exaggerated bad press often being seen as 'places of last resort'. The project will collate the international literature on the development of teaching nursing homes in the USA, Canada and Australia, and visit specific sites in Norway and The Netherlands. This knowledge will be shared with clinicians and academic partners across Lothian while undertaking a feasibility study to establish a CHIC in Edinburgh. A CHIC would not only be homely and a place of excellence for frail older people requiring 24-hour nursing care, but also challenge the perceptions of the care of frail older people and encourage a new generation of professional carers through training and research alongside empowering staff in local care homes.

### Improving palliative care in care homes: A community palliative care clinical nurse specialist led model of support



**Funder:** Marie Curie and the Robertson Trust

**Research team:** Anne Finucane, Emma Carduff, Barbara Stevenson, Libby Milton, Scott Murray

National and international policies call for care homes to provide reliably good end-of-life care. Building on previous research conducted by Dr Jo Hockley, this study aims to improve the delivery of palliative care in 29 nursing homes in the Edinburgh area.

Anne Finucane, Honorary Fellow at the University of Edinburgh and Research Lead at Marie Curie Hospice Edinburgh is also involved in a range of projects focused on palliative care in community, hospital and hospice settings. Anne is a co-investigator on a CSO funded study to improve palliative care for patients with advanced liver disease and collaborates on various Marie Curie funded projects including an evaluation of the effectiveness of palliative care days services. Other projects are focused on palliative care in care homes, ehealth interventions to improve access to palliative care, family and carer support and psychological approaches to reduce distress and improve communication in palliative contexts.

### Caring with Integrity: Developing the conceptual underpinning of relationship-centred palliative dementia care in care homes



**Funder:** ESRC PhD studentship

**PhD candidate:** Julie Watson. **Supervisors:** Heather Wilkinson, Marilyn Kendall

People with advanced dementia struggle to maintain relationships and can ultimately experience social death before their physical death. Understandings of, and assumptions about, the effect of dementia on personhood directly affect the way people with dementia are perceived by others, the quality of their relationships, the quality of their care and the quality of their life. This ethnographic study examined care-giving/care-receiving relationships in a specialist dementia care home. Findings show that people with advanced dementia continue to experience and respond to the world, and those around them, until they die, particularly in embodied ways. These findings are used to develop thinking on relationship-centred palliative dementia care. Ethic of Care theory is used to argue why a broad understanding of personhood is vital, not only at the frontline, but also in dementia and palliative care policy, if care is to have integrity.

## 5 All Nations

### Establishing integrated palliative care in 4 African countries



**Funder:** Tropical Health and Education Trust 2013-17

**Research Team:** Liz Grant, Scott Murray, Mhoira Leng, Liz Namukwaya, Mary Robertson, Julia Downing

We were awarded a £1.6m grant from the Tropical Health and Education Trust (THET) for an innovative programme to strengthen palliative care within the national health service of four African countries. Working in partnership with the African Palliative Care Association (APCA), and Makerere University Palliative Care Unit (MPCU) we are developing a new public and primary health approach to palliative care that includes service provision, support systems and supply chain mechanisms that are firmly integrated into the health system in order to enhance the provision of treatment, care and support for people living with life limiting illnesses. We work with twelve hospitals and their associated community clinics (3 in each country) to establish replicable models of palliative care. The different hospitals: university training hospitals, tertiary referral hospitals, district hospitals, and rural based hospitals are building palliative care according to their local context, with training, services, and outward networks reflecting their local context and service demands. In March 2015 meetings took place with the four national health ministries to plan for Palliative Care integration into national policy. From 2015-17 we will continue with a two year roll out programme of Palliative Care in Rwanda and a two year nurse leadership programme in Uganda. [See www.integratepc.org](http://www.integratepc.org)

### The experiences and expectations of patients living with advanced heart failure in Kenya



**Funder:** University of Nairobi PhD studentship

**PhD candidate:** Kellen Kimani. **Supervisors:** Liz Grant, Scott Murray

Kenya, like other countries in sub-Saharan Africa, faces a double burden of both infectious and chronic life limiting diseases. Cardiovascular diseases account for more than 10% of deaths. Yet, current palliative care services cater for patients living and dying with HIV/AIDS and cancer. In order to develop services which meet patients' needs, we are conducting serial qualitative interviews with people living with advanced heart failure. These interviews allow for a deeper understanding of patients' lived experience and expectations. Preliminary findings reveal that patients experience significant dynamic physical, psychological and spiritual distress. Notably, psychological distress is heightened in younger patients and exacerbates the cost of care. Patients expect to be cured of their illness and receive assistance with accessing treatment. This study will inform appropriate policy, practice, training and future research for patients living and dying with heart failure in Africa.

### Multidimensional needs and experiences of Ugandan patients with advanced heart failure



**Funder:** Charles Darwin Scholarship and Lennie Gordon PhD bursary

**PhD candidate:** Elizabeth Namukwaya. **Supervisors:** Liz Grant, Scott Murray, Mhoira Leng, Julia Downing

Heart failure and other non-communicable diseases are rapidly increasing causes of death and illness in developing countries such as Uganda. People with heart failure in these countries are younger, with the cause of illness differing from those in the developed world. This thesis has explored the multidimensional needs of patients with heart failure in Uganda, using serial qualitative interviews. Findings revealed following themes in the illness experience; unmet multidimensional need, health system challenges, influence of culture and beliefs, health illiteracy, coping methods, services available, health professional versus patients' views of patients' needs and improving care. This study aims to propose a culturally appropriate model of palliative care for these patients. Elizabeth graduates in July 2016.

### Developing palliative care in the community in Japan



**Funder:** Japan Student Services Organization

**PhD candidate:** Ai Oishi. **Supervisors:** Scott Murray, Liz Grant

Primary care plays a central role in community health, and has potential to provide early and integrated palliative care for people with all diagnoses in the community. This research will describe the current extent that primary care and family physicians provide palliative care in the community to individual patients according to need. The potential role of the GP to also take a public health role will also be explored.



# Carers

## A feasibility study of early identification, assessment and support for informal carers in primary care



**Funder:** Marie Curie and Dimpleby Cancer Care

**Research Team:** Emma Carduff, Scott Murray, Marilyn Kendall, Alison Jarvis, Anne Finucane, Gill Highet, Nadine Harrison, Jane Greenacre

Approximately 17% of the Scottish population provide unpaid care for a relative, friend or neighbour. Those supporting someone with terminal illness often cope until the situation becomes overwhelming. Earlier identification could enable more timely support.

We modelled and piloted a systematic approach to identify, assess and support carers in primary care. We found that general practices need to proactively identify carers using existing opportunities, resources and computer systems, and also adopt a public approach to raise carer awareness and perceived support within their communities. This work informed the Scottish Carer Bill which was passed in the Scottish Parliament in February 2016. Emma has now moved to lead research at Marie Curie Hospice in Glasgow and maintains close links with the group. <http://bmcfampract.biomedcentral.com/articles/10.1186/s12875-016-0414-2>

## Health Promoting Palliative Care

### Advancing education and support around death, dying and bereavement: hospices, schools and health promoting palliative care



**Funder:** Strathcarron Hospice  
**Dr Sally Paul**

Children are often excluded from conversation about dying and bereavement and this can result in negative experiences. Adopting the principles of health promotion to palliative care can address this. Such approaches have gained recognition internationally. This study used action research to explore, implement and evaluate interventions where hospices and schools can work together to advance education and support around death, dying and bereavement. Several practice innovations were taken forward. Hospices can develop community capacity in end-of-life and bereavement care with school communities. Sally is currently a lecturer in Social Work at the University of Strathclyde and is building on this work whilst being an active member of this research group. <http://bjsw.oxfordjournals.org/content/early/2013/02/12/bjsw.bct017.full.pdf+html>

### Contact

For a list of recent publications please see:  
[http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/projects\\_keypub.php](http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/projects_keypub.php)

For more information, please contact:

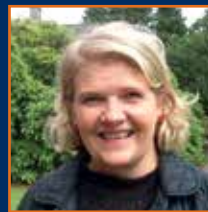
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Website <http://edin.ac/14vvnGn> | Twitter: @PPCRG

### Innovative collaborative work with St. Columba's Hospice



**Funder:** Creative Scotland  
**Research team:**

Erna Haraldsdottir, Marilyn Kendall, Amy Hardie

Strathcarron Hospice is collaborating in an innovative project working with Amy Hardie to make a film that will be shown in cinema and BBC television in 2015. Patients and staff are the main characters in the film which reflects the life story of 6 patients as well as hospice life. The film challenges the taboo around death, dying and hospices and is called "Singing Hospice". Erna Haraldsdottir has now moved to lead the Education Department at St. Columba's Hospice where she will facilitate research, while being an active member of our research group.

### Health promoting palliative care at St Joseph's Hospice, London



**Funder:** St Joseph's Hospice  
**PhD candidate:** Libby Sallnow  
**Supervisors:** Allan Kellehear, Heather Richardson, Scott Murray

Community engagement initiatives have great potential to help people live to the full at the end of life. Medical care, whether provided by hospices, hospitals or primary care comprises only one component of broad support a dying person and their family and friends need. Examples of empowered communities providing much of this social and supportive care exist in some economically poorer countries and now in the UK. This doctoral study is evaluating one such initiative at St Joseph's Hospice in London. Libby has recently published two papers to help build up the evidence base. <http://pmj.sagepub.com/content/early/2015/08/04/0269216315599869.full.pdf+html>