

News release

15 October 2013

Putting Scottish patients, carers and clinicians at the heart of palliative and end of life care research

A ground breaking partnership has been launched today to find out what palliative and end of life care research is important to people who are likely to be within the last years of life, their families, and the professionals who work with them.

Initiated by Marie Curie Cancer Care, a large number of organisations have come together to form “the Palliative and end of life care Priority Setting Partnership” (PeolcPSP) with the James Lind Alliance¹. This means that for the first time, people directly affected will get the chance to have their say in setting research priorities for palliative and end of life care. We are particularly seeking to hear from people who are likely to be in the last years of life, current and bereaved carers, and frontline social and healthcare professionals.

Palliative and end of life care is an under-researched area and requires greater attention and focus. The aim of the partnership is to ensure that future research brings the greatest possible benefit to people at the end of life, and their carers and families, by identifying what questions are of the greatest importance to them.

Co-funding partners are:

- Marie Curie Cancer Care
- Chief Scientist Office (CSO)
- National Institute for Health Research (NIHR)
- Motor Neurone Disease Association (MND Association)
- National Institute for Social Care and Health Research (NISCHR)
- All Ireland Institute of Hospice and Palliative Care (funded by Health and Social Care, Northern Ireland and the Health Research Board, Ireland)
- Macmillan Cancer Support
- Economic and Social Research Council
- Medical Research Council
- Cancer Research UK

Richard Meade, Marie Curie Cancer Care Head of Policy and Public Affairs, Scotland, said: “Research is crucial in improving end of life care and it is essential that we identify clear priorities. By getting the views of patients, their families, carers and the professionals who work with them we will ensure that future research will result in the greatest possible benefit to those at the end of life.”

Alan McNair, from the Chief Scientist Office of the Scottish Government, said: “We recognise the importance of research into end of life care and are delighted to join this partnership.

“Identifying what people want to achieve from research is an excellent example of putting patients at the centre of the work that we do and will allow the new partnership to guide researchers on the areas they should focus on in order to deliver greater benefits for patients.”

In addition, there are several other organisations represented on the Steering Group, which will oversee the partnership: Association for Palliative Medicine of Great Britain and Ireland, Help the Hospices, National Bereavement Alliance and Childhood Bereavement Network, National Cancer Research Institute (NCRI) Consumer Hub, National Council for Palliative Care, Royal College of Nursing, Scottish Partnership for Palliative Care and St Christopher's Hospice

To date, over 20 organisations – who can reach people with palliative and end of life care needs, life-limiting illnesses, families, carers, doctors, nurses and social care professionals – have pledged their support.

For more information or to get involved, email us at PeolcPSP@mariecurie.org.uk or telephone us on 020 7091 4153.

-ENDS-

Notes to Editors

Media Contact

Marie Curie Cancer Care

Tracy Barrett – Senior Media, PR and Campaigns Manager

Tel: 0207 599 7292 / Out of Hours: 0845 073 8699

E-mail: tracy.barrett@mariecurie.org.uk

¹ Background to the Palliative and end of life care Priority Setting Partnership

The James Lind Alliance (JLA) is a project which is funded by the National Institute of Health Research (NIHR). Its aim is to provide an infrastructure and process to help patients and clinicians work together to agree which are the most important treatment uncertainties affecting their particular interest, in order to influence the prioritisation of future research in that area. The JLA defines an uncertainty as a “known unknown” – in this case relating to the effects of treatment.

The Palliative and end of life care Priority Setting Partnership (PeolcPSP) was initiated by Marie Curie with the intention to address the dearth of evidence in palliative and end of life care and direct scarce resources at the issues most important to the ‘end users’ of research, i.e. patients, current and bereaved carers, clinicians and health and social care practitioners in general. Marie Curie committed the initial funding and is joined by a number of other funding bodies in the area (NIHR, CSO, NISCHR, the MND Association, Macmillan Cancer Support, Economic and Social Research Council, Medical Research Council and Cancer Research UK) who also want to see improvements in evidence-based care and treatments at the end of life and who committed to co-funding the partnership project. The results of the partnership will help direct future research funding by all the partners and beyond, for the benefit of patients, carers and families.

Marie Curie Cancer Care is the UK's leading end of life care charity. We provide free nursing care to people with a terminal illness, either in their own home or one of the charity's nine hospices. The charity is also a leader in research into the best ways of caring for people with a terminal illness. In addition, we design and advise on end of life services and work to ensure that the best possible care and patient choice is at the heart of commissioning end of life care across the UK. All Marie Curie services are completely free of charge. Around 70% of the charity's income comes from donations with the balance of funds coming from the NHS. For more information visit www.mariecurie.org.uk

The Chief Scientist Office, part of the Scottish Government Health and Social Care Directorates, supports and promotes high quality research aimed at improving the quality and cost-effectiveness of services offered by NHSScotland and securing lasting improvements to the health of the people of Scotland.

CSO supports research initiated by the research community in Scotland and advises the Scottish Government on how research contributes to improvements in health and healthcare. CSO's research strategy "Investing in Research: Improving Health" sets out our aims for 2010-14 and features changes to give greater emphasis to funding experimental and translational medicine research and health services and health population research. We also aim to deliver value for money through partnerships with other funding agencies and to foster Scotland-wide working through Health Science Scotland.