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PRAISE FOR GROUND-BREAKING PROJECT TO HELP DYING PATIENTS

The UK's National Director for Cancer and End of Life Care has paid tribute to a Liverpool-based European collaboration to optimise research for the care of cancer patients in the last days of life.

Speaking at a conference in Liverpool, Professor Sir Mike Richards said the work of the OPCARE9 project - involving 70 researchers from nine countries - will pave the way for improvements in the care of dying patients.

The project was co-ordinated by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) which is a partnership between the University of Liverpool, the Royal Liverpool & Broadgreen University Hospitals Trust and Marie Curie Cancer Care. The Institute focuses on delivering robust, high quality research, innovation and teaching in order to improve the quality of care of patients in their final hours or days.

Professor Richards was one of the key speakers at the OPCARE9 conference in Liverpool to mark the conclusion of the three-year European Commission 7th Framework project.

Professor Sir Mike Richards said: "The work of OPCARE9 has placed emphasis on how different countries and cultures provide care for the dying and how a collaborative approach to research can bring benefits to patients here in the UK and beyond. We need to continue to work between nations.

"There is no doubt that progress has been achieved in the care offered to dying patients across many countries over recent years, and the Liverpool Care Pathway for the Dying Patient (LCP) developed by the Marie Curie Palliative Care Institute Liverpool has played a critical role in this progress.

"The LCP has become embedded in care systems across many countries making a real difference to patient care and OPCARE9 has grown from the pioneering groundwork of the LCP Programme."

Professor Sir Howard Newby, Vice Chancellor, University of Liverpool, one of the Institute's partners, said: "OPCARE9 is about knowledge transfer - not just from the laboratory to the bedside but from one country to another. It is vital that we continue to share our experience and expertise among European colleagues and further afield to help improve care of the dying globally."

During the conference, OPCARE9 project members announced a six-point declaration - 'The Liverpool Declaration' - to signify their ongoing commitment to improving care for dying patients.

Professor John Ellershaw, Professor of Palliative Medicine, University of Liverpool and OPCARE9 Scientific Project Co-ordinator said: "As a collaborative we have produced a statement of beliefs which is the essence of our commitment to research excellence and patient care. This is the 'Liverpool Declaration.'

"Following OPCARE9 we are now launching the International Opcare Research Collaborative (IORC), in which we will collaborate on research protocols developed during OPCARE9, develop future research protocols for optimising care of the dying within an international framework, and ensure effective communications between members.

"Together, we can make a difference to the care of dying patients across the world."

Around 200 international delegates attended the one-day conference at the BT Convention Centre, part of ACC Liverpool, which also consisted of colloquium meetings over three days.

Findings and conclusions from seven specific work streams were presented to delegates by the multi-professional collaborators.

Speakers also included:

- Professor Lukas Radbruch, President of the European Association of Palliative Care (EAPC)
- Dr Dominika Trzaska, Scientific officer Directorate – General Research and Innovation, European Commission
- Professor Susan Block, Professor at the Department of Medicine & Psychiatry, Harvard Medical School, USA
- Tom Hughes-Hallett, Chief Executive Marie Curie Cancer Care



Photo caption: (from left) Tom Hughes-Hallett, Chief Executive of Marie Curie Cancer Care, Professor Sir Mike Richards, the National Clinical Director of Cancer and End of Life Care, Department of Health, Professor John Ellershaw, Professor of Palliative Medicine, University of Liverpool and OPCARE9 Scientific Project Co-ordinator, and Professor Lukas Radbruch, President of the European Association of Palliative Care (EAPC)

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Background information:

Specific aims of the three-year European Commission 7th Framework OPCARE9 project:

- Exploring ways of filling 'knowledge gaps' about care of the dying based on current available clinical evidence
- Measuring consensus from clinical experts
- Identifying appropriate ways of measuring care of dying
- Considering how technologies could lead to better care

Participating countries were UK, Germany, The Netherlands, Italy, Sweden, Slovenia Switzerland, Argentina and New Zealand.

Previous 3-day meetings were held in Chester (UK), Stockholm (Sweden), Cologne (Germany), Genoa (Italy) and Rotterdam (The Netherlands) and Weggis (Switzerland).

OPCARE9 was organised into five primary work packages whose objectives included:

- Developing innovative ways of addressing gaps in knowledge about care of the dying based on current available clinical evidence
- Measuring consensus from clinical experts
- Identifying appropriate ways of measuring care of dying
- Considering how technologies could lead to better care

A further two executive work packages were concerned with the process of multi-professional interdisciplinary collaboration and the continuing development of the Liverpool Care Pathway for the Dying Patient (LCP) in an international context.

Summary of work packages (WPs):

WP1 - *Signs and symptoms of approaching death.* Very little research has been carried out to determine the signs and symptoms routinely seen in patients as they enter the last days of their lives, yet a failure to recognise and respond to the dying phase (diagnosing dying) can lead to sub-optimal care.

There is a need to identify a consensus (based on current practice and available research evidence) regarding the most useful signs and symptoms of approaching death in order that appropriate care can be initiated and delivered in the final days of life. Where evidence is currently lacking, innovative research studies need to be developed to further clarify the situation.

Joint, collaborative effort between clinicians and researchers from across Europe (and beyond) has provided a forum in which to debate and determine such a consensus and to develop protocols for studies to test potential prognostic indicators.

WP2 - End of life decisions. End of life care often involves making difficult ethical decisions about the use of deep sedation to control symptoms and withholding and/or withdrawing life sustaining treatments such as artificial hydration and feeding, ventilation, dialysis, not attempting resuscitation in the event of cardiac arrest.

Robust research evidence concerning the effects of withdrawing/withholding treatments is relatively scarce and, at best, inconclusive. Here, as in all aspects of care at the end of life, cultural diversity (both within and between participating countries) will impact on such decisions and the opportunity to share and debate current knowledge with colleagues across Europe is invaluable.

There is clearly a need to establish firm evidence regarding the effects of such decisions on patients, carers and health professionals. In addition, how best to communicate around such sensitive topics in the last days of life and the effects of such decision making on issues like carers' adjustment to bereavement are topics worthy of further debate.

WP3 - Complementary comfort care. As patients enter the last days of life it is important that health care professionals adopt practices to promote patient comfort. The World Health Organisation (WHO, 2004) suggest a focus on communication, psychological, social and spiritual care as well as measures to promote the physical comfort of patients through non invasive, non technological therapies such as regular mouth care, bowel care, micturition and skin care and appropriate pain and symptom management (both pharmacological and non- pharmacological). This collaboration was aimed at facilitating discussion and knowledge transfer and enabled the development of a European consensus on optimum management of symptoms in the final days of life.

WP4 - Psychological and Psychosocial support to patients, families and caretakers. The opportunity for in-depth psychological and psychosocial assessments and interventions with either patients or carers is obviously limited in the last days of life, though carers may benefit from psychological and psychosocial support in the bereavement period.

This multi-national collaborative project was aimed at facilitating debate surrounding what constitutes appropriate communication with patients in the final days of life (and their families) (Ostgathe et al, 2007) and to identify any barriers in different countries and cultures across Europe and beyond.

WP5 - Voluntary Service. The model of care espoused by the modern hospice movement and palliative care effectively shifts the emphasis of care towards improving quality of life (and death) by promoting appropriate physical, psychosocial and spiritual care of dying patients and their families.

Palliative care services have developed very differently across Europe and in several countries (for example Germany, Italy and the UK) the volunteer movement has been at the forefront of the delivery of such care. In other countries, however, there is little available data to illustrate the quality and number of volunteer services integrated into the care of severely ill and dying patients.

This collaboration aimed to explore, share and compare current provision in each of the partner countries and to provide insights into the various roles undertaken by volunteers – i.e. support, supplanting and supplementing services (Payne, 1998).

Each of these five primary work packages has focused its attention specifically on the assessment of needs and the identification of quality indicators, technologies and the creation of protocols for future research within their own specific area.

In addition, two further 'executive' work packages were developed to supplement and support the work undertaken in the five primary work packages:

WP6 - Management, communication and dissemination – to ensure optimum communication between work package groups; the timely and on budget delivery of the milestones throughout the project and that the outputs of the collaborative are disseminated widely and appropriately

WP7 - Developmental Evaluation - to formally evaluate the project and to learn more about the process of collaborative decision making. Evaluation of the products of the project to potentiate the development of the LCP framework at an international level.

The OPCARE9 Liverpool Declaration:

1. Every person has the right to live in societies where death and dying are acknowledged as part of life. ***We commit ourselves to improving societal and public health approaches to meet this goal.***
2. Every person has the right to die receiving optimal care with respect to their wishes. ***We commit ourselves to improving awareness to meet this goal.***
3. Every person has the right to access adequate palliative and hospice care in all settings. ***We commit ourselves to improving healthcare structures to meet this goal.***
4. Every person has the right to this care given by professionals and volunteers who are appropriately trained. ***We commit ourselves to implementing care of the dying in all curricula for healthcare professionals and volunteers.***
5. Every person has the right to continuous improvement of palliative and hospice care through transfer of research results into practice. ***We commit ourselves to improving conditions for research for care of the dying and implementation of research results.***
6. Every person has the right to equitable access to high quality end of life care across all countries. ***We commit ourselves to the setting of international standards and evaluating their ongoing implementation.***

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