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WORLD EXPERTS ON CANCER CARE AT THE END OF LIFE GATHER IN LIVERPOOL

AROUND 200 international delegates are heading to Liverpool for a major conference focusing on the end of life care of cancer patients.

The OPCARE9 Conference at the BT Convention Centre, part of ACC Liverpool, on **Tuesday March 1st 2011** marks the completion of a three-year European Commission 7th Framework project involving clinicians, academics, and researchers from nine countries across the world.

European Union funding of €2.2million has enabled over 70 multi-professional collaborators to investigate ways of optimising research and clinical care of cancer patients in the last hours and days of life.

The project has been co-ordinated by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) which is also the UK representative. The Institute focuses on delivering robust, high quality research and teaching in order to improve the quality of care of patients, including cancer patients, in their final hours and days.

The Liverpool event comprises a three-day colloquium for project members and the one-day key dissemination conference which turns the spotlight on highlights and results of the three-year collaborative project.

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

Speakers include:

- Professor Lukas Radbruch, President of the European Association of Palliative Care (EAPC)
- Professor Sir Howard Newby, Vice Chancellor, University of Liverpool
- Professor Sir Mike Richards, National Clinical Director of Clinical and End of Life Care, Department of Health, England
- Dr Dominika Trzaska, European Union, Research Directorate
- Professor Susan Block, Professor at the Department of Medicine & Psychiatry, Harvard Medical School, United States

Professor John Ellershaw, Professor of Palliative Medicine, University of Liverpool and OPCARE9's Co-ordinator says: "This conference in the Institute's home city of Liverpool is an opportunity to celebrate the success of OPCARE9, where networks of expertise have developed. Working collaboratively across Europe and beyond has strengthened our commitment and capacity to undertake high quality, robust research and development to improve care of the dying in the 21st century."

For more details visit www.opcare9.eu

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Background notes for media:

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 are UK, Germany, The Netherlands, Italy, Sweden, Slovenia Switzerland, Argentina and New Zealand.

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

OPCARE9 is organised into five primary work packages whose objectives include:

- 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 are 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:

During the conference, OPCARE9 project members will announce a six-point declaration to signify their ongoing commitment to improving care for patients in the last hours and days of life. It is anticipated that this will motivate conference delegates to work together in the future through undertaking robust high quality research and development.

The '**Liverpool Declaration**' as it will be known states:

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.*

ENDS