

# The International Observatory on End of Life Care

David Clark and Michael Wright on a new research and development initiative in palliative care

## The global context

Around the world more than one million people die each week. It is estimated that 60 per cent of these could benefit from some form of palliative care, but only a tiny minority ever receive this support, despite the efforts of WHO and other agencies. Palliative care remains hugely underdeveloped in those resource poor countries where it is perhaps the most realistic and effective therapy to offer, and it is still significantly underdeveloped in many countries with otherwise 'advanced' health care systems. Now, more than ever, it is a time to be thinking globally, as well as acting locally.

A new research and development initiative for end of life care Since the beginning of the 1990s, together with many colleagues, we have developed experience of policy and needs assessment in palliative care, service evaluation, historical analysis, ethical and cultural reflection. Plans are now being made to establish a wider programme of activity focussing on comparative information relating to hospice/palliative care around the world: past, present and future. It will seek to generate such data from original studies, collate material gathered elsewhere, and above all turn this into useful intelligence that can influence current policy and service development.

## The International Observatory on End of Life Care

From September 2003 the International Observatory on End of Life Care is to be established at Lancaster University within the Institute for Health Research. It will be led by David Clark, working with a team of collaborating researchers, and in partnership with colleagues and organisations in many parts of the world. In addition to the Observatory's project-based research and development programme it will also house the digital

and paper archives of the Hospice History Project and contain an extensive collection of current reference materials.

## Features of the Observatory

The idea builds on successful public health observatories and in particular draws on the contribution of the European Observatory on Health Care Systems, but is unique in being focussed on end of life care and in its mission to go beyond a purely epidemiological frame of reference. It will provide data on key structural issues facing the development of palliative care, country by country, including: health care system and reimbursement issues; opioid availability; education, training and workforce development; audit and evaluation; partnerships and international collaboration. Additionally, it will contain country-based material on relevant cultural and ethnographic issues, as well as material relating to end of life care ethics - all seen in historical context. The Observatory website will make available this information for each country, and will be configured for searches of specific topics and issues across countries. It will also have links to other important websites. The website will also contain the current set of Hospice History Project web pages, those of Mortal Press (the Observatory's in-house publishing arm) and details of other related end of life care studies.

## Aims of the Observatory

- To provide clear and accessible research-based information on hospice and palliative care provision in the international context, incorporating public health, demographic, epidemiological and health care systems analysis as well as ethnographic, historical and ethical perspectives.
- To disseminate this information through the Observatory website and through published articles,



On March 14, 2003, a meeting was held in Lancaster to discuss partnership between Help the Hospices and the Observatory: (l to r) Professor Tony Gatrell, Director of the Institute for Health Research at Lancaster University, Professor David Clark, David Prail, Mick Thorpe and Nick Pahl from Help the Hospices.

monographs, reports, CDs and other media, in ways which facilitate cross-national comparative analysis and stimulate practical development.

- To undertake primary research studies and reviews
- To develop a small grants programme to support academic work relating to the aims of the Observatory in resource poor regions.
- To work in partnership with key organisations and individuals, nationally and internationally, in order to foster a sense of inclusion and participation in the work of the Observatory.

## Personnel and partnerships

The International Observatory on End of Life Care is seeking active and sustainable partnerships with organisations and individuals committed to the global development of palliative care. It has a growing network of collaborators across several countries and continents and already has key links in India and South America, as well as Eastern Europe, Central Asia and Africa. The Observatory already enjoys the support of the following organisations: Help the Hospices, International Association for Hospice and Palliative Care, Open Society Institute Public Health Network Program, Palliative Care Initiative Oxford University Press, The Diana, Princess of Wales Memorial Fund.

## Links

- [www.eolc-observatory.net](http://www.eolc-observatory.net)
- A list of relevant recent publications is available from: [info@eolc-observatory.net](mailto:info@eolc-observatory.net)