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**THE INTERNATIONAL OBSERVATORY ON END OF LIFE CARE (IOELC):
AN INFORMATION RESOURCE FOR PALLIATIVE CARE.**

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ABSTRACT

Although millions of people die each year throughout the world, and a large proportion of these would benefit from palliative care, services to provide care for dying people are under-developed through the world, but particularly in resource poor regions. This paper describes the development of an information resource on the World Wide Web, the International Observatory on End of Life Care (IOELC), to provide information on palliative care services in Eastern Europe and Central Asia. The paper describes the development of the IOELC, as well as the structure and how data were collected. It concludes with a discussion of plans to evaluate the web-site and to expand it to include other world region, with the aim of developing it into a global information resource for the development of palliative care services.

Keywords: Palliative Care; Information resource; World Wide Web.

INTRODUCTION

Annually, approximately 56 million people die throughout the world. Although about 60% of these people could benefit from palliative care, only a tiny minority of dying people ever receive the support of hospice and palliative care services. This is even though valid and simple methods exist, which cost little and are acceptable and maintainable at community level, and which can ensure the relief of suffering on a large scale. Such methods could assist millions of individuals dying of cancer, AIDS, and the advanced diseases of old age. The World Health Organisation (WHO) has promoted clear public health policies and advice for the rational implementation of pain relief and palliative care. However, palliative care is not available in many of those resource-poor countries where it is perhaps the most realistic and effective therapy to offer, and it is still hugely underdeveloped in many countries with otherwise 'advanced' health care systems.

Palliative care is a new and emerging speciality in medicine and its development faces many medical socio-economic, cultural and ethical problems. The sharing of information on palliative care among countries offers enormous potential benefits, if this information is used in conjunction with, and respects, local, regional and national cultural expectations and values. Therefore, there is a recognised need for a greater understanding and knowledge base on the current level of palliative care services in different countries throughout the world. This paper describes the development of such a knowledge base, the International Observatory on End of Life Care (IOELC), and it is hoped this will serve as an important information resource for those developing palliative care services throughout the world.

BACKGROUND TO THE IOELC

In May 2002, two of the authors of this paper, David Clark and Michael Wright, completed the first ever review of the development and current provision of hospice and palliative care in the 28 countries of Eastern Europe and Central Asia (Clark and Wright, 2002). The review provides an overview of activity and a comprehensive analysis of the current state of hospice and palliative care provision across the whole region, country by country (Clark and Wright, 2002). Since the report was published in May 2002, there is considerable evidence of its impact and it soon became clear that

further dissemination of the information gathered for the report could usefully be disseminated through the World Wide Web. We now describe the IOELC web-site and discusses ideas for its further development.

INTERNATIONAL OBSERVATORY ON END OF LIFE CARE (IOELC)

The original aim of the project was to use the existing material collected in Eastern Europe and Central Asia for the review by Clark and Wright (2002) to develop a web-site, called the International Observatory on End of Life Care (IOELC), and then to develop a methodology for its regular updating and enhancement, and its extension to other resource-poor regions of the world. The Observatory is the first ever research and development initiative to focus on comparative information relating to hospice/palliative care around the world. It seeks to generate such data from original studies, to collate material gathered elsewhere and above all, to turn this into useful knowledge, which can influence current policy and practice development. To achieve this a review methodology was developed for Eastern Europe and Central Asia and plans are underway to extend this data collection to other world regions.

DATA COLLECTION

The review methodology was developed to facilitate the collection of quantitative and qualitative data on palliative care services and factors influencing their development. These methods include:

- collating and comparing relevant quantitative epidemiological, demographic, health system data from governmental, public health and NGO sources.
- in-depth qualitative interviews with key personnel;
- analysis of published hospice, palliative care and related sources.
- production of country by country reports using a template from personnel undertaking work in individual countries and regions.
- case study analysis highlighting palliative care ‘success stories’ using site visits, interviews with key stakeholders and documentary analysis.
- development of a network of collaborating colleagues within each country to facilitate data collection.

- collaboration with relevant NGOs, charitable foundations, academic groups, policy makers and inter-governmental agencies.

ORGANISATION OF THE IOELC WEB-SITE

The IOELC web-site has been designed to facilitate use and access to information relating to the information on palliative care services and factors affecting their development on a country by country basis. The IOELC home page is located at: <http://www.ioelc-observatory.net/>. From the IOELC home page the user can access information on each country via an alphabetical list of countries or via a world map and regional maps.

Organisation of information

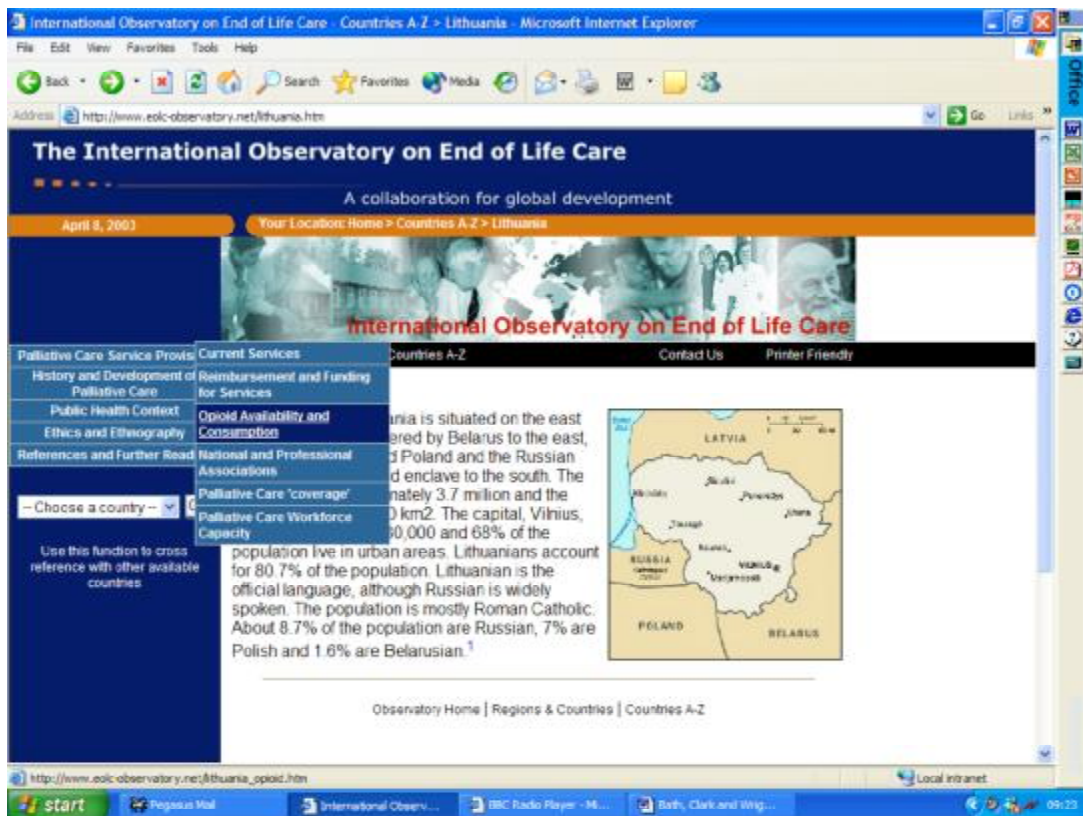
For each country, the information is organised into the following four main themes, each of which has its own sub-themes as indicated:

- Palliative Care service provision:
 - Current services.
 - Reimbursement and funding for services.
 - Opioid availability and consumption;
 - National and professional associations;
 - Palliative care “coverage”;
 - Palliative care workforce capacity.
- History and development of palliative care services:
 - Narrative History of Palliative Care;
 - Hospice/Beacon Case Studies ;
 - Life/Oral Histories;
- Public health context;
 - Population;
 - Epidemiology;
 - Health care system;
 - Political Economy;
- Ethics and ethnography:

- Ethical Issues;
- Ethnographic Studies.

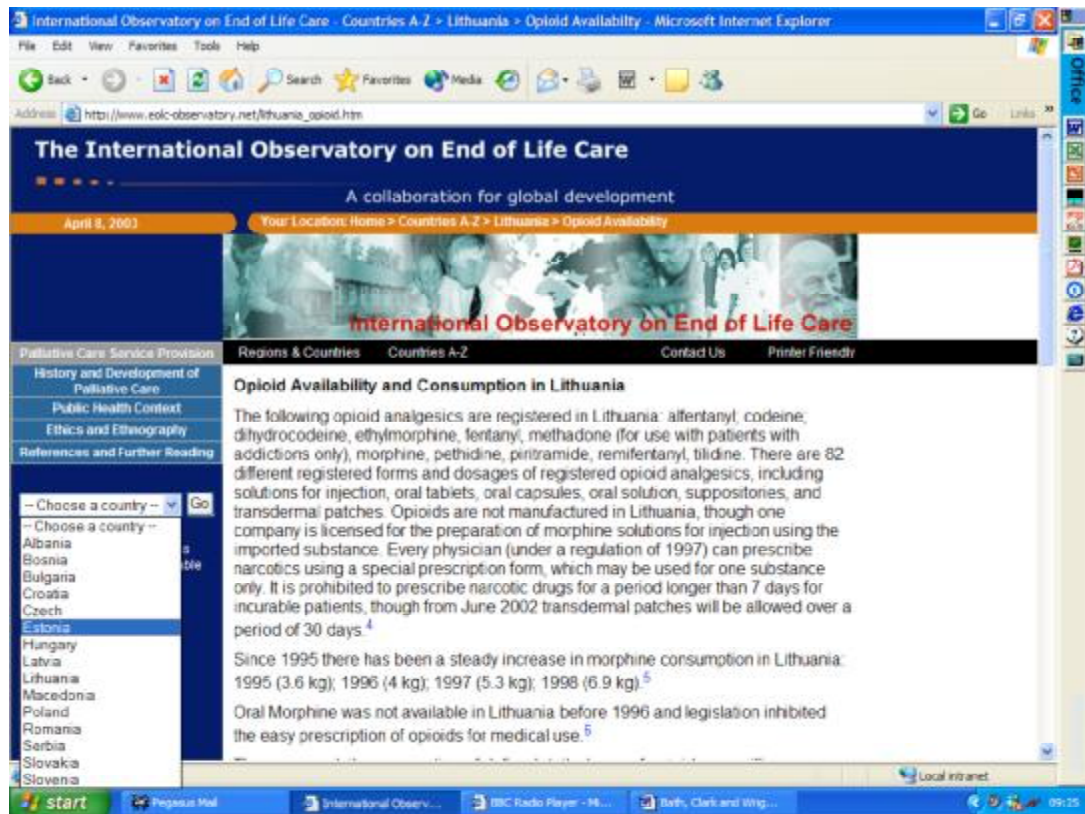
In addition, a list of key references further reading is available for each country. Each country has a home page which briefly describes the geo-political situation for the country and which provides a map of the country. From this home-page, the information on each of these sub-themes can be accessed by users by placing the cursor over the drop-down menus for each main theme on a vertical menu bar. Figure 1 shows the home page for Lithuania together with the drop-down menu highlighted for Opioid Availability and Consumption within the Palliative Care Service Provision theme.

Figure 1: Home page for Lithuania on the IOELC.



Once the user has arrived at that page, as shown for the page on Opioid Availability and Consumption for Lithuania in Figure 2, he or she can cross-reference to the same information for another country by using the drop-down menu entitled “Choose a country” located beneath the list of themes in the frames section.

Figure 2: Information on Opioid Availability and Consumption for Lithuania in the IOELC, showing the drop-down menu to access the equivalent information for other countries.



This facility to navigate across the countries for a particular sub-theme means that it is possible for the user to access easily the information on an area of interest to compare the information available across a number of countries.

In the near future, the IOELC will also contain links to other important websites, and eventually it will include PDF files of crucial policy and research papers, standards and guidelines, and educational curricula. Our vision is that the website will be enhanced by the incorporation of primary data gathered in original study, e.g., interview summaries pdf files of key documents and bibliographies, and multimedia will be used to include audio, image, as well as textual data.

FUTURE DEVELOPMENTS AND CONCLUSIONS

The work undertaken for the review and in developing the web-site for Eastern Europe and Central Asia indicates that research activities of this kind would be of considerable value in extending the existing knowledge base and in drawing wider attention to hospice/palliative care needs across the entire continent, as well as sub-regions within it. One of our aims for the IOELC is now to develop an understanding of how it is acting as a resource within the regions and to this end we are now devising an evaluation strategy for the Observatory to ascertain both the perceived value of the IOELC among users and to study wider knowledge and awareness of Observatory.

Possibilities are now being explored for conducting similar regional reviews of hospice/palliative care in other resource poor regions of the world, particularly Africa, India and Latin America, where the HIV/AIDS pandemic has caused the international community to pay increased attention to the question not only of prevention and treatment, but also to the palliative care of those affected. We anticipate that this information, when made available through the IOELC web-site, will increase the currently poor evidence base concerning what palliative care provision presently exists, will provide information on barriers to development and how they may be overcome and increase awareness among international funders and potential developers of services. In addition, we envisage that the web-site will become an important information resource for palliative care development and will permit comparative global analyses of palliative care services, as well as public health, ethnography and ethics. The Observatory has huge potential to help fill the current skills and knowledge gap that is holding back palliative care development and will seek to serve the national and global palliative care community.

REFERENCES

Clark D and Wright M (2002) *Transitions in End of Life Care: Hospice and related developments in Eastern Europe and Central Asia* Buckingham: Open University Press.