

health information via the internet and there are concerns about the availability and quality of that information. This review examined online information needs of people affected by cancer.

**Methods:** An online questionnaire was distributed on a European basis via Eurocancercoms [2] partners' websites and European patient organisations. The questionnaire was developed with the support of the ECCO [3] patient advisory committee and translated into 5 European languages. The questionnaire asked people who have been directly affected by cancer a range of questions relating to their experience of online information.

**Results:** A total of 476 people responded to the survey representing 26 European countries during a 6 month period in 2010. Respondents wanted information on all aspects of cancer: side effects and treatment options were the highest frequency responses. Other requests included; detailed, specific information on their own cancer type and an ability to 'chat on-line' and discuss experiences.

The majority of respondents (59.6%) thought that online health information is accurate or mostly accurate. It was observed that treatment decisions were always influenced (71.5%) and frequently influenced (24.7%) by Doctors or other health professionals; other factors such as information on line, advice from other patients/advocacy organizations were less likely to influence them (combined 'always' and 'frequently' totals <40%).

How you use internet site?	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
I search across several sites when looking for information	43.65%	39.09%	9.14%	5.58%	2.54%
I focus on one trusted site when looking for information	25.40%	37.04%	16.40%	16.40%	4.76%
I am satisfied that I can find reliable information about my condition	20.00%	47.37%	23.68%	6.84%	2.11%
I would have more confidence in online health information if endorsed by a professional body	37.82%	39.38%	15.03%	3.63%	4.15%
Having access to information from the internet has helped me make treatment decisions	18.52%	26.98%	24.34%	16.93%	13.23%
Having internet information has made me more confused about my condition and treatment options	5.38%	16.67%	20.43%	39.25%	18.28%

Table 1. Respondents' use of internet sites.

**Conclusions:** People affected by cancer want to easily access accurate and relevant cancer information on a wide variety of topics. Information provided should be understandable and of sufficient quality to enable the evolving consumer, to use online health information and social networking resources to make informed choices about their health care options.

This survey was performed as part of the Eurocancercoms project and supported by European Union funding.

## References

- [1] Coulter, A., J. Ellins, et al. (2006). 'Assessing the quality of information to support people in making decisions about their health and healthcare', Picker Institute Europe, Oxford, available at [www.pickereurope.org/Filestore/Downloads/Health-information-quality-web-version-FINAL.pdf](http://www.pickereurope.org/Filestore/Downloads/Health-information-quality-web-version-FINAL.pdf)
- [2] Eurocancercoms is a 7th framework programme (FP7) project funded by the European Commission. <http://www.eurocancercoms.eu/> Eighteen working parties are involved in the eurocancercoms project
- [3] ECCO, European Cancer Organisation

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POSTER

## Fast Track Guideline Update Successful

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**Background:** The Dutch Comprehensive Cancer Centre (in Dutch IKNL) was set up to improve treatment, patient care and clinical research within the field of oncology in order to provide cancer patients and their families access to comprehensive and high-quality care as close to home as possible. A major activity is guideline development.

**Material and Methods:** To perform guideline development and update in a timely and cost-effective way is a real challenge. Accordingly the 2005 guideline Oesophageal cancer was fully updated in 2010 using a new method. The guideline update was partly evidence based, partly consensus based. The time table was drawn first, working backwards from the dates the authorising societies meet. A broad and multidisciplinary

call for knowledge gaps was issued and used to generate the topics that needed evidence based updating. Five topics were selected including a topic from the patient association. The 22 experts and 2 patients were allocated to the topics and an agenda was set for monthly meetings with proceeding conference calls to ensure focussed meetings, without repetitive discussions over already decided issues. A party specialized in medical literature search and appraisal was contracted. They were promptly supported by the experts and also delivered the evidence tables. A web-based comment procedure was introduced, enabling quick gathering and response of the comments. After the first draft of the evidence based parts the consensus based update started simultaneously. A total of 6 meetings was needed to deliver the updated guideline. The last meeting was also used to generate the first draft of indicators to monitor guideline implementation. Putting it all together the updated guideline was submitted timely for authorisation.

**Results:** The professionals were enthusiastic; the process was rounded off within a year and even stayed within the budget limitations. A new pilot is started to update the guideline yearly, increasingly extending the evidence based parts.

**Conclusions:** A pilot to update a guideline within a year was successful and proved our fast track method effective. Web-based commentary round enables quick proceeding. Frequent and well prepared meetings during a short period of time are well appreciated by the professionals. A party to perform the literature search and evidence tables enables the professionals to focus on the content of the subject.

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POSTER

## Quality of Life of Family Caregivers During Ambulatory Care of Palliative Cancer Patients

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**Background:** Dedicated family members are an essential requirement for ambulatory care of incurable patients. However, the heavy burden of the care giving situation, psychologically and physically, often takes its toll on the caregivers' health. Previous research projects in the field of ambulatory palliative care are very limited, and even less attention have been given to the effects on family caregivers.

**Material and Methods:** In the research project initiated by the Department of Medical Psychology at Leipzig University in Germany 49 family caregivers of palliative patients were interviewed at their homes. The interviews took place at the beginning of the ambulatory care, on average three months before the patients' death. Health-related quality of life was assessed using The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30). It is a 30-item self-report survey. The test includes five functional scales, three symptom scales/items and one scale representing the global health status.

**Results:** 80% of the caregivers were the patients' partners. While the physical, cognitive and social domains of the family caregivers' quality of life are on average at quite a high level (values of 75–100), suggesting a good functionality, the values of their emotional functioning and global health status are considerably lower, occurring in the middle range from 51–75. At the beginning of the care giving situation the level of emotional functioning in the sample of caregivers (mean = 54, 08) is significantly lower than in the reference group of the general population ( $p = 0.000$ ).

With regards to the symptom-scales, no significant differences of arithmetic mean values were discovered.

**Conclusions:** The current results suggest that the emotional health of family caregivers is significantly poorer in comparison with the general population. Consequently, family caregivers should be offered much more professional support.