

# DIFFERENT WAYS TO PRODUCE INFORMATION FOR PATIENTS

KWF  
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BESTRIJDING



Cora Honing, MA  
International Relations Officer Dutch Cancer Society/  
President Association of European Cancer Leagues

‘Why didn’t I get this information earlier.’

‘Why was it so hard to get accurate information about my cancer’.

‘Why didn’t I know about other sources of information besides my doctor and the nurse after I was told the diagnosis?’

## Dutch Cancer Society:

- Largest private health fund in the Netherlands
- Patient education and support: core business
- Financing and collaboration with cancer patient organizations.

## Association of European Cancer Leagues:

- 26 member leagues: from Iceland to Turkey
- Range of activities: from cancer research to palliative care.

Focus of the presentation:

- Optimal availability of information to cancer patients
- Contribution of patient organizations to this availability.

The importance of patient information is beyond discussion:  
change in nearly 30 years:

- From lack of information to overload of information
- From one source of information to multiple sources
- From understanding illness and treatment (compliance)  
to partner in decision making (compliance and  
empowerment).

Information needs of cancerpatients differ from country to country:

- Influenced by:
  - Level of taboo on cancer in society
  - Role of the media
  - Openness about cancer in health care
  - Level of education in population
  - Expected role of patient.

## Information Need Assessment:

- Quantitative research: surveys
- Qualitative research: panels/interviews
- Input patient organizations
- Input professionals.

## Development of patient information:

- Importance of legal framework:
  - At national level
  - At European level.

Development of patient information:

- Importance of clinical guidelines:
  - Education policy included?

Example: guideline for 'bad news conversation': Comprehensive Cancer Centre North, includes advise to hand out a tape recording of this conversation.

## Development of patient information:

- Importance of National Cancer Control Programmes:
  - Patient education included in the programme?

Dutch NCCP:

‘The provision of care must do justice to the autonomy of the patients and those close to them.

Adequate information is indispensable in this regard, not just during the course of the disease, but also before and afterwards’.

## Development of patient information:

- Source of information:
  - The physician is perceived as the most important source of information:
    - A majority of patients state they do not get enough information from this source (survey of the Finnish Cancer Society 2008)
    - A small proportion of the patients rated the communication of the doctors 'optimal' (survey of the Danish Cancer Society 2006)
  - Internet is a growing source of information for cancer patients (survey of the Dutch Cancer Society 2008).

## Development of patient information:

- Content based on patient needs and state of the art research, clinical guidelines and best clinical practise
- Decision about sender of the information
- Choice of channel of information
- Cost-effectiveness aspects.

Contribution of patient organizations to the availability of patient information depends on:

- State of the art regarding patient information in national health care
- Position of cancer patient organization in cancer care
- Focus of the patient organization
- Status of professionalism of the patient organization
- Availability of partners in the area of patient information.

Role of patient organization regarding the availability of patient information:

- Advocate of patient information at the medical professional level and/or political level
- Partner in development and distribution of patient information
- Provider of patient information.

Improvement of availability of patient information:

- Uniting to defeat cancer: UICC
- Together we beat cancer: Cancer Research UK
- Linking hands to improve cancer control: Dutch NCCP

The key word: collaboration with respect to expertise and experience of all partners involved!!!