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## Current perspective

# Online information as a decision making aid for cancer patients: Recommendations from the Eurocancercoms project

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## ABSTRACT

A pan-European survey was conducted under the auspices of the FP7 Eurocancercoms project during the period September 2010–March 2011. It was designed to broaden public policy understanding of patients' specific needs when seeking online cancer information and aimed to identify gaps in the online cancer information provision across Europe. In this paper we describe the methodology and main findings of the Tenovus survey, and draw some recommendations on the use of online information as a decision making aid for cancer patients and their families, namely: (1) transparency and accountability of the sources of information presented online; (2) accreditation of information by different recognised forms of authority and expertise, i.e. both by health-care professional and by patients/public members belonging to patient advocacy groups; (3) scaling up of information: we envisage a 3-tiered system that would enable patients to access different levels of complexity and volume of information from summary to detailed; (4) embedding of custom search tools and interactive search technologies to allow users to define requirements tailored on their needs and be context-driven; (5) communication across discipline boundaries, as patients' and doctors' online communities have very little or no contact among one another. These recommendations were applied for building the online platform EcanHub, also under the auspices of the Eurocancercoms project, which by bringing together the different cancer communities seeks to break down traditional information boundaries, and through the interactions produce a surplus knowledge that could aid patients in difficult decision making times.

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## 1. Introduction

*'Information is a source of learning. But unless it is organized, processed, and available to the right people in a format for decision*

*making, it is a burden, not a benefit'*. This quote, usually attributed to William Pollard, an English Clergyman of the XIX century, could indeed be adapted to the plethora of information that can be found nowadays on the world-wide-web

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(hence, *www*). In particular, it could be adapted to the kind of health information patients are seeking on the *www* following a cancer diagnosis, or when they turn to the *www* looking for a second virtual opinion or for additional information to help them in a time of difficult decision-making. But, as Pollard aptly put it, unless it has been properly processed and organised, the information can become a burden for those patients. What does it mean to be ‘properly processed and organised?’ And what are the strategies that can be put in place to be sure it is? In order to answer this question, a pan-European survey was conducted under the auspices of the Eurocancercoms project<sup>1</sup> during the period September 2010–March 2011. It was designed to broaden public policy understanding of patients’ specific needs when seeking online cancer information and aimed to identify gaps in the current online cancer information provision across Europe. In this paper we describe the methodology and main findings of the Tenovus survey and draw recommendations on the use of online information as a decision-making aid tool for cancer patients and their families.

## 2. The Tenovus survey: materials and methods

An online questionnaire was designed and administered by the Welsh cancer charity Tenovus (a member of the Eurocancercoms project) to understand the views of those affected by cancer focusing on their on-line information needs and information seeking behaviours. A particular emphasis was placed on ensuring that the questionnaire covered the following specific areas:

- a. Consumer health status e.g. patient, carers, patient advocacy group;
- b. type of online information wanted;
- c. methods used to check the reliability of online information;
- d. sources used for getting and sharing information. (e.g. internet: including social media, printed material, health professionals);
- e. factors influencing Web searching.

The survey also included an open-ended question i.e.: ‘What other types of information would you like to access online?’, and in addition gave the users the opportunity to comment on other questions in the survey.

The questionnaire was reviewed and piloted by the Patient Advisory Committee of the European Cancer Organisation<sup>d</sup> following translation into German, French, Spanish and Italian. It was distributed on a European level to all patient and consumer organisations and a link to the questionnaire was available from the websites of Eurocancercoms and those of other project partners. A total of 476 people covering over 20 countries accessed the online survey, approximately 70% of whom fully or partially completed it. The majority of

responses were from the UK (22.8%), Denmark (20.1%), Italy (18.4%), Germany (15.7%), Spain (8%) and France (5.5%). Most respondents (82.9%) had had a cancer diagnosis, with 53.5% being diagnosed within the last 5 years.

## 3. The Tenovus survey: results

This survey found that people seeking cancer information wanted a variety of information about cancer, spanning the complete ‘cancer journey’ from treatment choices, side effects, to activities promoting recovery, help for daily tasks, advice on diet and nutrition and for long term planning, including financial advice and legal support.<sup>e</sup> Although side effects and treatment options were the highest frequency responses for types of online information wanted, over 50% of respondents strongly agreed or agreed that they wanted all the types of information listed above.

Regarding which sites people affected by cancer looked at and why; the survey found that 83% of responders ‘strongly agreed’ or ‘agreed’ they searched across several internet sites when looking for information, while in a separate question 62% ‘strongly agreed’ or ‘agreed’ that they focused on one single site that they deem to be trusted as an aid for decision-making. Most people (77%) ‘strongly agreed’ or ‘agreed’ that they would have more confidence in online health information if it was endorsed by a recognised professional body. The main factors that influenced respondents’ decisions to look at or use a particular site were: (a) facility to retrieve information; (b) qualification of authors; (c) type of organisation providing the information: (patient support or advocacy group/cancer professional body, etc); and (d) whether the information was considered up-to-date.

The survey also explored the ways in which patients communicate about their disease, and found that patients used social media to talk about their cancer, mainly by using emails (33%), forums (33%), social networking sites (9%), chat rooms (7%) and blogs (6%). The narratives of cancer journeys acquire a crucial importance in the eyes of patients going through similar experiences and their acquired ‘expertise’ may be weighted as much as or even more than the expertise of health care professionals by other patients with the same or a similar prognosis.

Just over half of respondents (56%) thought that online health information was ‘mostly’ accurate. This still left a major proportion (40.5%) considering information from the internet to be only ‘occasionally’ or ‘sometimes’ accurate, highlighting, therefore, the existing gap of accuracy of information.

## 4. Discussion

Our research and earlier studies have shown that patients like and can benefit from stories of other patients, and that the *www* is an important source of these stories.<sup>2</sup> Peoples’ shared stories and experiences are used not just for valuable

<sup>d</sup> The Patient Advisory Committee (PAC) was established to emphasise ECCO’s commitment to its patient interest agenda.

<sup>e</sup> An extensive publication of the results of the project can be found here: Accepted for *ecancermedicalscience*, publication 2011 (forthcoming for *ECMS* 2011).

emotional and psychological support – often not routinely supplied by health services – but also to acquire clinical knowledge and learn how other people have managed their similar immediate health care needs and long-term condition. As read on the iHealth Report developed by Jane Sarasohn-Kahn for the California HealthCare Foundation, ‘When patients managing the same chronic condition share observations with each other, their collective wisdom can yield clinical insights well beyond the understanding of any single patient or physician’.<sup>3</sup> While medical credentials are still regarded as a first source of recognised authority and expertise by patients seeking online information, in the era of Health 2.0 they are no longer the only ones, as patients more and more often regard the lived experience of other patients as a reliable source of expertise.<sup>4</sup>

In what follows we provide a few recommendations based on the results of the Tenovus survey for the use of online information as an aid in decision-making:

#### 4.1. Recommendation # 1: transparency and accountability of information

The sources of the information available from a determined website should be clearly identifiable. Any website should make it easy for people to know who is responsible for writing the information presented on the website. Also, any website that uses personal informational should explain clearly what the site will and will not do with that information. Although there are comprehensive guidelines for evaluating Web resources on health information,<sup>5,6</sup> a simpler checklist of advice displayed on the website could be more useful for the user. For example, the fact sheet for Evaluating Health Information on the Internet developed by the National Cancer Institute could be a good starting point for providing minimum criteria of trustworthiness of a website, while serving as an entry point of recognised reliability for an individual accessing a new website for the first time.<sup>7</sup>

#### 4.2. Recommendation # 2: accreditation of information by recognised authority and expertise

As spelled out above, in the Health 2.0 era medical credentials are no longer the only recognised form of expertise and authority by patients, who also look for information from the narratives of other patients. Therefore, we recommend that each website is ‘formally accredited’ (and possibly also rated in a way similar to other websites which are rated and reviewed by previous users) both by health care professionals who are recognised authorities in a particular field, and by other patients/patient advocacy groups who have gained their expertise through their lived experience of the disease.

Health care providers with expertise in specific areas can be encouraged to review websites and sort them by specific diagnoses prior to listing them as a source of additional information. The opinion of recognised ‘experts’ and ‘authorities’ in the field of oncology, e.g. professional cancer bodies, could indeed serve as an anchor and entry point both for fellow clinicians and for those patients who need, especially at their first visit to a new website, a reliable and authoritative

introduction to the content offered on that website. Likewise patients, who as we found, were happy to share recommendations for websites could be encouraged to categorise these further or use a rating system to contribute to and possibly elaborate further on particular areas of value/interest within particular sites. Patients will, with increasing confidence and the support of the peer community, be able to decide whether to renew the initial trust accorded to the website or not. Stories and experiences narrated by other patients will contribute to peer-reviewing the content of the website. We also consider that the narrower the scope of the expertise, the more reliable the expertise in that particular field. For example, we recommend not to have experts in a field as broad as ‘breast cancer’, but to have experts in ‘Her2 positive breast cancer’ or ‘metastatic breast cancer refractory to trastuzumab’, and so on and so forth.

#### 4.3. Recommendation # 3: scaling up of information

Patients differ not only in the kind of information they are looking at, but also in the depth of information they are seeking. Not all patients are willing – or have enough background knowledge – to approach and understand an article published on PubMed. As a matter of fact, an excess of information may not only benefit, but actually harm those patients who do not possess the tools to understand it. Going back to Pollard, for those patients an excess of information may become a ‘burden’. It also has to be noted that the clinical relevance of a scientific finding of an article published on PubMed may be null, but the patient may very well be unable to distinguish the relevance of a statistical scientific correlation between a genetic mutation and the onset of a particular tumour from the relevance of the same genetic mutation in terms of treatment. Therefore, for this reason and others along the same lines, we recommend a ‘scaling up’ of the information, where patients should not be overloaded from the first page by an excess of information, but they should be able – by clicking on it – to access different levels of complexity and volume of information. For example, we would envisage a 3-tiered system that would comprise the three following levels:

- (a) a brief summary or easily understandable explanation of the disease, treatment options or prognosis spectrum the patient is looking for. This could also include an audio-visual clip which could result in a more direct way to convey bullet points of essential information,
- (b) a more detailed description or explanation of (a), which could entail also diagrams or charts/table that illustrate graphically the statistics or epidemiology, or other aspects of the disease,
- (c) a comprehensive description or explanation including links and references to journal articles, making sure though that each reference was accompanied by a short 2–3 lines introduction explaining the relevance of the article for research or clinical outcome.

A more elaborated system for the scale-up of information could of course be envisaged and tailored depending on the kind of disease or question asked by the user, but the general

principles underlying the need for the system would remain valid.

#### 4.4. Recommendation # 4: custom searches for tailored needs

Related to previous point, it is a matter of fact that different users seek different kinds of information, and it often happens that they are overwhelmed by the wrong kind of information, which can turn out to be very counter-productive for them. For example, a patient retrieving information written in medical jargon and aimed at health care professionals may not only have difficulties in understanding it, but may very well misunderstand it with possibly very negative consequences for his/her well being and for the overarching goal of using online information as an aid in decision making. Along similar lines, the information derived by basic research in oncology can be misleading for those patients looking for information of clinical relevance, as spelled out above. Therefore, we recommend the inclusion on websites of a custom search of information based and tailored on the kind of user approaching the website. Towards this aim, we envisage a first step of identification of the user as 'patient', 'health-care professional' or 'researcher', which would lead to a second step in which the user were to retrieve only the information relevant for his/her sub-group. As spelled out in (1), the transparency of sources and accountability of the information would still be essential criteria that would need to be displayed in the second step of retrieving information.

Another way we recommend the information could be customised/tailored would be on the basis of geographical relevance. While many online users are nowadays able to access information in English (even though they may not be fluent in English), a major barrier remains the non-relevance of the information. Just to give an example, a user seeking information on clinical trials or on treatment options corresponding to his or her diagnosis will in most cases not be interested in results available on the other side of the ocean. Therefore, tools that could screen the results on the basis of a first step of identification of the geographical provenance of the query could greatly help the user in screening the information.

#### 4.5. Recommendation # 5: communication across discipline boundaries

Complementary to (4), and as highlighted by the Tenovus Survey and the other projects under the Eurocancercoms umbrella (e.g. the project led by EACR exploring how the www has impacted on communication among cancer researchers and scientists<sup>8</sup>), there is an existing and perceived gap among the different communities engaged in oncology. Patients advocacy groups online often have very little or no contact with doctors online communities, as highlighted by the recent health-care and social media conference Doctors 2.0 (Paris, 22 and 23rd June 2001, 2011)<sup>9</sup> where a pa-

tient-advocacy satellite workshop brought to the fore this pressing need of enhanced communication across boundaries and between disciplines, with the ultimate goals of creating knowledge and providing the best answer to a query as approached from different angles and expertise (see also recommendation # 2). It highlights the need of an online platform that could bring together the different cancer communities and which while providing custom searches based on context would also carve out spaces of communication across boundaries.

To summarise, there is a vast amount of cancer related information available 24 h a day to patients accessing the Internet, who may be overwhelmed with the sheer quantity of often conflicting information that is of questionable quality. Despite this much more information remains largely untapped and hidden from public view, as only a fraction of this information is retrievable routinely through search engines such as Google (which are generally the first resource used by users seeking online information on cancer) or does not display on the first page, beyond which most users do not usually navigate. We consider that the onus of reliability and trustworthiness of cancer related online information are shared by healthcare systems and patient organisations to alleviate the information burden on cancer patients, by ensuring that those likely to search for information (and most literature indicates that this is the majority) can do so confidently and easily. In order to further support patients to identify reliable health sites as an aid for decision-making, we envisage more customised and interactive search technologies that allow users to define their personal requirements, be context-driven, use the 'collective wisdom'<sup>10</sup> of people via social media, scaling of information to go from summary to detail, and enhanced access by underserved subgroups.

Our recommendations have been used as the basis for building the EcancerHub website,<sup>11</sup> also a resource developed within the Eurocancercoms project and endorsed by the most important and recognised cancer professional bodies in Europe.<sup>f</sup> The EcancerHub projects aim at sidestepping the problem of omission of information mentioned above, by providing a custom search engine which retrieves information in terms both of websites and of tools (e.g. risk calculators, decision aid tools, bioinformatics tools) that have been carefully selected and put together by experts belonging to the European cancer professional bodies and patient advocacy groups. The website is interactive also in another regard thanks to its embedded dynamicity, as it builds on the information shared by the users, which is then subjected to the peer-reviewed moderation of the other users across the different disciplines. Ecancerhub interacts directly with those patients who would like to head straight to one reputable site, but also to those who strive to contribute to the collective wisdom and best practise of the wider cancer community worldwide by participating in online debate and sharing useful resources and advice on different aspects of the cancer journey.

<sup>f</sup> The European Institute of Oncology – IEO, ECCO – the European Cancer Organisation, European Association for Cancer Research (EACR), European Organisation for Research and Treatment of Cancer (EORTC), SIOP Europe, the European Society for Paediatric Oncology (SIOPE), Organisation of European Cancer Institutes (OECI), The European Society of Breast Cancer Specialists (EUSOMA), The European Society for Medical Oncology (ESMO), The European Cancer Research Managers Forum.

It is in this regard that it represents the Eurocancercoms' answer to the perceived communication gap in oncology and, by being a bridge across the whole spectrum of the cancer communities, it also seeks to break down the traditional informational boundaries. It creates a supply of targeted information/knowledge that can aid the patient to take crucial decisions, and to live through and beyond cancer.

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### Conflict of interest statement

None declared.

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