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Original Research

# Mapping the cancer patient information landscape: A comparative analysis of patient groups across Europe and North America[☆]

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**Abstract** ***Aim:*** Little is known about how patient groups provide information for patients. We invited 838 patient groups from Europe and North America to participate in an online survey.

***Methods:*** The survey covered: (i) availability, accessibility and quality of information provided; (ii) methods by which patient groups communicate; (iii) ways in which patient groups acquire information and confirm its veracity/accuracy; (iv) how people access information online.

***Results:*** European patient groups were significantly less effective in providing medical-related information than their North American counterparts in: clinical trials, potential causes of cancer, medical research, diagnosis/screening, symptoms, treatments (all $p < 0.0001$); Recommendations of best practice/care ($p < 0.03$), healthcare services($p = 0.029$) and complimentary medicine ($p = 0.01$). Clinical trials ($p = 0.0006$), medical research ($p = 0.006$) and diagnosis/screening ($p = 0.0024$) were also areas where North American patients were more likely to require medical-related information.

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Similar patterns emerged for non-medical information with nutrition ($<0.0001$), watchful waiting ($p = 0.0003$), self-management of care ($p = 0.0003$), prevention ($p = 0.002$) and emotional issues ($p = 0.016$) being less effectively communicated by European patient groups. Nutrition was also an area where North American patients were more likely to require non–medical-related information.

The main barriers in accessing online information which showed differences between European and North American patients were: perceived lack of need, mainly due to faith in their doctors ($p = 0.0001$); limited access to the internet ($p = 0.0005$), limited computer skills ($p = 0.02$); and lower income ($p = 0.027$).

***Conclusion:*** These results emphasise the more mature nature of cancer patient engagement/information provision in North America, providing valuable insights and guidance to inform development of more robust and effective cancer patient information communication platforms in Europe.

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## 1. Introduction

Effective communication of information can underpin meaningful patient empowerment, while also embedding the patient's perspective in cancer control efforts [1–5]. Access to information is the underlying principle of the 1st Article of the European Cancer Patient's Bill of Rights, launched in the European Parliament on World Cancer Day 2014 [6]. Tonio Borg, the European Commissioner for Health and Consumer Policy at the time, praised this 1st Article, emphasising how *"information is key to enable the patient to play an active role in his/her treatment, rather than just being a passive recipient* [7].*"* However, the increasing volume and fragmentation of information, originating as it does from an array of sources, can often overwhelm patients [8.9]. This 'information overload' can hinder the patient's appreciation of and contribution to the best option(s) for discovery science to be translated to patient-focussed clinical implementation. The exponential increase in data can confuse patients and citizens [10,11], and this confusion, allied to potential distrust of particular information sources/providers, has led individuals to increasingly seek help from patient groups. However, these patient groups may have been established to provide more general support, to focus on particular disease, or to provide social assistance (including financial/legal help). Thus, they may lack relevant expertise to access, understand and provide co-ordinated, reliable and robust information for the cancer patient.

Publication of research through articles in scientific/medical journals, and its subsequent public dissemination, often happens via mainstream media, where key messages can frequently be unclear and/or distorted [12–15]. The majority of research is published in English; thus patients in non–English-speaking countries will receive translated information which may not have the same detail or provide the particular nuance intended in the original text. Decisions on what mainstream media publishes/highlights are usually based on what makes a "good" or "bad" news story; this may not necessarily reflect the interests/needs of cancer patients or health professionals [16]. Cancers affecting a smaller percentage of the population, the so-called "Cinderella cancers", tend to have lower media profiles than more highly prevalent and well-researched cancers such as breast, prostate and colorectal [17]. Innovative discoveries in rarer cancers such as pancreatic, lymphoma, sarcoma may not be disseminated as effectively as those for more common cancers.

Increasingly, patients use the internet to obtain health information about their disease [18,19]. There is no single trusted source of information suitable for advocacy groups and patients [20]. Patients are faced with a plethora of websites and a babel of conflicting statements and claims. Thus, it is essential to better understand the strengths and weaknesses of current patient information provision from organisations serving the cancer community. In this study, we utilised a survey approach to gain important insights on the nature of the cancer patient information landscape.

## 2. Methodology

Data were collected from patient groups via an online survey. The survey was conducted in five languages: English, French, German, Italian and Spanish. It was sent to all European patient groups listed in the world's most comprehensive database (PatientView) as providing information for cancer patients ($n = 767$). To allow benchmarking of the European data, the survey was also sent to patient groups based in North America ($n = 71$).

The survey covered five main areas:

1. Availability and quality of information provided by patient groups;

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