

Health information quality on the internet in gynecological oncology: a multilingual evaluation

N. Lawrentschuk^{1,2,3}, R. Abouassaly⁴, E. Hewitt⁵, A. Mulcahy⁵, D.M. Bolton¹, T. Jobling³

¹ University of Melbourne, Department of Surgery, Melbourne; ² Olivia Newton-John Cancer Research Institute, Austin Hospital, Melbourne

³ Peter MacCallum Cancer Centre, Melbourne (Australia)

⁴ Urological Institute, University Hospitals Case Medical Center, Case Western Reserve University, Cleveland, OH (USA)

⁵ University of Tasmania, Launceston General Hospital, Launceston (Australia)

Summary

Background: Oncological internet information quality is considered variable, but no comprehensive analysis of gynecological malignancies exists. The present authors' objectives were to compare the quality of common malignancy websites and to assess for language or disease differences; and secondly, to perform a quality comparison between medical and layperson terminology. **Materials and Methods:** World Health Organization (WHO) Health on the Net (HON) principles may be applied to websites using an automated toolbar function. Using a search engine (www.Google.com) 8,400 websites were assessed using keywords 'endometrial', 'uterine', 'cervical', 'ovarian', 'vaginal', 'vulvar', plus 'cancer', in English, French, German, and Spanish; repeated for alternate terms e.g. 'cervix', 'womb'. **Results:** Searches for "vaginal", "uterine", "cervical", and "endometrial" each returned millions of websites. The total percentage of all assessed HON-accredited sites was notably low across all search terms (median 15%; range 3-19%). Significant differences by malignancy type ($p < 0.0001$), language ($p < 0.0001$), and tertiles (thirds) of the first 150 websites returned ($p < 0.0001$). French language had most accredited websites. Using alternate terms demonstrated significant differences ($p < 0.001$) in accredited websites for most gynecological cancers. **Conclusions:** Internet data on gynecological malignancies is overwhelming. Further, a lack of validation of the majority of gynecological oncologic sites should be appreciated with discrepancies in quality and number of websites across diseases, languages, and also between medical and layperson terms. Physicians should encourage and more importantly their professional bodies should participate in the development of informative, ethical, and reliable health websites on the internet and direct patients to them.

Key words: Gynecology; Neoplasms; Internet; Patient education; Women.

Introduction

Patients appear to trust information on the Internet as much as from other media [1]. Thus it is unsurprising that the Internet and Social Media have become an accessible source of health-related information for patients and other interested parties [2]. Almost 80% of Internet users, which comprised almost 60% of all American adults, use the Internet to seek medical information [3, 4]. This highlights the importance of assessing the quality and validity of such information. The importance of the internet within obstetrics and gynecology was predicted in 1997 [5] and is likely to continue [6]. However, studies of the quality of oncological health information published on the Internet have found it restricted, variable, and overwhelming - patients may be faced with millions of results for a simple term search [7-9].

Patients and doctors are confronted with a confusing array of educational, promotional, and even complication-oriented websites regarding diseases and treatment options in oncology [10,11]. However, the content of internet resources and video forums is largely unregulated without the rigor that is applied to scientific publications [12]. There is

a danger of misinformation leading to a negative impact on patient's understanding, expectations, choice of therapy, choice of care, and ultimately quality of life [8, 13, 14]. Oncology poses other interesting challenges for patients. For example, if the cancer is endometrial, they may search for 'endometrial cancer' but equally may choose alternate terms such as 'uterine', 'endometrial adenocarcinoma' or even 'womb cancer'. The choice of descriptive terms for a type of cancer has been found to make a difference with the quality of information presented by an internet search [9]. Furthermore, information quality differs based on language [7-9, 15-17] which is of importance in multicultural societies and non-English speaking countries.

Clinicians are also placed in difficult situations when confronted with internet resources and need tools to identify quality information for themselves and to direct patients [8, 9]. Several systems have been developed to help identify quality and reliable health information [7, 8, 16]. The Health on the Net (HON) Foundation is a not-for-profit accreditation body supported by the World Health Organization (WHO) that is multilingual and has the goal of accrediting health websites using key principles of authority, complementarity,

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Table 1. — Results of the total websites returned for each term and also the percentage of HON accredited sites (poHONA). Also, the poHONA according to for websites in tertiles (first, second, and third 50) for each search returned is also indicated. Total websites and percentage of HON-accredited sites by treatment options.

Terminology	Term searched	Total websites returned ^a	HON accredited (600 per term) ^b		Total	PoHONA (%)	p value
			HONCODE +	HONCODE -			
Endometrial cancer	Endometrial cancer	1,320,00	111	489	600	19	
	Endometrial adenocarcinoma	321,000	86	514	600	14	
	Womb cancer	1,150,000	87	513	600	15	
	Uterine cancer	2,400,000	92	508	600	15	
TOTAL (median*, sum [^])		1,235,000*	376 [^]	2024 [^]	2400 [^]	15*	0.173
Cervical Cancer	Cervical cancer	16,939,000	112	488	600	19	
	Cancer cervix	12,939,000	113	487	600	19	
	Cervical intraepithelial neoplasia	570,440	55	545	600	9	
TOTAL (median*, sum [^])		12,939,000*	280 [^]	1520 [^]	1800 [^]	19*	< 0.001
Ovarian cancer	Ovarian cancer	15,100,000	80	519	600	13	
	Ovary cancer	2,010,000	94	506	600	16	
	Ovarian carcinoma	1,250,000	85	515	600	14	
TOTAL (median*, sum [^])		2,010,000	259 [^]	1540 [^]	1800 [^]	14*	0.501
Vaginal Cancer	Vaginal cancer	1,660,000	103	497	600	17	
	Vaginal SCC**	410,000	84	516	600	14	
	Vulvar cancer	441,000	98	502	600	16	
	Vulvar SCC**	215,000	82	518	600	14	
Total (median*, sum [^])		425,500*	367 [^]	2033 [^]	2400 [^]	15*	0.15
Grand total (median*, sum [^])		1,622,500	1066 [^]	5964 [^]	8400 [^]	15* (3-19)	

a – total web sites returned = total of four languages: English, French, German, and Spanish; b – Total of 600 per term = four languages x 150 web sites searched; **SCC = squamous cell carcinoma.

confidentiality, attribution, justifiability, transparency of authorship, sponsorship, and advertising [8, 18].

The present authors' objective was to compare the quality of gynecological oncology websites based on the HON principles and to assess for language or disease differences across Western languages being English, French, German, and Spanish. A further aim was to perform a quality comparison between search results when medical rather than layperson terminology or even alternate terms are used for a particular malignancy.

Materials and Methods

Internet searching for websites

The authors' methodology has been previously described and utilised in previous publications [8, 9]. Using the Google search engine (www.Google.com), in February 2014, the authors performed internet searches for 15 terms associated with gynecological oncology (e.g. endometrial and uterine cancer, Table 1) and assessed 8,400 websites. English and equivalent terms in French, German, and Spanish (translated from English through use of medical translation services and confirmed by laypersons and doctors having the non-English primary language as their primary language for term accuracy) were utilised.

Internet searching for accredited websites

Based on the observation that patients rarely access more than the first page of search results [19], the first 150 websites yielded by each search were then identified and sequentially screened for quality as defined by the HON Foundation. This was done by applying HON principles through the HONcode toolbar function [18]

for use on any personal computer and automatically activates or "lights-up" toolbar if a website is accredited by the HON foundation). The HON function has been used and assessed in several studies and was thus deemed to be a valid and high calibre tool [8, 20].

Analysis of accredited websites likelihood of being viewed

A secondary analysis of the first 150 websites encountered for each tumor type was undertaken as previously described [8, 16, 21]. Firstly, all returned websites for each cancer were divided into tertiles (first, middle, and last 50). The proportion of accredited sites in each organ and language was then analysed and compared using the Chi-square test. The purpose of this analysis was to determine where accredited websites were appearing preferentially i.e. in the pages least likely (last 50) versus the most likely to be viewed (first 50).

Quality control

For quality control, an English search ('cervical carcinoma'), had non-accredited sites within the first 150 discovered websites manually evaluated using the HON criteria to determine their HON status to ascertain if they fulfilled the criteria despite not being "officially" accredited.

Logistic regression examining variables associated with HON status

This was conducted using the three major variables of search term, language, and tertiles of the first 150 returned. The referent groups for each variable were the English version and the first 50 websites respectively as these had the highest percentage and/or number of HON accredited websites.

Analysis of website sponsors

For all organ groups, an analysis was undertaken from English language websites to determine the website sponsors (individual or

Table 2. — Differences in HON accreditation of websites by term and language. PoHONA = percentage of HON accredited sites. The *p* values refer to comparison within each terminology/treatment group.

Terminology/ Treatment	English			French			German			Spanish			<i>p</i> value
	HON CODE+	HON CODE-	Po HONA										
Uterine cancer													< 0.0001
Uterine cancer	24	126	19	33	117	28	20	130	15	15	135	11	
Endometrial cancer	33	117	28	39	111	35	13	137	9	26	124	21	
Endometrial adenocarcinoma	26	124	21	33	117	28	6	144	4	21	129	16	
Womb cancer	19	131	15	33	117	28	20	130	15	15	135	11	
TOTAL	102	498	20	138	462	30	59	541	11	77	523	15	
Cervical carcinoma													< 0.0001
Cervical cancer	37	113	33	42	108	39	10	140	7	23	127	18	
Cancer cervix	38	112	34	42	108	39	10	140	7	23	127	18	
Cervical intraepithelial neoplasia	25	125	20	15	135	11	4	146	3	11	139	8	
TOTAL	100	350	29	99	351	28	24	426	6	57	393	15	
Ovarian carcinoma													< 0.0001
Ovarian cancer	23	126	18	31	119	26	8	142	6	18	132	14	
Ovary cancer	37	113	33	31	119	26	8	142	6	18	132	14	
Ovarian carcinoma	22	128	17	29	121	24	10	140	7	24	126	19	
TOTAL	82	367	22	91	359	25	26	424	6	60	390	15	
Vaginal squamous cell carcinoma													< 0.0001
Vaginal cancer	24	126	19	23	127	18	22	128	17	34	116	29	
Vaginal SCC*	26	124	21	23	127	18	18	132	14	17	133	13	
Vulvar cancer	35	115	30	20	130	15	13	137	9	30	120	25	
Vulvar SCC*	16	134	12	26	124	21	24	126	19	16	134	12	
Total	101	499	20	92	508	18	77	523	15	97	503	19	
Grand total (median*)	385	1714	20.5*	420	1680	26*	186	1914	8*	291	1809	15*	

organization responsible for the website) and each was categorized according to prior studies of quality of websites on the internet [7, 8]. In summary, the sites were deemed sponsored by (1) lawyers; (2) non-profit organizations; (3) government organizations /educational institutions; (4) commercial; (5) surgeons/ physicians (and their professional organizations); (6) other health professionals; or (7) other. Sponsorship was determined independently by two examiners firstly by web page retrieved; if sponsorship was not obviously apparent, the website was explored until sponsorship could be determined. The concept of sponsorship is not to be confused with the Google terminology of “sponsored links” either highlighting pages at the start of retrieved search or appearing on the side of the page under a banner. As in prior analysis, such pages were not included throughout the entirety of this study [8].

Statistical analysis

Comparisons of proportions across types of cancer and language were performed using the Chi-square test (or Fisher’s exact tests when cell counts were less than 5). All statistical tests were two-sided and significance was defined as $p < 0.05$. Odds ratios and 95% confidence intervals (CI) were also calculated from the logistic regression analysis. Analyses were performed using SAS 9.1.

Results

Internet search results for accredited websites

The total number of websites for each disease term was variable (Table 1). The terms ‘vaginal’, ‘uterine’, ‘cervical’, and ‘endometrial’ each returned millions of websites. ‘Cer-

vical cancer’ the most around 17 million, closely followed by ‘ovarian cancer’ at 15 million, while ‘vulvar squamous cancer’ had the fewest - around 200,000.

Including all languages, the total percentage of all assessed HON-accredited (poHONA) sites was notably low across all search terms (median 15%; range 3-19%, Table 1). Most search terms did record at least 10% poHONA but this is still very modest. The quality control analysis of English language for ‘cervical carcinoma’ revealed further 4% of websites that would likely be of a standard equivalent to HONcode accredited sites but have yet to apply for accreditation.

In regards to linguistic differences (Table 2), French (median 26%; range 11-35%), had the greatest percentage of HON-accredited sites across all disease search terms, followed by English (21%; 12-34%), Spanish (15%; 8-29%) and German (9%; 3-19%).

When analysing by tertiles to determine where HON-accredited sites were more likely to appear, it appears that HON-accreditation was significantly more common in the sites that appear in first tertile (Figure 1).

Finally the ORs were calculated demonstrating significant differences with search terms, language or between groups (Table 3). Indeed it appeared an Internet search was almost equally likely to be accredited provided the key term for that malignancy was used. However, the first tertile was

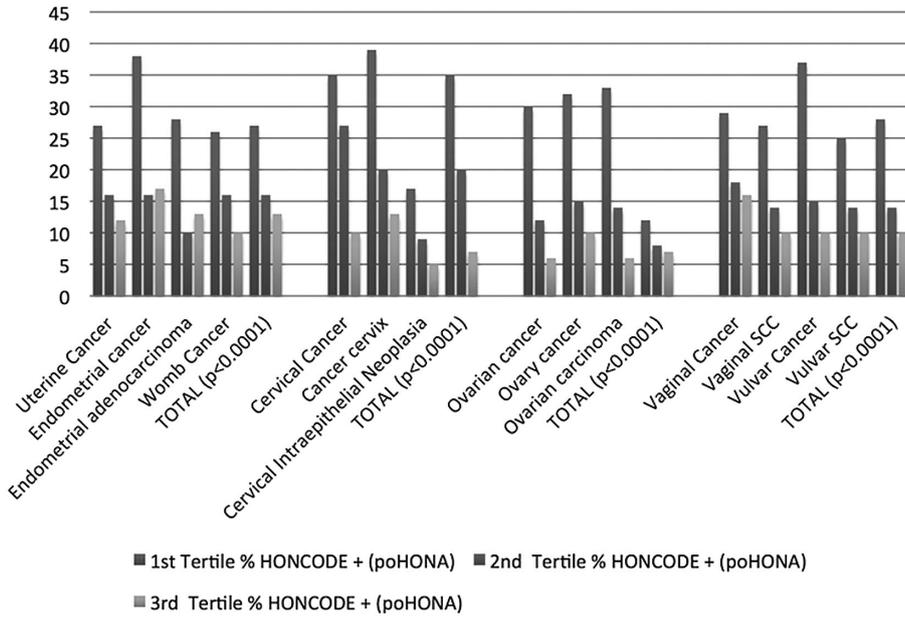


Figure 1. — Graph of the results of the percentage of HON accredited sites (poHONA) by organ group. Also, the percentage of HONCODE + accredited websites (poHONA) according to tertiles (first, second, and third fifty sites) for each search returned is also indicated. Statistical analysis of differences within each organ malignancy for tertiles is displayed in the total column.

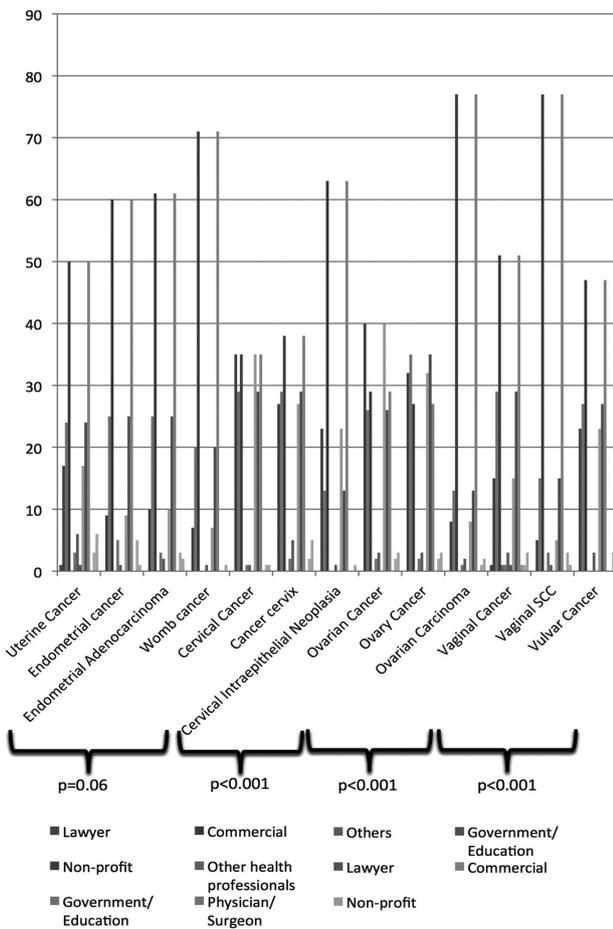


Figure 2. — Graph of the results of the analysis of website sponsors by organ malignancy (or alternate term) across the English language sites only. Statistical analysis for differences within each malignancy group is highlighted in the total columns.

Table 3. — Results of the logistic regression analysis comparing across gynecological oncology terminology, likelihood of an accredited website based on first, second, and third 50 websites returned and by language. Referents were chosen based on the term cervical carcinoma and its alternate terms being the standard; the first tertile returned because of this having the greatest percentage of HON accredited websites and English as the most common language.

Effect on HONCODE status	Odds ratio	95% confidence limits
<i>Category</i>		
Cervical carcinoma	1.00 (referent)	
Ovarian carcinoma	0.909	0.754 - 1.096
Uterine carcinoma	1.009	0.849 - 1.198
Vaginal/vulvar carcinoma	0.963	0.782 - 1.185
<i>Websites[^]</i>		
1 st tertile (0-50)	1.00 (referent)	
2 nd tertile (51-100)	0.501	0.435 - 0.577
3 rd tertile (101-150)	0.349	0.299 - 0.408
<i>Language</i>		
English	1.00 (referent)	
French	1.117	0.956 - 1.306
German	0.427	0.354 - 0.516
Spanish	0.710	0.600 - 0.840

[^]Of the first 150 websites examined, the first third or 50 (five pages) were reference group compared to second third and last third.

more likely to return an accredited site over the second (OR 0.50) and third (0.31). Comparing to English language, French sites were slightly more likely to return an accredited site (OR 1.12) while least likely in German (OR 0.43) with Spanish between (OR 0.71).

Analysis of website sponsors

The sponsor analysis of the 150 Websites in English language revealed (Figure 2) that the most commonly encountered sponsors were commercial sites (51%) followed by Government organisations or educational institutions (29%) and non-profit organisations (23%). Other sponsors (15%), other health professionals (4%), surgeons/physicians (4%) sponsored far less sites and lawyer-sponsored sites were rarely if ever encountered.

Discussion

The Internet is a tool that assists health providers and patients daily. Data exists that women and their families are seeking information specifically on the Internet and via social media [22, 23]. Interestingly they may even be asking questions on the internet that they find too private to even discuss with their doctors [24, 25]. It has been recognised that the internet has been utilised to improve colorectal cancer screening and this could be translated into ovarian or cervical cancer screening [26]. This adds to the logic that as physicians we need to direct patients to reliable information.

General gynecological related resources have demonstrated a pattern of poor quality [27, 28]. Website content for gynecological malignancies has never been specifically studied until now. The quality may appear low in this study but is in fact is similar to that found in surgical and urologic oncology where routinely around 20% or fewer websites are HON accredited [8, 9]. Gynecological malignancies are somewhat similar to breast (23%) [9] but performing similar to prostate cancer (16%) [8] on available data. Language differences exist regarding Website quality [7, 8, 15]. In the present study, French-language searches overall had more Website listings and ultimately had more HON-accredited sites as compared to English, German, and Spanish. At best, just over a quarter of French were HON-accredited and at worst, under one-tenth of German websites were HON-accredited. It is interesting that French again outperformed English as was the case with multiple common non-gynecological and non-urologic malignancies in a previous study [9]. English only outperformed French and others languages with urologic malignancies [8]. Combining this with the differences between malignancies suggests differing regional interest and resource allocation to specific malignancies based not just on incidence but other factors.

The incidence and prevalence of cancers as well as their “public profile” are all likely to be factors influencing the number of websites available to consumers. When search-

ing the different gynecological malignancies, ‘layperson terms’ generally performed worse than the correct medical terminology. This was also demonstrated in other organ oncological website searches attesting to the importance of gynecological oncology [29]. Teaching patients and their support groups how to search the Internet is important and adhering to medical terminology is an important finding for health providers and patients. Advising them of how to access the free HONcode toolbar to “screen” websites of higher quality would also be prudent.

The Internet although a wonderful “free” and “open access” resource is increasingly being subjected to commercialisation [16]. This is often at the expense of considered, well-balanced opinion. Website sponsorships which are often not obviously disclosed as well as the creation of hidden metrics for search retrieval means there may be biases in what information is returned. This study highlights the paucity of good quality comprehensive, multilingual information on available on the Internet and confirms commercial sponsors to be the greatest providers of such information.

There are a number of limitations of the study. The Internet is dynamic with Websites constantly being developed and uploaded. Thus search results may vary depending on time and location. Furthermore other search engines are available apart from ‘Google’, hence future analyses could investigate if alternate internet filter systems would significantly alter the quality of websites retrieved.

Internet data on gynecological malignancies is overwhelming. A lack of validation of the majority of gynecological oncologic sites should be appreciated with discrepancies in quality and number of websites across diseases, languages and also between medical and ‘layperson’ terms. Interestingly, the quality found is similar for oncological internet searches for other disease groups. Physicians should encourage and participate in the development of informative, ethical, and reliable health websites on the internet and direct patients to them. Importantly, professional bodies need to act swiftly to become “trusted sources” that physicians and patients may rely upon in an increasingly “digital world”.

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Address reprint requests to:
 N. LAWRENTSCHUK,
 M.B. B.S. Ph.D. FRACS (Urology)
 University of Melbourne
 Department of Surgery, Austin Hospital
 Suite 5 - 210 Burgundy Street - Heidelberg
 Victoria 3084 (Australia)
 e-mail: lawrentschuk@gmail.com