International Journal of Information Science and Management Vol. 21, No. 2, 2023, 175-195 DOI: <u>https://doi.org/10.22034/ijism.2023.1977867.0</u> / DOR: <u>https://dorl.net/dor/20.1001.1.20088302.2023.21.2.11.3</u>

Original Research

An infodemiological study of information-seeking behavior of users and scientific products of researchers in the field of multiple Sclerosis in Iran

Oranus Tajedini

Associate Prof., Department of Knowledge and Information Science, Shahid Bahonar University of Kerman, Kerman, Iran. <u>Tajedini@uk.ac.ir</u> ORCHID iD: <u>https://orcid.org/0000-0003-1963-2115</u>

Mahya Abdollahifaard

Master Student, Department of Knowledge and Information Science, Shahid Bahonar University of Kerman, Kerman, Iran. m.abdollahifard1396@uk.ac.ir ORCHID iD: https://orcid.org/0009-0005-0939-6560

Ali Sadatmoosavi

Associate Prof., Department of Medical Library & Information Sciences, Faculty of Management and Medical Information Sciences, Kerman University of Medical Sciences, Kerman, Iran. Corresponding Author: <u>moosavi56@gmail.com</u> ORCHID iD: <u>https://orcid.org/0000-0001-6800-3345</u>

Received: 13 June 2022 Accepted: 03 August 2022

Abstract

This infodemiological study examined the information-seeking behavior of users and the scientific production of Iranian researchers in the field of Multiple Sclerosis (MS). The present study was conducted using a mixed-methods research approach. In the qualitative part, the preferred terms and keywords used by Iranian users in the field of MS from 2009 to 2019 were extracted through focused group discussions. In the quantitative part, based on the keywords extracted from the focus group discussions, the data on the information-seeking behavior of Iranian users were collected through Google Trends (using data mining techniques). Besides, the data on the scientific production of Iranian researchers published on multiple Sclerosis in PubMed, Web of Science (WoS), and Scopus from 2009 to 2019 were collected (using scientometric methods). The data collected using web mining techniques consisted of the keywords obtained from the focus group interviews, and the data collected using scientometric techniques included scientific products of Iranian researchers indexed in PubMed, Web of Science (WoS), and Scopus databases. Finally, to investigate the relationship between the information-seeking behavior of Internet users and the scientific production of researchers in the field of MS, the cross-correlation method, Shapiro-Wilk test, and Pearson correlation test was used in R software. The results of the Shapiro-Wilk test indicated that the informationseeking behavior of users in Google Trends and the scientific production of Iranian researchers on MS were normal (P-value> 0.05). However, the two variables had a powerfully negative and significant correlation (r = -0.81). The data also revealed that the keyword MS had the highest search volume index in Google Trends and was considered the final keyword in each category. The core category in the searches conducted by Iranian users in the MS field was MS treatment; most searches were conducted in 2013. The study's findings also indicated that the countries with higher search volume indexes for the keywords "MS" and "Multiple Sclerosis" worldwide were Italy, Spain, France, Russia, and Greece. However, the United States had the highest volume of scientific production. The results of the present study showed that Iranian researchers working in the field of multiple Sclerosis ignore reducing the questions of Iranian users in this field and have conducted their research projects for other reasons; In fact, many factors contribute to increasing the volume of scientific production in multiple Sclerosis. However, users' demand for health information or their information-seeking behavior online cannot be considered one of these factors. Information-seeking behavior of Iranian users in Google Trends and the scientific production of Iranian researchers have a strongly negative and significant correlation. Thus, scientific production in the field of MS has increased over time. Still, Iranian users' tendency to engage in behaviors to seek information about MS in Google Trends has decreased over time. This implies that with scientific advancements in MS, physicians prevent most patients from searching the Internet for information about their disease. Nevertheless, the increasing use of online social media in recent years has effectively reduced the search volume index and changed information-seeking behavior.

Keywords: Infodemiology, Preferred Terms, Health Information, Scientific Production, Information-Seeking Behavior, Users, Multiple Sclerosis.

Introduction

The increasing development of new information technologies and digital media is changing attitudes in choosing paths that help people find valid health information (Eysenbach, 2006). Healthcare providers and patients regularly seek out the health information they need using search engines (Cooper, Mallon, Leadbetter, Pollack & Peipins 2005). Eysenbach, Powell, Kuss and Sa (2002) published an article at the Center for Electronic Health Innovation introducing infodemiology as a mechanism to measure information published on the Internet. Infodemiology, as an emerging concept in public health informetrics and a framework for identifying information-seeking behavior of Internet users in the health field, was developed based on the idea that there is a link between community health and communication and information patterns in electronic environments. This link creates solid epidemiological indicators or measures reflecting these communication and information patterns (Eysenbach, 2009). Infodemiology has been introduced as an analytical and methodological paradigm for describing health information dissemination and the factors affecting it in the digital era. It focuses on studying quality and accuracy indicators of public health information (Tan, Lee & Chae, 2015). Applications of infodemiological indicators range from early diagnosis to early management of chronic disease prevention (Eysenbach, 2008).

Regardless of the source of information, studies using a set of new methods such as computers, the Internet, and information technology to support health care and patient health and help solve medical, educational, and research problems in the field of medicine in electronic environments are called infodemiological studies (Eysenbach, 2011). It is worth noting that these measures are taken to measure, describe, and analyze health information and communication patterns (Ginsberg, Mohebbi, Patel, Brammer, Smolinski & Brilliant, 2009). Infodemiology analyzes the information-seeking behavior of individuals on the Internet (information demand) and examines the content produced by researchers on the Internet (information supply) to diagnose diseases and how they outbreak. It studies a group of diseases and seeks to provide information about health issues (Van Velsen, Van Gemert-Pijnen,

Beaujean, Wentzel & Van Steenbergen, 2012; Tan et al., 2015). Infodemiology can be used as a useful index for analyzing health researchers' scientific products and studying internet users' information-seeking behavior. Thus, the concepts in this field can be examined from two separate and related perspectives: The information-seeking behavior of Internet users from the epidemiological perspective of demand-based information and scientific products of researchers published on the Internet from the epidemiological perspective of supply-based information (Eysenbach, 2008).

According to the first perspective, information searches of users and their information behavior on the Internet are one of the most important infodemiological issues because tracking the information-seeking behavior of Internet users can provide researchers with data for conducting research and unlimited monitoring (in terms of time) on the process of these searches (Dehkordy, Carlos, Hall & Dalton 2014; Zheng, 2013). People can actively manage their health if they have access to health information. In addition, the study of Internet search trends used by health users is a unique resource to monitor people's self-reported diseases and information-seeking behavior across the community (Willard & Nguyen, 2013). One of the most important indicators of science research and production is the quantitative and scientometric study of research articles published on the Internet, especially articles indexed in reliable databases (Tajedini, Soheili & Sadatmoosavi, 2019).

In recent years, extensive research has been conducted using data collected from Google Trends (GT), Google Flu Trends, and Google Cloud Healthcare API. More and more research uses GT. Before the release of GT, early research was done on Google Flu Trends, a source of disease-related queries. Google Trends has been widely used as a study tool for various medical indications. GT is the source of reverse engineering data. It displays the content searched in Google, normalizes the data according to the search frequency, and displays it in relative search volume. The data are divided into years, months, and geographic regions (Springer, Zieger & Strzelecki, 2021).

This study focused on multiple Sclerosis because it is an almost emerging and less-known disease and therefore requires a lot of research (Mavragani, Ochoa & Tsagarakis, 2018). While searching the Internet by MS patients varies regarding factors such as age, income, and disease severity, most patients with MS use online counseling and information. In addition, they consider online information more reliable, accessible, and understandable than the information in books and manuals. Thus, they consider the Internet more useful and without adverse effects (Marrie, Salter, Tyry, Fox & Cutter, 2013; Lavorgna et al., 2017). This finding may be because MS mainly affects young people with a higher Internet use rate than people in other age groups (Atreja et. al., 2005). Furthermore, these people are increasing (Lavorgna et al., 2017).

Perhaps one of the criteria of quality assessment of scientific research - especially in the field of health - is the degree of compliance of researchers' scientific products with the general public's information needs. Thus, this study tried to examine users' information-seeking behavior (demand-based infodemiology) and scientific production in the field of Multiple Sclerosis (supply-based infodemiology). This study can contribute to guiding researchers in this field in selecting research objectives and promoting the quality of research in this field. To this end, Google Trends because of its ability to monitor the Internet activities of people on Google in a particular subject and provide valuable models for health information search behaviors (demand-based infodemiology) (Eysenbach et al., 2009; Siri, Khabbache, Al-Jafar, Martini, Brigo & Bragazzi, 2016) is used in this study. In addition, PubMed, Web of Science (WoS),

and Scopus databases are used in this study as they are reliable scientific tools for examining the scientific production published on the Internet (supply-based infodemiology). Accordingly, the present study aims to explore the information-seeking behavior of users and scientific production in the field of multiple Sclerosis using an infodemiological approach. To this end, the following questions are addressed in this study:

1. What are the preferred terms and keywords used by Iranian users to search the Internet for continuous health information in the multiple sclerosis field from 2009 to 2019?

2. What was the main focus/category of the internet searches of Iranian users in multiple Sclerosis from 2009 to 2019?

3. What are the aspects of the information-seeking behavior of Iranian internet users in terms of continuous health information demand in the field of multiple Sclerosis in Google Trends from 2009 to 2019?

4. What is the rank of Iran in terms of the average volume of Internet searches for online health information by users in the field of multiple Sclerosis compared to other countries around the world from 2009 to 2019?

5. How is the frequency distribution of the annual scientific products of Iranian researchers in terms of continuous health information in the multiple sclerosis field in PubMed, Web of Science (WoS), and Scopus databases from 2009 to 2019?

6. How is the quality of information-seeking behavior of Iranian internet users in comparison with one of the leading countries in terms of scientific production in the field of multiple Sclerosis in PubMed, Web of Science (WoS), and Scopus databases from 2009 to 2019?

7. What is the volume of scientific production in Iran compared to one of the countries with a higher health information search index of its Internet users in the multiple sclerosis field in Google Trends from 2009-2019?

8. What is the relationship between the information-seeking behavior of Iranian users in Google Trends with the scientific production in the multiple sclerosis field indexed in PubMed, Web of Science (WoS), and Scopus from 2009 to 2019?

Materials and Methods

Procedure

The present study is considered an applied study as its findings can help major health policymakers formulate a strategic plan, especially in the multiple sclerosis field. To this end, a mixed-methods research approach was adopted using an embedded design. Embedded design is the simultaneous collection of quantitative and qualitative data, with one form of data supporting the other. The supportive data augments the conclusions of the primary data collection. The benefit of this design is that it allows for one method to lead the analysis, with the second method providing additional information. Quantitative and qualitative methods naturally answer different research questions. Therefore, a study's research questions must be worded in a way that allows for cooperation between qualitative and quantitative, complemented by a qualitative (focus group) approach. In the quantitative part, data were collected in two parts: The data on the information-seeking behavior of Internet users were collected through data mining, and scientific products were identified using scientometric techniques. Table 1 describes the techniques used in each phase of the study to collect the data:

Research objectives	Data collection techniques	Research techniques	
Objective 1	Qualitative method	Focus groups	
Objective 2	Data mining (qualitative)	Web mining	
Objective 3	Data mining (qualitative)	Web mining	
Objective 4	Data mining (qualitative)	Web mining	
Objective 5	Data mining (qualitative)	Web mining	
Objective 6	Scientometric (qualitative)	Bibliometric	
Objective 7	Data mining (qualitative)	Web mining	
Objective 8	Scientometric (qualitative)	Bibliometric	
Objective 9	Data mining (qualitative)	Pearson correlation coefficient	

Table 1The data collection techniques based on the research objectives

In the first qualitative phase of the study, qualitative techniques, including focus groups and group discussions, were used to identify the keywords used by users to search for information about multiple Sclerosis. Focus groups were used in this study to find out the keywords selected by ordinary users who search for information about multiple Sclerosis in the Google search engine. This method identified and analyzed keywords used by users in natural conditions. This study phase focused on users' views and understanding of the phenomenon.

In the second phase, using the data mining method used by Google Trends, the search volume index for the English and Persian keywords identified in the previous phase was extracted through Google Trends. Afterward, the final model of the Internet information-seeking behavior of internet users was drawn for the subject area of MS. One of the data mining techniques used in this study is web mining which Google Trends have used in line with the second, third, and fourth, fifth, and seventh objectives of the present study. Google Trends uses a special web usage mining technique to discover patterns in web users to understand better and estimate users' needs. In this type of web mining technique, web usage data determines the websurfing behavior of users on the Internet. With the help of the Google Trends tool, the users' web usage data were explored, and meaningful patterns were extracted from the data generated in the interaction between users and the Google search engine. All the procedures, from data collection to presentation of web mining analysis, were performed in a single step. Thus, there were no problems such as violations of user privacy laws and the use of sophisticated web browsing methods.

Scientometric techniques were used in the third stage of the quantitative part of the present study. Scientometrics evaluates and accounts for the process of scientific development and orientation and increases the efficiency of scientific research by providing effective indicators. Bibliometric techniques that fall under scientometrics were used in line with the sixth and eighth objectives of the study. The productivity index¹, one of the indicators presented in scientometric research, was used in the present study to explore the articles published by Iranian researchers in the field of multiple Sclerosis from 2009 to 2019 in scientific journals worldwide. Besides,

¹ The productivity index refers to the number of articles published by Iranian researchers in the field of multiple sclerosis (MS) in scientific journals around the world from 2009 to 2019, and their bibliographic information is indexed in PubMed.

their bibliographic data indexed in the PubMed, Web of Science (WoS), and Scopus databases were also investigated.

Finally, in the fourth step of this study, we explored the ninth objective (the alignment of the information-seeking behavior of internet users and scientific production in the field of multiple Sclerosis from 2009 to 2019) using the cross-correlation method. Correlation analysis as a subset of descriptive (non-experimental) research is performed to show the relationship between variables. For this purpose, and considering the normality of data distribution in this study, Pearson product-moment correlation coefficient as a correlation technique was used. Pearson correlation always varies from -1 to +1, showing the perfect match and mismatch between two variables or constructs.

Research population, sampling, and sample size

The target population in the present study in the qualitative section included MS patients who were selected using purposive non-random sampling. To this end, four groups with 8 MS patients were selected using purposive and convenience sampling. The interviews were conducted with MS patients referred to MS treatment centers for various reasons, including exercising, taking motivational courses, etc. The participants were selected using the following criteria to attend the discussion group to minimize possible differences in the results of the interviews:

- The interviewee was a patient with MS.

- The interviewee had a bachelor's degree or higher.

- The interviewee was willing to respond to the questions and participate in a focus group discussion.

- The interviewee had access to the Internet and used the Internet to obtain the health information they need, especially in the context of MS.

The research population in the web mining phase to investigate the information-seeking behavior of Internet users included all equivalent words and terms related to the subject of multiple Sclerosis in both Persian and English. All these Persian and English keywords were extracted through a focus group discussion (the previous step). The reason for choosing these languages was users' high frequency of using Persian and English languages. The research population in the scientometrics phase to review scientific products included the articles published by Iranian researchers in the multiple sclerosis field from 2009 to 2019, indexed in PubMed, Web of Science (WoS), and Scopus databases.

Instruments

The instruments used in the present study to collect the data are presented in Table 2 based on the objectives of the study:

Research objectives	Data collection techniques
Objective 1	Focused group discussions (interviews)
Objective 2	Google Trends
Objective 3	Google Trends
Objective 4	Google Trends
Objective 5	Google Trends
Objective 6	PubMed, WoS, and Scopus
Objective 7	PubMed, WoS, Scopus & Google Trends
Objective 8	PubMed, WoS, Scopus & Google Trends
Objective 9	PubMed & Google Trends

Table 2The data collection methods by research objectives

Validity and reliability of the instruments

Since both quantitative and qualitative methods were used in this study, effective approaches should be used to assess the validity and reliability of the instruments. Although the concepts of validity and reliability have specific definitions and interpretations in the field of qualitative research, as will be discussed below, they do not evoke any objective and debatable concept in studies conducted with web mining and scientometric techniques (used in the qualitative part of the present study). The validity and reliability of the instruments used in the study (Google Trends and PubMed) do not need to be checked because these tools are the most reliable and widely used infodemiological tools.

Qualitative researchers seek to produce and present valid data to build readers' confidence that they have achieved a correct interpretation. Suppose researchers follow reliable procedures to evaluate the credibility of these interpretations. In that case, they will have a better chance of choosing one or more suitable interpretations from among the many possible interpretations. Thus, they validate these interpretations by evaluating various forms of triangulation and disjuncture evidence and revising interpretations with the help of t the participants and member validation (Fitzpatrick & Boulton, 1994). Triangulation is the comparison of two or more sets of evidence according to the research problem (Fitzpatrick & Boulton, 1994). Thus, in the qualitative phase of the present study, focus group interviews, note-taking, and audio recordings were used to triangulate the collected data. Accordingly, the data collected in this study using several techniques were merged to play a complementary role in presenting the findings. Hence, triangulation helps to converge the interpretations. To achieve this type of triangulation in all qualitative phases of the study, a library and health information specialist and an epidemiologist monitored all data collection steps in this study.

Member validation means that the researcher returns their findings to the research setting to determine whether they are correct and valid in the participants' opinion. The most basic method is to meet with one or two participants and ask them what they think about the researcher's descriptions, interpretations, and explanations. For this purpose, in the qualitative phase of the present study, the interviewees reviewed the collected data in two stages to achieve relative credibility through member checking.

Data analysis tools

An infodemiological study of information-seeking ...

In any research project - whether quantitative or qualitative – the collected raw data must be analyzed and interpreted to turn them into organized data and then into specific categories/subcategories and remove excess and redundant information. Since the present study used different methods to collect data, different tools were used to analyze the data (Table 3).

Jois by research objectives				
Data analysis tools				
Manual analysis				
Google Trends				
EndNote & Excel				
Google Trends				
EndNote & Excel				
R software				

Table 3

The data analysis tools by research objectives

Results

Since this applied study was conducted with a mixed (qualitative-quantitative) methods design, the findings are divided into qualitative and quantitative categories.

Qualitative Results

The first objective of the present study was to identify the preferred terms and keywords used by Iranian users to search the Internet for continuous health information in the field of multiple Sclerosis from 2009 to 2019. After conducting a focused group discussion under the supervision of a medical librarian and epidemiologist and manually analyzing the results, the interview findings with a physician with an MS fellowship were divided into 5 categories. In the next step, as detailed in Table 4, the preferred terms used by the interviewees in each category were extracted and revised in terms of the search strategy based on feedback from a medical librarian. The results were presented in the keyword column. In the last step, the keyword with the highest search volume index in Google Trends was identified and considered the final keyword in each category.

It is noteworthy that the public knows the field of multiple Sclerosis as both "MS" and "multiple sclerosis," so this issue was highlighted in the focus group discussion, and the interviewees preferred the use of the word "MS" in the compound keywords. This issue was also reviewed and confirmed through Google Trends. Thus, "MS" was used as a compound keyword (Table 4). Each English letter in this table represents one of the interviewees marked with A to H.

Table 4

The results of the focus group interviews in the field of Multiple Sclerosis

Categories	Participant code	Score	Preferred terms	Keyword(s)	The keyword with a higher search volume index
1	A, B, D, E,	15	MS symptoms	MS symptoms	MS symptoms

Categories	Participant code	Score	Preferred terms	Keyword(s)	The keyword with a higher search volume index
	F, G		MS symptoms Early signs of MS MS symptoms	MS symptoms MS signs Sign of MS	
2	A, B, C, D, E, F, G, H	11	Treatment of MS New treatments for MS MS medicine MS treatment in traditional medicine	MS treatment New treatment for MS MS medicine MS in traditional medicine Traditional treatment of MS	MS treatment
3	B, C, E, F	6	Nutrition for MS patients Nutritional therapy for MS Food for MS patients	Nutrition for MS patients Food for MS patients	Nutrition for MS patients
4	C, D, F	3	The lifestyle of MS patients Exercise for MS patients	The lifestyle of MS patients Exercise for MS patients	Exercise for MS patients
5	A, D, G	2	Famous MS patients The future of MS	Famous MS patients The future of MS	The future of MS

Quantitative Results

This section presents the findings of the quantitative phase of the study about the information-seeking behavior of Iranian internet users and the scientific production of Iranian researchers.

Information-seeking behavior of Iranian internet users

The data in this section were collected using web mining techniques and Google Trends to identify the main focus/category of the internet searches of Iranian users in the multiple sclerosis field from 2009 to 2019 (Figure 1).

First, based on the keywords with higher search volume index in each category (Table 4) used by Iranian users to search for information in the field of Multiple Sclerosis, the search volume indexes of the categories were matched to identify the leading category in Iranian users' searches in the field of MS.

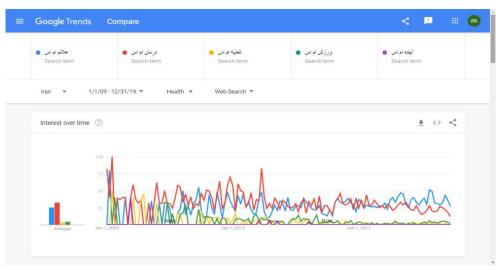


Figure 1: A comparison of MS categories searched from 2009-2019 in Iran

The third objective of this study was to identify the aspects of the information-seeking behavior of Iranian internet users in terms of continuous health information demand in the field of multiple Sclerosis in Google Trends from 2009 to 2019.

To assess the information-seeking behavior of people in Google Trends, we need to examine the annual internet search volume index. Besides, to determine the volume index of searches performed from 2009 to 2019 in the multiple sclerosis fields, the common term of searches in each category should be considered. However, it should be noted that the most common word in all categories in the field of a disease is the name of that disease. As mentioned earlier, multiple Sclerosis is also known as "MS." The study participants mostly searched the term "MS" to find their intended information. However, they acknowledged that sometimes they used either "MS" or "multiple sclerosis" to find information about the disease. Thus, the volume index of searches conducted by Iranian users of Multiple Sclerosis with the keywords "MS" in English and Persian were determined separately. Accordingly, the final patterns of the information-seeking behavior of Iranian users in the field of multiple Sclerosis using the keyword "MS" in English is shown with a red line, and their search volume index for the keyword "MS" in Persian is shown with a blue line:

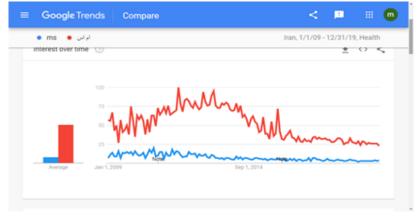


Figure 2: The search volume index for MS from 2009 to 2019

The search volume index is not the frequency or number of searches of individuals but is obtained in two steps: First, the shared search volume is calculated by dividing the total volume of searches for all search keywords. The shared search index is then optimized by dividing it by the population number. Search volume indexes provided by Google Trends are weekly and for longer periods, i.e. monthly. The annual search volume index was calculated by adding the monthly indexes, and the resulting index was equal to 5. The search volume indexes for spring, summer, autumn, and winter were 2111, 1951, 1989, and 1962, respectively. Moreover, the highest search index was 741 for November.

The fourth objective of this study was to determine Iran's ranking in terms of the average volume of Internet searches for online health information by users in the field of multiple Sclerosis compared to other countries around the world from 2009 to 2019. To find the search volume index in the field of multiple Sclerosis among countries (Figure 3), a common keyword used by people in different countries in this field was to be identified.

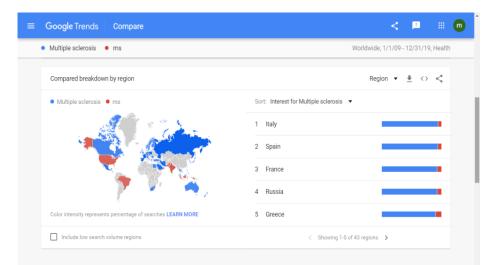


Figure 3: The five countries with the highest search volume indexes for both keywords "MS" and "Multiple Sclerosis"

Therefore, the terms "Multiple Sclerosis" and "MS" were used because English is an international language (Figure 4).

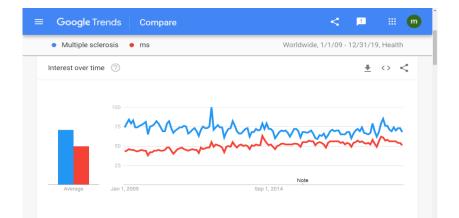
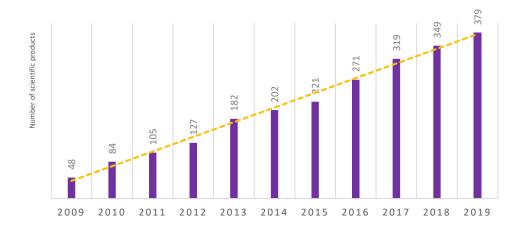


Figure 4: The search volume indexes for both keywords "MS" and "Multiple Sclerosis" worldwide

Scientific production of Iranian researchers published on the Internet

The scientific production of Iranian researchers was assessed using scientometric techniques and the data was extracted through web mining of PubMed, WoS, and Scopus databases and Google Trends.

The fifth objective pursued in this study was to determine the frequency distribution of the annual scientific products of Iranian researchers in terms of continuous health information in the field of multiple Sclerosis in PubMed, Web of Science (WoS), and Scopus databases from 2009 to 2019. The data needed to assess the annual scientific products of Iranian researchers were extracted from the PubMed, Web of Science (WoS), and Scopus databases from January 1, 2009, to December 31, 2019. Furthermore, the word "Iran" was searched in the mentioned databases to identify the scientific products of Iranian researchers. Accordingly, the records related to the articles published by Iranian researchers in multiple Sclerosis indexed in the mentioned databases from 2009 to 2019 were retrieved. It should be noted that the articles accepted in 2019 and published in 2020 were removed from the obtained records because, in demand-based infodemiology, the publication of scientific work is considered. Thus, duplicate items were removed by merging the search results in EndNote. By eliminating the duplicate articles, 2287 articles published by Iranian researchers on multiple Sclerosis from 2009 to 2019 in the three databases were identified. Finally, the data were analyzed manually in Excel using descriptive statistics and categorized by journals. Graph 1 shows the distribution of articles from 2009 to 2019:



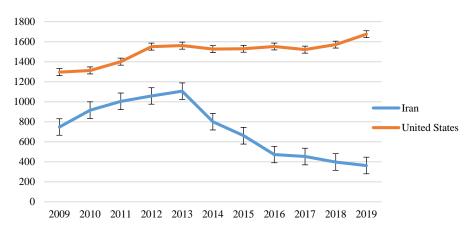
Graph 1: The number of scientific products published by Iranian researchers in three databases from 2009 to 2019

The sixth objective of the present study was to compare the information-seeking behavior of Iranian users in the Google search engine with one of the leading countries regarding scientific products indexed in PubMed, WoS, and Scopus databases in multiple Sclerosis from 2009 to 2019.

The articles in the multiple sclerosis field published in the three databases from 2009 to 2019 were retrieved. The outputs of WoS and Scopus were 41058 and 39239 articles, respectively. The United States was ranked first with 11844 and 12396 articles indexed in the two databases. Besides, Germany was second, and Italy was third in terms of the number of

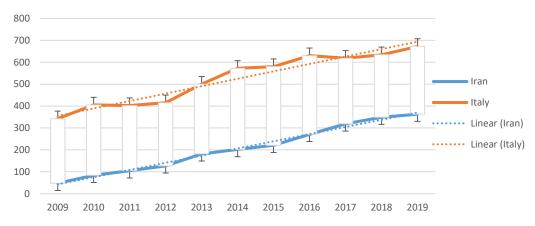
Mahya Abdollahifaard / Oranus Tajedini / Ali Sadatmoosavi

articles indexed in WoS but this ranking was reversed in Scopus. Since there was no analysis of the number of articles published by different countries in PubMed, a total of 100 articles on multiple Sclerosis published from 2009 to 2019 were selected randomly, and the data showed that the United States published the highest number of articles in the mentioned period compared to the other two countries. The information-seeking behavior of Internet users in Iran and the United States was compared using the data extracted from Google Trends, as displayed in Graph 2:



Graph 2: A comparison of the information-seeking behavior of Internet users in Iran and the United States

The seventh objective of the present study was to compare the volume of scientific production in Iran compared to one of the countries with a higher health information search index of its Internet users in the field of multiple Sclerosis in Google Trends from 2009-2019. A comparison of Iran's ranking with other countries in terms of the search volume index (Figure 9) showed that Italy has the highest search index in the field of multiple Sclerosis compared to other countries. Thus, to assess the scientific products of this country in the field of multiple Sclerosis from 2009 to 2019 and compare them with the scientific products of Iran in the mentioned period, the data retrieved from PubMed, WoS, and Scopus were used as shown in Graph 3:



Graph 3: A comparison of scientific products of Iranian and Italian researchers in the field of multiple Sclerosis from 2009 to 2019

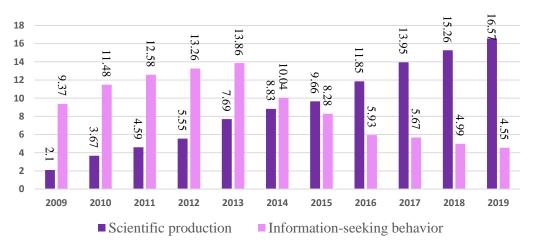
Finally, the last objective of this study was to assess the relationship between the information-seeking behavior of Iranian users in Google Trends and the scientific production in the field of multiple Sclerosis indexed in PubMed, WoS, and Scopus from 2009 to 2019. Table 5 shows the frequency of Iranian users' search volume index in Google Trends in the field of multiple Sclerosis from 2009 to 2019. As can be seen, the search volume index, which reflects the information-seeking behavior of users, increased in the field of MS from 2009 to 2013 and followed a declining trend compared to previous years. Therefore, 2013, with 13.86% of the total 11-year searches, is the most active year for Iranian users in the multiple sclerosis fields in the Google Trends database.

Table 5

Frequency distribution of Iranian users' search volume index in the field of Multiple Sclerosis

Year	Frequency	Percentage
2009	748	9.37
2010	916	11.48
2011	104	12.58
2012	1058	13.28
2013	1106	13.86
2014	801	10.04
2015	661	8.28
2016	473	5.93
2017	453	5.67
2018	398	4.99
2019	363	4.55
Total	7981	100

Graph 4 shows that Iranian researchers published the highest number of articles in the field of Multiple Sclerosis in the PubMed, Web of Science (WoS), and Scopus databases in 2019. Besides, according to the data, 2019 with 16.57% of the total scientific production in multiple Sclerosis has the largest share from 2009 to 2019.



Graph 4: The frequency of information-seeking behavior of Iranian users and scientific production of

Mahya Abdollahifaard / Oranus Tajedini / Ali Sadatmoosavi

Iranian researchers from 2009 to 2019

The average of the information-seeking behavior of Iranian users and their scientific production from 2009 to 2019 is shown in Table 6.

Table 6

The descriptive statistics for information-seeking behavior of Iranian users and scientific production of Iranian researchers from 2009 to 2019

Variable	Mean	Std. Deviation
Scientific production of Iranian researchers from 2009 to 2019	207.9	111.5
Information-seeking behavior of Iranian users from 2009 to 2019	725.5	274.9

The Shapiro-Wilk test was run to check the normality of the data for the informationseeking behavior of Iranian users and scientific production of Iranian researchers from 2009 to 2019, as shown in Table 7.

Table 7

The Shapiro-Wilk test for information-seeking behavior and scientific production

Variable	P-value
Scientific production of Iranian researchers	0.72
Information-seeking behavior of Iranian users	0.29

Since the p-value for both variables is greater than 0.05, the normality assumption of the two variables is confirmed (Table 8). Given the normality of the data in the field of Multiple Sclerosis, the Pearson correlation test was run in R software to check the correlation between the two variables:

Table 8

The correlation between information-seeking behavior and scientific production in the field of MS

Scale	Pearson correlation (r)	P-value
Information-seeking behavior and scientific production	-0.81	0.005

Discussion

Multiple Sclerosis (MS) is an autoimmune disease that is debilitating and chronic and is not fully understood despite much effort and research taken into this field (Broadway, 2005). This disease causes a substantial psychological and social burden due to its persistent impact on affected people (Bragazzi, 2013). The importance of this disease has led to numerous studies in this field. Thus, in addition to scientific products that show the attention of researchers and experts to the various aspects of this disease (Ford et al., 2012), Hay et al. (2008) found that most MS patients tend to search the Internet before and after a medical visit to understand better the technical terms used by physicians. In addition to the great volume of Internet searches of users about MS, which indicates an urgent need for information about MS, research on the disease generates data streams that can be analyzed in research projects, and the results can be used for health policy purposes (Lavorgna et al., 2017). To better discuss and share information with MS patients, physicians should know the most frequent searches and needs or knowledge gaps (Wales, Bruch, Foster, Gorman & Peters, 2014).

Furthermore, a review of scientific articles on MS published in reliable databases can improve the quality of research studies in this field and promote their impact on the country's health development (Gorji et al., 2010). To this end, the present study explored the information-seeking behavior of users and scientific products published in Iran in the field of multiple Sclerosis using an infodemiological approach. The insights from this study can contribute to guiding researchers in exploring research problems in this field.

The preferred terms and keywords used by Iranian users in the field of MS during the period from 2009 to 2019, based on Google Trends data, in each category were adequate to define the search volume index for that category. This confirms the extensive subject area of searches conducted by Iranian users in the multiple sclerosis field over the period in question. Accordingly, Brigo, Igwe, Nardone, Orioli and Otte (2016) stated that multiple Sclerosis encompasses an extensive set of terms not limited to just a few words.

Of the five more frequently searched categories, the most searched category was related to MS symptoms. A patient who has just been affected by MS has little information about the disease and considers this data a basis for their conversations with the physician during the first visit. Moreover, the second most frequently searched category was MS treatment. Similarly, Brigo et al. (2014) found that causes and symptoms of MS were users' most frequently searched keywords. Moreover, Bragazzi (2013), after the keywords related to the disease and symptoms, the category of treatment had the highest search volume index.

An analysis of Iranian users' information-seeking behavior through the common term "MS" in Persian and English during 2009-2019 indicated that the search volume index for this term has undergone many ups and downs during the period in question. Dividing the period in question into four seasons indicated that changing the season did not have much effect on the information-seeking behavior of Iranian users in the field of MS because the disease manifested its symptoms and problems in all seasons and the season has little effect on improvement or exacerbation of the patient's condition (Bragazzi, 2013). From 2009 to 2013, there was an upward trend in the search volume index. Leaps in the chart until 2013 show that this month coincides with the Iranian International Congress on Multiple Sclerosis, and perhaps the good performance of the MS Association, which is in charge of this congress, in organizing the congress and reflecting its news could account for intensifying information-seeking behavior of users. Since 2013, there has been a gradual decrease in the search volume index in Google due to specialists' advice not to use online health information through search engines. Contrary to these findings, Brigo et al., (2014) suggested that this kind of news does not affect the information-seeking behavior of Iranian users in the field of Multiple Sclerosis.

The highest index of online health information search volume was found in the cities of Tabriz, Isfahan, Tehran, Shiraz, and Mashhad, respectively. These cities are the metropolises in Iran. According to experts, anxiety is one of the possible causes of MS (Sharif et al., 2018). Thus, considering the anxiety caused by living in large cities, a high search volume index in these cities is not surprising. Air pollutants and heavy metals are also other possible factors in the candidacy of metropolitan residents for certain diseases (Kargarfard, Eetemadifar, Mehrabi, Maghzi & Hayatbakhsh, 2012), which is one of the reasons for not publishing accurate statistics

on the number of MS patients in some of these metropolises in recent years (Eskandarieh, Allahabadi, Sadeghi & Sahraian, 2018). However, given the physical distance of the mentioned cities from each other, the assumption of the effect of latitude and longitude on the incidence of multiple Sclerosis is ruled out, at least in Iran, as indicated by Bragazzi (2013).

Concerning the user search volume index, in the most pessimistic case, when only the keyword "MS" in English is considered, and the corresponding keyword in Persian with a much higher search volume index than its English counterpart is skipped, Iran is ranked 19th.

The number of scientific products indexed in PubMed, Web of Science (WoS), and Scopus databases have been growing. Furthermore, the volume of scientific production by Iranian researchers in the multiple sclerosis field from 2009 to 2019 has been increasing at a relatively constant rate. Although the growth rate slowed in 2012 and 2015, it was higher than the average in 2010, 2013, and 2017. The data on the frequency distribution of scientific products by Iranian researchers in the field of multiple Sclerosis from 2009 to 2019 indicated that the highest number of articles were published in the journal "Multiple Sclerosis and Related Disorders" with 61 articles and more than 10 articles have been published in only 5.35% of the total 821 journals. Journals with 5 to 10 articles accounted for 8.76% and journals with less than 5 published during 2009-2019 accounted for 85.62% of the total journals. However, 58.83% of journals have published only one article. In addition, a review of the language of scientific productions indicated that Iranian researchers in the field of multiple Sclerosis have a great desire to publish their articles in journals published in English, followed by the Persian language with 5.2% of articles. Similarly, Rutsaeret al. (2013) found that 90% of the scientific products in the multiple sclerosis field were released in the native language.

A comparison of the information-seeking behavior of Iranian users with those of users in the United States indicated that the most scientific production in the field of multiple Sclerosis was published during 2009-2019. Besides, the search volume index in both countries showed an upward trend until 2013 but declined afterward. This decline in Iran continued despite the ups and downs in the chart. However, the number of MS-related searches by American users has increased since 2018. If the decrease in MS-related searches in both countries is attributed to specialists' advice, the change in the direction of the search volume index of US users from 2018 could be considered a change in the policies of the health system of this country for using the Internet to access to reliable health information. Accordingly, Brigo, Lattanzi, Bragazzi, Nardone, Moccia and Lavorgna (2018) highlighted the change of health systems in developed countries from model PO to model P6 and the creation of new ways and scenarios in the field of multiple Sclerosis to provide understandable and clear information.

A comparison of the scientific products of Iranian researchers with the scientific products of Italian researchers, which has the highest search volume of users in the field of multiple Sclerosis among all countries, indicated that the total number of scientific products published in both countries in the field of multiple Sclerosis has increased from 2009 to 2019. The difference is that the scientific production curve of Italy shows some ups and downs and the scientific production curve for Iran is increasing at a steady pace. Overall, the difference in the number of productions has been maintained during these eleven years.

Conclusion

The data in this study confirmed a significant relationship between the information-seeking behavior of Iranian users and scientific products of Iranian researchers in the field of MS from 2009 to 2019, implying that in the years when the search volume index of Iranian users in the field of multiple Sclerosis has decreased in Google search engine, scientific productions of Iranian researchers in this field have increased. Thus, it can be argued that Iranian researchers working in the field of multiple Sclerosis ignore a decline in MS-related searchers by Iranian users and are engaged in conducting research projects in this field for other reasons, as evidenced by an increase in the number of articles published by Iranian researchers over the same period. On the other hand, the same specialists in the guise of physicians call for patients not to search the Internet and ignore this information about their disease due to concerns about incorrect information released on the Internet. Many factors increase the level of scientific production. However, internet users' MS-related information-seeking behavior is not one of these factors. Furthermore, after the procedure prohibiting patients from searching for information on the Internet, the leading countries in scientific productions used Web 2.0 tools to search the Internet and use the correct data provided by the health networks in these countries. Patients' experiences can also motivate conducting research projects to facilitate their life.

Research proposals

Each research in its work path benefits from previous research and is also a guide for subsequent research. According to the process and results of this research, these research proposals can be presented:

• Research to identify the real information needs of users: To identify the real needs of users, research should be conducted in the field of Multiple Sclerosis.

• Epidemiology of health information based on the information-seeking behavior of users with the Google Trends tool in other areas of health to conduct complete research with the Google Trends tool to map the prevalence of various diseases in the country, it is suggested It is recommended that domestic researchers by benefiting from this tool and monitoring the internet information seeking behavior of users, provide its data to the custodians of the Ministry of Health and institutions related to the health field for more systematic decision-making.

• A survey on the health information-seeking behavior of the country's users in the field of multiple Sclerosis: In a part of the current research, the health information-seeking behavior of users in the field of multiple Sclerosis was investigated on the web. It is suggested that in independent research, the health information-seeking behavior of the country's users in similar areas in the real space should be investigated through a survey, and its results should be compared with the results of this research.

• Conducting interviews to extract the preferred keywords of users in the epidemiology of demand-based information: interviews were conducted to extract the preferred keywords of users in different cities of the country, and the results were compared with the results of the present study.

References

- Atreja, A., Mehta, N., Miller, D., Moore, S., Nichols, K., Miller, H. & Harris, C. M. (2005). One size does not fit all: using qualitative methods to inform the development of an Internet portal for multiple sclerosis patients. In *AMIA Annual Symposium Proceedings* (Vol. 2005, p. 16). American Medical Informatics Association.
- Bragazzi, N. L. (2013). Infodemiology and infoveillance of multiple sclerosis in Italy. *Multiple sclerosis international*, 924029. <u>https://doi.org/10.1155/2013/924029</u>
- Brigo, F., Igwe, S. C., Ausserer, H., Nardone, R., Tezzon, F., Bongiovanni, L. G. & Trinka, E. (2014). Why do people Google epilepsy?: An infodemiological study of online behavior for epilepsy-related search terms. *Epilepsy & behavior*, 31, 67-70. https://doi.org/10.1016/j.yebeh.2013.11.020
- Brigo, F., Igwe, S. C., Nardone, R., Orioli, A. & Otte, W. M. (2016). Cancer information disparities on the Internet: an infodemiological study. *Journal of Cancer Policy*, 8, 33-37. <u>https://doi.org/10.1016/j.jcpo.2016.04.002</u>
- Brigo, F., Lattanzi, S., Bragazzi, N., Nardone, R., Moccia, M. & Lavorgna, L. (2018). Why do people search Wikipedia for information on multiple Sclerosis? *Multiple sclerosis and related disorders*, 20, 210-214. <u>https://doi.org/10.1016/j.msard.2018.02.001</u>
- Broadway, S. C. (2005). *Health information-seeking behaviors on the Internet among diabetic and healthy women*. Doctoral Dissertation. University of Florida. Retrieved from https://www.proquest.com/openview/1d0e5d3290bb11d94a125d68ee6b8100/1?pq-origsite=gscholar&cbl=18750&diss=y
- Cooper, C. P., Mallon, K. P., Leadbetter, S., Pollack, L. A. & Peipins, L. A. (2005). Cancer Internet search activity on a major search engine, United States 2001-2003. *Journal of medical Internet research*, 7(3), e36. <u>https://doi.org/10.2196%2Fjmir.7.3.e36</u>
- Creswell, J. W. (2021). A concise introduction to mixed methods research. University of Michigan, SAGE publications.
- Dehkordy, S. F., Carlos, R. C., Hall, K. S. & Dalton, V. K. (2014). Novel data sources for women's health research: Mapping breast screening online information seeking through Google trends. *Academic radiology*, 21(9), 1172-1176. https://doi.org/10.1016/j.acra.2014.05.005
- Ford, Jones, Middleton, Lockhart-Jones, Maramba, Noble, Osborne & Lyons (2012). The feasibility of collecting information from people with Multiple Sclerosis for the UK MS Register via a web portal: Characterising a cohort of people with MS. *BMC Medical Informatics and Decision making*, 12, 73. <u>https://doi.org/10.1186/1472-6947-12-73</u>
- Eskandarieh, S., Allahabadi, N. S., Sadeghi, M. & Sahraian, M. A. (2018). Increasing prevalence of familial recurrence of multiple Sclerosis in Iran: a population based study of Tehran registry 1999–2015. *BMC Neurology*, 18, 15. <u>https://doi.org/10.1186/s12883-018-1019-2</u>
- Eysenbach, G. (2006). Infodemiology: tracking flu-related searches on the web for syndromic surveillance. In *AMIA annual symposium proceedings* (Vol. 2006, p. 244). American Medical Informatics Association.

- Eysenbach, G. (2008). Credibility of health information and digital media: New perspectives and implications for youth. Digital media, youth, and credibility. In Miriam J. Metzger and Andrew J. Flanagin (Eds), *the John D. and Catherine T. MacArthur Foundation Series on Digital Media and Learning*. Cambridge, MA: The MIT Press. 123-154. htpps://doi.org/10.1162/dmal.9780262562324.123
- Eysenbach, G. (2009). Infodemiology and infoveillance: Framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. *Journal of medical Internet research*, 11(1), e1157. https://doi.org/10.2196/jmir.1157
- Eysenbach, G. (2011). Can tweets predict citations? Metrics of social impact based on Twitter and correlation with traditional metrics of scientific impact. *Journal of medical Internet research*, 13(4), e2012. <u>https://doi.org/10.2196/jmir.2012</u>
- Eysenbach, G., Powell, J., Kuss, O. & Sa, E. R. (2002). Empirical studies assessing the quality of health information for consumers on the World Wide Web: A systematic review. *Jama*, 287(20), 2691-2700. <u>https://doi.org/10.1001/jama.287.20.2691</u>
- Fitzpatrick, R. & Boulton, M. (1994). Qualitative methods for assessing health care. *Quality in health care*, 3(2), 107-113. <u>https://doi.org/10.1136/qshc.3.2.107</u>
- Ginsberg, J., Mohebbi, M. H., Patel, R. S., Brammer, L., Smolinski, M. S. & Brilliant, L. (2009). Detecting influenza epidemics using search engine query data. *Nature*, 457(7232), 1012-1014. <u>https://doi.org/10.1038/nature07634</u>
- Gorji, H. A., Roosta Azad, L., Hassanzadeh, H. M., Asghari, L., Atlasi, R., Shokraneh, F. & Bazrafshan, A. (2010). Ranking the faculty members of Iran University of Medical Sciences till to 2008 based on h-index, g-index, and m-index. *Health Information Management*, 13(42), 17-24. Retrieved from <u>http://jha.iums.ac.ir/article-1-763-en.html</u> [in Persian]
- Kargarfard, M., Eetemadifar, M., Mehrabi, M., Maghzi, A. H. & Hayatbakhsh, M. R. (2012).
 Fatigue, depression, and health-related quality of life in patients with multiple Sclerosis in Isfahan, Iran. *European journal of neurology*, 19(3), 431-437.
 <u>https://doi.org/10.1111/j.1468-1331.2011.03535.x</u>
- Lavorgna, L., Russo, A., De Stefano, M., Lanzillo, R., Esposito, S., Moshtari, F., Rullani, F., Piscopo, K., Buonanno, D., Morra, V.B. and Gallo, A. (2017). Health-related coping and social interaction in people with multiple Sclerosis supported by a social network: pilot study with a new methodological approach. *Interactive journal of medical research*, 6(2), e10. https://doi.org/10.2196/ijmr.7402
- Marrie, R. A., Salter, A. R., Tyry, T., Fox, R. J. & Cutter, G. R. (2013). Preferred sources of health information in persons with multiple Sclerosis: Degree of trust and information sought. *Journal of Medical Internet Research*, 15(4), e67. https://doi.org/10.2196%2Fjmir.2466
- Mavragani, A., Ochoa, G. & Tsagarakis, K. P. (2018). Assessing the methods, tools, and statistical approaches in Google Trends research: Systematic review. *Journal of Medical Internet Research*, 20(11), e270. <u>https://doi.org/10.2196/jmir.9366</u>
- Siri, A., Khabbache, H., Al-Jafar, A., Martini, M., Brigo, F. & Bragazzi, N. L. (2016). Infodemiological data of high-school drop-out related web searches in Canada correlating with real-world statistical data in the period 2004–2012. *Data in brief*, 9, 679-684. <u>https://doi.org/10.1016/j.dib.2016.09.032</u>

- Sharif, K., Watad, A., Coplan, L., Lichtbroun, B., Krosser, A., Lichtbroun, M., Bragazzi, N.L., Amital, H., Afek, A. & Shoenfeld, Y. (2018). The role of stress in the mosaic of autoimmunity: An overlooked association. *Autoimmunity reviews*, 17(10), 967-983. <u>https://doi.org/10.1016/j.autrev.2018.04.005</u>
- Springer, S., Zieger, M. & Strzelecki, A. (2021). The rise of infodemiology and infoveillance during COVID-19 crisis. *One Health*, 13, 100288. <u>https://doi.org/10.1016/j.onehlt.2021.100288</u>
- Tajedini, O., Soheili, F. & Sadatmoosavi, A. (2019). The centrality measures in co-authorship networks: Synergy or antagonism in researchers' research performance. *Iranian Journal of Information Processing & Management*, 34(3), 1423-1452. https://doi.org/10.35050/JIPM010.2019.044 [in Persian]
- Tan, A. S., Lee, C. J. & Chae, J. (2015). Exposure to health (Mis) information: Lagged effects on young adults' health behaviors and potential pathways. *Journal of Communication*, 65(4), 674-698. <u>https://doi.org/10.1111/jcom.12163</u>
- Van Velsen, L., van Gemert-Pijnen, J. E., Beaujean, D. J., Wentzel, J. & van Steenbergen, J. E. (2012). Should health organizations use web 2.0 media in times of an infectious disease crisis? An in-depth qualitative study of citizens' information behavior during an EHEC outbreak. *Journal of Medical Internet Research*, 14(6), e181. https://doi.org/10.2196/jmir.2123
- Wales, A., Bruch, S., Foster, W., Gorman, M. & Peters, J. (2014). International trends in health science librarianship Part 9: The UK–Scotland and Wales. *Health Information & Libraries Journal*, 31(1), 79-83. <u>https://doi.org/10.1111/hir.12050</u>
- Willard, S. D. & Nguyen, M. M. (2013). Internet search trends analysis tools can provide realtime data on kidney stone disease in the United States. *Urology*, 81(1), 37-42. <u>https://doi.org/10.1016/j.urology.2011.04.024</u>