

Precisionen av digital hälsoinformation - en systematisk översikt

The Accuracy of Online Health Information - a systematic review

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Introduktion: I dagens digitala tidsålder vänder sig många individer till internet som sin första källa till hälsoinformation. Forskning har dock visat att majoriteten av digital hälsoinformation är av låg kvalitet och har bristfällig korrekthet. En stor del av denna information består sannolikt av både desinformation och missinformation. **Syfte:** Syftet med denna studie var att sammanställa resultaten från peer-review granskade studier som utvärderar korrektheten hos digital hälsoinformation, med särskilt fokus på studier som använder expertgranskade texter utvärderade mot etablerade riktlinjer. **Metod:** Den 7 april 2024 genomfördes tre databaser – MEDLINE EBSCO, Scopus och PubMed. Totalt 21 artiklar inkluderades. Resultaten från dessa artiklar kategoriserades och analyserades induktivt utifrån Narro och Tjudes neo-ekologiska teori. **Resultat:** Fyra huvudkategorier skapades gällande informationens korrekthet: *god*, *måttlig*, *bristfällig* och *varierande*. Av de inkluderade artiklarna bedömdes 3 (14%) ha *god* korrekthet, 4 (19%) artiklar *måttlig* korrekthet, 13 (62%) *bristfällig* korrekthet och 1 (5%) hade *varierande*. Därtill ansågs 76% av det inkluderade materialet från *trovärdiga* källor ha bristfällig korrekthet. **Slutsats:** Majoriteten av de inkluderade studierna och det *trovärdiga* materialet har *bristfällig* korrekthet. Dessutom, tenderar studier som uppvisar en högre grad av korrekthet, ha sämre läsbarhet och den övergripande kvaliteten är ofta bristfällig, vilket även gör det svårt för konsumenter att förstå informationen.

ABSTRACT

Title: The Accuracy of Online Health Information – systematic review

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Introduction: In today's digital age, many individuals turn to the internet as their initial source of health information. However, research has shown that the majority of online health information is of poor quality and low accuracy. A significant portion of this information likely includes both misinformation and disinformation. **Aim:** The aim of this study was to synthesize findings from peer-reviewed research assessing the accuracy of online health information, with a particular emphasis on studies that utilize expert-reviewed content evaluated against established guidelines. **Method:** On 7 April 2024, three databases—MEDLINE EBSCO, Scopus, and PubMed—were searched. A total of 21 articles were included in the systematic review. The results from these articles were categorized and inductively examined through the lens of Narro and Tudge's neo-ecological theory. **Results:** Four primary categories were created concerning the accuracy of the information: *good*, *moderate*, *poor*, and *varied*. Among the included articles, 3 (14%) were deemed to have *good* accuracy, 4 (19%) articles exhibited *moderate* accuracy, 13 (62%) demonstrated *poor* accuracy, and 1 (5%) had *varied* accuracy. Additionally, 76% of the included material from *trustworthy* sources were categorized as having *poor* accuracy. **Conclusion:** The majority of the included studies and *trustworthy* material were found to have *poor* accuracy. Furthermore, even when studies exhibited a higher degree of accuracy, the readability and overall quality were often deficient, making it difficult for consumers to understand.

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1. INTRODUCTION

In an increasingly digitized society, the cultural mechanisms surrounding the publication and consumption of information are evolving, making access to information more readily available, including health information. With over 66 percent of the global population using the internet in 2023, there is no doubt that the consumption of health information on various online platforms is widespread (We Are Social, 2024). Today, many individuals with questions about health and illness primarily turn to the internet for answers (Hesse et al., 2005; Fox & Rainie, 2002), often consulting it before seeing a physician (Gualtieri, 2009). Moreover, a majority of Americans believe in protecting freedom of information, even if it means allowing potentially false information online (Mitchell et al., 2018). Simultaneously, the survey reveals that respondents also want the government to take action against false information (Mitchell et al., 2018). Consequently, the question arises regarding the accuracy of online health information. According to Eysenbach et al.'s (2002) systematic review of several studies analyzing over 7,000 different web pages and platforms, 70 percent of these sites are of poor quality. Several other studies depict similar findings, regardless of whether these websites are published by authorities or legitimate healthcare organizations (Zhang et al., 2015).

1.1. Types of false information

In everyday discourse, terms such as disinformation, misinformation, and malinformation are often used to describe inaccurate information. However, each term carries distinct meanings. According to Wardle and Derakhshan (2017), disinformation occurs when false information is intentionally shared to cause harm, misinformation arises when false information is shared without the intent to cause harm, and malinformation involves genuine information shared with the intent to cause harm, such as by moving private information into the public sphere. Therefore, the most appropriate terms in this context is mis- and disinformation. Misinformation contradicts the consensus of the scientific community and is subject to change as new evidence emerges or the evidence base develops. Therefore, the parameters for determining what constitutes misinformation are constantly shifting (Swire-Thompson & Lazer, 2020). It is crucial to differentiate between misinformation and disinformation, as the latter involves a deliberate intent to gain money or other advantages (Swire-Thompson & Lazer, 2020). Additionally, Fahy et al. (2014) identify a similar phenomenon that can be classified as a form of disinformation. This occurs when distorted or blatantly incorrect information is disseminated for marketing purposes, such as when for-profit organizations withhold information about harms or exaggerate the benefits of interventions, see Table 1.

The presence of misinformation on digital platforms, which may initially appear legitimate, can therefore have consequences for the questioning consumer (Fahy et al., 2014). However, health information online is often deemed to be of low quality regardless of the source (Zhang et al., 2015; Eysenbach et al., 2002). Nevertheless, the public considers social media to be the least trustworthy source when seeking information online (Statista, 2024).

Table 1. Defining the different types of health information (Polyzou et al., 2023; Swire-Thompson & Lazer, 2020; Wardle & Derakhshan 2017).

Type	Characteristics and intent	Example
(Mis)information	<ul style="list-style-type: none"> • Inaccurate information, contrary to scientific consensus • Changes as new evidence arises • Often spread unknowingly due to misunderstanding or lack of knowledge 	<p>Sharing outdated vaccine side effects that have since been debunked by recent studies</p> <p>Spreading false health benefits of a certain intervention due to misinterpretation of scientific studies</p>
(Dis)information	<ul style="list-style-type: none"> • False information created and disseminated with intent • Intend to mislead, harm reputations, or to gain financially • Often through sophisticated campaigns that aim to manipulate public opinion 	<p>Marketing campaigns with exaggerated benefits or withholding risks of a medical treatment for financial gain</p>
(Mal)information	<ul style="list-style-type: none"> • Based on reality, but shared with malicious intent • Typically private, sensitive information 	<p>Leaking private information about a person or corporation making it public</p>

1.2. Public health relevance

Public health, as defined by Gatseva and Argirova (2011), refers to "the science and art of preventing disease, prolonging life, and promoting health through organized efforts and informed choices of society, organizations, both public and private, communities, and individuals." Health information is a significant and crucial aspect of promoting health among the population, particularly given its easy accessibility facilitated by digitization. If the information is not accurate, it inevitably increases the risk of several adverse consequences among consumers (Swire-Thompson & Lazer, 2020). Therefore, it is essential that all information disseminated by health and disease organizations is of high quality and accuracy, enabling both professionals and the general public to make informed decisions, conduct meaningful research, and improve population health.

This importance is also reflected in the United Nations' (UN) Agenda 2030 Action Plan, which contains goals for transitioning to a sustainable society for both people and the planet (Regeringskansliet, 2023). In the realm of public health, Goal 3 focuses on ensuring good health and well-being. According to this goal, healthy lifestyles and well-being should be promoted and ensured for all individuals of all ages (Regeringskansliet, 2023). The goal also highlights how increased globalization brings heightened risks of spreading various health threats, which can be linked to online misinformation. One of its sub-goals, sub-goal 3.8, aims to provide access to healthcare for all (Regeringskansliet, 2023). It states (translated from Swedish): "Achieve universal health coverage, including financial risk protection, access to quality essential healthcare services, and access to safe, effective, quality, and affordable essential medicines and vaccines" (Regeringskansliet, 2023). Thus, the emphasis on quality healthcare underscores the importance of reliability in digital healthcare services.

Within the field of public health, particularly in health communication, the concept of health literacy is prevalent. Health literacy is rooted in the broader concept of literacy, which encompasses the capacity to read, write, and possess basic numerical skills (Wilson & Mabhala, 2009). Two forms of literacy are identified: general literacy and health literacy (Wilson & Mabhala, 2009). Health literacy is defined as the cognitive and social skills that determine individuals' motivation and ability to access, understand, and use information in ways that promote and maintain good health (Wilson & Mabhala, 2009; Nutbeam et al., 2010). According to Nutbeam et al. (2010), health literacy is more an outcome of health education and communication than a determinant of health outcomes. In other words, individuals with higher levels of health literacy are better equipped to make informed decisions and modify their personal behavior (Nutbeam et al., 2010). This concept also applies to digital health information, often referred to as eHealth literacy (O'Neil, 2019).

eHealth literacy refers to the ability to critically access, assess, and appraise health information from digital sources and the web (O'Neil, 2019). O'Neil (2019) highlights how increased digitization, along with the greater volume of misinformation and disinformation, imposes the need for the general public to find relevant information and critically evaluate it. Furthermore, O'Neil (2019) discusses how digital exclusion among groups with lower health literacy not only disadvantages individuals but also deepens social and digital health disparities. If people are unable to work with technology and access information online, disparities in health information access are inevitable (O'Neil, 2019). Lower eHealth literacy makes it harder to discriminate between inaccurate and credible information online, which can be harmful when making health-related decisions (O'Neil, 2019).

1.3. Theory

Urie Bronfenbrenner is a prominent figure in public health research, contributing significantly to ecological thinking (Eriksson et al., 2018). In the late 1970s, Bronfenbrenner began developing a socioecological theory, which has since evolved to provide a comprehensive perspective on human development (Bronfenbrenner, 1977; Bronfenbrenner et al., 2007). In the early 1980s, the theory shifted its focus to the individual's role and development. Ultimately, before his passing, Bronfenbrenner's work culminated in the development of the Process-Person-Context-Time (PPCT) model (Bronfenbrenner, 1977; Bronfenbrenner et al., 2007; Eriksson et al., 2018).

The theory posits that human development is influenced by multiple interconnected systems, including the immediate environment (microsystem), the mesosystem, and the broader macrosystem of societal influences (Bronfenbrenner, 1977; Bronfenbrenner et al., 2007; Eriksson et al., 2018). The theory highlights the importance of interactions between these systems, including family, peers, school, and cultural values, in shaping development. Context plays a significant role in this dynamic process (Bronfenbrenner, 1977; Bronfenbrenner et al., 2007; Eriksson et al., 2018).

1.3.1. Neo-ecological theory

Narro and Tudge (2023) have built upon Bronfenbrenner's ecological theory, specifically the PPCT model, to develop a neo-ecological theory that incorporates digitalization. In Bronfenbrenner's original theory, the microsystem is characterized by face-to-face interactions (Bronfenbrenner, 1977). However, Narro and Tudge (2023) recognize that the emergence of virtual spaces has introduced complexities to this concept. Narro and Tudge

(2023) propose that there are two distinct types of microsystems: virtual and physical. In the virtual microsystem, interactions occur through digital platforms, such as social media, where users engage with each other through posting and responding to content (Narro & Tudge, 2023). Another example of virtual microsystems is digital health platforms, which enable patients to interact with healthcare professionals (HCPs).

As described in Bronfenbrenner's theory, the mesosystem consists of two or more microsystems that influence each other (Eriksson et al., 2018). Narro and Tudge (2023) illustrate this concept by using healthcare as an example, where the mesosystem comprises both virtual and physical systems. For instance, a patient may use an online portal to manage and book appointments, while also engaging in physical interactions with HCP's during hospital visits. Bronfenbrenner's theory, as well as Narro and Tudge's (2023) work, discusses exosystems, which are broader systems that influence the microsystem without directly involving the individual. Examples of exosystems include policies, media, and work environments. Building upon Bronfenbrenner's view of macrosystems as social contexts, such as culture and lifestyle, that surround the micro- and mesosystems in the physical world, Narro and Tudge (2023) recognize that these norms also shape digital activities. Consequently, these norms can influence both virtual and physical microsystems, as well as the mesosystem. Indeed, it is clear that exosystems, such as culture, financial incentives, and consumer trends, can shape the micro- and mesosystems.

In the context of their digitally evolved theory, Narro and Tudge (2023) highlight several key features of virtual microsystems, including proximal processes. According to Bronfenbrenner (Bronfenbrenner & Morris, 2007), proximal processes are the 'engines of development', where individuals learn and develop through interactions with their environment, resulting in a reciprocal exchange of energy. In simpler terms, proximal processes involve a reciprocal interaction between the individual and their environment, which occurs over time and is closely accessible to the individual. For instance, a patient who actively participates in a patient-facing social media movement, sharing and discussing their diagnosis, may experience a proximal process that can impact other microsystems. Moreover, Narro and Tudge (2023) discuss the permanence and availability of online content, which remains accessible even after the virtual interaction or activity has concluded. This phenomenon highlights a key difference between virtual microsystems and Bronfenbrenner's original theory, as virtual microsystems are not limited by time and geography. As a result, content in virtual microsystems can be easily copied and shared in its original form, as noted by Narro and Tudge (2023). However, Narro and Tudge (2023) recognize that the permanence of virtual microsystems can have both positive and negative consequences. Regarding availability, virtual microsystems can facilitate both synchronous interactions (e.g., video meetings) and asynchronous interactions (e.g., email), a feature shared by some physical systems. Narro and Tudge (2023) emphasize that this aspect of availability is particularly important when considering proximal processes in virtual microsystems.

This adaptation of Bronfenbrenner's theory highlights the unique contributions of both virtual and physical settings to the human development process, emphasizing the importance of understanding these interactions in the context of health and digital health (Narro & Tudge, 2023). Narro and Tudge (2023, p. 15) stress that virtual microsystems are crucial contexts in the lives of young people, making them a vital area of study for researchers, practitioners, and policymakers.

According to the neo-ecological theory, two main factors play a role in making an individual more exposed to inaccurate information: proximity and accessibility. How close is the information, how often is it searched for, and is it readily available? It's been shown that most people searching for health information are turning to the internet as their first stop (Gualtieri, 2009). Since an increasing number of people have access to the internet, information is available asynchronously on demand. Therefore this theory is particularly relevant when examining the accuracy of online health information and its impact on individuals and society as a whole. This theory is deemed more suitable for understanding the broader impact of online health information, with a focus on information accuracy, whereas health literacy focuses on the individual's ability to navigate in the digital information landscape.

1.4. Previous research

Prior research has investigated various aspects of online health information, including credibility, quality, and comprehensiveness, across different types of online health information providers. Several methods have been developed to assess the quality of online health information, although most of these methods serve as proxies for accuracy and focus on factors such as the publisher, source, design, and references, rather than the actual content (Fahy et al., 2014). JAMA, HONcode, and DISCERN are three well-known quality evaluation tools used for all types of information; however, they have limitations, as they do not directly assess the accuracy of health information content (Fahy et al., 2014).. Surprisingly, websites that meet all of JAMA's criteria have been found to contain a higher proportion of inaccurate information, underscoring the limitations of these quality evaluation tools (Fahy et al., 2014). Fahy et al. (2014) contend that evaluating the accuracy of online health information requires specialized knowledge, which can be a significant barrier to conducting such studies. Daraz et al. (2019) similarly acknowledge the challenges of measuring accuracy due to the need for expert knowledge. As a result, the quality evaluation tools are more commonly used, despite their limitations, due to the difficulties in directly assessing accuracy.

Empirical studies reveal significant variations in the quality of online health information, depending on the measurement instruments, organizations, and specialties involved (Daraz et al., 2019). The impact of online health information is far-reaching, influencing patient safety, healthcare outcomes, healthcare expenditures, the management of chronic conditions, and the quality of life for individuals who rely on the internet for health information (Murray et al., 2003; Daraz et al., 2019). However, Daraz et al. 's (2019) systematic review evaluating the overall quality of online health information highlighted an urgent need to improve the quality of information for certain conditions and across different organizations. Their systematic review, which analyzed 153 studies and 11,785 web pages, revealed mixed results, with 37-79% of the websites meeting good quality standards, while the remaining 21-63% were deemed to be of poor quality, as measured by proxy instruments for information quality.

Systematic reviews by Zhang et al. (2015) and Eysenbach et al. (2002) agree and emphasize that suboptimal accuracy and overall quality of health information are extremely prevalent on social media. Zhang et al.'s (2015) systematic review examined 165 articles and evaluated the quality of health information on the web against predefined criteria. Their results revealed that the quality varied across websites and medical domains with the overall quality being problematic (Zhang et al., 2015). Eysenbach et al. (2002) examined the literature on the quality of online health information and the most common methodological frameworks used to evaluate it. They included 79 articles and came to the same conclusion, that both the

methods, quality criteria and topic chosen varied widely (Eysenbach et al., 2002). Seventy percent of the studies they reviewed concluded that the quality of information on the web is problematic, while 22 percent had a neutral conclusion and 9 percent had a positive one (Eysenbach et al., 2002).

Consistently, research has demonstrated that most consumers trust the health information shared by influencers on social media even though the information may not be entirely accurate (De Veirman et al., 2017). This trust in inaccurate information can lead to challenging physician-patient interactions and compromised healthcare outcomes. Murray et al. (2003) found that many physicians reported patients often brought inaccurate or irrelevant internet information to appointments, compromising healthcare outcomes and straining the physician-patient relationship.

1.5. Problem statement

Today, the majority of people today rely on online platforms to access health information (Hesse et al., 2005; Fox & Rainie, 2002; We are social, 2024; Mitchell et al., 2018). As a result, the accuracy of online health information is crucial, as it can have a significant impact on individuals' health outcomes. Furthermore, the dissemination of inaccurate health information can lead to adverse health outcomes (Murray et al., 2003; Eysenbach et al., 2002; Zhang et al., 2015). This issue is particularly concerning as it contradicts the United Nations' Sustainable Development Goals (SDGs), specifically Goal 3, which aims to ensure healthy lives and promote well-being for all. The consequences of inaccurate health information are plenty as shown in Table 2.

Table 2. Consequences of inaccurate health information.

Consequences of inaccurate health information	
Misdiagnosis and mistreatment	(Eysenbach et al., 2002; Do Nascimento et al., 2022)
Unnecessary mental health issues such as anxiety and stress	(Verma et al., 2022; Do Nascimento et al., 2022)
Mistrust in healthcare	(Do Nascimento et al., 2022)
Worsened patient-physician relationship	(Murray et al., 2003; Haluza et al., 2017)

There is a need to assess the accuracy of online health information, given the variability in quality across different measurement tools (Daraz et al., 2019; Eysenbach et al., 2002; Zhang et al., 2015). Therefore, this review aims to investigate the accuracy of online health information by analyzing expert-reviewed content. This review aims to provide valuable insights into the accuracy of health information accessed by billions of people daily.

2. AIM/OBJECTIVE

This study aims to summarize the accuracy of online health information by categorizing the results of articles that have evaluated online health information against guidelines or peer-reviewed literature.

3. METHODS

To address the research aim, a systematic review with an inductive approach was conducted. A systematic review can be defined in various ways, but according to Karolinska Universitet (2024), it is a review that gathers all available research within a specific area using a defined methodology. The characteristics include a clearly defined research aim, a reproducible search strategy, adherence to inclusion and exclusion criteria, a selection method, clear data analysis and synthesis methods, and critical appraisal and reporting of the risk of bias in the included studies (Krnjic Martinic et al., 2019). All the included articles were reviewed based on the STROBE checklist for cross-sectional studies.

3.1. Search strategy

The first step in data collection was to identify keywords for the search. These keywords were identified from key articles obtained through test searches and from articles with a systematic review study design. These searches were conducted between April 1st and 6th, 2024. The most relevant search terms identified included accuracy, content analysis, guidelines, websites, and recommendations, with additional details provided in Table 3. Synonyms were also identified using the Swedish MeSH and CINAHL subject headings. These keywords were then arranged into search blocks, which were combined into search strings using Boolean terms, as shown in Table 3.

Subsequently, the final search was conducted on April 7th, 2024, in three databases: MEDLINE EBSCO, Scopus, and PubMed. These databases were selected due to their relevance to healthcare subjects, aligning with the aim of this study.

Table 3. Detailed search strings from the systematic review.

Search date	Database	Search string	Additional filters	Hits	Read articles	Included
7/4-2024	Scopus	ALL FIELDS - "consumer health information" OR "online health information" OR "health information" AND Article title - internet OR online OR websites OR website OR youtube OR "social media" OR tiktok OR instagram OR facebook OR forum AND Article title - accuracy OR "content analysis" AND Abstract - guidelines OR recommendations OR guideline OR evidence OR recommended AND Abstract - Accuracy	2010 - Present Article Review English	57	34	16
7/4-2024	Medline EBSCO	ALL FIELDS - "consumer health information" OR "online health information" OR "health information" AND Article title - internet OR online OR websites OR website OR youtube OR "social media" OR tiktok OR instagram OR facebook OR forum AND Article title - accuracy OR "content analysis" AND Abstract - guidelines OR recommendations OR guideline OR evidence OR recommended AND Abstract - Accuracy	2009 - Present Article Peer reviewed English	32	3	1
7/4-2024	PubMed	((("consumer health information" OR "online health information" OR "health information") AND (internet[Title] OR online[Title] OR websites[Title] OR website[Title] OR youtube[Title] OR "social media"[Title] OR tiktok[Title] OR instagram[Title] OR facebook[Title] OR forum[Title])) AND (accuracy[Title] OR "content analysis"[Title])) AND (guidelines[Title/Abstract] OR recommendations[Title/Abstract] OR guideline[Title/Abstract] OR evidence[Title/Abstract] OR recommended[Title/Abstract])) AND (Accuracy[Title/Abstract])	2010 - Present	43	11	4
Total				132	48	21

3.2. Selected data sources

The inclusion criteria for articles were as follows:

- Peer-reviewed, articles that were relevant to the subject matter of this study, i.e. evaluating the accuracy of online health information
- Assessing accuracy based on clinical guidelines or peer-reviewed literature
- Clear criteria for assessing the trustworthiness of each digital health information source described in the articles
- Written in English
- Published from 2014
- The article had undergone peer review

The year 2014 was chosen to ensure the inclusion of recent and relevant articles. Critically, articles not utilizing expert review of health information, characterized by assessment via comparison to guidelines or peer-reviewed literature, were excluded. The reason for this was to steer clear of studies using the quality evaluation tools in accordance with its limitations mentioned earlier (Fahy et al., 2014).

Upon completion of the searches, the title of each article included in the search results was reviewed to determine if the study fit the aim of this research. If a title indicated that the article could be of interest, the abstract was thoroughly reviewed. If the article met the inclusion criteria, a full-text retrieval was attempted. If the full text could not be accessed, the article was excluded. The full texts were read independently by each author, with notes and comments made individually. Any discrepancies or uncertainties about the suitability of the articles were discussed until resolved. The journals of all articles considered for inclusion in this study were checked via Ulrichsweb (2024) to ensure they had undergone peer review. They were also evaluated for study quality using the STROBE checklist for cross-sectional studies (von Elm et al., 2007). Of the 48 articles considered for inclusion, four did not assess accuracy, and 19 were unclear on their methods of assessing accuracy. Additionally, four relevant articles initially selected were excluded due to their publication date being before 2014. This left 21 articles to be included in this study, as seen in Figure 1. Relevant characteristics from each study were extracted and organized into a spreadsheet for an overview and further analysis.

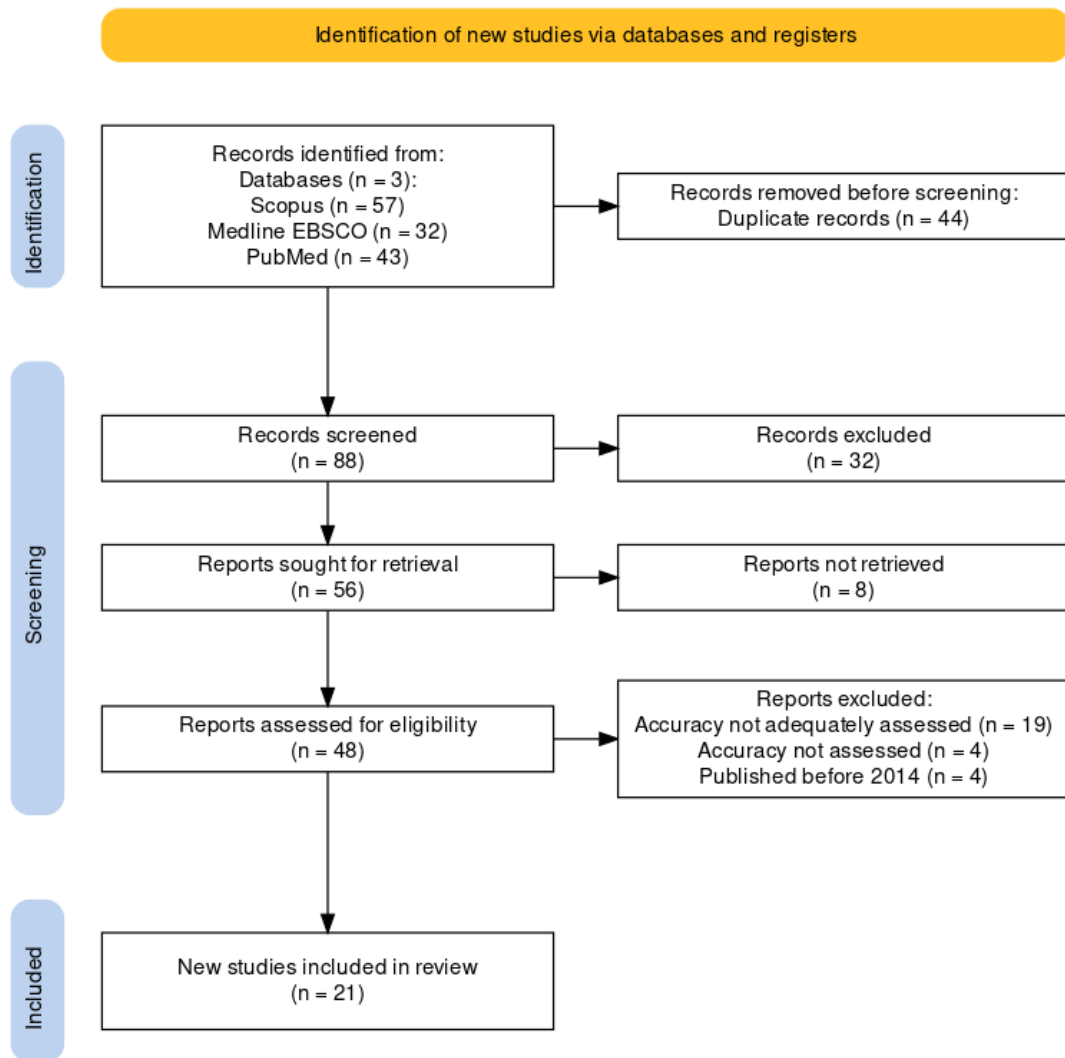


Figure 1. PRISMA Flowchart of the inclusion and exclusion of the study selection adapted from Haddaway et al. (2022)

3.3. Analysis

To generate and analyze the results, it was necessary to agree on the level of evidence of interest in the included studies before starting. The first preselected inclusion criterion was that the included articles assessed accuracy based on peer-reviewed literature or clinical guidelines. Furthermore, the data extraction categorized the material based on whether they assessed trustworthy or other sources. Only data that were assessed for accuracy were extracted.

3.3.1. Categorization of findings related to accuracy of online health information

The authors applied a systematic process to categorize the 21 articles from the structured search, resolving any disagreements or uncertainties regarding data extraction and categorization through thorough discussion. After analysis of the extracted data, criteria for the judgments of the authors of each included article were defined to ensure consistency in categorization. The categorization scheme was refined and developed through literature review, incorporating insights from Zhang et al. (2015) and Denniss et al. (2023), as detailed in Table 4. The criteria were created by the authors after reading the full texts. Examples of how the categorization scheme was used to classify articles are provided in Table 5.

Table 4. Criteria for categorization of articles

Category	Criteria
Good	<ul style="list-style-type: none">• Most of the results are >75% accurate• The authors have a clear positive judgment about the majority of their results
Moderate	<ul style="list-style-type: none">• Most of the results are ~50% or more accurate• The authors have a concerned or mixed judgment regarding their result and its implications
Poor	<ul style="list-style-type: none">• Most of the results are <50% accurate• The authors have a clear negative judgment about the majority of their results
Varied	<ul style="list-style-type: none">• The results of the study clearly fall into two different categories (good, moderate, poor)

3.3.2. Data extraction and categorizing of source

The online health information sources described in each article were categorized into two groups: *trustworthy* and *other*. Sources were categorized as trustworthy based on research by Ferreira et al. (2019), which found that governmental, institutional, and consumer advocacy sites are typically perceived as trustworthy by the public. Only health information sources clearly identified by authors as trustworthy, and where the amount of trustworthy material was quantified, were categorized as such. If there was any uncertainty about the source material it was categorized as *other*. The amount of material was quantified by counting each unique source described in the included articles, such as social media posts, websites, online forum responses, and YouTube videos, as individual data points.

Table 5. Example of categorization criteria, based on source findings

Assigned Category	Extracted texts
Good (Wang et al., 2017)	<p>“... we found that despite being accurate, online resources for articular cartilage defects are variable in quality and written at levels that far surpass the average reading level of the U.S. population.”</p> <p>“... we found that online resources for articular cartilage defects are generally very accurate.”</p>
Moderate (Ehrenreich et al., 2019)	<p>“Some websites provided overall high-quality information across the majority of key messages. However, consumers searching for information about diagnosis, treatment and what to expect after miscarriage are exposed to incomplete or missing information.”</p>
Poor (Ferreira et al., 2019)	<p>“Our findings suggest that websites of trusted sources are failing not only at conveying the accurate message on the benefits of guideline-endorsed and first-line treatment recommendations but also at dismissing ineffective treatment options such as bed rest for acute LBP, for which evidence on its ineffectiveness has long been known.”</p> <p>“... more than half of all treatment recommendations given by websites in our review were either inaccurate or unclear, which risks misleading the public”</p>
Varied (Huang et al., 2021)	<p>“While non-evidence-based or inaccurate statements were identified in nearly a quarter of videos, none were observed in videos authored by either academic or private hospitals. However, videos with inaccurate claims achieved greater viewer engagement than those without inaccuracies.”</p>

One study by Kedzior et al. (2019) included 72 Facebook groups, which, without more detail, was considered as 72 unique data points. Other data extracted included the number of reviewers, sample size, platform, criteria for evaluating accuracy, and the health topics covered, see Table 6. Only data concerning the accuracy of information were extracted. Following categorization, the distribution of materials was calculated and divided into *trustworthy* and *other* categories, as well as by platform.

Table 6. Characteristics of the included studies

Author	Health Topic	Data set size	Trustworthy n (%)	Accuracy evaluated against	Nr of reviewers	Category
(Alexander & Seenan, 2022)	Peripheral Artery Disease and Intermittent Claudication	62 websites	62 (100)	NICE and American Heart Association guidelines	2	Good
(Wang et al., 2017)	Management of Articular Cartilage Defects	53 websites	33 (62)	Guidelines from the American Academy of Orthopaedic Surgeons	3	Good
(Towne et al., 2021)	Endometriosis	53 Facebook pages and 307 posts	-	Peer-reviewed scientific literature	2	Good
(Madden et al., 2016)	Intrauterine Devices (IUDs)	105 websites	90 (86)	Guidelines and evidence-based references	2	Moderate
(Htet et al., 2018)	Polycystic Ovary Syndrome (PCOS)	15 websites	10 (66)	Peer-reviewed scientific journals	2	Moderate
(Kedzior et al., 2019)	Conception and fertility information for couples trying to conceive	41 websites, 169 tweets, 52 Instagram posts, 72 Facebook groups	-	Peer-reviewed scientific journals and fertility guidelines.	6	Moderate
(Ehrenreich et al., 2019)	Miscarriage (Early Pregnancy Loss)	11 websites	2 (18)	ACOG Practice Bulletin	3	Moderate
(Denniss et al., 2024)	Nutrition-related information	510 instagram posts	125 (24)	Australian Dietary Guidelines, Practice-based Evidence in Nutrition database, Nutrient Reference Values, and Metafact.	2	Poor
(Saleh et al., 2022)	Pulmonary Arterial Hypertension (PAH)	117 websites	82 (70)	International PAH guidelines	2	Poor
(Fisher et al., 2016)	Idiopathic Pulmonary Fibrosis (IPF)	181 websites	99 (55)	IPF clinical guidelines	2	Poor
(Boatwright & Sperry, 2020)	Medical marijuana	10 websites	1 (10)	Articles they referenced using an evidence-based evaluation process	2	Poor
(Abramson et al., 2023)	Prostate cancer screening	50 videos from YouTube and 50 from TikTok	-	American Urological Association (AUA) and National Comprehensive Cancer Network (NCCN) guidelines	3	Poor
(Farnood et al., 2022)	Heart failure	10 online health forums for patients, 639 responses from 204 original posts.	-	NICE and SIGN guidelines for heart failure symptoms and diagnosis	3	Poor
(Modave et al., 2014)	Weight loss	103 websites	14 (13)	Evidence-based literature for weight loss	3	Poor
(Ferreira et al., 2019)	Low Back Pain (LBP)	79 websites	79 (100)	NICE and American College of Physicians guidelines.	3	Poor
(Chang et al., 2016)	Weight gain during pregnancy	181 webpages	47 (26)	Institute of Medicine guidelines for weight gain during pregnancy	3	Poor
(Moore et al., 2021)	Complex Regional Pain Syndrome (CRPS)	30 websites	30 (100)	NICE and American Heart Association guidelines	2	Poor
(Mack et al., 2016)	Physical activity for individuals living with osteoporosis	57 websites	4 (7)	Physical activity guidelines for older adults and PA recommendations for individuals with osteoporosis	3	Poor
(Ling et al., 2024)	Statin use and side effects, primarily related to cardiovascular disease management	20 websites	9 (45)	Medical guidelines from the American College of Cardiology and the Australian Heart Foundation.	2	Poor
(Storr et al., 2016)	Pregnancy-related food and nutrition	693 web pages	205 (30)	Australian Dietary Guidelines	3	Poor
(Huang et al., 2021)	Nephrolithiasis (Kidney Stones)	102 videos with >5000 views from YouTube	21 (20)	AUA guidelines on the medical management of kidney stones	3	Varied

3.4. Ethics

This study does not involve any personal data, but ethical considerations are still highly central. The content of the included articles was presented truthfully and authentically, without plagiarism or misrepresentation.

Most included articles did not address ethical issues. The few that did, reasoned that ethical approval is not required due to looking at material which is part of the public domain. Furthermore, articles that contained material from social media, which sometimes can include personal information, no identifying information were published.

4. RESULTS

After analysis of the 21 articles, four levels of accurate information were identified, which were formed into a categorization scheme in which the included articles and their material were allocated (see Table 7). The first categorization level was *Good* which meant that most of the results were over 75 percent accurate and the overall judgment made by the researchers seemed to be positive. The second one was *Moderate* and included articles whose results were approximately 50 percent or more accurate, accompanied by an interpreted overall mixed judgment by the authors. Thirdly, articles were categorized as *Poor* if most of the results were less than 50 percent accurate and the researchers stated a clear negative judgment regarding their results. Lastly, the fourth category was *Varied*, which meant that the included material of an article's result were clearly in two different categories. The criterias for each category were done by inspiration Zhang et al. (2015) and Denniss et al. (2024) and constructed after reading through all of the included articles.

4.1. Characteristics

Among the analyzed studies, 15 focused on examining websites, while two investigated social media platforms. Additionally, one study explored forums and another two analyzed video content from YouTube and TikTok. Lastly, one study encompassed a combination of data sources.

Three studies focused exclusively on data derived from trustworthy sources, whereas four contained no identifiable trustworthy sources within their datasets. The remaining 14 studies demonstrated a varying degree of trustworthy material ranging from 7% to 86%. Of all the included source material 25% were *trustworthy*. For a detailed breakdown of the characteristics, see Table 6.

4.2. Overall accuracy of online health information

Of the 21 articles analyzed, 4 (16%) found online health sources as having *good* accuracy according to analysis. Additionally, 5 (20%) were classified as *moderate*, 13 (62%) as *poor* and 1 (4%) as *varied*. Furthermore, 11% of the included online health sources were deemed *good*, 13% *moderate*, 73% *poor* and 3% *varied*, as shown in Table 7.

Table 7. Results from the categorization of the included studies

Category	Nr of articles (%)	Total data set n (%)	Other data source n (%)	Trustworthy data source n (%)*
Good	3 (14)	422 (11)	327 (12)	95 (10)
Moderate	4 (19)	465 (13)	363 (13)	102 (11)
Poor	13 (62)	2720 (73)	2025 (72)	695 (76)
Varied	1 (5)	102 (3)	81 (3)	21 (2)
Total	21 (100)	3709 (100)	2796 (100)	913 (100)

* Included source material categorized as typically trustworthy by the public, and its distribution among the entire trustworthy data set.

4.2.1. Good

Out of the analyzed studies, 3 (14%) were considered to exhibit *good* results concerning the accuracy of information. The amount of material encompassed within this category constituted a mere 11% of the entire source material derived from all the articles included in this review. For example Wang et al. (2017) write "...despite being accurate, online resources for articular cartilage defects are variable in quality and written at levels that far surpass the average reading level of the U.S. population". The accuracy results in Alexander and Seenan (2022) study was *good*, despite low quality in other indicators of quality. They state "Websites recommending treatments and management of PAD and IC are mostly accurate but have low credibility, low comprehensiveness, and are too complex for the average person to understand".

4.2.2. Moderate

As seen in Table 7, 19 percent (n=4) of the included articles had *moderate* accuracy. The authors of these studies expressed less negativity but concerns for the public regarding the accuracy of information and the potential harms it can have. For example, Htet et al. (2018) stated the following in their discussion;

"Our findings may thus indicate women with PCOS may have incomplete and potentially ineffective health information which could limit their applying optimal lifestyle recommendations to real-world practice and consequently adversely impact on their health. This highlights that lifestyle information on PCOS websites should currently be interpreted with caution by women and health professionals."

A clear example of authors expressing concern regarding the accuracy of information is from Madden et. al., (2016) who states "Our study suggests that clinicians and public health advocates should remain cautious about referring individuals to online sources for IUD or general contraceptive information."

4.2.3. Poor

A majority (62%, n=13) of the included articles was deemed to have *poor* accuracy. Many studies explicitly stated that the majority of the information they reviewed was inaccurate and of low quality. Saleh et al. (2022) stated that "Online information on PAH is frequently outdated and inaccurate and often lacks transparency and quality with respect to treatment choices". The negative judgment was also often seen in cooperation with some kind of concern, Ferrieira et al. (2019) expressed that "...more than half of all treatment recommendations given by websites in our review were either inaccurate or unclear, which risks misleading the public". Farnood et al. (2022) even stated that low accuracy could be dangerous:

"Our novel findings suggest that online health forums for heart failure could not be considered a reliable source of high-quality evidence-based information on diagnosis of heart failure, with only 1% of the responses including wholly or partial evidence, and 10% (n = 29) of responses being non-evidence based and potentially dangerous".

Out of the *trustworthy* sources (n=913), 76 percent was identified as having *poor* accuracy as seen in Figure 2. However, Chang et al.’s (2016) study showed that for-profit websites had the most inaccurate information; “Additionally, for-profit websites currently dominate this online sphere, and these were most likely to contain inaccurate, incomplete, or no specific recommendations compared to other website types”. Two out of the three articles that exclusively reviewed trustworthy sources were categorized as having *poor* accuracy.

Distribution of categories and platforms

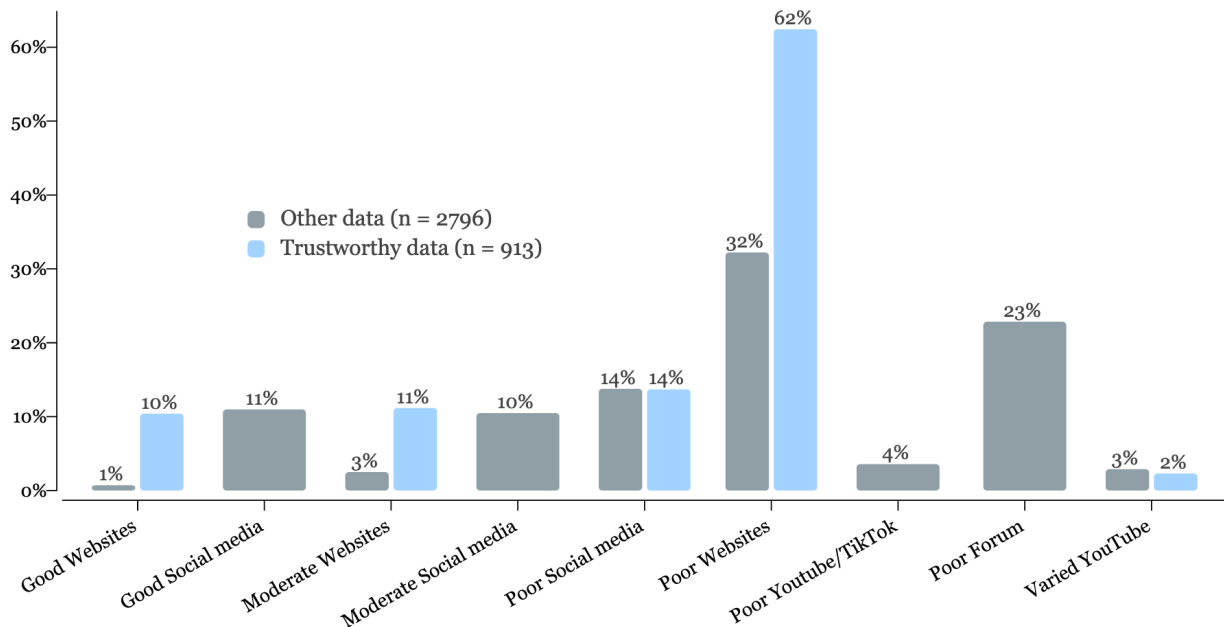


Figure 2. Distribution of sources included from all the studies (n=21). Categorized by *trustworthy* sources and *other*, and its distribution by accuracy and platform.

4.2.4. Varied

Only one study was considered having *varied* accuracy. Huang et al. (2021) expressed concern for health information on YouTube due to higher viewership among inaccurate videos, but found no inaccurate statements in videos from *trustworthy* sources. The authors state “...inaccurate statements were identified in nearly a quarter of videos, none were observed in videos authored by either academic or private hospitals”. This is also clear in the following statement “...videos with inaccurate claims achieved greater viewer engagement than those without inaccuracies”.

5. DISCUSSION

This review shows that the majority of digital health information sources described in the included articles, which were evaluated by experts against peer-reviewed guidelines and best practices, have overall *poor* accuracy and received negative judgments. This was observed regardless of whether the sources examined were classified as *trustworthy* or not. Contrary to expectations, *trustworthy* sources were categorized as *poor* more often (76%) compared to *other* sources (72%). This abundance of inaccurate information could potentially lead to harmful consequences.

5.1. Result discussion

The most significant discovery that this study has made is that there is a considerable amount of digital health information that has *poor* accuracy. This is consistent with what three other systematic reviews on the subject have reported (Eysenbach et al., 2002; Zhang et al., 2015; Daraz et al, 2019). However, it could be the case that some or all of the studies included in this review may also have been included in the other systematic reviews. Therefore, the results may not be entirely new or surprising. However, the consistency with previous studies strengthens the validity of the results, even if the findings are not entirely new (Bryman, 2018).

A majority (76%) of all *trustworthy* sources evaluated in the included articles was categorized as having *poor* accuracy. This does not fully align with Daraz et al. (2019) systematic review which showed that approximately 71 percent of all government sites were scored the highest as “very good”. However, their systematic review did not solely examine accuracy but utilized DISCERN and other measurement tools to evaluate the quality. The differing methodological approaches between this study and Daraz et al. (2019) likely contributed to the difference in findings. Specifically, while they utilized broader quality evaluation tools like DISCERN, our exclusive focus on studies evaluating the accuracy of information against guidelines and peer-reviewed literature may have resulted in the identification of a higher proportion of *poor* accuracy information, even among traditionally *trustworthy* sources. For example Wang et al. (2017) and Alexander and Seenan (2022), whose studies described digital health sources that were categorized as *good*, observed that despite the fact that their investigated websites were mostly accurate, other contributing factors to user experience were poor, including language that would require a high level of health literacy (Wang et al., 2017; Alexander & Seenan, 2022). Interestingly, the web platforms that Wang et al. (2017) noted having the highest percent of *trustworthy* sources, were the platforms where readability was least accessible.

While the majority of *trustworthy* sources were categorized as *poor*, it's important to note that a lot of the *other* sources were classified as *poor*, especially on websites and forums. Sources categorized in this study as *other* were three times larger than the *trustworthy* sources, which could play a role in the results. This study found that platforms providing *poor* accuracy of online health information seemingly do not solely demonstrate consistently false information, but in fact a mix of accurate and inaccurate. Studies categorized as *poor* accuracy still contain a lot of accurate information, which can make it hard to identify what is inaccurate. For example, if the first statement A made in a source is accurate, but then followed by an inaccurate statement B, the reader might already have gained a perception of credibility due to the presence of the correct statement. Additionally, inaccuracies in some studies are classified

as missing information, for example not mentioning harms of certain medical interventions which is highly relevant for a patient when making an informed decision about their health.

The blending of accurate and inaccurate health information online also triggers speculations regarding how different health topics or diagnoses can have a possible effect on the accuracy of online health information. For example, stakeholders with financial interests or other actors in society have vested interests in disseminating or withholding certain information. It's possible that certain patient groups have stronger impacts on the accuracy of health information published on digital platforms they frequent, which in turn can lead to either improving or worsening the quality. One example of this is the high accuracy seen on patient advocacy groups for endometriosis (Towne et al., 2021).

5.2. Neo-ecological theory

In relation to the neo-ecological theory, this study examines a specific aspect concerning the accuracy of health information, which in turn can play a role in an individual's virtual microsystems. Furthermore, the neo-ecological theory posits that information permanence, defined as the lasting nature of digital interactions and data, possesses novel characteristics, rendering it unrestricted by geographical limitations and temporal constraints. This is due to its availability at any given moment for individual users, rendering health information a highly proximal process for individuals. Moreover, it is highly probable that individuals encounter inaccurate information, as evidenced by this study's findings, which indicate that 62 percent of the examined studies and 73 percent of the analyzed material possess *poor* accuracy. One facet of this issue that has been scrutinized involves the potentially adverse impact on the relationship between patient and HCPs when exposed to such online health information from both perspectives (Murray et al., 2003; Haluza et al., 2017). Additionally, this exemplifies the manner in which a virtual microsystem interacts with a physical microsystem, specifically the patient-clinician interaction. This presents a challenge, as even with the recognition that inaccurate information negatively affects the rapport between patients and HCP, it is difficult to direct patients towards more reliable sources. Furthermore, this difficulty arises from the study's finding that 72 percent of *trustworthy* sources were deemed to possess *poor* accuracy.

In some cases, the virtual world can often be a more precise reflection of the physical microsystem than one might imagine. The accuracy of information available online, when compared to adherence to clinical care guidelines, shows a concerning similarity across various healthcare professions and environments. Furthermore, adherence to treatment guidelines in clinics is arguably as poor as the health information available online (Oh et al., 2011; Runciman et al., 2012; Amorin-Woods et al., 2014; Ebben et al., 2013; Zadro et al., 2019; Akindede et al., 2020; Niño de Guzmán et al., 2020). Interestingly, the high degree of accurate information about endometriosis on Facebook (Towne et al., 2021) could be a reaction to delayed diagnosis and dismissal of symptoms by HCPs (Arruda et al., 2003; Husby et al., 2003). This suggests that in some cases, the virtual world can compensate for deficiencies in the physical microsystem.

When considering broader perspectives such as macro- and exosystems in the context of accurate digital health information, economic incentives and commercial interests must be taken into account. These factors can drive poor medical care (Saini et al., 2017). For example, one study found that that for-profit sources had the highest degree of inaccurate health information, which, given the clear financial gain, could be considered disinformation (Chang et al., 2016).

The exosystem, or indirect environment, influencing an individual includes financial incentives and commercial interests. These factors can affect both the virtual microsystem of information and the clinical or physical microsystem that determines medical care, both of which can contribute to poor medical care (Saini et al., 2017). Moreover, when examining a larger context such as the macrosystem, cultural norms and traditions come into play. For instance, a strong belief in the biomedical model and the way the media represents health contribute to shaping this broader belief system. This, in turn, can explain why a majority of biomedical research fails to address questions aimed at helping patients, resulting in poorly designed studies and an overflow of flawed research and knowledge (Saini et al., 2017).

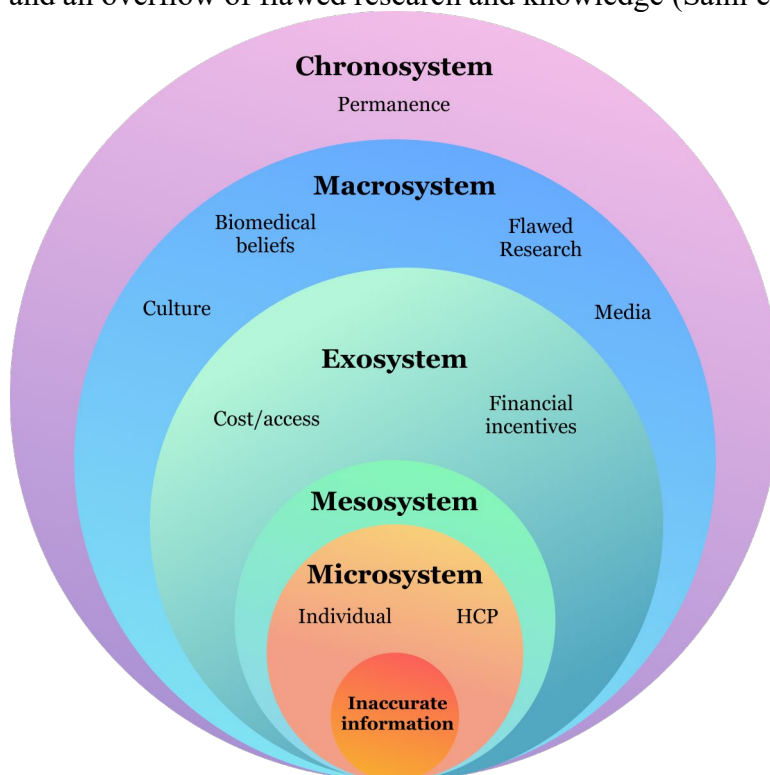


Figure 3. An adaptation of Bronfenbrenner's (1977) model with insights from the neo-ecological model regarding digitalization. With regards to contributors in the landscape of health information, particularly inaccurate healthcare information. Adapted from Bronfenbrenner (1977)

The neo-ecological model suggests that various layers contribute to the spread of inaccurate information, as portrayed in the center of Figure 3. At the microsystem level, individual and clinician interactions with information are pertinent. At the exosystem level, commercial and financial interests significantly contribute to the dissemination of inaccurate information. At the macrosystem level, social and cultural norms, such as biomedical beliefs, shape the nature of research questions and studies conducted, as well as patient expectations and clinical norms. Through the lens of permanence and online information in neo-ecological terms, these factors collectively contribute to the increasing prevalence of inaccurate information over time. Considering the source material analyzed in this study merely 11% were deemed to have *good* accuracy. Additionally, Huang et al. (2021) showed that inaccurate information has higher viewership, meaning more people will likely see inaccurate information. Thus, reproducing, replicating, and sharing poor information more than good information is not unlikely. With time, permanence, and the increasing availability of online health information, good information might become even harder to find.

5.3. Method discussion

The choice of a systematic review is considered reasonable in hindsight to address the aim. Because systematic reviews analyze and evaluate the results from all available original articles and answer a specific research question, they are typically regarded as strong evidence. The use of secondary data as a research method also enables the reviewer to process the data and discover new interpretations of existing research (Bryman, 2018). However, the main criticism of the method used in this study is that there is no universally accepted standard to judge the accuracy of digital health information. Systematic reviews are often easier to conduct when there is an accepted criterion by which to rank or categorize findings. Additionally, the method used impacts and restricts the research aim to a quantifiable answer. If a traditional literature review had been conducted instead, it could have provided more insights into the methods used to evaluate information accuracy in the selected studies and given more specific insights into the types of inaccuracies present within online health information.

In addition, the pre-selected inclusion criteria ensured objectivity during the data collection. However, it is possible that the inclusion criteria influenced the outcome, and some relevant studies on the accuracy of online health information may have been missed.

5.3.1 Strengths and limitations

The strategy to search three databases for articles is seen as a strength, as it minimizes the risk of bias. Additionally, both researchers conferring on the overall categorization of each selected article increased the reliability of the findings.

During categorization it was challenging to interpret and identify some of the data. Some sources required a thorough discussion by both reviewers to identify the appropriate category. This uncertainty could have affected the result and generalizability.

The primary limitation of this study is the absence of a recognized standard for assessing the accuracy of online information. The gold standard mentioned by Fahy et al., (2014), and used as a criteria for including articles in this review, does not encompass a universally accepted method for such evaluations. This issue is compounded by variations in diagnoses and evaluation of accuracy against different guidelines and literature, as well as discrepancies in whether the inaccuracy pertains to the content itself or the absence of content when studies report on the accuracy of information.

Narro and Tudge's Neo-ecological model, adapted from Bronfenbrenner's theory, is a broad theory that helps in understanding the societal impacts and contributors to our research question, but this is also its weakness. Because of its broad scope, it is difficult to gain clear insights from it that could be applicable to interventions. However, it was suitable for gaining insights into some major contributors to the state of the online health information landscape. Lastly, the Neo-ecological theory is recently published and thus a less established adaptation of Bronfenbrenner's original socio-ecological model, which can be considered a limitation. If a literature review had been conducted, the Health Belief Model could have been suitable for understanding the consequences to consumers of online health information. Nonetheless, a strength of this review is that the data collection was based on empirically researched material already available in databases with public health relevance.

5.3.2. Ethical aspects

Few of the included articles mentioned ethics, and those that did stated that the assessment of online health information required no prior ethical approval because it is part of the public domain. Considering that much of the information evaluated in the included articles was categorized as *poor*, one might question whether it is unethical not to take action against this inaccurate information. Wu and McCormick (2018) argue that HCPs have an ethical obligation to address and take action against false and misleading information that can lead to harmful health decisions. Additionally, they have an ethical responsibility to contribute to the public discourse even outside of the clinic, to help improve public health.

5.4. What can we do about the information landscape?

Research has shown enhancements in both public and medical professionals' knowledge and beliefs through implementing mass media campaigns (Buchbinder et al., 2001; Bailly et al., 2023). There is reason to believe other mass media campaigns can have positive effects on knowledge dissemination and warrant further investigation. An ongoing public health initiative, known as Choosing Wisely, is currently being implemented in over 20 countries to encourage better communication between patients and clinicians regarding evidence, risks, and benefits. This initiative seeks to reduce overtreatment and potentially harmful interventions by fostering informed discussions (Friedman & Mahant, 2017; Choosing Wisely, 2023). In addition, Wu and McCormick (2018) contend that medical professionals have an ethical obligation to challenge inaccurate health information, asserting that government regulation alone is insufficient. Furthermore, we propose that the regulation of commercial speech, as evidenced by restrictions on tobacco and alcohol advertisements, warrants further investigation regarding for-profit websites disseminating inaccurate health information or disinformation.

In a broader context, challenges regarding free speech and regulation, as well as who holds the ethical obligation and regulatory power, are evident today. For the sake of truly having an impact, we suggest that these significant questions be clarified. For smaller public health interventions, disseminating accurate information should be a high priority, as well as making it accessible and easy to comprehend for consumers of health information. Considering that this study shows only 11% of trustworthy sources have *good* accuracy, there is an opportunity to identify those sources and amplify their signal through the noise of inaccurate information. If society or regulatory bodies gained the financial tools to de-incentivize the spread of disinformation from for-profit sites, it could help reduce one of the streams of inaccurate information.

5.5. Conclusion

This review aimed to summarize the accuracy of online health information by categorizing the results of earlier studies that evaluated health information against guidelines or peer-reviewed literature. The results demonstrated that a majority of health information has *poor* accuracy, regardless of whether the source was deemed *trustworthy* or not. This is consistent with previous findings and potentially poses risks to public health. Furthermore, the few articles that had a high degree of accuracy were lacking in readability or quality, making them difficult for consumers to comprehend.

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