Viewpoint

# The 21st Century Cures Act and Multiuser Electronic Health Record Access: Potential Pitfalls of Information Release

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## Abstract

Although the Office of The National Coordinator for Health Information Technology's (ONC) Information Blocking Provision in the Cures Act Final Rule is an important step forward in providing patients free and unfettered access to their electronic health information (EHI), in the contexts of multiuser electronic health record (EHR) access and proxy access, concerns on the potential for harm in adolescent care contexts exist. We describe how the provision could erode patients' (both adolescent and older patients alike) trust and willingness to seek care. The rule's preventing harm exception does not apply to situations where the patient is a minor and the health care provider wishes to restrict a parent's or guardian's access to the minor's EHI to avoid violating the minor's confidentiality and potentially harming patient-clinician trust. This may violate previously developed government principles in the design and implementation of EHRs for pediatric care. Creating legally acceptable workarounds by means such as duplicate "shadow charting" will be burdensome (and prohibitive) for health care providers. Under the privacy exception, patients have the opportunity to request information to not be shared; however, depending on institutional practices, providers and patients may have limited awareness of this exception. Notably, the privacy exception states that providers cannot "improperly encourage or induce a patient's request to block information." Fearing being found in violation of the information blocking provisions, providers may feel that they are unable to guide patients navigating the release of their EHI in the multiuser or proxy access setting. ONC should provide more detailed guidance on their website and targeted outreach to providers and their specialty organizations that care for adolescents and other individuals affected by the Cures Act, and researchers should carefully monitor charting habits in these multiuser or proxy access situations.

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**KEYWORDS**

21st Century Cures Act; Open Notes; Information Blocking; multiuser EHR access; proxy EHR access; adolescent Health; health IT Policy; information technology; cures act; electronic health record; electronic health information; health information; patient care

## Introduction

“*Primum non nocere*” (“*First, do no harm*”) or nonmaleficence is a fundamental principle taught to every health care provider. It suggests that before applying any medical intervention, one needs to consider the potential negative effects on the patient. In this piece, we examine the potential for patient harm by the Office of The National Coordinator for Health Information Technology’s (ONC) Information Blocking Provision in the Cures Act Final Rule and the additional burden that health care providers, those who provide patient care and provide documentation in the electronic health record, will now face when documenting sensitive information.

On December 13, 2016, the 21st Century Cures Act (hereinafter referred to as the “Cures Act”) was signed into law with the intent to “accelerate the discovery, development, and delivery of 21st century cures, and for other purposes” [1]. The Act defined electronic health record (EHR) interoperability, addressed health information technology certification requirements, and prohibited information blocking—the practice that prevents or interferes with those with permission to access electronic health information (EHI) [2]. As the federal entity coordinating efforts to implement health information technology and exchange EHI, ONC, a division within the US Department of Health and Human Services (HHS) [3], developed the Cures Act Final Rule to direct the implementation of the Cures Act legislation [4].

## The ONC Cures Act Final Rule

The stated goal of the ONC Cures Act Final Rule is to empower patients to interact “with their health record in a modern health IT economy” [4]. ONC postulated that “putting patients in charge of their health record is a key piece of patient control in healthcare and patient control is at the center of HHS’s work towards a value-based healthcare system.” The Cures Act Final Rule also encourages innovations in health care technology and hopes to deliver the following:

- Transparency on cost and outcomes of care
- Competitive options in obtaining medical care
- Convenient access to medical records using smartphone apps
- Innovation and choice for patients, physicians, hospitals, payers, and employers through an app-based economy [4]

The Cures Act Final Rule promotes interoperability across EHR vendors through the adoption of data exchange standards and calls upon the health care information technology (IT) industry to adopt standardized application programming interfaces through specified Conditions of Certification. Additionally, ONC aims to increase patients’ access to their EHI through minimizing measures that block patient access to information [5-7].

## The Information Blocking Provision

The Information Blocking Provision of the Cures Act Final Rule mandates that patients have unfettered, free access to their EHI, and provides clear requirements for compliance by health care providers, institutions, health information exchanges, and EHR vendors [8].

The spirit of the Information Blocking Provision is similar to that of the OpenNotes movement, which over the past decade has been adopted by several health care institutions across the United States, Canada, and Sweden and provides patients with near immediate and full access to their EHI [9,10]. The Information Blocking Provision requires that patients have access to parts of their EHI defined by the United States Core Data for Interoperability (Figure 1) by April 5, 2021, with eventual expansion to all EHI by October 6, 2022 [11-13]. Of note, patients have had the right to access their medical record since the implementation of the Health Insurance Portability and Accountability Act (HIPAA). The Cures Act final rule does not increase the type of health information that patients and families can access, it only facilitates automatic release via patient portals and easier access electronically.

The Information Blocking Provision includes a means to report violations and enforcement options. ONC encourages anyone who experiences or observes information blocking by any health care provider, health IT developer, certified health IT, health information network, or information exchange to share their concerns through an information blocking portal on ONC’s website [11]. Health IT developers, health information networks, and health information exchanges can be subject to civil monetary penalties of up to US $1,000,000 per violation [14]. Health care providers found to have committed information blocking will also be subjected to penalties that are to be determined [14].

**Figure 1.** Elements of the United States Core Data for Interoperability [11].

**Allergies and Intolerances**
- Substance (Medication)
- Substance (Drug Class)
- Reaction

**Assessment and Plan of Treatment**
- Assessment and Plan of Treatment

**Care Team Members**
- Care Team Members

**Clinical Notes**
- Consultation Note
- Discharge Summary Note
- History & Physical
- Imaging Narrative
- Laboratory Report Narrative
- Pathology Report Narrative
- Procedure Note
- Progress Note

**Goals**
- Patient Goals

**Health Concerns**
- Health Concerns

**Immunizations**
- Immunizations

**Laboratory**
- Tests
- Values/Results

**Medications**
- Medications

**Patient Demographics**
- First Name
- Last Name
- Previous Name
- Middle Name (including Middle Initial)
- Suffix
- Birth Sex
- Date of Birth
- Race
- Ethnicity
- Preferred Language
- Current Address
- Previous Address
- Phone Number
- Phone Number Type
- Email Address

**Problems**
- Problems

**Procedures**
- Procedures

**Provenance**
- Author Time Stamp
- Author Organization

**Smoking Status**
- Smoking Status

**Unique Device Identifier(s) for a Patient's Implantable Device(s)**
- Unique Device Identifier(s) for a Patient's Implantable Device(s)

**Vital Signs**
- Diastolic Blood Pressure
- Systolic Blood Pressure
- Body Height
- Body Weight
- Heart Rate
- Respiratory Rate
- Body Temperature
- Pulse Oximetry
- Inhaled Oxygen Concentration
- BMI Percentile (2 - 20 Years)
- Weight-for-length Percentile (Birth - 36 Months)
- Head Occipital-frontal Circumference Percentile (Birth - 36 Months)

## *Exceptions to the Information Blocking Provision*

The Information Blocking Provision defines eight exceptions that do not constitute information blocking [15]. The preventing harm exception and the privacy exception are applicable to the documenting health care provider.

The preventing harm exception stipulates that provided certain conditions are met, a health care provider can prevent the access to a patient's EHI if it is "reasonable and necessary to prevent harm to a patient or another person" [15]. Key conditions include that the health care provider must reasonably believe that preventing access to a patient's EHI will significantly reduce a risk of substantial harm, and that the interference is no broader than necessary. The patient has the right to request a review of an individualized determination of risk of harm [16].

According to ONC’s guidance in the “Information Blocking Frequently Asked Questions,” the “Preventing Harm” exception does not apply to situations where the patient is a minor and the health care provider wishes to restrict a parent or legal representative’s access to the minor’s EHI to avoid violating the minor’s confidentiality and destroying the trust between the youth and the health care provider [12]. This lack of applicability in the case of adolescent confidentiality stands in tension with principles outlined by experts in the design and implementation of EHRs [17], endorsed by the American Academy of Pediatrics and Society of Adolescent Health And Medicine [18,19]. The concern over the implication of the Cures Act on adolescent confidentiality has been noted in the literature [20]. The premise underlying confidential care encourages adolescents to communicate with health care providers about sensitive topics such as sexual and reproductive health and substance abuse without the fear that their parents or guardians will have access to this information. Confidentiality on certain health care problems facilitates obtaining medical care that adolescents might forgo if information were shared with others. In the context of providing confidential care, the Cures Act’s broad focus on patient EHI access may cause a trade-off with patient–provider relationships, trust, and nonphysical types of harm. The text of the Final Rule specifically states that the desire to maintain confidentiality and to protect patient–provider relationships is insufficient to prevent the release of sensitive information. In certain multiuser access cases, this may erode the patient’s control over his/her information instead of increasing control. It is worth noting that HIPAA and the Cures act defer to the state laws that grant adolescents the ability to consent for certain conditions. While it is challenging to keep track of each state’s individual and varied confidentiality laws that result in 56 (one for each state and territory) different legal requirements for users of pediatric EHRs, these laws do provide clear legal backing to protect adolescent confidentiality.

The other exception to the Cures Act Final Rule’s patient access provision immediately relevant to health care providers is the privacy exception. Under this exception, interfering with access to EHI is deemed not to be information blocking when the intent is to protect the patient’s privacy. These exceptions, listed in Textbox 1, are included by ONC to comply with HIPAA and other state privacy regulations and allow patients the opportunity to request information not be shared. Depending upon institutional practices, providers and patients may have limited awareness of this exception. Notably, the privacy exception states that providers cannot “improperly encourage or induce a patient’s request to block information” [21]. This stipulation affects a provider’s ability to guide patients for fear of being found in violation of the Information Blocking Provision and fined. Institutional policies and procedures will affect the implementation and management of this exception. Providers may not be aware of the procedure for patients to request their information not be shared during an encounter. Depending upon when the patient places the request (eg, before, during, or after an encounter), the institution may not be able to fulfill the request in a timely manner relative to the immediacy of information being released. Additionally, the privacy exception does not clearly describe if and how a patient can block individual pieces of data (data segmentation) instead of all data. The exception only describes how patients can request to block access and can request to regain access. The interpretation and implementation of this exception is left to the institution and provider and, given the complex nature of the exception, necessitates deference to informatics expertise and legal resources with experience in state and federal privacy laws and statutes for interpretation and use.

**Textbox 1.** Privacy exceptions to information blocking.

**Exceptions:**

- More stringent state or federal preconditions to exchange is not met
- Information technology developer is not covered by the Health Insurance Portability and Accountability Act Privacy Rule
- Inability to validate a requester’s right to access
- The individual requests the information not to be shared

## *Limitations to the Information Blocking Provision: Multiuser or Proxy Access*

### Overview

The OpenNotes initiative has been shown to potentially increase patient activation, engagement, satisfaction, trust, and safety, and to improve the patient–physician relationship [22-25]. However, concern exists that the Information Blocking Provision will result in damaging breaches of confidentiality for cohorts of patients when parents or legal representatives are provided multiuser or proxy access to EHI [26,27]. In circumstances where EHI is made available within a web-based portal with multiuser or proxy access, the information could compromise the confidentiality of the patient, parent, or legal representatives and damage the relationship between the health care provider, patient, parent, or legal representative. The breach of confidentiality may occur bidirectionally as a caregiver may share information with a provider, which could be shared back with the patient. One recent study highlighted another area of concern: when guardians access an adolescent patient’s portal account. The study revealed that the estimated prevalence of guardian access could be as high as 76% of adolescent accounts and also showed a relatively low rate of proxy account creation [28]. When adolescents had their own portal account, proxy accounts for adolescent patients were created in only 0.3%-10% of cases [28]. The reality that many portal accounts are used and managed by guardians must be taken into consideration for adolescent patients who, in the context of their care setting, may lack the autonomy to prevent their guardians from accessing their personal patient portals.

## Pediatric and Adolescent Patients

Prior to the Information Blocking Provision, pediatric institutions participating in the OpenNotes movement had addressed the concern for violating confidentiality and damaging relationships by blocking all clinical notes from several clinics including adolescent, gynecology, psychiatry, substance abuse, and the child protection team [29]. Although the Cures Act Final Rule explicitly states that maintaining confidentiality and protecting relationships is not sufficient to prevent the release of sensitive information, the effects of releasing this information on patients, their parents or legal representatives, and the patient–provider relationship cannot be underestimated and are concerning to adolescent medicine providers and other health care providers who care for youth [30].

## The Adolescent–Health Care Provider Relationship

There are many situations that do not fit the “Preventing Harm” exception where adolescent patients may be adversely affected when their private information is accessed by others (Table 1). For example, an adolescent female with concerns for a sexually transmitted infection (STI) such as *Neisseria gonorrhoeae* or *Chlamydia trachomatis* may avoid seeking medical care to avoid repercussions or stigma if she knew her parents would have access to this information. This untreated STI could progress to pelvic inflammatory disease, a more serious infection, which may require hospitalization and intravenous antibiotic administration and could affect future fertility. Prior research has shown that 59% of surveyed females younger than 18 years would “stop using all sexual healthcare services, delay testing or treatment for HIV or other STDs, or discontinue use of specific (but not all) sexual healthcare services if their parents were informed they were seeking prescribed contraceptives” [31]. The concern for loss of confidentiality extends to other sensitive topics including mental health, substance use, gender identity, and sexual orientation and may conflict with federal and state laws.

**Table 1.** Hypothetical scenarios for potential harm related to either lack of clarity of the laws, technical limitations regarding the release of electronic health information, or a combination of both.

| At risk for harm | Third party receiving information | Domain | Mode of disclosure | Consequence |
|---|---|---|---|---|
| Patient | Parents or guardian | Mental health | Patient portal | Avoiding care or deterioration |
| Patient | Parents or guardian | Substance use | Patient portal | Avoiding care, overdose, or continued addiction |
| Patient | Parents or guardian | Sexual history or reproductive health | Patient portal | Avoiding care, complications from sexually transmitted infection, or infertility |
| Patient | Parents or guardian | Gender management or identity | Patient portal | Avoiding care, delay in gender reassignment, or psychological impact |
| Patient | Parents, guardian, or abuser | Violence or abuse (physical or sexual) | Patient portal | Avoiding care, continued abuse, complications, or death |
| Patient | Parents or guardian | Complex social situations | Patient portal | Avoiding care or delayed care |
| Patient | Parents or guardian | Neglect | Patient portal | Avoiding care, delayed care. or continued neglect |
| Child/Adolescent | Parents or guardian | Foster or custody issues | Patient portal | Avoiding care, delayed care, or family strife |
| Child/Adolescent | Parents or guardian | Misattributed paternity | Patient portal | Avoiding care, delayed care, or family strife |
| Parent/Care Giver / Legal Guardian | Patient, other parent, or other care giver | Perinatally acquired sexually transmitted infection | Patient portal | Avoiding care, delayed care, or family strife |
| Parent/Care Giver / Legal Guardian | Patient, other parent, or other care giver | Substance abuse | Patient portal | Avoiding care, delayed care, or family strife |
| Parent/Care Giver / Legal Guardian | Patient, other parent, or other care giver | Parent or caregiver’s mental health | Patient portal | Avoiding care, delayed care, or family strife |
| Parent/Care Giver / Legal Guardian | Patient, other parent, or other care giver | Violence, abuse, or legal problems | Patient portal | Avoiding care, delayed care, or family strife |
| Parent/Care Giver / Legal Guardian | Patient, other parent, or other care giver | Misattributed paternity | Patient portal | Avoiding care, delayed care, or family strife |
| Parent/Care Giver / Legal Guardian | Patient, other parent, or other care giver | Stress associated with chronic care | Patient portal | Family strife or mistrust |
| Provider | Patient, other parent, or other care giver | Patient or family disagreement with provider | Patient portal | Delayed or missing documentation |
| Provider | Patient, other parent, or other care giver | Neglect or abuse | Patient portal | Lawsuit or unsafe environment for the provider |

### Inadvertent Disclosure of Medically Relevant Information Obtained From Proxies

There may be situations in which health care providers may document pertinent information that they receive from parents, relatives, and legal representatives, which may adversely affect the patient, parent, or legal representative or damage relationships when disclosed (Table 1). For example, parents may disclose their difficulty in coping with an adolescent's chronic illness to a provider who documents it in the adolescent's chart. This information could then be seen by the adolescent in their patient portal and affect the parent–child relationship. Another example is if a parent discloses information about a drug use during pregnancy or perinatally acquired STI to the pediatrician caring for the newborn. This information would be accessible through the infant's electronic record by other users, such as the other parent. In both situations, disclosing medically relevant information may be disincentivized for fear of its discovery by another person having access to the medical record.

### Health Care Provider–Patient Relationship in Difficult Diagnostic Dilemmas

Disclosure of information can adversely affect health care provider–patient relationships, especially when there is disagreement between the health care provider and the parents or patient (Table 1). In functional disorders where the medical work up does not demonstrate an organic etiology for the complaint, the parents or patient may believe otherwise. For example, when the defined Rome's Criteria of Functional Abdominal Pain fits a patient's symptoms, parents or the patient may disagree with this diagnosis. In similar cases where the relationship among the patient, family, and health care provider is critical to helping the patient improve, documenting this information could further damage a fraught or tenuous relationship with the health care provider. Although providers should hold themselves to high standards for documenting information in the EHR, providers should not feel pressured to augment their documentation for fear of their medical opinion offending patients or proxies. This can be the case when child abuse is in a differential diagnosis, and documentation of this in the child's record may adversely affect the relationship between parent and health care provider if the parent feels unfairly accused or judged. There are situations where abuse is in a differential diagnosis, albeit with a very low index of suspicion, or where a provider may want to document that they have thought of but ruled out abuse or neglect. In these cases, it is unlikely the information will be compiled in “reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding” [32], which is clearly protected and eligible for legal blocking by HIPAA, and the remainder of the documented information may be of interest to the patient or proxy. The limited capabilities of data segmenting technology create an awkward or burdensome situation for providers.

## *Older Adult Patients*

### Overview

The complexity of care and the large number of comorbidities and treatments associated with aging make the electronic patient portal an attractive tool for persons with multiple health conditions. However, many older adults feel uncomfortable or ill-equipped using technology and rely on their caregivers for their health care–related tasks, necessitating proxy portal access. Less than 20% of US hospitals that allow caregiver proxy access also allow patients to filter or partially block the EHI passed on to their proxies [33]. Therefore, older adults are faced with many of the same challenges and potential harms that adolescents may experience.

### The Older Adult Patient–Caregiver Relationship

Despite an increase in STIs among adults over the age of 65 years, many older adults are reluctant to share a recent sexual encounter [34] with their health care provider, knowing that this information will be available to caregivers. Syphilis, which is a treatable condition, can mimic dementia and neurocognitive disorders in late stages of the disease if the diagnosis is missed. Similarly, older patients may withhold health information regarding mental health (including depression) and elder abuse (physical, sexual, emotional, neglect, abandonment, financial, and self-neglect) from their health care providers for fear of their proxy finding out (Table 1). Again, the emphasis on broad access may paradoxically erode the patient's control over who can access their data. One potential solution may be allowing patients to block all information related to a specific topic from all users of the patient portal, including themselves, and unblock it again when they become sole users of the portal.

### Inadvertent Disclosure of Medically Relevant Information Obtained From Caregivers

Caregivers may disclose emotional, physical, or mental exhaustion leading to burnout. If this information is documented and shared with the older adult patient, unintended consequences are feelings of guilt, overburdening, and depression (Table 1).

Of note, there is a clause in the HIPAA Privacy Rule that specifically addresses keeping third-party information confidential. According to this clause [35]:

> *Any information disclosed to the provider by another person who is not a healthcare provider that was given under a promise of confidentiality (such as that shared by a concerned family member), may be withheld from the patient if the disclosure would be reasonably likely to reveal the source of the information.*

Since the Cures Act defers to the HIPAA, this clause should be applicable under the Cures Act; however, this is likely not well-known or understood across institutions.

In some cultures, it is common practice for caregivers to withhold negative information such as the diagnosis of a cancer or a terminal illness. Caregivers are also frequently surrogate decision-makers and may for many reasons ask a health care provider to withhold a diagnosis [36]. Although we consider disclosure to the patient as the ethically preferable choice, we acknowledge that the inability to block information may not align with the cultural norms of certain patient groups [37]. The patient may also desire information blocking, such as when an older patient is afraid that disclosure of a new diagnosis of cancer or recurrence may burden their caregiver or lead to caregiver burnout.

### Health Care Provider–Patient Relationship in Difficult Diagnostic Dilemmas

Maintaining a good relationship with patients is critical for health care providers taking care of older adults, as dynamic shifts in health often require changing or transitioning goals of care. Even neutral personal descriptors such as “elderly” in a note can make patients feel judged and perceived themes of disrespect, errors, and surprises can lead to straining of a patient–provider relationship [38]. For example, the term palliative is often misinterpreted for end-of-life care when in fact the goal is symptom and quality of life improvement for any serious illness (even curative ones), irrespective of prognosis. Further, the National Center for Educational Statistics reports that 21% of adults in the United States (~43 million) are illiterate or functionally illiterate [39]. Misinterpreting documentation may prevent older adults from seeking care to relieve symptoms and stress and align treatment options with their goals. One unintended, but positive, consequence of the information blocking rules might be that it encourages providers to be more vigilant in their documentation to achieve language that is both medically accurate and affirming of the patient’s dignity.

## Where Information Blocking Went Too Far

Although the potential adverse outcomes previously discussed do not meet the Cures Act Final Rule definition of harm, in some cases, releasing this information may violate the foundational principles of a trusting provider–patient relationship.

### Information Blocking in the Multiuser EHR

While the Cures Act final has made it easier to access information electronically, this increase in access is not accompanied with the requisite technical advances to block access to data in appropriate circumstances. In the situations when information blocking can be legally used, strategies are limited in number and capability, especially in the context of a multiuser or proxy access. Information blocking is technically and logistically challenging, and the burden is placed upon the documenting health care providers to determine what EHI is and is not appropriate to block and to whom. For some health care providers, such as those practicing in adolescent medicine, family medicine, general pediatrics, pediatric subspecialties, internal medicine, and geriatrics, navigating information blocking may be a routine experience depending on patient needs.

At the institutional level, the hospital system can deactivate proxy access; however, this may be burdensome and can be delayed depending upon institutional implementation (eg, a health care provider clicking a button in the EHR versus contacting health information management and placing a ticket for a request to be completed). The ONC exceptions emphasize that information blocking should be no broader than necessary. It will be an infrequent occurrence that a patient or proxy is completely blocked from accessing all EHI and more common that the blocking will occur on a data-element-by-data-element (clinical documentation, laboratory tests, imaging, etc) basis. This may create a substantial burden for the health care institutions and be prone to user errors. Additionally, the absence of information may be conspicuous when a patient or proxy who usually receives information does not. There is an evolving standard called “Data Segmentation for Privacy” (DS4P) where a health care provider could mark portions of a note to be blocked from access; however, the adoption of this standard is minimal [40,41].

Beyond institutional policies and EHR technical capabilities, the health care provider can adopt new documentation workflows when information blocking is legally acceptable. For example, the health care provider could create one note that is appropriate to share with all users and another that includes the information which is then blocked (ie, shadow charting); however, this solution is time-consuming and burdensome and unlikely to be adopted as clinical documentation has already been shown to be a significant contributor to burnout among health care providers [42-46]. Further, duplicate documentation would also be error-prone, jeopardizing safety and creating additional work and confusion for other health care providers on the treatment team relying on documentation to support patient care. Health care providers may choose to avoid caring for patients who are more prone to these complicated situations.

Where information blocking is not acceptable, the health care provider, not wanting to damage a relationship or breach confidentiality, may decide to stop documenting certain information. This is a potentially dangerous practice that could affect medical care, reduce accurate billing, and result in incomplete communication about the patient’s medical history with other health care providers.

## Conclusions and Recommendations

The Cures Act Final Rule is undoubtedly necessary to facilitate significant improvements in patient care and innovation; however, in some cases of a multiuser or proxy access situation, the Information Blocking Provision conflicts with the standard that health care providers hold themselves to in the United States. Additionally, applying these exceptions to the Information Blocking Provision in legally acceptable cases will be burdensome and could lead to increased burnout among health care providers. Paradoxically, providing patients more control over their data may actually jeopardize their control and privacy in some scenarios. Although breaching confidentiality and damaging the patient–provider relationship will not necessarily cause substantial harm as defined by the text of the Final Rule, it may cause unnecessary anguish, limit the quality of care, or cause a patient to forgo or delay care, and lead to increased morbidity. Additionally, the privacy exception may be underutilized as it necessitates patients and providers be educated on the application of this rule and an institution's policies and procedures. In light of these concerns, we recommend that ONC provide more detailed guidance both on their website and targeted outreach to health care providers caring for patients in the adolescent health setting and other multiuser or proxy access situations. As clause 171.202 (b) of the Cures Act allows institutions to develop policies around information blocking, we encourage ONC to develop and publish sample policies that institutions may use or modify. Such guidance should outline the exact processes by which a patient can opt out of their health data being shared with a proxy user using the privacy exception and detail how providers can best guide patients through decision-making without the fear of being in violation of the information blocking rules. Where data segmentation for privacy is not feasible, we recommend that ONC considers carving out an option for providers to return to traditional sharing options to prevent breaches of privacy. We also urge ONC to interpret the privacy exception broadly and not penalize hospitals or providers for information blocking when proxy access is the reason for the information blocking. We suggest that ONC and researchers carefully monitor charting habits in these multiuser or proxy access situations by studying how often patients use the privacy exception compared with single-user EHR access scenarios, how much time is spent documenting for these scenarios, and how much shadow-charting is taking place. We also suggest researchers carefully monitor the effect of information blocking on patient, provider, and proxy relationships. Additionally, we recommend limited penalties on health care providers in multiuser or proxy access situations during the implementation process of the Cures Act Final Rule until technological capabilities advance to better segment notes and block them from certain users.

## Conflicts of Interest

ML has been compensated for presentations for the Texas Pediatric Society, for consulting on modules to educate providers for Texas Health Steps, for time working with the Texas Essential Knowledge and Skills Proclamation 2022 Review Adoption Review Panel, and as a consultant for the Texas Child Psychiatry Access Network. She was also awarded support funds through the Technology and Adolescent Mental Well Being (TAM) youth Advisory Board (funding to start in January 2022), received a grant from Texas Pediatric Society Foundation, and is a Nexplanon trainer for Organon. CUL owns shares in Celanese and Markel. The remaining authors have no conflicts to declare.

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## Abbreviations

**DS4P:** Data Segmentation for Privacy
**EHI:** electronic health information
**EHR:** electronic health record
**HHS:** US Department of Health and Human Services
**HIPAA:** Health Insurance Portability and Accountability Act
**IT:** information technology
**ONC:** Office of The National Coordinator for Health Information Technology
**STI:** sexually transmitted information
**TAM:** Technology and Adolescent Mental Well Being

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Letter to the Editor

# Understanding the Impact of Social Media Information and Misinformation Producers on Health Information Seeking. Comment on “Health Information Seeking Behaviors on Social Media During the COVID-19 Pandemic Among American Social Networking Site Users: Survey Study”

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social media; internet; communication; public health; COVID-19; usage; United States; information seeking; web-based health information; online health information; survey; mistrust; vaccination; misinformation

We congratulate Neely and colleagues on their recent work [1] describing the utilization of social media platforms as a source of information regarding the COVID-19 pandemic. The authors suggested that the majority of health information disseminated on social media was not fact-checked with a health care professional [1]. Furthermore, their results demonstrated that subjects following more credible scientific sources on social media were more likely to receive the COVID-19 vaccine [1]. These findings are corroborated by a recent study that concluded that there is a statistically significant relationship between disinformation regarding COVID-19 and lower vaccination rates [2]. However, both studies primarily focused on individual consumers of social media. While these studies are representative samples of the US population, they are unlikely to adequately describe the >200 million Twitter users and are likely subject to selection and recall bias from participants. While analysis of the consumer is revealing, understanding the publishers of information is of equal intrigue and utility.

An alternative methodology for addressing the investigative question proposed by Neely and associates would be to quantify content related to the COVID-19 vaccine and vaccination efforts and further classify this content as informed or misinformed. Data points could include the number of views and the frequency these posts receive subsequent dissemination. This approach would transition the focus from the consumers to the producers of this information. Studies of the aforementioned design come with their own set of limitations; however, we feel it is better suited to address the questions of the authors. Regardless of the study or methodology, social media platforms continue to grow, and health care professionals must recognize the potential effect they can have on social media.

Across social media platforms, it has been previously demonstrated that pro-vaccine individuals are more likely to reference credible sources than those from “antivaccine” groups [3]. Major social media platforms such as Facebook, Twitter, and Instagram have partnered with the World Health Organization in an attempt to target and flag misinformation [3,4]. This served to counter misinformed COVID-19 and other health information on social media. Given social media’s high availability and massive user base, there is a tremendous opportunity for physicians and health care organizations to interact with the American public through these virtual platforms. Establishing a stronger social media presence at both the systems (hospital, national governing medical body, academic center) and individual level is an underutilized opportunity for disseminating health information in an accurate manner. Most physicians (90%) have a presence on social media; however, it is unclear what advocacy impact these accounts have [5]. The introduction of a verification process for posts containing health information may have merit. Implementation of such a policy may increase consumer faith in factual health information, potentially enhancing public health advocacy in campaigns such as COVID-19 vaccinations. It appears that social media has a role to play in health care; an enhanced understanding of social media's scope of influence and increased physician representation may have a far-reaching impact.

## Conflicts of Interest

None declared.

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Original Paper

# Examining Diurnal Differences in Multidisciplinary Care Teams at a Pediatric Trauma Center Using Electronic Health Record Data: Social Network Analysis

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## Abstract

**Background:** The care of pediatric trauma patients is delivered by multidisciplinary care teams with high fluidity that may vary in composition and organization depending on the time of day.

**Objective:** This study aims to identify and describe diurnal variations in multidisciplinary care teams taking care of pediatric trauma patients using social network analysis on electronic health record (EHR) data.

**Methods:** Metadata of clinical activities were extracted from the EHR and processed into an event log, which was divided into 6 different event logs based on shift (day or night) and location (emergency department, pediatric intensive care unit, and floor). Social networks were constructed from each event log by creating an edge among the functional roles captured within a similar time interval during a shift. Overlapping communities were identified from the social networks. Day and night network structures for each care location were compared and validated via comparison with secondary analysis of qualitatively derived care team data, obtained through semistructured interviews; and member-checking interviews with clinicians.

**Results:** There were 413 encounters in the 1-year study period, with 65.9% (272/413) and 34.1% (141/413) beginning during day and night shifts, respectively. A single community was identified at all locations during the day and in the pediatric intensive care unit at night, whereas multiple communities corresponding to individual specialty services were identified in the emergency department and on the floor at night. Members of the trauma service belonged to all communities, suggesting that they were responsible for care coordination. Health care professionals found the networks to be largely accurate representations of the composition of the care teams and the interactions among them.

**Conclusions:** Social network analysis was successfully used on EHR data to identify and describe diurnal differences in the composition and organization of multidisciplinary care teams at a pediatric trauma center.

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**KEYWORDS**

pediatric trauma; multidisciplinary health team; multi-team systems; social network analysis; electronic health record; process mining; fluid teams

# Introduction

## Background

Multidisciplinary care teams in health care are increasingly being seen as a multi-team system (MTS) [1,2], where 2 or more teams communicate and coordinate to achieve overarching goals [3], such as providing optimal care. MTSs are different from traditional teams in that MTS constituent teams are interdependent, work across boundaries, share accountability, and function through a hierarchy of goals that determine how lower goals are accomplished to realize higher goals [3]. MTSs have three attributes as follows: (1) compositional attributes (eg, number of teams, size of teams, and changes in team composition), (2) linkage attributes (eg, interdependence, hierarchical structure, and communication structure), and (3) developmental attributes (eg, changes in team membership over time) [4], which support the specialization and flexibility that allow constituent teams to pursue lower goals while trying to achieve higher goals [5].

MTS are often seen in environments where tasks are ambiguous, multifaceted, dynamic, and urgent [5]. In health care, trauma teams that take care of patients with trauma are examples of MTS. The care of patients with trauma is complex, multidimensional, and time sensitive, requiring multidisciplinary collaboration among a variety of health care professionals (HCPs) with complementary expertise, [6] with high fluidity of team membership (ie, members join and others leave based on the needs of patients) [7]. In addition, staffing levels at trauma centers vary with the time of day and the day of week, such that services of HCPs deemed nonessential may not be available during *off hours* (nights and weekends) [8-11], necessitating changes and adaptation in MTS structures.

Assessment of MTS, as they perform their work in actual settings, is important to gain a better understanding of work as done (as opposed to work as imagined) [12] and to identify how to improve their performance given the *realities and variations of work* [1]. Social network analysis can enable the understanding and assessment of MTS at the compositional (ie, membership) and organizational (eg, subteam) levels [1,13]. Typically, such assessment is done through observation, which can be highly resource intensive and may not be practical to capture all the cognitive work of team members involved in the trauma. Moreover, a self-reported surveys [5], which relies exclusively on perceptions of care professionals may also be limited in its ability to provide rich details [3]. The ability to exploit *digital traces* [14], which may provide opportunities over survey data [15,16] or observational data, is desirable. Electronic health record (EHR) systems offer the opportunity to study the composition and organization of care teams working as part of an MTS [17]. EHRs capture many clinical activities that are performed by HCPs in the process of care delivery [17,18], and previous studies have shown the feasibility of obtaining plausible information about care teams from EHR data [17].

## Objective

This study aims to identify MTS and demonstrate the dynamic nature of the compositional and organizational structures of the MTS by describing diurnal differences at various locations in a pediatric trauma center using EHR data.

# Methods

## Research Setting

This study was conducted as part of a larger research project (AHRQ R01HS023837) [19-21] aimed at redesigning pediatric trauma work systems based on health information to improve care transitions and patient safety. This study builds on a core methodology that has been previously described and validated [22,23]. The core methodology is reproduced here from data set subsection to “generation of master event log” subsection with necessary modifications for this paper.

## Study Setting

This study was conducted at a large academic children’s medical hospital with a level I pediatric trauma center in the Eastern United States, which receives approximately 1000 pediatric patients with trauma per year. The participating hospital triages incoming patients into one of four trauma activation levels as follows: alpha (level I or highest severity), bravo (level II), critical trauma transfers (includes interfacility, but patients who are stable but critically injured, and is also known as a consult) and emergency department (ED) response, that are ordered by decreasing acuity and need for multidisciplinary care with ED response activations exclusively handled by the ED staff.

Trauma activation levels determine the composition of the trauma team, as specified by state [24] and institutional policy. The trauma team is derived from the ED staff, the general pediatric surgery service, pediatric intensive care unit (PICU), and the ancillary support staff (eg, child life specialists, chaplains, and social workers). Following resuscitation, if inpatient admission is required, patients with single-system injuries are admitted under the appropriate specialty service, whereas patients with multisystem injuries are admitted under the general pediatric surgery service, which is responsible for coordinating care among managing specialty services (eg, neurosurgery or orthopedic surgery).

The Johns Hopkins Medicine Institutional Review Board approved the study (IRB00076900).

## Data Set

Data were extracted from the pediatric trauma registry and the EHR data warehouse (ie, the Clarity database of Epic). We limited EHR data to encounters with trauma activation levels of alpha, bravo, and critical trauma transfers that were managed between January 1 and December 31, 2017. Demographic and encounter data including age, sex, origin of patient, trauma activation level, injury severity score, and Glasgow Coma Scale score were collected from the registry. Admission, discharge, and transfer (ADT) data and metadata of 5 clinical activities (ie, notes, procedure orders, medication orders, flow sheet entries, and medication administration entries) captured in the EHR were collected from the EHR data warehouse. For each EHR activity type, we obtained the encounter ID (visit ID), activity timestamp, unique ID, and generic clinical roles (eg, attending or resident) of the HCP that performed the activity.

The note metadata included the service of the authors, whereas the procedure orders, medication orders, and medication administration entries included the care location (eg, ED or PICU) where the activity was performed.

### Data Preparation

Each encounter was assigned a randomly generated, unique study ID. Timestamps of EHR metadata were normalized by replacing them with time (in minutes) from ED arrival, which ensured that the temporal sequence of events was maintained for each encounter. Activities without a full complement of data were excluded. Activities that were initiated by the EHR system and initiated by student roles (eg, nursing and medical students) were also excluded as they bore no accountability for patient care. As notes were typically signed off much later from when they were started, we considered the note creation time as the note completion time. As flow sheet and note data lacked care location data, we inferred the care location for each activity from the ADT data as follows: First, a location timeline was generated from the ADT data (ie, sequence of admissions to various hospital locations from ED arrival to hospital discharge). The normalized timestamps of each activity in the flow sheet and note metadata were then subsequently related to the location timeline, and the corresponding care location was taken as the care location where the flow sheet and note activities were performed.

### Identification of Functional Roles

We considered collaboration at the level of functional roles (eg, ED nurse, neurosurgery resident, PICU fellow, and surgery attending) rather than individuals, as past studies have shown that mirrors the reality of clinical practice [25]. To determine functional roles, we identified the service (eg, orthopedic or ophthalmology service) to which each identified HCP belonged and prefixed it to their generic role (eg, resident or attending). This service could be a service that is bound to a care location (eg, ED, PICU, or general care floor) or a service that operates across care locations (eg, general pediatric surgery service or physical therapy).

We assumed that the services of certain functional roles (eg, attending, fellows, physician assistants, and nurse practitioners working on specialty services) were fixed as determined from their notes. Chart reviews and directory lookups were conducted to identify the services of individuals whose services could not be determined from the extracted metadata. The services of medical residents, which frequently change as they rotate through various services for their training, were determined on an encounter basis derived from the service of the attending that cosigned the notes. The services of registered nurses, unit-based nurse practitioners, and allied HCPs (excluding radiology technicians) were determined by taking the mode of the frequency distribution of the location of the activities they performed. The services of radiology technicians were determined on an encounter basis similar to that of residents.

Activities by individuals whose services could not be determined were excluded. Since the location of flow sheet and note activities were inferred, the records were excluded if the inferred location did not correspond to the base unit of HCPs.

### Methodologic Approach

We used a process mining approach, which is a field of data science that *aims to discover, monitor, and improve real processes by extracting knowledge from event logs* [26]. The starting point for process mining is an event log, which contains a collection of events. Each event represents a discrete activity (eg, note writing) in a given process (eg, clinical care), performed by an actor (eg, ED resident), and relates to a case (eg, patient encounter). Each event is time-stamped (eg, order placed on January 22, 2000, at 10:45 AM), allowing all events for a patient encounter to be ordered chronologically [27]. By applying a *metric* described below, social network interactions and collaboration between different functional roles were obtained [28].

*Working together* is a commonly used metric for representing collaboration in unstructured processes with frequent ad hoc behavior such as in health care [29]. The working together metric counts how frequently 2 actors work together on same cases [28]. In its regular form, the working together metric does not accommodate for temporal distance between actors, which is important in health care where different HCPs are involved in patient care at different stages of care. Consequently, we defined a variant of the working together metric, referred to as *working closely together*, to account for temporal distance among actors. The working closely together metric counts the number of times 2 actors worked closely together with respect to time for a given patient relative to the number of times the 2 actors had the opportunity to work together. To operationalize this metric, we considered the shift rotation as the unit of clinical work and collaboration, and assumed that functional roles that were involved in the care of a patient during a shift had the opportunity to work together, whereas functional roles that were captured in the EHR within a similar time interval were *working closely together*. Therefore, this metric translates to functional roles that are jointly involved in completing the same tasks or completing disparate tasks within the same time interval.

### Generation of Master Event Log

EHR metadata were processed into an event log consisting of the study ID, normalized time, EHR activity type, unique ID, and functional role of the HCP, and care location. Multiple *same-time events* were generated from notes, procedures, and medication orders that involved multiple HCPs. The encounter timeline was divided into shift rotations (day: 7 AM-6:59 PM and night: 7 PM-6:59 AM) numbered 0 to N, and each event in the event log was labeled with the corresponding shift number and shift type (day or night). Events within each shift were partitioned into segments based on *natural breaks* in the continuity of events. We assumed a natural break to be a minimum of 30 minutes between adjacent events in the event log to accommodate the lag between the occurrence of activities in real life and registration in the EHR. The Jenks Natural Break Optimization algorithm [30] was used to determine the optimal break interval between 30 and 120 minutes in 5-minute increments.

## Generation of Sublogs

The master event log was divided based on shift type (day or night) and care location (ED, floor, or PICU) to obtain six individual event logs: ED morning, ED night, floor morning, floor night, PICU morning, and PICU night.

## Network Representation

For each individual sublog, an undirected edge (ie, the relationship among nodes) was created for all pairwise combinations of identified functional roles within each event segment. Unique edges across all segments across all shifts across all encounters were obtained as the collaboration network. The weight of the edges was obtained by dividing the number of shifts an edge was present between 2 functional roles by the number of shifts in which both functional roles were involved, which effectively normalized the weights and accommodated for variation in care team composition across encounters.

## Threshold Selection

To prevent the capture of spurious edges (ie, edges that do not really exist or edges with spurious weights) in network analysis, a threshold number of shared encounters among nodes (ie, functional roles) is usually applied to constructed networks. The eventual network structure is sensitive to the selected threshold. Various approaches that have been used to determine this threshold are subjective [31], including arbitrary selection [32], clinician informed [33], and retaining only a fixed top percentage of the strongest edges [34]. In this study, we attempted to take a more objective approach to threshold determination by introducing a heuristic method akin to the elbow method [35], which is used to determine the optimal number of clusters in k-means clustering. For each event log, we obtained and plotted the rate of change of the total number of edges removed as the threshold value (ie, representing the number of shared shifts) was incrementally increased from 2 to 20 and obtained a LOWESS (Locally Weighted Scatterplot Smoothing)-smoothed curve of the plot. The elbow point—the smallest threshold value at which the rate of change becomes insignificant or constant, was taken as the optimal threshold. The underlying assumption of this method is that as the threshold of the shared number of encounters is increased, trivial and spurious edges are removed, and the network structure changes up to a point where further increases in threshold value result in minimal removal of edges with little or no change in the network structure. At this threshold point, we assume that the network structure is relatively stable and only significant edges and nodes remain.

## Network Visualization and Analysis

We used the igraph 1.1.1 package [36] in R (version 3.4.0; R Foundation for Statistical Computing) [37] to create and visualize the networks. From each network, we obtained the node count (ie, number of functional roles) and edge count (ie, number of relationships among functional roles). We used the linkcomm package 1.0.11 [38] to identify the overlapping communities in the networks. A community is a subnetwork that contains a high density of edges among members but fewer edges with members of the larger network, thus represents a tightly knit subgroup [39]. The linkcomm package is an R implementation of the algorithm by Ahn et al [40] that, as opposed to other community detection algorithms that cluster nodes—clusters edges assuming a node can belong to multiple communities, thus enabling the discovery of overlapping and nested communities. The algorithm by Ahn et al [40] is the most commonly used overlapping community detection algorithm and tends to produce superior performance if multiple ad hoc behaviors result in a high degree of overlap in derived networks, as is commonly seen in health care settings [41,42]. The algorithm uses a hierarchical clustering method to produce a dendrogram that, in the default setting, is cut at a level that maximizes the partition density [40]. The linkcomm package offers a unique visualization that uses different colors to depict edges and nodes that belong to different communities. Nodes are sized to reflect the number of communities the node belongs to, with larger nodes belonging to more communities. Nodes belonging to more than one community are also presented as pies with the pies divided and colored based on the proportion of the edges for that node in various communities that the node belongs. We parameterized the algorithm with the McQuitty hierarchical clustering method, also known as the Weighted Pair Group Method with Arithmetic Mean [43], so that edge weights can be considered in community determination. We subsequently obtained community-depicted networks produced at maximum modularity that were visualized with easily understandable network layout algorithms.

## Statistical Analysis

We obtained and compared descriptive statistics of demographic, injury, and outcome characteristics of day and night shift encounters. We also compared composition of days and night shift event logs for each care location. Differences among interval and categorical variables were examined using Wilcoxon rank-sum and Pearson chi-square tests, respectively. Differences were considered statistically significant at an $\alpha<.05$. The analysis was performed using Stata 13 [44].

## Validation

Two forms of validation were conducted. In the first validation step, we compared the results of this study with the secondary analysis of data from and results of a previous study [45] in which we developed a *role-location matrix*, which is a 2×2 table of functional roles and the inpatient locations in which they typically worked via semistructured interviews with clinicians (n=21) and subject matter experts (n=22), and a review of the institutional and trauma registry protocol. We compared the functional roles and the locations in which the functional roles were found in this study to the role-location matrix. In the second validation step, we validated the collaboration patterns of pediatric trauma MTS via member-checking interviews (n=6) with care professionals (ie, pediatric trauma program director, PICU attending, and pediatric trauma nurses) that were involved in pediatric trauma care. The interviews were conducted by AD, KW, and GSD and APG as a group. During each session, the collaboration patterns of care teams were individually presented to the HCP, who were asked to comment on (1) the accuracy and completeness of the roles that were captured by location and shift; (2) whether the collaborative patterns mirrored reality or not; and (3) whether the differences between day and night patterns for a given care location (ie, ED, PICU, or floor) were suggestive of reality.

## Results

### Overview

There were 413 encounters in the cohort, of which 65.9% (272/413) and 34.1% (141/413) began during day and night shifts, respectively. Compared with patients who arrived during day shifts, those who arrived during night shifts were significantly older (median age 7 vs 10 years; *P*=.04), had a higher proportion of critical trauma transfers (8.8% vs 26.2%; *P*<.001), and had a higher proportion of penetrating injuries (5/272, 1.8% vs 11/141, 7.8%; *P*<.001; Table 1). There were no significant differences in sex, injury severity score, Glasgow Coma Scale, operating room and PICU admissions, ED, PICU, hospital length of stay, and mortality.

**Table 1.** Comparison of demographic and encounter characteristics by shift type[a].

| Variables | Day (n=272) | Night (n=141) | *P* value |
|---|---|---|---|
| Age (years), median (IQR) | 7 (3-11) | 10 (3-13) | .04 |
| Male sex, n (%) | 184 (67.7) | 83 (58.9) | .08 |
| **Trauma activation, n (%)** | | | <.001 |
| Alpha | 26 (9.6) | 5 (3.6) | |
| Bravo | 222 (81.6) | 99 (70.2) | |
| Critical trauma transfer | 24 (8.8) | 37 (26.2) | |
| **Origin, n (%)** | | | <.001 |
| Scene of injury | 245 (90.1) | 102 (72.3) | |
| Transfer | 2 (0.7) | 38 (27) | |
| Others | 2 (0.7) | 1 (0.7) | |
| **Injury type, n (%)** | | | .01 |
| Blunt | 259 (95.2) | 126 (89.4) | |
| Penetrating | 5 (1.8) | 11 (7.8) | |
| Others | 8 (2.9) | 4 (2.8) | |
| ISS[b], median (IQR) | 5 (2-10) | 5 (2-9) | .76 |
| GCS[c], median (IQR) | 15 (15-15) | 15 (15-15) | .48 |
| ED[d] LOS[e] (minutes), median (IQR) | 253.5 (187-361) | 254 (146-374) | .52 |
| OR[f] admission, n (%) | 41 (15.1) | 22 (15.6) | .89 |
| PICU[g] admission, n (%) | 43 (15.8) | 27 (19.2) | .39 |
| PICU LOS (days), median (IQR) | 1 (1-3) | 1 (1-2) | .48 |
| Hospital LOS (hours), median (IQR) | 7 (4-32) | 14 (4-41) | .21 |
| Mortality, n (%) | 7 (2.6) | 2 (1.4) | .72 |

[a] Day shift is defined as 7 AM to 6:59 PM, whereas night shift is defined as 7 PM to 6:59 AM.

[b] ISS: injury severity score.

[c] GCS: Glasgow Coma Scale.

[d] ED: emergency department.

[e] LOS: length of stay.

[f] OR: operating room.

[g] PICU: pediatric intensive care unit.

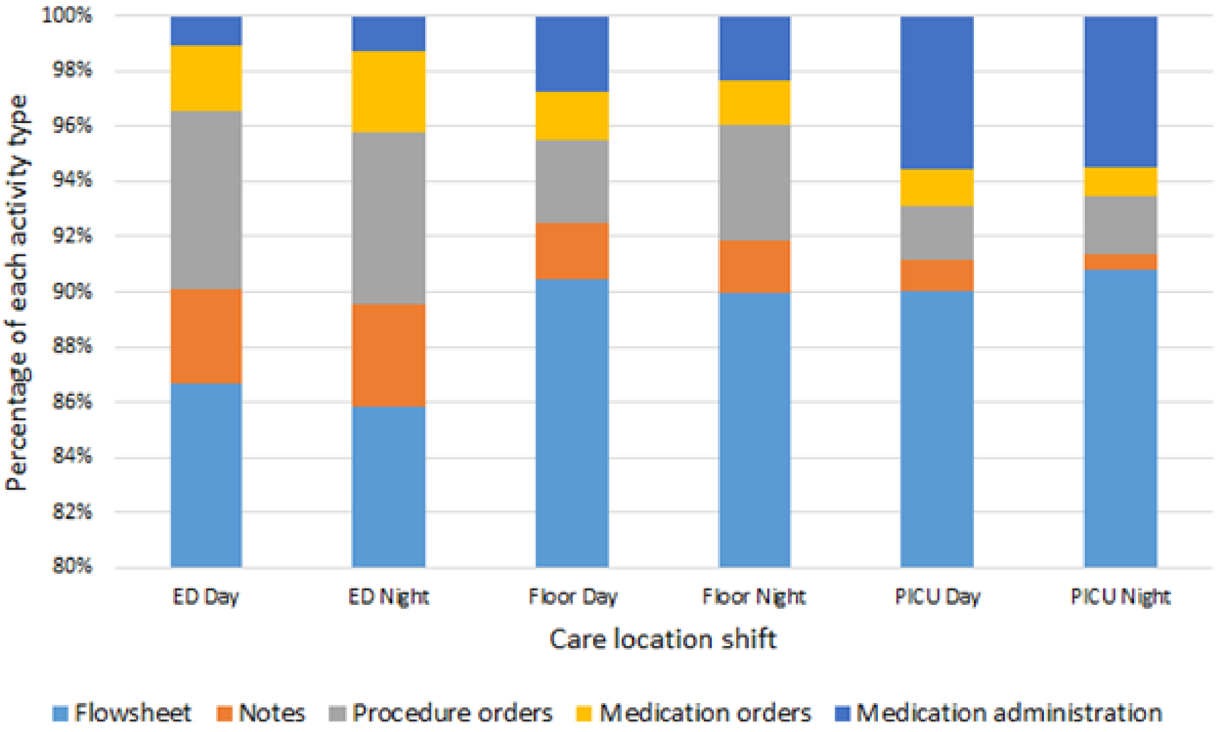
### Master Event Log Characteristics

There were 837,318 events in the initial event log, respectively. Only 0.19% (1564/837,318) of the events were excluded owing to the inability to resolve the functional role of the actor. Consequently, 835,754 events remained in the master event log. Flow sheet entries accounted for 89.45% (749,000/837,318) of all events in the log. A total of 1647 unique HCPs occupying 110 functional roles were identified, of which 58 functional roles were recorded in at least 4.8% (20/413) of encounters. The ED registered nurses were recorded in all 413 encounters, whereas the ED attending, ED resident, and ED radiology technician were recorded in 98.5% (407/413), 93.2% (385/413), and 80.6% (333/413) encounters, respectively.

### Comparison of Sublogs Obtained Based on Shift Type and Care Location

Figure 1 depicts the composition of the individual sublogs for each care location and shift duty. The proportions of various activities in the day and night logs for each care location were similar, with some notable differences. The ED night log contained more medication administration orders than the ED day log, which contained more flow sheet events. The floor day log contained more medication administration than the floor night, which contained more procedure-order events. The PICU day contained more notes events that the PICU night, which contained more flow sheet events.

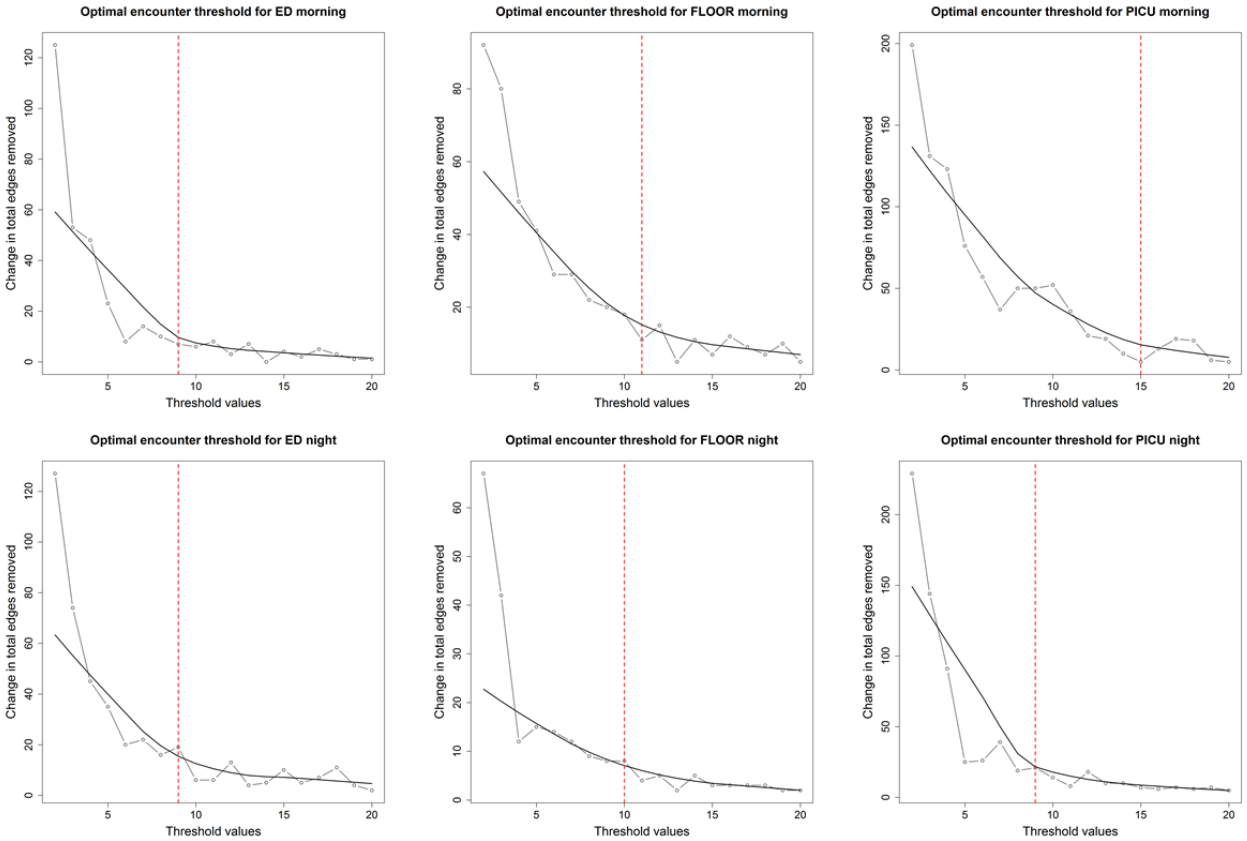
**Figure 1.** Comparison of the composition of various activity types by care location and shift type. ED: emergency department; PICU: pediatric intensive care unit.



### Threshold Selection

Figure 2 shows the plots of the rate of change of total edges removed against increasing threshold values. The gray line and point plot show the difference in edges removed as the threshold is increased, whereas the smooth black line is the LOWESS curve. Some LOWESS curves, such as the ED morning and PICU night, have sharply defined elbows, whereas others have subtle elbows. The red vertical lines indicate the selected threshold number of shared encounters by HCPs for each event log. For both ED day and night, the threshold was determined to be 9. For the floor, 11 and 10 were selected as the thresholds for day and night, respectively, whereas for the PICU, 15 and 9 were selected as the day and night thresholds, respectively.

**Figure 2.** Determination of encounter threshold for each event log. ED: emergency department; PICU: pediatric intensive care unit.



## Collaborative Care Teams in the Pediatric ED

Figure 3 shows the collaborative care team pattern in the ED during the day and at night visualized using the Kamada Kawai layout algorithm [46], which is a force-directed algorithm. Table 2 contains the meaning of the abbreviations used in Figure 3 and in all other network diagrams in this paper. The day pattern contained 18 nodes and 87 edges, whereas the night pattern contained 28 nodes and 160 edges. The night pattern was distinctively star-shaped and had 5 overlapping communities with the ED attending, residents, nurses, radiology technicians, and the general pediatric surgery attending and resident forming the core and belonging to all 5 communities. The day pattern had a less distinctively defined star pattern and had only 1 community. Attending-resident pairs from neurosurgery and orthopedic surgery services, and allied HCPs, including social workers, chaplains, and child life specialists, were at the periphery in both patterns. Attending-resident pairs from otolaryngology and plastic surgery were seen only in the night pattern and belonged to separate communities, whereas only the resident from the ophthalmology service was seen in the night pattern. The PICU nurse, resident, and the imaging data coordinator (IDC) were also seen in the night pattern.

**Figure 3.** Collaborative care team patterns in the emergency department. Left: day shift; right: night shift.

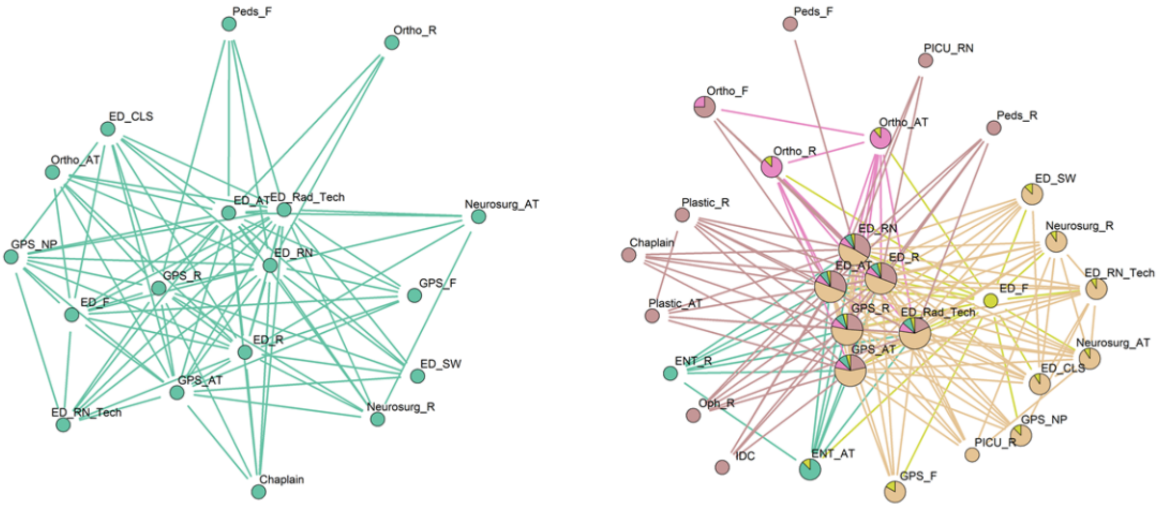


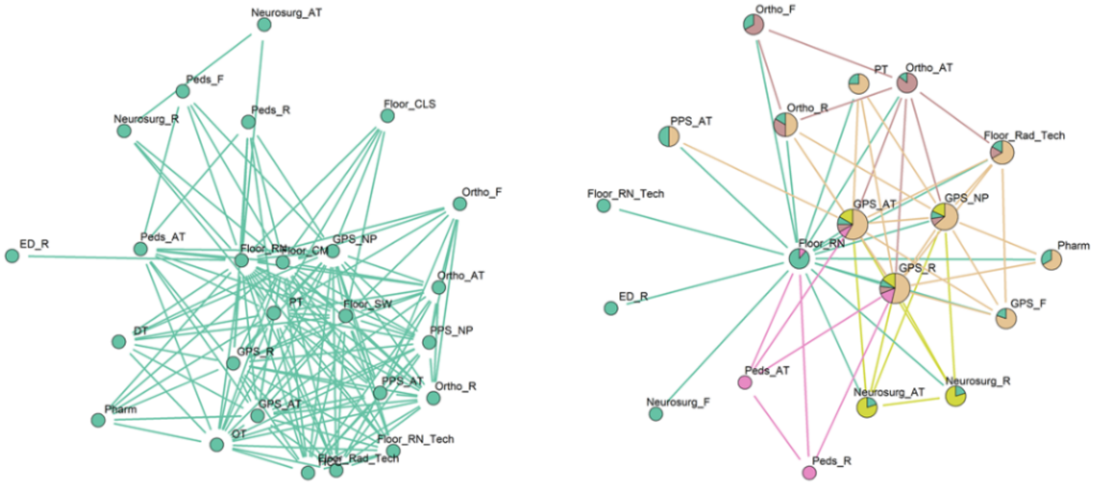
**Table 2.** Abbreviations used in the network diagrams.

| Abbreviation | Meaning |
|---|---|
| Anes | Anesthesia |
| AT | Attending |
| CLS | Child life specialist |
| CM | Case manager |
| DT | Dietitian |
| ED | Emergency department |
| F | Fellow |
| GPS | General pediatric surgery |
| HCC | Home care coordinator |
| IDC | Imaging data coordinator |
| Neuro | Neurology |
| Neurosurg | Neurosurgery |
| NP | Nurse Practitioner |
| Oph | Ophthalmology |
| Ortho | Orthopedic surgery |
| OT | Occupational therapy |
| PA | Physician assistant |
| Peds | Pediatrics |
| Pharm | Pharmacist |
| PICU | Pediatric intensive care unit |
| PMR | Physical medicine and rehabilitation |
| PPS | Pediatric pain service |
| PT | Physical therapist |
| R | Resident |
| Rad_Tech | Radiology technician |
| RN | Registered nurse |
| RN_Tech | Nurse technician |
| SW | Social work |

## Collaboration Patterns of Care Teams in the Floor

Figure 4 shows the collaboration pattern on the floor during the day and at night visualized using the large graph layout [47]. The day pattern contained 24 nodes and 135 edges, whereas the night pattern contained 19 nodes and 55 edges. The bedside nurse was at the center of both patterns. Functional roles present in the day pattern but absent in the night pattern were home care coordinators, case managers, social workers, child life specialists, occupational therapy, and dietitians. The ED resident was present in the night pattern but not in the day pattern. One community was identified in the day pattern, whereas 5 overlapping communities were identified in the night pattern with the neurosurgery, orthopedic surgery, and pediatric services having separate communities and the general pediatric surgery-resident and general pediatric surgery attending belonging to all 5 communities.

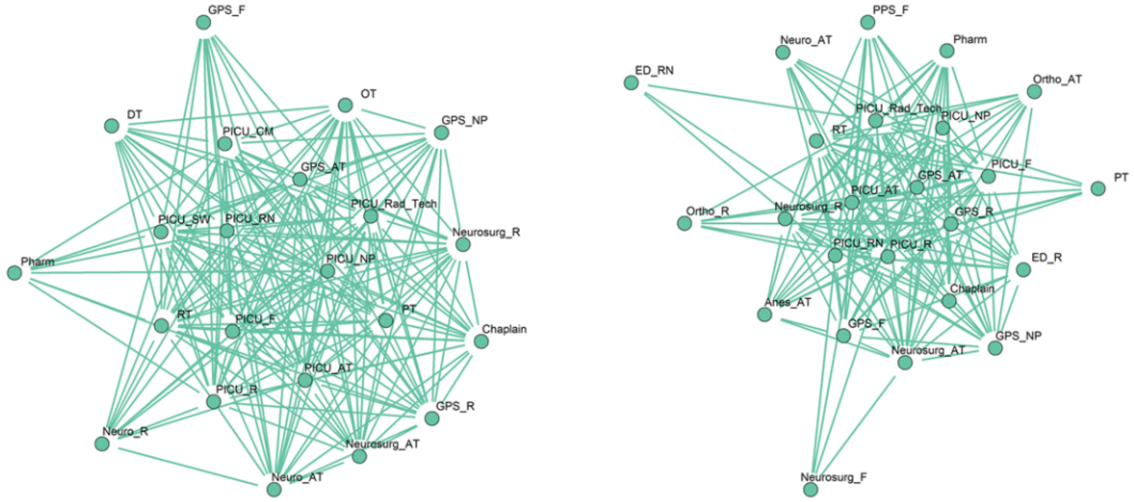
**Figure 4.** Collaborative care team pattern on the floor. Left: day; right: night. Only one community was identified in the day pattern while 5 communities (different colors) were identified in the night pattern.



## Collaboration Patterns of Care Teams in the PICU

Figure 5 shows the day and night collaborative care team pattern in the PICU visualized using the Frutchterman–Reingold layout algorithm [48]. The day pattern contained 30 nodes and 283 edges, whereas the night pattern contained 24 nodes and 175 edges. Both collaboration patterns had a large spherical core made up of functional roles from the PICU, general pediatric surgery, neurosurgery, and neurology services (day pattern only), and few *appendages* that include functional roles from the orthopedic surgery, ophthalmology and pediatric pain service. One community was identified in both the patterns. Functional roles present in the day pattern but absent in the night pattern were unit case managers, social workers, occupational therapists, and dietitians. Functional roles present in the night pattern but absent in the day pattern include the ED resident, ED nurse, orthopedic surgery team, and anesthesiology attending.

**Figure 5.** Collaborative care team patterns in the pediatric intensive care unit. Left: day; right: night.



## Validation

In a previous study that used semistructured interviews with care professionals [45], we identified 56 roles involved in pediatric trauma care across all care locations. In this study, we identified a total of 110 functional roles and 58 frequent functional roles across all locations. Eight functional roles were identified in a previous study but not in this study. These roles were ED documenting nurses, charge nurses, emergency medical services personnel, security, family or caregiver, pediatric trauma manager, perfusionist, and in-hospital transport team. A total of 54 functional roles were identified in this study but not in a previous study. Most of these roles belonged to specialty service roles that were not frequently involved in patient care.

Of the 58 frequent roles identified in this study, 15 (26%) were not identified in the prior study. These roles included dietitians, IDCs, home care coordinators, ophthalmology service, otolaryngology service, neurology service, pediatric pain service, and plastic surgery services.

A comparison between this study and the prior study showed that the locations of the functional roles they had in common mostly matched. For example, both studies confirmed that ED nurses, ED residents, and PICU nurses go to the floor, usually during patient transport. However, few differences exist. For example, in a previous study, it was revealed that the PICU attending, PICU fellow, and respiratory therapist responded to alpha traumas in the ED both during the day and at night, but this was not captured in this study.

The 6 HCPs who were interviewed for this study found the composition of the derived care teams to be largely accurate. However, they pointed out that some functional roles were not accurately captured. For example, PICU attendance, PICU fellows, and respiratory therapists were not identified in the ED collaborative care teams (Figure 3). This was attributed to the fact that PICU team members who responded to traumas rarely did any documentation while in the ED. They also pointed out that the team pattern for the PICU night did not capture the ED social worker who usually covers the PICU at night, and the floor care team patterns were missing functional roles from anesthesiology.

Regarding interactions among roles and communities that were identified, clinicians confirmed the general pediatric surgery coordinated care among specialist services and understood why they belonged to multiple communities. Clinicians explained why only 1 community was identified in the PICU, as concerted efforts have been made to improve coordination of care between the PICU and surgical services, and the PICU characteristically performed multidisciplinary rounds with other nonsurgical services and allied HCPs. However, clinicians acknowledged that collaboration with the orthopedic service, particularly in the PICU, can be further improved. Clinicians confirmed that the neurosurgery service was well integrated into the trauma team in the ED.

# Discussion

## Principal Findings

We compared diurnal differences in the composition and organization of collaborative care teams at 3 care locations in a level I pediatric trauma center using EHR data. Our study is unique in several ways. First, we introduced a heuristic for determining the threshold number of shared patient encounters for interaction between HCPs. The heuristic method allows a more objective approach to threshold selection. In 67% (4/6) of the scenarios, we obtained distinct elbow points, whereas in the other 33% (2/6) of the scenarios, we easily identified the appropriate threshold on closer examination. Second, we used an overlapping community detection algorithm that allowed a functional role to be part of multiple communities to reflect ad hoc clinical collaborations that clinicians form to address the unique needs of patients. In 33% (2/6; ED night and floor night) of the scenarios, we identified multiple overlapping communities suggestive of MTS, whereas in the other 67% (4/6), only a single community was identified. Third, we confirmed the presence of MTS using the EHR data. We also showed that the EHR data complemented interview data for identifying functional roles. Although interview data were especially helpful in identifying team members or roles who rarely document in the EHR, the EHR data enabled a more comprehensive and systematic analysis and identification of functional roles (56 functional roles identified with interviews vs 110 with EHR data).

There were 3 significant differences among patients who arrived during night shift compared with those who arrived during the day time. The patients who arrive at night tend to be older (median age 10 vs 7 years) and have penetrating injuries (11/141, 7.8% vs 5/272, 1.8%). This is likely related to prevailing epidemiological conditions and is consistent with what has been reported in the literature [49,50]. These patients also tended to arrive as transfers from other facilities (38/141, 27% vs 2/272, 0.7%). A higher percentage of transfers received at night reflects operational circumstances. Our pediatric trauma center is a level I trauma center that serves as a referral center for a large area. The decision to transfer patients is made by the originating facility, but several factors determine when patients physically arrive at our facility. First, the patients must be stabilized (to some extent) at the originating facility to ensure that they will survive transportation before departing the originating facility. Second, the level of staffing at the originating facility may influence transfer decisions such that patients who would be unsafe to manage at night when staffing is low are transferred to us after stabilization. Third, the distance of the originating facility and logistics of transportation can influence when transfer patients physically arrive at our facility.

There were some notable differences in the composition of event logs at various locations. The lower proportion of flow sheet activities in the ED is likely because of the relatively short time (usually <60 minutes) spent in the ED as compared with the entire hospital stay (usually days). The higher proportion of flow sheets and medication activities in the PICU compared with the ED and the floor reflects the intensive care provided in the PICU. The higher proportion of procedure orders in the ED compared with both the floor and PICU suggests the initiation and delivery of immediately necessary and likely lifesaving interventions.

Important differences were observed between the collaborative care teams in the ED during the day and at night. Compared with the day pattern, the night pattern had a better-defined core team made up of ED and general pediatric surgery personnel and involved more specialty services, which was reflective of the nature and severity of injury of patients presenting at night [8,51,52]. In addition, the neurosurgery team was part of both day and night patterns. However, in the night pattern, the neurosurgery team was part of the main community that included the core team and allied HCPs. This suggests that the neurosurgery team has a close relationship with the trauma team in the ED, which was confirmed by the interviewed clinicians. In addition, the collaborative care team in the ED at night included roles that did not exist in the day pattern. These roles include the IDC, a role that is responsible for uploading imaging data from transferring hospitals that do not use an interoperable EHR (which can be explained by the significantly higher number of trauma transfers arriving at night), and the PICU resident and PICU nurse, which suggested greater involvement at night, possibly to facilitate faster admission to the PICU). The orthopedic surgery attending and resident, and the ED resident and ED nurse were captured by the night pattern in the PICU but not during the day, which suggested greater involvement in PICU-related activities of trauma patients at night.

Compared with the day pattern, multi-team structures were more pronounced at night. Constituent specialty teams usually consisted of attending-resident pairs, except for the ophthalmology service, which consisted only of residents. Validation with clinicians confirmed that ophthalmology attending physicians do not take in-house night duty calls, given the seldom emergent nature of many ophthalmologic problems. Conspicuous multi-team structures reflected the presence of fewer ancillary support services that often serve as coordinators of care. In the ED, as ancillary support services were present at night, this may be reflective of the greater need of the patients received at night and the difficulty in coordination of care among the various services. On the floor, where ancillary support services are not present at night, this suggests that ancillary support staff play important roles in coordinating care and ensuring that various teams function as a unit. However, this was not the case in the PICU, where the night collaboration pattern was essentially similar to the day pattern despite the absence of ancillary support staff at night.

There are a number of reasons for the observed variations between day and night networks. As described, the level of staffing during the day was higher than that at night. During the day, more functional roles and support staff (care coordination, social work, etc) are present, and they participate in collaboration between teams. At night, some functional roles and nonessential staff are not available, which changes the dynamics of work and collaboration. In addition, more care activities (patient rounds, elective procedures, discharge planning, etc) occur during the day as opposed to nighttime. These activities create the need and opportunity for close collaboration compared with nighttime. Finally, there are likely differences in the manner of collaboration, for example, the use of non-EHR–based communications such as telephone and paging is more common during the night when team members tend to be more geographically dispersed, as opposed to during the day when they are geographically closer or physically working together.

In addition to organizational factors, methodological issues may also account for the variations. Only a single community was identified at all locations during the day. Although it is probable that the specialty teams actually do work very closely together during the day, it is likely that they do in a multi-team setup, which we did not identify by overlapping community detection. This may be owing to several reasons. The data may lack adequate *power* to detect overlapping communities during daytime. Certainly, smaller teams could be identified using cliques, which are unique subnetworks containing at least three nodes that are all connected to one another by edges. However, given the number of nodes involved, hundreds of overlapping cliques would be identified, which would be difficult to interpret. Another factor could be threshold selection. It is possible that by selecting different thresholds for day networks, we could identify overlapping communities. However, because the weights of the edges are considered by the community detection algorithm, such a sensitivity analysis was not required. Nevertheless, a narrow sensitivity analysis of the day networks using +/−1 the selected threshold did not show any major difference in terms of communities (Multimedia Appendices 1-3).

This study has several implications: the methodology can be adapted and used in other settings to identify and study MTS structures in an efficient manner. The methodology can also be adapted to study how MTS evolves over the care timeline of patients and identify areas in need of improvement. In-depth analysis of MTS across time, location, and team members using EHR metadata can provide insights to support management and operational decisions. For example, it can be used to derive insights into how HCPs and care teams organize themselves given the realities of *actual work*, rather than how they are supposed to organize according to protocols. Such insights can be used to inform staffing and team composition decisions, team training and development efforts, and complement efforts to improve collaboration and coordination to improve team-based health care delivery. In addition, the ability to compare temporal patterns in MTS dynamics based on EHR metadata enables assessment and evaluation of the impact of any quality improvement and intervention efforts aimed at improving MTS performance.

This study had several notable limitations. First, by only EHR data, we did not capture other important teamwork-related activities such as face-to-face and telephone conversations, which are a major part of clinical activities [53]. Second, we were less likely to capture functional roles that documented infrequently in the EHR. For example, we were unable to capture the PICU attending and PICU fellows in the ED patterns for both day and night, as these 2 roles rarely used the EHR for documentation while in the ED. We were also unable to capture several other HCPs, such as emergency medical services personnel, security, family and/or caregiver, pediatric trauma manager, perfusionist, and in-hospital transport team who rarely or never use the EHR for a trauma case, but are an integral part of the care team, as revealed by interview data. Other methods, such as in-depth interviews or direct observations, can be used to overcome these limitations. Third, our method for determining the functional roles was based on heuristics. Consequently, it is possible that not all possible roles were identified, and that some of the assigned functional roles were inaccurate. Nevertheless, as demonstrated, the methodology performs quite well; future EHR systems should be designed to support functional roles, which are the appropriate unit of clinical collaboration, rather than individuals; for example, clinical documentation could be primarily based on functional roles, but signed as individuals. Such systems have the potential to optimize collaborative work to deliver improved care and enable robust research using EHR data.

## Conclusions

We identified and described diurnal variations in MTS and collaborative care teams at various locations and stages of care, as well as various shift types in a pediatric trauma center using EHR data. We validated our results using qualitative data and showed that the derived structures can accurately represent reality. The methodology described can be adapted to study how MTSs evolve over time and across locations, and the insights can be used to support management and operational decisions.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Sensitivity analysis of the collaborative care team patterns for the emergency department day shift using +/−1 the selected threshold. At a lower threshold of 8, a minor overlapping community that included the orthopedic resident (Ortho_R) and imaging data coordinator (IDC) as additional members was identified.
[PNG File , 772 KB-Multimedia Appendix 1]

## Multimedia Appendix 2

Sensitivity analysis of the collaborative care team patterns for the floor day shift using +/−1 the selected threshold. At a threshold of 10, functional roles with single connection to the floor nurse were identified. However, these functional roles were removed as the threshold is increased with no functional role having a single connection at a threshold of 12.
[PNG File , 712 KB-Multimedia Appendix 2]

## Multimedia Appendix 3

Sensitivity analysis of the collaborative care team patterns for the pediatric intensive care unit day shift using +/−1 the selected threshold. At a higher threshold of 16, a minor community including the neurology resident as the only additional member was identified.
[PNG File , 855 KB-Multimedia Appendix 3]

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## Abbreviations

**ADT:** admission, discharge, and transfer
**ED:** emergency department
**EHR:** electronic health record
**HCP:** health care professional
**IDC:** imaging data coordinator
**LOWESS:** Locally Weighted Scatterplot Smoothing
**MTS:** multi-team system
**PICU:** pediatric intensive care unit

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Review

# Online Health Information Seeking Behaviors Among Older Adults: Systematic Scoping Review

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## Abstract

**Background:** With the world's population aging, more health-conscious older adults are seeking health information to make better-informed health decisions. The rapid growth of the internet has empowered older adults to access web-based health information sources. However, research explicitly exploring older adults' online health information seeking (OHIS) behavior is still underway.

**Objective:** This systematic scoping review aims to understand older adults' OHIS and answer four research questions: (1) What types of health information do older adults seek and where do they seek health information on the internet? (2) What are the factors that influence older adults' OHIS? (3) What are the barriers to older adults' OHIS? (4) How can we intervene and support older adults' OHIS?

**Methods:** A comprehensive literature search was performed in November 2020, involving the following academic databases: Web of Science; Cochrane Library database; PubMed; MEDLINE; CINAHL Plus; APA PsycINFO; Library and Information Science Source; Library, Information Science and Technology Abstracts; Psychology and Behavioral Sciences Collection; Communication & Mass Media Complete; ABI/INFORM; and ACM Digital Library. The initial search identified 8047 publications through database search strategies. After the removal of duplicates, a data set consisting of 5949 publications was obtained for screening. Among these, 75 articles met the inclusion criteria. Qualitative content analysis was performed to identify themes related to the research questions.

**Results:** The results suggest that older adults seek 10 types of health information from 6 types of internet-based information sources and that 2 main categories of influencing factors, individual-related and source-related, impact older adults' OHIS. Moreover, the results reveal that in their OHIS, older adults confront 3 types of barriers, namely individual, social, and those related to information and communication technologies. Some intervention programs based on educational training workshops have been created to intervene and support older adults' OHIS.

**Conclusions:** Although OHIS has become increasingly common among older adults, the review reveals that older adults' OHIS behavior is not adequately investigated. The findings suggest that more studies are needed to understand older adults' OHIS behaviors and better support their medical and health decisions in OHIS. Based on the results, the review proposes multiple objectives for future studies, including (1) more investigations on the OHIS behavior of older adults above 85 years; (2) conducting more longitudinal, action research, and mixed methods studies; (3) elaboration of the mobile context and cross-platform scenario of older adults' OHIS; (4) facilitating older adults' OHIS by explicating technology affordance; and (5) promoting and measuring the performance of OHIS interventions for older adults.

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**KEYWORDS**

older adults; online health information seeking; health information behavior; aging technology; systematic scoping review

# Introduction

During the past decade, the rapid development of information and communication technologies (ICTs) has increased laypeople's access to health information sources and is constantly reshaping their health information–seeking behaviors [1]. Online health information seeking (OHIS) serves multiple purposes, such as understanding disease symptoms, assessing disease risks, finding treatment choices, managing chronic conditions, and preparing for patient-doctor communication [2]. Studies have revealed that OHIS has become one of the most common everyday life experiences across the entire lifespan [3].

In recent decades, the aging of the world population has led to significant demographic transitions that have never occurred before in human history. Societies with large aging populations face great challenges to their health care sectors with respect to an increasing prevalence of chronic conditions among older adults and a sharply rising demand for health care resources. As older adults are more likely to experience illness and chronic conditions than younger people, they have a greater need for health information [4]. With the world population aging, increasing numbers of health-conscious older adults are seeking health information to make better-informed health decisions [5]. Many hopes are placed on ICTs to empower the aging population, promote public health, and alleviate the burden of health care systems. However, there is some skepticism regarding whether older adults really benefit from current technological advancements [6]. Although some studies have found that the adoption and use of ICTs to address health concerns have remained at a relatively low rate among older adults [7], other studies suggest that older adults are increasingly engaged in internet surfing [8]. These mixed results suggest that the OHIS behavior of older adults is still insufficiently investigated.

Despite scattered empirical studies on the topic, few scoping or systematic reviews have directly addressed the OHIS behaviors of older adults and synthesized this body of knowledge. Chang and Huang [9] recently reviewed antecedents that predict general consumers' OHIS behaviors (ie, health status, self-efficacy, health literacy, availability, credibility, emotional responses, and subject norms). Although the review found that age is a significant moderator of the correlations between the antecedents and OHIS, it provided few details on older adults' health information behaviors. Hunsaker and Hargittai [8] synthesized quantitative literature on general internet use among older adults. Although their review addressed the relationship between older adults' health and internet use, OHIS was neither specified nor teased out from the general internet use behaviors. Therefore, the type of health information sought by the participating older adults and the factors that influenced older adults' OHIS reported in the literature are unclear. Waterworth and Honey [10] reviewed 8 empirical studies of OHIS among older adults and discussed facilitators of and barriers to older adults' OHIS. However, the number of studies included in this review was limited, and it can hardly provide a comprehensive understanding of OHIS among older adults.

Gaps in the existing research indicate that a systematic scoping review on older adults' OHIS is necessary because it will not only enhance our knowledge of human information behaviors and practices but will also inform better health information system designs and ensure better information services for older adults. Motivated by the existing research gaps, this systematic scoping review examines the state of research on older adults' OHIS and reveals the types and sources of health information that the older adults seek, factors that influence older adults' OHIS, barriers to older adults' OHIS, and interventions that are available. The purpose of this systematic scoping review is to provide our readers with an overview of how OHIS among older adults has been studied and present implications for future research. It aims to answer the following questions:

1. What types of health information do older adults seek and where do they seek health information on the internet?
2. What are the factors that influence older adults' OHIS?
3. What are the barriers to older adults' OHIS?
4. How can we intervene and support older adults' OHIS?

# Methods

## Literature Search

This review follows the guidelines of the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) [11]. We were also inspired by the recommended framework for conducting systematic reviews in information-related fields by Okoli [12]. The bibliographic database search strategies were developed after consulting an academic librarian at the first author's university.

First, we searched the following databases: Web of Science; Cochrane Library database; PubMed; MEDLINE; CINAHL Plus; APA PsycINFO; Library and Information Science Source; Library, Information Science and Technology Abstracts; Psychology and Behavioral Sciences Collection; Communication & Mass Media Complete; ABI/INFORM; and ACM Digital Library. These databases were chosen because they cover the academic disciplines (eg, medicine, medical informatics, communication, psychology, and information and library science) that are most likely to study older adults' OHIS behaviors. Second, the search queries contained the following categories and keywords: people (older adults, elderly, aging, senior, seniors, older people, aged 60, aged 65), behavior (find, search, seek, access, retrieve), place (internet, online, web), object (information), and attribute (health, medicine, drug, nutrition, diet, wellness, illness). Specific queries were run in the topic, title, and abstract fields, depending on the database (see Multimedia Appendix 1). The initial search was performed in November 2020. Third, we captured additional articles using Google Scholar by tracking the citations and references in the articles found in the databases and in other relevant reviews. In addition, we supplemented relevant articles by searching Google Scholar directly. All the studies identified during the database searches were imported into the reference management software Zotero, and duplicates were removed.

### Eligibility Criteria

We developed a series of inclusion and exclusion criteria to identify articles relating to older adults' OHIS behaviors. The inclusion criteria were as follows: (1) The articles should pertain to health-related contexts, including areas such as health, mental health, diet, and nutrition. (2) The article should describe OHIS behaviors (eg, general OHIS, selection and use of health information sources, and adoption and use of health information). (3) The article should focus on older adults (Note that although the search strategies indicated 2 commonly accepted lower age boundaries, 60 and 65 years, to identify older adults, it did not exclude other ways to describe the population); studies that clearly mentioned the population of older adults or contained explicit, equivalent claims were eligible. (4) The research should be empirically based. (5) The articles should have been published in a peer-reviewed journal or in conference proceedings. (6) When we identified more than 1 paper published by the same author on the same topic, we selected only the most recent one. (7) The articles should be written in English.

Our exclusion criteria were as follows: (1) The articles did not pertain to a health-related context. (2) The articles were not about OHIS behaviors; for instance, some articles focused only on general ICT use or adoption behaviors, were more concerned with technology-related rather than information-related issues or addressed only older adults' health literacy or eHealth literacy and did not investigate their OHIS. (3) The articles did not focus on older adults; we specifically excluded articles that treated age merely as a predictor or moderator in studying the OHIS of the general population, as it is evident that age influences people's OHIS behaviors. (4) The articles were not based on empirical research; this criterion helped eliminate opinion pieces, brief communications, editorial commentaries, and reviews. (5) The articles were not peer-reviewed (eg, a self-archived manuscript). (6) The articles were not written as full papers (eg, abstracts, posters, or letters). (7) The articles were not written in English.

### Screening Procedure

The procedure for screening articles was based on the eligibility criteria. The initial search used database search strategies and identified 8047 publications. After duplicates were removed, the data set consisted of 5949 publications for screening.

The screening involved 3 stages. In the first stage, all the 3 authors reviewed the titles and abstracts of a sample of 300 articles from the search results, and then discussed and refined the screening criteria. In the second stage, we selected another 300 articles randomly from the search results as a test set. The feasibility criteria were verified independently by 2 of the authors (SS and MZ). Intercoder agreement ($\kappa$=0.816) indicated satisfactory reliability. Discrepancies were discussed and resolved by involving the third author (YZ), and the eligibility criteria were further refined accordingly. In the third stage, author MZ screened the remaining articles based on the eligibility criteria using the titles and abstracts, and author SS validated the results. Discrepancies were resolved by involving author YZ. The whole screening procedure resulted in 279 articles for full-text analysis.

To read and code the full-length articles downloaded from the databases, we used the MAXQDA 2020 software, which is designed for analyzing computer-assisted qualitative and mixed methods data, texts, and multimedia data. During the full-text analysis, we excluded 211 articles by applying the eligibility criteria. The remaining 68 articles were retained, and 8 more eligible articles were identified through citation tracking with the assistance of Google Scholar. In total, 75 articles were selected for the systematic scoping review.

### Data Extraction and Analysis

We used Excel (Microsoft Corporation) to extract and record the basic information of the articles in the sample, including the author(s), title, publication year, publication name, and publication type (eg, journal vs conference). We used thematic content analysis in an iterative manner to identify the evidence regarding our research questions [13]. Several lists of codes were generated during 2 rounds of full-text coding procedures. In the first round, all the authors participated in the open and selective coding processes until a coding schema emerged and converged. In the second round, MZ coded the full texts by applying the coding schema, and SS validated all the codes. The intercoder reliability of the thematic content analysis reached 85%. Discrepancies were solved by involving YZ in the discussion.

## Results

### Basic Characteristics of the Included Articles

After screening, the final sample consisting of 75 articles was obtained, as shown in Figure 1. The articles were published between 1997 and 2020 (see Multimedia Appendix 2). Trend observations revealed that the number of publications in this subject area increased over time and that the OHIS of older adults began to receive considerable attention in the last 3 years (see Figure 2). The articles in the sample were mostly published after 2006 (n=69, 92%), which relates closely to the boom in social media. Of all the articles, 72 (96%) were published in journals, and the remaining 3 (4%) were published in conference proceedings. The articles originated from 17 countries (based on the first author's affiliations), with the top 3 being the United States (n=44, 58.67%), Australia (n=5, 6.67%), and China (n=4, 5.33%). The top 4 journals publishing these articles include the Journal of Medical Internet Research (n=8, 10.67%), Educational Gerontology (n=4, 5.33%), Journal of Health Communication (n=3, 4%), and Library & Information Science Research (n=3, 4%), indicating the multidisciplinary nature of the sample.

**Figure 1.** Screening procedure. ACM: Association for Computing Machinery; APA: American Psychological Association; CINAHL: Cumulative Index to Nursing and Allied Health Literature; ICT: information and communication technology.

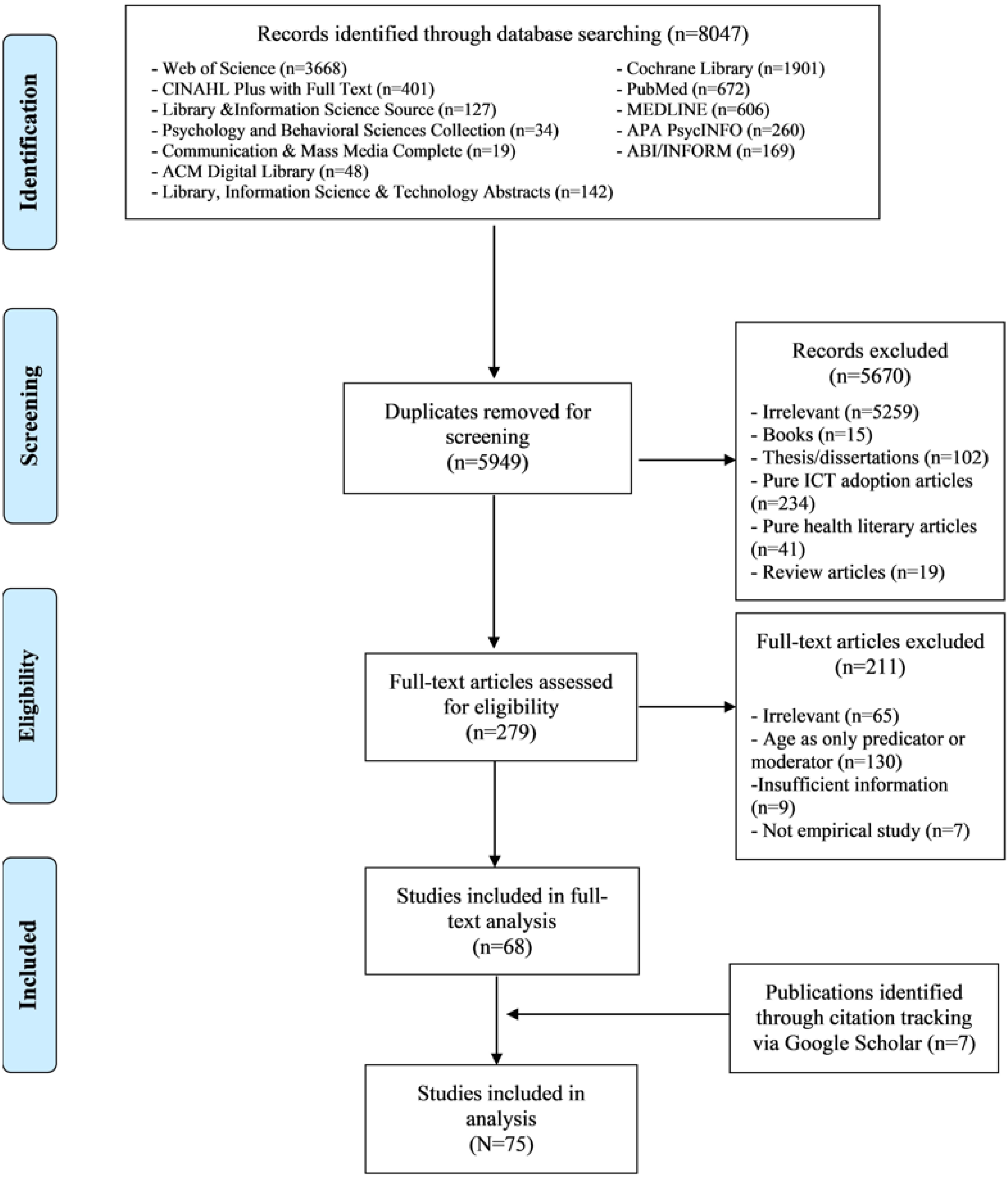
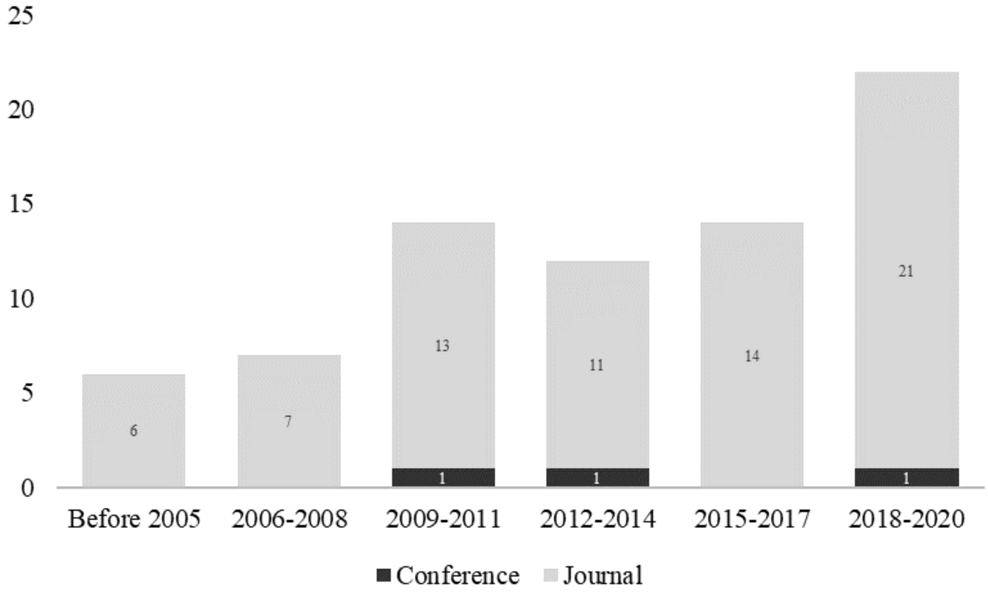


**Figure 2.** Distribution of publication years.



The systematic scoping review first investigated how the included 75 articles defined the target population of older adults. The cutoff ages for defining older adults were determined. More than half of the articles used samples of older adults aged above 60 years. Furthermore, 16 articles (21.33%) defined older adults as those aged 65 years and above, and 23 (30.67%) had cutoff ages ranging from 60 to 64 years. In addition, we noted some papers that defined the older adult group more loosely. For example, the cutoff age in 17 articles (22.67%) ranged from 50 to 54 years, and 14 articles (18.67%) used samples with minimum ages ranging from 55 to 59 years. Moreover, 5 of the articles (6.67%) did not specify precise age distributions.

The research methods varied across the 75 studies. Regarding methodological approaches, we found that 45 studies (60%) used quantitative approaches, 22 (29.33%) employed qualitative approaches, and 8 (10.67%) were based on mixed methods designs, using a combination of quantitative and qualitative methods. As for specific methods, surveys (n=28, 37.33%) and interviews or focus groups (n=25, 33.33%) were the primary methods used, followed by secondary data analysis (n=6, 8%) and experiments (n=4, 5.33%). In terms of data sources, most of the studies were based on primary data (n=65, 86.67%) and a few on secondary data (n=10, 13.33 %). Concerning the types of data, we found 59 studies (78.67%) based on cross-sectional data and 16 (21.33%) based on longitudinal data.

### Internet-Based Health Information Types and Sources

Information types and information sources are 2 frequently reported aspects of information in OHIS studies [14]. For our analysis, we adapted the typologies of health information types from Kent et al [15] and Ramsey et al [16]. The results presented in Table 1 suggest that older adults often search the internet for information on specific diseases because they want to obtain a general idea of their condition before diagnosis or treatment so that they know what to expect and can be better prepared to face stressful situations [17]. The health problems mentioned in these 75 articles are mainly cancer (n=10, 13.33%), mental health problems (n=5, 6.67%), chronic conditions (n=4, 5.33%), and physical diseases (n=4, 5.33%). Aside from this disease information, the most frequently mentioned types of information are related to medication or treatment, nutrition or exercise, medical research, disease symptoms, and health promotion. Some articles mentioned that older adults also use the internet to seek support groups or interpersonal advice, health insurance information, health news, and health policy information. Of note is that more than half of the articles (n=40, 53.33%) used the umbrella term health information, without specifying any type of health information content. Furthermore, the types of content were not mutually exclusive. For example, a single article might mention more than 1 type of information (eg, older adults seeking information for cancer-related symptoms and medication).

**Table 1.** Types of health information mentioned in the articles (N=75).

| Type of health information | Number of articles (n) |
|---|---|
| General health information | 40 |
| Specific diseases | 23 |
| Medication/treatment | 21 |
| Nutrition/exercise | 13 |
| Medical resource | 12 |
| Disease symptoms | 9 |
| Health promotion | 8 |
| Support groups/interpersonal advice | 4 |
| Health insurance | 4 |
| Health news/policies | 3 |

Most of the articles in the sample (n=58, 77.33%) used the general internet to represent all the web-based sources of health information. Further, 26 articles (34.67%) described health websites as sources of internet-based health information for older adults; among these, the owners of the websites varied, consisting of educational, commercial, government, and nonprofit entities. Moreover, general search engines such as Google were the third most frequently mentioned sources in the studies (n=17, 22.67%), suggesting that older adults often use general search engines to start OHIS [18-20]. Further, 11 articles (14.67%) mentioned older adults' use of social media (eg, Facebook, Twitter) and blogs in OHIS. Only 3 articles (4%) addressed older adults' use of patient portals, and 2 articles (2.67%) were about older adults' use of mobile internet services. Table 2 shows the health information sources mentioned in the studies.

**Table 2.** Internet-based health information sources mentioned in the studies (N=75).

| Source of internet-based health information | Number of articles (n) |
|---|---|
| General internet | 58 |
| Health websites (eg, WebMD, Mayo Clinic) | 26 |
| General search engines (eg, Google, Yahoo) | 17 |
| Social media/blogs (eg, Facebook, Twitter) | 11 |
| Patient portals | 3 |
| General mobile | 2 |

## Factors That Influence Older Adults' OHIS Behaviors

Among the 75 articles, 35 (46.67%) treated OHIS as a variable or construct. These articles quantitatively measured OHIS with various scales or proxy variables. Among them, 27 (36%) regarded OHIS as a dependent variable and explored the antecedents of older adults' OHIS. Further, 4 (5.33%) treated OHIS as an independent variable, and the remaining 4 (5.33%) treated OHIS as neither a dependent nor an independent variable but provided only descriptive analyses. Because the articles that employed quantitative approaches primarily concerned the antecedents of older adults' OHIS, we summarize the antecedents in Table 3.

We summarize the main influencing factors that appeared in the investigations. The antecedents of older adults' OHIS fall mainly into 2 categories, namely individual-related characteristics and source-related characteristics. Within the individual-related characteristics, 12 subcategories were observed, including demographics, anxiety, beliefs, attitudes, self-efficacy, personality, health status, medical history, health care service availability, source experience, health literacy and motivations. Among the source-related characteristics, credibility, usefulness, and ease of use were the 3 most frequently mentioned factors.

**Table 3.** Factors influencing older adults' online health information seeking behaviors.

| Influencing Factors | Studies |
|---|---|
| **Individual-related characteristics** | |
| **Demographics** | |
| Socioeconomic status | [18,21-35] |
| Education | [18,21-41] |
| Gender | [18,21-27,29-34,36-43] |
| Marriage | [21,22,24,29,31,34,36,37,42,43] |
| Race/ethnicity | [23,29,30,33-35,37,38,40,44] |
| Place of residence | [24,30,36,41] |
| No. of children | [36] |
| Living with children | [33,35] |
| **Anxiety** | |
| ICT[a]-related anxiety | [18,42,45] |
| Disease-related fears | [31,46] |
| Perceived susceptibility | [21] |
| **Beliefs** | |
| External control | [45] |
| Internal locus of control | [28] |
| Fatalistic belief | [31,40] |
| **Attitudes** | |
| Attitudes on patient-doctor relationship | [18] |
| Reliance on and compliance with doctor's decisions | [18] |
| Attitudes on ICT use | [39,42] |
| Attitudes on internet-based health information | [38,45] |
| Attitudes on patient-doctor relationship | [18] |
| **Self-efficacy** | |
| Self-efficacy in health | [36] |
| Self-efficacy in learning | [24,42] |
| Self-efficacy in ICT use | [42,45] |
| **Personality** | |
| Big five | [36,42] |
| General values and life goals | [41] |
| **Health status** | |
| General health conditions | [18,21,28-30,32,38,41,42] |
| Physical health | [22,33-39] |
| Mental health | [31,34,36,37] |
| Chronic conditions | [22,30-36,43,44] |
| **Medical history** | |
| Personal medical history | [21] |
| Family medical history | [21,31] |
| **Health care service availability** | |
| Health care use | [34,36] |
| Health insurance status | [34] |

| Influencing Factors | Studies |
|---|---|
| Medical financial burden | [33] |
| **Source experience** | |
| Experience in internet use | [18,38,39,45] |
| Internet use frequency | [26,34,39] |
| Experience with online health information seeking | [29] |
| Experience in ICT use | [35,42] |
| Internet knowledge | [27] |
| **Health literacy** | |
| Health literacy | [24,33,43] |
| eHealth literacy | [27,29] |
| **Motivations** | |
| Health information needs | [18] |
| Health information orientation | [27] |
| Health information overload | [46] |
| Subjective norms | [39,45] |
| **Source-related characteristics** | |
| **Credibility** | |
| Trustworthiness | [28,38] |
| Relevance | [45] |
| Output quality | [45] |
| Result demonstrability | [45] |
| **Usefulness** | |
| Perceived usefulness of internet health information | [45] |
| Perceived usefulness of internet use | [28,39] |
| Perceived importance of health information | [28] |
| **Ease of use** | |
| Perceived ease of use of internet health information | [45] |
| Perceived ease of internet use | [39] |
| Computer playfulness | [45] |
| Perceived enjoyment | [45] |

[a] ICT: information and communication technology.

## Barriers to OHIS of Older Adults

Rather than treating OHIS as a variable, 40 of the 75 articles (53.33%) treated OHIS as a process. Of these studies, 29 (38.67%) explored the barriers that older adults encounter during OHIS. The results suggest that older adults may experience many barriers preventing successful OHIS, as shown in Table 4. In the prior studies, we identified 3 main types of barriers (ie, individual, social, and ICT), 11 subtypes, and 38 specific issues.

**Table 4.** Barriers to older adults' online health information seeking behavior.

| Barrier types | Studies |
|---|---|
| **Individual barriers** | |
| **Functional decline** | |
| Vision impairment | [20,34] |
| Physical challenges (eg, back pain, knee injury) | [47,48] |
| Illness conditions | [32,35,36] |
| **Low literacy** | |
| English language literacy | [49,50] |
| Basic health knowledge | [51,52] |
| Digital literacy | [53,54] |
| Information literacy | [52,55,56] |
| Health literacy | [24,33,43] |
| eHealth literacy | [27,57] |
| **Low self-efficacy** | |
| Low efficacy and anxiety associated with computer use | [18,49,58,59] |
| Low efficacy in reading and learning | [49,60,61] |
| Low efficacy in OHIS[a] | [62,63] |
| Low efficacy in health information evaluation | [55,62] |
| **Negative attitudes** | |
| Attitude toward internet use | [39] |
| Attitude toward technology | [42] |
| Privacy concerns | [20,61,64] |
| **Health beliefs** | |
| External locus of control | [45] |
| Fatalistic beliefs | [31] |
| **Social barriers** | |
| **Social stigmas** | |
| Stigma of mental health problems | [65] |
| Stigma of sex-related health problems | [66] |
| **Lack of social support** | |
| Lack of informational support | [66,67] |
| Lack of organizational support (eg, health care services) | [17,50,68] |
| Lack of instrumental support (eg, instructions on computer use) | [57,65] |
| Lack of intergenerational support (eg, not living with children) | [49,69] |
| Lack of peer support (eg, hard to get support from friends) | [70,71] |
| **ICT[b] barriers** | |
| **Lack of IT[c] infrastructure** | |
| Lack of ICT devices | [29] |
| Low accessibility to medical records | [71] |
| **Problematic information quality** | |
| Misinformation | [64,72] |
| Conflicting health information | [73,74] |

| Barrier types | Studies |
|---|---|
| Irrelevant information | [65,73] |
| **Information overload** | |
| Overwhelming health information on the internet | [20,48,71] |
| Overwhelming extraneous information and pop-ups | [58,64,70] |
| **Unsatisfactory user experiences** | |
| Unsatisfactory interactivity and navigability | [75,76] |
| Unsuitable font sizes | [72,75] |
| Dense text and lack of visual elements | [76,77] |
| Confusing layouts | [51,72,75] |
| Insufficient ease of use | [39,45,78] |
| Frustrating user experiences | [51,56,59] |

[a] OHIS: online health information seeking.

[b] ICT: information and communication technology.

[c] IT: information technology.

Regarding individual barriers, some studies found that older adults' OHIS could be hindered by age-related functional decline, including vision impairment, poor eye-hand coordination, physical challenges (eg, back pain), and illness. Moreover, some studies reported several aspects indicating low literacy among older adults that prevented effective OHIS, including limited English language skills, lack of basic health knowledge, limited digital literacy, undeveloped information literacy, and low health or eHealth literacy. Moreover, some studies found that older adults' perceptions of low self-efficacy regarding computer use, reading, learning, and evaluation of health information reduced their willingness toward OHIS. Other findings revealed that negative attitudes toward internet use or general technology and privacy concerns about using technology decreased older adults' intentions to search information on the internet. The results also revealed that beliefs regarding the external locus of the control of health care and fatalistic beliefs reduced older adults' active OHIS.

As for social barriers, studies suggested that older adults may have some social stigma concerning OHIS when it comes to mental and sex-related health problems. Moreover, older adults often report a lack of social support in their OHIS, including informational, organizational (eg, health care services), instrumental (eg, instructions on computer use), intergenerational (eg, support from children), and peer support (eg, support from friends).

In terms of ICT use, analysis of the studies revealed that many older adults do not possess information technology devices, and they reported low accessibility to medical records. Moreover, the quality of general health information on the internet is problematic. Older adults are likely to encounter misinformation, conflicting information, and irrelevant information during their OHIS. Furthermore, they often confront information overload when reading health information due to overwhelming amounts of irrelevant information or pop-ups. Moreover, older adults' OHIS may lead to some unpleasant and frustrating user experiences, such as unsatisfactory interactivity and navigability, unsuitable font sizes, dense text lacking visual elements, confusing layouts, and complicated site designs.

## Interventions for Older Adults' OHIS

Given the abovementioned barriers, it is essential to provide older adults with additional support to facilitate their OHIS. We identified 11 studies (14.67%) among the 75 that used educational training programs to facilitate and intervene in older adults' OHIS, as shown in Table 5. Among these, 10 of the 11 studies provided offline workshops, and 1 conducted an online workshop. The offline workshops were conducted in community settings (eg, public libraries, schools, or medical centers) and included face-to-face instruction. We identified only 1 study that used an internet-based tutorial to improve older adults' ability to distinguish high-quality internet-based health forums from low-quality ones. Among the 11 articles, 9 described training programs with multiple sessions, each lasting 2 to 3 hours, and the duration of the programs varied from 1 to 4 months; the other 2 studies used 1-time training sessions.

**Table 5.** Interventions to support older adults' online health information seeking behaviors.

| Study | Main objective | Intervention format | Intervention setting | Intervention evaluation measures |
|---|---|---|---|---|
| Malone et al [20] | To improve the health literacy skills of older adults | Educational program: Participants could attend every class offered at their library or could select the classes most appropriate to their personal needs and interests.<br>No. of participants: 110 | 5 local libraries | Method: Pre- vs postsession surveys<br>Qualitative analysis with descriptive statistics:<br>Participants' confidence in their OHIS[a] increased, and the overall response to the program was positive. |
| Bertera et al [67] | To increase access to and use of 2 prominent health websites: MedlinePlus.gov and NIHSeniorHealth.gov | 2-step training:<br>(1) Training of internet navigators: 13 hours of basic training in computer skills over 13 weeks, plus a 4-hour specific training on 2 health websites and training on how to support peers during the process.<br>No. of participants: 8<br>(2) Training of older adults living in affordable housing: 2-hour session on basic computer skills and use of 2 specific health websites.<br>No. of participants: 42 | A computer learning center located in the community | Method: Pre- vs posttest surveys, face-to-face interviews<br>A significant improvement in the ability to use a computer or navigate the web was observed ($P<.001$).<br>The average navigational skills self-efficacy score for health web sites ($P<.001$) and computers ($P<.001$) improved. |
| Chu et al [68] | To assist older adults with retrieving and evaluating health information resources on the internet | Educational program: 2-hour sessions once a week over 5 weeks.<br>Partnering with Seniors for Better Health: Classes included 2 components, computer literacy and health information search strategies.<br>No. of participants: 112 | A computer lab offered at a facility of the YWCA[b] in Houston | Method: Pre- vs posttest surveys; survey conducted 6 weeks after training<br>Participants experienced reduced computer anxiety and increased confidence and sense of self-efficacy when retrieving and evaluating internet-based health information ($P<.001$). |
| Campbell [79] | To improve the ability to locate health information | Workshops: 2-hour sessions once a week over 5 weeks<br>The sessions used constructivist teaching techniques and self-directed learning.<br>No. of participants: 70 | A large suburban public library and 2 community centers for older adults | Method: Posttest interview<br>Qualitative assessment by asking participants questions such as "Did your levels of participation in your health care change since you began using the internet?" |
| Campbell and Nolfi [80] | To teach older adults to access health care information on the internet | Workshops: 2-hour sessions once a week over 5 weeks<br>No. of participants: 42<br>Follow-up survey 1 year after the workshops<br>No. of participants: 27 | A large suburban public library and 2 community centers for older adults | Method: Pre- vs. posttest surveys; survey 1 year after the training<br>Statistically significant differences were found between baseline and 5-week follow-up results for MHLC[c] in males ($P=.02$) and females ($P=.05$), as well as for Krantz HOS[d] information seeking scores ($P=.05$). |
| Hoffman-Goetz et al [81] | To improve the internet search skills of adults aged 50 years and older | Workshops: 2-hour workshops once a month, over 4 months.<br>The maximum number of participants per workshop was 15.<br>Total No. of participants: 44 | Public library with computer stations, led by a researcher, librarian, and university-based investigators | Method: Pre- vs posttest surveys<br>Participants' search difficulty decreased after the workshops ($P<.001$).<br>Participants' understanding of the internet improved after the workshops ($P<.001$). |
| Leung et al [82] | To improve basic skills for searching health information on the internet | Workshops: 3-hour training course<br>The number of participants per workshop was 30.<br>Total No. of participants: 88 | Local university and company, instructed by nursing lecturer and students | Method: Postsession telephone interviews 1 month after the workshop<br>Participants' confidence level in seeking health information was significantly associated with the level of satisfaction with the workshop ($P<.001$). |
| Campbell [83] | To improve health literacy skills among low-income, minority, and older adults | Workshops: 2-hour sessions once a week over 5 weeks<br>No. of participants: 36 | Computer labs in 2 low-income, minority residential buildings | Method: Pre- vs posttest surveys, survey 6 months after the training<br>Participants experienced reduced anxiety concerning computers and increased confidence in locating health information. |

| Study | Main objective | Intervention format | Intervention setting | Intervention evaluation measures |
|---|---|---|---|---|
| Xie and Bugg [84] | To teach older adults to access and use high-quality internet-based health information | Educational program: 2-hour sessions twice a week over 4 weeks.<br>The maximum number of participants per workshop was 7.<br>Total No. of participants: 100 | Public libraries | Method: Pre- vs posttest surveys<br>Participants showed significantly reduced computer anxiety (*P*<.001), increased interest in computers (*P*=.001), and improved efficacy (*P*<.001) from pretraining to posttraining. |
| Chu and Mastel-Smith [85] | To enhance older adults' ability to grasp and manage health-related information retrieved from the internet and act accordingly | Educational program: 2-hour sessions once a week over 5 weeks.<br>No. of participants: 12 | A parish-sponsored, older adult leisure learning center | Method: Pre- vs posttest surveys; survey conducted 6 weeks after the training<br>Participants experienced reduced anxiety, increased confidence, and a sense of self-efficacy at the end of the 5-week program and 6 weeks after program completion (*P*<.001). |
| Fink and Beck [86] | To improve the eHealth literacy of adults aged 50 years and older | Educational programs: 70 minutes to complete an educational online program and answer questions.<br>No. of participants: 64 | Internet-based setting | Method: Experimental group vs control group survey comparison<br>Compared to the control group, the experimental group participants rated higher usability and learned more information on a new website. |

[a] OHIS: online health information seeking.

[b] YWCA: Young Women's Christian Association.

[c] MHLC: multidimensional health locus of control.

[d] HOS: health opinion survey.

Further, 4 of the 11 programs were guided by established theories, models, or concepts (eg, the self-efficacy theory and the health belief model). All the studies involved some form of evaluation, including postsession surveys or interviews, pre- versus postintervention comparisons, and experimental versus control group comparisons. In addition, 5 studies evaluated the effectiveness of the intervention outcomes from a longitudinal perspective over a period ranging from 1 month to 1 year to the competence of the program. Among all the studies, 9 statistically assessed the effects of the intervention. Measures varied across the studies; these included opinions from surveys on the internet, self-efficacy in seeking health information, and anxiety regarding computer use. All the articles reported some positive outcomes of the intervention programs.

# Discussion

## Principal Findings

This systematic scoping review provides an overview of OHIS behaviors among older adults, as shown in Figure 3. Overall, the findings of this paper reveal core elements of OHIS among older adults. First, the types and sources of health information that older adults search for were clearly presented. Then, a portion of the studies explored the main factors influencing older adults' OHIS behaviors, which can be categorized as individual-related and source-related characteristics. Then, we identified the barriers to OHIS behavior in older adults from existing literature, including individual barriers, social barriers, and ICT barriers. Finally, this paper provides an in-depth analysis of the interventions mentioned in some of the included papers to support OHIS behaviors among older adults. We believe that the framework of this paper can, to some extent, help researchers to better position their research objectives in future studies so that the objectives correspond to specific dimensions for in-depth empirical investigation.

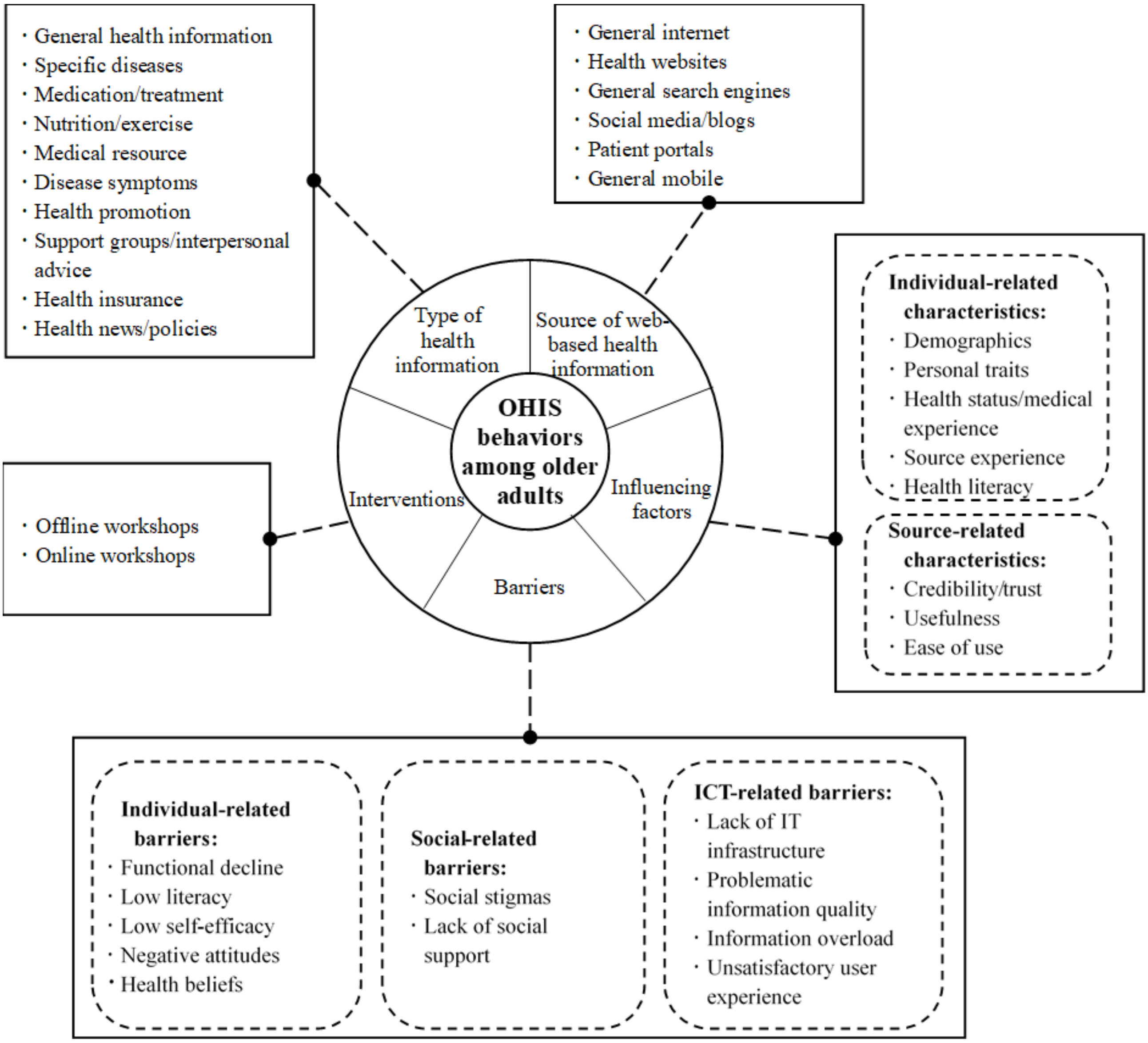
Regarding the first research question, the results show that older adults sought various types of health information on the internet, including information about specific diseases, medication and treatment, nutrition and exercise, medical resources, disease symptoms, health promotion, support groups and interpersonal advice, health insurance information, and health news or policies. The information sources included health websites, general search engines, social media and blogs, patient portals, and mobile devices. The types of health information sought differed from those that interest young people. According to a recent systematic review [87], adolescents and youths (<24 years) search the internet for daily health-related issues, physical and psychological well-being, sexual health, social problems, and culturally sensitive topics. Compared to the adolescent and youth population, older adults tend to search more for disease-related health information topics.

As for the second research question, the results point to 2 main types of factors influencing older adults' OHIS: individual-related characteristics and source-related characteristics. The individual-related characteristics include demographics, anxiety, beliefs, attitudes, self-efficacy, personality, health status, medical history, health care service availability, source experience, health literacy, and motivations. Among the source-related characteristics, credibility, usefulness, and trust were the 3 factors most frequently mentioned in the studies. We noted that the primary factors influencing older adults' OHIS differ from those influencing young adults. A systematic review of studies investigating young adults' (<24 years) OHIS [87] revealed that the most frequently mentioned influencing factors were gender, age, educational status, emotional characteristics, engagement in risky behaviors, and eHealth literacy.

The results for the third research question reveal that older adults might encounter 3 types of barriers during their OHIS, including individual barriers (eg, low literacy), social barriers (eg, social stigmas), and ICT-related barriers (eg, lack of ICT devices). These barriers may hinder effective OHIS behaviors of older adults. The results suggest some differences from the findings on young adults' OHIS. For the adolescent and youth population (<24 years), the main barriers to OHIS include online privacy and concerns about information credibility [87]. Although some studies report low health literacy among adolescents [88], older adults seem to have more difficulties in this respect than adolescents [89,90].

As for the fourth research question, the review found that many intervention programs have been created to support older adults' OHIS; they primarily use educational training workshops in offline and online formats. Most training programs contained multiple sessions, with each session lasting 2 to 3 hours; the duration of the programs varied from 1 to 4 months, and all the programs reported at least some positive effects in support of older adults' OHIS.

**Figure 3.** Overview of principal findings. ICT: information and communication technology; IT: information technology; OHIS: online health information seeking.



## Implications for Future Research

Overall, this systematic scoping review identified the need for more in-depth research on older adults' OHIS. As can be seen from the aforementioned evidence, a subset of studies have treated OHIS as a variable or construct and focused on exploring the factors influencing OHIS in older adults. Other studies treat OHIS as a process and investigate how the older adults search the internet for health information. However, given the complexity of the health conditions of older people and a projected future intensification of information overload, older adults will encounter more serious problems when searching for health information on the internet, such as how to select from among multimodal information sources, how to express health information needs, and how to evaluate health misinformation. Considering the growing population of older adults, the importance of internet-based information seeking for overall public health, and the lack of best practices, more research on this topic is needed. In this section, we propose several directions for future research based on gaps identified in the review.

### Investigations on the OHIS Behavior of Older Adults Above 85 Years

With the accelerating pace of global aging, the population of older adults is steadily growing. Instead of classifying the large population of older adults as one group, researchers are advocating for a more precise segmentation of this population, such as the youngest-old (65 to 74 years), middle-old (75 to 84 years), and oldest-old groups (above 85 years) [91]. Regarding OHIS, the age distribution of the samples in this systematic scoping review indicates that the exploration of OHIS by the oldest-old group is very limited [92]. Most articles included in this review have focused on the youngest- and middle-old groups [30], whereas there is a lack of research on the health information needs and behaviors of the oldest-old group. Future OHIS research can be appropriately skewed toward the oldest-old group to consider the physiological and psychological characteristics, the unique information needs, and explore the influences, processes, and health outcomes of the OHIS of this group more empirically within the framework of everyday information mastering [93].

### Conducting More Longitudinal, Action, and Mixed Methods Research

As for research methods, most current studies use cross-sectional data collection methods and pay little attention to longitudinal approaches. In future, more consideration can be given to the adoption of longitudinal methods, such as the experience sampling method and the ethnographic approach. In particular, for intervention studies on OHIS behaviors in older adults, educational training programs with long time spans could provide data to improve OHIS performance and the health literacy of older adults. More participatory action research at the community level would enrich the network of actors in OHIS for older adults and engage more participants, thereby promoting interdisciplinary and collaborative health information practices in this population. In addition, future studies might consider more mixed methods approaches to leverage the advantages of qualitative and quantitative approaches and triangulate primary data with secondary data. Existing mixed methods studies have been conducted mainly based on quantitative questionnaire analyses as well as qualitative focus groups, and a richer mix of methods is to be further explored for this topic in future. Finally, as prior studies have relied heavily on self-reported data, future studies could consider more behavioral data using methods such as eye-tracking and electroencephalograms.

### Elaboration on Mobile Context and Cross-platform Scenario of Older Adults' OHIS

Information types and information sources are the essential contextual factors in OHIS [94-96]. However, this review found that most studies on older adults' OHIS do not clearly explain what health-related information was involved or from where the information was gathered. In terms of information types, current studies mainly focus on searches for disease and treatment information. More studies are needed to address other types of health information that older adults might seek, such as information on environmental health and disease prevention.

Regarding information sources, studies are needed to investigate older adults' use of mobile devices for OHIS. With the development of the mobile internet and the internet of things, OHIS scenarios for older adults are changing. Mobile device–based health information access can more effectively meet the health information needs of older adults, facilitate daily health monitoring and self-tracking, and improve context-driven, health-related decision-making among older adults. For example, increasing numbers of older adults are seeking health information on their smart phones through short video apps like TikTok [97,98]. Furthermore, in addition to searching for health information on their mobile devices, increasing numbers of older adults are using mobile social apps to create content [99]. Future research could focus more on the relationship between OHIS and health-related content generation by older adults.

In addition, further exploration of complicated OHIS scenarios is needed. For example, with the popularity of wearable devices and the development of various health-related vertical search platforms, a portion of the older adult population with higher information literacy will become more proficient at searching for a full range of health information using various smart devices and immersive technologies [100], such as interacting with information through voice recognition and gesture control. Thus, explorations of cross-platform and cross-device seeking behaviors in OHIS by older adults are needed. Meanwhile, in addition to active information seeking, more types of seeking behaviors, such as passive exposure, information encountering, and surrogate health information seeking [101,102], deserve attention and further investigation. In particular, the influences and positive outcomes of searching as learning during OHIS by older adults is a topic worth exploring.

### Facilitating Older Adults' OHIS by Explicating Technology Affordance

This review revealed that current research on factors influencing OHIS in older adults focuses more on demographic issues and individual-related characteristics than on source-related factors. In recent years, increased emphasis has been placed on aging-friendly designs in human-computer interaction [103], and the user experience–oriented design of various social apps and smart devices is centered on the needs and behavioral preferences of older adults, with an interest in meeting their personalized requirements. We believe that the affordance of technology in aging-friendly design is also a highly influential factor for promoting OHIS in older adults. It would be fruitful to integrate the uses and gratifications theory with the affordance lens to better promote the positive impact of new media platforms on older adults' information-seeking behaviors [104,105]. More attention needs to be placed on the ease of use, usability, and sociability of aging-friendly information sources and information systems. In particular, in the upcoming human-centered artificial intelligence era, older people's perception of the trustworthiness of multimodal information sources and their trust in algorithm-based content recommendations will continue to change. Therefore, the age-appropriate design of OHIS needs to constantly break away from stereotypes of older people and re-establish a more adaptive mental model. The lens of the affordance theory could be applied to help situate OHIS for older adults in the context of information practices, promoting deep reflection on the interaction of actors with sociocultural environments and on the mediated nature of technology [106]. For instance, an OHIS platform should provide rich technology affordances for older adults and provide targeted support for active health information access, information encounters, and information avoidance problems in different sociocultural environments. Future research could focus more on how technology affordance can better mediate older adults' OHIS gratification by attempting to build a more detailed affordance typology [107]—such as handling, effecter, and motivational affordances—to measure older adults' gratifications for OHIS using social media.

### *Promoting and Measuring the Performance of OHIS Interventions for Older Adults*

The results show that older adults encounter many barriers in OHIS; thus, many intervention programs have been created to support their searching. However, current intervention programs still leave considerable room for improvement. First, current educational training programs are generally small-scale ones, making it difficult to reach a wide group of older adults; most programs are offline workshops, and there are few internet-based programs. Future OHIS interventions for older adults need to offer more technology-mediated web-based programs and provide richer formats than workshops and tutorials, such as distance education for older adults using gamification and immersive technology. Moreover, most current intervention programs operate in the United States; older adults living in less developed countries or areas received less attention. Future studies on OHIS in older adults must involve more trans- and cross-national, or regional and cross-cultural comparative studies to further explore the influence of sociocultural factors on older adults' OHIS behaviors. We also recommend that more information and communication technology for development (known as “ICT4D”) projects focus on upgrading OHIS and improving the same for older adults [108], thereby better promoting health literacy and health mobility for older adults in developing countries and regions.

In particular, researchers need to draw more on the design science research paradigm. Design science research is an innovative and often iterative problem-solving process that builds and evaluates artifacts [109]. In our research context, the purposeful artifacts could be search systems, training courses, workshops, tutorials, or citizen science programs. In the building phase of artifact development, most units of analysis relate to offline workshops and neglect other types of artifacts. It is also noteworthy that current intervention studies lack a theoretical lens, and only a few studies have designed interventions based on theoretical foundations. Future interventions for older adults’ OHIS need to embrace the theoretical considerations that design science research has been advocating [110]. In the evaluation phase of artifact development, current studies lack long-term assessments of intervention effects. Future studies should consider more participatory action research to iteratively test the effects of OHIS interventions on older adults and select some specific health domains—such as chronic diseases, cancer, and mental health—for attempting to verify the actual effects of OHIS interventions on information literacy, health literacy, and health outcomes of older adults. In addition, future studies could contemplate providing various forms of support based on the perspectives of older users, allowing them to participate in the project design process and thus help them overcome search barriers.

## Limitations

This systematic scoping review has several limitations. The first one is in terms of search sources. Owing to the interdisciplinary nature of OHIS research in older adults, although we tried to search multiple databases using relevant keywords and consulted academic librarians to improve our search strategy, it was nevertheless inevitable that some literature would be missed, especially relevant research in unofficially published conference proceedings. The backward and forward strategy can be further used to expand the literature search sources in future [111]. Second, in terms of the literature type, this review mainly focuses on empirical studies, whereas some opinion papers, descriptive cases, and short communications on OHIS for older adults were excluded from our literature pool, and some complementary analyses of such nonresearch articles can be conducted in future. Finally, in terms of the analytical approach for searching literature, this study did not conduct a comparative chronological analysis of the literature in different periods, which to a certain extent could not fully reveal the impact of technological and sociocultural changes on older adults’ OHIS behavior. In future, the introduction of knowledge graphs can be considered to map the themes of the literature at different stages.

## Conclusions

This review provides an overview of how older adults’ OHIS has been studied. It reveals that older adults search for various types of health information on the internet using different types of web-based sources and that their OHIS is jointly influenced by source-related and individual-related factors. Their difficulties in searching arise from individual, social, and ICT-related barriers. Some educational intervention programs that support older adults’ OHIS have been initiated in the form of web-based and offline workshops. Furthermore, the review reveals that the topic of older adults’ OHIS is understudied, although the number of studies is increasing. Nevertheless, more studies are needed to understand the problems associated with older adults’ interactions with health information and better support them in their decision-making when they are searching for medical and health information on the internet. Based on the findings of the review, the authors propose several objectives for future research.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Database search strategies.
[DOCX File , 14 KB-Multimedia Appendix 1]

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## Multimedia Appendix 2

Overview of included studies.
[DOCX File , 61 KB-Multimedia Appendix 2]

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## Abbreviations

**ICT:** information and communication technology
**OHIS:** online health information seeking

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Letter to the Editor

# Authors’ Reply: Understanding the Impact of Social Media Information and Misinformation Producers on Health Information Seeking. Comment on “Health Information Seeking Behaviors on Social Media During the COVID-19 Pandemic Among American Social Networking Site Users: Survey Study”

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**KEYWORDS**

social media; internet; communication; public health; COVID-19; usage; United States; information seeking; web-based health information; online health information; survey; mistrust; vaccination; misinformation

We appreciate Boudreau and colleagues’ [1] thoughtful consideration of our recent survey study [2], which examined American people’s use of social networking sites (SNS) to learn and stay informed about the COVID-19 pandemic. As they point out, we surveyed a representative sample of American adults (N=1003) and found that most SNS users had not fact-checked COVID-19–related information with a medical professional, and those who had opted to follow credible, scientific sources on social media were significantly more likely to undergo vaccination [2]. In reply, Boudreau and colleagues noted that our study—and others like it—has focused primarily on consumers rather than the producers and publishers of medical content on social media [1]. They propose that researchers should shift their focus “from the consumers to the producers of this information,” and, in particular, they emphasize the possibility of developing tools to assess and classify health-related posts on social media in order to help consumers distinguish medically valid guidance from potential misinformation.

We understand and affirm the underlying spirit of Boudreau et al’s [1] recommendation, and building on that, we would endorse an “all of the above” approach to the study of social media moving forward. A comprehensive research agenda—drawing on a diverse range of perspectives and methodological techniques—will be needed in order to understand and keep pace with social media’s growing and evolving role in health information seeking. This includes greater attention to issues of content and publisher credibility, as the authors suggest, though it should be noted that social media often obscures the distinction between publishers and consumers [3]. It also means that health professionals will need to gain awareness of and interpret emerging techniques in data mining, natural language processing, and network analysis. These are essential to identifying influential network nodes and understanding how health information spreads in complex social networks. For reference, we conducted a similar analysis during the 2015-2016 Zika virus outbreak [4].

However, in pursuing a comprehensive research agenda around social media, it is critical that researchers not lose sight of the consumer perspective. We agree that promoting and affirming accuracy “at the source” is critical, but so too is understanding which sources of health information consumers encounter, trust, and rely on. Unfortunately, recent studies have noted declining trust in science among many Americans, including the Institution of Medicine [5,6]. This is especially salient in the case of politicized public health emergencies, such as the COVID-19 pandemic. Add to this the politicization and fragmentation of social media platforms themselves, and we find ourselves immersed in an information environment where even quality markers are often interpreted as political statements. While health professionals are not to blame for these trends, it is nonetheless important that they be aware of and responsive to them. This means that it is critical for research and scholars to stay focused on understanding consumer-level preferences, behaviors, and outcomes while also working to improve health messaging at its source.

## Acknowledgments

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## Conflicts of Interest

None declared.

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## Abbreviations

**SNS:** social networking sites

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Original Paper

# Health Information Systems for Older Persons in Select Government Tertiary Hospitals and Health Centers in the Philippines: Cross-sectional Study

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## Abstract

**Background:** The rapid aging of the world’s population requires systems that support health facilities’ provision of integrated care at multiple levels of the health care system. The use of health information systems (HISs) at the point of care has shown positive effects on clinical processes and patient health in several settings of care.

**Objective:** We sought to describe HISs for older persons (OPs) in select government tertiary hospitals and health centers in the Philippines. Specifically, we aimed to review the existing policies and guidelines related to HISs for OPs in the country, determine the proportion of select government hospitals and health centers with existing health information specific for OPs, and describe the challenges related to HISs in select health facilities.

**Methods:** We utilized the data derived from the findings of the Focused Interventions for Frail Older Adults Research and Development Project (FITforFrail), a cross-sectional and ethics committee–approved study. A facility-based listing of services and human resources specific to geriatric patients was conducted in purposively sampled 27 tertiary government hospitals identified as geriatric centers and 16 health centers across all regions in the Philippines. We also reviewed the existing policies and guidelines related to HISs for OPs in the country.

**Results:** Based on the existing guidelines, multiple agencies were involved in the provision of services for OPs, with several records containing health information of OPs. However, there is no existing HIS specific for OPs in the country. Only 14 (52%) of the 27 hospitals and 4 (25%) of the 16 health centers conduct comprehensive geriatric assessment (CGA). All tertiary hospitals and health centers are able to maintain medical records of their patients, and almost all (26/27, 96%) hospitals and all (16/16, 100%) health centers have data on top causes of morbidity and mortality. Meanwhile, the presence of specific disease registries varied per hospitals and health centers. Challenges to HISs include the inability to update databases due to inadequately trained personnel, use of an offline facility–based HIS, an unstable internet connection, and technical issues and nonuniform reporting of categories for age group classification.

**Conclusions:** Current HISs for OPs are characterized by fragmentation, multiple sources, and inaccessibility. Barriers to achieving appropriate HISs for OPs include the inability to update HISs in hospitals and health centers and a lack of standardization by age group and disease classification. Thus, we recommend a 1-person, 1-record electronic medical record system for OPs and the disaggregation and analysis across demographic and socioeconomic parameters to inform policies and programs that address the complex needs of OPs. CGA as a required routine procedure for all OPs and its integration with the existing HISs in the country are also recommended.

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**KEYWORDS**

health information systems; the Philippines; aged; hospitals; community health centers; database; geriatric assessment; elderly; digital health; medical records; health policy

## *Introduction*

The world's population is rapidly aging, from the 12% estimate in 2015 to the 22% total global population in 2050 [1]. In the Philippines, 7.5 million, or 7.5%, of the total country population in 2015 were senior citizens (aged 60 years and above) [2]. Recognizing their complex health needs and considering that sound and reliable information is the foundation of decision making across all health systems, the World Health Organization (WHO) developed the Global Strategy and Action Plan on Aging and Health (GSAP 2016-2020), which includes adapting information systems to collect, analyze, and report data on intrinsic trends in the capacity of the aging population [3].

Comprehensive geriatric assessment (CGA) is a form of collecting, analyzing, and reporting data on the intrinsic capacity of an older person (OP). It is a multidimensional, multidisciplinary diagnostic and treatment process conducted by a team of health professionals through a systematic evaluation that identifies a variety of treatable health problems and leads to better health outcomes [4]. It is currently being utilized in different settings, government and private facilities, outpatient and inpatient care, primary care, and research. It contains multiple data points and essential health information about OPs that must be considered in providing holistic and integrated care. Based on findings of meta-analyses [5-10], CGA leads to improved detection and documentation of geriatric problems as well as improvement of health outcomes, such as improvement of functional status, prevention of hospitalization, and reduction in readmission rates or mortality, depending on the specific model and setting in which it is implemented [4]. Furthermore, recent evidence on the cost and effects of CGA showed a reduction in the need for hospital care days in a high-risk population of older adults, which could be of great importance in managing the increasing prevalence of frailty and multimorbidity [11]. This information is also crucial for program and policy development.

One of the main challenges of today's health system in the country is access to real-time information for decision making [12]. The 2018 Philippine's health system review highlighted that integrating and harmonizing all existing health-related information systems and data sources, and the inadequacy of a governance structure on information and communication technologies (ICT) are critical challenges [13]. Moreover, the privacy of heath information was also identified as a challenge in policy and practice [14].

The rapid aging of the population requires systems that support health facilities' provision of integrated care at multiple levels of the health care system. A health information system (HIS) that maintains "1 person, 1 record" facilitates efficient provision of services for OPs. Furthermore, the use of HISs at the point of care has shown positive impacts on clinical processes and patient health in multiple settings of care [15]. The adoption of health information exchange (HIE) programs has proven to lessen utilization of health care services, such as ambulatory care and hospital readmissions, and allow smooth transition from inpatient to outpatient care [16,17].

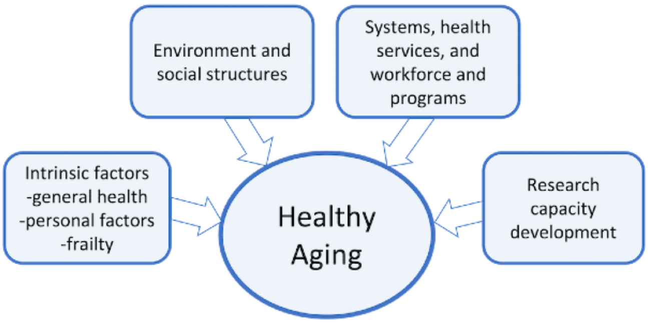
In recognition of the need for Filipino senior citizens to receive appropriate geriatric health care services, the Department of Health (DOH) provided funding for upgrading the 27 DOH-retained hospitals across regions where geriatric centers will be established [18]. CGA will be conducted in these centers and in primary care settings through Guidelines on the Adoption of Baseline Primary Health Care Guarantees for All Filipinos (DOH Administrative Order [AO] no. 2017-002) [19].

Given the rapid aging population, complex needs of OPs, importance of health information in the delivery of services, and challenges to health information in general, identifying the current status of HISs for OPs is significant in aligning the health system in the country to achieve healthy aging. This is especially true for government tertiary hospitals and health centers where OPs usually access health care.

Figure 1 shows the Focused Interventions for Frail Older Adults Research and Development Project (FITforFrail) framework adapted from the WHO Healthy Aging Framework, which defines healthy aging as the process of developing and maintaining the functional ability that enables well-being in older age [20]. The systems, health services, workforce and programs, intrinsic factors, environment and social structures, and research capacity development are essential parts of the whole-of-system approach that supports healthy aging.

Since healthy aging is the main focus of the GSAP, wherein 1 of the key strategies is aligning health systems to the needs of OPs [3], FITforFrail Study 1 concentrated on the analysis of current health systems for aging in the Philippines. The systems, health services, and workforce and programs, as well as aspects of the environment and social structures, were covered by Study 1, where mixed methods of data collection were utilized.

**Figure 1.** FITforFrail healthy aging framework. FITforFrail: Focused Interventions for Frail Older Adults Research and Development Project.



According to WHO, health systems need to be transformed and realigned to ensure access to evidence-based health interventions responsive to the needs of OPs [3]. A HIS is one of the building blocks of the health system. It provides the underpinnings for decision making where data generation, compilation, analysis and synthesis, and communication and use are its key functions [21]. With the advent of technology, eHealth or the use of ICT for health can maximize its potential toward integrated care of OPs.

The HIS is particularly under the systems, health services, and workforce and programs wherein review of policies related to OPs and listing of services and workforce specific for geriatric patients are conducted.

The data on HISs in general and even among specific population groups in the Philippines are limited. Thus, this paper sought to describe the existing HISs specific for OPs, especially among government tertiary hospitals and health centers across regions in the country. Specifically, it aimed to review the existing policies and guidelines related to HISs for OPs in the Philippines; determine the proportion of select government hospitals and health centers with existing health information specific for OPs, such as CGA, medical records, analysis of top causes of morbidity and mortality, and registry of specific diseases, and electronic medical records (EMRs); and describe the challenges related to HISs in select tertiary hospitals and health centers.

# Methods

## FITForFrail

FITforFrail is a research and development project funded by the DOH through the Philippine Council for Health Research and Development (PCHRD) under the Advancing Health through Evidence-Assisted Decisions with Health Policy Systems Research (AHEAD-HPSR) program. Using the WHO Healthy Aging Framework, the project aims to identify the current health system for the aging population and describe the health status of OPs in select communities. FITforFrail Study 1 analyzed the health system, and FITforFrail Study 2 evaluated the health status of OPs, with a focus on frailty.

## Study Design

A cross-sectional research study design using mixed methods of data collection was utilized. Mixed methods and community participation were hallmarks of this research. For this specific paper, a review of policies and papers related to OPs and a facility-based listing of health services and workforce specific for OPs were conducted to collect the data on HISs.

## Sampling

Purposive sampling was used in selecting study sites. The inclusion criteria for the hospitals were (1) Ministry of Health–/DOH-retained government tertiary hospitals and (2) geriatric centers identified through the Philippine Health Development Plan 2017-2022. For health centers, they had to be within the catchment area of the identified hospital in the region. All the 27 hospitals identified as geriatric centers and 17 health centers within the catchment area across all regions were included in the study.

## Study Setting and Participants

The researchers conducted a listing of health services and workforce specific for OPs in the 27 hospitals identified as geriatric centers and the 17 health centers within their catchment area. An advance copy of the listing tool along with the letter addressed to the heads of the institutions was sent prior to actual data collection. The heads of the institutions assigned and identified focal or point persons to be interviewed to provide their facility data. These identified point persons served as key informants. They were mostly in charge of the geriatric program in their institutions. The research team scheduled separate meetings with the informants to explain the study and obtain consent prior to actual data collection. Policies and the existing literature on HISs were also reviewed.

## Ethics Clearance

FITforFrail obtained a total of 6 ethics approvals from the University of the Philippines Manila Research Ethics Board (UPMREB), the Single Joint Research Ethics Board (SJREB), and 4 institutional review boards of hospitals (Multimedia Appendix 1). The UPMREB oversight applies to UP Manila researchers and non-UP Manila researchers doing research in non-UP Manila sites with no local ethics review committee (as mandated by the Philippine Health Research Ethics Board [PHREB]), while the SJREB is a joint review mechanism among the PHREB–duly accredited research ethics committees (RECs) of DOH hospitals. The rest of the reviews and approvals were from the DOH hospitals that required separate institutional review.

### Data Collection

#### Desk Review

Policies were collected through consultation, online search or bibliographic databases visits, and manual search or onsite library visits. For bibliographic databases and online search, the following search terms were used covering the period of 1980 to July 2020: "aging," "senior citizens," "older persons," "Philippines," "Republic Act," "memorandum," "circulars," "policy," "administrative order," "health information system," "information systems," and "programs."

#### Listing of Services and Workforce

A facility-based listing of services and workforce specific for OPs was conducted. The DOH hospitals identified as geriatric centers were selected as study sites. For primary care units, health centers within the catchment area of the identified regional hospitals were purposely selected across 17 regions in the country. A total of 27 DOH-retained hospitals identified as geriatric centers and 17 health centers were visited for the facility-based listing of services and workforce, with particular attention to HISs for OPs.

A checklist or facility-based listing form was used (Multimedia Appendix 2). The listing form was developed by trained research assistants through policy review and series of consultation meetings with the project and study leaders. The sections of the listing form are as follows: facility demographics, human resources, competencies and training, health services, health financing, information system, and health policies and programs. The specific section on HISs contains questions on patient medical records, disease registries, online databases, and reasons for not having such registries and databases. Moreover, the question on CGA was included under the Health Services section.

### Data Management and Analysis

The collected data from the listing were entered in a password-protected EpiInfo data entry program. Data verification and cleaning were conducted using Microsoft Excel through the help of a statistical assistant and under the supervision of a statistician. Cleaned data sets were endorsed to the statistician for analysis. Descriptive statistics (means, SDs, and frequency distribution) were calculated for all continuous and categorical variables measured using Stata (StataCorp).

## Results

### Policies and Guidelines on Health Information Systems for Older Persons

Republic Act No. 11223 or the Universal Health Care (UHC) Act of 2019 state that all health facilities are required to maintain a HIS consistent with DOH standards, which will be electronically uploaded on a regular basis through interoperable systems [22]. The DOH and PhilHealth will fund and manage the development, quality assurance, and maintenance of the information systems. Under the implementation of the UHC Act is the establishment of a HIS in every health facility, which requires multiple key players for the provision of population- and individual-based health services, including the services for OPs. The DOH, PhilHealth, and the Department of Interior and Local Government (DILG) will integrate all local health systems into a province-wide health system. The private sector will also be encouraged to participate in the integrated local health system through a contractual arrangement.

Prior to the UHC Act, the DOH issued standard policies, procedures, and guidelines governing all ICT-related work in 2005 [13]. It also established the Knowledge Management and Information Technology Service (KMITS); developed the Department of Health Enterprise Architecture (DOH EA) for HISs, which is national in scope; implemented information systems using client-server technology; and established an eHealth framework [23]. A part of the eHealth framework is the Philippine Health Information Exchange (PHIE) through the Joint DOH-DOST-PhilHealth AO no. 2016-001. It aims to achieve integrated health care services and delivery that are also seamlessly responsive, efficient, cost effective, and in real time [24].

The Joint AO no. 2016-003 of DOH and PhilHealth gave way to the adoption of PHIE Lite, which aims to institutionalize the implementation of a harmonized approach and system in developing applications and information systems [25]. OPs were included in the initial priorities of PHIE Lite interoperability as they are included as expanded primary benefit care (ePCB)-entitled sponsored members.

The National Health Data Dictionary (NHDD) and the Unified Health Management Information System (UHMIS), and interoperability standards were also developed and implemented through DOH AO nos. 2013-025 and 2015-037 [26,27]. Unfortunately, the latest version of the NHDD (version 2.0) [28] do not include standard age group classification (young, middle, and oldest old) and relevant diseases, such as geriatric syndromes (ie, dementia, frailty, malnutrition, polypharmacy, and incontinence).

A program dedicated to OPs, the National Health and Wellness Program for Senior Citizens (NHWPSC) through the DOH AO no. 2015-009, was established. One of its objectives is to establish and maintain a database management system and conduct research in the development of evidence-based policies for senior citizens [29]. To date, there is no database management system specific for OPs.

To summarize, multiple agencies are involved in the provision of services for OPs, with several records containing health information about OPs. Moreover, there is no system to integrate or enable interoperability of data systems of OPs at primary, secondary, or tertiary levels of care. Hence, a provider for an OP would be unable to access medical, social, or insurance information in a single record.

### Health Information Specific for Older Persons

Table 1 summarizes the health information for OPs in visited government tertiary hospitals and health centers across all regions in the country.

**Table 1.** Health information for OPs[a] in government tertiary hospitals and health centers, 2019-2020.

| Health information | Hospitals (N=27), n (%) | Health centers (N=16), n (%) |
|---|---|---|
| Facilities | 27 (100) | 16 (100) |
| CGA[b] | 14 (52) | 4 (25) |
| Medical records of patients | 27 (100) | 16 (100) |
| Data on top causes of mortality and morbidity | 26 (96) | 16 (100) |
| Registry of diseases of OPs | 20 (74) | 13 (81) |
| **Diseases in the registry** | | |
| Hypertension | 18 (67) | 13 (81) |
| Diabetes mellitus | 18 (67) | 13 (81) |
| CVD[c] | 18 (67) | 10 (62) |
| Stroke or cerebrovascular attack | 18 (67) | 10 (62) |
| Heart attack/myocardial infarction | 17 (63) | 10 (62) |
| Respiratory tract diseases | 20 (74) | 13 (81) |
| Cancer | 20 (74) | 5 (31) |
| Mental disorders | 7 (26) | 3 (19) |
| Disability | 9 (33) | 7 (44) |
| **Online web-based database** | | |
| Patient records | 23 (85) | 10 (62) |
| iHoMIS[d] | 15 (56) | 0 |
| UDRS[e] | 10 (37) | 1 (6) |
| iClinicSys[f] | 0 | 10 (62) |
| Others (Bizbox, MedSys, Medix, CHITS[g]) | 8 (30)[h] | 1 (6)[i] |
| Not updated regularly | 4 (15) | 6 (37) |
| **Reasons[j]** | | |
| No trained/not enough personnel | 4 (15) | 2 (12) |
| Unstable internet | 0 | 2 (12) |
| Use of an offline system | 2 (7) | 1 (6) |
| Technical issues | 0 | 2 (12) |

[a] OP: older person.
[b] CGA: comprehensive geriatric assessment.
[c] CVD: cardiovascular disease.
[d] iHOMIS: Integrated Hospital Operations and Management Information System.
[e] UDRS: Unified Disease Registry System.
[f] iClinicSys: Integrated Clinic Information System.
[g] CHITS: Community Health Information Tracking System.
[h] Values for Bizbox, MedSys, and Medix.
[i] Value for CHITS.
[j] Multiple responses possible.

## Comprehensive Geriatric Assessment

A total of 27 DOH tertiary hospitals and 17 health centers were visited. Of the 17 health centers, only 16 (94%) have facility-based listing data. There was no information obtained from a health center in Region IV-B, a cluster of islands in southern Luzon, Philippines [30]. The specific question on CGA was in the Health Service Delivery section of the checklist.

The study revealed that only 14 (52%) of the 27 hospitals identified as geriatric centers conduct CGA for their geriatric patients (Table 1). Of these, only 5 (18%) hospitals use CGA to screen for all their geriatric patients; the rest have specific conditions or guidelines regarding to whom they can administer CGA. Most hospitals would only utilize CGA in specific age brackets; other hospitals would only do so through referrals, when the patient is admitted, or when they think the patient is frail or at risk. Commonly reported reasons for not administering CGA to all OPs in hospitals include the lack of manpower, inadequate trained personnel, and the length of the assessment. However, of the 16 health centers, only 4 (25%) conduct CGA for their geriatric patients.

### Medical Records and Registries for OPs in Hospitals and Health Centers

All 27 hospitals and 16 health centers maintain medical records of their patients. The data on the top causes of mortality are available in almost all (26/27, 96%) visited hospitals and all (16/16, 100%) health centers. When asked whether the facilities have a registry of diseases of OPs, there are more health centers than hospitals that have these (13/16 [81%] vs 20/27 [74%]), as summarized in Table 1.

In terms of specific registries (Table 1), hospitals have better registries on cardiovascular disease (CVD; 18/27 [67%] vs 10/16 [62%]), stroke (18/27 [67%] vs 10/16 [62%]), heart attack (17/27 [63%] vs 10/16 [62%]), cancer (20/27 [74%] vs 5/16 [31%]), and mental disorders (7/27 [26%] vs 3/16 [19%]). However, health centers have better registries on hypertension (13/16 [81%] vs 18/27 [67%]), diabetes (13/16 [81%] vs 18/27 [67%]), respiratory tract diseases (13/16 [81%] vs 20/27 [74%]), and disability (7/16 [44%] vs 9/27 [33%]). Whether these registries are or are not CGA based is not known, as this was not covered by the study and was considered 1 of its limitations.

There are more hospitals that utilize online web-based database of patients records than health centers (23/27 [85%] vs 10/16 [62%]). More than half (15/27, 56%) of the hospitals utilize the Integrated Hospital Operations and Management Information (iHOMIS), and more than a quarter (10/27, 37%) utilize the Unified Disease Registry System (UDRS). iHOMIS is a Windows-based computerized hospital information system for government hospitals, while the UDRS is a unified registry that contains an injury surveillance system, an integrated noncommunicable diseases registry, a violence against children and women registry, and a persons with disabilities registry [31].

Other third-party providers, such as BizBox, MedSys, and Medix, were also reported. Bizbox is a PhilHealth-accredited health information technology provider that passed the eClaims certification on the case rate system [32]. The MedSys EMR is a web-based application developed for physicians and staff within a health care institution to ensure accuracy, privacy, and service efficiency [33]. Lastly, Medix is a cloud-based clinic management software that helps practitioners improve their clinic operations [34]. Some of these are also being utilized by government hospitals despite the availability of DOH-maintained iHOMIS.

For the health centers, more than half (10/16, 62%) utilize an online web-based database for patient records through the Integrated Clinic Information System (iClinicSys), while only 1 (6%) uses the Community Health Information Tracking System (CHITS), as shown in Table 1. iClinicSys is a system owned by the DOH that efficiently and effectively monitors patient cases in rural health units (RHUs) [31], while CHITS is an EMR system for government primary care health centers in the Philippines [35].

### Challenges Related to HISs in Select Tertiary Hospitals and Health Centers

In terms of management of HISs, the most common reasons for not regularly updating the web-based database are a lack of or inadequate trained personnel to maintain and manage the information systems (in 4/27 [15%] of hospitals and 2/16 [12%] of health centers), an unstable internet connection (2/16 [12%] of health centers), the use of an offline system (1/16 [6%] of health centers), and technical issues (2/16 [12%] of health centers), as shown in Table 1.

## Discussion

### Principal Findings

This study described HISs specific for OPs, especially among government tertiary hospitals and health centers across regions in the Philippines. It reviewed the existing policies and guidelines and determined the proportion of select government hospitals and health centers with existing health information specific for OPs, such as CGA, medical records, top causes of morbidity and mortality, registries of specific diseases, and EMRs. Furthermore, challenges related to HISs in select health facilities were described.

There are various HISs in the country. For primary care benefit providers, the following are the DOH-accredited EMR systems: iClinicSys, CHITS, Segworks Tecknologies (Seg-RHIS), the eHatid local government unit (LGU), Secure Health Information Network and Exchange (SHINE OS+), and Wireless Access for Health (WAH) [36]. Furthermore, the DOH maintains 10 information systems and databases. These include the Electronic Drug Price Monitoring System (EDPMS), iClinicSys, the Integrated Chronic Non-Communicable Disease Registry System (ICNCDRS), the Integrated Drug Test Operations Management Information System (IDTOMIS), iHOMIS, the Integrated TB Information System (ITIS), the Online National Electronic Injury Surveillance System (ONEISS), the Philippine Registry for Persons with Disabilities (PRPWD), the National Rabies Information System (NaRIS), and the Violence Against Women and Children Registry System (VAWCRS) [31]. In addition, there are other private or third-party providers of HISs in the country, such as BizBox, MedSys, and Medix.

Among the existing HISs maintained by the DOH, there is no specific one for OPs. The data on OPs can be distributed in almost all existing HISs (ie, PRPWD; ICNCDRS; online reporting of cancer, diabetes, chronic obstructive pulmonary disease, stroke, blindness, mental, coronary artery disease, and renal data from health facilities; ITIS; ONEISS; and other HISs). All these systems require log-in credentials; thus, only authorized personnel have access.

Based on the policies and literature review, there are policies and guidelines that support the establishment and integration of HISs for OPs. However, there is no current database management system specific for OPs to date, and the data from the existing HISs maintained by the DOH are not readily accessible. Geriatric syndromes, including frailty, malnutrition, dementia, incontinence, and polypharmacy, are not in the NHDD.

There are multiple information systems and agencies involved in the provision of services and sources of health information about OPs, which leads to fragmented health information about OPs in the country. Given the limited accessibility and fragmentation, coming up with evidence for program and policy development that will address the needs of OPs is a major challenge.

More than half of the hospitals identified as geriatric centers and only a quarter of the health centers conduct CGA for their geriatric patients. According to the DOH AO no. 2017-001, “All older patients with a positive risk screen should have a Comprehensive Interdisciplinary Geriatric Assessment for individual special complex needs” and the “Comprehensive Geriatric Assessment should be updated prior to discharge in chronic care facilities and made available to accepting facilities or carers and vice versa” [37].

This study found a limitation in the conduct of CGA, especially in the primary care setting. Not all visited DOH hospitals, although being identified as geriatric centers, conduct CGA. The commonly reported reasons for not administering CGA to all OPs in hospitals include the lack of personnel, inadequate trained personnel, and the length of the assessment.

All visited hospitals and health centers maintain medical records of their patients. The data on the top causes of mortality are available in all health centers and almost all visited hospitals. There are more hospitals that utilize online web-based databases of patients records than health centers. More than half of the hospitals utilize iHOMIS, and more than a quarter utilize the UDRS. In addition, there are third-party providers, such as BizBox, MedSys, and Medix.

There are more health centers than hospitals that have a specific registry of diseases. Hospitals have better registries on CVD, stroke, heart attack, cancer, and mental disorders. However, health centers have better registries on hypertension, diabetes, respiratory tract diseases, and disability. More than half of the health centers visited utilize an online web-based database for patient records through iClinicSys, while only 1 uses another information system, specifically CHITS.

Most of the information systems utilized by the hospitals and health centers are for all patients in general wherein data on OPs can only be extracted. However, the extraction of data on OPs is complicated due to the nonuniform age group categories. In some facilities, the data on patients aged 60-64 years could not be properly retrieved, as these are incorporated into the 45-64-year age group. Age group classification is not standardized across facilities. Having multiple platforms for managing health information deteriorates interoperability between different health facilities, which, in effect, reduces the ease of service delivery.

### Limitations

The study was able to cover facilities representing each region across the country; however, these are limited to the selected hospitals identified as geriatric centers and the health centers within their catchment area. Private health facilities were not covered by the study. Thus, the status of HISs in this study was limited only to public health facilities. Moreover, the status of the Philippines’ HISs in general was not within the scope the study and thus warrants further investigation.

### Comparison With Prior Work

In 1990, the BLACKBOX was the management information system for public health programs, vital statistics, mortality, and notifiable diseases. It handled and retrieved all data that were being routinely collected by public health workers all over the Philippines. It was developed toward a need-responsive and cost-effective health and management information system (HAMIS) [38]. Decades later, with the advancement of eHealth, there are various HISs in the country. For primary care benefit providers, there are 6 DOH-accredited EMR systems [36]. Furthermore, the DOH maintains 10 information systems and databases, which are being implemented in various health care settings through the UHMIS [31]. In addition, there are other private or third-party providers of HISs in the country. These are harmonized through the interoperability standards and guidelines issued by the DOH. However, based on the results of this study, there is no current database management and HIS specific for OPs to date.

The National Objectives for Health 2005-2010 and 2011-2016 prioritized the use of ICT in various reforms areas, critical health programs, and specific areas in health administration [39,40]. The Philippine eHealth Strategic Framework and Plan 2014-2020 was also developed [23]. The current and overall status of the PHIE warrants further investigation.

In terms of management of HISs, the most common reasons for not regularly updating the web-based database are a lack of or inadequate trained personnel to maintain and manage the information system, an unstable internet connection, the use of an offline system, and technical issues. These barriers are also consistent with the findings of other studies, such as a lack of standards, the use of different information systems, infrastructure issues for electricity and connectivity [35], a lack of human expertise [41], the need for training and support for human resources [41,42], and technical complexity [43,44]. In Malaysia, several issues have influenced overall HIS implementation in public hospitals, such as limited financial sources, maintenance by different departments, HIS implementation orders by the Malaysian Ministry of Health, addition of new systems, confidentiality issues, low acceptance levels, low satisfaction levels, different vendors, infrastructure issues, system breakdown, duplication of data, and different systems [45].

In developing countries, the establishment of well-coordinated information collection systems at various levels of the health care system using appropriate staff could contribute greatly to improvements in health care delivery [46]. Furthermore, ICT need to be seen as part of wider approaches involving technological, social, and institutional innovation; health workers need to be educated more broadly on the use of HISs for action [46,47]; health institutions need to adapt in many ways toward local accountability and patient and health worker empowerment; and software development for HISs needs to integrate computerized systems with work practices to make work more effective [47]. In decentralized and democratic governments similar to the Philippines, HISs can play a crucial role in supporting and sustaining processes by serving as a repository for generated and analyzed information at the local level so that primary health care can address the dynamic and unpredictable elements of health care planning in developing countries [48].

Routine HIS interventions in the European region were identified to be promising; however, different areas of improvement, such as technical, organizational, and behavioral elements, were identified [49]. In Japan, the areas of improvement in health care information technology include the necessity for leadership and IT knowledge in medical communities, provider incentives, legislation regarding accountability, security, privacy and confidentiality, inclusion of stakeholders in solution development, and creation of sustainable business models [50].

In terms of sustainability of HISs, many challenges are faced, and these could be addressed through the systems' technical design, stakeholder coordination, and the building of organizational capacity to maintain and enhance such systems [51]. Furthermore, effective collaboration between major actors (donors, developers, and the Ministry of Health) is fundamental to sustain HISs [52].

## Conclusion and Recommendations

The review of existing policies and guidelines provided a background on the status of HISs for OPs in the Philippines. The facility-based listing revealed the proportion of select facilities that conduct CGA and the status and challenges related to the HIS in select tertiary hospitals and health centers in the country.

Current HISs for OPs are characterized by fragmentation, multiple sources of health information, and inaccessibility. Barriers to achieving appropriate HISs for OPs include inability to update HISs in hospitals and health centers and a lack of age group and disease standardization.

A comprehensive assessment and care plan shared with all providers is one of the important elements of integrated care for OPs. In line with the universal health coverage and Sustainable Development Goal of "*Ensuring healthy lives and promote wellbeing for all at all ages*," an emerging landscape of innovation and development on integrated care of OPs is essential in order to address the multidimensional needs of the aging population.

A 1-person, 1-record EMR system for OPs is recommended in order to address their complex needs, as well as extract data to inform policies and programs. Furthermore, the data on OPs should be disaggregated and analyzed across geographic and social parameters in order to identify gaps in programs and provision of services.

Specifically, we recommend the following:

- Integration of data of OPs in the existing HISs in the country, wherein data can be derived and disaggregated across all health care facilities
  - Standardizing the definition of age groups (young, middle, and oldest old) and geriatric syndromes (ie, frailty, malnutrition, falls, dementia, delirium, incontinence, polypharmacy, deconditioning) and inclusion in the latest version of the NHDD (KMITS-DOH)
  - Funding and creating a dashboard for OPs (DOH, PhilHealth)
  - Conducting a CGA of all OPs as a clinical record to be shared across health care providers in all health settings, which will be integrated in the existing HIS
- Alignment of the integration of HISs for OPs with the existing mandates of the NHWPSC and health care provider networks (NHWPSC-DOH, centers for health development [CHDs], LGUs)
- Hiring and capacity building of personnel for management and maintenance of facility-based HISs (Health Human Resource Development Bureau [HHRDB]-DOH, regional hospitals, LGUs)
- Research, evaluation, and monitoring of the integrated HIS (National Commission of Senior Citizens [NCSC], National Privacy Commission [NPC], Health Policy Development and Planning Bureau [HPDPB]-DOH, academia, research institutions)

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## Authors' Contributions

APG performed protocol development, data collection, analysis, manuscript writing, and review and approval of the paper; SFDLV performed protocol development, data collection, manuscript writing, and review and approval of the paper; and SPM performed data collection, analysis, manuscript writing, and review and approval of the paper.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Ethics approval compilation.
[PDF File (Adobe PDF File), 24299 KB-Multimedia Appendix 1]

## Multimedia Appendix 2

Checklist for hospitals and health centers.
[PDF File (Adobe PDF File), 1053 KB-Multimedia Appendix 2]

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## Abbreviations

**AO:** Administrative Order
**CHITS:** Community Health Information Tracking System.
**CGA:** comprehensive geriatric assessment
**DILG:** Department of Interior and Local Government
**DOH:** Department of Health
**DOH EA:** Department of Health Enterprise Architecture
**EDPMS:** Electronic Drug Price Monitoring System
**EMR:** electronic medical record
**ePCB:** expanded primary benefit care
**FITforFrail:** Focused Interventions for Frail Older Adults Research and Development Project
**GSAP:** Global Strategy and Action Plan on Aging and Health
**HAMIS:** health and management information system
**HIE:** health information exchange
**HIS:** health information system
**iClinicSys:** Integrated Clinic Information System.
**ICNCDRS:** Integrated Chronic Non-Communicable Disease Registry System
**ICT:** information and communication technologies

**IDTOMIS:** Integrated Drug Test Operations Management Information System
**iHOMIS:** Integrated Hospital Operations and Management Information System.
**ITIS:** Integrated TB Information System
**KMITS:** Knowledge Management and Information Technology Service
**LGU:** local government unit
**NaRIS:** National Rabies Information System
**NHDD:** National Health Data Dictionary
**NHWPSC:** National Health and Wellness Program for Senior Citizens
**ONEISS:** Online National Electronic Injury Surveillance System
**OP:** older person
**PCHRD:** Philippine Council for Health Research and Development
**PHIE:** Philippine Health Information Exchange
**PHREB:** Philippine Health Research Ethics Board
**PRPWD:** Philippine Registry for Persons with Disabilities
**REC:** research ethics committee
**RHU:** rural health unit
**Seg-RHIS:** Segworks Tecknologies
**SHINE OS+:** Secure Health Information Network and Exchange
**SJREB:** Single Joint Research Ethics Board
**UDRS:** Unified Disease Registry System.
**UHC:** universal health care
**UHMIS:** Unified Health Management Information System
**UPMREB:** University of the Philippines Manila Research Ethics Board
**VAWCRS:** Violence Against Women and Children Registry System
**WAH:** Wireless Access for Health
**WHO:** World Health Organization

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Review

# The Effect of Digital Health Interventions on Parents' Mental Health Literacy and Help Seeking for Their Child's Mental Health Problem: Systematic Review

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## *Abstract*

**Background:** Many children with mental health problems do not receive professional help. Despite the frequent use of digital health interventions (DHIs) such as websites or web-based service navigation platforms, their effects on parents' mental health literacy, help seeking, or uptake of professional services are unclear.

**Objective:** This study aims to provide a systematic review and narrative synthesis to describe whether DHIs improve the aforementioned parental outcomes.

**Methods:** Databases, including CINAHL, Embase, MEDLINE OVID, PsycINFO, and PubMed (2000-2020), were accessed. Studies were included if they evaluated quantitative changes in mental health literacy, help seeking, or the uptake of services by parents of children with mental health problems. Theoretical frameworks, sample sizes, participant demographics, recruitment, interventions, DHI use, results, and health economic measures were used for data extraction.

**Results:** Of the 11,379 search results, 5 (0.04%) studies met the inclusion criteria. One randomized controlled trial found the reduced uptake of services after using a DHI coupled with a telephone coach for a child's behavioral problem. Of 3 studies, 2 (66.7%) found statistically significant improvement in mental health literacy for attention-deficit/hyperactivity disorder but had no control group. One study found nonsignificant improvement in mental health literacy and help-seeking attitudes toward anxiety and depression compared with those in active controls. All studies were rated as having a high or serious risk of bias. Search results were affected because of a single reviewer screening articles, overall low-quality studies, and a lack of consistent nomenclature.

**Conclusions:** There is no high-quality evidence that DHIs can improve parents' mental health literacy, help seeking, or uptake of services. More research is needed to evaluate DHIs by using rigorous study designs and consistent measures.

**Trial Registration:** PROSPERO International Prospective Register of Systematic Reviews CRD42020130074; https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020130074

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**KEYWORDS**

child; mental health; systematic review; caregiver; health literacy; digital health

# Introduction

## Background

Mental health problems are common among children [1,2]. They include internalizing problems, such as anxiety and lowered mood, and externalizing problems, such as hyperactivity, oppositional defiance, and aggression. Around half of these problems can progress to mental health disorders that are associated with adverse outcomes, including early school dropout, criminal justice system involvement, lower life satisfaction, poorer relationships, and lower earning potential [3-9]. Fortunately, there is a range of evidence-based treatments that have been shown to improve mental health problems in children, including the use of websites or web-based programs or other digital health interventions (DHIs) [10-13]. A DHI can be defined as the digital delivery of health information, such as through websites or apps, for health-related purposes [14]. Many of these treatments, including those delivered by DHIs and face-to-face interventions, focus on improving parenting—a key modifiable risk factor for these problems [15]. Despite treatments being available, many children with mental health problems do not receive professional help [2,16-18].

There are several recurrent barriers that prevent children receiving professional help. These barriers can be viewed along the help-seeking process, as parents need to recognize their child's problem and acknowledge their need for additional support, be aware of treatment options, overcome stigma in accessing treatment, and ultimately access available services or treatments [2,19,20]. A lack of problem recognition and awareness of available treatments reflect inadequate mental health literacy, which has been defined as the "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" [21]. Mental health literacy is important because it is linked to actions and mental health outcomes [22]. For children, especially young children, parents play a large role in recognizing the child's problem and facilitating help seeking (Figure 1).

Ideally, we should be able to improve parents' knowledge of mental health problems in children and where to find available and accessible services to help their children. This could be done by improving their mental health literacy, a known modifiable factor of help seeking [23]. However, previous research on interventions designed to improve mental health literacy and help seeking has been hampered by a lack of consistent measures of mental health literacy and a lack of focus on parents [22,24,25]. For parents, a US study with 165 children with mood disorders and other mental health comorbidities showed that face-to-face mental health literacy interventions can improve the quality of services accessed by families compared with waitlist control. The quality of services was measured by consensus among a group of blinded expert clinician researchers [26]. However, this intervention was intensive (8 group sessions lasting 90 minutes each) and may have been affected by attrition bias, as only 74% of participants completed the 18-month follow-up. In addition, several families dropped out of the waitlist control group after their child's symptoms improved, underscoring the need for controlled trials to account for the natural history of some mental health problems improving over time.

Digital delivery of this educational material to parents, such as through a DHI, may prove to be an effective, accessible, scalable, and desirable way to improve parents' mental health literacy and help seeking. Most parents search the web for health information and seek out the lived experience of other parents through forums, such as those on Facebook [27,28]. As parents seek out this information on the web, money and resources are devoted to building websites, apps, and platforms to help parents better understand their child's mental health and where to receive help. Child mental health websites, such as childmind.org, can have enormous reach with a recent mental health campaign reaching 275 million people [29].

The World Health Organization states that DHIs have many perceived benefits, including enhanced reach, accessibility, scalability, desirability, reduced stigma, and perceived cost-effectiveness [14]. DHIs' perception of cost-effectiveness comes from the potential for near-infinite scalability at low cost and targeted early intervention [14,30,31]. However, data on cost-effectiveness are rarely collected, despite recommendations to measure the economic impact as part of any DHI evaluation [32,33].

DHIs have been shown to improve mental health literacy in adults, based on the findings of 2 systematic reviews [34,35]. However, these reviews, which included a combined total of 28 studies, only included 1 study with parents.

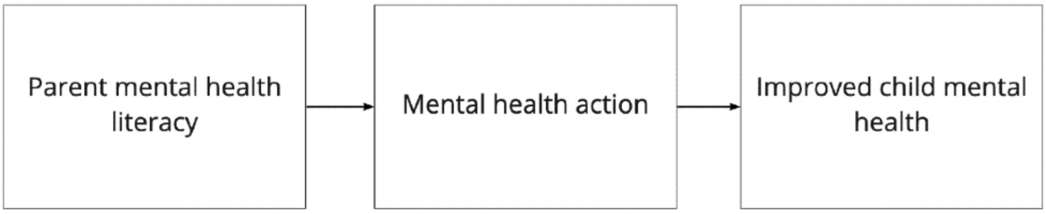
The single-parent study was a randomized controlled trial that found that a convenience sample of parents recruited from a single workplace improved their mental health literacy from a DHI [36]. This lack of focus on parents in previous reviews is important because parents are the agents of change for their child's mental health. Unlike adults seeking help for themselves, parents' willingness to receive help for their child's mental health problem is influenced by unique factors, such as whether the child participates in mental health treatment, or whether the treatment is framed in terms of child development [37,38]. With half of all adult mental health disorders originating in childhood, it is crucial to determine how DHIs can improve parents' mental health literacy, help seeking, and uptake of mental health services for their children [9].

However, there have been no consistent positive effects on parental help-seeking attitudes, with some low-quality studies finding a positive effect of DHIs, but most found no effects [34,35]. Studies in these 2 reviews had some limitations, specifically the common use of convenience sampling, the predominant focus on young people, lack of consistent measures, and low-quality evidence.

Recently, a universal education program delivered via SMS text messaging improved mental health literacy in the parents of adolescents compared with care as usual control. However, this study did not include parents of younger children or parents who were identified as having an adolescent with a mental health problem, who may be more likely to benefit from an intervention that facilitates help seeking [39].

Little is known about the effects of a DHI on the mental health literacy of parents, especially parents of young children, and even less is known about the effects on help seeking and uptake of services and cost-effectiveness. This is despite the frequent use of DHIs by parents and low uptake of services among many children with a mental health problem.

**Figure 1.** Link between parent mental health literacy and child mental health outcomes (adapted from a study by Jorm [22]).



### Objectives

In this study, we aim to conduct a systematic review of the literature to understand (1) whether DHIs targeting parents of children aged 2 to 12 years with a mental health problem improve mental health literacy and (2) whether the use of DHIs is associated with changes in parental help seeking or uptake of mental health services for their child. We also aim to report the cost-effectiveness of such DHIs.

## Methods

The systematic review was registered with PROSPERO (CRD42020130074). We conducted and reported a systematic review according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [40].

### Eligibility

We included studies that evaluated a DHI delivered directly to parents of children aged 2 to 12 years, with quantitative data reporting on outcomes of mental health literacy (specifically knowledge of treatment), help seeking (attitudes, intentions, and behaviors), or uptake of mental health services. Quantitative data were chosen to narratively synthesize the impact of DHIs on mental health literacy, help seeking and uptake of services.

For this review, we defined a DHI as a consumer-facing intervention using information communication technology targeting parents. The intervention could deliver information as a static webpage, a web-based parenting program, a web-based social network, a native mobile app, or other content delivered using digital means (other than telehealth). This definition was included in the PROSPERO registration.

We included DHIs targeting children with and without a mental health condition as long as the DHI was delivered as part of a program where some families were identified as having a mental health concern for their child. We included children aged 2 to 12 years. This age range was selected because of their likely dependence on parents to receive help for their mental health and the long-term impact of these early years on the well-being into adulthood [9]. We required a minimum of 1 outcome question on mental health literacy focusing on any of the following: knowledge of treatment, help seeking, or uptake of services.

Study designs included randomized controlled trials, quasi-randomized trials, and uncontrolled single-cohort studies. We restricted our analysis to articles published between January 2000 and December 2020 and written in English. We excluded conference proceedings and gray literature.

### Data Sources and Search Strategy

We developed our search strategy after consultation with a research librarian at The Royal Children’s Hospital, Melbourne, Australia. A pilot search was performed in MEDLINE OVID, followed by a review of keywords and further development of the search strategy. We searched the electronic databases CINAHL, Embase, MEDLINE OVID, PsycINFO, and PubMed in late 2019 and repeated the search in January 2021 to identify any more recent publications.

We also reviewed the reference list of the included studies to identify additional studies for full-text review. All search results were compiled in Endnote and then exported to Covidence for screening. The search strategy used for all the databases is given in Multimedia Appendix 1.

### Study Selection

One author (DP) screened the titles and abstracts of all articles produced from the search against the eligibility criteria. The full text of the remaining articles was obtained and screened again against the inclusion criteria. Any concerns about study eligibility were resolved in discussions with the supervising author (HH) during fortnightly supervision meetings. If there was insufficient evidence from the full-text study on whether it met the inclusion or exclusion criteria, DP attempted to contact the authors to obtain relevant information.

### Data Collection Process

Two authors (DP and MG) independently extracted data from the included studies using a pre-existing data collection form for intervention reviews from Cochrane [41].

### Data Items

Data extracted included study design; number of participants; type of comparison (where relevant); setting; recruitment; age and sex of participants and their children; the intervention, including the theoretical basis (a factor that may influence the success of a help-seeking intervention) [42] and measures of DHI use; outcome measures and whether they are validated measures; results; and economic outcomes. The data extracted were compared for accuracy, and the supervising author (HH) resolved any disagreements. Where possible, we calculated the effect sizes of the interventions and included these in Table 1.

**Table 1.** Primary outcomes of the interventions.

| Study | Design | Sample, n | Intervention | Timing of measures | Primary outcome | Measure | Outcome | *P* value | Validated measure |
|---|---|---|---|---|---|---|---|---|---|
| Montoya et al [43] | Pre or post single cohort | 35 | DISCERN tool assessing popular Spanish websites about ADHD[a] treatment | Unspecified time points pre, post parents using the DISCERN tool | Mental health literacy: ADHD specific knowledge and motivation for treatment | • The ADHD-knowledge and motivation for treatment questionnaire (ADHD-KMT).<br>• Basic knowledge subscale | • Pre: mean 49.09 (SD 9.46)<br>• Post: mean 63.21 (SD 9.45)<br>• Cohen *d*=1.49 | • <.01 | No |
| Ossebaard et al [44] | Pre or post single cohort | 195 | Web-based decision aid on ADHD treatment | Pre, post intervention, though exact timing unclear | Mental health literacy: ADHD knowledge and treatment | • "Would you please rate your knowledge on ADHD and its treatment possibilities" with a response on a 1-10 numerical scale | • Pre: mean 6.2 (SD 1.9)<br>• Post: mean 6.5 (SD 1.9)<br>• Cohen *d*=0.16 | • .60 | Unclear |
| Ryan et al [45] | Pre or post single cohort | 172 | Information-based website on ADHD management | Baseline: 28 days post-baseline | Mental health literacy: ADHD knowledge | • ADHD Knowledge and Opinions Survey-Revised (AKOS-R) – adapted<br>• Lower score (min: 30; max: 60)=higher knowledge | • Wilcoxon signed rank test showed a statistically significant moderate increase in knowledge; Z=−4.799; Cohen *d*=−0.503 | • <.01 | No |

| Study | Design | Sample, n | Intervention | Timing of measures | Primary outcome | Measure | Outcome | *P* value | Validated measure |
|---|---|---|---|---|---|---|---|---|---|
| Sapru et al [46] | Nonrandomized controlled trials | 27 | 3× PowerPoint presentations emailed to participants | Pre and post intervention, though exact timing unclear | Mental health literacy and help-seeking attitudes for depression | • Understanding mood disorders questionnaire<br>• Lower incorrect score=higher knowledge | • Median number of incorrect scores: Intervention: Pre 7, post 1; Control: Pre 7.5, post 4<br>• Within-group difference (pre or post) in PowerPoint group: Wilcoxon signed-rank test showed statistically significant improvement in responses (Z=−2.30; *P*=.04)<br>• Comparison between PowerPoint group and control (in-person group): One-way ANOVA showed no statistically significant improvement difference in responses | • Within-group difference (pre or post) in PowerPoint group: *P*=.04<br>• Comparison between PowerPoint group and control (in-person group): *P* value not reported | Not reported |
|  |  |  |  | Pre, post intervention, though exact timing unclear | Mental health literacy and help-seeking attitudes for anxiety | • Understanding of anxiety disorders questionnaire<br>• Lower incorrect score=higher knowledge |  | • Within-group difference (pre or post) in PowerPoint group: *P*=.04<br>• Comparison between Power Point group and control (in-person group): *P* value not reported | Not reported |

| Study | Design | Sample, n | Intervention | Timing of measures | Primary outcome | Measure | Outcome | *P* value | Validated measure |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | • Median number of incorrect scores: Intervention: Pre 9, post 2; Control: Pre 6.5, post 3.5<br>• Within-group difference (pre or post) in PowerPoint group: Wilcoxon signed-rank test showed statistically significant improvement in responses (Z=−2.30, *P*=.04)<br>• Comparison between PowerPoint group and control (in-person group): one-way ANOVA showed no statistically significant improvement difference in responses | | |
| Sourander et al [47] | Randomized controlled trial | 464 | Strongest Families' Smart website and 11× weekly 45-minute telephone coaching sessions | 6 months, 12 months, and 2 years after randomization | Uptake of services in the past 6 months | • Past service use evaluated using a yes or no question: "asking the parents if the child had received any behavioural treatment in the last 6 months" | • Number of participants reporting uptake of services: Intervention: 28 (18%); Control: 46 (28%); OR 1.8 [95% CI 1.1-3.1] | • .02 | No |

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[a] ADHD: attention-deficit/hyperactivity disorder.

## Risk of Bias

The included studies were assessed for quality against 1 of 2 instruments. For nonrandomized studies, we assessed the risk of bias using the Risk of Bias in Nonrandomized Studies of Interventions tool [48]. For randomized studies, we assessed bias using the revised Cochrane tool for assessing risk of bias in randomized trials [49]. The quality assessment was conducted independently by DP and MG. They compared their assessments and resolved any disputes by discussion or through the input of the supervising author (HH).

## Summary Measures

Whenever possible, we presented the outcome data of mental health literacy, help seeking, and uptake of services consistently, with parametric continuous data compared using means, nonparametric continuous data presented using medians, and categorical data presented as proportions. We also attempted to group the outcome data by validated and unvalidated measures.

## Synthesis

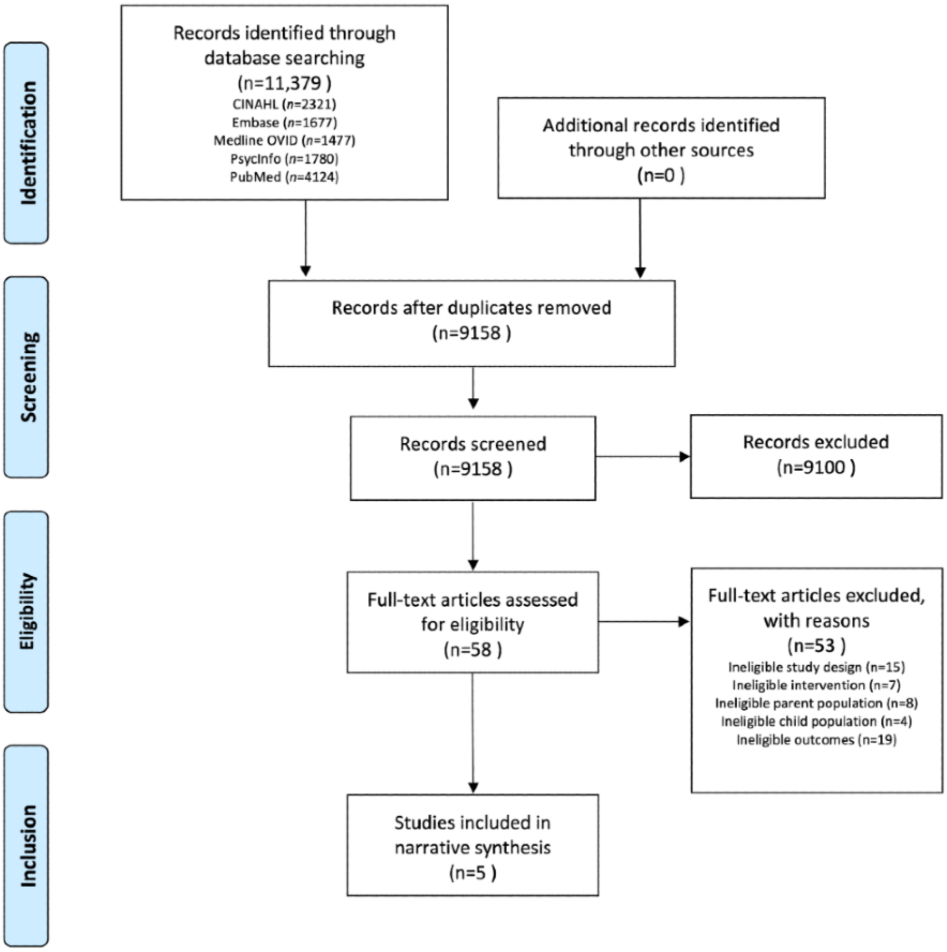
Owing to the heterogeneity in outcome measures, we could not conduct a meta-analysis. Accordingly, we used a narrative synthesis to describe the effects of the DHIs.

## Results

### Search Results

Through the search strategy detailed in the previous section, a total of 11,379 potentially eligible articles were identified. Of the 11,379 articles, 5 (0.04%) met all inclusion and exclusion criteria (Figure 2). The primary author (DP) reviewed the reference list of these included studies, which revealed no additional studies meeting inclusion and exclusion criteria.

**Figure 2.** PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of search results and study selection.



### Description of Included Studies

Of the 5 included studies, 1 (20%) was a randomized controlled trial [47], 1 (20%) was a nonrandomized trial of 2 interventions [46], and 3 (60%) were uncontrolled before and after studies [43-45] (Table 2).

All 5 studies were published between 2010 and 2018. There were 893 participants across the 5 studies, with the number of participants ranged from 27 to 464. The mean age of the children ranged from 4 to 10 years across the 5 studies. All studies were published in Europe or North America. Outcome measures included knowledge of attention-deficit/hyperactivity disorder (ADHD) treatment, knowledge and help seeking for anxiety and depression, and uptake of treatment for a child's behavioral problem.

A total of 3 studies included participants with concerns about, or a recent diagnosis of, ADHD [43-45]. Another study included only participants who were parents of children with high-level disruptive behavior on the Strengths and Difficulties Questionnaire and who recognized that their child had a problem [47]. The final study included participants who were referred to a tertiary center for management of the child's anxiety or depressive disorder, although the authors did not describe how the disorder had been diagnosed [46].

Participants were sampled using a variety of techniques. Of the 5 studies, 2 (40%) used consecutive sampling techniques to approach participants attending a scheduled universal health appointment [47] or a tertiary hospital mental health outpatient clinic [46]; 1 (20%) used a convenience sample of participants who had already attempted to access the intervention evaluated in the study [44]; and 1 (20%) used a convenience sample in which participants were selected by their child's physician or from a local advocacy group [43].

**Table 2.** Study description.

| Study | Country | Design | Sample, n | Participants | Recruitment | Intervention | Comparator | Theoretical basis for the intervention | Digital health intervention use | Economic outcomes |
|---|---|---|---|---|---|---|---|---|---|---|
| Montoya et al [43] | Spain | Single cohort pre or post study | 35 | Parents of children with a recent diagnosis of ADHD[a] | Parents selected by their child's physician or from a local advocacy group | Use of the DISCERN tool to assess the quality of 10 popular Spanish websites about ADHD treatment | Nil | Not reported | • Not reported | Not reported |
| Ossebaard et al [44] | Netherlands | Single cohort pre or post study | 195 | Parents of children with a recent diagnosis of ADHD | The web-based decision aid invited visitors to the website to participate in the study | Web-based decision aid on ADHD treatment | Nil | Yes | • About 7500 unique visits<br>• About 6 minutes on site<br>• About 8-9 clicks to navigate | Not reported |
| Ryan et al [45] | United Kingdom | Single cohort pre or post study | 172 | Parent or carer of a child with confirmed or suspected ADHD | Invited to attend if attending one of 3 pediatric outpatient clinics for suspected or confirmed ADHD | Information based website on ADHD management | Nil | Not reported | • Never used the website: 62 (41%)<br>• 1-2 times: 50 (33%)<br>• 4-5 times: 27 (18%)<br>• 5-6 times: 6 (4%)<br>• 7+ times: 8 (5%) | Not reported |
| Sapru et al [46] | Canada | Prospective nonrandomized controlled trial before and after study | 27 | Families referred to a tertiary hospital for management of a mood or anxiety disorder | Families on a waitlist for outpatient treatment of depression or anxiety were invited to attend | 3× PowerPoint presentations emailed to participants | 3 × 1-hour in-person group family psychoeducation sessions | Yes | • PowerPoint presentations completed: mean 2.7 (SD 2.7)<br>• Control group: mean 3.75 (SD 2.3) | Not reported |
| Sourander et al [47] | Finland | Prospective randomized controlled trial | 464 | Parents of children with high level disruptive behavior at a universal 4-year-old health check | Families attending a universal 4-year-old health check were screened and invited to attend | Strongest families smart website and 11× weekly 45-minute telephone coaching sessions | Brief website on positive parenting strategies and single 45-minute telephone coaching session and standard care | Not reported | • Not reported | Not reported |

[a] ADHD: attention-deficit/hyperactivity disorder.

### Description of the Included Interventions

Of the 5 interventions, 4 (80%) were delivered on the web through a website [43-45,47] and 1 (20%) was delivered via a series of PowerPoint presentations [46]. These PowerPoint presentations were emailed to each family every week for 3 weeks. The topics of the three PowerPoint presentations were (1) introduction and treatment options, (2) interpersonal illness and communication skills, and (3) problem solving and personal reflection [46].

A total of 2 (40%) web-based interventions were delivered with a cointervention [43,47]. One (20%) of these cointerventions consisted of 11 consecutive weekly telephone coaching sessions, in addition to access to the Strongest Families Smart Website [47]. This website features 11 sessions containing tailored content, exercises, and instructional videos and requires parents to complete knowledge and experience-based questions. This content is designed to help parents develop skills to promote positive behavior and a positive relationship with their children [47]. Another study by Montoya et al [43] used a cointervention. In this study, parents evaluated popular ADHD websites against the DISCERN instrument [50] to assess the quality of written consumer health information available on ADHD treatment [43].

The remaining 2 (40%) interventions consisted of a website focused on ADHD [44,45]. A study by Ossebaard et al [44] trialed a web-based decision aid designed to help support parents and caregivers through the decision-making process of ADHD treatment. The average visitor, which included participants and nonparticipants, visited the website for an average of 6 minutes [44]. The final ADHD website contained information on the management of ADHD [45]. The website was funded by the pharmaceutical company Shire, which was disclosed to the participants. The participants could access the website for 1 month, and most of the participants accessed the website once or twice during that time [45]. For these 2 ADHD websites, postintervention outcomes were measured immediately following the intervention [44], 30 days after the intervention started [45], or 2 years after the intervention commenced [47].

Of the 5 studies, 2 (40%) did not specify precisely when they recorded postintervention outcomes [43,46].

### Effect on Mental Health Literacy, Help Seeking, and Uptake of Services

Mental health literacy outcomes were the most common outcome assessed by the included studies, with 80% (4/5) of the studies measuring some form of mental health treatment knowledge (Table 1). The most common mental health problem assessed by the knowledge measures was ADHD [43-45], followed by depression and anxiety knowledge and help-seeking attitudes studied by Sapru et al [46]. Only 1 (20%) study measured the parent-reported uptake of mental health services [47].

### ADHD Knowledge

Despite 60% (3/5) of the studies intending to measure ADHD knowledge and all through survey responses, each study used a different measure. None of these measures were validated. An adapted version of a validated measure was used by Ryan et al [45], but the authors did not provide a description of how it had been adapted and whether it was still valid. All of the ADHD knowledge studies were uncontrolled pre-post studies, and all showed an improvement in parent ADHD knowledge scores, 2 (40%) of which were statistically significant [42,49].

In addition, changes in knowledge among those who accessed the website and those who did not were assessed by Ryan et al [45]. Their study [45] showed that those who accessed the website at least once had a moderately significant improvement in knowledge compared with those who never accessed the *ADHD and You* website.

Of note, evaluation of a web-based decision aid by Ossebaard et al [44] was affected by a large number of missing data. From the 7500 unique views to the site, all of whom were invited to participate in the study, only 195 participants were enrolled, leading to potential selection bias. In addition, of these 195 participants, only 12 (6.2%) provided outcome data before and after the intervention, leading to potential attrition bias.

### Depression and Anxiety Knowledge and Attitudes to Help Seeking

The only study that evaluated anxiety and depression-based mental health literacy and help-seeking attitudes was carried out by Sapru et al [46]. One measure was used for anxiety, and another for depression, with each measure assessing both knowledge and help-seeking attitudes within the same instrument. It was not reported whether these tools had been validated for this population.

Both the anxiety and depression measures showed an improvement in median scores of the intervention (web-based) compared with those of the control (in-person) group, although this difference was not significant in a small sample size.

Missing data and high attrition rates were again common, with outcome data provided for only 38% (5/13) of the intervention participants and 57% (8/14) of the control participants. The authors did not report why so many families failed to initiate or complete the programs and outcome measures. Two of the authors were contacted but did not provide further clarification on reasons for the missing data.

### Uptake of Mental Health Services

Only 1 (20%) study measured the uptake of mental health services, which was also the largest study and had the longest follow-up of 2 years [47]. A study by Sourander et al [47] asked parents to self-report whether they had received any behavior treatment for their child in the previous 6 months. This measure was recorded at 6, 12, and 24 months after starting the 11-week intervention. The authors did not report whether this measure had been validated. Fewer parents in the intervention group, consisting of a website and 11 weekly telephone coaching sessions, reported that their child had accessed behavioral treatments (28/160, 17.5% participants) than did parents in the control group (46/164, 28% participants; odds ratio 1.8, 95% CI 1.1-3.1; *P*=.02). This reduction in the uptake of behavioral treatments occurred in the context of a small but significant improvement in the child's behavior in the intervention group compared with the control group.

### Cost-effectiveness

No studies reported on the cost-effectiveness or costs of the DHIs.

### Assessment of Risk of Bias

One randomized controlled trial was rated as having a high risk of bias in 1 domain because of missing data, giving it an overall rating of high risk (Table 3) [47].

A total of 4 study designs were nonrandomized, with 3 (75%) of these studies [43,45,46] rated at serious risk of bias and 1 (25%) [44] rated at critical risk of bias (Table 4). The studies were rated at serious risk of bias because of a lack of identification of, or control for, potential confounders; potential for bias in selection of participants; and lack of objective outcome measures. The large number of missing participants also contributed to attrition bias and subsequent critical risk ratings.

**Table 3.** Risk of bias of randomized studies using the Cochrane tool for assessing risk of bias in randomized trials (RoB 2).

| Study | Randomization process or selection bias | Deviations from intervention | Missing outcome or attrition bias | Measurement of outcome or detection bias | Selection of reported result or reporting bias | Overall |
|---|---|---|---|---|---|---|
| Sourander et al [47] | Low | Low | High | Some concerns | Some concerns | High |

**Table 4.** Risk of bias in nonrandomized studies using the Risk of Bias in Non-randomized Studies–of Interventions (ROBINS-I) tool.

| Study | Confounding | Selection of participants | Classification of interventions | Deviations from intended interventions | Missing data | Measurement of outcomes | Selection of reported result | Overall |
|---|---|---|---|---|---|---|---|---|
| Montoya et al [43] | Serious | Low | Low | Low | Low | Moderate | Moderate | Serious |
| Ossebaard et al [44] | Serious | Critical | Low | Low | Critical | Serious | Moderate | Critical |
| Ryan et al [45] | Serious | Low | Low | Low | Moderate | Serious | Moderate | Serious |
| Sapru et al [46] | Serious | Serious | Low | Low | Moderate | Moderate | Moderate | Serious |

## Discussion

### Principal Findings

This study identified 5 studies of DHIs for parents of children with a mental health problem, measuring changes in mental health literacy, help seeking, or uptake of services.

Of those measuring mental health literacy, 80% (4/5) of the studies showed an improvement in parent knowledge. However, most of these studies focused on ADHD knowledge and were of low quality.

Of the 5 studies, 1 (20%), using a very small sample size of parents, measured both mental health literacy and help-seeking attitudes and used a nonrandomized control group, showing a nonsignificant trend to improved knowledge and help-seeking attitudes for child's anxiety and depression. For this study, the mental health literacy and help-seeking attitudes outcomes were evaluated using the same measure and results were not presented separately, precluding conclusions about whether this improvement was predominantly because of changes in knowledge or attitudes.

The only large randomized controlled trial measured uptake of services and found the use of a website coupled with a telephone coach, reduced uptake of services for the child's behavior, whilst simultaneously improving child behavior compared with a control group at 24 months follow up [47]. Despite the widespread use of websites and apps to help parents understand their child's mental health or find services to help their child, only one study evaluated a universally accessible website [43]. Of the 5 studies, 2 (40%) had a comparison group, and neither of these studies compared the DHI to an existing and previously evaluated face-to-face, web-based, or school-based intervention. Thus, the comparative efficacy, feasibility, and cost-effectiveness of DHIs and face-to-face interventions remain unclear.

Of the 5 studies, 2 (40%) reported using theory to inform the design of the DHI. Although there is no evidence to definitively support the use of theory in designing a DHI, it is recommended to use a theory, or theories, to inform the design of health promotion interventions, and it may be beneficial for DHIs targeting help seeking [42,51].

None of the studies reported health economic outcomes of the interventions, such as development costs, implementation expenses, or potential financial benefits from the intervention on the family or health services. The overall quality of the papers was low, with only 20% (1/5) of the studies being a randomized controlled trial. All studies were rated as either high risk of bias on the revised Cochrane tool or serious or critical risk of bias on the Risk of Bias in Nonrandomized Studies of Interventions tool.

In addition, the lack of consistent and validated measures made a meta-analysis impossible and limited our ability to compare efficacy among the interventions. The lack of consistent measures has been described previously [24].

This is the only review showing the impact of DHIs on mental health literacy, help seeking, and referral uptake in parents of children with mental health problems. We searched a wide range of databases, hand searched references from included articles, and attempted to contact authors where data were missing. This study included all quantitative studies evaluating a DHI across multiple time points and thus presented a wider scope of included study designs than existing review articles on DHIs for mental health literacy or help seeking. Finally, this was the only study that extracted data on the theoretical basis of the intervention and economic outcomes.

### Limitations

We included only studies with quantitative outcome measures. We recognize that we could have used categorical coding of qualitative data (eg, positive, neutral, or negative impact) to include qualitative research. This could be an area for future research. In addition, qualitative studies may provide more nuanced data into the effectiveness or otherwise of DHIs in this area, particularly on factors influencing help-seeking attitudes, intentions, and behaviors. In addition, a single reviewer (DP) evaluated all search results against the inclusion and exclusion criteria, which may have resulted in studies being missed at the screening stage. However, hand searching of references within these papers revealed no new studies, suggesting that it is unlikely that we missed any published studies. The studies included were of poor quality; therefore, the results must be interpreted with caution. This review only included peer-reviewed journals and did not include a search for gray literature. As such, there is potential for publication bias in the results. Finally, a lack of consistent nomenclature around help seeking and uptake of services may have resulted in the search strategy missing some studies that measured these outcomes.

### Impact

There is no high-quality evidence that DHIs improve parent mental health literacy, help seeking, or uptake of services, even for the most studied area of ADHD. There is low-quality evidence that parents' mental health literacy can be improved through the use of DHIs. There is also evidence that the use of a website and telephone coach may reduce the long-term uptake of mental health services for preschool children with disruptive behavior. The economic benefit of any DHI targeting parent mental health literacy, help seeking, or uptake of services remains unknown. This study cautiously supports the use of DHIs, especially ADHD websites, to improve parent mental health literacy. There is no evidence that any DHI can improve help seeking or uptake of services for children with a mental health problem.

### Future Research

Despite the widespread availability, enthusiasm for, and use of DHIs among parents, there is little rigorous evidence regarding the effect of DHIs on parent mental health literacy, help seeking, and uptake of services for their children. There is an urgent need to develop, implement, and rigorously evaluate DHIs designed to improve these outcomes, including an economic evaluation of their effects. Websites targeting parent mental health literacy, especially for mental health problems other than ADHD, should be evaluated to establish whether they increase mental health literacy. Ideally, this evaluation would compare new and previously evaluated interventions using validated measures of parent mental health literacy.

Researchers should conduct randomized controlled trials of new and existing DHIs, including existing interventions that are already frequently accessed by parents. Comparison of face-to-face and school- or community-based interventions would also prove helpful in understanding the role of DHIs within the broader context of child mental health services [25]. Outcomes should include validated measures of parents' knowledge of mental health problems in children and mental health actions, such as help seeking and uptake of services [25]. Consistent use of validated measures would allow a comparison of interventions and meta-analysis of their effects [52]. Research focusing on help seeking and uptake of services is especially important, given that so many children with mental health disorders are not receiving professional help. Until such research is conducted, we do not know whether a DHI can improve the uptake of mental health services among parents of children with mental health problems. A systematic review of qualitative studies may provide additional information on the influence of DHIs on parents' help-seeking behaviors.

### Conclusions

This review found low-quality evidence that DHIs may increase mental health literacy for ADHD and increase mental health literacy and help-seeking attitudes toward anxiety and depression. Overall, the heterogeneity of measures and high risk of bias across studies impacted our ability to confidently interpret these findings. We highlight the gap between parents' frequent use of web-based sources of health information and the paucity of published evidence on the effect of these DHIs on help seeking, the uptake of services, and cost-effectiveness.

### Acknowledgments

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## Authors' Contributions

DP conceptualized and designed the study, searched the literature, extracted data, conducted a quality appraisal, drafted the initial manuscript, and reviewed and revised the manuscript. MG extracted data, conducted a quality appraisal, and reviewed and revised the manuscript. HH conceptualized and designed the study, supervised the data extraction and quality appraisal, and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Search strategy.
[DOCX File , 20 KB-Multimedia Appendix 1]

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## Abbreviations

**ADHD:** attention-deficit/hyperactivity disorder
**DHI:** digital health intervention
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Review

# Sensing Apps and Public Data Sets for Digital Phenotyping of Mental Health: Systematic Review

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## Abstract

**Background:** Mental disorders are normally diagnosed exclusively on the basis of symptoms, which are identified from patients' interviews and self-reported experiences. To make mental health diagnoses and monitoring more objective, different solutions have been proposed such as digital phenotyping of mental health (DPMH), which can expand the ability to identify and monitor health conditions based on the interactions of people with digital technologies.

**Objective:** This article aims to identify and characterize the sensing applications and public data sets for DPMH from a technical perspective.

**Methods:** We performed a systematic review of scientific literature and data sets. We searched 8 digital libraries and 20 data set repositories to find results that met the selection criteria. We conducted a data extraction process from the selected articles and data sets. For this purpose, a form was designed to extract relevant information, thus enabling us to answer the research questions and identify open issues and research trends.

**Results:** A total of 31 sensing apps and 8 data sets were identified and reviewed. Sensing apps explore different context data sources (eg, positioning, inertial, ambient) to support DPMH studies. These apps are designed to analyze and process collected data to classify (n=11) and predict (n=6) mental states/disorders, and also to investigate existing correlations between context data and mental states/disorders (n=6). Moreover, general-purpose sensing apps are developed to focus only on contextual data collection (n=9). The reviewed data sets contain context data that model different aspects of human behavior, such as sociability, mood, physical activity, sleep, with some also being multimodal.

**Conclusions:** This systematic review provides in-depth analysis regarding solutions for DPMH. Results show growth in proposals for DPMH sensing apps in recent years, as opposed to a scarcity of public data sets. The review shows that there are features that can be measured on smart devices that can act as proxies for mental status and well-being; however, it should be noted that the combined evidence for high-quality features for mental states remains limited. DPMH presents a great perspective for future research, mainly to reach the needed maturity for applications in clinical settings.

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**KEYWORDS**

mental health; digital phenotyping; sensing apps; data sets; sensor data

# Introduction

## Background

Mental health issues have a high prevalence, with 1 in 10 people worldwide experiencing them at any one time [1] and common mental disorders such as depression being closely linked to suicide [2]. Mental disorders are "generally characterized by some combination of abnormal thoughts, emotions, behavior and relationships with others" [3]. Examples are depression, schizophrenia, excessive anxiety and stress, disorders caused by drug and alcohol abuse, and personality and delusional disorders. These disorders pose a significant burden on societies, both emotionally and financially. For example, the cost of mental health disorders in the European Union is estimated at €600 billion (~US $451 billion), or 4% of gross domestic product [4]. COVID-19 has had a further negative impact on global mental health [5].

Mental disorders are usually diagnosed exclusively on the basis of symptoms, which are identified from patients' interviews and self-reported experiences. Sometimes these experiences are gathered using ecological momentary assessment (EMA) solutions [6], but mostly therapists rely on patients remembering such experiences during sessions. EMA solutions are used as a research method to collect, at fixed or random moments, reports from individuals about perceptions of their behaviors and feelings, and what they have done or experienced. It is well known that the intervening time and current state of the patient bias his/her memory of the experience. In addition, biological tests to assist diagnosis remain hard to be developed [7]. Based on the need to develop solutions able to objectively diagnose and monitor mental health, different solutions have been proposed, such as mobile apps [8,9] and machine learning (ML) solutions [10], which are even more indicated today due to the global pandemic situation [11,12]. Digital phenotype solutions are examples that can expand the ability to identify and diagnose health conditions from the interactions of people with digital technologies [13]. Specifically, digital phenotyping of mental health (DPMH) [14] seems to be a promising approach not only to deal with the problem of diagnosing the issue, but also to be applied to the treatment.

The omnipresent adoption of pervasive devices, including smartphones and wearable sensors, provides novel opportunities for tracking mental health status and disorders. Digital phenotyping refers to the "moment-by-moment quantification of the individual-level human phenotype in-situ using data from smartphones and other personal digital devices" [15], thereby removing limitations created by the aforementioned bias in self-reports.

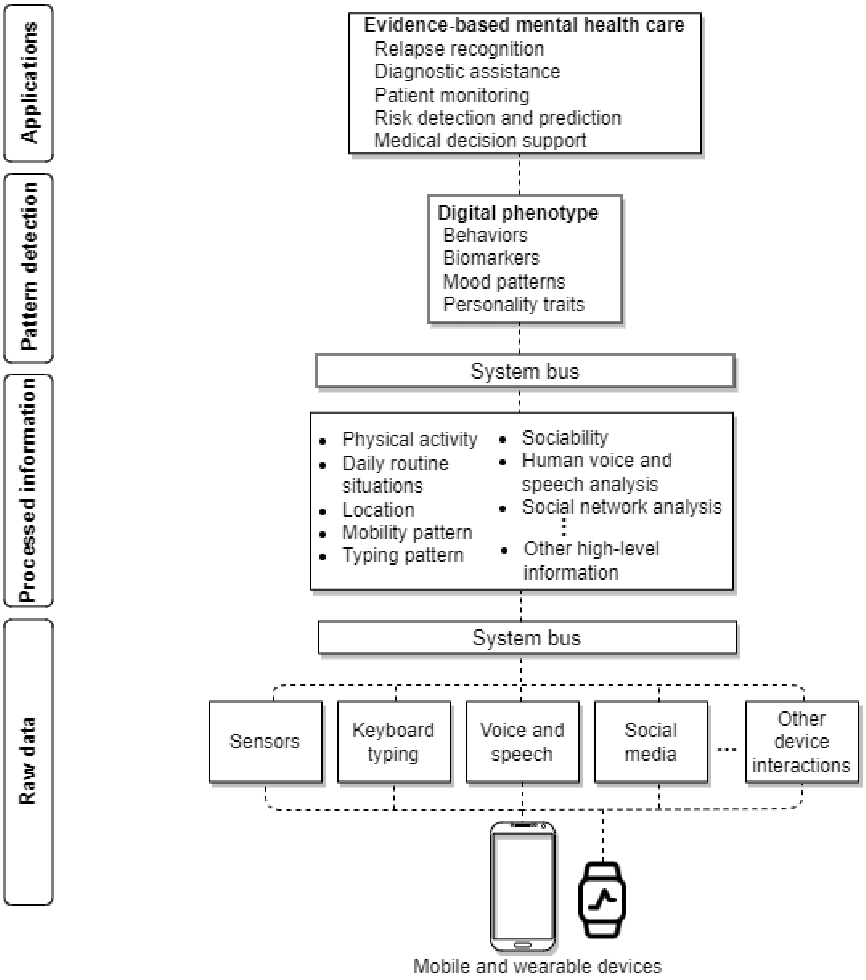
DPMH solutions require collecting and analyzing large amounts of different types of social and behavioral data that can represent experiences of the users and their interactions with people, places, and devices. These context data can be passively gathered, for instance, from ubiquitous sensors, social media, and health care systems [16]. After collection, pieces of raw data are usually preprocessed and transformed into useful data or data sets to be mined [17]. For example, these data sets may be analyzed or used as input to build ML models [18], including for DPMH, to produce valuable insights and evidence. Therefore, DPMH sensing apps are primarily responsible for collecting and preprocessing data, with the data sets produced being important for developing such models. This study systematically reviews the sensing apps and data sets for DPMH.

## Definitions

In the last few years, the number of smart devices, that is, mobile (eg, smartphone, tablet) and wearable (eg, smart band, smartwatch) devices, has grown globally. They have enabled the development of research in the health area, including mental health [10]. The term "digital phenotype", defined by Jain and colleagues [13], refers to the identification of human behavior patterns, whereas "digital phenotyping" is a monitoring approach that can collect patients' behavioral markers passively [19]. Therefore, DPMH solutions aim at collecting multimodal pieces of information from digital devices using sensing apps to combine them with electronic medical records to objectively contribute to the identification of symptoms of mental disorders. In this context, sensing apps are tools for mobile and wearable devices used to collect useful user information.

Our vision of the digital phenotyping process organized in layers is presented in Figure 1. The process starts at the first layer with the collection of raw data from different sources (eg, global positioning system [GPS] sensors, keyboard inputs, voice, and social media). These data can be collected both actively, in which user inputs are explicitly required, and passively [20], which only requires the user's permission to access context data. In the next layer, these data are processed to provide high-level information. High-level information represents not only human behaviors (eg, sociability, physical activity) and habits (eg, mobility, sleep) but also other information of interest for professionals (eg, environmental context, mood). Next, human behavioral patterns that compose digital phenotypes (eg, biomarkers, mood patterns) can be recognized using computational tools (eg, ML, data mining, statistical models). Finally, we visualize the application layer, which corresponds to digital phenotypes used by health professionals for evidence-based mental health care.

**Figure 1.** The process of digital phenotyping.



## Related Work

Since the aforementioned concepts were proposed in the literature, many research studies have been performed. For this reason, researchers have also reviewed different aspects regarding this research topic. Table 1 presents a list composed of related reviews.

**Table 1.** List of related review articles.

| Study | Description |
|---|---|
| Garcia-Ceja et al [10] | A survey on mental health monitoring using mobile and wearable sensors focused on multimodal sensing and machine learning solutions. |
| Cornet and Holden [21] | An SLR[a] on passive sensing using specifically smartphones focused on health and well-being. |
| De-La-Hoz-Franco et al [22] | An SLR aimed at finding data sets composed of sensor data for human activity recognition. |
| Trifan et al [23] | This SLR aimed to identify studies on the passive use of smartphones for generating outcomes related to health and well-being. It identified that one of the areas most explored by mobile passive sensing is mental health. |
| Seppälä et al [24] | An SLR on mobile solutions focused on uncovering associations between sensor data and symptoms of mental disorders (ie, behavioral markers). |
| Liang et al [14] | A comprehensive survey addressing different topics on DPMH[b]. |
| Benoit et al [20] | This SLR sought to map DPMH tools that use machine learning algorithms across the schizophrenia spectrum and bipolar disorders. |
| Antosik-Wójcińska et al [25] | This work presents an overview of studies about smartphone systems focused on monitoring or detecting bipolar disorder. |

[a] SLR: systematic literature review.

[b] DPMH: digital phenotyping of mental health.

This review differs from the previous ones in the following aspects: First, instead of focusing on a specific mental state/disorder, this review presents an overview of how different types of devices and detection modalities have been used to monitor a wide variety of different mental states within the DPMH area. Second, this review covers not only active collection solutions, which are emphasized in most reviews, but also passive sensing proposals. Third, this review focuses on the technical features of sensing apps and data sets (eg, size, sensors used to collect data, and types of context data). Technical features can be identified to serve as a basis for the use or development of new apps (eg, physical and virtual sensors used to collect data, operating systems for which the apps were developed, types of context data collected, inferred information). Finally, not all previous reviews were conducted systematically. Our article therefore provides researchers with an overview of the available technological framework for DPMH and can serve as a preliminary guide for current and further research.

### Objectives and Research Questions

This systematic review intends to provide a technical characterization and summary of sensing apps and public data sets for DPMH. By "public" we mean data sets that are available for free download for use in other research endeavors. These 2 topics (ie, sensing apps and public data sets) are jointly addressed in this review as complementary content. When researchers do not have access to DPMH data sets, they need sensing apps. This paper therefore can be a starting point not only to gain knowledge on the current sensing apps for DPMH (which consequently enables the development of new solutions), but also to find reusable ones. Therefore, the objectives of this article are to (1) present results from a systematic search on digital libraries and data set repositories, and then identify and categorize them by considering their characteristics; (2) summarize their main features (measurable pieces of data that can be used for analysis or creation of ML models, such as data collection time stamp, context data produced by DPMH solutions, and data self-reported by users), which are useful for researchers, either mental health or information technology ones, to conduct further investigation and comment on their usefulness; and (3) identify trends in and research opportunities for DPMH. Results of this systematic review are also relevant for data engineers and ML specialists who make efforts in developing DPMH solutions.

To achieve the objectives of this systematic review, we defined the following research questions for sensing apps (SA-RQs) and data sets (DS-RQs):

SA-RQ1: What context data are collected through DPMH sensing apps?

SA-RQ2: What high-level information can be inferred from the context data collected by DPMH sensing apps?

SA-RQ3: How is the identified high-level information used to support mental health?

DS-RQ1: What features are available in public data sets for DPMH?

DS-RQ2: What high-level information can be derived from public data sets for DPMH?

## *Methods*

### Design

This study was conducted based on the guidelines for systematic literature reviews in software engineering proposed by Kitchenham and Charters [26]. This review followed 3 main phases: planning, conducting research, and dissemination of results. These phases were supported by the *Parsif.al* [27] tool, which provides an online shared work environment for planning and executing systematic reviews. In this section, we present how this review was planned and conducted.

### Search Strategy

The search aimed to identify data sets and studies that have presented sensing apps capable of collecting data. Two (JM and IM) researchers conducted an exhaustive search on January 14, 2021, on data set repositories and digital libraries. The search for data sets was performed in 20 repositories (Multimedia Appendix 1). The search for articles reporting sensing apps was conducted in the following digital libraries: ACM Digital Library, DOAJ, IEEE Xplore, Web of Science, PubMed, PsycInfo, ScienceDirect, and Scopus. These databases were selected because they collect reliable studies related to mental health informatics.

We designed the search strings to retrieve data sets and articles presenting sensing apps for DPMH (Table 2). These search strings were carefully designed to meet the research focus. In the string to search data sets, we defined the 2 main terms (ie, mental health and digital phenotyping) and decided to use Boolean "OR" as the link for them to get comprehensive results. The search string for articles was developed based on the review objective, research questions, and their motivations. We used keywords and their synonyms to maximize results. To avoid missing papers, we evaluated the suitability of the string in a pilot search, in which we used those studies developed by Liang et al [14] (ScienceDirect) and Torous et al [15] (PubMed) as control articles. This pilot search was able to retrieve the cited studies, thus demonstrating its ability to find articles relevant for this review. At the end of the search, duplicate data sets and articles were identified and removed using the *Parsif.al* tool.

**Table 2.** Keywords and their synonyms.

| Search | Source | String |
|---|---|---|
| Data sets | Data set repositories | “mental health” OR “digital phenotyping” |
| Sensing apps | Digital libraries | (“mental health” OR “mental disorder*” OR “mental illness” OR “mental state” OR “mental disease”) AND (“mobile device” OR “smartphone*” OR “wearable device*” OR “sensor*” OR “wearable*” OR “mobile application*” OR “mobile health” OR “mHealth” OR “mobile phone*” OR “sensor data”) AND (“passive detection” OR “data collection” OR “digital phenotype” OR “digital phenotyping” OR “digital health” OR “monitoring” OR “passive sensing”) |

## Selection Criteria

A set of selection criteria was defined to track research articles and data sets. Textbox 1 presents the selection criteria for scientific studies with sensing apps and data sets. Importantly, no date range limits were applied to the literature included in the review. In the selection of scientific articles, criterion EC1 excluded studies presenting the development of EMA apps, and papers that do not present a new DPMH solution (eg, studies using a DPMH solution previously described/published in another paper). For data set selection, criterion EC1 excluded those data sets that were not publicly available, that is, those protected and not accessible to be reused by other researchers.

In the selection phase, 2 researchers (JM and IM) performed the data set selection process based on the inclusion and exclusion criteria. In a second step, the same 2 researchers independently performed the study selection process. This process consisted of 3 sequential phases: (1) study screening by means of metadata analysis (ie, title, abstract, and keywords); (2) full-text analysis of the articles selected in the screening phase; and (3) conducting backward snowballing [28]. Next, the level of agreement between the selections was calculated using the Cohen κ coefficient [29]. In the end, the 2 researchers conducted discussions to resolve selection conflicts and, when there was no consensus, judges (2 other authors, namely, AT and DV) deliberated on the disagreements.

**Textbox 1.** Selection criteria.

**Inclusion criteria (IC)**

*Scientific articles*

IC1: Primary studies that present pervasive solutions to collect data for digital phenotyping of mental health.

IC2: Full papers.

IC3: Papers in English language.

*Data sets*

IC1: Available to be downloaded and used in other research studies (ie, public data set).

IC2: Focused on mental health or specific mental disorders.

IC3: Relevant data (eg, behavioral, physiological, social) for mental health collected through pervasive technologies.

IC4: Content in English language.

**Exclusion criteria (EC)**

*Scientific articles*

EC1: Articles presenting research on digital phenotyping of mental health without involving a proposal of a pervasive solution.

EC2: Gray literature.

EC3: Articles that have other publications with a more current and complete version of the proposed solution.

*Data sets*

EC1: Not publicly available.

EC2: With no content related to mental health.

EC3: Data on treatments of patients with mental disorders without using pervasive devices.

EC4: Content in languages different from English.

EC5: Online surveys on ethnographic characteristics and prevalence of mental disorders.

EC6: Composed exclusively by multimedia data (eg, video, audio) or electroencephalography data.

## Data Extraction

In this step, data were extracted from the selected articles and data sets to answer the research questions defined in this review. For this purpose, a data extraction form was designed by 2 authors (JM and IM) and validated by the judges. Specifically, we designed the items in the form to extract relevant information presented by the reviewed studies and data sets, thus enabling us to answer the research questions, and identify open issues and research trends. Multimedia Appendix 2 presents the items in the data extraction form.

## Results

### Study Selection

An overview of the review process with results is presented in Figures 1 and 2. In Figure 2, 8 digital libraries were used to search for scientific articles that presented sensing apps for DPMH. A total of 2374 articles were returned. We removed 926 duplicate articles. The inclusion and exclusion criteria from Textbox 1 were applied to select 26 selected studies. The Cohen κ statistical test showed an agreement level of ≈0.87 between researchers, which is considered an almost perfect agreement [29]. Next, researchers used the 1-level backward snowballing approach and added 5 articles. This resulted in 31 articles for inclusion in the data extraction process.

In Figure 3, 20 data set repositories were searched to return 2581 data sets with 471 duplicates that were removed. After applying selection criteria (Textbox 1) and resolving conflicts, 8 data sets remained for analysis.

**Figure 2.** PRISMA-based flowchart describing the selection of studies.

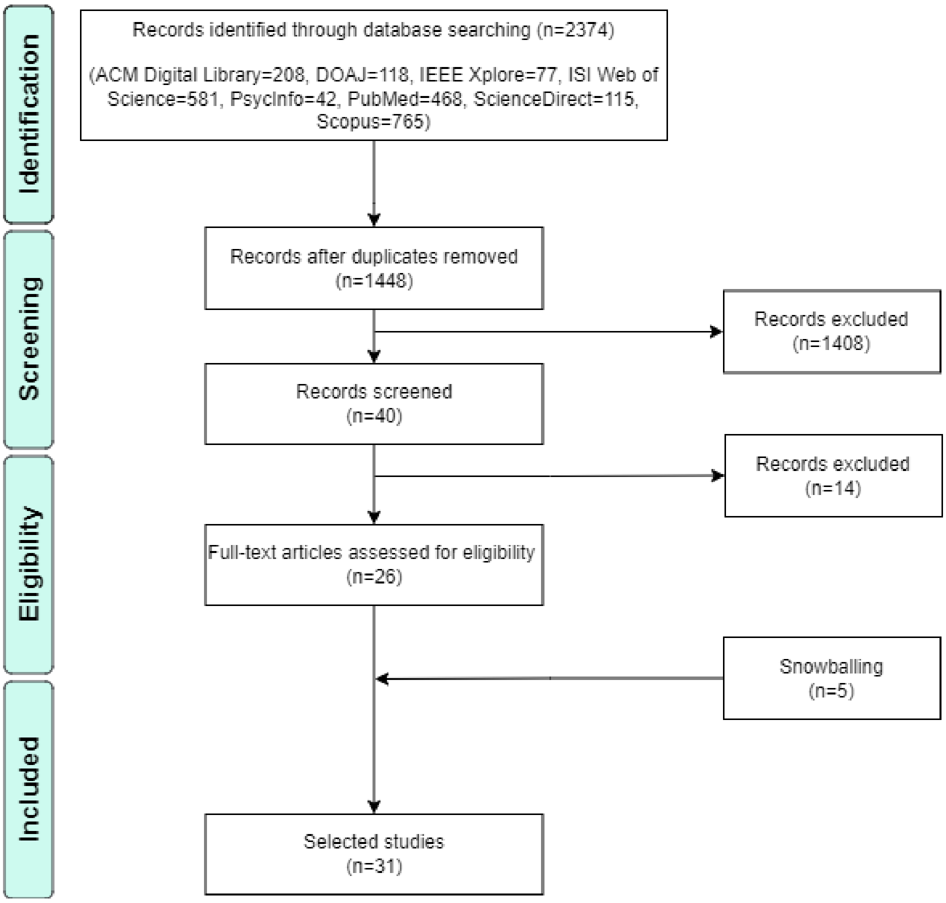
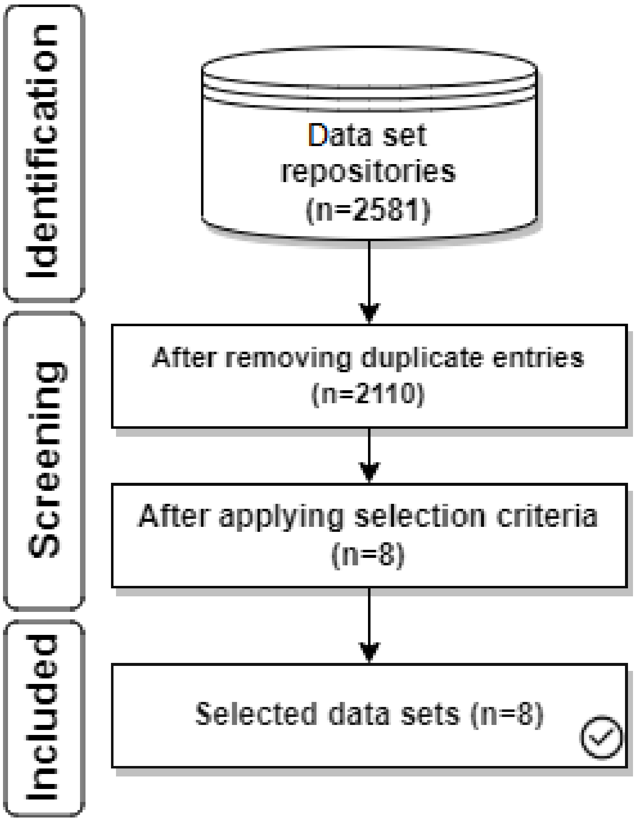


**Figure 3.** Flowchart describing the selection of data sets.



## Sensing Apps

Table 3 summarizes the 31 apps identified, which are presented in ascending order by year of publication. Multimedia Appendix 3 presents the full version of the table. Context data sources are categorized as follows to present the sensors used by the apps based on the work by Palaghias et al [30]: ambient (eg, microphone, camera), positioning (eg, GPS, Wi-Fi), virtual (eg, phone calls, SMS text messages), and inertial (eg, accelerometer, gyroscope). Table 3 also presents high-level information inferred and types of analyses performed on the collected data. Apps that do not infer information (ie, defined as “It does not infer information”) are only intended to collect data from smart devices. In this case, collected data are usually sent to servers for analysis. These apps are flagged as “Raw data collection” in Table 3.

**Table 3.** Summary of reviewed sensing apps.

| App | Context data source | High-level information | Type of analysis |
|---|---|---|---|
| Funf [31] | Positioning, inertial, and virtual | It does not infer information | Raw data collection |
| Mobilyze [32] | Positioning, inertial, virtual, and ambient | Mood, emotions, cognitive/motivational states, physical activity, social context | Mental state prediction |
| Purple Robot [33] | Positioning, inertial, and virtual | It does not infer information | Raw data collection |
| AWARE [34] | Positioning, inertial, and virtual | It does not infer information | Raw data collection |
| Sensus [35] | Positioning, inertial, virtual, and ambient | It does not infer information | Raw data collection |
| MOSS [36] | Positioning and virtual | Physical activity, mobility, device usage, sociability, app usage | Mental state classification |
| Beiwe [15] | Positioning, inertial, virtual, and ambient | It does not infer information | Raw data collection |
| EVO [37] | Positioning, inertial, and virtual | It does not infer information | Raw data collection |
| CrossCheck [38] | Positioning, inertial, virtual, and ambient | Sleep, sociability, mobility, physical activity, device usage | Mental state prediction |
| SituMan [39] | Positioning and inertial | Daily routine situations (eg, working, studying) | It recognizes daily routine situations using fuzzy logic |
| EmotionSense [40] | Positioning, inertial, virtual, and ambient | Semantic locations, physical activity, sociability | Correlation analysis and mental state classification |
| StudentLife [41] | Positioning, inertial, virtual, and ambient | Sociability, mobility, physical activity, device usage | Correlation analysis |
| Undefined [42] | Positioning, inertial, and ambient | Physical activity, mobility, and sociability | Correlation analysis |
| AMoSS [43] | Positioning | Mobility | Mental state prediction |
| eB2 [44] | Positioning and virtual | Mobility | Mental state classification |
| EARS [45] | Positioning, inertial, virtual, and ambient | It does not infer information | Raw data collection |
| SleepGuard [46] | Inertial and ambient | Posture/position of body when sleeping | Mental state classification |
| Moment [47] | Virtual | It does not infer information | Mental state classification |
| TypeOfMood [48] | Virtual | It does not infer information | Mental state classification |
| RADAR-base [49] | Positioning, inertial, virtual, and ambient | It does not infer information | Raw data collection |
| SHADO [50] | Positioning, inertial, and ambient | Physical activity, mobility, sleep, sociability | Correlation analysis and mental state classification |
| InSTIL [51] | Positioning, inertial, virtual, and ambient | It does not infer information | Raw data collection |
| Lamp [52] | Positioning | Physical activity | Correlation analysis |
| SOLVD [53] | Positioning, inertial, virtual and ambient | Mobility, sociability, context of daily life (eg, duration of sleep) | Correlation analysis |
| STDD [54] | Inertial, virtual, and ambient | Physical activity, mood, sociability, sleep | Mental state classification |
| Moodable [55] | Positioning, virtual, and ambient | Sociability and mobility | Mental state classification |
| Cogito Companion [56] | Positioning and Virtual | Mood, stress level, and well-being | Mental state classification |
| Strength Within Me [57] | Virtual | Sleep, mobility, and sociability | Mental state prediction |
| EuStress [58] | Ambient | It does not infer information | Mental state prediction |
| Mood Triggers [59] | Positioning, inertial, virtual, and ambient | Mobility and sociability | Mental state prediction |
| Data Collector [60] | Positioning and inertial | Physical activity and mobility | Mental state classification |

### Data Set Characterization

Table 4 shows the 8 selected data sets in descending order by number of participants. Two of them have sleep quality data: data sets DS1 and DS7, in which the data are derived from activity trackers such as Fitbit, smartwatches, and smartphones.

We identified 2 data sets (DS3 and DS5) with data collected from various sensors, which we refer to as multimodal. We identified 2 data sets (DS3 and DS5) that were generated by the StudentLife [41] and Beiwe [15] sensing apps, respectively, shown in Table 3.

**Table 4.** Summary of DPMH data sets.

| Data set | Study | High-level information | Features | Device type/operating System | Number of participants | Study duration | Size |
|---|---|---|---|---|---|---|---|
| DS1[a] [61] | [62] | Sleep quality | Fitbit data (eg, heart rate, sleep duration, sleep time, wake time) | Watch Fitbit | 482 | 3-11 nights | 392.32 KB |
| DS2 [63] | [64] | Activity | Actigraph (time stamp, activity measurement from the actigraph watch) | Actigraph watch | 55 | Average 12.6 days | 4.3 MB |
| DS3 [65,66] | [41,67] | Multimodal (stress, sleep, mood, physical activity, sociability, well-being) | Self-report questionnaires, activity, audio, Bluetooth encounters, conversation, lightness, GPS[b] coordinates, phone charge, screen on/off, Wi-Fi IDs | Smartphone (Android) | 48 | 66 days | 230 MB/5 GB |
| DS4 [68] | [69,70] | Sociability | Self-reports, battery level, Bluetooth encounters | Smartphone (Android, iOS) | 32 | 4 weeks | 9.7 MB |
| DS5 [71] | [15] | Multimodal (mobility, sociability, sleep) | Self-report questionnaires, accelerometer, app logs, Bluetooth encounters, call logs, GPS coordinates, power state, Wi-Fi | Smartphone (Android, iOS) | 6 | 3 months | 776.7 MB |
| DS6 [72] | [73] | Mood, depression symptoms | Self-report questionnaires | Smartphone (Android, iOS) | 3 | 14 days | 2.7 MB |
| DS7 [74] | — | Sleep quality | Start, end, sleep quality, time in bed, wake-up time, sleep notes, heart rate, number of steps | Wearable device and smartphone (iOS) | 1 | 4 years | 66.11 KB |
| DS8 [75] | — | Mood | Self-reported mood | Mobile social network (Twitter app) | 1 | 2 years | 131 KB |

[a] DS: data set.

[b] GPS: global positioning system.

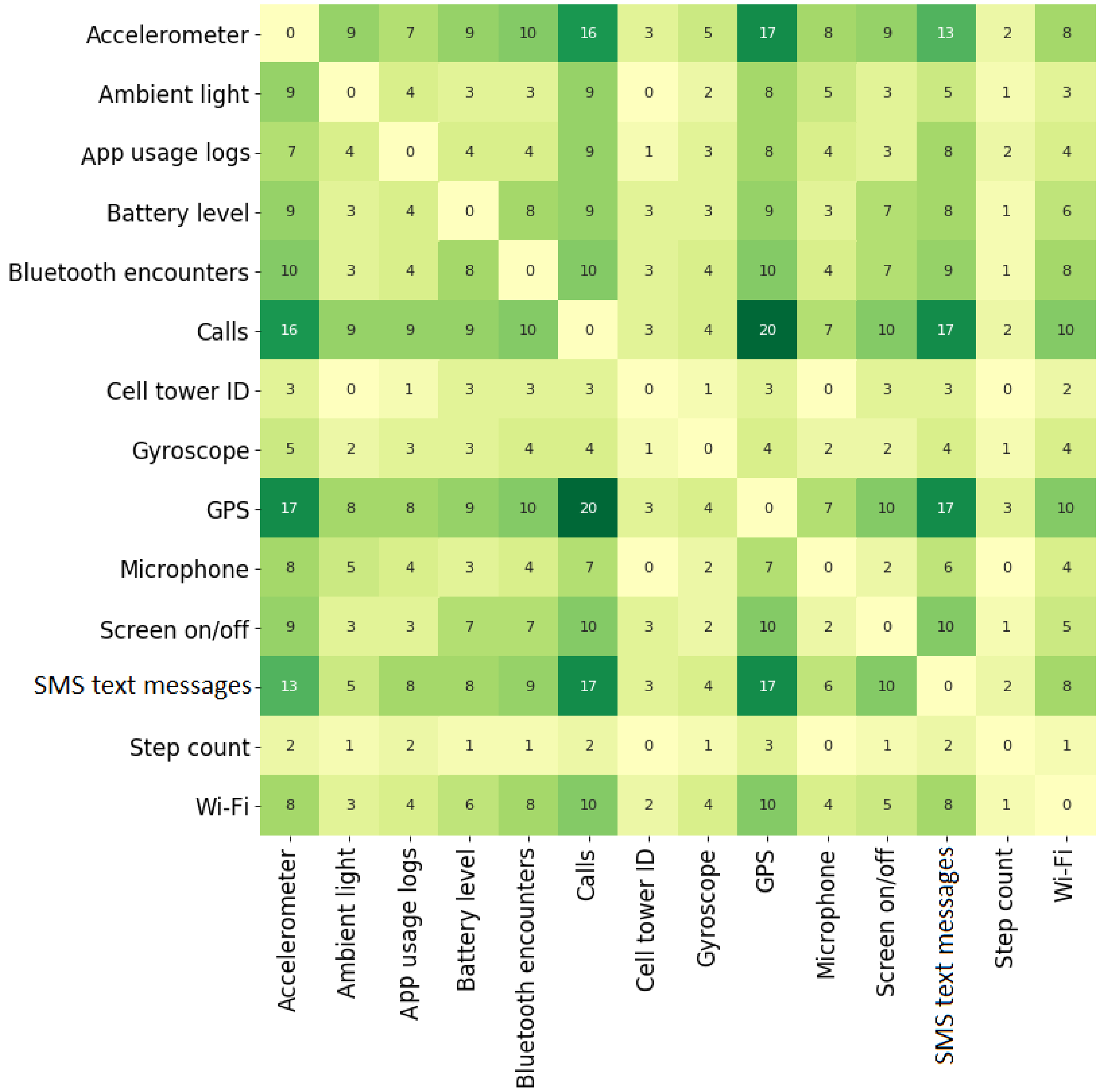
Data set DS1 [61] presents sleep data (eg, total sleep time and sleep efficiency) obtained from Fitbit Charge HR activity trackers used by 482 individuals [62], while data set DS2 [63] includes actigraphic data collected from patients with unipolar and bipolar disorders and 32 healthy controls [64]. Data set DS3 [65,66] contains data gathered from different sensors and EMA questionnaires collected from smartphones of 48 undergraduate and graduate students over 66 days [41,67]. Data set DS4 [68] comprises Bluetooth device scan, battery level, and EMA data collected at regular intervals for 4 weeks [69,70], while data set DS5 [71] presents passive data (eg, GPS, Wi-Fi, Bluetooth, and accelerometer) and active data (EMA survey responses) collected over 3 months [15]. Data set DS6 [72] contains EMA assessments of depression symptoms using the 9-item Patient Health Questionnaire (PHQ-9) [73]. Data set DS7 [74] presents sleep data collected through the Sleep Cycle mobile app [76]. Finally, data set DS8 [75] presents values extracted from Twitter posts collected from a person using Exist [77] over 2 years.

### Context Data Collected by DPMH Sensing Apps (SA-RQ1)

Sensing apps identified in this review collect context data from mobile and wearable devices to support DPMH. At a high level, the sensors that measure context data can be seen as physical and virtual sensors [78], which generate a diversified set of behavioral data. Physical sensors are hardware components embedded or connected to devices responsible for collecting context data. Some examples are accelerometers to measure user activity, light sensors to measure ambient light levels, and GPS to collect user's locations. Virtual sensors represent software components capable of recording interactions of individuals with devices or using a number of physical sensors (or other virtual ones) to construct a higher-level feature. Examples of such sensors are social interaction sensors that may use Bluetooth encounters (ie, co-location information between individuals or places), Wi-Fi network, and sound data to infer social activity; and user–device interaction sensor, which measures user interactions with devices (eg, call logs, SMS text messages, app usage, screen on/off).

Figure 4 presents a heat map of the combination of context data sources for the 31 sensing apps, showing the most used sensors in DPMH solutions. In this analysis, we investigated the frequency of the combination of each type of context data source, highlighting the main sets of sensors explored by the sensing apps. For example, Bluetooth encounters are often combined with accelerometer (n=10), battery level (n=8), calls (n=10), GPS (n=10), screen on/off (n=7), SMS text messages (n=9), and Wi-Fi (n=8), while app usage logs are often combined with accelerometer (n=7), calls (n=9), GPS (n=8), and SMS text messages (n=8). We also identified from this analysis that step count (Fitbit), cell tower ID, and gyroscope are combined less often with other context data sources. The analysis of the combination of context data sources (Figure 4) demonstrates an interest in performing data fusion to identify multiple high-level information and emphasizes the combination of context data sources resulting from the interest in monitoring such information. For example, we identify an interest in recognizing sociability information by combining call logs with Bluetooth encounters (n=10) and SMS text messages (n=17). We also recognize that GPS is often combined with Wi-Fi (n=10) to recognize mobility aspects. In addition, the interest in monitoring multiple high-level information in the same app resulted in different combinations of context data sources. For example, the combination of GPS with call logs (n=20), accelerometer (n=17), and screen on/off (n=10) is a result of an interest in monitoring sociability, physical activity, and device usage patterns, respectively.

**Figure 4.** Context data sources used in the reviewed studies. GPS: global positioning system.



| | Accelerometer | Ambient light | App usage logs | Battery level | Bluetooth encounters | Calls | Cell tower ID | Gyroscope | GPS | Microphone | Screen on/off | SMS text messages | Step count | Wi-Fi |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Accelerometer | 0 | 9 | 7 | 9 | 10 | 16 | 3 | 5 | 17 | 8 | 9 | 13 | 2 | 8 |
| Ambient light | 9 | 0 | 4 | 3 | 3 | 9 | 0 | 2 | 8 | 5 | 3 | 5 | 1 | 3 |
| App usage logs | 7 | 4 | 0 | 4 | 4 | 9 | 1 | 3 | 8 | 4 | 3 | 8 | 2 | 4 |
| Battery level | 9 | 3 | 4 | 0 | 8 | 9 | 3 | 3 | 9 | 3 | 7 | 8 | 1 | 6 |
| Bluetooth encounters | 10 | 3 | 4 | 8 | 0 | 10 | 3 | 4 | 10 | 4 | 7 | 9 | 1 | 8 |
| Calls | 16 | 9 | 9 | 9 | 10 | 0 | 3 | 4 | 20 | 7 | 10 | 17 | 2 | 10 |
| Cell tower ID | 3 | 0 | 1 | 3 | 3 | 3 | 0 | 1 | 3 | 0 | 3 | 3 | 0 | 2 |
| Gyroscope | 5 | 2 | 3 | 3 | 4 | 4 | 1 | 0 | 4 | 2 | 2 | 4 | 1 | 4 |
| GPS | 17 | 8 | 8 | 9 | 10 | 20 | 3 | 4 | 0 | 7 | 10 | 17 | 3 | 10 |
| Microphone | 8 | 5 | 4 | 3 | 4 | 7 | 0 | 2 | 7 | 0 | 2 | 6 | 0 | 4 |
| Screen on/off | 9 | 3 | 3 | 7 | 7 | 10 | 3 | 2 | 10 | 2 | 0 | 10 | 1 | 5 |
| SMS text messages | 13 | 5 | 8 | 8 | 9 | 17 | 3 | 4 | 17 | 6 | 10 | 0 | 2 | 8 |
| Step count | 2 | 1 | 2 | 1 | 1 | 2 | 0 | 1 | 3 | 0 | 1 | 2 | 0 | 1 |
| Wi-Fi | 8 | 3 | 4 | 6 | 8 | 10 | 2 | 4 | 10 | 4 | 5 | 8 | 1 | 0 |

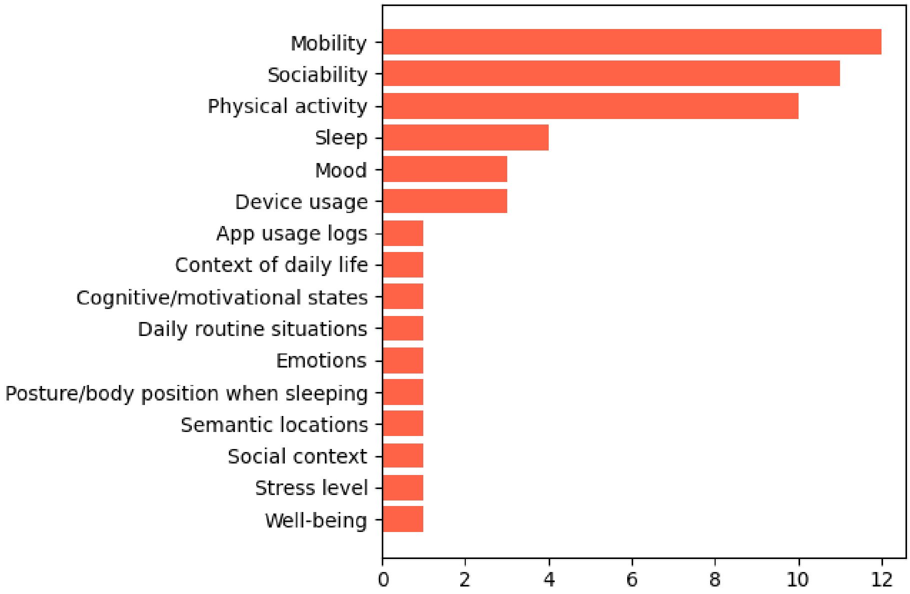
## High-Level Information Identified by Sensing Apps (SA-RQ2)

From the context data collected by sensing apps, researchers can extract high-level information representing different types of situations (eg, sociability, mobility). Table 3 presents the situations of interest identified from context data. Sensing apps aimed to identify information related to the physical and environmental aspects of the monitored individuals, such as mobility patterns [38] (eg, places visited, total distance traveled, time spent in locations), physical activities (activity type and duration), daily routine situations (eg, working, studying), and environmental context (eg, ambient temperature).

Figure 5 shows the types of high-level information generated by the sensing apps. The 3 types of information that stand out are human behavioral patterns related to mobility, sociability, and physical activity (n≥10). Information about the individual's condition was also derived, such as mood and sleep quality.

Researchers also explored information about device usage, which was derived from logs such as calls, SMS text messages, screen on/off events, and app usage. In general, studies have been able to build apps that achieve promising results of performance metrics (eg, accuracy, sensitivity, specificity) in identifying useful high-level information for mental health professionals. By contrast, there are some researchers developing apps that have not transformed context data into high-level information (ie, they focus only on raw data collection), and these are not shown in Figure 5.

**Figure 5.** High-level information summary.

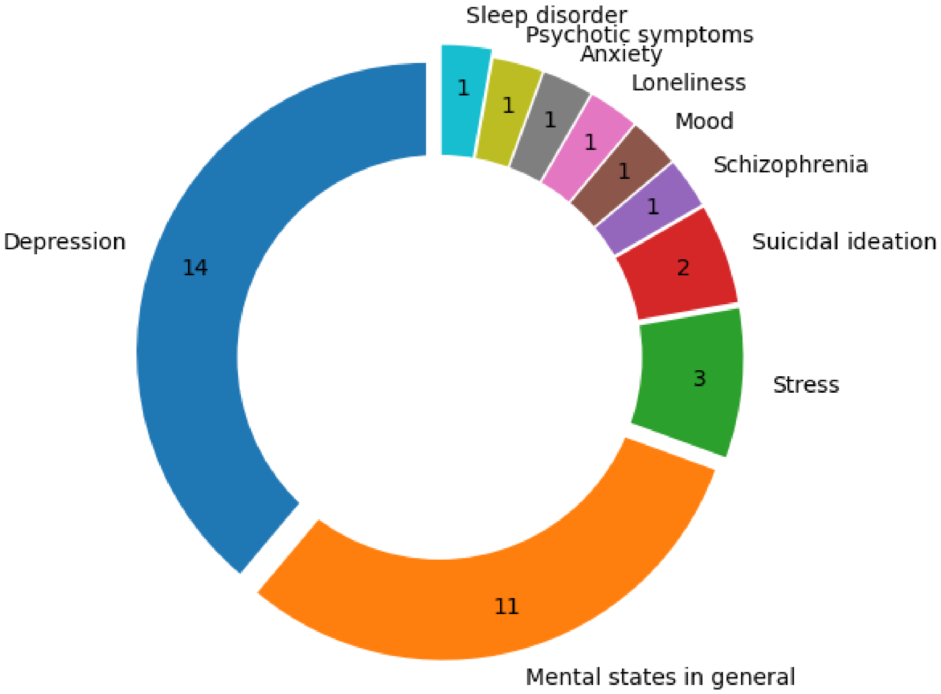


## Support for Monitoring Mental Health (SA-RQ3)

The sensing apps identified used high-level information to provide a variety of mental health services. Table 3 shows the types of analyses performed based on the high-level information identified. Some apps infer daily routine situations and send recommendations in real time [58], thus aiming to provide tools to improve services of health professionals. Most approaches to support mental health monitoring were as follows: correlation, classification, and prediction. Correlation analyses associate features extracted from high-level information with mental states of the monitored individual, that is, they aim to find evidence that identified behaviors have significant correlations with psychological well-being [79]. Researchers also used identified behaviors to design ML models capable of classifying and predicting mental states [32,80], which can be used as decision support tools for health professionals. Lastly, some studies [31,81,82] did not report on additional analyses, but concentrated on describing the features of their sensing apps to facilitate DPMH research.

Figure 6 shows the mental states/disorders studied by DPMH research. Apps classified as "Mental states in general" did not focus on a specific mental disorder; instead, they are generic to be used in studies for different mental health disorders. We found 14 articles with a focus on individuals with depression. Other mental states/disorders are schizophrenia, mood, suicidal ideation, stress, loneliness, anxiety, and psychotic symptoms, all with between 1 and 3 studies returned in our search. We identified 11 articles that did not specifically address a particular mental disorder in their studies.

**Figure 6.** Mental states/disorders targeted by sensing apps.



## Features Available in Data Sets (DS-RQ1)

The selected data sets have several types of features extracted from context data collected by sensing apps. These features model various aspects of human behavior that can be applied to the development process of new tools for monitoring and intervention in mental health. Table 4 presents the features available in the selected data sets. Data sets DS1 and DS7 contain features related to sleep. They provide information such as sleep start and end, sleep quality, time in bed, wake-up, sleep notes. Data sets DS4 and DS8 have features related to the social aspect such as self-reports of social interactions and Bluetooth encounter data, while data sets DS6 and DS8 provide actigraph data and self-reports, respectively. Data sets DS4 and DS5 have features capable of modeling more than 1 human behavior (ie, multimodal), thus providing data from different sources. These sources provide multimodal context data that can be fused to generate meaningful high-level information [10]. Moreover, multimodal data sets can support DPMH research under different aspects of interest for professionals, such as patient’s mobility and sociability.

## Possible High-Level Information Derived From Data Sets (DS-RQ2)

The selected data sets have features capable of modeling different types of human behavior. Therefore, to understand the potential for applying these data to DPMH, we identified high-level information that can be derived from these data sets based on the available context data. Table 4 presents high-level information inferred. Explicitly, these data sets can model the situations listed in Textbox 2.

Additionally, some data sets contain high-level information such as mood, mental status, and mental disorder symptoms. These types of information are self-reported by participants using questionnaires (eg, PHQ-9) and EMA solutions through smart devices.

**Textbox 2.** Situations modeled by data sets.

*Sociability*

This can be quantified using context data that allow characterizing social relationships of the participants such as interactions on online social networks, and face-to-face and device-mediated interactions [83]. These data sets contain context data such as posts on social networks, Bluetooth encounters, global positioning system (GPS) coordinates, or conversational activity inferred from microphone signals.

*Physical activity*

This is routinely measured using accelerometer and GPS data, resulting in either a log of user physical activities or an aggregate measure of energy expenditure.

*Sleep*

This is mostly measured in terms of sleep quality and sleep duration of the participants. In general, these data sets have features such as sleep quality, total sleep time, time in bed, and wake-up inferred from contextual data such as heart rate and screen on/off logs, and ambient light.

*Multimodal*

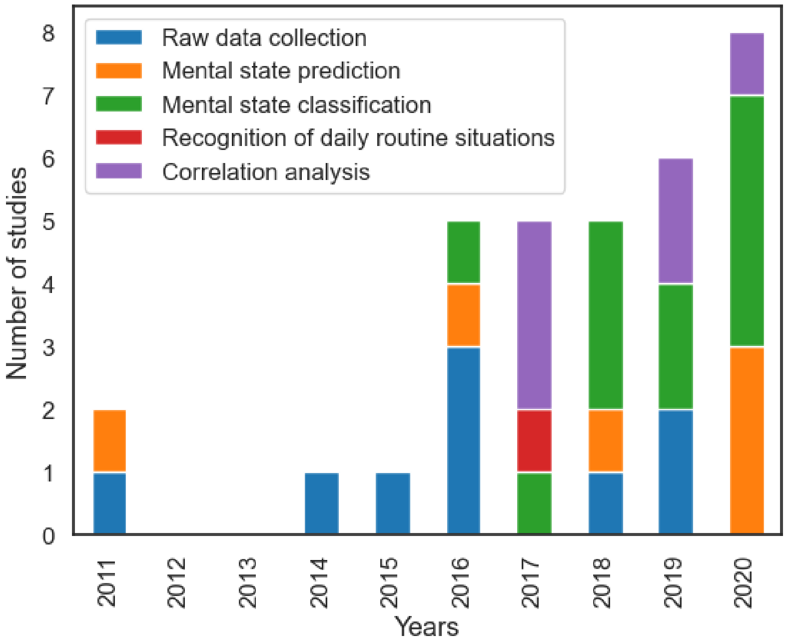
These data sets comprise several types of context data (eg, accelerometer, ambient light, battery level, Bluetooth, GPS, screen on/off, questionnaires [9-item Patient Health Questionnaire]), which allow characterizing more than 1 behavior of the participants such as sociability, mobility, and physical activity.

## Discussion

### Principal Findings

Our review shows that there are features that can be measured on smart devices that can act as proxies for mental status and well-being, but it should be noted that the combined evidence for high-quality features for mental states remains limited. Researchers have conducted several types of analysis on the data collected. In principle, we recognize a trend to design features from the data collected (Figure 7) to train ML models capable of classifying mental states/disorders (n=11) and predicting future mental states/disorders (n=6). We also note a substantial effort in analyzing correlations between features designed from the collected data and mental states/disorders (n=6). This type of analysis aims to find evidence of the viability and usefulness of DPMH for clinical practice. Furthermore, there are apps that only collect raw context data (n=9) to be analyzed subsequently, and 1 app (SituMan [39]) focused on the recognition of daily routine situations.

**Figure 7.** Number of published studies by year and types of analysis.



The literature mostly reports on the measurement of mobility, sociability, sleep, physical activity, and mood. Mobility represents high-level information derived from the movement sequence of individuals. These patterns are identified by processing GPS and Wi-Fi samples, which allow for the recognition of mobility traces. Sociability is measured using context data sources such as call logs, SMS text messages, Bluetooth encounters, and microphone data. These pieces of data allow identifying physical and virtual social interactions. Sleep information is measured by contextual data fusion such as ambient light, movement activity, screen on/off, and ambient sound. In addition, researchers have used Fitbit data to recognize sleep quality. Physical activity is recognized using data from inertial sensors (eg, accelerometer, magnetometer, gyroscope), making it possible to classify different types of activities such as walking, running, and stationary. Finally, mood has been recognized using different context data sources, such as accelerometer and heart rate monitor of wearable devices, combined with self-reports.

The different ways in which these features are inferred and reported make it impossible to compare results across studies, or combine data sets to achieve greater statistical power. For this reason, we believe the research community would benefit from a clear standard on the measurement of these behaviors. The data sets identified and studies in this review provide an interesting starting point for such consensus building. Particularly, the StudentLife data set [41] has been explored by many studies that propose solutions capable of supporting mental health professionals. Different solutions have used this data set to detect human behavioral patterns and perform association, classification, and prediction of mental states. For example, by using the StudentLife data set, Saeb et al [80] analyzed the correlation between mobility patterns identified from GPS samples and depressive symptoms reported by students. Farhan et al [84] designed a multiview biclustering model using various features (accelerometer, screen state, light, conversation data, and GPS) to identify clusters representing behavior subgroups. Morshed et al [81] developed a computational method to predict mood stability from behavioral features (eg, frequency of conversation, number of location changes, and duration of different physical activities) extracted from accelerometer, microphone, GPS, and Wi-Fi. Recently, de Moura et al [82,83] developed a solution capable of detecting sociability patterns and routine changes in social event streams (ie, conversation events).

A related issue is the predominance of solutions developed for Android OS, for which all apps have a version. This is expected as Android provides an open development platform, different from iOS, with significantly more flexibility to gather the data of interest. The divergent approaches to sensing on iOS and Android yield further issues in terms of standardization and the collection of comparable results across large cohorts, invariably with both Android and iOS users.

Our review further shows that studies use a mix of smartphone-based sensing and wearable device sensing. The latter may be useful where smartphones do not provide quality data (eg, for heart rate, physical activity during sport, or sleep quality), but do pose an issue in terms of interpretability of data given the variety of wearable devices available on the market, each of which use different algorithms. The interpretability of resulting information is further confounded as some of the most popular devices use proprietary algorithms to measure the behaviors of interest or provide aggregate data. Standards would need to consider the commercial pressure for device manufacturers that results in algorithms being proprietary and thus making it difficult to compare information from different devices.

Regarding the year of publication of the studies, most articles (n= 9) have been published in the last 3 years (Figure 7). These data reveal a growing trend in the number of solutions proposed for DPMH.

## Research Opportunities

From this review, we are able to identify different research opportunities for DPMH sensing apps, which are open issues for further investigation.

### *Wearable-Based Solutions*

Raw data have been generated mainly in smartphones, so few sensing apps have taken advantage of the potential of wearable devices to produce monitored individual's data ubiquitously. Wearables are capable of providing a lot of useful information about human behavior [79]. For example, wearable devices such as smartwatches and wristbands can collect users' context data even when they are performing intense physical activities such as running and swimming. Therefore, as these devices are smaller, meaning more imperceptible to the user, they can enrich the physiological data collection [85].

### *Explainable Models With a Focus on Human Behavior*

DPMH sensing apps that perform data analysis to design intelligent models have used traditional ML algorithms in different tasks [20]. These models sometimes lack transparency, which is not helpful for mental health professionals because evidence in decision support tools is required to be explainable. Although traditional ML models are very useful for generating valuable information that supports mental health treatment, an explanation of how they generate their outputs is desirable. This is fundamental because professionals need to interpret the patient's behavior to perform assessments and interventions. Therefore, explainable models [86] seems to be the way to apply machine and deep learning techniques more suitable to DPMH.

### *Real-Time Inference Engines*

Most sensing apps perform offline data analysis after collecting raw data (eg, to create ML models, to correlate self-reports with context data). Therefore, few solutions provide inference engines to produce high-level information in real time. These generated situations of interest are useful to have a better insight into the patient's behavior and to allow interventions to adapt to this information in real time. This is crucial in extreme cases such as signs of suicidal ideation, but generally useful where the goal is to implement ecological momentary interventions or just-in-time interventions that rely on just-in-time information on user status. In this sense, both rule-based engines (eg, fuzzy logic [39], complex event processing [82]) and ML-based approaches [20] are promising tools to process context data efficiently and infer high-level information in DPMH.

### *Extensible Solutions*

Sensing apps are not able to be customized for use in other research. Although general-purpose (eg, Sensus [35]) and reusable (eg, Beiwe [15] and SituMan [39]) apps can be applied to other research, none of the solutions identified in this review is extensible. Proposals of framework, middleware, and library are examples of extensible solutions that provide services, reusable code, and are prepared to be modified or consumed by apps. They would be very useful to allow DPMH researchers to extend solution's capabilities to different requirements. Therefore, this could reduce costs and time for research in specific scenarios.

By analyzing the results of the public data set review, we clearly identify the scarcity of data sets (n=8). This low number may be related to the privacy of information collected from study participants. DPMH researchers should possibly be concerned about whether collected data will become public, which could enable to identify participants from them. DPMH data sets may have sensitive personal information about the mental health treatment or monitoring, hence ethical issues arise [87]. Moreover, ethics committees where studies are recorded may restrict the sharing of collected data to the public. This barrier can generate great difficulty for the development of new research, because new ML models and engines for inferring high-level information are not possible to be designed and trained. Differential privacy seems to be a promising tool to break this barrier [88].

Another open issue is the standardization of data sets. Currently, there is no standard for data representation (eg, data type, precision, file format) and collection (eg, frequency, duration, presence of time stamps). As a result, data sets cannot be combined, nor can we easily compare the performance of different approaches or algorithms. Proposals for standardization would be a major contribution to the DPMH field.

It is beneficial for such standardization that there are efforts to design general-purpose sensing apps. We propose that the research community should endeavor to work on such apps collaboratively and make these apps available on a non-for-profit basis. This could not only result in an efficient use of commonly agreed standards, but would also reduce the wasteful effort of developing custom sensing apps. Such initiatives, however, are difficult to start and maintain, as has been shown by brave endeavors such as Beiwe [15], Funf [31], Purple Robot [33], and Sensus [35], which show that keeping such platforms up-to-date is an expensive process that can only be warranted if continued use guarantees continued resources for maintenance and further development.

Notwithstanding the benefits we believe would be derived from such standards, it should be acknowledged that self-reports will likely remain an important modality to improve the quality of automatically measured behaviors, or to measure behaviors or states that cannot be automatically measured. An opportunity that is not widely leveraged is using the automatically measured behaviors to trigger such self-reports. This would allow self-reports to be more appropriate to the user's context, further inform automated measures in case sensor measurements do not provide a clear enough picture, and be less intrusive. Software for such a functionality has been proposed previously [39,89], and we believe such a functionality should be part of standardized tools for capturing DPMH.

Finally, data sets are composed of few study participants. It may be difficult for researchers in attracting participants to the research and, at the same time, making them remain until the end of the study. The low number of participants can potentially compromise the use and validation of some data contained in the data sets, and this directly reflects the use of data sets in other DPMH surveys, where it requires a high number of participants to be validated.

### Limitations and Future Work

A first limitation is that data sets and articles published in languages other than English were not included in this review. Second, the search for sensing apps was restricted to 8 digital libraries, although we searched 20 sources with numerous public data sets. Finally, our review is limited by studies reported in the published literature and data sets available to be downloaded.

In addition, we did not focus on security and privacy aspects of DPMH apps in this review. Therefore, our plans include a systematic analysis on the security and privacy features provided by DPMH apps. As this is an extremely sensitive aspect in the development of new functionalities for current and new DPMH mobile systems, a particular characterization with deeper analysis is required. Therefore, we plan to dedicate efforts on this topic for further investigation.

### Conclusions

In this article, we described a systematic review that resulted in a deep analysis of 31 sensing apps and 8 public data sets for DPMH. Results showed a growth in DPMH sensing apps in recent years as opposed to a scarcity of public data sets. We answered the research questions, then showing, for example, the most used context data and their respective sources, the different types of high-level information generated by the analysis of the collected data, the features available in data sets, and the mental disorders that researchers have focused. From the results, we were able to identify trends and open issues that hinder the development of research in the DPMH area. As a consequence, by considering the growth in proposals for DPMH sensing apps and the impact of the COVID-19 outbreak on global mental health, we believe that DPMH presents a great perspective for future research not only to overcome open issues discussed in this review, but also to reach the needed maturity for application in clinical settings.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

List of 20 data set repositories.
[XLSX File (Microsoft Excel File), 102 KB-Multimedia Appendix 1]

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## Multimedia Appendix 2

Items used in the data extraction process.
[DOCX File , 8 KB-Multimedia Appendix 2]

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## Multimedia Appendix 3

Reviewed sensing apps.
[DOCX File , 10 KB-Multimedia Appendix 3]

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## Abbreviations

**DPMH:** digital phenotyping of mental health
**DS-RQs:** research questions data sets
**EC:** exclusion criteria
**EMA:** ecological momentary assessment
**GPS:** global positioning system
**IC:** inclusion criteria
**ML:** machine learning
**PHQ-9:** 9-item Patient Health Questionnaire
**SA-RQs:** research questions for sensing apps

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Original Paper

# Measuring Electronic Health Literacy: Development, Validation, and Test of Measurement Invariance of a Revised German Version of the eHealth Literacy Scale

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## Abstract

**Background:** The World Wide Web has become an essential source of health information. Nevertheless, the amount and quality of information provided may lead to information overload. Therefore, people need certain skills to search for, identify, and evaluate information from the internet. In the context of health information, these competencies are summarized as the construct of eHealth literacy. Previous research has highlighted the relevance of eHealth literacy in terms of health-related outcomes. However, the existing instrument assessing eHealth literacy in the German language reveals methodological limitations regarding test development and validation. The development and validation of a revised scale for this important construct is highly relevant.

**Objective:** The objective of this study was the development and validation of a revised German eHealth literacy scale. In particular, this study aimed to focus on high methodological and psychometric standards to provide a valid and reliable instrument for measuring eHealth literacy in the German language.

**Methods:** Two internationally validated instruments were merged to cover a wide scope of the construct of eHealth literacy and create a revised eHealth literacy scale. Translation into the German language followed scientific guidelines and recommendations to ensure content validity. Data from German-speaking people (n=470) were collected in a convenience sample from October to November 2020. Validation was performed by factor analyses. Further, correlations were performed to examine convergent, discriminant, and criterion validity. Additionally, analyses of measurement invariance of gender, age, and educational level were conducted.

**Results:** Analyses revealed a 2-factorial model of eHealth literacy. By item-reduction, the 2 factors information seeking and information appraisal were measured with 8 items reaching acceptable-to-good model fits (comparative fit index [CFI]: 0.942, Tucker Lewis index [TLI]: 0.915, root mean square error of approximation [RMSEA]: 0.127, and standardized root mean square residual [SRMR]: 0.055). Convergent validity was comprehensively confirmed by significant correlations of information seeking and information appraisal with health literacy, internet confidence, and internet anxiety. Discriminant and criterion validity were examined by correlation analyses with various scales and could partly be confirmed. Scalar level of measurement invariance for gender (CFI: 0.932, TLI: 0.923, RMSEA: 0.122, and SRMR: 0.068) and educational level (CFI: 0.937, TLI: 0.934, RMSEA: 0.112, and SRMR: 0.063) were confirmed. Measurement invariance of age was rejected.

**Conclusions:** Following scientific guidelines for translation and test validation, we developed a revised German eHealth Literacy Scale (GR-eHEALS). Our factor analyses confirmed an acceptable-to-good model fit. Construct validation in terms of convergent, discriminant, and criterion validity could mainly be confirmed. Our findings provide evidence for measurement invariance of the instrument regarding gender and educational level. The newly revised GR-eHEALS questionnaire represents a valid instrument to measure the important health-related construct eHealth literacy.

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**KEYWORDS**

eHealth; eHeals; health literacy; factor analysis; validation; measurement invariance; internet; health information

# *Introduction*

## Background

The concept of health literacy emerged in the 1990s as a competence to gather health information and use it to address health questions and problems [1]. Nutbeam [2] defined health literacy as "cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health." In the following years, health literacy has turned out to be an important predictor for various health outcomes (eg, behavior of patients with diabetes mellitus or heart failure) [3,4]. The World Health Organization has declared health literacy as a key determinant of health and defined it as a Sustainable Development Goal [5].

With the rise of the internet as a source of information, the gathering of health information was no longer limited to professional or face-to-face health sources but was available from many different health topic websites [6]. With the increasing availability of health information on the internet, the number of people using this source for seeking health information rose as well [7,8]. However, sources on the internet contain inconsistent information as contributions are not by professionals only [9]. As a result, the amount and differences in quality of information provided on the internet may lead to health information overload [10]. For example, in 2020, COVID-19 became a global pandemic, and disease-related information, especially from the internet, grew exponentially, leading to an "infodemic" [11,12]. Not only is a large amount of information available, but a significant amount of it must be considered misinformation because the sources of the information must be classified questionable [13,14].

For the context of information from the internet, Norman and Skinner [15] applied the concept of health literacy to electronic health literacy (eHealth literacy). With the development of the eHealth Literacy Scale (eHEALS) questionnaire [16], the concept of eHealth literacy became measurable and emerged as a growing interest in psychological and medical health sciences. Systematic reviews have shown that eHEALS is associated with different health-related outcomes, but findings could not be consistently confirmed [17,18]. Associations of eHealth literacy with different health outcomes have been found, such as health intentions [19], acquiring health knowledge [20-23], and health prevention behavior [21,24,25]. Furthermore, research showed associations between eHealth literacy and healthy behaviors like exercise behavior, balanced nutrition, and regular breakfast [26,27]. In the context of COVID-19, associations of eHealth literacy and lower psychological symptoms [28] and higher prevention behaviors [29] could be confirmed. To sum up, research indicates that eHealth literacy is associated with prevention behaviors, the acquisition of knowledge, and people's ability to cope with diseases, which confirms eHealth literacy as an important construct in examining people's health behavior.

To cope with information overload and use the information from the internet, Norman and Skinner [15] proposed a set of different competencies: skills to read, identify, and understand different information to distinguish helpful from less helpful or even false or harmful information. These competencies represent a sequential process of handling available information. In the first step, basic cognitive skills are needed to search for information regarding a certain topic. In a subsequent cognitive process, information available must be distinguished as helpful or less helpful in order to answer specific questions. These steps represent an elaborated cognitive information process rather than a heuristic one. The distinction of cognitive processes was formerly described within dual-process theories in psychological literature and confirmed in multiple studies [30-32]. Dual-process theories distinguish between fast cognitive processes, which describe heuristic and holistic approaches representing intuitive, implicit cognitions, and slow cognitive processes, which are analytic and rule-based and focus on explicit learning [33]. Slow cognitive processes run serially and require cognitive capacity to answer or address specific questions. In the context of eHealth literacy, the handling of health information from the internet clearly represents a serial process of subsequent cognitions that require different competencies building on each other.

## eHEALS: Translations of the Original eHEALS Questionnaire and its Limitations

Since its publication, the original eHEALS questionnaire has been translated into many languages, including Italian [34,35], Spanish [36], Dutch [37], Chinese [38], Serbian [39], Korean [40], Indonesian [41] and German [42]. However, some of these studies could not confirm the 1-factorial model as assumed by Norman and Skinner [16]. Looking at many different validation studies of the eHEALS questionnaire, a consistent factorial structure has not been verified; 1-factorial [16,37,43], 2-factorial [42,44,45], and 3-factorial models [46-48] have been identified in different validation studies and languages. These results indicate that the eHEALS questionnaire lacks consistent factorial structure.

The German version of the questionnaire validated by Soellner and colleagues [42] especially lacks methodological and content-related accuracy. They developed an initial instrument for assessing eHealth literacy for the German-speaking community (G-eHEALS). However, Soellner and colleagues [42] did not meet scientific criteria substantially; first, they did not meet the criteria scientifically recommended for translation of instruments. Second, in their 2-factorial model content validity was questionable because some items reflected the subdimension of information appraisal rather than the assigned subdimension of information seeking ("I know how to use the health information I find on the internet to help me" or "I feel confident in using information from the internet to make health decisions"). In addition, Soellner and colleagues [42] collected their data on a limited sample of 327 students aged 16 to 21 years at only one type of school (gymnasium: a German school type preparing for university attendance), and people of older age were not considered for validation. However, as people of older age may be less familiar using the internet [49-51] and eHealth literacy especially depicts a particular digital literacy, the model proposed by Soellner and colleagues [42] is possibly not valid for assessing eHealth literacy in older people. Moreover, the educational level of the participants could not be considered within their biased study sample. Juvalta and colleagues [52], who used the G-eHEALS, have also collected their data on a limited sample of young parents (88.5% female). In another German-speaking study, Reder and colleagues [53] have shown a 3-factorial structure for the G-eHEALS. However, only women participated in this study, which is a limited sample for examining the validity of the G-eHEALS. Inconsistent findings and methodological limitations of these studies indicate an unclear factorial structure of the G-eHEALS.

Another limitation of the original eHEALS questionnaire refers to insufficient representation of an elaborated cognitive information process. The original scale does not reflect the above-mentioned complexity of an information process in its entirety. Petrič and colleagues [54] focused on this limitation and developed an extended eHealth literacy scale (eHEALS-E). Creating a 20-item questionnaire, they found a 6-factorial structure. Despite this extension and other concepts and questionnaires [55-57], eHEALS is still the instrument most used for measuring eHealth literacy.

### Aims of This Study

In summary, the G-eHEALS validated by Soellner and colleagues [42] was a valuable first approach to the important topic of eHealth literacy, but it underlies significant methodological limitations and lacks in psychometric quality. Nevertheless, as eHealth literacy could be confirmed as an important construct of health-related outcomes, the possibility of assessing eHealth literacy is crucial for health care practitioners and researchers in understanding health competence in German-speaking people. In response to the practical and scientific demands and described limitations, we developed a new instrument for measuring eHealth literacy with 4 objectives:

- Extension of the existing questionnaire of Norman and Skinner [16] by 8 nonoverlapping items proposed by Petrič and colleagues [54]. By combining the questionnaires, a better representation of the construct of eHealth literacy regarding the cognitive processes of seeking, identifying, and evaluating health information should be achieved.
- German translation of the items according to common scientific recommendations [58,59] to ensure content validity.
- Validation of the revised GR-eHEALS at a convenience sample in terms of construct and criterion validity. We decided to collect data in a convenience sample to reach participants with varied socioeconomic backgrounds. Furthermore, our goal was not to limit the sample in order to develop a measurement model that is as generic as possible.
- To our knowledge, there is no study examining measurement invariance of eHealth literacy between gender, age, or educational level in a German sample. Nevertheless, the interpretation of statistical differences between different groups of people requires measurement invariance between these groups [60]. As eHealth literacy represents competencies that are important for people regardless of their sociodemographic status, its measurement should obviously be independent of these influencing variables.

All in all, we are pursuing the study goals to develop a revised and validated instrument for measuring eHealth literacy. Further, we sought to examine the measurement invariance of the instrument regarding relevant sociodemographic variables.

## Methods

### Development of the New Instrument

The revised eHealth Literacy Scale (GR-eHEALS) is based on the original items from the eHEALS [16] extended by adding items from the eHEALS-E questionnaire from Petrič and colleagues [54]. The translation was conducted following the guidelines proposed by Beaton and colleagues [58] and Guillemin and colleagues [59] for translation of academic literature to ensure content validity. Accordingly, in a first step, 2 of the authors translated the items into German and merged these translations into a first translation proposal. In the second step, this proposal was discussed within a systematic expert panel consisting of the 2 translators and 2 psychologists who are experts in the context of health care and eHealth. The resulting second proposal was translated back into English in the third step to confirm that the essential meaning of the items is consistent with the original items. In the fourth step, cognitive interviews were conducted to make sure that all items are easy to understand, do not include offensive speech, and do not discriminate for age or gender. Interviewees were aged 23 to 72 years and had different educational backgrounds. The resulting final version of the translated and extended version consisted of 16 items. The original items and the translated items are displayed in Multimedia Appendix 1. Items 1 to 8 are translated from the original eHEALS questionnaire from Norman & Skinner [16], and items 9 to 16 are translated from the questionnaire (eHEALS-E) from Petrič and colleagues [54]. All subsequent nominations of item numbers refer to the item numbers mentioned in Multimedia Appendix 1. To validate the GR-eHEALS, we performed a prestudy in which we aimed to check for any complications in answering the translated items and to conduct an item analysis The results of this analysis are displayed in Multimedia Appendix 2. As the prestudy showed solid item characteristics, the developed instrument was considered good fitting for the purpose of the main study.

## Study Design and Participants

The cross-sectional study was conducted via Unipark (Tivian XI GmbH), an online survey tool, between October and November 2020. The ethics committee of the Faculty of Medicine of the University of Duisburg–Essen reviewed and approved this study (20-9592-BO).

All data were collected anonymously. Participants for this study were recruited via personal and occupational networks and online social networks (Xing, Facebook, LinkedIn). In our analyses, only complete data sets were considered. From a total of 1634 participants, 524 have completed our questionnaire in full, which represents a completion rate of 32.1% and can be considered typical for an online survey [61]. We excluded cases in which participants took less than 5:34 minutes (5% percentile) or more than 25:45 minutes (95% percentile) to complete the survey. Furthermore, we excluded 1 participant for being under 18 years old. As only 1 person indicated gender as diverse, we excluded this case in order to perform the analysis of measurement invariance of gender. The resulting sample consisted of 470 respondents. The sample size is in accordance with recommendations for validation studies [62,63]. Answering the questionnaire took 11:32 (SD 4:24) minutes on average. All data supporting the conclusion of the study are included in Multimedia Appendix 3.

In the main study, it was our objective to validate the GR-eHEALS in a convenience sample to verify its convergent, discriminant, and criterion validity and test for measurement invariance.

We verified convergent validity by assuming a positive correlation between eHealth literacy and health literacy, which measures a similar construct but does not take the source of information into account. Furthermore, we assumed eHealth literacy to be positively interrelated with internet confidence and negatively associated with internet anxiety as eHealth literacy particularly focuses on the gathering of information from the internet.

To verify discriminant validity, we captured impulsivity and common personality traits assuming no significant interrelations. As eHealth literacy reflects competencies in dealing with health-related information [15] rather than a personality trait, there should be no content-related overlaps between eHealth literacy and personality traits.

Additionally, we considered the possible outcome variables mental and physical health status and life satisfaction to examine criterion validity. Criterion validity of an instrument describes the ability to prove relationships between the construct itself and possible outcomes [64]. Thus, we expected eHealth literacy to be associated with above mentioned health-related variables.

The survey included the following questionnaires (sample items presented below are translations). Most scales were assessed on 5-point Likert scales from 1=strongly disagree to 5=strongly agree. Exceptions are separately explained below. Scales contained inverted items that were recoded prior to statistical analyses.

## Measurements

### *Health Literacy*

Participants rated their health literacy on 16 items from the Health Literacy Questionnaire from Röthlin and colleagues [65]. A sample item is “How easy/difficult is it to find information about therapies for diseases that affect you?” Health literacy was measured on a 2-point scale (easy/hard). Therefore, it is used as a sum-score indicating the extent of health literacy between 0 and 16 (mean 12.63 [SD 2.99]). Cronbach alpha of this scale was .79.

### *Impulsivity*

We used the 8-item Impulsive Behavior–8 Scale from Kovaleva and colleagues [66] to measure impulsivity (eg, “Sometimes I spontaneously do things that I should not have done”). Cronbach alpha of this scale was .72 (mean 2.78 [SD 0.59]).

### *Personality Traits*

Personality traits (extraversion, neuroticism, openness, conscientiousness, and agreeableness) were each assessed by 2 items from Rammstedt and colleagues [67]. A sample item for neuroticism is “I get nervous and insecure easily.” Extraversion (mean 3.30 [SD 1.04]), neuroticism (mean 3.08 [SD 0.97]), openness (mean 3.61 [SD 0.99]), conscientiousness (mean 3.59 [SD 0.75]), and agreeableness (mean 3.15 [SD 0.76]) had Cronbach alphas of .79, .66, .62, .38, and .19, respectively. Due to low reliabilities, conscientiousness and agreeableness were excluded from the following analyses.

### *Further Constructs*

In addition, we asked for internet confidence (3 items; mean 3.74 [SD 0.72], Cronbach alpha .89), internet anxiety (3 items; mean 1.81 [SD 0.82], Cronbach alpha .81) and single items to measure physical (mean 7.37 [SD 1.58]) and mental health (mean 7.27 [SD 1.90]) on 11-point Likert scales from 0=very bad health to 10=very good health (all self-formulated), and life satisfaction at a 5-point Likert scale from 1=not satisfied at all to 5=totally satisfied (mean 3.76 [SD 0.83]) from Beierlein and colleagues [68].

Furthermore, sociodemographic variables (age, gender, marital status, educational level, financial situation, internet availability, and community size) were considered to make sure that the sample represents the population.

## Statistical Analysis

All data analyses were conducted using R (R Foundation for Statistical Computing), RStudio, and several packages.

Prior to conducting confirmatory factor analysis (CFA), we performed an exploratory factor analysis (EFA) to evaluate whether data were suitable for factor analysis. We used the Kaiser-Meyer-Olkin (KMO) and Bartlett test of sphericity for evaluation. Factor extraction was conducted using maximum likelihood estimation with Promax oblique rotation and number of factors were identified by scree plot inspection and Kaiser criterion (eigenvalue >1). Factor loadings ≥0.4 were considered as significant [69].

Subsequently, we performed consecutive CFA and compared fit indices and factor loadings to confirm the best-fitting model by considering the recommendations of Hu and Bentler [70] who assume to achieve a comparative fit index (CFI) and Tucker Lewis index (TLI) about 0.95 and root mean square error of approximation (RMSEA) and standardized root mean square residual (SRMR) about 0.06 and 0.08, respectively. We used the robust maximum likelihood estimator as our prestudy showed that items were slightly negative skewed, and a robust estimator is more likely to produce less biased model statistics than maximum likelihood estimator [71].

Two-tailed Pearson correlations were conducted considering a significance level of 5% to examine convergent, discriminant, and criterion validity.

We performed tests of measurement invariance on our final model to examine whether the measurement is reliable for both genders as well as 2 age groups and 3 groups of educational level. For this purpose, we performed consecutive multigroup CFA with progressively stricter model assumptions by fixing an increasing number of model parameters for each of 3 measurement invariance models.

Measurement invariance—as a prerequisite for the interpretation of mean differences—is verified by 3 consecutive steps with increasingly strict model assumptions for (1) the number of factors and the pattern of factor-indicator relationships (configural invariance), (2) factor loadings (metric invariance), and (3) intercepts of indicators (scalar invariance) [72]. These 3 steps assume that there are no differences between observed groups regarding these parameters, and interpretation of mean differences is valid when scalar invariance is confirmed [73]. Differences between groups should only be interpreted when measurement invariance is confirmed since otherwise differences between groups may occur due to the fact that an instrument does not measure equally between different groups [60,73,74].

We applied a cutoff criterion of a difference of CFI (ΔCFI) of 0.01 as it is proposed as appropriate to assume invariance between two models [75,76]. Thus, for evaluation of measurement invariance we considered the model fit indices and difference of CFI between compared models.

# Results

## Sample Characteristics

Mean age of participants was 37.16 (SD 13.4, min 18, max 82, median 33) years. Sample characteristics of all other sociodemographic variables are shown in Table 1.

**Table 1.** Summary of sample characteristics (n=470).

| Characteristics | Values, n (%) |
|---|---|
| **Gender** | |
| Female | 332 (70.6) |
| Male | 138 (29.4) |
| **Marital status** | |
| Married | 161 (34.3) |
| Not married, in partnership | 183 (38.9) |
| Single | 115 (24.5) |
| Other | 11 (2.3) |
| **Educational level** | |
| Lower secondary school | 5 (1.1) |
| Upper secondary school | 24 (5.1) |
| University entrance qualification | 77 (16.4) |
| Vocational training | 91 (19.4) |
| University degree | 273 (58.1) |
| **Financial situation** | |
| Very good | 9 (1.9) |
| Good | 47 (10.0) |
| Middling | 114 (24.3) |
| Bad | 220 (46.8) |
| Very bad | 80 (17.0) |
| **Internet availability** | |
| Always available | 288 (61.3) |
| Mostly available | 177 (37.7) |
| Occasionally available | 5 (1.1) |
| Not available | 0 (0.0) |
| **Community size** | |
| Big city (>100,000 inhabitants) | 244 (51.9) |
| Medium city (>20,000 inhabitants) | 88 (18.7) |
| Small city (>5000 inhabitants) | 76 (16.2) |
| Rural village (<5000 inhabitants) | 62 (13.2) |

## Exploratory Factor Analysis

KMO revealed a value of 0.92 and Bartlett test of sphericity was highly significant (*P*<.001), indicating that data were suitable for factor analysis. Empirical Kaiser criterion and scree plot implied a 2-factor model. Table 2 shows factor loadings of the 2 factors.

As item 14 did not significantly load on any of the 2 factors it was excluded from the following analysis. The remaining 15 items were considered in the CFA.

**Table 2.** Results of exploratory factor analysis.

| Item no | Factor 1 | Factor 2 |
|---|---|---|
| 1 | 0.88 | –0.06 |
| 2 | 0.80 | 0.03 |
| 3 | 0.84 | 0.00 |
| 4 | 0.97 | –0.06 |
| 5 | 0.49 | 0.37 |
| 6 | 0.10 | 0.62 |
| 7 | 0.03 | 0.70 |
| 8 | 0.28 | 0.49 |
| 9 | 0.00 | 0.78 |
| 10 | –0.12 | 0.78 |
| 11 | –0.11 | 0.75 |
| 12 | –0.07 | 0.56 |
| 13 | 0.12 | 0.56 |
| 14 | 0.32 | 0.31 |
| 15 | 0.44 | 0.01 |
| 16 | 0.44 | –0.09 |

## Confirmatory Factor Analysis

In model 1, 15 items were assigned on the 2 factors identified by the EFA. Based on the content meanings of the underlying items, factor 1 represents information seeking and factor 2 represents information appraisal. However, items 13, 5, and 15 did not fit the factor proposed by the EFA in terms of their content. Therefore, item 13 was reassigned to information seeking whereas items 5 and 15 were reassigned to information appraisal in model 2. For model 3, we removed 6 items due to low factor loadings (<0.65). Moreover, we excluded 1 more item to develop a parsimonious model resulting in a 2-factorial model with 4 items on each of the 2 factors. Table 3 shows the model fits of the 3 models. CFI, TLI, and SRMR practically meet the criteria of a good model fit. RMSEA is slightly above the recommendations of Hu and Bentler [70]. Considering the recommendations, model 3 shows an acceptable-to-good model fit.

Figure 1 depicts the structure of the 2-factorial model with its factor loadings. All item factor loadings were greater than $\lambda=0.71$.

Information seeking and information appraisal achieved satisfactory Cronbach alphas of .92 and .83, respectively. Table 4 shows the statistics of the final items. Based on mean and standard deviation, lower levels of information seeking and information appraisal are below a mean score of 2.99 and 3.20, respectively. Higher levels can be assumed above mean scores of 4.71 and 4.69, respectively.

**Table 3.** Results of the confirmatory factor analyses.

| Model | Chi-square | df | CFI[a] | TLI[b] | RMSEA[c] | SRMR[d] | AIC[e] | BIC[f] |
|---|---|---|---|---|---|---|---|---|
| 1 | 433.5 | 89 | 0.891 | 0.871 | 0.100 | 0.067 | 16029.832 | 16158.567 |
| 2 | 519.8 | 89 | 0.863 | 0.839 | 0.112 | 0.084 | 16136.608 | 16265.343 |
| 3 | 117.0 | 19 | 0.942 | 0.915 | 0.127 | 0.055 | 7782.043 | 7852.640 |

[a] CFI: comparative fit index.

[b] TLI: Tucker Lewis index.

[c] RMSEA: root mean square error of approximation.

[d] SRMR: standardized root mean square residual.

[e] AIC: Akaike information criterion.

[f] BIC: Bayesian information criterion.

**Figure 1.** A 2-factorial, intercorrelated model of eHealth literacy.

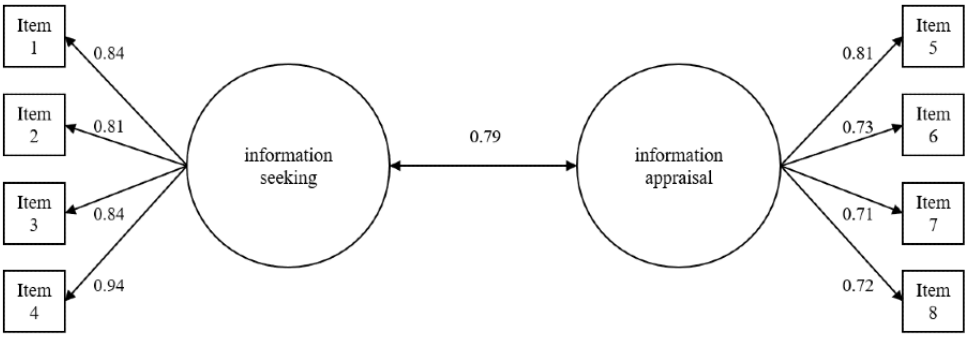

**Table 4.** Descriptive statistics of the revised German eHealth Literacy Scale (GR-eHEALS) items.

| Item | Mean (SD) | Median | Skew |
|---|---|---|---|
| **Information seeking** | 3.85 (0.86) | 4.00 | –0.78 |
| 1. Ich weiß, wie ich Internetseiten mit hilfreichen Gesundheitsinformationen finden kann. | 3.93 (0.95) | 4.00 | –0.93 |
| 2. Ich weiß, wie ich das Internet nutzen kann, um Antworten auf meine Gesundheitsfragen zu erhalten. | 4.04 (0.87) | 4.00 | –1.01 |
| 3. Ich weiß, welche Seiten mit Gesundheitsinformationen im Internet verfügbar sind. | 3.63 (1.00) | 4.00 | –0.60 |
| 4. Ich weiß, wo ich im Internet hilfreiche Gesundheitsinformationen finden kann. | 3.81 (1.01) | 4.00 | –0.89 |
| **Information appraisal** | 3.95 (0.74) | 4.00 | –0.77 |
| 5. Ich weiß Gesundheitsinformationen aus dem Internet so zu nutzen, dass sie mir weiterhelfen. | 3.91 (0.88) | 4.00 | –0.77 |
| 6. Ich bin in der Lage, Internetseiten mit Gesundheitsinformationen kritisch zu bewerten. | 4.18 (0.87) | 4.00 | –1.24 |
| 7. Ich kann zwischen vertrauenswürdigen und fragwürdigen Internetseiten mit Gesundheitsinformationen unterscheiden. | 4.07 (0.84) | 4.00 | –0.93 |
| 8. Ich fühle mich sicher darin, Informationen aus dem Internet zu nutzen, um Entscheidungen in Bezug auf meine Gesundheit zu treffen. | 3.62 (1.03) | 4.00 | –0.57 |

## Validation of the GR-eHEALS

To examine convergent, discriminant, and criterion validity of the GR-eHEALS, we performed correlation analyses with the 2 factors (information seeking and information appraisal). Moreover, correlations of the 2 factors with demographic variables were calculated. Results are shown in Table 5. Both factors were strongly positively correlated with health literacy and internet confidence and strongly negatively correlated with internet anxiety. None of the 2 scales correlated significantly with impulsivity or extraversion. Information appraisal was interrelated with neuroticism while information seeking was associated with openness. Information appraisal was correlated with mental and physical health and life satisfaction, which was not true for information seeking. Furthermore, information seeking was significantly associated with age.

**Table 5.** Pearson correlation coefficients of the eHealth literacy factors.

| Scales | Information seeking (*P* value) | Information appraisal (*P* value) |
|---|---|---|
| **Convergent validity** | | |
| Health literacy | 0.43 (<.001) | 0.53 (<.001) |
| Internet confidence | 0.17 (<.001) | 0.17 (<.001) |
| Internet anxiety | –0.21 (<.001) | –0.23 (<.001) |
| **Discriminant validity** | | |
| Impulsivity | –0.06 (.16) | –0.05 (.28) |
| Extraversion | –0.03 (.58) | 0.03 (.56) |
| Neuroticism | –0.08 (.09) | –0.14 (.001) |
| Openness | 0.10 (.03) | 0.07 (.12) |
| **Criterion validity** | | |
| Mental health | 0.06 (.20) | 0.19 (<.001) |
| Physical health | 0.06 (.21) | 0.12 (.01) |
| Life satisfaction | –0.01 (.83) | 0.12 (.01) |
| **Sociodemographic variables** | | |
| Age | 0.10 (.02) | 0.06 (.16) |
| Gender | –0.03 (.55) | 0.01 (.78) |
| Marital status | –0.02 (.71) | –0.07 (.15) |
| Educational level | –0.04 (.39) | –0.02 (.68) |
| Financial situation | –0.05 (.27) | 0.04 (.45) |
| Internet availability | 0.01 (.76) | 0.02 (.71) |
| Community size | 0.02 (.60) | –0.04 (.41) |

## Test of Measurement Invariance

Measurement invariance of the GR-eHEALS was performed to test whether the scale is a suitable measurement independently of gender, age, and educational level. Prior to these analyses, a median split was performed to separate participants into 2 groups according to age. Median age was 33 years. Also, to divide the study sample into 3 groups of educational levels, we separated participants into people who held a university degree, people who completed a vocational training, and people who had any school certificate. Results of the analyses are shown in Table 6.

Besides chi-square and fit indices, Table 6 shows the differences of CFI between models. Regarding measurement invariance of gender and education, all changes in CFI are below 0.01, indicating that model fits did not substantially decrease between more constraint models. Measurement invariance regarding age must be rejected as configural invariance could not be confirmed.

**Table 6.** Results of measurement invariance for gender, age, and education using multigroup confirmatory factor analysis.

| Model | Chi-square | df | CFI[a] | TLI[b] | RMSEA[c] | SRMR[d] | ΔCFI[e] |
|---|---|---|---|---|---|---|---|
| **Gender[f]** | | | | | | | |
| Configural[g] | 154.937 | 38 | 0.94 | 0.905 | 0.135 | 0.056 | 0.006 |
| Metric | 166.889 | 44 | 0.93 | 0.916 | 0.128 | 0.066 | 0.002 |
| Scalar | 181.273 | 50 | 0.93 | 0.923 | 0.122 | 0.068 | 0.002 |
| **Age[h]** | | | | | | | |
| Configural[g] | 187.672 | 38 | 0.92 | 0.883 | 0.150 | 0.059 | 0.021 |
| Metric | 185.713 | 44 | 0.92 | 0.901 | 0.138 | 0.059 | –0.002 |
| Scalar | 197.419 | 50 | 0.92 | 0.913 | 0.130 | 0.060 | 0.001 |
| **Education[i]** | | | | | | | |
| Configural[g] | 170.758 | 57 | 0.94 | 0.904 | 0.136 | 0.058 | 0.007 |
| Metric | 174.474 | 69 | 0.94 | 0.926 | 0.119 | 0.061 | –0.004 |
| Scalar | 196.107 | 81 | 0.94 | 0.934 | 0.112 | 0.063 | 0.002 |

[a] CFI: comparative fit index.

[b] TLI: Tucker Lewis index.

[c] RMSEA: root mean square error of approximation.

[d] SRMR: standardized root mean square residual.

[e] Change in CFI compared to preceding model.

[f] Female n=332; male n=138.

[g] Change of CFI compared to model 3.

[h] Age>median n=240; age<median n=230.

[i] University degree n=273; vocational training n=91; school certificate n=106.

## Discussion

### Principal Findings

The results of our factor analyses show that eHealth literacy consists of 2 factors, information seeking and information appraisal. Our first study aim was to examine whether the measurement of eHealth literacy could be improved by adding nonoverlapping items from the eHEALS-E [54] to the original eHEALS [16]. We performed an EFA and several CFAs to examine the factorial structure of our instrument. Our analyses show that the measurement of eHealth literacy could not be improved by adding additional items to the well-established eHEALS questionnaire.

However, our study significantly contributes to the existing measurement of eHealth literacy. By strongly following scientific recommendations regarding academic translations, we developed the GR-eHEALS with high content validity. By taking statistical and content-related consideration into account when conducting factor analyses, we developed a measurement model of eHealth literacy with high content validity and acceptable-to-good model fit. Cronbach alpha was satisfactory for the 2 factors indicating good internal consistency and confirming reliability of the instrument.

Our findings on the examination of convergent, discriminant, and criterion validity of our instrument were not completely consistent with our expectations and require critical discussion. As expected, the 2 factors showed significant correlations with the convergent constructs of health literacy, internet confidence, and internet anxiety. By contrast, while impulsivity and extraversion consistently showed, as expected, no significant correlations with the 2 factors, neuroticism and openness indicated more inconsistent interrelations. Neuroticism was strongly negatively correlated with information appraisal, but not with information seeking. On the other hand, openness was only correlated with information seeking but not with information appraisal. To understand these unexpected correlational patterns, we examined findings of studies discovering the associations of personality traits and health-related constructs. Other studies showed that neuroticism is associated with lower health behavior self-efficacy and health behaviors [77] and lower internet use for learning and education [78]. These findings could indicate that neuroticism distorts cognitive processes of higher elaboration that are required for information appraisal but not necessarily for information seeking. Regarding the personality trait of openness, Bogg and Vo [79] have shown that people with higher openness more often search the internet regarding health-related topics. One could think that openness promotes people to search for new information in a sense of curiosity. However, the subsequent and cognitively demanding process of information appraisal may not be promoted by people's openness.

Referring to the examination of criterion validity, positive correlations with the possible outcome variable mental health, physical health, and life satisfaction were expected, although only information appraisal was significantly related to these constructs. These results could be potentially explained by the idea that information seeking is a process that requires cognitive efforts but may not be sufficient to promote satisfaction and health status on its own but needs a high competency in information appraisal as a mandatory precondition. However, the search of information is a necessary process to perform the subsequent process of information appraisal.

To sum up, convergent validity of our instrument can be comprehensively confirmed. Examination of discriminant validity and criterion validity reveal unexpected findings that should be subjects of further studies. Despite our results not completely meeting our expectations, findings indicate that the 2 factors represent different cognitive processes in line with dual-process theories of analytic and rule-based processes: information seeking as a first of 2 consecutive competencies exclusively focuses on the process of searching information on the internet but not on a deeper application of the information found. Within a second consecutive competency built on information seeking, information appraisal describes a cognitive process of interpretation of information and its application on personal health-related questions.

Furthermore, we investigated the measurement invariance for gender, age, and educational level. The results of our study suggest that measurement invariance of the GR-eHEALS can be assumed for gender and educational level at a scalar level of invariance but not for age. Our study is the first to examine measurement invariance for these sociodemographic variables. Particularly regarding sample limitations of previous studies investigating eHealth literacy, the GR-eHEALS is the first instrument that can be deployed and interpreted regardless of gender and educational level. Therefore, future researchers are able to interpret statistical differences of these sociodemographic variables on eHealth literacy by using the GR-eHEALS. This is highly important as one could think of differential levels of eHealth literacy due to gender, which was confirmed for the construct of health literacy [80]. Regarding educational level, studies suggest that education also plays a role in the context of eHealth literacy [81,82], but, to our knowledge, neither used instruments confirmed to be measurement invariant.

Concerning the finding of inequality of our instrument with respect to age, one potential explanation could be that older people are less familiar with using the internet than younger people in terms of a digital divide [49] and have a different understanding of information seeking and information appraisal than younger people. Chesser and colleagues [83] suggest that age is a relevant variable in the context of eHealth literacy. Further, in our data we found significant interrelations of age and information seeking but not of age and information appraisal. This should be examined further in upcoming research.

In summary, prior research indicates that the investigation of differences of eHealth literacy of different groups of people is of high scientific interest. Nonetheless, previous studies were lacking considering statistical differences should not be interpreted unless measurement invariance is confirmed. With the GR-eHEALS, we close this gap and contribute substantially to the understanding of the concept of eHealth literacy and the interpretation of mean differences for gender and educational level.

Due to its high validity, the GR-eHEALS provides researchers and practitioners with a measurement for the increasingly important construct of eHealth literacy. As eHealth literacy is linked with many health-related outcomes and behaviors [19,26,27], the GR-eHEALS could provide a basis for educational programs to improve eHealth literacy by focusing on the main cognitive processes important for interpreting health information from the internet. Also, there is evidence that students lack in competencies regarding eHealth literacy [84]. Hence, the assessment and development of eHealth literacy should be a part of students' curriculum to provide young people with the competencies needed to maintain or improve one's health status. Consequently, the GR-eHEALS could be part of educational psychologists' diagnostic repertoire as well as a foundation for specialist training programs in schools and universities. We propose that the results of the GR-eHEALS should be interpreted based on the 2 competencies for diagnostic and interventions of eHealth literacy considering the described mean scores for higher and lower levels of information seeking and information appraisal.

## Strengths and Limitations

The main strengths of this study are the high methodological and psychometric standards applied to develop GR-eHEALS and confirm its content, construct, and criterion validity. Furthermore, confirmation of measurement invariance is a state-of-the-art approach with strong practical implications regarding the interpretations of group differences.

One limitation of our study was that we measured eHealth literacy by self-assessment only. Since this construct is intended to measure skills and competencies, eHealth literacy should either be compared with actual behaviors or assessed using behavior-based measurement. Furthermore, our data were collected in a cross-sectional study. Therefore, correlational directions show relationships but are not interpretable causally. Future research should explore if our 2 factors show different effects on health-related outcomes. Additionally, as we used an online survey, participation by people familiar with the internet was more likely than by people who rarely use the internet. Thus, the possibility of selection bias should be considered. In our sample, a high proportion of people holding a university degree limits the representativeness regarding the education level. As in Germany about 19% of the population hold a university degree [85], our sample with a proportion of 58% holding a university degree clearly overrepresents academic persons. Even though it was our goal to collect data on a convenience sample, our study sample consisted of 71% female participants and cannot be considered as population-representative. Therefore, future studies should replicate our findings using a population-representative sample.

## Conclusion

eHealth literacy reflects the important competence of people in maintaining and improving their health status. This competence will become more and more important since the internet provides a rapidly increasing amount of health information with considerable bandwidth of quality and trustworthiness. The GR-eHEALS, with its 8 items on 2 factors, is a validated instrument to capture eHealth literacy in the German language. The GR-eHEALS contributes to the measurement of eHealth literacy in 3 ways: (1) instrument has high content validity because of a translation following scientific recommendations, (2) instrument has an acceptable-to-good model fit and confirms measurement invariance for gender and educational level, and (3) instrument revises the existing G-eHEALS and fills an important gap in measuring eHealth literacy to provide researchers and practitioners an accurate and valid assessment.

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## Authors' Contributions

MM, GE, AB, and EMS conceptualized the study. Project administration was performed by MM, GE, and AB. Statistical analyses were conducted by MM. MM and GE interpreted the data and wrote the original draft of the manuscript. AB, EMS, and MT supervised the project and contributed to the study design, data collection, and critical revision of the manuscript. All authors reviewed and approved the final manuscript. All data supporting the conclusion of the study are included in Multimedia Appendix 3.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Original and translated items.
[PDF File (Adobe PDF File), 105 KB-Multimedia Appendix 1]

## Multimedia Appendix 2

Item statistics of the prestudy (n=50).
[PDF File (Adobe PDF File), 102 KB-Multimedia Appendix 2]

## Multimedia Appendix 3

Dataset.
[XLSX File (Microsoft Excel File), 391 KB-Multimedia Appendix 3]

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## Abbreviations

**CFA:** confirmatory factor analysis
**CFI:** comparative fit index
**EFA:** exploratory factor analysis
**eHEALS:** eHealth Literacy Scale
**eHEALS-E:** extended eHealth Literacy Scale
**G-eHEALS:** German eHealth Literacy Scale
**GR-eHEALS:** revised German eHealth Literacy Scale
**KMO:** Kaiser-Meyer-Olkin test
**RMSEA:** root mean square error of approximation
**SRMR:** standardized root mean square residual
**TLI:** Tucker Lewis index

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Review

# Interactive Visualization Applications in Population Health and Health Services Research: Systematic Scoping Review

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## Abstract

**Background:** Simple visualizations in health research data, such as scatter plots, heat maps, and bar charts, typically present relationships between 2 variables. Interactive visualization methods allow for multiple related facets such as numerous risk factors to be studied simultaneously, leading to data insights through exploring trends and patterns from complex big health care data. The technique presents a powerful tool that can be used in combination with statistical analysis for knowledge discovery, hypothesis generation and testing, and decision support.

**Objective:** The primary objective of this scoping review is to describe and summarize the evidence of interactive visualization applications, methods, and tools being used in population health and health services research (HSR) and their subdomains in the last 15 years, from January 1, 2005, to March 30, 2019. Our secondary objective is to describe the use cases, metrics, frameworks used, settings, target audience, goals, and co-design of applications.

**Methods:** We adapted standard scoping review guidelines with a peer-reviewed search strategy: 2 independent researchers at each stage of screening and abstraction, with a third independent researcher to arbitrate conflicts and validate findings. A comprehensive abstraction platform was built to capture the data from diverse bodies of literature, primarily from the computer science and health care sectors. After screening 11,310 articles, we present findings from 56 applications from interrelated areas of population health and HSR, as well as their subdomains such as epidemiologic surveillance, health resource planning, access, and use and costs among diverse clinical and demographic populations.

**Results:** In this companion review to our earlier systematic synthesis of the literature on visual analytics applications, we present findings in 6 major themes of interactive visualization applications developed for 8 major problem categories. We found a wide application of interactive visualization methods, the major ones being epidemiologic surveillance for infectious disease, resource planning, health service monitoring and quality, and studying medication use patterns. The data sources included mostly secondary administrative and electronic medical record data. In addition, at least two-thirds of the applications involved participatory co-design approaches while introducing a distinct category, *embedded research*, within co-design initiatives. These applications were in response to an identified need for data-driven insights into knowledge generation and decision support. We further discuss the opportunities stemming from the use of interactive visualization methods in studying global health; inequities, including social determinants of health; and other related areas. We also allude to the challenges in the uptake of these methods.

**Conclusions:** Visualization in health has strong historical roots, with an upward trend in the use of these methods in population health and HSR. Such applications are being fast used by academic and health care agencies for knowledge discovery, hypotheses generation, and decision support.

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**KEYWORDS**

interactive visualization; data visualization; secondary health care data; public health informatics; population health; health services research

## *Introduction*

### Background

As digital medicine advances, visualization applications in population health increasingly provide ways for researchers and practitioners to explore and communicate findings [1], supporting knowledge discovery from disparate large data sources [2]. Visual analytics (VA) has been defined as the “science of analytics reasoning facilitated by visual interfaces” [3], and it is an interdisciplinary field combining visualization, statistical analysis, and advanced analytics such as machine learning and cognitive sciences [4]. A specific approach within VA is the use of interactive visualization, which Ola and Sedig [2] define as computational tools that store, process, and visually represent data, to facilitate interactive exploration. Interactive visualization increases the potential for big data use in health care by supporting sense making, knowledge discovery, and hypothesis generation [2,5]. Simple visualizations such as scatter plots, heat maps, and bar charts typically present 2 facets of the data, displaying attributes and relationships between 2 variables such as a disease condition and risk factors. Interactive visualization methods allow for presentation of multiple related facets such as risk factors to be studied simultaneously, leading to insights through exploring trends and patterns [2,5].

Population health research involves the study of data related to health outcomes and determinants of population health [6,7], whereas health services research (HSR) studies the health system in relation to access, quality, costs, and patient outcomes [8,9]. Both fields involve the analysis of large secondary data sources such as clinical databases, administrative data sets, and electronic medical records (EMRs) [10-12]. In a prior review, we summarized evidence on VA applications in these interrelated fields of health care [13]; this review complements it by reviewing the evidence on interactive visualization applications in population health and HSR.

Recent systematic reviews have summarized visualization methods in varied areas of health care. Among the most cited reviews, the study by West et al [1] synthesized literature on the use of visualization approaches for exploratory analysis of electronic health records (EHRs). Similarly, another well-cited review by Carrol et al [14] summarized the literature on visualization and analytics tools used in infectious disease epidemiology, particularly in relation to geographic information systems (GIS), molecular epidemiology, and social network analysis methods. Islam et al [15] offered a comprehensive view on data mining and theoretical approaches in health care. Wu et al [16] summarized evidence on visualization and analytic technologies for characterizing evaluation methods in health informatics, an area primarily concerned with clinical care. The most recent related review by Chung et al [17] focused on visual approaches in mental health care policy and systems. To our knowledge, interactive visualization applications have not been studied as a body of literature separate from data visualization and VA; hence, this review is the first systematic synthesis on the subject.

### Rationale for a Companion Review

This companion review is our second synthesis of literature on visualization and analytics tools, techniques, and approaches in population health and HSR. Our first publication focused on VA methods in these areas, where we offered an updated definition of VA in health care as “an approach, method, or application for analytic reasoning, exploration, knowledge discovery, and sense making of complex data, using one or more interactive visual interfaces, employing analytic and visual engines” [13]. As part of VA applications, analytic engines involve advanced machine learning, database querying, and manipulation.

*Interactive visualization* applications typically engage a front-end visual engine such as Tableau [18], Qlik [19], and PowerBI [20]. Although all VA methods carry a visualization component, which may or may not be interactive, interactive visualization applications typically do not involve or report an analytic component. Hence, this companion review on interactive visualization applications illustrates the state of evidence in population health and HSR, focusing on contemporary methods, approaches, tools, and co-design from real-world use cases. This review will be helpful for health care researchers, practitioners, and decision-makers to understand and adopt visualization-based data analysis.

### Objectives

The primary objective of this scoping review is to describe and summarize the evidence on interactive visualization applications, methods, and tools being used in population health and HSR and their subdomains in the last 15 years, from January 1, 2005, to March 30, 2019. Our secondary objective is to describe the use cases, metrics, frameworks used, settings, target audience, goals, and co-design of applications.

## Methods

### Review Methodology and Protocol

*Scoping reviews* outline the size and scope of available literature and identify the quality and extent of research evidence [21]. We briefly describe the methodological processes relevant to the second part of the review in this section, whereas further details can be found in the published protocol [22]. We primarily followed the guidance provided by the Joanna Briggs Institute [23], as well as the framework for conducting scoping reviews described by Arksey and O’Malley [24], with improvements suggested by Levac et al [25] and Peters et al [26], while using the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist provided by Tricco et al [27] for reporting. The major steps were as follows: determining the research question, identifying relevant studies, abstracting data, and summarizing and reporting the results. The operational concepts and definitions are presented in Textbox 1.

**Textbox 1.** Operational concepts and definitions.

**Concepts and definitions**

- Population health, adapted from Kindig and Stoddart [6] and Kindig [7]
  - "The health outcomes of a group of individuals, including the distribution of such outcomes within the group," includes "health outcomes, patterns of health determinants, and policies and interventions that link these two"
- Health services research, adapted from the Canadian Institutes of Health Research [8] and National Libraries of Medicine filters for health services research [28]
  - Research with the "goal of improving the efficiency and effectiveness of health professionals and the health care system"
  - Access to services
  - Utilization of services
  - Cost of services
- Domains of population health and health services research, adapted from Islam et al [15]
  - Clinical populations include a health condition
  - Epidemiologic includes disease distribution and dynamics
  - Demographic includes population-related characteristics such as age and gender
  - Spatiotemporal includes events over time and space
- Problem categories, based on subject area and the aim or aims of the application
  - Epidemiologic monitoring or surveillance
  - Resources and services monitoring and planning
  - Medication use patterns
  - Visualization methodologies
  - Epidemiologic data exploration
  - Health service monitoring, planning, and quality
  - Patient or care pathways
  - Public or patient communication
- Interactivity, adapted from Ola and Sedig [29] and Pike et al [30]
  - Ability to reflect changes in the visual representation, based on one or more variables available on the analytic interface
  - Tasks such as filtering, determining ranges, and finding anomalies, clusters, and the like by providing menus, dropdowns, and other options on the visualization interface
- Tools
  - Software for developing an application
- Use case
  - Use of the application or method to one or more data sets
- Goal of the application, adapted from Islam et al [15]
  - Whether the application was meant for decision support, knowledge discovery, or both
- Analytic capability, adapted from Islam et al [15]
  - Descriptive or predictive analytics or visual exploration of data
- Functions of the visualization presentations from the Graphic Continuum by Schwabish and Ribecca [31]
  - Spatial
  - Change over time
  - Flow

  - Distribution
  - Ranking
  - Magnitude
  - Correlation
  - Part to whole
- Co-design, adapted from Ward et al [32]
  - Encompasses the partnership of health workers, patients, and designers who aspire toward change, depending on shared knowledge to achieve “better outcomes or improved efficiency”
  - Whether any participatory approach toward co-design was reported by the authors
  - Embedded research: applications developed in response to an expressed need within a health care organization
- Settings and target audience
  - On the basis of the location of the application developed and the overall objectives of the reported application
  - Categories include academia, government health care units, and industry
- Subject of applications
  - Exploratory word frequency analysis of included articles to yield major subject areas for which applications were developed or any other related finding using a word cloud
- Applications in current use, public availability, innovation, and limitations
  - For ascertaining whether the application could be adapted or replicated in future
  - Public availability to ascertain whether the application was developed for the public

## Eligibility Criteria

Eligible articles included peer-reviewed published journal and full conference papers in English related to use cases of interactive visualization in population health and HSR. We included articles on spatiotemporal visualization but excluded articles presenting cartographic methods and tools for GIS because these were outside the scope of the research objectives. Similarly, we did not include articles on human-computer interaction, user design, and articles without a use case. Non–peer-reviewed work such as editorials, conference abstracts, and short articles were excluded. The eligibility criteria are presented in Textboxes 2 and 3.

**Textbox 2.** Inclusion criteria.

**Inclusion criteria**

- Peer reviewed journal or full conference papers
- From January 1, 2005, to March 30, 2019
- Population health or health services research related
  - Articles with population level or health services research metrics: incidence, prevalence, events over time, and space, access, cost, utilization, disease or condition distribution, as well as social or multiple determinants of health
- Interactive visualization used for a use case with one or more data sets

**Textbox 3.** Exclusion criteria.

**Exclusion criteria**

- Articles not in English
- Editorials, projects, reviews, book chapters, short papers, or reports
- Articles on computer vision and medical imaging
- Studies conducted in clinical settings without a population level or health services component, such as from a single hospital or unit
- Articles on device or sensor data, without a population level or health services research component
- Studies reporting a visual analytics component or analytic engine

### Sources of Evidence and Search Strategy

The search strategy, its conceptualization, and steps for operationalization are detailed in the review protocol [22]. The search was externally peer reviewed using the Peer Review of Electronic Search Strategies Guideline [33] and included an extensive list of search terms and their variants to cover all related concepts of population health, HSR, visualization, analytics, and interactivity [22]. The 6 databases searched, their platforms, and results are summarized in Table 1. We further hand searched 10 relevant journals, in addition to internet searches [22]. We used the Covidence (Veritas Health Innovation Ltd) platform for screening citations [34] and EndNote (Clarivate) for reference management [35].

**Table 1.** Databases and search results (N=14,099).

| Database name | Search results, n (%) |
|---|---|
| MEDLINE (life sciences and biomedicine) | 4633 (32.86) |
| Embase (life sciences and biomedicine) | 1880 (13.33) |
| Web of Science (multidisciplinary) | 5396 (38.27) |
| Ei Compendex (engineering and technology) | 1267 (8.99) |
| IEEE Xplore (engineering and technology) | 151 (1.07) |
| Inspec (engineering and technology) | 772 (5.48) |

### Data Charting and Synthesis of Results

In all, 2 independent reviewers screened articles at each stage of the review, including title and abstract screening, full-text screening, and data abstraction. A third reviewer acted as an arbiter in case of conflicts and for validating the data abstracted for their content and level of detail.

The data abstraction encompassed the major concepts in 6 major themes: (1) study characteristics (country, problem category, settings, and target audience), (2) tools and techniques used, (3) data type and visualization methods, (4) domains of population health and HSR, (5) innovation of the application and its current availability and use, and (6) if the application was co-designed with the target audience.

## Results

### Selection of Sources and Presentation of Results

We identified 14,099 articles from the 6 databases searched. Given the varied sources of the articles, we adapted the method described by Bramer et al [36] for removing duplicate references using EndNote X9 [35]. Among the 14,099 articles, we considered major citation details and identified, double-checked, and removed 2078 (14.74%) duplicates, comparing the title, identifiers, publication platforms, and abstracts. From the remaining 12,021 articles, another 711 (5.91%) duplicates were removed after importing into Covidence [34]. We excluded 96% (10,819/11,310) of the references during the title and abstract screening and 89% (435/491) of the articles during the full-text screening. We did not find additional articles from reference lists of recent systematic and narrative reviews, hand searches of individual journals, and internet searches. Hence, of the initially identified 14,099 articles, we have summarized 56 (0.39%) for reporting in this review. The reasons for exclusion during the full-text-screening are detailed in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram (Figure 1), whereas the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews reporting checklist is presented in Multimedia Appendix 1.

We have also summarized our results in a visual format using a publicly accessible Tableau dashboard, a screenshot of which is presented in Figure 2 [37]. The abstracted data and complete workbook are available to support replication, adaptation, and further analysis. Operational concepts for each category and reported theme are detailed in the *Methods* section (Textbox 1).

**Figure 1.** PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart for article selection. VA: visual analytics.

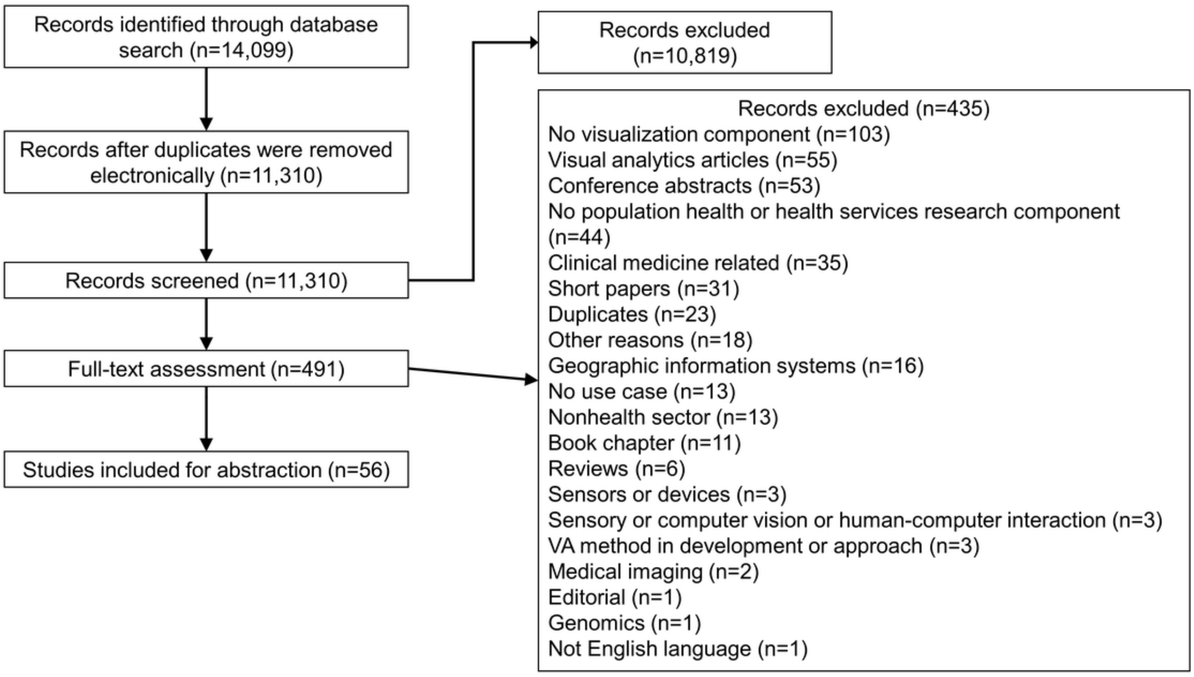
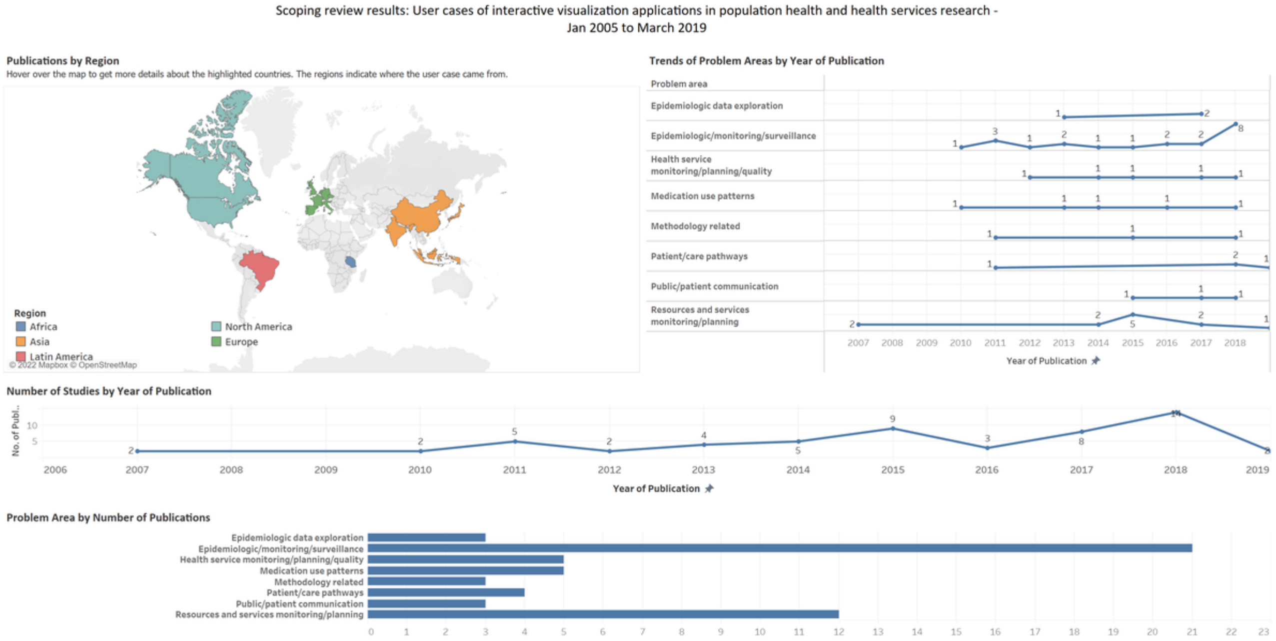


**Figure 2.** Screenshot of the results presented as a Tableau dashboard.


Scoping review results: User cases of interactive visualization applications in population health and health services research - Jan 2005 to March 2019

Publications by Region

Hover over the map to get more details about the highlighted countries. The regions indicate where the user case came from.

## Study Characteristics, Settings, and Target Audience

The 56 articles summarized were from 21 countries, including the United States (30/56, 54%), the United Kingdom (4/56, 7%), India (2/56, 4%), Indonesia (2/56, 4%), and Canada (2/56, 4%). Of the 56 articles, there was 1 (2%) each from the Netherlands, Spain, Puerto Rico, Czech Republic, Malaysia, France, Portugal, Tanzania, Slovenia, China, Germany, Brazil, Italy, Japan, and Korea, whereas 1 (2%) study included a comparison of health indicators from the United States, the United Kingdom, Costa Rica, Sweden, Croatia, Japan, Hong Kong, and China. Details on countries, settings, and target audiences are presented in Multimedia Appendix 2 [38-93], whereas these are summarized in Tables 2 and 3. Study settings included government ministry or health unit (39/56, 70%), academia (18/56, 32%), and industry (2/56, 4%). There was overlap between the government health unit and academia (1/56, 2%) and between the government health unit and industry (2/56, 4%).

The included studies often had more than one target audience. These were population or public health practitioners (53/56, 95%), clinicians (24/56, 43%), policy makers and decision-makers (21/56, 38%), public and patient groups (12/56, 21%), data scientists (5/56, 9%), and industry (2/56, 4%).

**Table 2.** Settings of the studies (N=56).

| Setting | Values, n (%) | Study |
|---|---|---|
| Government; ministry; health department | 39 (70) | Alibrahim et al (2014) [38], Barrento and De Castro Neto (2017) [39], Basole et al (2015) [40], BenRamadan et al (2017) [43], BenRamadan et al (2018) [44], Bjarnadottir et al (2016) [46], Brownstein et al (2010) [47], Henley et al (2018) [52], Hosseinpoor et al (2018) [53], Jia et al (2015) [56], Kirtland et al (2014) [58], Ko and Chang (2018) [59], Kubasek et al (2013) [61], Lanzarone et al (2016) [62], Lopez-DeFede et al (2011) [63], Mahler et al (2015) [64], Marshall et al (2017) [65], Mitrpanont et al (2017) [67], Moni et al (2015) [68], Monsen et al (2015) [69], Monsivais et al (2018) [70], Mozumder et al (2018) [71], Pachauri et al (2014)[73], Palmer et al (2019) [74], Pike et al (2017) [76], Podgornik et al (2007) [77], Pur et al (2007) [78], Raghupathi and Raghupathi (2018) [79], Ratwani and Fong (2015) [80], Rodriguez-Fernandez et al (2016) [81], Rowlingson et al (2013) [82], Shen et al (2018) [84], Sims et al (2011) [85], Sopan et al (2012) [86], Toyoda and Niki (2015) [87], Valdiserri and Sullivan (2018) [89], van der Corput et al (2014) [90], Wang and Yao (2018) [92], and Zhang et al (2011) [93] |
| Academia | 18 (32) | Becnel et al (2019) [41], Benítez et al (2017) [42], Bieh-Zimmert et al (2013) [45], Bjarnadottir et al (2016) [46], Cesario et al (2012) [48], Chui et al (2011) [49], Haque et al (2014) [50], Happe and Drezen (2018) [51], Hsu et al (2018) [54], Iyer et al (2017) [55], Kaushal et al (2018) [57], Krause (2015) [60], Martinez et al (2016) [66], Ortiz-Zuazaga et al (2015) [72], Pickle and Carr (2010) [75], Semple et al (2013) [83], Tsoi et al (2018) [88], and Wang et al (2011) [91] |
| Industry | 2 (4) | Ratwani and Fong (2015) [80] and Shen et al (2018) [84] |

**Table 3.** Target audience of the included studies (N=56).

| Target audience | Values, n (%) | Study |
|---|---|---|
| Population or public health practitioners | 53 (95) | Alibrahim et al (2014) [38], Barrento and De Castro Neto (2017) [39], Becnel et al (2019) [41], Benitez et al (2017) [42], BenRamadan et al (2017) [43], BenRamadan et al (2018) [44], Bieh-Zimmert et al (2013) [45], Bjarnadottir et al (2016) [46], Brownstein et al (2010) [47], Cesario et al (2012) [48], Chui et al (2011) [49], Haque et al (2014) [50], Happe and Drezen (2018) [51], Henley et al (2018) [52], Hosseinpoor et al (2018) [53], Hsu et al (2018) [54], Iyer et al (2017) [55], Jia et al (2015) [56], Kaushal et al (2018) [57], Kirtland [58] 2014, Krause (2015) [60], Kubasek et al (2013) [61] , Lopez-DeFede et al (2011) [63], Mahler et al (2015) [64], Marshall et al (2017) [65], Martinez et al (2016) [66], Mitrpanont et al (2017) [67], Moni et al (2015) [68], Monsen et al (2015) [69], Monsivais et al (2018) [70], Mozumder et al (2018) [71], Ortiz-Zuazaga et al (2015) [72], Pachauri et al (2014) [73], Palmer et al (2019) [74], Pickle and Carr (2010) [75], Pike et al (2017) [76], Podgornik et al (2007) [77], Pur et al (2007) [78], Raghupathi and Raghupathi (2018) [79], Ratwani and Fong (2015) [80], Rodriguez-Fernandez et al (2016) [81], Rowlingson et al (2013) [82], Semple et al (2013) [83], Shen et al (2018) [84], Sims et al (2011) [85], Sopan et al (2012) [86], Toyoda and Niki (2015) [87], Tsoi et al (2018) [88], Valdiserri and Sullivan (2018) [89], van der Corput et al (2014) [90], Wang et al (2011) [91], Wang and Yao (2018) [92], and Zhang et al (2011) [93] |
| Clinicians | 24 (43) | Basole et al (2015) [40], Becnel et al (2019) [41], BenRamadan et al (2017) [43], BenRamadan et al (2018) [44], Bjarnadottir et al (2016) [46], Brownstein et al (2010) [47], Haque et al (2014) [50], Happe and Drezen (2018) [51], Henley et al (2018) [52], Jia et al (2015) [56], Kaushal et al (2018) [57], Kirtland et al (2014) [58], Ko and Chang (2018) [59], Lanzarone et al (2016) [62], Marshall et al (2017) [65], Mitrpanont et al (2017) [67], Monsen et al (2015) [69], Mozumder et al (2018) [71], Palmer et al (2019) [74], Pike et al (2017) [76], Ratwani and Fong (2015) [80], Rodriguez-Fernandez et al (2016) [81], Semple et al (2013) [83], and van der Corput et al (2014) [90] |
| Policy makers and decision-makers | 21 (38) | Alibrahim et al (2014) [38], Becnel et al (2019) [41], Hsu et al (2018) [54], Jia et al (2015) [56], Lanzarone et al (2016) [62], Mahler et al (2015) [64], Marshall et al (2017) [65], Moni et al (2015) [68], Monsen et al (2015) [69], Monsivais et al (2018) [70], Pike et al (2017) [76], Podgornik et al (2007) [77], Pur et al (2007) [78], Raghupathi and Raghupathi (2018) [79], Rowlingson et al (2013) [82], Semple et al (2013) [83], Sims et al (2011) [85], Sopan et al (2012) [86], Toyoda and Niki (2015) [87], Valdiserri and Sullivan (2018) [89], Wang (2018) [92], and Zhang et al (2011) [93] |
| Public and patient groups | 12 (21) | Barrento and De Castro Neto (2017) [39], Bieh-Zimmert et al (2013) [45], Brownstein et al (2010) [47], Hosseinpoor et al (2018) [53], Hsu et al (2018) [54], Jia et al (2015) [56], Kubasek et al (2013) [61], Mozumder et al (2018) [71], Ortiz-Zuazaga et al (2015) [72], Semple et al (2013) [83], Tsoi et al (2018) [88], and van der Corput et al (2014) [90] |
| Data scientists | 5 (9) | BenRamadan et al (2017) [43], Pickle and Carr (2010) [75], Tsoi et al (2018) [88], Valdiserri and Sullivan (2018) [89], and Wang et al (2011) [91] |
| Industry (software, pharmaceutical, and insurance) | 2 (4) | Kaushal et al (2018) [57] and Toyoda and Niki (2015) [87] |

## Health Care Domains, Metrics, and Categories of Problems Addressed by the Applications

Among the domains of health, the categories overlapped, with articles falling under population health (38/56, 68%), HSR (29/56, 52%), and both population health and HSR (11/56, 20%). Among the articles in the population health category, their subdomains included clinical populations with 1 condition of interest (23/56, 41%), demographic population (28/56, 50%), epidemic monitoring and modeling (11/56, 20%), and spatiotemporal (16/56, 29%). For HSR, these included access to services (16/56, 29%), utilization (23/56, 41%), and costs (4/56, 7%).

The visual applications for these health care areas used different metrics in combination with the major categories, including prevalence (23/56, 41%), space and time (20/56, 36%), incidence (19/56, 34%), resources (6/56, 11%), mortality (4/56, 7%), hospitalization (1/56, 2%), events over time (1/56, 2%), and air quality (1/56, 2%).

The problem categories addressed by the applications included epidemiologic monitoring or surveillance (21/56, 38%), resources and services monitoring or planning (12/56, 21%), health service monitoring or planning or quality (5/56, 9%), medication use patterns (5/56, 9%), patient or care pathways (4/56, 7%), visualization methodologies (3/56, 5%), epidemiologic data exploration (3/56, 5%), and public or patient communication (3/56, 5%).

## Application's Analytic Capability, Goal, and Frameworks Used

There was overlap in the analytic capability of the tools with applications capable of descriptive analytics (53/56, 95%), predictive analytics (4/56, 7%), and visual exploration of complex data sets (37/56, 66%). Regarding the goal of the visualization application, there was overlap between knowledge discovery (56/56, 100%) and decision support (47/56, 84%). Of the 56 articles, 6 (11%) used a framework in their methods for developing the application. These frameworks are summarized in Table 4. Multimedia Appendix 3 [38-93] lists the analytic capability and goals of each application.

**Table 4.** Articles mentioning the use of methodological frameworks (N=6).

| Author and year | Methodological frameworks used in developing interactive visualization applications |
|---|---|
| Alibrahim et al (2014) [38] | Display principles for visual monitoring by Few et al [94] |
| Bieh-Zimmert et al (2013) [45] | Ten guidelines by Kelleher and Wagener [95] |
| Monsen et al (2015) [69] | Followed the Omaha System [96] |
| Ratwani et al (2015) [80] | Visualization principles (overview, zoom and filter, and details on demand) based on theories from Shneiderman [97] and Chen [98] |
| Semple et al (2013) [83] | For developing the web app, the 5-stage user-centered design model described by Kinzie et al [99] was used |
| Wang et al (2011) [91] | Align, Rank, and Filter Framework used for user interaction by Wang et al [100] |

## Data Characteristics: Source, Structure, Type, and Use Cases

Data sets used in the visualization applications were single (40/56, 71%) or multiple (16/56, 29%), and they were structured (48/56, 86%) or semistructured (8/56, 14%). The sources of data included administrative (45/56, 80%), spatiotemporal (17/56, 30%), EMR or EHR or medical records (15/56, 27%), registry (10/56, 18%), web or social media (2/56, 4%), and sensor data (1/56, 2%). Multimedia Appendix 4 [38-93] details the data types and sources with the primary tools used to develop the application.

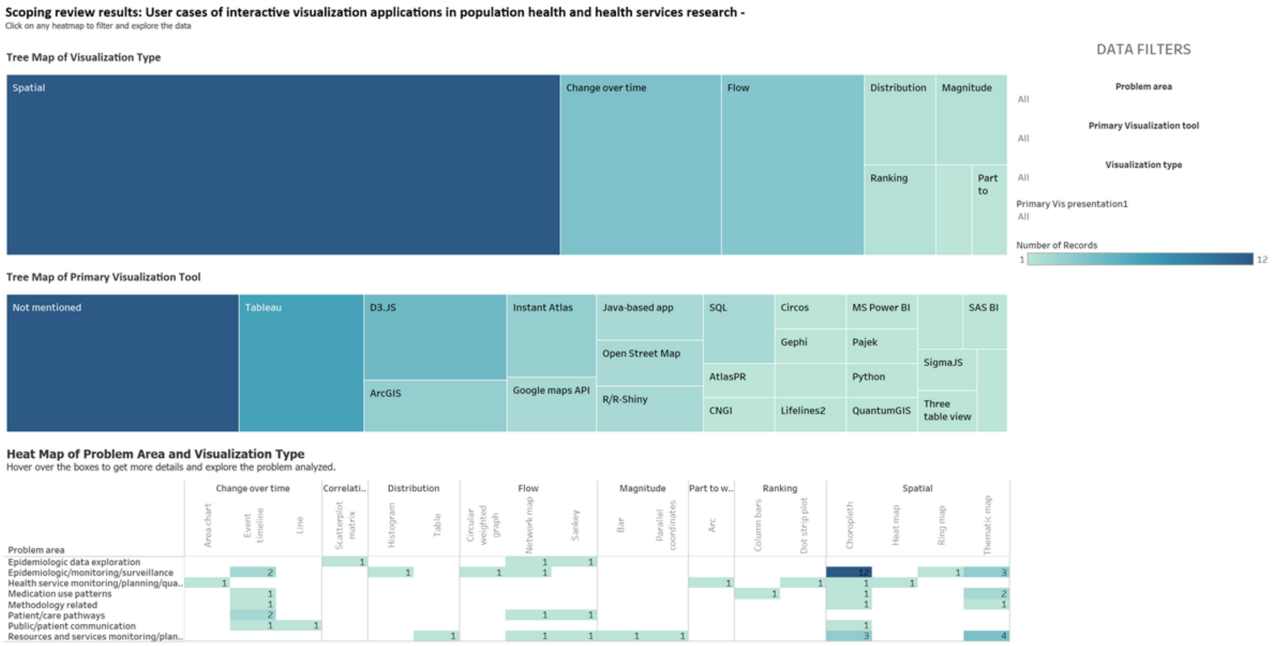
## Visualization: Primary Types, Presentation, and Tools

Regarding the functional aspects of the interactive visual presentations, the categories included spatial (31/56, 55%), change over time (9/56, 16%), flow (8/56, 14%), distribution (2/56, 4%), ranking (2/56, 4%), magnitude (2/56, 4%), correlation (1/56, 2%), and part to whole (1/56, 2%).

The primary visual presentations included choropleth map (19/56, 34%), thematic map (10/56, 18%), event timeline (7/56, 13%), network map (4/56, 7%), Sankey diagrams (3/56, 5%), area chart (1/56, 2%), parallel coordinates (1/56, 2%), column bars (1/56, 2%), circular weighted graph (1/56, 2%), line (1/56, 2%), dot strip plot (1/56, 2%), ring map (1/56, 2%), table (1/56, 2%), scatterplot matrix (1/56, 2%), bar (1/56, 2%), histogram (1/56, 2%), arc (1/56, 2%), and heat map (1/56, 2%). The relative distribution of visual presentations and software tools by problem category is provided in Figure 3. For details on the functional types and visual presentations included in each article, please refer to Multimedia Appendix 5 [38-93].

The different visualization software tools used included Tableau (7/56, 13%); D3.JS (5/56, 9%); ArcGIS and Instant Atlas (3/56, 5% each); R/R-Shiny, Open Street Map, Google Maps application programming interface (API), SQL, and Java-based application (2/56, 4% each); and MS Power BI, SigmaJS, RESTful API, CNGI, Lifelines2, AtlasPR, Circos, IBM Watson Analytics, SAS BI, Pajek, Gephi, pChart, Three Table View, Python, and QuantumGIS (1/56, 2% each). Some articles did not mention the visualization tool (13/56, 23%). Figure 4 shows a screenshot from the Tableau results dashboard with the primary visualization tools and heat map of problem category and visual presentation. This interactive dashboard is also available on the Tableau results dashboard [37].

**Figure 3.** Types of visualizations, primary software tool, and visualization type by problem area (screenshot).



**Scoping review results: User cases of interactive visualization applications in population health and health services research -**

Click on any heatmap to filter and explore the data

**Tree Map of Visualization Type**

**Tree Map of Primary Visualization Tool**

**Heat Map of Problem Area and Visualization Type**

Hover over the boxes to get more details and explore the problem analyzed.

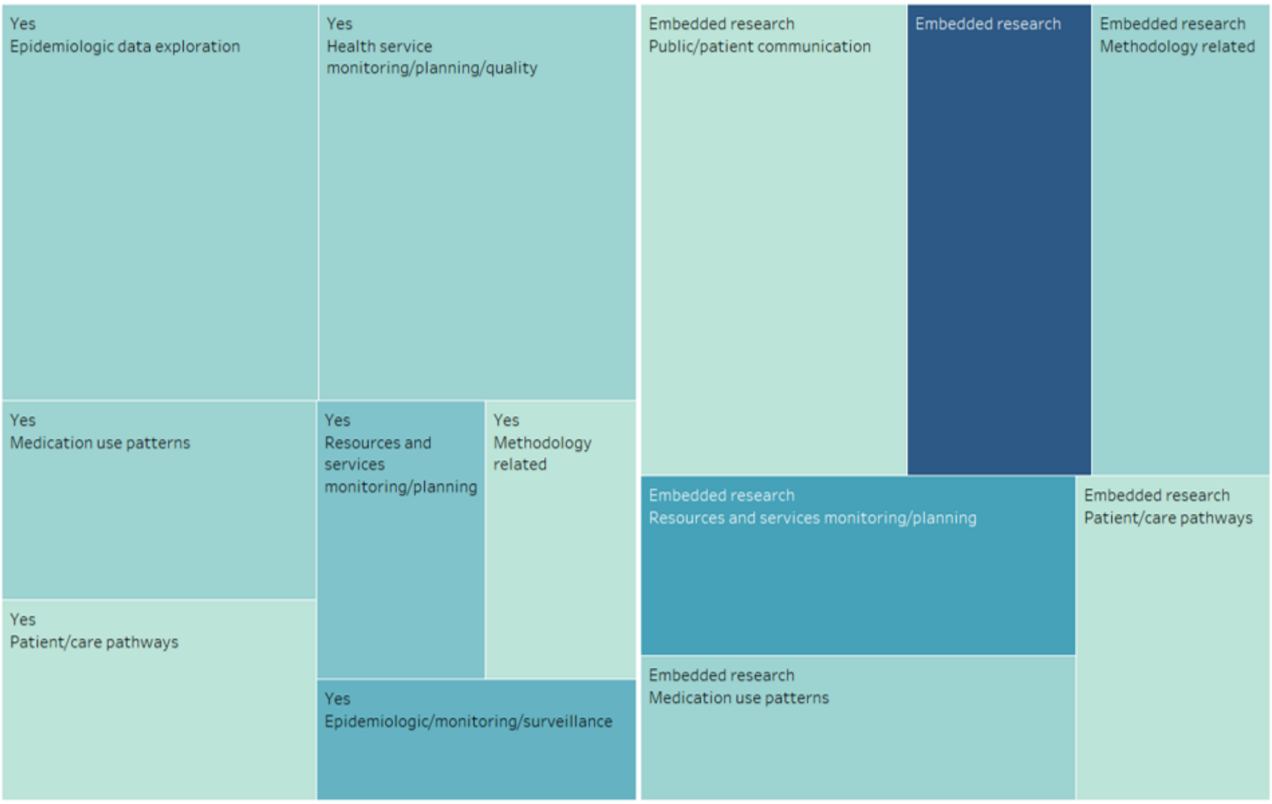
| | Change over time | | | Correlati.. | Distribution | | Flow | | | Magnitude | | Part to w.. | Ranking | | Spatial | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Problem area | Area chart | Event timeline | Line | Scatterplot matrix | Histogram | Table | Circular weighted graph | Network map | Sankey | Bar | Parallel coordinates | Arc | Column bars | Dot strip plot | Choropleth | Heat map | Ring map | Thematic map |
| Epidemiologic data exploration | | | | 1 | | | | 1 | 1 | | | | | | | | | |
| Epidemiologic/monitoring/surveillance | | 2 | | | 1 | | 1 | 1 | | | | | | | 12 | | 1 | 3 |
| Health service monitoring/planning/qua.. | 1 | | | | | | | | | | | 1 | | 1 | 1 | 1 | | |
| Medication use patterns | | 1 | | | | | | | | | | | 1 | | 1 | | | 2 |
| Methodology related | | 1 | | | | | | | | | | | | | 1 | | | 1 |
| Patient/care pathways | | 2 | | | | | | 1 | 1 | | | | | | | | | |
| Public/patient communication | | 1 | 1 | | | | | | | | | | | | 1 | | | |
| Resources and services monitoring/plan.. | | | | | | 1 | | 1 | 1 | 1 | 1 | | | | 3 | | | 4 |

**Figure 4.** Primary visualization presentations by health care problem area.

## Application Co-design

For participatory approaches to application development, some articles (35/56, 67%) mentioned co-design. Among these (20/35, 57%) were applications that were part of embedded research at health care organizations. Other articles (20/56, 37%) did not mention this aspect. Application co-design was found in the problem categories of epidemiologic monitoring or surveillance (13/56, 23%), resource and service monitoring and planning (8/56, 14%), medication use patterns (4/56, 7%), visualization methodology (3/56, 5%), epidemiologic data exploration (2/56, 4%), health service monitoring or planning or quality (2/56, 4%), patient or care pathways (2/56, 4%), and public or patient communication (1/56, 2%). Figure 5 shows a tree map of co-designed applications and embedded research.

**Figure 5.** Co-designed applications and related health care areas (screenshot).



### Applications in Current Use and Public Availability

Most of the applications were mentioned as being currently available and in use (31/56, 55%). Related to public access, a third of the applications were available to the public (18/56, 32%). There were applications using free or open source tools (18/56, 32%) and those using proprietary tools (19/56, 34%), or the tools were not mentioned (18/56, 32%).

## Discussion

### Significance of the Review

Data visualization in health has a lengthy history going back to the influential work of John Snow and Florence Nightingale in the 19th century. The field of interactive visualization has developed in parallel with computing power and the availability of large, complex health care data sets for diverse audiences such as clinicians, public health researchers, practitioners, and decision-makers [1,41], with considerable progress made in design methodologies [14]. Our review is a novel synthesis and summary of the literature from a vast body of research that had not previously been covered.

In this methodological review, we aim to capture the current state of knowledge and evidence on the topic of *interactive visualization applications* in population health and HSR, distinguishing them from conventional graphical presentations in health care and the related field of VA. We explored areas in population health and HSR to ascertain where these techniques have been used and identified trends and opportunities for the use of these applications.

As population health and health services researchers and practitioners, our perspective and interest in pursuing this research question were based on developing an in-depth understanding of the state of evidence on the use of visualization-based approaches for big health care data analyses. We anticipated that the review would help diverse audiences in population health and HSR learn from practical applications, inform future research endeavors, and help introduce the analytic method to researchers and students. We discuss our findings in this section with these overarching aims, contrasting the findings from previous reviews in other areas of health care using visualization approaches.

### Gaps and Opportunities for Application Co-design

Data visualization aims to convey information *at a glance*, although it assumes that the audience has expertise and visual literacy on the subject matter [101]. In their review of visualization-based applications in infectious disease epidemiology, Carrol et al [14] summarize the audience's information needs and learning behavior and point to 3 important barriers to relaying information to target audiences: (1) time constraints, (2) prior knowledge, and (3) cognitive load [14]. Hence, the design process is imperative for an effective application that allows the user to successfully understand the presented data. Various methodologies outlining effective design requirements and experiences from stakeholders to create new products and solutions have been explored [102-104]. For our scoping review, we opted to use the term *co-design*, which is more commonly used in health care literature, as opposed to *design thinking* and other related terms [13].

In this review, we found that at least two-thirds of the applications involved co-design approaches, involving stakeholders for developing interactive visualization applications. This was in contrast to a smaller proportion of co-designed VA applications (18%), which were mostly prototypes developed by and for data scientists at academic centers [13]. In line with this finding, more than half of the interactive visualization applications were developed in-house within health care organizations. We termed these initiatives *embedded research* as part of co-designed applications to indicate that these were initiated within the organizations in response to an identified data-driven need for knowledge generation and decision support. We could not find such applications in the VA literature [13]. This indicates an important trend because participatory design and development in health has proven to be a key element in better viability and uptake in planning and implementation of services [105,106].

Notably, a third of the articles in this review did not mention a co-design method, which could be due to authors either opting to omit it or because these were covered elsewhere. We recommend that future research indicate whether the application used co-design approaches. It is important to describe the context in adequate detail to appreciate stakeholder needs, experience, and satisfaction. Furthermore, to map and present methods in sufficient detail, we suggest using established frameworks such as the Munzner Nested Process [107] or Design Thinking for Visualization [108] as reporting tools.

### Contrasting Interactive Visualization and VA Applications

Through our recent work in studying visualization methods and applications in population health and HSR, we establish that the fields of interactive visualization and VA share communities of practice, methods, and approaches, but they are conceptually separate with important differences. We highlight the major ones here.

We found that interactive visualization applications were initiated by and targeted at researchers and practitioners within government health care organizations tasked with health services delivery, planning, and policy advice. In contrast, most of the VA applications were from and developed for data scientists [13]. In addition, most interactive visualization applications were developed using front-end engines, especially proprietary tools not requiring an advanced knowledge of coding [13]. Most VA methods and applications were prototypes developed using different combinations of tools, with a very small number using proprietary software [13]. Related to theoretical or conceptual frameworks, VA applications offered 13 different frameworks, whereas we could not identify any of these in this review of interactive visualization applications. However, the latter applications mentioned the use of frameworks at different stages of developing the applications. VA applications also expressly mentioned statistical and machine learning techniques as part of the analytic engine, whereas interactive visualization applications mostly used simple descriptive aggregative techniques. In another distinction, most VA applications were prototypes, whereas most interactive visualization applications were developed for knowledge generation and decision support [13].

Both the VA and interactive visualization techniques seem to have originated from North America and Europe [13]. The top 3 countries identified for VA applications were the United States (24/55, 44%), Canada (5/55, 9%), and Germany (3/55, 5%). The top countries for interactive visualization applications were the United States (30/56, 54%), the United Kingdom (4/56, 7%), and Canada and Indonesia (2/56, 4% each). Both our reviews indicated that most of the applications for both methods were descriptive analytics, with an overlap with exploratory analyses of complex data sets (23/55, 42% for VA and 37/56, 66% for interactive visualization), and a small proportion for predictive analytics. The application goals were comparable, with most being knowledge discovery (35/55, 80% for VA and 56/56, 100% for interactive visualization) or decision support (44/55, 80% for VA and 47/56, 84% for interactive visualization), with considerable overlap (29/55, 53% for VA and 47/56, 84% for interactive visualization). The data sets used for both types of applications were single (32/55, 58% for VA and 40/56, 71% for interactive visualization) and structured (40/55, 73% for VA and 48/56, 86% for interactive visualization). There were no unstructured data sets used for interactive visualization applications. Both types of applications used a small number of semistructured data sets (5/55, 9% for VA and 8/56, 14% for interactive visualization).

As population health and HSR are overlapping concepts, many articles in both reviews overlapped with their foci, methods, and the metrics studied. Among the VA articles, almost all (54/55, 98%) had a population health focus, whereas a third (18/55, 33%) were on HSR. There was a smaller overlap among the interactive visualization applications, with approximately two-thirds (38/56, 68%) focusing on population health and approximately half (29/56, 52%) on HSR.

Comparing the subdomains of population health and HSR, the 2 major categories of articles in the VA review focused on spatiotemporal aspects (27/55, 49%) compared with approximately a third (16/56, 29%) for interactive visualization applications. The next largest subdomains in VA included clinical populations focusing on a condition or cluster of conditions (17/55, 31%) or epidemic monitoring and modeling (18/55, 33%). Among the HSR articles for VA, these were mostly for health services' utilization (15/55, 27%), access to care (10/55, 18%), or costs (2/55, 4%). Conversely, in the interactive visualization literature, the most common subdomain for population health was the study of a demographic population (28/56, 50%), followed by a clinical population (23/56, 41%), and epidemic monitoring and modeling (11/56, 20%). There was a similar trend toward the use of both interactive visualization in HSR, with the most common subdomains being health services' utilization (23/56, 41%), followed by access (16/56, 29%) and costs (4/56, 7%).

The categories of problems have important similarities and variations with epidemiologic surveillance for infectious disease being the major category that the applications targeted (38%

for both VA and interactive visualization). The next problem categories for VA applications were medical record pattern identification (20/55, 36%), population health monitoring (9/55, 16%), and health system resource planning (2/55, 4%). For interactive visualization applications, these included resources and services monitoring or planning (12/56, 21%), health service monitoring or quality (5/56, 9%), and medication use patterns (5/56, 9%).

Interactive visualization applications mostly used administrative and EMR or EHR data sources. This can be attributed directly to the availability of data within health care organizations. VA applications were developed using varied data sources, including administrative (19/55, 35%), EMR or EHR (17/55, 31%), spatiotemporal (16/55, 29%), social media (8/55, 15%), and simulation data (6/55, 11%); for interactive visualization applications, the data sources were secondary administrative data (45/56, 80%), social media (2/56, 4%), and sensor data (1/56, 2%).

Comparing tools in current use, about a third (21/55, 38%) of the VA applications were in use at the time of publication, whereas others were either not available or were prototypes. Moreover, a few (7/56, 13%) applications were accessible for public use, while less than a third were developed using free open source tools (13/56, 24%). Among the interactive visualization applications, more than half (31/56, 55%) were mentioned as being in current use, whereas about a third (18/56, 32%) were available to the public, and the same proportion were developed using free or open source tools. There was a greater proportion of use of proprietary tools (19/56, 34%) for interactive visualization applications compared only a 10th of VA applications (5/55, 10%).

The trend for the use of visual presentations was toward the use of different maps in both applications. Choropleth maps were the most frequently used for interactive visualizations (13/56, 24%), followed by thematic maps (10/56, 18%), event timelines (7/56, 13%), and network maps (4/56, 7%). VA applications showed a similar trend with thematic maps (17/55, 31%), timelines (8/55, 15%), and heat or choropleth maps (6/55, 11%). This corresponds to the findings of the review by Chung et al [17] on visualization methods in the area of mental health systems, which indicated that the most common means of presenting data was through maps [17].

Because of the differences in the methods involved in developing the applications, software tools varied greatly. VA tools were a mix of software tools used for the analytic and visual engines, whereas interactive visualization applications reported visual engines alone. However, there were still similarities in the use of tools. Tableau was the most frequently reported tool for interactive visualization applications (7/56, 13%), followed by D3.JS (5/56, 9%); ArcGIS and Instant Atlas (3/56, 5% each); and R/R-Shiny, Open Street Map, Google Maps API, SQL, and Java-based applications (2/56, 4% each). The most common tools found for VA applications were R-based tools (7/55, 13%), followed by D3.JS (4/55, 7%); SQL (4/55, 7%), Java-based tools (3/55, 5%); and Python-based tools, HTML 5, or Google Maps API (2/55, 4% each). Front-end visual engines such as Tableau were used by only 1 VA application in combination with Weka as the analytic engine.

Finally, an issue that we identified in both our reviews was the lack of reporting detail in the articles, which is important for the replicability and adaptation of the methods used in developing applications. We suggest using part of the VA Reporting Checklist that we presented in our previous work on VA, particularly around the details on the *visualization engine* for the standard reporting of interactive visualization applications [13].

### Recent Trends of Using Interactive Visualization Methods

Our results showed that thematic mapping, including choropleth maps, was the most common visual presentation across all problem categories of population health and HSR. This was particularly the case for epidemiologic monitoring and surveillance. The recently created COVID-19 dashboards fall into the same category of applications [109]. Mapping also surfaced as a popular method for health resource monitoring, particularly for the planning of health care services [41,56,62,64,67,73,77,78,80,87,110,111].

Among different conditions of interest, a significant number of applications were developed for studying trends in cancer [43,44,52,61,71,88]. Being a worldwide population health issue, the greater use of interactive visualization methods in cancer could be due to the availability of dedicated registries and secondary administrative data [88]. In global health, applications focused on surveillance of communicable diseases [47], outreach campaigns [64], methods to examine health inequalities [53], and effects on health from global climate change [61]. In HSR, 6 applications directly or indirectly highlighted inequities in health, particularly in regard to effective planning and advising policy [43,53,63,70,82,89]. There was 1 article examining social determinants of health in HIV [63].

As two-thirds of the applications were focused on the visual exploration of complex data sets, this indicated a clear trend toward the use of this technique for exploratory analyses. Although most applications were meant for descriptive analytics and visual exploration of complex data sets, of the 56 applications, 4 (7%) were also capable of predictive analytics [39,68,71,93]. The methodological frameworks that were applied to developing the applications pertained to visual monitoring [38], level of detail in visual presentation [80], use of scientific publication visualizations [45], information management [69], user-centered web-based applications [83], and user interaction [91].

### Opportunities for Future Applications and Research

Experts highlight the preference of researchers for interactive graphics to facilitate data exploration and abstraction, and they suggest greater, varied learning opportunities from the use of interactive visualization tools [14].

In comparison with standard, traditional statistical analyses, interactive visualization techniques can play an important complementary role through knowledge generation as well as establishing associations and causality. Interactive visualization methods enable a *data* discourse, leading to in-depth data-driven insights, while having the advantage of improved perception with reducing cognitive load [2,5]. This interplay of direct data manipulation and analysis allows simultaneous study of trends and patterns in the analytic process, while formulating and testing hypotheses [13,112]. Furthermore, these methods are considered apt for studying correlations in high-dimensional data with a large number of time points [112]. This translates into a powerful technique for using big health care data, allowing a deep exploratory dive without an a priori hypothesis to identify data-driven trends and patterns.

In this review, although we observed various applications of interactive visualization, we found limited evidence of its use in global health. Given the massive open access data sets available from agencies such as the World Bank and the World Health Organization (WHO), research can focus on studying a plethora of population health and HSR indicators [113,114]. The WHO's Global Health Observatory provides population health–related data and statistics from 194 member states, particularly on nutrition, virological surveillance, workforce, and health systems, whereas the World Bank's open data repository features macroeconomic and social indicators such as gender and aid effectiveness. The methods can be helpful in ecologic studies, such as those comparing indicators across and within nations.

Related to this is another major opportunity for the use of interactive visualization in studying inequities, especially those rooted in social determinants of health. Although the social determinants of health have become a major focus for investigating structural inequities, we found only 1 article examining related aspects in the HIV sector [63]. Social determinants of health are defined by the WHO as "conditions in which people are born, grow, live, work and age...shaped by the distribution of money, power and resources at global, national and local levels" [115]. This is especially relevant for investigating structural inequities related to issues of access and use based on race, gender, disability, income distribution, and indigenous populations [116,117]. Taking Canada's example, investigating proximal factors for health among indigenous populations is one of the priority areas for improving health care [116]. Furthermore, high-quality Canadian data can be used to investigate inequities to better understand gaps in access and use of services by underserved populations. This can be done through national administrative data sources such as the Canadian National Ambulatory Care Reporting System, Discharge Abstract Database, and Hospital Morbidity Database, which store data for emergency and ambulatory care [118], as well as hospital inpatient discharges and day surgery [119].

Another major opportunity comes from the extension of using multiple data sources for studying patient journeys and care pathways. With the increasing use of EMR and EHR technologies, especially in primary care, there is an opportunity for researching patient populations along the continuum of care. Another such example is from the United Kingdom's Clinical Practice Research Datalink database, which forms the largest collection of anonymized primary care patient records [120]. In Ontario, Canada, the Electronic Medical Record Administrative Data Linked Database offers high-quality linked data for exploring trends and patterns in care and its provision with the advantage of capturing quality of care measures involving prescriptions and investigations [121].

In a recent review on visualization approaches for supporting mental health systems and policy research, Chung et al [17] indicate that there is a gap in studies that influence policy. Although policy was not our main area of focus for this review, the work indicates that there is an opportunity for informing and advising policy based on the use of big data, especially in the important area of mental health services.

Although the potential for the use of interactive visualization tools for bringing together disparate data sources is valued, there are related concerns for data interpretation, quality, accuracy, and handling [1,14]. Meeting the needs of diverse users and interdisciplinary teams as well as promoting the understanding of visual approaches are 2 related and important challenges to be cognizant of [1,14]. Researchers indicate that understanding the value of these techniques among health care organizations and public health agencies is key to realizing the potential of these methods regarding decision support [17].

## Implications and Value-add From the Review

Our work is unique in several respects. Complementing our work on VA applications in population health and HSR [13], this review amalgamates the findings from studies on interactive visualization applications, while delineating the literature to construct a holistic picture on the use of visualization approaches in these areas of health care. Interactive visualization is an increasingly popular method, especially for embedded research within health care organizations. Although traditional statistical methods inform causality and associations of various conditions, interactive visualization presents a complementary opportunity for knowledge discovery, hypotheses generation, and decision support using big health care data.

As a novel method, we present findings from both our scoping reviews on VA and interactive visualization in a dynamic, interactive, and visual format using Tableau dashboards [37,122]. In the interest of greater transparency and replicability, we provide the abstraction database with relevant fields for adaptation and further analysis [37].

We highlight opportunities in areas of research that could benefit from visualization-based methods to promote the understanding and uptake of the methods among the communities of research and practice. This work would also prove useful in further developing visualization-related analytic methods.

## Limitations

Although there are several important limitations that we are cognizant of in reporting this review, we made extensive efforts to identify relevant literature, delineate the body of literature on interactive visualization applications, incorporated rigor in our methods through all stages, and went through extensive steps toward validation to present our findings.

We cast a wide net in our literature search covering 6 databases, published the study protocol, and had our search strategy externally peer reviewed. However, we may have missed relevant literature residing in subject-specific databases such as those of digital art, mathematics, geography, and computer science. In addition, our review was limited to peer-reviewed literature from journal articles and full conference papers, and we focused on health care–related databases. We did not include CINAHL and ACM Digital Library because we could not find unique articles, separate from MEDLINE and IEEE Xplore, during the pilot searches.

In addition, in line with the first review on VA, this literature synthesis is limited to articles published between January 1, 2005, and March 30, 2019. We situate and report the review within the same period as the one on VA applications to complement and contrast findings. Many COVID-19–related visualization products that surfaced later are not included in this review for both reasons of feasibility and the subject being extremely specialized and falling under *outbreak analytics*. However, we plan a rapid analysis of COVID-19–related visual products later in the year. Although we describe interactive visualization applications, we allude only briefly to the challenges in the use of these methods because this was beyond the scope of this review.

## Conclusions

Visualization in health has strong historical roots. This systematic literature synthesis informs the state of evidence and trends toward the use of interactive visualization methods in the important and interrelated areas of population health and HSR. We note a significant trend in the use of interactive visualization applications being used in health care organizations, which we term *embedded research*. Such applications are being used by academic and health care agencies for knowledge discovery and generation, as well as decision support. Many of these applications have been co-designed with relevant stakeholders. Although we found a wide array of applications in different subdomains of population health and health services, there are multiple opportunities for the use of these methods in investigating global- and national-level indicators and social determinants of health, as well as constructing patient journeys for a holistic picture of the continuum of care.

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## Authors' Contributions

All authors contributed significantly to the conceptualization and reporting of the review. JC, IAB, AB, and JSM mainly wrote and revised the manuscript in consultation with the others. SA, MB and MI contributed to data abstraction. MI and JC validated the abstracted data. JC provided conceptual guidance on the Tableau visual dashboards, whereas AB and SFAT contributed significantly to the co-design, usability testing, and revisions to present the results. All authors reviewed the manuscript and its subsequent revisions.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) reporting checklist.
[PDF File (Adobe PDF File), 129 KB-Multimedia Appendix 1]

## Multimedia Appendix 2

Details of problems analyzed, settings, and target audience.
[DOCX File , 40 KB-Multimedia Appendix 2]

## Multimedia Appendix 3

Analytic capability and goals of the application.
[PDF File (Adobe PDF File), 124 KB-Multimedia Appendix 3]

## Multimedia Appendix 4

Data types, sources, and visualization tools.
[XLSX File (Microsoft Excel File), 29 KB-Multimedia Appendix 4]

## Multimedia Appendix 5

Functional types and details on visual presentations.
[XLSX File (Microsoft Excel File), 17 KB-Multimedia Appendix 5]

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## Abbreviations

**API:** application programming interface
**EHR:** electronic health record
**EMR:** electronic medical record
**GIS:** geographic information system
**HSR:** health services research
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses
**VA:** visual analytics
**WHO:** World Health Organization

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Original Paper

# Prevalence, Factors, and Association of Electronic Communication Use With Patient-Perceived Quality of Care From the 2019 Health Information National Trends Survey 5-Cycle 3: Exploratory Study

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## Abstract

**Background:** Electronic communication (e-communication), referring to communication through electronic platforms such as the web, patient portal, or mobile phone, has become increasingly important, as it extends traditional in-person communication with fewer limitations of timing and locations. However, little is known about the current status of patients' use of e-communication with clinicians and whether the use is related to the better patient-perceived quality of care at the population level.

**Objective:** The aim of this study was to explore the prevalence of and the factors associated with e-communication use and the association of e-communication use with patient-perceived quality of care by using the nationally representative sample of the 2019 Health Information National Trends Survey 5 (HINTS 5)-Cycle 3.

**Methods:** Data from 5438 adult responders (mean age 49.04 years, range 18-98 years) were included in this analysis. Multiple logistic and linear regressions were conducted to explore responders' personal characteristics related to their use of e-communication with clinicians in the past 12 months and how their use was related to perceived quality of care. Descriptive analyses for e-communication use according to age groups were also performed. All analyses considered the complex survey design using the jackknife replication method.

**Results:** The overall prevalence of e-communication use was 60.3%, with a significantly lower prevalence in older adults (16.6%) than that in <45-year-old adults (41%) and 45-65-year-old adults (42.4%). All percentages are weighted; therefore, absolute values are not shown. American adults who used e-communication were more likely to be high school graduates (odds ratio [OR] 1.95, 95% CI 1.14-3.34; *P*=.02), some college degree holders (OR 3.34, 95% CI 1.84-6.05; *P*<.001), and college graduates or more (OR 4.89, 95% CI 2.67-8.95; *P*<.001). Further, people who were females (OR 1.47, 95% CI 1.18-1.82; *P*=.001), with a household income ≥US $50,000 (OR 1.63, 95% CI 1.23-2.16; *P*=.001), with more comorbidities (OR 1.22, 95% CI 1.07-1.40; *P*=.004), or having a regular health care provider (OR 2.62, 95% CI 1.98-3.47; *P*<.001), were more likely to use e-communication. In contrast, those who resided in rural areas (OR 0.61, 95% CI 0.43-0.88; *P*=.009) were less likely to use e-communication. After controlling for the sociodemographics, the number of comorbidities, and relationship factors (ie, having a regular provider and trusting a doctor), e-communication use was found to be significantly associated with better perceived quality of care (β=.12, 95% CI 0.02-0.22; *P*=.02).

**Conclusions:** This study confirmed the positive association between e-communication use and patient-perceived quality of care and suggested that policy-level attention should be raised to engage the socially disadvantaged (ie, those with lower levels of education and income, without a regular health care provider, and living in rural areas) to maximize e-communication use and to support better patient-perceived quality of care among American adults.

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**KEYWORDS**

electronic communication; quality of care; person-related characteristics; patient preference; HINTS

## Introduction

Effective patient-clinician communication is a critical component of high-quality patient-centered care. With the rapid diffusion of advanced technology, the use of electronic services such as email, text messaging, and patient portals as a platform of communication (ie, electronic communication [e-communication]) between patients and clinicians has become increasingly popular [1]. Evidence shows that patients are enthusiastic about e-communication with clinicians regarding a wide variety of clinical contexts such as chronic condition self-management and follow-up examinations [2-4]. e-Communication has become a valuable supplement to traditional in-person communication through office visits [5,6]. It has fundamentally improved patients' interactions with the health care system and their engagement in shared decision-making with clinicians [7,8].

Despite the increasing popularity and potential impacts of e-communication on health care services, the actual use of e-communication among various patient populations still remains relatively low [9-12]. A review of patient portals for adults with diabetes found that 29%-46% of adults registered an account, but only 27%-76% of them actually accessed the portal [12]. A study of an encrypted message system in a pediatric clinic showed that only 4.3% of parents of chronically ill children made use of the system [11]. Similarly, a study of Health Information National Trends Survey 5 (HINTS 5)-Cycle 3 data in 2003-2005 indicated that only 10% of adult internet users communicated with the clinicians through web-based communication services [9]. Age can be a potential factor affecting the use of e-communication [13,14]. Clarke et al's [14] study showed that young adults preferred text messaging, middle-aged adults preferred phone calls, and older adults preferred paper-based and in-person interactions with clinicians. These findings imply that the prevalence of e-communication use might be lower among older adults as compared to that among young and middle-aged adults. Considering older adults' needs for technology-enabled health care support can help them become the major users of e-communication. In recent years, older adults' adoption of information and communication technology has been increasing, and they are likely to increasingly incorporate digital technology into their daily life [15]. Given the ever evolving technology and various populations' needs for support, it is important to understand how e-communication use varies across different age groups. Another commonly reported factor associated with patients' use of e-communication is patient-clinician relationships [16-20], for example, how much one trusts information from a doctor can influence the person's decision-making for using e-communication [19].

All these barriers can presumably affect both patients' use of e-communication [20] and their perceptions of quality of care [21]. However, there lacks empirical evidence to quantify the association between e-communication use and patient-perceived quality of care [22,23]. Patient-perceived quality of care refers to patients' perception of health care services received based on their experiences of what actually happened during the care process [24]. As one of the essential indicators of care quality, patients' perception of quality of care is an important driver of patient satisfaction, reflecting their desire for individualized high-quality care, which is also the main goal for those providing the care [25]. Factors that affect patient-perceived quality of care mainly include person-related conditions such as the patients' age, sex, education level, and self-reported health status, and external objective care conditions such as the organizational structure of care, competence of health care personnel, the size of the hospital, inpatient stay and occupancy, and comfortable environment [26]. Patient-clinician communication has been reported as one of the major factors driving patient perception of quality care in addition to hospital staff responsiveness, the care transition process, and hospital environment [27]. In the era of digital health, particularly with the increased popularity of e-communication between patients and clinicians and extended health care efficiency, the use of e-communication may increase the patient-perceived quality of care as opposed to no use of any e-communication [21]. However, the lack of empirical evidence to quantify the effectiveness of e-communication on patient-perceived quality of care may delay the promotion of e-communication adoption and the development of new models of patient-clinician interaction to satisfy patients' needs for high-quality health care services [21].

The purposes of this study were to examine the prevalence of patients' use of e-communication with clinicians and the potential factors (in particular, person-related factors such as age) associated with their use of e-communication and to explore the potential association between e-communication use and patient-perceived quality of care. Based on previous literature reports [21,24,25,27], we hypothesized that patients' use of e-communication was related to better patient-perceived quality of care.

## Methods

### Data Source

Data used in this study were from the HINTS 5-Cycle 3 [28]. HINTS is a nationally representative survey designed to understand American adults' knowledge of, attitudes toward, and use of cancer- and health-related information [29]. HINTS 5-Cycle 3 used a single-mode mail survey, with a 2-stage sample design, including a stratified sample of addresses and a selected adult within each sampled household [28]. The data were collected from 5438 respondents from January to May 2019 (English version only), with an overall 30.3% response rate [28]. Comprehensive reports on the sampling design for the HINTS survey have been published elsewhere [28-30]. The survey data were deidentified and are publicly available; institutional review board approval was not applicable.

## Variables

### *Perceived Quality of Care*

The outcome variable patient-perceived quality of care was assessed via self-report on a single question asking "*overall, how would you rate the quality of health care you received in the past 12 months?*" with a 5-point Likert scale from 1=poor to 5=excellent, with a high score indicating better perceived quality of care (see Table 1).

**Table 1.** Variables and survey measurements.

| Variable | Survey measurement |
|---|---|
| Patient-perceived quality of care | Overall, how would you rate the quality of health care you received in the past 12 months? (1=poor to 5=excellent) |
| **Use of electronic communication** | |
| 1 | In the past 12 months, have you used a computer, smartphone, or other electronic means to communicate with a doctor or a doctor's office? (1=yes, 0=no) |
| 2 | Have you sent a text message to or received a text message from a doctor or other health care professional within the last 12 months? (1=yes, 0=no) |
| 3 | In the past 12 months, have you used your online medical record to securely message health care provider and staff (eg, email)? (1=yes, 0=no) |
| 4 | In the past 12 months, have you used your online medical record to add health information to share with your health care provider, such as health concerns, symptoms, and side effects? (1=yes, 0=no) |
| 5 | Have you shared health information from either an electronic monitoring device or smartphone with a health professional within the last 12 months? (1=yes, 0=no) |
| 6 | Have you electronically sent your medical information to another health care clinician? (1=yes, 0=no). |
| **Sociodemographics** | |
| 1 | Age (young: ≥18 and <45 years, middle-aged: ≥45 and <65 years, and older adults ≥65 years) |
| 2 | Sex (0=male, 1=female) |
| 3 | Education level (0=less than high school, 1=high school graduate, 2=some college, 3=college graduate or more) |
| 4 | Marital status (0=not married, 1=married or partnered) |
| 5 | Race/ethnicity (0=White, 1=African American, 2=Hispanic, 3=other) |
| 6 | Household income (0=<US $50,000; 1=≥US $50,000) |
| 7 | Living status (0=living with others, 1=living alone) |
| 8 | Residency (0=nonrural, 1=rural) |
| Comorbidities | The number of comorbidities: Has a doctor or other health professional ever told you that you had any of the following medical conditions? Choices for this question included cancer, hypertension, diabetes, heart condition, chronic lung disease, and depression, and a sum score was used. |
| **Patient-clinician relationship** | |
| 1 | Having a regular health care provider: Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often? (0=no, 1=yes) |
| 2 | Trusting a doctor: In general, how much would you trust information about health or medical topics from a doctor? (1=not at all to 4=a lot) |

### *Use of e-Communication*

Patients' use of e-communication with clinicians in the past 12 months, such as using the computer, smartphone, text messaging, web-based messaging, web-based medical records, or any other electronic means to share medical information, were assessed through 6 survey questions (see Table 1). Survey responders who answered "yes" to either of the 6 questions were considered having e-communication with their clinicians, defined as users, while responders who answered "no" to all 6 questions were considered as nonusers.

### *Sociodemographics and Comorbidities*

Age was measured as a continuous variable in the HINTS 5-Cycle 3 and was categorized into 3 groups: young adults (≥18 and <45 years of age, 38.4%), middle-aged adults (≥45 and <65 years of age, 39.7%), and older adults (≥65 years of age, 19.7%). All percentages are weighted; therefore, absolute values are not shown. Other sociodemographic covariates included sex, education level, marital status, race/ethnicity, household income, living status, and residency. The number of comorbidities was a sum score of 6 doctor-diagnosed chronic conditions, namely, cancer, diabetes, hypertension, heart disease, lung disease, and depression (see Table 1).

### *Patient-Clinician Relationship*

Patient-clinician relationship variables included (1) having a regular health care provider (yes/no) and (2) trusting a doctor (rating from 1=not at all to 4=a lot) (see Table 1).

### Statistical Analysis

All analyses considered the complex survey design of the HINTS 5-Cycle 3 sample by using the HINTS-supplied final weights to estimate population estimates and 50 replicate weights to compute the standard errors with the jackknife replication approach [29]. Specifically, descriptive statistics were used to describe the prevalence and the characteristics of e-communication users and nonusers. Multiple logistic regression analyses were used to assess the association of sociodemographics and comorbidities (Model 1) and sociodemographics, comorbidities, plus patient-clinician relationship factors (Model 2) with e-communication use. Multiple linear regression analyses were used to examine the association between e-communication use and patient-perceived quality of care with the control of sociodemographics and comorbidities (Model 3) and the control of sociodemographics, comorbidities, plus patient-clinician relationship factors (Model 4). Missing data pattern analysis indicated that most variables had missing data <5% (see Table S1 in Multimedia Appendix 1). Multiple imputation was performed, and the pooled results of model 3 and model 4 were based on 50 imputed data sets using multiple imputation by chained equations. All analyses were conducted using Stata software (version 14; StataCorp). Results were reported as weighted point estimates and 95% CIs. The level of significance was .05.

## Results

### Prevalence and Characteristics of e-Communication Users

The overall prevalence of the use of e-communication was 60.3%. Most American adults who used e-communication with clinicians in the past 12 months were younger than 65 years, as older adults only accounted for 16.6% of e-communication users but 25.7% of nonusers (see Table 2). Table 2 also displays that most e-communication users were females (53.9%), had at least some college (41.7%), and 36.4% college graduates or more, were White people (65%), currently married (59.9%), with a household income ≥US $50,000 (63.9%), and did not live alone (85%) or in rural areas (89.5%). e-Communication users and nonusers were significantly different in all person-related characteristics. In addition, significantly more e-communication users had a regular health care provider than e-communication nonusers (72.9% vs 51.4%, respectively; *P*<.001) (see Table 2). All percentages are weighted; therefore, absolute values are not shown.

**Table 2.** Sociodemographic characteristics and comorbidities of electronic communication users versus nonusers.[a]

| Characteristics | All users (N=5438) | Nonusers (n=2092) | Users (n=3337) | *P* value |
|---|---|---|---|---|
| Age (years), mean (SD) | 49.58 (17.58) | 50.52 (19.06) | 48.06 (16.36) | *.005* |
| Comorbidities, mean (SD) | 1.12 (1.15) | 0.99 (1.14) | 1.08 (1.13) | .14 |
| Trusting a doctor, mean (SD) | 3.67 (0.58) | 3.56 (0.66) | 3.66 (0.59) | *.001* |
| Patient-perceived quality of care, mean (SD) | 3.96 (0.93) | 3.84 (0.92) | 4.01 (0.93) | *.002* |
| **Age categories (% weighted)[b]** | | | | *<.001* |
| Young adults (<45 years) | 38.4 | 36.5 | 41.0 | |
| Middle-aged adults (45-64 years) | 39.7 | 37.9 | 42.4 | |
| Older adults (≥65 years) | 19.7 | 25.7 | 16.6 | |
| Gender (female) (% weighted)[c] | 50.1 | 47.2 | 53.9 | *.003* |
| **Education level (% weighted)[d]** | | | | *<.001* |
| Less than high school | 6.8 | 12.2 | 3.6 | |
| High school graduate | 22.8 | 31.3 | 18.3 | |
| Some college | 39.1 | 37.7 | 41.7 | |
| College graduate or more | 28.7 | 18.7 | 36.4 | |
| Marital status (married or partnered, % weighted)[e] | 54 | 49.1 | 59.9 | *<.001* |
| **Race/ethnicity (% weighted)[f]** | | | | *.002* |
| White | 58 | 60.9 | 65 | |
| African American | 10.3 | 13.1 | 10.2 | |
| Hispanic | 15.4 | 20 | 14.9 | |
| Other | 7.7 | 6 | 9.9 | |
| Household income (≥US $50,000) (% weighted)[g] | 54.5 | 42.2 | 63.9 | *<.001* |
| Living alone (% weighted)[h] | 16.9 | 21.9 | 15 | *<.001* |
| Residency (rural) (% weighted)[i] | 13.3 | 17.4 | 10.5 | *.001* |
| Having a regular health care provider (yes) (% weighted)[j] | 63.3 | 51.4 | 72.9 | *<.001* |
| Use of electronic communication (yes) (% weighted)[k] | 60.3 | —[l] | — | — |

[a] Absolute values are not provided in this table because the percentages are weighted. The absolute values are summarized in the Multimedia Appendix 2. Significant *P* values are italicized.

[b] Age categories (0=young adults, 1=middle-aged adults, 2=older adults).

[c] Gender (0=male, 1=female).

[d] Education (0=less than high school, 1=high school graduate, 2=some college, 3=college graduate or more).

[e] Marital status (0=not married, 1=married or partnered).

[f] Race/ethnicity (0= White, 1=African American, 2=Hispanic, 3=other).

[g] Household income (0=less than US $50,000, 1=≥US $50,000).

[h] Living alone (0=living with others, 1=living alone).

[i] Residency (0=nonrural, 1=rural).

[j] Having a regular health care provider (0=no, 1=yes).

[k] Use of electronic communication with a clinician (0=no, 1=yes).

[l] Not available.

### Factors Associated With e-Communication

Table 3 presents the results of multiple logistic regression analyses on the sociodemographics, comorbidities, and patient-clinician relationship factors for e-communication use. In model 1, where only sociodemographic factors and comorbidities were considered, age (odds ratio [OR] 0.87, 95% CI 0.66-1.14), female (OR 1.44, 95% CI 1.17-1.77), education level (eg, for college graduates or more, OR 4.78, 95% CI 2.63-8.68), household income (OR 1.77, 95% CI 1.34-2.34), rural residency (OR 0.62, 95% CI 0.44-0.87), and number of comorbidities (OR 1.33, 95% CI 1.16-1.52) were associated with e-communication use (see Table 3). In model 2, after adding the relationship factors to the model, people who were females (OR 1.47, 95% CI 1.18-1.82), high school graduates (OR 1.95, 95% CI 1.14-3.34), having some college (OR 3.34, 95% CI 1.84-6.05), and college graduates or more (OR 4.89, 95% CI 2.67-8.95), with a household income at or greater than US $50,000 (OR 1.63, 95% CI 1.23-2.16), with more comorbidities (OR 1.22, 95% CI 1.07-1.40), or having a regular health care provider (OR 2.62, 95% CI 1.98-3.47) were more likely to use e-communication, whereas those who were older adults (OR 0.42, 95% CI 0.31-0.57) or rural residents (OR 0.61, 95% CI 0.43-0.88) were less likely to use e-communication.

**Table 3.** Factors associated with electronic communication.

| Variables | Model 1[a] | | Model 2[b] | |
|---|---|---|---|---|
| | Odds ratio (95% CI) | *P* value[c] | Odds ratio (95% CI) | *P* value[c] |
| **Age** | | | | |
| Young adults (<45 years) | Ref[d] | Ref | Ref | Ref |
| Middle-aged adults (45-64 years) | 0.87 (0.66-1.14) | .31 | 0.86 (0.65-1.15) | .30 |
| Older adults (≥65 years) | 0.51 (0.39-0.68) | *<.001* | 0.42 (0.31-0.57) | *<.001* |
| Female | 1.44 (1.17-1.77) | *.001* | 1.47 (1.18-1.82) | *.001* |
| **Education level** | | | | |
| Less than high school | Ref | Ref | Ref | Ref |
| High school graduate | 1.92 (1.09-3.39) | *.03* | 1.95 (1.14-3.34) | *.02* |
| Some college | 3.32 (1.82-6.07) | *<.001* | 3.34 (1.84-6.05) | *<.001* |
| College graduate or more | 4.78 (2.63-8.68) | *<.001* | 4.89 (2.67-8.95) | *<.001* |
| Married or partnered | 1.28 (0.97-1.69) | .08 | 1.26 (0.94-1.68) | .12 |
| **Race/ethnicity** | | | | |
| White | Ref | Ref | Ref | Ref |
| African American | 0.93 (0.62-1.38) | .70 | 1.03 (0.68-1.57) | .89 |
| Hispanic | 0.86 (0.63-1.17) | .32 | 1.04 (0.76-1.41) | .81 |
| Other | 1.44 (0.93-2.21) | .10 | 1.55 (1.01-2.39) | .05 |
| Household income (≥US $50,000) | 1.77 (1.34-2.34) | *<.001* | 1.63 (1.23-2.16) | *.001* |
| Living alone | 0.94 (0.69-1.29) | .70 | 0.95 (0.68-1.31) | .74 |
| Rural residency | 0.62 (0.44-0.87) | *.008* | 0.61 (0.43-0.88) | *.009* |
| Number of comorbidities | 1.33 (1.16-1.52) | *<.001* | 1.22 (1.07-1.40) | *.004* |
| Having a regular health care provider (yes) | —[e] | — | 2.62 (1.98-3.47) | *<.001* |
| Trusting a doctor | — | — | 1.14 (0.96-1.37) | .14 |

[a] Model 1 adjusted for sociodemographic factors (eg, age categories, gender, education, marital status, race/ethnicity) and comorbidities.

[b] Model 2 adjusted for sociodemographics, comorbidities, plus relationship factors (eg, having a regular health care provider, trust a doctor).

[c] Significant *P* values are italicized.

[d] Ref: reference value.

[e] Not available.

### Associations Between e-Communication Use and Patient-Perceived Quality of Care

Table 4 displays the results of the association between e-communication use and patient-perceived quality of care among American adults. After controlling for sociodemographic factors (age, gender, education, income), comorbidities, and patient-clinician relationship factors (having a regular health care provider, trust a doctor), the use of e-communication was statistically associated with better quality of care (β=.12, 95% CI 0.02-0.22; see Model 4 in Table 4).

**Table 4.** Association between electronic communication and patient-perceived quality of care based on 50 imputed data sets using chained equations.

| Variables | Model 3[a] | | | Model 4[b] | | |
|---|---|---|---|---|---|---|
| | β | 95% CI | *P* value[c] | β | 95% CI | *P* value[c] |
| Use of electronic communication | .20 | 0.09 to 0.30 | *<.001* | .12 | 0.02 to 0.22 | *.02* |
| **Age[d]** | | | | | | |
| Young adults | Ref[e] | Ref | Ref | Ref | Ref | Ref |
| Middle-aged adults | .06 | –0.06 to 0.17 | .36 | .06 | –0.05 to 0.17 | .27 |
| Older adults | .24 | 0.12 to 0.36 | *<.001* | .17 | 0.05 to 0.28 | *.005* |
| Female | .00 | –0.10 to 0.09 | .92 | –.01 | –0.10 to 0.08 | .84 |
| **Education level** | | | | | | |
| Less than high school | Ref | Ref | Ref | Ref | Ref | Ref |
| High school graduate | .09 | –0.30 to 0.12 | .39 | –.07 | –0.26 to 0.12 | .45 |
| Some college | –.07 | –0.27 to 0.14 | .51 | –.09 | –0.28 to 0.10 | .32 |
| College graduate or more | .01 | –0.20 to 0.22 | .90 | –.05 | –0.24 to 0.14 | .62 |
| Married or partnered | .03 | –0.11 to 0.17 | .65 | .04 | –0.09 to 0.17 | .53 |
| **Race/ethnicity** | | | | | | |
| White | Ref | Ref | Ref | Ref | Ref | Ref |
| African American | –.07 | –0.24 to 0.09 | .39 | –.01 | –0.17 to 0.14 | .86 |
| Hispanic | .00 | –0.15 to 0.15 | .96 | .06 | –0.08 to 0.20 | .40 |
| Other | –.25 | –0.46 to –0.04 | *.02* | –.23 | –0.44 to –0.03 | *.02* |
| Household income (≥US $50,000) | .11 | –0.01 to 0.23 | .08 | .08 | –0.04 to 0.19 | .19 |
| Living alone | .05 | –0.11 to 0.21 | .55 | .07 | –0.08 to 0.22 | .38 |
| Rural residency | –.02 | –0.18 to 0.15 | .82 | –.03 | –0.20 to 0.13 | .70 |
| Number of comorbidities | –.06 | –0.11 to –0.00 | *.03* | –.08 | –0.12 to –0.03 | *.001* |
| Having a regular health care provider | —[f] | — | — | .47 | 0.39 to 0.55 | *<.001* |
| Trusting a doctor | — | — | — | .20 | 0.10 to 0.31 | *<.001* |

[a] Model 3 adjusted for sociodemographic factors (eg, age categories, gender, education, marital status, race/ethnicity) and comorbidities.

[b] Model 4 adjusted for sociodemographics, comorbidities, plus relationship factors (eg, having a regular health care provider, trusting a doctor).

[c] Significant *P* values are italicized.

[d] Age categories: young adults (<45 years), middle-aged adults (45-64 years), older adults (≥65 years).

[e] Ref: reference value.

[f] Not available.

# Discussion

## Principal Findings

This study examined the prevalence of and factors associated with e-communication use and the potential association between e-communication use and patient-perceived quality of care in a nationally representative sample of American adults. To the best of our knowledge, this study is the first to explore the association of e-communication use with patient-perceived quality of care at the population level. Several important findings emerged in this study.

First, the majority of American adults (60.3%) used some forms of e-communication with clinicians throughout 2019, which was significantly higher than the reported 7% in 2003, 10% in 2005 [9], and 31.5% in 2014 from the previous HINTS [31]. This finding indicates that e-communication use has become increasingly popular for adults to interact with their clinicians. The increased prevalence rate can be attributed to the increased availability and popularity of electronic health devices [32,33] and supportive policies (eg, promoting patient access to their electronic medical records) [34]. Although our data showed an overall growing trend in the use of e-communication, it is important to note that older adults' use of e-communication still remained relatively low, and this rate was not much improved from that in 2003 and 2005 [12]. Literature indicates that older adults usually prefer direct in-person interactions with their clinicians [12], while there are increasing reports about older adults' positive attitude toward e-communication and their preference for email and messaging communication with clinicians that is similar to that for younger adults [35,36]. Our finding suggests that there is still a gap in the actual use of e-communication between older adults and young adults [31,37,38]. More studies are needed to explore the practical challenges that older adults may encounter in the use of e-communication. Older adults are potentially the major users of e-communication, considering their high level of health care needs. It is important to develop appropriate e-communication support for this population for their better health outcomes.

In addition to age, we also found that the use of e-communication varied by gender, education, income, and residency, indicating that individuals who are females, with higher education, higher income, and more comorbidities, or who reside in nonrural areas were more like to use e-communication with their clinicians. This finding is congruent with reports of the general adoption of eHealth in literature [39-42]. Consistent with our finding, the positive association between education and e-communication usage was reported in previous studies [31,39], which can be interpreted as individuals who have higher education might have more eHealth literacy skills and technological capabilities [43] to help them better use electronic forms of information [31,39]. However, Senft and Everson's recent study [44] reported that individuals who had lower levels of education and had negative care coordination experiences are more likely to use eHealth activities to communicate with clinicians [44], indicating that personal health care experiences can possibly interplay with education and thus influence the use of e-communication. However, it is unclear whether the limited use of e-communication among rural residents is related to lack of internet connectivity or awareness of e-communication services [45]. Additional studies can be conducted for further exploration.

Compared to those who did not use e-communication in the past year, in this study, e-communication users were more likely to have a regular health care provider and reported better trust in information from a doctor. However, trusting a doctor was not an independent predictor of e-communication use when having a regular health care provider was controlled for in the model. A previous qualitative study has indicated that a trusting relationship between patient-clinician is a significant contributor to better online patient-clinician interactions [20,46]. Even those who tend to frequently seek web-based health information are more willing to use the information provided by their trusted clinicians for their health decision-making [17,47]. Our findings suggested that patients with a regular health care provider had the greatest association with their use of e-communication. It is possible that patients who have a regular health care provider have already built a trusting relationship with their clinicians. Given the importance of trust in a provider in the patient-centered care process, future research directly examining possible confounding of this factor using longitudinal data is recommended.

Finally, it is not surprising that this study found that the use of e-communication was an independent predictor of patient-perceived quality of care. In 2001, the Institute of Medicine suggested that e-communication could improve the quality of care [48]. The previous literature review demonstrates that e-communication provides a convenient way of patient-clinician interaction, has a positive impact on patient satisfaction while saving time for patients and clinicians, and has the potential to extend health care efficiency [21,49]. The benefits and challenges of e-communication have been well addressed in the literature, while its benefits for the quality of care may not have been clearly quantified previously. The measures of quality of care can vary by the dimensions of care and care processes [50]. However, this study focused on the measure of the patient-perceived quality of care, which solely reflected patients' perceptions of health care services received based on their experiences of care [24]. It did not mean to measure any technical clinical quality, for example, cholesterol screening [51]. There is increasing interest in patient-reported measures, as experiences with care are more easily understood by patients. In addition, previous literature demonstrated that the measure of patient experiences of care was related to measures of the technical quality of care, which can serve as valid summary measures of hospital quality [52]. These study findings were based on the analysis of nationally representative survey data, which should be generalizable to all American adults. The positive association between the use of e-communication and perceived quality of care confirms that e-communication can serve as an important tool to improve patient satisfaction and their perceptions of quality of care. This finding is particularly significant and applicable in the current COVID-19 pandemic when traditional in-person communication is less feasible. It is expected that e-communication will continuously replace an adequate portion of traditional face-to-face encounters and has the potential to transform the health care system [21]. Future research can be conducted to explore the sustainable long-term effects of e-communication on patient-centered care outcomes.

## Limitations

This study has a few limitations. First, data were mainly based on self-reports, which might have introduced recall bias. Second, the survey questions regarding the use of e-communication did not specify the frequency of use; therefore, they did not accurately reflect responders' experiences of using e-communication and might affect their perceptions of quality of care. Third, a binary measure of e-communication use (yes/no) was used, which might result in the loss of information or power. However, considering the conceptual overlaps across 6 questions about e-communication behaviors in the survey, a combined continuous assessment for the number of e-communication behaviors would be conceptually inaccurate. Fourth, the e-communication was between patients and clinicians. However, the survey only focused on the patient side and thus, it was not possible to know clinicians' perceptions of e-communication use. Finally, the results could be underestimated by potential reverse causality owing to the nature of the study design. The prevalence of e-communication use was higher in our study than that that reported in previous studies. The difference may also be due to varying measurement methods across studies. In our study, we used 6 questions to measure e-communication, which are more than that used in other studies. Different measures might affect comparisons of the prevalence of e-communication use across studies.

## Conclusions

American adults' use of e-communication with clinicians has been significantly increased in the past decade, which may be due to increased patient needs and advanced support from technologies and policies. As a convenient way of patient-clinician interaction, the use of e-communication is significantly associated with patient-perceived quality of care. The findings of multiple factors associated with e-communication use and the positive association between e-communication use and patient-perceived quality of care suggest that policy-level attention is needed to engage the socially disadvantaged (ie, those with lower levels of education and income, without a regular health care provider, and living in rural areas) to maximize the use of e-communication and to support better patient-perceived quality of care among American adults.

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## Authors' Contributions

RY proposed the research questions, conducted data cleaning, data analysis, and manuscript writing. YJ proposed the research questions, was involved in the data analysis, data interpretation, and manuscript writing. KZ was involved in data interpretation, manuscript writing, and proofreading.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Missing data information.
[DOCX File , 18 KB-Multimedia Appendix 1]

## Multimedia Appendix 2

Absolute value data for weighted percentages.
[DOCX File , 13 KB-Multimedia Appendix 2]

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## Abbreviations

**e-Communication:** electronic communication
**HINTS:** Health Information National Trends Survey
**OR:** odds ratio

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Review

# The Effect of Online Health Information Seeking on Physician-Patient Relationships: Systematic Review

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## Abstract

**Background:** The internet has now become part of human life and is constantly changing people's way of life. With the increasing popularity of online health information (OHI), it has been found that OHI can affect the physician-patient relationship by influencing patient behaviors.

**Objective:** This study aims to systematically investigate the impact of OHI-seeking behavior on the physician-patient relationship.

**Methods:** Literature retrieval was conducted on 4 databases (Web of Science, PubMed, China National Knowledge Infrastructure, SinoMed), and the time limit for literature publication was before August 1, 2021.

**Results:** We selected 53 target papers (42 [79%] English papers and 11 [21%] Chinese papers) that met the inclusion criteria. Of these, 31 (58%) papers believe that patients' OHI behavior can enable them to participate in their own medical care, improve patient compliance, and improve the physician-patient relationship. In addition, 14 (26%) papers maintain a neutral attitude, some believing that OHI behavior has no significant effect on doctors and patients and others believing that due to changes in the factors affecting OHI behavior, they will have a negative or a positive impact. Furthermore, 8 (15%) papers believe that OHI search behavior has a negative impact on doctors and patients, while 6 (11%) papers show that OHI reduces Chinese patients' trust in doctors.

**Conclusions:** Our main findings showed that (1) OHI-seeking behavior has an impact on patients' psychology, behavior, and evaluation of doctors; (2) whether patients choose to discuss OHI with doctors has different effects on the physician-patient relationship; and (3) the negative impact of OHI on China's internet users is worthy of attention. Due to the low quality of OHI, poor health information literacy, short physician-patient communication time, and various types of negative news, patients' trust in doctors has declined, thus affecting the physician-patient relationship. Improvement of people's health information literacy and the quality of OHI are important factors that promote the positive impact of OHI on the physician-patient relationship.

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**KEYWORDS**

online health information; search behavior; physician-patient relationship; physician-patient consultation.

## Introduction

About 4.66 billion people worldwide have access to the internet [1]. The internet has gradually become part of human life, constantly changing people's lifestyle. As the availability and immediacy of information services provided by the internet continue to improve, and patients' private information can be concealed to a certain extent, internet health information services have become increasingly attractive [2]. In addition, the lack of medical resources makes people choose to obtain health information online to meet their own health information needs [3]. The online health information (OHI) that patients search for on the internet mainly includes information about diseases, nutrition, treatments, physical and mental health, etc [4,5]. The uneven quality of OHI has a major impact on patients. The credibility of information perceived by patients affects whether the patients use the internet as a frequently used and preferred information source [6]. Physicians are still the most popular source of health information, but the internet has gradually become another important source of health information [7].

OHI seeking can influence physician-patient relationships and patient compliance. Patients who can obtain more health information can better follow the treatment process and enjoy better therapeutic effects [8]. The rapid development of the internet has changed the access of patients to health information and affected the existing physician-patient relationship, which to a large extent determines the medical result that patients receive [9]. As mentioned before, patients choose to obtain health information online to meet their own needs. At the same time, the health information search results provided by the internet show that extreme situations, for example, advice that is contrary to the standard medical opinion or complex data provided by health care professionals, leads to misinterpretation, confusion, and other problems for patients [10]. Of course, the availability of health information on the internet is transforming many patients from passive medical service consumers to those who can participate in the medical process, which brings new challenges for many physicians [11,12]. When patients carry a lot of health information in a short consultation, can physicians deal with it as usual?

With the continuous development of the internet, the physician-patient relationship has attracted much attention. In terms of importance, the relationship between patients and physicians is second only to that of family [13]. It is viewed as extremely or very important by 67%, exceeding relationships with spiritual advisors, pharmacists, coworkers, and financial advisors [13]. Due to the patients' lack of understanding of diseases and communication barriers between physicians and patients, some patients cannot understand the results of diagnosis and treatment of the disease and the treatment behavior, which causes a series of problems [14]. Physician-patient communication is a complex clinical behavior whose main goal is to share medical information to improve the education of clinical diagnosis, treatment, and specific diseases [14]. The quality of physician-patient communication affects the physician-patient relationship. In the past, physicians made decisions and patients obeyed them, which constitutes the traditional physician-patient relationship [15]. Patients and medical staff advocate the transition to mutual participation, that is, shared power and responsibility [15]. Previous studies have shown that processing patients' OHI-seeking behavior in daily consultation can improve the quality of medical services [16]. In an ideal physician-patient relationship, patients should be guided instead of looking for OHI independently [17]. However, at present, patients are mainly looking for OHI by themselves, and they are unable to control the quality of information and other aspects.

In China, the total population is about 1.4 billion [18]. As of June 2021, the number of internet users reached 1.011 billion, and the internet penetration rate reached 71.6%. The “Healthy China” strategy is China’s priority development strategy [19]. By implementing internet medicine, the Healthy China strategy promotes the mobility of medical services, enhances the operation efficiency of the overall medical and health system, and optimizes the allocation of medical resources [19]. Due to China's large population and the impact of COVID-19, China's demand for medical resources is growing exponentially. Increasingly more doctors and patients are seeking health information through internet platforms, effectively breaking the time and space restrictions and giving China's unbalanced medical resources a chance to be redistributed [20]. Considering that OHI may have a positive or a negative impact on the physician-patient relationship, which is important in medical care, this study aims to examine the impact of OHI on the physician-patient relationship in China.

In recent years, studies on health information seeking have been increasing. It is of great significance to understand the impact of the current health information seeking on the physician-patient relationship. Thus, the purpose of this study is to systematically review the current studies on the impact of OHI seeking on the physician-patient relationship.

## Methods

### Literature Retrieval

In this study, English references were obtained from the databases Web of Science and PubMed. The PubMed database contains references related to medicine and life sciences. Web of Science includes the most influential core academic journals on natural science, engineering technology, biomedicine, and other research fields. Chinese references were obtained from the databases China National Knowledge Infrastructure (CNKI) and SinoMed. The CNKI is China's largest full-text journal database, while SinoMed focuses on collecting the biomedical literature in China.

After consulting with librarians, the search strategy for this paper consisted of all possible keywords related to 4 topics: (1) online OR internet OR web OR network, (2) wellness information OR health information, (3) search* OR seek* OR inquiry OR query, and (4) physician-patient communication OR doctor-patient communication OR physician-patient relation* OR doctor-patient relation* OR physician-patient interaction OR doctor-patient interaction OR physician-patient trust OR doctor-patient trust. The papers were published before August 31, 2021. Combinations of these keywords were searched in the 4 databases to make the literature search as comprehensive as possible. In addition, we searched the PubMed database separately with Medical Subject Headings (MESH). The Mesh terms were "patient-physician relations" and "internet."

This systematic review conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Multimedia Appendix 1).

### Inclusion and Exclusion Criteria of Publication Standards

To make the coverage of this study comprehensive enough, the types of papers included were journal papers, conference papers, and academic dissertations. Paper retrieval covered all regions and languages, but only papers with full text in English or Chinese were retained. Papers involving only OHI-seeking studies or only physician-patient relationship studies were excluded. We also excluded all nonempirical research papers, including reviews, research on websites, and research commentaries. Then, we evaluated the quality of the included papers. We used the Critical Appraisal Skills Programme quality assessment tool for qualitative studies, which comprises 10 questions [21] (Multimedia Appendix 2). We also used a quality assessment tool for quantitative studies that comprises 14 questions customized by Tan et al [22] (Multimedia Appendix 3). Papers with a quality assessment score lower than 0.7 were excluded.

### Paper-Screening Process

The literature screening in this study was independently carried out by 2 researchers. They screened the titles and abstracts, respectively, and read the full text to extract opinions. We compared the 2 researchers' screening results and the consistency of the extracted views, discussed the discrepancies to ensure the consistency and integrity of results, and used quality assessment tools to assess the quality of the papers. Endnote 20 was used to merge related search results and delete duplicate papers.

### Data Extraction and Management

The research data of papers were independently extracted by 2 researchers according to the predesigned table. It mainly included the following information: country, research design method, sample size, respondents, and conclusion. Where there was ambiguity, the 2 researchers discussed it and reached an agreement.

## Results

### Characteristics of the Papers

In this study, we searched the PubMed and Web of Science databases and retrieved 10,303 and 9345 records, respectively, for a total of 19,648 initially searched records and 15,801 (80.42%) exported records that remained after duplication removal using Endnote 20. According to the screening criteria, whether the papers discussed OHI seeking and the physician-patient relationship, 173 (1.09%) papers were included according to the title and abstract for further screening. Through the application of inclusion and exclusion criteria, of these 173 papers, 72 (41.6%) did not involve the impact of the physician-patient relationship; 7 (4%) were reviews; for 9 (5.2%), the original text could not be obtained; 19 (10.9%) did not have health information seeking as the main research object; 13 (7.5%) had full text in languages other than English; 10 (5.8%) were on nonempirical research; and 1 (0.6%) focused on physicians. The screening process is shown in Figure 1.

Finally, we included 42 of 173 (24.2%) English papers in the study; see Table 1. From the perspective of literature research methods, most of the studies were carried out in the form of questionnaires and interviews, and there were 11 (26%) studies in which research models and hypotheses were first proposed and questionnaires were designed for verification to study the mechanism of OHI seeking affecting the physician-patient relationship from different perspectives [11,23-32].

**Figure 1.** Flowchart of the selection process (English papers). OHI: online health information.

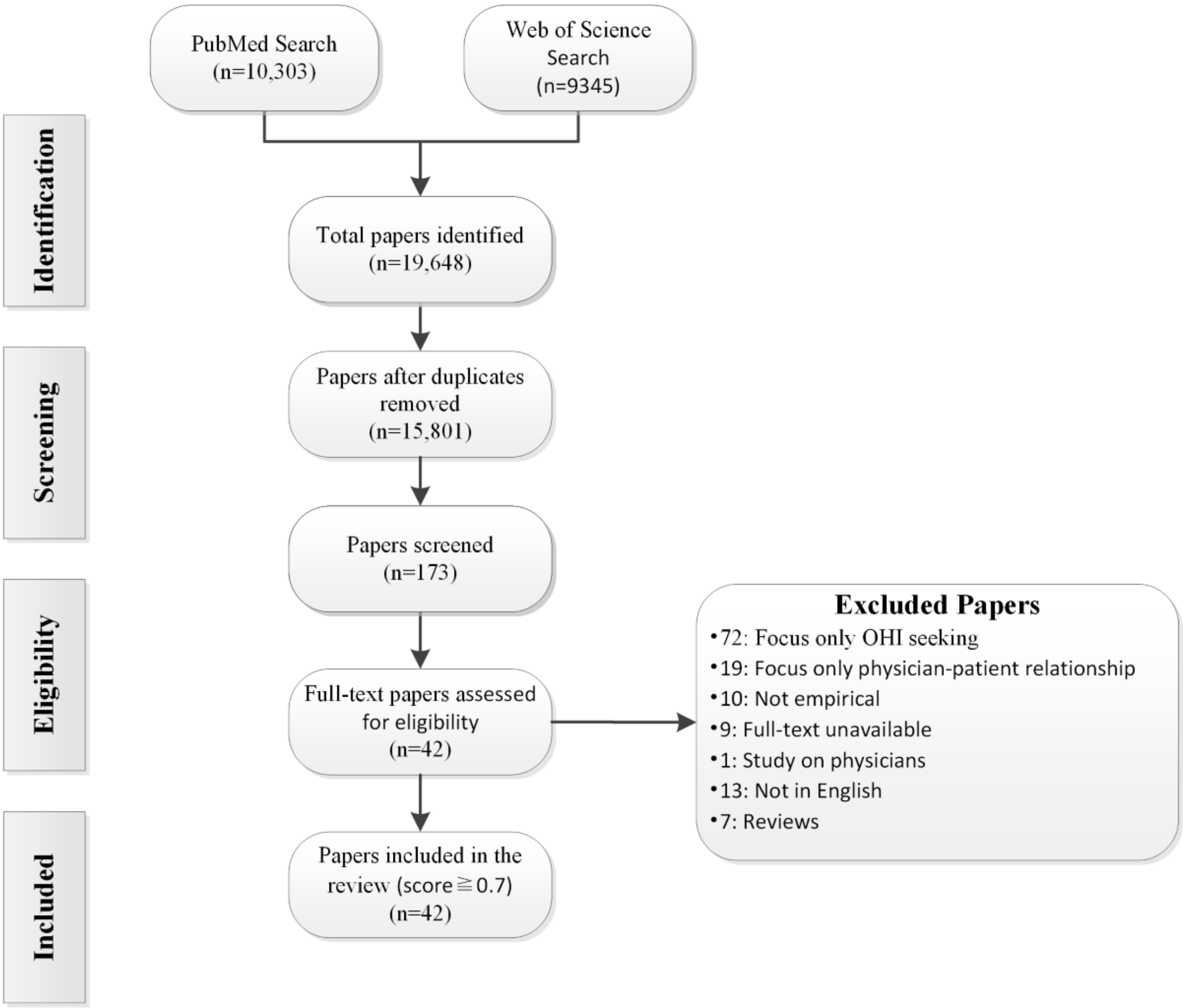

**Table 1.** Summary of included English papers (n=42).

| Number | Reference | Country | Method | Participants, n | Participant characteristics | Factors affecting OHI[a] use covered in this paper (Y=yes/N=no) | Impact of OHI seeking on patients covered in this paper (Y=yes/N=no) | OHI seeking affects patients' evaluation of physicians covered in this paper (Y=yes/N=no) | Discussion of OHI and physician-patient relationship covered in this paper (Y=yes/N=no) |
|---|---|---|---|---|---|---|---|---|---|
| 1 | [33] | United Kingdom | Semistructured interview | 22 (12 [55%] female, 10 [45%] male) | Adult patients with psychosis | Y | Y | N | Y |
| 2 | [7] | Austria | Email interview | 562 (332 [59.1%] female, 230 [40.9%] male) | Internet citizens | N | N | N | Y |
| 3 | [34] | United Kingdom | Survey | 202 (102 [50.5%] female, 100 [49.5%] male) | Consecutive adult hematology clinic patients | Y | Y | Y | N |
| 4 | [35] | Austria | Semistructured interview | 26 (12 [46%] female, 14 [54%] male) | Patients with schizophrenia | N | N | Y | Y |
| 5 | [36] | United States | Survey | 154 (98 [63.6%] female, 48 [31.2%] male, 8 [5.2%] missing data) | Patients at 3 osteopathic primary care medical clinics | N | Y | N | Y |
| 6 | [37] | United Kingdom | Focus group interview | 34 (12 [35%] female, 22 [65%] male) | Adult patients with diabetes mellitus, ischemic heart disease, or hepatitis C | N | N | N | Y |
| 7 | [38] | United Kingdom | Email interview | 31 (28 [90%] female, 3 [10%] male) | Health information seekers | N | Y | N | Y |
| 8 | [39] | Saudi Arabia | Survey | 431 (181 [41.9%] female, 250 [58.1%] male) | Adult dermatology outpatients | Y | N | N | Y |
| 9 | [40] | Canada | Semistructured interview | 56 (30 [54%] female, 26 [46%] male) | Adults aged ≥50 years | N | Y | N | Y |
| 10 | [41] | United States | Survey and semistructured interview | 120 (92 [76.6%] female, 28 [23.3%] male) | Patients new to the rheumatology clinic | N | N | N | Y |
| 11 | [42] | United States | Survey | 70 (42 [60%] recent internet users [RIUs], 28 [40%] ever internet users [EIUs]) | Breast cancer patients | Y | N | N | Y |
| 12 | [43] | United States | Survey and semistructured interview | 61 (49 [80%] female, 12 [20%] male) | New patients with multiple sclerosis | N | N | N | Y |
| 13 | [25] | United States | Individual and focus group interview | 20 (11 [55%] female, 9 [45%] male) | Older adults | N | Y | N | N |

| Number | Reference | Country | Method | Participants, n | Participant characteristics | Factors affecting OHI[a] use covered in this paper (Y=yes/N=no) | Impact of OHI seeking on patients covered in this paper (Y=yes/N=no) | OHI seeking affects patients' evaluation of physicians covered in this paper (Y=yes/N=no) | Discussion of OHI and physician-patient relationship covered in this paper (Y=yes/N=no) |
|---|---|---|---|---|---|---|---|---|---|
| 14 | [44] | United Kingdom | Telephone survey | 3209 (1765 [55%] female, 1444 [45%] male) | A household probability sample from the 48 contiguous states | N | Y | N | Y |
| 15 | [45] | United Kingdom | Semistructured interview | 47 (32 [68%] female, 15 [32%] male) | Patients with contact with health services for information/treatment in relation to hormone replacement therapy (HRT)/menopause and Viagra/erectile dysfunction | N | N | N | Y |
| 16 | [46] | Australia | Survey | 93 (44 [47%] female, 49 [53%] male) | Oncology patients | N | Y | N | Y |
| 17 | [47] | United Kingdom | Telephone survey | 15 females (8 [53%] high school certificate, 5 [33%] bachelor’s degree, 2 [14%] postgraduate degree) | Women faced with decisions concerning menopause and HRT | N | Y | N | N |
| 18 | [48] | Italy | Survey | 1039 (704 [67.76%] female, 335 [32.24%] male) | Adults aged ≥18 years selected from among parents of public school students | Y | Y | N | N |
| 19 | [49] | United States | Survey | 5075 (3141 [61.89%] female, 1934 [38.11%] male) | Participants in the Health Information National Trends Survey 2007 | Y | N | N | N |
| 20 | [50] | Australia | Survey | 400 (192 [48%] female, 208 [52%] male) | Adult emergency department patients | Y | Y | N | N |
| 21 | [51] | United States | Structured in-person interview | 1142 (346 [30.29%] female, 796 [69.71%] male) | Adults hospitalized for acute coronary syndromes | Y | N | N | Y |
| 22 | [9] | Australia | Interview | 33 males | Patients with prostate cancer | N | Y | N | Y |
| 23 | [10] | Switzerland | Semistructured interview | 32 patients (12 [38%] female, 20 [62%] male) and 20 physicians (4 [20%] female, 16 [80%] male) | Patients and physicians from primary care and medical specialist practices | N | Y | N | Y |
| 24 | [52] | Israel | Survey | 138 (83 [50.7%] female, 54 [39.3%] male) | Patients at 10 primary care clinics | Y | Y | N | N |

| Number | Reference | Country | Method | Participants, n | Participant characteristics | Factors affecting OHI[a] use covered in this paper (Y=yes/N=no) | Impact of OHI seeking on patients covered in this paper (Y=yes/N=no) | OHI seeking affects patients' evaluation of physicians covered in this paper (Y=yes/N=no) | Discussion of OHI and physician-patient relationship covered in this paper (Y=yes/N=no) |
|---|---|---|---|---|---|---|---|---|---|
| 25 | [53] | United States | Telephone survey | 2010 (1214 [60.39%] female, 796 [39.61%] male) | Participants in the Surveying the Digital Future, Year 4, national survey | N | N | Y | N |
| 26 | [54] | Canada | Survey | 39 (27 [70%] female, 11 [28%] male, 1 [2%] unknown) | Patients with thyroid cancer attending appointments with radiation oncologists at 2 tertiary cancer centers | N | Y | N | Y |
| 27 | [12] | Switzerland | Questionnaire survey | 459 (207 [45.1%] female, 252 [54.9%] male) | 460 patients aged ≥18 years | Y | N | N | Y |
| 28 | [26] | Netherlands | Questionnaire survey, interview | 90 (31 [34%] female, 59 [66%] male) | Patients recently diagnosed with colorectal cancer recruited from 6 hospitals in the Netherlands | Y | Y | N | N |
| 29 | [55] | United States | Questionnaire survey | 30 (15 [50%] female, 15 [50%] male) | Consecutive patients presenting for preoperative consults for hernia repair requiring surgical mesh | Y | Y | N | Y |
| 30 | [56] | Romania | Questionnaire survey | 485 (242 [49.9%] female, mean age 50.42 years) | Adult patients | Y | Y | N | N |
| 31 | [11] | Singapore | Web-based questionnaire survey | 423 (209 [49.4%] female, 214 [50.6%] male) | Internet users | Y | N | N | Y |
| 32 | [57] | Malaysia | Questionnaire survey | 381 (239 [62.7%] female, 142 [37.3%] male) | Patients in a hospital-based primary care clinic in the University of Malaya Medical Centre | Y | N | N | Y |
| 33 | [58] | Belgium | Qualitative semistructured interview | 40 (22 [55%] female, 18 [45%] male) | Adults between the ages of 50 and 64 years (middle-aged adults) and 65 and 80 years (older adults) | Y | N | N | Y |
| 34 | [59] | China | Focus group interview | 46 (34 [74%] cancer patients, 12 [26%] family members) | Patients with cancer or their families | Y | Y | N | Y |

| Number | Reference | Country | Method | Participants, n | Participant characteristics | Factors affecting OHI[a] use covered in this paper (Y=yes/N=no) | Impact of OHI seeking on patients covered in this paper (Y=yes/N=no) | OHI seeking affects patients' evaluation of physicians covered in this paper (Y=yes/N=no) | Discussion of OHI and physician-patient relationship covered in this paper (Y=yes/N=no) |
|---|---|---|---|---|---|---|---|---|---|
| 35 | [23] | China | Survey | 668 (320 [47.9%] preuse internet samples, 348 [52.1%] not-use internet samples) | Internet citizens | N | Y | N | N |
| 36 | [24] | China | Survey | 336 (180 [53.6%] female, 156 [46.4%] male) | Participants who underwent treatment with a month | N | Y | Y | N |
| 37 | [27] | China | Web-based questionnaire survey | 336 (180 [53.6%] female, 156 [46.4%] male) | Chinese individuals who received treatment in the past month and searched the internet for health information | N | Y | Y | N |
| 38 | [28] | China | Questionnaire survey | 316 (194 [61.4%] female, 122 [38.6%] male) | OHC[b] users | N | Y | Y | Y |
| 39 | [29] | China | Web-based questionnaire survey | 280 (114 [40.7%] female, 166 [59.3%] male) | Patients who visited the hospital within the past half year or who are visiting the doctor for the first time | N | Y | Y | N |
| 40 | [60] | Hong Kong | Questionnaire survey | 1179 (717 [60.81%] female, 462 [39.19%] male) | Patients attending the primary care clinic of a university in Hong Kong | Y | Y | N | Y |
| 41 | [31] | China | Questionnaire survey | 446 (224 [50.2%] female, 222 [49.8%] male) | Patients in Tongji Hospital in Wuhan and the Huazhong University of Science and Technology hospital | N | Y | Y | N |
| 42 | [30] | China | Online survey | 336 (180 [53.6%] female, 156 [46.4%] male) | Chinese individuals who have experience seeking health information and going to hospitals within the previous month | Y | N | N | N |

[a] OHI: online health information.

[b] OHC: online health community.

With searching in the CNKI and SinoMed, there were 5440 initially searched papers, of which 5219 (95.94%) exported papers in Chinese remained after duplication removal using Endnote 20. Of these, 88 (1.69%) papers were included according to the title and abstract for further screening. Through the application of inclusion and exclusion criteria, of these 88 papers, 54 (61%) did not involve the impact of the physician-patient relationship; 10 (11%) did not have health information seeking as the main research object; 7 (8%) were on nonempirical research; for 3 (3%), the original text could not be obtained; and 1 (1%) focused on physicians. The screening process is shown in Figure 2. All 13 (15%) papers met the quality rating except for 2 (15%). Finally, 11 of 88 (13%) Chinese papers were included in this study; see Table 2.

The conclusions of these papers were divided into 5 themes: (1) factors that affect patients' use of OHI, (2) the impact of OHI on patients, (3) OHI seeking affecting patients' evaluation of physicians, (4) discussion with physicians about OHI affecting the physician-patient relationship, and (5) the impact of OHI seeking on the physician-patient relationship, including positive effects, negative effects, and neutral views (Table 3). The neutral view refers to no significant effect or both positive and negative effects.

**Figure 2.** Flowchart of the selection process (Chinese papers). OHI: online health information.

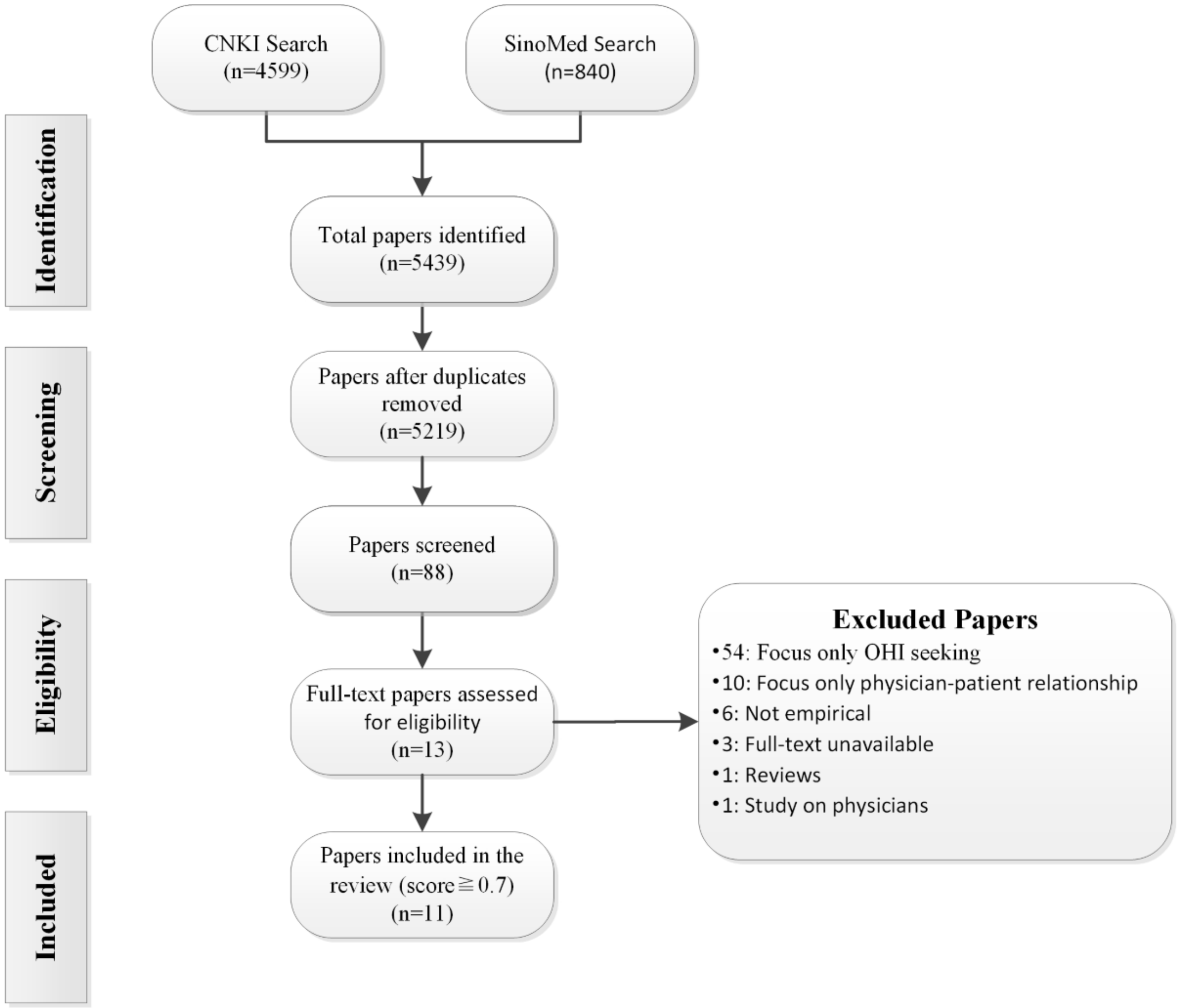

**Table 2.** Summary of included Chinese papers (n=11).

| Number | Reference | Country | Method | Participants, n | Participant characteristics | Factors affecting OHI[a] use covered in this paper (Y=yes/N=no) | Impact of OHI seeking on patients covered in this paper (Y=yes/N=no) | OHI seeking affects patients' evaluation of physicians covered in this paper (Y=yes/N=no) | Discussion of OHI and physician-patient relationship covered in this paper (Y=yes/N=no) |
|---|---|---|---|---|---|---|---|---|---|
| 1 | [61] | China | Survey | 179 (85 [47.5%] female, 94 [52.5%] male） | Outpatients with chronic diseases | N | N | N | Y |
| 2 | [62] | China | Survey, interview | 467 (277 [59.3%] female, 190 [40.7%] male) | Chinese citizens | Y | N | N | N |
| 3 | [63] | China | Survey | 446 (224 [50.2%] female, 222 [49.8%] male) | Health information seekers | N | Y | N | N |
| 4 | [64] | China | Survey | 951 patients (495 [52.1%] female, 456 [47.9%] male) and 888 physicians (348 [39.2%] female, 540 [60.8%] male) | Patients over 18 and doctors in each department | Y | N | Y | N |
| 5 | [65] | China | Survey | 1232 (611 [49.59%] users of OHI, 621 [50.41%] nonusers of OHI) | Chinese netizens | N | Y | Y | Y |
| 6 | [66] | China | China Family Panel Studies (CFPS) data | 29,647 (14,815 [49.97%] female, 14,832 [50.03%] male) | Chinese citizens | Y | N | Y | N |
| 7 | [67] | China | 2013 Chinese Social Survey data | 10,206 (2073 [20.31%] netizens, 4654 [45.6%] nonnetizens, and 3479 [34.09%] missing data) | Chinese citizens | Y | N | Y | N |
| 8 | [68] | China | Survey | 336 (180 [53.6%] female, 156 [46.4%] male) | ChunYu Doctors website users | N | N | Y | N |
| 9 | [69] | China | 2018 CFPS adult questionnaire data | 25,015 (13,083 [52.3%] female, 11,932 [47.7%] male) | Chinese citizens | Y | N | N | N |
| 10 | [70] | China | 2011 and 2012 Chinese General Social Survey (CGSS) | 5546 (in 2021) and 5797 (in 2012) | Chinese citizens | Y | N | Y | N |

| Number | Reference | Country | Method | Participants, n | Participant characteristics | Factors affecting OHI[a] use covered in this paper (Y=yes/N=no) | Impact of OHI seeking on patients covered in this paper (Y=yes/N=no) | OHI seeking affects patients' evaluation of physicians covered in this paper (Y=yes/N=no) | Discussion of OHI and physician-patient relationship covered in this paper (Y=yes/N=no) |
|---|---|---|---|---|---|---|---|---|---|
| 11 | [32] | China | Questionnaire survey | 464 (241 [51.9%] female, 253 [48.1%] male) | Chinese citizens | Y | Y | Y | N |

[a] OHI: online health information.

**Table 3.** OHI[a] seeking affects physician-patient relationships.

| Number | Reference | Country | Impact of OHI seeking on physician-patient relationship | | |
|---|---|---|---|---|---|
| | | | Positive effects covered in this paper (Y=yes/N=no) | Neutral views covered in this paper (Y=yes/N=no) | Negative effects covered in this paper (Y=yes/N=no) |
| 1 | [33] | United Kingdom | Y | N | N |
| 2 | [7] | Austria | N | Y | N |
| 3 | [34] | United Kingdom | Y | N | N |
| 4 | [35] | Austria | Y | N | N |
| 5 | [36] | United States | Y | N | N |
| 6 | [37] | United Kingdom | Y | N | N |
| 7 | [38] | United Kingdom | Y | N | N |
| 8 | [39] | Saudi Arabia | Y | N | N |
| 9 | [40] | Canada | N | Y | N |
| 10 | [41] | United States | N | Y | N |
| 11 | [42] | United States | N | Y | N |
| 12 | [43] | United States | N | Y | N |
| 13 | [25] | United States | Y | N | N |
| 14 | [44] | United Kingdom | Y | N | N |
| 15 | [45] | United Kingdom | N | Y | N |
| 16 | [46] | Australia | Y | N | N |
| 17 | [47] | United Kingdom | Y | N | N |
| 18 | [48] | Italy | Y | N | N |
| 19 | [49] | United States | N | Y | N |
| 20 | [50] | Australia | Y | N | N |
| 21 | [51] | United States | Y | N | N |
| 22 | [9] | Australia | N | Y | N |
| 23 | [10] | Switzerland | N | Y | N |
| 24 | [52] | Israel | Y | N | N |
| 25 | [53] | United States | Y | N | N |
| 26 | [54] | Canada | N | Y | N |
| 27 | [12] | Switzerland | N | Y | N |
| 28 | [26] | Netherlands | N | Y | N |
| 29 | [55] | United States | N | N | Y |
| 30 | [56] | Romania | Y | N | N |
| 31 | [11] | Singapore | Y | N | N |
| 32 | [57] | Malaysia | N | N | Y |
| 33 | [58] | Belgium | Y | N | N |
| 34 | [59] | China | Y | N | N |
| 35 | [23] | China | N | Y | N |
| 36 | [24] | China | Y | N | N |
| 37 | [27] | China | Y | N | N |
| 38 | [28] | China | Y | N | N |
| 39 | [29] | China | Y | N | N |
| 40 | [60] | China | N | N | Y |

| Number | Reference | Country | Impact of OHI seeking on physician-patient relationship | | |
|---|---|---|---|---|---|
| | | | Positive effects covered in this paper (Y=yes/N=no) | Neutral views covered in this paper (Y=yes/N=no) | Negative effects covered in this paper (Y=yes/N=no) |
| 41 | [31] | China | Y | N | N |
| 42 | [30] | China | Y | N | N |
| 43 | [61] | China | Y | N | N |
| 44 | [62] | China | N | N | Y |
| 45 | [63] | China | N | Y | N |
| 46 | [64] | China | Y | N | N |
| 47 | [65] | China | Y | N | N |
| 48 | [66] | China | N | N | Y |
| 49 | [67] | China | N | N | Y |
| 50 | [68] | China | Y | N | N |
| 51 | [69] | China | N | N | Y |
| 52 | [70] | China | N | N | Y |
| 53 | [32] | China | Y | N | N |

[a]OHI: online health information.

### Factors Affecting the Use of OHI

Studies show that education level, income, gender, age, health literacy, culture, and other factors can affect people's use of OHI [12,26,33,34,39,42,49,51,56]. Five papers showed that users with high education level and high income are more willing to use OHI [12,33,34,39,42,62]. This population has relatively high health literacy and can better deal with OHI. Patients with difficulties in understanding health information are less likely to ask questions or seek guidance during consultation. Gantenbein et al [12] found that women are more willing to conduct OHI searches, while Aref-Adib et al [33] found that young male psychiatric patients are more likely to discuss health information with their physicians. De Looper et al [26] and Drug et al [56] found that younger patients engage more in OHIS, but Waring et al [51] did not observe the age difference possibly because the large age-grouping scope could not reflect the difference between the elderly and the young. In addition to personal factors, Chiu et al [59] found that the cultural environment of patients may also affect the communication on health factors. In a hierarchical culture of patients and physicians, patients are unwilling to ask questions for fear that the physicians would be unhappy. Instead, they choose to listen to the advice of physicians [59]. In this paper, we only included papers studying the relationship between physicians and patients; however, maybe many other factors also affect the use of OHI by patients.

### Impact of OHI Seeking on Patients

Several studies have shown that OHI can enhance the communication ability and decision-making ability of patients. The study conducted by Iverson et al [36] showed that 46% of patients said they would change their health-related behaviors after searching for health information online. After searching the health information online, patients have a certain understanding of their own health status and disease treatment and can better understand the medical terms used by physicians when talking with them [25,38,59]. Murray et al [44] showed that people who discuss health information with physicians often have higher self-assessment ability to assess their own health. Liang et al [61] showed that patients who think that OHI is important and helpful to health decision making are more inclined to think that it will be beneficial to the physician-patient relationship.

However, some patients may show some negative effects after OHI query. Aref-Adib et al [33] found that some patients may have concerns over what they read and that they change medication adherence and behavior without communication with the physicians. Another concern raised by OHI seeking is related to the quality of OHI, such as the credibility and limitations of information [40]. OHI will affect patients’ decision making, but patients still regard physicians as the main source of health information [47]. Due to the uneven quality of OHI and the lack of quality control, in addition to patients lacking medical information literacy, the judgments made by patients based on OHI are generally unscientific and difficult to be recognized by doctors, which may have a negative impact on the physician-patient relationship [62].

### OHI Seeking Affects Patients' Evaluation of Physicians

The impact of OHI is mainly reflected in patients' trust in and satisfaction with physicians [42]. Patients' satisfaction with physicians is composed of many factors, among which the main influencing factors are related to the actual communication between patients and physicians [23]. However, most patients are afraid to challenge their doctors, so they are reluctant to discuss their OHI [41]. Patients' satisfaction with OHI has a direct and positive impact on psychological safety [34], while psychological safety might have a direct and positive impact on patients' trust in physicians [24]. When patients use the network health community, the trust relationship among community members also affects patients' trust in and satisfaction with physicians [71]. Liu [68] showed that continuous use of online health communities (OHCs) increases users' satisfaction with medical services.

### Discussion With Physicians About Health Information Affects Physician-Patient Relationships

After OHI seeking, some patients choose to share health information with their physicians. Part of the motivation for discussing health information with physicians is that patients want to meet their psychological and emotional needs [42]. Iverson et al [36] showed that 73% of patients like to discuss OHI with physicians mainly because they think physicians are willing to discuss OHI. The willingness of physicians to discuss health information with patients is crucial. After discussing their concerns about OHI with physicians, the patients' medication adherence and behavior remain unchanged and the anxiety caused by OHI reduces [33]. In addition, after discussing OHI with physicians, patients' satisfaction with physicians significantly improves [39]. People who discuss OHI with their physicians think it has a positive impact on the disease and their relationship with their physicians [7].

However, some studies have also proved that the main reason patients do not actively discuss health information with physicians is the fear of challenging physicians' authority [33,35,38,40,42,43,59]. Patients worry that when they talk about OHI, or express some opinions that physicians cannot refute, the physicians will feel criticized [35]. Of course, there are also some health care professionals trying to maintain the existing authority by not discussing OHI [45]. Guanghua [62] showed that the negative impact of OHI is greater, which creates greater obstacles in the communication between doctors and patients in China.

### OHI Seeking Affects Physician-Patient Relationships in China

A total of 53 papers were included in this study, of which 31 (58%) hold that OHI seeking has a positive impact on the physician-patient relationship, 14 (26%) have a neutral view, and 8 (15%) have a negative influence. It is worthy of in-depth study that 6 (11%) papers showed that OHI seeking has a negative impact on the physician-patient relationship in China. Therefore, the negative impact of OHI on China's internet users is worthy of attention. Due to the large population of China, the time for each patient to communicate with the doctor is short, and patients choose to search online for health information more for convenience than for accuracy or authority [67]. Some studies have shown that the inclusion of some wrong medical information and reports of malignant incidents in the physician-patient relationship have a negative impact on physician-patient trust, confirming media depression theory [67,69,70]. Feifei [64] found that for ordinary patients, due to the professional barriers of medical knowledge, it is difficult for them to distinguish between true and false after receiving false health information on the internet. This causes patients to question doctors and leads to difficulties in the physician-patient relationship [64]. Therefore, it is important to improve patients' health information literacy and the quality of OHI.

## Discussion

### Principal Findings

Based on the review of the included studies, we found that there are many factors that affect patients' choice of OHI, such as gender, age, education level, income, health literacy, and culture [33,34,39,42,49,51]. People with high income, education level, and health literacy are more likely to use OHI. The age difference is mainly between the young and the old. There is a digital divide between the elderly and the young [72]. One study found that older people prefer to choose people as sources of information, such as health care providers, pharmacists, relatives, and retired community workers [73]. From the perspective of patients, most of them think that OHI seeking does not affect the physician-patient relationship; some patients think it has a positive impact on the physician-patient relationship, and a few patients think it may have a negative impact on the physician-patient relationship [46]. As the impact of OHI seeking on the physician-patient relationship may be restricted by social and cultural factors, it may have adverse effects in a culture with distinct levels of patients and physicians [59].

The mechanism of OHI seeking affecting the physician-patient relationship is relatively complex. According to the study findings, OHI seeking can enhance patients' understanding of medical knowledge and enhance their decision-making ability and communication ability with physicians. At the same time, OHI seeking can also have an impact on patients' own psychology. Good quality of health information has a positive impact on the psychological safety of patients. Bylund [74] found that high satisfaction with OHI can promote patients' psychological security when communicating with physicians. Psychological safety has a certain impact on the distrust in the physician-patient relationship so as to affect the relationship [75]. Side effects of drugs and other information cause anxiety in patients. As the internet provides an opportunity to communicate with others about their concerns, anxiety tends to increase [76]. A small number of patients even have drug compliance changes and changes in their own medical behavior [76]. Previous studies have shown that that OHI can affect the consistency of communication between physicians and patients and the compliance of patients [33].

It is important that patients discuss health information with their physicians. Patients will seek OHI to prepare for seeing a doctor, fully participate in the decision making, and actively supplement their information during the process of seeking medical service [77]. However, this will also cause anxiety and a series of changes, such as compliance change and medical behavior change [33]. If patients do not discuss health information with physicians, the negative effects on some patients might even worsen. If patients discuss health information with physicians, these negative effects can be eliminated and alleviated. The survey results show that discussing health information with physicians is beneficial to patients' satisfaction with and trust in physicians. We must admit that patients need to discuss their health information with physicians to better promote the physician-patient relationship and improve medical services

[78]. Good physician-patient communication can improve the clinical outcomes of some diseases [79].

Several studies have mentioned that patients are afraid to discuss health information with physicians because they are afraid of challenging the authority of physicians and even of conflicts with physicians. The OHC is not well received by the professional medical staff. They have doubts about the quality of a lot of OHI and whether they can explain the medical information to the patients in a better way [16]. Patients tend to remain silent if they do not feel the physician's willingness to discuss OHI with them. When patients consult about traditional and nontraditional therapies, many physicians react defensively, resulting in adverse effects on patients’ trust in them and the communication between physicians and patients [80]. Some physicians try to maintain their authority as physicians by avoiding discussing OHI [45]. Due to the widespread popularity of OHI, physicians should be aware that many patients seek OHI before consultation, and actively discuss and exchange OHI with patients [81].

Of the included 53 papers, 21 (39.6%) studied the impact of OHI seeking on the physician-patient relationship in China, of which 2 (9%) papers specifically mentioned that cultural factors play a potential role in OHI seeking for physician-patient relationships [59,62]. In the culture of hierarchical physician-patient relationships in China, the patient fully follows the physician’s recommendations [59]. The popularity of OHI allows patients to play a more important role in the medical process. However, under the medical environment of “more patients, fewer physicians” in China, the communication time between each physician and patient is too short [62]. If the doctor cannot convince the patient and deny the patient's opinion directly without explanation, the conflict weakens the authority of the doctor and exacerbates the negative impact on the physician-patient relationship [62].

Several papers have shown that the internet usage time could reduce the patient's trust in the doctor [66,67]. Medical corruption, medical malpractice, physician-patient conflict, and other contents are more likely to spread among Chinese patients. Various types of negative news is frequently pushed to patients. The negative factors in the physician-patient relationship are magnified. The media often blame medical disputes on medical personnel, which exacerbates patients' distrust of doctors. In addition to negative news, the low quality of OHI has a negative impact on the physician-patient relationship [61,82].

OHI is a double-edged sword for the relationship between physicians and patients. It is becoming increasingly important in the relationship between physicians and patients. With high-quality OHI, it is relatively easier to have a positive impact on patients, thus promoting the physician-patient relationship. With the rapid growth and wide use of medical websites, there are important problems about the necessity of quality control [83]. The pattern of patients' access to health information is changing from passive recipients to active service seekers [77]. Health care professionals should not only discuss health information with patients but also guide them to correctly seek and use health information. Patients who can reasonably understand OHI can reduce the burden of physicians in the consultation and improve the communication [63].

## Limitations

This study has a wide range of retrieval. When references were included, the focus was on whether health information seeking has an impact on the relationship between physicians and patients. Papers studying the impact of health information seeking on patients were not included, which may have led to missing potential research. In addition, due to the lack of a large number of studies and more reliable evidence, we could not reach a strong conclusion about how health information seeking affects the physician-patient relationship.

## Conclusion

This study mainly focused on the effects of OHI on the relationship between physicians and patients. There are many factors influencing people's use of OHI, and young, female, highly educated, and high-income patients are more willing to search OHI. OHI seeking can affect patients' mentality and behavior. Through understanding OHI, patients can have a better understanding of medical knowledge, improve self-confidence during communication, and enhance self-decision-making behaviors. However, some OHI can lead to negative emotions and even change patients' health behaviors, due to the uneven quality of OHI. OHI seeking also affect patients' evaluation of doctors, including patients' trust in and satisfaction with physicians. OHI users choose to discuss OHI with doctors, which is beneficial to the physician-patient relationship in most cases. However, due to the subjective consciousness of patients, they may be concerned that it might affect the authority of physicians, which is the reason some patients do not initiate the discussion of health information. Moreover, the negative impact of OHI on China’s internet users is worthy of attention; due to the low quality of OHI, poor health information literacy, short physician-patient communication time, and various types of negative news, patients' trust in doctors has declined. At present, China's vigorous promotion of “internet + medical health” and the reform of the hierarchical medical will be of great significance to improving the physician-patient communication model and promoting harmonious physician-patient relationships. At the same time, improving people's health information literacy and the quality of OHI is the crucial step in facilitating the positive effects of OHI on the physician-patient relationship.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

PRISMA 2020 Checklist.
[PDF File (Adobe PDF File), 141 KB-Multimedia Appendix 1]

## Multimedia Appendix 2

CASP (Critical Appraisal Skills Program) quality assessment for qualitative studies.
[PDF File (Adobe PDF File), 190 KB-Multimedia Appendix 2]

## Multimedia Appendix 3

Quality assessment tool for quantitative studies.
[PDF File (Adobe PDF File), 224 KB-Multimedia Appendix 3]

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## Abbreviations

**CNKI:** China National Knowledge Infrastructure

**MESH:** Medical Subject Headings
**OHC:** online health community
**OHI:** online health information
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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