Review

Characteristics of the Measurement Tools for Assessing Health Information–Seeking Behaviors in Nationally Representative Surveys: Systematic Review

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Abstract

Background: The coronavirus pandemic (COVID-19) has also emerged as an infodemic, thereby worsening the harm of the pandemic. This situation has highlighted the need for a deeply rooted understanding of the health information–seeking behaviors (HISBs) of people.

Objective: The aim of this paper was to review and provide insight regarding methodologies and the construct of content in HISB surveys by answering the following research question: what are the characteristics of the measurement tools for assessing HISBs in nationally representative surveys around the world?

Methods: The Preferred Reporting Items for Systematic Reviews and Meta-Analyses was used as the framework for this study. A data search was performed through 5 international and 2 Korean databases covering the years between 2008 and 2020. Initially, studies performed among nationally representative samples were included to discover HISB survey instruments. The methodologies of the studies using HISB surveys were analyzed. For content analysis, 2 researchers reached a consensus through discussion by scrutinizing the contents of each survey questionnaire.

Results: A total of 13 survey tools from 8 countries were identified after a review of 2333 records from the search results. Five survey tools (Health Information National Trends Survey, Health Tracking Survey, Annenberg National Health Communication Survey, National Health Interview Survey, and Health Tracking Household Survey) from the United States, 2 instruments from Germany, and 1 tool from each of the countries of the European Union, France, Israel, Poland, South Korea, and Taiwan were identified. Telephone or web-based surveys were commonly used targeting the adult population (≥15 years of age). From the content analysis, the domains of the survey items were categorized as follows: information (information about health and patient medical records), channel (offline and online), and health (overall health, lifestyle, and cancer). All categories encompassed behavioral and attitude dimensions. A theoretical framework, that is, an information-channel-health structure for HISBs was proposed.

Conclusions: The results of our study can contribute to the development and implementation of the survey tools for HISB with integrated questionnaire items. This will help in understanding HISB trends in national health care.

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KEYWORDS

information seeking behavior; consumer health information; medical informatics; health care surveys; health information–seeking behavior; surveys

Introduction

Background

The recent global pandemic of COVID-19, determined to be a public health emergency of international concern, has changed many aspects of people’s daily lives [1]. When people wake up, they check health-related news, their signs and symptoms, methods of prevention, and restrictions on the use of a vaccine. While mass media have been releasing a myriad of information, individuals have also been reproducing and downloading news and information from internet webpages such as websites or blogs [2,3]. The tsunami of information has resulted in the production of several fake news that lack scientific evidence and convey misconceptions and misinformation about health [4]. In reality, misguided belief based on misinformation has caused the deaths of many people [5] and worsened COVID-19 infections [6,7]. In this way, the rise of incorrect information has led to abuse, or in other words, an infodemic [4,8]. The foremost solution to mitigate this issue would be to understand the information-seeking behaviors of individuals. It would be beneficial if governments or national institutes measure their behaviors to apply health and information policies appropriately [9].

Health information–seeking behavior (HISB) is a comprehensive term that describes an individual’s behavior of seeking information, including the intentional collection and unintentional receipt of information [10,11]. Some studies have shown HISBs by using certain measurement tools such as Health Information National Trends Survey (HINTS), Health Tracking Survey, and the Annenberg National Health Communication Survey (ANHCS). The limitations of these studies are that most surveys mainly target American subjects or web-based/digital HISB [12-18]. These limitations can be overcome by the design of a comprehensive survey instrument. Survey instruments are developed to collect information for certain research phenomena [19] or for finding the right answers by asking the right questions. It would be efficient and effective to obtain a holistic view by integrating the properties of worldwide national survey tools in a systematic approach and by scrutinizing the constructs and methodologies, including what aspects of HISBs are considered important or are missed out. Although there are preliminary studies using systematic reviews of HISB instruments, these topics are limited to the context of the United States and eHealth, thereby making it difficult to look into cross-national HISB [17,20]. Therefore, this study aims to review how HISBs are measured by identifying and comparing measurement tools based on nationwide surveys.

Objectives

The aim of this paper was to provide insights on the methodologies and the construct of content for HISB survey instruments based on nationally representative surveys.

Methods

Research Question

The SPIDER (sample, phenomenon of interest, design, evaluation, and research type) format was used to formulate the research question for this review [21,22]: what are the characteristics of measurement tools (evaluation) for assessing HISBs (phenomenon of interest) in nationally representative surveys around the world (sample and design)?

Protocol and Registration

This study was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses [23]. The protocol of this review paper is registered in PROSPERO (CRD42019122767).

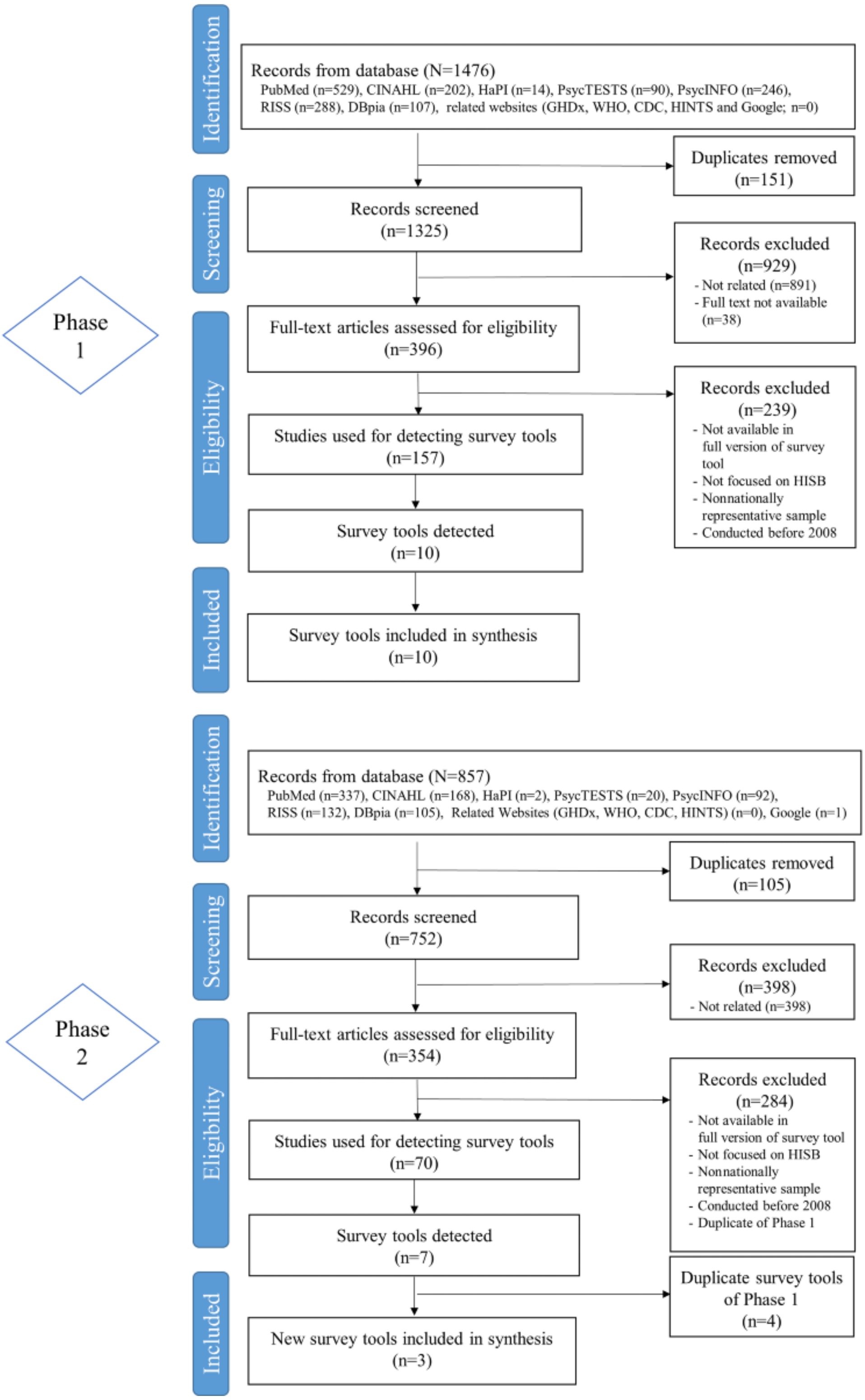
Eligibility Criteria

To answer the research question, inclusion and exclusion criteria were established. Survey tools were included if they were full versions of the tools for HISBs and if they targeted nationally representative samples. However, tools were excluded when the full versions of the instruments were not accessible, not HISB-focused, nor used for a nationally representative sample.

Information Sources

As we seek in this study to discover the national survey tools for HISB, articles, reports, and related websites were searched for clues to detect those instruments. The data search was performed in 2 phases. The phase 1 search covering 2008 to 2017 was conducted between October 09, 2017 and November 13, 2017 through 7 databases: 5 international databases, namely, PubMed, CINAHL Complete (Ebsco), HaPI, PsycTESTS, and PsycINFO (Ebsco), and 2 Korean databases (RISS [Research Information Sharing Service] and DBpia). Phase 2 was performed between February 19, 2021 and March 25, 2021 to obtain recent literature covering 2017 to 2020 with the same search strategy (Figure 1, Multimedia Appendix 1).

Figure 1. PRISMA flow diagram of literature search and selection process. CDC: Centers for Disease Control and Prevention; HINTS: Health Information National Trends Survey; HISB: health information–seeking behavior; RISS: Research Information Sharing Service; WHO: World Health Organization.



Search Strategy

Pilot searches were performed by the authors, and the final search strategy with the consultation of a librarian was utilized with MeSH terms (ie, information-seeking behavior) and free-text searching as well as the Boolean operators "OR" and "AND" (Multimedia Appendix 1). There was no limit on languages, but publication years were restricted between 2008 and 2020: January 1, 2008 to November 13, 2017 for phase 1 and January 1, 2017 to December 31, 2020 for phase 2.

Study Selection and Data Collection Process

Two authors (HC and GJ) initially reviewed the titles and abstracts of the papers and eliminated irrelevant documents. Then, HC and GJ scrutinized full-texts and filtered them according to the inclusion/exclusion criteria. As the purpose of the study was to seek nationally representative surveys of HISB, related websites were also accessed, such as that of The World Health Organization, which has the primary role of directing and coordinating international health, and Global Health Data Exchange [24], which is the most comprehensive catalog of surveys, censuses, vital statistics, and other health-related data in the world. In addition, to obtain the survey questionnaires, websites such as those of the National Cancer Institute, Centers for Disease Control and Prevention, European Commission, and Santé Publique France were searched. Academic papers, reports, and webpages identified through the previous steps were reviewed to discover HISB survey tools. To attain sufficient data (ie, full version of the item(s) of the survey, methodology, etc), we emailed 8 corresponding authors of the papers: 2 of the corresponding authors sent full version of the survey instruments, which were not related to the HISB; 1 author refused to provide a full version of the survey instrument; and 5 authors did not respond. To capture grey literature, footnote tracing was performed along with a review of the related websites described above. All documents identified through this process were managed with EndNote X20.0 software (Clarivate Analytics). During the whole process, consensus was reached through discussion if there was disagreement between the authors.

Data Items

We sought the characteristics of the selected instruments, including the name of the instrument, administrative institution, and funding sources, country, language, frequency of the survey, survey duration, sampling method, mode of survey administration, target population, total number of the population, and purpose of the measurement. In addition, the content of the survey instruments was scrutinized.

Risk of Bias in Individual Studies

The aim of this study was to identify the measures used to analyze HISB in national surveys. Therefore, this review paper focuses on questionnaires in the national surveys on HISB and the risk of bias assessment is not applicable.

Synthesis of Results

As this review is intended as content analysis, the authors thoroughly read the contents of the questionnaires of the selected HISB instruments. Themes emerged during this process as we used coding sheets with Excel and Word. The findings were provided through the process of reaching a consensus between the 2 authors on the coding sheets. Finally, the synthesized results were depicted in table and figure formats.

Results

Study Selection

A total of 2333 papers were identified through 2 phases of the search process. From phase 1 of the search, 1476 papers were identified in the following academic databases: PubMed (n=529), CINAHL (n=202), HaPI (n=14), PsycTESTS (n=90), PsycINFO (n=246), RISS (n=288), and DBpia (n=107). Duplicates (n=151) were removed and 929 papers were eliminated. A total of 396 full-texts were reviewed and 157 documents were used for detecting 10 survey tools: (1) HINTS [25], (2) Health Tracking Survey [26], (3) ANHCS [27] (n=5), (4) National Health Interview Survey (NHIS) [28], (5) Health Tracking Household Survey (HTHS) [29], (6) Flash Eurobarometer [30], (7) Baromètre Santé [31], (8) Gesundheitsmonitor [32], (9) Israeli survey [33], and (10) eHealth Consumer Trend Survey [34].

Phase 2 was performed to update the recent survey tools by using the same search strategy. As a result, 857 records were identified: PubMed (n=337), CINAHL (n=168), HaPI (n=2), PsycTESTS (n=20), PsycINFO (n=92), RISS (n=132), DBpia (n=105), and Google (n=1). Duplicates (n=105) were excluded, and 398 records were also removed after screening. The full texts of 354 papers were reviewed, and 70 records were used for detecting 7 survey tools. There were 4 duplicates of survey tools from phase 1. Therefore, 3 more survey tools, that is, Stiftung Gesundheitswissen (HINTS Germany) [35], survey of cancer and health-related information–seeking behavior (CHISB) for Koreans [36], and Taiwan Communication Survey [37] were also included for synthesis.

A total of 227 papers were related to the selected HISB instruments (Multimedia Appendix 2). About 96% of them (219/227) were related to 1 of the 5 US surveys: HINTS [25] (n=188), the Health Tracking Survey [26] (n=9), ANHCS [27] (n=7), NHIS [28] (n=11), and HTHS [29] (n=4). The remaining 8 studies identified 8 survey tools used in other parts of the world, that is, European Union (Flash Eurobarometer) [30] (n=1), France (Baromètre santé) [31] (n=1), Germany (Gesundheitsmonitor [32] [n=1] and HINTS Germany) [35] [n=1]), Israeli survey [33] (n=1), Poland (eHealth Consumer Trend Survey) [34] (n=1), South Korea (survey of CHISB) [36] (n=1), and Taiwan (Taiwan Communication Survey) [37] (n=1). Therefore, 13 survey instruments (Table 1, Multimedia Appendix 3) were included in this review [38-77].

Table 1. Brief characteristics of the instruments for measuring health information–seeking behaviors in nationally representative survey studies.

Country	Instrument	Survey version	Purpose of the measurement	Frequency	Target population	Total population in the survey (N)
USA	Health Information National Trends Survey (HINTS) [38-41]	2019, HINTS 5, Cycle 3	To investigate respondents' access to and use of health information, including information technology to manage health and health information	Every few years (1-2 year cycle)	Civilian noninstitutionalized adults aged 18 years or older	5247
USA	Health Tracking Survey [42-50]	2012	To assess pursuit of health taking place within a widening network of both online and offline sources	Irregular	Adults aged 18 years or older	3014
USA	Annenberg National Health Communication Survey [18,51-56]	2012	To capture national trends related to health behavior and behavioral intentions to media exposure, health knowledge and beliefs, and policy preferences and beliefs	One-cycle survey	Adults aged 18 years or older	3692
USA	National Health Interview Survey [57-67]	2020	To monitor the health of the population through the collection and analysis of the data	Annual	Household	33,138[a]
USA	Health Tracking Household Survey [68-71]	2010	To inform health care decision makers about changes in the health care system and the influence	Irregular (2-5 year period)	Household	16,671 individuals (n=9165 Family Insurance Units)
Europe	Flash Eurobarometer 404 (European citizen's digital health literacy) [72]	2014	To support increasing use of digital health care to help manage citizen's own health	One-cycle survey	EU residents aged 15 years and older	26,566 (28 EU countries)
France	French Health Barometer (Baromètre santé) [73]	2017	To gain a better understanding of French health knowledge, attitudes, beliefs, and behaviors	Annual	Adults aged 18-75 years	15,635[b]
Germany	Gesundheitsmonitor [74]	2015	To assess health-related knowledge, attitudes, and behaviors	Annual	Adults aged 18-79 years	1598
Germany	HINTS Germany [75]	2019	To close the gap in important health-related information actions and systematical health records	Every few years (1-2 year cycle)	Adults aged 18-79 years	2902
Israel	Not titled survey [33]	2014	To measure eHealth literacy for others, including perceived outcome of internet use	One-cycle survey	Adult aged 21 years and older	819
Poland	eHealth Consumer Trend Survey 2012[c] [76]	2012	To show the trends in the perceptions and preferences of Polish citizens regarding internet use and factors affecting their usage	Irregular	Adults aged 15-80+ years	1000
South Korea	Survey of cancer and health-related information–seeking behavior for Koreans [36]	2018	To capture national phenomena of cancer and health-related health information–seeking behavior of Koreans	One-cycle survey	Adults aged 18-65+ years	1012
Taiwan	Taiwan Communication Survey [77]	2016	To explore media use behaviors among the general public, including health, risk, and disaster communication	Annual	Adults aged 18 years and older	2098

[a] 2019 sample size was reported. Data and report for 2020 will be published in fall 2021.

[b] French Health Barometer: the survey questionnaires were changed according to the survey years. The 2017 version of the survey contains health information–seeking behavior and is included in this study.

[c] eHealth consumer trend survey of 2012 was modified from the eHealth Consumer Trends Survey (2007), which was conducted in Denmark, Germany, Greece, Latvia, Norway, Poland, and Portugal in the World Health Organization/European eHealth Consumer Trends project [78,79].

Key Characteristics of the Surveys

Country

HISB surveys were found in 8 countries (Table 1, Multimedia Appendix 3). The United States has 5 HISB surveys (HINTS, Health Tracking Survey, ANHCS, NHIS, and HTHS), and the other 7 countries or regions, namely, the European Union, France, Germany, Israel, Poland, South Korea, and Taiwan conduct surveys called Flash Eurobarometer, Baromètre santé, Gesundheitsmonitor, Israeli survey (not titled), the eHealth consumer trend survey, survey of CHISB for Koreans, and Taiwan Communication Survey, respectively.

Language

As the surveys focused on domestic people, official or national languages were used (Table 1, Multimedia Appendix 3). For instance, the HINTS from the United States used 2 versions of the survey: English and Spanish. The European Union also performed the survey using the mother tongue of the responders.

Instrument and Administration Institution

HISB surveys were administered by national, nonprofit, public institutions, or individual researchers (Table 1, Multimedia Appendix 3). Five instruments, that is, HINTS, Flash Eurobarometer, NHIS, Baromètre santé, and Taiwan Communication Survey, were developed and administered by national institutes, namely, the National Cancer Institute in the United States, the National Center for Health Statistics in the United States, the Directorate-General for Communications Networks of the European Commission, the National Institute for Prevention and Health Education in France, and the Ministry of Science Technology in Taiwan, respectively. Four instruments were obtained from nonprofit institutions: the Pew Research Center (HINTS), the Center for Studying Health System Change (ceased operation in 2013) (HTHS), Bertelsmann Stiftung (Gesundheitsmonitor), and Gesundheitswissen and Hanover Center for Health Communication at the Institute for Journalism and Communication Research (HINTS Germany). A survey (ANHCS) was conducted by 2 public institutions, namely, the Annenberg Schools for Communication at the University of Pennsylvania and the University of Southern California. Individual researchers developed 3 survey tools: the Israeli survey, the eHealth Consumer Trend Survey (Poland), and the survey of CHISB for Koreans (South Korea), with the Israeli and South Korean studies funded by national institutes.

Frequency of the Survey

The frequency of the surveys was found to be annual, every few years, one time, or irregular (Table 1, Multimedia Appendix 3). The annual or every few years surveys were HINTS (United States), NHIS (United States), Baromètre santé (France), Gesundheitsmonitor (Germany), HINTS Germany (Germany), and Taiwan Communication Survey (Taiwan). The others, namely, the Health Tracking Survey (United States), ANHCS (United States), HTHS (United States), Flash Eurobarometer 404, the Israeli survey, survey of CHISB for Koreans (South Korea), and eHealth Consumer Trend Survey (Poland) have been conducted once or irregularly.

Sampling and Mode of Administration

The most common approach has been randomization, in particular, sampling with random digit dialing and then administration through a computer-assisted telephone interview (Table 1, Multimedia Appendix 3). In addition, for sampling, two-stage sampling (stratifying sample addresses and selecting 1 adult within each household) was often used. When web-based panels were used for random sampling, units or strata layers divided by the population group, geographical districts, size of the settlement, and the locality's socioeconomic status were utilized to prevent clashes.

Population

The range of this study is restricted to researching tools used with adults (Table 1, Multimedia Appendix 3). The standard age of adulthood in each country varies from 15 years to 21 years. Mostly, adults are defined as people who are 18 years of age or older, but in Europe and Poland, those who are 15 years or older are considered part of the adult population. In Israel, people older than 21 years are considered adults.

Purpose

The purposes were similar among the measurements: to monitor the use of health information in accordance with the type of information technology such as online or offline (Table 1, Multimedia Appendix 3). However, the detailed outcome of the studies pursued was different. For instance, the Baromètre santé (France) aimed to discover knowledge, attitudes, and behaviors toward HISB; however, the ANHCS (United States) pursued HISB related to media exposure, health knowledge and beliefs, and policy preferences and beliefs.

Content Analysis of the Instruments

The contents of the questionnaire items for each tool were thematically reviewed and categorized by 2 researchers (HC and GJ). The themes were then merged and synthesized through consensus. Thus, 57 themes were detected and divided into 3 domains (Figure 2) and 7 subdomains: information, information about health and patient medical records; channel, offline and online; and health, overall health, lifestyle, and cancer. Two dimensions—attitude and behavior—were identified across the domains (Table 2, Multimedia Appendix 4). In this paper, attitude was defined as the emotional and cognitive tendency of a person toward a particular object, person, or thing, affecting behavior [80]. Behavior was also defined as an objectively observable activity [81].

Figure 2. Average percentage of theme occurrence in the domains.

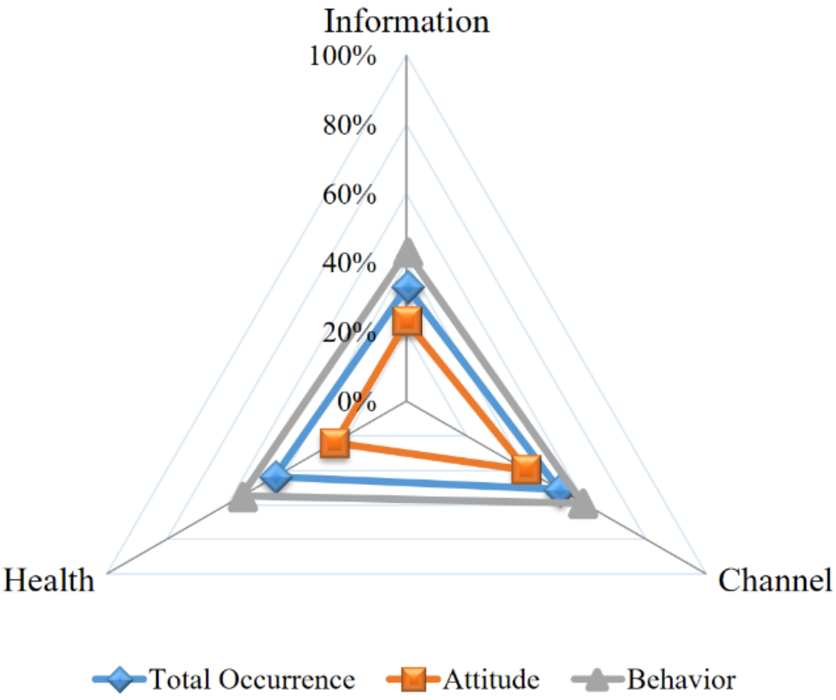


Table 2. Content analysis of 13 representative national health information–seeking tools.[a]

Domain, subdomain, dimension, theme	Theme occurrence (%)	Theme occurrence average percentage (SD)	Subdomain average percentage (SD)	Domain average percentage (SD)
Information				33.0 (14.9)
Information about health			44.9 (14.9)	
Attitude		26.9 (5.4)		
Perceived ease of use	30.8			
Perceived efficacy of seeking	23.1			
Behavior		53.8 (6.3)		
Search experience (frequency)	46.2			
Information source	61.5			
Type of information contents	53.8			
Purpose of search (for whom)	53.8			
Patient medical record			24.0 (6.4)	
Attitude		21.5 (6.4)		
Perceived privacy and confidentiality risk	23.1			
Perceived ease of use	15.4			
Perceived usefulness	23.1			
Intention to use	15.4			
Preference to provide access to others	30.8			
Behavior		28.2 (4.4)		
Access frequency	30.8			
Type of information contents sought	23.1			
Purpose of seeking a record	30.8			
Channel				50.5 (18.2)
Offline			50.5 (15.9)	
Attitude		41.0 (4.4)		
Perceived credibility	38.5			
Perceived ease of use	38.5			
Satisfaction with service quality	46.2			
Behavior		57.7 (18.3)		
Access frequency	84.6			
Type of health service	46.2			
Communication with health care provider	46.2			
Health-related decision making	53.8			
Online			50.5 (19.7)	
Attitude		39.6 (15.0)		
Perceived credibility	53.8			
Perceived ease of use	38.5			
Perceived usefulness	53.8			
Perceived eHealth literacy (technology efficacy)	53.8			
Satisfaction with web-based information	15.4			
Perceived confidentiality risks	30.8			
Intention to use	30.8			

Domain, subdomain, dimension, theme	Theme occurrence (%)	Theme occurrence average percentage (SD)	Subdomain average percentage (SD)	Domain average percentage (SD)
Behavior		59.0 (19.2)		
Access frequency	92.3			
Type of information technology device	61.5			
Health-related web and app (software use)	46.2			
Web-based resource (governmental website, Wikipedia, etc)	53.8			
Communication (consult) with health care provider	76.9			
Communication with friends and others (social media, forum, etc)	61.5			
Health-related decision making	69.2			
Tracking/managing health state	38.5			
Improvement of health knowledge	30.8			
Health				44.2 (20.6)
Overall health			53.8 (18.0)	
Attitude		34.6 (5.4)		
Perceived health efficacy	38.5			
Concerns and belief about health	30.8			
Behavior		59.3 (16.4)		
General health state	84.6			
Diseases diagnosed	69.2			
Height	61.5			
Weight	61.5			
Mental health	53.8			
Caregiving	30.8			
Social support	53.8			
Lifestyle			32.7 (21.3)	
Attitude		15.4 (8.9)		
Perception about nutrition	7.7			
Perception about physical activity	15.4			
Perception about alcohol	23.1			
Perception about tobacco	23.1			
Behavior		50.0 (13.3)		
Nutrition	30.8			
Physical activity	61.5			
Alcohol	53.8			
Tobacco	53.8			
Cancer			46.2 (13.3)	
Attitude				
Perception about cancer	38.5			
Behavior		50.0 (16.3)		
Cancer check-up	38.5			

Domain, subdomain, dimension, theme	Theme occurrence (%)	Theme occurrence average percentage (SD)	Subdomain average percentage (SD)	Domain average percentage (SD)
Cancer diagnosed	61.5			

[a] Total average percentage of the themes=44.0 (SD 19.3), total average percentage of attitude themes=30.4 (SD 13.5), and total average percentage of behavior themes=53.8 (SD 16.9).

Thematic Map

Three domains, namely, information, channel, and health (Figure 2) emerged through the content analysis (Table 2). The highest rate of theme occurrence among the domains was channel (average percentage 50.5%, SD 18.2), followed by health (average percentage 44.2%, SD 20.6) and information (average percentage 33.0%, SD 14.9).

Information

Information is a health-related, content-focused domain sought by the individual. There are 2 subdomains (Figure 3), namely, information about health and patient medical records. The information about the health subdomain was conceptualized by categorizing question items related to general health information through a set of options with comprehensive channels (online or offline). Patient medical records were related to a seeker's use of medical records online or offline. There were attitude and behavioral aspects for the themes found, and the detailed and representative questionnaire items of the themes are presented in Table 3. The subdomain information about health (average percentage 44.9%, SD 14.9), which consisted of 6 themes, was more commonly used among the selected tools than patient medical records (average percentage 24.0%, SD 6.4), which consisted of 8 themes. In both subdomains, the percentages of behavior-related themes was 1.3-2.0 times higher than those related to attitude.

Figure 3. Average percentage of theme occurrence in the subdomains.

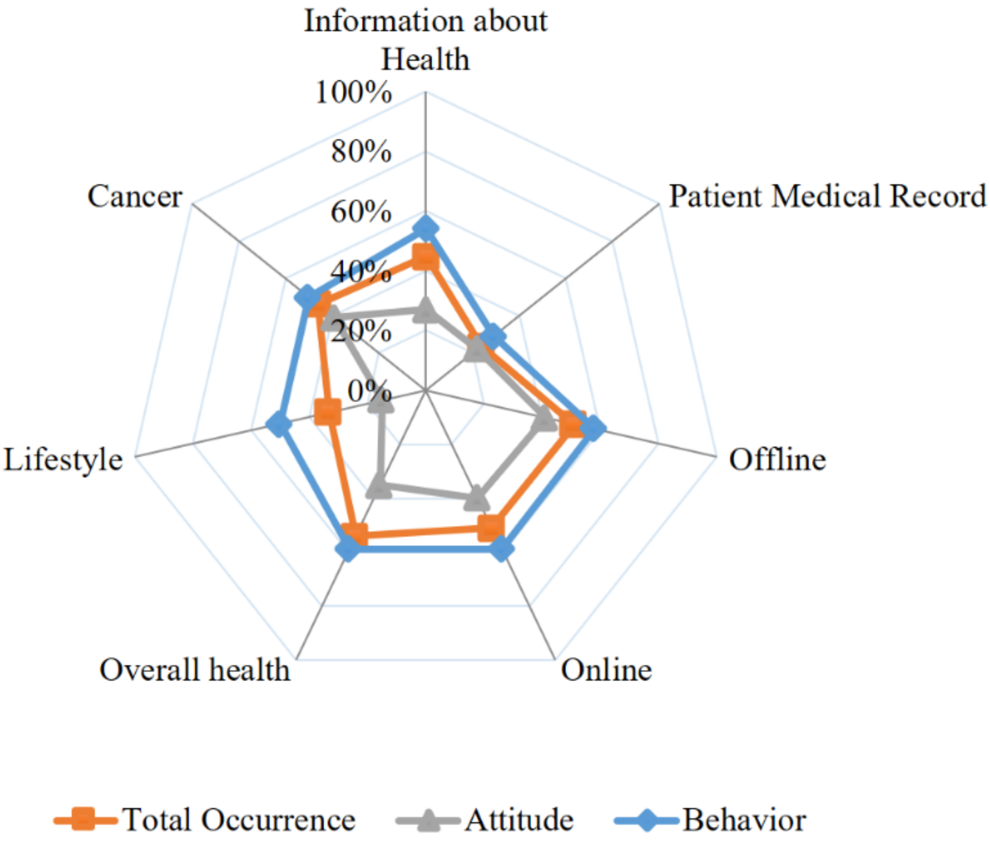


Table 3. Representative sample questionnaire items for health information–seeking behavior survey instruments.

Domain, subdomain, dimension, theme	Questionnaire items
Information	
Information about health	
Attitude	
Perceived ease of use	How much do you agree or disagree- it took a lot of effort to get the information you needed (HINTS[a])
Perceived efficacy of seeking	How confident are you that you could get advice about health if you needed it (HINTS)
Behavior	
Seek experience	Have you ever looked for information about health or medical topics from any source? (HINTS)
Information source	Thinking about the last time you had a serious health issue, did you get information from (selection of the information source)? (HTS[b])
Type of information contents	What type of health-related information did you look for? (Europe)
Purpose of search (whom for)	The most recent time you looked for information about health or medical topics, who was it for? (HINTS)
Patient medical record	
Attitude	
Perceived privacy and confidentiality risk	Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record? (HINTS)
Perceived ease of use	How easy or difficult was it to understand the health information in your online medical record? (HINTS)
Perceived usefulness	In general, how useful is your online medical record for monitoring your health? (HINTS)
Intention to use	Was denken Sie heute, werden Sie sich Ihre medizinischen Daten und Unterlagen mit Hilfe der Karte zukünftig näher anschauen? (What do you think today, will you take a closer look at your medical data and documents with the help of the card in the future?) (Gesundheitsmonitor, Germany)
Preference to provide access to others	In order to get a quick and valid diagnosis, I am positive about giving internet access to my medical record to a doctor in another location or abroad (Poland)
Behavior	
Access frequency	Have you approached your family doctor, specialist, or other health professional(s) over the internet to read your health record? (Poland)
Type of information contents sought	귀하의 온라인 의료 기록에 다음과 같은 의료 정보가 포함되어 있습니까? (Do any of your online medical records include the following types of medical information?) (survey of CHISB[c])
Purpose of seeking a record	In the past 12 months, have you used your web-based medical record to…(look up test results, monitor your health, etc) (HINTS).
Channel	
Offline	
Attitude	
Perceived credibility	Do you believe health-related information from medical staff at medical centers or pharmacies? (Taiwan)
Perceived ease of use	How difficult is it to contact a doctor or other health care providers at this place after their regular hours in case of urgent medical needs-very difficult, somewhat difficult, not too difficult, or not at all difficult? (HTHS)
Satisfaction with service quality	How satisfied are you with the health care you received in the past 12 months? (NHIS[d])
Behavior	
Access frequency	How many times have you personally been to the doctor within the last 12 months (Europe)
Type of health service	What kind of place do you go to most often - a clinic, doctor's office, emergency room, or some other place? (NHIS)

Domain, subdomain, dimension, theme	Questionnaire items
Communication with health care provider	In the past 12 months, did health care provider talk with you about all of the different prescription medicines you are using, including medicines prescribed by other doctors? (HTHS[e])
Health related decision making	The following questions are about your communication with all doctors, nurses, or other health professionals you saw during the past 12 months: did they involve you in decisions about your health care as much as you wanted (HINTS)?
Online	
Attitude	
Perceived credibility	Selon vous, l’information de santé que vous avez obtenue la dernière fois est-elle crédible? (In your opinion, is the health information credible you obtained the last time (on the internet?) (France)
Perceived ease of use	In general, how comfortable do you feel. (using computers, internet, etc) (ANHCS[f])
Perceived usefulness	How useful was the health information you found online? (HTHS)
Perceived eHealth literacy	I know how to use the internet to answer my health questions (Israel)
Satisfaction with web-based information	Overall, how satisfied or not are you with the health-related information you found on the internet? (Europe)
Perceived confidentiality risks	There are different reasons for not approaching your family doctor, specialist, or other health professional(s) via the internet. Which reasons apply to you? (I worry about confidentiality) (Poland)
Intention to use	Next time you want to get information on health-related questions, how likely are you to use the internet? (Europe)
Behavior	
Access frequency	Within the last 12 months, have you used the internet to search for health-related information? (Europe)
Type of information technology device	Please indicate if you have each of the following: tablet computer like an iPad, smartphone, etc? (HINTS)
Health-related web and app (software use)	What kind of health apps do you currently have on your phone? (HTS)
Web-based resource (governmental website, Wikipedia, etc)	Have you used any of the following internet resources for health information? (government websites, news sites, etc) (ANHCS)
Communication with health care provider	Haben Sie diese Gesundheits-Apps auf Ihrem Tablet oder Smartphone schon einmal dazu genutzt, … um auf Gespräche mit Ihrem Arzt, Heilpraktiker, Physiotherapeuten usw. besser vorbereitet zu sein? (Have you ever used these health apps on your tablet or smartphone...to be better prepared for discussions with your doctor, alternative practitioner, physiotherapist, etc? (HINTS Germany)
Communication with friends and others (social media, forum, etc)	Still thinking just about the last 12 months, have you posted a health-related question online or shared your own personal health experience online in any way? (HTS)
Health-related decision making	Haben Sie diese Gesundheits-Apps auf Ihrem Tablet oder Smartphone schon einmal dazu genutzt, …. um zu entscheiden, wie mit einer Erkrankung umgegangen werden sollte? (Has your tablet or smartphone…helped you make a decision about how to treat an illness or condition? (HINTS Germany)
Tracking/managing health state	Has your tablet or smartphone helped you track progress on a health-related goal such as quitting smoking, losing weight, or increasing physical activity? (HINTS)
Improvement of health knowledge	Improved your understanding of the symptoms, conditions, or treatments in which you were interested (Israeli survey)
Health	
Overall health	
Attitude	
Perceived health efficacy	Overall, how confident are you about your ability to take good care of your health? (HINTS)
Concerns and belief about health	Agree that my good health is largely a matter of good fortune (ANHCS)
Behavior	
General health state	How would you rate your level of health in general? (Europe)

Domain, subdomain, dimension, theme	Questionnaire items
Diseases diagnosed	Are you now living with any of the following health problems or conditions (diabetes, high blood pressure, etc) (HTS)
Height	How tall are you without shoes? (NHIS)
Weight	About how much do you weigh, in pounds, without shoes? (HINTS)
Mental health	Have you been diagnosed with any of the following medical conditions? (mental health condition) (ANHCS)
Caregiving	Are you a caregiver for an adult family member with any of the following medical conditions? (Alzheimer disease, cancer, etc) (ANHCS)
Social support	Is there anyone you can count on to provide you with emotional support when you need it, such as talking over problems or helping you make difficult decisions? (HINTS)
Lifestyle	
Attitude	
Perception about nutrition	How likely is it that eating 5 or more servings of fruits and vegetables every day will (make you look better)? (ANHCS)
Perception about physical activity	How likely is it that doing at least moderate exercise 3 or more times a week will (reduce your feelings of stress)? (ANHCS)
Perception about alcohol	How much do you agree or disagree with each of the following statements? (alcohol increases your risk of cancer) (HINTS)
Perception about tobacco	In your opinion, do you think that some smokeless tobacco products such as chewing tobacco, snus, and snuff are less harmful to a person's health than cigarettes? (HINTS)
Behavior	
Nutrition	In the past week, on average, how many servings of fruit did you eat or drink per day? Please include 100% fruit juice, and fresh, frozen or canned fruits. (ANHCS)
Physical activity	In a typical week, how many days do you do any physical activity or exercise of at least moderate intensity, such as brisk walking, bicycling at a regular pace, and swimming at a regular pace? (HINTS)
Alcohol	In your entire life, have you had at least 12 drinks of any type of alcoholic beverage? (NHIS)
Tobacco	Have you smoked at least 100 cigarettes in your entire life? (ANHCS)
Cancer	
Attitude	
Perception about cancer	귀하께서는 다음 문항에 얼마나 동의하십니까? … 일상에서 접하는 모든 것이 암을 유발하는 원인임 (How much do you agree or disagree with each of the following statements? … It seems like everything causes cancer, There's not much you can do to lower your chances of getting cancer, etc) (survey of CHISB)
Behavior	
Cancer check-up	When did you have your most recent prostate-specific antigen test to check for prostate cancer? (ANHCS)
Cancer diagnosed	Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind? (NHIS)

[a] HINTS: Health Information National Trends Survey.

[b] HTS: Health Tracking Survey.

[c] CHISB: cancer and health-related information–seeking behavior.

[d] NHIS: National Health Interview Survey.

[e] HTHS: Health Tracking Household Survey.

[f] ANHCS: Annenberg National Health Communication Survey.

Channel

The channel can be defined as the means-focused domain that enables seekers to acquire and transmit health information [50]. The contents of the questionnaires pointed out that there were 2 channels for HISB: offline and online. The offline channel includes any method that collects or transmits health information through non–web-based sources such as health care providers, books, magazines, friends, seminars, or other means, and the offline subdomain consists of 7 themes (Figure 3). The online channel refers to seeking health information via the internet with any information technology device; the online subdomain showed the largest number of themes, that is, 7 attitude and 9 behavior themes. The subdomains offline and online revealed a similar occurrence, with average percentages at 50.5% (SD 15.9) and 50.5% (SD 19.7), respectively. In particular, the average percentage of a behavioral dimension of the online channel, namely, access frequency, was counted as 92.3% in the selected HISB tools as well as 84.6% of the access frequency theme in the offline subdomain. The occurrence of behavior dimensions was 1.4-1.5 times that of the attitude dimensions.

Health

The health domain refers to the seeker's physical status and perceptions about health: overall health, lifestyle, and presence of cancer. Overall health refers to general health status, including physical, mental, and social health and concerns or beliefs about them. Lifestyle consists of 4 parts of a person's behavior and attitude: nutrition, physical activity, alcohol consumption, and tobacco consumption. Cancer themes focused on check-up and diagnosis with cancer perceptions. Overall health was the most frequently found subdomain out of the 7 subdomains (average percentage 53.8%, SD 18.0). The other subdomains, namely, lifestyle and cancer, revealed an average percentage of 32.7% and 46.2% with SD 21.3 and SD 13.3, respectively (Figure 3). In particular, the average percentage of behavioral themes in overall health and general health state accounted for 84.6% in the selected HISB tools, while perceptions about nutrition and physical activity accounted for the smallest percentage at 7.7%. Similar to other domains, the occurrence of behavior dimensions on the domain was 1.3-3.3 times higher than those of attitude.

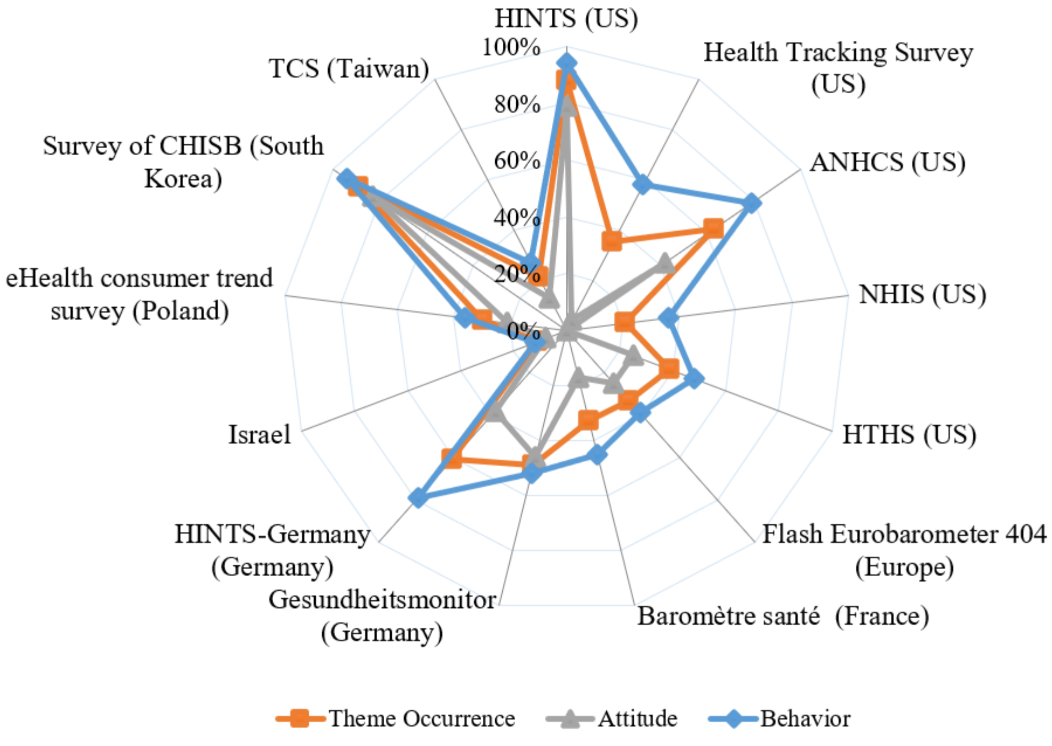
Person Characteristics

A person is the subject of HISB who seeks and utilizes information. A person's characteristics may affect HISB. The main considered characteristics throughout the instruments were age, sex or gender, nationality, race, language, education, income, occupational status, marital status, health literacy, health insurance, the number of household members, households with internet access, and preference for online or offline channels.

Themes Addressed by the Tools

The spider web diagram shows the average percentage of the themes in the selected HISB tools. Survey of CHISB (South Korea) and HINTS (United States) accounted for 89% (51/57) and 88% (50/57), respectively, which were found to be high average percentages among the tools (Figure 4). ANHCS (United States), HINTS Germany, and Gesundheitsmonitor (Germany) also contain 63% (36/57), 61% (35/57), and 49% (28/57) of the contents of HISB, respectively. Other tools including the HTHS (United States), NHIS (United States), the Health Tracking Survey (United States), the Flash Eurobarometer (Europe), Baromètre santé (France), the eHealth Consumer Trend Survey (Poland), and Taiwan Communication Survey (Taiwan) showed similar percentages of 21%-39% (12-22 out of 57 themes). The other HISB measurement from Israel showed only 11% (6/57) of the contents. All the tools focused more, by far, on the behavioral dimension than on attitude, showing a total average percentage of 53.8% and 30.4%, respectively; moreover, each average percentage of the behavior dimension accounted for 1.2-14.5 times more than the attitude throughout the instruments.

Figure 4. Average percentage of theme occurrence in health information–seeking behavior instruments. ANHCS: Annenberg National Health Communication Survey; HINTS: Health Information National Trends Survey; HISB: health information–seeking behavior; HTHS: Health Tracking Household Survey; NHIS: National Health Interview Survey; CHISB: cancer and health-related information–seeking behavior; TCS: Taiwan Communication Survey.



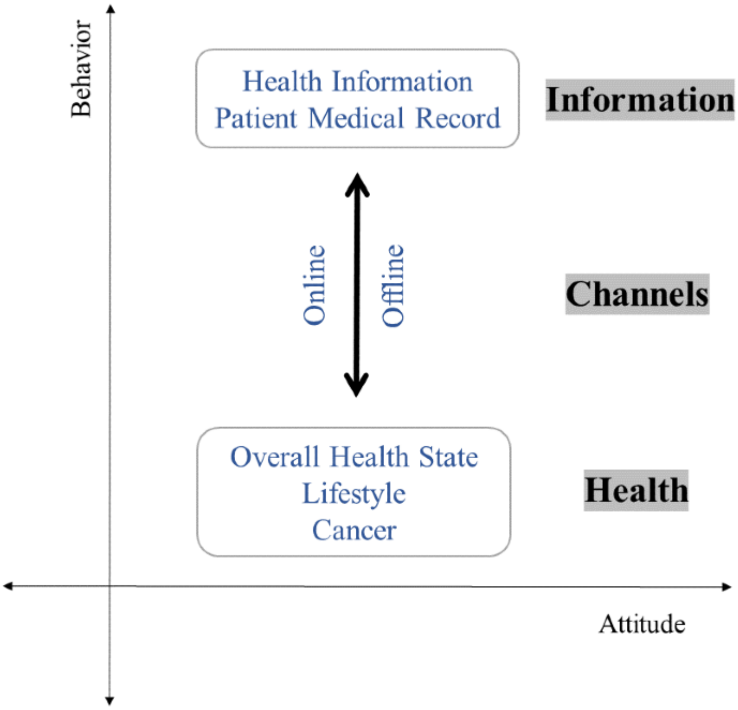
Sample Questionnaire Items

From the content analysis, representative sample questionnaire items from the 13 survey instruments were selected. Table 3 presents each questionnaire according to the domains, subdomains, and themes with attitude and behavior dimensions.

Proposed Theoretical Construct for Assessing HISB

Through the content analysis, a theoretical framework emerged. This study proposed the information-channel-health structure for assessing HISB (Figure 5). The theoretical structure shows reciprocal interaction between information and health through channels within the attitude and behavior dimensions. The information-channel-health concepts include the following: information, with information about health and patient medical records; channels, as online and offline; and health, with overall health state, lifestyle, and cancer. With the reciprocal structure of information-channel-health underlying 2 dimensions (attitude and behavior), the HISB phenomenon could be well illustrated with a comprehensive and holistic view.

Figure 5. A proposed theoretical construct for health information–seeking behavior.



Discussion

Principal Results

In this study, we investigated the main characteristics of the methodologies and the contents of the HISB survey tools used for over more than a decade (2008-2020) to answer the following research question: what are the characteristics of the measurement tools for assessing HISBs in nationally representative surveys around the world? The aim of this paper is to provide insights on the methodologies and the construct of content for HISB survey instruments from nationally representative studies. Through the systematic search, 13 survey tools were found in 2333 records related to HISB surveys. The features of this study's results are comprehensive and not limited to specific countries and specific topics or issue-based research. Other HISB-related review studies reported specific data such as age, college enrollment, adulthood, needs, and disease, including adolescent disease [82-84]. However, in this study, the results of the analysis were based on a tool for surveying healthy adults, who account for the highest proportion of the population density. Such a tool can lead to changes in the national policy.

The United States was found to have the most influential survey; 5 out of 13 tools developed in various countries were included in this study, a total of 188 research papers used data from HINTS, and HINTS identified 88% (50/57 themes) of the constructs, according to the findings. These strong features might be related to the purpose of HINTS to investigate respondents' access to and use of health information, including information technology to manage health and health information. The composition of most of the questionnaire tools was continuously updated according to the change of the cycle. However, in the current survey of HINTS 5 Cycle 4, researchers changed its scope to focus on cancer compared to prior HINTS surveys, which focused on health and medical topics. Therefore, HINTS 5 Cycle 3 was included for the contents analysis part of this study. In particular, owing to the influence of COVID-19, the questionnaire in France was changed twice in 2020 only to reduce the time of survey completion.

The contents of each country's survey tools contain the construct of HISBs. They can be categorized as information (information about health and patient medical records), channel (online and offline), and health (overall health state, lifestyle, and cancer), with dimensions of behavior and attitude. The questions are organized with more of the behavior dimension (average percentage of 53.8%) than attitude (average percentage of 30.4%) (Table 2). The analysis of the survey questionnaire contents conceptualized the HISB phenomenon, showing 3 domains, namely, information, channel, and health, with 2 dimensions, namely, behavior (objective outcome) and attitude (subjective tendency), emerging from the information-channel-health structure (Figure 5). In recent years, research has been conducted in parallel with existing reviews and meta-analysis to bring a theoretical framework to make some corrections [20] or to compare only specific variables to analyze the relationships [85] deductively. This study is meaningful as it derives a theoretical framework inductively after analyzing the contents by reviewing all the items of survey questionnaires. The findings of this study revealed that nationally representative surveys of HISB did not report theoretical frameworks when constructing the questionnaires. Therefore, it is believed that the outcomes of this study can be helpful in developing HISB-related tools or in establishing a theoretical framework prior to a large-scale investigation. This study included comprehensive (online and offline) HISBs. Recently, the terms eHealth and mobile health have become popular as many people use the internet and mobile access to manage their health. Therefore, preliminary review studies have focused on web-based HISBs or eHealth [17]. This research trend has a limitation in that it fails to address offline sources or face-to-face HISBs that still account for a large portion of HISBs.

This study found that all the survey instruments were from high-income countries, that is, United States, European Union, France, Germany, Israel, Poland, South Korea, and Taiwan, of the Organization for Economic Co-operation and Development [86]. The results can be interpreted as showing that there is information inequality, which may lead to a worsening of health inequality between high-income and low- and-middle-income countries. While low- and-middle-income countries still prioritize the establishment of universal health coverage focusing on the provider, high-income countries acknowledge the health information for individuals, empowering the health care consumer. The gap might be overcome through assessment of the trend of HISB in low- and-middle-income countries to contribute to the effective and efficient health care service to be provided. The details were analyzed by reviewing individual questions for the 13 survey tools, which were deeply rooted in the countries' differences. There are deviations in the questions according to the culture or medical system. For example, the question options vary depending on whether the countries are exposed to terrorism or have specific diseases or causes of cancer such as ultraviolet radiation exposure followed by a high incidence of skin cancer. In addition, questions about the type of health insurance and Medicare system also varied—for example, whether to visit in-store retail clinics, where to receive prescriptions, differences in the quality of and satisfaction with medical services, and accessibility to medical services.

The degree of information technology development in the country also has a great influence on the questions. The question asking whether the respondent has computers or mobile/smart devices depends on the development of information technology and the retention rate of mobile phones in each country. As an extension of this question, questions were subdivided into digital literacy, the type of fitness app, and whether web-based chat groups were used for health-related topics. With HINTS as a standard, related studies from Germany, South Korea, and China were also developed. HINTS Germany was established by HINTS (United States) and supported by the National Cancer Institute. In the case of South Korea, an individual researcher developed the survey questionnaires based on the content of HINTS and was funded by a national institute. HINTS China was excluded in this study because researchers did not conduct a nationally representative sample survey of the country. These studies would enable cross-national trend analysis and agenda for HISB.

Limitations and Recommendations for Future Research

For this study, we used databases in English and Korean, but there are some survey instruments that are neither English nor Korean. To overcome this limitation, we did not limit the languages in the search process. Moreover, it is obvious that English is the universal language of publication in the research field in the era of globalization. Therefore, we also used surveys in other languages, including 1 from France (French), Germany (German), and South Korea (Korean) in this paper. Some full versions of HISB survey instruments were not available for the review process. To attain the instrument, the researchers emailed corresponding authors for the HISB survey tools; however, these were found to be not related to HISB, or the author refused to provide a full version, or we received no response. In addition, the duration of the literature search was restricted to the period between 2008 and 2020. However, we mitigated this limitation because this study's findings cover the fundamental essence of HISB phenomena by analyzing existing tools over a more extensive period. The theoretical framework derived from this study could be used as a guide for nationally representative HISB surveys. From the findings of this study, we see that there was a lack of theoretical basis for the survey instrument. The framework including both the behavior/attitude and online/offline dimensions would provide integrative scope for national HISB phenomena. Moreover, this framework could be compared to other HISB-related theories, thereby enabling more comprehensive insight into the HISB phenomenon. As the study scope focused on HISB instruments that seek nationally representative samples, future studies could also analyze different populations, including certain regions, ages, genders, and occupations with HISB instruments. It would be worthy to compare the differences among the populations.

Conclusion

This study analyzed and synthesized current HISB survey questionnaires for nationally representative surveys. The findings of the methodology and content analysis provide a map and prototype for developing HISB-related instruments. A theoretical framework including both behavior/attitude and online/offline dimensions may provide integrative insight into real-world HISB phenomena. In sum, the findings of this study may contribute to better understanding of comprehensive HISB trends in nationally representative surveys.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategies used for the study.
[PDF File (Adobe PDF File), 208 KB-Multimedia Appendix 1]

Multimedia Appendix 2

List of studies related to each health information–seeking behavior survey instrument tool.
[PDF File (Adobe PDF File), 172 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Characteristics of the health information–seeking behavior survey instruments.
[PDF File (Adobe PDF File), 191 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Theme occurrence table.
[PDF File (Adobe PDF File), 241 KB-Multimedia Appendix 4]

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Abbreviations

ANHCS: Annenberg National Health Communication Survey
CHISB: cancer and health-related information–seeking behavior
HINTS: Health Information National Trends Survey
HISB: health information–seeking behavior
HTHS: Health Tracking Household Survey
NHIS: National Health Interview Survey
RISS: Research Information Sharing Service

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Review

Functionalities and Issues in the Implementation of Personal Health Records: Systematic Review

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Abstract

Background: Functionalities of personal health record (PHR) are evolving, and continued discussions about PHR functionalities need to be performed to keep it up-to-date. Technological issues such as nonfunctional requirements should also be discussed in the implementation of PHR.

Objective: This study systematically reviewed the main functionalities and issues in implementing the PHR.

Methods: This systematic review was conducted using Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines. The search is performed using the online databases Scopus, ScienceDirect, IEEE, MEDLINE, CINAHL, and PubMed for English journal articles and conference proceedings published between 2015 and 2020.

Results: A total of 105 articles were selected in the review. Seven function categories were identified in this review, which is grouped into basic and advanced functions. Health records and administrative records were grouped into basic functions. Medication management, communication, appointment management, education, and self-health monitoring were grouped into advanced functions. The issues found in this study include interoperability, security and privacy, usability, data quality, and personalization.

Conclusions: In addition to PHR basic and advanced functions, other supporting functionalities may also need to be developed based on the issues identified in this study. This paper provides an integrated PHR architectural model that describes the functional requirements and data sources of PHRs.

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KEYWORDS

personal health record; systematic review; functionalities; issues

Introduction

In health emergencies such as epidemics, natural disasters, or artificial disasters, access to reliable health information becomes crucial for the community [1,2]. As of 2020, the COVID-19 pandemic throughout the world has led to an increasing need for electronic health records (EHRs) to provide reliable health information [3,4]. According to the World Health Organization, the EHR that collects data from various health service providers will provide better patient care during a pandemic, such as preventing and detecting an outbreak [5]. The EHR's function will be more optimal if patients can share their health data with health care providers [6]. Personal health records (PHRs) can help patients share their data with health care providers and provide useful information during health emergencies [2].

The EHR aims to collect health data managed by health care providers, while the PHR aims to collect health data entered by individuals [1]. The PHR was developed with a patient-centered approach in the capture and storage of information [7]. In its simplest form, a PHR is a stand-alone application that is not connected to other systems. Users can access their PHR using commercially available applications to record and analyze daily activities and habits to maintain a healthy lifestyle. In a more complex form, the PHR's health information is connected to the EHR of the health care provider (tethered PHR) or to various health service data sources (integrated or interconnected PHR). A PHR integrated with an EHR, either through tethering or interconnectivity, provides far more significant benefits than a stand-alone PHR [1].

One of the important PHR research areas is PHR functionality [8]. Previous studies have provided data types and functionalities of PHRs [9] and a guide to evaluate PHR functionalities [10]. Some studies reviewed PHRs used for chronic diseases, which include discussions about their functionalities [11,12]. However, these studies focused only on PHRs in the United States and developed countries [9,11,12]. Moreover, previous studies have also discussed technological issues in implementing or using PHRs, such as data quality [13], personalization [14], privacy [13,15], and usability [14]. These studies still have no clear explanations about how these issues can be included as requirements in implementing PHRs.

Functions or features of PHRs are evolving [9,12], so continued discussions about PHR functionalities need to be held to keep the research up-to-date. In addition, technological issues as nonfunctional requirements [16] in the design and development of a system must be discussed. Technological issues can be defined as constraints and qualities related to the technology used to perform the function [17]. Thus, this paper aims to review the PHR studies focusing on the functionalities and technological issues in building the PHR system. This paper addresses the following research question: What are the main functionalities and issues in the implementation of PHRs? This study can provide PHR design or implementation recommendations to health care management, application developers, policymakers, or other related stakeholders.

Methods

This systematic review was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines [18]. PRISMA is suitable for studies related to health care interventions, and it focuses on ways in which authors can ensure the transparent and complete reporting of systematic reviews [19]. The PRISMA checklist for this study is provided in Multimedia Appendix 1.

Search Strategy

The search is conducted using the online databases Scopus, ScienceDirect, IEEE Xplore, MEDLINE, CINAHL, and PubMed. Terms or keywords used to search the articles: (“phr” OR “personal health record” OR “personal medical record” OR “personal health information” OR “personally controlled electronic health record” OR “pcehr” OR “patient portal”) AND (“functionality” OR “features” OR “issues” OR “implementation”). The search was conducted for journal articles and conference proceedings published between January 2015 and December 2020 to ensure that the data were current because the functions of PHRs are evolving.

Eligibility Criteria

The authors defined inclusion criteria as the review guidelines for study selection. The articles included for this study must have full text available and written in English, be original research articles, focus on discussing the electronic PHR platform, and discuss functionalities and/or issues in the implementation of PHRs.

In this study, the PHRs discussed are all PHR types (stand-alone, tethered, and integrated) that provide access to health information or records to patients electronically. Therefore, papers with related terms such as patient health records or patient portals are also included in this review. The authors also reviewed PHRs at the design stage to include conceptual papers in this review.

Study Selection

The study selection consists of the following phases:

1. Keyword or search string was searched in each online database previously mentioned. Duplicated records were checked and removed.
2. The title and abstract of identified articles were selected based on the eligibility criteria. Articles that did not meet inclusion criteria were eliminated.
3. Articles that were not eliminated in the previous stage were read in full text to determine whether they should be included in the review based on the eligibility criteria. Reference lists of the included studies were also checked to identify additional relevant articles.

The first author screened the titles and abstracts based on the eligibility criteria. The same author reviewed full-text versions of the articles that were not excluded from the previous screening. The first author extracted data from selected studies and the second author reviewed the extracted data. Disagreements between the two authors were resolved through discussion. If an agreement could not be made, the third author would determine the decision. We were unable to consistently evaluate the risk of bias due to the variety of methodologies within the studies.

Data Items and Synthesis

Data collection was performed manually using a data extraction form. Information extracted from each article consists of characteristics of selected articles, such as study location, PHR purpose, and methodology, and functionalities of PHRs and issues in PHR implementation

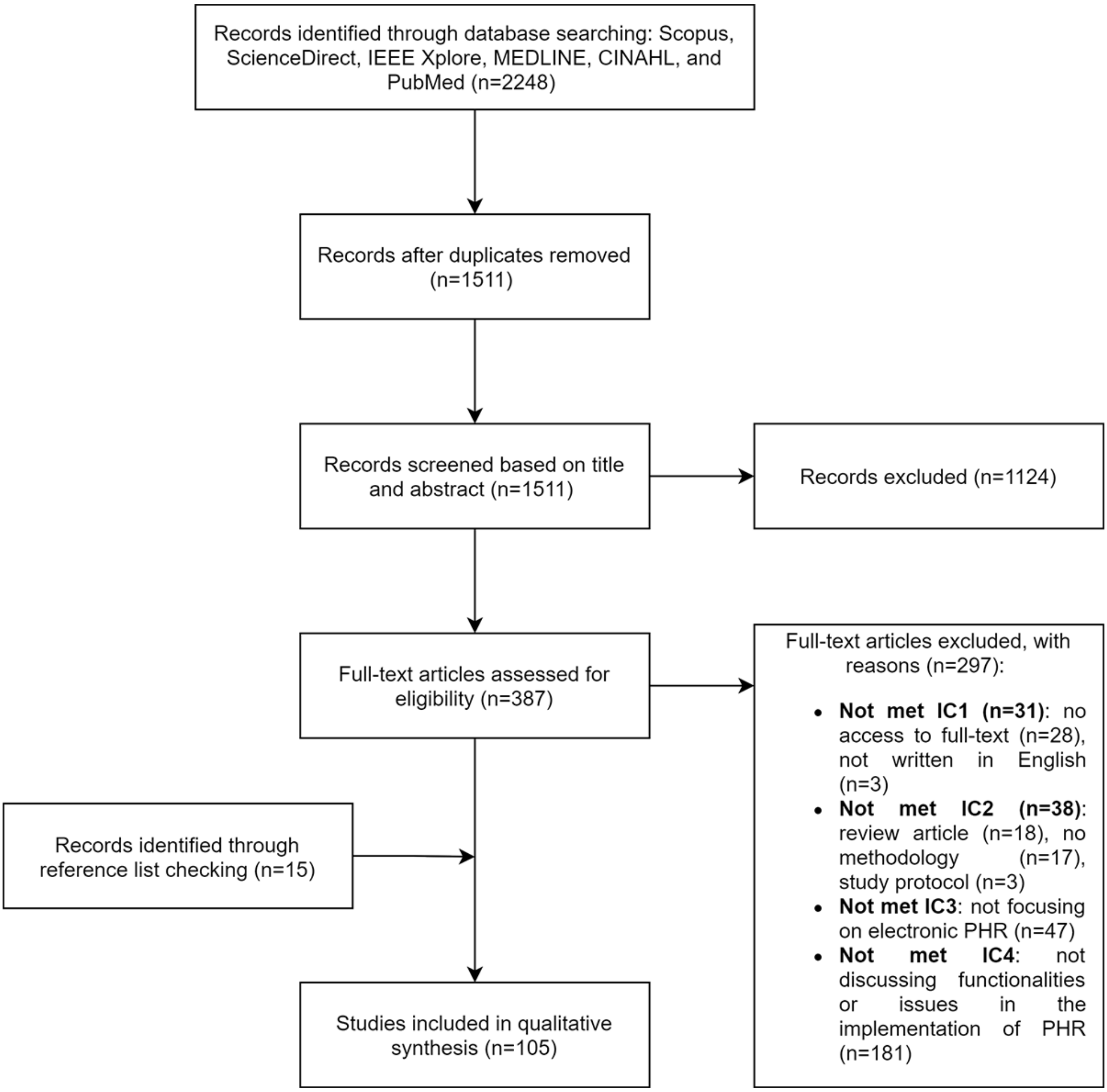
Authors categorized functionalities of PHRs based on their purpose as defined in Bouayad et al [9], Price et al [12], and Genitsaridi et al [10]. For each function category, the authors explained subfunctions or data elements that were implemented or recommended from the selected articles. Moreover, each function category was grouped based on basic and advanced functions defined by Detmer et al [20]. Basic functionalities help people collect, organize, and store health information, while advanced functionalities enable patients to play a more active role in their health [20]. The authors explained PHR implementation issues that are mentioned explicitly or implicitly from the selected articles.

Results

Study Selection

The database search results identified 2248 studies from 2015 to 2020. Next, duplicate records were removed, resulting in a total of 1511 studies; 124 studies were excluded after the title and abstract screening (articles that mentioned literature review and articles not related to PHRs, patient portals, or access to health records to patients were excluded at this stage). A total of 387 articles were assessed in full text, of which 297 were excluded because they did not meet the selection criteria. However, 15 additional studies were identified from reference lists checking, for a total of 105 studies included in this review (Figure 1).

Figure 1. Flow diagram for search results. IEEE: Institute of Electrical and Electronics Engineers; MEDLINE: Medical Literature Analysis and Retrieval System Online; CINAHL: Cumulative Index to Nursing and Allied Health Literature; PHR: personal health record.



Study Characteristics

The chosen articles showed that PHR research has mainly been done in developed countries such as the United States, Canada, and European countries compared to developing countries. This country classification was based on the United Nations World Economic Situation and Prospects 2020 [21]. Countries involved in selected studies consist of developed countries such as the United States (42 studies), Canada (10 studies), Germany (8 studies), Australia (5 studies), Italy (4 studies), Netherlands (4 studies), United Kingdom (4 studies), South Korea (3 studies), European Union (2 studies), New Zealand (2 studies), Austria (1 study), Belgium (1 study), Norway (1 study), Portugal (1 study), and Taiwan (1 study) and developing countries such as Argentina (3 studies), China (3 studies), Iran (2 studies), Sri Lanka (2 studies), Brazil (1 study), Colombia (1 study), India (1 study), Malaysia (1 study), Romania (1 study), and Thailand (1 study; Figure 2).

The purposes of PHRs (Table 1) in selected articles include general, not specific to the disease, health status, or population (48 studies); chronic diseases such as cancer, cardiovascular disease, and diabetes (31 studies); hospital patients such as inpatients and outpatients (10 studies), older adults (5 studies), women and child health (4 studies), mental health (4 studies), and other specific populations such as employees and foster youth (3 studies).

The study methods (Table 2) used in selected studies include qualitative (41 studies), quantitative (33 studies), conceptual paper (16 studies), and mixed method (15 studies). A summary table of the characteristics of the included studies is provided in Multimedia Appendix 2.

Figure 2. Countries involved in personal health record study.

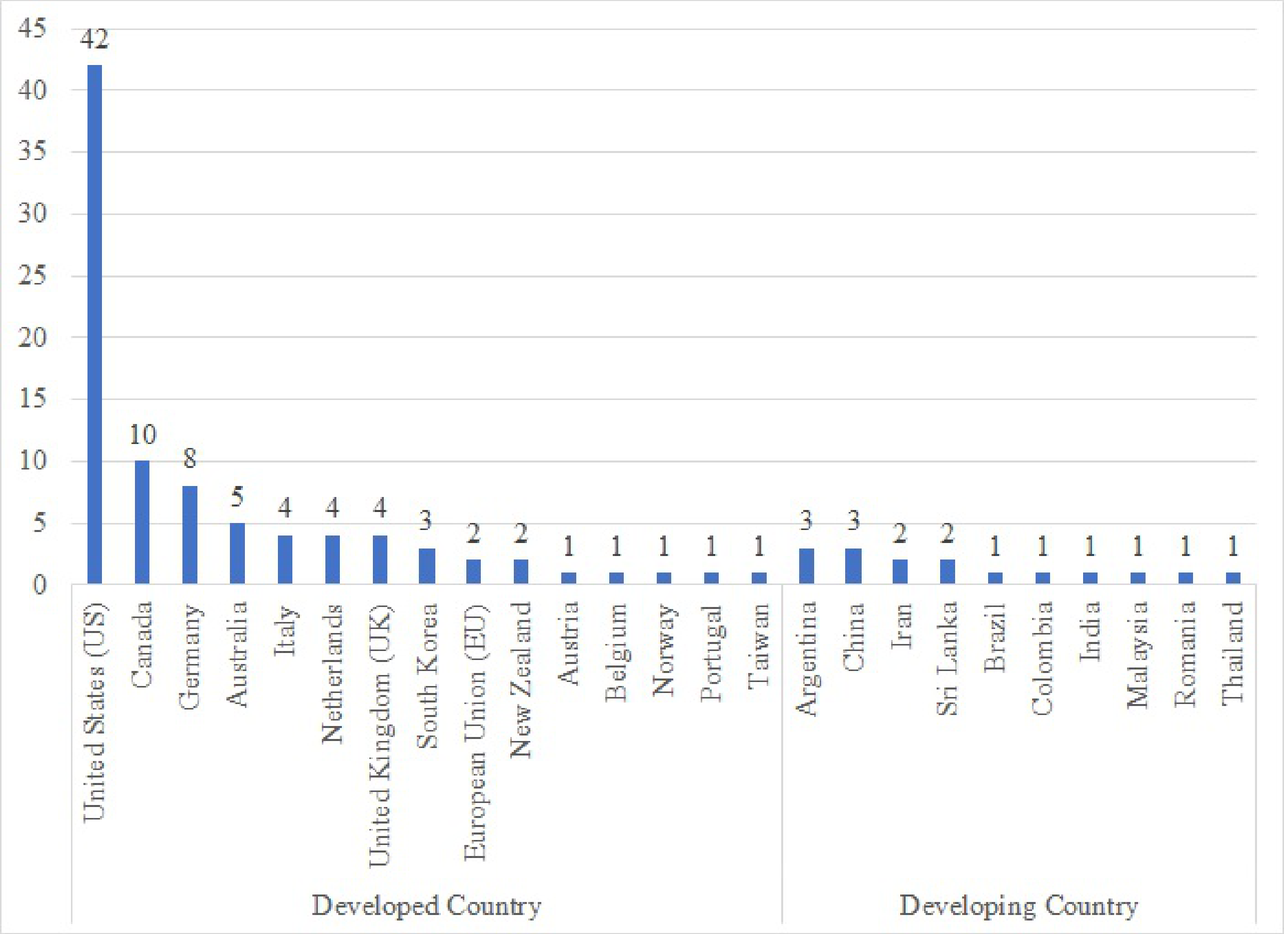


Table 1. Purposes of PHRs[a].

Category	Description	Number of studies
General	PHR designated not specific to any diseases, health status, or population.	48
Chronic disease	PHR for chronic diseases such as cancer, diabetes, or cardiovascular disease.	31
Hospital patients	PHR for patients who have visited the hospital, such as inpatients and outpatients.	10
Older adults	PHR for patients with the age of more than 50 years.	5
Women and child health	PHR for women, pregnancy, and pediatric health.	4
Mental health	PHR for mental health diseases, such as bipolar disorder.	4
Other populations	PHR for other specific populations, such as employees and foster youth.	3
Total	—[b]	105

[a] PHRs:patient health records.

[b] Not applicable.

Table 2. Methods used in the studies.

Method	Type of study	Number of studies
Qualitative	Interview and focus group discussion	41
Quantitative	Questionnaire, cohort study, and randomized clinical trial	33
Conceptual paper	—[a]	16
Mixed method	—	15
Total	—	105

[a] Not applicable.

Main Functionalities of PHR

Basic functions identified in this study consist of the health record and administrative record. Advanced functions consist of medication management, communication, appointment management, education, and self-health monitoring (Table 3). A summary table of the data elements and subfunctions is provided in Multimedia Appendix 3.

Table 3. Identified Functionalities in PHR[a].

Function	Description	References
Basic function		
Health record	Allows patients to view or access clinical documents from health providers' EHR[b].	[22-71]
Administrative record	Allows patients to manage personal information and view information related to health providers and insurance.	[22,25,26,30,31,34,39,42,44-46,55,59,66,68,70,72-78]
Advanced function		
Medications management	Allows patients to manage information related to medications and prescriptions.	[24-36,38-40,42,45,46,48,51-57,59-61,63,68-71,73,74,77,79-85]
Communication	Allows patients to interact and communicate with health care providers and others, such as support groups and families.	[22-24,27-32,36,38,40,42,43,46,48,49,51-53,55-57,59,61,62,67,69,71,74,75,80,82-84,86-94]
Appointment management	Allows patients to manage appointments with health care providers.	[22,23,25-31,33,34,36,40,42,47-53,55-57,59-61,63,64,67,71,73,77,78,81,85-87,92,94]
Education	Allows patients to access health-related education resources.	[22,30,31,40,45,46,55,57,59,61,70,71,76,77,90,95-99]
Self-health monitoring	Allows patients to manage their self-health data through clinical measures.	[23,26,30,33,39,44,58,66,67,70,72,81,85,86,90,93,95,96,98,100-105]

[a] PHR: patient health record.

[b] EHR: electronic health record.

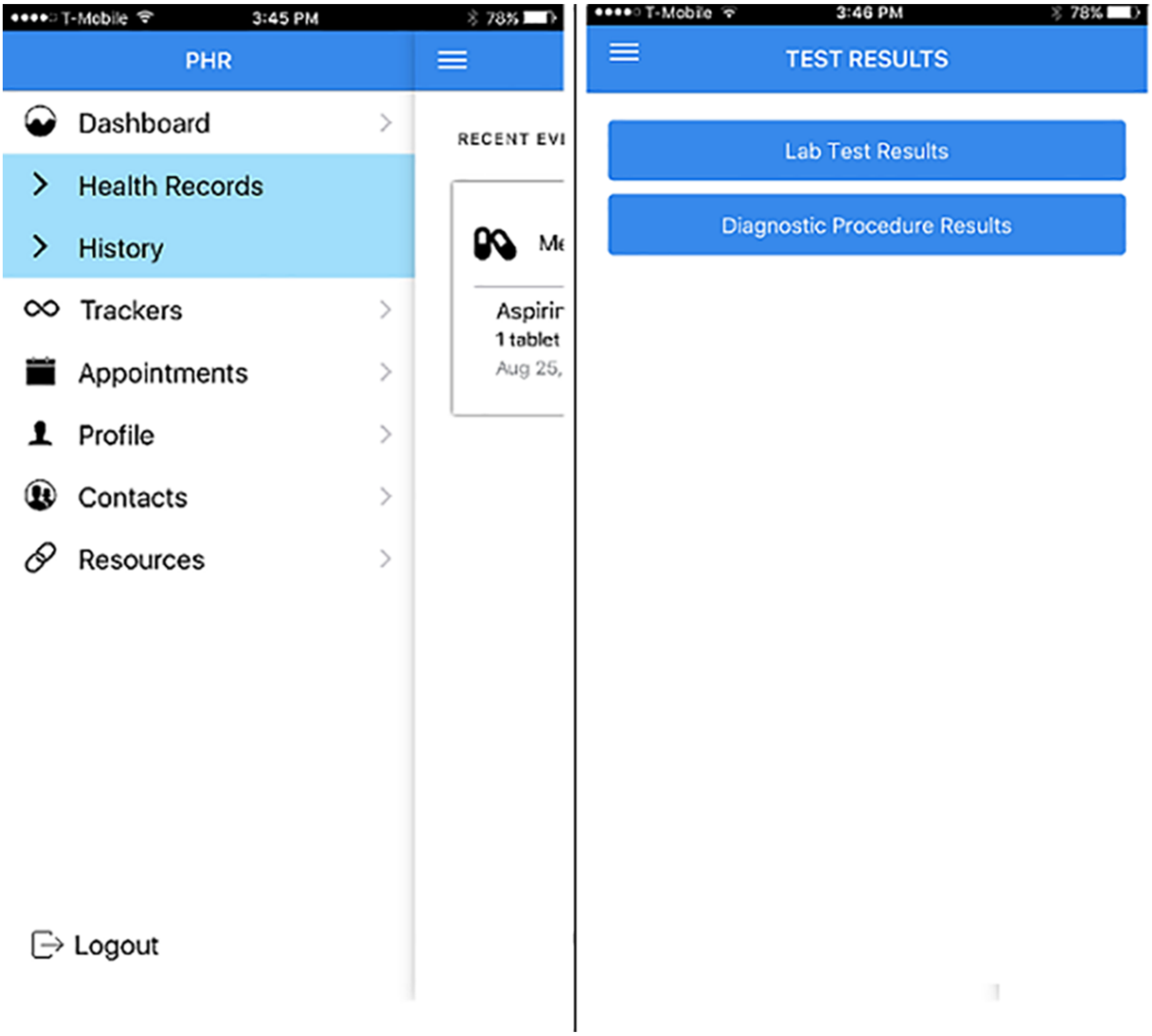
Basic Functions

Health Record

The health record function provides patients options to view clinical documents that can be retrieved from health providers' EHR [22,23,34]. This information can include problem lists [22,24-29,45,56,67-71], allergies [22,25-28,30-33,35-39, 56,67-70], immunization [22,26-28,30,32-35, 40-42,56,68-71], laboratory and test results [22,24,26-30,33,36,37, 40,42-61,67-71], diagnostic information [32,37,44,45,62], discharge information [31,34,63], and clinical notes [24,30,33,42,50,61,64,67,69]. Figure 3 shows an example of test results in PittPHR [33].

This function can also include information about medical history [22,24,30,33,35,37,39,45,51,57,64,65,67,68], family history [28,30,32,33,35,37,66], genetic history [45], surgical history [26,28,33,35,45,66,68], social history [32,33,35,37,45,68]. Some studies suggested that this function also supports patients' ability to print the record [24,36] and add comments or notes in health records [28,61].

Figure 3. Test results menu in the health records module of PittPHR [33].

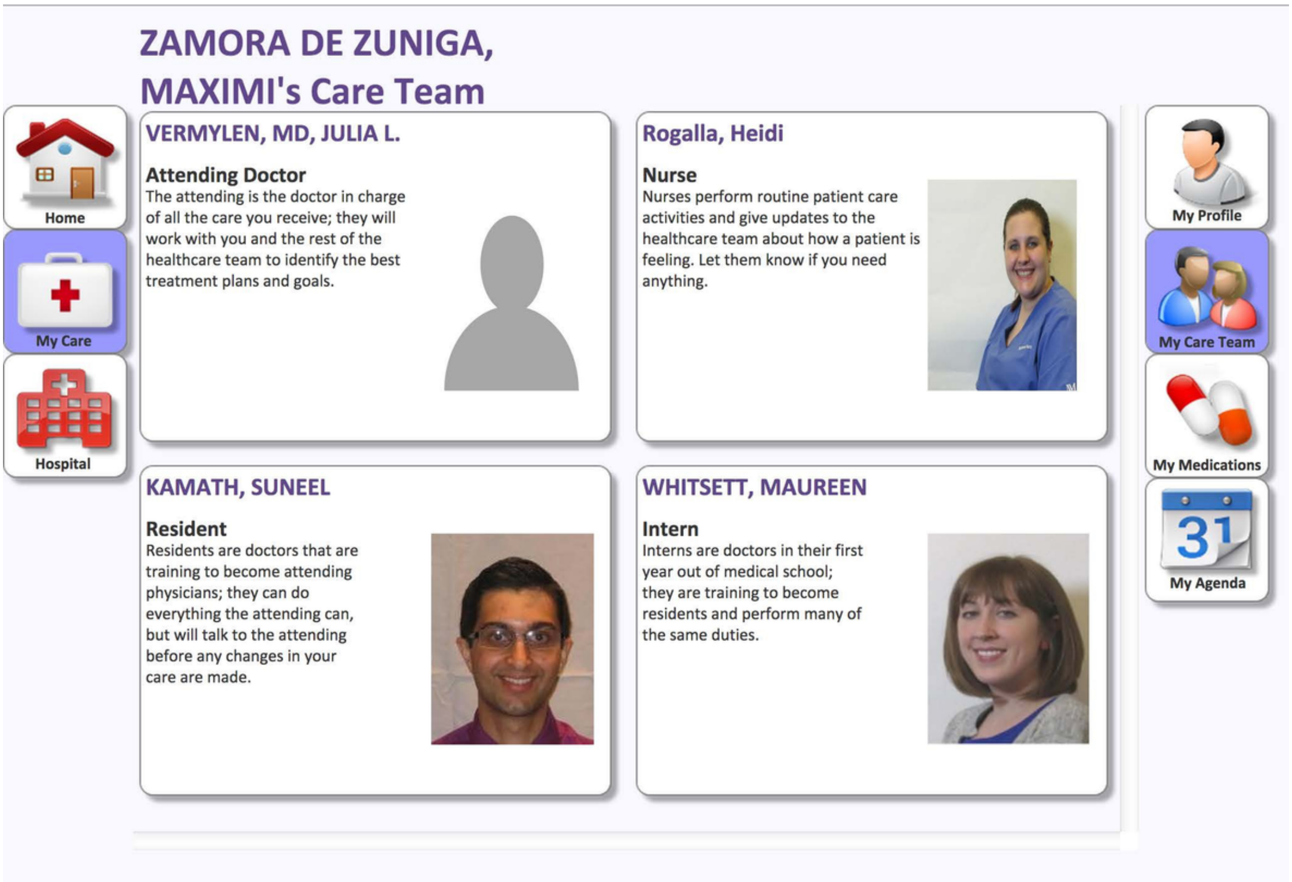


Administrative Record

This function enables the patient to manage information about demographics or personal information [25,26,31,44,45,68,72] such as name [25,39,44,72,73], gender [25,26,44,72], birthdate [25,26,44,72,73], blood type [39,44], contact information [25,31,68,72], and parents' names [25,45]. Patients can also change their information, such as change password, address, and email address [22]. Patients can enter this information [22,31,68,72] or retrieve it from a central patient registry, such as in Lifelong PHR [34].

Patients can also view health professionals' information, such as name of health worker [34,39,55,74], role [74,75], educational background [75], contact information [42,45], specialty [76], location [76], and pictures [46,55,59,74,77,78]. Patients can also view hospital information, such as location, contact info, address, navigation [70]. Patients can also view and pay bill [42,55,77] and get insurance-related information [22,30,34,45,66]. This data can be retrieved from the regional health care information system [34]. Figure 4 shows an example of the health care team information in the PHR app [74].

Figure 4. Health care team information menu [74].



ZAMORA DE ZUNIGA, MAXIMI's Care Team

VERMYLEN, MD, JULIA L.

Attending Doctor
The attending is the doctor in charge of all the care you receive; they will work with you and the rest of the healthcare team to identify the best treatment plans and goals.

Rogalla, Heidi

Nurse
Nurses perform routine patient care activities and give updates to the healthcare team about how a patient is feeling. Let them know if you need anything.

KAMATH, SUNEEL

Resident
Residents are doctors that are training to become attending physicians; they can do everything the attending can, but will talk to the attending before any changes in your care are made.

WHITSETT, MAUREEN

Intern
Interns are doctors in their first year out of medical school; they are training to become residents and perform many of the same duties.

Advanced Functions

Medication Management

Health care providers publish prescriptions to the patient's PHR, while pharmacists dispense the prescribed medication [34]. This function provides information about the list of medications that patients are currently taking [25,28,29,35,38,45,46,52,56,59,60,68,69], medication name and dosage [32,35,40,60,74,77,79,80], and list of past medications [28,29,36,42,45,46,60,69,70,73,81]. PHRs should also add information about the purpose or class of medications to give patients an understanding of the medication type [74] and allow pharmacists to explore the data according to their common questions [80].

This function also allows patients to view list of prescribed medications [26,30,39,54,79,82,83], prescribing physician [79], refill prescription [24,27,29-31,33,34,36,39,48,53,55,57,60,61,84], order medications [29,39,71], deliver purchased medication [79], as well as track the delivery of medication [36,39,42]. Some PHRs also provide medication schedulers and reminders of when to take medicines [28,70,83,85], drug or medicine reconciliation [42,51,63,83], and warning alerts of potential adverse interactions based on the medication and allergy list [38,68,73]. Figure 5 shows an example of medication management in medication management in My Chart in My Hand [85].

Figure 5. Medication management in My Chart in My Hand [85].

Communication

The patient can send messages to the health care provider to inform them of health condition [23], share doubts and worries [86], receive medical advice [56,86], or send nonurgent messages [40,46,71]. The communication can be in the form of messaging [23,27,29-32,36,38,40,42,43,46,48,49,51-53,55-57,59,61,67,69,71,74,75,82-84,86-92] or text where patients can write questions (Figure 6) [74,80]. Some PHRs also enable patients to contact others in a similar situation [28,29,83,88], support groups [62,87], family [75,89], or customer support and billing departments [22]. Some studies also suggested this function have the ability to maintain a record of past conversations [36] and provide email or text notification when a health care provider leaves a message on the PHR [24,93,94]. Moreover, some studies suggested tracking the status of a question [80], message multiple providers at the same time [24], and import selected emails and interactions on the social network to PHRs [86].

Figure 6. Comments or questions page in myNYP.org [80].

Welcome back, [redacted]

Record Comments or Questions to Ask Your Care Team

Tap here to enter a question or comment

Select Type: ● Question ○ Comment

History

Was Closure of breastbone completed with steel wire? If so is there anything we should know about it for traveling,X-rays, general health? Also patient adores gardening especially vegetables in his 40x40 garden. What restrictions / limitations do we have to know? Should he be taking a baby aspirin daily or any additional supplements to maintain healthy lifestyle. Thank you
19 Oct 10:54 AM

Loved reading about my whole open heart procedere. Easy to understand
19 Oct 08:21 AM

Appointment Management

Some PHRs may allow a patient to request or schedule appointments (Figure 7) [22,23,25-28,30,33,34,40,42,48-50,52,55,57,60,61,67,71,85,87,92], while others only allow patients to view their past and upcoming appointments [29,31,36,51,53,56,59,63,64,73,77]. The types of appointments can include patient-doctor visit consultation services and other health services such as specialist encounters, sample takings, hospital admissions, result withdrawal [86], therapies, and online consultation [23]. Moreover, some studies suggested that PHRs include reminders or notifications for upcoming appointments [33,42,47,48,60,61,81,94]. This reminder can be in the form of email notifications about the date and time of the appointment [42,81]. PHRs can also add a calendar to keep track of future appointments [34,78].

Figure 7. Appointment scheduling in mPHR [25].

Provider: Putra Jaya Hospital | Ahmed Al-Haiqi

Category: Office Visit

Date: 12.02.2017 Duration(min): 15

Start Time: 17:00 End Time: 17:15

Reason: Office Visit

Facility:

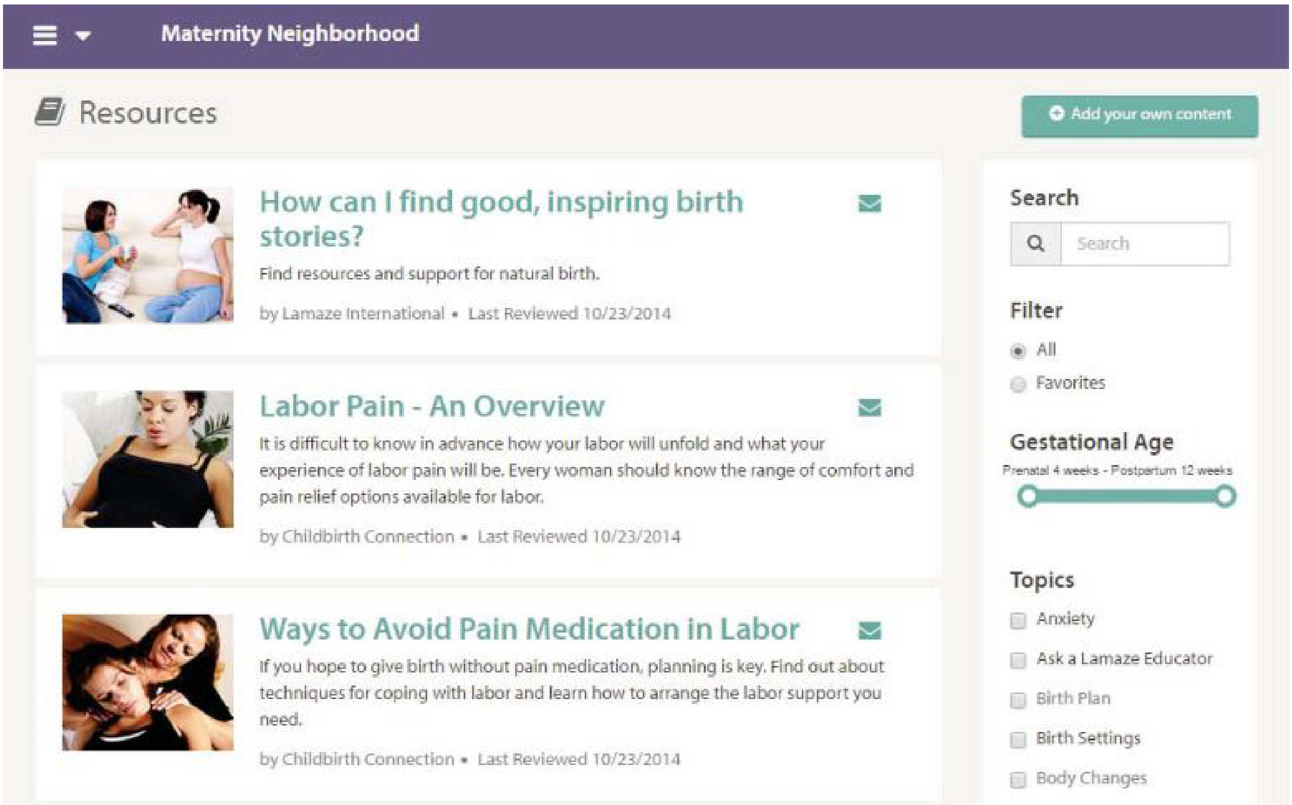
Status: * Reminder done

Comment: Regular visit

Education

The education function can include resources from trusted websites [45,90], health information libraries [22,30], video resources [46,59,95], or government supported information [95]. The information can consist of lifestyle management [45,57,71], first-aid information [40,70], discharge instructions [31], surgical procedure [77], physical activities guidance [96], or health-specific education such as pregnancy [97,98], mental health [45,61], or chronic diseases–related education [90,95]. Figure 8 shows an example of the education page in the Maternity Information Access Point [97]. Health providers are responsible for providing clinical topics and resources for credible information [55,76,99]. Moreover, PHRs should also have the ability to search for information using an intelligent search engine [99].

Figure 8. Education resources in Maternity Information Access Point [97].



How can I find good, inspiring birth stories?

Find resources and support for natural birth.

by Lamaze International • Last Reviewed 10/23/2014

Labor Pain - An Overview

It is difficult to know in advance how your labor will unfold and what your experience of labor pain will be. Every woman should know the range of comfort and pain relief options available for labor.

by Childbirth Connection • Last Reviewed 10/23/2014

Ways to Avoid Pain Medication in Labor

If you hope to give birth without pain medication, planning is key. Find out about techniques for coping with labor and learn how to arrange the labor support you need.

by Childbirth Connection • Last Reviewed 10/23/2014

Search

Filter
● All
○ Favorites

Gestational Age
Prenatal 4 weeks - Postpartum 12 weeks

Topics
☐ Anxiety
☐ Ask a Lamaze Educator
☐ Birth Plan
☐ Birth Settings
☐ Body Changes

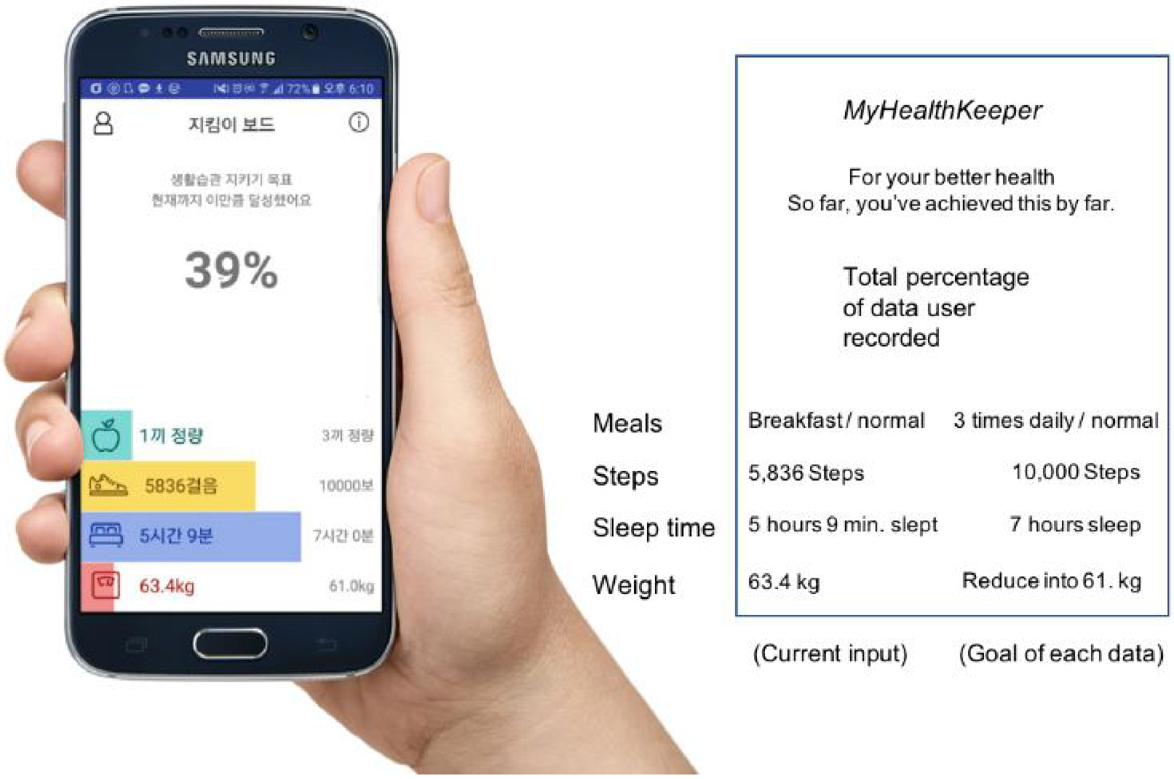
Self-Health Monitoring

Patients can manage their own health related to nutrition and diet information such as weight [30,33,39,58,66,67,72,85,86,90,98,100-102], height [39,58,66], physical activity or exercise [30,33,58,66,70,96,98,100,101], and food and meals [33,66,98]. Patients can also manage their vital sign data such as temperature [26,44], blood pressure [30,33,44,58,66,67,70,72,85,90,98,101,103], blood glucose [30,58,66,70,72,85,86,98,103], and heart rate [90]. Patients can also monitor other self-health data such as sleep [33,66,95,100,101], period [33,100], moods [98,100,101], and stress [66,70,100].

These clinical measures enable calculation such as BMI [39,66,70,85,100], body fat percentage [70], waist-to-height ratio [70], calorie [70], cholesterol level [66,86], and glycemia [86]. This information can also calculate disease risks such as cardiovascular disease risk and metabolic syndrome risk [85]. The data in this function can be retrieved from home monitoring devices [23,39,58,85,96,104,105] such as Bluetooth-enabled health monitors [104], accelerometers [105], blood pressure monitors [58], blood glucose meters [58,81,85,93], and pedometer [72] and fitness tracker apps [39].

The monitoring of health data can be shown as a dashboard that visualizes data in graphs, charts, or diagrams [30,33,70,72,81,86,101,102,105]. Key performance indicators can be different for each patient, depending on their conditions. For example, in the MyHealthKeeper app, the clinician provided individual diet and physical activity targets for each patient during an outpatient visit (Figure 9) [101]. This function can be integrated into a clinician's EHR, and clinicians could review these data and provide feedback about the health-related lifestyle management of their patients [101].

Figure 9. MyHealthKeeper interface for patient’s lifestyle data [101].



Issues in Implementation of the PHR

Some issues must be considered in implementing PHRs because these issues can define additional functionalities that can support the main functionalities in PHRs. The issues identified included interoperability, security and privacy, usability, data quality, and personalization (Table 4).

Table 4. Issues in implementation of the PHR[a].

Issues	Description	References
Interoperability	Ability of PHR to share or exchange data with other systems	[22,25,29,33,35,37-39,51,53,61-63,68,72,76,86,88-90,96,100,102,104,106-112]
Security and privacy	Safeguarding of data and personal information in PHR	[25,26,32-34,42,45,47,54,55,57,60-65,69,70,72-74,76,77,83,92,94,97,103,108,110,112-122]
Usability	Whether users can use PHR effectively and efficiently	[24,25,33-37,41,45,46,48,51,54,59,61,62,65,71,74,76,81,83,85,87,90,92-94,96,100,105,108,110,117-126]
Data quality	Ensures consistency, completeness, accuracy, and timeliness of the PHR information	[24,30,31,33-35,64,68,81,90,91,107,108,110-113,115]
Personalization	Ability of PHR to be tailored and adapted to patient needs and preferences	[22,33,52,57,59,78,87,88,95,99,102,112,117,118,123,125]

[a] PHR: personal health record.

Interoperability

An important issue raised in several studies is PHR compatibility with other systems [51,88,90,100,106]. Health service providers such as clinicians should input data from other systems into the PHR or vice versa, which was considered too time-consuming and unfeasible for daily practice [100]. This problem can also be caused by health organizations adapting their formats to use health records and not allowing health information sharing in their PHR to other applications or organizations [63,107]. As a result, a patient may have health records scattered in several applications [107]. To provide more benefits and ensure its successful implementation, PHRs should realize interoperability among various data and systems [106,108]. PHRs should have the ability to share information with others [88], such as health professionals [37,61,89].

In the tethered or integrated PHR, patients may connect their PHR to the health care provider system [25,62,72,76,86,102,104]. With this integration, health information is automatically transferred to the PHR [33,39,62,109,110]. This can reduce data entry load [33,96], improve data accuracy [62,96], prevent medical errors [38], reduce the health information recall [35], and contribute to users’ better perceptions about the system’s usefulness [111]. It is also suggested that PHRs be integrated into various health providers and not limited to one health provider [53,102]. Patients may also have the ability to share information with trusted institutions and insurance bodies to speed up reimbursement procedures [86] and access other family members' records [22,102].

It is necessary to create legislation to realize PHR interoperability [106]. Health providers need to provide standard definitions for data exchange and cooperate with other providers [63]. There are international standards or frameworks for interoperability, such as OpenEHR, Health Level 7 (HL7) Fast Healthcare Interoperability Resources (FHIR), and Integrating the Healthcare Enterprise and Continua Health Alliance specifications [29,68,72,107,112]. OpenEHR describes the management and exchange of data in EHRs for developing PHRs using specific language [68]. OpenEHR integrated with other standards in particular health data types, such as laboratory results [107]. Similarly, HL7 FHIR enables the management of a single data entity, group of entities, or a record using well-known standard languages [68]. FHIR application program interface allows any arbitrary system connected with another medical system already equipped with the FHIR application program interface [72]. FHIR allows the patient portal to be interconnected but independent [29]. Moreover, Integrating the Healthcare Enterprise specifies architectural approaches using international standards for the health data exchange and can fit the mobile platform's resources. At the same time, Continua enables communication from personal health devices to EHRs and PHRs [112].

Security and Privacy

PHRs contain personal and sensitive data [47,77,108,112-114]. Some people have concerns about storing these data online [54,103,108,113,115] and consent to use the system [116]. They may have concerns about identity theft and unauthorized access in PHRs [54,55,57,61,69]. Confidentiality and privacy of information in PHRs should be ensured through secured access to PHRs [110].

To ensure the security of information, PHRs should use a single sign-on mechanism [70], user authentication [26,33,64,72,73,112,117], authorization [42,112], identity verification [34,63], encryption [25,33,112,118] or pseudonymization [114], backup mechanism [25,33,72], and firewalls [72]. PHRs can also implement an access log so that users can see who viewed and downloaded information [76]. The use of complicated or complex passwords can improve the security of s [47,119]. However, some studies show that users have difficulty remembering their passwords [47,74,77,92,94,97,103,120]. Thus, PHRs should also add other methods such as fingerprint authentication [97], biometric identification [33,94], citizen digital certificate [121], and allow users to change their passwords [62,72].

To address privacy concerns related to data sharing, PHRs should have the ability for patients to choose what information to share and who can see that information [34,42,45,60,61,65,76,83,121,122] and provide a privacy policy in the system [32]. The consent model should also be considered in implementing PHRs [116]. Moreover, PHR systems need to follow specific legal requirements related to security and privacy defined on regional, national, or international levels [112]. For example, the Health Insurance Portability and Accountability Act ensures secure data exchange with entire clinics [76].

Usability

Some usability problems identified in selected studies include font or text size that are difficult to use [71,94], confusing format [81], unclear visualization of data [90], problem with navigation [51,59], and complicated data entry [85,118]. Complicated data entry may cause users to not enter data correctly into their PHR [118]. The reduction and simplification of PHR system data entry should be considered in PHR design [35,93,118]. Users prefer easy to use, simple, and user-friendly interface [24,41,45,54,61,62,65,92,94,110,118,120-124]. Users are also interested in attractive and interactive systems [25,33,108,110,120,124] such as the use of contrasting colors for scroll bars and menu items [59]. Moreover, it is also important to maintain consistency and standardization of interfaces [35,74,117,118]. A mobile app version of the PHR was also suggested because it was perceived as more user-friendly and easy to use [25,34,61,65,81,93,100].

A PHR may add a section to guide patients about the features in the PHR [46,54,59,61,65,83,90,96,118] and quick access to the essential functionalities [37,48,108]. The use of user-interface elements like buttons and a dropdown menu can enhance the user-friendliness and simplicity of the PHR interface [25,100]. However, icons should be avoided when designing for older adults since they may not recognize them [96]. PHRs should be easy to understand and navigate for all user groups [110], including those with basic computer knowledge and those who are not computer literate [94,118]. PHR usability should be determined using health literacy assessments and there should be different PHR versions for specific groups of users [36].

Developers should involve users in designing, updating, or improving PHR systems [48,71,119]. Using a user-centered design approach can facilitate users' involvement in PHR design [76,87]. The user-centered design process increased the development process's complexity, but the product quality was higher, especially satisfaction and user acceptance [105]. However, user-centered design may not apply to all PHR types, especially PHRs targeting the general population, which necessitates identifying specific user groups and specific use contexts [125]. Adopting a usability design framework that includes usability and user testing may help address PHR usability issues [126]. Standardization used for PHR design is International Standards Organization (ISO 9241-210), which focuses on the requirements and user needs [105], and ISO 9241-11 for software systems components that define usability [96].

Data Quality

Health care providers may doubt patient-entered data in a PHR [30,113]. Not all patients have enough knowledge to generate health data in a PHR [107,112]. Data uploaded by the patient may be inconsistent [91], incomplete [81,90,110], inaccurate [30,81,90,110,115], or not up to date [90]. PHRs require patient commitment to keep the system up-to-date and relevant over time [111]. This issue needs particular attention, especially when PHR data are transferred to EHRs and used in professional medical decision-making and treatment processes [112].

To ensure data quality of patient-generated data in PHRs, health care professionals need to take time to supervise the quality of information generated by patients in PHRs [110,112]. PHRs should differentiate patient-generated data from the health care provider's data [68]. Moreover, PHR design needs to define what information is required because an incomplete record is preferable to an inaccurate one from a provider's perspective [35]. Standardization of patient-entered information is essential to ensure data quality [33]. Input control should be comfortable and descriptive words should appear to help patients enter PHR data [108].

In tethered PHRs, which are tied to EHRs in health organizations, health information on the PHRs are created automatically from the original patient clinical reports to make this information more reliable [34]. However, this can be a problem if the EHR's information is incomplete [30,64] or if the information is not generated automatically. This can also be caused by health care providers not updating the PHR information consistently [24,31].

Personalization

Some users may have more health issues than others, such as older patients having more health issues, appointments, and information to manage [22]. People want the PHR to be tailored to their needs and capable of changing based on their health and well-being needs [59,78,88,102,123]. This person-specific health and well-being information can make the PHR system more appealing [118]. The PHR system needs to be adaptable and extensible to ensure successful operation [112]. It is also suggested that PHRs support customizability based on computer literacy [87].

PHR systems should provide medical information that can be dynamically adapted to patient preferences for simpler or more complex information [99] [117]. For example, in PittPHR, users can customize the trackers according to their own needs by hiding or unhiding available trackers in a given list and add or delete links in the resources module according to their own needs [33]. PHRs could also provide tailored health education materials based on patient health problems [52,57,95,117]. Despite the need for personalization, designers or developers need to define the extent to which PHRs can be personalized but still maintain standardization, uniformity, and simplicity [125].

Discussion

Principal Findings

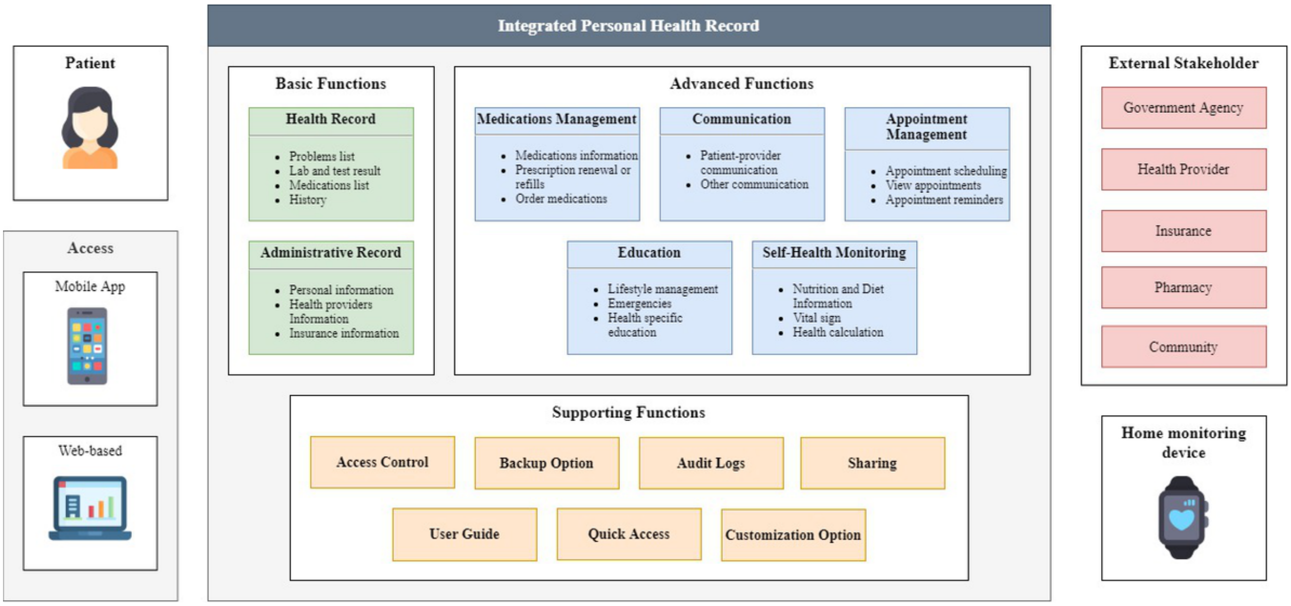
Seven function categories of PHRs are identified as the main functionalities of PHRs, which are grouped into basic and advanced functions. Basic functions (health records and administrative records) provide essential information for patients in their health care. Health records could provide a complete summary of patient health status and condition. Information on this function could reduce health workers' time gathering patient history and reduce redundant transactions and tests [20]. Information on administrative records such as personal information serves as a patient identifier on a PHR.

Advanced functions (medication management, communication, appointment management, education, and self-health monitoring) could support patient involvement in their health care. Involving patients in controlling their health information improves the chance that health providers would have a comprehensive view of patient health conditions [20]. Medication management functions such as medication scheduler and reminders could help patients take medicine on time. Moreover, the medication reconciliation option could avoid medication errors [127]. Communication functions such as messaging could free physicians from the limitations of phone and face-to-face communication [1]. Appointment management reduces the chance of a patient missing an appointment. Education could support health knowledge promotion [20], which may improve the patient's health literacy. The information recorded from the self-health monitoring function may help health providers with disease diagnosis and treatment [10]. This function could help patients track their progress to reach specific health goals [9] and monitor the impact of their behavioral changes [12].

In addition to these functionalities, other supporting functionalities may also need to be developed based on the issues identified in this study. To improve security and privacy, PHRs should implement access control, which includes authentication and authorization. PHRs can also provide a backup option to avoid data loss and audit logs to review who accessed the record and what data have been accessed. To improve usability, PHRs can provide quick access to the important information or functions that users frequently use and add a menu for help or a user guide about using features in the PHR. Customization options to show or hide specific health data according to patient health needs are also recommended to increase personalization.

Interoperability represents a key component of PHR architecture [8]. When PHRs are integrated with health providers, they provide more significant benefits and valuable content for users [1,20]. Interoperability can also reduce data entry load because health information is automatically transferred to the PHR. This can increase the usability and the quality of data on the PHR. PHRs need to provide standard definitions for data exchange and implement sharing functions to connect PHRs with other stakeholders, such as health providers, insurance, government agency, pharmacy, community or support groups, and other systems such as home monitoring devices. Figure 10 describes the integrated PHR architecture based on the result of this review.

Figure 10. Integrated personal health record architecture.



The main functionalities described in this review, such as health records, administrative records, medication management, communication, appointment management, education, and self-health monitoring, have also been described in previous reviews [9-12]. Most of these reviews [9,11,12] focus more on discussing the functionality of PHRs related to improving health service delivery. Only Genitsaridi et al [10] discussed supporting functionalities such as access control to be included in requirements on the PHR. Previous studies also have discussed technological issues [13-15]. Our research augments that of previous studies by translating these issues as supporting functionalities in PHR systems.

The functionalities in PHRs can help health care providers and patients obtain useful health information during public health emergencies such as natural disasters and pandemics. For example, in the COVID-19 pandemic, hospital services experienced a crisis [128]. Observations of health outside of standard hospital settings can be difficult [129]. Functions such as communication can help patients and health care providers consult without making eye contact. Furthermore, in the education function, PHR providers can provide information about updated COVID-19 and health care information. The health record function helps patients obtain and store test results. The self-health monitoring function increases the patient's ability to control and manage health conditions. Functions such as measuring body temperature can be used to detect early signs of infection [129]. Integrating PHRs into a broader telehealth infrastructure could improve emergency health care delivery by reducing patient spikes in health care facilities [2].

Comparison With Prior Work

The Health Level 7 Personal Health Record System Functional Model (HL7 PHR-S FM) defines a standardized model of the functions present in PHR systems [130,131]. The model consists of 3 sections: personal health (PH), supportive (S), and information infrastructure (IN). Personal health functions enable an individual to manage information about their health care. Supportive roles assist with the administrative and financial requirements within health care delivery. Information infrastructure functions support personal health and supportive functions.

Health records, medication management, communication, education, and self-health monitoring can be categorized into personal health sections. Administrative records such as managing patient profiles can be categorized into a personal health section, while information about health professionals, hospitals, and insurance can be categorized as a supportive section. Supporting functions defined based on PHR implementation issues, namely sharing, access control, audit logs, backup options, and customization, can be categorized in the information infrastructure section. This section ensures the privacy and security of PHRs, promotes interoperability between PHRs and other systems, and enables PHR function to be accessible and easy to use [130,131]. Table 5 summarized comparisons between functions identified in this review study and functions defined in the HL7 PHR-S FM.

Table 5. Comparisons between functions.

Functions identified and ID	Functions defined in the HL7 PHR-S FM[a]	
	Function name	Description
Basic functions		
Health record		
PH.2.5	Manage historical and current state data	Provide a summary of the patient's current medical state and history
Administrative record		
PH.1.2	Manage PHR[b] account holder demographics	Capture the patient's demographic information
S.1.3	Manage health care provider information	Import or retrieval of data necessary to identify a health care provider
S.1.5	Manage health care facility information	Import or retrieve of data necessary to identify a health care facility
S.2.1	Capture and read health insurance account and benefit information	Request and/or receive and read the information on health insurance benefits
Advanced functions		
Medications management		
PH.3.4	Manage medications	Help patients manage his or her medications
Communication (patient-provider communication)		
PH.6.3	Communications between provider and/or the PHR account holder's representative	Capture information in preparation for a consultation and maintain continuous communications with the health provider
IN.3.10	Secure messaging	Enable secure electronic communication with health providers
Appointment management		
PH.6.3	Communications between provider and/or the PHR account holder's representative	Capture information in preparation for a consultation and maintain continuous communications with the health provider
Education		
PH.4	Manage health education	Provide proper medical education and patient-specific knowledge based on information in the PHR
Self-health monitoring		
PH.3.1	Manage personal clinical measurements and observations	Provide the patient capability to enter personally sourced data and make it available to authorized health providers or other users or applications
Supporting functions		
Sharing		
IN.2	Standards-based interoperability	Interoperability standards enable the sharing of information between PHRs and other systems
Access control		
IN.3.3	Entity access control	PHR must perform authentication and authorization of users or applications
Audit logs and backup option		
IN.4	Auditable records	Provide system access and use audit capabilities to indicate who accessed the record, how, and when the action was taken
Customization option		
IN.1.3	Present ad hoc views of the health record	Provide ad hoc views of the PHR information
User guide		
PH.1.1	Identify and maintain a PHR account holder record	Offer user guide for the installation, initialization, registration, or operation of their PHR

[a] HL7 PHR-S FM: Health Level 7 Personal Health Record System Functional Model.

[b] PHR: personal health record.

The functionality identified in this review covers the main section (PH, S, IN) in the HL7 PHR-S FM. However, functionalities and data elements found in this review are on the individual level that focuses on improving health care. Functions that are not included in this review are functions related to the secondary use of health data. Secondary health data use applies to personal health information for uses outside direct health care delivery [132]. In the HL7 PHR-S FM, a population health and wellness (PH 3.6) function helps control public health risks to the population and patients. For example, it enables patients to export anonymized data for biosurveillance and public health reporting, and patients can get alerts or warnings regarding population health threats. A manage other resources (S.4) function supports patient enrollment in clinical trials or research [131]. From this review, only a few studies [34,91] mentioned that PHRs could be used for secondary health data use, but they did not explain specific data needed for this function. A discussion about secondary health data use in PHRs can be an opportunity for future research.

Not all functions in the HL7 PHR-S FM were found in this review study because the HL7 PHR-S FM is universal and generic by design. There may be additional constraints in certain realms or regions. PHR developers or designers can create a functional profile to define a selected set of applicable functions for a particular purpose, group of users, degree of interoperability, or custodian [130]. This study defines PHR functionalities based on the current state of research and provides more examples of data elements and subfunctions for each functionality. This study also found that the HL7 PHR-S FM only includes patient-provider communication. Other communications, such as communication with others in a similar situation and support groups, are not discussed in the HL7 PHR-S FM.

Limitations

This study is limited to reviewing the implementation of PHRs in research articles and does not address the implementation of commercial PHRs available on the internet. Thus, the functionalities and issues of the PHRs defined in this study may not reflect the state of the practice. This paper does not discuss which functions are more common or whether certain functions are used more frequently than others and does not discuss each function's benefits and impact on health outcomes. We cannot determine which functionality should be prioritized in the implementation of PHR. We only discuss the functions that are generally mentioned in the selected paper. Each function's data element may not be comprehensive and might not be generalizable to all patient populations. This is because each disease or condition has different specific data.

Conclusions

This systematic literature review paper discussed functionalities and issues in the implementation of PHRs. Seven function categories are identified in this review, which are grouped into basic and advanced functions. In addition to these functionalities, other supporting functionalities may also need to be developed based on the issues identified in this study. Based on the results, this paper provides an integrated PHR architectural model that describes the functional requirements and data sources of PHRs. This study can offer recommendations or guidance in implementing PHRs by health care facilities management, application developers, policymakers, or other related stakeholders. Functionalities (including data elements and subfunctions) listed in this study and architectural model (Figure 10) can be used when considering what features to implement in a PHR. The model (Figure 10) can also serve as the target data sources to be integrated into the PHR system. Moreover, technological issues explained in this study can be used to develop policies in the implementation of PHRs. For example, since security and privacy are identified as technological issues in this study, implementers of PHRs should develop policies that govern access control in PHRs. The findings of this study may be translated as functional and nonfunctional requirements of the PHR system. This study's findings can also serve as a basis and comparison for other researchers who will examine PHR functionality and use in the future. PHR integrated architecture (Figure 10) can be used as a model that other researchers can use to compare, map, or evaluate the PHR functionalities that will be examined. Furthermore, personal factors such as age, culture, and health and technology literacy levels can influence security, privacy, and usability issues. Future studies can be conducted to analyze the effect of personal factors on technological issues.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

PRISMA checklist.
[DOC File , 66 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Characteristics of the included studies.

[DOCX File , 50 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Data elements and subfunctions.
[DOCX File , 358 KB-Multimedia Appendix 3]

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Abbreviations

EHR: electronic health record
FHIR: Fast Healthcare Interoperability Resources
HL7: Health Level 7
HL7 PHR-S FM: Health Level 7 Personal Health Record System Functional Model
IN: information infrastructure
PH: personal health
PHR: personal health record
PRISMA: Preferred Reporting Items for Systematic reviews and Meta-analyses
S: supportive

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Original Paper

Web-Based Health Information Seeking Among African American and Hispanic Men Living With Chronic Conditions: Cross-sectional Survey Study

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Abstract

Background: Previous research has identified disparities in seeking and using web-based health information to inform health-related behaviors. Relatively few studies however have examined the correlations between web-based health information seeking and use based on race, gender, age, and the presence of chronic health conditions.

Objective: In this study, we identify factors associated with seeking and using web-based health information among a uniquely vulnerable and intersectional population—middle-aged and older (40 years and older) African American and Hispanic men living with one or more chronic conditions.

Methods: Survey responses were collected from a purposive sample of African American and Hispanic men using Qualtrics web-based survey management software. To qualify for inclusion in the study, respondents had to identify as African American or Hispanic men, report having at least one chronic condition, and be aged 40 years and older. A series of binary logistic regression models was created using backward elimination. Statistical significance was determined at $P<.05$ for all analyses.

Results: Web-based health information seeking among African American and Hispanic men is a function of education, the presence of multiple chronic conditions, frustration with health care providers, internet use, and the perceived reliability of web-based health information. The use of web-based health information to inform interactions with health care providers was more common among African American and Hispanic men, who rated their health as relatively good, perceived barriers to care, used technology regularly, and took more daily medications.

Conclusions: Understanding the factors that influence African American and Hispanic men seeking web-based health information may help improve the care and treatment of chronic conditions. African American and Hispanic men seek web-based health information as a substitute for routine care and to inform their discussions with health care providers.

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KEYWORDS

minority men; online information seeking; chronic disease; communication with health care providers; mobile phone

Introduction

Background

Information seeking encompasses the act of accumulating information to gain clarity or affirm knowledge about a specific topic [1]. Well-informed patients maintain a sense of control over their illness and are better able to cope with uncertainties related to outcomes and treatments [2-5]. Correspondingly, knowledgeable patients engage with medical providers in planning their care, managing their treatments, and adapting more readily to therapeutic schedules [6,7]. Insufficient health information, in contrast, can have unfavorable health consequences [2,8].

Health-related information can be obtained from supportive social networks, health care providers, and the media, including the internet, television, radio, books, or magazines [9,10]. Web-based health resources provide an *optimal way to disseminate health information* because there is the “immediacy of information access, the accessibility at any time of the day or night, the potential continual updating of information and the wider range of information available” [11]. However, disparities exist in terms of who pursues or seeks web-based health information and how the information is used to inform subsequent interactions with health care providers [7,12,13]. Although men use the internet more often than women, they use it less frequently to seek health information [14]. Men are also less likely to seek routine medical care than women and therefore have fewer opportunities to discuss web-based health information with their health care providers [15]. Race and ethnicity are also associated with internet-based health information seeking [16,17]. Historically, health information seeking was less common among racial and ethnic minorities because of limited internet access and lower health literacy skills [12,13,18-20]. However, recent research has suggested that these differences may be dwindling, with African Americans relying more heavily on web-based health information for health care [21,22].

Other factors associated with web-based information include education [19], self-reported health status [23,24], time spent with medical providers and frustrations in communicating with these providers [25,26], internet use [23,27], and the perceived reliability of web-based health information [28]. Previous research does not provide enough clarity on how these factors might affect internet-based information-seeking behaviors of African American and Hispanic men with chronic conditions; however, there is reason to expect some differences. Some studies have examined web-based health information seeking by race [29,30] or by sex, specifically for men with chronic diseases [31], but did not focus specifically on African American and Hispanic men with chronic conditions. This population has been found to experience important barriers to disease self-management [32], have less access to health insurance and preventative care [33], have higher rates of preventable hospitalizations [34], and are more likely to die from their chronic conditions compared with non-Hispanic White men [35]. Seeking and using credible web-based health information may represent an important health-promoting activity.

In this paper, we seek to understand web-based health information seeking among African American and Hispanic men. Our motivation is both substantive and methodological. First, African American and Hispanic men are less likely to seek preventative care and treatment, which subsequently affects health outcomes. Understanding the factors that lead to seeking web-based health information may lead to better health outcomes. Second, African American and Hispanic men are hard-to-reach populations in survey research, meaning that they are often underrepresented in probability-based samples.

Objective

In this 2-phase study, we contribute to the existing literature by investigating web-based health information seeking and use among African American and Hispanic men aged 40 years and older with one or more chronic conditions. In phase 1, we identify factors associated with seeking web-based health information in the past year about (1) a specific disease or medical problem and (2) medical treatments and procedures. Then, in phase 2, we identify factors associated with discussing web-based health information with primary medical professionals only among those men who sought health information on the internet and had a routine physician visit within the past year.

Methods

Overview

Due to increased costs and declining response rates, scholars increasingly rely on web-based panels when studying hard-to-reach or intersectional populations [36]. African American and Hispanic men with chronic conditions and aged 40 years or older, for example, are relatively small segments of the overall population, making random selection via probability sampling costly and inefficient. Due to distrust of medical providers, African American and Hispanic men are often less responsive to requests to participate in health-related research [37].

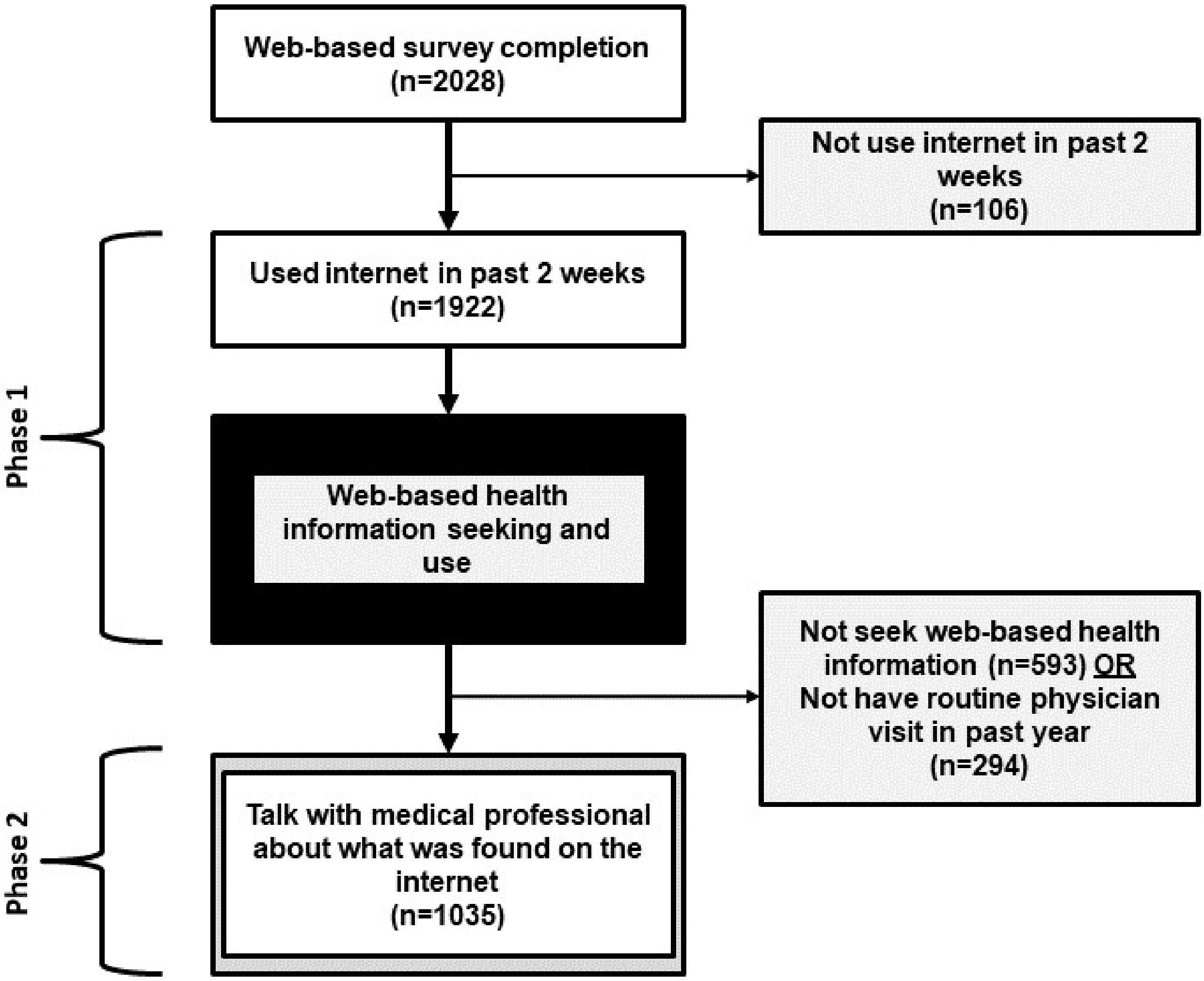
With this in mind, the sample in this study was designed using Qualtrics (Systems, Applications, and Products in Data Processing Societas Europaea) web-based panels to identify African American and Hispanic men aged 40 years and older with at least one chronic health condition. We used the Checklist for Reporting Results of Internet E-Surveys for web-based surveys in our description of data collection [38]. Qualtrics web-based panels are opt-in research panels ideal for studies targeting hard-to-reach populations. Qualtrics panels provide access to previously identified research participants with known characteristics, and panel participants are recruited and compensated for their participation by Qualtrics. Potential participants were directed to the programmed survey where they were provided with a description of the study and information relating to informed consent. The tradeoff for cost effectiveness using Qualtrics is that the sample might not be representative of the target population.

The survey questionnaire was constructed by the authors who identified validated questions from previous research related to web-based health information seeking and other health-related behaviors. An initial draft of the survey was carefully reviewed by experts in the field who were not a part of the research team and made suggestions for inclusion (or exclusion) of specific items. The final data were carefully reviewed by the research team, eliminating questionable responses (eg, respondents who completed the survey too quickly). In addition, filter questions for age, race, and the presence of one or more chronic conditions were used to further qualify potential respondents and ensure that only qualified respondents completed the survey questionnaire. The survey instrument included a wide range of health-related attitudes and behaviors. Overall, data were collected from 2028 men who met the inclusion criteria. This study was approved by the Institutional Review Board (#2018-1684) of Texas A&M University.

Inspired by Pettus et al [39], who examined internet use and web-based health information seeking among older women in a 2-phase study, we modeled this study to focus on web-based health information seeking among middle-aged and older men. To be included in phase 1 of our analytic sample, men also had to report using the internet within the past 2 weeks. Men who did not meet this criterion were excluded from phase 1 analyses. The 2 dependent variables in phase 1 assessed web-based health information seeking and use, which was measured using 2 items. First, participants were asked if they had looked for information on the internet about “a specific disease or medical problem.” Response choices for this item were “yes” and “no.” Second, participants were asked if they had looked for information on the internet about “a certain medical treatment or procedure.” Response choices for this item were “yes” and “no.”

Building upon findings in phase 1, to be included in phase 2 of our analytic sample, men must have reported “yes” to looking for information on the internet about “a specific disease or medical problem” or “a certain medical treatment or procedure.” In addition, to avoid confounding the results with issues of health care access, these minority men must have reported having a routine physician visit in the past year to be included in phase 2. Men who did not meet this criterion were excluded from phase 2 analyses. The dependent variable in phase 2 assessed whether men shared findings from their web-based health information seeking with medical professionals. More specifically, participants were asked if they spoke with a medical professional about what they found on the web. Response choices for this item were “yes” and “no.” Figure 1 illustrates the participant flow across both study phases based on the inclusion criteria.

Figure 1. Study flow by analysis phases.



We modeled web-based health information seeking as a function of demographics (age, race, education, marital status, and number of household members), health-related behaviors and status (number of chronic conditions, number of daily medications, having a routine physician visit in the past year, and self-reported health status), available resources for managing care (receiving help to manage care, ability to self-manage diseases, perceived barriers to care, health care frustrations, and participation in programs to prevent or manage chronic illness), and technology use and credibility (use of technology and reliability of web-based health information). We provide brief descriptions of each of these below.

Demographics

Age was measured in years, with all respondents reporting that they were aged 40 years or older. Race is a dichotomous variable indicating whether the respondent is African American (coded as 0 and serving as the baseline category) or Hispanic (coded as 1). Marital status was measured as a set of dummy variables indicating whether the respondent was single or never married, married or partnered, divorced or separated, or widowed. The number of household members was the total number of people (including the respondent) currently living in the household. The demographic variables in our models were primarily included as controls.

Health-Related Behaviors

This set of variables included health conditions, regular doctor visits, and self-reported health status. Overall, it is expected that individuals with worse health, meaning more chronic conditions and poor self-reported health status, would be more likely to look for health information on the internet. The number of chronic conditions was calculated using a “check all that apply” list of the following 19 chronic health conditions: (1) asthma, emphysema, chronic breathing problem, or lung problem; (2) arthritis or rheumatic disease; (3) cancer or cancer survivor; (4) chronic pain; (5) depression or anxiety; (6) diabetes; (7) heart disease; (8) high cholesterol; (9) hypertension; (10) kidney disease; (11) memory problem; (12) obesity; (13) osteoporosis; (14) obstructive sleep apnea; (15) schizophrenia or other psychotic disorder; (16) stroke; (17) thyroid problem; (18) urinary incontinence; and (19) another chronic condition not listed. In addition, participants were asked to report the number of different medications taken daily (range 0 to >6), whether they had visited a doctor in the past year (coded 1 if the respondent said yes; 0 otherwise), and a 5-point Likert scale measure of their self-reported health status ranging from poor (coded as 1) to excellent (coded as 0).

Resources for Managing Care

In addition to health-related behaviors and concerns, individuals with more resources available for managing care should be more likely to seek health information on the internet. This begins with perceptions of whether or not they are receiving the support they need to improve their health and manage their care, measured using a 5-point scale ranging from never (1) to always (5) [23,24]. Due to the skewed nature of the responses, these were collapsed into the never, rarely, or occasionally versus frequently or always range.

The disease self-management efficacy scale was included to gauge individual respondents’ sense of control over the management of their health care [25,26], Respondents were asked about their level of agreement (using a 4-point Likert scale) with the following statements: (1) when all is said and done, I am the person who is responsible for taking care of my health; (2) taking an active role in my own health care is the most important thing that affects my health; (3) I know what each of my prescribed medications do; (4) I am confident that I can tell whether I need to go see the doctor or whether I can take care of a health problem myself; (5) I am confident I can tell a doctor concerns I have even if he or she does not ask; (6) I am confident I can follow through on medical treatments I may need to do at home; (7) I have been able to maintain (keep up with) lifestyle changes such as eating right or exercising; (8) I know how to prevent problems with my health; (9) I am confident I can figure out solutions when new problems arise with my health; and (10) I am confident that I can maintain lifestyle changes like eating right and exercising, even during times of stress. Scores for this scale ranged from 4 to 40, with higher scores indicating higher efficacy.

The use of web-based health information may also reflect barriers to care, reflecting the need for help and support in managing care and treatment. The barriers to self-care scale were measured based on levels of agreement with the following statements: (1) I need help learning what I should be doing to take better care of my health; (2) I need help learning how to take better care of my health in a way that works for me and my life; (3) I do not have the money it takes to do things that will improve my health or condition; (4) I wish I could change and do things that are healthier, but I just do not think I can; and (5) all of my different health problems and conditions make it difficult for me to take better care of myself. Scale values ranged from 5 to 20, with higher scores indicating more barriers.

Patients also seek web-based health information when their experiences with medical providers are frustrating. The health care frustration scale assesses whether participants felt any of the following frustrations [23,24]: (1) felt tired of describing their same conditions and problems every time they went to a hospital or doctor’s office, (2) left the hospital or doctor’s office and felt confused about what they should do, (3) wished their doctor had more time to spend talking with them, (4) felt tired of feeling on their own when it came to taking care of their health problems, (5) felt that their doctor did not realize what it was really like for them at home trying to take care of their health problems, and (6) wished they had a friend or family member who could go to the doctor with them. Responses were coded as “never” (1), “occasionally” (2), or “frequently” (3). Scores for this scale ranged from 6 to 18, with higher scores indicating higher health care frustrations [34].

Finally, respondents might gain knowledge about their chronic condition and insight into their medical condition by participating in a program specifically designed to prevent or treat chronic illnesses [40-43]. For example, the Chronic Disease Self-Management Program (CDSMP) is a universal program that applies to any chronic condition, although disease-specific translations also exist to build skills to manage arthritis, diabetes, chronic pain, and HIV and AIDS [44]. Previous research has indicated that CDSMP improved outcomes while reducing costs [45].

Technology Use and Credibility

Aside from health concerns and conditions, web-based health information seeking is also a function of the level of comfort in using technology and perceptions regarding the credibility of information found alone. Technology use was measured by whether the respondent had used the following technologies in the past 2 weeks: computer (laptop, desktop, or tablet), smartphone, email (from a computer, smart phone, or tablet), internet (from a computer, smart phone, or tablet), Skype or other video systems (from a computer, smart phone, or tablet), or Facebook or other social media (eg, Twitter). Responses were coded from 0-6 depending on how many of these technologies individual participants reported having used in the past 2 weeks. Perceptions regarding the credibility of web-based information are measured with the question of how reliable they believe information on the internet is about health or medical conditions. Responses were coded from 0 (not at all) to 3 (extremely).

Data Analysis

All analyses were performed using SPSS version 25 (IBM Corporation). We calculated descriptive statistics for all variables of interest, which were compared across the 2 dependent variables in phase 1. Chi-square tests were used for categorical variables and two-tailed independent sample *t* tests were used for continuous and count variables, after assessing frequency distributions and tests for variance equality. As each dependent variable was dichotomous, we used logistic regression to estimate the models. Model selection was based on stepwise regression using backward elimination of nonsignificant predictor variables. Predictor variables were eliminated when they did not improve the overall model fit, as reflected by the likelihood ratio test. The final regression models included the fewest predictors from the model that provided the best fit to the data. Omnibus tests of model coefficients confirmed no significant loss of variance during backward entry steps for any of the 3 models fitted in this study. However, both full and final reduced regression models are presented in the tables described in the *Results* section. For all analyses, statistical significance was set at $P<.05$.

Results

Phase 1 Study Results

Table 1 provides the sample characteristics for the two phase 1 dependent variables. Among the 1922 men who had used the internet in the past week, 57.34% (1102) reported seeking information about a specific disease or medical problem and 50.83% (977) reported seeking information about a medical treatment or procedure. About 58.32% (1121/1922) of the participants were African American and 41.68% (801/1922) were Hispanic. The average age of the sample was 56.63 (SD 10.01) years. The majority of participants attended at least some college (1536/1922, 79.92%), over half were married or partnered (997/1922, 51.87%), and most reported having a routine physician visit in the past year (1627/1922, 84.65%). On average, participants reported living with 2.58 (SD 1.61) other people, having 3.93 (SD 2.9) chronic conditions, and taking 3.39 (SD 2.02) medications daily. About 57.7% (1109/1922) reported that they frequently or always received the help and support needed to improve their health and manage their health problems, and 17.43% (335/1922) reported attending a program to prevent or manage their chronic illness in the past year.

Table 1. Sample characteristics by web-based information-seeking behavior (N=1922).

Characteristics	Total (N=1922)	Looked for specific disease or medical problem					Looked for medical treatments and procedures				
		No (n=820)	Yes (n=1102)	Chi-square (*df*)	*t* test (*df*)	*P* value	No (n=945)	Yes (n=977)	Chi-square (*df*)	*t* test (*df*)	*P* value
Age (years), mean (SD)	56.63 (10.01)	57.77 (10.19)	55.78 (9.79)	N/A[a]	4.33 (1920)	<.001	57.22 (10.13)	56.05 (9.86)	N/A	2.56 (1920)	.01
Race or ethnicity, n (%)				3.1 (1)	N/A	.08			0.3 (1)	N/A	.59
African American	1121 (58.32)	497 (60.61)	624 (56.62)				557 (58.9)	564 (57.7)			
Hispanic	801 (41.68)	323 (39.39)	478 (43.38)				388 (41.05)	413 (42.27)			
Education, n (%)				20.2 (2)	N/A	<.001			19.3 (2)	N/A	<.001
High school or less	386 (20.08)	197 (24.02)	189 (17.15)				224 (23.7)	162 (16.58)			
Some college or 2-year degree	825 (42.92)	359 (43.78)	466 (42.29)				407 (43.06)	418 (42.78)			
4-year degree or more	711 (36.99)	264 (32.19)	447 (40.56)				314 (33.22)	397 (40.63)			
Marital status, n (%)				0.9 (3)	N/A	.82			1.5 (3)	N/A	.68
Married or partnered	997 (51.87)	427 (52.07)	570 (51.72)				481 (50.89)	516 (52.81)			
Never married	485 (25.23)	200 (24.39)	285 (25.86)				250 (26.45)	235 (24.05)			
Divorced or separated	365 (18.99)	162 (19.75)	203 (18.42)				178 (18.83)	187 (19.14)			
Widowed	75 (3.9)	31 (3.78)	44 (3.99)				36 (3.81)	39 (3.99)			
Persons living in household (including self), mean (SD)	2.58 (1.61)	2.47 (1.59)	2.67 (1.62)	N/A	−2.68 (1920)	.007	2.48 (1.57)	2.68 (1.63)	N/A	−2.76 (1920)	.006
Number of chronic conditions, mean (SD)	3.93 (2.9)	3.64 (2.76)	4.14 (2.98)	N/A	−3.8 (1920)	<.001	3.6 (2.73)	4.24 (3.02)	N/A	−4.85 (1920)	<.001
Number of medications taken daily, mean (SD)	3.39 (2.02)	3.36 (2.03)	3.42 (2.01)	N/A	−0.72 (1920)	.47	3.32 (2.05)	3.46 (1.98)	N/A	−1.51 (1920)	.13
Routine physician visit in past year, n (%)				0.2 (1)	N/A	.62			5.2 (1)	N/A	.02
No	295 (15.35)	122 (14.87)	173 (15.69)				163 (17.24)	132 (13.51)			
Yes	1627 (84.65)	689 (84.02)	929 (84.3)				782 (82.75)	845 (86.48)			
General health status, mean (SD)	2.85 (0.88)	2.91 (0.87)	2.81 (0.88)	N/A	2.55 (1920)	.01	2.89 (0.87)	2.82 (0.89)	N/A	1.78 (1920)	.08
Get the help or support needed to improve health and manage health problems, n (%)				8.3 (1)	N/A	.004			0.5 (1)	N/A	.48
Never or rarely or occasionally	813 (42.29)	316 (38.53)	497 (45.09)				392 (41.48)	421 (43.09)			
Frequently or always	1109 (57.7)	504 (61.46)	605 (54.9)				553 (58.51)	556 (56.91)			
Disease self-management efficacy (Cronbach α=.844), mean (SD)	28.54 (2.58)	28.58 (2.77)	28.5 (2.42)	N/A	0.69 (1920)	.49	28.61 (2.64)	28.47 (2.51)	N/A	1.22 (1920)	.22

Characteristics	Total (N=1922)	Looked for specific disease or medical problem					Looked for medical treatments and procedures				
		No (n=820)	Yes (n=1102)	Chi-square (*df*)	*t* test (*df*)	*P* value	No (n=945)	Yes (n=977)	Chi-square (*df*)	*t* test (*df*)	*P* value
Barriers to self-care (Cronbach α=.844), mean (SD)	11.48 (3.64)	10.96 (3.69)	11.87 (3.55)	N/A	−5.47 (1920)	<.001	11.04 (3.62)	11.91 (3.61)	N/A	−5.26 (1920)	<.001
Health care frustrations (Cronbach α=.856), mean (SD)	9.45 (3.13)	8.85 (2.93)	9.89 (3.2)	N/A	−7.4 (1920)	<.001	8.86 (2.9)	10.01 (3.24)	N/A	−8.2 (1920)	<.001
Sources of technology use in past 2 weeks, mean (SD)	4.98 (0.8)	4.87 (0.81)	5.07 (0.78)	N/A	−5.64 (1920)	<.001	4.85 (0.8)	5.12 (0.77)	N/A	−7.46 (1920)	<.001
Perceived reliability of information received on internet about health or medical conditions, mean (SD)	1.40 (0.69)	1.26 (0.69)	1.51 (0.68)	N/A	−7.75 (1920)	<.001	1.27 (0.68)	1.53 (0.68)	N/A	−8.4 (1920)	<.001
Ever attend program to prevent or manage chronic illness in past year, n (%)				22.4 (1)	N/A	<.001			38.7 (1)	N/A	<.001
No	1587 (82.57)	716 (87.31)	871 (79.04)				832 (88.04)	755 (77.27)			
Yes	335 (17.43)	104 (12.68)	231 (20.26)				113 (11.95)	222 (22.72)			

[a] N/A: not applicable.

When comparing sample characteristics by the 2 web-based health information–seeking behaviors (ie, both looked on the internet for information about specific diseases or medical problems and medical treatments and procedures), on average, participants who sought health information on the internet were significantly younger, lived with more people in their household, had more chronic conditions, reported more barriers to self-care, and reported higher health care frustrations. A significantly larger proportion of men who sought web-based health information were more educated and attended a program to prevent or manage their chronic illness in the past year. On average, participants who sought health information on the internet reported using more sources of technology and perceived health and medical information received on the internet to be more reliable.

Table 2 presents the results for seeking web-based information for a specific disease or medical condition among those reporting the use of the internet in the past 2 weeks. Compared with men who did not seek web-based health information for a specific disease or medical condition, men who had some college or a 2-year degree (odds ratio [OR] 1.35, 95% CI 1.04-1.74; *P*=.02), had a 4-year degree or higher (OR 1.91, 95% CI 1.45-2.50; *P*<.001), and attended a program to prevent or manage their chronic illness (OR 1.40, 95% CI 1.07-1.83; *P*=.01) were more likely to seek web-based information for a specific disease or medical condition. For each unit increase in self-reported chronic conditions (OR 1.04, 95% CI 1-1.08; *P*=.03), health care frustrations (OR 1.09, 95% CI 1.05-1.12; *P*<.001), sources of technology used (OR 1.27, 95% CI 1.12-1.44; *P*<.001), and perceived reliability of health and medical information received on the internet (OR 1.70, 95% CI 1.46-1.97; *P*<.001), the odds of seeking information on the internet for a specific disease or medical condition increased. For each unit increase in self-reported health status, the odds of seeking information on the internet for a specific disease or medical condition decreased (OR 0.86, 95% CI 0.76-0.97; *P*=.01).

Table 2. Factors associated with looking on the internet for information about a specific disease or medical problem (N=1922)[a].

Variable	Full model			Reduced model		
	β (SE)	*P* value	OR[b] (95% CI)	β (SE)	*P* value	OR (95% CI)
Age	−.01 (0.01)	.21	0.99 (0.98-1)	−.01 (0.01)	.09	0.99 (0.98-1)
Race or ethnicity						
African American	—[c]	—	1	—	—	1
Hispanic	.16 (0.10)	.12	1.17 (0.96-1.43)	.17 (0.10)	.09	1.19 (0.98-1.45)
Education						
High school or less	—	—	1	—	—	1
Some college or 2-year degree	.29 (0.13)	.03	1.33 (1.03-1.72)	.3 (0.13)	.02	1.35 (1.04-1.74)
4-year degree or more	.64 (0.14)	<.001	1.89 (1.43-2.49)	.65 (0.14)	<.001	1.91 (1.45-2.50)
Marital status						
Married or partnered	—	—	1	N/A[d]	N/A	N/A
Never married	−.02 (0.13)	.92	0.99 (0.76-1.28)	N/A	N/A	N/A
Divorced or separated	−.02 (0.14)	.89	0.98 (0.75-1.28)	N/A	N/A	N/A
Widowed	.20 (0.26)	.44	1.22 (0.74-2.03)	N/A	N/A	N/A
Persons living in household (including self)	.04 (0.03)	.25	1.04 (0.97-1.11)	N/A	N/A	N/A
Number of chronic conditions	.04 (0.02)	.049	1.04 (1-1.08)	.04 (0.02)	.03	1.04 (1-1.08)
Number of medications taken daily	.01 (0.03)	.63	1.01 (0.96-1.07)	N/A	N/A	N/A
Routine physician visit in past year						
No	—	—	1	N/A	N/A	N/A
Yes	.06 (0.15)	.69	1.06 (0.8-1.42)	N/A	N/A	N/A
General health status	−.13 (0.07)	.046	0.88 (0.77-1)	−.15 (0.06)	.01	0.86 (0.76-0.97)
Get the help or support needed						
Never or rarely or occasionally	—	—	1	N/A	N/A	N/A
Frequently or always	−.14 (0.11)	.22	0.87 (0.7-1.09)	N/A	N/A	N/A
Disease self-management efficacy	.01 (0.02)	.64	1.01 (0.97-1.05)	N/A	N/A	N/A
Barriers to self-care	.01 (0.02)	.38	1.01 (0.98-1.05)	N/A	N/A	N/A
Health care frustrations	.07 (0.02)	<.001	1.07 (1.03-1.12)	.08 (0.02)	<.001	1.09 (1.05-1.12)
Sources of technology use in past 2 weeks	.24 (0.06)	<.001	1.27 (1.12-1.44)	.24 (0.06)	<.001	1.27 (1.12-1.44)
Perceived reliability of information received on internet about health or medical conditions	.54 (0.08)	<.001	1.72 (1.48-1.99)	.53 (0.08)	<.001	1.7 (1.46-1.97)
Ever attend program to prevent or manage chronic illness in past year						
No	—	—	1	—	—	1
Yes	.31 (0.14)	.02	1.37 (1.04-1.79)	.34 (0.14)	.01	1.4 (1.07-1.83)

[a] Nagelkerke R^2=0.122 for full model; Nagelkerke R^2=0.119 (8 iterations) for reduced model.

[b] OR: odds ratio.

[c] Not available; referent category for independent variables.

[d] N/A: not applicable; referent category for dependent variable (not looking on the internet for information about a specific disease or medical problem).

Table 3 presents the results for seeking web-based information for medical treatments and procedures among those reporting having used the internet in the past 2 weeks. Compared with men who did not seek web-based information about medical treatments and procedures, men who had a college education or a 2-year degree (OR 1.32, 95% CI 1.02-1.72; *P*=.03), had a 4-year degree or higher (OR 1.72, 95% CI 1.31-2.25; *P*<.001), attended a routine physician visit in the past year (OR 1.48, 95% CI 1.13-1.94; *P*=.004), and attended a program to prevent or manage their chronic illness (OR 1.59, 95% CI 1.22-2.08; *P*=.001) were more likely to seek web-based information about medical treatments and procedures. For each unit increase in self-reported chronic conditions (OR 1.06, 95% CI 1.02-1.1; *P*=.001), health care frustrations (OR 1.12, 95% CI 1.09-1.16; *P*=.001), sources of technology used (OR 1.44, 95% CI 1.27-1.63; *P*<.001), and the perceived reliability of health and medical information received on the internet (OR 1.69, 95% CI 1.46-1.95; *P*<.001), the odds of seeking web-based information about medical treatments and procedures increased.

Table 3. Factors associated with seeking on the internet information about medical treatments and procedures (N=1922)[a,b].

Variable	Full model			Reduced model		
	β (SE)	*P* value	OR[c] (95% CI)	β (SE)	*P* value	OR (95% CI)
Age	0 (0.01)	.77	1 (0.99-1.01)	N/A[d]	N/A	N/A
Race or ethnicity						
African American	—[e]	—	1	N/A	N/A	N/A
Hispanic	.05 (0.1)	.61	1.05 (0.86-1.29)	N/A	N/A	N/A
Education						
High school or less	—	—	1	—	—	1
Some college or 2-year degree	.28 (0.13)	.04	1.33 (1.02-1.72)	.28 (0.13)	.03	1.32 (1.02-1.72)
4-year degree or more	.54 (0.14)	<.001	1.72 (1.3-2.26)	.54 (0.14)	<.001	1.72 (1.31-2.25)
Marital status						
Married or partnered	—	—	1	N/A	N/A	N/A
Never married	−.21 (0.13)	.13	0.82 (0.63-1.06)	N/A	N/A	N/A
Divorced or separated	.05 (0.14)	.70	1.05 (0.81-1.38)	N/A	N/A	N/A
Widowed	.04 (0.26)	.89	1.04 (0.63-1.72)	N/A	N/A	N/A
Persons living in household (including self)	.04 (0.03)	.24	1.04 (0.97-1.11)	N/A	N/A	N/A
Number of chronic conditions	.05 (0.02)	.006	1.05 (1.02-1.1)	.06 (0.02)	.001	1.06 (1.02-1.1)
Number of medications taken daily	0 (0.03)	.99	1 (0.95-1.06)	N/A	N/A	N/A
Routine physician visit in past year						
No	—	—	1	—	—	1
Yes	.40 (0.15)	.007	1.49 (1.11-1.99)	.39 (0.14)	.004	1.48 (1.13-1.94)
General health status	−.07 (0.07)	.32	0.94 (0.83-1.07)	N/A	N/A	N/A
Get the help or support needed						
Never or rarely or occasionally	—	—	1	N/A	N/A	N/A
Get the help or support needed: frequently or always	.04 (0.11)	.70	1.04 (0.84-1.3)	N/A	N/A	N/A
Disease self-management efficacy	−.01 (0.02)	.52	0.99 (0.95-1.03)	N/A	N/A	N/A
Barriers to self-care	.02 (0.02)	.32	1.02 (0.98-1.05)	N/A	N/A	N/A
Health care frustrations	.1 (0.02)	<.001	1.11 (1.07-1.15)	.12 (0.02)	<.001	1.12 (1.09-1.16)
Sources of technology use in past 2 weeks	.37 (0.06)	<.001	1.45 (1.28-1.65)	.36 (0.06)	<.001	1.44 (1.27-1.63)
Perceived reliability of information received on internet about health or medical conditions	.56 (0.08)	<.001	1.75 (1.51-2.03)	.53 (0.07)	<.001	1.69 (1.46-1.95)
Ever attend program to prevent or manage chronic illness in past year						
No	—	—	1	—	—	1
Yes	.44 (0.14)	.001	1.56 (1.19-2.04)	.47 (0.14)	.001	1.59 (1.22-2.08)

[a] Nagelkerke R^2=0.155 for full model; Nagelkerke R^2=0.148 (10 iterations) for reduced model.

[b] The same dependent variable and referent category is used for the full and reduced models.

[c] OR: odds ratio.

[d] N/A: not applicable.

[e] Not available; referent category for independent variables.

Phase 2 Study Results

Table 4 presents phase 2 results for the 1035 participants who discussed what they found on the internet with their medical providers among those who had a routine physician visit in the past year. Relative to the 71.4% (739/1035) of men who reported both web-based health information seeking behaviors (ie, disease-specific information and medical treatments or procedures), men who only looked for information about specific diseases on the internet were significantly less likely to discuss what they found with their medical provider (OR 0.52, 95% CI 0.37-0.74; *P*<.001). Relative to men who did not discuss their web-based findings with medical providers, men who were Hispanic (OR 1.41, 95% CI 1.09-1.83; *P*<.001) and attended a program to prevent or manage their chronic illness (OR 2.19, 95% CI 1.61-2.98; *P*<.001) were more likely to discuss the web-based findings with their medical provider. For each unit increase in the number of medications taken daily (OR 1.13, 95% CI 1.05-1.21; *P*=.001), barriers to self-care (OR 1.04, 95% CI 1-1.08; *P*=.04), and sources of technology used (OR 1.24, 95% CI 1.05-1.46; *P*=.01), the odds of discussing web-based information with medical providers increased.

Table 4. Factors associated with discussing online information with medical providers (n=1035)[a,b].

Variable	Full model			Reduced model		
	β (SE)	*P* value	OR[c] (95% CI)	β (SE)	*P* value	OR (95% CI)
Looked on the internet for health information						
Both	—[d]	—	1	—	—	1
Only about medical treatments and procedures	−.35 (0.22)	.11	0.7 (0.45-1.09)	−.37 (0.22)	.09	0.69 (0.45-1.06)
Only about specific diseases of medical problems	−.6 (0.18)	.001	0.55 (0.39-0.79)	−.65 (0.18)	<.001	0.52 (0.37-0.74)
Age	0 (0.01)	.77	1 (0.99-1.02)	N/A[e]	N/A	N/A
Race or ethnicity						
African American	—	—	1	—	—	1
Hispanic	.36 (0.14)	.01	1.43 (1.09-1.87)	.35 (0.13)	.01	1.41 (1.09-1.83)
Education						
High school or less	—	—	1	N/A	N/A	N/A
Some college or 2-year degree	.23 (0.19)	.24	1.25 (0.86-1.83)	N/A	N/A	N/A
4-year degree or more	.17 (0.2)	.39	1.19 (0.8-1.76)	N/A	N/A	N/A
Marital status						
Married or partnered	—	—	1	N/A	N/A	N/A
Never married	−.11 (0.18)	.56	0.9 (0.63-1.28)	N/A	N/A	N/A
Divorced or separated	−.13 (0.19)	.51	0.88 (0.61-1.28)	N/A	N/A	N/A
Widowed	−.06 (0.34)	.86	0.94 (0.49-1.82)	N/A	N/A	N/A
Persons living in household (including self)	0 (0.05)	.99	1 (0.91-1.1)	N/A	N/A	N/A
Number of chronic conditions	.01 (0.02)	.73	1.01 (0.96-1.06)	N/A	N/A	N/A
Number of medications taken daily	.11 90.04)	.003	1.12 (1.04-1.21)	.12 (0.04)	.001	1.13 (1.05-1.21)
General health status	.1 (0.09)	.26	1.1 (0.93-1.31)	.15 (0.08)	.07	1.16 (0.99-1.35)
Get the help or support needed						
Never or rarely or occasionally	—	—	1	N/A	N/A	N/A
Frequently or always	.21 (0.15)	.16	1.23 (0.92-1.65)	N/A	N/A	N/A
Disease self-management efficacy	.02 (0.03)	.43	1.02 (0.97-1.08)	N/A	N/A	N/A
Barriers to self-care	.04 (0.02)	.1	1.04 (0.99-1.09)	.04 (0.02)	.04	1.04 (1-1.08)
Health care frustrations	.04 (0.03)	.11	1.04 (0.99-1.09)	N/A	N/A	N/A
Sources of technology use in past 2 weeks	.2 (0.09)	.02	1.22 (1.03-1.45)	.22 (0.09)	.01	1.24 (1.05-1.46)
Perceived reliability of information received on internet about health or medical conditions	.15 (0.1)	.15	1.16 (0.95-1.41)	N/A	N/A	N/A
Ever attend program to prevent or manage chronic illness in past year						
No	—	—	1	—	—	1
Yes	.7 (0.16)	<.001	2.01 (1.46-2.77)	.78 (0.16)	<.001	2.19 (1.61-2.98)

[a] Nagelkerke R^2=0.112 for full model; Nagelkerke R^2=0.101 (10 iterations) for reduced model.

[b] The same dependent variable and referent category is used for the full and reduced models.

[c] OR: odds ratio.

[d] Not available; referent category for independent variables.

[e] N/A: not applicable.

Discussion

Principal Findings

This study examined health information seeking among a uniquely vulnerable and intersectional population, African American and Hispanic men aged 40 years and older with one or more chronic conditions. The specific results are worth discussing. First, internet-based health information is an important tool for African American and Hispanic men to use to learn about a specific disease or medical problem as well as medical treatments and procedures and to foster patient-provider conversations about these health-related internet searches, as illustrated by about half of the sample looking for information on the internet. Similar to previous studies, our study suggests that men who are younger [46-48], more highly educated [47,48], use technology more often [49], and believe the internet to be a reliable source [50] report seeking web-based health information in the past year to learn about a specific disease or medical treatment.

Those with more chronic conditions and greater health care frustrations were more likely to use the internet for both purposes (ie, to learn about a specific disease and medical treatments). Previous studies have demonstrated that people living with chronic conditions rely on the internet for help and support and might seek to learn about other people's experiences about a disease through web-based discussions [39]. People living with chronic conditions who experienced health care–related frustrations from unfulfilled needs in a medical encounter have been known to report greater functional limitations and greater self-care barriers to manage their condition or disease [51]. Internet-based health information could be used to help meet those needs.

Men who attended a disease prevention or management program in the past year were more likely to look on the internet to learn about a specific disease or medical problem and to learn about medical treatments and procedures. Considering that these evidence-based programs help increase participants' health behaviors and self-efficacy [52], program participants may feel encouraged to seek additional information to better understand the content of their program and their disease. Both web-based and traditional CDSMPs may also provide links, videos, and other resources to supplement the course materials, thereby encouraging program participants to seek this information on the internet as part of their disease self-management.

Interestingly, compared with men who used the internet only to learn about a specific disease or condition, men who reported both web-based health information–seeking behaviors were more likely to speak to their medical professional about what they found on the internet. It is possible that those who search on the web only to learn about a specific disease no longer feel the need to consult a physician, consequently substituting routine care [53]. Men who seek information on both diseases and treatments may have greater concerns about the credibility of web-based information or about their ability to evaluate this information [53]. Those who searched for treatments and procedures in addition to the general condition may also be exposed to web-based medical advertisements that encourage them to speak to their doctor about these treatment options [53-56]. Through their internet searches, patients reported increased confidence, control, and comfort in discussing their condition and treatments with their medical provider [57]; enhanced understanding of the medical jargon [58]; and satisfaction of feeling better informed [54]. Hispanic men more frequently discussed what they found on the internet with medical professionals. Studies suggest that web-based health information seeking gives Hispanic patients the confidence to discuss their health concerns with their doctors [30]. In the recent study by Camacho-Rivera et al [59] with a large representative sample of Hispanic adults in the United States, the authors found that Hispanics trusted cancer information from their doctors a lot (1014/1512, 67.06%) compared with information from the internet (309/1512, 20.44%). Although there was an important increase in trusting cancer information on the internet from 2014 to 2018, doctors remained the most trusted source of health information for Hispanics [59]. This study supports our findings that Hispanic men were more likely to talk with medical professionals about their web-based health searches.

Men with chronic conditions who had better general health statuses reported communicating with their medical professionals about what they found on the internet. This result contradicts previous studies [55], which suggest that those in poor health are more likely to talk to their medical providers about their web-based health information seeking than those in good health. However, higher medication intake is associated with poorer health (eg, frailty, disability, and fall risk) [60,61]. Poor health status can also lead to greater self-care barriers [62]. Those who take more medications daily also report more barriers to managing their chronic conditions [50]. Medication and self-care barriers were highlighted in our study as factors associated with discussing web-based health information with a medical professional.

It is possible that those with better health status, those who take more medications daily, and those with more self-care barriers may seek medical care more than once a year. It is known that increased physician visits to stay healthy and to get help to manage chronic conditions [63] may provide greater opportunities to discuss web-based health information–seeking behaviors. Increased visits may lead to better patient-physician interactions where bringing internet-based health information would not be seen as a threat but rather as something to be encouraged [64-66].

Limitations

This study has several limitations. The cross-sectional nature of this study did not allow for the assessment of causal relationships over time. On the basis of the funding mechanism supporting this study, data were only collected from African American and Hispanic men aged 40 years and older with one or more chronic conditions. Although these subgroups often report health-related disparities, additional insights might have been gained, including men of other races and ethnicities (eg, non-Hispanic White, Asian or Pacific Islander, and American Indian or Alaska Native). We hope that future research will expand the scope of this study and provide additional comparisons. This study excludes African American and Hispanic males with one or more chronic conditions who do not have access to the internet. This digital divide continues to disproportionately impact the health of minorities and contribute to social inequalities in the United States [67]. In addition, no information was gathered about health literacy, the types of web-based information sources they used, or the credibility of these information sources (eg, government websites). Future research on internet-based health information–seeking behaviors of African American and Hispanic men with chronic conditions should consider assessing the health literacy level of respondents as well as their knowledge of credible health information sources [68]. In addition, in this study, African American and Hispanic subgroups were included in the analyses. Given the potential differences across racial or ethnic subgroups in terms of sociodemographics, behaviors, perceptions, and health care use, future studies may consider performing analyses on these subgroups separately or making direct comparisons between them.

Conclusions

Overall, this study provides an overview of health information–seeking behaviors among African American and Hispanic men with chronic conditions. Understanding these factors is crucial to influencing internet-based health communication, improving patient-provider communication, and ultimately improving the care and treatment of African American and Hispanic men.

Conflicts of Interest

None declared.

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Abbreviations

CDSMP: Chronic Disease Self-Management Program
OR: odds ratio

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Original Paper

Hospital Productivity After Data Breaches: Difference-in-Differences Analysis

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Abstract

Background: Data breaches are an inevitable risk to hospitals operating with information technology. The financial costs associated with data breaches are also growing. The costs associated with a data breach may divert resources away from patient care, thus negatively affecting hospital productivity.

Objective: After a data breach, the resulting regulatory enforcement and remediation are a shock to a hospital's patient care delivery. Exploiting this shock, this study aimed to investigate the association between hospital data breaches and productivity by using a generalized difference-in-differences model with multiple prebreach and postbreach periods.

Methods: The study analyzed the hospital financial data of the California Office of Statewide Health Planning and Development from 2012 to 2016. The study sample was an unbalanced panel of hospitals with 2610 unique hospital-year observations, including general acute care hospitals. California hospital data were merged with breach data published by the US Department of Health and Human Services. The dependent variable was hospital productivity measured as value added. The difference-in-differences model was estimated using fixed effects regression.

Results: Hospital productivity did not significantly differ from the baseline for 3 years after a breach. Data breaches were not significantly associated with a reduction in hospital productivity. Before a breach, the productivity of hospitals that experienced a data breach maintained a parallel trend with control hospitals.

Conclusions: Hospital productivity was resilient against the shocks from a data breach. Nonetheless, data breaches continue to threaten hospitals; therefore, health care workers should be trained in cybersecurity to mitigate disruptions.

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KEYWORDS

cybersecurity; data breach; health information technology; health information; hospital data breach; hospital productivity; information technology; privacy

Introduction

Data breaches are an inevitable risk to hospitals operating with information technology (IT). The US Department of Health and Human Services (HHS) defines a data breach as the impermissible use or disclosure of protected health information [1] and can be categorized as follows: theft, loss, unauthorized access or disclosure, improper disposal, hacking or IT incident, and unknown or other breaches. In the Healthcare Information and Management Systems Society 2019 Cybersecurity Survey, more than 80% of responding hospitals have reported that they experienced a significant security incident in the past 12 months [2].

Another growing cybersecurity threat to hospitals is ransomware attacks. Ransomware denies users the access to data by encrypting the data with a key known only to the attacker [3]. The attacker demands a ransom payment in exchange for the key to decrypt the user's data. In one recent case, a hospital was forced to pay US $17,000 to regain access to its system. California-based Hollywood Presbyterian Medical Center reportedly experienced a malware attack, and employees stated that they were unable to access certain parts of the hospital network [4]. In a more severe case, University of California San Francisco paid over US $1 million to hackers to regain access to its system [5].

The Health Information Technology for Economic and Clinical Health Act regulates the notification of health information breaches in the United States. This act requires health care providers and entities covered by the Health Insurance Portability and Accountability Act of 1996 to notify a breach of protected health information, which affects more than 500 individuals to those affected individuals, HHS, and sometimes the media [1]. HHS maintains a public database called Breach Portal: Notice to the Secretary of HHS Breach of Unsecured Protected Health Information, which publishes the reported health data breaches submitted from October 2009 to the present [6].

Recovering from data breaches and ransomware attacks is costly for hospitals. Data breach remediation efforts were associated with lower hospital quality, including increased time-to-electrocardiogram and an increased 30-day acute myocardial infarction mortality rate [7]. In 2019, the average total cost of a data breach for all industries globally was US $3.92 million, and it took organizations an average of 279 days to identify and contain a breach. The average total cost of a data breach for all industries in the United States was US $8.19 million, which was more than 2-fold the global average [8]. The total costs include notification costs, productivity losses, re-establishing the image of the company, infrastructure costs, and repetition of work. The cost of a data breach is different across industries. The actual cost per breached record averages out at US $242 per record in the United States, and US $150 globally [8]. In the US health care industry, per-record breaches cost an average of US $429 [8]. Global losses from security breaches are forecasted to double from US $3 trillion per year in 2015 to US $6 trillion per year in 2021 [9]. In addition, breached hospitals potentially face investigation, fines, and several years of monitoring by the Office for Civil Rights (OCR) [10].

The additional costs associated with data breaches and their remediation has adverse implications for hospital productivity. The productivity of a firm is typically measured as the value of goods and services produced per unit of labor and capital input. For hospitals, productivity is the value of health care goods and services, such as pharmaceuticals and surgeries, per health care input [11-14]. The financial costs and regulatory burden associated with a data breach may divert resources away from patient care, thus negatively affecting hospital productivity. Disruptions in health IT systems after a breach may disrupt or delay the workflow of clinicians [7], thus negatively affecting hospital productivity. Employee layoffs and turnovers resulting from a breach are another factor that may reduce productivity [15]. Breach remediation required by the OCR, including changes to the health IT system and staff training, may take years to complete. Such an oversight by the OCR, which changes hospital policies and processes may disrupt hospital productivity in the long term. Organizational culture set by hospital administrators may have a strong influence on the productivity and security practices of the staff. Thus, hospitals with poor organizational culture may be involved in a breach and have poor productivity.

Despite the increasing importance of cybersecurity, little is known about its effects on hospital-level productivity. Health IT systems are intended to improve hospital productivity by reducing human error, but data breaches may have the unintended consequence of disrupting hospital productivity. Thus, in this study, we aimed to investigate the relationship between data breaches and hospital productivity by using data from California hospitals from 2012 to 2016. We hypothesized that data breaches may increase hospital costs and disrupt provider workflow, thus decreasing hospital productivity. We compared the productivity of the hospitals that experienced a data breach against control hospitals and investigated whether hospital productivity was significantly different for the breached hospitals before and after a breach.

Methods

Empirical Model

After a data breach, the resulting regulatory enforcement and remediation is a shock to a hospital's patient care delivery. Therefore, hospital data breaches can be modeled as a natural experiment to understand the relationship between data breaches and productivity. The association between hospital data breaches and productivity was estimated using a generalized difference-in-differences model with multiple prebreach and postbreach periods [16]. This model for an event study is a widely used approach to model observational data in the health economics literature.

We used the reported information on breaches as collected by HHS to create a panel of hospital-year observations from 2012 to 2016. Our model estimates the changes in productivity associated with hospitals that experienced a breach, controlling for hospital financial characteristics including total assets, total labor, IT capital, IT labor, bed size, and time trends. The model assumes that the breached hospitals would have followed a trend parallel to that of the control group if they had not been breached.

For a hospital in a given year, the dependent variable is the log of productivity measured as value added. Value added is defined as operating revenues' lesser intermediate inputs. Intermediate inputs include surgical supplies, linens, clothing, and other material inputs [11]. Financial control variables included the log of total capital, total labor, IT capital, and IT labor. Total capital assets include current assets, property, plant and equipment, intangible assets, assets whose use is limited, and other assets. Total labor (non-IT) is defined as the total conventional salaries, wages, employee benefits, and professional fees excluding any costs related to IT labor. IT capital is a summation of four components: purchased services, leases and rentals, other direct expenditure, and physical capital. IT labor is the summation of salaries and wages, employee benefits, and professional fees associated with data processing. For hospital control variables, we included the number of licensed beds and case mix index of a given hospital. For breach control variables, we included breach type and breach location. In addition, ownership, teaching status, and rural status were included in the descriptive summary, but they were omitted from fixed effects regression because they were time-invariant variables. Finally, the model included year fixed effects and hospital fixed effects. Assuming that hospitals' administration does not change in the short term, hospital fixed effects serve to control for the unobserved time-invariant hospital organizational culture that may be correlated with both breaches and productivity.

For the treatment, dummy hospitals were categorized into two groups: never breached (control) and breached. Moreover, the breached hospitals experienced their specific breach events at different timepoints. The difference-in-differences model was specified to capture changes in value added at –3, –2 –1, 0, +1, +2, and +3 years relative to the hospital-specific year of the data breach. The year of the breach was set as the reference category. For example, a hospital that was breached in 2014 was coded as –2 in 2012, –1 in 2013, +1 in 2013, and +2 in 2014. The coefficients on the event time dummies captured the changes associated with value added at a given timepoint.

The model assumed that a breach was a one-time event. Multiple breaches within a year are a possibility, but we did not find any hospitals that experienced multiple breaches in our sample. The difference-in-differences model was estimated using fixed effects regression. SEs were robust to heteroskedasticity and allowed for within-hospital correlation analysis. Statistical analysis was performed using Stata (version 15, StataCorp) [17].

Data

Breach data and California Hospital financial data were utilized in this study. Breach data published by HHS were used to identify hospital data breaches by hospital name and the date of the breach report [6]. All types of breaches were included (ie, theft, unauthorized access or disclosure, hacking or IT incident, improper disposal, and loss). Only breaches affecting 500 or more individuals were observed in our data; therefore, HHS data do not provide an exhaustive list of all hospital data breaches.

The California Office of Statewide Health Planning and Development (OSHPD) publishes audited financial data from approximately 450 participating nonfederal hospitals licensed by the state. Financial disclosure reports are filed annually by each licensed hospital. OSHPD data provided hospital characteristics and financial variables [18]. Hospital data breaches in the HHS data were merged with OSHPD hospital financial data in accordance with the hospital name and year. OSHPD provides a directory of hospitals and their business names and aliases, which uniquely identify each hospital. However, the HHS data do not provide a standard hospital identifier; thus, some breaches may have been merged incorrectly.

The study sample included general acute care hospitals from 2012 to 2016. For data consistency, hospitals whose financial statements spanned less than 1 year were excluded from the study. Breach activity prior to our study period could influence the response period assessed herein. Thus, hospitals that experienced a breach in the 2 years before our study period (2010 and 2011), were excluded for data consistency. Furthermore, all financial variables were trimmed at the top 1% to exclude outliers. The resulting study sample was an unbalanced panel of hospitals with 2610 unique hospital-year observations. Data breaches were reported by 31 hospital-year observations. The breached group had 205 hospital-years, and the control group had 2405 hospital-years.

Results

Descriptive Statistics

Descriptive statistics are summarized by breach status in Table 1. Hospital year observations were categorized as breached and never breached (control) groups. The number of hospital years was 205 in the breached group and 2405 in the never breached group. The breached group was larger with, on average, more than 2-fold the value added compared to the control group (US $429.4 million vs US $189.55 million, respectively). The breached group had almost 3-fold the total assets (US $685.06 million vs US $254.45 million, respectively) and more than 2-fold the labor spending (US $387.17 million vs US $169.84 million, respectively) than the control group. The breached group spent almost 3-fold more on health IT capital (US $32.43 million vs US $10.83 million, respectively) and spent almost 4-fold more on health IT labor (US $8.54 million vs US $2.20 million, respectively). The breached hospitals were more likely to be larger in bed size (348.8 vs 225.4, respectively) and higher in the case mix index (1.32 vs 1.27, respectively), less likely to be not-for-profit hospitals (43.41% vs 63.49%, respectively), and more likely to be public hospitals (26.34% vs 13.68%, respectively) and teaching hospitals (60.98% vs 6.65%, respectively).

Table 1. Descriptive summary of breached and never breached (control) hospitals.

Variables	Breached (n=205)	Never breached (n=2405)
Continuous variables: financial variables in US $ (million), mean (SD)		
Value-added operating revenue	429.40 (507.97)	189.55 (173.54)
Total assets	685.06 (916.47)	254.45 (323.21)
Total labor	387.17 (413.95)	169.84 (148.41)
Information technology capital	32.43 (71.58)	10.83 (19.07)
Information technology labor	8.54 (15.69)	2.20 (4.12)
Licensed beds	348.80 (211.11)	225.40 (158.10)
Case mix index	1.32 (0.38)	1.27 (0.36)
Categorical variables: ownership, n (%)		
Investor-owned hospitals	62 (30.24)	549 (22.83)
Not-for-profit hospitals	89 (43.41)	1527 (63.49)
Public hospitals	54 (26.34)	329 (13.68)
Teaching hospitals	125 (60.98)	160 (6.65)

A comparison of the financial characteristics of breached and control hospitals between 2012 and 2016 is shown in Table 2. The breached group had a higher growth rate of value added, total assets, and total labor than the control group between 2012 and 2016 (128.27% vs 115.81% for value added, 128.38% vs 121.35% for total assets, and 117.24% vs 111.43% for total labor, respectively). The breached group had a higher growth rate than the control group in IT capital (186.69% vs 178.96%, respectively) and in IT labor (183.96% vs 123.82%, respectively) from 2012 to 2016. The breached group had a higher growth rate in licensed beds (100.39% vs 98.73%, respectively) between 2012 and 2016.

Individuals affected by a breach, breach type, and breach location among breached hospitals are summarized as follows. The mean number of individuals affected by a breach was 136,613. The proportion of breach types indicated that data theft was the most common breach type (65.85%), followed by unauthorized access, loss, or other breach types (22.00%), further followed by hacking or IT incidents (11.71%). The proportion of breach location indicated that desktop computers or laptops were the most common breach locations (51.22%), followed by network servers, papers, films, or other sources (36.1%), further followed by electronic medical records (12.68%).

Table 2. Descriptive summary of breached and never breached (control) hospitals between 2012 and 2016.

Variables	Breached (n=205)		Never breached (n=2405)	
	Mean (SD)	2016 vs 2012, %	Mean (SD)	2016 vs 2012, %
2012, US $ (million)				
Value added	422.06 (494.78)	128.27	193.19 (172.91)	115.81
Total assets	659.66 (870.55)	128.38	262.89 (316.28)	121.35
Total labor	388.65 (416.00)	117.24	174.22 (151.02)	111.43
Information technology capital	29 (71.28)	186.69	9.71 (13.33)	178.97
Information technology labor	7.23 (11.52)	183.96	2.19 (3.33)	123.83
Licensed beds	346.30 (211.13)	100.39	226.96 (160.26)	98.73
2016, US $ (million)				
Value added	541.38 (634.86)	N/A[a]	223.73 (206.48)	N/A
Total assets	846.88 (114.84)	N/A	319.02 (437.35)	N/A
Total labor	455.64 (485.39)	N/A	194.15 (166.60)	N/A
Information technology capital	54.14 (98.85)	N/A	17.37 (36.87)	N/A
Information technology labor	13.30 (23.69)	N/A	2.72 (6.30)	N/A
Licensed beds	347.65 (207.02)	N/A	224.08 (153.52)	N/A

[a] N/A: not applicable.

Regression Results

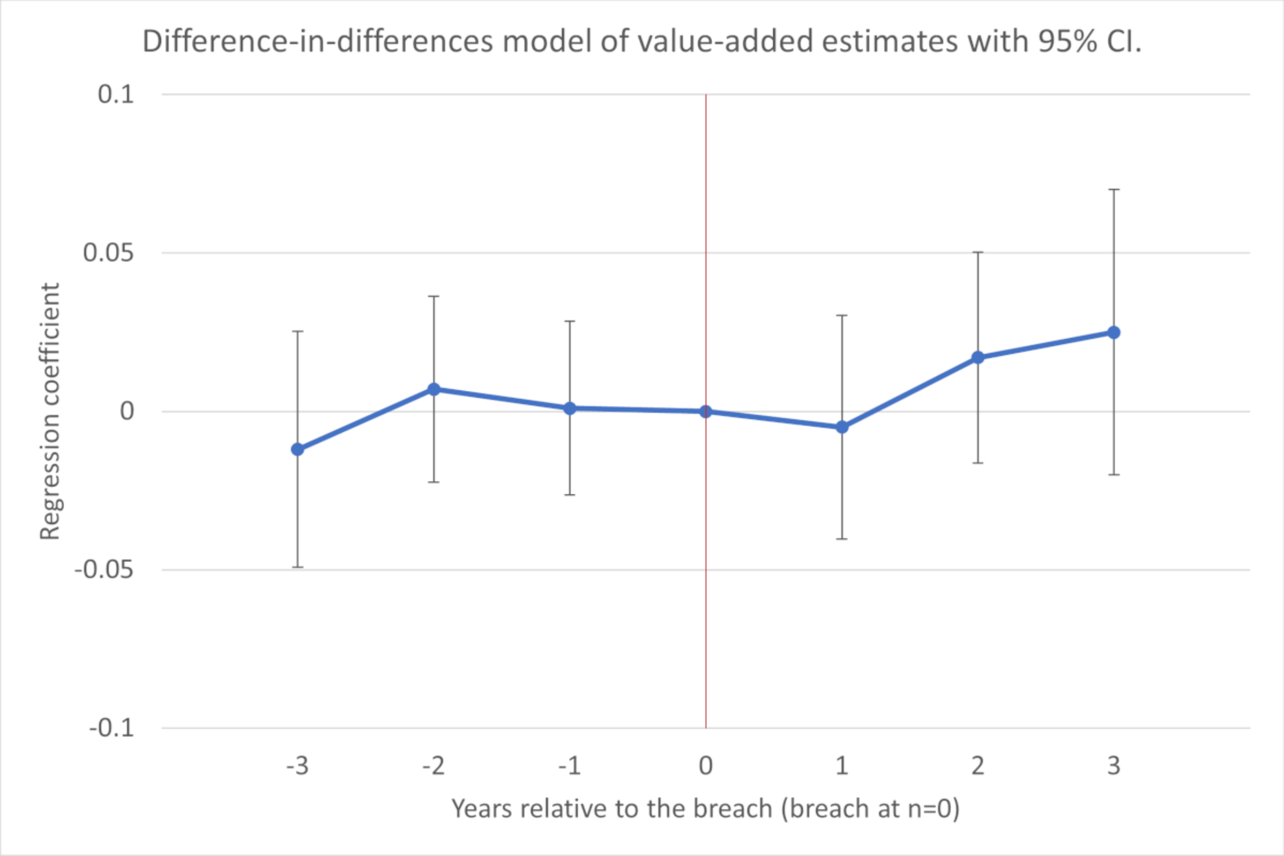
We estimated the change in value added associated with the years before and after a breach while controlling for hospital assets, labor, IT assets, IT labor, number of beds, case mix index, breach type, breach location, time trends, and hospital fixed effects. The regression coefficients are listed in Table 3 and visualized in Figure 1. We found that productivity remained practically unchanged before and after a breach relative to baseline, with constant observable time-varying covariates, time trends, and hospital fixed effects. Log-transformation of the dependent variable yielded regression coefficients that can be interpreted as multiplicative changes after exponentiation. Specifically, value added was associated with a 0.5% reduction [exp(-0.005)=0.995; *P*=.78] at 1 year after a breach, but the change was not significant. Furthermore, value added was associated with a 1.7% increase [exp(0.017)=1.017; *P*=.32] at 2 years after a breach, but the change was not significant. Moreover, value added was associated with a 2.5% increase [exp(0.025)=1.025; *P*=.28] at 3 years after a breach, but the change was not significant.

Table 3. Difference-in-differences model estimates for value added.

Breach parameters	Coefficient (SE)	*P* value
Breach time for which ln (revenue) was calculated (reference=0)		
–3	–0.012 (0.019)	.53
–2	0.007 (0.015)	.64
–1	0.001 (0.014)	.94
1	–0.005 (0.018)	.78
2	0.017 (0.017)	.32
3	0.025 (0.023)	.28
Total assets	0.055 (0.016)	.001
Total labor	0.600 (0.064)	<.001
Information technology capital	0.045 (0.007)	<.001
Information technology labor	0.007 (0.003)	.02
Number of beds	0.091 (0.043)	.04
Individuals affected	0.000 (0.000)	.27
Case mix index	0.126 (0.079)	.11
Breach type for which ln (revenue) was calculated		
Hacking or information technology incident (reference)	N/A[a]	N/A
Data theft	0.148 (0.035)	<.001
Unauthorized access, loss, or other	0.108 (0.021)	<.001
Breach location for which ln (revenue) was calculated		
Desktop computer or laptop (reference)	N/A	N/A
Electronic medical record	0.070 (0.033)	.04
Network server, papers, films, or others	0.099 (0.020)	<.001
Year for which the ln (revenue) was calculated (reference=2008)		
2009	0.024 (0.012)	.04
2010	0.042 (0.013)	.001
2011	0.049 (0.014)	.001
2012	0.052 (0.017)	.003
2013	0.037 (0.017)	.03
2014	0.021 (0.017)	.22
2015	0.084 (0.020)	<.001
2016	0.080 (0.024)	.001
Constant	5.042 (1.077)	<.001

[a] N/A: not applicable.

Figure 1. Difference-in-differences model of value-added estimates with 95% CI.



Estimates for all timepoints, from 3 years before to 3 years after a breach, were not significant. These estimates suggest that breaches were not associated with value added.

Total assets, total labor, IT capital, IT labor, and the number of beds were positively associated with value added. The number of individuals affected and the case mix index were not associated with value added. Breach type and breach location were associated with value added.

Discussion

Principal Findings

Hospitals' breach responses increase the financial burden on hospitals. The efforts to repair the damages from a data breach increase direct and indirect costs and may divert resources from improving patient quality of care. Health care data breaches reported to HHS, which includes breached health plans, physicians, and business associates in addition with hospitals, have grown from 329 in 2016 to 642 in 2020 [19]. Hospital data breaches were reported to increase hospital advertising expenditures [20] and IT spending [21] to remedy the damage due to a data breach.

Breached hospitals were larger in size, reflected in higher value added, total assets, and total labor, which is consistent with previous findings [7,22]. Larger hospitals have more access points, devices, and staff that could be breached, both intentionally and erroneously. Thus, the risk of a data breach is proportional to an organization's size.

However, data breaches were not associated with a reduction in productivity; that is, we did not observe a significant relationship between breaches and hospital productivity measured as the value added. Hospital productivity was resilient against the shocks from a data breach. We hypothesized that the financial cost and disruption associated with data breaches may decrease hospital production, but our results suggest that hospital productivity was unaffected. The stability in hospital productivity also implies that patient demand for hospital services was inelastic to data breaches. The remediation efforts and advertising to repair the reputation of the breached hospitals may have contributed to the steady demand.

Moreover, there are at least 2 more reasons to explain these results. First, there is incredible heterogeneity in the information type from a breach. For example, the release of patient records is likely to undermine the reputation of a hospital, whereas malware attacks are more likely to reduce cash flow rather than the hospital's reputation. The effects of different attack types may take longer to manifest for hospitals. Second, while many breaches take place without knowledge, as reflected by the large uncertainty about hospital vulnerabilities, those that detect incidents may not have an incentive to report the full financial impact [23]. Most hospitals are not-for-profit organizations. We are not aware of a federal or state law that requires not-for-profit organizations to disclose data breaches in their financial statements. The Sarbanes–Oxley Act of 2002 requires publicly traded firms to disclose data breaches, but investor-owned hospitals account for a small fraction of all hospitals.

Emphasis should be laid on the security training of health care workers. Treating patients and saving lives are the highest priority for health care workers, which makes them cautious in handling hospitals' security regulations and policies. However, nearly one-third of the health care workforce had never received cybersecurity-related training [24]. This lack of awareness results in improper handling and storage of patient files, with increasing usage of mobile devices. The most frequent breach type in our study sample was data theft, and the most frequent breach location was desktop and laptop computers. In health care, internal human error and misuse occur much more frequently than external attacks such as those that involve hacking [25]. Thus, to reduce the risk of a hospital data breach, health care workers should be trained in cybersecurity.

Hospitals are an attractive target for cyber attackers, and these attackers are affecting hospitals by using ransomware [26,27]. While our study data do did not capture ransomware attacks, these are considered much more disruptive than data breaches. To mitigate the threat, health care organizations should share threat information, experiences, and best practices to build the appropriate security architecture.

Limitations

Our analysis included reported health data breaches, which affected more than 500 individuals from 2012 to 2016; however, this is not an exhaustive list of data breaches. Smaller data breaches that affect fewer than 500 individuals are not published by HHS; hence, such breaches were excluded from our study. There is a nontrivial number of unpublished small data breaches [28]; however, such breaches tend to be less costly for organizations to remediate. There are various types of data breaches, and given the heterogeneity in potential breach effects, our small sample of breached hospitals limited the precision of our model estimates.

Conclusions

Hospital productivity was resilient against the shocks from a data breach between 2012 and 2016. The productivity trend of breached hospitals remained parallel with that of control hospitals in the years before the breach. Thereafter, the productivity of breached hospitals did not diverge significantly in the years after the breach. Nonetheless, data breaches continue to threaten hospitals today; therefore, health care workers should be trained in cybersecurity to mitigate these disruptions.

Conflicts of Interest

None declared.

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Abbreviations

HHS: US Department of Health and Human Services
IT: information technology
OCR: Office for Civil Rights
OSHPD: California Office of Statewide Health Planning and Development

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Original Paper

Experience Sampling and Programmed Intervention Method and System for Planning, Authoring, and Deploying Mobile Health Interventions: Design and Case Reports

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Abstract

Background: Health professionals initiating mobile health (mHealth) interventions may choose to adapt apps designed for other activities (eg, peer-to-peer communication) or to employ purpose-built apps specialized in the required intervention, or to exploit apps based on methods such as the experience sampling method (ESM). An alternative approach for professionals would be to create their own apps. While ESM-based methods offer important guidance, current systems do not expose their design at a level that promotes replicating, specializing, or extending their contributions. Thus, a twofold solution is required: a method that directs specialists in planning intervention programs themselves, and a model that guides specialists in adopting existing solutions and advises software developers on building new ones.

Objective: The main objectives of this study are to design the Experience Sampling and Programmed Intervention Method (ESPIM), formulated toward supporting specialists in deploying mHealth interventions, and the ESPIM model, which guides health specialists in adopting existing solutions and advises software developers on how to build new ones. Another goal is to conceive and implement a software platform allowing specialists to be users who actually plan, create, and deploy interventions (ESPIM system).

Methods: We conducted the design and evaluation of the ESPIM method and model alongside a software system comprising integrated web and mobile apps. A participatory design approach with stakeholders included early software prototype, predesign interviews with 12 health specialists, iterative design sustained by the software as an instance of the method's conceptual model, support to 8 real case studies, and postdesign interviews.

Results: The ESPIM comprises (1) a list of requirements for mHealth experience sampling and intervention-based methods and systems, (2) a 4-dimension planning framework, (3) a 7-step-based process, and (4) an ontology-based conceptual model. The ESPIM system encompasses web and mobile apps. Eight long-term case studies, involving professionals in psychology, gerontology, computer science, speech therapy, and occupational therapy, show that the method allowed specialists to be actual users who plan, create, and deploy interventions via the associated system. Specialists' target users were parents of children diagnosed with autism spectrum disorder, older persons, graduate and undergraduate students, children (age 8-12), and caregivers of older persons. The specialists reported being able to create and conduct their own studies without modifying their original design. A qualitative evaluation of the ontology-based conceptual model showed its compliance to the functional requirements elicited.

Conclusions: The ESPIM method succeeds in supporting specialists in planning, authoring, and deploying mobile-based intervention programs when employed via a software system designed and implemented according to its conceptual model. The

ESPIM ontology–based conceptual model exposes the design of systems involving active or passive sampling interventions. Such exposure supports the evaluation, implementation, adaptation, or extension of new or existing systems.

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KEYWORDS

mobile apps; mHealth; intervention; experience sampling; method; monitoring; Experience Sampling and Programmed Intervention Method; experience sampling method; ecological momentary assessment; just-in-time adaptive intervention

Introduction

Many factors impact the adoption of mobile health (mHealth) tools by professionals and their target population, as observed in Australia [1], Canada [2], USA [3,4], and in Europe [5,6]. As an example, clinicians' concerns when considering an mHealth tool include usefulness, ease of use, compatibility, technical issues, content, personalization, convenience, strict data privacy, workload, workflow, communication, management support, and policies [7-9]. Such themes align with those highlighted by Chinese public hospitals' managers [10], including perceived ease of use, system security and reliability, top management support, and government policy.

Toward employing mHealth interventions, professionals can generally choose among 3 options: using apps designed for other activities such as peer-to-peer communication, using purpose-built apps specialized in the required intervention, or using apps based on methods such as the experience sampling method (ESM) [11-13], and its descendent ecological momentary assessment (EMA) [14], including those exploring just-in-time adaptive interventions (JITAIs) [15]. The first alternative allows professionals to adapt their protocols to take advantage of popular apps [16] and to employ conventional SMS text messaging usually available to the underprivileged [17-19]. However, because interventions may require sending or collecting multiple types of questions and media and demand careful planning [20], deploying nonspecialized apps demands both adaptations in the protocol and overcoming obstacles when monitoring progress.

The second alternative led to the design of a wide range of mHealth-specialized apps [21-24] that enable reproducing interventions accurately. Their design engenders a dependency relationship between specialists and software developers. Moreover, specialized apps have little potential for reuse.

The third alternative involves using apps based on methods such as the ESM and EMA, as in the works surveyed by van Berkel et al [25]. Examples include studies [26-30] that employed the LifeData [31], the movisensXS [32], or the Mobile EMA [33] systems based on data collection methods. Additionally, ecological momentary interventions (EMIs) or JITAIs support interventions involving contextual data used for personalization according to users' needs [15,34,35].

In a complementary approach, if professionals were able to create their own apps [36], they could focus on the methodological processes of their work. While the ESM methods offer important guidance, current systems [31-33] do not expose their design at a level that promotes replicating, specializing, or extending their contributions as demanded in many areas. Thus, a twofold solution is required: a method that directs specialists in planning an mHealth intervention program themselves, and a model that guides specialists in adopting existing solutions while advising software developers on building new ones.

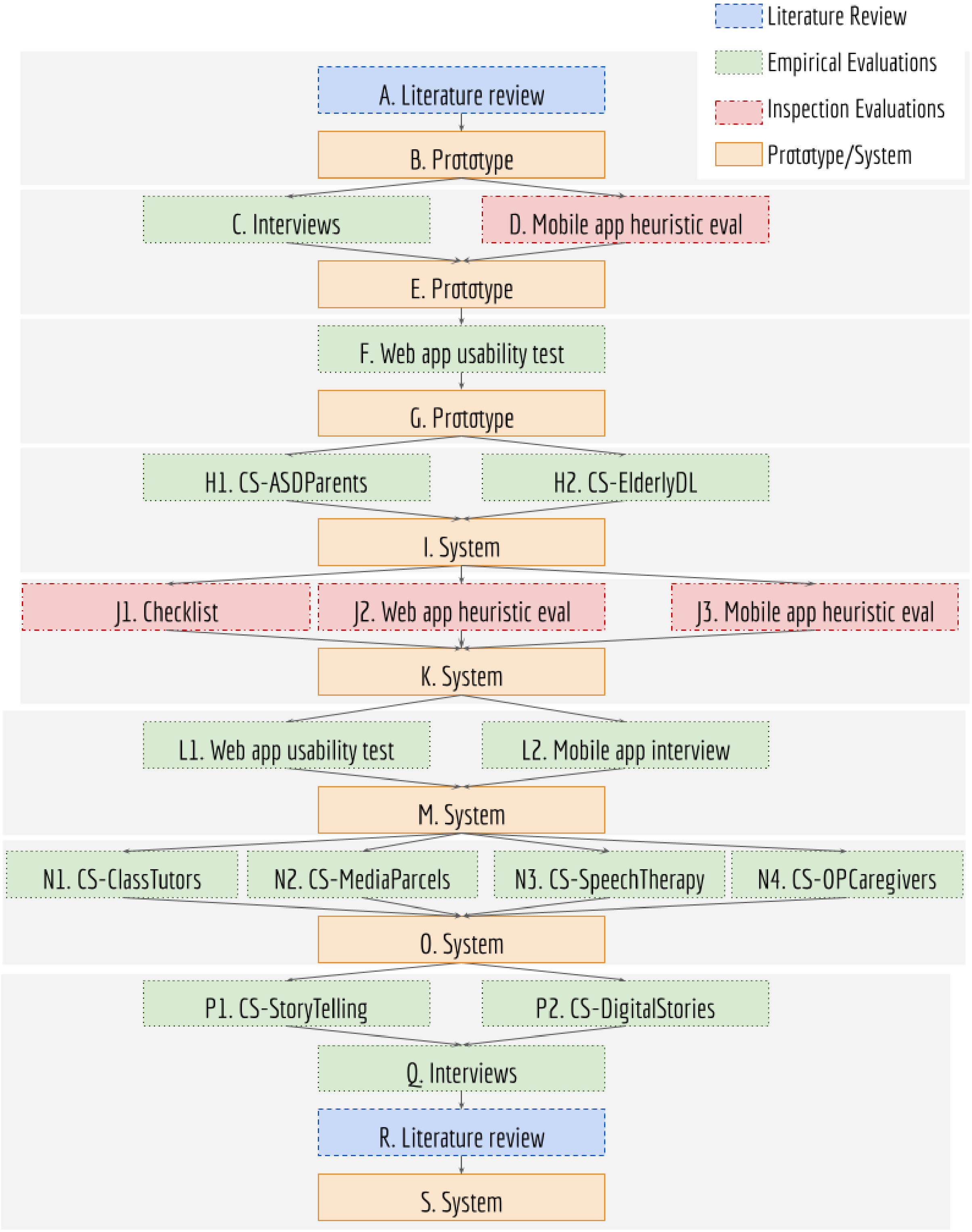
The 2 main objectives of this study are to design the Experience Sampling and Programmed Intervention Method (ESPIM), formulated toward supporting specialists in deploying mHealth interventions, and the ESPIM model, which guides specialists in adopting existing solutions and advises software developers on how to build new ones. A subsidiary goal is to conceive and implement a software platform allowing specialists to be users who plan, create, and deploy interventions (ESPIM system).

Methods

Overview

For designing the mobile-based ESPIM method, we adopted an iterative approach of co-design considering the participatory design practices [37,38]. Besides continuous review of state-of-the-art literature, the procedures adopted encompass early software prototype and predesign interviews with health specialists, iterative design sustained by a software system, support to real case studies, and postdesign interviews (Figure 1). The evaluation of ESPIM software employed the heuristic evaluation method [39] (see Textbox SM1 in Multimedia Appendix 1), usability tests [40] (see Textbox SM2 in Multimedia Appendix 1), the Semantic Differential Scale [41] (see Textbox SM3 in Multimedia Appendix 1), and the User Experience Questionnaire (UEQ) [42] (see Textbox SM4 in Multimedia Appendix 1).

Figure 1. Study Methods and Workflow. CS: case study.



The methods used in this study were approved by the Brazilian Research Ethics Committee under case number 57875016.3.0000.5390. Study participation was voluntary and respected anonymity.

Recruitment

Users were involved in the participatory design as specialists or target users. In the case of specialists, they form a convenience sample recruited via email at nearby research departments. Specialists took part as intervention planners; inclusion criteria were being a health or education professional and experience in planning and delivering interventions. Education specialists participated as educational issues are part of eHealth [43] and corresponding interventions influence, among others, socialization, cognitive support, and mental health [44-46].

Regarding the target users who participated in the case studies, specialists handled their recruitment as they were participants in their interventions.

The study also had the contribution of specialists in human–computer interaction (HCI). They were recruited via email from nearby research departments and software companies. Inclusion criteria were background in HCI and experience in conducting heuristic evaluations.

Professional designers, specialists in user interface (UI) and user experience (UX), were also recruited to design refined interfaces and validate them after the implementation. They were recruited via email from nearby software companies.

Participatory Design

Evolution of ESPIM

Following a participatory design approach, the ESPIM method evolved according to requirements gathered from literature reviews, interviews, prototyping, and implementation of software instances of the associated model, and gradual usability evaluations (Figure 1). As observed by Byambasuren et al [47], usability is a main barrier for prescription and adoption of mHealth apps, especially for older people. To overcome these barriers, usability and UX were evaluated through empirical and inspection-based evaluations, which provided new requirements and detailed existing ones [48-51].

Interview (Predesign)

During requirement collection, specialists of different domains participated in semistructured interviews (Figure 1C and Multimedia Appendix 2) to discuss their needs in carrying out remote data collection and interventions, to answer a survey of the difficulties they faced in data collection and interventions, to present the system prototype as a potential solution, and to collect requirements. These professionals worked, among others, with children and adults with typical and atypical development, older people, pregnant women, and individuals with motor impairments. All participants conducted academic research in their areas. They were individually interviewed at their workplaces (by IZ and KRHR). Each meeting lasted 1 hour and 30 minutes on average. Interviews were performed with all participants who accepted the invitation.

First Heuristic Evaluation (App Prototype)

Four HCI specialists (Figure 1D), 2 researching usability for older people and 2 accessibility, conducted the first heuristic evaluation of the mobile interface of the ESPIM app prototype (question based at the time) [49]. The session lasted 24 hours so specialists could evaluate the 4 daily temporal triggers besides initiating the program themselves. The questions were related to daily routines and aimed to connect the trigger time with locations, daily activities, information technologies used, and ongoing activities.

First Usability Test (Web Application Prototype)

The first usability test performed on the web interface of ESPIM prototype (Figure 1F) aimed at answering: Do the specialists clearly understand what is the system and its purpose? Do the specialists face difficulties creating intervention programs using the system? Are the specialists able to complete all stages of creating intervention programs, including the setup phase? The test protocol (see Textbox SM5 in Multimedia Appendix 1) evaluated the understanding and the performance of the prototype from the point of view of health specialists using the metrics task execution time, number of steps to complete tasks, number of completed tasks, number of errors, and overall satisfaction.

We provided a hypothetical scenario *Geriatrician* outlining the tasks conducted by a specialist (geriatrician) who plans an intervention program to an older person with cognitive impairment who is attended by a caregiver (see Table SM1 in Multimedia Appendix 1). The scenario comprises 8 tasks requested of the older person, who is aided by the caregiver if needed. We specified the most complex task as a diagram (see Figure SM1 in Multimedia Appendix 1).

Checklist

The UI/UX designers who designed graphical interfaces executed a checklist-based evaluation (Figure 1J). Upon interacting with the system, they enlisted improvements.

Heuristic Evaluation

HCI specialists performed an inspection-based evaluation on the web application interface (Figure 1L1). The evaluators received an email with instructions, a task checklist, links, and files. The links led to the informed consent form, a profile survey, and to the ESPIM web application. The files contained instructions on how to conduct the evaluation, a template for reporting issues identified along with the corresponding heuristics, and the hypothetical scenario *Geriatrician*, comprising the tasks to be analyzed (see Table SM1 in Multimedia Appendix 1). After individual inspections, the evaluators met to discuss the problems found in the interface and produced a consolidation report.

The second heuristic evaluation of the mobile app followed the same protocol, using the same files (Figure 1J3). Additionally, the evaluators received the app installation file which included an intervention program and corresponding task checklist of the hypothetical scenario *Nutrition*. Four evaluators inspected the app performing 6 tasks: install, initiate and give the permissions requested by the ESPIM app, log in with your Google account, start the “Nutritional Data Collection” intervention program and navigate through all screens planned by the nutritionist, explore the app settings, and disconnect from the app.

Second Usability Test (Web Application) and Interview (App)

The second usability test on the web application (Figure 1L1) and the interview about usability and interaction aspects of the mobile app (Figure 1L2) were conducted at the same time. The questions and the protocol were those used in the first usability test.

For testing the web application, we provided the scenario “Monitoring and evaluating the performance of the older people in digital literacy courses through remotely programmed interventions” (see Table SM2 and Figure SM2 in Multimedia

Appendix 1). Aspects of the web interface elements evaluated were ease of use, memorization, easiness to "undo" actions, learnability during use, intuitiveness, feedback/error messages, information organization, arrangement of interface elements, available features, and interface design. Participating specialists answered a 7-point Likert scale (1="Awful" to 2="Excellent") for each aspect. The specialists also provided a self-evaluation of their performance using the system by responding to 7 affirmative sentences using a 5-point Likert scale (1="Strongly agree" to 5="Strongly disagree"): I easily completed the required tasks, I completed the tasks rapidly and efficiently, I would need someone's support to use the system, I felt more productive during the interaction with the system, I easily found the information and functionalities that I needed, I needed to thoroughly think or remember before completing the tasks, and I would recommend the system to other people.

The specialists had previous experience as instructors or tutors in mobile digital literacy courses for elderly individuals (Figure 1H2) as part of the Case Study ElderlyDL (Table 1). They were interviewed regarding their learning while observing older people interacting with the app and commonly reported complaints. The questions asked were "Which errors or infrastructure problems were found? Which devices did not work? Which frustrations were observed while older people interacted with the app? For each type of task: What were the main difficulties of the older people? What were the issues? What could be better? What is good and should not change?."

Table 1. Eight case studies.

Case study	Specialists involved	Participants	Short description
CS-ASDParents	2 psychologists; 1 computer scientist	3 families (3 children with autism spectrum disorder and 3 parents)	Promoting engagement in educational activities between children diagnosed with autism spectrum disorder and their parents.
CS-ElderlyDL	3 gerontologists, 2 computer scientists, 1 psychologist, 1 statistician	365 older people (age 60+)	Supporting mobile digital literacy courses for elderly.
CS-ClassTutors	1 gerontologist, 1 computer scientist	12 tutors (graduates/undergraduate students)	Analyzing elderly digital literacy courses using tutors' feedback.
CS-MediaParcels	1 psychologist, 1 computer scientist	1 family (1 father and 2 children); 3 elderly friends (age 60+)	Encouraging multimedia interventions to promote social connection among elderly.
CS-SpeechTherapy	1 speech therapist	5 children (age 8-12)	Deploying speech therapy homework for children.
CS-OPCaregivers	1 occupational therapist	30 caregivers of older people	Providing informative contents for caregivers of elderly with dementia.
CS-OPStorytelling	2 computer scientists, 1 gerontologist	15 older people (age 60+)	Enabling the creation of digital storytelling by seniors.
CS-StoryReading	1 psychologist	45 children (age about 10)	Developing digital stories for children with reading disabilities.

Case Studies

Overview and Approval

The ESPIM method evolved supporting real case studies conducted by specialists (Figure 1) who used the method via the associated ESPIM system to manage interventions with their populations of interest [52,53]. These case studies are part of the empirical evaluations of the ESPIM system (Table 1).

Each case study was submitted and approved by the Brazilian ethics committee and all data were anonymized. Their common study protocol included the following: signing an informed consent form, filling out a pretest profile survey, filling out a posttest questionnaire about the interaction experience, and participating in a semistructured interview at the end of the study. Each specialist applied specific evaluation forms of their respective fields to analyze the results of their studies.

Case Study ASDParents

The case study ASDParents studied engagement in educational activities between children with autism spectrum disorder and their parents (Figure 1H1). Parents were instructed to conduct at least one out of three planned educational activities at home with their children, once a day, during the 6 weeks: the first 3 weeks used conventional paper-based written instructions, whereas the last 3 employed ESPIM. Psychologists employed ESPIM to send text and video tasks and to monitor task accomplishment and performance. All children studied at a Brazilian nongovernmental organization with a 2-hour/week workload. Three families (3 children and 3 parents) participated [54].

Case Study ElderlyDL

The case study ElderlyDL offered mobile digital literacy courses to older people (Figure 1H2). Computer science, psychology, and gerontology specialists employed the web application to design intervention programs as homework for the older people, who received and responded to the tasks via an app. During 13 weeks, the app sent, on weekdays, a notification around 7 pm alerting about the homework. The study involved 365 older people [48,50,55].

Case Study ClassTutors

Case study ClassTutors collected feedback from tutors assisting 3 instructors providing digital literacy courses for older people (Figure 1N1). The tutors were undergraduate and graduate students. One instructor (gerontologist) used the web application to guide tutors in evaluating the effectiveness of the classes and identifying situations of stress or struggle. The app sent 1 notification asking for feedback after the weekly class, the intervention being available throughout the week. A total of 12 tutors participated in this study for 4 months.

Case Study MediaParcels

In the Case study MediaParcels (Figure 1N2), 1 psychologist employed ESPIM as a multimedia exchange tool to investigate the impact of social interventions among older people and their connections. The specialist designed interventions to encourage participants to share self-revelations and media with affective content. The psychologist requested content from 1 participant, annotated the content with the meaning embedded in the original request, and forwarded it to the participant's connections. One study involved family members (father and 2 children) and another study involved 3 elderly friends. Both studies lasted 2 weeks [56].

Case Study SpeechTherapy

The case study SpeechTherapy was applied in the clinical context of speech therapy (Figure 1N3). The specialists planned reading, writing, and comprehension tasks to complement activities conducted at the clinic. They applied remote interventions with 5 patients (aged 8-12 years) with reading or writing issues. Five children participated in the 5-month case study.

Case Study OPCaregivers

The case study OPCaregivers delivered information to caregivers of older persons with dementia toward guiding and qualifying the care provided (Figure 1N4). One occupational therapist created interventions to present information related to feeding, personal hygiene, guidelines for maintaining a structured and stimulating routine, and tips for managing behavioral symptoms. Thirty caregivers participated in this study.

Case Study OPStorytelling

The case study OPStorytelling employed ESPIM interventions to guide the creation of video stories by users with little experience in producing digital content, especially older people (Figure 1P1). One specialist used ESPIM to create interventions as "storytelling scripts" that combined requests for text, video, image, and audio assets. A dedicated service, integrated into the ESPIM software, received the media assets, generated the corresponding video, and uploaded it to a YouTube private channel. This study employed 2 workshops to teach 15 older people to produce video-based narratives [57].

Case Study StoryReading

In the case study StoryReading, a specialist in psychology used the ESPIM system as a tool to create instructional programs in the form of text-based stories, augmented with images and animations (Figure P21). The target users were children with reading difficulties. The goal was to improve reading comprehension by delivering stories integrated with questions and corresponding interactive feedback.

Interview (Postdesign)

A member of the ESPIM team (BCRC) interviewed the specialists after their studies (Figure 1R). The specialists responded to a semistructured 2-part interview: area of expertise and related studies, and how they modeled interventions in their studies. The latter aimed to elicit how specialists designed, delivered, and monitored interventions using the ESPIM system.

Results

User Statistics

Predesign interviews (Figure 1C) involved 12 health specialists: 5 psychologists (4 specialized in special education and 1 in behavioral psychotherapy), 3 nurses (1 specialized in public health, 1 in health sciences, and 1 in mental health), 2 physicians (1 specialized in obstetrics and gynecology and 1 in psychiatry, geronto-psychiatry, and neurology), 1 physiotherapist (observer in neuropediatrics), and 1 occupational therapist (specialized in public health).

The first heuristic evaluation of the mobile app (Figure 1D) was conducted by 4 HCI specialists (2 specialized in usability for the older people and 2 in accessibility).

The first web application usability test (Figure 1F) involved 5 psychologists (3 specialized in special education; 1 in science, technology, and society; and 1 in biology).

The checklist-based evaluation was realized by 2 UI/UX designers (Figure 1J1).

The heuristic evaluation of the web application (Figure 1J2) and the second heuristic evaluation of the mobile app (Figure 1J3) involved 4 HCI specialists: 1 inexperienced (never performed this kind of evaluation), 1 had intermediary experience (conducted 3 evaluations), and 2 were experienced (executed more than 3 evaluations).

The second usability test of the web application (Figure 1L1) and the interview about usability aspects of the app (Figure 1L2) were performed, in the same session, with 5 gerontologists and 1 occupational therapist.

Postdesign interviews (Figure 1Q) involved 8 specialists: 2 psychologists, 2 gerontologists, 1 occupational therapist, 1 speech therapist, and 2 computer scientists who offered digital literacy courses for older persons in collaboration with one of the gerontologists.

Target users who took part in the interventions via the ESPIM mobile app included 431 older persons, 30 caregivers of older persons, 5 children, 12 undergraduate/graduate students, and 3 families with children with autism spectrum disorder (Table 1).

Participatory Design

Overview

The ESPIM comprises (1) a list of requirements for mHealth experience sampling and intervention-based methods and systems, (2) a 4-dimension planning framework, (3) a 7-step-based process for planning interventions, and (4) an ontology-based conceptual model. The ESPIM system and the cases study reports complement the contribution.

ESPIM's Functional Requirements

The functions demanded from ESPIM were elicited using literature review, predesign interviews, iterative prototyping, and postdesign interviews. The resulting functional requirements (Table 2) concern creating and managing (1) the "intervention programs," (2) the "persons" involved as observers and participants, (3) the "events" constituting the program and comprising triggers and tasks, (4) the "active tasks" specialists request to target users, (5) the use of "sensors" to capture data or trigger tasks, or both, and (6) the access to the "results."

Table 2. Functional requirements (FRs) for ESPIM.

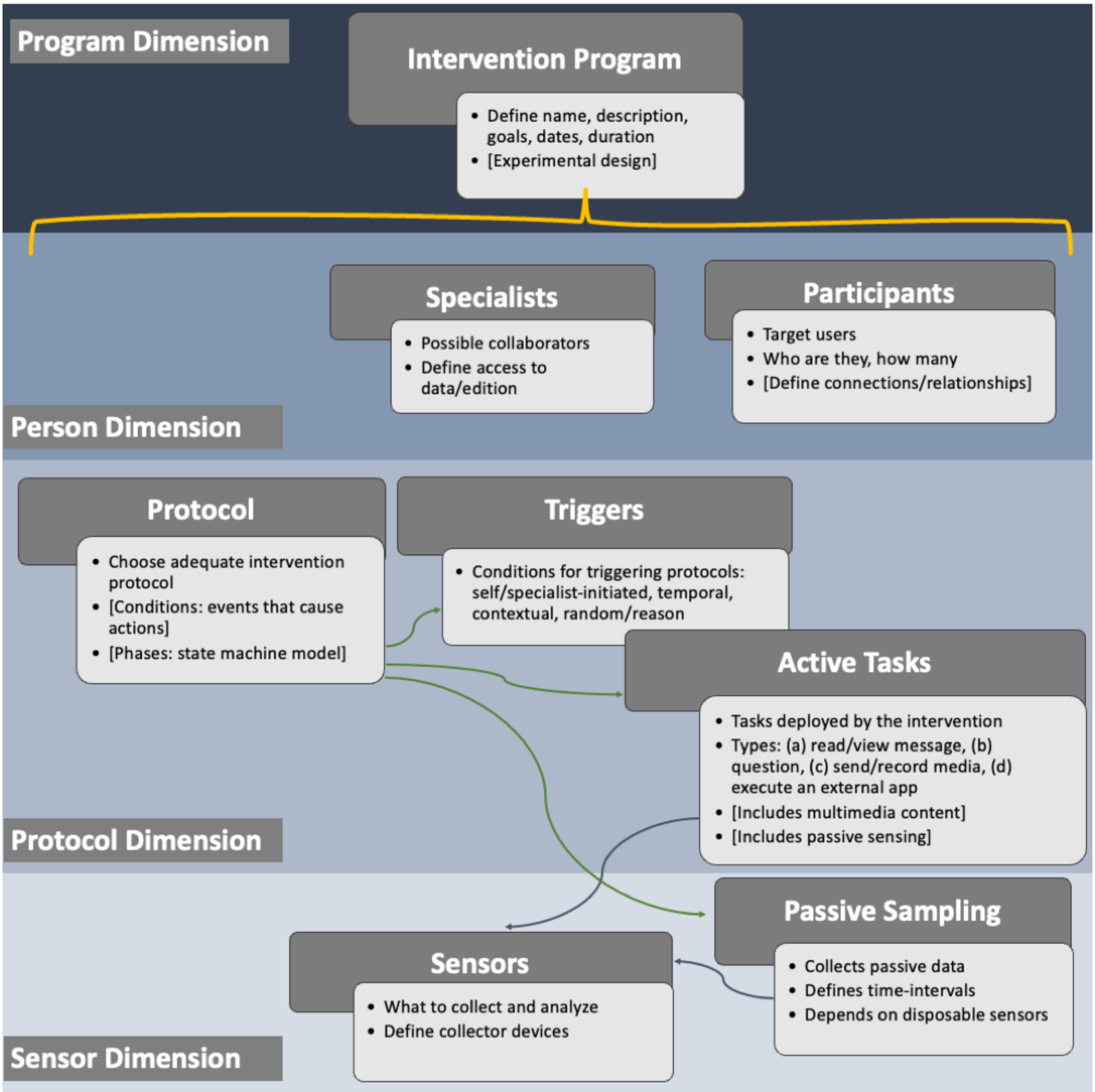
FR	Description
Intervention program	
FR01	Enable creation, management, and reuse of intervention programs.
FR02	Enable definition of open or fixed beginning and ending dates for programs.
FR03	Enable organization of programs into phases composed by different events.
Person	
FR04	Enable registration and management of observers.
FR05	Enable registration and management of participants.
FR06	Enable collaborative management of programs.
FR07	Provide user authentication/authorization with roles and permissions.
FR08	Enable multiple associations among participants and programs.
FR09	Enable creation of contact lists related to privacy control.
FR10	Enable the association of relationships among participants (eg, communication).
FR11	Enable importing participants’ data from external sources.
Event	
FR12	Enable creation of active tasks and sensor-based sampling.
FR13	Enable the association of triggers to events.
FR14	Enable configuration of intrusiveness level in triggers.
FR15	Provide trigger types: self- and specialist-initiated, temporal, contextual, random.
FR16	Enable definition of triggers’ timeout.
FR17	Enable color-coding events.
FR18	Enable annotations and follow up via participant’s app interface.
FR19	Enable configuration of triggers disabling when a condition is fulfilled.
FR20	Enable configuration of alert to inform when a participant did not answer a trigger.
FR21	Enable configuration of alert to inform when a participant answered a trigger.
FR22	Enable configuration of triggers rescheduling when a condition is satisfied.
FR23	Enable configuration of alert to inform of a specific answer (eg, risky behavior).
FR24	Enable configuration of automatic processing of responses (eg, condition based).
Active tasks	
FR25	Provide active tasks type message, question, media request, and external app launch.
FR26	Enable active tasks containing multimedia stimuli and emphases-enriched text.
FR27	Provide open-ended, multiple/single-choice (including pictures as choices) questions and scales (eg, Likert, sorting scale, grid).
FR28	Enable definition of mandatory active tasks.
FR29	Enable configuration of interaction flows (skip, branch, and loop).
Sensor-based sampling	
FR30	Enable configuration of sensor-based sampling while interacting with active tasks.
FR31	Enable definition of time intervals for sensor-based sampling.
FR32	Enable configuration of automated sensor-based sampling.
FR33	Enable sampling from software- or hardware-based sensors (eg, mobile and wearable devices, accessories, home sensors).
Results	

FR	Description
FR34	Provide different filter modes for results' visualization.
FR35	Provide date, time, and duration of the corresponding result.
FR36	Enable download of the results.
FR37	Enable configuration of automatic analysis of responses by dedicated algorithms.

ESPIM 4-Dimension Planning Framework

Defined upon the requirements, an ESPIM intervention program involves 4 dimensions: program, person, event, and sensor (Figure 2). The *program* dimension comprises the intervention program as a whole, and characterizes general intervention settings, such as name, definition, description, goals, duration, and, in research-based situations, its experimental design.

Figure 2. ESPIM Intervention dimensions: Program, Person, Event and Sensor.



The *person* dimension comprises the specialists in charge of the program and their target users, also called participants. Both professionals and researchers may work with collaborators who require distinct access control levels. Moreover, establishing target users is a key aspect of an intervention. In analytical work, the number of participants and their characterization are crucial, while individualized interventions and use case scenarios may demand the participation of other individuals (eg, parents, caretakers, partners). Relationships between participants and these connections, along with delimited data sharing, might be considered in the program.

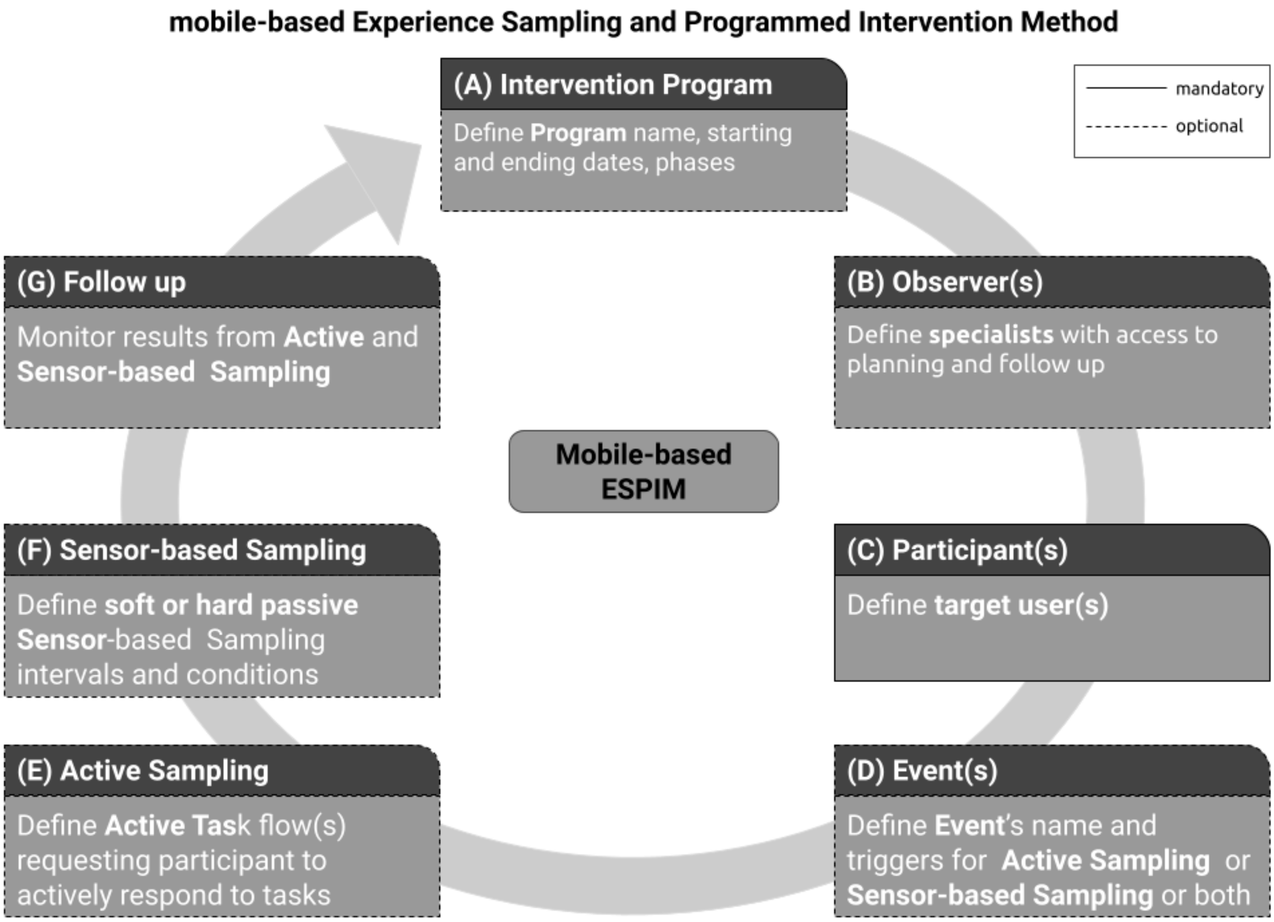
The *protocol* dimension comprises features provided by mobile technologies, aggregating the flow(s) that constitute the intervention along with the corresponding time- or sensor-based triggers. Finally, the *sensor* dimension allows expressing sensor-based support both for data collection and for triggering events.

ESPIM 7-Step-Based Process

Overview

ESPIM directs specialists in iteratively planning a mobile-based intervention program (Figure 3). The 7-step-based process suggests first identifying the intervention program by a name and defining its overall duration (Figure 3A), followed by the identification of who will have access to the planning procedures (Figure 3B) and who the target users are (Figure 3C). The intervention program is then defined in terms of 1 or more events (Figure 3D) which combine triggers to sampling procedures formulated as active tasks (Figure 3E) or sensor-based sampling (Figure 3F). Once the intervention program is deployed, specialists monitor participant's interaction and data collected (Figure 3G). These procedures are detailed next along with the corresponding requirements (Table 2).

Figure 3. ESPIM 7-step process.



Intervention Program: Name and Duration

The first step (Figure 3A) is to identify the intervention program by a name so that specialists can refer to the program for deployment, management, reuse, and change (FR01 in Table 2).

At the time of design, the intervention program deployment dates may not be determined. A program may be designed to be reused at distinct times, with different participants. Thus, when the intervention program is devised, the definition of starting or ending dates is optional (FR02).

An intervention program may be designed and structured to be applied in separate stages or phases delimited by time or other completion conditions (FR03).

Observers: Persons Who Have Access to the Planning Procedures

The second step is to register other specialists with access to the program (FR04 and FR06). This enables cases in which an intervention program is collaboratively designed or deployed, or both, by more than 1 specialist. Specialists that are responsible to manage intervention programs are called observers, and the optional step "observers" (Figure 3B) is employed when collaborators other than the one creating the intervention program should have access to its specification and results.

Participants: Persons Who Receive the Intervention Tasks via Their Mobile Device

The third step (Figure 3C) is to register the target users (participants) of the program (FR05). However, the actual target users may not have been determined when the intervention program is initially designed. Moreover, an intervention program may be designed to be reused with different participants at distinct times. Thus, when first creating the intervention program, the observer may not include real target users. Clearly, defining a participant is mandatory for deploying an intervention program. One strategy adopted by specialists in the case studies we report was to include themselves as participants, allowing them to test the intervention program before deployment by assuming a participant role (FR07).

Observers may include 1 or more target users in 1 or more programs (FR08). This characteristic is essential to provide flexibility to personalize programs for individualized monitoring or to monitor groups of target users. Specialists register participants' contact information and aliases targeting users' privacy (FR09).

Another type of participant represents persons having relationships to target participants, such as family members or caretakers, with whom specialists may interact. Thus, a requirement is support for relationship among participants and associating different events with distinct participant roles in the relationship, which should be personalized according to each case (FR10).

Finally, specialists may use existing information systems to import participants' data valuable to intervention planning. Therefore, a service-based approach should be considered for third-party system integration and information exchange (FR11).

Event(s): What Sets of Tasks Are Triggered, and When, in the Participant's Smartphone

An intervention program consists of 1 or more intervention events executed along a time frame. Each event (Figure 3D) is identified by a name which is used for reference within the intervention program itself or in other programs, warranting reuse of events in particular, additionally to the reuse of programs (FR01).

To each event, the observer associates a set of tasks to be put into effect in the participant's mobile device. The actual tasks are defined by means of an active set (Figure 3E) or via sensor-based sampling (Figure 3F), or both (FR12). In the first case, participants respond explicitly to a task, for instance, by answering a question or capturing a video. In the second case, data are gathered passively from the participant's smartphone, for instance, via sensors or automated logging routines.

Further, to each event the observer associates 1 or more triggers specifying the times in which event's tasks are to be executed in the participant's mobile device (FR13). This implies that, at the times planned by the specialists, the participant's smartphone receives a notification corresponding to the event. If the notification triggers a flow of active tasks (ie, intervention flow), a notification is presented in the participant's device at the level of intrusiveness specified (FR14); when the participant responds to the notification, the mobile app allows the participant to interact with the intervention flow. In cases in which the notification triggers a sensor-based sampling routine, the corresponding sensor or automated routine is executed.

Triggers should be of diverse types besides being time based (FR15) and should be associated with a timeout (FR16). Specialist-initiated triggers allow observers to launch tasks on their own initiative. Self-initiated triggers are necessary when specialists opt to allow users to execute an event at their own initiative by starting the mobile app themselves at any time. A random trigger is appropriated when specialists demand the event to start at unconventional times without a predetermined pattern. A contextual trigger is set off when a particular situation occurs, such as one defined by rules involving 1 or more conditions associated with physical sensors (eg, global positioning system coordinates or heart rate monitor) or software-based data (eg, agenda). In any case, the specialist may indicate that different events are of distinct types by using coding such as different colors (FR17). Moreover, an event that has been already completed may be indicated as such in the mobile app, along with other information that allows participants to be aware of their status in the intervention (FR18).

Furthermore, how a participant reacts to a trigger may be an important aspect to some studies; for instance, a trigger may need to be rescheduled or the observers should receive an alert when a participant did not answer (FR19-FR24). Contextual triggers (FR15) and automatic responses processing (FR24) are essential requirements if specialists consider ecological assessment for adaptive interventions (EMA and JITAI).

Intervention(s): What Flow of Tasks Are Explicitly Demanded via Participants' Devices

An intervention flow (ie, active set; Figure 3E) is specified by the observer (FR12) to be presented to the participant via a mobile app in a customizable flow of active tasks (FR25). An active task is an intervention-based component that may contain 1 or more multimedia stimuli allowing, among others, sending instructions and requesting information; text-based stimuli should support emphasis including bold and italics (FR26). A question is a type of active task which comprises different formats (FR27) and they may be mandatory or not (FR28). One type of question, single-choice question, allows associating a different flow with each of the alternatives defined, as a result, conditional parallel flows (FR29). An active task may interact with a third-party mobile app, for both activating that app with customized configuration and collecting data resulting from its execution (FR25). An active set may also trigger a passive collection of sensor data without the need for an explicit user intervention (eg, capturing the face expression during the task; FR30).

Passive Sampling: What Information Will Be Collected Without Explicitly Asking the User

Passive sampling is needed when the design of the intervention program makes use of passive data collection without interrupting the participant (Figure 3F). This can be initiated via the configuration of temporal intervals (FR31) or of automated sensor or software-based data collection (FR32), or via association with an active set (FR30). The collection may use sensors and software executing in devices other than the participant's smartphone such as wearable devices, accessories, and home sensors (FR33).

Passive sampling may be executed without an associated active set, as illustrated by Harari et al [58] when collecting data from sensors and logs. When this is the case, the observer specifies the sensors to be used as well as the conditions and the intervals of the collection.

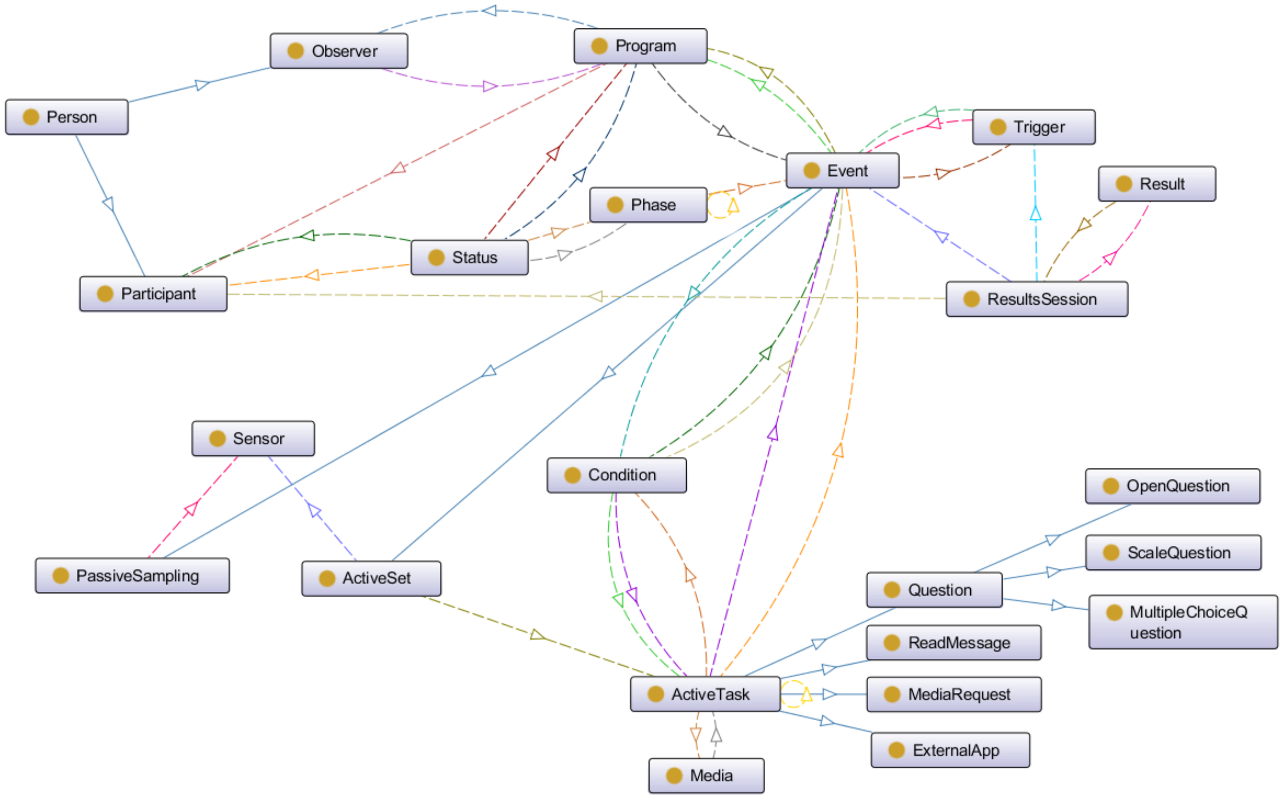
Results: When and How Participants Participated in the Intervention Program?

In some interventions, specialists demand monitoring how participants engage in the program to measure its impact or to adjust the intervention according to users' behavior and responses, or both (FR34 to FR37). When this is the case, observers need access to follow-up components which give access to results (Figure 3G). Another type is that in which specialists design an intervention program to provide information or to send instructions to participants, as is the case with tutorial apps or self-care apps [59]. When this is the case, the specialists do not need information on how and when users interacted with the program, which demands the follow-up procedure to be optional.

ESPIM: Ontology-Based Conceptual Model

Our study contributes to a conceptual model (Figure 4) guiding specialists in adopting existing software platforms or building new ones along with a software development team. We represent the conceptual model using an ontology given its wide adoption [60-64] and description power [65].

Figure 4. ESPIM: Ontology-based Conceptual Model.



In the ESPIM ontology, the *Person* class represents observers (specialists) and participants (target users). The person concept may retrieve data from existing information systems using a unique key (eg, email). Participants may have relationships with 1 or more users in the system (eg, child, caregiver, partner).

The *Program* class represents an intervention program that encompasses a set of events that defines sets of active tasks or sensor data sampling (sensor-based sampling). Observers manage programs individually or collaboratively.

The *Event* class represents personalized or standardized intervention events applied by observers. An event comprises sets of tasks (active set) or sensor-based sampling. The *Active Set* class represents tasks required explicitly for a participant, represented by classes contained in the *Active Task* class. The *Sensor* class represents tasks achieved via sensor-based sampling, which may demand continuous and unobtrusive data collection at defined time intervals. An active set can be associated with sensor-based sampling occurring while the participant performs the tasks. Events initiate according to defined trigger conditions (in *Trigger* class).

The *Trigger* class encompasses trigger conditions and an overall set up that determines when and how an event is triggered. A trigger can hold the following features: self-initiated, temporal, contextual, random/reason, and specialist-initiated trigger. A self-initiated trigger allows target users to start an event, a temporal trigger schedules events based on time and dates, a contextual-based trigger considers context information obtained by sensors or by device usage, and random/reason-based triggers randomly deliver a defined number of intervention events during a period. Observers may control triggers remotely. A trigger setup indicates notification timeout and obtrusiveness level.

The *Active Task* class corresponds to the delivery of stimulus that requires an interactive response. An active task contains at least one media stimulus (eg, text, image, audio, video). In the model, an active task comprises 4 types of stimuli: read message, question, media request, and external app.

In the *Active Task* class, the *Read Message* class represents sending multimedia messages to users. The *Question Active Task* class represents questions in different formats, including open-ended, multiple- and single-choice, and scales (eg, Likert). A question may include textual or other media elements. Choice questions represent loops and branches. A *Media Request Active Task* class represents the request for media assets (eg, audio). Finally, the *External App Active Task* class represents the activation of external apps, sending customized activation values and receiving completion results.

The *Media* class represents media stimuli employed in an active task instance. The model admits adding multiple media elements to a task.

The *Sensor* class represents the set up associated with sensor-based sampling: what should be collected (eg, social interaction, facial expressions) by which device (ie, wearable devices). Collection may occur over a period (sensor-based sampling) or during user interaction (active task).

The *Result* class represents data collected by the intervention program via active tasks or sensor-based sampling. Moreover, every participant interaction, or lack of interaction when expected, should be logged. Observers access instances of the *Results Session* class.

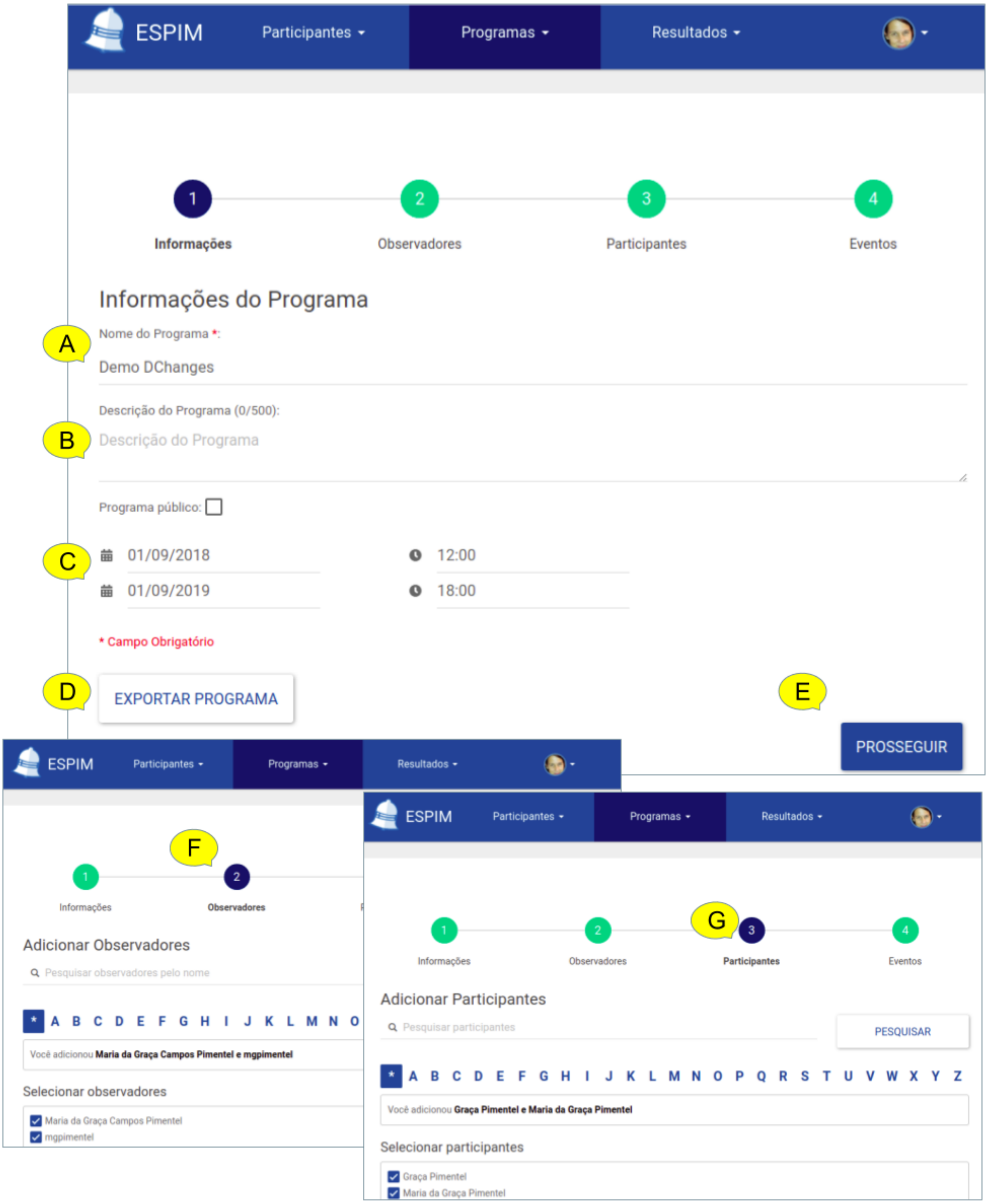
The *Condition* class represents actions triggered by conditional rules encompassing active (user interaction based) or passive (sensor based) data. For instance, if a participant fails to answer a notification, it is possible to execute an action such as alerting a particular observer or scheduling a new trigger.

The *Phase* class represents the organization of an intervention program in stages. The *Phase* class aggregates events, and each event may be included in 1 or more phases. A condition that defines when a participant should proceed to another phase defines a phase duration. Conditions may be time, contextual, or response dependent. Moreover, the *Status* class in the ESPIM ontology allows registering a participant's progress in an intervention program that has phases.

ESPIM Software

The iterative design leading to the ESPIM method (Figure 1) involved the iterative prototyping of the software instance (employed by specialists when authoring; Figures 5-8) and monitoring (Figures 9 and 10) an intervention program, and the mobile app used by participants (Figure 11; see Multimedia Appendix 3 for details).

Figure 5. ESPIM web application used by the specialist to create an Intervention Program. The first step (A) informs the program’s name and description (B), and duration (C). Options include exporting the program (D). The following steps register specialists (observers-F) and target-users (participants-G).



Informações do Programa

Nome do Programa *: Demo DChanges

Descrição do Programa (0/500): Descrição do Programa

Programa público: ☐

01/09/2018 12:00

01/09/2019 18:00

* Campo Obrigatório

Adicionar Observadores

Pesquisar observadores pelo nome

Você adicionou **Maria da Graça Campos Pimentel e mgpimentel**

Selecionar observadores

☑ Maria da Graça Campos Pimentel
☑ mgpimentel

Adicionar Participantes

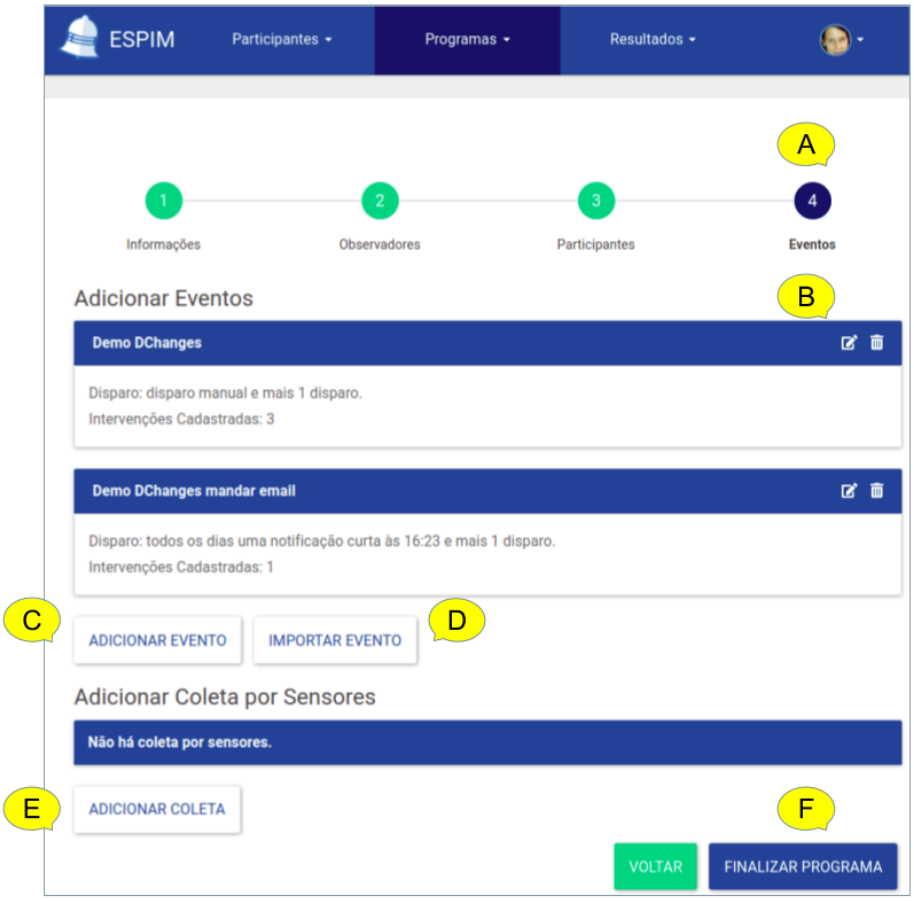
Pesquisar participantes

Você adicionou **Graça Pimentel e Maria da Graça Pimentel**

Selecionar participantes

☑ Graça Pimentel
☑ Maria da Graça Pimentel

Figure 6. ESPIM web application step with options for Events. Options in this step (A) include editing an existing event (B), editing a new event from scratch (C), or by importing an existing one (D), specifying collection based on sensors (E). Finalizing is always available (F).



Adicionar Eventos

Demo DChanges

Disparo: disparo manual e mais 1 disparo.
Intervenções Cadastradas: 3

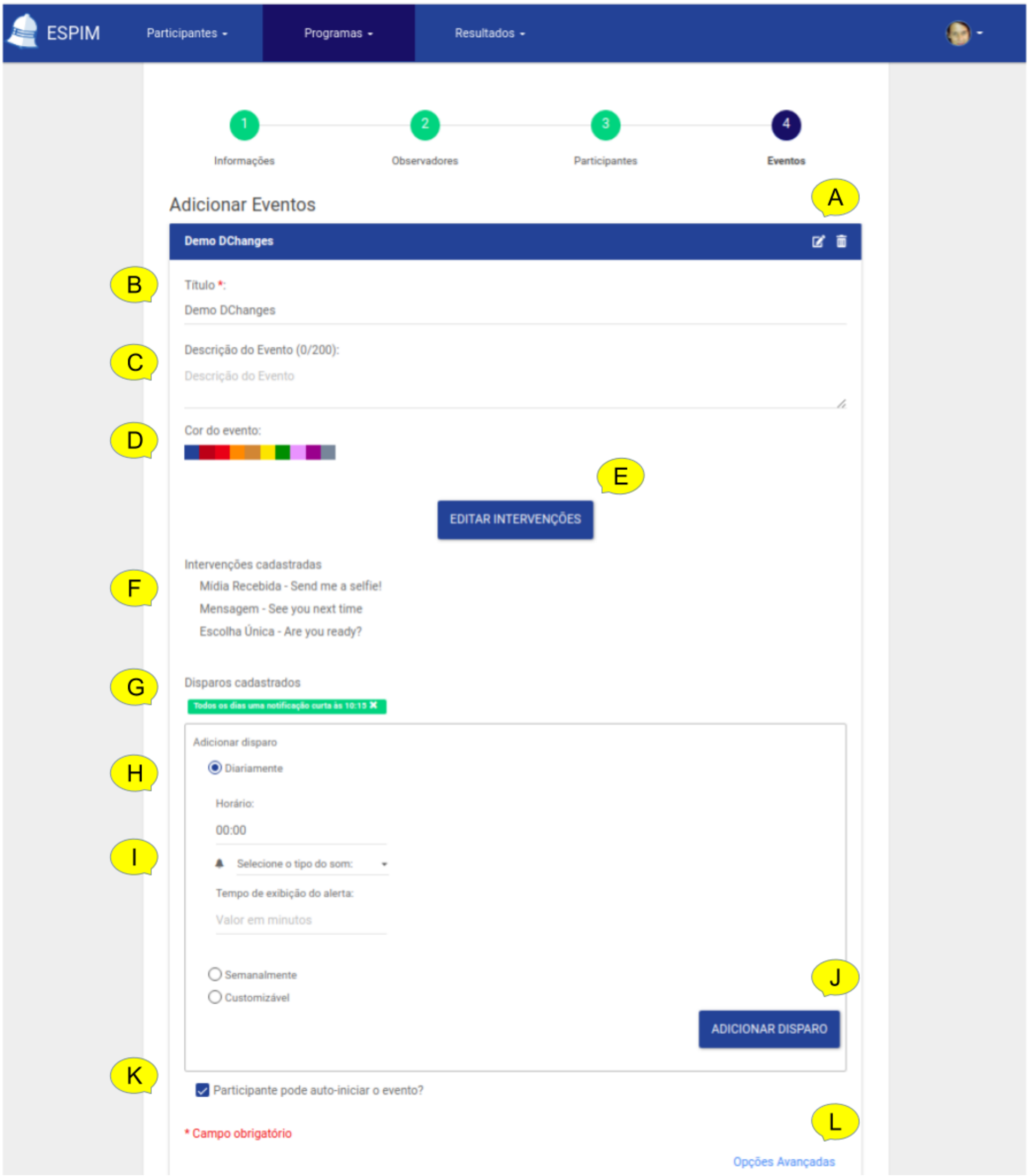
Demo DChanges mandar email

Disparo: todos os dias uma notificação curta às 16:23 e mais 1 disparo.
Intervenções Cadastradas: 1

Adicionar Coleta por Sensores

Não há coleta por sensores.

Figure 7. ESPIM web application step for editing one Event. For each Event (A), specialists provide a name (B), description (C), and color-coding (D). A button gives access to the interface for editing the corresponding flow of active tasks (E). This step shows the text from existing interventions (F) along with current triggers (G). Specialists create time-based triggers (H), and configure (I) and save the corresponding alarm types. Specialists can set self-initiated events (K) and configure that observers receive alerts when participants interact or miss an alarm (L).



Adicionar Eventos

Demo DChanges

Título *:
Demo DChanges

Descrição do Evento (0/200):
Descrição do Evento

Cor do evento:
🟦🟥🟥🟧🟧🟨🟩🟪🟪⬜

Intervenções cadastradas
Mídia Recebida - Send me a selfie!
Mensagem - See you next time
Escolha Única - Are you ready?

Disparos cadastrados
Todos os dias uma notificação curta às 10:15 ✕

Adicionar disparo
● Diariamente
Horário:
00:00
Selecione o tipo do som:
Tempo de exibição do alerta:
Valor em minutos
○ Semanalmente
○ Customizável

☑ Participante pode auto-iniciar o evento?

* Campo obrigatório

Figure 8. ESPIM web interface to create an Active Task Flow. This flow contains three interventions: a single-choice question (A), a task-based intervention requesting an image (B), and a message intervention (C). Specialists may include instructions using text (D) or other media (image (E), audio or video), or both. They must indicate the initial intervention (radio button in A), and mark each intervention as mandatory or optional (checkbox in A-C). The app shows arrows to indicate the flow (eg B>C). In a single-choice intervention (F), specialists may associate specific interventions to each alternative (A>B and A>C). Also, they can choose among many alternatives to choice- and scale-based questions (G). When specialists create a task requesting media (B), they indicate the type of media required (“image” in H). They must nominate at least one closing intervention (I). The specialist can zoom (K), and import and export (J) flows.

1 - Escolha Única

● 1ª intervenção

☑ Obrigatória

Digite a questão (14/800): Are you ready?

Alternativas

1 Yes — 3 (Solicitar Mídia)

2 No — 2 (Mensagem)

3 - Solicitar Mídia

○ 1ª intervenção

☑ Obrigatória

Digite a mensagem (17/800): Send me a selfie!

Tipo de mídia: Imagem

2 (Mensagem)

2 - Mensagem

○ 1ª intervenção

☑ Obrigatória

Digite a mensagem (17/800): See you next time

Finalizar

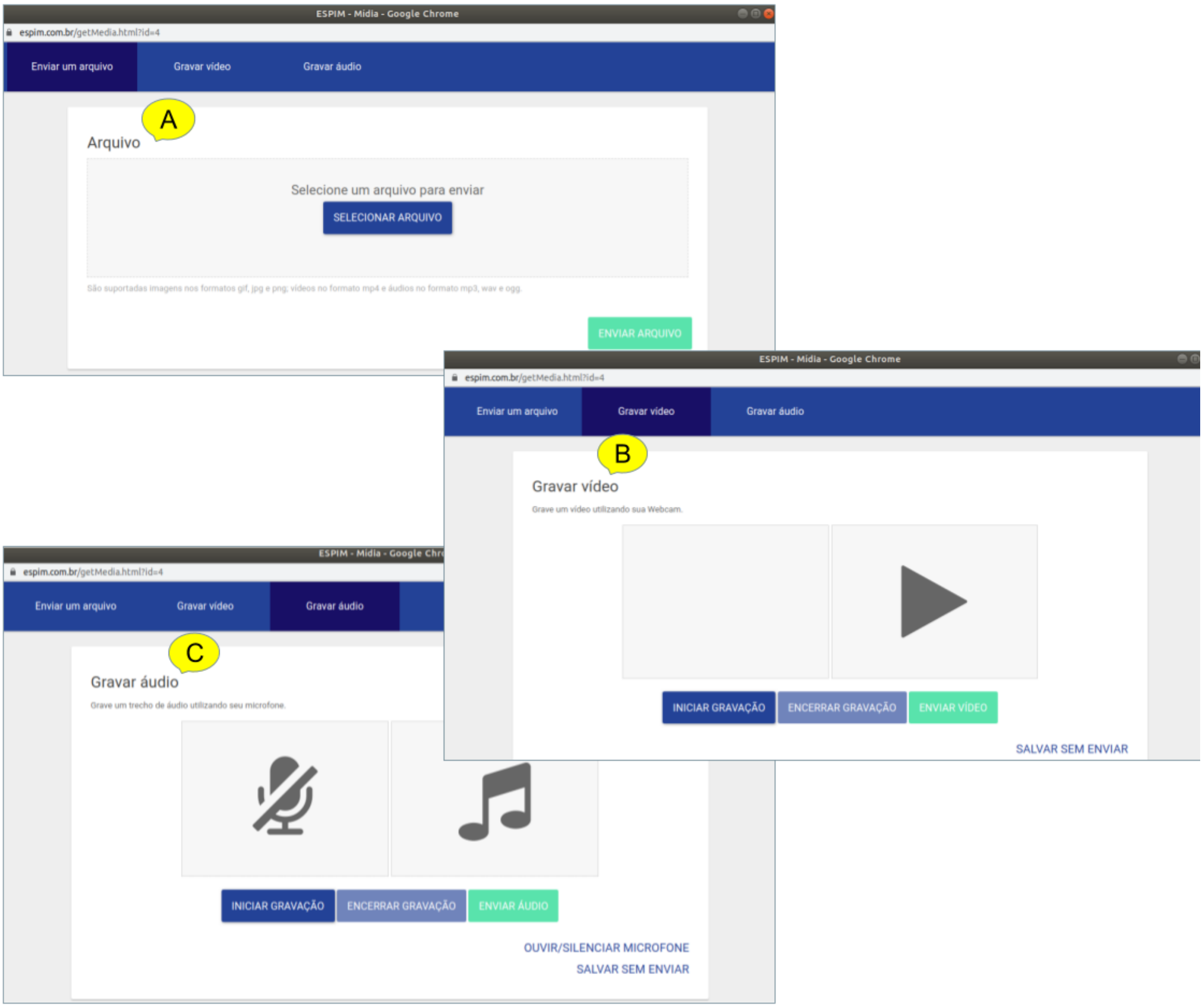


Figure 9. ESPIM web interface to upload media-based stimuli (A) and to record video (B) or audio (C).

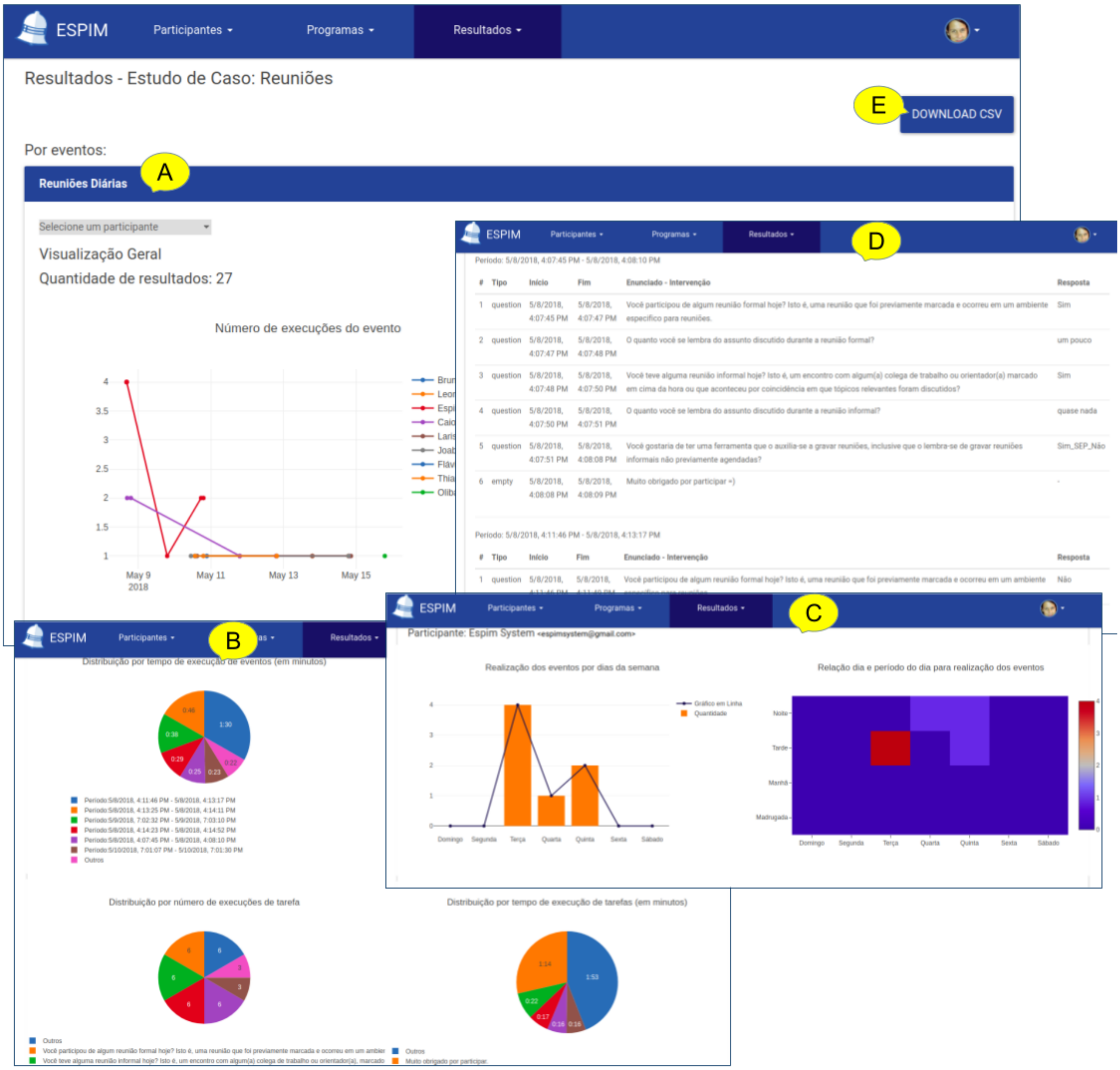
Selecione um arquivo para enviar

São suportadas imagens nos formatos gif, jpg e png; vídeos no formato mp4 e áudios no formato mp3, wav e ogg.

Grave um vídeo utilizando sua Webcam.

Grave um trecho de áudio utilizando seu microfone.

Figure 10. ESPIM web interface to visualize results includes an overview by a participant (A), distributions of responses both per task (B) and along the time (C), access to individual responses (D), and an option for download (E).



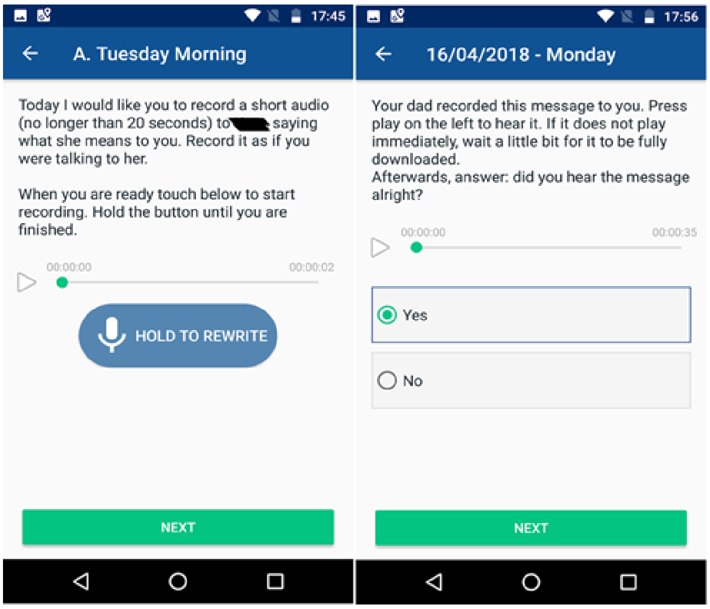
Período: 5/8/2018, 4:07:45 PM - 5/8/2018, 4:08:10 PM

#	Tipo	Início	Fim	Enunciado - Intervenção	Resposta
1	question	5/8/2018, 4:07:45 PM	5/8/2018, 4:07:47 PM	Você participou de algum reunião formal hoje? Isto é, uma reunião que foi previamente marcada e ocorreu em um ambiente especifico para reuniões.	Sim
2	question	5/8/2018, 4:07:47 PM	5/8/2018, 4:07:48 PM	O quanto você se lembra do assunto discutido durante a reunião formal?	um pouco
3	question	5/8/2018, 4:07:48 PM	5/8/2018, 4:07:50 PM	Você teve alguma reunião informal hoje? Isto é, um encontro com algum(a) colega de trabalho ou orientador(a) marcado em cima da hora ou que aconteceu por coincidência em que tópicos relevantes foram discutidos?	Sim
4	question	5/8/2018, 4:07:50 PM	5/8/2018, 4:07:51 PM	O quanto você se lembra do assunto discutido durante a reunião informal?	quase nada
5	question	5/8/2018, 4:07:51 PM	5/8/2018, 4:08:08 PM	Você gostaria de ter uma ferramenta que o auxilia-se a gravar reuniões, inclusive que o lembra-se de gravar reuniões informais não previamente agendadas?	Sim_SEP_Não
6	empty	5/8/2018, 4:08:08 PM	5/8/2018, 4:08:09 PM	Muito obrigado por participar =)	-

Período: 5/8/2018, 4:11:46 PM - 5/8/2018, 4:13:17 PM

#	Tipo	Início	Fim	Enunciado - Intervenção	Resposta
1	question	5/8/2018,	5/8/2018,	Você participou de algum reunião formal hoje? Isto é, uma reunião que foi previamente marcada e ocorreu em um ambiente	Não

Figure 11. Mobile app presenting interventions. Active task requesting the user to record an audio message (left). Active task inviting the user to respond to a single-choice question upon listening to an audio stimulus (right).



Today I would like you to record a short audio (no longer than 20 seconds) to [redacted] saying what she means to you. Record it as if you were talking to her.

When you are ready touch below to start recording. Hold the button until you are finished.

Your dad recorded this message to you. Press play on the left to hear it. If it does not play immediately, wait a little bit for it to be fully downloaded.
Afterwards, answer: did you hear the message alright?

● Yes

○ No

Evaluation Outcomes

Interview (Predesign)

The predesign interviews lead to eliciting requirements from a group of specialists from several backgrounds (Figure 1C). We consolidate the results into ESPIM's functional requirements (Table 2).

First Heuristic Evaluation (App Prototype)

For the app prototype (Figure 1D), the HCI evaluation team reported the following issues: (1) navigation problems (store navigation and branching paths, confirm before quitting, clear paths upon abandonment/finishing); (2) inconsistent display on different versions of the operating system; (3) improve screen use (landscape orientation and fix overlay in small screens when the virtual keyboard is visible); (4) generic/uninformative notifications; and (5) nonstandard fonts. We fixed these issues and applied the material design guidelines [66].

First Usability Test (Web Application Prototype)

Each specialist interacted individually with the web application (Figure 1F) according to an 8-task hypothetical scenario (see Table SM1 in Multimedia Appendix 1). ESPIM researchers (including KRHR and IZ) observed the interaction. Upon conclusion, specialists answered the evaluation questionnaires and participated in a semistructured interview to report problems, feelings, and expectations. Results from each task are as follows.

Specialist P1 could not complete tasks 7 and 8 as she could not find the "Save" button. Specialists P3 and P5 partially completed task 7 (see Figure SM1 in Multimedia Appendix 1) as they added extra activities to the intervention planned. Regarding errors, specialists P2, P3, and P5 made 4 errors; P4 and P1 made 6 and 9 errors, respectively. The errors included creating an existing observer or participant, opening an external page during the interaction, using the first intervention element (a star icon) as a "Save" button, trying to save an empty program, and unexpected interactions with the interventions' flow screen.

Regarding the tasks, specialists made more than 1 error in tasks 4 and 7. In task 4, all specialists were uncertain about the meaning and function of the "observers" role. Task 7 was the one in which the specialists presented more difficulty and made more mistakes. This task had several substeps and demanded more attention, so specialists spent the longest (mean 13 min [SD 0.55]).

Results from the subjective evaluation of the interface elements range from –3 to +3. Specialists rated positively most aspects evaluated. Aspects evaluated +2 (Good) and +3 (Excellent) were available features, ease of memorization, and learning during use. The items with the lowest ratings were feedback/error messages, ease to undo errors, and information organization of the system. One negative score (–1) was attributed to "ease to undo errors" by P1 and was consistent with her overall performance. P1 could not fulfill 1 task and partially fulfilled another (tasks 8 and 7, respectively). P1 also made the highest number of errors.

The results from the UX while interacting with the system were positive, ranging between 1.4 and 3 (–3 to +3 range), meaning that specialists associated their experience with positive qualifiers, concepts, or feelings. The most positive evaluations were "efficiency" (mean 2.55 [SD 0.60]) and "dependability" (mean 2.35 [SD 0.87]). Evaluation of the remaining factors were as follows: attractiveness, mean 2.16 (SD 0.79); perspicuity, mean 2.10 (SD 0.78); stimulation, mean 2.10 (SD 0.71); and novelty, mean 2.05 (SD 0.68). As a result, specialists considered that they could interact efficiently, execute tasks reliably, understand and find functionalities, and felt stimulated and motivated during the interaction. They also perceived the system as innovative and attractive regarding interface elements.

Checklist

The UI/UX designers who designed the graphical interfaces of the ESPIM web applications suggested 9 improvements to the corresponding implementation (Figure 1J), including components behavior according to the material design guidelines, user lists presentation order, and text size and spacing. We adjusted them accordingly.

Heuristic Evaluation

For the heuristic evaluation of the ESPIM web application (Figure 1J2), the evaluators' report contained 71 usability issues. They classified 24 problems with severity 1 (cosmetic), 16 with severity 2 (minor), 26 with severity 3 (major), and 5 with severity 4 (catastrophic). Evaluators associated problems with 4 heuristics: consistency and standards, user control and freedom, flexibility and efficiency of use, and aesthetic and minimalist design. The ESPIM team promptly solved issues classified with severity 3 and 4 to provide a version for tests with gerontologists (Figure 1L1 and Figure 1L2). We fixed the other problems in later versions [52,67].

For the heuristic evaluation of the ESPIM mobile app (Figure 1J3), the evaluators' report comprised 21 usability issues. They classified 4 problems with severity 1 (cosmetic), 6 with severity 2 (minor), 8 with severity 3 (major), and 2 with severity 4 (catastrophic). Although evaluators associated 1 issue with the user control and freedom heuristic (7/21), we argued that we purposely designed some guiding-based features to make the app accessible to a wide range of user profiles. Yet, evaluators considered that several icons and some nomenclature lack intuitiveness and associated the issues with the correspondence between the system and the real-world heuristic (5/21). Evaluators associated other issues with the following heuristics: system status visibility, recognition instead of memorization, flexibility and efficiency of use, and aesthetic and minimalist design. We solved the problems before tests with gerontologists (Figure 1L1 and Figure 1L2).

Second Usability Test (Web Application) and Interview (App)

For the second usability test of the web application (Figure 1L1), each specialist interacted with the system according to a set of 10 tasks contemplated by 1 hypothetical scenario (see Table SM2 in Multimedia Appendix 1). ESPIM researchers (including KRHR and BCRC) observed the interaction. According to the protocol, the specialists answered the evaluation questionnaires and participated in a semistructured interview (see Textbox SM5 in Multimedia Appendix 1).

Specialists P1, P4, P6, and P5 completed all tasks. Specialists P2 and P3 partially completed task 7 (see Figure SM1 in Multimedia Appendix 1) because they did not find the requested media for uploading in the computer used for the test. Regarding errors, most happened at the planning interventions screen (Figure 7). Some specialists (3/6) faced difficulties in defining the intervention flow, especially the beginning and end.

Regarding the tasks, specialists made more than 1 error in tasks 4, 7, and 8. In task 4 (creating and adding a new observer), the specialists had difficulties registering emails in the interface. Task 7 was again the one in which the specialists made more mistakes. They spent more time executing task 7 (planning intervention flow; mean 15 min [SD 0.7]) as this task required more attention and the most steps. In task 8 (adding triggers), specialists faced difficulties understanding interface elements. For all other activities, the average execution time of participants was less than 2 min (SD 0.43).

Results from the questionnaire reporting subjective evaluation of interface elements were positive in most aspects. Aspects evaluated between "good" and "excellent" were layout of interface elements, available features, and ease of memorization. Five of six evaluators rated the aspect "learning during the use" between "excellent" and "very good." Specialist P2, who did not complete the tasks, evaluated this aspect as "too bad," reported "I really liked using ESPIM, it seems to me a very pleasant, intuitive tool" and offered the following suggestion, which we incorporated later: "[...] sometimes I lost a description explaining what the specific term meant: having short and clear information would have facilitated my journey."

At the concluding interviews, the specialists provided input as instructors or tutors in digital literacy courses for older people (CS-ElderlyDL; Figure 1H2). Specialists remarked as positive the simple aesthetic of the interface with "well-chosen colors" (colors considered color-blind users) and the in-app back button, justifying that some older people face difficulties finding the smartphone back button. Interviewees related that the app improved the engagement and learnability of the older people in the classes (especially when compared with control groups), multimedia messages promoted positive emotions, and mobile-delivered homework helped avoid evasion. Interviewees also reported some issues: users did not understand the asterisk in mandatory fields (consider disabling the next button), users did not know how to react to open questions (consider the automatic display of keyboard), users did not notice that a media was already captured (consider feedback with media preview), users clicked outside of multiple-choice options (consider exhibiting them inside inline boxes), lack of configuration for notification intrusiveness, and lack of in-app configuration for enabling/disabling 3G network usage.

Interview (Postdesign)

We conducted semistructured interviews with 8 specialists to identify the limitations they faced while conducting their case studies (Figure 1R). We classified the limitations as related to the model or the software. Model-related limitations imply modifying or extending the model to allow representing the required solution. Implementation-related limitations are restricted by the current system version: the model represents the corresponding solutions, but these are not yet available in the system. Because the latter are implementation specific, we discuss only model-related limitations.

Interviewees reported 4 limitations that require revisions in the conceptual model. The first limitation is related to the lack of support to represent the management of participants' records. Such a support would allow specialists to register information they consider relevant. To allow representing such a feature, we must extend the model accordingly.

The second limitation concerns representing the organization of participants into groups other than direct relationships among participants (as per FR10). The solution requires creating a class that allows multiple associations between specialists, participants, and groups so that a participant may be part of various groups managed by different specialists.

The other 2 limitations concern groups of events: we should extend the model to represent both hierarchical and customizable groups of events. The analogous implementation would allow the corresponding visual customization of groups of events.

Although these limitations require changes in the conceptual model, they did not limit the planning, authoring, or deploying of the interventions by the specialists.

Discussion

Principal Findings

Our study tackles limitations faced by health professionals determined to conduct mHealth interventions. Our main results are the ESPIM method and the conceptual model, which succeeded in leading specialists in planning, authoring, and deploying mHealth intervention programs with the support of a representative software system. ESPIM comprises (1) a list of requirements for mHealth experience sampling and intervention-based methods and systems, (2) a 4-dimension planning framework, (3) a 7-step-based process, and (4) an ontology-based conceptual model. A subsidiary result is the ESPIM software.

The list of requirements, offered to specialists when planning and deploying interventions, results from literature review, predesign interviews, iterative prototyping, and postdesign interviews. The 4-dimension planning framework aims to guide the planning of mHealth interventions by specialists by clarifying elements to be considered when using mobile, wearable, and ubiquitous technologies. The framework helps designing an intervention program while supporting team communication. The 7-step-based process guides the procedures that support ESPIM-based software.

A main contribution of ESPIM is a conceptual model aimed at guiding specialists in adopting existing software platforms or building new ones. The ESPIM ontology–based conceptual model represents the requirements collected and refined during our long-term design experience with health specialists and their research/professional needs. As a conceptual model, it defines a process and a common vocabulary to plan mobile device–mediated interventions; it also aids the development of mHealth apps.

Overall, ESPIM components can guide the planning and deployment of an intervention program using existing solutions, drive selecting one among the available tools, or guide the implementation of a novel specific or general platform.

While inspection-based usability evaluations of the ESPIM interfaces identified problems, we used the HCI specialists' feedback to make continuous improvements to the ESPIM system. Such evaluations preceded usability tests with professionals and their target users, and the resulting adjustments lead to intuitive and satisfactory usability tests.

Limitations

Limitations of our study are associated with those of the contributions. With respect to the list of requirements, even though requirements were elicited via interviews, iterative design, and empirical evaluation, some requirements might be left out, in particular due to the lack of case studies that demand supporting relationships among participants (FR10) or that employ home sensors, wearable devices, and JITAIs along with machine learning–based triggers [68,69]. These limitations are reflected in the 4-dimension planning framework, in the sensor dimension which might be more detailed to support such scenarios that demand, for instance, human activity recognition [70]. In future studies, new interviews can be conducted until new requirements are not identified [71]. In addition, we are running accessibility studies to provide solutions that can be used by different target-user profiles.

Concerning the 7-step-based process, the last step "results" should be extended to further assist data collection such as retrospective surveys [72], data analysis, and study reports. Besides, as data collection grows, integrating data analysis algorithms may support building predictive user models [69,73,74]. Further, with the growing adoption of experience sampling and program-based mHealth interventions, support to the specialists should be provided toward the production of reports in sufficient details to allow both replication and theory building, as was the case with randomized controlled trials [75].

Limitations of the ontology-based conceptual model include those identified in the postdesign interviews, which can be tackled by supporting participants' records and by the organization of participants into groups and the organizing events into hierarchical groups. These and other features can be promoted with the formalization of the current integration with external services [57].

Furthermore, while our work included usability evaluations to improve both the method and the system, dealing with barriers highlighted by Byambasuren et al [47], and provided a complementary method for JITAIs guidelines, as proposed by Nahum-Shani et al [76], evaluations of mHealth interventions still are a prominent gap in the literature which ESPIM did not address, as precisely identified by Bradway et al [77] and Dick et al [78].

Finally, our study identified important nonfunctional requirements which have not been included in the method's list of requirements, even though they are in consonance with recent literature and are partially attended by the current system. As a result of a systematic review on mHealth-related apps, Llorens-Vernet and Miró [79] offer a list of criteria, grouped into categories, aimed at guiding the development of mHealth apps. The systematic review ensured the categories (usability, privacy, security, appropriateness and suitability, transparency and content, safety, technical support and updates, and technology) are consistent with those identified by other authors in related contexts [7-10].

Comparison With Prior Work

The ESM and EMA methods for mobile-based data collection are a popular alternative [25,80], while EMIs and JITAIs depend on mobile technologies to monitor contextual changings. Some contributions report authoring and deployment systems.

MyExperience [81] pioneered employing ESM via a customizable mobile app, supporting sensor data capture, contextual triggers configuration, and questionnaires authoring. The authors predicted several scenarios and inspired later works. However, ESM programs were added to mobile devices as XML files, and real-time monitoring was not possible. MyExperience's spin-off movisensXS [32] is a platform with a graphical interface for creating questions with flow logic and media capture, temporal and contextual triggers, and real-time monitoring.

PACO (Personal Analytics COmpanion) [82] is an open-source system that allows the authoring of questions and media capture with branching features associated with logical operators. Despite its simplicity, PACO was the first to present an end-user graphical interface.

The ExperienceSampler [83] and AWARE [84] frameworks simplify the creation of ESM apps through logical and declarative programming. ExperienceSampler allows users to implement apps with messages, questions, skip and branching logic, and random-based notifications. AWARE focuses on logging sensor-based context information; its flexible contextual model considers 8 question types, branching logic, time, context-based notifications, and conditional broadcasts (eg, announce when each user answers a question).

Among commercially available systems, LifeData [31] enables the authoring of 14 types of tasks, including capturing photos and exhibiting a website, with logic and temporal flows, and self-initiated and random-based triggers. LifeData also enables the configuration of conditional actions and relationships among target users. Mobile EMA [33] provides a complex authoring interface, and allows displaying images in questions and integrating smartwatches to collect sensor data. LifeData and Mobile EMA systems comply with many of the functional requirements discussed in this paper, being extensively used in academic research [26-30].

Rough and Quigley [36] present recommendations and requirements for ESM authoring systems. They conducted interviews with 13 researchers and clinicians, 2 one-hour clinical observations, and 3 case studies with psychology researchers. They also propose the block-based visual programming tool Jeeves. The authors elicit 5 functional requirements for ESM tools: (1) collaboration and (2) support/share of projects, (3) tailoring of protocols and reminders to individuals, (4) debriefing/feedback/reminders in addition to surveys (ie, alternative types of tasks), and (5) ability to test both appearance and contextual behavior.

Investigating intervention design by specialists, Nahum-Shani et al [35] provided a framework for organizing theoretical and practical evidence into a model that supports authoring JITAIs. The authors discussed approaches for defining elements including states of vulnerability/opportunity and receptivity, outcomes, and adaptation strategy. Later, Nahum-Shani et al [76] proposed key components and design principles for designing mHealth JITAIs. The authors remark that authoring demands specialists to be concerned with components such as content, media, types of signal, temporal and contextual opportunities, receptivity marks, among others.

These works are complementary to ESPIM as they guide aspects of interventions' planning. ESPIM provides a step-by-step model and ontology that allows organizing mHealth intervention components considering requirements from ESM, EMA, EMIs, JITAIs, and long-term studies with specialists from diverse areas. Furthermore, the ESPIM system demonstrates the feasibility of developing an authoring system based on the method, encompassing imperative features and providing flexibility for integrating ecological and just-in-time interventions.

Conclusions

The ESPIM comprises a list of requirements for mHealth experience sampling and intervention-based methods and systems, a 4-dimension planning framework, a 7-step-based process, and an ontology-based conceptual model. The ESPIM system encompasses web and mobile apps. Besides overseeing the planning of an intervention program, ESPIMs components guide the design of an ESPIM-based software platform as in our study. Moreover, current limitations point to further research as well as practical actions.

Eight case studies show that the ESPIM method and system allowed specialists to be the users who planned, created, and deployed interventions. The case studies encompassed interventions by professionals from psychology, gerontology, computer science, speech therapy, and occupational therapy. Specialists' target users were parents of children diagnosed with autism spectrum disorder, older persons, university students, children, and older person's caregivers. The specialists reported being able to create and conduct their studies without modifying their original design. A qualitative evaluation of the ontology-based conceptual model showed its compliance to the elicited functional requirements.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Evaluations protocols and tasks.
[DOC File , 1374 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Semi-structured interview questions.
[DOC File , 32 KB-Multimedia Appendix 2]

Multimedia Appendix 3

ESPIM system details.
[DOC File , 1028 KB-Multimedia Appendix 3]

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Abbreviations

EMA: ecological momentary assessment
EMI: ecological momentary intervention
ESM: experience sampling method
ESPIM: Experience Sampling and Programmed Intervention Method
FR: functional requirements
HCI: human–computer interaction
JITAI: just-in-time adaptive intervention
mHealth: mobile health
PACO: Personal Analytics COmpanion
UEQ: User Experience Questionnaire
UI: user interface
UX: user experience

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Original Paper

One Decade of Online Patient Feedback: Longitudinal Analysis of Data From a German Physician Rating Website

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Abstract

Background: Feedback from patients is an essential element of a patient-oriented health care system. Physician rating websites (PRWs) are a key way patients can provide feedback online. This study analyzes an entire decade of online ratings for all medical specialties on a German PRW.

Objective: The aim of this study was to examine how ratings posted on a German PRW have developed over the past decade. In particular, it aimed to explore (1) the distribution of ratings according to time-related aspects (year, month, day of the week, and hour of the day) between 2010 and 2019, (2) the number of physicians with ratings, (3) the average number of ratings per physician, (4) the average rating, (5) whether differences exist between medical specialties, and (6) the characteristics of the patients rating physicians.

Methods: All scaled-survey online ratings that were posted on the German PRW jameda between 2010 and 2019 were obtained.

Results: In total, 1,906,146 ratings were posted on jameda between 2010 and 2019 for 127,921 physicians. The number of rated physicians increased constantly from 19,305 in 2010 to 82,511 in 2018. The average number of ratings per rated physicians increased from 1.65 (SD 1.56) in 2010 to 3.19 (SD 4.69) in 2019. Overall, 75.2% (1,432,624/1,906,146) of all ratings were in the best rating category of "very good," and 5.7% (107,912/1,906,146) of the ratings were in the lowest category of "insufficient." However, the mean of all ratings was 1.76 (SD 1.53) on the German school grade 6-point rating scale (1 being the best) with a relatively constant distribution over time. General practitioners, internists, and gynecologists received the highest number of ratings (343,242, 266,899, and 232,914, respectively). Male patients, those of higher age, and those covered by private health insurance gave significantly ($P<.001$) more favorable evaluations compared to their counterparts. Physicians with a lower number of ratings tended to receive ratings across the rating scale, while physicians with a higher number of ratings tended to have better ratings. Physicians with between 21 and 50 online ratings received the lowest ratings (mean 1.95, SD 0.84), while physicians with >100 ratings received the best ratings (mean 1.34, SD 0.47).

Conclusions: This study is one of the most comprehensive analyses of PRW ratings to date. More than half of all German physicians have been rated on jameda each year since 2016, and the overall average number of ratings per rated physicians nearly doubled over the decade. Nevertheless, we could also observe a decline in the number of ratings over the last 2 years. Future studies should investigate the most recent development in the number of ratings on both other German and international PRWs as well as reasons for the heterogeneity in online ratings by medical specialty.

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KEYWORDS

physician rating websites; patient satisfaction; patient feedback; online ratings

Introduction

Feedback from patients is an essential element of a patient-oriented health care system [1]. Patients' views and opinions on the care they have experienced can help health care organizations and professionals identify areas that need to be improved and can also help other patients with decision making when choosing where to receive health care [2]. Health care organizations and professionals can gather patient feedback in a variety of ways, including by conducting patient surveys, audits, interviews, focus groups, and deliberative events [3]. Patients have also always been able to actively share their views and opinions about the care they received with family and friends or with health care organizations and professionals via unsolicited comments or complaints. However, patients increasingly also have the ability to share their views and opinions on the internet and social media [4-7].

Physician rating websites (PRWs) are one of the key opportunities for patients to provide feedback online [4,7]. A systematic search of PRWs in 2018 identified 143 websites from 12 countries; however, the majority of websites were commercially operated in the United States and Germany [8]. Previous research involving PRW ratings in Germany and other countries has highlighted some common themes, including incomplete lists of physicians, a low number of physicians rated, a low number of ratings per physician that are overwhelmingly positive, and unstructured and different rating systems, which has raised concerns about the representativeness, validity, and usefulness of feedback on PRWs [7,9-30]. Medical associations have also often expressed strong opposition to PRWs, concerned that they will be used for doctorbashing or defamation [31,32]. Countries have different legal frameworks with regards to data protection, and previous research suggests that restrictive legal environments (eg, Switzerland) may be having an impact of the types of ratings on PRWs [28,29]. However, the legal basis for PRWs in Germany is reasonably liberal and well established. The Federal Court of Justice of Germany confirmed in 2014 the permissibility of ratings on the basis of the right to freedom of expression and that the anonymity of raters can only be lifted in exceptional cases [33,34]. Research also indicates that PRWs in Germany are having some success in influencing patient decision making and quality improvement [17,35].

However, most studies examining PRWs ratings have typically focused on a certain year (eg, [13,18,21]), a certain medical specialty (eg, [22,23,36-40]), certain cities or regions (eg, [14,26,41]), or with a (more or less) randomly selected sample of physicians or ratings (eg, [14,21,26,36,41]). There is therefore a need for a more comprehensive examination of PRW ratings, to reveal a more generalizable view of ratings and allow trends in rating habits to be identified. As far as we are aware, only 2 studies from the United States [13] and Canada [27] have presented such findings.

This study takes a different approach from most previous studies and analyzes an entire decade of online ratings for all medical specialties on the German PRW, jameda [14,21,26,42] (Please note that the data are not publicly available but may be provided from the provider of the website for research purposes upon request.). Jameda was founded in 2007 and since 2016, has been a wholly owned subsidiary of Burda Digital GmbH. The commercial website provides users with a categorized search function to find suitable physicians, the ability to make appointments with physicians online, the possibility to have video consultations with physicians, an encyclopedia with information from experts on health topics, and an opportunity to rate physicians on a predefined grading system or leave narrative comments. In Germany, a total of 25 PRWs have been identified [8]; however, previous research has indicated that jameda is the German PRW with the highest public awareness, usage, and number of ratings given [4,14,26].

The aim of this study was to examine how ratings posted on the German PRW jameda have developed over the past decade. In particular, it aimed to explore (1) the distribution of ratings according to time-related aspects (year, month, day of the week, and hour of the day) between 2010 and 2019, (2) the number of physicians with ratings, (3) the average number of ratings per physician, (4) the average rating, (5) whether differences exist between medical specialties, and (6) the characteristics of the patients rating physicians.

Methods

Overview

All scaled-survey online ratings that were posted on jameda between 2010 and 2019 were provided by jameda. Ratings on jameda are given according to the 6-point grading system used in German schools (1=very good, 2=good, 3=satisfactory, 4=fair, 5=deficient, and 6=insufficient) [24], in relation to 5 questions: (1) satisfaction with the treatment provided by the physician, (2) the physician's explanation about the illness and treatment, (3) the relationship of trust with the physician, (4) the time the physician spent with the patient, and (5) friendliness of the physician. Additionally, a mean score ("overall performance") is calculated based on the results for Q1 to Q5 [24]. The data also contained the physician's year of birth and medical specialty, as well as the rating patient's gender, age, and health insurance status.

Statistical Analysis

Descriptive statistics included means and SDs for continuous variables as well as numbers and percentages for categorical variables. To analyze whether differences existed between 2 groups, the Mann-Whitney *U* test was used for continuous nonparametric variables, and the Kruskal-Wallis test was applied to determine differences between more than 2 groups. The Shapiro-Wilk test was used to examine the normality of the data distribution. Cohen *d* was calculated to measure the magnitude of the effect size by comparing the standardized difference between the means of 2 groups. All statistical analyses were conducted using SPSS version 22.0 (IBM Corp, Armonk, NY). Differences were considered to be significant if $P<.05$ and highly significant if $P<.001$.

Results

Distribution of Ratings and Mean Ratings

In total, 1,906,146 ratings were posted on jameda between 2010 and 2019 (see Table 1). The highest proportions of ratings were left in 2017 (293,744/1,906,146, 15.41%) and 2018 (292,721/1,906,146, 15.36%). In 2019, there was a decline in the number of ratings (232,739/1,906,146, 12.21%) in comparison with the previous years. Ratings were distributed throughout the months of the year relatively equally (minimum in December: 143,620/1,906,146, 7.53%; maximum in March: 173,865/1,906,146, 9.12%), but more variation was found by day of the week (minimum on Saturdays: 123,024/1,906,146, 6.45%; maximum on Tuesdays: 356,128/1,906,146, 18.68%) and by hour of the day (minimum during 3-4 am: 4659/1,906,146, 0.24%; maximum during 11-12 am: 152,606/1,906,146, 8.00%). Likewise, the mean ratings were relatively similar across years (minimum in 2019: mean 1.71, SD 1.52; maximum in 2013: mean 1.83, SD 1.56), months (minimum in January: mean 1.73, SD 1.49; maximum in August: mean 1.77, SD 1.54), and days (minimum on Sunday: mean 1.68, SD 1.45; maximum on Monday: mean 1.78, SD 1.54). However, more variation could be seen by hour of the day (minimum during 7-8 am: mean 1.67, SD 1.43; maximum during 2-3 am and 3-4 am: mean 2.05, SD 1.75 and mean 2.05, SD 1.72, respectively).

Table 1. Distribution of ratings (N=1,906,146) and mean ratings.

Timeframe	Ratings, n (%)	Mean rating, mean (SD)
Year		
2010	31,908 (1.67)	1.73 (1.42)
2011	61,726 (3.23)	1.74 (1.44)
2012	98,041 (5.14)	1.77 (1.50)
2013	154,119 (8.08)	1.83 (1.56)
2014	219,319 (11.51)	1.81 (1.54)
2015	237,354 (12.45)	1.79 (1.54)
2016	284,475 (14.92)	1.71 (1.48)
2017	293,744 (15.41)	1.73 (1.52)
2018	292,721 (15.36)	1.78 (1.57)
2019	232,739 (12.21)	1.71 (1.52)
Month		
January	170,699 (9.00)	1.73 (1.49)
February	167,728 (8.80)	1.77 (1.53)
March	173,865 (9.11)	1.77 (1.53)
April	151,098 (7.93)	1.77 (1.53)
May	152,995 (8.02)	1.76 (1.53)
June	147,422 (7.73)	1.76 (1.53)
July	160,596 (8.43)	1.77 (1.53)
August	151,544 (7.95)	1.77 (1.54)
September	155,261 (8.15)	1.75 (1.52)
October	161,630 (8.48)	1.77 (1.53)
November	169,688 (8.90)	1.75 (1.52)
December	143,620 (7.53)	1.73 (1.51)
Day of the week		
Monday	342,025 (17.94)	1.78 (1.54)
Tuesday	356,128 (18.68)	1.78 (1.54)
Wednesday	329,457 (17.28)	1.75 (1.52)
Thursday	337,364 (17.70)	1.76 (1.53)
Friday	267,234 (14.02)	1.77 (1.54)
Saturday	123,024 (6.45)	1.74 (1.52)
Sunday	150,914 (7.91)	1.68 (1.45)
Hour of the day		
0-1	23,689 (1.24)	1.96 (1.68)
1-2	11,852 (0.62)	2.00 (1.71)
2-3	6686 (0.35)	2.05 (1.75)
3-4	4659 (0.24)	2.05 (1.72)
4-5	5151 (0.27)	1.98 (1.70)
5-6	9681 (0.51)	1.82 (1.57)
6-7	22,818 (1.20)	1.70 (1.47)
7-8	51,225 (2.69)	1.67 (1.43)
8-9	90,270 (4.74)	1.71 (1.47)

Timeframe	Ratings, n (%)	Mean rating, mean (SD)
9-10	122,461 (6.42)	1.74 (1.50)
10-11	144,834 (7.60)	1.75 (1.51)
11-12	152,606 (8.01)	1.77 (1.53)
12-13	143,618 (7.53)	1.78 (1.54)
13-14	136,245 (7.15)	1.76 (1.53)
14-15	129,596 (6.80)	1.74 (1.50)
15-16	121,427 (6.37)	1.75 (1.52)
16-17	116,451 (6.11)	1.76 (1.53)
17-18	111,075 (5.83)	1.77 (1.54)
18-19	101,968 (5.35)	1.75 (1.53)
19-20	98,494 (5.17)	1.73 (1.52)
20-21	95,222 (5.00)	1.72 (1.51)
21-22	89,447 (4.69)	1.73 (1.51)
22-23	71,515 (3.75)	1.78 (1.54)
23-24	45,156 (2.37)	1.85 (1.60)

Number of Rated Physicians and Ratings Per Rated Physician

Between 2010 and 2019, a total of 127,921 physicians were rated on jameda (see Table 2). The number of rated physicians increased constantly from 19,305 in 2010 to 82,511 in 2018. In 2019, the number of rated physicians decreased to 73,071 rated physicians. The number of ratings that rated physicians received demonstrated an increasing trend. In 2010, 66.94% (12,923/19,305) of all rated physicians were rated only once, 30.88% (5961/19,305) were rated 2-5 times, 1.71% (330/19,305) were rated 6-10 times, and 0.47% (91/19,305) were rated 11-50 times. In 2019, 40.84% (29,843/73,071) of all rated physicians were rated only once, 46.89% (34,262/73,071) were rated 2-5 times, 8.21% (5998/73,071) were rated 6-10 times, 3.93% (2875/73,071) were rated 11-50 times, and 0.13% (93/73,071) were rated more than 50 times. Over the entire decade, 11.43% (14,625/127,921) of all rated physicians were rated once, and 4.23% (5413/127,921) were rated more than 50 times. Please note that the overall numbers cannot be summed up here. For example, one physician received 1 rating in 2010, 3 ratings in 2011, 5 ratings in 2013, 1 rating in 2015, 11 ratings in 2015, 23 ratings in 2017, and 19 ratings in 2019. In sum, this physician was rated 63 times and would be assigned to the category “≥51 Ratings.” Similarly, the overall average number of ratings per rated physician increased from 1.65 (SD 1.56) in 2010 to 3.19 (SD 4.69) in 2019. Comparing the number of ratings and rated physicians with the total number of physicians in the German outpatient sector [43], in 2010, 13.64% (19,305/141,461) of all physicians had been rated on jameda, 21.93% (31,335/142,855) in 2011, 29.22% (42,089/144,058) in 2012, 36.36% (53,065/145,933) in 2013, 42.71% (63,182/147,948) in 2014, 45.56% (68,392/150,106) in 2015, 50.51% (76,773/151,989) in 2016, 51.69% (79,799/154,369) in 2017, and 52.46% (82,511/157,288) in 2018 (see also Multimedia Appendix 1). Thus, more than half of all German physicians have been rated online on jameda each year in Germany since 2016.

Table 2. Overall ratings on jameda between 2010 and 2019.

Ratings	Year										Overall (n=127,921)
	2010 (n=19,305)	2011 (n=31,336)	2012 (n=42,089)	2013 (n=53,065)	2014 (n=63,182)	2015 (n=68,392)	2016 (n=76,773)	2017 (n=79,799)	2018 (n=82,511)	2019 (n=73,071)	
Overall number and percentage of rated physicians, n (%)											
1 rating	12,923 (66.94)	18,256 (58.26)	21,133 (50.21)	22,177 (41.79)	22,229 (35.18)	24,512 (35.84)	25,859 (33.68)	26,810 (33.60)	28,971 (35.11)	29,843 (40.84)	14,625 (11.43)
2-5 ratings	5961 (30.88)	11,877 (37.90)	18,389 (43.69)	25,321 (47.71)	31,422 (49.73)	33,751 (49.35)	38,263 (49.84)	39,808 (49.89)	40,602 (49.21)	34,262 (46.89)	31,507 (24.63)
6-10 ratings	330 (1.71)	933 (2.98)	1936 (4.60)	4085 (7.70)	6755 (10.69)	7061 (10.32)	8710 (11.35)	9099 (11.40)	9007 (10.92)	5998 (8.21)	26,285 (20.55)
11-50 ratings	91 (0.47)	259 (0.83)	604 (1.44)	1424 (2.68)	2683 (4.25)	2954 (4.32)	3787 (4.93)	3933 (4.93)	3801 (4.61)	2875 (3.93)	50,091 (39.16)
≥51 ratings	0 (0.00)	11 (0.00)	27 (0.01)	58 (0.11)	93 (0.15)	114 (0.12)	154 (0.20)	149 (0.19)	130 (0.16)	93 (0.13)	5413 (4.23)
Percentage of rated physicians, % (N)	13.64 (141,461)	21.93 (142,855)	29.22 (144,058)	36.36 (145,933)	42.71 (147,948)	45.56 (150,106)	50.51 (151,989)	51.69 (154,369)	52.46 (157,288)	N/A[a]	—[b]
Number of ratings per rated physician											
Mean (SD)	1.65 (1.56)	1.97 (2.51)	2.33 (3.22)	2.90 (4.05)	3.47 (4.84)	3.47 (4.95)	3.71 (5.43)	3.68 (5.09)	3.55 (4.92)	3.19 (4.69)	14.90 (24.04)
Maximum	39	137	151	149	165	154	197	143	215	148	943

[a] N/A: not available.

[b] Not applicable.

Rating Evaluations

Of the 1,906,146 ratings posted between 2010 and 2019, 75.16% (1,432,624/1,906,146) of all ratings were in the best rating category of "very good," and 5.66% (107,912/1,906,146) of the ratings were in the lowest category of "insufficient" (see Table 3). Furthermore, the percentage of ratings on both ends of the rating scale increased over time, from 71.95% (2010) to 78.17% (2019) for very positive ratings and from 3.91% (2010) to 6.12% (2019) for very negative ratings. However, the overall average rating remained relatively constant. The average rating was 1.73 (SD 1.42) in 2010 and 1.71 (SD 1.52) in 2019, with an overall average of 1.76 (SD 1.53).

With regards to the correlation between the average rating of a rated physician and the number of ratings per physician, physicians with a lower number of ratings tended to receive ratings across the rating scale, while physicians with a higher number of ratings tended to have better ratings (see Figure 1). Physicians with a single rating had a mean rating of 1.58 (SD 1.28). Afterwards, mean ratings get worse with increasing number of ratings. Physicians with between 21 and 50 online ratings received the worst ratings (mean 1.95, SD 0.84). Mean ratings then improve, with physicians having 51-100 ratings receiving a mean rating of 1.79 (SD 0.86) and physicians with more than 100 ratings receiving the best ratings (mean 1.34, SD 0.47; see Table 4).

Table 3. Overall rating evaluations on jameda between 2010 and 2019.

Overall rating evaluation	Year										Overall (n=1,906,146)
	2010 (n=31,908)	2011 (n=61,726)	2012 (n=98,041)	2013 (n=154,119)	2014 (n=219,319)	2015 (n=237,354)	2016 (n=284,475)	2017 (n=293,744)	2018 (n=292,721)	2019 (n=232,729)	
Rating based on the 6-point grading system, n (%)											
1=very good	22,957 (71.95)	44,952 (72.83)	72,066 (73.51)	111,043 (72.05)	160,263 (73.07)	175,416 (73.90)	217,533 (76.47)	224,527 (76.44)	221,951 (75.82)	181,916 (78.17)	1,432,624 (75.16)
2=good	3406 (10.67)	5783 (9.37)	7889 (8.05)	12,113 (7.86)	16,651 (7.59)	17,328 (7.30)	19,383 (6.81)	18,489 (6.29)	17,205 (5.88)	12,203 (5.24)	130,450 (6.84)
3=satisfactory	1036 (3.25)	2007 (3.25)	2920 (2.98)	4766 (3.09)	6200 (2.83)	6321 (2.66)	6655 (2.34)	6848 (2.33)	6665 (2.28)	4491 (1.93)	47,909 (2.51)
4=fair	1312 (4.11)	2635 (4.27)	4082 (4.16)	6631 (4.30)	9073 (4.14)	9444 (3.98)	9545 (3.36)	9678 (3.29)	10,021 (3.42)	7056 (3.03)	69,477 (3.64)
5=deficient	1948 (6.11)	3910 (6.33)	6233 (6.36)	10,694 (6.94)	15,121 (6.89)	15,658 (6.60)	16,493 (5.80)	17,339 (5.90)	17,537 (5.99)	12,841 (5.52)	117,774 (6.18)
6=insufficient	1249 (3.91)	2439 (3.95)	4851 (4.95)	8872 (5.76)	12,011 (5.48)	13,187 (5.56)	14,866 (5.23)	16,863 (5.74)	19,342 (6.61)	14,232 (6.12)	107,912 (5.66)
Mean (SD)	1.73 (1.42)	1.74 (1.44)	1.77 (1.50)	1.83 (1.56)	1.81 (1.54)	1.79 (1.54)	1.71 (1.48)	1.73 (1.52)	1.78 (1.57)	1.71 (1.52)	1.76 (1.53)

Figure 1. Scatterplot (bivariate) of the number of ratings per physician with the mean overall performance for rated physicians.

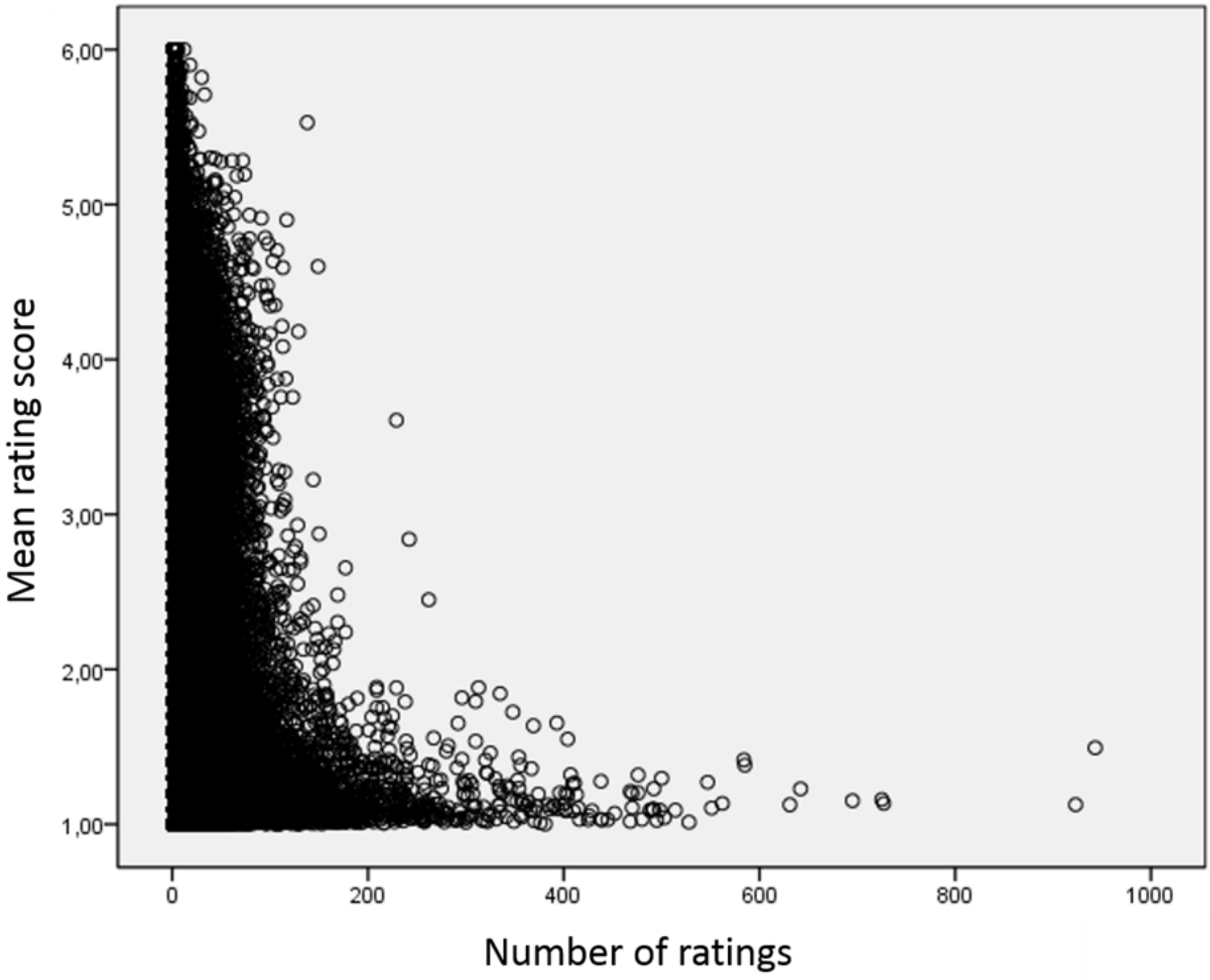

Table 4. Online rating results by the number of ratings per physician.

Number of ratings per physician	Average rating, mean (SD)	Rating based on the 6-point grading system[a], n (%)					
		1	2	3	4	5	6
1 (n=14,625)	1.58 (1.28)	11,741 (80.28)	1023 (6.99)	302 (2.06)	394 (2.69)	645 (4.41)	520 (3.56)
2-5 (n=31,505)	1.67 (0.96)	19,733 (62.63)	6204 (19.69)	3477 (11.04)	1395 (4.43)	471 (1.50)	225 (0.71)
6-10 (n=26,258)	1.76 (0.81)	12,505 (47.62)	9459 (36.02)	3096 (11.79)	961 (3.66)	214 (0.81)	23 (0.09)
11-20 (n=29,049)	1.86 (0.78)	12,243 (42.15)	11,188 (38.51)	4289 (14.76)	1162 (4.00)	159 (0.55)	8 (0.02)
21-50 (n=20,658)	1.95 (0.84)	8044 (38.94)	7833 (37.92)	3408 (16.50)	1195 (5.78)	176 (0.85)	2 (0.00)
51-100 (n=3933)	1.79 (0.86)	2084 (52.99)	1122 (28.53)	446 (11.34)	246 (6.25)	35 (0.89)	0 (0.00)
>100 (n=1445)	1.34 (0.47)	1181 (81.73)	220 (15.22)	28 (1.94)	10 (0.69)	5 (0.35)	1 (0.07)
Total (n=127,473)	1.77 (0.92)	67,531 (52.98)	37,049 (29.06)	15,046 (11.80)	5363 (4.21)	1705 (1.34)	779 (0.61)

[a] 1=very good, 2=good, 3=satisfactory, 4=fair, 5=deficient, and 6=insufficient.

Ratings by Medical Specialty

Between 2010 and 2019, general practitioners (343,242), internists (266,899), gynecologists (232,914), and orthopedists (229,481) received the highest number of ratings, while pediatricians (87,330), ophthalmologists (79,699), and urologists (63,703) received the lowest number of ratings (see Table 5). However, according to the relative distribution of ratings, the most frequently rated medical specialties in 2018 were orthopedists (6160/7302, 84.36%); oral maxillofacial surgeons (1017/1257, 80.91%); ear, nose, and throat (ENT) specialists (3559/4479, 79.46%); and dermatologists (3562/4632, 76.90%). In contrast, the least frequently rated medical specialties were radiologists (863/4078, 21.16%) and anesthesiologists (601/4247, 14.15%; see Multimedia Appendix 2). Among the 10 most frequently rated medical specialties, the best rated medical specialties were urologists (mean 1.50, SD 1.29), general practitioners (mean 1.64, SD 1.40), and internists (mean 1.68, SD 1.45). The lowest ratings were given to pediatricians (mean 1.92, SD 1.62), ophthalmologists (mean 2.06, SD 1.74), and dermatologists (mean 2.11, SD 1.77).

Table 5. Ratings by medical specialty.

Medical specialty	Year										Overall (n=127,921 rated physicians; n=1,906,146 ratings)
	2010 (n=19,305 rated physicians; n=31,908 ratings)	2011 (n=31,336 rated physicians; n=61,726 ratings)	2012 (n=42,089 rated physicians; n=98,041 ratings)	2013 (n=53,065 rated physicians; n=154,119 ratings)	2014 (n=63,182 rated physicians; n=219,319 ratings)	2015 (n=68,392 rated physicians; n=237,354 ratings)	2016 (n=76,773 rated physicians; n=284,475 ratings)	2017 (n=79,799 rated physicians; n=293,744 ratings)	2018 (n=82,551 rated physicians; n=292,721 ratings)	2019 (n=73,071 rated physicians; n=232,729 ratings)	
General practitioner											
Rated physicians, n (%)	4891 (25.34)	8161 (26.04)	10,533 (25.03)	13,077 (24.64)	15,767 (24.95)	17,016 (24.88)	19,289 (25.12)	19,586 (24.54)	19,967 (24.19)	16,818 (23.02)	33,414 (26.12)
Number of ratings	7241 (22.69)	13,737 (22.25)	19,210 (19.59)	27,952 (18.14)	39,914 (18.20)	42,188 (17.77)	51,504 (18.10)	51,725 (17.61)	51,682 (17.66)	38,089 (16.37)	343,242 (18.01)
Mean rating (SD)[a], n (%)	1.55 (1.21)	1.53 (1.21)	1.54 (1.24)	1.60 (1.33)	1.61 (1.35)	1.66 (1.40)	1.59 (1.35)	1.65 (1.43)	1.73 (1.52)	1.71 (1.51)	1.64 (1.40)
Internist											
Rated physicians, n (%)	3230 (16.73)	5286 (16.87)	6897 (16.39)	8779 (16.54)	10,635 (16.83)	11,511 (16.83)	13,374 (17.42)	13,849 (17.35)	14,634 (17.73)	13,306 (18.21)	23,734 (18.55)
Number of ratings, n (%)	5132 (16.08)	9381 (15.20)	13,697 (13.97)	20,853 (13.53)	29,728 (13.55)	31,611 (13.32)	39,619 (13.93)	40,616 (13.83)	41,642 (14.23)	34,620 (14.88)	266,899 (14.00)
Mean rating (SD)[a]	1.59 (1.27)	1.62 (1.32)	1.62 (1.36)	1.70 (1.44)	1.68 (1.43)	1.70 (1.46)	1.63 (1.40)	1.68 (1.47)	1.73 (1.53)	1.68 (1.49)	1.68 (1.45)
Gynecologist											
Rated physicians, n (%)	2157 (11.17)	3568 (11.39)	5084 (12.08)	6291 (11.86)	7163 (11.34)	7602 (11.12)	8165 (10.64)	8445 (10.58)	8653 (10.48)	7650 (10.47)	11,598 (9.07)
Number of ratings, n (%)	3901 (12.23)	7800 (12.64)	13,987 (14.27)	21,880 (14.20)	28,672 (13.07)	29,795 (12.55)	33,862 (11.90)	34,530 (11.76)	33,562 (11.47)	24,925 (10.71)	232,914 (12.22)
Mean rating (SD)[a]	1.66 (1.36)	1.64 (1.33)	1.69 (1.41)	1.79 (1.49)	1.79 (1.50)	1.80 (1.51)	1.74 (1.49)	1.73 (1.48)	1.76 (1.52)	1.69 (1.47)	1.75 (1.48)
Orthopedist											
Rated physicians, n (%)	1662 (8.61)	2548 (8.13)	3333 (7.92)	4007 (7.55)	4629 (7.33)	5051 (7.39)	5579 (7.27)	5907 (7.40)	6160 (7.46)	5894 (8.07)	8022 (6.27)
Number of ratings, n (%)	3412 (10.69)	6836 (11.07)	11,020 (11.24)	17,805 (11.55)	25,714 (11.72)	28,876 (12.17)	34,242 (12.04)	36,416 (12.40)	35,564 (12.15)	29,596 (12.72)	229,481 (12.04)
Mean rating (SD)[a]	2.08 (1.67)	2.06 (1.67)	2.12 (1.75)	2.15 (1.78)	2.05 (1.72)	1.93 (1.65)	1.82 (1.58)	1.80 (1.57)	1.82 (1.60)	1.70 (1.52)	1.89 (1.63)
Dermatologist (including venereologist)											
Rated physicians, n (%)	855 (4.43)	1354 (4.32)	1947 (4.63)	2467 (4.65)	2811 (4.45)	3003 (4.39)	3229 (4.21)	3415 (4.28)	3562 (4.31)	3232 (4.42)	4517 (3.53)

Medical specialty	Year										Overall (n=127,921 rated physicians; n=1,906,146 ratings)
	2010 (n=19,305 rated physicians; n=31,908 ratings)	2011 (n=31,336 rated physicians; n=61,726 ratings)	2012 (n=42,089 rated physicians; n=98,041 ratings)	2013 (n=53,065 rated physicians; n=154,119 ratings)	2014 (n=63,182 rated physicians; n=219,319 ratings)	2015 (n=68,392 rated physicians; n=237,354 ratings)	2016 (n=76,773 rated physicians; n=284,475 ratings)	2017 (n=79,799 rated physicians; n=293,744 ratings)	2018 (n=82,551 rated physicians; n=292,721 ratings)	2019 (n=73,071 rated physicians; n=232,729 ratings)	
Number of ratings, n (%)	1563 (4.90)	3199 (5.18)	5811 (5.93)	10,461 (6.79)	14,991 (6.84)	15,380 (6.48)	17,513 (6.16)	17,619 (6.00)	17,861 (6.10)	13,355 (5.74)	117,753 (6.18)
Mean rating (SD)[a]	2.06 (1.64)	2.18 (1.71)	2.35 (1.85)	2.28 (1.82)	2.25 (1.82)	2.16 (1.77)	2.05 (1.73)	2.04 (1.74)	2.04 (1.75)	1.94 (1.71)	2.11 (1.77)
ENT[b] specialist, otorhinolaryngologist											
Rated physicians, n (%)	835 (4.33)	1388 (4.43)	1876 (4.46)	2425 (4.57)	2828 (4.45)	3094 (4.52)	3345 (4.36)	3443 (4.31)	3559 (4.31)	3233 (4.42)	4709 (3.68)
Number of ratings, n (%)	1455 (4.56)	3018 (4.89)	5081 (5.18)	9013 (5.85)	13,494 (6.15)	14,626 (6.16)	17,107 (6.01)	16,914 (5.76)	16,118 (5.51)	13,077 (5.62)	109,903 (5.77)
Mean rating (SD)[a]	1.81 (1.50)	1.77 (1.46)	1.76 (1.50)	1.83 (1.57)	1.75 (1.51)	1.74 (1.52)	1.64 (1.43)	1.67 (1.47)	1.75 (1.56)	1.71 (1.53)	1.72 (1.51)
General surgery											
Rated physicians, n (%)	601 (3.11)	1027 (3.28)	1397 (3.32)	1836 (3.46)	2150 (3.40)	2463 (3.60)	2791 (3.64)	3054 (3.83)	3154 (3.82)	2859 (3.91)	4343 (3.40)
Number of ratings, n (%)	1061 (3.33)	2298 (3.72)	3661 (3.73)	6103 (3.96)	9084 (4.14)	10,908 (4.60)	13,240 (4.65)	14,678 (5.00)	14,162 (4.84)	12,272 (5.27)	87,467 (4.59)
Mean rating (SD)[a]	1.80 (1.49)	1.84 (1.57)	1.83 (1.59)	1.83 (1.59)	1.84 (1.61)	1.83 (1.62)	1.79 (1.60)	1.81 (1.63)	1.85 (1.67)	1.78 (1.62)	1.82 (1.62)
Pediatrician											
Rated physicians, n (%)	976 (5.06)	1570 (5.01)	2321 (5.51)	2996 (5.65)	3574 (5.66)	3891 (5.69)	4230 (5.51)	4315 (5.41)	4364 (5.29)	3620 (4.95)	6555 (5.12)
Number of ratings, n (%)	1529 (4.81)	2795 (4.53)	4941 (5.04)	7831 (5.08)	11,059 (5.04)	11,550 (4.87)	13,004 (4.57)	13,295 (4.53)	12,894 (4.40)	8432 (3.62)	87,330 (4.58)
Mean rating (SD)[a]	1.68 (1.35)	1.70 (1.38)	1.76 (1.46)	1.88 (1.57)	1.94 (1.61)	1.94 (1.61)	1.90 (1.60)	1.93 (1.64)	2.03 (1.72)	2.01 (1.73)	1.92 (1.62)
Ophthalmologist											
Rated physicians, n (%)	722 (3.74)	1225 (3.91)	1772 (4.21)	2366 (4.46)	2922 (4.62)	3131 (4.58)	3528 (4.60)	3809 (4.77)	3916 (4.74)	3520 (4.82)	5935 (4.64)
Number of ratings, n (%)	1085 (3.40)	2079 (3.37)	3570 (3.64)	6173 (4.01)	9154 (4.17)	9754 (4.11)	11,899 (4.18)	12,816 (4.36)	12,887 (4.40)	10,282 (4.41)	79,699 (4.18)
Mean rating (SD)[a]	2.07 (1.63)	2.09 (1.67)	2.26 (1.81)	2.20 (1.79)	2.15 (1.78)	2.11 (1.76)	1.98 (1.69)	1.97 (1.69)	2.05 (1.77)	1.96 (1.71)	2.06 (1.74)

Medical specialty	Year										Overall (n=127,921 rated physicians; n=1,906,146 ratings)
	2010 (n=19,305 rated physicians; n=31,908 ratings)	2011 (n=31,336 rated physicians; n=61,726 ratings)	2012 (n=42,089 rated physicians; n=98,041 ratings)	2013 (n=53,065 rated physicians; n=154,119 ratings)	2014 (n=63,182 rated physicians; n=219,319 ratings)	2015 (n=68,392 rated physicians; n=237,354 ratings)	2016 (n=76,773 rated physicians; n=284,475 ratings)	2017 (n=79,799 rated physicians; n=293,744 ratings)	2018 (n=82,551 rated physicians; n=292,721 ratings)	2019 (n=73,071 rated physicians; n=232,729 ratings)	
Urologist											
Rated physicians, n (%)	536 (2.78)	830 (2.65)	1221 (2.90)	1511 (2.85)	1820 (2.88)	1914 (2.80)	2139 (2.79)	2301 (2.88)	2415 (2.93)	2140 (2.93)	3329 (2.60)
Number of ratings, n (%)	845 (2.65)	1639 (2.66)	3221 (3.29)	5141 (3.34)	7207 (3.29)	7753 (3.27)	9556 (3.36)	10,264 (3.49)	9612 (3.28)	8465 (3.64)	63,703 (3.34)
Mean rating (SD)[a]	1.82 (1.54)	1.66 (1.37)	1.57 (1.33)	1.64 (1.41)	1.54 (1.30)	1.50 (1.28)	1.43 (1.20)	1.47 (1.26)	1.49 (1.29)	1.45 (1.25)	1.50 (1.29)
Others											
Rated physicians, n (%)	2840 (14.71)	4379 (13.97)	5708 (13.56)	7310 (13.78)	8883 (14.06)	9716 (14.21)	11,104 (14.46)	11,675 (14.63)	12,127 (14.69)	10,799 (14.78)	21,765 (17.01)
Number of ratings, n (%)	4684 (14.68)	8944 (14.49)	13,842 (14.12)	20,907 (13.57)	30,302 (13.82)	34,913 (14.71)	42,929 (15.09)	44,871 (15.28)	46,737 (15.97)	39,626 (17.03)	287,755 (15.10)
Mean rating (SD)[a]	1.78 (1.48)	1.77 (1.49)	1.68 (1.45)	1.76 (1.54)	1.70 (1.49)	1.65 (1.45)	1.59 (1.40)	1.62 (1.43)	1.66 (1.49)	1.57 (1.41)	1.65 (1.45)

[a] On a 6-point scale: 1=very good, 2=good, 3=satisfactory, 4=fair, 5=deficient, and 6=insufficient.

[b] ENT: ear, nose, throat.

Characteristics of Raters

The rating patients were mostly female (56.8%), between 30 and 50 years old (42.6%), and covered by Statutory Health Insurance (81.0%; see Table 6). However, there were some significant differences between genders, age groups, and health insurance status. Male patients gave significantly more favorable ratings than female patients (mean rating 1.61, SD 1.32 vs. mean 1.77, SD 1.48; *P*<.001). Older patients also gave significantly better ratings than younger patients (*P*<.001). For example, patients aged 51 years or older left a mean rating of 1.52 (SD 1.22), whereas patients aged 29 years or younger left a mean rating of 1.93 (SD 1.59). Finally, patients covered by private health insurance (mean rating 1.43, SD 1.11) gave significantly more favorable evaluations than did patients covered by statutory health insurance (mean rating 1.75, SD 1.47; *P*<.001). Nevertheless, effect sizes were small for all groups, varying between 0.114 and 0.289.

Table 6. Characteristics of raters.

Characteristic	Number of respondents, n (%)	Rating evaluation, mean (SD)	*P* value	Cohen *d*
Gender (n=1,107,092)				
Male	478,592 (43.23)	1.61 (1.32)	<.001[a]	0.114
Female	628,500 (56.77)	1.77 (1.48)		
Age (years; n=1,063,523)				
≤29	164,807 (15.50)	1.93 (1.59)	<.001[b]	0.117[c]; 0.289[d]; 0.171[e]
30-50	452,774 (42.57)	1.75 (1.46)		
≥51	445,942 (41.93)	1.52 (1.22)		
Health insurance (n=981,635)				
Statutory health insurance	795,107 (81.00)	1.75 (1.47)	<.001[a]	0.245
Private health insurance	186,528 (19.00)	1.43 (1.11)		

[a] Mann-Whitney *U* test.

[b] Kruskal-Wallis test.

[c] ≤29 years vs 30-50 years.

[d] ≤29 years vs ≥51 or years.

[e] 30-50 years vs ≥51 years.

Discussion

This study is one of the most comprehensive analyses of PRW ratings conducted to date and has resulted in a number of key findings: (1) just under 2 million ratings were posted on jameda between 2010 and 2019; (2) a total of 127,921 physicians were rated; (3) the overall average number of ratings per rated physicians nearly doubled; (4) three-quarters of all ratings were in the best rating category of “very good,” and the overall average rating remained relatively constant; (5) general practitioners, internists, gynecologists, and orthopedists were the most frequently rated medical specialties; and (6) the rating patients were mostly female, between 30 and 50 years old, and covered by Statutory Health Insurance.

The findings of this study confirm previous research in Germany that indicated that patient ratings show an increasing trend over the past decade [26]. For example, the percentage of all German physicians that had been rated on jameda increased constantly over time from 13.65% (19,305/141,461) in 2010 to 52.46% (82,511/157,288) in 2018. McLennan et al [26] also previously reported that the proportion of physicians from a sample of 298 randomly selected physicians from Hamburg and Thuringia that had been rated at least once had increased between 2010 (range 3.3%-27.8%) and 2014 (range 16.4%-83.2%). Similarly, the average number of ratings per physician also increased between 2010 (range 1.1-3.1) and 2014 (range 1.2-7.5). However, this study only used a small sample from 2 regions in Germany. Overall, there is little international evidence showing the exact development of online ratings over time, which makes it challenging to compare our numbers with those from other similar studies. To the best of our knowledge, more recent studies providing detailed information on a yearly basis are limited. However, 2 studies from the United States [13] and Canada [27] have presented similar findings. First, in 2012, Gao and colleagues [13] showed an increase in the number of rated physicians on RateMDs in the United States from 2475 in 2005 to 112,024 in 2010. Second, Liu and colleagues [27] analyzed a dataset from RateMDs, which included all physicians in Canada in 2018 and showed an increase in the number of ratings for physicians in Canada from 138 in 2005 to 640,603 in 2013. Nevertheless, it should be noted that this study found a plateau in the total number of ratings between 2017 (293,744) and 2018 (292,721). In 2019, a decrease of around 20% in the total number of ratings was seen in comparison with the previous 2 years. In recent years, jameda has implemented and promoted new features on its website (eg, making appointments, video consultations). This has possibly led to lower marketing efforts for collecting online reviews and may also lead to differences from PRWs not offering these addition services. Future studies should investigate whether this latest development can also be observed for other PRWs in Germany and other countries.

This study only provides information regarding jameda. Previous research has demonstrated much lower numbers of both ratings and rated physicians on other German PRWs [4,26]. For example, McLennan and colleagues [26] reported that between 16.4% and 71.1% (mean 41.4%) of physicians were rated on German PRWs overall, compared with 83.2% on jameda. Another study also showed a higher percentage of rated physicians on jameda (90.2%) compared with other relevant German PRWs (32.4% to 61.2%) [4]. Differences in the number of ratings between PRWs can also be shown in the international setting. For example, Trehan and colleagues [44] analyzed online ratings for 250 hand surgeons from the American Society for Surgery of the Hand member directory from 3 PRWs in the United States (HealthGrades, Vitals, RateMDs). Large differences were reported regarding the average number of ratings (13.4, 8.3, and 1.9, respectively) [44]. Further research is required to confirm that this increase in ratings is also true for other PRWs as well.

Furthermore, the percentages of ratings on both ends of the rating scale have increased. This may suggest that a “bimodal” trend in ratings is emerging on jameda, similar to that seen with the rating of products on websites like Amazon where "amateur" reviewers usually only leave a review because they either love or hate a product [45]. It would be helpful if future research examines if this trend continues and can be found on other PRWs, particularly as this trend is usually not seen on PRWs [26], despite qualitative research in Germany finding that a very positive or very negative experience in the health care relationship is a crucial precondition for patients to be willing to rate a physician [46].

Seven years after the first study on online patient ratings on jameda [18], general practitioners, internists, and gynecologists still receive the highest number of ratings in absolute terms. This does not seem surprising due to the high number of physicians in those medical specialty areas in Germany. Similar to previous research [18], it could also be shown that urologists, general practitioners, and internists were likely to receive more favorable ratings on jameda. In contrast, ophthalmologists and dermatologists are still likely to receive far less favorable ratings. This is also in line with the comprehensive analysis by Liu and colleagues [27] from Canada. Previous research findings have also reported that generalists are more likely to have better online ratings than specialists [10,13]. Qualitative research conducted in Germany by McLennan et al [46] found that factors concerning the physician-patient relationship to be some of the most important influencing people's willingness to rate their physician on PRWs. It is likely that differences in patients' relationships with physicians in various specialties (eg, duration and frequency of contact and the resulting level of trust) is a key factor for this heterogeneity.

The analysis of such a large number of ratings has also provided a more detailed picture of the association between the number of ratings a physician has and their overall evaluation. Although physicians with only 1 rating tended to have very good ratings (81% of all ratings were in the best rating category), this might potentially be explained, at least in part, by "fake ratings" left by physicians themselves or people connected to the physician. Regardless, it certainly calls into question whether results based on a single rating are meaningful at all [7]. Afterwards, more critical rating results were found. In line with previous studies from Germany [18] and the United States [37], the total performance range was found for physicians with a lower number of ratings. This possibly represents a more realistic picture of patient feedback because the percentage of ratings in the very best rating category declined constantly, and it is also likely that those physicians are not using PRWs as a marketing measure to collect a very high number or ratings [18]. However, in contrast to previous research, physicians who received a higher number of ratings were shown to have better ratings. When there were more than 51 ratings, ratings started to improve again, and physicians with more than 100 ratings received by far the most favorable ratings. It is likely that physician with more than 100 ratings are aware of PRWs and are using them as a marketing tool, potentially specifically asking satisfied patients to leave a (positive) rating on a PRW. However, it is possible that these physicians are simply providing outstanding quality of care, leading to the very favorable ratings on PRWs and, subsequently, more patients choosing to use this physician [18]. Future research should examine which assumption is true [18].

In 2019, Pike et al [37] reported a U-shaped relationship between the number of ratings and the overall rating from the Healthgrades website. A negative relationship between the number of ratings and the overall rating could be seen until physicians achieved 21 ratings; thereafter, a positive relationship was seen. It should be noted that, in contrast to jameda, a lower score on Healthgrades means a worse rating (1=poor; 5=excellent). Although regression analysis on the jameda data did not find a satisfying fit, the study provides further broad-scale evidence on the relationship between the number of ratings and the overall evaluation as discussed earlier in this manuscript.

Limitations

The key limitation of this study is that it analyzed online ratings from only a single German PRW, jameda. Although jameda has shown to be the most frequently used German PRW, there are a total of 25 PRWs in Germany [8], and it is unclear how generalizable the results are to other German PRWs or to other countries. In Germany, it would be particularly helpful for future longitudinal research to examine trends in ratings on PRWs run by public health insurers, as previous research has indicated that these PRWs have been able to quickly establish themselves as some of the most used German PRWs alongside jameda [26]. Another limitation of the study is that it only analyzed publicly available ratings; it is not known how many additional ratings jameda received but did not publish or what efforts jameda made to check whether published ratings are genuine and not fake. Indeed, jameda has often been criticized with regards to the number of fake reviews and its business model that offers physicians paid premium profiles. Recent research has raised concerns that online patient feedback is being inappropriately manipulated by many PRWs and that business models that make PRWs reliant on paying physicians may create financial incentives to suppress negative feedback [47]. Although further work is needed on criteria for determining which feedback is published [47], it is also important to have a comprehensive understanding of the ratings that are being viewed by the public on PRWs.

Conclusion

In conclusion, it can be stated that online ratings have been increasing tremendously over the past decade and seem to have become an essential element for patients to leave feedback on the care they receive. More than half of all physicians have been rated online on jameda each year in Germany since 2016. Indeed, with patients increasingly using the internet in relation to their health care [48], it is likely that online patient feedback will become even more important in the future. With online patient feedback mostly positive, physicians do not have to fear online ratings in general; the commonly expressed concerns regarding PRWs being used for "doctorbashing" or defamation [31] or as "platforms for denunciation" [32] have not proven true. Furthermore, less favorable patient ratings often address important elements of a patient-oriented health care system [1] and can help organizations and professionals identify areas that need to be improved [21].

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The number and percentage of rated physicians in Germany.
[PNG File , 127 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Number and distribution of ratings according to the medical specialty (2018).
[DOCX File , 37 KB-Multimedia Appendix 2]

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Abbreviations

ENT: ear, nose, and throat
PRW: physician rating website

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Original Paper

The Influence of Online Health Information Seeking Before a Consultation on Anxiety, Satisfaction, and Information Recall, Mediated by Patient Participation: Field Study

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Abstract

Background: Today, many cancer patients engage in online health information seeking (OHIS). However, little is known about how patients differ in their OHIS levels. In addition, OHIS might influence patient participation during a consultation with a physician, which might mediate the effects on patient outcomes.

Objective: The aim of this study is twofold: first, to provide insight into which personal characteristics and psychosocial factors affect patients' OHIS levels and, second, to test the hypothesis that the effects of OHIS on patient outcomes are mediated by patient participation during the consultation.

Methods: Patient participation was operationalized in terms of patients' absolute word count; the relative contribution of the patient, compared with the health care provider; and the number of questions and assertions expressed during the consultation. The patient outcomes measured were anxiety after the consultation, satisfaction with the consultation, and information recall. Participants in this study were patients recently diagnosed with colorectal cancer recruited from 6 hospitals in the Netherlands (n=90). Data were collected using questionnaires and audio-recorded consultations of patients with health care providers before their surgery.

Results: The results showed that younger patients, higher educated patients, patients with a monitoring coping style, and patients who experienced more cancer-related stress engaged more in OHIS. In turn, OHIS was related to patient participation in terms of the patient's absolute word count but not to the relative contribution to the consultation or expressing questions and assertions. We did not find a relation between OHIS and anxiety and OHIS and recall mediated by patient participation. However, we found that patients' absolute word count significantly mediated the positive association between OHIS and patients' satisfaction with the consultation.

Conclusions: Results indicate positive implications of OHIS for patients' care experience and, therefore, the importance of helping patients engage in OHIS. However, the results also suggest that OHIS is only successful in increasing a single aspect of patient participation, which might explain the absence of relations with anxiety and recall. The results suggest that more beneficial effects on patient outcomes may be achieved when health care providers support patients in OHIS.

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KEYWORDS

online health seeking; patients; aging; patient participation; memory; anxiety; patient reported outcomes; consultation; health communication; cancer

Introduction

Background

Today, the internet hosts a growing body of easily accessible cancer-related information [1]. In line with this, cancer patients increasingly engage in online health information seeking (OHIS) [2,3] about their illness and treatment [4]. OHIS about one's health or medical condition can contribute to feeling informed, which has been positively associated with patient outcomes [5]. For instance, better informed patients score higher on affective outcomes, for example, they are more satisfied with their treatment [6-9] and feel less anxious [5,10,11]. Moreover, OHIS can positively influence cognitive outcomes, such as better information recall [12,13].

Although patients generally seek web-based health information [14-16], it can be argued that the extent to which they engage in OHIS is associated with individual differences based on demographics or psychosocial characteristics [17,18]. For instance, experiencing feelings of anxiety or stress regarding a medical diagnosis can result in more information needs [19] and information seeking to cope with them [20].

Previous research did not look at the whole path from individual differences to OHIS and, in turn, patient outcomes but mainly focused on either predictors of OHIS in terms of demographics and psychosocial factors [21-24] or outcomes of OHIS [5,25-27]. More specifically, research that looked into the effects of OHIS did not take into account what happens between OHIS and patient outcomes in terms of consultations with health care providers [5,25]. This is a noteworthy omission because patients often engage in OHIS in preparation for consultations [15,16,28], which can result in a better informed and more empowered patient who feels comfortable in taking on an active role in consultations with health care providers [9,27,29]. In turn, this may lead to more active patient participation during consultations [9,30], for example, by patients expressing more concerns and asking more questions [31].

Subsequently, patient participation can positively influence factors related to the quality of care, such as satisfaction with the consultation and understanding of health information provided [32]. In addition, researchers found that patient participation is related to lower anxiety [33], increased satisfaction [34-36], and improved information recall [13,37]. However, knowledge about whether and how the effects of OHIS on these outcomes are mediated by patient participation during consultation is lacking. Therefore, the aim of this study is to examine the demographic and psychosocial factors that can predict OHIS and how OHIS, in turn, influences patient outcomes via patient participation during consultations.

Predictors of OHIS

Cancer patients vary in the extent to which they seek online health information. The Comprehensive Model of Information Seeking is one of the most widely adopted models to discuss factors that could influence health information seeking [22]. In this model, demographics and psychosocial factors are seen as important determinants of how much an individual is inclined to search for health information.

Demographics

In general, studies show that demographics such as age, education level, and gender correlate with OHIS [16]. However, results are ambiguous. For example, some have shown that younger individuals seek more online health information than older individuals [16,38-40], whereas others find that older adults tend to seek more information online than their younger counterparts [41] or find no correlations with OHIS at all [42]. Frailty, or "the risk for adverse outcomes due to losses in different domains of functioning" [43], is found to be related to a decline in patients' self-management abilities, more so than chronological aging. Therefore, the level of frailty, also called biological age, might better predict a patient's ability to engage in OHIS than chronological age. In addition, several studies have shown that females seek online health information more frequently than males [16,38,40,44], whereas other studies show no associations between OHIS and gender [41,42]. With respect to education level, there is some evidence that higher educated individuals seek more online health information than lower educated individuals [44]; however, other studies show no such associations [20,42,45]. Finally, the tendency to search for health information online can also differ according to one's degree of health literacy or "the ability to perform basic reading and numerical tasks required to function in the health care environment" [46]. As described in a review study, some studies show limited evidence that people with low health literacy search less frequently for health information online, compared with people with high health literacy, whereas other studies show no differences in OHIS based on health literacy [47].

Psychosocial Factors

In addition to demographics, OHIS can also be explained by patients' psychosocial characteristics such as their degree of stress or anxiety and strategies to cope with such feelings. Higher levels of fear and anxiety in cancer patients have both been associated with the tendency to avoid cancer-related information [28,48] and with increased information needs [49]. Seeking relevant health information online might help patients to deal with the feelings of anxiety, and some patients feel relieved or comforted by the information they find online [45,50]. However, cancer patients differ in their need for cancer-related information [48], based on how they cope with a health threat. Some patients prefer only a very limited amount of information (blunting coping style), whereas others prefer as much information as possible (monitoring coping style) [51-56]. As the results are inconsistent, more research is needed, resulting in research question (RQ) 1:

- RQ 1: Are cancer patients' demographic characteristics (ie, age, gender, education level, frailty, and health literacy) and psychosocial characteristics (ie, anxiety, cancer-related stress, and information-seeking coping style) related to OHIS?

Direct Relation of OHIS and Patient Participation

Patient Participation

OHIS may potentially better equip patients to participate in consultations with health care providers [57-59]. Actively participating in such consultations reflects patients' ability and willingness to express their needs, concerns, preferences, and expectations [32]. According to the linguistic model of patient participation in care, patients need a certain repertoire of informational resources to actively communicate during medical consultations [32]. Patients with sufficient knowledge about a topic or terminology related to the topic will discuss health issues more easily with their providers [60]. Therefore, the knowledge a patient possesses, which might be gained because of OHIS, influences a patient's ability to actively communicate and is an important factor in patient participation [29,32,61].

In addition, providing patients with an opportunity to gather information and seeking online health information can empower patients by giving them the feeling that they are better prepared for their consultations, thereby making them confident enough to actively participate during consultations [9,29]. A recent review showed that gathering online health information before a consultation resulted in patients feeling more self-assured and empowered during consultations [9].

In conclusion, seeking health information online can prepare patients for interactions with health care providers by increasing knowledge and feelings of empowerment and might, therefore, be a crucial predictor of patient participation. Therefore, we argue that more OHIS leads to greater patient participation during a consultation with a health care provider, resulting in hypothesis 1 (H1):

- H1: OHIS is positively related to cancer patients' participation during a medical consultation.

Indirect Relation of OHIS and Patient Outcomes: The Mediating Role of Patient Participation

Both OHIS and patient participation are believed to be important independent factors that influence affective and cognitive patient outcomes [6,62]. OHIS most likely influences these outcomes via patient participation because it can increase patients' illness-related knowledge and feelings of empowerment, leading to more patient participation [32]. Active patient participation can, in turn, positively affect factors that indicate quality of care [32]. Indeed, studies have found that patient participation results in less anxiety [6,33], more satisfaction [34-36], and better information recall [13,37].

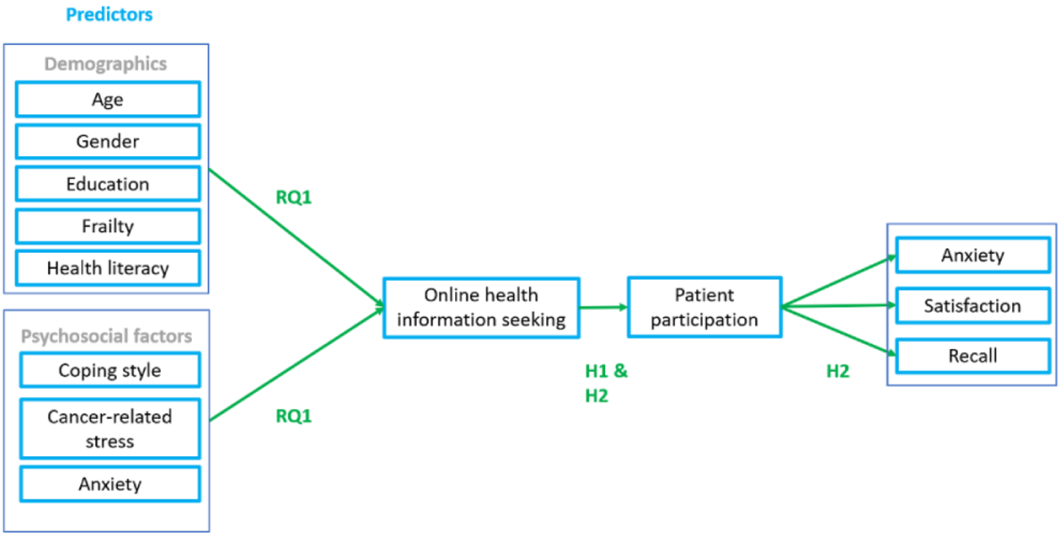
Anxiety

OHIS can positively influence emotional well-being in general, for example, by making the patient feel less stressed [5] and less anxious [10-12]. OHIS can also help patients gain knowledge about their illness [30], making them feel more empowered to discuss certain topics during consultations [9], which, in turn, can lower their stress and feelings of anxiety. If patients experience feelings of anxiety beforehand, or because of OHIS, actively participating during the consultation gives them a chance to discuss their issues with the health care provider, which might help decrease their anxiety.

On the other hand, in some cases, OHIS can increase feelings of worry and anxiety [27,63]. Patients can experience confusion because of seeking health information [27,30], which can result in feeling less comfortable to participate and act more reserved during consultations. If a patient already feels anxious because of seeking online health information and does not actively participate during consultations, the health care provider may not be able to adequately address the patient's anxiety. As a result, their anxiety may remain or increase even further. In line with this, we argue that the effect of OHIS on anxiety is mediated by patient participation during medical consultations (Figure 1), resulting in hypothesis 2a (H2a):

- H2a: Patient participation mediates the effect of OHIS on anxiety and stress after consultation.

Figure 1. Theoretical model. H1: hypothesis 1; H2: hypothesis 2; RQ1: research question 1.



Satisfaction

Generally, better informed patients are more satisfied with their health care processes [6,7,12,64]. Russ et al [8] found that patients who sought online health information were more satisfied with the information provided by the provider during a consultation when compared with patients who did not seek online health information.

A reason for this increase in satisfaction can be that seeking online health information before a consultation gives the patient a feeling of being prepared for the consultation [9]. Online information can help patients anticipate the discussion of certain topics during consultations or to consider possible treatments that will be proposed [65]. Knowing what to expect during the consultation can result in more active participation, including the expression of questions or expectations. These can subsequently be addressed by the health care provider, resulting in greater satisfaction with the consultation. In line with this, patients are more satisfied when providers are supportive of their search for online health information [66,67]. Therefore, it can be argued that OHIS leads to more satisfied patients through increased patient participation.

However, as discussed before, OHIS can also cause confusion, thereby inhibiting active patient participation. As a result, issues relevant to a patient may not be addressed, in which case the patient can feel disappointed and less satisfied with the consultation. Accordingly, research has shown that when the online findings do not match with the information discussed during consultation, for example, regarding diagnosis or treatment options, this can result in a less satisfied patient [68]. Therefore, we argue that the effect of OHIS on satisfaction with a consultation is mediated by patient participation (Figure 1), resulting in hypothesis 2b (H2b):

- H2b: Patient participation mediates the effect of OHIS on satisfaction with a consultation.

Recall

When patients engage in OHIS before a consultation and this leads to more participation during the consultation, this is likely to improve the recall of the information discussed [13,37,69-71]. One reason for the positive association between OHIS, participation, and recall is that repetition of the same information can improve information recall [72,73]. When patients search for online health information before the consultation and discuss the same information during the consultation by actively participating, this leads to a repetition in exposure to that information. In addition, exposure to a first piece of information can prime the interest for a second similar piece of information [74]. As this double exposure to the same kind of information stimulates deeper information processing, it is expected to positively influence information recall [75,76].

It can also be argued that patients who participate more actively during the consultation by asking more questions and expressing more concerns will receive more information from health care providers and are also more likely to understand the rationale and recommendations of the provider [32]. Moreover, actively participating patients are more involved and, therefore, process the information they receive during the consultations in an active manner. This active, deeper processing of information can result in better information recall [77]. Thus, we argue that the effect of OHIS on recall of the information provided during the consultation is mediated by patient participation (Figure 1), leading to hypothesis 2c (H2c):

- H2c: Patient participation mediates the effect of OHIS on information recall.

Methods

Design

A study was conducted in 6 Dutch hospitals among newly diagnosed colorectal cancer patients. All patients received the standard procedure of care provided by the hospitals without any alterations. All newly diagnosed patients who planned to undergo surgery were approached to participate in the study. Health care providers (surgeons and specialized nurses) and patients signed an informed consent form. Study participants received a consultation with a surgeon or specialized nurse in preparation for their surgery. This consultation was audio-recorded, transcribed, and content coded. Data were collected using questionnaires before and after the consultation.

This study was registered with Trialregister.nl (NTR5919) and was approved by the Review Board of the Amsterdam School of Communication Research (2017-PC-7979) and the medical ethical review boards of the hospitals that participated in the study (METC-nr: 13-061). The data collected to answer the RQs and hypotheses for this study were part of a larger investigation including multiple measurement moments.

Procedure and Participants

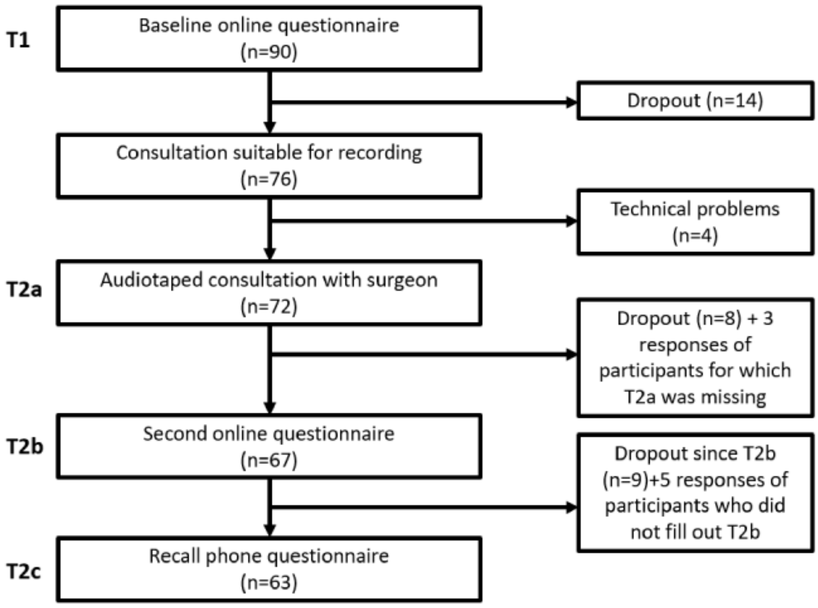
Participants included newly diagnosed colorectal cancer patients; those who had planned to undergo surgery, possibly in combination with other treatment and had sufficient command of the Dutch language, were able to read, and had no cognitive impairment according to their medical record (eg, dementia); and those who had provided written informed consent.

Once the consultation with the surgeon was scheduled, a specialized nurse or medical secretary asked the patients if they wanted to receive study information. Patients who agreed to being contacted about this study were approached, approximately 3 days before the consultation, by the study coordinator via phone to explain what study participation would entail. Consenting patients received additional information and the first online questionnaire at time point 1 (T1) via email. Patients were asked to complete the first questionnaire 1 day before the consultation.

The scheduled consultation was recorded at time point 2a (T2a), and 2 days thereafter at time point 2b (T2b), the patients received the second questionnaire partly via email, including standard questions that were the same for all patients. Patients were also contacted via telephone 2 to 3 days after the consultation at time point 2c (T2c) by the research assistant or researcher to assess recall using recall questions that were tailored to the consultation.

The final sample consisted of 90 patients, as seen by 23 health care providers (surgeons and specialized nurses) in 6 Dutch hospitals. During the study, 346 patients were reported to be suitable for participation by the specialized nurses or medical secretaries of the hospitals. A total of 285 patients were successfully approached to participate in the study. The other 61 patients either did not meet the inclusion criteria or could not be reached because of organizational or technical difficulties. Of the 285 patients who were successfully approached, 119 consented to participate in the study. As 29 of the consenting patients did not fill out the first questionnaire before the consultation, a total of 90 patients were included in the final analyses. Between the first and the following questionnaires, a number of patients dropped out, resulting in 72 consultation recordings, 67 responses on T2b, and 63 responses on T2c. More details about the dropout process are shown in Figure 2.

Figure 2. Flowchart of inclusion and dropout. T1: time point 1; T2a: time point 2a; T2b: time point 2b.



Measures T1

Demographics

Sociodemographic information was obtained in the first questionnaire with questions regarding age, gender, education level, living situation, and internet use. A total of 3 categories were formed for education level (low, middle, and high). In addition, hospital records were used to obtain medical information about diagnoses and treatments of patients.

Frailty

Frailty was measured using the Groningen Frailty Indicator [43]. This scale contains 15 items about physical functioning (mobility, multiple health problems, fatigue, and vision or hearing problems), cognitive functioning, social functioning, and psychological functioning (feelings of depression or anxiety). The total score could range from 0 to 15; however, in this study, patients scored from 0 to 11 (mean 2.80, SD 2.45), with a higher score indicating more frailty [43].

Health Literacy

A 3-item questionnaire was used to measure health literacy [46]. The items addressed one’s ability to obtain and read medical information and to fill out medical forms on a 5-point scale (α=.62). The total score ranged from 1 to 5, with a higher score indicating higher health literacy (mean 4.26, SD 0.71).

Anxiety (Preconsultations)

Anxiety was measured at T1 using the short Dutch version of the State Trait Anxiety Inventory [10,78]. Patients rated the degree to which they were currently experiencing anxiety on a 4-point scale ranging from 1 (not at all) to 4 (very much). Higher scores on the scale indicate higher levels of anxiety. Patients scored on average 1.95 (SD 0.55), with scores ranging from 1 to 3.67. Cronbach alpha was good (α=.82).

Cancer-Related Stress

Cancer-related stress was measured at T1, with a subscale of the Dutch version of the Impact of Events Scale [79,80], comprising 7 items (α=.84). Participants rated the items on a 4-point Likert scale (1=*not at all*, 2=*rarely*, 3=*sometimes*, 4=*often*), with a higher score indicating higher levels of cancer-related stress. Scores ranged from 1 to 3.71, and patients scored an average of 2.03 (SD 0.70).

Coping Style

Coping style was measured using the adapted shortened version of the Threatening Medical Situation Inventory at T1 [81,82]. The scale consists of 3 items measuring monitoring intentions regarding the patients’ medical situation. Items addressed intentions to (1) look for information within the threatening situation, (2) go deeply into the situation by reading about it, and (3) get information from the health care provider (α=.82). Participants responded to the statements with answer options ranging from 1 (*not at all applicable to me*) to 5 (*very much* *applicable to me*) and scored an average of 3.46 (SD 1.07), with a higher score indicating higher monitoring intentions.

OHIS

On the basis of previous research [20], patients were asked to indicate on a 5-point Likert scale how often they had used the internet to seek information about their illness or treatment options before the consultation (T1). The answer options were 1 (*did not use*), 2 (*used very little*), 3 (*used sometimes*), 4 (*used regularly*), and 5 (*used often*). Patients on average scored 2.23 (SD 1.32).

Measures T2a

Patient Participation

The audiotaped consultations were transcribed and manually coded by a research assistant using 3 measures to represent patient participation. This operationalization is in line with the methods used in previous research [83-86]. First, the absolute contribution of the patient to the consultation was measured using the patient’s absolute word count. Second, the relative contribution of the patient was measured by calculating the ratio of the number of words used by the patients compared with the number of words used by the health care provider. For these 2 measures, the coding process involved counting all the words used by the patient and the health care provider [83,84]. Third, the number of questions and assertions expressed by the patient during the consultation was coded using a codebook developed based on the method described by Street and Millay [32] (the complete codebook is given in Multimedia Appendix 1). A total of 10% (9/90) of the data set was double-coded by a second independent coder, resulting in acceptable intercoder reliability (κ=0.764; P<.001).

Measures T2b

Anxiety (Postconsultation)

Anxiety was measured postconsultation (T2b) in the same manner as in the preconsultation (T1). Patients on average scored 1.80 (SD 0.66). Cronbach alpha was good (α=.86).

Satisfaction With the Consultation

To measure patient satisfaction with the consultation (T2b), the 5-item *Patient Satisfaction Questionnaire* was used [87]. Items addressed the following: the extent to which the patient was satisfied in terms of needs that were met by the surgeon, if the patient felt actively involved during the consultation, the information received during the consultation, the emotional support received during the consultation, and the interaction during the consultation in general (α=.80) [84]. All the answer options ranged from 1 (*not satisfied at all*) to 5 (*completely satisfied*), and patients scored an average of 4.39 (SD 0.58).

Measures T2c

Information Recall

To measure information recall, the Netherlands Patient Information Recall Questionnaire (NPIRQ) [88] was used to compose the questions. The correct answers to the questions were (parts of) statements provided by the surgeon during the consultation. Therefore, the answers were literally derived from the transcribed consultations. Answers provided by the patients were scored as 0 (not recalled), 1 (partially recalled), and 2 (completely recalled). If the patient did not recall the information, there were 2 other answer option: “this information was not discussed” and “this information was discussed, but I can't remember the details,” both resulting in a score of 0 [88].

In line with the NPIRQ guidelines, a sum score was constructed by calculating the percentage of the obtained recall score (range 6%-100%) relative to the maximum achievable score (2-26 points), with higher scores indicating better recall. Patients scored an average of 60% (SD 0.19). A total of 10% of the cases (7/63) were double-coded by 2 independent coders to check intercoder reliability (mean κ=0.71; P<.001) [89].

Statistical Analyses

The analyses are based on a 2-step process. First, the correlations between demographic and psychosocial variables and outcome variables were tested. The variables that significantly correlated with the outcome measures at a significance level of .10 were selected for follow-up analyses as control variables. Second, multivariate regression analyses were carried out to test whether demographic variables (age, gender, and education level) and psychosocial factors (frailty, coping style, stress, and anxiety before the consultation) were related to OHIS (RQ1) and if OHIS was related to patient participation (number of words used by the patient during the consultation, relative contribution a patient had in the consultation in terms of the word count ratio, and number of questions and assertions expressed; H1). For the mediation effects in H2a, H2b, and H2c, regression analyses using an SPSS macro allowing for mediation, (PROCESS model 4) [90] were conducted. In addition, to determine whether the relation between OHIS and the outcome variables differed depending on clustering within health care providers, multilevel analyses were carried out if the dependent variable correlated with health care providers [91].

Results

Sample

The age of patients included in the final analyses ranged from 39 to 88 years (mean 69.93, SD 9.93), and about two-thirds of the patients were male (59/90, 66%). Half of the patients (45/90, 50%) had a medium level of education. Patients’ health literacy was relatively high (mean 4.25, SD 0.71), and they were not frail on average (mean 2.80, SD 2.45). Almost half of the patients (41/90, 46%) indicated that they did not use the internet, 12% (11/90) used the internet very little, 21% (19/90) used the internet sometimes, 16% (14/90) used the internet regularly, and 6% (5/90) used the internet often before the consultation. Nonresponse analyses revealed that participants did not differ compared with nonparticipants regarding gender ($F_{1,309}$=2.92; P=.09) but were on average significantly younger (mean 69.75, SD 9.93) than patients who did not wish to participate (mean 73.15, SD 10.30; $F_{1,297}$=7.24; P=.008). The background information of the participants is presented in Table 1.

Table 1. Sample characteristics.

Background variables[a]	Patients
Demographic information (n=90), mean (SD)	
Age (years)	69.93 (9.93)
Gender (n=90), n (%)	
Male	59 (66)
Female	31 (34)
Education level (n=88), n (%)	
Low	24 (27)
Medium	45 (51)
High	19 (22)
Health background information (n=90), mean (SD)	
Health literacy[b]	4.25 (0.71)
Frailty[c]	2.80 (2.45)
Psychosocial information (n=90), mean (SD)	
Coping style[d]	3.46 (1.07)
Online health information seeking behavior (n=90), n (%)	
Never	41 (46)
Very little	11 (12)
Sometimes	19 (21)
Regularly	14 (16)
Often	5 (6)

[a] All cells add up to 100% owing to missing data.

[b] A higher score indicates higher levels of health literacy (maximum range 1-5; reported range 1-5).

[c] A higher score indicates higher frailty (maximum range 0-15; reported range 0-11).

[d] A higher score indicates a higher information-monitoring coping style (maximum range 1-5; reported range 1-5).

Patient Participation

Recorded consultations (n=72) lasted between 4 minutes 26 seconds and 46 minutes 40 seconds, with an average duration of 20 minutes 19 seconds (SD 7.47 minutes). The number of words spoken during these consultations ranged from 488 to 6824 words (mean 2657, SD 1307.89). Patients spoke a minimum of 29 words and a maximum of 1347 words (mean 472.57, SD 295.46), whereas health care providers spoke at least 386 words and at the most 5124 words (mean 1998.83, SD 991.93). Patients scored a relative contribution to the consultation of 19.12% (472.57/2471.4) on average, ranging from 3.4% to 43.5% (SD 8.20); therefore, the ratio of health care providers ranged from 56.5% to 96.6%, with an average of 80.8% (SD 8.20).

A total of 69 patients asked at least one question, and 55 patients expressed at least one assertion. The number of questions ranged from 1 to 35 per consultation (mean 6.44, SD 6.36), and the number of assertions ranged from 1 to 10 per consultation (mean 2.30, SD 1.92). This resulted in a total number of questions and assertions ranging from 1 to 37 (mean 7.96, SD 7.03).

Predictors of OHIS

Demographics

Correlation analyses showed that age was negatively related to OHIS (*r*=−0.29; *P*=.005), suggesting that an increase in age was associated with less OHIS. Education level and OHIS were positively correlated (*r*=0.37; *P*<.001), suggesting that higher educated patients engage more in OHIS. No significant correlations were found between OHIS and gender (*r*=0.01; *P*=.91), frailty (*r*=−0.10; *P*=.35), and health literacy (*r*=0.15; *P*=.14; Table 2).

Table 2. Correlation matrix.

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.
1. Age	—[a]																
2. Gender[b]	0.021	—															
3. Education level[c]	−0.057	0.038	—														
4. Health literacy	0.039	0.074	0.220*	—													
5. Frailty	−0.157	−0.002	−0.183	−0.295**	—												
6. Anxiety (preconsultation)	−0.286**	−0.016	−0.113	−0.041	0.461**	—											
7. Cancer-related stress	−0.294**	−0.156	−0.02	−0.045	0.203	0.554**	—										
8. Coping style	−0.205*	−0.099	0.231*	0.112	−0.115	0.013	0.198	—									
9. Health care provider	0.096	−0.172	−0.275**	−0.097	−0.162	0.119	0.109	−0.061	—								
10. consultation time	−0.043	0.079	−0.056	−0.076	−0.250*	0.088	0.06	0.127	0.509**	—							
11. Online health information seeking	−0.289**	0.012	0.369**	0.151	−0.096	0.183	0.361**	0.453**	−0.1	0.143	—						
12. Patient participation word count	−0.061	−0.229*	0.099	0.02	−0.131	0.142	0.082	0.336**	0.392**	0.525**	0.326**	—					
13. Patient participation relative contribution	−0.074	−0.103	0.086	0.077	0.111	0.039	−0.003	0.168	−0.062	−0.156	0.22	0.574**	—				
14. Patient participation questions and utterances	0.065	−0.258*	0.147	−0.076	−0.034	0.147	0.114	0.223	0.285*	0.330**	0.176	0.633**	0.295**	—			
15. Anxiety (postconsultation)	−0.067	−0.231*	−0.144	−0.124	0.435**	0.601**	0.511**	0.152	0.085	−0.031	0.238*	0.187	0.166	0.278*	—		
16. Satisfaction	0.134	−0.200	−0.174	−0.044	−0.151	−0.169	−0.121	−0.127	0.227	0.141	−0.191	0.086	−0.178	0.005	−0.360**	—	
17. Recall	−0.105	0.021	0.080	−0.126	0.073	0.150	0.161	−0.176	0.081	0.061	0.016	0.208	0.139	0.040	−0.018	0.345**	—

[a] Not applicable.

[b] Gender was dummy coded into 1=female and 2=male.

[c] Education was dummy coded into 1=low, 2=medium, and 3=high.

**P*<.05, ***P*<.01, ****P*<.001.

Psychosocial Factors

In addition, correlation analyses showed that cancer-related stress was positively correlated with OHIS (*r*=0.36; *P*<.001), implying that higher stress levels can result in more OHIS. There was a marginally significant positive correlation between anxiety before the consultation and OHIS (*r*=0.18; *P*=.08), suggesting that patients who report higher anxiety levels might engage more in OHIS. Regarding coping style, a positive correlation was found (*r*=0.45; *P*<.001), meaning patients with higher levels of monitoring coping style engaged more in OHIS (Table 2).

Regression Analyses

To test whether these variables predict OHIS, a regression analysis was conducted, including all possible predictors that significantly correlated with OHIS (age, education level, cancer-related stress, anxiety before the consultation, and coping style). The results showed that education level (*B*=0.54; *P*=.002), cancer-related stress (*B*=0.48; *P*=.02), and coping style (*B*=0.41;

P=.001) were positively associated with OHIS. Thus, higher educated patients, patients experiencing more cancer-related stress, and patients with higher levels of a monitoring coping style more frequently engaged in OHIS. There was no relation between age and OHIS (*B*=−0.01; *P*=.24) and between anxiety before the consultation and OHIS (*B*=0.08; *P*=.74) based on the multivariate regression. To answer RQ1, education level, cancer-related stress, and coping style are positively related to OHIS.

Relation Between OHIS and Patient Participation During the Consultation (n=71)

The correlation analyses showed that gender was significantly related to the number of words used by the patient (*r*=−0.23; *P*=.005) and the number of questions and assertions expressed by the patient (*r*=−0.26; *P*=.003), suggesting that males used fewer words and expressed fewer questions and assertions than females. Coping style was also positively related to the number of words used by the patient (*r*=0.37; *P*=.004), indicating that patients with a more monitoring coping style used more words (Table 2). There were no significant correlations between the other variables and the number of words used, the relative contribution of a patient in the consultation in terms of the word count ratio, or the number of questions and assertions expressed by the patient.

Regression analyses were carried out to test the relation between OHIS and patient participation outcomes. On the basis of the correlation analyses, gender and coping style were included as control variables for the regression analyses regarding the number of words used by the patient and gender was included as the control variable for the regression regarding the number of questions and assertions expressed. No variables were included as control variables in the regression regarding relative contribution of the patient.

Results showed OHIS was positively related to the number of words used by the patient during the consultation (*B*=50.58; *P*=.02), when controlling for gender and coping style. The relation between OHIS and the relative contribution of the patient a patient had in the consultation in terms of the word count ratio was also significant (*B*=1.99; *P*=.02). OHIS was not related to the number of questions and assertions expressed (*B*=0.74; *P*=.26), when controlling for gender. In other words, patients who engaged more in OHIS used more words during the consultation and had a larger relative contribution to the conversation but did not express more questions and assertions. Regarding H1, we can conclude that OHIS is associated with some, albeit not all, indicators of patient participation during consultations.

Relation Between OHIS and Anxiety, Satisfaction, and Recall, Mediated by Patient Participation

The correlation analyses (n=90) showed that gender (*r*=−0.23; *P*=.005), frailty (*r*=−0.44; *P*<.001), anxiety before the consultation (*r*=−0.60; *P*<.001), and cancer-related stress (*r*=−0.51; *P*<.001) were significantly related to anxiety after the consultation. Gender was also significantly related to the number of words used by the patient (*r*=−0.23; *P*=.005) and the number of questions and assertions expressed by the patient (*r*=−0.26; *P*=.003), whereas coping style was also positively related to the number of words used by the patient (*r*=0.37; *P*=.004; Table 2). These variables were included as control variables in the regression analyses regarding anxiety after the consultation. Health care provider was only significantly related to satisfaction with the information (*r*=−0.23; *P*=.005). However, multilevel analyses showed the relation between OHIS and satisfaction was not dependent on health care provider ($F_{1,4}$=−0.04; *P*=.35). There were no significant correlations between the other variables and satisfaction with the information or information recall. Therefore, no control variables were included in the regression analyses regarding satisfaction and recall.

Anxiety (n=64)

When controlling for gender, frailty, anxiety before the consultation, and cancer-related stress, OHIS was not related to anxiety after the consultation (*B*=0.07; *P*=.17). Regarding patient participation, the number of words used by the patient *B*=−0.01 *P*=.44), the relative contribution of the patient in terms of the word count ratio (*B*=0.01; *P*=.14), and the number of questions and assertions expressed by the patient (*B*=0.01; *P*=.66) were also not related to anxiety after the consultation. There was no significant mediation of OHIS on anxiety after the consultation via the number of words used by the patient, relative contribution of the patient to the consultation, or the number of questions and assertions (Table 3); thus, H2a must be rejected.

Table 3. Mediation analyses.

Relations	*B*[a]	SE	95% CI values	*t* test (*df*)	*P* value
Direct effect of OHIS[b]					
On word count[c]	68.9740	27.8861	13.1535 to 124.7945	2.4734 (5,58)	.02
On word count ratio[d]	1.9918	0.8473	0.2958 to 3.6879	2.3508 (5,58)	.02
On questions and assertions[e]	0.7349	0.6469	−0.5601 to 2.099	1.1360 (5,58)	.26
On anxiety	0.0666	0.0517	−0.0369 to 0.1701	1.2890 (8,55)	.20
On satisfaction	−0.1029	0.0560	−0.2149 to 0.0091	−0.18377 (4,59)	.07
On recall	−0.0203	0.0189	−0.0581 to 0.0175	−1.0747 (4,58)	.29
Direct effects on anxiety					
Of word count	−0.0003	0.0003	−0.0009 to 0.0004	−0.7810 (8,55)	.44
Of word count ratio	0.0141	0.0096	−0.0051 to 0.0333	1.4679 (8,55)	.15
Of questions and assertions	0.0051	0.0117	−0.0184 to 0.0286	0.4365 (8,55)	.66
Indirect effects of OHIS on anxiety					
Mediated by word count	−0.0174	0.0231	−0.0385 to 0.0549	N/A[f]	N/A
Mediated by word count ratio	0.0280	0.0219	−0.0196 to 0.0694	N/A	N/A
Mediated by questions and assertions	0.0038	0.0162	−0.0470 to 0.0225	N/A	N/A
Direct effects on satisfaction					
Of word count	0.0008	0.0004	0.0001 to 0.0015	2.2207 (4,59)	.03
Of word count ratio	−0.0223	0.0109	−0.0442 to 0.0005	−2.0487 (4,59)	.04
Of questions and assertions	−0.0087	0.0139	−0.0365 to 0.0191	−0.6246 (4,59)	.53
Indirect effects of OHIS on satisfaction					
Mediated by word count	0.0529	0.0283	0.0053 to 0.1158	N/A	N/A
Mediated by word count ratio	−0.0319	0.0254	−0.0925 to 0.0068	N/A	N/A
Mediated by questions and assertions	−0.0068	0.0162	−0.0268 to 0.0416	N/A	N/A
Direct effects on recall					
Of word count	0.0002	0.0001	0.0000 to 0.0004	1.6737 (4,58)	.10
Of word count ratio	0.0004	0.0036	−0.0068 to 0.0076	0.1033 (4,58)	.92
Of questions and assertions	−0.0025	0.0047	−0.0119 to 0.0069	−0.5359 (4,58)	.59
Indirect effects of OHIS on recall					
Mediated by word count	−0.0131	0.0091	−0.0029 to 0.0333	N/A	N/A
Mediated by word count ratio	−.0004	0.0051	−0.0092 to 0.0127	N/A	N/A
Mediated by questions and assertions	−0.0015	0.0043	−0.0084 to 0.0101	N/A	N/A

[a] *B*: Standardized β.

[b] OHIS: online health information seeking.

[c] Number of words used by the patient.

[d] Relative contribution of the patient in terms of words used by the patient compared with words used by the health care provider.

[e] Number of questions and assertions expressed by the patient.

[f] N/A: not applicable.

Satisfaction (n=64)

OHIS was marginally negatively related to satisfaction with the consultation directly (*B*=−0.10; *P*=.07), suggesting that the more a patient engaged in OHIS, the less satisfied the patient was with the consultation. The number of words used by the patient was positively related to satisfaction with the consultation (*B*=0.0008; *P*=.03), meaning the more words a patient used, the more satisfied a patient was. The relative contribution of the patient to the consultation in terms of the word count ratio was negatively related to satisfaction (*B*=−0.02; *P*=.05), suggesting that the higher the relative contribution of the patients (and therefore automatically the lower the contribution of the health care provider), the less satisfied the patient was. There was no significant relation between the number of questions and assertions expressed by the patient and satisfaction (*B*=−0.01; *P*=.54). The indirect relation between OHIS and satisfaction, based on the number of words used by the patient, was also significant (*B*=0.05; 95% CI 0.0053-0.1158). This means that patients who engaged in OHIS used more words during the consultations, which, in turn, was positively related to more satisfaction with the consultation. Therefore, H2b is partly supported.

Recall

The analyses showed no significant correlation between OHIS and information recall (*B*=−0.02; *P*=.28). In addition, there was no significant relation between the number of words used by the patient (*B*=0.00; *P*=.10), the relative contribution of the patient to the consultation (*B*=0.01; *P*=.92), the number of questions and assertions expressed (*r*=−0.01; *P*=.59), and information recall. In addition, there was no significant mediation of OHIS on information recall via 1 of the patient participation measures (Table 3). This implies that H2c must be rejected.

Discussion

Review of Findings

The aim of this study is twofold. First, this study examined which demographic and psychosocial factors could predict OHIS of newly diagnosed cancer patients. Second, we investigated how OHIS subsequently relates to patient participation during consultations and how this, in turn, affects patients' anxiety, satisfaction, and information recall. Regarding demographic factors, the results showed that patients with higher levels of education were more inclined to engage in OHIS. With respect to psychosocial factors, higher levels of cancer-related stress are associated with more OHIS, and patients with a monitoring coping style also engage more in OHIS. In turn, OHIS was positively related to patient participation in terms of the number of words used by the patient during the consultation and the relative contribution of the patient in the consultation but not to the number of questions and assertions expressed.

The negative direct relation between OHIS and satisfaction shows that more OHIS leads to lower patient satisfaction. In addition, the number of words used by the patient was related to higher levels of satisfaction with the consultation, whereas the relative contribution of the patient in the consultation was related to lower levels of satisfaction. The results also showed a positive indirect relation between OHIS and satisfaction via the number of words used by the patient, meaning that patients who engaged more in OHIS used more words during the consultation, which, in turn, was positively related to satisfaction with the consultation. On the basis of these results, it can be concluded that OHIS can lead to both more and less satisfaction with the consultation, depending on the mediation of the number of words used by the patient.

Our results indicate that not all patients engage in OHIS. In particular, lower educated patients search less for health information online. This is in line with previous research in which education has been shown to positively influence OHIS [92]. Therefore, concerns raised almost 20 years ago by Lenhart et al [31,93] regarding the digital divide still appear to be valid. As our findings suggest that OHIS is related to patient participation and satisfaction with the consultation, it can be seen as problematic that a group of patients still does not engage in OHIS.

Our results show different relations between the different measures of patient participation and OHIS. First, our results seem to suggest that patients who engage in OHIS are inclined to use more words during the consultation, which, in turn, results in greater satisfaction with the consultation. This mediation may occur regardless of the reaction of the health care providers. However, satisfaction with the consultation might also be influenced by the interplay between the patient and health care provider. For example, patient participation can elicit a response in the health care provider, for example, discussing more information during consultations [94-96]. On the other hand, the health care provider may disregard the patient's input, which is more in line with studies that have shown health care providers to insufficiently meet the patient's needs [93-95]. If the relative contribution of the patient is higher, it could mean that even though the patient uses more words, the health care provider does not respond to the patient's input. This could explain why an increase in the relative contribution of the patient to the consultation is related to a decrease in satisfaction with the consultation.

Second, the undemonstrated relation between OHIS and the expression of questions and assertions contradicts previous research, suggesting that OHIS facilitates patients to express their needs and concerns [97-99]. One reason for this could be that online health content is often incorrect, incomplete, and biased [97] and is usually experienced by patients as difficult to comprehend [97-99]. If patients engage in OHIS but find information that confuses them, this might inhibit their expression of questions or assertions. In particular, if patients do not feel empowered and confident during the consultation, they might ask fewer questions and express less assertions. It might also be possible that patients did not find the right information to support them in asking questions or expressing assertions or that OHIS fulfilled patients' information needs and already answered questions patients had. This could have resulted in patients asking fewer questions during consultations. On the other hand, finding ambiguous information online could also lead to confusion resulting in patients asking more questions during the consultation. We swiftly examined the content of the transcripts to obtain a better understanding of the differences in relations between OHIS and the separate indicators of patient participation. The transcripts showed that patients who used more words but did not express more questions and assertions mostly engaged in small talk and discussed side issues unrelated to their ongoing situation. This implies that patients who are more active in OHIS are also more active during consultations in terms of using more words; however, the information they found online did not seem to empower them enough to express treatment-related questions or assertions.

We expected that OHIS would result in less anxiety after the consultation (H2a), via more patient participation, but our results did not support this. The fact that OHIS did not influence the expression of questions and assertions might explain why we also did not find an indirect relation between OHIS and anxiety via patient participation, as feelings of anxiety could not be partly dismantled by discussing them with the health care provider.

The aforementioned line of reasoning may also explain why OHIS did not lead to better information recall, indirectly via patient participation. By not expressing questions or assertions, but just talking more about other subjects, more information was added to the consultation. The amount of information this added to the consultation could have overshadowed the most important information about the diagnosis and treatment. Previous research has shown that the amount of information discussed during a consultation can negatively influence recall of the information discussed [88].

Strengths

This study is, to the best of our knowledge, the first to show a significant mediation of OHIS on satisfaction with the consultation via patient participation. Established models regarding the influence of OHIS on patient participation mainly focused on the ways in which patient participation can be increased by OHIS, for example, by increasing knowledge and feelings of empowerment [62], or how patient participation can influence patient outcomes [31,84,93]. Our findings help to connect and extend these models by linking these 2 processes together, considering both the influence of OHIS on patient participation and the relation between patient participation and patient outcomes.

A distinguishing feature of this study was the participants. Including newly diagnosed cancer patients is challenging because of the emotional burden the patients face. Therefore, another strength of this study is that we succeeded in collecting these data in a vulnerable population. The fact that this is a multicenter study, with participating patients being treated in 1 of 6 Dutch hospitals, made inclusion of the patients even harder. Although this is beneficial for the external validity of the study, differences occurred in the recruitment process between the hospitals and inclusion was more troubled in some hospitals than in others, resulting in varying inclusion rates between hospitals.

Limitations and Future Research

First, patient participation was operationalized using only quantitative measures. Therefore, we could only draw conclusions based on the quantity of patient participation and not on the quality of patient participation. Future research should also qualitatively address patient participation during consultations to gain more insight into the content of patient participation. In addition, only the utterances of the patients were analyzed. The utterances of health care providers were only included in terms of relative contribution to the consultation but not in terms of content. As it seems plausible that patients' communication is dependent on the interplay between the partakers in that consultation [31,84,92], it is advisable to analyze the behavior of all parties taking part in the consultation in future research. In addition, only behavioral measures were used in this study to measure patient participation. Adding measures of perceived participation would be a valuable addition and is, therefore, recommended for future research.

A limitation that could have influenced the relations with information recall is that in this study, the number of recall questions was based on the amount of information the patient received from the health care provider during the consultation. This means that the more information was provided, the more recall questions the patient had to answer. The amount of information is known to be negatively related to the ability to correctly recall this information [100,101], and a higher number of questions can mean a higher chance of making mistakes. The researchers of this study deliberately chose to tailor the recall questions to the consultations of each separate patient because asking a fixed set of recall questions meant asking questions about topics that were not discussed with the patient, which was seen as unethical. Researchers can decide on asking a maximum number of questions per topic in the case of long consultations.

Finally, as our results show that OHIS does not lead to expressing questions or utterances, we encourage researchers to further investigate the effects of other types of online health information, such as online tools specifically developed and offered to patients. Previous research has shown that online health information developed and offered to a specific patient population, including preparatory tools such as question prompt lists or information tailored to a patient's situation, can be effective in increasing patient participation [99,100].

Practically, as we see a relation between some measures of patient participation and satisfaction, but not all, this study shows the importance of providing patients with the right tools to search for online health information that stimulates participation by means of expressing questions and utterances during consultations. In particular, because OHIS can also increase worry and confusion [27,30,63], health care providers are advised to guide patients with clear instructions on how to search for information online. For example, hospitals could provide patients with flyers, including information about which websites are reliable and which websites are not.

Conclusions

This study showed that younger patients, higher educated patients, patients who experience more cancer-related stress, and patients with a monitoring coping style are more likely to engage in OHIS. OHIS is positively related to the patient's absolute contribution during a consultation, which, in turn, results in the patient being more satisfied with the consultation. The results are an important addition to established models regarding the influence of OHIS.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Codebook of patient participation.
[PDF File (Adobe PDF File), 159 KB-Multimedia Appendix 1]

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Abbreviations

H1: Hypothesis 1
H2a: Hypothesis 2a
H2b: Hypothesis 2b
H2c: Hypothesis 2c
NPIRQ: Netherlands Patient Information Recall Questionnaire
OHIS: online health information seeking
RQ: research question
T1: Time point 1
T2a: Time point 2a
T2b: Time point 2b
T2c: Time point 2c

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Original Paper

Barriers to Dissemination of Local Health Data Faced by US State Agencies: Survey Study of Behavioral Risk Factor Surveillance System Coordinators

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Abstract

Background: Advances in information technology have paved the way to facilitate accessibility to population-level health data through web-based data query systems (WDQSs). Despite these advances in technology, US state agencies face many challenges related to the dissemination of their local health data. It is essential for the public to have access to high-quality data that are easy to interpret, reliable, and trusted. These challenges have been at the forefront throughout the COVID-19 pandemic.

Objective: The purpose of this study is to identify the most significant challenges faced by state agencies, from the perspective of the Behavioral Risk Factor Surveillance System (BRFSS) coordinator from each state, and to assess if the coordinators from states with a WDQS perceive these challenges differently.

Methods: We surveyed BRFSS coordinators (N=43) across all 50 US states and the District of Columbia. We surveyed the participants about contextual factors and asked them to rate system aspects and challenges they faced with their health data system on a Likert scale. We used two-sample *t* tests to compare the means of the ratings by participants from states with and without a WDQS.

Results: Overall, 41/43 states (95%) make health data available over the internet, while 65% (28/43) employ a WDQS. States with a WDQS reported greater challenges (P=.01) related to the cost of hardware and software (mean score 3.44/4, 95% CI 3.09-3.78) than states without a WDQS (mean score 2.63/4, 95% CI 2.25-3.00). The system aspect of standardization of vocabulary scored more favorably (P=.01) in states with a WDQS (mean score 3.32/5, 95% CI 2.94-3.69) than in states without a WDQS (mean score 2.85/5, 95% CI 2.47-3.22).

Conclusions: Securing of adequate resources and commitment to standardization are vital in the dissemination of local-level health data. Factors such as receiving data in a timely manner, privacy, and political opposition are less significant barriers than anticipated.

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KEYWORDS

web-based data query systems, WDQS; health data; population health; dissemination of local health data

Introduction

It is widely acknowledged in the public health field that progress in information technology has paved the way for exciting opportunities to disseminate local level health data more efficiently [1,2]. The growth of the internet, mobile technologies, artificial intelligence, and other technological advances have enabled health information to become more easily accessible and widely available to a broader population [2-4]. There has been growing enthusiasm for the application of big data and its utility in public health, particularly for population-level health data [5]. Access to high quality population-level health data is essential for public health, as it informs us of disease tracking, health problems, and health surveillance at the subpopulation level [6,7]. Health informatics has enabled public health practitioners to assess public and population health information by accurately combining data from a wide range of disparate sources [7]. Despite the vast advances in technology, there are many challenges associated with availability of high-quality population-level health data [7,8]. These problems have been even further exacerbated during the COVID-19 pandemic, as there is a lack of consistency in the data and their reporting [9,10].

As each US state is responsible for its own health surveillance, decisions regarding technology implementation have varied from state to state [11]. One popular option is for state agencies to design and develop dynamic web-based data query systems (WDQSs), which allow users to customize data queries by choosing data sets, variables, measures, and the format for presenting query results [12]. There are many benefits to WDQSs, as state agencies are able to respond to data requests in a timely manner, provide data to a broader population, and contribute to the development of community health assessments and policy decisions [13]. Another popular option is for states to make static reports available to the public on the World Wide Web. Static reports are generally manually compiled by staff and are available in formats such as PDF, Microsoft Excel, and HTML. Static reports limit user choice to precalculated statistics and do not allow users to choose parameters for a query [14]. Given the advances in information technology, deployment of these outdated technologies, which can be difficult to use and plagued by missing or incomplete data, by US states is unfortunate [15]. In the private sector, industries such as finance have been successful in maximizing the potential of the internet, as changes in stock prices are made available within seconds to end users.

WDQSs were first implemented in the late 1990s, as states developed systems in which queries could be specified and results returned on the World Wide Web without requiring any additional software [12]. At the time, strong efforts were being made to achieve data liberation and use of open-source information technology solutions and collaboration to promote public health [15]. Collaboration has contributed to states sharing developments, ideas, and knowledge to meet a variety of public health assessment needs [16-18]. To reduce the cost burden, there has been a push toward open-source software, which costs little or no money to procure [19]. Open-source code can be easily shared, and its key benefits include free redistribution, inclusion of source code, easy modification of the code, and lack of need for an additional license [20]. For example, in 2000, Utah's legacy Indicator Based Information System–Public Health (IBIS-PH) was developed using open-source code, and states such as New Mexico and Kentucky adopted the system within the first few years of its development. However, over the last decade, efforts toward WDQS implementation have stalled, and progress has slowed. Public health is at risk of falling behind from a technological standpoint [21]. Despite the significant advances in technology, including faster processors, improved bandwidth, and lower cost of storage, state agencies commonly face data sharing barriers between organizations within their state [21]. The purpose of this study was to investigate the barriers faced by state agencies to the implementation of WDQSs from the perspectives of Behavioral Risk Factor Surveillance System (BRFSS) coordinators from each state. We aimed to understand how challenges and perceptions of systems differ between states that have implemented a WDQS and states that have not. We hypothesized that the perceptions and challenges reported by the BRFSS coordinators would vary across states because of the coordinators' significance in releasing health data and their role in technology decisions in their states [14].

Methods

Study Design and Sampling

We designed and administered a web-based questionnaire to BRFSS coordinators from all 50 states and the District of Columbia (n=51). The BRFSS, established in 1984, is a health-related telephone survey that collects state data from US residents in all 50 states regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. The BRFSS coordinator in each state is responsible for gathering information about health behaviors and is responsible for the management and oversight of the BRFSS survey [22,23]. First, we queried the coordinators on how states disseminate their data. In January 2015, each prospective participant was sent an invitation letter by US Mail. We found the names and contact information of all the BRFSS coordinators on the US Centers for Disease Control and Prevention website [24]. The letter provided details of the study and indicated that participation was confidential, as the results would not be disclosed to anyone except the study staff. The letter specified that the coordinators' participation was voluntary and that they could withdraw at any point of the survey. Each participant was sent a follow-up email containing a link to the survey with a secure user name and password within 1-2 weeks upon receipt of the letter.

We queried the participants on the basic characteristics of their data dissemination, including how their health data are disseminated, which technology is used, and which types of data are available. We asked, “Does your state present health data over the internet?” and participants answered yes or no. We also queried if their state presents data using an interactive WBQS, which types of data are publicly available (eg, BRFSS, births, deaths), and finally, which path they took to develop their software (eg, in-house, adopted from an outside vendor). We also asked participants to rate the level of challenges they face regarding the dissemination of their data on a 4-point Likert scale (1, not at all challenging; 2, not very challenging; 3, somewhat challenging; 4, very challenging). A Likert scale is a set of statements (items) offered for a hypothetical situation under study, in which participants are asked to show their level of agreement (eg, strongly agree, somewhat agree). We presented 2 to 4 questions for three different categories: cost, staffing and support, and other challenges. We then asked the coordinators how they would rate various system-related aspects of their health data systems. They were presented a list of items and rated each item on a 5-point Likert scale (1, poor; 2, fair; 3, good; 4, very good; 5, excellent). For the system aspects, 3 to 4 questions were presented for each category, including website performance, data quality, and accessibility and support.

Data Analysis

We obtained descriptive statistics and profile characteristics for the participants from each state. We also compared the means of the ratings of participants from states that have implemented a WDQS and from states that have not implemented a WDQS. The means were compared using two-sample *t* tests between states with and without a WDQS, with $P<.05$ used as the level of significance.

Ethics Approval and Consent to Participate

Ethics approval for the study protocol was received from the Human Subjects Protection Office at the University of Connecticut Health Center.

Results

Profile characteristics at the state level can be found in Table 1. A total of 43 of the 51 coordinators completed the survey, for an overall response rate of 84%. Of the 43 participants, 42 completed the web-based survey, while 1 participant completed the survey over the telephone. Of the 43 states, 41 (95%) had some form of health data available on the web, while 28 (65%) reported having implemented a WDQS. Data available included BRFSS (33/43, 77%), births (31/43, 72%), deaths (30/43, 70%), lead screening (5/43, 12%), and hospitalizations (4/43, 9%).

Table 1. Profile of health data characteristics at the state level (n=43).

Characteristic and responses	Value, n (%)
Health data are made available on the internet	
Yes	41 (95)
No	2 (5)
Health data are made available using an interactive web-based query system	
Yes	28 (65)
No	15 (35)
Types of data that are publicly available[a]	
BRFSS[b]	33 (73)
Births	31 (72)
Deaths	30 (70)
Lead screening	5 (12)
Hospitalization	4 (9)
Software development path	
In-house	13 (37)
Outside vendor	8 (19)
Adopted from another state	6 (14)
Off the shelf commercial software	4 (9)

[a] More than one response is acceptable for this question, as a state may have multiple data sources.

[b] BRFSS: Behavioral Risk Factor Surveillance System.

We report the mean ratings for the challenges faced and system aspects in Table 2. On a 4-point Likert scale, participants rated the cost of system development (mean score 3.33), consultants/vendors (mean score 3.05), and the cost of hardware/software (mean score 2.89) as the most challenging. The overall mean score for all challenges faced was 2.68 on the 4-point Likert scale. Participants reported the lack of political support (mean score 1.77) and issues with data privacy (mean 2.55) as less of a challenge. We analyzed the mean results of the reported challenges between states with and without a WDQS (Table 2). Participants from states without a WDQS reported the cost of hardware and software to be a greater challenge than those from states with a WDQS (mean score 3.55, 95% CI 3.09-3.78, vs mean score 2.63, 95% CI 2.25-3.00; P=.01). System aspects were rated higher (P=.01) for the standardization of vocabulary by participants from states with a WDQS (mean 3.32, 95% CI=2.94-3.69) versus those from states without a WDQS (mean=2.85, 95% CI 2.47-3.22).

Table 2. Participant ratings of challenges faced by state agencies and of system aspects (N=43).

Grouping and item	Overall mean score[a]	With WDQS[b] (n=28), mean (95% CI)	Without WDQS (n=15), mean (95% CI)	*P* value[c]
Challenges faced (scored on a 4-point Likert scale)				
Cost				
Cost of system development	3.33	3.05 (2.68-3.41)	3.6 (3.28-3.91)	.06
Cost of hardware/software	2.89	2.63 (2.25-3.00)	3.44 (3.09-3.78)	*.01* [d]
Cost of vendors/consultants	3.06	2.93 (2.44-3.41)	3.25 (2.63-3.86)	.42
Staffing and support				
Lack of internal information technology staff	2.97	2.90 (2.37-3.42)	3.10 (2.48-3.71)	.67
Help desk support	2.60	2.40 (1.80-3.02)	3.00 (2.25-3.74)	.27
Lack of trained staff who understand the data	2.62	2.42 (1.98-2.85)	3.00 (2.49-3.50)	.12
Receiving data in a timely manner	2.40	2.36 (2.07-2.76)	2.42 (1.98-2.85)	.85
Other challenges				
Privacy	2.55	2.37 (2.06-2.67)	2.9 (2.28-3.51)	.11
Political opposition	1.77	1.6 (1.10-2.11)	2.14 (1.47-2.80)	.23
System aspects (scored on a 5-point Likert scale)				
Website usability				
User-friendliness	3.15	3.15 (2.73-3.56)	3.00 (2.69-3.32)	.64
Website performance	3.34	3.54 (3.15-3.93)	2.92 (2.47-3.36)	.06
Standardization of vocabulary	3.14	3.32 (2.94-3.69)	2.85 (2.47-3.22)	*.01*
End user satisfaction	3.03	3.37 (2.89-3.84)	2.40 (2.08-2.71)	.11
Data quality				
Availability of race, gender, and other social determinants	3.91	4.05 (3.63-4.46)	3.64 (3.24-4.03)	.11
Quality of data	3.90	4.00 (3.62-4.37)	3.69 (3.28-4.09)	.33
Breadth of data	3.33	3.42 (2.96-3.87)	3.15 (2.71-3.58)	.46
Ability to link to multiple data sources	2.81	3.28 (2.57-3.98)	1.75 (1.26-2.24)	*.01*
Accessibility and support				
Accessibility to researchers	3.67	3.92 (3.56-4.27)	3.15 (2.66-3.63)	.06
Accessibility to nonresearchers	3.58	3.76 (3.39-4.12)	3.23 (2.69-3.76)	.11
Timeliness of support requests	3.53	3.68 (3.28-4.07)	3.27 (2.73-3.80)	.23

[a] The overall mean score represents the full sample.

[b] WDQS: web-based data query system.

[c] Two-sample *t* tests were used to compare the mean scores between states with and without a WDQS.

[d] Italic text indicates statistical significance at *P*<.05.

Discussion

To our knowledge, this is the first national study to investigate barriers faced by state agencies to the dissemination of their health data using informants in key roles. The findings revealed that BRFSS coordinators rated their systems more favorably in states where a WDQS was implemented. Interestingly, despite the high cost of technology, staffing, implementation, and maintenance of technology-based systems and other factors, BRFSS coordinators from states that implemented a WDQS perceived their systems more favorably. We hypothesize that these findings are indications of a favorable assessment of the cost-benefit ratio of implementation of technology-based systems relative to low-cost health data systems. Adequate staffing and funding for state health data systems is lacking, which has impeded or slowed progress or halted data dissemination efforts in these states [25,26]. Our findings are more important than ever, given the reliance of society on trusted, reliable, and accurate public health data [27,28].

Prior research has indicated that organizations are reluctant to share their data due to organizational, technical, and political barriers [15]. In the current study, respondents reported that state agencies are generally willing to share their data and do not perceive political barriers as a significant challenge to data sharing. However, these findings should be taken with caution, as there may be bias because these perspectives were based exclusively on the experience of BRFSS coordinators, which may not be representative of that of other key stakeholders across states. Respondents also reported lack of interoperability between systems, as data may be transmitted in formats that are incompatible with the originating system. These findings are in line with prior work, in which it was reported that departments lack adequate staffing and resources to profile, "cleanse," and manipulate these data so they are usable [15,29]. If data are not usable, they have limited utility and do not create significant opportunities for public health research. According to the latest Public Health Workforce Interests and Needs Survey (PH WINS), a nationally representative survey of the public health workforce, state agencies lack adequate trained staff who are able to handle and interpret these data [30,31]. Public health agencies are lacking workers in areas such as data-informed decision-making, health informatics, and data quality, which are essential in the dissemination of public health data [30-32].

Our findings should be interpreted with certain limitations in mind. First, the results may not be generalizable beyond the perspective of the BRFSS coordinator in each state. As each state may have multiple stakeholders who have a vested interest in the WDQS, the opinion of the BRFSS coordinator may not be representative of the consensus from that state. Secondly, our study may reflect bias, as BRFSS coordinators in states with a WDQS may rate their systems higher due to the additional investments states have made in this technology. Third, because the study includes a small number of participants, there is insufficient statistical power to detect small differences in ratings among states with and without a WDQS. Fourth, as BRFSS coordinators from 7/51 states (14%) did not respond to the survey, there may be systematic bias related to the missing information from these states. The reasons that the BRFSS coordinators from those states refused to participate are also unknown. Fifth, questions may be interpreted differently from one state to the next. Web-based expertise and technical maturity may also vary from one state to another, depending on their experience. Finally, although measures such as quality, timeliness, satisfaction, and access were assessed for multiple constructs, their definitions were not presented in the survey. Respondents may have interpreted these measures differently, potentially resulting in bias. For example, the definition of "quality" may be perceived differently from one state to the next. Despite these limitations, the current study is, to our knowledge, the first to compare system ratings and assessments of challenges to presenting health data to the public among states with more primitive versus more advanced data systems. Directions for future research include more comprehensive efforts to evaluate the utility of WDQSs, as evidence of their usefulness and their potential impact on public health may help justify the additional expenditures required. Additionally, it is recommended that state agencies aim toward collaboration and investigate open-source software options. This model has been successful in the clinical setting. For example, open-source software has been adopted by several hospitals and clinics. A similar model can be applied for future WDQS development, as states should aim to collaborate and work toward building robust systems that are easy adoptable. In summary, it is important to design systems that facilitate access to local health data; these data provide information regarding health challenges at the subpopulation level, which will ultimately help guide future public health research. These problems have been at the forefront during the COVID-19 pandemic [33,34] and should be urgently addressed moving forward.

Data Availability

Data and materials are available upon request.

Authors' Contributions

MA is the lead author and contributed to the design, analysis, and writing. RA contributed to the design, analysis, and writing.

Conflicts of Interest

None declared.

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Abbreviations

BRFSS: Behavioral Risk Factor Surveillance System
IBIS-PH: Indicator Based Information System–Public Health
PH WINS: Public Health Workforce Interests and Needs Survey
WDQS: web-based data query system

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