Original Paper

Adoption of Electronic Health Records (EHRs) in China During the Past 10 Years: Consecutive Survey Data Analysis and Comparison of Sino-American Challenges and Experiences

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Abstract

Background: The adoption rate of electronic health records (EHRs) in hospitals has become a main index to measure digitalization in medicine in each country.

Objective: This study summarizes and shares the experiences with EHR adoption in China and in the United States.

Methods: Using the 2007-2018 annual hospital survey data from the Chinese Health Information Management Association (CHIMA) and the 2008-2017 United States American Hospital Association Information Technology Supplement survey data, we compared the trends in EHR adoption rates in China and the United States. We then used the Bass model to fit these data and to analyze the modes of diffusion of EHRs in these 2 countries. Finally, using the 2007, 2010, and 2014 CHIMA and Healthcare Information and Management Systems Services survey data, we analyzed the major challenges faced by hospitals in China and the United States in developing health information technology.

Results: From 2007 to 2018, the average adoption rates of the sampled hospitals in China increased from 18.6% to 85.3%, compared to the increase from 9.4% to 96% in US hospitals from 2008 to 2017. The annual average adoption rates in Chinese and US hospitals were 6.1% and 9.6%, respectively. However, the annual average number of hospitals adopting EHRs was 1500 in China and 534 in the US, indicating that the former might require more effort. Both countries faced similar major challenges for hospital digitalization.

Conclusions: The adoption rates of hospital EHRs in China and the United States have both increased significantly in the past 10 years. The number of hospitals that adopted EHRs in China exceeded 16,000, which was 3.3 times that of the 4814 nonfederal US hospitals. This faster adoption outcome may have been a benefit of top-level design and government-led policies, particularly the inclusion of EHR adoption as an important indicator for performance evaluation and the appointment of public hospitals.

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KEYWORDS

medical informatics; health information technologies; electronic health records; hospitals; Sino-American

Introduction

Electronic health records (EHRs) are the most important component of health information technology (HIT), and their adoption rate in hospitals indicates a country's level of digitalization in medicine. In the United States, EHRs enable the electronic documentation of providers' notes, electronic viewing of laboratory and radiology results, and electronic prescribing [1]. The 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act allocated approximately US $3 billion to accelerate the meaningful use of EHRs in US hospitals. Ultimately, the adoption rates in nonfederal hospitals increased from 9.4% in 2008 to 96% in 2017 [2,3]. In Asia, the EHR adoption rate increased from 15.1% in 2010 to 58.1% in 2015 in Korean hospitals [4] and from 21% in 2008 to 53% in 2014 in Japanese public hospitals [5]. In Europe, the usage of EHRs in German hospitals increased from 39.9% in 2007 to 68.4% in 2017 [6]. In China, the "Technical Specifications for Hospital Information Platforms based on EMRs" issued by the National Health Commission in 2015 defines electronic medical records (EMRs, corresponding to hospital EHRs) as complete and detailed clinical information resources that are created, stored, and used electronically by medical institutions and are generated and recorded for citizens in all visits to medical institutions [7]. Since 2015, the Chinese central government has invested over US $3.5 billion in HIT and EHRs and has issued 31 national policies and 134 technical standards covering all aspects of medical care digitalization and the construction of a digital medical security system. Thus, in China, EMRs are legal records created in hospitals and outpatient environments that constitute the data source of EHRs [8]. In the United States, the Promoting Interoperability Programs, led by the Centers for Medicare & Medicaid Services (CMS), do not specifically distinguish between EHRs and EMRs. In this study, the term EHRs refers specifically to the definitions provided by the CMS and China's National Health Commission.

Funding, policy, social organizations, and other factors, which can all greatly challenge any government, affect in-hospital EHR adoption. The most important factors associated with EHR adoption rates in hospitals are policy support and national standards. In the United States, relevant policies and standards include the HITECH Act [9], CMS Meaningful Use programs [10], and Promoting Interoperability Programs [8]. In China, they include the "46312" strategy [11], EMR Grading Evaluation Standards [12], and Hospital Intelligence Service Grading Evaluation Standards [13]. The second greatest factor affecting EHR promotion in both countries is insufficient financial support for digitalization in medicine [14]. Finally, another main issue is the large gap between the expectations of EHRs from clinical medical staff and their actual clinical performance.

As the world's largest country in terms of both population and number of hospitals, China has a unique medical system [15], with particular challenges affecting in-hospital EHR adoption. Therefore, the progress and difficulties in EHR adoption in Chinese hospitals are an important reference for other countries. First, through consecutive survey data analysis research, the EHR adoption in Chinese hospitals from 2007 to 2018 and the challenges of HIT innovation were summarized, based on the Chinese Health Information Management Association (CHIMA) Annual Survey—the longest and most authoritative national HIT industry survey in mainland China. Second, with the Bass model, we horizontally compared the EHR adoption rates of China and the United States from 2008 to 2017 and analyzed the challenges faced by the hospitals of these countries based on data taken from the Healthcare Information and Management Systems Services (HIMSS) Annual Surveys of 2007, 2010, and 2014. This study provides an overview and suggestions for further advancement of EHRs in hospitals in both countries, shares these experiences with other countries, and promotes global popularization of HIT.

Methods

EHR Definition and Function Reconciliation

Due to the differences in medical systems and traditions, a one-to-one mapping of the functions of EMRs in China and the United States is difficult. Nevertheless, we should clarify the definition and function of EHRs in these 2 countries so that the research results can reflect the closest comparable rates.

As for the United States, the EHR evaluation systems have, mainly, 2 aspects. First, for the governmental aspect, the Office of the National Coordinator for Health Information Technology (ONC) divided EHRs into "basic EHRs" (with or without clinical notes) and "comprehensive" EHRs in 2009. The former focuses on data collection and sharing and only needs to be implemented in one ward, while the latter stresses the clinical process based on the former and requires hospital coverage [2,16] (details in Multimedia Appendix 1). Since 2011, to facilitate the realization of a financial stimulus program, the CMS divided EHRs into 3 stages according to whether they are meaningfully used [17]. Each stage requires core objects and optional menu objects. Second, at the industry level, HIMSS Analytics developed an EMR adoption model (EMRAM) in 2005, including levels 0 to 7 based on "how many departments to use, standardization, sharing in hospital, decision support, sharing outside the hospital" [18].

As for China, the National Health Commission has been promoting the construction of EHRs with various policies and financial support since 2010 and issued the latest requirements on the definition and implementation timeline of EHRs in August 2018 [19]. In this requirement, EHR is divided into levels 0 to 8: levels 0 to 2 (low stage, focusing on the data collection function); levels 3 to 4 (medium stage, focusing on data sharing within or between departments and simple clinical decision making); and levels 5 to 8 (high stage, focusing on clinical intelligent decision making, cross-hospital data sharing, and patient self-service; details in Multimedia Appendix 2).

There is no systematic comparative study of the evaluation systems of China and the United States. Our preliminary comparison study of EHRs in the top 2 tertiary hospitals in Beijing found that the Chinese EHR stage 4 hospitals can accomplish most (7 of 11) meaningfully used tasks in the United States [20]. However, the requirements for some specific functions of EHRs in the 2 countries are inconsistent, which complicates one-to-one matching of the 2 standards. Preliminarily, after comparing the common terms of the 2 standards, we think that Chinese EHR stages 3 and 4 roughly correspond to basic EHRs with notes and comprehensive EHRs, respectively. Unlike US EHR standards, Chinese EHR stage 1 requires Chinese hospitals to use the EHR for billing.

We did not use the data from HIMSS EMRAM, which was used in both countries as the research baseline, mainly because of the serious deviation of the sample distribution. Although about 74% of US hospitals passed HIMSS EMRAM stage 5 or above by the end of 2017, in China, the EMRAM is only a commercial trial project in a small number of hospitals. By June 2019, only 58 hospitals participated in the EMRAM evaluation and met or passed stage 6 [21].

Data Resources

Data on EHR adoption in Chinese hospitals were obtained from the CHIMA Annual Survey of Hospital Information Systems from 2007 to 2018 [22]. These are the only authoritative, national-level, long-term quantitative data of repeated surveys available on the EHR adoption rates in Chinese hospitals. Every March for a decade, the CHIMA surveyed the application of HIT in mainland China, covering 34 administrative regions. Survey respondents included general hospitals, teaching hospitals, specialty hospitals, traditional Chinese medicine hospitals, and integrated Chinese and Western medicine hospitals. In total, each survey was comprised of 9 parts. This study primarily used data from Parts I, IV, VI, and VIII, assessing respondents' basic information, information system application and adoption barriers, and data standardization.

Data on EHR adoption in US hospitals from 2008 to 2017 were obtained from data briefs by the ONC [2,3,16] and research by Jha et al [1,23-31]. Data on barriers faced in the information system implementation in US hospitals were obtained primarily from the HIMSS Annual Surveys in 2006, 2007, 2010, and 2014 [32-35].

Technology Diffusion Model and Bass Modeling

As one of our methods, Bass diffusion modeling was employed for the prediction and characterization of the progress in adoption of EHRs. Diffusion theory is an essential branch of communication theory [36]. The Bass model is widely used in the application and forecasting of new products and technologies [37,38], including many medical-related technologies [39-41]. The Bass model has 9 key assumptions [38,41], which mostly satisfy the scenarios of this study. For example, the market potential of a new product remains temporally constant; geographic boundaries of the social system are unchangeable throughout the diffusion.

Bass modeling has 2 important measures. First, the external influence coefficient, called the "innovation" effect and represented as the *p* coefficient, means the probability of using the product under the influence of public media or other external factors among users who have not used the product. Second, the internal influence coefficient, called the "imitation" effect and expressed as the *q* coefficient, depicts the probability of the same users using the product due to the influence of peers who have already used the product [42]. When *p* is high, the model indicates that the new technology has a rapid diffusion at the beginning of the propagation and that diffusion grows more weakly in the subsequent periods. When *q* is high, the model suggests that the new technology spreads slowly in the beginning, but it accelerates with further popularization and expansion. The Bass model is expressed as:

$$F\ (t) = \frac{1 - e^{-(p+q)t}}{1+\frac{q}{p}e^{-(p+q)t}} \quad \mathbf{(1)}$$

where *F(t)* is the portion of M adopted by time t, *p* is the coefficient of innovation, and *q* is the coefficient of imitation.

Data Analysis

We conducted statistical analyses and forecasts using linear optimization in Microsoft Excel for Mac 2011 (Microsoft Corporation, Redmond, WA). First, the analyses began with basic descriptive statistics regarding the respondents' basic information. Second, Bass diffusion modeling was employed to predict the progress of EHR adoption and analyze its characteristics. On one hand, we used the method of least squares to determine the optimal values of *q* and *p*. On the other hand, adjusted R^2 was used to evaluate the performance of the prediction model. The parameters of the Bass model were trained and estimated using SPSS 20 (IBM Corp, Armonk, NY).

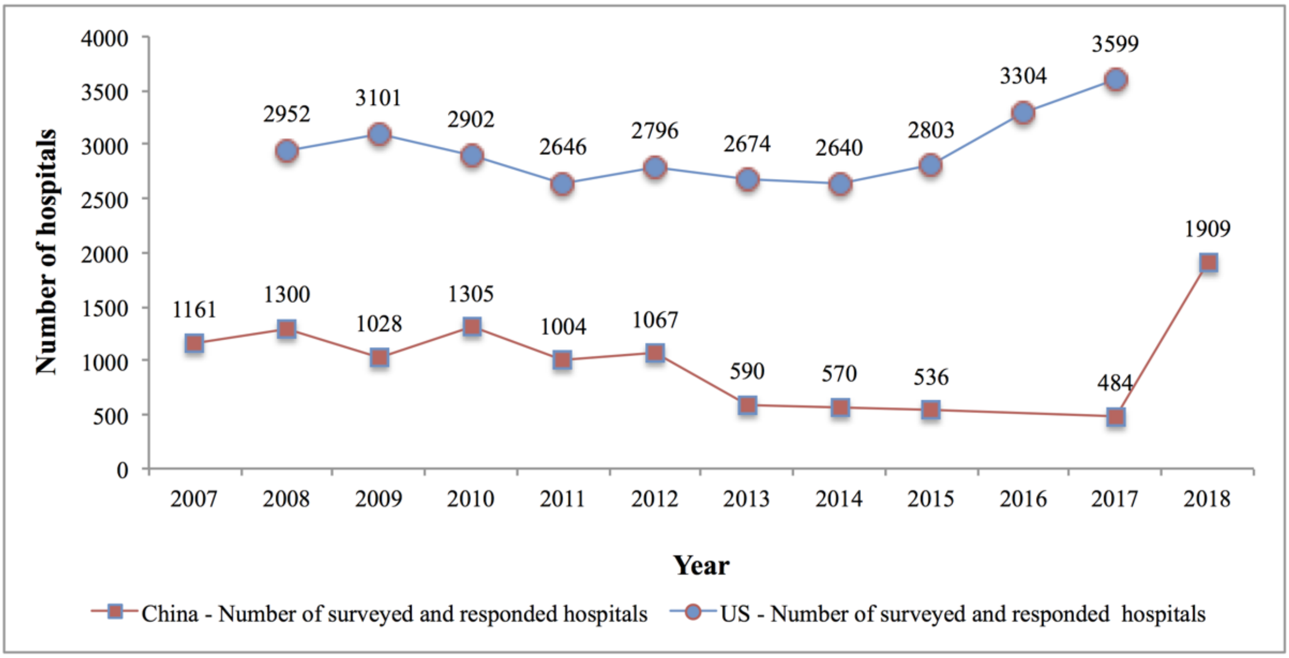
Results

Descriptive Analysis

Scale and Coverage of the Surveys

Figure 1 illustrates the number of the 2007-2018 CHIMA Annual Survey respondents (covering over 80% of China's provinces, municipalities, and autonomous regions) and the number of survey respondents for the adoption of EHRs in US hospitals from 2008 to 2017. In China, all hospitals are classified by the government board into 3 classes: Level I hospitals (roughly equivalent to community-based health centers in the United States), Level II hospitals (county- and municipal-level, small health care facilities), and Level III hospitals (large, advanced general or specialty hospitals) [43]. In this study, hospitals were divided into 2 categories: Level III hospitals vs Level II or lower hospitals. For the definition of economically developed and underdeveloped areas in China, please refer to Multimedia Appendix 3. Data on the adoption of EHRs in US hospitals from 2008 to 2017 were obtained from the ONC data brief [2,3,16] and research by Jha et al [1,23-31], in which large hospitals were defined as those with ≥400 beds, while small and medium hospitals were those with 6-399 beds. Jha et al did not publish the number of surveyed and respondent hospitals in various subcategories in 2011 [28] and 2013 [26]. Since the ONC changed its statistical method after 2015, it only published the overall EHR adoption rate of US hospitals but not the rates in various subcategories. Therefore, only the numbers of surveyed and respondent hospitals for 2016 and 2017 are included in Figure 1.

Figure 1. The number of respondents to the 2007-2018 Chinese Health Information Management Association (CHIMA) Annual Surveys of Hospital Information Systems and the surveys on the adoption of electronic health records (EHRs) in US hospitals from 2008 to 2017.

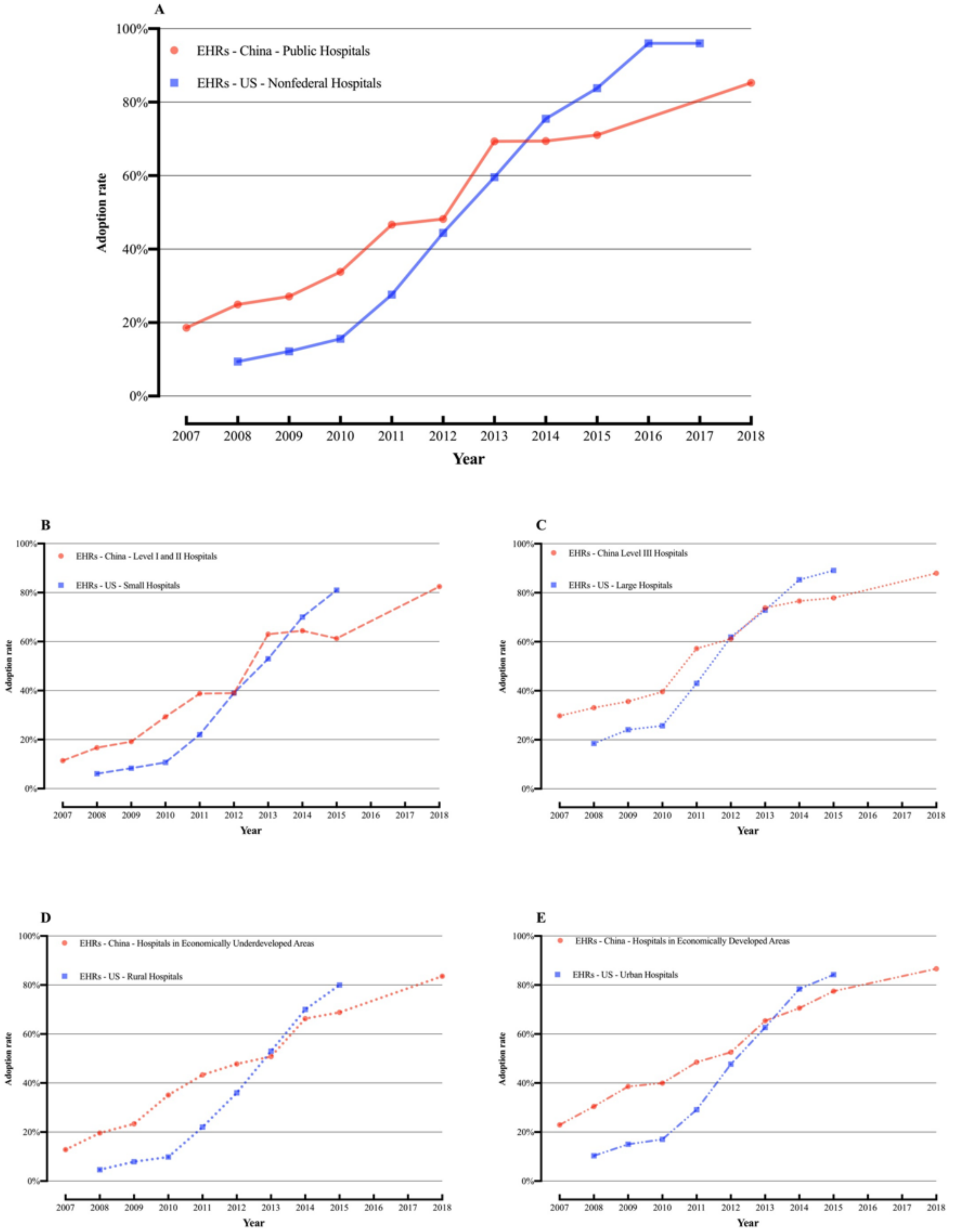


Detailed information about the scale of the Sino-American hospital (including the different hospital types) is provided in Multimedia Appendix 4.

Adoption of EHRs in Chinese and US Hospitals

Trends in EHR adoption in China and the United States were compared (Figure 2), which revealed 3 main characteristics. First, the EHR adoption rates in China were relatively high. Overall, the average EHR adoption rates of the sampled Chinese hospitals in 2018 (85.3%) were 1.5% higher than those of US hospitals in 2015 (83.8%), but lower than those of US hospitals in 2017 (96%). To note here, since the ONC changed its statistical method after 2015, it published only the overall EHR adoption rate of US hospitals but not the rates in various subcategories. Therefore, only the data for 2016 and 2017 are included in Figure 2A. Considering hospital scale, the adoption rates in Level II or lower Chinese hospitals (small-scale hospitals) were 1.5% higher than in small hospitals (fewer than 100 beds) in the United States in 2015 (the adoption rate of the former being 82.5% compared to the 81% of the latter). However, the average adoption rate of Level III hospitals in China (87.9%) was 1.2% lower than that of large US hospitals (89.1%). Considering regional economic development, the average adoption rate in Chinese hospitals in economically underdeveloped regions was 3.6% higher than in rural US hospitals—83.6% and 80%, respectively. The adoption rate in economically developed Chinese hospitals (86.6%) was 2.4% higher than that in urban US hospitals (84.2%).

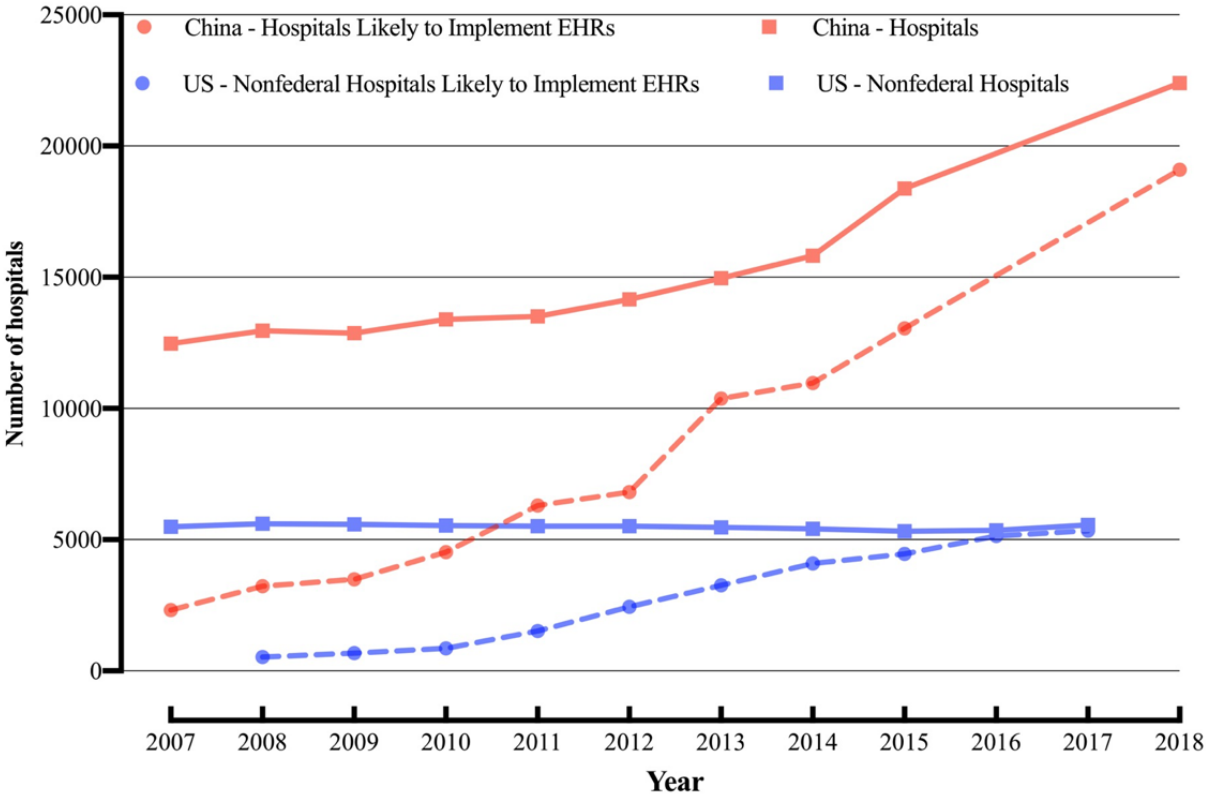
Figure 2. Trends in electronic health record (EHR) adoption rates in Chinese hospitals from 2007 to 2018 and nonfederal US hospitals from 2008 to 2017. (A) Overall adoption rate in China vs the United States and adoption rates in (B) small-scale hospitals, (C) large-scale hospitals, (D) hospitals in economically underdeveloped or rural areas, and (E) hospitals in economically developed or urban areas.



Because the overall number of hospitals in China exceeds the number of urban hospitals in the United States, the absolute number and challenges of Chinese hospitals adopting EHRs should be greater. The annual average number of hospitals adopting EHRs in China far exceeded the US average—1500 and 534, respectively. In 2007, China had 12,477 Level I-III hospitals [44] and an annual EHR adoption rate of 18.6%. According to sample projection, only 2322 Chinese hospitals used EHRs. In 2018, China had 22,396 Level I-III hospitals using EHRs [45], with an EHR adoption rate of 85.3% and a total of 19,094 hospitals. Thus, 16,772 hospitals in China adopted EHRs from 2007 to 2018—3.3 times the number of nonfederal hospitals adopting EHRs in the United States from

2008 to 2017 (4814), according to the projections based on the total number of nonfederal US hospitals (see Figure 3) [46].

Figure 3. Numbers of Chinese hospitals and those likely to implement electronic health records (EHRs) from 2007 to 2018 and the numbers of nonfederal US hospitals and those projected to implement EHRs from 2008 to 2017.



Difficulties With HIT Development in Chinese and US Hospitals

Figures 4 and 5 present the feedback from chief information officers (CIOs) on the barriers faced in the HIT application from the CHMIA and HIMSS surveys; as of 2015, the HIMSS Annual Survey no longer conducts a survey of hospital CIOs regarding the barriers to HIT application. Among Chinese hospitals, insufficient financial support and insufficient staff in the department were consistently identified as the first and second greatest obstacles, respectively. HIMSS Annual Survey data from the same years (2007, 2010, and 2014) show that US hospital CIOs also identified insufficient financial support and insufficient staff as their greatest challenges. This indicates a similarity in the main obstacles faced by China and the United States in hospital digitalization. In 2014, Chinese and US hospitals identified vendors' inability to deliver products and services to meet their demands as the third greatest obstacle. This may be because, with the increasing development of HIT in hospitals, hospital CIOs have become increasingly demanding with regard to the relevant software products.

Figure 4. Survey feedback on health information technology (HIT) development barriers faced by hospitals in China in 2007, 2010, and 2014. IT: information technology; ROI: return on investment.

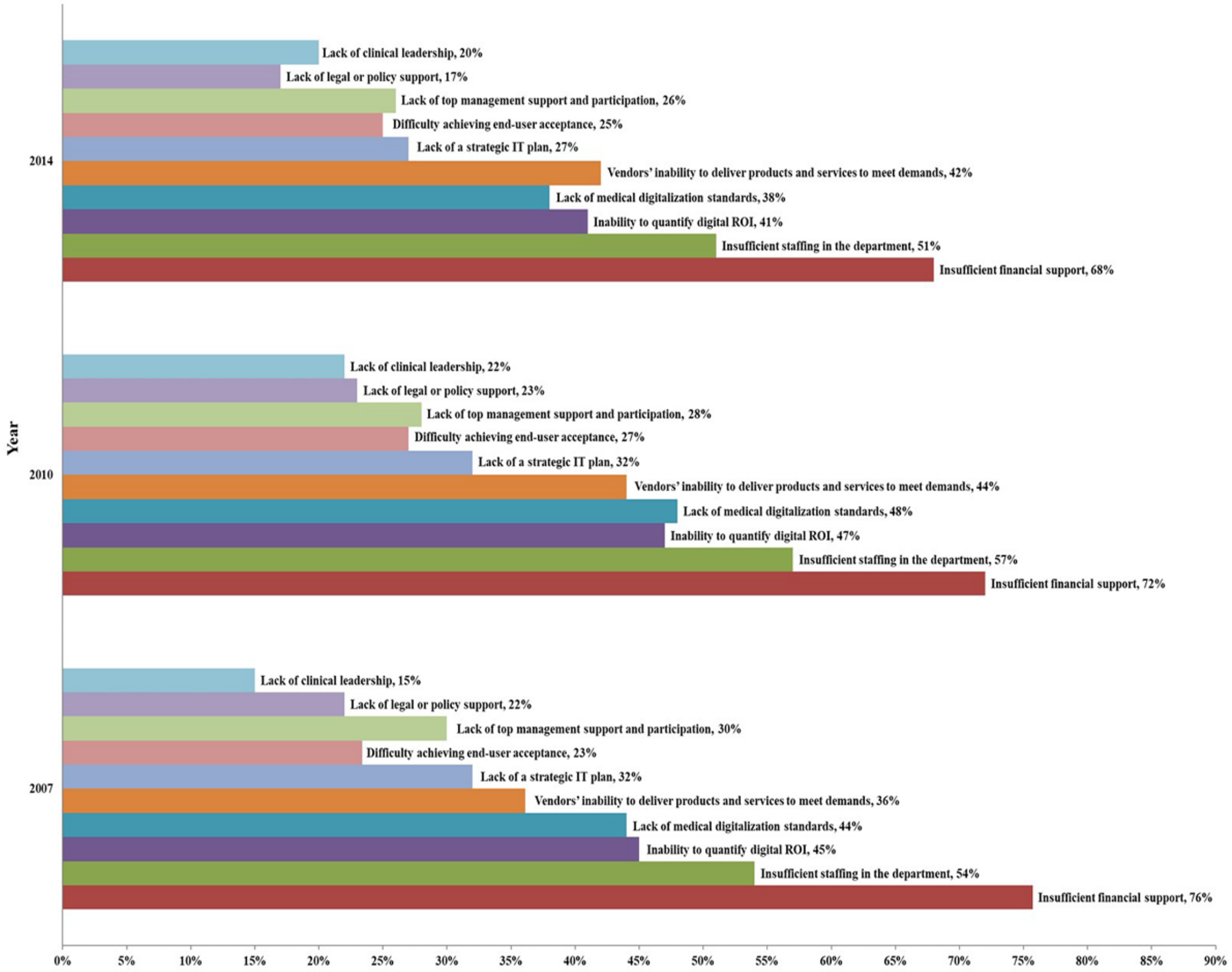
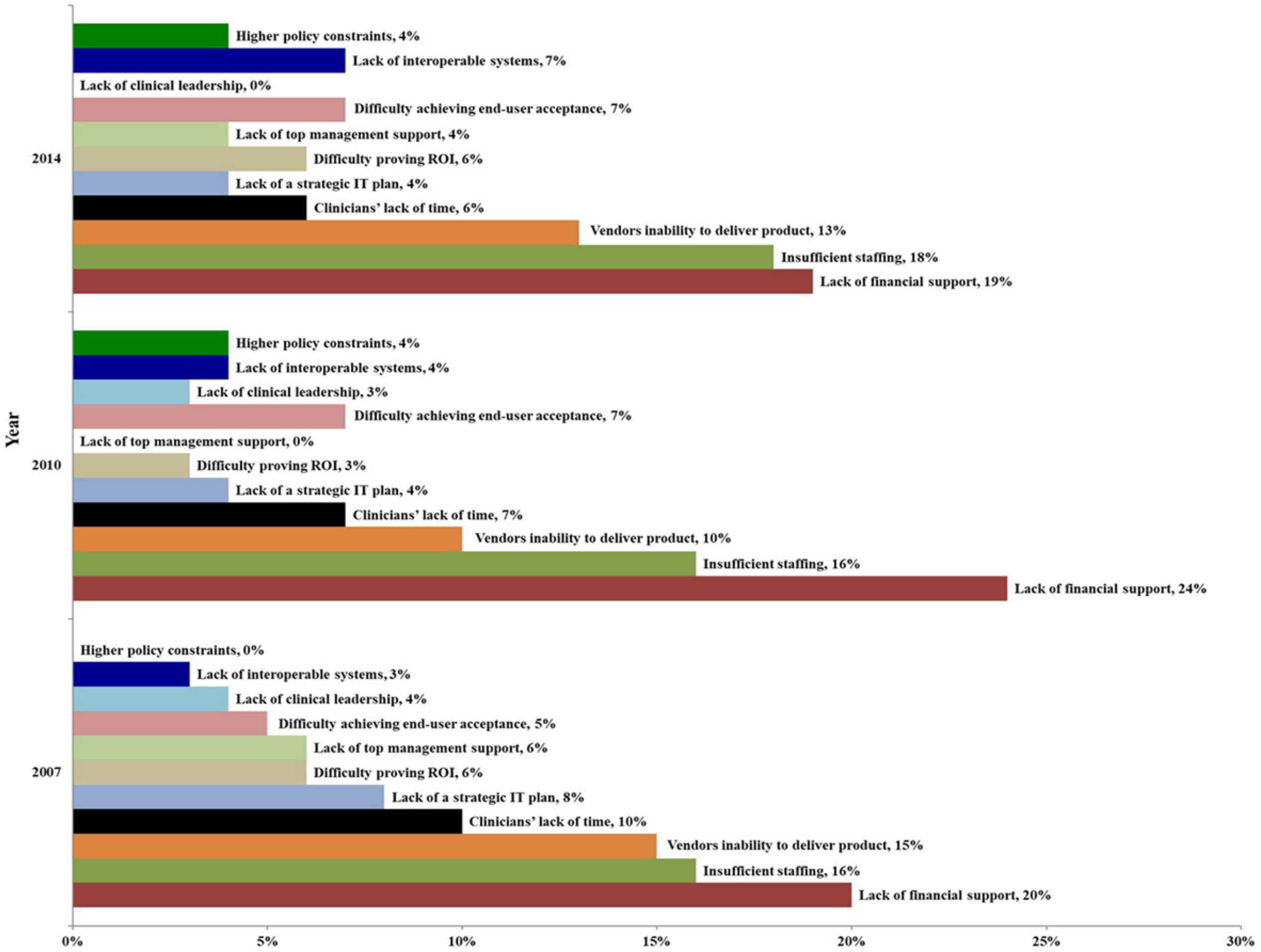


Figure 5. Survey feedback on health information technology (HIT) development barriers faced by hospitals in the United States in 2007, 2010, and 2014. IT: information technology; ROI: return on investment.



Bass Model Fitting and Prediction of EHR Adoption Rates in Chinese and US Hospitals

Considerable differences between Chinese and US hospitals in terms of the EHR technology diffusion modes were identified. Using Bass modeling and linear optimization, we estimated *p* and *q* coefficients based on the CHIMA data from 2007 to 2018 [22] and the surveys from 2008 to 2017 reported by the ONC [2,3,16] and Jha et al [1,23-31]. The parameter estimation results of the final model (Table 1) indicated that the Bass model fit the CHIMA dataset [22] and the ONC [2,3,16] and Jha et al [1,23-31] datasets. The adjusted R^2 was >0.9 for all models except the EHRs-China-Level III Hospitals model. Generally, each model shows a smaller motivation coefficient ratio (*q*/*p*) for Chinese hospitals compared to US hospitals. The largest difference (285-fold) was observed between the EHRs-China-Hospitals in the Economically Developed Areas model and the EHRs-US-Urban Hospitals model, which are the models of the largest-scale hospitals in these countries. In contrast, the smallest gap (14.8-fold) was observed between the EHRs-China-Surveyed Level I and II Hospitals model and the EHRs-US-Small Hospitals model, which are the models of these countries' smallest-scale hospitals. Moreover, the internal *q* of US hospitals was significantly larger than that of Chinese hospitals. The largest difference (57-fold) was observed between the EHRs-China-Hospitals in the Economically Developed Areas model and the EHRs-US-Urban Hospitals model, while the smallest (3.6-fold) was found between the EHRs-China-Level I and II hospitals model and the EHRs-US-Small Hospitals model.

Table 1. Bass model parameters for the prevalence of electronic health records (EHRs) in Chinese and US hospitals, based on Chinese Health Information Management Association (CHIMA) data from 2007 to 2018 [22] and survey data reported by the Office of the National Coordinator for Health Information Technology (ONC) [2,3,16] and Jha et al [1,23-31] from 2008 to 2017.

Model	Model parameters			
	p [a]	q [b]	q/p [c]	Adjusted R^2
EHRs-China	0.10	0.11	1.04	0.93
EHRs-China-Level I and II Hospitals	0.07	0.17	2.66	0.94
EHRs-China-Level III Hospitals	0.17	0.01	0.06	0.88
EHRs-China-Hospitals in Economically Underdeveloped Areas	0.08	0.13	1.51	0.98
EHRs-China-Hospitals in Economically Developed Areas	0.15	0.01	0.07	0.90
EHRs-US-Nonfederal Hospitals	0.02	0.58	24.33	0.97
EHRs-US-Small Hospitals	0.02	0.63	39.44	0.99
EHRs-US-Large Hospitals	0.07	0.45	6.64	0.95
EHRs-US-Rural Hospitals	0.01	0.65	46.29	0.99
EHRs-US-Urban Hospitals	0.03	0.57	19.66	0.98

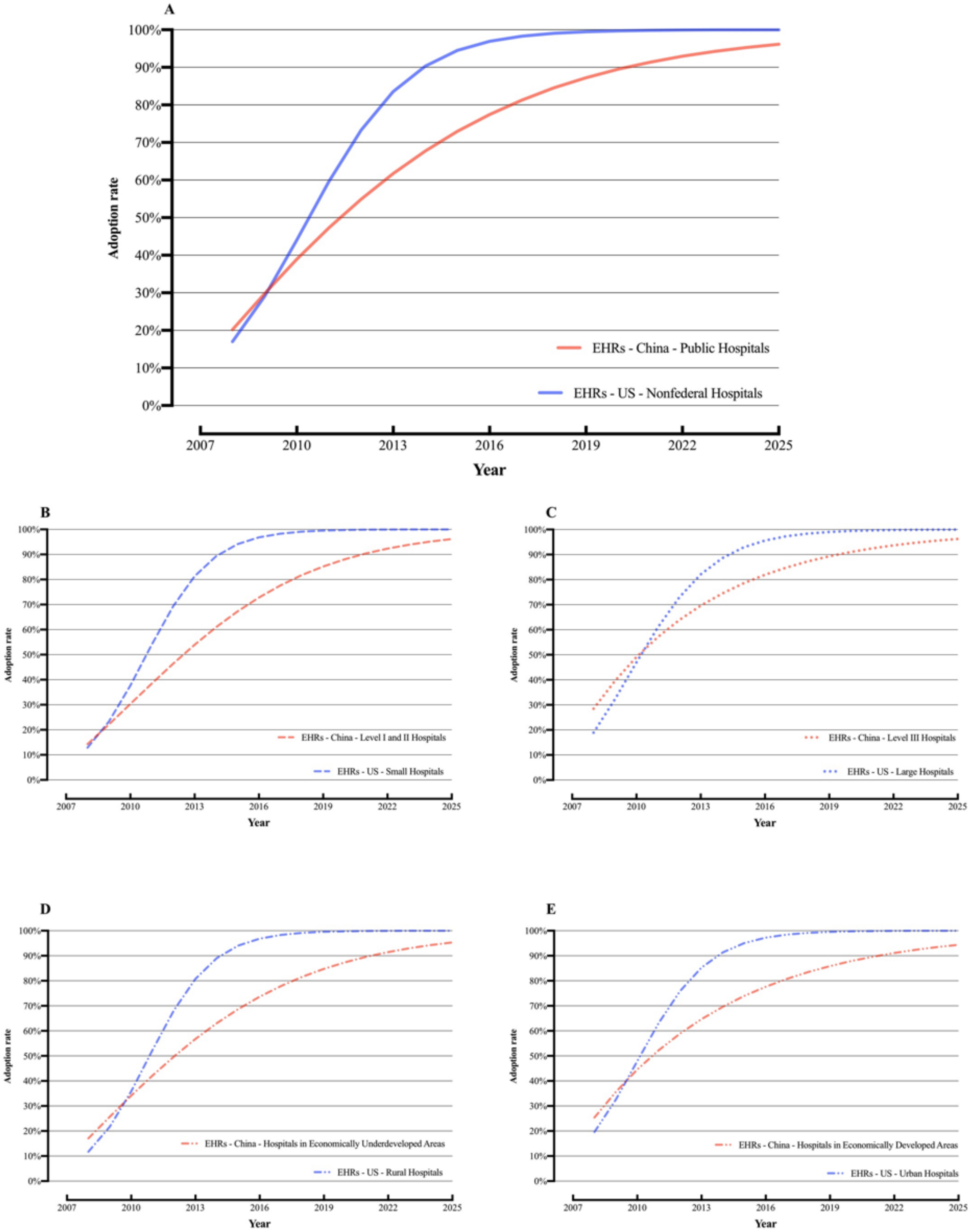
[a] p: external motivation coefficient.

[b] q: internal motivation coefficient.

[c] q/p: motivation coefficient ratio.

The differing diffusion patterns of EHRs in Chinese and US hospitals led to the differences in the patterns of the diffusion dynamics curves. By assuming that there will be no major policy adjustments or technological advancements in the future, we used the Bass model to fit and predict future EHR adoption in Chinese and US hospitals from 2019 to 2025, both in the overall scale and according to hospital scale and location (Figure 6). An Annual Survey was not conducted in 2016 due to changes in CHIMA's leadership. In 2017, the survey data from the software portion of the CHIMA Annual Survey deviated greatly; CHIMA does not recommend use of these data. Since the ONC changed its statistical method after 2015, it published only the overall EHR adoption rate of US hospitals but not the rates of various subcategories. Therefore, in Figures 6B, 6C, 6D, and 6E, the EHR adoption rates of various types of hospitals in the United States are predicted using the data from 2008 to 2015. The diffusion dynamics curve for EHRs in US hospitals forms a classic *S*-shape with a fast growth rate (p=0.03±0.02, q=0.58±0.07)—larger than that of Chinese hospitals (p=0.11±0.04, q=0.08±0.07).

Figure 6. Predicted electronic health record (EHR) adoption up to 2025 in Chinese hospitals (based on Chinese Health Information Management Association Annual Survey data from 2007 to 2018) and in US hospitals (based on annual survey data from 2008 to 2017 reported by the Office of the National Coordinator for Health Information Technology and Jha et al [1,23-31]). (A) Overall predictions and predictions for (B) small-scale hospitals, (C) large-scale hospitals, (D) hospitals in economically underdeveloped or rural areas, and (E) hospitals in economically developed or urban areas.



Discussion

Based on the 2007-2018 CHIMA Annual Surveys, we examined the progress and modes of EHR technology diffusion in sampled Chinese hospitals nationwide, identified major difficulties in HIT innovation, and compared them with US hospitals.

Principal Findings

From the perspective of EHR implementation in Chinese hospitals, Chinese hospitals demonstrated differences in EHR adoption and growth rates according to scale and location. Among the sampled hospitals in China, the adoption rates in small hospitals (Level II or lower) and in hospitals from economically underdeveloped areas were below average. However, the growth rate of EHR adoption in these disadvantaged hospitals surpassed that of advantaged hospitals, as shown by the considerably higher slope in the Bass curves in Figure 6. This phenomenon is linked to national conditions, the medical system, and the financial support policy for HIT in hospitals in China. First, China has a vast territory that varies greatly from region to region. Although a large number of Level II or lower hospitals has been set up to provide basic medical services for local residents, high-quality medical resources are concentrated in a few Level III hospitals. Second, because China has not established a graded hierarchical medical system, patients are more inclined to congregate in Level III hospitals, leading to significantly higher workloads for doctors and correspondingly higher economic benefits [47,48]. As a result, many hospitals that are smaller or located in underdeveloped areas lack funds, resources, and motivation to build and maintain EHRs. Fortunately, the government has recognized this problem. Policies and funds should favor Level II or lower hospitals or those in underdeveloped areas, whereas Level III hospitals or those in developed areas should mostly be guided by policies and required to generate their own funding. Furthermore, the allowing of disadvantaged hospitals that have implemented EHRs to join medical institution alliances based on regional HIT has retained more patients in local hospitals instead of them seeking care in Level III hospitals, which also works to increase disadvantaged hospitals' income [11]. With the rapid development and wide application of wearable device technology [49,50], more real-time health data can be included in EHRs, which will further promote this trend.

From the perspective of the comparison of the EHR adoption by Chinese hospitals and US hospitals, although both the Chinese and US governments have implemented policy guidelines and financial incentives to promote EHR adoption, the patterns of EHR diffusion between the 2 countries differ considerably. The graph shapes in Figure 2 show this difference. The US trend is more *S*-shaped and more typical of a market-driven diffusion pattern, while the Chinese trend is more linear and more like a top-down, policy-driven pattern. EHR adoption in Chinese hospitals follows the innovator mode (motion coefficient ratio *q/p* is only 0.06 to 2.66), indicating that hospitals began to use EHRs in the initial stages due to the influence of external administrative forces [51]. This is because, in China, most (about 71.1%) of the secondary and higher hospitals are funded and managed by the government, and the number of beds in public hospitals is 3 times higher (about 76%) than that of private hospitals. In 2010, the government began to invest considerable resources and funds into EHRs and issued relevant policies to guide and support their use. However, the HIT support strategy at the time did not provide a detailed, clear, and measurable meaning of EHRs in Chinese hospitals nor establish any quantitative rewards, penalties, or standards for the use of EHRs by hospitals. This led to weak growth after the initial implementation of financial support. Reliance on hospital motivation to promote EHRs without sufficient external financial and policy incentives was proven to be unrealistic and unsuccessful [4,5,52,53]. In contrast, the EHR adoption rate in US hospitals grew very slowly from 2008 to 2010, perhaps due to the adoption of the US Health Insurance Portability and Accountability Act [54] in 1996—a comprehensive personal electronic health information privacy and security protection law—and the fact that most (about 80%) of the hospitals are private, which should be promoted by economic interests. Since 2010, following the implementation of meaningful use programs with clear quantitative requirements for EHRs, the EHR adoption rate increased significantly, and most US hospitals started to use certified EHRs by 2017. In sharp contrast to the low effectiveness of the expansive HIT development strategy in China, the HITECH Act was a major driving force behind this progress [55,56]. The US government provides financial incentives to US hospitals that implement EHRs and meet meaningful use phased standards and imposes financial penalties on those that do not [30]. We believe that the financial support and policy guidance of this "carrot and stick" model is also one of the most important American experiences.

The most significant morphological difference between the hospitals' EHR diffusion curves of China and the United States is that the motion coefficient ratio *q/p* value of the US curve is much larger. On one hand, the *q* value of the Chinese curve is smaller, and the *P* value is larger. This may be because the rapid spread of EHRs in China is caused by external policy stimuli. The Chinese government takes the HIT system represented by EHRs widely implemented in hospitals as a kind of technological innovation guided by the government and considers HIT as a technical tool to promote regional medical consortium [57]. As of 2015, according to our previous research results based on the same survey data, about 57.2% of the investigated hospitals have joined the regional medical consortium, 81.9% of these hospitals that have joined the medical consortium support the interconnection of electronic data, and the gap between HIT systems of different levels of medical institutions in the medical consortium is gradually narrowing [11]. On the other hand, the relatively large *q* value of the US curve may be interpreted in relation to 2 aspects. First, imitating the words or power of peers or industry leaders may influence American doctors to use similar EHRs as a tool for recording and exchanging health information [58]. Second, American doctors may have a strong willingness to upgrade information technology [59].

The comparison of the effects and outcomes of EHR implementation shows that the Chinese government has done more work to improve the implementation quantity and quality, as well as the relevant strategies used; has made unique contributions; and, thus, has had more achievements. This comparison can be made from 3 perspectives.

First, as for the implementation quantity, the EHR implementation rate in China in 2018 (85.3%) is equivalent to that in the United States in 2015 (83.8%) but is lower than that in the United States in 2017 (96%). However, since the base number of the former surpasses the latter (number of Chinese hospitals in 2018 was 22,396, compared to the number of nonfederal US hospitals in 2017, which was 5564) [46], the number of hospitals adopting EHRs in Chinese hospitals is approximately 3.3 times that in the United States—16,772 and 4818, respectively. Moreover, the annual growth of the former (1500) is about 2.8 times that of the latter (534). As of 2018, although China's population (1.4 billion) is 4.28 times that of the United States (327 million), given that the Chinese gross domestic product (GDP) is only 67.8% that of the latter (the Chinese GDP being US $13.89 trillion, compared to the US $20.5 trillion GDP in the United States), the per capita GDP of China (US $9900) is only 15.8% that of the latter (US $62,500) and is below the world average (US $11,300). It also reflects that the former has made great progress in promoting EHRs in a short time (11 years), under the promotion of a huge subjective initiative.

Second, as for the implementation quality, the China Health Commission has conducted many top-level design policies. First, the connotation of EHRs is clearly defined, and EHR adoption is divided into Levels 0 to 8. Second, through administrative instructions, different deadlines are set for hospitals at different levels. For example, by the end of 2020, all Level III and Level II hospitals must use at least Level IV and Level III EHRs, respectively. Namely, by the end of 2020 [60], 11,565 secondary and tertiary hospitals in China, accounting for 52% of the country's 22,000 hospitals, must use at least Chinese stage 3 EHRs (roughly corresponding to basic EHRs with notes). This is 2.4 times the number of the 4818 nonfederal hospitals implementing EHRs in the United States in 2017 [2,16]. As of July 2020, 128 Chinese hospitals were tested and verified using EHRs that met the high-level (stages 5-7) standards—44 more than the same period of last year (84 hospitals)—of which 4 reached stage 7 (an increase of 2 hospitals) and 20 reached stage 6 (an increase of 15 hospitals) [61]. Moreover, the performance monitoring data of the Chinese government for public hospitals partially verify and support the prediction results of the BASS model. As of July 2020, the announcement on "the National Monitoring and Analysis of the Performance Appraisal of the National Tertiary Public Hospitals" released by the Chinese government in 2018 [62] shows that the participation rate of China's EMR level evaluation of tertiary hospitals was 94.58% by 2018, with an average stage of 2.72—a stage close to the level of basic EHR with clinical notes in the United States. Approximately 87% of tertiary hospitals reached EHR Level III or above, which is very close to the prediction result of the Bass model (87.2%). We believe that as of the end of 2020, China's tertiary hospitals were likely to achieve stage 4 EMRs (namely, comprehensive EHRs). The Chinese government has also released information, which was published near the end of 2020, on the results of the performance appraisal of hospitals, including the progress of the implementation of EMRs in public hospitals below the third level.

Third, as for the implementation strategy, evaluation is emphasized with the principle "promote construction with evaluation, promote improvement with evaluation." The Chinese government has adopted different direct capital investments and indirect policy guidance strategies for hospitals of different scales. For the Level III large hospitals, which are responsible for over 46% of outpatients in China, the government focused on policy guidance, released many guidelines [63] and management and normative documents from 2010 to 2019 to promote hospital digitization with EHRs as the core, and encouraged private capital investments [64]. Additionally, for small hospitals at a level lower than Level III, a strategy of direct finance and indirect guidance was adopted to gradually promote EHR implementation. Furthermore, in 2019, the State Council of China stipulated that the construction of EHRs was one major indicator for hospital-level assessment and appointment of public hospital presidents [64]. For example, in the 3-year national hospital evaluation, the EHRs used by tertiary hospitals must meet Chinese stage 4; otherwise, the hospitals will be downgraded, which will greatly affect the reputation and economic income of the hospitals.

Limitations

The data used here were collected from (1) repeated measurements of EHR constructions in the same batch of US hospitals affiliated with the ONC and American Hospital Association (2007-2017) and (2) repeated investigations through self-report questionnaires (2007-2015, 2018) of EHR construction from Chinese hospitals participating in annual conferences organized by the CHIMA. The latter was not independently verified. Therefore, such analysis might be affected by several potential confounding factors of data bias. First, due to the limitation of the CHIMA survey data, there may be limitations to the classification of EHRs in hospitals in China. However, the implementation rate of each classification of hospitals is only an added reference index. Moreover, there are no such hospitals in the United States, so this classification is not used mainly for the comparison of the same hospitals in China and the United States. Second, we did not use multivariate models to assess the independence among different factors (eg, grades, types, economic levels, or locations of hospitals). Third, the cumulative proportions of some repeated questionnaire data from CHIMA during 2007-2015 slightly declined. We think one explanation may be that throughout the repeated surveys, the sampling differences of hospital samples led to differences in the investigated data. Although we limit our deductions to our own samples, our analyses are valuable in that these data are the only available quantitative data concerning the trend in HIT development in China over a time span of 10 years and collected by the Chinese state-level academy in this field. These are the only authoritative, national-level, long-term quantitative data available on the rate of adoption of EHRs in Chinese hospitals. Therefore, these are the best available data that can reflect the status of EHR use in Chinese hospitals. Furthermore, due to the differences in the economic, cultural, and health systems between China and the United States, there are also some differences in the functional definition of necessary components of hospital EHRs. Therefore, we mainly analyzed the overall time trend of EHR implementation in hospitals of the 2 countries, and the horizontal comparison is only for an approximate reference.

Conclusion

Over the last decade, the Chinese government has identified HIT development, represented by hospital EHRs, as an important technical focus and starting point to support medical reform. According to the CHIMA Annual Surveys, the average EHR adoption rate in sampled hospitals in China increased by 3.6 times from 2007 to 2018, peaking at 85.3%, which exceeds that of 83.8% in US hospitals in 2015 but is lower than the 96% recorded in 2017. The difference in the EHR technology diffusion curves of China and the United States based on the Bass model is very likely due to the differences in the EHR promotion, implementation, and management policies, as well as the medical system, of the 2 countries. The former is mainly stimulated by external policies, while the latter is initiated by their own technological upgrading needs. The Chinese government has begun to amend relevant policies, gradually implementing both financial support and policy guidance measures and adding the assessment of secondary utilization based on precipitated data on EHRs and the use of various advanced functions. This action technically underlies several medical reform goals, such as improving clinical outcomes, user satisfaction, and interoperability. Various signs indicate that the Chinese government is gradually approaching and realizing its phase goals established in the second medical reform initiated in 2010, including the integration of medical resources, improvement of the popularization and quality of medical care, and the reduction of medical costs.

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Authors' Contributions

The work presented here was carried out in collaboration among all authors. JL conceived and designed the study. JL, XZ, TW, and YL performed the literature review and undertook data acquisition and data analysis. JL drafted the manuscript, and JL and JZ significantly revised the manuscript. ZZ, DS, BT, and JX supervised the review methodology and data interpretation and supplied valuable suggestions for improvement.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Electronic health record (EHR) functions used to define "basic without clinical notes," "basic with clinical notes," and "comprehensive" EHR systems.
[DOCX File , 21 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Chinese evaluation and management of application level of EHRs system.
[DOCX File , 18 KB-Multimedia Appendix 2]

Multimedia Appendix 3

The definitions of economically developed and underdeveloped areas in China from CHIMA Annual Surveys of Hospital Information Systems.
[DOCX File , 16 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Scale of the 2007-2018 CHIMA Annual Surveys of Hospital Information Systems and the 2008-2017 surveys on adoption of EHRs in U.S. hospitals.
[DOCX File , 19 KB-Multimedia Appendix 4]

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Abbreviations

CHIMA: Chinese Hospital Information Management Association
CIO: chief information officer
CMS: Centers for Medicare & Medicaid Services
EHR: electronic health record
EMR: electronic medical record
EMRAM: EMR adoption model
GDP: gross domestic product
HIT: health information technology
HITECH: Health Information Technology for Economic and Clinical Health
ONC: Office of the National Coordinator for Health Information Technology

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Original Paper

Online Medical Record Nonuse Among Patients: Data Analysis Study of the 2019 Health Information National Trends Survey

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Abstract

Background: Online medical records are being used to organize processes in clinical and outpatient settings and to forge doctor-patient communication techniques that build mutual understanding and trust.

Objective: We aimed to understand the reasons why patients tend to avoid using online medical records and to compare the perceptions that patients have of online medical records based on demographics and cancer diagnosis.

Methods: We used data from the Health Information National Trends Survey Cycle 3, a nationally representative survey, and assessed outcomes using descriptive statistics and chi-square tests. The patients (N=4328) included in the analysis had experienced an outpatient visit within the previous 12 months and had answered the online behavior question regarding their use of online medical records.

Results: Patients who were nonusers of online medical records consisted of 58.36% of the sample (2526/4328). The highest nonuser rates were for patients who were Hispanic (460/683, 67.35%), patients who were non-Hispanic Black (434/653, 66.46%), and patients who were older than 65 years (968/1520, 63.6%). Patients older than 65 years were less likely to use online medical records (odds ratio [OR] 1.51, 95% CI 1.24-1.84, *P*<.001). Patients who were White were more likely to use online medical records than patients who were Black (OR 1.71, 95% CI 1.43-2.05, *P*<.001) or Hispanic (OR 1.65, 95% CI 1.37-1.98, *P*<.001). Patients who were diagnosed with cancer were more likely to use online medical records compared to patients with no cancer (OR 1.31, 95% CI 1.11-1.55, 95% CI 1.11-1.55, *P*=.001). Among nonusers, older patients (≥65 years old) preferred speaking directly to their health care providers (OR 1.76, 95% CI 1.35-2.31, *P*<.001), were more concerned about privacy issues caused by online medical records (OR 1.79, 95% CI 1.22-2.66, *P*<.001), and felt uncomfortable using the online medical record systems (OR 10.55, 95% CI 6.06-19.89, *P*<.001) compared to those aged 18-34 years. Patients who were Black or Hispanic were more concerned about privacy issues (OR 1.42, 1.09-1.84, *P*=.007).

Conclusions: Studies should consider social factors such as gender, race/ethnicity, and age when monitoring trends in eHealth use to ensure that eHealth use does not induce greater health status and health care disparities between people with different backgrounds and demographic characteristics.

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KEYWORDS

online medical records; cancer; patient portals; communication; medical records; health information; eHealth

Introduction

Communication is a key element in providing high-quality health care services [1]. If communication is effective, it can lead to significant health care provision and positive outcomes, including decreased anxiety, guilt, pain, and disease symptoms. Moreover, effective communication can increase patient satisfaction, acceptance, adherence, and cooperation with the medical team, and it can improve the physiological and functional status of the patient [1]. Conversely, poor communication between doctors and patients can lead to poor quality and continuity of care [2]. Patients with communication-related disabilities or problems were 3 times more likely to experience medical or clinical complications compared to other patients [3]. Thus, ensuring good communication by recording, handling, and sharing health information with patients remains a necessity and an integral component of the health care process that may improve outcomes and limit or prevent costly duplication of tests and treatments [4,5].

Information exchange is not only limited to the visit. It is moving beyond that, as patients have the opportunity to access their information regardless of location or time via technologies [4]. Technological advancement has provided opportunities not only to improve doctor-patient information exchange but also to inform and empower patients' role in decision making. Information and communication technology is often used for communication and information exchange purposes and may be a valuable tool for handling these challenges [6,7]. Other potential solutions include means for patients to access their online medical records, including personalized health records [8-11] and patient portals [12]. These centralized health information systems could also have the greatest benefit for information transmission. Although patient portals such as MyPreventiveCare [13], Ask an Expert [14], and others are considered important tools for the development of patient-centered care, their current use is not optimal, and portals are still less patient-centered than they could be [15-17]. Known barriers to the use of portals for patients and providers include security and privacy concerns, the potential negative impact on provider workflow, and limited user friendliness [12,18].

The ability of patients or individuals to access their online medical records serves as one of the backbones to improve patient engagement in and the outcomes of our health care system. Historically, patients have had low access to online medical records. For instance, only 3 out of 10 patients were offered access to medical records in 2013, and almost half of those offered access viewed their online records at least once [19]. However, the use of online medical records has experienced significant growth in recent years, and technological improvements have been made to improve usability and implementation [20]. On the other hand, despite greater availability, there are many patients who still avoid using online medical records, though this may be changing with the current COVID-19 pandemic paradigm shift. The purpose of this study was to explore factors leading to the use or nonuse of online medical records across different groups of patients.

Methods

Data Source

Data for this study were derived from the National Cancer Institute's 2019 Health Information National Trends Survey (HINTS). HINTS is a nationally representative survey (of the US noninstitutionalized adult population) that collects data on the American public's need for, access to, and use of health-related information [21]. HINTS is publicly available on the web [22]. Data used in this study were from HINTS 5 Cycle 3, collected between January and May of 2019. Patients who gave information about their online medical records use were included (survey response rate: 4328/14332, 30.20%). Further details on survey design and sampling strategies are published elsewhere [23].

Study Variables

The following questions correspond to the measures used in the analysis of the study. The first question was, "How many times did you access your online medical record in the last 12 months?" We used this question to identify users and nonusers of online medical records. The respondents who reported accessing their medical record at least once were coded as *users* and respondents who reported accessing their records zero times were coded as *nonusers*. The primary population of interest of the study was nonusers. We specifically analyzed the responses of nonusers to the following questions (Table 1) regarding the reasons why they do not use online medical records.

Table 1. Questions for nonusers and corresponding factors.

Factor name	Question[a]
SpeakDirectly	You prefer to speak to your health care provider directly?
NoNeed	You did not have a need to use your online medical record?
ConcernedPrivacy	You were concerned about the privacy or security of your medical records' website?
NoRecord	You do not have an online medical record?
LogInProb	You found it difficult to login (for example, you had trouble remembering your password)?
Uncomfortable	You are not comfortable or experienced with computers?
MultipleRec	You have more than one online medical record?

[a] All questions had binary (yes or no) responses.

Data Analysis

Descriptive statistics for the HINTS 5 Cycle 3 populations were generated for demographic variables (gender, age, race/ethnicity) and the cancer diagnosis variable. We investigated the relationship between the use of online medical records and the demographic or diagnosis variables using an unadjusted model—Fisher exact test. We focused on patients who had not used online medical records to better understand the reasons behind their avoidance of this particular technology. We report odds ratios (OR) and corresponding 95% confidence intervals;

statistical significance was determined based on *P*<.05. All analyses were conducted using R statistical software (version 3.6.3; packages: Ime4 and Stats).

Results

Sample Characteristics

HINTS 5 Cycle 3 had a total of 4328 respondents, and 57.74% of the respondents (2499/4328) were female. Most respondents were older than 50 years (2926/4328, 67.61%) and non-Hispanic White (2992/4328, 69.13%), and 16% of respondents (693/4328) had been diagnosed with cancer (Table 2).

Table 2. Demographic characteristics of the patients.

Characteristic	Respondents (N=4328), n (%)
Gender	
Male	1829 (42.26)
Female	2499 (57.74)
Age (years)	
18-34	580 (13.40)
35-49	822 (18.99)
50-64	1406 (32.49)
≥65	1520 (35.12)
Race	
Hispanic	683 (15.78)
Non-Hispanic White	2992 (69.13)
Non-Hispanic Black	653 (15.09)
Cancer diagnosis	
Have cancer	693 (16.01)
No cancer	3635 (83.99)

Use of Online Medical Records

Among the 4328 respondents, 2526 (58.36%) were nonusers. The ratio of nonusers across demographics ranged between 53% to 67%, with patients who were Hispanic (460/683, 67.35%) and patients who were non-Hispanic Black being highest (434/653, 66.46%). Patients who were non-Hispanic White (1360/2992, 45.45%) and patients between 18 and 34 years of age had the highest online medical record use (269/580, 46.38%). Table 3 presents percentages of users and nonusers across demographics and nonuser comparisons.

Table 3. Use of online medical records.

Characteristics	All, n (%)	Nonuser, n (%)	User, n (%)	Odds ratio (95% CI)	*P* value
All	4328	2526 (58.36)	1802 (41.64)	N/A[a]	N/A
Gender					
Male	1829 (42.26)	1130 (61.78)	699 (38.22)	1	N/A
Female	2499 (57.74)	1396 (55.86)	1103 (44.14)	0.78 (0.69-0.88)	<.001
Age (years)					
18-34	580 (13.40)	311 (53.62)	269 (46.38)	1	N/A
35-49	822 (18.99)	450 (54.74)	372 (45.26)	1.04 (0.84-1.30)	
50-64	1406 (32.49)	797 (56.69)	609 (43.31)	1.13 (0.92-1.38)	
≥65	1520 (35.12)	968 (63.68)	552 (36.32)	1.51 (1.24-1.84)	<.001
Race					
Non-Hispanic White	2992 (69.13)	1632 (54.55)	1360 (45.45)	1	N/A
Hispanic	683 (15.78)	460 (67.35)	223 (32.65)	1.71 (1.43-2.05)	<.001
Non-Hispanic Black	653 (15.09)	434 (66.46)	219 (33.54)	1.65 (1.37-1.98)	<.001
Cancer diagnosis					
Have cancer	693 (16.01)	365 (52.67)	328 (47.33)	1	N/A
No cancer	3635 (83.99)	2161 (59.95)	1474 (40.05)	1.31 (1.11-1.55)	<.001

[a] N/A: not applicable.

Patients who avoided using online medical records were more likely to be male (OR 0.78, 95% CI 0.69-0.88, *P*<.001). The oldest patients (aged >65 years) were less likely to use online medical records (OR 1.51, 95% CI 1.24-1.84, *P*<.001). Patients who were non-Hispanic White were more likely to use online medical records than patients who were Hispanic (OR 1.71, 95% CI 1.43-2.05, *P*<.001) or non-Hispanic Black (OR 1.65, 95% CI 1.37-1.98, *P*<.001). Finally, patients diagnosed with cancer were more likely to use online medical records than patients without cancer (OR 1.31, 95% CI 1.11-1.55, *P*=.001).

Reasons for Nonuse of Online Medical Records

In the second phase of the analysis, we only focused on nonusers (n=2526) and explored factors regarding their preference for not using online medical records. We compared the different demographics for each factor. The survey had 7 listed factors asked to each respondent. Each participant responded to each question with "yes" or "no." We summarized the percentage for each demographic group among nonusers. The "desire to speaking directly to the health care provider" was the primary factor (1575/2526, 62.35%) influencing the nonuse of online medical records. Across all demographic characteristics, more than half of respondents answered "yes" for this question. For instance, 63.68% (889/1396) of female nonusers reported "desire to speaking directly" as one of the primary reasons. Almost half of the participants also expressed "no need" as a reason to avoid online medical records. The 18-34 years age group of nonusers had the highest rate of "no need" factor to explain their avoidance of online medical record use (194/311, 62.38%). Privacy concerns were not a primary reason to avoid online medical record use across all groups (range 12% to 23%). Table 4 illustrates all descriptive statistics for the overall nonuser population and each demographic group.

Table 4. Frequencies of reasons that explain nonuse of online medical records.

Characteristic	Factor, n (%)						
	SpeakDirectly	NoNeed	ConcernedPrivacy	NoRecord	LogInProb	Uncomfortable	MultipleRec
All	1575 (62.35)	1258 (49.80)	499 (19.75)	571 (22.60)	435 (17.22)	547 (21.65)	228 (9.03)
Gender							
Male	686 (60.71)	594 (52.57)	214 (18.94)	288 (25.49)	170 (15.04)	253 (22.39)	109 (9.65)
Female	889 (63.68)	664 (47.56)	285 (20.42)	283 (20.27)	265 (18.98)	294 (21.06)	119 (8.52)
Age (years)							
18-34	166 (53.38)	194 (62.38)	39 (12.54)	93 (29.90)	45 (14.47)	14 (4.50)	26 (8.36)
35-49	231 (51.33)	252 (56.00)	83 (18.44)	114 (25.33)	71 (15.78)	48 (10.67)	35 (7.78)
50-64	530 (66.50)	386(48.43)	179 (22.46)	173 (21.71)	130 (16.31)	163 (20.45)	77 (9.66)
≥65	648 (66.94)	426 (44.01)	198 (20.45)	191 (19.73)	189 (19.52)	322 (33.26)	90 (9.30)
Race							
Non-Hispanic White	1004 (61.52)	922 (56.50)	289 (17.71)	375 (22.98)	294 (18.01)	334 (20.47)	164 (10.05)
Hispanic	294 (63.91)	172 (37.39)	108 (23.48)	100 (21.74)	91 (19.78)	118 (25.65)	37 (8.04)
Non-Hispanic Black	277 (63.82)	164 (37.79)	102 (23.50)	96 (22.12)	50 (11.52)	95 (21.89)	27 (6.22)
Cancer diagnosis							
Have cancer	260 (71.23)	190 (52.05)	74 (20.27)	76 (20.82)	79 (21.64)	117 (32.05)	50 (13.70)
No cancer	1315 (60.85)	1068 (49.42)	425 (19.67)	495 (22.91)	356 (16.47)	430 (19.90)	178 (8.24)

The statistical analysis also yielded significant differences across the different demographics (Table 5). Older patients (≥65 years old) were more likely to avoid using online medical records. They preferred speaking directly to their health care providers (OR 1.76, 95% CI 1.35-2.31, *P*<.001), were more concerned about privacy issues caused by online medical records (OR 1.79, 95% CI 1.22-2.66, *P*<.001), and felt uncomfortable using the systems (OR 10.55, 95% CI 6.06-19.89, *P*<.001) compared to patients aged 18-34 years; however, they were more likely to be in need of online records (OR 0.47, 95% CI 0.36-0.62, *P*<.001).

Table 5. Reasons for not using online medical records.

Characteristic	Odds ratio (95% CI)						
	SpeakDirectly	NoNeed	ConcernedPrivacy	NoRecord	LogInProb	Uncomfortable	MultipleRec
Gender							
Male	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Female	1.13 (0.96-1.33)	0.81 (0.69-0.96)*	1.09 (0.89-1.34)	0.74 (0.61-0.90)**	1.21 (0.96-1.54)	0.92 (0.76-1.12)	0.87 (0.65-1.15)
Age (years)							
18-34	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
35-49	0.92 (0.68-1.24)	0.76 (0.56-1.04)	1.57 (1.02-2.44)*	0.79 (0.56-1.11)	1.10 (0.72-1.70)	2.53 (1.34-5.06)**	0.92 (0.52-1.63)
50-64	1.73 (1.31-2.2)***	0.56 (0.42-0.74)***	2.01 (1.37-3.01)	0.65 (0.47-0.88)**	1.15 (0.78-1.70)	5.44 (3.08-10.36)*	1.17 (0.72-1.94)
>65	1.76 (1.35-2.31)***	0.47 (0.36-0.62)***	1.79 (1.22-2.66)**	0.57 (0.42-0.77)*	1.43 (0.99-2.09)	10.55 (6.06-19.89)***	1.12 (0.70-1.84)
Race							
Non-Hispanic White	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Hispanic	1.10 (0.88-1.38)	0.46 (0.36-0.57)***	1.42 (1.09-1.84)	0.93 (0.71-1.20)	1.12 (0.85-1.46)	1.34 (1.04-1.71)*	0.78 (0.52-1.14)
Non-Hispanic Black	1.10 (0.88-1.38)	0.46 (0.37-0.58)***	1.42 (1.09-1.84)	0.95 (0.72-1.23)	0.59 (0.42-0.82)**	1.08 (0.83-1.41)	0.59 (0.37-0.91)*
Cancer							
Have cancer	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
No cancer	0.62 (0.48-0.80)***	0.90 (0.71-1.13)	0.96 (0.72-1.28)	1.12 (0.85-1.50)	0.71 (0.53-0.95)*	0.52 (0.41-0.67)***	0.56 (0.40-0.80)**

**P*<.05; ***P*<.01; ****P*<.001.

Female respondents were more likely to use online medical records, and they were more likely to have records (OR 0.74, 95% CI 0.61-0.90, *P*=.003 for female). Patients who were Black or Hispanic were more concerned about privacy issues (Black: OR 1.42, 95% CI 1.09-1.84, *P*=.007; Hispanic: OR 1.42, 95% CI 1.09-1.84, *P*=.007) but were more conscious about the need for online records (Black: OR 0.46, 95% CI 0.37-0.58, *P*<.001; Hispanic: OR 0.46, 95% CI 0.36-0.57, *P*<.001). Patients who were Black were more likely to have problems logging in to their records (OR 0.59, 95% CI 0.42-0.82, *P*=.002).

Patients with cancer preferred to speak directly to the health care providers (OR 0.62, 95% CI 0.48-0.80, *P*<.001) and were more likely to feel uncomfortable using online medical records (OR 0.52, 95% CI 0.41-0.67, *P*<.001).

Discussion

General

Many studies that aim to improve information sharing and technology use in health care settings are based on exploring design improvements in patient-centered tools. Some discuss the environmental and technical barriers of adopting these tools [12,18], and others focus on providing training to enhance use-related skills [24]. We used nationally representative data from 2019 and examined attitude and other factors influencing nonuse of online medical records across different groups of patients. The results portray trends just prior to the pandemic, which has undoubtedly precipitated a paradigm shift toward online and telehealth medical use since the beginning of 2020.

The results showed that online medical record use was improving compared to use in previous years—41% overall in 2019 compared to 28% in 2017 [25]. However, online medical record use was still only approximately 30% for older adults (65 years and above) and respondents who were Black or Hispanic. Older adults were less likely to use online medical records compared to younger patients. Previous studies have also found that those older than 65 years would be less likely to use the internet to find health information [26,27] and less likely to use electronic personal health records [28]. Another study [29,30] also demonstrated that older adults have rather negative attitudes toward computers. Patients who were Black or Hispanic in our sample were more likely to be nonusers of online medical records than patients who were White. This was consistent with the findings of a previous study [27] that collected data between 2010 and 2017; however, in our study, there were increased rates of online medical record use among minorities compared to those of previous years. Due to chronic underlying health conditions, adults aged ≥65 years and individuals who are Black or Hispanic were the two groups hit hardest by the COVID-19 pandemic [31]. These groups often need continued care due to chronic health conditions [32]; however, visiting hospitals and clinics during the pandemic may increase the risk of infection. The online medical use rate would likely to be increased among these groups due to the pandemic.

In this study, we explicitly focused on the reasons people avoid online medical record use across demographics. The major reason that emerged from the data is that patients would prefer to "see their physicians in person." This was the primary reason for all groups except younger patients. Older patients were more likely to prefer to "speak in person with physicians" than younger patients. Furthermore, the preference to "speak in person with physicians" was also high for all race groups (1575/2526, 62.35%). These findings are not surprising since most patients value in-person visits with their doctors due to the more personal nature of the interaction, the opportunity to use nonverbal cues, and the ability to explain specific symptoms to doctors more clearly. Since March of 2020, however, the health care system is experiencing a paradigm shift due to an unprecedented pandemic, and telehealth visits have become a new normal, often replacing in-person visits, especially for older and chronically ill patients who are at high risk for COVID-19 infection. There is a tremendous rise in virtual care via telehealth technology during the pandemic [33]. Future studies will undoubtedly show changes in the demand for in-person visits after these forced experiences.

In the event of a population-wide infectious disease outbreak such as COVID-19, people's online activities may affect public concerns and health behaviors. Many studies [34,35] have explored people's active use of online information in various crises, including a public health crisis. The recent COVID-19 pandemic also sparked a paradigm shift in using online health care communication tools such as telehealth. It showed the importance and necessity of information sharing and communication beyond the walls of clinics.

The technology acceptance model explains that people use technologies when they are perceived as useful and necessary [36]. Almost half of the nonusers stated that there was no need for them to use online medical records. Young respondents (aged 18-34 years) among the sample were shown to be more likely to use online electronic medical records. Those who did not use online medical records in this group were likely to express that they had "no need" for their online medical record during this time period. This showed a significant difference compared to older patients ($P<.001$). Intuitively, younger patients are healthier than older patients, but they also tend to be more comfortable using online health technologies. After the COVID-19 pandemic, a new necessity may emerge which also might influence young patients use of online medical records for any information exchange with their providers. Future HINTS data collected during or after the pandemic might also show this shift among young patients. Finally, respondents who were Black or Hispanic were less likely to state the reason of "no need" than respondents who were White.

Privacy has always been an issue for some users regarding the use of technologies for information sharing, especially information as sensitive and personal as medical records. Some participants also declared this as one of the factors for avoiding online medical record use. Respondents who were Black or Hispanic were more likely to have privacy concerns compared to those who were White. Historically, minorities have less trust in the health care system due to disparities they have experienced [24,37-39]. This might also influence their perception of privacy regarding any online health information exchange. Furthermore, older patients are highly likely to state "being uncomfortable using online record" as a reason for avoiding online medical records compared to younger patients. The US population had almost 52 million people older than 65 years as of 2018 [40]. This population will be the major consumer of health care systems for the foreseeable future; therefore, any online tools need to be redesigned to be user friendly (ie, for this population to use easily and comfortably).

Finally, our study also showed that patients with cancer use online medical records more than patients who do not have cancer. This was consistent with the findings of previous studies [41-43] showing that patients with such conditions may have a greater need for health tracking and sharing health information with multiple health care professionals than others. Among nonusers of online medical records, patients with cancer are likely to prefer speaking with physicians in person compared to patients who do not have cancer. The complexity of treatment options and the emotional aspect of visits make it more necessary for patients with cancer to meet with doctors in person. On the other hand, the health care system should have alternative plans to maintain quality online visits with these patients during the pandemic.

Limitations

This study also has limitations. First, the nature of HINTS data is cross-sectional and relies on subjective responses; therefore, it is not able to offer information on causality. Second, the low response rate (20%-30%) might raise some bias concerns, especially related to nonrespondents and sampling strategy. We should also note that the sampling and weighting strategy used by HINTS administrators helps minimize biases and improve national representativeness and generalizability of findings. Nonetheless, some local studies with more detail and a higher response rate should be conducted to validate the findings.

Conclusion

This study showed factors that lead people to avoid online medical record use across different demographics using a nationally representative survey. The findings show that there is an increased rate of online medical record use compared to previous years; however, this rate is still not at the expected level. The study shows that most patients still prefer speaking in person with their providers instead of using online medical records. Future studies should also look at how the education level of patients impacts these studied factors; our data did not have that component.

We also acknowledge that the recent COVID-19 pandemic has shifted the culture of virtual visits and online medical record use in health care. Future studies should look at online medical record use trends and factors during and after the pandemic to see how these have shifted. Finally, future designs and concepts of online medical communication technologies may also consider the importance of preparing a common ground for patients where different technology acceptance levels are respected.

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Conflicts of Interest

None declared.

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Abbreviations

HINTS: Health Information National Trends Survey

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Original Paper

Recommendations for Designing Health Information Technologies for Mental Health Drawn From Self-Determination Theory and Co-design With Culturally Diverse Populations: Template Analysis

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Abstract

Background: Culturally diverse populations (including Aboriginal and Torres Strait Islander people, people of diverse genders and sexualities, and culturally and linguistically diverse people) in nonurban areas face compounded barriers to accessing mental health care. Health information technologies (HITs) show promising potential to overcome these barriers.

Objective: This study aims to identify how best to improve a mental health and well-being HIT for culturally diverse Australians in nonurban areas.

Methods: We conducted 10 co-design workshops (N=105 participants) in primary youth mental health services across predominantly nonurban areas of Australia and conducted template analysis on the workshop outputs. Owing to local (including service) demographics, the workshop participants naturalistically reflected culturally diverse groups.

Results: We identified 4 main themes: control, usability, affirmation, and health service delivery factors. The first 3 themes overlap with the 3 basic needs postulated by self-determination theory (autonomy, competence, and relatedness) and describe participant recommendations on how to *design* an HIT. The final theme includes barriers to adopting HITs for mental health care and how HITs can be used to support care coordination and delivery. Hence, it describes participant recommendations on how to *use* an HIT.

Conclusions: Although culturally diverse groups have specific concerns, their expressed needs fall broadly within the relatively universal design principles identified in this study. The findings of this study provide further support for applying self-determination theory to the design of HITs and reflect the tension in designing technologies for complex problems that overlap multiple medical, regulatory, and social domains, such as mental health care. Finally, we synthesize the identified themes into general recommendations for designing HITs for mental health and provide concrete examples of design features recommended by participants.

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KEYWORDS

mental health; health information technologies; self-determination theory; eHealth; internet; digital health; adolescent; mental health services; young adult; LGBTQ persons; mobile phone; rural health

Introduction

Barriers to Accessing Mental Health Care for Young Nonurban Australians

Around 1 in 5 Australians experience mental ill health regardless of whether they live in an urban or a nonurban (ie, regional, rural, or remote) area [1]. However, compared with urban Australians, nonurban Australians experience worse mental health outcomes, such as higher self-harm, suicidal ideation, and suicide attempt rates [2]. Nonurban Australians experience many barriers to accessing services and supports, such as cost, distance, a relative lack of service providers, stigma, and an increased emphasis on privacy [3,4].

These barriers can lead to limited access to mental health care for young people living in nonurban areas. Notably, rural young Australians discontinue prematurely from care at higher rates than those from urban or regional areas [5]. As service provision declines with distance from major cities [6], the lack of public transportation in rural and remote communities increases young people's reliance on their supportive others (eg, parents) to take them to a service [7]. This reliance on others to access a service also raises the issue of anonymity, which can be problematic given the higher levels of stigma related to mental health issues in nonurban communities [4]. Furthermore, service opening times (often limited to weekdays during 9 AM to 5 PM), extensive wait times, and cost can add to these barriers to access mental health care [8].

Culturally Diverse Young People

For culturally diverse young nonurban Australians, such as Aboriginal and Torres Strait Islander people, people of diverse genders and sexualities, inclusive of and not limited to lesbian, gay, bisexual, transgender, queer, intersex, asexual, questioning, and pansexual people (henceforth referred to as LGBTQIA+ people in this paper), and culturally and linguistically diverse (CALD) people, multiple forms of inequality often intersect to create compounded barriers in the form of decreased mental health literacy, financial barriers, increased social and self-stigma, and a lack of mental health services compounded with geographic inaccessibility [7]. These culturally diverse groups experience both poorer mental health outcomes and reduced access to mental health care [9-13].

Barriers to accessing mental health care for Aboriginal and Torres Strait Islander people living in nonurban areas include a lack of trust in health services, lack of culturally appropriate care, and lack of available services in remote areas [10,14-16]. For young LGBTQIA+ people, reported barriers include concerns that health professionals would not be able to cater to an individual's specific identity or needs [17], a fear of experiencing homophobia and/or transphobia, and a reluctance to come out to a health professional [18]. Finally, it has been reported that young CALD people, including young people from migrant and refugee backgrounds, underutilize the public mental health system in Australia [19,20]. The key barriers to mental health care access for young CALD people include the stigma associated with mental illness, concerns regarding confidentiality, limited knowledge of available services, language barriers and communication difficulties, fear of discrimination, and a lack of trust in service providers [19,21]. These barriers to appropriate care for these 3 populations can be exacerbated in a rural setting because of fewer available culturally competent services and the increased emphasis on privacy within close-knit rural communities [4,7].

Technologies to Empower Mental Health Care Access

The term health information technology (HIT) has been defined as the "application of information processing involving both computer hardware and software that deals with the storage, retrieval, sharing, and use of health care information, data, and knowledge for communication and decision making" [22]. HITs have immense potential to address intersecting barriers to mental health help seeking in nonurban areas. They can provide individuals with access to mental health services regardless of geographical location, vulnerability, or socioeconomic status [23]; reduce the wait time to access mental health support; and remove constraints around service opening hours [24]. HITs can also make psychoeducation and help-seeking sources easier to locate and access [23]. Not only can HITs enable access to care, but they can also enhance the care delivered by mental health services, for example by using synchronous communication protocols such as video chat and real-time data tracking through apps and other software. However, if HITs do not achieve a minimum standard of usability (or ease of use) as well as user experience, they experience suboptimal uptake and dropout rates [23,25]. Given the varying levels of satisfaction (or lack thereof) of young people toward web-based mental health resources [26], it is important to ensure that HITs support the needs of their users appropriately.

To investigate how HITs can improve and transform mental health care in Australia, the University of Sydney's Brain and Mind Centre (BMC) established the Youth Mental Health and Technology Program (YMH and Tech Program). As part of this program, an HIT prototype known as the BMC Youth Platform was developed to enhance the quality of health care provided by traditional mental health services. The BMC Youth Platform consists of a set of web-based personalized clinical assessments and longitudinal tracking tools for young people to monitor psychological, neurocognitive, social, and medical characteristics and plan individualized and more effective longer-term interventions. It aims to support the delivery of mental health services and the management of mental health symptoms and as such is to be used by young people, their health professionals, and their supportive others. A summary of the key BMC Youth Platform components is presented in Table 1.

Table 1. Key components of the Brain and Mind Youth Platform.

Purpose	Component
Start page	Start page
Record of basic demographic information	About me page
Record of medical history	Health history page
Clinical assessment	Questionnaires
Holistic multidimensional tracking of mental health	Dashboard of multiple health cards (each representing a different health domain)
Recommended interventions	Care options

The BMC Youth Platform was implemented into 5 *headspace* centers (a primary mental health service for young people aged between 12 and 25 years) in urban locations within Sydney, New South Wales, and learnings from these implementations included the importance of ongoing co-design with end users to ensure iterative improvements to the HIT [24]. Our past research has also confirmed the suitability of, and the potential to further explore, the use of co-design methodologies when implementing HITs in nonurban areas of Australia. Crucially, co-design methodologies have been found to facilitate the implementation of more acceptable digital solutions for mental health in nonurban areas that take local circumstances (such as natural disaster rates) into account [27].

Iteratively Co-designing and Testing HITs

The BMC Youth Platform is the product of multiple years of co-design and user testing conducted, as part of the YMH and Tech Program, with various representative end user groups, including young people aged between 16 and 25 years and health professionals [28,29]. Co-design (also referred to as participatory design) is a key research methodology that enables the perspectives and preferences of the target end user population to influence subsequent development of the HIT [30]. When conducted appropriately, participatory design is effective in obtaining insights from population groups that are marginalized or otherwise affected by structural inequalities [31,32] and results in higher levels of end user acceptability of the final intervention [33].

One product of the YMH and Tech Program is the Project Synergy Research and Development Cycle, which applies co-design methodologies to the design, development, implementation, and feasibility testing of apps and technologies [28]. In total, 3 key principles underpin this cycle: involving target end user populations (including, but not limited to, young people, supportive others, health professionals, and other service staff) as active participants throughout the entire design process, treating young people as design partners, and continually and iteratively evaluating the acceptability of the technology from the perspective of its target audience.

Although previous co-design and user testing work done as part of the YMH and Tech Program focused on the needs of young Australians in urban areas [28] and expanded them to young Australians in nonurban areas [27], these methodologies have not yet been applied to culturally diverse young Australians in nonurban areas.

Objectives

This study aims to identify how best to improve an HIT (such as the BMC Youth Platform) for culturally diverse young Australians in nonurban areas and to synthesize findings into recommendations for designing HITs for mental health.

Methods

Ethical Approval

The University of Sydney’s Human Research Ethics Committee (protocol number 2018/130) approved this research study before the start of data collection.

Inclusion Criteria

To satisfy the inclusion criteria for participation in the study, participants were required to:

- be aged 12 years or above
- be either a young person attending a participating *headspace* center; a supportive other of a young person attending a participating *headspace* center (eg, family member, caregiver, friend); or a health professional, service manager, or administrator working at a participating *headspace* center
- be proficient in reading and speaking English
- complete the participant consent process.

Participants

headspace staff advertised this study using posters and postcards distributed throughout the participating centers. Recruitment was passive to avoid any perceived coercion, whereby a potential participant would contact the research officer listed on the advertisements to express their interest in the study and request further information. Upon the potential participant’s request, the research officer would then forward (via email) on the participant information statement, participant consent form, and screening survey to determine eligibility.

For participants under the age of 15 years, both the young person and their guardian were given detailed and age-appropriate information about the research study before the workshop via a parental information statement and a child assent form. At the beginning of the workshop, research officers reminded all participants about what the workshop would involve, provided an opportunity to ask any questions, and reminded them that the participation was voluntary. The research officers spoke separately to participants under the age of 15 years and their guardians to ensure that they understood what the workshops would involve and what the study was about. They also answered any questions and reminded the young person that they could withdraw from the study at any time without consequence. If a young person agreed to participate in the workshop, their guardian provided a signed parental consent form and the young person provided a signed child assent form.

The young people and their supportive others were reimbursed with a gift card valued at Aus $30 (US $23) for study participation.

Co-design Workshops

Workshop Location and Demographics

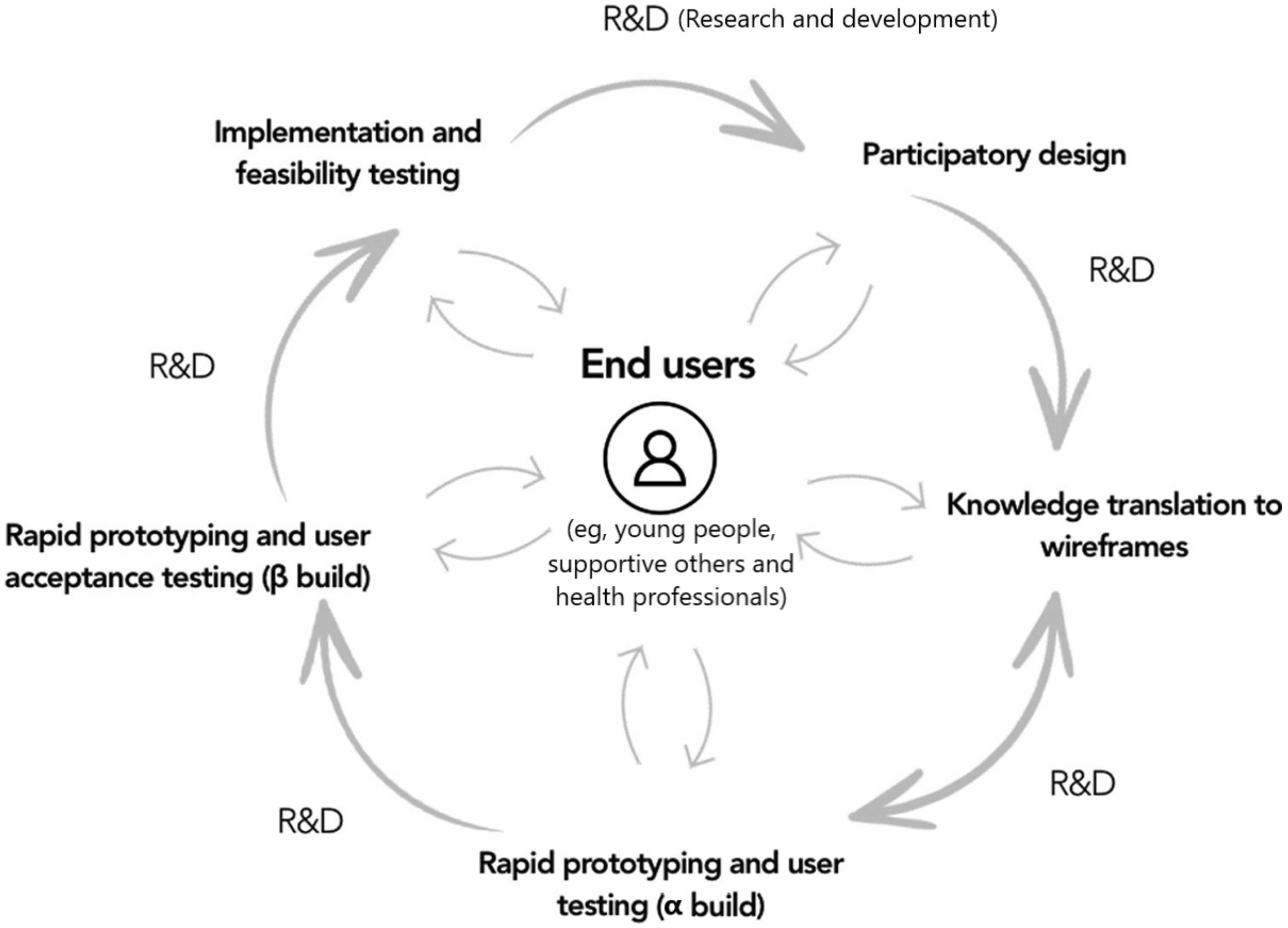
A total of 10 co-design workshops were held from July to September 2018 in *headspace* centers across the Australian states of New South Wales, South Australia, and Queensland.

We initially invited *headspace* centers to participate in this study, trying to ensure a representation of centers located in nonurban areas. Participating *headspace* centers were aware of the possibility of implementing this technology in their centers in the future. Although researchers did not specifically recruit Aboriginal and Torres Strait Islander people, LGBTQIA+ people, and CALD people, because of local population demographics, these groups were naturalistically represented in the participant sample.

Workshop Protocol

These workshops represent phase 1 of the Project Synergy Research and Development Cycle (Figure 1 [28]), where co-design workshops are rapidly conducted across different sites until theme saturation [28]. In these workshops, technology designs, ideas, and principles are evaluated by participants, sometimes iteratively (if enough time has passed for insights from a previous workshop to be translated into a testable wireframe or prototype). Previous work describing the process and outcomes of this methodology [28,29,34,35] as well as work on a separate mental health and well-being app [36] have been published.

Figure 1. Project synergy research and development cycle.



Although general workshop agendas were adhered to as appropriate, facilitators (the second, third, and fourth authors) also conducted workshops flexibly and followed up on topics in response to individual workshop dynamics. Certain topics were also given more priority to explore in different locations and contexts (eg, technology use and connectivity in nonurban areas). Therefore, the workshop content and outcomes varied slightly among workshops.

After each workshop, facilitators reviewed the workshop findings, adapting the general workshop agenda to remove data-saturated topics and add new and further topics of interest. An example of a workshop agenda is provided in Multimedia Appendix 1.

Owing to the number of participants and other contextual factors, workshops ranged from 2.5 to 4 hours in duration and consisted of the following stages: discovery, evaluation, and prototype. In the discovery stage, facilitators led discussion around the following topics: general technology use, technology use for the purposes of supporting health and mental health, and internet use and connectivity. In the evaluation stage, participants were presented with paper printouts of various components of the BMC Youth Platform and asked to annotate them with their thoughts and comments. Finally, in the prototype stage, participants were asked to brainstorm new ideas, functionalities, and wireframes (with marker pens and sketchbooks) for the BMC Youth Platform. Owing to the sensitivity of the subject matter, workshops were not audiorecorded or videorecorded to decrease the risk of identification and facilitate participant disclosure. Instead, scribes took notes at each workshop. All workshops included at least one facilitator who was appropriately qualified in mental health to provide counseling support to the participants if needed.

Knowledge Translation

All workshop data, including notes and artifacts from the evaluation and prototype stages, were collated and reviewed by an independent knowledge translation team consisting of 2 young people (listed in the Acknowledgments) who had never previously been exposed to the BMC Youth Platform or its concepts. The knowledge translation team summarized the outcomes of the discovery and prototype stages and conducted a procedure similar to descriptive content analysis [37] on the outcomes of the evaluation stage. Specifically, all annotations were reviewed by each team member, who noted their general observations. They then coded the annotations together, organizing codes according to semantic themes representing different components of the BMC Youth Platform (Table 1).

Template Analysis

To supplement knowledge translation insights and identify general recommendations on designing HITs for mental health, we conducted a type of codebook thematic analysis [38] known as *template analysis* [39,40] on the workshop data. Specifically, the data set consisted of the knowledge-translated, summarized outcomes of the evaluation stage (in tally form) and scribe notes from each workshop. In recognition of the fact that generic thematic analysis (including template analysis) is a method with many different approaches that reflect a wide variety of epistemological (theory of knowledge) and ontological (theory of being) assumptions [38], we located our approach within a philosophical position of qualitative neopositivism. This position assumes a realist ontology and epistemology.

The data set was coded with NVivo 12 (QSR International). The first author initially coded all the data using a bottom-up, descriptive approach at a level close to the data (eg, *avoid clinical jargon* and *worry that information is confronting*). At the conclusion of this first round, the first author determined that certain groups of codes fit well with self-determination theory [41,42]. Although self-determination theory is originally a theory of intrinsic motivation, human-computer interaction research has found it to be applicable to user engagement with digital technologies [43,44]. Self-determination theory has also been successfully applied to user needs, facilitators, and barriers for mental health technologies [45,46].

Using self-determination theory as a partial reference for a priori themes, the first author grouped these descriptive codes into a preliminary coding template. A second coder (the second author) then independently coded 10% of the data according to this preliminary coding template to check its quality. In this case, quality was defined as the clarity of definitions and whether the template comprehensively covered the data set [40]. Both coders then discussed all discrepancies in coding until they were resolved, and insights from this process were used to refine the coding template. This iterative process of independent coding, comparison, and refinement of the coding template was repeated until a satisfactory level of interrater reliability was reached (Cohen kappa for all codes >0.65), which took 3 rounds of coding. Following this, the final interpretation of the template in relation to addressing our study aim was conducted.

Results

Participants

Table 2 reports workshop details, including dates, location, and participant characteristics. All workshops except workshop 5 (Ashfield, New South Wales) were conducted in nonurban areas. All *headspace* clients are young people aged between 16 and 25 years unless specified otherwise. Staff included mental health clinicians (psychologists, mental health nurses, and social workers), youth workers, administrative staff, and center managers from *headspace*.

Table 2. Workshop and participant details (N=105).

Workshop number	Workshop date	Location	Facilitators, n	Participants, n	Participant demographic information		
					Gender	Participant role	Cultural or personal identification[a]
1	June 18, 2018	Edinburgh North, South Australia	3	10	8 female and 2 male	6 clients, 1 support person, and 1 staff member	None disclosed
2	June 20, 2018	Edinburgh North, South Australia	3	11	7 female and 4 male	5 clients, 3 support people, and 3 staff members	1 CALD[b]
3	July 20, 2018	Broken Hill, New South Wales	3	9	4 female, 4 male, and 1 transgender	6 clients, 1 younger client aged between 12 and 15 years, and 2 staff members	2 CALD and 2 Aboriginal or Torres Strait Islander people
4	July 25, 2018	Townsville, Queensland	2	11	6 female and 5 male	8 clients and 3 staff members	2 Aboriginal or Torres Strait Islander people and 5 LGBTQIA+[c] people
5	August 9, 2018	Ashfield, New South Wales	3	5	4 female and 1 male	3 clients, 1 younger client aged between 12 and 15 years, and 1 support person	5 CALD
6	August 14, 2018	Wagga Wagga, New South Wales	2	9	7 female and 2 male	2 clients, 2 younger clients aged between 12 and 15 years, 3 staff members, and 2 support people	None disclosed
7	August 22, 2018	Bathurst, New South Wales	2	11	5 female and 6 male	6 clients, 4 younger clients aged between 12 and 15 years, and 1 staff member	None disclosed
8	August 28, 2018	Orange, New South Wales	2	22	6 female and 16 male	7 clients, 11 younger clients aged between 12 and 15 years, and 4 staff members	5 Aboriginal or Torres Strait Islander people
9	August 30, 2018	Wollongong, New South Wales	2	7	4 female, 2 male, and 1 gender neutral	6 clients and 1 staff member	1 person with disability
10	September 4, 2018	Dubbo, New South Wales	2	10	7 female, 2 male, and 1 gender neutral	7 clients and 3 staff members	4 LGBTQIA+

[a] Participant demographic information, particularly gender and cultural or personal identification, was provided by participants on a voluntary basis and was therefore unable to be captured consistently across workshops.

[b] CALD: culturally and linguistically diverse people.

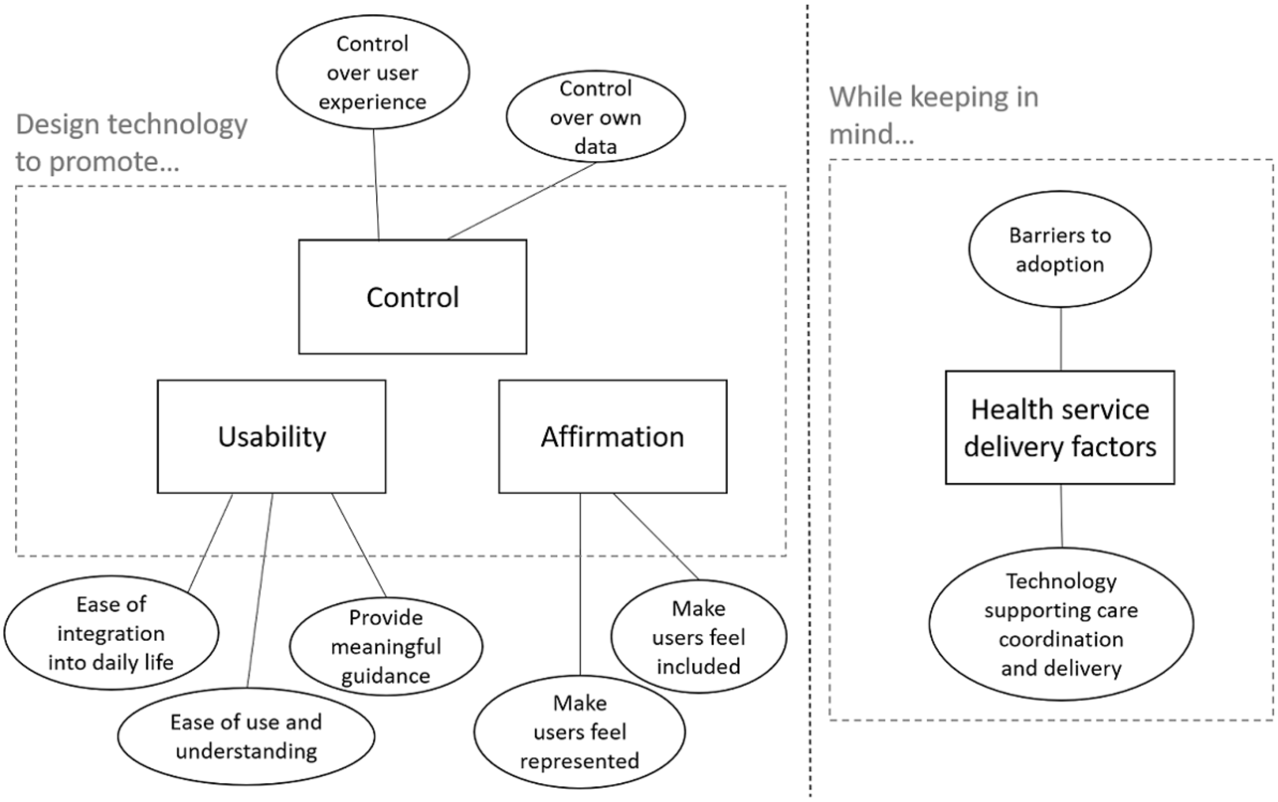
[c] People of diverse genders and sexualities, inclusive of and not limited to lesbian, gay, bisexual, transgender, queer, intersex, asexual, questioning, and pansexual people.

Template Analysis

Figure 2 shows the coding template following analysis and the refinement of the codes. During the analytical process, numerous codes were generated from the data set. These codes were organized into 11 low-level themes, which were then organized into the following high-level themes (design principles): control, usability, affirmation, and health service delivery factors. The full coding template (including a codebook of definitions) is presented in Multimedia Appendix 2.

Although many participants belonged to culturally diverse groups, they made many design recommendations applicable to universal human experience. These recommendations overlapped closely with the 3 basic psychological needs postulated by self-determination theory, namely, autonomy (corresponding to our theme of control), competence (corresponding to our theme of usability), and relatedness (corresponding to our theme of affirmation) [41,42].

Figure 2. Final coding template.



Give Users Control

First, participants emphasized the importance of having control over their user experience and their data.

Control Over User Experience

Participants made clear their expectations that any technology they use should give them the ability to control their own user experience, for example, by active customization of key design elements such as background color, layout, and the ability to upload an avatar. Participants from CALD backgrounds and participants with disabilities also expressed a desire to be able to change language and font size and to be able to consume information in different audiovisual formats (eg, text-to-speech options).

This desire for control also extended to the care being delivered to young people, with participants appreciating that they could make informed choices on which care options to embark on to progress their care. Participants also wanted to be able to arrange the health cards on their dashboard in ways that would make more sense or that they would find less overwhelming:

> *How the cards are ordered is important, [it] would be great to have the cards you want to work on together or first, group cards by color.* [Bathurst, young person]
>
> *Can you collapse aspects if [you're] feeling "shitty"?* [Wagga Wagga, young person]

Finally, participants also suggested providing mechanisms through which user feedback could be provided and actioned on, for example, through a dedicated feedback section.

Control Over Data

Participants also stressed the importance of having control over their own data at all times, not only through data security (authentication and encryption, eg, through password or personal identification numbers) but also through data privacy and sharing. A key feature of the BMC Youth Platform is that young persons' dashboards of results are visible to health professionals at their service. The young persons can also share their dashboards with trusted supportive others, such as parents or friends. Although participants found it acceptable to share their data in this form with their health professionals, they were more hesitant to share their data with their supportive others (eg, parents or friends). Participants wanted fine-grained control and the ability to grant or revoke their supportive others' access to certain health cards, particularly those deemed by young people to be more sensitive, such as substance and tobacco use:

> *I don't want mum to see smoking, but they can see anxiety.* [Edinburgh North, young person]

The consent and data sharing status of each of their health cards as well as other parts of their data (such as health history) would also need to be presented to the user clearly and transparently:

> *How long do they have access to the information? [It] needs expiry, for example when [you] repeat the questions, or between 1-30 days, can check in to add or remove people.* [Wollongong, young person]
>
> *Privacy setting on cards can be set with clinician at first appointment, then the parent or carer receives the email invitation. They might have their own dashboard to look at.* [Dubbo, headspace staff]

Make the Technology Usable

Second, participants expressed that the technology should not be difficult to use, that is, it should (1) be easy to use and understand, (2) provide meaningful guidance, and (3) be interoperable.

Ease of Use and Understanding

Participants specified that the technology should be easy to use and understand at first glance and that it should not be overwhelming or frustrating to use. The technology should be clear, unambiguous, and consistent in language and user interface (including layout, icons, and imagery), and clinical jargon should be avoided. The latter point was especially relevant for younger audiences aged between 12 and 15 years because of lower reading levels. However, although participants found clinical terms such as "social and occupational functioning" and "psychosis-like experiences" confusing and intimidating, it was difficult to come up with alternative, more acceptable terms. After considering the issue, many participants suggested using direct language and providing definitions.

Provide Meaningful Guidance

Participants further specified that the technology should present information in meaningful chunks or sequences (eg, displaying participants' data on the most important health domains first) to promote a gradual understanding of psychoeducational concepts. This was particularly the case for the onboarding stage, which was where many participants would encounter clinical terminology and their own data for the first time. In addition to presenting information in a staggered, chunked manner, the technology should also provide meaningful guidance on how to use and interpret the technology. Participants overwhelmingly endorsed a model of delivering information whereby a page was kept simple and clutter-free at first presentation (relating to the previous tenet of ease of use and understanding), with users being given the freedom to learn more via a *more information* button or by hovering over complex terms (eg, *mania*, *psychosis*, or *clinician*).

Similarly, participants expressed that the technology should provide prompts or mechanisms through which users could gain an understanding of how to use the technology and how the technology could help them, for example, via a help button or Frequently Asked Questions (FAQ) page or through prompts reminding them to check their dashboard and complete new psychometric questionnaires at appropriate time intervals. These prompts could be tailored based on their questionnaire responses:

> *If a health card is red, the health professional (or system) should keep close eye on this—and prompt you to repeat the questionnaire.* [Dubbo, headspace staff]

Interoperability

Participants also emphasized that any HIT should be easy to integrate into daily life. This technology should be able to compile data from other apps (eg, step tracking apps) and enable all information of a user to be accessed from one location. Similarly, some participants endorsed the idea of quick, convenient authentication via social media, although others were concerned about data security issues. Young people overwhelmingly expressed a preference for mobile usability (responsive web design) and mobile integration (eg, via SMS text messaging instead of email), as many of them had neither easy access to computers nor an email address.

Affirm Users' Identity and Preferences

Finally, participants emphasized the importance of an HIT making its users feel represented and valued.

Make Users Feel Represented

Despite one of the purposes of HITs being the facilitation of users' mental health care via routine outcome monitoring, participants (both health professionals and young people) felt that it should provide functionality to represent the user beyond traditional clinical information such as demographics and mental health status. Participants wanted to be able to define themselves in more nuanced ways and felt that the screenshots they were presented with reflected a technology that could not yet allow them to do so. Their suggestions for ways to define themselves comprehensively and accurately ranged from simple actions such as being able to specify their preferred pronoun and being offered a more diverse range of response options when specifying their demographics (eg, sexuality, gender, and ethnicity) to more comprehensive methods such as adding new health cards to provide more information on additional domains such as family violence and homelessness or elaborating on responses via free text. This was judged to be particularly relevant given that *headspace* also offers support for domains outside mental health (such as with work and study):

> *Dashboard needs to reflect what is important to me, [for example] culture, sexual health and homelessness.* [Dubbo, young person]
>
> *These questions are very mental health–focused but headspace does a lot more.* [Bathurst, headspace staff]

Some LGBTQIA+ participants also felt that their sexual identity and preferred pronouns should not "be hidden away" in a separate *About me* tab, as this made it harder for them to come out to their health professional, and that instead it should be reflected in the dashboard.

Participants also felt that HITs should cater to them. Not only should they be usable regardless of physical or mental ability (mental health status, disability, or other accessibility considerations) but they should also offer a personalized user experience and present their various components (questionnaires, care options, psychoeducation, language, etc) in ways that are tailored to their users' personal circumstances (eg, gender, culture, location, and questionnaire responses):

> *[It] should be designed like Spotify, when you select your music it also suggests other artist in the same sort of music. [On the BMC Youth Platform] if [you] choose tobacco it would also give you the other drug [questions] like alcohol and cannabis.* [Bathurst, young person]
>
> *Tabs at top [could link to psychoeducation resources]—possibly an option of "how to talk to my*

> *parents," "how to talk to my partner," [that is] some ideas about what you can do with this information in the meantime. It should be tailored to who the login "user" is, [that is] at a certain age it may be directed to something different than to a 13-year-old, or a parent.* [Edinburgh North]

Finally, the CALD participants emphasized that the technology should cater to their needs, namely, that their languages should be supported and that the technology should acknowledge that different cultures could approach mental health differently, for example, by viewing them as "life circumstances" instead of "mental illness."

Make Users Feel Valued

Both health professionals and young people were adamant that an HIT user should not feel reduced to a diagnosis or an assortment of diagnostic labels. Instead, the HIT should be designed to celebrate nonclinical aspects of personhood as well, such as a user's likes and aspirations (eg, via a *My Goals* section). Although these aspirations could relate to a user's mental health (eg, improving their mood or sleep), they could also reflect a user's other goals. Participants also suggested having a dedicated space for users to store personally meaningful resources, such as a journal, pictures of inspirational people, or self-care resources useful to them:

> *If clinicians can see this page [they] will have a more positive approach to the relationship [and] will be able to connect with the young person.* [Bathurst, young person]

Participants also raised concerns that the screenshots of the technology they were presented with could potentially frame users too negatively. Instead, they preferred a strengths-based, positive framing approach that provided positive affirmations, kept "users on track," and celebrated achievements and strengths. Participants also recommended adding gamification to the technology to increase motivation to engage and promote a sense of progress, for example, via markers of achievements (eg, ribbons or "becoming a BMC Youth Platform warrior") or a leveling and reward system. They further specified that any gamification should "reward effort more than outcome," that is, rewards should be assigned based on the level of long-term engagement and the extent to which the user has explored (or completed) the technology.

An HIT should also not alienate the user and make them feel alone in their struggles with mental health. Instead, the technology should promote a sense of social connection (even parasocial connection), for example, by providing testimonials and links to other people's mental health stories (eg, an "others that struggle with this issue" section) and by normalizing suboptimal mental health status (eg, "It's OK to feel bad").

Health Service Delivery Factors

In addition to the more universal design principles described above, participants also contributed insights into what could broadly be categorized as health service delivery factors. This included perceived barriers to the widespread adoption of HITs for mental health care and how HITs could be used to support mental health care coordination and delivery.

Barriers to Adopting HITs for Mental Health Care

Although this was not the key topic of investigation, during workshops, participants discussed barriers to adopting digital technologies for mental health care that were relevant to their regions and communities.

The limitations of internet connectivity in nonurban areas, raised in 7 of the 8 nonurban areas investigated, was the most commonly cited barrier, with slow internet speeds and a lack of access to home internet in certain geographic areas being the main issues. Participants were familiar with free Wi-Fi locations, such as libraries, local schools or universities, and fast-food restaurants. Using internet in nonurban areas was also associated with several costs that were unsustainable for young people, including the cost of purchasing smartphone apps as well as the cost of mobile data itself:

> *I use public Wi-Fi ([McDonald's] or university Wi-Fi) to get internet since my home connection is bad.* [Wagga Wagga, young person]

Health professionals who participated in the workshops also raised the issue of software fatigue. Currently, *headspace* protocols mandate multiple other pieces of software to be used to manage minimum data entry for its clients. Health professionals were hence cautious of new technologies, stating that "[it's a] real turn off to do the same questions more than once." Instead, they would prefer that client responses could be "shared between systems" in the case of overlap:

> *With 96 clients on my list [I] do not want 96 notifications via email as there is enough to review with the current system.* [Dubbo, headspace staff]

Technology Supporting Care Coordination and Delivery

Collectively, workshop participants outlined concrete suggestions through which HITs could support health professionals and clients during mental health care.

First, HITs could help health professionals and clients understand the progress of the client's care at all stages of the care. Before the first appointment, they could provide icebreakers to help potential clients become comfortable with their health professionals and provide health professionals with their client's dashboard of results to allow them to prepare for the first appointment more effectively. This was viewed as critically important given that at the time of the workshops, the Australian public mental health system only funded 6 1-hour sessions with a psychologist (extendible to 10 sessions given further referral) per year:

> *It would take the whole session to go over history alone, with only 10 sessions [we] can't afford to have a session devoted to not achieving anything.* [Wollongong, young person #1]
>
> *We need something [that isn't] telling your story again to a new psychologist each time. It's not schema therapy with 20 sessions, 6 sessions are precious.* [Wollongong, young person #2]

During the course of care, HITs could maintain a record of the client's health over time and over a variety of domains (multidimensional routine outcome monitoring) as well as a record of care options attempted over time. This record could then be used as a reference to prompt topics of discussion between the health professional and client:

> *I want to see my apps linked into the system to share with headspace, so they can see my progress in real time.* [Dubbo, young person]
>
> *[On the system] buttons could say "what can I do now?," "what to chat to my clinician about?"* [Wagga Wagga]

This record could be exported and transferred over to a new mental health service or a new health professional, should the client require it, to minimize administrative and psychological burden on the young person interacting with their new health professional:

> *Retelling your story is one of the hardest [things].* [Wollongong, young person]

By enabling tracking of a client's progress during care, HITs could also support the health professional and client in gaining a more unified understanding of how to direct the client's care. The health professional could tailor their support according to their clients' needs in mental health and other domains. Similarly, by seeing how their self-reported health changed over time and following different care options, the client could make more informed choices on which health domains and care options to focus on.

Such technologies could also improve the efficiency and safety of clinical care. For example, video calling functionalities could overcome long distances in large rural health catchments and allow for more flexible appointment scheduling. Young people also expressed that they would find it easier to complete questionnaires on a device rather than answer them face-to-face with a health professional. Finally, such technologies could alert mental health services when their clients are experiencing emergency scenarios in real time, assisting them in risk management.

Discussion

Using Self-Determination Theory to Design HITs for Mental Health

The findings of this study can be broadly categorized into (1) design recommendations for HITs for mental health and well-being and (2) health service delivery factors to consider when designing such technologies. In other words, the former category reflects how such technologies should be *designed* and the latter category reflects how such technologies should be *used*.

The design recommendations approximately map to the 3 basic psychological needs proposed by self-determination theory: autonomy, competence, and relatedness [41]. As mentioned before, self-determination theory is a theory of motivation (including both intrinsic and extrinsic motivation) that has been applied to the design of health technologies [44,47] as well as web-based help seeking for mental health problems [45,46]. The fact that we found our workshop findings to align with self-determination theory constructs is a further support for its application to the design and delivery of HITs. Currently, many HITs do not explicitly apply theories of engagement or health behavior change to their design and delivery [48]. However, our results suggest that the contribution of these theories to HITs is equally important as that of evidence-based clinical content.

Importantly, although our core design recommendations map neatly onto the 3 basic psychological needs, how they are executed in practice can simultaneously support multiple needs [46]. For example, from our data, we found technological accessibility to be a blend of *usability* (ease of use), *control* (eg, customizing visual elements such as font size), and *affirmation* (inclusiveness) and avoiding clinical jargon to be a blend of *usability* (not using difficult terminology) and *affirmation* (avoiding making users feel reduced to a diagnosis). A comprehensive list of recommended design features identified from our workshops is shown in Table 3.

Our results are broadly consistent with previous research, reflecting the importance of promoting social connection [32,46], personalization and customization [36,46], clear and casual language [36], and addressing data security and privacy concerns [7,49].

Our results also suggest that any recommendations from participants should be evaluated through the lens of self-determination theory, with explicit consideration given to how each suggested change could promote each of the basic psychological needs. This is in line with previous research on applying self-determination theory to help seeking for mental health problems [45,46]. This measured evaluation is important given that many participant suggestions involved broad concepts or specifications and may reveal that further expertise needs to be consulted. For example, participants recommended implementing gamification to "reward effort more than outcome" and suggested several mechanics through which HITs could be gamified, including level-based reward systems and achievements. However, gamification is not merely a collection of gamification elements but instead the deliberate integration of gameful mechanics into a technology to support its core functionalities [50]. Implementing this suggestion, therefore, would involve not only the iterative user testing of the gamified HIT with the target end user population but also the consultation of gamification designers to integrate gamification at a deeper, systemic level that promotes both the HIT's aims and user motivation to engage with the HIT (via the 3 basic psychological needs).

Table 3. Participants' recommended design features and corresponding basic psychological needs.

Broad design category	Recommended design feature	Supported basic psychological needs
User interface and experience	Customizable user interface (language, colors, layout, font size, etc) to accommodate user preferences and needs	Autonomy and competence
User interface and experience	Tailored user experience	Relatedness
User interface and experience	Meets international accessibility standards (eg, web content accessibility guidelines)	Competence and relatedness
User interface and experience	Customizable information input and output (eg, being able to submit free text that more accurately describes you and being able to organize how your data are displayed) for ease of tracking and understanding	Autonomy, competence, and relatedness
User interface and experience	Clear layout, icons, and imagery	Competence
Content and functionality	Ability to provide user feedback that will be actioned on (eg, feedback or evaluation section)	Autonomy and relatedness
Content and functionality	Instructional prompts giving guidance on what to expect and how the technology will help the user and reminder prompts to promote reengagement	Competence
Content and functionality	Provision of optional additional information not core to the experience; however, the user can consult to learn more (eg, psychoeducation or a frequently asked questions section)	Autonomy and competence
Content and functionality	Gradual onboarding and the provision of information in meaningful chunks to support learning and understanding (eg, showing the most important health domains first on a health dashboard)	Competence
Content and functionality	Consider element of fun (eg, gamification)	Relatedness
Content and functionality	Promote social connection with peers and communicate to users that they are not alone (eg, through peer support groups and testimonials)	Relatedness
Language and tone	Adopt a strengths-based approach and celebrate nonclinical aspects of personhood such as likes, aspirations, strengths, and achievements	Relatedness
Language and tone	Cultural competence	Relatedness
Language and tone	Clear, casual, unambiguous, and consistent language that avoids clinical jargon and loaded terms	Competence and relatedness
Interoperability	Ease of integration with other apps and technologies (eg, health apps or convenient authentication methods)	Competence
Interoperability	Mobile integration as young people do not use email or computers frequently	Autonomy and competence
Security and privacy	Industrial-grade data security	Autonomy
Security and privacy	Fine-grained (individual level) data sharing functionality	Autonomy

Often, participant recommendations seemed to contradict each other at the surface level. For example, we observed tensions within participant recommendations on language, with an emphasis on increasing understanding (eg, by using clinically accepted terms and providing definitions when needed) conflicting with an emphasis on using casual, simple, and nonloaded language. Similarly, the focus on ease of use (by presenting information clearly and in a manner that is not overwhelming) superficially conflicted with the desire to have access to contextualizing information as well as the desire to improve representation by increasing the number of psychosocial domains represented on the dashboard of results. When this contradiction was raised, participants proposed the solution of giving users the ability to customize their own user experience and make it as simple, or as complex, as they liked. Under self-determination theory, this solution would allow each user to satisfy their needs for autonomy, competence, and relatedness at an individual level.

However, although many contradictions were solved in a way that was acceptable to our participants on an individual level, some solutions raise implications on the service level. For example, an overarching recommendation from the workshops that participants overwhelmingly agreed on was the desired ability to provide more nuanced information about oneself via free text. On the service level, however, this solution would raise implications for, and potentially conflict against, clinical safety protocols unless the free-text fields were moderated and constantly monitored (on a 24-hour basis) for any indication of suicide risk. Currently, the role of this moderator would most practically be filled by a health professional employed at the service, a human resource allocation luxury many publicly funded mental health services do not have. Although it is important to adhere to clinical safety protocols, this situation is an example of a dilemma faced by decision makers where design practices that can best serve the intended user base are disincentivized by the wider public health and medical research systems, resulting, in some respects, in a lower-quality HIT. The complexities and often contradicting incentives in the public health and medical research spheres can have the effect of frustrating progress in what should be the shared aim of improving public health outcomes. In such cases, marginalized populations that face multiple compounding barriers to access to quality care are the ones that are the most adversely affected, particularly in acute, abnormal situations such as natural disasters or a global pandemic [51]. To achieve the most impact, HIT solutions and software development resources should directly solve problems such as this that disproportionately impact marginalized populations. For example, one method of overcoming this problem could be to automate content moderation via natural language processing [52].

Designing for Culturally Diverse Groups

The findings of this study suggest that although culturally diverse groups have specific concerns about design (eg, affirmation of diversity in sexual preference and gender identity and the provision of multiple language options), their needs fall broadly within universal design principles. For example, our LGBTQIA+ participants wanted a way to display their sexuality and pronouns alongside their dashboard of results. In addition to being able to represent themselves more fully, this would also increase their comfort levels with their health professional as they would not have to directly disclose this information face-to-face. The psychosocial context behind our participants' recommendations is crucial and cannot be divorced from the recommendations themselves without running the risk of developing solutions that could alienate the culturally diverse groups from which they hail. For this reason, we have synthesized our findings into general rather than specific recommendations.

Textbox 1 provides general recommendations on designing HITs for mental health that were drawn from co-design with culturally diverse populations and based on self-determination theory. Specifically, designers should consider the intended functionality of the HIT and how the HIT can fulfill its users' basic needs of autonomy, competence, and relatedness (by providing perceptions of control, usability, and affirmation). This would require identifying barriers to their access to, and adoption of, the technology (ideally through a co-design process similar to what was adopted in this study) and designing the technology to mitigate these barriers.

Textbox 1. General recommendations on designing health information technologies for mental health based on self-determination theory.

1. Identify the purpose of the health information technology (HIT) and the mechanisms through which it achieves it aims
2. Consider how the HIT can fulfill users' basic needs of autonomy, competence, and relatedness through providing perceptions of control, usability, and affirmation:
   - Control includes the ability to control user experience as well as the ability to control user data
   - Usability includes ease of use and understanding, the provision of meaningful guidance, and ease of integration into daily life (eg, interoperability)
   - Affirmation includes users feeling both valued and included within the target user base
3. Consider the possible barriers to adopting the HIT, including access and use, from all potential user groups
4. Consider how to design the HIT to directly address as many adoption barriers as possible while still preserving perceptions of control, usability, and affirmation

Adoption barriers that this study and previous research have identified include young people's lack of easy access to personal computers [53] as well as poor internet connectivity in many nonurban parts of Australia [54]. HIT designers should be aware of inequalities and how they compound and not perpetuate them. For example, they should neither enable discrimination nor systematically exclude groups of users who may not have adequate internet connectivity or reading level. Compassionate design that puts these barriers at the forefront of consideration is required to ensure that technologies can be accessed by all. Our study results underscore the importance of user testing with the target population to confirm that the technology satisfies their needs and to identify potential barriers that may prevent them from accessing these technologies.

Limitations

A limitation of this study was that the researchers did not exclusively advertise to and recruit participants from the populations of interest within this study (Aboriginal and Torres Strait Islander people, LGBTQIA+ people, and CALD people in nonurban areas). Instead, all young people attending *headspace* (aged between 12 and 25 years), *headspace* staff, and supportive others were invited to participate in the workshops. Therefore, although participants who identified as being of these populations were present at workshops, the data collected cannot be exclusively attributed to these populations. Future research should consider recruiting participants exclusively from these populations and provide appropriate support to ensure comfort in communication (eg, an Aboriginal or Torres Strait Islander person to facilitate the workshop tailored to that population). Artifacts from the *headspace* Dubbo workshop (annotated screenshots and drawings of technology prototypes) were not included in the analysis for this study, but all researcher-scribed notes were included.

Our inclusion criteria would also have excluded CALD participants who were not proficient in English. Hence, our study results cannot be fully generalized to CALD communities. As mentioned above, future research should recruit exclusively from CALD populations and provide appropriate support (eg, by conducting workshops in participants' native language or providing a translator).

Furthermore, our workshops included a mixed group of participants (young people, their supportive others, and health professionals). This gave facilitators the opportunity to address tensions and potential contradictions in what each of these groups wanted from an HIT for mental health. However, although workshop facilitators did their best to encourage open discussion, the implicit power difference among these groups could have discouraged this from participants belonging to less socially powerful groups (eg, young people). Similarly, workshops were not audiorecorded or videorecorded to facilitate discussion. However, this limited the details on which scribe notes could be taken.

Finally, these insights arise from a relatively narrow (though important) source, namely, representative end users, including young people, health professionals, and supportive others (our participants), further interpreted through the lens of independent knowledge translators (2 young Australian women) and mental health researchers (the authors). Although these groups have their own spheres of expertise, they are not the only important perspectives in the design of HITs for mental health. There are other considerations to account for in the design of such technologies, particularly in terms of specialist detail in user experience design, security, governance, and software engineering. As a result, the findings of this study should be taken as informed recommendations for how similar HITs can be structured as well as a validation of existing ideas only.

Conclusions

Recent research has underscored the importance of iteratively testing the acceptability of HITs with the target end user population [25,33]. Through a series of co-design workshops, this study sought to extend the scope of our previous research from urban and nonurban Australian adolescents to include culturally diverse populations in nonurban areas of Australia. Although we identified several barriers and preferences specific to these populations in our co-design workshops, our results support the application of theory-based design of HITs (eg, self-determination theory) to develop user experiences that fulfill the universal basic psychological needs of autonomy, competence, and relatedness, through providing perceptions of control, usability, and affirmation. Deeper reflection on our findings also reveals the inherent tensions and difficulties in balancing the multiple, sometimes contradicting requirements of mental health technology stakeholders, including, but not limited to, health professionals, regulatory bodies, individual users, service managers, and best practice of the software development industry.

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Conflicts of Interest

IH was an inaugural commissioner on Australia’s National Mental Health Commission (2012-2018). He is the Codirector, Health and Policy, at the University of Sydney’s BMC. The BMC operates an early intervention youth service at Camperdown under contract to headspace. He is the chief scientific advisor to and a 5% equity shareholder in InnoWell Pty Ltd. InnoWell was formed by the University of Sydney (45% equity) and PricewaterhouseCoopers (Australia; 45% equity) to deliver the Aus $30 (US $23.23) million Australian Government–funded Project Synergy (2017-2020; a 3-year program for the transformation of mental health services) and to lead the transformation of mental health services internationally through the use of innovative technologies. At time of publication, VC is now employed at the Australian Digital Health Agency. TD is now the Director (Research and Evaluation), Design and Strategy division, at the Australian Digital Health Agency. None of the other authors declare any conflicts of interest.

Multimedia Appendix 1

Example workshop agenda.
[DOCX File , 80 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Full coding template and codebook of definitions.
[DOCX File , 22 KB-Multimedia Appendix 2]

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Abbreviations

BMC: Brain and Mind Centre
CALD: culturally and linguistically diverse
HIT: Health Information Technology
LGBTQIA+ people: People of diverse genders and sexualities, inclusive of and not limited to lesbian, gay, bisexual, transgender, queer, intersex, asexual, questioning, and pansexual people
YMH and Tech Program: Youth Mental Health and Technology Program

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Original Paper

A Bespoke Electronic Health Record for Epilepsy Care (EpiToMe): Development and Qualitative Evaluation

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Abstract

Background: While electronic health records (EHR) bring various benefits to health care, EHR systems are often criticized as cumbersome to use, failing to fulfill the promise of improved health care delivery with little more than a means of meeting regulatory and billing requirements. EHR has also been recognized as one of the contributing factors for physician burnout.

Objective: Specialty-specific EHR systems have been suggested as an alternative approach that can potentially address challenges associated with general-purpose EHRs. We introduce the Epilepsy Tracking and optimized Management engine (EpiToMe), an exemplar bespoke EHR system for epilepsy care. EpiToMe uses an agile, physician-centered development strategy to optimize clinical workflow and patient care documentation. We present the design and implementation of EpiToMe and report the initial feedback on its utility for physician burnout.

Methods: Using collaborative, asynchronous data capturing interfaces anchored to a domain ontology, EpiToMe distributes reporting and documentation workload among technicians, clinical fellows, and attending physicians. Results of documentation are transmitted to the parent EHR to meet patient care requirements with a push of a button. An HL7 (version 2.3) messaging engine exchanges information between EpiToMe and the parent EHR to optimize clinical workflow tasks without redundant data entry. EpiToMe also provides live, interactive patient tracking interfaces to ease the burden of care management.

Results: Since February 2019, 15,417 electroencephalogram reports, 2635 Epilepsy Monitoring Unit daily reports, and 1369 Epilepsy Monitoring Unit phase reports have been completed in EpiToMe for 6593 unique patients. A 10-question survey was completed by 11 (among 16 invited) senior clinical attending physicians. Consensus was found that EpiToMe eased the burden of care documentation for patient management, a contributing factor to physician burnout.

Conclusions: EpiToMe offers an exemplar bespoke EHR system developed using a physician-centered design and latest advancements in information technology. The bespoke approach has the potential to ease the burden of care management in epilepsy. This approach is applicable to other clinical specialties.

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KEYWORDS

specialty-specific EHR; physician-centered design; clinical workflow; patient care management; clinical care documentation; physician burnout; interoperability

Introduction

Electronic Health Records

Electronic health records (EHR) have been broadly adopted in the United States in the last 2 decades to improve the quality of health care, increase patient satisfaction, and save health care costs [1-3], as mandated by the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 [4-7]. Compared to paper-based medical records, EHR has advantages that include easier access, higher working efficiency, increased patient satisfaction, reduced financial cost, better data exchange and interoperability, and opportunities for secondary use of clinical data for research [8-11].

While EHR brings such benefits to health care, EHR systems are often criticized as cumbersome to use, failing to fulfill the promise of improved health care delivery with little more than a means of meeting regulatory and billing requirements [12]. A recent study inspected the time allocation pattern among over 31 million transactions for 471 physicians from 2011 to 2014 and found that physicians spent progressively more time on “desktop medicine” and less on face-to-face patient care [13]. Another study inspected EHR event logs and showed that primary care physicians spend more than half of their workday interacting with the EHR during and after clinic hours [14].

EHR systems have been recognized as one of the contributing factors for physician burnout [15,16], an increasing health care crisis in the United States [17-20]. Burnout is on the rise and affects all specialties [21]. Studies show that burnt-out doctors are more likely to make medical errors [22], work less efficiently [23], and have higher referral rates [24]. A recent survey of nearly 6880 physicians reported that 1 in 50 planned to leave medicine altogether in the next 2 years, while 1 in 5 planned to reduce clinical hours over the next year [25]. Another study [26] reported that 26% of 1792 physician respondents reported burnout, and 70% of 1631 users reported EHR-related stress. The study also reported that high rates of fatigue among intensive care unit physicians were associated with low EHR efficiency [27].

Specialty-Specific EHRs

One recent study pointed out that different specialties had different unique requirements, and this difference should be reflected in EHR design and implementation [28]. Specialty-specific or bespoke EHR is a promising approach to overcoming the limitations of general-purpose EHR and mitigating physician burnout. A bespoke EHR is an EHR custom designed to meet the unique needs of providers in a specific specialty or care setting. Bespoke EHR can prevent clinicians from spending a significant portion of their workday sifting through large amounts of clinical data for the specific data elements they need. In another recent study [29], it was reported that a clinic-focused Sprint process can optimize EHR efficiency and have positive effects on physician burnout. Specialty-specific EHR improvement is one major intervention during the Sprint process. In general, specialty-specific EHR can better achieve the level of optimization and workflow management expected by physicians [30], although approaches based on EHR customization have limitations in what is achievable compared to a bespoke design built from the ground up. Standalone, specialty-specific EHRs have been around for a number of years in such areas such as emergency medicine, ophthalmology, and dermatology. However, broader adoption of such a specialty-specific approach faces challenges in interoperability between different EHR systems, capturing standardized structured data for documenting care, and supporting the data-readiness needs to drive a learning health system.

EpiToMe: A Bespoke EHR

We developed EpiToMe (an Epilepsy Tracking and optimization Management engine), a bespoke EHR system customized for epilepsy care created de novo. EpiToMe has evolved from and integrates clinical applications we have developed over the last decade [31-34]. EpiToMe provides patient data capture functions for electroencephalogram (EEG) reporting, daily reporting, and phase reporting for Epilepsy Monitoring Units (EMUs). It uses domain-specific epilepsy and seizure ontology (EpSO) [35] to (1) support structured entry of multimodal epilepsy data, (2) proactively ensure the quality of data through the use of ontology terms in faceted systems, (3) organize and index patient information for subsequent analytical queries and secondary use, and (4) seamlessly make just-in-time and right-in-context communications with the parent EHR. EpiToMe was developed following web interface–driven development [33], an agile software development methodology, in close collaboration with physicians. EpiToMe has a built-in physician dashboard optimized for physician needs to perform tasks without switching systems or changing navigation interfaces. EpiToMe's data entry pipeline allows other clinicians in the team such as EEG technicians and clinical fellows to take responsibility for appropriate patient data documentation work. EpiToMe also provides a tracker to provide an overview of patient status in the clinical care workflow.

Methods

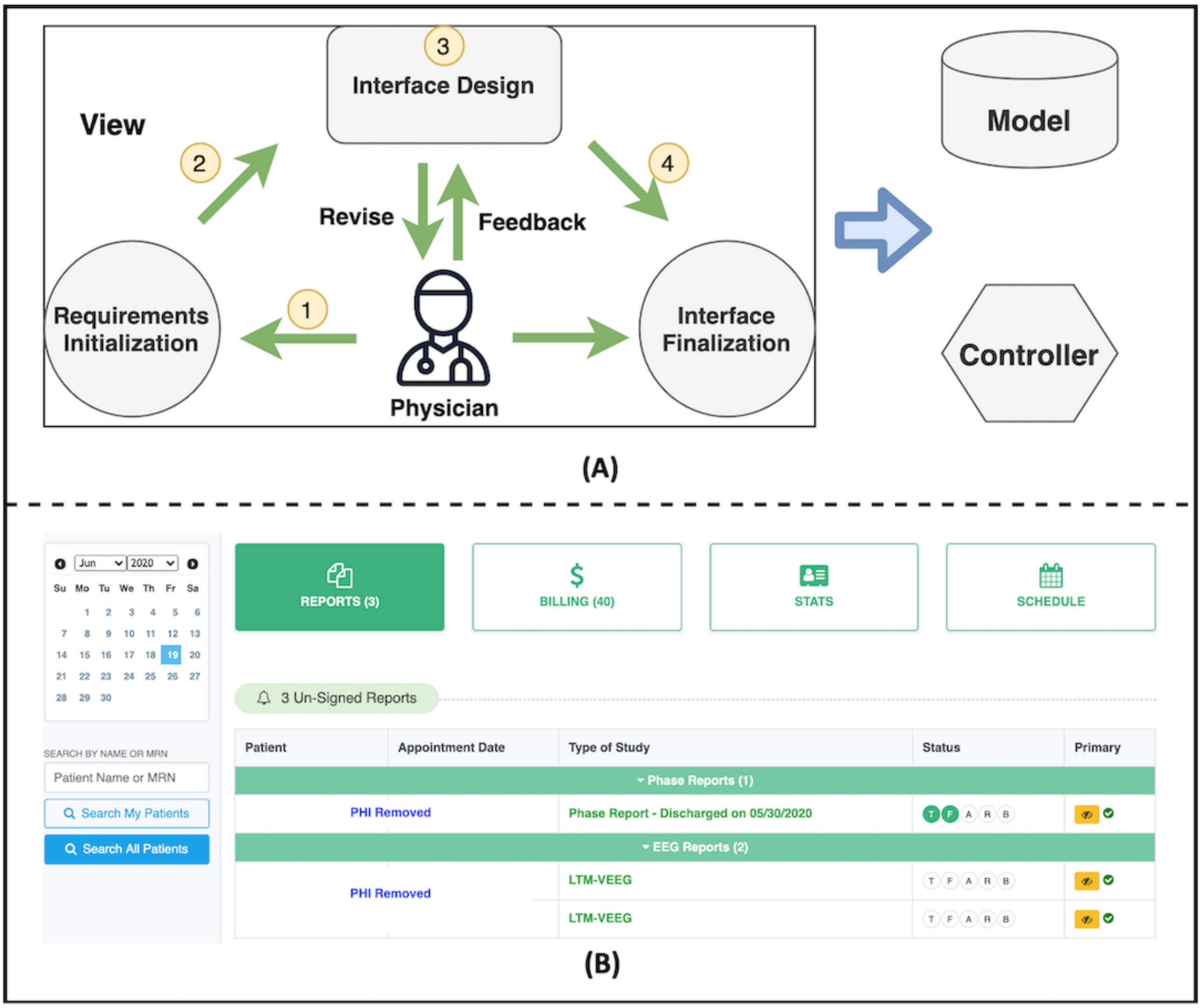
Physician-Centered Design and Interface-Driven Development

Physician interfaces play a critical role in EHR systems and are the most important factor affecting usability and clinical efficiency [12,29]. However, in the history of EHR development, physicians have rarely had a major role in deciding how an EHR interface should be built. Modern EHR systems (Allscripts, EPIC, and Cerner) offer physicians some opportunity to provide document templates, but physicians often neither have the expertise to optimize such templates nor do they have the flexibility to maintain or update these templates as needed.

In EpiToMe, we address this problem using an agile, physician-centered design and interface-driven development during all stages of the development process from inception. As depicted in Figure 1A, EpiToMe follows the classic model-view-controller architectural pattern. We use user interfaces to drive the development of data models and controllers. Our interface design process consists of 4 steps with physicians in the loop: (1) The process starts with physicians’ initial requirements; (2) then, informaticians complete the next iteration of the interface prototype incorporating such requirements; (3) physicians give feedback about the prototype and working interfaces and suggest revisions to be made in the future iterations; and (4) step 3 continues iteratively until the design is accepted and finalized by physicians and a testing or production version is deployed.

With this physician-centered design and interface-driven development method, EpiToMe ensures that the interfaces have the look, feel, and functionality desired by physicians, improving user satisfaction and optimizing clinical efficiency (eg, Figure 1B).

Figure 1. (A) Steps involved in our physician-centered design and interface-driven development process; (B) Exemplar physician dashboard resulting from our physician-centered design. LTM-VEEG: Long-term Video Electroencephalogram; PHI: Protected Health Information.

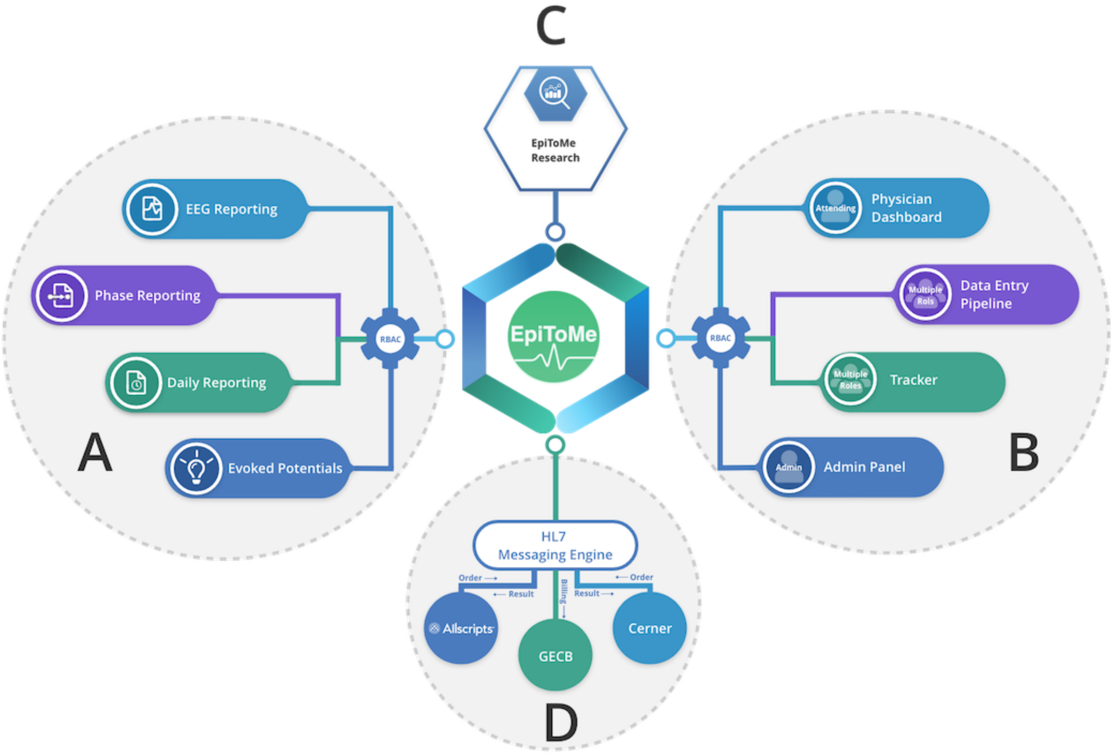


Patient	Appointment Date	Type of Study	Status	Primary
Phase Reports (1)				
PHI Removed		Phase Report - Discharged on 05/30/2020	T F A R B	✓
EEG Reports (2)				
PHI Removed		LTM-VEEG	T F A R B	✓
		LTM-VEEG	T F A R B	✓

Functional Architecture

Figure 2 shows the functional architecture design of EpiToMe, consisting of 4 major areas. Figure 2A shows the data capture interfaces for clinical reports. Currently, 4 types of clinical reports are built in EpiToMe: EEG Reporting, Phase Reporting, Daily Reporting, and Evoked Potentials. These interfaces capture essential diagnostic information for epilepsy care, which are then seamlessly pushed to the general EHR (see Figure 2D). Figure 2B shows the data dashboards. The Physician Dashboard allows a physician to track outstanding reports, file for billing, monitor statistics of activity in a given time interval, and review the service schedule. The tracker is an interactive, real-time interface displaying each patient's status in the entire epilepsy care workflow, from admission and discharge from EMU to postoperative evaluations. Figure 2C shows the clinical research query interface. This is a faceted interface for ad-hoc, on-the-fly identification and construction of epilepsy patient subgroups for research. In EpiToMe, all patient information including demographics, diagnoses, epilepsy-related clinical characteristics, and medications are indexed to make such information queriable and exportable. Figure 2D shows the interoperability through an HL7 messaging engine. HL7 is a widely used protocol for the transfer of clinical and administrative data among EHR systems [36]. EpiToMe implemented 3 primary HL7 standard message types: orders, results, and charges for epilepsy care. The EpiToMe HL7 messaging engine allows it to seamlessly communicate with the general EHR. EpiToMe receives orders from the general EHR and sends back the completed reports and billing messages.

Figure 2. EpiToMe's functional architecture with 4 major functional areas: (A) data capture interfaces for clinical reports, (B) data and analytical dashboards, (C) clinical research query interface, (D) HL7 messaging engine for communication with background electronic health record systems (Allscripts, Cerner, and EPIC). Role-based access control can be configured to manage who gets which levels of access to what information, as defined by their clinical roles. EEG: electroencephalogram.



Collaborative, Asynchronous Care Documentation

Clinical care comprises collaborative teamwork from different clinical stakeholders; patient data documentation should follow suit. We designed the EpiToMe data entry pipeline to be automatically triggered when an order is placed in the general EHR. An order message containing patient demographics and order details is sent to EpiToMe. Based on the message, EpiToMe will create a new report document for the order and notify EEG technicians that a patient report is waiting to be handled. Next, an EEG technician will perform the EEG recording on patients and document the EEG specifications in EpiToMe. EpiToMe will mark the report as “technician completed” and pass it to clinical fellows who read the EEG recordings and enter their interpretations in the report. After fellows complete their data entries, the report will appear in the physician dashboard, and the clinical attending physicians will take it over, review it, and finalize it.

Role-Based Access Control for Collaborative Data Entry

EpiToMe applies a role-based access control (RBAC) method to manage users’ access to data and interfaces. RBAC is a popular framework for implementing the security policy of an organization’s enterprise information system. In RBAC, permissions are associated with roles, and roles are assigned to users. We designed EpiToMe’s RBAC so that every user is assigned one or multiple roles, and each role defines what actions are allowed to perform within the system. To fully reflect the physician-centered interface design, RBAC needs to be implemented not only at the data access level but also at the interface level. Our RBAC method ensures that users can focus on the responsibility corresponding to individual clinical roles, thereby improving efficiency.

Ontology-Driven Data Capture

EpiToMe uses EpSO to provide a standard vocabulary and guide the data entry for all clinicians. EpSO provides more than 600 terms, which include epileptic diagnoses, epilepsy semiologies, epileptogenic zones, lateralizing signs, EEG activities, and etiologies. We designed a dedicated widget in the style of multilevel dropdowns for clinicians to enter patient data. This widget supports hierarchical “hover to expand” operation, allowing users to locate the desired terms efficiently. With the ontology-guided data entry method, users select data items instead of typing them, which prevents possible common data quality issues such as typos and inconsistencies.

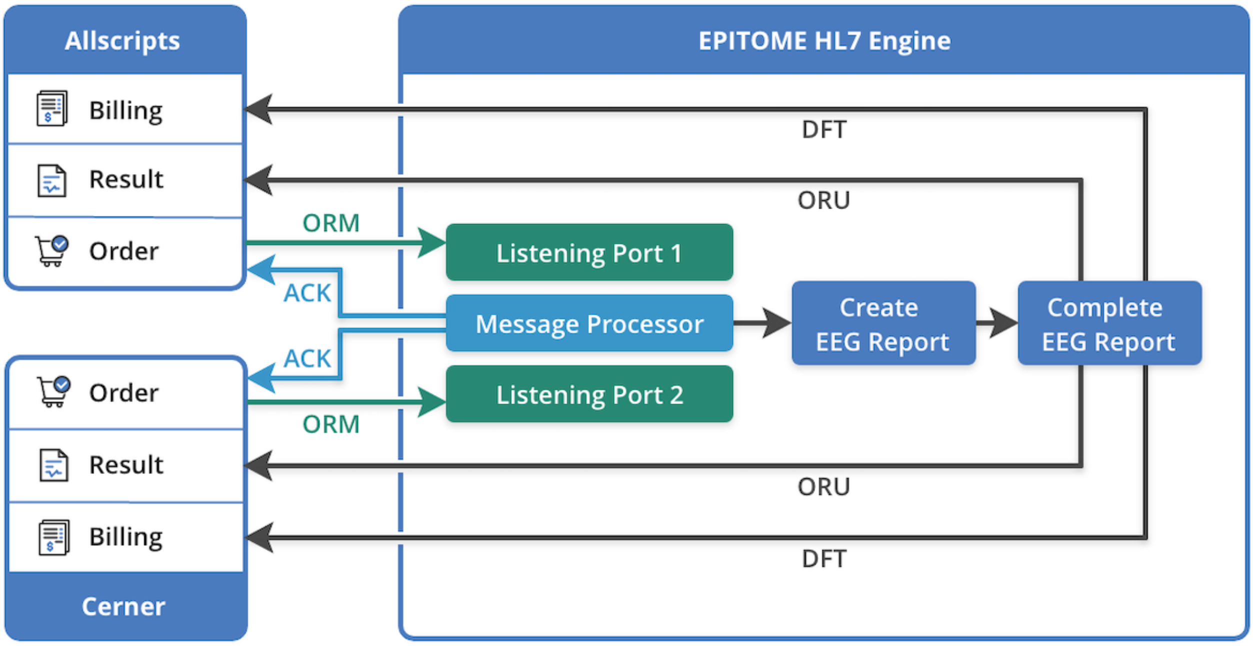
Interoperability Using HL7 Information Exchange

EpiToMe handles the epilepsy-related orders from multiple locations. Two different EHRs are used in these locations: Allscripts (EHR of University of Texas [UT] physicians) and Cerner (EHR of Memorial Hermann Health System). We designed an HL7 engine that can consume HL7 messages from multiple EHR vendors.

Figure 3 shows the architecture of the HL7 engine. HL7 messages are used to transfer electronic data between disparate health care systems. Each HL7 message sends information about a particular event such as a patient admission or a lab test order.

Three primary HL7 standard message types are handled in EpiToMe: orders (ORM), results (ORU), and charges (DFT). ORM messages contain patient demographic information and order-related data. ORU is usually in response to an order and provides clinical observations. DFT is used to send billing information. EpiToMe receives order messages from Allscripts and Cerner and creates patient reports with the embedded information in the order messages. EpiToMe confirms the order messages by sending back acknowledgement (ACK) messages. Physicians complete these reports in EpiToMe and then send them back to the original EHR system with ORU messages. After the results are accepted, physicians can continue to file billing messages using EpiToMe. Our HL7 engine design allows EpiToMe to seamlessly communicate with the parent EHR systems.

Figure 3. HL7 messaging interface between EpiToMe and the parent electronic health record systems. ACK: Acknowledgement; DFT: Detail Financial Transaction; EEG: electroencephalogram; ORM: Order Entry Message; ORU: Order Result.



Assessment Survey Design

To assess the EpiToMe’s effectiveness in improving the user experience with patient documentation and reducing physician burnout, we designed an online survey administered within EpiToMe. Physicians users of the EpiToMe system were invited to participate in the survey. The survey (Table 1) consists of 10 questions addressing the common concerns about physicians’ dissatisfaction with general EHR systems including the length of time spent on patient documentation, face-to-face interaction opportunities with patients, and catching up with care documentation in off-work time [13-16]. The specific EHR systems that are compared with EpiToMe in this survey are Allscripts and Cerner. Our design of the questionnaire was also informed by the Maslach Burnout Inventory Manual [37]. Questions 1-8 were designed to have Likert rating scales from 1 to 5, representing strongly disagree (1), disagree (2), neutral (3), agree (4), and strongly agree (5). Questions 9 and 10 are open ended to solicit input in free-text form. Specifically, question 9 asks physicians to enter which aspects of EpiToMe help with addressing physician burnout. Question 10 solicits the features physicians would like to see implemented in a future version of EpiToMe.

Table 1. The 10 survey questions and their answer options.

Question	Answer type
1. My overall workflow is less frustrating with EpiToMe compared to before.	1-5 rating scale
2. Completing patient reports with EpiToMe is easier and more intuitive than with EHR.	1-5 rating scale
3. I spend less amount of time billing using EpiToMe compared to using EHR.	1-5 rating scale
4. I spend less after-work time catching up with reports or billing using EpiToMe.	1-5 rating scale
5. EpiToMe allows me to spend more time on direct patient care.	1-5 rating scale
6. My oversight of the patient journey from the clinic to epilepsy surgery is better with EpiToMe.	1-5 rating scale
7. The dashboard in EpiToMe helps me to know my task list and complete it appropriately.	1-5 rating scale
8. For epilepsy reporting and billing, I would prefer using EpiToMe compared to EHR.	1-5 rating scale
9. In my opinion, the aspects of EpiToMe which help me address physician burnout are:	Free text
10. In my opinion, the additional features that I would like to see implemented in EpiToMe are:	Free text

Results

Physician Dashboard

Overview

With the physician-centered design, we created a physician dashboard—an integrated interface specially designed for epilepsy care providers. As shown in Figure 1B, the physician dashboard consists of 4 tabs: reports, billing, statistics, and schedule. EpiToMe directly leads physicians to this dashboard reflecting the present date status when they log in, where they can manage all the day-to-day tasks by selecting a specific day on the calendar without the need to navigate between different web pages or switch to different systems.

Reports

The default function tab is "Reports." The number of outstanding reports to be completed is displayed in the bracket following the tab title. Physicians can review and complete reports here and send the completed reports back to the parent EHR systems with one button click.

Billing

After the reports are accepted by the parent EHR, physicians can continue to work on the billing. As a bespoke EHR system, EpiToMe automatically pulls all billing-related information and displays it in a user-friendly style in the billing interface. Physicians can file billing for a report with 3 to 4 clicks. In contrast, it takes more than 24 clicks on multiple pages to complete the same task in the billing interface of the general-purpose EHR system.

Statistics

The "Statistics" tab provides an overview of reports completed, documented, and billed by physicians, including the number of reports by month and type of study.

Schedule

In the "Schedule" tab, physicians can review their service schedules for the whole year. It allows a physician to send requests to another physician to switch schedules, which was a significant challenge in the previous schedule management system. The implementation of the schedule functionality also allows EpiToMe to automatically link reports to their corresponding physicians.

Usage Summary

EpiToMe creates interfaces for 4 types of reports for epilepsy care: EEG report, EMU phase report, EMU daily report, and evoked potentials. Table 2 shows the statistics for these reports. The EEG report is the first type of reporting function for production use in EpiToMe. By September 21, 2020, clinicians had completed 15,417 EEG reports in EpiToMe since its first launch on February 18, 2019. The EMU phase report is the second reporting interface in production use since July 1, 2019. A total of 1369 EMU phase reports have been completed in EpiToMe. EpiToMe also has documented 2635 EMU daily reports since its production date of November 15, 2019. The evoked potentials reporting function is under testing. Combining these reports, EpiToMe has documented 19,421 reports for 6593 unique patients.

Table 2. EpiToMe report statistics.

Report type	Status	Status date	Number of reports (N=19,421)	Number of patients (N=6593)
EEG[a] report	Production	02/18/2019	15,417	6382
EMU[b] phase report	Production	07/01/2019	1369	1053
EMU daily report	Production	11/15/2019	2635	312
Evoked potentials	Test	N/A[c]	0	0

[a]EEG: electroencephalogram.

[b]EMU: Epilepsy Monitoring Unit.

[c]N/A: not applicable.

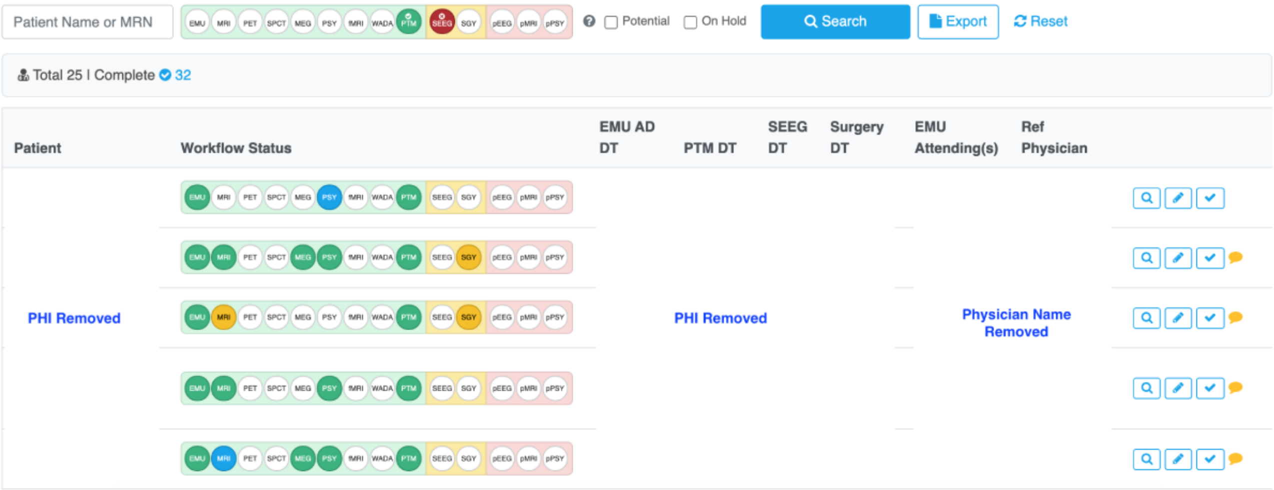
Patient Tracking Interface

Epilepsy care is a complex process that requires the collaboration of multiple clinical teams, including neurologists, radiologists, neuropsychologists, and neurosurgeons, especially for patients who are not responsive to seizure-control medications and treated as surgical candidates. It is critical to keep track of the patient status in the clinical workflow from 2 perspectives: (1) Keep different clinical teams on the same page, and (2) identify and resolve the bottleneck in the workflow. EpiToMe creates a patient tracking interface called a tracker. As displayed in Figure 4, the tracker records 14 possible steps of the patient journey in epilepsy care, which include admission to EMU, discharge from EMU, positron emission tomography scan, Ictal single-photon emission computed tomography, magnetoencephalography, neuropsychology, functional magnetic resonance imaging, Wada, patient management, stereoelectroencephalography, surgery, postoperative EEG, postoperative magnetic resonance imaging, and postoperative neuropsychology. Each circle represents a clinical step. Color codes are used to indicate the status of completion of each step: Blue indicates a test is ordered, yellow means a procedure is scheduled, and green shows that a step is complete.

The search functionality in the tracker provides a search mechanism for users to quickly find a patient or a cohort of patients. In addition to searching by name or medical record number, users can search patients by the completion status of each step and combine statuses to get results. In the search template, red status means a step has not started yet. Figure 4 shows an example of searching patients who have had patient management conferences but pending stereoelectroencephalography.

The tracker also provides comments functionality for users with the role of a nurse navigator, which is the specific user role responsible for updating the tracker in EpiToMe. The nurse navigator will enter comments once a bottleneck is identified and notify all related clinical teams to keep them alert and encourage teamwork to resolve the bottleneck.

Figure 4. Tracker of epilepsy surgery candidates. AD: admission; DT: date; EMU: Epilepsy Monitoring Unit; MRN: medical record number; PHI: protected health information; PTM: patient management; Ref: referring; SEEG: stereoelectroencephalography.



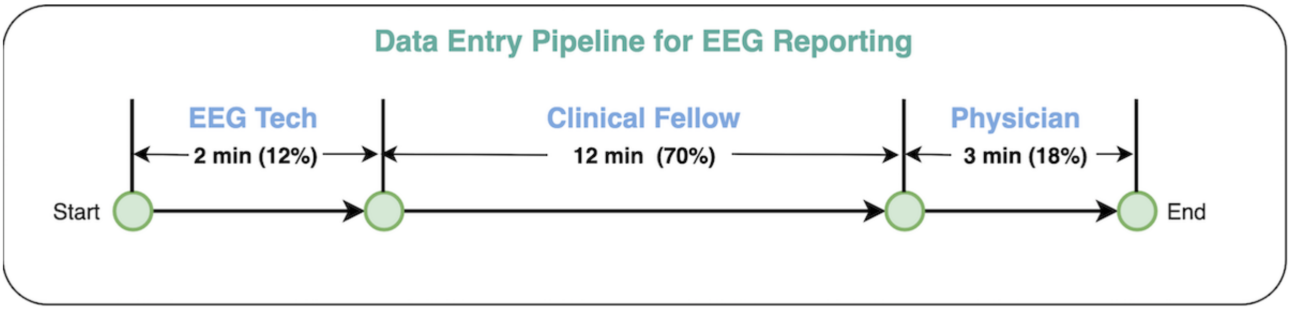
Total 25 | Complete 32

Patient	Workflow Status	EMU AD DT	PTM DT	SEEG DT	Surgery DT	EMU Attending(s)	Ref Physician
PHI Removed			PHI Removed				Physician Name Removed

Collaborative, Asynchronous, Data Entry Pipeline

With the physician-desired interface and RBAC in place, EpiToMe implements a collaborative data entry pipe to improve clinical efficiency and distribute patient documentation workload. Figure 5 shows the usage statistics of the data entry pipeline with EEG reporting. In this pipeline, the physician is not the only role that completes patient documentation. Instead, the result of inspecting the user activity logs shows that the physician's average time spent on the EEG reporting only occupies 18% of the total time of all clinical roles.

Figure 5. Collaborative data entry pipeline which reduces physician burden with patient documentation. EEG: electroencephalogram.



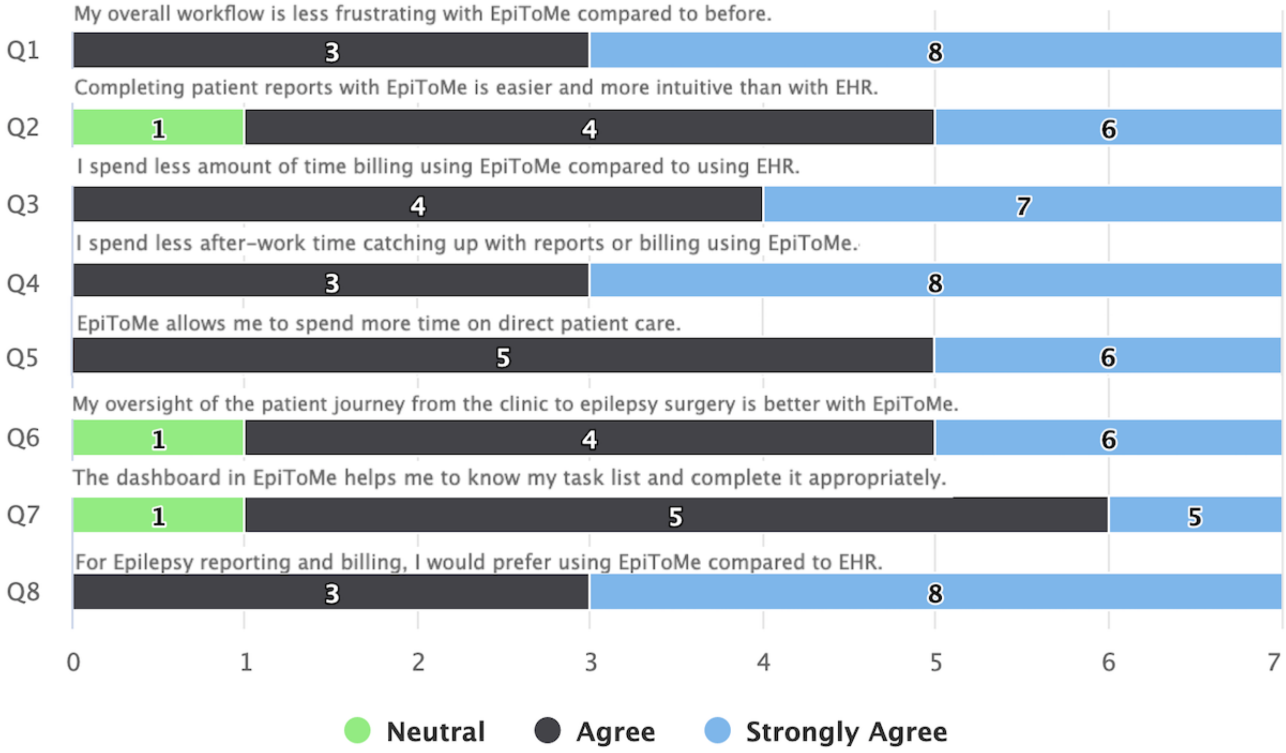
Survey Results

Of the 16 survey invitations sent to physicians, we received 11 completed responses. Answers to each of the questions 1-8 are displayed in Figure 6. In general, physicians favored EpiToMe for patient reporting and billing compared to the general EHR. All physicians agreed that the workflow with EpiToMe was less frustrating, and most (8/11, 73%) strongly agreed on this. Most physicians (10/11, 91%) thought EpiToMe made it easier to complete patient reports, and all physicians agreed that billing with EpiToMe took less time than previously using the general EHR systems. As a result, all physicians reported in question 4 that they spent less off-work time catching up with reports or billing, which is considered a significant factor for physician burnout. All physicians agreed that EpiToMe allowed them to spend more time on direct patient care, and most physicians (10/11, 91%) thought EpiToMe helped them better manage the patient journey and their task list.

For question 9, physicians described the aspects of EpiToMe that helped them address physician burnout. One respondent said: “Intuitive, fast, accurate, comprehensive interactions; everything makes sense; very little redundancy.” Another respondent pointed out “ease of reporting and billing” as well as “no need of separate data sets (eg, personal spreadsheets, email lists) to keep track of patients and testing.” Another physician endorsed the integrating role of EpiToMe as “It reduces the number of places (different EHR systems) I need to be working on simultaneously—the integration between reporting and billing reduces the amount of time spent on non-patient–care related work.” One physician also appreciated the collaborative data entry pipeline: “better time management and easier/more efficient interface with the fellows in terms of report writing and billing on time.”

In response to question 10, physicians proposed many constructive suggestions that can serve as future directions for EpiToMe. These include “more EHR interfaces,” “outpatient module,” and being more user-friendly such as “being able to have multiple sections within the report open while editing the report.”

Figure 6. Responses for survey questions 1-8. EHR: electronic health records.



Discussion

Physician Feedback

With a specialty-specific, physician-centered interface design, EpiToMe can improve overall clinical efficiency. For example, for EEG reporting, the average time delay (from the completion of EEG recording to the finalization of the EEG reporting) to complete an EEG report is 14 hours and 30 minutes for 98% of EEG reports. Patients obtain their EEG reports within the same day of visit rather than a couple of days or weeks later using the previous general-purpose EHR. Survey feedback by clinical attending physicians showed significant preference for using EpiToMe to perform reporting and billing tasks compared with general-purpose EHR systems. Within the 88 answers from 11 senior clinical attending physicians, 85 (96.6%) indicated that EpiToMe is better than the general EHR on specific tasks, with only 3 neutral answers.

Multisite Deployment

EpiToMe is a multisite system supporting interoperability with multiple types of EHR systems. Currently, EpiToMe has been deployed at 4 clinical centers including UT Physicians Clinic, Memorial Hermann Texas Medical Center, Memorial Hermann The Woodlands Medical Center, and Memorial Hermann Cypress Hospital. Within these medical centers, UT Physicians Clinic uses Allscripts as their general-purpose EHR system, while others use Cerner. We are making EpiToMe also interoperable with Epic as UT Physicians Clinic transitions from Allscripts to Epic.

Interoperability

HL7 is a widely used standard for data exchange in clinical information systems. Implementation of an HL7 messaging engine enables EpiToMe to interoperate and exchange information with general-purpose EHR systems, resulting in significantly reduced or eliminated redundant data entry. Our HL7 messaging engine also makes EpiToMe scalable: New clinical centers can be added in EpiToMe as long as their EHR platforms offer service to support HL7 communication standards.

Generalizability

EpiToMe is not a replacement for general-purpose EHR. Instead, it is complementary to existing general EHR solutions. EpiToMe relies on the availability of the parent EHR to admit and transmit patient demographic information and epilepsy-related orders, which triggers the corresponding, additional data capture process in EpiToMe. Although EpiToMe is optimized for epilepsy care, our methodology, design principle, system architecture, and interface elements are generally applicable. In fact, we are applying a similar approach in UTHealth Neurosciences service lines to derive similar benefits for other clinical specialties.

Survey Limitations

Our physician survey study is preliminary, as this is not the primary focus of the paper. Limitations of this survey include the small sample of survey participants and the lack of complete independence of survey participants and the informatics development team. Such limitations may present hidden bias in survey results, and larger-scale, anonymous surveys are the preferred approach for feedback. However, production-level deployment and long-term operation of interoperable bespoke EHRs implemented using physician-centered design and the latest information technology for clinical specialties are uncommon. Therefore, timely assessment of such bespoke EHRs, even on a smaller scale and with limitations, provides valuable and much-needed operational feedback to inform hospitals' adoption strategies. Surveys should also accommodate a strategy tailored to the tremendous effort and longer development cycle needed in designing, deploying, and operationalizing such systems in real-world clinical practice and patient care settings. After a few years of operation, a more systematic, comparative activity log analysis would provide more objective insight about where our bespoke approach made the most impact and where further enhancements may be needed.

Conclusions

Working closely with physicians, we used an interface-driven development approach to create EpiToMe de novo, to embody physician preferences and optimize clinical workflow for epilepsy care while ensuring interoperability with the parent EHR. EpiToMe offers an exemplar pathway to mitigate physician burnout and improve the quality and productivity of care by combining physician-centered design with the latest advances in information technology in a bespoke EHR system.

Acknowledgments

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Authors' Contributions

GQZ conceptualized this study. ST implemented the system with contributions from GQZ, SL, LC, and JH. SL, GQZ, ST, JH, and LC designed the survey. ST and SL administrated the survey. ST and GQZ developed and refined the manuscript with contributions from JH, LC, and SL.

Conflicts of Interest

None declared.

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Abbreviations

EEG: electroencephalogram
EHR: electronic health records
EMU: Epilepsy Monitoring Unit
EpSO: epilepsy and seizure ontology
HITECH: Health Information Technology for Economic and Clinical Health
RBAC: role-based access control
UT: University of Texas

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Original Paper

Opening a “Can of Worms” to Explore the Public's Hopes and Fears About Health Care Data Sharing: Qualitative Study

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Abstract

Background: Evidence suggests that health care data sharing may strengthen care coordination, improve quality and safety, and reduce costs. However, to achieve efficient and meaningful adoption of health care data-sharing initiatives, it is necessary to engage all stakeholders, from health care professionals to patients. Although previous work has assessed health care professionals’ perceptions of data sharing, perspectives of the general public and particularly of seldom heard groups have yet to be fully assessed.

Objective: This study aims to explore the views of the public, particularly their hopes and concerns, around health care data sharing.

Methods: An original, immersive public engagement interactive experience was developed—*The Can of Worms* installation—in which participants were prompted to reflect about data sharing through listening to individual stories around health care data sharing. A multidisciplinary team with expertise in research, public involvement, and human-centered design developed this concept. The installation took place in three separate events between November 2018 and November 2019. A combination of convenience and snowball sampling was used in this study. Participants were asked to fill self-administered feedback cards and to describe their hopes and fears about the meaningful use of data in health care. The transcripts were compiled verbatim and systematically reviewed by four independent reviewers using the thematic analysis method to identify emerging themes.

Results: Our approach exemplifies the potential of using interdisciplinary expertise in research, public involvement, and human-centered design to tell stories, collect perspectives, and spark conversations around complex topics in participatory digital medicine. A total of 352 qualitative feedback cards were collected, each reflecting participants’ *hopes* and *fears* for health care data sharing. Thematic analyses identified six themes under *hopes*: enablement of personal access and ownership, increased interoperability and collaboration, generation of evidence for better and safer care, improved timeliness and efficiency, delivery of more personalized care, and equality. The five main *fears* identified included inadequate security and exploitation, data inaccuracy, distrust, discrimination and inequality, and less patient-centered care.

Conclusions: This study sheds new light on the main hopes and fears of the public regarding health care data sharing. Importantly, our results highlight novel concerns from the public, particularly in terms of the impact on health disparities, both at international and local levels, and on delivering patient-centered care. Incorporating the knowledge generated and focusing on co-designing solutions to tackle these concerns is critical to engage the public as active contributors and to fully leverage the potential of health care data use.

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KEYWORDS

electronic health records; patient participation; data sharing; patient safety; data security

Introduction

Background

With the advent of the digital age, health care professionals have witnessed significant advancements in innovation and research. The increasing adoption of digital technologies and electronic health records (EHRs) has expanded the capacity for interoperability and data sharing, both for primary uses (ie, direct care) and secondary uses (ie, research, public health, health policy). Evidence suggests that health care data sharing may strengthen care coordination, improve quality and safety, and reduce costs [1]. However, the growing complexity of systems, stakeholders, and unbounded ecosystems, unsuccessful data sharing initiatives (eg, the care.data program in the United Kingdom), and recent cybersecurity incidents (eg, the WannaCry attack) and evolving regulations (eg, General Data Protection Regulation) [2] have contributed to the increasing lack of clarity and trust by the public [3]. Therefore, data sharing is becoming an increasingly controversial subject, with many researchers and patients reporting concerns about how and why health care data are shared [4]. Previous evidence highlights that the most common concern is patient privacy [5,6]; even when data are anonymized, there remains a risk that by using only a few data points, patients can be reidentified by their own health information [7]. Previous studies also highlight that public support is generally higher when data are used for the *greater good*, but the acceptance rates fall steeply when data are shared for use by commercial companies [8].

In recent years, several health care data sharing initiatives have been implemented globally. HealthData Research UK, as part of the Industrial Strategy Challenge Fund, has launched 7 new data hubs as part of a 4-year program to create a UK-wide system for the secure and safe use of large-scale health data [9]. In the United States, the Institute for Healthcare Improvement's Triple Aim Initiative uses geographic health data to comprehensively understand population health by location, with the aim of improving the experience of care, health of populations, and cost-effectiveness [10]. Innovative engagement programs, as opposed to traditional banners, posters, and advertisements, are especially promising for promoting an informed choice [11]. Over the past several years, social media campaigns and even live theatrical performances have been used to improve the understanding of data sharing practices [12,13]. However, to achieve efficient and meaningful adoption of health care data sharing initiatives, it is necessary to engage all stakeholders, including policy makers, health care professionals, researchers, patients, and the public. A broad understanding of their views, hopes, and concerns about data sharing is crucial to frame the breadth of perspectives, increase adoption, support progress, and enhance equity of care delivery.

Previous research has largely focused on health care provider perspectives and found that providers hope data sharing can have a positive impact by tailoring and improving care delivery [14-17]. Previous research addressing health care professionals' views identified several benefits of data sharing: improved population health, ease of access, and reduced costs [17-19]. However, talking about data sharing is like opening a metaphorical can of worms: when the subject is brought up, many concerns also emerge, including issues around patients' willingness to share, trust, privacy, transparency, confidentiality, and security [20].

If data are anonymized, many patients are comfortable with sharing for the improvement of health services and care [21], with as many as 88% of patients trusting the United Kingdom National Health Service (NHS) to store data safely and use it for ethical, research-oriented reasons [22]. Conversely, a recent survey showed that only one-tenth of people would share data willingly with a tech company [23]. Transparency seems to be a critical factor for patients' willingness to share their data, as the more transparent the organizations are with the public about the use of health care data, including, but not limited to, who has access, the rights to access, and the safeguarding processes in place, the greater the public support for data sharing initiatives [24]. However, a deeper exploration of the factors that contribute to the willingness to harness health care data from the general public perspective is still lacking.

In addition, policy and structural changes are necessary to promote a culture of safety and transparency in organizations across the continuum of care [25]. These changes must be standardized and embedded at every level of care, including primary care, secondary care, and community services at local and national levels, to ensure integrity and alignment, and should be guided by international quality standards. Understanding and integrating the public's hopes and concerns into these policy and structural changes is fundamental to ensure the development of patient-centered data sharing policies.

Objectives

This qualitative study aims to explore public views, particularly their hopes and concerns, around health care data sharing.

Methods

Overview

We developed an original, immersive public engagement interactive experience—*The Can of Worms* installation—with which we aimed to challenge the conventions of how members of the public receive and give information, using interdisciplinary expertise in research, public involvement and human-centered design, to tell stories, collect perspectives, and spark conversation around complex topics.

To meet the aims and objectives of this study, a qualitative descriptive approach was adopted. Qualitative methods were chosen because of their ability to capture descriptive data on individual perceptions, attitudes, and behaviors [26]. A multidisciplinary team including medical doctors (AN, SG, and AD), health service researchers (JG, LR, KF, and OL), designers (PB and LN), and a patient and public involvement specialist (AJ) with previous experience in qualitative research designed the *Can of Worms* concept and performed this study. Members of the public were involved in recruitment, developing the *Can of Worms* concept and reviewing materials.

Recruitment

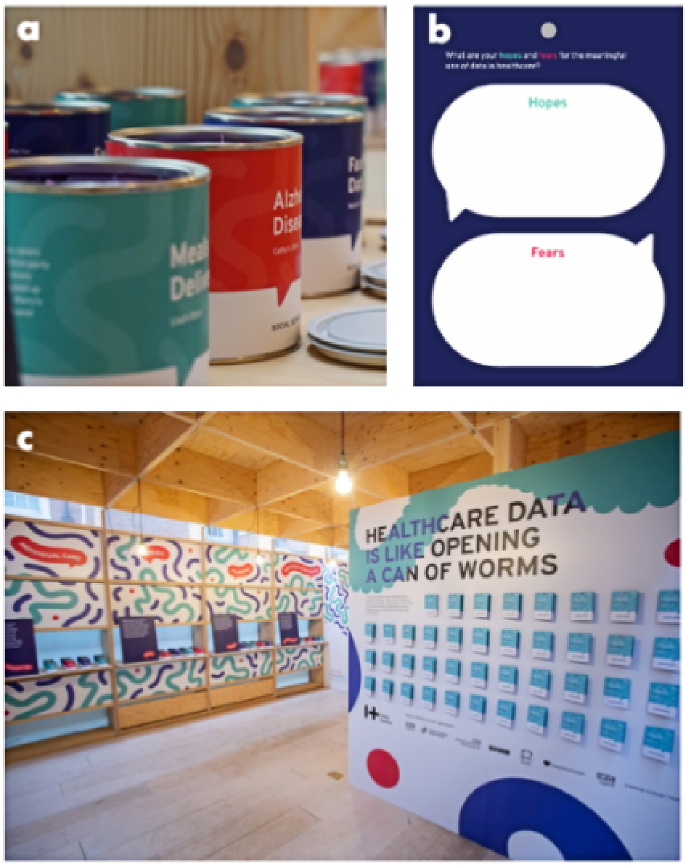
A combination of convenience and snowballing sampling was used, and no other exclusion criteria (apart from age) were adopted, to optimize the diversity of the sample. Members of the public (<18 years) were invited to participate through a combination of recruitment approaches, including public advertising through posters, distribution of flyers, partners' networks, social media, and word of mouth. The research team had no established relationships with the participants before the event. Free tea and coffee were offered to the participants; however, no financial incentives were provided for participation.

Concept Development

The *Can of Worms* metaphor was used as a novel way of bringing interest to the subject matter. The exhibition design employed a multidisciplinary team of designers, public members, and researchers to craft a user-centered experience for participants. The team prioritized flexibility, inclusivity, and engagement, principles that guided the design process.

People were invited to explore a free (no admission fee) and immersive installation (ie, in which the space was designed to impact the experience for visitors, as described below). Participants were prompted to reflect on the subject of health care data sharing through storytelling and conversation. Visitors were given a *can opener* and an information leaflet and were encouraged to open cans and listen to stories about health care data sharing, stored in a recorder within the can (Figure 1). Each of the 28 fictional stories fit under 1 of 7 categories: diagnosis, individual care, planning, policy, social services, treatment and prevention, and understanding disease. Topics included international data sharing among patients with chronic diseases, genomic analysis, and data-powered predictive algorithms. The fictional stories were developed by researchers based on anecdotal evidence of risks and benefits of data sharing to represent a balanced view. They were further reviewed by clinicians and lay partners to ensure that they were relevant, factual, and realistic, not harrowing, and in plain English. Stories were recorded by a variety of actors and public members to ensure that they were engaging and relatable. Large text-printed versions were also available for anyone with specific access needs. Examples of stories can be found in Multimedia Appendix 1 [27] and a full list of all stories used within the *Can of Worms* installations can be found at the project website [27].

Figure 1. Materials used in the *Can of Worms* events. (a) Cans containing audio stories focusing on a particular aspect of healthcare data sharing. (b) Blank response card used to collect participants' hopes and concerns towards data sharing. (c) Overview of the *Can of Worms* public engagement immersive installation.



Data Collection

Once participants finished listening to some of the recorded stories, they were asked to provide the following information on a card: age bands, hopes, and fears about the meaningful use of data in health care (Figure 1).

The first exhibition took place at the Helix Pop-up within St. Mary's Hospital in Paddington, London, in November 2018, which meant that the members of the public entering the space were mostly patients, family members, medical students, and passersby near the train station. To encourage the participation of people from seldom heard groups (eg, those from deprived backgrounds and minority ethnic groups), a free bus service was organized from White City and Woodlane to the event. The second was held over a weekend at The Great Exhibition Road Festival, South Kensington, in June 2019—*Can of Worms* was one of many exhibits at an event attracting 20,000 members of the general public, as well as students and staff. The third took place on one day at the NHS Digital Academy Residential in Tower Hill in November 2019—this event was open to participants on an academic program for digital health leaders.

Participants' responses were compiled verbatim and were not returned to the participants for comments and/or corrections. As anonymous, self-administered cards were used, only the participant was present when registering data. Participants had minimal knowledge of the research team; thus, the potential for bias and assumptions was kept to a minimum. No repeat interviews were conducted.

Data Analysis

The transcripts were compiled verbatim and systematically reviewed by four independent reviewers using the thematic analysis method to identify emerging themes. The themes were supported by participants' quotations. The Consolidated Criteria for Reporting Qualitative Research were used to ensure that the study met the recommended standards for qualitative data reporting [28].

Ethics

The project was reviewed by the Health Research Authority (HRA) Public Involvement Team HRA. Additional HRA approval by the NHS Research Ethics Committee review was not deemed necessary [29].

Results

Participant Characteristics

A total of 352 participants filled the response card (iteration 1 [Helix Centre]: n=175; iteration 2 [Exhibition Road Festival]: n=142; iteration 3 [NHS Digital Academy]: n=35). In iteration 1, the most frequent age band was 25 to 34 years (51/175, 29.1%). In iteration 2, the most frequent age band was below 18 years (55/142, 38.7%), and in iteration 3, the most frequent age band was 45 to 54 years (27/35, 77%).

The themes presented are listed in no particular order, and in line with the qualitative approach, no one theme is presented as more important than the other.

Hopes

The level of content and detail varied greatly between cards. Thematic analysis of the patients’ narratives revealed six emerging overall hopes: (1) enablement of personal access and ownership, (2) increased interoperability and collaboration, (3) generation of evidence for better and safer care, (4) improved timeliness and efficiency, (5) delivery of more personalized care, and (6) equality (Textbox 1).

Textbox 1. Hopes regarding health care data sharing.

Theme 1: personal access and ownership

- “Patients will hold their data and will share what they want with who they want” (ID 155)
- “Data will be there for every patient when they need it and it will follow them” (ID 144)
- “Having your medical data available on your mobile/smart watch could save many lives in an emergency in the future” (ID 65)

Theme 2: interoperability and collaboration

- “That we treat all data collected across the NHS as one, rich resource. At the moment, there are hundreds of data controls in the NHS and sharing is difficult” (ID 160)
- “For seamless, secure sharing of data between patients, GPs, A&E… so that patients can get the best care possible” (ID 37)
- “As a doctor, I find it difficult to provide the best care for my patients without full access to their past medical history, previous imaging and tests, and up to date medication lists. Data sharing between trusts and GPs” (ID 20)
- “The data can be shared to ensure that there is access to information, especially out of normal hours, so that clinicians can always make informed decisions” (ID 149)
- “That all my healthcare data is available to any medical professional I see! To save me time and inaccuracy” (ID 184)
- “Data sharing means I don’t have to tell my story again and again” (ID 185)
- “A more open and collaborative approach to healthcare across the globe” (ID 183)

Theme 3: evidence for better and safer care

- “Understandings that will help the whole healthcare sector from big data analysis” (ID 13)
- “Analysing huge amounts of data could help to find out what causes different diseases (...)” (ID 33)
- “I hope keeping and sharing patients’ data will lead to more efficient and accurate diagnoses avoiding human error and be able to draw on a bigger database that slips the human mind” (ID 186)
- “Data can be enhanced to improve outcomes for patients [via] better and quicker diagnosis” (ID 187)
- “Provides an evidence base for identifying effective treatments” (ID 143)
- “Analysing huge amounts of data could help to (...) see and predict how epidemic illnesses are spreading” (ID 33)
- “Less likely for mistakes to happen” (ID 55)
- “Investment and development of technology to achieve parity with industry with human factors and evidence-based design and implementation” (ID 152)

Theme 4: timeliness and efficiency

- “That data gets where it needs to at the time it needs to. Patient care is supported and improved by timely access to the right information” (ID 165)
- “(...) an ecosystem that provides pace and a streamlined service – think how much quicker we could help people” (ID 182)
- “Diseases can be detected early on” (ID 73)
- “Broad sharing and easy access of data to help in a quicker understanding of a healthcare issue and [potential cure]” (ID 4)
- “It creates a clear picture of who I am – so I can be helped better and minimize waste in the health service” (ID 180)

Theme 5: personalized care

- “That it will bring a smarter, more cohesive, personalized care” (ID 179)
- “Reduction in anxiety to have to tell your story [repeatedly]” (ID 157)
- “Improving preventive behavior through personalized interventions” (ID 148)

Theme 6: equality

- ”That greater ownership by patients of their data will encourage conversations of equality between them and their healthcare providers” (ID 181)
- “The patient data can be used and shared more effectively, for example, [in the care of] transgender patients, the proper pronouns can be used” (ID 9)
- “Data is a very powerful way to tackle inequalities and improve the level of care” (ID 87)

Personal Access and Ownership

Participants hoped that health care data sharing will enable patients access to their own medical records, improving their sense of ownership and involvement in their health and care. Participants also highlighted that improved accessibility of health care data by the patient could prove pivotal in improving safety in medical emergency situations.

Interoperability and Collaboration

The opportunity for enhanced interdisciplinary engagement across the health care field was another hope identified in this study. Participants from each iteration hoped for a more united health care system, ease of collaborative care, and fortified capacity for health care providers to make informed decisions anywhere at any time. Participants hoped for the treatment of data collected as a rich resource instead of the current, fragmented state, which compromises quality and safety of care.

Evidence for Better and Safer Care

Participants also highlighted that data sharing in health care can contribute to providing better and safer care. A significant number of participants from all iterations hoped that data sharing could pave the way for analytical and data mining approaches to improve clinical knowledge in several aspects, including understanding etiology and improving diagnosis and effectiveness of treatment. Some participants also acknowledged that health care data sharing can help understand and monitor the epidemiological nature of certain diseases.

Timeliness and Efficiency

Participants expressed how they hoped that health care might become more efficient as a result of data sharing, as data may be accessed anytime, anywhere. Some saw this from the angle that waste could be minimized and more patients helped if data were shared more widely.

Personalized Care

Another theme emerging from the responses was the hope that health care data sharing would lead to more personalized care. Participants highlighted that it could reduce the anxiety produced by having to tell their story repeatedly due to a lack of integrated health records. Data sharing could also result in a more cohesive health record that could allow care to be tailored to individual needs.

Equality

Participants expressed their hope that data sharing would allow patients to be treated equally, regardless of their backgrounds, predispositions, access to public care, or financial means for private care.

Fears

Regarding the main fears, the thematic analysis of the public's narratives revealed five emerging themes: (1) inadequate security and exploitation, (2) data inaccuracy, (3) distrust, (4) discrimination and inequality, and (5) less patient-centered care (Textbox 2).

Textbox 2. Fears regarding health care data sharing.

Theme 1: inadequate security and exploitation

- "Issues around privacy of data" (ID 194)
- "This data being used by companies to discriminate and make [profit]" (ID 37)
- "That conclusions are made without proper examination of the data [and] that the data is used for nefarious purposes" (ID 143)
- "That private companies could use this data purely for targeting the public health service, thereby driving up the costs" (ID 163)

Theme 2: data inaccuracy

- "Incorrect data" (ID 161)
- "Errors that could corrupt the data" (ID 158)

Theme 3: distrust

- "Horror stories delay inevitable progress" (ID 153)
- "That just one rotten egg will set us back years and we miss out on all the progress that could be made" (ID 196)

Theme 4: discrimination and inequity

- "Could widen inequalities for countries that can't afford these technologies" (ID 189)
- "Introduces bias and fails to support a patient-centered approach in a mental health and community setting" (ID 147)
- "Bias gets perpetuated" (ID 150)
- "That if my serious and ongoing medical conditions get out that it would limit or otherwise negatively impact my career pathway and job options" (ID 178)

Theme 5: less patient-centered care

- "The 'person' is being lost and replaced with numbers" (ID 195)
- ”We become too reliant on data and forget about the individual patient" (ID 169)
- "We no longer have conversations with healthcare professionals... many may be replaced by exchange of statistics" (ID 30)
- "Artificial intelligence is seen as a quick and cheap fix and patients get substandard care" (ID 159)

Inadequate Security and Exploitation

Participants conveyed their concerns that health care data sharing could be associated with a lack of privacy and security and would therefore be potentially used for nefarious purposes. Specifically, individuals feared the potential for private companies (ie, pharmaceutical companies) to leverage the data for profit at the expense of the public.

Data Inaccuracy

Data accuracy was also a concern, with some participants expressing worries about incorrect data in their records or computing mistakes that may corrupt their data. Participants expressed worry about the accuracy of communication between clinicians and were concerned that the overreliance on data might further compromise communication.

Distrust

Participants expressed a wide variety of perspectives that shared an overall feeling of distrust and apprehension about the potential for sustained and adequate adoption. Some were wary of the impact of previous negative experiences and how they may impact future initiatives of health care data sharing.

Discrimination and Inequity

Participants expressed concerns that increased health care data sharing would only be possible in better-connected regions, and this could widen the gap between these regions and those that do not have the resources to implement such technologies. On an individual level, participants writing from a patient's perspective were concerned that, if shared widely, certain details of their personal data may introduce or perpetuate biases.

Less Patient-Centered Care

Some participants were concerned about a negative impact on the delivery of care that is respectful of, and responsive to, individual patient needs, preferences, and values. Fears were expressed around health care, becoming too focused on data, with a negative impact on the patient-doctor relationship, communication, and quality of care received. Some were concerned that a strong focus on data and artificial intelligence could have a negative impact on patient centeredness.

Discussion

Principal Findings

The six main *hopes* that participants had for health care data sharing concerned (1) enablement of personal access and ownership, (2) increased interoperability and collaboration, (3) generation of evidence for better and safer care, (4) improved timeliness and efficiency, (5) delivery of more personalized care, and (6) equality. The five main *fears* that participants expressed in relation to health care data sharing were (1) inadequate security and exploitation, (2) data inaccuracy, (3) distrust, (4) discrimination and inequality, and (5) less patient-centered care.

Findings as Compared With Previous Studies

In this study, participants highlighted personal access and ownership over their health records as a key *hope* for data sharing. This sentiment has been expressed in previous studies; a public engagement exercise by the Wellcome Trust (2010) found that 92% of adults and 97% of young people surveyed supported patient access to their own health records [30]. Furthermore, a recent meta-analysis has shown that providing patients with access to their own records can improve several aspects of quality of care, particularly improving health outcomes and patient safety [31]. The growing body of evidence supporting policies that support data sharing with patients also raises important questions about equity and whether these interventions may exacerbate health inequities by improving outcomes for patients with access to their health care data, while further excluding those with low health literacy or poor access to digital technologies [32,33].

Interoperability and collaboration also emerged as key hopes for data sharing in this study and were described from various perspectives as allowing clinicians to make more informed decisions and avoiding the need for patients to repeatedly narrate their clinical information. Interoperability between systems and care settings is recognized as a key aspiration to achieve the full potential of data sharing [34], and it is necessary to engage stakeholders involved (patients, health care professionals, policy makers, and technical companies). Several aspects need to be considered, including the adoption of international standards [35], improved education and awareness of obstacles, and minimizing privacy and cybersecurity issues [34].

The hope that data sharing would provide evidence for better and safer care is in line with the findings of previous studies. A study by O'Brien et al [36] found that 94% of patients surveyed "thought data sharing would help their doctor to make better decisions about their health". In the last decade, the United Kingdom has witnessed a surge in the secondary use of health care data that has generated population-based evidence to inform the delivery of better care, particularly in the mental health space [37] and prescription patterns [38]. Similarly, in the United States, pilot studies have started predicting readmissions and estimating the risk of complications in newborns [37].

Improved timeliness and efficiency were also identified as key hopes in this study, whether it was for patient benefit (ie, early diagnosis and treatment, improvement in diagnosis) or for improved health care efficiency (ie, allowing care to be delivered faster and to more people). Our findings are in line with previous studies surveying patient perspectives, in which helping make new therapies available faster was one of the 2 most important perceived benefits of data sharing [36].

Importantly, participants hoped that data sharing might contribute to making health care more inclusive and increase transparency around demographic information, particularly gender preference, where the use of proper pronouns is of utmost importance to an individual's identity. Previous research suggests that allowing patients to self-label their gender in their EHRs and specifying their preferred names and pronouns could improve their health care experience [39].

The most common *fear* noted by participants was inadequate security and the exploitation of health data. Following the WannaCry attack of 2017, public confidence in the NHS to handle data has been negatively affected [40]. A web-based patient survey in the United Kingdom found that the most important data sharing risk identified by participants was health data being *stolen by hackers* and that in general they would be more comfortable if they were able to learn how their data were protected [36]. These findings mirror the hopes of health care professionals who acknowledged some of these concerns in previous research [41]. Closely linked with fears regarding inadequate security and exploitation of patient data is the idea that distrust can delay progress and hinder the realization of benefits from data sharing. In line with these findings, previous studies showed that the public opposed data sharing when there were financial gains or profits or the possibility of sharing their health care data with private or commercial companies [42].

Errors that resulted in data inaccuracies were feared by the study participants. Previous studies have also found that the public is concerned that errors in records may be difficult to correct and have a negative impact on their care [40]. Previous research highlights that when using data as evidence for better care, it is important that data quality is prioritized, as only with high quality, clean data to feed artificial intelligence algorithms can meaningful insights be extracted [43].

Fears that increased data sharing would give rise to discrimination and inequity of patients were voiced from different contexts. Our participants were concerned that health disparities would widen between more developed countries and those that could not afford these technologies. Others were concerned that some patients may be unfairly prioritized over others, a point of view that is shared with other studies [40]. In one study, those with a lower socioeconomic status expressed more concerns about data sharing and were less likely to consider the benefits that it offers to society [44]. Discrimination, stigmatization, exploitation, or other repercussions are concerns that have been voiced by participants in similar investigations [42].

Some participants expressed that the increased use of computers and artificial intelligence would diminish patient-centered care. The human touch aspect of being treated by a person rather than a computer was valued by members of the public, and there was concern that this would be attenuated significantly. Although digital solutions can improve patients' safety and efficiency of care, they are not able to replace humanistic skills (ie, compassion, commitment, or empathy) [45].

Strengths, Limitations, and Future Work

This study has several strengths. We used multiple iterations of data collection, coupled with the triangulation of interpretations between researchers with expertise in qualitative research, clinical research, and cognitive science. Data collection was performed in several settings to capture the perspectives, hopes, and concerns of a diverse study sample. This is crucial to inform an equitable approach to increase data sharing in the future.

This study employed a methodologically rigorous approach, leveraging qualitative methods to capture rich, descriptive data on individual perceptions, attitudes, and behaviors [46,47]. In addition, all data collection and analysis were performed according to the Consolidated Criteria for Reporting Qualitative Studies criteria [48].

On a broader scale, the *Can of Worms* installation is replicable and adaptable for different settings and contexts and can be implemented with relative ease for future installments, both for data collection purposes and to enhance awareness and behavioral change in diverse audiences on this subject.

Despite its strengths, this study has some limitations. The sample size (N=352) was small and was sourced from three locations in England. For this reason, and the fact that data sharing sentiments differ between countries, our results may not be representative of the wider UK population or extrapolated to international settings. The attempt to keep the length of the survey short and encourage those who do not normally engage to participate limited the amount of information collected on participant demographics. As contact information was not collected, it was not possible to send the themes back to the participants for feedback. Future research may benefit from involving patients more actively as part of this process, either by allowing them to provide feedback on the findings, or by providing training so that they can actively contribute to the thematic analyses.

However, the minimal request for participant disclosure of information could serve both as a limitation and a strength of this study, as it could also have increased participation rates and reduced information bias. Finally, the quasi-experimental nature of the study, in an attempt to elicit attitudes, may impact the generalizability of the resulting views, as participants were primed on the stories in the cans. The feedback cards were displayed on a feedback wall in the installation. Some people chose to read these before they wrote their feedback, which could have biased their results but, equally, may have prompted them to have a deeper reflection, including other participants' perspectives.

Future work should include methodologically robust quantitative studies focusing on how different factors (demographic and social, patient activation, health, and digital literacy) influence both the general public and professional views on data sharing. Future research should also explore the underlying reasons for the public sentiments expressed by collecting additional insights from a range of study participants. Therefore, this study can serve as a first step to unveil areas for future research, from which more actionable conclusions can be drawn. In addition, future work might benefit from international projects assessing data sharing perspectives, as this may help anticipate possible challenges and solutions before future translational implementation of data sharing mechanisms. Finally, future research may consider assessing social media responses to the installations in addition to qualitative responses based on prompts to highlight similarities and contrasting perspectives based on the feedback mechanism.

Conclusions

In the broader context of sharing health care data, involving the public is critical to create a patient-centric culture in health care systems [49]. This study sheds new light on the main hopes and fears of a sample of the UK public regarding health care data sharing. Importantly, our results highlight novel concerns from the public, particularly regarding the impact of health disparities on delivering patient-centered care. Incorporating the knowledge generated and focusing on co-designing solutions to tackle these concerns are critical to engage the public as active contributors to this decision-making process and to fully leverage the potential of health care data use.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Two examples of stories used in the Can of Worms events. The stories were read by amateur actors, volunteer patient advocates, and researchers. A more detailed overview of the stories is provided in the project website.
[PDF File (Adobe PDF File), 48 KB-Multimedia Appendix 1]

Multimedia Appendix 2

COREQ checklist.
[PDF File (Adobe PDF File), 491 KB-Multimedia Appendix 2]

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Abbreviations

EHR: electronic health record
HRA: Health Research Authority
NHS: National Health Service

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Viewpoint

Precision Assessment of COVID-19 Phenotypes Using Large-Scale Clinic Visit Audio Recordings: Harnessing the Power of Patient Voice

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Abstract

COVID-19 cases are exponentially increasing worldwide; however, its clinical phenotype remains unclear. Natural language processing (NLP) and machine learning approaches may yield key methods to rapidly identify individuals at a high risk of COVID-19 and to understand key symptoms upon clinical manifestation and presentation. Data on such symptoms may not be accurately synthesized into patient records owing to the pressing need to treat patients in overburdened health care settings. In this scenario, clinicians may focus on documenting widely reported symptoms that indicate a confirmed diagnosis of COVID-19, albeit at the expense of infrequently reported symptoms. While NLP solutions can play a key role in generating clinical phenotypes of COVID-19, they are limited by the resulting limitations in data from electronic health records (EHRs). A comprehensive record of clinic visits is required—audio recordings may be the answer. A recording of clinic visits represents a more comprehensive record of patient-reported symptoms. If done at scale, a combination of data from the EHR and recordings of clinic visits can be used to power NLP and machine learning models, thus rapidly generating a clinical phenotype of COVID-19. We propose the generation of a pipeline extending from audio or video recordings of clinic visits to establish a model that factors in clinical symptoms and predict COVID-19 incidence. With vast amounts of available data, we believe that a prediction model can be rapidly developed to promote the accurate screening of individuals at a high risk of COVID-19 and to identify patient characteristics that predict a greater risk of a more severe infection. If clinical encounters are recorded and our NLP model is adequately refined, benchtop virologic findings would be better informed. While clinic visit recordings are not the panacea for this pandemic, they are a low-cost option with many potential benefits, which have recently begun to be explored.

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KEYWORDS

communication; coronavirus; COVID-19; Machine Learning; natural language processing; patient-physician communication; patient records; recording

Challenges in Identifying COVID-19 Clinical Phenotypes

COVID-19 cases are exponentially increasing worldwide; however, clinical COVID-19 phenotypes remain unclear. A clinical phenotype is an observable characteristic (ie, symptom) of a disease in a particular individual. A meta-analysis of COVID-19–related symptom presentations reported that the most frequent clinical symptoms are fever, cough, fatigue, and dyspnea [1]. However, the meta-analysis reported considerable heterogeneity (I^2=84.9%-96.4%) among studies, potentially suggestive of the extreme heterogeneity among these symptoms at the individual patient level. Other less frequent COVID-19 symptoms include anosmia, dysgeusia, headache, sore throat, rhinorrhea, diarrhea, nausea, and myalgias [2]. However, their clinical implication, prevalence, and importance remain unclear.

A traditional reductionist approach to identifying COVID-19 treatments is not as simple as extrapolating the current knowledge toward our limited SARS-CoV-2 model. Clinical treatments are often based on a set of established biochemical markers, and reports of less frequent symptoms of a disease may reveal a biochemical pathway that can be subjected to pharmacotherapeutic intervention with previously unreported agents. Only laboratory tests can confirm a diagnosis of COVID-19, but such tests are in short supply. This presents an unprecedented need to develop better assessment methods to identify and generate heterogeneity in the clinical profile of COVID-19 and other viral diseases across the entire health care system. The urgency of this need cannot be understated, as it holds a key to understand how to identify and treat COVID-19 more accurately.

Using “Big Data” to Understand the Clinical Manifestations of COVID-19

Natural language processing (NLP) and machine learning may yield a method to rapidly identify individuals at a high risk for COVID-19 and to understand key symptoms upon clinical manifestation and presentation [3]. The existing applications of NLP and machine learning in medical diagnostics are based on a combination of structured (eg, symptom codes, medications, laboratory findings, etc) and unstructured (eg, visit notes, radiology reports, etc) data recorded by clinicians in patients’ electronic health records (EHRs). Using NLP and machine learning approaches, data on documented signs and symptoms in the EHR are already being used to identify clinical conditions (computational phenotyping) [4]. Such NLP-based efforts are currently being applied to unstructured text data captured in the EHR from telehealth consultations to develop better screening tools for COVID-19 [5]. Ancillary data can improve the accuracy of computational phenotyping, such as information from disease registries. However, the performance of any model is determined by the quality of data used to generate it, and concerns exist about the fullness of data captured in the EHR.

Limitations of EHR Data

This considerable degree of symptom heterogeneity reported among patients with COVID-19 can deter the accurate documentation of less frequently reported symptoms in the EHR. Documentation inaccuracies in electronic medical records are not a new phenomenon; an analysis of data from 105 clinics indicated that 90% of clinician notes had at least one error, including 636 documentation errors that accounted for 181 charted findings that did not take place and 455 findings that were not charted [6]. Data on such symptoms may not be accurately synthesized into patient records owing to the pressing need to treat patients in overburdened health care settings. In this scenario, clinicians may focus on documenting widely reported symptoms that suggest a diagnosis of COVID-19 albeit at the expense of infrequently reported symptoms because overburdened clinicians are more likely to be affected by cognitive biases such as anchoring and confirmation biases [7]. Additionally, codes of the International Classification of Diseases (10th revision), the mainstay of documentation in electronic medical records, do not adequately capture COVID-19–related symptoms [8]. While NLP solutions can play a key role in generating clinical phenotypes of COVID-19, they are limited by the resulting limitations in EHR data. A comprehensive record of the clinic visits is required—an audio recording may be the solution [9].

Clinical Phenotypes Based on Audio Recordings of Clinic Visits

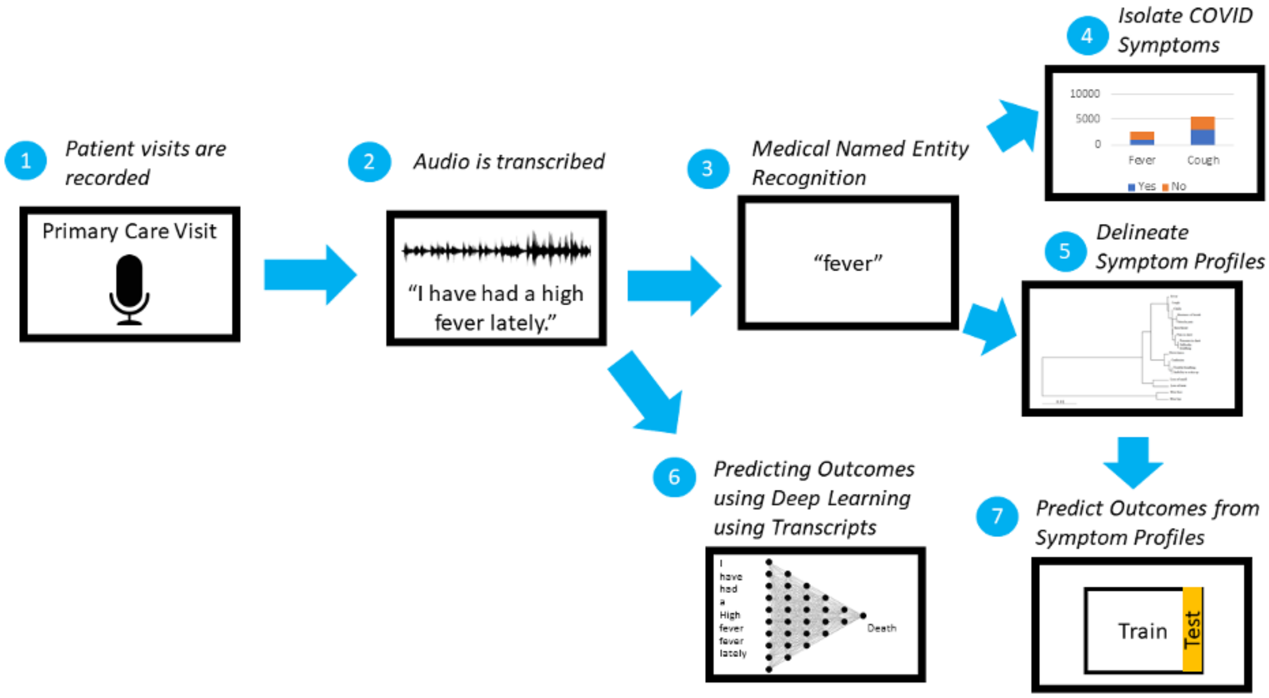
A small but growing number of health systems routinely obtain audio recordings, and, in some cases, video recordings of clinic visits [9,10]. For example, human scribes are commonly employed to review recordings of clinic visits and make detailed notes, thus reducing the documentation burden on clinicians and improving the accuracy of data entered in the EHR. A recording of the clinic visit represents a more comprehensive and accurate record of patient-reported symptoms. If performed at scale, a combination of data from the EHR and recordings of clinic visits can be used to power NLP and machine learning models, thus rapidly generating a clinical phenotype of COVID-19 and infections with subsequent SARS-CoV-2 strains. In addition to a more comprehensive record of symptoms discussed, recordings also asynchronously collect additional ancillary information such as the type and frequency of cough, which can help improve the precision of phenotyping.

The generation of NLP and machine learning models requires the transcription of vast quantities of conversations of patients being investigated for COVID-19 upon clinic visits (with subsequent confirmatory laboratory tests for the disease) and the annotation of these transcripts by annotators trained to identify symptom mentions. The performance of automated speech recognition algorithms has significantly improved [10], allowing for the real-time use of audio data rather than transcripts of audio data, which are more time-consuming to obtain. Real-time risk assessment is critical when responding to an infectious disease such as COVID-19, since it allows for individuals to identify their risk level and more rapidly self-isolate, thus reducing the risk of disease transmission. Data annotation to generate models that can accurately identify symptoms is not without its challenges, many of which have been summarized by Quiroz et al [11]. It can be difficult for annotators to identify vaguely indicated symptoms from the unstructured natural language used in clinic visit conversations, with a negative impact on model performance. Rigorous training of annotators can help mitigate this challenge; however, such training and annotation is time-consuming and would require a large team of annotators to rapidly meet the immediate need for such an analysis. In addition, model training requires human input and time. Furthermore, the generation of optimal data would require continuous data refinement, wherein records of suspected cases are replaced by the findings of confirmatory tests so as not to correspond to clinician views or biases.

Implications of the Adoption of Clinic Visit Recordings in Managing COVID-19

We propose the generation of a pipeline from the audio recordings of clinic visits to models based on clinical symptoms and the prediction of COVID-19 incidence (Figure 1). With vast amounts of available data, we believe a prediction model can be rapidly developed to promote accurate screening of individuals at risk of COVID-19. Beyond the challenge of generating a clinical phenotype, an unfiltered account of a patient's clinical experience of the disease allows us to answer other pressing questions, such as those related to understanding the constellation of patient characteristics that may predict a greater risk of a more severe infection. If clinical consultations are recorded and our NLP model is adequately refined, benchtop virologic findings are better informed. Recordings of clinic visits also provide a historic reference, such that we may be better prepared for subsequent pandemics.

Figure 1. Natural language processing pipeline from audio recordings to the establishment of a clinical phenotype of COVID-19.



With the mass transition to telehealth consultations and the availability of guidance for conducting remote assessments of COVID-19 via telehealth at primary care centers [12], an opportunity to capture audio recordings of consultations at scale is now available. An accurate model predicting a higher risk of COVID-19 could be applied to telehealth consultations with the added benefit of reducing the exposure risk among clinicians, patients, and the general public. The use of NLP for remote COVID-19 screening is already emerging; for example, audio recordings of cough sounds are being used to identify individuals with COVID-19 [13,14].

Data From Beyond the Clinic

While recordings of clinic visits are not the panacea for this pandemic, they are a low-cost alternative with many potential benefits that have recently begun to be explored. Beyond audio recordings, video recordings of telehealth consultations can provide additional diagnostic information such as skin appearance [12]. At-home voice-based technologies such as Amazon Alexa, Apple's Siri, and Google Home can also be used, allowing further information from outside of clinic visits to supplement predictive models [15]. For example, the Mayo Clinic has recently added a skill to Amazon Alexa called "Answers on COVID-19," which provides resources on COVID-19 and a virtual questionnaire to determine a person's symptoms and whether the person should get tested for COVID-19 [16].

Considering current accelerated efforts to manage COVID-19, care must be taken to rigorously protect sensitive data, with existing challenges in accessing the corpus of patient recordings needed to generate these models [11]. A data collection method should only be used entirely with an opt-in voluntary framework to preserve privacy and confidentiality; however, this method can help obtain data on COVID-19 symptom exacerbation at a scale unattainable with all traditional methods. This, as is often the case, points toward an evolving learning health system capable of managing computable knowledge.

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Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
NLP: natural language processing

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Viewpoint

A Novel Patient Values Tab for the Electronic Health Record: A User-Centered Design Approach

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Abstract

Background: The COVID-19 pandemic has shined a harsh light on a critical deficiency in our health care system: our inability to access important information about patients' values, goals, and preferences in the electronic health record (EHR). At Memorial Sloan Kettering Cancer Center (MSK), we have integrated and systematized health-related values discussions led by oncology nurses for newly diagnosed cancer patients as part of routine comprehensive cancer care. Such conversations include not only the patient's wishes for care at the end of life but also more holistic personal values, including sources of strength, concerns, hopes, and their definition of an acceptable quality of life. In addition, health care providers use a structured template to document their discussions of patient goals of care.

Objective: To provide ready access to key information about the patient as a person with individual values, goals, and preferences, we undertook the creation of the Patient Values Tab in our center's EHR to display this information in a single, central location. Here, we describe the interprofessional, interdisciplinary, iterative process and user-centered design methodology that we applied to build this novel functionality as well as our initial implementation experience and plans for evaluation.

Methods: We first convened a working group of experts from multiple departments, including medical oncology, health informatics, information systems, nursing informatics, nursing education, and supportive care, and a user experience designer. We conducted in-depth, semistructured, audiorecorded interviews of over 100 key stakeholders. The working group sought consensus on the tab's main content, homing in on high-priority areas identified by the stakeholders. The core content was mapped to various EHR data sources. We established a set of high-level design principles to guide our process. Our user experience designer then created wireframes of the tab design. The designer conducted usability testing with physicians, nurses, and other health professionals. Data validation testing was conducted.

Results: We have already deployed the Patient Values Tab to a pilot sample of users in the MSK Gastrointestinal Medical Oncology Service, including physicians, advanced practice providers, nurses, and administrative staff. We have early evidence of the positive impact of this EHR innovation. Audit logs show increasing use. Many of the initial user comments have been enthusiastically positive, while others have provided constructive suggestions for additional tab refinements with respect to format and content.

Conclusions: It is our challenge and obligation to enrich the EHR with information about the patient as a person. Realization of this capability is a pressing public health need requiring the collaboration of technological experts with a broad range of clinical leaders, users, patients, and families to achieve solutions that are both principled and practical. Our new Patient Values Tab represents a step forward in this important direction.

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KEYWORDS

electronic health record; health informatics; supportive care; palliative care; oncology

Introduction

Background

Besides inadequate personal protective equipment and limited intensive care surge capacity, the COVID-19 pandemic has shined a harsh light on another critical deficiency in our system of health care delivery: our inability to access important information about patients' values, goals, and preferences in the electronic health record (EHR) [1-3]. All over the United States, frontline clinicians in the field, emergency departments, intensive care units (ICUs), and on rapid response teams and hospital floors have struggled with urgent decisions about the use of life-supporting technologies to treat serious complications of COVID-19 infection without sufficient information about the patient as a person, what means most to this individual, how the patient defines living well, and whom the patient trusts to make important decisions about health care [4,5]. Such information is rarely accessible even for older adults and others with underlying diseases, such as cancer or chronic comorbid conditions, who are most vulnerable. Either this information was not previously elicited or, although it was discussed, it was not documented or is difficult to find in the EHR [6-9].

This is not a new problem, and it will certainly persist after COVID-19 in the absence of major innovative efforts. Although many clinicians consider the EHR to pose a barrier to patient-centered care by literally shifting the attention from the patient to the computer screen [10-12], the EHR is also a potentially powerful tool that can support clinician-patient communication, team collaboration, personalized and respectful care, continuity across settings, patient engagement, and shared decision making in accordance with patients' individual needs and priorities [13,14]. Several recent initiatives have utilized digital platforms and tools (eg, documentation templates, automated prompts, and electronic order sets) to optimize documentation of advance care planning and goals of care discussions [15-17]. Some have focused primarily on the documentation of advance care planning in patients who are older or have advanced disease [18,19]. A more recent initiative leverages the Epic EHR by assembling information about serious illness conversations, including prognostic information given by clinicians to the patient and family, the patient's understanding of the course of the illness, hopes and worries, priorities, and clinician recommendations, into a new EHR template [20].

At Memorial Sloan Kettering Cancer Center (MSK), we integrated and systematized health-related values discussions led by oncology nurses for newly diagnosed cancer patients as part of routine comprehensive cancer care, regardless of the patient's stage, prognosis, or treatment intent [21,22]. These discussions are revisited quarterly or as deemed appropriate after prespecified clinical events (eg, progression of disease through first-line therapy, hospitalization, or admission to the ICU). In this model, communication encompasses not only the patient's wishes for care at the end of life but also more basic and holistic personal values, including sources of strength, concerns, hopes, definition of an acceptable quality of life, and what the patient wants the clinical team to know about them as a person in order to provide the best care and preserve dignity [22]. In addition, oncologists and other physicians and advanced practice providers use a structured template to document their discussions of patient goals of care, which may address the expected course of the patient's illness, intent of the current treatment, goals identified by the patient, preferences for end-of-life care, and, if relevant, hospice enrollment.

The Patient Values Tab: Concept and Design

To provide ready access to these crucial communications between clinicians and patients as well as key information about the patient as a person with individual values, goals, and preferences, we undertook the creation of the Patient Values Tab in our center's EHR to display this information in a single centralized location. Our institution's EHR platform is Allscripts Sunrise Clinical Manager (Allscripts Healthcare LLC), which organizes data displays into tabs, as do many other EHR platforms. Here, we describe the interprofessional, interdisciplinary, iterative process and user-centered design methodology we applied to build this novel functionality [23].

Methods

Working Group and Stakeholder Interviews

We first convened a working group of experts from multiple departments, including medical oncology, health informatics, information systems, nursing informatics, nursing education, and supportive care (a multidisciplinary palliative care service), and a user experience designer. Members of the working group were selected for their previous experience leading large-scale institutional initiatives and unique expertise in the integration of supportive care and oncology. This core team met every 2 weeks to collaborate on the development and design of the new tab.

To understand the needs and perspectives of a broad range of institutional stakeholders, we also conducted in-depth, semistructured, audiorecorded interviews of over 100 key stakeholders based on a written guide prepared by the core team. Analysis of these interviews, which is reported in a separate publication (which includes selected stakeholder comments in an appendix), was used to inform content and format of the tab [24]. As active contributors to the creative process, those who were interviewed were more inclined to buy in to the ultimate product. In addition, many of these stakeholders held leadership positions within divisions and departments and went on to share enthusiasm about the upcoming tab with their colleagues, enhancing the visibility of the ongoing development effort among a broader group of users.

Mapping Tab Content

The core team sought consensus on the Patient Values Tab's main content, homing in on high-priority areas identified in the stakeholder interviews while also incorporating their input on format and considering suggestions on the logistics of the implementation process. The core content was mapped to various data sources within the EHR (as shown in Multimedia Appendix 1).

For example, oncology nurses use a structured document entitled "Assessment, Patient Personal Values" to summarize their values discussions. The patient's preferred name, language, and communication preferences are elicited through the digital patient portal system via an electronic care questionnaire, which the nurse verifies and updates as needed at the first clinic visit on the nursing health assessment. Education about health care proxy (HCP) and other advance directives is provided in the hospital by patient representatives, who also record designation of and information about the HCP in a specific clinical document.

High-Level Design Principles

As the data sources were clarified, we also established a set of high-level design principles (shown in Textbox 1) to guide this process.

Textbox 1. High-level design principles.

1. The Patient Values Tab should provide users with an at-a-glance understanding of the patient as a person.
2. The Patient Values Tab should offer easy access to data that can be viewed in aggregate in the context of other relevant information to support clinical decision making.
3. The Patient Values Tab will specify the context in which the information was collected (with the source and date the information was updated).
4. The Patient Values Tab will be in a read-only format (ie, the data displayed will be captured and edited elsewhere).
5. The Patient Values Tab will contain the most high-yield information while presenting this information in a succinct, streamlined way to minimize cognitive load for users.
6. The Patient Values Tab will be accessible to all health care team members across the spectrum of patient care.

One such principle was that the tab would be in a read-only display format, populated with existing source documents in the EHR that could not be directly edited in the tab itself. We chose this approach because we and various key stakeholders we interviewed were concerned that the content would become unwieldy and unstable, ultimately leading to inefficiency for users if multiple modifications were allowed. We concluded that reliance on existing workflows and processes would reduce the cognitive load for clinicians and enable a communal responsibility for the underlying documentation, with important roles for various team members as contributors to a shared understanding of the patient as a person.

User Testing

The next step was close collaboration with our user experience designer to create and refine wireframes of the tab design. During this process, the designer conducted usability testing with physicians, nurses, and other health professionals. All participants were asked to provide general usability feedback on the design. To obtain more detailed feedback, participants were presented with specific clinical tasks calling for the use of information contained in the Patient Values Tab in scenarios that the core team generated and adapted for particular roles and responsibilities. For example, in one scenario, the physician was preparing to "discuss serious results with the patient," while the nurse needed to "provide information for medication management." This process revealed a lack of familiarity among users with some of the underlying documentation that sourced the data displayed in the tab. To address this issue, we created a frequently asked questions tile (ie, section) in the tab including basic information about data sources and directing users to the appropriate underlying document to update the information, if needed.

Refinement and Validation

Additional design refinements incorporated (1) suggestions from the user experience designer (eg, creating a banner at the top of the tab with the preferred name information, color coding the different categories of information to help users recognize and navigate among them quickly, including a separate feedback tile within the tab inviting users' input and comments about their experience using the tab); (2) input from the core team (eg, placing the goals of care discussions and the nurse values summary in the most central, prominent positions in the tab; extracting and separately displaying the essential information regarding emergency contact, HCP, and next of kin for rapid access during clinical emergencies, with relevant advance directive scanned forms located below this information); and (3) insights gleaned from the stakeholder interviews (eg, providing expedited access to consultant notes from supportive care, psychiatry, and ethics as the highest yield and most consistently complete sources of information about patient values and personhood). During this iterative process, the designer shared mock-up options and elicited feedback from the core team via email and throughout the series of biweekly core team meetings.

Members of our core team with informatics expertise conducted data validation testing to ensure the fidelity of the information displayed in the tab to the underlying source of this information (ie, confirming that the tab displayed the correct information from the intended source document in the intended format for the correct patient). In addition, to detect delays in displaying information to the user that might decrease usability, we assessed the time to launch the tab content for selected patients. If time delays were identified, we worked with the information systems team to identify the source of the delay so that it could be rectified; specifically, technical optimizations were made to bring the load times in line with other feature load times in our EHR (ie, no longer than a few seconds).

Results

Initial Deployment and Implementation

We have already deployed the Patient Values Tab to a pilot sample of users in the Gastrointestinal (GI) Medical Oncology Service at our center, including the physicians, advanced practice providers (APPs), nurses, and administrative staff. We chose this service for this first phase of our pilot deployment because it is the largest solid tumor service at MSK, with approximately 40 physicians varying in age, gender, race and ethnicity, number of years in clinical practice, and disease focus who care for a large number of cancer patients with diverse demographics (eg, age, gender) and types and stages of cancer with wide variability in the pace of the disease process and overall clinical course. Patients of the GI Medical Oncology Service represent the largest proportion of admissions to our Memorial Hospital, thus frequently involving both outpatient and inpatient teams in their care.

We have executed a detailed implementation plan, which includes (1) discussion with the physician, APP, and nursing leaders of the service about the tab and its integration in clinical care by that service; (2) email notification to users about the availability and basic content of the new tab; and (3) presentations encompassing key features and functionality of the tab together with options for incorporating its use in regular clinical workflows. For each of these steps, we have targeted the professional groups individually, since they have different needs, roles, and workflows in providing patient care, although ultimately, they must all collaborate and communicate as a team to optimize this care.

Further Iteration and Evaluation

Learnings from this pilot will inform further refinement of the Patient Values Tab before broader implementation. We are measuring usage of the tab through audit logs, which specify the time, user, and patient involved each time it is launched. In addition, we have included a feedback tile within the tab itself that asks in closed-ended items for users' broad impressions ("It's great," "It's okay," or "It needs improvement") and provides space for free-text comments. In-depth feedback will be gathered from selected clinicians through brief individual interviews. We plan to select these clinicians based on audit log data indicating those who are low adopters or high adopters in terms of the frequency and timing of their tab use. Through the interviews, we will explore whether the tab fits with the clinician's workflow and patterns of use (or lack of use) in clinical practice, the perceived value of the tab to the clinician, and suggestions for improvement (eg, with respect to content and format).

Guided by this diverse user input, we have continued cycles of refinement and deployment to additional groups incrementally, with a plan for institution-wide rollout by the fall of 2020. The core team is continuing its biweekly meetings, monitoring every step in the implementation and evaluation process, and collaborating to address and incorporate user feedback in order to ensure that the use of the tab is maximized and sustained.

Early Findings

We already have early evidence of the positive impact of this EHR innovation. Audit logs show increasing use among different user groups. Among users who have engaged with the feedback section within the tab, 25 of 48 (52%) users reported that "it is great" compared with 18 of 48 (38%) users who reported that "it needs improvement" and provided specific constructive suggestions and 5 of 48 (10%) users who reported that "it is okay." Many of these initial user comments have been enthusiastically positive (Textbox 2).

Textbox 2. Illustrative quotes.

"[I] love the easy access to [health care proxy] and Advance directives!"

"Being able to quickly check the patient's preferred name is incredibly helpful!"

"I like that it captures information from many different areas and placed in one area. I will be using this tab."

"Numerous tiles you have developed give the patient a 'voice' in our [electronic health record]. Strong work….This will be a great advance in Cognitive Support for our clinical teams."

Users also suggested specific enhancements to the tab's content quality and design.

Our early pilot data have also revealed potential barriers to large-scale implementation, which include perceived lack of time to engage with the tab, competing priorities, incomplete or inaccurate tab content, technical glitches, and difficulty remembering to launch the tab as part of routine workflow. To address these challenges, we have enacted several proactive educational strategies when deploying to additional user groups, including (1) emphasizing that the tab is a display-only feature that is intended to save time by consolidating key information in a central location, (2) describing the processes by which incomplete or inaccurate tab content can be updated by the user, and (3) highlighting the "share feedback" section as a means for providing feedback on technical (or content-related) glitches that can be addressed by the Patient Values Tab interdisciplinary working group. In all circumstances, the Patient Values Tab working group follows up with each individual user who provides feedback to ensure closed-loop communication and enhance transparency in the ongoing effort to refine and optimize the tab's functionality.

We are also increasingly receiving reports of specific patient situations in which the information displayed in the tab, including the outpatient oncology nurse's values summary, allowed the hospital team to support families in difficult decisions about the use of intensive care therapies. In one such case, the family described hearing the ICU physician reading the values summary aloud as feeling that the patient, who no longer was conscious and had not discussed this type of situation with them previously, “was in the room, speaking directly to them,” clarifying his priorities, providing guidance, and relieving them of burden and guilt in deciding to limit life support at that time. Immediate access that the Patient Values Tab provides to primary physicians’ goals of care discussions greatly facilitates the work of our emergency department and rapid response team clinicians, who must act quickly in emergencies.

Similarly, we are hearing that the communication preferences section within the Patient Values Tab is particularly helpful to teams as they are preparing for family meetings and goals of care discussions. For example, one Patient Values Tab user recounted:

> *I did use it actually this week.…We were going to go have an impromptu family meeting and the attending physician asked, “Would the patient want to be involved?” and I said, “Well, let’s look at the Patient Values Tab”….We clicked there and it said “patient wants a lot of information with her partner present”…so…we used it in real time.*

In this case, knowing how the patient preferred to receive medical information (ie, in detail) and with whom present (ie, her partner) helped guide the health care team’s approach to having a goals of care conversation at a timely moment.

Discussion

Even at this pilot stage of deployment, it is becoming clear that the Patient Values Tab enables care and decision making that honors the personhood and values of our patients. During the COVID-19 pandemic, as life-threatening emergencies have occurred without warning to patients who were then too ill to speak for themselves, we have learned—again, in a more painful but perhaps more enduring lesson—that high-quality care is heavily dependent on immediate access to this crucial information. As implementation and usage of the tab expands and our center moves beyond the current COVID-19 crisis, we will be able to examine its impact on a variety of outcomes at the level of the patient, clinician, work process, and health care system. Although the Patient Values Tab was built in MSK’s specific EHR (ie, Allscripts), this software can be configured in other EHR platforms as well, including Epic (the predominant platform in the United States). Further research is needed on the best ways to optimize and enhance the patient centeredness of various EHR systems through the synergistic integration of tools that capture broader, holistic patient values (eg, the Patient Values Tab), with ongoing efforts that are primarily focused on advance care planning (eg, Epic’s Advance Care Planning tab).

All EHRs contain extensive quantitative information and voluminous data about patients that are mostly impersonal. Now, it is our challenge and obligation to enrich the EHR with information about the patient as a person, which is rarely included or readily accessible. Patient-centered care is highly prioritized by the Institute of Medicine [25], patients and families, and professional caregivers [26], but it can only be delivered if the patient’s personal values are as prominent as the laboratory values in the EHR on which health care professionals rely and spend the bulk of their time. Although it can be burdensome and distracting for clinical care, the EHR has tremendous untapped potential to support patient-centered care. Realization of this capability is a pressing public health need requiring the full collaboration of technological experts with a broad range of clinical leaders, users, patients, and families to achieve solutions that are both principled and practical. Our new Patient Values Tab is a step forward in this important direction.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Table S1. Mapping the Patient Values Tab content to source documentation.
[DOCX File , 20 KB-Multimedia Appendix 1]

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Abbreviations

APP: advanced practice providers
EHR: electronic health record
GI: gastrointestinal
HCP: health care proxy
ICU: intensive care unit
MSK: Memorial Sloan Kettering Cancer Center

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Original Paper

Infection Control Behavior at Home During the COVID-19 Pandemic: Observational Study of a Web-Based Behavioral Intervention (Germ Defence)

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Abstract

Background: To control the COVID-19 pandemic, people should adopt protective behaviors at home (self-isolation, social distancing, putting shopping and packages aside, wearing face coverings, cleaning and disinfecting, and handwashing). There is currently limited support to help individuals conduct these behaviors.

Objective: This study aims to report current household infection control behaviors in the United Kingdom and examine how they might be improved.

Methods: This was a pragmatic cross-sectional observational study of anonymous participant data from Germ Defence between May 6-24, 2020. Germ Defence is an open-access fully automated website providing behavioral advice for infection control within households. A total of 28,285 users sought advice from four website pathways based on household status (advice to protect themselves generally, to protect others if the user was showing symptoms, to protect themselves if household members were showing symptoms, and to protect a household member who is at high risk). Users reported current infection control behaviors within the home and intentions to change these behaviors.

Results: Current behaviors varied across all infection control measures but were between *sometimes* (face covering: mean 1.61, SD 1.19; social distancing: mean 2.40, SD 1.22; isolating: mean 2.78, SD 1.29; putting packages and shopping aside: mean 2.75, SD 1.55) and *quite often* (cleaning and disinfecting: mean 3.17, SD 1.18), except for handwashing (*very often*: mean 4.00, SD 1.03). Behaviors were similar regardless of the website pathway used. After using Germ Defence, users recorded intentions to improve infection control behavior across all website pathways and for all behaviors (overall average infection control score mean difference 0.30, 95% CI 0.29-0.31).

Conclusions: Self-reported infection control behaviors other than handwashing are lower than is optimal for infection prevention, although handwashing is much higher. Advice using behavior change techniques in Germ Defence led to intentions to improve these behaviors. Promoting Germ Defence within national and local public health and primary care guidance could reduce COVID-19 transmission.

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KEYWORDS

COVID-19; novel coronavirus; behavior change; digital medicine; infection control; infectious disease; protection; digital health

Introduction

The impacts of COVID-19 must primarily be tackled through changes in behavior undertaken by individuals and societies until a vaccine becomes available. In many countries (including the United Kingdom), people with COVID-19 infection are instructed to remain at home, together with cohabiting family or other household members, to prevent transmission between households. This increases the risk of within-household virus transmission. For example, in several environments where interhousehold movement is well controlled (eg, Taiwan, Ningbo, and Shenzen [1-3]), the virus continues to proliferate within close contacts.

To interrupt these transmission pathways, individuals must adopt *personal protective behaviors* [4]. Such targeted behaviors include handwashing, disinfection of surfaces, thorough cleaning and waste disposal, social distancing within the home (where possible), and wearing situationally appropriate personal protective equipment. A recent cohort study in Beijing, China demonstrated that performing these behaviors could dramatically reduce the likelihood of household transmission, but the highest risk of transmission was prior to symptom onset (typically before such behaviors are performed) [5]. Therefore, protective behaviors should be implemented before any household members develop symptoms. There is substantial individual variation in these behaviors, which are complex, environmentally and culturally dependent, and influenced by individual attitudes and beliefs [6]. Changing such complex behaviors effectively and rapidly within the context of COVID-19 requires an approach based on behavior change theory, evidence, and extensive participatory input [7].

Specific guidance for the public on protective behaviors has been developed in many countries and is widely recommended by politicians, the media, and public health and primary care networks [8]. However, few behavioral interventions have been used to support the public in these behaviors within their homes. A systematic review by our group has found evidence of only one digital intervention to date (Germ Defence [9,10]) that demonstrably improved health outcomes in respiratory tract infections within households. Germ Defence is a mobile-friendly website that provides targeted, tailored advice about how and why users should use infection control behaviors, aiming to supplement public health guidance with evidence- and theory-based behavior change techniques [11], optimized using extensive user feedback. In a large randomized controlled trial of 20,066 people (the PRIMIT [Primary Care Randomised Trial of an Internet Intervention to Modify Influenza-Like Illness and Respiratory Infection Transmission] trial) during the previous H1N1 (swine flu) pandemic [12], those randomized to use Germ Defence had reduced frequency and severity of respiratory tract infections, and reduced transmission to household members. Germ Defence is a freely available resource, and the intellectual property is held by the University of Southampton.

Germ Defence was rapidly adapted for the COVID-19 pandemic by a team of medical, public health and behavior change experts, and public contributors. It was then disseminated through multiple pathways (primarily but not exclusively in the United Kingdom), including public health and primary care networks (eg, by texting the website link to patients via general practitioner practices), national and local press, television coverage, and social media.

In this study, we aim to:

1. Examine current infection control behaviors in UK households
2. Compare current infection control behaviors with intentions to change behavior after using Germ Defence to control infection transmission

Methods

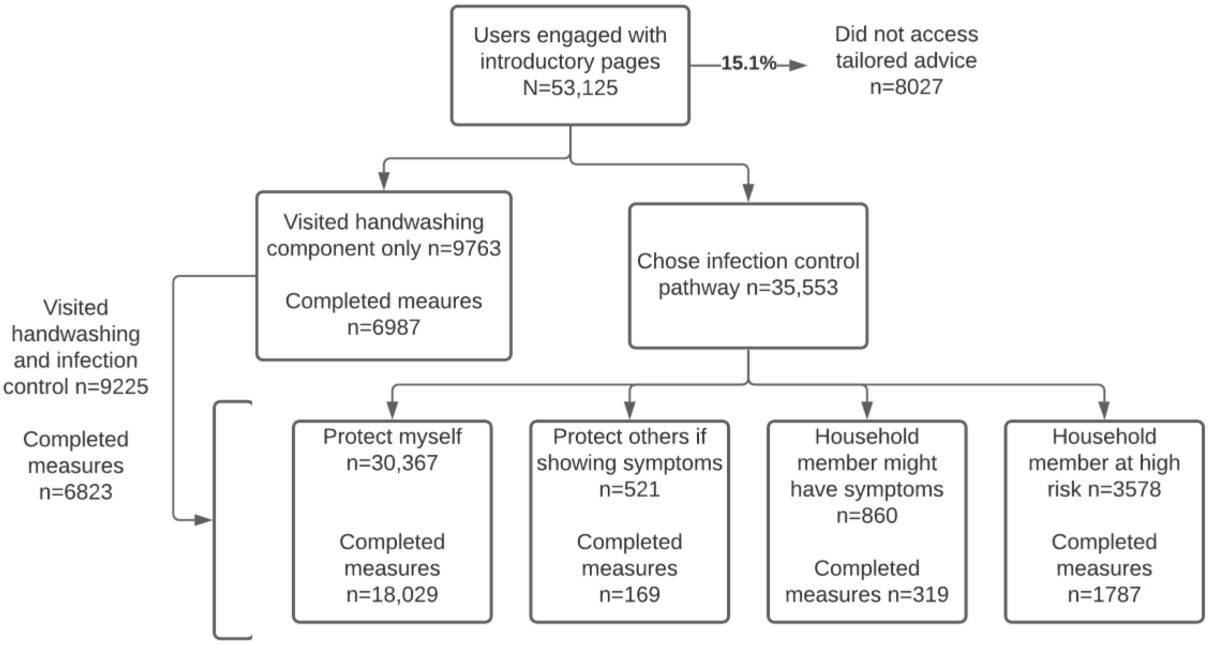
Design

This was a cross-sectional observational study of anonymous participant data from an active behavioral intervention. Consent was assumed from website use and acknowledged in the website privacy policy. All data was collected in line with General Data Protection Regulation EU Law. The study received ethical approval from the University of Bath (PREC reference 20-088). All time stamped data files used in analysis (and analysis scripts) are available at [13].

Participants and Data

The data analyzed were collected from users of the Germ Defence website between May 6 and May 24, 2020. Usage was driven by media coverage, and users were encouraged to share the intervention on social media and by email. During this period, 70,566 website hits were recorded, with 53,125 users completing the introductory content (first 3 pages) and 28,285 people completing the core module, which included measures of current and intended behavior. Website use and engagement data was collected using Google Analytics embedded in the site (see Figure 1 for full CONSORT [Consolidated Standards of Reporting Trials] use diagram).

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) diagram of Germ Defence website use and group categorization.



Data collection was kept to a minimum to reduce dropout. Behavioral measures were recorded through self-report questions within the website for current and intended behavior (see Table 1).

Table 1. Online self-report measures recorded during Germ Defence intervention

Behavior	Self-report item[a]
Reducing illness infection control	
Social distancing	When you were/are with them, how often were you/do you plan to be more than 2 meters/6 feet away from the people you live with?
Cleaning/disinfecting	How often did you/do you plan to clean things that might have viruses on them?
Putting shopping/packages aside	How often did you/do you plan to put something aside for at least 1 day that might have viruses on it?
Self-isolating	How often did you/do you plan to spend time in a room on your own?
Wearing face coverings	How often did you/do you plan to wear a face covering and glasses (and safely remove and clean them) when you are in the same room as other people?
Handwashing behavior	
Before snacking	How often did you/do you plan to wash your hands before you ate/eat with your fingers (eg, snack, fruit, or sweets)?
After coming home	How often did you/do you plan to wash your hands when you came/come into a house (eg, after work, shopping, travelling)?
After coughing	How often did you/do you plan to wash your hands after blowing your nose or sneezing/coughing on your hands?
After coming into contact with possible carrier	How often did you/do you plan to wash your hands after you had been/being close to someone who may have a virus (within 6 feet)?
After touching something	How often did you/do you plan to wash your hands after touching something that lots of other people have touched (eg, doors, money, or handrails)?
Website helpfulness (recorded on a scale of 1-10)	
Helpfulness score	How strongly do you agree or disagree that Germ Defence was helpful to you?

[a] Measures were all scored on a Likert scale with answers of 1 (almost never), 2 (sometimes), 3 (quite often), 4 (very often), and 5 (almost always). Users could also answer *not applicable* (eg, if they lived alone and therefore did not need to socially isolate within their household).

Intervention

Germ Defence content was developed using theoretical modeling and qualitative research [14] in line with the person-based approach [15], drawing principally on the theory of planned behavior [16], Leventhal's common sense model of illness [17], and protection motivation theory [18]. The intervention content, design, and structure were optimized iteratively using in-depth qualitative think-aloud interviews with public contributors (authors JB and CR) and members of the public to ensure the intervention was accessible, credible, and motivating for as many people as possible [15].

Based on process evaluations of the original randomized controlled trial [12] and a previous public dissemination [19], Germ Defence has been updated and streamlined for use during the COVID-19 outbreak, including broadening the infection control behaviors that were recommended. The intervention is a single session designed to be easily accessible with no sign-up or password required. Full details of the intervention structure and development are reported elsewhere [3,16,18,19] and archived copies are available at [20] (see Germ Defence v3). Intervention content was "frozen" during the reported data collection period. A structured outline of content is available in Textbox 1.

Textbox 1. A detailed outline of Germ Defence content and structure (note: the website and all associated content can be accessed for free).

Introductory content (3 pages)

- Introductory pages seek to increase users' perceived risk by emphasizing the personal and social health consequences of contracting COVID-19. These are followed by messages to increase skills and confidence to reduce exposure to the virus.

Website pathway selection (2 pages)

- To allow users to choose the advice they consider most personally relevant, the intervention is structured so that users initially select between two components of interest: handwashing and reducing Illness. The reducing illness component is tailored such that a user selects one of four streams of content (each lasting 11 pages) that is relevant to the user's situation: (1) to protect themselves generally, (2) to protect others if the user was showing symptoms, (3) to protect themselves if household member(s) showed symptoms, or (4) to protect a household member who is at high risk. The advice is tailored in this way to encourage users to adopt behaviors appropriate to the perceived level and pattern of risk in their household. For example, users in the protect themselves generally group would vary from very low to very high risk. It was not possible to provide specific tailored advice for every household combination of risks and resources (eg, based on the need and potential for household members to self-isolate within the home); therefore, Germ Defence aimed to educate users to adopt behaviors that were appropriate and feasible for their own circumstances.

Tailored infection control behavior advice (7 pages)

- Clear and detailed advice is then provided for self-isolating, social distancing, disinfecting/cleaning, wearing face coverings, and putting items aside that may have viruses on them such as shopping/packages. Advice is provided to the extent that users feel is appropriate for the perceived risk. These pages also contain ideas and information on how to structure the home and engage in behaviors safely. The handwashing component provides advice focused on handwashing that is relevant to all groups over 5 pages.

Goal-setting advice (3 pages)

- Both the handwashing and reducing illness components contain goal-setting sections where users indicate their behavior over the past week, view a motivational message, and then plan their behavior for the future. Users who do not select any improvement are encouraged to review their plan. After completing either the handwashing or reducing illness components, users are asked how helpful they found the website.

Additional information

- Users are then able to revisit the first two components, choose from two additional components with more detailed information about the same behaviors (eg, how to social distance with young children, how to stop touching your face), or view details about the website.

Statistical Analysis

We included data from all users who accessed the website during the study period.

For analysis, users were grouped according to the tailored website pathway they selected within the *reducing illness* component (*protect myself generally* vs *protect others if I am showing symptoms* vs *protect myself if a household member has symptoms* vs *protect a household member at high risk*). Users could also view the handwashing component, which was relevant to all groups. If they did not view *reducing illness*, they were not included in group comparisons, but handwashing responses were still recorded. Users could complete more than one type of tailored pathway, but we only analyzed responses for the pathway that was selected first.

To understand current infection control behaviors (aim 1), behavioral measures were analyzed individually and collapsed together to form an *average infection control behavior* score. When users completed a plan more than once (eg, if they received website feedback that their initial plan could be further improved), the *final* plan was used. If users did not think a behavior was relevant to them (eg, they lived alone so did not need to socially isolate or could not socially isolate from young children), they could answer *not applicable*. This was coded as missing data and not included in analysis. Linear regression compared between-group scores for behavior.

To compare current behaviors with intended behavior after using Germ Defence (aim 2), linear regression models comparing between-group scores for intentions controlled for current behavior were used. Paired *t* test comparisons examined the difference between current behavior and intended behavior within groups.

Results

Use of the Germ Defence Website

We considered data from 53,125 users who completed at least the initial introductory website pages. Users accessed Germ Defence from 129 countries (a full CONSORT diagram of use is presented in Figure 1). The majority (n=44,446, 83.7%) of users were from the United Kingdom (England: n=40,164, 75.6%; Scotland: n=2204, 4.2%; Wales: n=1459, 2.8%; Northern Ireland: n=566, 1.1%; other: n=73, 0.1%). The mean use time was 8 minutes 28 seconds, and the mean number of pages viewed was 19.9. Of the recorded sessions, 54.1% (n=28,740) lasted longer than 1 minute. Over half (n=28,687, 54%) of the users accessed Germ Defence using a mobile device, 31% (n=16,469) accessed with a tablet, and 15% (n=7968) with a desktop or laptop computer. Only 10.6% (n=5631) of users were *return users* visiting for a second time. Aggregated use statistics for users outside the United Kingdom are provided in Multimedia Appendix 1. Detailed use for each website component is presented in Figure 1. The overall mean helpfulness of the website was rated as 7.77 (SD 2.31) out of 10.

Infection Control Behaviors and Intended Behaviors in Users of Germ Defence

All groups (protect themselves generally, protect others if the user was showing symptoms, protect themselves if household members were showing symptoms, and protect a household member who is high risk) reported using most current infection behaviors sometimes or quite often within the home. Overall, users reported they would wear a face covering almost never or sometimes (mean 1.61, SD 1.19) and would socially distance sometimes or quite often (mean 2.40, SD 1.22). Users reported socially isolating in their own room sometimes or quite often (mean 2.78, SD 1.29) and putting packages and shopping aside sometimes or quite often (mean 2.75, SD 1.55). Users reported cleaning and disinfecting quite often or very often (mean 3.17, SD 1.18).

Frequency of the five infection control behaviors from the *reducing illness* pathway within each group is reported in Table 2 (with handwashing reported in a separate table), as well as mean differences and 95% CIs of group comparisons (each group vs the *protect themselves generally* group). The frequency of behaviors did not vary appreciably between groups; numerically, the *protect themselves generally* group were least likely to socially distance (mean 2.39, SD 1.22). People in the *protect others if user showing symptoms* group were least likely to clean and disinfect (mean 2.95, SD 1.26) and put aside shopping and packages (mean 2.39, SD 1.48) but most likely to wear a face covering (mean 1.91, SD 1.36). People in the *protect themselves if household members showing symptoms* group were most likely to maintain social distance (mean 2.57, SD 1.23), and users in the *protect household members at high risk* group were least likely to stay in their own room (mean 2.64, SD 1.16) and least likely to wear a face covering (mean 1.42, SD 0.99).

Table 2 shows some small differences in how often participants planned to perform behaviors in the future (corrected for levels of current behavior) between groups. Compared to people in the protect themselves generally group, people showing symptoms planned to clean and disinfect, and put aside shopping less frequently, but they planned to self-isolate more frequently. People in the protect themselves from household member with symptoms group planned to socially distance and self-isolate more frequently than those in the protect themselves generally group. People looking to protect a high-risk household member planned to conduct all of the behaviors slightly more frequently than the protect themselves generally group.

Paired *t* test comparisons examined differences between current and planned behaviors after using the Germ Defence website. Mean difference scores for each group and 95% CIs are reported in Table 3. The difference between intended and current behavior was largest for cleaning and disinfecting (mean difference 0.38, 95% CI 0.37-0.39) and putting aside shopping and packages (mean difference 0.49, 95% CI 0.47-0.50), and was lowest for self-isolating (mean difference 0.15, 95% CI 0.14-0.16). Overall, infection control behaviors increased (mean difference 0.30, 95% CI 0.29-0.31).

Handwashing behavior is reported in Table 4. Mean current handwashing behavior was higher than other infection control behaviors (mean 4.04, SD 0.84) with reported intended behavior consistently higher (mean increase 0.41, 95% CI 0.40-0.42).

Table 2. Current and intended infection control behaviors.

Behaviors	Protect themselves generally (n=18,029)[a], mean (SD)	Protect others if user showing symptoms (n=169)			Protect themselves if household member showing symptoms (n=319)			Protect a household member at high risk (n=1787)		
		Mean (SD)	Mean difference (95% CI)	Cohen *d*[b]	Mean (SD)	Mean difference (95% CI)	Cohen *d*	Mean (SD)	Mean difference (95% CI)	Cohen *d*
Current behavior										
Social distancing	2.39 (1.22)	2.52 (1.39)	0.13 (–0.07 to 0.33)	0.11	2.57 (1.23)	0.17 (0.04 to 0.31)	0.15	2.51 (1.20)	0.12 (0.06 to 0.18)	0.10
Clean/disinfect	3.18 (1.18)	2.95 (1.26)	–0.24 (–0.42 to –0.06)	0.20	3.05 (1.18)	0.17 (0.04 to 0.31)	0.11	3.19 (1.17)	0.003 (–0.05 to 0.06)	0.00
Put aside shopping/packages	2.74 (1.55)	2.39 (1.48)	–0.35 (–0.60 to –0.11)	0.23	3.00 (1.49)	0.26 (0.08 to 0.44)	0.17	2.82 (1.59)	0.08 (0.004 to 0.16)	0.05
Self-isolate in own room	2.79 (1.30)	2.85 (1.43)	0.05 (–0.15 to 0.25)	0.04	2.75 (1.26)	–0.04 (–0.19 to 0.10)	0.03	2.64 (1.16)	–0.15 (–0.21 to –0.08)	0.11
Wear face covering	1.63 (1.21)	1.91 (1.36)	0.28 (0.07 to 0.49)	0.24	1.75 (1.28)	0.12 (–0.02 to 0.27)	0.10	1.42 (0.99)	–0.21 (–0.27 to –0.14)	0.17
Overall behavior score[c]	2.67 (0.91)	2.61 (1.08)	–0.05 (–0.19 to 0.08)	0.06	2.68 (0.90)	0.01 (–0.09 to 0.11)	0.01	2.59 (0.80)	–0.07 (–0.12 to –0.03)	0.08
Intended Behavior										
Social distancing	2.63 (1.28)	2.79 (1.47)	0.05 (–0.06 to 0.16)[d]	0.12	2.88 (1.30)	0.12 (0.05 to 0.20)[d]	0.19	2.84 (1.27)	0.11 (0.07 to 0.14)[d]	0.16
Clean/disinfect	3.57 (1.16)	3.18 (1.33)	–0.14 (–0.25 to –0.03)[d]	0.33	3.46 (1.18)	0.001 (–0.08 to 0.08)[d]	0.09	3.63 (1.15)	0.05 (0.01 to 0.08)[d]	0.05
Put aside shopping/packages	3.24 (1.52)	2.73 (1.59)	–0.19 (–0.34 to –0.04)[d]	0.34	3.44 (1.41)	–0.02 (–0.12 to 0.09)[d]	0.13	3.37 (1.52)	0.06 (0.01 to 0.11)[d]	0.08
Self-isolate in own room	2.94 (1.28)	3.08 (1.41)	0.10 (0.02 to 0.18)[d]	0.12	2.97 (1.23)	0.07 (0.01 to 0.13)[d]	0.03	2.87 (1.17)	0.06 (0.04 to 0.09)[d]	0.05
Wear face covering	1.95 (1.37)	2.19 (1.50)	0.03 (–0.11 to 0.17)[d]	0.18	2.15 (1.47)	0.08 (–0.01 to 0.18)[d]	0.15	1.82 (1.28)	0.08 (0.03 to 0.12)[d]	0.09
Overall behavior score	2.97 (0.96)	2.86 (1.20)	–0.03 (–0.12 to 0.05)[d]	0.11	3.01 (0.96)	0.03 (–0.03 to 0.09)[d]	0.04	2.97 (0.89)	0.06 (0.03 to 0.08)[d]	0.00

[a] Between group comparisons compare each group to the protect themselves generally group. Scale: 1 is almost never, 2 is sometimes, 3 is quite often, 4 is very often, and 5 is almost always.

[b] Reported as the standardized mean difference between each group and the comparison group.

[c] Overall behavior scores are means calculated from all behaviors in which a response was recorded.

[d] Controlling for current behavior.

Table 3. Group differences between behavior and intention.

Behaviors	Protect themselves generally (n=18,029)[a]		Protect others if user showing symptoms (n=169)		Protect themselves if household member showing symptoms (n=319)		Protect a household member at high risk (n=1787)		Overall	
	Mean difference (95% CI)	Cohen *d*	Mean difference (95% CI)	Cohen *d*	Mean difference (95% CI)	Cohen *d*	Mean difference (95% CI)	Cohen *d*	Mean difference (95% CI)	Cohen *d*
Behavior										
Social distancing	0.22 (0.21-0.23)	0.35	0.26 (0.11-0.40)	0.30	0.33 (0.24-0.42)	0.41	0.31 (0.28-0.35)	0.43	0.23 (0.22-0.24)	0.36
Clean/disinfect	0.38 (0.37-0.39)	0.52	0.30 (0.17-0.44)	0.36	0.41 (0.31-0.51)	0.47	0.43 (0.39-0.47)	0.54	0.38 (0.37-0.40)	0.52
Put aside shopping/packages	0.49 (0.47-0.50)	0.49	0.39 (0.24-0.54)	0.42	0.41 (0.31-0.51)	0.47	0.53 (0.48-0.58)	0.50	0.49 (0.47-0.50)	0.49
Self-isolate in own room	0.14 (0.13-0.15)	0.28	0.23 (0.11-0.36)	0.30	0.21 (0.14-0.29)	0.33	0.22 (0.19-0.25)	0.34	0.15 (0.14-0.16)	0.29
Wear face covering	0.28 (0.27-0.30)	0.37	0.29 (0.12-0.47)	0.30	0.35 (0.25-0.46)	0.42	0.37 (0.33-0.42)	0.42	0.29 (0.28-0.29)	0.37
Average infection control score	0.29 (0.29-0.30)	0.53	0.27 (0.16-0.38)	0.38	0.32 (0.25-0.40)	0.49	0.36 (0.33-0.39)	0.57	0.30 (0.29-0.31)	0.53

[a] Group n values are taken across all behaviors.

Table 4. Paired comparisons between current and intended handwashing behavior.

Handwashing situation	Current behavior (n=12,981), mean (SD)	Intended behavior (n=12,981), mean (SD)	Mean difference (95% CI)	Cohen *d*
Before eating snacks	3.91 (1.28)	4.45 (0.99)	0.54 (0.52-0.56)	0.54
After coming home	4.66 (0.81)	4.80 (0.62)	0.14 (0.13-0.15)	0.26
After sneezing or coughing	3.45 (1.43)	4.11 (1.23)	0.66 (0.64-0.68)	0.59
After contact with possible carrier	4.22 (1.24)	4.53 (1.00)	0.30 (0.29-0.32)	0.36
After touching something	4.13 (1.23)	4.50 (0.97)	0.36 (0.35-0.38)	0.43
Overall score[a]	4.00 (1.03)	4.34 (0.91)	0.34 (0.33-0.35)	0.50

[a] Handwashing overall score was a separate item

Discussion

Summary of Findings

Germ Defence was accessed by a large number of users across 129 countries, primarily from the United Kingdom. This demonstrates public interest in adopting appropriate infection control behaviors in the home during the COVID-19 pandemic. After using Germ Defence, all groups reported intentions to increase the frequency of their infection control behaviors, including handwashing.

Except for handwashing, self-reported infection control behaviors in the home were only reported *sometimes or quite often* regardless of whether people were seeking to protect themselves, concerned about demonstrating COVID-19 symptoms, had a household member showing symptoms, or were seeking to protect a high-risk household member. The frequency of wearing face coverings was consistently the lowest of the behaviors, while cleaning and disinfecting was the most frequently reported of the behaviors outside of handwashing. All of these infection control behaviors were reported to be performed much less frequently than handwashing.

As would be expected, certain behaviors and intentions varied according to the circumstances of groups; for example, people seeking to protect others when showing symptoms reported higher current frequencies of wearing face coverings, while people seeking to protect a high-risk household member reported the intention to socially distance within the home more frequently.

Comparison With Existing Literature

This study provides the first up-to-date analysis of infection control behaviors and intentions across the United Kingdom in a large sample during the COVID-19 pandemic. Within-household transmission will be increasingly important as infection control measures become established in external, public environments [6,21]. Therefore, understanding current infection control behaviors within homes (and how to improve them) is vital to continue controlling the pandemic.

Self-reported infection control behaviors other than handwashing are lower than is optimal for infection prevention, even in Germ Defence users who were likely more motivated and willing to engage in protective behaviors than the general population (as they were seeking additional information) [22]. Increasing engagement in these behaviors is important as societal restrictions are released and perceived risk reduces [23].

Germ Defence users reported intentions to increase the frequency of infection control behaviors over their current rates. Although such intentions potentially misrepresent the observed behavioral change after an intervention (the *intention-behavior gap* [24]), our evidence suggests that Germ Defence may overcome this. Analysis of comparable data from the PRIMIT trial handwashing intervention showed slightly smaller behavior and intention differences (Cohen *d*=0.45). This change was sufficient to cause reduced infection transmission and severity within households after 16 weeks [12]. Comparable data during the current pandemic (reducing illness behaviors: Cohen *d*=0.53; handwashing: Cohen *d*=0.50) shows a slightly larger effect across a broader range of behaviors that may have a larger impact on infection rates.

Study Limitations

As a cross-sectional observation of an active intervention, Germ Defence lacks longitudinal follow-up. Care must be taken when interpreting findings within the rapidly changing context of the COVID-19 pandemic. Our method of categorization using website pathways may not be accurate for some users or might overlook individual differences within categories.

Our data may not be a representative sample from the wider UK population for several reasons. First, users of Germ Defence are likely to be more motivated and report higher frequencies of infection control behaviors. Second, although analytic data indicates that the large majority of the intervention's users were from the United Kingdom, we could not identify non-UK users within behavioral data. Finally, self-reported infection control behaviors may not be accurate reflections of actual behaviors occurring within households. However, none of these limitations affect our main findings; indeed, people are prone to overreport protective behaviors, further highlighting the need for improvement.

Implications for Practice and Research

A concerted effort to improve household infection control behaviors across the UK population is likely to be an efficient use of health resources, both to reduce current rates of infection and to prevent the likelihood and severity of future outbreaks. Handwashing behaviors are already relatively high—perhaps due to existing familiarity with the behavior supported by a focus in public health advice on increasing handwashing in earlier stages of the pandemic. Therefore recommending digital interventions such as Germ Defence to target other infection control behaviors within the home may help control the current pandemic.

Given the current rates of infection control behaviors within the home even within a motivated sample, it is vital to address barriers to engaging in them. For example, people living in crowded, working households are more likely to come into contact with the virus [5] and may find it difficult to self-isolate. Similarly, cultural differences, financial challenges, or caring responsibilities may cause barriers to social distancing [6]. Research should explore how to support these behaviors for as many households as possible. Indeed, digital interventions such as Germ Defence can use tailored content to target behaviors that are relevant for specific user groups.

Conclusion

Our findings show substantial room for improvement in protective behaviors across the United Kingdom—even in our motivated, self-selected sample—as societal restrictions are eased. People are not sufficiently self-isolating within the home to prevent household transmission, even when a household member or the individual themselves are demonstrating COVID-19 symptoms. Promoting evidence-based behavior change interventions might improve these behaviors, reducing transmission within households and the incidence and severity of infections.

Germ Defence is a scalable, evidence-based, acceptable, and free public health intervention with negligible safety risk, which could be included in public heath guidance and promoted via primary care networks at minimal cost for wide population coverage.

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Authors' Contributions

BA, SM, and LY conceived the study. BA and LY developed the study design. BA, BS, and JG analyzed the design. All authors interpreted the data and developed the intervention. BA drafted the manuscript. All authors reviewed the manuscript and approved the content.

BA and LY confirm that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and any discrepancies have been explained.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Comparison of aggregated use statistics for users outside of the United Kingdom (compared to users within the United Kingdom).
[DOCX File , 13 KB-Multimedia Appendix 1]

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
NIHR: National Institute for Health Research
PRIMIT: Primary Care Randomised Trial of an Internet Intervention to Modify Influenza-Like Illness and Respiratory Infection Transmission
UKRI: United Kingdom Research and Innovation

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Original Paper

Measuring Public Reaction to Violence Against Doctors in China: Interrupted Time Series Analysis of Media Reports

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Abstract

Background: Violence against doctors in China is a serious problem that has attracted attention from both domestic and international media.

Objective: This study investigates readers’ responses to media reports on violence against doctors to identify attitudes toward perpetrators and physicians and examine if such trends are influenced by national policies.

Methods: We searched 17 Chinese violence against doctors reports in international media sources from 2011 to 2020. We then tracked back the original reports and web crawled the 19,220 comments in China. To ascertain the possible turning point of public opinion, we searched violence against doctors–related policies from Tsinghua University ipolicy database from 2011 to 2020, and found 19 policies enacted by the Chinese central government aimed at alleviating the intense patient–physician relationship. We then conducted a series of interrupted time series analyses to examine the influence of these policies on public sentiment toward violence against doctors over time.

Results: The interrupted time series analysis (ITSA) showed that the change in public sentiment toward violence against doctors reports was temporally associated with government interventions. The declarations of 10 of the public policies were followed by increases in the proportion of online public opinion in support of doctors (average slope changes of 0.010, $P<.05$). A decline in the proportion of online public opinion that blamed doctors (average level change of –0.784, $P<.05$) followed the declaration of 3 policies.

Conclusions: The government’s administrative interventions effectively shaped public opinion but only temporarily. Continued public policy interventions are needed to sustain the reduction of hostility toward medical doctors.

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KEYWORDS

violence against doctors; government intervention; public opinion; patient–physician relationship

Introduction

With the improvement of Chinese people's living standard [1] and the attendant increase in personal wealth, individual Chinese citizens are paying more attention to their quality of life and health [2]. Health concerns have gradually become the focus of public discourse and are among the most popular topics on the internet in China. Concurrent with this trend, the plight of the strained doctor–patient relationship has become more evident, with violence against doctors, nurses, and other health care providers in China on the rise [3]. Incidents of violence against doctors increased from 20.6 incidents per hospital in 2008 to 27.3 in 2012 [4]. An editorial in *The Lancet* in 2012 called this situation a “crisis” for the Chinese medical field [5].

In this period of mass media, online commentary and discussion have increasingly been proven as a useful instrument for surveying the moods and attitudes of the general public. The prevalence of the media and the internet for use in health communication has already become standard in regions such as China/Taiwan, where the media plays a significant role in settling medical disputes and dealing with medical institutions for patients [2]. For instance, the online community may share viewpoints on an individual physician or medical facility, which considerably shapes the image and evaluation of the physician or medical facility for the general reading public [6]. Moreover, those with media access that can further express their thoughts through media outlets can affect how news is portrayed and its content [7].

Public interest in the doctor–patient relationship and the widespread use of the internet have made it relatively easy for violence against doctors events to trigger a dispute of public opinion online. It has been suggested that the rise of online public discourse on violence against doctors may negatively affect the doctor–patient relationship and exacerbate the perception of social chaos and loss of control [8]. While many may agree that public opinions online are symbolic of challenges in real life, as reflected by online expressions of attitudes, views, and emotions, their impact reaches beyond the virtual world. Many studies have shown that online public opinion is relatively consistent in its intensity and continuity, influencing uncivilized network behaviors and social uncertainty [9,10].

To maintain social stability both online and offline, the Chinese government has made great efforts to regulate online content. For example, it is illegal to create or spread rumors on the internet in China as it may disrupt public order and social security [11]. In addition, the government has implemented a series of policies to increase the punishment for the crime of violence against doctors, and a government bureau, the National Radio and Television Administration, has published a series of articles to guide public opinion. Moreover, in July 2014, the National Health and Family Planning Commission, Ministry of Justice, Ministry of Finance, China Insurance Regulatory Commission, and National Administration of Traditional Chinese Medicine issued a vital policy—Opinions of the National Health and Family Planning Commission, the Ministry of Justice, the Ministry of Finance and Other Departments on Strengthening the Work of Medical Liability Insurance [12]—to establish a medical risk-sharing mechanism with medical liability insurance as the primary form and make this mechanism essential in medical dispute resolution and medical risk management. The Chinese Medical Association has issued a statement calling for system-wide reforms. In October 2013, the Ministry of Public Security of the People’s Republic of China advised hospitals with over 2000 beds to hire “at least 100 security guards” [13]. However, increased security guards, metal detectors, and legal threats have been criticized for failing to deal with the underlying causes of the violence [14]. These policies have been attributed to some reduction in the acceleration of violence against doctors and calming of public opinion on doctor–patient conflicts [15]. Patients feel a lack of control due to the uncertainty of illness [16,17]. Many people require personal control over their lives and the surrounding environment, perhaps to avoid feeling the chaos and uncertainty in the world [18,19]. When people feel lower levels of personal control, they are more likely to show more support for government control [20].

However, whether such policies and interventions have made a practical positive impact on online public opinion has not been examined. One way to investigate this question is to compare the timeline of a turning point in public comments and the timing of the introduction of violence against doctors–related policies. Comments of the article instead of its content could provide more intuitive reflection of the patients side [21]. Accordingly, to gauge the overall public attitude toward doctors and the health care system in China, we endeavored to measure online reactions to mass media reports of violence against doctors.

Comments on violence against doctors incidents expose the attitude of the affected party groups to a certain extent. In recent years, an increasing number of violence against doctors events have affected people’s perceptions of the country in a period of social transition, where intense emotions and perceptions of people and affected groups are also influenced by perceived sense of control [22], and government policy interventions can provide a compensatory sense of said control [20]. Therefore, to understand the emotional valence (sentimental valence) of public comment on violence against doctors episodes, it is meaningful to check whether national policy has affected the stereotypes associated with the doctor–patient bond from a time perspective.

To assess the effectiveness of government interventions in influencing online public opinion in China, we retrieved significant media reports of violence against doctors events and time-relative related government policies (eg, Criminal law or rules and regulations of the National Health Commission) in a policy database from 2011 to 2020 [12,15,23,24]. We documented public attitudes by coding comments on online media. Overall, we expected that these data would provide a better understanding of the general public who utilize social media and the internet, as well as insight into their attitudes toward health, perceived quality of health care services, and health care information needs. Thus, our research questions were (1) what trends in attitudes do the readers show with respect to the actions of both patients and physicians? (2) Are these trends influenced by the introduction and direction of national policies?

Methods

Sampling and Data Collection

To identify which events are internationally influential, we visited well-known media sites, including the Wall Street Journal, New York Times, BBC, Economist, Washington Post, Telegraph, Times, New Yorker, South China Morning Post, International Business Times, National Public Radio, and The

Atlantic and found a total of 17 medical violence incidents reported in China between October 19, 2011, and April 4, 2020. In total, there were 29 English reports. We then traced these incidents to Chinese website media and crawled (using a web robot to collect scripts at high speed) them for encoding and analysis to estimate online public attitudes toward doctors and patients (Multimedia Appendix 1).

We selected popular Chinese news media (N=6) from the New Media Influence Index Report [25], and considered their lasting influence from 2011, as shown in Table 1. We selected these 6 news media for 2 reasons. First, when we traced back the Chinese violence against doctors reports in international media sources, these media had a higher report rate than other media [26]; second, we referred to the media influence from 2011 to 2019 and, according to the Kantar China Media Impact Report 2016 and 2019, these 6 news media were more influential during these years [27].

We obtained 17 cases and their comments from the selected news media (see Multimedia Appendix 2 for details). As 2 of the 17 cases occurred in private hospitals, pseudonyms were applied to both private and public hospitals. There were 3 second-class A hospitals, 1 second-class B hospital, 2 top-class B hospitals, and 9 top-class A hospitals. Thus, the study covers different levels of hospitals, consistent with the distribution of hospital ownership status and hospital level in the total sample of doctor–patient disputes [28]. As the median number of comments was 400 on each incident, based on the total media coverage, if the count exceeded 400, we took a random sample of 400. The comments of each case are arranged in chronological order and divided into X/2n areas, and 2 comments were randomly extracted from each area. If the count was under 400, all coverage was included in the analyses. We then eliminated the repeated and unrelated comments. If the number of meaningless comments in the selected final comment sample exceeded 20%, these comments were removed. The number of comments required was then supplemented by the above sampling method. The sampling method is based on a real-world situation. We then collated and analyzed all the comments we collected. The final comment numbers for each case are listed in Table 2.

Table 1. All news media used to obtain sample comments.

News media	Reference
Tencent News	[29]
Sohu News	[30]
iFeng News	[31]
Sina News	[32]
Tianya Forum	[33]
NetEase News	[34]

Table 2. Number of network reviews for all cases.

Case	2011 (N=255)	2012 (N=1245)	2013 (N=178)	2014 (N=1473)	2015 (N=889)	2016 (N=1003)	2018 (N=924)	2019 (N=721)	2020 (N=521)	Total (N=7209)
C1	254	428	1	3	—[a]	—	—	—	—	696
C2	—	384	—	5	—	—	—	—	—	389
C3	1	433	38	2	—	—	—	—	—	474
C4	—	—	139	474	247	—	—	—	—	860
C5	—	—	—	400	2	—	—	—	—	402
C6	—	—	—	189	—	—	—	—	—	189
C7	—	—	—	—	200	—	—	—	—	200
C8	—	—	—	—	158	—	—	—	—	158
C9	—	—	—	—	282	2	—	—	—	284
C10	—	—	—	400	—	—	—	—	—	400
C11	—	—	—	—	—	400	—	—	—	400
C12	—	—	—	—	—	400	—	—	—	400
C13	—	—	—	—	—	201	—	—	—	201
C14	—	—	—	—	—	—	396	3	121	520
C15	—	—	—	—	—	—	528	—	—	528
C16	—	—	—	—	—	—	—	539	—	539
C17	—	—	—	—	—	—	—	179	400	579

[a] "—" represents no count of the comments in the *given* year.

Ethical Approval and Consent to Participate

Ethical approval was obtained from the School of Public Health, Zhejiang University. As open data obtained through web crawlers do not include any personal data, informed consent was not required (waived by the ethics committee), and the study involved minimal risk.

Coding

Procedure and Steps

A coding group comprising 4 preventive medicine students was trained to analyze the coverages. The coding forms outlined 9 categories developed a priori based on previous literature [35,36] (Table 3). The coding was performed in MS Excel.

Table 3. Coding categories.

Category	Meaning/Definition
Blame Big System	The comments express dissatisfaction, anger, or blame for the whole society or social atmosphere.
Blame Medical System	The comments express dissatisfaction, anger, or blame for health policy or the hospital system.
Blame Doctor	The comments express dissatisfaction, anger, or blame for the doctor or his/her behavior, other doctors, or their behavior in the case.
Blame Patient	The comments express dissatisfaction, anger, or blame for the patient or his/her behavior, other patients, or their behavior in the case.
Blame Other	The comments express dissatisfaction, anger, or blame for other things, such as the news media, the legal system.
Support Doctor	The comments express understanding, sympathy, or support for the doctor or his/her behavior, other patients, or their behavior in the case.
Support Patient	The comments express understanding, sympathy, or support for the patient or his/her behavior, other patients, or their behavior in the case.
Support Other	The comments express understanding, sympathy, or support for other things.
N/A	Comments are unrelated to cases or do not belong to any of the above categories.

At the beginning of the evaluation, we trained the 4 raters in the method of "independent coding–proofreading–third party opinion discussion" and then ensured that the interrater reliability reached 0.9 or above before they began to evaluate the formal materials. All the formal comments assessments were completed according to the following steps.

Step 1

The coding team carried out training to define and unify the coding rules.

Step 2

Fifty sample comments were extracted, and each rater was asked to code these comments independently. We compared the coding results between raters to obtain the “interrater reliability” (interrater reliability = the number of entries with the same coding result/Total number of entries, ie, the consistency between all raters’ coding results). The final results were unified according to the coding rules.

Step 3

If interrater reliability was less than 0.9, we repeated the operations in step 2 until it reached 0.9. The coding team then began to code formal samples.

Step 4

The raters read and coded all the comments independently, without interfering or discussing with each other. Each comment could belong in 1 category or more.

Step 5

We compared the coding results of each rater to find comments that were inconsistent in the coding results.

Step 6

We established a discussion group to reread all the comments and to determine the coding results of comments that were inconsistent in step 4. Finally, the coding team completed the coding results of all the comments.

Step 7

For the comments between 2017 and 2020, we used a sentimental dictionary developed from the code between 2011 and 2016. The sentiment was Normalization as [0,1].

Constructing a Sentiment Dictionary

We collected all the comments, marked each sentiment of each comment, and then segmented these comments into words, and removed some stop words to obtain the probability P_{ij} of each word appearing in each sentiment:

$$P_{ij}=(e_j|w_i) = x = [C(w_i,e_j)]/[C(e_j)]$$

where P_{ij} represents the probability that w_i represents sentiment e_j, and $C(w_i,e_j)$ represents the number of times that w_i appears in sentiment e_j.

Comment Sentiment Judgment

Thereafter, when judging new comments, we first segmented each comment and removed some stop words. According to the naïve Bayes principle, a certain sentiment of each comment is the accumulation of the sentiments of all participles of the comment. To eliminate the polarization problem, the calculation is multiplied by the value related to the length of each comment:

$$q_{kj} = N^n \times \prod_{i=1}^{n} p_{ij}$$

Finally, a threshold value is selected according to q_{kj} to judge the sentiment determination.

Policy Content Quantitative Analysis

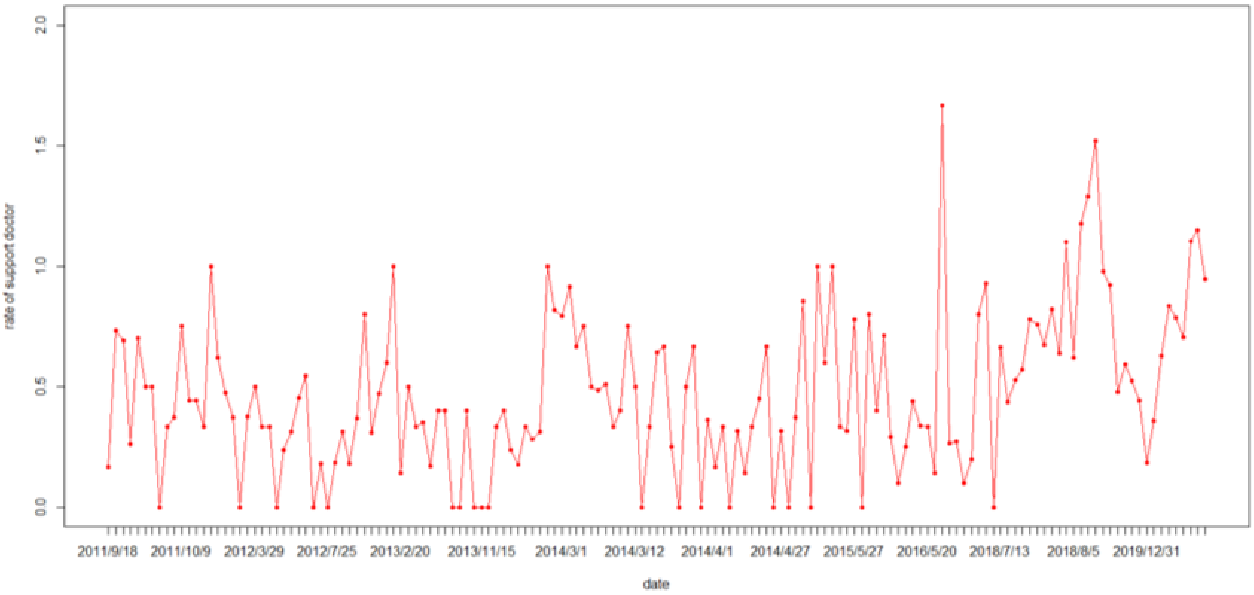
Policy content quantitative analysis is a semantic analysis method that combines quantitative and qualitative analysis of the content of policy literature. A proper policy database could display the essential information of the content of violence against doctors–related policy literature objectively [37].

This study used Tsinghua University’s policy analysis system, “ipolicy,” to retrieve policies. “ipolicy” is a unique characteristic analysis system, which can perform the specified analysis function according to users’ needs at different levels. At present, there are approximately 1,200,000 policy texts from 1949 to 2019 (including all the organs of the State Council, other central bodies, the National People’s Congress, and more than 34 provinces), which are still being updated [38].

In the retrieval module, the system provides various retrieval modes, and the content of the retrieval can be selected as full text or title retrieval. Advanced retrieval and retrieval in the results are also available to facilitate the user to find the text more accurately.

We used interrupted time series analysis (ITSA), a kind of longitudinal quasi-experimental design [39,40]. ITSA provides a segmented linear regression model, which could assess the effect of each central policy on changes in the “support doctor” and “blame doctor” online public opinion before the policy promulgation date and at 30 time points after the promulgation date. We combined some of the rates of sentimental categories to understand netizens’ (Internet Citizens [41]) attitudes toward violence against doctors events. Because the meanings of “blame doctor” and “support patient” are similar, we combined the 2 categories of results into the new category of “blame doctor.” Likewise, we combined the results of “blame patient” and “support doctor” into the new category of “support doctor.” Originally, we crawled 19,220 comments. For the sake of ITSA, we averaged the sentiments of comments of the same date. For those with only 1 comment on each day, we framed adjected comments of 3-4 days and selected the second date to represent the time point. Finally, we obtained 151 time points representing the online public opinion change (Figure 1). As the policy promulgation date overlapped with the 151 points, we finally obtained 15 policy intervention dates for ITSA. The models quantify both a level and slope change following the intervention, while accounting for the autocorrelation of rates. Autoregressive integrated moving average models were used to adjust for residual autocorrelation. We prepared the data with MS Excel, version 2019, and completed all statistical analyses with R statistical software package, version 4.0.2 (R Foundation for Statistical Computing), using a Type 1 error rate of .05 as the threshold for statistical significance.

Figure 1. The rate of support doctors at the 151 time points from 2011–2020.



The regression model used to fit these data is straightforward:

$$\text{outcome}_{jt} = \beta_0 + \beta_1 \times \text{time}_t + \beta 2 \times \text{level}_j + \beta 3 \times \text{trend}_{jt} + \varepsilon_{jt}$$

In this specific example (using the variable names from Table 7), the model is:

$$\text{sentiment rate}_t = \beta_0 + \beta_1 \times \text{time}_t + \beta 2 \times \text{policy}_j + \beta 3 \times \text{time after policy}_{jt} + \varepsilon_{jt}$$

Results

Number and Percentage of Coding Categories

Table 4 lists the preliminary results of coding, including the number of comments belonging to each category in the years 2011-2020, and the percentage of total comments in this period.

Table 4. Number and percentage of coding categories.

Coding category	Year								
	2011 (N=255)	2012 (N=1245)	2013 (N=232)	2014 (N=1473)	2015 (N=889)	2016 (N=1003)	2018[a] (N=924)	2019[a] (N=721)	2020[a] (N=521)
Blame Big System, n (%)	30 (11.8)	132 (10.6)	25 (10.8)	174 (11.8)	58 (6.5)	74 (7.3)	(1.11)	(1.32)	(3.25)
Blame Medical System, n (%)	8 (3.1)	79 (6.3)	24 (10.3)	36 (2.4)	41 (4.6)	70 (6.9)	(0.34)	(1.2)	(2.19)
Blame Doctor, n (%)	85 (33.3)	312 (25.1)	91 (39.2)	191 (12.9)	183 (20.6)	133 (13.2)	(2.54)	(1.85)	(4.86)
Blame Patient, n (%)	68 (26.7)	167 (13.4)	24 (10.3)	362 (24.6)	161 (18.1)	207 (20.6)	(4.08)	(2.34)	(12.71)
Blame Other, n (%)	4 (1.6)	13 (1.0)	3 (1.3)	47 (3.2)	24 (2.7)	24 (2.3)	(0.0)	(0.56)	(1.92)
Support Doctor, n (%)	65 (25.5)	210 (16.9)	46 (19.8)	264 (17.9)	113 (12.7)	340 (33.9)	(2)	(1.95)	(3.83)
Support Patient, n (%)	60 (23.5)	71 (5.7)	15 (6.5)	19 (1.3)	44 (4.9)	8 (0.8)	(0.53)	(0.92)	(2.52)
Support Other, n (%)	0 (0.0)	1 (0.1)	1 (0.4)	1 (0.1)	2 (0.2)	0 (0.0)	0 (0.0)	(0.55)	(1.92)
N/A, n (%)	25 (9.8)	443 (35.6)	47 (20.3)	562 (38.2)	391 (43.9)	461 (45.9)	(0.82)	(1.77)	(3.72)

[a] Because the rate of 2017-2020 was from data mining, n is not available.

As shown in Table 4, the proportion of “blame big system” is more stable than other categories; “blame doctor” peaked at 39.2% (91/232) in 2013, but decreased to 12.97% (191/1473) in 2014 and 4.86% in 2020; “support doctor” decreased from 2011 to 2012, but rose significantly from 2015 to 2020; “blame patients” reached the minimum of 10.3% (24/232) in 2013 and the maximum of 24.58% (362/1473) in 2014; “support patient” showed a downward trend, from the overall in 2020, when it was only 2.52% (Figures 2 and 3).

Figure 2. “Support doctor” proportion of public online opinion over time. Trend lines show slope change after lagged intervention date. Vertical dash line shows lagged intervention date of policy 2, Dec 20, 2013.

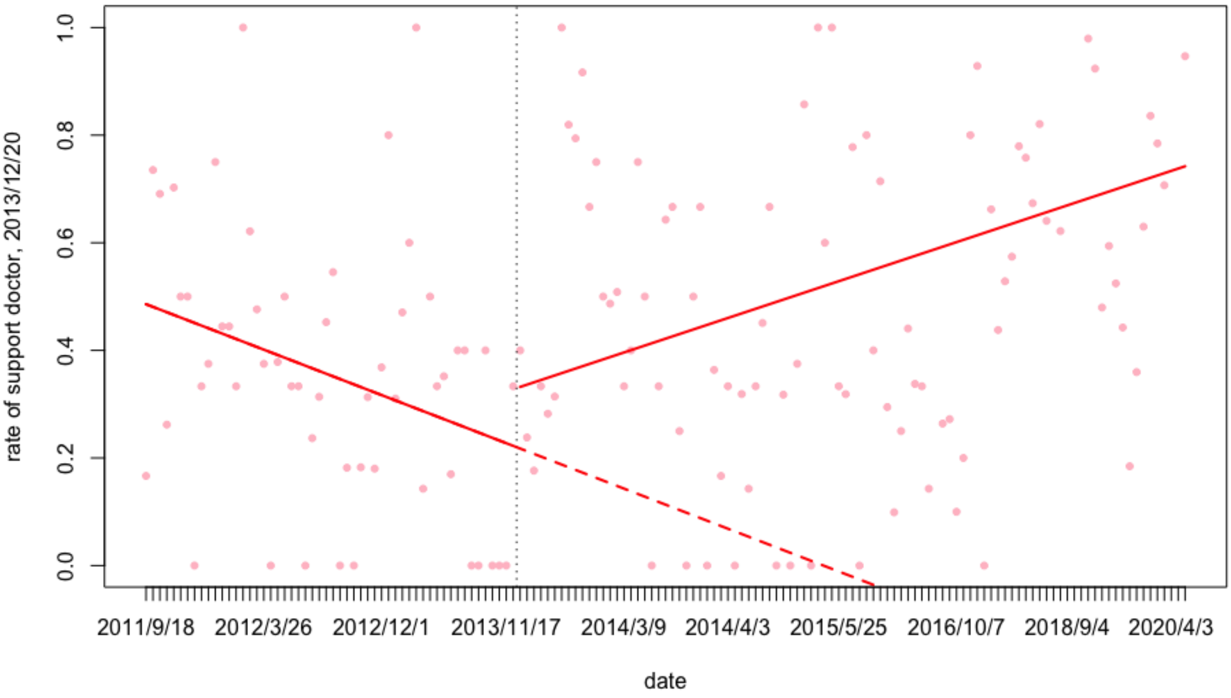
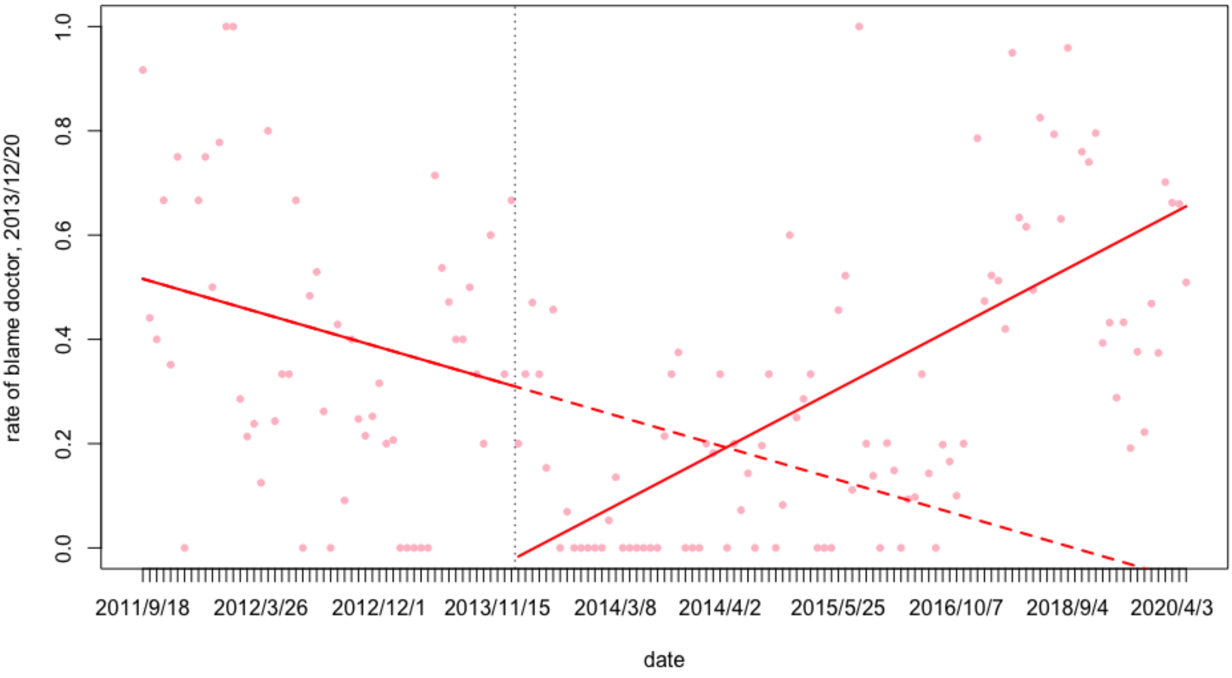


Figure 3. “Blame doctor” proportion of public online opinion over time. Trend lines show slope change after lagged intervention date. Vertical dash line shows lagged intervention date of policy 2, Dec 20, 2013.



Retrieval Results From the “ipolicy” System

The keywords we used to retrieve related policies were “doctor-patient,” “medical,” “violence,” “medical violence,” and “violence against doctors.” We then obtained related policies and regulations from 2011 to 2016 in China (Tables 5 and 6).

Table 5. Retrieval results from the “ipolicy” system.

Keywords	Results
Medical violence (医疗暴力)	Not related to the topic
Doctor-patient (医患)	Not related to the topic
Medical + violence (医疗或暴力)	Not related to the topic
Hurt doctors (伤医)	Two related entries in total
Violence against doctors (医暴)	Ninety-seven related entries in total

Table 6. Policy entries and netizens’ attitude trend.

Year	Policy entries, n			Netizens’ attitude trend, n	
	Total	Central policies	Local policies	Blame doctor	Support doctor
2011	12	0	19	—[a]	—
2012	24	11	12	↓[b]	↓
2013	27	16	11	↑[c]	—
2014	27	12	13	↓	↑
2015	4	4	0	↑	↓
2016	2	2	0	↓	↑
2017	3	3	0	↓	↓
2018	0	0	0	↓	↓
2019	0	0	0	—[d]	—
Sum	99	48	55		

[a] No change in attitude.

[b] Decrease in ratio of related attitude.

[c] Increase in ratio of related attitude compared with last year.

[d] Not available.

We browsed these 112 policies, and 19 policies were promulgated by the central government (Multimedia Appendix 3), of which the most relevant central policy documents are as follows:

1. Severe punishment of any illegal activities that would harm the safety of doctors or patients. We will severely punish illegal activities that disrupt regular medical order and improve the ability to solve medical disputes [15].
2. Keep improving awareness of and fight against illegal medical activities and crimes [23].
3. Resolutely combat crimes involving hospitals to maintain order and to punish mob behavior, etc. [24].
4. Establish a medical risk-sharing mechanism with medical liability insurance as the main form, and have this mechanism play an important role in medical dispute resolution and medical risk management [12].

As shown in Tables 7 and 8, for the first central policy (promulgated on October 26, 2012), at baseline (before the policy was promulgated), there was neither a significant level nor trend change in the rate of “support doctor.” However, there was a drop of 2% per time point in the “blame doctor” trend (Figures 2 and 3).

There was an increase in the “support doctor” trend after each policy promulgation (average trend changes of 0.011 of the policies 2-12, $P<.05$), but most of the slope change was not significant. At almost every time point in the policy promulgation, there was a decline in the proportion of “blame doctor” (average level drop of –0.784 of the policies 2-4, $P<.05$); however, there was also a trend change lag (average slope change of 0.018 of the policies 2-12, $P<.05$).

Table 7. Support doctor regression parameters at 15 policy time points.

Policy	Policy date	β1	*P*	β2	*P*	β3	*P*
1	October 26, 2012	–.009	.235	.035	.825	.013	.097
2	December 20, 2013	–.005	.124	.106	.391	.009	.010
3	January 29, 2014	–.005	.176	.126	.365	.009	.023
4	March 26, 2014	–.005	<.001	–.165	.034	.016	<.001
5	April 22, 2014	.001	.789	–.125	.169	.010	<.001
6	May 8, 2014	.001	.881	–.041	.679	.010	<.001
7	July 9, 2014	.001	.717	.005	.958	.010	<.001
8	September 4, 2014	.001	.943	–.064	.519	.011	<.001
9	October 27, 2014	.001	.660	–.104	.318	.012	<.001
10	June 24, 2015	.001	.688	.007	.929	.011	<.001
11	March 24, 2016	.001	.646	–.041	.708	.013	<.001
12	May 13, 2016	.001	.863	.067	.553	.011	.007
13	June 26, 2017	.001	<.001	.123	.272	.013	.066
14	July 31, 2018	.001	.081	.441	.025	.005	.781
15	March 5, 2019	.002	.109	.120	.587	.006	.766

Table 8. Blame doctor regression parameters at 15 policy time points.

Policy	Policy date	β1	*P*	β2	*P*	β3	*P*
1	October 26, 2012	–.017	.057	–.038	.8316	.020	.031
2	December 20, 2013	–.004	.2478	–.335	.007	.011	.002
3	January 29, 2014	–.005	.1259	–.277	.046	.012	.002
4	March 26, 2014	–.004	<.001	–.172	<.001	.015	<.001
5	April 22, 2014	–.005	<.001	.025	.4097	.016	<.001
6	May 8, 2014	–.005	<.001	.103	.001	.016	<.001
7	July 9, 2014	–.005	<.001	.128	<.001	.015	<.001
8	September 4, 2014	–.005	<.001	.151	<.001	.015	<.001
9	October 27, 2014	–.005	<.001	.256	<.001	.013	<.001
10	June 24, 2015	–.004	<.001	.332	<.001	.011	<.001
11	March 24, 2016	–.004	<.001	.435	<.001	.008	<.001
12	May 13, 2016	–.004	<.001	.398	<.001	.010	.018
13	June 26, 2017	–.002	.062	.358	.038	.004	.646
14	July 31, 2018	.000	.898	.120	.562	–.002	.937
15	March 5, 2019	.001	.716	–.251	.228	.008	.7322

Discussion

Principal Findings

In 2017, discussion in *The Lancet* suggested that recommendations to rebuild patient–physician trust in China should not only focus on the physician's side but also on the patient's side [42,43]. Recently, particularly during COVID-19, voices to stop attacks against health care personnel have been raised worldwide [44-46]. All the health professional associations, societies, and organizations from all specialties and disciplines should unite to protect staff, while the government should play a major role by enacting strong and appropriate policies [47].

The current research has found that the 14 violence against doctors–related policies promulgated by the Chinese central government are associated with the sentiment expressed in online public opinions. The rate of online comments supporting doctors tends to increase significantly (see Table 7 for significant values) after almost each policy promulgation, while the rate of blaming doctors declined at each policy promulgation time point. However, the trend of blaming doctors then rises later after every policy is enacted. The overall declining trend of blaming doctors (39.22% in 2013 versus 4.86% in 2020) and the increased ITS trend for each policy time point imply that policy effects are only temporary. Particularly, in recent years (2017-2020), there have been few polices, and the ITS trends are not significant. It is time to reflect on the effects of policies.

The recent discussions regarding the relationship between violence against doctors events and health care insurance are very lively. In 2018, China's Congress promulgated the Social Insurance Law of the People's Republic of China (2018 Amendment) [48]. Although China's medical security system is continually improving, there are still some problems. Furthermore, the severe current aging of our society and young people's increasing work pressure have led to an increase in the incidence of some major diseases. For some significant diseases, many drugs are not included in the medical insurance coverage, and patients must bear most or all of the medical expenses alone. Patients are likely to experience significant imbalances, and it is easy to dissolve this inconsistency. The balance is blamed on the medical institution and the most directly contacted population—medical staff [49-51]. Our study has provided this new patient viewpoint from the health and science education for the public. In this study, we focused on netizens' comments on major violence against doctors events and their attitudes toward doctors, patients, and the government as direct evidence to understand public opinions and the state of the physician–patient relationship. We found a significant relationship (see Tables 7 and 8 for significant *P*-values) between the time of implementation of government health reform policies and the shift of public opinion from "blame doctor" to "support doctor." In 2011 and 2012, the proportion of "blame doctor" and "support doctor" opinions were relatively balanced. However, in 2013, the proportions began to shift: the proportion of "blame doctor" rose while "support doctor" dropped. Because of this differentiation, the government had to adopt some policies. By the end of 2013, the public mood had eased up after the implementation of related health policies. In 2014, the number of related health policies peaked but then decreased in 2015. Thus, the proportion of "support doctor" opinions fell in 2015. Again, the situation improved after the enactment of central regulations in 2016 (Figures 2 and 3).

From the "ipolicy" system, we retrieved related policies and regulations from 2011 to 2016 in China and found the most relevant central policies to be those decreeing stricter enforcement and severe punishment for those endangering the safety of doctors and other medical staff [27]. Furthermore, in 2014 and 2016, further policies showed more awareness of fighting illegal medical activities [23] and concerns for resolving mob-related criminal behavior at medical hospitals [24]. Before these enactments, the enforcement of punishment for violence against doctors and the level of security for hospital staff were weak, allowing doctors and other medical staff to become victims [52].

Nonetheless, it is the role of the government to enforce proper regulations to prevent danger to medical staff. Our results show that the only interaction between attitude and turning point occurred from 2013 to 2014, which is connected with relevant policies between 2014 and 2016 contributing to a significant drop in citizens' "blame" of doctors (see Table 8 for significant *P* values). These efforts show that the Chinese government has heightened vigilance toward the problems displayed by increased violence against doctors incidents and more order in controlling the harms caused by such incidents. However, their efforts remain slightly below the US approach, suggesting that the Chinese government should continue to adopt more control and management roles in medical emergencies. According to the Chinese government, "Following the Occupational Safety and Health Act of 1970, 26 US states and two US territories require employers to develop detailed violence prevention programs. The Occupational Safety and Health Administration (OSHA) have also increased the number of visits to medical facilities, from 11 in 2010 to 86 in 2014. The American Government Accountability Office (GAO) gave a specific recommendation in its 2016 Work Report. Employers should be punished if they allow employees to be exposed to potential workplace violence, especially if they have a history of violence, assault or physical assault; provide additional information to inspectors in specific court summon cases to help develop a system of summonses; follow up confirmation of the need for further measures" [42,43,53].

In analyzing the comments rather than the news articles themselves, we provided a more direct measure of the public's perspective and attitude toward the health care sphere and their stance on the patient–physician bond. The data we collected on these comments can further be used as a potential indicator of health care quality, as few reliable measures exist. Wang et al [54] utilized medical malpractice incidents as a probable marker of health care quality, but a more robust and direct measure is needed to probe the difficulties experienced by the Chinese medical field. We analyzed the comments based on the variable of time, so we can see changes and patterns through time, compared to previous studies, which examined more qualitative methods to seek reliable measures of the patient–doctor relationship [55,56]. Comments made by the general public can reveal their emotions and opinions, as well as their perceptions and viewpoints on the shortcomings of the health care field and expose needed reforms for the improvement of trust in medical professionals.

Our study also contributes to the qualitative study of feelings of mistrust in the physician–patient relationship in China. A survey of 107 health care physicians in Guangdong province, China, reported that physicians are caught in a "vicious cycle of mistrust" due to various contributing factors of work overload, conflicts of interest, unreasonable requests of patients, and more [57]. Restoring public trust in their physicians requires a strong foundation supported by government regulations for effective delivery and more transparent methods of health care quality assessments.

The media play an essential role in contributing to overall public attitudes toward the physician–patient relationship and overall health care system when it documents violence against doctors events for citizens. Both print and electronic media have a responsibility not to sensationalize the news. Health care workers and officials have cited negative media coverage and sensationalism of violence against doctors events as a prime reason contributing to the deteriorating doctor–patient relationship and mistrust in the medical field [58]. The practice of medicine is highly complex. Diagnosis of a patient is an essentially hypothetico-deductive process, and with new evidence presented through investigations and knowledge, this process continues to be refined. However, whatever the diagnosis may be, patient management generally considers such uncertainties and treatment continues. One of the purposes of this paper has been to analyze whether the government's policies can affect public opinion on doctor–patient issues, mainly regarding the policies issued by the government on how to report violence against doctors events to influence public opinion. We expect that government policy could intervene in doctor–patient relationships through medical information and media, and our data demonstrate this. However, we do not expect that the decrease in netizens' blame of doctors and the increase in support for doctors will immediately end the trend of violent acts against doctors. Another purpose of our study was to understand the current trends in the medical network for violence against doctors and hope to find a breakthrough to ease public opinion. Although the media is not the initiator of such medical violence incidents, they are a vital participant in the aftermath, playing the critical role of disseminator of information. Thus, information authenticity and other aspects need to be considered.

In China, the internet environment is managed and controlled by the government, which pays attention to the impact of the network on society. If news media views drive the mood of internet users, then internet users' irrational speech will increase, also causing more extreme emotions and comments (broken window effect). Media reports tend to play an essential role in driving social norms, which influence people's behavior and outlooks on topics [57]. To prevent the news of medical violence harming public opinion, network administrators may need to carry out monitoring measures. In our study, we observed numerous emotionally charged comments, which indicate that these news media network comments have not been filtered by management; otherwise, there would be fewer "blame-style" comments. However, measuring the extent of comment monitoring of online news platforms is beyond the scope of our study. When an outlet is provided for netizens to discuss current events, express their views, and vent their emotions, it should guarantee as much free speech as possible, but it is unclear whether the same should apply in terms of medical violence.

China's intentional homicide has increased in our statistical data years—eg, from 10,285 in 2013 to 17,946 in 2015 [59]. The killing of a doctor is intentional homicide and with the increase in this crime, there has been an increase in the number of doctors killed. However, this does not mean that the relationship between doctors and patients has deteriorated further. The current research focuses on violence against doctors, not just homicides. According to statistics on other similar topics, the incidence of violent medical injuries in China has declined since 2015 [60].

Our study has several limitations. Our scope is limited to the violence against doctors events we selected for the study and to comments referring to those incidents, but we did not cover all types of medical incidents. Furthermore, the sample size, timeline, and number of comments are limited for objective reasons. Hence, we expect further research to be conducted to improve the study of people's emotional valence in violence against doctors events. In future research, we hope to study the key factors influencing people's emotions in violence against doctors events through randomized controlled trials. Future studies could also compare violence against doctors events across hospital types, for example, comparing violence against doctors events in private versus public hospitals. Examinations of violence against doctors events across departments within hospitals could also offer information on variations across specialties (eg, obstetrics, pediatrics, and other departments). Regional variations could be another area of inquiry. We seek to provide practical evidence and interventions to reduce the incidence of violence against doctors events and improve the doctor–patient relationship in China.

The causes of the rise and severity of violence against doctors in China are numerous and can be traced back to the systemic roots of inadequate investment in the health care system with subpar training and salaries for physicians, leading to higher chances of medical errors, administrative exploitation, and ineffective communication between patients and medical staff. Other factors may be cultural and societal, such as unfavorable and sensationalized news articles about doctors, the public's limited knowledge of medicine, unrealistic expectations from doctors and treatments, and detrimental out-of-pocket expenses for patients. As such, the impact of violence against doctors is of great concern and should not be taken lightly for the future of Chinese medicine. Further studies highlighting the role of the government and media should be conducted to improve the physician–patient relationship.

Conclusions

By matching the policy documents for medical violence with the online commentary attitudes, we found that the state's administrative intervention effectively guided public opinion. Notably, these findings provide scientific evidence and support for the government's role in intervention and prevention of both cyber and physical violence.

During the COVID-19 pandemic, many countries have been advocating home isolation, leading to a major increase in people's reliance on the internet for social support and health care information. During the pandemic, a harmonious patient–physician relationship has become an important guarantee for countries in responding to the epidemic. The results of this study show that the government's reasonable and effective policy guidance for violence against doctors has a significant impact (see Tables 7 and 8 for significant values) on the public's comments on online media reports, which in turn contribute to the normal medical order as well as epidemic prevention and control.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Comments acquisition.
[DOCX File , 16 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Details of the VAD cases reported by international media from 2011–2020.
[DOCX File , 18 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Nineteen policies promulgated by the Chinese central government.
[DOCX File , 18 KB-Multimedia Appendix 3]

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Abbreviations

ITSA: interrupted time series analysis

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Original Paper

Associations of Health Literacy, Social Media Use, and Self-Efficacy With Health Information–Seeking Intentions Among Social Media Users in China: Cross-sectional Survey

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Abstract

Background: Empirical research has demonstrated that people frequently use social media for gathering and sharing online health information. Health literacy, social media use, and self-efficacy are important factors that may influence people's health behaviors online.

Objective: We aimed to examine the associations between health literacy, health-related social media use, self-efficacy, and health behavioral intentions online.

Methods: We conducted a cross-sectional survey of adults 18 years and older (n=449) to examine predictors of health-related behavioral intentions online including health literacy, social media use, and self-efficacy in China using 2 moderated mediation models. Mediation and moderation analyses were conducted.

Results: Self-efficacy mediated the effects of health literacy ($B_{indirect}$=0.213, 95% CI 0.101 to 0.339) and social media use ($B_{indirect}$=0.023, 95% CI 0.008 to 0.045) on health behavioral intentions on social media. Age moderated the effects of health literacy on self-efficacy (*P*=.03), while previous experience moderated the effects of social media use on self-efficacy (*P*<.001).

Conclusions: Health literacy and health-related social media use influenced health behavioral intentions on social media via their prior effects on self-efficacy. The association between health literacy and self-efficacy was stronger among younger respondents, whereas the association between health-related social media use and self-efficacy was stronger among those who previously had positive experiences with health information on social media. Health practitioners should target self-efficacy among older populations and increase positive media experience related to health.

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KEYWORDS

behavioral intention; health literacy; self-efficacy; social media

Introduction

The remarkably fast growth of the internet has made it a major source for information sharing and acquisition. In the late 1990s, the internet became a main source for health information [1]. Advantages of using the internet for health information include (1) it is the most convenient and comprehensive source; (2) the information seekers remain anonymous; and (3) it helps reduce inequalities and eliminate barriers (eg, distance) [2]. A study [3] found that, in China, 76.3% of computer-based users and 68.8% of mobile-based (eg, smartphone) users sought health information on the internet [3]. Furthermore, the advent of social media has enabled more possibilities such as connecting people with similar health concerns or social support groups of patients [2,4].

With the rapid growth of social networking sites in China, the number of users and the variety of information on such sites have increased tremendously. As of 2018, there were 317 million active users of Weibo and 1 billion users of WeChat, which are the 2 main social media sites in China [5]. Weibo, a platform for microblogging, is often seen as the Chinese version of Twitter. WeChat is an instant messaging app that is similar to WhatsApp or Facebook Messenger, but it has more technological functions, such as free video or voice calls, group chat, public information sharing, mobile payments, and the ability to post pictures or videos [6].

Generally, extensive use of social media has been associated with informational or emotional need, professional development, social status, self-expression, and social interaction [7]. With an increasing awareness of health among the general public, a growing number of people in China are using social media for seeking and sharing health information [2,6]. Social media provide health information through multimedia affordances instead of solely text, which can increase the understanding of health information among populations with low health literacy [8]. Health literacy entails people's knowledge, motivation, and competency to access, understand, appraise, and apply health information in order to make judgments and decisions in everyday life concerning health care, disease prevention, and health promotion to maintain or improve their quality of life [9].

Additionally, a variety of health information and knowledge that used to be exclusive to health care providers are now available to health information seekers on social media [10]. Moreover, the user-generated nature of social media enables the sharing of health information and experiences, which provide views on health care from a patient’s perspective and increase patient empowerment [11]. Approximately, 40% of the individuals who sought health information on social media also shared their personal health experiences [12]. Furthermore, previous studies [13,14] have shown that use of social media has positive effects on health behaviors.

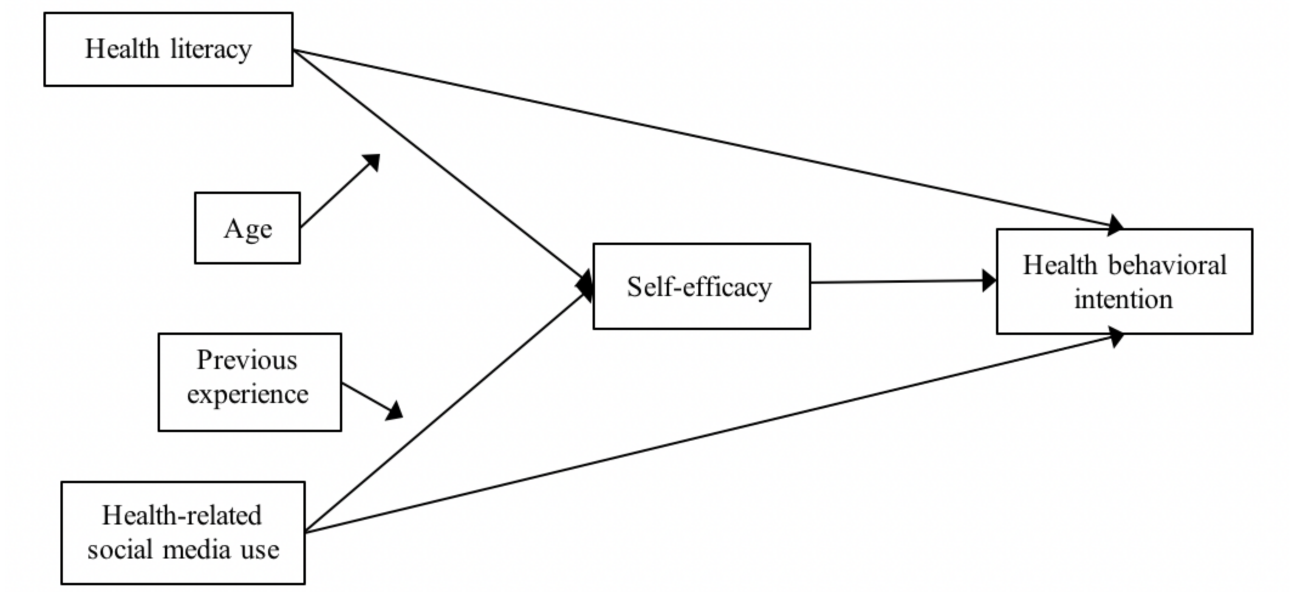
The health impact of social media in China has not been sufficiently studied and understood. For instance, research has focused on an examination of prominent health topics on social media [15] and how the general public views the impact of social media on health information acquisition [6]. Some studies have investigated the benefits and barriers [2], constructs of the theory of planned behaviors [16], cultural determinants, and doctor-patient communication [17] of health information intentions in China. Many studies in China have focused on health literacy among older adults or regionally [18-21]. However, no previous studies have comprehensively examined the potential relationships between health literacy, social media use, self-efficacy, and health behavioral intentions on social media in China based on the health literacy skills framework [22] and the social-cognitive perspective [23]. It is important to assess these constructs because studies have shown that health literacy levels in mainland China (the People's Republic of China excluding the special administrative regions of Hong Kong and Macau) remain low, which warrants further research regarding health literacy and related risk factors [24].

According to the health literacy skills framework, demographic factors, such as age, would moderate the development of health literacy while potential mediators, such as patient-provider communication [25] and knowledge [26], would mediate the effects of health literacy on health-related outcomes [22]. A number of studies [27-30] have found support for the mediating role of self-efficacy on health-related behavioral intentions [27,28]. Self-efficacy is the capacity to have positive effects on an individual’s health [29]. Lee et al [30] found that self-efficacy mediated the effects of health literacy on health behaviors.

It has also been documented that social media use plays a positive role in health behaviors [14]. Previous studies [16,31] in China also found the association between social media use and health behavioral intentions. In addition, previous research has identified the association between media use and self-efficacy [32]. Social-cognitive theory posits that one’s involvement with a subject grows over time through positive personal experiences, as one increases self-efficacy [33]. One study [34] found previous online health information seeking experience moderated seeking more of such information online. Therefore, health-related social media use and previous experience with using social media for health purposes could potentially influence self-efficacy and, consequently, impact health behavioral intentions.

The goal of this study was to examine the role of health literacy, social media use, and self-efficacy on health behavioral intentions on social media in China. Based on the literature, we proposed the following hypotheses (a conceptual model of the study is shown in Figure 1):

Figure 1. Conceptual framework.



- Hypothesis 1: Self-efficacy will mediate the effects of health literacy on health behavioral intentions on social media.
- Hypothesis 2: Self-efficacy will mediate the effects of health-related social media use on health behavioral intentions on social media.
- Hypothesis 3: Age will moderate the effects of health literacy on self-efficacy.
- Hypothesis 4: Previous experience with using social media for health will moderate the effects of health-related social media use on self-efficacy.

Methods

Recruitment

We disseminated an online survey on Sina Weibo (Sina Corporation) in China using a paid advertisement service. Participants were required to be social media users and be at least 18 years of age. The first page of the survey was an online consent form including study information. After reading the consent form, indicating that they agreed to participate and were 18 years or older, respondents were allowed to proceed. After completing the survey, respondents were entered in a raffle to win CNY ¥300 (approximately US $42.86). The study was reviewed by the university institutional review board and was approved as an exempt study.

Measures

Health-related social media use was measured by one question asking how frequently they have used social media for health information before on a scale ranging from 1 (never) to 7 (multiple times a day) (mean 4.01, SD 1.86). An English instructor at a Chinese university translated the questionnaire and used back-translation to ensure consistency in wording between English and Chinese versions of the survey.

Health literacy was measured by a scale adapted from Chinn and McCarthy [35] for health literacy measurement. This scale included seven 3-point items (rarely, sometimes, often), such as “When you talk to a doctor or nurse, do you give them all the information they need to help you?” and “Are you someone who likes to find out lots of different information about your health?” (mean 2.14, SD 0.40; Cronbach α=.71).

Self-efficacy was captured by the self-efficacy scale from Lee et al [29]. Five 7-point Likert-type items measured the degree of agreement with statements regarding self-efficacy in managing one’s health, such as “I have been able to meet the goals I set for myself to improve my health” and “I am confident I can have a positive effect on my health” (mean 5.04, SD 1.04; Cronbach α=.85).

Previous experience was measured by asking the respondents whether they found the health information on social media useful on three 7-point Likert scale items such as “In the past three months, health advice offered on social media sites has been useful to me” (mean 4.01, SD 1.58; Cronbach α=.91).

Behavioral intention was measured from an adapted multidimensional scale [36]. Three 7-point Likert-type items asked the extent to which respondents agree with the statements about their behavioral intention regarding health information on social media including “I will act upon the advice that is offered in the message in the near future,” “I will forward the message to my online acquaintances,” and “I will recommend the advice I read in the message to another person” (mean 3.84, SD 1.42; Cronbach α=.90).

We also measured demographic variables including age, sex, education, and family yearly income. Sex, education, and family yearly income were measured with 3 categorical questions while age was measured by asking participants to indicate their age in numbers (Multimedia Appendix 1).

Statistical Analysis

To test the hypothesized associations, we used estimated direct and indirect effects in mediation and moderation models using SPSS statistical software (version 25.0, IBM Corp; PROCESS macro [37]). Mediation models (PROCESS model 4) were used for hypothesis 1 and hypothesis 2, whereas PROCESS model 7 was used to test the moderated mediation effect. Age, sex, education, and family yearly income were controlled as covariates for hypotheses 1, 2, and 4, whereas sex, education, and family yearly income were controlled as covariates for hypothesis 3.

Results

User Statistics

A total of 608 respondents began the questionnaire; however, 127 were removed due to declining to participate or incomplete participation (defined as more than 50% of the survey not completed), and 32 were excluded due to missing data. We had a final sample size of 449 (women: n=345; men: n=104; age: mean 25.23 years, SD 5.23, range 18-66). There were 242 participants aged from 23 to 30 years old (242/449, 53.9%). The education level of the sample was high, with 52.6% of the respondents (236/449) reporting having a bachelor's degree, and 53.7% of the respondents (241/449) reported their family annual income was between ¥50,000 (approximately US $7150) to ¥200,000 (approximately US $28,600) (Table 1).

Table 1. Descriptive statistics.

Variable	Value
Behavioral intentions, mean (SD)	3.84 (1.42)
Health literacy, mean (SD)	2.16 (.42)
Self-efficacy, mean (SD)	5.04 (1.04)
Social media use, mean (SD)	3.80 (1.48)
Previous experience, mean (SD)	3.99 (1.60)
Gender, n (%)	
Female	345 (76.8)
Male	104 (23.2)
Age (years), mean (SD)	25.23 (5.23)
Education, n (%)	
High school degree or lower	16 (3.6)
College degree or some college	236 (52.6)
Graduate degree or higher	197 (43.8)
Family yearly income (CNY[a]), n (%)	
0-50,000	124 (27.6)
50,001-100,000	112 (25.0)
100,001-200,000	129 (28.7)
>200,001	84 (18.7)

[a] An approximate exchange rate of 1 CNY to US $0.143 is applicable.

Evaluation Outcomes

According to the results of model 4, self-efficacy mediated the effects of health literacy on health behavioral intentions on social media ($B_{indirect}$=0.213, SE 0.060, 95% CI 0.101 to 0.339). Thus, hypothesis 1 was supported. The participants who had higher health literacy also had higher self-efficacy and then would be more likely to intend to perform health behaviors based on information acquired on social media (eg, use the health advice they found). Self-efficacy mediated the effects of health-related social media use on health behavioral intentions on social media ($B_{indirect}$=0.023, SE 0.009, 95% CI 0.008 to 0.045), indicating hypothesis 2 was supported—the more the participants used social media for health, the higher their self-efficacy, and they would be more likely to have greater intentions to perform health behaviors on social media.

Moderated Mediation

The results of moderated mediation models are shown in Table 2 and Table 3. According to the results of model 7, age moderated the effects of health literacy on self-efficacy (*B*=–0.041, SE 0.019, *P*=.03). The interaction had a negative effect on self-efficacy. Thus, hypothesis 3 was supported. The moderated mediation model accounted for 10.7% variance in health behavioral intention. Health literacy had a direct effect (*B*=0.345, SE 0.141, *P*=.02) as well as an indirect effect (Table 4) on health behavioral intention.

Previous experience with using social media for health moderated the effects of health-related social media use on self-efficacy (*B*=0.058, SE 0.015, *P*<.001). The interaction had a positive effect on self-efficacy. Therefore, hypothesis 4 was supported. This moderated mediation model accounted for 31.3% variance in health behavioral intention. Health-related social media use had a direct effect (*B*=0.315, SE 0.0309, *P*<.001) as well as an indirect effect (Table 5) on health behavioral intention.

Table 2. Regression results for effects of self-efficacy, age, and health literacy on health behavioral intention (R^2=0.107, *P*<.001).

Variable	B^a (SE)	*P* value	95% CI
Sex	0.156 (0.152)	.30	–0.142 to 0.454
Education	0.214 (0.086)	.01	0.046 to 0.382
Family yearly income	0.141 (0.043)	.001	0.058 to 0.225
Health literacy	0.345 (0.141)	.01	0.068 to 0.621
Health literacy × age on self-efficacy	–0.041 (0.019)	.03	–0.077 to–0.004
Self-efficacy	0.318 (0.069)	<.001	0.183 to 0.453
Direct effect of health literacy on health behavioral intention	0.345 (0.141)	.01	0.068 to 0.621
Index of moderated mediation: age	–0.013 (0.006)	N/A[b]	–0.025 to –0.001

[a] Unstandardized final model coefficients.

[b] N/A: not applicable.

Table 3. Regression results for effects of self-efficacy, previous experience, and health-related social media use on health behavioral intention (R^2=0.313, *P*<.001)

Variable	B^a (SE)	*P* value	95% CI
Age	0.052 (0.011)	<.001	0.029 to 0.074
Sex	0.138 (0.136)	.31	–0.128 to 0.405
Education	0.259 (0.078)	.001	0.106 to 0.412
Family yearly income	0.145 (0.037)	<.001	0.071 to 0.218
Health-related social media use	0.315 (0.031)	<.001	0.254 to 0.376
Health-related social media use × previous experience on self-efficacy	0.058 (0.015)	<.001	0.029 to 0.087
Self-efficacy	0.250 (0.057)	<.001	0.137 to 0.363
Direct effect of health-related social media use on health behavioral intention	0.315 (0.031)	<.001	0.254 to 0.376
Index of moderated mediation: previous experience	0.015 (0.005)	N/A[b]	0.006 to 0.026

[a] Unstandardized final model coefficients.

[b] N/A: not applicable.

Table 4. Conditional indirect effects of health literacy on health behavioral intentions by age.

Age (years)	Effect	SE	95% CI
20	0.294	0.079	0.145 to 0.452
25	0.226	0.062	0.109 to 0.351
30	0.158	0.059	0.061 to 0.290

Table 5. Conditional indirect effects of health-related social media use on health behavioral intentions by previous experience.

Previous experience (score)	Effect	SE	95% CI
mean – 1 SD (=2.414)	–0.017	0.012	–0.044 to 0.002
mean (=4.005)	0.006	0.007	0.009 to 0.020
mean + 1 SD (=5.597)	0.029	0.010	0.011 to 0.050

Moderation Effects

Conditional indirect effects of health literacy on health behavioral intentions by age are shown in Table 4, and conditional indirect effects of health-related social media use on health behavioral intentions by previous experience are shown in Table 5. The positive indirect relationship between health literacy on health behavioral intentions was stronger among the younger segment of our sample (point estimate 0.294, SE 0.079, 95% CI 0.145 to 0.452). Additionally, the positive indirect effect of health-related social media use on health behavioral intentions was stronger among those participants who previously had positive experience with health information on social media, who were at one standard deviation above the mean (point estimate 0.029, SE 0.010, 95% CI 0.011 to 0.050). The moderated mediation results also revealed that self-efficacy remained a significant mediator no matter whether the participants were at 20, 25, or 30 years old. However, self-efficacy was only a significant mediator when the participants had the mean score of previous experience with health information on social media or one standard deviation above the mean score.

Discussion

Principal Findings

A substantial number of studies have examined health information on social media in China [6,16-18,28,38]; however, no previous studies have examined health behavioral intentions on a Chinese social media site from both the health literacy skills framework [22] or social-cognitive perspectives [23]. And there has been no study to comprehensively investigate how health information with different features on social media influenced the trust in such health information. Some studies [39,40] have examined the role of past experience and social media use individually, and some studies [18,20,21] have tested the associations between self-efficacy and other health outcomes; however, there are few empirical studies examining the relationship among health literacy, past experience, health-related social media use, and health behavioral intention on social media.

Our findings indicate that health literacy and health-related social media use influenced health behavioral intentions both directly and through their prior effects on self-efficacy in managing one’s health. Individuals with higher levels of health literacy had greater self-efficacy in managing their health and then, consequently, had greater health behavioral intentions on social media such as using the health information they found or sharing health information with others from the internet. Part of this finding is also consistent with those from previous studies [9,41,42] suggesting that health literacy is positively associated with information sharing. We also found that individuals who used social media for health purposes more frequently were more likely to report higher self-efficacy in managing their health and greater health behavioral intentions on social media. Social media usage for information could improve people’s psychological state and increase confidence and motivations to cope with uncertainties [43]. Therefore, people who use social media for health more frequently would be able to learn new information, cases, health experiences of others, and avoid potential risks, which could lead to a higher confidence in managing one’s own health. Our finding regarding the positive association between self-efficacy and health behavioral intentions is consistent with the social-cognitive theory perspective and previous empirical studies [44,45] examining effects of self-efficacy on different health behaviors and behavioral intentions.

Another important finding from our study pertains to the moderated mediation effects. Higher health literacy was associated with greater self-efficacy in health, which in turn was related to higher health behavioral intentions on social media. This relationship between health literacy and self-efficacy was moderated by age, suggesting that health literacy increased self-efficacy among younger social media users and eventually promoted their health behavioral intentions on social media. Younger social media users who had greater health literacy tended to have higher confidence in managing their own health and consequently had greater intentions to perform health behaviors. Among the older segment of social media users, no matter their health literacy level, their confidence in managing, improving, and generating positive effects on their health was lower than those of the younger groups. A number of studies [46-48] have found the negative association between age and self-efficacy. In one study [49], older adults who had lower incomes and lower education had relatively low self-efficacy, which was similar to our findings regarding the results of socioeconomic status and self-efficacy.

The positive relationship between health-related social media use and self-efficacy was stronger among those who had previously benefited from using social media for health. When people seek health information online, they usually not only experience increases in health knowledge but also find social support and help from people in similar situations [50]. Therefore, individuals with prior positive experiences using social media for health would have greater efficacy in exerting positive effects on one’s health. Previous experience with applying health advice found on social media in real life that resulted in good health results would improve their confidence in continuing to seek and use health information online.

Implications

With the rapid growth of social media use, this study has important implications for health practitioners. A framework for health behavioral intentions was constructed based on the components of the health literacy skills framework [22] and the social-cognitive perspective [23].

Health literacy influenced self-efficacy and health behavioral intentions, which highlights the importance of health literacy level in China. The concept of health literacy is not popular in China and the quality of medical services provided in China varies significantly based on areas. This makes it important to improve the health literacy level in China so that people can have the ability to take effective and accurate actions related to health. Given the moderating role of age, participants between the ages of 25 and 30 years in our sample require more customized interventions, such as including carefully evaluated digital elements [51,52], to improve their self-efficacy in managing their health in health interventions.

Greater health-related use of social media was associated with higher self-efficacy and health behavioral intentions, indicating the importance of social media in understanding health behavioral intentions. Since the association between health-related social media use and self-efficacy was increased by positive experience with social media for health, health practitioners and scholars should aim to improve users' experiences with social media regarding health information.

The findings are important for health scholars interested in understanding the factors that influence the intent to use health information on social media sites. This study also provides insights for health message designers who want to build effective health campaigns and distribute accurate and credible health information on social media platforms. Future studies should explicitly investigate how to improve health literacy levels and users' experience with social media, such as by developing health literacy education programs [53].

Limitations

Limitations in this study should be considered. First, we used a convenience sample on social media. The service used to advertise the survey link claimed to spread the survey post randomly, however, those who were interested in this study might share some similar traits (such as being in a younger population group or interested in this topic). Therefore, the sample was not truly representative of social media users in general, which might limit generalizability to other populations. Our sample was biased toward younger populations. Future studies could use different means to distribute the survey in order to reach a more diverse audience.

Second, while we asked people if they would act on the health information, we cannot verify or assess the potential accuracy of information that would be obtained. Future work should also consider credibility of the sources and information presented as part of the findings in terms of whether acting on information would be beneficial for health [54], especially in the online environment in which health misinformation may be rampant.

Finally, this study focused on investigating whether or not social media use could predict health-related behavioral intentions. Although previous research suggested that social media use could be influenced by cognition and behaviors [55], we did not test the reinforcing spiral framework of social media use in this study. This framework indicates that media use can influence attitudinal or behavioral outcomes, which can in turn affect habits of using media. According to this framework, media use can be an outcome of psychological processing and behaviors and also can influence psychological and behavioral results. Future studies should examine the reinforcing role of social media use in predicting health-related behavioral intentions on social media.

Conclusions

Health literacy and health-related social media use in China participants influenced health behavioral intentions on social media via their prior effects on self-efficacy in health. The association between health literacy and self-efficacy was stronger among younger respondents, whereas the association between health-related social media use and self-efficacy was stronger among those who previously had positive prior experience with health information on social media. Our results provide insights for health practitioners and researchers and increase understanding of the mechanisms behind using social media for health.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Variables.
[DOCX File , 29 KB-Multimedia Appendix 1]

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Original Paper

How Social Media Use at Work Affects Improvement of Older People's Willingness to Delay Retirement During Transfer From Demographic Bonus to Health Bonus: Causal Relationship Empirical Study

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Abstract

Background: With the increased older population in China and the subsequent reduced labor force, the "demographic bonus" is disappearing. The Chinese government proposed a Healthy China strategy in 2017. The transfer of the demographic bonus to a "health bonus" extended the working life of people and reduced the negative impact of the population's aging on the labor force structure.

Objective: This research focuses on the effect of older workers' social media usage at work on their work ability (related to both physical and mental health) and thus their willingness to delay retirement.

Methods: The questionnaire respondents were older than 55 years, and they obtained the questionnaire from social media, from June to July 2018. A total of 1020 valid questionnaires were collected, and SmartPLS 3.28 (SmartPLS GmbH) was used to analyze the data. Effects were analyzed using 2-tailed t tests.

Results: (1) Use of social media at work can improve information support (t_{14}=13.318, P<.001), emotional support (t_{14}=13.184, P<.001), and self-efficacy (t_{14}=6.364, P<.001) for older people; (2) information support is the main factor affecting the self-efficacy of older workers (t_{14}=23.304, P<.001), as compared with emotional support (t_{14}=1.799, P=0.07); (3) the impacts of emotional support on work ability (t_{14}=8.876, P<.001) and work stress (t_{14}=9.545, P<.001) are generally higher than those of information support (t_{14}=4.394, P<.001; t_{14}=5.002, P<.001); (4) self-efficacy has an impact on work ability (t_{14}=5.658, P<.001) and work stress (t_{14}=4.717, P<.001); and (5) the impacts of work ability (t_{14}=8.586, P<.001) and work stress (t_{14}=8.579, P<.001) on retirement willingness are greater than those of emotional support (t_{14}=2.112, P=.04) and information support (t_{14}=4.314, P<.001).

Conclusions: Our study confirms that the use of social media at work has a positive impact on older workers. Based on the findings, we have put forward proposals to extend people's working lives and help governments implement health bonus policies. In the future, we will compare the different values of willingness to delay retirement among older people in different occupations and different cultures.

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KEYWORDS

social media; older workers; social support; work ability; delayed retirement

Introduction

Background

The problems associated with an aging population have become a worldwide challenge, affecting multiple countries and regions. According to a World Health Organization report from late 2017, the proportion of the world's population older than 60 years will double by 2050, increasing from 11% to 22%. According to estimates, by 2050, the absolute number of people older than 60 years will increase from 605 million to 2 billion [1]. This aging population means that the "demographic bonus" has disappeared in a large number of countries. The demographic bonus refers to the situation where a falling birth rate reduces the number of minors, reduces the burden on the family, and forms a relatively rich labor force, which is conducive to economic development [2]. However, the aging population also means that the labor force's share of the population is falling, the dependency ratio is rising (ie, the dependency of older people and children), and the economy is developing slowly because of the shortage of labor. Therefore, it is necessary to find new sources of labor to reduce the negative impact of a labor shortage.

While high-income countries have the challenges of an aging population and declining demographic bonus, they also have a population of older adults (older than 60 years) who are healthier [3], with better working capabilities, compared with those in low-income countries. Therefore, developing human resources among older adults and promoting the generation of a second round of a demographic bonus has become a problem that needs to be solved by all countries troubled by the challenges of an aging population [4]. The Chinese government proposed a Healthy China strategy in 2017, promoting the transformation of the demographic bonus to a "health bonus," and improving working life, which will reduce the aging population's negative impact on the structure of the labor force. The health bonus refers to the situation where labor productivity is improved to alleviate the labor shortage caused by the aging population; this provides a foundation for the healthy growth of the population of older adults who have delayed retirement, as well as adults of childbearing age, by improving the health of the workforce [5].

Determining how to maintain and improve the physical and mental health level of older workers and optimize the working ability and work experience of older adults has become an important prerequisite to realize the health bonus. Compared with other age groups, older individuals are more susceptible to psychological and mental problems [6]. Effective social support can prevent and alleviate psychological problems and improve the physiological health of older adults, to a certain extent [7]. Therefore, increasing older adults' access to social support is of great significance to extending their working life and delaying their retirement. Especially for older working adults, different types of social support can not only help older workers to improve their physical and mental health but also help them to acquire work-related knowledge and skills and prevent the decline in work that is often caused by aging.

With the development of information and communications technology and the use of social media, access to social support is no longer realized through a single offline channel but can be realized through interactive online and offline channels [7]. Thus, using social media can help older people obtain social support. At present, social media has become an integral part of work. Some people think that the use of social media at work can have negative effects (such as reducing productivity and increasing disturbances) [8]. However, recent studies have shown that social media plays a positive role in work. By using social media at work, people can quickly assign work tasks and report work status and consultation, and workers can obtain different types of social support, which can have a positive impact on people in many ways. This social support can establish and strengthen connections among colleagues, help workers collect professional information, and promote knowledge and resource sharing [9]. Moreover, these behaviors can also promote people's achievement of self-efficacy and improve their self-confidence at work [10]. In addition, non–work-related social media use behaviors (such as entertainment behaviors on social media) can reduce work stress and psychological problems [9]. And interactions on social media related to health information (such as competitive step counting) can also promote exercise around the workplace and maintain people's level of health [11]. In conclusion, the existing research has suggested that the use of social media at work can improve workers' mental health and work ability.

However, the existing research on social media mainly targets "ordinary" employees, resulting in a gap in research on older workers (older than 60 years). Research targeting older workers focuses on their working status, with a gap in research on their willingness to delay retirement. For these older workers, the main factors affecting their retirement are not only economic factors but also health level and job satisfaction [12,13]. The use of social media at work can improve the physical and mental health of older workers to a certain extent and improve their working ability. Furthermore, it can improve the performance of older workers and make them more likely to achieve job satisfaction. Thus, the use of social media at work can affect older workers' willingness to delay retirement. Currently, there is a lack of empirical evidence to confirm that the use of social media at work can affect delayed retirement. In addition, further understanding the demands of employees older than 60 years, as well as how to enhance their ability to work and increase their willingness to delay retirement, promotes the development of this human resource and is of great economic and social value and important theoretical significance. Therefore, this paper puts forward the following questions to explore the impact of social media use at work on the intention of older workers to delay retirement:

1. How does social media use at work improve older workers' physical and mental health, and how does it affect work ability and job burnout?
2. Will social media use at work affect the expected working duration of older workers in the future?

Based on theories relating social support and work ability, this paper studies the work ability and working duration of older adults from the perspective of social media. This paper narrows the focus from all sectors of the community to the sector of older workers, so as to actively improve their workplace conditions and create a better environment for them, thus promoting the health bonus.

Literature Review and Hypotheses

Social Media at Work

Social media is a highly interactive platform based on information and communication technology. Individuals and communities can share, create, discuss, and modify user-generated content through these platforms such as WeChat, Facebook, Twitter, and QQ [14]. The functions of social media include identity, conversations, sharing, presence, relationships, reputation, and groups [14]. The use of social media at work has become a common phenomenon [15]. Some scholars believe that the use of social media at work will distract employees' attention and lead to a decline in work efficiency [8]. However, from a social support perspective, social media used at work is beneficial [16].

Social support is defined as the assistance an individual can access from the social resources of his or her social network [17]. Social support can be divided into four categories: material, emotional, information, and companion support [17]. The social support obtained at work mainly includes information support and emotional support [18]. These different types of social support are important for people to access work-related resources and improve their work-related abilities. Through the use of social media at work, people can more easily access various types of social support. Therefore, we believe that the positive effects of social media use at work include the following aspects:

First, the use of social media at work can increase social support for employees [18]. This kind of social support includes emotional and information support. Social media can make it easier for employees to connect and interact with colleagues [18]. This kind of interaction can facilitate the sharing of work experiences and exchanges of knowledge among employees (information support) [19]. For older people, the use of social media can help them maintain their existing relationships, while the process of learning the method to use social media is also a process of acquiring social support (information and emotional support) [20]. In addition, older people tend to need more attention and support [21]; for older workers, this kind of attention and support is extraordinarily important (emotional support). The characteristics of social media, such as conversations, sharing, presence, and relationships, can increase the acquisition of emotional support [20]. Based on the literature cited above, we believe that the use of social media at work can improve the level of social support for older employees, including emotional support and information support. Therefore, we propose the following hypotheses:

> H1: The use of social media at work can improve emotional support for older workers.
>
> H2: The use of social media at work can improve information support for older workers.

Second, social support gained through the use of social media can also increase self-efficacy. Self-efficacy refers to an individual's belief in his or her capacity to execute behaviors necessary to achieve specific performance outcomes [22]. At work, the level of self-efficacy often determines the individual's work ability and work performance. Factors that affect self-efficacy include knowledge, skills, experience, and social support [22]. Social support can significantly regulate an individual's self-efficacy [23]. On the one hand, social support can promote the acquisition of new knowledge and skills (information support), thereby improving self-efficacy [23]. On the other hand, emotional support can also affect people's self-efficacy. Self-efficacy is constantly changing on a daily basis [24]. The change in self-efficacy is often due to changes in interpersonal relationships [25]. As an important tool for maintaining an individual's interpersonal relationships, social media can help people maintain their social networks in a working environment and help them give or get emotional support. In addition, for older people, the use of social media directly affects an individual's sense of self-efficacy. Involvement in and use of social media can heighten an individual's sense of general self-efficacy, which will increase with a deepening use of social media [26]. In summary, the use of social media can improve people's self-efficacy at work in different ways. Based on the above conclusions, we put forward the following hypotheses:

> H3: The use of social media at work can improve older workers' self-efficacy.
>
> H4: The emotional support accessed from social media can improve older workers' self-efficacy.
>
> H5: The information support accessed from social media can improve older workers' self-efficacy.

Social Support and Work Ability

Work ability is defined as the sum of the factors enabling an employed person in a certain situation to manage his or her working demands successfully [27]. Older workers have abundant work experience and good working skills, but they inevitably experience a decline in physical fitness and cognitive ability with an increase in age. Therefore, for older people, work ability refers to the physical and mental health level that can meet the needs of the work [28].

Effective social support is of great significance to the work ability of employees, especially for older workers. Effective emotional support is an important way for people to maintain and improve their working ability. For example, Pohl and Galletta have demonstrated that emotional support provided by a supervisor in the workplace can improve employees' work ability and reduce their sense of fatigue [29]. A study by Karlsson et al showed that emotional support can help individuals better cope with injuries and combat the decline in work ability caused by injuries [30]. In addition, the work ability level is often associated with the mental health level. Especially for older workers, mental illness is an important reason for a decline in work ability [31]. Emotional support can help individuals prevent and alleviate the harm brought by mental illness [17].

Similarly, information support can also have an important impact on an individual's work ability. Information support at work mainly includes information sharing and the exchange of new knowledge and skills [19]. For older workers, learning new knowledge and skills can improve their work efficiency and prevent the decline in work ability caused by aging [32]. In addition, non–work-related information sharing also can improve older people's ability to work. For example, Edmunds et al confirmed that the support of colleagues related to health information can promote workplace exercise, improve workers' health level, and enhance their work ability [11]. Workplace exercise can not only improve the physical health of older adults but also improve their mental health, which is of great significance for maintaining their work ability [33]. To sum up, we believe that both emotional support and information support will impact the working ability of older workers. Therefore, we hypothesize the following:

> H6: Emotional support can improve older workers' work ability.
>
> H7: Information support can improve older workers' work ability.

Work stress reflects an interaction between individual characteristics and an individual's response to work characteristics [34]. Ganster and Rosen argued that work stress is a process where workers experience mental and physical changes in the short or long term caused by mental experiences and demands at the workplace (the source of stress) [35]. Work stress has negative effects on individuals, causing such physical problems as headache, heart disease, elevated blood pressure, gastropathy, and insomnia, and psychological disorders including depression, hostility, and withdrawal [36].

Good social support can improve employee performance and ease work stress [37]. Emotional support can help individuals better cope with work stress. For example, research by Yang et al shows that peer support and subjective emotional support can effectively help older employees cope with work stress [38]. Moeller and Chung-Yan also confirmed that emotional support from supervisors can improve employees' mental health and reduce their work stress [39]. Similarly, information support from supervisors can also effectively help employees cope with work stress [39]. This is because credible workplace information can reduce an employee's sense of unpredictability and powerlessness, which reduces psychological distress and work stress [39]. In addition, research by Chrisopoulos et al suggests that although emotional support can improve people's ability to cope with work stress, it cannot change the objective stress situation; information support related to tasks or technologies can improve people's work efficiency and reduce their work stress [40]. Based on the above conclusions, we put forward the following hypotheses:

> H8: Emotional support can relieve older workers' work stress.
>
> H9: Information support can relieve older workers' work stress.

Self-Efficacy and Work Ability

Self-efficacy greatly influences an individual's abilities and work stress [41]. First, individuals with higher self-efficacy can cope with work stress more effectively and are more positive about their work. Skaalvik and Skaalvik found a negative correlation between teacher stress and teacher self-efficacy [42]. Research by Lloyd et al shows that self-efficacy can improve people's intrinsic work motivation and reduce work stress [43]. Self-efficacy can also improve work ability in different dimensions. Self-efficacy can influence people's work ability by improving an individual's health, self-confidence, social function, and other factors [44]. Improving work-related self-efficacy and self-management can improve employees' work ability [45]. Higher self-efficacy can also reduce the incidence of mental illness [46]. A healthy state of mind can have a positive effect on work ability and status [31]. Based on the above findings, we believe that self-efficacy can improve older people's work ability and relieve their work stress. Therefore, we put forward the following hypotheses:

> H10: Self-efficacy can improve older workers' work ability.
>
> H11: Self-efficacy can alleviate older workers' work stress.

Willingness to Delay Retirement

The main influencing factors on the duration of older individuals' work lives are their individual health and financial pressures [12]. An individual's subjective will also plays a decisive role [12]. For example, Skaalvik and Skaalvik found that work stress is an important factor affecting one's willingness to retire [42]. Heavier work stress can lead to early retirement, while lighter work stress can prompt individuals to delay their retirement, even motivating teachers older than 65 years to continue working. The individual's sense of satisfaction about nonmaterial factors, such as enjoying working and social recognition, will affect the willingness of adults who reach retirement age to delay retirement [47]. Highly competent (as far as work ability) individuals tend to have greater enthusiasm for work. For individuals with greater enthusiasm for work, retirement can lead to a huge psychological gap [48]. In addition, when work is challenging, people with high work ability tend to be more willing to work longer and delay their retirement [49]. Therefore, for individuals with a passion for work and higher level of work ability, extending the duration of their working life as much as possible can help them maintain their existing social status and enjoy the fun of work. Therefore, we put forward the following hypotheses:

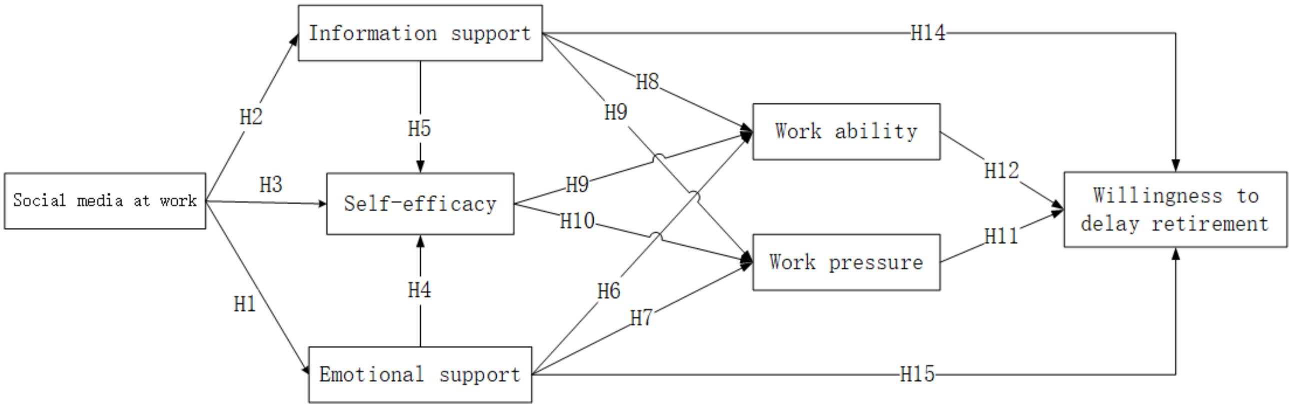
> H12: Work stress will have a negative impact on older workers' willingness to delay retirement.
>
> H13: Work ability will have a positive impact on older workers' willingness to delay retirement.

Finally, the social support gained at work also influences an individual's willingness to retire. According to Hofstetter and Cohen, for older adults, emotional support from colleagues (such as kindness and acceptance) will enhance people's happiness and affect their retirement intention [50]. Emotional support provided by an organization (such as caring for workers' general health) will affect the sense of belonging of older workers and their intention to retire [50]. In addition, continuous learning and development (information support) opportunities provided by organizations relate to the preference for postponing retirement [51]. By contrast, insufficient professional information support by colleagues will lead to career and job stagnation, which may lead to premature retirement [50]. Therefore, the work duration of older individuals is affected by social support. In summary, we believe that work stress, work ability, and social support impact older individuals' willingness to delay retirement. Therefore, we put forward the following hypotheses:

> H14: Information support will have a positive impact on older workers' willingness to delay retirement.
>
> H15: Emotional support will have a positive impact on older workers' willingness to delay retirement.

In summary, this study's proposed model studies the willingness of older workers to delay retirement from the perspective of their social media use at work, examining numerous hypotheses as depicted in Figure 1.

Figure 1. The research model.



Methods

Scale Development

In this study, the main measurement variables included social media at work, social support (emotional and information), work ability, willingness to delay retirement, work stress, and self-efficacy. The questionnaire adopted the form of a Likert 7-point scale. An answer from 1 to 7 indicated the degree to which respondents agreed with the question; 1 meant completely disagree, and 7 meant completely agree. All constructs' measures used in this study are listed in Multimedia Appendix 1 [9,52-59].

A scale showing the effects of social media at work was compiled on the basis of previous studies on an effective scale and was amended to adapt to this study's background. The questions to measure included those about frequency, improving work efficiency, improving communication skills, relieving pressure, learning on the job, and undertaking recreational activities [9,52,53]. In the presurvey sample, the scale had good internal consistency reliability, with a Cronbach α of .902.

The scale of work ability and willingness to delay retirement was based on the work ability index [54]. The Chinese version of the scale shows good reliability and validity [55]. We included 7 items and adapted them to fit the current context. The measured items for work ability included the self-evaluation of work ability, mental adaptability to the current work situation, and physical adaptability to the current work situation, as well as a work performance evaluation. The measured items for willingness to delay retirement included the willingness to retire, self-predicting of future work ability, and willingness to delay retirement. In the presurvey sample, the scale had good internal consistency reliability, with a Cronbach α of .873.

To measure social support, we adopted the social support scale by Cohen and Wills [60]. The scale has shown good reliability and validity in previous studies [56,57]. We adapted the original scale to our needs; the measure of dimensionality included information support and emotional support. In the presurvey sample, the scale had good internal consistency reliability, with a Cronbach α of .901.

Work stress was based on a job content questionnaire [61]. The Chinese version of the scale shows good reliability and validity [62]. The scale included 4 items that refer to quantitative, demanding aspects of the job (eg, time pressure, working hard, excessive work). In the presurvey sample, the scale had good internal consistency reliability, with a Cronbach α of .796.

The earliest general self-efficacy scale was compiled by Schwarzerin in 1981, and the Chinese version was compiled and used in 1995 [58]. The scale has shown good reliability and validity in previous studies [58]. We adapted the original scale to our needs and included 4 items in the questionnaire. In the presurvey sample, the scale had good internal consistency reliability, with a Cronbach α of .789.

Data Collection

The data collection process was divided into several stages. To ensure the quality of the questionnaire, 50 presurvey copies were randomly distributed in Bengbu, China; of these, 47 valid questionnaires were recovered. Some participants were interviewed to determine whether there were problems with the questionnaire, such as unclear language expression or rhetorical errors. Based on the presurvey results, we modified the questionnaire.

The formal questionnaire respondents (staff older than 55 years) were obtained through the Bengbu social security office, and they obtained the questionnaire from social media from June to July 2018. A total of 1500 questionnaires were issued, and

1291 were returned, giving a return rate of 86.1%. After eliminating invalid questionnaires (those that had many blank answers and a high repetition rate of answers), 1020 valid questionnaires remained, giving an effective rate of 79.0%. Table 1 shows the statistics for the demographics.

Table 1. The demographics of the sample.

Category	n (%)
Sex	
Male	521 (51.1)
Female	499 (48.9)
Age (years)	
55-60	146 (14.3)
61-65	629 (61.7)
66-70	175 (17.2)
>70	70 (6.9)
Marital status	
Unmarried	61 (5.9)
Married	772 (75.7)
Divorced	76 (7.5)
Widowed	111 (10.9)
Educational background	
Elementary school	328 (32.2)
Middle school	317 (31.1)
High school	106 (10.4)
College	122 (12.0)
Master’s degree	147 (14.4)
Income (¥)	
<1000	180 (17.6)
1000-2000	216 (21.2)
2000-3000	210 (20.6)
3000-4000	216 (21.2)
4000-5000	81 (7.9)
5000-6000	64 (6.3)
＞6000	53 (5.2)

Results

Model Overview

We used a structural partial least squares structural equation modeling (PLS-SEM) method to analyze the data obtained. The model framework was analyzed using SmartPLS 3.28 (SmartPLS GmbH). The PLS method has relatively loose requirements for the normal distribution of the research sample data and has flexibility in dealing with missing data. Therefore, PLS is suitable for exploratory factor analysis. In addition, PLS-SEM is a comprehensive method that can simultaneously examine all the relationships between the constructs in the measurement and the structural models and can also handle complex models with direct and indirect relationships [63,64]. Therefore, when the model complexity is high, PLS-SEM has more advantages than other methods.

Measurement Model

The measurement model includes the following steps: First, SPSS 22 (IBM Corporation) was used for data analysis. The Cronbach α coefficient value was .880, greater than .80, indicating that the reliability of the questionnaire was good. The test results show a Kaiser-Meyer-Olkin value of 0.899 and a significance level of P<.001. These values indicate that the scale used in this paper has good structural validity, and that the questionnaire is suitable for factor analysis.

To avoid multicollinearity, we tested the data. The maximum variance expansion coefficient was 2.015, much lower than the prescriptive diagnosis of 5 [65]. Moreover, for the goodness of fit, the standardized root mean square residual was measured. The standardized root mean square residual has already been used as the goodness of fit method in PLS-SEM measurement [66]. Standardized root mean square residual values of less than 0.10 or 0.08 (in the more conservative version) are considered suitable [66]. In this study, the standardized root mean square residual was 0.045, less than 0.08. Thus, the model was very well adapted.

Table 2 shows the statistical data of factor loading, composite reliability, Cronbach α, and average variance extracted (AVE). According to Hair, the value of the Cronbach α coefficient should be above .7; in this study, the Cronbach α coefficient was between .792 and .880, indicating that the reliability of the questionnaire was good [65]. The composite reliability value ranged from 0.873 to 0.909, which was higher than 0.7, indicating that the questionnaire had good convergent validity [65]. In addition, the average variance extracted was greater than 0.5, indicating that the observed items explain the variance more than the error term [65] and that the model aggregation validity is relatively high.

Table 2. Construct reliability and convergent validity.

Construct items	Loading	CR[a]	Cronbach α	AVE[b]
WDR[c]		0.878	.792	0.706
WDR1	0.839	N/A[d]	N/A	N/A
WDR2	0.818	N/A	N/A	N/A
WDR3	0.863	N/A	N/A	N/A
WS[e]		0.891	.838	0.673
WS1	0.798	N/A	N/A	N/A
WS2	0.845	N/A	N/A	N/A
WS3	0.811	N/A	N/A	N/A
WS4	0.825	N/A	N/A	N/A
ES[f]		0.883	.823	0.653
ES1	0.835	N/A	N/A	N/A
ES2	0.821	N/A	N/A	N/A
ES3	0.793	N/A	N/A	N/A
ES4	0.783	N/A	N/A	N/A
SMW[g]		0.909	.880	0.625
SMW1	0.792	N/A	N/A	N/A
SMW2	0.777	N/A	N/A	N/A
SMW3	0.822	N/A	N/A	N/A
SMW4	0.759	N/A	N/A	N/A
SMW5	0.789	N/A	N/A	N/A
SMW6	0.804	N/A	N/A	N/A
IS[h]		0.875	.810	0.636
IST1	0.807	N/A	N/A	N/A
IST2	0.8	N/A	N/A	N/A
IST3	0.8	N/A	N/A	N/A
IST4	0.784	N/A	N/A	N/A
SE[i]		0.893	.840	0.676
SE1	0.814	N/A	N/A	N/A
SE2	0.812	N/A	N/A	N/A
SE3	0.832	N/A	N/A	N/A
SE4	0.831	N/A	N/A	N/A
WAI[j]		0.873	.806	0.632
WAI1	0.78	N/A	N/A	N/A
WAI2	0.802	N/A	N/A	N/A
WAI3	0.8	N/A	N/A	N/A
WAI4	0.799	N/A	N/A	N/A

[a] CR: composite reliability.

[b] AVE: average variance extracted.

[c] WDR: willingness to delay retirement.

[d] N/A: not applicable.

[e] WS: work stress.

[f] ES: emotional support.

[g] SMW: social media at work.

[h] IS: information support.

[i] SE: self-efficacy.

[j] WAI: work ability index.

Table 3 shows that the square root of each factor’s AVE value is greater than the other factor correlation coefficients, indicating that the questionnaire had good discriminant validity [65]. In summary, the model has good reliability and validity.

Table 3. Measurement model results.[a]

Constructs	WS[b]	WAI[c]	IS[d]	ES[e]	WDR[f]	SMW[g]	SE[h]
WS	0.820	—[j]	—	—	—	—	—
WAI	0.741	0.795	—	—	—	—	—
IS	0.495	0.510	0.798	—	—	—	—
ES	0.469	0.477	0.460	0.808	—	—	—
WDR	0.703	0.710	0.492	0.479	0.840	—	—
SMW	0.488	0.467	0.456	0.445	0.433	0.791	—
SE	0.481	0.516	0.726	0.412	0.475	0.485	0.822

[a] The numbers on the diagonal are the square roots of the variance shared between the constructs and their measures. Off-diagonal elements are correlations among constructs. For discriminant validity, diagonal elements should be larger than off-diagonal elements.

[b] WS: work stress.

[c] WAI: work ability index.

[d] IS: information support.

[e] ES: emotional support.

[f] WDR: willingness to delay retirement.

[g] SMW: social media at work.

[h] SE: self-efficacy.

[j] —: not applicable.

Structural Model

We used SmartPLS 3.28 to calculate the significance of the model path coefficients using bootstrapping with 3000 samples and 2-tailed *t* tests. The results of direct effects are shown in Figure 2 and Table 4. We also test the total and indirect effects of social media at work on willingness to delay retirement, and the results are shown in Multimedia Appendix 2.

Figure 2. Model results. *$P<.05$, ***$P<.001$.

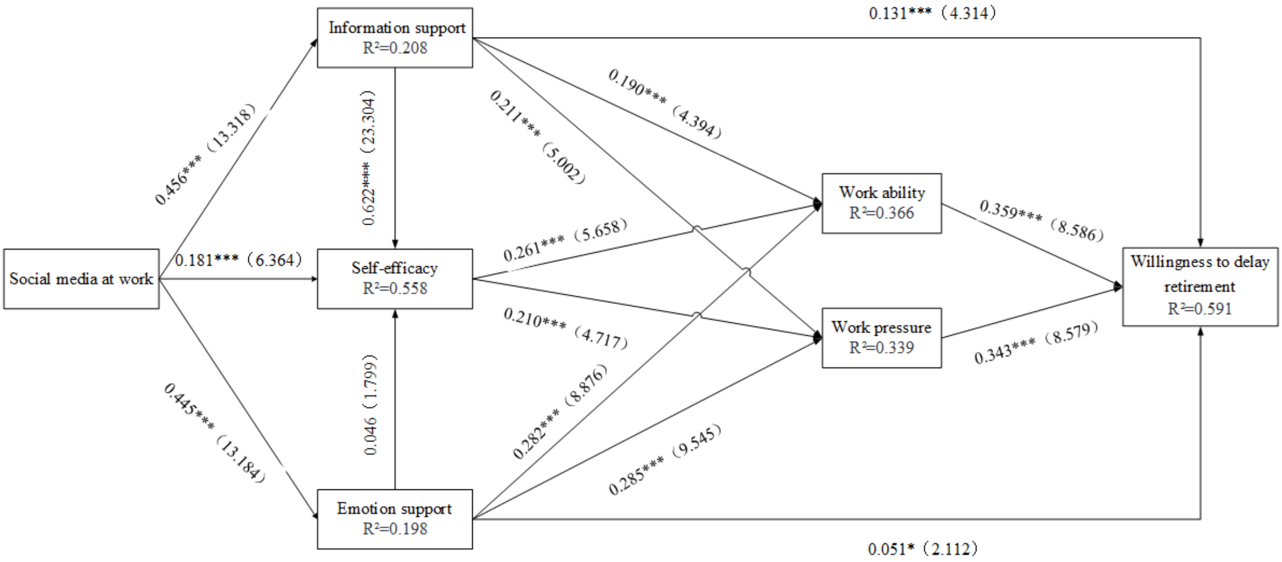


Table 4. Structural parameter estimate.

Hypothesized path	SPC[a]	*t* value	*P* value	Results
H1: The use of social media at work can improve emotional support for older people.	0.445	13.184	<.001	Supported
H2: The use of social media at work can improve information support for older people.	0.456	13.318	<.001	Supported
H3: The use of social media at work can improve older people's self-efficacy.	0.181	6.364	<.001	Supported
H4: The emotional support accessed from social media can improve older people's self-efficacy.	0.046	1.799	.07	Not supported
H5: The information support accessed from social media can improve older people's self-efficacy.	0.622	23.304	<.001	Supported
H6: Emotional support can improve older workers' work ability.	0.282	8.876	<.001	Supported
H7: Information support can improve older workers' work ability.	0.19	4.394	<.001	Supported
H8: Emotional support can relieve older workers' work stress.	0.285	9.545	<.001	Supported
H9: Information support can relieve older workers' work stress.	0.211	5.002	<.001	Supported
H10: Self-efficacy can improve older workers' work ability.	0.261	5.658	<.001	Supported
H11: Self-efficacy can alleviate older workers' work stress.	0.210	4.717	<.001	Supported
H12: Work stress will have a negative impact on older workers' willingness to delay retirement.	0.343	8.579	<.001	Supported
H13: Work ability will have a positive impact on older workers' willingness to delay retirement.	0.359	8.586	<.001	Supported
H14: Information support will have a positive impact on older workers' willingness to delay retirement.	0.131	4.314	<.001	Supported
H15: Emotional support will have a positive impact on older workers' willingness to delay retirement.	0.051	2.112	.04	Supported

[a]SPC: standardized path coefficient.

The hypotheses (H1, H2, and H3) that use of social media at work can improve social support for older people are supported. The effect levels of emotional support (standardized path coefficient=0.445, t_{14}=13.184, $P<.001$) and of information support (standardized path coefficient=0.456, t_{14}=13.318, $P<.001$), which are the two dimensions of social support, are quite similar. Compared with social support, social media has a slighter impact on self-efficacy (standardized path coefficient=0.181, t_{14}=6.364, $P<.001$).

In the hypothesis (H5) of the relationship between social support and self-efficacy, the influence of information support on self-efficacy is confirmed (standardized path coefficient=0.622, t_{14}=23.304, $P<.001$). However, the hypothesis (H4) on the effect of emotional support on self-efficacy proved to be untenable (standardized path coefficient=0.046, t_{14}=1.799, $P=0.07$).

The hypotheses that social support has a positive effect on the work ability (H6, H7) and work stress (H8, H9) of older workers are confirmed. The influences of emotional support on the work stress of older adults (standardized path coefficient=0.285, t_{14}=9.545, $P<.001$) and the ability to work (standardized path coefficient=0.282, t_{14}=8.876, $P<.001$) are bigger overall than those of information support for older workers' work ability (standardized path coefficient=0.190, t_{14}=4.394, $P<.001$) and work stress (standardized path coefficient=0.211, t_{14}=5.002, $P<.001$).

The hypotheses that self-efficacy has a positive effect on the working ability (H10; standardized path coefficient=0.261, t_{14}=5.658, $P<.001$) and work stress (H11; standardized path coefficient=0.210, t_{14}=4.717, $P<.001$) of older workers are confirmed.

The hypotheses that work stress (H12), work ability (H13), and social support (H14, H15) have an impact on the willingness of older workers to delay retirement are confirmed. Work stress (standardized path coefficient=0.343, t_{14}=8.579, $P<.001$) and work ability (standardized path coefficient=0.359, t_{14}=8.586, $P<.001$) have a greater impact on the retirement intention of older workers than does social support. The influence of emotional support (standardized path coefficient=0.051, t_{14}=2.112, $P=.04$) on the intention to delay retirement, which is included in social support, is smaller than that of information support (standardized path coefficient=0.131, t_{14}=4.314, $P<.001$).

Finally, we analyze the effect of social media use at work on older workers' willingness to retire after adding control variables. The *t* test results show that sex, age, marital status, educational level, and income have no significant effect on older workers' willingness to retire. This means that demographic characteristics have no significant effect on the analysis results.

Discussion

Findings

This paper examines the impact of social media use at work on elderly workers' willingness to retire. The empirical results show that 14 of the 15 hypotheses in the research model are confirmed, and 1 hypothesis is not supported. Social media positively impacts elderly workers' willingness to delay retirement. Information support affects their self-efficacy more than emotional support does, while emotional support has a greater effect on work ability and work stress. However, self-efficacy also impacts work ability and the ability to regulate work stress. The impact of work ability and work stress on willingness to retire is greater than that of social support. More detailed results are given in Multimedia Appendix 2.

Our study confirms that the use of social media at work has a positive impact on older workers. The findings suggest that the use of social media at work can help older workers improve their social support and self-efficacy (H1, H2, and H3), which is very important for older people; effective social support can enhance their physical and mental health and reduce the occurrence of psychological disorders such as depression and anxiety [11,17,33]. Similarly, self-efficacy also has positive implications for the mental health of older people [44,46].

In a work environment, information support is the main factor affecting the self-efficacy of older workers, as compared with emotional support. This is a new finding. In previous studies, there was a significant correlation between social support and self-efficacy [23-25]. However, in this study, only information support impacts self-efficacy (H5), and emotional support has no influence on self-efficacy (H4). This result can be explained by the fact that for older workers, past work experience helps them build enough confidence to complete the work they are given. Therefore, emotional encouragement and support have no significant effect on their work self-efficacy. In addition, information support can help older people understand relevant information and learn new skills needed in their work. This is a major finding that reveals new ways to improve the self-efficacy of older workers.

The results also show that the impact of emotional support on work ability and work stress is generally higher than that of information support (H6-H9). This result can be explained by the fact that older workers have established practices for handling their work based on past experience, and the acquisition of new knowledge and new skills is only complementary to their own work ability. They are also experienced enough to cope with work stress. For older workers, who are moving toward the last years of their lives, effective emotional support such as a sense of achievement and satisfaction, as well as respect, can help them to work better and handle work stress. Therefore, the impact of information support on older workers is less than that of emotional support, in this context.

The results show that self-efficacy impacts work ability and ability to regulate work stress (H10 and H11). This result confirms the results of previous research [41]. We believe that this result is due to the specific life stage of older adults. The intellectual and physical decline caused by aging requires effective internal motivation to help older adults stay active at work and alleviate work stress. In addition, considering the results of H6 through H9, social support can alleviate work stress. We found that compared with self-efficacy, social support can more effectively alleviate work stress for older workers. Considering the sources of work stress, we believe that for older workers, when they are doing complex work, they are less able to regulate emotions internally, and external support is needed to help them moderate their emotions. This also confirms the research of Isaacowitz et al [67].

The impact of work ability and work stress on willingness to delay retirement is greater than that of social support. This result indicates that among the influencing factors for older workers' willingness to delay retirement, the individual perceptions of work ability and work stress are the main factors. In addition, work ability and work stress have an equally important impact on one's willingness to delay retirement, while social support has a relatively small impact on this willingness. This result suggests that older people's willingness to delay retirement is mainly affected by work-related factors, and stronger work ability and lower work stress can extend their work duration and delay their retirement.

Implications for Research

This study has several theoretical contributions.

First, our study links the use of social media at work to the willingness of older workers to delay retirement. This is a topic that has not been considered in the past. Past research on the use of social media at work was not specifically targeted at older workers, and there was limited research on their willingness to delay retirement. This study fills this gap. It also demonstrates the influencing mechanism of social media on the special group of older workers. This finding reveals the positive role played by the use of social media at work and its applicability across different groups.

In the course of the study, we explored the impact of social support, work ability, and work stress on older people's willingness to delay retirement, which has never been explored before. The results show that an individual's work ability (internal factor) and work stress (external factor) are mainly affected by external support, while internal subjective motivation (self-efficacy) plays a smaller role than external support. This finding can provide a theoretical basis for guiding the establishment of an effective incentive model for delayed retirement in the future.

Second, our study shows the special nature of older workers. The link between social support and self-efficacy has long been confirmed via past studies [23]. It is generally argued that all dimensions of social support have a positive impact on self-efficacy. However, in this study, the emotional support dimension of social support does not influence self-efficacy. This result suggests that in the working environment, the social support that older workers gain from using social media at work is more intentional; that is, the support is in getting help, gaining new knowledge, or reducing stress at work. This result confirms the results of previous studies [9].

At the same time, we also found that emotional support at work is more important than information support for older people in terms of work ability and work stress. This result shows the special nature of older workers. That is, as older workers are at a late stage of life, they need emotional support more than other dimensions of social support. This result also confirms that different dimensions of social support play different roles at different stages. This is an interesting finding that develops and extends social support–related theories.

Research has shown that self-efficacy is often an important factor to help individuals cope with work stress and improve work ability. This result also confirms the results of previous studies [42]. Combined with the impact of social support on self-efficacy (H4 and H5), the result shows that the self-efficacy of older workers often comes from their acquisition of technology experience and ability, while successful practices from their pasts weaken the role of external emotional incentives. Considering the differences between this study and previous studies (age differences, work and nonwork differences), the results of this study help to further understanding of the special nature of older workers.

Implications for Practice

This study contributes to practice in the following ways:

Our study can provide a basis for relevant government departments in their development of a health bonus plan. Especially in China, the rapid aging and fertility decline of the overall population create an urgent need to develop a health bonus plan in line with national conditions. Moreover, our study can reduce resistance from older people when developing a deferred-retirement policy. The results of the study show that older people’s willingness to delay retirement is influenced by their work ability and work stress. Therefore, the differences between occupations and the actual situation of different types of groups of older adults can be taken into account during the formulation of a deferred-retirement plan, so as to make the plan more reasonable and effectively use the resources of the older adult population and promote the realization of the health bonus.

For companies, our study helps improve the management of, and optimize management plans for, older employees. Based on our conclusions, emotional support can better improve work ability and can reduce work stress more effectively for older workers. Therefore, companies can provide older employees with more emotional encouragement and care and can pay attention to their emotional state. From a social media perspective, companies should encourage and support older people in their use of social media at work, which is of positive significance. For example, company executives can show concern for older workers regarding their work status and mood by using social media. Additionally, colleagues can exchange work-related information, such as new knowledge and new job skills, or encourage each other with exercising by using social media.

The older workers’ acceptance and use of social media devices is important to realize positive aging; this is also an important prerequisite for realizing the health bonus. Our study confirms that using social media at work can improve both social support and self-efficacy, which can not only help older adults at work but also improve their mental health to prevent the physical and mental health problems caused by aging. This result can also help social media developers improve and develop social media features that are more suitable for older people.

Limitations and Future Directions

Due to limited time and other constraints, our study has the following limitations:

First, we studied the impact of social media on older people’s willingness to retire. While this impact is confirmed, social support accessed from social media is only studied in terms of information support and emotional support. Social support has multiple dimensions, and our study does not explore the impact of these other dimensions of social support on older people; examples include objective social support and perceived social support dimensions, and the impact of the availability of support on future deferred-retirement intentions. Therefore, future studies will subdivide social support into these other dimensions and explore in detail the relationship between different social support dimensions, in order to understand the intrinsic relevance of social support to older people’s willingness to delay retirement.

Second, this study does not subdivide occupations or take into account the different characteristics of different occupations. Our study is incomplete, and in the future different occupations will be compared to explore the differences in the willingness to delay retirement among older people in different occupations.

Finally, the main object of study in this paper is a segment of the older population in Anhui Province, China. It is unclear whether the same results would be obtained in other provinces or countries due to cultural differences. Future research based on the results of this study will compare the willingness to delay retirement in different cultures.

Conclusions

The need for deferred retirement has gained a general consensus in China and other developed countries. As China’s population is experiencing an accelerating aging process, how to promote the transformation of the demographic bonus to a health bonus and effectively formulate a deferred-retirement policy has become an urgent problem in China. This paper examines factors influencing older people’s willingness to delay retirement from the perspective of social media. The results of the study provide relevant references for solving this problem.

Our study shows that for older workers, the willingness to delay retirement is mainly affected by work ability and external work stress. Social support gained from social media can effectively help older people enhance their work ability and ease work stress. The results of the model hypothesis test provide the characteristics of older workers’ need of social support.

Based on the findings of this paper, we suggest that the government create deferred-retirement plans based on different occupations and demographic characteristics. We have put forward proposals to extend people’s working lives and help governments implement health bonus policies. Older adults themselves can also actively use social media to improve their social support and physical and psychological health.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Measurement scale.
[DOCX File , 22 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Indirect and total effects of social media at work on willingness to delay retirement.
[DOCX File , 16 KB-Multimedia Appendix 2]

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Abbreviations

AVE: average variance extracted
PLS-SEM: partial least squares structural equation modeling

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Original Paper

A Social Media Campaign (#datasaveslives) to Promote the Benefits of Using Health Data for Research Purposes: Mixed Methods Analysis

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Abstract

Background: Social media provides the potential to engage a wide audience about scientific research, including the public. However, little empirical research exists to guide health scientists regarding what works and how to optimize impact. We examined the social media campaign #datasaveslives established in 2014 to highlight positive examples of the use and reuse of health data in research.

Objective: This study aims to examine how the #datasaveslives hashtag was used on social media, how often, and by whom; thus, we aim to provide insights into the impact of a major social media campaign in the UK health informatics research community and further afield.

Methods: We analyzed all publicly available posts (tweets) that included the hashtag #datasaveslives (N=13,895) on the microblogging platform Twitter between September 1, 2016, and August 31, 2017. Using a combination of qualitative and quantitative analyses, we determined the frequency and purpose of tweets. Social network analysis was used to analyze and visualize tweet sharing (*retweet*) networks among hashtag users.

Results: Overall, we found 4175 original posts and 9720 retweets featuring #datasaveslives by 3649 unique Twitter users. In total, 66.01% (2756/4175) of the original posts were retweeted at least once. Higher frequencies of tweets were observed during the weeks of prominent policy publications, popular conferences, and public engagement events. Cluster analysis based on retweet relationships revealed an interconnected series of groups of #datasaveslives users in academia, health services and policy, and charities and patient networks. Thematic analysis of tweets showed that #datasaveslives was used for a broader range of purposes than indexing information, including event reporting, encouraging participation and action, and showing personal support for data sharing.

Conclusions: This study shows that a hashtag-based social media campaign was effective in encouraging a wide audience of stakeholders to disseminate positive examples of health research. Furthermore, the findings suggest that the campaign supported community building and bridging practices within and between the interdisciplinary sectors related to the field of health data science and encouraged individuals to demonstrate personal support for sharing health data.

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KEYWORDS

social media; public engagement; social network analysis; medical research

Introduction

Social Media Use by Academics

Social media platforms such as Twitter, LinkedIn, and Facebook have changed the way scientists interact with others, both socially and professionally. Although the specifics may vary between individuals, platforms, and scientific disciplines [1], common scholarly purposes for using social media among academics include discovering peers and enhancing collaboration, sharing links or citations to their own or others work, communicating the proceedings of conferences and meetings, raising their own profiles, engaging in discussions and keeping up to date with scholarly work, answering questions and solving problems, and discovering job opportunities [2-13].

There is also a growing interest in using social media to engage a wider audience about scientific research, including the public [6,14,15]. A recent scoping review of health scientists' strategies by Fontaine et al [16] identified 9 types of science communication strategies used by health scientists, directed at areas such as content, engagement, intention, presentation, and statistics. However, the same review concluded that empirical studies in this field were lacking, representing a missed opportunity to understand how to optimize science communication strategies.

A Social Media Campaign for Health Informatics Research: #datasaveslives

The social media campaign #datasaveslives [17] was established in 2014 by the Northern England branch of the Farr Institute for Health Informatics Research, a publicly funded, UK-wide research collaboration involving academic institutions and health partners. The campaign started with a simple goal: to promote the positive use of data in health research on social media. A select group of academic organizations belonging to, or affiliated with, the Farr Institute subsequently formally adopted #datasaveslives as part of their communications and stakeholder engagement strategies [18]. These supporters then encouraged a wider audience of people who supported health data research to use the hashtag #datasaveslives on social media sites (primarily Twitter) to index and share examples that demonstrate how health data from patient records and other sources could be used to create public health benefits. The second objective is to spark interest and dialog about using health data for research purposes among wider audiences, including patients, members of the public, health care professionals, and policy makers.

About Twitter

Twitter is a popular microblogging social media platform founded in 2006 [19]. It allows users to post short messages (previously 140 characters, more recently extended to 280) known as *tweets*, which may also include URL links, multimedia content (eg, images or videos) and/or references to other users (signified using the @ symbol, plus a username). Hashtags may also be used by assigning the # character to a term of their choice; this is a useful way of indexing and searching for tweets on a similar topic. Users can view and engage with tweets in a number of ways, including liking, replying to, and sharing (*retweeting*) others' posts. They can also follow others to *subscribe* to see their tweets. Tweets are public by default, although users can change their settings at any time to restrict their visibility to their Twitter followers. Users can also choose to write a short description about themselves (known as a *bio*) and add their location.

Study Aim

The aim of this study is to examine how the #datasaveslives hashtag has been used on Twitter in the context of the use of data in health research and by whom. The analysis will determine how often the hashtag has been used and shared and examine the content posted alongside the hashtag to determine the range of purposes for its use. This will provide insights into the strategic use of social media campaigns by academics and explore their potential for encouraging wider dialog within and between scientific communities and broader audiences.

Specifically, the following objectives (and research questions in brackets) were defined:

1. Determine the frequency of tweets and retweets featuring the hashtag #datasaveslives, including the most frequently shared tweets (how often was #datasaveslives tweeted?).
2. Characterize the range of stakeholder groups that use and share #datasaveslives and visualize retweet relationships between users (who tweets #datasaveslives and how were tweets shared between users?).
3. Identify and explore the different purposes that people used #datasaveslives for when tweeting (what did people use #datasaveslives to tweet about?).

Methods

Design and Objectives

We used a mixed methods design, combining elements of descriptive statistics, social network analysis, and qualitative research. This approach, which used a combination of qualitative and quantitative analysis, was adopted to allow a richer analysis of Twitter posts, over and above what could be achieved by available social media analytics tools.

Data Set, Variables, and Definitions

The data set comprised all publicly available tweets (N=13,895) that included the hashtag #datasaveslives posted between September 1, 2016, and August 31, 2017. This year was selected because it was perceived to represent a peak in campaign activity, thereby providing a sufficiently large and diverse sample of tweets for analysis. These were procured from Twitter's historical data service in January 2018.

The following variables pertaining to the tweet text and metadata associated with the tweet were retained for the analysis: tweet ID, tweet text (*body*), a list of hashtags included in tweets, number of retweets, and date posted (recoded into day, month, and year).

Twitter classifies each tweet as either an original *post* or a *share*. Posts were defined as tweets where the user either created a new tweet with their own original text or where a user shared another user's tweet and added new text to accompany it (*quote* tweets). Shares (more commonly referred to as *retweets*) referred to cases when the user had shared a post created by another user with their followers without changing or adding new text. In all cases, tweets were only included if they referenced #datasaveslives somewhere in the body of the tweet, whether in the shared text or the text newly added by the user.

Where available, we also retained the following data pertaining to individual users who posted tweets, specifically: username, bio (optional self-written text about the user in 160 characters or less), friend count (users they had elected to follow), and follower count (users who had elected to follow them).

For analysis purposes, we defined official supporters as the 6 user accounts belonging to the sites of the Farr Institute and the Connected Health Cities (CHC) programme, all of whom adopted #datasaveslives as part of their formal strategies (@FarrInstitute, @CHCNorth, @HeRC_Farr, @FarrScotland, @FarrCIPHER, and @FarrLondon).

Data Preprocessing and Analysis

Historical Twitter data were preprocessed using Python (version 3.7.2). Briefly, the *pandas* Python library was used to convert data from a JavaScript Object Notation (JSON) format into a two-dimensional data frame for cleaning, recoding, and validation tasks in preparation for data analysis.

Statistical analyses were completed using RStudio (version 1.1.456). To address objective 1, descriptive statistics were used to determine weekly and monthly frequencies of tweets featuring #datasaveslives and percentages of the most commonly shared tweets (retweets). Pearson R was used to determine the associations between weekly counts for posts and retweets. For the most commonly shared retweets, the total potential reach was estimated by summing the follower count for every user who shared the tweet.

To address objective 2, users were grouped according to tweet frequency, and their characteristics were analyzed in terms of median counts for followers, friends, and posts. Gephi (version 0.9.2), a social network analysis tool, was used to analyze and visualize relationships between users of #datasaveslives. We focused on the retweet network as a way of understanding the sharing practices and underlying network structures between users. Statistics about the overall network and individual vertices were generated based on who retweeted whom, including clustering coefficients and measures of centrality. These were used to produce an undirected network graph visualizing the connections (edges) between users (vertices). To detect communities and calculate modularity, we used the Louvain method for community detection, which has been shown to outperform similar modularity methods in terms of speed and efficiency [20]. The graph was laid out using the Force Atlas layout algorithm. Common words used in user bios and tweet texts were also identified for each cluster (excluding commonly used words, eg, *and*, *or*, *views*).

To address objective 3, thematic analysis [21] was used to analyze the textual content of tweets featuring #datasaveslives qualitatively. Owing to the large size of the data set, it was not deemed practical or necessary to read and code all tweets. All original posts accompanying the hashtag were imported into NVivo 12 [22] for analysis. After reading a convenience sample of tweets (the first 200 tweets in date order), we defined an initial coding structure, covering the range of purposes tweets appeared to be used for. All original posts were sorted using the random number generator function in Microsoft Excel and then reviewed, coded, recoded, and collated into key themes in an iterative fashion by LH. Tweets were coded until saturation occurred, that is, until no substantially new themes were found. Approximately 1000 tweets were manually reviewed in total. The final set of themes was decided upon following a discussion between the authors.

Ethics and Governance

Data were collected and processed in line with Twitter's terms and conditions. As this information was nonsensitive and already in the public domain, formal ethical approvals were not required to complete the project.

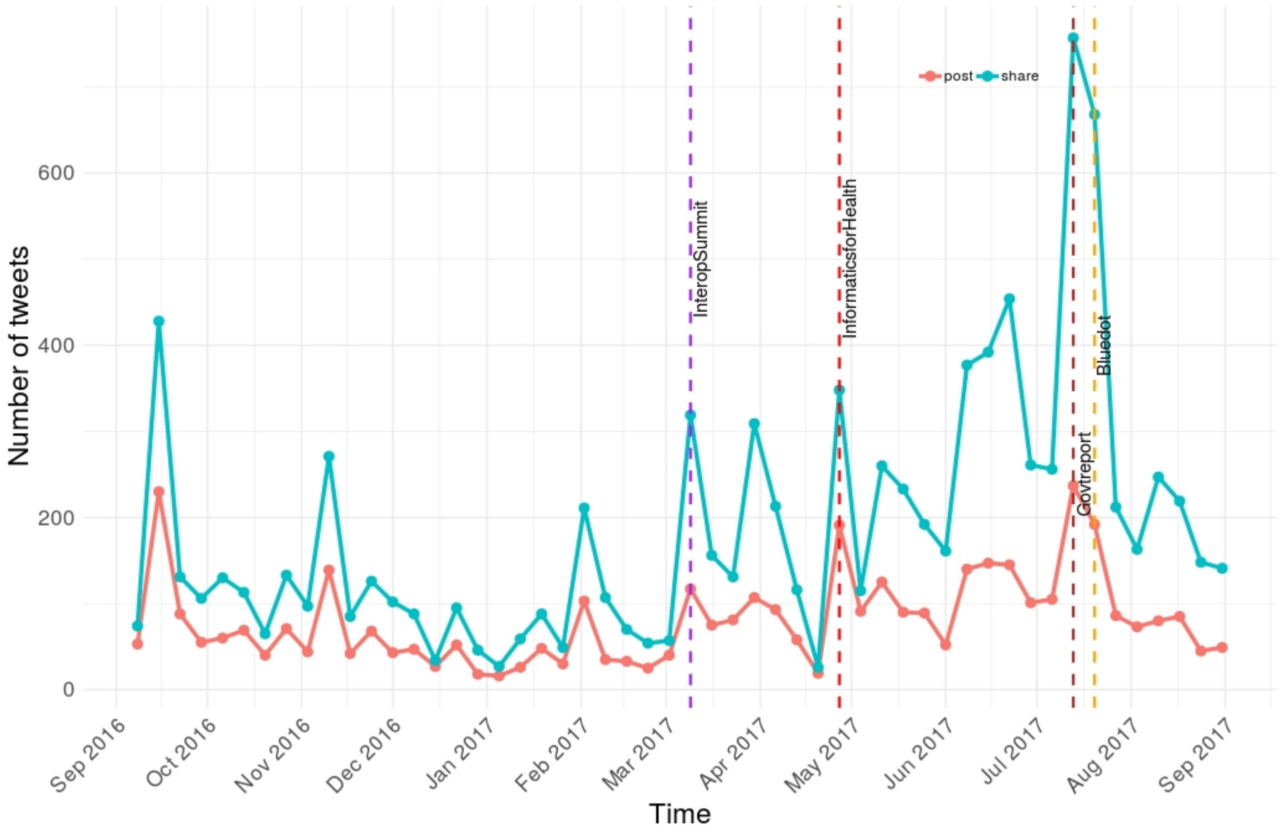
On advice from our university's research ethics office and in line with wider social media research guidelines [23], we took the following measures to protect Twitter users' privacy and confidentiality expectations: first, only tweets of users with accounts set to *public* were included in the analysis. Second, we gained permission to quote verbatim posts by individual users who were not clearly part of identifiable public groups or bodies or tweeting in an official capacity (eg, government organizations, university departments, heads of department). During the course of identifying popular tweets, we discovered that some posts or accounts had subsequently been deleted by users following the time of data collection; in such cases, tweets were not quoted although they were retained for the purposes of aggregated quantitative and qualitative analyses.

Results

How Often Was #datasaveslives Tweeted?

During the observation period, there were 13,895 tweets containing #datasaveslives (Figure 1). Overall, 30.05% (4175/13,895) were original posts and 69.95% (9720/13,895) were retweets. Among the original posts, 34.80% (1453/4175) were quote tweets. The mean number of total weekly tweets was 267.21 (SD 200.06), although this varied substantially (range 43-994). There was a strong positive correlation between weekly counts for posts and retweets (r=0.927, df=50; P<.001).

Figure 1. Tweet frequency over time by tweet type.



The highest number of tweets was observed during the week commencing July 6, 2017 (237 posts and 757 retweets), during which the UK government published a response [24] to a national review of security, consent processes, and opt-outs relevant to health data [25]. During the same week, there were also tweets about public engagement activities at high-profile cultural festivals in Cheshire (Bluedot Festival, England) and Edinburgh (Edinburgh Festival Fringe, Scotland). There were also high frequencies of tweets from official supporters during the week beginning April 20 (week 34), when there was a health informatics conference (Informatics for Health) hosted in Manchester in England.

Overall, 6 of the 10 most frequently shared tweets were from accounts associated with organizations, networks, or events (Table 1); only 1 originated from the account of an official supporter (@HerC_Farr). There was a modest, though significant, positive correlation between retweet count and follower count (*r*=0.214, *df*=4173; *P*<.001).

Table 1. The top 10 most frequently shared tweets.

Rank	Tweet[a]	Username and bio	Retweets, n	Group[b]	Total potential follower reach, n[c]
1	"Without data, this wouldn't be possible. We welcome the Govt's response to @NDGoffice review #DataSavesLives"	@NHSDigital; Information and technology for better health and care	58	7	274,311
2	"#DataSavesLives Our open letter from charities following the Government's response to the Caldicott Review"	@wellcometrust; We're a charitable foundation that exists to improve health for everyone. We support thousands of scientists & researchers, spark debate & take on big problems	51	3	206,171
3	Not available. Tweet deleted by the user	Bio not available	50	N/A[d]	N/A
4	"Remembering Alan Turing today, on his anniversary. An incredible scientist and human being, and an original believer in #datasaveslives"	@HeRC_Farr; An academic, NHS & Industry Partnership: Harnessing health data for patient and public benefit. #datasaveslives	41	1	52,544
5	"Better use of data means you don't have to tell your story again and again to doctors and nurses #DataSavesLives"	@NHSEngland; Health and high quality care for all, now and for future generations	40	10	212,478
6	"Using patient data is vital to improve health+care for us all #datasaveslives"	@NMRPerrin; Leading new Understanding Patient Data initiative. Interested in all things data, with a bit of science policy on the side	38	3	35,532
7	"Come + work with me! Understanding Patient Data team is recruiting a new policy/comms officer #datasaveslives"	@NMRPerrin; as above	37	3	138,791
8	"Register now for our Annual Scientific Meeting- Research in the Digital Age #DataSavesLives"	@SMHRN1; Scottish MH Research Network-supporting excellence in mental health studies as part of NHS Research Scotland	36	2	62,589
9	"New #INTEROPen board: an open collaboration of #interoperability networks to drive #OpenStandards in #health & #socialcare #DataSavesLives"	@INTEROPenAPI; Leading organizations supporting patients clinicians & new care models. Accelerating the delivery of #Interoperability #OpenStandards in health & social care	33	4	37,204
10	Not available. Tweet deleted by the user	Bio not available	31	N/A	N/A

[a] As of August 31, 2017.

[b] Group numbers cross-referenced with Table 3.

[c] Calculated as the sum of followers across all users who retweeted the original post. This method overestimates the total potential reach as it cannot account for the overlap of followers between users, and in any case, it is unlikely that all followers would view posts.

[d] N/A: not available.

Who Tweets #datasaveslives?

There were 3649 unique Twitter users who posted or shared content, including #datasaveslives (Table 2). Approximately 1 in 10 (1573/13895, 11.32%) of all #datasaveslives tweets, and 1 in 6 of posts that used original text (421/2722, 15.46%), were by official supporters. The tweet type was significantly associated with an official supporter status; official supporters used posts with original text relatively more often than others (26.76% vs 18.67%; $\chi_1^2=57.5$; $P<.001$).

Among the 3649 users who posted or shared #datasaveslives at any time during the time window observed, 64.87% (2367/3649) did so only once (range 1-455). Users who tweeted 10 times or more accounted for just 4.88% (178/3649) of users, yet produced 54.33% (7549/13,895) of tweets; 16 users tweeted 100 times or more. This included 5 of the 6 official supporters, plus the accounts of affiliated organizations and projects. A total of 13 of the 16 accounts were associated with groups. In addition to official supporter organizations, these included health charities, professional membership organizations, event organizers, and projects. Notably, one of these frequent tweeters was a patient advocate and campaigner (n=102 tweets).

Table 2. Tweet frequency by tweet type and user type.

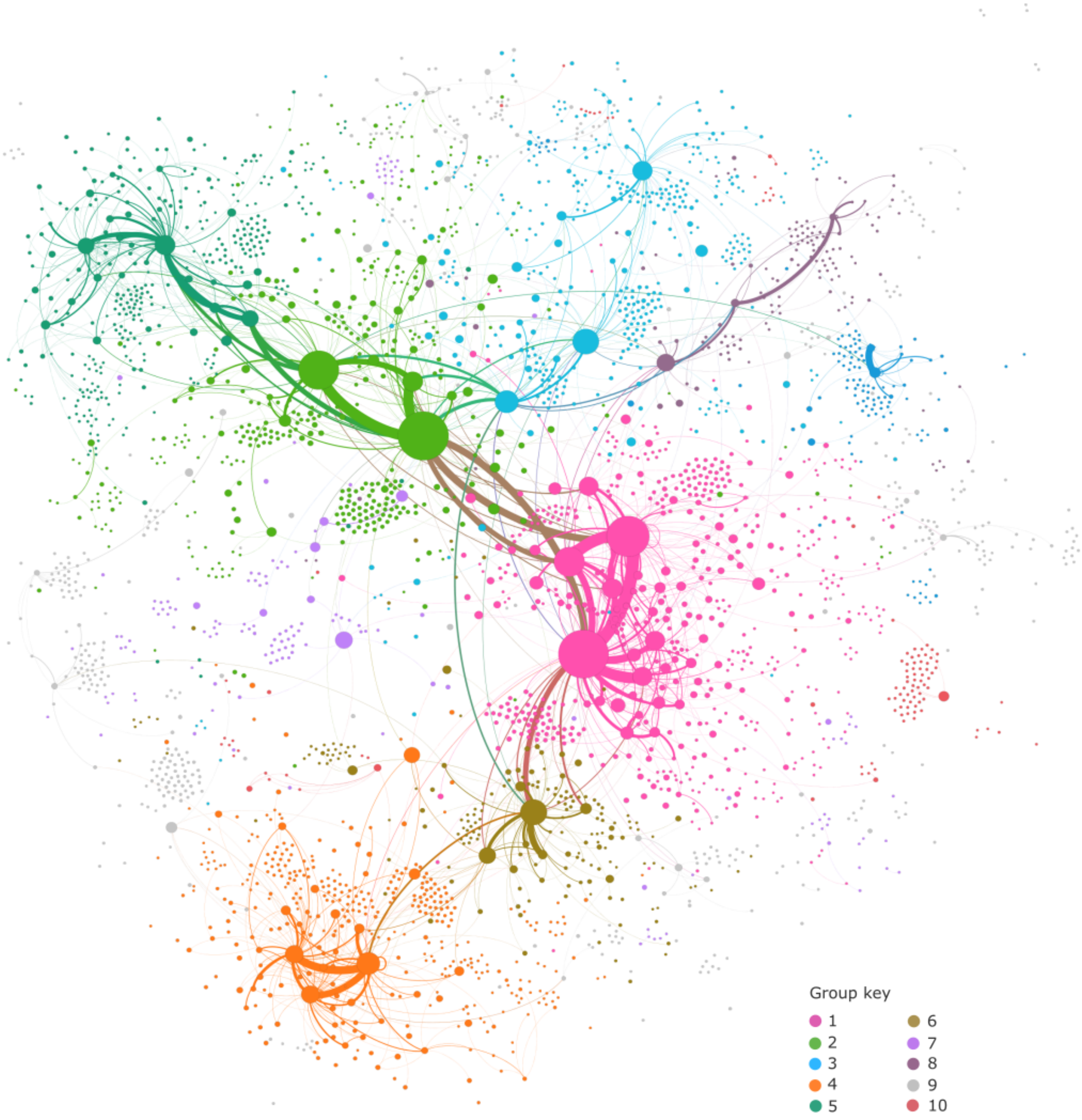
Tweet type	Tweet frequency by user type, n (%)		Total tweets (n=13,895), n (%)	Total unique users (n=3649), n (%)[a]
	Official supporter (n=1573)	Other (n=12,322)		
Original posts				
Original text	421 (26.76)	2301 (18.67)	2722 (19.60)	613 (16.80)
Quote	243 (15.44)	1210 (9.82)	1453 (10.46)	551 (15.10)
Shares				
Retweet	909 (57.79)	8811 (71.51)	9720 (69.95)	3157 (86.52)

[a] Owing to the overlap between users who use posts and shares, this column does not add up to 100%.

How Were Tweets Shared Between Users?

We visualized retweet relationships between Twitter users as an undirected network graph (Figure 2). Retweet connections were created when a user shared content by another user that included the hashtag. The analysis of retweets (n=9720) generated a network of 3392 users and 5749 unique connections between pairs of users (average degree=3.39; average path length=4.02; diameter=12).

Figure 2. Retweet network graph showing relationships between users who tweet and retweet #datasaveslives.



Cluster analysis using the Louvain method of community detection revealed 98 relatively well-connected groups (modularity=0.684). These were arranged in *hub and spoke* structures, with smaller numbers of relatively more tightly connected users at the center of each group. The 5 largest clusters or groups contained 60.70% (2059/3392) of users in the network; 69 groups were very small, containing 5 or fewer users.

We examined the size, users, and words used in user bios for the largest 10 groups yielded by the cluster analysis (Table 3). The largest 2 groups (1 and 2) included all 6 official supporter accounts and were closely connected. Groups 1 and 2 shared similar vocabulary, both for tweets and user bios (eg, *health*, *research*, and *university*).

Table 3. Users in the #datasaveslives retweet user network by group.

Group	Users, n (%)	Most influential organizational user accounts (eigenvector centrality)[a]	Top 5 words used in user bios (n)	Top 5 words used in user tweets (n)
1	533 (15.71)	@CHCNorth (0.99), @HeRC_Farr (0.82), and The _NHSA (0.35)	Health (154), Manchester (71), research (67), university (64), and science (43)	Data (198), health (189), great (80), #iforh2017 (70) and research (53)
2	405 (11.94)	@FarrInstitute (1.0), @FarrScotland (0.79), and @FarrCIPHER (0.37)	Health (163), research (154), data (59), university (40), and public (39)	Data (143), health (96), research (51), #iforh2017 (46), and case (37)
3	399 (11.76)	@Patient_Data (0.43), @AMRC (0.36), and @wellcometrust (0.20)	Research (112), health (98), views (82), policy (44), and care (38)	Data (145), health (122), patient (60), information (57), and using (50).
4	390 (11.50)	@InteropSummit (0.33), @INTEROPenAPI (0.33), and @oht_uk (0.14)	Health (100), views (77), care (72), healthcare (44), and NHS[b] (40)	#interopsummit (110), #interoperability (53), #interopwarrior (38), care (36), and data (35)
5	332 (9.79)	@cancerchallscot (0.37), @IHDPscot (0.30), and @ProductForge (0.29)	Health (60), Scotland (51), care (38), data (37), and cancer (36)	#cancerdatadive (73), cancer (61), data (58), great (29), and #hackathon (27)
6	181 (5.34)	@GreatNorthCare (0.50) and @AHSN_NENC (0.19)	NHS (34), health (33), clinical (22), care (21), and director (17)	NHS (34), health (33), views (32), clinical (22), and care (21)
7	151 (4.45)	@NHSDigital (0.31), @DeptHealthPress (0.16), and @Soc_Endo (0.13)	Health (26), digital (22), care (15), research (14), and NHS (13)	Views (36), health (26), digital (22), care (15), and research (14)
8	127 (3.74)	@useMYdata (0.32), @DNADigest (0.10), and @abcdiagnosis (0.09)	Cancer (54), breast (29), research (27), health (18), and advocate (13)	Cancer (54), breast (29), research (27), health (18), and views (17)
9	117 (3.45)	@UoLCardioEpi (0.18), @LabKey (0.04), and @HealthSciYork (0.02)	Research (24), care (4), health (14), cardiovascular (13), and university (10)	Research (24), care (14), health (14), cardiovascular (13), and views (13)
10	110 (3.24)	@NHSEngland (0.17), @MedineGov (0.10), and @CURE_ScHARR (0.04)	Health (23), care (16), views (13), NHS (12), research (9), and healthcare (9)	Health (23), care (16), views (13), NHS (12), and research (9)

[a] Maximum of 3 users in the top 10 accounts.

[b] NHS: National Health Service.

Closer examination indicated some distinctions between groups 1 and 2. Group 1 users were more strongly affiliated with Northern England (particularly Manchester), whereas group 2 users frequently referenced places, organizations, and events located in Scotland. Group 1 was closely connected with group 5, which had a distinct topic focus on cancer data. Group 2 showed a stronger connection with group 6, which was associated with major medical records information technology (IT) projects based in the North East of England. Group 6 was, in turn, connected with group 4, populated by National Health Service (NHS) staff and delegates of a major health care IT conference (indicated by *#interopsummit*).

Group 3 indicated connections with both groups 1 and 2, and included users with connections to the NHS, health care policy, and major charities. Commonly used words in this group suggested a more applied focus among users (eg, *policy* and *care*). Group 3 was also loosely connected to group 8, distinctly notable for comprising users who self-identified as patients, carers, and advocates.

What Did People Use #datasaveslives to Tweet About?

The thematic analysis of tweet content yielded 4 key ways in which #datasaveslives was used: to share information and updates, for reporting and discussion at events, to show support for data sharing, and as a call to action. Although themes have been described separately for clarity, in practice there was substantial overlap, with the same tweets often being classified under multiple themes (Table 4).

Table 4. Examples of tweets with overlapping themes.

Theme[a]				Example tweets
A	B	C	D	
✓[b]	✓	N/A[c]	N/A	"Today is #WorldHealthDay - Find out how we work to improve health & care for patients & public here: [link to website] #datasaveslives" [@FarrInstitute]
✓	N/A	✓	N/A	"Interesting paper from @[usernames] calls for clarity on conflicting data sharing guidance [link to website] #datasaveslives" [@Patient_Data]
✓	N/A	N/A	N/A	"We are using patient data to implement learning health systems across the #North. Find out more: [link to website] #datasaveslives" [@AMRC]
N/A	✓	✓	N/A	"The Farr Institute discusses importance of patient data at House of Commons event #APPGMedResearch #datasaveslives [link to website]" [@FarrInstitute]
N/A	✓	N/A	N/A	"Thank you to all of our speakers today, to find out more about their work follow @UoLCardioEpi #datasaveslives #LIDASeminar" [@LIDA_UK]
N/A	N/A	✓	✓	"Everybody should be able to find out how patient data is used. Read our case studies on how #datasaves-lives… [link to website]" [@Patient_Data]
✓	✓	✓	N/A	"We believe #DataSavesLives! As do #interopsummit lecturers VIDEOS of Day 2 lectures on @YouTube [link to website] #interoperability" [@InteropSummit]
N/A	✓	✓	✓	"If you're at #IforH2017 don't forget to take a selfie with #datasaveslives at our stall (12) - just like [first name] from @[username] [photo]" [@FarrScotland]
✓	N/A	✓	✓	"Help contribute to the latest inquiry by @LordsSTCom into the #LifeSciences #IndustrialStrategy and highlight that #datasaveslives [link to website]" [@AMRC]

[a] Qualitative theme descriptions: A, to index and share information; B, for reporting and discussion at events; C, to show support for data sharing; and D, as a call to action.

[b] Data are applicable to themes.

[c] N/A: not applicable.

To Index and Share Information

The most common types of posts featuring #datasaveslives, particularly by official supporters and members of groups 1, 2, and 3 (Figure 2 and Table 3), were tweets sharing information about users' own projects, research findings, and news. These included announcements about new projects or funding, updates on progress, and sharing results from research. Although some tweets directly referenced peer-reviewed scientific literature by linking to journal publications, more often they were linked to less formal sources, including project websites, case studies, blogs, and videos:

> *Thanks to data we know that the smoking ban in Scotland has been a success [link to case study on website] #datasaveslives* [@FarrScotland, Group 2]

> *Highlights from Informatics for Health 2017 by @HeRC_Farr: Watch the video at [website link] #IforH2017 #datasaveslives* [@FarrInstitute, Group 2]

Twitter users also used #datasaveslives to highlight the work of others and signpost wider news and policy developments in areas relevant to health data science. These included news stories published by universities, health service organizations, professional bodies, and reports in popular media, including the local and national press and television and radio programs:

> *BBC News - Artificial intelligence predicts when heart will fail [link to news report] #DataSavesLives* [@EmpowerD4H, Group 13]

In the vast majority of cases, references for data sharing were positive or at least neutral; occasionally, however, there was evidence of more critical commentary about certain uses of health data:

> *Check out how @ukhomeoffice using health information is denying patients healthcare [link to news story] #DataSavesLives until it doesn't* [@einsteinsattic, Group 2]

Among tweets in this category, hyperlinks to other websites were very common; indeed, a subgroup of tweets were identified that included a hyperlink and the hashtag, indicating the use of #datasaveslives as purely an index function. This was mainly used by official supporters.

For Reporting and Discussion at Events

Frequently, #datasaveslives was used to tag tweets related to events, including conferences, meetings, and public engagement activities. Tweets included the promotion of forthcoming events, discussion of past events, or even live reporting and commentary about events, talks, and discussions that were currently underway. In the case of larger events, such as conferences, #datasaveslives frequently appeared alongside other official event hashtags (eg, #iforh2017, #interopsummit). Images of slides, presenters, delegates, visitors, and stalls were commonly included alongside the text:

> *Looking forward to meetings workshops and exciting stuff at @ExpoNHS tmrw #datasaveslives#nhs* [@ruthlady, Group 1]

To Show Support for Data Sharing

One further use of #datasaveslives was to demonstrate personal support for sharing health data in general or backing the #datasaveslives campaign itself. A total of 26 users included the text #datasaveslives within their Twitter bio. Many tweets of this type included images of individuals or groups at events pointedly posing with eye-catching placards, badges, or clothing featuring the hashtag:

> *Thanks for coming to chat wear your badge with pride!* [@FarrInstitute, Group 1]

Some tweets included a positive statement about reasons for supporting data sharing, either within the tweet or written on placards pictured in the tweet. The reasons referenced included sharing health data for research, sharing data as part of routine health care, or sharing data as part of larger projects that combined elements of both. Some tweets within this category signposted wider evidence supporting data sharing, such as collections of case studies where health data had been used for patient benefit. These were especially common among groups 4 and 5. Some drew on first-hand experiences and opinions:

> *For more examples of how #datasaveslives in mental health read this @MQmentalhealth blog. See our case studies [link to website]* [@Patient_Data, Group 3]
>
> *The type of treatment that I had depended so much on the data of patients who went before me' - patient advocate - #datasaveslives* [@useMYdata, Group 8]

As a Call to Action

We also identified a category of tweets that were used to make requests for others to act, participate, or respond in some manner. Commonly, these included advertisements to register for or submit papers to future events, participate in research studies, visit exhibition stands at conferences, or apply for jobs. There were also requests to provide feedback, opinions, or information:

> *We're inviting applications for a 2yr Clinical Research Fellow to study for an MD. Cardiology trainees please. #heartattack #datasaveslives* [@UoLCardioEpi, Group 9]
>
> *Help guide our consent modelling framework: happy to share a copy of your care org's consent forms? TY/please DM #datasaveslives #ontology* [@GreatNorthCare, Group 6]

Discussion

Principal Findings

This study investigated how a dedicated hashtag was used to promote the reuse of health data for research purposes and public benefit, how often, and by whom. Originally launched by the Farr Institute for Health Informatics Research, #datasaveslives came to be adopted by several distinct, diverse, yet interconnected groups in the United Kingdom with shared interests in health informatics, policy, and research. Our findings suggest that reasons for tweeting #datasaveslives evolved beyond the original objective of indexing information to a broader range of purposes, including event reporting, encouraging participation and action, and showing support for sharing health data.

Comparisons With Previous Work

Among the wider range of communities who shared content tagged with #datasaveslives, we detected 2 communities in particular who were research-focused, geographically distinct, and strongly interconnected. These were, in turn, connected with distinct professional communities with wider interests—some with access to sizable networks, funding, and influence—including government departments, the NHS, policy makers, patient advocates, and major charities. Our findings fit with the wider literature, which indicates that scientists can use Twitter not only to communicate with each other but also to engage broader audiences, including policy makers and the public [3,6].

One of the initial, more obvious uses of the hashtag was to index information about the use of health data as part of research and innovation, and make it more readily retrievable to a wider, not exclusively scientific, audience. Moreover, people also used the hashtag to publicly demonstrate support for data sharing and each other. This is compatible with the wider literature, which suggests that academics use hashtags to categorize information [26] and encourage interaction and community building [27-29]. These uses seem pertinent, given that our period of observation followed the high-profile failure of the care.data scheme, a major government initiative in England to share patient data [30]. Indeed, two of the most frequently shared tweets in our analysis concerned subsequent proposals to change government policy, addressing data security and consent [24,25]. Previous studies have shown how responses to care.data on Twitter attracted critical commentary [31], including from interest communities in politics, health care, and the media [32]. Before the observation period examined in this study, concerns had been raised about access to patient data by commercial companies, especially where these uses were perceived to be primarily motivated by profit rather than public benefit [30,33-35]. This study contrasts with these findings, showing how #datasaveslives was used in the wake of public backlash to care.data to spread mainly positive messages about data use and reuse, and to increase transparency, demonstrate solidarity, and provide supportive networks among health, data, and IT professionals.

In declaring an intent to promote the reuse of health data for research purposes, the #datasaveslives campaign could be regarded as a behavioral intervention of sorts, encouraging credible users to endorse and share supportive messages. As with other behavioral interventions conducted via social media, attention should be directed toward identifying the active ingredients of interventions [36]. Our thematic analyses of tweet content revealed 2 noteworthy and interrelated strategies used as components to achieve campaign aims. First, #datasaveslives was used at events frequented by influential communities, generating spikes in activity generated by commentary about the proceedings of meetings and events in real time. So-called *live-tweeting* has become more common at scientific conferences and has the advantage of increasing transparency and rapidly disseminating information among a far larger audience over and above those who physically attend [37,38]. Using #datasaveslives, either alone or in addition to more specific conference hashtags, might have amplified the reach of information while avoiding the limited audience and *shelf-life* of more niche conference hashtags.

Second, offline activities at events were used to drive the generation of web-based multimedia content; events were used as photo opportunities for individuals willing to publicly endorse #datasaveslives, leveraged by attractive branded physical merchandise. Drawing on evidence from previous studies, which have identified health behavior change techniques particular to social media, reviewed by Simeon et al [36], these photo opportunities might be framed as *virtual rewards*, in turn encouraging further *overt endorsements* in the form of likes, retweets, and comments. Indeed, similar social media strategies have been used in both the health sciences and the corporate sectors, such as identifying target communities, gaining support from credible and/or influential users, developing engaging multimedia content, updating content regularly, improving the visual presentation of content, and encouraging participation via small concrete actions [16,39,40].

Strengths and Limitations

This study benefits from the analysis of a near-complete sample of #datasaveslives public tweets for an active year during the campaign. Nonetheless, we could not have captured all mentions and uses of #datasaveslives during this period. Private and previously deleted tweets were excluded. Owing to the limited use of other social media platforms by official supporters, our analysis only considered Twitter posts tagged with the keyword #datasaveslives. It is notable that other important public health outreach campaigns—including during outbreaks [41], as part of science communication [16] and to promote health behavior change [36]—have commonly used a wider range of social media platforms, particularly Facebook. The content, strategies, and communities observed in this study may be specific to Twitter and should not be generalized to other social media or content-sharing platforms. Furthermore, the network analysis was limited to retweets; we did not capture other types of engagement, such as follower networks, or use directed networks, as done by other studies [32]. Thus, certain nuances of information flow may have been lost, indicating influential relationships. Demographic data about users were not made available by Twitter for analysis, limiting our understanding of sample characteristics. Finally, we accept that we were unable to quantify, much less characterize, the much wider audience who saw, read, or otherwise engaged with tweets, in particular patients and members of the wider public not connected to organizations.

Future Research

The health data science community has stated a vision to be team-based, transparent, and inclusive, seeking involvement from a wide range of interdisciplinary stakeholders, including patients and the public [42]. Future research would benefit from examining how the use and users of #datasaveslives have changed over time and suitable ways of determining the overall impact of varying strategies to engage key communities, such as members of the public. Using such opportunities for social media to contribute toward building networks and engaging in dialog in open forums would seem eminently compatible with this vision.

Conclusions

The rise of social media has provided unprecedented opportunities for academic organizations and individual scientists to communicate with a much wider range of stakeholders than ever before, including the public. This study shows how a simple hashtag campaign on Twitter was used to disseminate credible scientific information and increase the visibility of research activities, with evidence to suggest this supported community building and bridging practices among interdisciplinary sectors allied to health data science.

Our findings are of interest to a variety of stakeholders who share an interest in supporting the reuse of health data for public benefit. By revealing the different communities who share such interests, analyzing content thematically, and demonstrating how information flows between them, our findings can be used to better understand the mechanisms underpinning stakeholder engagement campaigns conducted on social media and how to optimize these further.

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Conflicts of Interest

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Abbreviations

CHC: Connected Health Cities
IT: information technology
NHS: National Health Service

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Letter to the Editor

The Potential for the Internet and Telehealth in Caregiver Support. Comment on “Using Technology to Facilitate Fidelity Assessments: The Tele-STAR Caregiver Intervention”

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dementia; caregiver; technology

We read with interest the recent paper entitled “Using Technology to Facilitate Fidelity Assessments: The Tele-STAR Caregiver Intervention” by Lindauer et al [1]. The authors concluded that Tele-STAR contributed to low caregiver burden and showed good fidelity as an intervention method.

Internet-based videoconferencing technology is an important source of support for caregivers of persons with dementia. Researchers have previously demonstrated the positive potential of computer-mediated interventions and technology-based cognitive behavioral therapy interventions for caregivers of people with dementia [2,3]. Others have raised the difficulties in measuring intervention fidelity in a consistent manner [4,5], which raises the importance of consistency when considering fidelity evaluations. Moreover, as the study reported results that may be attributed to both in-home and telehealth intervention experiences of participants, it may be useful to consider the interplay of these aspects.

Lindauer and colleagues [1] reported a slight reduction in caregiver burden, attributed to an improvement in caregivers’ responses to patients with dementia, facilitated by the Tele-STAR intervention. Caregiver burden is an important consideration in the field of dementia care. A recent study found an internet-based intervention to be effective in increasing the positive aspect of subjective appraisal for caregivers of persons with dementia [6]. In addition, we have studied the subjective appraisal of both negative and positive aspects in this population [7]. Assessments that take into account both sides of subjective appraisal are capable of providing a broad understanding of a caregiver’s context, and we would argue that an outcome that takes both into account would be more useful than current practices allow for.

The support that can be offered to caregivers using internet-driven technologies should continue to be explored, and the study conducted by Lindauer and colleagues [1] provides useful data in this regard. We agree that internet-based interventions will be beneficial to caregivers of persons with dementia in the future.

Editorial Notice

The corresponding author of “Using Technology to Facilitate Fidelity Assessments: The Tele-STAR Caregiver Intervention” declined to respond to this letter.

Conflicts of Interest

None declared.

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Letter to the Editor

Data Leakage in Health Outcomes Prediction With Machine Learning. Comment on “Prediction of Incident Hypertension Within the Next Year: Prospective Study Using Statewide Electronic Health Records and Machine Learning”

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KEYWORDS

machine learning; data leakage; prediction

Applications of machine learning algorithms to predict the incidence of health outcomes have an enormous potential to improve clinical practice and lower health care costs [1]. Machine learning is a subset of artificial intelligence that uses data to improve decisions through experience, which is especially promising in a data-driven world. Dr Ye and colleagues’ article on hypertension incidence prediction in the *Journal of Medical Internet Research* adds to this literature [2], but its potential contribution and applicability are hindered by a major flaw.

The objective of the study was to “develop and validate prospectively a risk prediction model of incident essential hypertension within the following year.” The authors follow good prediction protocols by applying a high-performing machine learning algorithm (XGBoost) and by validating the results on unseen data from the following year. The algorithm attained a very high area under the curve (AUC) value of 0.870 for incidence prediction of hypertension in the following year.

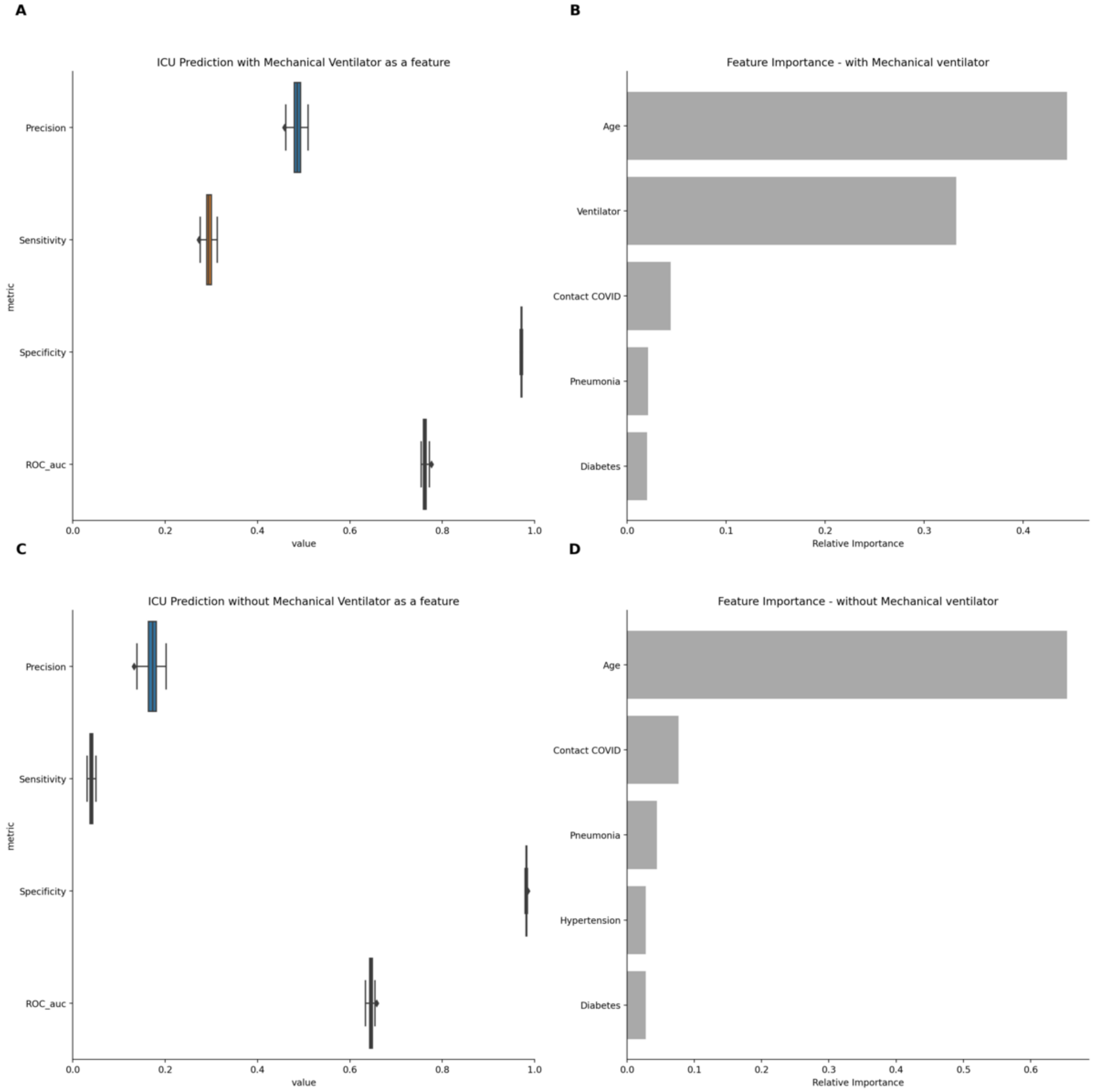
The authors follow this impressive result by commenting on some of the most important predictive variables, such as demographic features, diagnosed chronic diseases, and mental illness. The ranking of the variables that were most important for the predictive performance of hypertension is included in a multimedia appendix; however, the above-mentioned variables are not listed near the top. Of the six most important variables, five were: lisinopril, hydrochlorothiazide, enalapril maleate, amlodipine besylate, and losartan potassium. All of these are popular antihypertensive drugs.

Data leakage occurs when one or more features used to train the algorithm has hidden within itself the result of the outcome, and is considered one of the most frequent mistakes in machine learning [3]. This is different from predictive importance, that is, the relative effect of each variable in increasing or decreasing the expected outcome, as it usually comes after the outcome. Therefore, it is a consequence of the outcome that is being predicted and not the other way around.

A classic example from machine learning textbooks is the inclusion of the ID number of the patient as a predictor. While this should not have predictive importance if randomly assigned, it is common that patients coming from the same hospital have similar ID numbers in multicenter data sets. In the case of cancer prediction, for example, machine learning algorithms will learn that similar ID numbers that come from oncology hospitals have a higher probability of cancer.

As an example, we used real data to test the effect of including mechanical ventilation to predict intensive care unit (ICU) admission among patients with COVID-19 [4]. This is another example of data leakage, as mechanical ventilation usually only occurs after ICU admission and should not be used to predict its risk. Figure 1 shows the decrease in the prediction metrics for ICU admission with the exclusion of mechanical ventilation as a predictor, with the area under the ROC (receiver operating characteristic) curve decreasing from 0.76 to 0.64, and precision from 0.49 to 0.17.

Figure 1. Performance metrics for the prediction of intensive care unit (ICU) admission with and without the use of mechanical ventilation as a predictor.



By including the use of antihypertensive drugs as predictors for hypertension incidence in the following year, Dr Ye and colleagues' work opens the possibility that the machine learning algorithm will focus on predicting those already with hypertension but did not have this information on their medical record at baseline. While this would work for a prediction competition, where data science teams compete to produce the best predictive model such as in a Kaggle challenge [5], it is not of particular scientific or clinical interest. In the case of the latter, just one variable (the use of a hypertension drug) is sufficient for physicians to infer the presence of hypertension, while for the former, the knowledge of this being a highly predictable event (as measured by the AUC) is severely impaired.

In order to identify the presence of data leakage in prediction studies, it is important to have a conceptual pathway of how the predictors longitudinally affect the outcome variable, as there is no statistical method that is capable of pointing out the presence of data leakage. Improving the predictive performance of specific data sets for different diseases is an important new field in epidemiology and data science. The authors can still contribute to this literature by providing the new AUC of the prediction after addressing the data leakage issue.

Editorial Notice

The corresponding author of “Prediction of Incident Hypertension Within the Next Year: Prospective Study Using Statewide Electronic Health Records and Machine Learning” did not respond to our invitation to reply to this commentary.

Conflicts of Interest

None declared.

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Abbreviations

AUC: area under the curve
ICU: intensive care unit
ROC: receiver operating characteristic

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