Original Paper

Human-Technology Interaction Factors Associated With the Use of Electronic Personal Health Records Among Younger and Older Adults: Secondary Data Analysis

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Abstract

Background: An electronic personal health record (ePHR), also known as a personal health record (PHR), has been broadly defined as an electronic application through which individuals can access, manage, and share their health information in a secure and confidential environment. Although ePHRs can benefit individuals as well as caregivers and health care providers, the use of ePHRs among individuals continues to remain low.

Objective: The current study aims to examine the relationship between human-technology interaction factors and ePHR use among adults and then to compare the different effects of human-technology interaction factors on ePHR use between younger adults (18-54 years old) and older adults (55 years of age and over).

Methods: We analyzed data from the Health Information National Trends Survey (HINTS 5 cycle 3) collected from US adults aged 18 years old and over in 2019. Descriptive analysis was conducted for all variables and each item of ePHR use. Bivariate tests (Pearson correlation coefficient for categorical variable and *F* test for continuous variables) were conducted over 2 age groups. Finally, after adjustments were made for sociodemographics and health care resources, a weighted multiple linear regression was conducted to examine the relationship between human-technology interaction factors and ePHR use.

Results: The final sample size of 1363 (average age 51.19) was divided into 2 age groups: 18 to 54 years old and 55 years old and older. The average level of ePHR use was low (mean 2.76, range 0-8). There was no significant difference in average ePHR use between the 2 age groups. Including clinical notes was positively related to ePHR use in both groups: 18 to 54 years old (β=*.28, P*=.005), 55 years old and older (β=.15, *P*=.006). Although accessing ePHRs using a smartphone app was only associated with ePHR use among younger adults (β=.29*; P*<.001), ease of understanding health information in ePHRs was positively linked to ePHR use only among older adults (β=.13; *P*=.003).

Conclusions: This study found that including clinical notes was positively related to ePHR use in both age groups, which suggested that including clinical notes as a part of ePHRs might improve the effective use of ePHRs among patients. Moreover, accessing ePHRs using a smartphone app was associated with higher ePHR use among younger adults while ease of understanding health information in ePHRs was linked to higher ePHR use among older adults. The design of ePHRs should provide the option of being accessible through mobile devices to promote greater ePHR use among young people. For older adults, providers could add additional notes to explain the health information recorded in the ePHRs.

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KEYWORDS

electronic personal health records; human-technology interaction factors; clinical notes; smartphone app; ease of understanding

Introduction

Electronic Personal Health Record and Its Functions

An electronic personal health record (ePHR), also known as a personal health record (PHR), was broadly defined by the Markle Foundation (2004) to be an electronic application through which individuals can access, manage, and share their health information in a secure and confidential environment [1]. Unlike the electronic health record that is managed by health care providers, an ePHR is managed by individuals [2]. Pagliari and colleagues [3] summarized 7 potential functions of ePHRs: (1) access to health care providers' electronic clinical records (eg, history, drugs, test results); (2) personal health organizer or diary (eg, clinics, doctors, tests, dates, nonprescribed treatments, scanned documents); (3) self-management support (eg, care plans, graphing of symptoms, passive biofeedback, tailored instructive or motivational feedback, decision aids, or reminders); (4) secure patient-provider communication for scheduling appointments, reordering prescriptions, or seeking advice (eg, patient-doctor email); (5) links to static or informative information about illnesses, treatments, or self-care; (6) links to sources of support; and (7) collective data on symptom or health behavior data by self-report or objective monitoring through electronic devices.

Benefits of Using ePHRs

Using ePHRs allows individuals to access and coordinate their health information and to share appropriate parts to those who need it [1]. The use of ePHRs can benefit individuals as well as caregivers and health care providers [2,3]. For individuals, ePHRs provide them with credible health information, data, and guidance on potential ways to self-manage diseases and improve health, which facilitates collaborative disease tracking and improved communication between individuals (or their caregivers) and health care providers [2,3]. Moreover, ePHRs provide health care providers with more data on individuals, which allows the provider to make informed decisions, as well as improve the efficiency of care by empowering individuals' active involvement in health care and enabling PHR-mediated electronic communication [2,3]. For payers and purchasers of health care, the use of ePHRs has the potential to lower costs on chronic disease management, medications, and wellness programs [2]. Several studies have been conducted to evaluate some of the benefits of using ePHRs [4]. For example, a clinical trial testing the effects of ePHRs on advance care planning delivery in primary care settings revealed that using ePHRs improved advanced care planning documentation and quality, especially among patients between 50 and 60 years of age [5]. Another study evaluated the impact of using a decision module through ePHRs to inform cancer screening and demonstrated that participants' decision on cancer screening can be proactively facilitated through an ePHR decision module [6]. Aside from primary care and preventive care settings, ePHRs also play a positive role in mental health care settings. In a study that compared scores of Patient Health Questionnaire 9 between participants who used ePHRs with their collaborative care managers and those who did not use ePHRs, Pecina and colleagues [7] suggested that ePHR users had a higher number of contacts with care managers and showed higher depression remission.

ePHR Use and Age Disparity

Although ePHR use has been promoted and health care providers have offered most of their patients access to ePHRs [8], the use of ePHRs among individuals continues to remain low. Using data from the Health Information National Trends Surveys (HINTS) in 2008, 2011, and 2013, a study predicted that the ePHR adoption rate would exceed 75% by 2020 [9]. Although the most recent data of the ePHR use rate in 2020 are not available, a study analyzing data from the HINTS data set in 2018 reported that the use of ePHRs in the United States was only 31.4% [10]. The relationship between age and ePHR use has been documented in previous studies, which indicate that younger age is related to higher ePHR use and that patients who are younger are more likely to use ePHRs [11,12]. Pagliari and colleagues [3] pointed out that older adults had poor technical skills that might cause access disparities regarding use of ePHRs. When encountering technology, older adults face physical or cognitive challenges [13-15]. Age-related changes in functional abilities, such as sight loss, hearing loss, decreased kinesthetic ability, and decreased psychomotor and cognitive skills pose barriers for older adults to use technology [13,14,16]. Previous studies have documented barriers to adopting ePHRs among older adults, including a lack of confidence in the ability to use technology [17], concerns related to privacy [18], problems with access to computers or devices and the PHR system [15], and low health literacy or computer literacy [15]. Examining the human-technology interaction factors associated with ePHR use among individuals in different age groups might inspire tailored ePHR design and training regarding ePHR use among people from different age groups.

After reviewing 97 studies regarding factors that affect the use of ePHRs among patients, a systematic review identified 3 human-technology interaction factors that affect ePHR use: perceived usefulness (positively), internet access (positively), and privacy and security concerns (negatively) [19]. Previous studies have also suggested that other human-technology interaction factors including perceived ease of use [20,21], difficulty getting onto the system [22], and response costs [23] are associated with the use of ePHRs; however, Abd-Alrazaq and colleagues [19] believe that more evidence is needed to draw a firm conclusion regarding these factors.

This Study

Broadly, the use of ePHRs provides benefits not only to individuals and caregivers, but also health care providers. Thus, the US Department of Health and Human Services has made investments and efforts to improve ePHR use [8]. Despite the low rate of ePHR use and the digital divide between different age groups, previous studies have not investigated the different effects of human-technology interaction factors on ePHR use between different age groups. Controlling for sociodemographics and health care resources, the current study aims to examine the relationship between human-technology interaction factors and ePHR use among adults and to then compare the different effects of human-technology interaction factors on ePHR use between younger adults (18-54 years old) and older adults (55 years old and older). Although 65 years is widely used as a cutoff point for older adults, using 55 years as the cutoff point in this study was based on previous literature on technology use among older adults. In the United States, the National Telecommunications and Information Administration (2011) used 55 years as a cutoff point and reported that older Americans aged 55 years and older had the lowest adoption rate of broadband [24]. Moreover, a European project, "ICT 4 the Elderly", developed to improve older adults' digital skills, also defined older adults using 55 years as a cutoff point [25]. Other literature that has studied the use of health information technology among older adults has used 55 as a cutoff point as well [10,26,27].

Methods

Data Collection

In this study, we used the most recent iteration of the HINTS 5 (cycle 3) [28] collected from US adults aged 18 years old and over in 2019. HINTS is a national representative data set from the National Cancer Institute, and it routinely collects data about the American public's knowledge of, attitudes toward, and use of cancer- and health-related information. Since 2003, HINTS has been used by researchers to understand health communication through the internet in the information age among American adults. Two-stage sampling strategy and two-sampling strata (high- and low-minority strata) were applied during the data collection phase. Random samples of household addresses were selected in the first stage, and 1 adult within each sampled household was randomly selected in the second stage. All selected households received a total of 4 mailings: an initial mailing with a US $2 incentive, a reminder postcard, and 2 follow-up mailings. Participants were provided with 2 toll-free phone numbers (for English and Spanish calls) if they had questions, concerns, or requests for the Spanish survey. Each returned questionnaire was scanned, verified, cleaned, and edited. The final sample yielded 4448 potential respondents with a response rate of 30.2% (4448/14,730) and 3370 completed questionnaires. Only participants who had accessed their ePHRs at least 1 time in the past 12 months were included in this study. The final sample size of 1363 was divided into 2 age groups: 18 to 54 years old and 55 years old and older.

Dependent Variable

The dependent variable of interest was ePHR use. Participants who accessed their ePHRs at least once in the past 12 months were asked if in the past 12 months they used their online medical record to do any of the following: request a refill of medications; look up test results; request correction of inaccurate information; securely message health care provider and staff; download health information to a computer or mobile device, such as a cell phone or tablet; add health information, such as health concerns, symptoms, and side effects, to share with a health care provider; and help make decisions about how to treat an illness or condition. Each item was answered with a yes or no response by respondents (0=no, 1=yes). The eighth item of ePHR use pertained to sending health information electronically. Participants were asked if they had electronically sent their medical information to another health care provider, to a family member or another person involved with their care, or to a service or app that could help manage and store their health information. This response was also answered with a yes or no response for each option. Participants who selected yes on one of the options were coded as yes on sending health information electronically, while participants who selected no on all 3 options were coded as no on sending health information electronically (0=no, 1=yes). The total ePHR use score was obtained by summing up all 8 items and was analyzed as a continuous variable (range from 0 to 8).

Sociodemographics and Health Care Resources

Sociodemographics

Sociodemographic variables including gender (0=male, 1=female), urbanity (0=rural, 1=urban), and educational attainment (0=below bachelor's degree, 1=bachelor's degree and above) were included.

Health Care Resources

Having a regular health care provider (0=no, 1=yes) and frequency of visiting health care providers in the past 12 months (0=0-3 times, 1=4 times and above) were included. Having family or friends to talk to about health was also included and analyzed as a dichotomous variable (0=no, 1=yes).

Human-Technology Interaction Factors

Including Clinical Notes

Respondents were asked the following: "Do any of your online medical records include clinical notes (health provider's notes that describe a visit)?", with responses yes, no, and "don't know." After responses of no and "don't know" were combined into 1 category, a dichotomous variable was obtained (0=no/don't know, 1=yes).

Ease of Understanding

To determine ease of understating, a 4-point scale was used for participant responses to the following question: "How easy or difficult was it to understand the health information in your online medical records?" Ease of understanding was analyzed as a continuous variable ranging from 0 to 3 (0=very difficult, 1=somewhat difficult, 2=somewhat easy, 3=very easy).

Access via Smartphone App

Respondents were asked the following question: "Did you use a smartphone health app to access your online medical record?", with responses categorized as yes, no, and "don't know." Responses of no and "don't know" were grouped into 1 category; thus, a dichotomous variable was used for the accessibility of a smartphone app (0=no/don't know, 1=yes).

Statistical Analysis

Three researchers in this study devised the statistical analysis plan, and the statistical analyses were conducted by YL. The results and interpretation were reviewed by KD and CI. As the complex sampling procedure was applied in the HINTS data collection, the data analysis in this study was conducted using STATA/SE 5.1 (StataCorp), which allowed for incorporating the jackknife replicate weights to assess variation estimation. Descriptive analysis was conducted for all variables and each item of ePHR use. Bivariate tests (Pearson correlation coefficient for categorical variables and *F* test for continuous variables) were conducted over the 2 age groups. Finally, after sociodemographics and health care resource factors were adjusted for, a weighted multiple linear regression was conducted to examine the relationship between human-technology interaction factors and ePHR use. The final sample weight was used to obtain population estimates, and 50 jackknife replicate weights were used to obtain variation estimates. Listwise deletion of participants was also applied in all analyses.

Results

Description of Sociodemographics, Health Care Resources, and Human-Technology Interaction Factors

The average age of all participants was 51.18 years. According to Table 1, more than half of the participants were female (762/1266, 57.12% weighted), and less than half of the participants had a bachelor's degree or above (790/1334, 39.91% weighted). The majority of participants were from urban areas (1245/1363, 89.75% weighted). In terms of health care resources, more than three-quarters of the participants had a regular health care provider (1091/1339, 78.35% weighted), and around half of the participants visited health care providers more than 4 times in the past 12 months (690/1346, 49.43%). Most of participants reported that they had friends or family to talk to about health (1167/1332, 85.62% weighted). With regard to human-technology interaction factors of ePHRs, about 40% of participants reported that they accessed their ePHRs using a smartphone app (436/1290, 39.56% weighted), and half of the participants said their ePHRs included clinical notes (650/1278, 50.34% weighted). Participants tended to report that it was easy to understand health information in ePHRs (mean 2.31, range 0-3). Table 1 also shows the significant differences in having a regular provider and accessing ePHRs using a smartphone app between the 2 age groups (*P*<.001). More older adults (55 years old and older) reported having a regular health provider, while more younger adults (18-54 years old) reported accessing ePHRs using a smartphone app.

Table 1. Description of sociodemographics, health care resources, and human-technology interaction factors (N=1363).

Characteristic	All	18-54 years old	55 years old and older	*P* value
Sociodemographics, n (%)				
Gender				
Male	504 (42.88)	190 (41.4)	309 (45.7)	.27
Female	762 (57.12)	342 (58.6)	414 (54.3)	
Urbanity				.99
Rural	118 (10.25)	46 (10.2)	68 (10.3)	
Urban	1245 (89.75)	505 (89.8)	706 (89.7)	
Education				.10
Below Bachelor's degree	544 (60.09)	182 (58.0)	354 (64.2)	
Bachelor's degree and above	790 (39.91)	369 (42.1)	416 (35.8)	
Health care resources, n (%)				
Regular health care provider				<.001
No	248 (21.65)	150 (27.0)	86 (11.4)	
Yes	1091 (78.35)	395 (73.0)	676 (88.6)	
Frequency of visiting health care provider				.47
0-3 times in the past 12 months	656 (50.57)	297 (51.6)	334 (48.5)	
4 times and above in the past 12 months	690 (49.43)	253 (48.4)	421 (51.5)	
Having friends/family to talk to about health				.41
No	165 (14.38)	68 (13.5)	91 (16.2)	
Yes	1167 (85.62)	481 (86.5)	666 (83.8)	
Human-technology interaction factors, n (%)				
Accessing ePHRs[a] using smartphone app				<.001
No/don't know	854 (60.44)	305 (54.8)	528 (71.8)	
Yes	436 (39.56)	238 (45.2)	193 (28.2)	
ePHRs include clinical notes				.40
No/don't know	628 (49.66)	265 (51.1)	345 (46.8)	
Yes	650 (50.34)	275 (48.9)	369 (53.2)	
Ease of understanding ePHRs health information (range 0-3), mean	2.31	2.33	2.28	.42

[a] ePHRs: electronic personal health records.

Description of ePHR Use

Participants' ePHR use is reported in Table 2. The average level of ePHR use was low (mean 2.76, range 0-8). There was no significant difference in average ePHR use between the 2 age groups. Table 2 also shows the rate on each item of ePHR use. Specifically, the majority of participants used ePHRs to look up test results (1081/1277, 84.59% weighted). Around half of the participants used ePHRs to request a refill of medications (596/1276, 46.57% weighted) and securely message health care provider and staff (686/1278, 52.96% weighted). About one-quarter of participants used ePHRs to download health information to a computer or mobile device (292/1276, 25.88% weighted), add health information to share with health care providers (307/1278, 23.58% weighted), and help make a decision about how to treat an illness or condition (324/1274, 24.77% weighted). A small percentage of participants used ePHRs to request correction of inaccurate information (104/1263, 7.58% weighted) and electronically send health information (108/1268, 9.62% weighted). Significant differences between the 2 age groups were found related to using ePHRs to "download health information to a computer or mobile device," indicating that more younger adults used ePHRs to download health information to computers or mobile devices (*P*=0.04).

Table 2. Description of the use of electronic personal health records among participants (N=1363).

Participant use of ePHR[a] in the past 12 months	Total, n (%)	18-54 years old, n (%)	55 years old and above, n (%)	*P* values[b]
1. Request refill of medications	596 (46.57)	218 (44.0)	370 (51.8)	.13
2. Look up test results	1081 (84.59)	462 (84.2)	605 (85.3)	.75
3. Request correction of inaccurate information	104 (7.58)	39 (8.3)	63 (6.1)	.34
4. Securely message health care provider and staff (for example, email)	686 (52.96)	302 (54.9)	377 (49.0)	.10
5. Download your health information to your computer or mobile device, such as a cell phone or tablet	292 (25.88)	147 (28.7)	144 (20.1)	*.04* [c]
6. Add health information to share with your health care provider, such as health concerns, symptoms, and side effects	307 (23.58)	134 (24.0)	173 (22.8)	.74
7. Help you make a decision about how to treat an illness or condition	324 (24.77)	130 (24.7)	188 (25.0)	.94
8. Electronically send health information	108 (9.62)	65 (10.6)	41 (7.7)	.26

[a] ePHR: electronic personal health record.

[b] *F* test was used for all items.

[c] Italics indicate *P*<.05.

Weighted Multiple Linear Regression on Human-Technology Interaction Factors in Predicting ePHR Use Between 2 Age Groups

The regression analysis included 494 participants between 18 and 54 years old and 610 participants older than 55 years old. According to Table 3, at least 2 of the human-technology interaction factors of ePHRs were associated with the use of ePHRs among participants in both age groups. Including clinical notes was positively related to ePHR use in those 18 to 54 years old (β=.28; *P*=.005) and those 55 years old and older (β=.15; *P*=.006). Although accessing ePHRs using a smartphone app was only associated with ePHR use among younger adults (β=.29; *P*<.001), ease of understanding health information in ePHRs was positively linked to ePHR use only among older adults (β=.13; *P*=.003). Other than some human-technology interaction factors, having a regular health care provider and having friends or family to talk to about health were positively associated with the use of ePHRs among younger adults.

Table 3. Weighted multiple linear regression on human-technology interaction factors predicting electronic personal health record use between 2 age groups.

Predictor of use of ePHRs[a]	Standardized coefficient for 18-54 years old (β)	*P* values	Standardized coefficient for 55 years old and older (β)	*P* values
Sociodemographics				
Gender: female (ref[b]=male)	.01	.89	–.06	.27
Urbanity: urban (ref=rural)	.08	.40	.04	.76
Education: bachelor’s degree and above (ref=below bachelor’s degree)	–.05	.44	.11	.44
Health care resources				
Regular health care provider: yes (ref=no)	.14	.04	.12	.08
Frequency of visiting health care provider: 4 times and above (ref=0-3 times)	.02	.31	.05	.36
Having friends/family to talk to about health: yes (ref=no)	.12	.005	.10	.19
Human-technology interaction factors				
Accessing ePHRs using smartphone app: yes (ref=no/don’t know)	.29	<.001	.10	.14
ePHRs include clinical notes: yes (ref=no/don’t know)	.28	.005	.15	.006
Ease of understanding ePHR health information (range:0-3)	–.01	.89	.13	.003

[a] ePHRs: electronic personal health records.

[b] ref: reference.

Discussion

Principal Results and Comparison to Prior Work

Analyzing the most recent iteration of the HINTS collected in 2019, this study aimed to examine the relationship between human-technology interaction factors and ePHR use among adults and then to compare its different effects between younger adults (18-54 years old) and older adults (55 years old and older) while controlling for sociodemographics and health care resources.

The Level of ePHR Use Among Younger Adults and Older Adults

This study found that the average level of ePHR use was low (mean 2.76, range 0-8). This is in line with Hong and colleagues' [10] study that reported the use of ePHRs in the United States to be 31.4%. However, while Hong et al measured ePHR use by asking participants whether they had accessed ePHRs in the past 12 months (yes or no), our study only included participants who had accessed their ePHRs at least once in the past 12 months and measured the use level of different ePHR functions (eg, request refills of medications, look up test results, message health care provider and staff). This suggested that even among participants who accessed ePHRs, the use of ePHR functions is still low. The study also found that there was no significant difference in average ePHR use between the 2 age groups, which contradicts the findings of Greenberg et al [11] and McInnes et al [12], who reported younger age to be related to higher ePHR use. Including performance expectancy, effort expectancy, social influence, and facilitating conditions as independent variables, 2 studies conducted by Abd-Alrazaq and colleagues [29,30] found that age moderated the effects of performance expectancy, effort expectancy, and facilitating conditions on intention to use ePHRs. The moderating effect of age might be able to explain the nonsignificant finding of age difference in our study, which suggests that future studies are needed to explore the moderating effect of age using the current data set and measurements.

Human-Technology Interaction Factors Associated With ePHR Use

In terms of human-technology interaction factors associated with ePHR use, this study found that including clinical notes was positively related to ePHR use in both age groups. Previous studies examining the relationship between including clinical notes and ePHR use rates were not found. Nonetheless, in a survey evaluating veterans' access to an ePHR program called My HealtheVet Pilot, participants reported the highest rates (585/657, 89%) on using patient records including clinical notes or lab test results, and participants perceived that viewing medical records including clinical notes was the most useful feature of the ePHR programs [31]. In a qualitative study exploring participants' views on the My Health*e*Vet Pilot, participants identified that clinical notes promoted active patient participation by helping them prepare for the clinical visit, gain insight about their health and treatment plans, and gain insight into the providers' perspectives [32].

Regarding the different effects of human-technology interaction factors on ePHR use between the 2 age groups, accessing ePHRs using a smartphone app was significantly associated with ePHR use among younger adults while ease of understanding health information in ePHRs was significantly linked to ePHR use among older adults.

In terms of accessing ePHRs using a smartphone app, our findings are consistent with Bell et al's [33] findings that indicate accessing ePHRs through a mobile app to be associated with higher ePHR use. However, a conflicting finding was found in 2 previous studies: using the ePHRs only via a mobile device was related to infrequent use of ePHRs [34,35]. This discrepancy might be the result of samples with different characteristics in different studies being used. The study from Bell et al [33] was conducted among adults after elective orthopedic surgery, the study from Graetz et al [34] was conducted among adult patients with diabetes, and the study from Jung et al [35] was conducted with adults in South Korea. Moreover, previous studies showed that younger participants are more likely to use ePHRs only via a mobile device [33,34], which was also found in our study. The bivariate analysis of our study also indicated that younger adults were more likely to download health information to computers or mobile devices, such as a cell phone or tablet, which highlighted the significant role of mobile devices in ePHR use among younger adults.

Another human-technology interaction factor, ease of understanding health information in ePHRs, was found to be significantly linked to ePHR use among older adults but not younger adults. This finding is in line with Abd-Alrazaq et al's [29,30] studies, which suggested that perceived ease of use is positively associated with the intention to use ePHRs, with this relationship being stronger among older patients. This difference might be explained by the lower health literacy among older adults compared to their younger counterparts [36].

Conclusions

The purpose of this cross-sectional study was to examine the relationship between human-technology interaction factors and ePHR use among adults and then compare its different effects between younger adults (18-54 years old) and older adults (55 years old and older). The study found that the average level of ePHR use was low and that there was no significant difference in average use of ePHRs between the 2 age groups. Regarding the human-technology interaction factors, including clinical notes was positively related to ePHR use in both age groups, and accessing ePHRs using a smartphone app was positively associated with ePHR use among younger adults, while ease of understanding health information in ePHRs was a positive factor for ePHR use among older adults. The current study showed that there is a significant relationship between human-technology interaction factors and ePHR use and that the human-technology interaction factors associated with ePHR use vary across different age groups. In order to broadly promote the use of ePHRs, the design of ePHRs should take significant human-technology interaction factors into consideration, and the education or training regarding ePHR use should be provided for both health care providers and patients, especially for older adults.

Limitations

There are several limitations of this study. First, this study used a cross-sectional data set that was not able to examine causality between human-technology interaction factors and ePHR use. Second, the this study only included participants who were offered accesses to their ePHRs and accessed their ePHRs at least once in the past 12 months. Only 34% of US adults reported that they were offered access to their ePHRs [37], and, of those patients who were offered ePHR access, only 30% of patients actually accessed their ePHRs at least once in a year [11]. In order to promote meaningful use of ePHRs and maximize the benefit of ePHRs for patients, future studies may explore the factors that affect offering ePHR access to patients and patients' not accessing ePHRs even with access being granted. Finally, ePHR use in this study was measured by 8 self-reported items regarding the purposes for which participants used ePHRs, which might not have accurately recorded the actual use of ePHRs among participants. Future studies may consider using data including the frequencies and times that participants login to their ePHR accounts.

Implications for Practice and Future Research

Despite these limitations, this study is the first of its kind to examine the association between human-technology interaction factors and ePHR use among US adults and to compare its different effects between younger adults (18-54 years old) and older adults (55 years old and older). The findings of this study provide implications for practice and future research. This study found that including clinical notes was positively related to ePHR use in both age groups, which suggests that including clinical notes as a part of ePHRs might improve the effective use of ePHRs among patients. Although clinical notes can serve as a fundamental feature for ePHRs, participants in Woods et al's [32] study also demonstrated difficulties in seeing clinical notes, such as the use of derogatory terms, stress when seeing detailed personal information, and challenging conversations with providers. Although our study only examined "including clinical notes" as a single item, future studies are needed to explore patients' preferences on the type of clinical notes that should be included in ePHRs. This will also maximize the meaningful use of clinical notes. Moreover, this study found that accessing ePHRs using a smartphone app was associated with higher ePHR use among younger adults while ease of understanding health information in ePHRs was linked to higher ePHR use among older adults. The design of ePHRs should provide the option of being accessible through mobile devices to promote greater ePHR use among young people. For older adults, providers could add additional notes to explain the health information recorded in the ePHRs.

Empirical evidence has demonstrated that ePHRs provide consumers with easy and convenient access to their health data [1]. As the landscape of personal health care delivery changes due to increased technological advancements, there will be continued use of ePHRs. By addressing the concerns related to clarity in clinical notes for older adults and a simpler app platform for younger adults, ePHRs can increase access to health care data for both younger and older adults. With this increased use and access, it is important to highlight the benefits of using ePHRs in rural communities. Rural communities are often racially diverse, older, and tend to have lower incomes with limited access to health care [38]. In rural communities, telehealth is being used to address inequities in health care. Coupled with telehealth options, ePHRs can provide greater access to health data for individuals who reside in rural communities. This ease of access is also critical during times of prolonged crises, such as a pandemic. Since the coronavirus outbreak in March 2020 in the United States, the country has dealt with unprecedented circumstances in the medical field as medical staff continue to serve patient's routine and emergent health care needs. The use of and access to health care data through ePHRs has allowed patients to stay in touch with their providers while allowing protective social distancing measures to remain in place, especially for older adults who are at higher risk. Properly educating physicians and consumers on the benefits of ePHRs and how to use ePHRs to access data at any time will increase communication between the physicians and consumers. This will also aid consumers in adjusting to changes in health care delivery as it allows them to continue to feel connected to their health care provider during such a critical time in health care. During a pandemic, voluntary participation in data sharing via ePHRs would allow health authorities access to critical data on medical diagnoses that indicate who is at an elevated risk for additional negative impacts from COVID-19 [39]. This access could allow for valuable protective measures to be extended for at-risk populations and keep health authorities apprised of the success or failure of proactive measures to protect these higher-risk groups.

Authors' Contributions

YL contributed to the study conception and design, data analysis and interpretation, and manuscript preparation. KD contributed to manuscript preparation and editing. CI contributed to manuscript review and editing.

Conflicts of Interest

None declared.

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Abbreviations

ePHR: electronic personal health record
HINTS: Health Information National Trends Survey
PHR: personal health record

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Original Paper

Health Care Providers’ Acceptance of a Personal Health Record: Cross-sectional Study

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Abstract

Background: Personal health records (PHRs) are eHealth tools designed to support patient engagement, patient empowerment, and patient- and person-centered care. Endorsement of a PHR by health care providers (HCPs) facilitates patient acceptance. As health care organizations in the Kingdom of Saudi Arabia begin to adopt PHRs, understanding the perspectives of HCPs is important because it can influence patient adoption. However, no studies evaluated HCPs’ acceptance of PHRs in the Kingdom of Saudi Arabia.

Objective: The aim of this study was to identify predictors of HCPs’ acceptance of PHRs using behavioral intention to recommend as a proxy for adoption.

Methods: This cross-sectional study was conducted among HCPs (physicians, pharmacists, nurses, technicians, others) utilizing a survey based on the Unified Theory of Acceptance and Use of Technology. The main theory constructs of performance expectancy, effort expectancy, social influence, facilitating conditions, and positive attitude were considered independent variables. Behavioral intention was the dependent variable. Age, years of experience, and professional role were tested as moderators between the main theory constructs and behavioral intention using partial least squares structural equation modeling.

Results: Of the 291 participants, 246 were included in the final analysis. Behavioral intention to support PHR use among patients was significantly influenced by performance expectancy (β=.17, *P*=.03) and attitude (β=.61, *P*<.01). No moderating effects were present.

Conclusions: This study identified performance expectancy and attitude as predictors of HCPs' behavioral intention to recommend PHR to patients. To encourage HCPs to endorse PHRs, health care organizations should involve HCPs in the implementation and provide training on the features available as well as expected benefits. Future studies should be conducted in other contexts and include other potential predictors.

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KEYWORDS

personal health records; patient portals; Ministry of National Guard Health Affairs; UTAUT; eHealth; Middle East

Introduction

Overview

A wide range of eHealth technologies has become available over the past 2 decades as countries have introduced eHealth initiatives to support the goals for patient engagement and person-centered care [1]. Legislation around the world advocates for patients to have electronic access to their health information through personal health records (PHRs) [2]. PHRs are an eHealth tool to increase patient engagement and empowerment by allowing individuals to keep track of their personal health information. The Markle Foundation defined PHRs as "an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [3]. Person-centered care and patient engagement are considered pillars of any high-functioning health care system, and PHRs can contribute to both [4,5]. While various terms have been used interchangeably with PHR in the literature (eg, patient portal, patient web portal, computerized patient portal, patient accessible electronic health record [EHR], tethered PHR, electronic PHR), the broader term of PHR will be used predominantly throughout this paper.

PHR adoption has been associated with a wide range of benefits, including better patient–provider relationships, improvements in patient engagement, better medication adherence, positive health outcomes (eg, blood pressure and glycemic control), and increased organizational efficiencies [6]. As the benefits of PHR adoption are achieved, health care costs potentially decrease as individuals become empowered to take better control of their health and rely less on interactions with the health care system [6]. However, multiple studies have shown low adoption rates [7-9]. Even though the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act and its Meaningful Use criteria accelerated PHR access in the United States [10], only 15%-30% of patients use PHRs while 90% of health care systems offer them [11]. Outside of the United States, a systematic review showed adoption rates of around 0.13% in the United Kingdom and 5% in other European countries [7].

Various barriers to PHR adoption have been identified [7,9,12,13]. In the systematic review by Niazkhani et al [13], the barriers were characterized as patient demographic factors (eg, age, gender); environment/medical practice (eg, providers' communication about PHRs, physician resistance); technological (eg, perceived PHR usefulness, perceived PHR complexity); and chronic disease characteristics (eg, patients' feeling of control over the disease, number of comorbidities). Health care providers' (HCPs) attitudes are a major contributing factor in patients' adoption of PHRs [14-16]. HCPs play a key role in supporting and engaging patients through their attitudes, behavior, and endorsement of services [17]. Although studies have shown a high level of patient interest in PHRs [5,18-20], there has been a disconnect between interest and uptake. This is partially due to HCPs' reticence toward the acceptance and promotion of their use [5,21,22].

Researchers around the world have studied HCPs' attitudes and perceptions of PHRs. Nazi [22] explored the experiences and perspectives of HCPs (physicians, nurses, and pharmacists) related to patients' use of the My HealtheVet PHR in the United States and found that many HCPs had limited familiarity with the PHR features, contributing to its underutilization [22]. The author identified the following 8 factors to be key in the implementation, adoption, and use of PHRs: (1) showing the relevance of PHRs; (2) increasing the perceived value by focusing on unique services; (3) providing education and training; (4) integrating PHRs into the existing technology; (5) aligning PHR functions with the workflow; (6) offering incentives to individuals or teams; (7) making information accessible; and (8) supporting asynchronous and bidirectional communication.

A study in Finland, which included a wide range of HCPs (eg, nurses, social workers, dentists, physicians, physical therapists, and psychologists), found that the most important factors influencing HCPs' support for a national patient portal were expected positive influences on their work, the usability of the portal, and benefits for the patients [17]. However, only few (13%) respondents felt they had received adequate information about the portal. The authors recommended HCPs be informed about PHR benefits to garner their support. In Canada, Wiljer et al [23] endorsed institutional strategies such as "continuous organizational reassurance," education, and a physician champion to stimulate a paradigm shift to patient-centered care for successful PHR implementation. In a Swedish study of oncology HCPs (nurses and physicians), the authors compared HCPs working in outpatient clinics with those working in primary care units [24]. A greater proportion of HCPs in primary care believed there were benefits of patients using PHRs such as better adherence (50% vs. 35%), greater ability to clarify important information (50% vs. 26%), and improved patient communication (36% vs. 20%) [25].

In the Kingdom of Saudi Arabia, enhancing patient-centered care through patient involvement with technology is an objective of The National Transformation Program, a component of Vision 2030. The Ministry of National Guard Health Affairs (MNGHA) implemented the MNGHA Care PHR in 2018. No studies have evaluated HCPs' acceptance of PHRs in the country.

The aim of this study was to identify a set of factors that affect the intention to recommend the use of MNGHA Care PHR among HCPs. To promote patient engagement and patient-centered care, a better understanding of how HCPs perceive PHRs is needed.

Theoretical Background

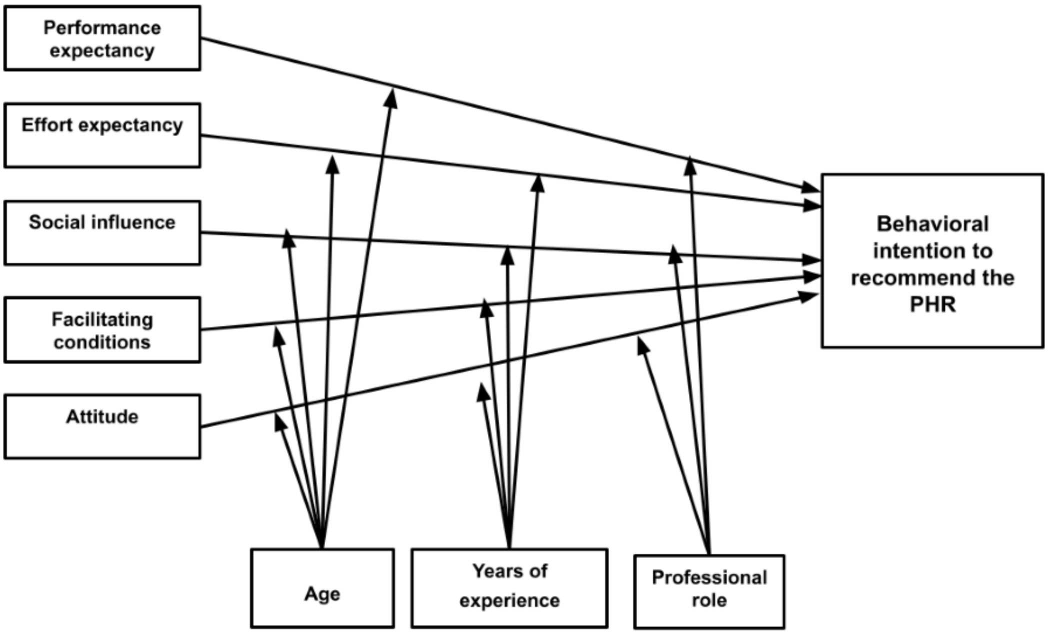
In 2003, Venkatesh et al [26] developed the Unified Theory of Acceptance and Use of Technology (UTAUT) to provide a comprehensive framework to explain acceptance, intention, and usage of information technology in organizations. It is an integration of 8 theories—theory of reasoned action, technology acceptance model (TAM), motivational model, theory of planned behavior (TPB), combined TAM–TPB, model of personal computer utilization, diffusion of innovation theory, and social cognitive theory [26]. The core constructs of performance expectancy, effort expectancy, social influence, and facilitating conditions directly act on behavioral intention and, ultimately, predict the use of the technology. Gender, age, voluntariness, and experience are moderators in the framework. The model explained approximately 77% of the variance in behavioral intention and 52% of the variance in technology use [26]. Since its development, UTAUT has been used to explain technology acceptance in different user groups in a wide range of contexts with various technologies, strengthening the generalizability [27]. UTAUT has also been used broadly in other health care areas, including telemedicine [28,29], electronic medical/health records [30-34], electronic documentation systems [35], picture archiving and communication systems [36], and health information systems [37,38].

Research Model and Hypotheses

Most studies have not examined the full UTAUT with the moderation effects but rather the main effects alone, combined with a subset of the moderators, or with new constructs or mechanisms [39]. Venkatesh et al [39] proposed that future research should use UTAUT as the baseline model to transform the theory from static to dynamic. New endogenous mechanisms or new moderation mechanisms are the most common types of extensions [39]. While UTAUT includes the technological dimension (performance expectancy and effort expectancy) and organizational/environmental dimension (social influence and facilitating conditions), the individual dimension is not included. Nonetheless, individual traits (attitude, personal innovativeness, computer self-efficacy) may significantly predict the acceptance of technology [27,40,41]. Constructs representing individual traits are frequently used as endogenous mechanisms to extend UTAUT.

The research model for this study includes the 4 core UTAUT constructs: performance expectancy, effort expectancy, social influence, and facilitating conditions (Figure 1). The construct of attitude was added as an individual characteristic. Unlike the original UTAUT model, we did not include behavior in the proposed model because we were unable to objectively assess use. Instead, we measured intention to recommend PHR, using it as a proxy for HCPs' acceptance. Behavioral intention is frequently a proxy for actual technology adoption in the literature [42-44].

Figure 1. Adapted UTAUT model. PHR: personal health record; UTAUT: Unified Theory of Acceptance and Use of Technology.



Proposed differences between this model and the original UTAUT model are shown in Table 1. The moderators chosen for this study were age, years of experience, and professional role. Previous literature indicated that age was inversely associated with eHealth adoption. For example, electronic medical record use was inversely associated with physician age [45]. A potential explanation is that, in the initial stages of technology use, older users are believed to be more influenced by experience, and ease of use is more important [26]. Next, years in practice has been associated with acceptance of eHealth [45]. As the number of years since medical school graduation increased, physicians became less likely to accept eHealth technologies [45]. There have also been differences in eHealth acceptance by professional role [45]. Nonphysicians used advanced EHR features less than physicians, and specialists (eg, obstetrician/gynecologists) were less likely to use an EHR in their practices [45]. Voluntariness of use and gender were dropped as moderators in the proposed model. PHR use is not mandatory; therefore voluntariness of use is not relevant [26]. In the health care context, professional role takes precedence over gender and no differences in acceptance by gender were expected [34].

Table 1. Original Unified Theory of Acceptance and Use of Technology (UTAUT) versus adapted UTAUT for health care providers.

Construct	Original UTAUT[a] moderators				Adapted UTAUT moderators		
	Gender	Age	Experience	Voluntariness	Age	Years of experience	Professional role
PE[b] → BI[c]	✓	✓			✓		✓
EE[d] → BI	✓	✓	✓		✓	✓	
SI[e] → BI	✓	✓	✓	✓	✓	✓	✓
BI → Use[f]							
FC[g] → Use		✓	✓				
FC → BI					✓	✓	
ATT[h] → BI					✓	✓	✓

[a] UTAUT: Unified Theory of Acceptance and Use of Technology.

[b] PE: performance expectancy.

[c] BI: behavioral intention.

[d] EE: effort expectancy.

[e] SI: social influence.

[f] Use: actual usage.

[g] FC: facilitating conditions.

[h] ATT: attitude.

This study tested the following hypotheses:

- H1: Performance expectancy positively influences behavioral intention to recommend the PHR
- H2: Effort expectancy positively influences behavioral intention to recommend the PHR
- H3: Social influence positively influences behavioral intention to recommend the PHR
- H4: Facilitating conditions positively influence behavioral intention to recommend the PHR
- H5: Attitude positively influences behavioral intention to recommend the PHR
- H6: Age, years of experience, and professional role selectively moderate the relationships between the main constructs and behavioral intention to recommend the PHR

Methods

Study Design

A cross-sectional study utilizing a survey was conducted at a large, integrated health care system in the Kingdom of Saudi Arabia. The survey was administered to HCPs across the organization to assess acceptance of the PHR. Since 2018, patients have had access to the MNGHA Care PHR, which includes the following features: scheduling appointments, requesting medical reports and prescription refills, viewing radiology reports, checking laboratory results, and receiving vaccination reminders [46]. Additionally, personal health information such as weight, blood pressure, blood sugar, and exercise details can be uploaded. Finally, MNGHA Care contains links to health education information and a self-assessment feature permitting patients to enter information related to pain control, performance status, and quality of life.

Setting and Participants

The study population consisted of HCPs from MNGHA hospitals and primary health care centers in Dammam, Riyadh, Jeddah, Madinah, Al Ahsa, and Qassim, including physicians, dentists, pharmacists, nurses, physical and occupational therapists, optometrists, technicians (pharmacy, medical imaging, medical and pathology laboratory, dental), paramedics, and dietitians.

Instrument and Data Collection

Data were collected using an anonymous self-administered online survey between April and May 2021. The initial version of the survey included 63 items adapted from previously published technology acceptance surveys used in health care in

3 parts [26,47-51]. The first part captured demographic characteristics including age, gender, region, facility type, profession, specialty area (for physicians), years in profession, years at MNGHA, and nationality. The second part contained 4 general PHR questions: (1) Have you heard of MNGHA Care?; (2) Do you have an MNGHA Care account?; (3) Have you used MNGHA Care yourself?; and (4) Have you recommended patients to use MNGHA? This section also included Likert-scale statements associated with PHR acceptance along with an open-ended question and a checklist. The third section related to acceptance of secure messaging and included Likert-scale statements, an open-ended question, and a checklist.

The instrument was built on QuestionPro [52] and pilot tested with 7 HCPs (2 physicians, 3 pharmacists, and 2 nurses) working within MNGHA. The QuestionPro survey link and a cover letter explaining the purpose of the study were emailed to these 7 HCPs to obtain feedback regarding survey length, clarity, and flow of the questionnaire. After comments were compiled, 12 items were removed, and some were modified to improve clarity and to decrease survey length. The final version of the survey included 51 items and was approved by the institutional review boards at the Virginia Commonwealth University and King Abdullah International Medical Research Center.

For this study, the focus was on parts 1 and 2 of the instrument. However, the open-ended question and checklist from part 2 are not included in this paper. Responses to the PHR acceptance items were provided on a 5-point Likert scale from strongly disagree (1) to strongly agree (5). Acceptance was operationalized as the intention to recommend patients use the PHR using the statement “I will probably recommend patients use MNGHA Care in the future” [49].

Performance expectancy was defined as the degree to which the HCP believes a PHR will be beneficial in the health care delivery process [20]. It was measured with the following 4 items:

1. MNGHA Care is a useful tool to help patients feel more involved in their care [47,53].
2. I believe MNGHA Care helps patients to better manage their health [48].
3. MNGHA Care will increase patient satisfaction with their health care [48].
4. MNGHA Care can improve the quality of patient care [51].

Effort expectancy is the degree of ease associated with use of the PHR [20]. It was measured with the following 3 items:

1. Information in MNGHA Care should be easy for our patients to understand [48,53].
2. I believe most patients have the skills needed to use MNGHA Care [47].
3. I think it is not difficult for our patients to learn to use MNGHA Care [47].

Social influence is the degree to which an individual perceives important others believe the PHR should be used [20]. It was measured with the following 2 items:

1. I believe our patients support the use of MNGHA Care [48].
2. In general, the organization has supported the use of MNGHA Care [26].

Facilitating conditions was defined as the degree to which an individual believes an organizational and technical infrastructure exists to support use of the PHR [20]. It was measured with the following 3 items:

1. I have enough information about MNGHA Care [26,48].
2. There is technical help for patients who use MNGHA Care [26].
3. I know the goals of MNGHA Care [26].

Attitude was defined as positive feelings related to patients using the PHR [54]. It was measured with the following 4 items:

1. MNGHA Care is a valuable tool [26,47].
2. It is a good idea for patients to use MNGHA Care [26,47].
3. MNGHA Care is a positive advancement in this digital age [47].
4. I believe MNGHA Care will be used by many patients [47].

Although behavioral intention and social influence used less than 3 items, partial least squares structural equation modeling (PLS) supports using single-item measures [55] and earlier research using PLS has used less than 3 items for measuring constructs [56,57].

Sampling

A snowball and convenience sampling strategy was used to recruit HCPs from across the organization. HCPs were initially recruited through the hospital’s email list in combination with WhatsApp as it is a widely used social media platform for professional communication. They were asked to forward the survey to other HCPs. Follow-up reminders were also sent out. The target sample size for this study was 200 HCPs, which has been considered a fair sample size for statistical analysis with structural equation modeling [58]. To encourage participation, there was a random drawing for twenty five 37.5 Saudi Arabian Riyal (US $10) Amazon gift cards.

Statistical Analyses

Descriptive statistics were analyzed using SPSS version 25 (IBM) [59]. PLS was used to test the research model using SmartPLS version 3.0 [60]. The advantage of PLS is the ability to estimate complex research models without distributional assumptions [61]. Compared with traditional SEM, PLS has greater statistical power, which means that there is a higher likelihood of identifying significant relationships if they are actually present in the population [61]. Furthermore, PLS has been widely used in empirical studies of technology acceptance, including with UTAUT [26,27,34] and with PHR acceptance [50,62]. To test the research model, a measurement model was used to evaluate construct reliability, indicator reliability, convergent validity, and discriminant validity. A structural model was tested after ensuring reliability and validity.

Results

Demographic Characteristics

Overall, 291 HCPs participated in the survey. However, after removing the data for missing values, a usable sample of 246 was used for further analysis. Table 2 presents the demographic characteristics. Most were 40-49 years old (95/246, 38.6%), female (158/246, 64.2%), non-Saudi (132/246, 53.7%), nurses (106/246, 43.1%), in Riyadh (81/246, 32.9%), over 10 years of experience (167/246, 67.9%) and over 10 years at MNGHA (128/246, 52.0%), and hospital based (228/246, 92.7%).

Table 2. Demographic characteristics (N=246).

Variables	Values, n (%)
Age	
20-29 years	37 (15.0)
30-39 years	77 (31.3)
40-49 years	95 (38.6)
50 years and above	37 (15.0)
Gender	
Male	88 (35.8)
Female	158 (64.2)
Nationality	
Saudi	114 (46.3)
Non-Saudi	132 (53.7)
Health care provider	
Physician	40 (16.3)
Pharmacist	57 (23.2)
Nurse	106 (43.1)
Technician	33 (13.4)
Other	10 (4.1)
Years in profession	
Less than 5 years	33 (13.4)
5-10 years	46 (18.7)
Greater than 10 years	167 (67.9)
Years working at MNGHA[a]	
<1 year	13 (5.3)
1-4 years	40 (16.3)
5-10 years	65 (26.4)
>10 years	128 (52.0)
Location	
Dammam	46 (18.7)
Madinah	35 (14.2)
Al Ahsa	51 (20.7)
Jeddah	33 (13.4)
Riyadh	81 (32.9)
Type of facility	
Hospital	228 (92.7)
Primary health care clinic	18 (7.3)

[a] MNGHA: Ministry of National Guard Health Affairs.

General PHR Use Characteristics

The majority of HCPs were aware of MNGHA Care (225/246, 91.5%), had an account (213/246, 86.6%), used MNGHA Care (202/246, 82.1%), and recommended it to patients (198/246, 80.5%).

Measurement Model

The measurement model testing results are summarized in Table 3. After removing missing data, the usable sample for hypothesis testing was 246. The variance inflation factor of all items was below the threshold of 5, showing no evidence of multicollinearity. Item loadings were all above 0.40 and in the range of 0.70-0.93. Composite reliability was above the threshold of 0.70, showing good internal consistency. Moreover, the average variance extracted (AVE) of the constructs were greater than 0.50 and in the range of 0.55-0.81, indicating convergent validity.

Discriminant validity was tested using the Fornell–Larcker criterion. The square roots of the corresponding AVE are shown in italics, with each construct's AVE higher than its highest correlation with any other construct (Table 4). Results in Tables 3 and 4 provide evidence of the validity and reliability of the constructs used in the model.

Table 3. Measurement model statistics.

Construct and items	Mean	SD	VIF[a]	Loadings	CR[b]	AVE[c]
Performance expectancy (PE)	4.09	0.73			0.95	0.81
PE1			2.526	0.87		
PE2			3.792	0.92		
PE3			3.711	0.92		
PE4			3.462	0.90		
Effort expectancy (EE)	3.75	0.67			0.79	0.55
EE1			1.099	0.81		
EE2			1.473	0.70		
EE3			1.465	0.72		
Facilitating conditions (FC)	3.60	0.78			0.88	0.71
FC1			1.756	0.85		
FC2			1.547	0.77		
FC3			2.023	0.90		
Social influence (SI)	3.82	0.69			0.85	0.74
SI1			1.3	0.84		
SI2			1.3	0.88		
Attitude (ATT)	4.08	0.63			0.94	0.80
ATT1			4.171	0.93		
ATT2			3.603	0.92		
ATT3			3.486	0.91		
ATT4			2.029	0.83		
Behavioral intention (BI)						
BI	4.18	0.68		1	1	1

[a] VIF: variance inflation factor.

[b] CR: composite reliability.

[c] AVE: average variance extracted.

Table 4. Discriminant validity of the constructs.[a]

Constructs	1	2	3	4	5
Attitude	*0.896*				
Effort expectancy	0.697	*0.742*			
Facilitating conditions	0.596	0.570	*0.843*		
Performance expectancy	0.742	0.708	0.527	*0.901*	
Social influence	0.646	0.671	0.645	0.602	*0.860*

[a] Square roots of the corresponding average variance extracted are shown in italics.

Structural Model

The R^2 was used to assess the structural model. Overall, the model explained 70% of the variance in the intention to recommend the PHR among HCPs (Figure 2). Table 5 presents the structural model results, while Table 6 presents the test for moderating effects.

Figure 2. Structural model showing path coefficients (β) and coefficient of determination (R^2) (*P<.05, **P<.01). PHR: personal health record.

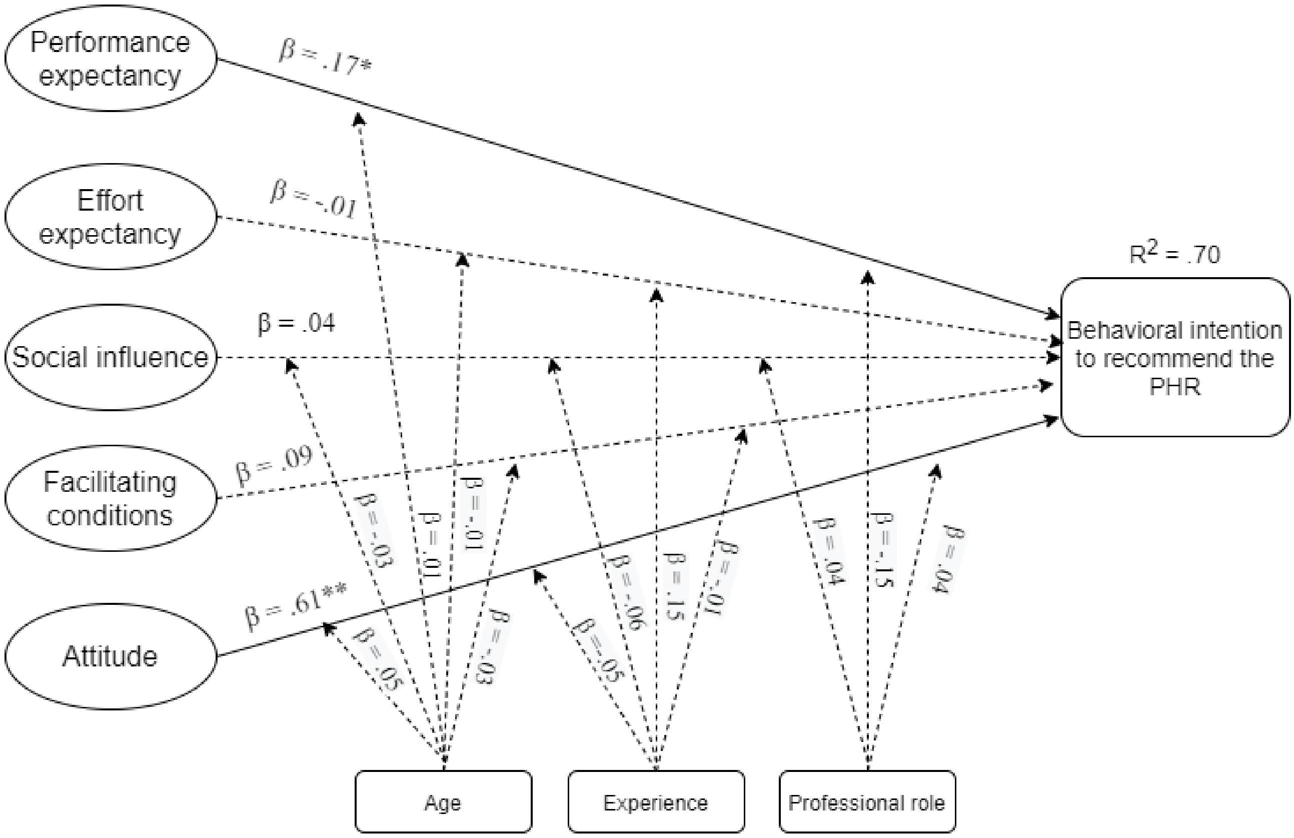


Table 5. Structural model results.

Structural model	β	*t*-statistics[a] (*df*)	*P* value	f^2
PE[b] → BI[c]	.17	2.132 (499)	.03[d]	0.035
EE[e] → BI	–.01	0.166 (499)	.87	0
SI[f] → BI	.04	0.473 (499)	.63	0.002
FC[g] → BI	.09	1.241 (499)	.21	0.013
ATT[h] → BI	.61	6.385 (499)	<.01	0.369

[a] Two tailed.
[b] PE: performance expectancy.
[c] BI: intention to recommend PHR.
[d] $P<.05$.
[e] EE: effort expectancy.
[f] SI: social influence.
[g] FC: facilitating conditions.
[h] ATT: attitude.

Table 6. Moderation analysis results.

Analysis	β	*t*-statistics[a] (*df*)	*P* value	f^2
Moderation of age				
PE[b] × AGE[c] → BI[d]	.01	0.118 (499)	.91	0
EE[e] × AGE → BI	–.01	0.159 (499)	.87	0
FC[f] × AGE → BI	–.03	0.360 (499)	.72	0.001
SI[g] × AGE → BI	.05	0.633 (499)	.53	0.003
ATT[h] × AGE → BI	–.03	0.307 (499)	.76	0.001
Moderation of experience				
EE × EXP[i] → BI	.15	1.688 (499)	.09	0.016
SI × EXP → BI	–.06	0.609 (499)	.54	0.003
FC × EXP → BI	–.01	0.205 (499)	.84	0
ATT × EXP → BI	–.05	0.597 (499)	.55	0.003
Moderation of professional role				
PE × HCP[j] → BI	–.15	1.598 (499)	.11	0.023
SI × HCP → BI	.04	0.620 (499)	.54	0.003
ATT × HCP → BI	.04	0.441 (499)	.66	0.002

[a] Two tailed.
[b] PE: performance expectancy.
[c] AGE: age.
[d] BI: intention to recommend PHR.
[e] EE: effort expectancy.
[f] FC: facilitating conditions.
[g] SI: social influence.
[h] ATT: attitude.
[i] EXP: experience.
[j] HCP: health care provider.

Discussion

Principal Findings

To the best of our knowledge, this is the first study to examine factors that influence HCPs’ intention to recommend PHRs to patients in the Kingdom of Saudi Arabia. Prior studies in the country evaluated the challenges in implementing PHRs and identified HCP resistance as a barrier [63,64]. Although HCPs are not the primary users of PHRs, their endorsement can positively influence patient engagement with this technology [12]. While some providers find promoting the PHR to be an additional burden, those providers who present a PHR to their patients as a tool to supplement their care can facilitate patient adoption [9]. Our study found a high level of awareness among HCPs, with 88.2% (217/246) having an account and 82.1% (202/246) recommending patients use the PHR. In our previous study in patients, HCPs and hospital staff were primarily responsible for recommending the PHR in 58.7% of patients who reported using MNGHA Care [18].

Predictors of patient adoption of PHRs may differ from those that affect HCPs to endorse a PHR [7,12]. Therefore, the research model for HCPs was slightly different from the one used for patients [18]. The proposed theoretical model explained 70% of the variance in HCPs’ behavioral intention to recommend PHRs to patients. Performance expectancy and attitude were significantly associated with behavioral intention to recommend the PHR. Much of the literature has shown performance expectancy as the strongest predictor of intention to use technology among HCPs [30,38,47]. In patient and consumer studies of PHRs, performance expectancy has also been a positive predictor of adoption [50,65-67]. However, the attitude was the strongest predictor of behavioral intention in our study. Other studies on PHR adoption have also found attitude to be an important predictor [47,51].

Our findings did not support the hypothesis that age, years of experience, and professional role moderate behavioral intention. Several studies have shown that older and more experienced HCPs are more resistant to health information technology and are less comfortable with using technology [35]. Physicians also have been found to be less enthusiastic about the introduction of eHealth services [33]. In our study, most had over 10 years of experience as an HCP (190/289, 65.7%) and more than 10 years in MNGHA (149/289, 51.6%). Furthermore, while Moll and Cajander [25] found differences in attitudes of HCPs who worked in primary care units compared with outpatient clinics, most HCPs in this study were from the hospital (265/284, 93.3%), limiting the ability to draw comparisons.

Implications for Theory

This research adds to the literature on HCPs’ acceptance of PHR using an adapted UTAUT model. To our knowledge, this is the first study to extend UTAUT with the construct of attitude in the context of HCPs’ acceptance of PHR. Only few studies evaluating HCPs’ acceptance of PHRs have used theory [68]. This study revealed that the adapted UTAUT model was a good predictive model of HCPs’ behavioral intention to recommend PHR use. While our model found that performance expectancy and attitude individually influence behavioral intention, it may also be the case that attitude mediates the relationship between performance expectancy and behavioral intention, as proposed by Dwivedi et al [40].

The original UTAUT explained 76% of the variance in behavioral intention. No studies on PHR adoption have used the original UTAUT model [50,65,66,69,70]. The advantage of the adapted model is a similar predictive power while parsimoniously eliminating the construct “use behavior” and the moderator “voluntariness” in the original model. Although the model explained 70% of the variance in behavioral intention and provided support for the proposed theoretical model, other factors may be important for HCPs’ acceptance of PHR. In the health care setting, UTAUT has been criticized for its focus on general technology acceptance factors and the inability to completely explain health information technology adoption [71]. Therefore, it is recommended that UTAUT be adapted to fit the health care context by incorporating health behavior theories, privacy and security issues, and negative factors that inhibit technology adoption [71].

Implications for Practice

This study provides practical contributions based on the proposed relationships and supports the need to focus on strategies to enhance perceived usefulness and a positive attitude toward the PHR in HCPs. While some patients view self-management as a burden and prefer the status quo [9], others will respond to HCP’s endorsement of the use of PHRs. Several studies identified HCP recommendation as an important factor in patients’ choosing to use PHRs [2,22,23,72,73]. Lyles et al [11] found one-on-one training to be the most effective intervention in PHR implementation in the United States. Providing short educational sessions to individuals or teams can facilitate acceptance among HCPs [48]. These training sessions could be conducted by each department. Training HCPs on the features available supports successful implementation by increasing skills and knowledge. Campaigns can also be directed at promoting awareness among HCPs. Through these interventions, HCPs will perceive the usefulness of PHRs and develop more positive attitudes regarding the benefits. Consequently, they will be more inclined to recommend PHRs to patients. Through their interactions with HCPs, patients will perceive PHRs as useful and are more likely to adopt them [66].

Limitations

There are several limitations to this study. While cross-sectional studies are useful for examining associations, a causal relationship cannot be established [74]. Snowball and convenience sampling, both nonprobability sampling strategies, were used to select participants, limiting generalizability; however, participants from multiple sites were selected to attain good representation across MNGHA. Self-administered online surveys are associated with various biases, including social desirability response bias, self-selection, and nonresponse bias [75]. To minimize social desirability response bias, participants had the option of not answering any question that made them uncomfortable. To minimize nonresponse bias, HCPs were contacted multiple times and offered an incentive to encourage a high response rate.

Recommendations for Future Research

Future studies should evaluate the proposed model in other contexts. This study involved a large integrated health care organization. Research in other organizations within the country and in this part of the world will increase the generalizability of our findings. Research should also be conducted in individual HCP groups. Differences in PHR acceptance have been observed based on a variety of characteristics, including age, gender, professional role, and practice setting. Future researchers should focus on HCP group–specific interventions. Finally, while this study used an open-ended question and checklist (analyzed separately) to achieve greater depth, one-on-one interviews would provide valuable data on the motivation of HCPs and nuances within this context.

Conclusion

This study examined factors affecting HCPs' behavioral intention to recommend PHRs to patients in the Kingdom of Saudi Arabia. The proposed model accounted for 70% of the variance in behavioral intention, indicating significant predictive power. Performance expectancy and attitude were significant predictors of HCPs' behavioral intention to support PHR use. Our results suggest that health care organizations should focus on strategies associated with these factors to improve HCP support and decrease barriers to patient use of PHRs. Future research should test this model and explore other predictors in order to develop successful interventions to encourage the adoption and continued use of the PHR among patients.

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Conflicts of Interest

None declared

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Abbreviations

EHR: electronic health record
HCP: health care provider
HITECH: Health Information Technology for Economic and Clinical Health
MNGHA: Ministry of National Guard Health Affairs
PHR: personal health record
TAM: technology acceptance model
TPB: theory of planned behavior
UTAUT: Unified Theory of Acceptance and Use of Technology

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Original Paper

Factors Affecting the Extent of Patients' Electronic Medical Record Use: An Empirical Study Focusing on System and Patient Characteristics

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Abstract

Background: Patients' access to and use of electronic medical records (EMRs) places greater information in their hands, which helps them better comanage their health, leading to better clinical outcomes. Despite numerous benefits that promote health and well-being, patients' acceptance and use of EMRs remains low. We study the impact of predictors that affect the use of EMR by patients to understand better the underlying causal factors for the lower use of EMR.

Objective: This study aims to examine the critical system (eg, performance expectancy and effort expectancy) and patient characteristics (eg, health condition, issue involvement, preventive health behaviors, and caregiving status) that influence the extent of patients' EMR use.

Methods: We used secondary data collected by Health Information National Trends Survey 5 cycle 3 and performed survey data analysis using structural equation modeling technique to test our hypotheses. Structural equation modeling is a technique commonly used to measure and analyze the relationships of observed and latent variables. We also addressed common method bias to understand if there was any systematic effect on the observed correlation between the measures for the predictor and predicted variables.

Results: The statistically significant drivers of the extent of EMR use were performance expectancy (β=.253; P<.001), perceived behavior control (β=.236; P<.001), health knowledge (β=–.071; P=.007), caregiving status (β=.059; P=.013), issue involvement (β=.356; P<.001), chronic conditions (β=.071; P=.016), and preventive health behavior (β=.076; P=.005). The model accounted for 32.9% of the variance in the extent of EMR use.

Conclusions: The study found that health characteristics, such as chronic conditions and patient disposition (eg, preventive health behavior and issue involvement), directly affect the extent of EMR use. The study also revealed that issue involvement mediates the impact of preventive health behaviors and the presence of chronic conditions on the extent of patients' EMR use.

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KEYWORDS

electronic medical record; patient safety; caregiver; chronic conditions; HINTS dataset; patient technology acceptance model

Introduction

Background

An electronic medical record (EMR), also called the online medical record system, is a kind of software that stores clinical information such as medication lists, laboratory results, physician observations, immunizations, allergies, and discharge information [1]. Due to the impetus provided by the Health Information Technology for Economic and Clinical Health Act, EMR usage by providers and hospital administrators surged significantly, leading to improved documentation, data availability, and streamlined order entry to decrease prescription errors [2].

Although physician adoption and use of EMRs have been widely investigated [3-10], patients' use of EMR warrants further research. Patient adoption and use of EMRs represent a different phenomenon contrasted with physician adoption and use of EMR. For example, patients are not subject to organizational pressures prevalent in physician adoption and use decisions. Other factors differentiating the two contexts derive from the fact that patients may not be familiar with the technology to access EMR, and their understanding of clinical terms may be limited.

It is crucial to increase patient use of EMR for various consequential reasons, specifically patient empowerment. According to the World Health Organization, patient empowerment is a process through which people gain greater control over decisions and actions affecting their health [11]. Patients' access to and use of medical records empowers them to take a more active role in managing their health [12] by placing more information in their hands, which can improve clinical outcomes. Further, a patient portal built on top of EMR offers several benefits to patients, including continuous monitoring of health information, improved interactions with providers, better patient engagement in health management, scheduling appointments, and messaging physicians [13].

This research investigates the factors that influence patients' adoption and use of EMRs using an extended version of the patient technology acceptance model (PTAM). Specifically, we focus on the effect of salient patient characteristics such as health conditions, issue involvement, preventive health behaviors, and caregiving status on the adoption and use of EMR systems because they remain understudied.

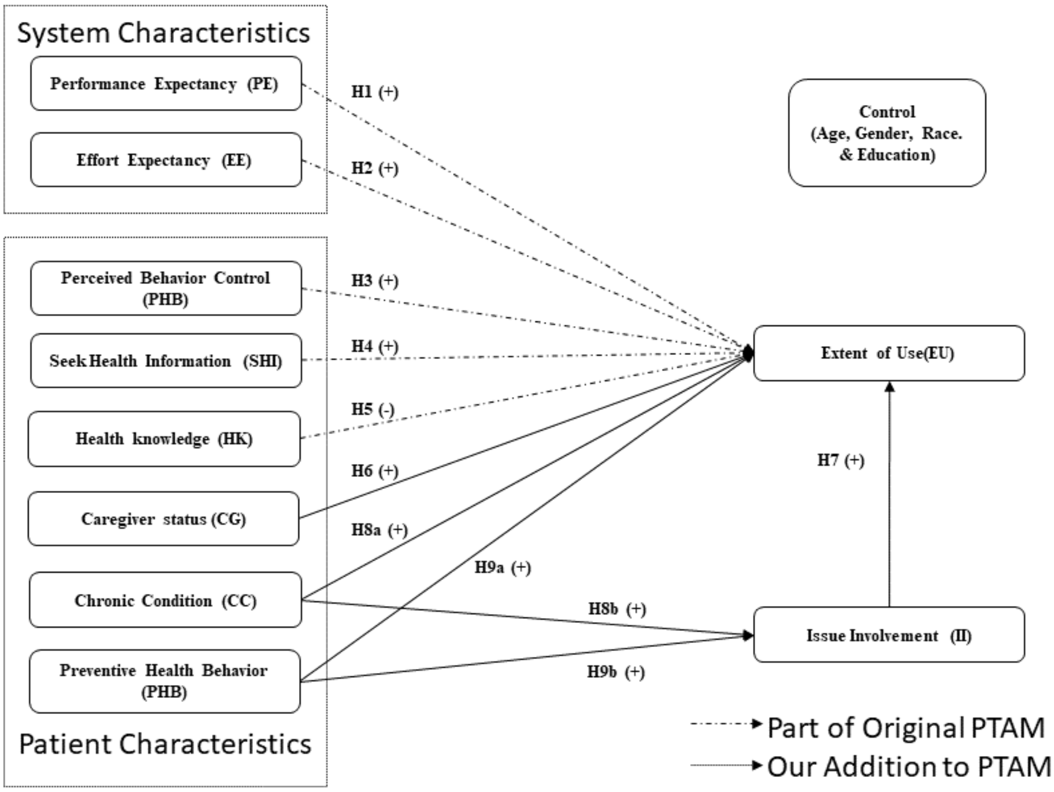
Hypotheses and Proposed Model

Overview

From a theoretical perspective, the unified theory of acceptance and use of technology has been employed to understand technology adoption and use in general [14]. It was adapted to the health care context with the addition of patient-centered factors (psychomotor, visual, and cognitive aspects) to study patients' adoption of technology [15] and was called PTAM. It considers perceived usefulness, perceived ease of use, perceived behavior control, subjective norm, and patient characteristics (psychomotor, visual, and cognitive aspects) as main predictors of the adoption and use of health information technologies by patients. PTAM was originally developed by Or et al [15] for the general context of patient adoption of technology. Since EMR is a specific technology for storing medical records, we had to adapt it to our context.

In this study, we not only considered factors such as performance expectancy (perceived usefulness), effort expectancy (perceived ease of use), perceived behavior control, but also extended the model with patient characteristics that are not part of the original PTAM, such as health condition, preventive health behavior, issue involvement, and patients' caregiving status. Following that, we introduced issue involvement as a mediator between the extent of EMR use and (1) chronic conditions and (2) preventive health behavior. Age, gender, education, and race were used as control variables in our study. Our proposed research model is illustrated in Figure 1. This adaptation contributes to the development of a theoretical foundation that could be used to improve our understanding of patients' EMR use.

Figure 1. Research model. PTAM: patient technology acceptance model



Performance Expectancy

Davis [16] defined perceived usefulness as one of the key predictors of new system adoption. Venkatesh et al [14] extended this notion of perceived usefulness by defining performance expectancy as the degree to which a person feels that using a system will help them perform a job more efficiently. In keeping with this understanding, we refer to performance expectancy as the degree to which the patient believes that using EMRs helps them monitor their health. Venkatesh et al [14] theorized that performance expectancy drives the intention to use information systems. Several researchers have also identified performance expectancy as one of the critical predictors of eHealth acceptance and use [15,17-21]. Because EMRs improve patient engagement and empower patients to access their health information anytime and anywhere [22], we propose the following hypothesis:

- H1: Performance expectancy is positively related to the extent of EMR use.

Effort Expectancy

Extending the ease of use construct [16], Venkatesh et al [14] defined effort expectancy as the degree of comfort associated with system use. Consistent with Venkatesh et al [14], we define effort expectancy as the degree of ease associated with understanding the health information in the online medical record. Venkatesh et al [14] suggested that effort expectancy has a positive effect on use intentions. Many researchers have also identified effort expectancy as one of the critical predictors of health adoption and use [15,19-21]. Studies have confirmed that ease of use is an essential predictor of intended use. Therefore, we propose the following hypothesis:

- H2: Effort expectancy is positively related to the extent of EMR use.

Perceived Behavioral Control

Or et al [15] defined perceived behavioral control as an individual's perception of their ability to do something (ie, self-efficacy). Many researchers have suggested that self-efficacy directly determines intent to use, especially online and mobile applications [23]. Lack of self-efficacy with computers and the internet is one of the most frequently identified barriers to adopting and using patient portals [24,25]. Turner et al [26] confirmed that the lack of comfort with computers is one of the common barriers to patient adoption of a portal. Thus, we posit that competency with technology is more likely to generate confidence in using EMRs. We hypothesize the following:

- H3: Perceived behavioral control is positively related to the extent of EMR use.

Seek Health Information

Seek health information (SHI) refers to individuals' urge to look for health-related information. Wilson and Lankton [27] argued that individuals seeking health information are more likely to adopt eHealth applications because such applications increase the availability of health information and reduce the effort needed to access that information. Or et al [15] extended the same concept and theorized that individuals who need to review health information are more likely to accept and use technology. As EMRs can help individuals get their health information and health history, and based on prior studies regarding health-information-seeking behavior, we propose the following hypothesis:

- H4: Seeking health information is positively related to the extent of EMR use.

Health Knowledge

Or et al [15] defined health knowledge as the knowledge that individuals feel they have about their health condition. Fowles et al [28] reported that sharing medical records with individuals has a modest positive impact on their knowledge. Wilson and Lankton [27] stated that an individual with little knowledge about their health is more likely to accept the eHealth tools managed by providers. Therefore, we hypothesize the following:

- H5: Health knowledge is negatively related to the extent of EMR use.

Caregiving

Caregiving implies providing paid or unpaid support and making medical decisions for a patient when appropriate [29,30]. In this study, we consider only an unpaid caregiver (generally family members or friends) who is currently caring for or making health care decisions for someone with a medical condition, behavioral or physical disability, or other condition.

King et al [31] provided evidence that caregivers use assistive health technologies (ie, any product, hardware, or software used to increase, maintain, or improve the functional capabilities of individuals with disabilities) to better care for children with a physical disability. Studies have also suggested that caregiver status strongly influences portal use, especially for caregivers who provide care for patients with chronic health conditions [32,33]. Caregivers' exposure to EMRs enhances their proficiency in using EMRs and makes them more likely to use EMRs themselves. Thus, we propose the following hypothesis:

- H6: Caregiving individuals are more likely to use EMRs extensively.

Issue Involvement

Issue involvement refers to how personally relevant people find an issue [34]. Abdelhamid et al [35] define issue involvement in the health care domain as "how relevant a specific health issue is to a patient." A more involved patient frequently visits providers, has several diseases, or has a severe health condition [36]. Consistent with Angst and Agarwal [36], we consider a patient with more physician visits (measured in our study as the number of physician visits in the past 12 months) as more involved with issues. Prior studies have demonstrated a positive relationship between issue involvement and the use of eHealth products [35,36]. Ross et al [37] argued that issue involvement has a significant positive impact on the adoption and use of EMRs. They found that EMRs better prepare patients for their upcoming visits with physicians by enhancing their knowledge of their medical condition, increasing their sense of control, and allowing them to seek clarification about treatment. Accordingly, we hypothesize the following:

- H7: Issue involvement is positively related to the extent of EMR use.

Chronic Conditions

Wagner et al [38] and Kruse et al [39] advocated for patients' use of health care systems and available resources to self-manage their health, especially for chronic health conditions. Studies have also suggested that patients with chronic conditions are more likely to use available eHealth applications to be better informed and manage their health [40-42]. A literature review [18] confirmed that patients with comorbidities are more likely to use electronic personal health record systems. Therefore, we posit that EMRs help patients track their improvement or deterioration in health and make informed decisions to better take care of themselves. Hence, we hypothesize that patients with existing chronic conditions are more likely to use EMRs.

Broemeling et al [43] demonstrated that a person with a chronic condition is more likely to visit a physician regularly. We, therefore, hypothesize that chronic conditions affect issue involvement (ie, frequency of physician visits). A higher number of chronic conditions may motivate patients to check their conditions, diagnostics, or prescriptions more closely, leading to greater EMR use. Those patients may also want to ensure that their records are correct to improve patient safety. Hence, we hypothesize that the extent of the chronic condition increases issue involvement and the need for frequent doctor visits.

- H8a: The presence of chronic conditions is positively related to the extent of EMR use.
- H8b: The presence of chronic conditions is positively related to issue involvement.

Preventive Health Behavior

Kasl et al [44] defined preventive health behavior as "any activity undertaken by a person who believes himself to be healthy for preventing disease or detecting disease in an asymptomatic stage." People with such drive are likely to monitor their health conditions through their EMRs. Studies have suggested that individuals use the available resources and skills to engage in preventive health behavior [35,45]. These resources may include accessing their records in EMR systems and seeking the help of physicians.

In psychology, motivation is described as a reason that drives action [46]. Thus, we posit that health motivators—in this case, preventive health behavior—influence people to engage in behaviors that improve their health outcomes and encourage frequent EMR use. This reasoning also finds resonance with earlier studies on the benefits of EMRs and the quality of health outcomes [47-49]. In this study, we consider a person to be involved in preventive health behavior if they exercise and eat fruits and vegetables as recommended by the US Centers for Disease Control and Prevention (CDC). This understanding is similar to the operationalization by Hart et al [50].

Näslund [51] concluded that an individual engaging in preventive health behavior would have more doctor visits; this tendency is more pronounced in women. Grembowski et al [52] argued that individuals with preventive health behavior are more likely to initiate preventive care and early treatment. Other studies have suggested that health information technology plays a significant role in self-management [53,54]. Therefore, we hypothesize that individuals practicing preventive health behavior are more likely to visit their physicians often and use EMRs.

- H9a: Preventive health behavior is positively related to the extent of EMR use.
- H9b: Preventive health behavior is positively related to issue involvement.

Figure 1 and Table 1 summarize the hypothesis and definitions of the variables used in this model.

Table 1. Summary of hypothesis and variables.

Hypothesis	Variable	Defined in this study as	Relates
DV[a] : extent of EMR[b] use (EU)[c]			
H1	Performance expectancy (PE)	Degree to which the patient believes that using EMRs help them monitor their health	Positively
H2	Effort expectancy (EE)	Degree of ease associated with understanding the health information in the online medical record	Positively
H3	Perceived behavioral control (PBC)	Individual's perception of their ability to use electronic means	Positively
H4	Seek health information (SHI)	Whether an individual looked for information about health or medical topic from any source	Positively
H5	Health knowledge (HK)	If an individual is confident about ability to take good care of health	Negatively
H6	Caregiving status (CG)	If an individual is providing unpaid care to a patient	Positively
H7	Issue involvement (II)	Frequency of doctor visits in last 12 months	Positively
H8a	Chronic conditions (CC)	Number of chronic conditions an individual has	Positively
H9a	Preventive health behavior (PHB)	An individual is considered to have preventive health behavior if they exercise, eat fruits and vegetables as recommended by CDC[d]	Positively
DV: Issue involvement (II)[e]			
H8b	Chronic conditions (CC)	Number of chronic conditions an individual has	Positively
H9b	Preventive health behavior (PHB)	An individual is considered to have preventive health behavior if they exercise, eat fruits and vegetables as recommended by CDC	Positively

[a] DV: dependent variable.

[b] EMR: electronic medical record

[c] Number of times the online medical record has been accessed in the last 12 months.

[d] CDC: Centers for Disease Control and Prevention.

[e] Frequency of doctor visits in the last 12 months.

Methods

Data Source

We used data collected between January and May of 2019 by the National Cancer Institute (NCI) for Health Information National Trends Survey (HINTS) 5 cycle 3 to test our hypotheses. NCI administered a paper-based questionnaire and an online questionnaire to survey participants with an overall response rate of 30.3%. This survey was completed by 5438 participants. These data are publicly available and can be accessed at the HINTS website [55].

We filtered the data to include only those respondents who had used EMRs at least once during the previous 12 months. The resulting sample size was 2110. Data did not include outliers. Additionally, missing values on critical variables were less than 5%.

Measurements

The main dependent variable, the extent of EMR by the individual, was measured with a single item. System characteristics variables, performance expectancy and effort expectancy, were also measured with single items. Single items are acceptable if the question does not leave room for interpretation [56] and is used in information systems research that uses structural equation modeling (SEM) in the health care domain [35,36].

The patient characteristic, issue involvement, was measured with a single item. Other patient-related characteristics such as caregiving status, seek health information, health knowledge, and perceived behavioral control were each measured with a binary choice question. There were 6 binary-choice questions for chronic conditions. The number of responses for chronic conditions was summed for analysis.

A formative measure of preventive health behavior was constructed using 3 items: the number of cups of fruit each day, the number of cups of vegetables per day, and the number of days per week with moderate exercise. According to the CDC [57], eating 1½ to 2 cups of fruit per day and 2 to 3 cups of vegetables per day is a healthy eating pattern. The CDC also recommends physical activity at least 2 days per week [58]. Based on these recommendations, we calculated the score for preventive health behavior as the sum of the responses to each item. Gender, age, race, income, and education were used as controls in the model. Please refer to Multimedia Appendix 1 for a detailed questionnaire, scale, and how they were used in this study.

Statistical Analysis

In this paper, we used SEM to conduct a path analysis. Although SEM is predominantly used to model latent variables, it is also applied to conduct path analysis in a mediation model, and in our study, we have 2 mediating relationships. First, issue involvement mediates the relationship between chronic conditions and the extent of EMR use. Second, issue involvement also mediates the relationship between preventive health behavior and the extent of EMR use. Therefore, we use SEM to test the model similar to prior scholars [59-61]. We used SEM with robust diagonally weighted least squares (DWLS) to test the hypotheses. DWLS is ideal for ordinal outcome variables [62-64]. We ran our model in R (version 4.0.2; R Core Team) using the “lavaan-survey” package.

Results

Descriptive Statistics

Table 2 shows the descriptive statistics of the survey respondents. The survey included questions about the extent of participants’ EMR use. Other questions focused on our model variables, including performance expectancy, effort expectancy, perceived behavioral control, seek health information, health knowledge, caregiving, chronic conditions, preventive health behavior, and issue involvement.

Table 2. Descriptive statistics.

Characteristics	Sample size, n (%)
Total responses	2110 (100)
Extent of EMR[a] use (EU)	
1 to 2 times	896 (42.46)
3 to 5 times	679 (32.18)
6 to 9 times	280 (13.27)
10 or more times	255 (12.09)
Performance expectancy (PE)	
Don't use	126 (5.97)
Not at all useful	26 (1.23)
Not very useful	145 (6.87)
Somewhat useful	831 (39.38)
Very useful	950 (45.02)
Effort expectancy (EE)	
Very difficult	22 (1.04)
Somewhat difficult	184 (8.72)
Somewhat easy	979 (46.4)
Very easy	883 (41.85)
Number of chronic conditions (CC)	
0	696 (32.99)
1	678 (32.13)
2	445 (21.09)
3	209 (9.91)
4	68 (3.22)
5	13 (0.62)
6	1 (0.05)
Issue involvement (II)	
None	86 (4.08)
1 time	225 (10.66)
2 times	390 (18.48)
3 times	336 (15.92)
4 times	354 (16.78)
5-9 times	438 (20.76)
10 or more times	272 (12.89)
Caregiver (CG)	
Yes	383 (18.15)
No	1682 (79.72)
Health Knowledge (HK)	
Not confident at all	15 (0.71)
A little confident	57 (2.7)
Somewhat confident	435 (20.62)
Very confident	1030 (48.82)
Completely confident	552 (26.16)

Characteristics	Sample size, n (%)
Perceived behavioral control (PHB)	
Yes	1701 (80.62)
No	385 (18.25)
Seek health information (SHI)	
Yes	1923 (91.14)
No	164 (7.77)
Preventive health behavior (PHB)	
0	515 (24.41)
1	729 (34.55)
2	537 (25.45)
3	329 (15.59)
Gender	
Male	815 (38.63)
Female	1259 (59.67)
Education	
High school or less	231 (10.95)
More than high school	1843 (87.35)
Race	
White	1596 (75.64)
Black	249 (11.8)
Others	148 (7.01)
Income, USD	
Less than $20,000	171 (8.1)
$20,000 to < $35,000	172 (8.15)
$35,000 to <$50,000	241 (11.42)
$50,000 to <$75,000	382 (18.1)
$75,000 or more	957 (45.36)
Age (years)	
Min	18
Max	97
Mean	54.21
SD	16.14

[a] EMR: electronic medical record.

Reliability and Validity

Table 3 shows the correlations between all the variables. Correlation coefficients are important as a high correlation among independent variables indicates a potential bias in coefficients due to multicollinearity. In this data set, the highest correlation is 0.41 between perceived expectancy and effort expectancy. None of the correlations were greater than 0.5, and they were within the acceptable threshold of 0.6 [65], so multicollinearity was not a concern in this analysis. Table 3 also provides the means and standard deviations for the principal variables.

Table 3. Correlation matrix.

	Mean (SD)	EU	EE	PE	PBC	SHI	HK	CG	II	CC	PHB
Extent of EMR use (EU)	1.97 (1.03)	1.00									
Effort Expectancy (EE)	3.33 (0.67)	0.12	1.00								
Performance Expectancy (PE)	4.22 (1.00)	0.26	0.41	1.00							
Perceived behavioral control (PBC)	0.83 (0.38)	0.24	0.10	0.23	1.00						
Seek Health Information (SHI)	0.93 (0.26)	0.07	–0.02	0.02	0.11	1.00					
Health Knowledge (HK)	3.99 (0.80)	–0.04	0.28	0.13	0.04	–0.01	1.00				
Caregiving Status (CG)	0.19 (0.39)	0.06	0.00	0.02	–0.02	–0.01	–0.01	1.00			
Issue Involvement (II)	3.44 (1.71)	0.37	–0.07	0.02	0.08	0.10	–0.14	–0.01	1.00		
Chronic Conditions (CC)	1.20 (1.13)	0.14	–0.08	–0.03	0.02	0.00	–0.27	–0.01	0.26	1.00	
Preventive Health Behavior (PHB)	1.33 (1.00)	0.06	0.08	0.08	0.05	0.05	0.21	0.02	–0.04	–0.17	1.00

Variance Inflation Factor

We used variance inflation factor (VIF) statistics to determine if data is suffering from multicollinearity. Multicollinearity refers to the linear relationship between 2 or more predictor variables [66]. VIF indicates the increase in the variance of a regression coefficient as a result of multicollinearity. Table 4 shows the VIF for each variable. The VIFs for all variables were well below 5.0, suggesting that the data did not suffer from multicollinearity [67].

Table 4. Variance inflation factors.

Variable	EE[a]	PE[b]	PBC[c]	SHI[d]	HK[e]	CG[f]	II[g]	CC[h]	PHB[i]
VIF[j]	1.29	1.26	1.08	1.03	1.20	1.00	1.10	1.16	1.07

[a] EE: effort expectancy.

[b] PE: performance expectancy.

[c] PBC: perceived behavioral control.

[d] SHI: seek health information.

[e] HK: health knowledge.

[f] CG: caregiving status.

[g] II: issue involvement.

[h] CC: chronic conditions.

[i] PHB: preventive health behavior.

[j] VIF: variance inflation factors.

Common Method Variance

Because the data were self-reported and collected through a single survey, the data may suffer from common method variance (CMV), which hampers the relationship between the variables [68]. Therefore, we assessed CMV bias using a marker variable technique [69]. A marker variable is a variable that is theoretically unrelated to one or more of the principal variables measured in the study and typically has a low correlation with the central variables.

Table 5 shows the correlation between the principal variables and marker variables. The theoretically unrelated construct “enjoy time in sun” (ETS) was used as a marker variable. The correlation between the marker variable ETS and other principal variables was low, meeting the threshold below 0.1 [69], except seek health information, which had a correlation of –0.11 with ETS. Similar findings were obtained using “morning-night person” as a marker variable (see Multimedia Appendix 1). The low correlation of the marker variable with the variables in the model indicates the absence of CMV.

Table 5. Correlation with marker variables.

	EU[a]	EE[b]	PE[c]	PBC[d]	SHI[e]	HK[f]	CG[g]	II[h]	CC[i]	PHB[j]
With marker variable "enjoy time in sun"										
Correlation	–0.04	0.03	0.05	–0.03	–0.11	0.03	0.01	-0.07	–0.06	0.01
P value	.07	.18	.02	.23	<.001	.20	.66	.002	.01	.77
With marker variable "morning-night person"										
Correlation	0.03	–0.04	–0.02	–0.01	0.01	–0.09	0.01	0.05	0.03	–0.09
P value	.27	.09	.33	.62	.57	<.001	.78	.03	.27	<.001

[a] EU: extent of EMR use.

[b] EE: effort expectancy.

[c] PE: performance expectancy.

[d] PBC: perceived behavioral control.

[e] SHI: seek health information.

[f] HK: health knowledge.

[g] CG: caregiving status.

[h] II: issue involvement.

[i] CC: chronic conditions.

[j] PHB: preventive health behavior.

Data Analysis

Overview

Since the NCI administered a paper-based questionnaire and an online questionnaire to survey participants, we regressed the dependent variable "extent of EMR use" on the mode of survey administration. We found that the relationship between the two was not significant, which means that the mode of survey administration did not affect the extent of EMR use.

Further, we ran our model in R using the "lavaan-survey" package. The overall fit statistics (χ^2=78.461; *P*<.001; comparative fit index=0.784, Tucker–Lewis index=0.982, root mean square error of approximation=0.056, root mean square residual=0.000, and goodness-of-fit statistic=0.935) of the structural model indicated a good model fit [70]. The SEM results are shown in Table 6. Table 7 presents the mediation analysis results for issue involvement with chronic conditions and preventive disease behavior.

Table 6. Results of structural equation modeling.

Variables	Standard estimates	CI lower	CI upper	*P* value	Significant
DV[a]: Issue involvement (II)					
Chronic conditions (CC)	0.237	0.163	0.261	<.001	Yes
Preventive health behavior	0.004	–0.047	0.055	.87	No
DV: Extent of EMR[b] use (EU)					
Performance expectancy (PE)	0.253	0.219	0.340	<.001	Yes
Effort expectancy (EE)	0.047	–0.009	0.170	.08	No
Perceived behavioral control (PBC)	0.236	0.544	0.868	<.001	Yes
Seek health information (SHI)	0.027	–0.099	0.341	.28	No
Health knowledge (HK)	–0.073	–0.176	–0.028	.01	Yes
Caregiving status (CG)	0.060	0.037	0.309	.01	Yes
Issue involvement (II)	0.353	0.343	0.430	<.001	Yes
Chronic conditions (CC)	0.071	0.013	0.127	.02	Yes
Preventive health behavior (PHB)	0.076	0.026	0.145	.01	Yes
Male	–0.091	–0.321	–0.097	<.001	Yes
Age	0.055	0.003	0.122	.04	Yes
High School or More	0.017	–0.134	0.264	.52	No
Black	0.032	–0.146	0.367	.40	No
White	0.056	–0.055	0.370	.15	No
Income	0.010	–0.037	0.054	.71	No

[a] DV: dependent variable.

[b] EMR: electronic medical record.

Table 7. Mediation results of structural equation modeling.

Mediation analysis	Standard estimates	CI lower	CI upper	*P* value	Significant
Chronic condition (CC)					
Direct	0.071	0.012	0.126	.02	Yes
Indirect through Issue Involvement	0.084	0.062	0.103	<.001	Yes
Total	0.155	0.099	0.205	<.001	Yes
Preventive health behavior (PHB)					
Direct	0.076	0.026	0.144	.005	Yes
Indirect through Issue Involvement	0.001	–0.018	0.021	.89	No
Total	0.077	0.031	0.142	.002	Yes

System Characteristics

H1 theorized a positive relationship between performance expectancy and the extent of EMR use. Our analysis revealed a positive and statistically significant path coefficient between performance expectancy and the extent of EMR use (βPE=.253; *P*<.001; see Table 6). This indicates that higher performance expectancy results in higher EMR use, thus supporting H1. In line with prior research [15,18-20], we theorized a positive relationship between effort expectancy and the extent of EMR use. The path coefficient was positive but statistically nonsignificant (βEE=.047; *P*=0.77; see Table 6). Therefore, additional research is warranted to examine the results further.

Patient Characteristics

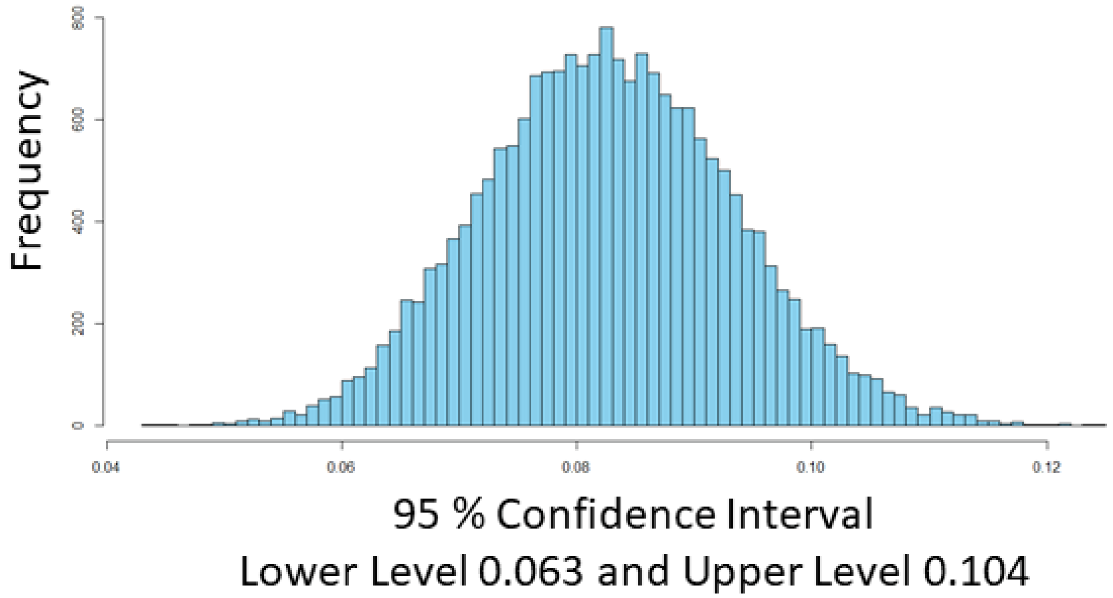
H3 anticipated a positive relationship between perceived behavioral control and the extent of EMR use. The path coefficient was positive and statistically significant (βPBC=.24; *P*<.001; see Table 6), suggesting that patients' higher perceived behavioral control results in higher EMR use, supporting H3. This result is consistent with the findings of prior studies relating to perceived behavioral control in other domains.

H4 theorized a positive relationship between SIH and the extent of EMR use. Although the path coefficient was positive, it was statistically nonsignificant (βSHI=.028; *P*=.28; see Table 6). Therefore, H4 was not supported. H5 theorized a negative relationship between health knowledge and the extent of EMR use. The path coefficient was negative and statistically significant (βHK=–.071; *P*=.01; see Table 6). Therefore, H5 was supported. H6 theorized a positive relationship between caregiving status and the extent of EMR use. The path coefficient was positive and statistically significant (βCG=.06; *P*=.01; see Table 6), thus supporting H6.

H7 proposed a positive relationship between issue involvement and the extent of EMR use. The path coefficient was positive and statistically significant (βII=.356, *P*<.001; see Table 6), suggesting that higher issue involvement results in higher EMR use. Thus, H7 was supported. H8a argued that a positive relationship exists between the extent of chronic conditions and the extent of EMR use. The path coefficient was positive and significant (βCC=.071; *P*=.02; see Table 6), suggesting that a patient with more chronic conditions is more likely to use EMRs frequently. Thus, H8a was supported. H8b predicted a positive relationship between the extent of chronic conditions and issue involvement. The path from chronic conditions to issue involvement was positive and statistically significant (βCC=.238; *P*<.001; see Table 6). The mediation analysis suggests that issue involvement partially mediates the effect of chronic conditions on the extent of EMR use.

Monte Carlo simulation, also known as the Monte Carlo method or a multiple probability simulation, is a mathematical technique used to estimate the possible outcomes of an uncertain event [71]. We used Monte Carlo simulation to draw a probability distribution of the indirect effect of chronic conditions on the extent of EMR use. Figure 2 provides the probability distribution of the indirect effect of chronic conditions on the extent of EMR use. As the Monte Carlo CI [72] of the indirect effect did not contain zero (CI=0.063-0.104), the mediation of issue involvement between chronic conditions and the extent of EMR use is supported (Table 7). The mediation effect of issue involvement accounted for 48.9% of the impact of chronic conditions on the extent of EMR use.

Figure 2. Distribution of indirect effect of chronic conditions on the extent of EMR use. EMR: electronic medical record.



H9a argued that a positive relationship exists between preventive health behavior and the extent of EMR use. The path coefficient was positive and significant (βPHB=.076; *P*=.005; see Table 6), suggesting that a patient with preventive health behavior is more likely to use EMRs frequently. Thus, H9a was supported. H9b predicted a positive relationship between preventive health behavior and issue involvement. The path coefficient was positive but statistically nonsignificant (βPHB=.001; *P*=.89; see Table 6). Thus, H9b was not supported, which excludes the possibility of any mediation.

The study results suggest that, among the patient characteristics, issue involvement (βII=.356; *P*<.001) is the most important factor, followed by perceived behavior control (βPBC=.236; *P*<.001). Figure 3 shows the research model with the path coefficients and their significance, and Table 8 summarizes the study results.

Figure 3. Model results. PTAM: patient technology acceptance model

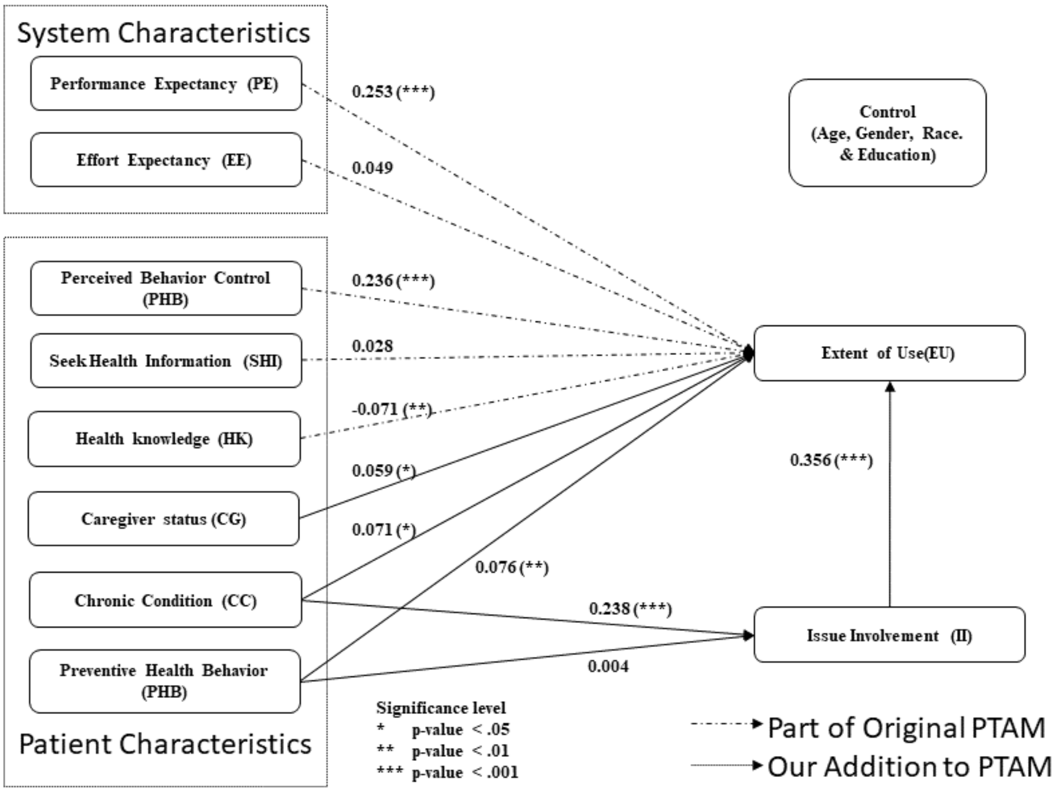


Table 8. Summary of study results.

Hypothesis	Independent variable	Result
DV[a] : Extent of EMR[b] use (EU)		
H1	Performance expectancy (PE)	Supported
H2	Effort expectancy (EE)	Not Supported
H3	Perceived behavioral control (PBC)	Supported
H4	Seek health information (SHI)	Not Supported
H5	Health knowledge (HK)	Supported
H6	Caregiving status (CG)	Supported
H7	Issue involvement (II)	Supported
H8a	Chronic conditions (CC)	Supported
H9a	Preventive health behavior (PHB)	Supported
DV: Issue Involvement (II)		
H8b	Chronic conditions (CC)	Supported
H9b	Preventive health behavior (PHB)	Not Supported

[a] DV: dependent variable.

[b] EMR: electronic medical record.

Discussion

Theoretical Implications

Our study extends the line of research on the PTAM [15] to explore patients' use of EMRs and examine the impact of factors that have not been studied by prior research. In line with prior studies [15,18,19], our statistical analysis showed that performance expectancy is a critical system characteristic that influences the patient adoption and use of EMRs. Further, this study finds perceived behavioral control [24-26] and caregiving status [32,33] significant variables for patient adoption and use of EMR. The number of chronic conditions and issue involvement also significantly impact the extent of EMR use by patients.

Our study also finds preventive health behavior to be a significant factor that impacts the extent of EMR use. However, seek health information is not statistically significant. A typical EMR captures the patient's medical history, including conditions, treatment decisions, medications, procedures, allergies, progress notes, and immunization records [73]. However, as noted by previous studies [15,27], it has not evolved into a source of medical information for patients who usually seek information from providers or the internet. Therefore, it is not surprising that seek health information emerged as an insignificant factor in determining the extent of EMR use. We also find effort expectancy nonsignificant, which is counterintuitive since several studies have found it critical in determining the extent of use [14].

Further, the study results suggest that issue involvement is the most critical patient characteristic, followed by perceived behavioral control as reflected by the model coefficients. Issue involvement refers to an individual's involvement with their health care issues and reflects their motivation to manage their health-related decisions. Therefore, it is natural that issue involvement emerged as a vital patient characteristic. Perceived behavioral control is another critical determinant of the extent of EMR use.

The study of the effect of chronic conditions and preventive health behaviors on the extent of EMR use is one of the most salient contributions of this article from a theoretical perspective. Unlike others, patients suffering from chronic conditions engage in continuous health monitoring, frequent interactions with medical providers, and an ongoing adjustment of medications. Such patients also require interactions with medical specialists, necessitating the frequent transfer of medical information among several physicians. Given the complexity of care and the patients' frequent interactions with providers, the statistical significance of chronic conditions as a determinant of EMR use is intuitive. Finally, the study highlights the value of caregiving in sensitizing and educating people about their health. Caregivers witness the challenges patients face and develop an empathetic understanding that increases their awareness and motivates them to adopt better health practices, including keeping track of patients' health information using EMRs.

In a nutshell, the contributions of this study include insights into how patients' characteristics and health conditions, along with their perceived system characteristics, influence the extent of EMR use. Our model adds (1) patient characteristics, such as caregiver status and preventive health practices, and (2) health conditions, such as chronic conditions and issue involvement, to the PTAM framework.

Practical Implications

Understanding the factors that influence the extent of EMR use by patients can be crucial in developing processes and systems that can enhance their adoption and usage. Given the significance of perceived behavioral control, we can institute inventions such as developing high-quality training modules and end-user support services. In addition to demonstrating the product features, training modules can also educate users on the potential value and utility of EMRs, thereby enhancing performance expectancy. The results of this study also suggest that practitioners and providers should dedicate efforts to educating and training patients about the benefits of EMR use. Also, we should promote success stories and best practices of patients using EMRs through case studies. Further, since chronically ill patients are more likely to use EMRs, patient engagement interventions should be directed at them. During the design and development phases, EMRs should also consider the role of caregivers.

Study Limitations

This study has several limitations. First, the HINTS data relied on self-reported information, so there is potential for CMV [68]. Using the marker variable technique [69], we evaluated that data are not suffering from CMV. Second, the study is based on secondary data and could only use variables present in the data. Certain key variables, such as social norms that may interest a general audience, were not included as these variables were not captured in the survey. Social norms, commonly defined as typical behaviors expected from people, are significant in original PTAM; consequently, the absence of social norms in this study might have inflated some of the estimates. However, since the patient adoption and use of EMRs is a relatively new phenomenon, the social norms around adopting and using EMRs are not well-established. Likely, its impact may not have been significant. Future studies should examine the impact of social factors and analyze their role in the extent of patients' EMR use. Third, the operationalization of chronic conditions was limited to only 6 major chronic conditions: diabetes, hypertension, heart disease, lung disease, depression, and cancer. To overcome these limitations, researchers should examine factors that affect patients' EMR use through longitudinal studies that include key variables such as social norms in addition to the variables in the current study.

Conclusions

Our study contributes to both theory and practice. First, we described how the phenomenon of patient adoption of EMRs is different from physician adoption of EMRs. Second, to understand the factors affecting patients' EMR use, we adapted the PTAM to the context of EMR use. This resulted in the addition of several new patient characteristics (eg, chronic conditions, preventive health behavior, issue involvement, and caregiving status) that influence the extent of EMR use. Thus, our study contributes to the literature on health information systems. We also found that effort expectancy had no significant effect on the extent of patients' EMR use. We found that health characteristics, such as chronic conditions, preventive health behaviors, caregiving status, health knowledge, and issue involvement directly affect the extent of EMR use. Our analysis also revealed that issue involvement has a mediating effect on the impact of the extent of the chronic condition on EMR use. EMR enables patients to track their health care history and understand the progress or deterioration in their health conditions. It also provides an opportunity for patients to examine their medical records and get the erroneous medical record corrected. Hence, improving EMR use contributes to patients' greater control over decisions and actions and adds to the larger goal of patient empowerment.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Operationalization of Constructs (source HINTS 5 cycle 3).
[DOCX File , 17 KB-Multimedia Appendix 1]

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Abbreviations

CDC: Centers for Disease Control and Prevention
CMV: common method variance
DWLS: diagonally weighted least squares
EMR: electronic medical record
ETS: enjoy time in the sun
HINTS: Health Information National Trends Survey
NCI: National Cancer Institute
PTAM: patient technology acceptance model
SEM: structural equation modeling
VIF: variance inflation factor

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Original Paper

An Audio Personal Health Library of Clinic Visit Recordings for Patients and Their Caregivers (HealthPAL): User-Centered Design Approach

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Abstract

Background: Providing digital recordings of clinic visits to patients has emerged as a strategy to promote patient and family engagement in care. With advances in natural language processing, an opportunity exists to maximize the value of visit recordings for patients by automatically tagging key visit information (eg, medications, tests, and imaging) and linkages to trustworthy web-based resources curated in an audio-based personal health library.

Objective: This study aims to report on the user-centered development of HealthPAL, an audio personal health library.

Methods: Our user-centered design and usability evaluation approach incorporated iterative rounds of video-recorded sessions from 2016 to 2019. We recruited participants from a range of community settings to represent older patient and caregiver perspectives. In the first round, we used paper prototypes and focused on feature envisionment. We moved to low-fidelity and high-fidelity versions of the HealthPAL in later rounds, which focused on functionality and use; all sessions included a debriefing interview. Participants listened to a deidentified, standardized primary care visit recording before completing a series of tasks (eg, finding where a medication was discussed in the recording). In the final round, we recorded the patients' primary care clinic visits for use in the session. Findings from each round informed the agile software development process. Task completion and critical incidents were recorded in each round, and the System Usability Scale was completed by participants using the digital prototype in later rounds.

Results: We completed 5 rounds of usability sessions with 40 participants, of whom 25 (63%) were women with a median age of 68 years (range 23-89). Feedback from sessions resulted in color-coding and highlighting of information tags, a more prominent play button, clearer structure to move between one's own recordings and others' recordings, the ability to filter recording content by the topic discussed and descriptions, 10-second forward and rewind controls, and a help link and search bar. Perceived usability increased over the rounds, with a median System Usability Scale of 78.2 (range 20-100) in the final round. Participants were overwhelmingly positive about the concept of accessing a curated audio recording of a clinic visit. Some participants reported concerns about privacy and the computer-based skills necessary to access recordings.

Conclusions: To our knowledge, HealthPAL is the first patient-centered app designed to allow patients and their caregivers to access easy-to-navigate recordings of clinic visits, with key concepts tagged and hyperlinks to further information provided. The HealthPAL user interface has been rigorously co-designed with older adult patients and their caregivers and is now ready for further field testing. The successful development and use of HealthPAL may help improve the ability of patients to manage their own care, especially older adult patients who have to navigate complex treatment plans.

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KEYWORDS

patient-centered care; health communication; audiovisual aids; user-centered design; software; natural language processing; patients; caregivers

Introduction

Background

Higher recall of medical information is associated with improved disease management, treatment adherence, and higher patient satisfaction [1,2]. Recall, however, is often low, with 40%-80% of medical information from a clinical visit being forgotten immediately by patients [3-8]. Although the poor recall of medical information is pervasive, it is most acute among older adults. As people age, they process information more slowly and have reduced working memory [9,10]. Older patients experience more challenges in recalling drug information, treatment recommendations, appointments, and disease information [11], especially those with multimorbidity [1,6,8,12-14] who report the *endless struggle* of managing their conditions [15,16]. Poor recall also impacts caregivers [17]. In a recent national survey of caregivers in the United States, 84% of respondents wanted more information on caregiving topics [17].

The last decade has seen significant efforts to increase patient access to medical information, especially clinic visit information. Mandated initially by the Health Information Technology for Economic and Clinical Health Act's meaningful use standards, clinics across the United States now offer patients an after-visit summary (AVS) [18]. The AVS is a summary of the clinic visit generated from the electronic medical record, printed during visits, or available via the patient portal and includes diagnoses, medications, allergies, clinician visited, and clinician comments. Although intended as a means of promoting self-management, there have been concerns about the AVS, including accuracy of medication lists, layout, and use of medical terminology on the AVS [19]. This is particularly challenging for patients who often report low health literacy and struggle with exclusively text-based information [2,3,20-22]. AVS can also represent a significant burden on clinician workload [7,23]. These factors have resulted in low AVS use [24]. An adjunct to the AVS may exist in recordings of the clinic visit.

Patients rely on verbal communication with their doctor [8] and some are now audio recording clinic visits to capture this valuable information [25-27]. In response, a small but growing number of clinics across the United States are beginning to offer patients recordings of clinic visits. Systematic reviews found that access to recordings leads to increased patient and family engagement, understanding, and recalling visit information; reduced anxiety; increased satisfaction; improved treatment adherence; reduced patients' clinic phone calls; and reduced decisional regret [25,28-33].

The absence of a safe and secure recording system is a barrier to the broader uptake of clinic recordings [27]. A recording provides all the visit details, yet navigating recordings is a challenge, as the benefit "depends on picking out...the crucial points..." of the visit [27]. Unstructured visit information increases the risk of overwhelming patients [27,34].

Electronic personal health libraries (PHLs) may be a solution, as they allow patients to manage, maintain, and organize health information on the web [34,35]. PHLs can range from medical records that patients can access tethered to a health system to stand-alone platforms where patients collect and manage their own data. PHLs are becoming more advanced through the application of data science methods such as natural language processing (NLP) [36]. These methods can identify patterns in unstructured data and classify text based on its meaning. Such NLP methods have been used to predict hospital readmissions [37], future radiology utilization [38], and medical conditions in clinical decision support systems [39]. In PHLs, data science methods have been used to automatically provide tailored information via guided searches for disease and self-care information [36]. Despite the availability of these methods, existing PHLs are yet to facilitate the integration of clinic recordings [40].

To address this gap, we planned to develop an audio PHL to facilitate the acquisition, organization, and management of clinic audio recordings—HealthPAL (personal audio library). On the basis of a review of patients' information-seeking behavior and needs [41], the basic features of HealthPAL include (1) identifying, organizing, and tagging elements of the clinic visit audio recording deemed important to patients; for example, parts of the visit recording where medications are mentioned would be automatically highlighted for patients; (2) a search function, allowing end users to search for information from their visit; and (3) linkage of key medical terms from the clinic visit audio recordings to trustworthy, layperson resources such as MEDLINE Plus, which can be retrieved, organized, edited, and shared by patients. For example, a hyperlink to learn more about the medication mentioned would be available to the patient. In the system's background, a transcript of the medical visit is automatically generated using speech-to-text software. However, because of concerns of inaccurate speech-to-text potentially providing incorrect written medical information, we chose not to expose full transcript text in our design.

Our user-centered design work falls in the history of design studies around *meeting browsers* [42]—software multimedia browsers of meeting recordings and associated meeting artifacts—where HealthPAL is the first to consider design and usability for the specialized context of patients meeting with their primary care provider. *Classroom 2000* [43] initiated the modern genre of meeting browsers, which focused on capturing a *recording* of a meeting or classroom lecture and its context, often focusing on live audio and video and linking to slides of a PowerPoint-like presentation, with some allowing users to add their own annotations or notes. Early evaluation work with a meeting browser found that such a system can allow users to more accurately answer questions about a meeting [44], whereas features that allow the user to focus on key phrases allowed them to answer questions about the audio content more quickly [45]. We hypothesize similar uses of annotated audio recordings in health care.

Objective

This study reports on the development of the HealthPAL user interface (UI). Results from our data science models are reported elsewhere. By adopting a user-centered design framework, we engaged end users throughout the iterative development of HealthPAL [40,41]. We followed the usability specification and evaluation framework developed by Yen and Bakken [46], which consisting of 5 stages: (1) system requirements, (2) system component development, (3) usability evaluation in controlled settings, (4) pilot field testing, and (5) large-scale field testing. We report on steps 1-3 in this paper. We hypothesized that through user-centered design, HealthPAL would be highly usable with high end user satisfaction.

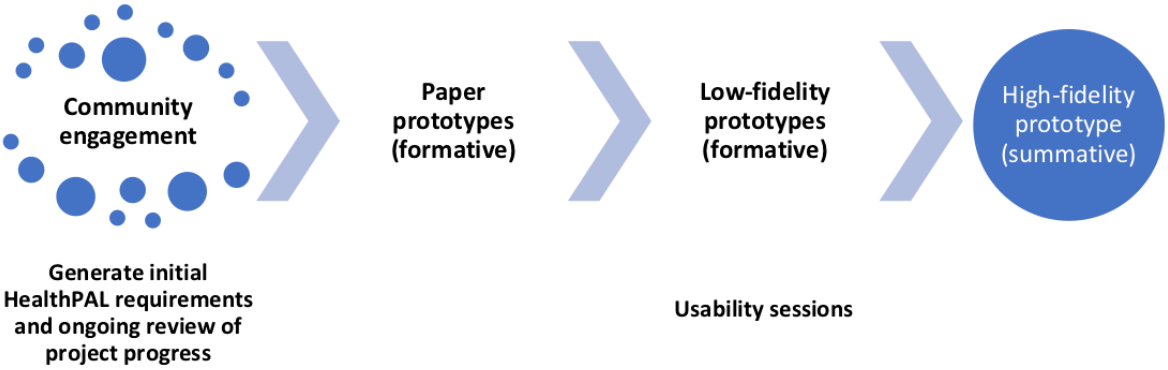
Methods

Study Design: Overview

Our approach incorporated UI development conducted through 5 iterative rounds of *usability sessions*. During the sessions, participants were asked to play the role of a patient or caregiver and complete a series of typical tasks within HealthPAL. The UI was iteratively refined in each round, with additional tasks added to assess the newly added features. We began with the paper prototype and formative sessions (rounds 1-3) in which participants worked with paper and low-fidelity software prototype designs before moving to the summative software sessions (rounds 4 and 5) in which they interacted with higher fidelity prototypes of the software (Figure 1). The sessions were structured so that participants would first listen to a fictitious clinic visit recording, and in the final summative software session (round 5), patients used their actual clinic visit recordings. Participants were presented with a set of typical user tasks to complete in the system being tested during their session.

Before each new iterative round of user testing, the research team completed heuristic evaluations and cognitive walkthroughs with HealthPAL to mitigate common usability problems before working with participants.

Figure 1. Overview of the user-centered design stages of HealthPAL.



Settings

Participants were recruited from the Upper Valley of New Hampshire and Vermont between 2016 and 2019. Individuals were recruited from multiple settings, including public libraries, the Dartmouth-Hitchcock Medical Center (DHMC) simulation and human-computer interaction lab, Dartmouth-Hitchcock (D-H) Heater Road Primary Care, D-H Patient and Family Advisors group, the D-H Aging Resource Center, and a local senior living community. This study was approved by the Committee for the Protection of Human Subjects, Dartmouth College and the D-H Health Human Research Protection Program (Committee for the Protection of Human Subjects Study #30397, 30531; D-HH HRPP 00030531).

Participants

Participants included individuals who represented the views of patients and caregivers. All participants were 18 years or older, able to communicate in English, and able to provide informed consent. Individuals with serious mental illness, self-reported significant uncorrectable hearing or visual impairments, or significant cognitive impairment (score of 4 or less on a 6-item screener) [47] were excluded from the study. Caregiver participants were individuals who self-identified as having previously cared for a family member or loved one. In the final round of user testing, we also recruited primary care clinicians to record the clinic visits of patients to be used during the usability evaluation sessions. Consented clinicians identified patients who met the eligibility criteria (18 years or older with 2 chronic health conditions) and who were facing a treatment decision or were discussing a diagnosis or medication; patients visiting solely for a procedure, such as blood draw, were excluded.

Our project initially focused on the general public, but additional funding received from the National Library of Medicine during the study allowed us to expand the proposed features and focus on older adults who account for the greatest use of health care and may benefit the most from the proposed system. Therefore, we oversampled older adults (≥65 years) and focused on this group in later rounds. As we moved to later rounds of user testing, it was also necessary for participants to have internet access at home to review the recording system before the usability session. A US $25-$30 honorarium was provided to participants. We targeted 5 individuals per round, a sample size that is considered adequate to detect up to 80% of usability issues [48,49]. All participants provided written informed consent. Participants from previous rounds could not participate in later rounds to reduce the potential impact of learning effects inflating usability evaluations.

Recruitment

In the initial paper prototype and formative sessions (rounds 1 and 2), we recruited participants from the DHMC Patient and Family Advisors group and from public spaces at a local library. Participants were approached by a research team member; informed about the project; and if interested, they were taken to a private space, they provided consent, and they began the usability session. For the final paper prototype and formative session (round 3), we focused on older adults, and recruitment moved to the Aging Resource Center and an older adult living community. Participants were sent physical mail and an email to inform them about the project. The screening was conducted by telephone with interested participants to determine eligibility, and participants were met on the day of the session to complete informed consent before beginning the usability session.

In the summative software sessions (rounds 4 and 5), we specifically targeted individuals from both *patient* and *caregiver* stakeholder groups separately. Caregivers were recruited from the Aging Resource Center using the procedures described above. Patients were recruited from a local primary care clinic, identified by participating clinicians, and received a screening telephone call from a research team member. Eligible patients were asked to come to the clinic 30 minutes earlier than their appointment to complete the informed consent process; once they provided consent, their clinic visits were recorded using the software. Participants were then asked to meet with the research team within a week to complete the usability session.

Community Engagement

In addition to the 5 rounds of user testing, 2 *Lunch and Listen* workshops were conducted with patients and family volunteers from DHMC, Lebanon, New Hampshire. These workshops were codeveloped and led by our study team's patient partners (RA and SP) to discuss key system concepts with community members. Responses from these workshops informed the initial layout, features, and desired functionality of the HealthPAL system that was tested during the usability sessions.

Usability Sessions

Overview

All sessions began with a description of the usability session, and participants were asked to *think aloud* [50,51] as they completed the tasks with the software. Paper prototype sessions were video-recorded along with participant and facilitator audio, and in later rounds where software prototypes were used by participants, screen video and audio were recorded to capture participants' use of the prototype and their verbal feedback. Upon completion of the round-specific tasks, participants completed a semistructured interview about the system and desired functionality. The session facilitator in the room made written field notes related to participants' interactions with the prototype.

UI Design

In all sessions, the UI primarily consisted of 2 pages. The first page was an interface allowing the user to choose which recordings the user is viewing (eg, choosing between their own visit recordings and the visit recordings of someone who they act as a caregiver for). The second page offered basic playback features (eg, play and pause, rewind, skip forward or back 10 seconds, and mute) for a visit recording. In addition, on that page, individual audio segments of the visit recording were *tagged* for 8 classes of information: diagnosis, follow-up, medication, patient education, recommendation, signs, symptoms and problems, test and imaging, and treatment options. The user could click on a segment to start playback at that point. New features were added to each round based on the user feedback.

Fictitious Clinic Visit Recordings

Fictitious primary care visit recordings were created and used throughout the user testing sessions, except in the final round of patient sessions. We created 2 fictitious characters, Chris Hill, a 58-year-old male patient, and his 81-year-old mother Linda, both of whom met with a fictitious primary care clinician named Dr Adams. The fictitious clinic visit recordings for both the characters were produced by rerecording 2 real primary care clinic visits, stripped of patient identifiers (a description of the recording is provided in Textbox 1).

Textbox 1. Fictitious clinic recordings.

Chris Hill

- Chris's recording was a clinic visit of approximately 7 minutes in which Chris and Dr Adams discuss Chris's allergies, and Dr Adams suggests increasing his dosage of Flonase. They also talk about Chris's stomach pain, and Dr Adams suggests increasing his dosage of Omeprazole. Chris talks about his emergency room visit from when he was having bad stomach pain, and Dr Adams reviews some test results from that visit.

Linda Hill

- Linda's recording was a clinic visit of approximately 11 minutes in which Linda and Dr Adams discuss the pain in her foot and back. Linda tells Dr Adams that she has stopped taking the nerve pain controller Gabapentin because of the side effects, but Dr Adams suggests Linda to try it again. They also discuss Linda's arthritis and the ganglion cyst on her hand. Dr Adams informs her that the cysts can be surgically removed if they bother her and also suggests that she visits a pain clinic for overall pain control.

Paper Prototyping and Formative Usability Sessions (Rounds 1-3)

Overview

The initial round began with a paper prototype before moving onto the low-fidelity prototypes of the software in rounds 2 and 3. During the paper prototype sessions, the facilitator adopted a *Wizard of Oz* technique, where they played back the appropriate recorded patient clinic visit audio in response to the participant's interactions with the prototypes [52]. Participants in these sessions (rounds 1-3) were asked to complete tasks in both patient and caregiver roles.

Patient Role

Participants were given the role of Chris. They began the round by listening to the entire fictitious audio recording for Chris before being presented with the paper prototype and before being asked to complete the tasks (Textbox 2). This was designed to replicate the experience of a patient who was present during the visit.

Textbox 2. Example of a role-based scenario and task for participants to complete in the prototypes.

Role

- In this study, you will play the role of *Chris*. Chris Hill is a 58-year-old male patient of Dr Adams, who last saw this doctor on June 20, 2017—1 week ago. Chris's mother, Linda, who is 81 years old, also sees Dr Adams.

Scenario

- Chris's doctor creates audio recordings of patients' visits and provides a web-based software app for patients to listen to their own visit recordings after they leave from each visit. Patients can also grant permission for other family members or caregivers to listen to their visit recordings. Chris also has access to listen to his mother's clinic visits, so that he can stay up to date on her health. Chris knows that his mother visited Dr Adams on June 14, 2017—her most recent visit. Chris also knows his mother and Dr Adams discussed possible surgery for the pain she has in her hand. They also discussed her restarting a medication for her foot pain that Linda had previously stopped taking. Later you will be asked to find and listen to important audio segments of her most recent visit in the website prototype.

Task

- Find where Dr Adams talks about considering surgery for Linda's hand pain (ganglion cyst) in her most recent visit. When you believe you are finished with the task, say "I found it" aloud.

Caregiver Role

Once participants completed tasks with Chris's recording, they were asked to find Linda's recordings in the system and asked to complete a series of similar tasks. They did not listen to Linda's recording before the tasks, replicating the experience of a caregiver who was not present at a visit.

Summative Software Usability Sessions (Rounds 4 and 5)

Starting from round 4, we recruited individuals who identified as either caregivers or patients and asked them to play only that role. All participants completed the same tasks, which required finding and listening to important parts of Linda's recording and new features, including finding and using hyperlinks to additional information on a medical concept. In the final round of user testing, round 5, patients reviewed a recording of their primary care visit with a high-fidelity version of HealthPAL with all desired features; caregivers continued to review fictitious recordings. In parallel with UI development, we are developing NLP models to automatically annotate the classes of information in recordings. However, at this stage of development, we used human transcription and manual tagging of recordings by 2 clinically trained annotators (JAS and WMO). Patients were emailed a link to log in to the system to access their recording within 3 days of their appointment. Participants were then asked to return for an in-person session to demonstrate how they used the system and complete a set of specific tasks within the system.

Data Collection and Analysis

Overview

We collected data on participant age, sex, race, ethnicity, and educational attainment for all rounds of usability testing. The System Usability Scale (SUS) [53] was administered from round

3 onward, as we moved to a web-based version of the software. Usability evaluation metrics included the SUS, critical incidents [54], and task completion ratios. We also gathered data on participant suggestions and views—general attitudes participants had toward the system.

Task Completion

For each task given to participants, we recorded whether the participant completed the task on their own, completed the task with help from the facilitator, or did not complete the task.

Critical Incidents

Recordings were coded for key critical incidents related to usability and interface design. These incidents included whenever a participant verbally or implicitly made known that they were struggling with an action, whether it was controlling the audio or finding the correct segment, regardless of task completion. Critical incidents also included whenever a participant took an action that deviated from the expected path, such as when participants clicked on a hyperlink instead of playing an audio segment.

Participant Suggestions

We recorded any feedback that participants provided about improving the website. This feedback included suggestions such as how the participants would like a feature to work or what the participants were expecting to see on a certain page.

Participant Views

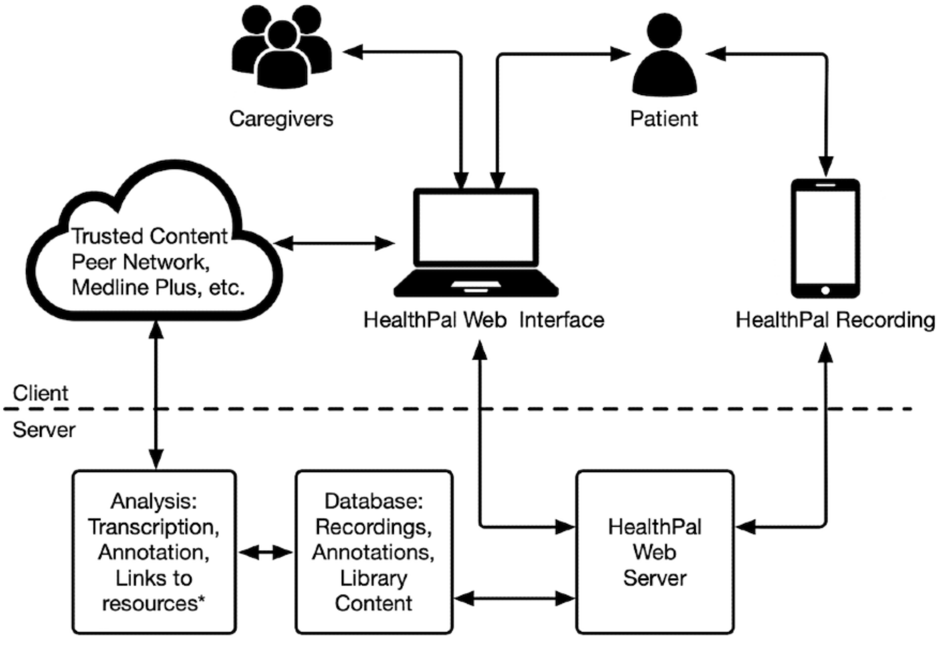
We recorded any comments that participants made regarding their general attitudes toward the system. These comments included positive remarks, such as how the system could be beneficial for keeping track of important health information, and concerns, such as the security and privacy of their health information.

Descriptive statistics of median and range were used for continuous data, and proportions and ranges were used for categorical data. SUS scores were calculated on a scale of 0-100, with a score of >68 indicating above-average satisfaction with the usability of a system [55-57]. Descriptive summary statistics of the above-mentioned usability metrics were guided by the TURF (Task, User, Representation, and Function) framework [58], with a focus on task completion and system usability. We used summative content analysis to identify key issues and suggestions from the usability sessions. Transcripts from usability sessions were reviewed by 2 coders (LO and CHG). Commonly identified suggestions, views, and critical incidents were coded and grouped into the main themes.

Software Architecture

We built the software prototype for this work as a web app, using the mature and widely adopted Ruby on Rails app development framework. The app is hosted on Dartmouth's secure server infrastructure, and all client-server communications are encrypted using an HTTPS protocol. In addition, the app software communicates with a PostgreSQL relational database, hosted on Dartmouth's infrastructure, and app data were encrypted at rest. Using this architecture, we were able to securely deliver the app to a range of devices, supporting both audio recording and playback while avoiding storing audio or other protected health information on users' devices. This architecture also allowed us to rapidly implement design changes that were made based on the results of each round of user testing (Figure 2). By using the Git version control system and an automated app deployment pipeline, we were able to track every deployment of the app code, thus producing a history of precisely which version of the software was running at any given time. The app prototype is available as open-source software under the MIT license. The source code can be obtained at the website [59].

Figure 2. HealthPAL system architecture.



* Transcription, annotation, and adding links to resources were all performed by humans during this phase of the project.

Results

Participant Characteristics

We completed usability sessions with 40 participants (including 10 self-identified caregivers) from October 2017 to May 2019. Participants were predominantly White non-Hispanic (39/40, 98%), with a median age of 68 years (range 23-89 years). There were 63% (25/40) female participants, and most participants (37/40, 93%) had some college education or higher (Table 1). The evolution of the UI during rounds of user testing is shown in Figures 3-7.

Table 1. Participant demographics (N=40).

Participant characteristics	Round 1 (n=8)	Round 2 (n=6)	Round 3 (n=5)	Round 4		Round 5	
				CG[a] (n=5)	P[b] (n=6)	CG (n=5)	P (n=5)
Age (years), median (range)	54 (23-80)	48 (26-81)	80 (68-89)	70 (52-83)	71 (66-88)	72 (59-77)	62 (30-67)
Females, n (%)	3 (38)	3 (50)	3 (60)	5 (100)	3 (50)	4 (80)	4 (80)
Race[c], n (%)							
Hispanic White	0 (0)	0 (0)	1 (20)	0 (0)	0 (0)	0 (0)	0 (0)
Non-Hispanic White	8 (100)	6 (100)	4 (80)	5 (100)	6 (100)	5 (100)	5 (100)
Black or African American	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (20)
Education, n (%)							
High school or no degree	0 (0)	1 (17)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
High school graduate	1 (13)	1 (17)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Some college	1 (13)	1 (17)	0 (0)	1 (20)	0 (0)	0 (0)	1 (20)
College degree (bachelors or associate)	2 (25)	2 (33)	3 (60)	3 (60)	2 (33)	2 (40)	4 (80)
Masters, doctorate, or professional school	4 (50)	1 (17)	2 (40)	1 (20)	4 (67)	3 (60)	0 (0)

[a] CG: caregiver role.

[b] P: patient role.

[c] More than 1 response allowed.

Figure 3. Initial paper prototypes of HealthPAL (round 1)—interface for finding a patient’s recording (left) and playing back the recording (center and right).

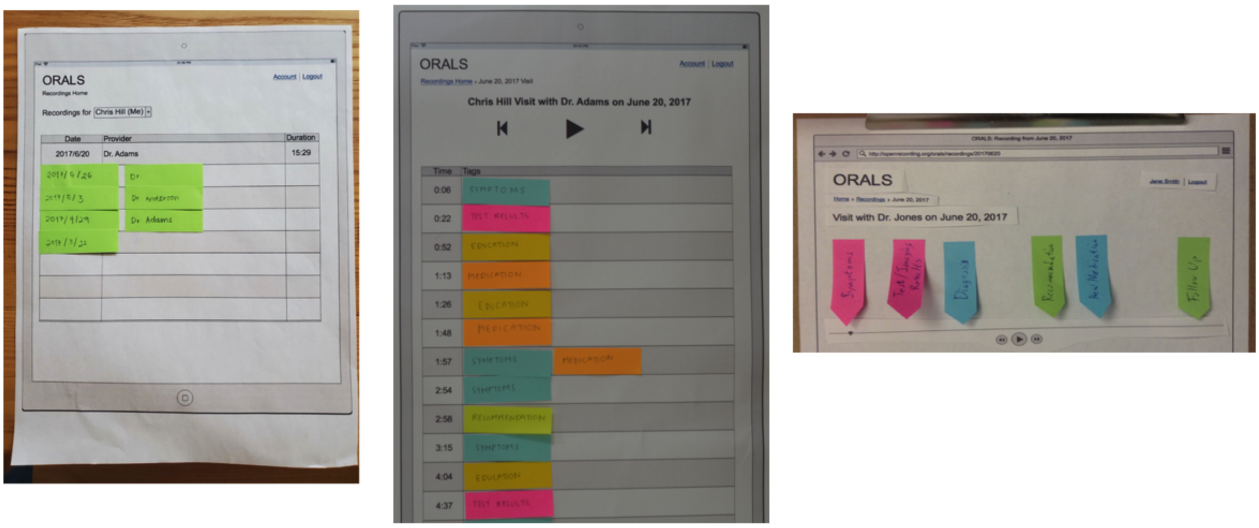
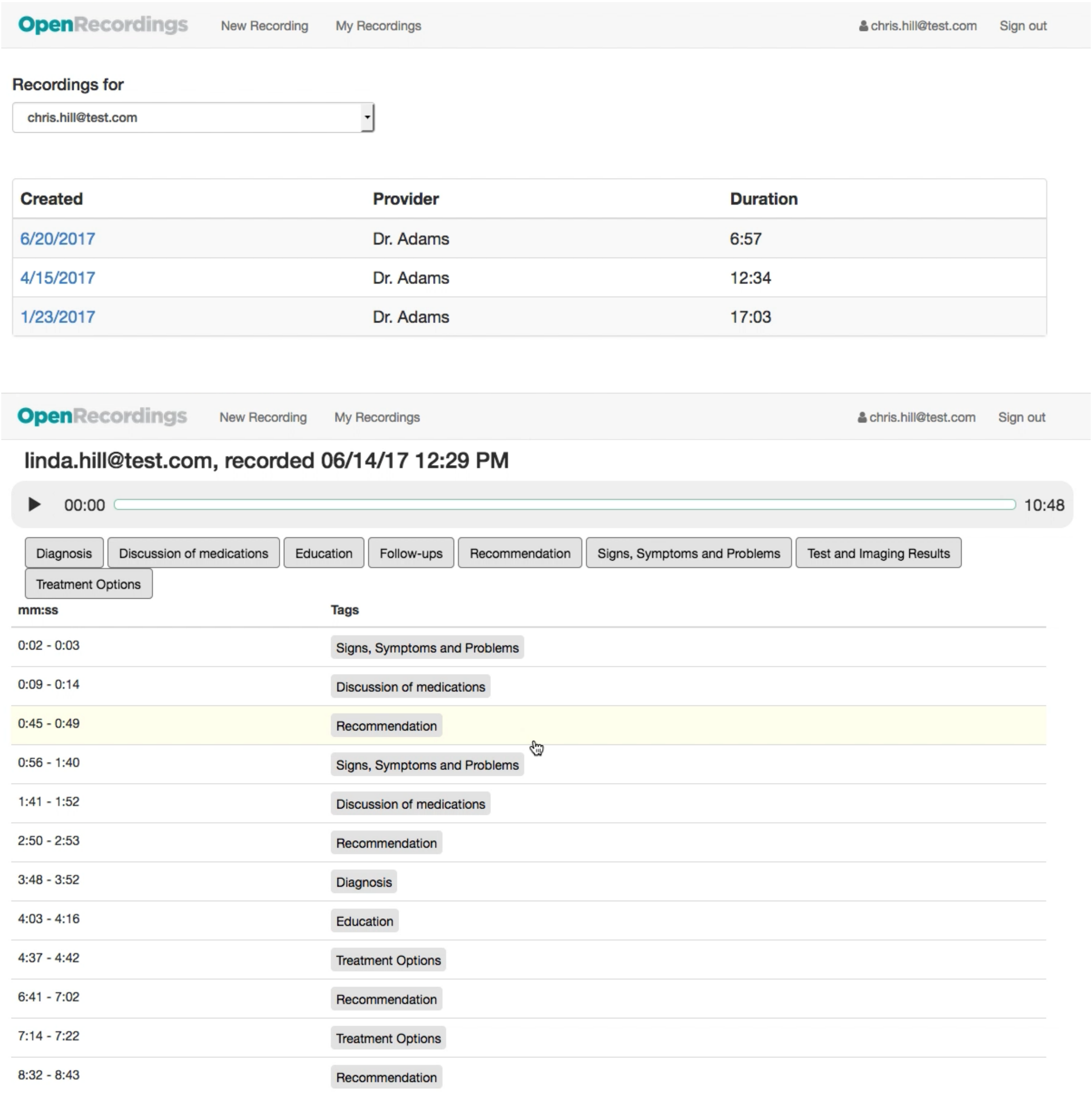


Figure 4. Initial software prototype (round 2)—interface for finding a patient’s recording (top) and playing back the recording (bottom).



Recordings for

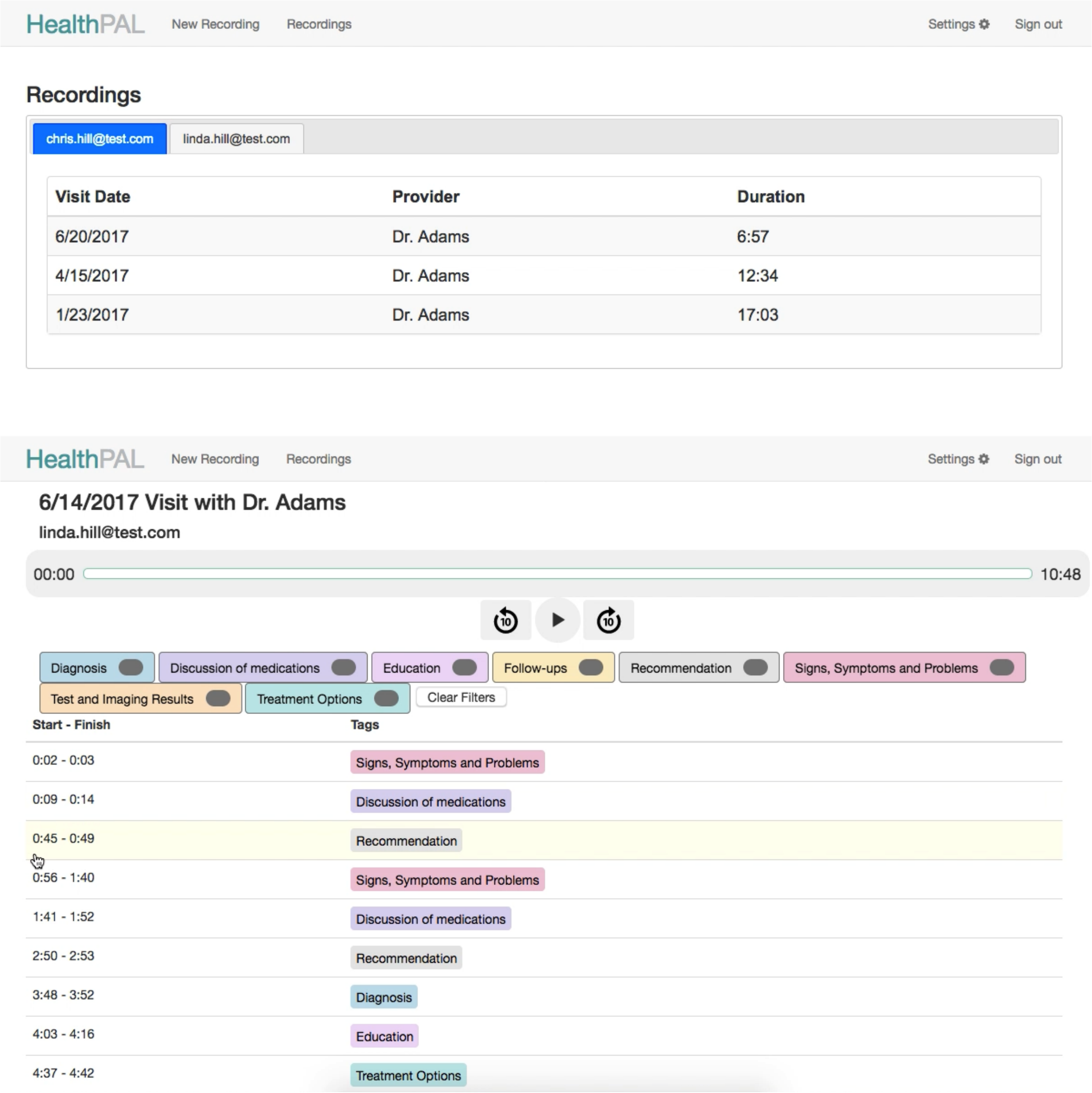
chris.hill@test.com

Created	Provider	Duration
6/20/2017	Dr. Adams	6:57
4/15/2017	Dr. Adams	12:34
1/23/2017	Dr. Adams	17:03

linda.hill@test.com, recorded 06/14/17 12:29 PM

mm:ss	Tags
0:02 - 0:03	Signs, Symptoms and Problems
0:09 - 0:14	Discussion of medications
0:45 - 0:49	Recommendation
0:56 - 1:40	Signs, Symptoms and Problems
1:41 - 1:52	Discussion of medications
2:50 - 2:53	Recommendation
3:48 - 3:52	Diagnosis
4:03 - 4:16	Education
4:37 - 4:42	Treatment Options
6:41 - 7:02	Recommendation
7:14 - 7:22	Treatment Options
8:32 - 8:43	Recommendation

Figure 5. Updated software prototype (round 3)—interface for finding a patient's recording (top) and playing back the recording (bottom).



Recordings

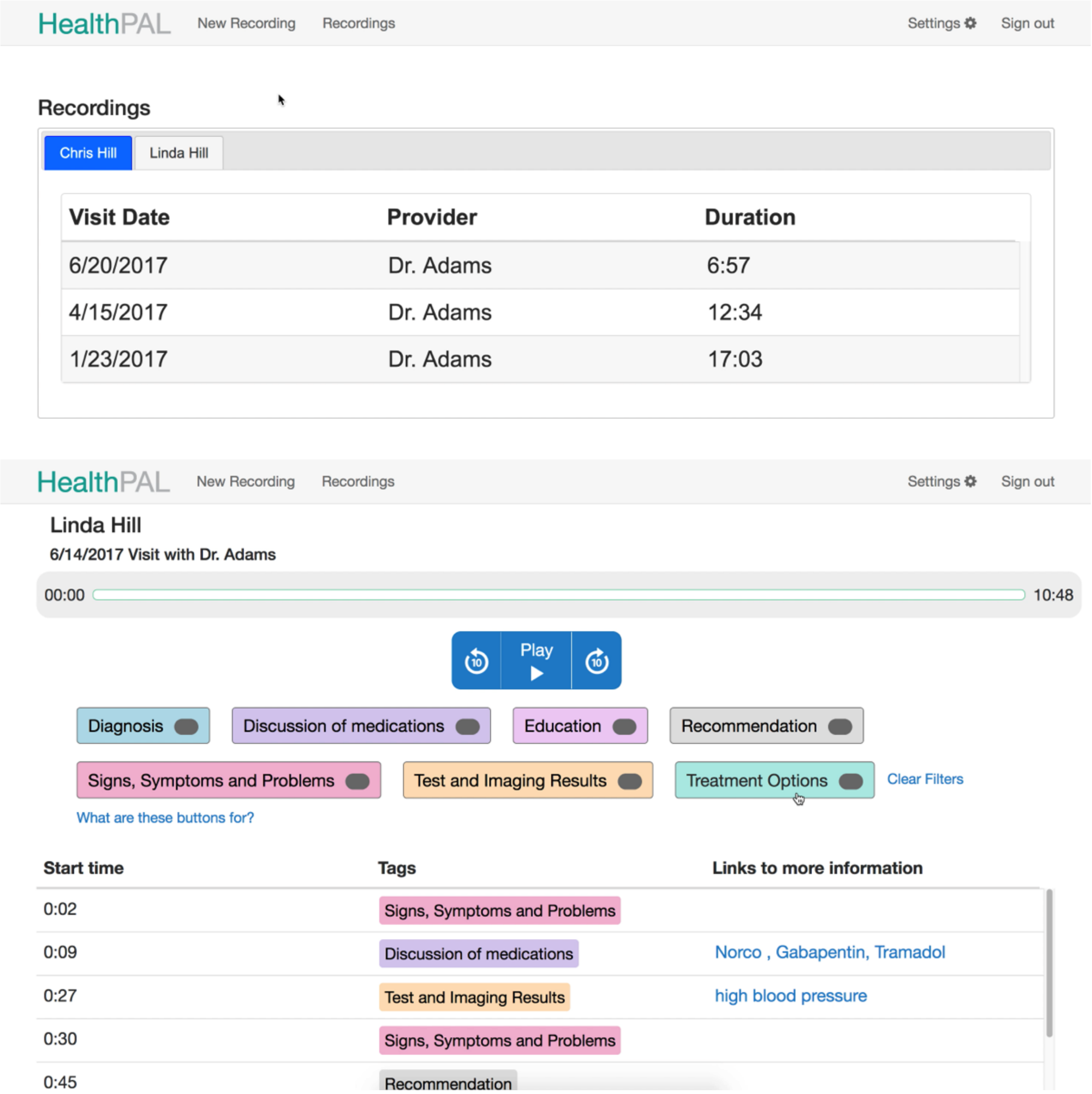
Visit Date	Provider	Duration
6/20/2017	Dr. Adams	6:57
4/15/2017	Dr. Adams	12:34
1/23/2017	Dr. Adams	17:03

6/14/2017 Visit with Dr. Adams

linda.hill@test.com

Start - Finish	Tags
0:02 - 0:03	Signs, Symptoms and Problems
0:09 - 0:14	Discussion of medications
0:45 - 0:49	Recommendation
0:56 - 1:40	Signs, Symptoms and Problems
1:41 - 1:52	Discussion of medications
2:50 - 2:53	Recommendation
3:48 - 3:52	Diagnosis
4:03 - 4:16	Education
4:37 - 4:42	Treatment Options

Figure 6. Updated software prototype (round 4)—interface for finding a patient’s recording (top) and playing back the recording (bottom).



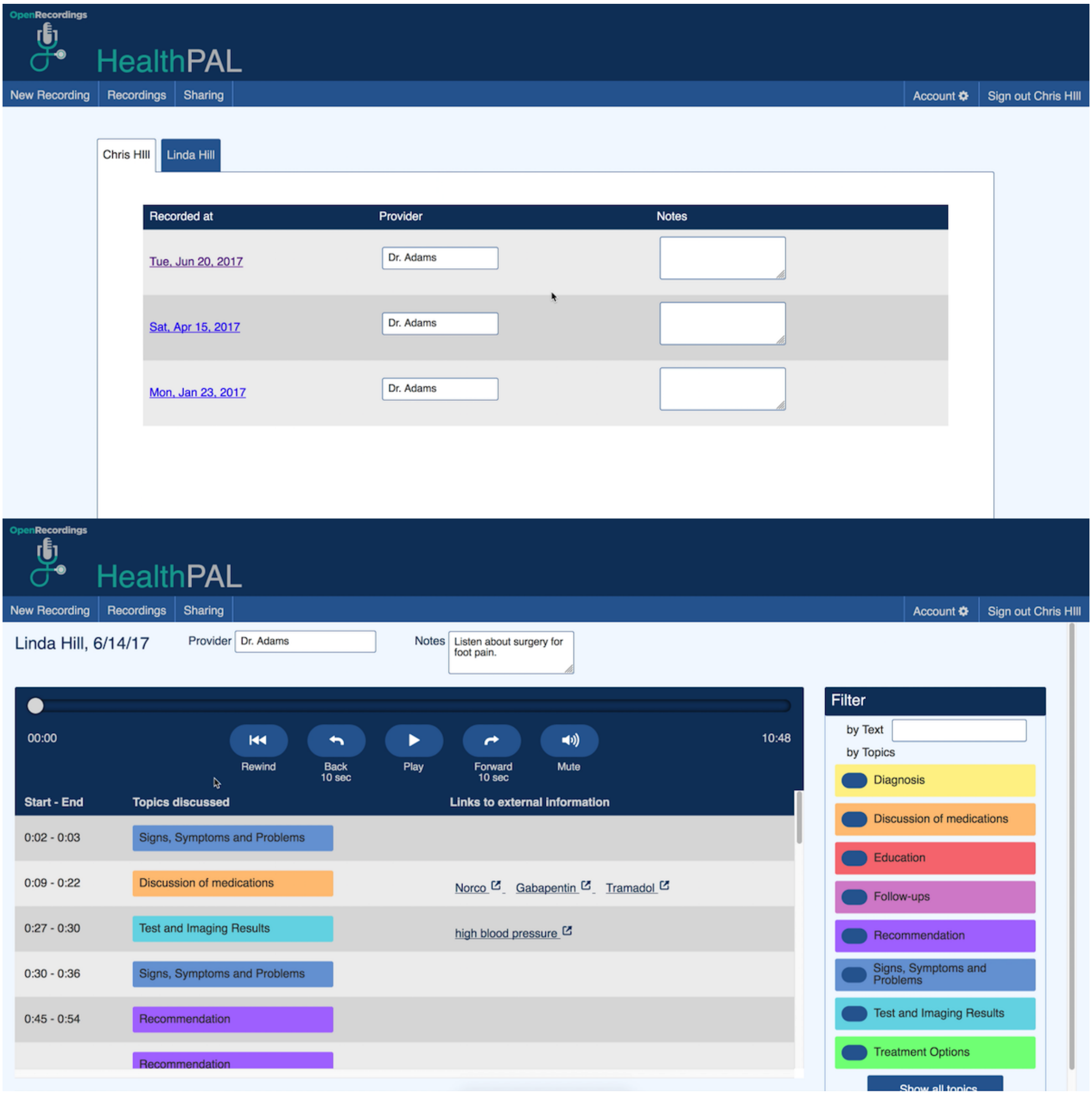
Visit Date	Provider	Duration
6/20/2017	Dr. Adams	6:57
4/15/2017	Dr. Adams	12:34
1/23/2017	Dr. Adams	17:03

Linda Hill

6/14/2017 Visit with Dr. Adams

Start time	Tags	Links to more information
0:02	Signs, Symptoms and Problems	
0:09	Discussion of medications	Norco , Gabapentin, Tramadol
0:27	Test and Imaging Results	high blood pressure
0:30	Signs, Symptoms and Problems	
0:45	Recommendation	

Figure 7. High-fidelity version of the software prototype (round 5)—interface for finding a patient's recording (top) and playing back the recording (bottom).



Recorded at	Provider	Notes
Tue, Jun 20, 2017	Dr. Adams	
Sat, Apr 15, 2017	Dr. Adams	
Mon, Jan 23, 2017	Dr. Adams	

Linda Hill, 6/14/17

Provider: Dr. Adams

Notes: Listen about surgery for foot pain.

Start - End	Topics discussed	Links to external information
0:02 - 0:03	Signs, Symptoms and Problems	
0:09 - 0:22	Discussion of medications	Norco Gabapentin Tramadol
0:27 - 0:30	Test and Imaging Results	high blood pressure
0:30 - 0:36	Signs, Symptoms and Problems	
0:45 - 0:54	Recommendation	
	Recommendation	

Evaluation Outcomes

Task Completion and System Usability

Task completion followed an inverted *U*-shaped distribution, with high completion rates in the early and later rounds and a drop in performance in between (Table 2). However, as new features were added, some tasks required further assistance (ie, find and play where medications are discussed on the recording), whereas the initial introduction of hyperlinks to further information resulted in poor task completion for these tasks. By round 5, the majority of tasks were completed without assistance. SUS assessments were introduced in round 3; the median SUS score improved across the rounds: round 3, 40 (range 38-68); round 4, 73 (range 35-100); and round 5, 78 (range 20-100). Scores for caregivers were lower than those for patients in both rounds 4 and 5.

Table 2. Task completion ratios and system usability (N=40).

Evaluation outcomes	R[a]1 (n=8)	R2 (n=6)	R3 (n=5)	R4 (n=11)		R5 (n=10)	
				CG[b] (n=5)	P[c] (n=6)	CG (n=5)	P (n=5)
Task (completed task alone:completed task with help:did not complete task)							
Find visit recording task	4:3:1	3:2:1	2:3:0	3:2:0	5:1:0	4:1:0	4:1:0
Find or play health issue task	8:0:0	5:1:0	3:1:1	2:2:1	4:2:0	2:3:0	4:1:0
Find or play medication task	8:0:0	5:1:0	0:3:2	1:4:0	6:0:0	5:0:0	4:0:1
Find more about health issue task	N/A[d]	N/A	N/A	2:1:2	1:0:5	5:0:0	3:0:2
Find more about medication task	N/A	N/A	N/A	3:1:1	3:0:3	5:0:0	5:0:0
Task completion, n (%)							
Total completed task (alone or with help)	23 (96)	17 (94)	12 (80)	21 (84)	22 (73)	25 (100)	22 (88)
Completed task with help	3 (13)	4 (22)	7 (47)	10 (40)	3 (10)	4 (16)	2 (8)
SUS[e] score (0-100), median (range)	N/A	N/A	40[f] (38-68)	73 (35-100)	75 (55-100)	65 (20-90)	95 (43-100)

[a] R: round.

[b] CG: caregiver role.

[c] P: patient role.

[d] N/A: not applicable.

[e] SUS: System Usability Scale; not administered in the first 2 rounds.

[f] Missing data for 1 person.

Critical Incidents

A summary of critical incidents (challenges that prevented participants from completing a task independently) is presented in Table 3. The greatest number of challenges was observed in round 4, where hyperlinks were added. This resulted in confusion in finding sections of audio recordings to play using tags and using associated hyperlinks to find further information. When asked to find additional information about a medical term in the visit recording (with our intent being they use the hyperlink we provided in HealthPAL), some participants simply opened a new tab in the browser and conducted a web search; we counted these responses as not completing the task. Further refinements to the UI resulted in a lower proportion of critical incidents by round 5.

Table 3. Summary of key critical incidents that occurred during user testing (N=40).

Critical incidents[a]	R[b]1 (n=8), n (%)	R2 (n=6), n (%)	R3 (n=5), n (%)	R4 (n=11), n (%)		R5 (n=10), n (%)	
				CG[c] (n=5)	P[d] (n=6)	CG (n=5)	P (n=5)
Issues switching to or from another user’s recordings	6 (75)	3 (50)	4 (80)	1 (20)	—[e]	1 (20)	—
Issues understanding which user the recordings belonged to	3 (38)	2 (33)	4 (80)	2 (40)	1 (17)	1 (20)	—
Issues navigating through the site	2 (25)	1 (17)	0 (0)	4 (80)	2 (33)	1 (20)	1 (20)
Issues finding the appropriate segment	7 (88)	4 (67)	4 (80)	2 (40)	2 (33)	1 (20)	0 (0)
Issues controlling or traversing the audio	5 (63)	0 (0)	5 (100)	5 (100)	5 (83)	3 (60)	3 (60)
Issues using the filters by topic	—	3 (50)	2 (40)	4 (80)	2 (33)	2 (40)	2 (40)
Issues using hyperlinks to find additional information	—	—	—	5 (100)	4 (67)	3 (60)	2 (40)
Issues using the filters by text	—	—	—	—	—	3 (60)	1 (20)

[a] Proportion of sessions with a critical incident.

[b] R: round.

[c] CG: caregiver role.

[d] P: patient role.

[e] Feature not available or not part of testing.

Suggestions

Participants made several suggestions regarding improvements and functionality of the system (Table 4). These suggestions were grouped into common themes across the rounds and were used to improve the UI and functionality. By round 5, few additional suggestions emerged.

Table 4. Proportion of key suggestions given during user testing by category (N=40).

Suggestion	R[a]1 (n=8), n (%)	R2 (n=6), n (%)	R3 (n=5), n (%)	R4 (n=11), n (%)		R5 (n=10), n (%)	
				CG[b] (n=5)	P[c] (n=6)	CG (n=5)	P (n=5)
Suggestions for making segments easier to find within a recording	7 (88)	4 (67)	2 (40)	2 (40)	2 (33)	2 (40)	1 (20)
Suggestions for making specific visits easier to find	5 (63)	2 (33)	3 (60)	0 (0)	0 (0)	1 (20)	1 (20)
Suggestions to make switching between recordings of different users more intuitive (ie, switching from personal to loved one's recording)	4 (50)	3 (50)	3 (60)	0 (0)	—[d]	1 (20)	—
Suggestions for supplementary text to include with recordings	3 (38)	3 (50)	2 (40)	3 (60)	0 (0)	1 (20)	2 (40)
Suggestions to make audio controls more intuitive	2 (25)	2 (33)	2 (40)	1 (20)	2 (33)	1 (20)	0 (0)
Suggestions to improve the filter by topic feature	—	1 (17)	0 (0)	1 (20)	0 (0)	3 (60)	0 (0)
Suggestions to improve the hyperlink feature	—	—	—	1 (20)	1 (17)	2 (40)	0 (0)
Suggestions to improve the filter by text feature	—	—	—	—	—	4 (80)	1 (20)
Suggestions for additional features	2 (25)	3 (50)	3 (60)	2 (40)	3 (50)	2 (40)	4 (80)

[a] R: round.

[b] CG: caregiver role.

[c] P: patient role.

[d] Feature not available or not part of testing.

Participant Views of an Audio PHL

Participants were overwhelmingly positive about the proposed system. Participants identified several benefits of having a visit recording. These included better recall of information for patients and the use of recordings as a historical artifact that could be revisited. For example, a participant said, "Because I had breast cancer 25 years ago and I'd like to go back and say, 'What was that now? What did they say?'" [r3p05]. Communication of clinic visit information to caregivers was considered a significant benefit, as a caregiver whose mother has cognitive issues stated, "it's cumbersome to try and get it from the doctor, so to have that in a place where you can go and access it [would be helpful]" [r4p04]. The added benefit of recording in comparison with written summaries was also mentioned. A participant considered written summaries as *minimal*, whereas another mentioned the ability "to listen to how the doctor said something and how much emphasis he or she was giving..." [r4p09] to clarify instructions; this reflects the added value recordings bring, including the information communicated through voice inflections. The use of hyperlinks was identified as an important feature as "you're getting the information a whole lot quicker than going and sifting through what Google results come up" [r6p03].

Some concerns were also raised. These included the need to keep the UI as user-friendly as possible and not assume "computer capability" [r3p01]. Concerns of information privacy were also raised, "You made this easy for an outside user to access some elements of it – you wouldn't want to let them in the whole thing" [r3p03].

Even when recordings would be shared with family members, patients reported the need for some caution: "I would want to be very careful about inviting relatives to get into the act" [r3p03]. It was mentioned that enabling features that allow partial sharing of recording may reduce this concern, which is not currently a function available in the system. Finally, there was concern from participants about the clinician giving permission for recording:

> *I can't imagine him agreeing to it, my parents' physician...I don't know, it could be used, in an odd way, against the doctor.* [r5p05]

Key Changes to HealthPAL Across Rounds

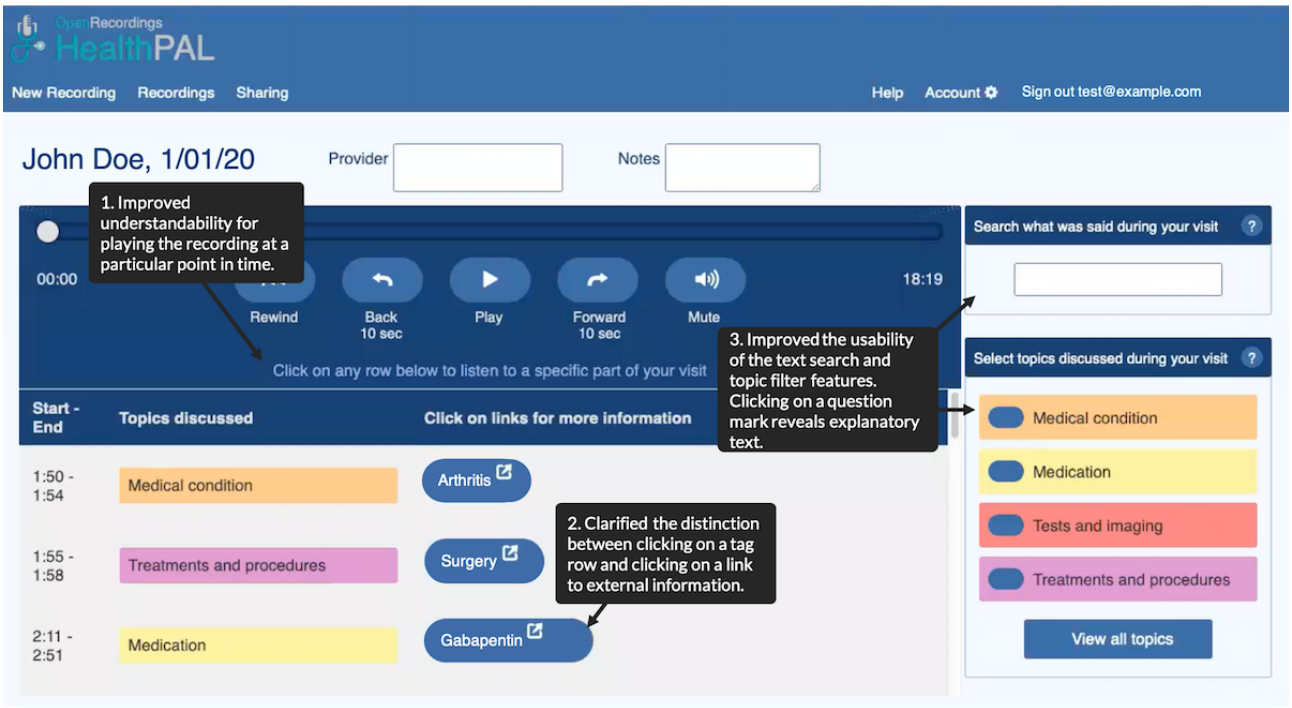
Textbox 3 outlines key changes made to the system and functionality added in response to user feedback, including color coding and highlighting of information tags, adding more prominent play and pause buttons, creating a clearer structure for switching between user accounts, adding tag filtering and descriptions, adding a 10-second forward and rewind control, a help link, and a search bar. Following our final round of user testing, we made minor modifications to clarify the elements of the interface that should be *clicked* for playback versus hyperlinks to new external information that was approved by our patient partners (RA and SP). Finally, a combination of user feedback and an attempt to optimize our approach to annotations, we reduced the information classes to medication, medical condition, test and imaging, and treatment and procedures.

Textbox 3. Summary of key changes to HealthPAL user interface.

Prototype Description and Updates

- Round 1
  - Initial paper prototype with audio controlled by the facilitator (Figure 3)
  - User quotes
    - “If there’s a way to get a finer level of detail [in the topic tags], that would probably be helpful.” [r1p03]
    - “[I would like] some sort of indication of where I am in the recording.” [r1p05]
  - Round 2
    - Initial software prototype based on feedback from round 1. Included clearer buttons to simplify navigation between recordings, highlighting of audio segments as a place marker, and topic filters to make audio segments easier to find (Figure 4)
    - User quotes
      - “[The topic tags] need to be different colors.” [r2p02]
      - “I didn’t even look – I looked up and saw the recordings [but not the account name they belonged to].” [r2p05]
- Round 3
  - Updated prototype to include color-coded topic tags, new affordances for selected filters, ahead and back 10-second controls, more prominent play or pause button, clear filters button, and more prominent display of all account names the user has access to (Figure 5)
  - User quotes
    - “I was wondering how I could [turn the audio] off.” [r3p05]
    - “Should you have some way to alert this [segment] is [about] the hand, the foot, blood pressure...” [r3p02]
- Round 4
  - Updated prototype to make playback controls more prominent; added external links to MEDLINE Plus for medications, diagnosis, and test results topics; and added help link and popover dialog for filter controls (Figure 6)
  - User quotes
    - “Why is there so much? We have the same things [in the filters] as [in the list of audio segments]...Can we make it so [the filters are] clearly going to help [find audio segments]?” [r4p11]
    - “Put a search in to specifically search for [the desired topic].” [r4p04]
- Round 5
  - Updated prototype to move audio playback closer to top of the window, moved filters to a shopping-like sidebar, added text search or filter, added editable notes field to recordings, renamed the clear filters button, added a mute button, and added a button to go back to the beginning of recording (Figure 7)
  - User quotes
    - “It’s a little confusing whether [the text search] is part of [the topic filters].” [r5p03]
    - “I did not see ‘Links to external information’ so I clicked on [the hyperlink].” [r5p04]
- Final user interface
  - Improved understandability for playing a particular audio segment, clarified the distinction between clicking on a tag-row and clicking on an external information link, improved the usability of the text search and topic filter features, and reduced the number of information classes (Figure 8)

Figure 8. Final version of the software playback user interface.



1. Improved understandability for playing the recording at a particular point in time.

2. Clarified the distinction between clicking on a tag row and clicking on a link to external information.

3. Improved the usability of the text search and topic filter features. Clicking on a question mark reveals explanatory text.

Discussion

Principal Findings

Following 5 rounds of user design sessions, we iteratively developed a highly usable interface that enables end users to seamlessly interact with desired functions, including playback and sharing of recordings, identifying key segments of the recording, and linking to trustworthy web-based resources. When presented with tasks to find specific topics in a visit recording, participants readily chose to use features (eg, tags, filters, and text search) that helped them more quickly find and play the audio related to that topic by simply listening to the entire recording. Participants were overwhelmingly positive about the concept of accessing a curated audio recording of a clinic visit; however, some participants reported concerns about privacy and the ability of participants to use a computer-based system to access recordings. Although patient partners felt that our final edits addressed confusion about the use of hyperlinks and playback in HealthPAL, further usability testing in less controlled settings is needed.

Comparison With Previous Work

Previous studies of audio or video recording in the health care context have focused primarily on providing a hard copy of a recording to a patient, for example, a CD, cassette, or digital recorder [27]. In more recent developments, commercial apps have emerged that allow the recording, sharing, and tagging of audio recording; however, user-centered design of the app is rarely reported, and concerns about the collection and sharing of patient data have been raised [60].

An exception is *SecondEars*, a recording app developed by Lipson-Smith et al [61] for use by patients receiving cancer treatment. Similar desired features in a recording platform were identified using the MoSCoW (Must Have, Should Have, Could Have, and Won’t Have) method in their study. Interestingly, although the SecondEars app focuses on providing a simple recording of oncology clinic visits, patients noted that the ability to link notes to a particular section (ie, minute and second) of an audio recording would be desirable—a unique feature in HealthPAL. The HealthPAL design and our evaluation align with this previous work in that our iterative design incorporated many of these effective meeting browser features: a compressed view of the recording, showing key terms with segment boundaries, and text search of the transcript. Our methodology took learning effects into consideration in our focus on usability for first-time use of the system by including unique patients in each round. In addition, we increased the validity of our findings by asking participants to adopt roles that were reflective of real-world use, that is, participants playing the patient role listened to the recording before using HealthPAL, as patients would be part of the clinic visit in the real world.

It is likely that the inverted *U*-shaped distributions of performance were the result of a younger age demographic and use of paper prototyping in earlier rounds, in addition to the introduction of newer features in the low-fidelity prototype. Although participants became comfortable with most features, some features such as hyperlinks, filters, and the advanced search caused some confusion in the final round of testing. These challenges may be explained by a lack of familiarity with the modern UI design [62], especially in the absence of explicit feedback on actions. Previous usability studies have also reported that, although older adults understand hyperlinks, they can become disoriented when trying to use them [63], and it is unclear which elements of the display can be clicked. It is recommended that hyperlinks appear *touch* interactive [64]. In future iterations of HealthPAL, we will take these additional insights to further improve the usability of the system for older adults before evaluation.

Participants' comments regarding the potential of HealthPAL to improve recall and understanding are supported by previous reviews, which found that sharing recordings can lead to such improvements [28]. However, previous research fails to determine the impact of sharing audio recordings on the ability of patients to manage their own care or the added value of annotated visit recordings. We plan to explore this knowledge gap through a pilot trial of our system.

Limitations

Our sample was predominately White and college educated, reflecting the demographics of the region where our study took place. Further work is needed with individuals from more diverse ethnic and racial groups and from those with lower educational attainment levels. Our project was conducted in controlled settings, where participants were asked to think aloud and received assistance, if needed, with tasks. Although this is important at this stage of user design, it does not reflect the user experience in naturalistic settings. We plan to conduct further field testing in less controlled settings, where clinic visits will be recorded, annotated using our machine learning models, and used at home by patients. During this phase of testing, we will gather information on implementation factors and include clinician feedback. We will also obtain feedback from caregivers using actual clinic recordings of their loved ones' visit. Some participants may have been unclear on the task instructions related to finding additional information (opening tabs outside of the UI), which may have resulted in the higher reported critical incidents in round 5 relative to our other usability metrics, that is, high SUS scores and task completion rate. In addition, our definition of *critical incident* was broad, including any change from the anticipated task path, not only those that resulted in task failure. Finally, we used a laptop computer for all usability testing sessions, but we hope to create a mobile adaptive UI, which will require further testing. Given the simplistic design concept, we believe that the interface can be quickly adapted to a mobile interface.

Conclusions

Sharing visit recordings with patients is an emerging strategy for improving the transparency and communication of visit information. We have developed a highly usable audio PHL, HealthPAL, designed to allow patients and their caregivers to access easy-to-navigate recordings of clinic visits, with key concepts tagged and hyperlinks provided to further information. The interface has been rigorously co-designed with older adult patients and their caregivers and is now ready for further field testing. Our design work has identified and evaluated key features: a tag-based visualization for finer-grained playback of the visit recording coupled with tag-based filtering and text search on audio segments of the recording, which we believe will inform future design of such systems. The successful development and use of HealthPAL may help improve the ability of patients to manage their own care, especially older adult patients who have to navigate complex treatment plans.

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Conflicts of Interest

PJB, WH, MDD, LO, KLB, JCF, SH, AKD, JAS, WMO, MLB, CHG, RA, and SP have no conflicts of interest to declare. GE has edited and published books that provide royalties on sales by publishers, including *Shared Decision Making* (Oxford University Press) and *Groups* (Radcliffe Press). GE's academic interests are focused on shared decision-making and coproduction. He owns a copyright in measures of shared decision-making and care integration, namely, collaboRATE, integRATE (measure of care integration), consideRATE (patient experience of care in serious illness), coopeRATE (measure of goal setting), incorpoRATE (clinician attitude to shared decision-making), Observer OPTION-5, and Observer OPTION-12 (observer measures of shared decision-making). In the past, he provided consultancy for organizations, including (1) Emmi Solutions LLC, which developed patient decision support tools; (2) the National Quality Forum on the certification of decision support tools; (3) Washington State Health Department on the certification of decision support tools; and (4) SciMentum LLC, Amsterdam (workshops for shared decision-making). He is the founder and director of &think LLC, which owns the registered trademark for Option Grids patient decision aids, and the founder and director of SHARPNETWORK LLC, a provider of training for shared decision-making. He provides advice in the domain of shared decision-making and patient decision aids to (1) Access Community Health Network, Chicago (adviser to Federally Qualified Medical Centers), (2) EBSCO Health (consultant), (3) Bind On-Demand Health Insurance (consultant), 4) PatientWisdom Inc (adviser), and (5) abridge AI Inc (chief clinical research scientist).

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Abbreviations

AVS: after-visit summary
D-H: Dartmouth-Hitchcock
DHMC: Dartmouth-Hitchcock Medical Center
MoSCoW: Must Have, Should Have, Could Have, and Won’t Have
NLP: natural language processing
PHL: personal health library
SUS: System Usability Scale
TURF: Task, User, Representation, and Function
UI: user interface

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Corrigenda and Addenda

Correction: Artificial Intelligence–Based Prediction of Lung Cancer Risk Using Nonimaging Electronic Medical Records: Deep Learning Approach

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Correction: Artificial Intelligence–Based Prediction of Lung Cancer Risk Using Nonimaging Electronic Medical Records: Deep Learning Approach

In “Artificial Intelligence–Based Prediction of Lung Cancer Risk Using Nonimaging Electronic Medical Records: Deep Learning Approach” (J Med Internet Res 2021;23(8):e26256), two errors were noted.

Due to a system error, the name of one author, Marvin Chia-Han Yeh, was replaced with the name of another author on the paper, Hsuan-Chia Yang. As well, the formatting of the author name "Yu-Chuan (Jack) Li" has been changed to "Yu-Chuan Jack Li" in the corrected version of the paper.

In the originally published paper, the order of authors was listed as follows:

> *Hsuan-Chia Yang, Yu-Hsiang Wang, Hsuan-Chia Yang, Kuan-Jen Bai, Hsiao-Han Wang, Yu-Chuan (Jack) Li.*

This has been corrected to:

> *Marvin Chia-Han Yeh, Yu-Hsiang Wang, Hsuan-Chia Yang, Kuan-Jen Bai, Hsiao-Han Wang, Yu-Chuan Jack Li.*

In the originally published paper, the ORCID of author Hsuan-Chia Yang was incorrectly published as follows:

> *0000-0001-6710-4435*

This has been corrected to:

> *0000-0001-9198-0697*

The correction will appear in the online version of the paper on the JMIR Publications website on October 15, 2021, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Technology report

Integrating third-party telehealth records with the general practice electronic medical record system: a use case approach

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ABSTRACT

Background The implementation of telemonitoring at scale has been less successful than anticipated, often hindered by clinicians' perceived increase in workload. One important factor has been the lack of integration of patient generated data (PGD) with the electronic medical record (EMR). Clinicians have had problems accessing PGD on telehealth systems especially in patient consultations in primary care.

Objective To design a method to produce a report of PGD that is available to clinicians through their routine EMR system.

Method We modelled a system with a use case approach using Unified Modelling Language to enable us to design a method of producing the required report. Anonymised PGD are downloaded from a third-party telehealth system to National Health Service (NHS) systems and linked to the patient record available in the hospital recording system using the patient NHS ID through an interface accessed by healthcare professionals. The telehealth data are then processed into a report using the patient record. This report summarises the readings in graphical and tabular form with an average calculated and with a recommended follow-up suggested if required. The report is then disseminated to general practitioner practices through routine document distribution pathways.

Results This addition to the telehealth system is viewed positively by clinicians. It has helped to greatly increase the number of general practices using telemonitoring to manage blood pressure in NHS Lothian.

Keywords: telehealth, eHealth, medical records

INTRODUCTION

Despite increasing evidence from clinical trials for the effectiveness of telemonitoring in long-term condition management, attempts to scale up its implementation have proved less successful than initially anticipated.[1] One factor is resistance from clinicians because of perceived increases to workload.[2,3] It is recognised that to overcome any reluctance to adopt telehealth systems it is important that the usability of the telemonitoring system is paramount and it is essential to ensure that the system will be successfully integrated into normal working patterns.[4] A recurring issue has been the inability to integrate telehealth patient generated data (PGD) into the electronic medical record (EMR) of family physicians,[5–7] and this has been identified as an issue that potentially determines the success and future of telehealth.[8]

Telehealth record data are usually stored on a separate website from the patient record, which necessitates additional security logons and, in some cases, the double entry of data which can result in lengthening of the consultation and possibly introducing data security issues.[9] For telehealth systems to work smoothly, all clinicians within a practice need to access the readings summary without the requirement to access the separate telehealth website. This has not been easy to achieve because of data protection concerns about recording identifiable patient data on third-party systems and a lack of standardisation in health record systems which have prevented seamless integration of the recording systems.

THE SCALE-UP BP PROJECT

Following the success of a local randomised controlled trial,[10] the Technology Enabled Care Programme[11] aims to introduce telemonitoring at scale for blood pressure (BP) in Scotland. Scale-up BP is part of this programme and is implementing home monitoring of BP with telehealth in general practices in Lothian. The telehealth system used[12] involves the patient texting their home BP reading to a mobile number to enable the readings to be sent by Short Message Service to a telehealth server. Patients are informed by text at the time of the reading if the BP is within target and depending on the level may be directed to contact their doctor routinely or urgently. The data are displayed on the patient's nurse or general practitioner (GP) computer via a secure web server. Although this program summarises the readings in graphical and tabular form as well as displaying the complete set of readings, it has to be accessed through a website with a secure login and is not part of the general clinical system. This has caused difficulties in previous pilot studies of telehealth with some clinicians at a practice not being able to access the information.[5,13]

DEVELOPMENT OF A REPORT INTEGRATED WITH THE ELECTRONIC MEDICAL RECORD

The Scale-up BP project included a proposal to establish a clinically appropriate, safe, and effective method that integrates PGD into the EMR in a summarised form. In our previous study,[13] we investigated the issues of integrating telehealth data into the general practice reporting system and clinicians' preferred format of receiving this. Clinicians wanted a system that was simple, compatible with the existing EMR system and to provide regular information summaries. Moreover, the data flows should be normalised to closely resemble existing incoming data flows and include a mechanism to feedback information to other care team members (as per usual practice routines). Graphical presentation and the use of colour were seen as helpful to summarise data over an agreed time period and indicate abnormal data parameters with access to the full dataset from the summary chart. Taking these suggestions into account, we developed a model with a use case approach using Unified Modelling Language[14] that described the interaction of the key actors in the system (Figures 1 and 2). The model shows the actors involved in the process interacting with the system to complete tasks along with the functional requirements and goal (the report) giving a schematic overview of the systems required. Figure 1 shows

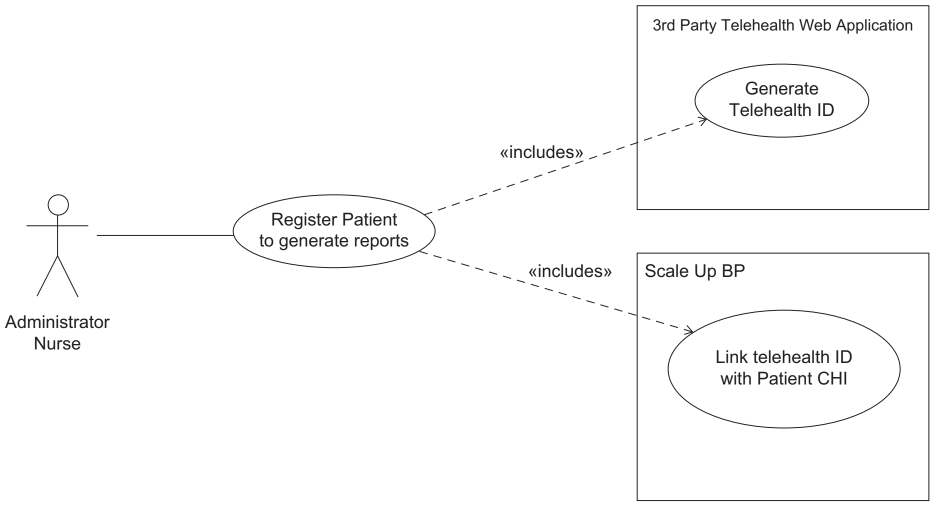


Figure 1 **Patient enrolment: a use case diagram**

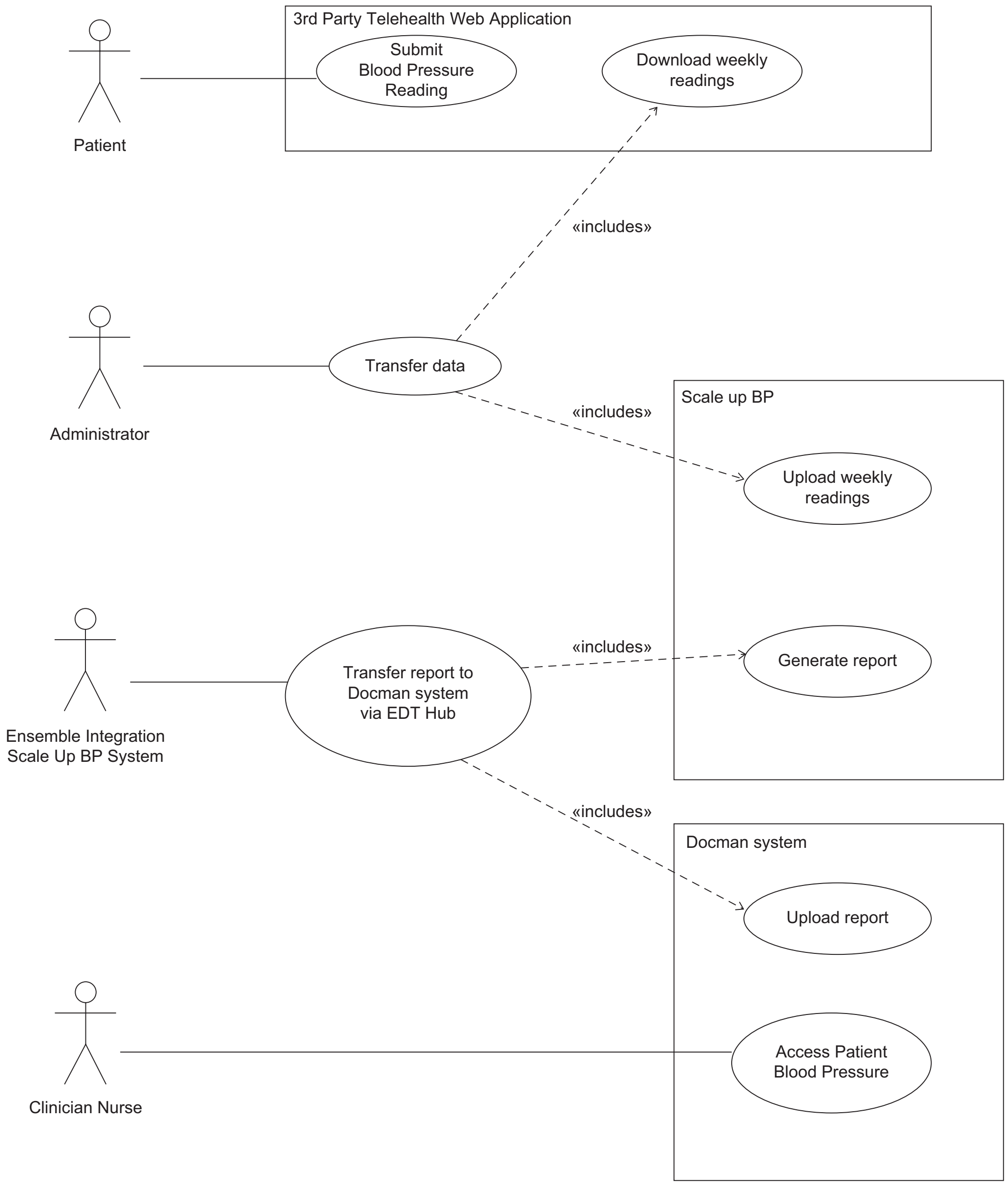
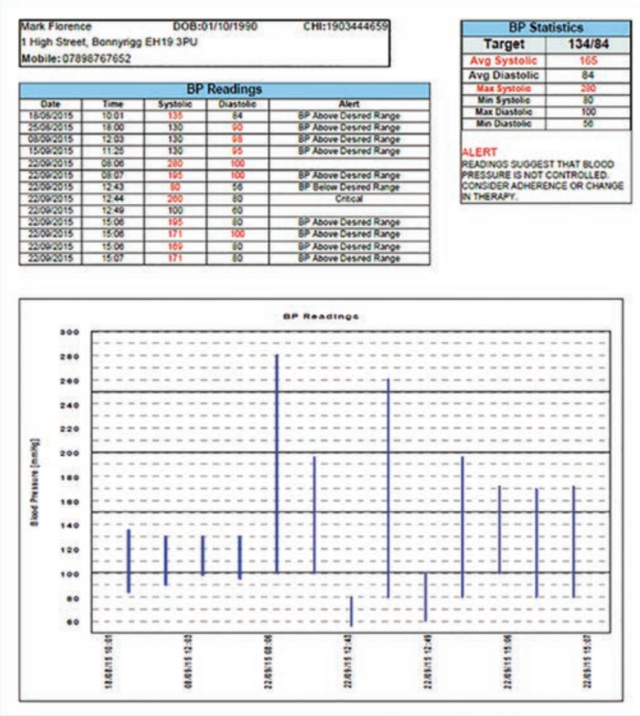


Figure 2 **Report creation: a use case diagram**

the initial interactions needed, and Figure 2 shows the report production process. Software was developed by the Scale-up BP project team based on this model which allowed the summarisation and transmission to GP practices of patient generated BP measurements using routine information flow channels, currently used for reviewing laboratory results and hospital letters, thus avoiding the necessity for clinicians to use two logins to review the readings, one for the telehealth website and one for EMR. We decided to use a routine reporting system rather than attempting to link the PGD directly with the EMR as data directly entering the patient record in the latter way would bypass the normal reviewing mechanisms currently in place in GP practices. All incoming summary reports are reviewed by clinicians as they do for routine laboratory results and can be acted on as required.

Information governance restrictions meant that it was not permitted to store the unique patient identifier, the Community Health Index (CHI) number, which is allocated to all patients in the NHS in Scotland and used for interactions in the Scottish health service, on the third-party (Florence)[12] system so it was not possible to link the telehealth records to GP records directly. This problem has been overcome by developing a simple web interface within the NHS network where, at the time of registering on the telehealth system, the clinician looks up the NHS patient hospital management system (TrakCare from Intersystems)[15] to select the correct patient using the CHI number. The patient's demographic details including the GP practice are retrieved and checked. The clinician then records the unique telehealth ID assigned when the patient is registered on the telehealth system and enters whether to receive reports on a monthly, three-monthly or six-monthly basis.

The anonymised telehealth data (with an ID only) are downloaded weekly from the third-party system to create the reports. Each record in the manual data extract is added to InterSystems Ensemble that allows for the development of new connectable applications. Scheduled tasks automate both the generation of a PDF graph and the sending of the report to the Electronic Document Transfer Hub for transmission to the GP practices using metadata that identifies the GP practice and matching it to its corresponding CHI number and reporting interval. The demographic and telehealth data for each patient are assembled into the Portable Document Format (PDF) report that displays the BP readings over the desired period graphically and in tabular form. It highlights those readings that are above or below target. The targets are set in the telehealth programme and follow national guidelines[16] for people with uncomplicated high BP and lower targets for those with chronic kidney disease or diabetes mellitus. The average systolic and diastolic pressure of the last five pressures during the chosen period are displayed and are highlighted if they are above or below target and trigger a statement saying 'Readings suggest that BP is not controlled. Consider adherence or change in therapy' (Figure 3).


Mark Florence DOB:01/10/1990 CHI:1903444659
1 High Street, Bonnyrigg EH19 3PU
Mobile: 07898767652

BP Readings

Date	Time	Systolic	Diastolic	Alert
18/06/2015	10:01	135	84	BP Above Desired Range
25/06/2015	18:00	130	90	BP Above Desired Range
08/09/2015	12:03	130	98	BP Above Desired Range
15/09/2015	11:25	130	95	BP Above Desired Range
22/09/2015	08:06	280	100	
22/09/2015	08:07	195	100	BP Above Desired Range
22/09/2015	12:43	80	56	BP Below Desired Range
22/09/2015	12:44	260	80	Critical
22/09/2015	12:49	100	60	
22/09/2015	15:06	195	80	BP Above Desired Range
22/09/2015	15:06	171	100	BP Above Desired Range
22/09/2015	15:06	169	80	BP Above Desired Range
22/09/2015	15:07	171	80	BP Above Desired Range

BP Statistics

Target	134/84
Avg Systolic	165
Avg Diastolic	84
Max Systolic	280
Min Systolic	80
Max Diastolic	100
Min Diastolic	56

ALERT
READINGS SUGGEST THAT BLOOD PRESSURE IS NOT CONTROLLED. CONSIDER ADHERENCE OR CHANGE IN THERAPY.

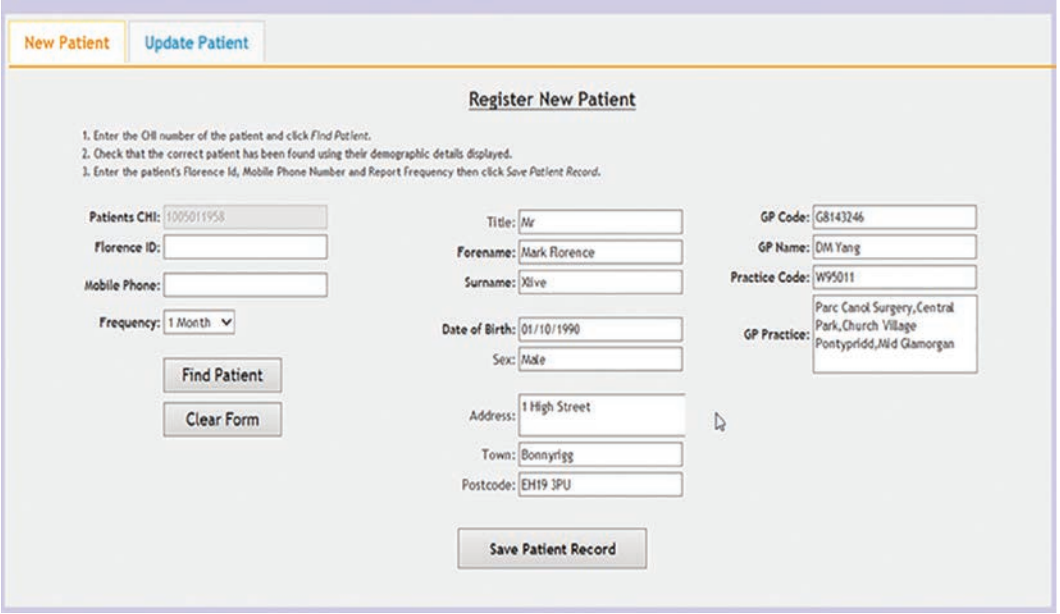
Figure 3 **Sample report of telehealth data sent to GP practices**

Each report is pushed out through the Docman system,[17] which is the most widely used document handling system in general practice and through which all hospital letters and laboratory results are managed, into the specified GP practice where it is assimilated into the normal electronic document handling processes. The reports are sent in a staggered way so that practices are not overwhelmed with a large number of results in one day. An algorithm, based on the day of the month that the patient started to use the telehealth system, decides which reports to send.

APPLICATION

Tests using dummy data were run before the live roll out. The report-based system was tested on seven early adopter practices in the project, initially with monthly reports. Clinicians found the system easy to use and reports were received as requested. The feedback on the layout of the report was favourable; the reports summarising the readings graphically and in a table with the average calculated were found to support and enhance clinical decision making. Occasionally, a patient is not recorded on the hospital management system because they have not had contact with a hospital and, hence, no record exists. Links with the Medical Health Records Department have had to be established to resolve this issue.

Nurses request a login to the patient registration system from central NHS Lothian IT services. The link to the registration webpage is easily accessed on the commonly used



Register New Patient

1. Enter the CHI number of the patient and click *Find Patient*.
2. Check that the correct patient has been found using their demographic details displayed.
3. Enter the patient's Florence Id, Mobile Phone Number and Report Frequency then click *Save Patient Record*.

Patients CHI: 1005011958
Florence ID:
Mobile Phone:
Frequency: 1 Month

Title: Mr
Forename: Mark Florence
Surname: Xlive
Date of Birth: 01/10/1990
Sex: Male
Address: 1 High Street
Town: Bonnyrigg
Postcode: EH19 3PU

GP Code: G8143246
GP Name: DM Yang
Practice Code: W95011
GP Practice: Parc Canol Surgery,Central Park,Church Village Pontypridd,Mid Glamorgan

Figure 4 **The web interface used to set up the linkage of the telehealth data with the electronic medical record**

intranet applications list. The nurse enters the patient's CHI number, the patient details displayed are checked and the telehealth ID from the telehealth system is added (Figure 4). This routine task can also be completed by an administrator in the GP practice to save clinician time. The reports are handled by GP practices following standard document handling procedures; all are checked, the average transferred into the patient notes and the document is then stored in the EMR and thus the information is accessible to all clinicians at the practice.

The system has now been rolled out to all practices taking part in the scale-up BP project. The project has proven very popular with almost half of GP practices in Lothian taking part in the scheme and currently 1200 patients have been recruited.

DISCUSSION

A system that has integrated the telehealth data directly into the EMR system has proved successful. The integrated reporting system is viewed very positively and is an important factor in persuading practices to take up the telehealth service. This method has addressed security concerns by keeping all NHS patient identifiers within the NHS. The report has also matched the suggested requirements in the Davidson paper.[13] The PGD are received by practices through routine information routes ensuring that it does not overwhelm the clinician with frequent unscheduled data. A facility to review discrete data in PDF reports through the routine documentation handling process is seen as a positive attribute of our method. Real-time reception of data by clinicians is available in the telehealth system, but is not a factor that is seen as essential in a condition such as hypertension. A review of evidence for mHealth[1] recommends interventions should be guided by a plausible theory of behaviour change. We have found that ensuring there are very few changes in routine behaviour within the practices by using the document reporting process, improves the implementation rate of telehealth.

The existing process could be improved if the third-party supplier provided an application program interface to allow automated retrieval of the results. There is potential to store patients' own results in the hospital TrakCare system and add value to consultations outside the primary care setting. The system has the possibility to be extended for use with other conditions and data types. We are also negotiating links to existing patient-facing portals operated within the NHS to increase its scope.

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Original Paper

The National COVID Cohort Collaborative: Analyses of Original and Computationally Derived Electronic Health Record Data

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Abstract

Background: Computationally derived ("synthetic") data can enable the creation and analysis of clinical, laboratory, and diagnostic data as if they were the original electronic health record data. Synthetic data can support data sharing to answer critical research questions to address the COVID-19 pandemic.

Objective: We aim to compare the results from analyses of synthetic data to those from original data and assess the strengths and limitations of leveraging computationally derived data for research purposes.

Methods: We used the National COVID Cohort Collaborative's instance of MDClone, a big data platform with data-synthesizing capabilities (MDClone Ltd). We downloaded electronic health record data from 34 National COVID Cohort Collaborative institutional partners and tested three use cases, including (1) exploring the distributions of key features of the COVID-19–positive cohort; (2) training and testing predictive models for assessing the risk of admission among these patients; and (3) determining geospatial and temporal COVID-19–related measures and outcomes, and constructing their epidemic curves. We compared the results from synthetic data to those from original data using traditional statistics, machine learning approaches, and temporal and spatial representations of the data.

Results: For each use case, the results of the synthetic data analyses successfully mimicked those of the original data such that the distributions of the data were similar and the predictive models demonstrated comparable performance. Although the synthetic and original data yielded overall nearly the same results, there were exceptions that included an odds ratio on either side of the null in multivariable analyses (0.97 vs 1.01) and differences in the magnitude of epidemic curves constructed for zip codes with low population counts.

Conclusions: This paper presents the results of each use case and outlines key considerations for the use of synthetic data, examining their role in collaborative research for faster insights.

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KEYWORDS

synthetic data; protected health information; COVID-19; electronic health records and systems; data analysis

Introduction

COVID-19 presents data and knowledge sharing challenges [1]. Clinical data exist at individual institutions; however, these data are rarely shared with external entities. Big data from multiple institutions allow for more comprehensive analyses, particularly for characterizing rare outcomes [2,3]. In response to this need, the National COVID Cohort Collaborative (N3C), an open science community, was formed to ingest and harmonize COVID-19 data from institutions across the United States [4]. The N3C sought a solution to preserve the privacy and confidentiality of these clinical data while enabling their broad dissemination [5-7] and partnered with MDClone (Beer Sheva, Israel) to computationally derive "synthetic" N3C data and support the rapid advancement of population health insights [8].

Since synthetic derivatives of data can enable privacy-preserving data downloads and accelerate discovery, these data assets can potentially be of great utility to the N3C and the broader informatics community. Our synthetic data validation workstream was established to assist the N3C community in better understanding the utility of synthetic data for research purposes. Our previous work demonstrated statistical equivalency between original and computationally derived data sets from a local instance of MDClone [9]. We also used synthetic data sets exclusively to apply machine learning to predict decompensation in heart failure [10]. Others have demonstrated repeatedly generated synthetic data sets from MDClone produced stable results that were similar to the original data [11].

However, the performance of MDClone—the comparison of original to synthetic data—has not been validated using data comprising multiple sources such as those originating across health systems. To that end, we tested three use cases, including (1) exploring the distributions of key features of the COVID-19–positive cohort; (2) training and testing predictive models for assessing the risk of admission among these patients; and (3) determining geospatial and temporal COVID-19–related measures and outcomes, and constructing their epidemic curves. We analyzed data for each use case using original and synthetic data. We conducted analyses using traditional statistics, machine learning approaches, and temporal and spatial representations of the data. Here we present the results of these analyses and describe the strengths and limitations of using synthetic data for research.

Methods

Overview

The Clinical and Translational Science Award Program developed N3C in response to a need for integrating, harmonizing, and democratizing individual-level COVID-19 data [4]. The N3C established a secure data enclave to store data and conduct collaborative analytics. The subsequent analyses resulted from a synthetic data pilot designed to evaluate the utility of computationally derived data for the N3C community. Synthetic data generation represents an emerging technology that can support population health research at scale. As described in more detail elsewhere [9], MDClone uses a computational derivation approach. Briefly, novel data whose features are queried independently for each distinct use case are produced in a multidimensional space that adheres to the statistical properties of the original source data. MDClone censors categorical values that are unique to few patients by removing the value and replacing it with the word "censored" in the computationally derived data set. Extreme numerical values also do not appear in the synthetic data set. Together, these approaches ensure that outliers in the original data set will not be identifiable in the synthetic data derivative.

All analyses were conducted using original data and computationally derived data, respectively, which allowed us to compare the results of analyses and assess the strengths and limitations of leveraging synthetic data for COVID-19 insights. All statistical analyses on the original and synthetic data sets were done outside of MDClone on the Palantir Foundry Analytic Platform (Palantir Technologies).

Analyses were conducted using Python (3.6.10l Python Software Foundation). We obtained institutional review board approval from our institutions for these analyses, in addition to completing data use agreements and requests with the National Center for Advancing Translational Sciences at the National Institutes of Health.

Use Case 1: Exploring the Distributions of Key Features of the COVID-19–Positive Cohort

The goal of this use case was to evaluate whether synthetic data had similar distributions of demographic and clinical characteristics among the COVID-19–positive cohort as compared to original data. Key characteristics (n=15) of the COVID-19–positive cohort were extracted from MDClone to compare distributions between the synthetic and the original data. The 15 features included age, gender, race, patients' state of residence, institution, median household income, BMI, number of days between testing positive and hospital admission (if hospitalized), diagnosis of diabetes, dyspnea, chronic kidney disease (CKD), fever, cough, and in-hospital mortality. We calculated mean and SD for continuous variables, and counts and proportions for categorical variables.

Use Case 2: Training and Testing Predictive Models for Assessing the Risk of Admission Among COVID-19–Positive Patients

The goal of this use case was to evaluate whether synthetic data would perform similarly when training and testing predictive machine learning models on synthetic data as compared to training and testing the models on original data. We included 230,703 patients who tested positive for COVID-19. Features for predictive modeling included 11 variables: age, gender, race, median household income, BMI, minimum oxygen saturation, diabetes, dyspnea, CKD, fever, and cough. These variables were chosen because of initial data suggesting their significant impact on COVID-19 outcomes.

We calculated odds ratios (ORs) and 95% CIs for admission within 14 days of a COVID-19 diagnosis by univariate logistic regression (LR) and multivariable LR using synthetic and original data, respectively. We then developed two widely used machine learning models, random forest (RF) and LR, to predict admission within 14 days of a COVID-19 diagnosis based on the 11 features. We randomly split the cohort into training (80%) and testing (20%) data. The models were trained on the 80% subset of the data and then tested on the remaining 20%. We used a variety of metrics, including accuracy, precision, recall, F1-score, area under the receiver operating characteristic (ROC) curve, and precision-recall curves to evaluate model performance. Each model was trained and evaluated on the synthetic data set, the results of which were then compared against a model trained and evaluated on the original data.

Use Case 3: Determining Geospatial and Temporal COVID-19–Related Measures and Outcomes, and Constructing Their Epidemiologic Curves

The purpose of this analysis was to assess concordance of geospatial and temporal relationships between the synthetic and original data to make the data actionable and interpretable according to geography and time. Our data sets (original: n=1,854,968 tests; synthetic: n=1,854,950 tests) were event-based with each row representing a patient's first COVID-19 test result. The data sets included the following variables: source partner with which the patient was affiliated; lab test result (negative/positive); lab test date and time (reference time point for data generation); age at confirmed lab test result; admission start date (days from reference if admission occurred within ±7 days of COVID-19–positive test result); admission length of stay (in days); death (yes/null) during admission; patient's state of residence; patient's 5-digit zip code; and median household income, percent of residents under the poverty line, percent without health insurance, and total population by zip code.

On both the synthetic and original data sets, we calculated the aggregate count, 7-day midpoint moving average, and 7-day slope (count – count 6 days prior) per day for positive tests. We then plotted epidemic curves (Plotly version 4.14.1, Plotly Technologies Inc) for positive tests with synthetic and original data overlaid in the same figure. To test for significant differences or equivalence between the synthetic and original data epidemic curves, the paired two-sided *t* test (scipy version 1.5.3, stats.ttest_rel) and two-sided Wilcoxon signed rank test (scipy version 1.5.3, stats.wilcoxon) were run for each metric (count, 7-day moving average, and 7-day slope) treating the counts for individual dates as pairs.

Next, we calculated the differences in the mean, SD, median, IQR, and missingness of zip code–level social determinants of health (SDOH) variables within the original data set. We then compared these original data SDOH values for unique zip codes in the original data that were censored versus uncensored in the synthetic data. We defined censored zip codes as those present within the original data set that could not be matched (n=11,222) within the synthetic data set either due to not being present or being labeled as *censored* within the synthetic data set. We defined uncensored zip codes as present within both the synthetic data and original data (n=5819).

Ethics

This study was reviewed and approved by the Washington University in St. Louis' and the University of Washington's institutional review boards.

Results

Use Case 1: Exploring the Distributions of Key Features of the COVID-19–Positive Cohort

The MDClone synthetic data process generated 230,650 participants, compared to 230,703 in the original data. Demographic and clinical variables comparing synthetic and original data sets are displayed in Table 1. The mean age from both data sources was the same (mean 41.6, SD 20.4 years; Table 1). Approximately 47% of patients were male and 53% were White in both data sources. The values of all means and SDs (or counts and percentages) were the same or very similar between original and synthetic data. Table 1 shows that the distribution of demographic and clinical variables was similar between original and synthetic populations.

Table 1. Comparison of patient characteristics of available demographic and clinical variables: original vs synthetic data.

	Original data (n=230,703)	Synthetic data (n=230,650)
Age (years), mean (SD)	41.6 (20.4)	41.6 (20.4)
Gender (male), n (%)	108,194 (46.9)	107,892 (46.8)
Race, n (%)		
White	121,706 (52.8)	121,564 (52.7)
Black	40,930 (17.7)	40,824 (17.7)
Asian	5203 (2.3)	5117 (2.2)
Other/unknown	62,864 (27.2)	62,733 (27.2)
Top 5 most prevalent states, n (%)		
1	29,875 (12.9)	28,617 (12.4)
2	21,191 (9.2)	20,671 (9.0)
3	21,045 (9.1)	20,319 (9.0)
4	18,006 (7.8)	16,998 (7.4)
5	14,391 (6.2)	13,840 (6.0)
Top 5 most prevalent institutions, n (%)		
1	33,413 (14.5)	32,743 (14.2)
2	24,533 (10.6)	23,986 (10.4)
3	15,578 (6.8)	15,065 (6.5)
4	11,870 (5.1)	11,255 (4.9)
5	11,354 (4.9)	10,850 (4.7)
Household income (US $), median (IQR)	56,738 (45,214, 71,250)	56,662 (45,223, 71,029)
BMI, mean (SD)	30.3 (8.4)	30.3 (8.2)
Admission start date (days from reference), mean (SD)	2.1 (3.3)	2.0 (3.2)
Minimum oxygen saturation, mean (SD)	90.9 (10.1)	91.0 (9.7)
Diabetes, n (%)	31,942 (13.8)	31,929 (13.8)
Dyspnea, n (%)	20,867 (9.0)	20,826 (9.0)
Chronic kidney disease, n (%)	11,225 (4.9)	11,194 (4.9)
Fever, n (%)	30,210 (13.1)	30,200 (13.1)
Cough, n (%)	39,703 (17.2)	39,689 (17.2)
Deceased, n (%)	1133 (0.5)	1008 (0.4)

Use Case 2: Training and Testing Predictive Models for Assessing the Risk of Admission Among COVID-19–Positive Patients

Features (n=11) used for prediction included age, gender, race, median household income, BMI, minimum oxygen saturation, diagnosis of diabetes, dyspnea, CKD, fever, and cough. Table 2 shows the OR for admission and for each of the 11 variables by univariable LR yielded by original and synthetic data sources, respectively. The comparison of ORs between original and synthetic data sources show that the values for all 11 features were the same or similar. For example, the OR for admission by age from the original data was 1.04 (95% CI 1.04-1.04), which was the same as that obtained from synthetic data.

Table 2. Logistic regression for admission: original vs synthetic data.

	Univariate LR[a], OR[b] (95% CI)		Multivariable LR, OR (95% CI)	
	Original data	Synthetic data	Original data	Synthetic data
Age	1.04 (1.04-1.04)	1.04 (1.04-1.04)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Male gender	1.20 (1.16-1.24)	1.14 (1.10-1.17)	1.11 (0.99-1.23)	1.03 (0.93-1.15)
Black race	2.15 (2.07-2.22)	2.09 (2.02-2.17)	0.99 (0.87-1.12)	0.93 (0.82-1.06)
Median household income	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
BMI	1.02 (1.01-1.02)	1.02 (1.01-1.02)	0.97 (0.97-0.98)	1.01 (1.00-1.02)
Minimum oxygen saturation	0.97 (0.96-0.97)	0.97 (0.96-0.97)	0.97 (0.97-0.98)	0.97 (0.97-0.98)
Diabetes	6.14 (5.94-6.34)	6.15 (5.95-6.36)	1.45 (1.29-1.62)	1.46 (1.30-1.63)
Dyspnea	4.79 (4.62-4.97)	4.79 (4.61-4.97)	1.23 (1.09-1.38)	1.25 (1.11-1.41)
Chronic kidney disease	7.20 (6.89-7.52)	7.17 (6.87-7.49)	1.23 (1.07-1.42)	1.26 (1.09-1.45)
Fever	2.62 (2.52-2.71)	2.62 (2.53-2.72)	1.44 (1.29-1.61)	1.45 (1.30-1.62)
Cough	1.38 (1.33-1.43)	1.38 (1.32-1.43)	1.50 (1.32-1.70)	1.45 (1.28-1.65)

[a] LR: logistic regression.

[b] OR: odds ratio.

The comparison of ORs between original and synthetic data sources shows that the multivariable LR yielded the same or similar results. For example, the OR for admission by Black race from the original data was 0.99 (95% CI 0.87-1.12), which was similar to that obtained from synthetic data (OR 0.93, 95% CI 0.82-1.06). Of note, the ORs that corresponded to a one-unit increase in BMI were on either side of the null (0.97 vs 1.01).

The machine learning models that were trained and tested on original data and then trained and tested on synthetic data used the same 11 features. Figure 1 shows the comparison of model prediction performance using original and synthetic data, respectively. We found the RF model achieved an under the ROC curve of 0.814 (0.816 by LR) using original data, and 0.812 (0.815 by LR) using synthetic data (Figure 1 A and C). Meanwhile, the RF model achieved an average precision of 0.298 (0.286 by LR) with original data and 0.308 (0.278 by LR) with synthetic data (Figure 1 B and D).

Figure 2 shows additional metrics for the evaluation of model performance. We observed the same or similar patterns by accuracy, specificity, precision, sensitivity, and F1-score when comparing models that were trained and tested on original data as compared to those trained and tested on synthetic data.

Figure 3 shows the feature importance according to RF (Figure 3 A) and LR models (Figure 3 B) using original (magenta) and synthetic (blue) data. Both the RF and LR models' demonstrated that features such as age, income, and minimum oxygen saturation were high-ranking informative features.

Figure 1. Prediction performance for the two models by receiver operating characteristic curves (A, C) and precision-recall curves (B, D) by using original and synthetic data. Results for the RF model are in the first row (A, B); the second row (C, D) is for LR. AUC: area under the curve; LR: logistic regression; RF: random forest.

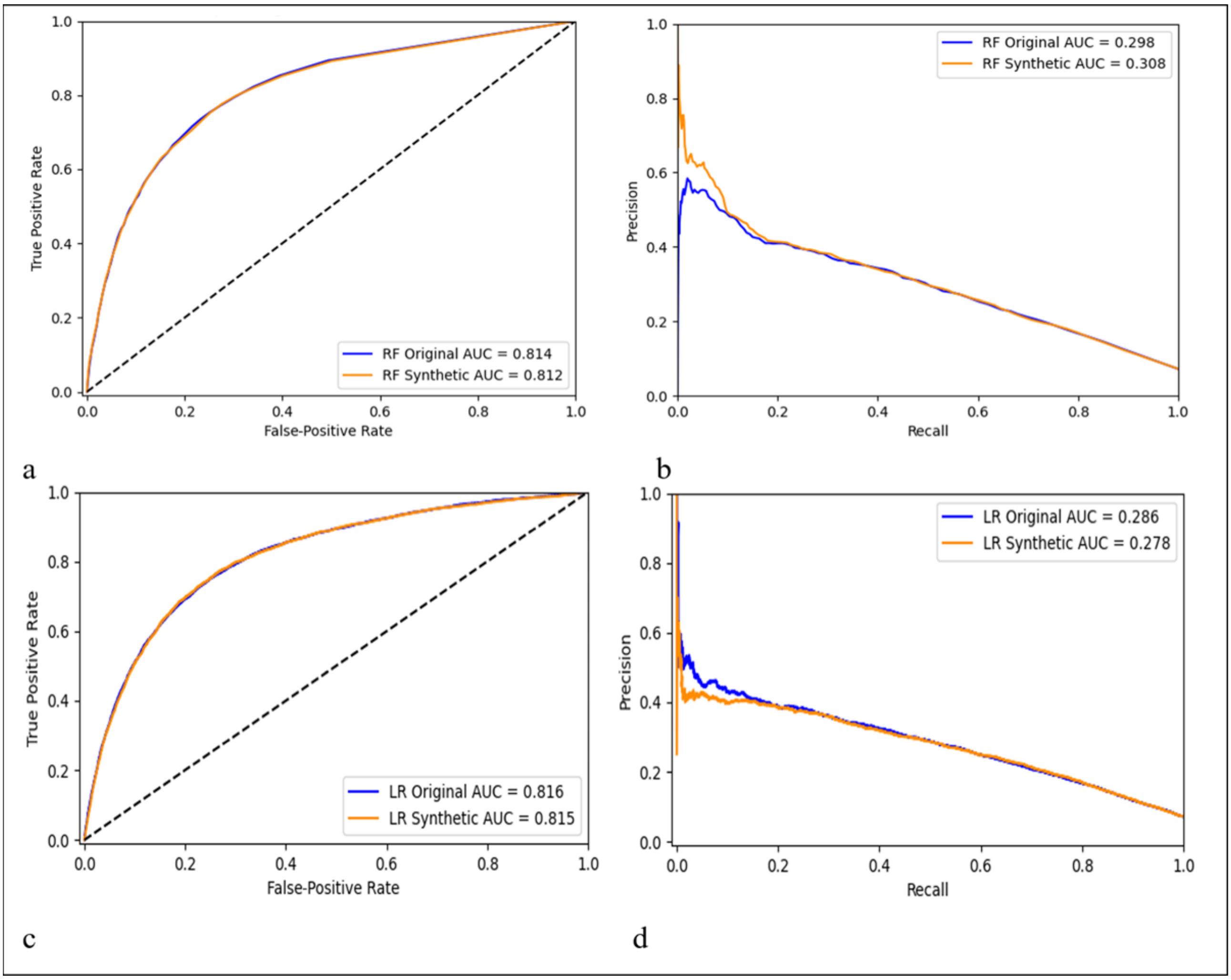


Figure 2. Model performance metrics from original (green) and synthetic (gold) data by accuracy, specificity, precision, sensitivity, and F1-score: RF model (A) and LR model (B). LR: logistic regression; RF: random forest.

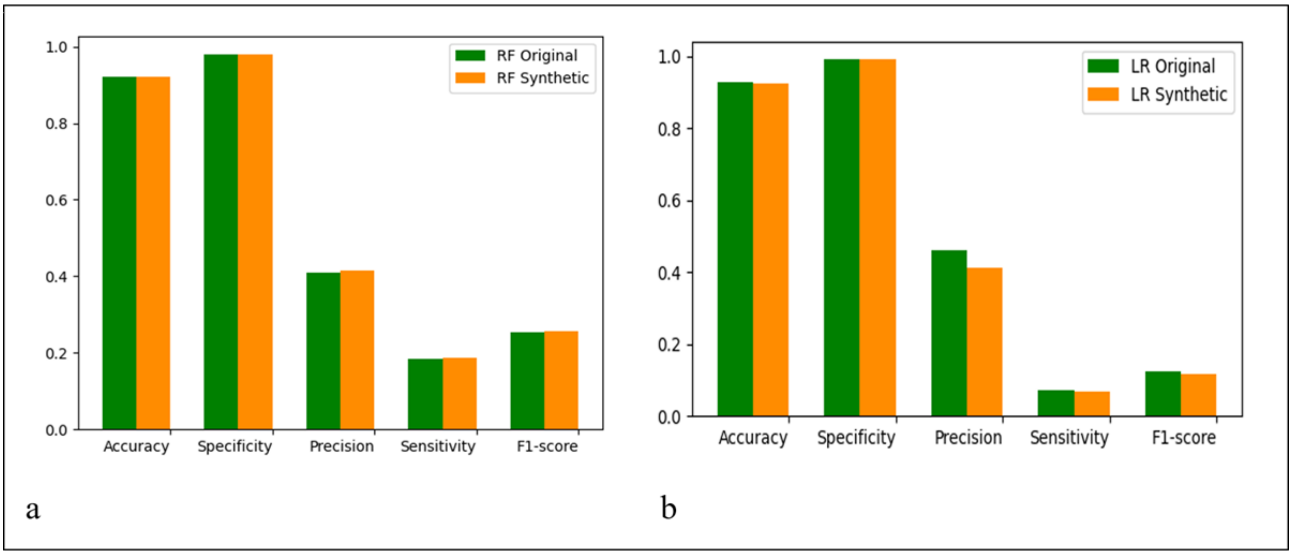
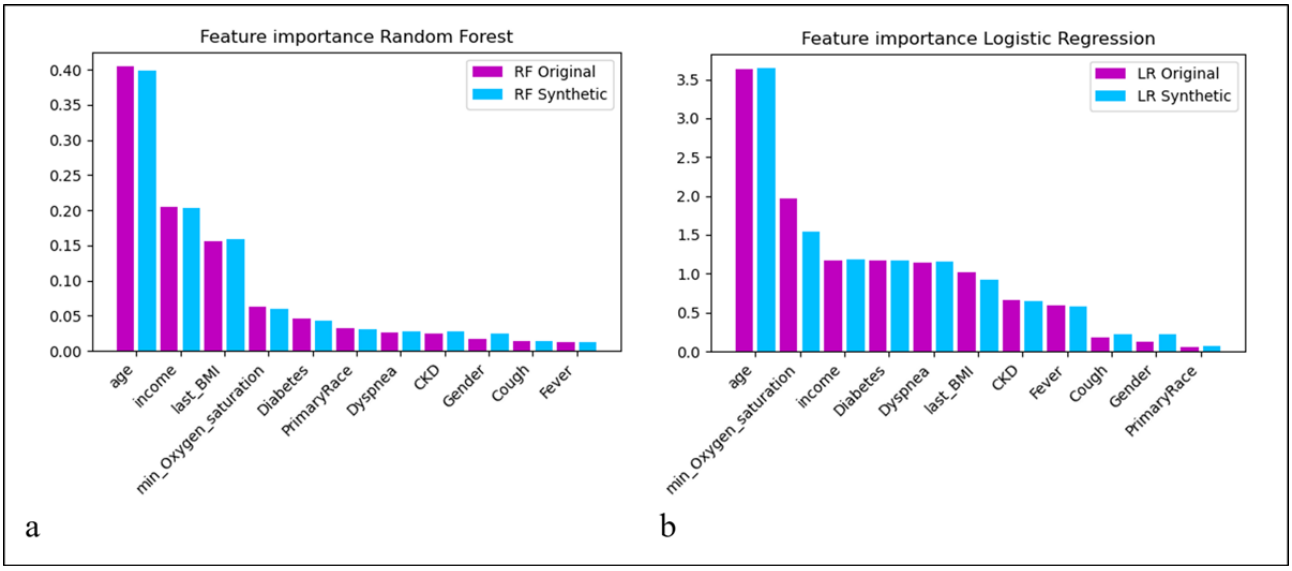


Figure 3. Feature importance for the 11 variables in RF (a) and LR (b) models: original vs synthetic data. CKD: chronic kidney disease; LR: logistic regression; RF: random forest.



Use Case 3: Determining the Zip Code–Level Distributions of COVID-19–Related Outcomes and Calculating Their Epidemiologic Curves

A graphical comparison of the epidemic curves for aggregate positive tests (cases) between the synthetic and original data is shown in Figure 4. Pairwise statistics for the epidemic curve metrics are shown in Table 3; no significant differences were found between the synthetic and original data epidemic curves across all metrics (Wilcoxon signed rank test *P* value range .50-.90; Student paired *t* test *P* value range .996-.998).

Compared to censored zip codes, uncensored zip codes had a higher median household income, a lower percentage of residents under the poverty line, a lower percentage of patients without health insurance, a higher total population, and fewer missing values for all four SDOH. Total population and data missingness were the two greatest differences between uncensored and censored zip codes. Uncensored zip codes had a 74% higher median total population and had approximately 70% fewer missing SDOH values than censored zip codes (Table 4).

Figure 4. Original data (light blue) and synthetic data (light red), with their overlap (purple).

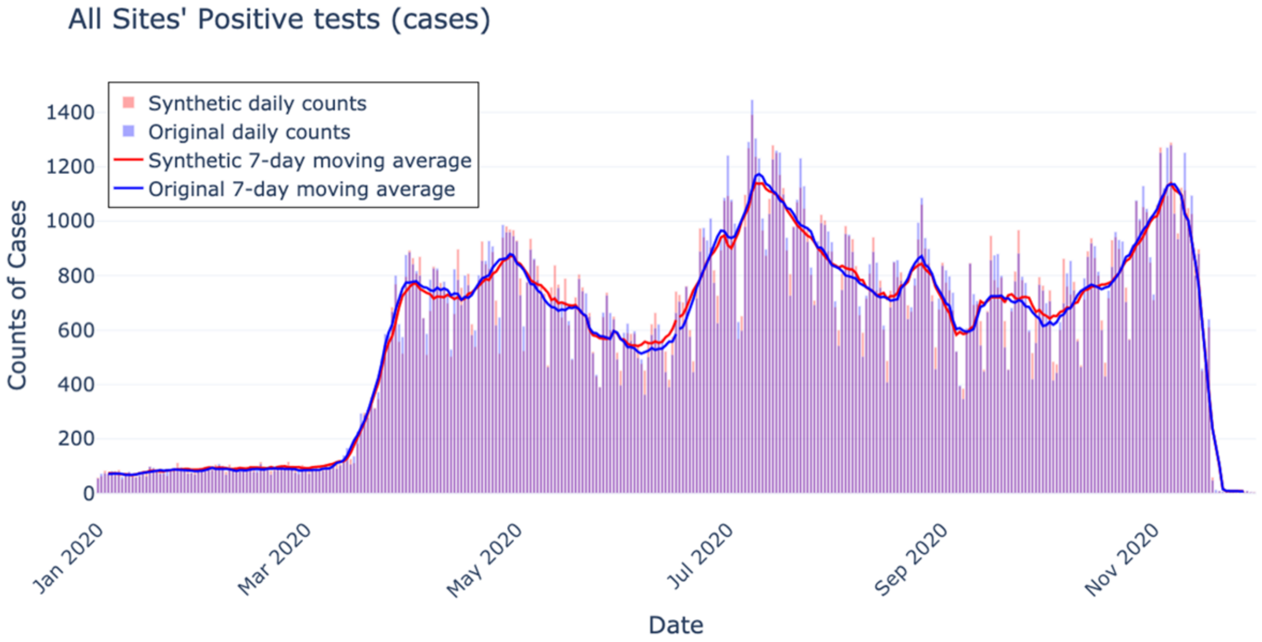


Table 3. Epidemic curves aggregate cases' paired statistical tests, comparing original to synthetic data.

Metric	Date range	Wilcoxon result	Wilcoxon *P* value	*t* statistic	*t* test *P* value
Counts	335	26,288	.50	–0.002	>.99
7-day moving average	329	26,005	.78	–0.006	>.99
7-day slope	329	25,788.5	.90	–0.002	>.99

Table 4. SDOH values for zip codes that were uncensored (n=5819) compared to censored (n=11,222) zip codes.

SDOH[a] and censored status	Mean	SD	Median	IQR	% missing
Median household income (US $)					
Uncensored	63,536	26,755	57,352	28,692	3.28
Censored	60,544	26,549	54,358	27,067	10.98
Difference (%)	+2992 (4.9)	+206 (0.8)	+2994 (5.5)	+1625 (6.0)	–7.70 (70.1)
Percent under poverty line					
Uncensored	12.89	8.74	10.80	10.40	2.92
Censored	13.87	10.15	11.60	11.50	9.12
Difference (%)	–0.98 (7.1)	–1.41 (13.9)	–0.80 (6.9)	–1.10 (9.6)	–6.20 (68.0)
Percent without health insurance					
Uncensored	8.52	5.09	7.50	6.50	2.84
Censored	9.65	7.09	8.10	8.00	9.00
Difference (%)	–1.13 (11.7)	–2.00 (28.2)	–0.60 (7.4)	–1.50 (18.8)	–6.16 (68.4)
Total population					
Uncensored	17,363	16,128	12,263	23,172	2.73
Censored	14,540	17,317	7048	21,436	8.69
Difference (%)	+2823 (19.4)	–1189 (6.9)	+5215 (74.0)	+1736 (8.1)	–5.96 (68.6)

[a]SDOH: social determinants of health.

Discussion

Principal Findings

Our main findings demonstrated that computationally derived data had the same or similar statistical output as the original data sets, with the caveat that zip codes with a lower population had data suppressed/censored for privacy reasons more often than zip codes with a higher population. In each use case, the results of the analyses appear sufficiently similar between the synthetic derivative and the original data across the various methods used to assess similarity (means, medians, $P>.05$, overlapping CI, etc) to draw the same conclusions with the exception of one OR on either side of the null in multivariable analyses (0.97 vs 1.01). In several instances, the results were exactly the same and rarely were there statistically significant differences between data sets.

Small sample sizes, missing values, and high dimensionality can all adversely affect the data synthesis process and the precision and interpretability of original data. Our geospatial analysis shows that zip codes that are censored to protect patient privacy have a lower population, which will likely make using these computationally derived data to study rural populations more challenging. Additionally, the lower original data quality found within censored zip codes—seen in greater SDOH missingness—as compared to uncensored may indicate broader data quality issues in rural zip code data. Such issues may pose a further challenge to data synthesis.

This was the first validation of computationally derived data using the N3C data. Our study adds to the growing literature of synthetic data validation in the following ways. First, our study is the first assessment of N3C synthetic data utility and has been conducted prior to the broad dissemination of N3C synthetic data. Thus, our study provides insight to the validity of N3C synthetic data prior to its dissemination for use by the broader N3C community. Second, our results from use case 3 support the temporal validity of these computationally derived data as an alternative to date-shifting when privacy must be protected yet temporality maintained.

For these descriptive and quantitative analyses, the synthetic data appear to produce similar patterns and results compared to the original data, except for in the context of high missingness. We acknowledge that these use cases may not represent all possible ways in which the synthetic data may be used by the N3C community and thus validation should continue. In addition to continuously validating these data for different use cases and analytic methods, we seek to explore the performance of other commercial systems in the N3C community and their approaches to synthetic data generation and the privacy-preserving aspects of each approach.

We also suggest that the synthetic data can be used by researchers for hypothesis generation to then be validated later on original data. Another potential use case that could be valuable to the N3C community, which we do not explicitly test here, is the potential for synthetic data to be used for software engineering projects that seek to develop digital health tools for combating the COVID-19 pandemic. Computationally derived data that are faithful to the original data could be used to develop and test such tools.

Limitations

For these analyses, we compared the data statistically and did not conduct privacy evaluations of the synthetic data that will be a focus of future investigations. We used a *P* value threshold of .05 to maintain simplicity of presenting results from multiple use cases. We acknowledge that such thresholds would (and should) vary by use case and specifically by the amount of error a researcher is willing to tolerate given the context of the research question. We also acknowledge that other statistical tests such as equivalence testing could be suitable to assess the equivalence of computationally derived data to original data. However, the threshold for equivalence will yet again depend on the use case. Our geospatial and temporal analysis was limited in scope. Our work is ongoing, and future analyses will assess validity of other measures (eg, tests, admissions, deaths, or positivity) over time—both in aggregate and at the zip code level—in greater detail.

Conclusions

We conclude that the potential for leveraging synthetic data for the conduct of COVID-19 research in N3C is substantial. We expect that the use of synthetic data will accelerate the conduct of data-driven research studies across the community, as it will allow the N3C to overcome data sharing barriers and rapidly create COVID-19 analytic insights [4]. Future directions for this work include developing and validating additional clinical risk prediction models, using a larger repertoire of analytic methods, conducting geospatial and temporal analyses in greater detail and at the zip code level, and evaluating additional strengths and limitations of computationally derived data for research [1].

Clinical Relevance Statement

Data synthesis platforms like MDClone are expected to enhance the N3C community's ability to use clinical data for faster COVID-19 insights and reduce barriers to data access by multiple stakeholders.

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The N3C data transfer to NCATS is performed under a Johns Hopkins University Reliance Protocol IRB00249128 or individual site agreements with the National Institutes of Health (NIH). The N3C Data Enclave is managed under the authority of the NIH; information can be found at [15].

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- Regulatory staff at data partner sites

- Individuals at the sites who are responsible for creating the data sets and submitting data to N3C

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- Publication committee review team: Carolyn Bramante, Jeremy Richard Harper, Wenndy Hernandez, Farrukh M Koraishy, Federico Mariona, Saidulu Mattapally, Amit Saha, and Satyanarayana Vedula

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Authors' Contributions

RF, JT, and AW contributed to the study conception and design; RF contributed to the generation of the data; AG and JT contributed to data analysis; authors RF, JT, AW, PROP, and NZ contributed to the writing and editing of the paper.

Conflicts of Interest

NZ is employed by MDClone Ltd. All other authors declare no competing interests.

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Abbreviations

CKD: chronic kidney disease
ITM: Institute for Translational Medicine
LR: logistic regression
NCATS: National Center for Advancing Translational Sciences
NIH: National Institutes of Health
N3C: National COVID Cohort Collaborative
OR: odds ratio
RF: random forest
ROC: receiver operating characteristic
SDOH: social determinants of health

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Original Paper

Adoption of Machine Learning Systems for Medical Diagnostics in Clinics: Qualitative Interview Study

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Abstract

Background: Recently, machine learning (ML) has been transforming our daily lives by enabling intelligent voice assistants, personalized support for purchase decisions, and efficient credit card fraud detection. In addition to its everyday applications, ML holds the potential to improve medicine as well, especially with regard to diagnostics in clinics. In a world characterized by population growth, demographic change, and the global COVID-19 pandemic, ML systems offer the opportunity to make diagnostics more effective and efficient, leading to a high interest of clinics in such systems. However, despite the high potential of ML, only a few ML systems have been deployed in clinics yet, as their adoption process differs significantly from the integration of prior health information technologies given the specific characteristics of ML.

Objective: This study aims to explore the factors that influence the adoption process of ML systems for medical diagnostics in clinics to foster the adoption of these systems in clinics. Furthermore, this study provides insight into how these factors can be used to determine the ML maturity score of clinics, which can be applied by practitioners to measure the clinic status quo in the adoption process of ML systems.

Methods: To gain more insight into the adoption process of ML systems for medical diagnostics in clinics, we conducted a qualitative study by interviewing 22 selected medical experts from clinics and their suppliers with profound knowledge in the field of ML. We used a semistructured interview guideline, asked open-ended questions, and transcribed the interviews verbatim. To analyze the transcripts, we first used a content analysis approach based on the health care–specific framework of nonadoption, abandonment, scale-up, spread, and sustainability. Then, we drew on the results of the content analysis to create a maturity model for ML adoption in clinics according to an established development process.

Results: With the help of the interviews, we were able to identify 13 ML-specific factors that influence the adoption process of ML systems in clinics. We categorized these factors according to 7 domains that form a holistic ML adoption framework for clinics. In addition, we created an applicable maturity model that could help practitioners assess their current state in the ML adoption process.

Conclusions: Many clinics still face major problems in adopting ML systems for medical diagnostics; thus, they do not benefit from the potential of these systems. Therefore, both the ML adoption framework and the maturity model for ML systems in clinics can not only guide future research that seeks to explore the promises and challenges associated with ML systems in a medical setting but also be a practical reference point for clinicians.

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KEYWORDS

machine learning; clinics; diagnostics; adoption; maturity model

Introduction

Machine Learning Systems for Medical Diagnostics

The ongoing digitalization is influencing the everyday activities of almost every individual, both in their private and professional lives. This transformation is particularly evident in health care, where the integration of health information technologies (HITs), such as electronic health records or clinical decision support systems, enables significant improvements in processes such as emergency medical care, diagnostics, and therapy [1-3]. However, the integration of HITs is not a panacea but leads to major challenges in clinics as, fueled by these technologies, physicians have to handle an ever-growing volume of patient data and complexity of interacting systems [4]. Moreover, societal problems further complicate the provision of health services to the population, as age-related diseases are on the rise because of demographic shifts and global pandemics such as the COVID-19 crisis are overburdening clinics, pushing medical personnel to the limits of their capacity [5,6].

Artificial intelligence (AI) as the “science and engineering of making intelligent machines, especially intelligent computer programs” [7] could help relieve this burden on physicians as AI is capable of solving tasks previously reserved for human intelligence [8]. In particular, machine learning (ML), as a subfield of AI, is currently one of the fastest growing technological approaches, opening up a wide range of possibilities for medicine [9,10]. Therefore, in the remainder of this research work, we focus on ML systems, that is, information systems (IS) that learn to perform certain tasks autonomously through experience without receiving explicit human instructions. Instead, ML systems use algorithms to search large amounts of data for patterns to create their own rules and strategies on how to deal with a particular problem. The identified rules can then be applied to solve a task [9,11-13]. ML systems can be particularly useful in solving problems for which the rules are difficult to derive and express. This is the case, for example, in image recognition; for instance, how can the image of a cat be explained in terms of pixels, what shapes of ears are allowed, and how can they be recognized in a picture [13]. From the prediction of patient admissions in clinics to therapy support, ML systems can help solve various problems in medicine [10,14]. However, one application area of particular value to researchers and practitioners in which ML systems could have a major impact on the overall well-being of the population is medical diagnostics [15,16]. In this context, ML systems can help identify patterns in medical data (eg, in medical scans, pathology slides, electrocardiograms, and written diagnoses) and sort possible conditions according to their likelihood [17,18]. A distinction can be made between ML serving to take over entire areas of responsibility from physicians and supporting them in their decision-making process. In the near future, ML systems will mainly be used as intelligent decision support rather than to automate medical diagnostics fully [10,17,19,20]. Thus, current cases in research and practice show that an increasing number of such assistive ML systems are presently finding their way into medical workflows. For example, ML systems are being developed, refined, and deployed to help in the early diagnosis of COVID-19 based on entered symptoms or medical images such as computed tomography scans and algorithms such as deep convolutional neural networks [21]. These systems raise the hope of making medical diagnostics of COVID-19 and also other diseases faster, more efficient, and consistent, and thus more valuable as they are able to compare patient data with a database that is larger than any physician’s experience. Consequently, applying ML systems in patient care could make the difference between life and death by enabling more effective and efficient diagnostics [10,17].

Challenges of Adopting Machine Learning Systems in Clinics

However, despite this enormous promise, the integration of ML systems also poses challenges that have prevented the widespread adoption of these systems in clinics to date [22]. More specifically, clinics cannot draw on their experience from adopting other HITs, as ML differs substantially from prior technologies. Specifically, ML systems learn from high volumes of data instead of being explicitly programmed [12]. Although traditional clinical decision support systems rely on rule-based systems that produce deterministic outputs, ML systems derive their solutions based on complex statistical methods, leading to several consequences. First, ML systems are becoming increasingly complex and commonly resemble black boxes; that is, their mechanisms for generating predictions are opaque to humans. For example, ML systems based on deep neural networks make predictions using millions of parameters, and humans cannot comprehend each and every calculation. Second, ML systems that learn from data will almost never be able to perform tasks perfectly, for example, make classifications with 100% accuracy [11,19]. This is mainly because of the ML system reliance on statistical patterns, which will never be able to cover all edge cases. Third, the operationalization of ML systems in practice is challenging, largely because complex relationships between different types of artifacts (eg, data sets, models, and source codes) have to be managed [23]. Whereas traditional clinical decision support systems rely on human-defined rules that are instantiated in software code, ML systems are a result of applying algorithms to data, thus creating an additional dependency. All artifacts have to be versioned, and their dependencies must be tracked to comply with regulations and ensure reproducibility. Owing to these complicating factors, organizations in various industries struggle to integrate ML systems into their processes. Therefore, initial research is looking at the challenges that ML systems pose in terms of organizational adoption [24-27]. However, clinics differ considerably from other organizations, as they not only possess unique structures, management processes, and requirements for HIT adoption but are also responsible for their patients’ lives [28]. In these medical settings, the characteristics of ML systems are particularly problematic as physicians and patients rely on profound diagnoses and the correct functionality of ML systems at any time [19]. Consistent with the call of Davison and Martinson [29] for more context-specific research, studies regarding the adoption of ML systems in clinics must, therefore, reflect on both, the specific characteristics of ML systems and clinics. Such context-specific research on the organizational adoption of ML systems in clinics is becoming more prevalent in recent times [10,30,31]. Thematically, researchers mainly investigate the individual acceptance of physicians [19,31] and the technical specifics of ML systems, such as their lack of transparency [32,33]. However, the problem with existing research is that most of these publications are merely reviews and rely on the personal understanding and experience of the authors. Rare exceptions are, for example, Hofmann et al [34], Sandhu et al [31], and Sun and Medaglia 35], who made use of qualitative research methods. Hofmann et al [34] examined the opportunities and challenges of ML systems in radiology, whereas Sandhu et al [31] and Sun and Medaglia [35] studied the introduction of 2 specific ML-based diagnostic decision support systems in clinics. Although these publications already offer a first insight into the possible factors along the adoption process of ML systems, they are not sufficient to understand the process in its entirety.

Objectives and Research Approach

In particular, to our knowledge, no work exists that theoretically embeds the organizational adoption process of ML systems in clinics and presents it based on empirical evidence. Rather, current research focuses on individual acceptance criteria instead of taking a holistic, organizational perspective [19,31]. Therefore, clinics lack an integral overview of the requirements that ML systems imply and that they need to address to harness the potential of these systems for their diagnostic processes. Guided by the call of Shaw et al [10] for more research on the adoption of ML systems in clinics and the lack of prior integral research, our study thus aims to answer the following first research question: which specific factors influence the adoption process of ML systems in medical diagnostics?

Moreover, previous research does not elaborate on how these factors may manifest in a range of different stages and how these stages determine an overarching maturity score. However, such a maturity model could shed further light on the adoption process of ML systems in clinics by providing an empirically grounded and operationalized construct to measure adoption progress [36,37]. Therefore, the maturity model could not only be applied in future empirical research but also allow clinics to assess their as-is situation and evaluate potential courses of action for ML adoption. Therefore, our research sets out to investigate the following second research question: how can the identified factors be used to establish a maturity model for the adoption process of ML systems in clinics?

To answer these research questions, we conducted a qualitative study based on explorative interviews (N=22) with experts working for clinics or suppliers of clinics. To structure the key findings of our empirical investigation, we referred to the health care–specific framework of nonadoption, abandonment, scale-up, spread, and sustainability (NASSS) for a conceptual basis [38]. Although this adoption framework provides a foundation, it is not sufficient to represent the full adoption process of ML systems in clinics, given the particular characteristics of ML systems. To provide a more context-specific framework [29], we drew on qualitative data to gradually adapt and expand the existing framework by several factors specific to the adoption process of ML systems for clinical diagnostics. Moreover, we used qualitative data to develop a maturity model that can help researchers and clinicians understand the possible range of ML adoption stages in clinics and determine an overarching maturity score. Overall, we aim to provide a practical reference point for clinicians to integrate ML systems more effectively into their diagnostic processes.

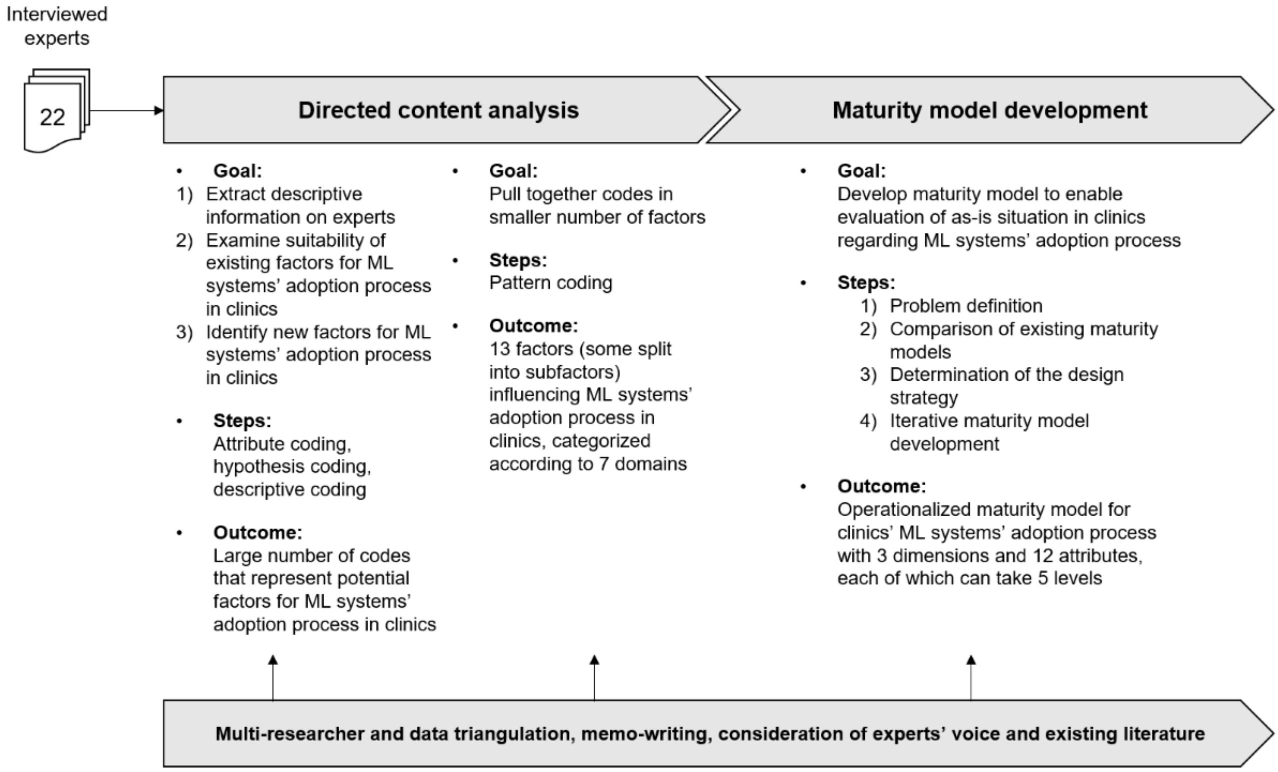
In the next section, we describe our qualitative research design, introduce directed content analysis as our basic data analysis methodology, and explain the development process of the ML maturity model in detail. We then present the empirical results of our study to provide a valuable basis for further research and guidance to clinics aiming to integrate ML systems within their diagnostic processes. Finally, we conclude by discussing the theoretical and practical implications of our study and showing perspectives for future research.

Methods

Overview

Qualitative data provide a rich source of information that can help to better understand emerging, highly complex research subjects [39]. Therefore, to understand the complex adoption process of ML systems and derive a maturity model, we used a qualitative approach to “see the world through the eyes of the people being studied” [39]. In this regard, we applied the key informant method and conducted in-depth interviews with experts (N=22) who have particular qualifications and specialized knowledge on the topic investigated [40]. We led these interviews according to a semistructured interview guideline to ensure that all relevant questions were posed. The questionnaire included general questions about the person, questions about previous knowledge in the field of ML systems, the assessment of potentials and challenges of ML systems for medicine, and further, more detailed questions about the prerequisites in clinics to adopt ML systems for diagnostics. Owing to the qualitative approach, we kept the guideline open and flexible to allow adaptations to the respective interviewed expert, their position, and knowledge base [41]. We analyzed the qualitative data with the help of *directed content analysis* [42] and the methodological approach for *maturity model development* [36]. For an overview of the research procedure, please refer to Figure 1.

Figure 1. Overview of research procedure, illustration based on Jöhnk et al [25]. ML: machine learning.



During the research process, we used several practices to obtain rigor and trustworthiness. To begin with, we defined 2 clear research questions and a conceptual framework that we used as input for our research design. Furthermore, we followed a theoretical sampling approach by iterating between data collection and analysis until we reached theoretical saturation [43]. In this way, we drew on the results from preceding interviews to select further experts and, for example, interviewed not only physicians and managers from clinics but also managers from HIT suppliers to obtain a more holistic perspective. In this regard, considering suppliers allowed us to gain an external, less biased perspective on the adoption of ML systems in clinics. Therefore, we found the additional supplier perspective to be particularly useful in triangulating the data and increasing the validity of our findings [44]. Moreover, different medical disciplines were considered in the interviews (eg, radiology, pathology, and internal medicine) to allow for different perspectives on medical diagnostic processes (eg, interpretation of medical scans, pathology slides, and electrocardiograms) and obtain more generalizable results [45]. The resulting number of interviews is comparable with those of other qualitative studies in IS health care research [31,34,46,47]. With regard to data analysis, we followed a structured and reproducible approach to evaluate the qualitative data [36,42]. During this whole process, a multiresearcher triangulation took place to include different perspectives on the research topic [44]. In that sense, we discussed all data analysis steps and results intensively with the authors and with further qualified researchers from the fields of IS, computer science, and medicine. We recorded the results of these discussions in the form of memos to make them available in the following analysis stages [48]. For later documentation of the results, we decided to include "the voice of participants" [49] and thus quote directly from the interviews while presenting our findings. Where possible, we have additionally incorporated existing—so far scattered—literature that backs up and contextualizes particular statements made by interviewed experts, thus demonstrating the relevance of the findings from the interviews [25].

Data Collection and Sample Selection

Qualitative data were collected in 2 rounds. We conducted a first round of in-depth interviews from the second to the last quarter of 2019. This round of interviews included most participants (15/22, 68% of experts) and formed the basis for content analysis and maturity model development. However, the adoption of ML systems in clinics has progressed significantly in recent times. Therefore, we conducted a further round of interviews (7/22, 32% of experts) in the first quarter of 2021 to capture potential new insights from clinics on the research subject. Moreover, we shared the identified factors and the complete operationalized maturity model with the second-round interview participants to verify and refine the findings from the first panel. All the interviews were conducted in 2 European countries (Germany and Switzerland).

To identify suitable participants for both rounds of interviews, we searched for experts in professional networks, clinic websites, and at relevant conferences on ML in medicine. We interviewed qualified experts, who had detailed knowledge of clinical processes, had profound experience with ML systems, and were involved in the respective decision-making processes [50]. Of the 22 interviewed experts, 5 (23%) were physicians, 8 (36%) held a hybrid position (ie, physicians with additional leadership responsibilities), and 9 (41) worked as full-time managers or information technology staff in the medical field. The participants worked for 11 different clinics and 5 HIT suppliers. Four clinics are privately financed, and the others are public, providing a view of both privately and publicly funded clinics. All clinics and suppliers are currently running projects related to ML. On average, each expert interview lasted 48 minutes and took place in a private space. The interviews were audio recorded and transcribed after mutual agreement. In 3 interviews, we only took notes as the participants did not consent to recording. For an overview of the experts, see Table 1.

Table 1. Overview of interviewed experts.

ID	Position	Specialty	Expertise (years)
Clinics: key informants of clinics			
C-01	Physician	Radiology	3
C-02	Physician	Radiology	15
C-03	Physician	Radiology	8
C-04	Physician	Cardiology	3
C-05	Physician	Neuroradiology	3
C-06	Physician[a]	Neuroradiology	9
C-07	Physician[a]	Internal medicine	19
C-08	Physician[a]	Internal medicine	35
C-09	Physician[a]	Pathology	18
C-10	Physician[a]	Radiology	37
C-11	Physician[a]	Gynecology	40
C-12	Physician[a]	Otolaryngology	25
C-13	Physician[a]	Cardiology	12
C-14	Chief technology officer	Cardiology	8
C-15	Chief technology officer	Biomedicine	20
C-16	Director	Internal medicine	12
Health information technology (HIT) suppliers: key informants of clinics' HIT suppliers			
S-01	Director	Nephrology	20
S-02	Director	Biomedicine	22
S-03	Director	Genetics	10
S-04	Head of research and development	Radiology	2
S-05	System-engineer	Pathology	3
S-06	Innovation project lead	Surgery	3

[a] Physician with leadership responsibilities.

Directed Content Analysis

Our first goal was to identify the factors that are specific to the adoption process of ML systems in clinics and are not yet sufficiently covered by existing theories. As ML systems have an innovative character because of their novel, complex technical characteristics, we followed the steps of directed content analysis to extend existing theory on the adoption of innovations [42].

The process of adopting innovations in organizations is an overarching process that evolves from initial awareness of technology to a solidified interest and a subsequent adoption decision, to its implementation in the organization, and finally to continued adoption [51]. Presently, adoption research regarding HITs has started to look beyond the mere awareness of a technology to include the later stages of the adoption process [38]. In this context, ML systems own highly specific characteristics that will necessitate a significant change in the organization structure and working routines eventually [11,19]. Therefore, the whole adoption process of ML systems should be considered thoroughly. To capture this, we used the NASSS framework as a conceptual basis. NASSS has primarily been developed for the health care context by combining established health and social care frameworks and can be used to analyze the full adoption process of an HIT, including the implementation phase and continued adoption of the technology. It includes several *domains*, namely *technology* and its features, the *organization* that aims to adopt the *technology*, the *wider system* of an *organization*, the *condition* to be diagnosed and treated, the demand and supply side *value proposition* associated with HIT, and the *adopter system* consisting of patients, their relatives, and medical staff. Furthermore, it explicitly conceptualizes the *embedding* and *adaptation* of the HIT within a clinic over time [38]. Each domain, in turn, comprises several *factors* that specify the domain considered. These are, for example, the regulatory issues related to a technology (wider system) or the value a technology can have for a patient (value proposition). The suitability of the NASSS framework for the topic under study is evidenced by recent research calling for the use of the framework for empirical work on the adoption process of ML systems in clinics [30]. The NASSS framework forms the basis for our research but is insufficient to explain the specific adoption process of *ML systems* in clinics and, therefore, needs to be reconsidered. In this regard, we used the framework as a starting point, and it was adapted and expanded, taking into account the qualitative data [42].

Specifically, we applied an iterative multicycle coding process that is in line with directed content analysis, which consists of 2 coding cycles, between which we moved back and forth [52]. The first cycle comprised 3 different types of coding. Using *attribute coding* enabled us to receive descriptive information concerning the participant. *Hypothesis coding* was used to consider the prespecified conceptual framework (ie, NASSS) and to examine the suitability of existing domains and factors regarding the adoption process (eg, domain: value proposition; factor: patients' value through ML). In contrast, the *descriptive coding* approach allowed us to identify new aspects that go beyond the conceptual framework by disregarding formerly identified domains and factors. As the coding procedure during the first cycle has led to a large number of constructs, we used *pattern coding* within the second coding cycle to pull together the codes into a smaller number of factors [52]. We performed the analysis using the NVivo 12 (QSR International) software. The result of the analysis is a holistic overview of domains, factors, and subfactors that influence the adoption process of ML systems for diagnostics (see section *Factors Influencing the Adoption Process of ML Systems in Clinics*).

Maturity Model Development

In a further step of our data analysis, we aimed to use (a subset of) the factors identified during content analysis to create a maturity model that can help clinics to assess their current state in the ML system adoption process. Organizations can have different maturities with regard to the management of technologies. To determine the maturity score of an organization regarding a certain type of technology, specified maturity (assessment) models can be used [36]. These models constitute an instrument for organizations to "measure and assess domain capabilities at a given point in time" [53]. In this context, maturity models are valuable tools for organizations to assess and document their as-is state and, based on this, achieve directions for transformation and prioritization of potential investments [36,54]. Therefore, a maturity model comprises different *dimensions* that are subdivided according to specific *attributes*, each of which can take different *maturity levels*. Dimensions represent capability areas, for example, in the field of technology management, that should be exhaustive and distinct from each other. Attributes further specify these dimensions and represent practices, activities, or measures that can be taken by the organization and contribute to an organization's maturity. Levels, on the other hand, are archetypal degrees of maturity which are often represented as a 5-step sequence of stages expressed by different labels [36,55-57]. Becker et al [36] differentiated 5 levels, namely, (1) *initial*, (2) *assessing*, (3) *determined*, (4) *managed*, and (5) *optimizing*. The descriptions characterizing these levels may vary depending on the level definitions and the subject of investigation. However, in general, an attribute is considered to be at an *initial* (1) level if the processes investigated are still in their infancy, chaotic, and not consciously controlled by the organization, whereas the most advanced level *optimized* (5) stands for those attributes whose processes are already actively and continuously improved with the help of standardized feedback mechanisms [55,58]. The overall maturity score of the organization, which can take one of the 5 levels described, results from the compilation of the individual attribute levels.

In recent years, maturity models have made their way into the health care sector. A literature review conducted by Carvalho et al [59] showed that clinical researchers and practitioners have established and applied various specified maturity models to understand and evaluate the integration of different HITs. However, there are no studies in the existing literature or insights from practice on a specific maturity model related to ML systems in clinics. To create a new maturity model for the ML adoption process in clinics, we followed the systematic development process outlined by Becker et al [36], which is loosely based on the design science methodology of Hevner et al [60]. This methodological approach includes 4 steps that structure the development of maturity models and 4 more that accompany the application of maturity models in practice. As our primary goal was to create a maturity model for the adoption process of ML systems in clinics rather than the subsequent application of the model in clinical practice, we focused primarily on the first 4 steps.

The first step of the maturity model development process by Becker et al [36] is to define the problem underlying maturity development. The aim of this study was to provide researchers and clinics with the opportunity to evaluate the clinic status quo in the adoption process of ML systems. As clinics still struggle to integrate ML systems into their processes, we consider this problem particularly relevant and topical [22]. After defining the problem domain and the target group, we searched for existing maturity models from adjacent research fields. In particular, we identified 3 maturity models that, although not specific to clinics, are drawn from the field of AI: the *artificial intelligence maturity model* by Alsheibani et al [61], the *five maturity levels of managing AI* by Lichtenthaler [62], and the *machine learning maturity framework* established by Akkiraju et al [63]. All of them use a 5-level maturity scale ranging from an *initial* (1) level to *optimized* or *integrated* (5). Although the framework by Akkiraju et al [63] was strongly technically oriented, Alsheibani et al [61] and Lichtenthaler [62] incorporated a management perspective as well. Although the identified maturity models helped provide a structure for the model to be built (eg, levels and potential attributes) and specific wordings that could be used (eg, "no data exist to train AI" [61]), no model is complete in itself or tailored to clinics. As clinics are highly specific in their structures and processes [28], we took initial ideas from the existing models but widely supplemented and concretized these ideas with the help of the content analysis results. In particular, we designed a new maturity model that is specific to ML adoption in clinics, but which incorporates some basic structures and descriptions from existing models. In the following core step, the actual development of the maturity model takes place. We adopted an iterative approach that included 4 substeps: design-level selection, approach selection, model design, and testing. In total, 3 iterations were performed to develop the maturity model. In the first iteration, the existing maturity models and the results of the directed content analysis were considered to build a basic concept. In the second iteration, additional researchers from the field of IS and computer science were brought in to discuss and optimize the maturity model. In the third round, the maturity model was shared, discussed, and tested with 8 of the medical experts [36]. Within these iterations, we decided to adopt a multidimensional maturity assessment based on the results of the previously conducted content analysis. In particular, a subset of 3 domains was used for the dimensions of the maturity model; the corresponding factors or subfactors form 12 attributes that further specify these dimensions. Thereby, only those domains and factors were selected that clinics can modify themselves and are not set by external forces that are beyond the clinics' reach (eg, from the wider system). The resulting attributes were then populated with individual-level descriptions using the qualitative interview data. Therefore, we started with the 2 extreme levels *initial* (1) and *optimized* (5) for each attribute, and the formulations for the levels in between were derived from the interview data, the existing maturity models and literature, or logical inference. The complete maturity model, including dimensions, attributes, and levels, was then discussed with 8 of the medical experts, who confirmed its comprehensiveness, consistency, and adequacy. Following Joachim et al [64], the maturity model was mathematically operationalized to enable clinics to calculate an overall maturity score. In addition, we have developed a web application for using the maturity model that clinicians can apply to calculate their maturity level in the process of ML system adoption. The result of these iterative development steps is an evaluated applicable maturity model that can help researchers and clinics assess the current state of clinics in adopting ML systems (see section *A Maturity Model for ML Systems in Clinics*).

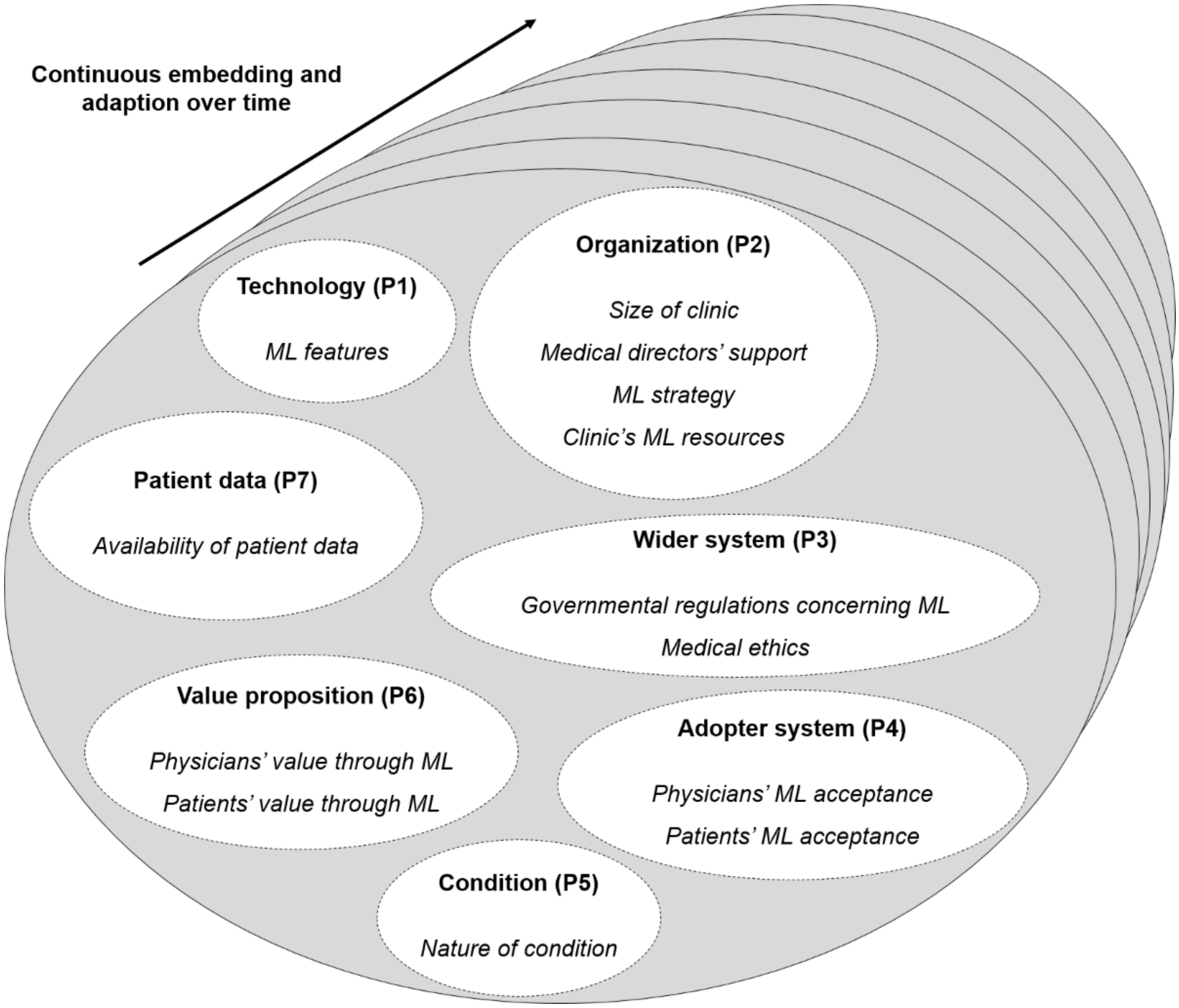
Results

Factors Influencing the Adoption Process of ML Systems in Clinics

Overview

As diagnostic procedures can differ within different medical specialties, the data analysis focuses on common factors that affect the adoption process of ML systems for diagnostics in clinics and can be derived across all disciplines. An integrative overview of these factors is shown in Figure 2. In the following section, we present and discuss the results of our directed content analysis. For this purpose, we structured our findings according to the domains: technology, organization, wider system, adopter system, condition, value proposition, and the new domain patient data. The aforementioned domains interact with each other to enable the continuous embedding and adaptation of ML systems in clinics over time [38,65,66]. In line with the existing literature, we thus did not formulate a separate domain to address the deep integration of ML systems across time. Rather, we assumed the embedding and adaptation over time to be a dynamic process in which, depending on the phase in the adoption process, specific domains and associated challenges are particularly relevant.

Figure 2. Integrative framework for the adoption process of machine learning systems in clinics. ML: machine learning.



Technology

The features of technology are factors that are already considered within the original NASSS framework [38]. Nevertheless, as outlined earlier, ML systems encompass several highly specific characteristics that cannot be compared with those of other HITs. Therefore, the existing general technical features factor is not sufficient to capture the properties of ML and has to be specified further.

As one subfactor of *ML features*, the interviewees pointed out the *lack of transparency* of ML systems as a major obstacle for the clinic's adoption of ML systems. ML systems based on neural networks can consist of multiple processing layers and up to billions of numerical weights, hampering the comprehensibility of ML systems to humans [11,32,33]. Especially in high-stakes decision-making processes such as medical diagnostics, this can lead to major issues, as ML systems do not always provide correct suggestions (S-05). As a result, the experts state that physicians need to know exactly what the critical features considered by ML systems are and how identified patterns lead to conclusions. This is required so that physicians can assess the ML system's recommendations and suggest an appropriate diagnosis and therapy. One of the experts underlines this aspect:

> *You will never make these existential decisions dependent on a black box, where it is not possible to understand what led to the recommendation.* [C-08]

Another subfactor of ML features is the *ability to adapt* their functioning if being retrained on novel data. This can become relevant either when the ML system is transferred to another context (eg, another clinic) or needs to be retrained after some time; for example, new medical research results are gained or the patient demographic structure shifts. Clinics thus have to deal with an opaque system that is able to change its reasoning, making the outcome of an ML system unpredictable. Accordingly, experts see the adaptability of ML systems as another factor that has to be addressed by clinics (C-08, S-01, S-03, and S-05). To adopt ML systems, clinics need to have a clear strategy in place on how to cope with the opacity and adaptability of self-learning ML systems. Thus, we state our first proposition:

- P1: The features of ML systems (ie, lack of transparency and adaptability) will impede their adoption in clinics.

Organization

Looking at the organization domain, 4 factors emerged during the interviews. These are the *size of a clinic*, *medical directors' ML support*, *ML strategy*, and *clinic's resources for ML*.

The size of a clinic is a newly identified factor that was not specifically considered in the original NASSS framework. However, the interviewed experts emphasize that small clinics usually have fewer resources than large clinics, which could hamper the adoption of ML systems (C-15). In the specific context of ML systems, larger clinics further care for a higher number of different patients and thus have access to more patient data, which are needed to train ML systems appropriately (S-01).

Furthermore, experts state that clinic medical directors need to support the adoption of ML systems for diagnostic processes to guarantee financial and nonfinancial support for the new technology (C-03). In this regard, ML systems for medical diagnostics affect the core business of clinics and thus have strategic relevance [67]. As medical directors develop the clinic's strategy, they are responsible for paving the way for the readiness of clinics to adopt ML systems. This is in line with prior research that states the significance of medical directors' support regarding the adoption of strategically relevant HITs in clinics [68,69].

As ML systems are a strategically relevant innovation, not only is the support of the directors necessary but also the establishment of an overarching, long-term ML strategy. The importance of an innovation strategy is also confirmed by an expert who emphasizes its relevance, especially against the background of the adoption of ML systems in a hospital network:

> *When I want to launch it to the 1900 other hospitals, I have to think about a classic transformation strategy.* [C-16]

Such a strategy should include a plan of structured activities that contribute to the successful adoption of ML systems over time and should be supported by the clinic's medical directors (C-03).

One of the most frequently stated factors within the domain organization is the clinic's resource. This factor is similar to the factor capacity to innovate already included in the original NASSS framework but is subdivided into novel subfactors (ie, *clinic's technical infrastructure*, *clinic's financing structure*, and *clinic's medical and ML methods expertise*). In line with existing literature [10,70], some of the experts report that clinics frequently rely on a wide range of clinical legacy systems, which are often proprietary to the suppliers, not connected, and based on outdated software and hardware:

> *The primary challenge [...] is that the clinic usually consists of [...] million proprietary systems that are not connected.* [C-01]

This difficulty is not only present within the clinic itself but also translates to the interorganizational level. Although some experts state that their clinics already have some special data networks in place, almost half of the experts stress that health care organizations have not yet connected their data to systems in and outside the clinic (C-01, C-03, C-04, C-05, C-06, C-08, C-09, C-13, C-15, and S-04). However, experts emphasize the importance of having a high-performance technical infrastructure that can efficiently access data from multiple sources, for example, via secure internal (within clinic) and external data networks (eg, clinic-to-primary care), which has the computing capacity needed to train ML systems (C-01, C-03, C-04, C-05, C-09, C-13, and S-04). Therefore, a clinic's existing technical infrastructure could pose a major challenge to the adoption of ML systems.

Furthermore, the interviewed experts pointed out the problem of the current financing structure of clinics, which leads to strict budgetary constraints, especially in publicly funded institutions (C-04, C-05, C-11, C-12, and C-13). In this regard, an interviewee states that one part of their budget is assigned to daily costs, such as medication. The other part of the budget can be used to purchase large-scale medical equipment, such as x-ray systems. Thus, the development and setup of ML systems are not covered by either of the 2 parts, and often, no specific ML budget can be claimed (C-08).

Beyond that, there is a lack of personnel in clinics having expertise in both medicine and ML methods such as data science or data engineering:

> *The shortage of medical specialists hits us twice as hard. We feel this at the medical professional side [...], but it is also very apparent at the technical side.* [C-14]

Both fields of knowledge are regarded as highly important for the adoption of ML systems by many experts (C-01, C-04, C-05, C-14, and S-02). Although a medical background can help identify relevant training data or assess the functionality of the ML system, ML method expertise is needed to train, integrate, and operate ML systems as presently, only scattered out-of-the-box ML systems exist for application in medicine, requiring clinics to develop and maintain ML systems by themselves (C-01, C-14, and S-02). Therefore, clinics need specific expertise in the field of ML methods in addition to their medical understanding to develop, set up, and run ML systems in clinics. In sum, we propose the following:

- P2: A larger clinic size, medical directors' ML support, formulation of an ML strategy, and availability of resources for ML (ie, technical infrastructure, ML budget, expertise in the field of medicine, and ML methods) will facilitate the adoption of ML systems in clinics.

Wider System

With regard to the wider system, there are 2 relevant factors influencing the adoption of ML systems: *governmental regulations concerning ML* and *medical ethics*. Governmental regulations are a factor already known from the original NASSS framework. Nevertheless, the interviews revealed some particularities that were not covered by the general concept and are described below. Medical ethics is a factor that has not been captured by the NASSS so far but has been identified through our study.

In the field of medicine, there are several governmental regulations that must be taken into consideration when adopting ML systems. The following subfactors could be identified: *medical approval of ML systems*, *accountability*, and the *protection of sensitive personal data*.

The experts drew attention to the fact that HIT offered in the market and used in clinics is subject to several laws. This includes the need for medical approval conducted by legal authorities or HIT suppliers themselves (C-03, C-05, and C-12). In the United States, the Food and Drug Administration is responsible for the admission of medical products. In Europe, the HIT suppliers themselves need to perform a conformity assessment procedure, for example, based on the Medical Device Regulation [71,72]. As mentioned before, most ML systems are currently being developed by the clinics themselves and have not undergone any approval process (C-03). However, legal approval of ML systems is not trivial, as the systems can learn from new experiences and adapt themselves as described above:

> *It is not obvious how evidence can be obtained for an [ML] model that differs significantly at the beginning, middle, and end of the study. If you want to approve a medical device today, you have to describe the intended use in detail.* [S-01]

The Food and Drug Administration addresses this legal uncertainty in an official statement that proposes an action plan for innovative approaches to more effectively approve adaptive ML systems [72]. The European Medicines Agency is also still in the early stages of defining and establishing an approval process for ML systems [73]. Therefore, legal ambiguities could represent a hurdle for clinics to adopt ML systems for diagnostics.

In addition to the medical approval of an ML system, there is the question of accountability for diagnoses. The experts interviewed indicated that it is questionable who takes over responsibility if the diagnosis prepared by an ML system is inaccurate (C-06, C-14, and S-05). It is also unclear who can be held liable—the HIT provider, the clinic, or the physician who is providing the medical diagnosis. An expert underlines this aspect with the following words:

> *Then there are certainly [...] legal problems, for example: who is responsible for the interpretation and possibly wrong results of the ML model?* [C-14]

According to the current state of the art, ML systems cannot be held responsible for their output, as a registered physician is always obliged to validate and interpret the system's results and perform the final diagnosis (C-16). However, it would ease the decision of clinics to opt for ML systems if there were a legal specification, especially if ML systems are increasingly able to automate steps of sensitive processes such as diagnostics (C-14 and C-15).

Another subfactor of governmental regulations, which could be identified as relevant for the adoption process of ML systems for diagnostics, is the protection of sensitive personal patient data. Patient data are widely considered as highly sensitive [74] and are under special protection by national and international laws (C-02, C-04, C-13, S-02, and S-05). For example, the General Data Protection Regulation in Europe only permits the processing of health data if the patient explicitly accepts or if the clinic can provide particular reasons for the use of the data [75]. Thus, the respondents emphasized the clinics' concerns in obtaining the necessary patient data to train the ML system (C-02, C-10, and S-06).

Using ML systems for diagnostic processes fueled medical ethics concerns among interviewees. On the one hand, ML systems are able to improve the efficiency and effectiveness of diagnostics (C-15, C-16, and S-02) and, on the other hand, the suggestions provided by ML systems are deduced based on statistical methods that recognize patterns in patient data that can be biased (C-15). Furthermore, the experts claimed that ML systems that are fed with patient data could determine whether a patient tends to develop a disease. This type of medical application would contradict the "patient's right not to know" (C-15). Summarizing these remarks, we set up the proposition:

- P3: Uncertainties in governmental regulations, strict requirements for the protection of sensitive patient data, and existing medical ethics will impede the adoption of ML systems in clinics.

Adopter System

The NASSS framework suggests that the successful adoption of ML systems is strongly influenced by individuals who are supposed to use the system or are affected by their suggestions. In this context, 2 ML-specific factors turned out to be relevant according to the interviews, which further specify the domain: *physician* and *patient ML acceptance*.

More than half of the interviewed experts stated that physicians' acceptance is essential for the adoption of ML systems in clinics (C-01, C-02, C-03, C-05, C-06, C-08, C-09, C-12, C-14, C-15, S-03, and S-06). As ML systems have the ability to solve tasks that were previously performed by humans, physicians might feel interchangeable in their job (C-03, C-07, S-03, and S-05). ML systems are trained on large sets of data that exceed the experience of any single physician, setting new standards for medical diagnostics. In this regard, most experts are concerned that physicians could reject ML systems for their daily work:

> *As a doctor who may have ten or 20 years of experience [...], would I like to be taught by a machine [...]?* [S-03]

These concerns have recently found their way into pertinent research, demonstrating the relevance of the topic [19,30,31,34]. However, it is also evident that the acceptance of ML systems differs among different age groups. In particular, physicians who belong to the group of digital natives are more willing to understand and ultimately use ML systems (S-04 and S-06).

Most interviewees stated the importance of patients' views on the use of ML systems for medical diagnostics. Although a physician is still involved in the decision-making process, patients might refuse the use of an ML system as the physician may be influenced by suggestions for possible conditions that are derived statistically and could be affected by biases. Furthermore, personal, sensitive patient data have to be processed to gain results. Therefore, experts state that patient acceptance of ML systems is highly relevant for the adoption of ML systems for diagnostics (C-02, C-06, and C-14). We thus conclude the following:

- P4: Physicians' and patients' acceptance of ML systems will facilitate the adoption of ML systems in clinics.

Condition

As specified within the NASSS framework, patient condition affects the applicability of a technology. This is not only the case for conventional HITs but also holds true for ML systems, as stated by the interviewed experts (C-02 and C-09). ML systems have a narrow focus and can only deal with specific delimited problems [11,12]. However, the human body is a highly complex and not fully understood system that can hardly be delineated. Medical conditions can be complex, poorly understood, or even unpredictable, for example, when multiple comorbidities are involved, making it difficult for ML systems to provide a clear diagnostic recommendation (C-02 and S-02). Therefore, the nature of the condition affects the applicability of ML systems, which can only handle delimited problems in the diagnostic process. Thus, the use of ML systems will be limited to the diagnosis of certain conditions:

- P5: The limited applicability of ML systems for the diagnosis of specific conditions will impede the adoption of ML systems in clinics.

Value Proposition

The value proposition is another domain of the NASSS framework that we were able to concretize by analyzing the interviews. According to the experts, the adoption of ML systems could result in the creation of *value for* both *physicians* and *patients* (C-03, C-10, and C-14).

Integrating ML systems in their daily work enables physicians to improve the effectiveness and efficiency of their diagnostics as they can base their decisions on a broad database that is evaluated within a few seconds (C-16):

> *If you have the choice among a pathologist who has already looked at 10,000 cuts [...] compared to one who has created only 500 findings, whom would you chose? But [...] AI has not only 10,000 but 500,000 findings in its memory.* [C-08]

In this regard, ML systems that are, for example, based on image recognition algorithms can surpass the ability of the human eye to capture details and patterns in x-rays [76]. If used for a second opinion, ML systems thus increase the quality of physicians' work (C-02 and C-11).

In addition, patients could directly benefit from a decision that is faster and more informed if physicians use ML systems for diagnostics as a supportive tool (C-10 and C-16). We thus propose the following:

- P6: The additional value for physicians and patients created through ML systems will facilitate the adoption of ML systems in clinics.

Patient Data

During the interviews, nearly all experts stated the *availability of patient data* as crucial for the adoption of ML systems for diagnostics. In this regard, patient data have to be available to develop and train the ML system in the first place and subsequently retrain it during use. This factor comprises various subfactors (ie, *digitization of patient data*, *unified data formats*, *data quality standards*, *data anonymization*, and *representativeness of training data*) which are described in the following section.

According to the experts, most clinics generate high volumes of patient data through their daily diagnostic processes (C-03, C-05, S-01, S-04, S-05, and S-06), which is basically a positive feature as an appropriate amount of data is needed to train ML systems [11,20,35,77]. However, although high volumes of data are generated, many processes in clinics are still paper-based, which lowers the proportion of patient data available in digitized form:

> *Data are often not digitized, much is still in paper files, not structured, which means that the data availability is really extremely [...] poor.* [C-03]

This observation is in line with prior research concerning clinics that are lagging behind at using digitized technologies and digitizing patient data [1]. As a consequence, the interviewed experts see the integration of an electronic medical record system as a prerequisite for the application of ML systems (C-16, C-03, C-04, and C-13).

Furthermore, interviewing the experts revealed that medical patient data, if available in digitized form, are usually provided in a variety of proprietary data formats as many disparate clinical legacy systems from different suppliers have to interact to enable physicians to provide laboratory tests, diagnostic images, or clinical notes. These proprietary data formats are often difficult or impossible to convert, making the generation of consistent formats highly problematic (C-03, C-04, and S-04). The problem of differing data formats in clinics has already been recognized outside the ML context, for example, in research on the adoption of cloud solutions in health care environments [78]. Nevertheless, it is particularly critical for the introduction and use of ML systems that the patient data be processed for training and retraining the system. Although the first research has been conducted to allow for the transformation of different medical data types in one format [79], most clinics have not yet been able to implement unified standards for patient data to enable processing and analysis by ML systems.

Furthermore, digitized patient data are often stored in unstructured file types, such as images, texts, or videos (C-01, C-03, C-07, C-13, C-15, and S-04). The experts cautioned that the quality of unstructured data is highly dependent on the particular clinic where the data are generated and their clinical staff (C-06, C-07, and S-04). For instance, physician letters are frequently written in free text formats, which are filled with synonyms and can be interpreted individually. More specifically, personal formulations are used, such as the description of a tumor size as compared with that of a walnut (C-07). Thus, patient data are not only hard to harness and have to be transferred to a machine-readable format first (C-03 and C-04) but also lack common quality standards (S-04), impeding the extraction of generalizable patterns through ML. Clinics aiming to adopt ML systems to support their diagnostics should therefore set standards for data creation, for example, by establishing a common language that physicians use when creating free texts. Such efforts are already being driven by some in-clinic as well as national initiatives (C-12 and C-16). In addition, other primary structured data sources could be connected, such as data from laboratory findings, to complement the unstructured data [80].

Moreover, the experts strongly emphasize that clinics that want to use patient data to train ML systems need to anonymize the sensitive data before processing them through an ML system (C-15 and S-06). However, anonymizing data might remove valuable information, which could be important for obtaining a diagnosis. For instance, information about a person's residence could facilitate a diagnosis if a disease is more prevalent regionally (C-15). Therefore, it is necessary for clinics to find the right balance of anonymization and information value to be able to use the data despite data protection regulations and still preserve all the information necessary to find meaningful correlations through ML systems. The first steps are already being taken in technical research to balance protection and the quality of sensitive data effectively [81,82].

According to the experts, the selection of the right training data is especially important in a health care context, as wrong diagnoses may have an impact on patients' lives. This leads to another aspect of patient data to be considered: the representativeness of training data. Patients in clinics vary in many aspects, from an outer perspective (eg, age, gender, and hair color) as well as from inner functioning (eg, size of organs and blood values; C-01 and S-05). If ML systems are trained based on an external database (eg, collected via data exchange) that is demographically or regionally skewed compared with the clinic's conditions, false conclusions could be drawn by the system. In this context, an expert raised the example of an ML system supporting the detection of skin melanomas, which is mainly trained on a sample of patients with a similar phenotype. Therefore, this pretrained ML system cannot be easily transferred to patients of other ages or with other skin pigmentations (C-01). In addition, the representativeness of the data is affected when different clinical systems, such as different radiographic systems, collect data as the resolution of the medical equipment may vary from provider to provider (S-04). As training data for supervised learning need to be labeled by humans, the same could be said regarding the expertise and working philosophy of physicians, which could be highly heterogeneous depending on the physician's knowledge state and working environment (C-09, C-14, and S-05).

The availability of patient data is a factor that is decisive for the adoption process of ML systems that need to be fed and retrained:

- P7: The availability and exchange of a large amount of digitized patient data for training (that are uniformly formatted, of high quality, anonymized but informative, and representative of the clinic) will facilitate the adoption of ML systems in clinics.

A Maturity Model for ML Systems in Clinics

Overview

Against the background that no maturity model for the adoption process of ML systems in clinics could be found in research and practice, we created a concept for a maturity model and present the model below. On the basis of our empirical results, the model is intended to enable researchers and clinics to quantify the overall maturity of clinics within the adoption process of ML systems. We followed the design process of Becker et al [36] to conceptualize a maturity model that comprises 3 dimensions and 12 attributes, each of which is operationalized by 5 corresponding levels (Multimedia Appendix 1). The dimensions and attributes are derived from a subset of the results presented in the previous section, whereby the dimensions were inferred from the domains and the attributes from the factors or subfactors that can be modified by the respective clinic itself. Specifically, the dimensions organization (P2), adopter system (P4), and patient data (P7) and their respective subfactors were taken into account, as these can be controlled by the clinic itself, whereas the technology (P1), the wider system (P3), the condition (P5), and the value proposition (P6) are influenced by factors that are not in the hands of a single organization.

It is necessary to operationalize the model mathematically to render the maturity model applicable for research and practice. To this end, we followed the approach of Joachim et al [64], which has already been used for the operationalization of other maturity models (eg, in the area of business intelligence [83]). We assume that maturity evolves linearly in 5 levels $l \in L$ with L={1,2,3,4,5}, starting with *initial* (1) and ending with *optimized* (5) [83]. The maturity model for the adoption of ML systems in clinics consists of 3 dimensions, d, each of which consists of a set of attributes I_d in turn. Therefore, the overall maturity score of a clinic is composed of the maturity score of all dimensions, whereby the maturity of each dimension d depends on the maturity within the corresponding attributes $a \in I_d$. As a clinic can have different maturities in the different dimensions and attributes of a dimension, a stepwise estimation of the overall maturity score must be made. Therefore, a two-step process is followed in which (1) the *maturity score of the dimensions* (ie, Mat_a) is determined first based on the respective attributes, followed by (2) the calculation of the *overall maturity score of a clinic* (ie, Mat).

Maturity Score of the Dimensions

At the lowest layer, each attribute a can take a value $x_a \in A$ with A={1,2,3,4,5} depending on the actual maturity of the clinic regarding the attribute, ranging from initial (1) to optimized (5). To determine the actual maturity value of each attribute in a dimension, a clinic must assess its own as-is situation by comparing the level descriptions (within each attribute) with their current adoption state in the clinic (Multimedia Appendix 1). For example, a clinic has a maturity value of x_a=1 for the attribute *digitization of patient data* if it has nearly no digitized data available for training ML systems and is thus at an initial level of maturity. In the next step, all maturity values x_a of the attributes within a dimension d are compared with all possible maturity levels l to determine the level with the smallest distance to the set of attributes of a dimension. To operationalize the comparison, a weighted Euclidean distance metric $Dist_d(l)$ is used in line with prior research [64,83]:

$$Dist_d(l) = \sqrt{\textstyle\sum_{a \in I_d} (x_a - l)^2} \text{ for } 1 \le d \le n_d = 3 \text{ and } 1 \le l \le n_l = 5 \quad (1)$$

where n_d represents the total number of dimensions and n_l is the total number of levels. As a result, each clinic receives 5 distance values (for 5 levels, l) per dimension. To obtain the maturity score of a dimension Mat_d, the level m associated with the minimum of these distance values needs to be selected per dimension:

$$Mat_d = m, \text{such that } Dist_d(m) = \min_{1 \le l \le n_l} (Dist_d(l)) \text{ for } 1 \le m \le n_l = 5 \quad (2)$$

Overall Maturity Score of the Clinic

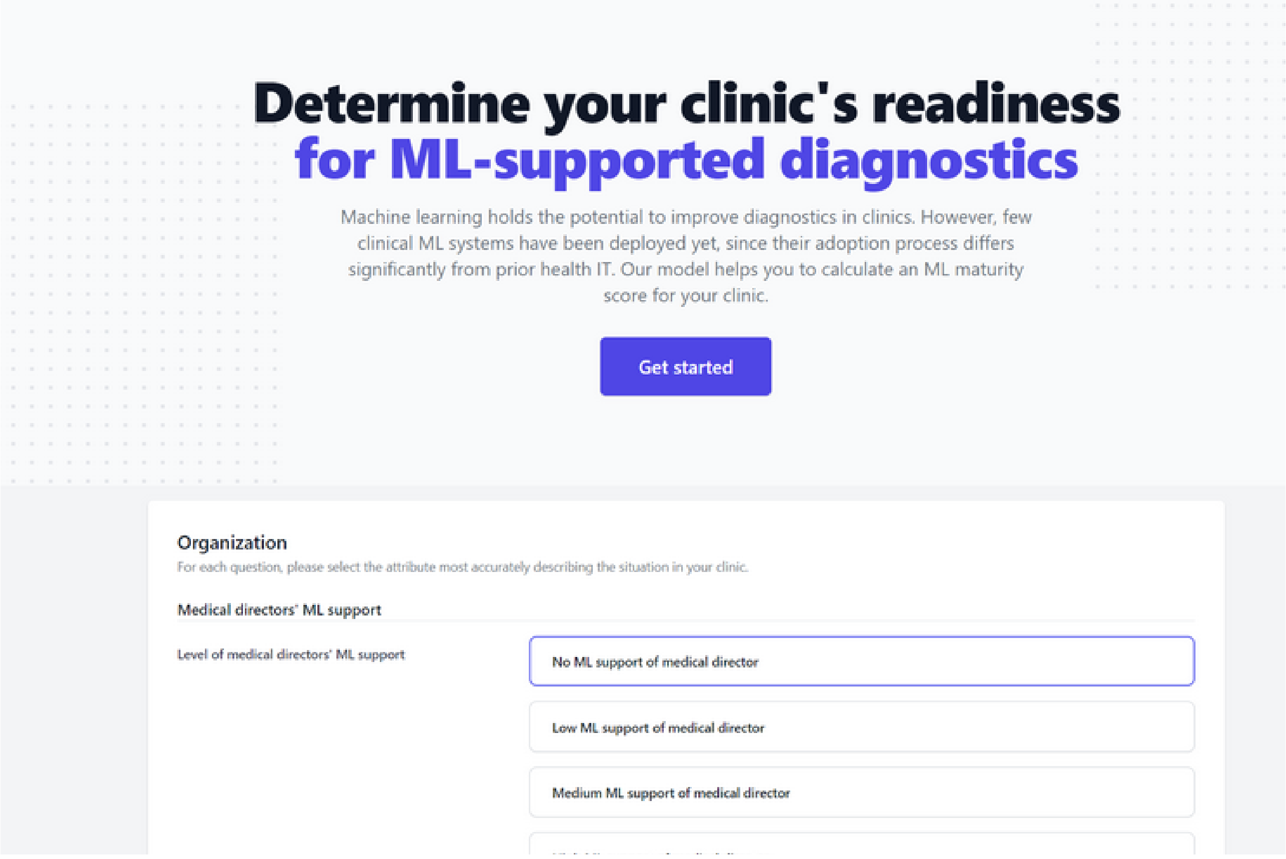
On the basis of the distinct maturity scores Mat_d of the 3 dimensions, the overall maturity score Mat can be calculated in the second step. Again, we use a Euclidean distance metric $Dist(l)$ to compare the maturity scores of the dimensions with levels l (Equation 3). The final overall maturity score of a clinic striving to adopt ML systems is determined by the minimum distance (Equation 4):

$$Dist(l) = \sqrt{\textstyle\sum_{d=1}^{n_d=3} (Mat_d - l)^2} \text{ for } 1 \le l \le n_l = 5 \quad (3)$$

$$Mat = m, \text{such that } Dist(m) = \min_{1 \le l \le n_l} (Dist(l)) \text{ for } 1 \le m \le n_l = 5 \quad (4)$$

To make the maturity model easily applicable for practitioners from clinics and researchers in the field of adoption science, we have developed a free-access web application based on the described mathematical operationalization, which calculates the maturity level of a clinic based on a questionnaire (Figures 3 and 4). This questionnaire includes the attributes as well as their level descriptions and is provided on the web [84].

Figure 3. Determine your clinic's readiness for machine learning–supported diagnostics (screenshot 1 of the web application). ML: machine learning.



Determine your clinic's readiness for ML-supported diagnostics

Machine learning holds the potential to improve diagnostics in clinics. However, few clinical ML systems have been deployed yet, since their adoption process differs significantly from prior health IT. Our model helps you to calculate an ML maturity score for your clinic.

Organization

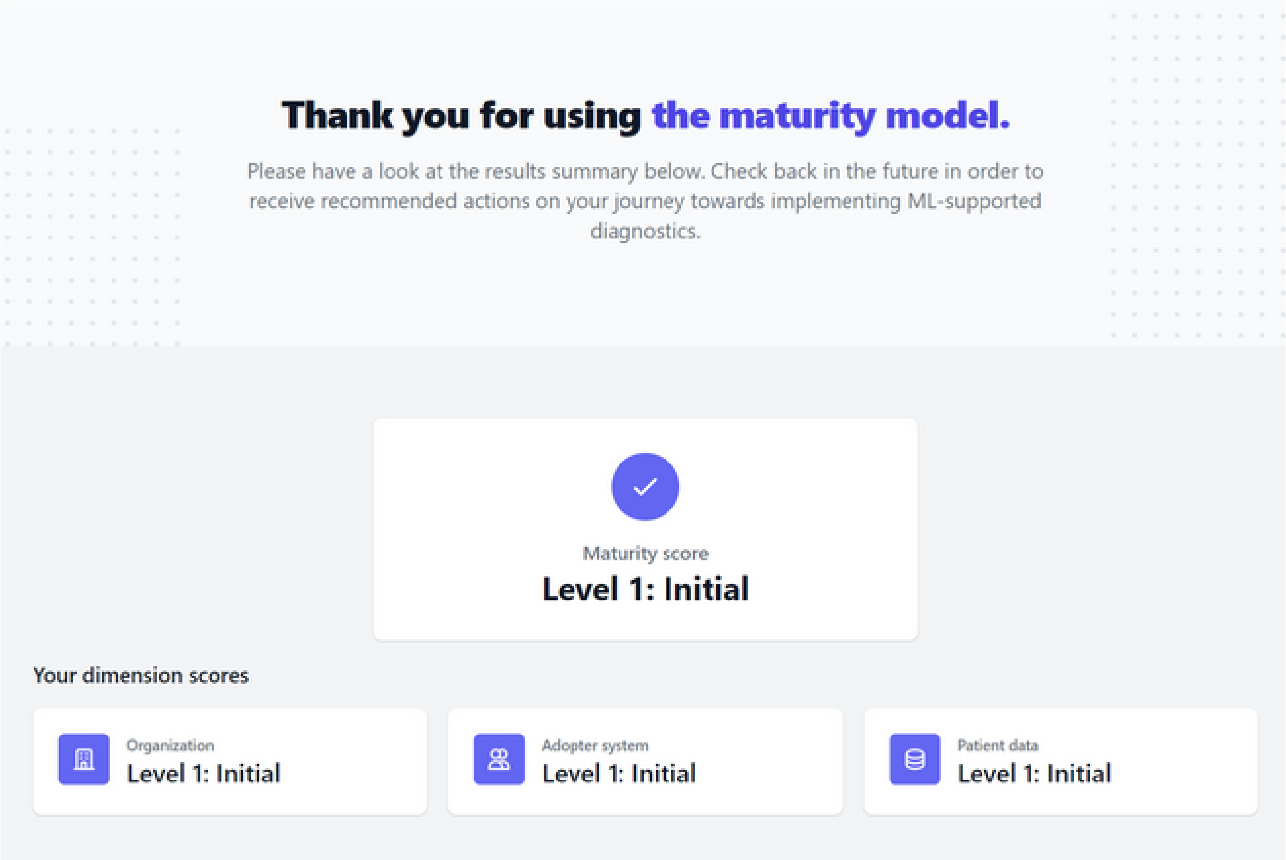
For each question, please select the attribute most accurately describing the situation in your clinic.

Medical directors' ML support

Level of medical directors' ML support

- No ML support of medical director
- Low ML support of medical director
- Medium ML support of medical director

Figure 4. Thank you for using the maturity model (screenshot 2 of the web application). ML: machine learning.



Thank you for using the maturity model.

Please have a look at the results summary below. Check back in the future in order to receive recommended actions on your journey towards implementing ML-supported diagnostics.

Maturity score
Level 1: Initial

Your dimension scores

Organization
Level 1: Initial

Adopter system
Level 1: Initial

Patient data
Level 1: Initial

Discussion

Principal Findings

ML has an impact on all areas of human life, including the health care system. In this regard, ML systems offer the opportunity to make diagnostics more efficient and informed. However, to harness ML for such an application, clinics need to deeply integrate ML systems into their clinical practice, a challenge that most clinics have not yet been able to overcome [20]. As clinics own highly individual, patient-oriented processes, it is crucial for researchers to reflect on this specific context [28,29]. However, prior research is lagging behind to provide empirically proven factors that influence the adoption process of ML systems in clinics for diagnostic processes. To address this shortcoming, we set up a qualitative study to (1) establish an integrated overview of factors specific to an ML system adoption process in clinics based on the NASSS framework and (2) create an operationalized maturity model that clinics can apply to assess their as-is state of ML adoption progress to decide on further actions and prioritize investments.

Limitations and Future Research Opportunities

Before we discuss our contributions to theory and practice in detail, it is necessary to clarify the limitations of this study and show room for further research. As we pursued a qualitative approach, our results are based on the expertise of the 22 interviewees. To counteract potential problems of generalizability, we have not only applied various criteria to ensure rigor and trustworthiness of our study (eg, theoretical saturation, multiresearcher and data triangulation, and inclusion of multiple medical disciplines) but also carefully selected only highly involved experts. Nevertheless, it might be interesting for further research to perform a follow-up study to validate the proposed framework and maturity model quantitatively. In this regard, it might be informative to evaluate the derived maturity model by applying it in clinics. In doing so, it could also be investigated whether practitioners attach different importance to attributes and dimensions. On the basis of these findings, the maturity calculation could be adjusted by introducing weights for attributes and dimensions.

Moreover, we conducted the interviews in only 2 European countries. As health care systems vary across nations, interviewing experts from other regions with different economic and cultural prerequisites could lead to differing results. Nevertheless, the relevance of the findings for the international context was substantiated with the help of existing literature and practice contributions from international authorities, which are cited in the *Results* section. For example, the report of the Food and Drug Administration shows that the issue of medical approval of ML systems is also being discussed in the United States [72]. However, replication of this study in other countries would be useful to highlight possible differences within the adoption process of ML systems in clinics.

In addition, the rapid development of increasingly advanced ML algorithms could lead to systems that can not only augment but also automate diagnostic processes. Investigating automated diagnostics, which has not yet been applied in clinics, could produce different findings, although the results obtained in this study could provide first indications.

Theoretical Contributions

Despite the limitations discussed, our study makes several important contributions to research. To begin with, we demonstrated that the NASSS framework can be applied but has to be adapted and expanded to explain the full adoption process of ML systems for diagnostics in clinics. To the best of our knowledge, this is the first study to provide an empirically proven and integrative overview of the factors determining the adoption of ML systems for clinical diagnostics and thus show what clinics need to consider to effectively integrate ML systems into their processes. Therefore, we contribute to and extend prior adoption research in health informatics, which has recently called for looking at the entire adoption process of HITs rather than just the initial awareness of the technology [38]. Although the identified factors are specific to diagnostic processes, it is conceivable that they may be applicable to other scenarios in which the cost of errors is high, such as ML-based treatment recommendations or medical prognoses in clinics.

Moreover, we have developed the first maturity model for ML system adoption in clinics, which contributes to the IS and medical body of knowledge by providing an empirically grounded and strategically derived artifact that depicts medical and ML-specific attributes and their level descriptions in detail. More specifically, the maturity model shows which attributes determine the status quo of clinics in adopting ML systems, how these attributes may manifest in descriptors according to 5 different maturity levels, and how clinics can evaluate their as-is state in the adoption process of ML systems. Researchers can apply the developed maturity model, for example, as an instrument in statistical studies investigating the adoption of ML systems in clinics. More specifically, the model can be used to operationalize the dependent variable in structural equation models or as a variable for multigroup comparisons [85], for example, to study the antecedents of clinical adoption of ML systems. Therefore, both the adoption framework and the maturity model for ML systems in clinics can guide future health care–centric research that seeks to explore the promises and challenges associated with ML systems in a medical setting.

Practical Contributions

In addition, the empirically based results hold relevant findings for practitioners, who are increasingly facing rising health care costs, demographic changes, and overcrowding of the clinics, and thus need to improve the efficiency and effectiveness of their clinical processes. ML systems could be a solution to these problems but have so far only been sporadically integrated into clinics [22]. In fact, our qualitative study shows that most clinics still have major problems integrating ML systems into their diagnostics. In this regard, the derived framework provides medical directors with a holistic overview of potential enablers and inhibitors during the adoption process of ML systems in clinics and could provide a roadmap for practitioners.

Moreover, the developed maturity model can be used by clinics to obtain the first impression of their as-is situation in the adoption process of ML systems and to quantify it in an overall maturity score (see the website [84] to easily apply the model). Assessing the maturity score with the help of the model not only helps to make external comparisons between clinics but also to identify internal deviations of certain attributes from the overall status. This allows clinics to invest especially in these attributes that are far from the present overall performance and lower the clinic’s maturity score significantly to date. Thereby, the maturity model allows practitioners working for clinics to analyze their clinic’s current status quo, identify shortcomings, prioritize possible courses of action, and efficiently allocate scarce resources depending on the respective degree of maturity. In this way, our research can help practitioners identify tailored requirements for the successful adoption of ML systems in clinics and build relevant capabilities and resources needed in the age of AI.

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Conflicts of Interest

This paper builds on a conference paper [86]. This paper extends the earlier work, in particular by expanding the underlying sample size and developing a maturity model.

Multimedia Appendix 1

Maturity model for machine learning systems in clinics.
[PNG File , 366 KB-Multimedia Appendix 1]

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Abbreviations

AI: artificial intelligence
HIT: health information technology
IS: information systems
ML: machine learning
NASSS: nonadoption, abandonment, scale-up, spread, and sustainability

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Original Paper

Transforming Anesthesia Data Into the Observational Medical Outcomes Partnership Common Data Model: Development and Usability Study

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Abstract

Background: Electronic health records (EHRs, such as those created by an anesthesia management system) generate a large amount of data that can notably be reused for clinical audits and scientific research. The sharing of these data and tools is generally affected by the lack of system interoperability. To overcome these issues, Observational Health Data Sciences and Informatics (OHDSI) developed the Observational Medical Outcomes Partnership (OMOP) common data model (CDM) to standardize EHR data and promote large-scale observational and longitudinal research. Anesthesia data have not previously been mapped into the OMOP CDM.

Objective: The primary objective was to transform anesthesia data into the OMOP CDM. The secondary objective was to provide vocabularies, queries, and dashboards that might promote the exploitation and sharing of anesthesia data through the CDM.

Methods: Using our local anesthesia data warehouse, a group of 5 experts from 5 different medical centers identified local concepts related to anesthesia. The concepts were then matched with standard concepts in the OHDSI vocabularies. We performed structural mapping between the design of our local anesthesia data warehouse and the OMOP CDM tables and fields. To validate the implementation of anesthesia data into the OMOP CDM, we developed a set of queries and dashboards.

Results: We identified 522 concepts related to anesthesia care. They were classified as demographics, units, measurements, operating room steps, drugs, periods of interest, and features. After semantic mapping, 353 (67.7%) of these anesthesia concepts were mapped to OHDSI concepts. Further, 169 (32.3%) concepts related to periods and features were added to the OHDSI vocabularies. Then, 8 OMOP CDM tables were implemented with anesthesia data and 2 new tables (EPISODE and FEATURE) were added to store secondarily computed data. We integrated data from 5,72,609 operations and provided the code for a set of 8 queries and 4 dashboards related to anesthesia care.

Conclusions: Generic data concerning demographics, drugs, units, measurements, and operating room steps were already available in OHDSI vocabularies. However, most of the intraoperative concepts (the duration of specific steps, an episode of hypotension, etc) were not present in OHDSI vocabularies. The OMOP mapping provided here enables anesthesia data reuse.

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KEYWORDS

data reuse; common data model; Observational Medical Outcomes Partnership; anesthesia; data warehouse; reproducible research

Introduction

Observational health data collected from electronic health records (EHRs) can be valuable not only for direct health care delivery but also for secondary uses (ie, data reuse) in research, evaluating quality of care, and public health [1,2]. Concerns on data reuse include data validity and lack of reproducibility [3-5]. These concerns have driven the need for a framework to enhance the secondary use of health data [6]. To support reproducible research over a distributed research network, Observational Health Data Sciences and Informatics (OHDSI) provides the Observational Medical Outcomes Partnership (OMOP) common data model (CDM) and a full range of open-source tools and methods [7-12]. OHDSI provides database scripts for implementing the CDM on various database systems, a terminology browser to navigate through vocabularies integrated into the OMOP CDM (Athena), a data quality tool used to characterize and visualize a database's conformity with the OMOP CDM (Achilles), methods for connecting to the OMOP CDM (DatabaseConnector), methods for the extract-transform-load process (WhiteRabbit, RabbitInAHat, and Usagi), methods for data extraction and transformation (OhdsiRTools and FeatureExtraction), and methods for statistical analyses and machine learning (PatientLevelPrediction, CohortMethod, CaseCrossover, and CaseControl) [13-15].

The OMOP CDM standardizes the vocabulary and structure of EHRs and medical claims data to promote interoperability and ensure that queries can be applied consistently to distributed databases. Integration of local data into the CDM involves conceptual mapping of local concepts into standard vocabulary concepts and structural mapping of local entities to standard entities in the OMOP CDM [8,16]. The essential conceptual and structural mapping of local data is time- and resource-consuming and may also result in the loss of information [11]. However, once mapped, the data offer new opportunities [8,11]. In 2020, more than 100 databases from 20 countries (corresponding to more than 0.5 billion patients) have been integrated into the OMOP CDM [12]. Most of the data come from claims databases studied for pharmacoepidemiological purposes [17-21] or from hospital clinical databases [22,23]. In the past decade, many studies have been carried out; they include patient-level predictions and estimations of the population-level effect [24-27]. Recently, Lane et al collected data on 9,00,000 patients in 15 centers using different software packages; this highlights opportunities for collaboration between centers and for increasing the power of such studies [28].

Even though many studies have been published, some aspects of integrating data into the OMOP CDM are still challenging. Cho et al showed that semantic mapping of concepts from organ transplantation registry forms was fastidious and that OMOP concepts covered only 55% of their vocabulary [29]. Michael et al mapped only 26% of local biospecimen records to the OMOP CDM owing to missing information [30]. Researchers have suggested adapting the CDM (by adding new concepts or new fields) to support the integration of biospecimen data. Warner et al added an extension to the OMOP CDM to support cancer treatments and handle episodes of care with a higher level of abstraction than that represented in the OMOP tables of low-level clinical events [31].

In the field of intraoperative management and anesthesiology, several retrospective studies have looked for links between hemodynamic variations (eg, hypotension) in the operating theater and negative postoperative outcomes (eg, death and acute kidney injury) [32-34]. Similar results were observed for the intraoperative tidal volume ventilation administered to patients [35]. In several cases, this work has made it possible to generate hypotheses for prospective studies, the results of which then validated the proposed hypotheses [36]. These studies were mainly performed with data automatically collected by anesthesia information management systems (AIMS) [37]. However, most of the studies were performed at a small number of centers, which reduced the results' external validity. The main specific features of data recorded in the operating room are their high frequency and high degree of precision, with 1 data point saved every 30 seconds for signals like the heart rate or the intra-arterial blood pressure. Another specific feature is the ability to transform raw data into more usable information or new variables that may better describe exposure to an insult. For example, the arterial pressure signal is computed into comprehensive hypotension events, including the number of episodes, area under the curve, and average time spent within or beyond a threshold [38,39]. In terms of anesthesia data, these data warehouse–based studies can be potentially extrapolated to an international dimension, with stronger evidence through data sharing. This sharing requires the prior homogenization of vocabularies, data formats, and data quality, as promoted by OMOP. However, anesthesia data have not previously been mapped into the OMOP CDM, and the proportion of the anesthesia vocabulary that has already been mapped has not been determined.

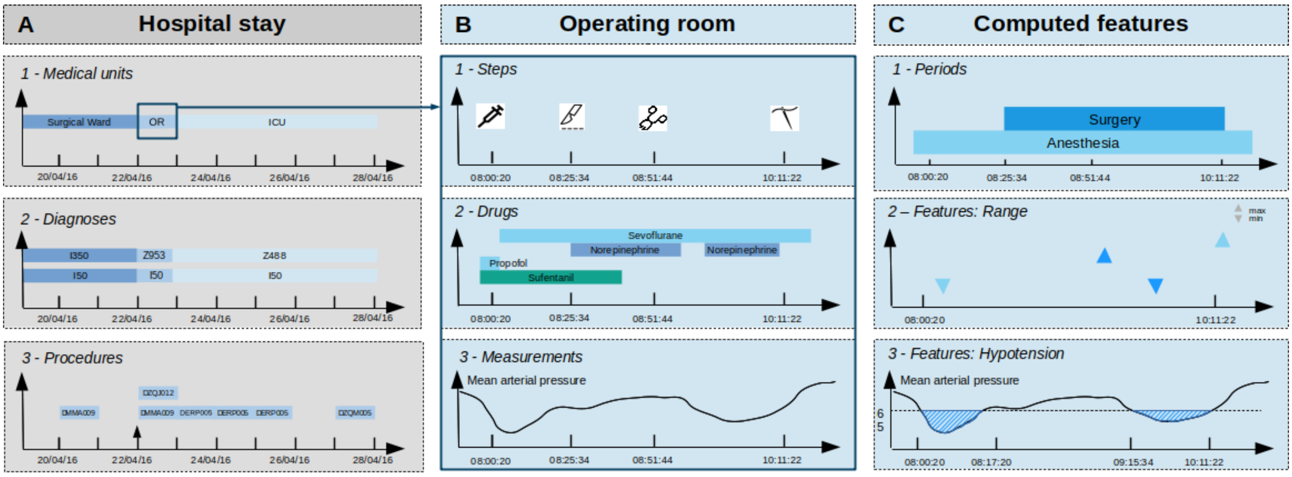
The primary objective of the present study was to standardize anesthesia data to the OMOP CDM. The secondary objectives were to provide vocabularies for the reuse of large-scale data and develop queries and dashboards related to the exploitation of anesthesia data using the OMOP CDM.

Methods

Study Data

Lille University Medical Center (Lille, France) has developed a clinical data warehouse with a local data model [40]. This data warehouse has been collecting data related to the hospital stay and operating room since 2010. Other features were also subsequently computed to facilitate data reuse. Hence, data were classified into three types, as shown in Figure 1: hospital stay data, operating room data, and computed features.

Figure 1. Example of local data organization for a cardiac surgery stay. A. hospital data from the Programme de Médicalisation des Systèmes d'Information database: medical units, diagnoses, and procedures. B. anesthesia information management systems data: steps in the procedures, drug administrations, and measurements. C. features computed from anesthesia information management systems data: periods of interest (anesthesia and surgery), features (range of mean arterial pressure during anesthesia and surgery, and the duration and number of episodes with a mean arterial pressure below 65 mm Hg).



Hospital Stay Data

Hospital stay data were extracted from the French national discharge database (Programme de Médicalisation des Systèmes d'Information [PMSI]) used by all hospitals in France and are presented in Figure 1A. The PMSI contains medical discharge reports entered after each hospital visit. The hospital stay data include all the characteristics of a patient's stay, such as the diagnosis (based on the International Classification of Diseases, 10th edition), medical procedures (based on the Classification Commune des Actes Médicaux), and admission and discharge dates. We have previously implemented the PMSI's administrative data into the OMOP CDM [20].

Operating Room Data

Operating room data were extracted from the hospital's dedicated AIMS [37] and are presented in Figure 1B. Various modules collect and centralize all the data referring to one case, from the preanesthetic evaluation to discharge from the postanesthesia care unit (PACU). These modules include continuously monitored parameters (eg, heart rate, blood pressure, respiratory rate, and tidal volume), drug administrations, and the main steps in anesthesia and surgery procedures.

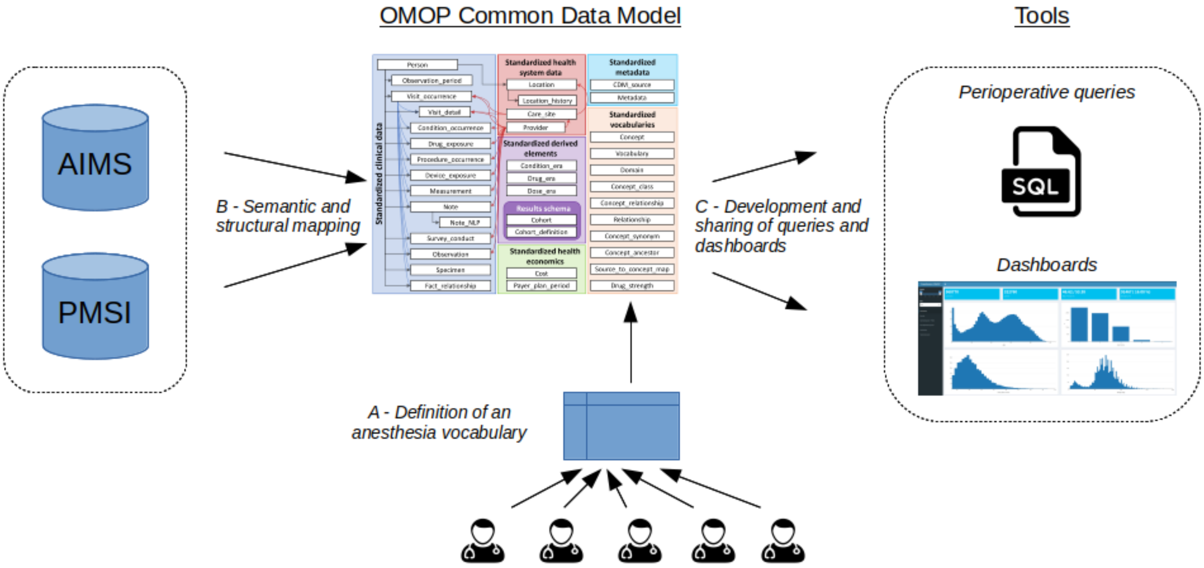
Computed Features

New features were computed to facilitate data reuse for research purposes [38,39]. First, we determined intraoperative periods of interest from events in time, as shown in Figure 1C-1. Second, we derived perioperative measurements and events from the periods of interest and then specified events (hypotension, tachycardia, and oxygen desaturation) as the ranges, medians, or means, indicated in Figures 1C-2 and 1C-3.

Semantic and Structural Mapping to the OMOP CDM

The vocabularies used to characterize the patients and anesthesia procedure were identified by 5 experts in anesthesia from 5 different centers (Lille, Amiens, APHP, Nancy, and Rouen) in France. The experts then selected the most relevant concepts for conducting care and research from within these vocabularies. Next, each local concept was mapped to a standard concept from the OHDSI vocabularies, as shown in Figure 2A. Figure 2B shows that structural mapping links the source data table to the OMOP data table and the source columns to the OMOP columns according to the OHDSI specifications [41]. The extract-transform-load process was implemented using a structured query language, and data were stored in a PostgreSQL 10.11 database (PostgreSQL Global Development Group) on Ubuntu 18.04.3.

Figure 2. Transformation of anesthesia data into the Observational Medical Outcomes Partnership common data model. A. selection of concepts related to anesthesia procedures by 5 anesthetists. B. semantic and structural mapping of anesthesia and Programme de Médicalisation des Systèmes d'Information data into the Observational Medical Outcomes Partnership common data model. C. development of shareable material for the exploitation of anesthesia data. AIMS: anesthesia information management systems; OMOP: Observational Medical Outcomes Partnership; PACU: postanesthesia care unit; PMSI: Programme de Médicalisation des Systèmes d'Information; SQL: structured query language.



Shareable Queries and Dashboards

To test the relevance of the OMOP CDM, we implemented 8 queries related to service audits and clinical research; these were based on the semantic and structural mapping implemented in our database. The queries were intended to provide the following information: (Q1) number of operations per year and per specialty department, (Q2) anesthesia procedures during an outpatient visit, (Q3) operations with fast-track surgery and no admission to the PACU, (Q4) operations with a mean arterial pressure below 65 mm Hg within 30 minutes of anesthesia induction, (Q5) administrations of norepinephrine, epinephrine, ephedrine, phenylephrine, dobutamine, or atropine received within 15 minutes of the first drop in the mean arterial pressure to below 65 mm Hg, (Q6) length of stay according to the score categories of the American society of anesthesiologists, (Q7) operations followed by a stay in the intensive care unit, and (Q8) characterization of the Mallampati grade.

In a previous work, we described the user-centered development, implementation, and preliminary evaluation of clinical dashboards related to anesthesia unit management and quality assessment in the Lille University Medical Center [42]. The user needs had been identified by conducting 21 end-user interviews. Several representations had been developed and submitted to end users for appraisal. After prioritization and feasibility assessment, 10 dashboards were ultimately implemented and deployed. Dashboards were evaluated by 20 end users (4 residents, 4 nurse anesthetists, and 12 anesthesiologists, including the head of the department and a unit manager). The mean (standard deviation) system usability score was 82.6 (11.5), which corresponded to excellent usability. As the dashboards were implemented from our data warehouse with local vocabulary and structured following a local data model, their codes could not be shared with other teams. In the current study, we selected 4 existing dashboards (population description, hemodynamic management, ventilation management, and postoperative outcome) and implemented them from the database now in the OMOP format, as shown in Figure 2C. The dashboards were implemented in R (The R Project for Statistical Computing) with the shiny, shinythemes, shinydashboard, and dplyr packages. The application was connected to the OMOP CDM via the DatabaseConnector package. We compared the new dashboards with the former versions to assess the possible loss of information.

Results

Semantic Mapping

The experts identified 8 types of vocabularies that had been custom-developed for the AIMS by software editors and anesthetists or that were used in the data warehouse: patient characteristics on the day of the procedure, types of visits, units, measurements, drugs, operation steps, periods, and features. Patient history–related vocabulary was not considered, as it was mainly documented manually, using synonyms, abbreviations, and negatives. From within the 8 mapped vocabularies, the experts selected the 522 concepts given in Table 1: 23 patient characteristics, 6 visits, 162 drugs, 45 measurement parameters, 67 units, 46 operation steps, 18 periods, and 155 features.

The experts looked for corresponding concepts in the OHDSI standardized vocabularies. Among the 522 concepts, 353 (67.7%) were successfully mapped to standard concepts for patient characteristics, visits, units, measurements, drugs, operation steps, and periods. All the concepts for patient characteristics, units, measurements, operation steps, and drugs were mapped. Further, 169 concepts (32.4%) in the visit, period, and feature vocabularies were not retrieved in the OHDSI standardized vocabularies and were thus added to the CONCEPT table. Specifically, the concept "operating room visit" was a new type of visit and helped distinguish visits to the operating room from the other types of visits in care units (eg, intensive care and emergency units). The semantic mapping is described in Table 1. All the concepts are listed in Multimedia Appendix 1.

Drugs were mapped to standard concepts of the class “ingredient,” as the clinical drug form is not correctly documented in the AIMS.

Table 1. Semantic mapping between anesthesia and Observational Health Data Sciences and Informatics vocabularies.

Source vocabularies	Concepts identified in source vocabularies, N	Corresponding standard OHDSI[a] vocabularies	Concepts mapped to standard OHDSI concepts, n (%)	New concepts added, n
Demographics	23	SNOMED[b]	23 (100)	0
Visits	6	Visit	5 (83.3)	1
Units	67	UCUM[c]/SNOMED	67 (100)	0
Measurements	45	LOINC[d]/SNOMED	45 (100)	0
Operation steps	46	SNOMED	46 (100)	0
Drugs	162	RxNorm	162 (100)	0
Period	18	—[e]	5 (28.8)	13
Feature	155	—	0 (0)	155

[a] OHDSI: Observational Health Data Sciences and Informatics.

[b] SNOMED: Systemized Nomenclature of Medicine.

[c] UCUM: Unified Code for Units of Measure.

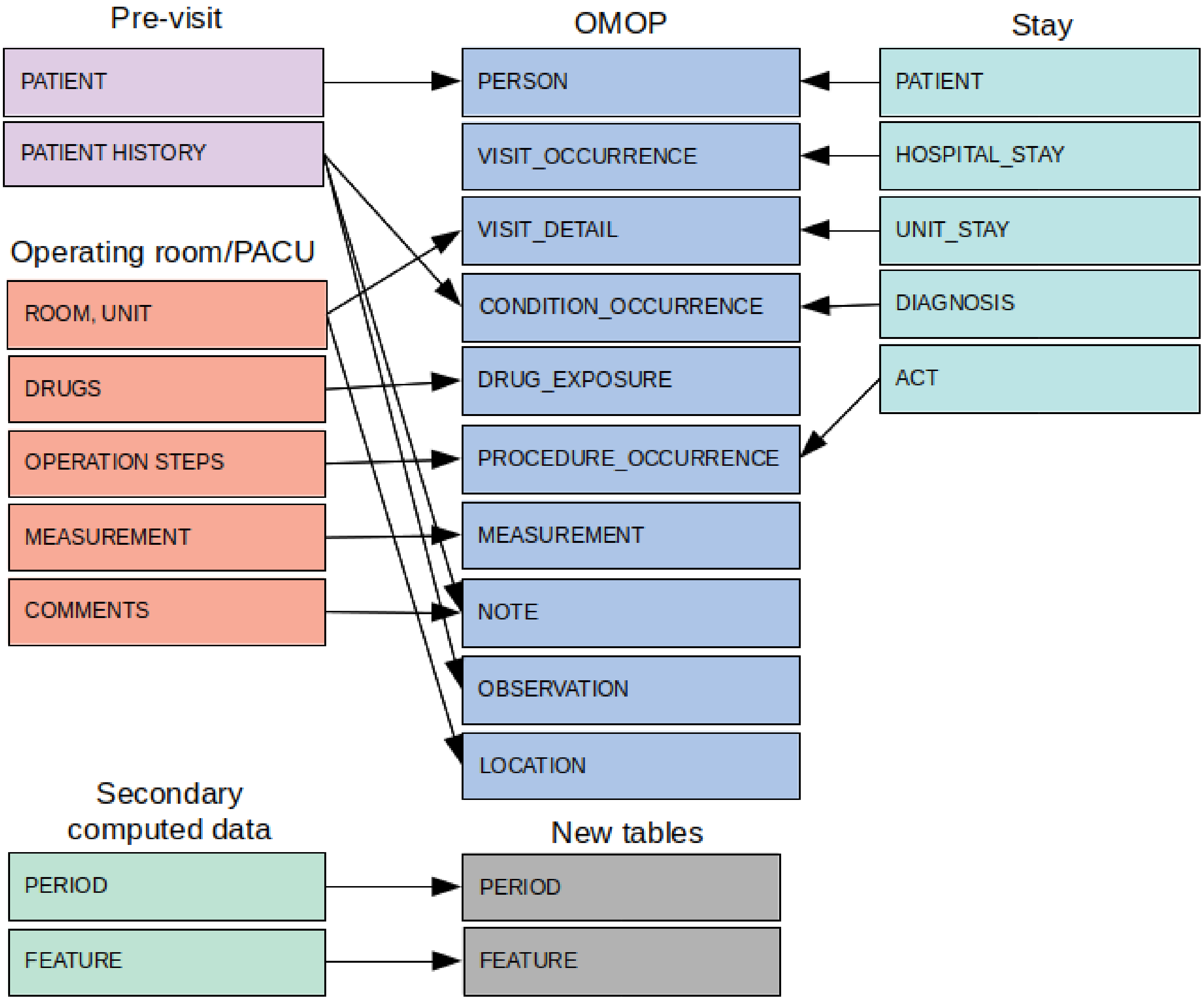
[d] LOINC: Logical Observation Identifiers Names and Codes.

[e] Not available.

Structural Mapping

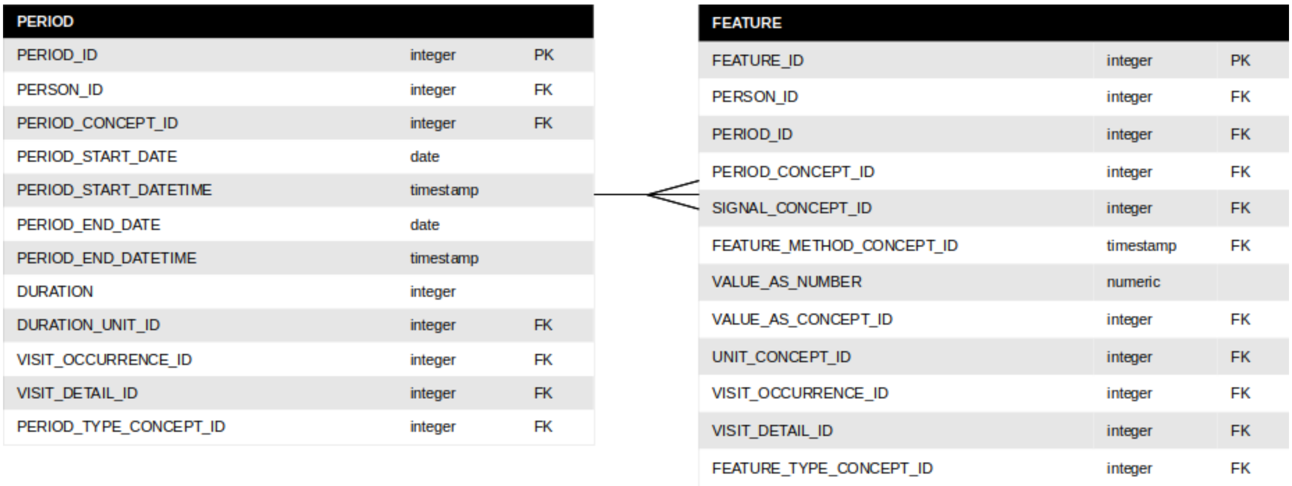
Each inpatient visit is defined a record in the VISIT_OCCURRENCE table. During a hospital stay, each move to a medical unit or an operating room for an operation is defined as a record in the VISIT_DETAIL table. Operating room visits were characterized with a new “operating room visit” concept, namely VISIT_DETAIL_CONCEPT_ID. This concept made it possible to differentiate between visits to care units and those to the operating room. Diagnoses and medical procedures documented in medical units were linked to the corresponding VISIT_DETAIL and VISIT_OCCURRENCE records. Measurements, drug administrations, and events documented in the operating room or PACU were linked to the corresponding operation by the VISIT_DETAIL_ID. Structural events were mapped to procedure_occurrence. Free-text entries from the preanesthesia consultation and those in the operating room were mapped to NOTE. Owing to the high volume, raw data for continuously monitored variables were not included in the measurement table but were kept aside in another schema. The RELATIONSHIP table was implemented with the relationships between the 214 anesthesia rooms (ie, preanesthesia consultation rooms, operating rooms, and the PACU) and the corresponding specialty departments. Structural mapping of the local clinical tables onto the OMOP tables is described in Figure 3.

Figure 3. Structural mapping of data related to the preanesthesia consultation and visits to the operating room, and the postanesthesia care unit in the Observational Medical Outcomes Partnership common data model. Integration of secondarily computed data necessitated the implementation of 2 new tables: PERIOD and FEATURE. OMOP: Observational Medical Outcomes Partnership; PACU: postanesthesia care unit.



We defined 2 new tables to store the computed data, namely period and feature. A period is defined by 2 milestones, a start event and an end event. The events may come from different sources: administration of a drug, a step in a procedure, consultation with a health care professional, or a visit to a health care unit. A period may be defined by an event date or time and a time interval, such as the start of a procedure and the next 30 minutes, or the administration of a drug and the last 10 minutes. A feature is defined by the combination of three concepts: a period (as defined above), a raw signal, and an aggregation method. The raw signal may include measurements of vital signs (eg, heart rate, arterial pressure, and oxygen saturation) or mechanical ventilation parameters (tidal volume, respiratory rate, and plateau pressure). The aggregation method may be a statistical indicator (eg, the mean, minimum, or maximum value) or an expert-driven rule [35]. The logical data model for these 2 tables is described in Figure 4.

Figure 4. Logical data model of PERIOD and FEATURE tables.



PERIOD		
PERIOD_ID	integer	PK
PERSON_ID	integer	FK
PERIOD_CONCEPT_ID	integer	FK
PERIOD_START_DATE	date	
PERIOD_START_DATETIME	timestamp	
PERIOD_END_DATE	date	
PERIOD_END_DATETIME	timestamp	
DURATION	integer	
DURATION_UNIT_ID	integer	FK
VISIT_OCCURRENCE_ID	integer	FK
VISIT_DETAIL_ID	integer	FK
PERIOD_TYPE_CONCEPT_ID	integer	FK

FEATURE		
FEATURE_ID	integer	PK
PERSON_ID	integer	FK
PERIOD_ID	integer	FK
PERIOD_CONCEPT_ID	integer	FK
SIGNAL_CONCEPT_ID	integer	FK
FEATURE_METHOD_CONCEPT_ID	timestamp	FK
VALUE_AS_NUMBER	numeric	
VALUE_AS_CONCEPT_ID	integer	FK
UNIT_CONCEPT_ID	integer	FK
VISIT_OCCURRENCE_ID	integer	FK
VISIT_DETAIL_ID	integer	FK
FEATURE_TYPE_CONCEPT_ID	integer	FK

Integration

Records spanning 10 years were integrated into the OMOP CDM. It corresponded to 5,72,609 operations for 3,29,633 patients. The numbers of records per OMOP table are shown in Table 2, and the number of records per operation and those per hospital stay are given in Table 3.

Table 2. Number of records implemented in Observational Medical Outcomes Partnership tables for the 2 data sources.

OMOP[a] table	Number of records
PERSON	3,29,633
VISIT_OCCURRENCE	48,84,220
VISIT_DETAIL (from PMSI[b])	15,40,677
VISIT_DETAIL (from AIMS[c])	5,72,609
CONDITION_OCCURRENCE (from PMSI)	15,13,544
CONDITION_OCCURRENCE (from AIMS)	5,67,442
DRUG_EXPOSURE	86,12,045
PROCEDURE_OCCURRENCE (from PMSI)	11,66,227
PROCEDURE_OCCURRENCE (from AIMS)	5,58,734
OBSERVATION (from PMSI)	18,644
OBSERVATION (from AIMS)	49,45,451
NOTE	92,88,981
PERIOD	40,26,665
FEATURE	3,48,09,015
LOCATION	1,348

[a] OMOP: Observational Medical Outcomes Partnership.

[b] PMSI: Programme de Médicalisation des Systèmes d’Information.

[c] AIMS: anesthesia information management system.

Table 3. Median (IQR) number of records per operation and per hospital stay.

OMOP[a] table	Median (IQR) number of records per operation (AIMS[b])	Median (IQR) number of records per hospital stay (PMSI[c])
VISIT_DETAIL	1 (1-1)	1 (1-1)
CONDITION_OCCURRENCE	1 (1-1)	2 (2-5)
DRUG_EXPOSURE	10 (5-17)	—[d]
PROCEDURE_OCCURRENCE	9 (4-12)	2 (1-4)
OBSERVATION	10 (8-10)	—
NOTE	31 (12-40)	—
PERIOD	7 (5-10)	—
FEATURE	71 (42-84)	—

[a] OMOP: Observational Medical Outcomes Partnership.

[b] AIMS: anesthesia information management system.

[c] PMSI: Programme de Médicalisation des Systèmes d'Information.

[d] Not available.

Shareable Queries and Dashboards

Based on the anesthesia and hospital stay data, we developed 8 queries for application to the existing VISIT_OCCURRENCE, VISIT_DETAIL, CONDITION_OCCURRENCE, PROCEDURE_OCCURRENCE, DRUG_EXPOSURE, NOTE, CONCEPT, and RELATIONSHIP tables and the 2 new PERIOD and FEATURE tables. The query steps and queried tables are described in Table 4. All queries are detailed in Multimedia Appendix 2.

Population description, hemodynamic, ventilation, and postoperative outcome are the 4 dashboards available, as shown in Table 5 and Figure 5. They provide an overview of the population treated in the operating room, compliance with hemodynamic guidelines, compliance with ventilatory guidelines, and postoperative outcomes. Each dashboard can be configured through filtering by year and department. The tables PERSON, VISIT_DETAIL, OBSERVATION, and FEATURE were queried to feed the dashboards. Although the format of the data source differed between the 2 versions of the dashboards (local format vs OMOP format), the figures and results obtained were identical.

Table 4. List of queries in the context of the operating room visits and hospital stays.

Query ID	Query	Requirement	Query steps and queried tables
1	Number of operations per year and per specialty department	Identify the visit to the operating room and the corresponding department	• Identification of visits to the operating room with the new concept "operating room visit" (VISIT_DETAIL) • Relationship between care_site_id of the operating room and care_site_id of the department (CONCEPT_RELATIONSHIP, CONCEPT)
2	Anesthesia procedure during an outpatient visit	Cross-check data from two sources: operating room (AIMS[a]) and hospital stay (PMSI[b])	• Identification of visits to the operating room with the new concept "operating room visit" (VISIT_DETAIL, VISIT_OCCURRENCE)
3	Operations with fast-track surgery and no admission to the PACU[c]	Identify a specific period of the operation	• Identification of visits to the operating room with the new concept "operating room visit" (VISIT_DETAIL) • Joining with PACU periods (PERIOD)
4	Operations with an MAP[d]<65 mm Hg within 30 minutes of inducing anesthesia	Cross-check data from two secondarily computed, operation-specific periods	• Period P1 of hypotension with MAP<65 mm Hg (PERIOD) • Period P2 of anesthesia (PERIOD) • Joining of P1 and P2 with the start date of P1 in 30 minutes following the start date of P2
5	Administration of norepinephrine, epinephrine, ephedrine, phenylephrine, dobutamine, or atropine received within 15 minutes of the first drop in MAP to below 65 mm Hg	Cross-check data from a secondarily computed period and specific drug administrations	• First period P1 of MAP<65 mm Hg (PERIOD) • Administration A of norepinephrine, epinephrine, ephedrine, phenyleprine, dobutamine, or atropine (DRUG_EXPOSURE) • Linking P1 and A with the start date and time of A in the 15 minutes following the start date of P1 • Aggregation by drug
6	Length of stay by ASA[e] status	Cross-check data from two sources: the operating room (AIMS) and hospital stay (PMSI)	• Extraction of ASA status conditions (CONDITION_OCCURRENCE) • Linking of the operating room visit details to the visit occurrence (VISIT_OCCURRENCE) • Aggregation of the duration of visit occurrence by ASA status
7	Operations followed by a stay in the intensive care unit	Cross-check data from two sources: operating room (AIMS) and hospital stay (PMSI)	• Identification of visits to the operating room with the new concept "operating room visit" VD1[f] (VISIT_DETAIL) • Identification of visits to the intensive care unit VD2 (VISIT_DETAIL) • Linking VD1 to VD2 according to the visit_occurrence identifier and with VD2 start datetime>VD1 end datatime
8	Characterization of the Mallampati grade	Query the preanesthesia consultation	• Extraction of Mallampati scores (NOTE) • Aggregation by score

[a] AIMS: anesthesia information management system.

[b] PMSI: Programme de Médicalisation des Systèmes d'Information.

[c] PACU: postanesthesia care unit.

[d] MAP: mean arterial pressure.

[e] ASA: American Society of Anesthesiologists.

[f] VD: visit detail.

Table 5. Description of dashboards implemented with the Observational Medical Outcomes Partnership common data model.

Dashboard	Information/objective	Numeric indicators (number or percentage)	Graphics	OMOP[a] tables
Population description	Overview of the population cared for in the operating room	• Number of operations • Number of patients • Male/female ratio (%) • Number of urgent operations (%)	• Histogram of age • Bar plot of the ASA[b] • Status histogram of the BMI • Histogram of the weight	PERSON VISIT_DETAIL OBSERVATION
Hemodynamics	Compliance with hemodynamic guidelines	• Number of operations with MAP[c]<65 mm Hg • Number of operations with MAP>120 mm Hg • Number of operations with HR[d]<60 bpm[e] • Number of operations with SpO2[f]<90%	• Bar plot of the duration with MAP<65 mm Hg (min) • Bar plot of the duration with MAP>120 mm Hg • Bar plot of the duration with HR<60 bpm • Bar plot of the duration with SpO2< 90%	PERSON VISIT_DETAIL FEATURE
Ventilation	Compliance with ventilatory guidelines	• Number of operations with expiratory tidal volume>8 ml/kg IBW[g] • Number of operations with expiratory tidal volume>10 ml/kg IBW • Number of operations with expiratory tidal volume (ml) • Number of operations with expiratory tidal volume/IBW (ml/kg)	• Bar plot of the expiratory tidal volume>8 ml/kg IBW by sex and year • Line plot of the expiratory tidal volume/IBW	PERSON VISIT_DETAIL FEATURE
Postoperative outcome	Overview of postoperative outcome: mortality, duration of hospital stay, and intensive care unit stay	• Number of operations followed by a death during hospital stay (%) • Duration of hospital stay • Number of operations followed by a passage in intensive care (%)	• Bar plot of the number of deaths per year • Line plot of the number of passages in intensive care per year	PERSON VISIT_DETAIL OBSERVATION

[a] OMOP: Observational Medical Outcomes Partnership.

[b] ASA: American Society of Anesthesiologists.

[c] MAP: Mean arterial pressure.

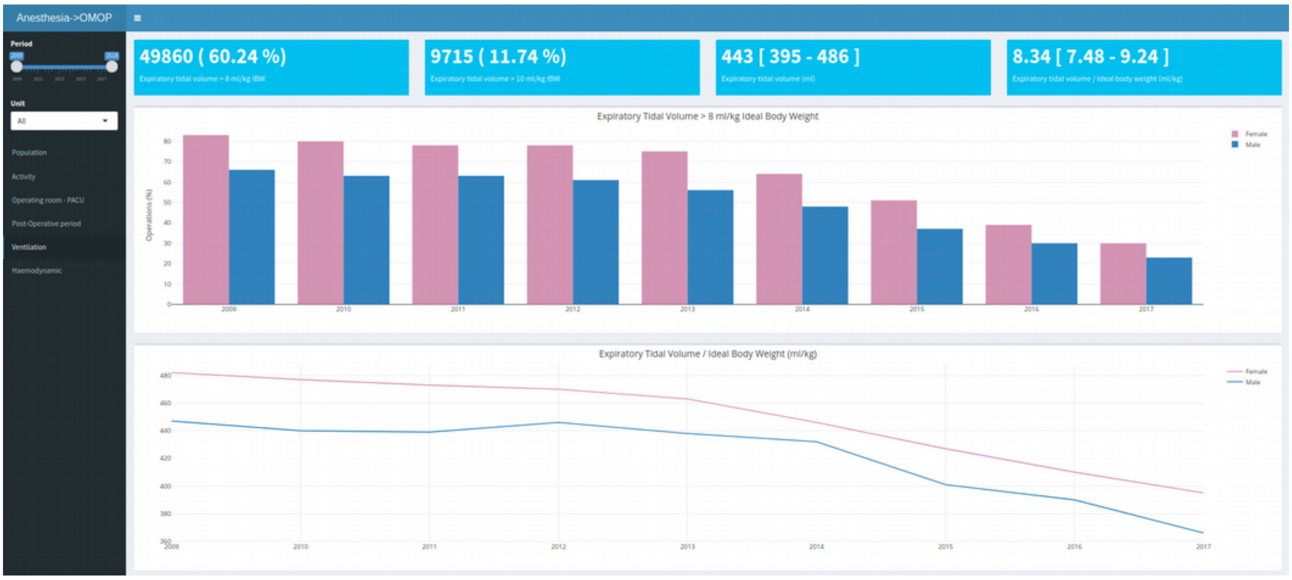
[d] HR: heart rate.

[e] bpm: beats per minute.

[f] SpO_2: oxygen saturation.

[g] IBW: ideal body weight.

Figure 5. Clinical dashboard for the assessment of ventilatory guidelines. Number of operations with tidal volume>8 ml.kg-1 of ideal body weight, number of operations with tidal volume>10ml.kg-1 of ideal body weight, median (IQR) expiratory tidal volume, median (IQR) expiratory tidal volume/ ideal body weight change over time in the proportion of operations with tidal volume >8 ml.kg-1 of ideal body weight and change over time in expiratory tidal volume/ ideal body weight over the year.



49860 (60.24 %)
Expiratory tidal volume > 8 ml/kg IBW

9715 (11.74 %)
Expiratory tidal volume > 10 ml/kg IBW

443 [395 - 486]
Expiratory tidal volume (ml)

8.34 [7.48 - 9.24]
Expiratory tidal volume / Ideal body weight (ml/kg)

The OMOP model has a row-oriented structure, with 1 data item per row. For example, each row of OBERVATION stores a single data item (ie, a weight or a BMI). In contrast, each query and dashboard must gather several data items (coming from a single table or several tables). Queries were developed with common table expressions, a syntax provided by PostgreSQL to write auxiliary statements for use in a larger query [43]. Dashboards needed to be implemented on top of the temporary tables gathering the results of a set of CTEs to reduce the response time of each query.

Discussion

Principal Results

In the present work, we integrated intraoperative anesthesia data into the OMOP CDM. To the best of our knowledge, this study is the first to have mapped intraoperative data into the OMOP CDM. First, experts from 5 French centers defined a list of concepts describing the anesthesia procedure and specific features. This list mainly comprised standardized concepts from the OHDSI vocabularies: patient history, patient characteristics on the day of the procedure, units, measurements, drugs, and procedure steps. When the corresponding concepts were missing, we added new concepts, particularly to characterize secondarily computed periods and features. Second, we implemented an extract-transform-load process to move perioperative data into the CDM. Third, we implemented common queries related to anesthesia procedures. As the OMOP CDM was initially developed for pharmacoepidemiology, we ensured that the mapping proposed for intraoperative data (and particularly the features specific to our work) could be easily queried. Finally, we developed shareable R scripts for the generation of anesthesia dashboards. These dashboards enabled us to ensure that hemodynamic and ventilatory guidelines were followed.

Limitations

First, we focused primarily on implementing the vocabulary related to the most common anesthetic procedures. Thus, it may not be sufficient to describe anesthetic management related to more specific procedures (obstetrics, ambulatory procedures, etc), but these could be added in the future. Second, the added concepts are not available in Athena at present and are therefore nonstandard concepts. While waiting for integration validation, the concepts are available on our git directory [44] and can be used and supplemented by other teams. Third, PERIOD and FEATURE are not supported by the OHDSI software stack. Further developments are needed to fully benefit from these new tables in the OHDSI tools and packages. Finally, CDMs may lose information owing to restrictions on the types of relationships proposed in relational models [45]. When integrating, care must be taken to ensure that the information realistically integrated is adequate to perform analyses afterward, and that any loss of information does not sanction the results and their interpretations.

Comparison With Prior Works

As observed in the studies that focused on specific data (apart from claims data) [29-31], we encountered difficulties with perioperative data. The main difficulty was using several local and custom vocabularies to document the intraoperative period; this contrasts with claims data, which are described according to terminologies. This problem required experts to define anesthesia-related concepts because the local concepts provided by the AIMS were not sufficient. Ryu et al have already reported that mapping by experts is an essential step [46]. Furthermore, the frequency of the recordings (every 30 seconds) in the operating theater produced a large volume of data. We decided not to retain the raw measurements in the measurement table so that the query response time remained acceptable. Raw measurements were stored in a similar measurement table on a twin schema. Finally, we had to compute new periods and features that did not fit in the OMOP CDM tables. To achieve this, we developed 2 new period and feature tables.

Our present work might offer opportunities for research collaborations on intraoperative data with other centers. The material provided here could be used and enhanced by other centers. In combination with federated learning [47], the OMOP CDM provides tools needed for conducting reproducible research.

Conclusions

Generic data concerning demographics, drugs, units, measurements, and operating room steps were already available in OHDSI vocabularies. However, most of the intraoperative concepts (the duration of specific steps, episodes of hypotension, etc) were absent in the OHDSI vocabularies. We have performed OMOP mapping for reusing anesthesia data.

Acknowledgments

We thank the InterHop association and the OHDSI community for their support and advice.

Authors' Contributions

All authors contributed to the study conception and design. OAA, AB, AP, VP, and MDM contributed to the vocabulary mapping. AL implemented the extract-transform-load process. AL, OAA, and AB implemented the common queries and dashboards. AL drafted the manuscript as the first author. All authors approved the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Anesthesia-related concepts.
[XLSX File (Microsoft Excel File), 18 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Common queries.
[DOCX File , 9 KB-Multimedia Appendix 2]

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Abbreviations

AIMS: anesthesia information management systems
CDM: common data model
EHR: electronic health record
OHDSI: Observational Health Data Sciences and Informatics
OMOP: Observational Medical Outcomes Partnership
PACU: postanesthesia care unit
PMSI: Programme de Médicalisation des Systèmes d'Information

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Original Paper

Identifying Frequent Health Care Users and Care Consumption Patterns: Process Mining of Emergency Medical Services Data

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Abstract

Background: Tracing frequent users of health care services is highly relevant to policymakers and clinicians, enabling them to avoid wasting scarce resources. Data collection on frequent users from all possible health care providers may be cumbersome due to patient privacy, competition, incompatible information systems, and the efforts involved.

Objective: This study explored the use of a single key source, emergency medical services (EMS) records, to trace and reveal frequent users' health care consumption patterns.

Methods: A retrospective study was performed analyzing EMS calls from the province of Drenthe in the Netherlands between 2012 and 2017. Process mining was applied to identify the structure of patient routings (ie, their consecutive visits to hospitals, nursing homes, and EMS). Routings are used to identify and quantify frequent users, recognizing frail elderly users as a focal group. The structure of these routes was analyzed at the patient and group levels, aiming to gain insight into regional coordination issues and workload distributions among health care providers.

Results: Frail elderly users aged 70 years or more represented over 50% of frequent users, making 4 or more calls per year. Over the period of observation, their annual number and the number of calls increased from 395 to 628 and 2607 to 3615, respectively. Structural analysis based on process mining revealed two categories of frail elderly users: low-complexity patients who need dialysis, radiation therapy, or hyperbaric medicine, involving a few health care providers, and high-complexity patients for whom routings appear chaotic.

Conclusions: This efficient approach exploits the role of EMS as the unique regional "ferryman," while the combined use of EMS data and process mining allows for the effective and efficient tracing of frequent users' utilization of health care services. The approach informs regional policymakers and clinicians by quantifying and detailing frequent user consumption patterns to support subsequent policy adaptations.

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KEYWORDS

process mining; frequent users; hospital care; emergency medical services; regional care networks; elderly; Netherlands

Introduction

A large part of regional health care consumption is attributed to "frequent users" (ie, patients who make repeated calls to hospital and nursing health care services) [1]. Although definitions differ, a threshold of 4 to 5 calls or more per year is generally used to classify a patient as a "frequent user" [2,3]. While frequent users represent a minority of emergency department (ED) patients (4.5%-8%), they may account for up to 21%-28% of all ED visits [4]. Frequent users appear heterogeneous as a group; however, they may be clustered into distinct categories relating to their health care needs and the health services provided to them [5].

The high workload and costs incurred by frequent users make them a relevant target group for regional policymakers and clinicians to consider as they attempt to make the best use of scarce resources. For example, due to the various health care needs related to advanced age, the “frail elderly” are known to be frequent users [6-9]. Their frailty is related to their status of being extremely vulnerable to endogenous and exogenous stressors, exposing them to a higher risk of negative health-related outcomes [8]. Importantly, they are often confronted with fragmented health care [6], inappropriate or delayed triage at EDs [10], and incorrect referrals. These observations suggest an inappropriate approach to their health care needs and the potential unnecessary use of health care services. Once their frailness is identified, advanced health care planning may be used to improve their health care continuity [8,11,12]. Therefore, tracing frequent users and their (shared) consumption patterns is a prerequisite for assessing the efficiency and effectiveness of current clinical practice, undertaking appropriate actions to improve it, and evaluating the added value of these actions and related policy changes.

Notably, many frequent users do not make calls to a single health care provider but are network users, making consecutive visits to multiple health care providers. Apart from their preferences, their network use may be explained, for example, by specialized health care needs. Thus, tracing frequent users requires a network-based approach, including all regional health care providers. Unfortunately, collecting data by interviewing health care providers or even extracting data from their local records tends to be cumbersome. Rules on patient privacy, competition among health care providers, incompatibility of information systems, and the effort required may present hurdles that are not easily overcome, adding to data collection costs. Most research designs limit their scope to single or related health care providers, with a primary focus on hospitals [13]. As a result, many frequent users may be overlooked. Moreover, their routings along different health care providers may appear fragmented due to a lack of information on major health care providers outside hospitals, such as nursing homes, which are particularly relevant to the frail elderly.

This article explores an alternative approach to tracing frequent users, relying on emergency medical services (EMS) data (ie, records of ambulance rides containing patient and logistic data). Acting as the “ferrymen” in the regional health care network, EMS theoretically direct subacute or acute patient routings, starting with a time-ordered sequence of ambulance rides. Therefore, their databases potentially offer an efficient means for identifying and tracing frequent users. Importantly, the EMS patient population is likely to accommodate many frequent users [14,15]. Moreover, patients served by EMS tend to require substantial health care resources, as indicated by their need for mobile nursing services and transport. However, the potential of using EMS data to identify frequent users and their consumption patterns has hardly been acknowledged in the literature [16].

This study aimed to show how the analysis of EMS records may contribute to tracing frequent users on a regional scale, especially the frail elderly, and reveal their health care consumption patterns. The novel analysis technique of process mining is instrumental to the study, enabling the automated identification of patient routings (ie, identifying health care providers consulted over time by combining the records related to ambulance rides). Frequent users can be identified by quantifying their number of ambulance rides via process mining. In turn, their consumption patterns are reflected in their routings, specifying health care providers and specialties involved over time. The aggregation of patient routings establishes trends in their annual demand for health care and the associated workload distribution over the network. Process mining has an advantage over other mapping techniques as it uses factual observations retrieved from data rather than man-made process models. Process mining has been successfully used to analyze health care processes, usually in an intrahospital context [17-27]. However, its application to regional health care networks is new.

As relevant background information, we briefly summarize that the Dutch system for chronic healthcare has for a long time been funded through national funds under the General Act Special Care Costs [28]. However, this funding scheme was deemed too inefficient and generous. Accordingly, as of January 1, 2015, a major system change was introduced, accompanied by new legislation (ie, the Long-term Care Act) [29]. The execution and implementation of health care for less severe indications in the home setting were transferred to the municipalities to achieve a better match and a more efficient system. The transfer was expected to result in more elderly people remaining in their homes, thus reducing chronic (elderly) health care costs. As of spring 2021, these expectations, to a large extent, have not materialized or even worsened the situation. Our study reveals problems that have emerged since the system’s change, including subsequent nursing home closures.

Using EMS records of the province of Drenthe, the Netherlands, this study shows how ambulance data allows for effective and efficient tracing and quantification of frequent users of health care services on a regional scale, considering frail elderly users as a focal group. The proposed approach builds on the role of EMS as the regional “ferryman,” implying the utilization of a single key source for data collection, covering many health care providers at the same time (ie, hospitals, nursing homes, and EMS). Process mining adds to the efficiency of the approach by enabling automated mapping of patient routings (ie, their consecutive visits to health care providers). Furthermore, the structure of patient routes is analyzed at patient and group levels, allowing us to gain insight into regional coordination issues and workload distributions among health care providers, which is helpful to policymakers and clinicians. In particular, we seek evidence for the effects of the Dutch governmental policies described above, including the impact of higher health care need entry requirements for nursing home admissions on regional health care consumption [30-32].

Methods

The Health Care Network of the Province of Drenthe

The province of Drenthe has a population of 491,867, with a population density of 183 inhabitants per square kilometer [33]. Hospital care is provided by 4 hospitals within the province and by several hospitals located in neighboring provinces. Among the 4 hospitals, 3 offer basic treatment, and 1 hospital has the necessary skills and resources to treat multilevel trauma. The reasons for referral to hospitals outside the province include being close to the patient scene, patient preferences, level of health care, or specialization related to specific treatments. Nursing care is also provided by a few dozen nursing homes, mainly located within the province. EMS is provided by a single operator, relying on a network of 17 bases in 14 towns or villages in Drenthe. Its services include both urgent (A-rides) and planned (B-rides) patient transport to hospitals and planned (B-rides) transport to nursing homes. B-rides are legitimized by patient health care needs prohibiting self-transport or transport by taxi. A-rides assume the presence of staff and equipment, enabling advanced life support (ALS; ie, advanced health care for critical patients). In contrast, B-rides may be offered with either ALS or basic life support, setting less strict medical skillsets and equipment requirements.

Data

Patient data were collected from EMS records of ambulance rides performed between January 1, 2012, and December 31, 2017. The data collected included the ride dates and times, destinations (ie, health care providers), patient age, urgency (A or B), and health care providers' medical specialty as indicated by the patient's health care needs. A unique identification number assigned to each patient identified patients' routings along different health care providers and services by combining their records and organizing them according to ambulance ride dates.

Based on our focus on the frail elderly population, frequent users, and EMS scope of services, 3 categories of health care providers were distinguished: hospitals, nursing homes, and the EMS. The latter was considered a formal health care provider when the treatment provided by the ambulance paramedics on the scene sufficed to address patient health care needs, designated EMS "see and treat" (EMS-S&T). This inclusion may also serve as an indicator of inappropriate or fragmented health care [6].

Process Mining

Like many regions worldwide, the province of Drenthe has increasing numbers of frail elderly people who utilize a significant part of the regional health care system. In terms of their visits to regional hospitals and nursing homes, their consumption patterns remain largely unknown, as regional health care providers do not disclose this type of patient information.

Process mining is a technique combining data science and process management to support the identification and analysis of operational processes (ie, sequential activities undertaken by an organization in satisfying its customers), thereby relying on event logs (ie, recordings of respective activities) stored in a database [34]. Process mining has been successfully used to map health care processes, clarifying how patients are served as a net effect of activities performed by health care providers. So far, most examples of its use in health care are related to an intrahospital context [17-27]. By automatically generating process maps using factual observations retrieved from data, process mining has important advantages over other modeling techniques that rely on manual observations of the actual system or inspection of documents [17,34].

EMS records referring to single rides are anonymized, cleaned by removing empty records (ie, records not relating to patients), and inspected for data accuracy to allow for process mining. If a record lacks information on the health care provider (eg, the destination of a ride), it was marked "unknown." Subsequently, Disco (version 2.2.0; Fluxicon) [35], a tool used to perform the process mining, traced patient routings by combining and ordering (time-wise) patient records referring to unique patients.

The health care consumption of frequent users (ie, patients meeting a threshold of 4 ambulance rides to regional health care providers within a year) is quantified by presenting their numbers and the number of calls, including annual trend figures and the distribution of frequencies. Frail elderly users (patients 70 years of age or more) were considered a subgroup among frequent users. They were analyzed for urgency using the ambulance ride categories A (urgent) and B (planned) as a proxy and for the volume of recognized categories of frequent users among them, specifically patients known to be in frequent need of dialysis, radiation therapy, or hyperbaric medicine (DRH). The "known" patient categories depend on local insight, thereby relying on EMS staff and records. For "unknown" patient categories, such a classification is lacking.

The health care consumption of frail elderly users was assessed at two levels (the patient level and the patient group level) using process mining for structural analysis. At the patient level, patient routings along the various health care providers are identified by the ride destinations, including the specialties being consulted. Patients are distinguished by two categories (low complexity and high complexity) as indicated by their routings. This complexity is considered from the perspective of health care consumption uncertainty. For instance, low-complexity patients are the "known" patients, involving few health care providers, and high-complexity patients are those for whom routings might not be fully understood. Although the term "low complexity" might suggest that these patients have a relatively mild health condition, they are frail and consume many resources and should also be recognized as a relevant subgroup.

Ethics Approval and Consent to Participate

Since the data originally were routinely collected for administrative purposes and completely anonymized, this study does not fall within the scope of the Medical Research Involving Human Subjects Act (Wet Medisch-weteschappelijk Onderzoek 2021) [31]. Accordingly, we obtained a full waiver for using anonymized data from the EMS services from the Medical Ethics Review Board of the University Medical Center Groningen (reference number METc 2018/402).

Results

Quantifying Frequent Users

Overview

Table 1 provides an overview of all patients served by regional health care providers based on EMS records. In total, 126,758 unique patients were identified between 2012 and 2017, involving 212,967 calls for services and omitting 2494 records not linked to patients. Table 1 shows call volumes have increased 25% over the years, from 31,300 to 39,235 calls. Similar changes are observed for frequent users' general health care consumption, including frail elderly users. Frequent users account for approximately 16% of total regional health care consumption, of which more than half is attributable to the frail elderly. The number of frail elderly users increased from 395 to 628 (59%), and their calls rose from 2607 to 3615 (39%). Strikingly, the largest growth in frail elderly users was observed from 2013 to 2015, increasing from 320 to 548 (71%) patients.

Table 1. Overview of patients served by regional health care providers.

Year	All patients, N	All patient calls, N	Frequent users, n	Frequent users, n (%)[a]	Frail elderly, n	Frail elderly, n (%)[b]
2012	22,551	31,300	731	5051 (16)	395	2607 (52)
2013	23,794	32,359	625	4636 (14)	320	2428 (52)
2014	24,355	34,568	844	5681 (16)	446	2792 (49)
2015	25,677	36,742	987	5976 (16)	548	3169 (53)
2016	27,146	38,763	999	6449 (17)	561	3333 (52)
2017	27,671	39,235	1043	6258 (16)	628	3615 (58)
Total	151,194 (126,758)[c]	212,967	5229 (4734)[c]	34,051	2898 (2700)[c]	17,944

[a] Calls made by frequent users as a percentage of calls from all patients.

[b] Calls made by frail elderly users as a percentage of calls from frequent users.

[c] Number of unique patients involved.

Frail Elderly

Details on the health care needs for frail elderly users and their urgency are shown in Table 2, which are categorized by distinguishing their EMS calls according to the medical specialty requested and the urgency of the ride (Tables 1 and 2). For example, among the 395 frail elderly users in 2012 (Table 1), 302 (76%) patients had been transported at least once in an urgent ride (A), while 345 (87%) patients had used at least 1 planned ride (B; Table 2). In addition, among patients transported in planned rides, 75 (19%) patients required dialysis, radiation therapy, or hyperbaric medicine (B-DRH), and 326 (83%) patients had other diverse health care needs and urgencies (B-other). The 2 patient groups overlap due to comorbidity; therefore, the sum of their patient numbers exceeds the overall annual number of frail elderly users. The right-hand side of Table 2 shows the number of calls, indicating the number of rides associated with the groupings mentioned above.

Table 2 reveals the number of urgent (A) calls among frail elderly users more than doubled between 2012 and 2017 (from 825 to 1729, 110%), in contrast to the modest growth in calls for rides planned in advance (B; from 1782 to 1886, 6%). In addition, between 2012 and 2017, the number of frail elderly users requiring either specific, predictable treatment or other treatments (Table 2, see columns B-DRH and B-other) increased from 75 to 104 (39%) and 326 to 487 (49%), respectively. However, annual calls made by DRH patients diminished between 2012 and 2017 (from 728 to 502, –31%), while a considerable growth in the number of calls made had occurred for the remaining group (from 1054 to 1384, 31%).

Table 2. Health care needs and urgency for frail elderly users.

Year	Frail elderly population					Frail elderly calls				
	All, N	Urgency of health care, n		Health care needs, n		All, N	Urgency of health care, n		Health care needs, n	
	A[a]+B[b]	A	B	B-DRH[c]	B-other[d]	A+B	A	B	B-DRH	B-other
2012	395	302	345	75	326	2607	825	1782	728	1054
2013	320	258	271	64	256	2428	664	1764	903	861
2014	446	372	370	74	353	2792	1019	1773	740	1033
2015	548	473	408	83	395	3169	1478	1691	533	1158
2016	561	498	417	99	398	3333	1552	1781	575	1206
2017	628	561	501	104	487	3615	1729	1886	502	1384
Total	2898 (2700)[e]	2464 (2303)[e]	2312 (842)[e]	499 (480)[e]	2,215 (2119)[e]	17,944	7267	10,677	3981	6696

[a] A: urgent transport.

[b] B: planned transport.

[c] B-DRH: patients in need of dialysis, radiation therapy, or hyperbaric medicine making use of EMS planned transport.

[d] B-other: patients with health care needs other than dialysis, radiation therapy, or hyperbaric medicine making use of EMS planned transport.

[e] Number of unique patients involved.

Identifying Regional Health Care Consumption Patterns Among Frail Elderly Users

Patient Level: Low- and High-Complexity Patients

Consumption patterns for frail elderly users are captured by ordered ride lists and process maps (Tables 3 and 4; Figures 1 and 2). Tables 3 and 4 show an excerpt of the routings of 2 frequent users, patient A and patient B, respectively. Patient A needs dialysis and is served by a single hospital (RegHospital 1). Patient A's routing exhibits low complexity, which is clearly shown by the process map in Figure 1. It illustrates how the patient was treated 145 times by RegHospital 1 while living in the nursing home between 2012 and 2017. Arcs in Figure 1 summarize information on the sequence of services consumed; for example, a ride to RegHospital 1 is directly followed by a ride to the nursing home 117 times, and a ride to the nursing home is directly followed by a ride to RegHospital 1 118 times. In some cases, transport to or from the hospital has not been organized by the EMS provider under study. For instance, a ride to RegHospital 1 is followed by another ride to RegHospital 1 27 times. Similarly, a ride to the nursing home is followed by another ride to the nursing home 27 times.

Table 3. Excerpt from the routings of patient A.

Date	Time	Urgency	Destination	Specialty
2012-01-06	16:06:15	B	Nursing home	Other specialties
2012-01-19	15:46:06	B	Nursing home	Internal medicine
2012-01-20	09:30:56	B	RegHospital 1-dialysis	Other specialties
2012-01-23	10:15:32	B	RegHospital 1-dialysis	Other specialties
2012-01-23	15:16:49	B	Nursing home	Internal medicine
2012-01-25	09:11:57	B	RegHospital 1-dialysis	Other specialties

Table 4. Excerpt from the routings of patient B.

ID	Date	Time	Urgency	Activity	Specialty
1	2013-09-13	06:50:39	A1	EMS-S&T[a]	OS[b]
2	2013-06-02	02:42:14	A1	Hospital A	OS
3	2013-06-16	13:50:06	A2	Hospital A	OS
4	2013-07-02	00:04:43	A1	Hospital A	P[c]
5	2014-02-01	20:40:56	A2	Hospital A	OS
6	2014-02-01	23:09:41	A2	Unknown	OS
7	2014-11-26	22:26:42	A1	Hospital A	OS
8	2014-12-06	11:22:00	A1	Hospital A	P
9	2014-12-08	12:51:39	A1	Hospital A	Surgery
10	2014-12-08	16:14:38	B	Unknown	OS
11	2014-02-17	11:42:49	A1	Hospital A	P
12	2014-04-02	09:37:52	B	RegHospital 2	OS
13	2015-09-05	08:43:23	A1	RegHospital 4	General
14	2015-09-05	11:04:53	B	Unknown	Unknown
15	2015-09-23	01:51:15	A2	Hospital D	General
16	2015-10-22	07:57:29	A2	Hospital D	General
17	2015-02-06	09:56:39	A2	Hospital A	P
18	2015-02-06	11:56:25	A2	Nursing home	P
19	2015-02-12	11:05:34	A1	Hospital A	P
20	2015-02-12	12:47:12	B	Nursing home	P
21	2015-02-26	08:57:59	B	Hospital A	OS
22	2015-02-26	10:47:32	B	Nursing home	OS
23	2015-01-07	08:16:58	A1	Hospital A	OS
24	2015-01-07	10:02:35	A1	Unknown	OS
25	2015-01-07	11:48:10	A1	RegHospital 1	Surgery
26	2015-03-15	05:22:40	A1	EMS-S&T	OS
27	2015-01-11	16:09:12	A2	Hospital A	OS
28	2015-01-11	17:46:08	B	RegHospital 1	OS
29	2015-04-30	14:39:22	A2	Hospital A	P
30	2015-04-30	16:02:48	B	Unknown	P
31	2015-01-14	08:55:44	B	Hospital A	P
32	2015-06-23	16:47:33	A2	Hospital A	P
33	2015-06-23	19:00:12	B	Unknown	P
34	2015-06-28	10:43:34	A1	Hospital A	General
35	2015-06-28	21:01:32	A1	RegHospital 1	P
36	2015-07-10	11:45:13	A1	Hospital D	General
37	2015-07-12	12:09:24	A1	RegHospital 1	IM[d]
38	2015-07-12	14:21:53	B	Unknown	IM
39	2015-01-21	21:39:06	A2	Hospital A	P
40	2016-01-14	08:58:03	A2	Hospital D	P
41	2016-01-02	22:08:36	A1	Hospital D	P

[a] EMS-S&T: emergency medical services “see and treat.”

[b] OS: other specialties.

[c] P: pulmonology.

[d] IM: internal medicine.

Figure 1. The process map of low complexity patient A.

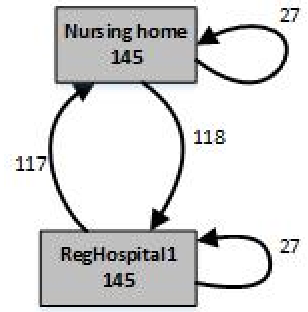
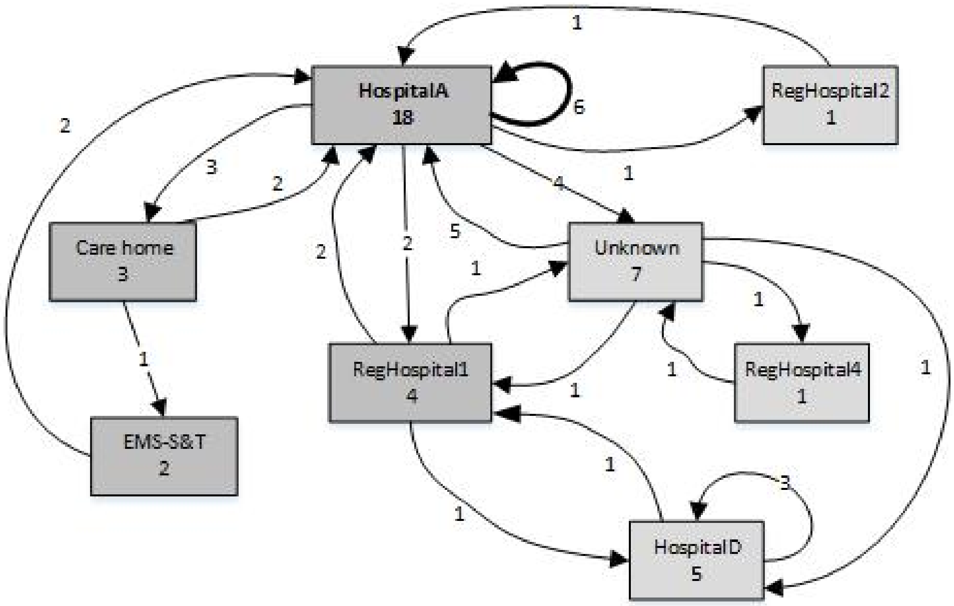


Figure 2. The process map of high complexity patient B. EMS-S&T: emergency medical services “see and treat.”



Whereas routings for patient A exhibit low complexity, other patients may have more complex routings, as illustrated by patient B in Table 4 and Figure 2. Patient B is among the very frequent users (between 2012 and 2017), with 41 ambulance rides and diverse health care needs as indicated by the specialties attending to the patient’s treatment, thus relying on several health care providers.

Patient Group Level: “Unknown” Patients

Figure 3 and Figure 4 show the workload distribution for frail elderly users who did not belong to a known category for 2012 (326 patients) and 2017 (487 patients; Table 2, see column B-other). Only the health care providers involved in at least 30 treatments and had arcs with frequencies of at least 8 are shown. The number of treatments provided by all health care providers rose considerably between 2012 (Figure 3) and 2017 (Figure 4), although the growth rate is quite different across health care providers. This is paralleled by the higher connectivity among health care providers in 2017, as indicated by the arc frequencies and new arcs (Figure 4, see arcs marked in red). However, developments were not necessarily unidirectional, as connections may disappear over the years (Figure 3, see arcs marked green).

Figure 3. Process maps of 2012 aggregated routings for frail elderly patients (non-dialysis, radiation therapy, or hyperbaric medicine). EMS-S&T: emergency medical services “see and treat.”

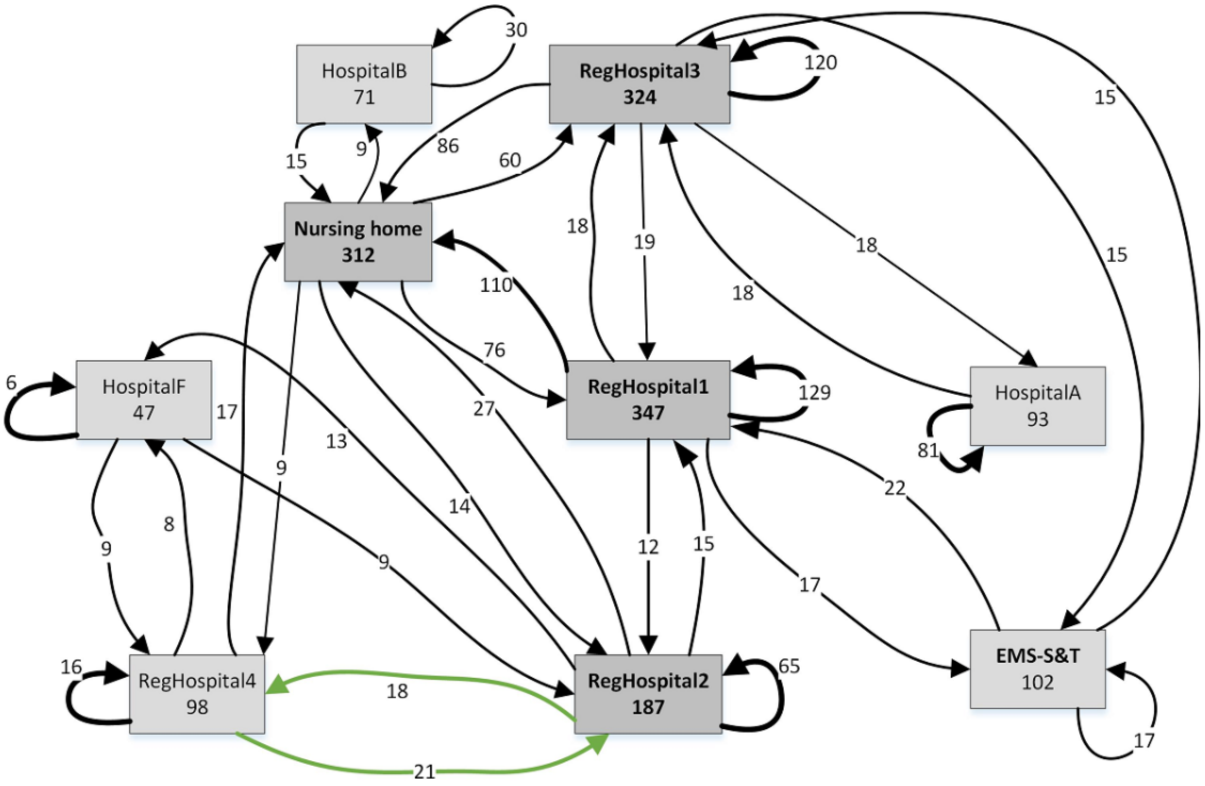
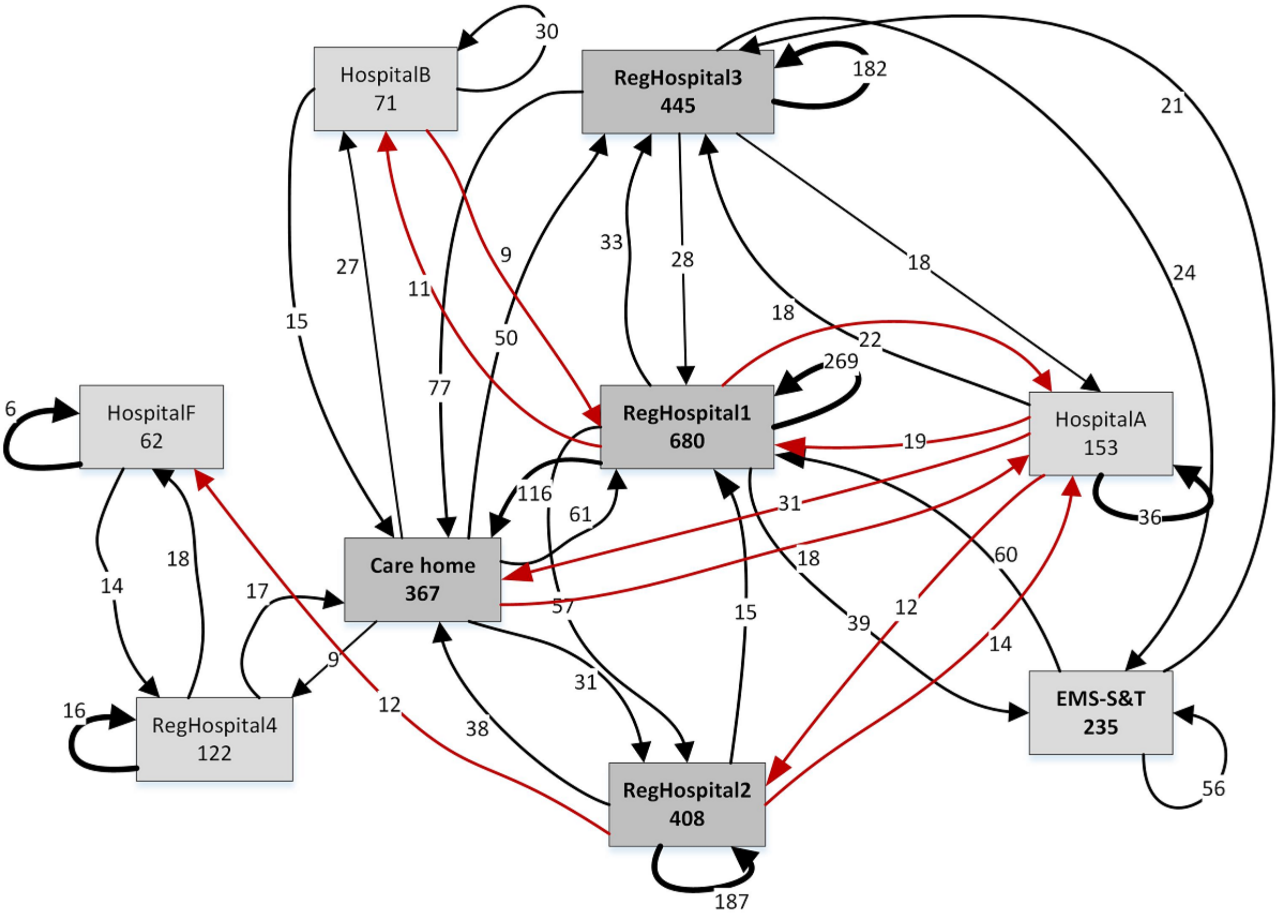


Figure 4. Process maps of 2017 aggregated routings for frail elderly patients (non-dialysis, radiation therapy, or hyperbaric medicine). EMS-S&T: emergency medical services "see and treat."



Discussion

Principal Findings

Frequent users, defined as patients making repeated calls to regional health care services, have a high impact on health care capacities and resource management. Tracing frequent users and their (shared) consumption patterns may be instrumental in regional policymaking. In this study, we combined EMS records and process mining in the Dutch province of Drenthe to trace frequent users and discern different types of users. The approach allowed us to develop and assess patient routings along various regional health care providers by combining their records on ambulance rides. This study demonstrates that this approach can effectively and efficiently trace and quantify frequent users and assess their consumption patterns. Considering frail elderly users as a focal group, the effectiveness of the approach benefits from its broad scope, spanning a large group of health care providers, including nursing homes. Moreover, using EMS records as a single source of data guaranteed the availability of data on all regional hospitals. Notably, data collection and analysis costs were low as the approach relied on a single data source that is routinely collected and the use of automated data analysis by process mining.

Process mining of EMS records confirms the relevance and impact of frail elderly users as a subgroup of frequent users [6-8], representing over 50% of frequent users and meeting a threshold of 4 calls in 1 year. Moreover, the number of frail elderly users and the number of calls they made to health care providers significantly increased during the observation period. Strikingly, the largest growth in frail elderly users was observed in 2014 and 2015, increasing by 100 patients a year, from 320 in 2013 to 548 patients in 2015 (71%). Also, the urgency of their calls increased as indicated by a steep increase in the number of urgent rides in this category (from 664 in 2013 to 1478 in 2015, 123%), substantially exceeding the background annual growth rate of EMS transports of 5.1% over the observation period [30,36].

Our observations parallel structural changes in the Dutch healthcare system of elderly health care (Wet Maatschappelijke Ondersteuning 2015) [37]. Closure of health care homes and stricter health care need entry requirements for nursing homes forced the elderly to continue living independently in their homes for as long as possible [32,38,39]. Although the respective transformations intended to reduce chronic health care costs, they resulted in more hospital admissions and acute situations that were no longer manageable in the home setting, which indeed may be considered counterproductive. We feel the structural change in the trend observed in EMS figures for 2014 and 2015 may indicate an unwanted and unexpected impact of national policy changes. Quantifying the health care consumption of the frail elderly population may be helpful to policymakers by showing their impact on the system and revealing the urgency to address their needs. Furthermore, understanding the health care consumption of the frail elderly can lead to discussions about residential and other health care homes or other forms of home health care. Our findings reveal a need for further action, such as capacity extensions, tailored home health care services, or advanced health care planning to improve elderly health care and its coordination.

Based on process mining, the structural analysis of patient consumption patterns revealed 2 patient groups: low-complexity "known" patients who require DRH and "unknown" patients often linked to complex routings and the use of several regional health care providers. Importantly, while the known group of frail elderly patients exhibited a growth rate mirroring demographic changes, the unknown group exhibited growth at a much higher pace, implying increased and unpredictable workloads. The workload related to the latter group tends to be increasingly distributed over the several regional health care providers, requiring them to become better connected over time to provide the best health care for the patients they jointly serve. This may be explained by ongoing regional specialization, calling for regional coordination in identifying and addressing patient needs and managing capacities. As a result, process mining further identifies the health care providers involved and the nature of their involvement in terms of specialties.

Of patients with high call frequencies, we evaluated 2 specific cases and noted that some of these patients might be considered low complex. For example, patient A needed frequent dialysis treatments but was mainly served by a single health care provider. Alternatively, patient B was associated with multiple health care providers. The latter patient may benefit from scrutinizing their treatment plan and organizing advanced health care planning if deemed necessary. However, using this method to identify such cases would assume that potential privacy issues are recognized and resolved, which is beyond the scope of this paper.

Policymakers and clinicians may use the results of our analyses to engage in discussions or assess the current standard of care. Our results indicate that frequent users with no clear indication, such as dialysis, are "shopping and hopping," representing an unmet need while utilizing excessive resources. The onus is on general practitioners and nursing home specialists to address this challenge. Advanced care planning and timely and appropriate care at the right location for this category of frequent users might enhance their quality of life while saving scarce resources. Providing sound evidence for the latter would require a different type of study.

Limitations

This study also has limitations. Firstly, only the frail elderly were studied at some depth, using EMS records for only one province in the Netherlands. Nevertheless, while health care consumption patterns are likely to be affected by regional characteristics, it is expected that the success of the proposed approach is not dependent on the latter. Secondly, EMS records only include frequent users who are not capable of self-transport. Thus, frequent users who do not or rarely use EMS will not be traced by the proposed approach. Thirdly, as it is explorative, the paper highlights the potential of the proposed approach in tracing frequent users and enhancing regional policymaking. Ongoing and future research should be directed toward confirming and expanding the method, including comparisons with alternative approaches.

Conclusions

The combined use of EMS data and process mining allows for the effective and efficient tracing of frequent users of health care services. The approach supports regional policymakers and clinicians by quantifying and detailing frequent user consumption patterns to support subsequent policy adaptations.

Acknowledgments

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Authors' Contributions

LM, DJZ, and EB contributed to the concept and design of the study and critical revision of the manuscript for important intellectual content. LM and DJZ analyzed and interpreted the data and drafted the manuscript. LM completed the data acquisition and provided statistical expertise.

Conflicts of Interest

None declared.

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Abbreviations

ALS: advanced life support
DRH: dialysis, radiation therapy, or hyperbaric medicine
ED: emergency department
EMS: emergency medical services

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Original Paper

Clinician-Created Educational Video Resources for Shared Decision-making in the Outpatient Management of Chronic Disease: Development and Evaluation Study

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Abstract

Background: The provision of reliable patient education is essential for shared decision-making. However, many clinicians are reluctant to use commonly available resources, as they are generic and may contain information of insufficient quality. Clinician-created educational materials, accessed during the waiting time prior to consultation, can potentially benefit clinical practice if developed in a time- and resource-efficient manner.

Objective: The aim of this study is to evaluate the utility of educational videos in improving patient decision-making, as well as consultation satisfaction and anxiety, within the outpatient management of chronic disease (represented by atrial fibrillation). The approach involves clinicians creating audiovisual patient education in a time- and resource-efficient manner for opportunistic delivery, using mobile smart devices with internet access, during waiting time before consultation.

Methods: We implemented this educational approach in outpatient clinics and collected patient responses through an electronic survey. The educational module was a web-based combination of 4 short videos viewed sequentially, followed by a patient experience survey using 5-point Likert scales and 0-100 visual analogue scales. The clinician developed the audiovisual module over a 2-day span while performing usual clinical tasks, using existing hardware and software resources (laptop and tablet). Patients presenting for the outpatient management of atrial fibrillation accessed the module during waiting time before their consultation using either a URL or Quick Response (QR) code on a provided tablet or their own mobile smart devices. The primary outcome of the study was the module's utility in improving patient decision-making ability, as measured on a 0-100 visual analogue scale. Secondary outcomes were the level of patient satisfaction with the videos, measured with 5-point Likert scales, in addition to the patient's value for clinician narration and the module's utility in improving anxiety and long-term treatment adherence, as represented on 0-100 visual analogue scales.

Results: This study enrolled 116 patients presenting for the outpatient management of atrial fibrillation. The proportion of responses that were "very satisfied" with the educational video content across the 4 videos ranged from 93% (86/92) to 96.3% (104/108) and this was between 98% (90/92) and 99.1% (107/108) for "satisfied" or "very satisfied." There were no reports of dissatisfaction for the first 3 videos, and only 1% (1/92) of responders reported dissatisfaction for the fourth video. The median reported scores (on 0-100 visual analogue scales) were 90 (IQR 82.5-97) for improving patient decision-making, 89 (IQR 81-95) for reducing consultation anxiety, 90 (IQR 81-97) for improving treatment adherence, and 82 (IQR 70-90) for the clinician's narration adding benefit to the patient experience.

Conclusions: Clinician-created educational videos for chronic disease management resulted in improvements in patient-reported informed decision-making ability and expected long-term treatment adherence, as well as anxiety reduction. This form of patient education was also time efficient as it used the sunk time cost of waiting time to provide education without requiring additional clinician input.

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KEYWORDS

Shared decision-making; chronic disease; outpatients; audiovisual aids; atrial fibrillation; educational technology; teaching materials; referral and consultation; physician-patient relations; physicians

Introduction

Chronic disease is the leading cause of disease burden and mortality worldwide, with increasing prevalence due to an aging global population [1]. Cardiovascular disease is one of the major categories of chronic disease, and atrial fibrillation (AF) is widely recognized as one of the most common chronic conditions [2].

Ongoing outpatient consultations are an essential component of chronic disease management [3], and one strategy that could have considerable utility in this setting is that of "shared decision-making" [4]. Shared decision-making involves bidirectional information exchange within the clinician-patient relationship before making management decisions [5], and can optimize the practice of evidence-based medicine [6]. Patients are informed and care is patient-centered as the patient is empowered to communicate their personal values and management preferences for the clinician to individualize suggested management options [7]. A patient's level of involvement in shared decision-making is influenced by their level of health literacy [8], and accordingly educational decision aids are facilitative [9]. Decision aids have shown potential benefit [10] when implemented while patients are waiting for the consultation [11].

Audiovisual education aids, including videos, can be an effective method of improving patient health literacy [10,12,13]. However, clinicians may be reluctant to use those that are commonly available (eg, those publicly available on health care websites or YouTube) if they are generic or contain information of insufficient accuracy, quality, or currency [14]. Patient care may benefit from clinicians creating their own audiovisual content and delivering it to their patients within the clinical setting.

Based on findings from the prior literature [15], we hypothesized that clinician-created audiovisual content could be created with limited resources and would be acceptable and improve the ability of patients to contribute to the decision-making process. Integral to this is understanding effects of the intervention on anxiety around consultation ("white coat" effects) [16] and potential long-term compliance to formulated management plans [17]. We aimed to evaluate this approach within outpatient management of chronic disease (represented by AF in this instance [2]), whereby clinicians create audiovisual patient education in a time- and resource-efficient manner for opportunistic delivery, using mobile smart devices with internet access, during waiting time before consultation. Specifically, we aimed to assess the following: patient satisfaction with the individual videos and the approach overall, patient response to clinician narration within the content, and the patient-perceived effect of the approach on patient decision-making, patient anxiety around consultation, and potential long-term treatment adherence.

Methods

Study Design

We conducted a prospective, nonrandomized, observational study of 116 patients presenting specifically for the outpatient management of AF. Patients provided informed consent through a validated electronic form before commencing the audiovisual module on a smart device. Ethical approval for the study was obtained from the Western Sydney Local Health Network Human Research Ethics Committee (item number 2011–18).

Setting and Participants

Consecutive patients presenting for outpatient management of AF were prospectively recruited at a specialist outpatient clinic within a large university teaching hospital in Sydney, Australia. The site was within a public metropolitan hospital that serves patients of the Western Sydney Local Health District. As of 2018, the district provides AUD $1.8 billion (US $1.3 billion) in public health care to over 120 suburbs consisting of a demographically diverse population; approximately 50% of the residents have chronic conditions [18]. Potential participants were identified by study personnel via screening of the specialist outpatient clinic lists.

Patients were eligible for inclusion if they had presented to the specialist outpatient clinic specifically for consultation for the management of AF, and were English speaking, willing and able to use smart devices, and could provide informed consent. Patients were excluded if they were unable to speak English, refused consent, or had visual impairment or any other factor that prevented them from using the provided tablet (eg, rheumatoid arthritis). All prospective patients who met the inclusion criteria were enrolled in the study.

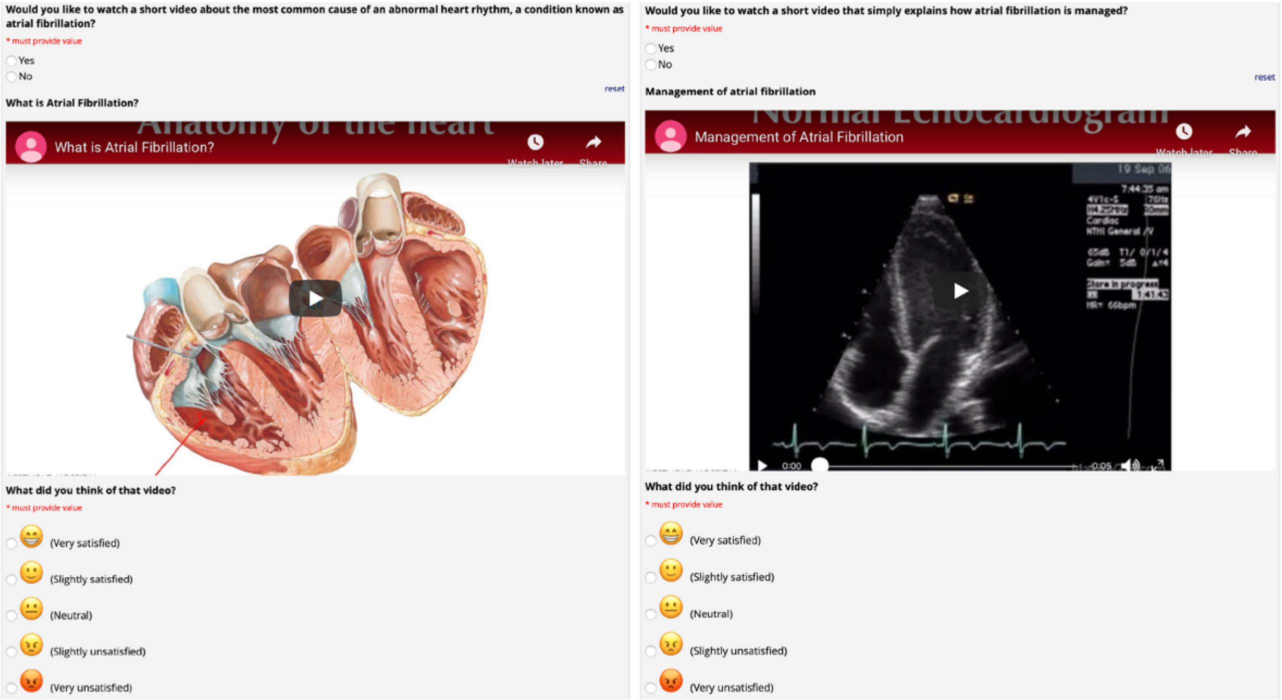
Development of the Audiovisual Module

The educational audiovisual module was designed to be a web-based combination of 4 short videos (privately hosted on YouTube) to be viewed sequentially, accompanied by questions gauging patient experience. The module was consolidated using Research Electronic Data Capture (REDCap) [19]. Data from the module were collected and coded on REDCap via a secure database.

The audiovisual module sought to provide a baseline level of disease-specific health literacy to patients that supplemented information provision and improved shared decision-making in the subsequent outpatient consultation. For this study, two of the authors (AT and JGK) consulted the latest guidelines and peer-reviewed literature, and decided on an up-to-date, reliable, yet simple syllabus covering the fundamental concepts of the pathophysiology, clinical presentation, diagnosis, and management of AF. For this, we searched for studies of any design, in any setting, within Scopus using the search term “atrial fibrillation” in all fields. To ensure that the most prominent recent AF literature was reviewed, the search was date restricted from January 2016 to December 2018, and the 46,393 resultant records were sorted in order of total number of citations. From the prominent recent AF literature that was reviewed, the two most cited guidance statements specifically relevant to the management of AF [20,21] were discussed by two authors (AT and JGK) and concepts and the syllabus outline were subsequently formulated by consensus. The resultant module contained four succinct videos encompassing the following topics: (1) “What is AF?” (2) “AF Management,” (3) “Stroke risk and anticoagulation,” and (4) “Lifestyle modification.”

For the measurement of outcomes, we used Likert scales and visual analogue scales, which have both demonstrated reliability and validity as health measurement tools [22]. The level of patient satisfaction for each individual video and satisfaction with the videos overall were recorded on 5-point Likert scales [23]. Further, 0-100 visual analogue scales were used to gauge the patient’s response to clinician narration, as well as the module’s patient-perceived utility in improving patient decision-making, anxiety around consultation, and potential long-term treatment adherence. The visual analogue scales and Likert scales were created and combined with the 4 videos for the audiovisual module using REDCap (Figure 1).

Figure 1. A sample of the web-based audiovisual educational module consolidated using REDCap.



Would you like to watch a short video about the most common cause of an abnormal heart rhythm, a condition known as atrial fibrillation?
* must provide value
○ Yes
○ No
reset

What is Atrial Fibrillation?

What did you think of that video?
* must provide value
○ (Very satisfied)
○ (Slightly satisfied)
○ (Neutral)
○ (Slightly unsatisfied)
○ (Very unsatisfied)

Would you like to watch a short video that simply explains how atrial fibrillation is managed?
* must provide value
○ Yes
○ No
reset

Management of atrial fibrillation

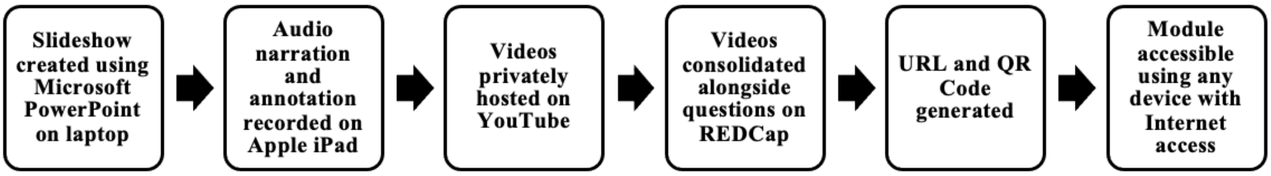
What did you think of that video?
* must provide value
○ (Very satisfied)
○ (Slightly satisfied)
○ (Neutral)
○ (Slightly unsatisfied)
○ (Very unsatisfied)

After the simple syllabus was formulated, the clinician (AT) developed the audiovisual module over a 2-day span between clinical commitments and within normal working hours (approximately 3 hours total). No disruption to regular clinical duties was experienced. The only material resources used in the process were that of a laptop containing Microsoft PowerPoint (Microsoft Corp) and an Apple iPad (Apple Inc), both of which were already owned by the clinician, thus not incurring any additional financial costs.

To make the 4 educational videos within the module, the clinician created 4 brief slideshows using PowerPoint on a laptop, then recorded audio narration simultaneously to annotate the slideshows using the Apple iPad using the Screen Recording function available by default on iOS 13 or later (Figure 2). The latter was done in a single take; on average, it took the clinician 3 minutes and 42 seconds to record the audio narration and annotation that complemented the slideshows within each individual video. The videos were subsequently privately hosted on YouTube in order to be consolidated alongside the patient experience survey on REDCap. This ensured that no advertising material was delivered with the videos by the YouTube website. REDCap then generated a URL, also known as a web address, and a Quick Response (QR) code, both of which enabled access to the educational module using any device with internet access.

All information provided within the module was only included following brief inspection of the latest peer-reviewed literature on the associated topics by the clinician to update existing knowledge. Further, the module was recorded in English with language and readability aimed below an eighth grade level to enhance accessibility for the general adult population [24]. The audiovisual module, along with all included images and visual media, was consolidated solely for private use limited to the duration of the study. It was not marketed or sold for commercial purposes.

Figure 2. Technique for audiovisual module creation by a clinician.



Delivery During Waiting Time

To minimize potential bias attributable to the halo effect [25], patients were approached by members of staff in the specialist clinic other than the clinician who created the educational videos. Following informed consent, patients completed the audiovisual educational module during the otherwise nonclinically utilized waiting time before their consultation for AF. Patients accessed the web-based module through either the URL or QR code generated by REDCap. This was done using either a tablet that was already owned by the treating specialist in the clinic or mobile smart devices that the patients already owned.

The entire audiovisual module was designed to take a maximum of 20 minutes for the patient to complete, so as to comfortably be completed during the expected waiting time before outpatient consultation [26]. Further, the cumulative duration of all four videos totaled 14 minutes and 46 seconds, so as to maximize concentration and minimize the chances of attention decline [27].

Data Elements

The primary outcome of the study was the audiovisual educational module's utility in improving patient decision-making ability during the subsequent outpatient consultation [17], which was measured in an anonymous manner using a 0-100 visual analogue scale. The secondary outcomes were the level of patient satisfaction for each video and satisfaction with the videos overall (both measured using 5-point Likert scales), as well as the patient's value for clinician narration, and the module's patient-perceived utility in improving anxiety around consultation and potential long-term treatment adherence (all measured using 0-100 visual analogue scales in an anonymous manner). Data were extracted by two authors (JGK and AT) from the secure REDCap database as a CSV file.

Statistical Analysis

Data were assessed in Python (open source, Python Software Foundation) using the Pandas library (version 1.0.4, open source, PyData), with results reported using medians and interquartile ranges. Figures were prepared using the Plotly (version 4.8.1) library. Friedman test and post hoc analysis were performed using Statsmodels (version 0.10.2, open source) as the data were not normally distributed, with repeated observations on the same individuals.

Results

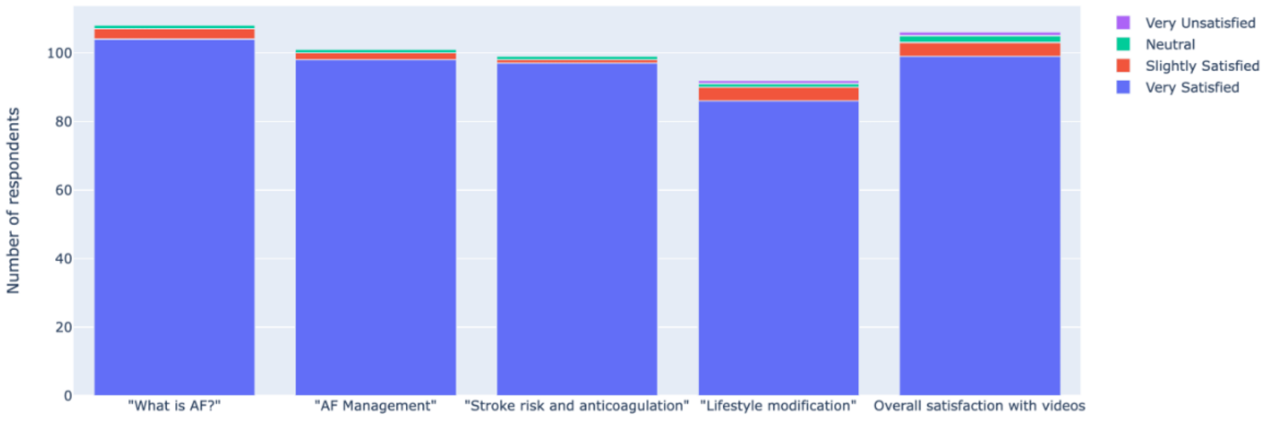
Overview

Between January 2019 and August 2019, all 116 prospective patients who met the aforementioned inclusion criteria were enrolled in the study. Response rates for the 5-point Likert scales progressively decreased with each successive video, with 93.1% (108/116) of the total cohort conveying their level of satisfaction with the first video ("What is AF?"), 87.1% (101/116) for the second ("AF Management"), 85.3% (99/116) for the third ("Stroke risk and anticoagulation"), and 79.3% (92/116) for the fourth ("Lifestyle modification"). In addition, 85.3% (99/116) of the total cohort reported the effect of the audiovisual module on consultation anxiety, decision-making ability, and likelihood of potential treatment adherence through the 0-100 visual analogue scales, with 84.5% (98/116) reporting the importance of clinician narration.

Likert Scales

The proportion of participants that were "very satisfied" with the educational video content ranged from 93% (86/92) to 96.3% (104/108) for the individual videos. In the final 5-point Likert scale assessing overall satisfaction with all 4 videos, 93.4% (99/106) of responders were "very satisfied," with 0.9% (1/106) reporting dissatisfaction. For the first video ("What is AF?"), 99.1% (107/108) of responders reported satisfaction with the content, compared to 99.0% (100/101) for the second ("AF Management"), 99.0% (98/99) for the third ("Stroke risk and anticoagulation"), and 98% (90/92) for the fourth ("Lifestyle modification"). There were no reports of dissatisfaction for the first 3 videos, and 1% (1/92) of responders reported dissatisfaction for the fourth video. Patient satisfaction with the clinician-created educational videos, as obtained through 5-point Likert scales, is represented in Figure 3.

Figure 3. Patient satisfaction with clinician-created videos. AF: atrial fibrillation.



Visual Analogue Scales

Median scores on the four 0-100 visual analogue scales ranged from 82 to 90. The audiovisual module resulted in median reported patient-perceived scores of 90 (IQR 82.5-97) for improving patient decision-making, 89 (IQR 81-95) for improving consultation anxiety, 90 (IQR 81-97) for improving potential treatment adherence, and 82 (IQR 70-90) for the clinician's narration adding benefit to the patient experience.

Patient responses to the 0-100 visual analogue scales are presented in Figure 4.

Friedman test results yielded a Friedman statistic value of 33.3 (*P*<.001). The Nemenyi post hoc analysis showed that only "Importance of clinician narration" was significantly different (*P*=.001) from all the other evaluations. The other evaluations did not differ significantly from each other. These results are presented in Table 1.

Figure 4. Patient responses to the audiovisual module.

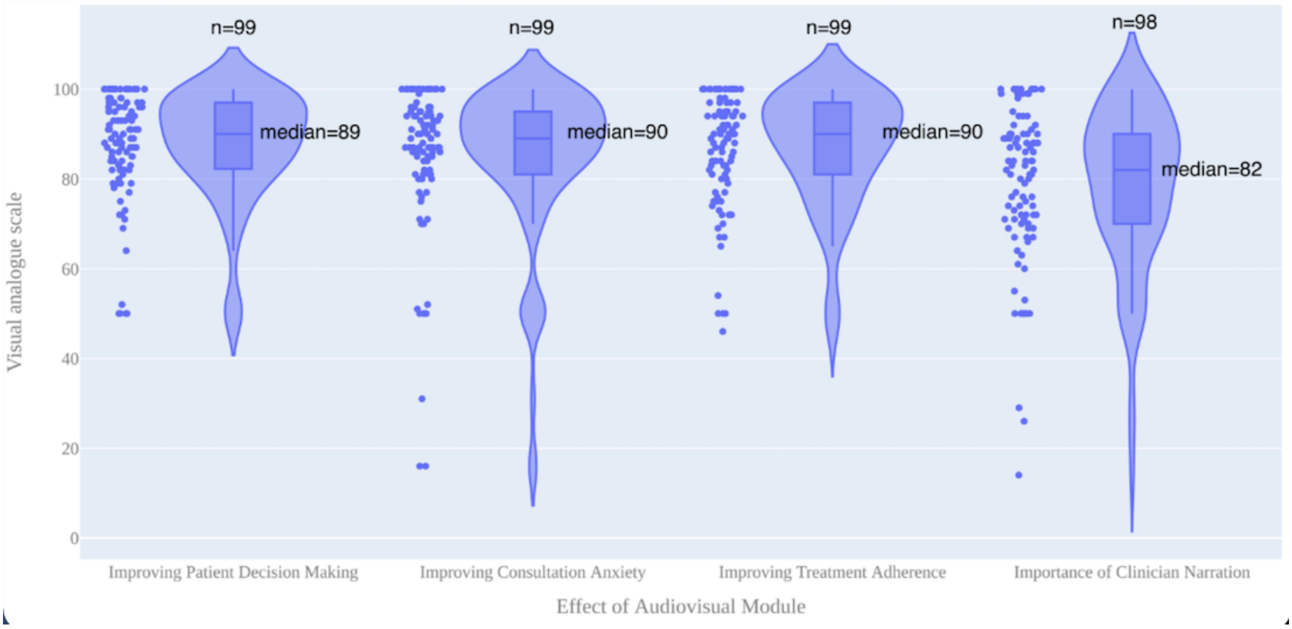


Table 1. Analysis of patient responses using the Friedman test.

Evaluation	Improving consultation anxiety	Improving patient decision making	Improving potential treatment adherence	Importance of clinician narration
Improving consultation anxiety	1	.70	.90	.001
Improving patient decision making	.70	1	.49	.001
Improving potential treatment adherence	.90	.49	1	.001
Importance of clinician narration	.001	.001	.001	1

Discussion

Principal Findings

A clinician-created audiovisual patient education module with content focusing on improving consultation efficiency and shared decision-making received scores indicating a high level of acceptability and patient-perceived utility. The video content was developed by a clinician using electronic resources that are relatively common in the developed world, during interstitial time between clinical duties, and was delivered using mobile smart devices while patients were waiting for their appointments. The majority of participants perceived the clinician's creation and narration of the module to be positive and effective in delivering the educational content of the disease-specific videos.

Shared decision-making provides a potential solution for achieving adequate efficiency while improving patient autonomy [28]; however, this may not translate to clinical practice if the appropriate approach to implementation is not taken [29]. An element of usefulness in our approach is that it not only improves shared decision-making, but also uses waiting time (sunk time cost) for an improved patient experience that does not add to the overall length of the consultation. Further, our approach demonstrates that clinicians can use off-the-shelf tools to simply create their own highly customized educational content tailored specifically for their patients. Further, it is implementable with minimal additional resources.

Patient education has been shown to be more effective when delivered in an audiovisual format than when presented solely through visual pamphlets or verbal one-to-one dialogue [30]. However, clinical utility for the management of chronic disease is limited when audiovisual patient education has required additional outpatient appointments [31]. This intervention used shorter duration, highly focused videos, allowing delivery in the waiting room so that patients would not have to make additional visits. Increasing access to unreliable, inaccurate, and outdated sources via the internet can increase confusion and cause difficulties during consultations for the management of patients' conditions [32]. This can potentially be reduced through the provision of up-to-date and reliable information directly from a patient's own treating clinician, as a supplement to scheduled consultations. Our approach allows for the provision of reliable health education in a manner that is streamlined for integration within both the clinician (through time and resource efficiency) and patient (through tailored, accessible education) experience of outpatient consultation.

The audiovisual educational module demonstrated utility in improving patient-reported decision-making ability for the subsequent outpatient consultation for AF management. However, due to a lack of any of the validated outcome measures or objective endpoints that are found within the existing literature of studies investigating shared decision-making in AF management [33], comparison between previous studies and our study is compromised. The high levels of patient satisfaction with both the videos and clinician narration suggest that there may be potential usefulness in clinician-created audiovisual educational content for the management of chronic disease. Further, anxiety [34], particularly that associated with the "white coat" effect [16], and long-term treatment adherence [17,35] have a significant impact on a patient's decision-making ability regarding the management of any chronic disease. Accordingly, our positive findings imply potential value in these domains. Our finding of patient-reported improvements to potential treatment adherence is in line with the existing literature, which has demonstrated the efficacy of video-assisted patient education in positively modifying the behaviors of patients with chronic disease if designed and delivered correctly [36].

There were limitations to this study that require future evaluation. Our study did not have a control group that enabled comparison; the study was observational and baseline characteristics of the participants were not collected. However, we prospectively included a consecutive series of eligible patients to limit patient bias, and all patients answered the same questionnaire. Our study was limited by subjective responses from patients as outcome measures, instead of outcome measures such as recurrence of AF or occurrence of its complications. The data collected referred specifically to the patients' own perceptions, which may carry inherent bias. We did not collect data using validated measures of patient-reported experience or health literacy. Further, we delivered the educational module only in English, and excluded non–English-speaking patients. Within the literature search that informed the curriculum for our educational module, sorting search results in Scopus by total numbers of citations identified the most prominent articles within the search time frame, but added a source of bias regarding the data informing our intervention. As our study was conducted in 2019, any evidence published since then has not been integrated. Further, only one database was searched prior to the development of our curriculum, so some literature may have been missed. The study was limited to a single center, so this approach's multicenter applicability has not been tested. Additionally, although the clinician in our study was able to carry out our approach in a time- and resource-efficient manner, this approach may not translate to certain doctors with different levels of resources, time within schedules, and technology skills.

Findings from this pilot study may be useful for future research in this area. Although audio narration was used in this study, future studies may benefit from the inclusion of video of the treating clinician and investigation of subsequent effects on patient trust, anxiety reduction, and potential adherence. Clinical interactions within settings outside the management of chronic disease at outpatient clinics may also benefit from this approach and should be investigated. Usefulness of the approach relative to the socioeconomic status of the health care provider may be important to delineate for the maximization of global scalability. Further, exploration of utility for health professionals in other areas of medicine, surgery, nursing, and allied health ought to be explored. Study design in this future research can be improved by incorporating a comparison (ideally with randomization) against other forms of patient education as well as more concrete endpoints, such as objective health metrics or validated scoring schemas. The measures of patient perceptions that were recorded in this pilot study may be better assessed via a longitudinal approach that facilitates the evaluation of temporal trends. Explanations for changes in patient perceptions throughout the course of the videos may have greater clarity if more qualitative data points are also collected in addition to measures of satisfaction.

Conclusions

This approach to outpatient consultation for the management of chronic disease may provide benefit for shared decision-making between clinicians and patients, overall leading to the improvement of care while maintaining a patient-centered focus. It benefits clinicians by combining their individual content knowledge with technology to create highly customized disease-specific audiovisual educational material for their patients. It benefits patients by allowing them to learn about their condition in a nonconfrontational situation without additional investment of time or effort. Patient satisfaction may be improved by converting a potentially negative situation (the sunk time cost of waiting for a medical appointment) to a positive experience. This pilot study demonstrated the potential utility of this approach in a specific setting; however, it may have widespread applicability across a large number of clinical scenarios, including those outside the management of chronic disease and outside the outpatient setting. Future research should explore this potential widespread applicability of our approach through studies of larger size and strong design.

Authors' Contributions

JGK was involved in the design of the study, the development of the associated intervention, and the preparation of this manuscript. DM was involved in the development of the associated intervention, data collection, and the preparation of this manuscript. WWBC was involved in data collection and the preparation of this manuscript. CKC was involved in the preparation of this manuscript. AT was involved in the design of the study, the development of the associated intervention, and the preparation of this manuscript.

Conflicts of Interest

CKC is supported by an NHMRC (National Health and Medical Research Council) Investigator grant. The other authors have no conflicts to declare.

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Abbreviations

AF: atrial fibrillation
QR: Quick Response
REDCap: Research Electronic Data Capture

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Viewpoint

Harnessing Machine Learning to Personalize Web-Based Health Care Content

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Abstract

Web-based health care content has emerged as a primary source for patients to access health information without direct guidance from health care providers. The benefit of this approach is dependent on the ability of patients to access engaging high-quality information, but significant variability in the quality of web-based information often forces patients to navigate large quantities of inaccurate, incomplete, irrelevant, or inaccessible content. Personalization positions the patient at the center of health care models by considering their needs, preferences, goals, and values. However, the traditional methods used thus far in health care to determine the factors of high-quality content for a particular user are insufficient. Machine learning (ML) uses algorithms to process and uncover patterns within large volumes of data to develop predictive models that automatically improve over time. The health care sector has lagged behind other industries in implementing ML to analyze user and content features, which can automate personalized content recommendations on a mass scale. With the advent of *big data* in health care, which builds comprehensive patient profiles drawn from several disparate sources, ML can be used to integrate structured and unstructured data from users and content to deliver content that is predicted to be effective and engaging for patients. This enables patients to engage in their health and support education, self-management, and positive behavior change as well as to enhance clinical outcomes.

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KEYWORDS

internet; online health information; personalized content; patient education; machine learning

Introduction

The internet is a key medium in the consumption of health care–related content. Two-thirds of internet users in the United Kingdom and the United States access health-related information on the internet [1-3]. Furthermore, patients are increasingly motivated and able to participate in developing this growing repository of information by sharing their lived experiences [4]. Health care professionals also consume as well as create and share web-based health care information [5].

A vast array of web-based content types and delivery media and channels are available, including videos, webpages, podcasts, images, online discussion groups and communities, and social media [6-10]. A systematic review reporting on the assessment of web-based content quality identified key domains, including accuracy, completeness, accessibility, presentation, and design, which were important overall in determining how useful and engaging content was for patients [11]. However, there is considerable variability in the quality of such content [12]. Berland et al [13] demonstrated that using search engines for common health conditions retrieved relevant content in only one out of five searches, suggesting that patients are likely to come across irrelevant content when seeking information about health. Moreover, only half of the topics that physicians thought important to convey were accurately and appropriately covered [13].

The concept of content personalization is a powerful approach that addresses the previously described features of quality by presenting the user with relevant information that is both appropriate and engaging. A more engaged patient is more likely to understand information about their health, partake in healthy behaviors, and adhere to treatment, leading to better health outcomes [14].

Machine learning (ML) is a subset of artificial intelligence that uses algorithms to study patterns in data and develop models that improve predictions about the data over time through supervised learning, unsupervised learning, or reinforcement learning [15]. Many industries use ML techniques to analyze accrued *big data* to personalize content for users [16]. The health care sector may be well served by considering these advances in other industries to personalize experiences for people seeking health care content. ML-assisted personalization can be considered for both large groups and populations or for individuals.

In this review, we aim to first outline why the health care sector should recognize the importance of personalizing content (*Why Personalizing Web-Based Health Care Content Is Important*). We then explore the current landscape of content personalization (including ML and non-ML) both within and outside health care (*Content Personalization*). Finally, we discuss practical applications of personalization in health care, outline a model that demonstrates how ML can personalize web-based content, and consider the anticipated benefits and drawbacks (*Potential Lessons to Learn for Health Care*).

Why Personalizing Web-Based Health Care Content Is Important

There has been an increased focus on empowering patients to engage with their own health. The delivery of information to patients has been recognized as a tenet of health care policy, resulting in almost universally positive outcomes for patients, health care staff, and communities [17]. The UK National Health Service Five Year Forward View outlined the need to facilitate patient activation by improving access to information, supporting self-management, and increasing patient control over the care they receive, with particular emphasis placed on harnessing digital technology [18]. This aligns with the *patient-centered* model [19], which improves patient satisfaction, quality of life, and quality of care provided [20]. Personalization facilitates the patient-centered model by delivering health care content that accounts for the preferences and needs of individual patients. The proliferation of easily accessible web-based content provides an opportunity to enable *patient-centered* information delivery at scale.

A randomized controlled trial of the provision of computer-based information to cancer patients reported that patients preferred to receive personalized information (based on their medical records) as opposed to generalized information [21]. They were more likely to share these resources with family members, and additionally, this approach was associated with a reduction in anxiety levels. A similar effect was demonstrated with personalization of booklets [22] and tailored information packs [23].

It is well established that the health care content needs to vary between different patients and also change over time. Uncertainty, the inability to determine the meaning of illness-related events, has been shown to have a deleterious effect on patient experience and outcomes [24,25]; therefore, timely and accurate delivery of information is important to address information needs. However, patients' information needs vary according to stage of disease, stage of patient journey, age, previous experiences, and coping styles [26]. A blanket *one-size-fits-all* strategy for designing and delivering health care content is unlikely to be effective.

Another advantage of personalizing health care content is its potential to improve health-related choices. One of the principles of the *patient-centered* model is sharing responsibility for clinical decisions with patients (shared decision-making) [27]. Patient decision aids are evidence-based tools designed to assist in shared decision-making. They facilitate information exchange by helping patients understand the clinical conditions and the available options for treatment. They have been demonstrated to improve patient knowledge and facilitate decision-making that is more aligned with patient values and preferences [28,29].

A study on improving patient decision-making related to prostate cancer screening found that personalizing a patient decision aid based on a number of factors that patients considered important (eg, survival, unnecessary biopsy, overdiagnosis, quality of life, burden of treatment, and burden on caregivers) improved patient opinion on screening and the quality of their decision [30]. Decision quality was assessed using an instrument that allows patients to self-rate and weigh separate elements of decision quality, including the perceived clarity of options provided, relative importance and likelihood of possible outcomes, trust toward the information delivered, support received throughout the decision-making process, sense of control over the decision, and commitment toward acting on the decision [31].

It is increasingly recognized that delivering health information without consideration for personalization and the relevance of content experienced limits the potential to change health behavior [32,33]. A meta-analysis on behavior choices from 40 web-based interventions, which used personalized strategies including interactive multimedia content, tailored feedback, discussion groups, and personalized management plans, showed a positive impact on behavior outcomes related to smoking cessation, alcoholism, physical activity, diet, and chronic disease management [34]. These findings are corroborated by other meta-analyses evaluating tailored content for similar health-related behavior outcomes [35-38]. However, given the significant heterogeneity in the intervention modality, design, and features, it is challenging to identify the specific factors that are most associated with behavior change.

With a greater understanding of these factors, there is significant scope to integrate personalized content into both large-scale public health initiatives as well as individual treatment plans to encourage self-management, adherence to treatment, and positive lifestyle changes.

Content Personalization

Content Personalization in Health Care—Current State

The paths patients take to encounter web-based content can be described by a number of discrete patient journeys. First, patients can independently find web-based information using internet search engines. Although this offers patients a plethora of information, quality (as previously discussed in the *Introduction* section) is variable [12]. Without strict content moderation and regulation, patients may struggle to parse out factual and relevant content, instead relying on content that is superficially engaging (*clickbait*) or appears credible. Furthermore, subtle differences in search terms can significantly alter the quality of the retrieved information [39].

Health care organizations and services hold repositories of quality-controlled content and can serve as gateway sites for other similar websites [40]. These provide credible and accurate information but hold limited quantities of content and may not be directly relevant to every patient. Health care professionals can assess individual information-seeking needs during consultations and refer patients to high-quality and engaging content [5]. However, this solution lacks scalability because most web-based health care searching encounters are *unsupervised* by health care providers. Limitations on how patients access health information can be addressed with content personalization, which mandates an understanding of what factors may be important in personalizing content.

Patients' information needs are affected by several factors that may influence how patients respond to web-based content, as discussed in *Why Personalizing Web-Based Health Care Content Is Important* section. For example, in the context of age, older patients often report difficulty in accessing useful web-based content because of complex website layouts, lack of navigational aids or instructional tools, and too much information being presented [41]. Younger patients may be more prone to uncertainty and worry about their health, resulting in information-seeking behavior [42]. A study that allowed cancer patients to self-tailor web-based educational content based on text, visual, and audio-visual modes demonstrated increased satisfaction among younger patients in comparison with nontailored content [43].

With regard to factors that affect the decision to select or reject web-based content, a study found several content and design features that influenced whether patients trust web-based information related to hormone replacement therapy [44]. An initial poor impression of design factors—including inappropriate website name, complex layout, poor navigation aids, dull design, small print, and excessive text—constituted 94% of cited reasons for rejection. Content features were then comparatively more important in selecting trustworthy websites. This consisted of informative content, accessible explanations, illustrations, breadth of topics covered, unbiased information, age-related information, clear language, discussion groups, and a frequently answered questions section. Source factors were also key, such as explicit author or organization credibility and authors with similar social identities.

Other studies have evaluated the design and content factors that influence patients' engagement in web-based videos, particularly on the video streaming website YouTube, which is one of the most popular websites with over 2 billion daily views [45]. These include educational resources on a range of medical topics for both patients and health care professionals [46-51]. These studies also assessed the quality of content uploaded on YouTube, which is not strictly regulated and is liable to misinformation [7]. However, the correlation between engagement and quality of content is conflicting [7], suggesting that other factors are important for gaining user attention in educational resources.

An analysis of 390 scientific communication videos on YouTube found that user-generated content, videos with regular presenters, and rapidly paced videos were more engaging than their counterparts [52].

Similarly, another study concluded that patient experience videos were more popular than videos created by health care professionals, as assessed by the video power index [53]. The video power index is an innovative tool that measures video performance by assessing its effectiveness on all platforms, comparing it with industry leaders, and aiding strategies to engage target audiences [54]. In terms of webpage content, Finnegan et al [55] found that engaging content categories were first-person narrative articles, articles that answer questions posed by readers, and articles with videos embedded in the webpage. These are all potential factors that can be considered when personalizing video content toward patients.

Sorice et al [56] examined patients' preferred social media content related to plastic surgery on six social media platforms (Facebook, Instagram, Pinterest, Snapchat, Twitter, and YouTube) [56]. Patients used Facebook and YouTube as the most favored posts relating to before and after photographs and the surgery practice information. Second, the content that engaged plastic surgeons and patients differed. The authors concluded that this information should guide the web-based activity of plastic surgeons to effectively target the desired patients.

A systematic review evaluating factors associated with engaging web-based content revealed the following key categories: textual information, discussion boards and web-based groups, video content, visual or pictographs, device accessibility, stage of patient journey, credibility, and completeness of information [57]. A framework was developed for each category describing the factors that should be considered when designing an effective content. Evidently, the manner in which users engage with health care content is influenced by both design and content factors, many of which are likely not yet identified.

Content Personalization Outside Health Care—Current State

With increasing volumes of web-based data available for extraction, storage, and processing, ML is useful in improving the efficiency and accuracy of data processing models without human input. Its application spans a wide range of disciplines, including marketing, engineering, computer science, finance, bioinformatics, and health care. In the context of personalizing health care content, ML applications may fall into the following categories: facilitating market segmentation, content analysis, and recommender systems.

In marketing, maximizing user—or customer—engagement is obviously a key driver. Customer segmentation and personalization of content in these segments in a competitive environment is easy to appreciate. Furthermore, 59% of customers believe that personalization influences their purchasing habits [58]. A study reporting over 30,000 campaigns by one company revealed that targeted campaigns resulted in greater customer retention, engagement, and conversion into active users compared with generic campaigns [59]. Audience segmentation for web-based marketing aims to split the customer population based on characteristic features (eg, demographic, psychographic, geographic, behavior, and product preference) [60]. Individual customer segments can be targeted with specific content and products predicted to elicit the most attention, resulting in sales and profits [61]. However, customer segmentation performed by human marketers is limited by the amount of data that can be amassed, analytical methods that can be used, and the number of conclusions drawn. ML using clustering techniques can process larger volumes of data and uncover complex patterns to draw more practical conclusions and create better-defined segments for targeting. Infamously, this approach can also be used to target groups with messages that may affect behavior, such as political elections [62], but is less likely to be a useful method to personalize health care content for individuals, as there will still be differences in the needs and preferences of individuals within segments.

Recommender systems are used by the entertainment, e-commerce, and marketing industry to personalize content discovery and information retrieval in the context of massive item repositories [63-66]. Established methods include collaborative filtering, which applies the behavior of similar users to suggest new items of interest; content-based methods, which analyze content similarities with previous user preferences to produce recommendations; and hybrid methods, which combine both. Although the research landscape has predominantly focused on collaborative filtering [67], increased interest has gathered around content-based filtering with techniques emerging to identify content features [68], including user-generated tags and reviews [69], and advances in video [70] and image [71] analysis capabilities.

As one of the largest platforms for creating and sharing content, the YouTube recommender system uses deep learning to generate and rank candidate videos by incorporating a rich set of user and video features, such as the user's history, context, and interaction with similar videos [72]. This facilitates access to a small set of engaging personalized content from an ever-increasing repository of videos. Other studies have demonstrated several content factors that can also influence personalization. For example, a study incorporated textual content features including video metadata and nontextual features consisting of audio, scenes, and motion to enhance personalized recommendations for videos; this was more accurate in effective personalized video recommendation from large video data sets (Netflix and MovieLens) over existing models that use single specific content features [73].

Social media recommender systems provide insights into how companies personalize other media content discovery for users. Instagram analyzes content that users have previously interacted with and uses natural language processing to identify similar accounts to recommend content that the user is likely to interact with on their *Explore* page [74]. In addition, content analysis of social media pages reveals several factors that also influence user engagement and may further refine content personalization. In a study on over 13,000 Instagram posts, using an image application programming interface (API) to extract visual features from posts, several creator-related, context, and content factors predicted user engagement [75]. In particular, images containing people, scenery, and emoticons associated with positive emotions engaged users more strongly. Other content features on Instagram that correlate with user attention are photos with faces [76] and filters enhancing warmth, exposure, and contrast [77]. An analysis using a natural language processing API on over 100,000 messages on Facebook found that emotional and philanthropic content enhances engagement, whereas informative content reduces engagement in isolation, but further invokes attention when combined with persuasive features [78].

Advances in recommender systems have further improved the personalized recommendations. For instance, movie recommender systems traditionally use higher semantic features (eg, tags, plot, genre, and actors) suggested by users or experts to personalize recommendations [79]. A recent work using a deep learning neural network found that extracting low-level stylistic features (eg, colors, texture, and lighting) outperformed traditional semantic-based methods in recommending content [70]. With developments in algorithmic approaches and deep learning [68], high- and low-level content features can be integrated to generate more personalized content recommendations.

Recently, open-source services that leverage ML have become available on commercial platforms with the Google Cloud Artificial Intelligence as a foremost example [80,81]. These services require minimal ML expertise and consist of custom models using AutoML and pretrained models, which include video intelligence API (analyze video metadata), natural language API (analyze text), vision API (image segmentation and classification), and speech API (transcribing audio). Similar platforms exist with Amazon Rekognition image and video analysis [82], Microsoft Azure video indexer, text analytics and personalizer [83], and IBM Watson video content analysis and natural language understanding [84]. Amazon's predictive user engagement service offers to improve user engagement by analyzing real-time activity to personalize recommendations and notifications for users [85,86]. The prospect of designing custom ML may have been prohibitive for many industries previously, but these open-source platforms provide an opportunity to adopt it into the mainstream of a variety of disciplines for large-scale data processing.

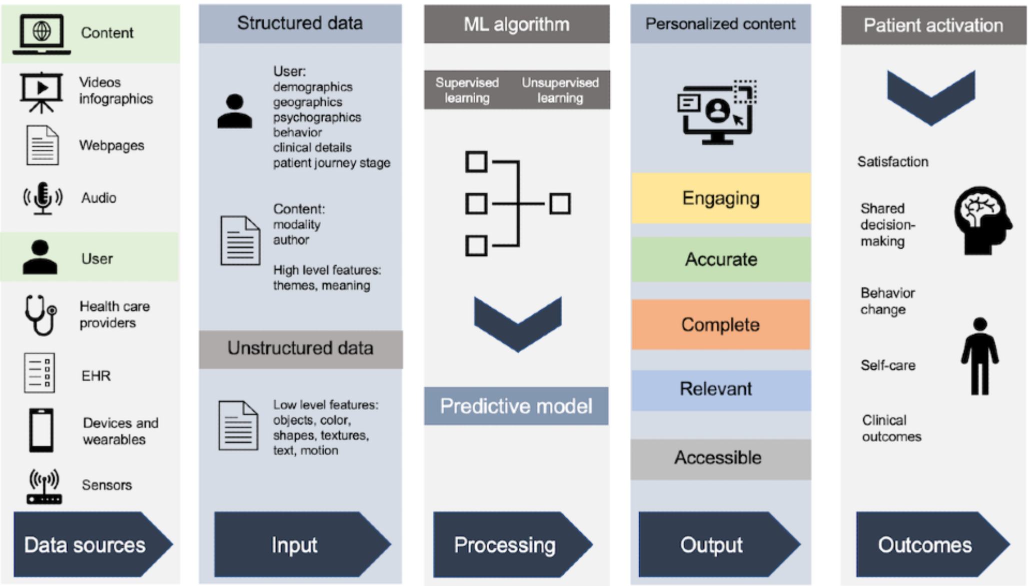
Potential Lessons to Learn for Health Care

The previous sections described user segmentation, targeted advertisements, and personalization based on recommender systems using ML techniques. With the vast amount of web-based health care content readily accessible to patients, cross-disciplinary collaboration and the use of open-source platforms indicate that these techniques may be feasible. If this is achieved, the aim of personalizing web-based content and enhancing outcomes is possible. However, clinical studies and clinical applications related to this are sparse.

Big data in health care can transform the field of health marketing (an established concept in public health medicine), drawing principles from traditional marketing to create, communicate, and deliver information in a patient-centered manner [87]. This aims to identify population segments and market health care messages to them in terms of the segments that are likely to respond [88]. A systematic review of health marketing research identified a number of studies that used hierarchical and nonhierarchical clustering techniques to segment health consumers in unique ways [88]. However, the studies did not explore whether these segments were meaningful (predictive segmentation) or whether personalized interventions affected outcomes. Furthermore, there was a reliance on rudimentary data such as survey, service, and basic clinical data, which limits the clustering process as opposed to truly *big* data. Although these strategies may have beneficial effects for groups of people, it is difficult to imagine their utility to individuals.

We propose a model that leverages ML algorithms to personalize content for an individual person (Figure 1). Health care big data consists of diverse data types, including clinical data, electronic patient records, biometrics, sensor-generated data, population data, social media posts, and webpages [16]. Electronic health records are accumulating data at an exponential rate. With the increasing use of medical devices, sensors, wearable technology, and social media, more personal data can be recorded [89]. These consist of potential sources of structured and unstructured data that may be fed into ML algorithms. Structured data include labeled user features such as demographics, geographics, psychographics, behavior, and clinical details, as well as content features consisting of modality, themes, and author information. Unstructured data, comprising 80% of all health care data [90], can be processed by video, image, and natural language processing APIs into structured formats [91]. ML algorithms using supervised and unsupervised learning can process these data to produce a predictive model for content personalization.

Figure 1. Suggested model using machine learning to personalize web-based health care content. EHR: electronic health record; ML: machine learning.



User features can be matched to content features (whether video, text, infographics, or audio) to create a model predicting which content is likely to be engaging to which people. Content features need not be limited to the content or design features identified in the *Content Personalization* section. Meta-level information encompassing object identification (colors, shapes, and texture), person or face identification, motion features, patterns, textual analysis, medical tags, higher semantic meaning, and significantly more may be extracted and analyzed. The content for patients can be created with these specific features in mind. Recommender systems could automatically predict other content that is useful and engaging to patients, conveying education that is likely to affect them.

Metrics related to view count, likes, shares, and positive comments have traditionally been used as an indicator of popularity, but they may only provide a superficial measure of engagement and fail to capture key outcomes for patients. Similarly, no single outcome metric is likely to be sufficient. Possible surrogate measures to consider include shared decision-making [27], patient satisfaction [92], objective clinical outcomes and symptoms [93], changes in attitude and behavior [94,95], and physiological signals [96]. These factors can aid in content personalization.

Harnessing data from personal digital devices such as wearables, phones, and computers has led to research into digital phenotyping and personal sensing, which refer to the analysis of data streams from personal devices to build a human phenotype by identifying behaviors, traits, thoughts, and feelings [97,98]. This field has been adopted predominantly in psychiatry, where the objective identification of behavior patterns can aid in the diagnosis and stratification of mental health conditions, as well as their treatment (digital health interventions) [97]. In a recent study of internet-based cognitive behavioral therapy, ML was used to identify different behavior patterns among segments of patients, consisting of low engagers, late engagers, high engagers with rapid disengagement, and the highest engagers [99]. Each patient subtype was more likely to engage with different intervention tools (eg, core modules, goal-based activities, mood trackers, and mindfulness tools), leading to varying improvements in depression and anxiety symptoms. The authors concluded that this information could be used to tailor specific intervention types to different patient subtypes to improve engagement and adherence to treatment.

There are clear similarities between these digital health concepts and the proposed model to personalize web-based health care content. In particular, ML can be used to analyze data streams that include sensor measurements, user activity on personal devices, and user-generated content to identify individual behavior patterns. This can then be used to personalize interventions, of which personalized content could form a part of the intervention, or, at the very least, to inform patients about their health and engage them in making healthy behavior choices.

The successful implementation of big data and ML in personalizing web-based content requires the input and collaboration of several multidisciplinary stakeholders [100]. Health care professionals must produce accurate and engaging user-centered content, which is consumed by patients who can use recommender systems to discover related content and are also able to create content on their own. ML algorithms based on the model described in Figure 1 were designed by computer scientists and ML engineers and further optimized by several data streams provided by patients and health care organizations. There should be ongoing collaborative research between clinicians and computer scientists to take advantage of developments in ML, such as the use of deep learning.

However, current inadequacies in the digital infrastructure of health care systems can pose a significant challenge to this process. For example, as outlined in the UK government policy paper on their future digital strategy plan [101], patient data are often stored in disparate systems between different hospitals and health care settings that are unable to communicate with each other. One of the priorities should, therefore, be to create data standards that facilitate the interoperability of patient health records, which would enable seamless access, storage, and processing at scale. It is promising that government agencies have already taken steps to outline frameworks to achieve secure access, interoperability, and sharing of health-related patient data [101,102].

Other drawbacks of big data and personalized health care must also be considered in addition to the benefits. Maintaining the privacy and security of sensitive patient data is paramount and poses significant challenges with the volume of data recorded from an increasing number of sources. No single legal or ethical framework covers all aspects of health information privacy [103]. Furthermore, many laws are outdated and insufficient for the current era of big data, which includes user-generated data (eg, wearables and sensors) and nonhealth information that can lead to health inferences (eg, social media habits) [104]. Therefore, governments and health care bodies must also act as key stakeholders to ensure that laws are updated to allow ML to be harnessed for the benefit of patients while maintaining privacy and security. This may necessitate the development of oversight agencies to strictly regulate the use of ML, as well as collaboration with cybersecurity experts [100]. The principles of consent in digital data research and use need to be established and will require input from governments, national data regulators, medical ethicists, legal experts, and, most importantly, patients [105].

There are several principles for maintaining private and secure data, including collecting data from trusted sources, encrypting and anonymizing stored data, maintaining strict authorization and access control, and securing processing environments [106]. However, a cybersecurity report in 2016 revealed a 320% year-on-year increase in breaches of protected health information in US hospitals, with 81% of breached records resulting from hacking attacks [107]. This compromised over 16 million individual patient health records, indicating a pressing need to continue monitoring and developing security systems in the face of both malicious and unintentional data breaches.

Conclusions

The proliferation of web-based content and increased participation of patients in interacting with said content provides an opportunity to understand what features of content are engaging to people. Harnessing ML technologies to process *big data* in health care will allow health care providers and other users to create and contribute to personalized content. These insights may be leveraged to facilitate patient activation and enable patients to make healthy choices, ultimately improving outcomes.

Authors' Contributions

UJ constructed themes for the manuscript. AG and PN wrote the paper. PN, AHD, and UJ critically revised the manuscript. All authors reviewed and approved the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
ML: machine learning

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Original Paper

Feasibility of a Mobile Health App for Routine Outcome Monitoring and Feedback in SMART Recovery Mutual Support Groups: Stage 1 Mixed Methods Pilot Study

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Abstract

Background: Mutual support groups are an important source of long-term help for people impacted by addictive behaviors. Routine outcome monitoring (ROM) and feedback are yet to be implemented in these settings. SMART Recovery mutual support groups focus on self-empowerment and use evidence-based techniques (eg, motivational and behavioral strategies). Trained facilitators lead all SMART Recovery groups, providing an opportunity to implement ROM.

Objective: The aim of this stage 1 pilot study is to explore the feasibility, acceptability, and preliminary outcomes of a novel, purpose-built mobile health ROM and feedback app (*SMART Track*) in mutual support groups coordinated by SMART Recovery Australia (SRAU) over 8 weeks.

Methods: *SMART Track* was developed during phase 1 of this study using participatory design methods and an iterative development process. During phase 2, 72 SRAU group participants were recruited to a nonrandomized, prospective, single-arm trial of the *SMART Track* app. Four modes of data collection were used: ROM data directly entered by participants into the app; app data analytics captured by Amplitude Analytics (number of visits, number of unique users, visit duration, time of visit, and user retention); baseline, 2-, and 8-week follow-up assessments conducted through telephone; and qualitative telephone interviews with a convenience sample of study participants (20/72, 28%) and facilitators (n=8).

Results: Of the 72 study participants, 68 (94%) created a *SMART Track* account, 64 (88%) used *SMART Track* at least once, and 42 (58%) used the app for more than 5 weeks. During week 1, 83% (60/72) of participants entered ROM data for one or more outcomes, decreasing to 31% (22/72) by the end of 8 weeks. The two main screens designed to provide personal feedback data (*Urges* screen and *Overall Progress* screen) were the most frequently visited sections of the app. Qualitative feedback from participants and facilitators supported the acceptability of *SMART Track* and the need for improved integration into the SRAU groups. Participants reported significant reductions between the baseline and 8- week scores on the Severity of Dependence Scale (mean difference 1.93, SD 3.02; 95% CI 1.12-2.73) and the Kessler Psychological Distress Scale-10 (mean difference 3.96, SD 8.31; 95% CI 1.75-6.17), but no change on the Substance Use Recovery Evaluator (mean difference 0.11, SD 7.97; 95% CI –2.02 to 2.24) was reported.

Conclusions: Findings support the feasibility, acceptability, and utility of *SMART Track*. Given that sustained engagement with mobile health apps is notoriously difficult to achieve, our findings are promising. *SMART Track* offers a potential solution for ROM and personal feedback, particularly for people with substance use disorders who attend mutual support groups.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12619000686101; https://anzctr.org.au/Trial/Registration/TrialReview.aspx?id=377336

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KEYWORDS

mHealth; SMART Recovery; mutual support group; mutual aid; routine outcome monitoring; treatment progress feedback; addiction; mobile phone

Introduction

Background

Routine outcome monitoring (ROM) is central to evidence-based health care for a range of chronic conditions [1], including addictive behaviors [2,3]. ROM is central to understanding, evaluating, and improving service delivery [4-6]. A range of clinical benefits have been identified [7-9], particularly for those people identified as *not on track* early in the course of treatment [10,11]. Emerging evidence suggests that providing clients with tailored feedback may be central to demonstrated improvements in client outcomes [12].

To date, ROM and feedback have been implemented in a range of mental health [13] and addiction [14,15] treatment settings but not in mutual support groups. Mutual support groups offer an important source of fee-free, accessible support to people experiencing a range of addictive behaviors. Mutual support is particularly important for people experiencing addictive behaviors, given the often long-term and nonlinear process of recovery [16]. Mutual support groups may be attended before, during, after, or in lieu of engagement with formal treatment services, providing the potential for continuity across the recovery process. Although accumulating evidence highlights the importance and benefits of participating in mutual support [17-21], a major limitation is the lack of systematically collected data evaluating the outcomes. Unlike other clinically endorsed [2,3] models of mutual support for addictive behaviors (eg, 12-step approaches), SMART Recovery groups use a trained facilitator. This provides a unique opportunity to work with group facilitators to embed ROM and personal feedback as a standard component of the groups.

Integrating ROM and tailored feedback into routine service provision is not without challenges [22,23]. Common barriers include the *time burden* associated with completing, scoring, interpreting, or discussing outcome assessments [22,24], as well as skepticism regarding the perceived relevance of the outcomes assessed and feedback generated [25,26]. Additional limitations include the traditionally clinician-centric nature of ROM (see studies by Carlier and van Eden [7] and Thompson et al [13] for a discussion and studies by Lambert et al [8], Goodman et al [12], and Burgess et al [27] for common instruments) and accompanying feedback [28,29]. Improved acknowledgment of the client perspective during assessment [30] and greater client involvement in the feedback process [31] are both important clinical and research priorities.

The idea of using technology to track progress within health care settings is not new, but current approaches are limited [32]. Unlike other health information technology approaches (eg, web-based platforms), mobile health (mHealth [33]) apps offer a quick, easy, interactive, and engaging platform for tracking and accessing information about health and health-related behaviors [34]. A key benefit of mHealth apps is their ability to provide timely, individualized feedback [35]. Given the ubiquity of smartphone ownership [36,37], smartphone apps can engage individuals in real time and in their natural environment and by offering moment-to-moment support as needed [38]. Indeed, a recent systematic review of digital support services highlighted that their *on-demand* nature is a key benefit [39].

Although not specifically designed for the purposes of ROM and feedback, mHealth apps with the capability to track a variety of health behaviors, conditions, or outcomes [40-45], including alcohol consumption, substance use, and other addictive behaviors [39,44-52], have been developed. However, a key limitation is the ever-increasing gap between the availability of mHealth apps and their scientific validation [40,52-55].

Moreover, the level of end-user involvement throughout the development process is often unclear. This is important because inadequate consideration of the needs and preferences of the end user has been implicated in mHealth attrition [56-58]. Accordingly, we worked alongside end users to develop a purpose-built mHealth app for ROM and feedback in SMART Recovery Australia (SRAU) mutual support groups (*SMART Track*), which was then evaluated in this study.

Objective

The aim of this stage 1 nonrandomized, single-arm pilot study is to explore the feasibility, acceptability, and preliminary outcomes of a novel mHealth ROM and feedback app (*SMART Track*) in mutual support groups coordinated by SRAU.

Methods

Overview

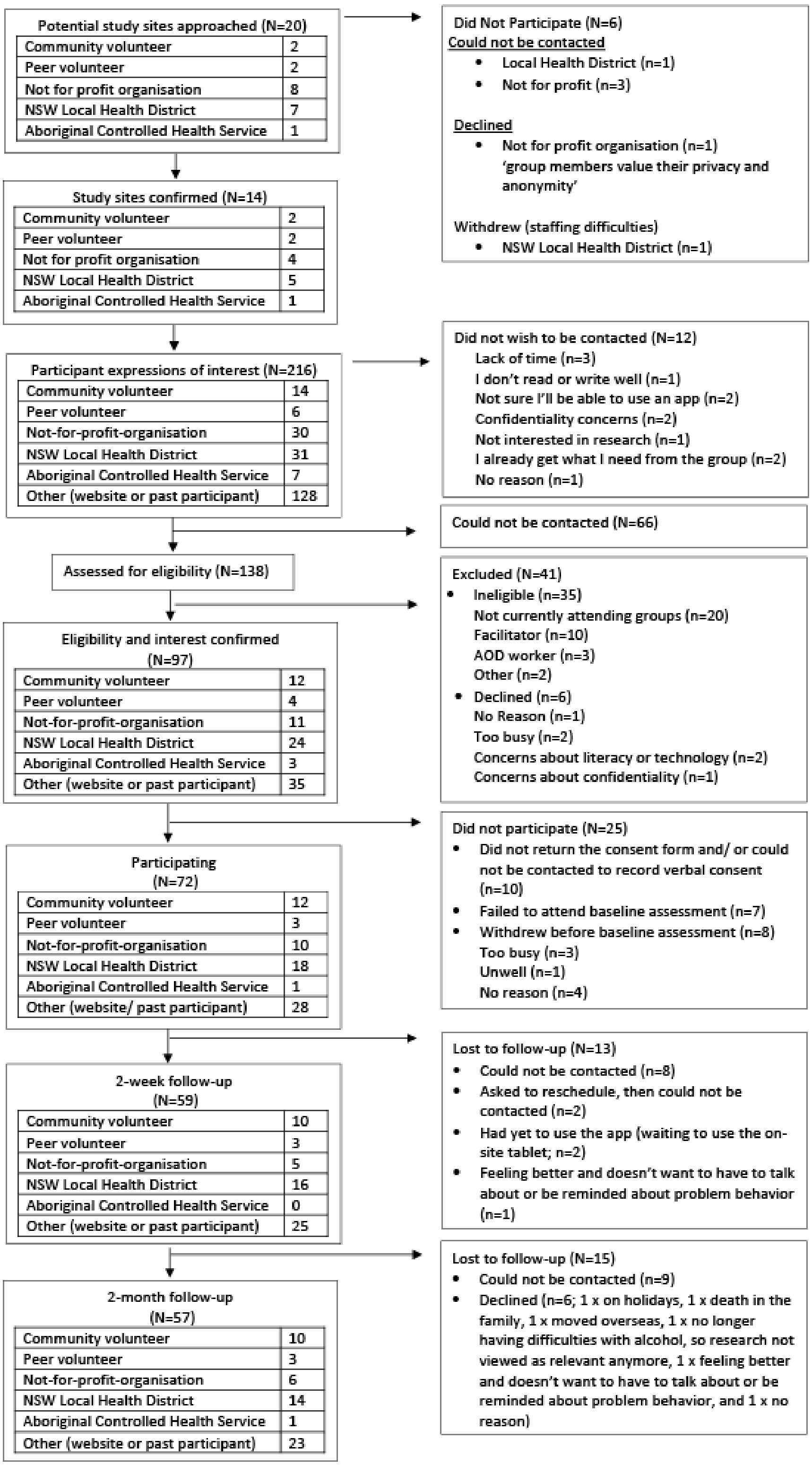
Approval was granted by the University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee (2018/099; HREC/18/WGONG/34). The study was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12619000686101), and a protocol was published [59]. The reporting of this study follows the CONSORT (Consolidated Standards of Reporting Trials)-EHEALTH checklist [60].

Setting

Participants were recruited from the SMART Recovery groups registered with SRAU. Detailed accounts of SMART Recovery groups have been published [61]. Briefly, SMART Recovery groups originated in the United States and are now available across 23 countries. They offer support for people experiencing a range of addictive behaviors, including substance- and non–substance-related behaviors. SMART Recovery groups focus on self-empowerment and use evidence-based techniques (eg, cognitive behavioral therapy and motivational interviewing) [62]. These groups are held in a variety of community, inpatient, outpatient, residential rehabilitation, and clinical health settings. Online support groups are also available.

We invited 20 sites in New South Wales, Australia, to participate in this study, and 14 (70%) agreed (Figure 1). To enhance generalizability, the invited sites were selected to reflect a range of geographical locations and service providers. We sought to recruit 100 study participants. A sample of this size was selected to allow estimation of the recruitment rate and 95% CI with a margin of error of no more than 7%.

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) flow diagram depicting the number of participants referred, lost, and retained according to the referral source. AOD: alcohol and other drugs; NSW: New South Wales.



Potential study sites approached (N=20)

Community volunteer	2
Peer volunteer	2
Not for profit organisation	8
NSW Local Health District	7
Aboriginal Controlled Health Service	1

Did Not Participate (N=6)

Could not be contacted

- Local Health District (n=1)
- Not for profit (n=3)

Declined

- Not for profit organisation (n=1) 'group members value their privacy and anonymity'

Withdrew (staffing difficulties)

- NSW Local Health District (n=1)

Study sites confirmed (N=14)

Community volunteer	2
Peer volunteer	2
Not for profit organisation	4
NSW Local Health District	5
Aboriginal Controlled Health Service	1

Participant expressions of interest (N=216)

Community volunteer	14
Peer volunteer	6
Not-for-profit-organisation	30
NSW Local Health District	31
Aboriginal Controlled Health Service	7
Other (website or past participant)	128

Did not wish to be contacted (N=12)
Lack of time (n=3)
I don't read or write well (n=1)
Not sure I'll be able to use an app (n=2)
Confidentiality concerns (n=2)
Not interested in research (n=1)
I already get what I need from the group (n=2)
No reason (n=1)

Could not be contacted (N=66)

Assessed for eligibility (N=138)

Excluded (N=41)

- Ineligible (n=35)
  Not currently attending groups (n=20)
  Facilitator (n=10)
  AOD worker (n=3)
  Other (n=2)
- Declined (n=6)
  No Reason (n=1)
  Too busy (n=2)
  Concerns about literacy or technology (n=2)
  Concerns about confidentiality (n=1)

Eligibility and interest confirmed (N=97)

Community volunteer	12
Peer volunteer	4
Not-for-profit-organisation	11
NSW Local Health District	24
Aboriginal Controlled Health Service	3
Other (website or past participant)	35

Did not participate (N=25)

- Did not return the consent form and/ or could not be contacted to record verbal consent (n=10)
- Failed to attend baseline assessment (n=7)
- Withdrew before baseline assessment (n=8)
  Too busy (n=3)
  Unwell (n=1)
  No reason (n=4)

Participating (N=72)

Community volunteer	12
Peer volunteer	3
Not-for-profit-organisation	10
NSW Local Health District	18
Aboriginal Controlled Health Service	1
Other (website/ past participant)	28

Lost to follow-up (N=13)

- Could not be contacted (n=8)
- Asked to reschedule, then could not be contacted (n=2)
- Had yet to use the app (waiting to use the on-site tablet; n=2)
- Feeling better and doesn't want to have to talk about or be reminded about problem behavior (n=1)

2-week follow-up (N=59)

Community volunteer	10
Peer volunteer	3
Not-for-profit-organisation	5
NSW Local Health District	16
Aboriginal Controlled Health Service	0
Other (website or past participant)	25

Lost to follow-up (N=15)

- Could not be contacted (n=9)
- Declined (n=6; 1 x on holidays, 1 x death in the family, 1 x moved overseas, 1 x no longer having difficulties with alcohol, so research not viewed as relevant anymore, 1 x feeling better and doesn't want to have to talk about or be reminded about problem behavior, and 1 x no reason)

2-month follow-up (N=57)

Community volunteer	10
Peer volunteer	3
Not-for-profit-organisation	6
NSW Local Health District	14
Aboriginal Controlled Health Service	1
Other (website or past participant)	23

Participants

Participants were eligible if they were aged at least 18 years, were currently participating in SRAU groups (either face-to-face or online), had (or were willing to obtain) an email address, and comprehended English at a level sufficient to complete the study requirements. Participants were eligible irrespective of self-reported computer or smartphone literacy, and they did not have to own a smartphone. The study sites were provided with an Android (Samsung Galaxy Tab A) tablet for on-site participant use. No restrictions were placed on concomitant care or the frequency or duration of SMART Recovery group participation. The only exclusion criterion was inability or unwillingness to provide informed consent.

Recruitment

A group facilitator or member of the research team provided potential participants with standardized written and verbal information at the beginning of the SMART Recovery group session. Potential participants were asked to provide their preferred contact details, and they were contacted directly by a member of the research team. To avoid any potential coercion or desirability bias arising from the working relationship between facilitators and participants, the researcher (not the facilitator) was responsible for confirming participant interest and seeking informed consent. To boost accrual, during the final month of recruitment, a web-based expression-of-interest form (displayed prominently on the SRAU website) was introduced. Potential participants could contact the research team directly through email, phone, or the web-based expression-of-interest form. All participants provided verbal or written informed consent. The participants were reimbursed (Aus $30 [US $22.02] supermarket voucher) for their time, travel, and effort associated with each interview: baseline and 8-week assessments, as well as qualitative interviews (up to a total of Aus $90 [US $66.06]).

SMART Track: ROM and Feedback mHealth App

Development

Overview

The preparatory qualitative work [63] and development process [64] have been reported separately, and further details are available in the published protocol [59]. Briefly, three frameworks [56,65,66] informed the design, development, and content of *SMART Track*. Although each framework can be used in isolation, we chose to combine these approaches to ensure that app development was informed by a more comprehensive set of guidelines that included foci related to the end user (ie, *person*; *person-based* [56]); best practice recommendations for mHealth development (Behavioral Intervention Technology Model [65]); and a collaborative, iterative development process involving the research team, app developers, and participants (Integrate, Design, Assess, and Share Framework [66]). *SMART Track* is grounded in behavioral theory (Self-Determination Theory [67] and Social Control Theory [68]) and the guiding principles of SMART Recovery (self-management, mutual aid, and choice [69]). Behavioral strategies are drawn from the Behavior Change Taxonomy (self-monitoring, feedback, action planning, prompts or cues, and nonspecific reward [70]) and process motivators (choice or control, competence, context, curiosity, personalization, and reframing [66]). The agency contracted for app development and design was GHO, Sydney [71].

Beta-Testing

The initial beta version of the app was submitted to the Apple App Store and Google Play Store for approval in March 2019. The functionality of the app was initially tested with 3 members of the research team (beginning April 5, 2019). Several bugs were identified and fixed before the emended beta version was released (June 4, 2019) for further testing to a convenience sample comprising 40 members of the SRAU Research Advisory Committee, SRAU steering committee, and SMART Recovery board, as well as SMART Recovery facilitators. Further refinements were made in line with the feedback (bug fixes and minor amendments to functionality and content). The participant version of *SMART Track* was available in the Google Play Store (version 0.0.7) and Apple App Store (version 0.7) on July 15, 2019. *SMART Track* is freely available for Android [72] and Apple [73] devices.

Revisions and Updating

The time frame of the weekly period of ROM data collection was emended in July 2019 (from closing 24 hours after the nominated meeting began to closing 30 minutes after the nominated meeting began). This was to enable the next week of data collection to begin during the meeting such that the participants could set a new 7-day plan at the end of the meeting (rather than having to wait 24 hours). Cloud functions were updated in September 2019 to fix to participant reports (4/72, 6%) that they had not received the expected prompt from *SMART Track* to complete the ROM items.

Overview

Summary

The *SMART Track* app is designed for participants attending SMART Recovery groups (either face-to-face or online). *SMART Track* comprises core ROM and feedback functionality and several additional features to enhance engagement (resources, customizable supports, personal motivations, interactive urge log, and pop-up motivations and self-management strategies, as described below). The content is distributed across five main screens (Figure S1 of Multimedia Appendix 1).

ROM Domains and Items

Consistent with clinical guidelines [2,3] and published recommendations [7,31], *SMART Track* provides multidimensional assessment and feedback. The items included in the app are detailed in Table S1 of Multimedia Appendix 2 [74-83] as a function of target domain and assessment frequency. Further details are available in the published protocol [59]. Briefly, the participants were prompted each week to answer a set of questions, and their responses were used to provide tailored progress feedback.

Progress Feedback

Feedback consists of tailored visual and written feedback across eight domains (7-day plan, behavior of concern, effect of substance use, self-care, relationships, outlook on life, resources, and mental health; see Tables S2 and S3 of Multimedia Appendix 2 for the scoring algorithms).

Resources

The *Resources* screen is able to deliver a maximum of 10 pieces of content. This was distributed across seven self-management resources (including SMART Recovery resources) and three motivational stories (extracted with permission from the *Lives of Substance* website [84]). Content upload was managed by the research team using *WordPress* according to the schedule outlined in Table S4 of Multimedia Appendix 2.

Customizable Supports and Personal Motivations

Participants have the option of tailoring app content by uploading one or more contact numbers, support services or personal motivations for change (photo, audio, video, or text) into the *Me* section of the app.

Interactive Urge Log

In addition to tracking the number, frequency, and strength of urges, when the participant reports an urge, this interactive tool prompts them to manage their urges, log triggers, and reflect on how to maintain or improve effective urge self-management. The interactive urge log contains a range of urge management strategies or motivational content (Table S5 of Multimedia Appendix 2). The content was derived from SMART Recovery manuals [85,86] and transcripts of participants' qualitative interviews [63] and presented to the participants in random order. The participants could also use the *Me* section of the app to enter their own personal strategies and motivations. Participant-entered content is always shown before prespecified content, and it is not accessible to other participants.

Pop-up Motivations and Self-management Strategies

The participants received *pop*-up messages when they opened the app for the first time each day (Table S6 of Multimedia Appendix 2). This content is derived from transcripts of qualitative interviews [63]. A combination of direct excerpts and emended content (modified for clarity) was used.

Implementation

Orientation

After completion of the baseline assessment, the researcher asked the participants to use *SMART Track* at least once a week to complete the ROM questions and enter their 7-day plan and use the other app functions *as needed*. This was reinforced in an introductory email, which also contained the Google Play Store and Apple App Store links to download the app. SMART Recovery facilitators were asked to prompt the participants at the beginning and end of each group session. No additional training or support was provided (outside of what may have been naturally provided by facilitators and peers as part of the group session). A *walk-through* is included in the app to orient participants to the app (Figure S1 of Multimedia Appendix 1).

Prompts and Reminders

The 7-day plan and ROM questions were linked to the day and time that the participant used *SMART Track* in their regular SMART Recovery group session. Tasks were set for 7 days after the meeting. The 7-day plan notifications were customizable. For each task, the participants elected whether and when to receive a reminder notification. A notification to complete the ROM questions was automatically sent 24 hours before the nominated group session. If the questions were not answered, additional reminders were sent 12 hours and again 30 minutes before the group session. The ROM notifications could not be *switched off* by the participant.

Privacy and Confidentiality

To allow participants to reset their password, *SMART Track* captures the email addresses of all end users. However, it is up to the participant to decide whether the email address they choose to use contains any element of personal information (eg, their name). Given the potential impact of privacy- and confidentiality-related concerns on participant engagement with *SMART Track*, a comprehensive privacy and confidentiality policy is available.

Data Collection Procedures

Overview

The study activities are outlined in Figure 2. The four modes of data collection included (1) participant-completed ROM data collected through *SMART Track* (Table S1 of Multimedia Appendix 2); (2) app data analytics captured using Amplitude Analytics (Amplitude, Inc; number of visits, number of unique users, visit duration, time of visit, and user retention) [87]; (3) baseline, 2-week, and 8-week follow-up assessments conducted over the telephone by AKB; and (4) qualitative interviews with the study participants and group facilitators (conducted over the telephone by RMG). The primary and secondary objectives, measures, and indicator variables are summarized in Table 1.

Figure 2. Flowchart of study activities.

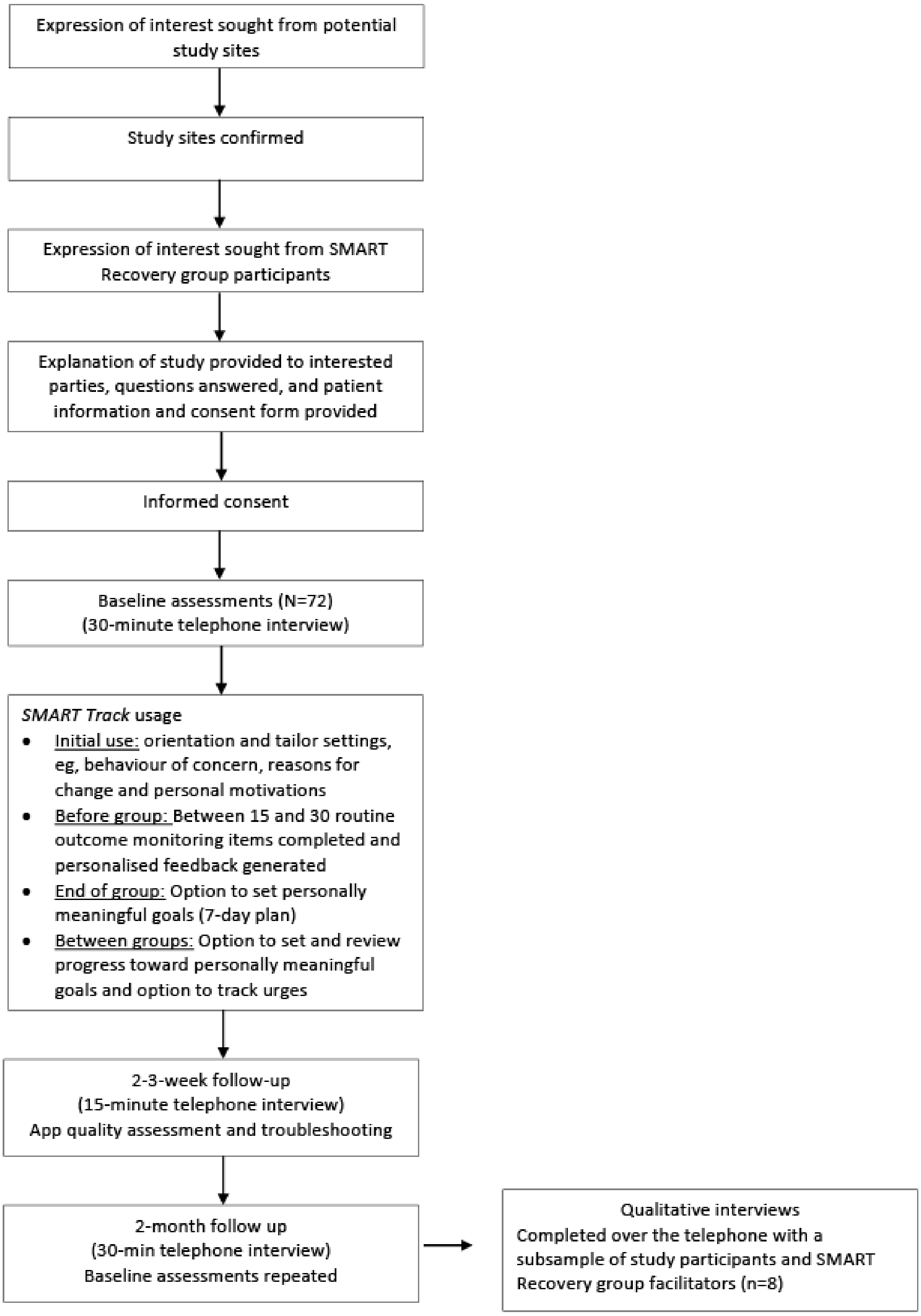


Table 1. Primary and secondary objectives, measures, and indicators.

Objectives	Variables
Primary objectives (measures and indicators)	
To explore the feasibility of using *SMART Track* as part of SMART Recovery groups	• Proportion of eligible participants who consent to the study, create an account, and use SMART Track • Proportion of missing data for each of the routine outcome monitoring items and instruments at each week of administration across the 8-week period of SMART Track use • Engagement and use patterns indexed through data analytics captured daily across the data collection period • Costs associated with developing SMART Track and maintaining the app until the completion of data collection
To explore the acceptability of using *SMART Track* as part of SMART Recovery groups	• Detailed qualitative feedback from SMART Recovery group members and facilitators to explore their experience of, and satisfaction with, SMART Track (8-week follow-up) • Quality ratings as assessed by participant ratings of the end-user version [87] of the Mobile App Rating Scale [88] at 8-week follow-up • Digital therapeutic alliance ratings as assessed by participant ratings of the Digital Working Alliance Inventory at 8-week follow-up
Secondary objective (secondary end points)	
To provide preliminary evidence for participant-reported outcomes	• Participant-reported progress across the 8-week period of app use in (1) substance dependence (Severity of Dependence Scale [89]), (2) addiction recovery (Substance Use Recovery Evaluator [74]), and (3) mental health (Kessler Psychological Distress Scale [75,90])

Key Measures and Assessment Instruments

Overview

The study measures and assessment instruments are detailed in the published protocol [59] and summarized in Table 2. Feasibility and acceptability were informed by data analytics captured using Amplitude Analytics (number of visits, number of unique users, visit duration, time of visit, and user retention) [87]; qualitative interviews; quality assessment conducted using the simplified, end-user version [88] of the Mobile App Rating Scale (MARS) [89] and the Digital Working Alliance Inventory (DWAI) [92]; and a cost analysis informed by a *cost capture template* [93-95] and an adapted version of the Client Service Receipt Inventory—*Generic* UK Mental Health [96]. Preliminary evidence for participant-reported outcomes after the use of *SMART Track* in conjunction with SMART Recovery groups was captured using the Severity of Dependence Scale (SDS) [90], Kessler Psychological Distress Scale-10 (K-10) [97], and the Substance Use Recovery Evaluator (SURE) [74].

Table 2. Schedule of data collection.

	Baseline	Daily	Weekly	2-week follow-up	8-week follow-up
SMART Recovery participants					
***SMART Track* app**					
Data analytics		✓[a]			
ROM[b] items[c]			✓		
Demographics	✓				✓
NADA[d] COMS[e]					
Severity of Dependence Scale	✓				✓
Drug and Alcohol Use	✓				✓
Kessler 10+	✓				✓
The World Health Organization Quality of Life 8	✓				✓
NSW[f] Minimum Data Set items (living arrangements and income)	✓				✓
BTOM-C[g] items on arrests	✓				✓
BTOM-C items on risky drug using practices	✓				✓
Substance Use Recovery Evaluator	✓				✓
Client Services Receipt Inventory	✓				✓
Mobile Application Rating Scale–User Version				✓	
Digital Working Alliance Inventory				✓	✓
Qualitative interview (n=20)					✓
SMART Recovery facilitators					
Demographics					✓
Mobile App Rating Scale					✓
Qualitative interview (n=8)					✓

[a] Data collected.

[b] ROM: routine outcome monitoring.

[c] See Multimedia Appendix 2 (Table S1) for a detailed description of routine outcome monitoring items as a function of assessment domain and frequency of administration.

[d] NADA: Network of Alcohol and Other Drugs Agencies.

[e] COMS: Client Outcomes Management System.

[f] NSW: New South Wales.

[g] BTOM-C: Brief Treatment Outcome Measure—Concise.

Nested Qualitative Evaluation

Qualitative interviews were conducted by RMG after the 8-week period of app use to explore the experiences and opinions of participants with diverse engagement with *SMART Track*. The participants were sampled to reflect the diversity of their characteristics (gender and primary behavior of concern), referral source, and pattern of *SMART Track* use. An independent qualitative researcher (RMG) used a topic guide (Table S7 of Multimedia Appendix 2) to ask additional open-ended questions of a selection of participants (n=20) and facilitators (n=8). The participants and facilitators were sampled to reflect diversity in gender, geographical location, and (for participants only) behavior of concern. For the app users, this included the pathway to SMART Recovery groups (opening and warm-up), perceptions and experiences of app use, initiation circumstances for the app, motivation to join the trial and use the app, and suggestions for improvements. The facilitators were asked similar questions, but the focus was on their professional capacity rather than on their personal experience with apps. The interview started by eliciting information about how they came to be a facilitator, how the app was initiated with their group, their perceptions and experiences in implementing the app with the service users, their motivation levels related to the implementation of the app, and suggestions for improvements. All interviews were audio recorded and transcribed by a professional transcriber working under a confidentiality agreement.

Analysis

Feasibility Indicators

Enrollment and Engagement

Data analytics were captured daily from the time the app was launched until the last participant completed their 8-week follow-up interview. The first participant was given the download details on July 15, 2019, and follow-up data collection was completed on December 2, 2019. Weekly summaries for the total number of unique users and the average number of visits per user were downloaded from Amplitude Analytics. Unique user codes were linked, and the number of weeks that each study participant used the app was calculated.

Use Patterns

To explore how the participants engaged with the various features of *SMART Track*, weekly analytics (total number of visits, total number of unique users, and total duration) for each of the *SMART Track* features (*Urge button*, *Urges* screen, *Resources* screen, *Me* screen, and *Overall Progress* screen) and the time of day that the app was used were downloaded from Amplitude Analytics and descriptive statistics calculated. Retention was characterized using weekly summaries from the *User Lifecycle* feature of Amplitude Analytics. This feature categorizes participants into the following mutually exclusive categories:

1. New users (used the app for the first time that week).
2. Current users (used the app at least once that week and at least once during the preceding week).
3. Resurrected users (used the app at least once during the week after being dormant during at least the previous week).
4. Dormant users (did not use the app that week but did use the app at least once during the preceding week).

Proportion of Missing ROM Data

ROM use (yes or no) for each week of the 8-week follow-up period was defined as participant entry of *SMART Track* data for at least one outcome domain (7-day plan, ROM questionnaire, and Urges). This was used to calculate the weekly proportion of participants who entered the data.

Research and Development Costs

An economic costing analysis was conducted to assess the research and development (R&D) costs related to the creation of the *SMART Track* app. This included both the costs of developing the technology and the research costs (mainly time) that were integral to the development of the app, such as workshops to assess development and testing. Furthermore, an estimate of the total time spent in meetings across the R&D process was estimated, from steering group meetings to the conduct of focus groups. The number of hours were estimated to provide additional context of the time invested in the R&D process in developing a comprehensive and user-friendly app.

Acceptability Indicators

Nested Qualitative Evaluation

The qualitative analysis component of the study was undertaken through two processes: first, as a thematic study to provide insights into the acceptability of the app and the meetings more broadly, which was described in detail in a previous paper [63], and second, as part of the nested evaluation process [98], where the qualitative data were used to support app development and contribute to the experimental nature of the study. Unlike strictly triangulated studies, nested research studies use a combination of data to enrich insights and provide points of comparison to generate new hypotheses [98]. Research questions and interview topics informed the first more deductive coding frame. Categories were summarized and presented with pertinent quotes to the broader team for discussion, which continued until consensus was reached. The analysis sought to shed light on specific questions about the feasibility and acceptability of the app from the perspective of end users. We also explored accounts of the experience of submitting ROMs. Although thematic saturation was not the aim of this part of the analysis, we noticed recurring themes in 12 interviews.

Quality Ratings and Digital Therapeutic Alliance

The MARS–User Version (uMARS) [88] and DWAI [92] domain as well as overall mean scores were calculated at the 2-week follow-up.

Preliminary Outcomes

Paired sample two-tailed *t* tests were used to compare participant-reported outcomes on the SDS, K-10, and SURE between baseline and the 8-week follow-up.

Results

Sample Characteristics

A total of 72 participants were enrolled in this study (Figure 1). The participant characteristics were comparable with prior accounts of SRAU group characteristics [99]; the average age of the participants was 44 years (SD 11), with more men (44/72, 61%) than women (28/72, 39%; Table 3). Most of the participants were born in Australia (59/72, 81%), and 6% (4/72) reported being of Aboriginal, Torres Strait Islander, or both Aboriginal and Torres Strait Islander descent. Employment was the main source of income for almost half of the participants (35/72, 48%).

At baseline, the participants reported attending an average of 6.63 (SD 5.44) SMART Recovery meetings in the preceding 12 weeks (range 0-24). Excessive alcohol consumption was the most common primary behavior of concern, endorsed by 68% (49/72) of participants over the preceding 4 weeks. Injecting drug use (ever) was reported by 25% (18/72), and 11% (8/72) of the sample reported a recent arrest (past 3 months).

Table 3. Participant characteristics (n=72).

Variables	Values
Age (years), mean (SD)	44 (11)
Gender, n (%)	
Male	44 (61)
Female	28 (39)
Born in Australia, n (%)	59 (81)[a]
Aboriginal, Torres Strait, or both Aboriginal and Torres Strait Islander descent, n (%)	4 (6)
Primary source of income[b], n (%)	
Employment (full-time, part-time, or self-employed)	35 (48)
Temporary benefit (eg, unemployment)	10 (13)
Pension (eg, aged and disability)	13 (18)
Other (eg, retirement fund, savings, and investment)	7 (9)
No income or dependent on others	5 (6)
Highest completed level of education or training, n (%)	
High school or less	19 (26)
Certificate, diploma, or trade	26 (36)
Bachelor’s degree	16 (22)
Postgraduate degree	11 (15)
Usual accommodation[b], n (%)	
Own home	33 (45)
Rented home (public or private)	33 (45)
Other (eg, friends, family, and rehab)	4 (5)
Marital status[a], n (%)	
Single or unmarried	27 (38)
Married or defacto	28 (39)
Separated	7 (9)
Divorced	8 (11)
Widow or widower	1 (1)
Ever received treatment for a mental health problem	54 (75)
Self-reported diagnosis received, n (%)	
Depression	9 (12)
Anxiety	8 (11)
Depression and anxiety	22 (30)
Other (eg, posttraumatic stress disorder, bipolar disorder, borderline personality disorder, and schizophrenia)	15 (20)
Addictive behavior causing the greatest concern, n (%)	
Alcohol	49 (68)
Amphetamines	7 (9)
Cannabis	6 (8)
Another drug (eg, cocaine, ecstasy, γ hydroxybutyrate, benzodiazepines)	5 (6)
Another behavior (eg, gambling and food)	5 (6)
Injecting drug use, n (%)	
Within the last 3 months	3 (4)

Variables	Values
More than three but less than 12 months ago	3 (4)
12 months ago or more	10 (13)
Never injected	54 (75)
Arrested in the last 3 months?[b], n (%)	8 (11)
Overdose (any drug) in the last 3 months[b], n (%)	1 (1)
Service use (preceding 3 months), n (%)	
Detoxification or withdrawal management	11 (15)
Residential rehabilitation	4 (5)
Alcohol or other clinic	13 (18)
Psychiatrist	13 (18)
General practitioner	47 (65)
Psychologist	30 (41)
Other allied health care provider (nurse, social worker, or counsellor)	17 (23)
SMART Recovery	69 (95)[c]
12-step	13 (18)
Source of referral to SMART Recovery, n (%)	
Self	23 (31)
Alcohol and/ or other clinic treatment service	17 (23)
Mental health care service	13 (18)
Legally recommended or mandated	9 (12)
Family member or friend	4 (5)
Other health care provider or service	6 (8)

[a] Missing data for 1 participant.

[b] Missing data for 2 participants.

[c] Three new SMART Recovery participants reported that their first meeting (scheduled for the week before baseline assessment) had been canceled. These participants were due to participate in their first group the week of the baseline assessment.

Feasibility Indicators

Enrollment and Engagement

In total, 216 people expressed interest in participating in the study. Of these 216, 97 (44.9%) were deemed eligible, and 72 (33.3%) went on to enroll. Of the 72 participants enrolled in the study, 68 (94%) created an account, 64 (88%) subsequently used *SMART Track* at least once, and 57 (79%) used *SMART Track* multiple times (mean 16.39, SD 16.10; range 2-83 visits). More than half of the participants (42/72, 58%) used *SMART Track* for ≥5 weeks across the study period (Table 4). *SMART Track* was accessed on 74 unique devices (ie, some participants used the app across multiple devices). Apple iPhone (n=33) and Samsung Galaxy (n=21) smartphones were the primary devices used.

Table 4. Frequency of SMART Track use expressed as the proportion of study participants per time interval across the 20-week study period (n=72).

	Participants, n (%)
Never	8 (11)
1 week	7 (10)
2-4 weeks	15 (21)
5-8 weeks	25 (35)
>8 weeks	17 (24)

Use Patterns

The number of participants using *SMART Track* each week gradually increased across the recruitment period (ie, until the week beginning September 16, 2019), with a gradual decline thereafter (Figure 3). In any one week, the maximum number of study participants using the app was 49% (35/72), and the number of visits to the app ranged from 2.47 to 5.27 (mean 3.39, SD 0.75; Figure 3).

The changes in the number of new, current, resurrected, and dormant users each week (Figure 4) suggest that the participants typically used *SMART Track* intermittently rather than on a regular (weekly) basis.

Figure 3. Total number of study participants using SMART Track each week and the corresponding average number of visits per user.

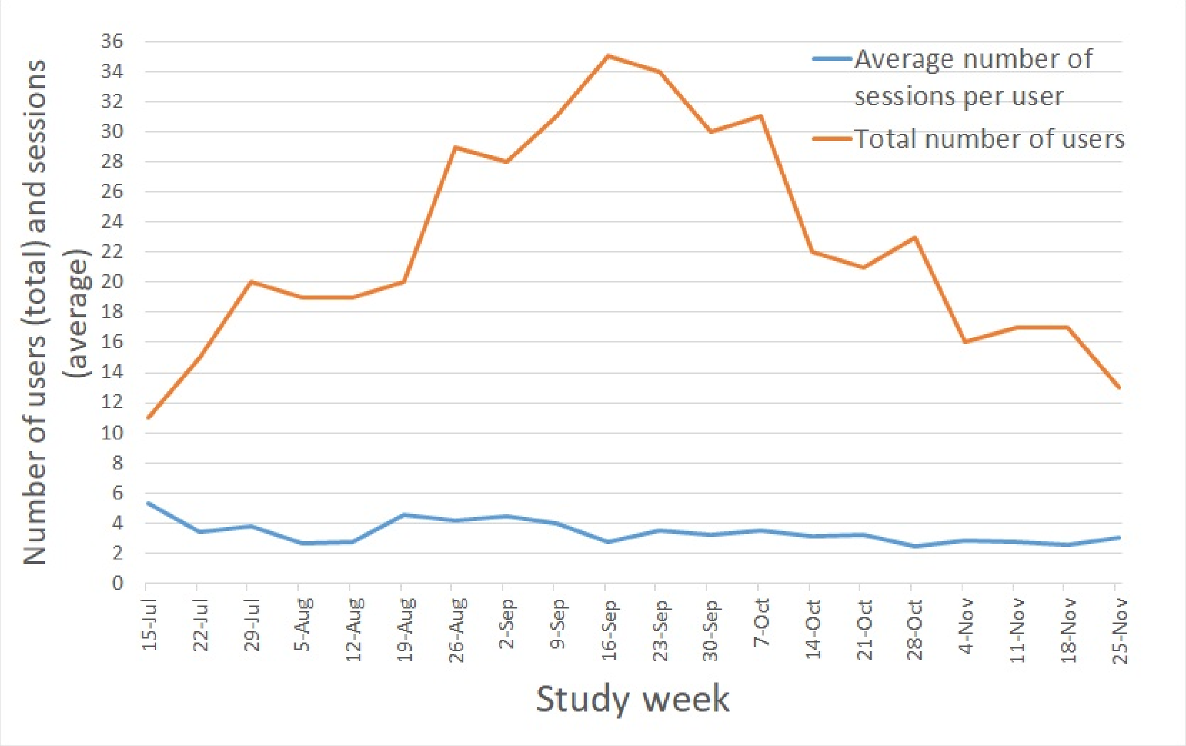
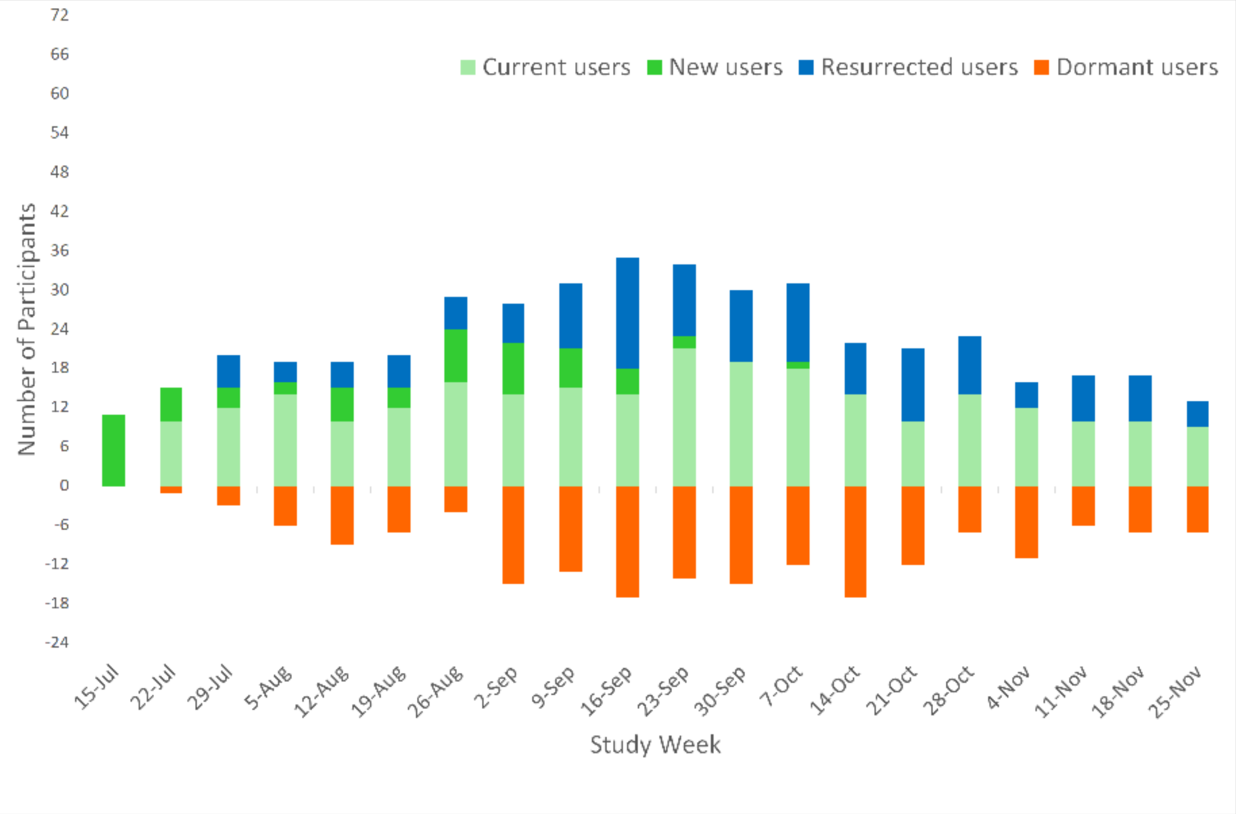


Figure 4. Incoming and outgoing users each week expressed as current versus new versus resurrected versus dormant users.



The two main *SMART Track* screens designed to provide feedback data (*Urges* screen and *Overall Progress* screen) were the most frequently visited sections of the app (Table 5). The participants spent the most time (minutes) using the *Me* screen and the least time viewing the *Overall Progress* screen (Table 5).

Table 5. Use of SMART Track features, expressed as the total number of visits to each of the main screens and the total time spent using each of the main screens.

	Total visits	Total duration (minutes)
Urge button	361	—[a]
Track urges	913	2468.4
Resources	587	443.62
Me	467	3915.94
Overall progress	789	321.33

[a] Duration is not provided for the urge button as use requires a single brief click and is therefore not captured.

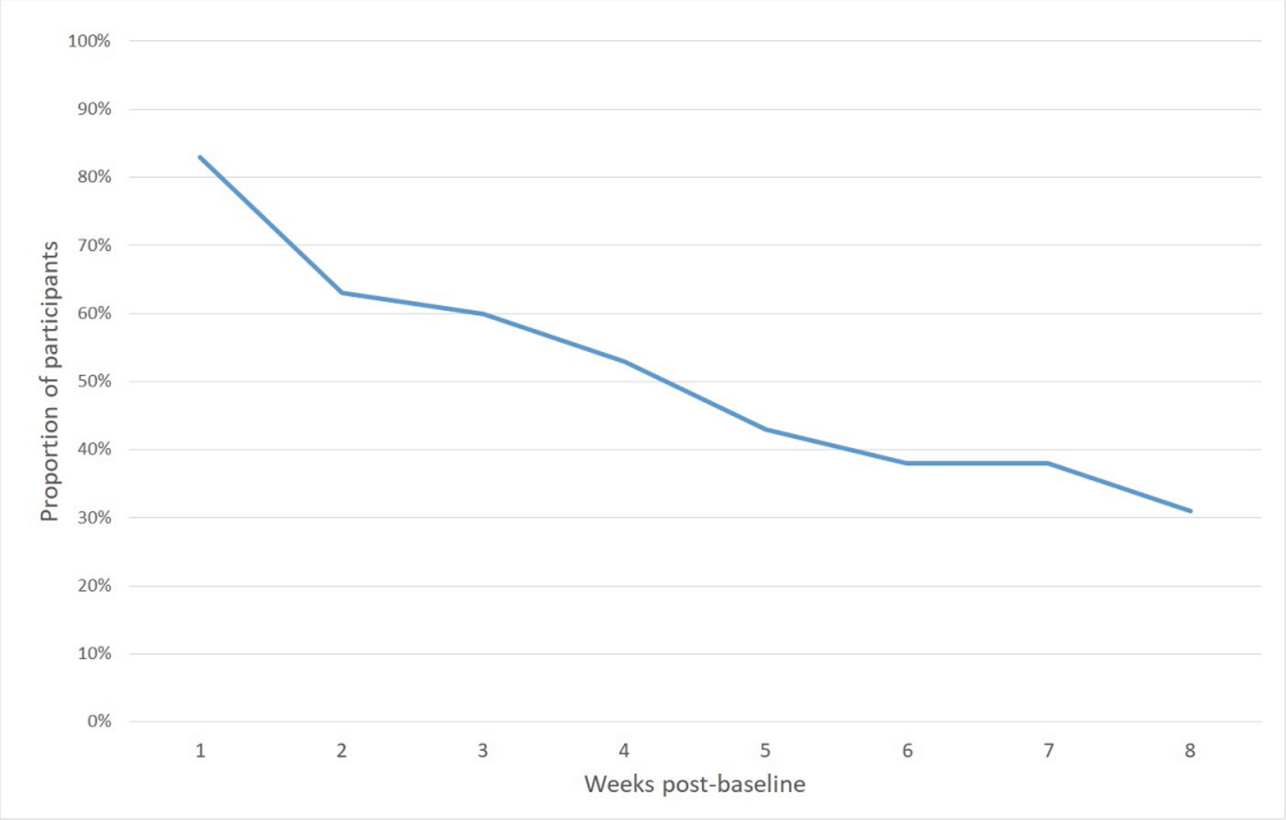
Considerably fewer visits were documented for each of the individual progress screens. These sections of the app were visited, on average, only once or twice per week across the duration of the study by a maximum of 8% (6/72) of the participants (Figure S2 of Multimedia Appendix 1).

The study participants most frequently used the app between 6 PM and 9 PM, with almost a quarter of all visits (500/2166, 23.08%) occurring during this time frame. In the morning, use was greatest between 9 AM and midday (Figure S3 of Multimedia Appendix 1).

Proportion of Missing ROM Data

During the first week of app use, 83% (60/72) of the participants had used *SMART Track* to enter data for at least one ROM instrument (7-day plan, ROM questionnaire, or urge log). There was a reduction across time in the number of participants completing the ROM items. At the end of 8 weeks, almost a third (22/72, 31%) of the participants had provided ROM data, reflecting a 50% reduction compared with week 1 (Figure 5).

Figure 5. Proportion of study participants using SMART Track to enter routine outcome monitoring data.



R&D Costs

To develop the *SMART Track* app, the developer (GHO) received Aus $76,500. However, the true cost to GHO was more than double (Aus $154,034) when the actual time invested by GHO staff (8 staff members; 876 hours) was fully accounted for (Table 4). Furthermore, the research costs to support the development of the app, such as workshops to assess feasibility and usability testing, were estimated at Aus $127,023 (Table 6). This also includes staff time spent by the trial coordinator and qualitative researcher on development activities. These costs exclude the academic research and evaluation costs that were conducted alongside app development (eg, ethics, recruitment, and economic evaluation; Table 7).

In total, the R&D cost incurred was Aus $203,523. If the true costs to GHO Sydney were included, then the total R&D cost would have been Aus $281,058. Finally, an estimate of the total number of hours invested in the R&D process was estimated at 1485 hours (Table 7). More than three-quarters were in-kind costs and goodwill.

Table 6. Cost of SMART Track development and research costs to support development.

Variable	Hours	Rate	Cost (Aus $)
Development costs			
App developer	452	160	72,320
Account director	48	180	8640
Project manager	73	150	10,875
User experience designer	22	180	3870
User interface designer	209	180	37,530
Strategy director	16	250	4000
Creative director	48	350	16,800
Total	868	1450	154,035
Cost of research to support SMART Track development			
Trial coordinator	983	69	67,813
SMART Recovery technology lead	224	56	12,617
Facilitator support for app	156	58	8992
Qualitative researcher	208	144	29,880
Transcription (20 interviews, focus group)	N/A[a]	N/A	1759
Administrative support	156	38	5962
Total	N/A	N/A	127,023

[a] N/A: not applicable.

Table 7. Total hours spent to support the research and development processa.

	Meetings	Duration	People	Person hours
Expert advisory committee	14	45	10	105
Steering committee	2	30	8	10.7
Trial coordinator and external steering committee members	6	30	7	42
Original development company	4	60	7	56
Interviewing new developers	5	5	3	1.3
GHO: preliminary workshops	3	120	15	1080
GHO meetings: design and development	14	60	8	56
GHO: usability testing sessions	9	30	5	22.5
Qualitative researcher meetings	4	60	6	48
SMART Recovery facilitators: focus groups	8	60	8	64
Total	69	500	77	1485.4

[a] Over three-quarters of time was *in-kind*.

Acceptability Indicators

Qualitative Findings

In total, 28 in-depth qualitative interviews were conducted with 20 app users (group members) and 8 facilitators. The participants tended to perceive and describe their use of *SMART Track* within their broader experiences and competencies related to information and communication technology. Of the 20 app users interviewed, the level of knowledge and prior experience of mHealth apps and other digital resources varied widely and were not related to their age or education level. Moreover, the participants' prior knowledge and experience of apps did not seem to be connected to their use of *SMART Track*. For example, those who demonstrated *high* use of *SMART Track* often described themselves as *new* to apps. Participants with "lots of experience" with apps often described ceasing use after a short time (Alec, group member, low app use).

Compared with another sample of SRAU participants who provided input to inform the development of *SMART Track* [63], the participants in this study expressed less concern about digital support tools replacing face-to-face meetings. These group members tended to perceive the app as complementary to their mutual aid group and described using the resources within it to "stay on track between meetings" (Jasmine, group member, high app use). For these participants, "logging urges and tracking progress" were more desirable than completing routine outcome measures (Campbell, group member, low app use), except when the outcomes data were available to them in "more detail" (Harold, group member, high app use). It is therefore possible that increasing the usability of outcome data tracking activities would increase app users' engagement with outcome measurements. Consistent with other research, end users seem to be more open to completing repeated and routine outcome measures when their understanding of their outcomes is aligned with the outcome measures selected by the program designers [30,74].

The group facilitator seemed to play a key role in implementing the app and collecting routine outcome data. Facilitators who were knowledgeable about the app and purposefully integrated its use in meetings were more likely to report higher app use among the participants. This is consistent with feedback received from client-participants, who described the facilitators' efforts, or lack of efforts, when "inspiring" group members to use the app (Mitchell, group member, high app use). Given the lack of experience that some facilitators have with app use and other information and communication technology, it is possible that basic training would have improved their engagement with implementation. In summary, the posttrial interview findings suggest that *SMART Track* is an engaging platform for collecting routine outcome data, and participant concerns expressed at the pretrial time point were not described after the trial.

Quality Ratings

The uMARS ratings (Table 8) confirmed the acceptability of *SMART Track*. The overall app quality score was *good*, and every domain was rated as either acceptable or good (ie, uMARS rating >3).

Table 8. Quality assessment as indexed by participant responses to the uMARS[a] and DWAI[b].

Variable	Values, mean (SD)	Value, median (range)
uMARS[c]		
Engagement	3.6 (0.5)	3.6 (2.0-5.0)
Functionality	4.1 (0.7)	4.0 (2.5-5.0)
Aesthetics	4.2 (0.6)	4.3 (3.0-5.0)
Information	4.3 (0.5)	4.5 (2.5-5.0)
Overall quality	4.0 (0.5)	4.1 (3.0-4.9)
Subjective quality	3.8 (0.8)	4.0 (1.0-5.0)
Perceived impact	3.7 (0.9)	3.7 (1.7-5.0)
DWAI[d]		
Goals	3.5 (1.0)	3.5 (1.0-5.0)
Tasks	3.7 (1.0)	3.5 (2.0-5.0)
Bond	3.4 (1.1)	3.5 (1.5-5.0)
Overall	3.5 (0.9)	3.7 (1.7-5.0)

[a] uMARS: Mobile App Rating Scale–User Version.

[b] DWAI: Digital Working Alliance Inventory.

[c] All items are rated on a 5-point scale from 1 (inadequate) to 5 (excellent).

[d] All items are rated on a 5-point scale from 1 (seldom) to 5 (always).

Digital Therapeutic Alliance

The DWAI ratings (Table 8) also support the acceptability of the app with the domain scores indicating that, on average, the participants rated the key elements of therapeutic alliance (goals, tasks, and bonds) as being present between *fairly* often and *very* often.

Preliminary Evidence on Outcomes

There was a significant reduction between baseline and 8-week follow-up for the SDS (mean difference 1.93, SD 3.02; 95% CI 1.12 to 2.73) and K-10 scores (mean difference 3.96, SD 8.31; 95% CI 1.75 to 6.17), but there was no change in the SURE scores (mean difference 0.11, SD 7.97; 95% CI –2.02 to 2.24).

ROM Reliability

There was a strong relationship between the clinician-administered SURE [74] (at baseline) and the app-administered SURE (week 1; r=0.89; P<.001). For the quality-of-life item, there was a moderate relationship between baseline clinician administration as part of the EUROHIS-QOL 8-item index [76] and as part of the app-administered measures 2 weeks later (r=0.61; P=.005). For the Kessler Psychological Distress Scale-6 (K-6) [75], there was a moderate relationship between baseline clinician administration as part of the K-10 [97] and app administration as part of the K-6 2 weeks later (r=0.51; P=.02). The internal consistency (Cronbach α) for the SURE and K-6 was high across time points and when collected through clinician-interviewed telephone assessments or within the app (SURE: .86 to .94; K-6: .86 to .90).

Discussion

Principal Findings

This study was designed to assess the feasibility, acceptability, and preliminary outcomes of *SMART Track* for ROM and feedback in SRAU. The qualitative and quantitative findings support the feasibility, acceptability, and utility of *SMART Track* for ROM and feedback in SRAU. The findings also provide insight into avenues for enhancing sustained engagement. SMART Recovery participants were willing to use *SMART Track*, demonstrated sustained use across the 8-week follow-up interval, engaged most with the two main progress screens (*Urges* and *Overall Progress*), and experienced *SMART Track* as useful and consistent with SMART Recovery principles and strategies. Although it is difficult to attribute it directly to the use of *SMART Track* or SMART Recovery, the participants also showed clinical improvement over the 8-week follow-up, specifically reductions in the severity of dependence and psychological distress. Varied rates of ROM completion, minimal use of domain-specific feedback screens, and qualitative feedback suggest that the utility of *SMART Track* would be improved by making minor changes to app functionality and improving attention to implementation strategies.

Engagement With SMART Track

To put engagement with *SMART Track* in perspective, it is helpful to consider the rates of engagement with other mHealth apps. One of the challenges with such comparisons is the considerable variation in the metric used to capture mHealth use (eg, mean number of log-ins, sessions, modules, activities completed [100]) and the degree to which these variables are reported [101,102]. Although several systematic reviews of digital recovery support services [39], digital measurement feedback systems [32], and addiction-related mHealth apps are available [54,103-105], the focus tends to be on content, experience, or outcomes, with little to no data examining participant engagement or use. However, the use of mHealth apps by people in recovery from substance use has been shown to vary from as high as 90% in the first few weeks to as low as 18% after 6 weeks [105]. For people with mental health conditions, engagement varied according to the target mental health condition. The number of *nonusers* (individuals who fail to download or use the intervention) has been calculated as 41% (range 25%-58%) for apps targeting depression and 8% (range 0%-16%) for apps targeting anxiety [100]. Reduced engagement over time was common [100]. Compared with these data, participant engagement with, and sustained use of, *SMART Track* is at least comparable, if not higher than the available evidence.

Another useful point of comparison comes from use trends within the global app marketplace. In 2019, data derived from more than 12,000 apps demonstrated that a quarter of the users will abandon an app after one-time use [106]. In comparison, of the 94% (68/72) of the participants in this study who created a *SMART Track* account, more than one occasion of use was documented for 79% (57/72) of the participants. Benchmarks pertaining specifically to lifestyle-related apps (which include fitness-, health-, and travel-related apps) indicate that the average 2-month retention rate is 36% [107]. In comparison, more than half of the participants in this study used *SMART Track* for between 5 and 8 weeks (25/72, 35%) or longer (17/72, 23%), and week 8 ROM data were provided by 31% (22/72) of the study participants.

Uncertainty exists around what is considered a *good* level of mHealth use. Some addiction-related apps (eg, *In My First Year of Recovery* and *A-CHESS* mHealth interventions) have documented high levels of sustained participant engagement (78% program completion and 4-month retention, respectively [105]). In contrast, *SMART Track* use was intermittent, with a proportion of the participants using the app weekly, whereas others disengaged and re-engaged every few weeks. Emerging evidence suggests that engagement with digital recovery support tools may be influenced by recovery duration [39]. Accordingly, engagement with *SMART Track* is likely to vary widely, given that SRAU caters to people across the spectrum of recovery experiences. It is also possible that users may perceive apps as a *short-term commitment* [108]. Therefore, compared with the use of other digital platforms (eg, the web), app use may be shorter and more sporadic [109]. Moreover, training in *SMART Track* was not extensive. The researchers met with the facilitators at each site to orient them to the features of the app. The participants received an email with brief instructions and an in-app onboarding process, although analytics showed that this was used by less than 45.2% (105/232) of users who downloaded *SMART Track* during the study period. The exemplary use rates documented by *In My First Year of*

Recovery and *A-CHESS* may have been due to the more active role of counselors in encouraging mHealth use [105] and point to the importance of improved integration of *SMART Track* into SMART Recovery groups. Identifying participant and contextual factors that influence engagement represents an important challenge for future research.

Routine Outcome Monitoring

A few studies have examined ROM implementation report data on engagement and attrition rates [8,25,28,110,111]. Compared with recent data from the Netherlands, however, the proportion of participants using *SMART Track* to input ROM data is largely comparable, and in some cases, greater than traditional clinician-completed methods [112]. A 50% response rate has been recently suggested as an acceptable benchmark for ROM data and is likely sufficient to protect against bias and yield valid information about patient progress (see study by de Beurs et al [112] for a discussion). In this study, this benchmark was achieved each week across the first month of data collection, with 83% (60/72), 63% (45/72), 60% (43/72), and 53% (38/72) of the study participants completing at least one of the ROM instruments across the first 4 weeks of app use. ROM completion continued to decline during the second month of data collection, with 31% (22/72) of the sample providing ROM data during week 8. Ongoing efforts are needed to improve ROM completion and understand the participant characteristics associated with drop-off (eg, through attrition analyses). For example, given the voluntary, open-enrolling format of SMART Recovery groups and individual variation in group attendance (0-24 in this study), it would be interesting to examine whether app use varies according to group engagement.

Cost Analysis

The R&D costs of *SMART Track* were estimated at Aus $203,523. However, the developer offered considerable in-kind support, and the overall true cost was Aus $281,058. It is important to reiterate that these are essentially *sunk costs*. If *SMART Track* had been rolled out routinely in SMART Recovery groups, the cost of implementation would have consisted of costs related to app hosting, infrastructure, maintenance, and training. The dynamic nature of the industry makes it difficult to estimate these costs and points to the need for ongoing data collection to understand the long-term real-world feasibility of *SMART Track*.

Opportunities

To maximize participant engagement in ROM, a clear rationale for why the data are being collected and what they will be used for is essential [25]. The measures must be experienced as *relevant* [110] and the process deemed *worthwhile* [113]. Analytics revealed that few people accessed the detailed, personalized feedback provided within each of the domains listed on the summary page. Qualitative feedback highlighted a mismatch between the effort expended and satisfaction with the feedback provided. Given that the participants were asking for feedback that was already provided in the app (but not accessed), we expect that modifications to improve the visibility of these sections of the app will further enhance ROM completion. Importantly, the regular and frequent use of app self-monitoring features has been linked to a longer period of use and reduced likelihood of abandoning apps [114]. Additional features that have been linked to mHealth engagement include an esthetically pleasing interface, ease of use, degree of personalization, reinforcement (eg, rewards and reminders), communication (with peers or professionals), message presentation (including language, tone, and design), and credibility (encompassing trustworthiness and confidentiality [115]). Although these features were considered throughout the design of *SMART Track* (and positively evaluated as part of the quality assessment), an opportunity exists to further enhance the user experience (eg, through improved personalization, greater use of rewards, and the addition of information-sharing or communication capabilities).

Organizational resources are essential for ensuring the sustained implementation of digital interventions to reduce substance use [105], for example, ensuring leadership support; providing adequate training and resources to both staff and service users; leveraging the expertise of service users to contribute to training; and having a process in place to monitor, evaluate, provide feedback, and respond to uptake rates [116]. Training is a particularly important consideration and provides a forum to (1) build clinician knowledge and confidence in app use and features, (2) practice introducing it to participants, and (3) identify and overcome any concerns or perceived barriers to implementation of mHealth to support routine care [117]. The next steps for *SMART Track* include improved facilitator training and support and leveraging of participant and facilitator *champions* (ie, individuals who actively support the use of *SMART Track*).

Strengths

The development of *SMART Track* was grounded in theory [40,57] and user-centered design [57]. Consistent with recommendations for enhancing measurement-based care, *SMART Track* includes both standardized and idiographic outcome assessment and harnesses technology to overcome traditional barriers to ROM (eg, scoring and providing tailored feedback [110]). Quality assessment was conducted using a psychometrically valid tool [88], and *SMART Track* surpassed the minimum acceptable quality benchmark (≥3 [88]) on each of the domains assessed by the uMARS, with an overall quality rating of *good*. This is superior to several published accounts [50]. The observed quality of *SMART Track* likely reflects the user-centric approach to development. However, because the ratings were collected as part of a telephone interview with the researcher, the contribution of response bias cannot be ruled out.

Evidence from mental health settings suggests that mHealth apps that have a clear purpose and simple user interface and are easy and time efficient to navigate and demonstrate were more likely to be used as part of routine practice [117]. Quantitative and qualitative data indicate that *SMART Track* possesses these attributes. Pending minor upgrades and improved training and support, this finding further bolsters our confidence in the routine uptake of *SMART Track* within SMART Recovery groups.

Limitations

This study includes several limitations. In its current format, *SMART Track* is not suitable for people who cannot adequately read and comprehend English. The reliance on written and visual information may also compromise the suitability of *SMART Track* for people with vision impairment. The use of cloud functions for collecting and storing data means that *SMART Track* needs a reliable internet connection to function. The study's approach to assessing engagement is consistent with recommendations for a multidimensional approach using mobile app data analytics (index of *microengagement*), indices of behavior change (macro level of engagement), and participant subjective experience [102]. However, differences in how various studies define engagement and use make it hard to position *SMART Track* within the context of existing studies. Recent guidelines for the measurement and reporting of engagement data in digital interventions may be beneficial in the future [118].

The current findings are derived from a small sample of participants who attended a limited sample of SRAU groups. We did not collect data on the number of participants attending SRAU groups across the study period; therefore, although participant characteristics are comparable with published accounts [99], generalizability is unclear. Furthermore, the short-term nature of the study makes it challenging to position the findings within the often long-term, nonlinear experience of recovery [16]. Finally, because this is a stage 1 feasibility study, our finding that participants reported reduced severity of dependence and psychological distress from baseline to 8 weeks needs to be interpreted cautiously.

Conclusions

The qualitative and quantitative findings support the feasibility and acceptability of *SMART Track* and lend insight into avenues for enhancing sustained engagement. Low rates of engagement and high rates of attrition are known challenges for services working with participants who experience substance use and mental health–related difficulties [119]. Sustained engagement with mHealth apps is notoriously difficult to achieve. In light of these challenges, our findings are promising. *SMART Track* offers a potential solution for ROM and feedback, particularly for people with substance use disorders who attend mutual support groups. Future research should focus on identifying relevant demographic, clinical, and contextual factors that may influence the engagement, attrition, and perceived utility of this promising mHealth app.

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Conflicts of Interest

RM is the executive director of SRAU. AA is employed by SMART Recovery as the National Program Manager and Trainer. PJK, FPD, ALB, AS, LH, VM, BL, AKB, JFK, and AA all volunteer as members of the SRAU Research Advisory Committee. The potential perceived conflicts of interest are negligible. The role of study investigators on the research advisory committee or as an employee of SMART Recovery is freely available on the SRAU website (and study participants can be directed to this information as required). Furthermore, the team responsible for informing the study design and overseeing the conduct of the study and data analysis also consists of researchers, clinicians, and statisticians independent of SMART Recovery.

Multimedia Appendix 1

Supplementary figures.
[DOCX File , 142 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Supplementary tables.
[DOCX File , 65 KB-Multimedia Appendix 2]

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
DWAI: Digital Working Alliance Inventory
K-10: Kessler Psychological Distress Scale-10
K-6: Kessler Psychological Distress Scale-6
MARS: Mobile App Rating Scale
mHealth: mobile health
R&D: research and development
ROM: routine outcome monitoring
SDS: Severity of Dependence Scale
SRAU: SMART Recovery Australia
SURE: Substance Use Recovery Evaluator
uMARS: Mobile App Rating Scale–User Version

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Original Paper

Sharing Government Health Data With the Private Sector: Community Attitudes Survey

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Abstract

Background: The use of government health data for secondary purposes, such as monitoring the quality of hospital services, researching the health needs of populations, and testing how well new treatments work, is increasing. This increase in the secondary uses of health data has led to increased interest in what the public thinks about data sharing, in particular, the possibilities of sharing with the private sector for research and development. Although international evidence demonstrates broad public support for the secondary use of health data, this support does not extend to sharing health data with the private sector. If governments intend to share health data with the private sector, knowing what the public thinks will be important. This paper reports a national survey to explore public attitudes in Australia toward sharing health data with private companies for research on and development of therapeutic drugs and medical devices.

Objective: This study aims to explore public attitudes in Australia toward sharing government health data with the private sector.

Methods: A web-based survey tool was developed to assess attitudes about sharing government health data with the private sector. A market research company was employed to administer the web-based survey in June 2019.

Results: The survey was completed by 2537 individuals residing in Australia. Between 51.8% and 57.98% of all participants were willing to share their data, with slightly fewer in favor of sharing to improve health services (51.99%) and a slightly higher proportion in favor of sharing for research and development (57.98%). There was a preference for opt-in consent (53.44%) and broad support for placing conditions on sharing health information with private companies (62% to 91.99%). Wide variability was also observed in participants' views about the extent to which the private sector could be trusted and how well they would behave if entrusted with people's health information. In their qualitative responses, the participants noted concerns about private sector corporate interests, corruption, and profit making and expressed doubt about the Australian government's capacity to manage data sharing safely. The percentages presented are adjusted against the Australian population.

Conclusions: This nationally representative survey provides preliminary evidence that Australians are uncertain about sharing their health data with the private sector. Although just over half of all the respondents supported sharing health data with the private sector, there was also strong support for strict conditions on sharing data and for opt-in consent and significant concerns about how well the private sector would manage government health data. Addressing public concern about sharing government health data with the private sector will require more and better engagement to build community understanding about how agencies can collect, share, protect, and use their personal data.

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KEYWORDS

big data; health information systems; health data; private sector; data linkage; public opinion; consent; trust; public interest; social license

Introduction

Background

Every day, people produce large amounts of health information about themselves through their interactions with health professionals, hospitals, and other government and nongovernment agencies. Beyond being a record of their health care, this information can be collated for a wide range of *secondary* uses, such as monitoring the quality of hospital services, researching the health needs of populations, and testing how well new treatments work.

As the secondary use of health data increases, so does the interest in what the public thinks about such data sharing [1-5]. This interest is related in part to growing public awareness of the risks associated with secondary use of health data, accentuated through recent data breaches and public controversies [6-10]. These events call attention to the fragility of public trust in the institutions that collect, hold, and use health data and highlight the need to understand what health data sharing the public will support, under what circumstances, for what purposes, and with whom.

Evidence from systematic and narrative reviews demonstrates broad public support for the secondary use of health data, particularly for health research [11-15]. However, research also shows that this support may not extend to sharing health data with the private sector, particularly if there is scope for commercial gain from such use [2,4,16-18]. The risks related to sharing health data, such as the potential for privacy violations, inaccuracy, misuse, discrimination, reputational damage, and embarrassment, are generally regarded as greater when sharing data with the private sector, even if it is for the purposes of research and development.

Public reticence about sharing health data with the private sector does not seem to be matched by similar concerns among governments. Rather, sharing health data with the private sector has become a component of many governments' health and economic strategies [19-21]. For example, the use of large public data sets to support all stages of therapeutic development is one area of focus in Australia's 2016 National Research Infrastructure Roadmap [22]. Internationally, many other countries have made similar moves through regulatory changes to increase access to and use of large public data sets [19,20]. If governments intend to share health data with the private sector, it is essential to know what the public considers important.

Aim

This paper reports a national survey that aimed to explore public attitudes in Australia toward sharing health data with private companies for research on and development of therapeutic drugs and medical devices.

Methods

Ethics Approval

This study was approved by the University of Wollongong Ethics Committee. All participants provided consent before participating in the study.

Survey Instrument

To develop the survey, we carried out an extensive review of the literature and identified demographic and sociocultural factors that might influence how the public view sharing personal health information with the private sector. We searched the peer-reviewed literature for tools to measure public attitudes toward data sharing. We developed a new instrument by combining questions from pre-existing tools with new questions and drawing on insights from the literature [16,23].

We used Survey Monkey (Momentive Inc) software to design a web-based version of the instrument [24]. To support instrument readability, the survey was piloted with a convenience sample of the general population (n=10) aged ≥14 years. We selected pilot participants to provide a diverse group with respect to age, gender, education, ethnicity, and the presence or absence of long-term illness. These participants provided feedback on the meaning of each question, the design and layout as a whole, and how long it took to complete the survey. We then refined the survey instrument, with the final survey taking approximately 9 minutes to complete. The survey was then programmed by McNair yellowSquares on the Web Survey Creator survey platform and checked for usability and technical functionality before launching.

The 11-page survey instrument included a half-page summary explaining the concepts of data linkage and sharing, including potential benefits and risks. We mentioned research and development of new drugs and medical devices and ended the introduction with the following statement: "We would like to know what you think about sharing this information with private companies such as drug companies and medical device manufacturers where the goal is to support the development of new treatments for diseases and disabilities."

This was followed by a 29-item instrument covering sociodemographic and health-related information about participants; support for sharing health information with private companies; general views about private companies; and experience with health data collection, consent, and conditions on sharing (the survey instrument is provided in Multimedia Appendix 1). A single open-ended question at the end of the survey invited additional comments. To help participants understand that each question referred to *deidentified* government health data, the following banner appeared at the top of each page: “The questions below are about your government health information which has personal information removed, e.g. no name, no address, no date of birth, no Medicare number.”

Recruitment and Procedures

An experienced market research company, McNair yellowSquares, recruited an opt-in sample of 2500 participants drawn from its online panel. McNair yellowSquares was asked to secure a sample that would be nationally representative by age, gender, and location. The company purposively selected participants from its panel to meet this requirement. Although potentially less ideal than probability sampling, this methodology had the practical advantage of ease of implementation and was considered appropriate for this exploratory study [25].

Australian participants of the online panel were emailed an invitation to participate in the closed survey via a unique one-time use link. Once the survey was completed, the link was disabled to prevent duplicates and the panel was regularly checked for duplication with various data points. The survey was not advertised in any manner. Up to 2 reminder emails were sent over the 3-week period during which the survey was open (May 17, 2019 to June 7, 2019). Upon completing the introductory section to establish the quotas, participants were directed to the participant information sheet, which described the researchers, purpose of the study, risks and benefits, time needed for completion, and data protection and storage. Participants were asked to indicate that they understood the participant information sheet; on assenting to this, they were directed to the first page of the survey. All questions were mandatory, and some items provided “I do not know” and “I prefer not to answer” as options. Participants were not able to view their responses by moving backward. There was no randomization of items, and all responses were captured on the McNair yellowSquares Web Survey Creator survey platform. Participation was voluntary, and participants received a small reward upon completion of all items in the survey.

McNair yellowSquares provided deidentified participant responses to the research team. All data and analyses were stored on a secure University of Wollongong server, only accessed by the research team.

Statistical Analysis

IBM SPSS [26] was used to analyze the data. Only completed survey data were analyzed. First, we provided a descriptive summary of the survey outcomes by showing a frequency table with relative frequencies for each question of interest. The association between variables is given in cross tabulations, and P values are provided to answer the specific questions of interest. To support population inference, we analyzed the survey data using poststratification gender-by-age-by-state weights. We used the 2016 Australian Bureau of Statistics census data to obtain the Australian population characteristics of gender, age, and state and calculate the survey weights based on the realized sample characteristics after combining categories with small sample counts. All results except for participant demographic in this paper are obtained using the SPSS Complex Samples procedure. Raw proportions are reported to show the distributions of demographic information about the participants of this study (Table 1).

The open-ended question was analyzed inductively in NVivo (QSR International) [27]. Coding was conducted by 1 author (RB), with a second author (LC) coding half of the responses to ensure coding integrity. The authors compared coding and resolved differences before presenting the analysis to the entire research team for further discussion. The quotes in the *Results* section present examples of the diversity of responses in relation to different parts of the survey and indicate how respondents interpreted this question. A thorough analysis of this question will be presented in a separate paper.

Table 1. Demographics of participants (N=2537).

Characteristics	Values, n (%)
Gender (N=2537)	
Male	1243 (48.99)
Female	1285 (50.65)
Other	9 (0.38)
Geographical area (N=2537)	
Metropolitan	1682 (66.29)
Nonmetropolitan	855 (33.7)
Employment (n=2526)	
Full-time and part-time employed	1481 (58.63)
Unemployed	120 (4.75)
Home duties	250 (9.9)
Student	112 (4.43)
Retired	456 (18.05)
Unable to work	107 (4.24)
Age (years; N=2537)	
<29	552 (21.76)
30-49	873 (34.41)
50-64	652 (25.7)
≥65	460 (18.13)
Highest level of education (n=2525)	
No formal qualifications	45 (1.80)
Year 10 or school certificate	265 (10.5)
Finished high school	422 (16.71)
Vocational education (trade or technical education)	840 (33.27)
University	953 (37.74)
Self-rated health (N =2537)	
Poor or fair	758 (29.88)[a]
Good	991 (39.06)[a]
Very good or excellent	788 (31.06)[a]

[a] The Australian population—adjusted proportion.

Results

Participant Demographics

This data set contains responses from participants recruited by a market research company who completed the full survey. A total of 2537 participants were recruited for this study. The market research company employed to recruit participants set the location, age, and gender quota matrix to +1%. This allows for additional participants in the case of individuals being removed after data checks (eg, not located in Australia). Fewer potential participants were removed than was expected by the authors, resulting in a data set with slightly more participants than initially planned. There were equal number of male and female participants, with approximately two-third residing in metropolitan areas and 59.99% being employed. More than 20% of the participants were aged <29 years, approximately 35% were aged 30-49 years, 25% were aged 50-64 years, and 18% were aged ≥65 years. A total of 71.04% of the participants had a university or vocational qualification, and a similar proportion of the participants rated their health as good, very good, or excellent. Demographic information about the participants is provided in Table 1.

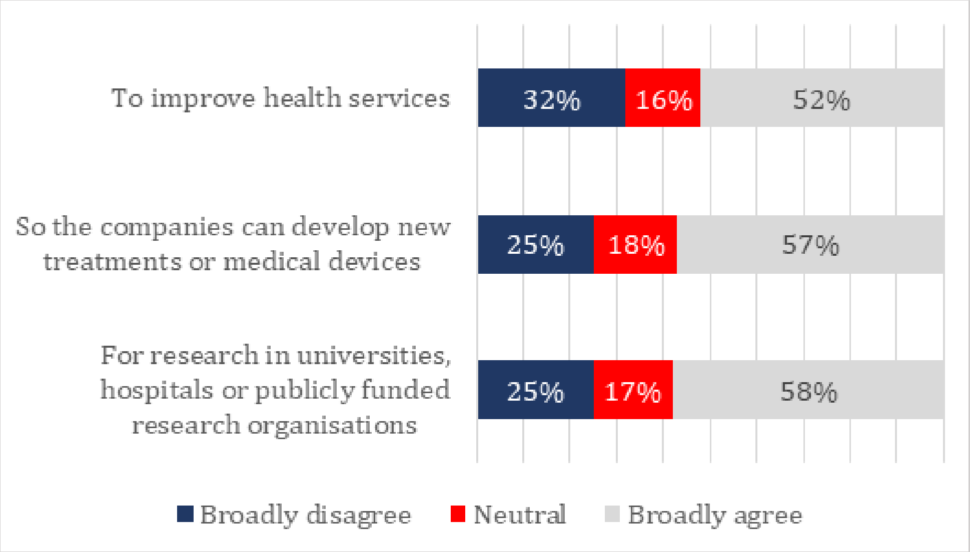
Participants were also asked if they had a My Health Record [28]. The My Health Record is a web-based summary of one’s health status, which was first launched as an opt-in record in Australia in 2012 and then controversially amended to an opt-out model in 2018. Approximately 1 in 10 Australians opted out of the system when it was amended. Just over 40.99% of participants in our survey said they had a My Health Record, 35.98% said they did not, and 23.02% were unsure.

Sharing Health Information With Private Companies

Overall, participants were ambivalent about whether or not to share their health data with private companies. Between 50.02% and 59.99% of all participants were willing to share their data, with a slightly fewer proportion in favor of sharing to improve health services and a slightly higher proportion in favor of sharing for research and development. Figure 1 shows the degree of support for sharing health data for various purposes. The range of views was reflected in participants' comments at the end of the survey:

> *I am happy to share my information if it benefits me and others.* [Male, 55-59 years, metropolitan]
>
> *Sharing health information with private companies is ok if the goal is to support the development of new treatments for diseases and disabilities.* [Male, 18-24 years, metropolitan]
>
> *I don't think that information is any use to anybody for developing new drugs or procedures.* [Male, ≥75 years, metropolitan]
>
> *I don't like my information being used by a private company.* [Male, 60-64 years, metropolitan]

Figure 1. Support for sharing government health data with the private sector (N=2537): "To what extent do you agree with the government sharing your health information with private companies, such as drug companies or medical device manufactures?".

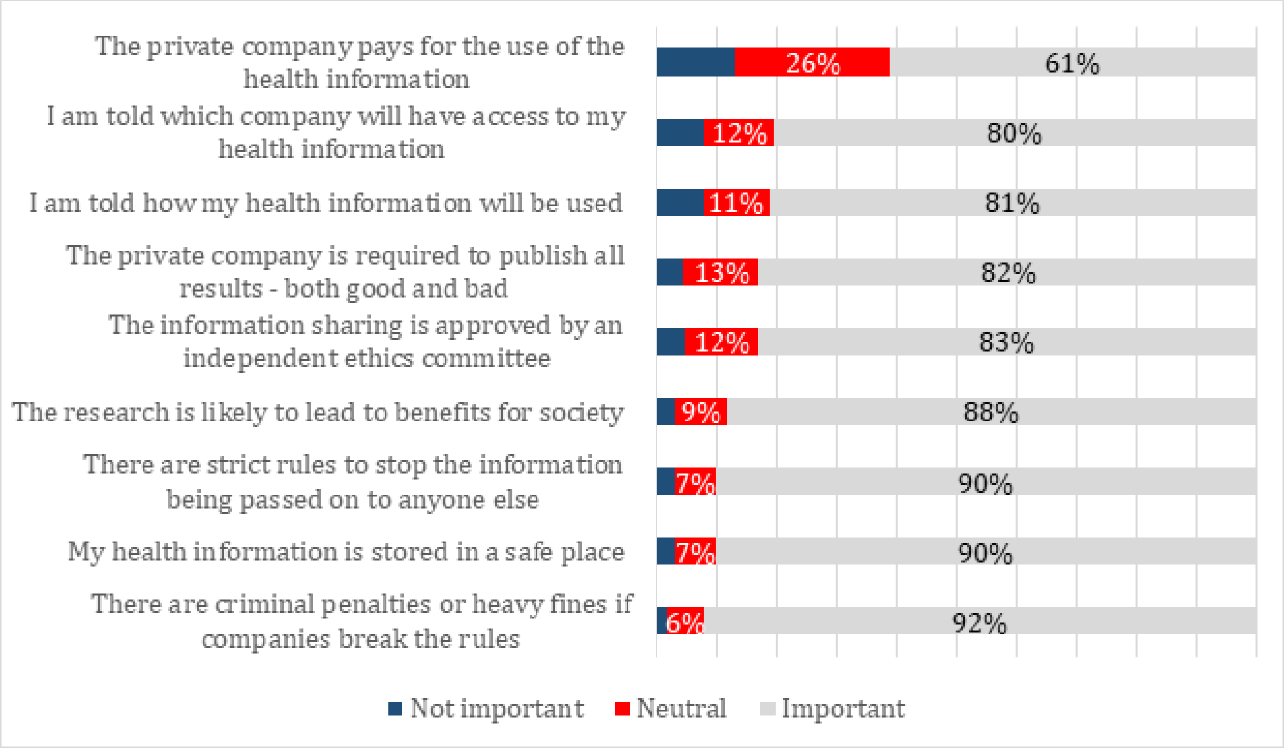


Conditions on Sharing

Participants were asked to assume that the government had decided to share their health information with a private company and to indicate the importance of various conditions on sharing. The participants responded on a scale of 1-7 with the anchors *Not important at all* and *Very important* and 4 in the neutral position. For all statements except one, 80.02% or more of the participants agreed that the condition was important. For one statement—private companies should pay for the use of the information—a small majority of participants (61.01%) considered the condition to be important. Figure 2 shows participants' responses to the conditions on sharing government health data with private companies.

For the aforementioned conditions, we compared the responses of participants who had previously indicated that they were willing to share government health data (for all three purposes) with those who were neutral or not willing to share data (Multimedia Appendix 2). In general, participants who were willing to share data were more concerned that the conditions be met; the differences were relatively small (7.64% to 28.54%), but *P* values suggest that the differences are statistically significant. The exceptions to this finding were being told which companies would have access to health information (for all 3 purposes), how information would be used (for development and research purposes), and whether the company would pay for the data (for research purposes). For these conditions, there were no differences between the 2 groups.

Figure 2. Conditions on sharing government health data with the private companies—adjusted percentages of (N=2537): “How important are various conditions if governments are to share data with private companies?”.



Views About Private Companies

A series of statements were designed to assess participants’ views about what private companies could or would do if they had access to government health information (Figure 3). Participants reported their level of agreement using a 7-point Likert scale ranging from *strongly disagree* to *strongly agree*. In reporting, these have been collapsed to *broadly disagree* (1-3), *neutral* (4), and *broadly agree* (5-7). Figure 3 shows the level of broad agreement for each of the statements.

There was wide variability in participants’ responses to these statements (Figure 3). Over one-third of the participants considered that private companies could be trusted to act for the good of society or would store information safely, but these views were almost equally balanced by participants who thought the opposite. Approximately 59.99% of the participants thought that the government could not stop private companies from misusing information or control how they used it, but, again, approximately 1 out of 5 participants disagreed. Just under half of the participants said that their data could be reidentified, but at the other end of the scale, 23.02% of the participants did not think that reidentification was possible. Over half of the participants thought that private companies should not be allowed to make a profit from using the information, but one-fourth of the participants disagreed. For each statement, at least 1 in 5 participants was undecided.

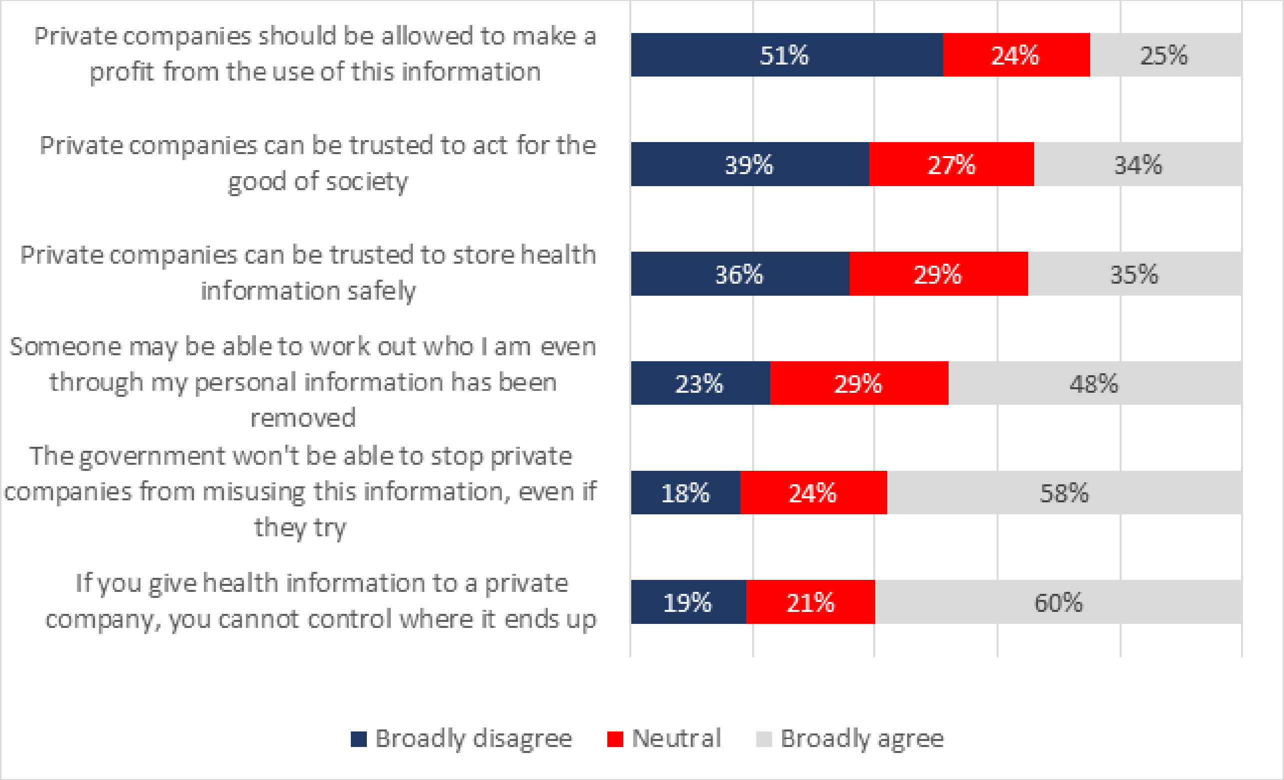
The comments at the end of the survey illustrated this range of views, and concerns about corporate interests, corruption, and profit making were recurrent themes:

> *I think private companies will inevitably use our information for profit rather than for the greater good.* [Male, 25-29 years, metropolitan]
>
> *The idea of greed preventing progress and a cure is 99% of my concerns.* [Female, 18-24 years, rural]
>
> *I just worry that my information will not be safe.* [Female, 30-34 years, metropolitan]

Although this was not a survey about how the public sector held and used health data, a number of participants were equally as concerned that the government could not keep their information secure:

> *The current government’s record of online information processing has not been good. Look at what happened with the census.* [Male, 45-49 years, metropolitan]
>
> *Government is not very good at stopping anything in the past, e.g. bin full of census papers.* [Male, 60-64 years, rural]

Figure 3. Views on sharing government health data with private companies—adjusted percentages of (N=2537): “To what extent do you agree with the following statements about private companies using government health information to support development of new treatments?”.



We examined the relationship between the participants’ willingness to share government health data (for all 3 purposes) and their views about the private sector (Multimedia Appendix 3). The participants who had indicated that they were willing to share health data were more likely to say that private companies could be trusted (by between 51.3% and 60.82%), and that they should be able to make a profit from using government health data (51.31% to 45.62%). They were also slightly less concerned about the risk of identification (0.6% to 5.9%). Both groups of participants, who had indicated a willingness to share data and those who were neutral or did not wish to share data, were equally likely to think that any controls on data release would not work and that the government would not be able to control misuse by the private sector.

Consent Preferences

The consent preferences of the participants are shown in Multimedia Appendix 4. There was a preference for *opt-in* consent (54.98%): it was 3 times more popular than any other option. The participants’ comments at the end of the survey reflected this view:

> *I would want total control over how, when and to whom my information is used and or shared with me giving the say so.* [Female, 60-64 years, rural]

> *It MUST be voluntary and OPT IN only.* [Male, 65-69 years, rural]

Each of the three other options for consent—refuse to share information at all, opt out, and *don’t need to know*—attracted approximately 13% of the participants. For those who wanted opt-in consent, 62.51% requested that they be asked *every time* and 23.58% wanted to give general consent and then be recontacted from time to time, whereas the rest wanted to give consent just once. Multimedia Appendix 4 shows the adjusted percentages of consent preferences.

Participants in the opt-in group were slightly more likely to rate as important the conditions that could be placed on sharing their health information than those in the opt-out group (Table 2). The largest difference was related to how their health information would be used (89.98% stating that this was important compared with 81% in the opt-out group), and the smallest difference was related to payment for use of information (62.98% compared with 59.99%).

Opt-in and opt-out participants held similar views about private companies, with differences between the 2 groups very small (2.7% to 6.6%) and nonsignificant for all but one statement (Table 3).

Table 2. Relationship between participants' views on consent (opt in vs opt out) and level of agreement with the conditions on sharing data.

Conditions on sharing	Type of consent		*P* value
	Opt in (n=1356), n (%)	Opt out (n=352), n (%)	
I am told how my health information will be used	1215 (89.6)	284 (80.6)	<.001[a]
I am told which company will have access to my health information	1189 (87.7)	284 (80.6)	.001[a]
My health information is stored in a safe place	1285 (94.8)	312 (88.7)	<.001[a]
The private company pays for the use of the health information	848 (62.5)	210 (59.7)	.38
The information sharing is approved by an independent ethics committee	1187 (87.5)	286 (81.2)	.007[a]
The private company is required to publish all results—both good and bad	1180 (87.0)	288 (81.9)	.02[a]
The research is likely to lead to benefits for society	1246 (91.9)	304 (86.3)	.004[a]
There are strict rules to stop the information being passed on to anyone else	1275 (94.0)	310 (88.1)	<.001[a]

[a] Indicates level of significance at *P*<.05.

Table 3. Relationship between participants' views on consent (opt in vs opt out) and views about private companies.

Views about private companies	Type of consent		*P* value
	Opt in (n=1356), n (%)	Opt out (n=352), n (%)	
Private companies can be trusted to store health information safely	494 (36.4)	119 (33.7)	.38
Private companies should be allowed to make profit from the use of this information	346 (25.5)	98 (27.8)	.41
Private companies can be trusted to act for the good of society	473 (34.9)	105 (29.9)	.10
If you give health information to a private company, you cannot control where it ends up	868 (64.0)	202 (57.4)	.04[a]
Someone may be able to work out who I am even though my personal information has been removed	679 (50.1)	157 (44.6)	.09
The government won't be able to stop private companies from misusing this information, even if they try	818 (60.3)	199 (56.6)	.24

[a] Indicates level of significance at *P*<.05.

Sociodemographic Patterning of Responses

We investigated the impact of various sociodemographic factors on participants' views about whether health information should be shared and the conditions under which sharing might be acceptable (Multimedia Appendices 5-7). In general, demographic factors seemed to have only a small impact on participants' views, with differences being less than 5.99% for most demographic factors. There were a small number of exceptions. *Older people* (aged >65 years) were more willing than the youngest age group (60.2%-70.1% compared with 49.2%-56.4%) to share their health information with private companies. They were slightly less troubled than younger people about knowing which companies would have access to their data and more committed to publishing negative results (89% compared with 78.01%). The 3 oldest age groups were more supportive of criminal penalties, and the youngest age group was least likely to agree that ethics committee oversight was needed.

Across all measures, differences between people living in *metropolitan* and *nonmetropolitan areas* were small, with the largest difference (5.01%) between the groups showing nonmetropolitan dwellers slightly less likely to support data sharing for research.

The participants' *level of education* was related to their views, but only for some domains (Multimedia Appendices 5-7). The participants' level of education was not related to the degree of support for sharing government health data. However, participants with higher levels of education were generally more concerned about having conditions placed on the release of data, with differences between the least and most well-educated groups ranging from 16.98% to 40.01%. For example, 81.99% of the participants with university-level education wanted ethics committee oversight of data sharing, compared with 54% for participants with only year 10-level education. Compared with participants with year 10-level education, participants with university-level education were also more likely to want to know how their information would be used (81% compared with 46.98%), which company would access their data (81% compared with 50.02%), and that all results would be published (81.98% compared with 42.01%). A history of employment in the health sector or research did not appear to influence participants' responses.

Participants with *poorer self-reported healthstatus* were slightly less likely to support (5.01% to 5.99%) sharing their health data with the private sector, as were those who *took prescribed medications* (2.99% to 5.01%). However, participants (5.01% to 7.02%) who reported *having a chronic condition* were slightly more likely to support sharing data with the private sector.

Participants who said they had a *My Health Record* were between 17.2% and 20.4% more likely than those who said they did not have a record to support sharing data with private companies for health services improvement, development, or research.

Open-ended Question

The final question in the survey asked, “Is there anything else you would like to tell us about your views on sharing government health information with private companies where the goal is to support the development of new treatments for diseases and disabilities?” Approximately 18.01% of all respondents provided comments, primarily describing concerns about sharing government health information and the conditions under which they would support sharing or indicating support for data sharing.

Lack of trust in both private companies and the government was the most common concern. The participants cited corporate interests, corruption, and profit making as the main reasons for their distrust of private companies. They also referenced the poor track record of the government in handling data, and they questioned the ability of the government to keep their data secure and prevent misuse. Support for regulated access to health information was linked to respondents’ concerns about security:

> *There have been recorded cases of information being misused, be it metadata to health information. The current government’s record of online information processing has not been good. Look at what happened with the census.* [Male, 45-49 years, metropolitan]
>
> *Not in favour at all as I don’t trust private companies with any sort of information & same goes for this bloody lying, corrupt government!!!* [Female, ≥75 years, metropolitan]
>
> *I think private companies will inevitably use our information for profit rather than for the greater good.* [Male, 25-29 years, metropolitan]

The respondents explained that if government health information is to be shared with private companies, certain conditions need to be met. The most common requirement was anonymization of health information and a guarantee that all personal information be removed. In addition, a large subset of participants believed that data sharing needs to deliver public benefits or support the common good. They provided examples of public benefits, including developing new treatments, finding cures, or improving the health of society. Giving consent was a prerequisite to sharing health information for many participants and the right to *opt in* rather than *opt out* was highlighted by a subset.

Discussion

Principal Findings

This nationally representative survey provides preliminary evidence that Australians are uncertain about sharing their health data with the private sector. Although just over half of all respondents supported sharing health data with the private sector, there was also strong support for strict conditions on sharing data and for opt-in consent. These views were reinforced by participants’ ambivalence about the roles, motives, and actions of the private sector with respect to health data. Although, as a short survey, it represents relatively uninformed positions, it does indicate how people might react initially to reports of data sharing with the private sector in the news media or in public documents.

The findings of this survey demonstrate how difficult it may be to achieve policy change in this area in directions that are also acceptable to the community. Some of the conditions that participants wanted to impose on data sharing, such as using opt-in consent and providing information about each instance of use to each person who has provided data, are also conditions that some advocates of sharing would argue cannot be implemented [23,29-31]. Some intuitively attractive conditions, such as ensuring safe storage or compelling private companies to publish findings, may be difficult to enact through legislation and even more difficult to police. For example, despite decades of lament about publication bias in health research [32], relatively little headway has been made to change the practice [33-35].

A second set of challenges for policy makers may lie in identifying exactly which members of the community are concerned about what aspects of data sharing. In this survey, sociodemographic differences in views were generally small, and there were widely divergent views about what private companies could or would do if they had access to government health information. The participants who were willing to share health data were more cautious about the conditions under which they would be willing to share, but they were also more willing to trust the private sector and more willing to allow the private sector to take profits. The reasons for these findings are unclear, but they could suggest that participants had variable understandings of the private sector when answering the survey or that they had particular companies in mind. Whatever the reason, educating people about why it might be acceptable for the private sector to use public administrative data is unlikely to resonate equally across the community.

In its 2017 report on data availability and use in Australia, the Productivity Commission concluded that Australia lags behind other countries in its use of public sector data, particularly in the private sector [36]. In the Commission’s view, Australia’s foot-dragging has multiple causes, with limited community understanding and fragile trust at the top of the list, closely followed by legislative complexity, lack of leadership, data breaches, and poor data quality.

Our survey findings support the Commission’s concern about the lack of community trust in data sharing. The participants in our survey were uncertain about whether the private sector could be trusted, with at least one-third of the participants doubting the motivations and behaviors of the private sector when it came to their health information. However, many participants also agreed that sharing their health information with the private sector could yield public benefits, with just over half of all participants supporting the use of health information by private companies.

Recent scholarly studies of public views on using health data for secondary purposes also emphasize the importance of these 2 domains of trust and public benefit [15,37-39]. These recent studies cohere with our findings that understanding the benefits that can arise from using health data is necessary, but not sufficient, if the public is to entrust its health data to the private sector [10,40]. Many people are still uncomfortable with the idea of private companies accessing their government health data [41], and they have particular concerns about data privacy [42] and passing information on to marketers or insurers [43].

Building trust is not just a matter for the private sector. Trust in government is also important because it is the government that collects, holds, and releases health information in the first place [44]. This disquiet was reflected in the comments in our survey, although we did not actually ask participants to tell us their views on how well governments manage health data. Recent studies have also highlighted public misgiving about the public sector's ability to implement and manage data sharing and linkage safely, both in general and with private companies [37,41,42]. In her article examining Australian women's views and experiences of the My Health Record, Lupton [42] highlighted a number of well-publicized data breaches in Australia that may have contributed to participants' cynicism about their government's ability to keep health data protected.

At the time of this survey, we found no other Australian studies that provide a quantitative estimate of public support for sharing data with the private sector. The small number of international studies placed support for data sharing between 15% and 65% [45-47], a much larger range compared with our finding of 52% to 58%. These point estimates are helpful, but different research approaches are needed to reveal what lies beneath these numbers. Studies using focus groups, particularly in vulnerable populations; engagement and feedback through publicly focused websites; and deliberative methods such as citizens' juries will all help explain why participants are reticent to share their health data. For some topics, the use of different methods may yield different answers. For example, we found strong support for opt-in consent in this survey, whereas deliberative studies suggest that people may become less concerned about consent when they understand that shifting to opt-in consent for the secondary use of administrative health data would make the conduct of most big data research impractical and the findings untrustworthy [16,48]. The participants in our study were probably not all that different from other people in struggling to understand how data sharing, deidentification, and data linkage work or even how administrative health data could be used for research and development.

Limitations

This survey was conducted with an online panel of members of the public who had signed up to participate in research questionnaires, and it, therefore, has a number of limitations. In particular, as the participants were members of a panel who expressed interest and willingness to participate in research surveys, they may be more likely to be supportive of research, or at least more interested than the general public in research. The participants also probably had a reasonable level of confidence in using information technology and the internet, although what this meant for their attitudes to sharing their health data with the private sector was unclear. In addition, although participants were directed to focus on pharmaceutical companies and medical device manufacturers, it is possible that they also had other private health industries such as marketing and insurance companies in mind. This may have influenced the participants' responses.

Conclusions

Although there is broad public support for the secondary use of health data, our survey findings suggest that this support only extends to sharing health data with the private sector under tightly controlled circumstances. However, significant concerns are likely to remain. Addressing public concern about sharing government health data with the private sector will require more and better engagement to build community understanding about how agencies can collect, share, protect, and use their personal data.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Community attitudes survey.
[PDF File (Adobe PDF File), 145 KB-Multimedia Appendix 1]

Multimedia Appendix 2

The proportion of participants who were willing to share government health data by proportion of participants who agreed or disagreed that specific conditions should be met before sharing could occur.
[PNG File , 66 KB-Multimedia Appendix 2]

Multimedia Appendix 3

The proportion of participants who were willing to share government health data by proportion of participants who agreed or disagreed on the views of private companies.
[PNG File , 63 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Consent preferences—adjusted percentages (N=2573): “What do you think about your health information being used by private companies for the development of new medicines or devices?”.
[PNG File , 21 KB-Multimedia Appendix 4]

Multimedia Appendix 5

Adjusted percentages of willingness to share government health data with private companies by sociodemographic pattering (N=2537): “To what extent do you agree with the government sharing your health information with private companies, such as drug companies or medical device manufacturers?”.
[PDF File (Adobe PDF File), 122 KB-Multimedia Appendix 5]

Multimedia Appendix 6

Adjusted percentages of conditions on sharing government health data with private companies by sociodemographic patterning (N=2537): “How important is it that each of the following conditions be met when information is shared with the private sector?”.
[PDF File (Adobe PDF File), 153 KB-Multimedia Appendix 6]

Multimedia Appendix 7

Adjusted percentages of views on sharing government health data with private companies by sociodemographic patterning (N=2537): “To what extent do you agree with the following statements about private companies using government health information to support development of new treatments?”.
[PDF File (Adobe PDF File), 140 KB-Multimedia Appendix 7]

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Original Paper

Examining the Trends in Online Health Information–Seeking Behavior About Chronic Obstructive Pulmonary Disease in Singapore: Analysis of Data From Google Trends and the Global Burden of Disease Study

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Abstract

Background: Chronic obstructive pulmonary disease (COPD) is the third leading cause of death globally, and timely health care seeking is imperative for its prevention, early detection, and management. While online health information–seeking behavior (OHISB) is increasingly popular due to widespread internet connectivity, little is known about how OHISB for COPD has changed in comparison with the COPD disease burden, particularly at a country-specific level.

Objective: This study aimed to examine the trends in OHISB for COPD and how that compared with the estimates of COPD disease burden in Singapore, a highly wired country with a steadily increasing COPD disease burden.

Methods: To examine the trends in OHISB for COPD, we performed Prais-Winsten regression analyses on monthly search volume data for COPD from January 2004 to June 2020 downloaded from Google Trends. We then conducted cross-correlational analyses to examine the relationship between annualized search volume on COPD topics and estimates of COPD morbidity and mortality reported in the Global Burden of Disease study from 2004 to 2017.

Results: From 2004 to 2020, the trend in COPD search volume was curvilinear (β=1.69, t_{194}=6.64, P<.001), with a slope change around the end of 2006. There was a negative linear trend (β=–0.53, t_{33}=–3.57, P=.001) from 2004 to 2006 and a positive linear trend (β=0.51, t_{159}=7.43, P<.001) from 2007 to 2020. Cross-correlation analyses revealed positive associations between COPD search volume and COPD disease burden indicators: positive correlations between search volume and prevalence, incidence, years living with disability (YLD) at lag 0, and positive correlations between search volume and prevalence, YLD at lag 1.

Conclusions: Google search volume on COPD increased from 2007 to 2020; this trend correlated with the upward trajectory of several COPD morbidity estimates, suggesting increasing engagement in OHISB for COPD in Singapore. These findings underscore the importance of making high-quality, web-based information accessible to the public, particularly COPD patients and their carers.

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KEYWORDS

online health information seeking; infodemiology; Google Trends; Global Burden of Disease study; chronic obstructive pulmonary disease; respiratory health

Introduction

Chronic obstructive pulmonary disease (COPD) is the third leading cause of death globally [1] and affected approximately 251 million of the world's population in 2016 [2]. In Singapore, it is the tenth leading cause of death [3] and affects approximately 5.9% of the general population [4] and 26% of the population aged 55 years and above [5]. The number of deaths caused by COPD in the South East Asia region is projected to increase from 1.04 million in 2016 to 1.43 million in 2030 [6]. Despite its significance, COPD still has poor awareness and understanding by both the public and health practitioners [7]. Therefore, understanding whether and how health information on COPD is accessed in proportion to the size of the disease burden is critical.

Barriers to health care seeking in COPD often lead to fewer prompt diagnoses and poorer disease management among those already diagnosed. For instance, misdiagnoses in primary care settings have been attributed to underuse of and lack of expertise with spirometry and COPD diagnostic guidelines [8]. Furthermore, patients' knowledge of COPD may be suboptimal because of the complexity of its name, not only in English but also in other languages [9]. Arguably, these barriers can be at least partially attributed to inadequate knowledge of COPD, which can be improved by making high-quality health information more accessible. According to the Health Information National Trends Survey in 2012, the internet was the first source of health information for 70% of adult US internet users [10], suggesting its increasing influence as a source of general and potentially, disease-specific health information.

Disease-specific online health information–seeking behavior (OHISB) among patients with COPD has been studied in several US-based surveys. A postal survey of 1077 patients with COPD in 2007-2008 found that 65% had internet access and 25% of this group used the internet to seek information on COPD at least once weekly. Their frequency of seeking COPD information online was associated with experiencing exacerbations or dissatisfaction with health service providers and treatments [11]. A web-based survey of 445 patients with COPD in 2016 found that physicians were the primary source of COPD information followed by the internet. The patients' online health information needs were primarily related to symptom control and COPD treatments; also, over 60% of the patients had discussed COPD information on the internet with their health care providers [12]. Another web-based survey of 176 COPD patients found that eHealth literacy, defined as the capacity to seek, locate, understand, evaluate, and apply health information from the internet, was higher in patients with more severe COPD [13]. These findings suggest that, at least in the United States, OHISB is common among COPD patients with internet access, and more frequent OHISB appears to be associated with more unmet needs in disease management.

A frequent method for examining OHISB is Google search data [14]. It is freely downloadable from Google Trends, a publicly accessible portal hosting data on aggregate search activity on the Google search engine delineated by time periods and regions. Since Google is the most popular search engine worldwide, its aggregate data are used as a surrogate indicator for OHISB at the population level.

In 2019, Boehm and colleagues [15] published a study using worldwide Google Trends data that found no change in search volume for COPD in the 15 years from 2004 to 2018. Yet, the number of deaths due to COPD was estimated to have increased by 11.7% from 1990 to 2015, despite a decrease of 41.9% in the age-standardized death rate in the general population [16]. This contrasts with other leading causes of death, such as diabetes and stroke, which have evidenced increased search volumes over the same period. The clear divergence between the rising prevalence of COPD and stagnant OHISB pattern for COPD is a cause for concern, but there are limitations in the study's methods. The analyses by Boehm et al [15] were performed on worldwide COPD search data without accounting for variation in COPD disease burden between countries and other country-level characteristics such as internet coverage; both factors are essential considerations for developing and implementing country-specific policy changes.

Our study improves upon the work by Boehm et al [15] by situating the enquiry within a single country, Singapore, and comparing Google Trends data with COPD disease burden estimates. Singapore is an opportune context for this research because of high internet penetration, popularity of Google search, and high COPD prevalence [4,5]. Furthermore, Singapore has a rapidly aging population with an increasing burden of chronic diseases. With this in mind, this study was designed to address 2 research questions. First, we aimed to examine the trend in OHISB for COPD (indicated by monthly Google search data) in Singapore from 2004 to 2020. Second, we aimed to compare online search volume with disease burden estimates to assess the extent to which OHISB for COPD reflects the disease burden reported in the Global Burden of Disease study (GBD 2017) over time. To our knowledge, this is the first study that examined trends in OHISB in conjunction with disease burden indicators in COPD.

Methods

Search Volume Data From Google Trends

Search query data relating to COPD were obtained from Google Trends, an online portal that displays search queries made worldwide on the Google search engine since 2004. The tool aggregates monthly volumes of search queries, delineated by time period and region, into a metric known as relative search interest (RSI). RSI is computed as a function of a search query's own highest query share. Its values range from 0 to 100, where 100 represents peak popularity. Google Trends excludes duplicate searches made by the same person over a short period of time. Search queries on Google Trends can be defined either as a search term (the exact search query, accounting for plural and singular forms and spelling mistakes) or a topic (groups of terms that share the same concept in any language).

Following the approach in Boehm et al [15], all search queries were defined as a topic and downloaded as monthly search data. In total, there were 198 monthly data points. When annual data were required for comparison with GBD data, the annual averages were computed from monthly averages.

Disease Burden Data From GBD 2017

The following data relevant to COPD were obtained from GBD 2017: prevalence, incidence, disability-adjusted life years (DALY; the sum of years lived with disability [YLD] and the years of life lost [YLL]), YLD, YLL, number of deaths (mortality). GBD studies are conducted annually by The Institute for Health Metrics and Evaluation, and reports are typically issued every 2 years. These data are accessible online [17]. Currently, the data come from 195 countries and include 354 diseases and injuries. The data sources are diverse, including published literature, hospital and clinical data, surveillance and survey data, and inpatient and outpatient medical records. A detailed description of the methodology of the GBD 2017 can be found in the article by the GBD 2017 Disease and Injury Incidence and Prevalence Collaborators [2]. The most recent and publicly available GBD data were for 2017, and so the time period used for our study spanned from 2004, the first year for which Google Trends data were available, to 2017.

Statistical Analyses

As noted in previous works [18], performing Google Trend queries with similar parameters at different times can produce somewhat different data. To mitigate this problem, we performed the same query over 7 consecutive days, from June 22, 2020 to June 28, 2020. To assess the reliability of the data, two-way random model intraclass correlation coefficients (ICCs) were computed. The 7 time series data were averaged to produce a single time series for further analyses. Due to the nature of autocorrelated residuals in time series data, the Prais-Winsten estimation method was used to examine the trend in search volume. To compare search volume with disease burden estimates, a cross-correlation function was used to examine the correlation between the 2 annual time series data. The annual time series for search volume was computed by averaging the monthly search volume over the 12 months of each year.

Results

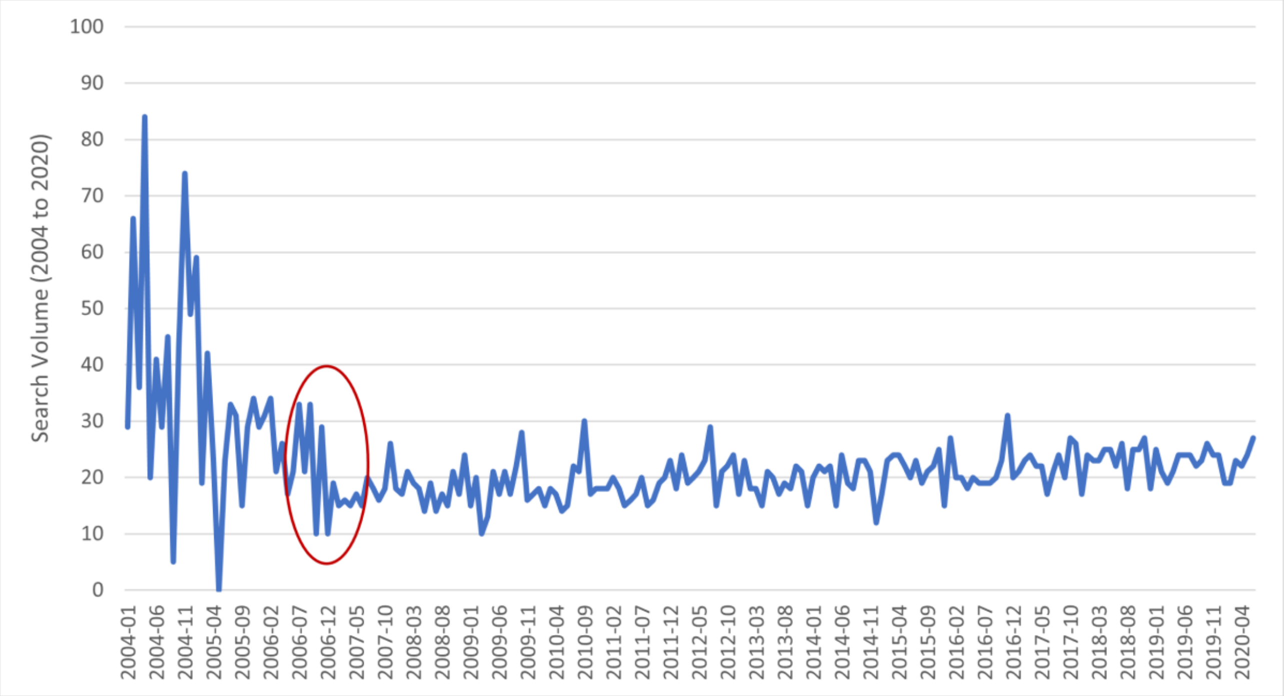
Reliability

The reliability of search volume data was moderate for the single time series data (ICC=0.55) and strong for the averaged time series data (ICC=0.90). The subsequent analyses were performed on the averaged time series data.

Trends in Monthly Search Volume for COPD From January 2004 to June 2020

The trend in monthly search volume for the COPD topic, shown in Figure 1, was examined using Prais-Winsten regression.

Figure 1. Relative search volume for chronic obstructive pulmonary disease (COPD) from 2004 to 2020. The red circle indicates an apparent slope change in search volume.



The Durbin Watson statistic [19] was 2.05. The autocorrelation coefficient was 0.09 (SE 0.72). For the overall model, R^2 was 0.22 (SE 8.16). Time demonstrated a quadratic effect on search volume (β=1.69, t_{194}=6.64, *P*<.001), as shown in Table 1. A quadratic effect suggests that there was 1 slope change over the entire period.

Table 1. Prais-Winsten regression examining the effect of time on monthly search volume for chronic obstructive pulmonary disease (COPD; 2004-2020).

Predictors	β[a]	*t* (*df*=194)	*P* value
time	–1.84	–7.22	<.001
$time^2$	1.69	6.64	<.001

[a] Standardized coefficients.

In Figure 1, the slope change appears to have happened at the end of 2006 and beginning of 2007, circled in red. To examine the trend before and after the apparent slope change, Prais-Winsten regressions were conducted for the 2 periods: 2004-2006 (36 months) and 2007-2020 (162 months). In addition, due to improvements in Google's algorithms for search volume from 2011, the trend from 2011 to 2020 was also examined. The analyses are presented in Table 2.

Table 2. Prais-Winsten regression examining the effect of time on monthly search volume during 3 different periods of analysis.

Predictor: time	β[a]	*t*	*P* value
2004 to 2006	–0.53	–3.57 (*df*=33)	.001
2007 to 2020	0.51	7.43 (*df*=159)	<.001
2011 to 2020	0.45	5.27 (*df*=111)	<.001

[a] Standardized coefficients.

From 2004 to 2006, the Durbin Watson statistic was 1.91. The autocorrelation coefficient was –0.17 (SE 0.17). For the overall model, R^2 was 0.28 (SE 16.08). Time demonstrated a negative linear effect on search volume (β=–0.53, t_{33}=–3.57, *P*=.001), suggesting a reduction in monthly search volume during this period.

From 2007 to 2020, the Durbin Watson statistic was 1.91. The autocorrelation coefficient was –0.03 (SE 0.08). For the overall model, R^2 was 0.26 (SE 3.25). Time demonstrated a positive linear effect on search volume (β=0.51, t_{159}=7.43, *P*<.001), suggesting that monthly search volume exhibited a positive linear trend from 2007 to 2020.

From 2011 to 2020, the Durbin Watson statistic was 1.99. The autocorrelation coefficient was –0.07 (SE 0.10). For the overall model, R^2 was 0.20 (SE 3.08). Time demonstrated a positive linear effect on search volume (β=0.45, t_{111}=5.27, *P*<.001), suggesting a positive linear trend consistent with that from 2007 to 2020, despite improvements in Google Trend's algorithms.

Cross-Correlation Between Annual Search Volume and Disease Burden Indicators (2004-2017)

Table 3 presents cross-correlations between annual COPD search volume and disease burden indicators at lags 0, –1, and 1. There were positive correlations between search volume and prevalence, incidence, and YLD at lag 0, suggesting that these pairs of variables were contemporaneously correlated. There were also positive correlations between search volume and prevalence, as well as between search volume and YLD at lag 1, suggesting that higher prevalence and YLD coincided with higher search volume 1 year later. Correlations at all other lags were nonsignificant.

Table 3. Cross-correlation analysis of annual chronic obstructive pulmonary disease (COPD) search volume and COPD disease burden indicators (2004-2017).

Disease burden indicator	Annual search volume		
	Lag –1	Lag 0	Lag 1
Prevalence	0.31	0.84[a]	0.60[a]
Incidence	0.36	0.92[a]	0.50
Disability-adjusted life years (DALY)	0.04	0.06	0.49
Years living with disability (YLD)	0.29	0.84[a]	0.59[a]
Years of life lost (YLL)	–0.00	0.08	0.41
Mortality	–0.01	0.00	0.40

[a] Exceeds the 95% CI threshold.

Discussion

This study examined the trends in OHISB for COPD in Singapore using Google search volume data between 2004 and 2020 and compared them with the trends in disease burden indicators for the same time period.

Principal Findings

The first objective was to examine the trend in search volume in COPD from 2004 to 2020. During this period, the trend in COPD search volume was curvilinear, with a slope change at the end of 2006. Further analyses examining the trends before and after this slope change revealed a downward trend from 2004 to 2006 and an upward trend from 2007 to 2020. The downward trend from 2004 to 2006 was surprising. We speculate the reason to be noisy data due to low and inconsistent search volume from 2004 to 2006, a period during which personal computing and high-speed internet connectivity were growing rapidly but not yet widespread in Singapore. From 2007 to 2020, the search volume exhibited a positive linear trend. A search of news and events from 2004 to 2020 revealed no significant events (eg, COPD health campaigns) to explain this trend. Our finding contrasts with an analysis of global data that showed no change in the trend in COPD OHIBS from 2004 to 2018 [15] and highlights the value of adopting a country-specific approach for revealing patterns that might be diluted when countries are aggregated.

The second research objective was to compare the trend in Google search volume with the disease burden indicators of COPD. From 2004 to 2017, there were positive correlations between search volume and several COPD disease burden indicators (prevalence, incidence, YLD) in the GBD study, suggesting that the trend in COPD search volume reflected the increase in some COPD morbidity indicators in the country. Search volume was not correlated with COPD mortality and YLL due to the disease, suggesting that Google search volume might be driven by the need to manage the illness for those living with COPD. This is consistent with the observation that improved health care has prolonged the living years of patients living with chronic illnesses, such as COPD.

The positive correlations between OHISB trends and COPD disease burden indicators (particularly prevalence and YLD) suggest that increased prevalence of COPD morbidity may have manifested in increased OHISB. COPD patients might be searching for health information on the internet to cope with their illness. Some of these increased searches might also have been performed by carers and family members of patients with COPD [20] or health care workers, especially those still in training. Patients with COPD appear to rely on their physicians as their primary source of information [12], but OHISB may still have a significant role when access to formal health care is limited. In Singapore, it is common for consultations with general practitioners to last for ≤5 minutes, so patients need to be well informed to optimize the brief consultation. Several patient-related barriers to timely COPD diagnoses have been reported in the literature. Patients tend to adapt to and underreport their respiratory symptoms, leading to potential underdiagnosis of COPD [21]. Older patients may also mistake symptoms such as shortness of breath as normal signs of aging [22]. Increased awareness of the significance of these symptoms among high-risk patients (eg, smokers) can increase the likelihood of a more timely diagnosis and prompt management of exacerbations.

Recommendations should be given to providers of online health information to make their materials more credible and user-friendly, reducing the barrier to timely health care seeking. Health knowledge can empower COPD patients to actively manage their own illnesses and make informed decisions about their conditions. For patients who seek health information online regularly, health care professionals can recommend trustworthy websites to complement their illness management [12].

In adopting a country-specific approach, this study seeks to present a nuanced picture of OHISB in Singapore's rapidly aging population with high internet penetration and increasing COPD burden. Heterogeneous patterns may be concealed when countries are aggregated for analysis. Furthermore, findings from single-country studies are more useful for formulating policies, which need to be tailored to the specific conditions of the target country.

Limitations

The findings of this study should be considered in the light of its limitations. First, while Google is the most popular search engine by a large margin, it nevertheless does not encompass all OHISB for COPD. Future research needs to study COPD OHISB on other platforms, such as social media, to understand how those OHISB change in accordance with COPD morbidity. Second, although Google indicated that Google Trends data should be understood as a metric of interest relative to searches on other topics, the specific way in which Google Trends data are derived is still unknown. Third, we note that the positive linear trend in COPD search volume is only moderate, and the interest level in this condition is low relative to some other health conditions. Finally, we acknowledge that this study is observational in nature, and the observed relationships were associative rather than causal. An additional analysis of search volume data on tuberculosis, a condition with a mostly static disease burden in Singapore, also revealed an upward trend, but to a lesser degree than COPD, suggesting a possible general increase in OHISB across medical conditions. Hence, increasing disease burden may be only one of the many factors driving OHISB in COPD.

Conclusion

Using Google search data, this study found an increasing trend in OHISB for COPD from 2007 to 2020 in Singapore, consistent with the increases in COPD morbidity estimates over the same time period. This suggests increasing engagement in OHISB for COPD in the population, many of whom may be COPD patients and their carers. The COPD disease burden is increasing, and timely seeking of health care is imperative for its prevention, early detection, and management. Greater public awareness is essential for minimizing the disease burden. Therefore, improving access to high-quality, web-based information on COPD is recommended for fulfilling COPD patients' information needs and improving their health outcome.

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Conflicts of Interest

None declared.

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Abbreviations

COPD: chronic obstructive pulmonary disease
DALY: disability-adjusted life years
GBD: Global Burden of Disease Study
ICC: intraclass correlation coefficient
OHISB: online health information–seeking behavior
RSI: relative search interest
TARIPH: Academic Respiratory Initiative for Pulmonary Health
YLD: years living with disability
YLL: years of life lost

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