User Expectations and Willingness to Share Self-Collected Health Data

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Abstract. The rapid improvement in mobile health technologies revolutionized what and how people can self-record and manage data. This massive amount of information accumulated by these technologies has potentially many applications beyond personal need, i.e. for public health. A challenge with collecting this data is to motivate people to share this data for the benefit of all. The purpose of this study is to survey and examine factors that may motivate sharing this data. We asked 447 participants four questions related to health data sharing and motivation. Participants with a chronic disease were concerned about data sharing but also willing to share health data if personalized feedback is provided. Functionality, ease of use, and privacy are regarded as crucial features of health apps.

Keywords. Public health, mHealth, motivation, health surveys, health data sharing.

1. Introduction

The ubiquitous nature of smartphones, wearables, and sensors have revolutionized the way people collect health-related data. An increasing number of people collects large amounts of data for disease-management, fitness, and self-surveillance. In a recent study, more than 60% of American participants tracked various health parameters, including diet, weight, and physical exercise, where 21% relied on fitness tracker technology [1]. People with chronic diseases use different technologies, e.g. mHealth apps and continuous glucose monitors for diabetes management, collecting and processing health data for their self-management. This data can potentially be used as a secondary source of information for public health, including tracking of disease trends, behavioural patterns over time, chronic diseases status, research, and policy work [2, 3, 4, 5]. The impact of these self-collected data highly depends on people's willingness to share their data for the intended purpose. Considering the potential of these data to inform about individual and population health, understanding the users' expectations and willingness towards mass data sharing is an important area of research. Various factors could affect people's motivations to engage in mass data sharing, e.g. lack of trust, which is mainly

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subject to data security, privacy, and confidentiality issues [6]. When sharing such data, expectation and willingness often differ in different patient groups, as well as in healthy people [7, 8], e.g. people with type 1 diabetes have a high need to record health data several times per day. Here, we examine factors related to people's knowledge and expectations toward raising motivation for sharing of health-related data and comparing these factors across different groups.

2. Method

We created an online survey with questions related to motivational factors around mHealth apps and data sharing. Questions were derived from 16 in-person interviews [6]. The survey was conducted among English-speaking internet users in a Swiss cohort of healthy people and also in English and Norwegian online diabetes groups. We collected data between 11/2018 and 08/2019. The questions related to data sharing are: 1) How concerned are participants about sharing health data, 2) what do participants expect in return when sharing health data, 3) which data types are participants willing to share anonymously for research, and 4) how important are different criteria in order to agree to install an application that collects and shares data from their wearable device. Options were on a 4-point Likert scale from "not important at all" to "very important" (including "I don't know"), or multiple-choice. We stratified responses into three groups: 1) People with diabetes (PWD), 2) people with other chronic disease and 3) people without a chronic disease. Details about the questionnaire are available at DataverseNO [9]. We report descriptive statistics on age, gender, experience using wearable devices and mobile health apps and wearables for sharing health or activity data.

3. Results

Four hundred forty-seven (447) participants finished the survey, of which eight did not answer whether they have a disease, and nine selected "Do not want to answer". Further analyses are based on the remaining N=430. Sixty-one (61) participants had diabetes, 82 participants had another chronic disease, and 285 had no chronic disease. The majority of participants came from Switzerland (187), Norway (59), US/UK/Australia/Canada (77), France (26), and Germany (13). Remaining 46 came from 35 countries covering all continents. Table 1 gives their demographics, familiarity with mHealth apps, and sharing experience. There was no age (p=.083) or gender (p=.133) difference between the groups. However, 97% in the diabetes group use a wearable device for collecting activity or other health data, compared to only 51% in the "no disease" group, and 55% in the "other chronic disease" group, $\chi^2(423)=44.04$, p=.001. Many PWD has experience in sharing data, less so people without a chronic disease, $\chi^2=19.6$, p < .001.

Table 1. Demographics and familiarity with mHealth apps. Na= no answer.

	With diabetes	With other chronic diseases	Without chronic disease
Age: <30 y; 30-50y; >50y	15; 17; 27 (Na: 2)	9; 32; 40 (Na: 1)	34; 96; 146 (Na: 6)
Gender: female; male; other	35; 25; 1	59; 20; 3	177; 99; 3
Wearable device: yes; no	59; 2	44; 36	143; 137
Sharing experience: yes; no	24; 27 (Na: 10)	22; 45 (Na: 14)	47; 160; (Na: 11)

3.1. Technologies use for health tracking

87% of those with diabetes use a health-specific device, in addition to often using a Physical Activity (PA) tracker. 3% use no sensor or wearable device. Among those with other- or no chronic diseases, the use of sensors integrated in the smartphone and PA trackers are most common. 25-30% use mobile health apps. Generally, participants preferred to discuss health issues with health providers. PWD would discuss it with others PWD (17%), but rarely with their family (6%). This is in contrast to persons with other- or no chronic disease, where 19% and 20%, respectively, would discuss health issues with their family and friends, see Figure 2b. This difference with whom to share was statistically significant, $\chi^2=34.67$, p<.001.

3.2. Concerns about data sharing

Regarding what people are most concerned about sharing health data, persons with no chronic disease are in general least concerned, and all three groups rate storage as least and transparency as most concerning. Figure 1a shows how each group rate concerns about confidence and trust, data ownership, storage location/availability, and transparency of third party usage. Figure 1b shows how important certain features are for each group in order to agree to install an application that collects and share health data from their wearable device.
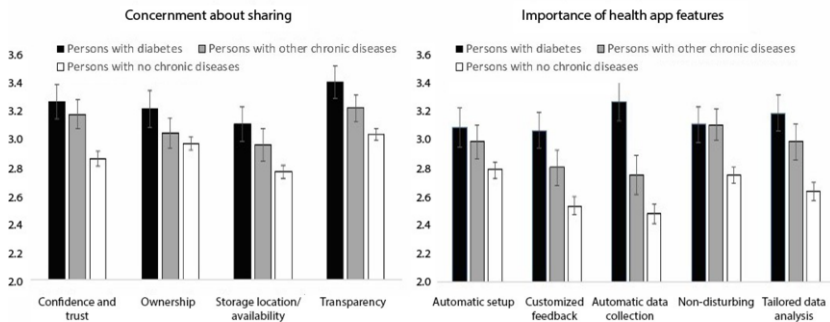

Figure 1. a: Concerns about different aspects of data sharing. b: Importance of features, answer option 1 to 4.

3.3. Participants expectations for sharing health data

Regarding what participants expected in return for sharing their health data, personalized feedback was chosen by 60% of participants, integrated view (i.e. aggregated results), was chosen by 53%, decision support by 36%, and least chosen (16%) was comparing

status with others. There was no difference between the groups in their expectations, smallest p > .74, but comparing with others was rated as least important (Figure 2a).
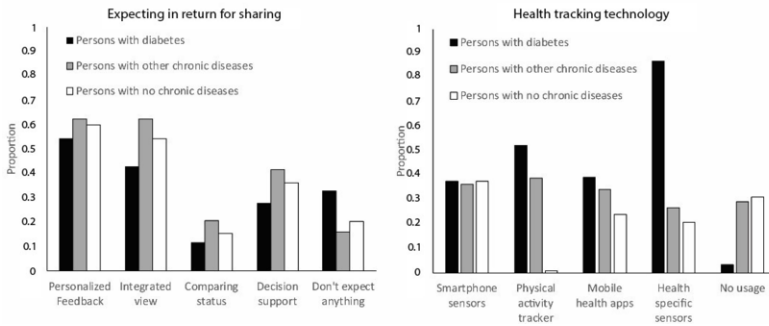

Figure 2. a: Expectations for sharing data. b: Group distribution of health tracking technology.

3.4. Willingness to anonymously share given data types in a research project

Groups do not differ in sharing lifestyle/dietary information, signs of infection, daily mood, geographical location, sleep duration, social environment (corrected for multiple comparisons). Participants are least willing to share their geographical location. Persons with chronic disease are more willing to share medication intake, physiological indicators and their weight. An overview is given in Table 2.

Table 2. Overview of willingness to share specific health data by group. Chr. = chronic.

	Medication intake and treatment	Lifestyle/ dietary intakes	Signs of infection	Physiological indicators	Daily mood	Physical activity	Geographical location	Sleep duration	Weight	Social environment	None of these
N	213	219	195	202	193	248	87	240	221	173	89
Diabetes	53	41	31	46	29	43	20	43	43	30	5
Other chr.	44	45	45	40	46	54	16	50	49	35	16
No chr.	116	133	119	116	118	151	51	147	129	108	68
X^2	43.48	9.05	5.22	24.39	5.73	8.93	6.92	8.29	15.48	2.87	7.59
p-value	<.001	.011	.074	<.001	.057	.012	.031	.016	<.001	.238	.023

3.5. Features' importance in mHealth app

Regarding which features of a health-app is important to participants (1=not important to 4=very important), non-disturbed tracking and automatic setup is rated by most as important, i.e. the main effect of feature, $F(3.83, 1163.75)=3.389$, p=.01, $\eta^2= .011$. All features were more important to people with a chronic disease, $F(2, 304)=12.09$, p<.001, $\eta^2=.074$. PWD rate automatic data collection as most important, yielding a significant interaction effect, $F(7.66, 1163.75)=2.104$, p=.035, $\eta^2=.014$.

4. Discussion

Mass sharing of health data could provide vital information for individual health management and public health. Continuous collection of quality health-related data and willingness to share these are limited by the user's motivation and expectations. The rate of acceptance of health tracking devices among clinicians is increasing [10], but

retention is decreasing [11]. Compared to PWD who use wearable sensors, participants with no- and other chronic disease reported higher adoption of sensors integrated in the smartphone and PA trackers. Automatic data collection, easier interface, e.g. voice command, tailored and personalized feedback is likely to increase usage and long-term engagement in such devices.

Concern about health data sharing is dependent on the type of data, and related concerns on issues such as privacy, security, confidentiality, transparency, and ownership. Participants with no chronic disease are less concerned compared to people with a chronic disease. Indeed, potential consequences of data leakage like repeated low blood glucose level (hypoglycemia) might result in the suspension of one's driving license or disqualification of health insurance enrollment in some countries. Some privacy and security shall be kept, i.e. many participants do not want to share their geographical location.

This study on how to motivate health data sharing is a collaboration between several projects where different systems for health data collection are under development. Results from the present study, and upcoming publications on related topics, will be used to direct the implementations of these systems for maximum acceptance. Future works include data collection, data quality and accuracy analysis, and detecting health patterns at the population level and in people with specific chronic diseases. Fulfilment of participant's expectations and resolving individual concerns could motivate sharing health-related data. Results indicate that participants expect some kind of immediate benefits from sharing their data, including tailored and personalized data analysis, integrated view, feedback and others. Comparison of status among peers was found to be less relevant.

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