Cancer Patient Perspectives on Sharing of Medical Records and Mobile Device Data for Research Purposes

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Abstract

Sharing data is critical to advancing science, improving health, and creating advances in the delivery of health care services. The value of sharing data for cancer research purposes is well established, and there are multiple initiatives under way that address this need. However, there has been less focus on cancer patient perspectives regarding the sharing of their health information for research purposes. This study examined cancer patient perspectives on the sharing of de-identified health data for research purposes including both data from medical records and mobile applications. This cross-sectional study used survey methodology to collect data from cancer patients/survivors (N = 677). Overall, we found that participants were largely willing (71%) to share de-identified medical data and were most motivated (88%) by a desire to help other cancer patients. Patients were less likely to be comfortable sharing mobile application data (34%). It is vital that we understand patient perspectives on data sharing and work with them as partners, valuing their unique contributions, and attending to their preferences.

Keywords

cancer, oncology, data sharing, patient perspectives

Introduction

Sharing data is critical to advancing science, improving health, and creating advances in the delivery of health care services (1). Data sharing is particularly salient in cancer, with over 1.7 million new cases diagnosed in the United States each year (2). As of 2019, there were almost 17 million cancer survivors in the United States, and this is expected to increase to over 22 million by 2030 largely due to improved detection methods and technology and innovative treatment options, coupled with an aging population (3). Facilitating data sharing across the entire cancer care continuum is a key to further accelerating advances in cancer research and discovery. As such, one of the main goals outlined in the Cancer Moonshot of the Obama Administration was to create a Cancer Data Ecosystem (4). The value of sharing data for cancer research purposes is well established. However, there has been minimal focus on cancer patient perspectives regarding the sharing of their health information for research purposes.

Although, not limited to cancer patients, a recent systematic review found that patients in the United States were generally willing to have their health data shared with other academic and/or medical researchers and willingness increased if the data were de-identified (5). Other studies reported that patients wanted potential risks in data sharing to be identified before agreeing to share their data (6), and some patients were not as comfortable with their data being shared with researchers outside of the United States (7). A recent study found that although patients are willing to share anonymized health records for research, they noted a lack of transparency and limited awareness of how their data would be used for research (8). Among cancer patients, willingness to share their medical data for research purposes may be related to their relationship with the institution where they received their cancer care (5), as patients were less willing to

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have their data shared with researchers who were not affiliated with the local research team (9–11). Additionally, previous research has explored the uses and users with whom cancer patients are willing to share health information but did not address types of health information, rationale for sharing information, and/or what would make them more willing to share information and what makes patients uncomfortable sharing health information (12). A recent systematic review specifically noted that there is limited research on how patient sociodemographic factors are related to broad consent and data sharing (5).

To address this gap in the literature, this study aims to (1) describe cancer patient perspectives on sharing de-identified health data for research, (2) examine differences in patient perspectives on data sharing based on the proposed use of data, and (3) examine sociodemographic differences in patient perspectives on data sharing based on the type of health data shared (eg, medical records, mobile applications/wearables).

Method

Study Design

This cross-sectional study used survey methodology to collect data from individuals in the United States who had received a cancer diagnosis at some point in their life. Participants were recruited for this study via nonprobability convenience sampling by the Cancer Support Community (CSC), a nonprofit advocacy organization for people impacted by cancer. Recruitment methods included reaching out to potential participants via CSC's Cancer Experience Registry via email and advertising the study on social media platforms (Facebook, Twitter). Survey data were collected via SurveyMonkey. A total of 677 cancer patients/survivors completed the online survey in April and May of 2018. Criteria for inclusion included the following: (1) age 18 years or older, (2) can read the survey in English, and (3) has received a cancer diagnosis in their lifetime. Informed consent was obtained prior to survey administration. The study protocol was approved by Ethical and Independent Review Services (E&I, Independence), an external institutional review board. The full survey is available in Online Appendix A.

Study Measures

Sociodemographic characteristics. Study participants were asked to respond to questions about their sociodemographic characteristics (such as age, race/ethnicity, sex, educational background, household income, and insurance type) and cancer history (type and stage as well as type of setting in which they received cancer treatment).

Patient perspectives on data sharing. Participants were asked a series of questions regarding their perspectives and willingness to share data from their de-identified medical records and mobile applications. Participants were asked if they

were willing to share their de-identified medical records, or information generated by mobile applications and tracking devices, for research purposes with the following institutions: (1) academic medical center or university, (2) government agency, (3) nonprofit organization, and (4) commercial entity. Responses were dichotomous (1 = yes; 0 =no). Participants were asked to rate their willingness to share de-identified medical records for research purposes on a scale from 1 to 5 (1 = not at all; 5 = very much) in the following scenarios: (1) if there were a financial incentive, (2) if it would help other people with cancer, and (3) if they would get a report on the research findings. Participants were asked if they were to donate their data or biosamples for research, how important it would be for them to control which research studies their data were used for on a scale of 1 to 5 (1 = not all and 5 = very). Participants were also asked if they were to contribute their data for research, how important would it be for them to receive feedback on what was discovered from their data and similar data from other individuals on a scale of 1 to 5 (1 = not all; 5 = very).

Qualitative items. Participants were provided an opportunity to provide qualitative feedback on 2 questions including (1) what else would make you more willing to share your deidentified medical records/data from mobile applications for research purposes? and (2) if you are not comfortable sharing your data for any purpose, please share your reasons so that we can better understand your perspective.

Data Analysis

Descriptive statistics were utilized to describe the sample characteristics. Two-tailed independent samples t tests were used to examine differences in participant characteristics for continuous variables (willingness to share medical records or mobile application data). One-way analysis of variance tests were conducted to determine differences in willingness to share medical records or mobile application data for education level, which was collapsed into 3 categories (1 = HS)degree or less; 2 = Some college/2-year degree; 3 = Bachelor's degree or higher). Pearson correlations were conducted to determine whether there were associations between continuous variables (age, income, and willingness to share medical records or mobile application data). All quantitative data were analyzed using SPSS V25. Statistical significance was defined by P < .05. Qualitative data were analyzed utilizing inductive (13) coding. Two individual coders analyzed the data separately and compared codes. The initial interrater reliability was 90% and differences were discussed until consensus was reached.

Results

Participant Characteristics

A total of 677 cancer patients and/or survivors participated in this study. The mean age was 60.4 years old (range:

Table I. Sample Characteristics.^{a,b}

Variable	% (n)
Sociodemographic characteristics	
Gender	
Male	18.1 (121)
Female	81.9 (546)
Race	
White	90.8 (614)
Nonwhite	9.2 (62)
Marital status	. ,
Married	67.5 (449)
Not married	32.5 (216)
Employment status	
Employed	41.6 (278)
Not employed	58.4 (390)
Annual household income	
Less than \$20,000	7.3 (39)
\$20 000 to \$59 999	28.8 (154)
\$60 000 to \$99 999	30.2 (161)
\$100 000 or more	33.7 (180)
Highest level of education	
HS degree or less	6.6 (44)
Some college/2-year degree	27.9 (187)
Bachelor's degree or higher	65.5 (439)
Health insurance	
Employer plan	47.8 (319)
Medicare	33.7 (225)
Other ^c	15.8 (106)
Not insured	2.7 (5)
Cancer characteristics	
Most common cancers	
Breast cancer	55.2 (373)
Skin cancer/melanoma	11.2 (76)
Prostate	6.7 (45)
Cancer treatment settings ^d	. ,
Academic medical center	41.4 (262)
Physician owned practice/group	30.3 (192)
Hospital/health system owned practice/group	51.0 (323)
Community hospital or health center	27.8 (176)

 ${}^{a}N = 676.$

^bn's range due to occasional missing data.

^cOther types of insurance included the following: military, private plan, insurance purchased through the marketplace, and Medicaid or some other form of state insurance.

^dParticipants could select more than one option, so percentages add up to more than 100.

25-91years). Study participants were predominantly female (81%), white (92%), non-Hispanic (95%), and reported household incomes of \$60 000/year or higher (64%). Characteristics of study participants are shown in Table 1.

Cancer Patient Perspectives on Sharing Heath Data for Research

Overall, participants indicated a willingness to share their de-identified medical records for research purposes, with 71% of participants saying they were either *quite a bit* or *very much* willing to do so. Participants, however, were less

Table 2. Willingness to Share De-Identified Data for Research Purposes and Rationale.^a

Variable	% (n)
Willingness to share de-identified data from medical	
records with the following organizations":	
An academic medical center or university	93.7 (622)
A nonprofit organization	86.4 (567)
A government agency	83.2 (538)
A commercial entity	56.9 (359)
Willingness to share de-identified data from medical	
records for the following reasons ^c :	
To help others with cancer	67.8 (448)
If a report on findings is provided	56.8 (377)
Incentives are provided	44.2 (296)
Willingness to share de-identified data generated by	
mobile apps with the following organizations ^b :	
An academic medical center or university	67.9 (444)
A government agency	55.8 (359)
A nonprofit organization	62.5 (404)
A commercial entity	38.4 (241)
Sharing de-identified medical records data vs. both	()
medical records and mobile app data ^d	
Willing to share only medical records data	27.1 (170)
Willing to share both medical records and mobile	72.9 (67.8)
app data	()
^a N - 676	

^bThese percentages represent the people who indicated they were willing to share their data with the organizations listed.

^cThese percentages represent the participants who answered "very much" when asked how willing they were to share de-identified medical records under the conditions listed.

^dLimited to participants who were willing to share medical records data.

likely to be willing to share their de-identified information generated by mobile applications and tracking devices for research purposes with 34% responding that they were *quite a bit* or *very much* willing to share.

Rationale for Patient Willingness to Share Health Data for Research

As shown in Table 2, most participants were most likely to be willing to share both medical records and mobile application data with academic medical centers or universities (94% and 68%, respectively). The most common reason participants reported their motivation to share their deidentified medical records data for research purposes was a desire to help others with cancer (88%) followed by an opportunity to receive a report of the research findings (82%) and a financial incentive (65%).

Sociodemographic Differences in Perspectives on Sharing Heath Data for Research

As shown in Table 3, the majority of participants were "quite a bit" or "very much" willing to share their de-identified medical records (71%) or mobile health app data (34%)for research purposes. However, there were significant

Variable	Medical records data		Mobile app data	
	Mean (SD)	t test statistic	Mean (SD)	t test statistic
Gender		-2.23 ^b		-0.61
Male	3.78 (1.29)		2.79 (1.51)	
Female	4.06 (1.11)		2.89 (I.5I)	
Race	()	0.63	· · · · ·	-0.0 I
White	4.03 (1.13)		2.86 (1.51)	
Nonwhite	3.90 (1.16)		2.92 (I.54)	
Marital status	()	0.95	· · · · ·	2.70 ^c
Married	4.03 (1.15)		2.99 (1.52)	
Not married	3.94 (1.13)		2.65 (1.47)	
Employment status	()	0.22	· · · · ·	-1.44
Employed	4.01 (1.09)		2.76 (1.51)	
Not employed	3.99 (1.18)		2.93 (I.5I)	
	()	F test statistic	· · · ·	F test statistic
Highest level of education		2.87		0.17
HS degree or less	3.77 (1.33)		2.95 (1.54)	
Some college/2-year degree	3.89 (1.17)		2.82 (1.55)	
Bachelor's degree or higher	4.08 (1.10)		2.88 (1.49)	
	Pearson's r		Pearson's r	
Age (in years)	-0.05		-0.09 ^b	
Annual household income	0.07		0.07	

Table 3. Differences in Patient Characteristics Regarding Willingness to Share De-Identified Data.^a

Abbreviation: SD, standard deviation.

^b*P* < .05.

°P < .01.

differences in willingness to share de-identified medical records data based on gender (see Table 3). Women indicated a significantly greater willingness to share their de-identified medical records data for research purposes, t (160) = -2.23, P = .027. Married participants were significantly more likely to be willing to share their de-identified mobile health data, t (649) = 2.67, P = .008. Lastly, age was significantly associated with willingness to share mobile application data. Younger participants were more willing to share mobile application data (r = -.09, P = .024). There were no other significant differences in socioeconomic characteristics in willingness to share medical records or mobile application data.

Patient Willingness to Share Data

Qualitative data provided additional context underlying patient preferences on data sharing. When asked what else would make participants more willing to share their deidentified medical records for research purposes, 456 participants responded, and 6 main themes emerged. These included (1) the need for additional information, (2) altruism, (3) trust, (4) incentives, (5) institution type, and (6) enhancing access to care.

Additional information. The largest number of qualitative responses (16%; n = 72) focused on participant need for

additional information about each specific research study before data sharing could occur. Participants also reported a desire to receive study findings. One participant said they would need to know, "exactly who, where, [and] how my information will be used, and . . . [would also need to be] informed of the study results."

Altruism. Of those who responded to the opportunity to provide qualitative feedback, 15% (n = 70) focused on altruistic reasons as their rationale for being more willing to share their de-identified medical records. Two subthemes of altruism emerged, including (1) a desire to help others and (2) a hope to find a cure for cancer. One participant said, "I believe in paying it forward. I may not be helped personally, but if providing insight...[into]my diagnosis and treatment can help others, then I'm all in."

Trust. Approximately 12% (n = 54) of those who provided qualitative responses focused on the need to ensure trust in order to be willing to share their de-identified medical records for research purposes. Three subthemes of trust emerged, including (1) confidentiality, (2) privacy, and (3) transparency. Most of the participants who discussed trust said they would be comfortable with their data being shared as long as they could not be connected to it in any way; however, some were skeptical that remaining disconnected from their data was possible, particularly when utilizing the

 $^{{}^{}a}N = 676.$

internet or mobile devices. The concepts of confidentiality and privacy were important foundational tenets for participants who mentioned trust, and a few focused on the need to prevent repercussions that could result from the sharing of data in medical records, including discrimination. For example, one participant said, "I would need absolute assurance that this [medical record data] would never be used against me for...insurance or employment...and [I would need assurance] that there would be no way to trace this [information] back to me and my records."

Incentives. In terms of incentives to share data, 3% (n = 15) of participants focused on a desire to be compensated (either with money or gift cards) for their data. The desire for incentives was particularly pronounced when participants believed that external institutions might be able to profit from the use of their data. One participant said that the institution using the data should donate to a cancer organization in return for participant willingness to share their data.

Institution type. Nine (2%) participants said they would likely not be comfortable with their data being shared with a forprofit organization. One participant noted they would need assurances, such as, "certainty that no for-profit group would gain profits from my information." However, another participant expressed hesitancy to share their data, but an overarching desire to help others, stating they would be, "very willing for my information/experience to be used for research purposes, [but I would be] hesitant to share [my data] with companies and for-profit institutions but if there were the possibility of it helping patients I might be open to that."

Access to care. Five (1%) participants focused on the impact future research could have on their access to cancer care. For example, one participant said, "for data to be shared with forprofit organizations, they must contractually agree to keep drug prices sustainable." Another participant focused on their rare cancer and stated that data sharing should lead to an investment in research and additional treatments for their particular cancer.

Rationale for Not Sharing Data

Additionally, participants were asked to provide their reasoning if they were not comfortable sharing their data for any purpose. Three main themes emerged that paralleled some of the sentiments expressed in the previous qualitative question. These included (1) trust, (2) institution type, and (3) additional information.

Trust. For participants who were unwilling to share their data for any purpose, the most common reason was trust, again including the subthemes of (1) confidentiality, (2) privacy, and (3) transparency. Some participants were concerned with the notion of "tracking" particularly when it came to

mobile applications or wearables. Other participants were worried about the potential for hacking and exposure of their identities. One participant said they were, "... really uncomfortable with mobile tracking devices, [as these devices are]too intrusive and always a risk of stolen identifiers [identifying information]."

Institution type. Approximately 16% (n = 33) of participants who responded to this qualitative question mentioned the type of institution they would not be comfortable sharing their data with. These participants were not comfortable with for-profit companies, and to a lesser extent, the government, handling their data. Reasons for this perspective included "trust issues," concern about purposes not being "altruistic," or ultimately higher prices for the treatments and services that they need. This was slightly tempered if the end goal of the for-profit companies or the government using their data was to ultimately help s with cancer patients. One participant noted that they would not be willing to share with for-profit companies, "… if it [their data] were to be used to hike prices or [create] availability restrictions on medicine, [that could]… be used against people who need help."

Additional information. Eight (2%) participants said they would need additional information about the specific research study their data would be used for, in order to be willing to share their de-identified medical records. The additional information participants wanted included both information about the study and an assurance that they would receive study results. One participant said "medical data is personal and I wouldn't just share it to share it. I want it to make sense and make sure it's used for the correct purposes. I understand you are talking about de-identified data but I'd still like to know what I am contributing to."

Discussion

This study examined cancer patient perspectives on the sharing of de-identified health data for research purposes including both data from medical records and mobile applications. Overall, we found that cancer patients and survivors were largely willing to share de-identified medical data and were most motivated by a desire to help other cancer patients. This is consistent with previous research results showing that patients are usually interested in sharing de-identified data with academic or medical researchers (5,12,14), including cancer patients in clinical trials who were willing to allow a central research team to access their health information (15). However, just over 25% of cancer patients in this study were only willing to share medical records and were not willing to also share data generated by mobile applications. The reduced willingness to share data from mobile applications may be explained by related research showing that patients are comfortable sharing medical data with their health care providers but do not see value in sharing lifestyle data (such as the data collected by mobile applications) (16). Further, patients were motivated to share their data with trusted institutions and less compelled to do so what they deemed to be corporate profits.

Important reasons exist for patients to share their data, and while this article illustrates that patients are largely willing to do so, several recommendations emerge from their feedback. First, patients need to understand the purpose for sharing their data and must have complete trust that their information will be used expressly for that purpose and that purpose only. They must be assured that their identity will be kept confidential and private and that there will be no tracking without their consent. These findings are similar to previous research that found patients specifically want any risks in data sharing to be identified before agreeing to share their data (6). For patients who are comfortable with sharing their data with for-profit companies, they should be seen as partners and should be offered not only incentives to participate but also benefits commensurate with their participation such as access to treatments and potentially a future financial stake if companies are profitable as a result of the data sharing. Finally, patients deserve feedback on the use of their data and results of research studies and/or commercial pursuits. This is consistent with research that has shown patients feel there is a lack of transparency about how their data would be used for research (8) and therefore, patients desire more information.

Several study limitations exist and should be considered when considering study results. First, this study was crosssectional and exploratory in nature. Participants were largely homogenous in terms of gender and race with a large proportion representing a single cancer type. The qualitative findings have limited generalizability, given that not all survey participants provided data. Additionally, certain survey questions did not provide specific explanations or examples for participants and the survey was not pilot tested prior to conducting the study. Therefore, certain terms could have been interpreted in multiple ways by participants (eg, mobile applications and tracking devices), which may limit the conclusions that can be drawn. Despite these limitations, this study explores a concept that will continue to gain importance as innovation emerges from a partnership between patients, researchers, industry, and other health care stakeholders.

Conclusion

It is vital that we understand patient perspectives on data sharing and work with them as partners, valuing their unique contributions, and attending to their preferences. Decisions are often made on this topic (and many others) that impact patients without a robust understanding of how patients approach data sharing including situations in which they are not comfortable sharing data, guardrails to enhance their comfort levels, and assurances that they will contribute to science that will ultimately benefit cancer patients. As new technologies continue to emerge, it will be particularly important to understand how these technologies fit into the lives of cancer patients and survivors, and how we can best partner with patients to ensure altruistic uses of the data generated. It is important to obtain the full consent of patients, regarding the sharing of their medical data for research purposes, to allay concerns, while expanding opportunities for innovation. Future studies can further explore awareness and willingness related to data sharing among patients and survivors of cancer.

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Supplemental Material

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