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

Elizabeth F Franklin, PhD, MSW1, Helen M Nichols, PhD, MSW1, Linda House, RN, MSN, BN1, Joanne Buzaglo, PhD2, and Kim Thiboldeaux, BA1

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

1 Cancer Support Community, Washington, DC, USA
2 Concerto HealthAI, Philadelphia, PA, USA

Corresponding Author:
Elizabeth F Franklin, Cancer Support Community, 734 15th Street NW, Suite 300, Washington, DC 20005, USA.
Email: efranklin@cancersupportcommunity.org
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 sys-
tematic 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 (e.g., medical records, mobile applica-
tions/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 sam-
ping by the Cancer Support Community (CSC), a nonprofit
advocacy organization for people impacted by cancer.
Recruitment methods included reaching out to potential par-
ticipants 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 sur-
vey administration. The study protocol was approved by Eth-
cal 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 willing-
ness 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 track-
ing devices, for research purposes with the following insti-
tutions: (1) academic medical center or university, (2) gov-
ernment agency, (3) nonprofit organization, and (4) com-
mercial 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 or 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 at 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 de-
identified 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 educa-
tion level, which was collapsed into 3 categories (1 = HS
degree or less; 2 = Some college/2-year degree; 3 = Bache-
lor’s degree or higher). Pearson correlations were conducted
to determine whether there were associations between con-
tinuous 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 ana-
lyzed 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:
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 Health 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 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 de-identified 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 Health 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

---

### Table 1. 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) |

\(^aN = 676.\)
\(^b\)n’s range due to occasional missing data.
\(^c\)Other types of insurance included the following: military, private plan, insurance purchased through the marketplace, and Medicaid or some other form of state insurance.
\(^d\)Participants could select more than one option, so percentages add up to more than 100.

---

### 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\(^b\): |         |
| 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 for 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\(^d\): |         |
| 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 app data | 72.9 (67.8) |

\(^aN = 676.\)
\(^b\)These percentages represent the people who indicated they were willing to share their data with the organizations listed.
\(^c\)These percentages represent the participants who answered “very much” when asked how willing they were to share de-identified medical records under the conditions listed.
\(^d\)Limited to participants who were willing to share medical records data.
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 de-identified 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

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

| Variable                        | Medical records data | Mobile app data       |
|---------------------------------|----------------------|-----------------------|
|                                 | Mean (SD)            | t test statistic      | Mean (SD)            | t test statistic      |
| Gender                          |                      |                       |                      |                       |
| Male                            | 3.78 (1.29)          | -2.23b                | 2.79 (1.51)          | -0.61                 |
| Female                          | 4.06 (1.11)          | 2.89 (1.51)           |                      |                       |
| Race                            |                      |                       |                      |                       |
| White                           | 4.03 (1.13)          | 2.86 (1.51)           |                      |                       |
| Nonwhite                        | 3.90 (1.16)          | 2.92 (1.54)           |                      |                       |
| Marital status                  |                      |                       |                      |                       |
| Married                         | 4.03 (1.15)          | 2.99 (1.52)           |                      |                       |
| Not married                     | 3.94 (1.13)          | 2.65 (1.47)           |                      |                       |
| Employment status               |                      |                       |                      |                       |
| Employed                        | 4.01 (1.09)          | 2.76 (1.51)           |                      |                       |
| Not employed                    | 3.99 (1.18)          | 2.93 (1.51)           |                      |                       |
| Highest level of education      |                      |                       |                      |                       |
| 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)           |                      |                       |
| Age (in years)                  |                      | Pearson’s $r$         |                      | Pearson’s $r$         |
|                                 | -0.05                | 0.07                  | -0.09b               | 0.07                  |
| Annual household income         |                      |                       |                      |                       |

Abbreviation: SD, standard deviation.

*a* $N = 676$.

*Superscripted numbers indicate statistical significance. *b* $P < .05$.

*Superscripted numbers indicate statistical significance. *c* $P < .01$. 

1118 
Journal of Patient Experience 7(6)
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 for-profit 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 for-profit 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 patients 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 cross-sectional 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.

**Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The author(s) received no financial support for the research, authorship, and/or publication of this article.

**ORCID iD**

Elizabeth F Franklin https://orcid.org/0000-0001-6897-5670

**Supplemental Material**

Supplemental material for this article is available online.

**References**

1. Manion FJ, Harris MR, Buyuktur AG, Patricia MC, Lawrence CA, David AH. Leveraging EHR data for outcomes and comparative effectiveness research in oncology. Curr Oncol Rep. 2012;14:494-501.
2. American Cancer Society. Cancer Facts & Figures 2019. Report. American Cancer Society, Inc; 2019.
3. Miller KD, Nogueira L, Mariotto AB, Julia HR, Robin YK, Catherine MA. Cancer treatment and survivorship statistics, 2019 [published online ahead of print]. CA Cancer J Clin. 2019:69:363-85.
4. National Cancer Institute. Build a national cancer data ecosystem. National Cancer Institute; 2018. Retrieved February 4, 2019, from: https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/implementation/data-ecosystem
5. Garrison NA, Sathe NA, Antommaria AHM, Ingrid AH, Saskia CS, Maureen ES. A systematic literature review of individuals’ perspectives on broad consent and data sharing in the United States. Genet Med. 2016;18:663-71.
6. Haga SB, O’Daniel J. Public perspectives regarding data-sharing practices in genomics research. Public Health Genomics. 2011;14:319-24.
7. Long MD, Cadigan RJ, Cook SF, Kaaren H, Kriste K, Robert SS. Perceptions of patients with inflammatory bowel diseases on biobanking. Inflamm Bowel Dis. 2014;21:132-8.
8. Spencer K, Sanders C, Whitley EA, David L, Jane K, William GD. Patient perspectives on sharing anonymized personal health data using a digital system for dynamic consent and research feedback: a qualitative study. J Med Internet Res. 2016;18:e66.
9. Helft PR, Champion VL, Eckles R, Cynthia SJ, Eric MM. Cancer patients’ attitudes toward future research uses of stored human biological materials. J Empir Res Hum Res Ethics. 2007;2:15-22.
10. Pentz RD, Billot L, Wendler D. Research on stored biological samples: views of African American and White American cancer patients. Am J Med Genet A. 2006;140:733-9.
11. Rogith D, Yusuf RA, Hovick SR, Susan KP, Allison MBC, Yisheng LI. Attitudes regarding privacy of genomic information in personalized cancer therapy. J Am Med Inform Assoc. 2014;21:e320-5.
12. Grande D, Asch DA, Wan F, Bradbury AR, Jagsi R, Mitra N. Are patients with cancer less willing to share their health information? privacy, sensitivity, and social purpose. J Oncol Pract. 2015;11:378-83.
13. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. Am J Eval. 2006;27:237-46.
14. Kim J, Kim H, Bell E, Bath T, Paul P, Pham A, et al. Patient perspectives about decisions to share medical data and biospecimens for research. JAMA Netw Open. 2019;2:e199550.
15. Hay AE, Leung YW, Pater JL, Brown MC, Bell E, Howell D, et al. Linkage of clinical trial and administrative data: a survey of cancer patient preferences. Curr Oncol. 2017;24:161-7.
16. Wetzels M, Broers E, Peters P, Feijs L, Widdershoven J, Habibovic M. Patient perspectives on health data privacy and management: “where is my data and whose is it?”. Int J Telemed Appl. 2018;2018:3838747.

Author Biographies

Elizabeth F Franklin is Executive Director of the Cancer Policy Institute at the Cancer Support Community and a social worker by training.

Helen M Nichols is a research fellow at the Cancer Support Community and a social worker by training.

Linda House is President of the Cancer Support Community and an oncology nurse by training.

Joanne Buzaglo is Executive Director of PRO Solutions at Concerto HealthAI and a psychologist by training.

Kim Thiboldeaux is the Chief Executive Officer of the Cancer Support Community and a longtime patient advocate.