Pediatric Cancer Patients, Survivors, and their Families:
A Survey of Knowledge, Attitudes, and Opinions About Big Data

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Background and Aims

There is little evidence in academic literature regarding the perspectives of pediatric cancer patients and their families toward the use and sharing of their cancer-related data. This question becomes even more critical to understand as the use of big data in pediatric cancer research advances.

With this study, we aimed to

1) Assess the awareness of pediatric cancer survivors and their families regarding the lifecycle of their medical information and clinical trials data,
2) Assess their level of concern about this knowledge, and their interest in learning more about the lifecycle of their data
3) Examine the relationship between these ratings and demographic and medical history-related variables

Methods

We received IRB approval for the project with exempt status. We worked with various pediatric cancer non-profit organizations, who distributed a REDCap survey to pediatric cancer patients, survivors, and their family members through their listservs on our behalf.

With the survey, we gathered information on demographics of the respondent as well as the medical history of the patient. We asked the respondents to rate their awareness of various stages of the lifecycle of their cancer-related medical information and clinical trials data on a scale of 1 to 5. We also asked them to rate their concern regarding their current level of awareness and interest in learning more on a scale of 1 to 10.

We used R and Excel to analyze the responses by calculating statistical variables and performing t-tests.

Demographics:

In total we received 289 responses.

Parent/Survivor	n (%)
Parent	272 (94.1%)
Survivor	17 (5.9%)
Clinical Trial Enrollment	n (%)
Enrolled	119 (41.2%)
Not enrolled	170 (58.8%)
Patient Survival Status	n (%)
Alive	197 (72.4%)
Deceased	66 (24.3%)
Sex	n (%)
Female	251 (86.9%)
Male	35 (12.1%)
Education	n (%)
Less than college degree	64 (22.1%)
College degree or more	221 (76.5%)
Race and Ethnicity	n (%)
American Indian or Alaska Native	5 (1.7%)
Asian	10 (3.4%)
Black or African American	5 (1.7%)
Hispanic or Latinx	13 (4.4%)
White	256 (87.8%)

Table 1: Demographic and Medical-History Variables

Results:

Awareness:

Figure 1: Medical Data Awareness

Figure 2: Clinical Trials Data Awareness
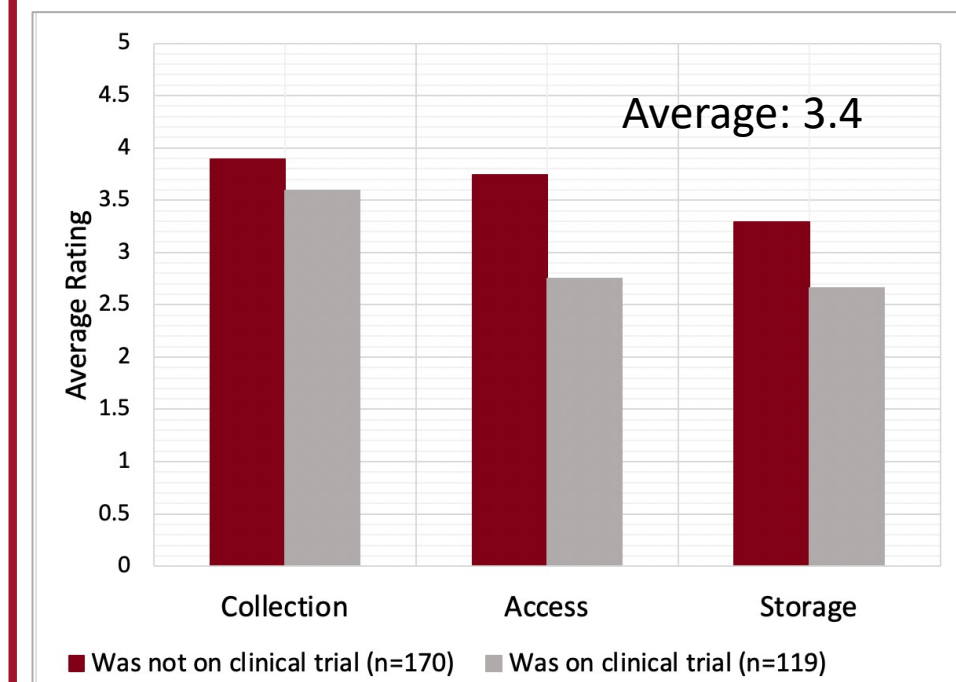
Self-reported awareness ratings generally decreased toward the later stages of the data lifecycle for both data types (Figures 1 and 2). Participants reported higher awareness for the lifecycle of medical information compared to clinical trials data (p=0.08). For medical information, participants who weren't enrolled in a clinical trial reported higher awareness compared to participants who were (p<0.01)
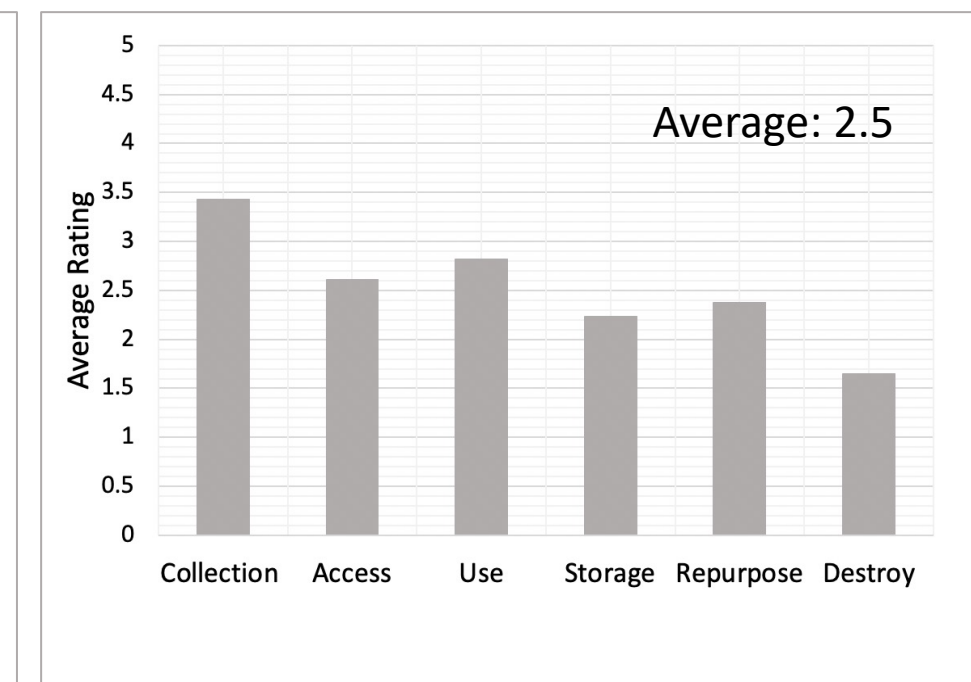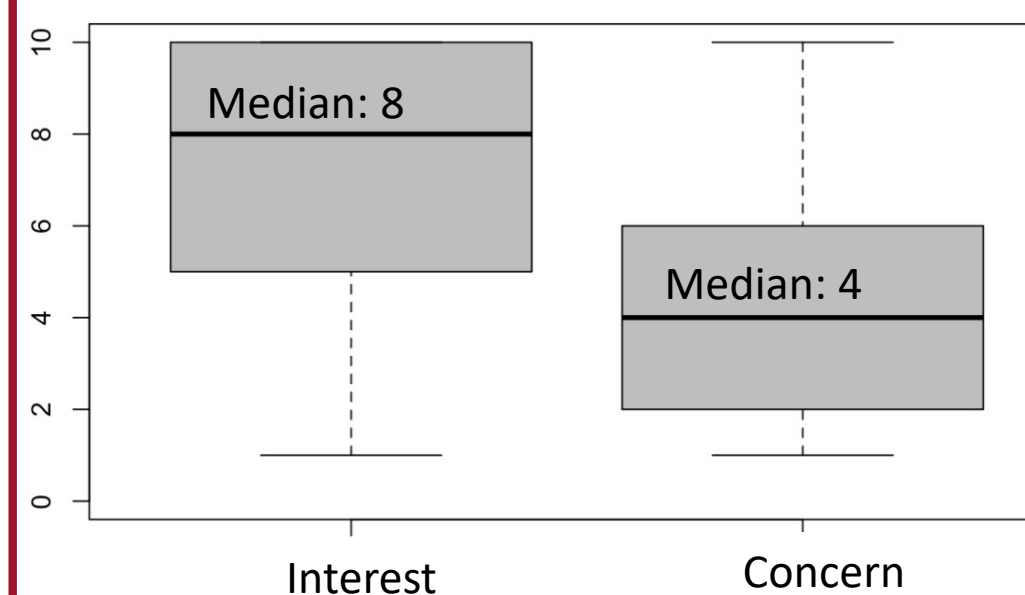
Concern and Interest:

Figure 3: Concern and Interest Distribution

Interest in learning more about the lifecycle of data was generally high (Figure 3) with a mean of 7.5. Concern was present but not as high (Figure 3) with a mean of 4.2. There was a positive correlation between concern and interest ratings and no strong relationship between concern or interest and awareness ratings.

On average, higher ratings for concern and interest were reported by non-white participants (p=0.26 for concern, p=0.93 for interest), participants with a college degree or higher (p=0.08, p=0.06), and participants with living children (p=0.13, p=0.13) although differences were not statistically significant.

Conclusion

These results suggest an opportunity for big data initiatives such as the Pediatric Cancer Data Commons to engage with patients and families about the lifecycle of pediatric cancer data. Additional investigation would be required to determine what information would be of most interest and utility to pediatric cancer patients, survivors, and their families.