Winter 4-13-2021

Kids Kicking Cancer Canada: Health information privacy and storage

Claire Millard
cmilla8@uwo.ca

Guillermo Antonio De Paz Linares
gdepazli@uwo.ca

Thomas Qu
tqu6@uwo.ca

Kids Kicking Cancer Canada: Health information privacy and storage

For our community engaged learning (CEL) project we had the opportunity to work with the amazing not-for-profit organization Kids Kicking Cancer Canada (KKCC). KKCC is the Canadian branch of Kids Kicking Cancer whose mission is "to ease the pain of very sick children while empowering them to heal physically, spiritually and emotionally". Through their programs, KKCC strives to uphold their mission by providing P*ower, Peace, and Purpose* to children with cancer or other illnesses. A major program provided by KKCC is their Heroes Circle class which merges modern integrative medicine and traditional martial arts to help children cope with their illness. This program is provided on the foundation that through the teachings of martial artists, children can increase their sense of empowerment through breathing, visualization, and relaxation techniques, in addition to traditional martial arts moves. This community organization is very inspiring, and through our work with our community partner, we had the opportunity to experience the rewards of supporting community programs such as those provided by KKCC.

Kids Kicking Cancer Canada receives numerous registration and consent forms as well as maintains important documents such as program attendance sheets to keep their programs running smoothly. Currently, KKCC is collecting registration and consent forms on a google cloud system on the administrator's computer, and some are collected on systems held by other program coordinators. Furthermore, the attendance sheets are stored on google forms which at an initial assessment, does not comply with privacy regulations. With the current COVID-19 pandemic, the increased work from home online, and the quick turnover to online classes and

registration drastically increased the concern for proper storage of this information and led to our proposed CEL research question. The purpose of our CEL project was to centralize participant and volunteer registration information while ensuring systems meet health information privacy guidelines. We looked to examine laws and regulations that surround the collection and storage of health information and identify a process to document and store participant information online.

Our initial step to approach this project was to review and examine the current processes used by Kids Kicking Cancer Canada for both storage and collection of registration and consent forms. These forms are collected from both participants and volunteers for registration purposes only. From the information gathered from this review, we looked to determine areas of interest for policy and regulation research as well as to establish areas of improvement. After examining the current systems used by KKCC, we researched Ontario as well as other Canadian Acts, policies, and regulations to create a policy that could set a foundation for our system recommendations. In forming a foundational information privacy policy for Kids Kicking Cancer Canada, we also reviewed existing policies held by hospitals and non-profit organizations for use as a template to guide the principles outlined in our policy. After drafting a health information policy, we researched possible alternatives for a solution to information storage and collection. Through our research, we found cloud-based storage solutions that complied with the major laws and regulations implemented in Ontario and Canada for health information. Upon consideration of these solutions, and further examination of the current google cloud systems used by KKCC, we also explored alterations and adjustments that could be made to the current system so it would conform to the laws and regulations that were used as criteria for a new system. As the final

steps in our projects, we outlined the deliverables for our community partner to make policy and storage recommendations for futures.

In our project, we presented three main deliverables for KKCC. The first of our deliverables was a privacy policy consisting of 10 different principles (Appx. A). The principles dictate the way that KKCC will handle all private health information, ensuring that it is safe, accurate, and available to the parents upon request. The second and third deliverables included recommendations for the storage and collection of information at KKCC. We made specific recommendations concerning the current program they are using and how they should be collecting and storing information and documents such that it complies with all policies regarding personal health information within Canada while also improving overall efficiency (Appx. B). These recommendations included the use of a hierarchy system for access and document placement. Additionally, we made a recommendation on a new centralized cloud storage system, EGNYTE, that fits the requirements of what KKCC is looking for in terms of a new storage system (Appx. C). It provides sufficient space within their budget, enables seamless collaboration, and guarantees safety of all personal files for their clients.

While the project itself was a rewarding experience, there are many challenges that we overcame to deliver the final project. One main challenge that we faced was the ongoing COVID-19 pandemic. This issue affected us and our peers as our projects had to be designed to be entirely online. COVID-19 has forced the KKCC classes to be online, which has had an impact on participants, their families and all of the members of KKCC that organize these events. As such, it was important for us to coordinate our project approach and to make use of online resources

available to us. We used Zoom for group and partner meetings which allowed us to keep updated on project progress and any changes in the project direction. Additionally, we used Google Slides and Google Docs to complete assignments, prepare presentations, and keep track of our progress. Specifically, our project also had various obstacles that we worked through as a group. We first had to determine how to search for information on health information-related collection and storage in Canada. We also had to find a way to understand and organize the information we found so that we could compose an information storage policy for KKCC. Furthermore, we had to examine the cloud-based system that KKCC is currently using with respect to its compliance in safeguarding health-related information, as well as research possible alternatives for the current system.

Initially, we struggled to find useful information concerning health confidentiality policies and regulations, as we did not know where to look. Fortunately, by contacting Maren, a guest speaker in our course, she provided us with guidance on how to search for this information. By modifying the way in which we conducted our research, and using the databases available at Western Libraries, we were able to find information on PHIPA and PIPEDA, and how they oversee the proper storage of health-related information. However, there was not a concrete answer on how this information should be handled with regards to a non-profit organization, such as KKCC which led to our next main obstacle. We overcame this by basing our KKCC health information policy on a combination of the guidelines offered by PHIPA, PIPEDA, and the LHSC's health information confidentiality policy. Furthermore, revising the current system that KKCC uses for storing information presented some challenges as no members of our team had previous experience with computer science. We opted to take a bottom-up approach to solve

this problem and began by looking for cloud-based storage services that complied with Canadian policies focusing on the security and compliance that each service provided with relation to information storage. In contrast, we took a more top-down approach when it came to evaluating the current service, Google Cloud, that KKCC uses. By comparing Google Cloud with the other services we researched, and by determining the amount of data storage and accessibility required by KKCC, we determined that this service suited their needs. By overcoming these obstacles, we were able to successfully complete our project and produce deliverables that can benefit KKCC.

The deliverables that Jill had presented to us were to help KKCC transition online as a result of of Covid-19. Our deliverables will help ease the transition to the online space while also providing their clients with peace of mind knowing that their files are safe and secure. The creation of the privacy policy will help KKCC provide valuable information to both the parents of participants as well as new employees. As KKCC continues to grow in size, the spread of personal health information will continue to grow, and they will need an infrastructure in place that ensures that the files are safe and secure, from external threats as well as from individuals within the organization that should not have access. By having the policies in place, parents can be assured that the information they have provided to KKCC is secure. Additionally, the policy will allow for KKCC to train and educate future employees on how information needs to be collected, handled, and stored. The recommendation to the current system and the potential new cloud-based storage system will help streamline the way in which files are utilized and handled within the organization. The current system mainly relies on Jill manually sharing each individual file from her personal google drive to each person that requests access. However, utilizing google cloud or a different cloud-based system such as EGNYTE will allow for files to

be uploaded to the cloud, where Jill could assign an access level thus, allowing all individuals who require access to the files to be able to view and edit them. The alternative cloud-based storage software also allows all KKCC partners and employees to collaborate seamlessly, as it can accommodate almost every file type on every device. Additionally, using either cloud-based service allows for both KKCC as well as its clients to be secure about the personal health information as files stored within the services are encrypted using industry leading technology, thus, preventing data leaks and access from external sources. Lastly, due to EGNYTE also adhering to guidelines involving personal health information around the globe, KKCC will be able to share documents with other branches of Kids Kicking Cancer without needing to worry about the guidelines within other nations.

With our project coming to a close, we would like to see a continuation of projects and studies that will benefit KKCC. We were able to provide KKCC with a possible alternative to their current cloud-based storage system, however, we recommend future efforts work to stay updated on new services that may offer improved user interfaces. This could help KKCC with developing an easy-to-use cloud storage space that would fit the needs of all members. Furthermore, new providers could offer increased certification for information protection which is of great importance given the sensitivity of health information.

While KKCC is already present on social media platforms, it would be interesting to engage in a project focused on strengthening this area of marketing such as through infographics. This could help KKCC connect potential new participants with classes and provide families with information on cancer topics or their programs background. Since we are mostly online due to

the pandemic, increasing social media presence would likely have a great impact at delivering information to people in the community. Furthermore, projects could expand to designing at home programs to allow children to work on their own time. For example, mindfulness exercises following a *word of the week* concept could allow children to continue with their training focus on a determined aspect of their training apart from schedules Heroes Circle sessions.

Our project has helped KKCC to establish a basis for the collection of health-related information, as well as creating organized accessibility to forms and health-related information that comply with KKCC's new privacy policy. We reviewed the current storage system and determined it compliant with Canadian regulations. We also provided a potential alternative to the current system. Finally, despite the challenges encountered, we enjoyed working on this project and with an amazing, positive, non-profit organization. We hope that future studies, whether done through CEL or as part of KKCC, can greatly enhance the impact of this organization on the lives of these inspiring children.

Word count: 1964

APPENDIX

A. Kids Kicking Cancer Canada Health Information Policy

1. Complies with:
    a. PHIPA, PIPEDA, and health information privacy policies followed by hospitals and health care organizations; and
    b. FIPPA and MFIPPA privacy acts of Ontario.
2. Create and post a public statement under the *Contact Us* tab.
    a. Statement should read: *"Collection of personal health information is for registration and safety purposes of the programs provided for, and run by, Kids Kicking Cancer Canada."*
3. This document should be posted in a link underneath of the *Contact Us* tab along with the public statement of use of information.
4. This document consists of 10 policies that outline and describe the use, storage, and accountability for information collected by Kids Kicking Cancer Canada.
5. This document is also provided in PDF format.

Principle 1 - Accountability for Personal Health Information

Kids Kicking Cancer (KKCC) is responsible for personal information under our control.

KKCC complies with PHIPA by:

- Implementing policies and procedures to protect your personal health information, and all other confidential information including information relating to patients, family and affiliates (Affiliates include physicians, students, volunteers, researchers, and hospitals);
- Responding to complaints and inquiries;
- Educating staff and affiliates about privacy policies and practices.

Principle 2 - Identifying Purposes for the Collection of Personal Health Information

KKCC will identify the purposes for which personal health information is collected at or before the time of collection. These purposes will be conveyed by means of the KKCC website.

The primary purpose to collect, use, and share personal health information is to deliver appropriate programming to children and their families. We also use personal information for administrative purposes, statistics, and to comply with our legal and regulatory requirements.

Principle 3 - Consent for the Collection, Use, and Disclosure of Personal Information

We rely on your implied consent for the purpose of statistics and administrative purposes but will seek written consent for any unspecified purposes.

You have the right to know why we are collecting your information and how it is being used.

You also have the right to withdraw your consent at any time, unless the collection, use or sharing is required or permitted by law.

Principle 4 - Limiting Collection of Personal Health Information

Only the information necessary for the purposes identified may be collected.

Principle 5 - Limiting Use, Disclosure, and Retention of Personal Information

Personal health information may be used only for the purposes for which it was collected, except with your consent or as required by law.

The information is retained only as long as necessary, and securely destroyed in accordance with legislation, hospital policies, guidelines and procedures.

Principle 6 - Ensuring Accuracy of Personal Health Information

KKCC will make every effort to ensure the information we hold is accurate, complete and up to date.

Principle 7 - Ensuring Safeguards for Personal Information

KKCC applies security safeguards appropriate to the sensitivity of personal health information to protect it against loss, theft, unauthorized access, disclosure, copying, use, or modification, regardless of its format. Protection may include physical measures (i.e., locked filing cabinets and restricted access), organizational measures (limiting access on a "need-to-know" basis), and technological measures (use of passwords). New staff and affiliates are required to complete and sign a confidentiality agreement.

Principle 8 - Openness About Personal Information Policies and Practices

KKCC makes information about their privacy policies and practices available by means of the Kids Kicking Cancer Canada website. Information provided includes: a contact form to which complaints, questions, or inquiries can be sent to.

Principle 9 - Individual Access to Own Personal Information

Upon request, within a reasonable time and at a reasonable cost, an individual will be informed of the existence, of his or her personal information and will be given access to it. They can challenge its accuracy and completeness and have it amended as appropriate.

Exceptions to providing access will be limited and specific. This may include information that cannot be disclosed for legal, security or proprietary reasons. An individual must provide sufficient information to permit KKCC to identify the existence of personal health information.

Principle 10 - Challenging Compliance with Privacy Policies and Practices

If, for any reason, you are concerned about our compliance with our Privacy Policy, you may contact our Office by the Contact Us page on our website.

B. Recommendations for Current System

1. Relocate attendance form from google sheets to the current google cloud system.
    a. Provide access on google cloud to necessary instructors; and
    b. Provide access to Kids Kicking Cancer overhead for attendance statistics.
2. Create and implement hierarchy list of file access on current google cloud system
    a. Provide employees with access to google cloud files;
    b. Access will be determined by the position held by the individual and their need for access to specific files and information.
3. Benefits of maintaining current system:
    a. Ease of use with no storage transition period;
    b. Cost effective: due to low volume of storage needed, no additional costs would be required;
    c. Data is encrypted in transit between facilities and at rest, providing a trusted cloud interface for storage
    d. Privacy of information storage complies with HIPPA regulations, thus, following and upholding regulations that comply with the Canadian counterpart PHIPA

C. Possible Alternative - EGNYTE

1. Change to this storage interface could provide additional features that are not achievable through google cloud storage:
    a. Mobile app;
    b. Desktop app; and
    c. Easy editing of documents in Google Workspace or Microsoft Office Online.
2. Trusted security of information:
    a. Basic two-factor authentication
    b. Strong password policy enforcement
    c. Granular sub-folder permissions
    d. File link expiry
    e. Static link expiry
    f. Privacy of information storage complies with HIPPA regulations, thus, following and upholding regulations that comply with the Canadian counterpart PHIPA
3. Cost of transfer to EGNYTE cloud-based storage system:
    a. $10/user/month paid annually