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A Pediatric Nurse Practitioner's initiative to support parents of children undergoing neurosurgical care: The Neurosurgery Kids Fund Website Evaluation

by

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Abstract

Parent with children undergoing neurosurgery need access to specialized information as well as support resources. The public is becoming more active in managing their own health care and they often turn to the Internet as a starting point in their quest for health information resources. The Neurosurgery Kids Fund (NKF) in Edmonton, Alberta was created by two pediatric nurse practitioners and launched in 2013 in an effort to help meet the information, support, and resource needs of this unique and special population. Google Analytics, a web analytic software program, an online survey questionnaire, and a focus group interview were used to evaluate parents' usability and perspectives about a custom designed website about pediatric neurosurgery. Findings included that a health website, if carefully constructed, can meet the information needs and offer support resources to parents with critically ill children. Parents described *timing* in their child' illness trajectory as a determinant to when they used the Internet to gain health information about their child's medical condition or accessing support resources. Factors influencing avoidance of the Internet included fear, uncertainty, and being advised against it by healthcare professionals. The most frequently identified reason for accessing the NKF website was for information on Camp Everest. The next most frequently identified reasons were for medical, social support, and resource information. Parents reported accessing the NKF website regularly and will continue to use it in the future. Nurses and Advanced Practice Nurses (APNs) are now charged with assessing how and what parents are seeking online to meet their needs, and helping to direct them to safe, credible and reliable health websites. Further, issues in the future will revolve around how healthcare professionals are to evaluate health websites to recommend to their patients and parents.

Preface

This thesis is an original work by Tina Kovacs Vogel. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Evaluation of a pediatric website”, No. Pro00046135, June 16, 2014.

Dedication

To my dear late father, Peter Kovacs, who inspired in me as a child the value and importance of lifelong learning.

"A good head and good heart are always a formidable combination. But when you add to that a literate tongue or pen, then you have something very special."
— Nelson Mandela

Acknowledgments

The writing of this thesis has been one of the most significant academic challenges I have had to face. Without the support, patience and guidance of the following people, this study would not have been completed. It is to them that I owe my sincerest and deepest gratitude.

First and foremost, I would like to express my gratitude to my supervisor, Dr. Shannon Scott whose expertise, understanding, and patience, added considerably to my graduate experience. I will always be grateful for your empathy when I was balancing being a mom and wife, pursuing my degree, and working as a nurse practitioner. I could not have wished for a better supervisor and mentor.

I would like to thank the other members of my committee, Dr. Sandra Davidson and Dr. Manal Kleib for their assistance throughout the research and writing of this thesis. Thank you for your feedback and contributions.

To my family, you are my greatest achievement of all. My husband, Steven, thank you for your love, patience, and support throughout my graduate studies journey. My children, Ava and Christian, I hope that I can inspire you both to seek out and pursue your dreams. I love you.

To my mother, Agnes, thank you for always believing that I could do whatever I set out to achieve. I hope that I have made you and dad proud - and dad, I hope you know that I will be honored to hang my master's degree right along next to yours.

To my sister, Suzanne, thank you for cheering me on and I will always cherish the many care packages that you sent my children when I had my nose in the books. To my twin sister and best friend, Cindy, I will always be grateful that I never had to face any of life's challenges without you, not withstanding my graduate studies. HB.

The Neurosurgery Kids Fund. – the inspiration for this thesis project. What began as a simple wish to send a few children to camp has grown into something we can be so proud of. I am blessed to be part of such an amazing organization.

I would like to acknowledge the Faculty of Nursing, especially James Doiron, who provided the support and equipment I needed to produce and complete my thesis.

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Abbreviations

NKF: Neurosurgery Kids Fund; APN: Advanced Practice Nurse; TAM: Technology Acceptance Model ; OS: Operating System

Chapter 1: Introduction

This thesis is an outcome of my master's program in Advanced Practice Nursing and my involvement in the Neurosurgery Kids Fund (NKF). Through my experience as a pediatric Registered Nurse, and later a pediatric Nurse Practitioner, I became interested in bridging the gap between parents' health information needs and using information resources available on the web. I have also been fortunate to be a founder of the NKF and through various fundraising efforts, enough funds were realized to venture forth and create a specially designed website targeting Canadian parents and children undergoing neurosurgery. Together with some colleagues, the Neurosurgery Kids Fund was established as part of the Stollery Children's Hospital Foundation in Edmonton, Alberta. One of the NKF's primary initiatives was to design, create, and launch a unique website targeting Canadian parents of children who have undergone neurosurgery. The NKF website, www.neurosurgerykids.com, was launched in Spring 2013. The NKF website was developed during my Master's program.

The purpose of my research is to evaluate and describe how parents of children who have undergone neurosurgery are using the NKF website as well as their general perceptions and experiences using it. The findings of this study demonstrates how to improve the NKF website to better support these parents' health information, support, and resource needs. This "paper based" thesis consists of three chapters. Chapter 1 consists of an introduction and a background of the study in order to provide a frame of reference for the manuscript that follows in Chapter 2. In Chapter 3, a discussion of the findings, contributions, implications for nursing, and suggestions for future study are included. A comprehensive Google Analytic report prepared for the Neurosurgery Kids Fund and other supplemental materials are located in the appendices.

Background of the Study

Through my work as a pediatric nurse, I became increasingly interested in the concept of using health information resources available on the web to meet parents' information, resource, and support needs. Browsing the Internet is a common first step for many parents in their quest to gather any and all information about their child's diagnosis, prognosis, treatment and support options (DeLuca, Kearney, Nortion, & Arnold, 2011; Patel, Garg, & Khan, 2010; Peterson, Aslani, & Williams, 2003). Appealing characteristics associated with using the Internet for health information include minimal costs, anonymity, accessibility 24 hours/day, endless opportunity for repetition, and the provision of updated, detailed information (AlSaadi, 2012; Van Uden-Kraan et al, 2009). The increasing use of mobile phones and tablets, now widespread practice at the bedside, has offered the public direct access to a chasm of health literature that was once in the purview of academia only. When I reviewed the literature about health websites, I realized that no research had been conducted involving Canadian parents of neurosurgical children, particularly, how they secure their health information and their usage of health websites. The number of health websites is dramatically on the rise, yet little is known on how these health websites are being found and utilized by parents (Kurup et al, 2012). Further, much of the literature published is targeted at the adult patient with implications for self-directed care. However, as stewards of their children, parents are challenged with health information gathering to guide decision making for their child's health and wellness as well as with fulfilling their own information, support and resource needs. I therefore decided to evaluate parents' experiences and usage of the NKF website.

Description of the Neurosurgery Kids Fund website

The Canadian-based NKF website was created primarily by two pediatric nurse practitioners with the goal of enhancing the lives of children affected by brain and/or spinal surgery, information sharing, parent and family education and support, and providing world-class neurosurgical care. The design and construction of the NKF website was guided using the key determinants of The Technology Acceptance Model, *perceived usefulness* and *perceived ease of use.* As such, one-click buttons presenting the major headers and tabs were used on the Homepage. In addition, the same one-click buttons were streamlined on all the pages throughout the website to ease navigation. Visual attractiveness was also an important element used in the development of the website. The NKF website is a public website and adults and children have access to it. Google Analytics was embedded within the website at the time of its inception enabling the tracking of user behavior on the site.

Key headers and tabs on the website are targeted at 'News and Events' specifically supporting this unique population, 'Family Resources' including information on various neurosurgical medical conditions and diagnoses, clinic and hospital details, funding resources, and a compiled list of other valuable website links and literature.

A separate section dedicated to a 'Media Center' where children, families, friends, and camp staff can share their photographs, videos, and podcasts is also offered. Furthermore, unique to this website is its very own social network link, 'Join the Community', where those affected by pediatric neurosurgery can join at no charge to connect with others for shared experiences, support, and guidance. Lastly, a 'Just for Kids' tab, targeted solely at children, linking them with online resources written at various reading and comprehension levels is provided. Particularly symbolic and meaningful to the children and their families, is the free strung-bead jewelry

program, ‘Hope Stones’, where any child with a medical diagnosis, not exclusive only to neurosurgery, can receive a special bead that represents a specific procedure, surgery, or treatment to represent their medical journey. Appendix B offers screenshots of the aforementioned features of the NKF website.

Purpose

The purpose of this thesis project was to evaluate parents' experiences and usage of a pediatric nurse practitioner (PNP) designed Canadian website about pediatric neurosurgical patient and medical information, support, and resources.

Research Question

The research questions guiding this thesis were: What is the usability of the Neurosurgery Kids Fund website? What are the demographics, experiences, and perceptions of users (parents) of the Neurosurgery Kids Fund website?

Significance of the Study

The significance of this study is threefold. First, there is no literature that addresses the use of a PNP designed website targeting parents of children who have undergone neurosurgery. This study demonstrates the implications of using a specially designed Canadian health website to address parents' information, support, and resource needs. The literature has shown that patients [parents] are taking more control over managing their own [child's] care and have become empowered to do so with the accessibility and effectiveness of the Internet. Second, results of this study will shed light on the potential of webpages for disseminating health information to the public. The literature supports that parents are using the Internet for health information seeking, and thus, there are also significant clinical practice implications as the information they are receiving may be influencing their medical decision-making. Third, this study uses newer research tools, Google Analytics, to evaluate website usage in combination with other research methods.

Manuscript Overview

This manuscript describes the findings of a multi-methods study including two quantitative and two qualitative methods: Google Analytic reports, online survey questionnaire results and a focus group interview and field notes. The manuscript is formatted according to the manuscript requirements for a submission (post-defense) to the Journal of Medical Internet Research.

Firstly, Google Analytic reports, a web analytic tool, for the Neurosurgery Kids Fund website were collected and analyzed for the first six months after the website was launched. These reports offer statistical data about website user behavior for the purpose of understanding and optimizing Web usage. An online survey questionnaire consisting of twenty closed and open ended questions was also designed and conducted to further augment usability understanding on the NKF website. Fifty-two surveys were completed and included in this study. Finally, the Google Analytic reports data and online survey questionnaire results were analyzed and guided further inquiry in the focus group interview involving four parents. Parents were asked to describe their experiences using the NKF website, in particular its usability and perspectives about design, content, and usefulness. Field notes were collected to offer opportunity for reflection and clarification of details.

General Discussion

This section consists of a general discussion of issues associated with the study, how the findings contribute to existing research, implication for nursing and advanced practice nurses, Implications for future study are touched on.

Appendices

The first appendix includes a Google Analytic report prepared for the Neurosurgery Kids Fund (Appendix A). Other materials included in the appendices include the Screenshots from the NKF website (Appendix B), the online survey questionnaire advertisement and participant information sheet (Appendix C), the focus group interview advertisement, participant information sheet, and consent form (Appendix D), the online survey questionnaire (Appendix E), Glossary of Google Analytic terms (Appendix G), and Semi-structured interview questions (Appendix H).

Chapter 2: A Pediatric Nurse Practitioner's Initiative to Support Parents of Children Undergoing Neurosurgical Care: The Neurosurgery Kids Fund Website Evaluation.

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Abstract

Background: Parents often turn to the Internet as a first step in health information seeking about their child's diagnosis and condition. Information, support, and resources regarding pediatric neurosurgery are scarce, difficult to find, and comprehend. A pediatric nurse practitioner (PNP) designed Canadian website (www.neurosurgerykids.com) was created to address this gap. As a result, analyzing the impact of the Neurosurgery Kids Fund (NKF) website as well as the perspectives of the end users is critical to its future development and success.

Objectives: To explore parental usage of the NKF website, to track visitors' behaviors, evaluate the usability and design of the web site, establish ways to improve the online user experience, and potentially highlight ways to redesign the website.

Methods: A multi-methods approach was used in this study. Firstly, Google Analytic reports were collected and analyzed for the period April 23, 2013 to November 30, 2013 tracking the usage on the NKF website. Second, fifty-two online survey questionnaires targeted at the usability of the NKF website were completed and statistically analyzed. A focus group interview was also conducted with parents to explore their perceptions and user-experiences using the NKF website and analyzed using an inductive content analysis approach. The focus group also provided a forum for further inquiry and verification following analysis of the web analytic reports and survey results.

Results: Google Analytic reports revealed 2,998 sessions on the NKF website were logged in this six month period. In addition, 8.818 pageviews, 2.94 pages per session, a 56.20% bounce rate, an average of 2 minutes 24 second session duration, and 56.24% new sessions were realized. The majority of NKF users were Caucasian females (92%), aged 36-45 years (48%), with a university or college degree or diploma (69%). Half of the parents (n = 26) plan to use the

health information found on the NKF in discussion with their child's physician, nurse practitioner, or other medical personnel. Over half of the parents reported turning to the Internet in search of health information and spend two to four hours a day online at home. Forty percent of parents reported using the NKF website in search of health information. Parents stated the NKF website is very easy to understand, found what they were looking for, and plan to use the website in the future. The focus group interview demonstrated that the three most common reasons parents used the NKF website were: 1) to gather information about the two specially designed camps, Camp Everest and L'il Everest, 2) explore the Media Center tab for photographs of their children attending various functions, and 3) stay abreast of the News and Events supported by the NKF. These findings corroborated the survey results. Parents were unanimous that the NKF website was pleasing in color and design, very easy to use and navigate, useful, and would continue to access it regularly.

Conclusions: These findings indicate that parents perceive the NKF website to be useful and easy-to-use in meeting their health information needs, finding social support, and learning about resources relevant to their child. A custom designed website, if carefully designed and constructed, can be used to augment parents' health information needs by reinforcing, supplementing, and improving their understanding of their child's medical needs. The NKF website has achieved these objectives and has acted as a social support 'hub' for both parents and their children.

Keywords: Pediatric; neurosurgery, website, evaluation, parents, children, web analytics, information needs, knowledge translation.

A Pediatric Nurse Practitioner's Initiative to Support Parents of Children Undergoing Neurosurgical Care: The Neurosurgery Kids Fund Website Evaluation.

Canadian children requiring neurosurgery are a small, unique population with highly specialized medical needs. Information, support and resources regarding pediatric neurosurgery are scarce, difficult to find, and to understand. Furthermore, connecting with other parents or caregivers whose children are also affected by neurosurgical conditions or illnesses can be even more difficult given the rarity of these diagnoses.

Searching for information on the Internet is a common first step for parents to gain knowledge about a child's diagnosis, prognosis, treatment and support options (DeLuca, Kearney, Norton, & Arnold, 2012; Patel & Khan, 2010; Peterson, Aslani, & Williams, 2003). Once being considered passive receivers of care, the public today has become active consumers of health care where they want to be involved in the decision-making in managing their health care and how to mitigate risk factors and complications (Klemenc-Ketis & Kersnik, 2013). E-Health, the use of the Internet as a source of health information, offers many benefits including complementing the physician's information, "the provision of anonymity in health information-seeking, a means of information exchange and community support, and empowerment in seeking help for, and understanding, medical conditions" Glynn, O'Duffy, O'Dwyer, Colreavy, & Rowley, 2013). People use online health information as a source of knowledge for many reasons. These reasons may include: getting immediate answers, learning about the diagnosis, treatment options, prognosis, supplementing what the physician's information, or for finding support and sharing with others having similar experiences (AlSaadi, 2012; Bauer & Scharl, 2000; DeLuca et al., 2012; Glynn et al., Plantin & Daneback, 2009; Thomas, 2006; Walsh, Hyde, Hamilton, & White, 2012). Parents of sick children report using the Internet for searching and seeking health

information because of worrying about their child's health, feeling rushed and receiving limited guidance or advice from doctors, convenience and accessibility, and needing to connect with others in similar situations (Plantin & Daneback, 2009; Walsh et al., 2012).

Up until now, knowledge translation efforts have largely focused on ensuring that healthcare professionals use the latest research to inform their practice; however, initiatives that target healthcare consumers (e.g., parents) can inform parental decision making, expectations, and shape their treatment outcomes (Gage & Panagakis, 2012; Plantin & Daneback, 2009; Roche & Skinner, 2009). Patients now have access to what was once privileged health information, potentially changing their understanding of their medical condition, treatment options, medical decision-making, and relationships with health care providers (Roche & Skinner, 2008). Knowledge translation in child health is unique given family-centered care and the extent and level of parental involvement (Lewis, Gundwardena, & El Saadawi, 2005). It is important to examine knowledge translation interventions, such as websites developed specifically for parents, are needed information, resources and support tools. Understanding parents' motivation, expectations, and behaviors on the NKF webpages will add to the growing knowledge base of using health information available on the web.

Methods

Design

This study used a multi-methods approach including both quantitative and qualitative designs. Firstly, Google Analytics (www.googleanalytics.com), a sophisticated web analytic service, was employed to collect statistical data about NKF usage behavior. Second, a twenty question online survey questionnaire directed at parents about the usability of the NKF website was designed and collected using determinants of the Technology Acceptance Model (TAM)

(Chutter, 2009; Davis, 1989). Lastly, a focus group interview with parents about their experiences using the NKF website was conducted to augment the Google Analytic and online survey questionnaire data. The Google Analytic reports and online survey questionnaire results were used to inform and direct the focus group interview. Distinctions between *usability* and *user experience* are needed because the former is the ability of the user to use the website to carry out a task successfully (e.g., *ease of use:* using the NKF website to meet health information needs in the survey) and the latter takes a broader look at the individual's interaction with the website, as well as the thoughts, perceptions, and experiences that results from that interaction (e.g., focus group) (Van der Heijden, 2001). Usage refers to the ways a website is used (e.g., Google Analytics of number of users, number of pageviews, time spent on page). However, it is noteworthy that usability is *one* layer that influences user experience.

Ethical approval was obtained from the University of Alberta Health Research Ethics Board. Consent was not required for Google Analytics as it is an embedded web tool that collects anonymous grouped data. Participation in the online survey questionnaire and focus group interview was voluntary and signed consent was obtained for the focus groups.

Sampling

Recruitment was targeted at parents who have children, aged 0 to 16 years, that have undergone neurosurgery at the Stollery Children's Hospital in Edmonton, Canada. Parents also had to be familiar with the NKF website for inclusion in the online survey questionnaire and focus group interview. Purposeful sampling was used in the focus group to ensure for a breadth of age (for both the child and parent), parental education level, their usage of mobile devices, tablets, and/or computers, and their child's neurosurgical diagnosis. Parents were excluded from

the study if their English fluency prevented them from completing the survey or conversing in the focus group.

Data Collection

Methodological triangulation was used and four sources of data collected: (1) Google Analytic reports, (2) online survey questionnaire results, (3) focus group interview with parents, and (4) field notes. Survey and focus group data were uploaded and kept secure in the Health Research Data Repository in the Faculty of Nursing at the University of Alberta. First, the Google Analytic data collection and analysis were conducted for the web analytic and survey phases. With these results, revision of guiding questions for the focus group interview was performed. Google Analytic reports about NKF website usage was obtained from April 23, 2013 to November 30, 2013. This web analytic tool uses client sided data collection, called 'page-tagging', to collect raw data from the user's browser. Google Analytics turns that raw data, or statistical numbers, into meaningful and usable information. Using a web analytic tool, such as Google Analytics, removes bias, ensures speed, rigorous structure and an abundance of data can be collected (Bauer & Scharl, 2000; Velez & Pagan, 2011).

The survey consisted of twenty multiple-choice and check box type questions with principals of the TAM underpinning the framing of the questions. The survey was developed after a review of the literature and piloted with twelve parents to ensure for content validity and reliability. Developed by Davis (1985), the TAM suggested *perceived usefulness* and *perceived ease of use* to be fundamental determinants of system use (Davis, 1989). To summarize, a system, such as *using* a website, is more likely to be accepted and used by parents if they *perceive* it to be *useful* and *easy to* use. Questions focused on the *usability* of the NKF website: how parents seek health information, how and why they accessed the NKF website, whether their

information, support, and resources needs were met online, if they discussed any health information found online with their health care provider, and *perceived ease of use* and *usefulness*. In addition, demographic data about the parents was collected including age, gender, ethnicity, location of residence, highest level of formal education, and computer usage.

A semi-structured interview guide was used in the focus group asking parents about their experiences using the NKF website, its usability, and it lasted approximately 60 to 90 minutes (Appendix G). The interview was recorded in real-time by a court reporter (Scott et al., 2009). Benefits to using a court reporter to transcribe the focus group interview verbatim include increased data accuracy, timeliness, preserving confidentiality, and affordability (Scott et al., 2009). Transcript-based data collection and analysis represents the most rigorous and time-intensive mode of analyzing focus group data (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). The transcribed interview was cleaned by comparing the audio-recording with the transcript. Any identifiable information in the transcript was removed for anonymity. Field notes were also obtained before, during, and after the interview to capture the context in which the data was collected. The field notes were reflected on during the data analysis to help situate when and how the responses were elicited (e.g., nonverbal expressions or linguistic patterns).

Data Analysis

Google Analytics of the NKF website was analyzed using the Audience, Acquisition, and Behavior reports. The Audience report offers an overview snapshot of the time period selected including the number of sessions logged, number of users, percentage of new sessions, number of pageviews, average session duration, bounce rates, number of pages per session, and location and languages used by the user. Also, reports about what type of Browser & Operating System (OS) was used and a mobile device overview and breakdown were analyzed. The Acquisition

reports examine how a user arrived at the website which may reveal what they were on the website to do. Traffic analysis examines how well a website is supporting users who come to the site with specific information. Subheaders of channels and mediums, all traffic sources, all referrals, and keywords are metrics that were identified in this study. Lastly, the Behavior reports offer information about what the user actually did when they arrived on the site: what page they landed on, how much time they spent on each page, the number of pageviews they performed, the percentage of exits and what page they exited the site from were analyzed.

Survey data was collected and entered into SPSS v.21 from a text file and uploaded into a secure data repository. Data was verified for accuracy and cleaned. Seventy-four surveys were completed but after data cleaning, fifty-two were used in data analysis. Twenty-one respondents were not parents or primary guardians of children with neurosurgery and one respondent indicated English was a second language with poor fluency, and therefore were excluded from this study. Data was coded and descriptive data were computed for all the variables.

The focus group interview data was analyzed using an inductive content analysis approach to address the purpose of the study (Shuyler & Knight, 2003). The transcript was read as a whole several times and concepts, patterns, and themes were identified. With further immersion in the data, a coding system was developed and subsequent grouping and categorizing of the data as they belonged to the recurring themes was performed. New codes and themes emerged throughout the analysis period and the data was continuously re-examined. The qualitative analysis software program NVivO10 was used to assist with data management and analysis. In addition, a classic analysis strategy was used because it helps make analysis a visual and concrete process (Krueger & Casey, 2009).

Credibility was achieved in this study with methodological triangulation between the quantitative and qualitative data (Duffy, 1987, Streubert, Speziale, & Carpenter, 2007). Both qualitative and quantitative methods were used together in an iterative process with neither method being weighted superior to another method (Duffy, 1987). Triangulation also allowed for the use of new research methods, web analytics, to balance with the other methods in this study.

Credibility of the data was further achieved with transparency using an audit trail of all methodological processes. Reliability was achieved with the audit trail such that the results of this study could be replicated. Equivalence and internal consistency criterion were met because there was one researcher who was the only moderator and coder of the focus group data. Validity was enhanced with method triangulation because two or more methods demonstrated the same results and strict adherence to principles of qualitative research were done. Field notes were reviewed to ensure that the findings were reflective of the focus group interview and not a reflection of any personal biases (Thomas, 2006).

Results

Google Analytic Reports.

Appendix A offers a full Google Analytics report that was prepared for the Neurosurgery Kids Fund.

Audience. For the first 6 months after the NKF website was launched, 2,998 sessions and 1,686 unique users visited and 56.3% returning visitors were logged. There were 8,818 pageviews with an average of 2.92 pages viewed per session. The site bounce rate was 56.2% and the average session duration was 2 min 24 s. Using IP addresses to track and measure where a user is located, 90.23% users were from Canada (85.55% were from Alberta with 50.35% of

them being in the Edmonton area). The remaining users were from: United States (5.74%), United Kingdom (1.17%), India (0.50%), Australia (0.27%), Ukraine (0.20%), and Philippines, Saudi Arabia, and South Africa (0.17%). The majority of users (99.11%, n = 2,971 sessions) viewed the NKF website in English. The remaining users accessed the website used French, German, Mandarin/Cantonese or Arabic.

The lowest bounce rate was from the Philippines (40.00%). Users from the Philippines also had the longest average session (4 min 5 s) followed by Canadians (2 min 33 s), and the United Kingdom (1 min 28s). Apple's Safari browser was the most frequently used (n = 1,354 sessions) followed Internet Explorer (n = 690 sessions). Chrome browser users ranked third (n = 360) and outranked Mozilla Firefox users ranked fifth (n = 183 sessions). Android browser users ranked sixth with 117 sessions. The majority of NKF website users accessed the site using desktop/laptop computers (n = 1,628 sessions). Mobile users accounted for 31% of all sessions (n = 931) and tablet users logged 15% of all sessions (n = 439). Mobile users had the highest bounce rate with 68.74%, whereas computer and tablet users showed bounce rates of 50.06% and 52.39%, respectively.

Acquisition.

Direct traffic accounted for 42.56%, or 1,276 of visitors who arrived at the NKF website via its URL. Organic search traffic using the medium of Google yielded 32.52% (n = 975) users. Bing generated only 1.37% (n = 41) users, and Yahoo brought only 1.03% (n = 31) users to the NKF website.

Referral traffic accounted for 22.41% (n = 672) of the sessions. Average session duration was 2 min 5s, with 2.82 pages per session, and a bounce rate of 54.76%. Of significance is that 24.76% of new users to the NKF site were acquired via referral sources. When mobile devices

and tablets are combined, 70.09% of all referrals were generated from Facebook, with a 50.41% bounce rate, and an average of 3.25 pages per session.

The NKF does not have any paid AdWords with any search engine company so only organic inbound keywords were analyzed. Organic search traffic yielded 1,050 sessions, with an average session duration of 2 min 28 s, 3.03 pages per session viewed, and a 54.10% bounce rate. Variations of *pediatric* and/or *neurosurgery* and/or *kids* and/or *fund* accounted for twelve of the top twenty organic inbound keyword searches, or 24.86% of sessions. Of note, 48.48% of all sessions did not provide a keyword – this traffic arrived via a referral, used the URL directly, or had bookmarked the NKF website. The highest average session duration, using *www.neurosurgerykids.com* as a keyword, was 9 min 12 s, a significant outlier. The remaining top eight keywords were related to specific fundraisers or events that were happening at that time. Only one medical term, *arachnoid cyst*, was included in the top twenty organic keyword searches. One search included the name of a pediatric neurosurgeon from the Stollery Children's Hospital.

Behavior.

The All Pages report for the NKF site illustrated a fairly typical distribution of the top ten pageviews – the Homepage was the most viewed with 21.05%, followed by other pages that can be accessed from the Homepage with one-click buttons: About NKF (9.55%), Media Centre (7.62%), Join the Community (3.62%), Events (3.40%), Just for Kids (2.98%), Donate (2.88%), and Hope Stone (2.82%). The Media Centre's subcategories of photographs and videos of children attending the NKF Camp or other events garnered the lowest bounce rate on the NKF website with 23.53%.

The NKF Homepage was the top-landing page with 52.97% (n = 1,588) of all sessions. Noteworthy are the three landing pages that are buried further into the NKF site: arachnoid cyst (n = 66), Just for Kids (n = 47), and Hope Stones registration (n = 45) sessions each. The NKF website did not have any significant outliers in the *time spent on pages* when combined with *pageviews* and *unique pageviews.* The range difference between pageviews and unique pageviews was 14-38%. The Donate page attracted 216 pageviews, with 92 of those being unique, and those users spent a lot of time there with 2 min 37 s, however, their bounce rate was 85.87%.

Online Survey Questionnaire.

Fifty-two parents of children who have undergone neurosurgery and all resided in Alberta. User demographics included: Caucasian (90%, n = 47) females (92%, n = 48)), aged 36-45 years (48%, n = 25), with a university or college degree or diploma (69%, n = 36). Baseline characteristics and computer use for the respondents are described in Table 1. Ninety-six percent of parents (n = 50) reported accessing the Internet from home and 52% (n = 27) spent approximately two to four hours a day online, with 21% (n = 11) going online less than an hour a day, and 25% (13) surfing the Internet for five or more hours a day.

Ninety-eight percent of parents (n = 51) reported relying on health care providers for their health information, followed by 77% (n = 40) from family and/or friends with 60% (n = 31) going online to health websites. In addition, one-third of the sample accessed medical journals and another third reported favoring print media to supplement their health information search. One-fifth of parents reported using TV or radio programming. Table 2 summarizes the health information resources parents used. Table 3 describes how parents found reading health information on a computer compared to a book or pamphlet: 42% (n = 22) reported it to be very

easy, 25% (n = 13) somewhat easy, 21% (n = 11) neither easy or difficult, and 8% (n = 4) stated it was somewhat difficult.

Sixty-nine percent of parents (n = 36) responded that they learned about the NKF website from medical staff at a clinic or hospital visit, followed by 37% (n = 19) hearing about it from family or family, and 14% (n = 7) came across it from an Internet search. Two respondents learned about the NKF site via Facebook or a local television/radio program. Table 4 presents the reasons parents visited the NKF site. Finding more information about Camp Everest and L'il Everest Camp accounted for 67% (n = 35) of visits. Forty percent (n = 21) reported wanting to learn about upcoming events and news related to the NKF, 33% (n = 17) came to generally check out the site, 21% (n = 11) for social support and resources, 17% (n = 9) to get their child their Hope Stones, and 14% (n = 7) came to make a donation. One fourth of parents (n = 12) reported visiting the NKF to find more health information about their child's diagnosis or condition.

Half of the parents (n = 26) have discussed, or plan to discuss, with their child's physician, nurse practitioner (NP), or other medical personnel involved in their child's care the health information found on the NKF site. Six percent of parents (n = 3) reported looking for health information from other sources. One third of the sample (n = 17) will discuss findings with family and friends and have contacted, or plan to contact a support group. In the survey, approximately 20% (n = 10) stated the health information received may influence future health decisions from their child and has improved their understanding of their child's condition, surgery, or illness. Table 6 summarizes these findings. Table 7 illustrates whether the health information they found on the NKF added to what their child's physician, NP, or other medical personnel had told them: 30 parents (58%) strongly or somewhat agreed, 19 (37%) neither agreed or disagreed and two parents strongly or somewhat disagreed (3.8%).

Parents were asked about their 'favorite' parts of the NKF website and were allowed to give multiple responses. Seventy-nine percent (n = 41) favored Camp Everest and L'il Everest Camp information. Health information garnered 40% (n = 21) and being of Canadian content appealed to 37% (n = 19) of parents. Sixty-five percent (n = 34) reported the News and Events page to be a favorite part, 50% (26) being fond of the Hope Stones, 44% (n = 23) liking the social support and resources information, and 29% (n = 15) appreciated donation information. Forty-two percent (n = 22) stated the NKF site was easy to use and 32% (n = 17) felt it had an attractive design and layout (Table 8). Table 9 summarizes what parents reported as being a favorite part(s) of the NKF website.

Focus Group Interview.

Parents were all mothers who had a child who had undergone neurosurgery a minimum of two years ago. The mothers' ages ranged from 35-44 years, two had university or college degrees, and all had high school diplomas. Three of the four parents self-reported their computer literacy as proficient and one described it as poor. All of the parents had familiarity and used mobile phones and tablets regularly, and all of their children had attended Camp Everest. Characteristics of the parent sample are summarized in Table 10. The interview took place in a room with audiovisual equipment, and the NKF website was loaded and "surfed" throughout the interview.

Parents were asked to describe their experiences about where and how they began searching for information about their child's neurosurgical diagnosis. All four of the parents strongly responded that they were reluctant to search online for mainly two reasons: one, the *timing* of their child's diagnosis was a chaotic time, and "when you're in the hospital, it's all very overwhelming" so searching online for information was not a priority. The second reason

was that three of the four parents were advised by a physician or nurse to avoid using the Internet. Two mothers explain (Table 11).

> Parent 2: So when that's all happening and you're bringing in a priest to give someone last rites, you're really not thinking about a computer. [Physician B] was very adamant, 'Don't you dare touch that Internet, do not look at it, do not – you listen to what I say, I'm the boss, and this is the way it's going to run'.
>
> Parent 3: "I remember both [Physician A & Physician B] saying don't Google it…[so later when searching online]…I remember typing it in and feeling guilty about it…I just wanted the definition…I just wanted to know what the words meant…"

Despite receiving cautionary warnings, most of the parents reported going online eventually when their child was in stable health. Parents reported that they typed in a keyword, such as VP shunt, cerebral palsy, or third ventriculostomy into a browser. One parent expanded to describe also using a "big encyclopedia book of brain and thinking, well, it doesn't really have what I'm looking for". One participant (with poor self-reported computer literacy skills) did not seek information on the Internet about her son's diagnosis because "I've already lived that nightmare".

All parents reported hearing about the NKF website by "word of mouth" from staff. One parent reported not accessing it "until I was ready to go and do that", further illustrating the impact of *timing*. All parents reported that the webpages were easy to navigate, "colorful, inviting, and joyful' and even for the parent who mentioned, "I'm not a computer person…I can just click that right there on the front, and that's what I like". All reported accessing the NKF website on their mobile phones without any difficulties, but when they wanted to read or explore the website at length, they used their home computers. One parent made many positive references to using her mobile phone to follow the NKF's news and events via social media (e.g., Twitter, Facebook). Difficulties on the website included the some technical errors (e.g., not

receiving a confirmation for registration into Camp Everest) and broken links (e.g., brain tumor information page reported only an error message). Another parent agreed with the problem of broken links and also mentioned that some pages are not updated regularly. Parents described these two reasons for why the 'medical conditions' pages were among the pages with the fewest pageviews. Findings from the Google Analytics data identified that the 'Community Resources' page was infrequently viewed and used. Following up with parents on this identified some potential reasons for low pageviews and infrequent usage. Parents reported they did not know it existed, did not see the link, or had never visited the webpage. One parent questioned, "Is that the best name for it?". This led into discussion among the parents with a resolution that 'Community Funding Support Resources' would more accurately describe the content.

Participants consistently used language of "safe" and "credible" when discussing the NKF website. The parents expressed feelings surrounding "fear" and "mistrust" of what they may find on the Internet and thus preferred to place their trust in their primary care providers [and the NKF website] to mediate the health information they received. This sense of legitimacy of the information on the NKF website is described by two parents (Table 11):

> Parent 1: This [NKF website] is a verifiable source…[safe said by other parent]…definitely…so they've kind of [sifted] out some of it so it isn't this flukey, you know, therapy or surgery or doctor. Yeah, I felt safer…and if the doctors are telling parents not to Google it, if they are able to say, 'Yeah, this is a verifiable source' -you know" (other parents nodding in agreement).
>
> Parent 3: "…this is a safer place…definitely more…yeah, its' credible…I had just the right information… here, I felt like, again, it's been-someone's already, you know, looked at it and thought, 'This is right, this is perfect for what our parents are going to hear or read or see', and I'd feel safer if it was through there [NKF website]".

Parents also expressed fear surrounding accessing the Internet in search of health information and finding upsetting stories or poor outcomes (Tables 11 & 12):

> Parent 2: "…I would never read…about trauma and stuff, I've already lived that nightmare, so I wouldn't want to read that because I've already lived it, so I would never click that right now because I already know what it is".
>
> Parent 3: "…I try and stay clear of reading other people's stories or surgeries or mishaps or things like that or what went wrong all that kind of things that you're going to find".

A theme to emerge from the interview was the need for social support, resources, and opportunities to volunteer. One parent summarized (Table 13):

> "I'd be very happy to be able to say to somebody, 'Hey you can get through this'. In fact, I went and did a talk at the [hospital] and it felt good to do it, sort of give some hope back, I guess…I know when I was going through it, I was pretty much a wreck…"

The NKF website is enabled with its own password protected social network webpage, 'Join the Community,' that is designed to function and serve as a forum or blog for parents, caregivers, and their children. Parents give consent for their children to use it by requiring them to register their minors. Despite the 'Join the Community' tab being on the home page, with access using a one-click button, it was a seldom viewed and utilized feature of the NKF website. Parents were directed to the 'Join the Community' tab for discussion and only one parent reported using it. The parent explained placing a message post on the dashboard, never receiving a response and thus abandoning using it altogether. The parents continued to explain reasons for the limited use of the 'Join the Community's page including not being aware of it at all, not really knowing its purpose, and having some technical difficulties (Table 14).

Parents also described preferring to have 'another tab' [place on the NKF website] just for their children "because I'd love for her to connect outside of camp with some of these kids". When informed that this was the intended purpose of the 'Join the Community' page, parents collectively identified hesitance to using it. The parents wanted a 'safe' place to connect with

other parents, or to ask a question, *and* they wanted their children, who are often too young or vulnerable to go online seeking peer support (e.g., Facebook) to have a different 'tab' to ensure a completely distinct and separate forum. One parent explains:

> Parent 1: "[my son] is absolutely terrified of needles, so if a parent is talking about, yeah, in this procedure you have to get this many needles kind of thing, so he's not having to read that…if the kids amongst themselves want to talk about, Hey, this is what I did, that's different than coming out of our fear as parents".

When prompted, the parents elaborated further (Table 13):

> Parent 1: "…If you had a tab for adults and a tab for kids…I think would be better you know…just letting them go into their own site…I just think - so the kids - if a parent is asking a question about something that maybe a parent doesn't want their child to see, you know, like something went wrong…if the kids amongst themselves want to talk about, hey, this is what did, you know, that's different than coming out of the-our fear as parents…[kids' own site]…so they're not seeing the kind of…I think would be better you know?".
>
> Parent 3: "…I think you have to get the kids involved with it too. I showed him all of the pictures. I think the pictures really helped… but I was hoping that there could be a little bit more of that…because this is a safer place".
>
> Parent 4: "…I think …I wonder about whether you want the kids – like, I kind of think sometimes the kids should almost have a different area than the adults for some of that stuff".

Discussion

This study builds upon the literature demonstrating the legitimacy of using an online health website, www.neurosurgerykids.com, for supporting parents seeking health information and fulfilling their social and resource needs. Several studies have found that the Internet is a popular and efficient mode for distributing health information and offering social support because it is inter-active, user controlled, offers anonymity, and is available around the clock (AlSaadi, 2012; Glynn, O'Duffy, O'Dwyer, Colreavy, & Rowley, 2013; Klemenc-Ketis &

Kersnik, 2013; Patel &Khan, 2010; DeLuca, Kearney, Norton, & Arnold, 2012; Shuyler & Knight, 2003). In 2010, eight out of ten Canadian households (79%) had access to the Internet, with the second highest rate being in Alberta at 83% (StatsCan., 2010). Among those, 70% of Canadians reported searching for medical or health related information online (StatsCan., 2010).

Parents' approaches to searching the Internet

In this study we found that parents are increasingly accessing the Internet, particularly health websites, in search of health information, support and resource needs. Hand, McDowell, Glynn, Rowley, & Mortell (2013) found that 83.4% of parents reported going online in search of information regarding their child's health. Deluca et al., (2012) and Kurup et al., (2010) found that parents are increasingly consulting other sources, mainly the Internet, even before visiting a healthcare professional. Parental usage of health websites for getting immediate answers, learning about the diagnosis, treatment options, prognosis, adjunction what the physician has explained, or for finding support groups and sharing with other having similar experiences is well documented in the literature (DeLuca et al., 2012; Hand et al., 2013; Klemenc-Ketis & Kersnik, 2013; Roche & Skinner, 2008; Shuyler & Knight, 2003; Tuffrey & Finlay, 2002; Walsh, Hyde, Hamilton, & White, 2012).

During the focus group, the parents explained not using the Internet to search for health information, primarily because their child's neurosurgical diagnosis came *during* the acute phase of the illness – a time when life-saving decisions are needed in a very stressful situation. The parents in the focus group further described being overwhelmed, not wanting to relive the "nightmare", and that the fear and uncertainty of their child's health outweighed their desire to go online. Similarly, DeLuca et al., (2012) found that parents wanted to learn about the medical condition, but were too anxious to directly search the Internet because of fear of being

overwhelmed, further fueling their anxieties, or the potential for obsessing over negative content. In contrast, Tuffrey and Finlay's (2002) research involving parents of paediatric outpatients had a generally positive attitude towards the Internet and 88% felt that doctors should suggest suitable websites to parents. Another study found that most people (72%) believe that all or most of the health information on the Internet is credible (Pew Internet & American Life, 2002).

Is Internet health information seeking context dependent?

Gage and Panagakis's (2011) study proposed that the *type* of health issue [e.g., life threatening condition versus routine health information] being confronted may be a critical dimension in understanding how, when, and why parents use the Internet as a source of health information. A study involving patients before and after cardiac surgery, found that only 21% of the patients had used the Internet for health information (Murero, D'Ancona, & Karamanoukian, 2001). Conversely, Chisolm (2010) found that health crises were consistent predictors of increased Internet use by patients for health information. Knapp et al., (2010) similarly stated that 76% of parents of children with life threatening illness used the Internet for medical information. Further, DeLuca et al., (2012) found that nearly every parent acquired online information in the first hours and days after learning of the referral [to a genetics specialist]. Despite the parents in the focus group describing cautious use of the Internet for neurosurgical information, 60% of the surveyed parents reported using websites for health information which is also comparable to the Canadian national average of 70% (StatsCan., 2010).

Influence of healthcare providers on parents' health information seeking

Similar to DeLuca et al. (2012) study, some of the parents in my study were advised against seeking medical information on websites by their child's healthcare providers. The literature is replete with reasons why healthcare providers may be cautious referring their

patients to the Internet as a health resource: it may be inaccurate, unreliable, possibly even dangerous, has not been critically appraised such as a peer review, or even threatening to the image of the primary care provider (Dorman & Oermann, 2006; Gage and Panagakis, 2011; Jariwala, Paterson, Cochrane, Abboud, & Wigderowitz, 2005). However, as Nichols and Oermann (2004) stated, caution may well be advised when using the health information received on the Internet because of the unregulated nature of the medium, potentially giving way to obsolete and inaccurate information.

This study found that 98% of parents with a sick child prefer to receive specific health information from a trusted healthcare provider rather than on the Internet and other studies found similar findings (DeLuca et al., 2012; Glynn et al., 2013; Plantin & Daneback, 2009; Lowes & Gregory, 2004). Similarly, Gage and Panagakis (2011) cited that during the highly emotional period following a diagnosis, parents may not want to be empowered through the Internet, but prefer to transfer some of the burden of decision-making to a trusted healthcare professional. Knapp et al., (2010) found that parents were more likely to trust healthcare provider information versus the information they located from Internet sources. AlSaadi (2012) found that 68% of parents used healthcare providers as their main source of health information, although 79% of these same parents also reported using the Internet to gain information on their child's health. However, what is unique about the NKF website is that this information is created and provided by healthcare professionals.

Parents' usage and experiences using the NKF website

The results of this study showed that it is more common to seek health information on the NKF website among young to middle aged Caucasian women, with higher levels of education, and direct access to the Internet at the home. Similar characteristics have been found in many

other studies and has been dubbed the "digital divide" (Fox, 2013; Kurup et al., 2013; Glynn et al., 2013; Plantin & Daneback, 2009; Underhill & McKeown, 2008). With the increasing ubiquity of mobile devices and tablets, this socioeconomic disparity may be negligible in the near future. Glynn et al., (2013) dubbed the burgeoning use of 'wireless communication devices' [mobile] as a subsection of eHealth called mHealth. In my study, parents reported that being able to access the NKF website on their mobile devices or tablets [at their child's bedside] day or night, was a vital source of information and support.

In this study, 40% of the parents reported using the NKF website for health information. Despite 60% of the parents in this study reporting that the NKF health information added to their knowledge, only 20% reported that it may influence their medical decision making. Similarly, Glynn et al (2013) found that 29.1% of the parents felt that the health information found online would influence the treatment decisions for their child. In contrast, another study found that 68% of patients reported that the health information received online impacted their medical decision-making (Pew Internet & American Life, 2002). However, 50% of the parents who received health information on the NKF website had discussed, or planned to discuss their findings with their healthcare providers as compared to 34% of parents in another study (Tuffrey & Finlay, 2002). Glynn et al (2013) similarly found that over half of the parents in their study had discussed, or intended to discuss health information with their surgeon. Only 6% of the parents in this study reported looking for health information elsewhere other than the NKF website. One of the parents in the focus group stated that the health information on the NKF website has been "verified" and is "just right for what our parents need". Other studies found that some of the information available on the Internet is too technical in nature, which is not easily understood by the layman (AlSaadi, 2012; DeLuca et al., 2012).

Support for using Google Analytics for evaluation

Crutzen, Roosjen, and Poelman (2012) argued that in contrast to self-reported exposure measures, tracking user behavior [e.g., via dedicated software such as Google Analytics] is independent of visitor's memory, interpretation or social desirability and when combined with qualitative methods, such as interviews, can yield a fuller and richer picture. In Google Analytics, each visitor to the NKF website brings along his own set of data that can be collected, measured, analyzed, and reported and is an effective website evaluation tool guided by an analyst (Ledford, Teixeira, and Tyler, 2010). Similarly, Wilfert (2009) asserted that Google Analytics yields only statistical data but when paired with qualitative methods, a narrative unfolds with storylines including "how people got to the site, what they searched for when they were there, what they looked at and what they did not".

While the marrying of web analytic, survey, and interview data created a picture of NKF website use, it can potentially lead to more confusion and questions. For example, both the Google Analytic and focus group data revealed that the 'Medical Conditions' information pages (e.g., hydrocephalus, achondroplasia,) on the NKF website were less frequently visited compared to other pages (e.g., Hope Stone page, NKF News and Events page, Media Centre page). In contrast, the survey results reported that almost 25% of the parents visited the NKF website in search of health information and 40% of the surveyed parents rated it as one of their favorite parts. Inconsistencies in the findings can be perceived as a strength using methodological triangulation because it provides an opportunity to capture an unexpected new concept or theme (Duffy, 1987). Careful collection and insightful interpretation guided the concepts of *timing* and *sample* as potential reasons for the inconsistency in this study's findings. The Google Analytic data was collected during the first six months after the website was launched and collected data

about *anyone* in the public accessing the site (e.g., not parents with a sick child). For these visitors, digging deeper into the health information pages may not have held any relevance, and thus they avoided those pages. All the parents in the interview had children who had been diagnosed sometime ago, described how they were more in the 'chronic' phase in their child's illness trajectory, and thus their health information needs were already met. In addition, the sample size was small and therefore these parents' perspectives may not be representative of all NKF users. This example justifies why it is important to combine Google Analytic reports with other qualitative methods.

Evaluating the NKF website's usability

MacCulloch, Nyhof-Young, Nicholas, Donaldson, & Wright (2010) stated that website quality and presentation are critical elements in order for a website to be used effectively. The findings demonstrated that the NKF website's usability was evaluated to be: very easy to use, very easy to read and understand, informative, attractive, colorful and inviting, and easy to navigate. The parents reported the NKF website to have great "responsiveness", meaning the dimensions were able to 'flex' to the device (e.g., mobile phone, tablet) being used - despite the Google Analytic reports indicating a high bounce rate for mobile phone users. When examined further, it was found that when parents used their mobile phones, it was mostly for quick fact finding, such as an address or contact information, or they were 'on the go' and didn't have time to graze on the NKF website.

Findings in this study suggest that the NKF website is congruent with the Technology Acceptance Model whose underpinning premise is that a website is more likely to be accepted and used by parents if they *perceive* it to be *useful* and *easy to use* (Chutter, 2009; Davis, 1989). However, some technical errors or broken links were identified by the parents and addressing

these points and maintaining current updates would be an area of improvement for the NKF website to improve usability and usage. Pew Internet and American Life (2002) found that 37% of users will leave a website if there are inadequate updates. It is encouraging that 94% of the parents found what they were looking for on the NKF website, thus suggesting good usability. Ninety two percent of parents plan to use the NKF website in the future suggesting a good user experience.

Parents use of the Internet and NKF website for social support and resources

One of the most prevalent themes to emerge out of the collected data was the use of the NKF website for social support, connecting with peer parents and resources. Plantin and Daneback (2009) found that using the Internet to establish connections with others in similar situations is of particular importance for parents who children have serious medical conditions. Google Analytics revealed that six of the top seven landing pages were "social-related" pages. MacCulloch et al., (2010) found a strong endorsement from the parents in their study for an online peer-based support network. Similarly, Holtslander et al., (2012) found in their study involving parents with diabetic children, that when parents can share experiences, it may more rapidly enable parents to achieve 'normalization' following a life-altering diagnosis. Results in this study revealed that 67% parents reported using the NKF website for socially-related information and support: Camp Everest and L'il Everest Camp information, followed by parents 'staying on top of things' by tracking the NKF's News and Events (e.g., fundraisers, parties, social gatherings), and 70% arrived at the site via Facebook – another social gathering webpage.

Limitations

This study has some potential limitations. There was one focus group interview and the sample size was small (n = 4), however, parents brought a range and depth of experiences about

having a child with neurosurgical concerns and their health information, support, and resource needs. The findings from the combined data of the Google Analytics, online survey questionnaire, focus group, and field notes were similar, indicating the main issues were identified (e.g., theoretical saturation was met). The sample was predominantly mothers and the relevance to fathers may be inappropriate. In future studies, *health information* should be clearly defined because it may mean different things to different people. Strict adherence to criteria for ensuring qualitative research trustworthiness increased confidence in the findings. There is small potential for a margin of error in the Google Analytics data because *all* crawlers were granted access to the NKF website. In the future, to refine exploring only parents' usage, a robot.txt file should be encrypted in the NKF website. The data was also collected over a relatively short period of time. Findings of website usage and experiences among parents of children undergoing neurosurgery may not be generalizable given the NKF website is targeted to the Edmonton, Alberta region.

Conclusions

There is a lack of research about the specific health information, support, and resource needs of parents with children undergoing neurosurgery. There is even less known about *when* they seek health information online, *what* health websites they are visiting, *how* useful the information was or was not, how e-literate they are, and especially, *why* they are visiting the health websites that they do (Lewis, Gundwardena, & El Saadawi, 2005). This study aimed to assess and evaluate whether a custom designed health website, could be used to meet parents' health information, support, and resource needs. From this study, the majority of parents felt that the NKF website is credible, useful, and informative. After visiting the NKF website, many parents reported that the health information improved their understanding of their child's

condition, surgery, or illness. Other parents found the website to be a portal for joining the 'NKF family' and for connecting with other parents for support and shared experiences. The method of healthcare delivery is being transformed by the ubiquity of the Internet and the newly empowered, computer-literate public is making a claim in becoming partners in managing their health. Such changes have the potential to bring about positive outcomes, such as improved medical decision making, increased efficiency in the clinic or hospital appointment, and strengthening the relationship between primary healthcare providers and their parents. The time is now for the healthcare profession to respond to the "Internet-informed" parent by guiding them to reliable health information websites, giving them an "Health website prescription", and collaborating with them in obtaining and analyzing the information received.

Abbreviations

NKF: Neurosurgery Kids Fund**;** PNP: Pediatric Nurse Practitioner**.**

Table 1

Characteristics of Parents from the online survey questionnaire data

	Sample n	Characteristic	Frequency n	Percent of Sample %
Role	n = 52			
		Parent	52	100
Gender	n = 52			
		Female	48	92.3
		Male	4	7.7
Age in years	n = 52			
		18-25	1	1.9
		26-35	15	28.8
		36-45	25	48.1
		46-55	8	15.4
		56 +	3	5.8
Level of Education	n = 52			
		University or College Degree/diploma	36	69.2
		Some university or college	5	9.6
		Highschool diploma/GED	7	13.5
		Did not finish high school	4	7.7
Race or Ethnicity	n = 51			
		Caucasian	47	90.4
		Asian or Pacific Islander	2	3.8
		Hispanic	1	1.9
		Other	1	1.9
Province	n = 52			
		Alberta	52	100
Location of Nearest Computer for Use	n = 52			
		At home	50	96.2
		At work	2	3.8
Hours per Day using the Internet	n = 51			
		0 to 1	11	21.2
		2 to 4	27	51.9
		5 or more	13	25.0

Percentages do not sum to 100% due to missing values

Table 2

Health information resources used by parents

	Frequency n	Percent of Sample %
Healthcare providers	51	98.1
Family and/or friends	40	76.9
Websites	31	59.6
Print media	18	34.6
Medical journals	16	30.8
TV/Radio	10	19.2
Other (naturopath/acupuncturist)	1	1.9

Percentages do not sum to 100% because of multiple responses

Table 3

Ease of accessing health information on a computer (n = 50)

	Frequency n	Percentage of Sample %
Very easy	22	42.3
Somewhat easy	13	25.0
Neither easy or difficult	11	21.2
Somewhat difficult	4	7.7
Very difficult	0	0

Percentages do not sum to 100% due to missing values

Table 4

Sources of how parents learned about the Neurosurgery Kids Fund website

	Frequency n	Percentage of Sample %
From medical staff at a clinic or hospital visit	36	69.2
From family and/or friends	19	36.5
From an Internet search	7	13.5
From a local TV/Radio/Newspaper	1	1.9
Other (Facebook)	1	1.9
Not familiar with this website	0	0

Percentages do not sum to 100% because of multiple responses

Table 5

Reason(s) for visiting the Neurosurgery Kids Fund website

	Frequency n	Percentage of Sample %
To find out more about Camp Everest or L'il Everest Camp	35	67.3
To learn about upcoming events or news related to the Neurosurgery Kids Fund	21	40.4
To generally check out the website	17	32.7
To find more health information about my child's diagnosis or condition	12	23.1
To find social support or resources	11	21.2
To get my child their Hope Stones	9	17.3
To make a donation to the Neurosurgery Kids Fund	7	13.5

Percentages do not sum to 100% because of multiple responses

Table 6

Usage or plan of usage, of the health information found on the Neurosurgery Kids Fund website

	Frequency n	Percentage of Sample %
Discussed, or will discuss with my child's doctor, nurse practitioner, or other medical personnel involved in my child's care	26	50.0
Discussed, or will discuss with family and/or friends	17	32.7
Have contacted, or will contact, a support group	17	32.7
Has influenced, or may influence, future health decisions for my child	10	19.2
Has improved my understanding of my child's condition, surgery, or illness	9	17.3
Looked for, or will consider looking for more health information	3	5.8

Percentages do not sum to 100% because of multiple responses

Table 7

NKF website enhanced information gained from healthcare professionals (n = 51)

	Frequency n	Percentage of Sample %
Strongly agree	15	28.8
Somewhat agree	15	28.8
Neither agree or disagree	19	36.5
Somewhat disagree	1	1.9
Strongly disagree	1	1.9

Percentages do not sum to 100% due to missing values

Table 8

Parents rating of information on the Neurosurgery Kids Fund website as being easy to understand (n = 52)

	Frequency n	Percentage of Sample %
Very easy	34	65.4
Somewhat easy	11	21.2
Neither easy or difficult	6	11.5
Somewhat difficult	1	1.9
Very difficult	0	0

Table 9

Parents' part(s) of the Neurosurgery Kids Fund website

	Frequency n	Percentage of Sample %
Camp Everest and L'il Everest Camp information	41	78.8
News and Events	34	65.4
Hope Stones	26	50.0
Social support and resources	23	44.2
Ease of use	22	42.3
Health information	21	40.4
Canadian content	19	36.5
Attractiveness, design, and layout	17	32.7
Donation information	15	28.8
Join the Community	13	25.0

Percentages do not sum to 100% because of multiple responses

Table 10

Demographics and characteristics of parents involved the focus group.

	Characteristic	Frequency &
Number of Participants		n = 4
Parental Age	Range (35-44 years)	$\bar{x}$ = 40 years
Parental Role		
	Mother	n = 4
*Child's Age	Range (7-11 years)	$\bar{x}$ = 9.25 years
*Child's Gender		
	Male	n = 3
	Female	n = 1
Parental Education		
	University or college degree	n = 2
	High school diploma	n = 4
Computer literacy		
	Proficient	n = 3
	Poor	n = 1
Mobile Phone & Tablet use	Often	n = 4
Child attended Camp Everest 2014		n = 4

* Children's diagnoses included cerebral palsy requiring a dorsal rhizotomy, ventriculoperitoneal shunt secondary to hydrocephalus, traumatic brain injury, and a brain tumor.

Table 11

Parental expression of feelings using the NKF website

Parental expressions of feelings using the NKF website	
Parent 1	"This [NKF website] is a verifiable source…definitely…[safe said by other parent…so they've kind weeded, you know, therapy or surgery or doctor, you know, kind of thing. Yeah, I felt safer…and if the doctors are telling parents not to Google it, if they are able to say, Yeah, this is a verifiable source or-you know" (parent looking at other participants and continued on with supportive nods)
Parent 2	"Safe" (in agreement to Parent 1).
Parent 3	"…this is a safer place…definitely more…yeah, its' credible…I had just the right information…[looking at other sources for health information]…but I will if it was linked to here, because I've tried to stay clear of reading other people's stories or surgeries or mishaps or things like that or what went wrong and all that kind of things that you're going to find. However, if it was here, I felt like, again, it's been-someone's already, you know, looked at it and thought, This is right, this is perfect for what our parents are going to hear or read or see, and I'd feel safer if it was through there [NKF website]".
Parent 4	"[safe said by other parent]…yeah for sure".

Table 12

Concepts and examples of parental experience using, or not using the Internet

Concepts	**Example**
<u>Timing</u> Timing at acute phase of illness	**Parent 3:** "It was boom, boom, boom…everything happened at a very fast rate…I remember [nurse] saying going onto the NKF group, but I didn't go home immediately and do it. I mean it-it sat there for a bit-until I was ready to go and do that" (arms gesturing dramatically in the air). **Parent 2:** "We were thrown into it…so you don't have any time to do any research—so when that's all happening and you're bringing in a priest to give someone last rites, you're not really thinking about a computer…see, and I would never read-when you had that thing up about trauma and stuff, I've already lived that nightmare, so I wouldn't want to read that because I've already lived it, so I would never click that right now because I already know what it is" (shaking her head, voice low and controlled, and pointing at the NKF screen)
Timing at chronic phase of illness	**Parent 1:"**Because he was born so early…we did that later [searched online] before you had this [NKF website] set up". **Parent 3:** [Now] we're okay-you, we're in that stage of our lives where, you know, there's nothing for us to do [search online]. We have the support that we need". **Parent 4:** "I think for us just because [child] has been stable for so, so long that really I go on here mostly about camp…I know we've been blessed so far that – touch wood-that, you know, we're not really going in for a lot of medical stuff". **Parent 2:** "…because [child] is pretty stable right at this moment".
<u>Influence of Medical Staff</u>	**Parent 3:** "Well, I remember both [Physician A & Physician B] saying don't Google it…we were directed by [nurse]. and the doctors saying don't go really anywhere" (all other parents nodding). **Parent 2:** "[Physician B] was very adamant. Don't you dare touch that Internet, do not look at at, do –you listen to what I say, I'm the boss, and this is the way it's going to run" (parents nodding). **Parent 4:"**When we did research, it was basically only [Physician C]".

Table 13

Parental expression about having a blog or forum as a source of support

Parental expression about having a blog or forum as a source of support for parent-to-parent	
Parent 3	"If somebody was going through a similar situation, you could offer that I've been there, and you give…so even though it may not pertain to you, because right now [your daughter] is doing well and you already lived with it, as somebody else new comes, too, you could pop in and say…where you need to connect with others and chat…" (looking at parent 4).
Parent 4	"…yeah. I'd be very happy to be able to say to somebody, Hey you can get through this. In fact, I went and did a talk at the [hospital] and it felt good to do it, sort of give some hope back, I guess…I know when I was going through it, I was pretty much a wreck…"
Parental expression about having a blog or forum as a source of support just for the children	
Parent 1	"…If you had a tab for adults and a tab for kids…I think would be better you know…just letting them go into their own site…I just think - so the kids - if a parent is asking a question about something that maybe a parent doesn't want their child to see, you know, like something went wrong…if the kids amongst themselves want to talk about, hey, this is what did, you know, that's different than coming out of the-our fear as parents…[kids' own site]…so they're not seeing the kind of…I think would be better you know?".
Parent 3	"…I think you have to get the kids involved with it too. I showed him all of the pictures. I think the pictures really helped… but I was hoping that there could be a little bit more of that…because this is a safer place".
Parent 4	"…I think …I wonder about whether you want the kids – like, I kind of think sometimes the kids should almost have a different area than the adults for some of that stuff".

Table 14

Parental expression about technical faults that impacted use of the NKF website

Parental expression about technical faults that impacted use of the NKF website	
Parent 1	"The only thing, that Camp Everest wasn't updated…[improve] the confirmation [response]
Parent 2	"Is that the best name for it? [what are your thoughts in response]…Support..
Parent 3	"And a few of the links were broken, so they weren't-some of them no longer exist…so there were a few broken links…and I just couldn't get it to work"
Parent 4	"…[website] I don't think it says that on there…well, maybe I should email, maybe I shouldn't, because you feel like you shouldn't ask. You almost feel weird asking…"

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Chapter 3: General Discussion

Use of the Neurosurgery Kids Fund (NKF) website to meet parents' health, support, and resource information needs have several influences and it is important to gain insight from the end users to understand the main issues. In order to refine and improve the NKF website's usability and user experience, parents' behavior, perspectives, and opinions need to be explored and understood. Integrating quantitative and qualitative methods during evaluation yields rich detail about what is being studied that either method could not do alone (Crutzen, Roosjen, & Poelman, 2012). Usability studies on patient [parent] information websites are scarce (Knijnenburg et al., 2013; Tuffrey & Finlay, 2002). Timing of their child's illness, acute versus chronic phase, and the influence from medical staff may have a significant impact on parents' use of the Internet and NKF website (Roche & Skinner, 2009; Gage & Panagakis, 2012). Thus a multi-methods approach involving parents was used in this study.

Study Design

No 'gold standard' tool was found in the literature on how to evaluate a health website. The tools in this study included Google Analytics which tracked NKF website traffic and usage, a specially designed online survey questionnaire targeted at parents' perspectives and usability on the NKF website, and lastly, a focus group interview to capture parents' perceptions and experiences using the NKF webpages. Field notes were also collected and reflected upon throughout the study.

Google Analytics measures and tracks *all* the traffic and user behavior of *anyone* who visited the NKF website. As such, using this tool may be helpful in offering an 'overview' about the usage and usability but it cannot isolate whether *parents*' health information, social, and resource needs were met [user experience]. Further, there is a potential for a margin of error

when using Google Analytics because the software cannot distinguish between *human* users and *crawlers* who have disguised themselves to mimic human users. For example, if the *crawler* has been encrypted to appear as a search engine, Google Analytics cannot recognize the difference. Ledford and colleagues (2010) assert "it's generally a small margin of error, and considered acceptable in analytics, but a margin of error nonetheless" (p. 81). Web crawlers, however, can be controlled for: a robot.txt file containing directives about how a website can or cannot be crawled can be implemented by a webmaster. For example, the NKF website may wish to block *all* crawlers to the entire NKF website to gain a better representation that it is mostly parents who are being tracked in the web analytics data. Some users prefer to activate a privacy mode or disable JavaScript on their browsers and therefore web analytic data cannot be collected on these users. Beasley (2013) states "what makes web analytics useful is that the data are consistently accurate to within 10% of actual traffic numbers" (p.28). An improvement to the NKF website, however, would be to enable the Conversion options in Google Analytics. Conversions, are the ways a website can set goals, and Google Analytics will track data specific to that conversion (Beasley, 2013). For example, the NKF analysts could measure how many people clicked on the Craniosynostosis podcast, how many people downloaded a PDF medical information sheet, or how many visitors completed the online registration form for Camp Everest. Enabling this feature would further refine the data to track and measure key features that are identified as important to the NKF website.

In retrospect, analyzing the web analytic data for the six months immediately after the NKF website was launched may have not been the ideal time period. For example, the data that was collected in this time frame included statistics involving the NKF web designer company personnel (presumably for quality assurances) or people who may have simply been curious to

look at it. Future studies using web analytics for the NKF website should incorporate a wider time period in the study. Despite these limitations, merging the data collected from all three sources added to the understanding of parents' health information needs and NKF website usage.

The survey questionnaire was developed after a review of the literature and piloted with twelve parents to assess content validity. However, the survey tool used in this study could be modified and improved upon. Firstly, a clear definition about 'health information' may influence parents' responses. There is an assumption that the researcher and respondents share underlying assumptions about language and interpret statement wording in a similar manner (Rattray & Jones, 2007). This may be why the web analytic and focus group data conflicted with the survey findings in terms of using the NKF website for health information seeking. Second, there were no questions inquiring about mobile phone and tablet use. The findings from the web analytics and focus group showed that wireless devices were widely used by the parents and are dramatically on the rise, and thus, further examination of how these tools are used would be insightful (Plantin & Daneback, 2009). If I had analyzed the Google Analytics data *prior* to developing and launching the survey, I would have been able to add questions specific to devices used. I had also collected field notes, and as the study progressed, I was able to reflect on how I would have altered some methodological processes such as this. Third, questions regarding usability were addressed on the survey, however, specific questions related to whether the parents encountered technical difficulties or errors may have offered more information as to why some pages were more viewed than others. Fourth, a default setting, in Fluid Surveys, prompting the user to complete any omitted questions before final submission may have influenced the completeness of some of the responses. Lastly, a question about the *timing* and *nature* of their

child's neurosurgery or hospitalization would be added to gain further insight into parents' experiences and usage of the NKF website (Gage & Panagakis, 2012).

Benefits of conducting the focus group included allowing for a more in-depth exploration about parents' perspectives and experience and also provided a forum for teasing out themes not identified via web analytics or the survey (Rattray & Jones, 2007). Conducting more focus groups in this study was impacted by several factors: parents were unable to secure childcare (especially as it was summer holidays), proximity to the city limiting accessibility, and work schedules inhibited participation. In future studies, considerations to these factors involving parents, especially whose children have higher needs, would be well advised.

The purpose of the study and the nature of what is to be explored determine the sample type and size (Krueger & Casey, 2009). The quantitative survey findings in this study would have been enhanced with a larger sample size >100 to allow for some non-parametric testing (e.g., Chi-square test) — I was unable to study the relationship between the NKF parents' characteristics and behaviors against national statistical data, or with other's study findings (e.g., parental use of the Internet by parents with children who have undergone neurosurgery versus parents of children with serious conditions). Obtaining a larger sample would have meant collecting the survey data over a longer period of time. Additionally, the sample size for the focus group was small and conducting more than one interview may have enriched the qualitative findings.

As the study was unfunded, recruitment efforts and advertisement to participate were dependent on using the existing NKF website and the NKF Facebook pages. This offered a convenience sample of 52 parents for the survey and a purposeful sample of 4 parents for the focus group. These parents may not be representative of all the NKF users, and as such, the

findings are only suggestive. Advertising efforts to participate in this study would likely have been enhanced if postings were identified in the patient clinic areas for pediatric neurosurgery, as well as being approached by a research assistant during these encounters who could explain the purpose of the study. The roles of being the researcher, the Director of Camp Everest and being a founder/director of the NKF may have influenced the responses from some parents. For example all the parents who participated in the focus group had children who had just returned from Camp Everest. This may have influenced their responses about why they used the NKF website.

The majority of respondents were Caucasian mothers with higher levels of education and English fluency and thus, may limit the generalizability of the data collected. Statistics Canada (2011) reported that approximately 1 in every 5 Alberta households most frequently speaks a non-official language at home. With this consideration, assessing the e-literacy (reading level) of the NKF website and possible translations are suggested to reflect the population.

Contributions

Evaluating the NKF website is vital to its continued success as a source of health information, support, and resources. Understanding parents' experiences, usability, and usage of going online is affected by multiple factors. This study suggests the following:

1. Parents prefer to receive health information directly from healthcare professionals, but readily use a website if their healthcare providers suggest it as they perceive it to be safe and credible.

2. Parents access the NKF website as a major source of social support – enrolling their children in camp, learning about the different activities, fundraisers, and events that the children, parents, and family can attend, and connecting and sharing experiences with others.

3. Parents would utilize the NKF's social network page, 'Join the Community', if it was separate from their children's own social network page to ensure privacy and a 'safe' place to vent and connect with peer parents.

4. Timing and context during their child's illness trajectory may impact usage of online health resources.

Implications for Nursing

Nurses and advanced practice nurses (APN) play an integral role in supporting and educating parents with a child undergoing neurosurgery. With the popularity of using mobile phones, tablets, and computers for information health seeking and support, it is paramount for healthcare professionals to recognize this format as an opportunity to adjunct the clinical or hospital visit (Roche & Skinner, 2009). Sechrest (2010) claims that healthcare providers need to recognize the hidden value of the information component, not just the physical component, and to dedicate similar attention to in the delivery of healthcare to their patients. Family centered care emphasizes the importance of patient-provider-caregiver information-sharing to ensure the understanding of health information (Lewis, Gundwardena, & El Saadawi, 2005). Nurses and APNs are ideally poised to explore parents' perspectives and usage of online health websites because they have regular, direct access and interaction with their patients, thus allowing for quality information sharing opportunities. Discussing with parents their Internet searches may offer the nurse and APN an opportunity to assess the kinds of information that parents are seeking and help in securing those needs by directing them to credible websites. The APN can give parents an "Internet prescription" to guide them to accurate and complete websites, and perhaps more importantly, steer them away from potential harmful-to-patient care webpages (Glynn et al, 2009). Further, the APN will be challenged on what criteria to use to evaluate the

quality of the health websites. Suggestions to assessing the quality of websites may include examining the qualifications of the authors; for example, assessing if the information is from a government site or from a recognized university. Also, checking for clear references or sources of the health information should be made available. Transparency of any financial profit or any personal conflicts of interest should be claimed. Any advertising must be clearly distinguished from editorial content. A clear privacy policy should also be made available to allow the user to see what information is being collected about them and how it may be used. Lastly, any credible website should make a disclosure that any health information found on that website should be viewed as complimentary to medical advice and not to replace it.

Future Implications

The findings of this study contribute to health care professionals understanding, acceptance, and adoption of using websites to target pediatric health information needs of parents in an efficient, accessible and attractive e-tool. Ideally, the findings in this study will contribute to discourse regarding the use of health websites directed toward a clinical audience as well as the public. Future studies should focus on analyzing the different types of health information being sought online to explore the potential that *timing* and *context* may have in parents' online health information seeking, or not seeking it, as suggested by Gage and Panagakis (2012). Measuring the effectiveness of websites has become a key issue for practitioners and researchers (Hong, 2007). If parents feel more confident using websites that have been 'vetted' by their child's healthcare professionals, nurses and APNs are now challenged with assessing their health information literacy, and to direct parents to additional, supplemental resources online (Walsh et al., 2012). Lastly, future studies about methods for parents and healthcare professionals to use in evaluating health websites to ensure credibility are much needed.

Conclusion

Parents are increasingly accessing the Internet seeking health information about their child's [neurosurgical] diagnosis, condition, treatment, and prognosis. In addition, health websites specifically tailored to their child's condition, treatment options, and connecting with peer parents are identified in the literature as being vital in parents' coping and meeting their information needs (Holtstander, Kornder, Letourneau, Turner, & Paterson, 2012). This study analyzed the usage and usability of a PNP designed Canadian website about pediatric neurosurgery to evaluate parents' experiences using the NKF website. This study used emerging methods in health research, such Google Analytics, in combination with online questionnaire survey results and a focus group interview to answer the research question. The TAM framework provided a satisfactory bridge connecting NKF website features and parental user experience, usability, and usage. This study's findings assert that a custom designed website, if carefully designed and constructed, could be used to augment parents' health information needs by reinforcing, supplementing, and improving their understanding of their child's neurosurgical diagnosis and treatment outcomes. Further, the NKF website serves as a communal 'hub' for many parents in search of peer support and provides credible, reliable, and relevant information. In this digital age, nurses and APNs are charged with accepting the role of online health websites in our patients' information quest and management of their health. However, the challenges in the future will relate to what methods healthcare professionals should use to evaluate the quality of the respective health websites.

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APPENDIX A

A Google Analytic Report prepared for the Neurosurgery Kids Fund

A Google Analytic Report prepared for the Neurosurgery Kids Fund

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August 2014

A Google Analytics Report for the Neurosurgery Kids Fund

Google Analytic software was embedded in to the Neurosurgery Kids Fund website at the time of its development. This has provided the opportunity to track visitor demographics, behavior and usage since the website's inception. This report analyzes the data collected from April 23, 2013 until November 30, 2013, also the first six months after the website was launched. When performing web analytics, one is looking for the same basic patterns: the highest values for a metric, the lowest values for a metric, and pages that have metrics that deviate from the average value, although "there is no objective standard of high or low or good or bad" (Beasley, 2013, p.110). Beasley (2013) stated, "there is no perfect way to collect data about users' actions…[but]…what makes web analytics useful is that the data are consistently accurate to within 10% of actual traffic numbers" (p. 28).

Key concepts in web analytics are *metrics* and *dimensions.* Metrics are the quantifiable or numeric measurements describing users' behaviors such as how long they spent viewing a page or how many times they viewed a page (Beasley, 2013). Dimensions are defined as the categories that user data may be grouped into, such as, how they got to the website, whether they used a computer or mobile device, or what keywords were used to find the website (Beasley, 2013). The power of web analytics is when metrics are *paired* with dimensions to illustrate a more accurate impression of the end user. For example, simply counting up how many pageviews a website receives is not as informative until one *pairs* it with page dimensions, such as how many pageviews *each individual page* received: e.g.: Suppose web analysts have concluded that higher donations are directly correlated to donors' understanding about the charity's purpose. If web analytics data reveals that the

"About Us" [individual] page is garnering very few pageviews and the charity's success is reliant upon donations, the web designers may use this information to improve upon the "About Us" page with goals of increasing their donations. This study will begin with a general overview analysis of the website, and then explore the main headings in Google Analytics of Audience, Acquisition, and Behavior reports.

Audience Reports

The Audience Overview page provides a snapshot of user activity, including the number of sessions logged, number of users in that time period, the number of pageviews, average session duration, the number of pages per session, bounce rates, percentage of new sessions, a pie graph depicting new versus returning visitors, and the primary languages used to access the website. For the time period of this study, 2,998 sessions and 1,686 users were logged, suggesting a fairly good returning visitor rate also illustrated by the pie chart indicating 56.3 % of returning visitors and 43.7% being new visitors. The number of pageviews (a metric measuring each time a single page was viewed by a user) was 8,818 with an average of 2.92 pages viewed per session. A pageview over 1.00 is considered favorable as the user did not simply land on the NKF site, not find anything worthy and leave immediately (Hong, 2007). The bounce rate was 56.2% which is also considered fairly positive as reaching 50% on this metric is actually quite good for organic in-bound results, e.g., unsolicited searches in Google – not AdWords (Lexford, Teixeira, & Tyler, 2010). That is, the users knew what they were looking for and found the website via their browser. The average session duration was 00:02:24 and that is impressive because, "a minute is a long time and two minutes is an eternity for the Internet" (Beasley, 2013, p. 110). Collectively, these Audience Overview statistics are referred to as Visitor Analysis

data in Google Analytics and typically analyzed in an exploratory manner, looking to see if any patterns emerge about visitor behavior or characteristics. New and returning visitor information for the time frame of this study is not very informative as it was the first six months after the launch and therefore, an overwhelming number of new visitors would be expected.

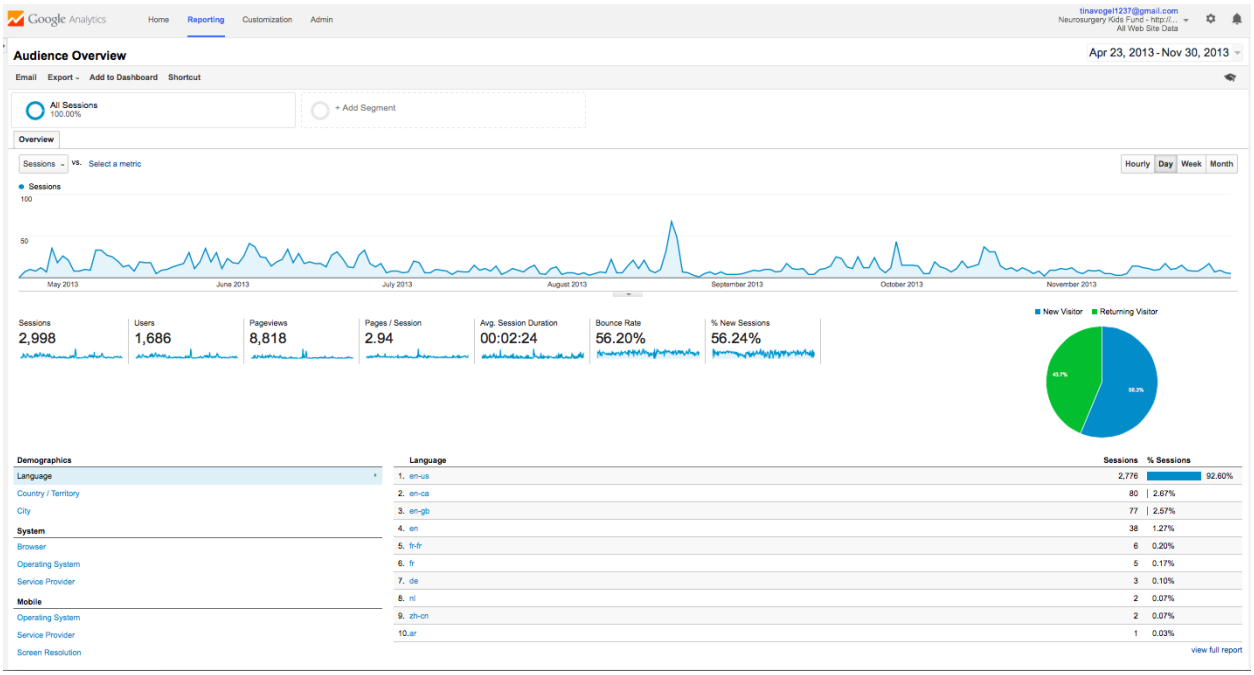


Figure 1: Screenshot of the Audience Overview page on the NKF dashboard.

Location and Language

Location by country and languages used.

Google Analytics uses IP addresses to track and measure where a user is located by country, province or state, and city or town. Knowing the geographical location of the NKF website users is especially important as the site is geo-targeted to the Edmonton, Alberta region. Not surprisingly, 90.23% of all users were from Canada, 85.55% of those users from Alberta, and further, 50.35% of users were from the Edmonton area. Google Analytics also offers a glimpse into worldwide site users: 5.74% United States, 1.17% United

Kingdom, 0.50% India, 0.27% Australia, 0.20% Ukraine, and 0.17% Philippines, Saudi Arabia, and South Africa. As the website is written in English, the majority of users, 99.11% or 2,971 sessions, viewed the NKF website in English. The remaining 0.89% of users who accessed the website using French, German, Mandarin/Cantonese or Arabic.

Country / Territory	Acquisition			Behavior		
	Sessions ↓	% New Sessions	New Users	Bounce Rate	Pages / Session	Avg. Session Duration
	2,998 % of Total: 100.00% (2,998)	56.27% Site Avg: 56.24% (0.06%)	1,687 % of Total: 100.06% (1,686)	56.20% Site Avg: 56.20% (0.00%)	2.94 Site Avg: 2.94 (0.00%)	00:02:24 Site Avg: 00:02:24 (0.00%)
1. Canada	2,705(90.23%)	52.75%	1,427(84.59%)	53.79%	3.07	00:02:33
2. United States	172(5.74%)	91.28%	157(9.31%)	78.49%	1.77	00:00:50
3. United Kingdom	35(1.17%)	91.43%	32(1.90%)	80.00%	1.34	00:01:28
4. India	15(0.50%)	93.33%	14(0.83%)	86.67%	1.13	00:00:10
5. Australia	8(0.27%)	87.50%	7(0.41%)	75.00%	2.25	00:01:09
6. Ukraine	6(0.20%)	0.00%	0(0.00%)	100.00%	1.00	00:00:00
7. Philippines	5(0.17%)	100.00%	5(0.30%)	40.00%	2.00	00:04:05
8. Saudi Arabia	5(0.17%)	80.00%	4(0.24%)	80.00%	3.60	00:00:54
9. South Africa	5(0.17%)	100.00%	5(0.30%)	100.00%	1.00	00:00:00
10. (not set)	4(0.13%)	100.00%	4(0.24%)	25.00%	3.75	00:07:44

Figure 2: Screenshot of location by Country.

Bounce Rate & Average Session Duration

Surprisingly, the lowest *bounce rate* was not realized in Canada with 53.79%, but in the Philippines at 40.00%. The bounce rate is a good metric to measure whether the user was interested and stuck around on the webpage – the lower the bounce rate, the more likely the website had something of value to the user (Beasley, 2013). The Philippines also logged the longest average session duration at 00:04:05. The *average session duration* by Canadians was the second lengthiest at 00:02:33, followed by the United Kingdom at 00:01:28, Australia at 00:01:09, Saudi Arabia at 00:00:54, United States at 00:0:50, India at 00:00:10, and the Ukraine and South Africa at 00:00:00 (these users landed on the first page and left immediately therefore logging a 100% bounce rate). Much of the NKF website information is geo-focused to the local Edmonton region user, however, from the metrics results for *average session duration*, it suggests that there may be other useful information

to the international users as well. This may be an area of development for the NKF website to consider.

On first impression it would appear that the Philippines' users were the most engaged in the website because of their lowest bounce rate but when paired with having the lengthiest average session duration, it may signify that the user may have had more trouble navigating around the website or took longer to read the information. For example, the Philippines' users viewed an average of 2.00 pages per session. What can be interpreted from this is: either the user found what they were looking for and were engaged in the content on the site to look beyond the homepage, or the user took some time to plough through the pages or navigate around the website. This is a classic example of how Google Analytics will offer the *who, what, where,* and *how* the user did what they did, but not the *why* they did what they did. Supportive information from the online questionnaire survey or focus group interviews may shed light on the *why* of the end user's actions or intentions.

Location by province.

Albertans accounted for 85.55% of the total of sessions, followed by British Columbia at 7.50%, then Ontario at 3.59%, Saskatchewan at 1.52%, Quebec at 1.33%, and Manitoba, Nova Scotia, New Brunswick, Newfoundland and Labrador, and the Northwest Territories logging less than 1.00%. The Alberta Health Services region serves the populations of Northern Alberta, Northern British Columbia, Northern Saskatchewan as well as the Northwest Territories and as such, the interest by users in these provinces is as would be expected. The higher rate of interest from Ontarians is likely reflective of the location of The Hospital for Sick Children (also known as SickKids Hospital) which is

Eastern Canada's primary hospital for children requiring tertiary and quaternary care. The comparative hospital in Western Canada is the Stollery Children's Hospital in Edmonton, Alberta. As such, there is a close working relationship between these two hospitals that may account for the higher sessions rates in Ontario.

Region	Acquisition			Behavior		
	Sessions ↓	% New Sessions	New Users	Bounce Rate	Pages / Session	Avg. Session Duration
	2,705 % of Total: 90.23% (2,998)	52.75% Site Avg: 56.24% (-6.19%)	1,427 % of Total: 84.64% (1,686)	53.79% Site Avg: 56.20% (-4.30%)	3.07 Site Avg: 2.94 (4.50%)	00:02:33 Site Avg: 00:02:24 (6.17%)
1. Alberta	**2,314** (85.55%)	52.20%	1,208 (84.65%)	51.82%	3.19	00:02:44
2. British Columbia	**203** (7.50%)	43.84%	89 (6.24%)	71.92%	1.96	00:01:19
3. Ontario	**97** (3.59%)	75.26%	73 (5.12%)	58.76%	2.60	00:01:32
4. Saskatchewan	**41** (1.52%)	63.41%	26 (1.82%)	53.66%	3.66	00:02:37
5. Quebec	**36** (1.33%)	50.00%	18 (1.26%)	58.33%	2.17	00:01:20
6. Manitoba	**4** (0.15%)	100.00%	4 (0.28%)	100.00%	1.00	00:00:00
7. Nova Scotia	**4** (0.15%)	100.00%	4 (0.28%)	75.00%	2.25	00:00:22
8. New Brunswick	**2** (0.07%)	100.00%	2 (0.14%)	50.00%	1.50	00:01:10
9. Newfoundland and Labrador	**2** (0.07%)	100.00%	2 (0.14%)	50.00%	22.50	00:12:30
10. Northwest Territories	**1** (0.04%)	100.00%	1 (0.07%)	100.00%	1.00	00:00:00

Figure 3: Screenshot of location by Provinces in Canada.

Location by city.

Predictably, Edmonton had the highest rate of users on the NKF website with 50.35%, followed distantly by Calgary with 10.31%, Sherwood Park with 5.18%, Vancouver with 4.88%, Grande Prairie with 4.18%, Leduc with 2.59%, Barrhead with 2.48%, Spruce Grove with 1.96%, Toronto with 1.85%, and lastly, St. Albert with 1.53%. The geo-focused traffic (Edmonton and close surrounding regions) and relevant content for these local users is clearly demonstrated in the GA reports and the high rate of these users is suggestive that marketing and communication efforts in the local area are effective.

City	Acquisition			Behavior			Conversions		
	Sessions	% New Sessions	New Users	Bounce Rate	Pages / Session	Avg. Session Duration	Goal Conversion Rate	Goal Completions	Goal Value
	2,705 % of Total: 90.23% (2,998)	52.75% Site Avg: 56.24% (-6.19%)	1,427 % of Total: 84.64% (1,686)	53.79% Site Avg: 56.20% (-4.30%)	3.07 Site Avg: 2.94 (4.50%)	00:02:33 Site Avg: 00:02:24 (6.17%)	0.00% Site Avg: 0.00% (0.00%)	0 % of Total: 0.00% (0)	$0.00 % of Total: 0.00% ($0.00)
1. Edmonton	1,362 (50.35%)	53.08%	723 (50.67%)	50.51%	3.38	00:02:45	0.00%	0 (0.00%)	$0.00 (0.00%)
2. Calgary	279 (10.31%)	58.06%	162 (11.35%)	59.14%	2.29	00:01:57	0.00%	0 (0.00%)	$0.00 (0.00%)
3. Sherwood Park	140 (5.18%)	60.71%	85 (5.96%)	50.71%	3.16	00:01:52	0.00%	0 (0.00%)	$0.00 (0.00%)
4. Vancouver	132 (4.88%)	44.70%	59 (4.13%)	71.97%	1.72	00:01:06	0.00%	0 (0.00%)	$0.00 (0.00%)
5. Grande Prairie	113 (4.18%)	18.58%	21 (1.47%)	74.34%	2.04	00:01:23	0.00%	0 (0.00%)	$0.00 (0.00%)
6. Leduc	70 (2.59%)	57.14%	40 (2.80%)	50.00%	3.09	00:02:26	0.00%	0 (0.00%)	$0.00 (0.00%)
7. Barrhead	67 (2.48%)	26.87%	18 (1.26%)	49.25%	2.40	00:02:52	0.00%	0 (0.00%)	$0.00 (0.00%)
8. Spruce Grove	53 (1.96%)	69.81%	37 (2.59%)	41.51%	3.49	00:03:25	0.00%	0 (0.00%)	$0.00 (0.00%)
9. Toronto	50 (1.85%)	78.00%	39 (2.73%)	64.00%	2.18	00:01:24	0.00%	0 (0.00%)	$0.00 (0.00%)
10. St. Albert	46 (1.70%)	67.39%	31 (2.17%)	34.78%	4.04	00:04:30	0.00%	0 (0.00%)	$0.00 (0.00%)

Show rows: 10 Go to: 1 1 - 10 of 100

This report was generated on 8/8/14 at 1:31:59 PM - Refresh Report

Figure 4: Screenshot of location by Cities in Alberta.

Technology

Browser & OS, Mobile, & Devices Breakdown Reports.

Analyzing the technology used would be performed to optimize user experience on the NKF website. The Browser & OS reports offer information about what browser and operating system the users have and what versions they used. The reasoning for examining this data would be to answer questions such as, "How many users would the NKF website gain if they optimized the user experience for Chrome browser users? How many could be lost if they do not improve aspects for the Mozilla browser users? The NKF website users overwhelming used Apple's Safari browser with 1,354 of total sessions followed by 690 sessions using Internet Explorer. Interestingly, Chrome browser users ranked third and outranked Mozilla Firefox users (ranked fifth) with 360 sessions versus 183, respectively. According to StatCounter, a web traffic analysis tool that offers statistics about web usage, states that Google Chrome has approximately 45% worldwide usage share of all web browsers, indicating that it is the most widely used web browser in the world (StatCounter, 2014). If the NKF were interested in extending its audience globally, it may want to better optimize the user experience for Chrome browser users. Android browsers ranked sixth

with only 117 sessions of the total 2,998 sessions – this statistic can be further corroborated with analyzing the Mobile reports and examining which devices the users used.

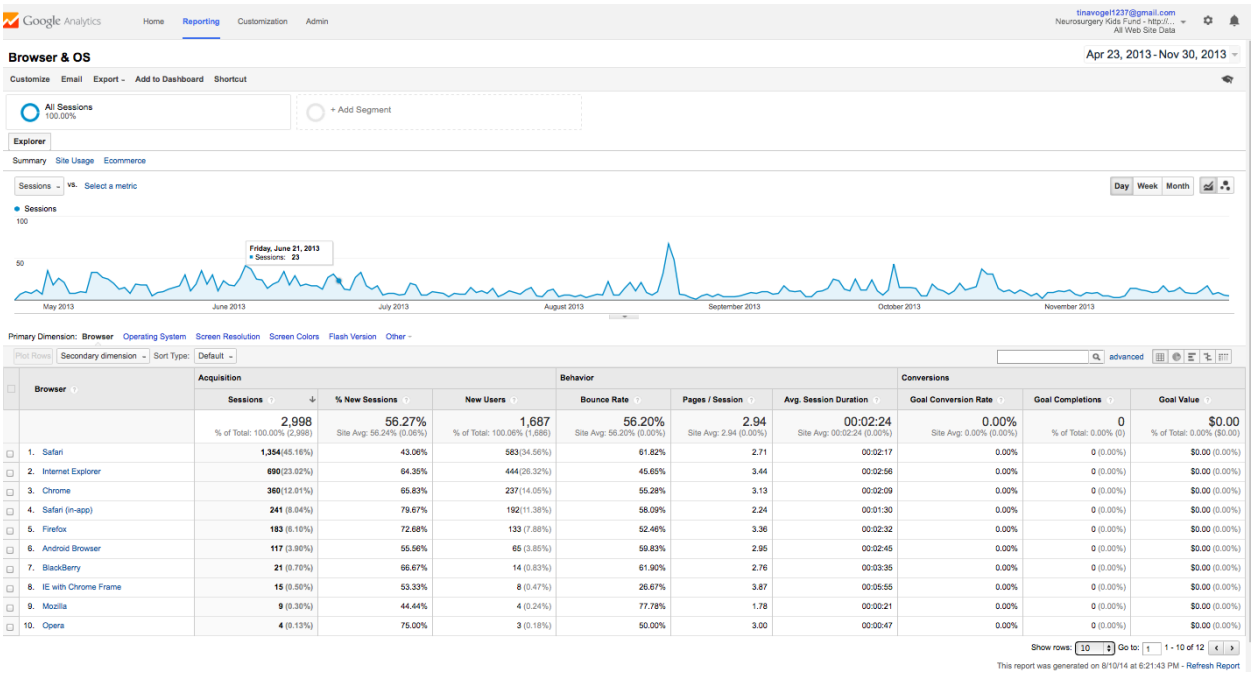


Figure 5: Screenshot of the Browser & OS report.

Rationale for examining the Devices report would be to explore what method the visitors used: a desktop/laptop computer, a mobile, or a tablet. Exploring what kind of device used is important for web development because the usage of mobile devices in recent years is steadily and rapidly growing each year (Beasley, 2013). The vast majority of users to the NKF website used desktop/laptop computers with 1,628 of the total 2,998 sessions. Mobile users accounted for 931 and tablet users logged 439 sessions. What is more telling is when this metric is paired with bounce rates; both computer and tablet users had fairly good bounce rates with 50.06% and 52.39%, respectively. Mobile users, however, had a high bounce rate with 68.74% - this may suggest that the user experience on cellular phones may be inadequate.

Websites are rated as “responsive” if they are accommodative to a variety of devices with the ultimate goal of making the user’s experience an easy and enjoyable one (Beasley, 2013). Using one of the many online commercial resources measuring a website’s responsiveness [www.ami.responsivedesigns.ca]. Figure 6 illustrates that the NKF’s homepage loads very well on desktop/laptop computers and tablets, but rather poorly on phone devices. This may be one of the reasons for the high bounce rates by mobile users because evidently the user experience appears to be compromised. This would be an area for the NKF website to develop – the web programmers need to make the website’s responsive template ‘flex’ to the dimensional requirements of the user’s device.

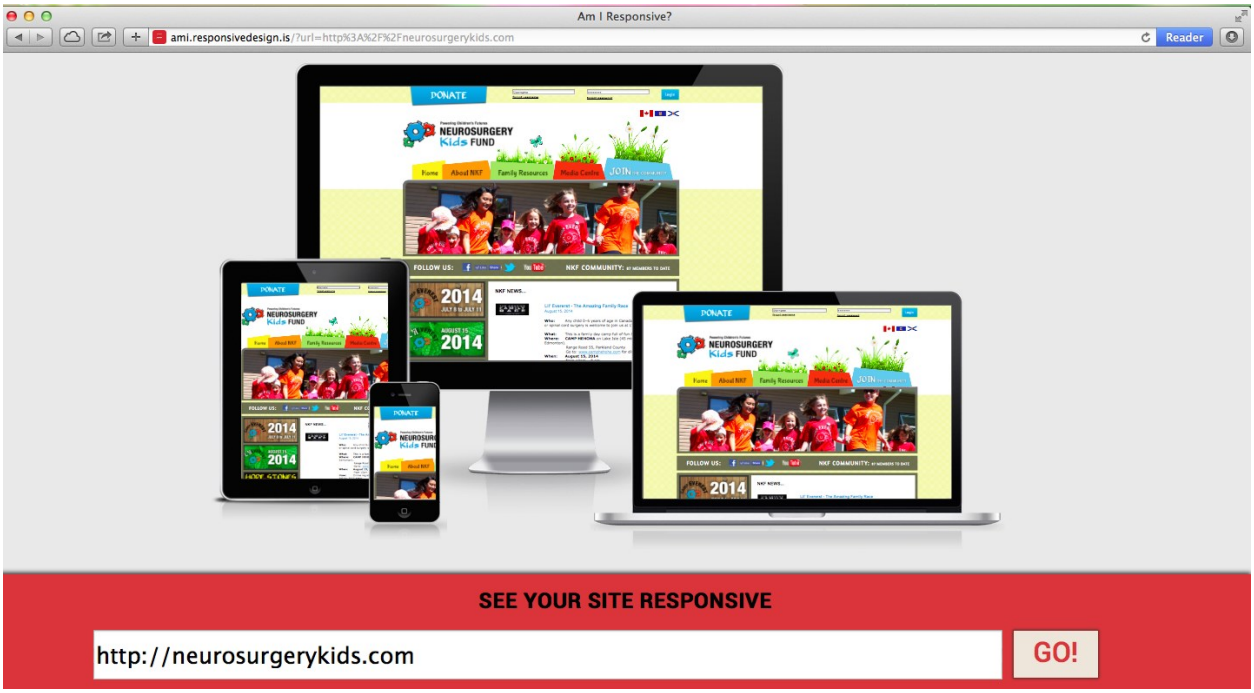


Figure 6: Screenshot illustrating website responsiveness on devices.

The Mobile reports offer information about what kind of devices the users have, for example, iPhones versus Android cellular phones. This would be valuable information for a web designer to examine – if the website was not doing a satisfactory job of supporting

users with mobile devices, this report would help make a case for doing so. It has already been established that the NKF website needs to be more accommodative to mobile users so further breakdown on what type of devices used in particular would not be that helpful. What is significant information on the Devices Breakdown report are the metrics of pages per session and average session durations. Pages per session ranged from 1.25 to 5.00 that is significantly higher than the site's average of 2.94. The average session duration was 00:02:08 which is comparable to the site's average of 00:02:24. What can be extrapolated from these results is that mobile users are spending a fair amount of time accessing the NKF website, exploring several pages, and therefore, the user experience for these users must be optimized to accommodate them.

Acquisition Reports

Channels and Mediums

Examining how a user *arrived* at the website may also reveal what they are on the website to do and this is called *traffic analysis* in web analytics. Traffic analysis examines how well a website is supporting users who come to the site with specific information. For the purposes of this study, the following channels of most interest are: organic, referral, and direct (none). Channel data was not available prior to July 25, 2013 and thus will not be discussed in this study (Google Analytics, 2014). *Organic* mediums refer to users who used a search engine to arrive on the website such as Google or Bing. *Referral* mediums are people who clicked on a link to get to the website, such as clicking the NKF logo on a Facebook page or any other website. And *direct (none)* mediums in GA, refers to those who used the URL [www.neurosurgerykids.com] directly High-level analysis of what medium is

being used to access the website may be valuable knowledge because users coming from different mediums may interact with the website differently (Beasley, 2013).

All Traffic

Direct Traffic.

In Google Analytics, under the main header of Acquisition, is a report called All Traffic. This report outlines the top ten sources and mediums of how users got to the NKF website. An overwhelming 42.56%, or 1,276, of users were direct (none), meaning they accessed the NKF website via its URL. Of note, Google Analytics does *not* make a differentiation of how many users typed in the URL into their browser each time they came to the site, whether they clicked on an email that had the URL link attached, or whether they had bookmarked the webpage on their computer. This is an important distinction, for example, users who may have clicked on the link via an email from a friend informing them about the NKF website may only have done so because of curiosity – that is, the individual may have clicked the link, arrived at the NKF homepage, decided they are not altogether that interested in exploring any further, and left as a result. This user would have been logged in Google Analytics as a new user, with a very high bounce rate, very low pageviews, very low average session duration, and very low time spent on page. On the other hand, a user who has bookmarked the URL will not yield any information about keywords that they may have used to find the NKF website or the pathway of how they may have arrived at the website. As such, any assumptions made about direct users, should be made with a degree of caution.

Organic Traffic.

Organic traffic using the medium of Google yielded 32.52%, or 975 users suggesting that users may have used keywords such as neurosurgery or NKF, and therefore were directed to the NKF website. This is also a favorable discovery because if the NKF was interested in paying for AdWords (paid search keywords) in the future, it may want to do so on Google versus another medium - Bing generated only 1.37%, or 41 users and Yahoo brought only 1.03%, or 31 users to the NKF website. At the time of this study, the NKF did not have any AdWords with any search engine company.

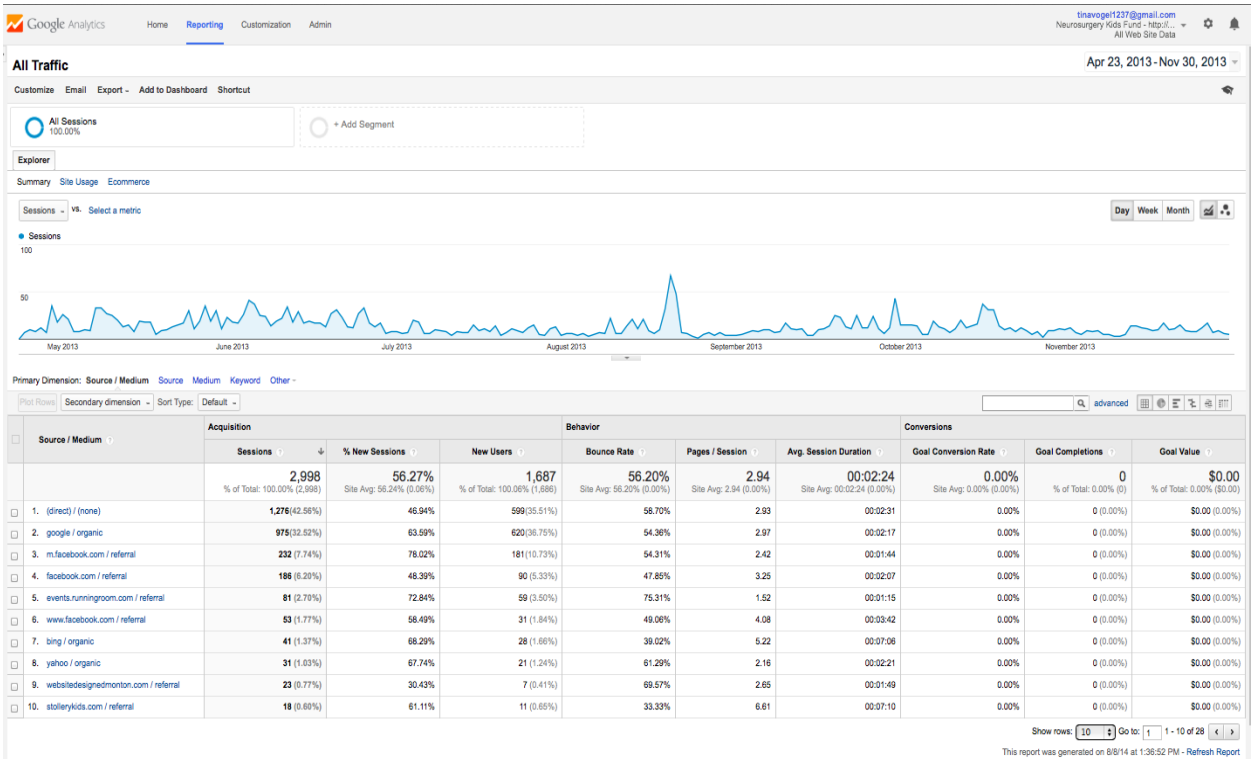


Figure 7: Screenshot of All Traffic report on the NKF website.

Referral Traffic

Referral traffic are visitors who come to the website via a link or alterative source first. For example, these users may have arrived at the website after they had been logged

in on Facebook, saw a link to the NKF website, and clicked on it. In Google Analytics, *m.facebook.com/referrals* are users who used a mobile device whereas *facebook.com/referrals* are users who used a desktop/laptop to link from Facebook to the NKF website. The NKF website garnered 7.74%, or 232 users from Facebook via their mobile devices and 6.20%, or 186 users via their desktop/laptop computers. Three other referral sources of traffic were from the Events page on the NKF website (Running Room fundraiser advertisement), websitedesignedmonton.com (the digital company that was hired to build the website – presumably for their own advertising purposes) and stollerykids.com (The Stollery Children's Hospital Foundation in Edmonton, Alberta who manages the Neurosurgery Kids Fund financial operations). No conclusions can be inferred by these referrals —the Running Room fundraiser was time sensitive to the period analyzed only, and the other two source may only have generated traffic because both may have a personal vested interest in the website. Noteworthy are the 181 of 232 mobile users of Facebook who were also new users, again suggesting the NKF should optimize the user experience on mobiles and tablets. As would be expected, 599 users were new users of the 1,276 total users who used the URL directly, suggesting that the remaining users may have bookmarked the NKF webpage or clicked on a link.

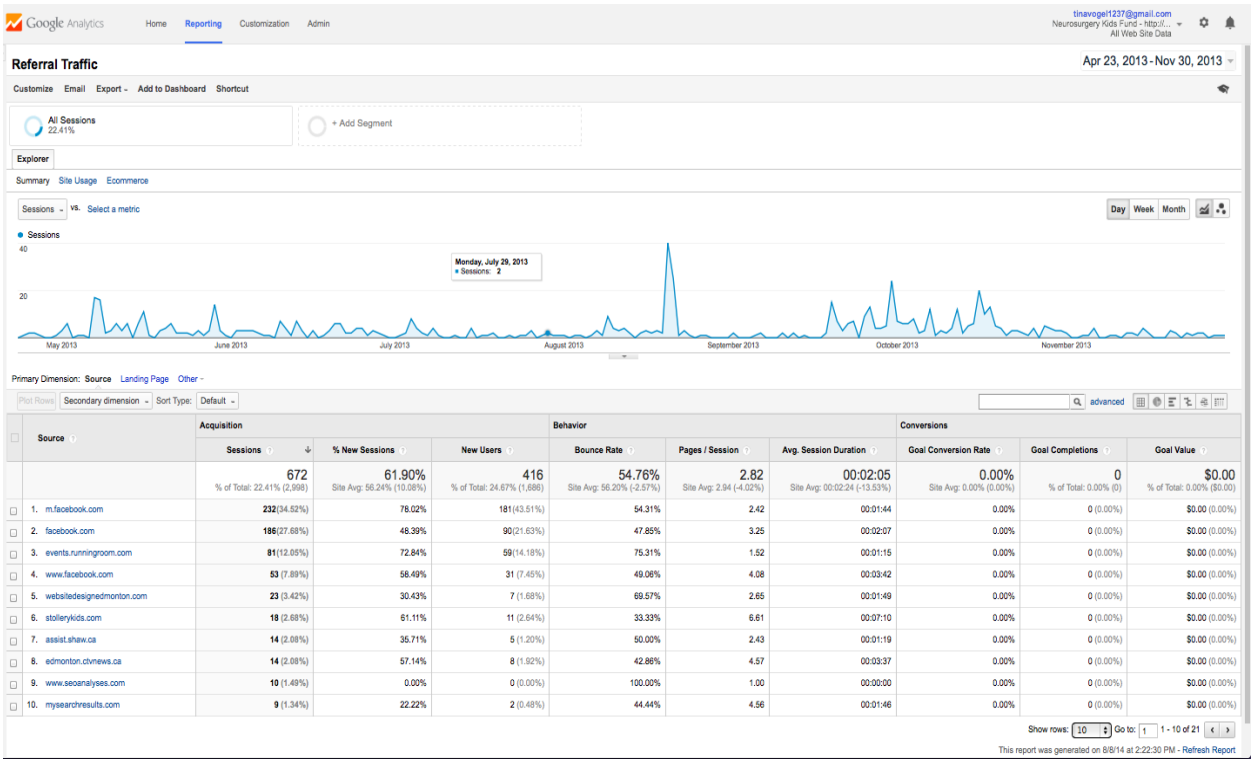


Figure 8: Screenshot of the Referral Traffic report.

Social

Google Analytics offers a distinction between *referral* traffic and *social referral* traffic. In the case of the NKF website, there is a fair amount of overlap as Facebook had high metric values in both overall referral as well as social traffic. Visitors to the NKF website via social referral networks used sources such as Facebook, LinkedIn, and Twitter. Of the total number of sessions on the website (2,998), 480 of those were directed from social networks with Facebook being the most popular at 471 sessions, followed by LinkIn and Twitter with 5 and 4 sessions, respectively. When this metric is analyzed further, Facebook users averaged 2.93 pages per session, Twitter users averaged 3.00 pages per session, and LinkIn users viewed an average of 1.40 pages per session. These values were comparable to the overall website's average pages per session (2.94). What can be deduced

is that social referral traffic were interested enough on the NKF website to explore further than just the Homepage and likely had a fairly clear expectation of what information may be offered on the website. This is all that can be fairly interpreted from these reports and no information about the motivation of the users, whether their information needs were met, or any other conclusions with merit can be made.

However, examining the *Social Users Flow* report may be worth looking at – where did users go on the website after landing on the NKF Homepage? Were the users able to link between the pages with ease? Are there pages that are visited more frequently? Other pages, not at all? Figure 9 shows a basic Social User flow chart but tells us little about the actual connections between the pages – it only depicts how many users visited which pages. By manipulating the level of detail in Google Analytics, one can see in Figure 10 that the pathways between the pages is actually quite promising as there does not seem to be major disconnected pathways or drop-offs, or pages that are omitted altogether. However, making major conclusions about the navigating around the NKF from these flow charts would be an assumption. In-depth analysis of the Navigation summary by a web analyst or user experience professional would offer sounder conclusions, however, following up with other research methods, such as asking users in focus group interviews would also be valuable.

Of significance is that the main tab on the NKF website, *Family Resources*, that is not listed in the user flowcharts as a frequently visited page. This is a major finding, especially when analyzing whether the NKF website has met the information needs of parents. The following open-ended questions may then be asked: Are there difficulties reaching these pages? Are visitors searching only for information about what the NKF is about, how to

make donations, what events are happening, or what the media section has to offer? Do users go elsewhere to find information about specific medical information? The answers to these questions may be found by exploring the content of specific pages or keywords used on the website as well as probing this area in the focus group interviews.

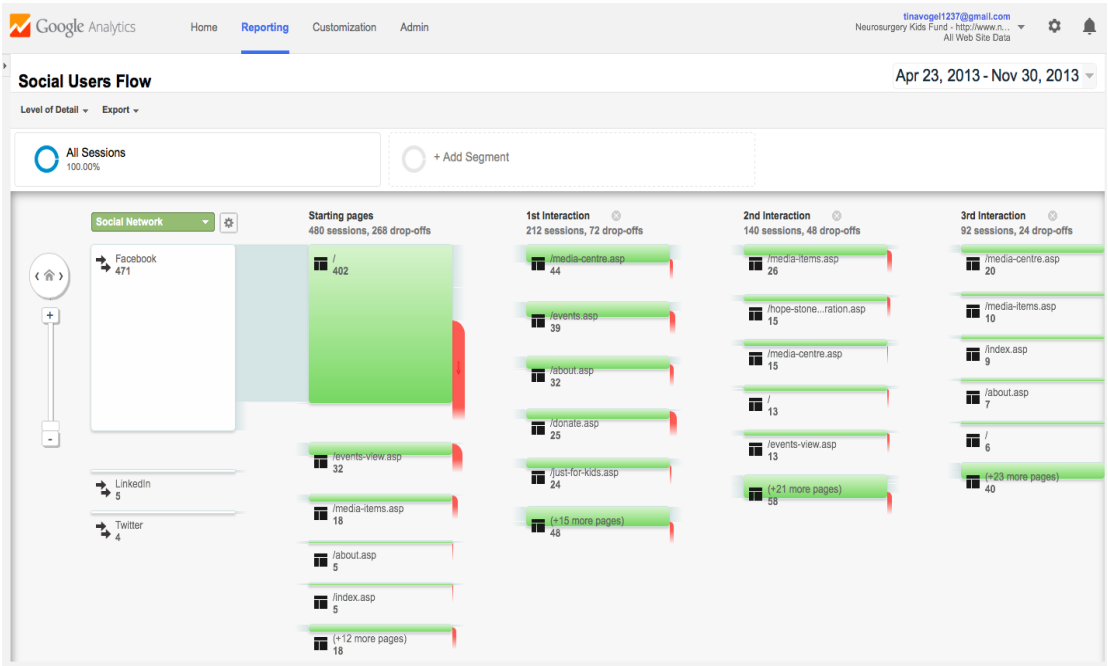


Figure 9: Screenshot of the Social User Flow report without pathways.

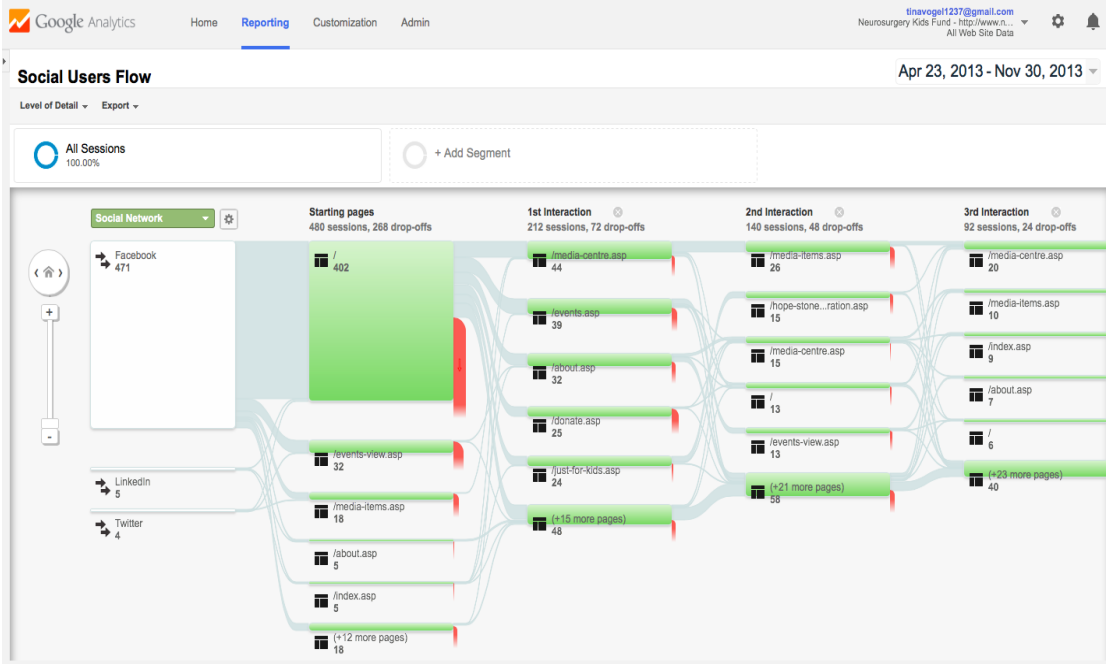


Figure 10: Screenshot of the Social User Flow report with pathways.

Keywords

Analyzing keywords is very important in Google Analytics because it offers an insight into what the users were looking for and the ways they expressed those information needs. Keyword analysis comes in two varieties: *organic* and *paid*. Because there are no paid AdWords for the NKF website, only organic keywords were analyzed. Trying to understand what information needs the user is expressing via their behavior, or what *keywords* they used on the website, may have significant implications in the information architecture or design of the website. Examining the information needs of the end user is vital when analyzing a content-based website. One caveat about web analytics: it can only offer data about the users who used keywords *and* as a result, landed on your webpage. It does not however offer any information about other keywords that users used and *did not* end up on the NKF website – that is, web analytics can not give you information about how

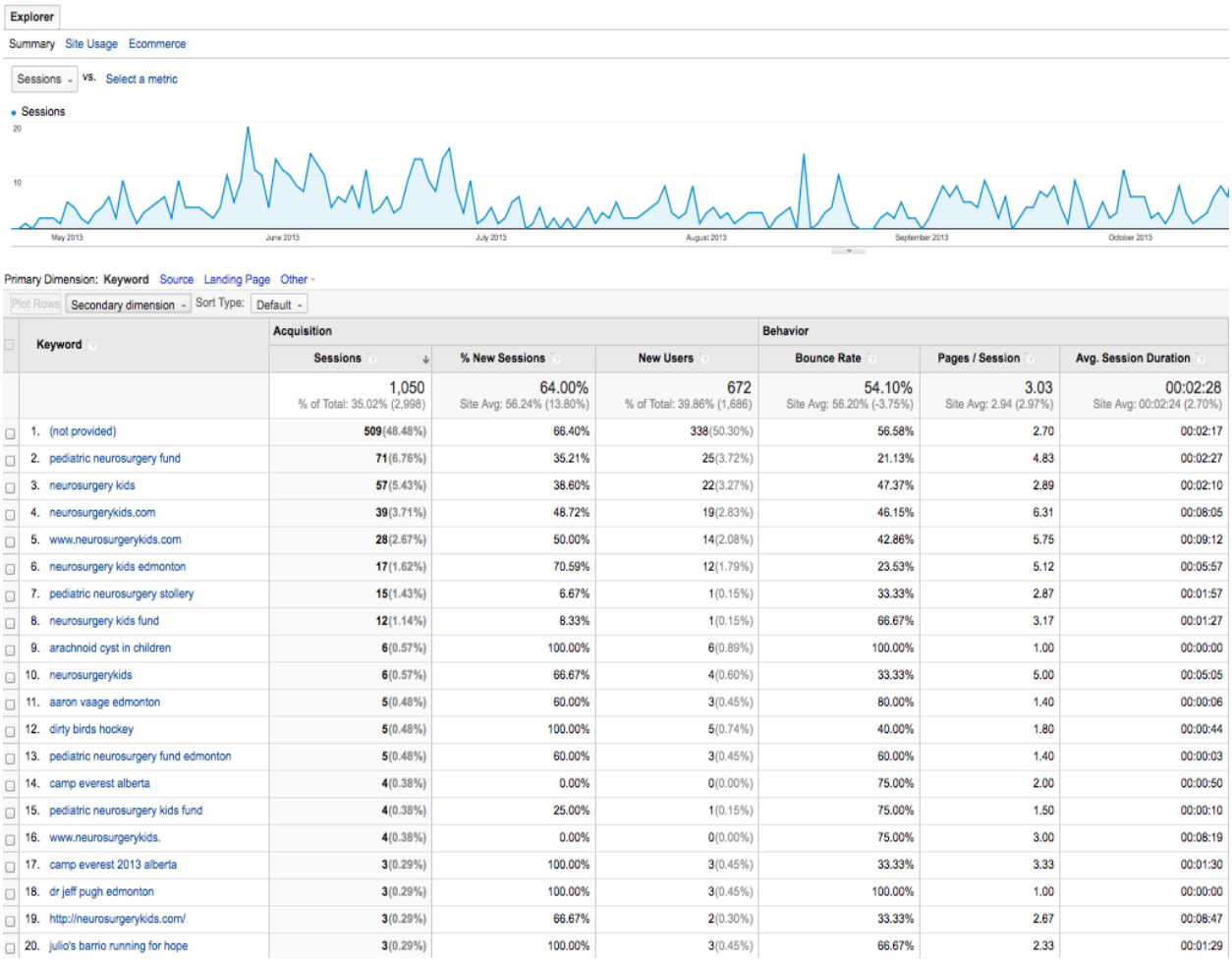
many users were lost in cyberspace who never found your website. This is another reason conducting online survey questionnaires and focus group interviews in this study is important as it may offer a glimpse into how parents came to learn about the NKF website, how they accessed it, and what they were looking for when they got there. In addition, the NKF website was embedded with a *search* window on each of its webpages where users can type in any keywords to direct them to the page where that information may be located. This key feature was embedded in to the NKF website at the time of its development as guided by principles of the Technology Acceptance Model of *ease of use* and *usefulness* – if a website is easier to use, then users may find it more useful and accept using the technology.

Organic Inbound Keywords

Only the top twenty organic inbound keywords will be analyzed because Google Analytic reports for this metric provide the top 249 keywords. The rationale for simplifying it to the top twenty keywords is because there is much repetition after the first twenty results and the keywords numbered 21 to 249 account for less than 0.29% of total sessions. The top ranking search of *"(not provided)"* account for users who linked into the website without using keywords in a search engine and therefore, not helpful in this part of the analysis. More importantly is that "pediatric neurosurgery fund" was listed as the top ranking keyword(s) search with less than a 22% bounce rate which is much better than the overall 56% bounce rate of the whole NKF website. Also, users who used this keyword(s) spent an average session duration time of 00:2:27 on the website which as previously discussed is a good indication that the user found something they were looking for. Variations of the keywords, *pediatric* and/or *neurosurgery* and/or *kids* and/or *fund*

accounted for twelve of the top twenty organic search keywords indicating that the NKF's communication or marketing strategies were effective – users were able to find the NKF website using keywords and stuck around for a while exploring the website. The highest average session duration was 00:09:12 – a high outlier number like this suggests that users who used the specific keyword neurosurgerykidsfund [as a whole] knew exactly what they were looking for and were enticed in the website. The remaining top eight keywords were related to specific fundraisers supporting the NKF that were happening specifically at that time. Only one search included keywords involving one of the pediatric neurosurgeons at the Stollery Children's Hospital in the top twenty.

Just as high value outliers are noteworthy, so are low values or no values on certain metrics, or pages. Interestingly, the NKF website has a distinct separate tab on its Homepage called Family Resources that is dedicated to parents about specific neurosurgical diagnoses, treatment options, and resources, however, only one neurosurgical condition, *arachnoid cyst in children*, was found in the top twenty organic search keywords. Only speculations could be made as to why only this condition was searched for frequently – was this a repeat user who accessed the website multiple times or is this an area of little information in the medical literature available on the internet? This type of information is vital to the development and improvement of the NKF website and will be a topic for further exploration in the focus group interviews - e.g.: why did/didn't you use the NKF website to learn about specific medical diagnoses and treatments? Was it helpful? Where do you search for medical information and resources?



Keyword	Acquisition			Behavior		
	Sessions	% New Sessions	New Users	Bounce Rate	Pages / Session	Avg. Session Duration
	1,050 % of Total: 35.02% (2,998)	64.00% Site Avg: 56.24% (13.80%)	672 % of Total: 39.86% (1,686)	54.10% Site Avg: 56.20% (-3.75%)	3.03 Site Avg: 2.94 (2.97%)	00:02:28 Site Avg: 00:02:24 (2.70%)
1. (not provided)	509(48.48%)	66.40%	338(50.30%)	56.58%	2.70	00:02:17
2. pediatric neurosurgery fund	71(6.76%)	35.21%	25(3.72%)	21.13%	4.83	00:02:27
3. neurosurgery kids	57(5.43%)	38.60%	22(3.27%)	47.37%	2.89	00:02:10
4. neurosurgerykids.com	39(3.71%)	48.72%	19(2.83%)	46.15%	6.31	00:08:05
5. www.neurosurgerykids.com	28(2.67%)	50.00%	14(2.08%)	42.86%	5.75	00:09:12
6. neurosurgery kids edmonton	17(1.62%)	70.59%	12(1.79%)	23.53%	5.12	00:05:57
7. pediatric neurosurgery stollery	15(1.43%)	6.67%	1(0.15%)	33.33%	2.87	00:01:57
8. neurosurgery kids fund	12(1.14%)	8.33%	1(0.15%)	66.67%	3.17	00:01:27
9. arachnoid cyst in children	6(0.57%)	100.00%	6(0.89%)	100.00%	1.00	00:00:00
10. neurosurgerykids	6(0.57%)	66.67%	4(0.60%)	33.33%	5.00	00:05:05
11. aaron vaage edmonton	5(0.48%)	60.00%	3(0.45%)	80.00%	1.40	00:00:06
12. dirty birds hockey	5(0.48%)	100.00%	5(0.74%)	40.00%	1.80	00:00:44
13. pediatric neurosurgery fund edmonton	5(0.48%)	60.00%	3(0.45%)	60.00%	1.40	00:00:03
14. camp everest alberta	4(0.38%)	0.00%	0(0.00%)	75.00%	2.00	00:00:50
15. pediatric neurosurgery kids fund	4(0.38%)	25.00%	1(0.15%)	75.00%	1.50	00:00:10
16. www.neurosurgerykids.	4(0.38%)	0.00%	0(0.00%)	75.00%	3.00	00:08:19
17. camp everest 2013 alberta	3(0.29%)	100.00%	3(0.45%)	33.33%	3.33	00:01:30
18. dr jeff pugh edmonton	3(0.29%)	100.00%	3(0.45%)	100.00%	1.00	00:00:00
19. http://neurosurgerykids.com/	3(0.29%)	66.67%	2(0.30%)	33.33%	2.67	00:08:47
20. julio's barrio running for hope	3(0.29%)	100.00%	3(0.45%)	66.67%	2.33	00:01:29

Figure 11: Screenshot of the Organic Search Traffic and top twenty Organic Search Keyword report.

All Pages

This report in Google Analytics offers information about page-level metrics, such as pageviews, unique pageviews, average time on page, entrances, bounce rates, and percentage of exits. The All Pages report for the NKF site illustrates a fairly typical distribution of the top ten pageviews – the Homepage was the most viewed, with 21.05%, followed by other pages that can be accessed from the homepage with one-click buttons: About NKF (9.55%), Media Centre (7.62%), Join the Community (3.62%), Events3.40%), Just for Kids (2.98%), Donate (2.88%), and Hope Stones (2.82%). Not surprisingly, the

About NKF page garnered a fair amount of pageviews, because the time analyzed in this study overlapped with the time of the launch of the NKF website and inevitably people would have been curious about it. Interestingly, the Media Centre (e.g.: Youtube video link) attracted a large amount of pageviews, with the lowest bounce rate of the whole website at 23.53%, despite there being very little content uploaded at the time – this would suggest media content is of great interest to the users and would be an area for further development on the NKF website.

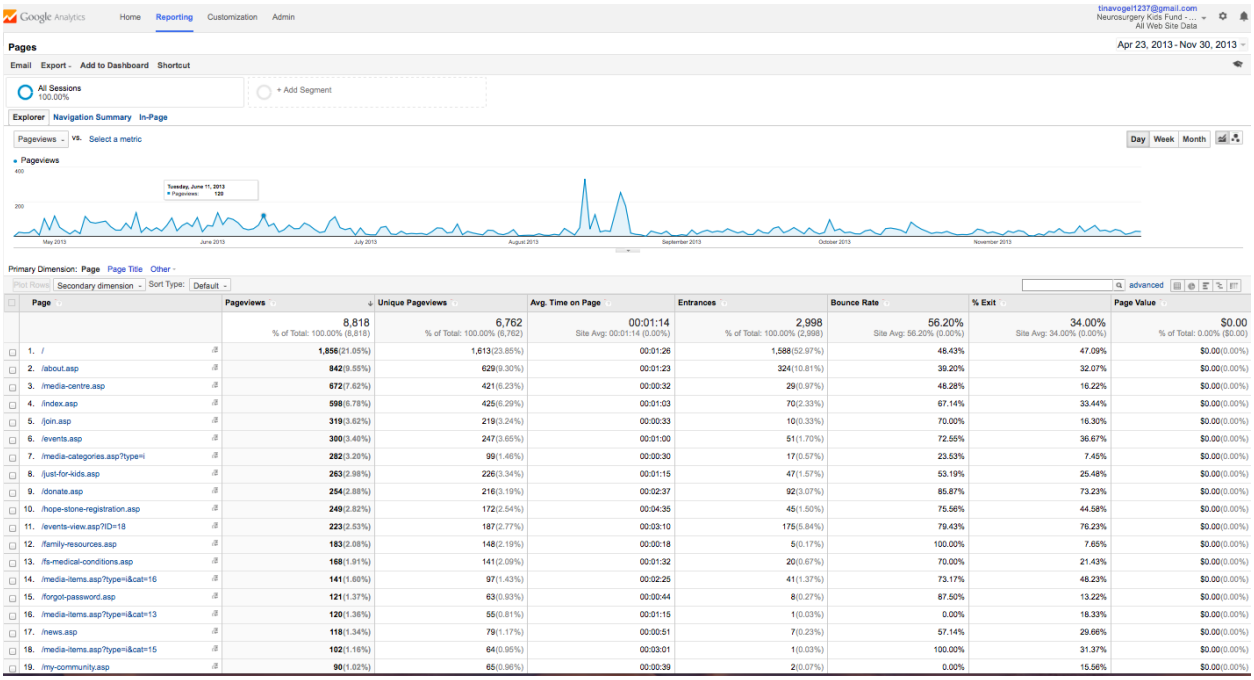


Figure 12: Screenshot of the Pages report.

Entrances

Of note, were the number of *entrances* to the NKF website via the Medical Conditions page which is buried a little deeper within the NKF website. Entrances, also referred to as landing pages, in Google Analytics is the actual page that users enter a website on. As previously discussed when analyzing *organic inbound searches*, users did not typically use any particular medical term to find the NKF website and yet there were 20

entrances on the Medical Conditions page. What can then be extrapolated from this is that users did not use specific diagnoses to arrive at the NKF website, such as brain tumor or shunts, but used a more general term " Medical conditions" to find information about the various neurosurgical diagnoses. These same users also spent 00:01:32 on the website which is favorable and reveals that the users were interested in that particular type of information. This suggests that the NKF website should make neurosurgical Medical Conditions more accessible – and when a page is easier to find, a Google or Bing search will rank those pages higher and therefore offer this information more easily to parents.

Time on Page

Pageview data reveals some clues about whether a page was intriguing to users, but this metric is best paired with another metric such as *average time on page* to really gain a clearer picture of the user's behavior. As previously stressed, in web analytics, pageviews can only reveal how many users viewed the page but not *why* they did. For example, just because a page had many views, does not indicate that the page is a great success, but when it is paired with a higher average time spent on those pages, one can make a sounder conclusion that the high number of pageviews was not simply because of perhaps poor navigational issues (e.g.: users have to click on to it to get to somewhere else) but because the page had some value to the user. Overall, the *average time on page* for the NKF website was rather promising with more than half of all pages measuring over one minute in duration, which is favorable. As aforementioned, this metric is best interpreted in combination with other metrics because other reasons for logging *high*er time on pages may be due to the user actually reading a lot of content or watching a video or podcast, but could also be because the page took a long time to download (e.g.: lots of graphics take

longer to download) or the user had a difficult time finding their way around the page (which typically would be reflected in higher bounce rates). *Lower* average time on a page may be because the content was poorly written, sparse, or didn't match what users thought they were going to get, or because the page was very well organized and users satisfied their needs or goals quickly or the page's purpose was to direct users to another page – a navigation hub (e.g.: the Camp Everest page directs users to the Registration form)(Beasley, 2013).

Pageviews & Unique Pageviews

Unique pageviews is a metric that is useful when viewed in combination with [all] pageviews. Typically, pageviews will be higher than unique pageviews (a new page viewed in that visit), but if there is more than 40-50% of a difference, then perhaps there may be some navigational issues on the website (Beasley, 2013). The NKF website did not have any significant outliers in the *time spent on pages* combined with *pageviews* and *unique pageview* metrics, suggesting that the user's were not flailing around the website searching for something. For example, low time on page combined with high page views and lower unique pageviews would be a red flag that the website has serious design flaws. The NKF ranged from 14-38% difference between pageviews to unique pageviews – suggesting the information architecture of the website is satisfactory.

The majority of the unique pageviews paired with entrances did not reveal anything noteworthy with the exception of the Donate page. The number of unique pageviews for the Donate page was 216 and the users spent a lot of time there at 00:02:37. What is significant is that 92 of those unique pageviews were also the entrances to the website. What this means is that the NKF website should support the task that brought the user to

the website. Unfortunately, the bounce rate for the Donate page was 85.87% suggesting that the platform is not supporting the users in an effective manner. This would be a critical area for improvement on the NKF website.

Percentage of exits

The percentage of exits is a metric that "shows you what portion of pageviews were the last time a user viewed a page" on the website (Beasley, 2013, p. 114). When interpreting this metric, caution should be exercised because it should be analyzed in conjunction with the page's purpose. For example, a higher percentage of exit may be a very appropriate finding for the Hope Stone registration page – the user found the page, completed the order form, and subsequently left the NKF website. As with all metrics, any significant variance from the average would be worth exploring, however, any assumptions made would be weak because analytics can only reveal the quantifiable measurements of the user's behavior but not whether they accomplished the task that they set out to do or whether they found the webpage bogglesome, and simply left in frustration. Usability testing or focus group interviews would highlight these answers more accurately. The NKF did not have major outlier values in this metric.

Site Search & Click-Path Analysis

A valuable metric offered by Google Analytics are the Site Search reports that offer in depth data about the usage of the *site search* feature including specific terms used and what pages were searched for. Unfortunately, the NKF website was not enabled with a site search box feature on its webpages, and thus, was not activated for tracking in Google Analytics. This is a gross oversight on the part of the web designer and adding a site search box should be done immediately. Analyzing what search words the users typed in the

search boxes would have clearly shown what they came to the website to do. Click-path analysis is a good way to explore the Navigation Summary and Visitor Flow reports. These two reports are important for a user experience (UX) professional, however, to perform and interpret because these intricately detailed reports are beyond the scope of the researcher and this study.

Google Analytic reports in this study have illuminated a fair number of suggestions for improvement for design, content, and usability for the NKF website. The various reports and findings have also created a platform for further exploration that will be examined during the focus group interviews and compared with the results from the online survey questionnaire.

APPENDIX B

SCREENSHOTS OF THE NEUROSURGERY KIDS FUND WEBSITE

Figure 13. Homepage of the Neurosurgery Kids Fund website.

Figure 14: Screenshot about the Hope Stones, bead program.

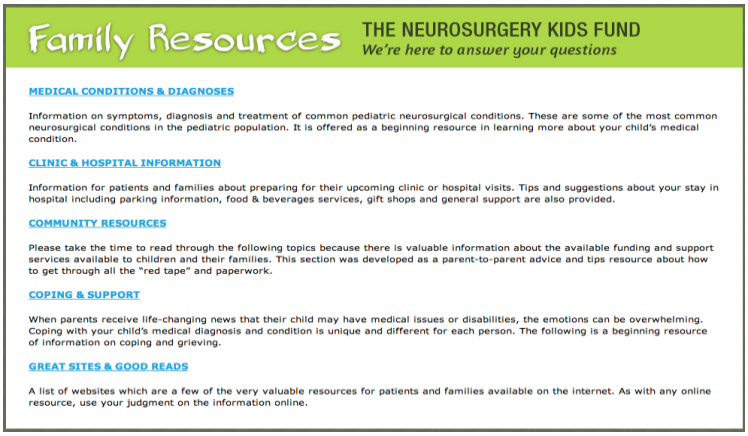


Figure15: Screenshot of Family Resource page.

Figure 16: Screenshot of Camp Everest registration page.

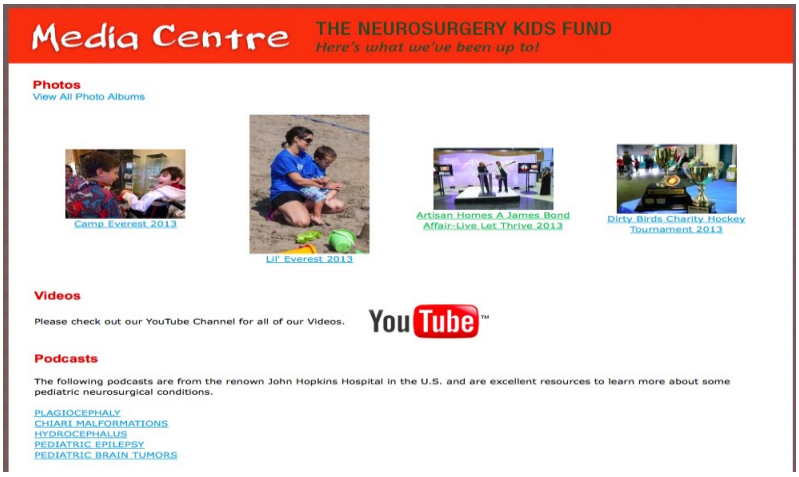


Figure 17: Screenshot of the Media Centre.

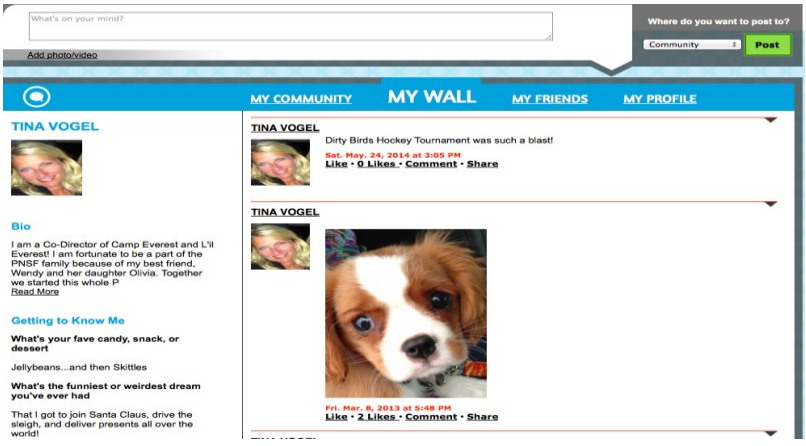


Figure 18: Screenshot of the Join the Community.

APPENDIX C

ONLINE SURVEY QUESTIONNAIRE ADVERTISEMENT & PARTICIPANT INFORMATION SHEET

UNIVERSITY OF ALBERTA

Are you a parent of a child who has had neurosurgery? Have you visited the Neurosurgery Kids Fund website at www.neurosurgerykids.com? We'd like to hear from you! Do you have 5 minutes to go online?

- **Are you a parent of a baby or child who has had neurosurgery at the Stollery Children's Hospital?**
- **Have visited the Neurosurgery Kids Fund website?**
- **Be willing to complete a short online survey questionnaire?**
- **Have access to a computer with basic computer skills.**

TO PARTICIPATE:
Go to: http://fluidsurveys.com/surveys/christina-vogel/evaluation-of-the-neurosurgery-kids-fund-website/
Or go www.neurosurgerykids.com and click on the link for: Evaluation of the Neurosurgery Kids Fund website
Facebook at: https://www.facebook.com/neurosurgerykids and click on the link for: Evaluaton of the Neurosurgery Kids Fund website
Or call Tina Vogel, RN, BScN, MN Student (Researcher) at (780)-983-4705 or email: cakovacs@ualberta.ca
Dr. Shannon Scott, Associate Professor, Faculty of Nursing, University of Alberta (Supervisor) – (780)-492-1037
The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participants rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

UNIVERSITY OF ALBERTA

ONLINE SURVEY QUESTIONNAIRE INFORMATION SHEET

Title of Study: A Pediatric Nurse Practitioner's initiative to support parents of children undergoing neurosurgical care: The Neurosurgery Kids Fund Website Evaluation

Principal Investigator: Dr. Shannon Scott, Associate Professor, Faculty of Nursing, University of Alberta (780) 492-1037

Research Graduate Student: Tina Vogel, RN, BScN, MN Student, Faculty of Nursing, University of Alberta (780) 983-4705

Why am I being asked to take part in this research study? You are being asked to participate in this research study because you are a parent of a child who has had neurosurgery at the Stollery Children's Hospital as well as used the Neurosurgery Kids Fund website.

What is the reason for doing the study?

Canadian children requiring neurosurgery are a small, unique group of kids with highly specialized medical needs. Parents often turn to the Internet as a first step in finding health information about their child's medical diagnosis and condition. Information, support, and resources about pediatric neurosurgery are few, hard to find, and to understand. A pediatric nurse practitioner designed Canadian website (www.neurosurgerykids.com) was created to address this gap. As a result, analyzing the usage of the Neurosurgery Kids Fund website by asking the parents their thoughts and opinions about it is critical to its future development and success.

What will I be asked to do?

You will be asked to go online to www.neurosurgerykids.com and complete an anonymous online survey questionnaire. The first section will ask for information about participant's age, gender, ethnicity, location of residence, and highest level of education. In the second section, participants will be asked about how they find health information online, whether they discuss any health information found online with their health care provider, and overall computer use. The final questions comprise the third section and are specific to the Neurosurgery Kids Fund website. Participants will be asked about the frequency of visits to the NKF website, how they came to learn about the website, the main reason for their visit, and whether their needs or expectations were met from the website. The survey is made up of 19 multiple choice questions and is expected to take 5-10 minutes to complete.

What are the risks and discomforts?

There are no anticipated risks associated with participating in this research study. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant

What are the benefits to me?

You are not expected to get any benefit from being in this research study. This study may help other health care professionals design or develop health websites, or improve on existing ones, to better meet the needs of their patients.

Do I have to take part in the study?
Being in this study is your choice and there is no obligation to participate or answer any specific questions even if you are participating in the study. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the healthcare that your child receives and is entitled to. To withdraw from this study, all you have to do so, exit out of the survey at any time or email the researcher to state your withdrawal. In addition, you can have any collected data withdrawn and not included in the study. Data can be withdrawn up to two weeks after completion.

Will my information be kept private?
During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. All of the data will be protected and held in the Health Research Data Repository (HRDR) in the Faculty of Nursing at the University of Alberta. The HRDR is a secure, confidential online environment that holds health information data. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.
After the study is done, we will still need to securely store your health data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study. If you leave the study, we will not collect new health information about you, but we may need to keep the data that we have already collected.

What if I have questions?
If you have any questions about the research now or later, please contact: Tina Vogel, RN, BScN, MN Student, Faculty of Nursing, University of Alberta. Ph:(780) 983-4705 or Dr. Shannon Scott (Supervisor) at the Faculty of Nursing, University of Alberta. Ph. (780) 492-1037.
If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.
There are no conflicts of interest identified in this study.

By completing and submitting this online survey questionnaire, you are voluntarily implying consent to participate in this research study.

APPENDIX D

FOCUS GROUP INTERVIEW ADVERTISEMENT, PARTICIPANT INFORMATION SHEET, & CONSENT FORM

UNIVERSITY OF ALBERTA

Are you a parent of a child who has had neurosurgery? Have you visited the Neurosurgery Kids Fund website at www.neurosurgerykids.com?

If so, I would like to hear about your experience.

To Participate in this Study you must:

- **Be a parent of a child who has had neurosurgery at the Stollery Children's Hospital**
- **Have visited the Neurosurgery Kids Fund website**
- **Be willing to be interviewed in a small group by the researcher**
- **Feel able to describe your experience using the website**

To participate, please call Tina Vogel, RN, BScN, MN Student (Researcher) – 780-983-4705 or email: cakovacs@ualberta.ca
Dr. Shannon Scott, Associate Professor, Faculty of Nursing, University of Alberta (Supervisor) – 780-492-1037

UNIVERSITY OF ALBERTA

FOCUS GROUP PARTICIPANT INFORMATION SHEET & CONSENT FORM

Title of Study: A Pediatric Nurse Practitioner's initiative to support parents of children undergoing neurosurgical care: The Neurosurgery Kids Fund Website Evaluation
Principal Investigator: Dr. Shannon Scott, Associate Professor, Faculty of Nursing, University of Alberta (780) 492-1037
Research Graduate Student: Tina Vogel, RN, BScN, MN Student, Faculty of Nursing, University of Alberta (780) 983-4705

Why am I being asked to take part in this research study?
You are being asked to participate in this research study because you are a parent of a child who has had neurosurgery at the Stollery Children's Hospital as well as used the Neurosurgery Kids Fund website.

What is the reason for doing the study?
Canadian children requiring neurosurgery are a small, unique group of kids with highly specialized medical needs. Parents often turn to the Internet as a first step in finding health information about their child's medical diagnosis and condition. Information, support, and resources about pediatric neurosurgery are few, hard to find, and to understand. A pediatric nurse practitioner designed Canadian website (www.neurosurgerykids.com) was created to address this gap. As a result, analyzing the usage of the Neurosurgery Kids Fund website by asking the parents their thoughts and opinions about it is critical to its future development and success.

What will I be asked to do?
You will be asked to participate in a small group interview with up to seven other parents of children who have had neurosurgery at the Stollery Children's Hospital in Edmonton, Alberta and who have also used the Neurosurgery Kids Fund website. Your permission will be needed to transcribe the interview using a court reporter to provide an accurate recording of the interview. The court transcriptionist will type out word-for-word the interview to allow the researcher to look for common themes about parents' thoughts, opinions, and usage of the Neurosurgery Kids Fund website.
The group interviews will take place in May/June 2014 and at a time that is convenient for the participants. The group interview will take about 60-90 minutes. The participant will not be paid and there will be no cost to the participant, other than your time.
Before you make a decision one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What are the risks and discomforts?
A potential benefit of study participation includes the freedom to share your experience when trying to find health information about your child's neurosurgical condition as well as how or why you used the Neurosurgery Kids Fund website in a confidential arena. It is recognized that some parents may not feel comfortable talking about their child's neurosurgery experience or medical journey. As well, discussing personal opinions or perspectives related to information

gathering, resources, or support needs may be distressing to some parents. If counseling is requested, this will be addressed on an individual basis and local resources can be explored. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?
This study may help other health care professionals design or develop health websites, or improve on existing ones, to better meet the needs of their patients. You are not expected to get any direct benefit from being in this research study.

Do I have to take part in the study?
Being in this study is your choice and there is no obligation to participate or answer any specific questions even if you are participating in the study. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the healthcare that your child receives and is entitled to. In addition, you can have any collected data withdrawn and not included in the study. Data can be withdrawn during or after the interview for up to two weeks. Any data that can identify you will be destroyed. Please feel free to let any one of the researchers know if you would like to withdraw. A follow-up phone call or email will be done to check on your wellbeing afterwards.

Will I be paid to be in the research?
You will not be paid to participate in this study. You will be offered a $10.00 Starbucks coffee giftcard as a show of gratitude for your time. Any parking costs incurred by the participant will be reimbursed up to $15.00 each with a receipt provided. Even if you withdraw, you will have parking cost reimbursed as well as being offered the coffee gift card.

Will my information be kept private?
During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. All of the data will be protected and held in the Health Research Data Repository (HRDR) in the Faculty of Nursing at the University of Alberta. The HRDR is a secure, confidential online environment that holds health information data. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private

After the study is done, we will still need to securely store your health data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study. If you leave the study, we will not collect new health information about you, but we may need to keep the data that we have already collected.

Every attempt will be made to ensure your confidentiality while participating in this group interview study. The researcher will review at the beginning of each interview the importance of protecting everyone's right to privacy and to not share any information to anyone outside the study.

What if I have questions?
If you have any questions about the research now or later, please contact:

Tina Vogel, RN, BScN, MN Student, Faculty of Nursing, University of Alberta. Ph:(780) 983-4705 or Dr. Shannon Scott (Supervisor) at the Faculty of Nursing, University of Alberta. Ph. (780) 492-1037.

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

There are no conflicts of interest identified in this study.

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FOCUS GROUP PARTICIPANT CONSENT FORM

Title of Study: A Pediatric Nurse Practitioner's initiative to support parents of kids undergoing neurosurgical care: The Neurosurgery Kids Fund Website Evaluation

Principal Investigator: Dr. Shannon Scott, Associate Professor, Faculty of Nursing, University of Alberta. Phone number: (780) 492-1037

Researcher Graduate Student: Tina Vogel, RN, BScN, MN Student, Faculty of Nursing, University of *Alberta. Phone number: (780) 983-4705*

	YES	NO
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time without having to give a reason and without affecting your child's future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records (including personally identifiable health information)?	☐	☐

Who explained this study to you?

I have read and understood this consent form and I agree to take part in this study:
Signature of Research Participant: _____

(Printed Name) : _____ Date: _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Researcher_____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX E

ONLINE SURVEY QUESTIONNAIRE

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Online Survey Questionnaire

Evaluation of the Neurosurgery Kids Fund website

There are 20 multiple-choice and check box questions in this online survey questionnaire. The time to complete the survey should take about 5-10 minutes. By completing and submitting this survey, you are voluntarily consenting to participate. Once you have submitted your answers, you can not change or withdraw your answers.

Question 1
What is you role in this child's medical care?

- ○ Parent
- ○ Guardian or primary caretaker
- ○ Other

Question 2
What is your gender?

- ○ Female
- ○ Male

Question 3
What is your age?

- ○ 18-25 years
- ○ 26-35 years
- ○ 36-45 years
- ○ 46-55 years
- ○ 56+ years

Question 4
What is your highest level of education?

- ○ University or college degree/diploma
- ○ Some university or college
- ○ High school graduate or equivalent (GED)
- ○ Did not finish high school

Question 5
Which is the following that best describes your race or ethnicity?

- ○ Caucasian
- ○ First Nations, Metis, or Inuit
- ○ African Canadian
- ○ Asian or Pacific Islander
- ○ Hispanic
- ○ Other

Question 6
Which province do you live in?

- ○ Alberta

- ○ British Columbia
- ○ Northwest Territories, Nunavut, & Yukon
- ○ Saskatchewan
- ○ Other

Question 7
Where is the location of the nearest computer you can use?

- ○ At home
- ○ At work
- ○ At the hospital
- ○ At a public library
- ○ At a friend or family's location
- ○ Other

Question 8
On average, how many hours a DAY (both at home and work) do you check for email or use the Internet?

- ○ 0 to 1 hour
- ○ 2 to 4 hours
- ○ 5 or more hours
- ○ Other

Question 9
Which of the following health information resources do you use? Please check ALL that apply.

- ○ Healthcare providers
- ○ Family members or friends
- ○ Health websites
- ○ Medical journals
- ○ Print media (newspapers/books/magazines/pamphlets/brochures)
- ○ Other

Question 10
Do you find it easy or difficult to read health information on a computer compared to a book or pamphlet?

- ○ Very easy
- ○ Somewhat easy
- ○ Neither easy or difficult
- ○ Somewhat difficult
- ○ Very difficult

Question 11
How did you come to learn about the Neurosurgery Kids Fund website? Please check ALL that apply.

- ○ From an Internet search
- ○ From medical staff at a clinic or hospital visit
- ○ From family or friends

- From a local TV program, radio, newspaper, etc.
- I am not familiar with this website
- Other

Question 12
What was the MAIN reason you visited the website?

- To find more health information about my child's diagnosis or condition?
- To find out more about Camp Everest or L'il Everest Camp
- To make a donation to the Neurosurgery Kids Fund
- To learn about upcoming events or news related to the Neurosurgery Kids Fund
- To find social support or resources
- To get my child their Hope Stones
- To generally check out the website
- Other

Question 13
Did you find what you were looking for when you visited the Neurosurgery Kids Fund website?

- Yes
- No

Question 14
Overall, was the information on the Neurosurgery Kids Fund website easy or difficult to understand?

- Very easy
- Somewhat easy
- Neither easy or difficult
- Somewhat difficult
- Very difficult

Question 15
How did you use or plan to use the health information that you found on the Neurosurgery Kids Fund website? Please check ALL that apply:

- Discussed, or plan to discuss with my child's doctor, nurse practitioner, or other medical personnel involved in my child's care.
- Discussed, or will discuss with family and/or friends
- Has improved my understanding of my child's condition, surgery, or illness.
- Has influenced, or may influence future health decisions for my child
- Have contacted, or will contact a support group
- Looked for, or will consider looking for more health information online
- Other

Question 16
Please rate your level of agreement with the following statement: The health information I received on the Neurosurgery Kids Fund website added to what my child's doctor, nurse practitioner, or other medical personnel told me about my child's condition, surgery, or illness?

- Strongly agree

- ○ Somewhat agree
- ○ Neither agree or disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Question 17
If you have NEVER visited the Neurosurgery Kids Fund website, please tell us the reason(s). Please check ALL that apply:

- ○ I do not have access to a computer
- ○ I do not use the Internet because it is too complicated
- ○ It is difficult for me at times to understand written health information
- ○ I prefer print resources such as books or pamphlets
- ○ English is not my first language
- ○ I prefer another Internet source for health information rather than the Neurosurgery Kids Fund website.
- ○ Other

Question 18
What was you favourite part(s) of the Neurosurgery Kids Fund website? Please check ALL that apply:

- ○ Health information
- ○ Camp Everest and L'il Everest information
- ○ Social support and resources
- ○ Hope Stones
- ○ News and events
- ○ Join the Community
- ○ Attractiveness, design, and layout
- ○ Ease of use
- ○ Canadian content
- ○ Donation information
- ○ Other

Question 19
I plan to use the Neurosurgery Kids Fund website in the future.

- ○ Yes
- ○ No
- ○ Not sure

Question 20
Are there any suggestions or comments that you would like to tell us about the Neurosurgery Kids Fund website? Please explain:

APPENDIX F

GLOSSARY GOOGLE ANALYTICS TERMS

Glossary of Google Analytic Terms
(Source: Beasley, 2013; Ledford et al., 2010).

Bounce Rate: Single page view visits divided by entry pages. It can be calculated for a specific page or group of pages. A site wide bounce rate represents the percentage of total visits that were single page view visits.

Exit Page: The last page on a site accessed during a visit, signifying the end of a visit/session.

Landing (entrances) Page: A page intended to identify the beginning of the user experience resulting from a defined marketing effort.

Medium: derived category containing one or more sources of the same type (e.g., "organic search" being the medium that contains Google or Bing).

Metric: unit of measurement

New Visitor: The number of Unique Visitors with activity including a first-ever Visit to a site during a reporting period.

Organic: people who used a search engine to find the website but did not click on one of the ads.

Page: A page is an analyst definable unit of content.

Page Views: The number of times a page (an analyst definable unit of content) was viewed.

Referrer: The referrer is the page URL that originally generated the request for the current page view or object.

Return Visitor: The number of Unique Visitors with activity consisting of a Visit to a site during a reporting period and where the Unique Visitor also Visited the site prior to the reporting period.

Source: specific place that a user came from (e.g., Facebook, Google).

Unique pageview: The total number of unique visitors to a given web page during the same session.

Unique Visitor: The number of inferred individual people (filtered for *crawlers*), within a designated reporting timeframe, with activity consisting of one or more visits to a site. Each individual is counted only once in the unique visitor measure for the reporting period.

UX: acronym for user experience that describes the practice of utilizing user research and design techniques.

Web analytics: a way of learning how users interact with websites and mobile apps by automatically recording aspects of users' behavior and then combining and transforming the behavior into data that can be analyzed.

Visits: A visit is an interaction, by an individual, with a web site, consisting of one or more requests for an analyst-definable unit of content (i.e. "page view"). If an individual has not taken another action (typically additional page views) on the site within a specified time period, the session will terminate.

Visit Duration: The length of time in a session. Calculation is typically the timestamp of the last activity in the session minus the timestamp of the first activity of the session.

APPENDIX G

SCREENSHOTS OF THE GOOGLE ANALYTICS REPORTS FOR THE NEUROSURGERY KIDS FUND WEBSITE

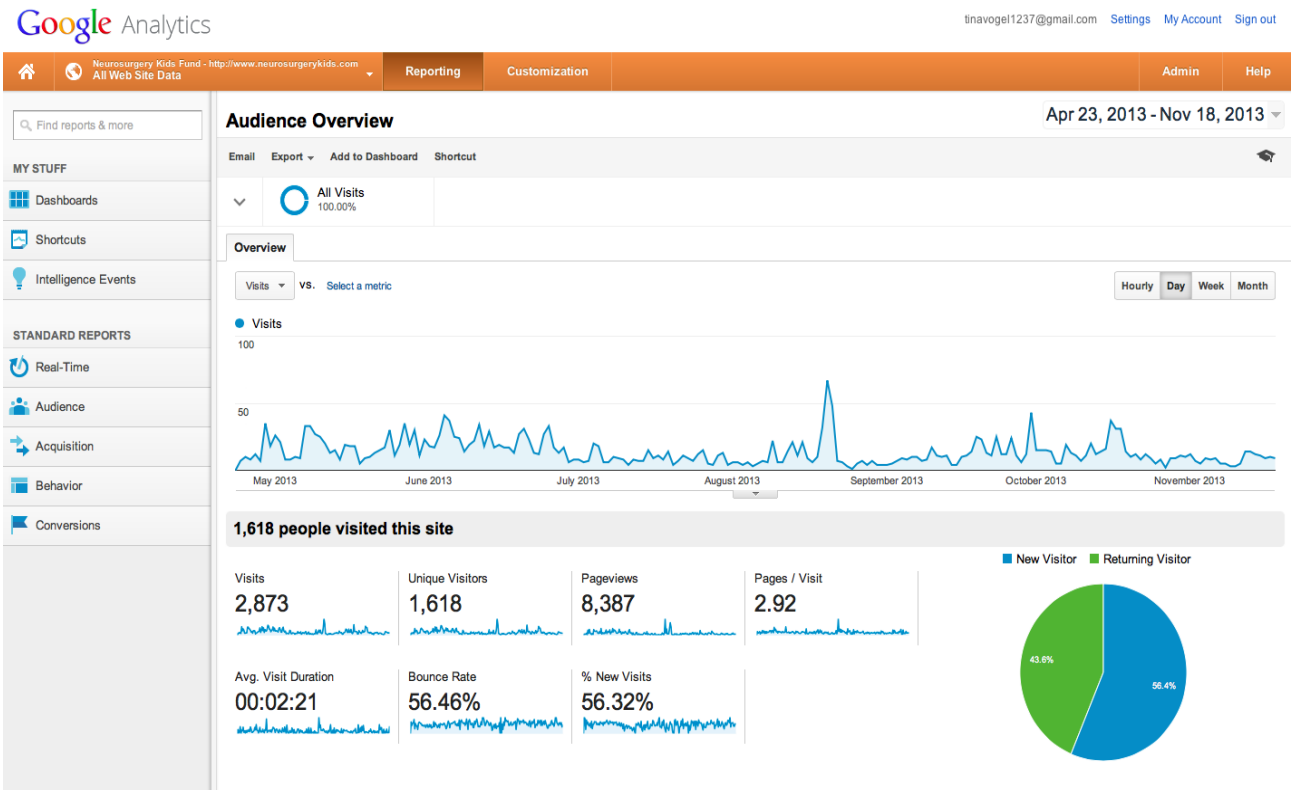

Figure 19: Screenshot of the Audience Overview of the NKF website.

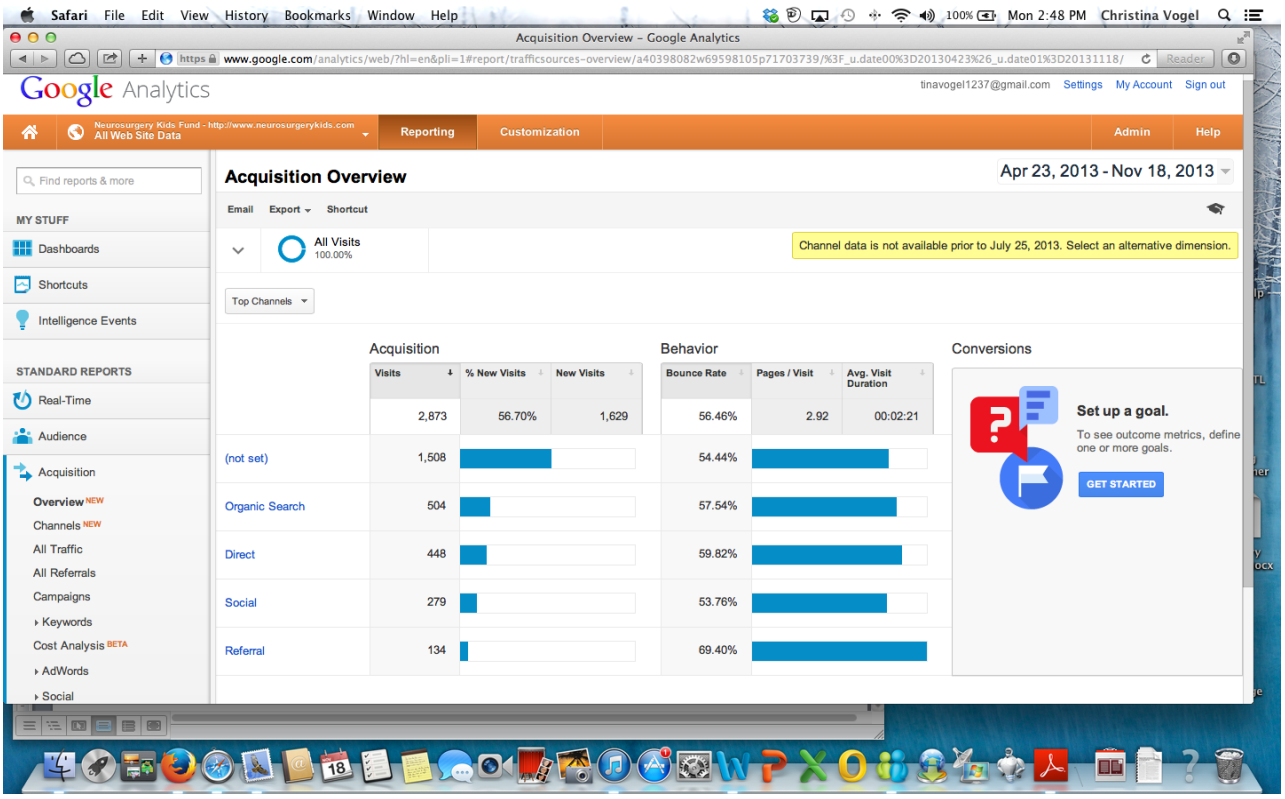

Figure 20: Screenshot of Acquisition Overview of the NKF website.

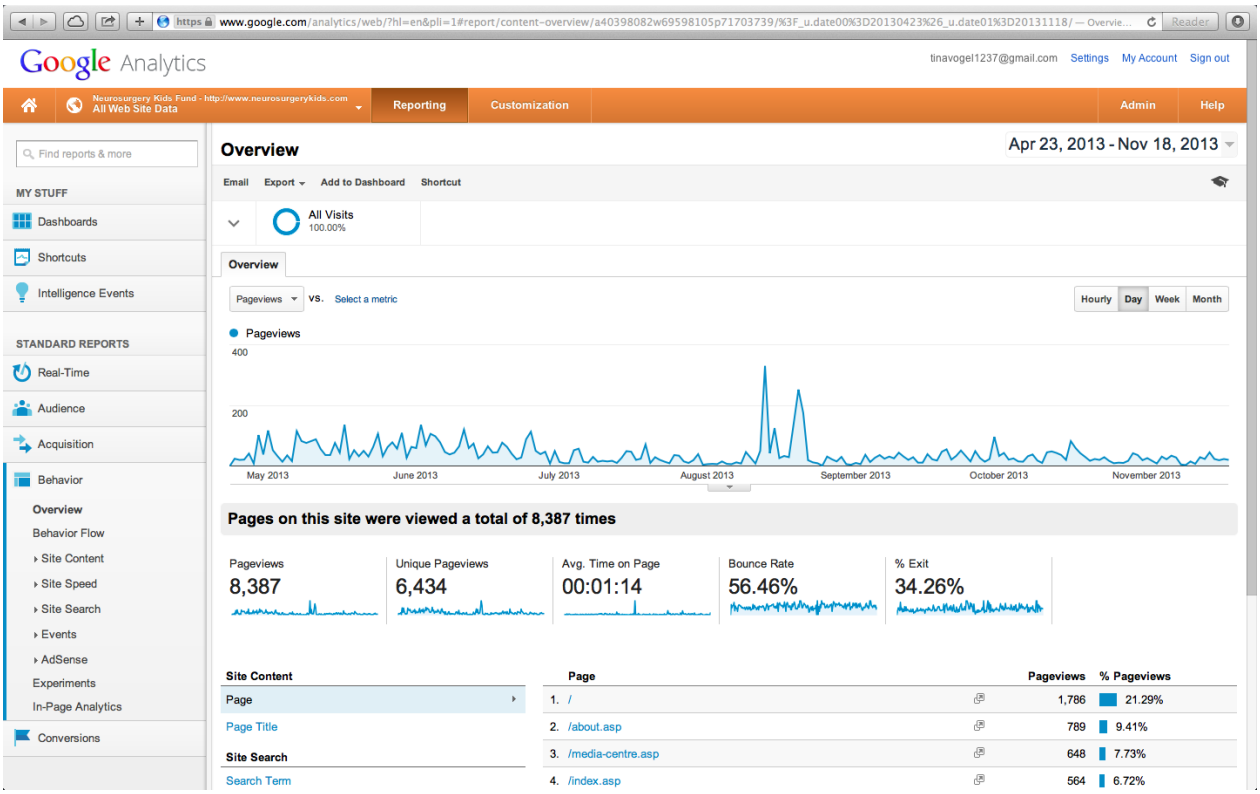

Figure 21: Screenshot of Behavior Overview of the NKF website.

APPENDIX H

SEMI STRUCTURED INTERVIEW QUESTIONS

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Guiding Focus Group Interview Questions

I have collected statistics about how people are using the NKF website. Those numbers have helped me get an idea of ***how*** people are using the website but it doesn't tell me ***why*** or ***what*** people are using the website for. This is what I'd like to ask you about today. To begin:

1. Tell me about your experience as parents of children who have had neurosurgery looking for information? What kind of information are you looking for?

2. What prompted you to use the Neurosurgery Kids Fund website?

3. Tell me about your experience with using the Neurosurgery Kids Fund website?
    a. What did you think of the website in general? Design?
    b. How did you find getting around the different pages?
    c. What were the things you liked or found useful about the website? Tell me about them.
    d. Was anything on the website not useful or something about it you didn't like?
    e. If you could suggest for improvements on the website, what would that be?

4. Has using the NKF website influenced you as a parent of a child with health concerns?

5. I am going to share with you some of the statistics about our website. I would like you to share your perception about them.
    a. Why do you think the Medical Conditions pages were seldom viewed?
    b. Why do you think the numbers show that a lot of traffic is going to Camp Everest? Poor traffic to Join the Community?