Patient portal engagement at a pediatric office:

Reasons why individuals are not using the portal.

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Dedication

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Abstract

This descriptive study explores the reasons individuals bringing their child(ren) to the pediatric office are not using the patient portal. There was negligible use of the patient portal as shown by a retrospective review of data usage reports via the eClinicalWorks software. Additionally, staff reported that they still answered many calls for information (immunization records, lab results, medication refills, appointment scheduling, and care-related questions), all of which were easily obtained through the portal. The objective of this study is to determine the reasons why individuals bringing the child(ren) to a rural pediatric practice in Central Pennsylvania are not using the patient portal. The scope of the survey is broad, as overall knowledge of the patient portal and its capabilities is assumed to be low based on current usage data. A convenience sample of individuals was pursued. The survey questions focused on the potential contributing factors to the individual's lack of portal usage. Demographic data were obtained as part of the survey to identify the characteristics of the participants. The results revealed that the lack of patient portal usage/engagement would be responsive to change with some practice planning and education.

Chapter 1

Introduction

Portal is a term, commonly synonymous with a gateway for a World Wide Web. It is the initial site for individuals to connect to the Web or to visit as an anchor site (TechTarget, (n.d.). There are various types of portals, including general and niche portals. Patient portals are an example of a niche portal.

> Patient portals not only provide access to parts of the individual's health records, but also offer services such as customized educational materials, messaging, prescription requests, and appointment scheduling. U.S. healthcare organizations are using patient portals more and more as a way to provide patients with partial access to their health records while complying with the "meaningful use" of the Health Information Technology policy released by the Federal Government (Nambisan, 2017).

Direct access allows individuals to be proactive in their healthcare, while the centralized records system facilitates operational efficiencies within the provider's office (Ahlers-Schmidt & Nguyen, 2013). This is noteworthy as "Pediatricians in the United States are caring for children with mounting rates of chronic disease and complex medical needs" (Ray, Bogen, Mehrata & Miller, 2015, p. 622). To assist with managing the growing number of patients, many pediatricians are increasingly using patient portals within their practice. However, studies examining the adoption rates of patient portals have reported limited adoption and use by individuals, especially among the medically underserved population (Nambisan, 2017).

The objective of this study is to generate findings to determine the reasons why individuals are not using the patient portal at a pediatric office in rural, central Pennsylvania.

Background of the Problem

With the continued focus on personal health records, patient portals, portal engagement (usage), patient-centered care, and the management of one’s health, features of the patient portal are rather compelling. Various studies have reported patient portal benefits such as improved communication between the provider and patient, greater responsibility for one's wellness and disease management, convenience with use (i.e., the portal can be accessed and used 24/7), and decreased call volumes and wait times with the provider and patient. Combine these aspects with the fact that approximately 68% of adults in the United States have a smartphone and 45% of adults have a tablet (Yen, Walker, Smith, Zhou, Menser, McAlearney, 2017), non-usage remains a challenge.

According to Showell (2017), barriers can interfere with various aspects of portal adoption by individuals, including the choice to start using the portal; continued use of the portal; and the various barriers encountered at different phases of portal adoption. A solid understanding of the barriers is vital to understand why individuals are not using the patient portal within a healthcare setting.

The patient portal can be an effective means to facilitate self-management for individuals and the health of their child(ren). However, not all individuals are utilizing this electronic resource (Powell & Myers, 2018). Perceived barriers commonly cited by individuals for not using the patient portal begin with difficulty accessing the patient portal. This may be due to password, computer, or server problems. Some individuals forget the password; have too many passwords to remember; encounter problems with the screen freezing, or the inability to access the portal the first time they try to sign-in. The combination of frustration with the portal and busy schedules may contribute to individuals not coming back to the patient portal to try again

(Powell & Myers, 2018). Others report that the portal features are not beneficial; they did not know that the portal features existed, or did not have access to disease-specific information to better understand their child(ren)'s health issues. Some users prefer to interact with the staff member or the provider versus a portal; others favor talking on the phone; and even some wish to ask providers a question in person (Powell & Myers, 2018).

Population demographics may significantly influence patient portal adoption as disclosed in an article from the *Journal of the American Board of Family Medicine.*

> The researchers found that patients who were male, non-white, Hispanic, Spanish-speaking, and lower-income were less likely to adopt patient portals than their female, white, and higher-income cohorts. Uninsured patients or those insured through Medicare or Medicaid were also less likely to adopt patient portals than patients with private insurance (Heath, 2016, para. 3).

Provider-specific barriers to portal promotion within the organization include obstacles such as staff not having time to assist individuals with sign-in procedures or teaching the various aspects of the portal to encourage future use; reimbursement concerns, including integrating the portal into the payment structure; and, administrative difficulties (Powell & Myers, 2018). At the center of this study is the effort to understand the reasons why portal usage remains negligible at the pediatric practice in rural, central Pennsylvania.

The theoretical model serving as the foundation for this study is *The Technology Acceptance Model (TAM).* Application of the model is most significant with its relevance in forecasting and describing the end users' reactions to health information technology such as the patient portal (Holden & Karsh, 2010).

Variables of the Technology Acceptance Model (TAM) support the scope of this study as it addresses health information technology broad themes such as behavior, usage, intention, attitude, perceived ease of use (PEOU), perceived usefulness (PU), perceived behavior control (PBC), and behavioral benefits (including normative and control beliefs) with information technology (Holden & Karsh, 2010).

The creators of the model maintain that to increase usage, providers must know what the individuals’ intentions are to use the technology. TAM has been applied to survey development questions with the goals of not only identifying the end users future intentions to use the technology but to give the organization information to direct factors to promote acceptance and use of the technology.

The Statement of the Problem

Pediatric medicine is projected to benefit from the use of telehealth technology (e.g., portals) by improving patient access to care in medically underserved rural areas. This technology also extends the reach of pediatric subspecialists at academic and tertiary medical centers to patients and colleagues in more distant community hospitals and clinics (Utidjian & Abramson, 2016). The objective of this study is to identify the reasons why individuals are not using the patient portal at a pediatric office in rural, central Pennsylvania.

Significance of the Problem

Patient portals provide access to medical information and allow individuals enhanced communication with their providers while promoting self-management practices. As several studies have established the benefits of the patient portal within the adult population, less is known about whether parents/legal guardians perceive electronic tools as helpful in managing their child(ren)'s health care (Britto, Hesse, Kamdar, & Munafo, 2013).

Based on the results of a national survey in conjunction with the C.S. Mott Children's Hospital National Poll on Children's Health (NPCH), pediatric providers may find that roughly half of their parents have positive perceptions about utilizing patient portals while the other half of parents may choose not to engage in portals (Clark, Costello, Gebremariam, & Dombkowski, 2015). Even when providers make considerable attempts to promote portal use among parents and offer technical support, it is likely that they will need to continue to offer support to foster portal engagement (Clark, Costello, Gebremariam, & Dombkowski, 2015). Further highlighting the challenge of individuals adopting patient portals into their daily lives is the 2017 Government Accountability Office (GAO) report underlining ninety-percent of providers offer patient portal access, with less than one-third integrating the tool and even less reporting regular use (Heath, 2018, para. 4).

For this reason alone, it is imperative for pediatricians to identify the barriers that keep individuals within their practice from using the portal.

Need for the Study

Patient portals grant individuals access to personal medical data, while presenting opportunities to improve knowledge, competence, productivity, and engagement in health care (Ancker, Snezana, Osorio, Cole, Silver, Kaushal, 2015).

Developments with the Health Information Technology for Economic and Clinical Health Act (HITECH) are aimed at facilitating improvement in the delivery of health care by incentivizing the implementation of electronic health records (EHR). "In stage 1, health care professionals must demonstrate meaningful use by providing patients with timely online access to their health information" (Lanzo, Taeger, Huston-Paterson, Tomaszewski, Trent, 2016, p. S18).

Once promised to revolutionize health care, patient portals have yet to reach their potential of improving communication and partnership between patients and clinicians. This study aims to identify the factors affecting the low patient portal engagement within a pediatric practice in rural, central Pennsylvania.

Research Question

The research question guiding this study: What are the reasons why individuals are not using the patient portal at a pediatric office in rural, central Pennsylvania?

Hypotheses

The research (directional) hypothesis for this study:

- Null hypothesis (Ho): Individual lack of awareness about the patient portal is not a primary factor for low patient portal usage
- Alternative hypothesis (HA): Individual lack of awareness about the existence of the patient portal is the primary factor for low patient portal usage.

Definition of Terms

The word **engagement** "describes everything from patient portals to social media strategies, from tracking vitals with wearables to patients actively participating in their health and wellness" (Noteboon, 2015, para. 3). Patient engagement combines the patient's knowledge, skills, ability, and willingness to manage one's health (Noteboon, 2015).

“A **patient portal** is a secure online website that gives patients convenient, 24-hour access to personal health information from anywhere with an Internet connection. Using a secure username and password, patients can view health information” (HealthIT.gov, (n.d.), para. 1). Some patient portals also allow the user to securely message the provider; request prescription refills; schedule non-urgent appointments; update contact information; make payments; download and complete forms; and view educational materials (HealthIT.gov,(n.d.), para. 2).

The **individual (participant)** in this study is identified as the person bringing the child(ren) to the appointment the day the survey is completed. This may include, but may not be limited to the following titles: parents, grandparents, legal guardians, aunts, uncles, friends, sibling over 18 years of age, or other.

The **pediatric patient** is the patient (birth to 18 years of age) under the care and medical supervision at the pediatric practice and the child(ren) visiting the office the day the survey is completed.

Assumptions of this study include:

- Pediatricians, physician assistants, nurses, medical assistants, and other staff members will positively promote the participation in the study
- Individuals bringing the children to the office will want to participate in the survey to identify the reasons why they are not using the patient portal
- The survey results will provide a foundation for practice changes and educational interventions with the aim of increasing patient portal usage

Limitations of this study include:

- It is a single-site study
- Individuals completing the survey may not be representative of the population and end users of the portal
- Sample size may not readily generalize to broader pediatric populations
- The timeframe to collect survey data may not be sufficient and may not account for seasonal differences in the number of visits to the practice (e.g., summer versus fall volumes)
- The use of only paper-based surveys may have impacted the sample size as a more significant number of participants may have been achieved through the use of an electronic survey posted on the pediatric practice website
- Some participants selected more than one answer when they should have only chosen one answer per question

Summary of the Problem

The patient portal use within the pediatric practice is negligible despite its existence since 2014. Individuals still routinely call the office to request immunization records, lab results, medication refills, schedule appointments, and ask care-related questions. All of these concerns can be addressed via the patient portal. The objective is to generate findings to determine the reasons why individuals are not using the patient portal at a pediatric practice in rural, central Pennsylvania.

Chapter 2

In the review of the literature, the following areas of research were addressed: portals, patient portals, the benefits of patient portals, and why individuals do not use portals (potential barriers), all of which will serve as the foundation for this study.

Web portal. A web portal is a term, generally synonymous with *a gateway*, for a World Wide Web and is the initial site for individuals to connect to the Web or to visit as an anchor site. There are general and niche (specialized) portals (TechTarget, (n.d.), para. 1). Patient portals are an example of a niche portal.

Patient portal. The patient portal not only provides access to parts of the individual's health records, but also offer services such as customized educational materials, messaging, prescription requests, and appointment scheduling (Nambisan, 2017). Healthcare organizations in the United States are increasingly using patient portals as a means to provide patients with partial access to their health records and thereby comply with the “meaningful use” of Health Information Technology policy issued by the U.S. Federal Government. For these reasons alone, the use of patient portals continues to expand, and sustained momentum is crucial.

Patient portal perceived benefits. The patient portal may influence care delivery for individuals and ease access to services, which may have a positive impact on satisfaction as well as the way the individual seeks care for their child(ren).

Patient portals allow individuals access to personal account information and health records in an asynchronous (self-service) matter providing direct access to patient registration, scheduling, past medical and surgical history, medications, immunizations, laboratory and radiology reports, health and wellness education, messages to and from the practice, as well as appointment reminders (Ahlers-Schmidt & Nguyen, 2013).

In addition to the perceived benefits by patients, providers also share positive attributes of the patient portals: reports of uncomplicated integration of the portals into the daily workflow and processes; more effective and efficient communication with the patients via the messaging center of the portal; decreased reliance on and loss of paper forms; increased access to patient information during operating and non-operating hours; and more in-depth discussions and appointments as a result of the patient reviewing test results and other data prior to meeting with the provider (Powell & Myers, 2018).

Patient portal perceived barriers. Twiddy (2015) identifies various barriers to remove if a practice wants to enhance portal use: the providers' self-limiting perceptions and barriers to their own portal use and practices; concerns with practice economics and portal use (i.e., lack of reimbursement for communication time via the portal); staff barriers and biases to portal use; patient resistance to portals; technological limitations; and security and privacy concerns with technology.

Each potential barrier is explored in detail, beginning with the physicians themselves. Although studies have revealed that portals can enhance and simplify interactions and treatments with patients, some physicians are not easily persuaded of the portal's value or have questions and apprehensions about the technology itself. Some physicians are concerned about the volume of emails, and the time it will take to answer with portal messaging (Twiddy, 2015).

A second potential barrier for the providers focus on the economics of patient portals. "Other than receiving meaningful use incentive payments and avoiding penalties, providers do not receive direct reimbursement for their time for using the portal" (Twiddy, 2015, p. 28). Some providers worry that answering secure messages may result in decreased revenue because of the operational efficiencies achieved through the portal instead of meeting appointment capacity (Twiddy, 2015).

As addressed by providers, integrating a portal can be somewhat disruptive to the practice and requires staff to manage increased quantities of online messages; changes in their daily practices, the office systems, and various processes (Twiddy, 2015).

Another consideration with patient portals is “the researcher and the pediatric practice need to take into account sociodemographic data, clinical information, attitudes toward telemedicine (and patient portals), perceived advantages of the patient portal, fears, and willingness to use the patient portal” (Russo, Campagna, Ferretti, Agricola, Pandolfi, Carloni, . . . Tozzi, 2017, p. 17).

Theoretical framework

Serving as a framework for this study is The Technology Acceptance Model (TAM), which addresses the explanation of end users’ reaction of health information technology such as patient portals (Holden & Karsh, 2010). This model has applicability for the pediatric practice staff in this study and the individuals (end users) of the portal who have the authority to manage the child(ren)’s health care.

Variables of the Technology Acceptance Model (TAM) support the scope of this study as the model addresses critical factors related to health technology (patient portals): behavior, use, behavioral intention, attitude, perceived ease of use (PEOU), perceived usefulness (PU), perceived behavior control (PBC), and behavioral benefits (including normative beliefs, control beliefs) with information technology. The following are TAM-specific definitions to ground the reader with the terminology presented with the model (Holden & Karsh, 2010):

- Behavior: the action (specific or general) of interest
- Use (USE): specific behavior performed by individuals concerning information technology (e.g., patient portals)
- Behavioral intention (BI): an individual’s motivation or willingness to engage in the target behavior (e.g., use the patient portal)
- Attitude (ATT): an individual’s evaluation of the target behavior (e.g., good/bad, harmful/beneficial, pleasant/unpleasant)
- Perceived ease of use (PEOU): an individual’s perception that using an IT system (i.e., patient portal) will be free of effort or require minimal effort
- Perceived usefulness (PU): an individual’s perception that using an information technology system (e.g., patient portal) will enrich job performance
- Image (output quality): real or perceived attributes of information technology (e.g., patient portal) that influence its perceived worth
- Perceived behavior control (PBC): an individual’s perception of how easy or difficult it is to perform the target behavior (self-efficacy that can be experienced with the use of the patient portal), the circumstances that inhibit or facilitate the use of the portal (facilitating conditions), or the amount of influence one has over performing the behavior (controllability)
- Behavioral beliefs (normative and control beliefs): an individual’s perceptions about positive and negative outcomes of using the portal, specific groups or people who encourage or discourage portal use, and specific components that make the portal engagement simple

The Technology Acceptance Model (TAM) is the "gold standard" (Holden & Karsh, 2010, p. 159) when considering acceptance and reactions to information technology in a variety of industries, and is gaining widespread acceptance in healthcare.

The following databases were used in the inquiry for the research question development: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Medline, and general searches via the Penn State University, Clarion University, and Edinboro University libraries (General and Advanced Search Categories), Google, Google Scholar, and Google Images. Keywords in the search included: patient portal, telehealth, telemedicine, pediatrics, parents, perceptions, and education with Boolean phrases (and, or) and MeSH terms (patient portals, pediatrics, barriers, engagement, and meaningful use). Domestic and international studies and sources published in the English language from the past nine years (2009-2018) were examined with broad content type (e.g., journals, articles, books). Full online text articles, peer and scholarly reviews within the medical, nursing, social work, and public health disciplines were included while researching the common themes:

- Populations: parents, providers, families of children, pediatricians
- Interventions: journals, interviews (in-person and phone), questionnaires, surveys, descriptive articles
- Comparisons: surveys, attitudes toward telehealth/patient portals
- Outcome variables: patient portal use; demographics, technology profile, usability
- Study types: descriptive, action, qualitative, retrospective

The review of literature demonstrated the need and context for this study by providing definitions, various benefits, and barriers associated with patient portals. The theoretical framework provided structure to the objective of generating findings to determine the reasons why individuals were not using the patient portal at a pediatric office in rural, central Pennsylvania.

Chapter 3

Methodology

The objective of this study was to generate findings to determine the reasons why individuals were not been using the patient portal at a pediatric office in rural, central Pennsylvania. A convenience sample of individuals was approached regarding the study. The paper survey, completed by each participant, had a total of eight (8) questions, focusing on aspects of the patient portal, reasons for not using the portal, and finally, demographic information. See Appendix C: Patient Portal Survey, as it served as the tool to generate the study findings.

Research Design

This descriptive study explored the reasons individuals bringing their child(ren) to a pediatric office had not been using the patient portal. A retrospective review of patient portal usage was obtained using the eClinicalWorks software. Data were collected regarding the practice call volume and the reasons individuals were calling the office (during operating and non-operating hours).

Research Question

The research question guiding this study: What are the reasons why individuals are not using the patient portal at a pediatric office in rural, central Pennsylvania?

Setting

The setting for this descriptive study was a pediatrics office in rural, central Pennsylvania. The practice has estimated call volumes of 40,000 – 50,000 annually with a significantly higher number of calls between October and March and in August with back-to-school appointments.

Additional practice-related information includes estimated 30,000 patient visits per year; payer mix of 65% Medicaid, 35% commercial health insurance, and 5% cash or self-pay. The racial and ethnic categories were primarily Caucasian with 1% Asian & African American (Chopra, personal communication, 2017).

As to a further itemization of the call volumes, categorical estimates of calls include:

- 35% requested appointments
- 25% left messages for the office staff or providers with updates
- 15% sought medical advice or symptom management
- 15% requested prescription refill(s)
- 8% asked questions regarding billing and account matters
- 2% requested directions to the office, inquired about office hours or other administrative matters

Sample and Recruitment Process

Sample. A convenience sample of individuals bringing the child(ren) to the practice was approached to participate in the survey. Inclusion criteria for the participants of the survey: individuals (>18 years of age) with child(ren) (newborn to 18 years of age); English-speaking and reading, and individuals who have not used the patient portal to date. Exclusion criteria for the participants of the survey: individuals (< 18 years of age bringing children to the practice; patients >19 years of age; non-English speaking and reading, and individuals who have used the patient portal to date.

Recruitment process. The timeframe for approaching potential participants, obtaining consent, and survey completion began November 1, 2018, with a terminal date of January 31, 2019. The flyers for the study (Appendix A) were posted in the waiting area, hallways, and the restrooms before the start of the study. The co-investigator conducted an informative session with the medical, nursing, and general staff before the launch to share the background of the study, allow for question and answers, and to reinforce their role in promoting the study by directing individuals to the flyers.

Starting November 1, 2018, recruitment began after the check-in procedure was completed with the office staff; the child(ren) had height and weight measurements, vital signs recorded, and the individual bringing the child(ren) to the practice discussed the reason(s) or chief complaint for the visit. All confidential steps and documentation were completed within the exam room while the co-investigator remained in the hallway. The medical assistant notified the co-investigator when she could enter the exam room to approach the individual regarding study participation and to obtain informed consent if all inclusion criteria were met. The co-investigator discussed the purpose of the study and asked the individual if he or she had used the patient portal to date. Only individuals stating that they had not used the patient portal were further approached about study participation. Next, the co-investigator reviewed the consent and allowed time for the individual to ask questions before determining if he or she wanted to participate in the survey. If the participant stated that he or she wanted to participate in the study, the Edinboro University Informed Consent form was reviewed, signed, and dated before the start of the paper survey. The informed consent and paper survey remained separate during the study.

The co-investigator directed the participant to the survey, asked if there were any questions, and then exited the room to give the individual privacy to complete the survey. The co-investigator remained outside the exam room to offer support or answer questions the individual might have during the completion process. The individual placed the completed survey in the envelope that was provided by the co-investigator. The envelope was sealed and hand-delivered by the participant and placed into the secured lock-box at the checkout area of the practice. The staff member located at the checkout area thanked the individual for his or her participation in the survey. The study took place during regular business hours, 0900 – 1800 Monday through Friday.

Instrumentation

Utilization of flyers (See Appendix A) in the waiting room and various areas within the practice were posted to promote the survey and its purpose. After the confidential check-in process, the co-investigator approached individuals in the exam rooms to participate in the survey. The eight-question paper survey focused on questions to address why the individuals were not using the patient portal as well as demographic data collection. (See Appendix C: Patient Portal Survey).

Data Collection

The Edinboro University Consent to Participate form was utilized for purposes of the survey. Only the co-investigator (DNP Student) obtained consent before the survey completion.

The co-investigator approached the individuals by stating, *"Hello, my name is Sherry DelGrosso. I am a registered nurse and a DNP student with Edinboro and Clarion Universities.*

I am working with Dr. Chopra to learn more about portal usage within the practice. Have you ever used the patient portal?"

If the individual affirmed, "Yes," to prior portal usage, the co-investigator thanked the individual for using the patient portal and encourage continued use with the following statement, "*Thank you for using the patient portal. Please continue to use this valuable tool. If you have any questions about the portal, please ask any staff member to assist you. At this time, we are interested in learning from individuals who have not used the patient portal to date. Thank you for your time."*

If the individual stated, "No," to the question about prior portal usage, the co-investigator stated: "*As someone who has not used the portal, would you be willing to participate in a five-minute voluntary paper survey?"* With a verbal commitment to participate in the study, the individual was directed to the Edinboro University Consent to Participate form. The consent form was read and reviewed with the individual. The following script was utilized to conclude the consent process (prior to the individual providing his or her signature and date). "*Thank you for considering participating in this brief, paper-based survey. Your signature acknowledges the following."*

☐ I had a chance to ask questions about the study.
☐ My questions were answered to my satisfaction.
☐ I realize that being part of this study is my choice (voluntary).
☐ I will receive no preferential treatment because of participation or non-participation.
☐ I have not used the patient portal to date.
☐ I am 18 years of age or older.
☐ The child(ren) at today's appointment are newborn to 18 years of age.
☐ I can read and speak English.

Following the completion of the consent process, the individual handed the signed consent to the co-investigator. Only the co-investigator had access to the individual's identity through the signature of the Consent to Participate in the Survey (See Appendix B: Consent to Participate in

Survey)**.** The consent was placed in a secured lock box within the pediatrician's office. The survey data was stored and secured in a lock box within the practice, and the co-investigator only accessed the box. The door to the office was locked at all times. With the possibility of future publication or presentation, no personally identifiable information was shared.

Before exiting the exam room, the co-investigator asked the individual if there were any questions about the survey or in general. If there were no questions, the co-investigator thanked the participant for his or her time and exited the room. If there were questions, the co-investigator answered the questions to the satisfaction of the participant. Once the individual verbally acknowledged that all questions were satisfactorily answered, the co-investigator left the room and remained in the hallway to serve as a resource for the participant to answer additional questions. At no time did the co-investigator have to return to the room to answer additional questions.

The individual completed the survey in the privacy of the exam room before the provider entered the room. The first portion of the survey included questions about the portal with the collection of individual demographic data of the person completing the survey. (See Appendix C: Patient Portal Survey).

If a confidentiality breach had occurred, the committee, Dr. Chopra, and the Edinboro University IRB would have been immediately notified, and appropriate next-steps followed, including the use of the Edinboro University Unanticipated Problem Report form located in Appendix D.

Survey Development

The survey developed for this single-site study was a result of general searches regarding "barriers to patient portal engagement" which were explored and discussed in chapter two. The survey instrument most closely examined was that from Ancker, Snezana, Osorio, Cole, Silver, Kaushal (2015). The instrumentation included questions about potential correlates of portal use in four categories (demographics, health issues, technology use and attitudes, and patient activation). The survey by Ronda, Dijkhorst-Oei, & Rutten (2014), regarding patient portal usage among patients with diabetes mellitus, and an industry review of patient portal preferences from IndustryView in 2014 were also explored. The following table provides the reader with the unit of analysis for this study:

Name of the population	Individuals: the person bringing the child(ren) to the office the day the survey is completed.
Subgroup for comparison	All individuals who meet the inclusion and exclusion criteria; who voluntarily agreed to participate in the survey and signed the disclaimer were included in the study. No subgroups.
Sources for data	Patient portal usage via eClinicalWorks software, data provided by the lead physician, Dr. Chopra; the survey
Sample population	A convenience sample from Nov. 1, 2018, to Jan 31, 2019.
Inclusion criteria	Inclusion criteria for the participants of the survey: individuals (>18 years of age) with child(ren) (newborn to 18 years of age); English-speaking/reading; individuals who had not used the patient portal to date.
Exclusion criteria	Individuals (parent/legal guardian) less than 18 years of age; patients >19 years of age; individuals who had used the patient portal in the past.
Timeframe	November 1, 2018, to January 31, 2019.

The detailed variables for the patient portal survey

Variable Name	Variable Description	Data Source	Possible Range of Value	Level of Measurement	Timeframe for Collection
Patient portal usage prior to study date	-Yes -No -Unsure	Potential participant answer	1= Yes 2= No 3=Unsure	Inclusion criteria	During the recruitment of potential participants for the study
Factors that prevent individuals from using the patient portal?	-Did not know the portal exists -Do not know how to access the portal -Unsure how to sign-in -Do not understand how it functions -Perceived lack of time -Do not see the value or benefit of using -No access to technology -Prefer to call the office -Medical data privacy concerns -Other	Self-report via the survey	1=Did not know the portal exists 2=Do not know how to access the portal 3=Unsure how to sign-in 4=Do not understand how it functions 5=Perceived lack of time 6=Do not see the value or benefit of using 7=No access to technology 8=Prefer to call the office 9=Medical data privacy concerns 10=Other	Percentage	During data collection via the survey
The technology the individual will most likely use to access the patient portal	-Home computer -Home tablet -Work computer -Work tablet -Public computer -Cell/mobile phone -Do not have access -Other	Self-report via the survey	1=Home computer 2=Home tablet 3=Work computer 4=Work tablet 5=Public computer 6=Cell/mobile phone 7=Do not have access 8=Other	Percentage	During data collection via the survey
Primary preference for future educational models to learn about patient portal	-Small group instruction -One-on-one demonstration -Web-based instruction -Pamphlet or Handout -Learn on my own -Other	Self-report via the survey	1=Small group instruction 2=One-on-one demonstration 3=Web-based instruction 4=Pamphlet or Handout 5=Learn on my own 6=Other	Percentage	During data collection via the survey
Individual's age of the person bringing the child(ren) to the office and completing the survey	Years of age	Self-report via the survey	1. 18-25 2. 26 – 35 3. 36 – 45 4. 46 – 55 5. 56 – 65 6. 66 – 75 7. 75+	Percentage	During data collection via the survey
Gender	-Male -Female -Other	Self-report via the survey	1= female 2 =male 3=other	Percentage	During data collection via the survey
Title of the individual bringing the child(ren) to the pediatrics office and completing the survey	-Parent -Step-parent -Foster-parent -Legal or -Appointed Guardian -Grandparent -Sibling ≥ 18 yrs. -Friend -Other	Self-report via the survey	1=Parent 2=Step-parent 3=Foster-parent 4=Legal/Appointed Guardian 5=Grandparent 6=Sibling ≥ 18 yrs old 7=Friend 8=Other	Percentage	During data collection via the survey
How often the individual completing the survey is the person who brings the child(ren) to the office	-Seldom -Sometimes -Often -Always	Self-report via the survey	1=Seldom 2-Sometimes 3=Often 4=Always	Percentage	During data collection via the survey

Ethical Considerations

Approval from The Edinboro University of Pennsylvania Institutional Review Board was obtained. The lead pediatrician, Dr. Chopra, initially provided a verbal agreement and commitment to the project and then subsequently furnished a Letter of Permission to the co-investigator to work with the practice and conduct the survey to determine the reasons why individuals were not using the patient portal. There were no other Institutional Review Boards to collaborate with during the study, as the study took place at a single-site (private practice). The potential risks to the participants were minimal. According to Rid, Abdoler, Roberson, Pine, & Wendler (2014),

> The probability and magnitude of harm or discomfort anticipated in the research were no more significant than those ordinarily encountered in daily life using the patient portal as long as the participants met the inclusion criteria and followed the study protocol (p. 391).

General benefits of study participation may include personal satisfaction, the individual learning the definition of the patient portal, recognition that the practice has a patient portal, the discovery of potential uses and benefits of the portal, and appreciation of personal contribution to the pediatric practice and healthcare in general.

Chapter 4

Results

Prior to sharing the results, it is imperative to review the research question guiding this study: What are the reasons why individuals are not using the patient portal at a pediatric office in rural, central Pennsylvania? The survey results will be used by the lead pediatrician to guide future patient portal educational endeavors to increase portal usage within the practice.

Sample Selection Process

Before launching the study, the ideal sample size was calculated using the online Qualtrics tool, *Ideal Sample Size Calculator* (2019). The following numbers were entered into the calculator to determine the ideal sample size: The estimated practice population of 7500 patients, the proposed confidence level (95%), and the margin of error (10%). The calculated ideal sample size was ninety-five participants for this study. The ideal calculated sample size criterion was met as ninety-six surveys were used in the study and data analysis as displayed in table one.

Table 1. Calculation of Ideal Sample Size

Calculation Ideal Sample Size
Confidence level = 95%
Population size = 7500
Margin of Error = 10%
Calculated Ideal Sample Size = 95

Per DataStar (2019), an identified ‘confidence level’ qualifies a statistical statement by expressing the probability that the observed result cannot be explained merely by sampling error. The 95% confidence level means that there is 95% likelihood that the difference is valid and not just an oddity of the sampling. With a small sample size of 50 respondents, a 14% margin of error is conventional, whereas 100 respondents typically yield a 10% margin of error. The margin of error reveals the imprecision fundamental in survey data (Hunter, 2019). A 10% margin of error was applied for the sample size calculation in this study.

A convenience sample of individuals bringing the child(ren) to the practice was approached to participate in the study. Of the 126 individuals approached to participate in the study, n=100 (79.37%) affirmed they had not used the patient portal to date, while n=20 (15.87%) affirmed they had used the patient portal. The participation response was strong with only n=6 (4.76%) declining to participate in the study. Reasons cited for not participating in the survey included: four individuals stated they were not interested in participation and provided no explanation; one individual stated “My spouse takes care of this” and the other individual said, “I am the grandmother and know nothing about the portal.”

Table two addresses the total number of individuals approached to participate in the study. Twenty individuals who used the patient portal before the study were not eligible to participate in the study, while six individuals chose not to participate in the study. Thus, the co-investigator had 100 individuals who met inclusion criteria for the study.

Table 2. Patient portal usage prior to study

Patient portal usage prior to study		
Variable	N	**%**
Yes	20	15.87%
No	100	79.37%
Declined Participation	6	4.76%
Total	126	100.0%

N=number of respondents

The N=100 served as the foundation for the study as it represents the individuals who met inclusion criteria and agreed to participate in the study (e.g., the number of respondents). Informed consents were obtained from these individuals and surveys were provided to each participant per the guidelines outlined in Chapter three. The response rate was strong with ninety-seven surveys being returned to the lock box. After initial review by the co-investigator, one survey was removed from the study due to partial survey completion. Ninety-six surveys were utilized for data entry and analysis.

The participants completed an eight-question survey (See Appendix C). After the consent was obtained, the survey was distributed to the individual. Overall, the questions focused on determining if the individual had set up a patient portal account for the child(ren); what prevented the individual from using the patient portal, as well as the individual's preference for learning to use the portal in the future. Select demographic information was collected regarding the individual’s age, gender, relationship to the child(ren), and how often s(he) brought the child to the pediatric office.

Table three details the results from the survey with the questions, number of respondents, number of responses and , and corresponding percentages. The findings were supportive of the research hypothesis:

H_A: Individual lack of awareness about the existence of the patient portal is the primary factor for low patient portal usage. Survey question two revealed that 50% of the responses revealed that participants did not know that the patient portal existed.

Notes

Please refer to page 33 for all survey questions, number of respondents, number of responses, and percentages as displayed in Table three.

- Questions one, four, five, six, seven, and eight asked the participant to provide <u>one answer</u> per survey question
    - N = number of respondents
- Questions two and three asked the participant to provide <u>all answers</u> that applied to the survey question
    - n = number of responses per variable

Table 3. Patient portal survey responses

Q1: Do you have a patient portal account? (Select one answer)	**N**	**%**
Yes	18	18.8%
No	63	65.6%
Unsure	15	15.6%
Total	*96*	*100.0%*
Q2: What prevents you from using the patient portal? (Select all answers that apply)	**n**	**%**
Did not know it exists	59	50.0%
Do not know how to access	11	9.3%
Unsure how to sign in	9	7.6%
Do not understand how it functions	1	0.8%
Perceived lack of time	12	10.2%
Do not see value or benefit of using	2	1.7%
No access to technology	0	0.0%
Prefer to call into the office	16	13.6%
Medical data privacy concerns	1	0.8%
Other (Specify)	7	5.9%
Total	*118*	*100.0%*
Q3: Which technology are you most likely to access the patient portal? (Select all answers that apply)	**n**	**%**
Home computer	35	22.3%
Home tablet	22	14.0%
Work computer	8	5.1%
Work tablet	2	1.3%
Public computer (school, library)	1	0.6%
Cell/mobile phone	88	56.1%
Do not have access to technology	0	0.0%
Other	1	0.6%
Total	*157*	*100.0%*
Q4: What is your PRIMARY preference for learning how to use the patient portal in the future? (Select one answer)	**N**	**%**
Small group instruction	5	4.4%
One-on-One Demonstration	9	7.9%
Web-based instruction	17	14.9%
Pamphlet/Handout	32	28.1%
Learn on my own	48	42.1%
Other	3	2.6%
Total	*114*	*100.0%*
Q5: What is your current age in years? (Select one answer)	**N**	**%**
18-25	15	15.6%
26-35	45	46.9%
36-45	28	29.2%
46-55	4	4.2%
56-65	2	2.1%
66-75	2	2.1%
76+	0	0.0%
Total	*96*	*100.0%*
Q6: What is your gender? (Select one answer)	**N**	**%**
Female	80	83.3%
Male	16	16.7%
Other	0	0.0%
Total	*96*	*100.0%*
Q7: What is your relationship to the child(ren) with you today? (Select one answer)	**N**	**%**
Parent	89	92.7%
Step-parent	1	1.0%
Foster-parent	0	0.0%
Grandparent	4	4.2%
Legal or Appointed Guardian	1	1.0%
Sibling (18+ years of age)	0	0.0%
Friend	0	0.0%
Other (specify) - Aunt	1	1.0%
Total	*96*	*100.0%*
Q8: How often are you the person bringing the child(ren) to the pediatric office? (Select one answer)	**N**	**%**
Seldom	2	2.1%
Sometimes	8	8.3%
Often	17	17.7%
Always	69	71.9%
Total	*96*	*100.0%*

N = number of respondents **n = number of responses per variable**

The survey data presented in Table three was further analyzed using the Chi-square test to determine if there was a statistically significant association between the patient portal account and the following variables: age, gender, and the relationship of the participant to the child. Cross-tabulations were conducted using SPSS software with questions one, five, six, and seven serving as the data source for evaluation. With all cross-tabulations, $p < .05$ represents a statistically significant relationship between the two variables.

The following served as the foundation for the case summaries for the Chi-square tests: Ninety-six surveys were utilized, and no surveys were missing from the data set. Of the ninety-six surveys, 63 (65.6%) individuals revealed that they did not have a patient portal, 18 (18.8%) stated they did have a patient portal account and have not used it, while 15 (15.6%) were unsure if they had a patient portal account.

Table five denotes the cross-tabulation between the patient portal account and the age range of the participants completing the survey. The p-value of 0.954 indicated that there was no statistically significant association between the patient portal account and the age range of the participant completing the survey.

Table 5. Existence of a patient portal account and age range of participant

	Age range (in years) of participant completing the survey							
Do you have a patient portal account?		18-25	26-35	36-45	46-55	56-65	66-75	76+
	Yes	2	9	6	1	0	0	0
	No	11	27	19	2	2	2	0
	Unsure	3	8	4	0	0	0	0
	Total	16	44	29	3	2	2	0

	p-value
Pearson Chi-Square	0.954

Table six details the cross-tabulation of the patient portal account and the gender of the participants completing the survey. The p-value of 0.928 revealed no statistically significant association between the patient portal account and the gender of the participant completing the survey.

Table 6. Existence of a patient portal account and gender of the participant

		Gender of the participant		
		Female	Male	Other
Do you have a patient portal?	Yes	15	3	0
	No	53	10	0
	Unsure	12	3	0
	Total	80	16	0

	p-value
Pearson Chi-Square	0.928

Other variables that were cross-tabulated included the patient portal account and the relationship of the participant to the child(ren) brought to the pediatric office as displayed in Table seven.

Table 7. Existence of a patient portal account and the participant relationship to the child(ren)

		Relationship of the participant to the child(ren)							
		Parent	Step parent	Foster-parent	Grand-parent	Legal Guardian	Sibling (18+)	Friend	Other
Do you have a patient portal?	Yes	17	0	0	1	0	0	0	0
	No	58	0	0	3	1	0	0	1
	Unsure	14	1	0	0	0	0	0	0
	Total	89	1	0	4	1	0	0	1

Other = aunt (indicated by the participant in the survey)

	p-value
Pearson Chi-Square	0.513

The p-value of 0.513 revealed that there was no statistically significant association between the patient portal account and the relationship of the participant to the child(ren).

Since the above analyses did not bare statistical significance in the association between the patient portal account and the age, gender, or relationship of the participant to the child, further evaluation was conducted to aid future educational interventions to increase patient portal usage within the practice. Cross-tabulations were conducted using the SPSS software with survey question five as it related to the reported age range (in years) of the individual completing the survey and the answers provided in question two, which addressed factors that prevented the participants from using the patient portal, specifically “didn’t know that the patient portal existed” and communication preference of “calling the office. ”

Table eight revealed that there was no statistically significant association between the two variables as evidenced by the p-value of 0.221.

Table 8: Participant age range and knowledge of the existence of the patient portal

Age range of the participant	Did not know the patient portal existed
18-25	12
26-35	24
36-45	16
46-55	3
56-65	2
66-75	2
76+	0
Total	59

	p-value
Pearson Chi-Square	0.221

With the results from Table eight not revealing a statistically significant association between the two variables, the next analysis included the age range of the participant and the cross-tabulation from survey question two, where the individuals indicated they “Preferred to call into the office." Table nine revealed that there was no statistically significant association between the variables as evidenced by the p-value of 0.910.

Table 9. Participant age range and preference to call into the office

Age Range of the Participant	Prefer to call into the office (n)
18-25	3
26-35	8
36-45	5
46-55	0
56-65	0
66-75	0
76+	0
Total	16

Pearson Chi-Square	p-value
	0.910

Lastly, the Chi-square test was conducted on the participant age range and survey question three, "Which technology are you most likely to access the patient portal?" The choice "cell/mobile phone" was the leading answer to this question. Table 10 provides the results of this cross-tabulation with a p-value = 0.009, which shared a higher statistical significant association between any two variables reviewed.

Table 10. Participant age ranged and preferred technology to access the portal

Age Range of the Participant	Cell phone: preferred technology for patient portal access (n)
18-25	16
26-35	41
36-45	26
46-55	1
56-65	2
66-75	2
76+	0
Total	88

Pearson Chi-Square	p-value
	0.009

Discussion

The survey answers provided insight into the research question: "What are the reasons why individuals are not using the patient portal at a pediatric office in rural, central Pennsylvania?" Survey question two shared valuable information regarding the factors that prevented the participants from using the patient portal. Fifty percent of the responses per variable indicated that the survey participants "did not know that the patient portal existed;" 10.2% of the responses per variable specified "perceived lack of time" to be a factor, and 9.3% of the responses per variable listed "did not know how to access the portal." Additionally, 13.6% of the responses per variable revealed that participants "preferred to call into the office" to handle matters. These findings offered clarity as to the barriers contributing to the low patient portal usage. Other noteworthy findings revealed the cell/mobile phone as the technology most likely to be utilized to access the patient portal in the future, followed by the home computer. Future educational interventions can be tailored with the top learning preferences as identified by the participants: learn on my own with the use of a pamphlet or handout and web-based instruction. In closing, the female parent between the ages of 26-35 and 36-45 years of age was the profile of the individual always bringing the child(ren) to the pediatric office.

Chapter 5

Summary, Conclusion, and Recommendations

Summary

The study provided valuable information as to the reasons why individuals were not using the patient portal at a pediatric office in rural, central Pennsylvania. Question two outlined valuable elements that were preventing the participants from using the patient portal. There was no statistically significant association between the patient portal account and the following variables: age, gender, and the relationship of the person to the child. Also, statistical significance lacked with age range and factors preventing the individual from using the patient portal, the preference to call into the office for care-related matters, and the use of a cell/mobile phone as the technology most likely to be accessed in the future by the participants to use the patient portal.

Limitations

Limitations that may have influenced the findings and conclusions include the following elements: it was a single-site study; individuals completing the survey may not be representative of the larger population and/or the end users of the patient portal; the small sample size may not readily generalize to broader pediatric populations in other rural and metropolitan areas; the timeframe to collect survey data may not have been sufficient and may not account for seasonal differences in the number of visits to the practice (e.g., summer versus fall volumes); the use of only paper-based surveys may have impacted the sample size as a more significant number of participants may have been achieved through the use of an electronic survey posted on the pediatric practice website; and lastly, some participants selected more than one answer when they should have chosen only one answer per question.

Conclusion

The survey confirmed the directional hypothesis for this study as the individuals lacked awareness about the existence of the patient portal. It was the primary variable for low patient portal usage. Continued efforts will be needed to ensure that patient portal usage increases over time.

Recommendations

The results of the survey revealed that the lack of patient portal usage/engagement may well be responsive to change with some practice planning and possible educational interventions. First, strong leadership is necessary. Specifically, strong project leaders will be needed to coordinate marketing and educational efforts. The pediatric office will need to work closely with the marketing team and project leader to tailor the patient portal engagement campaign. Marketing materials in the form of pamphlets, handouts, and web-based instruction will need to address the fundamental factors preventing the individuals from using the patient portal while ensuring that the portal is mobile compatible, user-friendly, and supports the individuals' desire to utilize the patient portal more efficiently than calling into the office. Personnel (either within the office or sub-contracted with the patient portal vendor customer service team) will need to be deployed during the marketing campaign with the anticipated surge in patient portal account registration to support the individuals. Patient portal software or other technologies may be needed to capture patient portal usage rates and other variables during the marketing campaign in order to analyze key trends in usage, technology complications, and consumer feedback about the portal.

Educational materials and marketing campaigns need to be clear and aesthetically pleasing. Future educational interventions and marketing campaigns will need to target a variety of populations to alert the individuals bringing the child(ren) to the pediatric practice of the existence of the patient portal and how to access it. Because the individuals preferred to call into the office and perceived “lack of time” as barriers to using the patient portal, strategic and operational plans need to be developed and executed to support the individuals as they transition to the patient portal as the primary means to request immunization records, lab results, medication refills, schedule appointments and ask care-related questions, all of which may now be managed via the patient portal. Step-by-step instructions for patient portal access, troubleshooting, and frequently asked questions need to be provided using paper and electronic formats. Studies will need to be reviewed and utilized to effectively share healthcare information with such a broad audience.

Participants indicated that they plan to use their cell phones for future patient portal access. Thus, the project leader must ensure portal compatibility with mobile devices. It must be user-friendly and efficient for the individuals to decrease the calls to the office. Otherwise, portal engagement will remain low. Organizational policies and practices will need to be updated accordingly while reflecting all standards of care and regulations. As telehealth technologies grow within the practice, the patient portal will need to support the continuous flow of information across the electronic medical record, the patient portal mobile app, and the computer-based platform.

The pediatric practice, project leader, and marketing team will need to review studies for the effectiveness of delivering healthcare information to individuals to ensure health and computer literacy skills. Programs and incentives may need to be instituted to encourage the individuals to sign-up and use the patient portal. One example may include entering new and experienced patient portal account users into drawings and awarding weekly, monthly, and yearly prizes for patient portal usage. Continued efforts, surveys, and studies will be needed to ensure that patient portal usage is increasing over time.

Future Research

Prospective research should include additional qualitative studies to systematically address the patient portal engagement and variables affecting the usage within the pediatric practice after this study. It will also be beneficial to have convenience sampling or mixed-methods approaches to assess the impact of the marketing campaign as it pertains to the ongoing process improvement measures with the patient portal engagement. Additionally, a review of select sub-populations (ADHD, asthma, and pediatric obesity) within the practice may afford the opportunity to address the impact the patient portal usage may be having on health outcomes, patient and family knowledge as it relates to the care of the patient, as well as the impact the patient portal usage may be having on care metrics (cost, quality, and safety).

Future studies may include additional pediatric and adult practices, hospitals, and health care systems within other rural and metropolitan areas to increase healthcare partnerships and sharing of valuable information to promote patient portal engagement.

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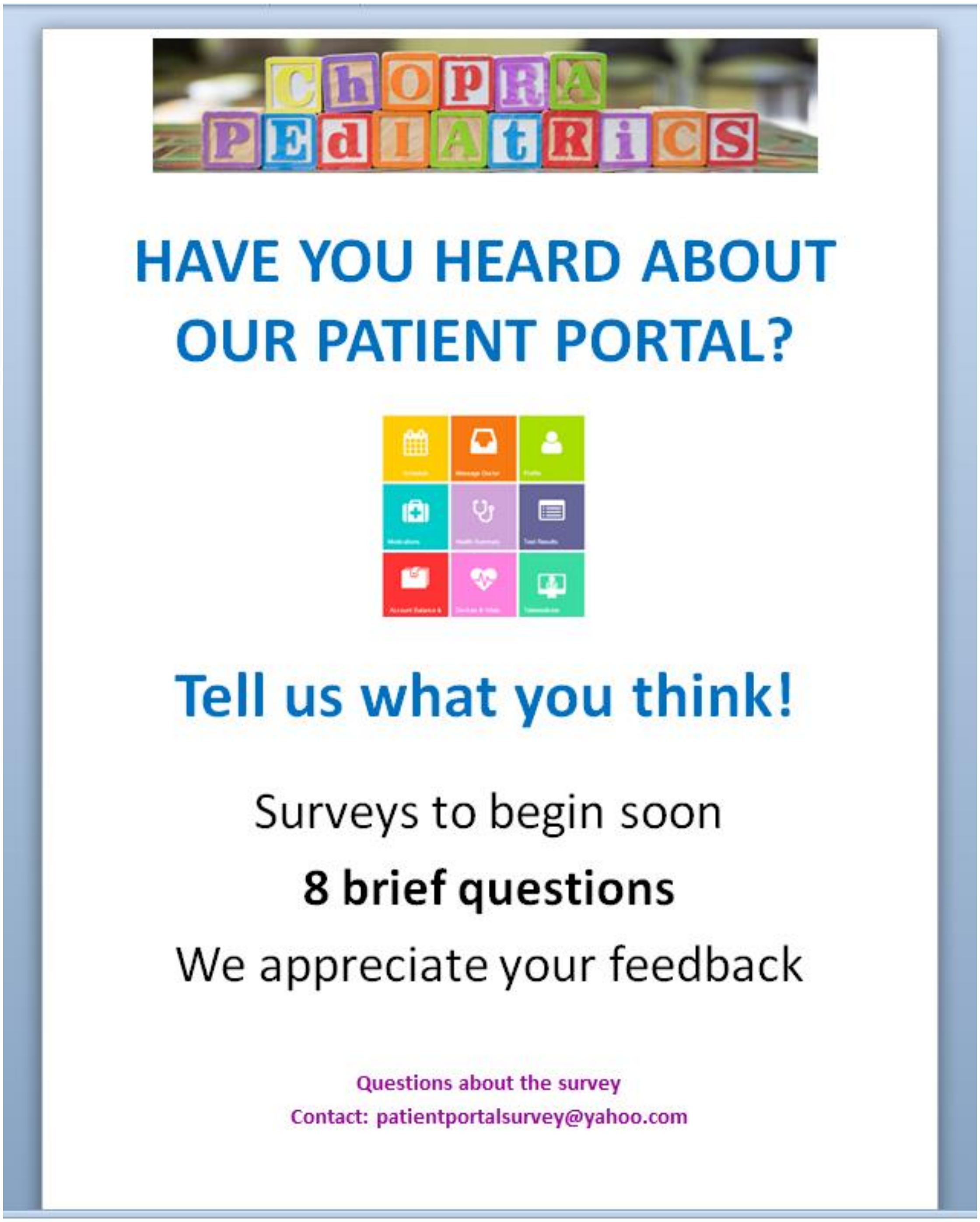
Appendix A: Flyer Promoting the Survey



ChOPRA PEdIATRiCS

HAVE YOU HEARD ABOUT OUR PATIENT PORTAL?

Tell us what you think!

Surveys to begin soon

8 brief questions

We appreciate your feedback

Questions about the survey
Contact: patientportalsurvey@yahoo.com

Appendix B: Consent to Participate in Survey Edinboro University Consent

EDINBORO UNIVERSITY OF PENNSYLVANIA
Edinboro, Pennsylvania
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Study: Patient Portal Engagement at a Pediatric Office: Reasons Why Individuals are Not Using the Portal.

Principal Investigator: Dr. Meg Larson
Co-investigator: Sherry DelGrosso, MSN, RN, LNC

Introduction

The study, ***Patient Portal Engagement at a Pediatric Office: Reasons Why Individuals are not using the Portal*, is** being conducted at Dr. Chopra's office, 1224 7th Avenue Altoona, PA (Blair County).

"A **patient portal** is a secure online website that gives patients convenient, 24-hour access to personal health information from anywhere with an Internet connection. Using a secure username and password, patients can view health information" (HealthIT.gov, (n.d.), para. 1). Some patient portals also allow the user to securely message the provider; request prescription refills; schedule non-urgent appointments; update contact information; make payments; download and complete forms; and view educational materials (HealthIT.gov,(n.d.), para. 2).

- You are being asked by Sherry DelGrosso, MSN, RN, LNC (co-investigator) to be in a research study.
- You should understand that this study involves research. This consent describes your role as a participant in the study.
- In this study, you will complete a brief paper survey, which has a total of eight (8) patient portal and demographic questions.

Purpose of the Study

The purpose of the study (through the brief paper-survey) is to explore the reasons individuals bringing their child(ren) to the pediatric office are not using the patient portal.

What Will Happen During the Study?

Only individuals stating that they have not used the patient portal to date will be approached further about survey completion.

The survey will focus on:

- Reasons why the individuals are not using the portal
- Primary preference for learning how to use the patient portal in the future
- Demographic data collection

What Are the Possible Risks or Discomforts?

The potential risks to the participants are minimal. The co-investigator will be available to answer any questions; address any issues and work with the participant to decrease frustration or any concerns.

What Are the Possible Benefits of Being in This Study?

- General benefits may include, but not be limited to personal satisfaction and general appreciation of personal contribution to the pediatric practice and healthcare in general.
- The study-specific benefits to the participants may include an understanding of the patient portal (definition), its benefits and how to access the portal in the future for key requested information (immunization records, lab results, request for medication refills, messages (questions) to the provider for care and follow up.

Are Other Treatments Available?

You may choose not to participate in the patient portal study, as it is voluntary.

How Will the Data Collected Be Kept Confidential?

- You should know that your name will be kept as confidential as possible, within local, state and federal laws.
- Completed surveys will be stored in a sealed envelope and stored in a secured lockbox within the pediatric practice.
- The signed consent form and the completed survey may be reviewed by the Edinboro University Institutional Review Board (IRB), if necessary.
- The results of this study may be shared in aggregate form at a meeting or in a journal, but your name or individual results or information will not be revealed.

What Happens If I Have More Questions?

- Sherry DelGrosso will answer your questions about the research study at 814.944.8784 or in person at the time of survey completion.
- If you have a question about your rights as a research participant that you need to discuss with someone, you can call the Edinboro University Institutional Review Board at (814) 732-2856 or at irb-chair@edinboro.edu.

What Will Happen If You Decide Not To Be in the Study?

- Your participation is strictly voluntary
- The survey will be conducted within the exam room after the children have completed the check-in process, had height and weight measurements, vital signs, discussed the reason(s) for the visit with the medical assistant (chief complaint), and all confidential steps and documentation have been completed within the exam room
- You may choose to quit at any time without any penalty, retribution, or repercussion.
- You will not be given preferential treatment or have your appointment time advanced as a result of participation or non-participation

SUBJECT'S STATEMENT

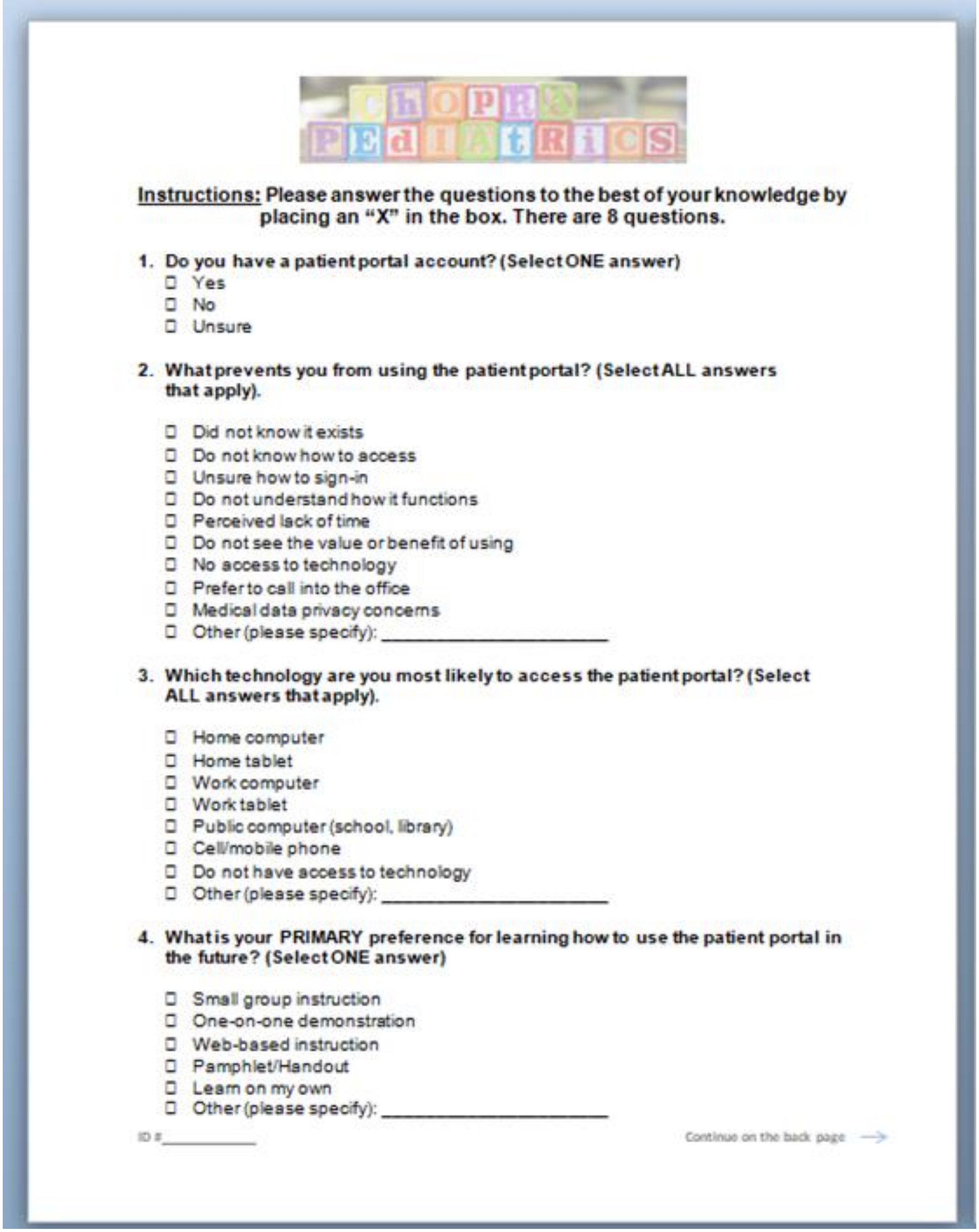
- ☐ I had the opportunity to ask questions about the study.
- ☐ My questions were answered to my satisfaction.
- ☐ I realize that being part of this study is my choice (voluntary).
- ☐ I received no preferential treatment because of participation or non-participation.
- ☐ I have not used the patient portal to date.
- ☐ I am 18 years of age or older.
- ☐ The child(ren) at today's appointment are newborn to 18 years of age.
- ☐ I can read and speak English.

____ ____________________

SUBJECT'S SIGNATURE DATE

Rev. 09/04/14

Appendix C: Patient Portal Survey



ChoPRA PEdIAtRICS

<u>Instructions:</u> Please answer the questions to the best of your knowledge by placing an "X" in the box. There are 8 questions.

1. **Do you have a patient portal account? (Select ONE answer)**
   - ☐ Yes
   - ☐ No
   - ☐ Unsure

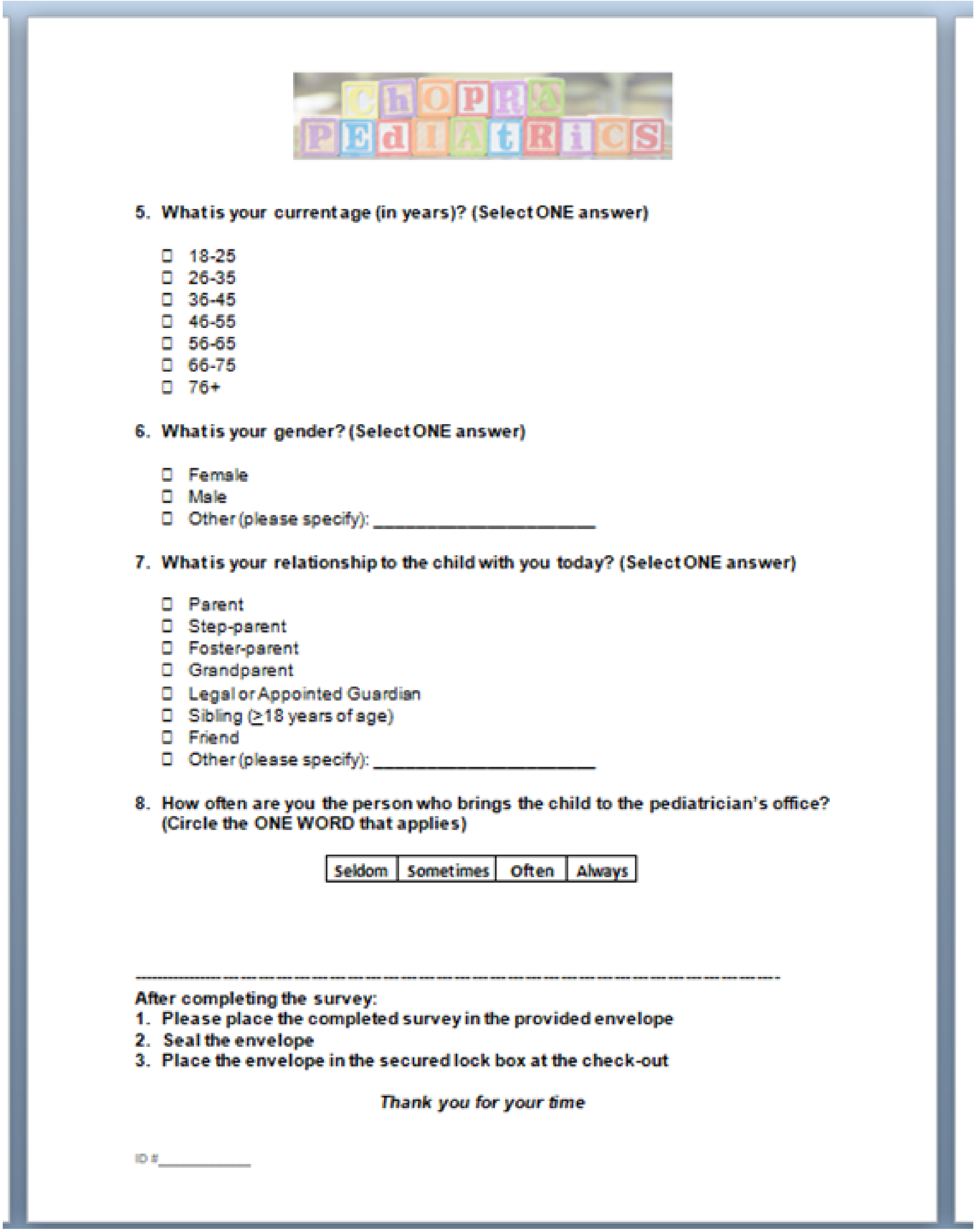
2. **What prevents you from using the patient portal? (Select ALL answers that apply).**
   - ☐ Did not know it exists
   - ☐ Do not know how to access
   - ☐ Unsure how to sign-in
   - ☐ Do not understand how it functions
   - ☐ Perceived lack of time
   - ☐ Do not see the value or benefit of using
   - ☐ No access to technology
   - ☐ Prefer to call into the office
   - ☐ Medical data privacy concerns
   - ☐ Other (please specify): ______________________

3. **Which technology are you most likely to access the patient portal? (Select ALL answers that apply).**
   - ☐ Home computer
   - ☐ Home tablet
   - ☐ Work computer
   - ☐ Work tablet
   - ☐ Public computer (school, library)
   - ☐ Cell/mobile phone
   - ☐ Do not have access to technology
   - ☐ Other (please specify): ______________________

4. **What is your PRIMARY preference for learning how to use the patient portal in the future? (Select ONE answer)**
   - ☐ Small group instruction
   - ☐ One-on-one demonstration
   - ☐ Web-based instruction
   - ☐ Pamphlet/Handout
   - ☐ Learn on my own
   - ☐ Other (please specify): ______________________

ID #__________

Continue on the back page →



ChOPRA
PEdIAtRiCS

5. **What is your current age (in years)? (Select ONE answer)**

- ☐ 18-25
- ☐ 26-35
- ☐ 36-45
- ☐ 46-55
- ☐ 56-65
- ☐ 66-75
- ☐ 76+

6. **What is your gender? (Select ONE answer)**

- ☐ Female
- ☐ Male
- ☐ Other (please specify): ______________________

7. **What is your relationship to the child with you today? (Select ONE answer)**

- ☐ Parent
- ☐ Step-parent
- ☐ Foster-parent
- ☐ Grandparent
- ☐ Legal or Appointed Guardian
- ☐ Sibling ($\geq$18 years of age)
- ☐ Friend
- ☐ Other (please specify): ______________________

8. **How often are you the person who brings the child to the pediatrician's office? (Circle the ONE WORD that applies)**

Seldom	Sometimes	Often	Always

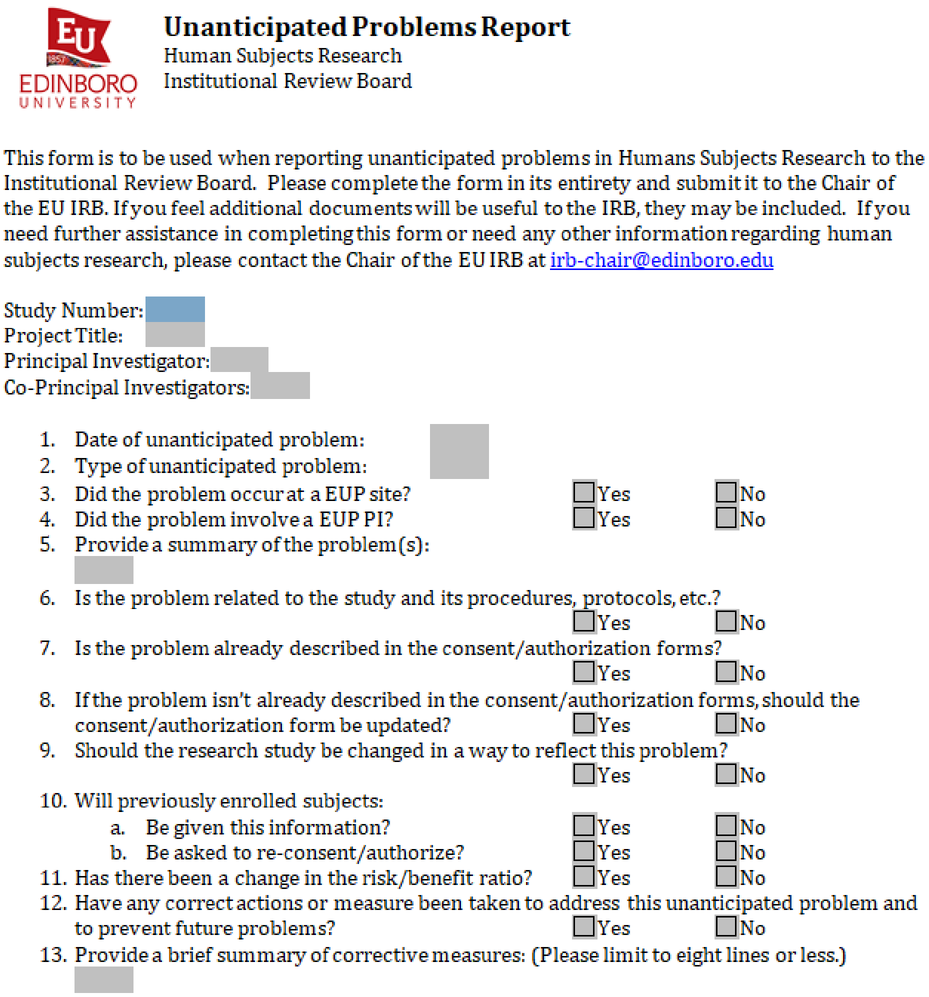
After completing the survey:

1. **Please place the completed survey in the provided envelope**
2. **Seal the envelope**
3. **Place the envelope in the secured lock box at the check-out**

Thank you for your time

ID #__________

Appendix D: Edinboro University Unanticipated Problem Report



EDINBORO UNIVERSITY

Unanticipated Problems Report

Human Subjects Research
Institutional Review Board

This form is to be used when reporting unanticipated problems in Humans Subjects Research to the Institutional Review Board. Please complete the form in its entirety and submit it to the Chair of the EU IRB. If you feel additional documents will be useful to the IRB, they may be included. If you need further assistance in completing this form or need any other information regarding human subjects research, please contact the Chair of the EU IRB at irb-chair@edinboro.edu

Study Number:
Project Title:
Principal Investigator:
Co-Principal Investigators:

1. Date of unanticipated problem:
2. Type of unanticipated problem:
3. Did the problem occur at a EUP site? ☐Yes ☐No
4. Did the problem involve a EUP PI? ☐Yes ☐No
5. Provide a summary of the problem(s):
6. Is the problem related to the study and its procedures, protocols, etc.? ☐Yes ☐No
7. Is the problem already described in the consent/authorization forms? ☐Yes ☐No
8. If the problem isn't already described in the consent/authorization forms, should the consent/authorization form be updated? ☐Yes ☐No
9. Should the research study be changed in a way to reflect this problem? ☐Yes ☐No
10. Will previously enrolled subjects:
    a. Be given this information? ☐Yes ☐No
    b. Be asked to re-consent/authorize? ☐Yes ☐No
11. Has there been a change in the risk/benefit ratio? ☐Yes ☐No
12. Have any correct actions or measure been taken to address this unanticipated problem and to prevent future problems? ☐Yes ☐No
13. Provide a brief summary of corrective measures: (Please limit to eight lines or less.)