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I, Patricia Lynn Bender, hereby submit this DNP Project scholarly document in partial fulfillment of the requirements for the degree Doctor of Nursing Practice in Population Health Leadership.

Title of DNP Project: Implementation of a Parent-Generated Electronic Family Health History Tool in an Urban Pediatric Primary Care Setting

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Implementation of a Parent-Generated Electronic Family Health History Tool in an Urban Pediatric Primary Care Setting

A scholarly project submitted to the
Xavier University
College of Professional Sciences
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In partial fulfillment of the
Requirements for the degree of
Doctor of Nursing Practice
by

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Abstract

As the United States (U.S.) health care system moves towards a health promotion model, identifying those at risk for common health conditions is crucial. Comprehensive family health history (FHH) data collection and analysis has been proposed as a low cost, highly efficient and effective way to screen for common health conditions. However, patients' electronic health records (EHRs) currently do not contain enough FHH information to adequately assess for health risks. The purpose of this DNP Scholarly project was to implement a parent completed electronic family health history (eFHH) tool in a socially disadvantage, pediatric population receiving care in an urban primary care clinic. A descriptive observation study design was used to evaluate parents' use of My Family Health Portrait (MFHP), an eFHH tool. Forty parent participants were observed for ease of MFHP use to determine the feasibility of using a parent completed FHH tool. The majority of parents (85%) were able to complete the MFHP tool prior to completing provider evaluations, with 70% of parents completing a four generation family history assessment using MFHP. Facilitators for completion included: desire to enter their own information, perceived positive benefit, ease of use, internet access and enjoyed entering information. Barriers to completing the MFHP tool were: program was not intuitive, issues with unknown information, clinic interruptions, complexity of health categories, and the tool is not pediatric focused. Results support the possibility of using a parent-generated electronic family health history tool in a pediatric care setting.

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Chapter One - Introduction

Background of the Problem

As the United States (U.S.) health care system moves towards a health prevention/promotion model, identifying those at risk for disease is essential in the prevention of common health conditions (Nash, Fabius, Skoufalos, Clarke & Horowitz, 2016). A step towards identifying health risks can be achieved by collecting and analyzing ones family health history (FHH) (Rahimazdeh & Barlett, 2014; Tarini & McInerney, 2013). A FHH is the systematic collection of multigenerational patient and family members' health/disease status. Family Health History tools are designed to collect this information in paper, digital or web-based formats in a low cost, highly efficient and effective ways (Beadles et al., 2014; Buchanan et al., 2015; Carroll et al., 2017; de Hoog, Portegijs & Stoffers, 2014; Kemper et al., 2010; Williams, Collingridge, & Williams, 2011). Family health history tool offer the potential to improve population health, by identifying individuals, at risk for common complex health conditions (Kemper et al., 2010). They use a series of questions to elicit information about patients and their families' health over a period of at least three generations (Bennett, French, Resta & Doyle, 2008). The FHH information is recorded using a standardized format, which highlight health risks and patterns of inheritance so that clinical experts can interpret this information (Daelemans, Vandevoorde, Vanintejan, Borgermans, & Devroey, 2013; Emery, Reid, Provost, Ravine, & Walter, 2014; Williams et al., 2011).

Lack of FHH tools in clinical practice. During the past two decades, the U.S. Surgeon General established government requirements promoting FHH adoption, including payment for inclusion of service by Medicaid/Medicare (CMS, 2012; Kaiser Family Foundation, 2013). Health care providers acknowledged FHH tools have the potential to stratify an individual's risk for common complex health conditions, yet the use of these tools in the primary care setting remains limited (CMS, 2012; Kaiser Family Foundation, 2013; Levenson, 2012; Owens, Marvin, Gekehrter, Ruffin IV, & Uhlmann, 2011; Williams et al., 2011). Difficulty integrating FHH tools into routine clinical practice has been attributed to multiple barriers, such as: lack of standard formats, incomplete records, time limitations, concern of quality of information, difficulty interpreting and utilizing information gathered and inability to provide appropriate interventions based on provider report (Daelemans, et al., 2013; Van Esch, Heideman, Cleijne, Cornel, & Snoek, 2013). Other studies regarding lack of FHH tools in clinical practice have focused on measuring patient and provider's perceived importance as a possible reason for poor integration. However these studies noted FHH is perceived as important, so this would not be a presumed barrier (Berger, Lynch, Prows, Siegel, & Myers, 2013; Christianson et al., 2012; Kanetzke, Lynch, Prows, Siegel, & Myers, 2011; Mathers et al., 2010; Newcomb, Canclini, Cauble, Raudonis, & Golden, 2014).

Development of electronic FHH tools. The recent development of electronic tools are intended to advance the adoption and analysis capabilities of FHH information (Buchanan et al., 2015; Cohn et al., 2010; Facio et al., 2010; Orlando et al., 2013). Electronic FHH (eFHH) tools are software program using a digital or web-based platform to collect and document FHH information (Cohn et al., 2010). Several electronic versions of FHH tools have been designed to systematically record information, improve documentation and electronic access, complete a health risk analysis, and be data minable (Buchanan et al, 2015; Cohn et al., 2010; Facio et al., 2010; Orlando et al., 2013). Electronic FHH tools have the foreseeable potential to eliminate many barriers while concurrently increasing usability of the FHH information (de Hoog et al., 2014; Rahimazdeh & Barlett, 2014). However, further information and experience is needed regarding the feasibility of using eFHH tools in general practice (Berger et al., 2013; Newcomb et al., 2014; Owens et al., 2011).

Lack of eFHH tools studies with diverse populations. A gap in the literature exists regarding the use of eFHH tool in pediatrics, with socially disadvantaged, and minority populations (de Hoog et al., 2014). Electronic FHH trials in clinical practice have been limited to populations of predominantly middle/upper class, higher educated, individuals in private adult primary care clinics (Beadles et al., 2014; de Hoog et al., 2014; Orlando et al., 2011; Yoon, Scheuner, Jorgensen, & Khoury, 2009). Therefore, further studies are indicated to test the feasibility of integrating eFHH tool with vulnerable populations (Berger et al., 2013; Hartmann, Marshall, & Goldenberg, 2015; Halbert et al., 2016; Murray, 2013; Newcomb et al., 2014).

Current method of collecting FHH. Collection of FHH is meant to be an ongoing process, as each person in the family ages the development of chronic diseases can be used to inform the health of younger generations (Carroll et al, 2017). The clinics current method for collecting FHH information occurs as part of the initial patient encounter. When patients join the practice, which could be as young as one week of age, FHH information is collected. However there is no standard process regarding when FHH information should be updated or a plan for a comprehensive review of all family health conditions. As a result of this, FHH information from the initial patient encounter to late adolescence may never be updated, thereby missing an important opportunity to capture critical health information such as diabetes, cancers or heart disease which develops in other family members. Only after this information is collected can appropriate risk screening and/or preventive services can be implemented.

Background of the Proposed Project

Current electronic documentation system. In addition to outdated information, there is also the possibility of inaccurate or poorly recorded FHH information initially. The current EHR system includes approximately 250 health conditions in a list format, which can be selected by scrolling through the entire list, or by searching for exact terminology. This check list is completed by an interviewer, typically a medical assistant, who has no expertise in family history collection. Also, the computer program was designed to record nuclear families only; without consideration of half siblings, egg or sperm donation conceptions, or adoptions. This nuclear family list automatically assigns siblings, parents, aunts, uncles, and grandparents, which may not be an accurate representation of the family structure. For example, if there are no aunts or uncles these must be manually edited out, increasing the need for staff time and technical knowledge to modify the program.

The ability to rapidly view and use a format that facilitates interpretation of FHH information is also necessary. Currently information can be condensed to show health conditions occurring within the family; however, this information is provided in a list format. Pedigrees, a graphic format used to display multiple generations, familial relationships and health conditions, can be constructed using some eFHH tools (Bennett et al., 2008). Pedigrees are especially useful to easily view patterns of inheritance, such as autosomal dominant health conditions, which can pass from generation to generation.

The ability to integrate an eFHH tool successfully within an underprivileged population and among the youngest individuals could improve patients' longitudinal health care records, heighten patient/provider awareness of health risk, and provide target areas for lifestyle and behavioral modifications for prevention and health promotion (Fuller, Myers, Webb, Tabangin, & Prows, 2009). The advantages to using an eFHH tool include:

- provide structured format for FHH data collection,
- improved quality of data collected,
- data can be entered by patient/family,
- information is readily viewable in the EHR,
- can decrease redundancy of data collection among provider
- the eFHH can be updated or modified with consecutive visits to improve FHH accuracy (Christianson et al., 2012; Owen et al., 2011; Welch et al., 2015).

Problem Statement

Studies indicate most EHRs do not contain enough information to accurately assess health risk (Christianson et al., 2012; Powell et al., 2013; Murray et al., 2013; Welch et al., 2015). However, electronic FHH tools exist which improve documentation by allowing individuals to enter their own health information using a structured format (de Hoog et al., 2014). Validation and feasibility studies using eFHH tools have predominately been completed in adult private practice settings that consisted of middle age individuals of average to above average educated levels, (Buchanan et al., 2015; Christianson et al., 2012; Newcomb, et al., 2014; Orlando et al., 2014; Wu et al., 2013). Therefore, it is unknown if it feasible to integrate eFHH tools in an underprivileged, urban, pediatric primary care population.

Clinical Significance

Significance for nursing. Nurses, certified nursing assistants, and medical assistants are typically assigned the task of collecting and recording patient health information including FHH, in the primary care setting (Skirton, O’Connor, & Humphreys, 2012; Williams et al., 2011).

Electronic FHH tools not only have the potential to improve data collection, but also make it possible to be self- completed, thereby decreasing dependence on staff to provide this documentation (de Hoog et al., 2014).

Computer analysis algorithms developed with the eFHH tools can identify health risk. These programs can alert nurses who previously may not have recognized health risk patterns to the need for health intervention (Facio et al., 2010; Orlando et al., 2013; Yoon et al., 2009). The nursing profession is ideally situated to be leaders, educators, and designers of programs which target health promotion/prevention (Porter-O'Grady & Malloch, 2015). Nurse experts may also be involved in program development of eFHH tools, as well as the implementation, development, and validation of tools in other areas of research associated with eFHH data collection (Zaccagnini & White, 2014).

Significance for organization and stakeholders. The Centers for Medicare and Medicaid Services' (CMS) mandates the inclusion of FHH documentation in greater than 80 percent of patient's medical records as part of their quality initiatives (CMS, 2012). Cincinnati Children's Hospital Medical Center (CCHMC) acknowledges the increasing FHH documentation requirements to meet CMS standards, but strategically is also committed to reducing the burden of document (CCHMC, 2016). Ultimately the balance could become one of cost, penalty or reduced payment versus the cost to increase/improve documentation. Parent-completed eFHH tools could prove to be a cost effective way to improve documentation requirements while sharing the effort burden and simultaneously increasing patient/family engagement.

Integration of electronic data collection tools such as an eFHH through a customization EHR is a complex and costly pursuit (Lee, 2015; McGonigle & Mastrian, 2015). The proposed feasibility project is one way to justify the cost by demonstrating the advantages of parent completed eFHH tools and identifying barriers to their use. This justification for CCHMC stakeholders is necessary to support wide scale adoption of eFHH to better serve patients, the institutions and potentially others (Lee, 2015).

Significance to population health. Population health is an organized, systematic approach to health care which considers the distribution of health conditions, social determinants, health policy and there interconnected effects on health outcomes (Nash, Fabius, Skoufalos, Clarke, & Horowitz, 2016). The U.S. Surgeon General proposed the use of FHH information as a tool to improve population health outcomes (Surgeon General, 2015). FHH tools integrate comprehensive method that included the variability of health conditions and social determinant of health to influence care recommendations. Another way to envision the possible scope of eFHH on population health is by applying the Triple or Quadruple Aim framework. Consistent with this framework, eFHH tools were designed to improve patient outcomes, build on a quality patient experience, reduce cost, and improve the healthcare providers' experience (Institute for Healthcare Improvement [IHI], 2017a; Institute for Healthcare Improvement [IHI], 2017b). Since eFHH tools can identify at-risk individuals, use could be instrumental for behavioral and lifestyle modifications to improve health outcomes (Cohn et al., 2010, Emery, 2005; Facio et al., 2010, Orlando et al., 2013). Patient-facing eFHH tools were designed to facilitate patient engagement with a focus towards improving the quality and experience of the individual at the center of this health initiative (Berger et al., 2013; Buchanan et al., 2015; Newcomb et al., 2014). Since the eFHH tools are prevention or earlier detection focused, their use could reduce costs (Welch et al, 2015). Lastly, shifting the FHH documentation burden to the patient would allow staff to focus on the important information contained within the FHH, rather than the task of document collection (Owens et al., 2011). The increasing burden of documentation by health care providers affects not only the quality of the health care provider experience, but also the patient's experience and the outcome (Porter-O'Grady & Malloch, 2015).

Purpose of Project

The use of FHH tools in the urban pediatric care setting could support the identification of familial health risks and allow for early health education and lifestyle promotion interventions. However, a lack of evidence supporting the use of eFHH tools in pediatric primary care is hindering their integration. The purpose of this project is to determine if an eFHH tool, completed by parents during a routine pediatric visit in an urban clinic setting, is a feasible option for collecting and documenting family health history data.

Specific Aims

1. Develop and implement a process for integrating a parent generated electronic FHH tool, My Family Health Portrait (MFHP), into a routine pediatric visit in an urban clinic setting.
2. Assess the data collected from the parent generated web based, electronic FHH screening tool, My Family Health Portrait (MFHP) for completeness of generational, health/disease specific information.
3. Identify operational and technical barriers and facilitators encountered by parents completing an electronic FHH screening tool during a routine pediatric visit.

Chapter Two – Literature Review

Synthesis of Evidence

History of FHH assessment methods. A pedigree is an inexpensive diagnostic tool used to record a familial lineage, gender, health and developmental conditions, age of disease onset for living and deceased relatives, current age or date of birth, and age and cause of death (Beadles et al., 2014). Historically, they have been used in clinical genetics but can be used by anyone (Bennett, French, Resta, & Doyle, 2008; Williams et al., 2011). Family Health History information is collected to assess for health risks, diagnostic decision making, reproductive counseling, and it defines' relationship among family members (Bennett, et al., 2008; Tarini & McInerney, 2013). Pedigree formats are typically preferred because graphical representation of information can be easily and quickly comprehended by providers (Beadles et al., 2014). Pedigrees have historically been hand recorded, by providers, during patient appointments and require this information be an uploaded document since EHR systems are not designed to capture health information in a pedigree format (Rinke et al., 2014). Hand recorded FHH documents are of less value, as data cannot be easily modified, mined or analyzed (McGonigle & Mastrian, 2015).

Another method to collect FHH is through the use of standardized questionnaires and screening tools designed to identify individuals at risk for a single or multiple common disease conditions (de Hoog, et al, 2014; Emery, 2005; Emery et al., 2014; Van Esch et al., 2013; Walter et al., 2013). These tools were designed for self-completion, in a variety of formats, and are scored to quantify risk and provide intervention recommendations (de Hoog et al., 2014). Questionnaires and screening tools were the precursors to more sophisticated eFHH tools (Cohn et al., 2010; Facio et al., 2010; Orlando et al., 2013).

FHH collection barriers. Primary care providers' state lack of time as the biggest barrier to collecting FHH (Christianson et al., 2012; Daelemans et al., 2013; Kanetzke et al., 2011; Mathers et al., 2010; Tarini & McInerney, 2013; Williams et al., 2011). However, many others barriers exist in FHH collection including: lack of standardized collection format, documentation issues, lack of knowledge regarding how to collect a health history, lack of reimbursement, lack of updated health information, unreliable or incomplete health information, patient's does not perceive value of information being collected, patient confusion about use of information and concern of potential liabilities (Christianson et al., 2012; Daelemans et al., 2013; Kanetzke et al., 2011; Mathers et al., 2010; Tarini & McInerney, 2013; Williams et al., 2011). Computer system documentation limitations and the inability to record information directly within pre-existing EHR negatively impacts resources (De Hoog et al., 2014; Welch et al., 2015). The lack of eFHH tools with EHR also complicates the ability to systematically gather and analyze data, which if adopted could eliminate some barriers (Van Esch et al., 2013).

Nursing perceptions regarding the importance of completing a quality family health history is another potential barrier, as nurses are often delegated the role of family history intake. Pestka, Meiers, Shah, Junglen, and Delgado found the majority of nurses who believe pedigrees can be useful for preventive health were also in favor of learning more about pedigree use and were in favor of collecting them (2013). However, the nursing profession is unprepared to adequately record and answer basic application questions as they pertain to family/genetic risk assessment (Skirton, O'Connor, & Humphreys, 2012; Thompson & Brooks, 2011).

Development of eFHH Tools. During the past decade, programs with the capability for electronic documentation FHHs with clinical decision support capabilities have begun emerging (De Hoog et al., 2014). Currently, there are several options that facilitate the electronic documentation of a web-based patient completed, also referred to as patient-facing, pedigree oriented FHH tool. MeTree, Health Heritage, and My Family Health Portrait are three eFHH which have all been tested and validated in the primary care setting (Cohn et al., 2010; Facio et al., 2010; Orlando et al., 2013). These FHH tools are accessible via the internet, completed by the patient and allow for the recording of prompt health information for three to four generations, including the patient's offspring (Cohn et al., 2010, Orlando et al, 2014; Surgeon General, 2015). These tools provide individualized risk categorization based on genetic susceptibilities, environmental conditions, and unfavorable lifestyle behaviors for each disease condition analyzed (Cohn et al., 2010; Facio et al., 2010; Orlando et al., 2013). These tools are also able to provide recommendations for health modifications and treatment interventions to the patient and primary care provider based on evidence based clinical care guidelines (Emery 2005; Facio et al., 2010; Orlando et al., 2014). However, eFHH tools do not currently interface with an individuals' EHR which prevents streamlined and shared documentation (de Hoog et al., 2014).

Electronic FHH tools were designed to be patient facing, meaning the patient enters the information into the program and the risk information and questions are asked from this individuals' perspective (Christianson et al., 2012). The series of questions about ones' personal and families health are documented and generate the information in a pedigree format. Currently no eFHH tools are designed to be parent-facing; which will require modifications to eFHH tools to prompt parents to enter information from their child's perspective (de Hoog et al., 2014).

Advantages to eFHH tools. Several studies have demonstrated the advantages to using eFHH tools. Volk et al. noted 53% of EHR had no FHH information for six common conditions (breast cancer, coronary artery disease, colon cancer, diabetes, osteoporosis and glaucoma) documented, in either the problem list or in the FHH section (2007). When patient where asked to electronically report the presence of six common conditions, the new information provided increased documentation of the six conditions from 32% to 95% (Volk et al., 2007). Carroll et al. compared the use of self-completed screening tools for reporting common health risks to current EHR documentation and found a greater identification by patients than had been previously recorded, especially for diabetes and coronary artery disease (2017).

Utilization of eFHH tools also revealed providers positive perceived usefulness of FHH to guide care, including: increased confidence in using family history, improved practice efficiency, and enhanced patient-provider relationship (Williams et al., 2011). These concepts were reiterated by Fuller, Myers, Webb, Tabangin, & Prows when the majority (73%) of primary care pediatricians felt computer generated tool would improve their ability to access health risk compared to their current data collection method (2009). These same providers also believed that using the eFHH tool would have no effect on or even increase their ability to see more patients per day (Fuller et al., 2009). Other providers' positive decisions regarding care improvement were based on the tools' analytical capability being able to provide care recommendations tailored to the individual patient (Buchanan et al., 2015).

Electronic FHH tools allow patients to engage in their care by completing their own independent risk assessment (Tarini & McInerney, 2013). The family health information is entered into a web based eFHH tool and can become a joint effort, between patient and provider, to improve knowledge of patient/family health conditions (Wu et al., 2013). Higher levels of patient engagement have demonstrated increased ownership of health promotion behaviors (Porter-O'Grady & Malloch, 2015).

Adoption of FHH tools. FHH tools seem to have another challenge. How does one make providers adopt their use? Despite the need for a family history for every patient, only

31% of providers agreed/strongly that 3 generation pedigrees were actually collected (Rinke et al., 2014). Murray et al., compared current EHR data to patient entered data using three different portals, telephone voice interaction, secure internet portal, and a waiting room lap top to determine if one data method collection impacted use of eFHH tools (2013). Murray et al. observed increases from all methods of data collection, however patient using the portal were the highest (23.1%) rates, followed by in clinic entry (20.3%) compared to new information entered by staff (1.7%) (2013).

Selecting a setting which can combine patient/parent completed eFHH tools in a prevention care environment would be ideal. For this reason, the primary care setting is best suited for implementation of FHH tools. In addition to being health educators and promotors, the longitudinal nature of the primary pediatric care providers' relationship with the patient/family allows for multiple opportunities to obtain, and continually update, FHH information (Scott & Trotter, 2013). Family health history tools can promote patient engagement by using personalized health notes to empower individuals to be responsible for their own health outcomes (Sidorov & Romney, 2016; Tarini & McInerney, 2013). Another reason to integrate eFHH tool in primary care is they raise awareness and increase health communication among family members (Hovick, 2014). The development of eFHH tools which do not over burden the resources of primary care providers, but instead empower patients to become stewards of their own health information are necessary for adoption (Daelemans et al., 2013).

FHH and social determinant of health. The Commission on Social Determinants of Health, 2008, recognized social factors as having a significant impact on health behaviors and outcomes (Halbert, et al., 2016). Social determinants of health include: access to health care, individual behaviors, social and physical environment, genetics, individual biology, disabilities and disparities such as race, ethnicity, socioeconomic status, geography, gender, and age (Nash et al., 2016). Family health history tools are designed to improve access to health care by supporting direct public access to the tools. The intent of the U.S. Surgeon General's focus on launching MFHP, as part of the Family Health Initiative, was to increase public awareness by providing greater access to an eFHH tool with risk analysis capabilities for colon cancer and diabetes (Surgeon General, 2015). FHH tools incorporate genetics, but recognize the impact other determinants such as environment, disparities, individual behaviors and individual biology have on influencing health risk. Vulnerable adult populations have also raised the concern that multiple factor combinations make one more susceptible to diseases then genes alone; potentially impacting their perception of eFHH tools to usefulness (Hartman et al., 2015).

Studies focused on disparities and FHH tools while limited, have provided some insight into race, gender, and age differences. African Americans were noted to have limited knowledge about genetics and concepts of FHH application to disease, however they are more likely than whites to gather/ask family members about their FHH information (Ashida, Goodman, Stafford, Lachance, & Kaphingst, 2012; Halbert et al., 2016; Kessler, Collier, & Halbert, 2007). Despite being more likely to gather the information, African Americans were less likely to report/record FHH information, even when perceived as important (Thompson et al., 2013). Younger women are more likely to record FHH than older women (Halbert et al., 2016). Historically, higher proportions of women record FHH information then men, with lowest reporting from males of racial and ethnic minority groups. Family Health History tools detect conditions, such as increased diabetes and heart disease, which are more common in racial minorities, emphasizes the potential benefit of eFHH tool adoption to assess for increased health risks (Yoon et al., 2012).

Another consideration is the impact of disparities on literacy levels. Wang, Gallo, Fleisher, & Miller assessed the literacy level of 47 FHH tools (2010). Their findings revealed the majority of tools were at the 12 to 13 grade reading level, well above the national literacy average (Wang et al., 2010). Wang et al. findings support the need to simplify FHH tools to make them usable for the general population (2010).

Studies using My Family Health Portrait (MFHP). Studies utilizing MFHP began with a validation study demonstrating the tool showed high sensitivity and specificity for four, breast, colon, ovarian cancer and diabetes, of the six common conditions tested (Facio et al., 2010). Kanetzke et al. evaluated pediatric primary care providers' perceptions of utilizing MFHP in clinical practice (2011). The providers recognized the benefits of adopting it as a tool since it could improve FHH information gathered and facilitate targeted education and prevention recommendations (2011). These pediatricians also reported time as the most significant barrier to FHH data collection with the ability to collect FHH information prior to the appointment the most needed facilitator (2011). An evaluation to assess the perception of using MFHP in clinical practice for tool mechanics, possible clinical application and barriers with future providers' was completed using medical students (Owens et al., 2011). The tool was well received with potential concerns of access, accuracy, technology limitations and the need for further education for providers for interrupting risk were expressed (2010).

Two studies evaluated MFHP with different population groups. The first introduced MFHP into a faith-based community setting by using faith-based community nurses (FCN) to integrate the tool (Newcomb et al., 2014). The FCN educated the community on FHH usages, the MFHP tool, and assisted with data collection (2014). FCN were selected to determine if a trusted provider, within the community, could influence use of integration; however, one significant barrier noted was the FCN's mistrust in the electronic storage of date (2014). The second study evaluated mothers' perception of the benefits of using MFHP and their willingness to complete tool (Berger et al., 2013). Perceived benefits were sharing information with child's health care provider and option for preventative screening based on FHH information collected (2013). The tool was reported to be user-friendly and would be able to be completed prior to health care appointment (2013).

Different administration modalities were tested to determine if the location or method of completion improved completion rates (Murray et al., 2013). Participants were asked to collect FHH information using a telephone-based interactive voice response system, internet portal and in clinic computer access to standard care (2013). Documentation was higher for all three alternative methods of collection to standard care, with internet portal providing the highest completion rate, closely followed by clinic access (2013).

Concepts and Definition

Ability/Completeness **-** defined as the capacity of the participant to enter personal health information, family member numbers, family member's personal health information, addition of extra family members and inclusion of health conditions in MFHP tool.

Additional interruptions - defined as any process which stopped the participant from continuing to enter data in MFHP, which were not part of standard clinic intake, interaction or process.

Clinic interruptions - include moving location, completion of clinic questionnaire – health, developmental and social, registration process, triage/vitals, nursing or medical assistance intake, resident evaluation, attending evaluation, nursing interventions, and discharge.

Down time: time not spent interacting with registration or clinical staff which would impact the quality or length of patient visits.

FHH – Multigenerational information, typically 3 generation or more, document patient and families members health/disease status (Beadles et al., 2014).

FHH tools – An instrument used to systematically collect family health history information (Williams et al., 2011).

eFHH tool – A FHH tool completed using a software program to collect and document information (Cohn et al., 2010).

Parent-Generated – (also known as parent completed) – Means FHH information is entered and tool completes the collection of data.

Patient-Completed (also known as Patient-Facing) – The documentation/process is completed by the patient, not the provider. In the use of eFHH tools patient completes the tool independently, the provider does not enter FHH information (Orlando et al., 2013).

Pedigree - A diagram of standardized nomenclature used to record a familial lineage, gender, health and developmental conditions, age of disease onset for living and deceased relatives, current age or date of birth, and age and cause of death (Beadles et al., 2014).

Points of Difficulty – These are notations marked on field notes detailing at what point in the MFHP tool participants asked for assistance.

Risk/risk identification – The ability to quantify an individual is at greater likelihood to develop a health complication, condition or disease (Carroll et al., 2017).

Theoretical/Conceptual Framework

Nola Pender's Health Promotion Model (HPM) was selected as the theoretical framework, for the DNP Scholarly project, because the use/completion of an eFHH tool is a health promotion behavior, a process to actively avoid illness or detect it early (Zaccagnini & White, 2014). Pender's overarching concept, in her framework, was each person responds differently based on their personal characteristics and prior experiences (Pender, Murdaugh, & Parson, 2011). It is through recognition of these characteristics and experiences nurses can promote the health behavior by identifying and modifying barriers to assist health promotion behavior (2011). The HPM will be used to provide guidance for researcher field observations and to structure study findings regarding the feasibility of an eFFH tool use, as health promotion behavior, with a vulnerable pediatric population.

The premise of the HPM is that psychosocial components, personal biology, psychology, and sociocultural influences, affect health promotion behaviors (Pender et al., 2011). The desired health behavior to be adopted is the use of the eFHH tool among parents of a vulnerable urban pediatric population. However, the parents' prior related behaviors and personal factors will influence their ability and interest to participate (2011). Prior related behaviors could include: the impact perceived benefit of completing the eFHH tool, perceived barriers to completing the eFHH tool, perceived self-efficacy and the belief they possess the ability to complete the eFHH tool, and beliefs regarding how the process of completing the eFHH tool might affect them personally (Zaccagnini & White, 2014). Personnel factors are separated into two areas: interpersonal influences (such as family, peers, healthcare providers, social supports and through modeled behaviors) and situational influences (such as options, demands and environmental aesthetics) (Pender et al., 2011).

Use of an eFHH could be swayed by families' influence of health risks, strong rapport with health care provider supporting health promotion behavior, while a busy life style limiting time to complete eFHH or no portal access to eFHH could negatively affect participation (Pender et al., 2011). Either positive or negative influences impact the participant's plan to act or initiate participation and attempt to complete the eFHH tool. Immediate competing demands such as multiple interruptions by clinic flow, meeting demands of child/children while in clinic, or preference to leave prior to tool completion if patient's appointment is over could also disrupt completion of the eFHH tool. The goal of the HPM is to meet a particular health promotion behavior (Pender et al., 2011). As it related to this the goal would be the successful completion of the MFHP tool.

Every participant has prior personal characteristics and experiences which will influence the option to become a participant and the participation process. These are defined as behavior-specific cognitions & affect and will either motivate them to participate or decline. Motivational factors could include: perceived personal benefit, a sense of empowerment from completing eFHH tool or being able to share information positively. Perceived complexity of tool, difficulty using computers, limited family knowledge or not wanting to be inconvenienced could all be potential barriers to participation. Interpersonal influences, such as attending the appointment with family, willingness to please healthcare providers, and modeling of other parents seen participating could be potential participation influencing factors. The ability to provide an environment supportive of completing the eFHH tool, which will include: tablets with internet access, comfortable setting area, toys and a play area for children to occupy themselves could also prompt parents to participate. This combination of behavior-specific cognition and affect factors lead to completing informed consent and initiating the participation process. After initiation, there are other factors, such as immediate competing demands, such as clinic flow, or preferences, such as responding to text message or cell phone, which could impede the completion of the health behavior, eFHH tool. The role of the nurse could/will be to positively impact the motivators, barriers, influences and competing demands to support the health promoting behavior of completing the eFHH tool.

Summary

The use of eFHH tools has been proposed as a systematic approach to assessing for common health risks (Buchanan et al., 2015; Carroll et al., 2017; Kemper et al., 2010). The ability to have patient/parent entered data in electronic format could improve documentation and functionality of FHH information. This information would be viewable to anyone in the individuals' EHR and also enables computer generated health risk analysis to be performed (De Hoog et al., 2014). Multiple reasons have been attributed to the inability to successful integrate FHH collection into routine health care; the most commonly reported barrier is burden to the clinical staff (Christianson et al., 2012; Daelemans et al., 2013; Kanetzke et al., 2011; Mathers et al., 2010; Tarini & McInerney, 2013; Williams et al., 2011). By transferring the burden of data collection/documentation of FHH to the patient/parent; health care workers could use this time to focus on health care needs, education and prevention. This DNP scholarly project proposed was intended to increase knowledge regarding how eFHH tools could be used in a pediatric primary care setting.

Chapter Three – Methodology

Overview

The use of FHH tools in the urban pediatric care setting could support the identification of familial health risks and allow for early health education and lifestyle promotion interventions. However, a lack of evidence supporting the use of eFHH tools in pediatric primary care is hindering their integration (Beadles et al., 2014; De Hoog et al., 2014; Owens et al., 2011). The purpose of this DNP scholarly project was to determine if an eFHH tool completed by parents during a routine pediatric visit, in an urban clinic setting, is a feasible option for collecting and documenting family health history data.

The specific aims of the project were to:

1. Develop and implement a process for integrating a parent generated, web based, electronic FHH tool, My Family Health Portrait (MFHP), into a routine pediatric visit in an urban clinic setting.
2. Assess the data collected from the parent generated electronic FHH screening tool for completeness of generational, health/disease specific information.
3. Identify operational and technical barriers and facilitators encountered by parents completing an electronic FHH screening tool during a routine pediatric visit.

Project Design

This descriptive observational project was designed to implement and assess the feasibility of using a parent completed eFHH tool in an urban, pediatric, primary care clinic. A descriptive design was chosen to allow for structured observations of participants to quantify their ability to complete the eFHH tool. Ability was defined as the capacity of the participant to open the program, enter personal health information, family members and their family members' personal health information, addition of extra family members, and inclusion of health conditions in the MFHP tool. Additionally, this project described facilitators and barriers experienced by families when using the electronic FHH tool, MFHP. The clinic selected is part of a large tertiary teaching hospital designed to provide high volume primary care to an urban, pediatric population. Participants were asked to complete the MFHP tool and a brief questionnaire regarding ease of use, preferred completion setting and internet access to facilitate current understanding and future considerations. Demographic questions were asked to define the study population.

Participants. A convenience sampling method was used to select 40 participants. Potential participants were identified using the clinic's patient list and their presence in the waiting area. Initially, the researcher proposed to select well child care visit types only as the focus is on preventive interventions and health education and family health history could be used to guide recommendations. However, the clinic's research committee recommended utilizing patients from all visit types, as well visits within their clinic population are often not scheduled and preventive care is routinely incorporated within ill visit appointments. Therefore, all parents of pediatric patients present for clinical evaluation were considered for enrollment. After initial registration was completed, potential study participants were approached by the primary researcher in the waiting area to explain the project, offer enrollment and obtain verbal consent. Enrollment was voluntary and termination of participation or completion was determined by the participant. Participants were provided a copy of the study information sheet, which included information regarding purpose of study, an explanation of the study, study contact information, inclusion and exclusion criterion, risk, privacy, protection of health information and refusal/termination options (see Appendix A for Study Information Sheet).

Inclusion and Exclusion Criteria. Participants who were considered for participation met the following:

Inclusion Criteria

- Patient’s biological mother or father
- Patient was less than 18 years old
- Patient was present for clinical visit
- Parent was able to read and/or verbally understand the English language.

The following were excluded from participation:

Exclusion Criteria

- Adoptive parents, foster parents or court appointed guardian accompanied patient to clinic appointment
- Patient was a legal adult, 18 years of age or older
- Biological parent was unable to read, speak or verbally understand the English language.

Parents of patient’s ranging in age from one week to 17 years regardless of their gender, race, ethnicity or socioeconomic status were asked to participate in the study. If English proficiency became an issue for participants after beginning to fill out the MFHP, the researcher would have read the MFHP electronic tool to them and either allowed them to document their responses or have them recorded by the researcher. This option was included to minimize any embarrassment to a participant who had English proficiency difficulties and to increase understanding of limitations or barriers parents might have completing the MFHP. However, the researcher did not have to read the tool to any participants.

Instruments

Instrument – My Family Health Portrait (MFHP). The U.S. Surgeon General's web based eFHH tool, My Family Health Portrait, was selected for this project. My Family Health Portrait was designed for the general population to enter their (1) own health information and some basic biological data, (2) family members' health information, (3) build a pedigree, (4) complete analysis for common disease health risks, (5) provide personalized intervention plan and (6) encouragement to share this information with their primary care provider (Surgeon General, 2015). MFHP demonstrated varied sensitivity ranging from 67 to 100 % for recording the six conditions, diabetes, colon, breast and ovarian cancer, coronary artery disease and stroke, when present, correctly in MFHP, compared to FHH information verbally collected by a genetic counselor (Facio et al., 2010). The specificity for a condition not being recorded, when it was absent, ranged from 92 to 100% for the same six conditions, diabetes, colon, breast and ovarian cancer, coronary artery disease and stroke (2010).

MFHP is written at a10.7 reading grade level (Wang et al., 2010). Questions asked by the program were simplified, by the tool's designer, to the lowest reading level. However, health condition or disease name(s) are typically at a higher reading level, that even with the use of lay terminology the reading level remained high.

Directions to complete the MFHP tool are contained within the program. A verbal explanation by the researcher and a written guide for participants with modifications for collection of personal information was provided immediately prior to beginning MFHP (see Appendix B for Participant's Instructions). This, written guide was added to remind participants they were not to enter their name, but only mom or dad, nor enter their height and weight to avoid a private identifier being recorded. Participant's date of birth was required by the program to be entered; however the tool only reports age in years. Examples of the questions as they appear on the MFHP tools were included in Appendices C-E as:

- Appendix C - Questions asked about the person completing the tool, including: mom or dad in the name field, gender, age, twin status, adoption status, height, weight, health conditions and age of onset, consanguinity, race and ethnicity.
- Appendix D – Questions regarding the number(s) of family members, brothers, sisters, sons, daughters, aunt and uncles which is used to generate the pedigree.
- Appendix E- Questions which are asked about each participant’s family member including: name, gender, living/deceased, age, adoption status, health conditions and age of onset, consanguinity, race and ethnicity. These same questions are generated for each family member added in the pedigree. The example is for personal information about the participant’s father.

After questions were answered about each full, immediate relative, blood relative; other relatives (such as cousins, nieces, nephews, half siblings and grandchildren) were able to be added. Non-blood relatives, including step-relatives, household members or spouses are not included in the pedigree program (Surgeon General, 2015).

Questionnaire regarding participants’ views following MFHP use.

A questionnaire was developed, by the researcher, to gather additional information about the participants’ views regarding FHH information as it pertained to their child(ren)’s health care. This questionnaire, which was administered after the parent completed the MFHP, used a five point Likert scale to score questions about:

- Ability to complete MFHP independently
- Ability to complete MFHP at home or outside of clinic setting

- Intention to ask family members about unknown health information
- Ability to add unknown information at a later time by internet
- Enjoyment in entering FHH information
- View that tool was easy to use
- View that tool was difficult to use
- Intention to complete MFHP if integrated as part of child's appointment
- Belief that providing FHH is important to child's health care (see Appendix F for Participants' Views Following MFHP Use).

The purpose in gathering this information was to further inform on the feasibility of utilizing an eFHH tool with the proposed population. The questionnaire was reviewed by two independent nursing research experts, one with prior research experience with FHH tools and MFHP, for clarity of content and usability.

Field notes. A two-page document, field notes, was created by the researcher prior to beginning the study. The first page of the document was designed to facilitate recording the researcher's observations when participants were filling out the electronic MFHP tool. This document was used to record: start/stop time to fill out the MFHP, number of times participant were interrupted while filling out MFHP, the reason for the interruption, did the participant complete data entry for each section of MFHP (personal health information, number of family members to build pedigree, and family members' health information) and space for recording researcher's observations or participants comments (see Appendix H for Field Notes). The second page was used to record and tally information such as number of family members added and where in the patient pathway the parent completed the MFHP and to ensure a copy of the tool was printed.

Demographic questionnaire. A demographic questionnaire was designed, by the researcher, to define the parent population that participated in this DNP scholarly project (see Appendix G for Demographic Questionnaire). Demographic questions included: participants and child's age, if mother or father was filling out the eMFHP, number of people living in the household, race, ethnicity, parent's marital status, employment status, education level, household income, and insurance type. The choices for race and ethnicity were exactly the same as the categories within the MFHP (Surgeon General, 2015). The categories for parent's marital status, employment status, education and insurance type were based on other demographic tools (Pew Research Center, 2017). The household income categories were based on federal poverty level, as the number in household and the income, would have allowed the population to be categorized as above or below poverty level (Jobs and Family Services – Ohio, 2017). This questionnaire was also reviewed by two independent nursing research experts, for clarity of content and usability. However, there was an error in the questionnaire which was not noted until the time of analysis, the income question had a category from $20,420-$28,720 which should have been divided into two categories, $20,420 - $24,600 and $24,600 - $28,720. The project population selected was predicted to be an urban population of lower socioeconomic and education levels, who have higher percentages of government provided or subsidized insurance, and consist of higher minority percentages than the general population for the county.

While participants were asked to complete the MFHP during their child(ren)'s appointment(s), additional questions were asked regarding possible tool completion preferences, which were categorized as facilitators or barrier. Participants were to select if they would have preferred having someone ask and record FHH in their child's EHR, current process, or if they would have preferred to complete FHH questions on their own. Participants were also asked if they would have preferred to complete the MFHP tool at home, or if the clinic was the preferred setting. To assess if participants would even have the option to complete an eFHH tool away from a clinic setting, participants were asked if they had internet access in their home or community (see Appendix G for Demographic Questionnaire).

Project Plan

Preparation. Multiple steps were completed in preparation for data collection. Individual packets were assembled, including project information sheet (see Appendix A for Study Information Sheet), participant instructions (see Appendix B for Participant's Instructions), field notes (see Appendix H for Field Notes), and participant's perceptions, beliefs and intentions and demographic questionnaires (see Appendices F for Demographic Questionnaire and G for Participants' Perceptions Following MFHP Use Questionnaire). Clipboards and pens were obtained for participants to complete the questionnaires.

Electronic tablets were donated for use during the study by CCHMC's Patient Services Department. Short cut links to the MFHP tool were placed on the tablets to allow direct access to the MFHP tool. Tablet to printer access was established to facilitate printing copies of the MFHP tool immediately after participant completion, thereby allowing the researcher to place all completed documentation together in an envelope for later data analysis. Permission to use clinic printers was obtained to allow researcher to provide a copy of the parent completed MFHP tool to participants prior to leaving if requested.

Project Details

Participant involvement.

Step 1 – Participant identification. Potential parent participants were identified following the initial registration process for their child's appointment by verification in the clinic's appointment log and/or researcher present in the clinic waiting area.

Step 2 – Participant enrollment. Participants were approached by researcher in the waiting area. Self-introduction of researcher, explanation of project, and inclusion/exclusion criterion were provided. If parent met participation criterion and was interested in participating, the project information sheet (see Appendix A for Study Information Sheet) was reviewed and further information was provided regarding completion of a web based medical and family history tool called My Family Health Portrait. Participants were told following use of MFHP there would be two paper questionnaire, one demographic and the other about participants view related to using the MFHP.

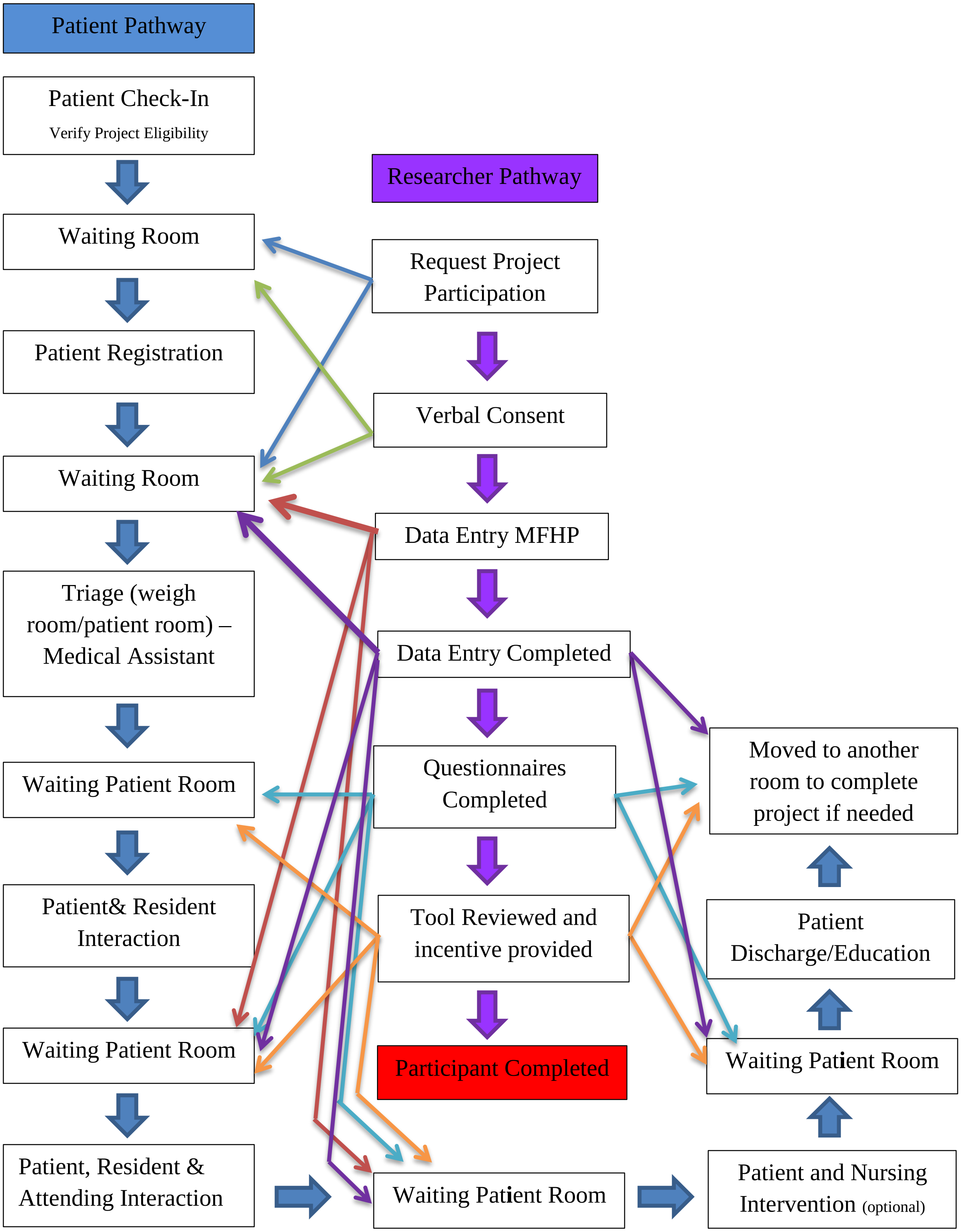
Step 3 – Participant engagement. Participants were provided with necessary project materials, including a paper copy of written instruction to assist the participant with completing the web based MFHP tool (see Appendix B for Participant's Instructions). An electronic tablet for data entry of FHH information in the MFHP tool was provided. Paper copies of the participants' perceptions following MFHP use questionnaire (see Appendix F for Participants' Perceptions Following MFHP Use Questionnaire) and demographic questionnaire (see Appendix G for Demographic Questionnaire) were provided with clip boards and writing utensils for completion after the MFHP tool. Participants were given the option to ask further questions prior to beginning, and were instructed to ask for assistance if needed.

Step 4 – Participant wrap-up. Following participants' completion of the MFHP, a paper copy was printed to record the information entered, for data collection. No electronic copy was saved. A project identifier number was recorded on the paper copy, top right corner, of the MFHP generated tool, in pedigree format. A second copy was printed for participants to retain, if desired. Copies of the MFHP tool documentation and questionnaires were placed into an envelope and sealed for later data analysis.

Project setting and length. It was anticipated completion of the MFHP tool and questionnaires could occur in several locations, such as the waiting area, weigh room and patient room (see Figure 3.1). Time to complete the tool could also be interspersed with other clinic tasks, such as patient triage questions, other health and developmental questionnaires, clinical evaluation, immunizations and patient education. Participation with this project was secondary to patient and clinic demands. If the child's entire evaluation was completed prior to their parent completing the MFHP and two questionnaires, participants could stay and complete MHFP and the questionnaires, stop filling in MFHP data and complete the questionnaires, or had the option to leave without completing MFHP and the questionnaires.

Participants and researcher's involvement in data collection. Data collection began when participants started filling out the MFHP and ended when all documentation was completed, printed and placed in an individually marked envelope for later data analysis. Data collection consisted of participants completing the MFHP instrument, the questionnaire regarding participants' views following MFHP use, and the demographic questionnaire. Observational data was recorded on the field notes and consisted of the researcher

Figure 3.1: PPCC Proposed Integration Process Map



noting:

- number of times participant were interrupted (stopped entering data into MFHP)
- the reason for the interruption
- point of difficulty (reason participant asked for assistance)
- operational or technical barriers
- operational or technical facilitators.

The researcher was present during participant completion of the MFHP to answer questions or assist as requested, while observing for barriers and facilitators to completing the MFHP tool.

Ethical considerations and consent. A project proposal was submitted to Cincinnati Children's Institutional Review Board (IRB) and the study was deemed exempt (see Appendix I for CCHMC IRB Exemption). Xavier University required copies of CCHMC study application, proposal, and appendices to be submitted for review prior to completing an alliance agreement with CCHMC IRB (see Appendix J for IRB Alliance Agreement Signature Page). Signed copies of the alliance agreement and IRB required documents were retained by CCHMC, XU, and primary researcher. Prior to submission with CCHMC IRB additional reviews were also completed with Patient Services and the Research Review Committee in the Pediatric Primary Care Clinic.

Because the study was exempt, informed written consent was not required for participants to participate in this DNP scholarly project. However, an information sheet (see Appendix A for Study Information Sheet) was requested and approved, by IRB, to be provided to participants with the following information:

- Introduction to research (project)
- Why research (project) is being completed

- Who is in charge of research (project), including primary researcher’s name and contact information
- Criterion for who should not be in study (project)
- What will happen in study (project)
- What are the bad things that can happen from this research (project)
- What other choices are there
- How will information about you (participant) be kept private
- What if new information is learned during the research
- Will it cost you (participant) anything extra to be in the research study (project)
- Will you (participant) be paid to be in the research study (project)
- Who do you (participant) call if you (participant) have questions or problems?

The information sheet was to guide verbal consent, outline patient/families rights, and provide contact information to the researcher if needed.

Participation in this DNP scholarly project was not intended to be of direct benefit to the participant. Participation in study was intended to increase the researchers understanding of the feasibility of integrating an eFHH tool in a vulnerable population. Participation in the study was not expected to present any physical, psychological, economic risks or discomforts. Participants were expected to spend 20-30 minutes completing the eFHH tool and questionnaires. The intention was to complete the eFHH tool and questionnaires during waiting or downtime in combination with patient evaluation for their clinic visit. However, if this time was limited, completion after the appointment was requested, but not required. In acknowledgement of their efforts, each participate was provided with a ten dollar gift card, this information was relayed at time of study introduction and the gift care was provided when participant's self- reported they were finished.

Budget. An incentive, ten dollar gift card, was provided to all participants regardless of completeness. Total cost of project was four hundred dollars, paid by researcher, in the form of a ten dollar gift card to Kroger's, Target, or Walmart to each participant.

Data storage and access. The project design allowed for information to be collected without personal identifier begin recorded. Participant and patient's age was collected, on the questionnaire, instead of date of birth to eliminate a direct identifier. Zip codes were collected to define geographic location; however there was no ability to identify a specific area within the zip code. Copies of MHFP, the participants' views following MFHP use questionnaire, the demographic questionnaire, and field notes were coded with a unique study identifier to keep all of the participants' data together for later analysis. The researcher did not obtain or keep any patient identifiers which could be link data collected to the participant or patient. Project data were stored in a locked cabinet in the researcher's office and will remain there until three years following completion of study and then destroyed. Information when entered into an Excel spreadsheet for analysis was listed by unique identifier. Raw non-identifiable data may be shared with research committee members, project and/or statistical experts. Raw data were stored on a locked server secure individual computer.

Timeline

A project timeline was included outlining completion of tasks from submission of Chapters 1-3 coinciding with DNP project defense and concluding with the presentation of the DNP capstone (see Appendix K for Project Timeline).

Resources

Completion of the project required governmental, intellectual, institutional, organizational and personal resources. Government resources were used to develop MFHP tool and complete an initial validity and reliability study (Surgeon General, 2015). Independent intellectual resources were committed to validate clinical feasibility and utilization comparisons with different populations (Berger et al., 2013; Facio et al., 2010; Kanetzke et al., 2011; Murray et al., 2013; Newcomb et al., 2014). Institutional (CCHMC and XU) resources were spent by faculty and staff supporting development, review and approval of this project. Xavier University also provided the use of IBM SPSS Statistical Software package for computing descriptive statistics. Cincinnati Children's Hospital Medical Center supported use of resources for completion of data collection process: tablets, printers, copiers, paper and use of clinical space. Personal resources included: cost of incentives and the research time and effort developing, designing, implementing, analyzing and reporting on the project.

Evaluation Plan

Specific aim 1. Specific aim 1 was to develop a process for integrating a parent-generated, web based, electronic FHH tool, My Family Health Portrait (MFHP) into a pediatric visit in an urban clinic setting. A process map was designed prior to project initiation, based on clinic flow assessments, which was used to define the patient and researcher's pathway for project integration (see Figure 3.1). The patient pathway highlights the different stages of the child's appointment: check-in, registration, triage, resident evaluation, resident and attending evaluation, nursing intervention(s), and discharge. Waiting periods could occur between any of these stages and took place in the waiting room or patient room. The researcher's pathway includes: request to participate, verbal consent, observation of MFHP data entry on tablet, providing demographic and participant's views following MFHP use questionnaires and reviewing tool and providing copy of paperwork and incentive at completion. The arrows in Figure 3.1 from the researcher's pathway to the patient pathway show when each step might be completed. Completion of each step is done in sequential order using the patient's downtime (not being seen by clinic staff) for the parent to be able to participate in the project. Modifications were made to simplify the PPCC Proposed Integration Process Map following initial data collection, to include when data entry began and was completed or stopped on the MFHP

Specific aim 2. The second specific aim was to assess for general completeness and inclusion of health information when using a parent-generated MFHP tool for collection of FHH data. Measures to assess for completeness included: completion time, completion of data entry for all three sections of the MFHP (personal health information, family member numbers, and family member's personal information), number of times and reason data entry was paused/stopped (interruptions), addition of extra family members and inclusion of health conditions. Descriptive statistics were used to summarize length of time, percentage of completion, range and average of family members, total number and average of interruptions, total and average number of health conditions recorded.

Degree of MFHP completeness was measured for each of the three individual sections and collectively. This evaluation began by measuring completion of Section 1 for personal health data entry; which required participant's to enter their date of birth, which was recorded by the program as an age, race and ethnicity to advance to section 2 of the MFHP. Section 2, family member numbers, was measured as complete by participant advancing to section 3 of the MFHP. To advance to section 3, a response was required to all questions in section 2. Section 3, family member's personal health information, required more data entry and was more complex to measure. For each family member added, it was necessary to open a personal health information sheet and respond to the following questions: name, gender, living/deceased, age, adoption status, health conditions and age of onset, consanguinity, race and ethnicity.

Descriptive statistics were used to express first, how many participants completed data entry for all family members and secondly how much information was recorded per family member. Data were used to determine how much information was recorder per family member, how many individual family member's personal health information screens were opened, how many family members had recorded personal information such as age, race or ethnicity, how many family members had recorded health conditions and how many health conditions were recorded.

The number of interruptions, pause/stopped entry of information into MFHP tool, and reason for the interruptions were recorded on the field notes. Interruptions were divided into two categories for measuring, clinical and additional, as defined by operational definitions. Clinical interruptions were any activity which stopped entry of information into MFHP and is part of the standard clinic intake, interaction, or process; such as: moving location, completion of clinic questionnaire – health, developmental and social, registration process, triage/vitals, nursing or medical assistance intake, resident evaluation, attending evaluation, nursing interventions, and discharge. Additional interruptions were defined as any process, which stopped the participant from continuing to enter data in MFHP, which were not part of standard clinic intake, interaction or process. Descriptive statistics were used to highlight the total number and types of interruptions collectively, but were also divided into two categories for comparison of those who reported completing section 3, family health information, and those who did not.

Data variables and statistics. A data variable set was developed to define, for Specific Aims 1 &2, what information was collected for IRB review and to assist the researcher with analysis (see Appendix L: Data Variables). Data were coded and entered into an excel file for analysis. IBM SPSS Statistics, Version 24, completed the computation for this project.

Specific aim 3. The third aim was to identify operational and technical barriers and facilitators encountered by parents while completing an electronic FHH screening tool during a pediatric visit. Researcher's observations, during completion of the MFHP, recorded in the field notes were assigned to one of four categories: points of difficulty, barriers, facilitators and parent recommendations. Barriers and facilitator measurements were structured using Pender's Health Promotion Model (HPM). Operational barriers and facilitators, within the HPM framework, could include: prior behaviors, personal factors, behavior-specific cognitions and affects, and completing demands and preferences (Pender, Murdaugh and Parsons, 2011). Technical barriers and facilitators could include: preparation for tablet use, properly functioning website and printer, and situational influences within the setting.

A questionnaire, Participants' Views Following MFHP Use, was used to further assess participants views following MFHP use (see Appendix F: Participants' Views Following MFHP Use). The questions on this tool, Participant's Views Following MFHP Use, were scored as: 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree and 5 = strongly agree and later condensed into three categories disagree, neutral, and agree. Participants responses to the Participants' Views Follow MFHP Use Questionnaire were then categorized as, operational or technical, barriers or facilitators, based on the majority responding favorably or negatively.

Responses to questions from the demographic questionnaire regarding internet access, preferred data entry setting, and participant's preference for assistance versus self-completing the MFHP were summarized using descriptive statistics. Presence of home and/or community internet access, for possible use to the MFHP outside of the clinic setting, was measured to determine if this could be a possible facilitator or barrier. Preferred setting for completing the MFHP was asked to assess if clinic versus home setting could be a potential operational barrier or facilitator. The last question asked was would you (participant) have liked having someone ask and record the questions about your families health or did you like completing the questions on your own. Depending on their response, this information was considered an operational facilitator or barrier.

Participant's demographics. Demographic variables were collected to describe the population by parent's age, gender, race, ethnicity, household size, parent's marital status, education level and employment, zip code, insurance coverage, and age of their child who was visiting the clinic (see Appendix G for Demographic Questionnaire). Descriptive statistics were used to define the population.

Sample Size

The sample size, for this feasibility project, was set at forty participants. The population was anticipated to be fairly homogenous based on known clinic demographics. Ongoing analysis of data, during the data collection phase, was completed to assess for variability indicating potential need to adjust sample size.

Logic Model

A logic model was included to visually highlight the projects components, activities, outcomes and potential long term outcomes (Kellogg Foundation, 2004). The model begins by listing all of the resources (also known as inputs) necessary to establish and maintain the project (see Appendix M for Logic Model). The next step is to define the target population. The target population for this project was the parents of pediatric patients receiving care in an urban primary care clinic. The goals were to: develop a process map for integrating an eFHH tools, assess parents' ability to complete the MFHP, assess the data collected for completeness of an electronic FHH screening tool, MFHP, and identify barriers or facilitators to integration.

Activities needed for project completion included: establishing relationship with clinical setting, understanding of clinic flow, selection of eFHH tool, formalization of project, acquiring physical resources (tablets, printers, copiers, space), implementing test cycle, and analysis of data. Initial outputs will include: meeting the defined goals and increasing exposure to eFHH tools and innovation, increase the understanding of the feasibility of integrating an eFHH tool, increase understanding of the use of MFHP with a vulnerable population and disperse project findings by sharing with institutional stakeholders and publication. A potential long term outcome could be the development of a parent-generated, pediatric based eFHH tool which could be interfaced through patient's EHR portal.

Methodology Summary

The purpose of this project was to implement a parent-generated electronic family health history (FHH) tool with an urban, pediatric, primary care population. Parent participants were asked to record their FHH using an electronic tablet in MFHP and complete two questionnaires. A proposed clinic process map was used to guide project integration. Descriptive statistics were used to define project integration success, tool completeness, documentation of health conditions, interruptions, tool ease of use, preferred completion setting, internet access, and the patient population. Project barriers and facilitators were recorded and categorized as operational and technical. Project results, demonstrating the potential integration of a parent-generated FHH tool, are summarized in the following chapter.

Chapter 4 – Results

Forty parent participants completed an electronic FHH tool and two questionnaires (participant's views following MFHP use and demographics) to evaluate the feasibility of collecting and documenting family health history data during a pediatric visit in an urban clinic setting. The specific aims of the project were to:

1. Develop and implement a process for integrating a parent generated, web based, electronic FHH tool, My Family Health Portrait (MFHP), into a routine pediatric visit in an urban clinic setting.
2. Assess the data collected from the parent generated electronic FHH screening tool for completeness of generational, health/disease specific information.
3. Identify operational and technical barriers and facilitators encountered by parents completing an electronic FHH screening tool during a routine pediatric visit.

Demographics

Parent and child's demographics. Forty biological parents, of children present for appointments, ranging in age from 21 to 52 years, with a mean age of 31 years, participated in the DNP project, 39 mothers and 1 father (see Table 4.1). However for five children, while both parents were present for the child's appointment, only one of parent completed the project. Four potential parents declined participating, 3 mothers and one father. A total of forty-four children were present for appointments for the 40 parents who participated in the DNP project. The children ranged in age from 2 weeks to 13 years of age with a mean age of 4.14 years (see Table 4.1). Additional demographic data regarding race and ethnicity and marital status are listed in Table 4.1, and, employment, parent education level, income, insurance coverage, and household size are listed in Table 4.2.

Table 4.1

Participant Demographics

Demographics	Participants (N=40) n (%)
Parent	
Mother	39 (97.5%)
Father	1 (2.5%)
Parent Participant's Age	
21 – 25 years - 10 (25%)	10 (25%)
26 – 30 years – 11 (27.5%)	11 (27.5%)
31 – 35 years – 13 (32.5%)	13 (32.5%)
40 – 45 years - 3 (7.5%)	3 (7.5%)
46 – 50 years – 1 (2.5%)	1 (2.5%)
50 – 55 years – 1 (2.5%)	1 (2.5%)
Participants' Child's Age*	
Under 1 year of age	12 (27.3%)
1 -2 years of age	11 (25%)
3 – 5 years of age	7 (15.8%)
6 – 9 years of age	6 (13.5%)
10-13 years of age	8(18%)
Race	
Black/African American	26 (65%)
White	11 (27. 5%)
Mixed Races	2 (5%)
No Response	1 (2.5%)
Ethnicity	
Not Hispanic or Latino	30 (75%)
No Response – 9/40	9 (22.5%)
Hispanic or Latino	1 (2.5%)
Marital Status	
Single – 35/40 (87.5%)	35 (87.5%)
Married – 3/40 (7.5%)	3 (7.5%)
Widowed -1/40 (2.5%)	1 (2.5%)
Divorced – 1/40 (2.5%)	1 (2.5%)

Note: Some participants had more than one child attending appointment, N=44 children.

Table 4.2

Parent Employment, Education and Income Level, Household Size and Insurance Status

Category	Participants (N=40) n (%)
Employment	
Full-Time (≥30 hours/week)	22 (55%)
Part-Time (< 30 hours/week)	11 (27.5%)
Unemployed	7 (17.5%)
Educational Level	
Some High School	7 (17.5%)
High School Graduate/GED	5 (12.5%)
Some College	17 (42.5%)
Trade, Technical or Vocational Training	3 (7.5%)
College Graduate	8 (20%)
Income Level	
Under $16,240	13 (32.5%)
Between $16,240 - $20,420	4 (10%)
Between 20,420 - $28,780	9 (22.5%)
Between $28,780 - $32,960	4 (10%)
Above $32,960	3 (7.5%)
Choose Not to Answer or Blank	7 (17.5%)
Household Size	
2 Members	4 (10%)
3 Members	8 (20%)
4 Members	12 (30%)
5 Members	8 (20%)
6 Members	5 (10%)
7 Members	2 (5%)
9 Members	1 (2.5%)
Insurance	
Medicaid	28 (70%)
Government Subsidized	6 (15%)
Private	5 (12.5%)
No Response	1 (2.5%)

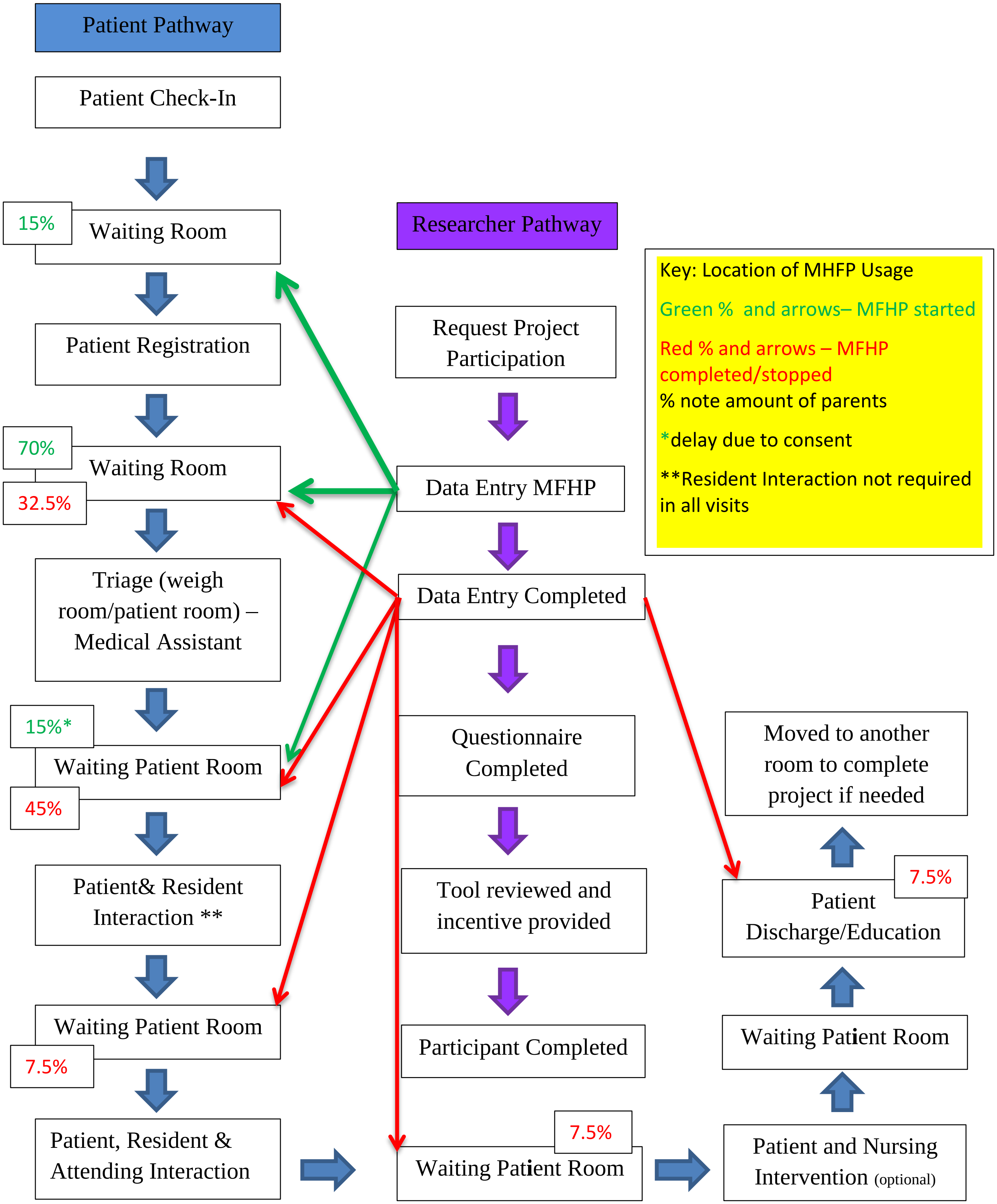
All project participants resided within Hamilton County, Ohio. When comparing participants to Hamilton county demographics, the participants were a higher percentage of African American, higher percentage of single parentage, larger households, slightly higher education level, similar employment levels, and very low income. Demographics for Hamilton County were: White/Caucasian – 68.3%, Black/African American – 26.4%, Hispanic/Latino – 3%; average household – 2.35; high school education level or higher – 91%; and average yearly county income $53,229 (U.S. Census: Hamilton County, Ohio, 2017).

Specific Aim 1

Specific aim 1 was to develop a process for integrating a parent-generated, web based, electronic FHH tool, My Family Health Portrait (MFHP), into a pediatric visit in an urban clinic setting. To aid in the development of this process, a proposed process map for integration was designed prior to implementing this project (see Figure 3.1). This map tracked potential flow of the child and parent during their clinic visit, to measure initiation and completion of the MFHP.

Parents were approached to participate in the project, in the waiting area, after initial check-in or after registration for clinic appointment. Fifteen percent of the participants were able to begin completing the MFHP prior to registration, 70% were able to begin completing the MFHP following registration and/or clinic questionnaires, and the remaining 15% began after triage and initial medical intake (see Figure 4.1). Explanation of DNP Scholarly project and completion of required clinic health, developmental and social questionnaires delayed the initiation of data entry into the MFHP tool. Despite this, 77.5% of parents were able to complete the MFHP tool prior to patient-resident interaction. An additional 7.5%, (77.5% + 7.55%) total of 85%, were able to complete MFHP prior to the patient- resident-attending interaction portion of patient evaluation allowing for integration of family history information into the health

Figure 4.1: PPCC Integration Process Map Completion Outcomes



decision process. The remaining participants (15%) were divided equally between, completing immediately after the resident interaction and nursing interventions and reaching the end of the clinic visit without full completion.

Specific Aim 2

Specific aim 2 assessed for general completeness and inclusion of health information from parent-completing the electronic FHH tool, MFHP. Measures to assess for completeness included: completion time, three sections in the MFHP tool (personal information, family members/pedigree, family member's personal information), number and type of interruptions, number of family members and addition of extended family members, and inclusion of health conditions. This information was collected by the DNP researcher using the eFHH tool, MFHP sections on: personal health information, family pedigree and family members' health information (see Appendices C for MFHP Personal Information Questions, D for MFHP Family Member Entry Questions and E for MFHP Family Members' Personal Information Questions), a questionnaire (see Appendix F for Participants' Views Following MFHP Use Questionnaire) and utilizing a field note (see Appendix H for Field Notes).

Completion time. Time to complete the MFHP tool electronically was measured by the number of minutes from the participant opening the tool to stating they were finished with the MFHP. The average time for all participants to complete/finish (even if not completely filled out) MFHP was 26.6 minutes with a range 7 to 76 minutes. Comparison between the lengths of time to complete, for those who completed all sections of MFHP to who did not complete MFHP showed little difference until the 75th quartile for non-completers (see Table 4.3). The number and length of interruptions, to complete MFHP tool, was not subtracted from the total completion time because the complexity of tracking and recording this information was an oversight in the study design and the intent of using the tool was to incorporate the tool without slowing down the pre-existing clinic flow/time for evaluation.

Table 4.3: Time to Complete My Family Health Portrait (MFHP) in Minutes

	Completed MFHP (n=28) Minutes	Incomplete MFHP (n=12) Minutes (partially completed, section 3-family health information)
Average Completion Time	25.8	28.4
Range of Minutes	9 – 76	7 – 67
25th quartile	15.3	15.3
50th quartile	23	22.5
75th quartile	33	41.5

Completeness of My Family Health Portrait (MFHP). Completeness was measured based on finishing each of three sections within MFHP: personal health information, family pedigree and family members' health information. All participants (100%) completed the required information in the section on personal health information. However ten participants asked clarification questions or asked for assistance regarding completion of their personal health information. Assistance was requested for: difficulty entering date of birth, recording name, who were questions about – participant or their child, difficulty entering age of diagnosis, difficulty entering height, unintentionally exiting program, how to enter health condition, and how to enter half siblings.

The second section required the participant to answer question regarding their family pedigree and to record the number of brothers, sisters, sons and doctors, paternal aunts and uncles and maternal aunts and uncles. All participants (100%) were able to complete this section. One participant asked for assistance regarding difficulty viewing information on the electronic tablet, minimized screen, and another asked for clarification regarding who questions were about, participant or their child.

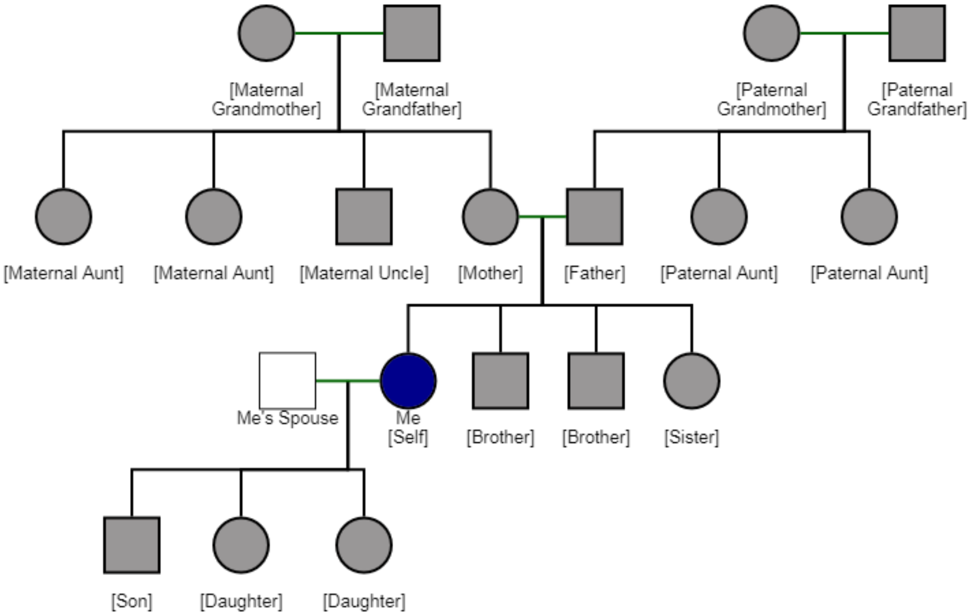
Participants were less complete documenting in the third section, family health information. Only seventy percent (28/40) completed this section of the program. The remaining thirty percent did not complete this section due to : two (5%) children were discharged prior to completion, two (5%) stopped due to child needs – illness and poor behavior, one (2.5%) stopped due to high clinic questionnaire demands (total of four for 2 child visit) and seven (7.5%) expressed preference to stop, one because it was too lengthy (2.5%), another one stated their family was too large (2.5%), two because there was no need to edit if healthy (5%), one didn't know the information (2.5%) and one just wanted to quit (2.5%). Most of the parent participants (35 of 40) asked questions or for assistance, in the family health information section, some more than once. Their questions were regarding what to do/how to edit, how to enter health condition, do they need to enter for each person, who was self – participant or child, what if cause of death was unknown, what to enter if no information was known about family members, difficulty with entering birth dates, clarification of health conditions categories, and what to do if more than one health condition.

Clinic interruptions. Types and number of interruptions, during completion of MFHP, were recorded by the researcher. Interruptions were divided into two categories, anticipated clinic interruptions and additional interruptions. Clinic interruptions included: moving location, completion of clinic questionnaire – health, developmental and social, registration process, triage/vitals, nursing or medical assistance intake, resident evaluation, attending evaluation, nursing interventions, and discharge. Collectively, there were 120 clinic interruptions for twenty six (65%) and none for 14 (35%) participants. Moving locations, triage vitals and nursing or medical assistance intake represented 74% of the interruptions. For those who quit completing the MFHP (N=12), there were 51 clinic interruptions, an average of 4.25 per participant compared to the 69 clinic interruptions, average of 2.46 for those who completed the MFHP.

Additional interruptions. Added interruptions were defined as any process which stopped the participant from continuing to enter data in the MFHP, which were not part of the standard clinic flow. Many parents were observed to be talking with children or others present at visit but as this did not stop them from entering data these were not counted as interruptions. There were 58 additional interruptions: interaction with children (48%), behavioral correction for children (26%), researcher (9%), phone calls (10%), other adults present with visit (3 %), child tantrum (2%) and fell asleep/narcolepsy (2%). Comparing those who did not complete MFHP to those who did for added interruptions, the non-complete group (N=12) had 11 interruptions and the completed group (N=28) had 47 interruptions. There was an outlier in the non-complete group, one individual with 7 interruptions because she had to stop and correct here child's behavior. The remaining 11 non-complete participants (N=12) had 4 interruptions, average of 0.333 interruptions per participant, while the completed groups (N=28) had an average of 1.7 interruptions per participant.

F**amily members.** Family member information, number(s), gender(s) and generational level was completed by all participants using the family pedigree section (see Appendix C for MFHP Personal Information Questions). Each participant was prompted to enter a four generational pedigree; including children, siblings, parents, aunts, uncles and grandparents (see Figure 4.2 for Four Generation Pedigree Example). While the MFHP offers the option to add cousins, nieces, nephews, half siblings and grandchild, no additional family members were added by any participants. Family size ranged from 8 to 39 family members, with an average family size of 21 people, with 8 people being the minimal number allowed by the program.

Figure 4.2: Four Generation Pedigree Example



Family health information. Overall, family information was added for 10.4 family members, average family size was 21. Even though thirty percent (12/40) of participants did not report completing section 3, family health information, only one did not record any family information. The reason this participant did not record family information in this section was due to quick evaluation of their child, with check in time to discharge at less than 20 minutes. However, it was noted that the family health history screen was opened by the participant more often, 11.6 times. This could be because the participant intended to add information and incorrectly save the content or the screen was opened and the participant elected not to add information.

When assessing health/disease conditions, personal health conditions were recorded for 14 (35%) participants. Meaning, one third of all parents had at least one health condition. It is not known if the remaining participants' have health conditions or if they were not recorded. Eight hundred and fifty-seven family members were recorded by participants, of which 166 family members, 19% were reported to have at least one health condition. The average of recorded health conditions for all family members was 4.15 per family. Participants and individuals, in some cases, had more than one health condition listed per person. A total of 195 conditions were reported.

Analysis of participants' responses for family member health information was also assessed for differences among those who complete versus those who did not complete section three. Family size was smaller for those that completed section three, average of 20 to 27 members (see Table 4.4). Participants 7, 9, 20, 23, and 33, reported reasons for quitting prior to completing section three was their family size was too large, there were too many screens to enter information and it was too lengthy – time consuming. These participant's family sizes ranged from 21 to 39 members. This is consistent with a higher mean number of family members for all of those who did not complete section three. For those that completed section three, the average size of the family was 20 people with information recorded for 13.4 people and 15 family member's information entry screens were opened. Indicating for those that reported completed section 3 at least 2/3 of the family members had completed health information.

Table 4.4

Comparison of Family Member's Personal Information Regarding Completion of Section 3: Family Health Information

Categories	**Reported Completion of Section 3 - Family Health Information (n=28)**	**Reported Incompletion of Section 3 - Family Health Information (n=12)**
Number of Family Members	Mean = 20	Mean = 27
Number of Family Members for Whom Personal Information Screen was Opened	Mean – 15 25th - 8.5 50th - 15 75th - 19.8	Mean – 3.7 25th – 2.0 50th – 3.5 75th -4.8
Number of Family Members with Recorded Personal Information	Mean – 13.4 25th – 8.0 50th – 14.5 75th – 18.8	Mean – 3.5 25th – 2.0 50th – 3.0 75th – 4.8
Number of Family Members with Health Conditions Recorded	Mean – 5.2 25th - 3.0 50th - 4.0 75th – 7.0	Mean – 1.7 25th - 0 50th – 1.0 75th – 2.0
Total Number of Health Conditions (average per family)	Mean – 5.89 25th – 3.0 50th – 4.0 75th – 7.0	Mean – 2.5 25th - 0 50th – 1.0 75th – 2.0

Specific Aim 3

The third aim was to identify operational and technical barriers and facilitators encountered by parents while completing an electronic FHH screening tool during a routine pediatric visit. Barriers were defined as any event prohibiting completion of MHFP and included points of difficulty when a participant asked for assistance. Facilitator's were defined as any event or process which promoted or supported completion of the MFHP tool. Operational and technical barriers and facilitators included direct verbalizations by the participant, observations made by the researcher and responses to the participant's views following MFHP use and a selection number of demographic questions regarding internet access, preferred completion setting and preference for self-completion or clinic provider completion. Barriers and facilitators were summarized as observation by researcher of participant and setting or participant reported using formatted questions (see Appendices F: Participant's Views Following MFHP Use and G: Demographic Questionnaire).

Researcher observed points of difficulty. Barriers noted during the completion of MFHP were: confusion regarding how to enter date of birth (25%), who participants were recording information about (12.5%), how to edit information (27.5%), how to enter health condition (17.5%), what to record if cause of death unknown (10%), what to enter if information about family members is unknown (17.5%), and difficulty using tablet touch screen to enter information (see Table 4.5). Transitioning to section 3 of MFHP, family health information, prompted parents to ask for assistance (12.5%) or they (17.5%) asked to confirm how they were to enter information.

Table 4.5

Points of Difficulty and Barriers When Using My Family Health Portrait (MFHP)

	Task, Question, Comment or Points of Difficulty*
Operational Barriers	Difficulty remember health information MFHP not designed for pediatric MFHP not EPIC compatible
Technical Barriers	How to edit family health information Difficulty entering date of birth (type specific) What to enter if health information is unknown How to enter health condition, categories Who to enter information about, self or child Asked what to do next Do I need to select each family member, if healthy What to record if cause of death is not known Touch screen difficult to use Too much information to enter, family to large Asked clarification about entering names Difficulty entering height Inadvertently exited program How to enter half-siblings Viewing difficulties on screen

*Note: Source from researcher observation, Participant's Views Following MFHP Use, and demographic questionnaire.

Researcher observed facilitators and participant's verbal recommendations.

Primary facilitators included ability to ask for clarification regarding data entry (17.5%), activities readily available for children both in general waiting area and patient rooms, and adults/teens present and able to assist with data entry (7.5%) (see Table 4.6). Participants also offered recommendations to improve process, although this was not requested; the most common were: difficulty with using the electronic tablet, laptop would be better option (10%), program needs to more intuitive – observed participants touching family information grid in each section instead of editing pencil (10%), difficulty to enter date of birth should be drop down (12.5%), and one should only need to edit family health if condition present (7.5%) (see Table 4.7).

Table 4.6

Facilitators for Completion of My Family Health Portrait (MFHP)

	Task, Questions, or Comments *
Operational Facilitators	Clinic flow – wait time Registration system – prompt need for questionnaire to be completed Activities for children – readily available Activities provided for children Quiet waiting room Infant sleeping in carrier Talking to child, continued entering information Able to complete FHH without help Could complete FHH tool at home or offsite Would ask family unknown health history Could add by internet unknown FHH Liked entering health information with MFHP Would complete FHH tool as part of visit Positive perception of parental benefit to FHH Preference for Self-Completion Setting preference
Technical Facilitators	Ease of Use Internet Access (Home & Community) Confirmed how to enter family information Computer entry assistance – family member Computed dates of birth on phone Texted family member to ask about health condition

*Note: Source from researcher observation, Participant’s Views Following MFHP Use, and demographic questionnaire.

Table 4.7

Parent Recommendations for Family Health History Integration

Parent Recommendations
Drop Down Screen – Date of Birth Touch Screen of Family Grid Edit Family Member only if health condition Prefer laptop, to tablet Autocorrect when typing health condition

Participant's views following MFHP use. To expand our knowledge of possible facilitators and barriers further regarding use of an eFHH in an urban pediatric clinic; fourteen additional questions, ten from the Participant's Views Following MFHP Use and four included on the Demographic Questionnaire, were asked of the participants. The responses from the Participant's Views Following MFHP Use questionnaire and the four demographic questions were all categorized as either operational or technical facilitators (see Table 4.6).

Operational facilitators from participant's views. Participants' viewed the collection of family health information highly important. Ninety percent reported they believed providing family health information was important for their child's care and 80% of parents stated they would complete the FHH tool if it were part of their child's visit (see Table 4.8). In addition, 70% of participants expressed they liked putting information into the computer themselves to share with their child's healthcare provider. While 22.5 were neutral and 7.4% reported not enjoying entering their child's health information.

Table 4.8

Participant's Views Following Use of an Electronic Family Health History Tool, My Family Health Portrait (MFHP)

Questions	Disagree or Strongly Disagree	Neutral	Agree or Strongly Agree
I was able to complete the family health history tool without any help.	12.5%	20%	67.5%
I could complete the family health history tool at home (or someplace else) on a computer.	7.5%	10%	82.5%
I would ask a family members health information I did not know.	15%	10%	75%
I could add family history information I did not know, by internet, after talking with my family.	12.5%	7.5%	80%
I liked putting information into the computer myself to share with my child's health care provider.	7.5%	22.5%	70%
The family health history tool was easy to use.	2.5%	17.5%	80%
The questions on the tool were easy to understand.	*	15%	82.5%
The computer program was difficult to use.	85%	10%	5%
I would complete the family history tool if it were part of my child's visit.	10%	10%	80%
I believe providing family health information is important for my child's care.	2.5%	7.5%	90%

*Note: 1 response left blank (2.5%)

Participant's reported they (82.5%) could complete the tool from home or outside of clinic and only 12.5 % felt they may not be able to complete without any assistance. Subsequently, the participants were asked if they could enter family health information they did not initially know, by internet, after talking with family members from home (or after the clinic visit). While 80% reporting they could enter the information, only 75%, agreed/strongly agreed they would ask, 10% were neutral and 15% indicated they would not ask family members for further information.

Technical facilitators from participant's views. Two questions were asked of parents about the FHH tool use. Overall, 80% and82.5%, found MFHP easy to use and understand (see Table 4.8). Reversely, when asked if the program was difficulty to use only 20% reported agreement.

Facilitators noted on demographic questionnaire. Parent participants were asked their preferences regarding the use of an eFHH to collect family history. Most parents (92.5%) wanted to self-complete/record their own FHH, while 5% preferred someone helping, and 2.5% marked both options. Despite the majority of parents (92.5%) having internet access in their homes; the preferred location to complete the electronic family health history tool was the clinic (55%), followed by home (30%) location with the remaining fifteen percent having marked both locations.

Summary

Results from the DNP project supported the feasibility of utilizing an eFHH tool as a means to collect FHH during a pediatric clinic visit. More than three fourths of the participants were able to complete FHH documentation prior to clinical evaluation by their primary care provider. Specific aims 2 and 3 highlighted parents' ability to use the MFHP tool and operational and technical facilitators and barriers to begin providing justification for a modified eFHH tool with a pediatric focus. Chapter 5 will focus on interpretation of the results and the application to clinical practice.

Chapter 5 – Discussion and Conclusion

The intent of this DNP Scholarly project was to implement a parent completed electronic family health history (eFHH) tool in a socially disadvantage, pediatric population receiving care in an urban primary care clinic. Prior testing of eFHH tools has predominantly been completed using a population of middle aged, higher-educated, white, private practice patients with tools that focus on adult patients. An overview of the project's results, limitations, recommendations for continuation, at site and within organizations strategic plans, implications for practice, application to other settings, future research, and application to the DNP role will be addressed.

Interpretation of results

Specific aim 1. The intent of specific aim 1 was to develop a process for integrating a parent-generated eFHH tool into a routine pediatric visit in an urban clinic setting. An initial assessment of the clinic patient flow was used to develop a proposed clinic process map (see Figure 3.1) for integration. The map proposed early introduction of the MFHP in the clinic visit, preferably in combination with the registration process. Study results supported this plan. The majority (85%) were able to begin the MFHP while present in the waiting room, prior to beginning the clinical evaluation process, with the remaining 15% beginning the process immediately following clinical triage (see Figure 4.1). The clinic currently uses the registration process to initiate the completion of clinical care, development and social questionnaires. This process mimics, when and how MFHP was introduced and could be used to integrate the tool permanently with minimal disruption to current clinical practice. Over three fourths of participants were able to complete the MFHP tool prior to the initial provider evaluation, patient-resident. This supports the feasibility of using an electronic FHH tool during a pediatric primary care visit for parent documented family health history information.

Specific aim 2. The objective of specific aim 2 was to assess the data recorded in MFHP for completeness of generational and health/disease specific information. Parents demonstrated they were able to record a significant amount of family history information. All were able to record their own personal health information (section 1) and responding to a series of questions to build a four generation pedigree (section 2) (see Figure 4.2). The third section of MFHP, family member's personal health information, presented several challenges as it requires answering multiple questions about every family member individually. Having a larger family, limited knowledge about family members' health, repetition of question for healthy family members and brief clinic evaluations were the most common reasons given for not completing this section. Despite these barriers, seventy percent of participants completed all three sections, the entire program resulting in documented disease specific information added for 19% of family members.

There was no observable difference in completion times between those who did and did not complete section 3. However, the number of clinical interruptions was noticeable higher for those who did not complete section three. There was no appreciable difference in additional interruptions, indicating presence of child(ren), cell phone and talking did not seem to impact tool completeness. The impact of clinic interrupters, on in clinic completion of eFHH tools, has not been previously studied. What has been noted is significantly more FHH being recorded when MFHP was self-complete in clinic than standard staff data collection process (Murray et al, 2013).

There are two considerable barriers to MFHP. The first is that the tool is designed for self-completion. Currently, there are no eFHH tools which prompt data collection from another family member's perspective (de Hoog et al, 2014). The other was seen in the project, participants did not use the program to record half-siblings, nieces, nephews, or cousins, which would be expected in at least some families. This process requires additional screens to be completed and is not set up as direct questions in section 2. This is a known weakness in the program; it assumes a nuclear family of monogamous parentage with no half-siblings, which increases the likelihood of poor/inaccurate documentation.

Specific aim 3. The goal of specific aim 3 was to identify operational and technical barriers and facilitators encountered by parents completing an eFHH tool during a routine pediatric visit. Barriers and facilitators included participant's verbal comments and questions, participant's responses to questionnaires, and researcher observations. Participant's verbal comments and questions were primarily categorized into technical barriers and facilitators, while researcher observations and questionnaire responses were predominately operational facilitators.

Technical barriers. The primary technical barriers were the result of participant expectations that the MFHP program would be more intuitive. Participants struggled the most with: how to enter family members health screens to add information, entering date of birth in specific format, how to enter disease conditions, who to enter information about (parent or child perspective), what to do next and did they need to record any information about healthy family members. The program has written instruction regarding all of these comments, but participants expected to be able to use touch screens to select family members, scroll screens for dates of birth, and prompt buttons directing them to the next step. The expectations regarding functionality are likely due to the advancement of computer applications. MFHP was developed over 7 years ago, which was before the widespread use of touchscreens (McGonigle & Mastrian, 2015). Previously reported parental challenges with MFHP included similar findings: difficulty with incomplete FHH information, use of preset conditions increased difficulty selecting health condition and technical/program challenges adding information (Berger et al., 2013).

Technical facilitators. When identifying key *barriers and facilitators* for the feasibility of integrating a parent-completed eFHH tool into clinical practice, parent's preference should be the primary consideration. The vast majority of participants want to self-complete the data entry of FHH, supporting transition of this responsibility to parents. Despite participants (92.5%) having internet access in their homes, the majority preferred to enter data while in the clinic. Internet use was a preferred method in 30-45% of participants and because parents reported confidence being able to complete MFHP independently after trialing the eFHH tool, a multi-model entry model documentation process may better support tool completion.

Operational barriers. A challenge noted is how the MFHP program questions are asked. My Family Health Portrait, along with other eFHH programs, was designed to have the questions answered by an adult, about themselves (Facio et al, 2010). Berger et al asked mothers completing the tool to interpret the question as if they were answering for their child which they found confusing and lead to increased difficulty with its use. During the DNP project, parents were asked to complete the questions about themselves and include their child/children as part of the family history. This allowed for the program to be used and interpreted as intended, but does not lend itself as easily to integration within a child's medical record. Prior to wide scale adoption in pediatrics an eFHH tool must be designed or modified to be completed by one family member about another family member, such as parent about their child or a grandparent for their grandchild. Additionally, the tool must allow for integration within the patient's EHR and allow for linking family health records.

Another significant barrier to completing MFHP is knowledge regarding family members' health, which has been reported in other MFHP studies (Berger et al., 2013; Murray et al., 2013; Newcomb et al., 2014). This may only be an immediate barrier as most parents (74%) reported they would ask a family member about unknown conditions and 80% reported they could enter the information into MFHP using internet access. This does not however demonstrate if it would be done.

Operational Facilitators. Key facilitators observed were supporting activities for children such as games and toys, option for clarification regarding the tool, and family member available to assist parent with health information or program. The majority of participants reported the program was easy to use and could be completed in a clinic or an offsite location, but preferred clinic setting. While lack of health knowledge of relatives was an identified barrier, participants reported they would ask about unknown family history, could enter this information later with web access, they liked and preferred enter this information on their own and had the ability to do so from within their homes. Perhaps the strongest indicator of feasibility is participants highly (>90%) regarded the importance of providing health information and reported they would complete the tool as part of their child's visit.

Prior studies indicate African American, while more likely to gather information, are less likely to report/record this information (Thompson et al., 2013). Direct observation during this project showed a limited number of participants asking other family members present, calling family and figuring out information on their phone to record information in MFHP. One mother was observed being asked to verbally by a clinic nurse to provide family health information to be recorded in her child's medical record during the patient visit. Upon reviewing her information entered into MFHP, she reported more health conditions/information electronically then she did verbally to the staff nurse. Younger women and women in general are more likely to record health information then older people, males and those of minorities (Halbert et al., 2016). Therefore, recording health information when patients' are young and accompanied to health appointments by their younger mothers can presents opportunities to build the patient's longitudinal FHH record.

Parent Recommendations. Project participant's also offered suggestions for improvement as they knew the purpose of the project was to learn more about tool integration (see Table 4.7). These included changes to how the program was formatted and were consistent with suggestions from Berger et al. study; easier birth date entry, no need to record race/ethnicity for every family member, easier use of health condition sets, revision to how half-siblings entered, increased intuitive entry ability and ability to include more information (2013).

Demographic comparisons. Comparison studies of participants using MFHP, the eFHH tool utilized in the project, are limited. The tool validation population was a convenience sample of participants, age 45 – 65 years, with a mean age of 56.6 years (Facio et al, 2010). The 40 participants were gender neutral, with 95% white, 97% on non-Hispanic/Latio ethnicity, highly education – 46.7% master's/doctoral degrees, and of higher incomes – more than half above $100,000 yearly household income and less than 3% below $49,999 per year (Facio et al, 2010). Three other studies using MFHP had some similar populations characteristics to the initial validations studies, married, higher education levels, completed predominantly by females but each attempted to modify for whom or how the information was being collected to determine feasibility of use (Berger et al., 2013; Murray et al., 2013; Newcomb et al., 2014). Berger et al trialed MFHP with parents and had a high percentage (48%) of African American who participated, but economically were non-comparable.

The participant population in this DNP Scholarly project demonstrated a higher level of education than initially anticipated, with only 17.5% not having completed high school or a graduation equivalent degree and 62.5% reported having some college or completion of a college degree. The higher education level can be speculated to be the result of Ohio government assistance programs which support completion of HS level education and associate college degrees. Despite higher level of education the majority of participants were single, African American mothers of low socioeconomic status, a novel population for a MFHP integration trial

Study Limitations

There were multiple limitations to the project design, most were anticipated and steps were taken to minimize the effects. The first was the impact of the researcher's presence which may have impacted the completion process by: providing participants the opportunity to ask questions, participant attempting to impress/please researcher, perceived value or curiosity in project, incentive for participants' efforts, and participant seeking conversation with researcher resulting in increased completion time. Another limitation was the researcher designed questionnaires, Demographics and Participants Views Following MFHP Use, were designed based on prior demographic studies, knowledge of potential variable which could impact integration and federal poverty guidelines. An error on the demographic questionnaire was not appreciated till analysis; when classification of participants as below poverty guidelines was not able to be discerned due to in accurate income categories. Researcher error regarding observations of potential barriers or facilitators may have occurred. From a research perspective, the project design and sample size does not allow for evaluation beyond summation of results.

Recommendations for CCHMC

Organizations strategic plan. The use and future applications of eFHH tools with pediatric patient currently aligns with four of CCHMC's six pillars of the organization strategic plan (CCHMC, 2016). The care pillar premise is the Triple Aim; to provide quality, safe and affordable care. The use of comprehensive eFHH tools has been proposed as a low cost, highly efficient and effective way to screen for health conditions (Buchanan et al., 2015; Carroll et al., 2017; Kemper et al., 2010). The use of the MFHP at CCHMC demonstrated the ability to document FHH using a systematic process which places the focus of documentation on parents, freeing up time/cost of clinical staff recording information. This process of streamlining documentation to be parent-entered and recorded for analysis meets the people pillar and would also improve documentation requirements for Medicare reimbursement. The pillars of discovery and community are focused on using new technology for health prevention. Family health history tool offer the potential to improve population health, by identifying individuals, at risk for common complex health conditions to allow for disease prevention though the use of health promotion (Kemper et al., 2010).

Recommendations for continuation of project. At the institutional level prior to investing considerable resources to addressing the challenge of expanding patient health documentation, more information was needed, specific to CCHMC about how this might be accomplished. Therefore, one step to continue, with possible expansion, is to review the project findings with CCHMC stakeholders who are interested in electronic documentation of FHH and the PPCC research committee who granted permission for use of the clinical site. During the past five years, multiple versions for recording FHH in CCHMC patient medical records have been considered as they were available at no additional expense, but they all require clinical staff to enter information and do not allow for quick documentation in an easily viewed format, such as a pedigree. This pilot project suggests the use of an electronic parent-completed FHH maybe a feasible way to gather data which could be beneficial in multiple ways.

Nationally, the National Human Genome Research Institute has established integration of eFHH tools within EHR as part of their own going research initiative, IGNITE 2. IGNITE 2 is a multicenter, multiyear, NIH funded research project focused on practical application of genomic advancement. CCHMC is currently attempting to be granted an award for IGNITE 2. The DNP Scholarly project was submitted, in the application, as institutional experience with site integration of eFHH tools. If CCHMC is selected to be a study site, this would drive the testing, development and adoption of eFHH integrated within the EHR at an accelerated pace.

Application of findings in other CCHMC settings. The Pediatric Primary Care Clinic was selected for this project for two reasons, one use of family health history for health education and counseling is a focus of primary care. Secondly, it was to determine if the program could be used in a mixed racial setting, with younger participants who internet access and resources might limit use of an eFFH tool over the internet. What was found, suggests that families may prefer different settings for completing FHH information. As recording FHH information is not unique to primary care, but has applications in all areas of CCHMC, the ability to spread the use of an eFHH to all clinic areas would be reasonable and a patient need.

Future research

Consideration for future develop of eFHH tools, integration with the EMR and across research would incorporate the two remaining pillars, impact and enablers. As mentioned, eFHH tools recording and analysis capabilities have been limited in scope of application to adults (DeHoog et al., 2014). Integration of an evolving FHH document within the patient's medical record, could improve comprehensive health records for the child, but also as they age into adulthood. Collection of family health history can have direct impact on health recommendations for the individual. However, large scale use of this information could impact population health. For instance, biobanks linked to family health information can be used to hunt for genetic determinants in complex common health conditions. Another consideration is the development of analytical software to calculate risk and health care recommendations for pediatric populations.

Application to DNP roles

Potentially there are many DNP roles which could impact future research and development of eFHH tools. Nursing informatics could and should be an integral part of developing a family focused eFHH tool. During development, clinical testing and trials to modify and validate the tool could be completed by the DNP and integration within the initial and subsequent setting is ideally suited to this role. Ongoing clinical evaluations of outcomes related to completing and utilizing information can be completed by a DNP with quality improvement expertise. The DNP can participate as part of or leading the interdisciplinary team responsible for disease risk analysis algorithms to guide health promotion. Once risks are identified, the DNP nurse educator and clinician can develop, utilize and evaluation health education and intervention programs based on FHH information.

Project Summary

The purpose of this project was to determine if an eFHH tool, completed by parents during a routine pediatric visit in an urban clinic setting, was a feasible option for collecting and documenting family health history data. A process map was developed, based on clinic flow, to allow for entry of FHH information prior to clinical evaluation. Utilizing the ability to initiate the tool, in the clinic waiting area, prior to clinical evaluation 77.5% of parents were able to complete the tool before evaluation with their child's health care provider. Clinic interruptions and other barriers, such as unknown family health information, complex health categories, difficulty with navigating some aspects of the tool did not deter participants from completing the program. Almost all parents (97.5%) entered information in all three sections of MFHP, 70% completed all three sections and 50% entered health information for every family member in their four generation pedigree they completed. Reported facilitators for use of MFHP in this setting were: ease of use, internet access, parents perceived positive benefit, enjoyment in completing and they want to personally enter their health information. The project findings support the possibility of using a parent-generated electronic family health history in a pediatric care setting.

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Appendix A: Study Information Sheet

Study Information Sheet

Implementation and Evaluation of a Parent-Generated Electronic Family Health History Tool in an Urban Pediatric Primary Care Setting

INTRODUCTION

We are asking you to be in a research study so that we can learn new information that may help others. If you decide not to be in this study, we will still take good care of you. If you decide to be in this study, you may change your mind at any time during the study and you can stop being in the study. Take all the time you need to make your choice. Ask us any questions you have. It is also okay to ask more questions after you decide to be in the study. You can ask questions at any time.

WHY ARE WE DOING THIS RESEARCH?

In this research study we want to learn more about how to collect patient and families' health information. We are asking you and other people with children who are cared for in the Pediatric Primary Care Clinic (PPCC) to be in the research to learn how to improve family health information collection to guide health care.

WHO IS IN CHARGE OF THE RESEARCH?

Patricia Bender, RN, MSN is the researcher at Cincinnati Children's Hospital Medical Center (CCHMC) that is in charge of this study. She is the person who asked if you were interested in participating and would be assisting with the study. She can be reached after the study at (513)636-4539 if you have more questions. CCHMC is not being paid by anyone to do this study.

WHO SHOULD NOT BE IN THE STUDY

You can not be in this study if you have any of the following:

- Must be a birth parent of child present for clinic appointment
- Adoptive parents, foster parents or court appointed guardian accompanying patient to clinic appointment may not participate
- Difficulty speaking or verbally understanding the English language which could limit ability to complete study, researcher is provide help if difficulty reading English.

WHAT WILL HAPPEN IN THE STUDY?

The researcher will explain what you will be requested to do and will give you a handout that explains each step. You will be able to ask questions to decide if you want to participate and to assist you as needed during the study. If you qualify and decide you want to be in the study, you will proceed with completing the computer program and paper questions.

These are the things that will happen during the study:

- You will enter information about you and your family in a computer program. Questions will be about age, race, health and illness.
- You will be asked questions about the computer program.
- You will be asked to complete questions on paper about your age, education level, employment, and household.
- The researcher will record information about questions or comments you make about the computer program. This information is to improve the researched understanding of how others may have the same questions.

The computer program and paper questions can be completed while waiting for your child's appointment. If your child's appointment is quick the researcher would like you to still complete the study, but this is not required.

Appendix A (cont.): Study Information Sheet

WHAT ARE THE BAD THINGS THAT CAN HAPPEN FROM THIS RESEARCH?

You may become frustrated if you are asked questions during testing that you do not know how to answer or have difficulty with the computer program. Most people do not know all the answers to the questions asked. You do not need to answer any question that you do not wish to answer and you can stop the study at any time.

WHAT OTHER CHOICES ARE THERE?

Instead of being in this study, you can choose not to be in it. Participating will not change the care provided to your child.

HOW WILL INFORMATION ABOUT YOU BE KEPT PRIVATE?

Making sure that information about you remains private is important to us. To protect your privacy in this research study we will: not record any information that can identify you directly, information you do share with us will be stored in a locked cabinet, and destroyed 3 years after completion of study.

WHAT IF WE LEARN NEW INFORMATION DURING THE RESEARCH?

The researcher will tell you if they find out about new information from this or other studies that may affect your health, safety or willingness to stay in this study.

WILL IT COST YOU ANYTHING EXTRA TO BE IN THE RESEARCH STUDY?

THERE IS NO COST TO YOU OR YOUR CHILD FOR THIS STUDY.

WILL YOU BE PAID TO BE IN THIS RESEARCH STUDY?

You will be provided a $10 gift card for your effort in participating in this study.

WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

For questions, concerns, or complaints about this research study you can contact the study person listed on page 1 of this document. If you would like to talk to someone that is not part of the research staff or if you have general questions about your research study rights or questions, concerns, or complaints about the research, you can call the CCHMC Institutional Review Board at 513-636-8039.

AUTHORIZATION FOR USE/DISCLOSURE OF HEALTH INFORMATION FOR RESEARCH

To be in this research study you must give your verbal permission (or authorization) to use and disclose (or share) your “protected health information” (called PHI for short).

What protected health information will be used and shared during this study?

CCHMC will need to use and share your PHI as part of this study. This PHI will come from:

- Your CCHMC medical records – limited to registration information
- Your research records – information we collect as part of the study

Who will share, receive and/or use your protected health information in this study?

- Researcher at the research study site (PPCC) and who provides services to you as part of this study
- The members of the CCHMC Institutional Review Board and staff of the Office of Research Compliance and Regulatory Affairs.

How will you know that your PHI is not misused?

People that receive your PHI as part of the research are generally limited in how they can use your PHI. In addition, most people who receive your PHI are also required by federal privacy laws to protect your PHI.

Can you change your mind?

You may choose to withdraw your permission/information during the time you are participating in the study. Linked identifiers are not being used to protect the information you provided. Since information is non- identified the researcher would not know which set of data belongs to any participant to exclude it from study.

Appendix B: Participant's Instructions

Instructions

Step 1: Click here **Create a Family Health History** **to enter**

Step 2: Enter your information

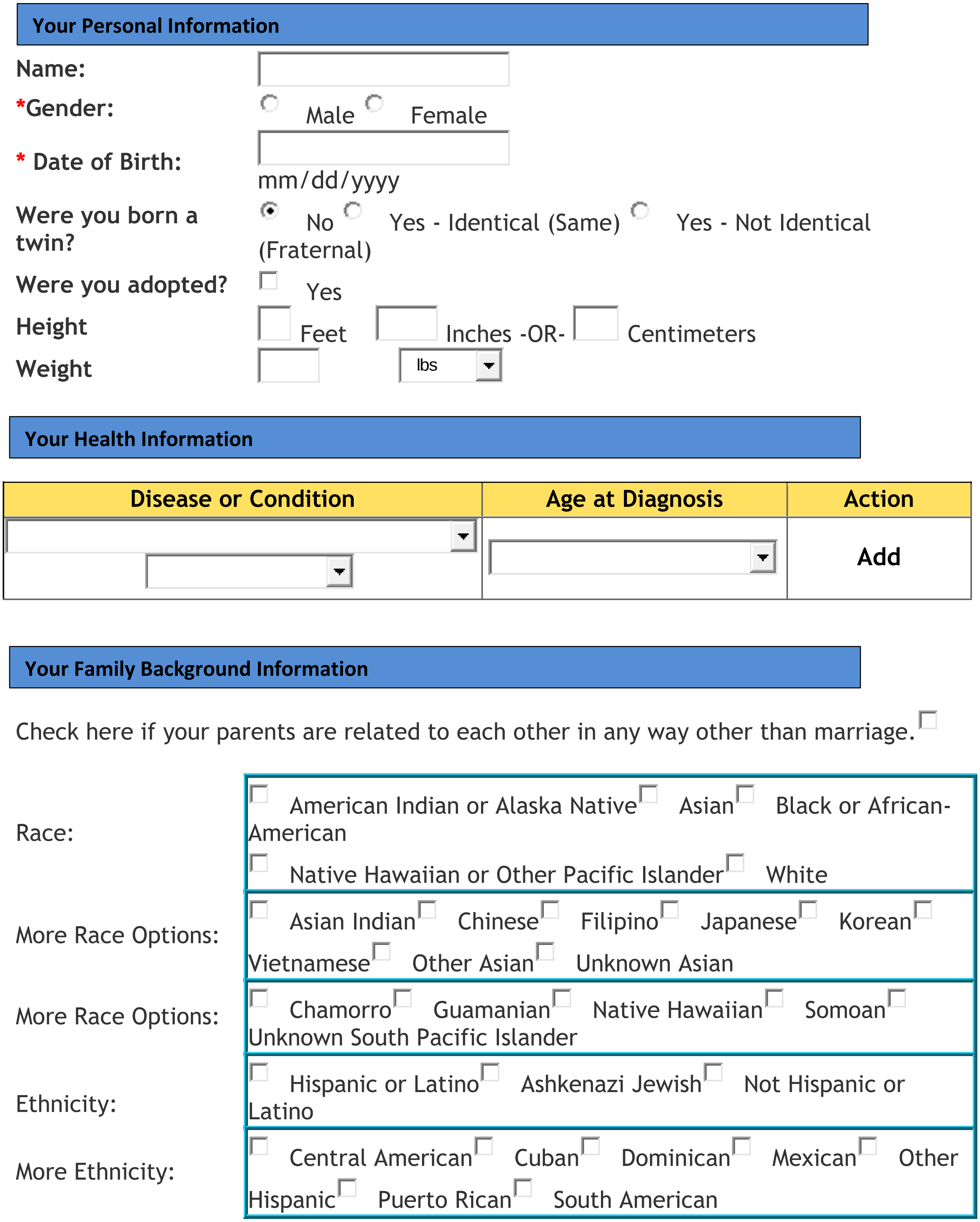
- **Do not enter your name – type Mom or Dad**
- **You do not need to enter weight or height**
- **Fill in the questions as asked, if you need help the nursing student is able to help.**
- **You do not need to manage your data (save data); we will print a copy for you and the nursing student.**

Step 3: After you fill in the questions about yourself, you will be asked to fill in them about your family

- **Click on the Pencil in the Update History row – enter information about each family member**
- **You can add other family members if you want by clicking**

  Add a Family Member

Appendix C: MFHP Personal Information Questions



Your Personal Information

Name: ☐

***Gender:** ○ Male ○ Female

*** Date of Birth:** ☐ mm/dd/yyyy

Were you born a twin? ● No ○ Yes - Identical (Same) ○ Yes - Not Identical (Fraternal)

Were you adopted? ☐ Yes

Height ☐ Feet ☐ Inches -OR- ☐ Centimeters

Weight ☐ lbs

Your Health Information

Disease or Condition	Age at Diagnosis	Action
☐ ☐	☐	Add

Your Family Background Information

Check here if your parents are related to each other in any way other than marriage. ☐

Race: ☐ American Indian or Alaska Native ☐ Asian ☐ Black or African-American ☐ Native Hawaiian or Other Pacific Islander ☐ White

More Race Options: ☐ Asian Indian ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Vietnamese ☐ Other Asian ☐ Unknown Asian

More Race Options: ☐ Chamorro ☐ Guamanian ☐ Native Hawaiian ☐ Somoan ☐ Unknown South Pacific Islander

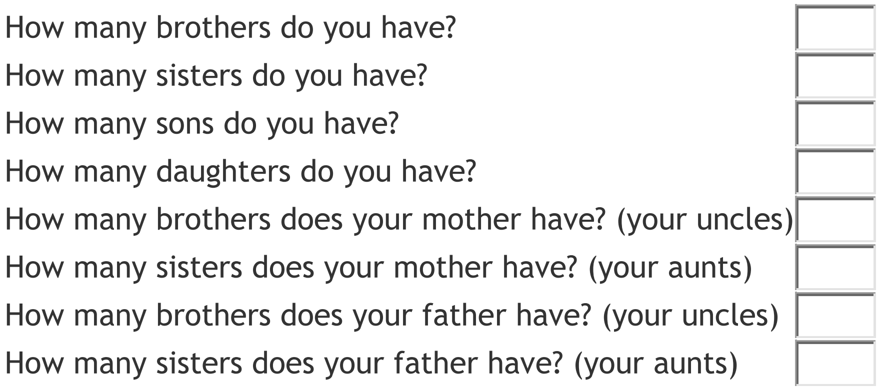
Ethnicity: ☐ Hispanic or Latino ☐ Ashkenazi Jewish ☐ Not Hispanic or Latino

More Ethnicity: ☐ Central American ☐ Cuban ☐ Dominican ☐ Mexican ☐ Other Hispanic ☐ Puerto Rican ☐ South American

From U.S. Surgeon General (2015). My Family Health Portrait [Measurement instrument]. Published instrument. Bethesda, MD: U.S. National Institutes of Health.

Appendix D: MFHP Family Member Entry Questions for Building Pedigree

Add Family Members:



How many brothers do you have?
How many sisters do you have?
How many sons do you have?
How many daughters do you have?
How many brothers does your mother have? (your uncles)
How many sisters does your mother have? (your aunts)
How many brothers does your father have? (your uncles)
How many sisters does your father have? (your aunts)

From U.S. Surgeon General (2015). My Family Health Portrait [Measurement instrument]. Published instrument. Bethesda, MD: U.S. National Institutes of Health.

Appendix E: MFHP Family Members' Personal Information Questions

Personal Information for your Father

Relationship:	Father
Name:	
***Gender:**	○ Male ○ Female
Is this person still alive:	
Was this person born a twin?	● No ○ Yes - Identical (Same) ○ Yes - Not Identical (Fraternal)
Was this person adopted?	☐ Yes

Your Father' Health Information

Disease or Condition	Age at Diagnosis	Action
		Add

Your Father's Background Information

Check here if your parents are related to each other in any way other than marriage. ☐

Race:	☐ American Indian or Alaska Native ☐ Asian ☐ Black or African-American ☐ Native Hawaiian or Other Pacific Islander ☐ White
More Race Options:	☐ Asian Indian ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Vietnamese ☐ Other Asian ☐ Unknown Asian
More Race Options:	☐ Chamorro ☐ Guamanian ☐ Native Hawaiian ☐ Somoan ☐ Unknown South Pacific Islander
Ethnicity:	☐ Hispanic or Latino ☐ Ashkenazi Jewish ☐ Not Hispanic or Latino
More Ethnicity:	☐ Central American ☐ Cuban ☐ Dominican ☐ Mexican ☐ Other Hispanic ☐ Puerto Rican ☐ South American

From U.S. Surgeon General (2015). My Family Health Portrait [Measurement instrument]. Published instrument. Bethesda, MD: U.S. National Institutes of Health.

Appendix F: Participants' Views Following MFHP Use Questionnaire

For the questions below select the answer which best describes how you feel. Circle one number for each question.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Q1. I was able to complete the family health history tool without any help.	1	2	3	4	5
Q2. I could complete the family health history tool at home (or someplace else) on a computer.	1	2	3	4	5
Q3. I would ask a family members health information I did not know.	1	2	3	4	5
Q4. I could add family history information I did not know, by internet, after talking with my family.	1	2	3	4	5
Q5. I liked putting information into the computer myself to share with my child's health care provider.	1	2	3	4	5
Q6. The family health history tool was easy to use.	1	2	3	4	5
Q7. The questions on the tool were easy to understand.	1	2	3	4	5
Q8. The computer program was difficult to use.	1	2	3	4	5
Q9. I would complete the family history tool if it were part of my child's visit.	1	2	3	4	5
Q10. I believe providing family health information is important for my child's care.	1	2	3	4	5

Thank you for participating today, your help is appreciated.

Appendix G: Demographic Questionnaire **Study ID: ___________________**

Your age: **Your zip code:**	**Parent: (check one)** ☐ **Mother** ☐ **Father**	**Child's age with appointment**	**How many people are living in your home:**
Race: (check one) ☐**American Indian** ☐**Alaskan Native** ☐**Asian** ☐**Black/African American** ☐**Native Hawaiian** ☐**Pacific Islander** ☐**White** ☐**Mixed Race**	**Ethnicity: (check one)** ☐**Hispanic or Latino** ☐**Ashkenazi Jewish** ☐**Not Hispanic or Latino**	**Parent's Marital Status: (check one)** ☐**Single, never married** ☐**Married** ☐**Widowed** ☐**Divorced** ☐**Separated**	**Do you work? (check one)** ☐**Full time (more than or 30 hours a week)** ☐**Part time (less than 30 hours a week)** ☐**Not working** ☐**Retired**

Your Education Level: (check one) ☐**some high school** ☐**some college** ☐**trade, technical or vocational training** ☐**high school graduate or GED** ☐**college graduate**
Total household income before taxes: (check one) ☐Under $16,240 ☐Between $20,420 -$28,780 ☐Above $32,960 ☐Between $16,240 - $20,420 ☐Between $28,780 – $32,960 ☐Choose not to answer
Insurance: (check all that apply) ☐Private ☐Government Subsidized ☐Medicaid ☐Military ☐ Self Pay – No insurance
Do you have internet access in your home? (check one) ☐Yes ☐ No
Do you have access to the internet in your neighborhood? (check one) ☐Yes ☐ No
Would you have liked someone to ask and record the questions about your families help or did you like completing questions yourself? (check one) ☐Someone Helping ☐ Complete by yourself
Would you prefer to enter information at home or while in clinic? ☐Home ☐ Clinic

Appendix H: Field Notes (side 1)

Study ID: ______

Initial of Study (Time): _________ Number of Interruptions: ___________

Completion of Study (Time): _________

Data Completion Entry

Personal Data Entry: Yes NO

Notes:

Family Pedigree Build: Yes No

Notes:

Family Member Data Entry: Yes No

Notes:

Appendix H Continued: Field Notes (side 2)

Printed Pedigree: Yes No

Number of Family Members Enter on Pedigree: ____________

Extra Family Members added: Yes No

Cousins: Yes No

Nieces: Yes No

Nephews: Yes No

Half Siblings: Yes No

Grandchildren: Yes No

Number of Family Members Personal Information Noted: __________

Number of Family Members with Edits: _____________

Number of Family Members with Conditions Recorded: ___________

Number of Conditions Recorded: ____________

Visit Point of MFHP Completion: ______________________

Number of People present for visit:

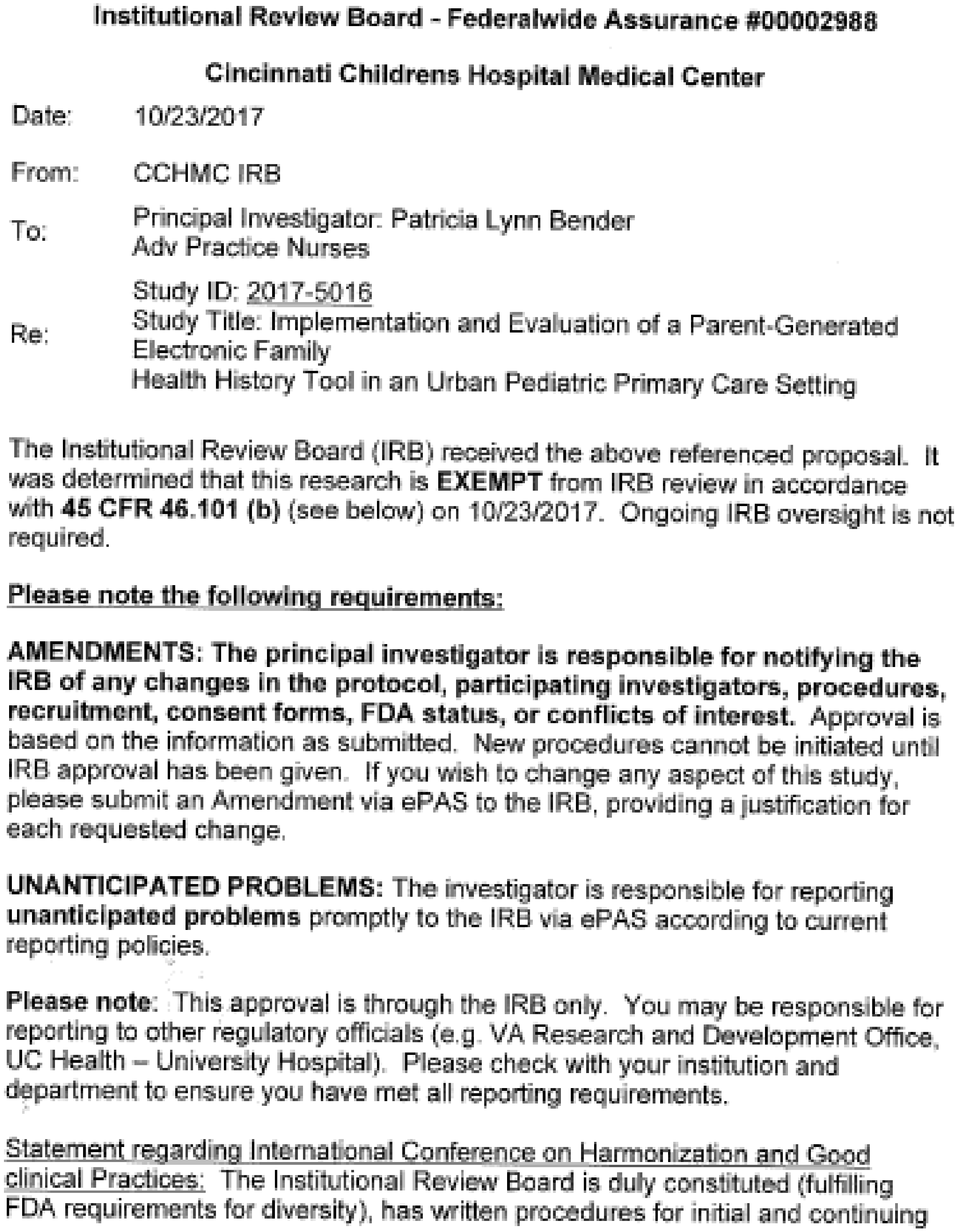
Adults: _____________

Teens: _____________

School age: ___________

Toddlers or younger: _________

Appendix I: CCHMC IRB Exemption



Institutional Review Board - Federalwide Assurance #00002988

Cincinnati Childrens Hospital Medical Center

Date: 10/23/2017

From: CCHMC IRB

To: Principal Investigator: Patricia Lynn Bender
Adv Practice Nurses

Re: Study ID: 2017-5016
Study Title: Implementation and Evaluation of a Parent-Generated Electronic Family
Health History Tool in an Urban Pediatric Primary Care Setting

The Institutional Review Board (IRB) received the above referenced proposal. It was determined that this research is **EXEMPT** from IRB review in accordance with **45 CFR 46.101 (b)** (see below) on 10/23/2017. Ongoing IRB oversight is not required.

Please note the following requirements:

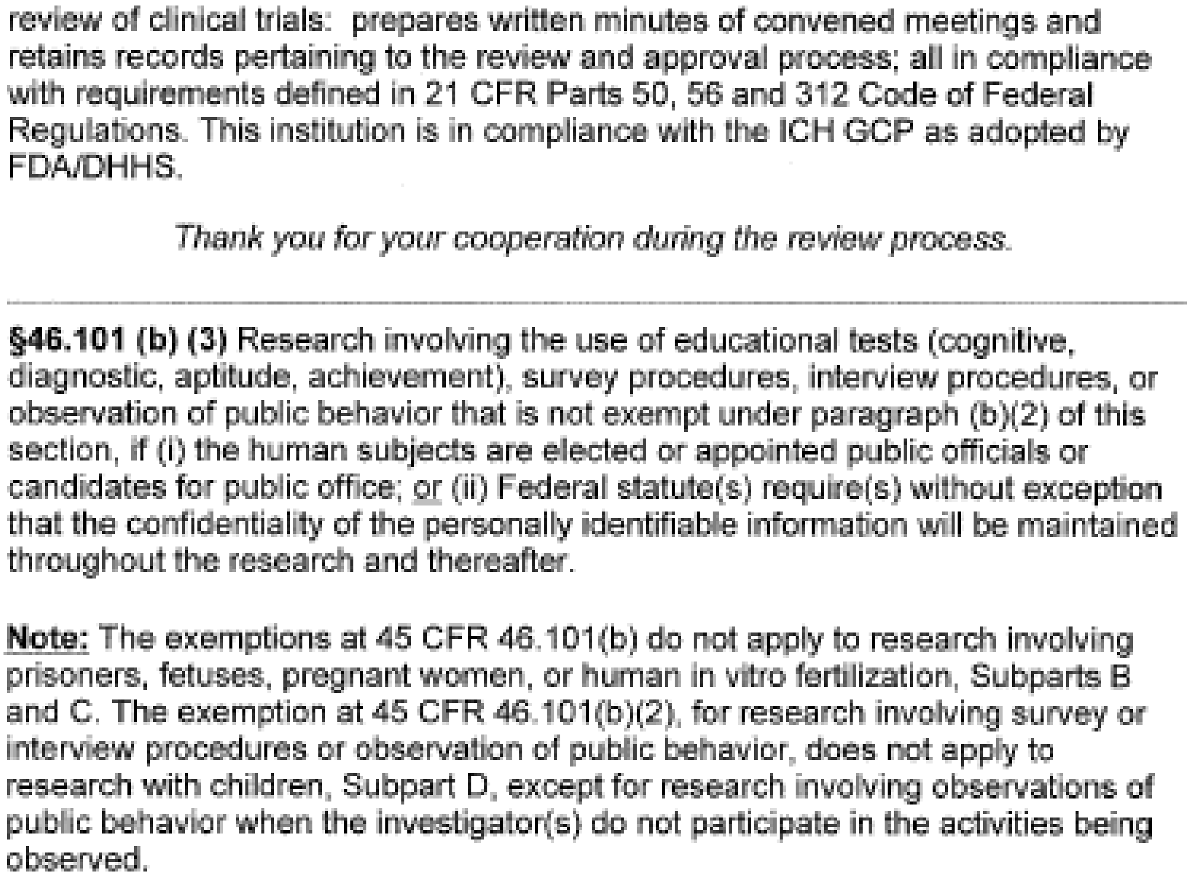
AMENDMENTS: The principal investigator is responsible for notifying the IRB of any changes in the protocol, participating investigators, procedures, recruitment, consent forms, FDA status, or conflicts of interest. Approval is based on the information as submitted. New procedures cannot be initiated until IRB approval has been given. If you wish to change any aspect of this study, please submit an Amendment via ePAS to the IRB, providing a justification for each requested change.

UNANTICIPATED PROBLEMS: The investigator is responsible for reporting **unanticipated problems** promptly to the IRB via ePAS according to current reporting policies.

Please note: This approval is through the IRB only. You may be responsible for reporting to other regulatory officials (e.g. VA Research and Development Office, UC Health – University Hospital). Please check with your institution and department to ensure you have met all reporting requirements.

Statement regarding International Conference on Harmonization and Good clinical Practices: The Institutional Review Board is duly constituted (fulfilling FDA requirements for diversity), has written procedures for initial and continuing

Appendix I (continued): CCHMC IRB Exemption



review of clinical trials: prepares written minutes of convened meetings and retains records pertaining to the review and approval process; all in compliance with requirements defined in 21 CFR Parts 50, 56 and 312 Code of Federal Regulations. This institution is in compliance with the ICH GCP as adopted by FDA/DHHS.

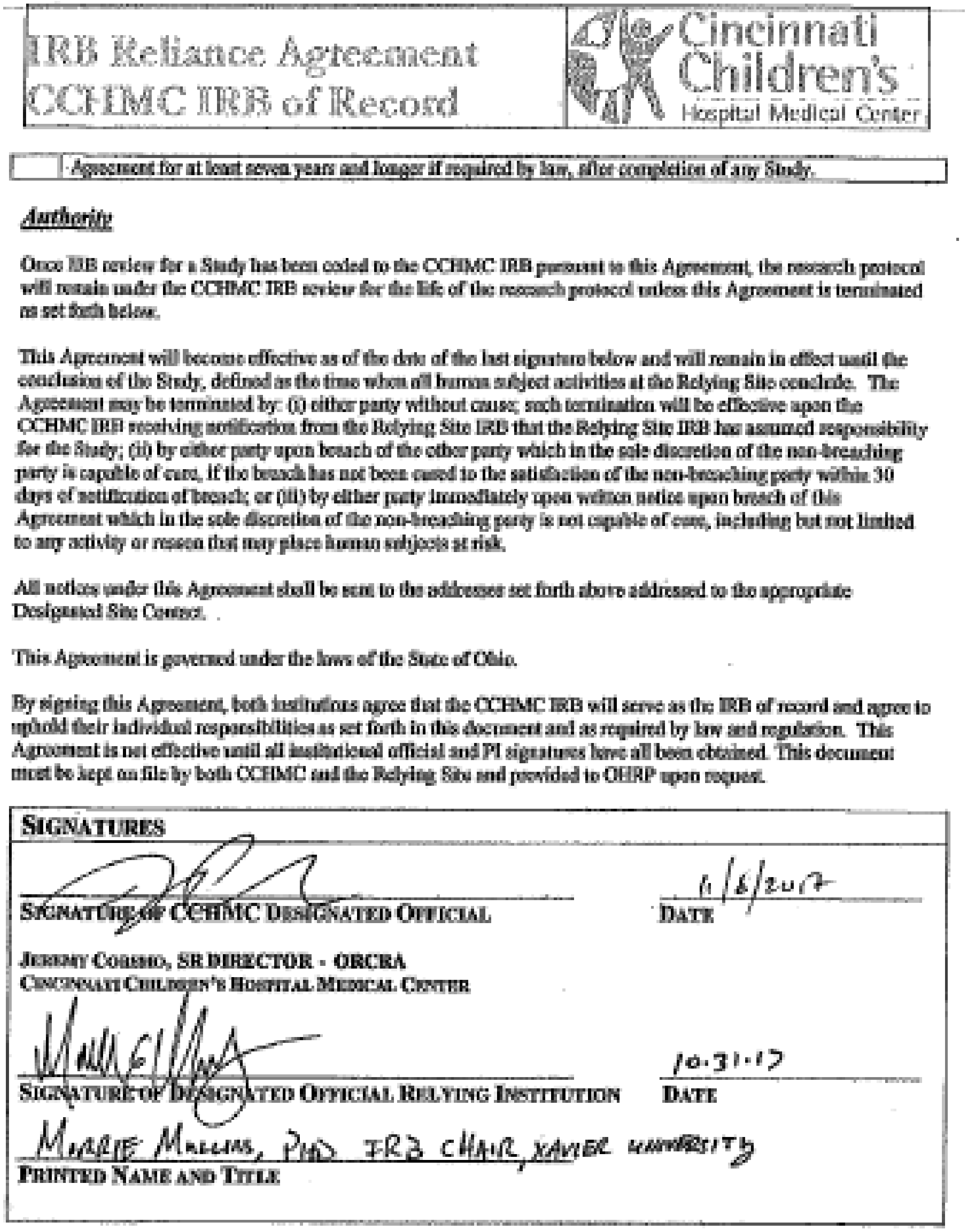
Thank you for your cooperation during the review process.

---

§46.101 (b) (3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

Note: The exemptions at 45 CFR 46.101(b) do not apply to research involving prisoners, fetuses, pregnant women, or human in vitro fertilization, Subparts B and C. The exemption at 45 CFR 46.101(b)(2), for research involving survey or interview procedures or observation of public behavior, does not apply to research with children, Subpart D, except for research involving observations of public behavior when the investigator(s) do not participate in the activities being observed.

Appendix J: IRB Alliance Agreement Signature Page



IRB Reliance Agreement
CCHMC IRB of Record

Cincinnati Children's Hospital Medical Center

☐ Agreement for at least seven years and longer if required by law, after completion of any Study.

Authority

Once IRB review for a Study has been ceded to the CCHMC IRB pursuant to this Agreement, the research protocol will remain under the CCHMC IRB review for the life of the research protocol unless this Agreement is terminated as set forth below.

This Agreement will become effective as of the date of the last signature below and will remain in effect until the conclusion of the Study, defined as the time when all human subject activities at the Relying Site conclude. The Agreement may be terminated by: (i) either party without cause; such termination will be effective upon the CCHMC IRB receiving notification from the Relying Site IRB that the Relying Site IRB has assumed responsibility for the Study; (ii) by either party upon breach of the other party which in the sole discretion of the non-breaching party is capable of cure, if the breach has not been cured to the satisfaction of the non-breaching party within 30 days of notification of breach; or (iii) by either party immediately upon written notice upon breach of this Agreement which in the sole discretion of the non-breaching party is not capable of cure, including but not limited to any activity or reason that may place human subjects at risk.

All notices under this Agreement shall be sent to the addresses set forth above addressed to the appropriate Designated Site Contact.

This Agreement is governed under the laws of the State of Ohio.

By signing this Agreement, both institutions agree that the CCHMC IRB will serve as the IRB of record and agree to uphold their individual responsibilities as set forth in this document and as required by law and regulation. This Agreement is not effective until all institutional official and PI signatures have all been obtained. This document must be kept on file by both CCHMC and the Relying Site and provided to OHRP upon request.

SIGNATURES

11/6/2017

SIGNATURE OF CCHMC DESIGNATED OFFICIAL **DATE**

JEREMY CORSMO, SR DIRECTOR - ORCRA
CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER

10.31.17

SIGNATURE OF DESIGNATED OFFICIAL RELYING INSTITUTION **DATE**

MORRIE MULLINS, PhD IRB CHAIR, XAVIER UNIVERSITY

PRINTED NAME AND TITLE

Appendix K: Project Timeline

Date (s)	**Project Objectives**
8/1/2017	**DNP Project Paper – Chapters 1 – 3**
8/1 – 8/20/2017	**Committee Review - Feedback**
8/7/2017	**PPCC Research Committee Submission Review**
8/8/2017	**Proposal Defense/Candidacy**
8/9 -8/18/2017	**Grant Submission – Sigma Theta Tau** **Project Incentives (Tentative)**
8/12/2017	**IRB Proposal to Chair**
8/9 – 8/20/2017	**Revisions to Proposal/IRB**
8/12/2017	**Project Submission to CCHMC Patient Services**
8/21/2017	**IRB Divisional Review**
9/6 – 9/10/2017	**Final IRB Revisions**
9/11/2017	**IRB Submission - CCHMC**
11/15/2017	**IRB Approval - CCHMC**
11/16/2017	**IRB Submission - XU**
12/15/2017	**IRB Approval - XU**
12/15 – 2/15/2018	**Practice Change – Electronic FHH Tool Trial**
2/15 – 3/5/2018	**Evaluation of Practice Change**
3/5 – 3/30/2018	**Finish Draft DNP project paper**
4/1 – 4/10/2018	**Defense Presentation Preparation**
4/10– 4/17/2018	**Defense**
4/23/18	**Final DNP Project Submission - Paper**

Appendix L: Data Variables

Variable Name	Variable Description	Data Source	Possible Range of Values	Level of Measurement
ProID	Unique assigned identification number	Investigator assigned	N/A	Text
SDate	Study Participation Date	Questionnaire	11/1/2017 – 3/1/2018	Date/Time
ParAge	Parent Age	MFHP	14 – 100	Continuous
ChildAge	Patient's Birthday	Questionnaire	11/1/1998 – Present Day	Date/Time
BioPar	Biological Parent: Mother , Father	MFHP	1= mother 0= father	Dichotomous - Nominal
ParRace	Participant's Race	Questionnaire	1=American Indian or Alaska Native 2= Asian 3= Black or African American 4= Native Hawaiian or Other Pacific Islander 5= White 6=Mixed Race	Categorical - Nominal
ParEthnicity	Participant's Ethnicity	Questionnaire	1=Hispanic or Latino 2=Ashkenazi Jewish 3= Not Hispanic or Latino	Categorical - Nominal
Zip	Patient's Zip Code	Questionnaire	00000 - 99999	Continuous
ParEduc	Participant's Education Level	Questionnaire	1= some high school 2= high school graduate/GED 3= some college 4= trade/technical vocational training 5=college graduate	Categorical - Nominal

Variable Name	Variable Description	Data Source	Possible Range of Values	Level of Measurement
ParStatus	Parent's Marital Status	Questionnaire	1= Single, never married 2= Married 3= Widowed 4= Divorced 5= Separated	Categorical - Nominal
HHnumb	Number Reside in Household	Questionnaire	2 - 30	Continuous
Income	Household Income	Questionnaire	1= Under $16,240 2= Between $16,240 - $20,420 3= Between 20,420 - $28,780 4= $28,780 – $32,960 5 = above $32,960 6= No Response	Categorical - Nominal
Work	Employment Status Participant	Questionnaire	1= full time 2= part time (20 hours or less a week) 3= not working 4= retired	Categorical - Ordinal
Q1	Do you think you can complete the family health history tool without help?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q2	Do you think you could complete the family health history tool at home?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q3	If you did not know health information about all of your family members would you ask them if it could improve your child's health care?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal

Q4	If you did not know health information about all of your family members, do you think you could add it later by internet?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q5	Would you like putting information into the computer yourself to share with your child's health care provider?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q6	Was the family health history tool easy to use?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q7	Were the questions on the tool easy to understand?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q8	Was the computer program difficult to use?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q9	Would you complete this if it could improve care for your child?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Q10	Would you complete this program before your child's appointment to be able to discuss with health care provider?	Questionnaire	1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree	Categorical - Ordinal
Start	Start Time	Field Notes	0700 - 2000	Time

Stop	Time MFHP completed	Field Notes	0700 – 2000	Time
IntRup	Number of interruptions during MFHP	Field Notes	0 – 20	Continuous
PerData	Completion of Personal Data Entry	Field Notes	1= yes 2= no	Dichotomous -Nominal
Pedigree	Completion of family member’s numbers to build pedigree	Filed Notes	1= yes 2= no	Dichotomous -Nominal
FamData	Completion of Family Data Entry	Field Notes	1= yes 2= no 3= partial	Dichotomous -Nominal
Print	Printed MFHP Data	Field Notes, MFHP -Print Out	1= yes 2= no	Dichotomous -Nominal
NumFam	Number of family members on pedigree	MFHP - Print Out	9 - 40	Continuous
ExtraFam	Extra family members added	MFHP – Print Out	1= yes 2= no	Dichotomous -Nominal
Cousins	Cousins added to pedigree	MFHP – Print Out	1= yes 2= no	Dichotomous -Nominal
Nieces	Nieces added to pedigree	MFHP – Print Out	1= yes 2= no	Dichotomous -Nominal
Nephews	Nephews added to pedigree	MFHP – Print Out	1= yes 2= no	Dichotomous -Nominal
HalfSibs	Half-Siblings added to pedigree	MFHP – Print Out	1= yes 2= no	Dichotomous -Nominal
GrKids	Grandchildren added to pedigree	MFHP – Print Out	1= yes 2= no	Dichotomous -Nominal
FmInfo	Recorded Family member personal information	MFHP – Print Out	0-40	Continuous
Edit	Family member screen entered	Field Log	0-40	Continuous
FmWCond	Family members with conditions recorded	MFHP – Print Out	0-40	Continuous
NumCond	Number of conditions recorded	MFHP – Print Out	0- 60	Continuous

Appendix M: Logic Model

Logic Model for MFHP Feasibility Trail in Urban Pediatric Primary Care Setting

Inputs

Academic Partnership

Preceptor

Advanced Technology

Physical Resources

Data Management System

Measurement Tool

Parents/Patients

Funding

Target Population

Pediatric patients' parents attending well child care visit in urban pediatric primary care clinic

Goals

Goal 1: Develop process map for the integration of an eFHH tool into a pediatric primary care setting

Goal 2: Assess for completeness and inclusion of health/disease specific information in parent completed eFHH tool

Goal 3: Identification of barriers and facilitators encountered when utilizing an eFHH tool during a pediatric well child visit

Major Activities

Initial assessment of practice site, target population and interprofessional team

Develop theoretical process map

Formalize partnership – PPCC review

Introduction to staff – project and researcher

Selection of eFHH tool and development of supplemental questions

Development of Participant Instruction & Field Notes

Computer/Printer set up

Design data management system

Implement test cycle

Ongoing data analysis

Modify process map

Outputs

Opportunity for increased exposure to eFHH tool and innovation concepts

Increased understanding regarding the feasibility of integrating an eFHH tool

Increased understanding of use of MFHP with vulnerable population

Identification of barriers and facilitators for ongoing eFHH tool development

Report to CCHMC shareholder the finding regarding parent entered FHH information

⇓

Long term outcome:
Development of parent portal based data entry and expansion of eFHH tool to be pediatric focused with integration of health promotion/prevention in early childhood.