Lack of Data and Undeveloped Information Exchange Systems as a Barrier to Accessible

Healthcare for Foster Youth

A Thesis

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Contents

Abstract

Physical, mental, and developmental health is a monumental unmet need for foster care youth. The absence of relevant health data and developed electronic information sharing systems inhibit the accessibility and quality of healthcare for foster youth. When used effectively, technology and digital tools can facilitate communication and care coordination among the many stakeholders involved in the care and wellbeing of a foster child. This study investigates the technical barriers on the storing and sharing of health information in order to identify gaps and inadequacies in current information exchange systems and provide recommendations for improvements. Five in-depth interviews were conducted along with a thorough review of prior literature. This study hypothesizes that the design, implementation, and wide-spread adoption of effective information exchange systems would contribute to improving the accessibility, quality, and timeliness of healthcare for foster youth and children. The findings support this hypothesis. It was found that technical barriers include lack of interoperability and siloed systems, outdated paper-based systems, lack of data recording and transmitting standardization, privacy policies and patient consent management, incompatible technological components, patient identification and matching, and the inconsistencies in education and practice. In essence, closing the information sharing gap depends on utilizing the right data in the right way at the right time.

Introduction

On any given day, there are over 391,000 children in foster care in the United States. In California, that number exceeds 60,000 youth and children (Child Welfare Information Gateway, n.d.; Foster Care Facts, 2021). Foster youth and children are considerably more likely, as compared to their peers, to experience developmental delays, obesity, ADHD, anxiety, depression, behavioral problems, asthma, speech, hearing, and vision problems, and a number of other physical and mental health issues (Turney & Wildeman, 2016). Approximately 90% of children involved in the child welfare system experience physical health problems, 50% experience two or more chronic conditions, and 80% struggle with significant mental health problems (California Association of Local Behavioral Health, n.d.). The latter statistic can be compared to children and youth who are not involved in the child welfare system, for which 18-22% struggle with significant mental health problems. Regardless of this, however, in 2018, only 54% of noninstitutionalized youth who were enrolled in Medicaid or the Children's Health Insurance Program (CHIP) - the two most common pathways through which foster youth receive healthcare - and who experienced a major depressive episode received mental health treatment (Medicaid and CHIP Payment and Access Commission, 2021). Additionally, children in foster care have significantly more hospitalizations and subspecialty office visits than children not in foster care and higher health-care charges on average. The average health-care charges for children in the foster care system are $14,372 per year, as opposed to $7,082 per year for children not in foster care (Bennett et al., 2020). Thus, heightened concerns have been raised regarding the physical, mental, and emotional health of children in the child welfare system. The American Academy of Pediatrics, through the Healthy Foster Care American Initiative, identified mental and behavioral health as the "greatest unmet need for children and teens in

foster care" (California Association of Local Behavioral Health). Reasons behind these health discrepancies between youth and children in the child welfare system as compared to their peers are numerous, complex, and in many cases, confounding. One reason, however, is the inadequacies in care coordination, communication, and sharing of the medical information of foster youth and children. This problem has been recognized in prior literature and research as the information sharing gap. Some of the reasons for the information sharing gap include technical barriers, data sharing privacy issues and concerns, identifying what information should be available to whom and when, and a lack of funding (Greiner MV et al., 2019). This project will aim to further investigate these factors with the aim of identifying technological reasons for the information sharing gap.

This study investigates the design, implementation, and adoption of a fully electronic health information exchange (HIE) system and considers the required components and infrastructure. The HIE is an architectural framework for the recording, sharing, and retrieving of protected health information (PHI) among relevant parties in a secure and efficient manner. Components include the personal health record (PHR), which can be generated by the patient, physician, pharmacist, or hospital but is managed by the patient or another authorized individual, as well as the electronic health record (EHR), which is a digital record of a given patient's protected health information (PHI) that is generated and managed by a physician or doctor. An additional essential component of health information exchange for children in the child welfare system, specifically, is the Health and Education Passport (HEP). The HEP is used in some states, including California, but not all. Where it is used, each child in foster care is issued an individual HEP that houses current and previous health information as well as relevant educational information. An infrastructure must exist that ensures interoperability, patient

consent management, security, data entering and querying processes, and governed access to PHI. Interoperability is defined as the ability of a system to work with or use the parts or equipment of another system (Merriam-Webster, 2023). Different states and counties in the U.S. have different systems, so this study takes a look at the current system in California as well as the design components and methods from which all health information exchanges could benefit. Findings from this study indicate that when investigating the role technology and data play in HIE systems for foster children, it is impractical and unfruitful to look solely at technological factors because there are many external factors which impact the successful use of technology. Therefore, this study acknowledges the interconnection of these confounding factors.

This study conducts research in two forms. The first, secondary research, will be conducted through a literature review showcasing prior research. Insights gained from the secondary research will be drawn from information available through scholarly databases and articles, the websites of national and local child welfare and foster care agencies, government web pages and databases, and other online literature sources. Findings from the secondary research have been synthesized and organized into the literature review. The second method of research is primary research through 5 in-depth interviews with individuals who currently or have previously worked with or for foster youth and children. The purpose of the in-depth interviews is to expand upon the information gained from the secondary research, tapping into specific topics and concerns that are brought to light by the literature review. These topics will include the various pathways through which foster youth receive healthcare, who is responsible for ensuring that a given foster child receives the necessary mental health care and treatment, the transfer of health information when a child move's living placements, their observed experience

of the quality and accessible of healthcare for foster youth, factors which affect healthcare access and quality, and their perspective on the medical information exchange infrastructure.

Literature Review

Information Sharing Gap and Design of HIE Systems

Prior research has informed and directed the topics of interest and the interviews conducted in this study. Greiner MV et al. (2019) discussed the unsuccessful utilization, to date, of technology for the purpose of sharing health information. This leads to what is called the "information sharing gap". The authors identified four primary reasons for the information sharing gap, which include technical barriers, data sharing privacy issues and concerns, identifying what information should be available to whom and when, and a lack of funding. An information sharing system is a critical component of healthcare delivery for all populations, but especially for vulnerable populations, such as children in the child welfare system. Furthermore, previous research discussed the existing health information sharing systems in the United States and the numerous challenges and shortcomings of these systems. Shortcomings of the current HIE systems in the U.S. relate to the information sharing gap because remedying these shortcomings is imperative in the effort to close the gap. These challenges center around the unsuccessful utilization of the right data at the right time and in the right way, and include fully digitizing the health information sharing process, lack of interoperability, incompatible technological components, regional inconsistencies in education and practice, lack of data recording and transmitting standardization, patient consent management, and patient identification and matching. Each of these factors has the potential to serve as either an enabler or a challenger of successful information sharing. While they are currently identified as

challengers, this discussion will also describe how they may, in the future, be corrected to serve as enablers.

Previous research has examined the effective design and implementation of electronic HIE systems by identifying the core components and capabilities of HIE. An HIE is a framework or architectural design that enables the exchange of protected health information (PHI) among relevant parties in a secure and efficient manner. Relevant parties can include entities that have an interest in the patient's health and care and are authorized to participate in the sharing of information. When the patient is a foster child, relevant parties may include biological parents, foster parents, relatives, physicians, nurses, specialized healthcare providers, health insurers, child welfare agencies and social workers, judges, court appointed special advocates (CASA), schools and educational representatives, and the foster child themself. In the context of healthcare outcomes for children in the child welfare system, a secure and electronic information sharing system serves as an accurate, consolidated source from which multiple stakeholders can coordinate and communicate about the many facets of a foster youth's health (Greiner MV et al., 2019). The Institute of Medicine (US) Committee on Data Standards for Patient Safety (2004) backed the importance of electronic HIE systems and argued that the architecture of such a system must include data acquisition methods and user interfaces, healthcare data standards, data repositories and clinical event monitors, data mining techniques and capabilities, and digital sources of evidence or knowledge (Institute of Medicine (US) Committee on Data Standards for Patient Safety, 2004). These components are required to build an HIE and are each necessary to facilitate communication, provide secure and reliable access to patient information, enable data management, and inform decision-making.

The data acquisition process extracts data through paper records or electronic records. Paper or electronic health records that contain the PHI of foster youth are typically created, updated, or edited by a healthcare provider, physician, nurse, child welfare agency or social worker, or a judge. The type of data that is acquired can vary, but may include speech, free text, document imaging, clinical imaging, motion videos, binary electronic data representation, waveforms, graphical codes, and indexing encoding. (Institute of Medicine (US) Committee on Data Standards for Patient Safety, 2004). Data acquisition presents a major pain point in closing the information sharing gap because raw health data takes many forms and, therefore, cannot all be analyzed in the same way. Some health data can easily be analyzed quantitatively, while other health data is more qualitative in nature. Because of this, the process of organizing and analyzing all of the necessary and informative health data for a given patient is challenging and complicated. Furthermore, the data acquisition method and capabilities vary by domain, and some domains practice greater standardization in their acquisition processes than others. Data acquisition, however, can be refined or standardized to benefit data storing and sharing standardization. Data that is acquired through a standardized terminology is more useful for the purpose of data sharing. Waegemann et al. (2002) suggested a process for the optimal information capture and recording that exercises standardized processes to yield more shareable information. This process purports that technology should provide for unique identification of the patient, ensure the use of standards-based terminologies, ensure completeness of information, reduce duplication, enhance the timely retrieval of the appropriate data at the point of care, have interoperable functions with another clinical information system, implement authentication and security measures for data protection, and ensure traceability of data to its source. It must be acknowledged that a tradeoff is made when data acquisition and storage methods are

standardized. A higher level of standardization enables a higher level of data shareability and exchange, but may also decrease the meaningfulness or richness of the data. Important health information about a patient that may be qualitative or conceptual in nature may be filtered out during the data standardization process. Additionally, health data that is more easily quantified and analyzed may be prioritized in the information exchange process, leading to a biased view of a patient's health status. Thus, a critical decision that must be made in the design of HIE addresses the level of standardization to be applied to the data acquisition in contrast to the completeness of the data shared.

Healthcare data standards impact the data exchange standards which, in turn, ensure semantic interoperability and outline technical specifications for the functioning of HIE systems. Semantic interoperability is the ability to receive and understand the data from another system. Data exchange standards may include reference information sharing models, message definition frameworks, document architectures, structured terminology, and hierarchical organization of information, with the latter two being the most critical data sharing standards (Institute of Medicine (US) Committee on Data Standards for Patient Safety, 2004). The National Committee on Vital and Health Statistics (NCVHS) recommended use of the standardized terminology developed by several researchers (Campbell, 1998; Chute et al., 1998; Cimino, 1998). This terminology is organized hierarchically, depending on the level of specificity, in the order of patient problems, interventions, and health outcomes.

A data repository is a database that collects and stores information from various sources. The data is aggregated and synthesized to generate insights and produce a longitudinal record of a patient's health data. Well-kept and up-to-date data repositories are especially important in the context of the health information of patients in foster care because the repositories house data

from many sources, which may include clinical laboratories, pharmacies, primary health care offices, and specialty medical care offices. Foster children often receive medical care from numerous providers. This is because all foster children have experienced at least one housing placement change, and many experience more than one, and because foster children are more likely to require subspecialty healthcare. These various providers all hold data that is important to understanding the full, comprehensive view of the child's health history and concerns.

Data mining techniques extract useful and relevant information from large repositories and data warehouses. Techniques include data collection, extraction, manipulation, summarization, and analysis (Berson, 1997; Fayyad et al., 1996; Mitchell, 1999). Natural language processing (NLP) is a common data mining technique used for health care data because this data is often narrative (Bates et al., 2003). NLP applications for health care data analysis, however, lack adequate standardization practices and regulations, limiting its realized effectiveness. Additionally, NLP is a difficult task which requires a significant level of expertise to implement (Fiszman and Haug, 2000; Friedman et al., 1995; Haug et al., 1990). Future investments in the use of NLP for healthcare data would be fruitful.

The final essential component of an HIE, digital sources of evidence, refers to digital sources of healthcare knowledge. Digital knowledge bases provide the foundation of evidence-based practices and, therefore, help to ensure patient safety and care quality by providing clinical guidelines and diagnostic decision support. Currently, many digital sources of evidence are siloed, which prevents integration with other clinical information systems. An interoperable electronic HIE infrastructure would benefit from the communication and integration of these currently siloed knowledge bases.

The Health Management Associates (2021) added to the discussion of designing a thorough HIE system and proposed that it should comprise three parts, where each subsequent component is built upon the previous one. The three components are a personal health record (PHR), electronic health record (EHR), and health information exchange (HIE) system. According to their guidebook, the PHR should support the EHR, which in turn supports the HIE (Health Management Associates, 2021). Therefore, the following discussion will synthesize previous research on the design and implementation of each of these core components, first discussing that of PHR, then EHR, and finally, HIE.

The guidebook recommended ways to consider options for establishing a portable PHR for children and youth in foster care that is comprehensive and interoperable. The PHR, which allows a patient to securely view, maintain, manage, and share their health information, simply supports health information sharing, as opposed to being a replacement or form of the legal medical record (Health Management Associates, 2021). A PHR may be, but is not always, linked to an EHR. Linked PHRs and EHRs are referred to as being "tethered," and this link ensures secure patient-provider communication, allows patients to perform certain tasks - such as appointment scheduling and adding medications - and can be accessed on a number of different electronic devices. A PHR that is not tethered to the EHR is likely to have self-reported or manually entered information (Cho and Jackson, 2016). Proposed types of PHR implementation are the PHR State Vendor Platform, PHR Regional Managed Care Model, and the Statewide Managed Care Model. In the state vendor platform, the state enters a contract with a single vendor and the platform is composed of information from the state's HIE community information exchange (CIE), which draws data from health and social services and other state systems. In the PHR Regional Managed Care Model, each managed care organization (MCO)

would create and operate the PHRs for the medical members assigned to them. The MCO would

coordinate with regional HIE, CIE, and other data sources to build a comprehensive PHR. The

statewide managed care model would require enrollment for all foster youth in the state into a

statewide MCO. This is similar to the regional managed care model because the MCO would

coordinate with state HIE, CIEs, and other data systems to compile the PHR, but would provide

greater statewide consistency and interoperability because all PHRs in a given state would follow

the same procedures and standards. Thus, the statewide managed care model yields fruitful

outcomes for the foster child population due to the mandatory enrollment, ensuring care for all

foster children, and statewide continuity.

The group, LeadingAge (2022), discussed the various designs and types of HIEs that

exist currently and provided guidance on selecting an HIE solution that best fits a company, the

company's services, and available data. (LeadingAge, 2022) The article discussed the

implementation of HIE for the general population and the aging population, but the concepts

discussed in the article can, in part, be applied to the design of HIE within the child welfare

system. Eight essential components or aspects to consider when designing an HIE system are

defined and include the following:

1. Service Location

Service location refers to the geographical region that the HIE serves. Options include

regional, statewide, nationwide, and vendor to vendor. Research has made clear that access to

healthcare for foster children varies by geographical region. This discrepancy is caused by a

number of reasons, including interoperability, data linkage, patient matching, limited broadband

adoption of EHRs, and lack of widespread provider adoption of EHRs. The Institute of Medicine

(US) Committee on Data Standards for Patient Safety (2004) explained that, currently, many data

exchange systems operate within the boundaries of a single health system or overarching institution despite the fact that many providers engage in practices outside of a single health system. Therefore, selecting a service location that is larger than regional, whether that be statewide or nationwide, is optimal.

2.   Modality of Exchange

Modality of exchange determines the way the data is queried, transmitted, and accessed. Options include directed exchange, query-based, and consumer mediated. Directed push exchange is used both to deliver notifications and pieces of data to a provider automatically and to enable secure messaging between two providers. Query-based exchange allows providers to identify and pull information from another provider. Consumer mediated exchange allows the patient to manage their own health information. The importance of exchange modalities is supported by the Institute of Medicine (US) Committee on Data Standards for Patient Safety (2004), who explained that the accessibility of the correct data at the correct time can help to eliminate redundancies and to aid in the correct medical decision making on the part of the clinician or care provider. These benefits resulted in a reduction of duplicated procedures, reduced number of imaging procedures, lower costs to both patients and the healthcare company, improved population health, reduced use of laboratory testing, and improved patient safety.

3.   Type of HIE Entity and Network

The type of HIE entity and network refers to the specific use case, required services, participating parties, and data available for the HIE. Options include national HIE networks, and state and regional HIE. Ensuring interoperability requires clear and mutually exhaustive data sharing standards on a state or national level (Institute of Medicine (US) Committee on Data Standards for Patient Safety, 2004). This ensures interoperability within and across various

organizations. Interoperability is imperative for the scalability and governance of an HIE. When a company intends to grow and expand their existing HIE system, they do so by adding new modules or components to the existing system. Compatibility issues, however, present when the new modules to be integrated were designed and built by a different group or vendor than the original system. Therefore, coordination is required among the healthcare organization hoping to scale their HIE and HIE vendors to ensure compatibility and interoperability among the technical components. Additionally, governance of technical elements equates to ensuring interoperability through the practice of assisting and encouraging care providers to implement Meaningful Use of certified EHR technology in order to promote interoperability. Meaningful Use refers to an EHR Incentive Program through the Centers for Medicare and Medicaid Services (CMS) and encourages providers to adopt and utilize certified EHR technology in a manner that fulfills the program requirements.

4. Type of data exchanged

The type of data exchanged may include some of, but is not limited to, the following: ADT (admission, discharge, transfer) data, demographics, care plan, allergies, medication list, history and physical records, patient's advance directives, electronic reporting immunizations, problem list, SBAR (situation, background, assessment, and recommendations), INTERACT (electronic intervention to reduce acute care transfers admission form), laboratory results, imaging results, public health reporting, discharge summary, functional assessment, cognitive assessment, and physician orders for life-sustaining treatment (LeadingAge, 2022). One relevant role of data standardization is addressing how much information to share and in what format to ensure that stakeholders have access to the right data at the right time. It is important to achieve a practical balance between allowing too much information to be shared and not allowing enough

to be shared. The Institute of Medicine (US) Committee on Data Standards for Patient Safety (2004) agreed with the importance of clearly determining the type and amount of data to be shared, as well as the level of detail with which to share it. Doing so ensures standardization in the data collecting, storing and sharing process. This includes common standards for data acquisition, messaging formats, terminology standards, and a generic information model adopted by all participants.

5.   Services Offered

Services offered may include some of, but are not limited to, the following: Consolidated Clinical Summary Record Exchange, consolidated summary EHR record from multiple providers, patient centered data home, HISP (health information service provider), electronic authentication as shared service, patient matching, provider directory, consent management, alerts and notifications, referral services and notifications, patient portal access, and quality reporting (LeadingAge, 2022). Within a patient health portal, the most frequently accessed sections are the contact information and the health information (Institute of Medicine (US) Committee on Data Standards for Patient Safety, 2004). Health information includes diagnoses, allergies, medication history, and surgical history. Therefore, it is crucial that focus is placed on ensuring that contact and basic health information can be recorded, shared, and retrieved efficiently. An additional area of focus should be providing alerts and notifications.

6.   Communication Method

The method of communication impacts the security and privacy of the exchanged health information, which is a highly important consideration and often of concern for patients and other relevant parties. Therefore, it is important to select the communication method that not only fits the needs and abilities of the company, but also ensures data security. The selected

communication method may be through secured web services, TCP/IP over VPN, secured FTP (file transfer protocol), and secure email. Communication through TCP/IP over VPN is the most interoperable option, while secure email often ensures the most data security.

7. Consent Policies

Consent policies allow patients to make decisions regarding the sharing of their health information through an HIE. Consent decisions often allow a patient authority over whether their health information will be released, under what circumstances their health information will be released, and by whom. Greiner MV et al. (2019) found that when implementing the HIE system, the data sharing agreement task was the most challenging and time consuming piece. The data sharing agreement task involves both the issues of consent management and privacy concerns. Health Management Associates (2021) further supported the importance of considering patient consent when designing HIE.

8. Contact information

Contact information includes patient name, phone number, e-mail address, and membership inquiries link.

Pain Points in Health Data Exchange for Foster Youth

The second function of the literature review is to guide and inform the interviews conducted in this study. Prior literature informed and guided the interviews conducted in this study. The questions asked in each interview aim to expand upon and further investigate several relevant topics identified in previous literature. These topics include the pathways through which foster children can and typically do receive healthcare, the roles of the involved stakeholders, care coordination among the various stakeholders, the current health data sharing infrastructure,

health data sharing policies and regulations, and what factors or circumstances may exacerbate the healthcare gap between a foster child or youth and their peers.

The Child Welfare Information Gateway (2022) provided important background information and an overview of the various pathways through which foster children can receive healthcare coverage. These pathways include securing healthcare through Medicaid, which is the most common, and other, less traditional, healthcare coverage pathways. In support of this, Greiner MV et al. (2019) described the pathways through which a foster child can receive healthcare through Medicaid. Healthcare coverage through Medicaid options include through title IV-E eligibility, mandatory Medicaid eligibility for children under age 19, youth formerly in foster care and under age 26, and youth who age out of foster care in states that offer the chafee option, which allows youth who age out of the foster care system to be receive Medicaid coverage until they turn 21. Other healthcare coverage options include the Children's Health Insurance Program (CHIP), health insurance through one's employer, and healthcare coverage opportunities for families receiving child welfare services provided by the Affordable Care Act.

Prior research revealed that there are many parties involved in providing healthcare for foster children, including various stakeholders and independent organizations with unique missions and services related to aiding in the delivery of quality healthcare for children in the child welfare system. Examples of these types of independent organizations include non-profit organizations, church-led or religiously affiliated groups, and for-profit programs. Care coordination is dependent on the cooperation of all stakeholders in supporting and accepting the implementation of HIE systems. Health Management Associates (2021) explained that it's common for different stakeholders to have similar sounding roles and, while these many participants provide numerous benefits and vital services, there can also be confusion within this

ecosystem regarding who, ultimately, is responsible for ensuring that a given foster youth receives the necessary healthcare services. For example, it is sometimes assumed that the foster parent is responsible for ensuring that their foster child receives the necessary medical care in a timely manner, while at other times this is assumed to be the responsibility of the social worker. This lack of clarity and confusion leads to the gaps in care delivery described by Greiner MV et al. (2019). Lohr et al. (2018) agreed with this, explaining that, while the process varies by state, it is common for the responsibility to fall on a child welfare worker, typically the child's assigned social worker, when the parent's decision-making rights have been removed or suspended by a judge. However, it is commonly reported that a given social worker has a very heavy caseload which often prevents them from devoting enough attention toward a single case to fully understand their needs and circumstances. (Lohr et al., 2018) Adversely, however, Chipungu and Bent-Goodley (2004), stated that there are cases in which pediatricians have a responsibility to ensure that a child receives the necessary medical care through the means of pediatric services, healthcare coordination, and advocacy on behalf of the child. Due to these discrepancies and the potential for confusion, interview questions are asked to gain a better understanding of this problem and consider future improvements. Questions regarding the current health information exchange infrastructure were guided by the Health Management Associates discussion of the various benefits and drawbacks of the current use of PHRs in the state of California and recommendations for improved data sharing and standardization. Thus, the interview questions inquire about the interview participants' personal perspective of the current infrastructure. The U.S. Department of Health and Human Services discussed relevant HIPAA requirements and confidentiality concerns specific to child welfare, prompting questions related to privacy regulations and concerns. The privacy regulation related interview questions aim to better

understand the magnitude of impact that privacy concerns and policies have on actual health data sharing practices. Risley-Curtiss & Stites (2007), Cho & Jackson (2016), and Chipungu & Bent-Goodley (2004) indicated that there are various individualized conditions or circumstances that may further challenge a foster youth from receiving the necessary healthcare. This discussion highlights the various intersectional issues that exist within the healthcare delivery ecosystem, such as geographic location, race, ethnicity, age at time of entry, adverse childhood experiences, and socioeconomic status of the biological parent. Inquiries related to these intersectional issues aid in pinpointing where and why information sharing gaps occur.

Primary Research: Methodology and Process

The second research approach used in this Thesis gathered primary research findings through a series of five in-depth interviews with individuals who currently or have previously worked with or for foster youth and children. The in-depth interviews functioned to expand on the information gained from the secondary research, tapping into specific topics and concerns that relate to technological aspects and inadequacies that impact the sharing of the health data of foster youth. These topics include the various pathways through which foster youth receive healthcare, who is responsible for ensuring that a given foster child receives the necessary physical, behavioral, and mental health care and treatment, the transfer of health information when a child's living placement changes, interviewees' observed experience of the quality and accessibility of healthcare for foster youth, factors they believe affect healthcare access and quality for this population, and their perspective on the current medical information exchange infrastructure. The research methodology process includes institutional review board approval, participant recruitment, conducting one-on-one interviews, analyzing interview responses, and drawing conclusions.

The participant recruitment for the interview was based on the personal and professional networks of the primary researcher. This includes connections that have been made based on recommendations from and connections of professors at the University of San Diego, previous employers, and through a local philanthropy the researcher is connected with. The participants recruited for interviews included a child right's law professor and legal representative of delinquent and dependent youth, a lead attorney in dependency law, a supervisor of CASAs (Court Appointed Special Advocates) in San Diego County and liaison for the various stakeholders within the child welfare system, a public health nurse (PHN) and supervisor for a foster youth healthcare program, and the director of an organization which advocates for improved health information sharing in California. Hereafter, the legal representative of delinquent and dependent youth will be referred to as "Participant #1", the dependency law attorney as "Participant #2", the CASA supervisor as "Participant #3", the PHN as "Participant #4", and the advocate for improved health information sharing in California as "Participant #5". These participants were selected for recruitment to promote the diversity of perspectives to be included in this study. Each interview participant had a different expertise area and background. Participants #1 and #2 provided the legal perspective and insight. Participant #3 provided the more personal perspective and experience that CASAs are exposed to as a result of working directly with an individual foster child. Participant #4 contributed a health-focused perspective, and Participant #5 offered insights on the sociotechnical aspects of health information flow and data exchange systems. Therefore, each participant contributed unique perspectives regarding their experience with the health information exchange infrastructure and the greatest pain points within this system. The recruitment process intentionally sourced from a diverse set of expertise areas in order to mirror the many stakeholders involved in the information sharing of foster

children's health data. Additionally, anonymity of the interviewees was ensured to promote

honest and genuine answers. Removing personal identifiers and separating the personal opinions

and experiences of the interviewees from that of their employer or organization was conducive to

the insightfulness and authenticity of the interviews. The in-depth interviews took place through

a 30-minute, one-on–one zoom meeting. Interviews were guided by a predetermined set of

questions and all participants were asked the same questions. The findings from the interviews

will be analyzed in a qualitative manner and will be used to validate, contradict, or be

incorporated into the researcher's hypothesis.

Interview Instrument Questions

The questions included on the Interview Questionnaire appear below.

1. Can you tell me about the position(s) that you have held or currently hold in the child welfare system? Could you talk about your daily roles and responsibilities, who you typically interact with on a daily basis, typical level of interaction with the children and youth who's cases you're responsible for or who you support in your role, what that interaction looks like? You do not need to provide the name of the organization for which you have been or are currently employed by.
2. With what type(s) of foster care placement are the youth that you work with typically placed? (Licensed foster family homes, group homes, foster family agencies, independent living, transitional housing, etc.)
3. From your knowledge, what are the various pathways through which foster youth are able to receive healthcare? What pathway(s) are the most common?
4. Who is responsible for ensuring that a given foster child receives the necessary medical care and treatment?
5. Who is responsible for ensuring that a given foster child receives the necessary mental health care and treatment?
6. When a foster youth's living situation changes, what is the process of ensuring that the necessary and appropriate health information about the child is transferred from the previous caretaker to the new caretaker? If this living situation change requires that the child begins to see (a) new medical care provider(s), what is the process of ensuring that the child's health and medical records are transferred from the previous medical

care providers to the new medical care provider? (For example, if the child moves from southern California to northern California and requires a primary care provider located in northern California.)
7. From your experience, have you observed any recent trends in the quality and accessibility of healthcare for foster youth? Has the quality and accessibility improved, decreased, or remained the same?
8. From your experience, have you observed particular factors which affect a foster youth's access to quality healthcare? Factors may include race or ethnicity, gender, caretaker income, geographic region, existence of mental health conditions, length of time in foster care, age at which youth entered foster care, etc.
9. Can you speak to the information exchange infrastructure (whether this is related to information about the child's health records, education records, living status and history, etc.) within the child welfare system? What is the level of data sharing and standardization, from your observations?

Primary Research: Findings

The following section will synthesize and discuss the findings from the primary research that was conducted in the form of interviews. Due to the diverse backgrounds and knowledge bases of the interview participants, both similarities and differences can be seen in the responses. The findings center around the identification of how and where information sharing gaps exist in current health data sharing and exchange systems. Findings support that gaps exist due to human related issues, regional differences, governance issues, and technological issues.

In our current systems and processes, both humans and computers play a role in the recording and sharing of data. Information exchange systems are created by humans, who then interact with the computer by inputting data into the digital system, querying data, editing data, and performing various other functions. This interaction between humans and computers when recording and sharing data can, and often does, create gaps. This is because humans excel in certain skills, such as creativity, emotional intelligence, adaptability, abstract thought, judgment,

intricacy, and problem solving when there are many variables involved. Computers excel in others, such as iterative and repetitive tasks, complex mathematical tasks, and decision making when there are a small number of variables involved. Problems arise and important aspects may be overlooked when the "human versus data-processing-machine interaction" does not optimize these skills. Four out of the five interview participants expressed this to be a relevant problem to be addressed.

These problems are typically rooted in the lack of standardization and insufficiency of data. Any individual who enters health information into an information exchange system on behalf of a foster youth is susceptible to these problems. These individuals most often include a social worker or a medical care provider. Therefore, this distinction between technological problems and human-caused problems is relevant to the discussion of the role of technology in data sharing in order to understand the origin of a problem and where to allocate resources for improvement. More specifically, human error can lead to inconsistencies in the data stored in PHRs, EHRs, HIEs, HEPs, and other data storing and sharing systems. The data stored in an information system is only as good as the practices of the person who entered the data into the system. Participant #4 explained this, attributing this to the individual's training and knowledge regarding what data to input, where to input data, when to input data, the necessary level of detail, appropriate terms and jargon, appropriate use of punctuation, and other grammatical elements. Interview participant #5 supported this further, explaining that the problem is further exacerbated because although data storing standards are regularly updated and clearly defined in California, people often fail to remain educated or disciplined when storing data. Interview Participant #3 discussed the impact of this on HEPs as well. They explained that while a number of stakeholders, including judges, social workers, and CASAs, are given access to the HEP, there

is often missing data in the HEP, which inhibits its effectiveness in communicating important health-related information. They agreed that these inconsistencies originate back to the individual who is responsible for populating information into the HEP. Greater complexities, however, must be considered as to why this form of human error and shortcomings occur. Reasons that an individual may relay inaccurate or insufficient information are often due to unmanageable caseloads and lack of time, lack of training, or lack of coordination and communication with other regions and organizations regarding how information should be inputted. Additionally, Chipungu & Bent-Goodley (2004) found that 90% of state child welfare agencies report difficulty in recruiting and retaining workers (Chipungu & Bent-Goodley, 2004, p.83). Thus, providing support for social workers, physicians, and nurses is a building block to the eventual improvement of health data exchange.

Regional disparities have been identified in previous literature as a contributor to the information sharing gap, and findings from the interviews further support this claim. Regional inconsistencies in the effectiveness of health information exchange systems primarily impact data recording practices and funding. In the context of child welfare data, information exchange systems in California are county based and operated. Different standards and practices are implemented in different counties. Because of this, sharing information across counties presents a challenge. Interview Participant #2 shared that much of this is caused by uneven resource distributions, where certain regions benefit from a greater access to resources than others. In California, smaller counties in the northern regions of the state tend to experience greater gaps in health information sharing because of the lack of resources. These counties are smaller than counties in southern California both geographically and in population. It is more common for a foster youth in northern California to frequently seek medical care in a nearby or neighboring

county. For example, a given individual may require primary medical care in one county, dental care in another, and mental health care in yet another. Additionally, a foster youth who is changing living placements in northern California is more likely to be placed in a different county. Therefore, greater coordination and communication is required among smaller counties than in a region with larger counties. However, the current reality is that although these smaller counties require a greater level of care coordination and communication, they are also underfunded in comparison to larger counties. This exacerbates and further challenges the regional discrepancies.

Governance is a challenge that has been identified both by LeadingAge (2022) and by several interview participants. Improved governance on data sharing is two-fold. It determines, first, standardization processes and, secondly, privacy concerns and consent management. Governance requires standards to be set on how and when health data is shared, who can share and view the data, and level of detail. The impact of unorganized governance on data sharing is the lack of standardized data recording and sharing procedures that result in discrepancies in how different social workers and medical care providers record and transmit information. First, statewide standardized data acquisition methods, structured terminology, structured message definition and level of detail, and document architectures should be mandated. Secondly, privacy concerns and policies are interconnected with technological issues because they inhibit the type and amount of data that is shared through electronic systems. Data sharing policies and procedures require clarity and specificity, but they should not be excessively complex or difficult to interpret. Participants #1 and #4 highlighted an important point relating to health privacy and consent management. Participant #1 discussed that confusion regarding data privacy arises when genetic health conditions or risks and family medical history becomes relevant. The participant

posed the question: "Whose data is it?" to insinuate that it may be nonsensical to eliminate

family health history or genetic health risks from a foster child's health record. Conversely,

Participant #4 maintained that this type of health information is typically not recorded because it

is considered to be health data belonging to the foster child's biological relatives, and not that of

the foster child themselves. Secondly, Cho and Jackson (2016) explained that a "lack of

understanding of laws leads to inappropriate over and under sharing" of data. Participants #1 and

#5 noted that the lack of education and understanding of data privacy regulations often leads

people to falsely believe that there are more barriers to health information sharing than there are

in reality. They explained that regulations, in fact, are a means of providing opportunities to

share information, but that excessive caution is often exercised in the face of confusion, deterring

people from sharing any information at all. Furthermore, both participants #1 and #5 conveyed

their wish for regulations to help enable people to share more information in a safe and secure

manner, but that this remains an area in need of improvement. Additionally, improved

governance would have beneficial impacts on data sharing and the data sharing agreements

among multiple organizations and stakeholders. Greiner MV et al. (2019) identified the data

sharing agreement task as being the most difficult task in the process of implementing HIE.

Governance on data sharing agreements would clarify and define the interpretation of various

data sharing practices and policies, ensuring that all participants have clear understanding and

can be held accountable to the data sharing agreement to which they are committed. Participant

#5 emphasized the importance of navigating a balance of data sharing and consent. This balance

would both honor patient consent rights while also encouraging the exchange of rich and

insightful health data.

Technological issues include standardization and a lack of available data. Interview participant #4 works closely with the health and education passports (HEP) that play a fundamental role in sharing medical information for children in the child welfare system. It is useful to look at the current HEP system in order to identify and understand the technological issues that exist for the health information sharing of foster youth. The HEP is a paper-based document that is structured with a predetermined set of sections under which social workers and medical care providers can enter relevant information. Participant #4 described that a generic HEP that has not been populated with data is 8 pages and was described as excessively lengthy and not organized in a reader-friendly manner. The interview participant described the section titles of the HEP in order. These sections include "Demographics", "Current Health Information", "Alerts", Allergies", "Summary of Current Health Conditions", "Well Child Exams", "Immunizations", "Developmental and Mental Health Screenings", "Past Health", and "Education". The participant maintained that the HEP proves helpful when a foster child changes living placements because it provides medical history, such as immunizations. However, the HEP is less beneficial for daily information recording and sharing activities, as it is very lengthy and is often more detailed than is necessary. Another considerable obstacle is that the current HEP is a physical, paper-based document. Therefore, the electronic transfer of the information recorded in an HEP is extremely difficult. Evaluating the HEP as a benchmark for health data exchange for foster youth is insightful, since the HEP is a very common way that a foster child's health data is stored and shared, and demonstrates why improving standardization protocols and transferring the current paper-based system to a digital system is important.

The lack of available data can manifest in several forms. First, the required data may not have been recorded in any way at any time. The second possibility arises when the required data

was recorded, but in the wrong place and at the wrong time. Participant #3 discussed a few of the reasons why data may not be recorded. The lack of legal documentation either of the child or the biological parent, the immigration status of the child or parents, or the attempts of caregivers to hide signs of abuse all serve as potential reasons why a foster child's PHR may lack data. Participants #1 and #5 discussed the ways in which data may not be shared in the right way at the right time. This often occurs when systems are siloed. More specifically, information systems often contain physical health data, while another may contain mental health data, and yet another contains developmental data. When these systems are not integrated and fail to communicate with each other, important data may be lost or hidden.

Analysis, Recommendations, Limitations, and Additional Research Questions

The analysis of this study's research findings will discuss the main pain points identified, recommendations for future improvement, limitations, and future research questions to be addressed. This discussion will compare and contrast the responses recorded from interview participants in relation to the responses of other interview participants and to findings from the literature review.

Analysis and Recommendations

This study identifies the main pain points that create inhibitors to successful and effective health information exchange systems serving foster children and provides recommendations for improvement. The main pain points include untethered PHRs, incompatible electronic systems, siloed systems, the data standardization tradeoff, and improved NLP techniques. Following the consideration of these pain points, this Thesis provides a recommendation for an HIE system architectural framework to optimally serve the foster care population. Recommendations include both HIE components and capabilities.

A PHR which is not tethered to the corresponding EHR has three major negative consequences. These include lack of accountability, heightened chance of manually entered data, and increased risk of bias. A tethered PHR increases accountability and the ability to credibly source the information contained in an EHR because the information stored within the PHR can be easily traced to the information stored in the EHR. Furthermore, a longitudinal and seamless story can be compiled for a patient's health and health history, thus minimizing the chance of duplications, gaps in medical history, missing data, and contradicting data entries. Conversely, when these two systems are not able to interact and connect, there is a heightened chance of data being manually entered, specifically into the PHR (Cho & Jackson, 2016). Manually entered data, while at times beneficial, typically is not inputted in a standardized format and therefore may be inputted into the system incorrectly or inaccurately interpreted. This is supported by Interview Participant #3 who explained that the effectiveness of HIEs are often a reflection of the way in which the data was originally entered. The presence of inaccurate data is often the result of human biases, such as recall error or recency effect. Recall error occurs when people are asked to recall past events or experiences and misremember all or parts of the event or forget parts of the event altogether. The recency effect describes the common phenomena in which people better remember the last few ideas, facts, or items from an event that occurred earlier. Thus, a PHR that is not tethered to an EHR can proliferate the inaccuracy of the health record.

The implementation of HIE is commonly inhibited by incompatible technological components and siloed systems. The design of HIE modules should allow for scalability and expansion. This requires compatibility between the original HIE components and newly added components. A strategic collaboration among HIE vendors and the organization which is implementing the HIE to ensure a smooth integration among various HIE modules could yield

mutually beneficial outcomes for all parties. Secondly, siloed computer systems and information technologies occur when various units of data are separated from other parts of an organization's data or information. Health Management Associates (2021) found that the "coordination and planning of care across the various systems is typically limited due to the siloed nature of agencies that serve this population." (Health Management Associates, 2021) Child welfare health data exchange is siloed on several fronts. These include geographical siloes, as confirmed by the majority of the interview participants, siloed healthcare delivery and healthcare coverage organizations, and siloed healthcare data repositories. Participant #2 provided an example of siloed healthcare coverage organizations. In San Diego county, many foster children are covered by Tricare, which the participant described as being simpler to navigate, though offering fewer services than most coverage plans. Conversely, most foster children in California who live north of San Diego country are covered by alternate plans, such as Medicaid. Tricare and Medicaid do not interact efficiently, so if a child who previously received treatment through Tricare later requires treatment through Medicare, or vice versa, they would encounter problems. Siloed healthcare data repositories pose challenges because, as Participant #1 explained, these systems often "don't talk" and this becomes especially problematic when the data repositories containing information about a child's physical health are not interoperable with repositories containing information about a child's mental health, developmental health, and so on. Siloed health data systems are problematic because care providers are unable to glean a holistic and accurate understanding of a patient's health status and history, thus preventing comprehensive and well-informed care decisions and delivery.

Considerations for several tradeoffs must be made in designing and implementing HIE. The first, the data sharing-data standardization tradeoff is determined by data standardization

procedures and data sharing policies and regulations. Waegemann et al. (2002) proposed a

standardized data acquisition process in which the technology supports patient identification,

standards-based terminologies, minimization of duplication, ensuring completeness of entries,

timeliness and availability of data, interoperability, authentication processes, auditing

procedures, and security protocols. However, a tradeoff is made when data acquisition and

storage methods are standardized. A higher level of standardization enables a higher level of data

shareability and exchange, but may also decrease the meaningfulness or richness of the data.

Important health information about a patient that may be qualitative or conceptual in nature may

be filtered out during the data standardization process. Additionally, health data that is more

easily quantified and analyzed may be prioritized in the information exchange process, leading to

a biased view of a patient's health status. One mitigation technique would be to strengthen the

capabilities and expertise of NLP techniques as they apply to the analysis of health data. Thus, a

critical decision that must be made in the design of HIE addresses the level of standardization to

be applied to the data acquisition in contrast to the completeness of the data shared. The second

tradeoff, the data sharing-data privacy tradeoff, outlines the balance between sharing enough

information to enable actionable and informative insights while also protecting the privacy of the

patient. Interview Participant #3 explained that this is often both the most crucial and the most

difficult task to accomplish in the HIE design process because it requires transparent

communication between all stakeholders. An understanding must be gained regarding the goals

and needs of all stakeholders and how a middle ground can be achieved to honor all

stakeholders.

      This study has explored the various options for HIE implementation in order to

recommend an optimal synthesis of components to better support the health information

exchange for foster children. It was found that a statewide managed care model would best

support the health information exchange for the child welfare use case because, when discussing

the geographical factors that are at play, several interview participants emphasized that

disparities occur across county lines. The optimal communication method is TCP/IP over VPN.

This communication method provides the greatest level of interoperability and connectivity,

which would aid in the inclusion of all relevant regions and service providers. Additionally, this

method provides specifications regarding data formatting, transmitting, sharing, routing, and

retrieval of data. These specifications help to maintain standardization. Such standardization,

specifically regarding data formatting and data sharing, would address the concerns of Interview

Participants #1, #3, and #4 that the individual entering and querying data in an HIE often utilizes

the HIE inaccurately.

For designing HIE systems to serve children in the child welfare system, the most

necessary services include consolidated summary EHR records from multiple providers,

electronic authentication, patient identification and matching, provider directory, and alerts and

notifications. The goal of the consolidated summary EHR record from multiple providers is to

reduce redundancies, an important capability to HIE systems serving children in foster care, as

Participant #1 explained that this population is commonly served by numerous different

providers at various points in their life, all of whom have a precedent for siloed data systems.

Electronic authentication as a shared service implements proofing and authentication controls,

which sets the foundation for secure access. Participant #3 acknowledged the concerns of many

stakeholders around the privacy and security of sharing medical data. Therefore, ensuring secure

data sharing remains a top priority would appeal to these stakeholders and implement checks on

health data sharing. Patient matching capabilities ensure that a care provider can locate and link

patient records across the disparate data sources that commonly make up a foster youth's health history. A provider directory enables the sending and receiving of provider and health organization information. Alerts and notifications help impose accountability among foster youth and their care providers to stay up to date with appointments and follow through with referral services. Interview Participant #3 discussed the importance of alerts and notifications for the foster youth population. Commonly, at the point when a child enters the foster care system, they are already behind on various medical and educational needs because those needs were not being fulfilled previously. At the early stages of a child's time in foster care, they become booked with appointments to make up for the prior years of deficiency. This creates a snowball effect, where medical and educational needs begin to pile up because they have lacked adequate care for an extended amount of time, problems or health needs are just now being identified, and follow up appointments and referrals further populate a child's schedule. Alerts and notifications help a foster youth and their caretakers to remain organized, informed, and up-to-date on unmet needs.

The optimal HIE should allow for direct exchange, query-based exchange, and consumer mediated exchange because one specific service is likely to require a specific exchange modality. Direct exchange would support alerts, notifications, and provider services. Query-based would support consolidated clinical summaries and patient matching. Consumer-mediated exchange would support patient portal access and consent management. Therefore, the inclusion of direct exchange, query-based, and consumer mediated exchange modalities is highly important, and focus should be placed on ensuring the functionality of each of these modalities. Additionally, the statewide network model supports both query-based and direct exchange modalities, further making it the optimal network model.

Further recommendations for the improvement of HIE systems are the implementation of blockchain technology for data recording and storing. Also, improving user experience would lead to widespread adoption and willingness to remain knowledgeable on the standards and best practices of HIE (Mahajan, H.B., *et al., 2022)*.

Limitations

Limitations of this study are the qualitative nature of the primary research and the small sample size included in the research. The interview responses were analyzed in a qualitative nature, thus evoking a more conceptual discussion. Although it is not a statistically representative form of data collection, the qualitative analysis was advantageous to capture perspectives and nuances that are difficult to quantify. Additionally, the interview-based primary research consisted of a sample size of 5. Maintaining a small, focused sample size allowed the researcher to analyze the interview responses more thoroughly. Consequently, this allows for a higher level of bias, which serves as a limitation. However, the interview participants represented various stakeholder perspectives, which is a positive enabler to the insightfulness and efficacy of the study. The findings suggest that future research on this topic would, logically, incorporate a larger sample size to reduce the impact of this limitation.

Additional Research Questions

This Thesis identifies several research topics and questions that could not be thoroughly addressed in this study but require future attention and study. These topics include optimizing the way humans can work with computers, Medicaid-related issues and the lack of Medicare funding, mental health concerns for foster youth, and reproductive health concerns for foster youth. This study discusses the interconnectedness of the many contributing factors to the inaccessibility and reduced quality of healthcare for foster youth, which includes

human-computer collaboration and division of work. This study discussed this topic and its relation to technological inefficiencies of information exchange, but further research is necessary to thoroughly investigate this topic and recommend steps for improvement. Similarly, child welfare health information exchange for the foster youth population is often intertwined with the Medicare system. Therefore, the unintended effects and consequences of the current Medicare system requires further examination. An additional topic of significance is that multiple interview participants mentioned mental health and reproductive health as being particularly burdensome concerns for the foster youth population. Although these topics deviate from the focus of this study, they both have implications for the overall accessibility and quality of healthcare and necessitate further research.

Conclusion

Access to timely and quality healthcare, including care for physical, mental, and behavioral health, for foster youth and children is significantly disadvantaged in comparison to healthcare access for children who are not in the child welfare system. This has been exemplified in numerous prior research efforts which have highlighted discrepancies in health outcomes between these two populations. This study investigates the various reasons for the inadequacies in care coordination and communication, stipulating that the lack of relevant and available data and undeveloped information exchange systems serve as a contributing factor. The research found that technological barriers do impact the accessibility and quality of healthcare for foster youth and that these barriers are primarily caused by the continuing existence of a partially-paper system, a lack of interoperability, incompatible technological components and siloed systems, lack of standardization and the failure to utilize the right data at the right time, patient consent management disagreements, patient identification and matching and the availability of data, the

gaps which prevail through the collaboration of people and technology, insufficient allocation of resources toward education and training, undeveloped NLP techniques, and inadequate consideration for the data acquisition-data standardization tradeoff. The design of a successful HIE for the foster care population requires careful consideration of the population's specific needs. Thus, this study considers these requirements and provides recommendations for improvements.

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