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# **Research and Applications**

# Sharing personal health record data elements in protective custody: youth and stakeholder perspectives

Judith W. Dexheimer,<sup>1,2,3</sup> Mary V. Greiner,<sup>3,4</sup> Sarah J. Beal,<sup>3,5</sup> Darius Johnson,<sup>1</sup> Andrea Kachelmeyer,<sup>1</sup> and Lisa M. Vaughn<sup>1,3</sup>

<sup>1</sup>Division of Emergency Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA, <sup>2</sup>Department of Biomedical Informatics, University of Cincinnati College of Medicine, Cincinnati, Ohio, USA, <sup>3</sup>Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, Ohio, USA, <sup>4</sup>Division of General and Community Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA, and <sup>5</sup>Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA

Corresponding Author: Judith Dexheimer, PhD, Division of Emergency Medicine, Cincinnati Children's Hospital Medical Center, MLC 2008, 3333 Burnet Avenue, Cincinnati, OH 45229-3039, USA (Judith.Dexheimer@cchmc.org)

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# ABSTRACT

**Objective**: The study sought to develop the necessary elements for a personalized health record (PHR) for youth emancipating from child protective custody (eg, foster care) by collecting thoughts and ideas from current and former foster youth and community stakeholders who have a significant amount of experience working with emancipating young people.

**Materials and Methods:** We employed a mixed methods, participatory research design using concept mapping to identify key features for PHR across stakeholders.

**Results**: In the clusters, common themes for necessary elements for a PHR included health education, health tips, medication instructions, diagnoses including severity, and website resources that could be trusted to provide reliable information, and addressed data privacy issues such as the primary user being able to choose what diagnoses to share with their trusted adult and the ability to assign a trusted adult to view a part of the record.

**Discussion:** By directly involving youth in the design of the PHR, we are able to ensure we included the necessary health and life skills elements that they require. As a PHR is created for foster youth, it is important to consider the multiple uses that the data may have for emancipated youth.

**Conclusion:** A PHR for foster youth needs to include an appropriate combination of information and education for a vulnerable population. In addition to providing some of their basic health and custody information, a PHR provides an opportunity to give them information that can be trusted to explain common diagnoses, medications, and family health history risks.

Key words: medical informatics applications, child, foster, concept mapping, pediatrics

# INTRODUCTION

There are 479 000 children<sup>1</sup> in the custody of child protective services (eg, foster care) in the United States. Children remain in custody an average 19 months, with 26% of children in foster care for more than 2 years. Approximately 24 000 youth emancipate from foster care between the ages of 18 and 20 years old annually.<sup>2</sup> Children often enter foster care traumatized by maltreatment and are placed in foster or group homes with unfamiliar caregivers who do not know

© The Author(s) 2019. Published by Oxford University Press on behalf of the American Medical Informatics Association. All rights reserved. For permissions, please email: journals.permissions@oup.com their health histories. Children in foster care are significantly more likely to suffer from emotional, behavioral, medical, and dental problems<sup>3–7</sup> that require healthcare services at higher rates than children in the general population.<sup>8</sup> Despite their needs, foster youth fail to receive appropriate health care,<sup>9</sup> in part due to the lack of access to health information for foster youth or their caseworkers. Records are lost and health care is disrupted when children enter foster care or change placements.<sup>10</sup> To address this issue, our study team developed IDENTITY (Integrated Data Environment to eNhance ouTcomes In cusTody Youth),<sup>11,12</sup> a data hub that shares merged child welfare administrative records and electronic health records (EHRs) with caseworkers and clinicians. IDENTITY allows near real-time information exchange of pertinent custody data and vital medical history data with medical providers and county caseworkers. Unfortunately, adolescents in foster care are a particularly vulnerable group and are unable to also access this information for themselves.

While adolescents are in custody, access to their medical records is managed by their caseworker; adolescents report limited access to health information<sup>13</sup> and caseworkers and caregivers report not having sufficient health information for the children in their care.<sup>10,14</sup> Adolescents experience an average of 7 placement changes during their time in foster care, disrupting their relationships to the adults who can provide health information to them. This lack of health information results in foster youth reporting no knowledge of how to access primary care,<sup>15,16</sup> poor management of chronic conditions,<sup>16–18</sup> and increased preventable disease.<sup>6,19</sup> Foster youth aging out of custody have poor health outcomes,<sup>20</sup> including being more likely to define their health as poor and identify as having a disability.<sup>21</sup>

Only 15% of youth receive transition planning assistance while they are in foster care, and those with chronic conditions are particularly vulnerable.<sup>22</sup> Those youth with chronic conditions are vulnerable and are more likely to have medical complications because they lack proper information and a transition plan.<sup>22</sup> Foster youth who emancipate are also faced with transitioning from pediatric to adult care. Transitioning to adult care includes self-management, a need for caregiver support, and effective communication.<sup>22</sup> The transition planning elements can be important components of a personalized health record (PHR).

Adolescent privacy is a major concern to considering when sharing their medical data in EHRs and PHRs. To protect their privacy and confidentiality, additional education and training is needed for providers, families, and adolescents. The American Academy of Pediatrics has endorsed that "confidentiality protection is an essential component of adolescent health care."<sup>23,24</sup> For children in protective custody, data access is more complex. While caseworkers have legal access to the health data and a limited amount is available for families of origin, foster caregivers are not afforded access to the record. For adolescents, certain elements of their data are protected, such as sexually transmitted infection testing results, and it is important to pay special attention to sharing these when developing an electronic means of sharing data.<sup>23</sup>

Providing health data from the EHR, including basic information on prescribed medications, major diagnoses, and mental health services could improve health knowledge, care coordination, and patient outcomes in this vulnerable population. We employed concept mapping to include foster and recently emancipated youth and key stakeholders in the area of foster care in the design of the PHR. Concept mapping employs a 4-step procedure of data collection using idea generation, unstructured sorting, feasibility, and importance ratings.<sup>25</sup> We followed the concept mapping methodology laid out by Kane and Trochim.<sup>26,27</sup> The purpose of our study was to develop the necessary elements for a PHR for youth emancipating out of care by collecting thoughts and ideas from foster youth and community stakeholders, to inform the future development of a PHR for foster youth emancipating out of care.

# MATERIALS AND METHODS

We employed a mixed methods, participatory research design using concept mapping to identify key features across all stakeholders. We worked with stakeholders and youth to conduct a concept mapping project that generated and prioritized specific strategies to address PHR data and display. Through brainstorming and sorting steps followed by multidimensional scaling and hierarchical cluster analysis, concept mapping resulted in a structured, data-driven visual representation of thoughts or ideas of these stakeholders group.<sup>26</sup> Concept mapping has been used to address substantive issues in health care improvement,<sup>28</sup> culturally competent intervention services,<sup>29</sup> and health disparities.<sup>30</sup> Extensive work has demonstrated both the validity and utility of concept mapping methodology.<sup>31,32</sup> Through this process, a diverse perspective of stakeholders was able to emerge. This study was approved by our institutional review board.

# Concept mapping procedure

The stakeholders and foster youth collaborated with the research team to conduct the concept mapping project and identify stakeholders divided among: (1) caseworkers, (2) community members and other foster youth, and (3) healthcare providers. Snowball sampling,<sup>33,34</sup> whereby initial participants recommend other participants with similar characteristics, was used.

Concept mapping involves 3 main steps. Before beginning, the participant categories are chosen (foster youth and community members) and focus prompts are developed to guide what should be answered. In step 1, idea generation, the participants respond to the prompts. These responses are combined to remove redundancies and then in step 2 are provided to a set of participants for unstructured sorting of the ideas. From here, the third and final step involves applying multidimensional scaling and hierarchical cluster analysis to create a concept map of the ideas grouped by clusters. Last, the maps are interpreted and utilized to inform the next step of the research, which in this case was the create of a web-based PHR for foster youth.

#### Study participants

We created a foster youth council (FYC) who met and provided input throughout the design process. Without the voice of youth, research can miss the contextual input necessary to represent the unique youth experience, lowering the potential impact and sustainability. As the intended users of the PHR, we involved current and former foster youth in the research design and creation of the PHR prompts. We worked directly with foster youth who were recruited from existing FYCs and caseworker recommendations with additional youth identified peer to peer. The FYC was asked to share opinions and thoughts on health care, their access, the foster system, and what they feel is missing in their current health education.

We also reached out to community stakeholders to advise the research team in the design and development of the elements in the PHR. Guardians ad litem, court-appointed special advocates, case workers, foster caregivers, and community healthcare providers were invited to participate.

# Step 1: idea generation

A purposeful sample of diverse community stakeholders and foster vouth were asked to generate statements that complete 4 openended prompts relevant to providing foster youth PHR access (eg, "To improve health outcomes and promote healthy behaviors in foster youth, I believe we need to..."; "A successful and user-friendly personal health record for foster youth will include..."; "The medical information foster youth need is..."; "A successful and easy-touse personal health record for foster youth should NOT include..."). Prior to starting the questions, PHR was defined for the participants. This step was conducted via an interactive website, via a telephone discussion, or through email. Statements were captured verbatim. If on paper, the participants filled out the forms on their own in their own language. The results of this step were a diverse set of statements from multiple perspectives relevant to the issue of providing coordinated PHRs to foster youth and helping promote long-term healthy behaviors and help provide tools necessary to transition from pediatric to adult care. Responding to prompts took a few minutes of each participant's time and could be done during a FYC meeting, online, through email, in person, or over the phone. The goal was to get input about how best to approach and engage foster youth transitioning to adulthood, what factors are most relevant, and the format that will be most helpful for sharing and understanding the PHRs. All statements generated were combined regardless of which participant group initiated them and then were reviewed by three members of the research team to ensure that they were at a similar level of detail, responsive to the focus prompt, and not redundant. In condensing the responses, we combined the 4 prompts into 2 main focus areas, given the similarity of stakeholder responses: (1) primary information included in a PHR and (2) additional information necessary to help the PHR be useful. The final responses were edited for grammar and clarity of expression without altering the original response meaning.

#### Step 2: unstructured sorting

Foster youth individually sorted the 2 sets of statements into groups of similar ideas or concepts.<sup>35,36</sup> The youth sorters received 2 decks of cards representing responses from each of the 2 focus areas. Each card contained 1 item generated in response to the focus

areas along with an identification number. The sorters were asked to individually sort cards into

groups based on their perception of similar ideas. Next, the sorters were directed to place each group of cards into separate envelopes. On the front of the envelope, the sorters were asked to provide a label or name for each group of cards.

#### Step 3: concept mapping data analysis

We combined the 4 prompts into 2 main themes for analysis. The 2 key themes that emerged were primary information for the PHR, including data elements that should be included in a PHR, and additional information for the PHR, which were items necessary to help make a PHR useful. These 2 themes were used to sort the individual statements and redundancies were removed.

Using open source software in R,<sup>37</sup> multidimensional scaling and cluster analysis of the sorting results for each focus area created concept maps to illustrate the conceptual similarity of specific ideas and the aggregation of these ideas into clusters.<sup>27,38</sup> Statistical analysis

included creation of a summed matrix of responses. Each participant sorted N cards, and for each participant, an NxN matrix was created. If a given participant sorted 2 cards together, the cell representing the intersection of those 2 cards was scored as 1. If a given participant sorted 2 cards separately, the cell of their intersection was scored a 0. The matrices were summed across all participants. In the resulting matrix, the higher the number in any given cell, the more often those 2 items (ie, the items whose row and column intersect at the given cell) were sorted together. Higher numbers were represented on the concept map by closer points on the map (closer x, y coordinates), while lower numbers were represented by larger distances between points on the concept map. This resulted in a 2dimensional visual representation of the data wherein points close together represent ideas that were closely linked in the minds of the sorters, and points farther apart represent less similar ideas.

Subsequently, the x, y coordinates were analyzed using cluster analysis. Cluster analysis provides a framework to segregate the data points into clusters of similar ideas. Cluster analysis results in as many cluster as sorted responses so a judgement must be made about the appropriate number of total clusters. The goal is to have the fewest clusters possible but express sufficient detail throughout the interpretive process. The final cluster solutions chosen balanced detail with restraint. In the concept map results, a "stress value" for each cluster solution is chosen to best fit the relationship strength of ideas. The stress value helps determine if the map of ideas represents the data and the strength of relationship between distances on the map.<sup>27,39</sup> A value of 0.27 (focus area 1) and 0.22 (focus area 2) indicates a good fit which is defined as less than 1% chance that the arrangement of ideas were random. The research team reviewed multiple cluster solutions before determining the appropriate number of clusters. A label for each cluster was created that succinctly expressed the theme and allowed a clear meaning. The research team used labels created by the youth in the sorting process as a guide for creating final names for the clusters.<sup>40</sup>

# RESULTS

Data collection during idea generation included a sample of relevant stakeholders and foster youth (n = 76). Of the participants that shared demographic information, 31 were current and former foster youth (41%), 10 were foster parents or caregivers (13%), 10 were community stakeholders (13%), 12 were health care professionals (16%), and 13 were social service workers (17%). Fourteen youth completed the sorting for focus area 1, and 9 completed the sorting for focus area 2. Unfortunately, data for 2 sorts had to be excluded because all the cards were not sorted. We analyzed 13 sorts for focus area 1 and 8 for focus area 2. It is common within concept mapping to have different samples for each step of the process.<sup>40</sup>

Stakeholders generated a total of 493 ideas for all the prompts (Table 1). After combining the prompts into 2 main focus areas (primary information included in a PHR and additional information necessary to help the PHR be useful) and removing redundancies, there were 368 unique ideas to be included. The overall responses were represented by 66 unique statements for focus area 1 (primary information included in a PHR) and 53 for focus area 2 (additional information necessary to help the PHR be useful).

#### Concept maps

Sorting of the responses for focus area 1 (primary information included in a PHR) was completed by 13 foster youth. The research team chose a 7-cluster solution (stress value = .27) for the focus area 1 (primary information included in a PHR) as the combination of related themes for each of the sorting response categories (Figure 1). The second focus area (additional information necessary

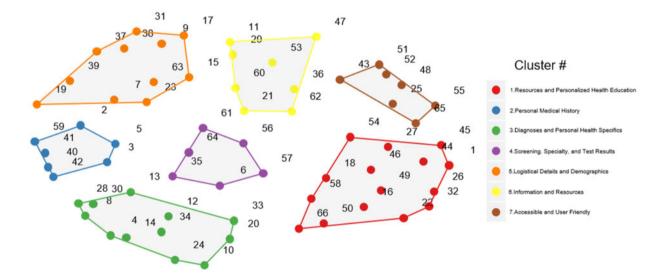
 Table 1. Initial responses from all stakeholder and foster youth prompts

Prompt	Initial responses
To improve health outcomes and promote	77
healthy behaviors in foster youth, I believe we need to	
A successful and user-friendly personal	280
health record for foster youth will include	
The medical information foster youth need is	88
A successful and easy-to-use personal	48
health record for foster youth should NOT include	

to help the PHR be useful) was completed by 8 foster youth. The research team chose a 5-cluster solution (stress value = 0.22) as the combination of related themes for each of the sorting response categories (Figure 2). The concept maps are shown in the figures. Tables 2 and 3 shows example responses in each cluster for the prompts.

## Primary information included in a PHR

Table 2 lists cluster titles and example responses for each of the 7 clusters. Resources and personalized health education included common responses of health education, health tips, medication instructions, and website resources that could be trusted to provide reliable information. Clusters 2 and 3 are heavily related. In Cluster 2 (personal medical history), responses included past medical history specifically prior visits, and past injuries or mental illness diagnoses. In Cluster 3 (diagnoses and personal health specifics), specific items such as blood type, allergies, and immunization records were men-





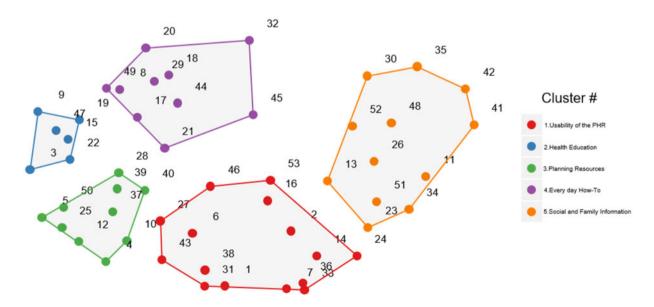


Figure 2. Additional information concept map. PHR: personalized health record.

Cluster Title		Cluster Title	
1. Resources and per- sonalized health ed- ucation	<ul> <li>Education of lots of medical topics</li> <li>How to treat bullet illness (flu, cold, etc.)</li> <li>Health tips (fitness, nutrition, injury prevention)</li> <li>Sexual education (condoms, birth control)</li> </ul>	1. Usability of the PHR	<ul> <li>Choice of what diagnoses to share</li> <li>Choice of what trusted adult can view it</li> <li>Interactive</li> <li>Severity of diagnosis (what does my diagn sis mean)</li> </ul>
2. Personal medical history	<ul> <li>Any past healthcare visits or hospitalizations</li> <li>Surgical history</li> <li>Medications (current and past)</li> <li>Mental illness (genetic history)</li> </ul>	2. Health education	<ul> <li>Ideal forms of therapy or services</li> <li>How to manage a healthy lifestyle and promote resources for physical and mental health</li> <li>Sex education</li> </ul>
3. Diagnoses and personal health specifics	<ul> <li>Description of diagnoses/medical conditions</li> <li>Blood type</li> <li>Dental info</li> <li>Lab and radiology results</li> <li>Disabilities</li> <li>UW Gradies</li> </ul>	3. Planning resources	<ul> <li>Basic health information and education</li> <li>Improved understanding of the doctor's p scription</li> <li>Crisis and safety planning</li> </ul>
4. Screening, spe- cialty, and test results	<ul> <li>HIV Status</li> <li>Visual and hearing test results (including prescription for glasses)</li> <li>Legal information (privacy, confidentiality, consent, DNR)</li> <li>Bears durting health data (ang (heart surge))</li> </ul>	4. Every day how-to	<ul> <li>Celebrate health successes (eg, set goals, exercising, gold stars)</li> <li>Parenting resources</li> <li>Management plans for my diagnosis</li> <li>Life skills (eg, call gas/electric company, negative company)</li> </ul>
5. Logistical details and demographics	<ul> <li>Reproductive health data (pap/breast exam)</li> <li>Metabolic screen</li> <li>Contact information for primary care providers</li> <li>Height/weight/temperature</li> </ul>		<ul> <li>parenting resources)</li> <li>How insurance works</li> <li>How to make a doctor appointment</li> <li>Contraception (birth control, condoms, STIs)</li> </ul>
6. Information and resources	<ul> <li>My real parent's names</li> <li>Updated social history (living environment, drug/alcohol abuse)</li> <li>My placements through JFS</li> <li>Health insurance information</li> <li>Information I can give to other physicians and community agencies</li> </ul>	5. Social and family information	<ul> <li>Birth certificate, social security card and E</li> <li>Food stamp status</li> <li>Sibling information and where they are located</li> <li>Emancipation information</li> <li>Family history to understand diagnoses</li> </ul>
7. Accessible and user friendly	<ul><li>Clear print with good organization</li><li>Internet accessible</li><li>Easily understandable</li></ul>	PHR: personalized he	ealth record; STI: sexually transmitted infection.

Table 2. Example responses for each cluster for the personalized health record focus area

Table 3. Example responses for the additional information for the PHR focus area

	Choice of what trusted addit can view it
	Interactive
	• Severity of diagnosis (what does my diagno-
	sis mean)
	• Ideal forms of therapy or services
2. Health education	• How to manage a healthy lifestyle and pro-
	mote resources for physical and mental
	health
	Sex education
	<ul> <li>Basic health information and education</li> </ul>
3. Planning resources	<ul> <li>Improved understanding of the doctor's pre-</li> </ul>
5. Framing resources	scription
	<ul> <li>Crisis and safety planning</li> </ul>
	<ul> <li>Celebrate health successes (eg, set goals,</li> </ul>
	exercising, gold stars)
	<ul> <li>Parenting resources</li> </ul>
	<ul> <li>Management plans for my diagnosis</li> </ul>
4. Every day how-to	<ul> <li>Life skills (eg, call gas/electric company,</li> </ul>
4. Lvery day now-to	parenting resources)
	<ul> <li>How insurance works</li> </ul>
	<ul> <li>How to make a doctor appointment</li> </ul>
	<ul> <li>Contraception (birth control, condoms,</li> </ul>
	STIs)
5. Social and family	<ul> <li>Birth certificate, social security card and ID</li> </ul>
information	<ul> <li>Food stamp status</li> </ul>
intormation	<ul> <li>Sibling information and where they are</li> </ul>
	located
	Emancipation information     Eastilla history to understand diagnoses
	• Family history to understand diagnoses
DUD	hele and a CTTI and a line to a manifester of in factories of
rnk: personalized hea	lth record; STI: sexually transmitted infection.
	hoalth mlanning magazingas) is also alty malated to

DNR: Do Not Rescucitate; HIV: human immunodeficiency virus; JFS: Job and Family Services.

tioned. Cluster 4 (specialty and test results), included any laboratory results that could be shared, active subspecialist visits, and discharge summaries. Cluster 5 (logistical details), included next of kin and birth certificates, while cluster 6 (information and resources) also included items such as their health insurance information and their most recently listed pharmacy. Finally, cluster 7 (accessible and user-friendly), addressed the actual look and feel of the data, including that it be internet accessible, easily understandable, and have clear print with good organization.

# Additional information necessary to help the PHR be useful

Table 3 lists cluster titles and example responses for the 5 clusters in focus area 2. In additional information, the first cluster (elements of the PHR) addressed data privacy issues such as the primary user being able to choose what diagnoses to share with their trusted adult, the ability to assign a trusted adult to view a part of the record, and sharing the severity of their own diagnoses (eg, bipolar diagnosis compared to strep throat). Cluster 2 (health education and information) included how to manage a healthy lifestyle and promote responsible mental health as well as basic health information and

education. Cluster 3 (health planning resources) is closely related to cluster 2 including celebrating health successes, exercise, management plans for common diagnoses, and parenting resources for the youth themselves. Cluster 4 (everyday how-to) focuses on the life skills that are frequently taught at home including how to make a doctor's appointment, how insurance works, and other independent living skills such as how to set up gas and electric. Last, cluster 5 (social and family information) focused on data from the county that the youth do not readily have access to including placement information, emancipation information, and siblings and where they are located.

# DISCUSSION

PHRs currently exist in multiple forms, however, creating a PHR for youth in foster care presents a unique opportunity to provide not just basic medical information, but limited custody information as well as health education and coaching. Concept mapping is an important user-involved tool to employ across stakeholder groups. These concept maps will inform the future design and building of the PHR.

Common elements available in PHRs include demographics, allergies, medications, major diagnoses, and immunizations.<sup>41,42</sup> All of these elements were listed by our participants to be included and additional elements included health planning resources (eg, what does a given diagnosis mean?), every day how-to (eg, how to make a doctor appointment), and the social information that can be provided by the county (eg, number of custody placements, birth certificate, social security number). Many of the attributes suggested for the ideal PHR were also identified by the participants, including being electronic, continuously updated, able to include paper documents (such as from outside providers), and private and controlled by the individual. While the participants did suggest common data elements, the vital elements to the adoption and use of the PHR will be in the additional information section (Table 3). The foster youth expressed an interest in having trusted sources to obtain medical information, encourage a healthy lifestyle, and have step-based walk-throughs of life tasks so they could be easily completed the first time.

The foster youth were interested in including their social and medical histories, their immunizations, life skills, and how to restrict access to their data to either a trusted adult or to themselves. A common theme was found that while the youth may have been given a diagnosis, it was not adequately explained or they did not believe it was accurate. The community stakeholders and healthcare professionals were more focused on including how to promote healthy lifestyles, how to encourage exercise, and teach health and behavior to a receptive audience. The foster youth are more focused on the privacy of their medical data than anticipated. The youth in custody may have experienced a lot of perceived invasion of privacy due to the many nonfamilial adults in their lives with legal rights to their personal data, such as caseworkers, guardians ad litem, courtappointed special advocates, etc. The community stakeholders were more focused on anticipatory guidance (eg, how to promote a healthy lifestyle) than originally thought. This may be because they see more of a need of including related to efforts to improve overall health status and know that this education is lacking in these adolescents. These 2 themes highlight the importance of including all stakeholders in the design of a new system. All the initial responses generated were from all stakeholders but then the sorters were foster youth only because we wanted them to drive the design of the EHR.

In our concept mapping, we included foster youth who were 18 years of age or older. In Hamilton county, youth can remain in protective custody until 21 years of age. Data privacy was not provided as a prompt; however, it was addressed in the usability of the PHR (Table 3), where it was requested for adolescents to be able to control which data elements they shared with a trusted adult and how they could provide or revoke that access. Privacy issues will need to be continually addressed while building and ultimately with dissemination of the PHR.<sup>43</sup> There is an additional need to empirically evaluate this in future work, and as a start, this will be addressed with the end users in the design of the application.

For the sorting task, all concepts were combined and not separated based on who initiated it. Across the 2 focus areas, much of the information in the clusters overlapped. For example, medications appeared in personal medical history and diagnoses and personal health specifics. While these 2 concepts were named differently in sorting, fundamentally, they represented the same type of information to be provided in the PHR. All of the youth and community stakeholders wanted to be able to access the information electronically and have it be clear and easy to read, and printable so that the information could be easily shared when transitioning to a new care team.

Many of the novel topics in the additional information to be included in the PHR are skills that might have been taught in a more traditional family setup (eg, living with 1 or more parents). These topics included crisis and safety planning, how insurance works, what the diagnosis actually means, and even how to set up electric or gas in order to be independent. A consistent theme heard from the foster youth for including additional information was a need for accurate and timely contraception information that could be trusted. Along with this, foster youth frequently requested parenting resources for helping with their own children.

Concept map results will set the stage to ensure that key areas are considered for inclusion. Not all data elements requested will be able to be displayed or shared for the foster youth. For example, while it may be relatively easy to provide medication history or vital signs, a comprehensive guide to common diagnoses will be difficult and will need to link to an outside resource. The data merging and sharing for the application have already been performed with IDEN-TITY, but no outside resources have been identified.

There are existing hospital-based and vendor PHR systems.<sup>41,44-47</sup> The hospital-based systems may not contain data outside their network and by having a modifiable PHR, we are allowing the users to update their record. And vendor systems may not be integrated with any hospital and therefore force the user to enter in all of their own data. Neither of these solutions is ideal for foster youth as they may be seen in different hospitals, but they also may not have any of their past history as a basis for a PHR.

As a PHR is created for foster youth, it is important to consider the multiple uses that the data may have for the emancipated youth. These uses may include transition to adult care and learning skills that would normally have been taught at home. Through the usercentric design, the PHR aims to help address 2 major issues, the first being the lack of access to available health and custody information and the second being the eventual transition to adult care. It is important that both of these roles are addressed as well as information necessary for the youth, their caseworkers, and their providers.

Youth-driven development is key to having a successful PHR application, but is also vital to having a sustainable and engaged population. Youths are frequently not involved in the development and analysis of research involving themselves<sup>48</sup> and using concept mapping allows us to ensure they are active participants in the research. Foster youth must frequently learn to live independently without external adult assistance.49 They often must learn everyday life skills as well as how to take care of their own health. By directly involving youth in the design of the PHR, we are able to ensure we included the necessary health and links to trusted educational elements that they requested and currently lack. This is a difficult to study population as, when emancipated, they can be difficult to track down or unwilling to work within the system. It is of vital importance to keep them involved in the design and ultimate implementation of the PHR so that a truly useful and user-friendly system results from the collaboration.

Our concept mapping did have limitations. The foster youth are more transient population than other adolescents and may not be as willing to be involved in research. We approached as many adolescents as possible and sought volunteers at existing foster youth meetings. We found a core group of about 5 youth that attended the majority of monthly FYC meetings but many others only participated sporadically as work schedules and transportation permitted. Previous work in concept mapping has shown that there is minimal variation in the final maps after approximately 20 sorts<sup>26</sup>; we used a purposeful sample of foster youth that were available to participate in the sorting activity and recruited from several venues to ensure a more diverse sample. The stakeholders and healthcare providers represented a convenience sample of those who attended community meetings, were available during the study period, and had an interest in helping the foster youth population. The youth who participated in our study may also present a bias. The ones who participated are likely more engaged and higher functioning than others are. Those facing more challenges were less likely to participate and may have reported different needs from a PHR.

With the number of children and adolescents in foster care throughout the United States, we foresee difficulties for most youth emancipating from care with identification and coordination of their own data. These youth are frequently seen in many different settings and may not know all of their past medical history. A PHR created for this population could help to serve the foster youth but also eventually may help foster care providers have a record of the child's care to better understand their history. This coordination of knowledge sharing could help foster parents, caseworkers, and even future providers allowing the PHR to benefit more than just 1 population.

In the next steps of building the user interface for the PHR, we will continue to evaluate whether the information requested from the youth can be extracted and displayed from the existing databases. We will also work with 3-4 foster youth, community stakeholders, and the LiveWell Collaborative to design a user interface that is intuitive and clear. The foster youth must be involved in the design steps to ensure their voice continues to be heard, included, and evaluated in the design and ultimate implementation of the PHR.

# CONCLUSION

Concept mapping allowed us to take disparate thoughts and have a motivated team of individuals help to identify important elements to be included in a PHR for foster youth. A PHR for foster youth is an appropriate combination of information and education for a vulnerable population. While the youth lack access to some of their basic health and custody information, this also provided an opportunity to give them information to explain common diagnoses, medications, and family health history risks. At the same time, these youth may be lacking in "home-taught" skills, from contraception to how to set up a gas and electric line for independent living. By providing this information, we will ensure that the youth receive the information they want in a format that is user-friendly and helps them to feel comfortable trusting and learning all of the information.

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# **AUTHOR CONTRIBUTORS**

All authors contributed materially to the production of this manuscript. JWD conducted and coordinated the study, conceptualized the work, and wrote the manuscript. MVG participated in the conception of the project, drafting of the manuscript, and critical revisions. SJB participated in the conception of the project, drafting of the manuscript, and critical revisions. DJ participated in acquisition of data, manuscript review, design, and revisions. AK participated in acquisition of data, manuscript review, design, and revisions. LMV designed and organized the concept mapping, analyzed the results, and created the tables and figures.

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# **CONFLICT OF INTEREST STATEMENT**

None declared.

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