

Design of Personal Health Libraries for People Returning from Incarceration in the United States

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Abstract

Individuals with a history of incarceration face many barriers to accessing resources to meet their basic needs when returning to community settings. Digital health tools have potential to reduce health inequities by facilitating connections to health and social services, and peer support. This study aimed to employ a user-centered design approach to create a digital Personal Health Library (PerHL) for previously incarcerated individuals. The design process included in-depth interviews followed by rapid analysis, interpretation sessions, and user experience/user interface (UX/UI) design of a high-fidelity prototype. Semi-structured interviews were conducted with individuals with a history of incarceration (n=20) to understand their experience

rejoining their communities. Findings highlight the need for an app that allows users to easily access resources for employment, housing, healthcare and medical needs, formal and informal support, and legal counsel.

Keywords: carceral settings, mHealth, mobile applications, digital health, user-centered design

1. Introduction

In the United States (US), approximately 610,000 people are released from correctional facilities every year (Sawyer, 2022), the majority of which consists of racial and ethnic minoritized individuals from lower-income households (Blankenship et al., 2018).

Studies have shown that individuals with a history of incarceration are at higher risk of developing chronic health conditions such as lung cancer, cervical cancer, and hypertension (Binswanger et al., 2009; Puglisi et al., 2020).

Incarceration further contributes to a reduced degree of self-efficacy in individual health management due to the highly regulated prison environment that affords incarcerated people little decision-making opportunity or control over health behaviors, such as diet, exercise, and medication management (Loeb et al., 2011). Within the carceral setting, some people are newly diagnosed with chronic health conditions and have never had the opportunity to learn how to manage these conditions while in the community -- making appointments, obtaining and refilling prescriptions. Upon returning to the community, they are at high risk for poor health outcomes – higher rates of hospitalization and mortality (Binswanger et al., 2007; Rosen et al., 2008; Wang et al., 2013). Given the established positive association between self-efficacy, self-health management, and health outcomes (Hoffman, 2013; Skowroński & Talik, 2021), the disproportionate disease burden combined with the greater challenge of self-health management urgently calls for systematic solutions to address the challenges that individuals with a history of incarceration face upon returning to community settings.

Digital health tools (eg, mobile health apps) have potential as innovative solutions to reduce the inequitable health burden of this population (Rantanen et al., 2022). In particular, personal health information technology (PHIT), broadly referring to digital repositories of health resources and patients' health information (Roehrs et al., 2017), can assist individuals' health management by providing an efficient and easy-to-use platform for the organization of health information. By facilitating easy access to up-to-date medical resources, supporting health maintenance and coordinated care with multiple health systems and providers, assisting clinical information sharing, and mitigating the burden and inefficiency of the written referral process, PHIT can lead to improved primary care engagement, self-efficacy, and likely improved quality of care and overall health conditions. Previous research has also associated the use of health information technologies with lower healthcare costs for patients (Jen et al., 2022). The potential for use of digital technologies to improve health outcomes is promising; however, there is limited human-computer interaction research that has centered individuals' challenges during the reentry period in the design of these technologies.

Incorporating recommendations from intended users can help mitigate potential intervention-generated inequalities (Veinot et al., 2018).

This study thus set out to bridge the gap by adopting and discussing principles of user-centered design in the development of a digital Personal Health Library (PerHL) for previously incarcerated individuals and aims to serve as a one-stop health and social services information resource and address the fundamental barriers to technology use in this population through equity-driven design strategies. Content and features were tailored to create a mobile application (app) to support individuals with a history of incarceration as they rejoined the community.

2. Background

2.1. Incarceration in the United States

The US incarcerates more people per capita than any other nation in the world, at a rate of 565 per 100,000 residents (Sawyer & Wagner, 2023). Black people are incarcerated at disproportionate rates. In 2017, 12% of the US adult population were Black, however, they made up 33% of the prison population (Gramlich, 2019). Females account for approximately 7% of the US prison population (Federal Bureau of Prisons, 2023). Despite making up a significantly smaller percentage of those incarcerated, women are the fastest-growing prison population, with 75% identifying as Black or Latinx (Hutchinson-Colas et al., 2022). Moreover, Black women are imprisoned at 1.7 times the rate of White women, and Latinx women 1.3 times the rate of their White counterparts (Monazzam, 2023).

The COVID-19 pandemic highlighted the effects of mass incarceration on the morbidity and mortality among those incarcerated. Incarcerated individuals were more likely to acquire COVID-19 and develop severe symptoms, due to a higher burden of poor underlying health conditions among those incarcerated, compounded by overcrowding, congregate living situations, and minimal attempts to mitigate the spread of infection (Akiyama et al., 2020; Esposito et al., 2022; Kinner et al., 2020). The pandemic also revealed glaring racial inequalities within the prison system. Infection rates were disproportionately spread among incarcerated subpopulations, where Black individuals had 2.3 times the risk of getting COVID-19 than their White counterparts (Nowotny et al., 2021).

2.2. Reentry to community settings

Highlighted by the US Department of Justice in the National Inventory of Collateral Consequences of Conviction, individuals involved in the criminal justice system suffer from enduring indirect costs following their incarceration, primarily driven by individual- and structural-level stigma and prejudices that negatively impact an individual with a history of incarceration's already limited opportunities to acquire health-promoting resources (Justice, 2023). Past studies have shown that previously incarcerated persons rejoining community settings in the US experience a multitude of challenges and barriers, including in healthcare (Marlow et al., 2010), housing (Keene et al., 2018), employment (Emmert, 2019), social support, limited health literacy, and overall societal stigmatization (Hadden et al., 2018).

One critical facilitator to one's reentry is access to healthcare services and resources, which are known to improve mortality rates and decrease the risk of recidivism (Woods et al., 2013). However, previously incarcerated individuals face multi-layered difficulties in healthcare access. First, many people have Medicaid suspended when incarcerated and upon release have to go through the process of having coverage reactivated. In the case that an individual with a history of incarceration relocates to a different state, eligibility must be re-established, which may result in delays or ineligibility (Albertson et al., 2020). Second, given the limited coordination between criminal justice and public health systems in the US, many prisons lack the infrastructure to support their workforce to educate and enroll incarcerated people for health-related resources and health care resources such as health insurance prior to release (Rich et al., 2014), enhancing the difficulties for those reentering the community to access, understand, and utilize information to facilitate well-informed decisions about their health care. Third, while access to technology and digital literacy has been identified as social determinants of health (SDoH) (Benda et al., 2020; McCall et al., 2022), people with a history of incarceration are often from systematically under-resourced communities with limited digital access and opportunity to gain digital skills; and once incarcerated, few correctional facilities in the US provide adequate technology training (Reisdorf & DeCook, 2022). Additionally, individuals from minoritized communities are more likely to be impacted by poverty, racism, and poor access to healthcare, which may increase risk of morbidity and mortality. In the context of COVID-19, obtaining access to resources and services transitioned from in-person appointments to digital

interactions, compounding the difficulties for individuals upon release as they navigate digital healthcare options, telemedicine visits, and online resources for health information. These barriers call for more resources to readily address and ensure successful long-term community reintegration (Semenza & Link, 2019).

2.3. Research gap

The personal health library is a consumer mobile health app that enables the access, collection, organization, utilization, and storage of a wide range of personal health information (Olusanya, 2021). Patients' access to the personal health library supports the self-management of chronic diseases and facilitates shared decision-making (Surkan, 2021), leading to improved engagement in and compliance with care, self-empowerment, and better health outcomes (Olusanya, 2021). Personal health library apps can be used to meet patients' need for health-associated information management. Health and health-related information can be overwhelming for people to understand when they are not able to reach out to medical professionals. Most of the time, self-management of disease and health information extends beyond primary care facilities. Mobile apps can be used to manage health information since "unanchored" health information management activities can take place when people are not at home and do not have access to their desktop computers, when patients' judgment is compromised due to medications, or when other uncertain situations occur (Klasnja, 2010).

Currently, a number of personal health library mobile apps target chronic disease management. For example, HealthWeaver Mobile is an app that helps patients with cancer manage their health information during treatment (Klasnja, 2010). Functions in this app include access and storage of different formats of documents and files, images, audio, and web pages; logs of medications and symptoms; notes from consultations with health care providers and linkage to the calendar (Klasnja, 2010).

With greater acknowledgement that optimal health requires addressing social needs, integration of SDoH data and social services resources into personal health technologies has become increasingly important. Another interesting example, HemPHL incorporates electronic health records (EHRs) and other sources of health-related information such as multidimensional SDoH data and data from physical activity trackers to assist both patients with hemophilia and healthcare providers in obtaining and

sharing information in different scenarios (Olusanya, 2021).

There are optimistic health outcomes for the aforementioned apps, however they have been designed and tested in a general population. Well-known digital inequities exist; low-income earners and Black communities as well as other communities of color are less likely to have broadband internet services at home and more likely to access the internet using their mobile devices (Atske & Perrin; McCall et al., 2022). People of color, lower income individuals, or people with a history of incarceration are also underrepresented in research and design of new technologies (Ahalt et al., 2018; Varma et al., 2023).

Personal health technologies are unlikely to mitigate the social, economic, cultural, or other needs that previously incarcerated individuals have (Surkan, 2021), yet may be able to facilitate their access to information resources. Current apps created with previously incarcerated individuals focus on providing resources (Fuller et al., 2021; Zhang et al., 2022) or cardiovascular health (Zachary et al., 2020), but have not incorporated the function of health and social needs information management. Thus, applying a user-centered design approach to understand their needs in the context of accessing and organizing information and resources is a critical step in the development of technology to promote health and well-being.

3. Methods

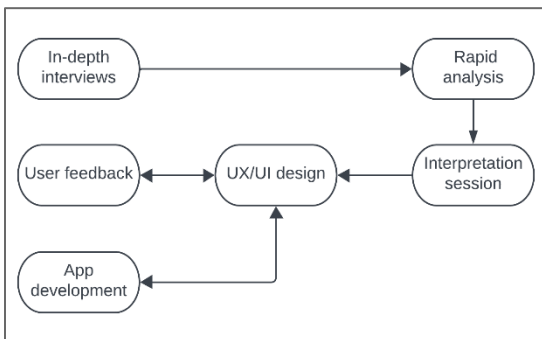


Figure 1. Design process.

The design process was iterative and included in-depth interviews followed by rapid analysis, interpretation sessions, user experience/user interface (UX/UI) design of a high-fidelity prototype, user feedback, and app development (Figure 1). Semi-structured interviews were conducted with individuals with a history of incarceration (n=20) to understand their experience rejoining their

communities after release from incarceration. We explored individual, organizational, and systemic factors that serve as barriers or facilitators to accessing health and social services and resources post-release, and how technology can be used to support them during this transitional period. The team members' domains of expertise include human-computer interaction, research on health and mass incarceration, social work research, community health and community advocacy, medicine, and community-engaged informatics. The methods for UX/UI design of the PerHL mobile app are presented in this paper. Detailed methods for the full study are outlined in the protocol paper (Foumakoye et al., 2023). The study was approved by the Yale University Human Subjects Research Committee Institutional Review Board (IRB #200028862).

3.1. Interviews

Interview participants were recruited by a team member (MS), through connecting with organizations that serve individuals with a history of incarceration in New Haven, Connecticut and surrounding areas. To participate in the study, individuals had to be 18 years of age or older, diagnosed with at least one chronic health condition (e.g., diabetes, heart disease), speak English, and released from a correctional facility within the past year (Foumakoye et al., 2023). All participants completed a consent form prior to the interview and received a US \$50 gift card as remuneration for their time. The study team created an interview guide for people released from incarceration, which included questions about participants' experiences with technology, information-seeking behavior, and needs during their reentry period (Foumakoye et al., 2023). Three team members served as interviewers for the study; two are experienced qualitative researchers (MF, MCB) and one was trained during the time the study was conducted (MS). All interviews were audio-recorded and professionally transcribed. Personally Identifiable Information was removed from the transcript for confidentiality.

3.1.1. Rapid analysis. The analytic team consisted of four team members (MF, MCB, MS, KW). They have more than 10 years of experience serving structurally marginalized populations, such as individuals with a history of incarceration. Rapid qualitative analysis methods were used to efficiently process and distribute the interview data to members of the study team who incorporated the findings into the design and development of the app (Hamilton, 2013; Vindrola-Padros & Johnson, 2020). The

analysts created a template to organize (Hamilton, 2013) data on participant's experiences preparing for release from incarceration, their views on priorities for individuals during reentry, and the types of information needed, shared, and used to support them rejoining the community.

Following independent review and rapid analysis of each interview transcript, the analytic team met as a group to discuss and compare their findings and perspectives of the interview and field experience. The team recorded emerging themes and processes through memoing and visualizations. Following the group discussions, the team conducted interpretation sessions.

3.1.2. Interpretation sessions. Five interpretation sessions were conducted between July and August 2022 to transform raw data from the first 10 in-depth interviews with previously incarcerated individuals into draft design models. Each interpretation session included a moderator (TM), all interviewers (MF, MCB, MS, KW), and two recorders and modelers (MP, AL). The moderator was responsible for guiding sessions to focus on mainline conversation, such as what happened in each interview and what the team could learn from it. The interviewers informed the team about insights gained during their interviews and interactions with potential users, which were typically extracts from retrospective accounts from interviewees. The recorders took shared notes of each session using concise language to capture main points, important observations, and challenges related to the design process. The modelers were responsible for creating appropriate contextual design models to capture data that were most useful to the project focus. Session 1 oriented the team to the purpose and structure of an interpretation session and how to create affinity diagrams in Miro using digital sticky notes. Sessions 2 to 4 focused on constructing the affinity diagram, summarizing the main insights for design, and facilitating in-depth discussions around the main themes of insights, respectively. The last session concluded the first round of interpretation sessions by evaluating and prioritizing the finalized ideas for design and discussing content and next steps as a team. The aforementioned procedures were followed for the last round of interpretation sessions (two sessions conducted from February to April 2023) focused on the next 10 interviews. The team specifically aimed to identify themes and insights for design that were not previously discovered in the first round of interpretation sessions.

3.2. App design

The design methodology curates an iterative and collaborative user-centric approach allowing the design process to co-exist with the project goals. The strategy also allows Figma, a robust collaborative web app for interface design, to be used to design, test, and prototype our app based on the input from our team, and community members, particularly those with lived experiences of incarceration.

3.2.1 Low and high-fidelity designs. The comprehensive consolidation of interpretation sessions involving detailed discussions with all stakeholders helped the design process to identify the must-haves for the app. These low-fidelity designs enabled the team (TM, AL, MP, VH, KZ, MS, ST) to discuss, iterate, and enhance the architecture of the app design before creating high-fidelity prototypes. After several iterations, the low-fidelity prototypes were transformed into high-fidelity prototypes representing the app's complete user journey, including navigational elements, user interactions, and information architecture.

3.2.2 Mockup presentations. The next iteration step involved detailed, fully functioning prototype presentations to study team members, including healthcare workers with experience serving individuals with a history of incarceration, and a team member with lived experience. The presentations included exhibits of color schemes, user interactions, user experiences, and journeys in the app. The feedback provided was used to inform the next iteration of the design, ensuring that the voices of our stakeholders and the community were represented to ensure the app is useful and accessible to intended users.

3.2.3 Feedback integration. The feedback from the review session informed the focus for the next iteration steps, including designing a new community board, revamping accessibility features, and ensuring the app's continuous refinement to be accessible, intuitive, and responsive to the needs of the intended users – individuals with a history of incarceration.

4. Results

4.1. Participant overview

Individual interviews were completed with 20 people with a history of incarceration (Table 1, see last page). Participants ranged in age from 21-64

years (mean age 41.7 years, SD 11.4 years), with four participants identified as female and 16 as male. Most participants identified as Black (80%), completed high school or had a GED (75%), household income of less than \$10,000 (75%), and were incarcerated for up to two years (60%).

4.2. Interpretation sessions

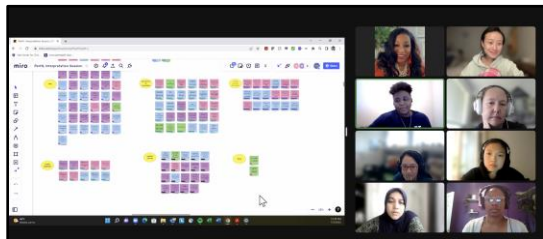


Figure 2. Interpretation session.

The interpretation sessions were completed in two phases by seven study team members (TM, AL, MP, MS, MCB, MF, KW) (Figure 2). TM led the team in the process of creating an affinity diagram to organize the data collected in the interviews into groups or themes based on their relationships (Figure 3, see last page). The first 10 interviews were analyzed over five sessions. The findings revealed themes and priorities that highlight the need for content and features that allow users to easily access resources for employment, housing, healthcare, and medical needs (including mental health and substance use), community health workers, formal and informal support, and easy navigation of Department of Corrections rights. Additionally, 10 more interviews reiterated the same insights with emphasis on the need to ensure trauma-informed design principles are followed in development of the app, and there are features to facilitate peer support (eg, virtual and in-person support groups for women with a history of incarceration).

4.3. App design

The final design of the app carefully considered user needs through multiple iterations of designs, and collaboration with the team and stakeholders. Informed by themes and priorities identified from the interviews, the app includes features that address key considerations, such as community boards, resource checklists for navigating social services, events, and support for mental health and well-being (Figure 4).

With accessibility and usability in context, the app's intuitive, simple navigation, including accessible fonts and colors, reduces the user's cognitive load. With multiple feedback and iterations,

the design philosophy is rooted in understanding users and iterating based on their feedback. We are currently in a development sprint and planning for usability testing to gather additional feedback and make any necessary refinements before the pilot trial.

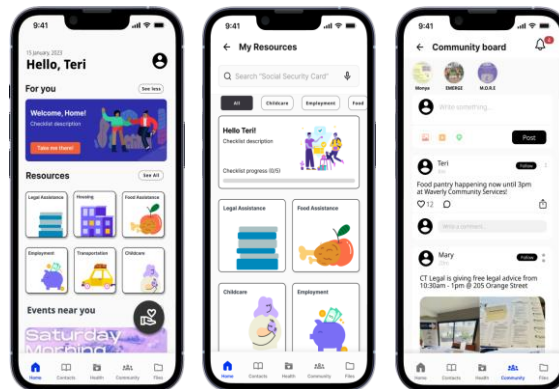


Figure 4. The app home, resources, and community board screens.

5. Discussion and conclusion

Individuals recently released from incarceration have many barriers upon returning to communities. They are often provided little support when leaving the carceral facilities to obtain resources to meet basic needs such as housing, employment, identification, and legal assistance. Furthermore, there is a need for social support and mental health resources, including substance use service.

Using this iterative user-centered design process which consisted of in-depth individual interviews with intended users, rapid analysis and group discussion with study team members, interpretation sessions, and user experience/user interface (UX/UI) design of a high-fidelity prototype, we have a greater understanding of the needs of the population and opportunities to use mobile technology to support their return to the community. We were able to engage people with a history of incarceration, most are lower income, and primarily have a high school education. We partnered with them to identify their needs and preferences for content and features that are important to support their return to the community. Through this app, they want reliable information to connect them with resources and services -- employment, housing, healthcare and medical needs, formal and informal support, and legal counsel.

Future engagement strategies should seek to inform, establish trust, and ensure access to up-to-date information within the app. Preferences and appropriateness of modalities for providing support

should be assessed on an individual basis. Furthermore, measures to protect users' privacy and transparency on data ownership, use, and sharing policies are necessary.

The main limitation of our study was that the interviews were conducted in New Haven, Connecticut; therefore, the findings may not be comprehensive in including all the needs of individuals returning to their communities from carceral settings. However, we have identified basic needs that may apply to most if not all individuals during their reentry period.

6. Future directions

Recognizing the population is not homogenous, and there are subgroups that may need additional support, we have conducted supplementary focus groups to ensure we are able to understand their unique needs and preferences. Specifically, the imprisonment rate of Black women in the US was 1.7 times the rate of their White counterparts (83 per 100,000 vs. 48 per 100,000) (Carson, 2020). Therefore, we are in the process of completing focus groups with Black women with a history of incarceration to understand their experiences and needs and will incorporate these findings into the design process. Formal usability testing with intended users will be completed, and the findings will be used to inform further refinement of the app prior to the pilot. A randomized pilot trial will be conducted to test the acceptance and use of the app among individuals with a history of incarceration.

Although this app will not eliminate all reentry barriers, this work has provided insights into social

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and structural drivers creating information and digital inequities for people with a history of incarceration. For example, future work includes establishing partnerships across disciplines and sectors to facilitate access to health information; access to digital skills training and resources prior to/and on peoples' return to the community; and to facilitate the tailoring and use of existing digital resources (eg, apps for health information management). Lastly, this work shows us that people with a history of incarceration are invested in their successful transition back to the community, have critical insights into their health and health-related information needs, and should be a key partner in the development and design of personal health information technologies.

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Table 1. Characteristics of study participants (N=20).

ID	Age	Sex	Race	Education	Income	Incarceration (Time)
P01	52	M	Black	Less than High School Diploma	Less than \$10,000	0-2 Years
P02	42	M	-----	High School Diploma/GED	\$50,000 - 100,000	0-2 Years
P03	48	M	-----	Less than High School Diploma	Less than \$10,000	10+ Years
P04	30	M	Black	High School Diploma/GED	Less than \$10,000	0-2 Years
P05	56	M	Black	Some College	Less than \$10,000	0-2 Years
P06	45	M	Black	Some College	\$10,000 - 24,000	0-2 Years
P07	48	M	Black	High School Diploma/GED	Less than \$10,000	10+ years
P08	22	M	Black	High School Diploma/GED	Less than \$10,000	0-2 Years
P09	48	M	Black	High School Diploma/GED	\$10,000 - 24,000	Greater than 2, less than 5 years
P10	45	M	Black	High School Diploma/GED	Less than \$10,000	0-2 Years
P11	52	M	White	Some College	Less than \$10,000	2-5 Years
P12	34	F	Other	Some College	\$10,000 - 24,000	0-2 Years
P13	21	M	Black	Less than High School Diploma	Less than \$10,000	2-5 Years
P14	28	M	Black	High Diploma/GED	Less than \$10,000	0-2 Years
P15	33	M	Black	Some College	Less than \$10,000	5-10 Years
P16	52	M	Black	Less than High School Diploma	Prefer not to say	0-2 Years
P17	39	F	Black	Less than High School Diploma	Less than \$10,000	0-2 Years
P18	64	M	Black	High Diploma/GED	Less than \$10,000	10 plus years
P19	38	F	Black	Trade/Technical Training	Less than \$10,000	0-2 Years
P20	36	F	Black	Some College	Less than \$10,000	-----

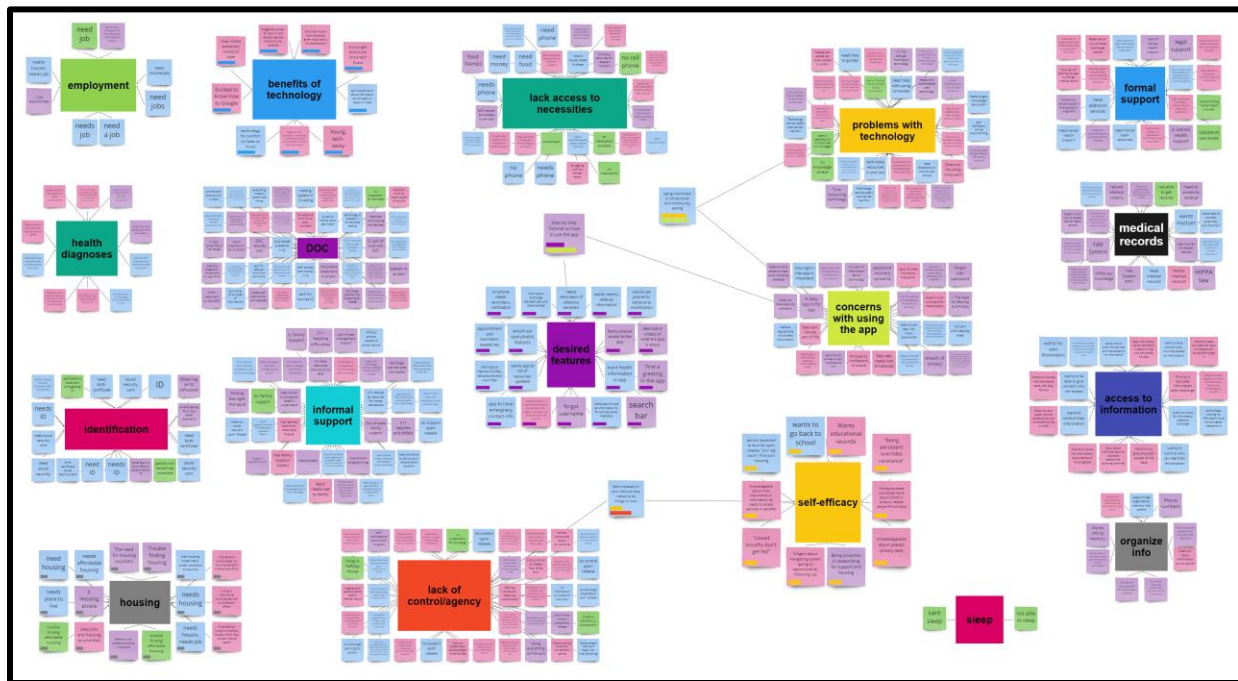


Figure 3. Affinity diagram.