

# Health Information at Intersections: Toward More Inclusive Personal Health Records for Marginalized Users

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## Introduction

Health care systems in the United States have long betrayed deep systemic biases against people of color and people with disabilities (Brooks, 1991; Centers for Disease Control and Prevention, 2013; Wong et al., 2015). Generally, user-centered design emphasizes the importance of designing information systems around the needs of specific groups of users (Norman, 1988), and requires some knowledge of user behavior. More specifically, designing racially-, gender-, and disability-inclusive health systems and services requires “a clear focus on specific communities at risk, a commitment to listen and collect meaningful data to understand local needs and priorities, a conviction to make progress, and ongoing assessment of health outcomes” (Wong et al., 2015).

This poster applies selected themes from two qualitative information seeking studies to initial design of a personal health library intended to support information literacy and seeking among traditionally marginalized groups.

## Methods

**Study A: Deconstructing Information Poverty** – Autism (DIPS Autism) study (Gibson & Hanson Baldauf, 2019) is part of an ongoing study on information seeking and exchange among autistic people and their families in North Carolina. In this study, the researchers conducted thematic analyses of sixteen 60–90 min interviews with autistic individuals (ages 12-35) and their parents (n=32) in North Carolina. Participants discussed a broad range of information seeking and sharing practices.

**Study B: Healthy Girls Know** was a multimethod study following a group of 6 Black and Latina girls (ages 12-15) in Durham, North Carolina. Participants engaged in thirteen 1.5-hour focus group and Information world mapping (Greyson et al., 2017) sessions over a 16-week period (total of 19.5 hours of focus group data). Participants discussed their experiences seeking information about specific health topics (one health topic per week). The researchers conducted inductive analysis of the data to determine the significant themes (Charmaz, 2014).

## Research Questions

### DIPS-Autism Research Questions

1. What are the information needs of our local ASD communities?
2. How do the information or service needs of members of the local ASD communities differ from other local community members?
3. Where and how do members of the ASD community currently look to fulfill their information, technology, and service needs?
4. How does the library currently fit into the information worlds/horizons of people with ASD and their families?
5. What gaps exist between information resources and ASD community member information needs?
6. What social interactions/dynamics help or hinder library access?
7. What previous and current models for assessing and meeting the needs of local disability communities exist in LIS practice and research?
8. To what extent has critical disability theory been integrated into LIS theory, research, and practice?

### Healthy Girls Know Research Questions

How and where do young black women seek information about their own well-being (personal health, personal safety, and environmental health issues)?  
 What social, cultural, and environmental factors influence the development of young black women’s information horizons, worlds, and information pathways? What factors influence their decision-making about how, where, and when to engage in information-seeking?

## Findings

### Content Themes

The following basic content themes reflected information needs related to accessing healthcare, and managing health information:

1. Archiving and accessing personal health records.
2. Need for understandable information about health and health conditions.
3. Support in framing discussions with healthcare providers.
4. Support in practicing difficult discussions with healthcare providers.
5. Guidance regarding patient rights and responsibilities.

## Special Considerations

Theme/Value	Study A: DIPS Autism	Study B: Healthy Girls Know Study	Implications for Personal Health Record/Library
<b>Trustworthiness: Helping users make decisions about what information sources to trust</b>	Relying on structured safety/security systems/community for safety; Trusting family but wary of overprotection; Wary of being taken advantage of by others.	Trust family for “important things”; Trust friends/self/professionals; Wary of unknown - strangers; “Testing behaviors” for untrusted information sources	Allow multiple means for judging authority/trustworthiness of sources, while allowing users to choose information sources. E.g.: Recommendations from friends/connected family/caregiver accounts; Verified non-commercial information sources (NLM, CDC, etc.).
<b>Privacy: Actions taken to control access to personal information</b>	Intentional disengagement - “hiding” (avoiding spaces/conversations) ; Avoiding potentially threatening situations	Intentional disengagement – Silence (choosing not to speak/respond); Progressive disclosure of information	Give users control over disclosure of personal information & user behavior on system. E.g.: Ability to send private questions to pediatrician/physician without parents having access to message logs.
<b>Formatting and modality: User Needs (Font, colors, size, brightness, contrast)</b>	Diverse (among group members) but strong, individually consistent user needs & preferences Video & short audio most popular. Written text least popular.	Expressed no explicit concerns about controlling formatting. Video, audio (music), and pictures were most popular.	Allow personalization re: formats and preferred mode of receiving information; ensure that information is readable. E.g.: Information presented as short video (with visual examples and captioning), in podcast format, and in transcript, written at 4 <sup>th</sup> -grade level. Transcript should allow user to control font & background color.
<b>Control over information disclosures</b>	Once trust established, disclosed personal information freely. Trust based on sense of cognitive/administrative authority	Progressive Disclosure of Personal Information Berry-picking (Bates, 1989)	Should allow user to control personal information disclosure, and to revoke personal information if desired. Should encourage prompt and just in time responses from medical practitioners/other trusted information sources.

## Discussion & Conclusion

While values are expressed differently by different groups, these differences highlight the need for attention to the needs of specific marginalized groups. Future work could incorporate this list into a heuristic framework for evaluation or design of personal health record or library systems.

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