# Qualitative Research Design and Analysis


**Presenters**

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# Objectives

- To review basic principles of qualitative research
- To explain how to design and conduct qualitative research from conceptualization to analysis, including barriers and facilitators to remote research
- To discuss and practice qualitative methods, including data collection, coding, and thematic analysis
- To review applications and examples of qualitative research in healthcare

# Qualitative Research vs. Quantitative Research

| | Qualitative Research | Quantitative Research |
|---|---|---|
| **Objective and Purpose** | How? Why?<br><br>To uncover and describe prevalent trends in perspectives, thoughts, beliefs and opinions<br><br>To gain an understanding of underlying reasons and motivations | What? Who? Which? When? Where?<br><br>To quantify data and generalize results from a sample to the population of interest<br><br>Sometimes followed by qualitative research to explore findings further |
| **Sample** | Small, Focused, Purposeful | Larger number of cases representing population of interest |
| **Data collection** | • Semi-structured interviews/transcripts<br>• Focus groups/transcripts<br>• Open ended questionnaires and surveys<br>• Diaries, journals<br>• Observations and field notes<br>• Visit summaries, office notes<br>• Case studies<br>• Visual data: drawings, videos, photos<br>• Observation, participant observation and ethnography | • Close ended questionnaire<br>• Surveys<br>• Checklists<br>• Large-scale data sets |
| **Data Analysis** | • Inductive categorization, comparison<br>• Coding of categories, meanings<br>• Looking for patterns and themes<br>• Building theory | • Statistical analysis (numerical, categorical), Conclusive and descriptive findings |

# Strengths and Limitations

## Strengths

- Gain insider perspectives into issues that are often missed (subtleties, complexities)
- Understanding relationships, causes, and effects, and dynamic processes surrounding issues
- Allows for ambiguities/contradictions and nuances in the data which reflect social reality and the multifaceted nature of many major issues
- Give voice to issues of certain populations that may be overlooked, and examine sensitive and complex issues in detail (e.g. sexuality, violence, drug use)
- Descriptive, narrative style which provides rich data

## Limitations

- Lengthy and complicated designs
- Difficult to replicate study because of central role of the researcher and context
- Data analysis and interpretation is time consuming
- Subjective – open to misinterpretation
  - Caution against personal/professional bias leading to over-reaching analysis

# Developing a Qualitative study – Types of Qualitative Methodologies

| | In depth interviews | Focus Group Discussion | Observation |
|---|---|---|---|
| **Objective** | Individual perceptions, beliefs, feelings and experiences | Range of opinions on specific issue, community norms, or evaluation | Observe how people act and interact in certain social situations or environments |
| **Research instrument** | Semi-structured Interview guide | Discussion guide | Observation guide |
| **Advantages** | • Gain in depth information<br>• Identify personal experiences<br>• Useful for sensitive issues<br>• Identify context | • Group interaction provides range of issues and opinions<br>• Discussions provide detail, justification, and clarification<br>• A lot of information collected quickly | • Unobtrusive<br>• Contextual information<br>• Supports data from other sources<br>• Identify people's actual behavior |
| **Disadvantages** | • No interaction or feedback from others<br>• Individual perceptions only<br>• Multiple interviews may be needed to identify range of issues | • Less depth of information<br>• Less suitable for personal experiences<br>• Managing group dynamics and the focus group process | • Interpretation of observations may be subjective<br>• Distinction between participant observation and strict observation is needed |

# Applications in Health Research

- **Qualitative research in health and healthcare**
  - Key to understanding the complex and diverse human experience of health and illness from the insider's perspective
  - Medical anthropology - sociocultural context of health and illness
  - Learning from and collaborating with "insiders"
    - **CBPR** – community-based participatory research
    - **Patient reported outcomes** – information from patients without interpretation (QoL, satisfaction, function).
  - "Insiders" = can include patients, caregivers, community members, health providers, service providers, clinic staff, administrators, advocates, policy makers/government
- **Implementation Science**
  - Guide/enhance the implementation and delivery of an intervention or program
- **Program evaluation**
- **Development of relevant assessment tools**
- **Health policy**
- **Health care practice and quality**
- **Health needs assessment**

# Examples of Qualitative Health Research

- **Understanding health, disease, healthcare experiences from the insider's perspective**
  - The Health Care Transition Experience of Young Adults with Sickle Cell Disease
  - Hurricane Experiences of Older Floridians: Identifying Barriers to Preparedness and Response
  - Lives in Isolation: Stories and Struggles of African American Women Experiencing Panic Disorder
  - Latinas with Panic Disorder: Barriers to Care within Kin, Social and Provider Networks
  - Exploring the Cultural and Social Context of Black Infant Mortality
  - Diet, Nutrition and Acculturation among Puerto Rican Women and Children
  - Barriers and Facilitators to Prenatal Care among Caucasian/White and African American/Black Women in Leon County

# Examples of Qualitative Health Research

- **Implementation Science**
  - Electronic Health Record Monitoring of Youth HIV Prevention and Care Continua
  - Female Patients with Panic Disorder: Cultural Differences in Preferences for Treatment
- **Program evaluation**
  - Formative Evaluation of a VA Home INR Monitoring Project
- **Development of relevant assessment tool**
  - Development and Evaluation of a Sickle Cell Quality of Life and Health Outcomes Assessment Instrument
- **Health policy**
  - Victim Advocates' Perspective on Domestic Violence in Florida during COVID-19

# Examples of Qualitative Health Research

- **Health care practice and quality**
  - Barriers and Facilitators to Conducting Adolescent Health Risk Assessments in Primary Care
- **Health Needs Assessments**
  - Emergency Preparedness for Children with Autism: A Needs Assessment for a Vulnerable Population
- **Community-based Participatory Research**
  - All-inclusive Hurricane Resilience to Bridge the Divide for Special Needs Populations Living in Rural Communities
- **Medical education**
  - Threshold Concepts in Behavioral Medicine and Psychiatric Education

# Developing your qualitative interview/focus group guide

- The interview guide is a *guide*
  - Typically qualitative visits are semi-structured
  - Does not need to be read verbatim
  - Interviewer needs a very good understanding of the **research question** and **probes**
  - Core questions are set and will be covered across interviews or focus groups, but allows for flexibility of discussions
    - Create a certain amount of order on topic areas
    - Follow in a reasonable order, but you can alter order of questions and allow for discussion of relevant tangential topic areas depending on how the participant leads the conversation)
  - Types of questions
    - Background
    - Behaviors or experiences
    - Opinions or beliefs
    - Knowledge
    - Sensory experiences
  - Focus on research question and formulate questions that are concretely oriented to answer to it
  - Use language that is relevant and understandable to participants
  - Include discussion probes

# Activity 1: Developing an interview guide

In your breakout groups, pick a population, a data collection technique, and a research question. Develop at least 5 open ended questions. You can include content probes.

**What are content probes?

- Ideas or follow up question that generate further explanation from participants
- Example: What did you do over your summer break? (Probe: Outdoor activities? Working? Vacation?)

Time: 15 minutes

# Post Activity 1 Discussion

Share 2-3 questions your group developed

What was the most difficult aspect of developing your guide? What was the easiest?

What additional background data would you need to further hone your guide?

# Qualitative during COVID-19 – Remote visits

What are some disadvantages and benefits to delivering remote qualitative research?

# Conducting Remote Qualitative Research

**Challenges**

- Technology issues
  - IT, internet technical breakdowns
  - Technology divide - underserved, low income, rural populations
    - Hardware, internet access, costs to participants
- Delivering mixed methods approaches
- Consenting
- Participant payments
- Sample sizes in focus groups
- Privacy issues
  - Shared living spaces
  - Insight into participants private world

**Benefits**

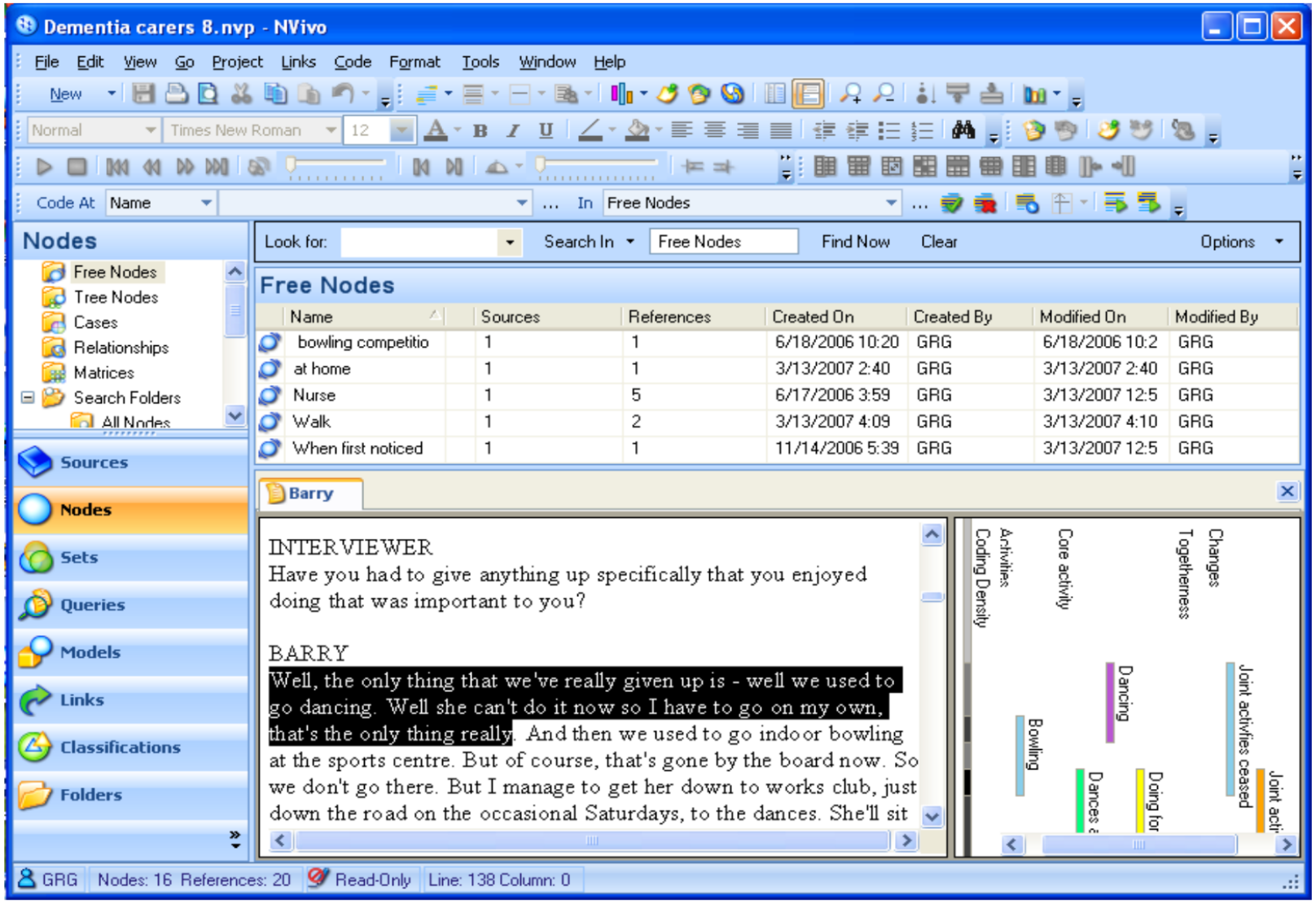
- Removes transportation barriers
- Accessing populations that may be hesitant regarding in person research
- Facilitates eye contact and face to face connection
- Shared living spaces
- Insight into participants' private world

# Interviewing Challenges and Considerations

- Incomplete, inaudible data
- Communication styles and personality types
- Participant disclosure
- Audio/video/technology issues
- Disease state barriers
- Unplanned complications, confounding variables
- Disgruntled, angry
- Cross over roles – researcher, clinician, mandatory reporting
- Participatory nature of qualitative research
  - Participants' lives affect yours as a researcher

# Data Analysis

# Data Analysis Software: NVivo



# Qualitative Analysis Approaches

- Methods may differ based on philosophical approaches (e.g. linguistics, analytic philosophy, structuralism)
- Categorisation, structure, relationships
- Recognising relationships and developing the categories you are using to facilitate this
- Developing and testing hypotheses to reach conclusion
- Different approaches can be used together
- Memos
- **Thematic Analysis** – Inductive method of identifying and analyzing themes/patterns.
- **Content Analysis** – Quantify and analyze the presence, meaning and relationships of certain words, themes, or concepts.
- **Discourse Analysis** (Conversational analysis)- Analyze patterns of speech, language use
- **Ethnography and participant observation** – Analyze social setting, customs and culture

# Coding

- **Research goals, objectives, specific aims may guide coding**
  - Codes – short handed notation for ideas, categories that emerged in the data
  - Naming the segments of your data with descriptive words or category names
  - Means to organize data and reduce material into organized categories
  - Main categories may be broken into subcategories and sub-sub categories.
  - Interpreting categorical material still needs to be occur – interpretations develop during the coding process
  - Theoretical constructs
  - Applied focus - e.g., design, implementation, evaluation
- **Generally small ideas, details per code**
  - Capture detail at the outset that may be meaningful later
  - Larger grouping, branching to construct structure and themes from smaller ideas
  - Small codes can carry large meaning

# Qualitative Analysis Process

Identifying, coding, categorizing themes

**Thematic Analysis**
- Codes qualitative information
- Process of identifying themes
- Identify why specific categories chosen

E.g., What is the meaning of the lived experience of this phenomenon?

**Grounded Theory**
- No preconceived framework or hypotheses
- Data provides abstract concepts
- Researcher builds 'theory'
- Theoretical saturation

E.g., How does the basic social process of X occur in the context of Y ?

**Discourse Analysis**
- Language beyond sentences
- What and how people communicate
- Visual communication

E.g., How does communication shape identities/ activities?

# Types of Coding

## Structural Coding (Descriptive)

- Describe characteristics of the data itself (who, where, how)
- Typically *a priori*

## Thematic Coding (Topic)

- Most commonly used type of coding
- Coding to describe topic; any passage will include several topics
- Creating a category or recognizing one from earlier
- Links themes and categories with particular instances in the data

## Analytic Coding

- Going beyond gathering by topic to analysis
- Pursue comparisons
- Ask yourself “ What is this all about?”

# Structural Coding

"We think that sometimes parents, we don't talk about sex to our daughters. Therefore when they start to have sexual relations, they don't have as much knowledge on how to use a condom and that puts them at higher risk. They say that girls have a higher risk because there is less information about sex."

- Who? Father, 40 years old
- Where? Interviewed at Boston Medical Center
- Research Question: Why do you think people don't protect themselves from HIV?

# Thematic Coding

"We think that sometimes parents, **we don't talk about sex to our daughters.** Therefore when they start to have sexual relations, they don't have as much knowledge on how to use a condom and that puts them at higher risk. They say that girls have a higher risk because there is less information about sex."

**Codes**

- Parent-child communication
- Lack of knowledge
- Vulnerability of girls

# Analytic Coding

"We think that sometimes parents, we don't talk about sex to our daughters. Therefore when they start to have sexual relations, they don't have as much knowledge on how to use a condom and that puts them at higher risk. They say that girls have a higher risk because there is less information about sex."

- Make new categories based on what you see across interviews.
- Revisit categories to see if they still fit or change definition as you add more data.
- Ex: Do parents who feel comfortable talking about HIV with their children have different thoughts than parents who feel uncomfortable talking about HIV with children?

# Example Coding Matrix

| AFRICAN AMERICAN WOMEN WITH PANIC DISORDER | | |
|---|---|---|
| **Codes** | ***How things are*** | ***How things should be*** |
| **Illness expression** | • Crazy<br>• Like being in a bubble<br>• Panic attack<br>• Stress<br>• Anxiety<br>• Sad and gloomy<br>• Like a shadow over you | • Feel better<br>• Be seen like having any other disease<br>• Feel "normal" |
| **Social Network** | • Rejection<br>• Judging you<br>• Looking down on you<br>• Ridiculing me<br>• Takes your spirit<br>• Faith in God is not strong enough | • Someone to talk to that would listen<br>• Understand you<br>• Care about you<br>• Church that is open minded about mental health<br>• To be loved<br>• Patience<br>• Be active in your care by educating others |
| **Providers** | • Do not understand<br>• Rely on medication - just take a pill<br>• Do not educate about the illness<br>• Primary care – may diagnosis, but no treatment, follow-up, education | • Feel comfortable with<br>• Understand what you are going through<br>• Know more about/be more familiar with mental health<br>• Make one feel and treated as a human being<br>• Somebody that could relate to me<br>• Feel better when I come out of the office<br>• Be more personable<br>• Empathize<br>• Have sensitivity<br>• Education<br>• Support |

| CAUCASIAN WOMEN WITH PANIC DISORDER | | |
|---|---|---|
| **Codes** | ***How things are*** | ***How things should be*** |
| **Illness expression** | • Anxious, Nervous<br>• A spell, black out, paralyzed from the neck up<br>• Freak out, flipped out<br>• Panic attack<br>• Stressed out<br>• Bad nerves<br>• On the edge<br>• Crazy, nuts<br>• Losing it<br>• Bouncing off the walls<br>• Not feeling yourself, out of sorts, having a bad day | • Chemically balanced<br>• It's a disorder |
| **Social Network** | • Embarrassed of mental health patients<br>• Label you<br>• Denial<br>• Alienate you, rarely let you be around | • Be seen as equal<br>• Avoid labeling<br>• Encouraging words from family<br>• Be accepted |
| **Providers** | • Labeled patients<br>• Make feel inferior<br>• Somatic providers did not hear you when you have a mental illness | • Concerned; listen<br>• Compassionate<br>• No judgement<br>• Make feel he/she is on the same level<br>• Be more "personal" and less "clinical"<br>• Provide medications to help<br>• Make feel comfortable |

# Codebook

- Create a codebook from the beginning-record of your emergent codes
- Review periodically – maintaining list provides opportunity to organize and reorganize codes into major categories and subcategories
- What to put inside your codebook?
  - Codes, sub-codes, sub sub codes
  - Definition or content description of code
  - Guidelines for when to use/when not to use the code
  - Sample text/passage

# Activity 2: Coding

Split up into breakout groups. Look at the interview on the provided materials and create codes based on emerging topics and ideas.

Time: 15 minutes

# Coding and Themes

- Once you develop your list of codes and codebook, you start developing themes, or categories/trends you notice in the data
- For example: What activities do kids enjoy in the summer?

| Codes | Theme 1 | Theme 2 | Theme 3 |
|---|---|---|---|
| 1. Riding bicycles | Looking at 1, 2, 3, 4 Theme may be Enjoying outdoor activities<br><br>Looking at 1, 2, 4 Theme may be enjoying sports based activities | Looking at 3 and 5 Activities with friends, social activities | Looking at 3, 4, and 6 Cool, low temperament based activities |
| 2. Playing with a frisbee | | | |
| 3. Going to a waterpark with friends | | | |
| 4. Going swimming | | | |
| 5. Multiplayer Computer games | | | |
| 6. Eating popsicles | | | |

# Activity 3: Developing Themes

You will be separated into breakout rooms and given a sample study that includes population, research question, and a list of codes. With your group members, take the codes and categorize into themes.

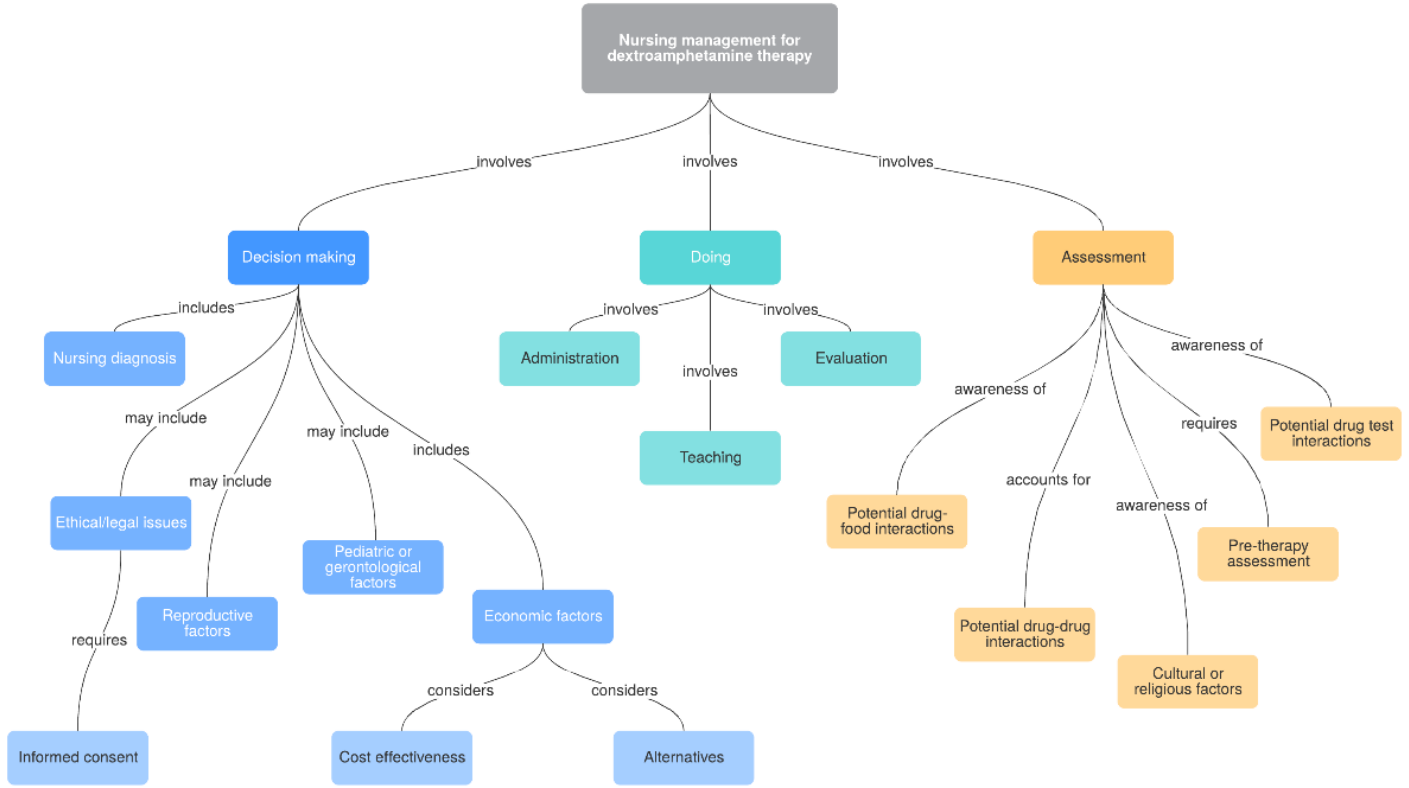
Time: 17 minutes

# Post Activity 3 Thoughts

- What was the most difficult part of this exercise?
- What factors helped you determine themes?
- What was the experience like to work with other people and to reach consensus about themes?
- How might you apply your results?

# Visualizing Codes, Categories and Themes

- **Concept Map** – displaying relationship between categories and themes



# African American Women's Perception of Black Infant Mortality in Leon and Surrounding Counties:

## A Cross Generational Community-Based Participatory Research Project

**Ivana Simpson, BS; Miaisha Mitchell, BS; Alexandra Nowakowski, PhD, MPH; Jessica De Leon, PhD; Joedrecka Brown Speights, MD**

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The Florida State University College of Medicine

## Statement of Problem

- Despite the overall declining trend in total infant mortality rates between 1999-2012, there has been a persistent disparity in the black infant mortality rate.
- Community-Based Participatory Research (CBPR) offers an opportunity to create interventions that may effectively address community-identified needs and eliminate health disparities.

## Data analysis & results

- Participant's perceptions about the black infant mortality disparity were gleaned in three semi-structured group discussions.
- Constant comparison and thematic coding qualitative analysis delineated twenty-four themes summarized into 6 categories.
- The 6 categories are interconnected; impact or are impacted by the individual, family, community/place, healthcare system, and society; and, are influenced by discrimination, socioeconomic factors, and female burden.

## Discussion

- The perceptions of African American women in Leon and Gadsden counties influence how their care is accessed and received, this may impact infant mortality.
- Consistent with prior studies, protective factors and risk factors across the life course play a role.
- A dissemination weekend event occurred to share the results and determine next steps per the CBPR approach.

Image courtesy of africa/ FreeDigitalPhotos.net

## Design & Methods

**Community Board**
Composed of individuals from the community, community agencies, faith-based organizations, and FSU College of Medicine.

↓

**Project Planning**
Shared decision making involving the community.

↓

**Focus Groups**
3 Focus groups : African-American Women (1) Childbearing age * (2) Beyond child bearing age (3) Mixed age groups.

↓

**Data Analysis/Theme Based Concept Mapping**
Themes based on current literature, community advisory board and focus group discussion.

↓

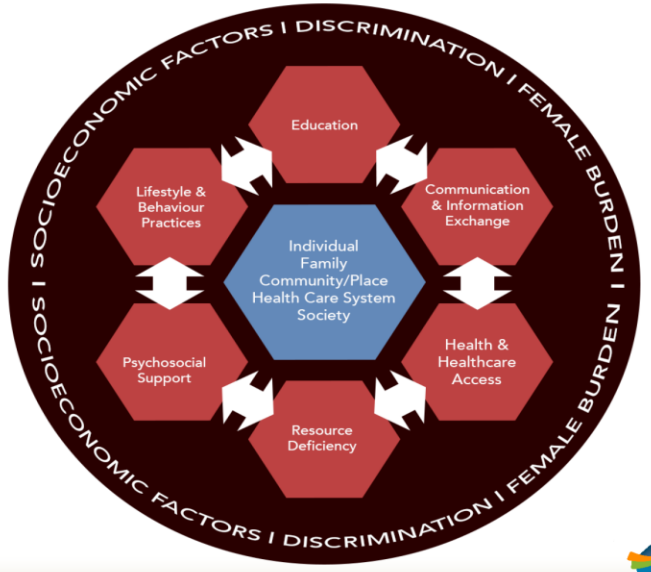
**Data Sharing**
Sharing with focus group participants and the greater community.

↓

**Community Action**
*In Leon County.
Action from the community.

PARTICIPANTS: African American Women (n=20), ages 19 to 68 from Leon and Gadsden Counties.

**Social Determinants of Black Infant Mortality**




Graphic courtesy of Euedoo Software, LLC

## Conclusions &Next steps

- The disparity in black Infant mortality is of multifactorial etiology and will require attention from multiple levels to eliminate.
- Community perspectives may uniquely inform participatory research to eliminate infant mortality in this community.
- Further dissemination of results through education, community engagement, and advocacy is planned.
- A community-based, collaborative intervention is being developed.

Components:

-Community-navigator led Inter-professional graduate health student teams

-Preventive, preconception, and primary care focused over the life course

-Holistic approach with input from those affected by the disparity (stakeholders)

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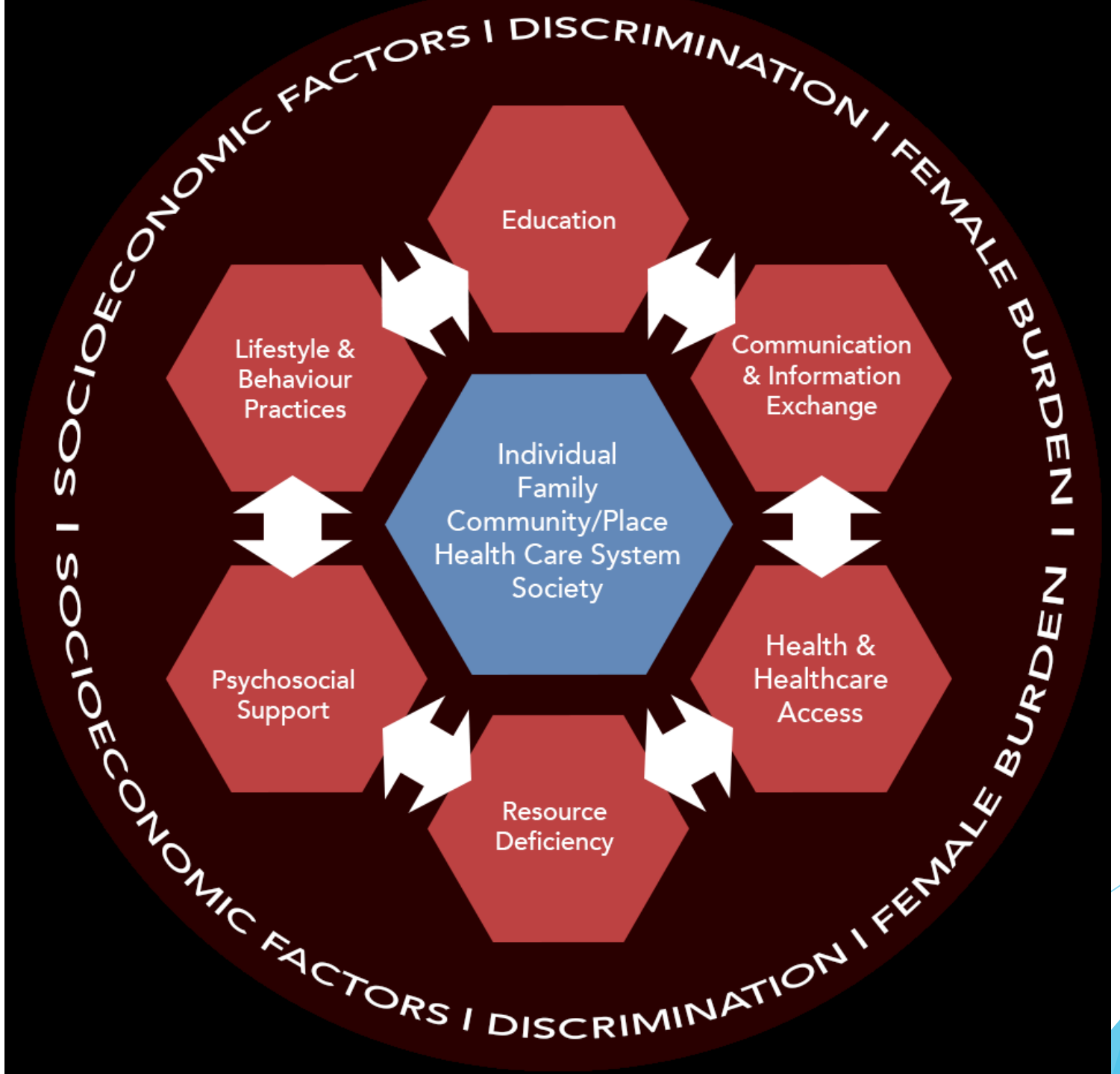
Image courtesy of Lisa McDonald / FreeDigitalPhotos.net


SOCIOECONOMIC FACTORS I DISCRIMINATION I FEMALE BURDEN I
Education
Communication & Information Exchange
Health & Healthcare Access
Resource Deficiency
Psychosocial Support
Lifestyle & Behaviour Practices
Individual
Family
Community/Place
Health Care System
Society

# "It could potentially be dangerous... but nothing else has seemed to help me." Patient and provider perspectives on benzodiazepine use in opioid maintenance treatment

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## Introduction

Benzodiazepine use among patients receiving opioid maintenance treatment (OMT) presents a conundrum: benzodiazepines can increase overdose risk, yet patients commonly have anxiety or insomnia that can be relieved by benzodiazepines. The optimal therapeutic role for benzodiazepines among patients receiving OMT is unclear. The purpose of this study is to explore in OMT patients and providers: 1) motivations for benzodiazepine use and prescribing, 2) understanding of the benefit and harms of benzodiazepine use, and 3) facilitators and barriers to discontinuing benzodiazepine use.

## Methods

We conducted semi-structured, qualitative interviews with 26 OMT patients using benzodiazepines regularly, presently or in the past, and with 10 OMT providers. Participants were recruited from an office-based buprenorphine clinic at an academic health center and from a methadone maintenance clinic using purposive sampling. Interviews lasted between 45 and 90 minutes and were audio-taped and transcribed. The study team then reviewed transcripts and double-coded 100% of the interviews. Data analysis was guided by elements of grounded theory and thematic analysis.

## Preliminary Results

**Table 1.** Patient Demographic Characteristics.

| | N=26 |
|---|---|
| Age in Years: Mean ± SD | 42.9 ± 9.7 |
| Sex n (%) | |
| Male | 11 (42.3%) |
| Female | 15 (57.7%) |
| Time on OMT in Years: Mean ± SD | 6.4 ± 6.0 |
| OMT Type n (%) | |
| Buprenorphine | 9 (34.6%) |
| Methadone | 17 (65.4%) |
| Current Benzodiazepine Use n (%) | |
| Prescribed | 14 (53.8%) |
| Non-prescribed | 8 (30.8%) |
| Discontinued use | 4 (15.4%) |

**Table 2**. Provider Demographic Characteristics.

| | N=10 |
|---|---|
| Current Role at Institution | |
| MD/NP | 6 (60%) |
| RN | 2 (20%) |
| Therapist/Counselor | 2 (20%) |
| Years in Role: Mean ± SD | 5.7 ± 6.9 |
| Sex n (%) | |
| Male | 4 (40%) |
| Female | 6 (60%) |

## Results (cont.)

### Patient motivations for benzodiazepine use

*"And then after a while, it seemed like I needed more to be calm and I was taking them sometimes to get high. I'd take more to get high, and after a while you just have to...you have to take more and more. And so I at least need to take something, that way I'm not sick."* - *Patient*

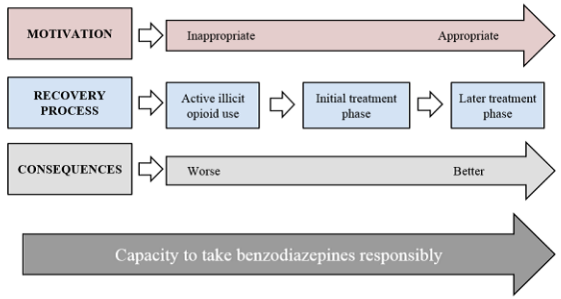
*"They make it so that I can function in society because I have a lot of trauma and PTSD and anxiety... I'm also in recovery from opiates, that's why I'm in the clinic. So with that combination of my anxiety and my addiction being treated, it's been working... I would be too afraid to even walk into a place and speak to the person at the register without my medication... I don't know what I would do without them."* – *Patient*

### Patient learning to use benzodiazepines appropriately

*"If anything could go wrong, it was going wrong, you know? My life came to a point where, you know, I'm getting older, I had to do something about my situation, therefore I got a job. I work nights now. So, it's not like I couldn't take them like that anymore, there's just no need to take them like that? Especially if they're helping me now, you know, by taking them the correct way."* - *Patient*

*"My experience has been to take them as needed and I can kind of tell if I am taking them too long or if I am taking too many during the day, like if I take too many during the day, I'll be more sleepy and out of it. But I don't want to be out of it. I just kind of want to be calm and be neutral. Not be too up and not be too down. I think they are a good thing and they're a bad thing. It just depends on where you are in your life or your addiction."* - *Patient*

**Figure 1. Conceptual framework of benzodiazepine use in individuals with opioid use disorder**




## Results (cont.)

### Patient-provider priority misalignment

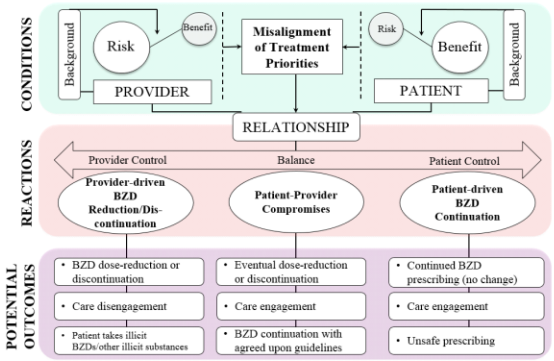
*"My understanding of the research is that benzodiazepines are not good long-term treatments for anxiety and they're better for a short-term treatment and long-term, the risks outweigh the benefits."* – *Provider*

*"My main point is safety. Patients.... they're not thinking about benzos, I mean about safety. They just like, oh my God, I'm always anxious. I have to have this for me to be calm. That is where their mind is."* - *Provider*

### Patient and provider treatment compromises

*"Well I have tried to get them down, but I mean I've got one guy right now who's been on eight [mg]. I think I've gotten him to six [mg] and it's been like a six-month process to get there. And that's still a dose that I'm certainly not comfortable with, but it had been stable. He'd been stable on it for years."* - *Provider*

**Figure 2. Potential outcomes of patient-provider priority misalignment**




## Conclusions

OMT patients and providers report risks and benefits of benzodiazepine use but weigh those risks and benefits differently, leading to a misalignment of priorities. Furthermore, the risk-benefit analysis of benzodiazepine prescribing may depend on whether the patient is stable in opioid treatment. Future work among patients and providers is warranted to determine how to better balance patient and provider priorities in order to deliver safe prescribing practices and maintain patient engagement in care.

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# Barriers and Facilitators to Conducting Adolescent Health Risk Assessments in Primary Care

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[1]Florida State University College of Medicine, [2]University of Florida College of Medicine, [3]University of Florida College of Medicine-Jacksonville

## Background

- Most morbidity and mortality results from preventable risk factors. Unhealthy behaviors that begin in adolescence contribute to adult chronic disease, negatively impacting health and health care costs.
- Clinical guidelines recommend adolescents have annual preventive health visits that include health risk assessments (HRAs) to identify health risks and provide counseling and referrals.
- Despite the role HRAs and preventive services can play in adolescent health, the delivery of such services does not meet recommended clinical guidelines. This study used qualitative research methods to explore barriers and facilitators to the administration of adolescent health risk assessments in primary care to increase their administration, quality and effectiveness.

## Methods

Nine semi-structured focus groups were conducted with healthcare providers and staff from September 2011 to February 2012. All focus groups were moderated by researchers trained in qualitative methods, and were audio-recorded and transcribed verbatim. Inductive content analysis was assisted with qualitative analysis software (Atlas.ti) to uncover themes surrounding current and general barriers and facilitators to adolescent HRAs, counseling and referral. A purposeful sample of diverse primary care settings, as well as participants representing a variety of clinic personnel, were recruited to provide a broad view of the challenges to conducting adolescent HRAs.

## Results

| RESPONDENTS (N=65) | RESEARCH SITES and HEALTHCARE SETTINGS | |
|---|---|---|
| • Pediatric & family medicine physicians<br>• Pediatric residents<br>• Nurses<br>• Medical & nursing assistants<br>• Office/administrative staff | **Four Florida cities:**<br>• Gainesville<br>• Jacksonville<br>• Orlando<br>• Tallahassee | • Pediatric residency programs<br>• Federally qualified health centers<br>• Private practices<br>• Hospital-based adolescent clinics<br>• School-based clinics |

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| PROVIDER | Barriers | Time Constraints | • To conduct HRAs<br>• Engage in meaningful discussion/provide counseling<br>• Discuss multiple or critical issues<br>• Provide preventive care plus HRA |
| | | Behavior | • Providers not comfortable discussing sensitive issues<br>• Displaying surprise or shock at patient responses |
| | Facilitators | Behavior | • Non-judgmental, non-threatening, non-confrontational, respectful communication<br>• Being comfortable discussing sensitive topics with teens<br>• Ability to put patients at ease<br>• Treat patients as mature individuals responsible for their own health care |
| | | Knowledge | • Having knowledge of patient's family, home life, and community<br>• Cultural competence: understands and incorporates patient's cultural beliefs, values, and behaviors |
| | | Health Education | • Instill patient "buy in" through education: explain links between behavior and health ,and relay importance of preventive care |
| | | Relationships | • Open, honest, trusting patient-provider relationships<br>• Long-term, consistent patient-provider interaction with rapport built over time |

## Results

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| PATIENT | Barriers | Literacy and Language | • Low literacy<br>• Low health literacy<br>• Non-English speakers |
| | | Confidentiality and Communication | • Privacy/confidentiality concerns<br>• Discomfort/apprehension to discuss private and sensitive issues<br>• Socially acceptable responses, rather than honest disclosure<br>• First time patients (not comfortable, no history/relationship with provider)<br>• Parents present during administration |
| | | Time Constraints | • Constraints of busy parents/families<br>• Healthcare conflicts with school schedules and responsibilities |
| | | Health Issues | • Teens' general apathy towards health issues and preventive care<br>• Cognitive disability |
| | | Access | • Lack of transportation<br>• Paying for services |
| | Facilitators | Disclosure | • Teens' desire to discuss health behaviors with knowledgeable, trusted adults<br>• Patients' comfort with provider |

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| PRACTICE | Barriers | Clinic Layout | • Small clinic size or physical layouts that hinder privacy |
| | | Staffing | • Sole or small number of clinicians<br>• Not having personnel or resources to deal with issues that are uncovered |
| | | Communities | • Small communities where anonymity is lacking |
| | | Culture | • Lack of culturally appropriate resources (e.g., interpreters, multilingual education-al materials) |
| | | Environment | • For school-based clinics, pressure to return patients to class<br>• For school-based clinics, lack of privacy because clinic is on campus |
| | Facilitators | Staffing | • Staff that enjoy working with teens<br>• Staff who are experienced in adolescent health<br>• Healthcare teams (e.g., physicians, health educators, social workers) bring different areas of expertise, interact differently with patients and debriefing across team provides better understanding of patient |
| | | Communities | • Small communities where providers have known patients for many years |
| | | Finances | • Billing systems to recoup costs |
| | | Scheduling | • Longer appointment times for adolescent patients |
| | | Environment | • "Adolescent friendly" environment (reading materials, educational materials, etc. are teen-oriented) |

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| REFERRAL | Barriers | Lack of Resources | • Adolescent-specific<br>• Mental health<br>• Nutrition<br>• Primary care, especially in rural communities<br>• Resources and programs disappear when funding ends/budgets reduced |
| | | Staffing | • High turn over rate of counselors/behavioral specialists |
| | | Access | • Uninsured<br>• Low income patients<br>• Lack of transportation |
| | Facilitators | Linkages | • Up-to-date knowledge/lists of available resources and programs<br>• In-clinic presence or linkages with social workers/community-based personnel<br>• Linkages with academic institutions that provide services<br>• Establishing referral networks in advance via contact from providers |

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| HRA TOOLS | Barriers | Language | • Language not appropriate for younger teens<br>• Vocabulary that is too technical, formal, or outdated<br>• Medical terminology<br>• Family members acting as interpreters (all or correct information may not be relayed) |
| | | Length | • If too long, teens lose interest and takes too much time to administer |
| | | Content | • Domains not appropriate or comprehensive |
| | | Format | • Paper instruments: gives teens time to consider answering honestly; reduces confidentiality; teens lose, forget, or throw away paperwork<br>• Looks like a test |
| | Facilitators | Content | • Move from less to more sensitive issues<br>• Questions that are short, straightforward, explanatory and inclusive<br>• Responses that trigger needed discussion are easily located<br>• Domain screening questions that guide administration or non-administration of subsequent questions; use of skip logic if IT-based<br>• Current/missing teen health issues, e.g., bullying, cyberbullying, sex and social media, high caffeine products, occupational health risks, gender identity issues, self-injurious behavior<br>• Able to clarify responses or ask for more discussion<br>• Consent/privacy issues presented at beginning and end of survey |
| | | Format | • Brief, streamlined instruments<br>• Electronic/IT-based<br>• Easy to read fonts<br>• Easy and quick to respond<br>• Visually attractive |

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| PROCESS | Barriers | Time Constraints | • Time constraints in busy primary care practices limits administration and counseling<br>• Slowed workflow because of time needed for administration and counseling<br>• Time needed for verbal administration to low-literacy patients |
| | | Finances | • Inability or difficulty recouping costs associated with the time spent conducting HRAs |
| | | Language and Culture | • Conducting non-English HRAs |
| | | IT | • Guarding against theft, damaged devices |
| | | Educational Materials | • Providing written educational materials instead of verbal discussion (literacy issues, teen may discard to preserve confidentiality) |
| | | Scheduling | • Annual visits: long time frame between visits may cause opportunities to intervene to be missed |
| | Facilitators | Confidentiality and Communication | • Assurance to patients that providers are available to discuss sensitive topics at any time<br>• Describe HRA content and explain why the HRA is being administered<br>• Addressing teens directly, rather than talking to parents or parents responding for teens<br>• Start with general discussions, "small talk" to put patient at ease<br>• "Normalize" behaviors, e.g., "many people your age have issues with..."<br>• Discuss topics at every visit; primes patient and promotes discussion and disclosure<br>• Providers available who are trained to deal with critical issues or triggered emotional responses<br>• Prime parents in advance about HRA administration, patient privacy and teens taking charge of their healthcare |
| | | Administration | • Use of wait time or staff time to assist to complete HRAs<br>• Gender-matching patients and providers |
| | | Language and Culture | • Culturally competent, meaningful and appropriate tools |
| | | Information Technology | • Engages patients by capitalizing on teens' interest in IT; more appealing, enjoyable and less tedious<br>• Saves time<br>• Increases privacy<br>• Reduces provider paperwork<br>• Can be linked to electronic health records for billing and continuity of care<br>• Can provide immediate access to educational materials/instructional videos |

## Conclusions

- Barriers and facilitators to conducting adolescent health risk assessments are multidimensional and multifactorial.
- The use of HRAs in primary care can be expanded and enhanced by addressing barriers and the means to facilitate HRA improvement, administration and application.
- Qualitative research with healthcare providers and staff can inform researchers on techniques to conduct effective intervention studies in community-based clinical settings.

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health IMPACTS FOR FLORIDA
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# Resources

**Technology – Coding and analysis software**

- NVivo, Atlas.ti

**Books**

- “Qualitative Inquiry and Research Design: Choosing Among Five Approaches” by John W. Creswell
- “Qualitative Data Analysis: A Methods Source Book” by Matthew B. Miles, A. Michael Huberman, and Johnny Saldana
- “Qualitative Research Methods” by Monique Hennink, Inge Hutter, and Ajay Bailey

# Thank you!