



*Wait, Won't! Want:
Barriers to health
care as perceived
by medically and
socially
disenfranchised
communities*

Electronic Self-
Management
Resource Training
to Reduce Health
Disparities
(eSMART-HD)

*RC2 MD004760
National Center on
Minority Health and
Health Disparities, NIH*

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**1st phase in a
larger project,
aim of which was
to develop
an intervention**

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Study Aim

The purpose of this project was to identify themes in communications with healthcare providers that individuals from medically and socially disenfranchised groups perceive as preventing them from getting what they need to manage their health.

Recruitment and Sampling



HOW'S YOUR HEALTH CARE?

Do you have a hard time getting what you need from your doctor?

WE WANT TO HEAR YOUR STORIES!

We are looking for African American, Hispanic/Latino, LGBT, and Russian individuals to tell us about their experiences with their healthcare providers.

PLEASE CALL (216) 368-3067.

You will be paid for your time.



- Flyers posted throughout the community
- Ads in buses

Sample

- Eleven focus groups
 - African-American (n=20)*
 - Hispanic/Latino (n=15)*
 - Lesbian/Gay/Bisexual/Transgender (n=21)*
 - Russian Immigrant (n=4)*

- 28 women and 32 men

*data are as self-identified, observations suggest that several (~12) participants could have identified in more than one target group

Data Collection

- Held in the community
 - churches (3)
 - coffee shops (3)
 - community centers (2)
 - public libraries (3)

Data Collection

Focus groups were digitally recorded and transcribed (guided by three questions):

1. *From your own perspective, what, when you go, like your clinic visit or something, what just seems to get in the way of getting what you want or what you need when you go there?*
2. *Think of a time when you had a visit that went really well, who was there and what was happening?*
3. *If you could improve just one thing in your interactions with healthcare providers, what would that one wish be?*

Data Analytic Strategy

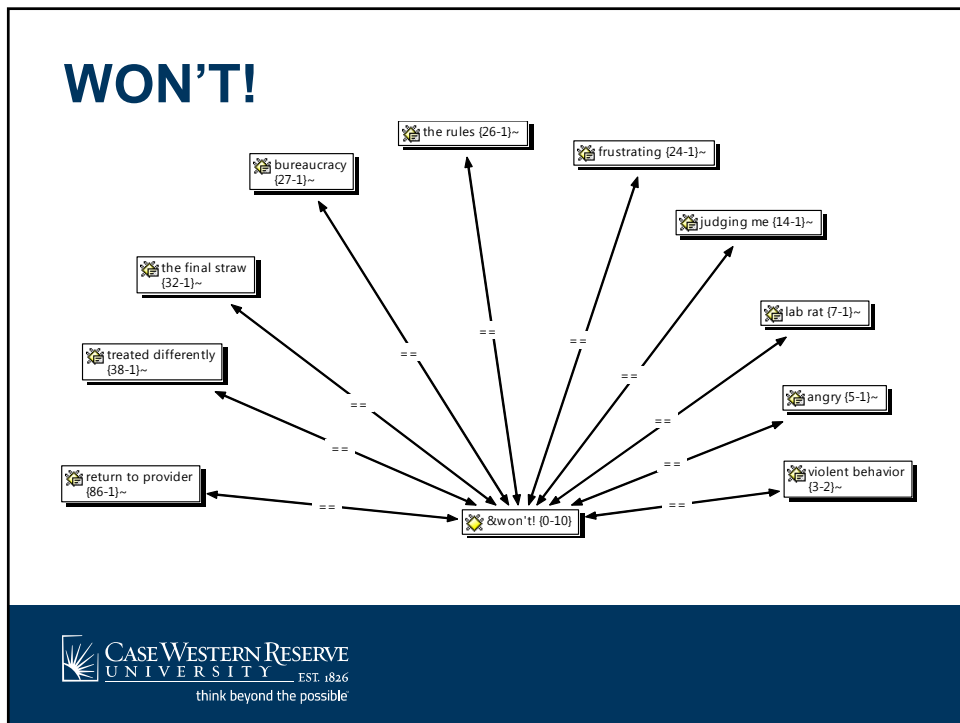
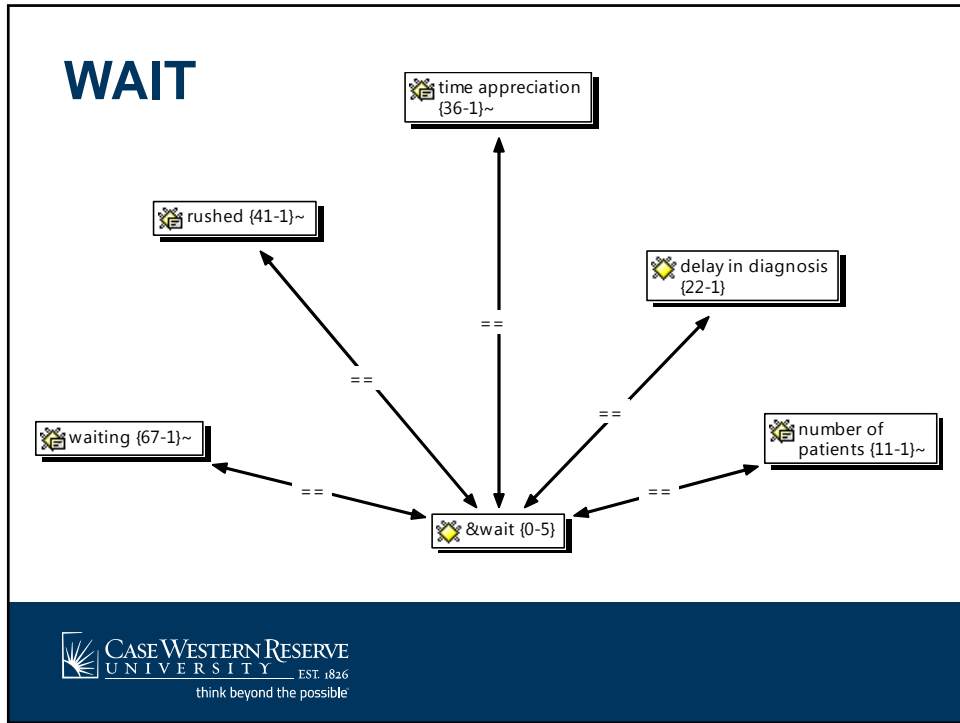
Data were analyzed using **Atlas.ti** by assigning **in-vivo codes** to the words of respondents by three researchers, independently. The coding was merged and reconciled. The in-vivo codes were grouped under more **abstract (axial) codes** by the patterns or themes that emerged from comparing shared characteristics and meanings. The themes were then **validated in meetings with community participants**.



Results

	Proximal	Intermediate	In Vivo	Definition	N			
	Codes							
WANT (177)	N/A		delay in diagnosis	Delay for a resolution or diagnosis	22			
			number of patients	Patient queue/ provider having many patients	11			
			rushed	Perception of feeling or not feeling rushed	41			
			time appreciation	Someone made them feel like their time was not as important as the provider	36			
WONT (274)	Participate (193)		waiting	Kept waiting for what they needed or wanted	67			
			bureaucracy	Red tape (policies, programs, etc.)	27			
			lab rat	Lab rat/ lab specimen/ guinea pig/ not a person anymore	7			
			paperwork	Paperwork	15			
			return to provider	Refers to their own selection of provider, clinic or hospital	86			
			the final straw	Participant terminated interaction with provider or system	32			
			the rules	Strict about following the guidelines	26			
			angry	Angry, irritated, irritable	5			
			frustrating	Expresses agitation/ irritation/ annoyance/ or is disturbed	24			
			judging me	Perception of being judged	14			
WANT (955)	Tolerate (81)		treated differently	Difference by _____ (race, sexual orientation, ethnicity, gender, etc.)	38			
			System Characteristics (108)	efficient	Efficiency of the system or a provider/ it was easy to get what they needed	15		
				access to provider	Navigation through the gatekeepers to the provider	34		
				choices	Having or not having a choice.	27		
WANT (955)	Provider Behavior & Actions (283)		quality	Quality of care expectation	32			
			being informed	Was kept updated	42			
			provider cares	Perception that the provider cares about them	55			
			follow through	Provider says they are going to do something they do in a timely fashion	35			
			helps me understand	Someone helped them understand something	60			
			listens	Providers are not acknowledging needs or simply not listening	71			
			not refer around	Being sent from provider to provider or practice to practice	20			
			WANT (955)	Provider Relationship & Process (382)		fairness	Equity/ equally or unequally applied rules/ being treated the same or different	38
						feel comfortable	Provider actions perceived as: comforting, creating a safe environment, calming	42
						safe	Compassion /connected on a human to human level	51
little bit of humanness	Statements about open or the lack of open communication	46						
open communication	Worried about a leak of sensitive information	8						
privacy	Perception of provider's personality experienced thru behavior	67						
provider approach	Awareness of patients needs	92						
sensitive to patients								





WON'T!

274 quotations

Participate – adhere, engage, follow through

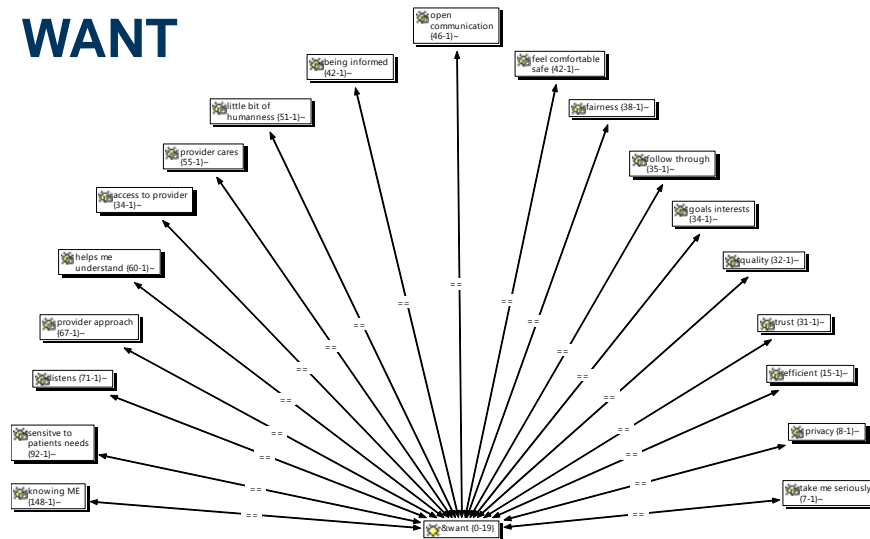
- bureaucracy (27)
- lab rat (7)
- paperwork (15)
- return to provider (86)
- the rules (26)
- the final straw (32)

Tolerate

- angry (5)
- frustrating (24)
- judging me (14)
- treated differently (38)



WANT



WANT

955 quotations

- System Characteristics
- Provider Behavior and Actions (what)
- Provider Relationship and Process (how)
- To Be Known (outcome)

WANT

- System Characteristics
 - access to provider (34)
 - choices (27)
 - efficient (15)
 - quality (32)

WANT

- Provider Behavior and Actions (what)
 - being informed (42)
 - cares (55)
 - follows through (35)
 - helps me understand (60)
 - listens (71)
 - refer around (20)

WANT

- Provider Relationship and Process (how)
 - fairness (38)
 - feels comfortable safe (42)
 - little bit of humanness (51)
 - open communication (46)
 - privacy (8)
 - provider approach (67)
 - sensitive to patients' needs (92)
 - take me seriously (7)
 - trust (31)

WANT

- To Be Known (outcome)
 - knowing **me** (148)
 - goals interests (34)

Exemplar

“I’ve seen it happen too many times, so I don’t accept anything ‘cause I know what I want, I know what I need, and if they try to give me anything other than that, then we have a problem.”

(African-American man with AIDS and hypertension)

Discussion



eSMART

<http://fpb.case.edu/esmart>

(216)368-3067

