

# Engaging African-American Females with Lupus in Community Focus Groups

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## Background



- Lupus significantly impacts African-American females.
- Women comprise 90% of people with lupus and African-American females are 3 times more likely than Caucasian females to acquire the disease.
- An intervention such as the Popular Opinion Leader (POL) model utilizing social networks can be adapted to diffuse messages and start conversations about lupus awareness.

## Research Objective

- To hold focus groups with African-American women using qualitative information about their experiences with lupus to inform the development of the intervention for the POL model.

## Methods

- Focus group methods were used to engage African-American females diagnosed with lupus.
- Participants were recruited by contacting supporters of the Lupus Society of Illinois (LSI) and community stakeholder organizations maintained by Northwestern University's Alliance for Research in Chicagoland Communities (ARCC).
- Data were analyzed using constant comparative methods.

## Results

- Two focus groups were conducted: including females with lupus 18-35 (n=10); and females with lupus 36-75 (n=9).
- Focus group themes identified patient and provider issues.
- Topics discussed included experiences before diagnosis, emotional support needs, work/career, the personal impact of lupus to family networks, and understanding health care options.
- Provider issues included improved healthcare provider training to discuss signs and symptoms of lupus and further communicate with patients as a trusted bearer of information to address concerns.

## Focus Group Responses

### When you first received your diagnosis of lupus, how did you feel? What was your reaction?

*"I went to the emergency room, because my joints on my hands had swollen so my knuckles were black. And I got to the point where I couldn't open a bottle of water. I would get in the tub. I couldn't use my hands to get out. I just had to get on my forearms and stuff to get out. So using my hands, and walking upstairs had gotten virtually nonexistent. So when I finally went to the emergency room, the emergency room doctor looked at me and said, "Go home, take some Tylenol, it'll go away." He didn't even know what it was. So I left."*

### We're going to move onto family reaction. Who wants to share their experiences?

*"I would say my family was physically very supportive. Because this is when I was initially diagnosed. So physically, the family was supportive, initially, but I don't think that they understood. I don't think they did a whole lot of time educating themselves about the disease. So for a long time, I was the knowledge. I was the one that knew about the disease and understood it, in terms of knowledge-wise, education-wise."*

### What is one thing that you wish everyone knew about lupus?

*"It doesn't have to be a death sentence."*

*"It's not easy to diagnose."*

*"Not to judge us by how we look."*

## Limitations

- Small sample size
- Sample sizes for male and caregiver groups were too small to be viable so are not represented in this study

## Conclusions

- The focus groups' findings are informing the development of the Popular Opinion Leader program targeting African-American women.
- Model adaptation is ongoing in Chicago and Boston utilizing focus group findings from participants to address social, emotional, and health support issues.