THE POPULAR OPINION LEADER MODEL AND CLINICAL TRIALS

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Background and Introduction

- Lupus Clinical Trials Program
  - 4 year partnership between health centers and communities to increase lupus awareness

- Use the **Popular Opinion Leader (POL) Model** to Lead Community Education Strategies

- Use **Social Networks** to Educate Communities About Chronic Diseases
Background on Lupus

- Lupus is a **chronic (permanent) inflammatory disease** that can affect any organ of the body
- The causes of lupus are still unknown
- Lupus is not a contagious (like the flu) or hereditary disease (like sickle cell disease)
How Common is Lupus?

- **Prevalence** - a measurement of all individuals affected by a disease at a particular time (Center for Disease Control and Prevention)

- In 2008, the United States had a lupus prevalence of about **161,000 patients with definite lupus** and **322,000 with definite or probable lupus** (Helmick et al., 2008)
How Common is Lupus?

- Different Populations have Different Prevalence Rates for Lupus
  - Blacks (128 people/100,000)
  - American Indians/Alaska Natives (178/100,000 people)
  - Hispanics (90.5/100,000 people)
  - Asians (94.7/100,000 people)
  - All have higher prevalence rates than Whites (47.5/100,000 people)

- Lupus can affect people of any age, race or ethnic origin, and gender identity, and there is no way to prevent lupus
The Popular Opinion Leader (POL) Model

- Popular Opinion Leaders
  - Present in all communities. Usually respected, well-informed, and trusted members of a social group

- The Popular Opinion Leader Model *
  - A community-level intervention designed to influence norms, behaviors, intentions and prompt actions in a specific community

*developed by CDC for community prevention studies
How does a POL Influence Their Community?

- **Social Network** - a set of individuals or organizations who share common interests

- POLs can spread information about health and scientific research through their social networks
How do POLs Help Their Communities?

- By spreading information, POLs help to...
  - Increase **awareness and understanding** of lupus in a community
  - Help lupus patients reach **specialists** to help care for their lupus
  - **Spread positive messages** about science-based research and clinical trials
  - Build **partnerships** between researchers and the surrounding community
How Do POLs Spread Information?

- POLs spread the information they know by speaking with communities, congregations, and their own social networks.
- Participate in round-table discussions or community forums.
- Conduct surveys or ask others about their knowledge of lupus, clinical trials, and healthcare, and spread the information they know.
- Give out fact sheets, info-cards, or other tools as “conversation starters” and to remind people of the information they discussed.
How is a POL’s Success Measured?

- The POL model is often used in partnership with academic centers.
- POL participation in studies is just as valued as professional input.
- POLs record who they’ve spoken with and observations about meetings.
- POL success if measured by the number of people they are able to engage and persuade with the intended message.
- POLs demonstrate their influence by changing health seeking norms, in this case increasing the understanding of lupus clinical trials in their communities.
Summary

- **Popular Opinion Leaders**
  - A trusted person in their community who is able to **spread information** through their social network
  - POLs can help spread information about lupus, clinical trials, and healthcare
  - POLs help strengthen researcher-community partnerships
QUESTIONS?
THANK YOU!
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