

# Special Populations Networks

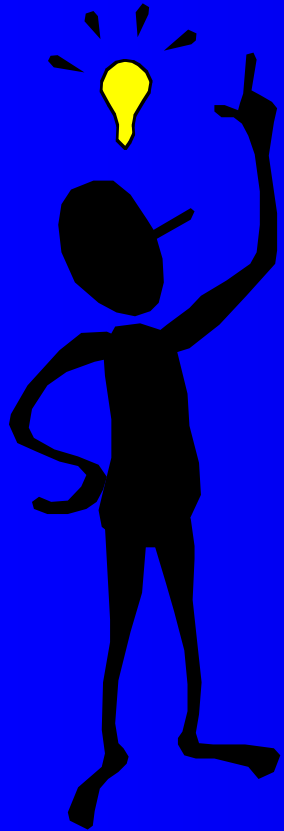
Barriers to Racial/ethnic Minority  
Participation in Medical Research  
A Concept Mapping Project



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# Purpose

- Identify barriers to medical research participation
- Determine the perception of the relative importance of specific barriers
- Examine congruence in perceptions of SPN steering committee members and community partners.
- Highlight specific barriers for different racial/ethnic minority groups.



# Brainstorming

One specific barrier to racial/ethnic minority participation in medical research is ...

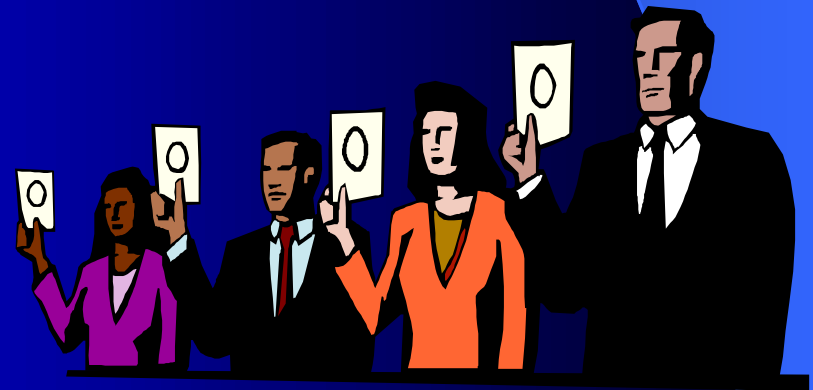


# Sorting

Participants sorted statements into groups based on their similarity.

# Rating

Participants rated statements based on their perceived importance to the research participation of the racial/ethnic minorities represented by their network.



# Data collected

- Network affiliation
- Type of affiliation
- Participant occupation
- Recruitment status of network (actively recruiting/not recruiting)



# Statistical Methods

- Multivariate statistical methods including:
  - Multidimensional scaling
  - Hierarchical cluster analysis

# Participating Networks

<u>Network</u>	<u>Brainstorming</u>	<u>Sorting</u>	<u>Rating</u>
AANCART	X	X	X
Arkansas SPN		X	X
ATECAR	X	X	
CC for AI/AN's	X	X	X
CANIMP	X		X
DSN	X	X	X
East Harlem	X		X
Imi Hale	X	X	X
LACRC	X	X	X
Maryland SPN		X	X
NBLIC	X		X
PICCN	X	X	X
Redes en Accion		X	X
SPN for CC		X	X

# Sample of brainstormed statements

- ...involvement in medical research is perceived as something adverse
- Not enough minorities as PI's or in leadership positions on research teams
- Ulterior motives
- Lack of understanding, knowledge, trust and support among minority communities
- Lack of health care coverage, strong relationship with provider and family support.
- More pressing concerns about day-to-day survival

# SPN Cluster Rating Map

Resources/  
Financial  
Considerations

Physician/Researcher Bias

Research  
System  
Issues

Issues in  
Research Method,  
Design & Mgmt.

Recruitment  
Issues

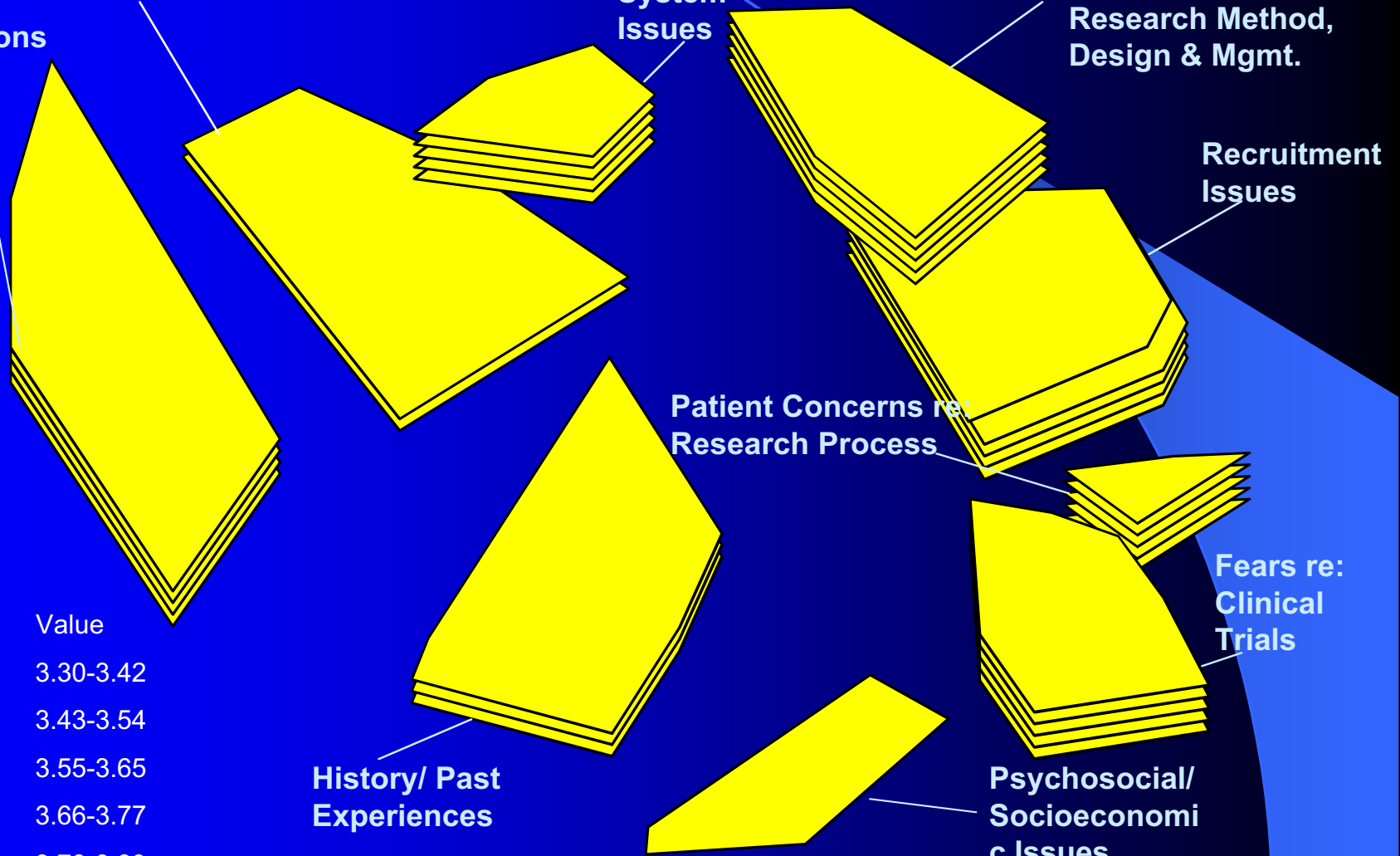
Patient Concerns re:  
Research Process

Fears re:  
Clinical  
Trials

History/ Past  
Experiences

Psychosocial/  
Socioeconomic  
Issues

Layer	Value
1	3.30-3.42
2	3.43-3.54
3	3.55-3.65
4	3.66-3.77
5	3.78-3.89



# Racial/Ethnic Minority barriers to Medical Research Participation

Researcher- Physician

Physician/  
Researcher  
Bias

Issues in Research  
Method, Design & Mgmt.

Research  
System  
Issues

Recruitment Issues

History/Past  
Experiences

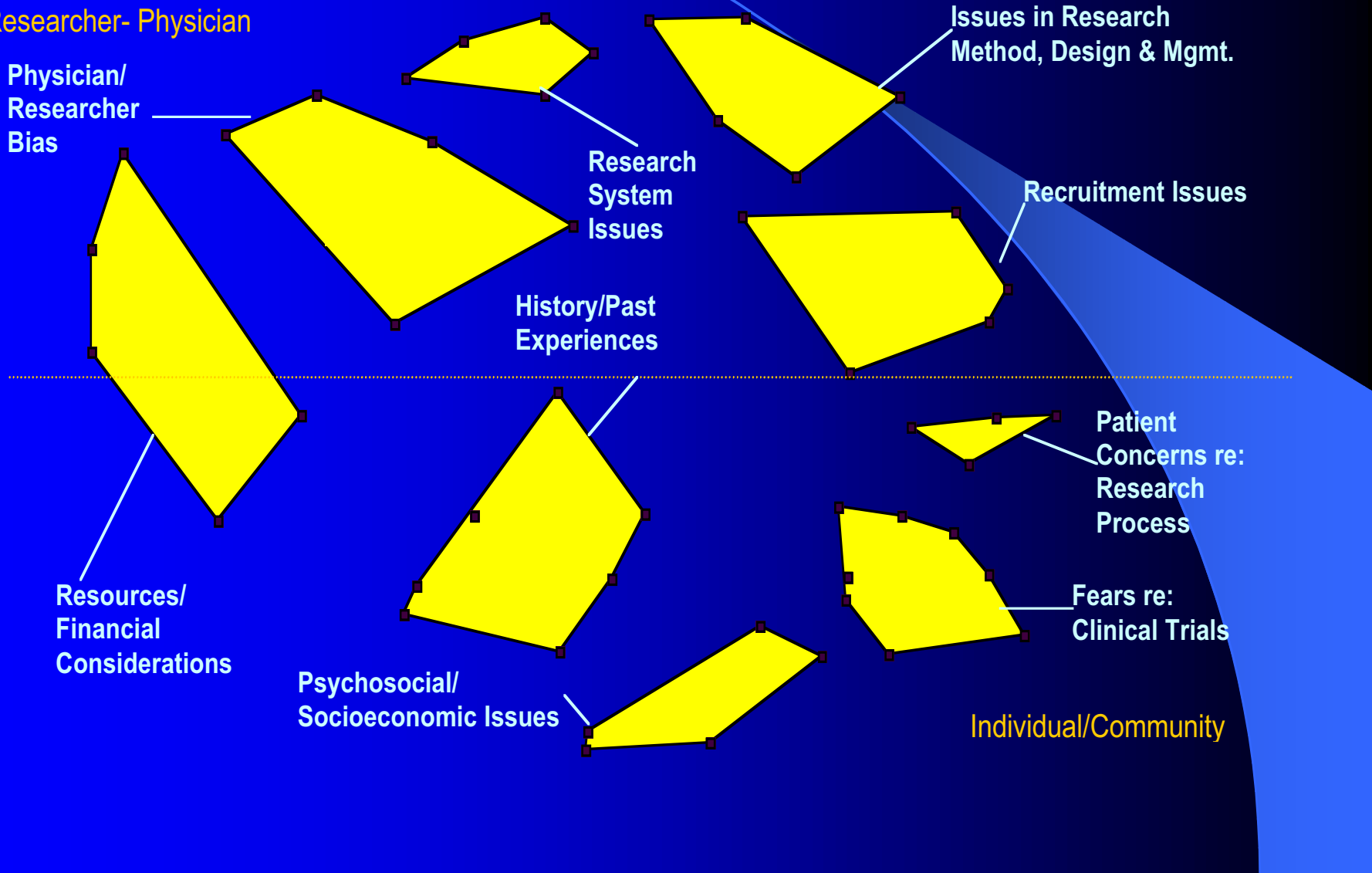
Patient  
Concerns re:  
Research  
Process

Resources/  
Financial  
Considerations

Fears re:  
Clinical Trials

Psychosocial/  
Socioeconomic Issues

Individual/Community





# Congruence by affiliation

<b>SPN advisory and community groups</b>	<b><u>r</u></b>
Community Advisory and Steering Committee	0.89
Community Advisory and Regional Advisory	0.76
Steering Committee and Regional Advisory	0.69
Lay Community and Community Advisory	0.12
Lay Community and Steering Committee	0.11

r= correlation coefficient

# Congruence by occupation

	<u>r</u>
Clinical practitioner, researcher, other HP vs. other	0.72
Clinical practitioner and researcher	0.65
Outreach worker and clinical practitioner	0.29
Lay community member and outreach worker	0.16





# Conclusions

- Barriers deemed most important by the lay community relate directly to the individual.
- Barriers deemed most important by researchers/health profession relate to the research system.
- Data suggest that the perspectives of the community may differ from that of the steering committee.
- Strategies that solely focus on the perspective of steering committees may not target barriers deemed by the community to be important.