Gulf Coast Community Bioethics Dialogue: Methods and Results

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• Establish model for ongoing bioethics dialogue in diverse communities
• Elicit and disseminate stakeholder ethical values regarding patient-centered outcomes research (PCOR)
• Conduct ongoing qualitative assessment of group processes
• Compare the ethical views of different groups
Community Bioethics Dialogues

- Support informed populace
- Sustain over time
- Articulate ethical values
- Inform policy
- Serve as transformative experience
- Reflect "real-life" decision making
- Encourage participation in decision processes


Each group:
- Was invited by their leadership
- Chose their facilitator to lead them through the dialogue
- Developed ground rules for their interaction
- Provided a safe space for discussion
- Selected day/time to meet

Community Bioethics Dialogues
Process

Planning
- Topic selection
- Literature review
- Recruitment

Dialogue Sessions
- Case studies
- Literature
- Independent Research

Draft Final Report
- Rank value statements
- Classify into themes
- Circulate

Review & Approve Report
- Revise
- Vote on approval
- Evaluate process

Disseminate Report
- Finalize
- Distribute/post online

Evaluation & Analysis
- Partnership between organizations and academic team
- Select topic, prepare informational materials, recruit participants
• Six 2-hour meetings
• Assisted by trained facilitator
• Informational materials, independent research and discussion
• Case studies
• Expertise from speakers (added for second round)
• Round I: Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER) – four community groups (two African-American, one Latino, and one White

• Round II: Mental Health and Seniors – two community groups (African-American and White)
Round I Discussion Topics

• Meaning of patient-centeredness
• Ethics of cost containment and health care rationing
• PCOR's impact on patient autonomy and relationship with health care professional
• Involvement of private industry (conflicts of interest)
• Limitation of population-wide research methodologies to address individual cases
Round II Discussion Topics

• Sources of mental health issues for seniors
• Types of brain decline, effects on individuals and families
• Caregiver issues, care options and impact on autonomy
• Medications as sources and treatments for mental health issues
• Issues in society resulting from mental health concerns
• Refine & rank ethical value statements
• Draft, review, and approve report
• Disseminate online and other venues

http://www.utmb.edu/pcor/

Dialogue Reports
• Were conclusions reached independently?
• Did values differ among groups?
• What new ideas emerge?
• Is there a “training effect”?
• How can process be improved?

Evaluation and Analysis
Lessons Learned

• Effective means of engaging populace with health care issues
• Limited Resource Requirements
• Time period: four to eight weeks
• Materials: combination of lay and academic readings targeted to specific group that includes a glossary of terms and short case studies
Lessons Learned

• Limited Resource Requirements
  • Space: comfortable ambiance that is free from temperature extremes and excessive noise
• Facilitator: knowledgeable and ease with diverse ideas
• Compensation: nice, but not necessary
• Challenge: encourage action to apply information
Next Steps

• Publicize results
• Encourage formation of dialogues in other areas
• Compare values among different groups
• Consider other topics for dialogues
PLAY VIDEO HERE!
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