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## 09. Essential elements of design: Partnerships, funding and evaluation

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### Recommended Citation

Gehlert, Sarah, "09. Essential elements of design: Partnerships, funding and evaluation" (2011). *2011 St. Louis OHRP National Research Forum and Community-Engaged Research Conference*. Paper 21 Human Research Protection Office.

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# Essential Elements of Design: Partnerships, Funding, & Evaluation



## Community-Engaged Research: Exploring the Unique Community-Academic Relationship

September 26, 2011

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# Definition of Community-Engaged Research (CEnR)

**A process of inclusive participation in research in which academic researchers and community stakeholders act in concert to create a productive working and learning environment that extends from before a research project begins to after its completion**

# Community & Academic Partnerships & Research Projects

Partnership  
begins



Project #1



Project #2



Project #3



Project #4



What's the problem?

What is the cause?

What is a solution?

How do we do it?

Did it work?

# Categories of Community-Academic Research



# **Benefits of Community & Academic Partnerships**

# Research Process Through Two Lens: The Best of Both Worlds

Community Perspective  Academic Perspective

Step	Community Perspective	Research Perspective
Formulating question & hypotheses	Matches life experiences of community members	Testable by science
Obtaining background info.	Community voices; experiential knowledge	Professional literature
Methods <ul style="list-style-type: none"> <li>• sample</li> <li>• measures</li> <li>• data collection</li> <li>• analysis</li> </ul>	<ul style="list-style-type: none"> <li>• those who know</li> <li>• meaningful to community</li> <li>• culturally appropriate</li> </ul>	<ul style="list-style-type: none"> <li>• objectively obtained to achieve statistical power</li> <li>• psychometrically sound</li> <li>• scientifically rigorous</li> <li>• statistical methods</li> </ul>
Evaluating results	Clinically significant	Statistically significant
Drawing conclusions	Relate to life experiences	Relate to original hypotheses
Disseminating results	Lay media; community presentations	Scientific journals

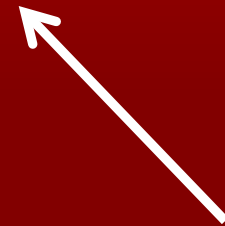
# Goal = Balance Between Community & Academic Perspectives

Community Reality

Academic Rigor



Gives faith that finds  
are translatable



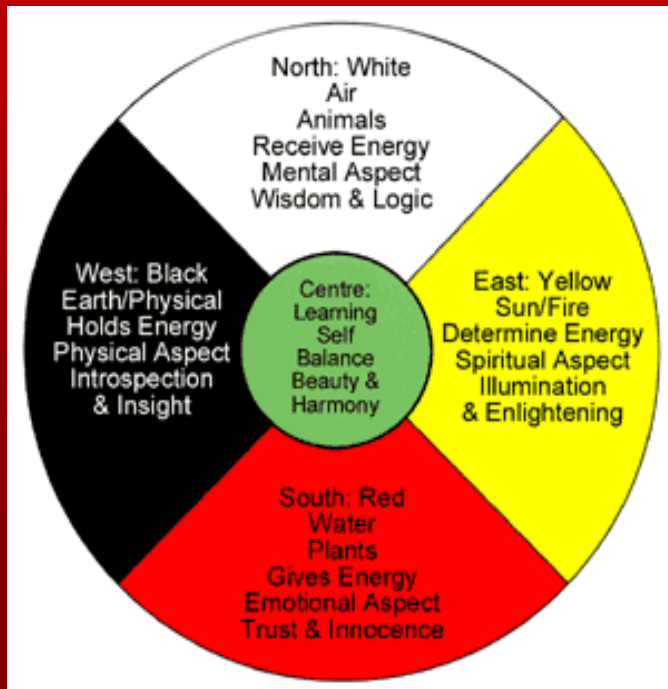
Gives faith that  
findings are real



# Academic Conceptual Schemes or Models

- **Elements in linear form or progression**
- **Time implied from left to right**
- **Focus on cause and effect**

# Community Conceptual Schemes or Models



**Native American Medicine Wheel**

**The goal is to communicate, negotiate, and find a balance between the two perspectives**

# **Establishing Community & Academic Partnerships**

# Engaging Communities

**Determine research questions**



**Define partner appropriate to the question or goal**



**Explore existing partnerships**

**Create new partnerships**



**Focus groups**

**Town hall meetings**

# Who Initiates the Partnership

The ideal is for ideas to originate in communities  
Yet, many projects would not occur without the  
initiative of an academic researcher

It is important for:

- projects to be high on the agendas of communities
- researchers to have the skills & knowledge to ensure that partnerships are balanced & fair so that projects lead to sustainable change

# How Can Academics Get the Interest of Individuals & Organizations?

- **work through existing partnerships with structured groups & broach topic**
- **create partnerships with those who have an interest by virtue of their health status & history**
- **put out “calls” using established community channels (newsletters, AM radio, announcements in churches, community group meetings, etc.)**
- **convey complex material in understandable terms (without oversimplifying it)**

# Mechanisms of Community Engagement

**Focus groups**  
**Community-advisory boards**



**Collaborations/Coalitions/Partnerships**

# Focus Groups

**Research discussion groups conducted by a facilitator or facilitators and designed to create a free-flowing exchange/conversation about one or more issues related to a general topic**

**Usually 10-12 persons**



# Focus Groups

## Advantages

- Interviews can be conducted & data analyzed in a relatively short time
- Interview schedule can be flexible; possible to probe & clarify

## Disadvantages

- Recruiting can be difficult
- Responses may not be completely independent of one another

# Community Advisory Boards

**Groups of community stakeholders representing key constituencies that meet regularly to provide community perspectives, help set research agendas, review research, and advise on issues that arise throughout the research process**

# Community-Advisory Boards

- usually 9-15 persons
- should be those who will evaluate the process and issues fairly and critically
- must meet regularly face-to-face
- need a system of achieving rapid feedback at other times
- should be compensated for time
- should represent the stakeholders of focus re age, gender, religion, SES

# Coalitions/Collaborations/Partnerships

- Longer-term entities
- May span research projects
- Heightens sustainability
- Increase odds of policy change
- Take time to develop

Metropolitan Chicago Breast Cancer Coalition



Illinois Reducing Breast Cancer Disparity Act (PL95-1045)

**Helping to Ensure that Community &  
Academic Partnerships are Equitable**

# Topics & Modes of Communication

- 1. Define as a group what you mean by “equitable partnership” & what it would look like if worked**
- 2. Develop Memoranda of Understanding (MOUs)**
  - Document each partner’s roles in concrete terms, including compensation & milestones for achievement
  - Lay out the decision making process
  - Outline expectations for meeting & communication between face-to-face meetings
- 3. Decide on a process for resolving (inevitable) conflict, including when resolution cannot be achieved internally**

# Cultural Responsibilities of Community and Academic Partners\*

## Community Partner

- Recognize good will & try to excuse well-meaning errors
- Collaborate when collaboration entails parity
- Insist on evoking power & sustainable change as an outcome of partnership
- Learn about the culture of your partner community

## Academic Partner

- Look for & recognize bias when you see it; challenge & educate your colleagues
- Recognize your privilege-how you may have gotten to “third base”
- Ask for help when you need it
- Learn about the culture of your partner community

\*Adapted from Campbell, J.C. et al. (2003).

# **Funding Community & Academic Partnerships**



# How do We Locate and Secure Funding?

## Local opportunities

- **courses on CEnR grant preparation for community stakeholders through CTSA's & other sources**
- **funding opportunities through CTSA's (e.g., Harvard Catalyst)**
- **other local opportunities (e.g., Community/University Health Research Partnerships [St. Louis University, Washington University, BJC HealthCare & the St. Louis Regional Health Commission]; California Breast Cancer Research Program Community Research Collaboration awards)**

# How do We Locate and Secure Funding?

## Federal Opportunities

- 1. Special Emphasis Panels at NIH's Center for Scientific Review (CSR)**
  - Community-Level Health Promotion
  - Health Disparities and Equal Promotion
  - Community Influences on Health Behavior
- 2. R01, R03, R21, P30 mechanisms**
  - NIH
  - CDC
  - AHRQ

# **CEnR Proposals Fail to Survive the Review Process for Two Main Reasons**

**community partnerships are strong, but not written about systematically and scientifically**

**strong scientific projects, but fail to demonstrate community engagement**

# **Evaluating Community & Academic Partnerships**

# Stages & Type of Evaluation

Stage	Type
Planning	
Implementation	Formative; process
Completion	Summative; outcome; impact
Implementation & reporting	

**There is ample evidence that the work of building & maintaining an effective partnership is as important as the work to address the health problem of focus**

# Evaluation Questions by Stage of Partnership

	Types of Evaluation Questions	
Evaluation Stage	Quantitative	Qualitative
Planning	What is the prevalence of the problem?	What are the values of the stakeholders? What are the expectations and goals of participants?
Implementation	How many individuals are participating? What are the changes in performance? How many/what resources are used during implementation?	How are participants experiencing the change? How does the program change the way individuals relate to or feel about each other? To what extent is the intervention culturally or contextually valid?
Outcome	Is there a change in quality of life? Is there a change in biological & health measures? Is there a difference between those who are involved in the intervention & those who are not?	How has the culture changed? What themes underscore the participant's experience? What metaphors describe the change? What are the participant's personal stories? Were there unanticipated benefits?

# Elements for Process Evaluation

- 1. Leadership**
- 2. Community & academic investigators**
- 3. Staff**
- 4. Committees**
  - Appropriateness of function(s)
  - Appropriateness of structure (e.g., membership)
- 5. Internal documents (e.g., meeting minutes)**
- 6. Partnership agreements**
  - MOUs
  - Subawards

# Approaches to Evaluation

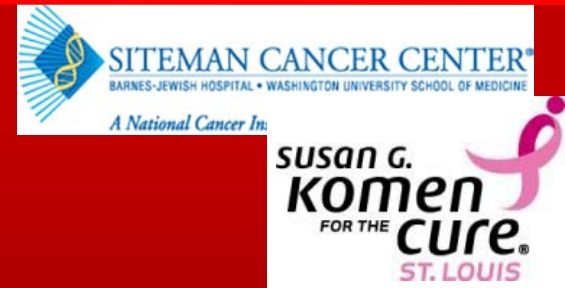
Approach	Description
Traditional	Conducted by outside expert with input from partners
Participatory	Involves key stakeholders in evaluation using multiple methods, perhaps with outside expert as facilitator
Empowerment	Transfers evaluation from an external evaluator to stakeholders; steps include identifying strengths & weaknesses, establishing goals, & developing strategies



# Case Example

## The St. Louis Komen Project

# The St. Louis Komen Project



**CRnR project with four community and one academic partner with the purpose of understanding how gaps in the provision of services of women in North St. Louis contribute to the African-American and white disparity in breast cancer mortality**

# Overarching Mission

**Identify shortfalls or gaps in the breast cancer treatment of African-American women living in North St. Louis City that will help to explain their disproportionate rates of breast cancer mortality compared to white women, with an ultimate goal of remedying these shortfalls or gaps**

# Problem Scheme

Quality of Inter- and intra-organizational referrals (e.g., community clinics to hospitals)



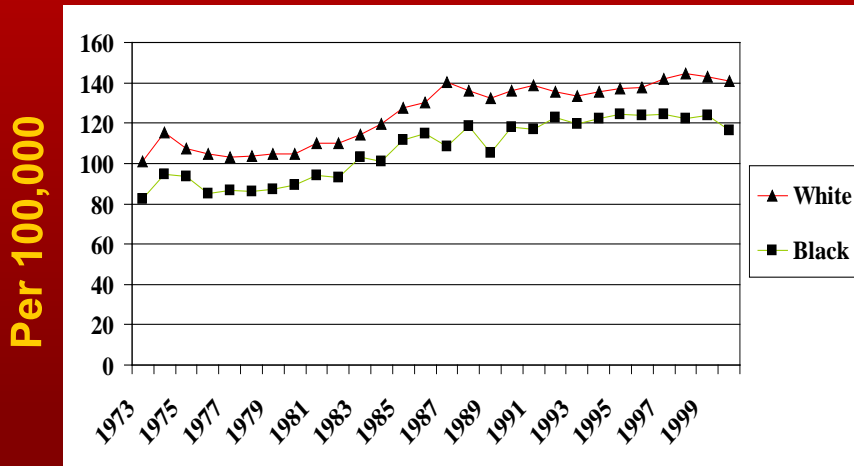
Completion of prescribed breast cancer treatment



African-American & white breast cancer mortality disparity

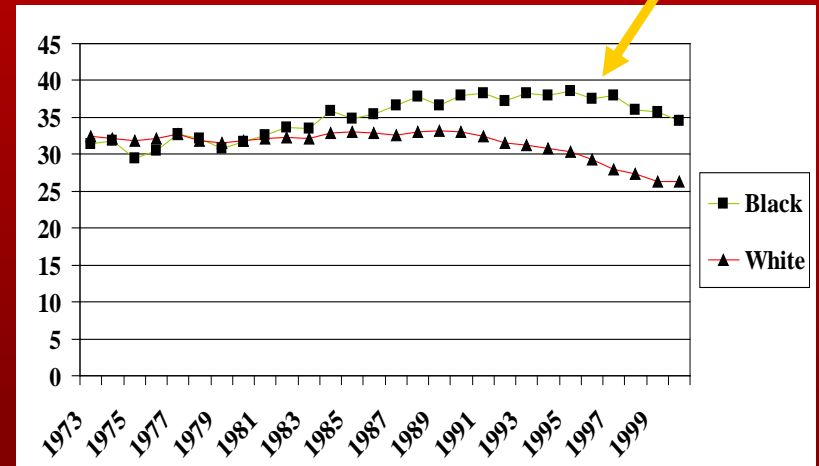
# Black and White Age-Adjusted Breast Cancer Statistics, 1975-2000

## Incidence

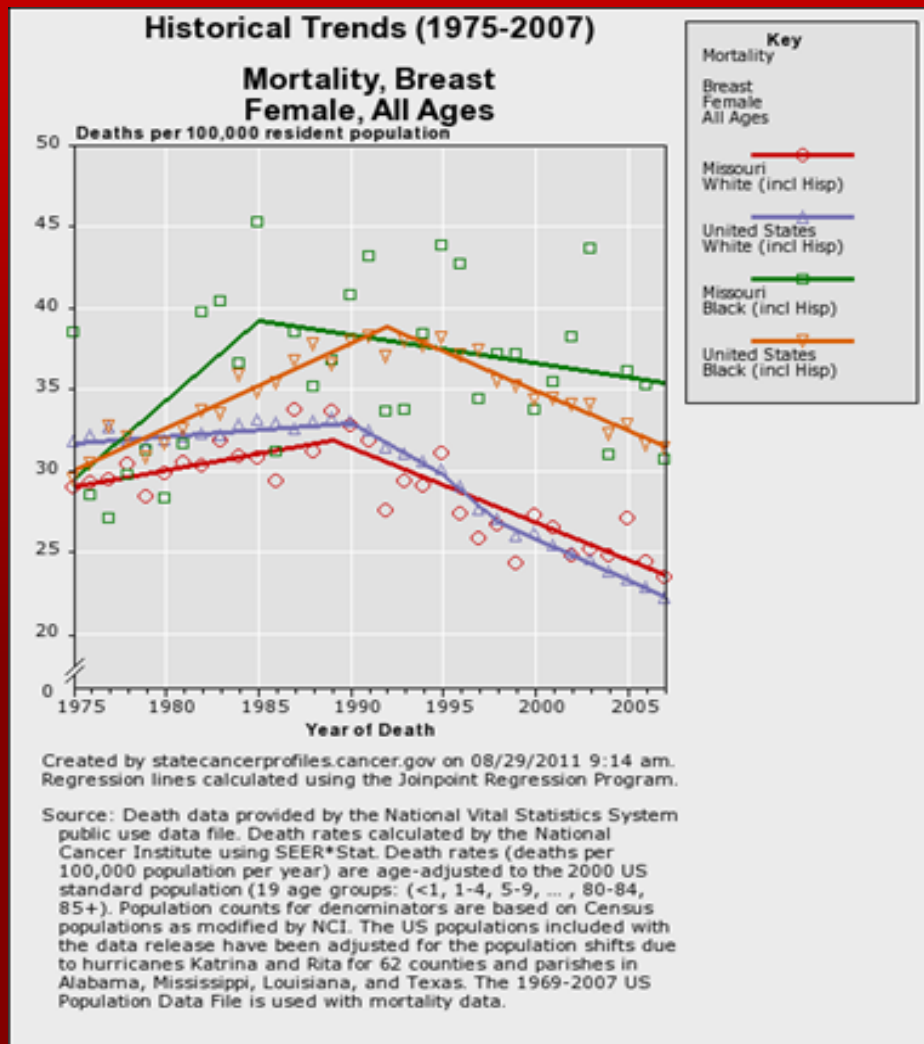


Black women 37% higher

## Mortality



# African-American and White Breast Cancer Mortality, Missouri and US

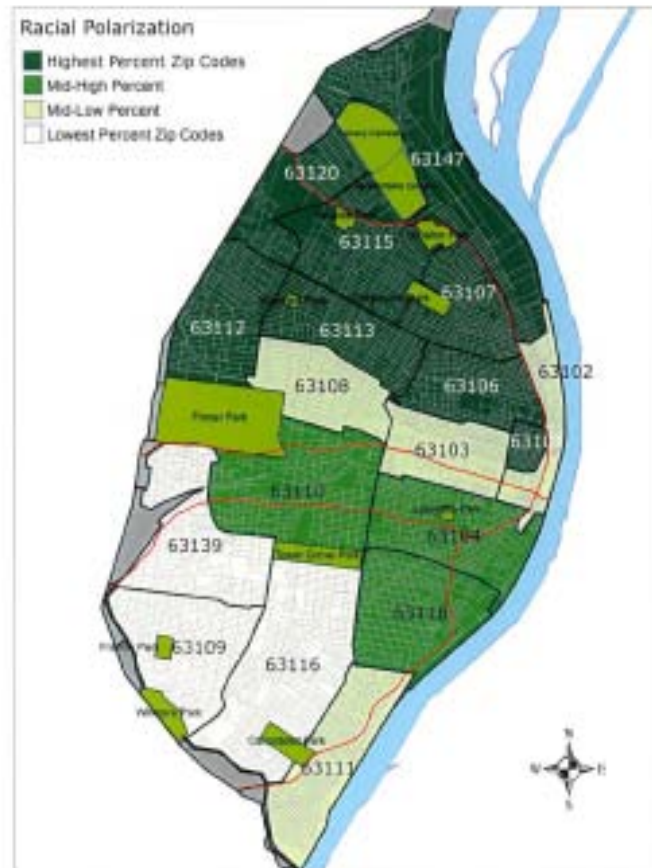


# Racial Polarization by Zip Code, St. Louis City, 2007

% Racial Makeup

ZIP Codes	%Black	%White	%Other	Map Quartile
63115	97.4	0.9	1.7	4
63113	97.2	1.2	1.6	4
63106	93.6	4.4	2.0	4
63120	92.8	5.8	1.5	4
63101	90.3	6.7	1.0	4
63147	89.6	8.9	1.5	4
63107	89.5	8.7	1.9	4
63112	75.6	19.6	4.8	4
63118	57.1	33.9	9.0	3
63104	56.0	40.3	3.7	3
63110	55.0	40.0	5.0	3
63103	45.2	47.8	7.0	2
63102	38.6	55.4	6.0	2
63108	38.2	54.9	6.9	2
63111	29.0	62.6	8.5	2
63116	21.3	68.3	10.4	1
63139	6.7	88.5	4.8	1
63109	3.2	92.9	3.9	1
<b>STL</b>	<b>50.9</b>	<b>43.7</b>	<b>5.4</b>	
<b>MO</b>	<b>11.4</b>	<b>84.0</b>	<b>4.6</b>	
<b>US</b>	<b>12.4</b>	<b>73.3</b>	<b>14.3</b>	

\*Asian, Native Hawaiian and Pacific Islander, American Indian and Alaska Native, two or more races, Hispanic is an ethnicity not a race.



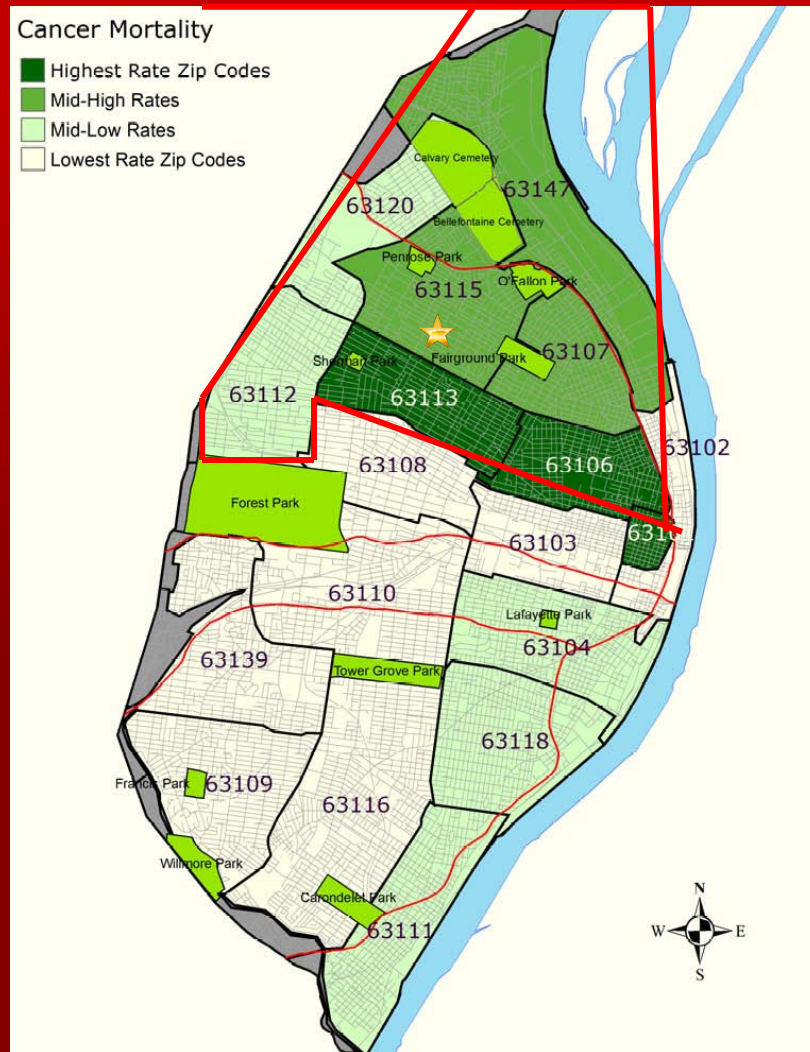
racial polarization

# Breast Cancer Mortality by Zip Code, St., Louis

## Deaths/100,000 Population

Zip Code	Cancer	Map Quartile
63101**	472.3	4
63113	349.9	4
63106	336.4	4
63115	280.2	3
63107	268.2	3
63147	265.2	3
63104	256.8	2
63120	255.7	2
63118	253.7	2
63111	242.6	2
63112	228.4	2
63108	211.8	1
63116	208.4	1
63110	205.0	1
63109	204.5	1
63139	187.4	1
63103	178.8	1
63102**	153.7	1

\*\*small population interpret with caution





# Community & Academic Partners

Partners	Principal Investigator	Partner Type
Betty Jean Kerr People's Health Clinic	Dwayne Butler, CEO	Provider
Christian Hospital	Ron McMillan, President	Provider
Women's Wellness Unit SL Effort for AIDS	Cheryl Oliver, CEO	Organizational
Committed Caring Faith Communities	Rev. Isaac McCullough, President	Organizational
Washington University	Sarah Gehlert, PhD	Academic

# Specific Aims

- 1. Use Missouri Cancer Registry, provider partner data, & outreach to identify women diagnosed with breast cancer living in seven zip codes of North St. Louis, & determine where they were treated**
- 2. Interview African-American women living in the zip codes to determine their breast cancer treatment histories in their own voices**
- 3. Increase trust among residents through a drop in center at 3335 North Union Boulevard, town hall meetings, training in research, & community presentations**

# The St. Louis Komen Project

## Partner Equity

- Monthly partnership meetings that rotate among partners' offices
- Carefully written Memoranda of Understanding
- Written plan for resolving conflict

## Funding

- Each project task delineated & “costed out”
- Partners chose tasks
- Funding for tasks goes to responsible partner

## Evaluation

- Evaluation plan with milestones and deadlines
- Progress discussed at monthly meetings