Participatory research in PBRNs
Lyndee Knox and Don Nease

objectives

• understand the role of participatory methods in PBRN research
• begin to gain a working knowledge of key methods
• brainstorm how participatory methods might inform your own work

why?

• community/patient participation ensures results that are more quickly translatable
• keeps us researchers honest
• changes the trajectory in a meaningful way
• it’s more fun!
We're from the University. We're here to help!

### Trajectory Change

| Idea with community | Planning with community | Grant writing with community | Conduct project in community with community | Data collection with community | Analysis and publication in journal with community with dissemination back to community |

### basic principles

- CBPR
- recognizes community as a vital entity
- builds on strengths and resources within the community
- facilitates collaborative, equitable, and meaningful partnerships (initial phase proposed)
- integrates knowledge and intervention for mutual benefit of all partners
- promotes a disempowering and empowering process that attends to social inequalities
- involves cyclical iterative processes
- addresses health from both positive and ecological perspectives
- disseminates findings and knowledge gained to all partners
- involves long-term commitment by all partners
it’s about relationships

PBRN’s & CBPR

Medical Home is Relationship
LA Net’s experience

LA Net - some lessons learned about CBPR

1. Just because it says “community” doesn’t mean it is “community” --- CBPR is not just about method – it’s about power (and money)(COMR)

2. Timing is important – university timelines and community timelines are not the same – plan to produce quarterly reports on “findings” on issues that matter to community

3. Hard to get tenure on community work – slower process, softer outcomes, less money

Patient-partnered redesign
1. Community councils and advisors are common method for incorporating community – but not always “meaningful”

2. VA very strong commitment to community had vets participate in QI meetings. Provided their input but not meaningful

3. Needed vehicle/method to made their input powerful

Developed new process: Patient- partnered redesign

A. QI coach meets with patient-partner
B. Maps story of recent visit (then what happened and then...)
C. Meet with care team, clinic
D. Map the visit as it was
E. Work together with patient to map the visit as “wished” it were
F. Develop improvement goals from these discussions
Outcomes from this:

1. Meaningful and powerful participation by veterans
2. Teams recognized important role of clerks
3. Customer service training for clerks
4. Greater and escort for people from parking lot & building

Another group: change in 6 month wait time for surgery

Boot Camp Translation
PBRN CBPR - Colorado style!
What is Boot Camp Translation (BCT)?

- A process by which academic researchers and staff and community members partner to translate evidence-based medical information and jargon, and clinical guidelines into concepts, messages, and materials that are locally relevant, meaningful, and engaging to community members.

BCT Steps

Using their local community expertise and research skills, community members and research teams partner to:

1. Evidence - Meet to learn about a topic that is affecting their community.
2. Relevance - Determine the information to pass along to community.
3. Target - Determine patients and community members that need to be reached.
4. Action - Identify what we want people to do.
5. Create - Create messages, materials, and dissemination strategies.

Successful Impact on SMS Care Using a Boot Camp Translation Intervention: A Report From the INSTTEPP Trial

Donald Nease Jr, MD; L. Miriam Dickinson, PhD; Douglas Fernand, MA; David Hahn, MD, MS; Barany Levy, MD, PhD; Matthew Simpson, MD, MPH; Paige BacklundJanisan, MPH; Jeanette Daly, PhD; Katherine Judge, MS(Ed); Lynne Michaels, France Legris, MD, MSc, PhD, CSEM; John Westfall, MD, MPH; L. J. Fagan, MD
Aims

1. Implement the AHRQ SMS Library/Toolkit across four participating networks and 16 practices using Boot Camp Translation in a stepped-wedge design.
2. Assess the impact of implementation on practice staff and patients engaged in chronic care management.
3. Identify the factors related to successful implementation.

Numbers

- 4 PBRN’s (SNOCAP, ORPRN, WREN & IRENE)
- 16 practices
- 320 patients
- > 80 clinicians and staff

Methods

- Stepped wedge design with 5 waves
- BootCamp Translation in each PBRN with patients & practices
- Implementation evaluation:
  - Interviews and observations in each practice x 2
  - Qualitative Comparative Analysis
- Outcomes evaluation:
  - Surveys of patients (PAM & PACIC) and practices (CS-PAM & TPI)
  - Quantitative tests for shifts \\& slope changes in outcome measures
Four networks - Four BCT’s

- Colorado team traveled in March (ORPRN), May (WREN) and July (IRENE)
- 2 days on-site to prep the local team, lead the BCT kick off, debrief and prep for phone calls
- Additionally we coached each team through remainder of their calls
- Colorado kicked off in Sept.
Four SMS tools produced

Data Analysis for Patients: General Linear Mixed Effects Model

- Level 1 model: Repeated measures within each person:
  \[ y_{ij} = \beta_0 + \beta_1 x_{ij} + \epsilon_{ij} \]
  where \( y_{ij} \) is the individual outcome at time \( i \), \( x_{ij} \) is the linear growth rate for person \( i \), and \( \epsilon_{ij} \) is the term that represents the random deviation of observation within person.

- Level 2 model: Individual level model includes intervention status and covariates: \( \beta_1 \). Month of enrollment is included as a covariate to assess for possible temporal trends:
  \[ y_{i} = \beta_0 + \beta_1 x_i + \epsilon_i \]

- Level 3 model: Practice level models:
  \[ y_{ij} = \beta_0 + \beta_1 x_{ij} + \epsilon_{ij} \]

- Level 4 model: Model where \( \epsilon_{ij} \) is a second level random effect (time-varying) to account for differences in linear growth rate for intervention subjects in practice, and the \( \epsilon \) are population random effects.

- Level 5 model: Final level model:
  \[ y_{ij} = \beta_0 + \beta_1 x_{ij} + \epsilon_{ij} \]

- \( \epsilon_{ij} \) is the linear growth rate for controls, and \( \epsilon_{ij} \) represents the between-differences between control and intervention; \( z_{ij} \) is the linear growth rate for controls, and \( z_{ij} \) is the difference in linear growth rate for intervention subjects.

- That is, we hypothesize that improvements in outcomes (i.e., change) will be greater in intervention patients than control patients.

Patient Outcomes - quantitative

<table>
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<tr>
<th>Measure</th>
<th>Survey</th>
<th>Control</th>
<th>Intervention (Baseline)</th>
<th>Intervention (Final)</th>
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<tbody>
<tr>
<td>Patient Activation Measure</td>
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<td>66.72</td>
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<td></td>
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<td>66.86</td>
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<tr>
<td>Process of Care (PROMIS)</td>
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<tr>
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<tr>
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<td>3</td>
<td>30.20</td>
<td>30.32</td>
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<tr>
<td>Self-reported health status (score in better)</td>
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<td>p=0.023</td>
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<tr>
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Adjusted for age, gender, number of chronic conditions, diabetes, chronic pain
how about your ideas?