# Participatory research in PBRNs

Lyndee Knox and Don Nease

## objectives

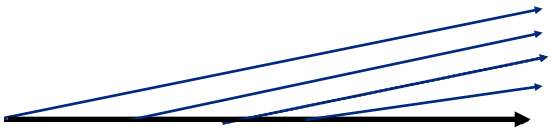
- understand the role of participatory methods in PBRN research
- begin to gain a working knowledge of key methods
- brainstorm how participatory methods might inform your own work

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

Westfall J, Zittleman L. Colorado Immersion Training in Community Engagement. 2011

## basic principles

- CBPR…
  - recognizes community as a unit of identity
  - builds on strengths and resources within the community
  - facilitates collaborative, equitable involvement of all partners in all phases of research
  - integrates knowledge and intervention for mutual benefit of all partners
  - promotes a co-learning and empowering process that attends to social inequalities
  - involves a cyclical and iterative process
  - 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

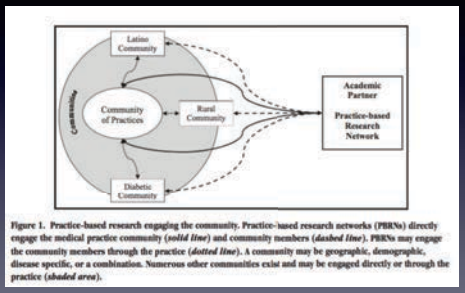
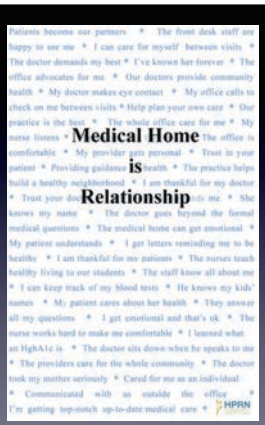



**Figure 1. Practice-based research engaging the community. Practice-based research networks (PBRNs) directly engage the medical practice community (*solid line*) and community members (*dashed line*). PBRNs may engage the community members through the practice (*dotted line*). A community may be geographic, demographic, disease specific, or a combination. Numerous other communities exist and may be engaged directly or through the practice (*shaded area*).**

Westfall JM, Fagnan LJ, Handley M, Salsberg J, McGinnis P, Zittleman LK, et al. Practice-based research is community engagement. J Am Board Fam Med. 2009 Jun;22(4):423–7.



# 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

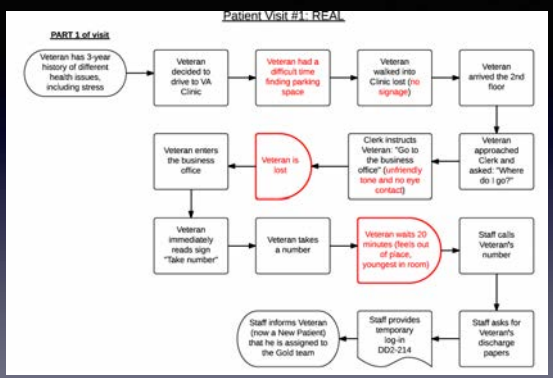
1. Community councils and advisors are common method for incorporating community – but not always “meaningful”

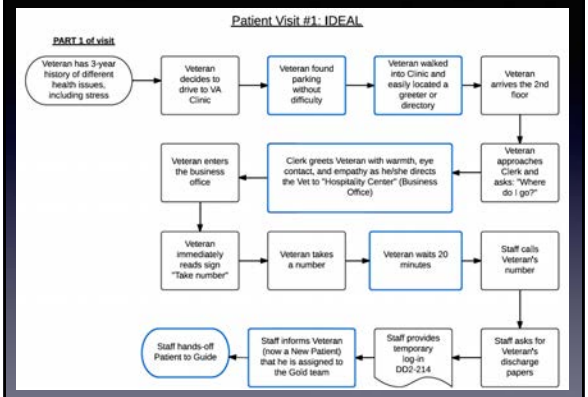
2. VA very strong commitment to community had vets participate in QI meetings. Provided their input but not meaningful

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. Greeter 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.

Meta-LARC

## 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 Fernald, MA; David Hahn, MD, MS; Barcey Levy, MD, PhD; Matthew Simpson, MD, MPH; Paige Backlund Jarquin, MPH; Jeanette Daly, PhD; Katherine Judge, MSSW; LeAnn Michaels; France Legare, MD, MSc, PhD, CCMF; John Westfall, MD, MPH; L.J. Fagnan, MD

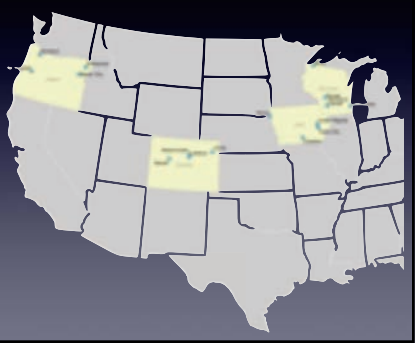
ORPRN PCRC LAVAL SNOCAP IRENE

# 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



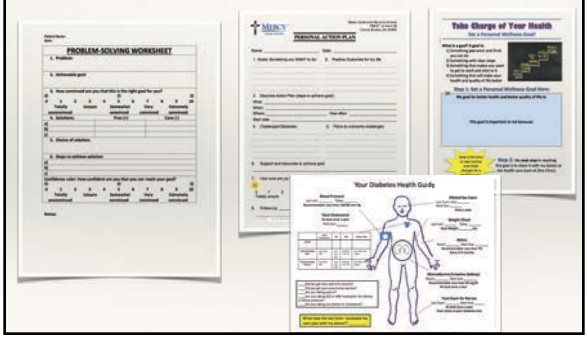
# Methods

- 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 & TPB)
  - 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.
- $Y_{tij} = \pi_{0ij} + \pi_{1ij}(\text{time})_{ij} + \varepsilon_{tij}$
- where $\pi_{0ij}$ is the individual status at time 0, $\pi_{1ij}$ is the linear growth rate for person ij, and $\varepsilon_{tij}$ is the term that represents the random deviation of observation t within person ij
- ***Level 2 model***. Individual level models include intervention status and covariates ($X_j$). Month of enrollment is included as a covariate to assess for possible temporal trends.
- $\pi_{0ij} = \beta_{00j} + \beta_{01}(\text{intervention}) + \beta_{02j}(\text{month}) + \Sigma\beta_{0pj}(X_j) + r_{0ij}$
- $\pi_{1ij} = \beta_{10j} + \beta_{11}(\text{intervention}) + r_{1ij}$
- where $\beta_{00j}$ represents the status of patients with no practice, no baseline covariates and enrollment for control subjects in practice j, $\beta_{11j}$ represents the difference in linear growth rate for intervention subjects in practice j, and the r's are person-level random effects.
- ***Level 3 model.*** Practice level models
- $\beta_{00j} = \gamma_{000} + u_{0j}$ $\beta_{01j} = \gamma_{010}$
- $\beta_{10j} = \gamma_{100}$ $\beta_{11j} = \gamma_{110}$
- where $\gamma_{000}$ is initial status for controls; $\gamma_{010}$ represents the baseline difference between control and intervention; $\gamma_{100}$ is the linear growth rate for controls, and $\gamma_{110}$ is the *difference* in linear growth rate for intervention subjects. The u's are community random effects. Thus, the primary hypothesis of intervention effectiveness can be tested as $H_0: \gamma_{110}=0$ vs $H_\Sigma \gamma_{10}\neq 0$.
- ***That is, we hypothesize that improvement in outcomes (i.e. slope) will be greater in intervention patients than control patients.***

**Thank you Miriam!!!!**

# Patient Outcomes - quantitative

| Measure | Survey | Control | Intervention | Differential Intervention Effect |
|---|---|---|---|---|
| Patient Activation Measure | 1 | 66.72 | 66.07 | F(,840)=0.87, p=.3515 |
| | 2 | 66.79 | 66.72 | |
| | 3 | 66.86 | 67.36 | |
| Process of Care (from PACIC) | 1 | 31.32 | 30.19 | F(1,791)=16.75, p<.0001 |
| | 2 | 30.76 | 31.25 | |
| | 3 | 30.20 | 32.32 | |
| Self-reported health (lower score is better) | 1 | 3.17 | 3.35 | F(1,832)=4.89, p=.0273 |
| | 2 | 3.16 | 3.25 | |
| | 3 | 3.16 | 3.16 | |

Adjusted for age, gender, number of chronic conditions, diabetes, chronic pain

## how about your ideas?