

# Scientific Rigor with Hard to Reach Populations

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## Acknowledgements

- CBCRP funding for our pilot and main study, *Expanding Rural Access: Distance Delivery of Support Groups*
- Community Partners: Mary Anne Kreshka, Rebecca Parsons, Jim Perkins, Susan Ferrier, Kathy Graddy, Speranza Avram
- Research Partners: Kate Collie, Tyson Holmes, Marlene von Friederichs-Fitzwater, Xin-Hua Chen

## Overview

- The challenges and tensions for meeting scientific standards for recruitment in a hard to reach geographic area where recruitment difficulties are an issue.
- Successful strategies for realistically recruiting participants while achieving scientifically meaningful results.



## Evaluating a support group intervention for rural communities delivered via video-conferencing and guided by the content of "One In Eight"



## Our challenges in recruiting women with breast cancer in rural communities

- Vast geographic region (9 counties: Modoc, Plumas, Siskiyou, Shasta, Lassen, Trinity, Sierra, Nevada, and Tehama) covers over 33,000 square miles of rugged terrain (one-fifth of California)
- Isolated towns are connected by two-lane highways that in the winter are often impassable.
- The region is sparsely populated, so it is hard to gain momentum in recruiting.

## Additional recruitment challenges

- Lack of large medical systems through which recruitment can occur: Many women must drive hours to obtain breast cancer treatment.
- Social norms of privacy and self-sufficiency reduce awareness of breast cancer in the community

## Dealing with recruitment challenges demands team effectiveness

- Take concrete steps to build trust and open communications among all partners.
- Schedule regular communications between community and research partners that address different levels of project needs.
- Specify and communicate clear roles and procedures for who does what and when.

## Use multiple modalities to reach out

- Adapt recruitment strategies to local conditions
- Employ the Community Advisory Board
- Allocate grant resources to outreach (role of Co-PI Mary Anne Kreshka as Community Advocate, also role of Local Community Coordinators)
- Build relationships with local health providers
- Tap into local knowledge of telehealth coordinators
- Hold a “kick-off” event
- Publicize via mass media as well as posting flyers



## Tensions between Scientific Standards and Practical Considerations

## The scientific preference to study a very narrowly defined population

### ISSUES: Community Partners and our C.A.B. wanted to include:

- Women with all stages of breast cancer
- Women diagnosed many years ago as well as women very recently diagnosed
- Women who vary in their initial levels of distress

### SOLUTIONS:

- Include all of these women in our study AND:
- Address these issues in our qualitative research
- Explore these issues in our quantitative research
- Explicitly acknowledge these limitations in our publications

## Science's gold standard for control group

### ISSUE:

- Reviewers and Research Partners recommended research designs in which women randomized to a control condition would not receive the support group intervention.
- Community Partners argued that all eligible women in these underserved communities must be offered support groups.

### SOLUTION:

- The study now uses a wait-list comparison condition so that all women will receive the group intervention--half immediately, and the other half relatively soon after.

## Scientific partner's institutional record keeping

### THE ISSUES:

- Research Partners' institution requires all participants in clinical trials to be registered as medical patients at its medical center even if they receive no care there.
- Community Partners felt that if research participants are to be enrolled as patients at the medical center, this should be meaningful and the participants should be fully informed.

## Addressing scientific partner's institutional record keeping policies

- The Community Partners requested a full detailed description of the "rights, responsibilities and privileges" of research participants enrolled as medical patients so that participants could be fully informed.
- The Research Partner's institution decided that given the geographic distances involved, this study will not be required to officially enroll the participants as medical patients.

## Conclusions

To address these challenging issues, we have learned to:

- focus inward and reflect with one another;
- focus outward and be inclusive; and
- be flexible and creative!