CBPR approach to parent involvement in research:
A Latino parent mentor group involved in a PCORI-funded research study.

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Kathleen Thomas, PhD.
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Acknowledge our Partners

• **Mentor parents:** Ms. C. Ayala, C. Martinez, P. Osorio, V. Becerra and Ms. Munoz.

• **Partner clinic – El Futuro:** L Smith, K Siu and staff

• **Research team:** M Martinez, G Stein, L Guzman, C Williams, B Sleath, J Prandoni, A Kulish, A Hoet and J Morrissey

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  – PCORI: The Patient Centered Outcomes Research Institute (AD-12-11-4900)
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Community Based Participatory Research (CBPR)
Community Based **Participatory** Research (CBPR)

- **Active** partnerships from all involved
- Research **initiated** with partners
- Partner’s voice on **design, implementation** and dissemination
- Action taken **during the study**
PCORI VISION

• “Patients and the public have information they can use to make decisions that reflect their desired health outcomes.”

• Fund studies that compare new and/or enhanced interventions to reduce or eliminate disparities in health and healthcare.
PCORI VISION

• Engagement Rubric Tool:

http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf
Padres Efectivos (Parent Activation): Skills Latina Mothers Use to Get Healthcare For Their Children

Principal Investigator
Kathleen Thomas, MPH, PhD

Organization
University of North Carolina Chapel Hill

State
North Carolina

Year Awarded
2013

Funding Announcement
Addressing Disparities

Project Budget
$1,478,811

Project Period
3 years
How are we meeting PCORI expectations?

1. Building an active relationship with our research partners

1. Creating a structure for parent mentoring

1. Using partners’ input to inform study protocols
1. Building an active relationship

• Being invited to our partners’ community
1. Building an active relationship (Cont.)

• Incorporating partners’ ideas during proposal:

Minimize drop-out

Parents learn to be active partners in their child’s therapy
2. Creating a structure for parent mentoring

- **Mentor Parent Group**
  - Parent graduates
  - **Meet at a trusted context**
  - Meet to prepare a PCORI report/presentation
  - Growing group size
  - Thank you notes ($20)
  - Sharing feedback
### 3. Informing study protocols: Recruitment

<table>
<thead>
<tr>
<th>MPG Recommendation</th>
<th>OUR ACTIONS</th>
<th>Contribution to the study</th>
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</thead>
</table>
| Welcome parents in the group **even** if they have missed a meeting or their child is no longer receiving services at the clinic | *Allow parents enough time to find a group  
*Invite them to return to a group even if they had to miss a session  
*Offered ‘En Acion’ group at the end for all parents who wish to attend further | 72% of participants attended at least 3 of 4 group sessions  
3% drop out rate                                                        |
## 3. Informing study protocols: Measures

<table>
<thead>
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<tbody>
<tr>
<td>Include school issues such as lack of communication with teachers</td>
<td>*School activation and Quality of Interaction with Teacher measures added</td>
<td>Preliminary data show promising outcomes</td>
</tr>
<tr>
<td>*Parents new to the system are different</td>
<td>*Identify novice vs. experienced parents</td>
<td>Data collection phase</td>
</tr>
<tr>
<td>*Need to distinguish between self-report (enthusiasm) and actual skills</td>
<td>*Include both self-report PAM and audio-recorded visit qualitative data</td>
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3. Informing study protocols: Methods

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<td>Compare parents fairly!</td>
<td>*Confirmed our statistical approach – DD</td>
<td>Data collection phase</td>
</tr>
<tr>
<td></td>
<td>*Validation of our qualitative measure</td>
<td></td>
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*Confirmed our statistical approach – DD
Lessons Learned

• CBPR has shown our commitment to our partners

• Easier implementation of CBPR for vulnerable families within a ‘trusted context’

• A formal structure to incorporate parent/patient input into study protocols in a timely manner has contributed to their successful implementation
Next Steps

• Dissemination & Evaluation of our findings:
  – Conferences
  – Community Events
  – Encounters at El Futuro (e.g., Schools)

• Address unanswered questions:
  - What are the family characteristics and experiences that support or hinder a mom learning and using activation skills?
  - Do moms begin to teach activation skills to their children?
  - What infrastructure does a clinic like El Futuro need to serve as a broker to hard to reach patients and support participation in on-going research?
Conclusions

A CBPR approach consistently implemented throughout a research study can build on-going channels of communication to support collaboration between patients, service providers and researchers.
Your questions, comments and suggestions are welcome!
PADRES EFECTIVOS
Who are the parents included in February’s report?

- Participants: 32 mothers
- Average family income: $1,207.19
- Average age: Mother → 37 years old and child → 11 years old
- Most mothers (69%) completed 11 years of schooling or less (some high school / upper school)
Health of the children included in February’s report

• According to what mothers reported:
  – Almost half of children (45%) had an excellent or very good physical health
  – Only 22% of children had an excellent or very good mental health
Levels of the Parent Activation Measure (PAM)

Nivel 1  
Does not feel in change of the health care

Nivel 2  
May lack knowledge about treatment options

Nivel 3  
Obtains basic information

Nivel 4  
Have made changes

Increasing level of activation
Mothers’ activation levels at the beginning of the project

- Nivel 1: 31%
- Nivel 2: 22%
- Nivel 3: 34%
- Nivel 4: 13%