“Mag-PCOR Muna Tayo”

Nationwide Capacity Building for Filipino-Americans to Engage In PCOR and CER

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What is PCORI, PCOR, and CER?

- **PCORI** – Patient-Centered Outcomes Research Institute
  - The funding agency for this project
  - “PCORI funds research that offers patients and caregivers the information they need to make important healthcare decisions.”
    - [www.pcori.org](http://www.pcori.org)
- **Eugene Washington Patient Engagement Award**
  - “Engagement program gives patients, caregivers, clinicians, and other healthcare stakeholders opportunities for meaningful involvement in all our activities.”
- **PCOR** – Patient-Centered Outcomes Research
- **CER** – Comparative Effectiveness Research
  - Compare the effectiveness of one treatment against another
Why Filipino-Americans?

- Asians are the fastest growing immigrant populations in the United States (US).
- Filipinos and Filipino-Americans (FAs) represent the third largest Asian group, with about 3.9 million in 2016 (US Census Bureau, 2016).
- FAs have mostly filled labor shortages in agriculture, the military, and nursing (McNamara & Batalova, 2017).
- Prevalence of chronic diseases in this population is alarming.
  - Cardiovascular disease and diabetes is higher in FAs than whites, blacks, and other Asian groups (Bloom & Black, 2016).
  - Compared to other Asian subgroups, FAs have higher rates (27%) of uncontrolled hypertension.
  - Cardiovascular disease and stroke have been identified as the leading causes of mortality (Domingo et al., 2018).
  - Other FA health issues include cancer, dementia, depression, gout, and infectious disease such as tuberculosis.
Why Filipino-Americans

• Attention has to be given to FAs since they are a growing minority population.
• However, limited research exists on their healthcare needs, priorities, and research engagement.
• Most research is limited in key states, i.e., New York, California, and Hawaii (Ursua et al., 2017; Kim et al., 2008).
• However, significant populations of FAs also exist in Illinois, Texas, Washington, New Jersey, Nevada, Florida, and Virginia (US Census Bureau, 2016).
• There needs to more research done in this population, not only in NY, CA, and Hawaii but also in other states where there are significant numbers of FAs.
Aims of the project

• To create a community-based nationwide network of FAPCOR *nayon* (villages) to engage FAs in their healthcare.

• The network will provide the infrastructure for engaging FAs and other key community stakeholders
  • To address the specific needs of FAs so that they can make informed healthcare decisions.
  • To engage in patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) to promote patient outcomes
Short-Term Objectives

• 1) To engage FAs and key stakeholders in productive collaborative discussion of PCOR/CER.
• 2) To identify what FAs need to make highly effective, better-informed healthcare decisions.
• 3) To identify the critical gaps in knowledge and the PCOR/CER priorities among FAs.
• 4) To identify how FAs want to receive their PCOR and CER findings.

- Collaborative Discussions in FA PCOR Nayons in 5 States: HI, CA, TX, NY, and NJ

- Use the Philippine Nurses Association of America (PNAA) infrastructure
Long-Term Objectives

• To develop the PCOR Community Capacity Building and Engagement Toolkit for Filipino-Americans (“Toolkit”).

• This Toolkit will include a communication plan, capacity-building and engagement strategies, and resources based upon identified needs of each of the FAPCOR “nayon.”

• For clinicians and researchers to increase the understanding of what FAs need to make informed healthcare decisions, their potential engagement in PCOR/CER, and how they want to receive PCOR and CER findings.
FA PCOR National Leadership Team

- **FA PCOR National Level**
  - **FA PCOR National Partnership Team** – based at UT Health San Antonio
  - **FA PCOR Consulting Team** – provide advise on specific issues

- **FA PCOR Nayon Leaders** – work collaboratively to recruit, engage and dialogue with the community

- **FA PCOR Academic Research Collaborators (ARCs)**
  - FA nurse scientist who is actively engaged in the Filipino community within their respective state and the PNAA.

- **FA PCOR Patient Advocate Leaders (PALs)**
  - An FA who is an engaged patient advocate actively involved in the FA community within their respective states
Expected Activities by State

• Focus group ("Pulong at sama-sama" or PASS) to take place every other month
• First PASS will have to take place in May, 2019 and every other month thereafter.
• At least one month before the set meeting, the Nayon ARC will contact the UTHSCSA team for the venue.
  • Information needed in order to order the food for the event
• Both ARC and PAL will invite up to 8 key stakeholders to attend the meeting
  • Stakeholders – FA patients, their families, and/or caregivers, healthcare providers, policymakers, and anyone who are engaged in or affects FA health.
  • Key stakeholders will receive a $10 electronic gift card for their participation, and $5 parking reimbursement, where appropriate
Preparation of Activities

• At least one week prior to the meeting, the ARC will prepare an agenda for the meeting. This consists of guide questions to be asked at the meeting – some prepared by the national team. ARC shares the agenda with the PAL.
  • Guide questions will be sent from the National Partnership Team (NPT)

• The ARC also prepares other documents for the meeting
  • Sign-in sheet – will be sent to all ARCs from NPT
  • Consent statement - will sent to all ARCs from NPT.

• The ARC will receive confirmation from NPT with regards to food for the meeting.

• The PAL will be the main spokesperson for the nayon and will engage and encourage community participation to meetings and activities.
Day of PASS

- Each attendee will be welcomed by ARC and PAL and asked to sign-in
  - To get their electronic gift card and parking reimbursement (where appropriate), each attendee has to provide their e-mail address because
  - Gift card is sent by e-mail
- The PAL reads the consent template and leads the meeting.
  - Plenty of time is provided for discussion but make sure that it also flows, and participated by everyone.
- The ARC takes notes of the meeting.
  - It is important to have statements as said by the stakeholders so that we truly represent them.
After the PASS

- After the PASS, the ARC must send the sign-in sheet to the NPT (Fil.Am.PCOR@gmail.com) within 48 hours after the meeting.
  - This ensures that the attendees will receive timely compensation.
  - A scanned copy or a legible photograph of the sign-in sheet is acceptable.
- The ARC is expected to send the field notes of the meeting within two weeks after the PASS.
  - Template of field notes will be sent to the ARCs from the NPT.
  - A training videoconference on field notes will be conducted in April.
Other Activities

- Website development - NPT
- Quarterly Meeting – NPT, Consultants, ARCs, and PALs
- Planning Meetings - NPT, Consultants, ARCs, and PALs
- Reports to PCOR – every 6 months
- Literature reviews – topic decided by nayon; review conducted by NPT
- *Nayon* visits – by the Dr. Lapiz-Bluhm
- *Pinoy PCOR Balita* – newsletter to all *nayons* highlighting activities, individuals, etc. – by NPT
- FA PCOR Retreat – at the end of the Year 1/early Year 2 – organized by NPT for all
- Creation of the *Nayon* State Advisory Committee – PALs and ARCs
- FA PCOR Toolkit – final deliverable to PCOR - NPT
Compensation

- Consultants, ARCs, PALs will be paid for their time.
  - Very limited budget
  - Dr. Bluhm will communicate to each group their expected amount
- Please make sure that your e-mail is correct because we will be sending the forms to you to arrange for the payment.
  - Will probably be paid every 6 months or yearly, depending on UTHSCSA’s accounting instructions.