Closing the circle between research and the community

Abel Kho MD, MS

November 1, 2017
1,000 persons

800 report symptoms

327 consider seeking medical care

217 visit a physician’s office (113 visit a primary care physician’s office)

65 visit a complementary or alternative medical care provider

21 visit a hospital outpatient clinic

14 receive home health care

13 visit an emergency department

8 are hospitalized

< 1 is hospitalized in an academic medical center
1000 persons

248 visit a physician’s office
27 are seen in an outpatient clinic
16 are seen in the ED
13 have a home health visit
7 are hospitalized

248 visit a physician’s office
205 are captured by any EHR
184 are captured by a certified EHR
129 are able to exchange secure message with physicians
116 are able to view, download, or transmit their own health information
104 can have their PHI shared with other providers
67 can have their PHI shared with hospitals

23 visit an inpatient setting (ED + Hospitalizations)
22 are captured by a certified EHR
16 can have their PHI shared with any provider
14 can have their PHI shared with ambulatory provider
12 can have their PHI shared with other hospitals
## EHR data fragmented across institutions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Non Deduplicated</th>
<th>Deduplicated</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diabetes (Type II only)</strong></td>
<td>n=135,779</td>
<td>n=103,177 24.0% reduction</td>
</tr>
<tr>
<td><strong>Asthma</strong></td>
<td>n=110,640</td>
<td>n=79,563 28.0% reduction</td>
</tr>
<tr>
<td><strong>Myocardial Infarction</strong></td>
<td>n=6,049</td>
<td>n=5,384 10.9% reduction</td>
</tr>
</tbody>
</table>

A RESEARCH ENGAGEMENT PROGRAM TO TRAIN FAITH BASED AMBASSADORS IN THE SKILLS OF SURVEYING THEIR COMMUNITIES FOR HEALTH AND WELL-BEING TOPICS FOR RESEARCH

Bishop Simon Gordon, Chairman
Rev. Walter Turner, Co-Chairman
Dr. Paris Davis, MBA, PhD, ED, PI
Dr. Rebecca Johnson, PhD, Co-PI, Instructor
Dr. Diana Ingram, PhD, Co-PI; Regina Greer-Smith, MPH, Co-PI
What is Pastors4PCOR (P4P)?

“A partnership of *faith-based communities, health researchers, and other stakeholders working together to create a survey skills training program for faith based community members supporting health and well-being.”

Word of the Day: #4 and #5

*“A faith-based community* is driven by a group of people of faith who share a common interest relating to spiritual, social, and/or cultural matters within the areas that they serve and live. *pdd 8/16*

“A church, also known as a faith-based entity, is generally a legally structured organization driven by a group of people of similar faith to meet a specific purpose within its community.” (aka - Organism) *pdd 10/05*
Who We Are

Program Trainers and Content Developers:

Regina Greer Smith email: healthcareresearch@sbcglobal.net
Dr. Rebecca Johnson email: rebecca.johnson@northwestern.edu
Dr. Diana Ingram email: dlynn210@yahoo.com
Dr. Paris Davis email: drpdavis77@gmail.com

Chairman: Bishop Simon Gordon
Guiding principles of P4P ...

- Being Informed
- Having Respect for lived experience
- [http://www.pcori.org/funding-opportunities/what-we-mean-engagement](http://www.pcori.org/funding-opportunities/what-we-mean-engagement)
- Trust

• **Working together** on issues that matter to all partners
Research engagement study participation

**Informed Consent** = making sure **everyone** knows what the study is about and understanding they can withdraw at any time

**Confidentiality** = requires a clear explanation of how data sharing will be respected and processed
When engaging people you know in research or research related studies, special considerations for ensuring voluntariness are needed. Personal and professional relationships can affect people’s perceptions of their true ability to say “no.” In so many other areas of life, there are consequences for saying “no.” But there should not be such consequences in research engagement.

- What are some of the reasons someone might find it hard to say no to taking part in our study?
- What are the ways to ensure people participate voluntarily?
Voluntariness

Ensuring Voluntariness

- Participants should not be:
- Pressured
- Made to feel bad
- Threatened (with loss of services, for example)
- Offered lots of money to do risky things

Source: http://ccts.uic.edu/content/ccts-resources
About You

<table>
<thead>
<tr>
<th>GENDER</th>
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<tbody>
<tr>
<td></td>
<td>male</td>
<td>female</td>
</tr>
<tr>
<td></td>
<td>80%</td>
<td>20%</td>
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<table>
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<tr>
<th>EDUCATION</th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>college or higher</td>
<td>some college</td>
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<tr>
<td></td>
<td>75%</td>
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<tr>
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<th>21-30</th>
<th>31-40</th>
<th>41-50</th>
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<td>4</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>1</td>
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</table>
Your Church

CHURCH SIZE

CHURCH DISTRIBUTION
Technology and Social Media

[Bar chart showing technology use by individuals and all churches.]

TECHNOLOGY USE

- Internet
- Smart phone
- Email
- Facebook
- Twitter
- Do not use

You vs. All churches
Question 1: What are the prevalent health conditions in your faith based community?

Chart shows 20% responses or higher
Question 2: Which condition would you like to learn more about from researchers?

Chart shows responses of 25 or more
Question 3: Which health related factors should faith based communities focus on?

Chart shows responses of 20% or higher.
Question 4: Health factors faith based communities should focus on first

In your opinion where should we start?
90% of participants agreed or strongly agreed that they are able to describe PCOR projects in Illinois;

100% that they understand the components of a PCOR questions

100% that they understand the rules and regulations protecting community members.

100% also agreed or strongly agreed that they understood the steps needed to take the survey into the community.
Pledging to address a Health Condition Priority

Pastors4PCOR Priority Health Year

- **January**: Mental Health Awareness Month
- **February**: Nutritional Month
- **March**: Men’s Health Awareness Month
- **April**: National Public Health Week
- **May**: National Childhood Obesity Awareness Month
- **June**: Wear Blue
- **July**: Summer Wellness
- **August**: National Health Center Week
- **September**: Every Body Walk!
- **October**: American Diabetes Month
- **November**: World AIDS Day

The image depicts a calendar-like chart with various health awareness months and campaigns for the year.
Use Case

Adaptable
The Aspirin Study

pcornet
The National Patient-Centered Clinical Research Network

CAPriCORN

7ADAPTABLE, http://theaspirinstudy.org
Community-Based Recruitment Workflow

Adaptable
The Aspirin Study

Community Organizations

De-identified Hashing Output
"Golden Ticket" Assignment If Match
Community Participant Uses "Golden Ticket" for Portal Access & Follow-Up

CAPriCORN Data Hub/Honest Broker (conducts linkage)

De-identified Hashed Data

Follow-Up Queries Sent for Participant Clinical Health Information

CAPriCORN Participating Sites in ADAPTABLE

Clinical Trial Hub/Patient Portal

MRMIA

PCORnet

Northwestern Medicine
Feinberg School of Medicine

CHiP CENTER FOR HEALTH INFORMATION PARTNERSHIPS

Duke Clinical Research Institute
From Thought Leadership to Clinical Practice

mytrus
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Contact and further information
Dr. Paris Davis, Executive Director, Total Resource Development Community Organization
drdavis77@gmail.com