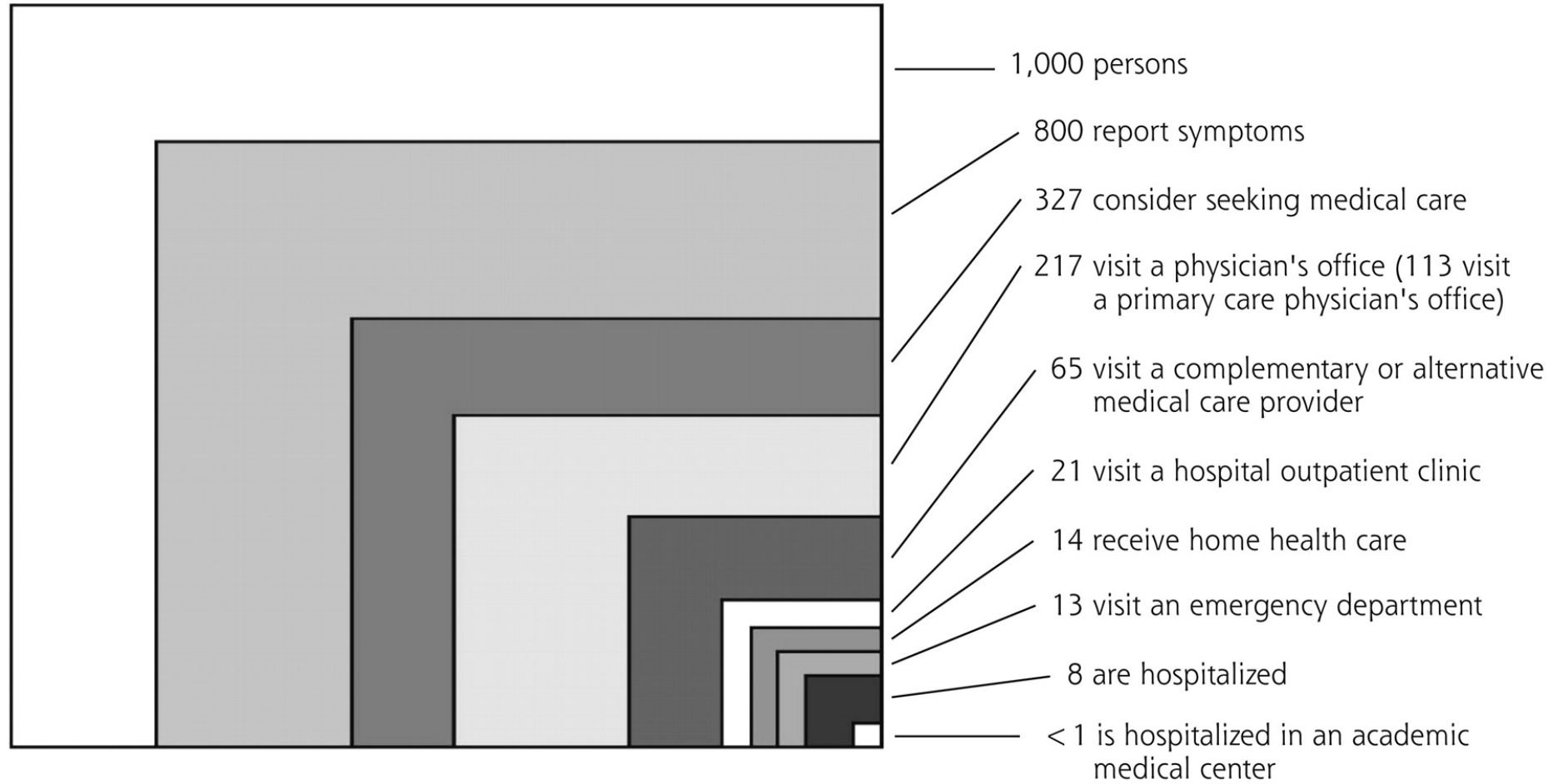


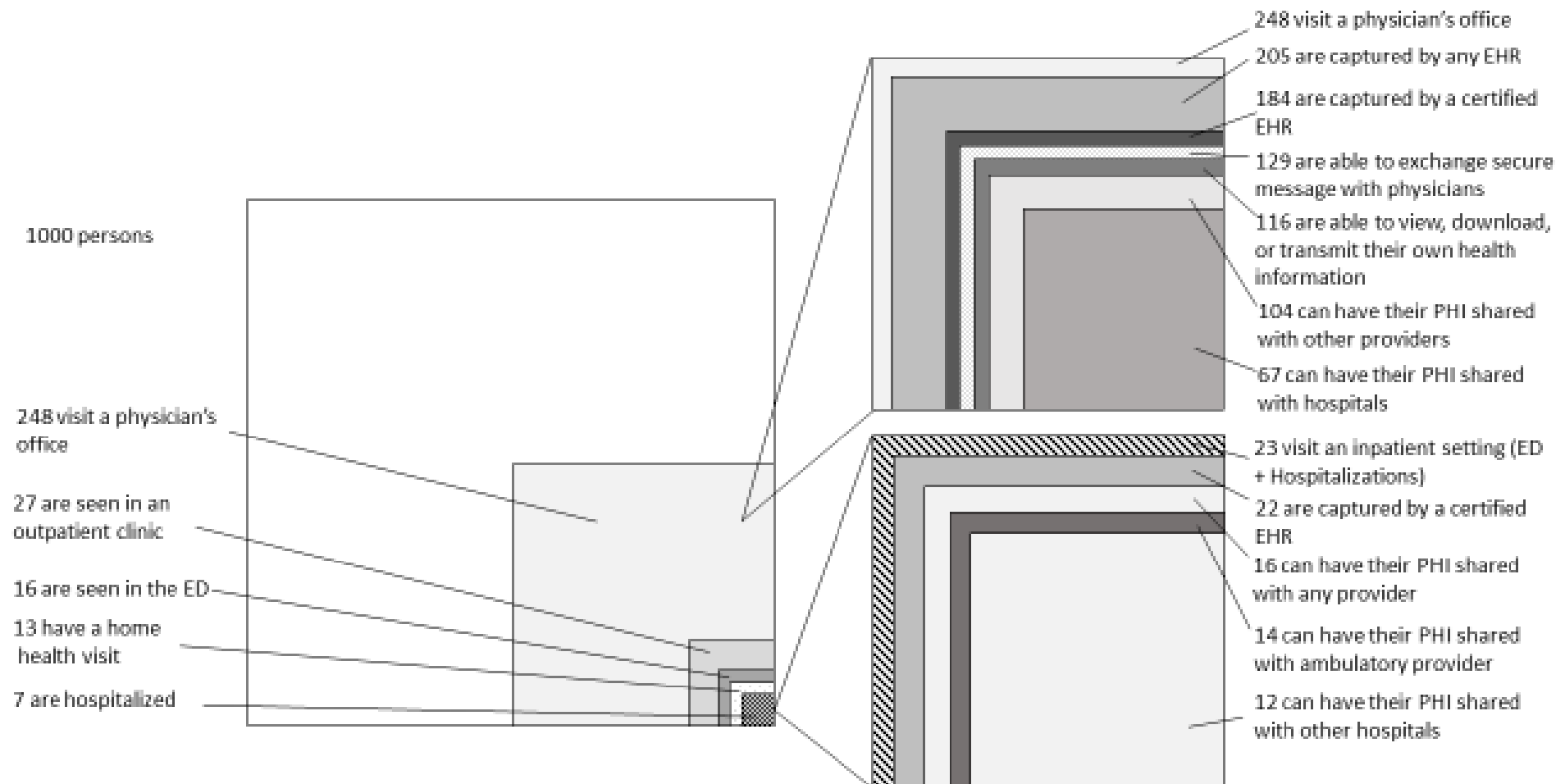
Closing the circle between research and the community

Abel Kho MD, MS

November 1, 2017

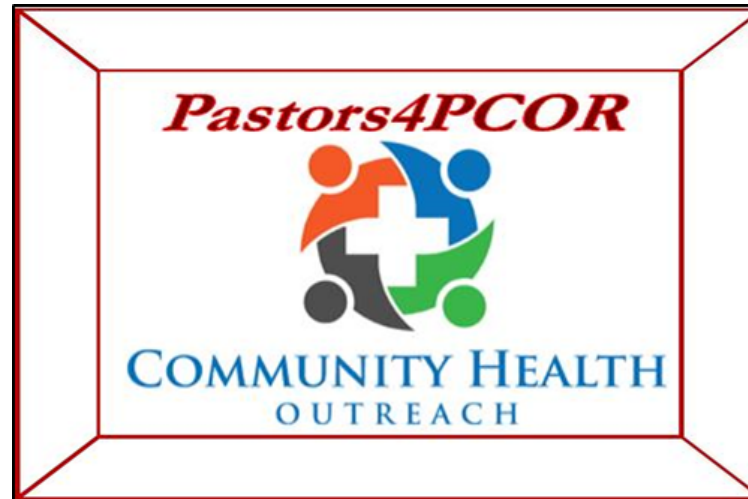


Green et al, The Ecology of Medical Care
Revisited. NEJM 2001



EHR data fragmented across institutions

	Non Deduplicated	Deduplicated
Diabetes (Type II only)	n=135,779	n=103,177 24.0% reduction
Asthma	n=110,640	n=79,563 28.0% reduction
Myocardial Infarction	n=6,049	n=5,384 10.9% reduction



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

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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>
- 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

Voluntariness

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

CONSENT

NESS

el like they can

0).

participate or

ing in research.

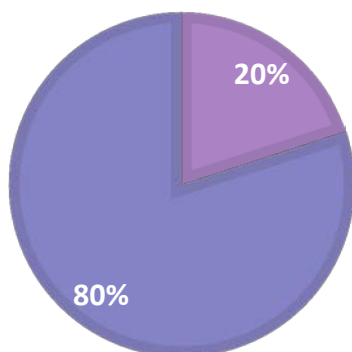
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Source: <http://ccts.uic.edu/content/ccts-resources>

About You

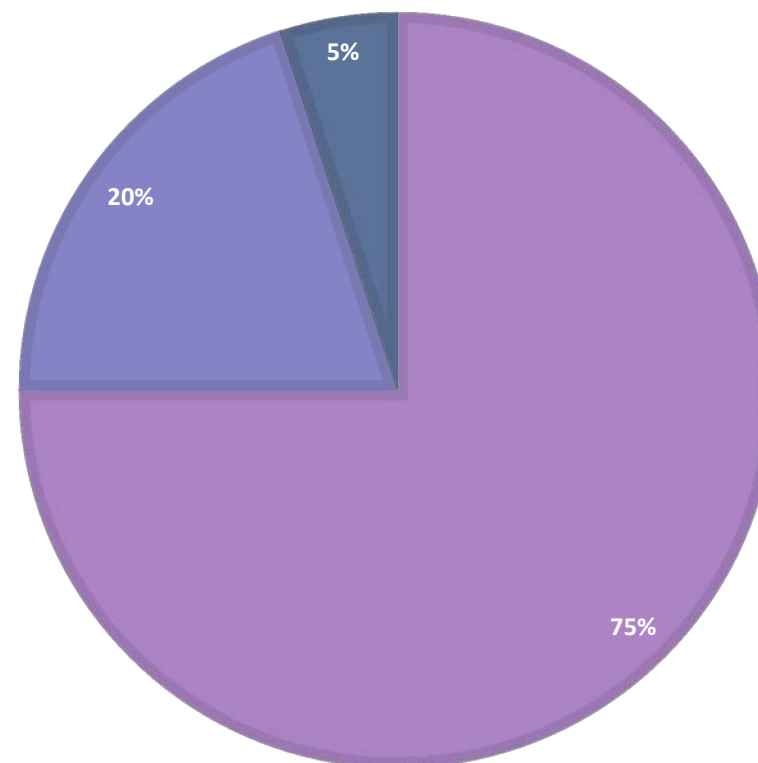
GENDER

■ male ■ female

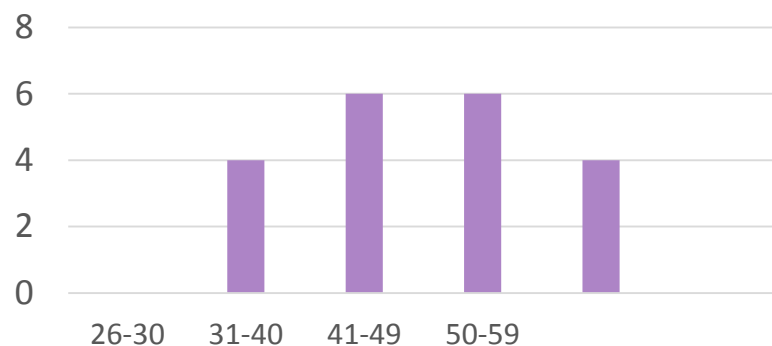


EDUCATION

■ college or higher ■ some college ■ Missing

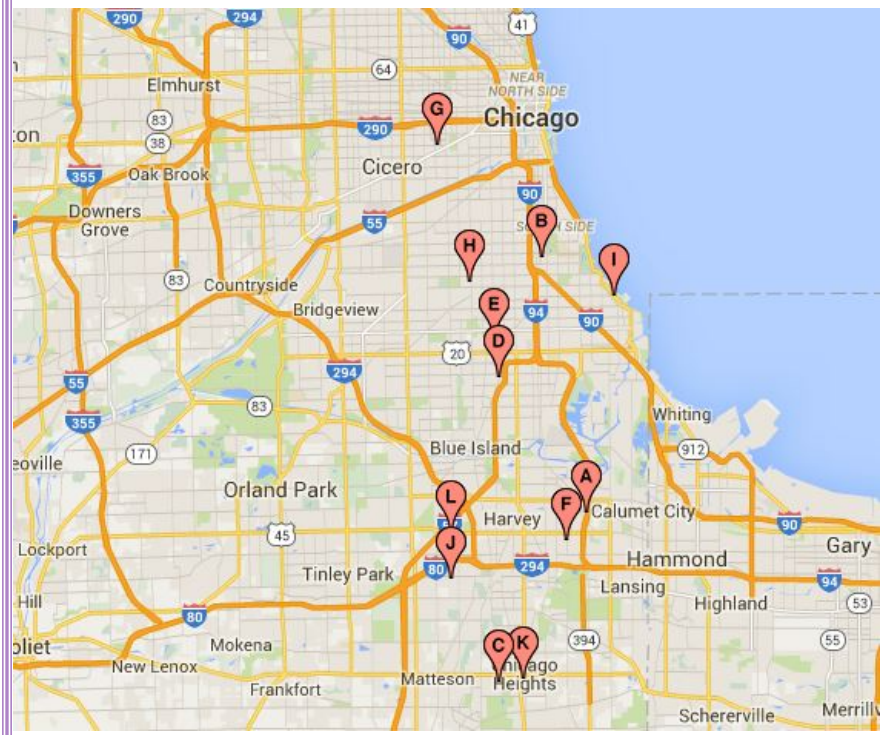
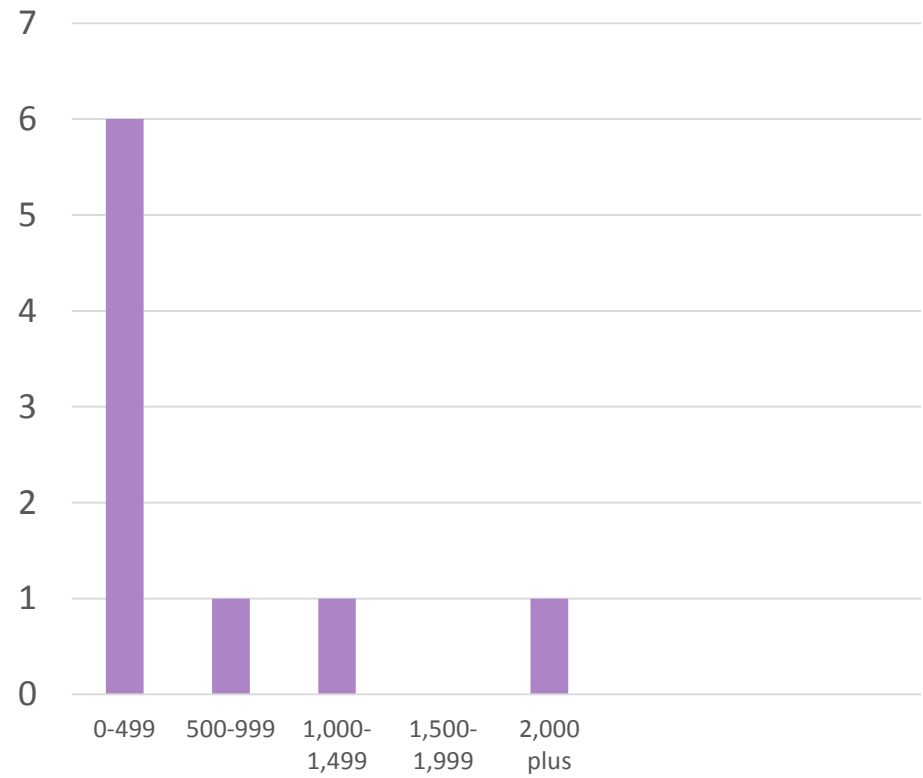


AGE



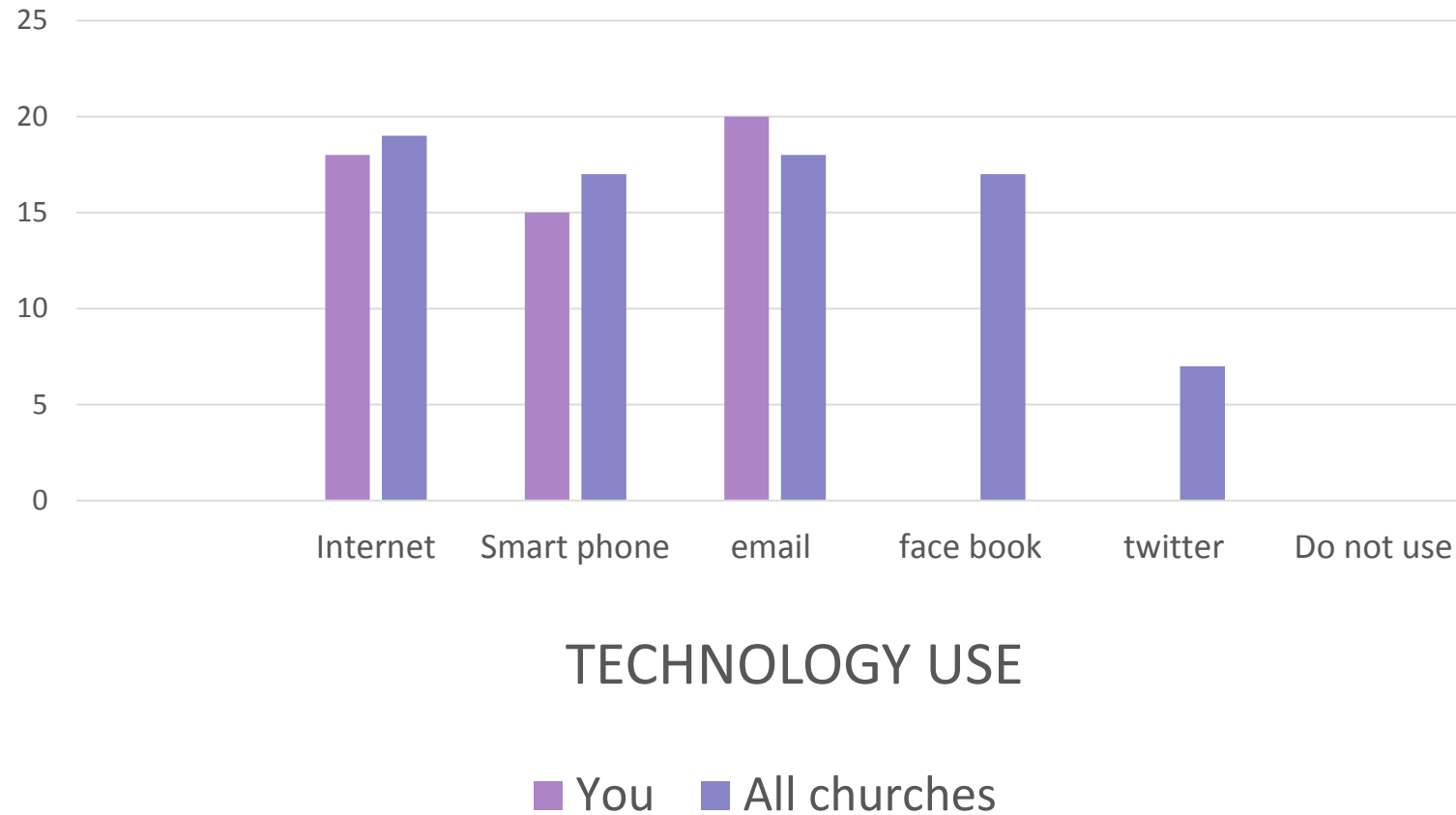
Your Church

CHURCH SIZE



CHURCH DISTRIBUTION

Technology and Social Media



Question 1: What are the prevalent health conditions in your faith based community?

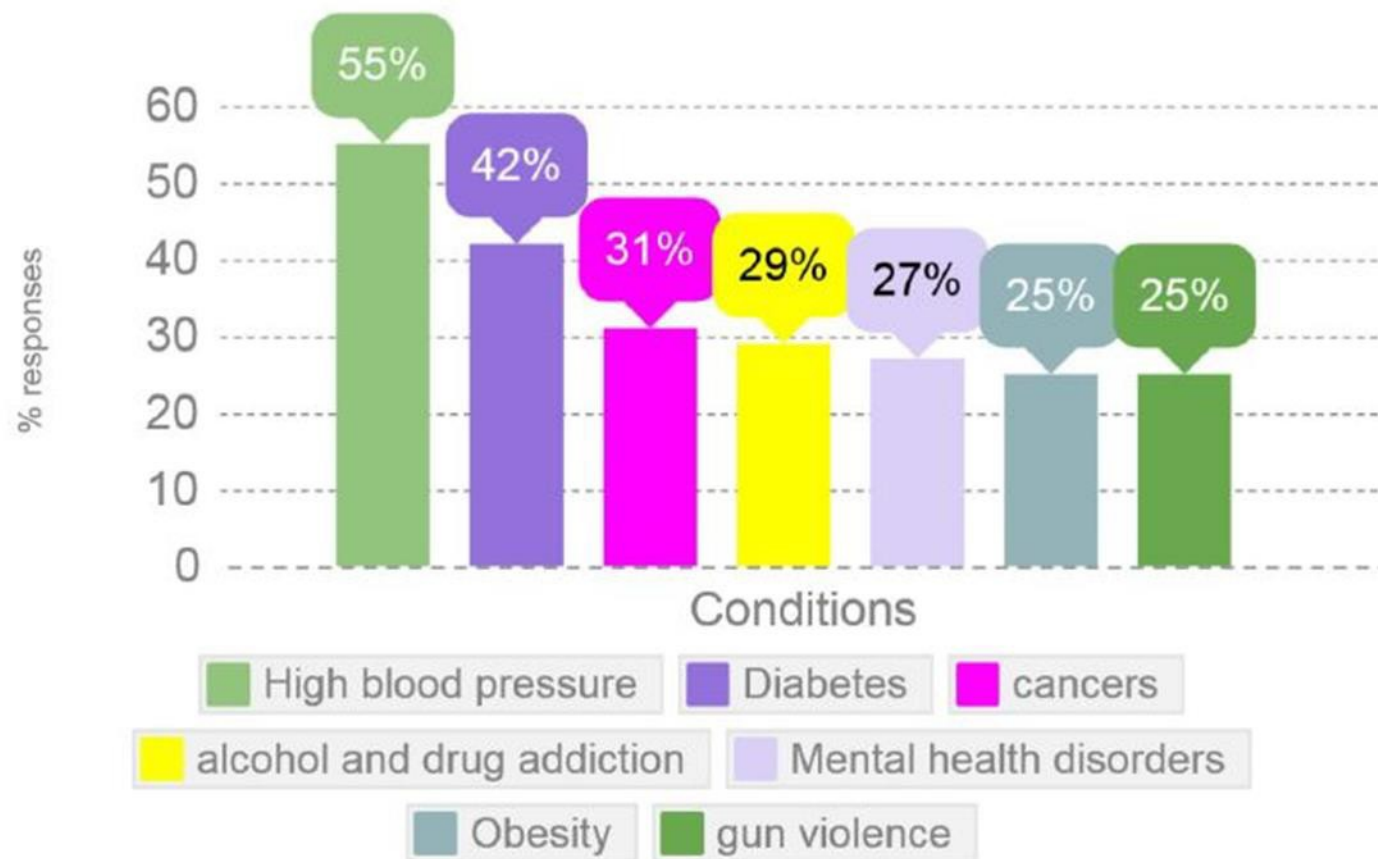


Chart shows 20% responses or higher

Question 2: Which condition would you like to learn more about from researchers?

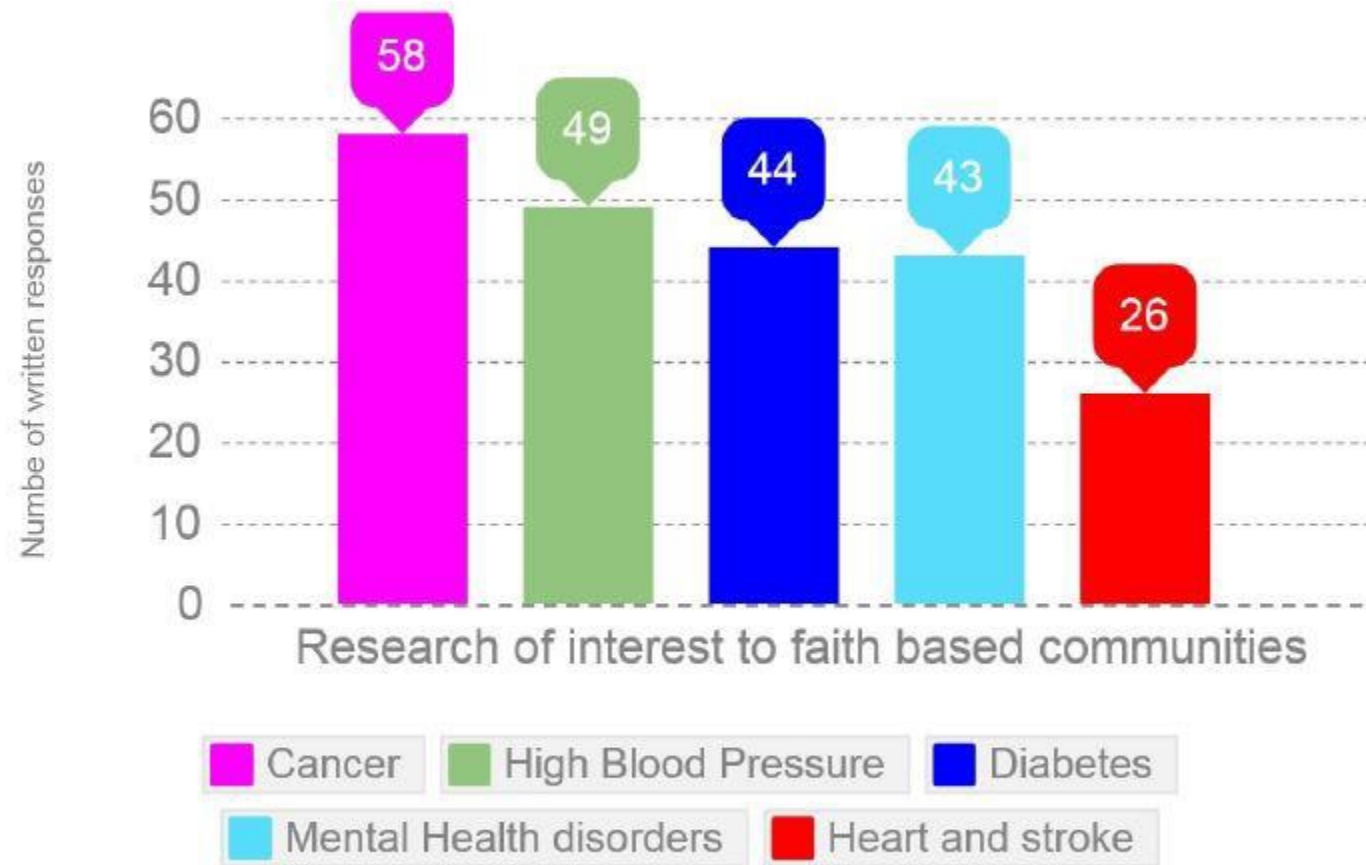


Chart shows responses of 25 or more

Question 3: Which health related factors should faith based communities focus on?

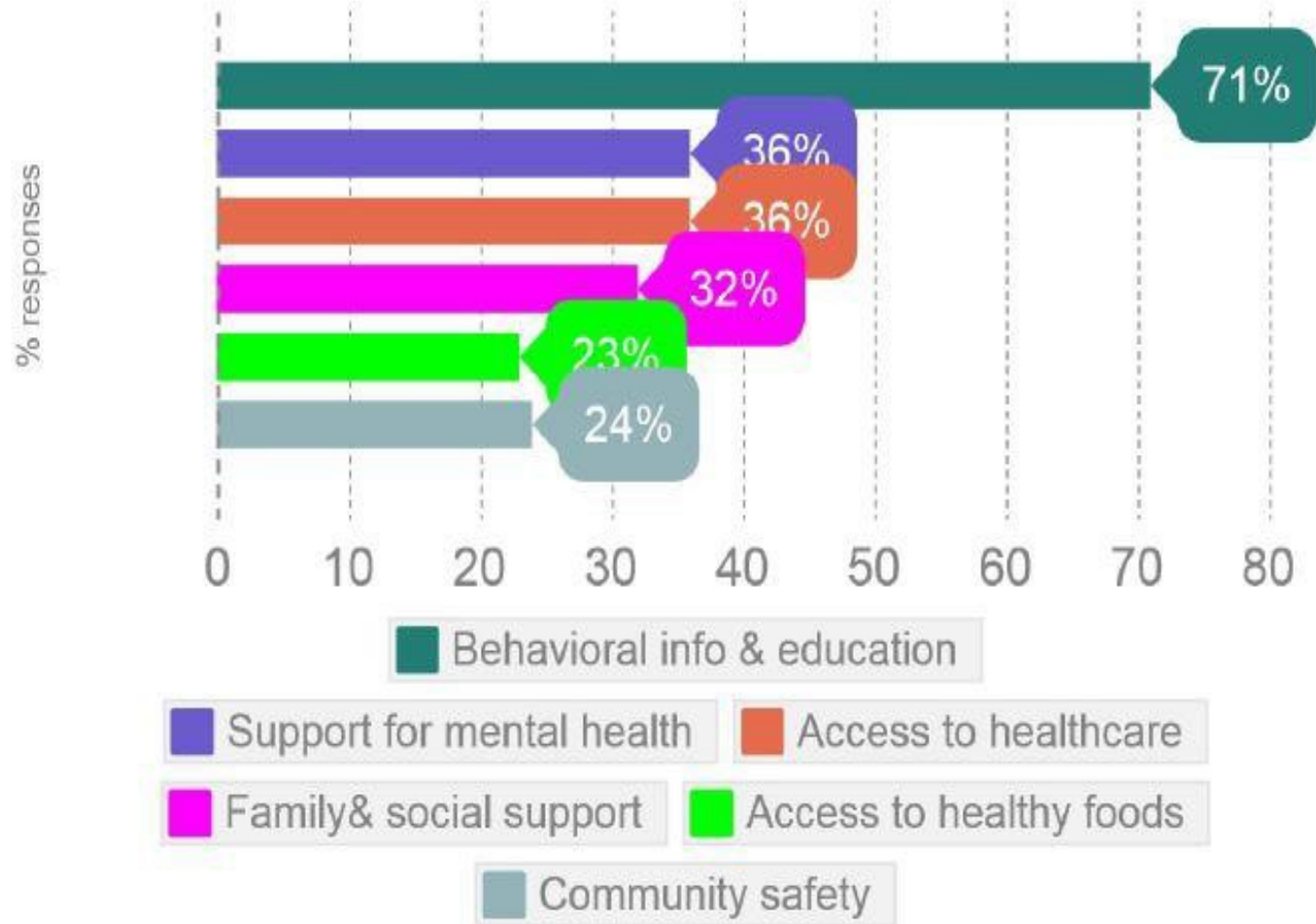
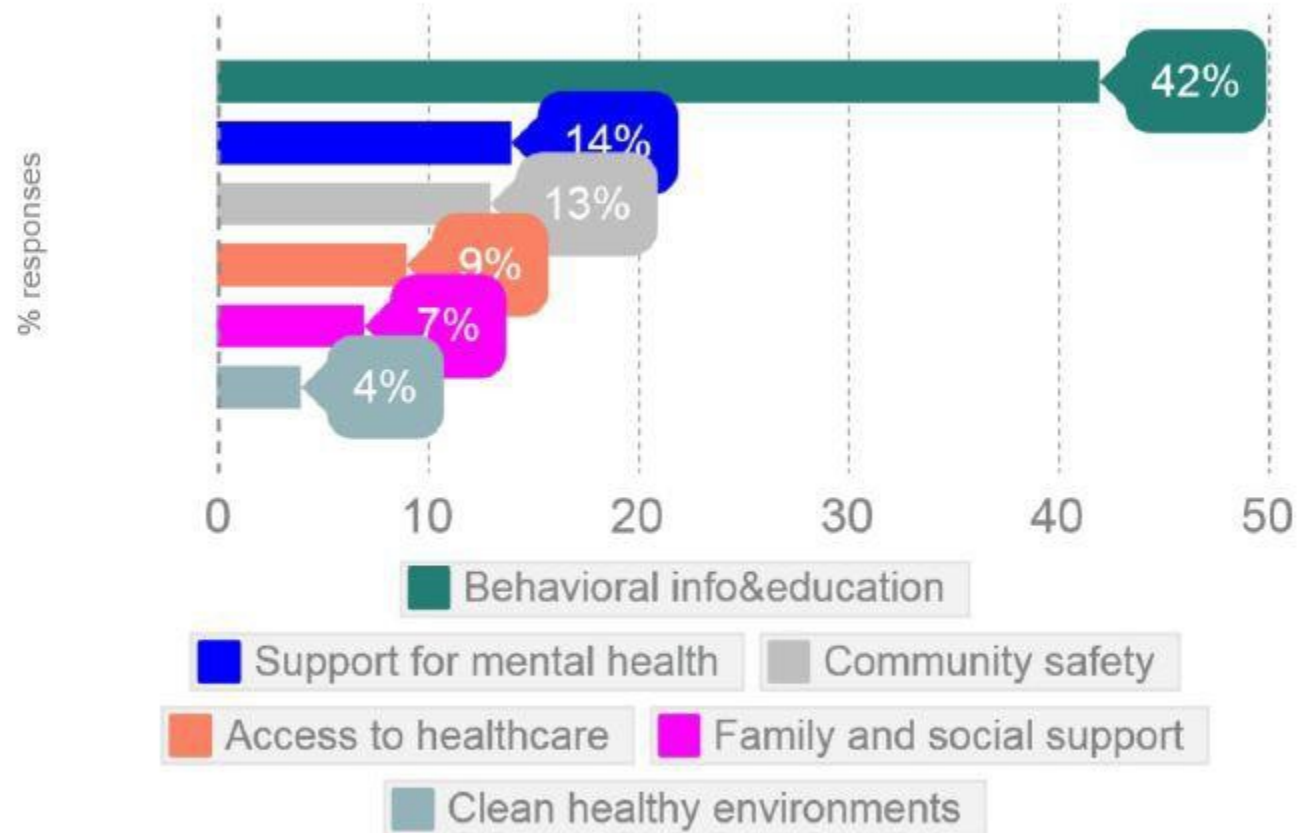


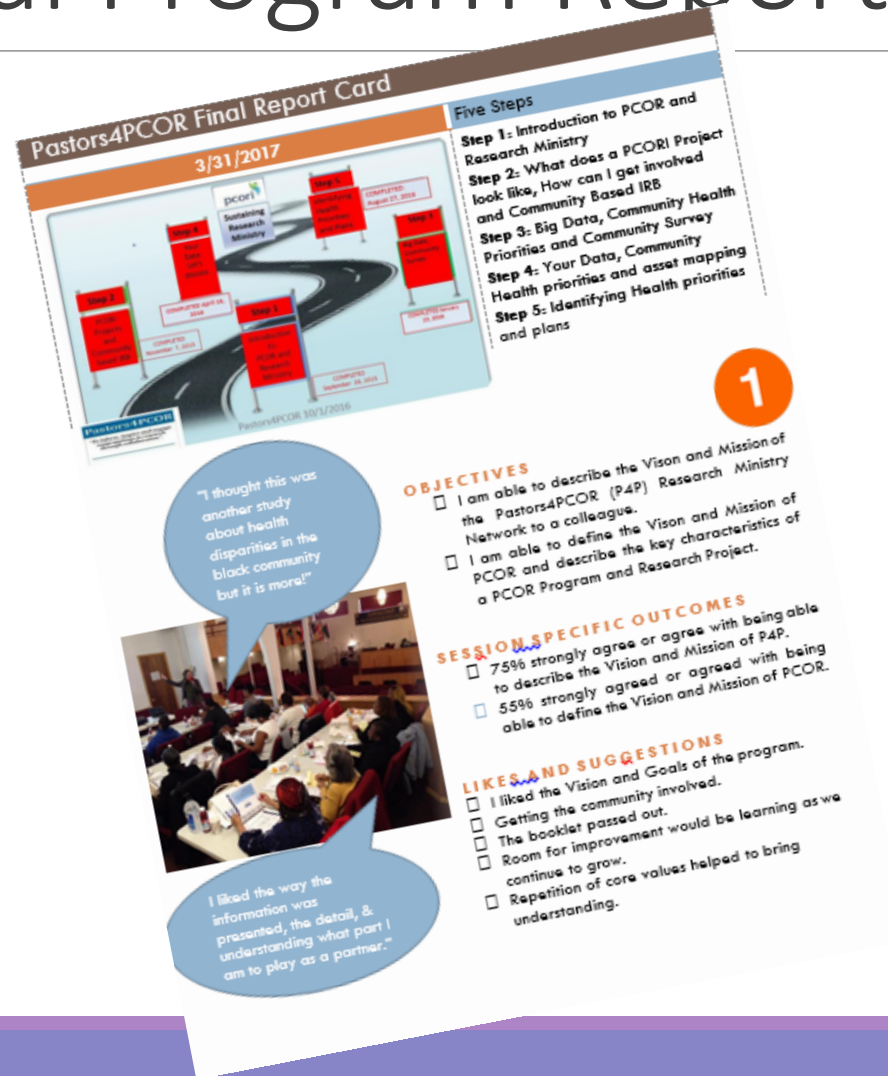
Chart shows responses of 20% or higher.

Question 4: Health factors faith based communities should focus on first



In your opinion where should we start?

Final Program Report Card



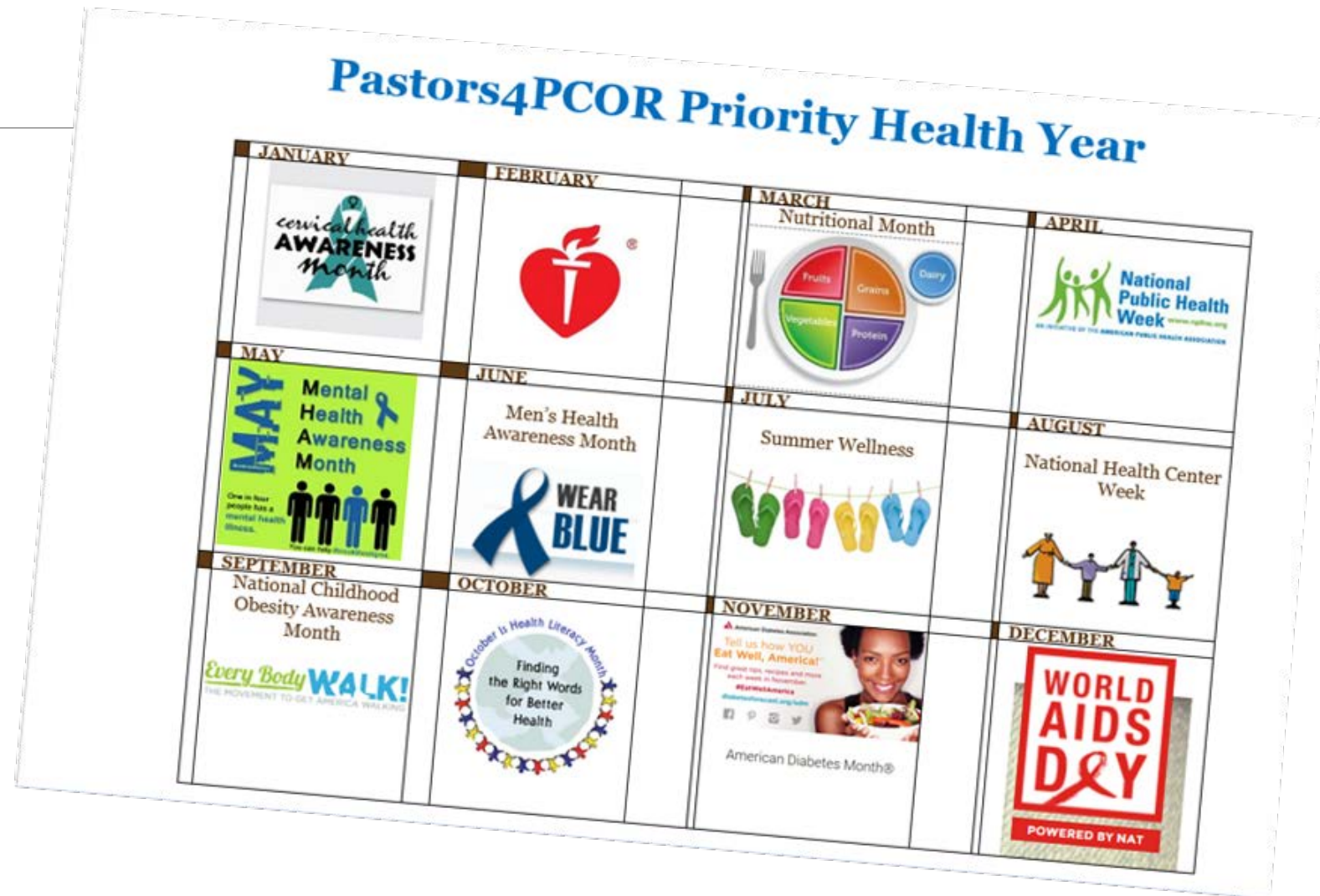
90% of participants agreed or strongly agreed that they are able to describe PCOR projects in Illinois;

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



Use Case



Adaptable

The Aspirin Study



pcornet®

The National Patient-Centered
Clinical Research Network



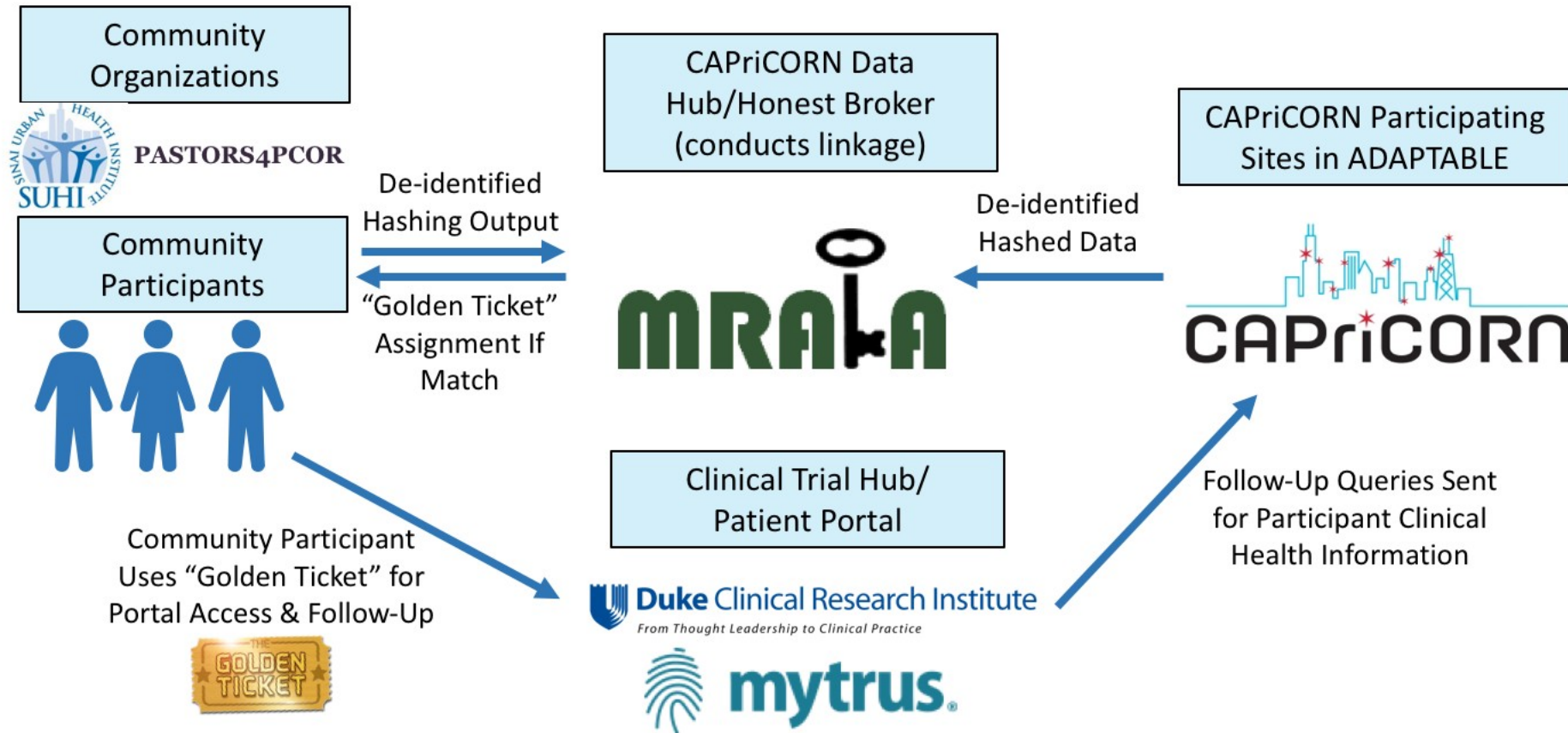
7ADAPTABLE, <http://theaspirinstudy.org>

8The National Patient-Centered Clinical Research
Network, <http://pcornet.org/about-pcornet/>

Community-Based Recruitment Workflow



The Aspirin Study





Acknowledgements

Acknowledgements

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Disclaimer. The views, statements, opinions presented are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

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