Welcome, Introductions, and Review Agenda

Jean Slutsky, PA, MSPH
Chief Engagement and
Dissemination Officer

Sue Sheridan, MIM, MBA, DHL
Director of Patient Engagement

Charlotte W. Collins, JD
Chair
Compensation Subcommittee

Darius Tandon, PhD
Chair
Evaluation Subcommittee

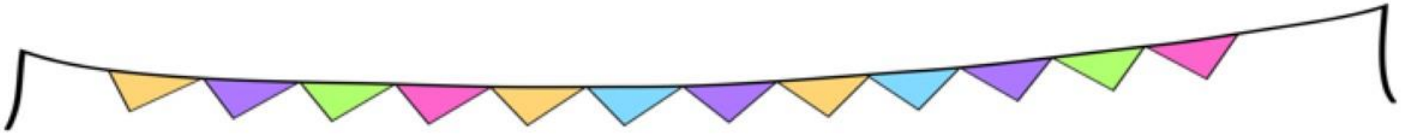
Conflict of Interest Statement

Disclosures of conflicts of interest of members of this panel are publicly available on PCORI's website and are required to be updated annually. Members of the Advisory Panel Patient Engagment (PEAP) are also reminded to update conflict of interest disclosures if the information has changed by contacting Rachel Melo.

If the PEAP will deliberate or take action on a matter that presents a conflict of interest for you, please inform the chair so we can discuss how to address the issue. If you have questions about conflict of interest disclosures or recusals relating to you or others, please contact Rachel Melo.

Agenda

10:30 a.m.	Welcome, Introductions and Review Agenda
11:00 a.m.	Evaluation Update
12:00 pm.	Lunch
12:45 p.m.	Group photo
1:00 p.m.	Session with Communication and Dissemination Research (CDR) Panel
2:30 p.m.	Break
2:45 p.m.	Rethinking the Pipeline
3:15 p.m.	PEAPs in Action
4:30 p.m.	Discussion & Wrap-up
5:00 p.m.	PEAP Meeting Adjourned



Welcome

Glad you're here!

John Chernesky	Patient/Caregiver/Patient Advocate
Emily Creek	Patient/Caregiver/Patient Advocate
Libby Hoy	Patient/Caregiver/Patient Advocate
Megan Lewis	Researchers
Suzanne Madison	Patient/Caregiver/Patient Advocate
Ting Pun	Patient/Caregiver/Patient Advocate
John Westfall	Clinician
David White	Patient/Caregiver/Patient Advocate

New Engagement Dissemination & Implementation Staff Introductions

Chris Gayer, PhD

Program Officer

Dissemination and Implementation

Kristen DeCaires, MPH

Program Associate

Dissemination and Implementation

Arielle Gorstein, MPH

Program Associate

Dissemination and Implementation

Merit Review

Whitney McInvale, MPH

Program Associate

National Urban Fellows

Tania Guaman

Jacqueline Gannon

Evaluation Update

Laura Forsythe, PhD, MPH

Associate Director, Evaluation and Analysis

pcori

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Agenda

- Incorporating PEAP feedback in the PCORI Evaluation Framework
- Recent results: Learnings about research engagement
  - Effects of engagement on the project
  - Effects of engagement on the partners
  - PCOR principles in action
- Discussion & recommendations

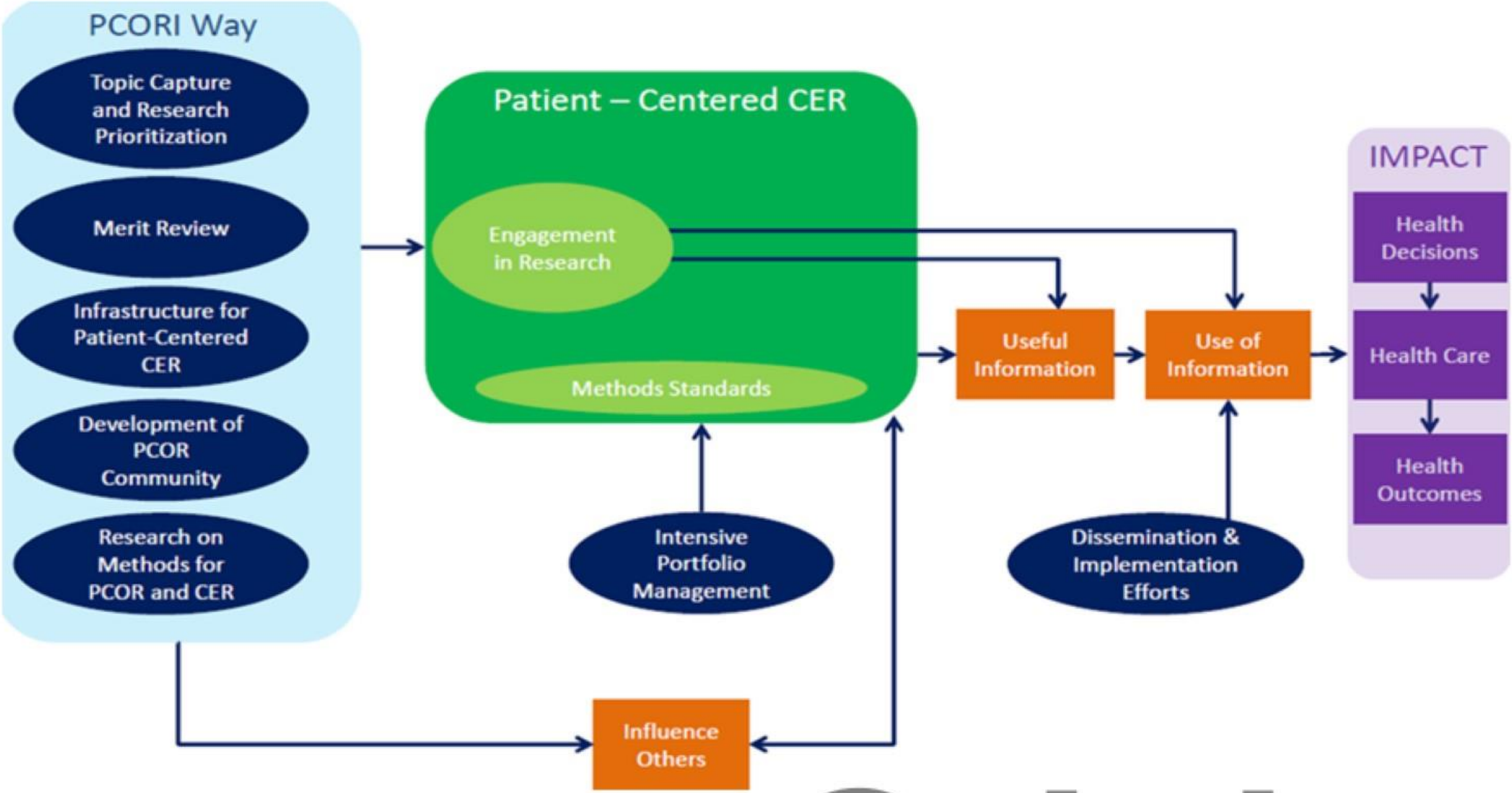
Incorporating PEAP Feedback in the PCORI Evaluation Framework

Incorporating PEAP Feedback in the PCORI Evaluation Framework

- Revised evaluation framework graphics, particularly regarding the impacts of engagement in research , to increase clarity

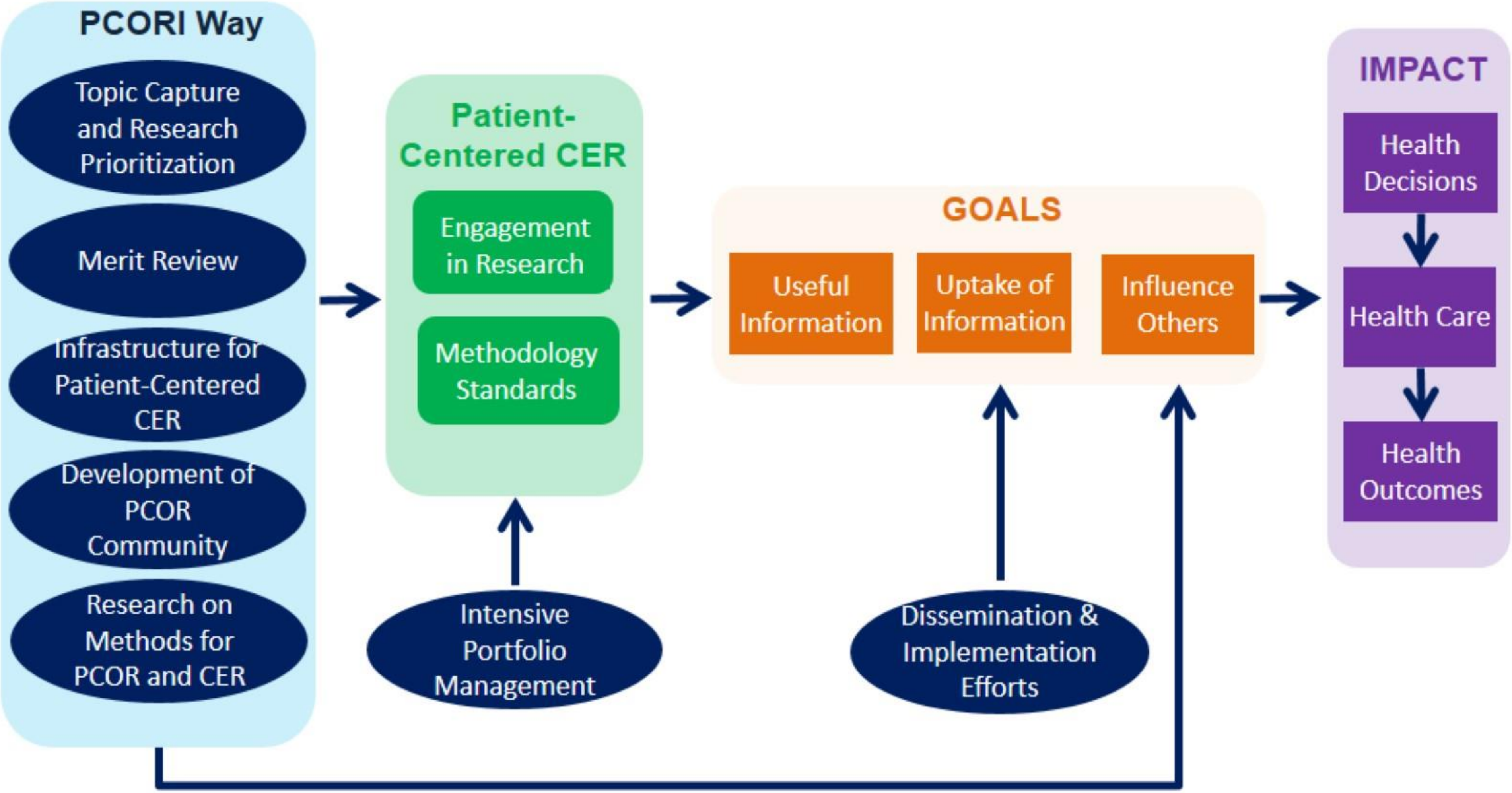
PCORI's Overall Evaluation Framework

"Original" Format



Original

PCORI's Overall Evaluation Framework



PCORI Way

- Topic Capture and Research Prioritization
- Merit Review
- Infrastructure for Patient-Centered CER
- Development of PCOR Community
- Research on Methods for PCOR and CER

Patient-Centered CER

- Engagement in Research
- Methodology Standards

Intensive Portfolio Management

GOALS

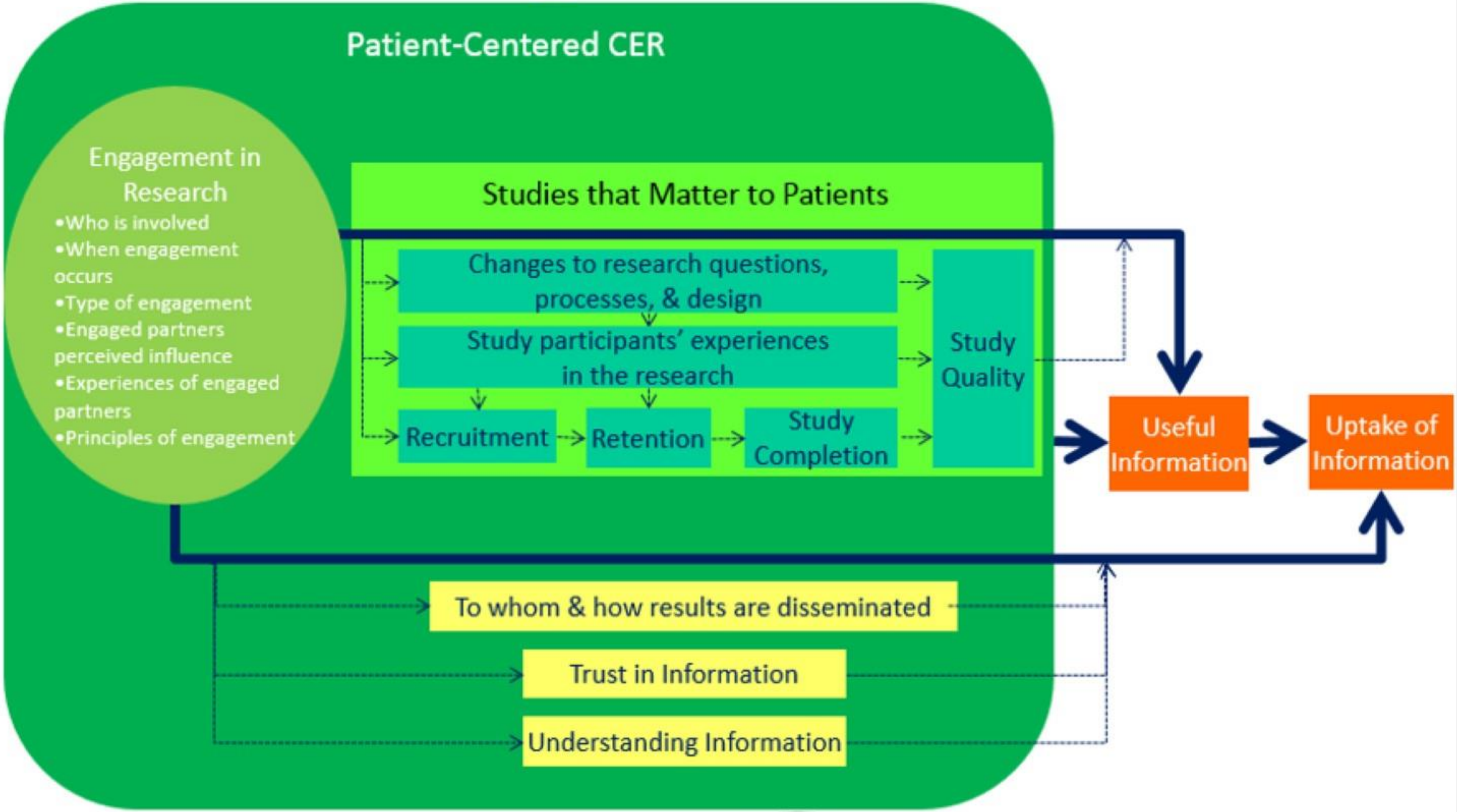
- Useful Information
- Uptake of Information
- Influence Others

Dissemination & Implementation Efforts

IMPACT

- Health Decisions
- Health Care
- Health Outcomes

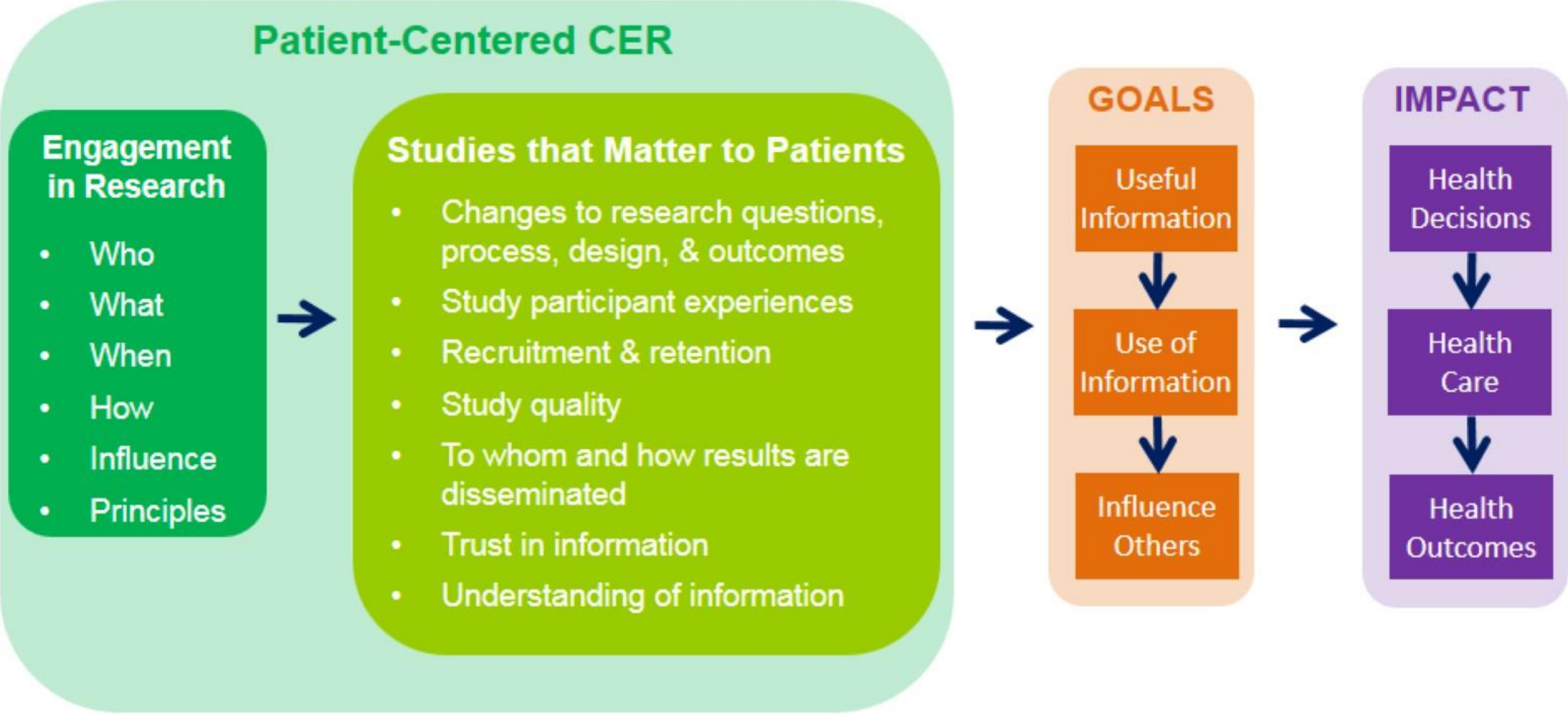
Evaluation Framework: Engagement in Research "Original" Format



Original

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Evaluation Framework: Engagement in Research



Patient-Centered CER

Engagement in Research

- Who
- What
- When
- How
- Influence
- Principles

→

Studies that Matter to Patients

- Changes to research questions, process, design, & outcomes
- Study participant experiences
- Recruitment & retention
- Study quality
- To whom and how results are disseminated
- Trust in information
- Understanding of information

→

GOALS

Useful Information

↓

Use of Information

↓

Influence Others

→

IMPACT

Health Decisions

↓

Health Care

↓

Health Outcomes

Incorporating PEAP Feedback in the PCORI Evaluation Framework

- Revised evaluation framework graphics, particularly regarding the impacts of engagement in research, to increase clarity
- Evaluation questions that can be answered now or soon are prioritized
- Measuring diversity of applicants and awardees

In the longer-term, we are:

- Exploring ways to include engagement metrics in the PCORI dashboard
- Considering ways to measure diversity among Merit Reviewers, Peer Reviewers, etc.
- Identifying ways to assess PCORI awardee engagement of patients in future projects funded by others

Incorporating PEAP Feedback in the PCORI Evaluation Framework

Assessing the Development of the PCOR Community

- Refined this evaluation question: “What is effect of PCORI’s unique approach to building a ***skilled*** PCOR Community?”
- Ensured language reflected both patients and other stakeholders throughout
- Evaluating both whether PCORI is building community, and the effectiveness of that community
- Including metrics for attendees at PCORI workshops and events, and recipients of PCORI communications
- Assessing perceptions of value of partner input from both researchers and partners

Incorporating PEAP Feedback in the PCORI Evaluation Framework

Assessing the Impact of Engagement in Research

- Current priorities include:
  - Assessing relevance of research from the perspective of patients and caregivers
  - Comparing PCORI studies to those of other funders
  - Understand relationship between patient engagement and study rigor
  - Learning about engagement for dissemination, and sharing those learnings widely

In the longer term , we are:

- Exploring options for software platforms that allow tracking of online access to study products and tools
- Considering ways to work with patient organizations and PPRNs/CDRNs to assess views about usefulness and relevance of the PCORI portfolio

Incorporating PEAP Feedback in the PCORI Evaluation Framework

Assessing PCORI's Influence

- Including examples of PCORI influence on the broader healthcare eco-system (beyond healthcare research)

In the longer term, we are:

- Considering ways to capture PCORI influence on clinical practice

Example of PCORI Influence Beyond Research

(1 of 2)

Dr. Sharron Close ***(July 2016)***

- The PCORI Engagement Award *"Family & Science: Bidirectional Translation of Knowledge and Need in Sex Chromosome Aneuploidy"* was funded to:
  - Build stakeholder community engagement to direct research toward outcomes that matter to them;
  - Plan family and scientific conferences;
  - Expand awareness of X & Y chromosome variations; and
  - Assist in the design of new intervention studies
- Dr. Close reports that the project has **led to unexpected outcomes beyond research**.

Example of PCORI Influence Beyond Research
(2 of 2)

- Listening to patients' needs led to a recognition that only some patient-important outcomes could be address through research. The team's response to these needs led to:
  - Increasing Awareness about X & Y Variations (official state of Georgia Proclamations declaring an Awareness Day and an Awareness Month (policy change)
  - Establishing the first Southeast Regional X & Y Support Group
  - Creation of a new regional multidisciplinary clinic "The eXtraordinarY Kids Clinic of Atlanta"
  - Development of educational materials for physicians, schools, insurers and the justice system

"The engagement process has indeed empowered patients and families to change not only research and patient-centered outcomes, but also to expand awareness and knowledge that may influence policy to their benefit." Dr. Close

Recent Results: Learnings about Research Engagement

- Impact of engagement on the project
- Impact of engagement on the partners
- PCOR principles in action

Information Sources on Engagement in Research

Research Awardees
PCORI Interim Progress Reports (IPRs)

Pipeline to Proposal Awardees and Partners
LEarning About Partnerships (LEAP) tool

Literature Searches
Awardee publications as case studies

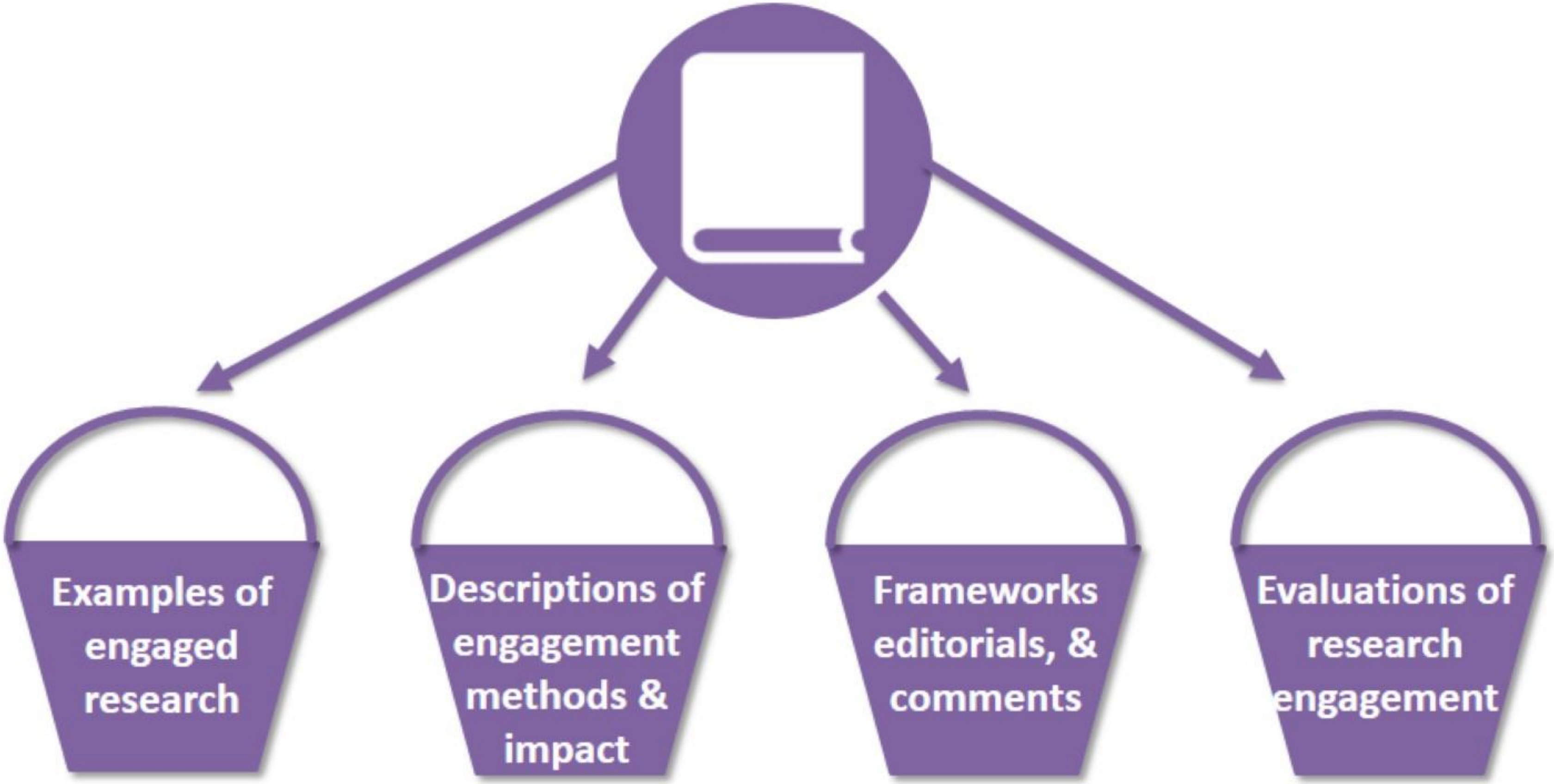
Research Partners
Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT)

Stakeholder Views
Surveys (patients, caregivers, clinicians, and researchers)
Focus Groups (payers, purchasers, and industry)

PCORI Awards
Pilot projects, Improving Methods portfolio, Engagement Awards

Literature Repository on Research Engagement

- Searchable and sortable
- Tagged for phase of research, communities engaged, PCORI funding



Examples of engaged research

Descriptions of engagement methods & impact

Frameworks editorials, & comments

Evaluations of research engagement

PCORI Awardee Articles as Case Studies

Engaging stakeholders to design a comparative effectiveness trial in children with uncontrolled asthma

Journal of **Comparative Effectiveness Research**

Kim Erwin[*,1], Molly A Martin[2], Tara Flippin[1], Sarah Norell[1], Ariana Shadlyn[1], Jie Yang[1], Paula Falco[1], Jaime Rivera[1], Stacy Ignoffo[3], Rajesh Kumar[4], Helen Margellos-Anast[5], Michael McDermott[6], Kate McMahon[7], Giselle Mosnaim[8], Sharmilee M Nyenhuis[2], Valerie G Press[9], Jessica E Ramsay[5], Kenneth Soyemi[10], Trevonne M Thompson[2] & Jerry A Krishnan[2,11]

ELSEVIER

Contents lists available at ScienceDirect

Contemporary Clinical Trials

journal homepage: www.elsevier.com/locate/conclintrial

Using patient engagement in the design and rationale of a trial for women with depression in obstetrics and gynecology practices☆

Ellen Poleshuck[a,b,*], Marsha Wittink[a], Hugh Crean[c], Tara Gellasch[d], Mardy Sandler[e], Elaine Bell[a], Iwona Juskiewicz[a], Catherine Cerulli[a]

Recent Results: Evaluation of Research Engagement

- **Effects of engagement on the project**
- Effects of engagement on the partners
- PCOR principles in action

Method 1: Cross-sectional Content Analysis

(N = 258 awardees, 254 partners)

Reporting Time 1

Reporting Time 2

Reporting Time …

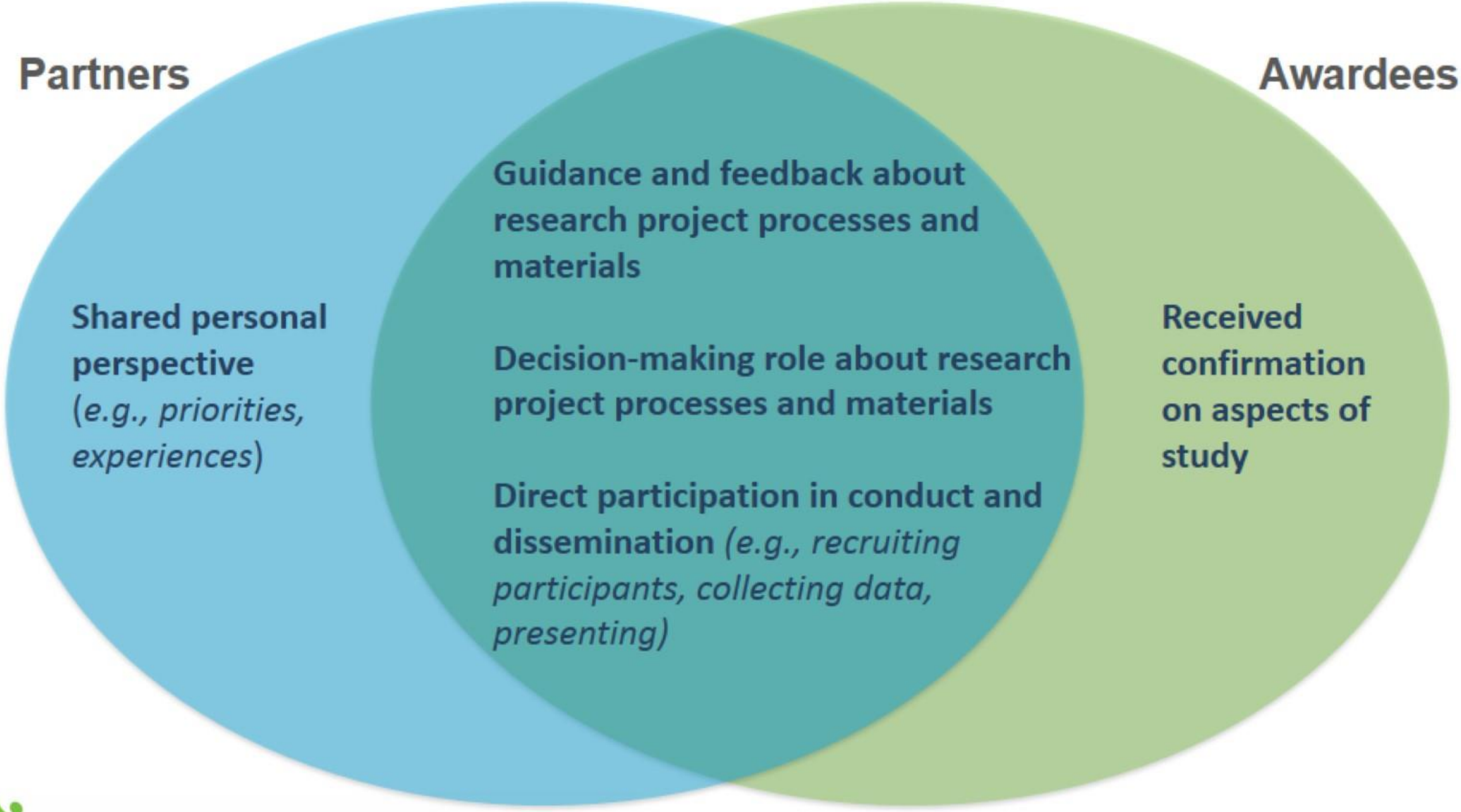
PCORI Project 1

PCORI Project 2

PCORI Project …

What are common engagement activities?

Researchers & Partners reported partner activities in the last year
(N = 258 awardees, 254 partners)



Partners

Awardees

Shared personal perspective (*e.g., priorities, experiences*)

Guidance and feedback about research project processes and materials

Decision-making role about research project processes and materials

Direct participation in conduct and dissemination *(e.g., recruiting participants, collecting data, presenting)*

Received confirmation on aspects of study

In what ways is engagement making a difference?

Themes from qualitative data analysis (N = 258 awardees, 254 partners)

Awardees

- **Refined aspects of the study**
  - Catalyst for research question
  - Interventions or comparators
  - Outcomes and measurement
  - Data collection processes
  - Recruitment/retention processes
- **Increased patient-centeredness**
  - Interventions or comparators
  - Outcomes & data collection processes
  - Recruitment materials
- **Enhanced enrollment rates**

All themes found in >10% of responses about that phase, themes in green found in >25%

In what ways is engagement making a difference?

Themes from qualitative data analysis (N = 258 awardees, 254 partners)

Awardees

- **Refined aspects of the study**
  - Catalyst for research question
  - Interventions or comparators
  - Outcomes and measurement
  - Data collection processes
  - Recruitment/retention processes
- **Increased patient-centeredness**
  - Interventions or comparators
  - Outcomes & data collection processes
  - Recruitment materials
- **Enhanced enrollment rates**

Partners

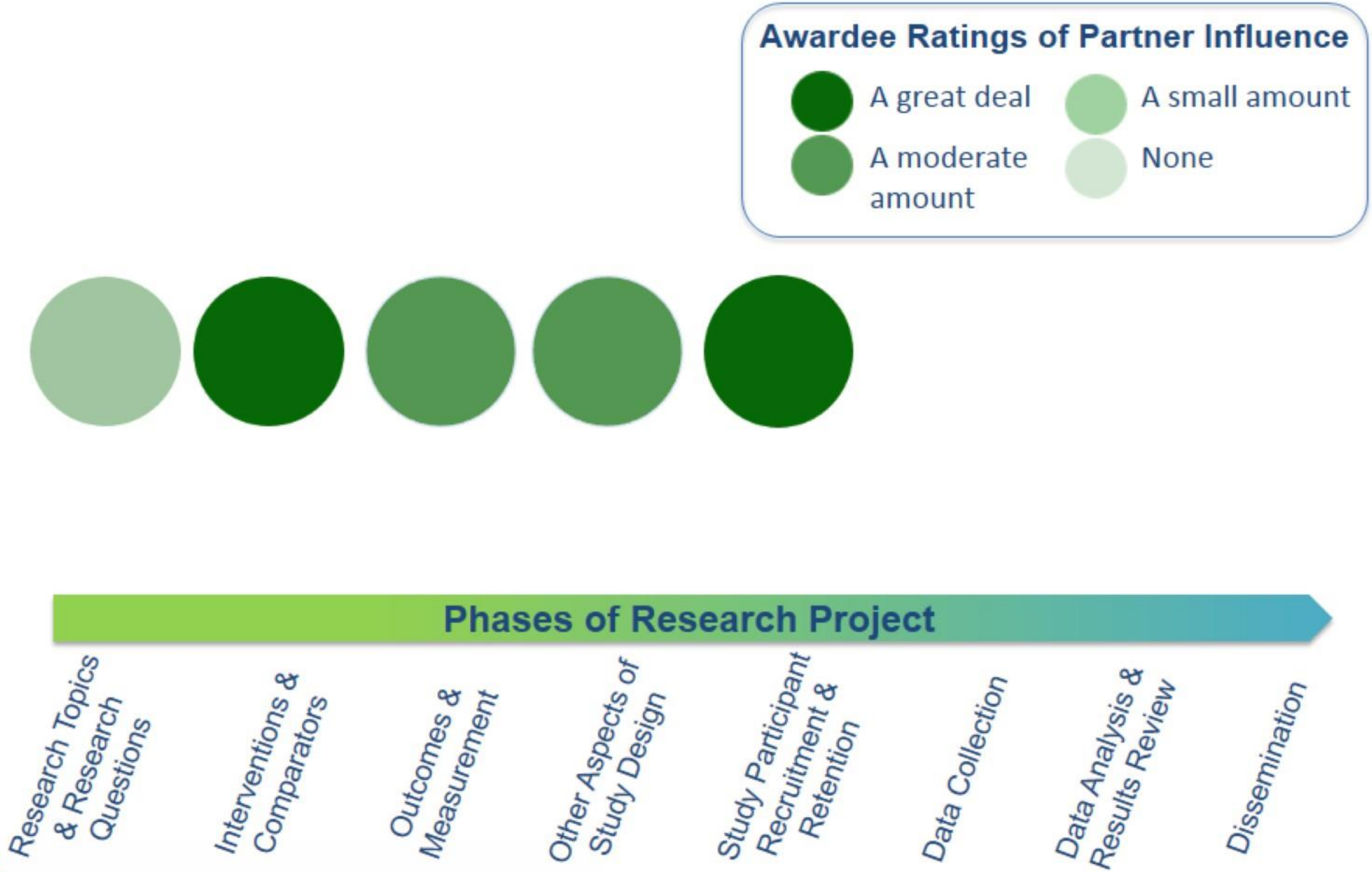
- **Understanding partner perspectives**
- **Refined aspects of the study**
  - Research question
  - Interventions or comparators
  - Outcomes and measurement
  - Recruitment/retention processes
- **Increased patient-centeredness**
  - Interventions or comparators
  - Outcomes
  - Recruitment materials
- **Enhanced enrollment rates**
- **Interpretation of results**

Found in >50% of responses about that phase

Method 2: Longitudinal Content Analysis

(N = 13 projects)

Longitudinal Analysis: Effects of Engagement (Case #13)



Awardee Ratings of Partner Influence

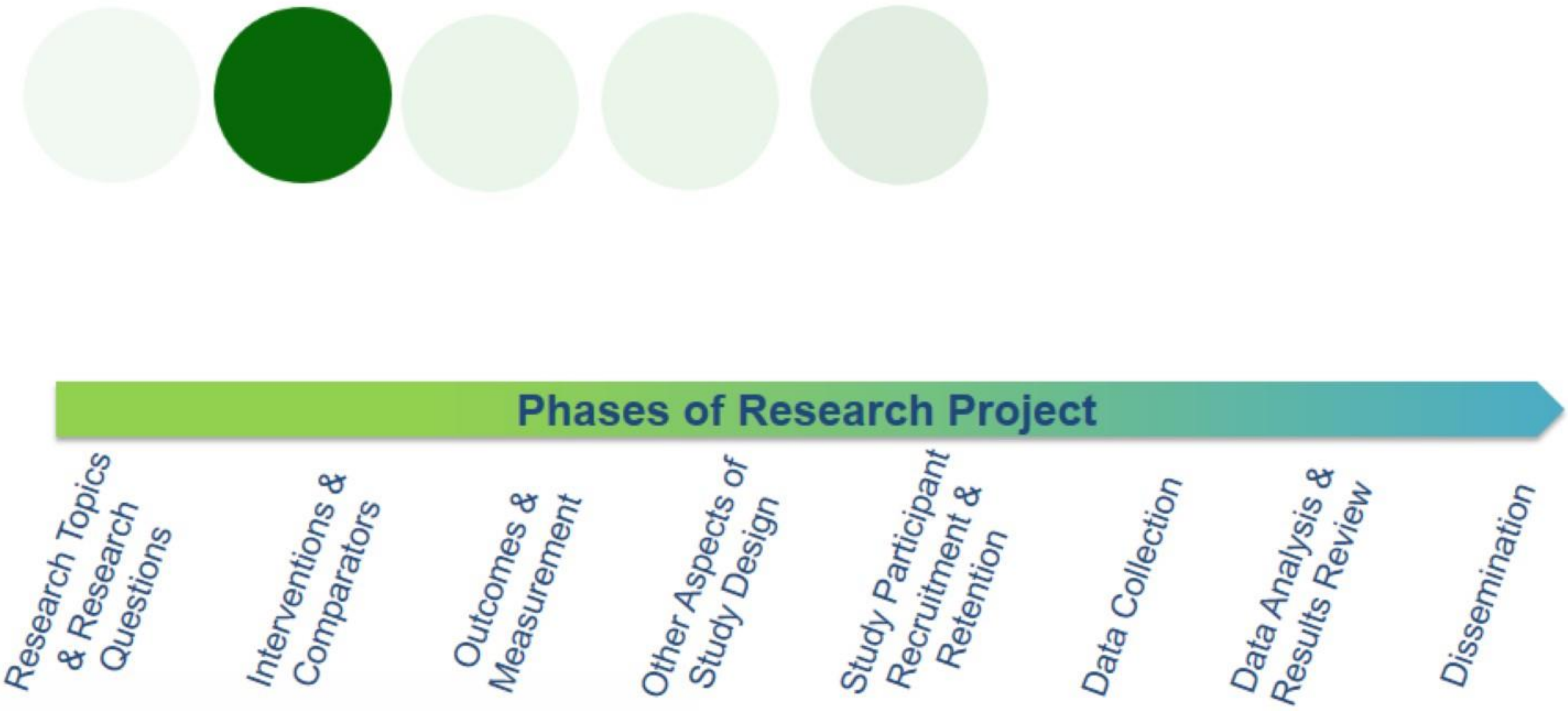
- ● A great deal
- ● A moderate amount
- ● A small amount
- ● None

Phases of Research Project

- Research Topics & Research Questions
- Interventions & Comparators
- Outcomes & Measurement
- Other Aspects of Study Design
- Study Participant Recruitment & Retention
- Data Collection
- Data Analysis & Results Review
- Dissemination

Interventions & Comparators

> We gave our opinion on **what information families would like** to have available to them…what order the information should be presented, …**The team was able to tweak the presentation to make it more user friendly**.
> *– Caregiver/Family Member*



Phases of Research Project

- Research Topics & Research Questions
- Interventions & Comparators
- Outcomes & Measurement
- Other Aspects of Study Design
- Study Participant Recruitment & Retention
- Data Collection
- Data Analysis & Results Review
- Dissemination

Outcomes & Measurements

> [I] discussed my priorities with researchers. They described how they would measure those issues. *-Payer (public or private insurance)*

> All stakeholders assisted us in deciding on important outcomes to measure… **This input resulted in our primary medical outcome being disability days at one year after treatment.** *-Awardee*

Phases of Research Project

- Research Topics & Research Questions
- Interventions & Comparators
- Outcomes & Measurement
- Other Aspects of Study Design
- Study Participant Recruitment & Retention
- Data Collection
- Data Analysis & Results Review
- Dissemination

Study Participant Recruitment & Retention

> “We brainstormed ways to **change their approach so that families are more at ease**…they changed how they reach out to patients based on feedback.
>
> We discussed why families might choose to withdraw from the study and … about better ways to communicate with families that are involved in the study. [As a result], **more families stayed in the study**. – *Caregiver/Family Member*

> “These changes **increased enrollment in the trial from 65% to 95% and increased retention from 58% to 85%.** -*Awardee*

Phases of Research Project

Research Topics & Research Questions
Interventions & Comparators
Outcomes & Measurement
Other Aspects of Study Design
Study Participant Recruitment & Retention
Data Collection
Data Analysis & Results Review
Dissemination

PCOR Principles in Practice

> Our success in achieving these goals stems in part from involving stakeholders throughout the entirety of the project, **building strong ongoing relationships, fostering open communication, and appreciating all opinions**. - *Awardee*

> Our child enjoyed that the researchers asked for her thoughts and opinions and **took her input seriously**. – *Caregiver/Family Member*

> We got together quarterly as a team, we shared a meal together and sat at a big round table where we were asked and given the opportunity to express our thoughts, ideas and opinions. **Everyone was given the chance to share and respond.**
> – *Caregiver/Family Member*

Phases of Research Project

- Research Topics & Research Questions
- Interventions & Comparators
- Outcomes & Measurement
- Other Aspects of Study Design
- Study Participant Recruitment & Retention
- Data Collection
- Data Analysis & Results Review
- Dissemination

Recent Results: Evaluation of Research Engagement

- Effects of engagement on the project
- **Effects of engagement on the partners**
- PCOR principles in action

Most Common Effects of Engagement on Partners

- **Established new relationships**
- **Improved personal health management**
- **Made a difference in the lives of others**
- Personal growth or self-improvement
- Gained new knowledge and insights about research
- New professional opportunities
- Belief in patient/stakeholder representation in research

Effects of Engagement on Partners: Established New Relationships

> “Our patient and family **panel has become a ‘family’**. We care about each other and what each and every one is going through!
>
> – *Patient/consumer*

Effects of Engagement on Partners:
Improved Personal Health Management

> Understanding the various health disparities leading to diabetes, kidney disease **has made me assess my personal life, my level of physical activity and my food intake**. **I have made changes in my lifestyle** which include exercising 3 x per week and encouraging my family to take part in physical activities such as hiking, basketball and so forth… **This was an eye opener.**
>
> –*Other type of Stakeholder*

> Patients I've been working with have taught me to be a better patient, to self advocate. – *Caregiver/Family Member*

Effects of Engagement on Partners:
Made a Difference in the Lives of Others

> “As an ‘older’ citizen, with mobility limitations**, this involvement has allowed me to … contribute "to the better good".** Although I have personal medical issues and challenges, … doing what I can in my very limited capacity to improving opportunities for broader patient involvement in healthcare decision making and the shaping of healthcare to reflect patient needs.
>
> – *Patient/Consumer*

Recent Results: Evaluation of Research Engagement

- Effects of engagement on the project
- Effects of engagement on the partners
- **Examples of PCOR principles in action**

PCOR Principles in Action: Reciprocal Relationships

> “When we started the project the…team took the time to explain the big picture and **everyone’s role in the project**.
>
> *– Representative from Clinic/Hospital/Health System*

PCOR Principles in Action: Co-learning

> “Even though I knew my vocabulary wasn't up to medical par, and research was brand new to me, I truly do understand that it is my "voice" as a patient and caregiver that is my contribution to the. Anytime I offered a suggestion during our weekly team meetings, they were welcomed and compassionately responded to.
>
> – *Caregiver/Family Member*

> “They have a rich storehouse of experiences to help guide our projects.
>
> *-Awardee*

PCOR Principles in Action: Partnerships (1 of 2)

> “We share ideas openly. No one takes it personal if we disagree. We all come with different perspectives and **we respect each other’s opinions and are committed to working together for the best outcomes**.
>
> *– Caregiver/Family Member*

> “We got together quarterly as a team, we shared a meal together and sat at a big round table where we were asked and given the opportunity to express our thoughts, ideas and opinions. Everyone was given the chance to share and respond. They were also very respectful of our time.
>
> *– Caregiver/Family Member*

PCOR Principles in Action: Partnerships (2 of 2)

> “Having the round table discussions where every persons ideas were valued equally was really important. It made it so that everyone was more willing to share honestly because they weren't intimidated or made to feel that the doctors/researchers knew better than we as parents/caregivers did.
>
> *-Caregiver/family member*

> “**Demonstrating that [partners’] opinions have been incorporated have increased their perception of the value of engagement.** For example, stakeholders were shown the final patient activation tool and they were pleased that their suggestions were taken into account. In addition, a quarterly update is sent to stakeholders regarding the progress of the study and how their suggestions have impacted the study. *-Awardee*

PCOR Principles in Action: Trust, Transparency, & Honesty

> “We have shared trust and honesty with the team by **sharing our honest opinions and receiving their honest opinions in return**. In addition, I feel that the **team truly cares** about our family. Our daughter was at the hospital for a different reason, not involving the study, and members of the team sent her well wishes while she was in the hospital.
>
> *–Patient/Consumer*

> “Our success in achieving these goals stems in part from involving stakeholders throughout the entirety of the project, **building strong ongoing relationships, fostering open communication, and appreciating all opinions.** *-Awardee*

Discussion

- Which findings are most meaningful to you?
- What else do you want to know about the effects of engagement on PCORI projects? On the partners?

Lunch with CDR

12:00-12:45pm

At 12:45 please meet at the registration desk for a group photo

Dissemination Opportunities at PCORI

Lia Hotchkiss, MPH

Director, Eugene Washington PCORI Engagement Awards

Bill Lawrence, MD, MS

Senior Program Officer, Communication and Dissemination Research

Chris Gayer, PhD

Program Officer, Limited Competition Dissemination and Implementation

Background

- There is a gap between what we know optimizes healthcare delivery and what actually gets implemented in everyday practice (Green et al., 2009)
- It takes years for new evidence from clinical research to influence health care (Balas, 2000)
- PCORI authorizing legislation recognized this issue and charged us with addressing it

Green LW, Ottoson JM, Garcia C, Hiatt RA. Diffusion theory and knowledge dissemination, utilization, and integration in public health. Annu Rev Public Health. 2009;30:151–174. doi: 10.1146/annurev.publhealth.031308.100049.

Balas EA, Boren SA. Managing clinical knowledge for health care improvement. In: Bemmel J, McCray AT, editors. Yearbook of Medical Informatics 2000: Patient-Centered Systems. Stuttgart, Germany: Schattauer Verlagsgesellschaft mbH; 2000:65-70.

Authorizing Legislation

"The purpose of the Institute is to **assist patients, clinicians, purchasers, and policy-makers in making informed health decisions** by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed **through research and evidence synthesis…**

… and the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services…"

-- from PCORI's authorizing legislation

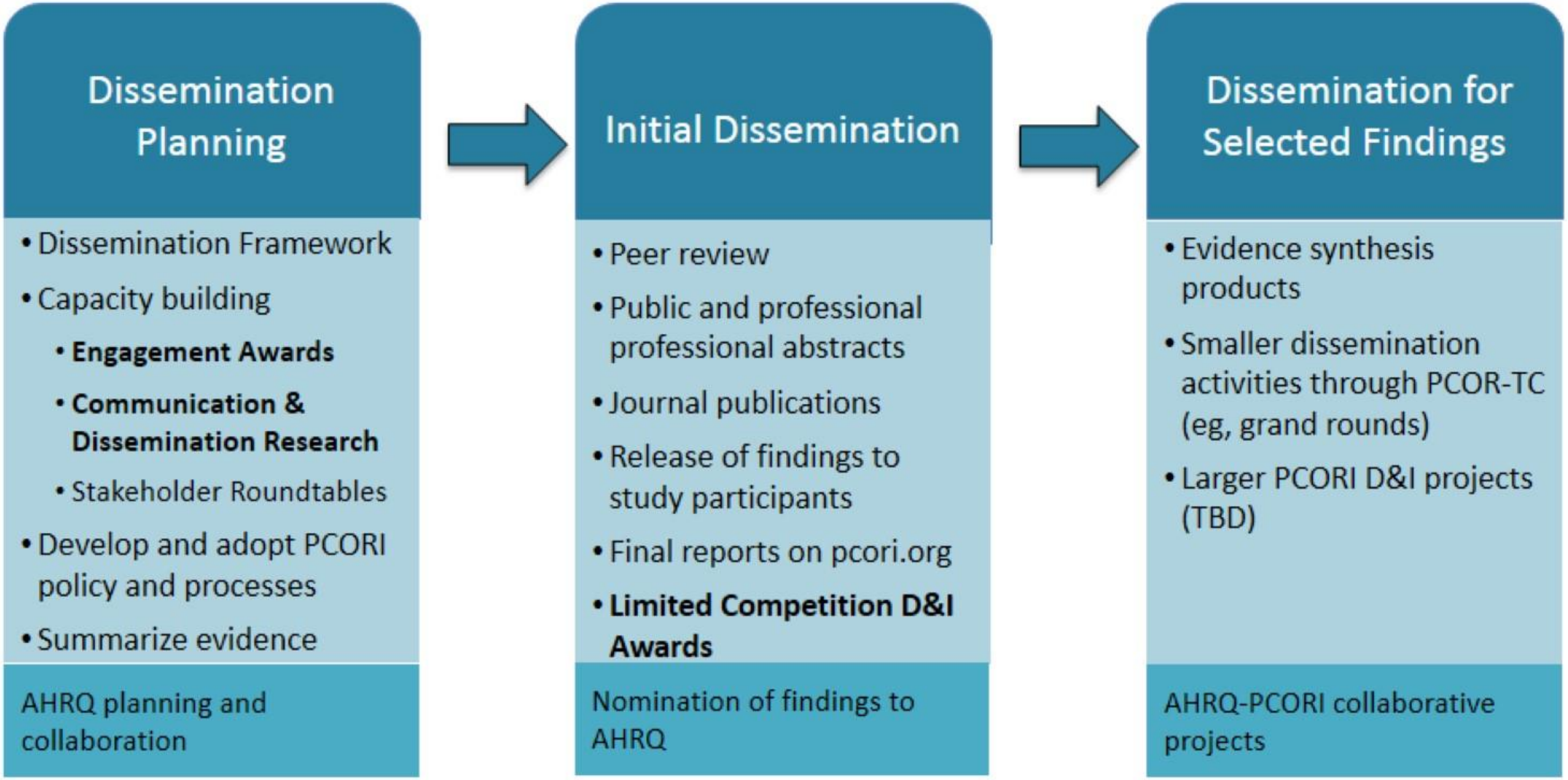
Dissemination and Implementation Program

Using PCORI Research to Improve Healthcare

What is the goal of the D&I Program?

- The D&I Program is charged with heightening awareness of the results of PCORI-funded research, and with advancing efforts to put these findings into practice to improve healthcare delivery and health outcomes.

PCORI D&I Activities Overview



Dissemination Planning

- Dissemination Framework
- Capacity building
  - **Engagement Awards**
  - **Communication & Dissemination Research**
  - Stakeholder Roundtables
- Develop and adopt PCORI policy and processes
- Summarize evidence

AHRQ planning and collaboration

Initial Dissemination

- Peer review
- Public and professional professional abstracts
- Journal publications
- Release of findings to study participants
- Final reports on pcori.org
- **Limited Competition D&I Awards**

Nomination of findings to AHRQ

Dissemination for Selected Findings

- Evidence synthesis products
- Smaller dissemination activities through PCOR-TC (eg, grand rounds)
- Larger PCORI D&I projects (TBD)

AHRQ-PCORI collaborative projects

Key D&I Initiatives Underway

TRANSLATION

- PCORI submits all research findings to peer review before releasing them.
- Once peer review is complete, the Dissemination & Implementation Program oversees the translation of these findings into accessible and comprehensible summaries:
  - one targeting patients and the general public
  - one for a professional audience.
- These 500-word abstracts, prepared by PCORI's Patient-Centered Outcomes Research Translation Center, are posted on pcori.org.
- PCORI's website along with other materials describing the study and its results.

Key D&I Initiatives Underway

PROMOTING ACCESS TO PUBLISHED PCORI RESEARCH FINDINGS

- PCORI stipulates that manuscripts be deposited to PubMed Central so that they are available to all.
- To promote even faster availability of findings, PCORI works with journals to pay the open access fees for articles that report key findings in peer-reviewed journals.

Eugene Washington PCORI Engagement Award Program:

Focus on Dissemination

Lia Hotchkiss, MPH

Director, Eugene Washington PCORI Engagement Award Program

Engagement Award Program Overview

- Programmatic funding opportunity, launched in Feb 2014
- Supports projects that will build a community better able to participate in PCOR/CER and serve as channels to disseminate study results
- Engagement Award projects will produce deliverables that are useful to awardees, PCORI, and the broader PCOR community for increasing patient and stakeholder engagement in PCOR/CER

Develop Community Skilled in PCOR

Involve Community in Research Processes

Engage Community in Dissemination

Engagement Awards

- Engagement Award (EA) projects
  - build our knowledge base about how patients and other stakeholders want to participate in PCOR/CER or receive research findings;
  - implement training or skill development initiatives to build capacity for engaging in PCOR/CER; and/or
  - strengthen channels for disseminating PCOR/CER findings.

- Engagement Award Initiative Notice (EAIN) meetings/conferences
  - align with PCORI's mission and strategic plan, and facilitate expansion of PCOR/CER in areas such as:
    - research design and methodology
    - research development
    - dissemination and implementation

Awards of **up to $250,000** per project, up to **two years** in duration

Emphasis On Planning for Dissemination of PCOR Findings

- Organizations with strong ties to end-user audiences
- To <u>prepare</u> to disseminate and implement PCOR/CER results
- Focus on strengthening infrastructure, relationships and approaches to actively disseminate and implement research results or products derived from PCORI studies or other high-quality PCOR/CER findings consistent with PCORI's research priorities
- Separate from PCORI Limited D&I funding opportunity
- Infrastructure, relationships and approaches developed must be sustainable with the potential to be scaled
- Information and tools generated must be generalizable and made public

Examples of Projects of Interest

Processes

- Place existing or emerging PCOR/CER research results within the context of the body of evidence in the topic area identified.
- Develop, demonstrate, and evaluate the **processes** necessary to incorporate research results from these studies into decision-making settings of your population.

Collaborations

- Establish multi-stakeholder **collaborations** to ID effective pathways and approaches for reaching a target audiences for disseminating a set of PCOR/CER research results on a topic relevant to your organization's mission.
- Propose and develop strategies and tools necessary to implement them. Test and refine the strategies.

Approaches

- Design innovative **approaches** to actively disseminate PCOR/CER findings that are oriented to your target population.
- Demonstrate that approaches reach your audience and describe strategy for how approaches would be used to improve uptake of findings.

Funded Engagement Awards with Dissemination Focus

“Improving Care for Critically Ill Patients & Families Through Research Dissemination/Implementation”

Challenge

- Focusing on patients’ needs and preferences requires that healthcare clinicians have knowledge of PCOR and can implement the findings in clinical practice.

Objectives

- Engage patients and caregivers to participate in PCOR-based initiatives;
- Develop a learning collaborative for disseminating and implementing PCOR;
- Design an “e-community” learning network to engage clinicians, patients, and families to share strategies for enabling PCOR to improve care.

Ruth Kleinpell, PhD, RN
Society of Critical Care Medicine

Project Collaborators:
Rush University Medical Center/Center for Clinical Research and Scholarship; and Patient & Family National Advisory Board Members

Engagement Award Project, awarded December 2015

“Reducing Cancer Disparities by Engaging Stakeholders”

Objectives

- Develop a learning community with a common agenda related to reducing cancer screening-related disparities;
- Determine disparities in screening rates;
- Identify evidence-based approaches that increase screening and reduce screening disparities;
- Adapt effective intervention approaches for use in primary care practices;
- Disseminate a model approach to intervention adaptation in health systems;
- Evaluate learning community engagement and related outcomes.

Ron Myers, PhD
Thomas Jefferson University

***Project Collaborators**:*
Two regional health systems (Lehigh Valley Health Network and Delaware Valley Accountable Care Organization); a patient and stakeholder advisory committee from each health system; insurers; a state and a local health department; regional employer groups; a national advocacy organization; a regional advocacy organization; and Children’s Hospital of Philadelphia

Engagement Award Project,
awarded October 2015

“PCOR Dissemination at Work: How Employers Use Evidence to Make Employee Health Investment Decisions”

Objectives

- Identify existing PCOR/CER evidence of high relevance to a working population
- Understand how employers use such evidence
- Improve the uptake and implementation of this PCOR-based evidence in employee health investment decision-making

Methods

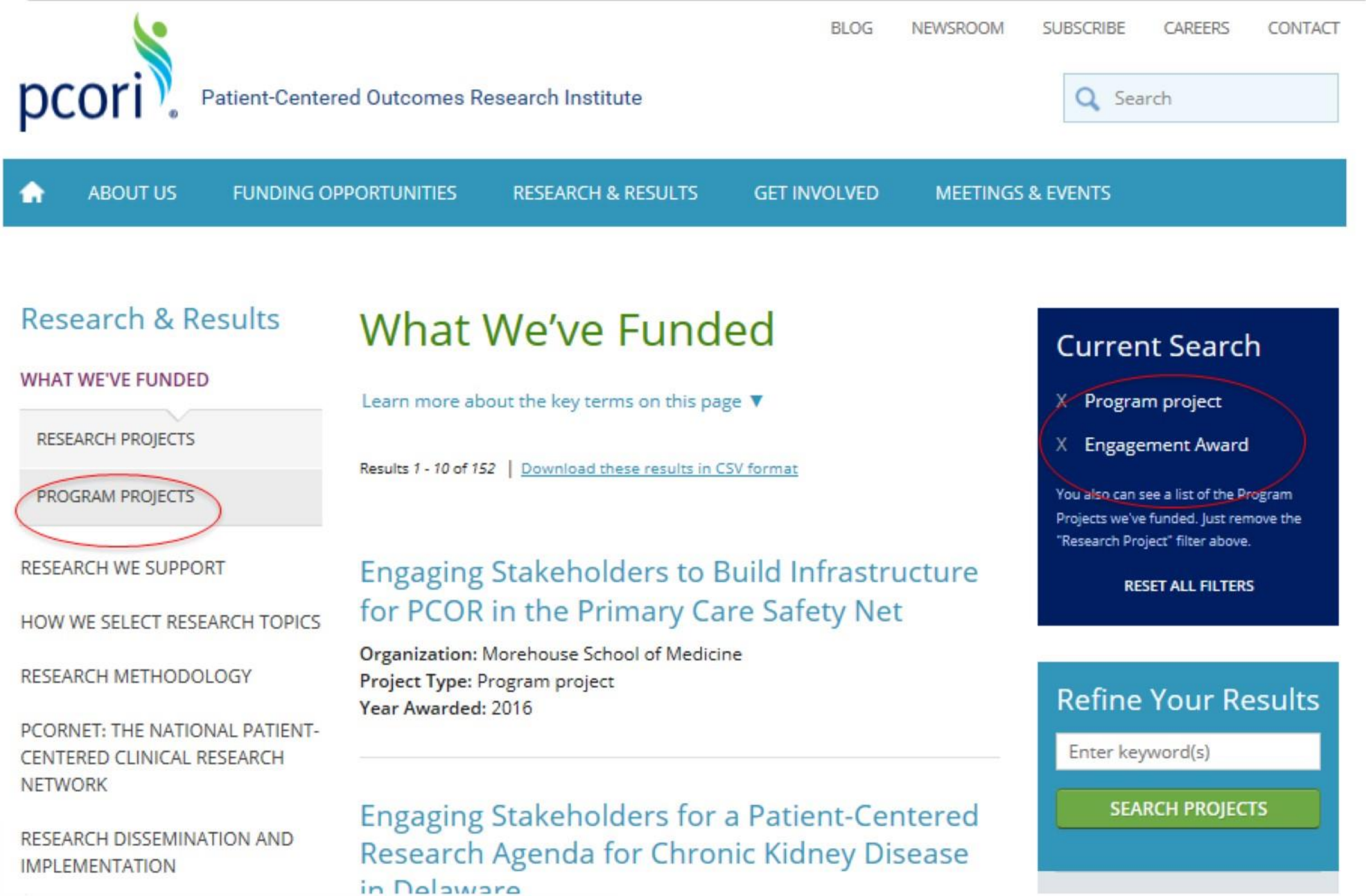
- Employer case studies, expert panel, employer interviews, stakeholder-specific communications materials, and dissemination events

Kimberly Jinnett, PhD
The Center for Workforce Health and Performance

***Project Collaborators**:*
Integrated Benefits Institute; Center for Value-Based Investment Design; RAND; employers

Engagement Award Project, awarded May 2016

What We've Funded



What We've Funded

Learn more about the key terms on this page ▼

Results *1 - 10 of 152* | Download these results in CSV format

Engaging Stakeholders to Build Infrastructure for PCOR in the Primary Care Safety Net

Organization: Morehouse School of Medicine
Project Type: Program project
Year Awarded: 2016

Engaging Stakeholders for a Patient-Centered Research Agenda for Chronic Kidney Disease in Delaware

Current Search

X Program project
X Engagement Award

You also can see a list of the Program Projects we've funded. Just remove the "Research Project" filter above.

RESET ALL FILTERS

Refine Your Results

Enter keyword(s)

SEARCH PROJECTS

Next Steps

- Emphasize desire for future Engagement Awards to focus on <u>preparing</u> for dissemination of PCORI research findings
  - Continue to refine guidance on PCORI website
  - Work with Dissemination and Implementation team to promote PCORI's dissemination funding opportunities
  - Discuss dissemination ideas with key stakeholders to explore potential fit for Engagement Award funding

Thank you

Contact Information:

Lia Hotchkiss, MPH
Program Director, Eugene Washington PCORI Engagement Awards
Patient-Centered Outcomes Research Institute (PCORI)
1828 L Street, NW 9th Floor
Washington, DC 20036

Telephone: 202-494-3441
Email: lhotchiss@pcori.org

Visit: http://www.pcori.org/funding-opportunities/programmatic-funding/eugene-washington-pcori-engagement-awards

Communication and Dissemination Research (CDR)

William Lawrence, MD, MS

Senior Program Officer, Communication and Dissemination Research

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

CDR Team

Jean Slutsky
Chief Engagement and Dissemination Officer

Bridget Gaglio
Senior Program Officer

Michelle Henton
Program Associate

Aisha Hussain
Program Assistant

Kim DiGioia
Program Associate

Bill Lawrence
Senior Program Officer

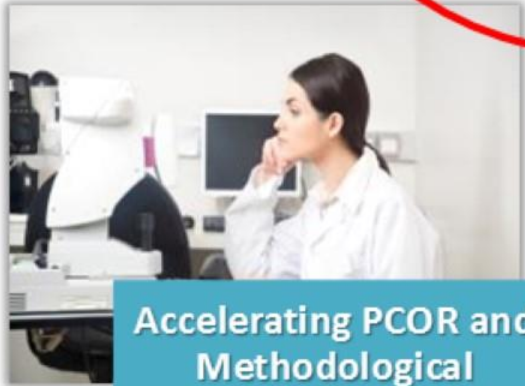
The Research We Fund Is Guided by Our National Priorities for Research

Assessment of Prevention, Diagnosis, and Treatment Options

Improving Healthcare Systems

Communication and Dissemination Research

Addressing Disparities



Accelerating PCOR and Methodological Research

PCORI Mission Statement

PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

Importance of CDR

Producing information is not enough.

- Clear communication approaches and active dissemination of findings to all audiences, in easy to understand formats, are critical to increasing the awareness, consideration, adoption, and use of research by patients, caregivers, and healthcare providers
- In other words, information itself is of little use unless:
  - It reaches those who need it
  - It is clear and comprehensible

CDR Funding Objective

The CDR program seeks to fund comparative effectiveness research (CER) that:

- directly compares two or more efficacious health communication and dissemination interventions or strategies
- that engage patients, caregivers, and providers
- in the context of real-world clinical-care settings and situations
- to enable patients and caregivers to make the best possible choices among available options for care and treatment

CDR Funding Priorities

Focus on **CER** in the following three key areas:

1. **Communication strategies** to promote the use of health and healthcare CER evidence by patients and clinicians
2. **Dissemination strategies** to promote the use of health and healthcare CER evidence by patients and clinicians
3. **Explaining uncertain health and healthcare CER evidence** to patients and clinicians

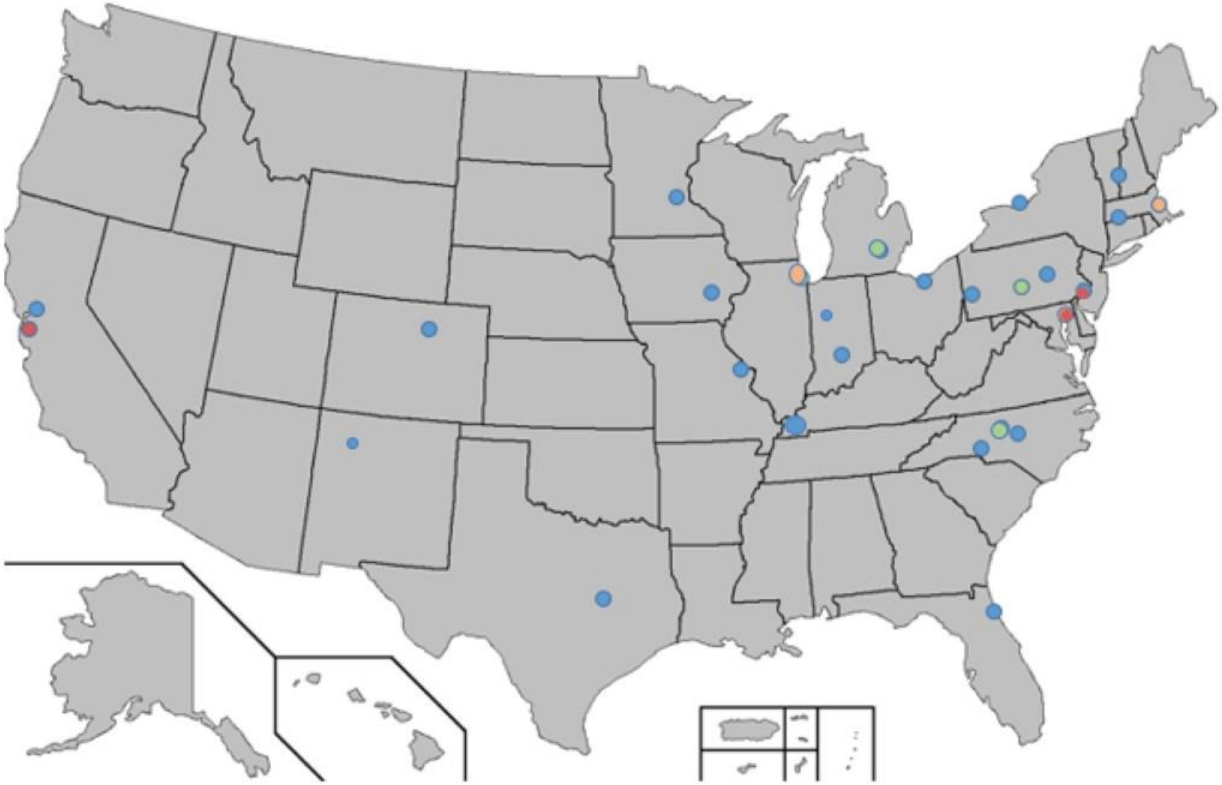
Communication and Dissemination Research

Available Funds: Up To $8 Million

Total Direct Cost Per Project : $1.5 million

Maximum Project Period: 3 years

Current Portfolio



● =1 studies
● =2 studies
● = 3 studies
● = 4 studies

Number of Projects:

44

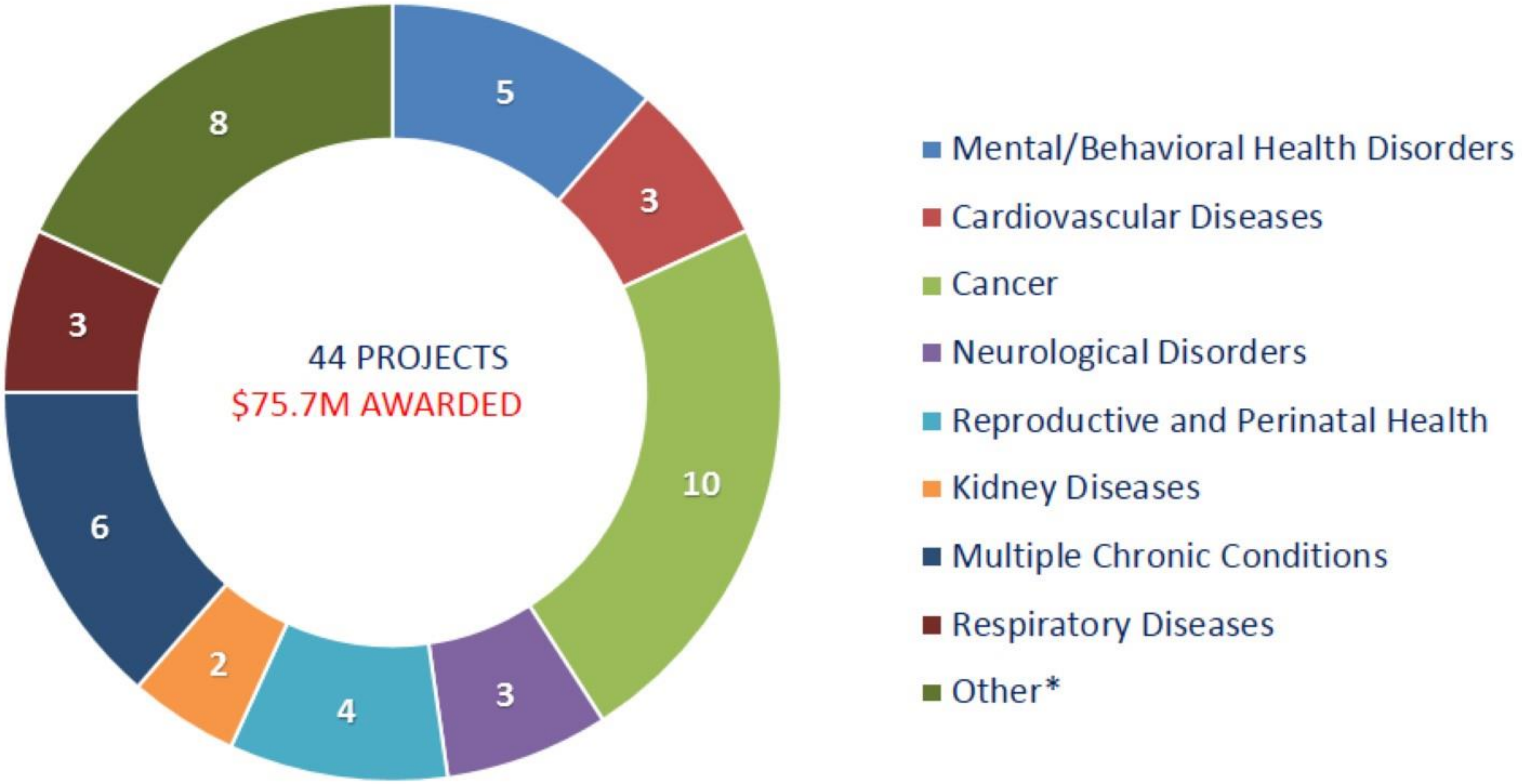
Amount Awarded:

$75.7 million

Number of states where we are funding research:

21

Portfolio by Disease/Condition



* Other includes: Diabetes (1), CT Scan Radiation Dose (1), Rare Genetic Disorders (1), etc.

Thank You!

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

D&I Limited Competition PFA

Chris Gayer, PhD

Senior Program Officer, Limited Competition Dissemination and Implementation

Purpose and Objectives

- ***Purpose***: This announcement gives PCORI awardee teams an opportunity to propose **investigator-initiated** strategies for disseminating and implementing findings from their PCORI funded studies
  - **propose the next step(s) for making their research results and any corresponding product(s) more useful, actionable, accessible and available to targeted end users**

D&I Activities We Aim to Fund

- We seek to fund projects:
  - designed to **actively** disseminate and implement research results and products
  - using approaches that are informed and guided by established dissemination and implementation models and frameworks
  - in real world settings
- This mechanism **does not** support passive dissemination strategies
  - Manuscript writing and publication
  - Scientific conference support

Supported D&I Activities

1. Develop, demonstrate, and evaluate approaches for **incorporating PCORI research results in specific decision-making settings**
2. **Adapt the content, format, or vehicle for delivering CER research evidence**, to improve its use for different populations and across settings.
3. Take results and products found effective **"to scale"** in diverse settings and populations.
4. **De-implement** or reduce the use of interventions that are not evidence-based, have been prematurely widely adopted, or are harmful or wasteful.

<u>Note</u>*: All D&I projects must* ***actively*** *disseminate/implement findings to targeted end users and* ***evaluate*** *the success of the dissemination and implementation strategy.*

2016 Application Cycles by the Numbers

	Cycle 1	Cycle 2	Cycle 3
LOIs Received	19	5	12
Full Applications Received	6	5	?
# Proposed for Funding	*In process*	n/a	?

- *D&I funding slates are approved by the Chief Engagement and Dissemination Officer.*
    - *Cycle 1 approvals in early November*
- ***Eligibility**: PCORI must be in receipt of PCORI draft final research reports corresponding to the PCORI funded research study prior to submission of full application*
- *PCORI DFRR's received to date = 15*

Questions?

15 Minute Break

Rethinking the Pipeline (P2P)

Courtney Clyatt

Program Officer

October 19, 2016

Seeking Guidance from PEAP

- **Are the overarching goals of the P2P still relevant?**

- **Are the P2P near term goals of developing PCOR capacity (as defined in our evaluation framework) still a priority for PCORI?**

- **What more do we need to know to determine the ideal structure of Pipelines going forward (i.e.: Are all three tiers valuable/necessary)?**

- **Is our current evaluation framework providing PCORI with the relevant information to determine "success" based on the P2P goals?**

- **What are the options for the structure of P2P going forward?**

Overarching Goals of P2P

- Enabling the non-researcher community (including individual patients) to drive partnership development and research project (flip the funding)
- Developing research partnerships, infrastructure and a diverse, skilled PCOR community especially in underserved and underrepresented communities
- Creating a robust Dissemination and Implementation network that recognizes the PCORI brand
- Submission of high quality PCOR/CER proposals to PCORI and other funders with strong engagement plans
- Learning about promising pre-engagement practices and methods in the P2P (P2P as a learning laboratory) and share with broader research community

Current Progressive Pipeline

Tier I
Up to $15,000
Up to 9 month term

Tier II
Up to $25,000
Up to 12 month term

Tier III
Up to $50,000
Up to 12 month term

PCORI Funding

Tier I – Pre-Engagement/Community Projects

Awardees can be patients, stakeholders or researchers. By the end of the Tier they must form a partnership with someone from a different category – e.g.: patient awardee must form partnership with researcher, researcher awardee must form partnership with patient, stakeholder awardee must form partnership with patient and researcher. Awardees must identify CER ideas.

Tier II – Partnership and Infrastructure Development Projects

Awardees must be a research partnership team. By the end of the Tier awardees will have identified CER questions in preparation for a research proposal.

Tier III Proposal Development Projects

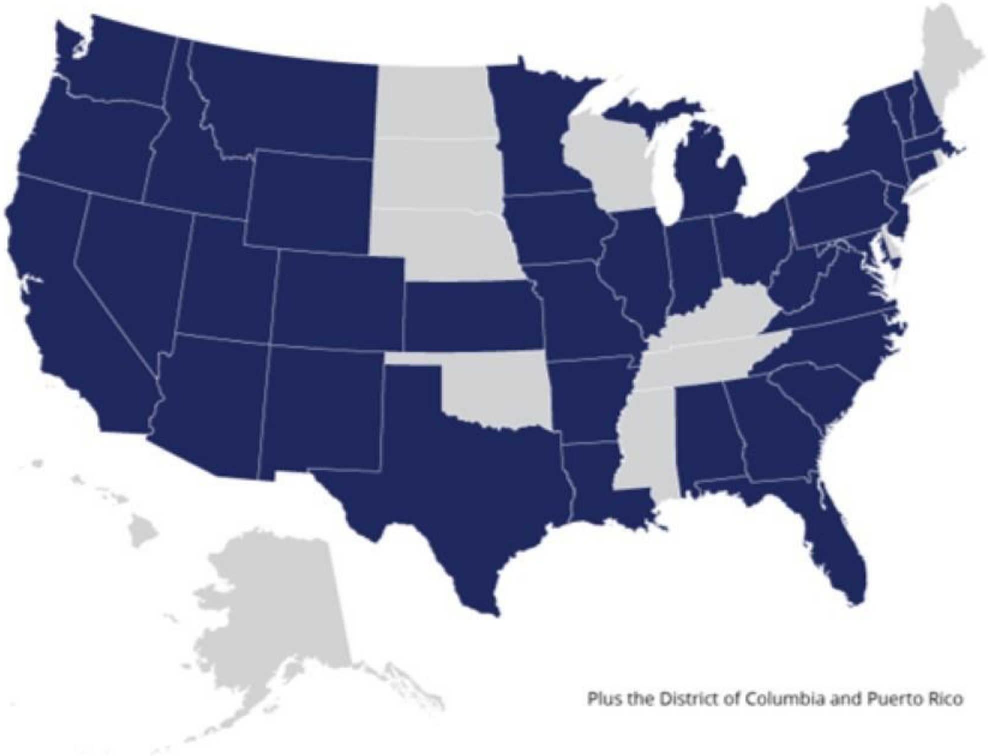
Awardees are research partnerships who will work on crafting their CER proposals during the award period. By the end of the project period they will have submitted an LOI for a PFA and will have completed an Engagement Plan for a research project.

P2P - Strengthening PCOR Nationwide

Number of projects awarded:
Tier I – 123
Tier II – 71
Tier III - 22

Amount awarded:
$4.7 Million
(Tier I Cycles 1, 2 & 3 and Tier II Cycles 1 & 2, Tier III Cycle 1)

Number of states where we are funding projects:
37 states, District of Columbia and Puerto Rico
As of July 1, 2016



Plus the District of Columbia and Puerto Rico

Outputs/Achievements from P2P

- 216 projects have yielded more than 1,000 partnerships
- 71 out of 76 Tier I projects met their deliverables and advanced to Tier II
- 22 out of 27 Tier II projects were funded for Tier III awards
- 2 Tier II projects submitted an LOI for a Research PFA and were invited to submit a full proposal
- 1 Tier II project was awarded a PCORI research project; awardee submitted for a PFA while in Tier II. All 22, Tier III Cycle 1 projects are required to submit an LOI by 3/8/17
- More than 700 project leads and partners trained on: PCOR
  - PCORI 101 –History, Mission, and Vision
  - PCOR/CER
  - Applying to PCORI
  - Merit Review Criteria
  - Methodology Standards
  - Meaningful Engagement
    - PCOR Guiding Principles
    - Engagement Rubric

Examples of Organizations with P2P Awards *

Patient Stakeholder Organizations

- Beautiful You MRKH Foundation
- Center for Practical Bioethics
- CysticLife
- Dravet Syndrome Foundation
- F.O.C.U.S. Greater Syracuse, Inc.
- Family Voices
- Family-Run Executive Director Leadership Association (FREDLA)
- Hudson River HealthCare, Inc.
- National Association of School Nurses
- National Fibromyalgia and Chronic Pain Association
- National Council of La Raza/CSULB Center for Latino Community Health, Evaluation and Leadership Training
- National Psoriasis Foundation
- SolSurvivors
- Spina Bifida San Diego
- St. Anna's Episcopal Church
- The Sickle Cell Association of New Jersey
- Zero Breast Cancer

Hospital Systems

- Children's Mercy Hospital
- Columbia Gorge Family Medicine
- Department of Orthopaedic Surgery, Hospital for Joint Diseases, NYU Langone Medical Center
- Henry Ford Health System
- Miners' Colfax Medical
- Palo Alto Medical Foundation
- Patient-Centered Primary Care (PCPC) Team, K-6 Adult Medicine Clinic, Highland Hospital"
- Seattle Children's Hospital
- Sutter Health, University of Utah

Universities and Research Centers

- Adelphi University
- Billings Clinic Center for Clinical Translational Research
- Georgetown University
- Georgia Center for Oncology Research and Education
- GW Cancer Institute, GW School of Medicine
- Loma Linda University
- Medical University of South Carolina
- Minneapolis Medical Research Foundation
- New Mexico State University
- Northeastern University
- Northwestern University
- The Board of Trustees of the University of Illinois
- Tufts University
- Tulane University
- UC Davis Medical Center, Section of General Thoracic Surgery
- University of Arkansas for Medical Services
- University of Colorado Denver - College of Nursing
- University of Florida Board of Trustees
- University of New Mexico
- University of Nevada-Las Vegas
- University of North Carolina-Chapel Hill
- University of Rochester
- University of South Florida
- University of Southern California
- University of Utah School of Medicine
- Washington State University College of Nursing
- Wayne State University

*this list is not inclusive of all awarded organizations/individuals

Independent Tier III

Tier III

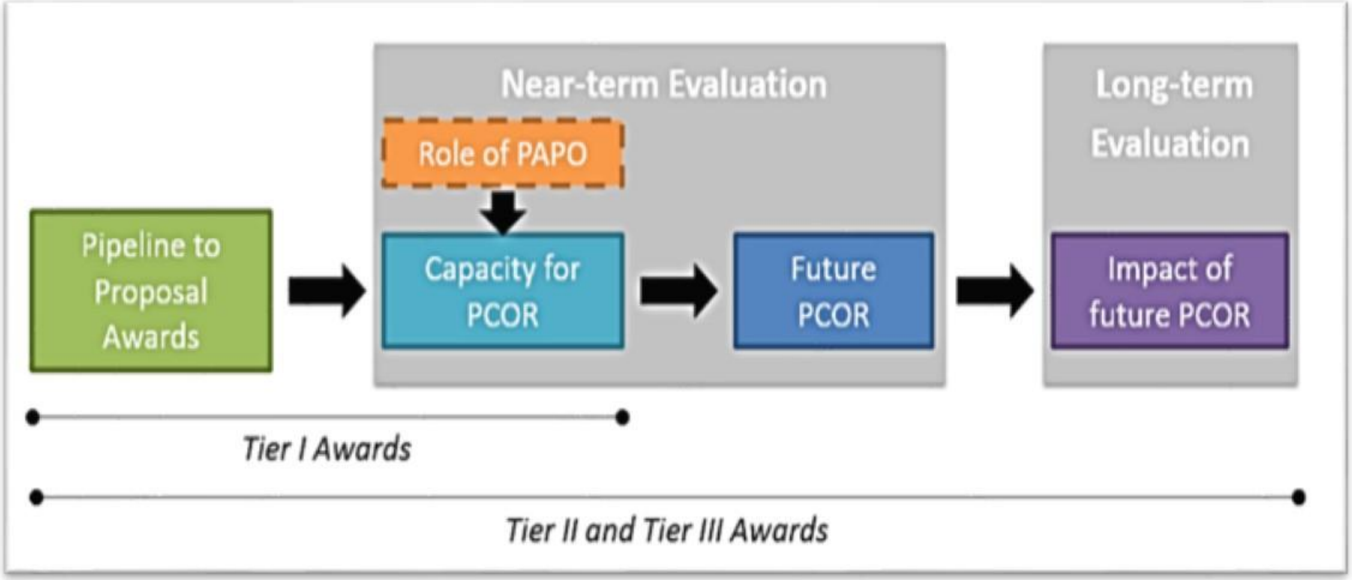
Up to $50,000

Up to 9 month term

PCORI Funding

Awardees are established research partnerships who will work on crafting their CER proposals during the award period. By the end of the project period they will have submitted an LOI for a PFA and will have completed an Engagement Plan.

Evaluating the Pipeline to Proposal Awards



We hypothesize that Pipeline to Proposal Awards will **promote capacity for PCOR** (e.g., organizational structures, resources, collaborative relationships, policies, procedural protocols, and commitment to patient-centeredness needed to conduct PCOR). Moreover, we expect that this capacity will **lead to future PCOR** which will ultimately have a scientific and clinical impact.

Evaluation Activities

2015 - Contracted with AIR to answer the following:

1. Are these investments successful in fostering partnerships?
2. What are some elements of successful partnership structures?
3. Did these partnerships embody the PCOR Engagement Principles?
4. To what extent did this project prepare Awardees to pursue research funding from PCORI or another funder?

2016 – Contracted with AIR to address the following:

1. How did these partnerships among patients, stakeholders, and researchers embody the PCOR Engagement Principles?
2. What additional, crosscutting, themes from the Tier I, Cycle 1 analysis were apparent among the Tier I, Cycle 2 responses?
3. What new themes were identified among responses from Tier I, Cycle 2 awardees and partners?

Are there other questions that the PEAP would like answered?

PCOR Principles in the Pipeline (as Reported by Tier I Cycle 2 Awardees)

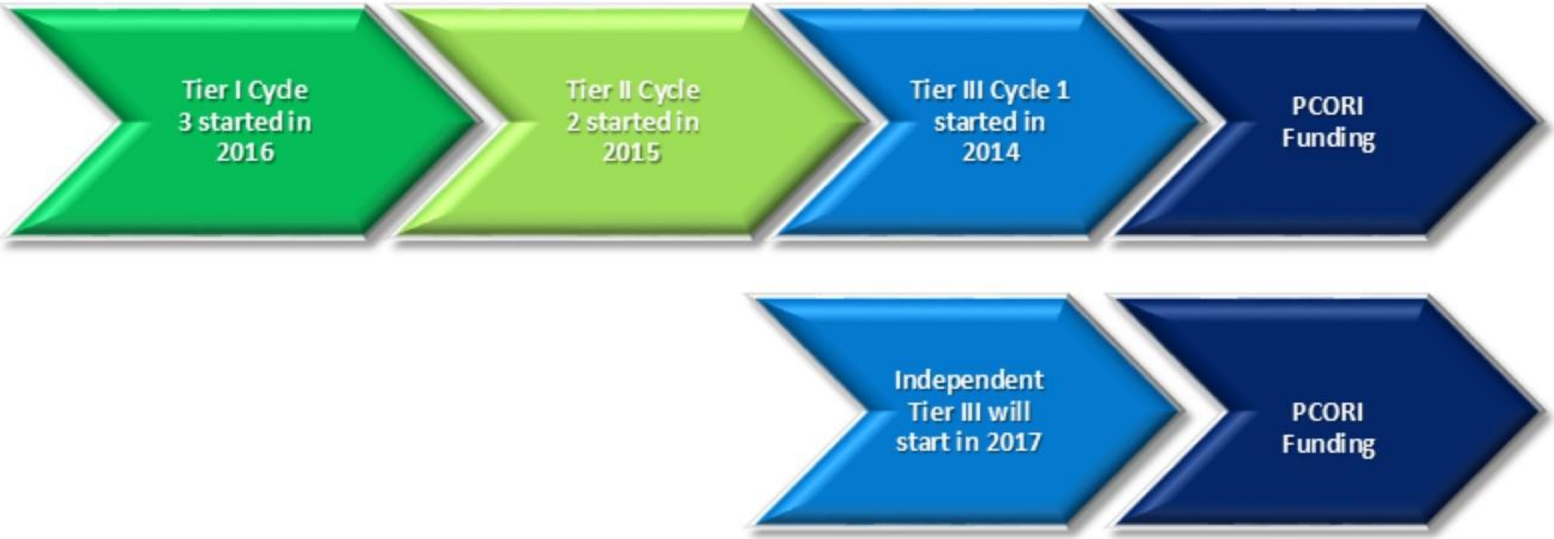
Co-learning	• "There is a **lot to learn about how a study is worked,** numbers needed, testable and who we might need to assist us" **(**Patient)
Reciprocal Relationships	• **"Relationship building** is vital and time consuming. The partnership development piece in itself is a **significant endeavor** and we are very thankful to PCORI for providing us the opportunity to focus on establishment of Governance and Stakeholder Engagement/Communication" (Researcher) • "Very important to create a **sense of team** - Important to have **relationship building** experiences - Very important to have someone directly in charge of making sure **families/patients feel connected and heard**" (Researcher)
Trust/Transparency/Honesty	• "The PI had to go out and find these partners…and carefully did so and worked to build relationships first. This has led to a great amount of goodwill and **trust** and respectful team work in this first part of Tier 2." (Researcher)
Partnership Building	• **Partnership** takes a whole lot of **work and time**, but the final results are **more reliable** and reflect the views of more than one individual. Partners bring **different assets** to the group which help tremendously with the project" (Clinician)

Next Steps

What should be the next step in the pipeline?

- Continue "as is" and launch a new progressive cycle in 2017?
- Only launch another Independent Tier III in 2017?
- Launch another Cycle AND an Independent Tier III in 2017?
- Make Tier III Competitive
- Redesign/Streamline Tiers

Length of the Pipeline



Tier I Cycle 3 started in 2016

Tier II Cycle 2 started in 2015

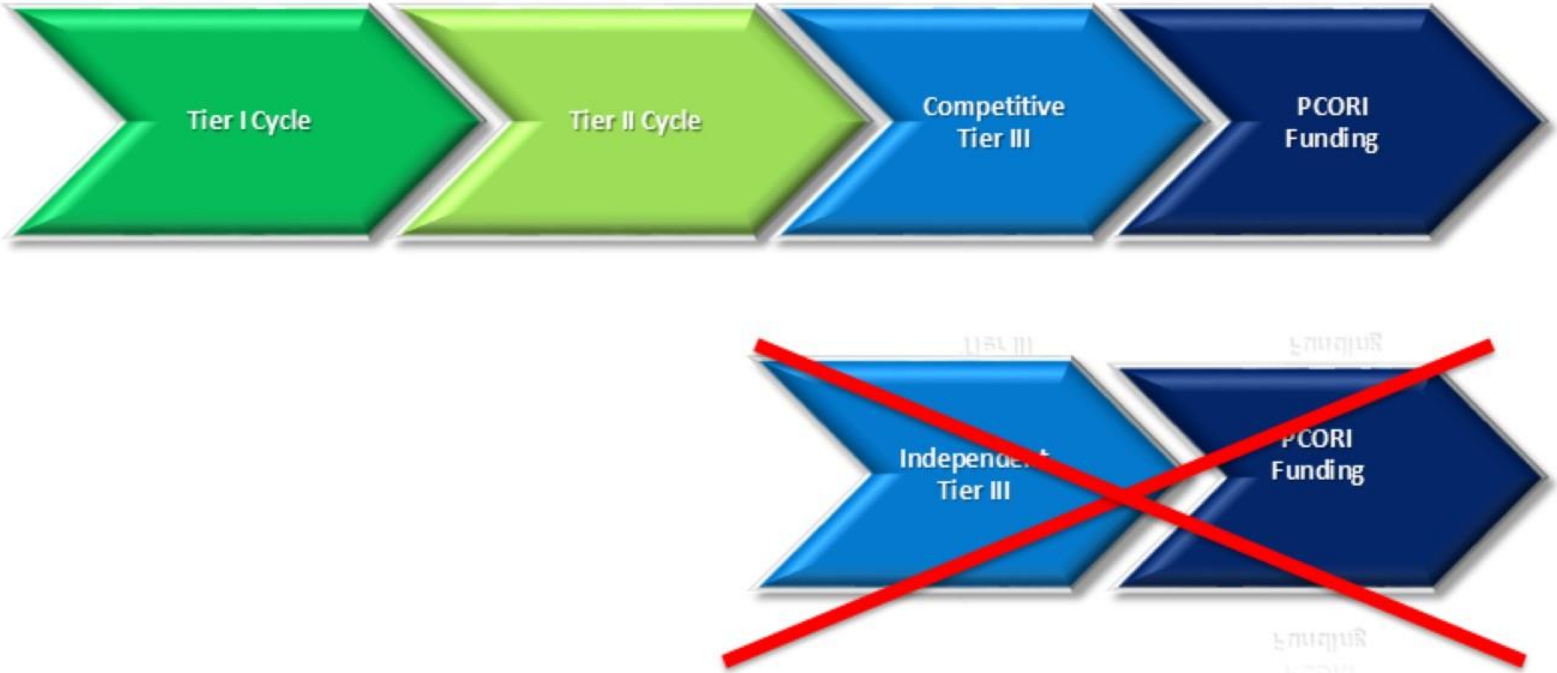
Tier III Cycle 1 started in 2014

PCORI Funding

Independent Tier III will start in 2017

PCORI Funding

Competitive Tier III



Tier I Cycle

Tier II Cycle

Competitive Tier III

PCORI Funding

~~Independent Tier III~~

~~PCORI Funding~~

Streamlining the Pipeline Combining Tiers I & II with a Competitive Tier III

Tier I/II

Up to $40,000

Up to 12 month term

Competitive Tier III

Up to $50,000

Up to 6 month term

PCORI Funding

Engagement Resources may help streamline proposal-development process

- **PCORI's "Engagement Rubric"**
  http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf
- **Sample Engagement Plans**
  http://www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf
- **PCORI Compensation Framework**
  http://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf
- **Engagement in Research website page**
  http://www.pcori.org/content/engagement-research
- **PCORI's Methodology Standards PC-1 to PC-4**
  http://www.pcori.org/assets/PCORI-Methodology-Standards1.pdf

Seeking Guidance from PEAP

- **Are the overarching goals of the P2P still relevant?**
- **Are the P2P near term goals of developing PCOR capacity (as defined in our evaluation framework) still a priority for PCORI?**
- **What more do we need to know to determine the ideal structure of Pipelines going forward (i.e.: Are all three tiers valuable/necessary)?**
- **Is our current evaluation framework providing PCORI with the relevant information to determine "success" based on the P2P goals?**
- **What are the options for the structure of P2P going forward?**

Discussion

PEAPs in Action

John Chernesky – Consumer Engagement in Spinal Cord Injury Research at the Rick Hansen Institute

Lorraine Johnson – LymeDisease.org

Anjum Khurshid – Children's Comprehensive Care Clinic

Megan Lewis – Delphi Panel Study

Regina Greer Smith – Pastors4PCOR and CAPriCORN CDRN Patient Clinician Advisory Council

Jack Westfall – High Plains Research Network Community Advisory Council

Pastors4PCOR
COMMUNITY HEALTH
OUTREACH

Pastors4PCOR

Building the Capacity of Faith-based Communities to Engage in Health Research Initiative:

Pastors4PCOR (P4P) Celebration of Research Ministry Ambassadors

October 1, 2016, Chicago, IL

Dr. Rebecca Johnson
Northwestern University

Dr. Diana Ingram
Rush University Medical Center

Dr. Paris Davis, Executive Director, Triedstone Total Resource CDO

Regina Greer-Smith, MPH, LFACHE, S.T.A.R. Initiative

How it all began ….

S.T.A.R. Initiative©
STRATEGICALLY TARGETING APPROPRIATE RESEARCHERS

+

Southland Ministerial Health Network
"Providing Information, Inspiration and Resources"

+

Academic Partner

"A community advocate and faith-based partners focused on the promise that PCOR (patient centered outcomes research) holds for underserved communities and joined an activated faith-based partner seeking social justice in healthcare and answers to its community health status" ***-Regina Greer-Smith***

CHICAGO, ILLINOIS

Short Distances to Large Gaps in Health

Follow the discussion
#CloseHealthGaps

© 2015 Robert Wood Johnson Foundation

Road map to healthy communities

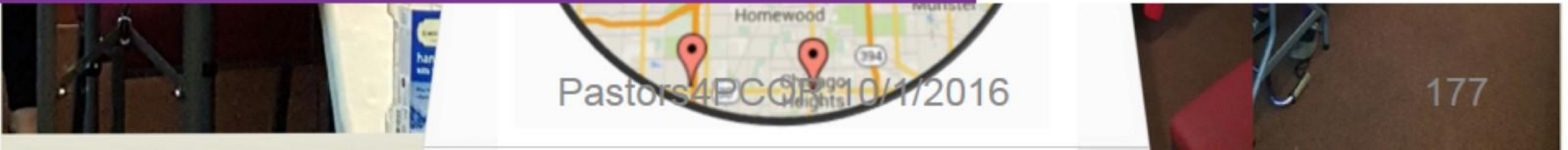
Health Outcomes

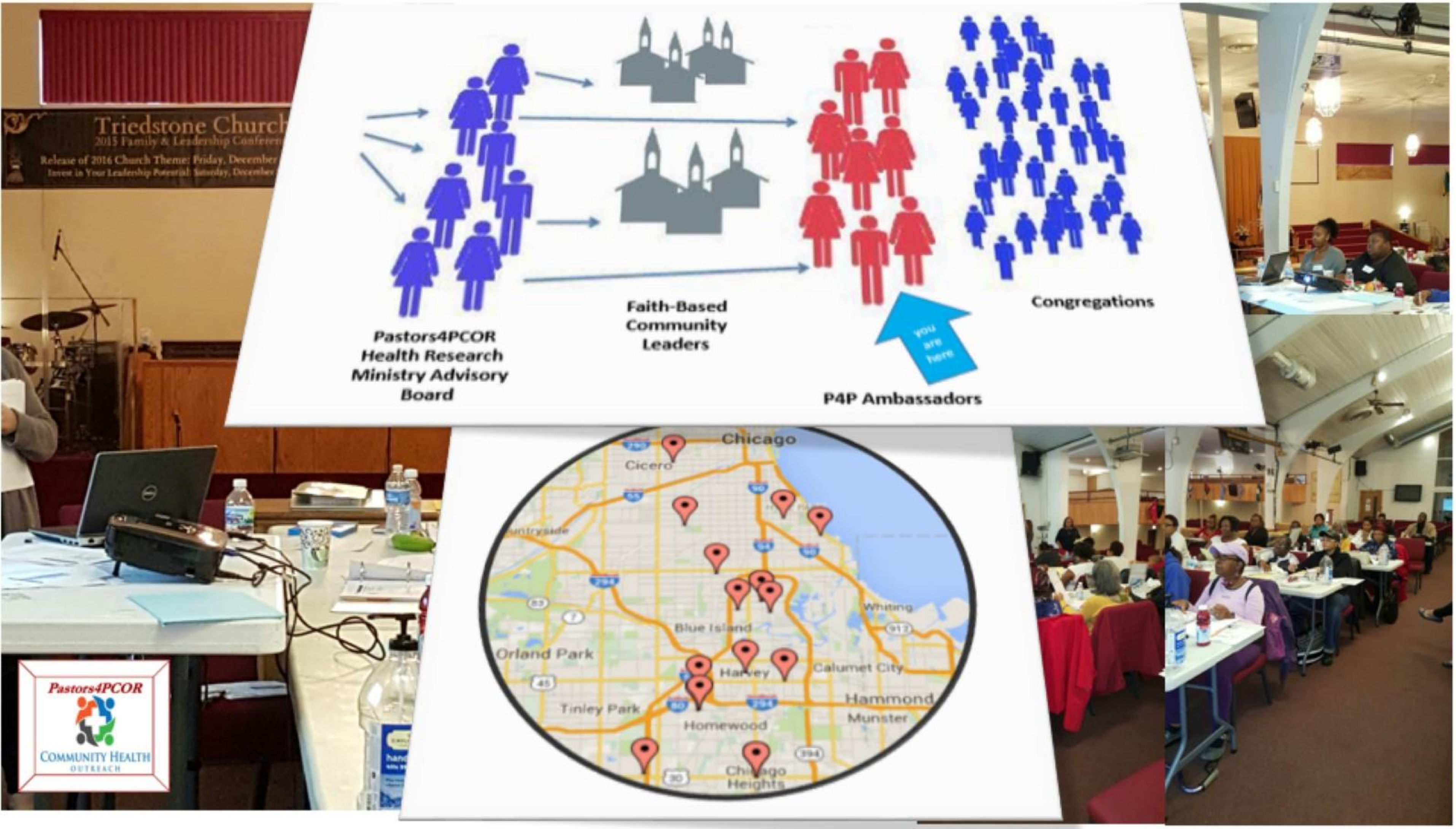
Life expectancy data Chicago

Illinois and Cook County data

Faith based communities

Health Factors





Pastors4PCOR Health Research Ministry Advisory Board

Faith-Based Community Leaders

P4P Ambassadors

you are here

Congregations

Pastors4PCOR
Community Health Outreach

Pastors4PCOR: Engaging Faith-based Communities

Guiding Principles

- Partners commit to open and honest communication
- Major decisions are made inclusively and information is shared
- Partners communicate study back to their own communities in meaningful and usable ways

Pastors4PCOR
COMMUNITY HEALTH
OUTREACH

Pastors4PCOR's Mission

"To increase the participation of underserved communities of color in comparative effectiveness research and patient centered outcomes research through the design, development and implementation, reporting and dissemination of research."

<u>We will achieve this by</u>:

✓Fostering relationships to build a robust research infrastructure in the church communities; and

✓Building the capacity of faith-based communities to engage in health research.

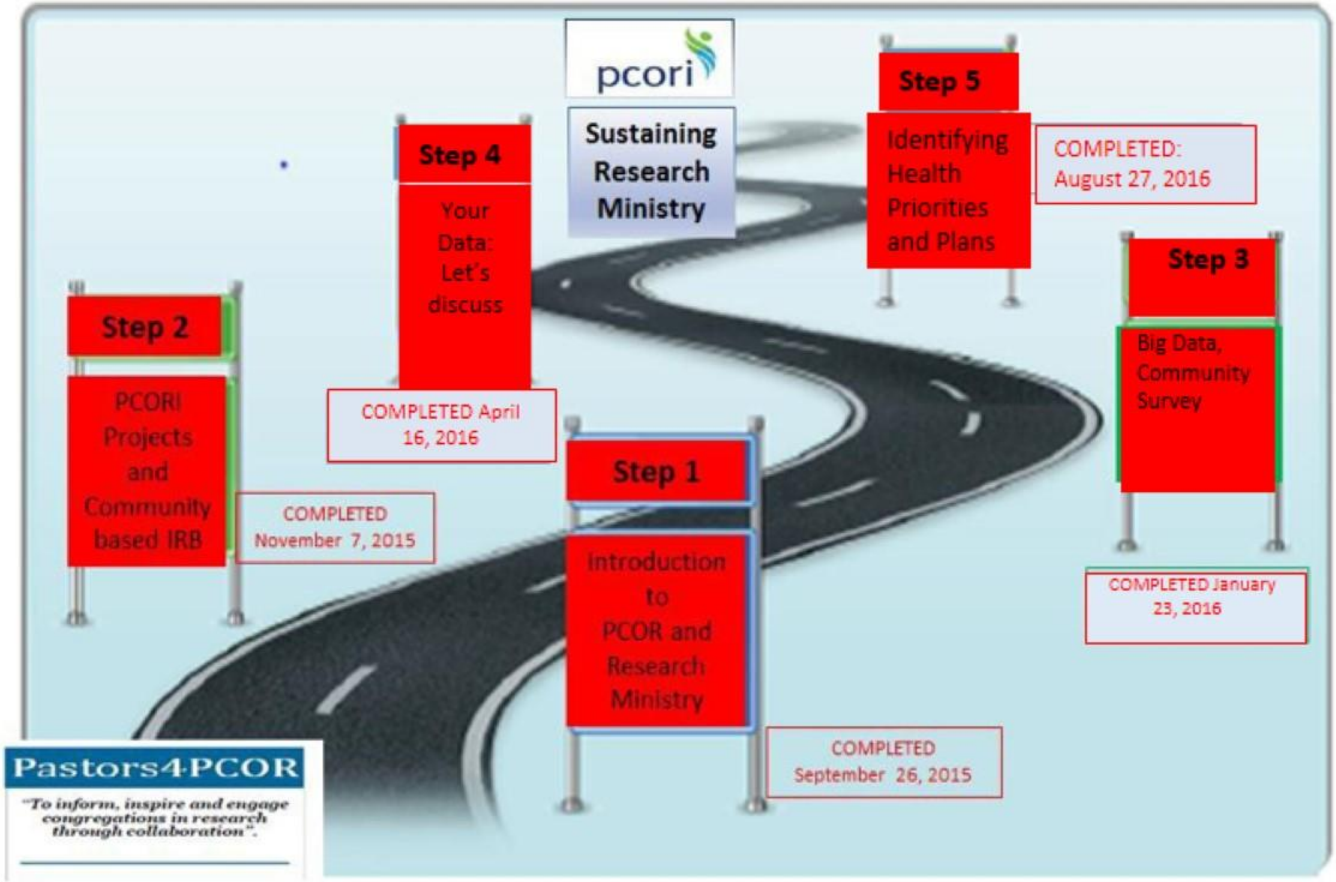
✓Partnering with researchers from academic research centers;

P4P BOARD OF DIRECTORS

First Name	Last Name	Board Role	Affiliations
Simon	Gordon	Advisory Board Chairman	Bishop, Triedstone Baptist Full Gospel Church
Walter	Turner III	Advisory Board Co-Chairman	Senior Pastor – New Spiritual Light Church
Paris	Davis, PhD, MBA	Executive Director	Total Resources Development Corporation- Triedstone Baptist Full Gospel Church
Rebecca	Johnson, PhD	Advisory Board Member Academic partner	Buehler Center for Aging, Health & Society, Feinberg School of Medicine Northwestern Memorial Hospital
Regina	Greer-Smith, MPH, LFACHE	Advisory Board Member Community Advocate	Healthcare Research Associates, LLC S.T.A.R. Initiative
Diana	Ingram, PhD, MPH	Advisory Board Member Academic partner	Rush University Medical Center
Gennadyi	Voronov, MD	Advisory Board Member Health care systems	John H. Stroger Hospital of Cook County Health and Hospitals System
Ralph	Martire	Advisory Board Member Community Advocate	Center for Tax and Budget Accountability (CTBA)
Beverly	Rogers, BA, CWA	Advisory Board Member Community	Community Member – Caregiver Advocate Jeremiah Community Outreach Services
Dena	Craig	Advisory Board Member Community	Media

Pastors4PCOR
Research Ministry Ambassadors and Project Team

Our Journey Completed!



pcori

Step 1

Introduction to PCOR and Research Ministry

COMPLETED September 26, 2015

Step 2

PCORI Projects and Community based IRB

COMPLETED November 7, 2015

Step 3

Big Data, Community Survey

COMPLETED January 23, 2016

Step 4

Your Data: Let's discuss

COMPLETED April 16, 2016

Step 5

Identifying Health Priorities and Plans

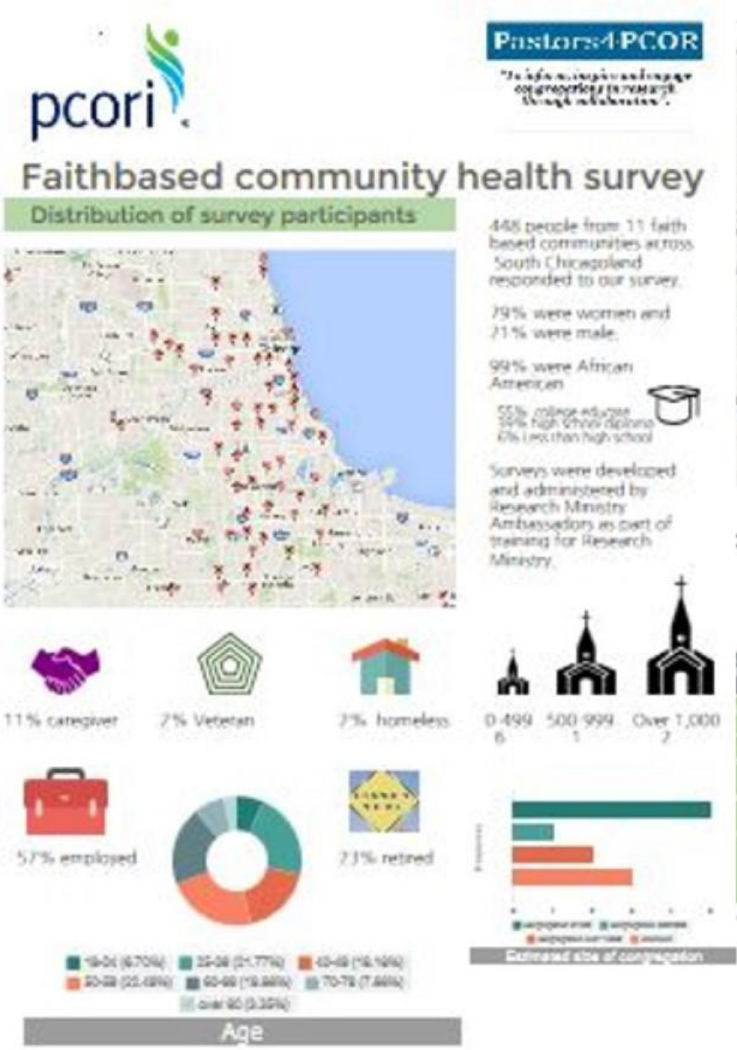
COMPLETED: August 27, 2016

Sustaining Research Ministry

Pastors4PCOR

"To inform, inspire and engage congregations in research through collaboration".

Pastors4PCOR
COMMUNITY HEALTH OUTREACH



pcori

Pastors4PCOR

Faithbased community health survey

Distribution of survey participants

448 people from 11 faith based communities across South Chicagoland responded to our survey.

79% were women and 21% were male.

99% were African American

55% college educated
39% high school diploma
6% less than high school

Surveys were developed and administered by Research Ministry Ambassadors as part of training for Research Ministry.

11% caregiver

7% Veteran

7% homeless

0-499
6

500-999
1

Over 1,000
2

57% employed

23% retired

Estimated size of congregation

Age

TRIEDSTONE

Highlighting Triedstone faith based community members survey responses

pcori

01 | DEMOGRAPHICS

OF TRIEDSTONE COMPLETED THE FAITH BASED
VEY. TRIEDSTONE HAS A CONGREGATION OF OVER 2,000.

Triedstone differences ...

76% of Triedstone respondents were female and 23% were male.

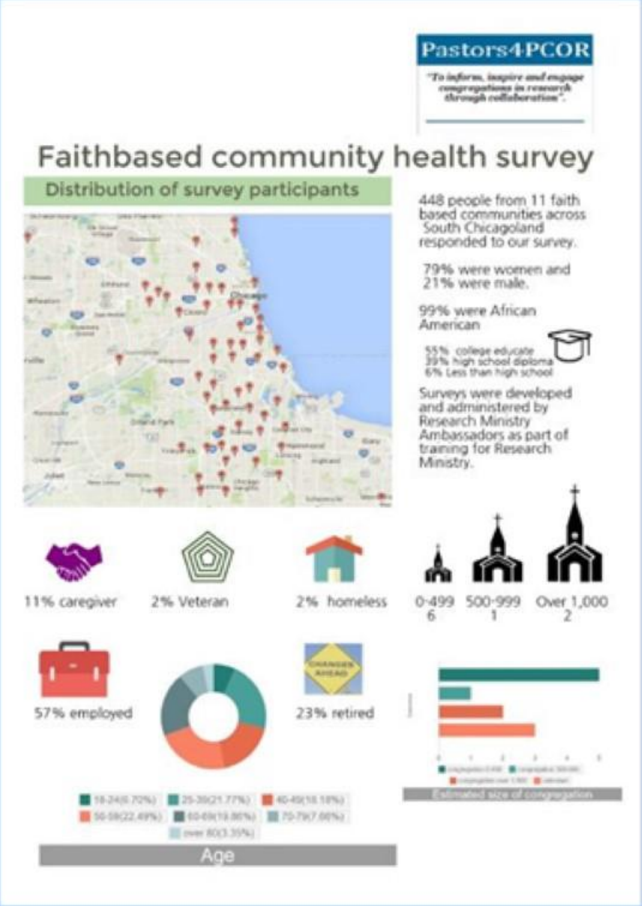
22% of Triedstone respondents were caregivers

Most Triedstone respondents were aged between 26 and 69 and none were aged 80 or above

Fewer were retired and more were in employment.

Pastors4PCOR
COMMUNITY HEALTH OUTREACH

Priority Health Conditions: Survey Results



Pastors4PCOR

"To inform, inspire and engage congregations in research through collaboration".

Faithbased community health survey

Distribution of survey participants

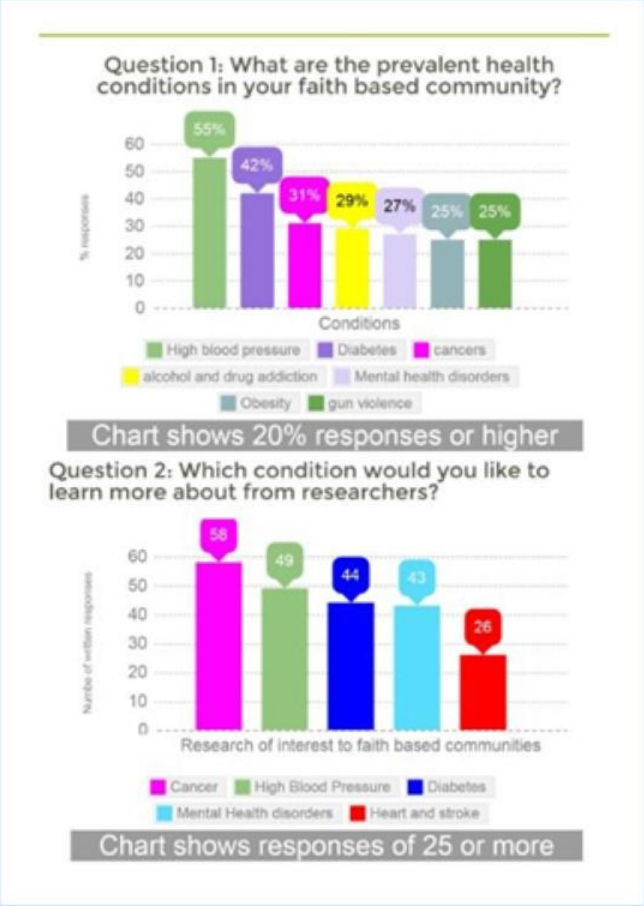
448 people from 11 faith based communities across South Chicagoland responded to our survey.

79% were women and 21% were male.

99% were African American

55% college educate
39% high school diploma
6% Less than high school

Surveys were developed and administered by Research Ministry Ambassadors as part of training for Research Ministry.



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

Health Factors and Resources: Survey Results

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

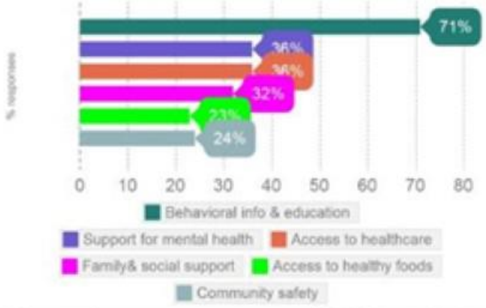
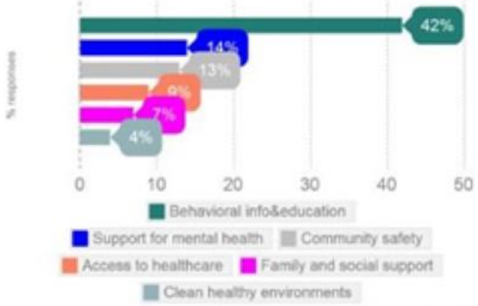


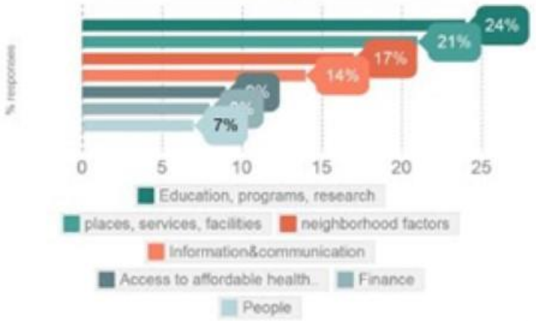
Chart shows responses of 20% or higher.

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



In your opinion where should we start?

Question 5: What are the resources your faith based community needs to address the health conditions and factors you have identified?



Resources needed to support faith-based community efforts to improve health

Occupational experience

Faith based community members and the health industry

Things We Learned Together While Developing P4P Network:

Successes

- Open lines of communication
- Working relationships
- Complement of skills and personalities
- Finding funds to sustain project
- New partnerships

Challenges

- Time
- Getting to know each others processes and infrastructure
- Mapping the geography of faith based communities

Things we learned together about Engaging Faith-based Communities with Health Research:

Successes

- Support from pastors
- Growing confidence of learners
- Learner enthusiasm and engagement
- Community based IRB certification
- New partnership opportunities for individuals and churches

Challenges

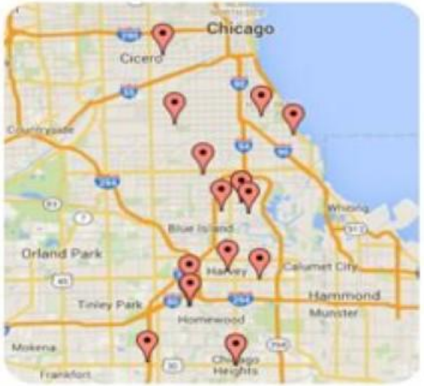
- Time for support and mentoring
- Difficult for participants to attend every step
- Finding time when everyone can attend meetings
- Engagement research is time consuming
- Research is temporary and no substitute for health services

Pastors4PCOR
COMMUNITY HEALTH
OUTREACH

Key Project Deliverables

- ✓ 11 Churches members of P4P Network
- ✓ 14 Trained RMAs
- ✓ 100% RMAs IRB Certified
- ✓ 3-5 Health Factors Identified
- ✓ 3-5 Health Conditions Identified
- ✓ Partnership with Health Research Team Agreed

Research Ministry Next Steps



Planning your year...

Pastors4PCOR Research Ministry 2016

JANUARY
FEBRUARY
MARCH
APRIL

MAY
JUNE
JULY
AUGUST

SEPTEMBER
OCTOBER
NOVEMBER
DECEMBER

RMA Graduation!

ADAPTABLE Partnership

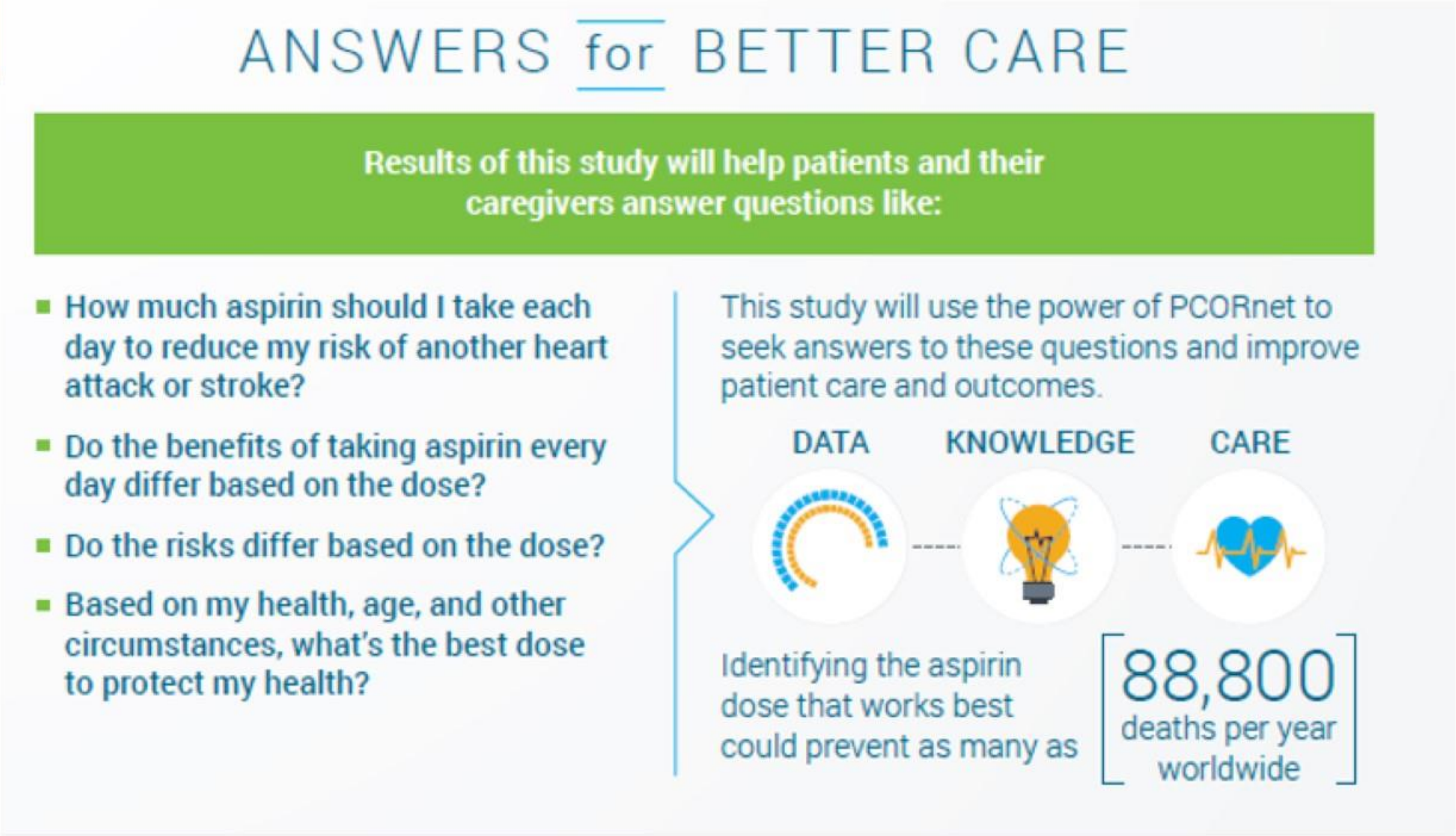
Plan to Attend RMA 2017 1
Quarterly Meetings!

Letter of Intent for EA Award: Train the Trainer

Work with Another RMA!

Schedule Forum

P4P and ADAPTABLE



ANSWERS for BETTER CARE

Results of this study will help patients and their caregivers answer questions like:

- How much aspirin should I take each day to reduce my risk of another heart attack or stroke?
- Do the benefits of taking aspirin every day differ based on the dose?
- Do the risks differ based on the dose?
- Based on my health, age, and other circumstances, what's the best dose to protect my health?

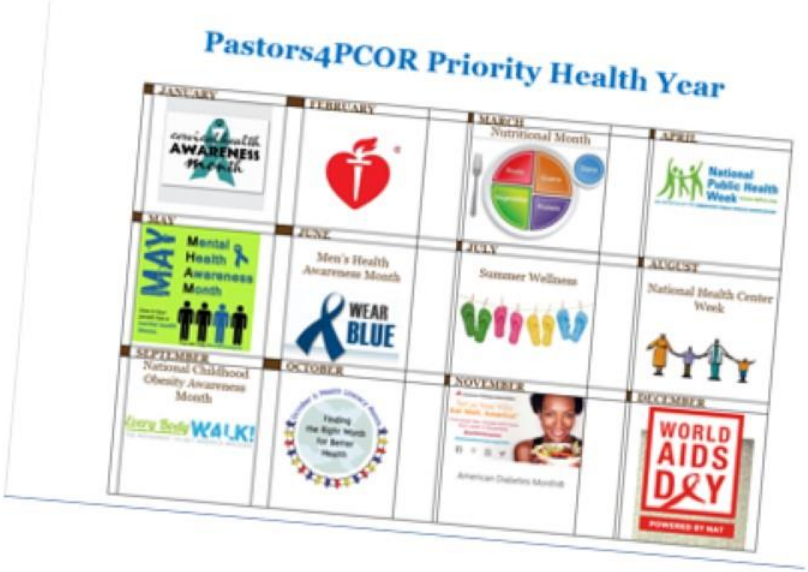
This study will use the power of PCORnet to seek answers to these questions and improve patient care and outcomes.

Identifying the aspirin dose that works best could prevent as many as

88,800 deaths per year worldwide

Other Tools to Sustain Research Ministry

- Research Ministry Ambassador Alumni meeting – February/March 2017
- Pastors4PCOR Priority Health Year



Pastors4PCOR Priority Health Year

JANUARY	FEBRUARY	MARCH Nutritional Month	APRIL
MAY	JUNE Men's Health Awareness Month	JULY Summer Wellness	AUGUST National Health Center Week
SEPTEMBER National Childhood Obesity Awareness Month	OCTOBER	NOVEMBER American Diabetes Month	DECEMBER

Research Ministry Ambassador Pledges, Session #5

"One thing I liked about the session is that I have a Pledge to help my church and community with health issues!"

I pledge to schedule an educational / informational forum by November, 2016.

- I pledge to help raise men's awareness about the importance of participating in Health Research.
- I pledge to become more involved in community-based/faith-based research activities.
- I pledge to work with others to assist his/her church in health fairs. (Commit to at least 1 RMA!)
- I pledge to do more research networking on the PCORI website.
- I pledge to participate in ADAPTABLE.
- I pledge to seek out others to come and join Pastor4PCOR.
- I pledge to be an Ambassador for Health Education for Seniors. (Healthy Eating, Exercise, etc.)

I have been energized to take things forward in my faith-based community Health Ministry.

Research Ministry Ambassador Certificate

GRADUATION CELEBRATION HELD ON OCTOBER 1 2016, TRIEDSTONE

Certificate of Appreciation

This is to certify that

PASTORS4PCOR

Regina Greer-Smith

Expressing our appreciation from the Pastors4PCOR Board of Directors and Research Ambassadors for all the time and effort you put in to personally make the Pastors4PCOR Health Research Ambassadors Program a success. The Training Program consisted of training for Community Involvement in Human Research Protections for (non-Academic) Community Research Partners, and included but was not limited to: (2) Community At-Large Outreach Events and the following modules:

Training Module #1	**Introduction to PCORI, Funded Projects and Networks (PPRN and CDRNs)**
Training Module #2	**CIRTification: Community Based-IRB for Research Partners**
Training Module #3	**Big Data, Clinical Research and the Relevance to Faith-based Communities**
Training Module #4	**Participant Surveying of Faith-based Community Health Priorities and Resource Asset Mapping**
Training Module #5	**Community Survey Generation, Administration, & Interpretation**

Bishop Simon Gordon, Chairman

Rev. Walter Turner, Co-Chairman

Dr. Paris Davis, Executive Director

"Faith Joining
Community
for
Health Research"

Presented by:
Lia Hodgkiss
PCORI Engagement Award Officer.
October 1, 2016

Research Ministry Ambassador Certificate

GRADUATION CELEBRATION HELD ON OCTOBER 1 2016, TRIEDSTONE CHURCH

Contact Information

Project Lead

Dr. Paris Davis email: drpdavis77@gmail.com

Research Ministry Ambassador Trainers

Regina Greer-Smith email: healthcareresearch@sbcglobal.net

Dr. Rebecca Johnson email: rebecca.johnson@northwestern.edu

Dr. Diana Ingram email: diana_ingram@rush.edu

Patient Engagement Advisory Panel, PCORI

Patient-Centered, Story-telling App for Complex Needs Children

Rahel Berhane, MD
Anjum Khurshid, MD PhD

October 21, 2016

Challenges

- Health care delivery system relegates patients to passive recipients of care

- Health care technology shortcomings inhibit engagement
  - Fragmented stories – data siloes
  - Information overload
  - Institutional culture –Data blocking
  - Privacy – Legal hurdles

Objectives

- Design and implement a patient-centered community health data ecosystem in a pediatric multidisciplinary care clinic

- Evaluate use rate and its effectiveness in enhancing patient engagement and self management

Comprehensive Care Clinic

- Two separate programs

  - Medical Home for medically fragile children

  - "Clinic without walls" – Community based program for children with behavioral complexity

Project Plan

- Phase I
  - Define the project as " Collaborative Story telling"
  - Design a prototype
- Phase II
  - Define a governance structure for data ecosystem
  - Develop a platform for data aggregation
- Phase III
  - Implement " Collaborative Story telling" application
  - Evaluate outcomes
- Phase IV
  - Scale up to a community-wide platform
  - Engaged patients/caregivers participate in research collaboration

Partners and Stakeholders

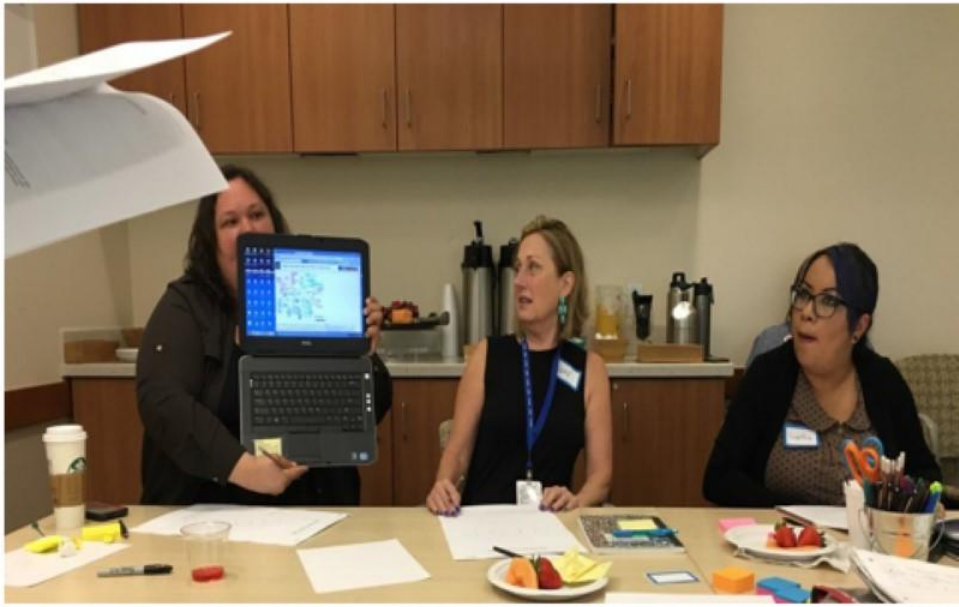
Technology Partners

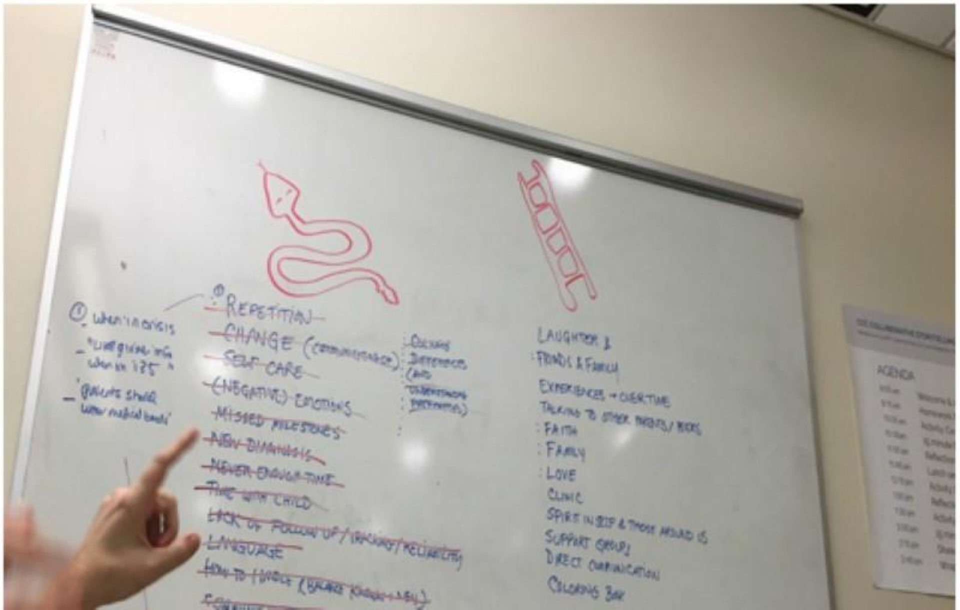
- Theresa Neil Strategy and Design
- Cloud Forest Solutions
- Privacera

Stakeholders

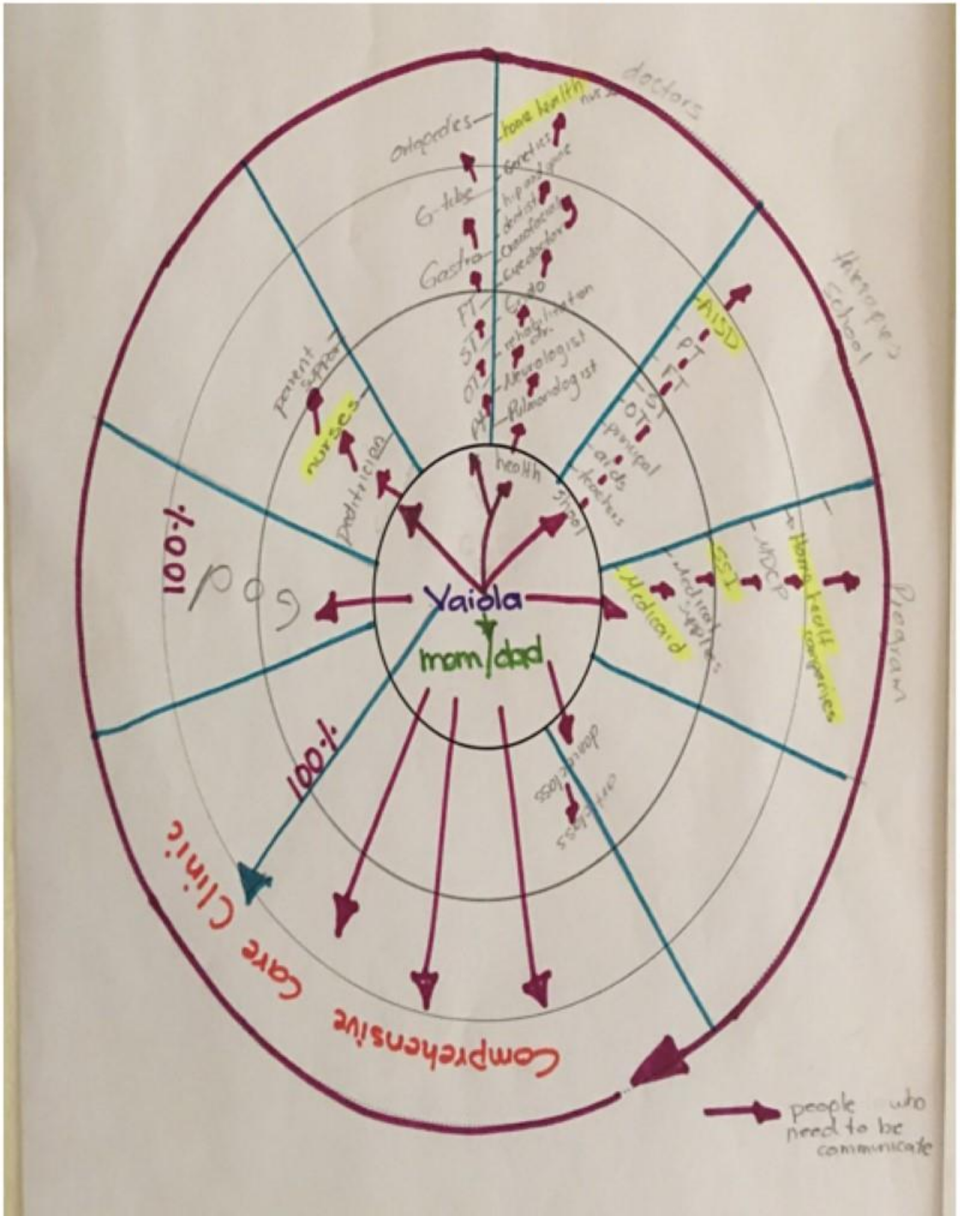
- Parents of children in CCC clinic
- Providers and case managers at CCC
- Managed Care Organizations (Superior, BCBS)
- Community (AISD; Family Resource Center)
- School nurses
- DME/Home health/Therapy agencies

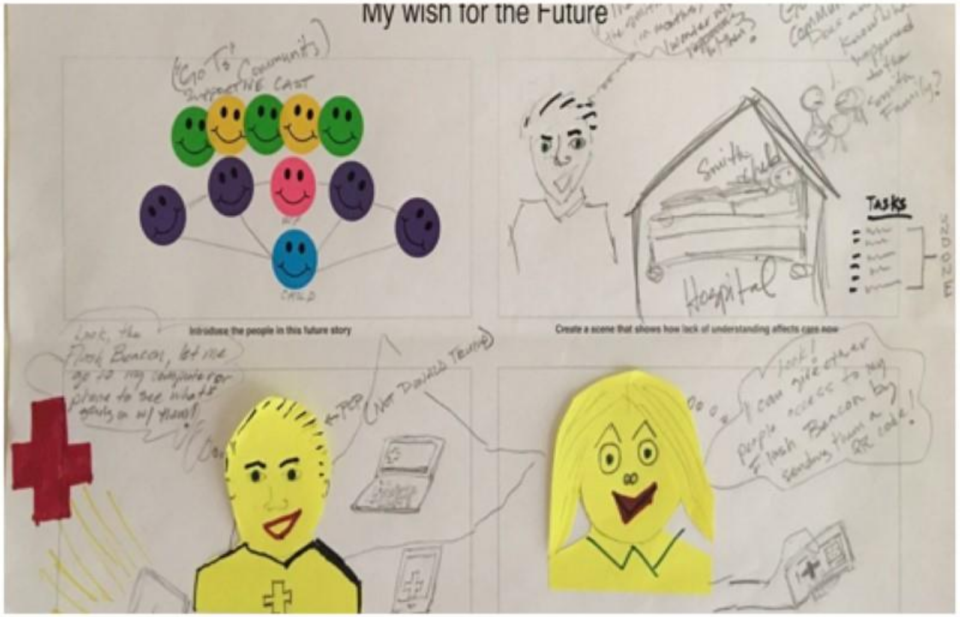
Day 1: Family Perspective

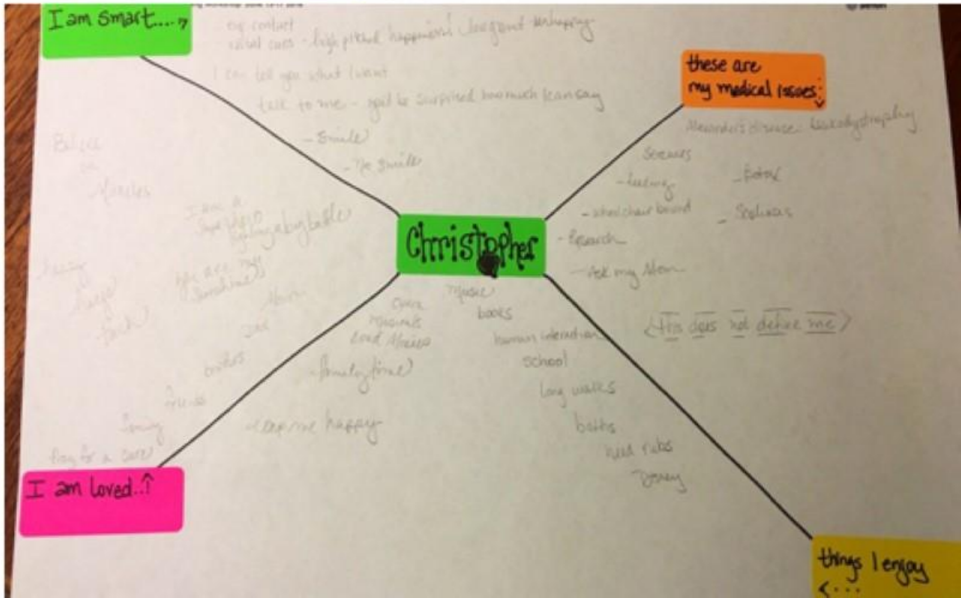




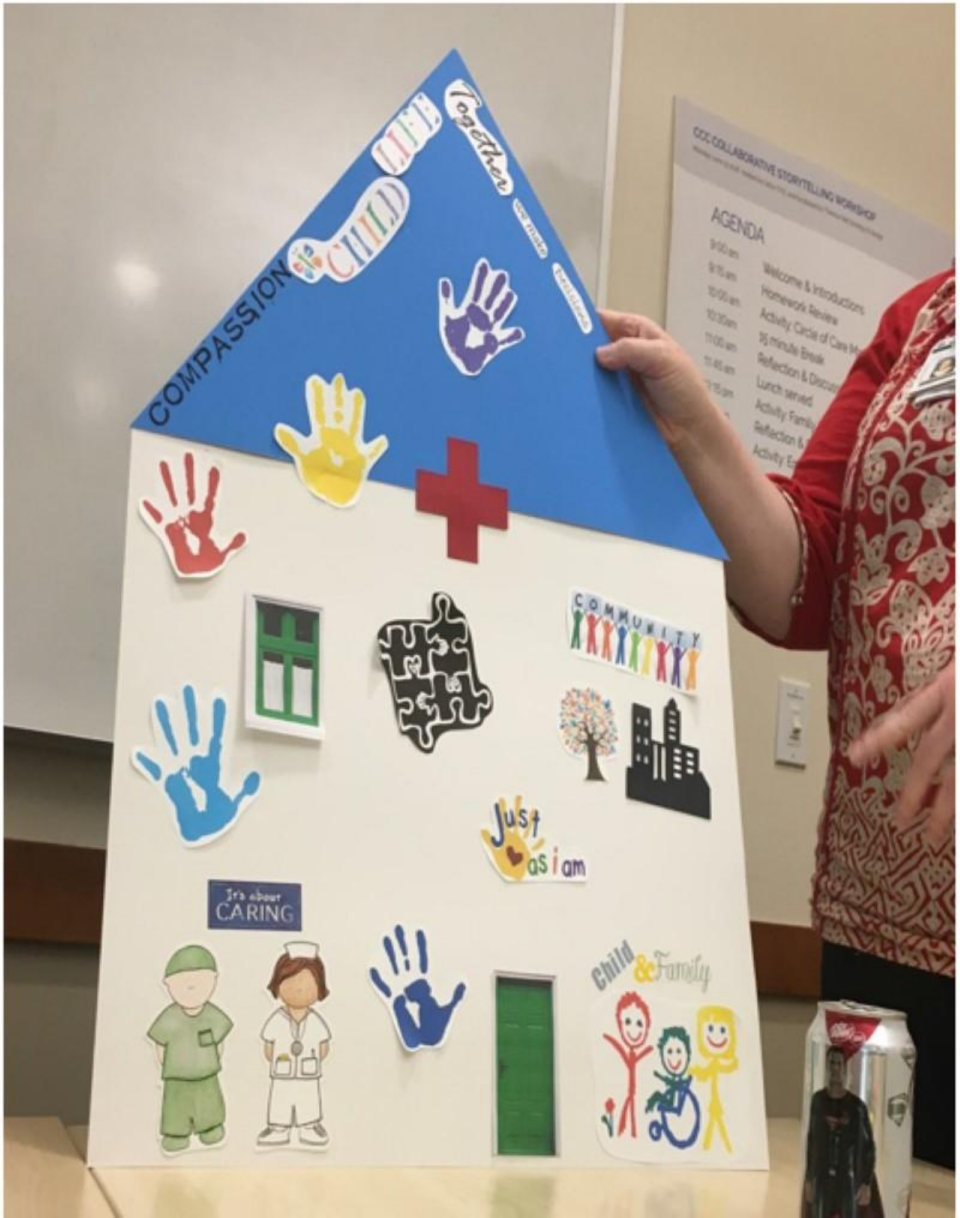
Day 1: Family Perspective



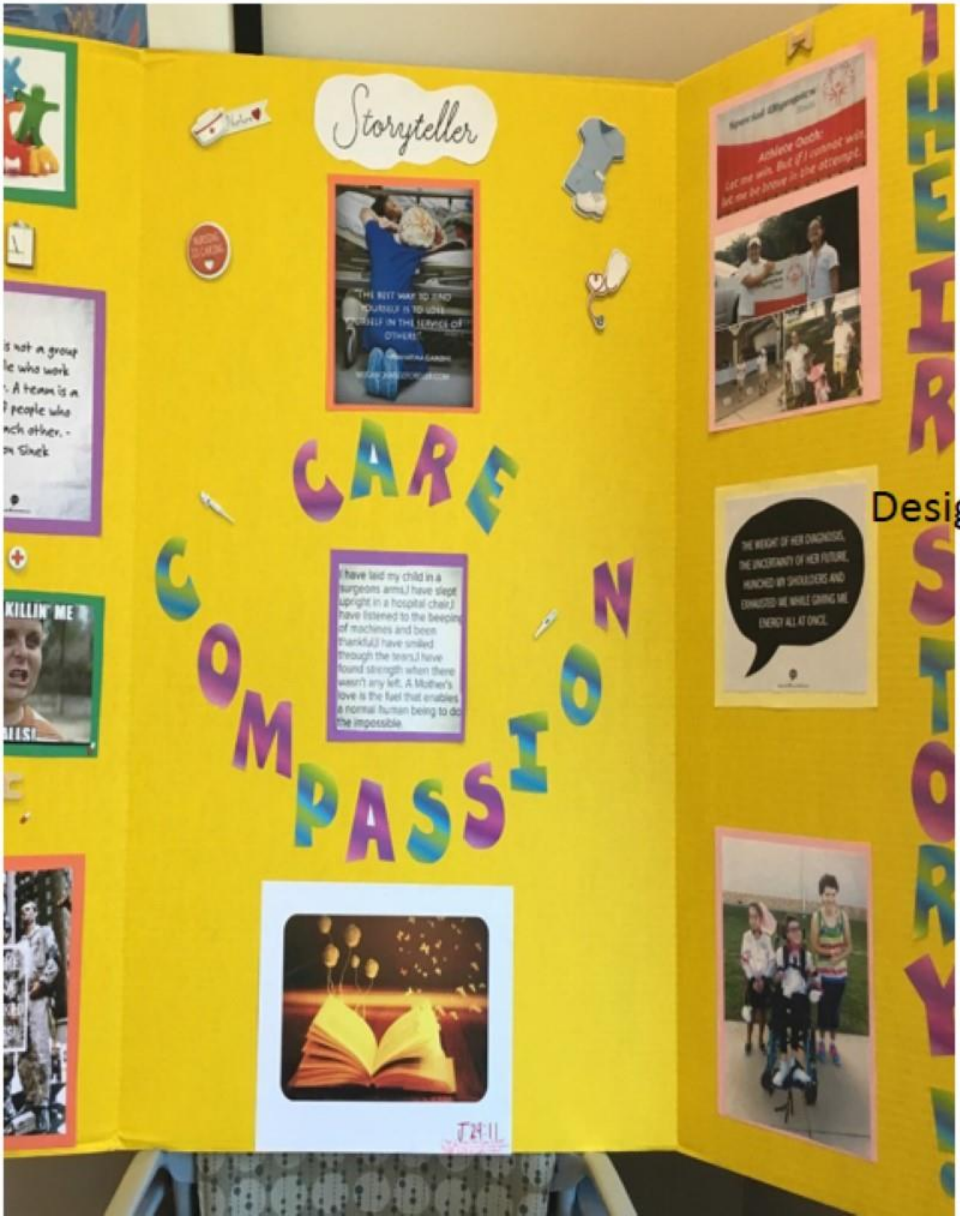




Day 2: Extended Care Circle Perspective

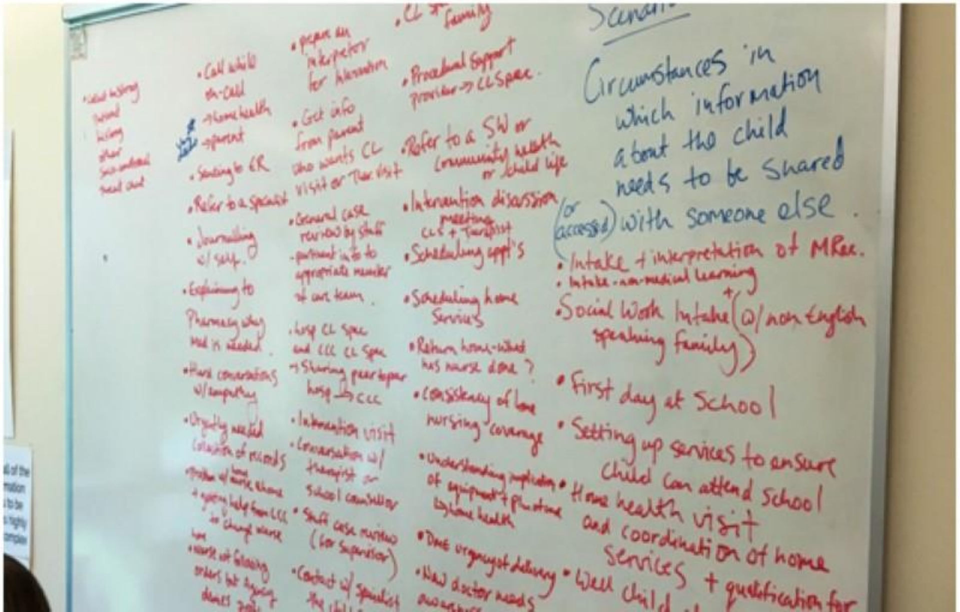


Day 3: Primary Care Provider Perspective



Designing Prototype

Day 4: Family-Provider Relationship



Scenari

Circumstances in which information about the child needs to be shared (or accessed) with someone else.

- Call while on-call → home health → parent
- Sending to ER
- Refer to a specialist
- Journaling w/ self.
- Explaining to Pharmacy why med is needed.
- Hard conversations w/ empathy
- Urgently needed collection of records
- Get info from parent who wants CL visit or Ther visit
- General case review by staff
- pertinent info to appropriate member of care team.
- Hosp CL spec and CCC CL spec → Sharing pear to pear hosp → CCC
- Intervention visit
- Conversation w/ therapist or school counsellor
- Staff case meeting (for Supervisor)
- Contact w/ Specialist
- CL family
- Procedural Support provider → CL Spec.
- Refer to a SW or community health or child life
- Intervention discussion meeting CLS + Therapist
- Scheduling appt's
- Scheduling home Services
- Return home - what has nurse done?
- Consistency of home nursing coverage
- Understanding implication of equipment + placement by home health
- New doctor needs
- Intake + interpretation of MRec.
- Intake - non-medical learning
- Social Work Intake (w/ non English speaking family)
- First day at School
- Setting up services to ensure child can attend school
- Home health visit and coordination of home services + qualification for
- Well child

Insights and Themes

- Need to take the onus off the family for being the only one holding and sharing the big picture.
- A synthesized story pulled from different sources can ensure greater transparency & accountability
- Without trust, families will not share the important personal aspects of their story
- An integrated story-based view will help providers understand the patient and family situation before they walk in the room
- Fit the storytelling into the natural flow of families lives by leveraging the tools they already use (mobile phones)

Patient Story

Quality of Life

Patient Family

Current Medical

Historical Medical

Current Medications

Equipment

Supplies

School

Schedule

Appointments

Nursing

PCP

RNCM

Social Worker

Child Life

Therapy

School

Support Community

Insurance

PDN

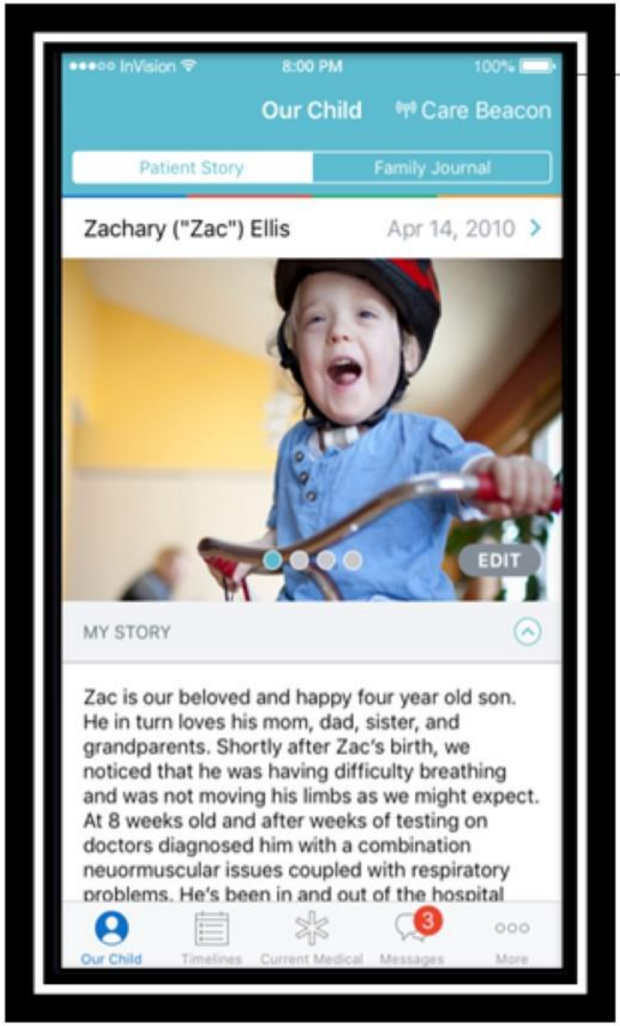
DME

Pharmacy

Specialists

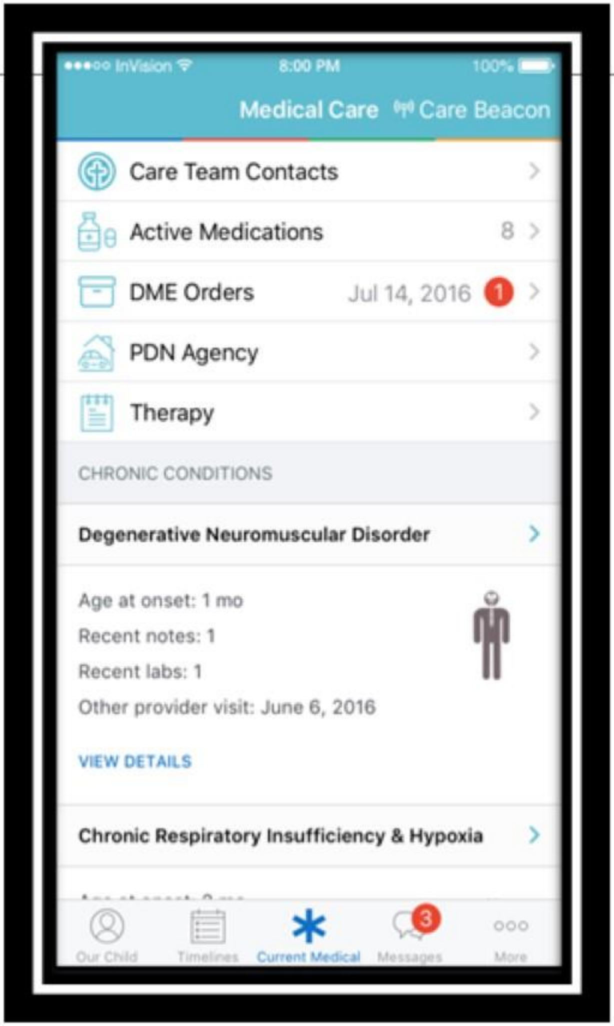
ER/Hospital

Mobile application



Zachary ("Zac") Ellis Apr 14, 2010

Zac is our beloved and happy four year old son. He in turn loves his mom, dad, sister, and grandparents. Shortly after Zac's birth, we noticed that he was having difficulty breathing and was not moving his limbs as we might expect. At 8 weeks old and after weeks of testing on doctors diagnosed him with a combination neuormuscular issues coupled with respiratory problems. He's been in and out of the hospital



Degenerative Neuromuscular Disorder

Age at onset: 1 mo
Recent notes: 1
Recent labs: 1
Other provider visit: June 6, 2016

Chronic Respiratory Insufficiency & Hypoxia

Home Care Nurse 11:04 AM
Yes Zac was able to handle his meal much better today

Specialist 1 & Specialist 2 9:45 AM
Yes, Swallow Study has now been scheduled and should be complete...

School Nurse 4:23 PM
Agree, we will let you know how that approach works tomorrow

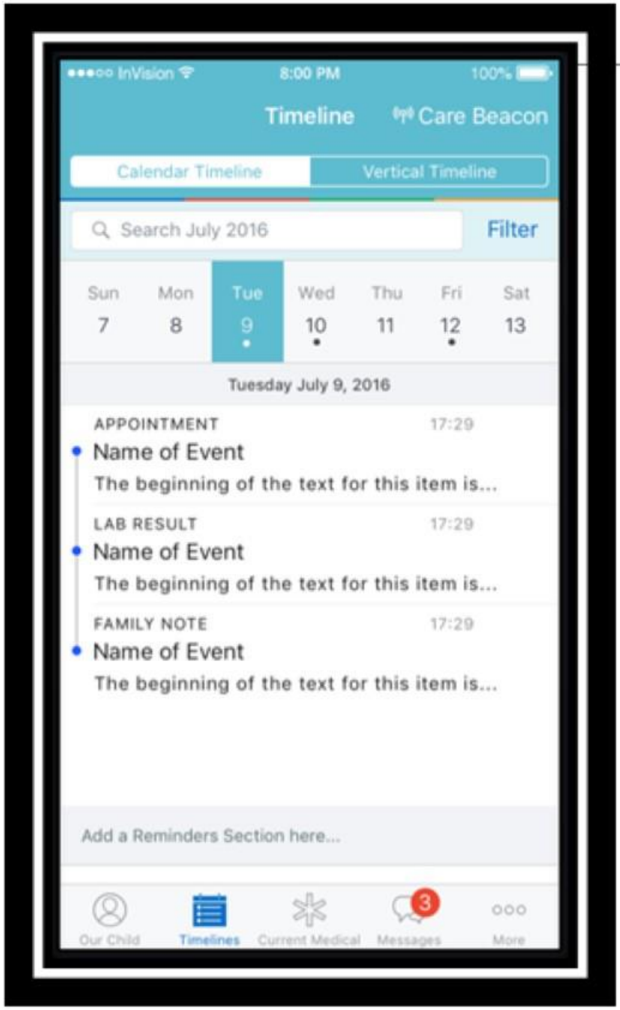
DME Representative Yesterday
Glad you are back home, we will resume normal shipments startin...

CCC NCM & Family Yesterday
See you in a few days!

ENT & CCC NCM Yesterday
Looking for the date on that most recent test, will follow up in later to...

Therapist Last Week
Correct, thanks for checking!

Mobile application


●●●○○ InVision 8:00 PM 100%

Timeline | Care Beacon

Calendar Timeline | Vertical Timeline

Search July 2016 | Filter

Sun	Mon	Tue	Wed	Thu	Fri	Sat
7	8	9	10	11	12	13

Tuesday July 9, 2016

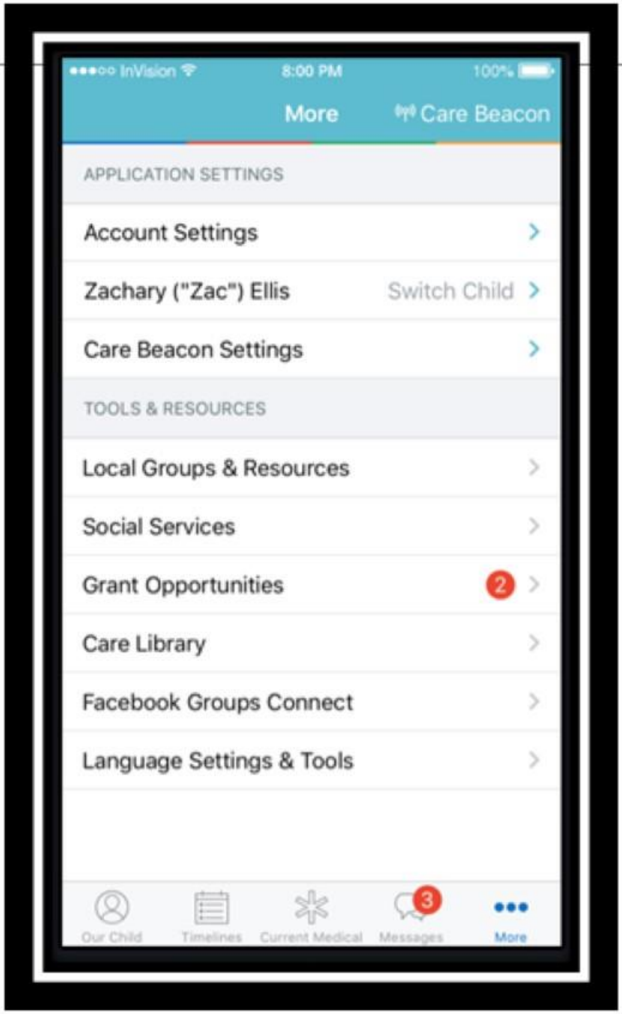
APPOINTMENT 17:29
Name of Event
The beginning of the text for this item is...

LAB RESULT 17:29
Name of Event
The beginning of the text for this item is...

FAMILY NOTE 17:29
Name of Event
The beginning of the text for this item is...

Add a Reminders Section here...

Our Child | Timelines | Current Medical | Messages 3 | More


●●●○○ InVision 8:00 PM 100%

More | Care Beacon

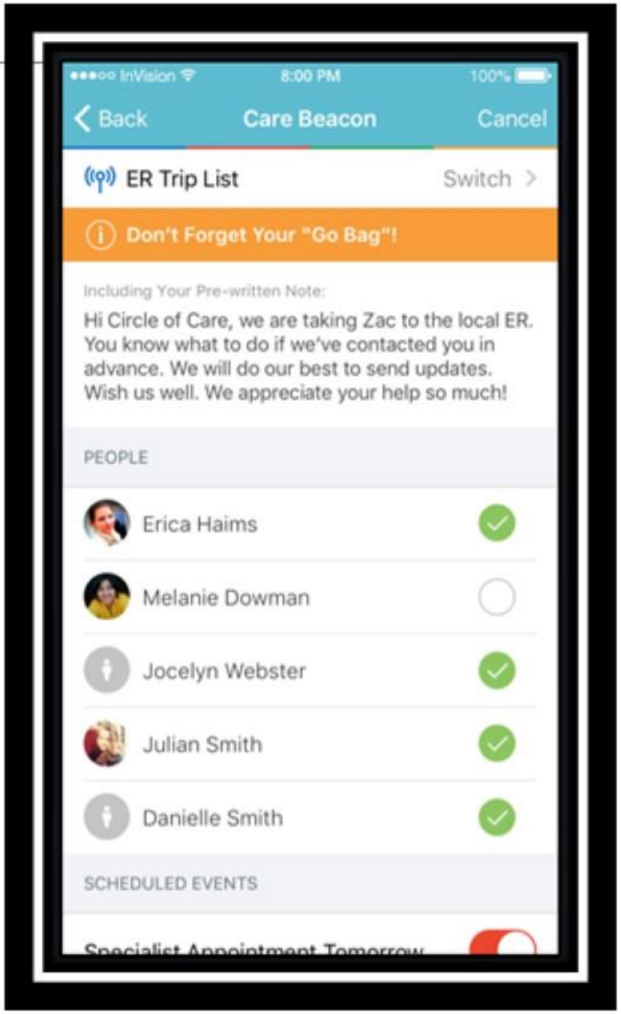
APPLICATION SETTINGS

- Account Settings
- Zachary ("Zac") Ellis — Switch Child
- Care Beacon Settings

TOOLS & RESOURCES

- Local Groups & Resources
- Social Services
- Grant Opportunities 2
- Care Library
- Facebook Groups Connect
- Language Settings & Tools

Our Child | Timelines | Current Medical | Messages 3 | More


●●●○○ InVision 8:00 PM 100%

Back | Care Beacon | Cancel

ER Trip List — Switch

Don't Forget Your "Go Bag"!

Including Your Pre-written Note:

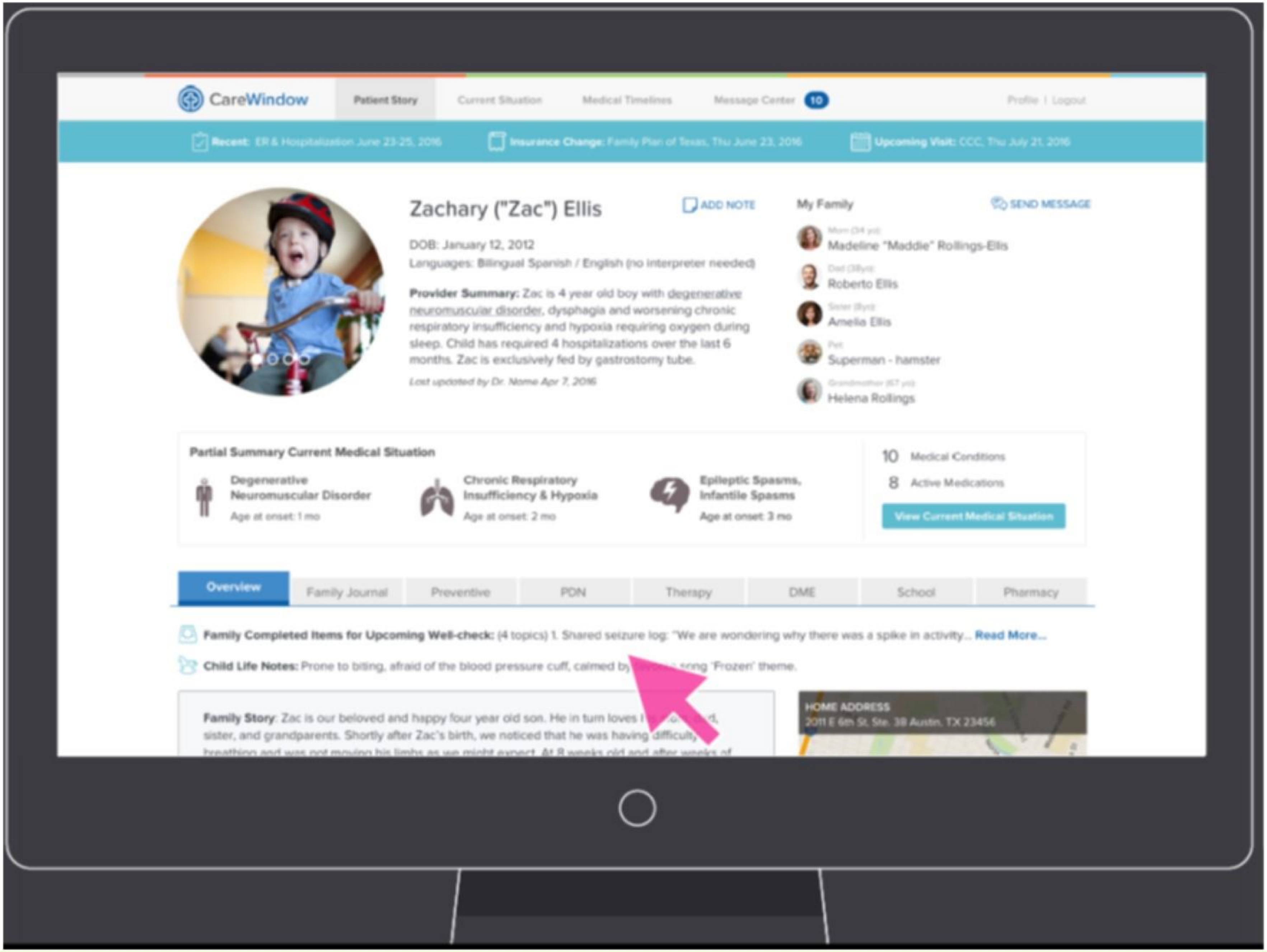
Hi Circle of Care, we are taking Zac to the local ER. You know what to do if we've contacted you in advance. We will do our best to send updates. Wish us well. We appreciate your help so much!

PEOPLE

- Erica Haims ✓
- Melanie Dowman ○
- Jocelyn Webster ✓
- Julian Smith ✓
- Danielle Smith ✓

SCHEDULED EVENTS

Specialist Appointment Tomorrow



Recent: ER & Hospitalization June 23-25, 2016

Insurance Change: Family Plan of Texas, Thu June 23, 2016

Upcoming Visit: CCC, Thu July 21, 2016

Zachary ("Zac") Ellis

DOB: January 12, 2012

Languages: Bilingual Spanish / English (no interpreter needed)

Provider Summary: Zac is 4 year old boy with degenerative neuromuscular disorder, dysphagia and worsening chronic respiratory insufficiency and hypoxia requiring oxygen during sleep. Child has required 4 hospitalizations over the last 6 months. Zac is exclusively fed by gastrostomy tube.

Last updated by Dr. Name Apr 7, 2016

My Family

Mom (34 yo)
Madeline "Maddie" Rollings-Ellis

Dad (38yo)
Roberto Ellis

Sister (8yo)
Amelia Ellis

Pet
Superman - hamster

Grandmother (67 yo)
Helena Rollings

Partial Summary Current Medical Situation

Degenerative Neuromuscular Disorder
Age at onset: 1 mo

Chronic Respiratory Insufficiency & Hypoxia
Age at onset: 2 mo

Epileptic Spasms, Infantile Spasms
Age at onset: 3 mo

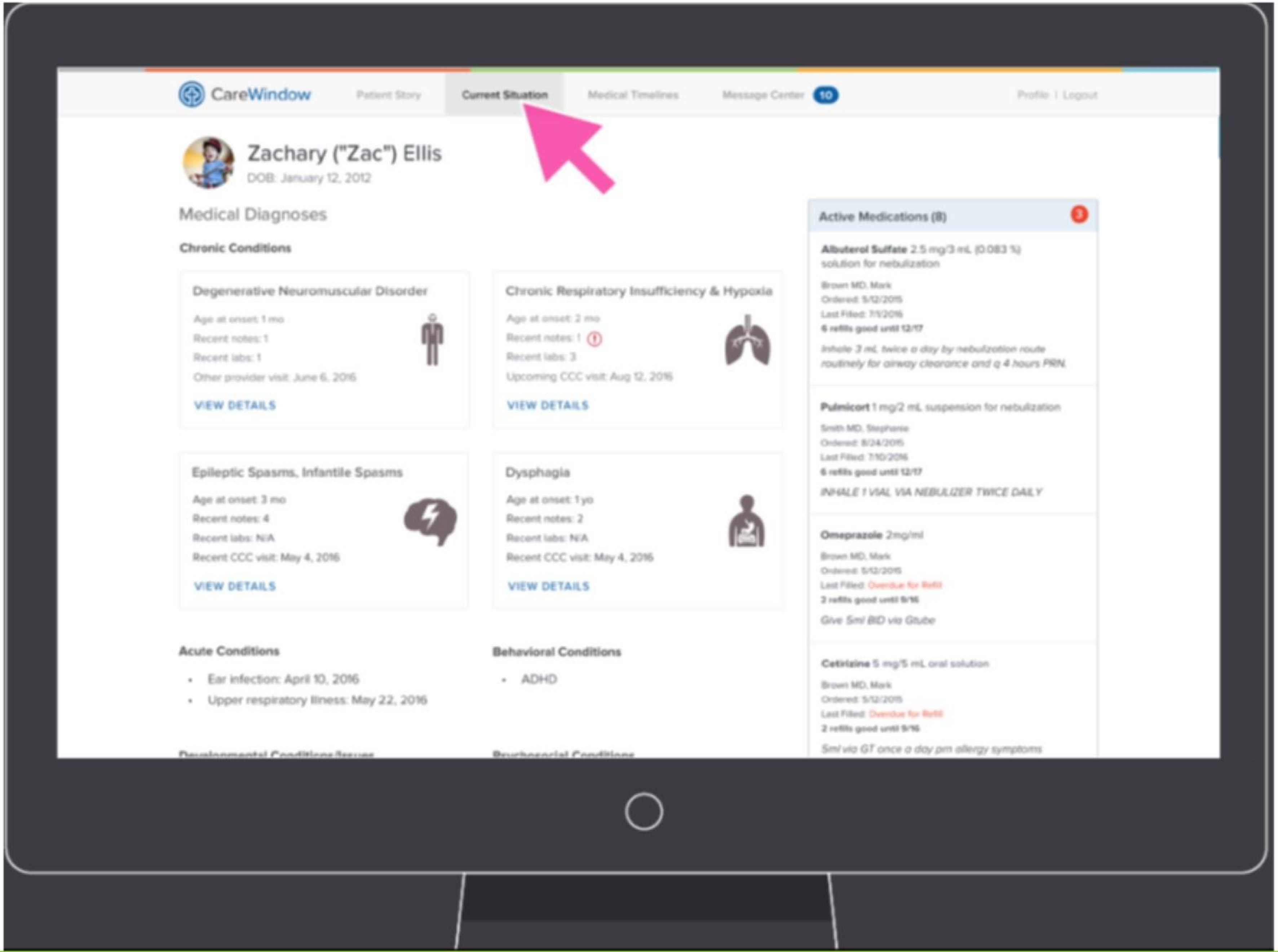
10 Medical Conditions
8 Active Medications

Family Completed Items for Upcoming Well-check: (4 topics) 1. Shared seizure log: "We are wondering why there was a spike in activity...

Child Life Notes: Prone to biting, afraid of the blood pressure cuff, calmed by [illegible] song 'Frozen' theme.

Family Story: Zac is our beloved and happy four year old son. He in turn loves h[illegible] dad, sister, and grandparents. Shortly after Zac's birth, we noticed that he was having difficulty breathing and was not moving his limbs as we might expect. At 8 weeks old and after weeks of

HOME ADDRESS
2011 E 6th St. Ste. 38 Austin, TX 23456



Zachary ("Zac") Ellis
DOB: January 12, 2012

Medical Diagnoses

Chronic Conditions

Degenerative Neuromuscular Disorder
Age at onset: 1 mo
Recent notes: 1
Recent labs: 1
Other provider visit: June 6, 2016

Chronic Respiratory Insufficiency & Hypoxia
Age at onset: 2 mo
Recent notes: 1 ⓘ
Recent labs: 3
Upcoming CCC visit: Aug 12, 2016

Epileptic Spasms, Infantile Spasms
Age at onset: 3 mo
Recent notes: 4
Recent labs: N/A
Recent CCC visit: May 4, 2016

Dysphagia
Age at onset: 1 yo
Recent notes: 2
Recent labs: N/A
Recent CCC visit: May 4, 2016

Acute Conditions

- Ear infection: April 10, 2016
- Upper respiratory illness: May 22, 2016

Behavioral Conditions

- ADHD

Developmental Conditions/Issues

Psychosocial Conditions

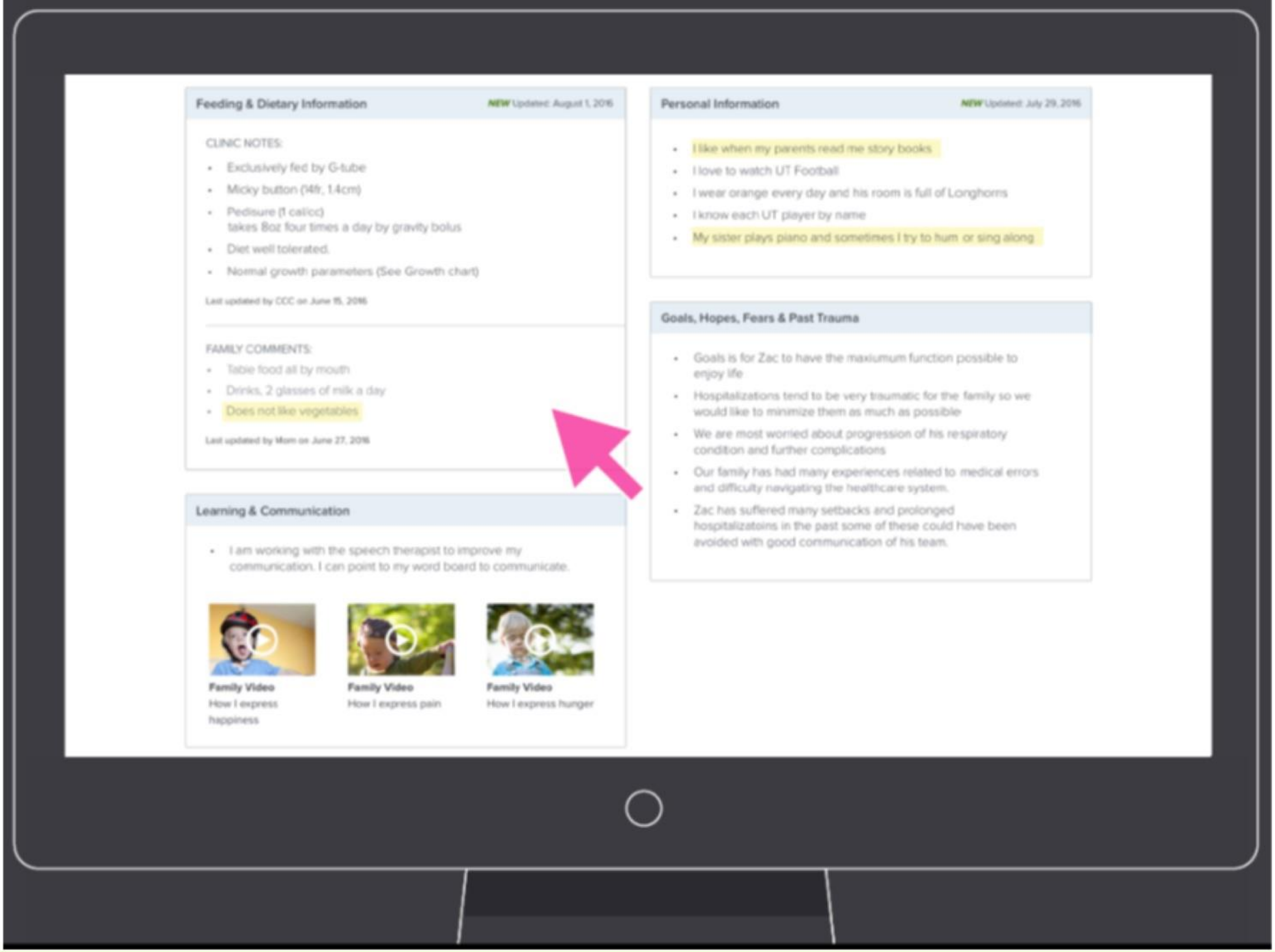
Active Medications (8)

Albuterol Sulfate 2.5 mg/3 mL (0.083 %) solution for nebulization
Brown MD, Mark
Ordered: 5/12/2015
Last Filled: 7/1/2016
6 refills good until 12/17
Inhale 3 mL twice a day by nebulization route routinely for airway clearance and q 4 hours PRN.

Pulmicort 1 mg/2 mL suspension for nebulization
Smith MD, Stephanie
Ordered: 8/24/2015
Last Filled: 7/10/2016
6 refills good until 12/17
INHALE 1 VIAL VIA NEBULIZER TWICE DAILY

Omeprazole 2mg/ml
Brown MD, Mark
Ordered: 5/12/2015
Last Filled: Overdue for Refill
2 refills good until 9/16
Give 5ml BID via Gtube

Cetirizine 5 mg/5 mL oral solution
Brown MD, Mark
Ordered: 5/12/2015
Last Filled: Overdue for Refill
2 refills good until 9/16
5ml via GT once a day prn allergy symptoms



Feeding & Dietary Information NEW Updated: August 1, 2016

CLINIC NOTES:

- Exclusively fed by G-tube
- Micky button (14fr, 1.4cm)
- Pedisure (1 cal/cc)
  takes 8oz four times a day by gravity bolus
- Diet well tolerated.
- Normal growth parameters (See Growth chart)

Last updated by CCC on June 15, 2016

FAMILY COMMENTS:

- Table food all by mouth
- Drinks, 2 glasses of milk a day
- Does not like vegetables

Last updated by Mom on June 27, 2016

Learning & Communication

- I am working with the speech therapist to improve my communication. I can point to my word board to communicate.

Family Video
How I express happiness

Family Video
How I express pain

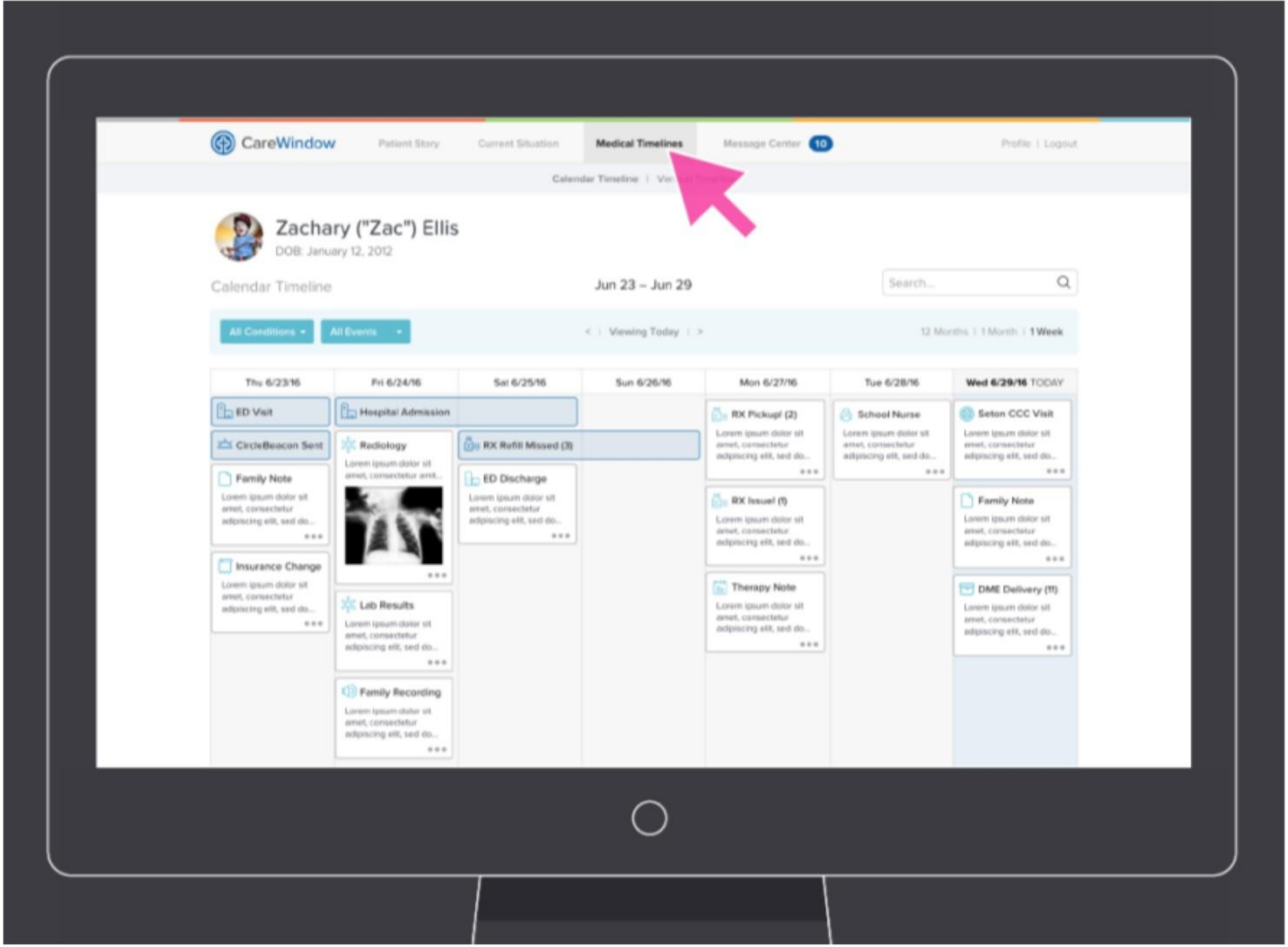
Family Video
How I express hunger

Personal Information NEW Updated: July 29, 2016

- I like when my parents read me story books
- I love to watch UT Football
- I wear orange every day and his room is full of Longhorns
- I know each UT player by name
- My sister plays piano and sometimes I try to hum or sing along

Goals, Hopes, Fears & Past Trauma

- Goals is for Zac to have the maxiumum function possible to enjoy life
- Hospitalizations tend to be very traumatic for the family so we would like to minimize them as much as possible
- We are most worried about progression of his respiratory condition and further complications
- Our family has had many experiences related to medical errors and difficulty navigating the healthcare system.
- Zac has suffered many setbacks and prolonged hospitalizatoins in the past some of these could have been avoided with good communication of his team.



Zachary ("Zac") Ellis

DOB: January 12, 2012

Calendar Timeline

Jun 23 – Jun 29

Thu 6/23/16	Fri 6/24/16	Sat 6/25/16	Sun 6/26/16	Mon 6/27/16	Tue 6/28/16	Wed 6/29/16 TODAY
ED Visit CircleBeacon Sent Family Note Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do... Insurance Change Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do...	Hospital Admission Radiology Lorem ipsum dolor sit amet, consectetur amit... Lab Results Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do... Family Recording Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do...	RX Refill Missed (3) ED Discharge Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do...		RX Pickup! (2) Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do... RX Issue! (1) Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do... Therapy Note Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do...	School Nurse Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do...	Seton CCC Visit Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do... Family Note Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do... DME Delivery (11) Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do...

Contacts:

Rahel Berhane, MD

- RXBerhane@seton.org

Anjum Khurshid, MD PhD

- akhurshid@gmail.com

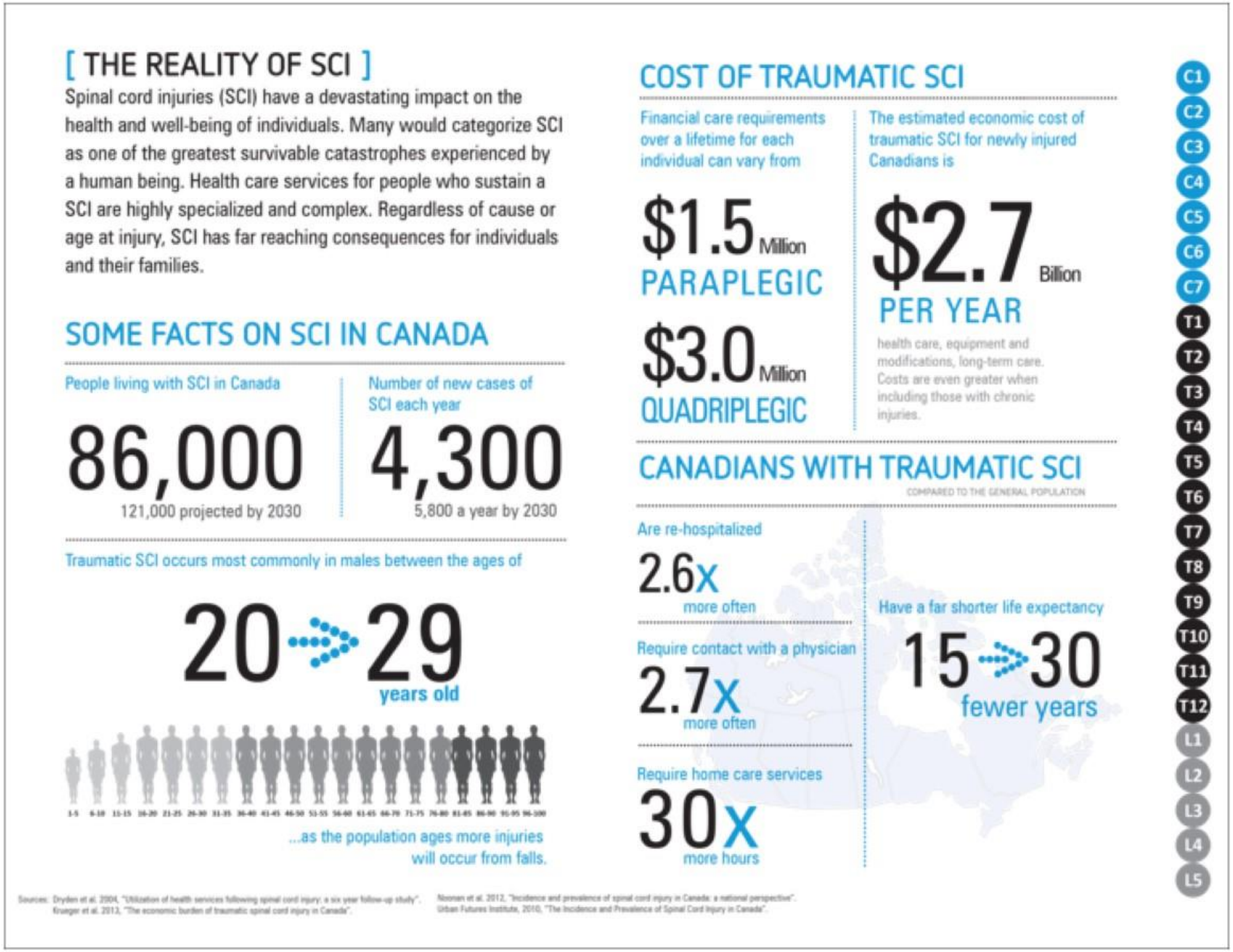
Rick Hansen Institute
Institut Rick Hansen

Consumer Engagement in Spinal Cord Injury Research at the Rick Hansen Institute

John Chernesky
October 21, 2016

@rhinstitute

The Reality of SCI



[THE REALITY OF SCI]

Spinal cord injuries (SCI) have a devastating impact on the health and well-being of individuals. Many would categorize SCI as one of the greatest survivable catastrophes experienced by a human being. Health care services for people who sustain a SCI are highly specialized and complex. Regardless of cause or age at injury, SCI has far reaching consequences for individuals and their families.

SOME FACTS ON SCI IN CANADA

People living with SCI in Canada

86,000

121,000 projected by 2030

Number of new cases of SCI each year

4,300

5,800 a year by 2030

Traumatic SCI occurs most commonly in males between the ages of

20 → 29

years old

...as the population ages more injuries will occur from falls.

COST OF TRAUMATIC SCI

Financial care requirements over a lifetime for each individual can vary from

$1.5 Million

PARAPLEGIC

$3.0 Million

QUADRIPLEGIC

The estimated economic cost of traumatic SCI for newly injured Canadians is

$2.7 Billion

PER YEAR

health care, equipment and modifications, long-term care. Costs are even greater when including those with chronic injuries.

CANADIANS WITH TRAUMATIC SCI

COMPARED TO THE GENERAL POPULATION

Are re-hospitalized

2.6x

more often

Require contact with a physician

2.7x

more often

Require home care services

30x

more hours

Have a far shorter life expectancy

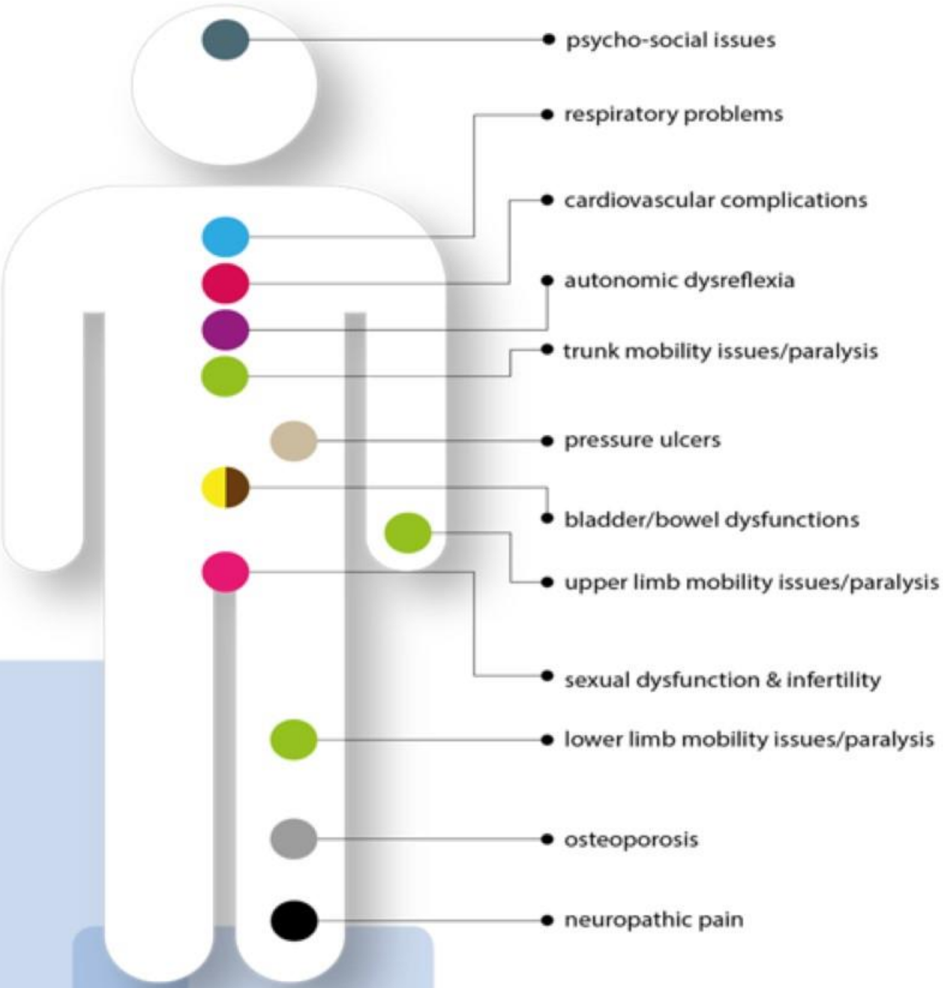
15 → 30

fewer years

Sources: Dryden et al. 2004, "Utilization of health services following spinal cord injury: a six year follow-up study". Krueger et al. 2013, "The economic burden of traumatic spinal cord injury in Canada". Noonan et al. 2012, "Incidence and prevalence of spinal cord injury in Canada: a national perspective". Urban Futures Institute, 2010, "The Incidence and Prevalence of Spinal Cord Injury in Canada".

Effects of SCI

spinal cord injury + your body



SCI:

- **Affects every** physiological system
- **7 to 30** secondary complications
  - Average is 15
- **Chronic and complex** condition

Barriers to Participation in SCI Research

- Heterogeneity
- Acute Interventions (< 12 hours)
- Lack of Urgency
- Autonomic Dysfunctions
- Secondary Complications
- Mobility
- Income Disparity

Vision Statement

A world

without paralysis

after spinal cord injury.

Mission Statement

To lead collaboration

Across the global spinal cord injury community by providing resources, infrastructure and knowledge; and to…

- identify, develop, validate and **accelerate** the **translation** of **evidence** and **best practices** to reduce the incidence and severity of paralysis after SCI,
- **improve** health care **outcomes**,
- **reduce** long-term **costs**, and
- **improve** the **quality of life** for those living with SCI

RHI's Core Programs

CURE

CONSUMER ENGAGEMENT

CARE

COMMERCIALIZATION

Consumer Integration at RHI

- Founded by Rick Hansen
- Consumers on Board of Directors
- Advisory Committees
- Priority setting, strategic planning and project review
- Praxis 2016

Engaging people with SCI in research and helping them make evidence-based decisions about their health

SERVES

- Persons with SCI, their family and friends, as well as consumer-focused community organizations and advocacy groups

OBJECTIVES

- Provide resources and tools to help answer people's most critical questions about their injury
- Promote self-management of health to reduce the incidence of secondary complications
- Identify activities and opportunities to engage consumers and increase involvement in research

Consumer Program at RHI

- SCIRE Community
- Self Management
- Patient-partners in research
- Education to newly injured
- Central patient recruitment
- Video’s in partnership with Comm. Org’s
- Advocating for change in practice to improve clinical care

Questions?

John Chernesky

Rick Hansen Institute
6400-818 West 10th Avenue
Vancouver, BC Canada V5Z 1M9

rickhanseninstitute.org
jchernesky@rickhanseninstitute.org
604 827 2428
/RickHansenInstitute
@rhinstitute

PCORI and the ripple effect: Patient communities

Lorraine Johnson, JD, MBA

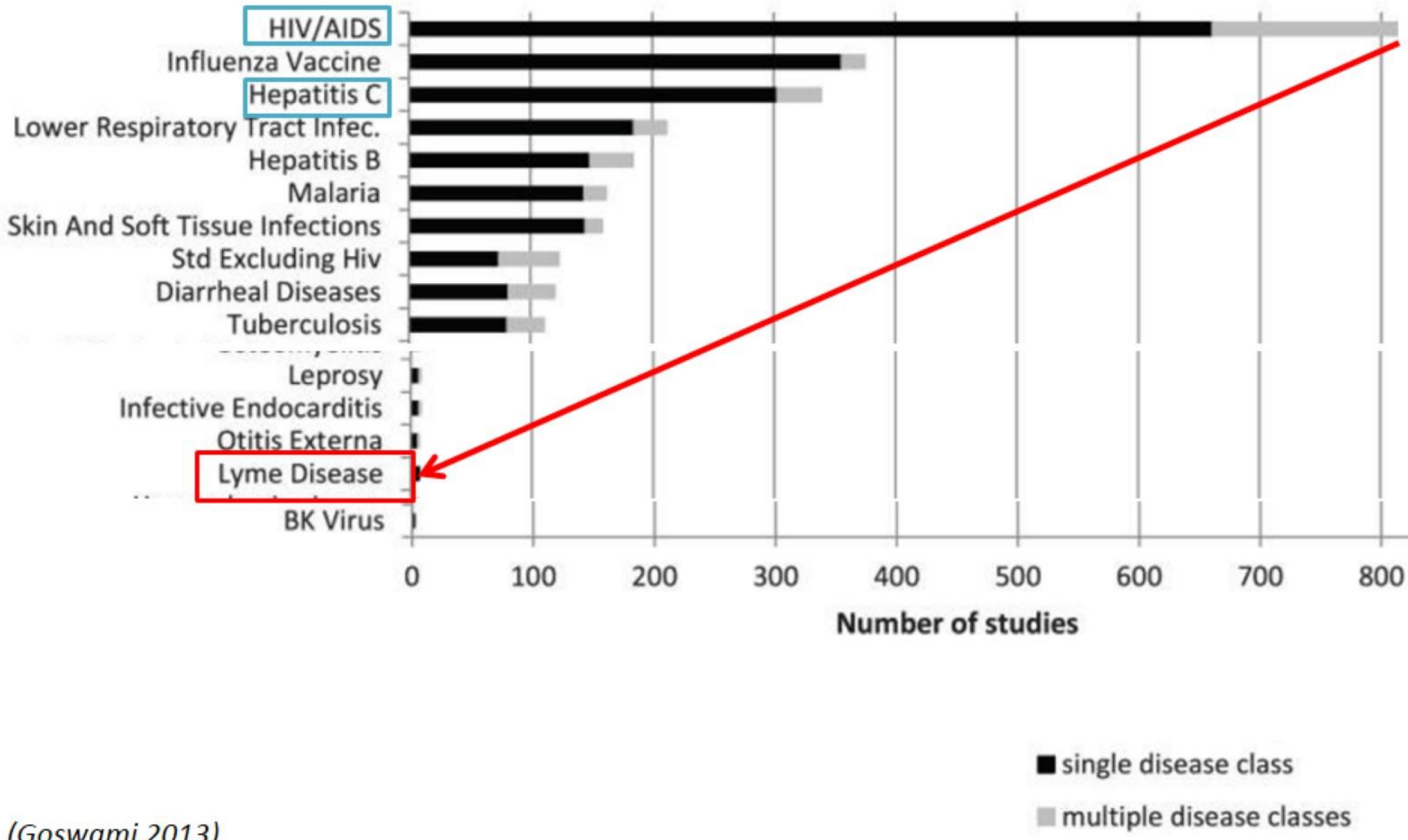
Patient Engagement Advisory Panel, Patient Centered Outcomes Research Institute
Co-Chair Consumers United for Evidence-Based Healthcare; CEO, LymeDisease.org
October 21, 2016 PCORI PEAP

PCORI and patient-centered research

pcori

- Patient engagement rubric
- Patient compensation rubric
- Top 10 research priorities of patients
- PCORnet—patient-powered big-data research

Lyme disease is a research disadvantaged



(Goswami 2013)

The democratization of science

THE
LYME TIMES

Volume 27 • Number 3 • 2015

The Journal of LymeDisease.org

THE DEMOCRATIZATION OF SCIENCE

PCORI

IMAGINE A WORLD where people with Lyme disease are diagnosed and treated correctly and go back to living their lives.

YOU CAN BE PART OF MAKING THIS HAPPEN

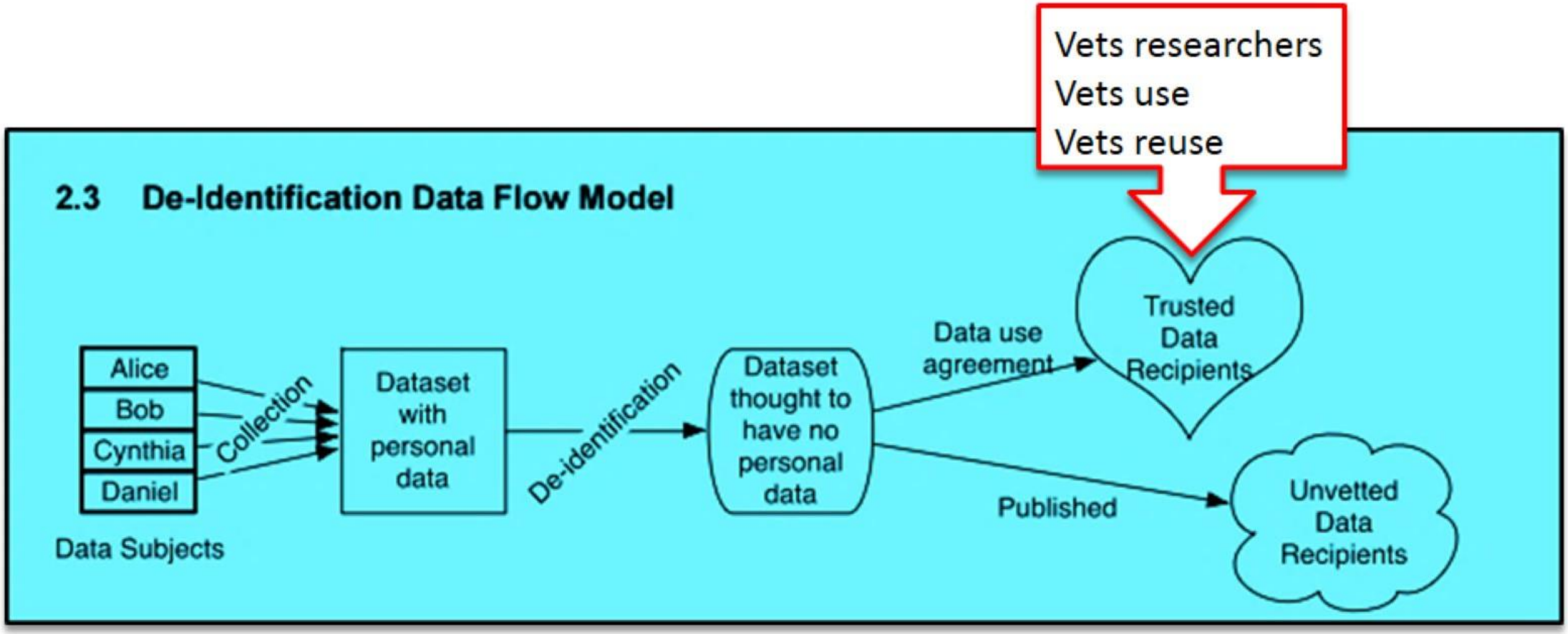
MyLymeData

To learn more, visit lymedisease.org/mylymedata

MyLymeData expects to gather more data about Lyme disease than any research study has done before

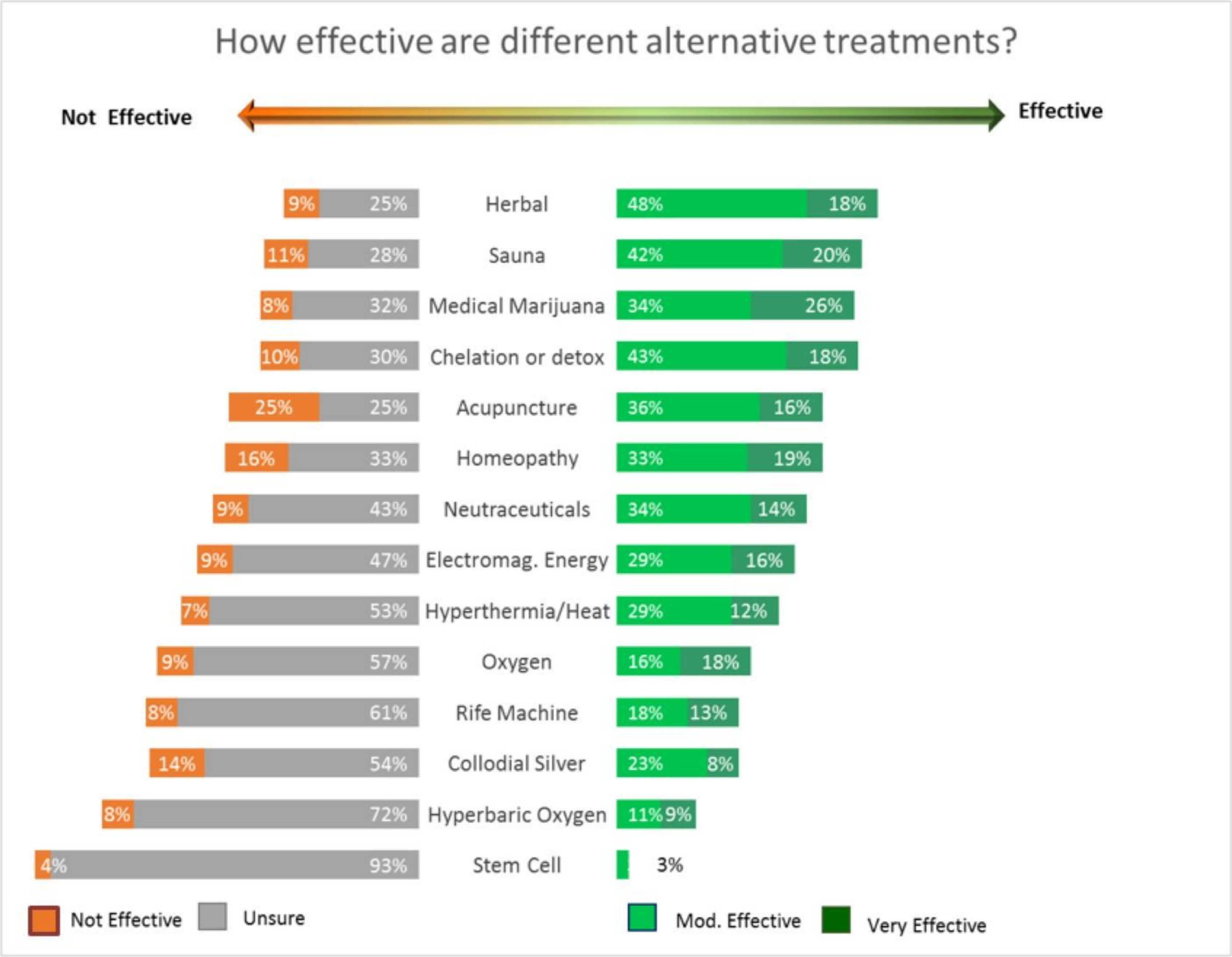
- First national large-scale longitudinal study of patients with Lyme disease
- Over 5,100 patents are enrolled, (Fastercures over 5,000 = top 10% of patient powered registries)
- Patient centered
- Phase I was launched in November 2015
  - Exposure, diagnosis, labs, sick/well status, and quality of life impairment.
- Phase 2 was launched in October 2016
  - 3 month follow-up
  - SF-36
  - General health history
  - Decedent survey

Open publication of data or a trusted intermediary role



Vets researchers
Vets use
Vets reuse

2.3 De-Identification Data Flow Model

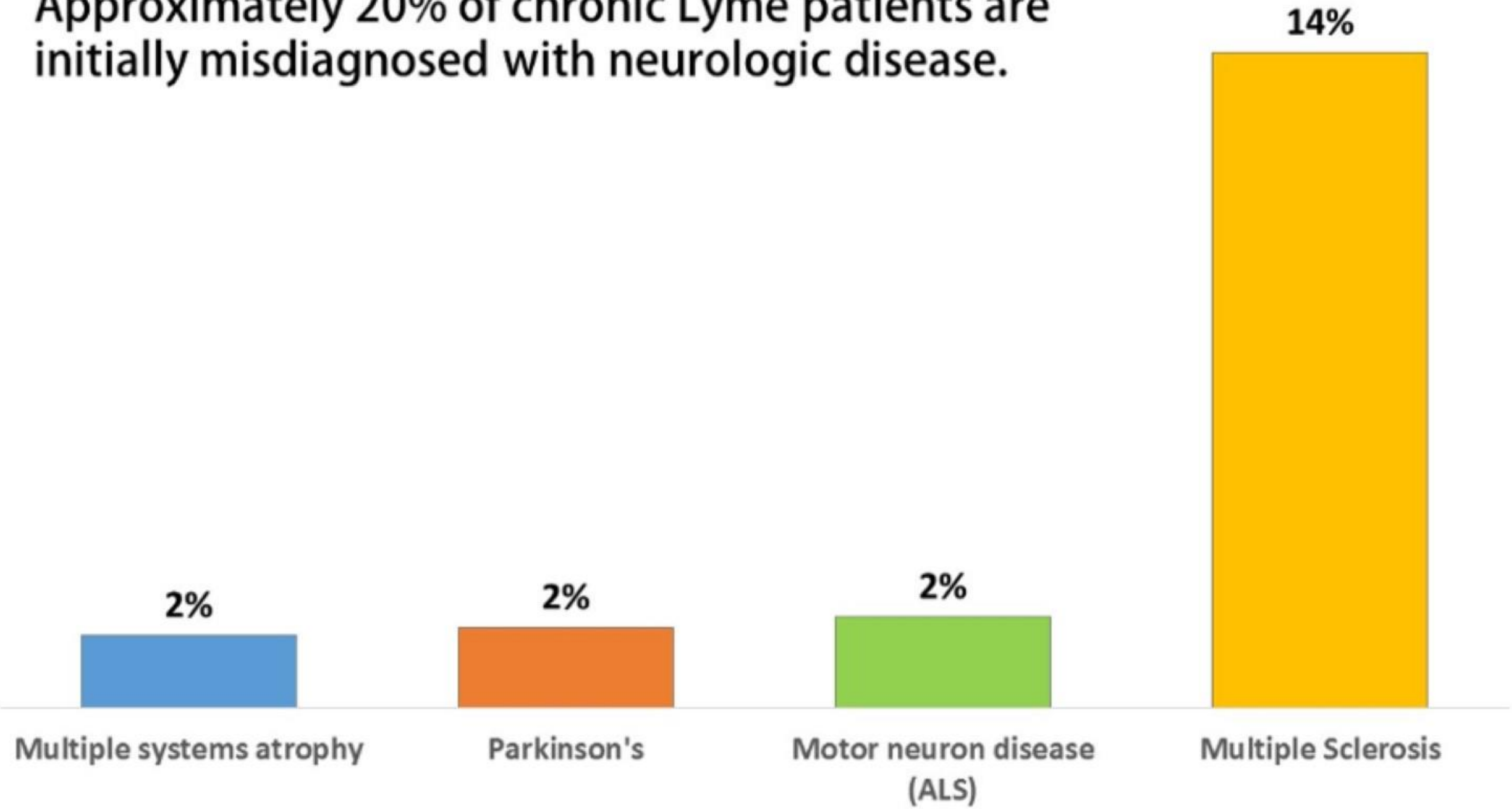

How effective are different alternative treatments?
Not Effective
Effective
9% 25% Herbal 48% 18%
11% 28% Sauna 42% 20%
8% 32% Medical Marijuana 34% 26%
10% 30% Chelation or detox 43% 18%
25% 25% Acupuncture 36% 16%
16% 33% Homeopathy 33% 19%
9% 43% Neutraceuticals 34% 14%
9% 47% Electromag. Energy 29% 16%
7% 53% Hyperthermia/Heat 29% 12%
9% 57% Oxygen 16% 18%
8% 61% Rife Machine 18% 13%
14% 54% Collodial Silver 23% 8%
8% 72% Hyperbaric Oxygen 11% 9%
4% 93% Stem Cell 3%
Not Effective
Unsure
Mod. Effective
Very Effective

19
APR
2016

LYMEPOLICYWONK: Misdiagnosis of Lyme disease as MS –MyLymeData Quick Bytes

This is the first in what I hope will be a series of "quick bytes" (2-minute videos) of some of the preliminary results we are getting from MyLymeData. You can choose to watch the video or read the blog. Today I am going to talk about what we are finding with misdiagnosis. Most of us know that Lyme disease is commonly misdiagnosed as chronic fatigue, fibromyalgia, or depression. But did you know that 20% are misdiagnosed with uncurable progressive neurologic diseases?

Approximately 20% of chronic Lyme patients are initially misdiagnosed with neurologic disease.



BE PART OF THE CONVERSATION

Let us know your experience.

Have you been diagnosed with Lyme disease by a healthcare provider?

○ Yes

○ No

○ Unsure

Were you initially misdiagnosed with a progressive neurological disease?

○ Yes

○ No

○ Unsure

○ Not applicable

What neurologic disease were you initially misdiagnosed with?

Setting Research Priorities for Lyme disease

Priority Setting Partnerships

Tackling treatment uncertainties together

- Based loosely on James Lind Alliance process but quick and broader—internet based large scale surveys
  - Conference of researchers, clinicians, and patients generated 20 questions
  - MyLymeData participants vote on this and suggest additional research priorities
  - Broader community invited to then vote on these

Using PCORI rubrics to jointly apply for grants

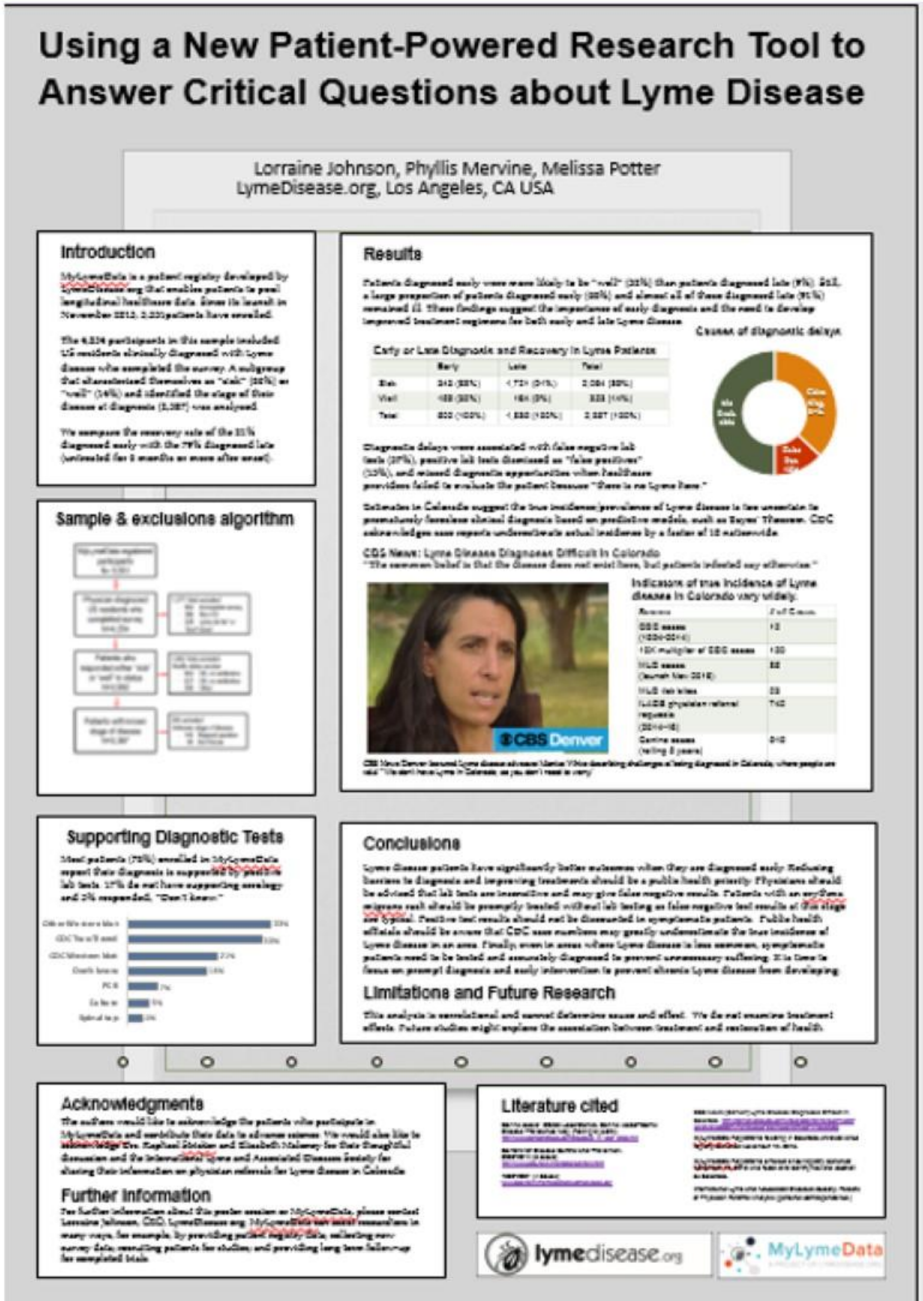
About Funding

The National Science Foundation funds research and education in most fields of science and engineering. It does this through grants, and cooperative agreements to more than 2,000 colleges, universities, K-12 school systems, businesses, informal science organizations and other research organizations throughout the United States. The Foundation accounts for about one-fourth of federal support to academic institutions for basic research.

NSF receives approximately 40,000 proposals each year for research, education and training projects, of which approximately 11,000 are funded. In addition, the Foundation receives several thousand applications for graduate and postdoctoral fellowships.

The agency operates no laboratories itself but does support National Research Centers, user facilities, certain oceanographic vessels and Antarctic research stations. The Foundation also supports cooperative research between universities and industry, US participation in international scientific and engineering efforts, and educational activities at every academic level.

Presenting at conferences to engage researchers



Using a New Patient-Powered Research Tool to Answer Critical Questions about Lyme Disease

Lorraine Johnson, Phyllis Mervine, Melissa Potter
LymeDisease.org, Los Angeles, CA USA

Introduction

Sample & exclusions algorithm

Supporting Diagnostic Tests

Results

Causes of diagnostic delays

CBS News: Lyme Disease Diagnoses Difficult in Colorado

Indicators of true incidence of Lyme disease in Colorado vary widely.

Conclusions

Limitations and Future Research

Acknowledgments

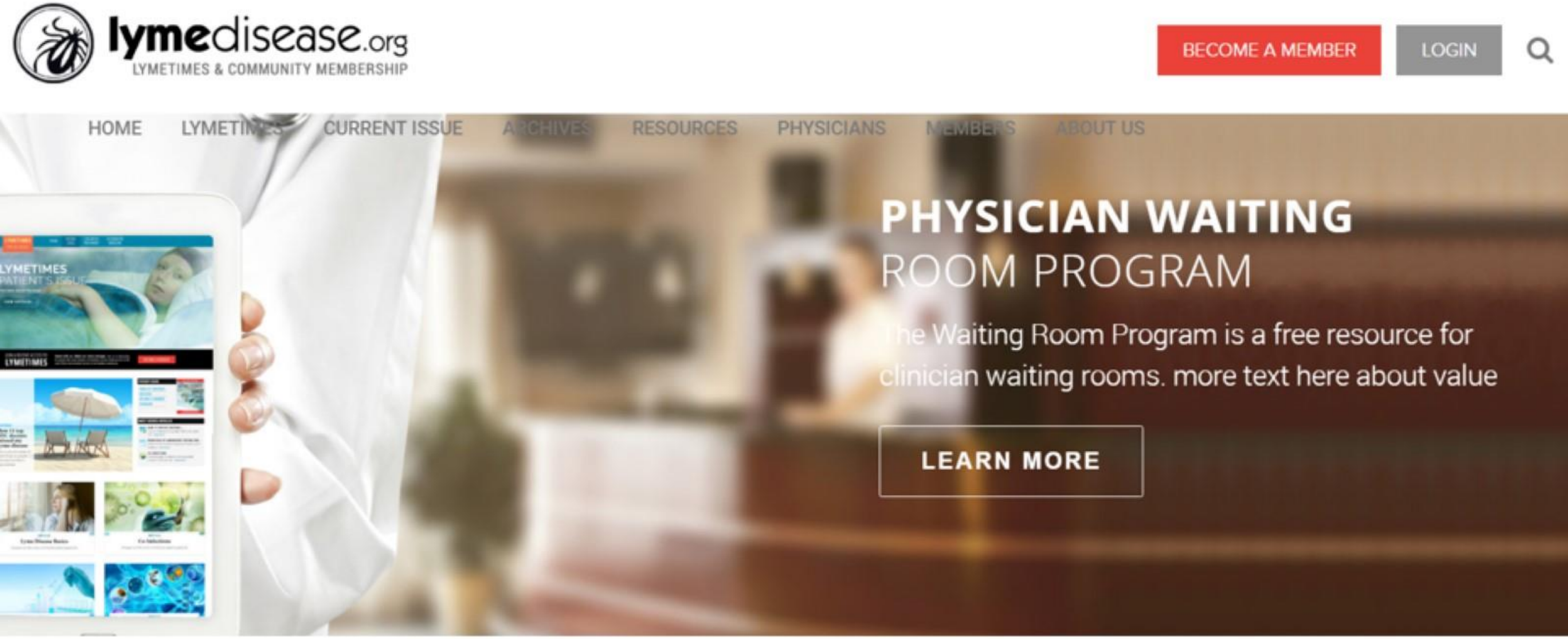
Further Information

Literature cited

lymedisease.org

MyLymeData

Physician engagement

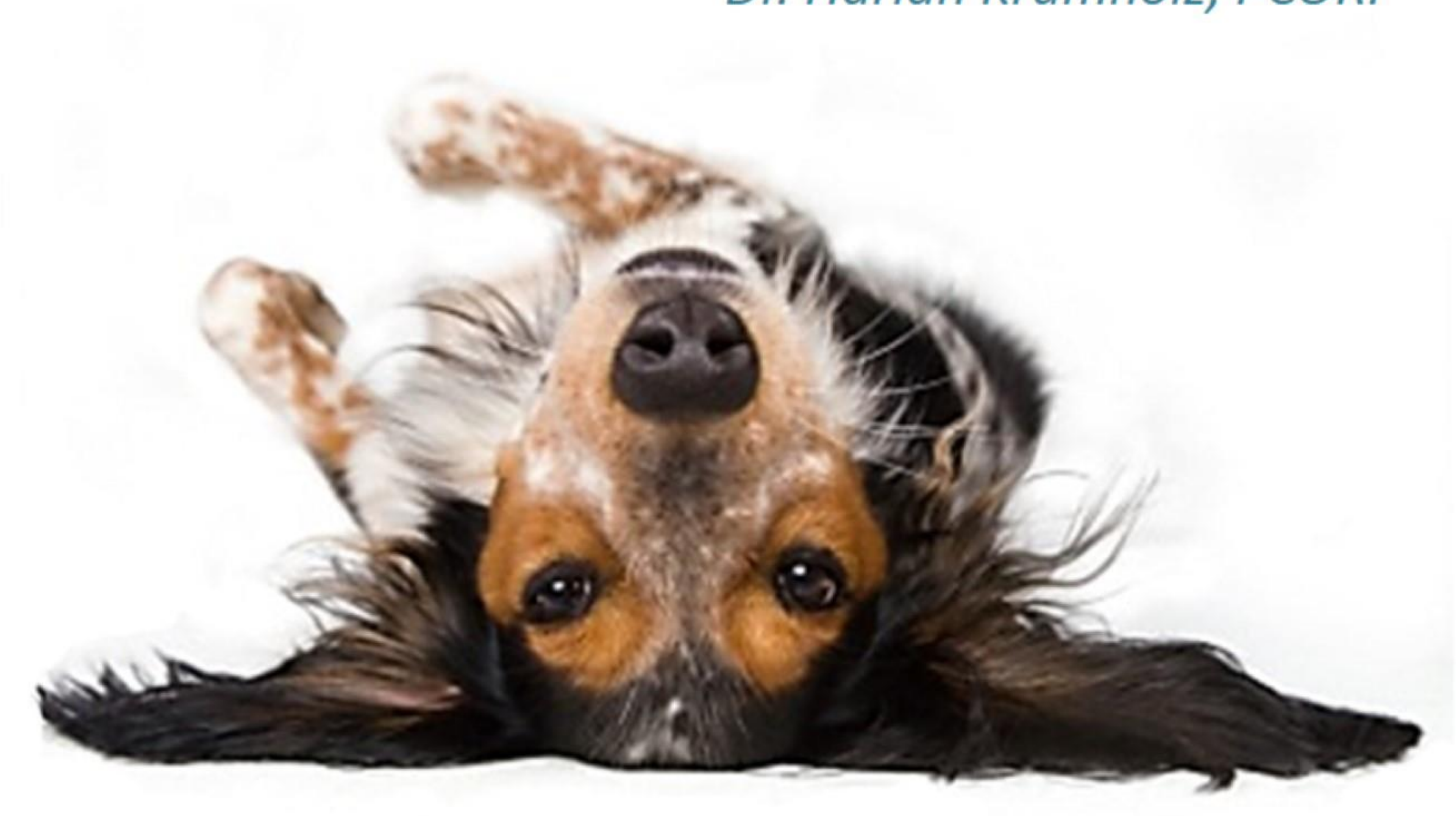


PHYSICIAN WAITING ROOM PROGRAM

The Waiting Room Program is a free resource for clinician waiting rooms. more text here about value

Is it business as usual or do we "have the chance to turn the world **upside down** just a bit?"

Dr. Harlan Krumholz, PCORI



lymedisease.org

INTERNATIONAL

www.rti.org

A Consolidated Model of Patient Engagement

Megan Lewis, PhD

Director, Patient and Family Engagement Research Program
Center for Communication Science

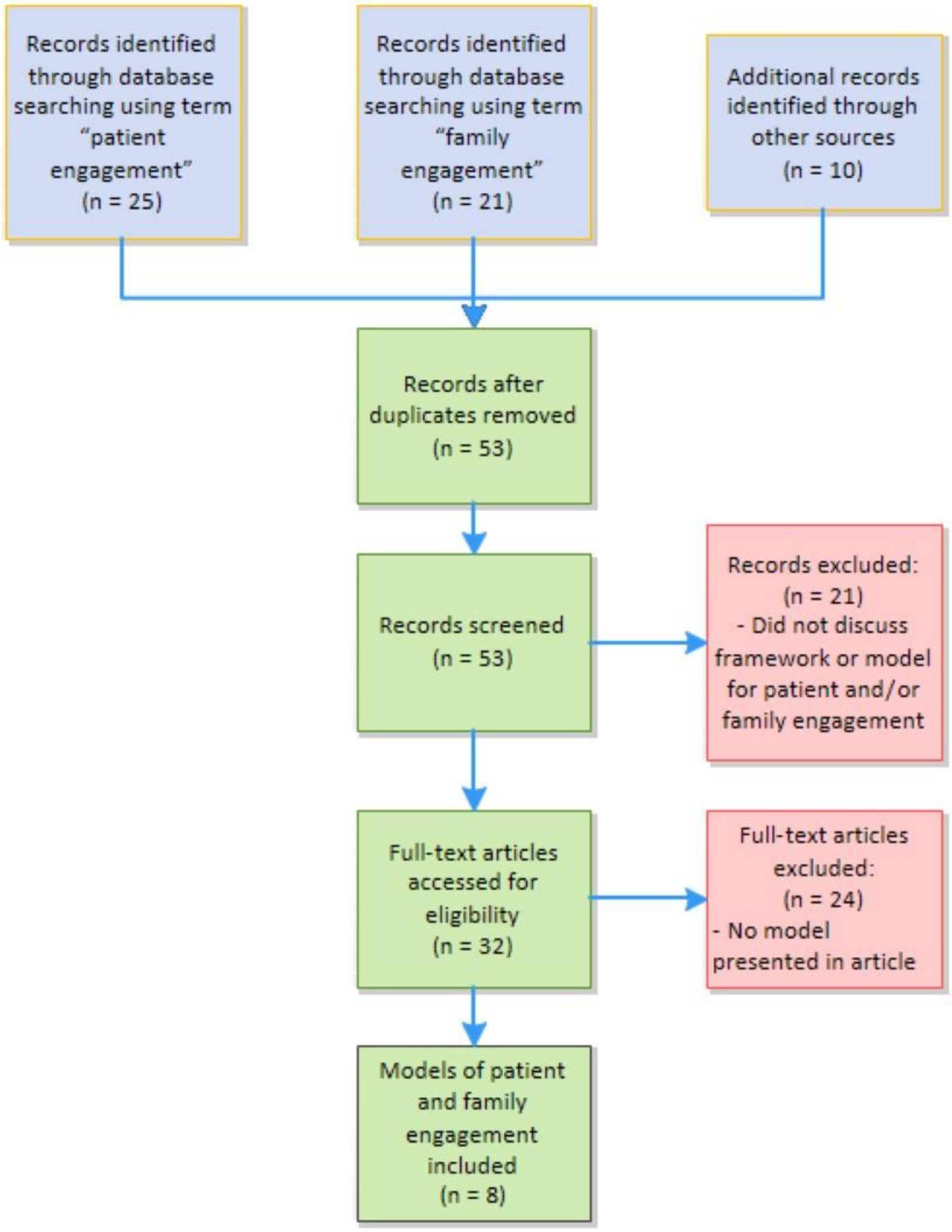
Why is a Consolidated Model Needed?

- A plethora of models creates:
  - Conceptual confusion
  - Problems with measurement and defining relevant outcomes
  - Barriers to capitalizing on the potential synergy of Patient Engagement within or across domains
- A consolidated model facilitates:
  - Common definitions
  - Specific and relevant intermediary and long-term outcomes
  - Capturing a range of mechanisms that can be examined in comparative effectiveness research (CER)

Why is a Consolidated Model Needed? (cont.)

- A consolidated model can:
  - Facilitate comparison of findings across studies
  - Speed translation of evidence-based research to practice
  - Ensure patients, family members, and stakeholders involved in patient-centered endeavors understand the larger picture
  - Ensure that researchers involved in specific areas of patient engagement research see the “sight line” across different domains

Search Process for PE Models



Records identified through database searching using term "patient engagement" (n = 25)

Records identified through database searching using term "family engagement" (n = 21)

Additional records identified through other sources (n = 10)

Records after duplicates removed (n = 53)

Records screened (n = 53)

Records excluded: (n = 21)
- Did not discuss framework or model for patient and/or family engagement

Full-text articles accessed for eligibility (n = 32)

Full-text articles excluded: (n = 24)
- No model presented in article

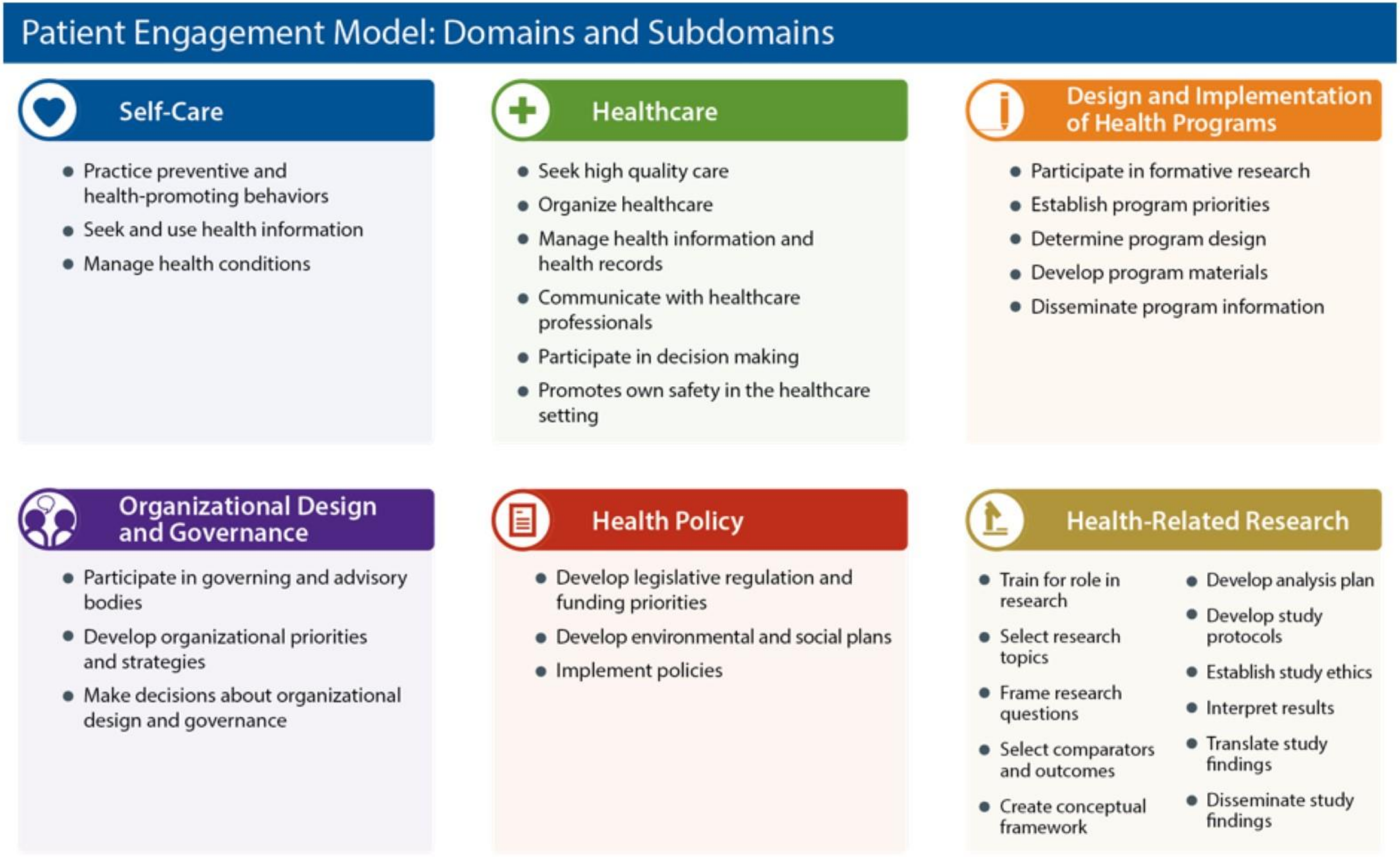
Models of patient and family engagement included (n = 8)

Overlaps and Gaps Found During Literature Search

- Overlap
  - Most models focus on 1 or 2 domains:
    - Self-care
    - Health care
    - Organizational design and governance
    - Health policy
    - Health research
  - Most models focus on self-care or health care
  - Most models focus on processes or “how” it should work

- Gaps
  - Models do not include all relevant domains
  - Intervention development and implementation domain was missing
  - No systematic inclusion of family engagement
  - Outcomes not systematically specified
  - “Engagement” outcomes not defined systematically as intermediary outcomes
  - Some models do not reflect current standards of practice (e.g., use of health IT)

Domains and Subdomains



Patient Engagement Model: Domains and Subdomains

Self-Care

- Practice preventive and health-promoting behaviors
- Seek and use health information
- Manage health conditions

Healthcare

- Seek high quality care
- Organize healthcare
- Manage health information and health records
- Communicate with healthcare professionals
- Participate in decision making
- Promotes own safety in the healthcare setting

Design and Implementation of Health Programs

- Participate in formative research
- Establish program priorities
- Determine program design
- Develop program materials
- Disseminate program information

Organizational Design and Governance

- Participate in governing and advisory bodies
- Develop organizational priorities and strategies
- Make decisions about organizational design and governance

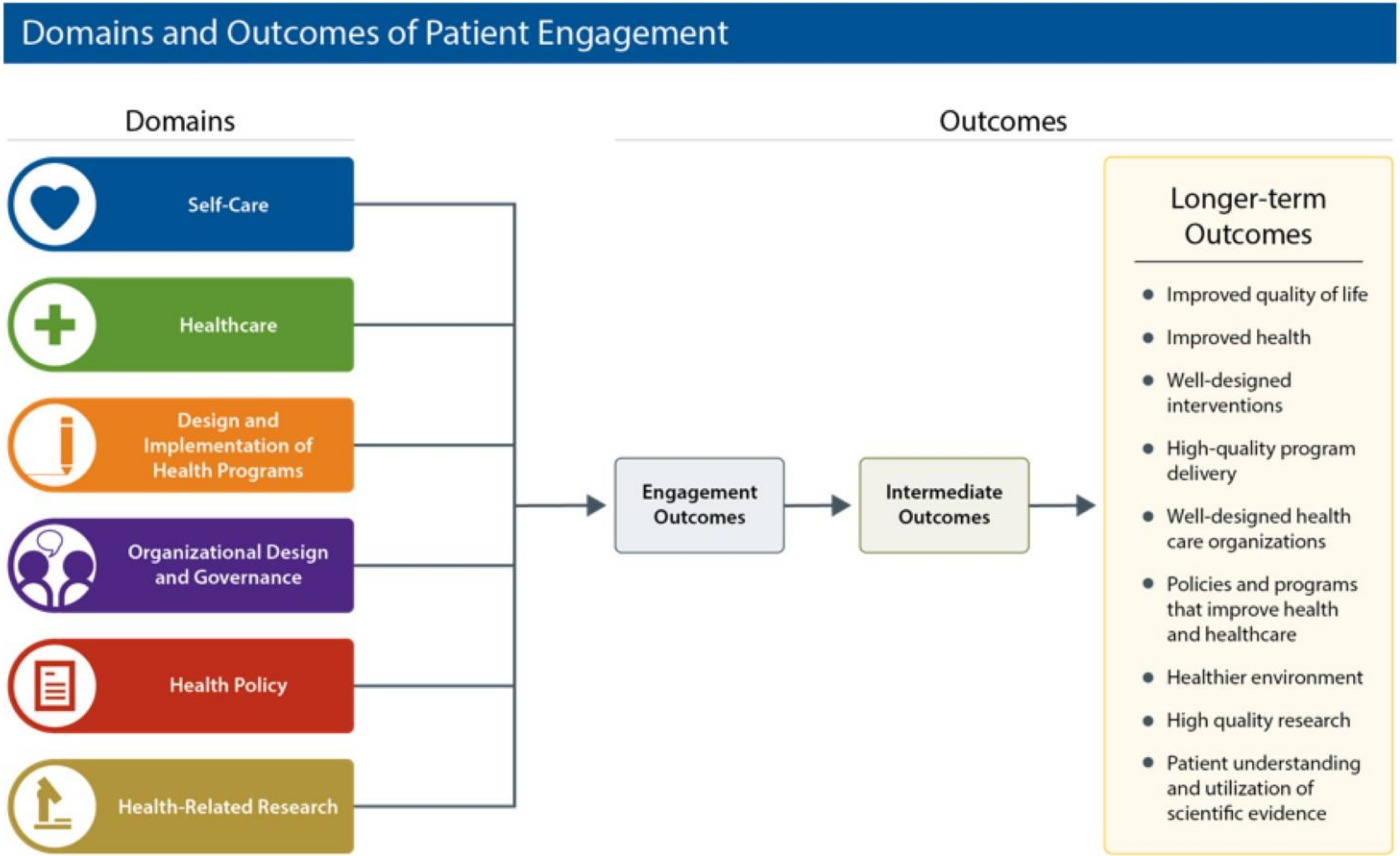
Health Policy

- Develop legislative regulation and funding priorities
- Develop environmental and social plans
- Implement policies

Health-Related Research

- Train for role in research
- Select research topics
- Frame research questions
- Select comparators and outcomes
- Create conceptual framework
- Develop analysis plan
- Develop study protocols
- Establish study ethics
- Interpret results
- Translate study findings
- Disseminate study findings

Consolidated Model of Patient Engagement



Domains and Outcomes of Patient Engagement

Domains

- Self-Care
- Healthcare
- Design and Implementation of Health Programs
- Organizational Design and Governance
- Health Policy
- Health-Related Research

Outcomes

Engagement Outcomes → Intermediate Outcomes →

Longer-term Outcomes

- Improved quality of life
- Improved health
- Well-designed interventions
- High-quality program delivery
- Well-designed health care organizations
- Policies and programs that improve health and healthcare
- Healthier environment
- High quality research
- Patient understanding and utilization of scientific evidence

Delphi Panel Participants

- 20 participants approached based on experience in the different domains of patient engagement.
- Included researchers, clinicians and patient advocates.
- In total, 19 experts agreed to participate.
  - Gender:
    - 13 female and 6 male
  - Background:
    - 8 from academic medical schools or university departments
    - 5 from a non-profit organization
    - 3 are independent patient advocates
    - 3 are from independent research organizations

Delphi Study Overview

- Delphi study composed of three surveys to reach consensus on model domains, subdomains, and outcomes and their definitions
- All responses anonymous
- In each round, participants

(1) selected to include or exclude domains and subdomains,

(2) indicated whether they agreed with the definitions of subdomains and domains,

(3) indicated whether they agreed with the engagement outcomes included in the original model, and

(4) provided feedback on intermediate and longer term outcomes, as shown below.

Overview of Surveys

Survey 1	Survey 2	Survey 3
• Domains to include • Domain definitions • Subdomains to include	• Domain definitions • Subdomain definitions • Engagement outcomes	• Domain definitions • Subdomain definitions • Intermediate outcomes • Longer term outcomes

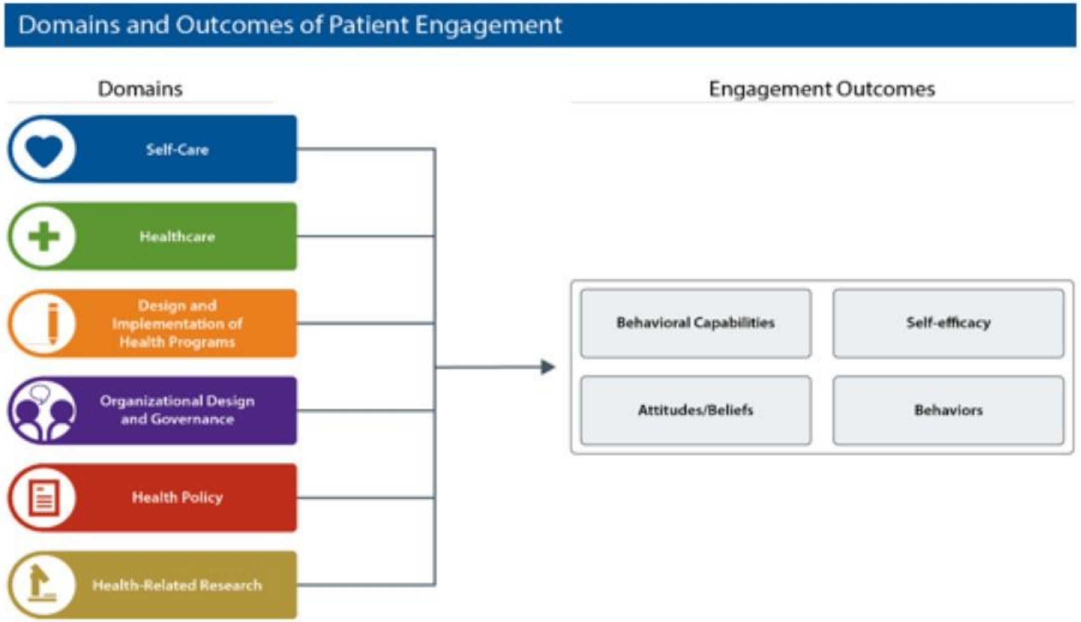
Results: Domains and Subdomains

- After Survey 1:
  - 97% overall agreement on inclusion of domains.
  - 58% agreement on definitions across the 6 domains.
- After Survey 2:
  - 90% agreement on definitions across the 6 domains.
  - 83% agreement on definitions across the subdomains.
- Survey 3 is ongoing:
  - Preliminary results suggest >90% on definitions across the 6 domains.

Results: Engagement Outcomes

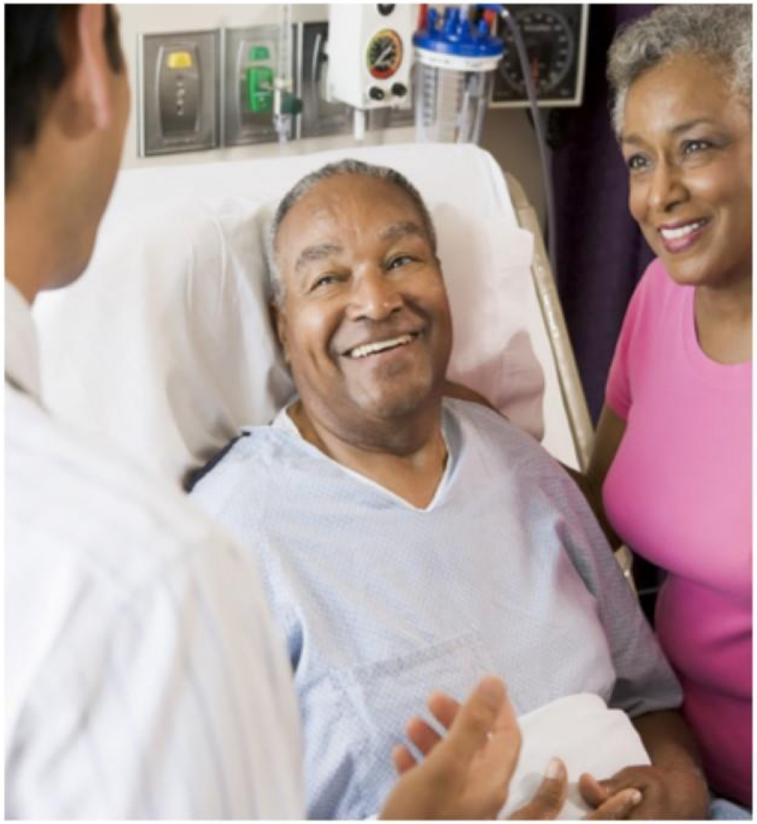
- Developed a framework for how engagement outcomes could be conceptualized
  1. **Behavioral Capabilities:** Having the knowledge and skills to perform a given behavior
  2. **Self-efficacy:** An individual's confidence in performing a particular behavior and overcoming barriers to that behavior
  3. **Attitudes/Beliefs:** An individual's values and perceptions about an issue
  4. **Behaviors:** Carrying out a particular behavior

- 72% agreed with the framework we developed



Implications for Patient Involvement

- Help prioritize the ways we involve patients in research and identify gaps
- If patients are going to be involved in research, we need to develop measures of engagement



Study Team and Support

- Katherine Treiman
- Catherine Slota
- Brittany Zulkiewicz
- Nupoor Kulkarni

- Supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR001111

Discussion & Wrap-up

Thank you

and

Safe Travels!