Leveraging Core Competencies of Collaboration and Innovation to Create a Health System Patient Advisor Resource

Patient Experience Summit
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Engaging Patients with Research

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Objectives

- Define Patient-Centered Outcomes Research (PCOR)
- Describe Role of Patient Engagement in PCOR
- Provide an Example of Patient Engagement in PCOR

Patient-Centered Outcomes Research

What is patient-centered outcomes research (PCOR)?

- Assesses the benefits and harms of preventive, diagnostic, therapeutic, palliative, or health delivery system interventions to inform decision making, highlighting comparisons and outcomes that matter to people
- Is inclusive of an individual's preferences, autonomy and needs, focusing on outcomes that people notice and care about such as survival, function, symptoms, and health related quality of life

What is patient-centered outcomes research (PCOR)?

- Incorporates a wide variety of settings and diversity of participants to address individual differences and barriers to implementation and dissemination; and
- Investigates (or may investigate) optimizing outcomes while addressing burden to individuals, availability of services, technology, and personnel, and other stakeholder perspectives

What is patient-centered outcomes research (PCOR)?

- PCOR places the patient’s health priorities first
- Moves away from a disease-centered model of health care to a patient-centered model
- What types of questions can be answered by PCOR:

Expectations	Options	Outcomes	Decisions
“Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”	“What are my treatment options and what are the potential benefits and harms of those options?”	“What can I do to improve the outcomes that are most important to me?”	“How can clinicians and the care delivery systems help me make the best decisions about my health and healthcare?”

Modified from the “PCORI Update on a New Era in Research” presentation

The Patient-Centered Research Model

Patient Engagement

- Understanding the choices patients face

Patient-Driven Research

- Aligning research questions and methods with patient needs

Dissemination

- Providing patients and clinicians with information for better decisions

Modified from the “PCORI Update on a New Era in Research” presentation

Example of Patient-Centered Outcomes

- Quality of Life
- Mobility
- Ability to carry out certain tasks
- Ability to focus
- Ability to return to work
- Side effects/risks of treatment
- Symptoms (e.g. pain)
- Survival

Engaging Patients in Research

Patient Engagement in Research

- Role of patients in research can cover wide range:
  - Passive role: Patient is a data point
  - Active role: Patient is a researcher
- Patients can be engaged as participants in the research process:
  - Focus groups
  - Interviews/surveys
  - Serve on study board or advisory council
  - Member of research team
- Engagement possible at every step in research process

Challenges in Engaging Patients in Research

- Patient frustration
  - Time to conduct a research study
  - Logistics of participating
- Patients can become “tokenistic” or “checking a box”
- “Scope creep”: patients have other agendas/priorities that make the research infeasible

Domecg et al 2014 BMC Health Services Research

Benefits of Engaging Patients in Research

- Improved enrollment
- Improved retention in study
- Improved credibility of study results
- Improved dissemination of study results
- Meaningful results for participants and community

Example of Patient Engagement in a Research Study

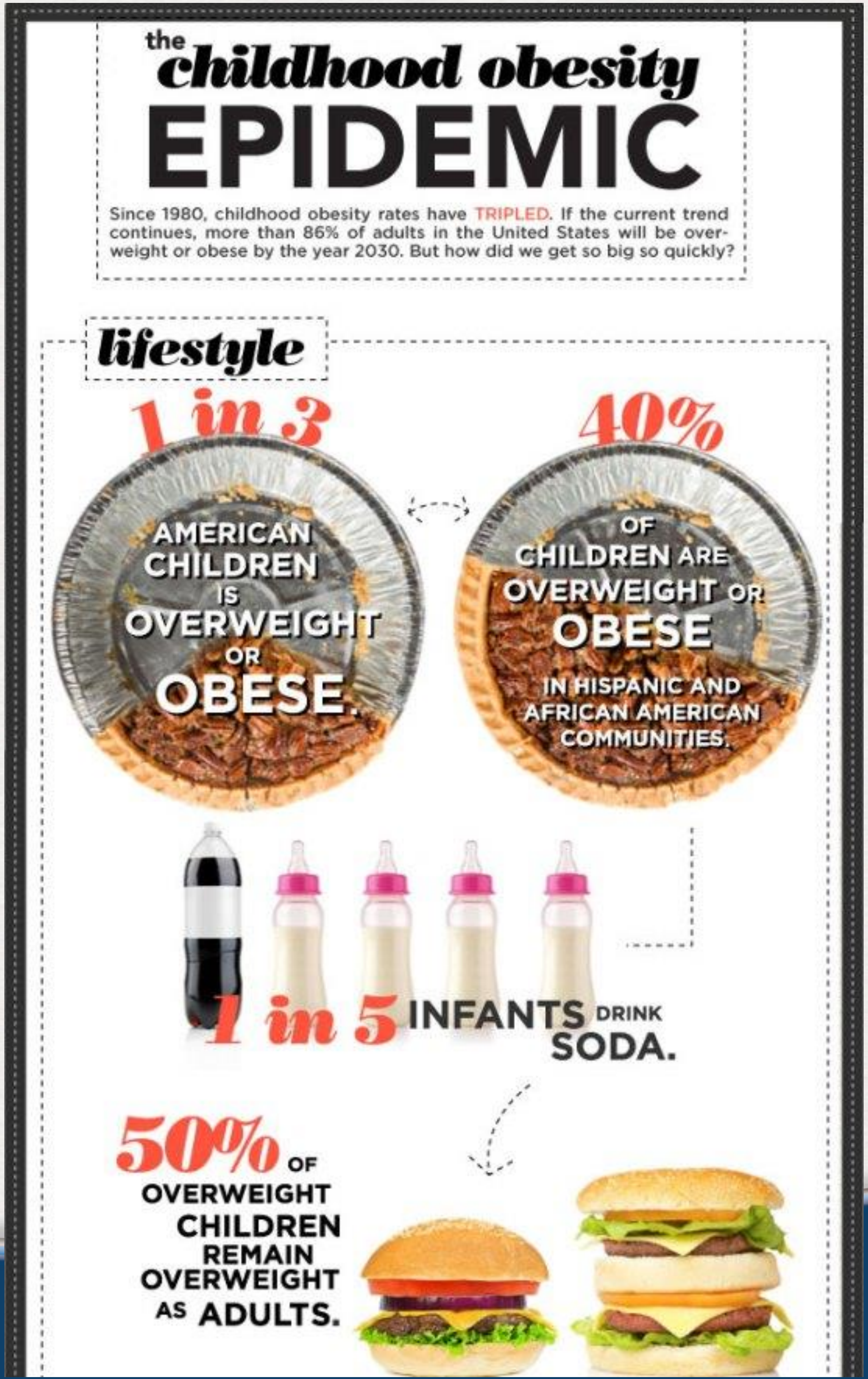
Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

Johnson (PI) 1R24HS022417-01 Personalizing Care for Obese Patients in an Urban Health System

A Family-Centered Approach to Screening for Obesity and Related Conditions During the Well Child-Visit

Aims of the Well-Child Visit Study

- Examine current trends in screening and management of obesity and obesity-related conditions in a real-world urban practice setting
- Examine the family (patient and parent/guardian) and clinician preferences for the identification and management of obesity and obesity-related conditions
- Design and conduct a Phase II pragmatic cluster randomized trial (PCRT) of an educational intervention in providers for guiding screening for obesity and obesity-related conditions during the well-child visit that incorporates and leverages PCO



the childhood obesity EPIDEMIC

Since 1980, childhood obesity rates have TRIPLED. If the current trend continues, more than 86% of adults in the United States will be overweight or obese by the year 2030. But how did we get so big so quickly?

lifestyle

1 in 3 AMERICAN CHILDREN IS OVERWEIGHT OR OBESE.

40% OF CHILDREN ARE OVERWEIGHT OR OBESE IN HISPANIC AND AFRICAN AMERICAN COMMUNITIES.

1 in 5 INFANTS DRINK SODA.

50% OF OVERWEIGHT CHILDREN REMAIN OVERWEIGHT AS ADULTS.

Image from: http://www.infographicszone.com/health/top-5-childhood-obesity-infographics

Patient- and Family- Centered Care

American Academy
of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Organizational Principles to Guide and Define the Child
Health Care System and/or Improve the Health of all Children

POLICY STATEMENT

Patient- and Family-Centered Care and the Pediatrician's Role

- Philosophies, principles and practices that put the family at the heart or center of services
- Family is the driving force
- Based on the understanding that the family is the child's primary source of strength and support and that the child's and family's perspectives and information are important in clinical decision-making

Principles of Patient and Family-Centered Care

1. Listening to and respecting each child and his/her family
2. Ensuring flexibility in policies so services can be tailored to each child/family
3. Sharing complete, honest information with child/family

Principles of Patient and Family-Centered Care, cont….

4. Providing and/or ensuring formal and informal support for child and family
5. Collaborating with child/family at all levels of health care
6. Recognizing and building on strengths of individual children/families

What do we know about PCO important in childhood obesity?

- Clinical Outcomes:
  - Lose ## pounds by XX date
  - Move BMI percentile down ## points
- PCO:
  - I want to shop in the regular size department
  - I want to walk the mile in gym without a break
  - I don’t want my peers to call me a name

Barkin et al *Pediatrics* (2012)

Strategies for Patient Engagement

- Focus Groups
- In-depth interviewing
- Research Patient Advisors

Focus Group Work

- Focus groups held with adolescents (14-17 years), parents and providers
- Aimed to identify views and experiences with the well-child visit and conversations related to weight, blood pressure, and cholesterol.

Focus group findings (adolescents)

Awareness and/or Knowledge of Weight’s Impact on Health

- “I know what diabetes is, but I never understood why it’s related to having a higher weight, but they never really explained it to me.”
- “Being able to do stuff without health issues and not necessarily being really fit.” “Overweight depends on how you distribute the weight.”
- “Depends on your perspective of what you think healthy is, like your height and bone structure because… if you have larger bones, you could still be healthy. BMI scales, I don’t think they are entirely accurate. If it tells you you’re overweight, you might be – depends on you as a person.”
- ‘I have always thought you get high blood pressure from stress.’

Focus group findings (parents)

- For some parents, weight conversations are a barrier to care
  - "Well, my one daughter, um, is pretty sensitive about her size. And she has specifically asked, "I don't want to see Doctor So-and-So. I'd like to see," uh, but it's—it's nothing that was, um, wrong or bad. It was really the truth, just not presented in how she wanted to hear it."
- Parents have seen the BMI chart but are unsure with what it means or are concerned with its validity
  - "…I mean they give you this chart, but I don't think that, uh, most children are within those guidelines. I mean none of mine were ever within those guidelines because I had all big kids. [Asked why they think child is not in guidelines] "Hereditary."

Focus group findings (providers)

- Patient-centered care is hard to define or interpret
  - “So patient-centered care would be care where the patients are intimately involved in the outcomes, the history, and the outcomes, and that you basically work together to find a treatment plan that is beneficial and that they will more likely, um, agree with.”
- Providers prefer to discuss health and lifestyle factors, not weight
  - “For the middle and the, um, high schoolers and the high elementary also, I do not like to emphasize weight. I just say, you know… health.”
  - “Being healthy.” (agreement from many)
  - “We talk about charts.”

Incorporating Focus Group Findings

- Developing provider education tool to incorporate PCO discussions in well-child visit
- Utilize focus group findings to guide language used

Research Patient Advisors

- Recruited two parents to join research team
- Monthly meetings
- Currently reviewing study materials

Patient-Centered Outcomes Research Institute (PCORI)

- Independent non-profit organization funded through the Patient-Centered Outcomes Research Trust Fund (PCORTF)

- PCORTF was authorized by Congress as part of the Patient Protection and Affordable Care Act of 2010

- PCORTF receives income from two funding streams: the general fund of the Treasury and a small fee assessed on Medicare, private health insurance and self-insured plans

- Expected to receive an estimated $3.5 billion from the PCORTF to fund PCOR through September 30, 2019, the date through which the Act authorizes the fund to remain in operation

Modified from the “PCORI Update on a New Era in Research” presentation

Building and Testing the Infrastructure Model

Karen E. Kippen, MSA

Executive Director, Patient-Engaged Research Center

Objectives

- Healthcare Systems
    - Patient-Engaged Research Center Model for Engagement
- Quality, Research & Patient Engagement
    - Head and Neck Cancer Patient Advisory Council
- Leveraging the Engagement Model
    - Learning and Improving

Healthcare Systems

IOM 6 Domains of Quality

Patients Included

- **Safe**: Avoiding harm to patients from the care that is intended to help them.
- **Effective**: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
- **Patient-centered**: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- **Timely**: Reducing waits and sometimes harmful delays for both those who receive and those who give care.
- **Efficient**: Avoiding waste, including waste of equipment, supplies, ideas, and energy.
- **Equitable**: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status

Bringing the Pieces Together

Patient-Engaged Research Center (PERC) Strategic Plan 2015-2020

1. Sufficient and highly trained research staff
2. Create a large network of community organizations (30) and patient advisors (300)
3. Develop efficient core structures, processes and clearly defined models for research
4. Grants and publications to disseminate scientific knowledge.

System-wide Patient Engagement Connections

Location	Team Name	Quality/ Safety	Service	Funded Research	Other
System	Board of Trustee Quality Sub-Committee	✓			
	System Quality Forum (SQF)	✓			
	Care Transitions Patient/Family Advisory Council	✓			
	Patient Experience Patient Family Advisory Council	✓	✓		
HFH/HFMG	ENT Patient/Family Advisory Council	✓		✓	
	Research Core Patient Advisors (3 Teams)			✓	
	Transplant Institute Patient Family Advisory Council	✓			
	Caring Conversations Team	✓			
	Ethics Committee				✓
HFWH	Patient/Family Advisory Council	✓	✓		
HFWBH	Breast-Feeding Friendly Hospital	✓			
HFMH	Patient/Family Advisory Council*				

* Currently Recruiting for June Start

The Role of a Patient Advisor

Flexible Models for Patient Engagement

ENT Patient & Family Advisory Council

Improvement & Engagement

HFHS Advisors

ENT Advisory Council

- ~24 member PFAC
- 1st Meeting 12/14
- Planning & Charter
- Created a new patient resource guide
- Created a Survivorship Clinic
- Added Dental Resources
- QoL Survey selection (FACTH&N)

Research Advisors /Funding

“SCOOP”

(Squamous Cell Carcinoma of the oro-pharynx)

- Funded by PCORI P2P (Tier I)
- CER- Quality of Life
  - Rad. vs. Surgery/Chemo
- Tier II- engage HCSRN Cancer Research Network
- Tier III or Full NIH/PCORI Funding

Power of Engagement

Pragmatic Advice from Advisors

HFHS Insights Community Survey

Precision Medicine Benefits and Barriers (n=1576)

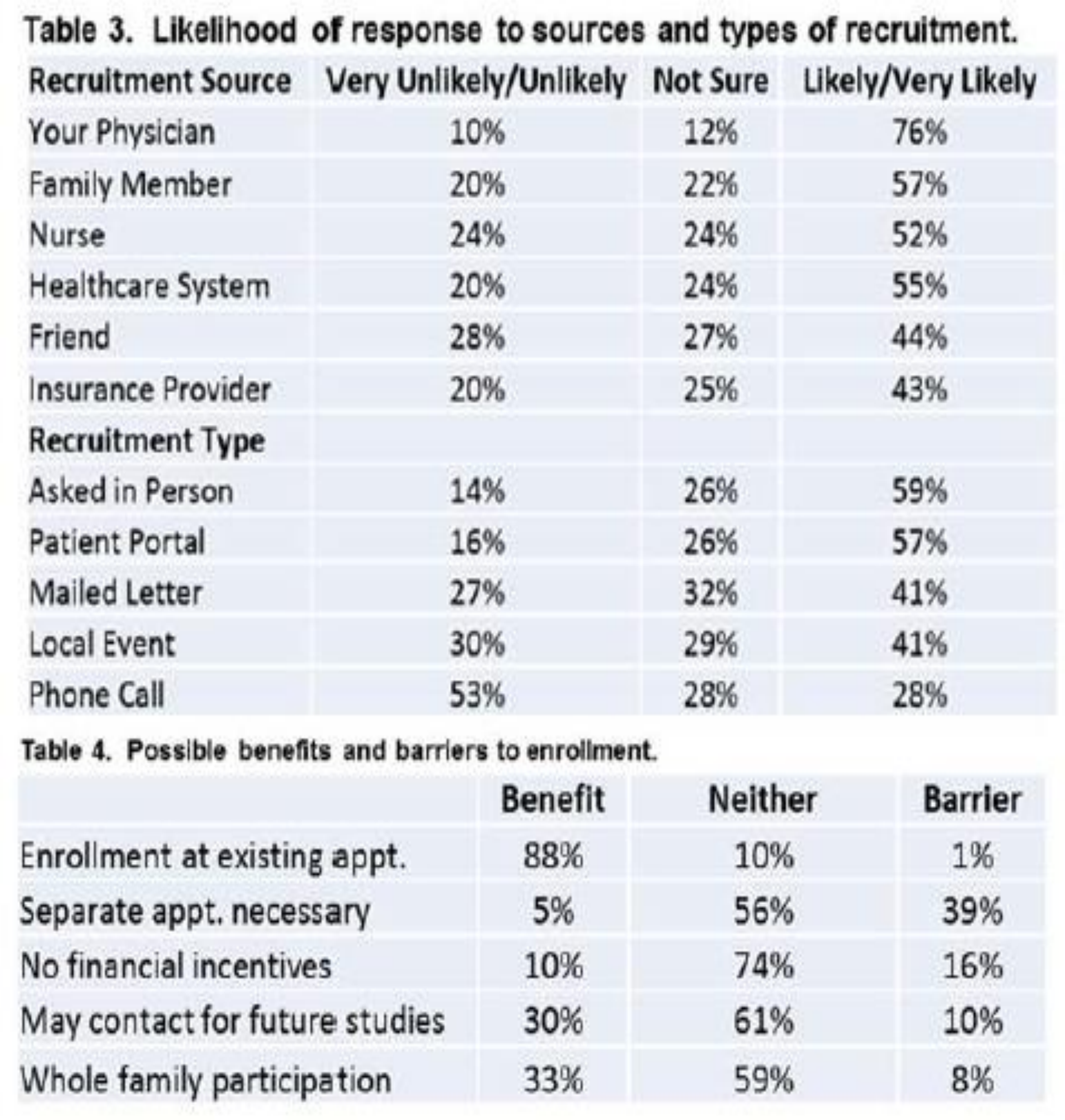


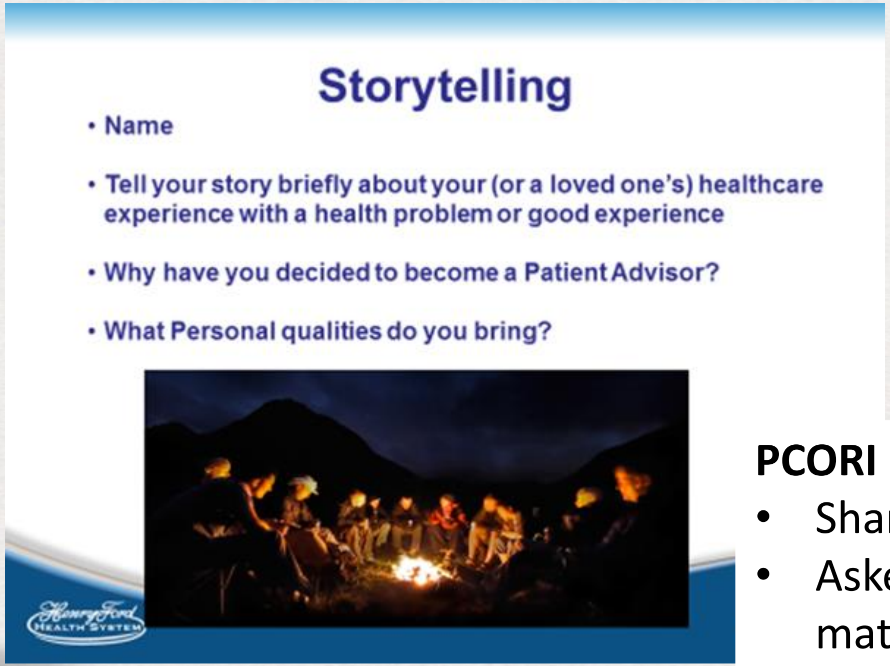
Table 3. Likelihood of response to sources and types of recruitment.

Recruitment Source	Very Unlikely/Unlikely	Not Sure	Likely/Very Likely
Your Physician	10%	12%	76%
Family Member	20%	22%	57%
Nurse	24%	24%	52%
Healthcare System	20%	24%	55%
Friend	28%	27%	44%
Insurance Provider	20%	25%	43%
Recruitment Type			
Asked in Person	14%	26%	59%
Patient Portal	16%	26%	57%
Mailed Letter	27%	32%	41%
Local Event	30%	29%	41%
Phone Call	53%	28%	28%

Table 4. Possible benefits and barriers to enrollment.

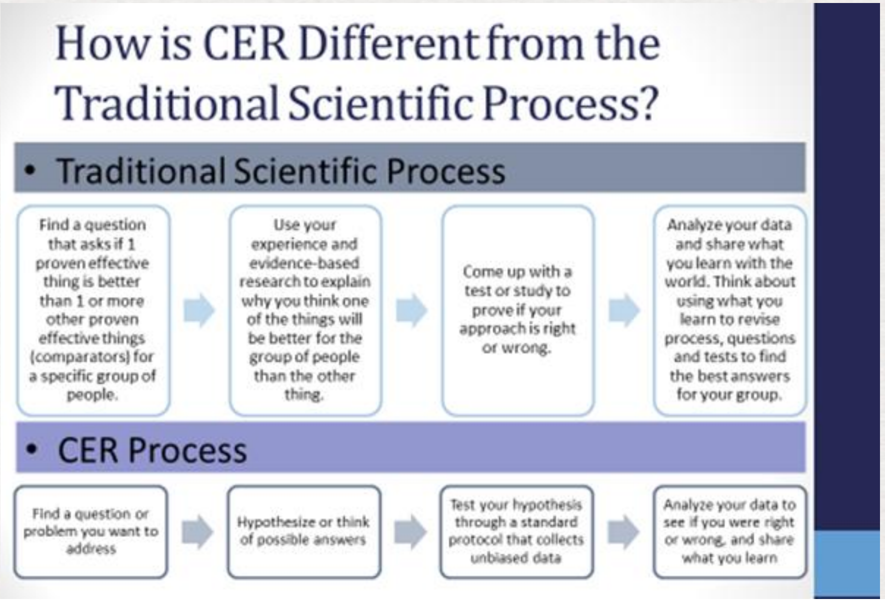
	Benefit	Neither	Barrier
Enrollment at existing appt.	88%	10%	1%
Separate appt. necessary	5%	56%	39%
No financial incentives	10%	74%	16%
May contact for future studies	30%	61%	10%
Whole family participation	33%	59%	8%

Patient Advisor Storytelling can lead to……. Comparative Effectiveness Research Questions



Storytelling

- Name
- Tell your story briefly about your (or a loved one's) healthcare experience with a health problem or good experience
- Why have you decided to become a Patient Advisor?
- What Personal qualities do you bring?



How is CER Different from the Traditional Scientific Process?

- Traditional Scientific Process

Find a question that asks if 1 proven effective thing is better than 1 or more other proven effective things (comparators) for a specific group of people. → Use your experience and evidence-based research to explain why you think one of the things will be better for the group of people than the other thing. → Come up with a test or study to prove if your approach is right or wrong. → Analyze your data and share what you learn with the world. Think about using what you learn to revise process, questions and tests to find the best answers for your group.

- CER Process

Find a question or problem you want to address → Hypothesize or think of possible answers → Test your hypothesis through a standard protocol that collects unbiased data → Analyze your data to see if you were right or wrong, and share what you learn

PCORI Pipeline to Proposal Project

- Shared information about Comparative Effectiveness Research (CER) Process
- Asked Patient Advisors to use their own story to develop a question that matters to them and their families
- Developed 8 CER broad question topic as a foundation for future research proposals

Summary

- **Collaboration leads to innovative solutions** and opportunities for Health System patient engagement
- **Create a flexible patient advisor engagement model** that meets the needs of all stakeholders (patients, families, researchers, providers and senior leadership)
- **Engage with patient advisors early and often** to develop novel approaches to Patient Experience, Research and Care Delivery in the future

IF EVERYONE IS MOVING FORWARD TOGETHER, THEN SUCCESS TAKES CARE OF ITSELF.

HENRY FORD

Meet the Team

Patient Engaged Research Center

Team Members