

# Research Advocacy

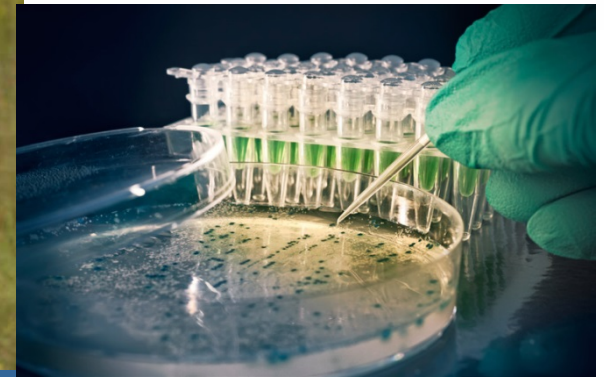
## Senior Patient and Family Caregiver Network Advocate Mentors Training Webinar



Catalyzing Innovation for Healthy Aging



SCIENCE CAN HELP  
PEOPLE LIVE LONGER,  
MORE PRODUCTIVE LIVES



## WHO WE ARE

The Alliance for Aging Research is the leading non-profit organization dedicated to accelerating the pace of scientific discoveries and their application in order to vastly improve the universal human experience of aging and health. [WWW.AGINGRESEARCH.ORG](http://WWW.AGINGRESEARCH.ORG)

**Catalyzing Innovation for Healthy Aging**

# Goals for Today

## **To better understand...**

- ✓ How and why medical research happens
- ✓ What Patient Centered-Outcomes Research (PCOR) is and why it is important
- ✓ What to expect at our upcoming Research Advocacy Training

# Research Advocacy Training

## DATES AND GOALS

**Tuesday, May 23, 2017** – DINNER in *Ballroom B* at St. Gregory Hotel 6:00 p.m. – 8:30 p.m.

**Wednesday, May 24, 2017** –TRAINING at *McLean Room*, 10<sup>th</sup> Floor, Akin Gump 7:30 a.m.–4:00 p.m.

### Goals

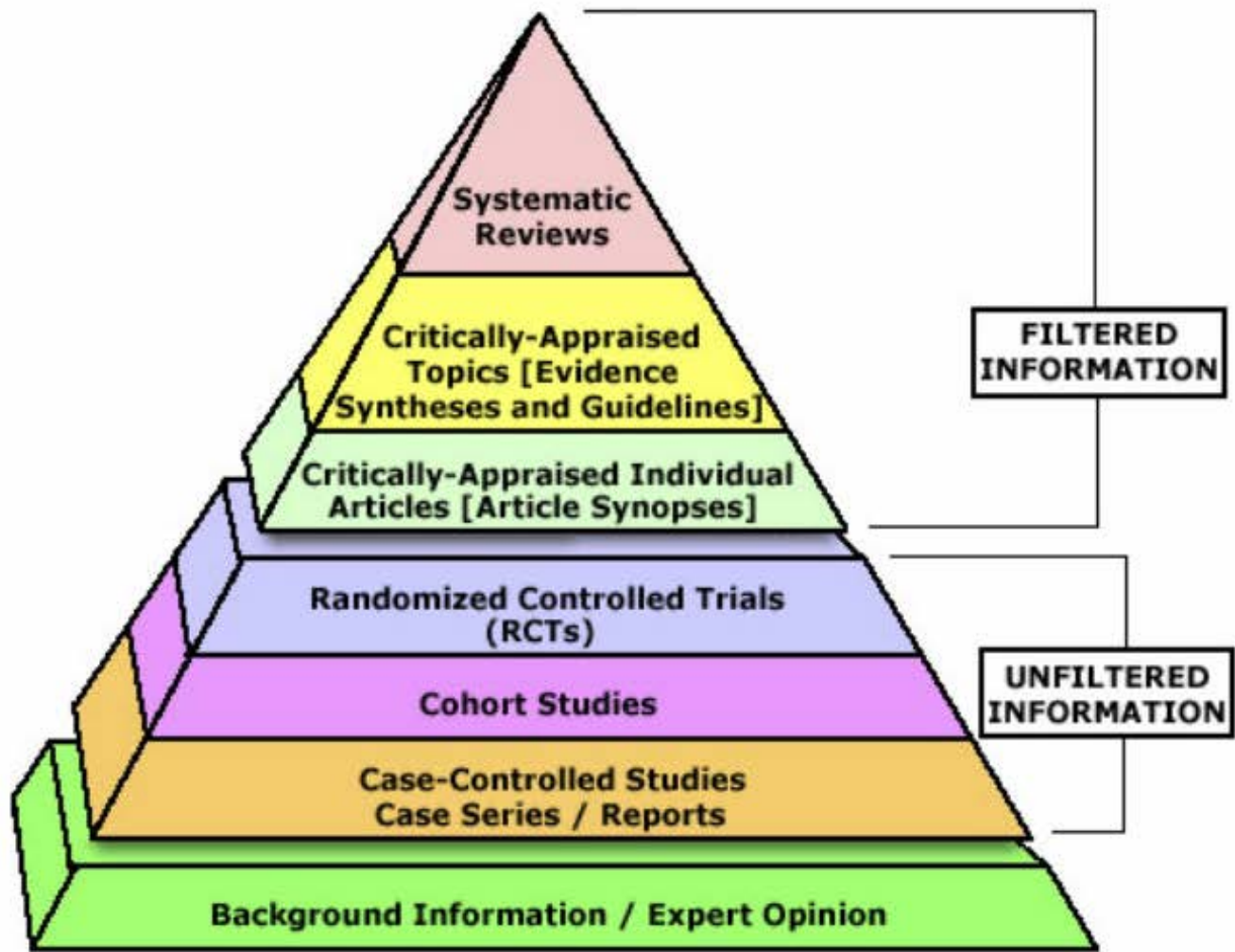
- ✓ expand your influence in aging-related health research
- ✓ educate your communities about research advocacy

# How Does Medical Research Happen?

Wait, isn't ALL health care based on scientific evidence?

## Evidence-Based Health Care

# How Does Medical Research Happen?





# How Does Medical Research Happen?

There are different types of studies based on when and how the subjects are enrolled into the study:

- 1) In **prospective studies**, researchers follow participants into the future to record when and how they developed a particular outcome
- 2) In **retrospective studies**, researchers jump back in time to look at records of patients and follow their histories to determine when, why, and how they developed a particular outcome

There are two types of data used to measure outcomes:

- 1) Data that is **quantitative** can be expressed as a number, or quantified
- 2) Data that is **qualitative** cannot be expressed as a number

# How Does Medical Research Happen?

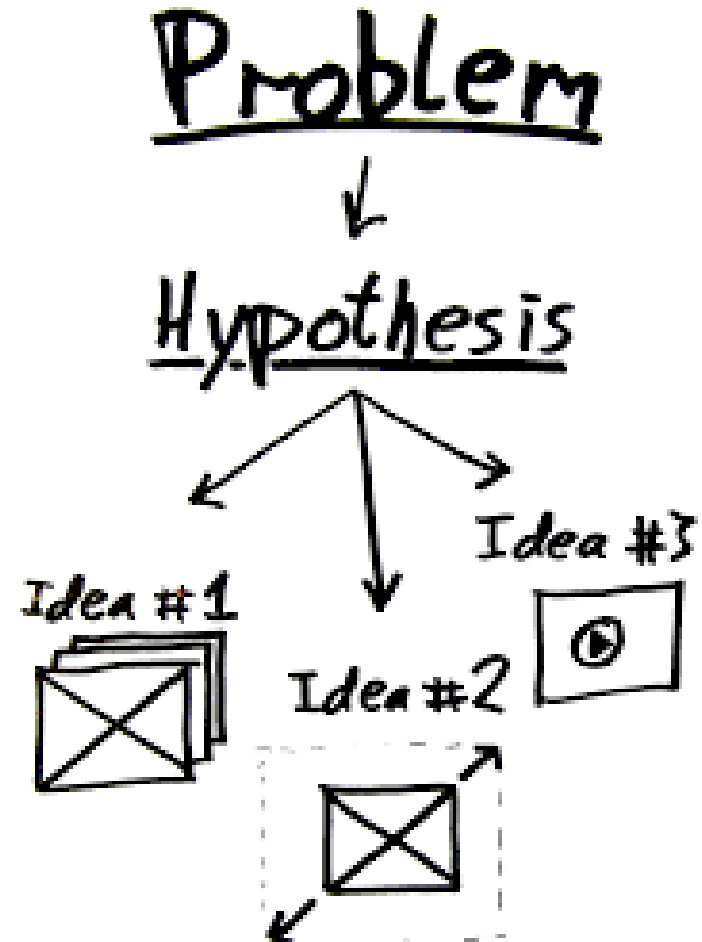
There are four key ingredients for the scientific method:

- 1) **Hypothesis:** an educated guess that can be tested
- 2) **Randomization:** assigning or arranging in a random way
- 3) **Protocol:** a detailed plan of a scientific or medical experiment
- 4) **Reproducibility:** the extent to which an experiment can be duplicated by following the same protocol



# How Does Medical Research Happen?

## Hypothesis



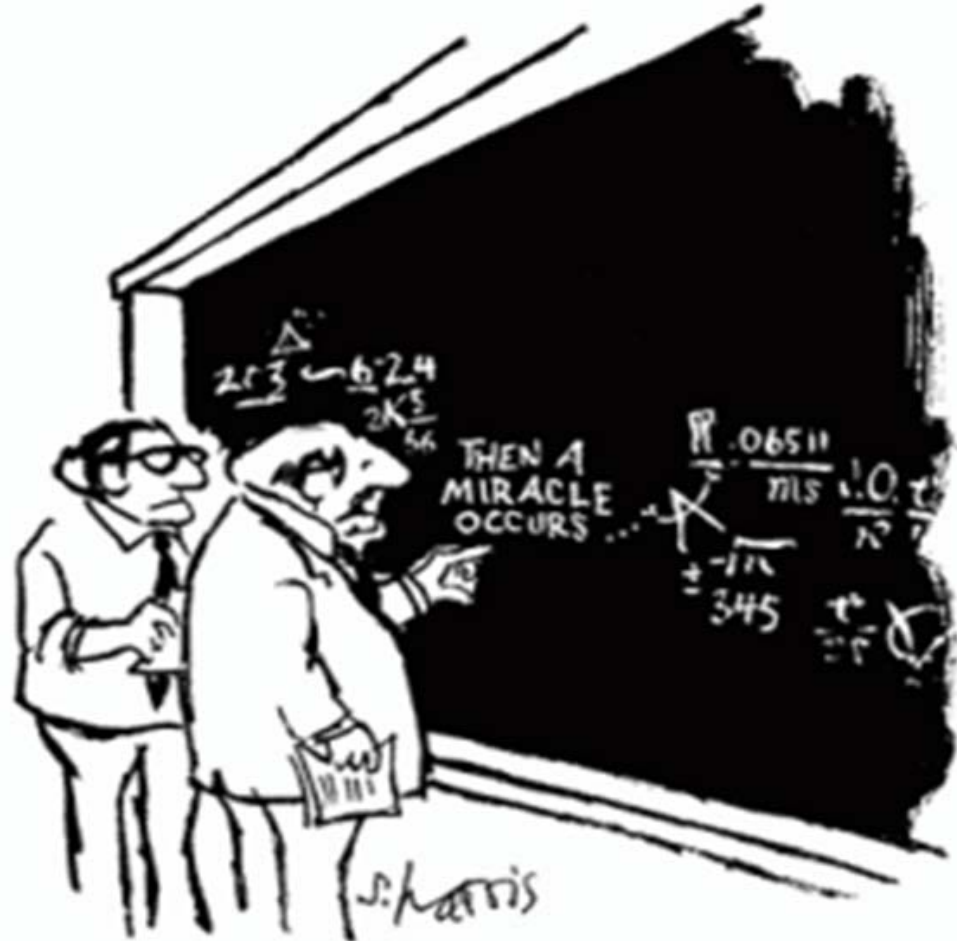
# How Does Medical Research Happen?

## Randomization



# How Does Medical Research Happen?

## Protocol



"I think you should be more explicit here in step two."

# How Does Medical Research Happen?

## Reproducibility

### UNBELIEVABLE PESACH BROWNIES

FROM PAGE 243 OF PASSOVER BY DESIGN

YIELD: 18 BROWNIES

**INGREDIENTS:**

- nonstick cooking spray
- 4 large eggs
- 2 cups sugar
- 1 cup vegetable oil
- 1/2 teaspoon fine sea salt
- 1/4 cup Dutch process cocoa powder
- 1 cup potato starch
- 1/2 cup semi-sweet chocolate chips (optional)

**DIRECTIONS:**

1. Preheat oven to 350°F.
2. Spray an 11- by 7-inch brownie pan with nonstick cooking spray. Set aside.
3. In the bowl of an electric mixer, beat the eggs and sugar until smooth. Add the oil and salt. Mix. Sprinkle in the cocoa powder and mix to make the batter chocolate. Add the potato starch and mix to combine. Scrape down the sides with a spatula. Stir in the chocolate chips if using.
4. Pour into prepared pan. Bake for 35-40 minutes. Allow to cool before serving.

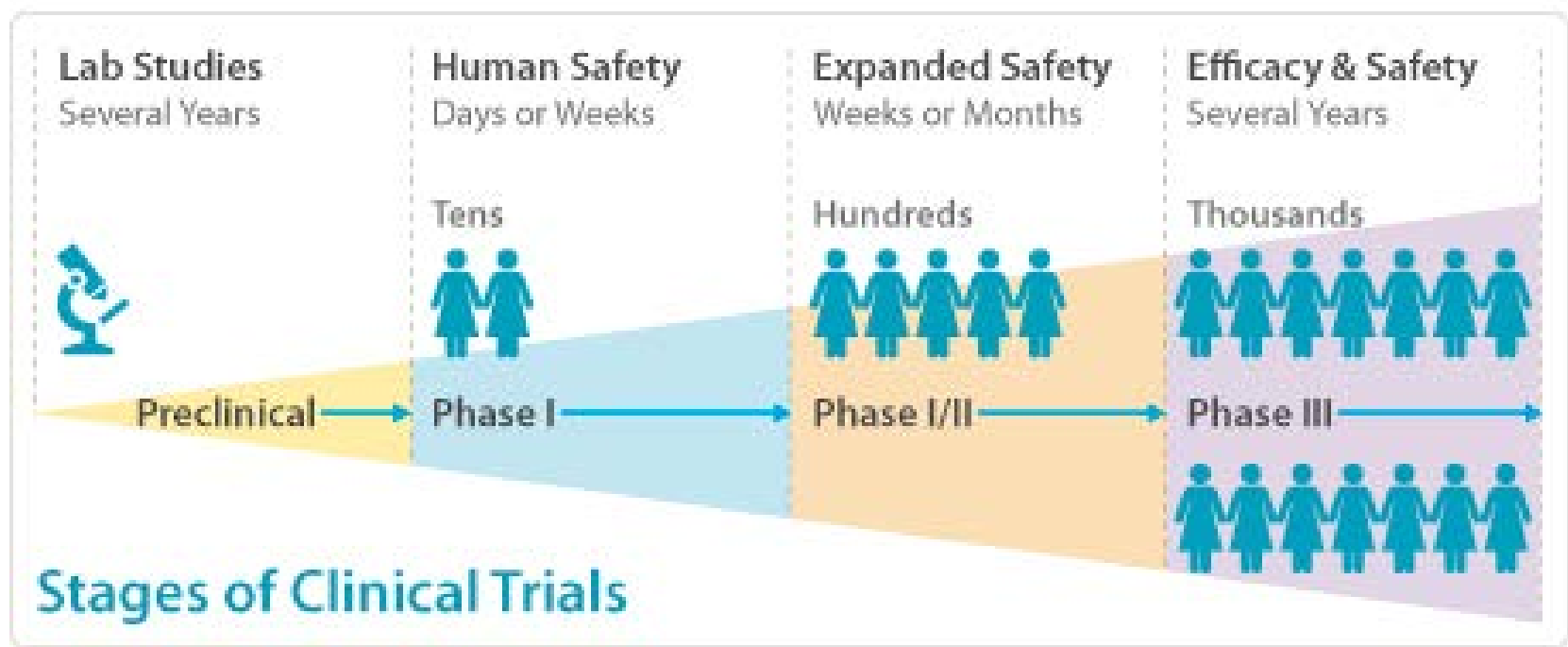


MEAT PARVE DAIRY

DESSERT

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# How Does Medical Research Happen?



# Who Funds Medical Research?

- Federal Government (National Institutes of Health, other departments like the Dept. of Agriculture and Dept. of Defense, also the National Science Foundation)
- State and Local Governments
- Industry (Pharmaceutical, Biotechnology, etc.)
- Foundations
- Medical Research Organizations
- Disease-Focused Organizations
- Universities and Colleges



# Who Funds Medical Research?

Government

# Industry

Pharmaceutical  
Biotechnology  
Medical Devices

**\$100 billion  
annually  
worldwide**



Catalyzing Innovation for Healthy Aging

# What is Patient-Centered Outcomes Research?

How does it work?

How is it different from other kinds of research?

# What is Patient-Centered Outcomes Research?

## Terms to Know

### Comparative Effectiveness Research (CER)

The direct comparison of two or more treatments to determine what works best for which patients

### Patient Centered Outcomes Research (PCOR)

A kind of comparative effectiveness research that specifically answers patient-centered questions

# What is Patient-Centered Outcomes Research?

Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?

What are my options, and what are the potential benefits and harms of those options?

How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?

What can I do to improve the outcomes that are most important to me?

# What is Patient-Centered Outcomes Research?

## Terms to Know

### Efficacy Trials

Could it work in ideal settings?

### Effectiveness or Pragmatic Trials

Does it work in the real world?

# What is Patient-Centered Outcomes Research?

## Terms to Know

### Patient **Reported** Outcomes

Any report about a patient's health condition that comes directly from the patient, without interpretation by a clinician or anyone else.

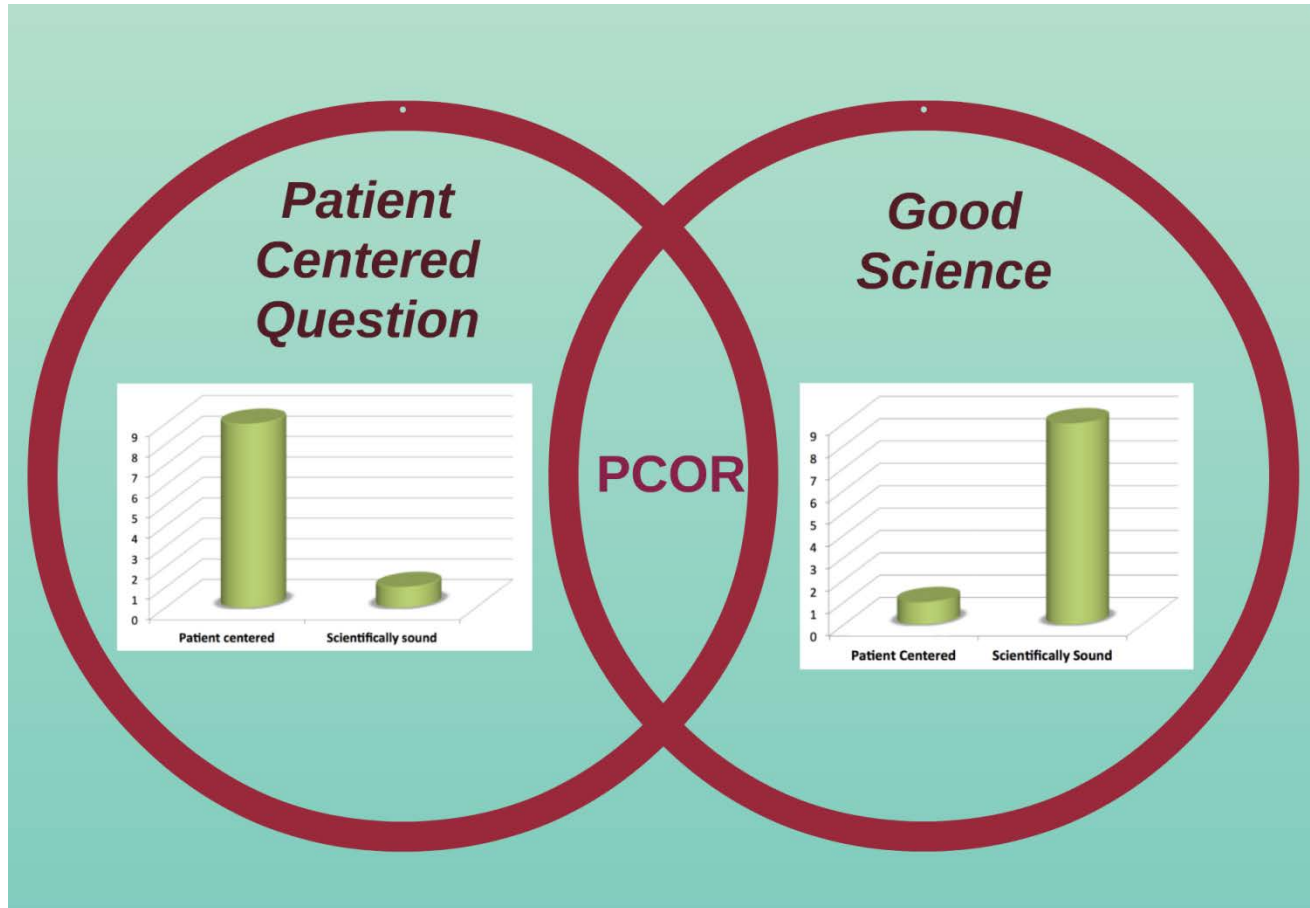
### Patient **Centered** Outcomes

A health result (event or nonevent) that actually matters to patients.

### Patient **Engagement**

Including patients in the research process itself.





# What is Patient-Centered Outcomes Research?

## Terms to Know



**Patient Centered Outcomes Research Institute (PCORI)**

# What makes PCOR different?

Patients can participate in PLANNING the research.

Patients can participate in CONDUCTING the research.

Patients can participate in DISSEMINATING of the research.

# Translating Concerns Into Research Questions

## **THE PEOPLE**

This is the population of interest.

## **THE OPTIONS** INTERVENTION and COMPARATOR

These are the decisions the research is intended to inform.

## **THE OUTCOMES**

These are the factors that people will consider when making a decision between/among options.

# Translating Concerns Into Research Questions



What are the comparative benefits and risks of nursing home, assisted living, and home-based care ... for older adults with dementia?



**PEOPLE:** the group of people to be studied

**OPTIONS:** the choices or options that should be compared

**OUTCOMES:** what good and bad things a patient can expect from each option to help them

# Homework

1. Two short videos about patient-centered outcomes research
2. One document that provides an overview of the research process (7 pages)
3. One on-line training about the Food and Drug Administration



# What to Expect

## Before the training:

- A bit of homework (just a bit)
- An email confirming logistics

## At the training:

- On Tuesday we will start at 6pm; dinner will be provided
- On Wednesday breakfast and lunch will be provided at the meeting room

## What else?

- Bring a computer or other electronic device if you have one
- Wear comfortable clothes