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

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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
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, 10th 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?

- Systematic Reviews
- Critically-Appraised Topics [Evidence Syntheses and Guidelines]
- Critically-Appraised Individual Articles [Article Synopses]
- Randomized Controlled Trials (RCTs)
- Cohort Studies
- Case-Controlled Studies Case Series / Reports
- Background Information / Expert Opinion

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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.
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

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How Does Medical Research Happen?

Randomization

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How Does Medical Research Happen?

Protocol

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

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How Does Medical Research Happen?

Reproducibility

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How Does Medical Research Happen?

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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

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Who Funds Medical Research?

$100 billion annually worldwide

Pharmaceutical Biotechnology Medical Devices

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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.

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Patient Centered Question

Good Science

PCOR

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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**
These are the decisions the research is intended to inform.

**INTERVENTION and COMPARATOR**

**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

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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

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