




<p>MODULE 1: RESEARCH: WHAT, WHY, AND WHO</p> <hr/>    <p>Veterans Health Administration Durham VA Health Care System</p> <p>VA HEALTH CARE HONORING SERVICE EMPOWERING HEALTH</p>	<p>Welcome: Facilitators should welcome participants to the group and thank them for their willingness to serve as a Veteran Representative</p>
<p>ICEBREAKER ACTIVITY</p>	<p>Icebreaker Activity Options:</p> <ol style="list-style-type: none">1. Introduce Your Neighbor: Ask everyone in the room to find a partner (including facilitators). Ask each pair to introduce themselves and share their military history (if they would like), why they were interested in joining this group, and one interesting fact about themselves. Afterwards, go around the room and ask each person to introduce their partner to the group and share their interesting fact.2. Simple introduction: Ask each person to introduce themselves and share their military history (if they would like), why they were interested in joining this group, and one interesting fact about themselves.

<p style="text-align: center;">Objectives</p> <ul style="list-style-type: none">• Discuss what research is, and why we do it• Explain how research fits within VA's structure and mission• Define the "players" in research• Describe the role of Veteran and Caregiver representatives in research <hr style="border: 2px solid #0056b3;"/>	<p>Provide overview of the schedule and topics that will be covered in the presentation today, as well as topics that will be covered in additional presentations.</p> <p>Talking points: Today we will be discussing what research is and why we do it, who is involved in research, how research fits into the VA's structure and mission, and the role of individuals involved in this group. In future trainings we will talk more about research ethics and how research is conducted</p> <p>Provide framing for the training. Sample language: <i>We all have different experiences and knowledge about research. We want everyone to be on the same page and able to understand the research that we are talking about, so today and in future training modules we will be going over some of the basic concepts about health research. We are all here to learn from each other and will be asking for people to share their perspectives throughout the training. Feel free to ask questions at any time. We also welcome suggestions for training topics that we can cover at another date [have a piece of poster paper on the wall where you can record these].</i></p>
<div style="background-color: #800000; color: white; padding: 20px; text-align: center;"><h2>WHAT IS RESEARCH?</h2><hr style="border: 1px solid white;"/></div>	<p>Discuss: <i>When you hear the term "research," what comes to mind?</i></p> <p>Allow time for participants to share. Write responses on a flip chart or dry-erase board.</p>

Research is a way to answer questions using an organized and systematic approach.

Talking points [Connect ideas participants generated about research during previous slides into definition on this slide]:

- Research is a way to answer questions using an organized and systematic approach

RESEARCH IN THE VA

Talking points:

- Health research happens in lots of settings. In VetREP, we will be focusing on health research that happens at the VA. In the next slides, we'll talk about how research helps the VA achieve its mission to serve Veterans, and how research fits into the overall structure of the VA.

Why Research is Important to VA

- VA's mission: To fulfill President Lincoln's promise "To care for him who shall have borne the battle, and for his widow, and his orphan" by serving and honoring the men and women who are America's Veterans.
- VA research is focused on improving the health of Veterans and improving health care for Veterans.



Talking points:

- Research is a very important part of the VA's work
- As you can see written here, the VA's mission is: To fulfill President Lincoln's promise "To care for him who shall have borne the battle, and for his widow, and his orphan" by serving and honoring the men and women who are America's Veterans.
- VA research is focused on improving the health of Veterans and improving health care for Veterans.
- By learning more about Veteran health and improving the healthcare the VA provides, we are better able to care for and serve Veterans.

Evidence-based Medicine

- At the VA, it's important to us that the treatments we provide are based on **evidence** about what is best for Veterans.
- This evidence comes from research.



D.L. Sackett et al, BMJ 1996; 312: 71-72

Talking points:

- At the VA, it's important to us that the treatments we provide are based on evidence about what is best for Veterans
- This evidence comes from research. Research helps us understand which treatments or prevention strategies are most effective so we can make better decisions.
- As this diagram shows, the evidence from research is one factor that influences the healthcare Veterans receive. Care providers still play a role, because they have to evaluate all of the information available to help determine which evidence can be applied to the situation. Patients' values and expectations matter too and influence the care they receive.

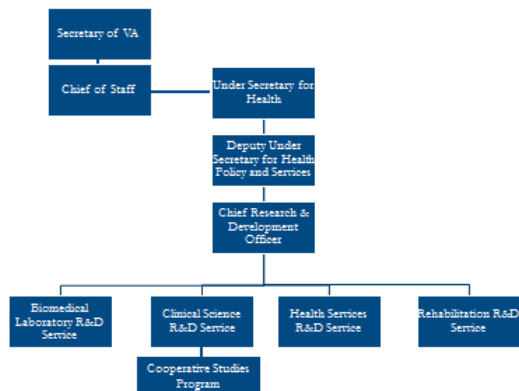
Where does Research fit into the VA?



Talking Points:

- On this slide, you can see a big chart showing how the VA is organized. Don't worry about reading all the fine print, but as you can see, the VA is very large, and research is just one aspect of the work the VA does.
- We have included a copy of this chart in your packet in case you'd like to look at this chart more in-depth

Where does Research fit into the VA?



Talking Points:

- Several different research programs are housed within the VA Office of Research and Development
- The four major research services are:
 - Biomedical Laboratory Research and Development – conducts preclinical research at molecular, genomic, and physiological levels
 - Clinical Science Research and Development – does human subjects research. Conducts intervention and effectiveness studies, clinical, epidemiological and technological studies
 - Within this service, the Cooperative Studies Programs conducts multi-side clinical trials and system-wide epidemiological studies
 - Health Services Research and Development- conducts research related to VA healthcare
 - Rehabilitation Research and Development- conducts research related to improving quality of life for disabled Veterans

Additional info: <http://www.research.va.gov/about/>

Durham VA Research Centers

- The VA has several research programs which have different focuses.



- In Durham:
 - Durham Center for Health Services Research in Primary Care
 - The Cooperative Studies Program Epidemiology Center (CSPEC) - Durham

Talking Points:

- VetREP will be hearing about research projects within two different research centers that are located in Durham.
 - The Durham Center for Health Services Research in Primary Care is part of Health Services Research and Development
 - The Cooperative Studies Program Epidemiology Center (CSPEC)- Durham is part of the Cooperative Studies Program, which falls under the Clinical Science Research and Development service
- At Durham, HSR&D and CSPEC work closely together, even though they are part of different VA research programs.

Health Services Research & Development (HSR&D) Centers of Innovation (COINs)



HSR&D focuses on **finding and testing strategies** for patient care, care delivery, improving Veteran health outcomes, improving healthcare costs, and improving healthcare quality within VA.

Talking Points:

- HSR&D focuses on **finding and testing strategies** for patient care, care delivery, improving Veteran health outcomes, improving healthcare costs, and improving healthcare quality within VA.
- There are 19 different HSR&D Centers of Innovation, or COINs. Durham is one of these centers
- Each COIN has a primary research focus, and Durham's is Primary Care.

Durham HSR&D Research Topics

- ✓ Physical activity & diet to help with weight loss
- ✓ Counseling to quit smoking
- ✓ Improving access to cancer screenings
- ✓ Support programs for caregivers
- ✓ Peer support for women Veterans at risk for heart disease
- ✓ Telemedicine to deliver diabetes care
- ✓ ...And many more!



Talking points:

- This slide shows some examples of the research topics we explore here in HSR&D

Cooperative Studies Program (CSP) Centers



Durham is one of the CSP Epidemiology Centers, which means CSPEC Durham researchers study the **health trends and causes of health conditions** of Veterans across the country.

Talking points:

- There are many different CSP Centers across the country.
- Some CSP centers do large, multi-center clinical trials (e.g., testing medications). Others focus on epidemiology research.
- Durham is one of the **CSP Epidemiology Centers**, which means CSPEC Durham Researchers study the health trends and causes of health conditions of Veterans across the country

CSPEC-Durham Research Topics

- ✓ Risk factors related to illnesses such as ALS, colorectal cancer, and Gulf War Illness
- ✓ How to carry out large, national research projects involving Veterans
- ✓ Gulf War Era Veterans' thoughts and preferences about research
- ✓ ...And many more!

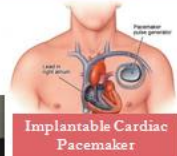


Talking points:

- This slide shows some examples of the research topics we explore here at CSPEC-Durham
- As you can see, both HSR&D and CSPEC in Durham conduct research on a wide variety of topics about Veterans' health and ways to improve Veterans' health and healthcare

WHY RESEARCH?

What do these have in common?

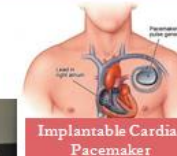


Discuss: *What do these have in common?*

Talking points:


- All are health innovations developed through research
- The health innovations seen here had to be researched to make sure that they are safe, effective and meet the needs of people


VA Research Accomplishments!

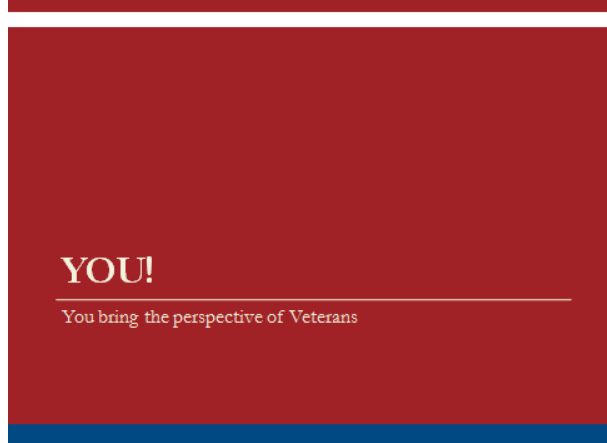


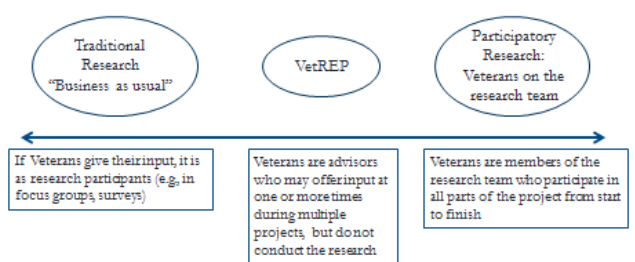
Talking points:

- Another thing that all these have in common is that they are all VA Research accomplishments!

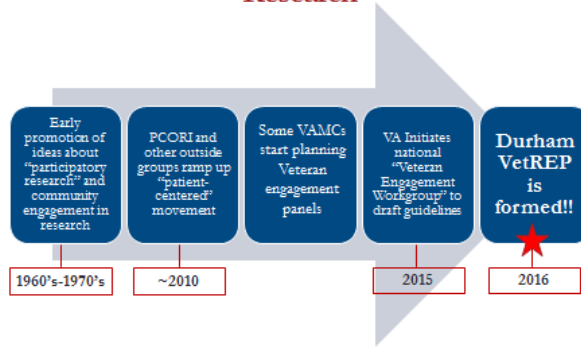
<p style="text-align: center;">Why research?</p> <p>Example: Your friend at the gym says that drinking green tea helped him lose weight. Should VA recommend that everyone who wants to lose weight should drink green tea?</p>  <p>Why or Why not?</p> <hr style="border: 5px solid blue;"/>	<p>Discussion: Present the group with a case study example: Your friend at the gym says that drinking green tea helped him lose weight. Should VA recommend that everyone who wants to lose weight should drink green tea?</p> <p>Discuss: <i>Why or why not?</i></p> <p>Discussion Format Options:</p> <ol style="list-style-type: none">1) Debate: Split the group into two teams. One team argues that yes, VA should recommend this. Another team argues that no, VA shouldn't. Bring the group together after the debate and discuss the question as a whole.2) Think/Pair/Share: Ask participants to discuss the question with a partner. Ask each pair to share their thoughts with the group3) General group discussion <p>Talking points: These are reasons we may not want to recommend that everyone drink green tea based only on personal experience:</p> <ol style="list-style-type: none">a. Other factors besides green tea could be affecting this person's healthb. Green tea might have a harmful effect on some people, such as individuals who cannot have caffeine;c. Different people might be affected by green tea in different ways
<p style="text-align: center;">Why research?</p> <ul style="list-style-type: none">• There are often conflicting ideas about the best way to address a particular problem• What works for one set of conditions might be ineffective or even dangerous in a different set of conditions <hr style="border: 5px solid blue;"/>	<p>Talking points: Health research is important for several reasons:</p> <ul style="list-style-type: none">• Research helps us identify problems people experience, and helps us figure out who is experiencing them• There are often conflicting ideas about the best way to address a particular problem. Research lets us compare different products, ideas and approaches to see what is most effective• Research allows us to learn from other people's experience• What works for one set of conditions or for some people might be ineffective or dangerous in a different set of conditions or for different people• Research helps us consider external factors that might influence the results that we see

	
<p>Who are the players?</p> <ul style="list-style-type: none">• Researchers<ul style="list-style-type: none">• Principal investigator• Co-investigators• Special consultants• Research staff<ul style="list-style-type: none">• Project managers• Interventionists (e.g., nurses, dietitians)• Participants/patients• Review boards<ul style="list-style-type: none">• Grant – reviews and scores grants based on importance and quality• IRB – decides whether research adequately protects research subjects• Other oversight agencies (e.g., FDA)• Funders (e.g., VHA, NIH, Non-profit foundations)• Others?	<p>Introductory talking points: <i>There are lots of people involved in health research, and they have many different roles.</i></p> <p>Discussion activity:</p> <ol style="list-style-type: none">1. With a partner, ask participants to discuss which terms on the slide are familiar, what they think they do, and which are new to them.2. After a few minutes, bring the group together to debrief. Ask: <i>What are your initial thoughts after looking at this list? Are you familiar with any of the roles listed? Are any a surprise?</i><ol style="list-style-type: none">a. Throughout this discussion, provide an explanation of roles as needed (if participants do not provide explanation through discussion). Talking points:<ol style="list-style-type: none">i. Investigator has training and experience in research. Brings scientific and research perspective.ii. Principal Investigator is responsible for all aspects of studyiii. Research staff – manage and implement aspects of researchiv. Participants/Patients/Veterans – those who volunteer to be part of the study, and as such will help improve things for others.v. Review Boards<ol style="list-style-type: none">1. Grant review boards: reviews and scores grants based on importance and quality

	<ul style="list-style-type: none"> 2. Institutional Review Board (IRB): If funded, the IRB reviews the research to protect the study participants- note- will discuss this further in Module 2 vi. Other oversight agencies- ex. FDA oversees drug development vii. Funders- provide funding to complete study <p>3. Ask participants to brainstorm who else is involved in research. Examples include: community members, family members, consultants, etc.</p>
	<p><i>You play an important role in the research process!</i></p>
<p>Why might it be helpful to have the voice of Veterans and their caregivers in research?</p> <hr style="border: 2px solid blue; margin-top: 20px;"/>	<p>Discuss: <i>Why might it be helpful to have the voice of Veterans and their care partners in research?</i></p> <p>Talking points:</p> <ul style="list-style-type: none"> • In addition to your thoughts about how VetREP members can help improve VA research, here are some ideas we had: • You help bring the perspective of the participants/patients. You can help researchers understand questions such as: <ul style="list-style-type: none"> • What have you and other Veterans experienced that might affect your views about health care? • How does VA healthcare impact you and your fellow Veterans? • What healthcare needs aren't being addressed for Veterans? • What is the value of this research to you and other Veterans? • What's the best way to reach out to Veterans for participating in

	<p>research studies?</p> <ul style="list-style-type: none"> • How can we improve the experience of Veterans who participate in research studies? • Ways you may help include: <ul style="list-style-type: none"> • Shaping research questions by describing Veteran priorities • Brainstorming recruitment plans for specific studies – how to get Veterans to participate, where to find Veterans who might be interested in participating • Reviewing study materials and alert researchers to things that are unclear or confusing
<p style="text-align: center;">The Spectrum of Veteran Involvement in Research</p>  <p style="text-align: center;"> Traditional Research "Business as usual" ← VetREP → Participatory Research: Veterans on the research team </p> <p style="font-size: small;"> If Veterans give their input, it is as research participants (e.g., in focus groups, surveys) ← Veterans are advisors who may offer input at one or more times during multiple projects, but do not conduct the research → Veterans are members of the research team who participate in all parts of the project from start to finish </p>	<p>Talking Points:</p> <ul style="list-style-type: none"> • Here is where we see VetREP fitting into the spectrum of Veteran involvement in research • On the left is “traditional research.” Traditionally, researchers and participants have had separate and distinct roles. In this approach, if Veterans give their input, it is as research participants (e.g., in focus groups, surveys) • On the right is participatory research. In this model of research Veterans are involved at every step of the research project, from deciding on the research topic to analyzing the data. Veterans are members of the research team who participate in all parts of the study • We see VetREP as falling somewhere in between these two ends of the spectrum. Researchers will have the chance to ask you for feedback on different aspects of research projects. By providing your ideas and feedback, you can help improve research projects at the VA. However, you won’t be involved in actually collecting data and conducting the research. • Important to note: We often have multiple roles in different contexts. I might be a participant in a research study, but in this room, I’m a VetREP member. VetREP members are not participants and not co-investigators.

History of Veteran Engagement in Research



Talking Points:

- We also wanted to share some of the history of Veteran engagement groups like VetREP.
- Ideas about participatory research and community engagement in research have been around for a long time, starting in the 1960s and 1970s
- Since 2010, there has been a movement within research in general to make research more patient-centered and to involve communities more in the research process.
- Following this movement, the VA has started to develop guidelines for engaging Veterans in research. Many VA researchers also worked with the Patient-Centered Outcomes Research Institute (PCORI) or the Agency for Healthcare Research and Quality (AHRQ) on the university side and became familiar with the principles
- A few VA's began to implement Veteran engagement initiatives before the VA's workgroup started advocating the practice and disseminating recommendations (Portland, Denver, Durham)
- Recently the Veteran Engagement Workgroup began presenting recommendations via a Webinar series, which has further promoted Veteran engagement within VA research
- **In 2016, Durham VetREP was formed!**
- Veteran engagement in research groups like VetREP are new and innovative – only a few HSRD centers have active Veteran research panels. However, we expect to see more of these with time!

<p>Veteran Research Engagement Panel (VetREP) Roles and Responsibilities</p> <p>By attending regular meetings of the group, Veteran and Caregiver Representatives:</p> <ul style="list-style-type: none">✓ Provide input on new and current VA research projects✓ Review research project materials created for Veterans and their families✓ Help make sure the research speaks to Veterans' concerns✓ Help find ways to improve the spread and use of health information	<p>Talking Points:</p> <ul style="list-style-type: none">• This slide outlines some of the roles and responsibilities that you will have as a member of the Veteran Research Engagement Panel (VetREP)• By attending regular meetings of the group, Veteran and Care Partner Representatives:<ul style="list-style-type: none">○ Provide input on new and current VA research projects○ Review research project materials created for Veterans and their families○ Help make sure the research speaks to Veterans' concerns○ Help find ways to improve the spread and use of health information <p>Ask: <i>Does anyone have questions about the role of this group?</i></p>
<p>DISCUSSION ACTIVITY</p> <ol style="list-style-type: none">1. What do you hope to get out of participating in this panel?2. What are you interested in learning more about?3. What do you want VetREP to accomplish?	<p>Discussion activity options:</p> <p>Free-write and discuss:</p> <ol style="list-style-type: none">1. Ask participants to spend a few minutes writing their thoughts about the following questions:<ul style="list-style-type: none">• What do you hope to get out of participating in this panel?• What are you interested in learning more about?• What do you want VetREP to accomplish?2. After the free-write time, discuss these questions as a group. As a group, decide on a few group goals for the next year. Record these goals on poster paper. <p>Group Brainstorm:</p> <ol style="list-style-type: none">1. Have participants break into groups of five to six people2. Give individuals post-its of three different colors- each color pertains to a specific question3. Each individual answers the questions on the slide on a post-it note of the corresponding color4. Group members put their post-it notes on poster paper (one for each question) and organize their answers by themes5. Allow each group to share their themes with the larger group

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