Module 1:

Introduction to CRITICAL
Module 1 Contents

In Module 1: Introduction to CRITICAL you will learn about:

- The study team
- The goal and aims of the project
- The values that will guide how we work together
Meet the Study Team!

Dr. Nathaniel Mohatt, Research Psychologist and Assistant Professor

Dr. Lisa Brenner, Board Certified Rehabilitation Psychologist and Associate Professor

Carlee Kreisel, Professional Research Assistant
Introduction to CRITICAL

- Coalition for Recovery and Innovation in Traumatic Brain Injury Care Across the Lifespan

- Goal: To improve long-term patient-centered care for those living with moderate to severe TBI

- 3 aims...
Project Aims

1. Establish a coalition of stakeholders

2. Identify strategies for engaging individuals living with TBI as research advisors

3. Develop a new Patient-Centered research agenda to improve the health and wellness of individuals living with TBI
Values of CRITICAL

- Valuing patient and caregiver perspectives
  - Recommendations for the research agenda will be based on the input of patients and caregivers
- Shared responsibility
  - We will work together to develop the Coalition’s products
- Mutual respect and equality
  - Every partner is treated with respect and as an equal
- Learning from each other
  - Every partner has valuable knowledge to contribute
Module 2:
Orientation to the Role of an Advisory Coalition
In Module 2: Orientation to an Advisory Coalition, you will learn:
- The role of the coalition
- Who will be part of the coalition
- Some of the steps and processes including
  - The 3 coalition meetings
  - Trainings
  - Interviews
- How to use effective communication to be a valuable partner
Project Aims

1. Establish a coalition of stakeholders

2. Identify strategies for engaging individuals living with TBI as research advisors

3. Develop a new Patient-Centered research agenda to improve the health and wellness of individuals living with TBI
Role of Coalition

- Provide feedback to researchers and clinicians to aid in developing a research agenda to improve the lives of those living with TBI

- Advise researchers and clinicians on the health care priorities of people living with TBI
Who is part of the Coalition?

- 24 stakeholders total:
  - 12 individuals living with a history of TBI or their caregivers
  - 9 professionals representing clinical providers, researchers, and advocates
  - 3 research team members
Coalition Meetings

3 in-person workshops:

1) Two-day workshop for training, capacity development, and mutual learning
2) Half-day workshop to develop a prioritized list of research questions
3) One-day consensus meeting to finalize the research agenda
Project Aims

1. Establish a coalition of stakeholders

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Engagement and Training

- Online orientation – The training modules you are working on
  - Orient you to the project and processes
  - Teach you what Patient-Centered Outcomes Research is
  - Practice skills that will help you contribute to the Coalition

- First In-Person Workshop
  - Meet and get to know each other
  - Review the training materials
  - Finalize the Coalition Membership Agreement
  - Gather an initial list of TBI health care priorities
Interviews

- Every six months
- Help us evaluate the patient engagement process
- We will ask you about your experience with the study:
  - What you did
  - How you were involved
  - What you learned
Effective Communication and Teamwork

As a member of the Coalition, you will be providing feedback and insight in a group setting. Good communication is key. Here are some important things you can do to facilitate communication:

- Listen carefully
- Wait for others to finish before you talk
- Speak with others as you would like to be spoken to
- Use positive body language
***Please take out and complete “Communication Self-assessment”
Module 3:
Orientation to Research
In Module 3: Orientation to Research, you will learn:

- What research is and how academic research is different than personal research
- What patient-centered outcomes are
- What Patient-Centered Outcomes Research is
- What Clinical Effectiveness Research is
Project Aims

1. Establish a coalition of stakeholders

2. Identify strategies for engaging individuals living with TBI as research advisors

3. Develop a new Patient-Centered research agenda to improve the health and wellness of individuals living with TBI
Introduction to Research

- Research is an organized and systematic way of producing evidence to answer questions.

1. Identify interest or problem
2. Narrow topic to particular question
3. Decide what and how to measure
4. Observe or measure
5. Analyze data
6. Reach conclusions

- Anybody could use this process to research something. But when academic researchers follow these steps, they have to meet certain standards for quality. Let's compare how you might use these steps to do some personal research compared with how an academic researcher uses them.

# Steps in Research Process

<table>
<thead>
<tr>
<th>Steps in Research Process</th>
<th>Requirement for Completing Step?</th>
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<tbody>
<tr>
<td></td>
<td><strong>Personal Research</strong></td>
</tr>
<tr>
<td>1. Identify interest or problem</td>
<td>No. You can research whatever you want.</td>
</tr>
<tr>
<td>2. Narrow topic to particular question</td>
<td>No. You can ask any question you like.</td>
</tr>
<tr>
<td>3. Decide what and how to measure</td>
<td>No. You can use whatever resources you like.</td>
</tr>
<tr>
<td>4. Observe or measure</td>
<td>No. You can take whatever type and amount of information you want from your resources.</td>
</tr>
<tr>
<td>5. Analyze data</td>
<td>No. You can judge what’s most important in the information you gathered.</td>
</tr>
<tr>
<td>6. Reach conclusions</td>
<td>No. You can make decisions however you like.</td>
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***Please take out and review “Ethics Handout”
What Do We Mean by Patient-Centered Outcomes?

Outcomes of medical care that are important to patients

Health and wellness goals or challenges that are important to people living with TBI

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Patient-centered Outcomes Research (PCOR)

- Helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options

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Patient-centered Outcomes Research (PCOR)

This research answers patient-centered questions, such as:

- “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?”
- “What can I do to improve the outcomes that are most important to me?”
- “How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?”

Clinical Effectiveness Research (CER)

- Research that compares the effectiveness of two or more interventions or approaches to health care, examining their risks and benefits.

- Findings assist clinicians, patients and other stakeholders in making informed decisions that improve health care for both individuals and populations.

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***Please take out and review “Skills Checklist”
Module 4: Developing a Research Agenda
Module 4 Contents

In Module 4: Developing a Research Agenda, you will learn:

- How you will help develop a research agenda
- The steps we will take to put together a new research agenda
Steps to Forming a Research Agenda: In-person Meetings

- 3 in-person workshops:
  1) Two-day workshop for training, capacity development, and mutual learning
  2) Half-day workshop to develop a prioritized list of research questions
  3) One-day consensus meeting to finalize the research agenda
Aims

1. Establish a **coalition** of stakeholders

2. Identify strategies for engaging individuals living with TBI as research advisors

3. Develop a new Patient-Centered **research agenda** to improve the health and wellness of individuals living with TBI
Developing a National Research Agenda: Research Questions

- You will help us identify, refine, and prioritize research questions through
  - In-person workshops
  - Online surveys
- You are not in a study, you’re advising researchers who are doing the study
Steps to Forming Research Questions: In-person Meetings

- 3 in-person workshops:

  1) Two-day workshop for training, capacity development, and mutual learning
  2) Half-day workshop to develop a prioritized list of research questions
  3) One-day consensus meeting to finalize the research agenda
Steps to Forming Research Questions

1. To begin developing the research questions, you will provide input on your experiences, interests, and priorities related to long-term TBI recovery and care at the first workshop.

2. Then, we will send you an online survey and ask you to propose question and research topics.

3. Afterwards, the research team will conduct a literature review related to the topics and questions the coalition proposes.

4. At the second workshop we will further prioritize the research questions.

5. You will receive another online survey and will rank each question.
Research Questions

As we form research questions, we will keep the following in mind:

- Clinical Effectiveness Research - compares the effectiveness of two or more interventions or approaches to health care
- Patient-centered outcomes - outcomes of medical care that are important to patients
Steps to Developing a National Research Agenda: Agenda Setting

1. You will meet with the study team to review research questions and prepare for the final workshop
2. You will attend a final workshop to review the results of question prioritization and help us arrive at a consensus
   - You will tell us whether you feel your priorities and concerns are sufficiently represented
   - We will then refine the agenda until all coalition members feel they can support the research agenda
***Please take out and review “CRITICAL Membership Agreement MOU”
Acknowledgements

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