



SUMR 2022 - ENGAGING PATIENT VOICES TO IMPROVE OUTCOME MEASUREMENT IN SERIOUS ILLNESS

Presented By: Dania Turner

Introduction: Who are you and your mentor?

- Me

- Dania Turner
- Rising senior from Howard University.
- International student from Jamaica.
- Pre-med track
- Interests: Working with children, art, tennis
- Goal to become a pediatrician in the future

- My Mentor

- Catherine (Katie) Auriemma, MD, MSHP
- Her work focuses on improving the value of adult critical care medicine by better aligning medical care with the values and preferences of patients and their families. She works to develop and validate patient- and family-centered outcomes for studies of critically and seriously ill populations.

Overview

- Project #1 Overview - Investigating MEAsures of SURvival-REsidence composite outcomes among persons with Dementia
 - Key Definitions
 - Significance
 - Aims
 - Methods
 - Findings
- Project #2 Overview - Developing Quality-Weighted Hospital-Free Days as a Novel, Patient-Centered Outcome for Trials of Patients with Acute Respiratory Failure
 - Key Definitions
 - Significance
 - Study Design

ALZHEIMER'S DEMENTIA & OTHER RELATED DEMENTIAS



Investigating MEAsures of SURvival-REsidence composite outcomes among persons with Dementia

- Overview
- The I-Measured project focuses on exploring hospital free days for patients suffering with varying stages of ADRD.

ADRD is debilitating condition that impair memory, thought processes, and functioning, primarily among older adults.

Hospital Free Days



Inpatient hospice



Short- or long-term nursing homes



Home

Significance

- In the United States, AD/ADRD affects as many as 5 million people
- Roughly 13.2 million older Americans are projected to have AD/ADRD by 2050.
- The use of measure of survival and residence such as hospital free days have been used to effect change in care and policy
- There are evident knowledge gaps in the research relating to ADRD and the application of this composite measure to this disease is limited.

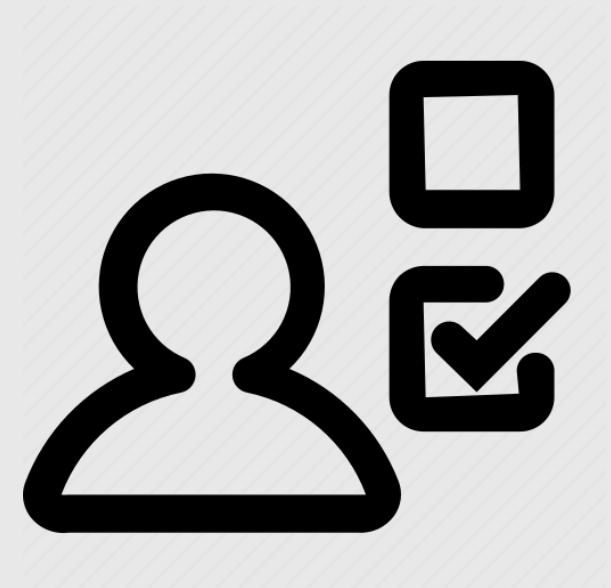
Aims

- This research will aim to bridge some gaps in improving long term outcomes and quality of life for patients with ADRD
- The outcome will provide a patient centered measure and approach to increase the use and effectiveness in care for this affected population and their families.
- This will ultimately provide the researchers with an appropriate time period to assess the optimal survival-residence outcomes for patients and how this could be used to provide optimal care.

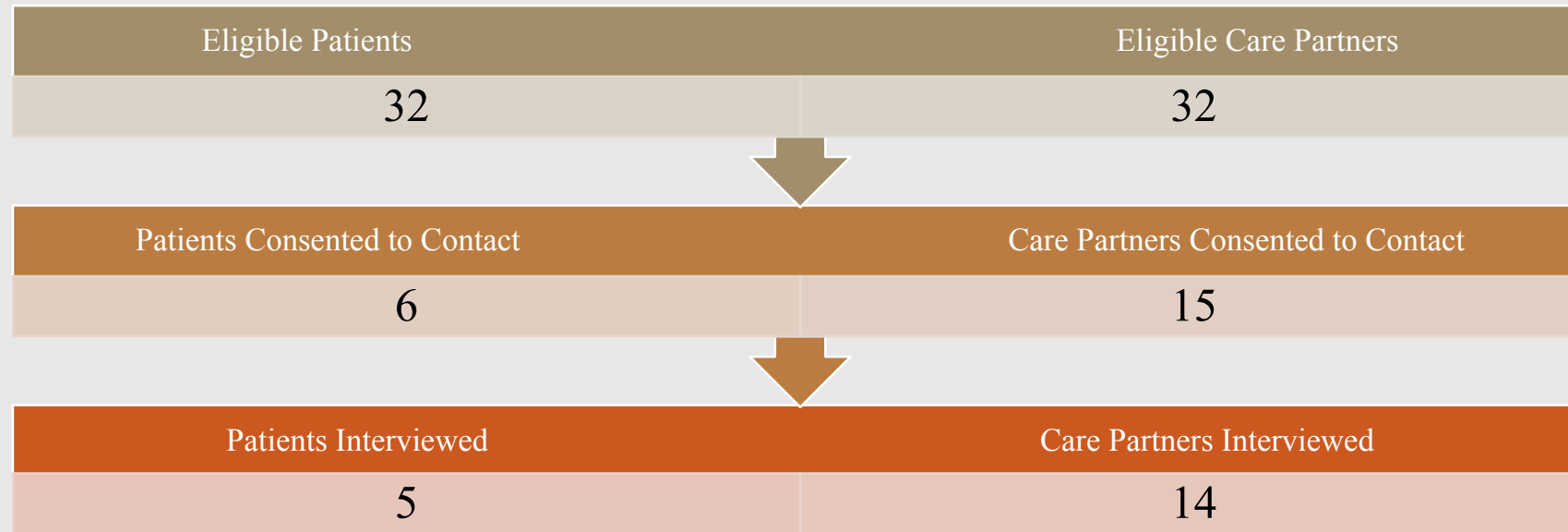
Methods

- Qualitative research design
- Mixed methods approach:
 - A) Exploring perspectives on outcomes using qualitative interviews
 - B) Quantify valuations for those attributes in a discrete choice experiment
 - C) Determine patient and family assessments of the time horizon for assessing such outcomes
- Utilizing interviews, surveys and discrete choice experiments

Discrete Choice Experiment - a quantitative technique for eliciting preferences that can be used in the absence of revealed preference data.



Preliminary Findings



Total Interviews Completed: 19

Interviews Pending: 2

Preliminary themes identified: Social and familial isolation, loneliness, financial burden, loss of self, guilt, neglect, lack of support

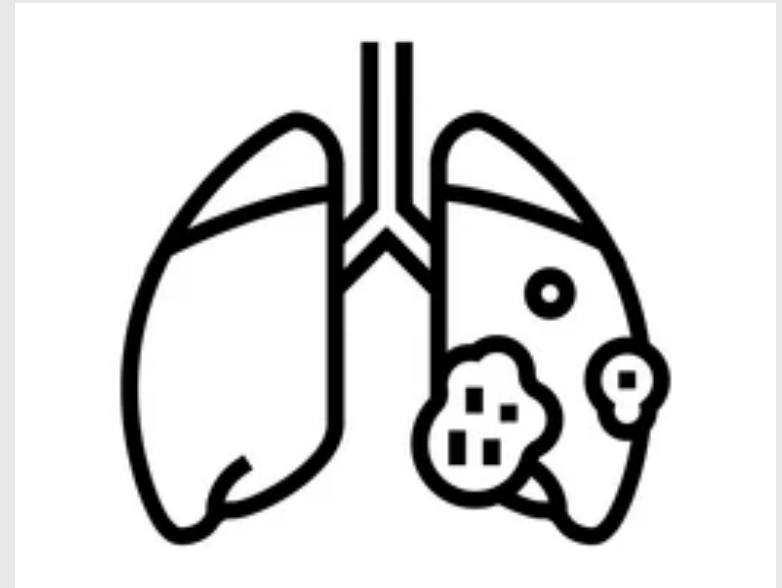
Developing Quality-Weighted Hospital-Free Days as a Novel, Patient-Centered Outcome for Trials of Patients with Acute Respiratory Failure

- **Overview**

- The K23 project focuses on developing novel methods to quality weight hospital free days for patients suffering with ARF

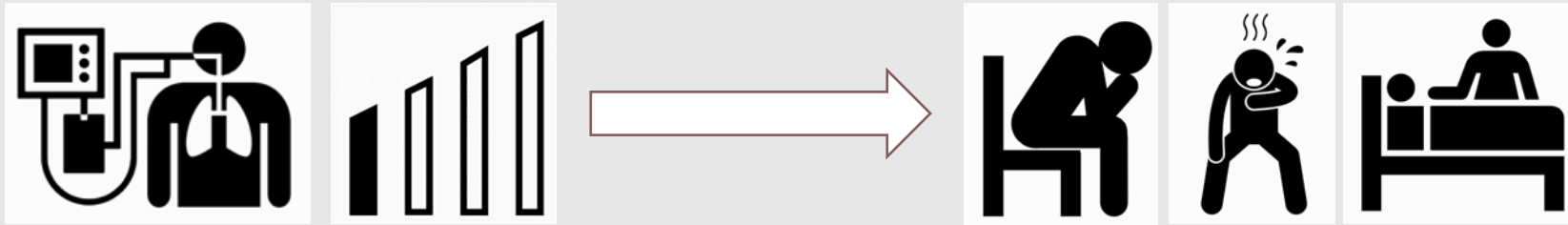
ARF: Acute Respiratory Failure

- ARF happens quickly and is often caused by a disease or injury that affects your breathing, such as pneumonia, opioid overdose, stroke, or a lung or spinal cord injury.

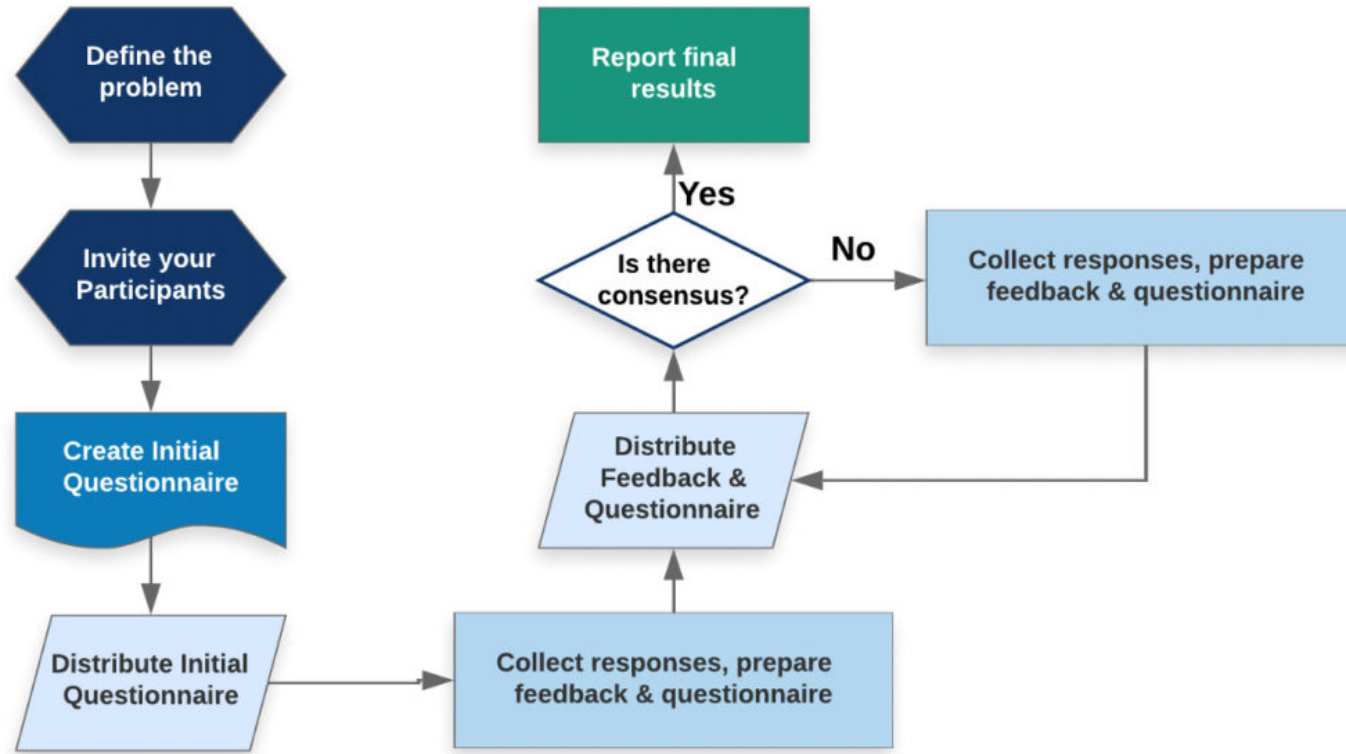


Significance

- More than 4 million Americans are admitted annually to an intensive care unit (ICU) with acute respiratory failure.



- Efforts are hindered by the absence of survivorship endpoint
- This project will aim to develop new measure and ways to improve long term outcomes for ARF patients.



Delphi Method

- Incorporate a group of participants, or panelists, selected for their relevant and specialized knowledge on a topic.
- Often conducted across a series of two or more sequential questionnaires
- After each questionnaire round, there is an evaluation phase

Study Design

- This project set out to explore the perspectives on survival residence outcomes through a variety of methods with patients, care providers, clinicians, patient advocates and trialist.
- This will ultimately provide the researchers with an appropriate measure to quality weight hospital free days using statistical analysis of the data.
- Instrument Exploration:
 - The exact instrument(s) that will be used have not been identified yet.
 - Research is being conducted as it relates to the potential instrument(s)