Me & My Wishes

Project Training & Protocol Manual

Me & My Wishes: An efficacy trial of long-term care residents with Alzheimer's using videos to communicate care preferences with caregivers

National Clinical Trial (NCT) Identified Number: NCT03861429
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Sponsor: University of Utah
Grant Number: R21AG058094
Funded by: NIA
August, 2019

Table of Contents

INTRODUCTION

PROCEDURES

Chapter Six: Video Production

Chapter Seven: Post Video Viewing - Family

DATA COLLECTION AND MANAGEMENT

INTRODUCTION

Chapter One

Background and Significance

Nursing Home Basics

"The last place we go to live." - Gail Towsley

Definition

A nursing home (NH) is a place where people who are too sick to be cared for at home, but who also don't need to be in the hospital, can live. Most nursing homes have skilled nurses and nurse assistants on hand 24 hours a day. Some NHs are set up like a hospital to provide rehabilitation services, and residents can receive medical care, physical, occupational and speech therapy. Other NHs are set up to feel more like a home, and provide long-term care. Often in this type of setting there is no fixed schedule, and kitchens might be open to residents. Some NHs have specialty care units for people with cognitive impairment, such as Alzheimer's disease. NHs are not only for the elderly, but for anyone who requires 24-hour care.

Culture Change

The culture-change movement that began in the 1980s in NHs is a broad effort to transform NHs from impersonal health care institutions into person-centered homes where long-term care is provided. Prior to the efforts that began three decades ago, residents often faced boredom and experienced learned helplessness, among other negative traits. The culture-change movement, however, set goals to individualize care for residents promoting person-centered care through reorientation of the facility's culture itself. Culture change strives to honor resident's individual rights, and enhances their quality of life and the quality of care that they receive. Ideally, facilities would adopt the following principles to facilitate person-centered care aligned with the culture-change movement: resident direction; homelike atmosphere; close relationships; staff empowerment; collaborative decision-making; and quality-improvement processes.

Care Conference

Care conferences are held for every resident in the NH to help the care team share information and to create a plan of care together that meets the resident's needs. A care plan includes what the resident's needs are, what the team's goals are for meeting those needs, and what steps are planned to meet the goals. Care conferences are held at least quarterly for each resident, and include the following people in the care team: the resident; family (when the resident asks them to come); nursing staff (e.g. resident care manager); social services staff; rehab staff (if applicable); activities staff; and dietary staff. In some instances the doctor may attend. At each care conference a shared assessment is given (a list of resident needs) by the team to help create the plan of care or to revisit the goals already set. The care conference team also discusses facts about the residents, especially at the first conference, including family and work background, medical and social needs, attitude and interests, likes and dislikes. This information allows the team to create a plan (based on their completion of assigned sections of the minimum data set (MDS)). Each member knows their part, but also knows what the others are doing in the care of each resident.

End-of-Life Care Basics

"There may be no single thing that can teach us more about life than death." – Arianna Huffington

Definition

End-of-Life (EOL) care includes the support and medical care provided to a person during the time surrounding death. Older adults often live with one or more chronic illnesses and need a lot of care in the final days, weeks and sometimes months prior to dying, therefore care can begin long before death, and continues for some time following with bereavement care for loved ones and caregivers.

No one experiences death in the same way, and preferences for care at this time are highly individual. The term "good death" means something different for each person. Some people want to know when death is near in order to say final goodbyes and get responsibilities in order. Some wish for death to come more quickly, or suddenly, to avoid lingering. Others may wish to pass away at home, and still others may wish to have everything possible done to treat the disease or to prolong life, which often requires admission to the hospital, where many older adults end up passing away. Some want to be surrounded by family, and others may want to be alone.

EOL care involves directing health care efforts to address physical comfort, mental and emotional needs, spiritual issues, and practical tasks. Physical needs include managing pain and difficulty breathing, maintaining skin integrity or treating irritation or wounds, addressing any digestive issues and managing fatigue. Hospice care is one way to facilitate EOL health care, though many do not receive this specialized care for various reasons including fear that electing Hospice care means doing nothing to treat illness.

Importance of Advance Care Planning

- Advance Care Planning (ACP) is about doing what is possible to ensure that the health care you may one day receive is consistent with your wishes and preferences should you be unable to make decisions and/or speak for yourself. There are many ways to record your wishes and preferences that are discussed in the next section. These are called Advance Directives.

- ACP is more than just creating Advance Directives, however. It involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, appointing a surrogate decision-maker, and making sure that the surrogate knows, understands and will follow your care preferences through focused conversations. These conversations allow individuals to discuss things that are not in Advance Directive documents, such as the desire for the family to make peace, be present at the time of death or not, and more.

- ACP is part of an ongoing, comprehensive care plan for those with progressive, chronic illness that considers social support, care preferences and the likely course of illness, called disease trajectory. It is important that the patient and family understand the medical and functional condition of the patient, and should consider what that might look like or how that might change in the upcoming months or years to anticipate what events can happen. ACP can help to alleviate unnecessary suffering, and improve quality of life. The goals of ACP are to promote proactive decision-making and to understand patient values, rather than reacting to changes in condition.

- Goals of Care. Ideally, Goals of Care (GOC) occur with medical providers, residents (patients) and their caregivers. Goals of care discussions include identification of what is important to the person, and may provide prioritization of their specific goals. GOC may be a formal document found easily in a medical chart, or it may be tucked in with other advance directives or staff notes including nursing or social service notes.

  - ➢ Potential Goals:

    i. Cure of disease
    ii. Avoidance of premature death
    iii. Maintenance of or improvement in function
    iv. Prolongation of life (live longer)
    v. Slow the progress of decline
    vi. Relief of suffering (provide comfort care/palliative care)
        a. Symptom management
    vii. Optimized quality of life (improve quality of life)
    viii. Maintenance of control (preserve independence/autonomy)
    ix. Accomplish something particular (personal goal)
    x. A good death (preparation for death)
    xi. Support for families and loved ones
    xii. Other (spiritual needs, remain at home, strengthen relationships, etc.)

Types of Advance Directives:

- Living Will. The living will provides a way for an individual to instruct a physician or other health care provider as to when to use, withhold or withdraw life-sustaining treatment when that individual no longer has the ability or capacity to make decisions about life-sustaining treatment.

- Health Care Proxy. A health care proxy is sometimes called a "health care surrogate," and is a durable power of attorney specifically designed to cover medical treatment.

- Durable Power of Attorney. The durable power of attorney document states the types of treatments an individual does and does not want, but in addition allows the surrogate decision-maker to make decisions beyond those listed in the document when the individual is unable to do so.

- Physician Orders for Life-Sustaining Treatment. This document is generally known as the "POLST" form, and was first developed in Oregon. This tool is best supplemented by other advance care planning, and requires discussion between patient and/or surrogate with the treating provider to determine the patient's EOL care goals and wishes. Several aspects of resuscitation are represented on this form, including artificial nutrition and hydration, and comfort care versus more aggressive treatment. One of the primary benefits of the POLST form is its transferability through various institutions and also that it is to be recognized by all health care professionals.

- **Do Not Resuscitate Order. Otherwise known as "DNR" orders, this document addresses the unwanted resuscitation of a terminally ill person. Without this order, emergency medical service providers are obligated to try to resuscitate someone whose heart or breathing has stopped.
- **Do Not Hospitalize Order. A do not hospitalize (DNH) order is a type of advance directive that indicates that a patient does not wish to be hospitalized. A DNH order is written by a physician and applies to the patient's current health status.

**Technically, not an advance directive but sometimes classified as one

Significance

NHs are unique settings because they serve as both a place of residence and a place in which to receive care. NH residents often have multiple chronic conditions, and need assistance with activities of daily living. Person-centered care in the NH includes increased exchange of information about the health care system, symptom experience, and both current and EOL care preferences, yet this rarely happens in depth. Knowing resident preferences is essential to providing high-quality care. Unfortunately, research indicates that the quality of care in NHs is often suboptimal, citing deficits in staff training, symptom management, treating residents with dignity and respect, and communication.

Though family and staff are often solicited for information on their experiences, it is the resident's voice that is critical to discussion about care preferences. However, more often than not, these conversations are missed. Dr. Towsley found in initial research that the reasons for missed conversations about resident's EOL preferences are related to three main categories: inquiry, assumptions, and conveying. Residents were either not asked, their preferences were assumed to be known, or the information that the resident shared was not passed on to others. Herein lies the basis for *Me & My Wishes*.

Chapter Two

Purpose and Objectives

Communication Tool for Care Preferences

Few NH facilities have systematic approaches to elicit and communicate information about resident preferences. The goal of this research is to test the efficacy of a communication tool that conveys residents' current day-to-day and EOL care preferences. There is strong evidence that compared with verbal instructions and narrative alone, video decision aids and visual images more effectively communicate patient education messages and inform patient decision making.

Me & My Wishes offers a systematic approach to discussing, listening, and viewing residents' preferences for daily and EOL care. Starting with preferences for today, *Me & My Wishes* begins a pathway for ongoing communication about a resident's preferences for care rather than a sole conversation focused on EOL. Sharing the video with staff and family allows multiple viewers to receive consistent information and can facilitate conversation with residents. *Me & My Wishes* videos have the potential to improve communication between residents, family and staff, and integrating these videos into care practices is novel to any clinical environment - especially NHs.

Stage II Efficacy

The IOM report Dying in America acknowledges the need to facilitate meaningful conversations with patients, families, and caregivers to promote awareness, raise expectations about care options, and have open exchanges about end of life (EOL).[1] Such conversations are infrequent in nursing homes[2] and even rarer for persons with mild to moderate dementia (Alzheimer's disease and other dementias, or ADRD) even though the majority (67%) of persons with dementia die in this setting.[3] Consequences of not having these conversations include residents not receiving the care and treatment they want, as well as family distress, uncertainty, or conflicts due to residents' unknown wishes in the face of needed family decision making.[4-5] Only once family and nursing home staff become aware of residents' preferences can care be truly person-centered and congruent with resident wishes. We have developed and demonstrated feasibility for an innovative systematic intervention—**Me & My Wishes**—that communicates residents' preferences via personalized video recorded conversations. Me & My Wishes are videos of nursing home residents talking about their preferences for care, and include four sections: About Me, Preferences for Today, Preferences for Medical Intervention and End of Life, and Afterthoughts.[6] Videos are approved by the resident, and shared with nursing home staff and family.

The long-standing challenge for U.S. nursing homes is to provide high-quality care tailored to the unique needs and preferences of the 1.4 million older adults who live and die there.[7,8] Studies indicate that nursing home quality of care can be suboptimal with deficits in staff training and support, symptom management, treating residents with dignity and respect, and communication.[9-12] Contrary to what many care providers believe, persons with mild to moderate dementia can accurately express their everyday and EOL prferences.[13-16] Our feasibility study included these individuals and demonstrated that they were capable of communicating their preferences in the videos. Including individuals with mild to moderate cognitive limitations in advance care planning discussions and expressing their EOL preferences is warranted, viable and an ethical approach.[13,14] Incorporating Me & My Wishes into the care planning process is expected to provide an efficient and effective way for residents to communicate their care preferences for today and at EOL, and to positively influence confidence in communicating preferences and in facilitating documentation of care planning documents.

Our long-term goal is to scale and fully incorporate Me & My Wishes into multiple settings providing long term services and supports. Ultimately, integrating Me & My Wishes videos into the electronic health record or another platform allows for video viewing by multiple individuals and disciplines in various settings. Our short-term goal, and the goal of this proposal, is to conduct Stage II efficacy testing of Me & My Wishes. We will employ a randomized wait-list control design of six nursing homes (48-54 residents). Three nursing homes will be assigned to an early intervention group (residents will share videos initially) and three assigned to the wait-list controls (residents will delay sharing videos). Videos can be viewed two ways: 1) in resident quarterly care conferences; and 2) via a secured web-based link for resident-identified family members. After video viewing, the resident, family and staff can discuss key messages and preferences of the video and add to the care plan.

Specific Aim 1: Examine the efficacy of the Me & My Wishes intervention among a sample of nursing home residents with dementia.

Hypothesis 1: Compared to the waitlist control group (Group 2), the intervention group (Group 1) will have an increase in the proportion of residents with documented goals of care discussions or self-reported conversations about preferences 90 days post video viewing.

Specific Aim 2: Examine self-efficacy of communicating preferences among residents with dementia, informal (family) and formal (staff) caregivers.

Hypothesis 2: Compared to the waitlist control group (Group 2), the intervention group (Group 1) will have greater self-efficacy scores for communicating preferences 90 days post video viewing.

Hypothesis 3: Compared to the waitlist control group (Group 2), the intervention group (Group 1), the proportion of residents with documented new or changed care planning documents (e.g. advance directive) will increase by 90 days post video viewing.

Specific Aim 3: Describe congruence of preferences observed in the Me & My Wishes video, care conference audio recording, medical record (e.g. POLST), and in family and staff surveys.

PROCEDURES

Training Checklist for Research Staff

Orientation to Project

____ CITI/GCP Trainings
____ Read: Towsley (2015) and Towsley (2017) Articles
____ Review: R21 Research Plan
____ Read: Training Manual Introduction
____ ID Badge
____ UBox
____ IRB (ERICA)
____Encryption
____Skype for Business

Recruitment/Enrollment

____ Review Documents: Eligibility Checklist, Demographic & Clinical Information, Consents
____ Practice approaching residents and describing the study
____ Practice consenting process
____ Practice approaching NH staff and families to describe the study
____ Practice contacting family/friends via telephone (consent and survey procedures)
____ Create a Tickler System/Calendar for MMW video recording, care conference and follow ups

Video Production

____ Practice facilitating the Conversation Guide
____ Video Recording and Equipment
____ Video Editing (see detailed process on page X)

Data Collection & Management

Cloud Storage

____ REDCap: Orientation, Survey Entry and Data Management
____ Data Security: Information Storage and Confidentiality
____REDCap participant tracking (enrollment, refusals, withdraws)
____ Participant Tracking: IDs, Calendar, Study Enrollment

Nursing Facility (Site)

____ Discuss how to perform the Chart Review
____ Practice administering the Resident Surveys (baseline, time of sharing, 90 days)
____ Discuss the logistics of administering the Staff and Family surveys in care conference
____ Discuss how to set up Care Conference Audio Recording and Equipment
____ Practice administering Staff and family surveys (baseline, time of sharing, 90 days)

Data Analysis

____ Audio Transcription and verification
____ REDCap – how to run reports (e.g. accrual reports)
____NVivo – (e.g. uploading documents, coding)

Chapter Three

Eligibility, Recruitment and Enrollment

Eligibility Criteria

Use the Eligibility Checklist (Appendix A) to document whether selected residents are eligible to participate in this study or not.

- Resident Inclusion Criteria

  We will include assisted living (AL) residents in addition to nursing home (NH) residents. Inclusion criteria:
  - Identified as having Alzheimer's or related dementia (both nursing home and assisted living residents).
  - BIMS 8-15 (MDS C0500; nursing home residents only);
  - Makes Self Understood and Understood By Others (medical record forNH and AL);
  - reside at the facility at least 2 weeks;
  - identified as a long-term resident;
  - age >65 years; and
  - able to speak English

- Resident Exclusion Criteria
  - Limited communication capacity (e.g. aphasia)
  - Comatose state
  - Severe cognitive impairment (BIMS<7; Understood by others and makes self understood > 1).

- Staff Inclusion Criteria
  - Able to speak English
  - Willing and able to watch the videos and participate in short surveys

- Family Inclusion Criteria
  - Able to speak English
  - Willing and able to watch the videos and participate in short surveys (online or in person)

Ineligible Participants

Document ineligible residents using the Eligibility Checklist and include the reason(s) for ineligibility.

Change in Participant Eligibility

Need to document if someone becomes not eligible (e.g. control group) after delayed start.

Role of the Study Coordinators:

Study Coordinators will share responsibility for participant recruitment, enrollment, and data collection. The Study Coordinators will share responsibility for data entry, management and cleaning. In addition, the Study Coordinators will work as a pair to conduct and film the Me & My Wishes videos with residents. The Study Coordinators will coordinate editing of the videos with the Video Editor and assist as needed. In addition, the Study Coordinators will share the videos with the appropriate formal and informal caregivers. Study Coordinators will complete training in study-specific recruitment, protection of the rights of human participants and confidentiality, Good Clinical Practices, and cultural competence prior to interacting with potential participants. Other responsibilities include:

- Providing a description of the study to eligible residents allowing for questions and time to consider participation.

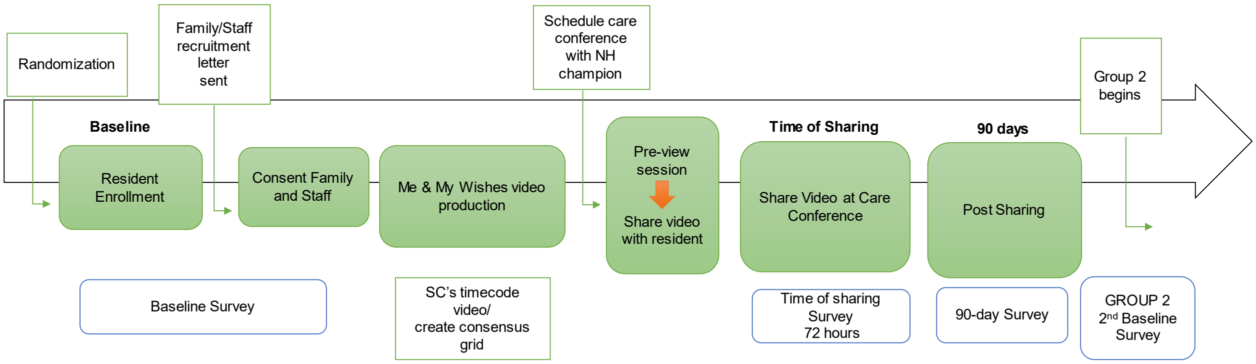
- Describing the background of the study, including what was found in the Towsley (2005) study:
    - Many times, residents aren't asked about their wishes.
    - Often, we assume that others already know what we'd want.
    - Advance Directives are narrow in focus and have not shown to guarantee that care will be provided as the resident wishes it was.
    - Advance Directives don't meet unmet needs.
    - Conversations are not often passed on to others or recorded.
    - Preferences for care today and at the end-of-life can be a difficult topic to discuss.
    - When they do occur, conversations often happen too late or at times of crisis or transition such as hospitalization.
    - Advance Care Planning (ACP) is associated with higher quality of life and satisfaction with care.
    - ACP is also associated with decreased rates of depression and anxiety among bereaved loved ones.
    - Lack of ACP often results in more invasive care than is desired.

- Reviewing the consent forms and obtaining consent from those who wish to participate.
- Scheduling the date video recording will take place and informing NH staff, as well as other scheduling.

- Performance of the Chart Review and completion of the Demographic and Medical Record Review Forms as described later in this chapter.

Staff, Family and Resident Recruitment

Staff Consent



- ❖ Care Conference Staff
  Care Conference Team Consent Letter (Appendix F)

Care Conference Staff Consent

Recruitment of staff members will occur in person. The care conference team members of the resident will receive a recruitment letter and staff caregiver consent either in person or via email stating the purpose of the study or at a staff meeting or care conference prior to video sharing. The SC will explain the study, review the IRB-approved informed consent document, and answer any questions the care conference team member might have. Ample time will be provided for the staff member to consider participation. A follow-up visit can be readily scheduled by the SC. For staff members who agree to participate, we will document affirmation of consent. Potential interdisciplinary care team participating in care conference will be nurse manager, social services director, dietary manager, nurse's aide

Strategies for Communicating Research to Staff Members.

Information session in standup meeting

Attend Resident Council Meeting

Attend All-Staff meeting

Approach staff members 1:1 on scheduled time

- May include positive testimonials if applicable

Me and My Wishes: Study Stand-Up Checklist

- NH Champion preferred day/time to meet weekly/bi-weekly (obtain more than one date since we will be juggling a few facilities).
- NH champion's preferred introduction schedule. Do they prefer to introduce SC's to residents all at same time or separately after each consent?
- NH champion speaks to resident with no bias introduced (such as "this resident would be a good person for this study").
- Only SC's explain MMW study to resident.
- Does NH champion know of any additional people coming to care conference that are not aware of study?
- When calling NH champion confirm residents are available for consenting/video recording.
- Ask if there are any recent admissions that would meet criteria.

Family Consent and Survey Scripting

A recruitment letter and a copy of family caregiver consent will be sent either by mail or email to the family members identified by the resident stating the purpose of the study and that a follow-up phone call will be made. The letter will include information of who to contact if they wish to opt out. If the family member declines we can ask the resident if they want to share the video with anyone else

- ❖ Family (process for contacting/recruitment)
  Family Recruitment and Consent Letters (Appendix G)
  Family Sub Study Consent Letter (Appendix G1)

This process should be practiced with a member of the MMW team prior to live implementation.

Hello is this (family member's name)?—response.

This is (your name) from the University of Utah College of Nursing and the Me & My Wishes project. I am calling to verify that you received the letter about the project and to see if you have some time today to learn more about the project. Is this a good time?—response.

At this point in the conversation please refer to the *Family Consent Cover Letter.* Proceed by reading the first two paragraphs of the consent.

Does this sound like something that you would be interested in?—response.

If yes: Great, thank you. Let's take the next few minutes to review more details about the study, your participation, and obtain your consent to participate. If you would like, I can send you a copy of the consent via mail/email?—response.

Do you have 15-20 minutes now to go over the initial survey?—response.

Proceed to the family baseline survey.

Do you have any questions?—response. (answer questions). If mail/email address is not known, obtain for the purposes of sending $5 gift certificate.

Outline the next steps for the participant.

As mentioned in the consent you may watch your family member's/friends personal video by attending care conference at the facility or at the time that we share the video I can send you a link to view the video from your home computer and complete a brief survey.—response.

I will also follow-up with you in 90 days to complete the final follow-up survey.—response.

Before we conclude our time together, do you have any questions?
Thank you so much for your time and efforts to participate!

Resident Recruitment

Successful recruitment in research participation relies on several strategies: access to the appropriate population, communication and trust building, providing for comfort and security, and expression of gratitude. Positive interaction in the NH by *Me & My Wishes* staff will facilitate a working relationship that supports all parties. All staff should remember to express appreciation, respect, and flexibility (when able/appropriate) throughout this process.

- Approach:
    - Gain eye contact with the resident and face them when speaking, at their level. If the person has hearing loss, make sure that he/she is wearing hearing aids (if available) and confirm that they can hear you. The resident may prefer you speak to them on one side, if they hear better on that side. Some people prefer to read your lips as you speak to fully understand.
    - Pay attention to the tone, pitch and speed of your speech. You may need to adjust from person to person. Older adults are a diverse group, and one person may need you to speak up and slow down, while the next may feel you are too loud at the same level.
    - Hearing aids often pick up surrounding noise and make it difficult to concentrate or hear when the TV or other conversations are going on nearby. Try to limit background noise and distractions. You may need to ask to move to another, more quiet location.

- Show Respect:
    - Introduce yourself and the project.
    - Thank the resident for meeting with you.
    - Ask how the resident prefers to be addressed (e.g. Mr/Mrs/Ms. [insert last name], first name, or nickname). Do not refer to older adults as “sweetheart,” or “honey,” (for example).
    - Ask if now is a good time to talk, and if it is not, plan another time to come back.
    - Ask where the resident would like to discuss study participation. The resident may share a room with another person. Allow the resident to choose whether they would like to speak in a more private location.

Introducing the study and providing the background can be more difficult than it seems. It is helpful to write down a general statement that can be used by all research staff when discussing the project with residents. An example of this is provided below:

> *Me & My Wishes* is a project that will study and develop a new approach to assist talking about the care preferences of long-term care residents, like yourself, by creating a video recorded conversation. Knowing what residents want and don’t want is essential for facilities to provide quality care, and it also helps others to understand your wishes. We are doing this project because research studies have shown that asking about resident preferences and then communicating those preferences to staff and family members is challenging. Recording the conversation on video provides an efficient and effective way for residents to communicate their care preferences, and may align the care they receive with those wishes. The conversation will include preferences for today and for end-of-life care, and we are giving participants the option to share their videos with the facility staff and/or their families if they choose.

Barriers to Recruitment and Enrollment:

- mistrust
- medical concerns
- indifference
- sensory and cognitive limitations
- frail health
- restrictions to eligibility
- lack of confidentiality
- fear of safety
- scheduling conflicts
- lack of knowledge
- language/cultural differences

- inability or unwillingness of researchers to understand community dynamics and establish positive relationships with community members and leaders

Indifference, disinterest and wavering are the most common barriers in this process. Preparing for such comments as:

> "I don't think I care about this topic."
> "I'm too tired/old for this."
> "I'm too busy."
> "This doesn't sound like something that would benefit me."
> "I don't know. Is anyone else doing it?"
> "Do you think I should?"
> “I don’t speak well.”
> “I don’t like to be photographed.”

… might help the RA to respond in a productive and positive manner. Potential responses may include:

> "I want to make sure I explained clearly. Could you tell me what we are asking you to do?
>
> “I want to make sure I was clear about the pros and cons of participating in this study. Could you tell me what we are asking you to talk about on the videos?”
>
> "Would you like me to come back another time?"

If resident declines

Remember that participation in a study, and completion of the materials, can cause anxiety for some participants. This may be due to confusion or poor comprehension of data measurement tools, general fatigue and/or worry about what the researcher wants, or sensory limitations. Advancing age and lower education contribute to increased odds for participants to drop out of studies after enrollment. Understand what makes this population vulnerable and plan for additional time and support to boost participation. Thoughtful consideration of the study environment, research tasks, resources and any special needs or obstacles of the study population is necessary.

Refusal to Participate

Residents may refuse to participate for a number of reasons. Track how many residents were approached about participation, and how many refused by documenting the reason for refusal on the Eligibility Checklist and in the Participant Tracking and Refusal form.

Especially for those who decline for not wanting to be photographed/filmed, ask if Me & My Wishes was offered in a different format (e.g. audio), would their interest in talking about their preference change. For example, Currently, we do not offer MMW in other formats and I understand that you do not wish to be photographed. We are trying to determine if future projects should offer MMW in different formats. If we offered MMW in a different format (e.g. audio), would that have changed your interest?

Resident Enrollment

A 3-step process will be used to enroll residents: 2) NH champions will be identified to introduce the SCs to residents who meet the eligibility criteria, 2) SC will consent the resident; consent includes a teach back component allowing residents to state participation requests in their own words. Residents unable to complete teach back component or with surrogate decision makers will be excluded, and 3) 1) SC will review medical record to ensure residents meet inclusion criteria.

The Resident Consent and Authorization Document (Appendix C) reviews in detail the background of the study, purpose, procedure, risks, benefits, confidentiality, person to contact with questions, voluntary nature, costs and compensation, authorization for use of protected health information, and includes a signature with name and date. It is appropriate to paraphrase this document for the participant, however the individual may request to read it on his or her own or have the entire document read aloud to them. If paraphrasing, bundle the certain information together, such as contact information. Also, be sure to take a break after each section and remember to ask if the resident has any questions so far. It may be necessary to disclose who is funding the project and the number of participants if you are asked. If enrolled, a copy of this document (signed) is to be left with the resident at the close of this encounter.

➢ Enrollment Tips:

- Practice the recruitment and enrollment process with the team, each taking a turn being the RA and the resident. Complete at least 4-5 sessions practicing. Feedback on these practice sessions from an outside perspective (third person) is also very helpful.
- Be broad about the study topic when describing the project.
- Use a range of examples to demonstrate the importance of the study (e.g. "Some people have made these wishes clear to their family and caregivers, but others have not had this opportunity. We want to have participants from both sides of the spectrum represented.").
- Pay attention to the language that is being used (e.g. using the words "activities" or "surveys" vs. "test"; "feeling upset," "uncomfortable" or "bothered" vs. "stressed" or "traumatized"; emphasizing that the resident can volunteer to participate, etc.).
- Express and highlight confidentiality, voluntary participation.

- Interruptions may occur, such as the resident may need to take a break or use the restroom. Anticipate how to respond and what to do such as contacting facility staff and excusing yourself from the room if the resident prefers you to.
- Focus on the creation of a video for person-centered care rather than the possibility of sharing that video early on in this process. This is a novel project focused on the patient's preferences.
- Use the teach-back method to ensure the resident understands (e.g. "I want to make sure I explained what participating in the study means, what is your understanding of what I have just told you about this project?"
- Express gratitude and thank the resident for their time.

Chart Review

Once the consent is signed, the Demographic and Medical Record Review Forms are used to document selected demographic and clinical information obtained from the resident chart. To obtain this information we will need to review the resident's Electronic health record. Sometimes, depending the facility, POLST forms or other advance directives are kept in hard copy at a location in the facility (e.g. nurses station).

When and how will charts that will need to be reviewed get identified and by whom?

- PI/Study coordinator (SC) will work with administrator to obtain a temporary password to EHR to start the process of data extraction
- Study coordinators will notify administrator ahead of time, before arriving to the facility, about needing to use EHR for data extraction
- Charts to be reviewed will be identified after Eligibility Criteria Checklist form and obtained consent for the Me & My Wishes Study from the resident is completed
- Data extraction happens before video recording begins

Where will the SC review the chart to complete data extraction?

- Study Coordinators will request a private place in the nursing home to review chart and extract data; if login info is provided to access files offsite, chart reviews will be conducted in a private space
- Study Coordinators will not open other files or charts in EHR other than to find the data/identifiers needed (see page 2) to complete the Demographic and Clinical Data form for the study.

After data extraction…

- After SC completes reviewing the chart and extracting data, SC will log out from the resident chart.
- If SC cannot find the data/identifiers needed, she will communicate with the administrator or resident care manager. *Note: this will be done only when it is absolutely needed and as a last resort to keep interfering with the routine work of

the NH to a minimum. Data that cannot be found on the chart such as education level can be obtained from the resident before video recording begins.

Confidentiality of data

- Only study ID number will be used in the Demographic and Medical Record Review forms and surveys
- The hard copy will be kept in a locked cabinet and will be transferred to RedCap which is password protected and in an encrypted computer
- Only PI, co-investigators and research team will have access to the extracted data
- The de-identified extracted data will be stored in a locked cabinet at the College of Nursing.

List of data/information to be extracted from the resident chart:

- Age
- Gender
- Education
- Pay source
- Marital status
- Insurance
- Diagnoses
- Mood
- Level of care
- Length of stay
- Presence of documents such as Advance Directives, POLST, or Code Status
- Presence of goals of care conversations (may be found in nursing/social services notes). Document location of where found on form (facilities may differ on where this type of information is located).

Tips where to look for the data in the EHR:

- Demographic form
- Kardex
- Care plan
- Face-sheet
- MDS
- Documents
- *Refer to FAQ for more tips

Frequently Asked Questions (FAQ) during data extraction time:

1. I cannot find information about education anywhere in the chart?

This is common. You can ask the resident after video recording.

2. I found the racial background information but not the ethical background on the chart?

   You can ask the resident about her or his ethnic background before video recording begins.

3. What is the difference between 'pay source' and 'Insurance'?

   The demographic and clinical form gives you option about what to fill out. Most NH residents have Medicaid and/or Medicare. But you will need to find that information in the chart. And then you will need to see if the resident also have other private insurance (e.g. Elderplace or a type of Medicare Advantage).

4. The resident has a list of diagnoses (old and current) and I'm not sure if I need to write each one of them on the form?

   Include at least 10 diagnoses on the form. If available, you can ask a clinician which are most relevant. You may have to make a judgment call about which DXs to include.

5. I found several admission dates on the chart; which ones do I write on the form?

   We will collect the initial admission date and the <u>*most recent*</u> admission date, look at the chart carefully and make sure you have the correct dates. If the original date and most recent date is the same, enter the same date for both.

6. Do I count the length of stay from the most recent admission date?

   We track two admission dates (initial admission date and most recent admission date). Please calculate length of stay from both these dates.

7. What is the best way to find the Advance Directive information?

   This depends. Some charts have this information on the demographic tab and Documents tab and some only have this information on the POLST form. You will need to look carefully in multiple places. POLST may be a separate document on its own. Once you find the form, you will need to look at it carefully to find the rest of the information.

8. I found the care plan but I'm not sure if the goals for the care are consistent with resident preferences.

   You may or may not find evidence of resident preferences written on the care plan. Review the care plan carefully and look for any evidence that is consistent with the resident preferences such as resident statements – this may be written in quotes.

9. Could there be any other place where the resident preferences is documented?
   Yes. There may be a standardized document that has the resident preferences. If the facility has such as form, you will need to include the source and location of information.

10. When I do a 90-day follow-up data extraction on the same chart, how do I get access to the chart and what is the procedure?
    You will need to notify the NH administrator ahead of time about your intent and when you will be at the facility. Other than that, you will follow the same procedure outlined on the data extraction protocol for initial Demographic and Medical Record Review Forms.

Participant Confidentiality

Participant identification (ID) numbers will be assigned for all individuals approached to track those who enroll and those who decline. Study sites will be randomly assigned to an intervention or wait-list control group. Use the REDCap database to track all individuals (even though who decline). This number will be used instead of the participant's name on all forms and tracking. Write the participant ID on the top right hand corner of all documents except for the consent forms.

Data Security

- Documents
  Consent forms are stored separately from all other recruitment and enrollment documents, including surveys where appropriate.

- Audio Recordings
  Audio recordings are to be uploaded to the appropriate folder on UBox, then deleted from the audio recorder. Audio recordings are deleted once transcription has been completed, compared to audio recording, and finalized.

- Chain of Custody Documentation
  Use the Chain of Custody forms to document exchange of the audio recorders, laptops and video equipment. The form must be filled out completely, including the name of the person in custody of the equipment and the dates in which the possession occurred.

Withdrawal of Participation /Attrition

Document any withdrawals of participation in REDCap along with reason.

Chapter Four

Administering Surveys

Surveys will be administered to residents, staff and family at three time points (baseline, sharing/within 72 hours of sharing, and 90 days post sharing).

Resident Surveys

The Resident Baseline Survey will need to be collected at the time of enrollment and read aloud to the resident. Follow same procedures for time of sharing and 90-day surveys.

Care Conference Staff Surveys (Time of sharing the video)

The Care Conference Staff Baseline Survey is provided at the time of enrollment (at a staff meeting or care conference prior to video sharing).

Family Surveys

The family baseline survey will need to be completed at the time of enrollment. Except for consent, follow same procedures for completing time of sharing and 90 day surveys.

Care Conference Staff and Family Compensation

Facility staff and family members are compensated with a $5 gift card following the completion of each survey taken. If family are not present at care conference, their gift card can be mailed/emailed.

Care Conference Audio Recording and Data Collection Procedures

Care conference at the time of sharing will be audio-recorded using two audio recorders.

Most likely, staff and family caregivers will have completed the consent process at the time of the care conference meeting when the video is shared. In the event that an individual has not been consented (e.g. new staff to the care conference team), we will meet with the individual in a private space to review the recruitment letter and caregiver consent and upon agreement the informed consent process will be completed prior to starting the meeting.

Care Conference Video Sharing and Survey Collection Guidance

Briefing points for team member facilitating video sharing and discussion

- SC turn on/off 2 audio recorders.
- Let participants know video is approx. 20min, opportunity for discussion at end of video facilitated.
- At end of video sharing the care conference team member facilitator will **prompt conversation** with care conference participants to identify the most important aspects of the video to be discussed and addressed in the care plan.
- At end of video/discussion, please give each participant **a post video sharing survey** (staff or family member surveys depending on who is present). Once completed please collect and put in a sealed envelope
- Please give the **envelope and audio recorders** to the SC who will be waiting outside the room
- Provide **gift cards** for staff and family members

Chapter Five

Facilitating the Conversation

Role of the facilitator:

While any one can have this type of conversation with an older adult, there are a few things to be aware of when in the role of facilitator. It is common to feel like there needs to be a resolution; a way to address the resident's wish not to have any treatment or to offer solutions when further discussion or a change in the advance directive is warranted. For the purposes of this study, however, the main objective is to enhance communication and promote conversation. Be aware of your own background, opinions and experiences and reflect on how that might affect this role. The facilitator of the *Me & My Wishes* conversation must possess the following attributes:

- Knowledge:
    - Basics of nursing homes and end-of-life care and processes.
    - Physical aspects of ageing and the care of older individuals.

- Modeling:
    - Demonstrate warm, compassionate and patient communication.
    - Attention - Acknowledge the individual by showing appreciation and respect. Show affection by providing comfort and presence.
    - Acceptance of the person and their preferences.

- Skills:
    - Listening skills.
    - Self-awareness.
    - Flexibility.

- Values:
    - Empathy.
    - Genuineness.

- Style:
    - Use personal communication style to enhance authenticity. Emotions of all kinds may be triggered (sadness, happiness, laughter, joy, fear, anger).

- Use the following checklist to guide the facilitator training process:

Create a training schedule that includes the following steps in order:

1) Review of the Conversation Guide as a group. Practice reading questions and incorporating the probes.

2) Practice facilitating with three people, each take a turn being the facilitator and the resident, using resident roles (see below). Repeat this process at least 2-3 more times.

3) Practice facilitating with three people: the main facilitator, a person to act as the resident, and a person to act as note taker to provide feedback. Repeat at least 1-2 more times.

4) Practice facilitating with Dr. Towsley present.

5) Dry Run of entire process with four people: the main facilitator, the main person who will be consenting/enrolling participants, a person to be the resident, and a person to take notes.

6) Dress Rehearsal of the process with an older adult volunteer.

____ Review the following interview tips, as well as the process for administering the Conversation Guide below.

____ Discuss potential challenges, when to make referrals, and other concerns in case of unanticipated problems such as adverse events.

<u>Resident Roles for Practice Sessions:</u>
1) Young Old (persons aged 65-75)
2) Oldest Old (persons aged 85+)
3) Sensory Impairments – (e.g., vision, hearing)
5) Mild to moderate cognitive impairments

- <u>Interview Tips:</u>
  - Show respect
    - Ask how the participant prefers to be addressed (e.g. Mr/Mrs/Ms. [insert last name], first name, or nickname). Do not refer to older adults as “sweetheart,” or “honey,” (for example).
  - Provide for comfort and security
    - Offer water, or tissues as necessary.

    - Inform the participant that they can take breaks at any time. May suggest to complete recording at a different time.
    - Inform the participant about next steps (i.e. debriefing interview, video-editing and showing, etc.).
- Express gratitude
    - Thank the resident for participating and for their willingness to share their time and information.
    - Remind participant that they will receive a copy of the edited video and we will be contact when ready for their approval/review.

Process for Administering the Conversation Guide:

Note: When facilitating the conversation, it is important to stop and take a break after each module. This not only gives the resident time to take a break, but is necessary for the video-recording process as well. Stop the tape and allow the resident to get a drink of water or use the restroom while the next module is set up.

The *Me & My Wishes* video consists of four modules:

1) About Me
2) Preferences for Today
3) Preferences for Medical Intervention and End-of-Life Care
4) Afterthoughts

After greeting the participant and setting up interview, read the introduction to the Conversation Guide aloud. Begin the interview by introducing Module 1: About Me. Then, proceed to the first question as outlined below on the conversation guide.

Notes on Modules:

- About Me. The first module includes introductions, short biographies, and may include a history of their family, work or significant life events.
- Preferences for Today. In this module, desired caregiver approaches may be included, as well as what is important to residents while living in the NH.
- Preferences for Medical Intervention and End-of-Life Care. The third module includes care preferences should the resident become sick or near the end-of-life. Questions include preferences for being transferred to the hospital, use of medication, and psychosocial preferences. This module may also include what residents want their family or staff to know and who they would want to speak on their behalf.
- Afterthoughts. The final module includes after death preferences, such as the request for burial or cremation.

To complete the interview, read the conclusion aloud. If necessary, identify resources for follow-up intervention including meeting with the NH Social Service staff if there are emotional concerns or if the participant would like to re-visit their advance directives.

Potential Challenges:

- Communication Styles of Residents
    - Tangential Speaking
    - Emotional responses, etc.
- Questions/Misinformation
    - Referrals Process
- Red Flags
    - Highly emotional (sad, depressed, angry)

Fidelity

Using fidelity checklists, a co-investigator will review video recordings (10% of videos in both the intervention and wait-list groups) using our protocol to validate the inclusion of critical elements and note unusual circumstances.

Chapter Six

Video Production

Video Recording
Timeline
Setting up the room

Video Editing
Decision Rules

Steps for Coding Video in Preparation for Editing

Watch the video

Watch the full video (all four modules) before beginning individual grid. This is important to see the "big picture" and understand the resident's preferences and personality.

Individual Coding

Within one week from video recording complete individual coding grid

1. Access the Individual Coding Grid Template in Box under *Editing Resources and Logs*. On the top left hand corner of the template, fill in the participant ID and the reviewer name and date.
    a. In UBox, open the folder called *Video Production*; select *Video Recordings*, then open the folder with the video number you are coding.
    b. After watching the video, you are ready to begin coding. Begin with the video that has the smallest sequential number. Example: MVI_0022 is the video for the first module "About Me", and MVI_0023 will be the second module video. There should be 4 videos for each participant.
    c. Review the questions in the left-hand column that apply to that module. When you listen to the video, keep these questions in mind as you select the participant's answers that you think answer the questions.
2. Determine what clips to keep (repeat this process for all four modules)
    a. Document clips that are to be included in the middle column (heading *Yes-Keep)* in the final video using the following format:
        i. Begin with the time stamp the segment is to begin and the first few words of the clip.
        ii. On the next line put the end time stamp followed by the last few words of the clip and the word Stop.
        iii. Precision of the exact start and stop times and words becomes very valuable for the individual consolidating the coding, and helps the video editor.

Example:
09:37 What is important for
09:57 around with them. Stop.

    b. If you think that participant's answer requires the inclusion of the interviewer's question to provide context, then start the clip with the time when the question begins.
    c. If you think that a question should be captioned in the video, then put a lower third graphic and the facilitator question in the first column next to the corresponding time stamp. For example, "**L3 Graphic: (FAC): And how would you describe your health?".**

    d. Concepts that are repeated, phrases that you have questions about, or anything that you want clarified, should be noted the third column under the heading *Notes*. Also in this column identify the video module number at the top of each section (example MVI_0023) Place comments across from the corresponding time frame in the *Yes-Keep* column and note the start and stop times of the clip you are referencing. Here is an example:
        i. 02:12-02:35 Long pauses in this section, comments are restated in the following clip.
        ii. Information for the third (far right side) column may include the following:
            1. Explanation regarding why clips were deleted (e.g. talking about roommate).
            2. Questions for review in consensus meeting or by Gail.
            3. Identifying repetition in resident conversation
            4. Noting a clip you feel strongly about including
            5. Relevancy to the question and resident preferences
            6. How the information speaks to who he/she is as a person
            7. Any other information or insights you would like noted

3. Each coder will calculate the time for their edited clips (total time and time for each module) and record it in the right column. Use a timecode calculator to calculate clip durations. Record the totals from each module for a grand total at the bottom of the document. Use time calculator to add total clip times.
    a. Keep overall time to 18 minutes or less.
    b. Make sure to mark the clips that are more important, as well as the clips you're willing to part with. This will help cut down the time if someone goes over 20 minutes.
4. Decisions about redundancies in video production process/coding.
    a. We will note redundancies as captions at specific time points. This essentially means that when a resident talks about something multiple times throughout the video, the coders will decide upon the time point that expresses that preference the best and put the caption there. Other references to that same preference can be cut but track the number of times the preference was stated. Noted redundancies should only be stated preferences.
    b. On the coding grid, coders will write down the timestamp where each caption should go, as well as what the caption should say. This can be noted in the notes

section on the final consensus grid, under the question that asks about redundancies.

    c. The purpose of a & b above is to ensure the editing process does not remove the emphasis the resident placed on issues that were so important they were mentioned repeatedly.
        i. Include the module number and time stamp where the comment would be most appropriate.
        Example:
        Module 2: 08:33 She stated five times that she enjoys painting and it is important to her quality of life.
5. Upload the Coding Grid
    a. Upload the grid to UBox in the file labeled *Participant View Review Grids – Your Name.* Name the document *Grid 0000-00-00_YourName Comments* (with the 0000 changed to the participant number).

Consensus Meeting

Two weeks from video recording to have a consensus meeting

1. Skype for Business meeting: All team members who created an individual grid will participate in the consensus meeting, with one person acting as the Meeting Leader.
    a. All individual coders will meet via Skype to review the clips coded: clips kept/deleted.
    b. The meeting leader will pull up a copy of their individual grid and rename it as the consensus grid while the other team members have their individual grids pulled up.
    c. The leader will edit the consensus grid during the meeting to reflect the decisions that are made by the team on what to keep and what not to keep by modifying start and stop times, wording, and by deleting unwanted clips.
    d. The team will look at each time clip and discuss it. Keep in mind time totals from each coder; in cases where the times may be too long, identify as a team places where cuts can be made if needed to keep the final video under 18minutes. During consensus meeting, also discuss notes and comments as well as redundancies from the last column and the bottom of the page.
        i. Some clips will require watching again, and some will just need to be talked about

Completing Final Grid

Following the consensus meeting, the leader will:

1. In the upper left corner of the template, fill in the participant ID, Reviewers names (designate leader), and the date
2. Check that all clips are formatted correctly
3. Calculate the consensus times for each individual module and for the total video; also fill in times for the raw footage of each module and the total video footage.
    a. The final edited time on the Participant Tracking and Refusals Sheet is the final edited time that the editing team produced.

        i. Any discrepancies in time would be due to adding slides, captions, etc.
    b. Establishing if a clip is agreed upon
        i. How can we capture the same content in the shortest amount of time?
        ii. Number of raters: Did all coders that created a grid add this clip? If yes, then it is agreed upon.
        iii. Content in the clip: Are the coders trying to encompass the same content in the clip If yes, it is agreed upon.
4. Copy and paste any redundancies to be noted with the information regarding where the comments should be included
5. Include any notes to Gail or video editor
6. Upload the consensus grid to UBox in the file Final Consensus Grids and name it using the following format: Grid 0000-00-00_Final (with the 0000 changed to the participant number).

Editing Process

Editing timeline: two weeks

Formatting for Final Coding Grid Title:

Template: Grid XXXX-XX-XX_Final.docx
Example: Grid 1012-00-00_Final.docx

Chapter Seven

Family

Family Post Video-Viewing Survey (REDCap)

How to send a resident video and follow-up survey using REDCap

Log in to REDCap→Select/click on Me & My Wishes: Feasibility and Acceptability→In the left tool bar select/click on Record Status Dashboard→In column 7 of the spreadsheet find *Family Post Video-Viewing Survey* →Scroll down to the appropriate participant/record ID number→click on the clear circle (the following screen will appear)

Click on the drop-down tab labeled *Survey options* → Select *Open Survey* → a window web browser will open with the participant's video and follow up survey→copy and paste the URL into the following email template:

Dear (Name) –

Below is the link to the Me & My Wishes video of your family member/friend. Please view the video and complete the corresponding survey. You may open the survey in your web browser by clicking the link below:

Family Post Video-Viewing Survey

If the link above does not work, try copying the link below into your web browser:
[insert link]

Please contact me or Gail (cc'd on the email) if you need help accessing and viewing the video.

This link is unique to you and should not be forwarded to others. The family consent form reviewed with you on the telephone is attached.

Thank you so much!

Name
Title

Make the necessary updates—participant name, and your name and title→ Remove the survey/video link in the template (highlighted yellow)→Replace with previously copied URL→ Create a hyperlink for the section highlighted in pink (see the next section for instruction on how to create a hyperlink)→Send email.

Creating a Hyperlink in Outlook

Select the following text in the email *Family Post Video-Viewing Survey* →
In the email window task bar, next to font color, (show below) click on the globe icon with chain. Paste the URL and click ok→ You have created a hyperlink!-->

Chapter Eight

Unanticipated Problems and Events

Unanticipated Problems
The University of Utah requires investigators to report all potential unanticipated problems and events to the IRB. Unanticipated problems (UPs) are defined as any incident, experience or outcome that meets all of the following criteria:

- Unexpected (unforeseen by the researcher or the research participant) in terms of nature, severity, or frequency, given the research procedures and the subject population being studied;

- Related or probably related to participation in the research, or if the event or problem probably or definitely affects the safety, rights and welfare of current participants;

- Suggests that the research places subjects or others at a greater risk of harm (including physical, psychological, economic or social harm) than was previously known or recognized.

Definitions:
Adverse event: An event in which care resulted in an undesirable clinical outcome-an outcome not caused by underlying disease-that prolonged the patient stay, caused permanent patient harm, required life-saving intervention, or contributed to death.

Protocol deviation: A departure from study procedures as specified in the IRB-approved protocol. Examples:

- Protocol deviation: Consenting someone who should not have been consented (not eligible)
- Protocol deviation: Survey completion by someone who was not eligible to participate.

Reporting
Report unanticipated problems and events to the PI immediately who will promptly report to IRB in accordance with University of Utah IRB policies.

Chapter Nine

Data Collection and Management

Care Plan Meeting Audio Recordings

Formatting for Final Transcription Title:
Template: XXXX-XX-XXTYPE_Final.docx
Example: 1015-00-00CC_Final.docx

Quantitative Data

Participant Confidentiality and Tracking - IDs

Orientation to Research Electronic Data Capture (REDCap)

To create surveys, access the Online Designer Tool on the Project Setup page.

Surveys

- Review for completeness
- Enter into REDCap
- See Data Code Book for handling:
  Incomplete Surveys
  Missing Surveys/Information
  Two answers

Audit Schedule –review data every week at team meetings

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Abbreviations

ACP (Advance Care Planning)

CITI (Collaborative IRB Training Initiative)

DNH (Do Not Hospitalize)

DNR (Do Not Resuscitate)

EOL (End of Life)

IRB (Institutional Review Board)

NH (Nursing Home)

NPCRC (National Palliative Care Research Center)

POLST (Physician Orders for Life-Sustaining Treatment)

RA (Research Assistant)

REDCap (Research Electronic Data Capture)

VP (Vice President – University of Utah)