

# Using health literacy to improve follow-up data collection

*A Case Study from  
the STRIDE Study at Brigham & Women's Hospital,  
developed with the MRCT Center*



BRIGHAM AND  
WOMEN'S HOSPITAL

(C) MRCT Center



**MULTI-REGIONAL  
CLINICAL TRIALS**

THE MRCT CENTER of  
BRIGHAM AND WOMEN'S HOSPITAL  
and HARVARD

# The Opportunity:

The STRIDE Study is a multi-site study on fall prevention in adults age 70 and over.

The study team recognized the need for health literacy during ongoing data collection. Data collection was also challenged by occasional participant death.

To address this, if a participant passed away while on study, a letter was sent to surrogates to gather additional information.

The letter needed to be written in such a way as to promote a high level of follow-up data collection while maintaining sensitivity and respect.

# How STRIDE started working on it:

1. Drafted and revised the proposed letter with **patient stakeholder feedback**
  - Patient stakeholders made important suggestions to each iteration of the letter.
  - Specifically, patient stakeholders paid close attention to the tone of the letter.
2. Improved reading level
  - With help from the patient stakeholders, the reading level was improved from an 8<sup>th</sup> grade level to a 6<sup>th</sup> grade level.
  - The letter was shortened without loss of content.
3. Improved the visual design of the letter.

## Stride Letter head

# BEFORE

Mr./Mrs. Doe  
Address  
City, State, Zip

Dear Mr/Mrs. X

I am writing on behalf of the Stride Fall Prevention study. I am not sure if you are aware that your Mother/Father/Friend/Spouse is among over 5000 older adults who agreed to help us in this fall prevention study. Your parent's/ spouse/ friend's participation has been vital to the success of the study. We have included some information about this important national research project with this letter in order to familiarize you with the study.

We understand, from the health plan, that your parent/friend/Spouse has passed away. We are saddened to hear the news. It is important for the study to complete some questions regarding the time period since we last had contact with \_\_\_ and his/her passing. This phone call will not take long and we will be happy to call at your convenience. Our toll free number is 844-978-7433 and, if you will leave us a message letting us know where and when to best reach you, will we call you back.

The doctors and staff at the Stride Study are committed to learning how best to support senior citizens as they grow older and develop fall risk factors. Your parent's/ spouse/ friend's experience will help us to that end and we appreciate your help in the process.

We look forward to hearing from you.

Sincerely yours,

Thomas M. Gill, M.D.

# AFTER

Dear X,

We are very sorry to hear about the death of your Mother/Father/Spouse/Friend. He/she was one of more than 5,000 older adults across the country who joined our STRIDE Fall Prevention Study. We want to let you know how thankful we are for your Mother/Father/Spouse/Friend's help in this important research.

We know this is a difficult time. When you feel able to answer some questions about your Mother/Father/Spouse/Friend, please let us know. You may call our toll-free number at 844-978-7433. Leave a message with your phone number and the best time to reach you. We will call you back for a brief conversation. Your willingness to talk to us will be greatly appreciated.

The doctors and staff at the STRIDE Study are committed to learning how to prevent falls and fall injuries as we get older. We look forward to hearing from you.

Sincerely,

Study Staff Y



# Detailed Content Comparison

## Before

## After

I am writing on behalf of the Stride Fall Prevention study. I am not sure if you are aware that your mother is among over 5000 older adults who agreed to help us in this fall prevention study. Your parent's participation has been vital to the success of the study. We have included some information about this important national with this letter in order to familiarize you with the study.

We are very sorry to hear about the death of your mother. She was one of more than 5,000 older adults across the country who joined our STRIDE Fall Prevention Study. We want to let you know how thankful we are for her help in this important research.

# Detailed Content Comparison

## Before

## After

We understand, from the health plan, that your parent has passed away. We are saddened to hear the news. It is important for the study to complete some questions regarding the time period since we last had contact with \_\_\_ and her passing. This phone call will not take long and we will be happy to call at your convenience. Our toll free number is 844-978-7433 and, if you will leave us a message letting us know where and when to best reach you, will we call you back.

We know this is a difficult time. When you feel able to answer some questions about your mother, please let us know. You may call our toll-free number at 844-978-7433. Leave a message with your phone number and the best time to reach you. We will call you back for a brief conversation. Your willingness to talk to us will be greatly appreciated.

# Detailed Content Comparison

## Before

## After

The doctors and staff at the Stride Study are committed to learning how best to support senior citizens as they grow older and develop fall risk factors. Your parent's experience will help us to that end and we appreciate your help in the process.

We look forward to hearing from you.

The doctors and staff at the STRIDE Study are committed to learning how to prevent falls and fall injuries as we get older.

We look forward to hearing from you.

# Who was involved?

## **Recruitment and Assessment Center**

- Screening, Recruitment and Retention Director drafted initial content and worked with Central Project Management and Patient Stakeholders to finalize the letter.

## **Central Project Management**

- Study Director provided input and coordinated edits from all collaborators.

## **Patient Stakeholders**

- National Patient Stakeholder Council Chair (NPSC) and a key caregiver stakeholder provided input. All STRIDE Study patient-facing letters and phone scripts received input and approval from NPSC.



# Successes

## **High rate of follow-up data collected**

- The data collection team found that the letter was effective in facilitating communication with surrogates and achieving the goal of collecting the needed data.

## **Positive surrogate feedback about the tone of the letter**

- One surrogate was eager to help, and thanked the study team for the very “lovely and kind” letter she had received.

# Challenges

## **Letter writing “by committee” can be cumbersome.**

- Adding the patient stakeholder review process added effort, commitment, and time.
- Getting the language right – with patient stakeholder input– meant that the letter went through many revisions.
- The study team learned to anticipate the time requirements that allow for adequate patient stakeholder review of materials to be incorporated.

# Lessons Learned

- Throughout this study, engaging patients contributed to the study team's ability to collect data successfully
  - Specifically, engaging patients in the process of updating the letter was felt to be critical to successful ongoing follow-up data collection
  - Additionally, the tone of the information being sent to surrogates was carefully vetted

# Recommendations

Work to get all members of the study team on board with the process of integrating patient stakeholder feedback into the review of all research materials that are developed for study participants.

Engage patient stakeholders throughout your processes starting from the very beginning.

Build enough time into your processes for patient stakeholder review and feedback

# Resources

- MRCT Center Health Literacy on-study information:  
<https://mrctcenter.org/health-literacy/trial-life-cycle/overview/on-study/>
- MRCT Center Health Literacy tools and resources:  
<https://mrctcenter.org/health-literacy/tools/overview/>
- More information about the STRIDE Study:  
<https://www.stride-study.org/>