

**NORMS OF ENGAGEMENT FOR NURSING HOME RESEARCH  
PART 1: ENGAGING NURSING HOME LEADERSHIP<sup>1</sup>**

Conducting research in a nursing home is a **partnership** between the research team and nursing home administrators and other nursing home staff. Conveying and respecting the effort as a partnership may determine whether nursing home leaders agree to participate in research.

**This document provides a list of topics to discuss and questions to answer during an introductory meeting when inviting nursing home leaders to participate in a research project.**

An introductory meeting is typically held with the administrator, and depending on the study, may also include clinical leaders such as the Director of Nursing. When scheduling the meeting, explain the overall focus of the study and suggest that the administrator/leaders invite all individuals they determine appropriate.

Preparing answers to the “**why, what, how, when, who**” questions in this document in advance of the meeting will facilitate a comprehensive yet focused discussion, allowing you and the nursing home leadership to determine whether partnering on the research project is feasible and appropriate. As you prepare the answers, consider whether and how the study protocol -- such as recruitment and data collection procedures -- may be tailored to a specific nursing home.

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<sup>1</sup> **Norms of Engagement for Nursing Home Research Part 2: Working in Partnership with a Nursing Home** (a separate document) addresses topics that may arise when conducting research.

TOPICS TO DISCUSS WITH NURSING HOME LEADERSHIP	PREPARATORY NOTES
<p><u>WHY: Study Goals</u></p> <ul style="list-style-type: none"> <li>● What are the goals of the study?               <ul style="list-style-type: none"> <li>○ <i>Be prepared to explain how they may align with nursing home priorities.</i></li> </ul> </li> </ul>	
<p><u>WHAT: Study Activities</u></p> <ul style="list-style-type: none"> <li>● If there is an intervention, what is it, and how may it impact standard care?               <ul style="list-style-type: none"> <li>○ <i>In advance, consider standard nursing home care and workflow.</i></li> </ul> </li> <li>● What are the study activities?               <ul style="list-style-type: none"> <li>○ <i>Be prepared to discuss how participants are identified and consent/assent is obtained; data sources; frequency of data collection, and related issues.</i></li> </ul> </li> <li>● What support do you need from the nursing home?               <ul style="list-style-type: none"> <li>○ <i>Explain necessary supports such as access to records/data systems, space, or locating and being introduced to residents.</i></li> </ul> </li> <li>● Who will be asked to participate, and what will it entail?               <ul style="list-style-type: none"> <li>○ <i>In advance, consider if participation will/must be during work hours, if it will affect regular activities, and if so, how disruption will be minimized.</i></li> </ul> </li> <li>● Are reimbursement/resources offered to recognize participation?               <ul style="list-style-type: none"> <li>○ <i>Reimbursement (if allowed), in-service training, refreshments, and other options are appreciated, and best not referred to as an “incentive.”</i></li> </ul> </li> <li>● What are the benefits to the nursing home/staff/residents/families?               <ul style="list-style-type: none"> <li>○ <i>Benefits may include a certificate of participation, informing others of involvement, and that future residents may benefit from study findings.</i></li> </ul> </li> <li>● What are the risks to the nursing home/staff/residents/families and what protections are in place to limit risks (including to sensitive information)?               <ul style="list-style-type: none"> <li>○ <i>It is helpful to discuss oversight of an Institutional Review Board, and that the nursing home may choose to not be identified in dissemination.</i></li> </ul> </li> </ul>	

TOPICS TO DISCUSS WITH NURSING HOME LEADERSHIP	PREPARATORY NOTES
<p><u>HOW: Paperwork and Materials</u></p> <ul style="list-style-type: none"> <li>● Are HIPAA release forms and/or a HIPAA waiver necessary?               <ul style="list-style-type: none"> <li>○ <i>Be prepared to explain why a HIPAA waiver may be necessary to the study to collect/and or use personal health information (PHI), and how PHI will be protected.</i></li> </ul> </li> <li>● What materials will you be providing, and can leadership request changes?               <ul style="list-style-type: none"> <li>○ <i>It is helpful to be receptive to requests to individualize material (e.g., consent forms, recruitment flyers) if possible.</i></li> </ul> </li> <li>● Is nursing home leadership required to sign anything to participate?               <ul style="list-style-type: none"> <li>○ <i>Unless necessary (e.g., for data sharing or payment), it is best to limit paperwork considering that participation is voluntary.</i></li> </ul> </li> </ul>	
<p><u>WHEN: Study Timeline</u></p> <ul style="list-style-type: none"> <li>● How long does the study last?               <ul style="list-style-type: none"> <li>○ <i>Include time from participant identification through final data collection.</i></li> </ul> </li> <li>● What happens at the end of the study?               <ul style="list-style-type: none"> <li>○ <i>Be prepared to discuss how the results are shared, and if an intervention, whether/which activities may be terminated at study end.</i></li> </ul> </li> <li>● By when must leadership make the decision to participate?               <ul style="list-style-type: none"> <li>○ <i>Consider if the study launch date is flexible, especially if leadership needs approval from others or the timing is not optimal.</i></li> </ul> </li> </ul>	
<p><u>WHO: Key Partners</u></p> <ul style="list-style-type: none"> <li>● Who are the points of contact on the study team and in the nursing home?               <ul style="list-style-type: none"> <li>○ <i>It is helpful to provide your business card and request a designated (and secondary) nursing home liaison.</i></li> </ul> </li> </ul>	