

NORMS OF ENGAGEMENT FOR NURSING HOME RESEARCH

It is important to conduct nursing home research to understand resident care needs and how to optimize care. Partnering in research need not create burden as long as everyone understands and has a voice in the process. The list below includes topics to discuss and questions to ask when talking with researchers as you consider whether to engage in research; it also provides space for you to take notes.

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| <p><u>Goals:</u></p> <ul style="list-style-type: none"> ● What are the goals of the study? (<i>Consider if they align with your priorities.</i>) ● Is the study an intervention? (<i>An intervention changes care practices.</i>) <ul style="list-style-type: none"> ○ What is the new practice? How does it affect our standard care? | |
| <p><u>Overall Activities:</u></p> <ul style="list-style-type: none"> ● Who will participate in the study? (<i>Participants may include direct care or other staff, residents, families, administrators, and others.</i>) <ul style="list-style-type: none"> ○ Will (type of participant) participate during work hours? How long will it take? Will participation affect regularly planned activities? ● What are the study activities? (<i>Activities include how consent is obtained and participants are identified, the source of the information that will be collected and how and how often it will be collected, and others.</i>) ● Will you need access to our medical records or other data systems? ● What space is needed for the research? ● Can we choose to participate in some, but not all, activities? | |
| <p><u>Timeline:</u></p> <ul style="list-style-type: none"> ● How long does the study last? (<i>The timeline includes when consent is obtained, data are collected, and the study is completed.</i>) ● How long can we have to decide whether we'll participate? ● If we don't participate now, can we participate in the future? ● If we agree to participate, can we end our participation at any time? | |
| <p><u>Benefits of and Risks to Participation:</u></p> <ul style="list-style-type: none"> ● What are the benefits to our nursing home/staff/residents/families? ● What are the risks to our nursing home/staff/residents/families? <ul style="list-style-type: none"> ○ What protections are in place to limit these risks? ● How will personal/sensitive information about residents be protected? ● Has the study been reviewed by an oversight committee? (<i>Examples include a university Institutional Review Board [IRB], and others.</i>) ● Will there be potential liability based on the findings? ● Will we receive recognition for participating? (<i>Examples include certificate of participation, acknowledgement in dissemination materials, and others.</i>) | |
| <p><u>Paperwork:</u></p> <ul style="list-style-type: none"> ● Are we required to sign anything to participate? (<i>Examples include a Memorandum of Agreement, Data Use Agreement, and others.</i>) ● If asked by our organization, will you sign or modify related paperwork? (<i>Examples include consent forms, confidentiality agreements, and others.</i>) | |

Additional Helpful Information

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| <p><u>Communication:</u></p> <ul style="list-style-type: none"> ● Who on your team is our primary point of contact, and what is their contact information? What should I do if they aren't available? ● Who will be your point of contact within our nursing home? ● Can I refer staff/family/residents to your team if they have questions? ● Will study activities be offered in multiple languages? | |
| <p><u>Materials:</u></p> <ul style="list-style-type: none"> ● What materials will you be giving to our staff/residents/families? (<i>Materials include informational handouts, consent forms, and others.</i>) ● Do I have the option to review and approve project materials? | |
| <p><u>Reimbursement:</u></p> <ul style="list-style-type: none"> ● Is the nursing home reimbursed or provided other resources to recognize their participation? (<i>An example of other resources is inservice training.</i>) <ul style="list-style-type: none"> ○ What paperwork will be required? (<i>Examples include tax documentation, direct deposit documentation, and others.</i>) ● Are participants reimbursed or provided other resources to participate? | |
| <p><u>Study End:</u></p> <ul style="list-style-type: none"> ● Will I receive the research results, and when will I receive them? <ul style="list-style-type: none"> ○ Will they be specific to my nursing home, or will they include others? ○ Will they be shared with participants? ○ Can we share the results in our marketing and other materials? ● Will my nursing home be named/acknowledged in dissemination materials? (<i>It is your choice if you prefer to <u>not</u> be named.</i>) ● Will I lose access to study components after the study is completed, such as training or other intervention materials? | |
| <p><u>Research Team:</u></p> <ul style="list-style-type: none"> ● How many people are on the research team? ● What are their roles and training? | |