**Advance Directive for Research Participation**

Background and Purpose

Research helps us learn new things. For example, researchers do studies with people to find new ways to prevent and treat disease. To find new ways to help people who have health problems, researchers need to include people in studies. Before you can be enrolled as a participant in a research study, your informed consent to participate is necessary. Sometimes people are too sick to make a choice about being part of a study. Or they may have a condition, like dementia (or Alzheimer’s disease), that makes it hard for them to remember things and make decisions.

In an attempt to understand your wishes about future participation in research, UW-Madison has created this form for you to specify the person you would want to make research participation decisions for you if you are unable to make those decisions personally. That person is known as your agent or surrogate decision-maker for research purposes. This Directive will tell people your wishes, such as your family, your doctor or researcher. Your Directive will help them know whether or not you want to be involved in research activities.

You do not have to complete this form to participate in research at UW-Madison. It is entirely voluntary.

Your Choice for a Substitute Decision Maker

I request that the person(s) named below be asked to make decisions for me about my participation in research in the event I am unable to make these decisions for myself. I permit the person below to act as my surrogate decision-maker if I lose my ability to understand the research activities and instruct the person(s) named below to decide whether it is a good idea for me to enroll in a study or continue my participation. The decision should be based on what they think I would want.

First decision-maker Second decision-maker (used if First is unavailable)

Name: Name:

Address: Address:

Telephone #: Telephone #:

Your Wishes About Research Participation (Optional)

If you lose the ability to make decisions, you may continue your participation in a study or be enrolled in a new study if your substitute decision-maker agrees. To help your substitute decision-maker, you have the option to initial the following statements to reflect your current wishes. If at any time you are able to express your preference not to participate in a particular research activity, that preference will bar your participation, regardless of whether your substitute decision-maker has consented to your participation previously.

If I lose the ability to make my own decisions (initial any that apply):

\_\_\_\_\_ I am willing to participate in research that may help me.

\_\_\_\_\_ I am willing to participate in research that will not help me directly, but might help others and involves no more than minimal risk of harm to me. Minimal risk means the harm is not more than you encounter in your everyday life, such as a routine physical exam or blood test.

\_\_\_\_\_ I am willing to participate in research that will not help me directly, but might help others and involves more than minimal risk of harm to me.

You can use this section below to indicate any specific desires, goals or limitations that you would like to guide your research participation. For more space, attach another sheet of paper.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Expiration Date

If you would like this document to expire upon a certain date or condition, specify here: \_\_\_\_\_\_\_\_\_\_\_\_

If you do not specify a date, this Directive will not expire unless you tell us you do not want to use it anymore.

Signature and Date

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Participant Signature Date Print Name

I witnessed the above individual sign this form. The individual appeared to sign this form willingly and free from duress.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Witness #1 Signature Date Print Name

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Witness #2 Signature Date Print Name