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SUMMARY EXPLANATION OF RESEARCH *(Spokesperson)*

Penn State College of Medicine
Penn State Health

Title of Project: Choosing an Effective Healthcare Spokesperson: An Interactive Intervention

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You are being invited to volunteer to participate in a research study. Research studies include only people who voluntarily choose to take part. This summary explains key information about this research. You are urged to ask questions about anything that is unclear to you.

- This research is being done to better understand what characteristics people find most important when choosing a surrogate decision-maker (also known as a spokesperson).
- If you choose to take part in this research, you will complete a short survey online through a link on your smart phone.
- The completion of the questions should take less than 10 minutes. Information from this activity may help our research team improve consistency between patients and their surrogate decision-makers (spokespersons).
- There is risk of loss of confidentiality if your information or your identity is obtained by someone other than the investigators, but precautions will be taken to prevent this from happening. The confidentiality of your electronic data created by you or by the researchers will be maintained to the degree permitted by the technology used. Absolute confidentiality cannot be guaranteed. For the named spokesperson who completes this online survey, no personally identifiable data will be collected will be collected except or your first name, last initial and your location by state.
- You may not benefit directly from taking part in this research study, but the results of this may improve consistency between patients' wishes for end-of-life medical care and the choices made by their surrogate decision-makers.
- Electronic records will be stored on the Penn State Health IT file server. Only permitted users will have access to the stored files.
- We may use your research information in future studies or may share your information or with other investigators for future research without your additional informed consent. Before we use or share your information we will remove any information that shows your identity.

- This research is financially supported by the National Institutes of Health.
- This research is covered by a Certificate of Confidentiality from the National Institutes of Health. This means that the researchers cannot disclose information that identifies you to anyone not connected with the research. This protection also prevents this information from being used or disclosed for legal proceedings, such as being accessed through a court order. The Certificate of Confidentiality however does not prevent disclosures required by law, such as information about child abuse or neglect and harm to yourself or others. Also, your information may be disclosed in accordance with any consent you provide, including your medical treatment or use in other research. Additionally, the Certificate of Confidentiality does not prevent your information from being disclosed to the National Institute of Nursing Research in order for it to evaluate or audit the research, or prevent disclosures required to meet FDA requirements. For additional information, ask the Principal Investigator or a member of the study team or Contact the Human Subjects Protection Office at (717) 531-5687.

You have the right to ask any questions you may have about this research. If you have questions, complaints or concerns or believe you may have been harmed from participating in this research, you should contact Benjamin H. Levi, MD, PhD at 717.531.7887. If you have questions regarding your rights as a research subject or concerns regarding your privacy, you may contact the research protection advocate in the HMC Human Subjects Protection Office at 717-531-5687. You may call this number to discuss any problems, concerns or questions; get information or offer input.

You do not have to participate in this research. Taking part in the research study is voluntary. Your decision to participate or to decline the research will not result in any penalty or loss of benefits to which you are entitled.

Your completion of this questionnaire implies your voluntary consent to participate in the research.