ACTIVITY TITLE:

Usability testing of an oncology patient-facing symptom management website

PRINCIPAL INVESTIGATOR:

[redacted]

VERSION DATE:

9/9/2019

1.1 Purpose

This is a usability study of a website prototype being developed for the Northwestern IMPACT study titled "Implementation and Evaluation of an Expanded Bilingual Electronic Symptom Management Program across a Multi-site, Fully-integrated Comprehensive Cancer Center" (Grant Number: [redacted] IRB Number: [redacted]). As part of the larger IMPACT study, the resulting website will be provided to study participants. Here, we are recruiting patients to review the prototype of the website to provide feedback and identify any problems with the design of the website. This study focuses on reactions to the site, rather than on the participants.

1.2 Procedures

In this small study, ten individuals who identify as cancer patients or survivors and have received care at Northwestern's Lurie Comprehensive Cancer Center will be recruited for an individual 30 minute usability testing session through physician referral. Participants will be informed that this is a research study, that their participation is voluntary, and that it will not impact any care they receive at the Lurie Comprehensive Cancer Center. Participants will be asked to provide verbal consent. As documented in the attached session protocol, participants will be asked to "think aloud" while navigating through a prototype of a patient-facing website, and will provide feedback on the prototype. As a small thank you for participating in these sessions, participants will receive $50.

1.3 Data and/or specimens

To provide context for the usability testing, participants will be asked to report their age, gender, cancer diagnosis, date of diagnosis, and treatment status (i.e. in active treatment, not in active treatment). Participants will not be prompted to provide any personal identifiers.

Primary data collection for this study focuses on navigation through the prototype of the website (see attached protocol). This data includes time

required to complete specific tasks within the prototype and qualitative feedback on prototype use.

3.4 **Protected Health Information (if applicable):**

If you are requesting the use of protected health information, the Northwestern IRB in its role as the Privacy Board will need to consider if a HIPAA Authorization is required or if it can be waived.

In order to make that decision, the Privacy Board will consider the following:

1. The use or disclosure of protected health information involves no more than a minimal risk to the privacy of individuals, based on, at least, the presence of the following elements. Describe:
    a. Your plan to protect the identifiers from improper use and disclosure.
    b. Your plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law.
    c. Written assurance that the protected health information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of protected health information for which an authorization or opportunity to agree or object is not required by 45 CFR 164.512.
2. The research could NOT practicably be conducted without the waiver or alteration.
3. The research could NOT practicably be conducted without access to and use of the protected health information.

Participants will be asked to report their cancer diagnosis, date of diagnosis and treatment status and this data will be saved separately from their identifying information. Identifying information (e.g. name, contact information) will be deleted after study sessions. Participants will be provided with written assurance that the protected health information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of protected health information for which an authorization or opportunity to agree or object is not required by 45 CFR 164.512. Obtaining information about participant diagnosis is valuable for contextualizing their reports of website usability and for ensuring that the recruited sample is similar to the targeted end users for the website.