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**UNIVERSITY OF WYOMING
PROJECT INFORMATION AND CONSENT
TO SERVE AS A PARTICIPANT IN A RESEARCH PROJECT**

v.1

Project Title: Social Media and the Patient Experience of Cancer Ghosting: A Phased Qualitative Analysis

Project Team:

Home Institution: Fay W. Whitney School of Nursing, University of Wyoming (FWWSON)

- 1) Primary Investigator: Jennifer Stephens, MA, PhD, RN, OCN, CCNE (FWWSON)
- 2) Co-Investigator: Jenifer Thomas, PhD (FWWSON)
- 3) Research Assistant: Carlos Garcia, BS (Iverson Memorial Hospital Cancer Clinic)

You are being asked to participate in a nursing research project conducted through the Fay W. Whitney School of Nursing at the University of Wyoming in Laramie, Wyoming, USA.

Please read this description and discuss any questions or concerns with the PI.

Purpose of the Project:

The purpose of this study is to better understand incidents of cancer ghosting as experienced by those who have been diagnosed with cancer. Our team seeks to understand the concept of *cancer ghosting* from a patient viewpoint including the background of the experience, possible presumed rationale, specific details, and patient suggestions for healthcare professionals around interventions to help patients with self-efficacy and coping.

This qualitative study has data collection in two phases: a netnographic study of public social media postings (phase 1) and short, concise interviews with cancer patients who have experienced the phenomenon of ghosting due to their diagnosis (phase 2). Phase 1 has been completed and is currently being written up for publication. Your perspective as an oncology

patient in phase 2 will help us understand about specific incidents of cancer ghosting you have experienced with the hope of finding ways to help navigate this in your journey.

Explanation of Procedures:

As this is a qualitative study, a semi-structured interview will be conducted in a manner that works best for you. This could be an interview lasting about 10 minutes over ZOOM, TEAMS, or phone. **This interview will be digitally recorded** and then transcribed so the data can be explored within the context of all the interview data collected. The PI or the Research Assistant will be performing the interview. You may leave your camera off if you choose.

Your participation in this interview is entirely voluntary. If you agree to participate in an interview, you can refuse to answer any question at any time. You are able to withdraw from this study up to 3 days after the interview was completed and before the interview is transcribed. Refusing to answer questions or withdrawing from the study at any point will not compromise you in any way.

All interview data and the identity of the interviewees will be kept strictly confidential. Following the interview, the PI will transcribe the recording into text through an artificial intelligence (AI) transcription service such as ZOOM, TEAMS, or otter.ai. The digital recordings will be stored in a secure University of Wyoming laptop file for five years before they are permanently deleted. Transcripts of the interviews will be kept in electronic format on a password-protected computer with access limited to the research team members (listed above).

The transcript from your interview will not include any names or identifying features (such as personal information or organizational information) that could identify you or other individuals, and no identifying information will be included in any written reports or presentations. Your participation in this interview is anonymous to everyone except the PI and Research Assistant, and you will be assigned a code by the PI that will identify you in the database.

Possible Risks and Benefits from this Study:

There is minimal risk to participants in this study. However, you may be asked personal questions that they do not feel comfortable answering or that might provoke uncomfortable memories. Participants may find the questions difficult and may not feel comfortable sharing the entirety of their experience. All questions asked in this study as part of the structured interview are optional and the participant may stop the interview at any time without repercussion.

Honorarium for Participating in this Study:

As a thank-you for participating in this study, an electronic Amazon.com gift card for \$25 will be sent to you after completing the interview. This gift card will be delivered to the email address you provide on the consent form. Should you like to refuse this gift card, that is entirely at your discretion.

Anticipated Ways this Data will be Used:

We anticipate drafting several manuscripts arising from data gathered during interviews. These may include both lay audience manuscripts and academic manuscripts. On-line presentations and conference presentations may also result from the cumulative material collected by this study. We also may use data for secondary studies that pertain to this study.

Ethics

This study has been reviewed by the University of Wyoming Ethics Review Board, certificate # XXXXXXXXXX. Should you have any questions or concerns about your treatment as a participant in this study *or about your rights as a research participant, please contact the University of Wyoming IRB Administrator at 307-766-5322 or at irb@uwyo.edu.*

Questions?

If you have further questions or concerns about this study, please contact the PI at 1-307-766-6563 or jsteph35@uwyo.edu.

PATIENT INFORMED CONSENT FORM

**Social Media and the Patient Experience of Cancer Ghosting:
A Phased Qualitative Analysis**

Your signature on this document means that:

- You have read what this research project is about and understood the risks and benefits.
- You have had time to think about participating in the project and had the opportunity to ask questions and have those questions answered to your satisfaction.
- UW or the research team is not responsible for any damages that may result from this study.
- You understand what the research project is about and what you will be asked to do.
- You understand that you and your personal information will be kept confidential by the research team.
- You understand that you are free to withdraw your participation in the research project until your interview has been transcribed (or up to 3 days after the interview), without having to give a reason, and that doing so will not affect you now, or in the future.
- You understand that your data is being collected anonymously and identifiers will be scrubbed from the interview transcript, and therefore cannot be removed once your interview has been transcribed (or after 3 days after the interview).
- You understand that participating in the project is entirely voluntary and that you may end your participation at any time prior to the completion of data transcription without any penalty or negative consequences.
- You have a copy of this Informed Consent form for your records.
- You agree to participate in this research project.

*Please sign this document (an e-signature or typed name is sufficient), date, and then send as a PDF to jsteph35@uwyo.edu. A picture as a JPEG will also suffice.
If you cannot provide a signature, you can still be in this study. Digitally-recorded oral consent will be requested at the start of an interview.*

Signature of Participant

Date

Consent for Recording

This study will require the digital recording of my voice that will be used for a hard-copy transcription. By signing below, I consent to for this interview to be digitally recorded.

Signature of Participant

Date

Consent for \$25 Amazon.com Electronic Gift Card

I would like to receive my \$25 Amazon.com electronic gift card for participating in this study. Below is my email address:
