Survey for Caregivers of Patients with Dementia

This survey will help the investigators identify the specific needs of individuals diagnosed with dementia. The data gathered will be used to develop software application modules that can also aid you, the caregivers, in the care and management of individuals with dementia.

Before answering the survey, please read the informed consent form indicating information on the project, your participation as a respondent, and how the data you contribute will be managed.

Thank you very much.

INFORMED CONSENT FORM FOR CAREGIVERS

Choose Language
Pumili ng Wika

English

Requirements for E-Care System (Alz-e-Med) to Support Patients with Dementia

INTRODUCTION

ALZ-e-Med, developed by the BYSGrup Consulting services in collaboration with Istanbul University and Ankara University, is an e-care tool designed to assist patients with Alzheimer's Disease and their caregivers. This project will perform the REQUIREMENTS ANALYSIS to identify specific needs for dementia care in the Philippines, addressing both the needs of caregivers as well as patients, and matching these needs with what Alz-e-Med has to offer.

Your insights and experience as a caregiver of dementia patients is valuable to the conduct of this study. In this regard, we request for your participation in this project. It is important that you have read this document thoroughly and have understood it before giving your consent. This form will only be valid as long as the project is being implemented.

PROCEDURE

The following have been explained to you properly and you have fully understood them before signing this consent form:

What is this project and why is it being implemented?
This project is a requirements analysis of the needs of dementia patients and their caregivers in the Philippines. The results of the requirements analysis are needed to prepare for future work in: 1) developing additional software application modules in Alz-e-Med for specific needs in the Philippines that are not yet addressed by the current version, and 2) conducting a pilot study using the revised Alz-e-Med, including the new modules from 1 (if any), in psychiatric and neurological clinics as well as community-home settings.

How many participants are needed in this study?
One hundred (100) participants are needed to conduct the study.

How long will the study be implemented?
The project will be conducted for 12 months.

What kind of participation is expected from you?
Your participation in this study is VOLUNTARY.
As a caregiver of a patient or patients with dementia, your insights on the said practice will be documented through a 1) survey and, if chosen, you will also be invited to join an 2) online focus group discussion (FGD).
You will NOT be asked to give your patient's name in both the survey questionnaire and focus group discussion. If patient names come up anytime during the discussion, their names will be manually deleted in the FGD recording and transcript prior to archiving.

Who will encode your responses?
Your answers in the survey will be encoded using an electronic data collection tool developed using the Research Electronic Data Capture (REDCap) software (V. 9.7.8). The FGDs will be recorded and transcribed by a data specialist hired by the University of San Agustin Center for Informatics (USACFI).

How will the data be handled?
The development and implementation of the tool will be the responsibility of the University of San Agustin - Center for Informatics (USA-CFI) as data stewards.

Access to your answers in the survey questions, and the archived recording and transcript will be limited to project team members. The data gathered will only be used for this requirements analysis project.
The measures of personal data protection for this study are in accordance with the Data Privacy Act of 2012.

What are the potential benefits of this study?
The successful completion of this project is a baseline for dementia care in the Philippines which will eventually benefit patients, their families and overburdened mental healthcare workers.

How long will my participation in the study be?
The survey will take 20-30 mins to complete, and each FGD session will take 1 hour.

What are potential risks that may affect participants in this study?

Data leakage is a possibility that may affect the privacy and confidentiality of caregiver data. This can be prevented by including users rigorously trained on ethical data practices, and the use of laptops dedicated solely for encoding and analysis of survey questions and FGD responses, and online FGD sessions.

What will I benefit from joining this study?

Should you need psychological support due to caregiver fatigue, you will be referred to institutions or individuals (psychiatrists, psychologists) offering mental health services that may address your needs.

Will I be given compensation for my efforts in the study?

You will not be receiving any monetary payment while you are participating in this study. Monetary support worth 500 Php will be provided to compensate for expenses that may be incurred for your travel to and from the hospital to answer the survey and/or attend the FGD.

Will my responses be used in other projects?
Your responses may be made available to other researchers working on mental health projects and/or dementia care

Will I be allowed to know the results of the study that used my responses?
Yes. You will be provided a link to an online, non-downloadable summary of the results and analysis of de-identified data in this study.

Am I free to withdraw or to refuse participation in the study?
Any new data that will affect your decision to participate in the study will be communicated to you via messaging or verbally, and in a timely manner.
You are free to withdraw from the project anytime without loss of benefits for you and your patient.

Will I be given time to consider my decision?
You will be given enough time to consider your decision.

Who can I contact and ask for information regarding this study?

You may contact the following project proponents any time the following persons if you have any questions or concerns related to the study:

Dr. Romulo de Castro09959566505
Principal Investigator
University of San Agustin – Center for Informatics
09959566505, rdecastro@usa.edu.ph

This study has been approved by the Single Joint Review Ethics Board (SJREB) of the Department of Health (DOH). You may contact their office if you have any questions or concerns about your rights and responsibilities as participants to this study/project.

Dr. Jacinto Blas Mantaring III

SJREB Chair

Contact details: 651-7800 locals 1328/1326; sjreb.doh@gmail.com
Address: DOH Building 3, San Lazaro Compound, C. S. Gatmaitan Ave, Manila, 1003 Metro Manila

By signing below, I testify that I have read the informed consent and my involvement in this project has been explained to me. All the questions that I have regarding my participation have been properly addressed and I am giving my consent voluntarily to participate in this study.

Signature

* must provide value

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