Collaborative Access Control for People with Mild Dementia

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Problem

Dementia is a progressive condition that affects cognitive abilities, making it increasingly problematic for individuals to manage their affairs. One of the critical challenges faced by people with mild dementia is maintaining control over their privacy and autonomy while ensuring that caregivers, including family members and professionals, can assist them effectively. As dementia progresses, privacy and data sharing preferences may change, which must be managed to respect the patient's autonomy while ensuring their safety and well-being.

Goals

This project aims to design, develop, and evaluate a collaborative access control system tailored for people with mild dementia and their caregivers. The system will allow patients to define and adjust their privacy preferences over time and provide caregivers with appropriate access to data, such as location or home monitoring information, depending on the stage of dementia. An essential aspect of the system will be allowing patients to define when and how their caregivers can override their preferences (referred to as metapreferences), ensuring that any override respects the patient's will and autonomy, even as their cognitive abilities decline.

Scope

The project will be divided into three main phases: Design, Deploy, and Evaluation.

Design Phase

A thorough review of recent research will be conducted to identify current limitations in existing access control systems for dementia care. Then, a survey will be designed and distributed to people in their 60s, a demographic at higher risk of dementia, to understand their perspectives on privacy, the information they would be comfortable sharing with caregivers, and under what circumstances they would allow caregivers to override their preferences. This phase will conclude with an analysis of the survey data to inform the design of the access control system, including how to implement and respect patients' meta-preferences.

Deploy Phase

A proof-of-concept web application will be developed based on the insights gained from the design phase. This application will integrate data from various sources, such as smartwatches or home monitoring devices, and allow patients to configure their privacy preferences as well as meta-preferences regarding caregiver overrides. The interface will provide caregivers access to this data, depending on the patient's preferences, while ensuring that any override mechanism respects the meta-preferences established by the patient. This phase will involve building the user interface, implementing API connections, and developing the access control features.

Evaluation Phase

The system will be evaluated through role-playing scenarios involving caregivers and patients to assess its usability, effectiveness, and ethical considerations. Feedback from these sessions will inform potential improvements to the system, particularly regarding how well it respects patients' preferences and meta-preferences.