

Project 7/8 Social Buddy

Literature research: The ethical and practical concerns of using tracking devices on elderly people at risk of wandering

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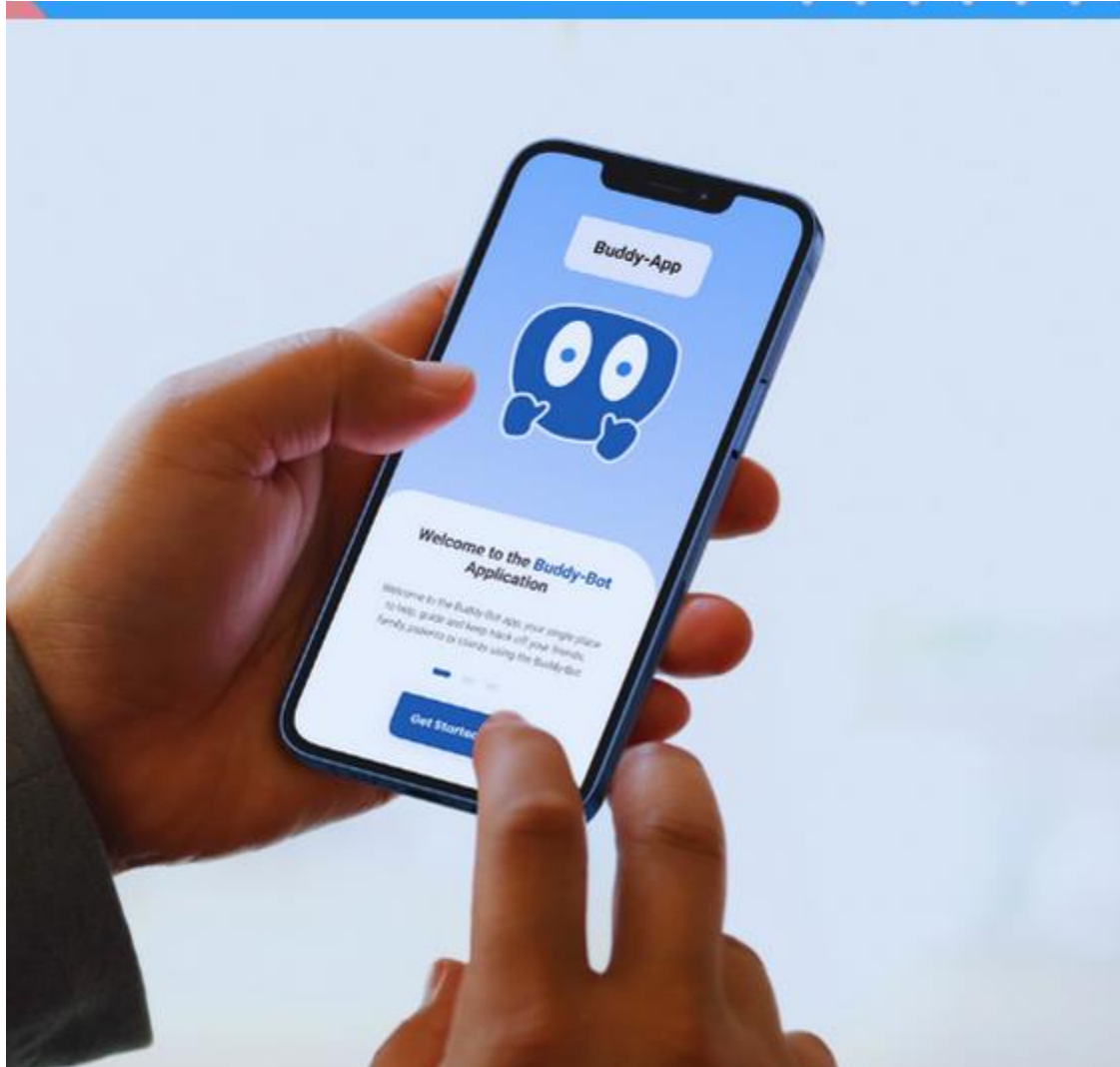


Table of Contents

Table of Contents.....	2
Summary.....	3
Introduction.....	4
Theoretical Framework.....	5
Methodology.....	6
Research	6
Existing usage of trackers within at-risk groups and views on its usage	6
Usage and views	7
Risks to the pwd's wellbeing	9
Security and privacy incidents in pwd tracking.....	9
GDPR regulations.....	9
Conclusion	11
Recommendations	11
Bibliography.....	12

Summary

The project revolves around an app named Social Buddy. Social buddy is an app designed to aid caretakers in nursing homes with assisting elderly people. It features systems like medicine reminders, video calling with the caretaker and a “Tamagotchi” style avatar that responds to movements from the user through computer vision.

The project was tasked with implementing a warning system that alerts caretakers when patients with dementia (referred to as pwd) have wandered beyond a certain distance and duration from the nursing home.

Such a feature raises important ethical questions. Regarding the pwd’s autonomy, privacy and safety that comes with tracking their movements.

This literature research covers the ethical and practical considerations that must be made before the full implementation of such tracking system.

Location trackers have been shown to improve the quality of life for the pwd and their families as it provides an early warning system for caretakers when they’re at risk of wandering. Thus, able to prevent incidents like drowning etc. Increases the pwd’s autonomy as they aren’t locked inside in their own safety.

Due to handling sensitive information of their users. Considerable care must be taken in securing data generated by these geolocation actors. GDPR regulations must also be followed, highlights include article (35) in which a full data protection assessment must be made before full implementation.

On the ethical front there isn’t a clear-cut consensus on the usage of these trackers. There is a strong emphasis on ensuring the autonomy, privacy and safety of the pwd is preserved. Social buddy must take great care following recommendations as stipulated in (Landau et al.,2011) and this report.

Introduction

The Social Buddy Bot is an app that is designed to aid caretakers in nursing homes by providing care to their senior citizens. The Social Buddy App, henceforth shall be known as Social Buddy, is an app that runs on a tablet that is always on. One could compare it to a product like the Google Nest Hub. A tablet that is always on in the background and notifies the user of important reminders.

Such reminders as: Notifications for reminding seniors to take their medicine, video calling to the caretaker from the Social Buddy and an animated avatar that responds to the user's movement through the camera, which is supposed to alleviate some loneliness in users.

For this phase of the development, the project team was tasked to develop two independent features.

- Integrating the flic button with the social buddy app
- Create a system to warn caretakers when a senior has strayed far from bounds.

This report covers the second feature as it raises an important ethical question

The feature has been outlined as such according to the product owner.” There should be a feature to warn caretakers when an elderly person at risk of wandering when they have been further than a set distance for a certain amount of time from the nursing home, furthermore integration with something like an apple air tag is most preferred for their user friendliness”

This raises an important ethical question

To what extent can we invade someone’s personal privacy (their location when they’re out and about) to justify the increase in safety? And what risks can we encounter (Ethically, Privacy, Safety)) with the usage of trackers?

As such a system could lead to potential liabilities that must be taken to account lest we endanger patients and caretakers should such an incident arrive. For example:

- Databreaches, (What to do when locations of buddy bots are compromised and leaked to the internet?)
- Malicious Actors, (criminals could target the backend of the buddy bot and gauge when a senior is out wandering)

- Ethical questions (“Should we force people at risk to use such trackers for their own safety?”, “How could such a system infringe on their individuals rights?”)

This report will cover existing projects and pilots in nursing homes utilizing trackers for this exact purpose, which is to advise the product owner about the risks, measures that needs be taken in order for this system to be safely used and not risks the patients safety, autonomy and rights.

Theoretical Framework

The following literature report will go over the papers covering previous implementations of such tracking technology for seniors a risk of wandering. For user brevity these seniors will just be referred as pwd’s. (Person with dementia)

This report aims to explore potential problems that arise when location tracking for the supposed safety of the pwd’s. Especially on the ethical front. One couldn’t be faulted to draw similarities between having trackers for pwd’s and criminals on house arrest. Thus, when implementing such technologies the project must raise the following questions

- How will the privacy of the pwd be protected even when they’re not fully aware when they’re tracked and/or unable to give informed consent?
- In the event of a data security breach what happens to the location data obtained by a malicious actor?
- What is the psychological impact on a pwd when they notice that they are monitored 24/7
- The use of tracking technologies raises ethical questions about consent, especially for pwd’s with impaired cognitive abilities who might not fully understand what they are consenting to.

This research covers the following questions:

- How are existing tracking implemented elsewhere, what problems have they run into and what steps have they taken in order to mitigate them.
- What are the potential risks to the pwd’s wellbeing resulting from its usage.

Methodology

For this literature research the following topics were explored:

- Existing usage of trackers within at risk-groups and views on its usage
- Potential risks to the senior's wellbeing stemming from the usage of trackers

Information is acquired through direction from ChatGPT, which points us to relevant papers. These papers are checked by the DOI number in google scholar to verify that it's not a hallucination.

Google Scholar is a handy way to quickly check the validity of a given reference, given that google scholar lists how many times a particular research document gets cited. This by itself is not a perfect indicator of research quality but this prunes any document that might be less trustworthy due to whichever factor one might decide not to cite a particular document. (Quality of writing, research methodology, etc.)

The work in this research is heavily based on research done by Ruth Landau and Shirley Werner, due to their involvement in several tracker related projects relating to the usage for people with dementia and will reference a big part of the findings in the report. The following articles served as a nexus point for this report *Landau, R., & Werner, S. (2011). Ethical aspects of using GPS for tracking people with dementia: recommendations for practice. *International Psychogeriatrics*, 24(3), 358–366.
<https://doi.org/10.1017/s1041610211001888>*

and *Bartlett, R., Brannelly, T., & Topo, P. (2019b). Using GPS Technologies with People with Dementia. *Tidsskrift For Omsorgsforskning*, 5(3), 84–98.
<https://doi.org/10.18261/issn.2387-5984-2019-03-08>*

Research

Existing usage of trackers within at-risk groups and views on its usage

Using trackers to decrease the risk to the pwd's wellbeing from wandering has been studied in many different papers. Examples include:

- The Norwegian Centre for E-Health research (Bartlett et al., 2019)

- Research published on BMC Geriatrics (Hall et al., 2019) which evaluated 3 nursing homes implementing trackers as a measure of safety
- The Canadian “Safe Tracks” program uses GPS devices to help locate elderly individuals that go missing. (*SafeTracks GPS | Personal Wellness GPS Electronic Monitoring*, z.d.)

Usage and views

The common thread throughout these articles is that there hasn't been any good ethical consensus on the usage of trackers to aid the care of at-risk individuals. It does reveal that when properly informed and monitored. The usage of trackers can help improve the quality of life for the individual.

Proponents for the trackers argue that it provides especially, family caretakers with a sense of peace regarding the individual's whereabouts. Some elderly at risk individuals reported a sense of safety and autonomy. As they're not locked indoors in fear of wandering into dangerous situations by either their family or nursing home caretakers. Improving their quality of life and sense of autonomy. An important factor to consider is the increase in safety for at risk individuals. As they can be tracked faster and retrieved earlier before any incidents such as drowning etc., can occur. Which is an important variable to account for. (Bartlett et al., 2019b)

Detractors meanwhile argue that it violates their privacy especially when there isn't good, informed consent on the individuals, such eventualities must also be accounted for when considering the ethical nature of this topic. Especially regarding policymaking and healthcare policies. (Rialle et al., 2008), (Wey, 2008)

Interestingly, in an article, it mentions that depending on if the caretaker is responsible for the patient, they would be more willing to employ the usage of such trackers. While when they're not responsible for the patient, the caretaker stance would err more on the side of the patient's autonomy. (Landau et al., 2010)

Views of people suffering early-stage dementia but still able to give their views and stances, indicate that informed consent and the ability to disconnect from such systems as paramount and must needs be considered when setting up a system for tracking an individual's movement.

Important is also the individuals and the family's receptivity to the usage of these trackers. Instances such as “annoying beeping sounds” can hamper compliance of tracker usage.

Ultimately, the usage of trackers has been shown to improve the pwd's quality of life. While the individual would have less privacy, they would be afforded more autonomy of movement and an increase in safety. The ethical concern thus rests on the fact that at what point can the caretaker or family force the usage of trackers on individuals, for their own safety. And to what extent this infringes on the pwd' rights to be able to refuse such a mandate. Which makes this a very difficult question to tackle. As the at-risk individual naturally will experience a degradation in their ability to make decisions. Policies must consider these.

In the two articles [Landau et al., 2011) and (Bartlett et al., 2019b)] some recommendations are made based on their findings. The running theme amongst the recommendations is ensuring that the rights and safety of the individual must be preserved when deciding on the usage of these trackers. The following recommendations made by the article (Landau et all., 2011) are highlighted and must be considered for the project when such a system is deployed in nursing homes

“It is crucial to maintain balance between the needs of persons with dementia for protection and safety and their need for autonomy and privacy.”

“The decision on using GPS for tracking elderly people with dementia should be made jointly by the person with dementia and family caregivers.”

“People with dementia should be asked for their informed consent regarding the possible use of GPS in tracking their outdoor mobility, and they should not be coerced into being tracked.”

“In deciding whether to use GPS for tracking people with dementia, not only the prior attitudes and values of people with dementia but also the best interests of both the persons with dementia and their family caregivers must be considered”

Thus, when implementing such a system for the project. Much care is needed to ensure that the patient's wishes, views and that of their family are respected. This means when considering the usage of these trackers. Caretakers must fully inform the patient and family about the risks and advantages to using these systems in their care. Recommendations for advance directives and the power of an attorney can do well to ensure that the informed consent of the patient is safeguarded.

The article also highlighted that the timing of these conversations could matter as well. Highlighting that deciding early, setting expectation and chains of decisions (What the family + caretaker + individual decides what to do over the period of the beginning stages to

the end of life) Is especially important as the individual would progressively lose their ability to reason and give an appropriate amount of consent.

Such onus must fall on the family and the caretaker, but decisions must be informed by the prior wishes of the patient. In (Landau et al. 2011) When the patient does not possess the mental capability to give such consent. Consent can then be asked from in order (1) spouse, (2) most involved family member (3) the person inflicted with dementia themselves.

This was the conclusion of the article but is also limited to the scope of the population surveyed (N=296) of which; (1) Cognitively intact elderly (N=44); (2) family caregivers of pwd[People/person with dementia] (N=94); (3) social workers (N=51); (4) other professionals (nurses, dieticians, occupational therapists) (N=48); (5) social work students.

Risks to the pwd's wellbeing

While ethical considerations are paramount, the security and privacy concerns of the implementation of trackers are of utmost importance as well. As the project deals with sensitive geolocation data. Compliance with GDPR regulations and mitigations against security and privacy risks must be duly considered lest the project endangers the pwd's wellbeing.

Security and privacy incidents in pwd tracking

1. Privacy Invasion. When not given full informed consent, the risks to the pwd's well-being can worsen when the pwd realize in a moment of lucidity that they're being tracked without the knowledge of the intent or full extent can be perceived as a serious invasion of privacy
2. Data and security Breaches. An incident occurred in 2018 when a security breach in the NHS system exposed thousands of individuals personally identifiable data. This could expose the pwd to dangers as malicious actors can access their walking routine, habits and behavior.
3. Reliability of the tracker. If the tracker malfunctions there could be a risk that it is not noticed and can therefore lead to a false sense of security if not detected.

GDPR regulations

When storing personally identifiable data the following articles in the General Data and Protection Regulation are of utmost importance. When referring to the GDPR they mention

entities as controllers. These are basically entities (companies, orgs etc.) that manage some form of information for the purposes of business. (Social Buddy in this instance would be the controller referred to in the article) These are the few articles that the project believes social buddy must pay extra attention to.

Article 7 Conditions for consent

- **Informed Consent:** Consent must be freely given, specific, informed, and unambiguous. This can be challenging when dealing with elderly individuals with cognitive impairments, as they might not fully understand the implications of their consent.
- **Withdrawal of Consent:** Individuals must have the right to withdraw their consent at any time, and this process must be as easy as giving consent.

Article 32 Security of processing

The controller must implement appropriate technical and organizational measures to ensure protection of private and sensitive data appropriate to the risks. Such as:

- Psuedoanonymisation and encryption of personal data
- Ability of ensuring ongoing CIA measures (Confidentiality, Integrity and Accessibility)

Article 35 Data Protection Impact assessment

DPIA stipulates that when data processing can likely result in a high risk to the rights and freedoms of natural persons (which this feature does apply since it involves the monitoring of the geolocation of at-risk individuals) The controller shall and must before processing data, create an assessment on the impact and measures that must be taken in order to safeguard their clients privacy and seek advice from data protection officers for consultation.

Article 33-34 Notification in case of a data breach

These two articles cover the responsibility that social buddy must abide by in the event of a data breach. This means notifying the supervisory authority in the event of a data breach and notifying their data subjects as well (which in this case is the pwd , caretaker and family)

Conclusion

Location trackers have been shown to improve the quality of life for the pwd and their families. They provide an early warning for when the pwd is amiss and it allows their caretakers to retrieve them quickly before any accidents fatal or not occur.

When implementing such a system, compliance with the GDPR is of greatest importance. And the product owner must take the necessary steps to safeguard the privacy of their users.

Though the implementation of such a tracking system raises considerable and important ethical dilemmas and there is no clear-cut consensus on the appropriate usage of these trackers. Considerable care must be taken when suggesting the usage of location trackers. The project urges their product owner to consider the recommendations of (Landau et al., 2011) before the usage of these trackers. The recommendations that are made revolve around safeguarding both the pwd's autonomy, privacy and safety. Social buddy and the caretaker must at least have these procedures in place before considering the usage of trackers.

Recommendations

1. The pwd and their family must be fully informed on the risks and benefits of the usage of trackers, the pwd must be able to give informed consent, and if not, the next best person (in order; spouse, most involved family caretaker, the pwd themselves)
2. There must be regular meetups and check-ins on the pwd with their family and caretakers to assess future steps. This is quite important as the pwd's decision-making capability will reduce throughout the duration of their care.
3. The wishes, perspectives and the autonomy of the pwd must be respected. By advance directives and the power of an attorney if need be.
4. In deciding on the usage of trackers, the prior attitude and values of the pwd and the best interests of their family and caretaker must be considered.

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