

Ethics and DEI

Consent at the Core: Ethical Perspectives from Stakeholders of the Côte Saint-Luc Living Lab

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Purpose Better supporting aging in place includes exploring how telehealth solutions (such as telemonitoring of activities of daily living [ADLs]) and neighbourhood-based partners (cities, community organizations, healthcare providers, families, and older adults) might work together to this end [1]. Even if smart home health technologies can improve older adults' self-management and independent living, multiple barriers are impeding actual use in everyday life, including usability and social acceptance [2]. Considering that telemonitoring has not yet been integrated into a real-life complex support ecosystem of community partners, and as such, some ethical considerations from the perspective of key stakeholders remain unclear [1]. This study aimed to clarify the ethical perspectives of various stakeholders in the design of a city-wide support ecosystem that includes smart environments to better support aging in place. **Method** This study employed a user-centred design (UCD) as part of a broader action design research framework (ADR) within the City of Côte Saint-Luc Living Lab (CSL-LL). The overarching objectives of the CSL-LL project were to a) understand partners' roles in the support ecosystem, b) co-design the support ecosystem, including smart environments, c) integrate and d) evaluate the service, and e) complete a process evaluation. "Smart environments" refer to individual living spaces equipped with ambient wireless sensors to collect data about a person's sleep, meal preparation, hygiene and outings. The data collected are transmitted to a secure web-based platform, which processes them using activity recognition algorithms and presents information about ADLs in various formats, including tables and figures [3-6]. This study addressed the second objective of the CSL-LL. Co-design workshops were held from October to December 2022 and facilitated by two research team members, with all sessions audio-recorded and transcribed for analysis. Two transdisciplinary groups of 6–8 participants—including representatives from the City of Côte Saint-Luc, older adults, caregivers, and partners from community organizations, private companies, and the public social and healthcare system— took part in the workshops. The older adults had no major cognitive impairments and were actively involved as central participants in the co-design process. Qualitative data from audio recordings from the co-design workshops were analyzed using the Miles, Huberman and Saldaña [7] approach. **Results:** Participants in the co-design workshops emphasized that older adults should be first to receive telemonitoring data about their daily activities before making the decision to share with others in their support ecosystem. Participants suggested that older adults should also decide which of the daily activities they want to share. Moreover, one of the key ethical considerations shared by participants was to establish a comprehensive ongoing consent process for older adults. They also underscored the importance of prior informed consent, allowing older adults sufficient time to understand what the technology looks like and does, as well as why the deployment of telemonitoring technologies could be beneficial. This approach would ensure that older adults fully comprehend what telemonitoring entails, the types of data being collected, and how these data contribute to building a comprehensive picture of their daily routines. **Discussion** The findings from the co-design workshops highlighted the central importance of considering older adults as the primary users in the context of home care services. This means obtaining both their prior informed consent and ongoing consent, as they better understand what the technology is about and how the data can be used to ensure better home care services.

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