

POSTER SESSION 1

How can self-sovereign identity be applied among data of lost persons with dementia?

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Purpose Canadian data on persons who go missing due to dementia-related wandering is lacking. Due to statistics being a requirement to influence policy (Nagy, 2018), there is a need to determine initiatives that would assist in the national collection of this information in Canada. Self-sovereign identity (SSI), an identity management system which allows individuals to fully own and manage their digital identity, could be a potential solution to this problem by allowing persons with dementia to share their data anonymously for research purposes (Muhle, Gruner, Gayvoronskaya & Meinel, 2018). To date, SSI has yet to be integrated in a healthcare context. As a result, the present working definition is scientific in form making it difficult for members of the dementia community to understand. The purpose of this project was to develop a lay definition of SSI that is understandable to persons with dementia and their caregivers. **Method** A working definition of SSI was first developed following a hybrid model for concept development (Schwartz-Barcott & Kim, 2000). This involved identifying the current definition of SSI from the grey and scholarly literature. A series of interviews with persons with dementia and their caregivers were then conducted to elicit informant thoughts and perceptions of the current definition and use of SSI, and were asked to provide suggestions regarding a colloquial term for this concept that others living with dementia and their caregivers would be willing to use and understand (Rogers, 2000). Subsequent focus groups were conducted with the same participants to finalize the lay definition of SSI. **Results & Discussion** The literature described 13 scholarly and 24 grey publications within the literature. Definitions describing SSI were derived from 9 countries with the majority being from the Netherlands (30%) and the United States (25%). Elements of how SSI was defined in the literature ranged from individuals or organizations having sole ownership of their digital identity; individuals storing the own identity data on personal devices, the use of blockchain technology for identity data; and the elimination of personal information being owned by centralized authorities. From the interviews, persons with dementia and their caregivers demonstrated overall positive views of the potential use of SSI, however a common concern included the guardianship of the person with dementia's personal data when they are no longer able to consent for themselves. A lay definition of the SSI was developed following the completion of the interviews and focus groups. Future directions include the development of a suite of communication tools that describe the lay definition of SSI for future education sessions with the dementia community. The findings from this study will also be used to inform future case studies that explore the feasibility and usefulness of integrating SSI to assist in the collection of data of missing persons with dementia.

References

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