

Factors Impacting Long-Term Care and Retirement Home Populations' Participation in Immunity Research: A Qualitative Study Using the Framework Method

Summary

We looked at the factors that affect participation in immunity research among Ontario's long-term care homes (LTCHs) and retirement homes (RHs). As part of the Wellness Hub (WH) study, we interviewed staff, staff household members, and caregivers about the challenges they faced and what helped encourage them to take part. We also asked what they believe are the main barriers that might prevent LTCHs and RHs from joining this type of research in general, and what could help increase participation. Overall, we found that most challenges were linked to motivation, people's ability to participate, and the opportunities available to take part. Most suggested strategies for improving participation focused on addressing these barriers.

Implications

This study shows the importance of using tailored approaches that support participants' motivations, abilities, and opportunities to enhance research engagement among the LTCH and RH population, especially during health emergencies.

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What is the current situation?

- The COVID-19 pandemic had a large impact on long-term care homes (LTCH) and retirement homes (RH), as residents were at higher risk of poor outcomes due to age and pre-existing health conditions.
- Many studies were started to understand how COVID-19 spread in these settings. One of these was the [Wellness Hub \(WH\) study](#), which also provided resources to help LTCHs and RHs manage the pandemic, such as providing resources for infection prevention and control.
- The pandemic added to existing pressures faced by staff and caregivers in LTCH and RHs, making it harder for these homes to take part in urgent research that inform the spread of COVID-19 during a health emergency.
- This study explored the challenges that discourage LTCH and RH populations from participating in immunity research, as well as the supports that could encourage participation, to inform future research during health emergencies.

What did we do?

- We interviewed a total of 24 participants across Ontario, Canada, including LTCH/RH staff, staff household members, and caregivers.
- Participants shared their experiences in the WH study and suggested ways to encourage participation in future research that involve the collection of biological samples.
- Using established scientific frameworks, we analyzed the interviews, identified key themes, and mapped the findings to a model to develop recommendations for future research.

What were the results?

- Participants described personal motivation, capability (such as knowledge and skills), and opportunity (social influences, environmental context and resources) as challenges in taking part in research. Most suggestions for improving participation focused on increasing knowledge, making participation more convenient, and offering incentives to boost motivation.
- In the WH study, challenges included busy data collection environments that raised confidentiality concerns, discomfort with blood sampling, long wait times for results, and long consent forms.
- However, participants were motivated to take part in the WH study by a desire to learn about their own immunity status, contribute to scientific progress, and trust in the study team.
- Participants perceived general challenges to research participation in LTCH and RHs as limited understanding of study details, privacy concerns, and time constraints. They suggested that participation could be improved through on-site data collection, clear information in multiple formats, sufficient time for participation, and compensation.

What does this mean for future pandemic planning?

- These findings suggest that future research should be co-designed with LTCHs and RHs to be inclusive, consider participants' motivation to participate, and make sure that participants have the knowledge and opportunity to take part.