

Who benefits and who loses from the integration of algorithmic surveillance into health care? Lessons learned from a failed implementation of RTLS in dementia care

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private governance in our
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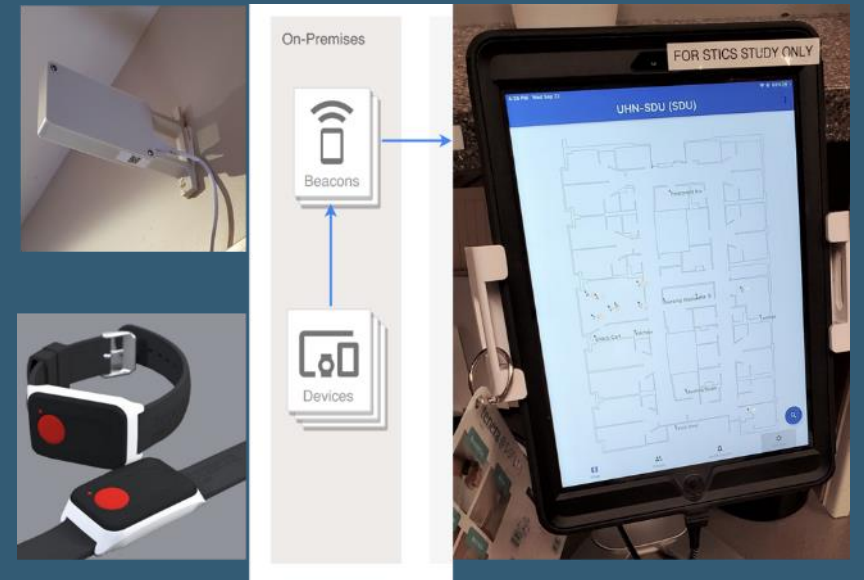
Disclosures & Acknowledgements

- Research team members not named on the title slide:
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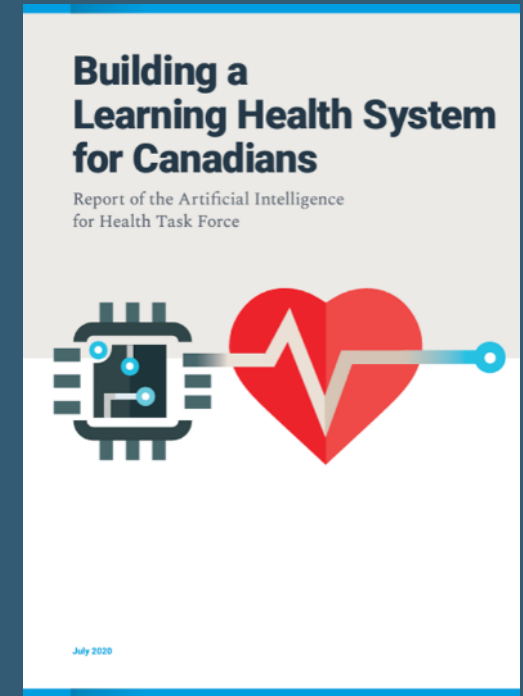
RTLS in Aged Care

- AI and data intensive technologies are increasingly being developed and implemented to expand the reach of care, increase its “efficiency” and to reduce caregiver burden
- An example are real-time location systems (RTLS) that are used to locate and track people or assets across time and space
 - Wearable (bracelet or tag)
 - Sensor in wall/ceiling
 - Software (e.g. digital map)



RTLS, AI, and Dementia Care

- Used to collect data to develop clinical algorithms for decision support (e.g. to identify and predict changes in health status or behavior).
- The clinical, policy, and research on AI/RTLS in healthcare is dominated by enthusiasm about their capacity to solve the imagined crisis of growing number of older adults and disabled people who need care.
- An “ageing and innovation” triple win rhetoric (Peine & Neven, 2017), by which investment in these technologies is unquestionably positioned as a “good thing” for all (societal, economical and individual benefits).



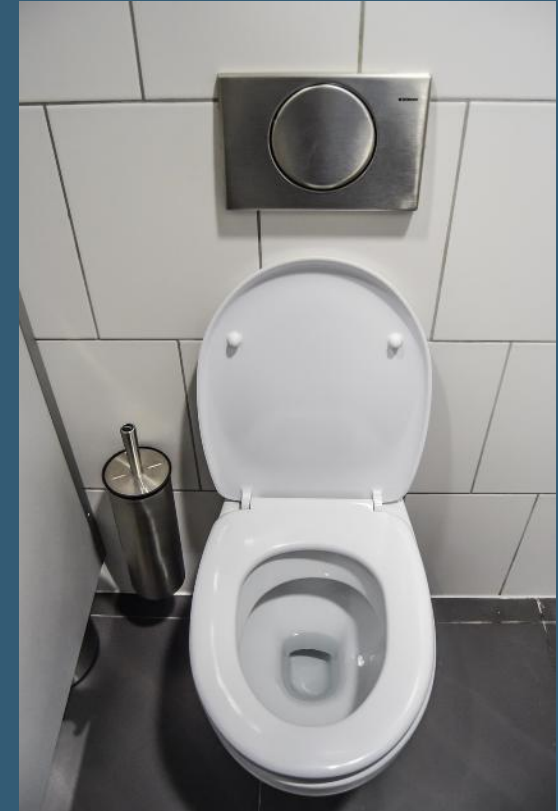
Methodology

- Mixed methods, longitudinal evaluation of an RTLS implemented in 1 for-profit LTCH in urban Ontario.
- Online questionnaire + interviews at baseline and 6 months post installation.
- Participants (n= 47) included 7 residents, 23 Care partners (CPs) and 17 staff and admin.
- Analysis was informed by sociotechnical approaches to AI and critical data studies
 - Individual and social impacts of RTLS
 - Ethical values implicated in adoption, rejection, and perceptions of impact



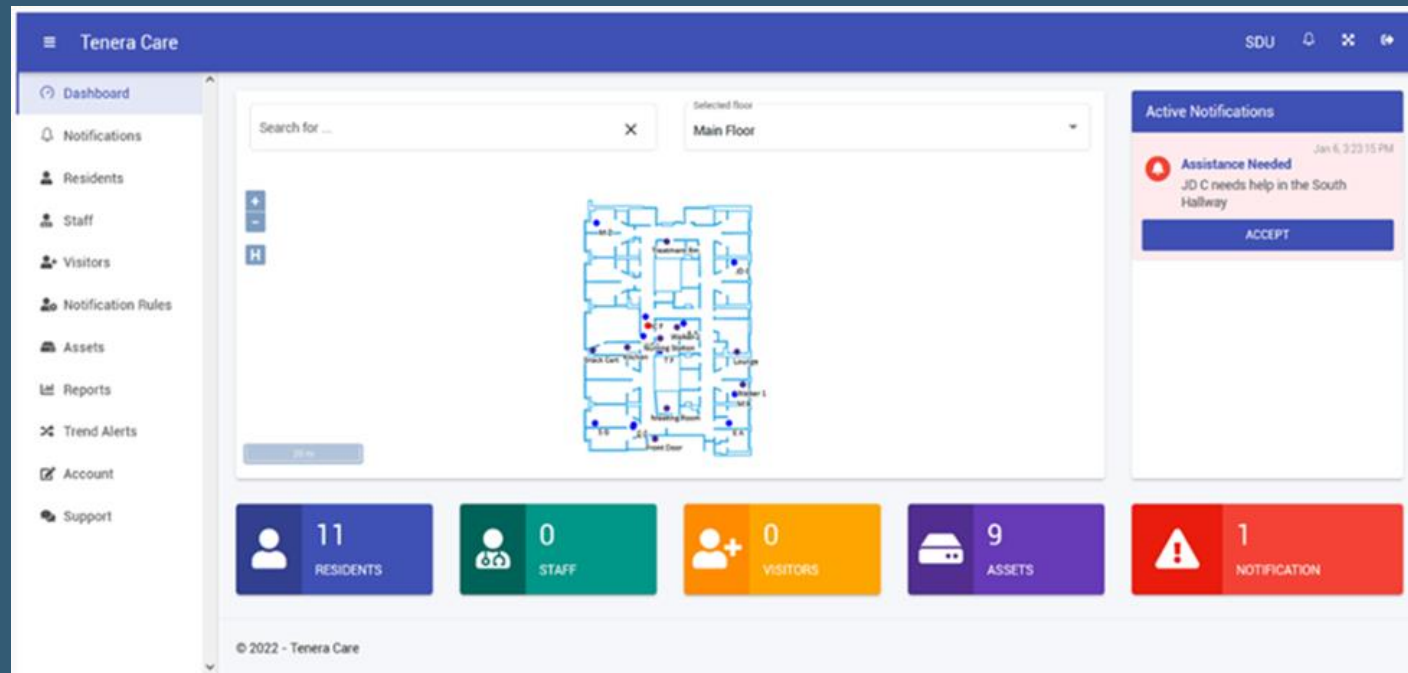
Main Benefit is Increased (Feeling of) Safety

I'm okay with [using RTLS] to find residents. Because ultimately, we're **responsible for resident safety**, so even though you don't have to actually see them in person per se, it's good to know their whereabouts, in case you do need to locate them, you can see, oh, they're in the washroom or wherever. (DM04).



RTLS also Reassures Care Partners

Gives me a peace of mind that they would know where she is at all times. (CP01)



Little Concern with Residents' Rights

Sometimes when I've approached residents [about consenting to the RTLS], they say, I don't want people to know where I am all the time. I'm not sure what their thinking is about that, but it's always for **resident safety**, and for the most part, they've agreed to that. (DM01)

I don't think that [a concern with privacy] would be a problem.... and it all depends how much information that I would feed my mom on the bracelet. If I told her that she's being watched constantly, then maybe it would bother her, but if I kept the information to a minimum and once she got used to wearing it, it'd be like a watch. (CP01)

Privacy As Incompatible with LTC life

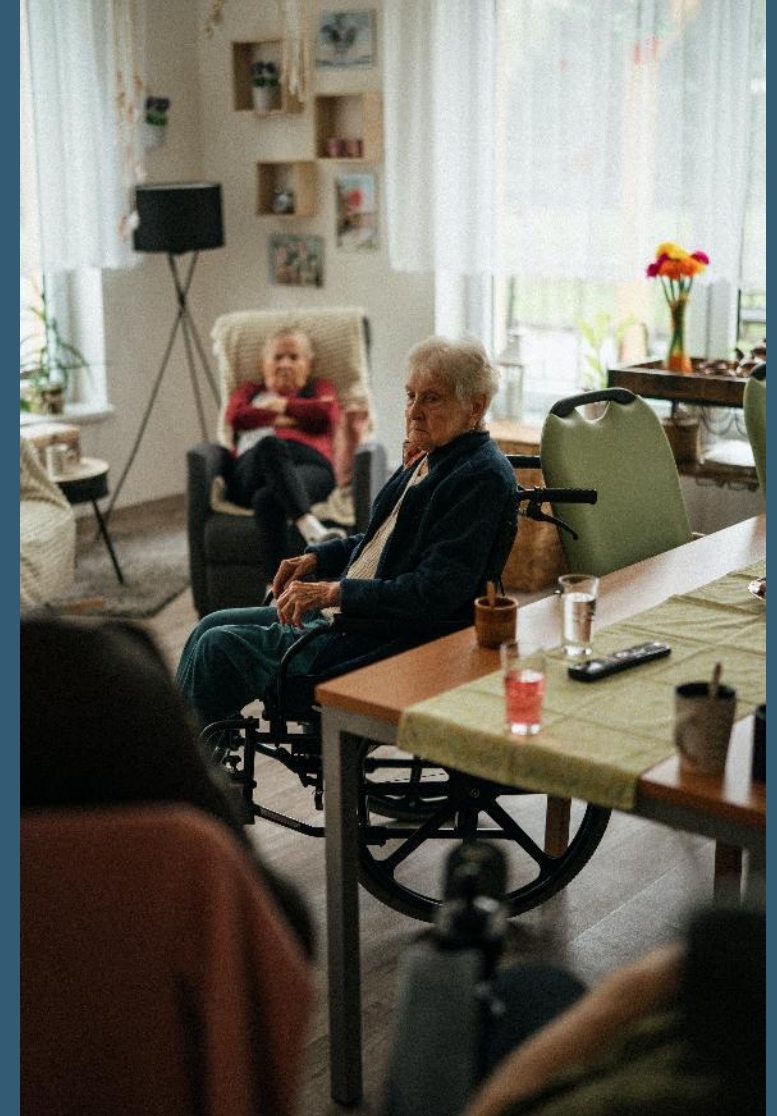
Well, they track where she is, so what? She's under their care to begin with. She's already lost the independence and privacy that she had at home... I just think tracking her movement, that is nothing to be concerned about. (CP016)



More Information = Better Care?

It's helping us to understand what goes on with the residents...how much time they're spending in their room, how many activities they're engaging... if their behaviors improve or not. (DM09)

Who they're spending their time with and [in] what areas...my mom would spend every day in her room if she could. (CP04)



Some Residents Reject RTLS

I think it's none of their business ... I don't think that [information] should be on it. If I knew that's what it [the bracelet] did, I might not wear it. (R01)

I: What don't you like about it?

R_04: You have to wear it all the time... It feels uncomfortable.



Implications and Future Directions

- AI/data intensive technologies in healthcare constrain and contain older and disabled adults and subject them to greater control by staff and families
- Reliance on informed consent reaffirms power asymmetries and provides an ethical loophole that offers little protection from algorithmic harms.
- We need to push back against a “try-first” AI innovation culture in healthcare; rigorous evaluation prior to deployment + **comprehensive regulatory protections** that center disabled and older people’s rights.

Thank you! Questions?

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