

Data-informed decision making in long-term care for older adults: what do we need?

Key highlights:

- Long-term care organizations (LTC), which provide care for some of the most vulnerable in society, lag heavily behind other care echelons in data-informed decision making.
- Living labs which include a network of diverse stakeholders, such as scientific researchers, care professionals, clients and their informal caregivers, can play a crucial role in data-informed decision making.
- A vision on data-informed decision making and a corresponding investment strategy are of utmost importance for data-informed decision making in LTC organizations.

Sil Aarts, PhD

Living Lab in Ageing and Long-Term Care

Department of Health Services Research

Data is invaluable to health care: the availability of increasing amounts of data offers new possibilities to support personalized health care (1). Long-term care organizations (LTC) collect large amounts of data at client, staff and organizational levels. Data in Electronic Health Records (EHRs) (e.g., about the functioning and mental health status of a person) or data collected by technological devices such as sensors or wearables, and also qualitative data in the form of text from written documentation or conversations are collected (2). Hence, long-term care organisations collect a wealth of data and information. However, to date, the vast amounts of data are collected and stored, but not processed or analysed. Decisions in care are not made on the basis of data alone (data-driven), but also on previous experiences and qualitative input from clients, relatives and healthcare professionals (3). Currently, this data-informed decision making is lacking, suggesting that clients do not receive the most appropriate care.

Example

Clients with dementia can display challenging behaviors (e.g., aggression), which results in diminished quality of life of these clients, and increased workload for nursing staff. Data obtained from a diverse set of sources can aid in our understanding of this behavior. Innovative analysing methods such as artificial intelligence (AI) and Natural Language Processing (i.e., an AI approach in which computers detect patterns in EHR text, for example) can be used for analysis to better understand the underpinnings of such behavior (2). Hence, data and innovative methods of analysis can provide time-scaled

patterns (in months, days, hours or even minutes), by which behaviors or symptoms can be detected to facilitate timely intervention.

LTC organizations see added value in data-informed care, but are overloaded with various types of data from different sources, such as EHRs and technological devices. Hence, LTC organizations are looking for ways to use this data to provide appropriate care and thus create value. This article discusses how data could become a more prominent part of long-term care for older adults, using an approach developed in our Living Lab in Ageing and Long-Term Care (4). The Living Lab is a formal multidisciplinary network consisting of Maastricht University, nine large long-term care organizations, Gilde and VISTA College (vocational training institutes) and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands (4).

(Creating a) Learning network within LTC organizations

Large bulks of data alone are insufficient to make decisions and predictions: the existence of data and innovative analyzing methods do not automatically lead to novel insights (3). A learning community is needed to discuss data-related issues. In 2020, we formulated the Core Group Data Science within the Living Lab: an existing network where knowledge is gained and shared about data, data science and data-informed care. The goal of the core group is to keep up with developments in other healthcare domains, such as hospital care, to expedite the use of data in LTC. This is done by sharing experiences and formulating practical daily care problems into research questions. All organizations contribute to this group (e.g., the content of meetings or grant applications), so that the tasks and output of the group are widely supported.

Vision on data and related data themes

Within long-term care organizations there are often dozens of different technological devices and systems that all collect data. Due to the diversity of technology and data, it is important to formulate a vision and central focus framework. By formulating the framework, we can ensure that data initiatives do not fragment, and that the use of data is of value for daily care. The purpose of a vision is to ensure that the use of data within an organization is aligned with the mission of an organisation: it should not describe separate entities. It should provide answers to questions such as: “Why do we find data important?”, “What data do we collect?”, and “What added value do we expect from data?”. In addition to documenting a vision, objectives that logically follow from this vision must be described (i.e., the strategy that an organization pursues with regard to data).

Invest in data-informed care

When formulating a vision on data, organizations should ask themselves whether and how they want to contribute to data-informed care: is this something that they want to invest in?

The answer to this question may not always be a firm yes. If organizations want data to be a prominent part of daily work processes, a corresponding commitment and investment (including investment in time) are needed. For example, a 5-year strategy plan can aid organisations in stating their primary objectives, but also the way in which/by whom these objectives will be achieved along with the (financial) resources required.

Multidisciplinary teams

To achieve impact, a transition period is needed in which stakeholders from all organizational levels are empowered to learn with and from data (5); this may best be achieved by forming a multidisciplinary 'data team' within a LTC organization. A diverse group of people is needed for these teams (e.g., data/ICT specialist, innovation manager, care staff, scientist and client (representative)). Clients are especially important to ensure that the topics and results are understandable and relevant. The question arises as to which competencies are required for those involved: a multidisciplinary team must consider diversity in background, education (level) and experience of the members. Furthermore, "interaction" between the data team and the board/management of an organisation is warranted, for example, through periodic feedback (both on content and process).

Embedding in daily care processes

To support data-informed decision-making in mental health care for older adults, data should be integrated into daily care processes. A theme such as this should be included in an organization's vision document: how does an organization want to use data to improve care for clients? How will care staff get on board with this new way of thinking? Suppose we want to translate the huge amounts of data collected into meaningful information. In that case, the findings must be checked and interpreted (initially by the data team) within the context of daily care processes.

Conclusion

Using big data to generate new insights is a fairly new concept in LTC, and organizations may find it challenging to use data to optimize care processes. To set up a sustainable ecosystem for data-informed care, the topics presented in this guide can be discussed by and between stakeholders. Time, commitment and open communication are needed to ensure that data can lead to new developments aimed at improving daily care. Initiatives that support a close collaboration between science and daily care practices can function as the perfect vehicle for achieving this goal.

Dr. Sil Aarts is an assistant professor of the Living Lab in Ageing and Long-Term Care. The living lab is a formal multidisciplinary network consisting of Maastricht University, nine large long-term care organisations, Gilde Intermediate Vocational Training Institute,

VISTA College (secondary vocational education) and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. Her expertise lies in (ethical use of) data (science) and technology in long-term care for older adults. She founded the Core Group Data Science and is part of several committees regarding data and AI in healthcare, either within academia or outside.



For further reading:

1. Borges do Nascimento IJ, Marcolino MS, Abdulazeem HM, Weerasekara I, Azzopardi-Muscat N, Goncalves MA, et al. Impact of Big Data Analytics on People's Health: Overview of Systematic Reviews and Recommendations for Future Studies. *J Med Internet Res.* 2021;23(4):e27275.
2. Hacking C, Verbeek H, Hamers JPH, Sion K, Aarts S. Text mining in long-term care: Exploring the usefulness of artificial intelligence in a nursing home setting. *PLoS One.* 2022;17(8):e0268281.
3. Fijten R, Wee L, Dekker A, Roumen C. Data-driven shared decision-making: a paradigm shift. *Journal of Radiation Oncology Informatics.* 2021;11(2).
4. Verbeek H, Zwakhalen SMG, Schols J, Kempen G, Hamers JPH. The Living Lab In Ageing and Long-Term Care: A Sustainable Model for Translational Research Improving Quality of Life, Quality of Care and Quality of Work. *J Nutr Health Aging.* 2020;24(1):43-7.
5. Aarts S. Ethical usage of data in long-term care: how do we proceed? *Moral Design and Technology.* Wageningen: Wageningen Academic; 2022. p. 267-82.