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Decoding death and dying in people with dementia by digital thanotyping: a longitudinal observational study protocol

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ABSTRACT

Introduction As individuals approach the end of life, physical, mental and social functions decline. However, reliable methods to detect and characterise symptoms of the terminal phase in people with dementia are lacking. Advances in non-invasive sensor technologies and oral sampling methods offer new opportunities to improve assessment of this phase.

Methods and analysis This is a 5-year longitudinal observational study using a mixed-methods and multidisciplinary approach. The project, *Decoding Death and Dying in people with Dementia by Digital thanotyping (5-D)*—with 'thanotyping' derived from the Greek *thánatos* (death) and *phaino* (to reveal)—aims to develop methods and tools to accurately characterise the dying process in people with dementia. The study integrates clinical assessments with advanced sensing technologies to monitor pain and distressing symptoms. Oral examinations will be conducted with biomaterials from the oral cavity. Prediction model development will draw on dynamic systems theory, signal processing, artificial intelligence with a human-in-the-loop approach and statistical modelling to identify patterns and trajectories associated with end-of-life processes. A sample of approximately 270–300 participants is required to obtain at least 95 end-of-life trajectories. While focusing on established symptoms of the dying phase, some phenomena may be difficult to capture due to the complex and multifactorial nature of the dying process.

The use of digital modelling to predict end-of-life trajectories raises important ethical considerations. These include challenges in obtaining valid informed consent from individuals with impaired decision-making capacity, potential risks of psychological harm and compromised dignity, and the possibility that predictive output may inadvertently influence clinical decision-making in a self-fulfilling manner. Further concerns include uncertainty and bias in model predictions, as well as issues of data privacy, ownership and governance. The study emphasises transparency in model development, minimisation of participant burden and appropriate clinical oversight.

Ethics and dissemination The 5-D study has been approved by the National Committee for Medical and Health Research Ethics (NEM 2023/166) and the Regional Committee for Medical and Health Research Ethics (REC Vest; 657596), including the approval for storage of saliva and dental plaque samples in a biobank at the University of Bergen, Norway. Findings will be disseminated through peer-reviewed publications, conference presentations and engagement with stakeholders, including clinicians, families and policymakers.

Trial registration number NCT06437132.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study uses a systems-based analytical framework to examine temporal relationships among multiple physiological and clinical indicators during the dying process.
⇒ Continuous monitoring with wearable and contact-free sensors provides objective, high-resolution measurements that are less dependent on observer ratings.
⇒ Non-invasive wrist-worn and wall-mounted devices enable longitudinal data collection while minimising participant burden in a frail population.
⇒ Continuous monitoring in end-of-life settings may result in missing or incomplete data because of clinical, technical and logistical challenges.
⇒ Recruitment may be constrained by the need for proxy consent when participants lack decision-making capacity.

INTRODUCTION

Across high-income countries, the circumstances of dying have changed profoundly. People are living longer with chronic and neurodegenerative diseases, and death increasingly occurs in institutional settings rather than at home.[1] Older adults, and particularly those with dementia, often experience prolonged periods of decline characterised by multimorbidity, frailty, pain and other distressing symptoms.[1–3] Yet, despite decades of progress in geriatric and palliative care, clinicians still lack reliable methods to recognise the onset of dying in people with

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dementia.[4] Traditional clinical indicators remain insufficiently sensitive, and decision-making relies on subjective judgement, contributing to both overtreatment and undertreatment in the final phase of life.[5] Palliative and hospice care in advanced dementia increasingly emphasise comfort-focused approaches, caregiver support and alignment of care with individual needs and preferences at the end of life.[6–8] Accurate identification of the dying phase is therefore essential to enable timely and appropriate care delivery.

Dementia is a life-limiting condition characterised by increasing functional dependency. However, the transition from advanced disease to the active dying phase is difficult to determine.[1 4 5] Cognitive impairment limits self-report, while behavioural and psychological symptoms, including pain, dyspnoea, agitation and oral health problems, may go unrecognised. These challenges compromise the quality of care, hinder clinicians' communication with families and delay the timely initiation of symptom-directed care. The prospective Resource Use and Disease Course in Dementia (REDIC) trial reported that 53% of people with dementia experienced dyspnoea, 46% pain and 31% anxiety on the day of death.[5] Among study participants, 39% died unexpectedly, and 19% experienced death rattle on the day of death.[5] Oral health problems are also common but often insufficiently addressed.[9] Mortality models exist but rely on registry data and lack the granularity for short-term deterioration.[10–12] Emerging technologies offer new opportunities.[13] Wearable sensors and digital health tools enable continuous, non-invasive monitoring.[14] Combined with analytical methods, these tools may improve characterisation of end-of-life trajectories.

The Decoding Death and Dying in people with Dementia by Digital thanotyping (5-D) project aims to address these gaps by developing a comprehensive methodology to identify the onset of dying with greater accuracy and clinical relevance. The multifactorial complexity of the dying process may result in considerable heterogeneity in symptom type, severity and combinations. Using a multimodal framework, 5-D seeks to characterise the temporal dynamics and interdependencies of end-of-life symptoms. This approach introduces the concept of digital thanotyping, defined as a data- and knowledge-driven representation of the physiological and behavioural changes that signal the point of no return, beyond which recovery is unlikely, and somatic and cognitive functions decline irreversibly. Through interdisciplinary collaboration and human-in-the-loop validation, the project aims to develop actionable tools that support clinicians, inform families and ultimately contribute to more dignified and person-centred end-of-life care.

This study is based on the premise that monitoring temporal symptom patterns and their interdependencies may enable the identification of a point of no return.

METHODS AND ANALYSIS

5-D is a 5-year multicentre prospective cohort study (2024–2028) designed to develop and validate methods that integrate clinical data with systems modelling. We will recruit people with dementia from nursing homes in Bergen and surrounding areas (≈2500 residents), with potential expansion to additional municipalities. Participating nursing homes will support recruitment, communication with relatives and data collection through clinical assessment, questionnaires and digital monitoring. Because most people with dementia in Norway die in nursing homes,[15] this setting enables systematic, longitudinal follow-up. Residents commonly have multimorbidity, with dementia severity ranging from severe (52%) to mild (16%).[16] Inclusion criterion includes residents aged >64 years with dementia or cognitive impairment who have lived in the facility for at least 6 weeks. Inclusion requires informed or presumed consent. Exclusion criteria include participation in other studies and intolerance to sensing technology.

The novel 5-D concept

Digital thanotyping is defined as the moment-to-moment quantification of physiological states to model end-of-life processes. Within the framework, dying is conceptualised as a probabilistic state of irreversible decline emerging from the combined temporal evolution of multiple physiological and clinical signals. Models are developed through interdisciplinary collaboration between engineers and clinical experts, with user involvement to ensure relevance and acceptability. Model outputs are iteratively refined with clinician validation (figure 1). Sensor-based data will be collected at baseline and for 1 week every 6 months, transitioning to continuous monitoring when end of life is clinically suspected, enabling near real-time tracking of individual trajectories. Multimodal sensor and clinical data will be integrated to estimate key predictors, including agitation, sleep, pain, salivation, swallowing, dyspnoea and death rattle. At each time point, these collectively describe the individual's physiological state, within which this state of irreversible decline may be identified.

Sample size calculation

A sample of approximately 270–300 participants is required to obtain at least 95 end-of-life trajectories, the primary analytical units. This estimate is informed by prediction model development principles[17] and incorporates seven key predictor domains identified in prior research: heart rate variability, respiratory symptoms (including dyspnoea and death rattle), movements, cognition, sleep, somatic function and oral health.[5] This yields an events per parameter of 13.6, consistent with recommendations for stable model estimation. Event prevalence (0.33) was derived from ongoing unpublished cohort data, in which 50 deaths were observed over 1.5 years, with increasing rates over time. These data have not been deposited in a public repository and were solely to

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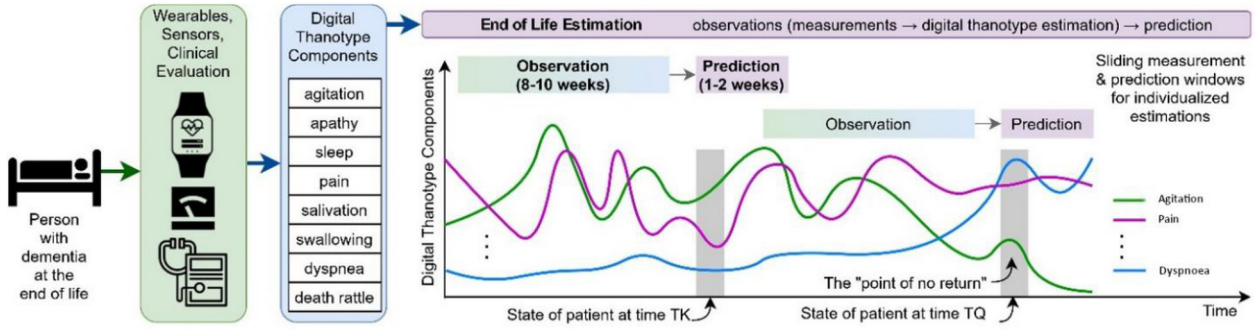

Figure 1 Model of the 5-D digital thanotyping framework. Wearable sensors (Garmin Venu 3S) and environmental sensor (Somnofy radar; Vital Things, Trondheim, Norway) detect physiological symptoms to be assessed 1 week at baseline and every sixth month, with continuous measurements during the assumed end of life. TK, current known time point. TQ, a future query/prediction time point. 5-D, Decoding Death and Dying in people with Dementia by Digital thanotyping.

inform the expected number of events during the study period. The data indicate that the required number of events will be reached within the study period, supporting model development and internal validation. Given the longitudinal and dynamic modelling framework and the absence of a single binary endpoint, this sample size is considered appropriate despite the limited applicability of traditional power-based approaches.

Clinical assessment instruments

Clinical assessments will use validated instruments covering cognitive, functional, behavioural and symptom domains relevant to people with dementia at the end of life. Cognitive impairment will be assessed with the Clinical Dementia Rating (CDR; range 0–3).[18] Frailty will be measured using the Clinical Frailty Scale (range 1–9, with scores ≥5 indicating frailty),[19] and comorbidity will be assessed using the General Medical Health Rating (GMHR).[20] Behavioural symptoms will be evaluated using the Neuropsychiatric Inventory–Nursing Home version, with scores for each domain calculated as frequency (scored 1–4) × severity (scored 1–3) across 12 domains.[21] Pain will be assessed using the Mobilization, Observation, Behaviour, Intensity, Dementia–2 Pain Scale (0–10), which captures both musculoskeletal and non-musculoskeletal pain.[22] Symptom burden will be measured using the Edmonton Symptom Assessment System–Revised (0–10) across domains.[23] Functional status will be evaluated using the Bristol Activities of Daily Living Scale (0–60),[24] and the Resident Assessment Instrument–Palliative Care will be used to assess the oral health.[25] Participants with a CDR <1 or GMHR score of 9 will be excluded.[5] Routine clinical data (eg, heart rate, blood pressure, weight, comorbidities and medication use according to Anatomical Therapeutic Chemical codes) will also be collected. Assessments will be conducted every 6 months to capture clinically meaningful change while minimising burden. All instruments are validated in dementia populations and are available in Norwegian.

Oral assessment

Oral health is a key component of the 5-D study, as oral problems can lead to pain, eating difficulties and diminished quality of life among palliative and terminally ill patients.[26] An experienced dentist will perform examinations at baseline and every 6 months and during relevant clinical events, where feasible. The interval reflects the slow progression of dental caries.[27] Lesions will be staged according to WHO criteria as non-cavitated or cavitated.[28] Assessments will include the oral mucosa, gingival tissues and salivary flow and will document hard and soft tissue conditions, including caries, periodontitis and oral dryness. In addition, oral biological samples (saliva and dental plaque) will be collected to investigate factors associated with oral diseases and to characterise changes over the disease trajectory.

Sensing technology

The 5-D study will use two multimodal sensing systems to capture physiological and environmental data. The Garmin Venu 3S is a wrist-worn wearable that uses photoplethysmography (PPG), whereby green light is emitted onto the skin at the wrist to detect changes in blood volume associated with each pulse wave. PPG detects heart rate, beat-to-beat interval and respiration. The Garmin Venu 3S also contains accelerometer and gyroscope sensors to detect linear acceleration and angular velocity across three axes.[29] The Somnofy system (Vital Things) is a wall-mounted, contactless radar device that measures sleep parameters (sleep stages, sleep efficiency, time in bed, latency to sleep, sleep score, etc), in addition to environmental information (ambient light, sound, humidity and air quality). Sleep data will be collected using signal processing algorithms by Vital Things to detect movement and respiration without physical contact.[30 31] Based on recent experience, these devices are expected to be acceptable to nursing home residents.[32] If any discomfort or distress is observed, the device will be removed.

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Data collection timeline

People with dementia living in a Norwegian nursing home have a median stay of less than 1.5 years,[33] underscoring the importance of longitudinal follow-up to capture the transition to end of life. Participants will be enrolled during a relatively stable phase of advanced cognitive impairment or dementia and must not be considered actively dying at the time of inclusion. Repeated assessments will be conducted longitudinally, allowing comparison of baseline physiological and behavioural measures with changes occurring during the final stages of life.

Study participants, who have resided in their respective nursing home facilities for at least 6 weeks, will undergo periodic monitoring until clinical deterioration is observed, after which data collection will transition to continuous monitoring until death. The data collection strategy comprises three components: baseline assessments, scheduled semiannual telemonitoring and continuous sensor-based monitoring during the terminal phase (figure 2). This design provides sufficient temporal resolution to model gradual physiological decline while minimising burden for residents and staff.

Digital thanotyping modelling and algorithm design

The digital thanotype framework reflects the multidimensional nature of the dying process and integrates four core elements: data processing, estimation of component states, modelling of interdependencies and prediction of irreversible decline. Model development will commence after 50 end-of-life trajectories to estimate preliminary components (figure 3). At this stage, algorithms will be developed to estimate individual components, model their temporal interactions and generate initial predictions. Model development will proceed iteratively alongside ongoing data collection, with refinement as additional data accrue (targeted ≈95 deaths). The final output will include a digital interface presenting model estimates through interpretable visualisations, followed by clinician-guided validation to optimise model structure, parameters and usability.

Data processing

All data will be pseudonymised using study-specific identification numbers, with linkage keys encrypted and stored separately. Data will be processed through a three-step pipeline:[34] (1) cleaning, including removal of artefacts and handling of missing values; (2) filtering using device-appropriate noise reduction methods[35]; and (3) normalisation to a common scale (typically 0–100) to ensure comparability across instruments.[36] To characterise temporal patterns, signal-processing methods (eg, fast Fourier transform) will be applied to time-series data enabling analysis across multiple time scales, including day–activity cycles.[37]

Systems theory and intelligent modelling

Systems theory methods will be used to characterise how physiological and behavioural variables evolve and interact over time. Dynamical models will represent these trajectories using parameters estimated from individual-level data enabling analysis of temporal change.[38] Given the non-linear human physiology, data-driven and knowledge-informed approaches will be combined to enhance interpretability and robustness.[39 40] To address the limitations of fully automated artificial intelligence (AI), the framework applies transparent, rule-based models (eg, fuzzy logic, figure 4) to support clinically interpretable decision-making.[41] Modelling components will adhere to core principles of trustworthy AI, including transparency, data protection and preservation of human autonomy.[42] Model performance will be evaluated using SE and classification metrics (eg, accuracy, sensitivity, precision) alongside agreement between observed and model-derived outputs.[43]

Statistical methods

The analytical framework combines approaches to characterise digital and clinical data across multiple scales. An exploratory profile-based analysis will examine temporally structured digital data in relation to clinically derived profiles, enabling interpretation of observed patterns in relation to clinical states. Cluster analysis will be applied to identify distinct symptom groupings based on patterns of symptom co-occurrence. Longitudinal data will be analysed using mixed-effects models and generalised estimating equations to account for within-individual correlation, irregular observation intervals and clustering at nursing home level. Random effects will capture individual and site-level variation, with time-varying covariates reflecting changes over time. Where appropriate, joint models will link longitudinal and time-to-event outcomes, and latent class or trajectory analyses will



Figure 2 Data collection timeline in the 5-D study: figure baseline assessments, scheduled telemonitoring and continuous monitoring initiated with clinical deterioration indicating entry into the end-of-life phase. Periodic monitoring captures the broader disease trajectory, while continuous monitoring provides high-resolution data during the terminal phase. 5-D, Decoding Death and Dying in people with Dementia by Digital thanotyping.

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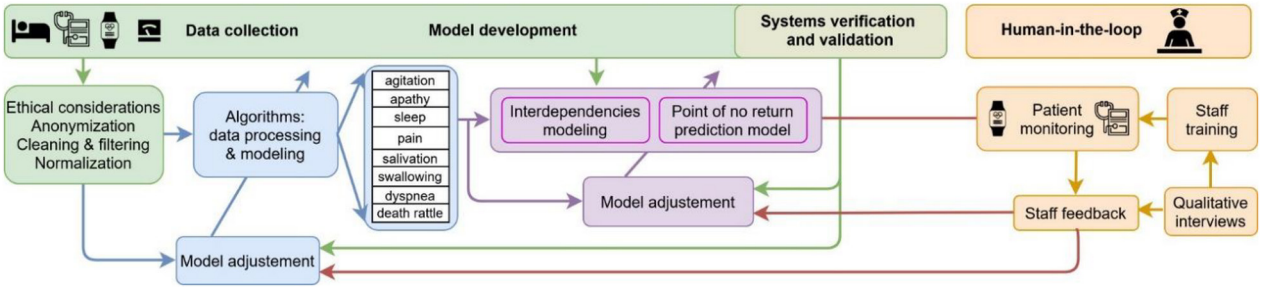

Figure 3 Methodology overview. Data collection, model development, system verification and human-in-the-loop validation.

identify subgroups with distinct progression patterns. The primary outcome is the assessment of symptom trajectories towards the end of life, modelled according to prespecified predictors (agitation, sleep, pain, salivation, swallowing, dyspnoea and death rattle). Analyses will adjust for potential confounders and effect modifiers, including age, gender, medication use, comorbidities and environmental factors. The extent, timing and mechanisms of missing data will be explored descriptively. Primary analyses will use linear mixed-effects models, which permit valid inference under a missing-at-random assumption and make use of all available repeated measures without requiring imputation. Analyses will follow a predefined statistical plan using validated software.

ETHICS AND DISSEMINATION

Ethics approval and consent to participate

Participants are people with dementia, a vulnerable population in whom decision-making capacity may be impaired. In accordance with Norwegian legislation, informed consent will be obtained directly where possible, or presumed consent provided by a legal representative when capacity is lacking, the participant does not object and the study poses minimal risk. Consent will cover all study procedures. Participants and representatives will receive verbal and written information about the study and may request additional information at any time.

Clinically relevant incidental findings (eg, suicide risk, untreated oral disease or medication-related issues) will be communicated to the responsible nursing home physician. The nursing home staff will also be able to continuously monitor the participant's sleep results through the Vital Things online dashboard. Participation is voluntary, and individuals may withdraw at any time without consequences for their care. Data may be withdrawn until analyses and publication. Any signs of distress or discomfort will lead to immediate cessation of the relevant procedures.

Data will be securely stored at the University of Bergen in accordance with data protection regulations. Ethical approval has been obtained from national (NEM 2023/166) and regional (REC Vest, 657596) committees, including biobank storage of saliva and plaque samples. The study is registered at ClinicalTrials.gov (NCT06437132). The study follows the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.

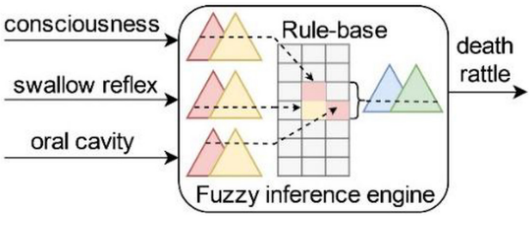

Figure 4 Abstract example of a fuzzy structure to estimate the appearance of death rattle.

Technological consideration

This approach assumes that no single clinical or digital marker is sufficient to indicate imminent decline; rather, combinations of signals over time provide the most informative patterns. Continuous or scheduled monitoring offers temporal resolution than periodic clinical assessments, and model outputs are iteratively refined with clinical validation. Signal patterns may not consistently precede death across individuals or may only become meaningful when observed repeatedly within broader trajectories. Consequently, digital thanotyping is intended for risk stratification rather than precise prediction, supporting anticipatory and person-centred end-of-life care.

Societal considerations

End-of-life research in people with dementia requires a high degree of ethical oversight. The 5-D approach incorporates process-based consent with ongoing monitoring of assent, minimises burden through unobtrusive sensing and predefined stopping rules and positions algorithmic outputs as decision support to reduce automation bias. Data protection is insured through the General Data Protection Regulation-compliant stewardship and proportional study procedures. Digital signals (eg, respiratory patterns and restlessness) are context dependent and must be interpreted alongside clinical judgement to avoid misinterpretation. Previous initiatives such as the Liverpool Care Pathway have demonstrated both

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benefits and risks of identifying dying, including potential unintended harms, underscoring the need for transparent and robust approaches.[44] These challenges are particularly pronounced in people with dementia, whose impaired ability to self-report increases the risk of both overtreatment and undertreatment.[45] The 5-D framework addresses this through its emphasis on interpretability, clinician validation and multimodal data, supporting more informed end-of-life care.

Findings will be disseminated through peer-reviewed publications and presentations at national and international conferences. Results will be communicated to clinical, academic and stakeholder audiences to support implementation and impact.

Patient and public involvement

Relatives of people with dementia and experience of end-of-life care contributed to the development of this study through a dedicated user panel, providing feedback on study procedures, participant acceptability and implementation. Collaborating nursing homes are engaged through stakeholder workshops held two times a year to provide feedback on study conduct and feasibility. Project updates are communicated through biannual newsletters. The user panel and collaborating nursing homes will continue to contribute to the conduct and dissemination of the study.

Strengths and limitations

This study has several strengths and limitations. A key strength is its multimodal, longitudinal and systems-based design, integrating clinical, behavioural and physiological data within routine nursing home care to capture the interdependent temporal dynamics of end-of-life trajectories, with identification of a potential irreversible transition point. The use of continuous, unobtrusive sensing technologies enhances ecological validity. While providing objective, high-resolution and standardised measurements, the sensors reduce reliance on subjective assessments and minimise participant burden with protocols to ensure immediate device removal in case of discomfort. Furthermore, the emphasis on interpretability and clinician validation supports translational relevance. However, the study is resource intensive, requiring sustained monitoring and robust workflows. The study also relies on proxy-rated measures that may affect data accuracy by introducing reporting bias. Data quality from the sensors may be affected by noise, artefacts, intermittent loss and missingness, reflecting both technical challenges. In addition, both interpersonal variability and individual dying trajectories can produce statistical challenges. A substantial proportion of deaths in nursing homes occur unexpectedly (≈39%),[5] which may limit complete trajectory capture and follow-up. Recruitment may also be constrained by reliance on proxy consent when participants lack decision-making capacity. Variation in the interval from baseline to death will result in heterogeneous trajectory lengths and temporal resolution. Sample size estimation is guided by modelling requirements rather than conventional power calculations. Interpretation of physiological and behavioural measures may be complicated by symptom-directed treatments, such as opioids and sedatives, and by the inherent challenges of assessing discomfort and suffering in individuals with advanced dementia. Observed physiological and behavioural trajectories may be influenced by comorbid conditions and concurrent medical events that are difficult to distinguish from progression towards death in routine clinical practice. Sensing technologies not fully validated in advanced dementia may influence data quality and generalisability. Furthermore, conventional statistical models may inadequately capture nonlinear symptom trajectories, while knowledge-informed approaches rely on expert assumptions that may limit reproducibility and external validation. Finally, modelling interdependencies between physiological and behavioural signals may yield unstable estimates. These challenges will be mitigated through minimally intrusive sensing, predefined strategies for handling missing data and staged model development with iterative validation.

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Competing interests None declared.

Patient and public involvement Patients, relatives, and nursing home staff are involved throughout the study. During recruitment, patients and their relatives are provided with information about the study. Nursing home staff are actively involved during the human-in-the-loop component of the project, contributing to the implementation and refinement of study procedures. Participating nursing homes are engaged through regular feedback and dissemination activities, including biannual 5-D seminars where study progress and preliminary findings are presented, as well as newsletters distributed to each participating ward. In addition,

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study updates are communicated to the wider public through online newsletters and dissemination in local and national media. A user panel collaborates closely with the research team and contributes to the development of study procedures, as well as the design of participant and family information materials. This ongoing involvement ensures that the study is aligned with user needs and clinical practice.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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