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Proposing a person-centred health data ecosystem framework to optimise digital innovation and artificial intelligence for dementia prevention and cognitive longevity

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ABSTRACT

Global healthcare systems need to evolve to ensure optimal, safe, and ethical utilisation of health data and the latest digital technologies, such as Artificial Intelligence (AI), Privacy Enhancing Technologies (PETs), and Quantum Technologies, to meet the challenges of a global ageing population. Simultaneously, the increasing capabilities of remote measurement technologies, including the advent of quantum sensing, and the proliferation of 5G networks demonstrate that digital technologies are now more accessible to a much larger population, offering an opportunity for decentralised and democratised health data use that supports individual agency. Given the significant international human and economic cost of cognitive decline and dementia, we propose that a person-centred decentralised health data ecosystem, underpinned by these emerging technologies and opportunities, would reduce burden on cognitive healthcare systems by intervening earlier, accelerate clinical research innovation in dementia, and extend cognitive healthspan. It is of particular importance to reach out to underserved populations and ensure their data is not excluded. Crucially, we argue for the importance of including the individual, as well as other key stakeholders, in the development, continuing operation, and as a shared beneficiary of any potential accrued value emerging from this cognitive longevity ecosystem. We frame a structured, evidence-based framework and specify its core components, suggesting a roadmap for systematic implementation and evaluation as a pivotal move toward enhanced cognitive health outcomes and accelerated equitable innovation in dementia prevention.

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Introduction

On the 15th of November 2022, the United Nations projected that the world's population surpassed 8 billion people [1]. It is estimated that 1 billion of this total are aged 60 years and over, and are increasingly becoming a larger sub-group as the pace of population ageing accelerates [2]. An older population comes with associated age-related multimorbidity [3], including diseases resulting in dementia [4], with the proportion of people aged 65+ in the UK having four or more diseases predicted to double by 2035 [5].

A significant portion of this burden is a result of the impact of cognitive impairment and dementia. According to the Global Burden of Disease (GBD) study, the prevalence of dementia is estimated to triple from 57.4 million in 2019 to 153.8 million worldwide by 2050, with the greatest increases predicted in lower- and middle-income countries (LMICs) [6]. However, the recent Alzheimer's Disease International World Alzheimer report (2022) suggests that this projection only represents 25% of true global dementia cases, as the remaining 75% of people living with dementia are yet to be diagnosed (with up to 90% undiagnosed in LMICs) [7]. The World Health Organisation estimates the global cost of known dementia cases in 2019 was US$1.3 trillion, rising to US$2.3 trillion by 2030 [8], with the true cost substantially higher if accounting for estimated undiagnosed individuals. Moreover, there is

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an extremely pressing need to effectively identify and diagnose dementia cases earlier to a) facilitate healthy cognitive ageing practices by modifying known risk factors which may prevent or delay up to 45% of dementia cases [9], and b) accelerate innovation in clinical dementia research by engaging people with research earlier and with shared equity, particularly for historically underrepresented groups and individuals from LMICs.

Current state of dementia treatment and research

Since the dementias are characterised by progressive deterioration over time, independent functional capacity must be protected by intervening as early as possible. This is reflected by the recent clinical trial successes of monoclonal antibodies in early symptomatic AD, Aducanumab [10], Lecanemab [11,12], and Donanemab [13]. Lecanemab is the first disease-modifying treatment (DMT) to demonstrate reduction in both underlying Alzheimer's Disease (AD) neuropathology and clinical cognitive impairment, but crucially only in patients with early AD [14]. It obtained regulatory approval from the FDA (US) in 2023, and MHRA (UK) and EMA (EU) in 2024. Aducanumab, controversially achieved a reduction in AD neuropathology, but only demonstrated potential improved cognition, leading to accelerated FDA approval in 2021 [15]. Donanemab received traditional FDA and MHRA approval in 2024 after it was found to significantly slow cognitive and functional decline in a phase III clinical trial in early AD [13], however it is still being considered by the EMA with an outcome anticipated in early 2025. All other therapeutic agents for AD only temporarily improve symptoms without targeting the underlying pathology [16]. These therapeutic successes really highlight the pressing need for early identification of AD signs and symptoms so that timely medical intervention can be enacted.

Unfortunately, despite the aforementioned successes, dementia clinical trials historically have much poorer translational success, higher screening failure rates, higher costs, and longer durations than other disease areas. A report by USC Schaefer estimated that 99% of potentially eligible participants for dementia clinical trials were not being referred, and that DMT trials take more than twice as long as trials in oncology, neurology, psychiatry, and cardiovascular disease [17]. Similarly, a recent report by Alzheimer's Research UK found that only 2% of dementia patients sign up to the largest UK 'research-ready' registry, 'Join Dementia Research' [18]. Common reasons reported for these barriers to research are: limited awareness of trials for patients and clinicians; lack of standardised research-relevant biomarkers; stigma towards or lack of dementia diagnosis; limited access to diagnostics; overburdened healthcare systems; poor outreach from trial operators (particularly towards typically underrepresented groups); and lack of effective engagement, activation and retention procedures and technological tools. To address these, a recent meeting of experts identified 27 recommendations, including incorporating digital innovation and virtual decentralised trials, engaging the public at the source, integrating research and clinical ecosystems, and novel pay/reimbursement structures [19].

Altogether, the human and economic cost of dementia, partnered with the historical poor translational success of new therapies and lack of diverse sampling, highlights the pressing rationale to disrupt the current dementia clinical trials ecosystem. Individuals need to be recruited into clinical studies more efficiently by working more closely with healthcare systems and underrepresented communities, to develop innovative treatments and to translate them through the clinical trials regulatory pipeline.

In this paper, we aim to address these challenges by proposing a novel person-centred decentralised health data ecosystem framework that prioritises individual agency and equitable value distribution while accelerating innovation in dementia prevention and cognitive longevity. Our specific objectives are to:

A. Evaluate the limitations of current centralised health data approaches.
B. Analyse how emerging technologies including AI, privacy-enhancing technologies, and distributed-ledger technologies can enable a more equitable health data ecosystem.
C. Propose a conceptual framework that places individuals at the centre of health data ownership and value; and,
D. Provide recommendations for implementation that address ethical considerations, equity concerns, and practical challenges.

Methodology

This paper employs a conceptual framework development approach, integrating insights from multiple disciplines including health informatics, artificial intelligence, blockchain technology, privacy engineering, ethics, and dementia research and clinical practice. The framework was co-created with a multidisciplinary team, including industry practitioners, who pooled real-world implementation

experience to ground the concepts in concrete dementia prevention applications. In other words, beyond literature synthesis, our methodology also involved structured iterative discussions among co-authors with hands-on expertise, ensuring the framework reflects the complex, multifactor ecosystems where these ideas must operate. We analysed current literature on centralised and decentralised data approaches in healthcare, evaluated the limitations and benefits of emerging technologies for health data management, and synthesised these findings to develop a novel person-centred framework. Our approach is grounded in the principles of value-based healthcare, digital ethics, and participatory design, with particular attention to issues of equity, accessibility, and sustainability. While not presenting primary empirical research, this paper offers a theoretical contribution intended to stimulate discussion, guide future research, and inform practical implementation of more equitable health data systems for cognitive longevity.

Discussion

Technological innovation for cognitive health and research

Applied data science and artificial intelligence

Internationally, healthcare systems are moving towards more 'data-driven' healthcare models using health informatics to inform system- and patient-level decision making and resource provision. Within this digital ecosystem, there is an increasing use and exploration of applied Artificial Intelligence (AI) in medicine [20]. AI broadly refers to a machine's capability to simulate human cognitive processes such as learning, reasoning and self-correction [21]. AI is not new - it was established as an academic discipline in the 1950s [22]. However, renewed excitement for AI has arisen in the past 10–15 years with increased availability of high-quality data, improved data processing capabilities, the development of advanced analytics methods such as 'Deep Learning' (DL), often in the form of deep neural networks (DNNs) [23], and most recently, the application of Generative AI and Large Language Models (LLMs) [24]. DL is credited for its ability to assimilate high-dimensional multifactorial data – a primary characteristic of age-related data - to identify patterns and produce actionable insights. Importantly, this process is autodidactic and iterative, incorporating longitudinal temporal knowledge by gathering new data over time while storing the insights from historical data (held within the DNN layer weightings), and learning from the new data. The potential benefits of DL in health and care include progress being made in medical imaging [25], early diagnosis and warning of chronic health issues, treatment planning and patient monitoring (e.g. decision-support systems [26], predicting prognostic pathways [27], and patient facing tools (e.g. chatbots and wearables) [28]. For a comprehensive review of AI innovation in dementia research, see Ranson & colleagues [29].

More recently, Generative AI and Large Language Models (LLMs) in dementia clinical practice and research have shown promising advancements in early diagnosis, patient care, and research methodologies. LLMs can enhance diagnostic accuracy by identifying linguistic markers in patient records, support patients and caregivers through AI-powered chatbots, and streamline research by analysing large datasets [30]. This has been found specifically for detecting changes in cognitive capacity in elderly patients using clinical notes [31]. However, crucially, it should be noted that this could also be achieved directly from the patient before they enter the clinical ecosystem, from their personal devices and wearable technologies, potentially providing an avenue for accelerated detection of symptoms.

Despite these promising findings, it is important to acknowledge the significant limitations and challenges associated with LLMs in healthcare contexts. Current LLMs lack robust validation in clinical settings, with most studies involving small participant numbers and limited evaluation of long-term effects [32]. These models can produce 'hallucinations' or fabricated information presented as factual, which poses serious risks in medical contexts. Additionally, the environmental impact of training and operating LLMs is substantial, with significant energy consumption and carbon emissions that cannot be overlooked in discussions of sustainable healthcare technologies [33]. According to recent research, training a single large language model can consume thousands of megawatt hours of electricity and produce carbon emissions equivalent to the lifetime emissions of several cars. Without appropriate safeguards, LLMs may perpetuate or amplify existing biases in medical data and practice [32]. Therefore, while LLMs show promise, their implementation in healthcare requires careful evaluation, robust validation protocols, and appropriate safeguards to ensure both clinical efficacy and ethical deployment. We advocate for extending ethical oversight frameworks to explicitly include environmental impact assessments and long-term sociotechnical effects of such models. The presented framework offers such an approach.

Arrival of LLMs and foundational models opens further avenues for discovery research by enabling the use of not only structured but also unstructured

data, which is substantially more ubiquitous. Although the former remains most valuable, the latter are often underutilised in traditional data analysis methods. They include free-text, images, audio, video, sensor data and other non-tabular formats.

Additionally, exciting advances in the field of quantum computing (QC) and quantum sensing (QS) have the potential to optimise and accelerate AI applied to cognitive longevity, dementia detection, and drug discovery (for example, see [34]). QC, based on principles of quantum mechanics like superposition, interference, and entanglement, performs tasks much faster and with less energy than traditional computers, allowing for greater computing capacity to train and run AI models [35]. QS also leverages these principles of quantum mechanics to achieve better sensitivity and specificity for sensing technologies (such as wearables). Quantum entanglement, where particles become interconnected and their states are interdependent, allows quantum sensors to achieve exceptional sensitivity, while quantum superposition enables these sensors to exist in multiple states simultaneously, enhancing their ability to detect minute environmental changes [36]. However, it should be noted that quantum technologies are still in very early stages of development – much of the opportunity described above is theoretical – there is a lot of work to ensure that they are reliable, pragmatic, valid and acceptable at scale in the clinical ecosystem and in the community (i.e. within commercially available sensor technologies such as wearables). For sensor data from wearables and other monitoring devices, established signal processing techniques remain the most appropriate methods for analysis rather than LLMs, which are primarily designed for text processing. Signal processing has a long history of robust methodologies for extracting meaningful information from sensor data [37]. Integration of these processed signals with clinical notes and other text data analysed by LLMs could potentially provide a more comprehensive view of patient health, creating an avenue for accelerated detection of symptoms even before patients enter the clinical ecosystem. For example, in a person-centred cognitive longevity ecosystem, sensor-derived features such as gait irregularities or sleep fragmentation could be annotated with context or cross-referenced with patient-reported outcomes using an LLM-powered interface. This hybrid approach retains the interpretability and robustness of domain-specific pipelines while enabling more accessible patient-clinician communication and integrated reasoning across modalities.

The issue for successful implementation of AI in healthcare has never been lack of data, but rather the lack of FAIR data (that is, Findable, Accessible, Interoperable and Reusable), compounded by concerns over clinical validity, ethics, shared equity, and data security/regulatory compliance. These issues, collectively contribute to create a siloed, non-interoperable data ecosystem, as succinctly outlined by Ngiam & Khor [38], who emphasise the need for standardised pre-processing of health data in particular. Moreover, Li et al [39] describe the need for a "delivery science for artificial intelligence in healthcare", proposing that effective implementation can only be achieved by involving multi-stakeholder groups that can advise on the validity of the data and systems, and address concerns on ethics and equitable access.

The current dominant data curation zeitgeist is to focus on collecting and curating data into centralised, secure, and standardised repositories [40,41]. For example, in the UK, 'Trusted Research Environments (TREs)' have been proposed by Professor Goldacre and colleagues in their review, "Better, broader, safer: using health data for research and analysis" [42], where interested parties apply for access to healthcare data. A core mission of TREs is to optimise data use by reducing unnecessary bureaucracy for access and sharing; upskill the healthcare workforce; prevent the emergence of 'health data monopolies'; ensure meaningful transparency, accountability and replicable open science methods become the norm; and standardise the process of informing and engaging with public and patient groups [43]. Similar international centralised data initiatives exist for healthy ageing and age-related disease research data, for example: 'Dementias Platform UK' [44], 'Alzheimer's Disease Data Initiative' [45], 'ATHLOS' (Ageing Trajectories of Health: Longitudinal Opportunities and Synergies) project [46], 'Gateway to Global Aging Data' [47], 10/66 Dementia Research Group [48], and 'ROADMAP' [49].

While these centralised and bespoke consent solutions address many of the barriers described above, like standardisation, interoperability, security, and clinical validity, they also have distinct disadvantages. These include the monumental financial and time cost of curating all this data, finalising legal/IP agreements, inherent data privacy and confidentiality vulnerabilities which increase with the number of aggregated records, unnecessary data traffic and duplication, data breach risks of a single trusted data holder, and creation of unintentional data monopolies that favour data aggregators (which we are seeing in other industries, such as internet company data monopolies) [50]. Federated learning ('FL') addresses these specific issues by allowing data custodians to keep their data locally, maintaining confidentiality and security, and using transfer learning to

train AI models by 'distributing the algorithm to data sources'. An FL network can function either in a decentralised fashion or with a central aggregator that interacts with all nodes. In a decentralised setup, each site independently trains a model. The updated model is then passed sequentially to other sites in the network, which initialize from the received model, continue training, and pass it on. In a centralised aggregator setup, each site trains a machine learning model, and the final model updates are sent to a central aggregator. The aggregator merges these updates to form a new global model, which is then redistributed to all sites for further local training. This cycle continues until the global model achieves a predefined convergence criterion [51]. This federated model updating based on the distributed data sources resolves the "information silo" problem of health data, in addition to combining the advantages of secure computing techniques (local data remains at source) while efficiently lowering computational demands and enhancing scalability. The London Centre for Value Based Healthcare & Medical Imaging has been very successful thus far utilising this approach [52] and the UK Government has stated their plans for using FL for genomic data management [53]. However, it should be stated that while FL avoids the transmission of the raw data between the centre server and data source, recent research has shown that the privacy leakage risk still exists as sensitive information can still be recovered from the shared gradients [54]. Usually, necessary encryption methods like secret sharing [55], homomorphic encryption [56], differential privacy [57], and obfuscated circuits [58] are required to be applied on the shared gradients. These encryption strategies improve the security against the model inversion attack while introducing high computational cost for encryption and increased transmission cost that harms edge computing solutions.

Despite its theoretical advantages, implementing federated learning in healthcare contexts presents significant practical challenges. Unlike centralised approaches where expertise and resources are concentrated, federated learning distributes computational burdens to local sites, each requiring skilled personnel for implementation, maintenance, and troubleshooting [51]. These sites need expertise in machine learning, software engineering, and healthcare informatics to effectively participate. Additionally, ensuring consistent version control across distributed nodes, managing regular software updates, and maintaining hardware infrastructure all require substantial investment and coordination. These distributed costs may be prohibitive for smaller healthcare organisations or those in resource-limited settings, potentially creating new forms of digital exclusion rather than resolving existing inequities. However, FL is an illustrative example of a principled, socio-technical framework for accessing distributed data, managing participation incentives, and automating model orchestration without centralizing raw records. FL permits sites to retain data on-premise (mitigating GDPR/HIPAA compliance risks) and tools such as embed version control, secure communication, and CI/CD pipelines so that regular code updates and maintenance don't fall entirely on local staff [59]. Furthermore, FL paves the way for incentive and compensation mechanisms such as Shapley-value rewards or crypto-backed micropayments, linking to economic efficiency and organisational behaviour factors. Of course, any distributed approach still relies on human roles (data-governance teams, IT, compliance, and domain experts), but FLformalises those processes under a unified, scalable architecture. We build on these foundations in our proposed methodological approach.

Privacy-enhancing and distributed-ledger technologies

In 2023, the Royal Society published a report supporting the exploration and adoption of Privacy Enhancing Technologies (PETs), with specific emphasis within the healthcare and clinical research sector [60]. PETs encompass novel encryption methods (e.g. as described above), anonymisation tools, synthetic data & digital twins [61], that facilitate collaborative data science using sensitive data. As a result, PETs have also been termed: "Partnership Enhancing Technologies" or "Trust Technologies". Moreover, PETs are increasingly important for health data governance and security. However, for health data, patient and public groups have argued that it is not enough to just be secure, data collection and use also needs to be transparent, equitable, and inclusive [62,63]. Further, one potential pathway forward would be to explore a combination of Distributed-Ledger Technologies (DLTs), such as blockchain, and PETs to achieve privacy and security alongside transparency, equitability and inclusivity.

These aspects are highly attractive for the 'healthcare AI' sector, where trust, transparency, security, confidentiality, and cost optimisation are imperative for effective adoption. As mentioned previously, in contrast to the centralised approaches, an advantage of decentralised computing is its scalability. With the former approaches, assimilation of data or learning must be done by a single server; but in decentralised computing this processing can be shared across many servers, meaning that as more blocks are included in the chain, their individual processing

and information power is additive rather than a consolidated burden on a central processor. Decentralised FL, and the combination of DLTs and AI, have been termed 'decentralised AI'. Decentralised AI arguably represents a perfect alliance in healthcare – AI is one of the best tools for retrieving actionable information from patterns in data, and decentralised frameworks incorporating PETs are information-sharing technologies with high transparency, accountability, and trust. In addition, queries can be tailored to the context of the specific data source, resulting in better integration with the underlying data structure and semantics, improving accuracy and relevance. Modern federated query engines enable distributed execution and intelligent query planning across multiple data sources.

One method using decentralised AI in a private blockchain is 'Swarm Learning' (SL). SL combines edge-computing and private permissioned blockchain - known here as a 'Swarm' - to share insights and knowledge from training models of local data, without sharing raw data and the need for a central coordinator [50]. As a repurposed technology from fintech, the researchers had the advantage of using 'smart contracts' with legal precedent that could be adapted for the purpose of their specific swarm. Computation is conducted by an 'SL library', and decentralised data is used for iterative AI transfer learning. Warnat-Herresthal and colleagues present multiple use cases of applied SL in healthcare: COVID-19, Tuberculosis, and lung pathologies [50]. Using shared learning from blood transcriptome and chest x-ray data, they found that SL disease classifiers outperformed those developed at individual sites, while abiding by all local data protection and security regulations.

A critical consideration for both federated learning and distributed-ledger technologies is their dependence on robust digital infrastructure. According to the European Commission's 2023 Broadband Coverage Report, significant disparities persist in internet connectivity between urban and rural areas across Europe. Rural regions, where approximately 48% of households have access to FTTH/B (Fiber to the Home/Building) connections compared to 79% in urban areas, may face exclusion from these advanced data-sharing technologies [64,65]. Healthcare organisations in these underserved regions may be unable to participate fully in decentralised health data networks, potentially exacerbating existing healthcare inequities. Additionally, blockchain technologies face security challenges including vulnerability to false information injection and node validation issues [66]. While proof-of-work validation models exist, their excessive computational demands make them unsustainable for healthcare applications. These infrastructure and security considerations must be addressed to ensure equitable access to and benefit from decentralised health data systems. Low rural broadband coverage means that data from under-served areas are systematically missing, so any AI trained on that patchy input will inherit and even amplify existing biases. In practice, healthcare models end up overfitting to urban or well-connected populations, then perform poorly (and unfairly) when deployed in regions with low connectivity. That makes continuous bias monitoring (e.g., auditing feature and outcome distributions) and rigorous data-quality validation (e.g., checking for missingness patterns by geography or demographic) critical if we hope to avoid perpetuating these inequalities.

Unfortunately, these federated learning and data exchange approaches between healthcare organisations overlook an essential opportunity to access health-relevant data of individuals before they enter the healthcare ecosystem. This is particularly pertinent for detecting pre-symptomatic signals of dementia and cognitive impairment, especially for many who are undiagnosed cases.

Integrating continuous requirements assessment and ethical AI monitoring for cognitive health innovation

In an AI-driven health data ecosystem focused on dementia prevention and cognitive longevity, the need for ongoing, value-based assessment of technology implementation is critical. Such assessment ensures that the systems remain responsive to emerging challenges, including shifting ethical, clinical, and societal expectations. Thorough assessment and regular evaluation of system capabilities, involving diverse stakeholders - patients, carers, clinicians, researchers, and policymakers - together with wide-ranging data integration, and simulation-based predictive models, can identify areas for improvement and prevent potential misalignments between system outputs and user needs. Such an iterative process not only supports innovation but also reinforces the system's commitment to equitable and person-centred care.

AI systems designed for early detection, intervention, and research in dementia must incorporate robust ethical monitoring. Beyond performance metrics like predictive accuracy, ethical considerations such as fairness, inclusivity, and transparency must be systematically evaluated. AI models trained on diverse, decentralised datasets can improve representativeness while ensuring that marginalised populations - such as those in LMICs or digital-poor settings - are

equitably included. Monitoring frameworks must address algorithmic bias, the transparency of decision-making processes, and the proportionality of system interventions to ensure AI systems support ethical and informed decision-making [67].

A person-centred decentralised health data ecosystem must embed ethical metrics throughout its operations, from data collection to AI model training and deployment. These efforts must ensure that individuals and communities actively participate in shaping the ecosystem and benefit equitably from its outcomes. Embedding these practices within a dynamic feedback loop will enable the ecosystem to address the complexities of cognitive health while maintaining the trust and engagement of all stakeholders.

Crucially, responsibility for implementing these ethical AI practices must be clearly assigned and distributed across stakeholders. While many AI-enabled healthcare products are developed by commercial entities that may prioritise speed to market and profit margins over time-consuming ethical review processes, the burden cannot fall solely on industry self-regulation. Regulatory bodies must establish clear requirements and enforcement mechanisms for ethical AI development. Healthcare institutions must develop expertise to evaluate AI systems before adoption. Research funders should mandate ethical AI practices as funding conditions. Professional organisations should establish standards of practice. Moreover, governments should consider policies that incentivise transparency and accountability in healthcare AI, potentially including tax benefits for companies demonstrating robust ethical practices or penalties for those failing to meet standards. Without this explicit assignment of responsibility across the ecosystem, ethical AI principles risk remaining aspirational rather than operational. Additionally, the regulatory landscape is rapidly evolving: for example, the EU AI Act and a patchwork of local regulations and organisational policies are attempting to define who bears which responsibilities in AI development and deployment. However, these efforts remain geographically fragmented and often struggle to keep pace with technological advances. That gap means formal rules alone aren't enough; a comprehensive, socio-technical framework, like ours, provides the necessary structure to systematically think through and build interventions that remain robust even as regulations and technologies continue to evolve.

Ensuring equity and fairness of AI-enabled systems

Ethical data assessment is a cornerstone of effective implementation of AI systems aimed at improving cognitive health outcomes. Validating datasets for accuracy, completeness, and fairness ensures that AI models provide reliable insights without perpetuating biases or inequities [68]. This is particularly critical in the context of underserved populations, which include those marginalised by age, ethnic background, geographical location, or digital poverty. Historically, these groups have been underrepresented in health datasets, leading to AI models that fail to address their unique needs or circumstances. To build better AI models, data collection efforts must actively engage these populations through culturally sensitive outreach, dynamic consent processes, and collaborations with local community organisations. Furthermore, integrating diverse, representative datasets with robust validation mechanisms improves the generalisability of AI outputs and ensures that decision-making processes align with ethical and person-centred principles. By embedding these practices into the decentralised health data ecosystem, the system can address disparities, enhance model robustness, and support equitable advancements in dementia prevention and cognitive health research.

Increased access to the exposome via digital innovation

The potential of AI is amplified by the proliferation of 5G telecommunication networks, clinically valid remote sensor technology, and the applications of Internet of Things (IoT) that increase the omnipresence and accessibility of data in healthcare and health-relevant data in the 'exposome' outside the health and social care system. The exposome is a concept getting increasing attention (see [69]) with three overlapping domains: 1) a general external environment to include factors such as the urban environment, climate factors, social capital, stress; 2) a specific external environment with specific contaminants, diet, physical activity, tobacco, infections, etc, and 3) an internal environment to include internal biological factors such as metabolic factors, gut microflora, inflammation, oxidative stress [70]. This conceptual framework is now being operationalised through real-world "exposomic testbeds" in cities such as Rotterdam, Utrecht, and Barcelona, where comprehensive urban exposome initiatives integrate environmental sensors with health records to assess how urban design affects resident health. The emerging discipline of "exposomics" is developing standardised assessment methods for both internal and external exposures, moving beyond laboratory research to test interventions with diverse populations in real-world settings [71].

The current consensus for our best chance to defeat the dementia diseases and cognitive decline have centred on earlier detection of disease pathology and symptomology, with increasing focus on using digital technology and sensors to detect change in cognition earlier, and to collect population-level exposomic data efficiently and at scale [72,73]. For example, remote cognitive assessment can now be facilitated through: new digitised and mobile applications such as the 'Integrated Cognitive Assessment' (ICA) [74] which demonstrates 90% accuracy in correctly identifying cognitive impairment and significantly outperforms GP referral accuracy to memory services [75]; using wearable sensor CE-marked technology e.g. 'RADAR-AD' [76]; as part of nascent remote memory clinics (which have had boosted popularity as a result of the COVID-19 pandemic) [77]; using multimodal sensors in household environments e.g. "SPHERE" [78]; and via public online regular cognitive assessment cohorts such as the 'PROTECT' platform [79]. Not only can we use these technologies to derive cognitive digital biomarker signatures, but if also combined with electronic health records, 'omic's data, and other health-relevant data in the wider exposome, it would assume a deeply powerful, and efficient resource for clinical research innovation and optimised patient outcomes. However, realising this potential requires regulatory reform to unlock data silos and enable the safe sharing of consented personal data through initiatives such as personal data intermediaries, as evidenced by emerging UK data legislation [71]. Distributed SL has the potential to naturally blend clinical data and continuous daily monitoring data for early symptom identification and temporal modelling and facilitate the transition to a cost-efficient family-based care of cognitive ageing related health conditions. Advancing real-world personalised prevention and healthcare can be enabled by predictive indications based on simulations of individual health conditions.

Incentivising health data sharing and equitable returns

Highly phenotyped and clinically validated health data will naturally accrue vast value, particularly as it expands in breadth and over time, thereby attracting significant commercial attention. For example, according to Forbes, the healthcare analytics market is estimated to be over $67 Billion by 2025, and the telehealth market and the healthcare insurance market to be over $559 Billion and $4 Trillion by 2027 respectively [80]. In a recent report by Ernst & Young, they estimated the value of data within the UK's NHS as ~£5bn per year, with a further £4.6bn in potential operational savings [81]. Bradley and colleagues argue that better management of public healthcare data is needed to ensure equitable returns for the NHS, patients and public [82]. The authors argue that healthcare data could be better utilised to facilitate potentially lucrative private-public partnerships, attracting significant international investment, stimulating cutting-edge innovation, and founding a 'health-data marketplace economy' that can be accessed by all. Currently these transactions occur without consideration of the individual in a 'shadow data economy'. For example, a recent report found that mental health data in the US often exchanged hands in a largely unregulated setting, with significant lack of clear protections and rights for the original owners of the data [83].

In federated learning, the methods of data contribution computation have been explored as a basis of participation incentive schemes [84]; however, practical applications require development of implementation frameworks that would consider the socio-technical factors unique for the health research and care contexts.

A decentralised AI within a private permissioned blockchain approach could essentially pilot the development of an open health-data economy. A promising example of this was the EU Horizon 2020 project, 'My Health My Data' [85], which aimed to develop the first open biomedical information network built on underlying blockchain infrastructure that connected organisations and individuals. Importantly, they included a 'dynamic consent' option for individuals to what type of data is shared, how it is shared, and to whom it is shared with. However, the investigators did not test the feasibility of value exchange within this framework. For example, data is not created equal. The type of data, its level of missingness, its clinical validity, and its source (e.g., from LMICs - Lower- and Middle-Income Countries - or underrepresented groups) will all impact its value. This aspect needs to be further explored.

A critical aspect of dynamic consent that requires further exploration is the threshold beyond which meaningful consent withdrawal becomes challenging or impossible. Once individual health data has been integrated into AI models, particularly through techniques like federated learning where model weights rather than raw data are shared, complete removal of an individual's contribution becomes technically complex [86]. This raises important questions about the temporal boundaries of consent in evolving AI systems. Potential solutions include implementing 'forgetting' mechanisms in models, designing AI

architectures that can be retrained without specific data points, and establishing clear timeframes and procedures for consent expiration. Additionally, individuals should be explicitly informed about these limitations during the initial consent process, providing transparency about when their right to withdraw consent may become practically limited due to technical constraints. This represents an emerging area requiring both technical innovation and ethical guidance, that consider practical constraints such as that once an individual's data contributes to training a model, their "influence" becomes irrevocably embedded in the learned parameters, making true retroactive removal technically infeasible: modern deep networks intermix information at a level that prevents isolating and excising one person's contribution. Under regulations like GDPR, the right to be forgotten stops future processing but does not mandate removing someone's impact from an already-trained algorithm. In practice, therefore, meaningful consent withdrawal must occur before a training cycle begins (or at least before the next retraining), because after models go live, unlearning individual data points is, for now, more theoretical than operational.

DLT's could use its immutable and transparent 'value-transfer' capability to incentivise good health behaviours (like attending check-ups/completing optional annual assessments, achieving predefined health outcome targets, and collecting and sharing data by using wearable devices etc) at an individual and organisational level. This would not necessarily be in the form of monetary value, but could be alternative value domains such as 'points/tokens/discounts' for healthy products and activities; revenue or profit shares; reducing costs in taxes/health insurance; or others described by Ghafur and colleagues [87]. This is especially true if we eventually move to a health system whereby individuals own their own data in a 'personal health data-driven economy' – an example model of this hypothetical reality is described in-depth by Mamoshina and colleagues [88]. Successful examples of giving the 'power to the person' by facilitating control over their own data, and incorporating them into the revenue stream using a dynamic consenting model, have been demonstrated in other sectors e.g. by internet companies like 'Gener8' [89] that give control over cookies back to users, offering a choice not to be tracked at all, or to elect to be rewarded from offering their cookies to interested parties.

Ultimately, if individuals can be persuaded that practicing healthy ageing behaviours aligns not only with prolonged healthy longevity, but also increasing economic returns, we propose this would increase overall population health and wellbeing and result in higher resilience to nascent international health crises such as increasing prevalence of the dementias. For example, researchers have previously found that individuals are more likely to share their wearable data when they feel they have shared equity in the potential returns [90]. Crucially, these returns can also be used to incentivise engagement and collaboration with historically underrepresented groups and LMICs to ensure research and clinical outcomes are more representative, particularly given the projected substantial increase in dementia in LMICs by 2050.

Person-centred decentralised health data ecosystem

Person-centricity principles require a careful design of ways to assess and optimise representativeness and ethics of AI models; find novel ways to efficiently communicate to patients' complex concepts of privacy, technology roles and AI-assisted decision making; and develop collaborative system design approaches that engage the diverse sets of stakeholders from patients, carers, clinicians, industry representatives, and policymakers.

We propose a person-centred decentralised health data ecosystem (Figure 1) as a paradigm to maximize the value of healthcare, research, and exposomic data. This ecosystem offers numerous key benefits:

Prevention of Dementia Cases: Incentivising individual action on modifiable dementia risk factors could prevent up to 45% of dementia cases worldwide [9].

Early and Accurate Diagnosis: This ecosystem enables earlier and more accurate diagnosis of dementia, including potentially undiagnosed cases.

Equity and Democratisation: By decentralising data ownership, individuals (data owners) and data generators (health and social care services, academic and publicly funded organizations, exposome data collectors) can share equity and decision-making power.

Enhanced Engagement in Clinical Research: This ecosystem encourages participation in dementia clinical research, particularly among underrepresented groups, and fosters multiparty investment.

Accelerated Access to Data and Patients: By integrating healthcare, research, and exposome health data, academic and clinical research teams can access data and potential patients more efficiently, ultimately accelerating research progress.

Improved Ecological and Clinical Validity: The integration of diverse data sources enhances the ecological and clinical validity of research findings,

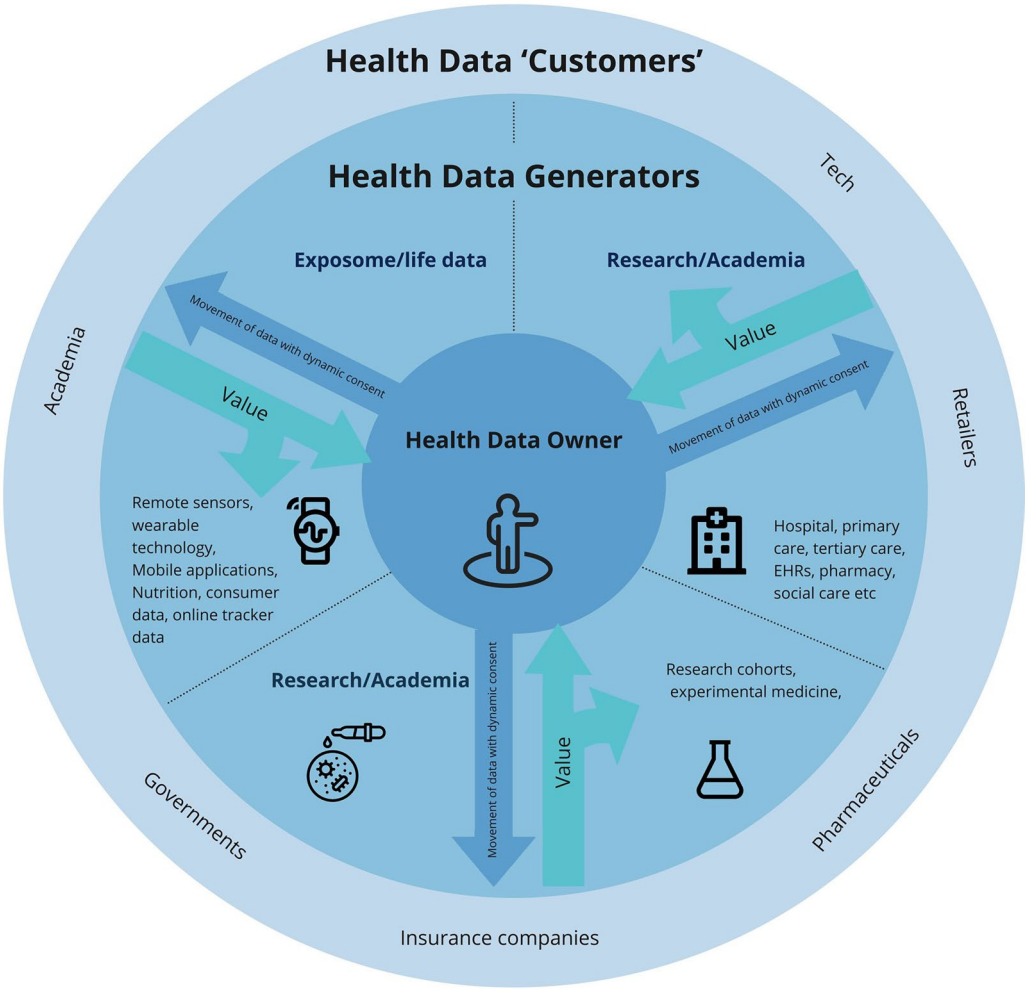

Figure 1. A person-centred decentralised health data ecosystem.

leading to more effective interventions and improved health outcomes.

Key embedded concepts in the framework

Dynamic Consenting: individuals have power to consent to what type of data is shared, how it is shared, to whom it is shared with, and what form of value they prefer.
Blockchain-supported value exchange: transactions are immutable and can be tracked on a private-permissioned distributed ledger system. This ensures transparency and accountability.
Federated learning and data transfer options supported: there is an option to either transfer data and/or knowledge between parties depending on what the individual has consented to.

This model isn't dissimilar to the growing 'content creator' economy where individuals create content for social media and technology platforms, estimated to be worth over $100 Billion, which is shared between creators and content platforms [91]. However, in contrast, with the value of the health data market considerably higher, there is a succinct opportunity for the genesis of a 'health data creator' economy, where the value of the data is shared between data owners and data generators. Perhaps most importantly ethically, this model puts the individual in full control of their own health data and how it is used.

Putting the person at the centre of the ecosystem also aligns closely with nascent and promising clinical research innovations such as N-of-1 studies and digital twins. N-of-1 clinical trials are particularly pertinent for a precision medicine approach to patient care due to their focus on individualized treatment responses [92]. These studies allow for the detailed observation and analysis of how a specific patient responds to various treatments over time, providing highly personalised data. This approach is beneficial in precision medicine because it acknowledges the heterogeneity in patient responses to treatments, which is often overlooked in traditional randomized controlled trials (RCTs). By tailoring interventions based on the unique characteristics and responses of an individual patient, n = 1 studies can optimise therapeutic outcomes and minimize adverse effects, ultimately leading to more effective and personalised patient care. Our proposed framework would facilitate wider and accelerated adoption of N-of-1 studies.

Digital twins are virtual replicas of patients that can simulate and analyse real-time data to optimise personalised treatment plans and improve patient outcomes [61,93]. They offer significant benefits in clinical research and practice by creating virtual replicas of patients, enabling 'P4 medicine' (personalised, predictive, preventive and participatory) [94], and optimising treatment plans. They allow for precise simulations of medical interventions, reducing the need for animal and human trials, and accelerating drug development. In the context of cognitive health and aging, digital twins can model individual cognitive functions and predict the progression of cognitive decline, facilitating early interventions and personalised treatment strategies [95]. This technology enhances our understanding of cognitive aging and supports the development of targeted digital therapies to maintain cognitive health in older adults [96], which, in an age of increasing digital use and technological ubiquity, is highly applicable for healthy cognitive ageing in the 21st century.

Implementation recommendations for public health stakeholders

Implementing a person-centred decentralised health data ecosystem framework requires coordinated action from public health stakeholders across multiple levels. At the policy level, governments should develop regulatory frameworks that recognise individual health data ownership rights while establishing standards for secure data exchange and ethical AI development. These frameworks should include provisions for monitoring algorithmic bias and ensuring equitable access to both data infrastructure and resulting benefits.

Healthcare systems should invest in technical infrastructure that supports secure data sharing, with particular attention to addressing the digital divide. This includes not only providing physical infrastructure in underserved areas but also developing simplified interfaces and support mechanisms for populations with limited digital literacy. Community health workers could serve as intermediaries between complex digital systems and vulnerable populations, helping to ensure informed participation rather than exclusion.

To address potential biases affecting disadvantaged populations, implementation should include:

A. Proactive recruitment strategies targeting underrepresented groups, with appropriate compensation for their participation.
B. Development of culturally sensitive consent processes in multiple languages with varying complexity levels.
C. Regular bias audits of both data collection processes and resulting AI models; and,
D. Community oversight boards with representation from diverse socioeconomic backgrounds to review data governance practices.

Educational initiatives should be developed to improve health and data literacy across populations, enabling more informed decision-making about health data sharing. These should be tailored to various educational levels and cultural contexts, avoiding technical jargon that can exclude non-specialist participants.

Finally, public health organisations should establish monitoring systems to track who benefits from health data ecosystems, identifying and addressing emerging inequities. This involves developing metrics not just for data contribution but also for value distribution, ensuring that the promised benefits of personalised medicine and early intervention reach all population segments rather than exacerbating existing health disparities.

Conclusion

The proposed person-centred decentralised health data ecosystem framework offers significant potential to transform dementia prevention and cognitive longevity research and care. By balancing technological innovation with ethical considerations, equitable access, and practical implementation challenges, this framework provides a roadmap for creating more inclusive and effective health data systems. Success will depend on addressing the technical limitations of AI and quantum computing, bridging digital infrastructure gaps, establishing clear implementation responsibilities, and developing robust consent mechanisms that respect individual autonomy throughout the data lifecycle.

Regular calls for "dementia moon-shots" [97] or dedicated research taskforces [98–100] could be enhanced by this broader participatory approach that engages the global population in both contributing to and benefiting from advances in cognitive health. As we conclude, it bears emphasising that we should be pushing beyond merely "human-in-the-loop" AI toward truly "human-at-the-centre" AI - a distinction that recognises individuals not just as data points but as active stakeholders with agency, rights, and shared interests in the value their data helps create.

CRediT (contributor roles taxonomy) author contributions

Christopher P Albertyn: conceptualisation, project administration, writing – original draft; **Svitlana**

Surodina: conceptualisation, visualisation, writing – original draft; **Paweł Świeboda**: writing - review & editing; **Bo Tan**: writing - review & writing; **Tina Woods**: writing - review & editing; **Lynne Corner**: writing - review & editing; **Dag Aarsland**: supervision, writing - review & editing, and **Richard C Siow**: conceptualisation, supervision, writing - review & editing.

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Author TW is the director of Collider Health.

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