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EDITORIAL

Call to collaborate on data science for older people across Europe: an EuGMS Big Data Special Interest Group position paper

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Key summary points

1. Data science and AI may improve outcomes for older people through enhanced prognostication, clinical trial design, and service evaluation using routinely collected electronic health data.
2. Ageing research data science requires collaboration across the boundaries of multiple disciplines.
3. A pan-European approach could examine variation in outcomes among older people, test common clinical decision aids and prediction tools, and evaluate different services and interventions for older people in a variety of contexts.
4. Standardisation and shared learning across Europe are important to identify and share best practice for older people and advocate for this standard of care across the continent with the aim of improving equality and equity of health services.
5. The EuGMS Big Data Special Interest Group aims to deliver harmonised, pan-European ageing research data science to transform health and care services for older people.

Introduction

Worldwide, the population is living longer and growing older, with most people now living to the age of 60 years and older [1]. By 2100, the number of people living in Europe over the age of 65 years will have increased to one-third of the population [2]. Population ageing brings new challenges for health and social care, with a need to improve the efficiency and sustainability of care delivery, in addition to minimising inequalities within and between countries. Approximately, 51% over the age of 60 years live with two or more long-term conditions (multimorbidity) [3]. The concept of healthy ageing—maximising independence at all stages of later life—is more important than ever to ensure that people live well into older age [4, 5].

Data science and artificial intelligence (AI) are rapidly growing fields within healthcare. Technological advancements, increased data availability through digitisation of healthcare records, and advancing workforce expertise have led to a rapid increase in the use of data science with a spectrum of applications [6]. Ageing research data science is an interdisciplinary field which integrates domain knowledge with statistics, AI, computer science, engineering, and social sciences to collect, process, link, and analyse large amounts of data for the purpose of improving well-being and healthcare services in later life, working in partnership with older people (Fig. 1).

This position paper explores how data science and AI could be used within the field of geriatric medicine to improve the care of older people over the next decade, and how Europe-wide collaboration could raise quality of care and harmonise data-driven research for older people.

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Fig. 1 Ageing research data science requires interdisciplinary collaboration to apply different skills sets and knowledge domains across the data science pathway from data entry to clinical application
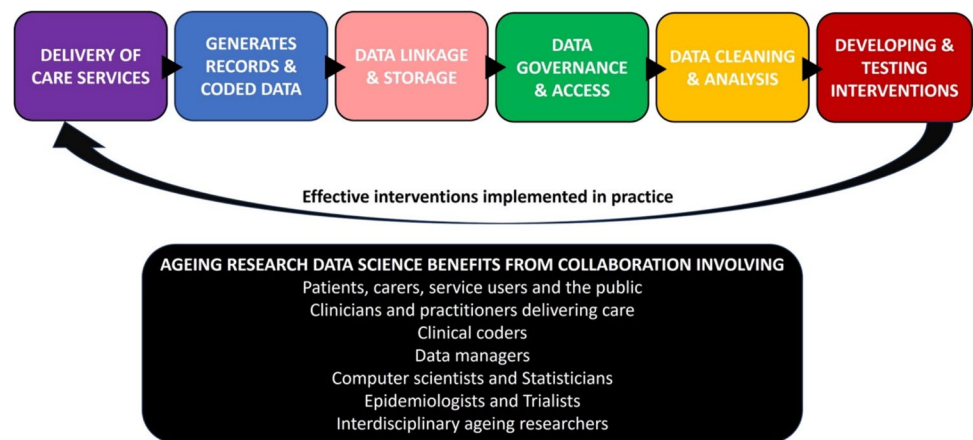
Why focus on data science for older people?

Older people are the main users of health and social care, representing a heterogenous and complex group with unique needs that vary between individuals due to the interaction between geriatric syndromes such as immobility or falls with multimorbidity, frailty, behavioural, environmental, and social factors [7].

Worldwide, age-related discrimination can act as a barrier for older people seeking health and social care [8]. This can lead to health inequities, with older people facing a disproportionately higher risk of preventable harm, increased disability, and poorer mental and physical health than younger individuals [9]. Randomised controlled trials frequently underrepresent older people, particularly those living with multimorbidity or cognitive impairment, and do not reflect the age or frailty distribution expected in clinical practice, even when the condition studied disproportionately affects older people (e.g. COVID-19) [10, 11]. Whilst there is a move to avoid upper age limits in research, other exclusion criteria such as cognitive impairment, reduced kidney function, and physical barriers to research inclusion can lead to more older people being excluded than from other age groups [10, 12].

In a time of limited financial resources, efficiency in health and social care is important. Innovation and technological advancement are being increasingly shaped by the growing digitisation of healthcare systems. The availability and utility of data collected routinely during clinical care from electronic health records (EHR) present an opportunity with transformative potential to increase the inclusion of older people in research. Many of the long-standing challenges faced by the lack of an evidence base to guide the design and delivery of healthcare services for older people could be addressed.

What could data science be used to address?

There is huge variability in geriatric medicine provision both between and within European countries [13]. Comparison of services and the ability to identify service gaps to better target under-served groups will need data that is feasible to collect on an international scale. This requires a pragmatic approach to facilitate collaboration across Europe.

The potential benefits of harnessing EHR for research include opportunities to improve stratification of care, clinical trials, and service evaluation [14]:

1. **Stratification of care:** Routine data are already being used to aid in the identification of frailty and target management of other geriatric syndromes such as falls [15–19]. Prognosis methods enable stratification of older people according to baseline risk or response to therapy [20, 21], helping us to understand how to tailor complex interventions to meet individual patient needs. However, there are often challenges with prediction tool performance or implementation. There is scope to develop models further to aid identification of other under-recognised geriatric syndromes (e.g. delirium, incontinence) across care settings [22]. External validation of new prediction tools in different countries using routinely collected data would accelerate uptake of these tools across Europe [23].

2. **Clinical trials:** Novel trial design harnessing routine data can enable the identification of older people for trial enrolment and reduce loss to follow-up [24]. Observational data using causal inference methods can emulate clinical trials, to estimate whether different treatment strategies have led to differences in outcomes in otherwise matched individuals [25].

3. **Service evaluation:** Access to routine data enables the examination of processes of geriatric care, to understand variation in outcomes. For example, if a patient is diagnosed with delirium, it would be helpful to compare processes of care alongside clinical outcomes associated with delirium in a particular setting (such as (re-)hospitalisation, time to death, need for social care support) [26].

Why look across Europe?

European countries have similar societies, but heterogeneous and evolving health and social care systems [27]. This provides the potential to examine variation in outcomes for older people, test common clinical decision aids and prediction tools, and evaluate different interventions for older people in a variety of contexts. Standardisation and shared learning can help identify and disseminate best practices for older people and advocate for a consistent level of care across the continent. This work is a priority of the EU Commission's European Health Data Space, which aims to foster a collaborative platform for electronic health record systems for both primary and secondary use for research across European countries [28]. The European Health Data Evidence Network (EHDEN) already provides a federated network of multiple local databases including electronic health data records enabling analysis across countries without the underlying data ever leaving the institution where it resides [29].

There is a need to develop widespread consensus, as even within individual nations, healthcare services are variably configured and collect and record data in a myriad of formats and structures. Population characteristics, healthcare structures, and variation in data language contribute to a complex environment from which a harmonised database can be difficult to construct. Solutions working towards data harmonisation are required to maximise opportunities for comparison, increase scale and generalisability.

What do we plan to do within the next 5 years?

The formation of the EuGMS Big Data Special Interest Group is motivated by a shared vision to promote the use of data science in improving care for older people (Fig. 2).

Within this group, we aim to champion harmonised, pan-European ageing research data science to transform health and care services for older people. Our objectives are:

1. To **improve health and social care for older people** through novel data science methods, including AI-based approaches, to develop and evaluate:
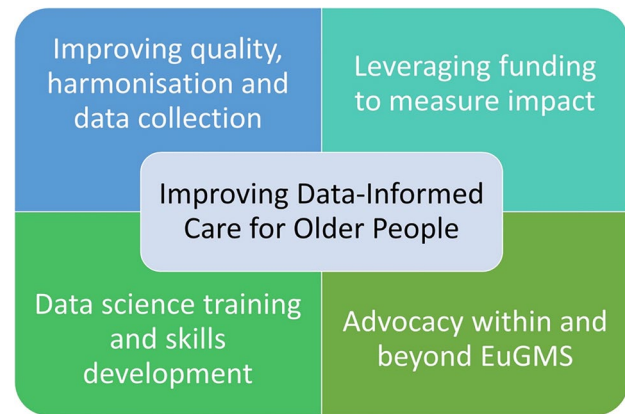

Fig. 2 The principles of the EuGMS Big Data Special Interest Group

a. Prediction models and decision support systems on outcomes important to older people that can be easily implemented in routine clinical care
b. Interventions and novel care pathways, suitably targeted for populations of older people

2. To **leverage cross-European funding** to measure the impact on clinical outcomes of our novel data science outputs.

3. To **develop data-sharing methods and infra-structure** for federated analysis by:

a. Improving the routine collection, coding and harmonisation of routine data relevant for the care of older people across Europe by extending our ageing research data science network across Europe in collaboration with the EHDEN network of existing routine data sets
b. Establishing a research-ready, agile and responsive network with multi-national data to address early policy and research calls across Europe
c. Advocate for the inclusion of measures relevant to older people and Patient Reported Outcome Measures in routine healthcare records

4. To **support data science training** for the clinical and academic multidisciplinary team working with older people to have better opportunities to share data and develop greater understanding of important data/indicators as part of usual care. This should be achieved through:

a. Raising awareness around the role of healthcare records as a tool for research.
b. Highlighting funded research opportunities.
c. Advocating for the inclusion of data science training for the wider workforce across Europe.

d. Supporting the development of novel clinical questions which harness data assets using statistical and AI-based approaches.

5. To **develop an effective advocacy group** within EuGMS to:

a. Advocate to European funders for dedicated ageing research data science questions to improve the health and social care of older people.

b. Champion the engagement of older people themselves to guide the use of their routine data to improve the services for older people.

c. Promote integration of quality indicators and consensus codes derived from routine data in service evaluation and clinical care guidelines for older people.

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Declarations

Conflict of interest All authors and collaborators declare that they have no conflicts of interest.

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