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## NEW HORIZONS

# New horizons in the role of digital data in the healthcare of older people

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## Abstract

There are national and global moves to improve effective digital data design and application in healthcare. This New Horizons commentary describes the role of digital data in healthcare of the ageing population. We outline how health and social care professionals can engage in the proactive design of digital systems that appropriately serve people as they age, carers and the workforce that supports them.

**Keywords:** digital, data, older people, frailty, workforce

## Key Points

- Healthcare improvements have resulted in increased population longevity and hence multimorbidity.
  - Shared care records to improve communication and information continuity across care settings hold potential for older people.
  - Data structure and coding are key considerations.
  - A workforce with expertise in caring for older people with relevant knowledge and skills in digital healthcare is important.
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## Introduction

The twentieth century saw the largest gain in life expectancy in history [1, 2]. The prevalence of non-communicable disease and the resources required to maintain life and reduce disability have dramatically increased [2, 3]. The Global Burden of Disease Study 2010 reports that whilst age specific mortality has been falling, the burden of chronic disability is rising [4].

Healthcare improvements have resulted in increased population longevity. Whilst older people are likely to be healthier than in the past, [5] they are more likely to live with multimorbidity (two or more conditions) [6]. Multimorbidity is estimated to affect over a third of adults globally and over half of people aged over 60 years old [7], with a higher prevalence in the most deprived communities. The interplay of increasing health complexity and increased social care needs as people age frequently results in multiple health and social care providers. These care interactions generate an increasing volume of data commonly in multiple separate systems [8]. In this paper, we will explore the current landscape, challenges and future considerations around digitally generated healthcare data concerning older people and the implications for the health and social care workforce.

## Electronic health and social care records

The wide variation in healthcare systems globally is echoed in the progress in electronic health and social care records. The need for improved joined-up data in health and social care is recognised by policymakers, and a global strategy on digital health has been recommended by the World Health Organization (WHO) [9]. The Global Digital Health Partnership (GDHP) is a collaboration of governments and the WHO, formed to support the effective implementation of digital health services [10]. Models for progressing the evolution of electronic health and social care records vary, but it is important to leverage digital health advancements globally. It is important to consider informed consent for information sharing in digital healthcare records within a clear governance framework [11]. Improved digital records and communication may be particularly important in caring for older people, who have increased healthcare utility and complexity and are vulnerable to adverse outcomes [12].

One key aspect of digitalisation is interoperability between health and social care providers. Interoperability is defined as the ability of a system or product to transfer meaning of information within and between systems or products without special effort on the part of the user [10]. Standardised clinical coding systems facilitate interoperability and improve data quality. A lack of structure and standardisation can be a barrier to effective use of electronic health records and can compromise data quality and validity. Electronic records enable detailed clinical coding that relates to the International Statistical Classification of Diseases and Related Health Problems (ICD), which is now on its 11th version: ICD 11 [13]. Standardised coding enables

data to be used efficiently for public health surveillance, quality and cost evaluation. Whilst digital platforms and software vary, standardised coding approaches combined with increased agility provide the potential for replicating extraction systems across different clinical digital providers, creating more real-time feed in and interpretation than has been feasible previously. There are economic barriers to data standardisation, through direct costs such as software or indirect costs such as training or additional time taken in consultations [10].

There are important limitations of reliance on coded data to measure performance. The data validity should be considered in analyses, particularly when associated with financial reimbursement [14]. This can still be problematic within free at the point of care healthcare systems such as the National Health Service (NHS) in the UK; standardised care meeting set quality criteria are rewarded, whereas person-centred deviation from guidelines, such as in frailty or multimorbidity, can incur financial penalties to providers [15]. There is ongoing work to define how to measure the impact of digitalisation by the GDHP. Whilst the direct impact of improved digital healthcare data on clinical outcomes in ageing has not been established to our knowledge, it is a key aspect of international examples of integrated care delivery in frailty and multimorbidity [16, 17].

## Patient held records

The WHO emphasises the importance of person-centred digitalisation [9]. Patient held records are an attractive option for transfer of information and patient engagement in patient held records. For example, in Australia, 'My Health Record' is a secure online summary of key patient health information, which patients and healthcare providers can use to collate healthcare information [18]. As with many electronic healthcare records globally, there was a surge in use of the system with COVID to provide vaccination status. There are now more than 23.5 million My Health Record—over 90% population coverage. The meaningful use of personal health records requires end user and health and social care use: 95% of public healthcare services are using My Health Record, but only 14% of private health services [18]. There are also effective examples of increased digitalisation in middle and lower income countries. For example, Uruguay has developed a National Electronic Clinical Record, which is in place for ~80% of the population and enables improved continuity of information [19]. The appropriate flow of information to patient held records should be considered, as early access to results without clinical interpretation can impact on patients [20].

Patient held records require population level digital upskill. Older adults are more likely to be digitally excluded than any other group, with around a third never having used the internet [21]. Barriers to digital inclusion are also clustered in minority ethnic groups, related to low digital literacy and financial hardship [22]. A distinction between 'un-problematic non-use' of the internet and genuine digital

exclusion must be made in considering how patient held records might be utilised by older people. It should not be presumed that older people are unable to use digital resources and Portz *et al.* [23] found that older adults were in fact interested in using patient portals, but careful consideration in relation to aspects such as usefulness and ease of use were required. A study by Lenca *et al.* [24] confirmed that older people view digital technologies positively if they contribute overall positively to general wellbeing, and especially if designed in a patient-centred manner. There are also positive examples of digital enabling, for example, the Digital Heroes scheme in Wales in which confident users of tech can support others to get online [25].

## Frailty

Proactive identification of people with frailty in both primary and secondary care can trigger Comprehensive Geriatric Assessment (CGA), shown to improve patient care and outcomes [26]. Frailty registers are used variably, with some exemplars ensuring real-time updates and continuity of advanced care plan and primary secondary care interface communication, such as alerts on hospital admission. Identification of frailty by electronic health record screening is used to support claims data in the USA and Canada, with a range of frailty prediction models used, some of which lack robust validation studies [27].

In the UK, frailty screening was introduced in the 2017/18 General Practitioner (GP) contract. This has largely been implemented via the electronic frailty index (eFI), which uses routine primary care data to generate a cumulative deficit score based on 36 conditions to predict those at highest risk of frailty. It generates categories of non-frail and mild, moderate or severe frailty. The eFI was predictive of care home and mortality outcomes in derivation data from England [28] and has since been validated in primary care data sets from Scotland, Wales and Australia [27, 29, 30]. The identification of people living with frailty can help clinicians and commissioners to review and plan service provision to better meet their patients' needs.

Older people have higher rates of hospital admission: in 2021–22, people aged over 75 years old comprised 27% of hospital admissions in England [31], where quality standards for frailty mandate screening for frailty within 30 min of unplanned hospital attendance [32]. Currently, this is mainly done through assessment of the patient using the Rockwood Clinical Frailty Scale (CFS) [33]. Whilst the CFS is based on clinical judgement, the documentation can be optimised in the digital record through the use of digital forms or smart phrases, supported by frailty training. The Hospital Frailty Risk Score is based on harnessing and subsequently validating NHS hospital admission data and can aid proactive identification of frailty in secondary care [34], as well as enabling a dashboard for frailty benchmarking.

Electronic patient data are being used in a variety of ways to support the identification and care of people with

frailty but have limitations when used in isolation. Clinical corroboration can add to the validity of frailty coding [27]. The Pathfields Tool is an example of an adaptation of eFI combined with additional use of primary care data to support the identification of those with frailty by integrating additional variables such as residing in a care home, having received a home visit in the last year and having difficulty mobilising at annual review [35]. A key aspect of this tool was that the healthcare team were asked if a patient was notably slower at walking or struggling to stand compared with a fit or well person at a similar age. These data would not have been available in the derivation and validation data for the eFI and add important granularity, showing the utility of integrating clinical judgement and corroboration into an otherwise data-driven risk assessment. The eFI and Hospital Frailty Risk Score both identify cohorts of older people at risk of adverse outcomes during and following an acute hospital admission, but the correlation between the scores is low [36]. Whilst recognition of frailty can be improved through these tools, the impact on individuals identified as frail requires further research.

## Comprehensive Geriatric Assessment

There is good evidence supporting the use of CGA in the care of older people with frailty [26]. This involves multidimensional assessment by a multi-professional team to support a patient-focussed management plan [37]. A single multidisciplinary digital care plan is proposed in the Getting It Right First Time (GIRFT) geriatric medicine report [38], removing the need for multiple assessments and conversations, but this would need considerable cultural and infrastructural changes [27] to standardise recording of clinical assessments. By harnessing digital capability, in the future, CGA continuity could be more feasible across primary, secondary, social care and community practice, as well as benefitting from information from older people and their carers through remote digital communication and assessment [59]. There are examples of successful digital CGA combined with clinical assessment. Aronoff-Spencer *et al.* [39] developed a digital CGA and referral system linking medical, dental and psychosocial needs by real-time CGA-derived metrics for 996 older adults (age  $\geq 60$ ) was implemented as part of a continuous quality improvement project. Successful digital CGA should be appropriate to the specific health service and population requirements.

## The UK context

Approximately 98% of the UK population are registered with the NHS [40], making it potentially more amenable to aligned digital transformation than other more disparate health systems with higher use of private providers. However, health and social care data are captured across multiple systems, typically with separate primary and secondary care, mental health and social care records, which duplicate

information and rarely cross-populate or update between records. The GIRFT report found wide variations in how well data pertaining to geriatric medicine and frailty was used between healthcare organisations [38]. With well-planned digital structure, digital tools can be integrated to measure existing practice against national quality standards, highlight inadequacies, identify priority areas, prioritise patient safety and support improvements in care. Policymakers across the UK have published digital plans for health and social care data that aim to make rapid progress in digitalisation of healthcare records [41, 42]. The importance of leveraging healthcare data for optimisation of patient safety, clinical services and research is well recognised [43, 44].

The Professional Records Standards Body (PRSB) provides guidance on care record minimum standards to ensure that the right information is recorded correctly and can be easily accessed [45]. This provides a framework for secure data sharing that ensures adherence to the UK General Data Protection Regulations. The PRSB has published guidance on key stages of transfer of information in the patient journey, including the core information that can be shared, referral to secondary care, discharge from hospital, emergency care, care homes and end of life care. Importantly, the PRSB recommends the inclusion a person-focussed section, which includes a record of the things that a person feels it is important to communicate about their needs, strengths, values, concerns and preferences to others providing support and care [45]. This places person-centred care at the forefront of the digital record and Patient-Reported Outcome Measures (PROMs) are now being measured routinely in some areas of healthcare [46, 47].

Improved digital records and interoperability could support monitoring and quality improvement of acute and chronic disease in the NHS, currently limited by the validity and completeness of digital records [41]. There is the potential for streamlining of population of specific national audits relevant to geriatric medicine, such as the Sentinel Stroke National Audit Programme, the National Hip Fracture Database and the National Dementia Audit, which are labour intensive and subject to transcribing errors through manual data transfer. Data dashboards, such as those maintained by the NHS benchmarking network [48] and NHS digital [49], can aid data visualisation for scrutiny by clinicians, commissioners and outside bodies such as the Care Quality Commission. The National Commissioning Data Repository portal combines data and intelligence to provide an overview of activity and spend in dashboard format. The most clinically useful dashboards should assimilate information from different sources across the health and care system and present it clearly for interpretation. A theograph is a visual representation of the contacts that individual patients have with health and care services over a period of time. Theographs can illustrate the increasing intensity of care provision (health or social), which can be a signal that more assertive and holistic case management is required.

Shared care records are recommended as a quality standard for people with multiple long-term conditions or living with frailty, [13, 50] supported by NHS England and NHS Digital [51]. This would ideally populate key information for the individual from primary and secondary care, as well as mental health and social care providers. A shared care record may be more feasible in areas with joined up health and care services via integrated care systems (ICS), such as those used in Leeds (<https://www.leedscarerecord.org/>) and Manchester (<https://gmwearebettertogether.com/>). Shared care records can also be used for standardising advanced care plan communications, such as the Red Bag pathway in Sutton [52]. Federated data platforms are being developed to share operational and planning data to inform interventions and foster collaboration, with each trust and ICS having a federated platform which will work alongside their existing systems [53].

Social care digital recording remains limited, with 45% still using paper-based records [41]. Research is helping to inform digitalisation in caring for people as they age. One example is the Developing research resources And Minimum data set for Care Homes' Adoption and use (DACHA) study (Box 1) [54]. A key goal of DACHA is to combine data generated within the care home with existing routinely-collected health and social care data, reducing the burden on care home staff.

#### Box 1: DACHA

- The DACHA study (Developing research resources And Minimum data set for Care Homes' Adoption and use) aims to synthesise existing evidence and data sources with care home-generated resident data to deliver a minimum data set (MDS) that is usable and authoritative for different stakeholders [58].
- Although UK care homes collect and manage significant amounts of detailed data about the individuals they support, there is a lack of meaningful joined-up data about those living in care homes at a national and regional level [59].
- Although the NHS and local authorities generate and hold information about care home residents, often this is not shared with the care home.
- The MDS will be tested in a pilot feasibility study in three regions of England [1].
- In addition to learning from the practical, technical and information governance requirements of linking these data, focus groups and interviews with care home staff and external stakeholders will be used to explore implementation and perceived value of such an MDS in a UK care home context.
- Nine core principles have been developed to inform development, the first of which is to ensure the MDS must primarily focus on measuring what matters most to support those living in care homes through systematic data collection and sharing [54].



- There is a risk of national and regional data about care home residents being dominated by health measures because of lack of availability of data that is not health data.
- A wider range of data is needed to understand the heterogeneity and diversity within the care home sector, supporting older adults with complex needs in context.

## Workforce development

To develop digital records and systems suitable for older people it is vital that health and social care professionals are upskilled in digital healthcare to support transformation.

The importance of healthcare workforce digital upskilling is included in both the Topol and the Goldacre reviews [44, 55], which recommend embedding digital learning into essential clinical training. We should be supporting and driving this as early training of people with enhanced digital skills will allow them to enter the workforce empowered to support digital change.

Globally, there are opportunities for digital leadership training and roles in healthcare systems at organisational, regional and national levels. In the UK, qualifications in digital healthcare leadership are available, including those provided by the NHS Digital Academy, which is a partnership between Health Education England and NHSX [56]. There are also opportunities for work placements with NHS Digital. The UK lacks an established career pathway to develop senior digital leaders, but this is becoming better defined through the work of the Faculty of Clinical Informatics and the Chief Clinical Informatics Officer campaign supporting the appointment of senior clinicians in the NHS, both medical and nursing, to informatics roles including representation at board level. There are increasing opportunities for digital fellowships to be integrated with clinical training, particularly as hospital seeks clinical input into digital transformation.

Collaboration with business analysts and data scientists is important to share tools, case examples and resources, to design digital systems and services that meet the needs of older people. The Geridata network [57] is a collaborative of data analysts, clinicians and researchers working in the digital space to enhance the care of older people and is supported by the British Geriatrics Society. A key aim of this collaborative is to develop a platform for comparison of outcomes in older people using different healthcare data sets. Comparison between different pathways and systems of care in various regions and countries would allow us to better understand which models of geriatric care are best performing to share best practice and drive quality improvement.

## Conclusion

Digitalisation of health and social care systems globally has been prioritised and progress accelerated as a result of the COVID-19 pandemic. The value of accessible, joined-up, high quality data has been recognised and there is momentum in working towards digitally integrated health and social care systems. This period of rapid digital transformation is an opportunity to optimise system changes to ensure that they truly align with the needs of providing health and social care for people as they age. This is vital for both high quality clinical care and to facilitate high quality research. Geriatricians and other professionals involved in the care of older people need to be involved at highest level, to advocate on behalf of those they care for. Digital transformation must include health and social care professionals who understand the complexity of caring for older people and are able to engage older people in systems change. Such transformation will require sufficient investment to realise potential benefits and ensure interoperability.

This is a call to action for geriatricians and other health and social care professionals working in the care of older people to upskill and lead digital development in the UK and globally to ensure that systems are co-designed to support the requirements of older adults and our workforce.

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