

Kent Academic Repository

Davey, Vanessa, Healey, Janice, Liddle, Jennifer, Beresford, Bryony, Rand, Stacey, Goodman, Claire M., Spilsbury, Karen and Hanratty, Barbara (2025) Routine data collection in home care: a national survey of home care providers in England. Quality in Ageing and Older Adults, 26 (1). pp. 56-69. ISSN 1471-7794.

Downloaded from

https://kar.kent.ac.uk/108513/ The University of Kent's Academic Repository KAR

The version of record is available from https://doi.org/10.1108/QAOA-06-2024-0039

This document version

Publisher pdf

DOI for this version

Licence for this version CC BY (Attribution)

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title* of *Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).

Routine data collection in home care: a national survey of home care providers in England

Vanessa Davey, Janice Healey, Jennifer Liddle, Bryony Beresford, Stacey Rand, Claire Goodman, Karen Spilsbury and Barbara Hanratty

Abstract

Purpose - Mandatory digital social care records and a standardised schedule for collecting information on home care clients are proposed for regulated adult social care providers in England. This could facilitate the introduction of a minimum data set (MDS). This study aimed to understand current data collection practices in home care, and identify where support for implementation of an MDS is needed.

Design/methodology/approach - An online survey of English home care providers was conducted in 2023, asking about the information they collect, store and share about their clients. Data were analysed using descriptive statistics and logistic regression.

Findings - One hundred and fifty five responses were received from home care providers in all regions of England, a majority were for-profit organisations (89%). All collected a range of data on client characteristics and observations about care delivered. Monitoring of changes in client wellbeing and use of standardised measurement tools (e.g. functioning, mood or quality of life) were uncommon. Over twothirds (71%) reported that they reviewed the content of care packages at least every six months. Providers with a majority of self-funding clients were more likely to regularly update information on care needs and client/family preferences.

Practical implications - Data collection in UK home care will require expansion, to implement an MDS, which has resource implications for providers. Home care staff will need the skills to collect and use data to enhance client care.

Originality/value - To the best of the authors' knowledge, this is the first national survey of home care providers on their routine data collection practices.

Keywords Social care, Home care, Long-term care, Aged, Digital records, Minimum data set Paper type Research paper

Introduction

Home or domiciliary care is an essential community-based service to enable people with care and support needs to maintain their independence and live at home. The range of home care services is wide, from intensive support with activities of daily living, to food preparation and companionship. Support is usually provided at varying times throughout the day, or in some cases, over a 24h period. In England, publicly-funded home care accounts for just over two thirds of support provided, and will normally include (but may not be limited to) personal care (e.g. help with washing, dressing, using the toilet) (LaingBuisson, 2021). Home care supports almost one million people with long-term care needs in the UK, approximately twice the number of people living in care homes (Berg, 2024a, 2024b). It has a critical impact on the individuals and families who receive support (Boyle et al., 2023; Rand et al., 2017; Rand et al., 2022) but also accounts for a significant component of public sector spending (Allan et al., 2021; Gridley et al., 2022; NAO, 2021). Data availability has been a major barrier to increasing our understanding of this important

(Information about the authors can be found at the end of this article.)

Received 10 June 2024 Revised 7 October 2024 22 January 2025 Accepted 22 January 2025

© Vanessa Davey, Janice Healey, Jennifer Liddle, Bryony Beresford, Stacey Rand, Claire Goodman, Karen Spilsbury and Barbara Hanratty. Published by Emerald Publishing Limited. This article is published under the Creative Commons Attribution (CC BY 4.0) licence. Anyone may reproduce, distribute. translate and create derivative works of this article (for both commercial and non-commercial purposes), subject to full attribution to the original publication and authors. The full terms of this licence may be seen at http://creativecommons. org/licences/by/4.0/legalcode

This project is funded by the NIHR Health Service Research and Delivery programme (HS&DR NIHR127234) and supported by the NIHR Applied Research Collaboration East of England, Several authors are supported by the NIHR Applied Research Collaborations in East of England (CG); North East and North Cumbria (VD, JL, BH) and Yorkshire and Humber (KS). The views expressed in this publication are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. NIHR Health Service Research and Delivery Programme; No. HS&DR NIHR127234.

area of care. Home care clients may have physical, mental and/or cognitive impairments, but unlike health service patients, information on their characteristics is not readily available (Curry and Oung, 2021).

The organisation and funding of home care services in England precludes systematic exchange of client information across health and social care services (Author's own, In Review). As a result, organisations have to collate their own information. The content of records at provider-level is loosely specified in the UK, unlike other countries where documentation is often standardised and structured for both administrative *and* evaluation purposes (Mitchell *et al.*, 2023; Morandi *et al.*, 2024; Puustinen *et al.*, 2021). Such specifications are often termed Minimum Data Sets or "MDS".

Ambitious targets mandating digital social care records (DSCR) for England are expected to transform the content and availability of data at provider level (DHSC, 2022b, 2022c, 2023). The current programme of work, led by NHS England Digital (the national information and technology partner to the health and social care system using digital technology to transform the NHS and social care) is focused is on structured care planning and facilitating information exchange. This includes design specifications for all DSCR providers (DiSC, 2024) with data capture fields to promote person-centred care (PRSB, 2021), alongside specifications to standardise quantitative content, compliant with international e-health data standards (NHSE, 2022; NLM, 2023). The latter will support integration of DSCRs with NHS applications and allow care workers a filtered view of a client's electronic healthcare record (DHSC, 2022a; NAO, 2018). This standardisation programme also aims to align data content at provider-level, making it *potentially* suitable for aggregation.

Data collected by UK local authorities currently include a measure of quality of life (QoL) as the main outcome of social care (NHSE, 2023a, 2023b). This information is collected by survey, but coverage is limited, and the data cannot be linked to service delivery (Aznar et al., 2021). The digitalisation of home records offers an opportunity to collate client-level data on the home care population. If this approach is mandated, it would represent a dramatic change in responsibility for data collection. In particular, home care providers will need to use standardized measures to record client characteristics and wellbeing, something that is not currently part of the Adult Social Care Record Data Standard (MODS) (DiSC, 2024).

Information on home care clients could have many applications, including quality improvement, and enhancing understanding of services provided to people who pay for their own care (known as self-funders) (Allan *et al.*, 2024). Linkage to other sources of information, (e.g. using a unique client identifier such as an National Health Service or National Insurance number) offers population level insights into how health, care and support needs change over time (Burton *et al.*, 2022; Dickins *et al.*, 2023; Gordon *et al.*, 2025).

Despite rapid implementation of digital records in England, and the expectation that a minimum specification for client level data collected by home care providers will eventually be embedded within future DSCRs in England (BSG, 2023), little is known about what kind of information home care providers currently collect about their clients and how well current practices would support the introduction of an MDS.

Methods

Study aims

The survey aims were to describe the data routinely collected by home care providers to establish if the range and content of data currently collected are sufficient to support the move to standardised methods of data capture.

Study design

We conducted an electronic survey, hosted on the Qualtrics survey platform (Qualtrics, Provo, UT, USA), to ask UK home care providers about the information they collect and store about their clients.

The survey comprised 45 questions, organised into six sections. In this paper, we report on data collected on the following topics: data collected at outset and frequency of care package review, information to support care delivery, routine use of standardised measures for assessment or monitoring and routine measurement of satisfaction with the service. In a separate article published elsewhere, we describe progress towards, and experiences of, digitalisation amongst home care providers (Healey *et al.*, 2024).

The survey was developed in three stages. A prototype was developed with questions informed by a similar survey with care home providers, that aimed to identify the range (and method) of data collected by care home organisations (Hanratty *et al.*, 2023). The prototype was reviewed by a small number of academics independent of the research team, and representatives of two national organisations representing UK home care providers. A version was then piloted in Qualtrics with senior managers of two home care providers using cognitive interview techniques (Ryan *et al.*, 2012). Revisions were made and tested in a second pilot. A copy of the survey questions is provided in Supplementary File #1.

Data collection

In England there are 11,204 home care providers registered with the regulator Care Quality Commission (CQC), with many providers affiliated to membership bodies. To reach regulated organisations that were providers of regular home visits, an email invitation to take part in the survey (including anonymous hyperlink to the survey and with the study information sheet attached) was distributed by national, regional and local membership bodies representing both for-profit and not-for-profit home care providers. The research team also distributed the email invitation via their existing networks and posted information about the survey on social media. One email reminder was sent out by all routes mentioned above. The online survey was operational between 19th October and 9th December 2022. Survey completion was anonymous, but respondents could volunteer the name of their home care organisation. Instructions requested completion by the owner/director or a manager including obtaining informed consent for participation.

Data analysis

The data were cleaned in Excel and imported into SPSS (SPSS 25.0) for descriptive analysis and logistic regression to explore relationships between key characteristics of home care organisations and the types of data collected (e.g. funding source, organisation size measured by caseload size, number of operating bases, regional footprint, use of digital records, nature of home care provided).

Results

Sample

One hundred and 55 responses were received. A majority were from for-profit organisations (n=134, 89%), and independent businesses (n=94, 60%). Just under one third were care/home care chains (17, 30%), and one fifth "franchise" owners (home care organisations run independently but in accordance with the franchisor branding and standards) (30, 19%) (Table 1).

Caseloads ranged from fewer than 20, to more than 250 clients. Compared to national regulator data on home care providers, our respondents were more likely to have high or

Table 1 Survey of home care providers: sample characteristics				
Home care provider characteristics	Frequency (n)	%		
Respondent's role within the home care organisation				
Business owner/franchisee	56 (155)	36		
CEO/executive director or other director	28 (155)	18		
Senior manager	24 (155)	15		
Registered manager	41 (155)	26		
Other	7 (155)	4		
Home care provider type				
Franchise*	30 (155)	19		
Local office/branch of chain business	8 (155)	24		
Independent business+	94 (155)	60		
Local authority in-house service	5 (155)	5		
Chain business (head office)	9 (155)	6		
Other	10 (155)	6		
Scale of home care organisation (by N of branches)				
1 office/operating base	79 (112)	71		
2–3 branches/offices	18 (112)	16		
4–10 branches/offices	8 (112)	7		
11–19 branches/offices	2 (112)	2		
20+ branches/offices	5 (112)	4		
Caseload\$				
< 20 clients	21 (152)	14		
20–49 clients	37(152)	24		
50–99 clients	34 (152)	22		
100-249 clients	29 (152)	19		
250 and above	31 (152)	20		
Spread of home care organisation				
Only one region	132 (152)	86		
1–3 regions	13 (152)	8		
4 regions and above	9 (152)	6		
Financial structure				
For profit	134 (151)	89		
Not for profit	16	10		
Social enterprise	0	0		
Other	1	<1		
Services provided				
Regular domiciliary care visits	145 (155)	93		
Reablement	51 (155)	33		
Live-in care	56 (155)	36		
Continuing health care (CHC) funded care	94 (155)	60		
Other	9 (155)	6		
Main funding source				
All or mostly LA or NHS funded (incl. DP)	65 (151)	43		
All or mostly self-funded	54 (151)	36		
Roughly equal	32 (151)	21		

Note(s): *This is a home care agency run independently but in accordance with franchisor branding and standards; *Nationally, 65% of home care organisations registered by CQC are independent businesses (LaingBuisson, 2021); *Nationally 41% of registered home care organisations have < 20 clients, 29% have between 20–49 clients, 17% have been 50–99 clients, 10% have 100–249 clients and 2% have 250 clients and above (Ibid)

Source(s): Table by authors

very high caseloads and less likely to be micro-providers (<20 clients). Thirty-eight per cent of our respondents had a caseload below the national average (47 clients), compared to 58% of all providers (LaingBuisson, 2021). From caseload data, we estimate that survey respondents represent around 6.5% of services provided in England. In addition to regular

domiciliary care visits, just over a third of respondents were from organisations providing reablement or restorative care (a short-term intervention delivered to people living in their own homes which seeks to restore, or maximise, independence in activities of daily living). Reablement represent around 4% by value of the homecare provided in England (LaingBuisson, 2021). A similar proportion were providing 24 h live-in care. Organisations that offered more than one type of home care were likely to be providing multiple types.

Providers responded from all regions of England, more than half (51%) from London and the Southeast. Responses were in line with variations in regional market fragmentation (LaingBuisson, 2021). Most providers (86%) operated in only one region. The proportion of small providers (up to 49 clients) amongst respondents varied by region, from 42% in London to 14% in the Northeast. Large providers (> 250 clients) accounted for around one third of the sample in all regions, except the Northeast where 50% of the sample had >250 clients.

Organisational size was associated with funding source. Very small (<19 clients) small (20–49 clients) and medium (50–99 clients) organisations were more likely to have a high proportion of clients who had local or national government funding (Local authority or National Health Service (NHS)). Providers were split between those that used all or predominantly digital records (n = 77, 50%) and those that used a mix of digital and paper records (n = 71, 46%). A minority were entirely paper-based (n = 7, 4.5%).

Data collected at outset and frequency of care package review

Administrative data routinely collected at entry point to a service almost always included the origin of the referral (n=138,88%) and funding source (n=142,90%). Fewer than half of responding home care providers recorded NHS number and only six in ten recorded a local authority reference number. This practice was associated with funding status, and much more likely to be recorded by home care providers who were mostly reliant on local authority and/or NHS funding (X^2 (1, n=150) = 26.838, p=<0.001). Similarly, organisations that routinely record NHS number were likely to record information on primary care and community health care (X^2 (1, n=155) = 5.740, p=0.017) but were not more likely to record hospital services involved (Table 2). Organisations that *did not* report recording NHS number, were more likely to only provide standard home (domiciliary) care (X^2 (1, n=155) = 6.142, p=0.013) and also record their clients' National Insurance number.

Over two-thirds of home care providers (71%, n=95) reported that they reviewed clients' care packages every six months, or more often. Organisations providing continuing health care (n=94, 60%) were more likely to review clients' packages at least every 6 months (X^2 (1, n=134) = 4.270, p=0.039), while organisations only providing regular domiciliary care were less likely to do so (X^2 (1, n=134) = 6.270, p=0.012). Frequency of client review was not associated with funding source, caseload size, number of operating bases or use of digital care records.

Information to support care delivery

Home care providers reported the collection of a wide range of information to support care planning and delivery (Table 2). This included data on health conditions, disabilities, involvement of other services and unpaid carers, care needs, goals and preferences, care package details and a range of information recorded in a client's care record as part of daily observations.

Almost all responding home care providers recorded observations about care at each visit, including tasks undertaken, medication prompts/administration and adverse events. Documentation of perceived changes in psychosocial wellbeing (mood, loneliness or social networks) was seldom recorded in a standardised format (Table 3). However, most providers record observed changes in wellbeing in aspects *such as* pain, confusion, mood

Table 2 Information on health, functioning and care delivery, routinely collected in home care Frequency of updating When Only at care Not No standard Not stateda changes package Types of client information collected Frequency (n) % occur (%) review (%) practice (%) updated (%) Information about health conditions and disabilities Diagnosed physical health conditions 148 (155) 95 90 3 7 92 3 11 Diagnosed mental health conditions 144 (155) 86 Memory or cognitive impairment 146 (155) 94 85 3 12 Sight or hearing impairment 143 (155) 92 83 4 13 93 84 3 12 Communication needs 145 (155) <1 74 2 30 116 (155) 65 3 Diagnosed learning disabilities 3 43 Autism diagnosis 94 (155) 60 54 <1 Information on the involvement of other services and informal carers 89 11 Other social care services 138 (155) 132 (155) Primary care/ community health care 85 85 15 Health clinics/ services involved 117 (155) 75 75 25 Informal carers 126 (155) 81 81 19 Information about care needs, goals and preferences and care package details Care needs (e.g., person care, domestic, mobility) 90 86 3 10 140 (155) 1 Regular medications 139 (155) 90 88 1 10 Client/ family desired outcomes/ goals for care 89 74 10 4 <1 11 138 (155) Preferences for how care is delivered 139 (155) 90 81 8 10 Care package details 137 (155) 88 84 4 <1 12 Information routinely collected in a client's daily care file/record (paper or digital) 3 1 10 Care tasks completed at each visit 153 (155) 99 86 Medication prompting and administered (MAR) 154 (155) 99 88 10 1 1 Any healthcare tasks (e.g., wound care, health 150 (155) 97 74 10 4 11 status monitoring) Adverse events or incidents 153 (155) 99 81 8 1 10 Observed changes in client's wellbeing (e.g., pain, 142 (155) 92 84 4 <1 12

Note(s): ^aNot stated' includes organisations that stated that they do record the information but did not state when they update, and organisations that did not indicate that they record the information

Source(s): Table by authors

confusion, mood)

in a non-standardised way (Table 2). Updating of the latter was variable: sometimes only at care package reviews. Others provided no data on regularity of updates, suggesting that formal documentation was not the primary means for exchanging information on these aspects of client wellbeing. Otherwise, most information to support care delivery was updated when changes occur, but less so for health care tasks. There was no association between this, and the provision of NHS funded "continuing health care".

Home care providers serving all or a majority of self-funding clients were significantly more likely to report that they regularly update information on care needs, client/family desired outcomes, goals for care, preferences for how care is delivered and care package details when changes occur (X^2 (1, n = 150) = 4.334, p = 0.037, X^2 (1, n = 150) = 7.454, p = 0.006, X^2 (1, n = 150) = 4.666, p = 0.031, X^2 (1, n = 150) = 4.426, p = 0.035, respectively).

Overall, use of digital records did not appear to be associated with the types of information collected to support care delivery, or how often data items were updated. Providers who used some paper records were more likely to report that they routinely update information on client/family desired outcomes, when changes occur (X^2 (1, n = 155) = 7.265, p = 0.007).

Client diagnoses of learning disabilities and autistic spectrum disorder were recorded by 75% and 60% of the 155 respondents. Providers with 20–49 clients were more likely to collect these data (X^2 (1, n=151) = 4.907, p=0.027). This reflects the size of organisations providing care to people living with these conditions.

Routine use of standardised measures for assessment or monitoring

Routine measurement of independence/functioning, physical activity and mood was limited, as was data collection on skin integrity and nutrition (Table 3). Routine observation of pain using standardised measures was reported by just under a fifth of respondents. Medium sized providers (caseloads of 50–99 clients) were less likely than providers of other sizes to use standardised measures of physical wellbeing (independence/functioning, frailty, physical activity and sleep) (X^2 (1, n = 136) = 4.086, p = 0.043), but as likely as any size of organisation to monitor skin integrity or pain using recognised tools.

There was no relationship between the provision of reablement services and recording of data on frailty, independence/functioning or physical activity. However, it should be noted that the survey only captured home care providers that were providing reablement services in addition to standard domiciliary care services.

Psychosocial aspects of wellbeing (social networks and loneliness) were recorded by just 3% of the sample. Routine collection of measures of psychosocial wellbeing (comprising either/or, mood, loneliness or social networks) was negatively associated with providing live-in care (X^2 (1, n=139) = 3.713, p=0.054) but more frequent among home care providers with extremely small caseloads (<20 clients).

Quality-of-life measures were not being systematically used by the majority of providers. Of the options offered (Table 3) the most frequently used was the Social Care Related Quality of Life measure (ScRQoL), ASCOT. We received one free text response, describing use of a measure not listed. ScRQoL was in routine use in 13% (n = 20) of responding organisations, which were more likely to have very low caseloads (<20 clients) (X^2 (1, n = 130) = 3.848, p = 0.050). There was no evidence of any relationship between use of digital care records and routine use of standardised measures of physical wellbeing, psychosocial wellbeing and quality-of-life.

Routine measurement of satisfaction with the service

Most providers used client satisfaction surveys, either a bespoke tool (n=121,85%), or one developed elsewhere (n=17,12%). Development of an in-house client satisfaction survey was positively associated with provider size, as measured by caseload. Organisations with over 250 clients were particularly likely to have developed their own measures (X^2 (1, n=139) = 5.297, p=0.021).

Discussion

The need for enhanced data in home care is widely acknowledged, but understanding of current practice is limited. This study focused on collection of information about clients within UK home care and aimed to describe the data routinely collected by home care providers, to establish if the range and content of data currently collected are sufficient to support the move to a home care MDS.

Providers are collecting a range of data on client characteristics and daily observations about care delivery, but few are routinely recording changes in client wellbeing over time using standardised tools. Any home care MDS that contains accurate and up-to-date information on health, care, support needs and QoL would require standardised data collection. Our findings suggest an absence in routine use, of standardised measurement tools in home care, ranging from measures of independence/functioning, physical activity and mood to physical and psychosocial aspects of wellbeing and QoL. This has important implications for the implementation of a home care MDS.

In parallel work, examining information collected about residents in care homes as an indicator of feasibility of implementation of a MDS in care homes, Hanratty et al. (2023) have

Table 3 Home care data collection: Referral, care package review and use of standardised measurement tools				
	Fi	requency (n)	%	
How often client packages are reviewed Annually Every 6 months, or more frequently		39 (135) 95 (135)	29 71	
Types of client information collected Who made the referral (e.g., client, family, LA) Who is funding the care (e.g., self, DP, LA) NHS number Local authority reference number National insurance number	138 (155) 142 (155) 71 (155) 93 (155) 19 (155)		88 90 45 60 12	
Routine use of standard measurement tools	F	0/ Danas d'as hassa	0/ 0	
Physical wellbeing Independence/ functioning (e.g., Barthel index) Frailty (e.g., clinical frailty score) Physical activity (e.g., physical activity scale for the Elderly - PASE) Sleep (e.g., Sleep quality scale) Skin condition (e.g., waterlow scale) Nutrition (e.g., MUST screening scale)	15 (140) 19 (140) 9 (140) 7 (140) 59 (140) 57 (140)	% Responding home care organisations 11 14 6 5 42 41	% Care homes (Hanratty et al., 2023) 85 28 84 92 85 68	
Psychosocial wellbeing Mood (e.g., Geriatric depression score Loneliness (e.g., UCLA loneliness scale) Social networks (e.g., lubben social networks scale) Other Pain (e.g., Abbey pain scale)	16 (140) 4 (140) 4 (140) 27 (140)	11 3 3 19	86 - - 62	
Routine use of quality-of-life tools* Adult social care outcomes tool (ASCOT) ICECAP quality of life measure Euro-QoL EQ-5D (or EQ 3-D) R-Outcomes	20 (155) 5 (155) 1 (155) 5 (155)	13 3 <1 3	- - - -	
Routine use of satisfaction tools Client satisfaction survey/ questionnaire	139 (155)	89	-	
Note(s): *Other quality of life tools noted were, Personal Outcomes other, non-specified $(n=3)$ Source(s): Table by authors	Scale (Ghent) (n	= 1), Outcomes Wheel (n $=$	1), UDSET (<i>n</i> = 1) and	

demonstrated that care homes are familiar with a wide range of standardised measurement tools for tracking physical wellbeing, despite having minimal training, akin to home care workers. Their lack of use in home care may reflect the context. In care homes, where 24 h care is provided, it is important for staff to have a detailed understanding of a resident's medical history, any current conditions, their treatment and potential consequences. In England, people are more reliant on primary care to address their health needs and the older person, family and primary care team generally retain responsibility for ongoing health monitoring. The type of information that is routinely recorded in home care settings is indicative of the perceived scope and purpose of home care in England (Author's own, In Review) contrasting with norms for routinely collected data in other countries (e.g. Puustinen et al., 2023).

In home care, lone workers may have a focus on discrete tasks rather than all aspects of care, and have fewer regular interactions with nursing and other allied health professionals than care home staff (Hamblin *et al.*, 2023). Yet, even among organisations where we might expect a focus on health related information (i.e. those providing NHS funded care), and clients whose care needs frequent review, we found little evidence of any particular

emphasis on monitoring the impact of care or client changes over time. Independent home care organisations have no history of information sharing. Our results show that many organisations do not record clients' health or local authority identifiers that would be required for data sharing to promote integrated care.

Our findings show that in home care, priority in data recording is given to areas that may be actively reviewed by the regulatory body or funders, such as medication management and adverse events. The recommendation that home care providers "actively encourage feedback about the quality of care" (Health & Social Care Act, 17(2)(e)) has not led many providers to embrace routine measurement of QoL as an indicator of care quality and responsiveness to fluctuating need. The paucity of use of QoL measures was not unexpected, but our findings show a substantial gap between voluntary adoption in care homes 31% – Hanratty et al. (2023) and home care settings (13%).

Current conditions in care must be considered alongside the information that is already routinely used in care. Home care in England experiences significant recruitment and retention challenges, and a mismatch between service delivery costs and funding. Recent estimates suggest that 38% of home care workers are on zero hours contracts, versus 10% in care homes (Skills for Care, 2024). The home care sector relies more heavily on public funding than care homes (cf. LaingBuisson, 2021). Questions remain about the extent to which recording changes in client wellbeing over time (using standardised tools) aligns with the core task of providing home care services in this context. Contracts are tightly prescribed and care vists are both time-poor, and focused on task-based care (Atkinson and Crozier, 2020; Backhouse and Ruston, 2022; Davies et al., 2022). It is important to understand what information home care staff consider to be relevant to providing care, how any requirements to collect data would interplay with existing support needs for care workers (cf. Leverton et al., 2021) and how home care organisations would use the data. Home care providers appear to recognise the importance of measuring QoL and using standardised measured to monitor other key aspects of wellbeing. However, they fear that it may be "asking a bit too much" (Davey et al., 2024) of staff on minimal pay, to facilitate outcomes assessment. There are also concerns about alignment with existing data collection requirements and integration into existing workflows and digital systems used by home care providers (Davey et al., 2024).

Despite these concerns, our findings show that where home care organisations rely more heavily on *private* clients (self-funders) – consistent with receiving higher payment rates for care and being less time-constricted in care visits – there seems to be a more personalised approach to data capture, emphasising recording and updating client and/or family orientated goals. This may reflect what people expect from services. It is also consistent with service user and family members' expectations for care records (Davey and Killett, 2024) which raises questions about the relationship between data collection practices and perceived quality of care. The requirements for new data collection may be used to support care practices, including the kinds of personalized relationships valued by service users and their families (Hall *et al.*, 2024). Future research may be useful, with organisations whose data collection is already aligned to a potential MDS for home care.

Finally, our survey data also allowed us to examine the influence of the implementation of DSCRs. DSCRs do not appear to be changing the types of information routinely collected, or moving it towards less task-orientated content, despite the expected ease of use and potential for shaping recording and updating of information (CQC, 2024). Indeed, we found that recording client and family desired goals for care and monitoring and updating of psychosocial aspects of wellbeing were more common among the very small home care providers and those who were still partly reliant on paper-based systems.

Our findings are specific to England, but there are parallels with observations of information collected in home care in other countries. In Norway, home care documentation systems have a limited focus on long-term care needs beyond clinical information, with limited collection of data on psychosocial needs, despite national recommendations (Veenstra et al., 2020). Likewise in Finland, research has found that information on daily activities is most consistently completed, based on a narrow view of individual needs, despite guidance on integrating and recording the views of older people on planning and delivery of their care (Puustinen et al., 2021: e144). Neither country has wholly standardised or digitised formats for collecting data in home care and research on the experiences of home care workers in processing client information via mobile devices is still very limited (Perez et al., 2022; Vasalampi, 2017).

Limitations

Home care organisations with high caseloads were overrepresented in the sample and small organisations were somewhat underrepresented. Larger organisations may have been more likely to be part of provider networks that circulated the survey and have the capacity to respond. Financially robust organisations are also more likely to embrace digitalisation and the economies of scale that can be realised for example, in back-office costs (LaingBuisson, 2021). The proportion of medium sized provider respondents matched national figures, which is an important achievement as they tend to be reliant on public funding (Davies *et al.*, 2020). We had little information on respondent location to preserve anonymity, so we were unable to explore any impact of rural or coastal geographies on data collection.

This survey offers the first broad insight into routinely collected data in home care in England, and how comprehensive this is. It does not provide information on the perceptions of people receiving home care services and their families, and questions on how the data are used are reported elsewhere (Healey *et al.*, 2024). Inconsistencies and variable quality in routinely collected data have been described in the UK (e.g. Brown *et al.*, 2022) and other countries (Puustinen *et al.*, 2021; Tshering *et al.*, 2024; Veenstra *et al.*, 2020).

Conclusion

A home care MDS embedded within mandated DSCRs could offer an efficient and complete means of monitoring the impact of home care, representing a sea change in how data are collected in English adult social care. Our work suggests that routine data collection on health, wellbeing and QoL is currently limited in home care. The introduction of a home care MDS would require profound adjustments in the types of routinely collected data and work to identify which measures are feasible to include. Home care organisations reliant on public funding are amongst the least prepared to implement an MDS. Extensive support for implementation of DSCRs and an MDS is likely to be required, ranging from extending data collection to staff training and promoting a culture of joint working. It will be important to reach a consensus on MDS content, balancing the interests of diverse stakeholders. The potential gains from improved data collection should not be offset by unrealistic demands on home care providers and staff. Any new data collection will have to harmonise with current workflows and support care practices if it is to be accepted by care providers. This survey is a critical first step in examining the readiness for a home care MDS.

References

Allan, S., Roland, D., Malisauskaite, G., Jones, K., Baxter, K., Gridley, K. and Birks, Y. (2021), "The influence of home care supply on delayed discharges from hospital in England", *BMC Health Services Research*, Vol. 21 No. 1, p. 1297, doi: 10.1186/s12913-021-07206-5.

Allan, S., Rand, S., Towers, A.-M., De Corte, K., Tracey, F., Crellin, E., Lloyd, T., Carroll, R.E., Palmer, S., Webster, L., Gordon, A., Smith, N., Akdur, G., Killett, A., Spilsbury, K. and Goodman, C. (2024), "Factors associated with care home resident quality of life: demonstrating the value of a pilot minimum data set using cross-sectional analysis from the DACHA study", medRxiv, 2024.2005.2030.24308190, doi: 10.1101/2024.05.30.24308190.

Atkinson, C. and Crozier, S. (2020), "Fragmented time and domiciliary care quality", *Employee Relations: The International Journal*, Vol. 42 No. 1, pp. 35-51, doi: 10.1108/ER-05-2018-0142.

Aznar, C.L., Blake, M., Mackie, M., Pickering, K. and Reshi, A. (2021), "Representativeness of adult social care surveys", Main Report, IPSOS Mori.

Backhouse, T. and Ruston, A. (2022), "Home-care workers' experiences of assisting people with dementia with their personal care: a qualitative interview study", *Health & Social Care in the Community*, Vol. 30 No. 3, pp. e749-e759, doi: 10.1111/hsc.13445.

Berg, V. (2024a), "Care home stats: number of settings, population & workforce", available at: www.carehome.co.uk/advice/care-home-stats-number-of-settings-population-workforce (accessed 1 October 2024).

Berg, V. (2024b), "Home care statistics: number of providers, service users & workforce", homecare.co. uk2024, available at: www.homecare.co.uk/advice/home-care-facts-and-stats-number-of-providers-service-users-workforce (accessed 1 October 2024).

Boyle, N., Seddon, D. and Toms, G. (2023), "Exploring overnight social care for older adults: a scoping review", *Quality in Ageing and Older Adults*, Vol. 24 No. 4, pp. 127-138, doi: 10.1108/QAOA-11-2022-0070.

Brown, P., Leverton, M., Burton, A., Harrison-Dening, K., Beresford-Dent, J. and Cooper, C. (2022), "How does the delivery of paid home care compare to the care plan for clients living with dementia?", *Health & Social Care in the Community*, Vol. 30 No. 5, pp. e3158-e3170, doi: 10.1111/hsc.13761.

BSG (2023), "Smarter data, better care: empowering care homes to use data to transform quality of care", *British Geriatric Society (BGS)*, available at: www.bgs.org.uk/sites/default/files/content/attachment/2023-12-04/BGS%20Smarter%20data%20better%20care_0.pdf (accessed 28 September 2024).

Burton, J.K., Wolters, A.T., Towers, A.-M., Jones, L., Meyer, J., Gordon, A.L., Irvine, L., Hanratty, B., Spilsbury, K., Peryer, G., Rand, S., Killett, A., Akdur, G., Allan, S., Biswas, P. and Goodman, C. (2022), "Developing a minimum data set for older adult care homes in the UK: exploring the concept and defining early core principles", *The Lancet Healthy Longevity*, Vol. 3 No. 3, pp. e186-e193, doi: 10.1016/S2666-7568(22)00010-1.

CQC (2024), "Digital record systems: achieving good outcomes for people using adult social care services", Care Quality Commission, available at: www.cqc.org.uk/guidance-providers/adult-social-care/digital-record-systems-adult-social-care-services

Curry, N. and Oung, C. (2021), "Fractured and forgotten? The social care provider market in England", *Nuffield Trust*, available at: www.nuffieldtrust.org.uk/research/fractured-and-forgotten-the-social-care-provider-market-in-england (accessed 4 October 2024).

Davey, V. and Killett, A. (2024), "Expectations and sense of ownership of care records – comparison across digital and non-digital and care setting", British Society of Gerontology conference 2024, Newcastle University, Newcastle-Upon-Tyne.

Davey, V., Lazo Green, K., Inskip, A., Beyer, F., Spiers, G. and Hanratty, B. (2024), "Exploring the content of a minimum data set for homecare", NIHR Policy Research Unit Older People and Frailty/NIHR Policy Research Unit Healthy Ageing.

Davies, K., Dalgarno, E., Angel, C., Davies, S., Hughes, J., Chester, H., Jasper, R., Roberts, A. and Challis, D. (2022), "Home-care providers as collaborators in commissioning arrangements for older people", *Health & Social Care in the Community*, Vol. 30 No. 2, pp. 644-655, doi: 10.1111/hsc.13169.

Davies, S., Hughes, J., Davies, K., Dalgarno, E., Jasper, R.E., Chester, H., Roberts, A. and Challis, D. (2020), "Changes in commissioning home care: an English survey", *Quality in Ageing and Older Adults*, Vol. 21 No. 1, pp. 3-14, doi: 10.1108/QAOA-10-2019-0055.

DHSC (2022a), "Data saves lives: reshaping health and social care with data", Department of Health & Social Care, available at: www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data#improving-data-for-adult-social-care (accessed 28 September 2024).

DHSC (2022b), "People at the heart of care: adult social care reform", Department of Health & Social Care, available at: www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper/people-at-the-heart-of-care-adult-social-care-reform (accessed 28 September 2024).

DHSC (2022c), "A plan for digital health and social care", Department of Health & Social Care, available at: www.gov.uk/government/publications/a-plan-for-digital-health-and-social-care/a-plan-for-digital-health-and-social-care (accessed 28 September 2024).

DHSC (2023), "Care data matters: a roadmap for better data for adult social care", Department of Health and Social Care, available at: www.gov.uk/government/publications/care-data-matters-a-roadmap-for-better-data-for-adult-social-care/care-data-matters-a-roadmap-for-better-data-for-adult-social-care

Dickins, M., Joe, A. and Lowthian, J.A. (2023), "Ten-Year trends and predictors of unplanned hospitalisation in community-dwelling older people receiving Home-Based care", *Health & Social Care in the Community*, Vol. 2023, p. 9332777, doi: 10.1155/2023/9332777.

DiSC (2024), "Adult social care record data standard (MODS)", available at: https://data.digitisingsocialcare.co.uk (accessed 30 November 2024).

Gordon, A.L., Rand, S., Crellin, E., Allan, S., Tracey, F., De Corte, K., Lloyd, T., Brine, R., Carroll, R.E., Towers, A.-M., Burton, J.K., Akdur, G., Hanratty, B., Webster, L., Palmer, S., Jones, L., Meyer, J., Spilsbury, K., Killett, A. and Goodman, C. (2025), "Piloting a minimum data set for older people living in care homes in England: a developmental study", *Age and Ageing*, Vol. 54 No. 1, p. afaf001, doi: 10.1093/ageing/afaf001.

Gridley, K., Baxter, K., Birks, Y., Newbould, L., Allan, S., Roland, D., Malisauskaite, G. and Jones, K. (2022), "Social care causes of delayed transfer of care (DTOC) from hospital for older people: unpicking the nuances of 'provider capacity' and 'patient choice", *Health & Social Care in the Community*, Vol. 30 No. 6, pp. e4982-e4991, doi: 10.1111/hsc.13911.

Hall, A., Davey, V., McGarrigle, L., Astbury, J., Lazo Green, K., Ahmed, N., Williams, O., Beyer, F., Hanratty, B. and Price, D. (2024), "The meaning of 'quality' of homecare for older people: a scoping review", NIHR Policy Research Unit Older People and Frailty/NIHR Policy Research Unit Healthy Ageing.

Hamblin, K., Burns, D. and Goodlad, C. (2023), "Technology and homecare in the UK: policy, storylines and practice", *Journal of Social Policy*, pp. 1-17, doi: 10.1017/S0047279423000156.

Hanratty, B., Wolters, A.T., Towers, A.-M., Spilsbury, K., Meyer, J., Killett, A., Jones, L., Gordon, A., Burton, J.K., Akdur, G., Irvine, L., Warmoth, K., Liddle, J. and Goodman, C. (2023), "Data collection in care homes for older adults: a national survey in England", *Journal of Long-Term Care*, doi: 10.31389/jltc.199.

Healey, J., Davey, V., Liddle, J., O'Rourke, G., Hanratty, B. and Beresford, B. (2024), "UK homecare providers' views about, and experiences of, digitalisation: a national survey", *Digital Health*, Vol. 10, p. 20552076241255477, doi: 10.1177/20552076241255477.

LaingBuisson (2021), "Homecare and supported living", Fourth Edition, LaingBuisson Ltd., London.

Leverton, M., Burton, A., Beresford-Dent, J., Rapaport, P., Manthorpe, J., Mansour, H., Guerra Ceballos, S., Downs, M., Samus, Q., Dow, B., Lord, K. and Cooper, C. (2021), "You can't just put somebody in a situation with no armour'. An ethnographic exploration of the training and support needs of homecare workers caring for people living with dementia", *Dementia (London)*, Vol. 20 No. 8, pp. 2982-3005, doi: 10.1177/14713012211023676.

Mitchell, L., Poss, J., MacDonald, M., Burke, R. and Keefe, J.M. (2023), "Inter-provincial variation in older home care clients and their pathways: a population-based retrospective cohort study in Canada", *BMC Geriatrics*, Vol. 23 No. 1, p. 389, doi: 10.1186/s12877-023-04097-5.

Morandi, A., Zambon, A., Crippa, M., Re, M., Riva, L., Lombardi, F., Mazzola, P., Scaccabarozzi, G. and Bellelli, G. (2024), "Predicting 60-Day mortality in a Home-Care service: development of a new Inter-RAI 49-Frailty index in patients with chronic disease and without a cancer diagnosis", *Journal of the American Medical Directors Association*, Vol. 25 No. 3, pp. 521-525, doi: 10.1016/j.jamda.2023.10.028.

NAO (2018), "Health & social care integration", National Audit Office, London.

NAO (2021), "The adult social care market in England", National Audit Office, London.

NHSE (2022), "FHIR UK core", N. England, available at: https://digital.nhs.uk/services/fhir-uk-core

NHSE (2023a), "Adult Social Care User Survey (ASCS) 2022-23 guidance and materials for councils", NHS England, available at: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/adult-social-care-user-survey-ascs-2022-23

NHSE (2023b), "Measures from the adult social care outcomes framework, 2022-23", NHS England, available at: https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof/england-2022-23 (accessed 28 September 2024).

NLM (2023), "Unified medical language system. The CORE problem list subset of SNOMED CT ®. N. L. o. Medicine", available at: www.nlm.nih.gov/research/umls/Snomed/core_subset.html (accessed 4 October 2024).

Perez, H., Neubauer, N., Marshall, S., Philip, S., Miguel-Cruz, A. and Liu, L. (2022), "Barriers and benefits of information communication technologies used by health care aides", *Applied Clinical Informatics*, Vol. 13 No. 1, pp. 270-286, doi: 10.1055/s-0042-1743238.

PRSB (2025), "About me standard, professional records standards body", available at: https://theprsb.org/standards/aboutme/ (accessed 27 March 2025).

Puustinen, J., Kangasniemi, M. and Turjamaa, R. (2021), "Are comprehensive and individually designed care and service plans for older people's home care a vision or a reality in Finland?", *Health & Social Care in the Community*, Vol. 29 No. 5, pp. e144-e152, doi: 10.1111/hsc.13255.

Puustinen, J., Kangasniemi, M., Pasanen, M. and Turjamaa, R. (2023), "Recognising older people's individual resources and home-care-specific tasks in home care in Finland: a document analysis of care and service plans", *Scandinavian Journal of Caring Sciences*, Vol. 37 No. 2, pp. 507-523, doi: 10.1111/scs.13135.

Rand, S., Forder, J. and Malley, J. (2017), "A study of dyadic interdependence of control, social participation and occupation of adults who use long-term care services and their carers", *Quality of Life Research*, Vol. 26 No. 12, pp. 3307-3321, doi: 10.1007/s11136-017-1669-3.

Rand, S.E., Silarova, B., Towers, A.M. and Jones, K. (2022), "Social care-related quality of life of people with dementia and their carers in England", *Health & Social Care in the Community*, Vol. 30 No. 5, pp. e2406-e2418, doi: 10.1111/hsc.13681.

Ryan, K., Gannon-Slater, N. and Culbertson, M.J. (2012), "Improving survey methods with cognitive interviews in small- and Medium-Scale evaluations", *American Journal of Evaluation*, Vol. 33 No. 3, pp. 414-430, doi: 10.1177/1098214012441499.

Skills for Care (2024), "The state of the adult social care sector and workforce in England", Skills for Care, available at: www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/publications/national-information/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx (accessed 17 January 2025).

Tshering, G., Troeung, L., Walton, R. and Martini, A. (2024), "Factors impacting clinical data and documentation quality in Australian aged care and disability services: a user-centred perspective", *BMC Geriatrics*, Vol. 24 No. 1, p. 338, doi: 10.1186/s12877-024-04899-1.

Vasalampi, A. (2017), "Adoption and use of a mobile system at home care", *Studies in Health Technology and Informatics*, Vol. 242, pp. 1042-1046.

Veenstra, M., Skinner, M.S. and Sogstad, M.K.R. (2020), "A nation-wide cross-sectional study of variations in homecare nurses' assessments of informational continuity – the importance of horizontal collaboration and municipal context", *BMC Health Services Research*, Vol. 20 No. 1, p. 464, doi: 10.1186/s12913-020-05313-3.

Author affiliations

Vanessa Davey is based at Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK.

Janice Healey is based at Social Policy Research Unit, University of York, York, UK.

Jennifer Liddle is based at Faculty of Medical Sciences, Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, UK.

Bryony Beresford is based at Social Policy Research Unit, University of York, UK.

Stacey Rand is based at Personal Social Services Research Unit, University of Kent, Kent, UK.

Claire Goodman is based at School of Health and Social Work, Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, UK.

Karen Spilsbury is based at Faculty of Medicine and Health, School of Healthcare, University of Leeds, Leeds, UK.

Barbara Hanratty is based at Faculty of Medical Sciences, Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, UK.

Supplementary material

The supplementary material for this article can be found online.

Corresponding author

Vanessa Davey can be contacted at: vanessa.davey@newcastle.ac.uk