



## DACHA Final Consultation on Minimum Data Set Feedback Report

### Key points

- The third and final consultation (2023-24) of the DACHA Study focused on the relevance, usability, and perceived benefits and challenges of the minimum data set (MDS).
- The consultation involved different stakeholder groups who work in/with care homes or have experience of being a care home resident or a relative of a resident.
- The consultation was divided into two activities: focus group meetings (Stage 1) and an online survey (Stage 2).
- Stage 1 took place between December 2023 and March 2024. 33 participants from various stakeholder groups joined role-based expertise meeting groups with DACHA researchers.
- All Stage 1 participants indicated that the MDS would be relevant and usable as part of their professional/carer roles.
- The Stage 2 online survey had an expanded range of questions about the MDS compared to Stage 1, including questions on the quality of life (QoL) section of the MDS.
- The survey was open in February and March 2024, and received 62 responses from stakeholders who work in/with care homes or are relatives of residents.
- Approximately one third of the Stage 2 respondents indicated that they found the whole of the MDS relevant, and more than half stated they found certain sections relevant.
- One third of the respondents did not use or refer to quality of life (QoL) information about residents in their current roles. More than 70% of the respondents were favourable towards using QoL information in the future if the MDS was made available to them.
- Respondents stated that key factors such as training, national/regional mandates, financial incentives, ease of access and use, and positive stories from early MDS adopters, could encourage health and social care professionals to use the MDS in the future.
- Objectivity, confidentiality, accuracy, and completeness of data were identified as crucial for consideration in the sharing, use, and interpretation of data from the MDS.
- The need for clear guidelines and demonstrated benefits of the MDS was echoed in both stages of the consultation.
- The MDS was generally seen as a tool to aid in decision-making at both individual and organisational levels and was perceived to have the potential to improve research and care outcomes in care homes.

## Introduction

The DACHA project started in 2019 with the question:

*“What is the minimum amount of information that it is feasible and appropriate for care homes to collect routinely and how can that be linked to routinely held information by GPs and hospitals?”*

Over the past four years, the DACHA research team have developed a prototype for a care home **minimum data set (MDS)**. Its development drew on evidence from evidence reviews, work with representatives from health and social care, national consultations, public engagement and involvement activities, and a pilot study in 45 care homes. In DACHA, we define a minimum data set as: a standardised account of the demographic, social, and health characteristics and needs of older people living in long-term care (care home) settings.

The intention is that the MDS will improve the quality of information that staff collect about people living in care homes to support the care of residents. The DACHA MDS aims to link data about residents, around 2-3 times a year, that is collected by care home staff for the purposes of care with information held about residents in primary, secondary, community care and by the Care Quality Commission and Adult Social Care.

Consulting with people who work with or in care homes and who use/share care home data is threaded throughout the DACHA project. The project had three rounds of interlinked activities throughout 2021, 2022 and 2023-24. The 2021 and 2022 national consultations of the DACHA project directly informed the development of a prototype of a minimum data set (MDS) for care homes, which has been a key deliverable of the DACHA Study. Consultation events were designed to confirm that the resources generated by the research team aligned with the interests of various stakeholder groups associated with care homes.

This report will provide a brief overview of the past DACHA consultation events (2021 and 2022) whilst providing detailed information on the third and final consultation (2023-24) of the study. This final consultation focused on the relevance, usability, and benefits of the MDS for different stakeholder groups and the stakeholders’ perceptions on what the future challenges could be.

## 2021 and 2022 DACHA Consultation Events: Recap

In 2021, we consulted 40 individuals in England and Wales in a series of seven online consultation meetings. In these meetings, there were: local authority officials; old age researchers, old age psychiatrists, and geriatricians; government officials; data analysts and data researchers; primary health care professionals; care home staff; senior operations and care home managers. We focused on questions relating to the use of care data during the COVID-19 pandemic, such as:

- What care home resident data have you used and shared the most during the COVID-19 pandemic?
- Is there information on care home residents that you routinely collect but do not use often?
- If information about care home residents and staff was collected and accessed the same way by multiple organisations, what would the challenges be?

We found out that it is essential to develop a mutual understanding of the data currently collected in care homes to facilitate discussions within and between stakeholder groups regarding the expectations and feasibility of data collection. All groups acknowledged the challenges in gathering data that consistently and meaningfully reflects the quality of life (QoL) of the residents<sup>1</sup>.

---

<sup>1</sup> More information on care home data use during the COVID-19 pandemic is available in the 2021 feedback report: <http://dachastudy.com/wp-content/uploads/2021/10/Report-DACHA-consultation-2021.pdf>

During the 2022 consultation, we focused on quality of life (QoL) measurement in care homes and how the QoL priorities of the stakeholders can be translated into actions for the MDS. Respondents' criteria for the most important quality of life principles and aspects were included in the decisions around shortlisting the most applicable QoL measures that could be included in the MDS. This consultation was divided into two rounds: Round 1 received 30 responses, and Round 2 attracted 72 respondents representing care home staff, family carers, managers, clinicians, regulators, and commissioner groups. In the first round, we found that resident inclusivity was the top ranked principle, and mental health was the top ranked aspect that should be included in any QoL measurement instrument in care homes. Taking into consideration the other top ranked principles and aspects as well, we shortlisted five QoL measures that could potentially be added in the MDS. In Round 2, we asked respondents their perceptions of these five measures by providing summaries for each measure. The scores were higher for these measures: ASCOT-Proxy, ICECAP-O, EQ-5D-5L Proxy and QUALIDEM. These four measures were included in the trial of the prototype MDS in care homes in 2023<sup>2</sup>.

The 2021 and 2022 consultations helped the stakeholders offer their perspectives and opinions on matters relating to the organising of the minimum data set at two different points in the study process. The third and final consultation (2023-24) looked at how useful and relevant the structured version of the DACHA minimum data set is for stakeholders, and what should be considered for the future of MDS.

## 2023-24 Final DACHA Consultation

The third and final DACHA consultation was divided into two activities:

- Focus group meetings
- Online survey

### Stage 1: Focus group meetings

Stage 1 took place between December 2023 and March 2024. 33 participants from various stakeholder groups joined role-based expertise groups and had focus group meetings (or individual interviews where applicable) with DACHA researchers. These expertise groups and the number of stakeholders from each group are shown below:

- friends/family of care home residents (n=6)
- care home staff (n=2)
- care home managers (n=4)
- primary care professionals (n=7)
- commissioners/regulators/senior care providers (n=4)
- care home residents (n=10)

Except for the care home residents' group, all meetings (and individual interviews) were held online either on Zoom (version 5.17.11) or on Microsoft Teams (version 2023.43.01.22). The care home residents' group meeting took place in a Hertfordshire care home with the participation of 10 older people with capacity to participate. The meetings lasted approximately 1-1.5 hours.

Stage 1 was not open to public participation and the participants either had taken part in previous consultation activities or they were invited via a DACHA researcher's immediate network.

---

<sup>2</sup> More information on the quality of life consultation and outcome measures is available in the 2022 feedback report: <http://dachastudy.com/wp-content/uploads/2022/12/DACHA-2022-Consultation-report-FINAL-.pdf>

All stakeholders were given a copy of the minimum data set<sup>3</sup> and a briefing document prior to the meeting. During the meeting, they were asked the following questions:

- a) How is the MDS relevant for your work/role?
- b) What information from the MDS can you already access and share with others as part of your work/role?
- c) Is there particular content that could improve how you make decisions and communicate information about residents if you had access to it?
- d) Are there any parts of the MDS you would be unlikely to use?
- e) If the MDS was to be used by different groups who work in and with care homes, what do you think needs to be in place to make the implementation successful?

Based on the responses provided during Stage 1, findings were summarised into descriptive themes summarising recurring issues to be able to feed them into Stage 2 – online survey. Please see Figure 1 below.

The DACHA MDS aims to reduce the administrative burden on staff who have to report the same information about residents to different organisations in different formats. Stakeholders from several groups still expressed concerns that filling in the MDS could duplicate the work carried out by care home staff. They identified the need for evidence on how MDS would reduce the administrative burden to accompany effective MDS implementation. Standardisation of systems, financial incentives, and national/regional mandates were often mentioned as important by various stakeholders during the meetings. It was emphasised by different groups that a high-level buy-in is necessary for implementation of the MDS and that MDS should be made into a routine task, with training provided, for all parties involved for its continuous use.

All stakeholders found the MDS relevant and usable in their role. Although the care home residents' and resident relatives' groups focused on how health and social care professionals should access the MDS for better care for residents. There was little expectation they would access the MDS themselves or review aggregate data. In earlier stages of the project, the family carers of the DACHA PPIE (patient and public involvement and engagement) Panel were advocating that family members would welcome access to information directly from their family member's record, and that having direct access to this record could reduce the burden for staff of answering relatives' questions about their family member and their care.

---

<sup>3</sup> The version of the minimum data set that was presented to the stakeholders during the 2023-24 consultations is available here: <https://dachastudy.com/wp-content/uploads/2024/01/DACHA-Minimum-Data-Set-012024.pdf>

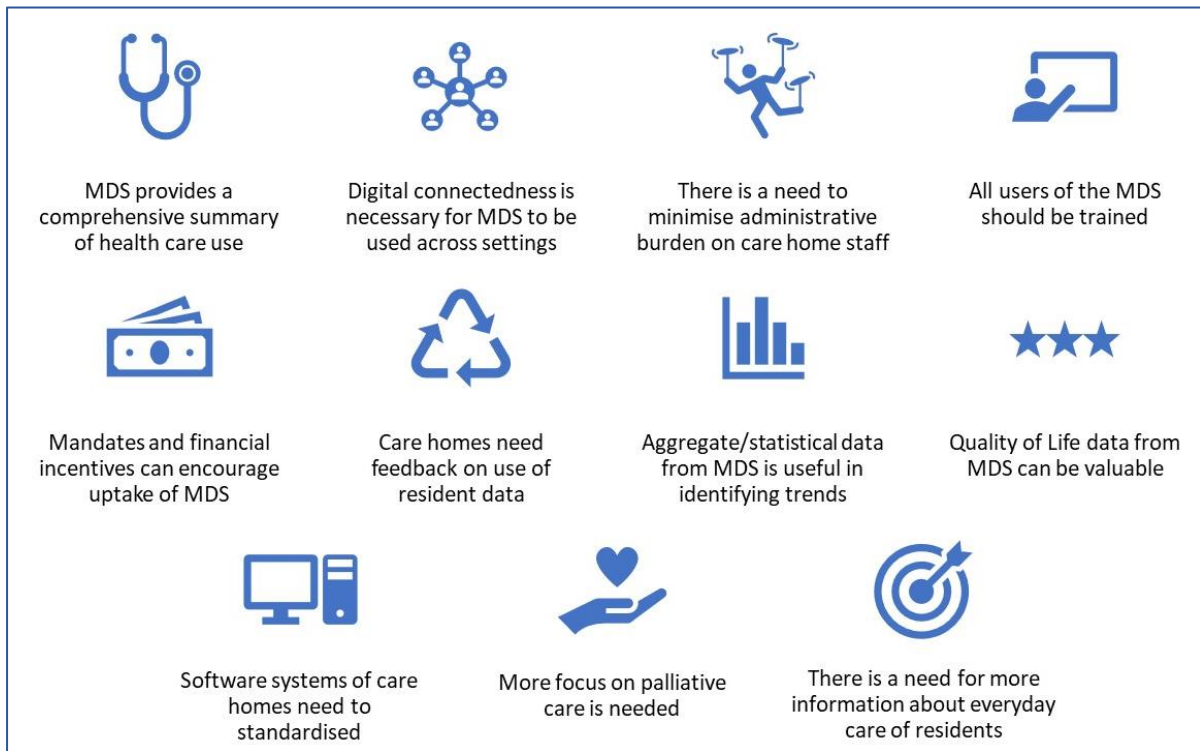


Figure 1. Stage 1 consultation findings summarised into themes

## Stage 2: Online survey

For Stage 2, the DACHA team contacted a wider range of networks via utilising DACHA's X/Twitter social media account; previous DACHA Lunchtime Webinar Series participants<sup>4</sup>; NIHR Applied Research Collaboration East of England newsletter; NHS CHAIN Network mailing list; NHS England and NHS Scotland contacts; DHSC contacts; The Queen's Nursing Institute care home network contacts; Office for National Statistics representatives; and NIHR Clinical Research Network (CRN) contacts from West of England, North Thames, East Midlands, North East North Cumbria, North West Coast, North West London, and Wessex.

The Stage 2 online survey was hosted on the University of Hertfordshire server of the Joint Information Systems Committee (JISC) Online Surveys platform. The survey was piloted with five people working in the DACHA research management team, from different work packages. The survey took around 25 minutes to complete. The survey had an expanded range of questions about the minimum data set compared to Stage 1 (Appendix 1), including questions on the quality of life (QoL) section of the MDS. Stakeholders were shown an explanatory video, at the beginning of the survey and then were provided with a copy of the DACHA minimum data set (<https://dachastudy.com/wp-content/uploads/2024/01/DACHA-Minimum-Data-Set-012024.pdf>). The survey aimed to understand how relevant and usable the minimum data set is for the respondents, in what ways they would use specific information from the MDS, and what future recommendations they have for successful MDS implementation.

The survey was open for six weeks during February and March 2024, and received 62 responses from stakeholders belonging to these role-based groups:

- old age specialists (clinical or researcher),

<sup>4</sup> More information on the DACHA Lunchtime Webinar Series is available on the ARC East of England website: <https://arc-eoe.nihr.ac.uk/dacha-webinar-series-lunchtime-webinars>

- family members/friends of care home residents,
- care home staff members,
- care home managers / senior operational managers,
- primary care professionals,
- commissioners/regulators/senior care providers,
- and 'other'

(This cluster is for those who work with care home data but do not fit in any of the above categories. Some role names noted down under 'other' were: Trustee, interested professional, and analyst.)

The demographic information for the stakeholders and how long they have been in their role/occupation is shown below in Figures 2 and 3. Most respondents were from the old age specialist (researcher/clinical) cluster, with 21 responses. We did not receive any responses from care home residents despite the survey having been publicised in care homes as well. However, we received five responses from relatives of care home residents, and 15 responses in total from care home staff members and managers. Participation of relatives and care home staff/managers ensured the representation of voices from care homes. Three quarters of the respondents indicated that they have worked in/with care homes for more than five years. For relatives of residents (n=5), the average time they had a relative in a care home was around 1-1.5 years.

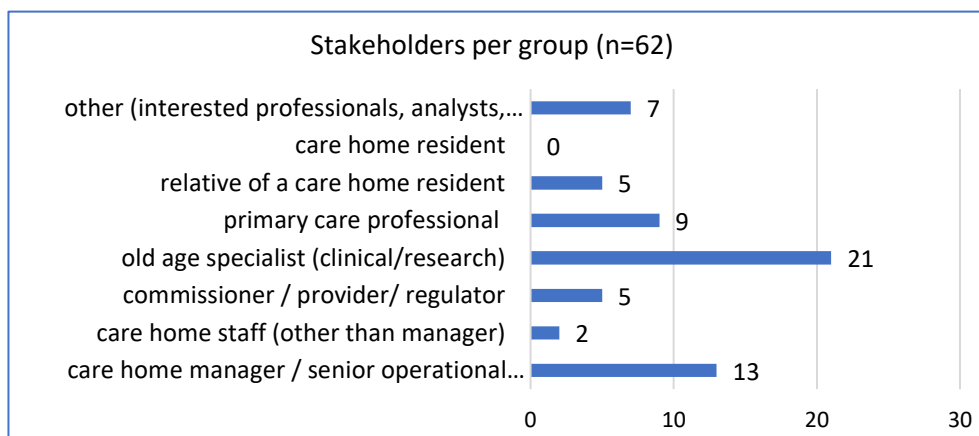


Figure 2. Stage 2 stakeholders per group

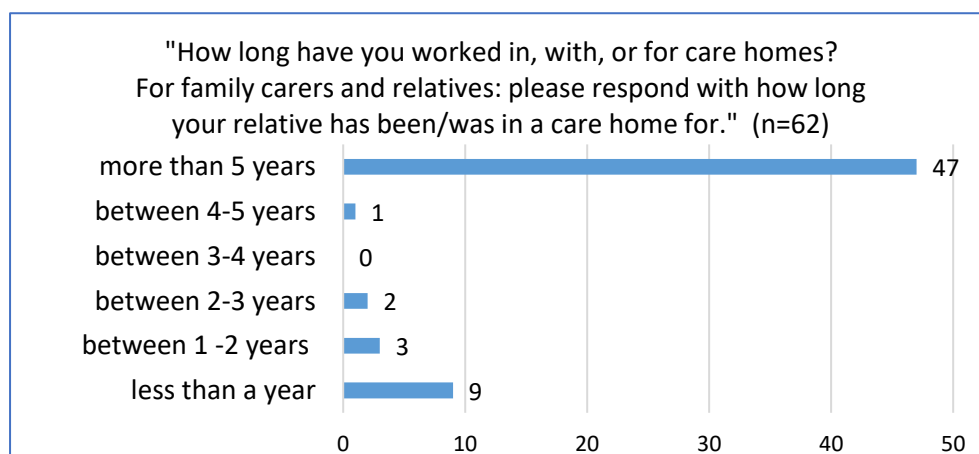


Figure 3. Duration of time that respondents worked in/with care homes or had a relative in a care home for

Approximately one third (32%) of the respondents indicated that they found the whole of the MDS relevant and useful in their roles, and more than half (55%) stated that they find certain sections of the MDS relevant. Only 13% (n=8; 'No' and 'Not sure') of the respondents were unsure about MDS's relevance in their roles (Figure 4).

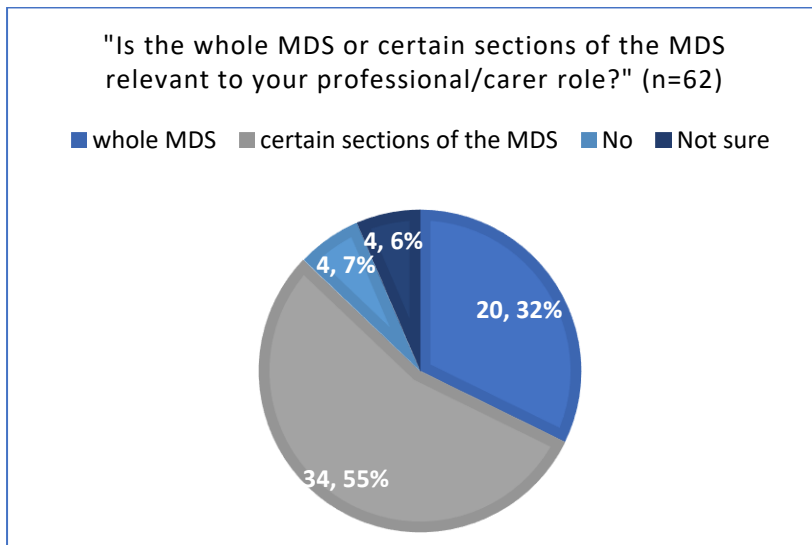


Figure 4. Relevance of DACHA minimum data set

When asked about in what ways the stakeholders would use the minimum data set or why they would not use it, they listed their perceived benefits and concerns about the MDS. The role of the MDS as a means of making social care visible to external organisations was a recurring comment amongst many respondents. The findings can be seen in Table 1 below.

Perceived MDS related benefits	Perceived MDS related concerns
<ul style="list-style-type: none"> <li>Useful for initial and comprehensive assessments, and for developing personalised care plans.</li> </ul>	<ul style="list-style-type: none"> <li>Some confusion around the purpose of the MDS and its practical application. Clearer guidance would be needed on its aims.</li> </ul>
<ul style="list-style-type: none"> <li>Sections on quality of life, medical conditions, and cognitive abilities are useful to inform decision-making.</li> </ul>	<ul style="list-style-type: none"> <li>Lack of emphasis on palliative care/end of life care.</li> </ul>
<ul style="list-style-type: none"> <li>More data helps raise the social care profile with the integrated care boards (ICB), NHS and DHSC.</li> </ul>	<ul style="list-style-type: none"> <li>Concerns about the relevance of certain sections.</li> </ul>
<ul style="list-style-type: none"> <li>Useful for research and quality improvement in care homes.</li> </ul>	<ul style="list-style-type: none"> <li>Lack of information regarding the involvement of family carers.</li> </ul>
<ul style="list-style-type: none"> <li>Useful for evaluating care home performance and for benchmarking against performance of other care homes, e.g. emergency service use.</li> </ul>	<ul style="list-style-type: none"> <li>Concerns around the training costs.</li> </ul>

<ul style="list-style-type: none"> <li>▪ Training needs can be identified.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Administrative burden on staff and possible duplication of work.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Enables improved data to assess adult social care needs and delivery.</li> </ul>	
<ul style="list-style-type: none"> <li>▪ Useful for communication between carers and family members, ensuring consistent views on care needs.</li> </ul>	
<ul style="list-style-type: none"> <li>▪ Enables informed decisions about care home selection for relatives.</li> </ul>	

Table 1. Perceived benefits and concerns about the minimum data set

The MDS was generally seen as a tool to aid decision-making at both individual and organisational levels and was perceived to have the potential to improve research and care outcomes in care homes. Similar insights to those from the consultation groups were echoed in the survey: the need for clear information on how the MDS is going to be used, who will be trained and how, and whether this would initiate additional tasks mainly for care home staff members.

In the quality of life (QoL) section of the survey, stakeholders were asked questions regarding the four QoL outcome measures that have been used in the DACHA feasibility trial of the prototype MDS in care homes during 2023. These measures were: ASCOT-Proxy, ICECAP-O, EQ-5D-5L Proxy, and QUALIDEM. Stakeholders were asked how often they use QoL information as part of their roles currently, and how often they would use the information provided by the above four QoL measures if they had access to it to refer to QoL information about care home residents.

Figure 5 shows the responses for the stakeholders' current behaviour versus future intention to use the QoL information that come from ASCOT-Proxy, ICECAP-O, EQ-5D-5L Proxy, and QUALIDEM<sup>5</sup>. We found that one third (33.8%) of the respondents did not use or refer to QoL information at all in their current roles; however, only 8% of respondents indicated that they would not use the QoL information in the future if the MDS data were made available to them. More than 70% of the respondents were favourable towards using QoL information as part of their roles. For those who had access to QoL data, most were using it on a weekly (16%) and monthly (17.7%) basis. For future use, many stakeholders were keen to use or refer to the QoL information about residents on a monthly (25.8%) and quarterly (14.5%) basis. Of all respondents who indicated they would use the data less than yearly (n=7), six of them were old age specialists (researcher/clinical).

<sup>5</sup> More information about the QoL measures is available in the 2022 consultation feedback report: <http://dachastudy.com/wp-content/uploads/2022/12/DACHA-2022-Consultation-report-FINAL-.pdf>



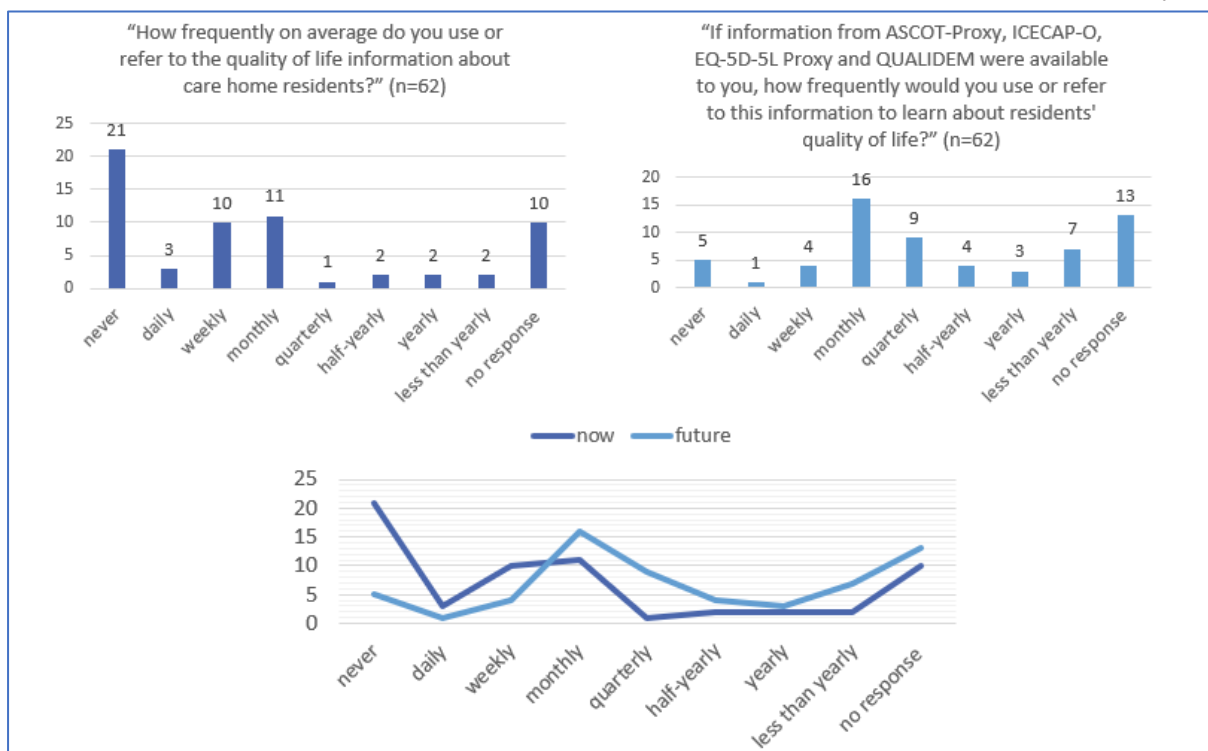


Figure 5. Current access to and potential future use of QoL information by stakeholders

When asked about how the stakeholders would use the QoL information from the four QoL outcome measures, the following actions were cited the most often by the stakeholder groups as indicated in the **brackets**:

- To learn about areas of improvement in care homes (**care home manager**)
- To inform the activities provision in care homes (**commissioner/provider/regulator**)
- To understand how quality of life changes in relation to staffing levels (**commissioner/provider/regulator**)
- Evaluation as part of research and quality improvement projects (**old age specialist**)
- QoL data can be valuable in specific research studies (**old age specialist**)
- To gain a quantifiable measure of resident quality of life (**primary care professional**)
- To plan care needs and identifying resources and support (**primary care professional**)
- To gain an understanding of resident’s changing presentation and needs (**resident relative**)

Stage 2 respondents were asked to reflect on the findings from the Stage 1 consultation meetings (Figure 1). They predominantly agreed with these reflections and perceived challenges, especially those regarding palliative care and quality of life. Some provided additional feedback on what additional information they would have liked to see in routinely collected data, such as more data on: risky resident behaviour to self/others, dental care, safeguarding, and past mental health status. Due to the comprehensive nature of the minimum data set, some respondents also reflected that each section of the MDS might require different frequencies of data collection, therefore it could be beneficial to report how often the data is captured for each MDS section for each resident.

In the final section of the survey, two open-ended questions regarding the future implementation of MDS were directed to the stakeholders. Respondents stated that the following factors could make a difference to encourage health and social care professionals to use the MDS in the future:

- Providing clarity around how the MDS can help the professionals on a daily basis
- Clear evidencing of the benefits, and sharing positive outcomes from early adopters
- Ease of access and use of the MDS
- Interoperable systems that talk to each other to prevent duplication and additional work
- National or regional mandates
- Financial incentive schemes
- Full integration into work IT systems
- Training and awareness
- Starting the adoption with a small trial and expanding slowly

The need for clear guidelines and demonstrated benefits of the MDS was echoed in both stages of the consultation. Professionals who use diverse systems as part of their work referred to training needs throughout the consultation. Mandates and incentives were also cited as other significant factors in both stages. This could be due to the fact that health and social care environments often have multiple electronic systems in place, and that an institutional approach might be required to ensure the regular use of a specific data set.

Finally, when asked about what important factors should be taken into account when sharing, using, and interpreting data from the minimum data set, the stakeholders focused mainly on the objectivity, confidentiality, accuracy, and the completeness of the MDS data. They emphasised that regular updates and reviewing of data would be essential, and that the data should always be interpreted in context. For effective interpretation, the need for different kinds of expertise were cited: such as statistical expertise in the interpretation of certain trends, and mixed method expertise to complement quantitative analysis with observations or other qualitative data.

## Abbreviations

ARC – NIHR Applied Research Collaboration

ASCOT – The Adult Social Care Outcomes Toolkit

DACHA – Developing research resources And minimum data set for Care Homes’ Adoption and use

DEMQOL-CH – Dementia Quality of Life: Care Home

DHSC – Department of Health and Social Care

EQ-5D-5L – EuroQol Group 5 Dimension-5 Level

ICECAP-O – ICEpop CAPability measure for Older people

MDS – Minimum Data Set

NHS – National Health Service

NIHR – National Institute for Health and Care Research

PPIE – Patient and Public Involvement and Engagement

QoL – Quality of Life

QUALIDEM – Quality of Life for People with Dementia

## Contact

For any queries, please contact Dr Gizdem Akdur at [g.akdur@herts.ac.uk](mailto:g.akdur@herts.ac.uk) (senior research fellow) or Prof Claire Goodman at [c.goodman@herts.ac.uk](mailto:c.goodman@herts.ac.uk) (DACHA principal investigator)

DACHA X: [https://twitter.com/DACHA\\_Study](https://twitter.com/DACHA_Study)

DACHA website: <http://dachastudy.com/>

Previous DACHA consultation reports: <https://dachastudy.com/consultation-events/>

## Acknowledgement and Disclaimer

This report was created and edited by Gizdem Akdur (University of Hertfordshire), Adam Gordon (University of Nottingham), Anne Killeth (University of East Anglia), Karen Spilsbury (University of Leeds) and Claire Goodman (University of Hertfordshire) from the DACHA research management team.

DACHA is funded by the National Institute for Health and Care Research (NIHR) Health Service Research and Delivery programme (HS&DR NIHR127234) and supported by the NIHR Applied Research Collaboration (ARC) East of England. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

## Appendix 1

### Stage 2 online survey questions

- Is the whole MDS or certain sections of the MDS relevant to your professional/carer role?
- If relevant, how would you use the information from an MDS? If not relevant, what are the reasons you would not use this information?
- What sections from the MDS can you already access and/or share with others?
- Which sections in the MDS are (or would be) the most relevant for you?
- Which sections in the MDS have the most limited value for you?
- In your current profession or carer role, how frequently on average do you use or refer to the quality of life information about care home residents?
- If information from all four measures (ASCOT-Proxy, ICECAP-O, EQ-5D-5L Proxy, and QUALIDEM) were available to you, how frequently would you use or refer to this information to learn about residents' quality of life?
- In what ways would you use the information provided by these four quality of life measures as part of your role?
- Do you have any comments or reflections on the ideas raised [in consultation meetings] and is there anything else you would like to add?
- In your opinion, what is needed to encourage health and social care professionals to regularly use the minimum data set?
- What do you think everyone should be mindful of when sharing, using, and interpreting data from the minimum data set?