



DACHA 2022 Quality of Life Consultation Feedback Report

KEY POINTS

- The 2022 DACHA consultation exercise focused on participants' views of care-related Quality of Life (QoL) measures.
- The aim was 1) to identify what care-related quality of life measures should include for people living in long term care, and 2) to inform which of the measures that met participants' criteria were included in the DACHA minimum data set (MDS).
- The DACHA team collaborated with Thiscovery (THIS Institute, University of Cambridge) to carry out a two-stage online consultation between June and September 2022, with 88 stakeholders representing groups who live, visit, work in and with care homes.
- The Round 1 of the consultation with 30 responses showed the most important principles and aspects to consider when measuring care-related quality of life in care homes. This information led to a shortlist of five QoL outcome measures for possible inclusion in the MDS.
- The shortlisted measures were ASCOT-Proxy, ICECAP-O, EQ-5D-5L Proxy, QUALIDEM, and DEMQOL-CH.
- The Round 2 of the consultation attracted 72 participants representing care home staff, family carers, managers, clinicians, regulators and commissioner groups. Overall, the confidence levels in all the shortlisted QoL outcome measures were high. A majority of stakeholders stated they would use the information generated from the measures to inform their work, despite not being familiar with the measures before the consultation. More stakeholders favoured the use of QUALIDEM over DEMQOL-CH.
 - ASCOT-Proxy, ICECAP-O, EQ-5D-5L Proxy and QUALIDEM were added to the prototype minimum data set.

2021 Consultation Events: Recap

Consulting with people who use care home data is threaded throughout the DACHA project. Consultation events aim to ensure that early findings and resources produced by the research team address what is of core importance to different stakeholder groups who work in and with care homes. The consultation work directly informs the development of a prototype of a Minimum Data Set (MDS) for care homes.

*A **Minimum Data Set (MDS)** is a standardised account of the demographic, social, and health characteristics and needs of older people living in long-term care (care home) settings.*

The first online consultation event (2021) with stakeholders took place between February and June 2021. We ran online group discussions with each representative group from England and Wales:

- 1- Local authority and CCG officials
- 2- Researchers, old age psychiatrists, geriatricians
- 3- Government officials
- 4- Data analysts and data researchers
- 5- Primary health care professionals
- 6- Care home staff who use electronic records in care homes
- 7- Senior operational and care home managers

Forty individuals participated commenting on the DACHA study's early findings, and how access to information about care home residents had changed during the Covid-19 pandemic. Participants were asked what care home resident data they used the most, how the Covid-19 pandemic had affected data sharing, information they would like but cannot easily access and data they have access to, but rarely use. Whilst discussing the use of care home data during the pandemic, one data specific issue raised was that it was difficult to obtain data that meaningfully and consistently captured residents' quality of life in care homes. You can access the summary of the findings from 2021 here: <http://dachastudy.com/wp-content/uploads/2021/10/Report-DACHA-consultation-2021.pdf>

2022 Consultation Exercises

The 2022 consultation, in the form of two online exercises, took place between June and September 2022. The consultation focused on the care-related Quality of Life measures that could be included in the DACHA study MDS to complement the review work. The development of the minimum data set was based on:

- A review of assessment and outcome measures used in care home research
- A review of MDS indicators currently used in other countries to understand care home residents' characteristics, their health, care needs and use of health and social care services
- A review of how minimum data sets have been implemented in other countries and what needs to be in place to support care home staff to link data capture to care delivery
- Workshops on priority areas for measurement to identify information about care home residents that already exists in routine datasets held by the NHS, Local Authorities and Urgent and Emergency care
- A national survey of the information that care homes already collect about their residents

Rationale and Design

The **health** metrics of the MDS reflect a broad consensus from practice and research on what is essential information to collect on residents. There is less clarity or agreement about how to define and measure **care-related quality of life (QoL)** for someone living in a care home often with dementia. While measuring how care is delivered (process) can be useful, it is also important to understand the impact of care on someone's quality of life.

Care-related quality of life refers to the quality of life of care home residents as impacted by the care they receive, and what gives their life meaning. It includes social relationships and feeling valued within a supportive environment. It is more than a measure of health and the care received.

There are multiple QoL measures including those that focus on older people living in long term care settings and could be included in an MDS.¹ The 2022 consultation discussed with a range of stakeholders who use information about residents as part of their work or have a vested interest in residents' wellbeing, which QoL principles and aspects should be prioritised, and which QoL measures can be included in the MDS.

The consultation on care-related quality of life addressed the bias in current systems on measures of health care needs. The focus on social care measures considers the experience of living in a care home and residents' and staff's priorities. Evidence from DACHA's national care home survey found that only 31% of care homes in England were systematically collecting QoL information on their residents for inclusion in records.

The online consultation, had two rounds that aimed to establish:

- Which criteria and properties (principles and aspects) are important to capture as part of QoL measurement in care homes;²
- How the groups would use the information provided by the different QoL measures, if they had access to it, or why they would not use it;
- Which dementia-specific quality of life outcome measure to include in the DACHA MDS.

The two rounds of the online consultation were organised in collaboration with [Thiscovery](#), part of THIS Institute, based at the University of Cambridge. Thiscovery is an intuitive platform for remote collaboration, engagement, and research, offering varied audiences, opportunities to contribute their knowledge and experience to solving real-life problems in health and social care. It is accessible, easy to use, and enables researchers to reach larger and more diverse audiences. It ensures those involved in health and care are involved in building recommendations for improvement. Launched by THIS Institute in 2019, it was developed with funding from The Health Foundation.

¹ See Siette et al.'s paper (2021) for a review of 29 instruments for assessing quality of life in older adults: <https://bmjopen.bmj.com/content/11/11/e050892>

² These principles and aspects refer to what different stakeholder groups would see as important to be able to apply a quality of life outcome measure and use the information it generates, which is applicable for use in the UK setting.

Round 1: Forty participants who were part of the 2021 consultation and familiar with the goals of the study were invited. These stakeholders represented the following groups:

- care home staff
- care home managers
- commissioners/providers
- clinical and research old age specialists
- relatives of care home residents

We planned to use the findings of Round 1 to identify existing Quality of Life measures that meet the criteria for inclusion in Round 2.

Round 2: We reached out to a wider group of participants (up to 100) from across all the stakeholder groups (same as Round 1) via dissemination through DACHA team networks, social media channels, and bulletins/newsletters of relevant health and social care bodies.

Round One: Consultation on QoL Principles and Aspects

The first consultation activity took place between 28 June and 25 July and attracted 30 responses.

We provided a short explanatory video (access [here](#)) on what a minimum data set is, and why this consultation is taking place. We asked the participants two overarching questions:

- 1- What should a measure of care-related quality of life be able to do?
- 2- What aspects of care-related quality of life are most important to measure?

We presented participants with 12 principles and 9 aspects of quality of life and asked them to rank each with a max score of 9, and 5 as the neutral score. Principles and aspects of care-related quality of life measurement for the purposes of the DACHA study assume the following:

TWELVE PRINCIPLES (Question 1)	NINE ASPECTS (Question 2)
Sensitive to change: QoL measures need to measure changes in care home residents' needs and circumstances over time.	Physical health: refers to functional status, physical conditions and their related symptoms, pain, and perceptions of overall health
Reflect differences in care received: QoL measures need to be sensitive to the impact of care received (differences in care models/quality of care etc).	Mental health: refers to items that capture mental and cognitive health conditions, as well as clinical symptoms that would indicate mental health problems
Inform day to day care: QoL measures need to have the potential to inform direct care when included in digital care records	Emotional state: refers to items which capture experiences of positive and negative emotions which are not obviously symptoms of mental health. This includes items which explore feelings of peace, calm, happiness and loneliness, among others.
Have a numeric score: QoL measures in an MDS need to be suitable for quantitative/numeric analysis.	Social connection: refers to items addressing the frequency and quality of social interactions. Items addressing feelings of belonging, friendship and support were also categorised under this domain.
Resident inclusion: QoL measures need to be for all residents, including those with dementia. QoL measures need to be feasible to collect about all residents, not only those who can self-report.	Environment: refers to items addressing living conditions and deployable resources. Included in this domain are items addressing satisfaction with social care services as well as items which ask respondents to reflect on the emotional, psychological and physical effects of living conditions.
Completion by staff: QoL measures need to be completed by the staff providing care to residents.	Personhood: relates to items addressing levels of satisfaction with personally and culturally meaningful activities which provide joy and a sense of identity. This domain also refers to items that address identity continuity, and effects of ageing on identity and sense of self.

Completion by residents: QoL measures need to be completed directly by residents receiving care, if they are able to.	Autonomy: relates to items addressing capacity and satisfaction with one's ability to manage activities of daily living. Emotion-centric items associated with dependence and autonomy are also categorised as relating to autonomy.
External access: QoL measures need to be useful to commissioners and external organisations working with care homes (e.g. Care Quality Commission) to inform decision making.	Spiritual connection: covers feelings of faith, and inner peace, as well as involvement in religious or spiritual practices like prayer.
Quick to complete: Each QoL measure needs to be completed in less than 10 minutes by the staff providing care.	Overall quality of life: relates to single items asking respondents to rate their QoL as a whole.
Easy to complete: QoL questions need to be clear, unambiguous, and not upsetting to residents or staff.	
Inform decisions: QoL measures need to be able inform the decisions of visiting health care professionals.	
Written in notes: QoL measures need to include descriptive notes on residents, e.g., notes on how the resident's day was, what they ate, etc.	

Table 1. Quality of Life Principles and Aspects

Only two care home staff members, and one family relative of a care home resident took part in Round 1. From other stakeholder groups, there were seven professionals from commissioner/ provider/ regulator bodies; eight old age specialists (clinical or research); four primary care professionals; and eight care home managers involved in the survey.

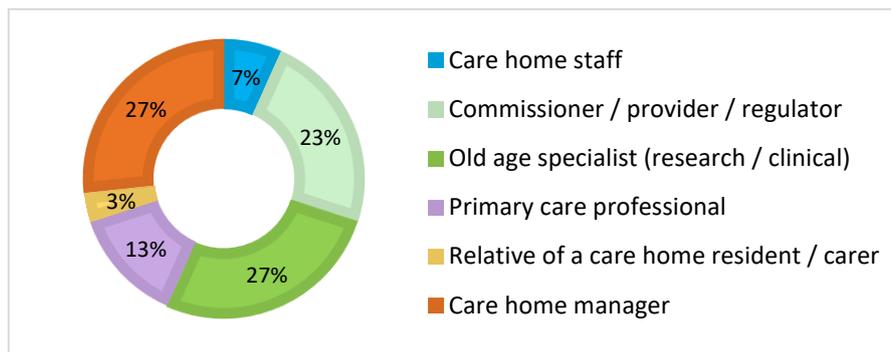


Figure 1. Stakeholder analysis by role/profession (Round 1)

The participants ranked the importance in measuring quality of life of each principle and aspect from 1 (not important at all) to 9 (very important), with 5 as the neutral score.

At the end of this round, we found that the three highest ranked quality of life principles were resident inclusion, ease to complete, and informing day to day decisions. The three highest ranked aspects were mental health, emotional state, and social connection. You can see the full list of all principles and aspects below, from the highest to the lowest, as ranked by 30 participants:

	Principles	Mean score
1	Resident inclusion	8.57
2	Easy to complete	7.93
3	Inform day to day care	7.77
4	Completion by residents	7.60
5	Sensitive to change	7.43
6	Inform decisions	7.30

7	External access	7.23
8	Reflect differences in care received	7.00
9	Quick to complete	6.90
10	Written in notes	6.70
11	Have a numeric score	6.50
12	Completion by staff	6.03

Table 2. QoL principles listed from the highest to the lowest ranked

	Aspects	Mean score
1	Mental health	8.27
2	Emotional state	8.27
3	Social connection	8.20
4	Physical health	8.03
5	Personhood	8.00
6	Autonomy	7.93
7	Environment	7.70
8	Overall quality of life	7.57
9	Spiritual connection	7.33

Table 3. QoL aspects listed from the highest to the lowest ranked

An important message from the first round was that measures used should include all residents, not just those who can self-report. When asked about what aspects of quality of life we should measure to aid decision making about care home residents, the scores show that the stakeholders favoured measures that capture: mental and cognitive health and clinical symptoms that would indicate mental health problems; positive and negative emotions; and frequency and quality of social interactions.

We know that previous attempts at introducing an MDS in the UK care home settings had foundered because of the difficulties around ease and speed of completion; however, whilst this is important, the Round 1 results demonstrated that 'Quick to complete' was the fourth lowest ranked principle, suggesting that speed was not as much of a top priority as ease to complete (the second highest ranked principle).

Preparation for Round Two on Preferred Care-Related Quality of Life Outcome Measures

Based on the rankings from Round 1 and evidence on their applicability for use in UK care homes, five quality of life outcome measures were short listed for possible inclusion in the DACHA MDS. These shortlisted measures all satisfy the top three principles: inclusive of residents with dementia, easy to complete, and having the potential to inform direct care. They also capture individuals' mental health, emotional state, and social connection aspects.

The shortlisted measures are as follows:

1. ASCOT-Proxy (general quality of life)
2. ICECAP-O (general quality of life)
3. EQ-5D-5L Proxy (general quality of life)
4. QUALIDEM (dementia-specific quality of life)
5. DEMQOL-CH (dementia-specific quality of life)

A pilot exercise with five team members established that each of these measures should not take more than 3 minutes to complete when filled in by trained staff. A short summary of each measure is provided in the **Appendix**.

The two dementia-specific quality of life measures (QUALIDEM and DEMQOL-CH) were very similar, and the decision was to ask the stakeholders if they preferred one over the other.

Round Two: Consultation on the Quality of Life Outcome Measures

Round 2 took place between 12-30 September 2022. There were 72 responses. Previous attendees from Round 1 were individually invited to the second survey; almost half of the participants from Round 1 took part. To maximise participation, invitations to Round 2 were advertised on DACHA's social media page, disseminated via a bulletin of the NHS CHAIN network, and emailed to social care networks of the DACHA RMT members. These activities attracted 58 new participants. Queen Elizabeth II's mourning period in September 2022 impacted the levels of participation in Round 2 due to an institutional embargo on dissemination activities taking place during this period.

As with Round One, a short introductory video (access [here](#)) was provided to familiarise the participants with the DACHA project and the aims of the consultation exercise.

In Round 2, we asked the participants:

- Their familiarity with the shortlisted quality of life outcome measures
- Their confidence levels in the usability and usefulness of measures
- Their potential use of information provided by the measures
- Their choice of dementia-specific QoL measure (QUALIDEM or DEMQOL)

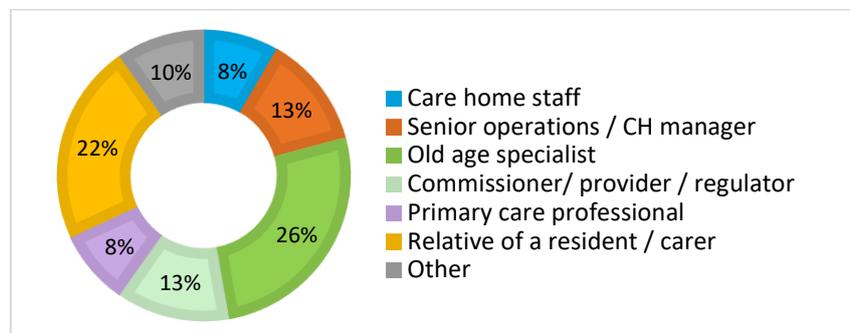


Figure 2. Stakeholder analysis by role/profession (Round 2)

Unlike Round 1, the responses from relatives of care home residents and care home staff constituted almost a third of all responses received in Round 2. Old age specialists (clinical and/or research) formed more than a quarter of all responses.

None of the primary care and hospital professionals were familiar with the measures, whereas the rates of familiarity between care home staff and care home resident relatives were similar (around 30%). Asked about their familiarity with at least one of the QoL outcome measures before this consultation, half of the participants said no. ASCOT and DEMQOL-CH were the most recognised measures, by 35% and 32% of participants respectively. Unsurprisingly, 80% of the researcher and clinical old age specialists knew about at least one of the measures prior to the consultation.

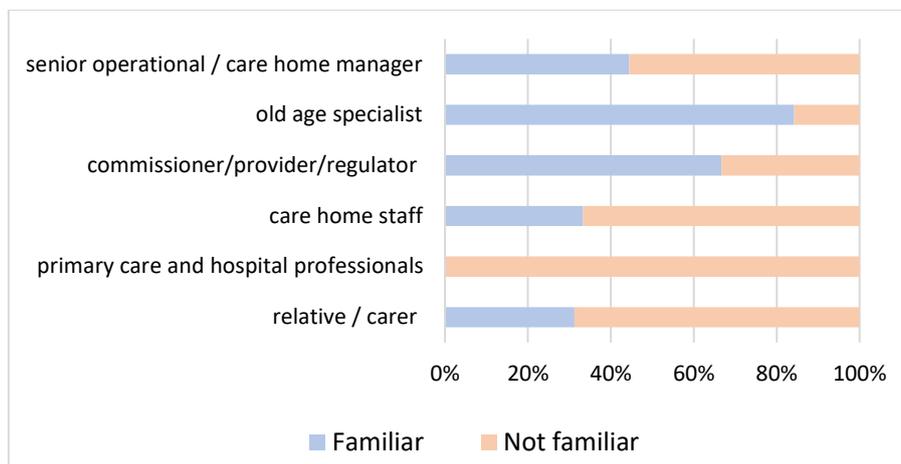


Figure 3. Stakeholder familiarity with the five QoL outcome measures

The participants were given a short summary of each instrument and an option to view the actual measure on a separate window. Due to copyright, only a summary of the EQ-5D-5L measure was provided and not the measure itself (the summaries of all the measures can be found in the Appendix).

All QoL measures were perceived to be useful by stakeholders in their professional work or carer role; responses indicated that the information provided by the outcome measures would be useful in their work/role. ASCOT was perceived to be the most usable of all by 50 participants (69% of all responses).

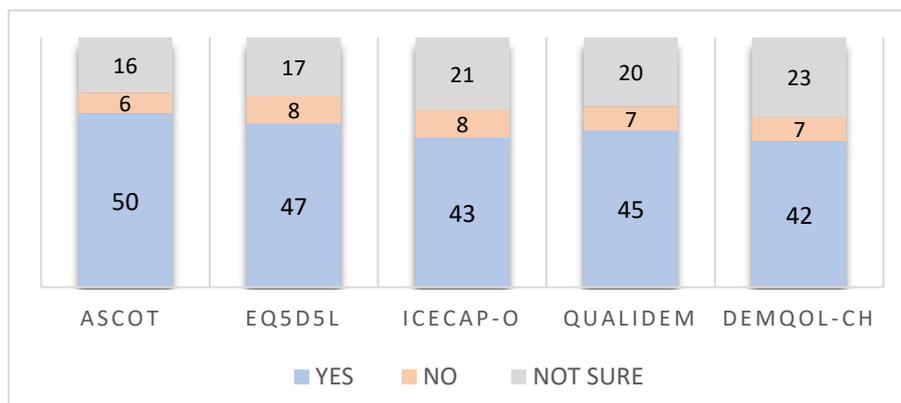


Figure 4. Stakeholder response to the question "Would you use the information provided by this measure in your work or carer role?"

Stakeholders ranked each instrument between 1 (not confident at all) and 9 (very confident) in its ability to capture quality of life for care home residents. The mean confidence level for each measure was higher than 5 (the neutral score), and the median score for each was 6.

	Mean	Median	St. Dev.
QUALIDEM	5.97	6	1.94
ASCOT	5.79	6	1.76
ICECAP-O	5.77	6	2.19
DEMQOL-CH	5.72	6	1.94
EQ-5D-5L	5.59	6	1.93

Table 4. Mean, median, and standard deviation confidence level scores for the QoL measures by all stakeholder groups combined

Comparing the mean score for each measure from each stakeholder group, amongst the general QoL outcome measures, the mean confidence level scores for ASCOT was the highest for care home staff, old age specialists (clinical/research), and family relatives of care home residents. ICECAP-O had the

highest scores from care home managers, commissioners/providers/regulators, and from family relatives of care home residents.

For the dementia-specific QoL measures, there was less clear consensus; QUALIDEM attracted higher scores from 4 stakeholder groups, whilst DEMQOL-CH had higher scores from 3 groups. More participants chose QUALIDEM (36%) over DEMQOL-CH (21%), and 43% of participants were undecided.

<i>General QoL measures</i>	Care home staff	Care home managers	Commissioners / providers / regulators	Old age specialists	Primary care + hospital professionals	Resident relatives + carers
ASCOT	5.17	5.33	5.33	5.84	5.63	6.31
EQ-5D-5L	5	5.89	5.22	5.68	5.75	6.13
ICECAP-O	4.17	6.44	5.67	6	5.13	6.31
<i>Dementia-specific QoL measures</i>						
QUALIDEM	5.17	6.11	5.56	6.21	5.38	6.47
DEMQOL-CH	5.83	5.33	5.67	5.16	5.38	6.27

Table 5. Mean confidence level scores for the five QoL outcome measures by stakeholder group, rated between 1 [not confident at all] and 9 [very confident]

For each question where the participants scored the outcome measures, a comment box was provided asking them how they would use the information provided by the measure in their role, or why they were unsure about using this information. Populating these qualitative insights and summarising them showed several perceived advantages and perceived challenges attached to all the shortlisted QoL outcome measures (see Table 6).

	STAKEHOLDERS' PERCEIVED ADVANTAGES	STAKEHOLDERS' PERCEIVED CHALLENGES
ASCOT-Proxy	<ul style="list-style-type: none"> • Holistic approach • Basis for care planning and quality improvement 	<ul style="list-style-type: none"> • Repetition/duplication of work in care plans • Limited in its range of questions • Proxy reporting
EQ-5D-5L Proxy	<ul style="list-style-type: none"> • Good documenting of changes • An early warning system to avoid escalation 	<ul style="list-style-type: none"> • Focusing on the wrongs more than positives • Too health centric • Too task-oriented • Proxy reporting
ICECAP-O	<ul style="list-style-type: none"> • Simple documenting of how residents are feeling • A positive exploration of resident's own state of mind and feelings about everyday life • Very quick to complete due to being short 	<ul style="list-style-type: none"> • Vague • More appropriate for older adults in the community
QUALIDEM	<ul style="list-style-type: none"> • Better understanding of residents and their care needs • Understanding the quality of life of residents with dementia from a regulator view • Easier to report than DEMQOL-CH due to its layout 	<ul style="list-style-type: none"> • Too much information • The length • Proxy reporting

DEMQOL-CH	<ul style="list-style-type: none"> • Useful evaluation of interventions aimed at improving mood, anxiety, and memory • Mood assessment for meds optimisation or deprescribing 	<ul style="list-style-type: none"> • Too much information • The length • Proxy reporting • Overemphasis on emotional wellbeing
-----------	---	--

Table 6. Perceived advantages and perceived challenges of the five QoL outcome measures (Collated from the qualitative responses from stakeholders)

Learning for DACHA

These consultation exercises provided insights from multiple stakeholder groups about what they would want from a quality of life outcome measure to inform their work and understanding of residents' experience.

All the shortlisted measures have been used in UK settings as valid and reliable tools for data collection within research studies. This consultation wanted to establish if including these measures in the MDS would be supported by those who, with access to the MDS, would use the information for planning, care, review, and decision making. Stakeholders were shown to have confidence in all measures they were presented with, and the number of participants who indicated they would use the information provided by the measures was high. The findings informed our decision to include QUALIDEM dementia-specific QoL measure in the prototype MDS. QUALIDEM will be used alongside ASCOT-Proxy, EQ-5D-5L Proxy and ICECAP-O during the DACHA pilot study, which is currently recruiting care homes and residents until February 2023.

There is evidence that self-reported QoL assessments are feasible for people with mild to moderate dementia, but not for those with severe cognitive impairment. Ensuring that information about *all* residents was included was a highly valued QoL principle, yet completion by staff was the lowest ranked principle. Qualitative feedback about the individual measures raised concerns about the perceived challenge of proxy reporting when measures were completed by staff. Self-report is a perceived advantage, even though this has to be balanced against ability to collect data from those unable to self-report. While self-report is the ideal, many care home residents are unable to self-report (even with help and support). Even if proxy report by staff was rated lowest, it offers a fair and consistent way of capturing quality of life data for all residents. Three of the four measures that are included in the DACHA minimum data set – ASCOT-Proxy, EQ-5D-5L Proxy, and QUALIDEM – are proxy assessments completed by staff, while ICECAP-O is a self-report assessment. During DACHA's feasibility work in care homes in 2023, we will ask care home staff filling in the minimum data set what their experiences are like in assessing the resident quality of life via these proxy and self-report outcome measures.

Abbreviations

ASCOT – The Adult Social Care Outcomes Toolkit

CCG – Clinical Commissioning Group

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

DEMQOL-CH – Dementia Quality of Life: Care Home

EQ-5D-5L – EuroQol Group 5D-5L

ICECAP-O – ICEpop CAPability measure for Older people

MDS – Minimum Data Set

THIS Institute – The Healthcare Improvement Studies Institute

QoL – Quality of Life

QUALIDEM – Quality of Life for People with Dementia

Contact

For any queries, please contact g.akdur@herts.ac.uk

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

DACHA Twitter: https://twitter.com/DACHA_Study / @DACHA_Study

To learn more about Thiscovery, visit: <https://www.thiscovery.org/>

Acknowledgement and Disclaimer

This report was created by [Prof Claire Goodman](#), [Dr Gizdem Akdur](#), [Lisa Irvine](#), and [Dr Stacey Rand](#) 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

ASCOT-Proxy

ASCOT (The Adult Social Care Outcomes Toolkit) is a suite of tools designed to measure the aspects of quality of life most affected by social care. We propose to use the ASCOT-Proxy, which is designed to be completed by staff on behalf of people who struggle with self-report (e.g., due to cognitive impairment).

There are eight domains of *social care-related quality of life* (SCRQoL) in ASCOT and one question per domain. The care worker is asked to rate the resident's SCRQoL in two ways: (1) how they rate the resident's SCRQoL in that domain, and (2) how they think the resident would rate themselves, if they were able (so 16 responses in total).

The eight domains of SCRQoL are:

1. Food and drink
2. Accommodation (cleanliness and comfort)
3. Personal (cleanliness and comfort)
4. Social participation
5. Occupation (spending their time doing things they value and enjoy)
6. Control over daily life
7. Safety
8. Dignity

EQ-5D-5L Proxy

EQ-5D-5L (EuroQol Group 5D-5L) is designed to measure health-related quality of life. EQ-5D-5L asks carers to rate the resident's health today on five dimensions, each with five levels of severity. There is also a final question about overall quality of life.

There are 6 questions in total, which relate to:

1. Mobility - problems in walking
2. Self-care - problems in washing/dressing oneself
3. Problems in doing usual activities
4. Level of pain/discomfort

5. Level of anxiety/depression
6. Scoring overall health (scale 0-100)

ICECAP-O

ICECAP-O (ICEpop CAPability measure for Older people) is designed to measure of capability in older people, and focuses on wellbeing defined in a broader sense, rather than health. ICECAP-O asks the resident to rate own quality of life “at the moment”, with four levels of severity.

There are 5 questions in total which relate to:

1. Attachment (love and friendship)
2. Security (thinking about the future without concern)
3. Role (doing things that make you feel valued)
4. Enjoyment (enjoyment and pleasure)
5. Control (independence)

QUALIDEM

QUALIDEM (Quality of Life for People with Dementia) is designed to measure dementia-related quality of life. QUALIDEM asks how the carer would rate the residents based on observations during the past week. There are 40 questions in total, which relate to:

1. Relationship with caregivers (7 questions)
2. Positive and negative feelings (9 questions)
3. Restless tense behaviour (3 questions)
4. Positive self-image (3 questions)
5. Social relationships (6 questions)
6. Social isolation (3 questions)
7. Feeling at home (4 questions)
8. Having something to do (2 questions)
9. Other (Enjoy meals, does not want to eat, likes to lie down) (3 questions)

DEMQOL-CH

DEMQOL-CH (Dementia Quality of Life: Care Home) is designed to measure dementia-related quality of life. DEMQOL asks the carer how their resident felt during the past week. There are 32 questions in total, which relate to:

1. Positive and negative feelings (11 questions) - *Are they cheerful? Frustrated? Sad? Content? Lively? Irritable?*
2. Memory or forgetfulness (9 questions) - *Do they forget people’s names? Where they are? What day it is? Muddled thoughts?*
3. Everyday life (11 questions) - *Keeping clean? Getting in touch with people? Playing a useful part in things? Things taking longer than they used to?*
4. Overall quality of life (1 question)