

DACHA

Developing resources And minimum data set for Care Homes' Adoption



DACHA Stakeholder Consultation 2022: Measuring care related Quality of Life (QoL) in care homes

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How can we best measure and record care-related quality of life for residents in care homes?

You are invited to take part in a consultation exercise for the DACHA study to decide how we should measure and collect information about care home residents' quality of life.

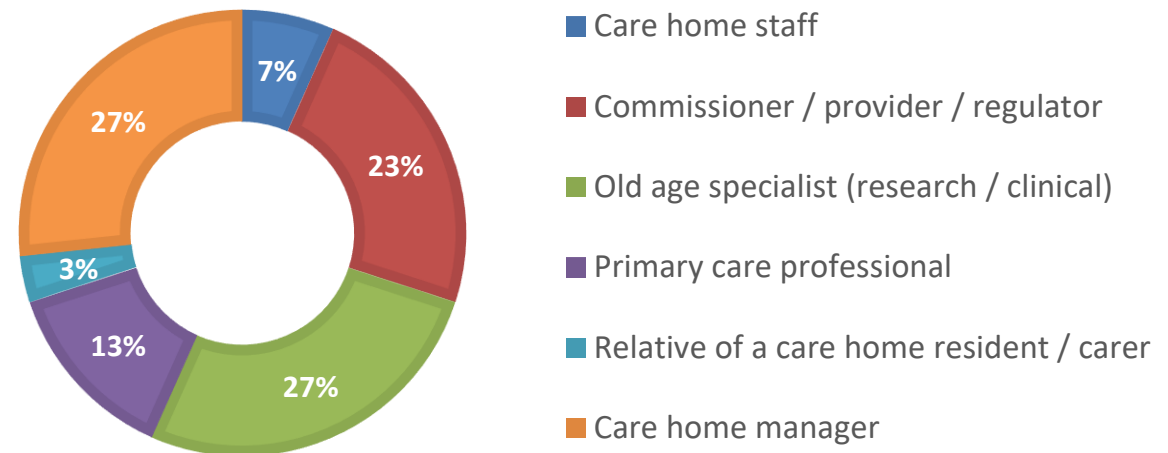
Register

Not your first project?

- DACHA team collaborated with [Thiscovery](#) and had the consultation in the form of two surveys.
- The aim was to focus on the quality of life (QoL) section of the DACHA minimum data set (MDS).
- The consultation took place in two parts:
 - **Round 1 (June-July 2022):** Finding out the most important factors to consider when measuring care related quality of life in care homes.
 - **Round 2 (September 2022):** Finding out the consultees' confidence levels in shortlisted QoL measures and their preferences in dementia QoL measures.

Round 1

- What are the most important factors to consider when measuring care home resident quality of life?
- Date: 28 June-25 July 2022.
 - We sent the invitation to our immediate networks.
 - 30 experts from various stakeholder groups participated.
- 12 principles and 9 aspects of quality of life (QoL) were ranked 1 (not important at all) to 9 (very important).



Round 1 – top principles and aspects ranked

Rank	Principle	Mean score	St. Dev.
1	Resident inclusion	8.57	0.90
2	Easy to complete	7.93	1.48
3	Inform day to day care	7.77	1.10
4	Completion by residents	7.60	1.96
5	Sensitive to change	7.43	1.94
6	Inform decisions	7.30	1.73
7	External access	7.23	1.68
8	Reflect differences in care received	7.00	1.84
9	Quick to complete	6.90	1.97
10	Written in notes	6.70	2.52
11	Have a numeric score	6.50	1.46
12	Completion by staff	6.03	1.77

Rank	Aspect *	Mean score	St. Dev
1	Mental health	8.27	0.91
2	Emotional state	8.27	0.94
3	Social connection	8.20	1.10
4	Physical health	8.03	1.00
5	Personhood	8.00	1.51
6	Autonomy	7.93	1.46
7	Environment	7.70	1.34
8	Overall quality of life	7.57	1.74
9	Spiritual connection	7.33	1.71

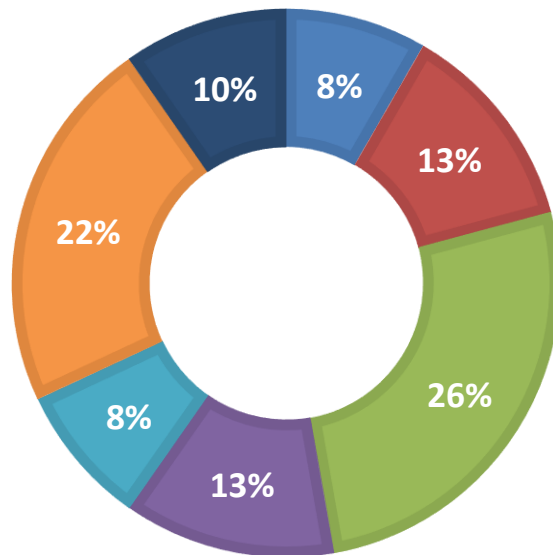
*Aspects adapted from Siette et al's (2021) domains
<https://bmjopen.bmj.com/content/11/11/e050892>

Round 2 overview

- Based on literature evidence and based on consultation findings from Round 1, we created a shortlist of five QoL outcome measures that are applicable to be used in UK care homes.
- 4 of these outcome measures will be included in the DACHA minimum data set (MDS) pilot in care homes (with one dementia QoL measure only).
 - **ASCOT**
 - **ICECAP-O**
 - **EQ-5D-5L**
 - **DEMQOL-CH (dementia related quality of life)**
 - **QUALIDEM (dementia related quality of life)**
- In Round 2, we asked consultees:
 - Their **familiarity** with the shortlisted Quality of Life instruments
 - Their **confidence levels** in the instruments
 - Their potential use of data provided by the instruments
 - Their choice of dementia specific QoL instrument (QUALIDEM or DEMQOL)

Round 2 participation

- Timeline: 12-30 September 2022
- Responses with full completion: **72**
- Responses not included in the sample (less than half completion level): 12
- Public audience: Invitations were advertised on DACHA's social media, disseminated via the NHS Contact, Help, Advice and Information Network (CHAIN), and ARC network, and sent as personal emails to immediate networks of the DACHA research management team members.

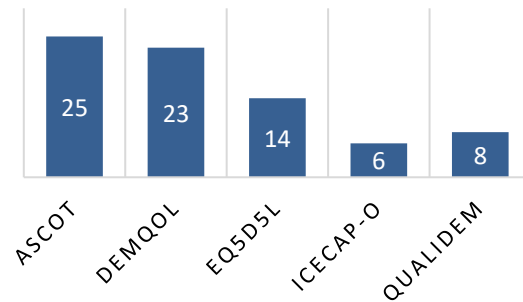


- Care home staff
- Senior operations / CH manager
- Old age specialist
- Commissioner/ provider / regulator
- Primary care professional
- Relative of a resident / carer
- Other

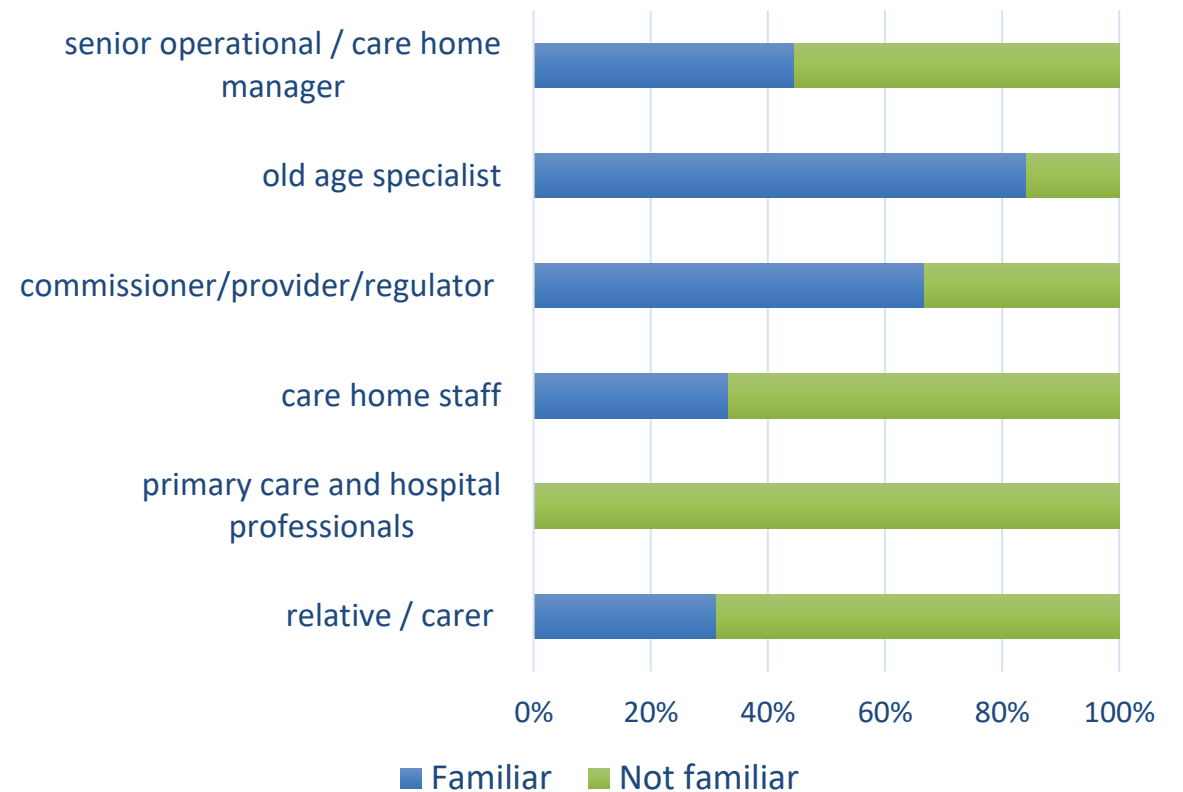
Familiarity with the five quality of life measures

- **Familiarity with at least one of the five quality of life measures:**

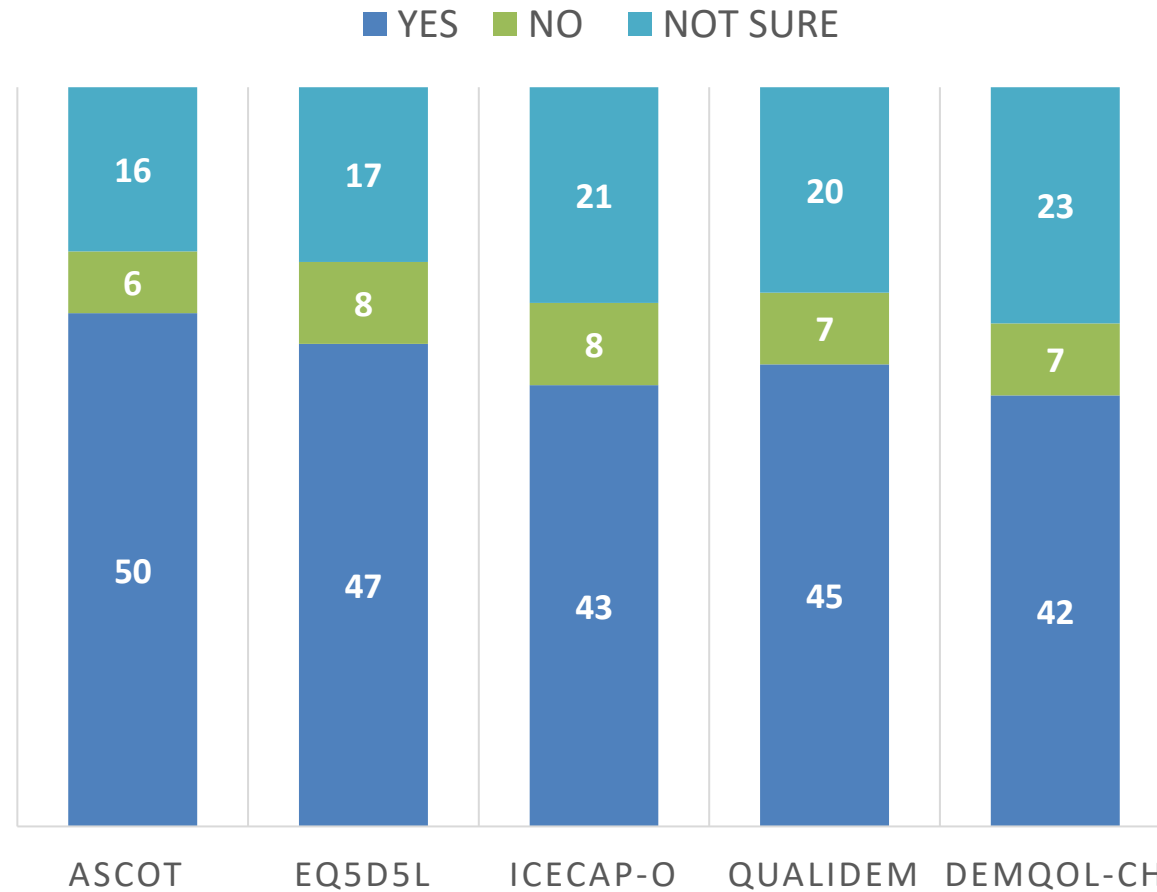
- **Yes: 36**
- **No: 36**



- 11 out of 16 relatives of residents / carers are not familiar with any of the measures.
- None of the primary care professionals and hospital healthcare professionals (n=8) are familiar with the measures.
- Most of clinical or researcher old age specialists are familiar with at least one of these measures.



“Would you use the information provided by this measure in your work or carer role?”



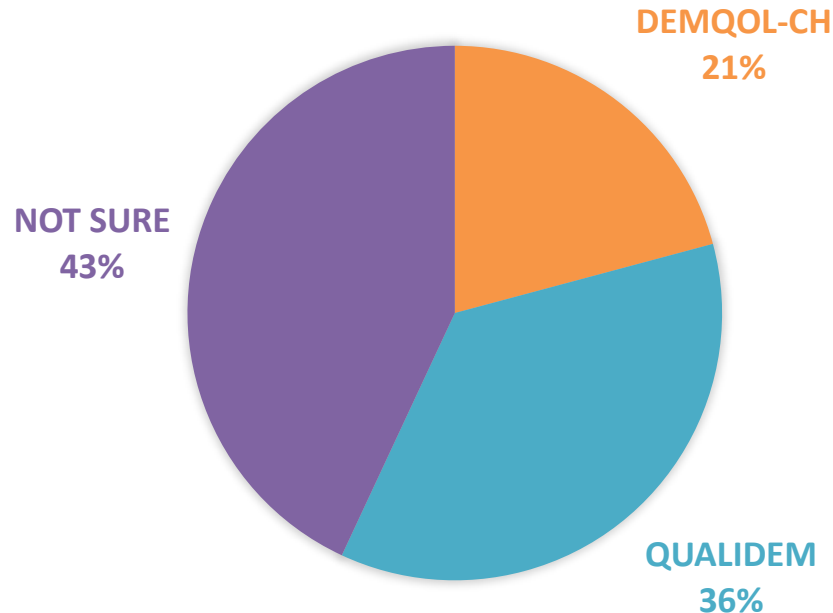
Confidence levels in the measures

- The participants 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 average score for each instrument is higher than 5 (the neutral score).
- The median score for each instrument is 6 (max possible score is 9).

	Mean Score	Median Score	Standard Deviation
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

QUALIDEM or DEMQOL

- We asked the consultees which dementia related quality of life measure they would prefer over the other based on their review of the content of both tools.



Quotes from consultees:

“Easier to report due to layout” (QUALIDEM)

“As a relative responsible for someone in a Nursing Home and a Health Care Assistant working with Dementia Patients, I feel QUALIDEM is a simpler and more effective system.” (QUALIDEM)

“The DEMQOL-CH seems to measure a greater range of the domains of Quality of life” (DEMQOL-CH)

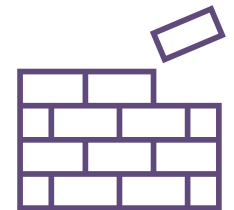
“I think both are useful. The DEMQOL-CH looks slightly challenging to use on first glance” (NOT SURE)

Perceived advantages and challenges

	Perceived Advantages	Perceived Challenges
ASCOT-Proxy SCT4	<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 report
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 report
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 · Length · Proxy report
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 · Length · Proxy report · Overemphasis on emotional wellbeing

DACHA final consultation: 2023-24

- Implications of DACHA minimum data set and recommendations for future
 - Focus groups with representatives from the same stakeholder groups
 - Care home staff including managers, commissioners, providers, regulators, old age specialists (clinical / research), primary care professional, relatives / family carers of care home residents
 - Follow-up survey
- Send an email to g.akdur@herts.ac.uk to register interest



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