CARER QOL TOOL (2014/15): STEP-BY-STEP INSTRUCTIONS

The carer quality of life (QOL) tool calculates an **adjusted carer-reported quality of life score** which takes into account the characteristics of the carer and care-recipient that are known to affect quality of life but are beyond local authority control (e.g. age, health and employment status of carer).[1] This adjusted score provides a more accurate indication of *service impact or organisational performance* than ASCOF 1D alone and, as the characteristics of carers and care recipients may vary widely over time and/or between LAs, a **more meaningful measure for benchmarking activities**.

This Excel-based tool is available for download in the analysis and interpretation element of the MAX toolkit, and automatically calculates adjusted QOL scores for individual respondents and the entire dataset. The tool also generates numerical and visual summaries of the variables underlying the calculations and can be used to guide further analysis (e.g. by identifying potential areas of unmet need) and/or in survey analysis reports.

These instructions show you how to input the data from your NHS Digital data return needed to perform the adjusted QOL calculations and to make sense of the adjusted scores.
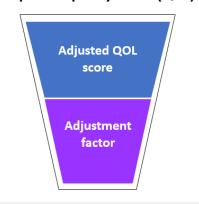
> Additional guidance, in the form of pre-recorded presentations, is provided on the **QOL page** of the MAX toolkit.

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[1] These factors were identified during the Identifying the Impact of Adult Social Care (IIASC) project, which was also conducted at PSSRU, and were used to develop the adjustment calculation. Further information about these factors can be found in the IIASC report - http://www.pssru.ac.uk/publication-details.php?id=4633 - while additional details about the calculation can be found in the IIASC plain English report - http://www.pssru.ac.uk/archive/pdf/5158.pdf.

> **Carer quality of life and service impact**
>
> The carer-reported quality of life (as measured by ASCOF 1D) may be thought of as consisting of two elements: an adjustment factor and the adjusted QOL score.
>
> **Reported quality of life (QOL)**
>
> [Adjusted QOL score]
>
> [Adjustment factor]
>
> The **adjustment factor** isolates the factors associated with the carer and care-recipient that are known to affect QOL but are beyond the control of LAs. This factor is calculated by the Carer QOL tool and can be thought of as a person's QOL without services.
>
> The **adjusted QOL score** is the residual (reported QOL – adjustment factor) and provides an estimate of the impact or effect of services on carer-reported QOL.
>
> Thus, if a carer-reported QOL score is 8.9 and the adjustment factor is 5.2, then the adjusted QOL score (the impact or effect of services) is 3.7.

STEP-BY-STEP INSTRUCTIONS

Step 1: Open the Carer QOL tool and the NHS Digital data return.

Step 2: Select, copy and paste the relevant data from the NHS Digital data return into the **data tab** of the Carer QOL tool, taking care to ensure columns match.

Column Ref [QoL tool]	Variable	Survey Question	Column Ref [Data Return]
D	Care recipient have dementia	Q2a	X
E	Care recipient have sensory impairment	Q2c	Z
F	Care recipient have mental health problem	Q2d	AA
G	Carer living situation	Q3	AG
H	Carer employed full-time	Q19b	BH
I	Carer has physical disability	Q24a	CC
J	Carer has mental health problem	Q24c	CE
K	Carer age	Q26	F
L	Carer gender	Q27	G

M	Carer ethnic group	Q28	H
N	Occupation	Q7	AX
O	Control	Q8	AY
P	Personal care	Q9	AZ
Q	Safety	Q10	BA
R	Social participation	Q11	BB
S	Encouragement and support	Q12	BC

Questions in shaded rows are used to calculate Carer QOL composite score

The data tab contains **hidden formulas** that calculate the **individual carer QOL score** (ASCOF 1D) [column T] and the **individual adjusted QOL score** [column U] for each survey respondent.

Some cells within Columns T and U may have a **MISSING** error message. This means that some of the data required for that particular calculation was not included in the data return (e.g. due to data inputting errors, which can be corrected, or because the respondent did not answer that patricular question). These rows of data will not be included in the final calculations and summary tables.

Step 3: Go to **summary tables tab** of the Carer QOL tool. This tab contains **hidden formulas** that calculate the **average Carer QOL** [ASCOF 1D] and the **average adjusted Carer QOL** for the entire dataset, and the descriptive statistics (i.e. frequencies and percentages) for all the other variables used in the QOL calculations.

Screen shot of the summary tables tab

SUMMARY SHEET

		Number	Percentage
Average Carer SCRQoL		7.15	
Average Adjusted Carer SCRQoL		3.53	
Does the person you care for have dementia?		Number	Percentage
1	Yes	175	48.9
2	No	183	51.1
-9	No response	0	0.0
	Total respondents and non-respondents	358	100.0

INTERPRETING AND REPORTING THE ADJUSTED CARER QOL SCORE

The adjusted score provides an estimation[2] of the **impact or effect of care and support services on carer-reported quality of life (QOL)**. This score will be lower than the average carer quality of life score [ASCOF 1D] – this is to be expected – and can be positive or negative.

Positive adjusted score (e.g. 4.21) indicates that services are having a positive impact and are helping carers to enjoy a better quality of life.

Negative adjusted score (e.g. – 1.2) indicates that services are having a negative impact and are, in fact, reducing carer-reported quality of life.

The **adjusted score for the entire dataset may be used in a comparative way**: for example, by comparing scores within an LA over time or, if the scores are available, between comparator organisations. These comparisons should be reported alongside the current (unadjusted) scores in the ASCOF and can, where conducted, be accompanied by the relevant findings from associated analysis.

Reporting adjusted carer-reported quality of life scores: example based on dummy data

The impact of our care & support services on carer-reported quality of life [ASCOF 1D]

Carer-reported quality of life	2011/12	2014/15	2016/17
Unadjusted [ASCOF 1D]	6.75	6.92	7.15
Adjusted	3.2	2.9	3.53

The adjusted score provides an estimation of the impact of our care & support services on carer-reported quality of life [ASCOF 1D] by controlling for the factors that are known to affect quality of life that are beyond the control of local authorities [add link to further info if required].

Comparisons of our adjusted carer-reported quality of life scores over time indicate that our services are helping carers to enjoy a better quality of life. Adjusted scores have increased slightly since the last data collection (+.3) and further analysis has indicated ….. [add findings from further research, if conducted].

Please note that the relative standing of your organisation as measured by unadjusted carer-reported quality of life scores [ASCOF 1D] may not be the same as measured by adjusted carer-

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[2] The adjusted scores remove the effects of the most influential external factors (i.e. the factors associated with the carer and care recipient that have the greatest impact on carer-reported quality of life). Other factors, however, may also have an effect so the adjusted score can, therefore, only be treated as an estimation.

reported quality of life scores: the adjusted score takes into account the characteristics of the carer and care recipient that are known to affect quality of life. These characteristics may vary between data collections and organisations and, as a result, may change the relative standing of your organisation during benchmarking comparisons. For example, unadjusted scores may show a steady increase in carer-reported quality of life over time, while adjusted scores may show fluctuation. This is shown in the example provided for guidance.

POTENTIAL USES FOR ADJUSTED CARER-REPORTED QUALITY OF LIFE SCORES

Estimating the impact of services: the adjusted carer-reported quality of life score provides a more accurate and meaningful estimation of the impact of care and support services provided by an LA on carer-reported quality of life.

Information sharing and knowledge exchange: adjusted carer-reported quality of life scores can be compared at regional performance meetings and may help you to identify knowledge and/or areas of practice that can be shared between organisations.

Q&As

How is the adjusted carer-reported quality of life score calculated?

The adjusted carer-reported quality of life (QOL) score is calculated by statistically adjusting the care-related quality of life score [ASCOF 1D] to factor out the effect of other key influences on quality of life that are outside of the direct control of local authority adult social care services (e.g. age, individual general health, difficulty with I/ADLs, design of home and local environment).

The adjusted carer quality of life score

Adjusted carer SCRQoL score = 3.88 + 0.604 × carer SCRQoL score + 0.055 × (carer SCRQoL score) ^{2} − carer adjustment factor

Carers adjustment factor =		14.353
Care recipient: has 'dementia', then subtract:	(−)	1.820
Care recipient: has 'mental health problem', subtract:	(−)	0.703
Care recipient: has 'sensory impairment', subtract:	(−)	1.508
Carer: is 45+, then subtract:	(−)	1.807
Carer: is 'male', then add:	(+)	1.437
Carer: is 'white', then add:	(+)	0.634
Carer: is 'employed full-time', then subtract:	(−)	0.036
Carer: if the 'carer lives with care recipient', then subtract:	(−)	3.339
Carer: if the carer has a 'physical problem', then subtract:	(−)	2.401
Carer: if the carer has a 'mental health problem' then subtract:	(−)	1.419

A brief summary of the concept and methodology underlying the adjusted calculation can be found here: http://www.pssru.ac.uk/archive/pdf/5158.pdf.

How were the variables included in the adjustment factor identified as important?

The adjustment factor is based on the work conducted during the Identifying the Impact of Adult Social Care (IIASC) project, which included literature review and extensive statistical modelling to identify the factors to include in the adjustment calculation. Further information about this work can be found in Section 6 of the following IIASC report, available at http://www.pssru.ac.uk/archive/pdf/4633.pdf.

The variables used in the adjustment factor were also guided by the data currently available in the Carers' survey.

How do we identify the carers that are in greatest need?

The adjusted score does not give an indication of carers' need. It is an indicator of the average effect of services on quality of life that may be used for comparisons over time or (if available) by comparator organisations.

You should use the **(unadjusted) carer quality of life data** – in other words, the data underlying the Carer-reported quality of life score [ASCOF 1D] – to identify the carers in greatest need (i.e. those that have reported a low QOL or unmet needs).

As you have copied and pasted the relevant data from your NHS Digital data return into the Carer QOL tool, you can use this tool as the starting point for your analysis. You may, however, also want to refer back to the data return for additional analysis (e.g. dissatisfaction with services).

A brief review of the **data tab** and **summary tables tab** of the Carer QOL tool may help you to identify potential areas for further analysis. For example:

- **Low average QOL scores for each domain underlying carer-reported quality of life score [ASCOF 1D]** (shown in the summary tables tab).

Average Carer SCRQoL score in each domain as a percentage of the total possible score (unweighted)	Current %
Occupation	63.04
Control over daily life	64.99
Looking after yourself	77.21
Personal safety	94.19
Social participation and involvement	67.88
Feeling supported and encouraged	71.72

- **Responses to individual questions underlying the carer-reported quality of life score** (e.g. no needs met [3], shown in the summary tables tab)

5 Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?	Number	Percentage
1 I have as much social contact as I want with people I like	90	25.3
2 I have some social contact with people but not enough	189	53.1
3 I have little social contact with people and feel socially isolated	77	21.6
Total respondents	356	100.0
-9 No response	0	

- **Low carer-reported quality of life scores [ASCOF 1D] for individual respondents** (shown in the data tab) may also be worth exploring. The data in this tab can be sorted to help you identify relevant carers and please note:

  - The criteria for determining low QOL scores are down to you to decide. You could, for example, focus on respondents who score less than a particular QOL score or all those respondents that fall into the bottom X% percentile.

  - You will need to establish if your final sample is large enough before conducting further analysis.

> Further guidance on how to conduct further analysis on your PSS SACE dataset is provided in the **PSS SACE FURTHER ANALYSIS GUIDE**.

DISCLAIMER

The MAX toolkit and website are based on independent research commissioned and funded by the NIHR Policy Research Programme (Maximising the value of survey data in adult social care (MAX) project and the MAX toolkit implementation and impact project). The views expressed on the website and in publications are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care or its arm's length bodies or other government departments.