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Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me)**

Availability	The instruments are freely available here: ASCQ-ME website .
Classification	Supplemental - Highly Recommended: Sickle Cell Disease (SCD)
Short Description of Instrument	<p>ASCQ-Me is a patient-reported outcome measurement system that assesses the physical, social, and emotional impact of Sickle Cell Disease (SCD) on adults.</p> <p>The development of ASCQ-Me measures used a wide range of qualitative and quantitative research methods which included methods similar to those used to develop the Patient Reported Outcome Measurement Information System (PROMIS).</p> <p>ASCQ-Me measures were developed based on formative research with 120 adults with sickle cell disease from regions across the U.S. They were evaluated using both classical and modern psychometric theory.</p>
Comments/Special Instructions	N/A
Measures	<p>The development of ASCQ-Me measures used a wide range of qualitative and quantitative research methods similar to those used for the Patient-Reported Outcomes Measurement Information System (PROMIS), an NIH Common Fund initiative. Like PROMIS, ASCQ-Me uses computer adaptive testing (CAT) technology and item response theory (IRT) models to make the development of standardized patient reported outcomes possible, while reducing respondent burden.</p> <p>The concepts behind the ASCQ-Me measures were based on a conceptual framework of how SCD affects adult lives which, in turn, was based on a comprehensive program of formative research including the:</p> <ol style="list-style-type: none"> 1. NHLBI Adult SCD Working Groups (WGs) 2. ASCQ-Me literature review (LR) 3. ASCQ-Me patient focus groups (FGs) 4. ASCQ-Me patient critical incident interviews 5. ASCQ-Me patient advisors


6. [ASCQ-Me provider critical incident interviews \(CIIs\)](#)
7. ASCQ-Me clinical researcher advisors

The resulting ASCQ-Me includes questions enabling adults to describe their functioning and wellbeing according to seven topics:

1. [Emotional Impact](#)  (CAT, 5-item short form)
2. [Pain Episodes](#)  (5-item fixed form)
3. [Pain Impact](#)  (CAT, 5-item short form)
4. [SCD Medical History Checklist](#)  (9-item short index)
5. [Sleep Impact](#)  (CAT, 5-item short form)
6. [Social Functioning Impact](#)  (CAT, 5-item short form)
7. [Stiffness Impact](#)  (CAT, 5-item short form)

References

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Keller S, Yang M, Treadwell MJ, Werner EM, Hassell K. (2014). [Patient Reports of Health Outcome for Adults Living with Sickle Cell Disease: Development and Testing of ASCQ-Me Item Banks](#).  *Health and Quality of Life Outcomes*,22:125.

The work to develop ASCQ-Me was funded by a contract from the National Heart, Lung, and Blood Institute; National Institutes of Health, to the American Institutes for Research, Contract No. HHSN-268-2005-74264C and by Research and Development funds from the American Institutes for Research.

The work to develop this ASCQ-Me website was supported by a sub-award to AIR from Northwestern University (NU) as part of the U2CCA186878 NIH Cooperative award to NU (David Cella, PI) and by Research and Development funds from the American Institutes for Research.

<http://www.ascq-me.org/Acknowledgements>