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**Disclosure to Participants**

- I have nothing to disclose

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**Assessing Quality of Life in Diabetes: extending beyond glucose control**

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**Diabetes and Quality of Life**

- Diabetes is associated with both short- and long-term consequences that can significantly impact health and emotional well-being
- Regimen requirements include changes in diet and exercise, taking medications regularly, monitoring blood glucose multiple times a day, episodes and fear of hypoglycemia, medication side effects, and living in fear of long-term consequences
- In addition to the actual development of diabetes-related complications, diabetes may lead to reduced health-related quality of life (HRQOL)

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**What is Health Related Quality of Life?**

- HRQOL refers to personal/emotional well-being as a function of diabetes and its treatment
  - Individuals with diabetes report **reduced** HRQOL compared with age-matched persons without diabetes
  - HRQOL **decreases** with disease progression and the onset of different complications associated with diabetes
  - There are different experiences of HRQOL for people at different points in their life that are impacted by their type of diabetes, and length of time they have had diabetes

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### Measuring HRQOL: An Issue of Context

- Diabetes specific instruments for persons (children and adults) with both type 1 and type 2 diabetes
  - "Generic" instruments that measure components impacting HRQOL but not specific to diabetes
  - There are clearly different components to assessing Quality of Life including impact on physical functioning and limitations, cognitive and emotional status, social relationships, fear of future, and job/school and possibly spiritual aspects
- This decision of specific vs. generic reflects the complexity of assessing HRQOL; it is more than simply glucose control!

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### Considerations



- **HRQOL is not a unitary construct:**
  - It encompasses **both** positive and negative aspects of living with diabetes in terms of social/interpersonal interactions, personal experiences, mood, behavior, management demands in the workplace or at school, and impact on physical functioning/well-being, among other domains of everyday life
  - Disease specific measures of HRQOL may not be related to generic measures of HRQOL domains. Moreover, different HRQOL domains may be unrelated to each other

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### Considerations: 2

- Both global and specific HRQOL domain measures often are unrelated to behavioral aspects of self-management or A1C.
  - A treatment may have excellent therapeutic efficacy, but not result in improvements in quality of life, or even have a negative impact due to treatment burden
- Similarly, a therapeutic approach can result in dramatic changes in HRQOL over time without corresponding changes in disease, treatment, or functional status

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### Suggested Guidelines: 1

- Consider the primary outcome of the intervention or program and clearly identify the very specific, primary goal: **What are you trying to accomplish?**
- Consider what effect that the goal(s), if achieved, will have on a participant: **In what ways will the participant be affected?**
- Distinguish between patient reported outcomes (PRO) in general and QOL specifically
- Avoid using solely composites of component measures. Doing so risks reducing the chances of detecting specific changes

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### Suggested Guidelines: 2

- Consider the impact of an intervention on the QOL of other close family and caregivers as well as the targeted patient
  - This provides a broader picture of the impact of the intervention, and allows for a fuller documentation of changes in QOL
- Carefully consider the timing of assessment. Changes in QOL do not necessarily follow the same trajectory as changes in behavior or A1C. Often, QOL changes occur after changes in other variables or even well before

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### Conclusion

- With more accurate assessment tools the enable us to better understand the impact of treatment(s) and compare between therapies, HRQOL can eventually become part of the clinical decision-making process and improve patient care



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