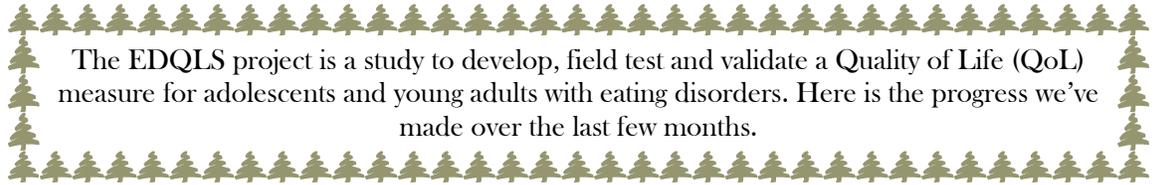




## The Quality of Life in Eating Disorders Project (EDQLS)



The EDQLS project is a study to develop, field test and validate a Quality of Life (QoL) measure for adolescents and young adults with eating disorders. Here is the progress we've made over the last few months.

### LONG TIME NO SPEAK...WHAT HAVE WE BEEN UP TO?

**Validation Instrument Testing**—Late last spring we pre-tested the set of measures that will be used to validate our new instrument. The purpose of the test was to measure completion time as well as acceptability and comprehensibility across the full age range of interest.

The set includes five instruments: the SF-12, the 16-D Health related QL, the Quality of Life Inventory and the Stages of Change questionnaire. Our “testers” included eight (1 male and 7 females) aged 13 to 31. The average response time was 21 minutes and only a few wording changes were suggested. Testers characterized the set of instruments as easy, interesting and “not extremely time consuming or strenuous”.

**Focus Group Validation**—Our main pre-occupation this summer was with the focus groups, that were organized and held

in the Calgary Eating Disorder Program. Their purpose was to obtain immediate feedback and validation on the derived domains, and to reconcile some difficult issues with particular items. We have been striving to develop items that use the patients' own language but also reflect their broader life experiences and the impact of treatment on their quality of life. The exercise turned out to be extremely valuable. Our participants were able to articulate reasons why various items resonated for them more than others, and offered many suggestions for revising items. We are truly grateful for their insights and enthusiastic participation.

On page 2, we describe the methods and specific findings of the focus group exercise and what we did next with the item set.



### Dr. Carol Adair, EDQLS Co-Principal Investigator



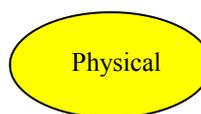
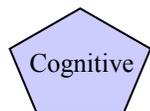
Dr. Carol Adair, PhD, is currently Associate Professor in the Departments of Psychiatry and Community Health Sciences at the University of Calgary (U of C). She earned her MSc. in Healthcare research (1992) and her PhD in Epidemiology (1996) from the U of C. She has been involved in mental health services research with a focus on performance and outcomes measurement for the past 12 years, and has most recently headed up a Research Program on Continuity of Care.

She has also served as Research Director for the Alberta Mental Health Board, where she was responsible for the identification of outcomes measures for a variety of services. The idea for development of a QL measure for eating disorders came after no disease-specific instrument was found in a comprehensive literature review of measures for the new Eating Disorders Program in Calgary. She has found collaboration with Eating Disorders researchers, clinicians, and participants to be enormously rewarding and looks forward to collaborating with colleagues across Canada in the national field test.

*We would like to thank our funders: the Alberta Children's Hospital Foundation, the Calgary Health Region's Mental Health Research Fund, and the Alberta Heritage Foundation for Medical Research.*

## FOCUS GROUP VALIDATION DETAILS

The focus groups were organized around the following tasks a) validation of domains identified so far, b) testing specific items of concern to the investigators. The focus groups included participants of various ages (15-22) and at various stages of treatment. After introducing the purpose and process, we presented participants with 12 domains—Appearance, Cognitive, Coping, Eating, ED symptoms/behaviors, Emotional, Future, Free time, Physical, Psychological, Relationships, and School/Work/Vocation. The domains were presented visually as shown in the following examples:



Participants were asked to consider these questions while reviewing the domains: Did the domain names capture the areas of their life that they would consider to be important to quality of life? Was anything missing? Next, the 59 items of concern were presented one by one and participants were asked a) whether the item captured their language and the language of their peers accurately, b) whether the item was relevant to their quality of life i.e. did it fit for them, and c) whether there was anything they would add or change. The following is an example of a domain (Relationships) with sub-domains (family, friends, etc.) and accompanying items presented to the participants for feedback:

### Relationships

I have an honest close relationship with someone outside my family

**Family:** I feel accepted by my family

**Friends:** I turn down opportunities to go out with friends

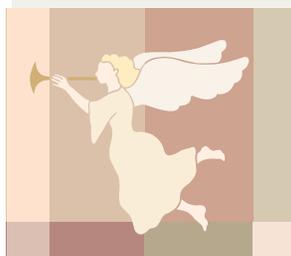
**Intimate/Sexual:** I'm able to have intimate relationships

### *So... WHAT DID WE LEARN?*

- Participants noted that we seemed to be tapping the broader life experience that many other instruments they've completed didn't, and that having the opportunity to respond to an issue on paper helped address some of the tough topics they would feel embarrassed about bringing up themselves.
- They were able to identify how they might respond to a particular item at various stages of treatment.
- They also confirmed the well-known truths about questionnaire design—that items need to be specific, direct and concise. Otherwise they feel disinclined to answer in a thoughtful and honest manner.
- They noted the difficulty of answering questions that ask for responses related to a specific time period. Our groups told us they feel they aren't able to recall and will often just guess at their response.

### *Next Steps...*

- In the next newsletter we'll describe how we got from over 500 items in the master list, down to 130 to be pre-tested and we will share what the final item list for national field testing looks like.
- We'll be holding our national teleconference with everyone who has expressed interest in participating in the national multi-site Field Testing of the new Quality of Life in Eating Disorders instrument on January 10th at 11:30am mountain time. This will provide an opportunity to connect and plan the next steps.



Please forward any questions or comments you have to the Principal Investigator:

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The Co-Investigators include clinicians and researchers from the University of Calgary, the University of Alberta, and the Calgary Eating Disorders Program: Carol Ewashen, Dr. Brian Cram, Dr. Sandra Ziolkowski, and Janet Chafe.

### **QUALITY OF LIFE IN EATING DISORDERS PROJECT**

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