

Using cognitive interviews to assess and refine the Coeliac Disease Assessment Questionnaire (CDAQ)

Helen Crocker, Crispin Jenkinson, Michele Peters

Nuffield Department of Population Health, University of Oxford, UK



Aims

The Coeliac Disease Assessment Questionnaire (CDAQ) is a new patient-reported outcome measure developed to assess quality of life in adults with coeliac disease. The aim of this study was to identify and resolve possible sources of response error in the questionnaire through the conduct of cognitive interviews, as part of the measure's development.

Cognitive interviews aim to evaluate the cognitive processes experienced by the respondent while answering survey questions in order to identify sources of response error.

Methods

Cognitive interviews (n=10) were conducted with adults with coeliac disease in two rounds, with revisions to the questionnaire occurring after each round. Participants were recruited through online social networking groups and from a pool of those who had expressed an interest in participating in the qualitative interview phase of the study. Cognitive interview participants were aged between 24 and 80 years old and had been diagnosed with the condition for between 3 and 16 years (see Table 1). Interviews were conducted over the telephone and lasted for approximately one hour. Participants completed the CDAQ during the interview and answered generic and item-specific questions about their experience of doing so retrospectively (see Box 1).

Table 1. Summary of cognitive interview participants (n=10)

Participant characteristic	Summary
Age range (years):	24 – 80
Gender (n):	Female (7), Male (3)
Marital status (n):	Single (2), Married (5), Widowed (1), Divorced (2)
Ethnic origin (n):	White British (9), White Irish (1)
Occupational status (n):	Full-time employment (5), Part-time employment (1), Self-employed (1), Retired (3)
Time since diagnosis (years):	3 – 16

Box 1. Example probes used in the cognitive interviews

- **Generic probe:** Did you have difficulty understanding or answering any of the questions on this page?
- **Item-specific probe:** What does the term 'cross-contamination' mean to you?

Results

In total, 50 questionnaire items were reviewed, of which nine items were revised, one item was deleted, and two items were added. The items added to the questionnaire were alternative wordings of existing items, which were tested in subsequent stages of the CDAQ's development. The questionnaire's instructions and formatting were also revised.

Sources of response error identified in the cognitive interviews were due to participants answering items in general rather than in relation to their coeliac disease; interpreting words or phrases in different ways to each other; and interpreting items not as the developer intended. Examples of the issues identified and amendments made can be found in Table 2.

Table 2. Response error categories and examples of amendments made following the cognitive interviews

Response error category	Example – 'During the past 4 weeks, how often...'		
	Original item	Summary of participants' comments	Revised item ^a
1. Participants answered items in general rather than in relation to their coeliac disease	Example 1: Item revised ...have you been affected by nausea (feeling sick) or vomiting?	Some participants considered their experience of nausea and vomiting in general rather than in relation to their coeliac disease. All participants understood the term 'nausea' as intended.	...have you been affected by nausea or vomiting that you think was caused by your coeliac disease?
	Example 2: Instruction revised During the past 4 weeks, how often...	Some participants reported having some difficulties determining whether certain items were asking about issues in general or in relation to coeliac disease. The instructions were revised in order to clarify that all items should be answered in relation to coeliac disease.	Thinking about your coeliac disease, during the past 4 weeks, how often...
2. Participants interpreted words or phrases in different ways to each other	Example 3: Item revised ...did you feel excluded from social activities?	'Excluded' was interpreted by participants as either meaning partial exclusion (i.e. feeling like an outsider or 'not part of the group') or complete exclusion (i.e. not being able to attend). The latter interpretation is the intended concept and the item was revised to reflect this.	...did you feel excluded from attending social activities?
3. Participants interpreted items not as the developer intended	Example 4: Item revised ...did you worry that you would be unwell while away from your home?	Many participants interpreted 'away from your home' as holidaying or being away for the weekend, rather than any instance of being away from their home as intended. In order to clarify the item's meaning, 'away from your home' was amended to 'out of the house'.	...did you worry that you would be unwell when out of the house?
	Example 5: Item deleted ...was your choice of food affected?	Many participants interpreted this question as asking whether their choice of food was affected by their coeliac disease, i.e. their need to select gluten-free food as opposed to gluten-containing. The intended meaning was whether choice was affected <i>within</i> their gluten-free diet, e.g. selecting a naturally gluten-free option to minimise the risk of gluten consumption. The item could not be reworded to reflect the intended meaning and therefore it was deleted.	<i>Item deleted</i>

^aThis is the final version of the revised item after both rounds of cognitive interviews

Conclusions

Conducting cognitive interviews as part of the development of the CDAQ allowed potentially problematic items to be identified and resolved. The questionnaire's instructions and formatting were also improved. The psychometric properties of the final version of the questionnaire are currently being assessed. A study assessing the CDAQ's responsiveness to change is also underway.

