

Appendix A: Psychometric and health scales

Generic quality of life scales

The [EuroQol 5-dimension health questionnaire \(EQ5D\)](#) was adopted. It is a descriptive system of health-related quality of life states consisting of five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) each of which can take one of a set of defined levels.

In the EQ5D-5L the levels of mobility, self-care, usual activities, pain/discomfort, anxiety/depression can take one of 5 levels. This scale was adopted for adults answering regarding themselves.

There is no validated 5-level version of the EQ5D available for parents answering regarding their children. Hence in the Parent questionnaire the EQ5D-3L parent proxy instrument was adopted.

Respondents also used the Visual Analogue Scale (VAS) to record their (child's) health on the day of the survey. The VAS is represented visually as a thermometer-like scale ranging between values of 0 and 100.

Psychometric scales concerning Food Hypersensitivities

A number of validated scales exist for food allergy, and the Food Allergy Quality of Life Questionnaires (FAQLQs) was adopted. FAQLQs were developed as part of the [EuroPrevall study](#) and is the most widely used and validated.

The FAQLQs have also been used as a basis to develop versions for people with food intolerance and these were used where available.

Proxy quality of life scales were used for:

- parents of teens aged 13-17 years with food allergy (FAQLQ-TF-PF) and
- parents of children aged 0-17 with food intolerance (FIQLQ-CF-PF)

There was no available validated scale for children or teens with food intolerance so we used the adaptations of the FAQLQ for children and teens which were developed in Workstream 1.

Following Workstream 1 of the project, the Coeliac Disease Quality of Life scale for adults (CDQ) and Coeliac Disease quality of life scale for children parent-proxy (CDDUX parent proxy) were adopted in this phase of the project (see Appendix B).

The FAQLQ and FIQLQ use scales running from 1 (least impairment on quality of life) to 7 (maximal impairment on quality of life). The CDQ is rated on a five-point scale, with totals adding up from 20-100 and cut off points (1-20, 20-40, 40-60, 60-80, 80-100) to denote different levels of quality of life.

On all scales, higher scores indicate a bigger impact on quality of life. Each scale consists of food hypersensitivity specific subscales.

For those completing the FAQLQ, these are:

- Allergen Avoidance and Dietary Restrictions (AADR), which considers the impact that a restrictive diet has on quality of life and the impact this also has on social activities
- Emotional Impact (EI) relating to the worries and concerns about having an allergic reaction or consuming allergens
- Risk of Accidental Exposure (RAE), relating to vigilance and awareness needed to avoid ingesting allergens
- Food Allergy related Health (FAH), relating to specific health anxiety about having an allergy or reaction
- For the FIQLQ scale, subscales comprise
- Emotional Impact (EI), related to the stresses and concerns of having to be aware of foods that could cause a reaction;
- Social and Dietary restrictions (SDR), related to the impact that having an intolerance has on diet and social activities (e.g., eating out)
- Reactions and Avoidance (RAV), related to negative feelings about having a reaction (for example, embarrassment and discouragement).

For the CDQ, subscales comprise of:

- limitations, relating to social and dietary limitations of having coeliac disease
- Dysphoria, related to negative feelings of having coeliac disease
- health concerns, concerns about the wider impact having coeliac disease will have on health
- inadequate treatment, feelings that there are not enough treatment options for the disease.

Table 1: The validated scales used to measure quality of life

Respondent group	Quality of life scales	Development and validation reference
Adults with food allergy	Food Allergy Quality of Life Scale (FAQLQ)	Flokstra de-Block et al., 2009

Respondent group	Quality of life scales	Development and validation reference
Adults with food intolerance	Food Intolerance Quality of Life Scale (FIQLQ)	DunnGalvin et al., 2018
Adults with coeliac disease	Coeliac Disease Quality of Life Scale for adults (CDQ)	Dorn et al., 2010
All adult respondents	EQ5D-5L	Hernandez-Alava et al., 2018
All adult respondents	Visual Analogue Scale (VAS)	-
Parents of children aged 0 to 12 years with food allergy	Food Allergy Quality of Life Scale for children parent form (FAQLQ-PF)	DunnGalvin et al., 2008, 2010
Parents of children aged 13 to 17 years with food intolerance	Food Allergy Quality of Life Scale for teens parent form (FAQLQ-TF-PF)	Workstream 1 of the FoodSensitive Study
Parents of children aged 0 to 17 years with food intolerance		Workstream 1 of the FoodSensitive Study
Parents of children with coeliac disease		Van-Doorn et al., 2008
-	-	Lins et al., 2015
All parent respondents	EQ5D-3L parent proxy	Hernandez-Alava et al., 2018
All parent respondents	Visual Analogue Scale (VAS)	-