



# What does the Family Reported Outcome Measure (**FROM-16**) score mean?

## Study Summary Report for Family Members/Partners

### Impact of a Relative's Disease on Family Members/Partners

Date: July 2023



Authors:  
Rubina Shah  
Professor Andrew Y Finlay  
Professor Sam Salek  
Stuart Nixon (Patient research partner)

# What does the Family Reported Outcome Measure (**FROM-16**) score mean?

## Background

The lives of family members are often affected by a person's health condition, but this important impact is often ignored. Our research team at Cardiff University has created a simple questionnaire, the '**Family Reported Outcome Measure**' (**FROM-16**), to measure this impact. FROM-16 comprises 16 items with a total score range of 0 – 32 (lower scores mean better Quality of Life (QoL)). To make FROM-16 suitable for routine practice and help clinicians understand what different FROM-16 scores mean, **we conducted a study to put scores into meaningful score bands.**

## Methods



In 2021 we asked family members (aged 18 years and older) of patients registered with 58 patient support groups, including patient research support groups such as "HealthWise Wales", "Join Dementia" and "Autism Research Centre", to complete an online questionnaire. Family members were asked to complete a FROM-16 questionnaire and another standard questionnaire called the Euroqol Five Dimension (EQ-5D-3L). The family members also answered a question about the overall impact of their relative's health condition on their QoL with a 5-point response (**No effect** on QoL, **small effect**, **moderate effect**, **very large effect** and **extremely large effect** on QoL). We used this information and family members' FROM-16 responses to create **five score bands for FROM-16.**

## Results



**A total of 4,413 family members** of people with more than **200 health conditions** completed the questionnaire. This meant that we included family members with a wide range of impacts from no effect to extremely large effect on their QoL, which was important to create the bands. **Figure 1** shows the proposed FROM -16 banding. **This study has been published in BMJ Open and can be**

accessed at <https://bmjopen.bmj.com/content/bmjopen/13/3/e066168.full.pdf>. A copy is also attached.

**Figure 1** Proposed FROM -16 score banding: Impact on the QoL of the family member/partner

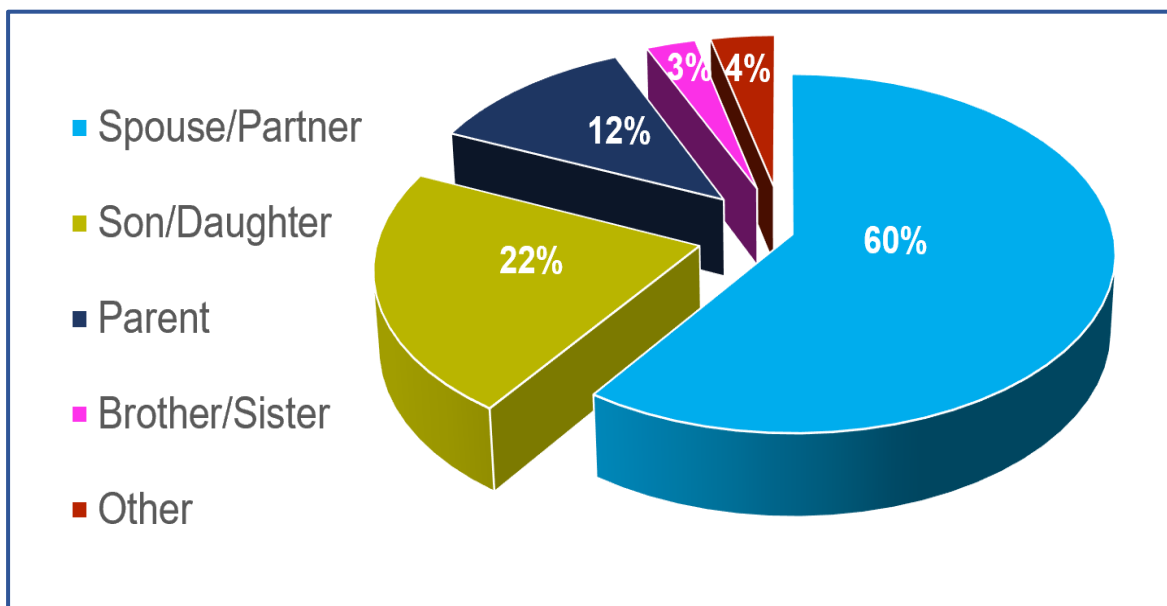
FROM-16 Banding	0-1	2-8	9-16	17-25	26-32
	No effect	Small effect	Moderate effect	Very large effect	Extremely large effect



This means that healthcare professionals such as Doctors, Nurses or Pharmacists can now identify family members/partners who are most affected and provide them with the right kind of support.

65% of the family members were females. 60% of the family members were spouses/partners, followed by sons/daughters, parents and brothers/sisters of the person with the health condition (see Figure 2).

**Figure 2** Family member's relationship to the patient



*Other: Grandson/Granddaughter, Son/Daughter-in-law, Father/Mother-in-law, Brother/Sister-in-law, Uncle/Aunt, Nephew/Niece, Step-parent, Step-Son/daughter, friend*

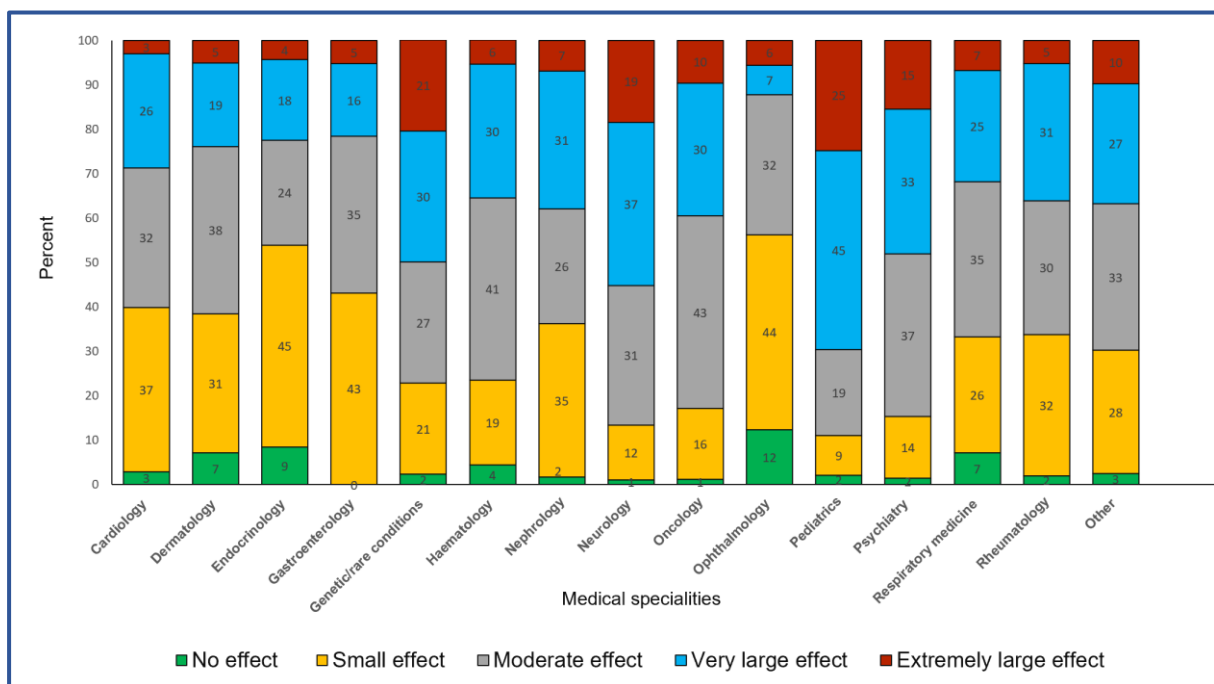


This means FROM-16 can now be used to understand the wider impact of a relative's disease.

The average FROM-16 score for family members was 15.2 (range 0-32). However 42% of family members had a FROM-16 score of 17 or over, meaning a “Very

**large effect on their quality of life**". We compared the FROM-16 scores of family members of patients across different disease areas. Although the impact on family members can be seen across all areas in **Figure 3** below, **parents/family members of children** were most impacted, with **70%** experiencing **very large and extremely large effects**, followed by family members of people with **neurological 56%, genetic 51%** and **mental health conditions 48%** (See **Figure 3**). The 'Other' category included **13 disease areas**; of these the family members of people with **critical illness, stroke, movement disorders** and **urological conditions** were most affected.

**Figure 3** QoL impact on family members of patients across different disease areas



*Other: Audiology, Chronic Pain, Critical Care, Gynaecology, Hepatology, Immunology, Infectious diseases, Movement disorder, Multiple health conditions, Orthopaedics, Otolaryngology, Stroke, Urology and Wound Healing.*



**These results show that there is a great need to measure this impact in routine care to identify and provide support to family members.**



As well as the “banding” work, results from this study were also used to create a way **to use FROM-16 to find out how well new treatments work**. **When this is published you will be able to find out about this on the FROM-16 website:** <https://www.cardiff.ac.uk/medicine/family-reported-outcome-measure>.