

Questionnaire & Survey

A. Questionnaire

Questions asked in the questionnaire relating to the perceived role of the dietitian amongst people with cystic fibrosis (PwCF).

1. Which one of the following describes you? (Please select all that you feel apply)

Person with CF

Parent of a person with CF

Carer/caregiver of a person with CF

Family Member of a person with CF

Friend of a person with CF

CF Charity Team Member

Other – (Please state)

2. What is your gender?

3. Please indicate your age

Less than 10 years

10-15 years

16-19 years

20-29 years

30-39 years

40-49 years

50-59 years

60-69 years

70 years +

Prefer not to answer

4. If you are not the person with CF (e.g. a parent, carer or friend etc.) please indicate the gender of the person with CF

5. If you are not the person with CF (e.g. a parent, carer or friend etc.) please indicate the age of the person with CF

6. What is your home country?

7. Please indicate how important the CF diet is to you.

Very Important	Of Interest	Neutral	Not Important	Do not wish to know
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8. How often do you ask the CF dietitian in order to obtain information relating to cystic fibrosis?

Always Frequently Sometimes Seldom Never

9. How often do you consult the following educational resources in order to obtain information relating to cystic fibrosis?

Always Frequently Sometimes Seldom Never

Medical/Scientific Journals

Medical Scientific search engines e.g. PubMed

10. How reliable is the information you receive from:
CF dietitian?

Medical/Scientific Journals?

Medical Scientific search engines e.g. PubMed?

Very Reliable Generally Not Sure Limited Totally
 Reliable Reliability Unreliable

11. Rank your top five preferences for research topics relating to CF.

B. Survey

Likert scale questions were used to assess respondents' attitudes to the role of the CF dietitian in communicating information, including current research findings, with particular reference to the CF diet and CFRD. Free text and closed questions were used to collect respondent demographics. The questionnaire was co-designed, reviewed and approved by several CF national charities including the Cystic Fibrosis Foundation (USA), Cystic Fibrosis Trust (UK), Cystic Fibrosis Ireland and Cystic Fibrosis Canada. The questionnaire was subsequently translated into Hebrew, Arabic and Canadian French.

Following consideration by the UK NHS Health Research Authority, formal ethical approval was not required, as the survey was not considered Research, as defined by the UK Policy Framework for Health and Social Care Research. However, the survey was conducted using the guiding code of ethics and practices established by the American Association of Public Opinion Research (AAPOR) (www.aapor.org), which address ethical considerations for survey researchers. The questionnaire was purposely designed to avoid any potential for identification of individual respondents and so excluded name, date of birth, address and any other potential identifiers.

An online survey tool, SurveyGizmo (Louisville, Co., USA) was employed to present and securely data handle responses from survey respondents. In accordance with the AAPOR code of ethics and practices, respondents were made aware that the survey was entirely voluntary, non-incentivising and anonymous. None of the questions were mandatory and respondents could voluntarily choose not to answer any questions and could withdraw from the survey at any time without consequence. There were no face-to-face interactions with respondents nor were there any interviews or other interactions with respondents. A hard copy version of the questionnaire was also available to respondents at some CF centres, who anonymously completed the hard copy version and returned the completed form for manual input to SurveyGizmo by project staff. The online survey was performed amongst people with CF (PwCF), parents of children with cystic fibrosis, families, carers, friends and CF charity personnel during the period 2018-2019. The online survey was publicised by national CF charities to their respective memberships through their respective social media network platforms.

Statistical analysis was conducted using IBM SPSS Statistics version 26 (SPSS, UK). Descriptive statistics included frequencies and percentages in relation to respondent groups. As the survey data was ordinal, statistical analyses were performed using nonparametric methods. The Kruskal-Wallis test was performed comparing continent, respondent and PwCF information (independent) to the various question answers (dependent). If statistically different, further Mann-Whitney U tests were performed.