14th November 2024

Salt Supplementation Survey
University of Portsmouth, United Kingdom

'Why are we doing this survey?

Traditionally it has been believed that people with CF lose an increased amount of salt through sweat, especially during exercise or when in a hot environment. Despite exercise being an important part of clinical care for people with CF, there is a lack of clear guidelines on salt supplementation or hydration when exercising with no exercise-specific guidelines. Similarly, there are no guidelines on salt supplementation or hydration available for during hot weather or exercising in hot environments.

New treatments for CF known as CFTR modulator therapies (e.g Kaftrio/Trikafta®, Symkevi/Symdeko®, Orkambi® and Kalydeco®) are now raising even more questions around salt supplementation as current guidelines only consider salt losses prior to the availability of modulator therapies. However, not everyone has access to these modulator therapies, and it is important we understand more about people with and without access to these treatments.

As a group of clinicians and researchers we want to help build the research to develop clearer guidelines.

We need your help to understand your experiences of:
1. Physical activity and exercise behaviours
2. Experiences of symptoms of dehydration and heat-related illness
3. Current salt intake and use of salt supplements (e.g. tablets etc.) at rest, during exercise, during exposure to hot environments and whilst exercising in hot environments.

As well as your current knowledge of salt supplementation and hydration guidelines or recommendations from specialists in your clinical CF care team.

Please also see links below (we have two versions; a version for pwCF 16 years and older and a parent/guardian version for pwCF <16 years old):

16+ version: https://portsmouth.onlinesurveys.ac.uk/salt-supplementation-in-cf

Parent version: https://portsmouth.onlinesurveys.ac.uk/salt-supplementation-in-cf-parent-version

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