

An International Survey of Experiences and Attitudes towards Pacing using a Heart Rate Monitor for people with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome.

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Background and objectives

People with Myalgic Encephalomyelitis (PwME) may have a blunted heart rate (HR) response to maximum exercise and a reduced anaerobic threshold (AT)¹. If PwME keep their heart rate below their AT it can lead to less post-exertional malaise (PEM)². PwME use heart rate monitors (HRM) to assess their physical activity and to set alerts³. There are no studies identified that explore the use of HRMs in PwME, therefore, the aim of this study was to identify the experiences and attitudes of PwME towards pacing using a heart rate monitor

Methods

Ethical approval was obtained. An online survey was developed and 40 questions were devised. The link for the survey was sent out via facebook, twitter and websites. Participants read the information sheet before completing the online survey. The survey was open for three weeks.

Results

515 PwME completed the survey. 87% were female, mean age group 35 – 50 years (see figure 1). 54% had ME for 10 years or more (see figure 2). Over 30 different types of HRM were being used. Over 30 benefits were identified(see figure 3). Main benefits were understanding PEM triggers better (72%) and real-time feedback on effects of current or prior activity (68%). Over 30 negatives were identified. Main negatives were financial (44%) and difficulty with initial restrictions (42%). 32% identified that they had an improved ability for Activities of Daily Living, 23% had increased time with family and friends and 23% were able to enjoy a hobby as a result of pacing with a HRM. Only 14% stated that healthcare professionals (HCPs) were supportive.

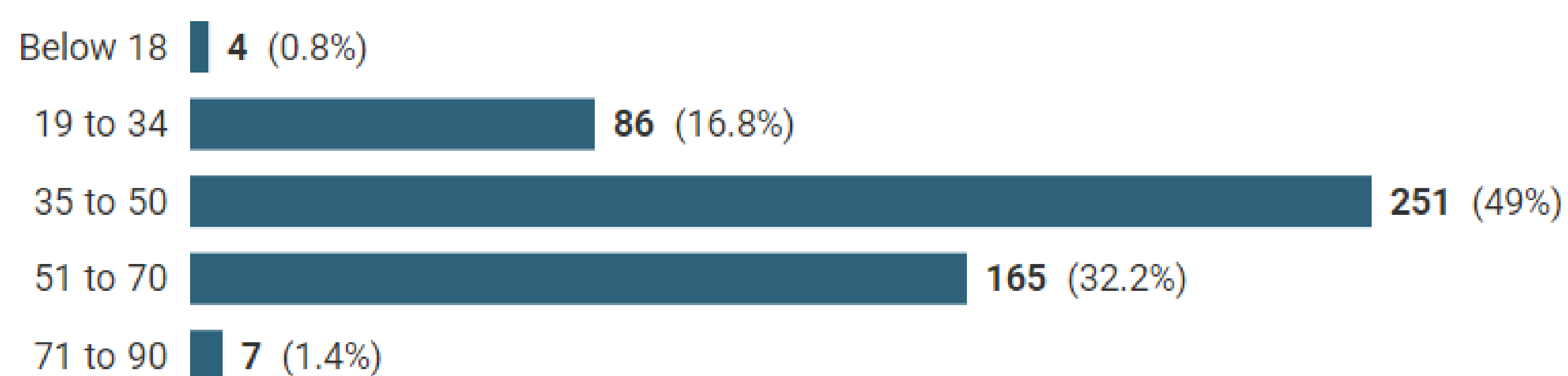


Figure 1. Distribution of age groups



Figure 2. Length of time with ME in years

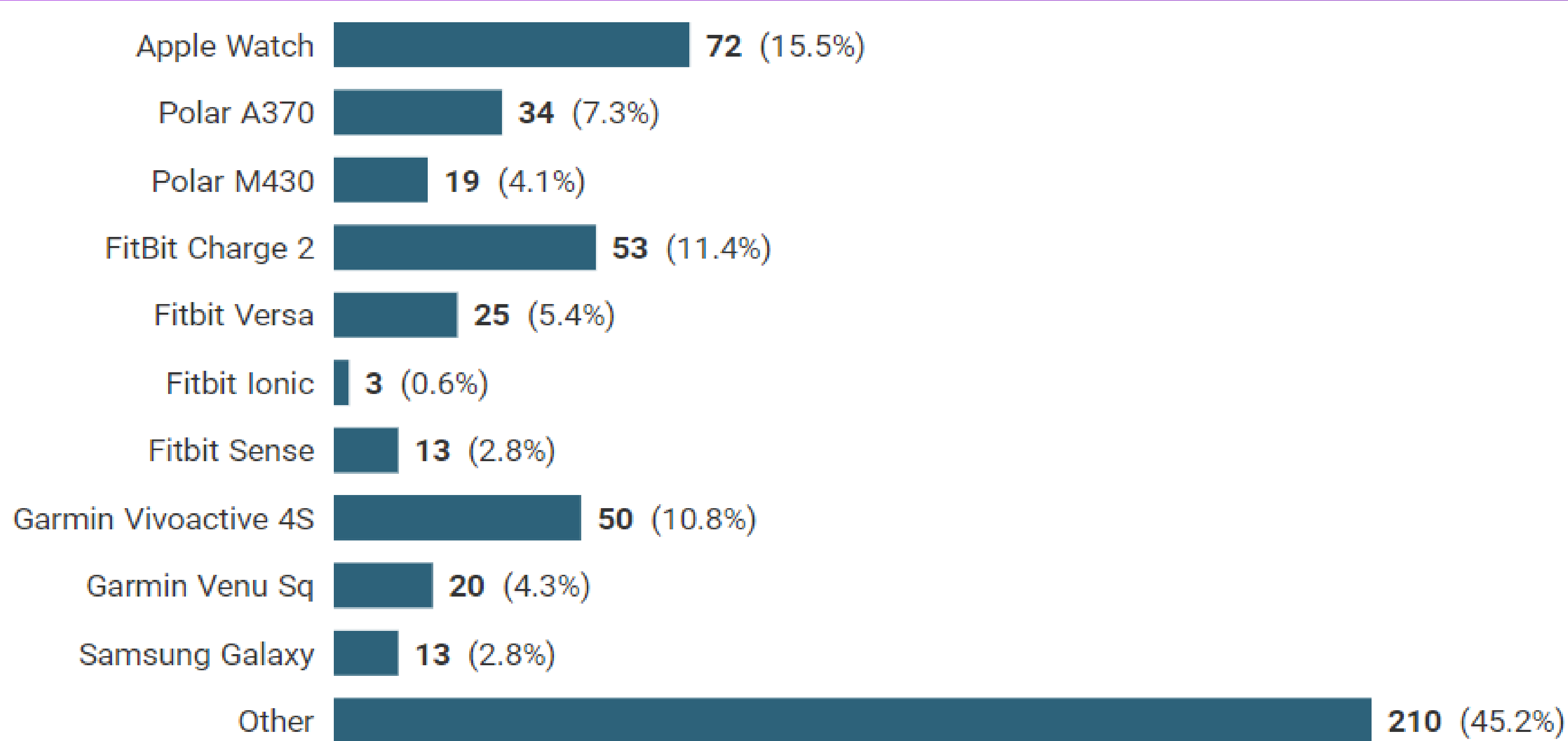


Figure 3. Types of HR monitor



"Mostly they don't care a lot".

"My kids were brilliant. Telling me to lie down when it went off and I was ignoring it to finish a task".

"Family and friends have been supportive but not medical professionals"

Benefits

"It has narrowed the intensity and types of symptoms. Mostly dysautonomia symptoms and very reactive HR are my current PEM symptoms, and I can avoid a lot of the other more severe ones by stopping activity quickly when HR begins to rise".

"Less Pain"

"sharing objective data w med professionals".

"Improved sleep, pain, mood"

Is there anything you can do since HRM Pacing that your illness had prevented you from doing before HRM Pacing?

"My concentration in class is better. This is because the monitor helped me to realise that I had POTS and that gave me evidence to show to my doctor"

"Exercise is possible as HRM ensures I stay within limits: mostly stretching & core strength in supine and slowly walking within HR limits".

Negatives

"switched off alerts quite early on as I found I wasn't able to do anything without it going off which was stressful & too noisy (sensory overwhelm)"

"apps and watches are set for healthy people...need customised ME/CFS ones".

How have carers, physiotherapists, medical professionals responded to you doing pacing with HRM?

Discussion and Conclusion

Pacing with a HRM is beneficial for most PwME leading to more understanding of their ME and PEM and increased activity in some people. HCPs need to learn about and support PwME to use pacing with a HRM.

References

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3. Workwell Foundation. ME/CFS Activity management with a Heart Rate Monitor [online] 2021 [Accessed 3 Nov 2021]. Available at: <https://workwellfoundation.org/wp-content/uploads/2021/03/HRM-Factsheet.pdf>

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