Consumer Driven Research Outcomes for Postural Orthostatic Tachycardia Syndrome (POTS)

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Abstract

Aim: Despite the adverse impacts on quality of life associated with Postural Orthostatic Tachycardia Syndrome (POTS), there is limited evidence to guide management, and with most research utilising heterogenous study outcomes. Through a series of focus groups, we sought to identify targeted research outcomes that would make a meaningful difference to individuals living with POTS.

Method: Participants were recruited from The Australian POTS Registry, which has ethics approval from The University of Adelaide (H-2021-052). Participants required a physician confirmed POTS diagnosis as per international criteria. Six focus groups were conducted via zoom across three age groups, from September 2023 to May 2024. Qualitative outcomes were analysed by a semantic inductive thematic approach, consisting of data familiarisation, coding of data, and generation, review and definition of themes.

Results: A total of 21 participants were included (95.2% female, mean age 35 ± 11.3 years). The main themes identified were: (1) functionality is important, but unpredictable due to symptom burden; predominantly fatigue and brain fog (2) loss of identify and impact on relationships (3) wider awareness of diagnostic criteria, translatable treatment options and access to support (4) objective data is important, but less valuable over time, and (5) understanding of the intersection of other conditions with POTS, and long-term trajectory.

Conclusion: Participants rated functionality as the most important outcome measure. Interventions focussing on fatigue and/or cognitive dysfunction were also highly rated. Future studies in POTS populations should utilise measures of functionality as a primary outcome measure, to reflect consumer prioritised values.