**BACKGROUND**
Charcot-Marie-Tooth disease (CMT) is a hereditary motor and sensory neuropathy that affects the peripheral nervous system, leading to muscle atrophy and impaired sensitivity to touch, vibration, heat and pain.

CMT compromises patient lifestyles, everyday activities, and career and family choices.

CMT is rare, and there has been little research into its impact on patients’ lives. The collection of real-world data, direct from patients, may therefore provide valuable insights.

**OBJECTIVES**

The objective of this analysis was to examine patient-reported standards of CMT care in the UK and US, including promptness of diagnosis and access to appropriate healthcare professionals.

**METHODS**

Adults with CMT were recruited to an ongoing two-year international observational study exploring the real-world burden of CMT. Data was collected via a mobile app, through which participants were asked to provide data on demographics, CMT management-related, and quality of life.

This updated interim analysis data cut 30 May 2019, approximately seven months into the study, examined participants’ responses to in-app surveys about demographic characteristics and the following aspects of their CMT care:

- **Time to diagnosis**
- **Annual visit frequency to healthcare professionals**

**RESULTS**

Demographics

Characteristics of participants who responded to demographic profile questions are presented in Table 1.

The proportions of respondents from the UK and US were similar. Almost two-thirds of respondents were women.

The most common CMT subtype was CMT1A, followed by CMT2 and Unknown.

**DISCUSSION**

Diagnosis and care standards for CMT were generally aligned with guidelines. However, respondents experienced average delays of several years from seeking care to receiving their CMT diagnosis. This may reflect poor awareness of CMT, leading patients to consult a variety of healthcare professionals until they receive a diagnosis.

**CONCLUSIONS**

CMT care standards in the UK and US are broadly in alignment with guidelines; however, there may be scope to improve time to diagnosis and access to specialist care team members.

This ongoing study will provide further real-world insights into areas for the development of CMT care.