TITLE: MJDhub: A online clinical monitoring and education platform for people with MJD

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**ABSTRACT:**

Aboriginal Australian communities in the NT have the highest prevalence of Machado-Joseph Disease (MJD) in the world. These communities can face barriers to effective clinical monitoring and specialist care, including infrequent specialist neurology input, and cultural and language limitations of existing assessment tools, especially those used to assess cognitive and emotional aspects of MJD.

Through a collaborative project between Monash University and the MJD Foundation, we aimed to develop an innovative online platform to allow Aboriginal Australians with MJD and their healthcare professionals to assess and track their symptoms over time, and to connect with specialist resources.

Drawing on clinical experience from working with the NT MJD community, we developed a culturally- and linguistically-appropriate online questionnaire assessment of self-reported MJD symptoms across multiple domains including movement, speech, cognition, and emotions. We also developed a questionnaire evaluating participation in meaningful activities, based on the Staying Strong Toolbox (Carr *et al*. 2021). We additionally created educational materials tailored to the MJD community. We set up a portal-style website called ‘MJDhub’ to allow individuals to access a personalised page with links to these resources, and to a series of online game assessments evaluating fine motor function and reaction time.

We piloted the use of MJDhub amongst people with MJD attending annual MJD neurology clinics in Darwin, Groote Eylandt, and Ngukurr. Participants with MJD completed the game and questionnaire assessments with the support of a healthcare worker, and completed a feedback survey about their experience with the platform. Questionnaire response data were provided to the treating clinic neurologist, to supplement the neurology clinic assessment. Neurologists were invited to provide feedback on the utility of this supplementary information.

Eleven individuals with MJD have used MJDhub as part of the pilot study, mostly involving a single use session. Our pilot data so far indicates, qualitatively, that people with MJD generally enjoyed using the platform and found it easy to complete the assessments. Neurologist feedback indicated that the data from the questionnaires provided insights into their client’s functioning and had some influence on their care of the client.

Data collection is ongoing. In particular, we intend for MJDhub to be used for serial assessments (e.g., monthly), to give insights into symptom progression over time and between clinic visits. Our work thus far indicates the MJDhub is a promising resource that may enhance existing clinical care.

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**REFERENCES**

Carr JJ, Lalara J, Lalara G, Lalara G, Daniels B, Clough AR, Lowell A, Barker RN (2021) Staying Strong Toolbox: Co-design of a physical activity and lifestyle program for Aboriginal families with Machado-Joseph disease in the Top End of Australia. *PLOS One* **16**, e0211311. doi: 10.1371/journal.pone.0244311