

# **Living with TMAU study (2021)**

Preliminary report for MEBO members and participants.

Thank you to everyone who submitted a survey response at the beginning of the year, your efforts are greatly appreciated. We would like to update you on the results, progress and potential outcomes of the study. In total, we received **43 responses to the survey**.

The survey generated lots of data which takes a lot of time to process. In due course this data will be published in the scientific literature so it will be visible to researchers and clinicians. Furthermore, a more detailed report will be produced that people can use to explain TMAU to teachers, doctors, HR etc.

There are many written responses to the survey. These responses are all anonymous but show the traumatic experiences that many people with TMAU have lived through. These comments will be used by MEBO in an upcoming project which will aim to raise awareness of TMAU and those living with the condition.

If you have any questions about the survey, please feel free to contact us.

**Professor Elizabeth Shepherd**

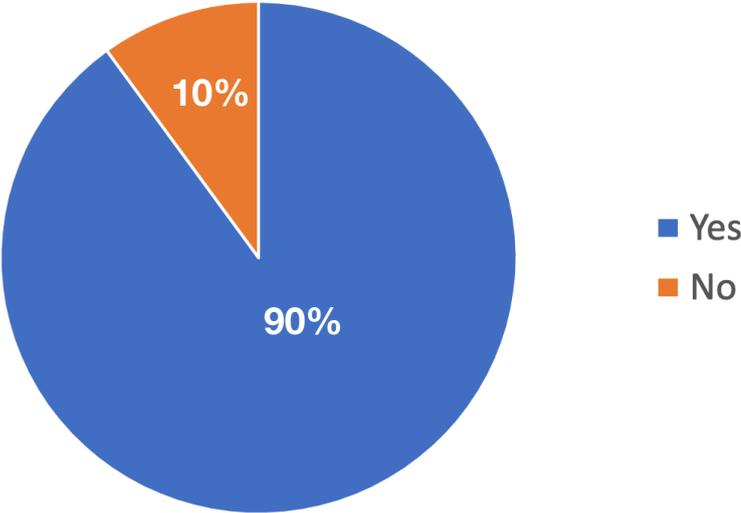
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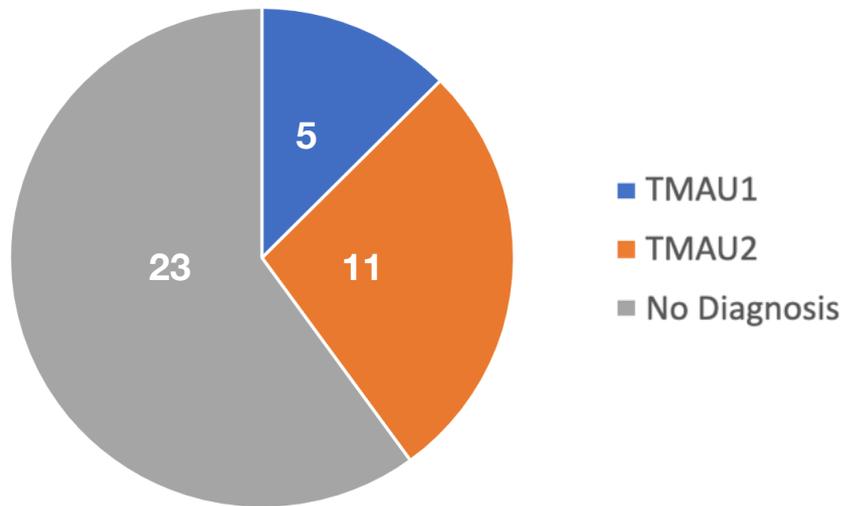
**90% of respondents had experienced bullying, harassment, ostracism or other negative experiences in the workplace.**

Have you experienced bullying, harassment, ostracism or another negative experience in the workplace?

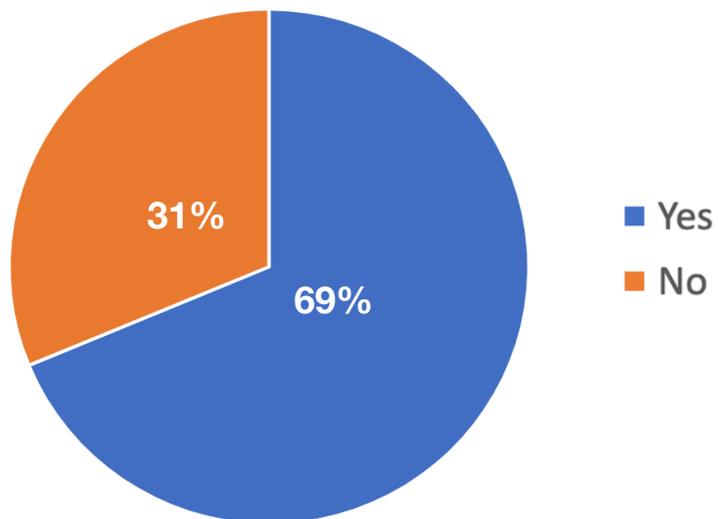


**Only 40% of respondents had received a diagnosis of TMAU1 or TMAU2, and 69% of these individuals had experienced problems or delay in achieving this diagnosis.**

Have you received a diagnosis of TMAU1 or TMAU2?



If you have received a diagnosis, did you experience problems or delay in achieving this diagnosis?



**68% of respondents dislike the name 'fish odour syndrome' and would like to see it removed from official sites in favour of 'trimethylaminuria' or 'TMAU'.**

TMAU is often called fish odour syndrome. Would you like to see this term removed from official sites where it is currently used as an acceptable alternative name to TMAU?

