TRANSLATIONAL SENSORY & CIRCADIAN NEUROSCIENCE UNIT

TUMCREATE

Patient-reported diagnostic pathways, functional impact and online community involvement in sighted Non-24-hour Sleep-Wake Disorder

Manuel Spitschan[1], Diane Boivin[2], María Ángeles Bonmatí-Carrión[3], Philippe Boudreau[2], Andrew Cowen[4], Pierre-Alexis Geoffroy[5], Hannah Sophie Heinrichs[1], Jana Kopřivová[6], Klaus Martiny[7], Peter Mansbach[4], Pillar Quinn[4], Héloïse Rach[8], Alexandra Wharton[4]

[1]Technical University of Munich · [2]McGill University · [3]University of Murcia · [4]Circadian Sleep Disorders Network (CSD-N) · [5]Université Paris Cité · [6]National Institute of Mental Health · [7]Mental Health Center Copenhagen · [8]Assistance Publique – Hopitaux de Paris

Background & Objective

- Non-24-hour sleep–wake disorder (Non-24) occurs when sleep timing does not stay aligned with the 24-hour day, often shifting progressively later and cycling around the clock.
- In sighted people, Non-24 may go unrecognised or be mistaken for poor sleep habits or mental health problems, while disrupting work, education and everyday life.
- Objective: **Understand patients' diagnostic journeys, functional difficulties and use of online communities for recognition and support.**

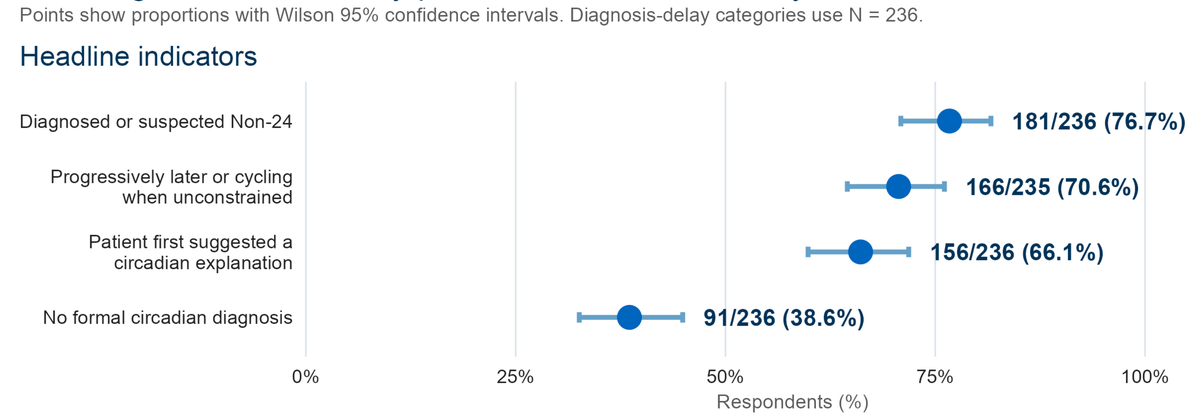
Methods

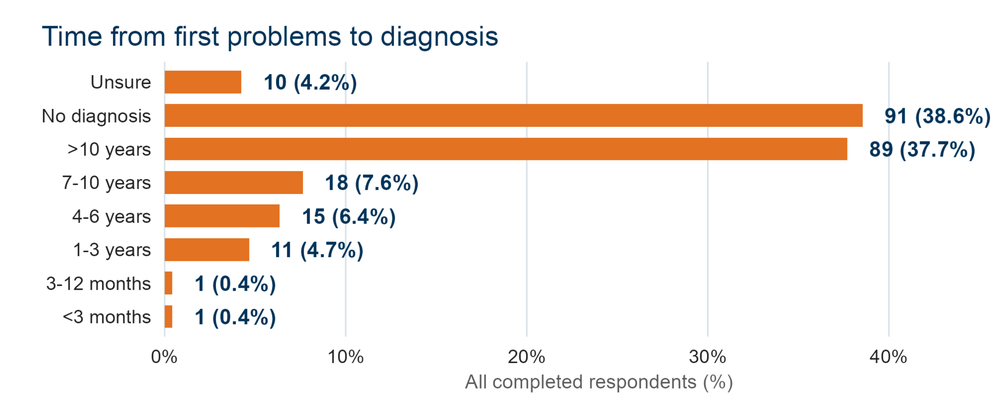
- Anonymous online survey deployed in REDCap developed with CSD-N and patient-community input.
- Recruitment through N24 Discord, Reddit, the CSD-N mailing list, Facebook and related networks.
- Descriptive analysis of 236 consenting adult completers; median age band 25–34 years (reported bands 18–24 to 65+); 91/235 (38.7%) reported male sex at birth.

Results

A Recognition was usually patient-led and often delayed

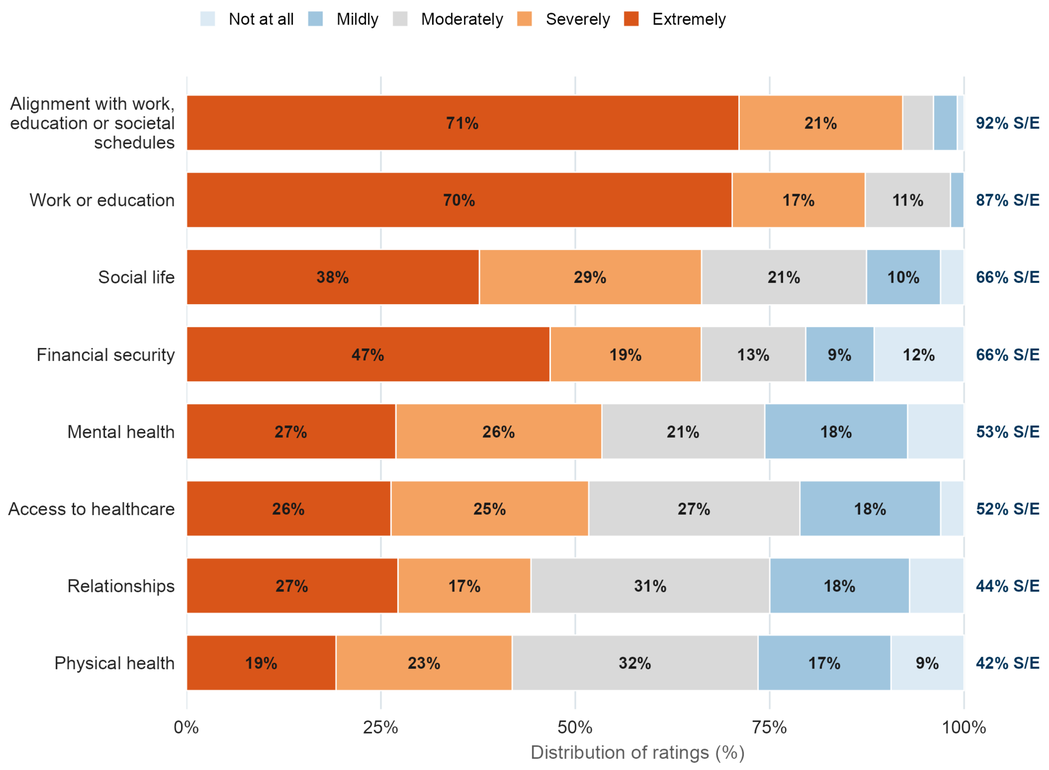
Points show proportions with Wilson 95% confidence intervals. Diagnosis-delay categories use N = 236.





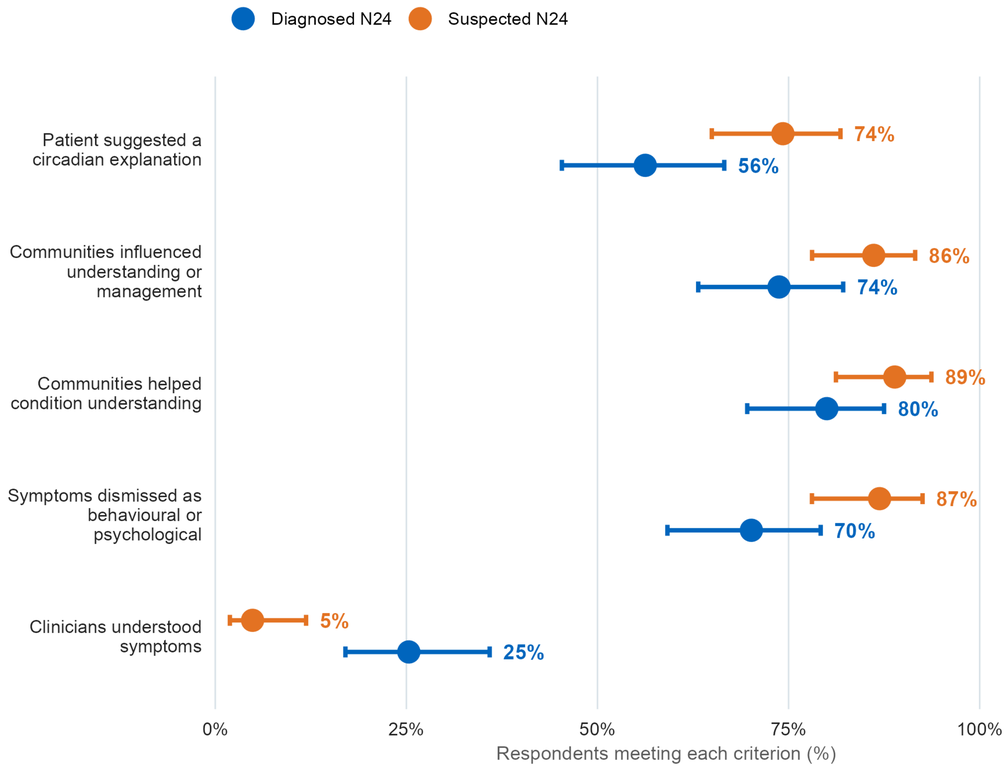
B Circadian symptoms disrupted schedule alignment and work most severely

Distribution among respondents rating each domain; item denominators range from 216 to 234.



C Suspected N24: more community reliance, less clinician understanding

Descriptive comparison of diagnosed N24 (n = 80) and suspected N24 (n = 101). Item-specific denominators are used.



Conclusion

- Sighted Non-24 needs earlier clinical recognition: patients frequently identified the circadian problem themselves while formal diagnosis was absent or delayed.
- The reported burden extended far beyond sleep, disrupting education, employment, financial security and access to healthcare—making recognition and practical support equally important.
- These findings call for patient-centred diagnostic pathways that draw on online-community experience, alongside flexible care and research that accommodate shifting sleep timing.