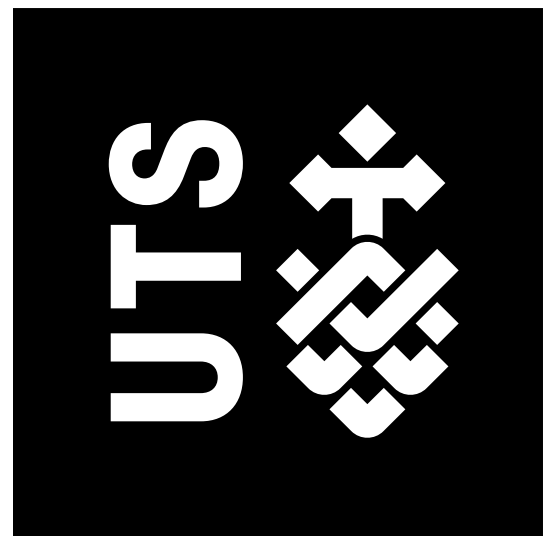




Interactive, personalised online tools for parents of children with genetic neurodevelopmental conditions in Australia: An environmental scan

Helen Willacy, Elizabeth Callinan, Dr Lisa Dive, Dr Erin Turbitt
University of Technology, Sydney

INTRODUCTION

- Parents of children with genetic neurodevelopmental conditions in Australia seek online support that is strengths-based, balanced and informed by lived experience¹. Key needs include high-quality information, social support, hopeful and realistic future planning, and empowerment^{2,3}.
- Prior analyses of static web-based content of the description and prognosis of a range of genetic neurodevelopmental conditions show an overemphasis on deficit-focused information⁴.
- Interactive tools may address this gap by enabling paced, staged, and revisitable information delivery tailored to different needs and time points^{1, 5}.
- It is not known whether such interactive, personalised tools are available in Australia.

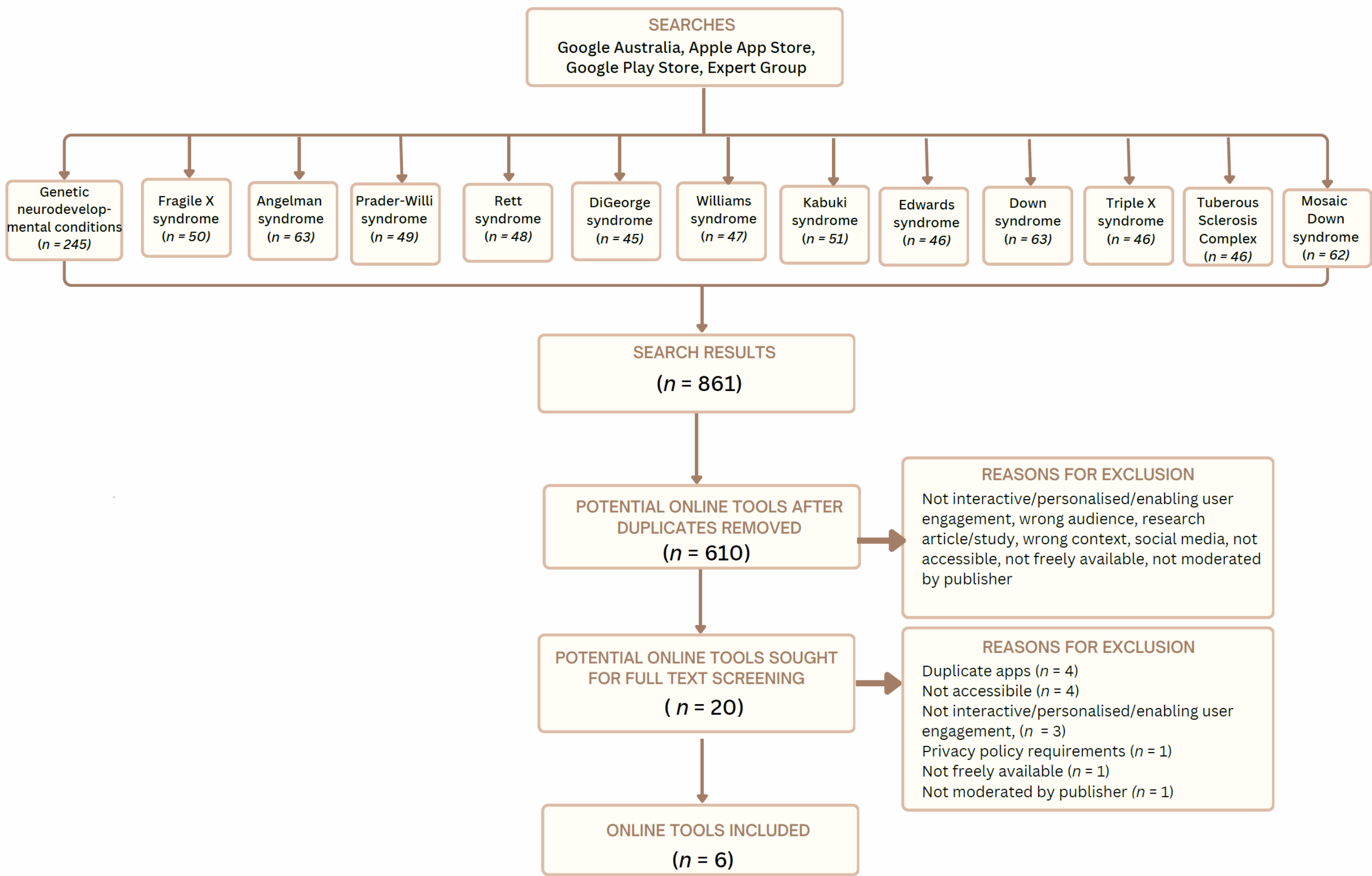
AIM

To identify and describe interactive, personalised online tools available for parents of children with genetic neurodevelopmental conditions based in Australia.

METHODS

- Environmental scan of freely available websites and apps. Searches were conducted using Google Australia, Apple App Store, and Google Play Store with predefined natural language search terms. An expert panel also identified tools.
- Tools were screened against inclusion and exclusion criteria. We extracted descriptive data and used content analysis to examine features and information. Framing of information sections was analysed using the tool developed by Gokoolparsadh et al.⁴.

RESULTS – ENVIRONMENTAL SCAN



- Six tools were identified (five apps, one website). Four were developed by patient advocacy groups and were free to access. Two were commercially developed, offering limited free content and also paid subscriptions (USD4.99–19.99/month).
- One tool was Australian-based. Five included parent input in design. Three were available in languages other than English. Four cited references.
- Tools included features to support personalisation, such as journals, activities or strategies, AI chatbots, options to hide information, information mapping, multimedia content, and links to support services.

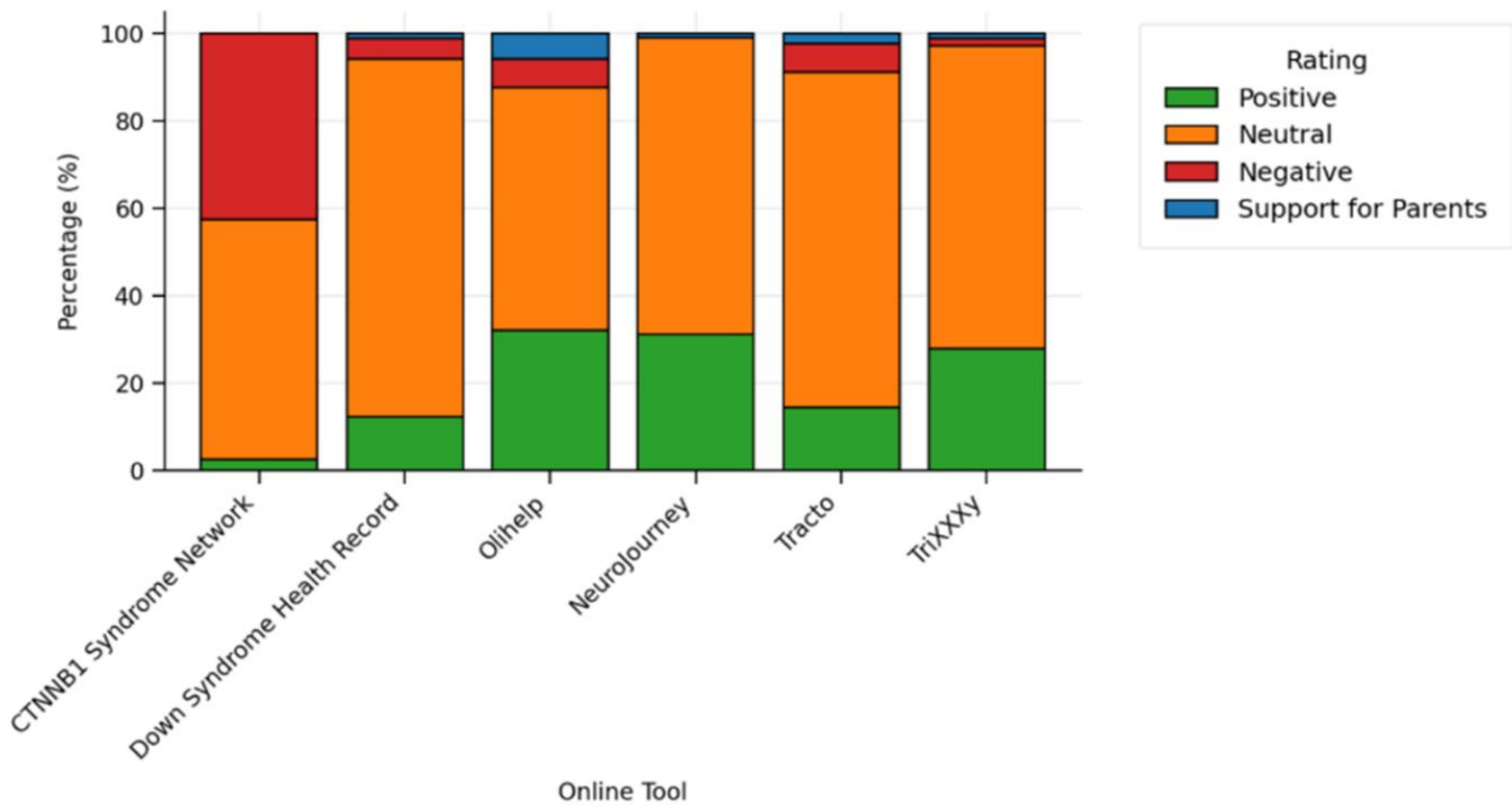
Acknowledgements

Thanks to the key informants for their participation. This research was undertaken as part of Helen Willacy's UTS Master of Genetic Counselling degree.

RESULTS – CONTENT ANALYSIS

Readability: Flesch–Kincaid Levels ranged from 7.1 (Year 7, early secondary school) to 15.1 (university level).

Ratings of framing of information by online tool:



- NeuroJourney contained no negatively framed information.
- The highest proportion of negatively framed content (42.6%) was identified in a tool developed by a patient advocacy group.

Ratings of domains of need met by online tool:

Name of Tool	Strengths-based, balanced language	Social support	Accessible, high quality information	Hopeful and realistic future-planning	Empowering
CTNNB1 Syndrome Network	☐	☒	☐	☐	☐
Down Syndrome Health Record	☐	☒	☐	☐	☐
Olihelp	☒	☐	☒	☒	☐
NeuroJourney	☒	☐	☒	☒	☒
Tracto	☐	☒	☒	☐	☐
TriXXy	☒	☒	☐	☒	☒

Evidence from online tools

Supported individuals are likely to do pretty well in life, especially if they get help early.

To find support in your state or territory, visit: downsyndrome.org.au

Explore with Oli

The more you consider your goals and what's important for your child and family, the more confident you will feel at the time you are faced with these challenges.

Let's go!

DISCUSSION

- There are few interactive, personalised online tools available for parents of children with genetic neurodevelopmental conditions in Australia.
- Most tools (n=5/6) are condition-specific.
- Many do not address key domains of need identified in prior research, including some developed by patient advocacy groups.

CONCLUSIONS

- These findings highlight a gap in accessible, Australian-relevant online tools for parents.
- Future work should develop tools that address parent-identified needs and reflect the Australian healthcare and social context.
- Further research involving parents is needed to assess the quality and usefulness of existing tools.
- Further research could develop a library of recommended tools.

References

- Turbitt, E., Callinan, E., Shakes, P., McEwen, A., & Amor, D. J. (2024). Fostering hope and acknowledging uncertainty: Meeting parents' needs and preferences when communicating prognosis in genetic neurodevelopmental conditions. *Current Developmental Disorders Reports*, 11(1), 21–31. <https://doi.org/10.1007/s40474-024-00291-1>
- Baumbusch, J., Mayer, S., & Sloan-Yip, I. (2019). Alone in a crowd? Parents of children with rare diseases' experiences of navigating the healthcare system. *Journal of Genetic Counseling*, 28(1), 80–90. <https://doi.org/10.1007/s10897-018-0294-9>
- Hatem, S., Long, J. C., Best, S., Fehlberg, Z., Nic Giolla Easpaig, B., & Braithwaite, J. (2022). Mobile apps for people with rare diseases: Review and quality assessment using mobile app rating scale. *Journal of Medical Internet Research*, 24(7), Article e36691. <https://doi.org/10.2196/36691>
- Gokoolparsadh, A., Bourne, M., McEwen, A., Amor, D. J., & Turbitt, E. (2025). Parents' perspectives on conversations about prognosis and an assessment of prognostic information available online: A mixed-methods study. *Disability and Health Journal*, 18(2), Article 101718. <https://doi.org/10.1016/j.dhjo.2024.101718>
- Martin, S., Roderick, M. C., Lockridge, R., Toledo-Tamula, M. A., Baldwin, A., Knight, P., & Wolters, P. (2017). Feasibility and preliminary efficacy of an internet support group for parents of a child with neurofibromatosis type 1: A pilot study. *Journal of Genetic Counseling*, 26(3), 576–585. <https://doi.org/10.1007/s10897-016-0031-1>