## **Submission by**



# to Stats NZ Tatauranga Aotearoa

#### on the

"Data as a driver of national competitive advantage – fostering improved wellbeing and economic growth"

Consultation Document

28 January 2022

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#### **Summary**

ADHD NZ thanks Stats NZ Tatauranga Aotearoa for the opportunity to provide feedback on Stats NZ's Long-term Insights Briefing: Data as a driver of national competitive advantage – fostering improved wellbeing and economic growth.

ADHD NZ supports the overall direction of Stats NZ Tatauranga Aotearoa's consultation of the long-term insights briefing for 2022, where:

- there is an integration of transparency, ethics and sovereignty into the framework
- on-gong governance provides oversight and direction to its longevity, and
- the collation and use of aggregated data improve key metrics in wellbeing, inclusion and participation.

We invite you to engage further with us. We can provide further detail and assistance on this and future submissions.

### **Background**

Formed in 1979, we are New Zealand's longest-standing non-profit organisation. We are committed to supporting those living with ADHD.

ADHD NZ advocates for the better management and mitigation of the negative impacts of ADHD.

Last year alone ADHD NZ's community membership grew by over 220%. Our community now consists of more than 25,000 individuals who live with and support ADHD.

However, we are falling short of our vision - to advance the ADHD community by providing practical information and support. There are an estimated 280,000 Kiwis who have ADHD.<sup>1</sup>

As reflected in the growth of our community, mental health and wellbeing have also grown in importance in New Zealand. The health industry is struggling to manage COVID-19, let alone the resulting mental health crisis caused by the pandemic.

As a representative of all neuro-diverse communities in New Zealand ADHD NZ has engaged with the government on several fronts, including health-related submissions. We welcome the opportunity to engage with Stats NZ and other bodies and the industry on matters relating to the well-being of our neuro-diverse community.

New Zealand Ministry of Health, New Zealand Health Survey: Prevalence/mean 2020/21, 2021



#### Comments and recommendations

# Q. Is the proposed topic: Data as a driver of national competitive advantage – fostering improved wellbeing and economic growth, a valuable issue to consider?

ADHD NZ supports consideration of this topic where the collation and use of aggregated data improve key metrics in wellbeing, inclusion, and participation. The better the information, the better the support and outcomes for all.

From our experience, much of the data is already existing. Whether it is within medical data (Pharmac and DHBs), the Education Sector or other social services, it already exists. Collating, aligning, and interpreting the data will be a valuable step in improving the wellbeing and potential of all.

#### Q. Are the proposed focus areas the most important to explore further?

#### We cannot change what we cannot measure.

Data collection in other countries gives us an insight into what the New Zealand experience may be for those with ADHD - but this is no substitute for collecting local data.

In Canada, we know that around one child in every classroom has ADHD – often undiagnosed. Many families and schools are in crisis, without the knowledge and strategies needed to support the ADHD community. It is devastating for these individuals that having ADHD can result in a score of 8-10 per cent lower in literacy and numeracy than their classmates. Students with ADHD are also 2.7 times more likely to drop out of school before graduating.<sup>2</sup>

Further research from the United States suggests that the challenges continue into adulthood for nine out of 10 children.<sup>3</sup> By the age of 30, an adult with ADHD has a 10 per cent chance of being unemployed, earns 33 per cent less, and 15 per cent also require 'social assistance'<sup>4</sup>.

Without the appropriate data in New Zealand, we speculate that these figures are similar.

<sup>&</sup>lt;sup>2</sup> Centre for ADHD Awareness Canada, <u>Information and resources for educators</u>, sourced online April 2021

<sup>&</sup>lt;sup>3</sup> Margaret H. Sibley, Ph.D., L. Eugene Arnold, M.D., James M. Swanson, Ph.D., Lily T. Hechtman, M.D., Traci M. Kennedy, Ph.D., Elizabeth Owens, Ph.D., Brooke S.G. Molina, Ph.D., Peter S. Jensen, M.D., Stephen P. Hinshaw, Ph.D., Arunima Roy, Ph.D., Andrea Chronis-Tuscano, Ph.D., Jeffrey H. Newcorn, M.D., Luis A. Rohde, M.D., Ph.D., for the MTA Cooperative Group, <u>Variable Patterns of Remission From ADHD in the Multimodal Treatment Study of ADHD</u>, The American Journal of Psychiatry, August 2021

<sup>&</sup>lt;sup>4</sup> Conway, Jillian, 2019, <u>Adult ADHD in Motion: Workplace Physical Activity and Improved Occupational Outcomes for Adults With ADHD</u>, Master's thesis, Harvard Extension School, sourced online April 2021



In our ideal world, we understand where we are as a community so that we can focus on and support the most challenging areas of concern. Knowing this may help alleviate the current pressures on already stressed resources, such as those that the health industry is facing considering the COVID-19 pandemic and the resulting negative impact on mental health. Data would provide the impetus for this. Consequently, policymakers and associated bodies could devise the mechanisms to minimise future negative impacts.

The development and provision of a single data repository ('source of truth') would save money and time spent by multiple parties to achieve the same goal.

In addition, other opportunities could include:

- a community where individuals and organisations can present the challenges that they are addressing, and other participants can post their solutions (either in response to the challenges or separately)
- the development of a sandbox for use by individuals and businesses accessing the data, and
- learnings are documented and shared to foster faster innovation.

#### Q. Are there other opportunities or implications that we should consider?

Data is useful when the data sources, users of the data, and their purpose for the data, is known.

In anticipating the development of a data repository that provides core metrics and integrated data insights, we recommend identifying key users and use cases to develop a framework.

In addition, we also recommend sharing the methodologies devised to standardise, interpret, and represent data.

This process would facilitate trust in the parameters of the life of the data.

However, making the same data available to everyone (in New Zealand) would see exponential growth in trust and transparency and lead to the greater wellbeing of our community.

#### Q. Are there any topics you would like Stats NZ to consider for future briefings?

We anticipate the development of a data ethics/sovereignty policy that outlines the guiding principles for collating and using data.



#### Conclusion

Thank you for the opportunity to provide feedback on the consultation document. We are happy to engage further with you to discuss our submission in detail and provide further assistance.

If you have any further queries, please do not hesitate to contact me.

#### Darrin Bull

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