

Australian Epilepsy Research Register

Wave 2 - 'Out of the Shadows': needs, perceptions and experiences of people living with epilepsy in Australia, 2010

Summary

- In 2011 there were 621 people on the Australian Epilepsy Research Register of which 343 participants responded (response rate, 55%) to the Wave 2 survey. Participants in the survey had an average age of 43 years and most were female (57%). The biggest proportion of participants had a Year 11 or lower education level (38%) or had trade-related education (TAFE, apprentice, diploma – 25%) and a Bachelor's degree or above (31%). However, the level of education did depend on the age group surveyed.
- Employment rates and possibly underemployment across all ages were lower than the national average. Only 16% of the total number of participants had full-time jobs (38% of all participants were employed). Income was generally very low with 49% living below the current Henderson poverty line. Seizure activity and levels of seizure control were explored. Only 33% of participants reported having no seizures over twelve months. This was lower than that which has been reported in the literature. Injuries and hospitalisations were reported as high amongst this group (55% and 64%).
- People with epilepsy reported experiencing varying levels of stigmatizing behaviour. While many felt they had been fairly treated and had not suffered any discrimination the numbers who reported unfair treatment were still high at 45%. For some people this led to social isolation. A substantial proportion (32%) of people with epilepsy reported that they had experienced a lack of understanding from Government bodies that they had turned to for assistance. Driving remains a highly desirable and necessary component in the quality of a person's life; being a driver or being driven by someone else remains the preferred mode of transport.

A full copy of the report is available to download at -
www.epilepsyfoundation.org.au/australian-epilepsy-research-register/