

Australian Epilepsy Research Register

Wave 3 - The Social Impact of Epilepsy, 2013

Summary

- In 2013 there were approximately 883 people on the Australian Epilepsy Research Register (AERR) of which 318 participants responded (response rate, 36% – due to an increase in registrants) to the Wave 3 survey. Participants in the survey had an average age of 40 years and most were female (63%).
- The biggest proportion of participants had a Bachelor's degree or above (30%), a Year 11 or lower education level (26%) or had trade-related education (TAFE, apprentice, diploma – 15%). 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 20% of the total number of participants had full-time jobs (44% of all participants were employed).
- Income was generally very low with 55% living below the current Henderson poverty line. A large proportion of participants (58%) who were not working were on disability pensions. More than a quarter of participants had missed work in the previous 12 months (of those who responded to this section). There were 34 participants who missed between 1 and 365 working days. Further, there were 11 participants who missed part of a day or less than one day. This is a total of 1483 working days lost or an average 33 days.
- For those attending school, 34 students missed school due to their epilepsy and 16 students missed between 1 and 83 days. On average it was found that 10 school days were lost per student with epilepsy. Lower incomes may lead to financial distress or difficulty in affording necessary items on a regular basis. There were 40% of participants who felt they were 'just getting along', 'poor' or 'very poor'. For families with epilepsy, the result was 2 – 3 times higher. This is in comparison to a national survey in which 21% of participants felt financial distress.
- Most participants reported that they were not able to plan ahead for savings – 54% unable to think beyond the next few months and 20% more than 5 years. Most participants felt they had a lower level of personal control and prosperity. There were only 10 participants who considered themselves in prosperous financial circumstances, but felt they had a low sense of personal control.

- Within the past 3 years, 40% of participants had suffered injuries due to seizures, with most occurring at home. Of these participants, 62% required hospital treatment and a small minority required dental treatment, stitches at the GP or a 'wait and see' approach.
- A large proportion of participants felt that their epilepsy impacted on the way they felt about themselves, their self-esteem, their plans and ambitions for the future, their confidence and their relationships with their partners or family members.

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