

Prevalence and clinical profile of adults with cerebral palsy: a population-based study

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Background

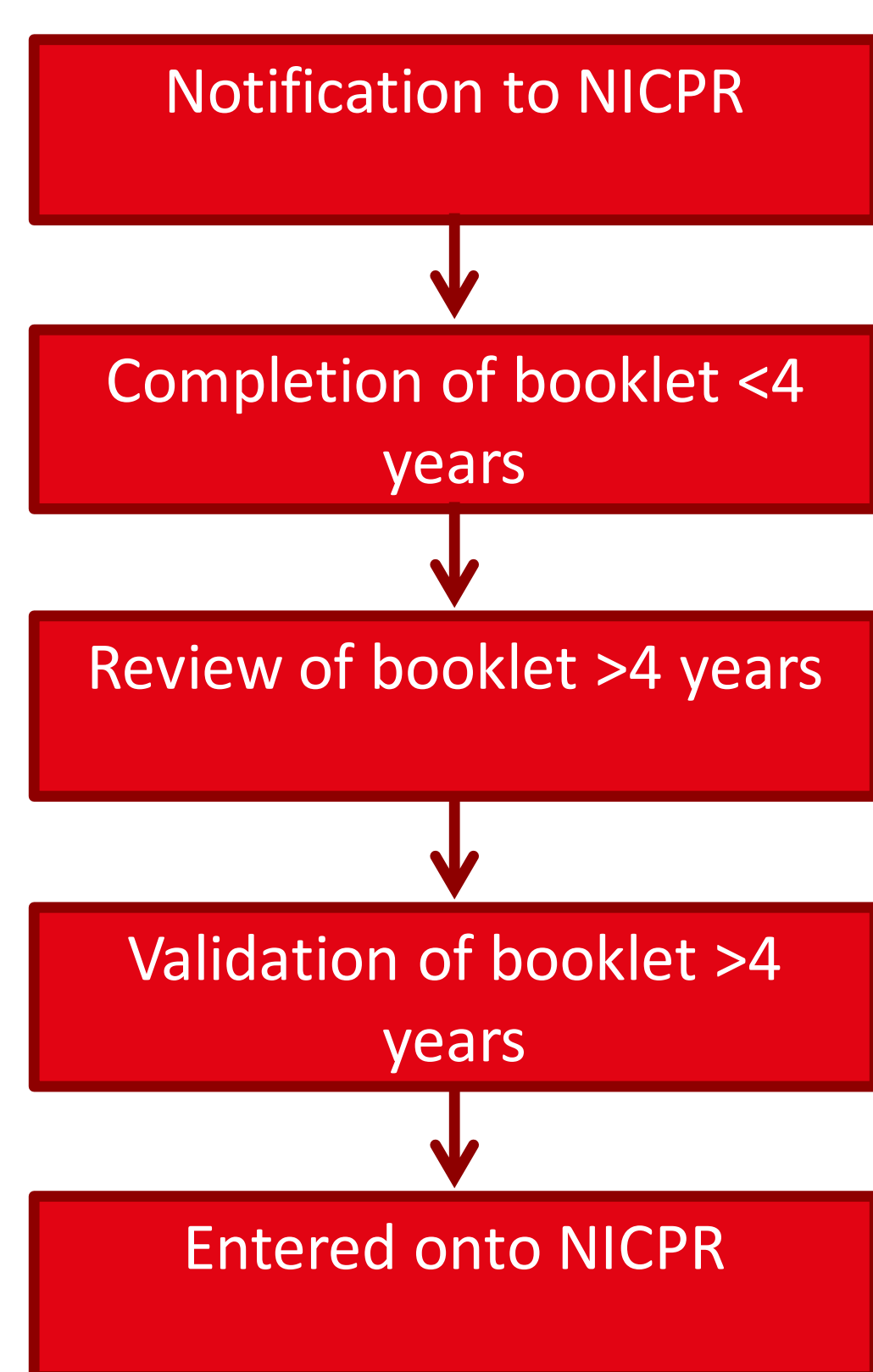
Although research in cerebral palsy (CP) has traditionally focused on children, the majority of this population survive into adulthood and require ongoing access to many health and social care services throughout life. Barriers to successful transition from paediatric to adult services, insufficient service provision for adults with CP and lack of continuity of care have been reported. Understanding the prevalence and clinical characteristics of CP in adults will help inform planning and delivery of health and care services.

Purpose

To report prevalence and clinical characteristics of adults with CP in one region of the United Kingdom.



Methods



Study design: Cross-sectional, population-based study using the Northern Ireland Cerebral Palsy Register (NICPR).

Method of the NICPR: The NICPR adheres to Surveillance of Cerebral Palsy in Europe guidelines and processes regarding eligibility and classification of cases.

Participants: All validated cases known to the NICPR, born 1981-2001 and alive and resident in the region at the time of accessing adult health services were included (age 19 years+).

Data analysis: The prevalence rate of CP was calculated per 1000 age-matched population. Descriptive statistics were used to summarise data relating to CP type, walking ability, upper limb function and associated impairments.

Results

Prevalence

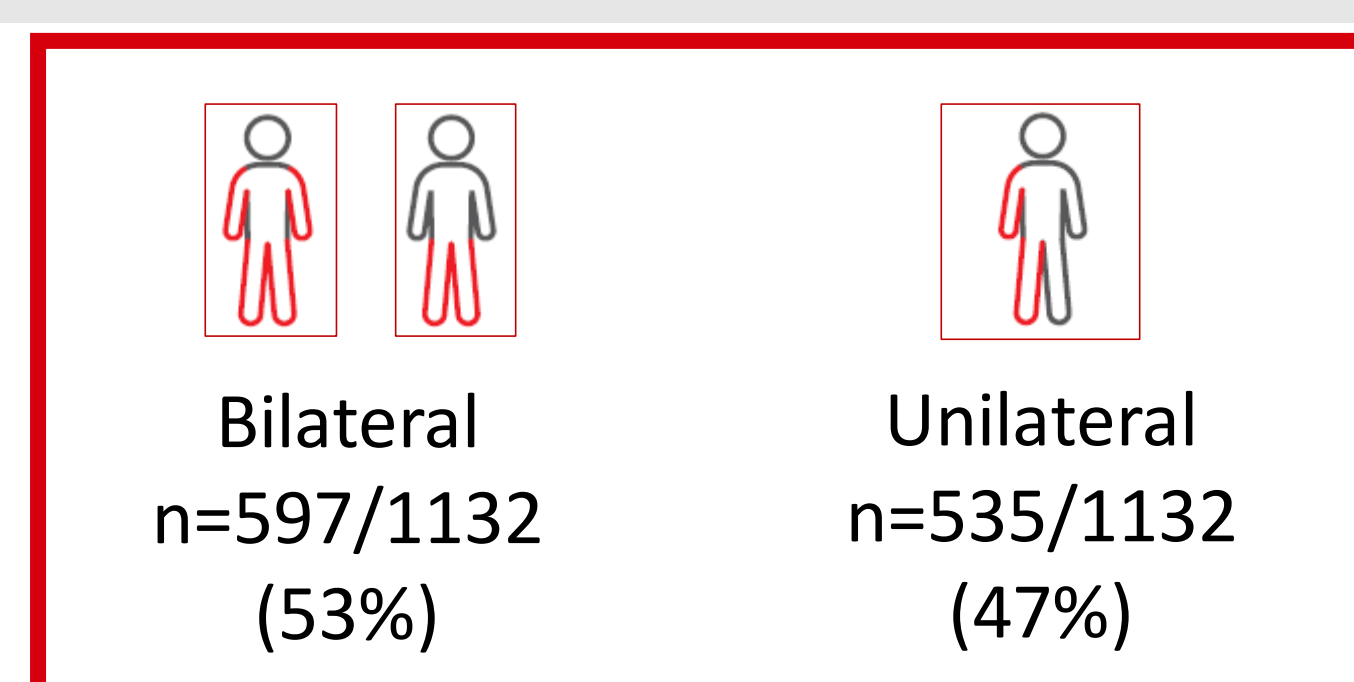
Of the 1369 cases born 1981-2001 and known to the NICPR, 151 were excluded because they had died (n=113) or moved out (n=38) before the age of accessing adult services. Thus 1218 cases aged 19-39 years were included in the study sample (93% of paediatric registered cases, n=1218/1369).

The period prevalence of CP in adults (born 1981-2001) was **2.38 per 1000** population.



CP type

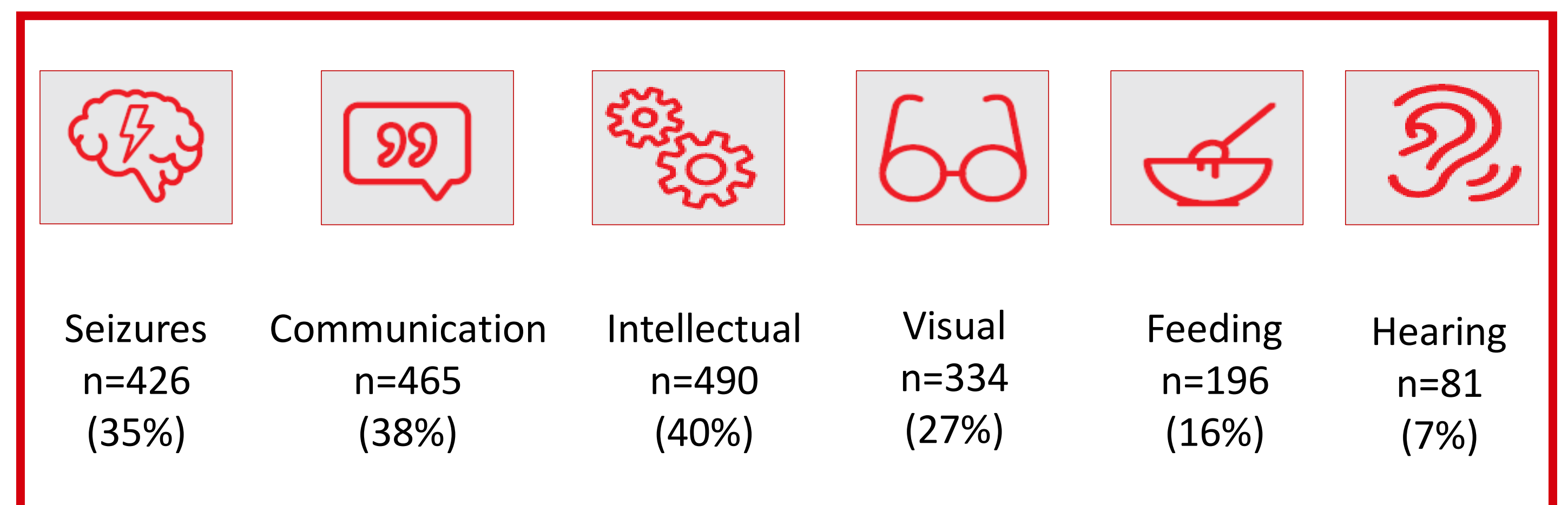
The majority of cases had **spastic CP** (n=1132/1218, 93%).



Motor function

Almost a quarter of the population used a wheelchair (269/1218, 22%) and almost one third required assistance of another person to eat and/or dress (n=365/1218, 30%).

Associated impairments



Died in adulthood

Of the 1218 cases included, 46 died in adulthood. These cases had more complex CP: 39 cases had bilateral spastic CP and 40 cases were wheelchair-users.

Conclusions

The study demonstrates that over 90% of paediatric CP cases will require health and care services in adulthood, with approximately one third having significant ongoing health, care and rehabilitation needs.



Implications

Population-based registers, such as the NICPR, provide useful estimates of numbers and needs of people with CP to facilitate care planning and service delivery. Supported transition from paediatric to adult services and ongoing access to health, care and rehabilitation services in adulthood is required for people with CP to optimise and maintain activity and participation. Further research describing function over time in adults with CP is required, as is research documenting rehabilitation, health service use and unmet needs in this population.

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