AHDR Annual Report 2021

Introduction

The Australian Hand Difference Register (AHDR) is a database of children born with a congenital upper limb difference (CULD). The AHDR aims to:

- find out how many children are born with a hand/arm difference in Australia
- learn more about possible causes and risk factors
- gain information to help plan services
- identify possible participants for future research
- identify the effects of hand differences on children
- decide how best to manage hand differences

Changes in 2021

Covid-19 continued to provide challenges throughout 2021. Recruitment remained slow across the country, but we were able to welcome two new sites to the team.

- Sunshine Hospital, Victoria
- Flinders Medical Centre, South Australia

2021 also saw the introduction of the Patient Reported Outcome Questionnaire (PROM). These are a series of short questionnaires that are sent out to the family when a child turns 5, 8, 11, 14 and 17 years of age. These questionnaires allow the team to assess how the child views their hand difference and how it affects their function and behaviour, if at all.

Presentations and publications

Publications

David O'Keefe: Junior Doctor in Obstetrics & Gynaecology at the Mercy Hospital for Women

David O'Keefe, Joanne Kennedy, David McCombe, Chris Coombs, Lisa Hui, Daniel Wilks, Jane Halliday. 'Prenatal and postnatal diagnosis of congenital upper limb differences: The first 3 years of the Australian Hand Difference Register'. *J Paediatrics and Child Health* 2021 Aug 3. doi: 10.1111/jpc.15673.

Research project

Carmen Chong, Master of Health Information Management student, La Trobe University, Victoria.

Carmen undertook a six-week placement at The Royal Children's Hospital (RCH), Parkville under the primary supervision of Dr Daniel Wilks. Co-supervisors were Professor Jane Halliday and Joanne Kennedy. Carmen used the Victorian data available in the AHDR and the RCH Electronic Medical Record (EMR), with the aim to:

- determine if the AHDR is a representative sample of the population with a CULD in the RCH EMR.
  Result: Yes, it is.
- examine the distribution of the CULD population in the AHDR according to their socio-economic status.
  Result: There is an even distribution across socio-economic areas as represented by quintiles in Figure 1 below. The quintiles are a measure of socioeconomic status dividing the population into 5 groups, with 1 being the lowest to 5 being the highest.
- determine and compare frequency of CULD diagnoses between AHDR and RCH EMR.
  Result: There are similarities and differences within the two databases. Some diagnoses do not appear in both databases due to different classification systems used.

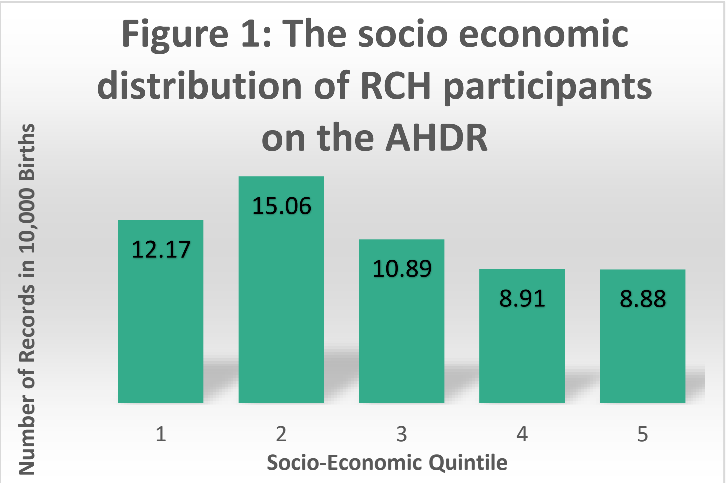

Figure 1: The socio-economic distribution of RCH participants on the AHDR.

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Summary of data for 2021

There were 220 children enrolled into the AHDR in 2021. A summary of their data is shown below.

Figure 2: Gender data are similar to previous years with a slightly higher number of males enrolled (55% male : 45% female).

Figure 3: Victoria still remains the state with the highest number of enrolments (56%).

Figure 4: The top five diagnoses remain similar to previous years with radial polydactyly being the most common (20%).

Figure 2: Gender

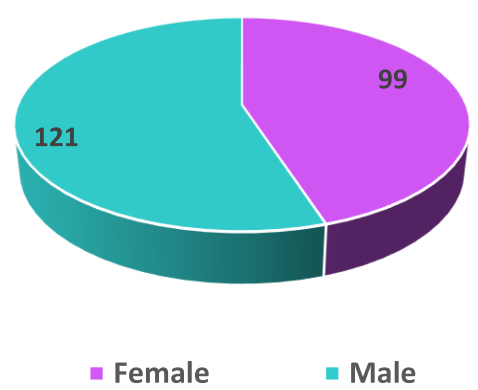


Figure 3: Place of birth

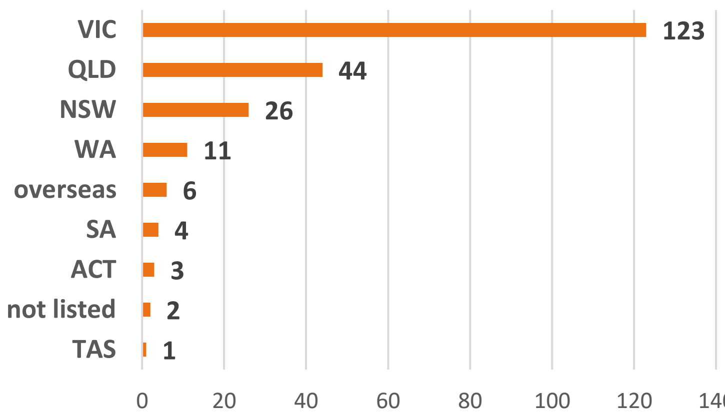
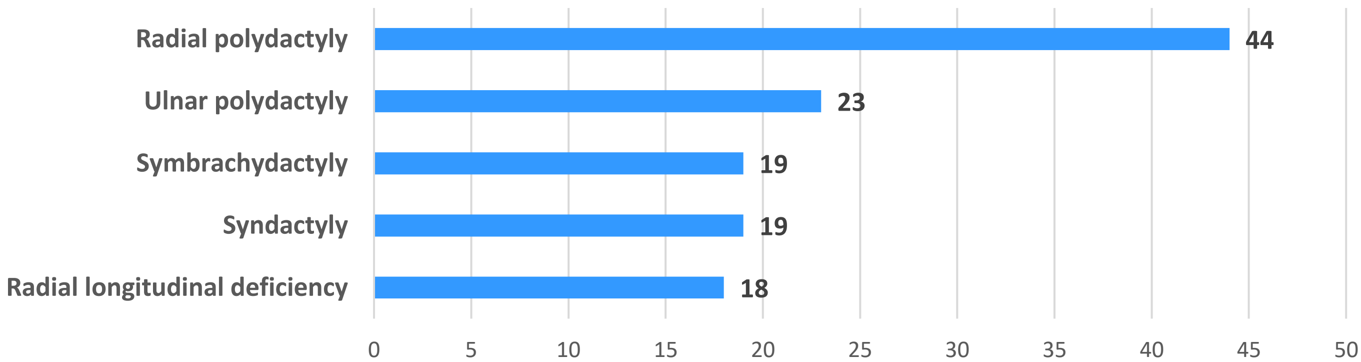


Figure 4: Top 5 diagnoses



Acknowledgments

The AHDR team would like to thank the families who have generously shared their time and experience by participating in the register.

We would also like to thank the McNally Family Foundation and the Aussie Hands Foundation for their ongoing support.

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