



AHDR Annual Report 2022

Introduction

The Australian Hand Difference Register (AHDR) is a database of children born with a congenital upper limb difference (CULD). Established in 2017, the AHDR aims to:

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

Welcome

In June, the Royal Hobart Hospital joined the AHDR. We now have a recruitment site in every state and the Northern Territory.



Media

Liz Wright, the ABC's national disability affairs reporter, contacted the AHDR team for a story about limb difference. A/Prof David McCombe was interviewed and appeared on the ABC 7pm news on Sunday 3 July. The story also appeared in the ABC online news the same day.

You can read it [here](#).

Research

In 2021, we introduced a series of Patient Reported Outcome Measures (PROM's) to capture a person's thoughts about their own health by using a set of standardised questionnaires. These are collected every three years from the age of five. These questionnaires allow our participants to provide insights about aspects of their life including overall health, hand/arm function, peer relationships, pain, anxiety, and depressive symptoms.

As of December 2022, 171 questionnaires have been sent, with 98 completed (57% completion rate).

If you have any research questions you think the AHDR could be addressing, please contact us with your thoughts.

Presentations

The International Federation of Societies for Surgery of the Hand (IFSSH) conference was held in London in June 2022. The AHDR was represented by several presentations, including:

Dr Lucy McDougall (Image 1) presenting "The psychosocial impact of congenital hand and upper limb differences on children: a qualitative study."

Dr Daniel Wilks presenting Dr David O'Keefe's paper "Prenatal and postnatal diagnosis of Congenital Hand Differences: The first 3 years of the Australian Hand Difference Register."



Image 1: Dr Lucy McDougall



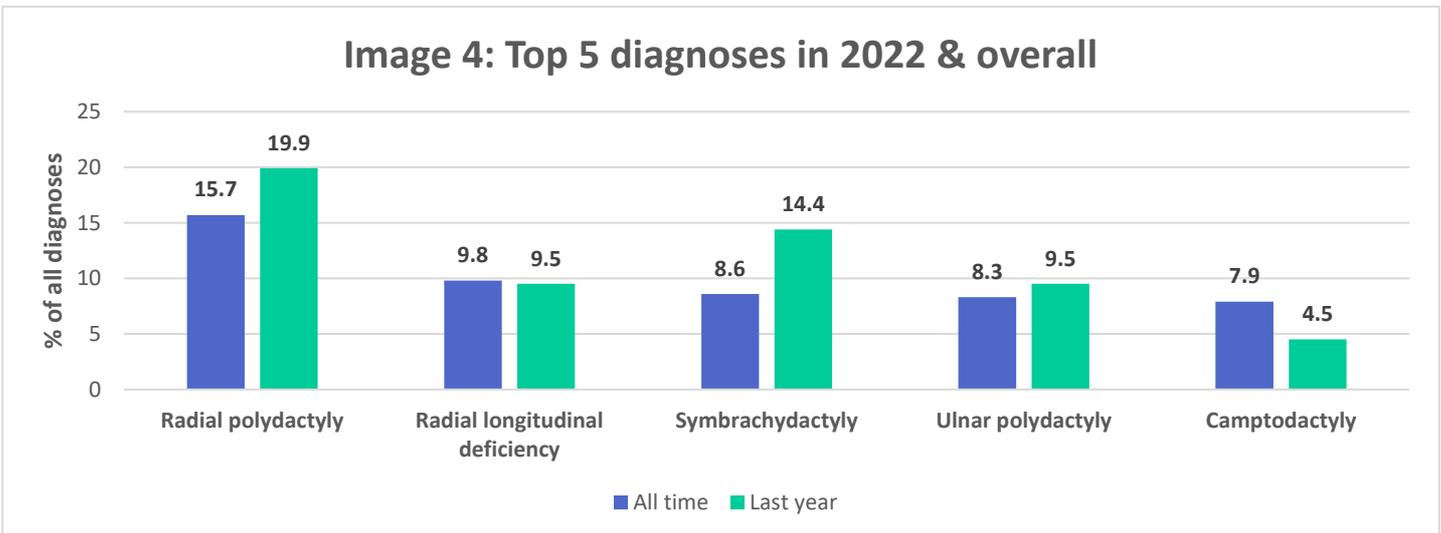
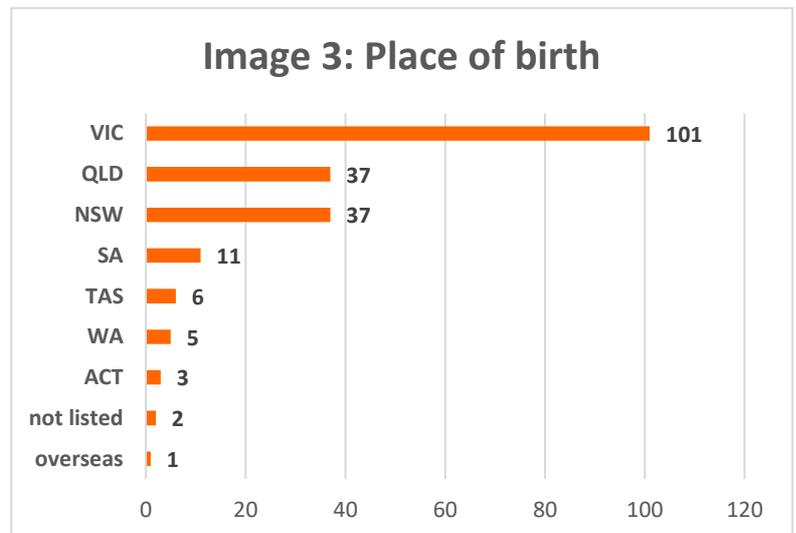
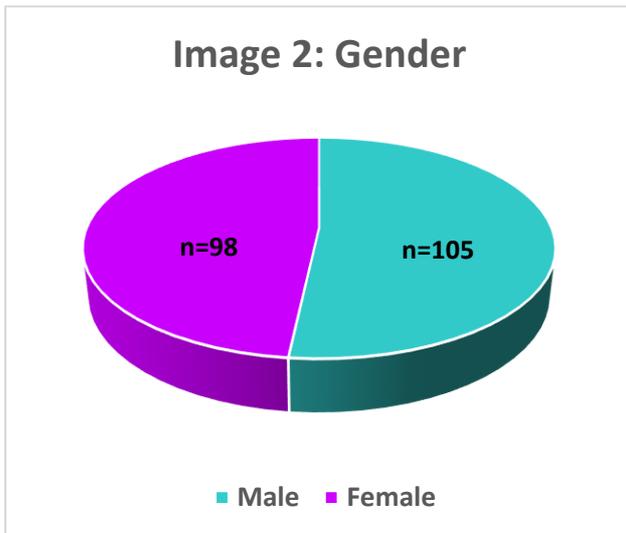
Summary of data for 2022

There were 203 children enrolled into the AHDR in 2022. A summary of their data is shown below.

Image 2: Gender data are similar to previous years with a slightly higher number of males enrolled, (52% male:48% female).

Image 3: Victoria remains the state with the highest number of enrolments (50%).

Image 4: The top five diagnoses in 2022 were similar to previous years, as well as over the lifetime of the register. Radial polydactyly is still the most common diagnosis.



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.