The Australian hand difference register: sharing clinical experience

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Clinical registries are increasingly recognised as a powerful tool in many areas of healthcare as they provide timely data of critical importance including disease incidence, treatment outcomes and medical device safety. Plastic and reconstructive surgeons in Australia have embraced this mode of data collection with the development of the Australian breast device registry (ABDR) and the Australia and New Zealand burns registry (BRANZ), both of which were established with the financial support of the Australasian Foundation for Plastic Surgery (AFPS). These registries have already made significant contributions to patient care and outcomes.1,2

Children born with a congenital hand difference are a diverse group who, with their families, share the common trait of carrying what can be both a significant functional and social burden for life. While the various hand differences have been thoroughly described, classified and reclassified, and multiple operations designed for each of them—as all plastic surgery registrars preparing for their examinations will attest—the data that informs families and assists in decision-making is sparse and often historical. It is this gap that the Australian hand difference register (AHDR) aims to fill by providing nationally collected and standardised data on incidence, demography and long-term outcomes in order to assist patients, families and treating clinicians.

The value, and therefore the success, of the AHDR depends upon it meeting criteria by which all such registries are measured. Broadly, these measures...
relate to the collection or input, maintenance and reporting of the data in a timely and meaningful way.

The effective input of data depends on a number of factors: the identification of a defined patient group, the active engagement of those supplying the data and the ability to standardise the data to allow for accurate categorisation. In the case of the AHDR, the patient group is well defined—being children less than 18 years of age living or born in Australia, with a congenital hand or upper limb condition. There has been enthusiasm for the project by parents and children, as well as by clinicians from the major children's hand surgery clinics across the country, all of which have enrolled as data collection centres. The third issue of standardising the data has been more challenging, given the degree of complexity and breadth of variation in phenotype. However, the development and validation of the Oberg, Manske and Tonkin (OMT) classification, which has been widely accepted by the hand surgery community and similar international registries, offers a solution to this problem.

Maintenance of the data depends on the provision of adequate infrastructure and resources, together with appropriate processes for auditing and security. The AHDR is housed within the Murdoch Children's Research Institute, drawing on that institute's expertise and infrastructure, with data entry available nationally through an online portal. The development of the AHDR was funded by the Aussie Hands Foundation with ongoing funding from the AFPS to extend the register across the country.

Meaningful and timely reporting of information is the main purpose of the register, and ultimately justifies its creation. Reporting needs to address the needs and concerns of the various stakeholder groups (children, parents, clinicians, institutions) and to meet the goals that motivate them to contribute. The AHDR will provide general and specific diagnostic incidence data, further demographic and perinatal history data obtained from parents, and a range of data linkages to other health records. This will not only allow annual reporting of pooled, de-identified data on hand differences and their treatment, it will provide a resource for longer-term cohort outcome studies of adequate size to provide meaningful answers to questions surgeons pose, as well as those asked of them.

The AHDR presents a clear opportunity for plastic surgeons, through our role in congenital hand surgery clinics and through the AFPS, to collaborate with our colleagues in orthopaedic surgery and paediatrics, with scientists in research laboratories and, most importantly, with our patients and their families, to establish a resource that provides assistance and greater certainty, and hopefully some answers to the puzzles surrounding congenital anomalies of the limbs. The future challenge is to maintain the existing momentum and engagement with clinicians and families, as well as to garner further resources to ensure the longevity of this invaluable register.

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References