

Research Policy

Updated and approved June 2017

Down Syndrome Australia (DSA) supports research that can enhance the lives of those living with Down syndrome. We can provide information about research projects through social media and provide information to the Federation members (the eight states and territory organisations) from research projects that have been approved by DSA.

Please note that if a project is approved, direct access to members is subject to approval by each DS Federation organisation. A research project may be approved by DSA for advertising through our direct streams, it does not necessarily mean that Federation organisations will advertise the study.

In order to be accepted by DSA, Projects need to meet the following criteria.

- All project materials must be prepared in accordance with the National Health and Medical Research Council (NHMRC) [National Statement for Research](#) with particular consideration of the information contained in:
Chapter 4.2 Children and young people
and
Chapter 4.5 People with a cognitive impairment/intellectual disability.
- All project information that will be viewed by participants (flyers, brochures, information statements etc) should be written using appropriate and respectful person first language (e.g. "person/child with Down syndrome" not "Down syndrome person/child").
- The research outcomes should have the potential to enhance the lives of people with Down syndrome and/or their families.
- Any information/consent forms aimed at people with Down syndrome should be written in a way that can be understood by the desired participants. We are able to provide guidance if required.
- A summary of the project outcomes is to be forwarded to Down Syndrome Australia within 6 months of completion of the project for addition in our journal, VOICE.

To obtain approval from DSA:

Ensure that your application meets our stated criteria. Also note that ethics approval from a properly constituted committee will be required before final approval from DSA. Please submit all relevant project information including:

- the final version of the study protocol

- all participant information statements
- a cover letter containing details of the specific membership group to which you seek access (e.g. parents of children aged 2-5 years, adults (over 18yrs) with Down syndrome.
- Letter of approval from Human Research Ethics.

Promotion of any individual project is up to the discretion of the DSA CEO and Board. If the project meets the research guidelines of Down Syndrome Australia and is approved by the CEO, we will provide information about your project to our Federation members, on our social media platforms, and in our newsletter. *We are unable to endorse specific projects. Individuals will be encouraged to discuss the project with the researchers and/or their health professional.*