

Our research policy

Down Syndrome Victoria (DSV) is keen to facilitate research that can enhance the lives of those living with Down syndrome. We can provide access to our membership for research projects that have been approved by both the DSV Board of Management (BOM) and an Institutional Human Research Ethics Committee.

Projects need to meet the following criteria.

- a) All project materials must be prepared in accordance with the National Statement for Research (link to website) 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](#).
- b) 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”)
- c) The research should have the potential to enhance the lives of people with Down syndrome and/or their families.
- d) 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.
- e) A summary of the project outcomes is to be forwarded to Down Syndrome Victoria within 6 months of completion of the project.

There are 2 possible ways to obtain approval from the BOM

1. Apply to DSV before applying for Human Research Ethics approval (preferred approach)

Ensure that your application meets our stated criteria. Please submit all relevant project information at least one week before a BOM meeting date (link to BOM dates) 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)

If the project meets the research guidelines then a letter of conditional support will be sent to the research team within a week of the BOM meeting stating:

“The Board of Management of Down Syndrome Victoria has agreed in principle to offer access to their members/staff in the form of a mail out of an approved project flyer. This is on the condition that the final HREC approval letter and all participant information is reviewed by the BOM.

We are unable to endorse specific projects and members/staff will be encouraged to discuss the project with the researchers and/or their health professional.

2. Applying to DSV after obtaining Human Research Ethics Committee approval

If institutional approval has already been granted the researchers are requested to submit the letter of approval, the research protocol and the final version of all participant information documents to Down syndrome association as above for BOM approval. Access to members/staff will not be allowed until this has been sighted and approved.

Once your project has been approved by the BOM

We will provide a single mail out of a project flyer in order for members/staff to contact you directly. The project flyer (see template) will be sent to relevant members/staff with the following statement:

*The BOM of Down syndrome Victoria have examined this research proposal and agreed to pass on this request for recruitment from ****.*

We do not endorse this research and advise you to read all project information carefully and ask questions before you agree to participate. You may wish to discuss the project with your GP or health practitioner.

Please note that we will not provide access to members/staff for projects that do not fulfil our criteria, even when institutional Ethics approval has been granted.

Approval is granted for one mail out only and we do not endorse subsequent contact of our membership/staff without notifying the BOM.

Due to the voluntary nature of the BOM it is not possible to fast track applications.

If you have any questions about documentation or access to members/staff please contact (name and contact details)

Checklist

- Research protocol (and approval letter if already granted)
- All materials that will be sent to participants
- Cover letter describing the specific membership group/staff that you wish to access and details of the expected benefit for people with Down syndrome