

## Research Policy 2022

The Fragile X Society welcomes research into all aspects of Fragile X Syndrome (FXS) and Fragile X Premutation-Associated Conditions. In order to safeguard our families and members we have instituted the following policy governing which research projects we can disseminate to our members.

1. **Research must be in the best interests of our members.** Some of those with FXS may not be able to make informed decisions for themselves; we would not wish a research project to do them harm or cause distress.
2. **Information about research participation sent to families must be clear and concise.** We will review documents and advise whether they are understandable and appropriate.
3. **All projects must have full ethical approval by the appropriate UK body.**
4. **We must see the consent form that families will be required to sign.** This must comply with UK GDPR.
5. **We will disseminate approved projects via our email networks, on our website and through social media as appropriate.** We will not provide lists of addresses and will not do mailshots.
6. **We will consider being a partner to a project.** This will be assessed on a case-by-case basis and can include being part of the proposal at the outset and/or writing letters of support for researchers applying for funding. Please see our Partnership Form.
7. **We will require feedback on the results of research** in the form of a report which may be published in our newsletter and/or website. This report should be easy for our families to understand, with a link to further information or the published paper.

The Fragile X Society seeks to encourage a range of research, behavioural, psychological, educational, sensory, occupational and medical. Our Research Officer and Research Committee is very happy to consider all proposals. We will feedback any queries.

Please submit the following form, along with these documents, for consideration by our Research Committee, who may seek the advice of our Honorary Advisors:

- The Society's Research Policy, signed, and Research Proposal Form
- Proposed consent form
- Proposed family participation information leaflet
- Proof of ethics committee approval
- Your DPIA, if applicable

Please email this form and accompanying documents to our Research Officer at [anne@fragilex.org.uk](mailto:anne@fragilex.org.uk)

**I agree to the terms as set out in the Fragile X Society's Research Policy**

**Printed Name** \_\_\_\_\_

**Signature** \_\_\_\_\_ **Date** \_\_\_\_\_