



Fragile X International

Research Protocol

Fragile X International welcomes research into all aspects of Fragile X Syndrome (FXS) and Fragile X Premutation-Associated Conditions (FXPAC).

In order to safeguard our member organisations' families, we have instituted the following policy governing which research projects we can disseminate to our members and which can be considered for International research cooperations.

Guidelines

Safeguarding people with FXS

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.

Clear communication

Information about research participation sent to families must be clear and concise. We will review documents and advise whether they are understandable and appropriate.

Ethical approval

All projects must have full ethical approval by the appropriate institution. Research proposals with ethics approvals granted by committees with insufficient knowledge background about FXS and FXPAC may be rejected.

Consent transparency

All forms that are intended to be sent out to possible research participants for signing must be submitted to FraXI research committee first and will be reviewed. All communication must comply with the European Union's GDPR (<https://gdpr.eu>).

Circulating project information

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.

Partnerships

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.

Reporting

We 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.

Suggesting a research project

Fragile X International seeks to encourage a range of research: behavioural, psychological, educational, sensory, occupational, medical. Our Research Committee is very happy to consider all proposals. We will give you feedback on any queries.

Please submit the following documents, along with the form below, for consideration by our Research Committee:

- Research project protocol
- Proposed consent form
- Proposed family participation information leaflet
- Proof of ethics committee approval

Research Proposal Form

Please email the form and the accompanying documents to our Research Committee at info@fraxi.org :

| Question | Answer |
|---|--------|
| 1. Project Title | |
| 2. Project description in lay terms (including hypotheses and objectives of research) | |
| 3. Methodology | |

| | |
|---|--|
| 4. Name of lead researcher and contact details | |
| 5. Other organisations involved | |
| 6. Funding bodies (if applicable) | |
| 7. Project start date and estimated completion date | |
| 8. Any other information you would like to share | |

I agree to the terms as set out in the Fragile X International Research Protocol.

Printed Name _____

Signature _____

Date _____