



BDEF CIO External Research Requests Policy

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Purpose

The purpose of this policy is to set out how external researchers (academic, commercial, voluntary sector, etc.) may request to conduct research involving the members, participants, or data from BDEF CIO (Bristol Disability Equality Forum). The policy makes sure that such research is conducted ethically, respects the rights and dignity of Disabled people, supports our organisational mission, and ensures that any benefits are meaningful to the community.

Scope

This policy applies to any external individual or organisation (“Researcher”) requesting to carry out research involving:

- BDEF members, their carers / support persons, or Disabled people who access our services / engage with us;
- our internal data or records;
- our premises or events;
- participation in research methods such as interviews, focus groups, surveys, user-testing, etc.

Definitions

External Researcher: any researcher not employed or contracted by BDEF.

Lived Experience: individuals who have personal experience of being a Disabled person.

Participant: someone who takes part in the research (survey, interview, focus group etc).

Ethics Approval: formal approval by an independent ethics review board or equivalent.

Principles

Research involving BDEF or its community must:

- Respect the dignity, autonomy, privacy, equality, equity and rights of participants.
- Ensure meaningful involvement of people with lived experience in all relevant stages of research (design, data collection, analysis, dissemination)- using a co-production approach.
- Be transparent about aims, methods, risks, benefits, and funding.
- Ensure accessibility of participation (reasonable adjustments, accessible materials etc).
- Involve participant/community payment for involvement (e.g. having the option of monetary, voucher, charitable donation or no payment readily available including any preparation in making sure that payment doesn't affect a participants benefit entitlements).
- Have potential meaningful, tangible impact for the community.
- Be lived experience run **or/and** run by trauma-informed, experienced researchers.
- Protect data and privacy in line with GDPR and relevant laws.
- Ensure findings are shared back with the community in accessible formats.

Criteria for Approval

An external research request must satisfy the following minimum criteria:

<u>Requirement</u>	<u>Description</u>
Ethics	Must have or provide proof of ethics approval from a recognised body or equivalent risk assessment/assurance of safety.
Relevance	Demonstrated relevance to Disability Equality / the community we represent.
Participant protection	Details of informed consent, anonymity/confidentiality, risk mitigation, safeguarding.
Lived experience involvement	Plan for involving Disabled people or people with lived experience in design, conduct, analysis.
Language	Use social model, Disability Equality language i.e. Disabled people rather than 'people with disabilities' or 'impairments' rather than 'disabilities'. Further information can be found on our website .
Accessibility	That any sessions will be held in a physically accessible space if in person, that the medium to meet online is virtually accessible for the community and information communicated will be created in accessible formats.
Data handling	Clear plan for data collection, storage, access, retention and disposal.

Dissemination	Plan for sharing findings with us and the community; ideally accessible/public facing.
Compensation	How participants (especially people with lived experience) will be recognised / compensated.
Resources	Assessment of burden on our organisation; who bears what costs, staff time, etc.

Application Process

Researchers should submit a request to info@bristoldef.org.uk, which must include:

- Title and aims of the project; background / rationale.
- Research questions; methodology (how data will be collected, who from, how).
- Ethics approval or plans to obtain it.
- Recruitment strategy and participant materials (information sheets, consent forms).
- Data protection plan.
- Accessibility / reasonable adjustments plan.
- Timeline.
- Budget, if relevant (including payment for involvement compensation for participants).
- How findings will be disseminated (reports, community briefings, academic articles, etc).

We will aim to acknowledge receipt of the application within 5 working days, and aim to make a decision after a trustee meeting (which is held on the third Thursday of each month).

Review and Decision

- The initial response will come from BDEF's staff team but the project will not be officially reviewed until BDEF's trustees meet and review the proposal.
- Trustees meet on the third Thursday of each month and they will be able to provide the official response to the research request.
- Decisions may be: approve, approve with modifications, reject.
- If modifications are required, the researcher will be asked to revise parts of the proposal.

Conditions and Agreement

If approved, the researcher must sign an agreement which may include:

- Obligations for data protection, confidentiality, GDPR compliance.
- Rights of withdrawal for participants.
- Acknowledgments or authorship / credit to BDEF.
- Copy of findings to be shared with BDEF.
- Agreement on dissemination / publication (with accessible summaries).
- Liability / indemnity clauses.

Monitoring and Oversight

If deemed necessary by BDEF:

- Researcher to provide periodic updates / progress reports.
- BDEF may monitor compliance with agreed terms.
- If a researcher breaches conditions, BDEF may revoke permissions or require modifications.

Publication and Feedback

- Final report / copy of academic output to be given to BDEF.
- At least one accessible version for the community (e.g., plain-language summary, accessible PDF, etc).
- Where possible, presentations or discussions with our membership / community on outcome.

Capacity, Resources and Limits

Recognise that BDEF's capacity is finite. We reserve the right to decline or defer requests if:

- Projects require more resources (staff time, administrative) than available.
- There are many concurrent projects.
- Researcher unwilling to meet conditions.

Legal and Data Protection Compliance

- All data handling in line with UK GDPR and Data Protection Act.
- Where personal or sensitive data is involved, appropriate consent and security measures are required.
- Comply with equality, safeguarding, accessibility and legal obligations.

Appeals and Disagreements

- Researchers may request reconsideration, providing additional information, if application is rejected.
- Disputes will be escalated to the trustees. You can contact trustees at chair@bristoldef.org.uk.

Versions

There is an Easy Read version of this document in development. When it is finalised and signed off, it will be linked to here.

Review

This procedure shall be reviewed every 2 years upon its adoption. An earlier review may take place if:

- We approve a proposal that changes the policy
- There's a change to the organisation that will change the policy
- There's a change in the law that affects the policy