HIKIKOMORI UK

Research Engagement Policy

Last updated: August 2026

Our approach

Hikikomori UK is primarily a volunteer-led information network for parents, carers, and families affected by prolonged social withdrawal. We also seek to ensure that the dignity, autonomy, and perspectives of individuals experiencing hikikomori are respected in all research activities.

Hikikomori UK welcomes research that improves understanding of hikikomori and prolonged social withdrawal. Research has an important role in informing public understanding, policy, support services, and future interventions.

The wellbeing, dignity, and autonomy of people experiencing social withdrawal must always come before research objectives. Many individuals within our community are vulnerable, may experience significant anxiety, and may have spent years avoiding social interaction. Participation in research should never compromise recovery or wellbeing.

We believe people experiencing social withdrawal should be partners in research, not simply subjects of it.

Research we particularly welcome

We are especially interested in:

- Participatory research
- Co-produced research
- Lived experience-led projects
- Arts-based research
- Educational resources

- Projects designed alongside people with experience of social withdrawal

1. Recovery comes first

The welfare of participants takes priority over research outcomes. We will not support research activities that are likely to increase distress, anxiety, or withdrawal.

2. Participation must be voluntary

We will not encourage families to recruit, persuade, or pressure individuals experiencing social withdrawal to participate in research projects.

Any decision to participate must be made freely by the individual concerned where they have capacity and wish to engage. Choosing not to participate will always be respected.

3. Informed consent is essential

Participants should fully understand:

- The purpose of the research
- How information will be used
- Who will have access to the findings
- Any potential risks and benefits
- Their right to withdraw

Researchers should provide information in accessible and understandable formats.

4. Agency and control matter

Participants should have meaningful control over their involvement, including what they share, whether they remain anonymous, and whether they can withdraw.

Participants should be told before taking part whether they can review quotations or contributions before publication, and any limits on review, anonymity, or withdrawal should be explained in detail and in advance.

5. Lived experience should remain central

Wherever possible, individuals experiencing prolonged social withdrawal should have the opportunity to share their own experiences.

Parents and carers are participants in their own right and offer important insights into the impact of hikikomori.

Understanding the condition requires attention to both individual and family experiences.

6. Privacy and safeguarding

Researchers should have robust procedures in place to protect anonymity, confidentiality, and participant wellbeing.

Particular care must be taken when engaging with vulnerable young people and their families, who may participate while experiencing profound grief, shame, self-blame, stigma, or emotional exhaustion.

Engagement should adopt a compassionate approach that values experiences without attributing blame or reinforcing stigma.

Researchers must not gain access to support groups, online communities, forums, or private communications through deception or other covert methods.

7. We do not recruit participants

Hikikomori UK does not provide researchers with direct access to members of the community. We will not provide access to private groups, meetings, or personal contact details for research purposes.

Where appropriate, opportunities may be shared with our community, but any decision to make contact rests entirely with individuals and families.

8. What we ask researchers

Before contacting our community, please consider:

- What is the purpose of your research?
- How will participants benefit?
- How will confidentiality be protected?
- What ethical approval has been obtained?
- What safeguarding measures are in place?
- How will distress be managed?
- Can participants withdraw?
- How will findings be shared?

Families considering a research request may also find our guidance for parents and families helpful.