

Partnerships and collaboration policy

Autistica's vision is a long, healthy, happy life for autistic people and their families. We know we can't achieve our vision on our own and that is why one of our key values is collaboration.

We (Autistica) embrace the power of working in partnership. We work and are willing to work nationally and internationally with autistic people, families, autistic-led and family-led organisations, research funders, charities, governments and industry to achieve our vision.

Scope

We use the word "scope" to refer to what this policy will deal with.

We use the word "partnerships" in this document to refer to any form of collaborative activity.

This policy considers partnerships in respect of charitable activity, including advice or support with:

- Recruitment of participants
- Policy and public affairs
- Co-funding of research
- Involvement of the community (this could include anyone with a direct relationship to autism)
- Communications, dissemination and PR
- Brand association
- Consultancy

This policy excludes philanthropic or charitable gifts (including sponsorship) which would be guided by our ethical fundraising policy. Philanthropic gifts will not factor in decision related to support or access to assets described above; these must be applied for in the same way as any other applicant.

Partners could include autistic people, families, autistic-led and family-led organisations, research funders, charities, governments and industry (such as the pharmaceutical, biotechnology and technology sectors).

This policy does not cover activities carried out by Autistica employees working in other capacities unconnected to Autistica.

Purpose

To ensure that our approach to partnerships is consistent with Autistica's vision, mission and values as outlined in our [research strategy](#).

We aim to achieve our vision by maximising the benefits for:

- Autistic people and families by improving the quality of autism research or autism-related activity and the chances of successfully generating research outputs of value to them.
- Autistic people and families by increasing focus on outcomes, and overcoming issues which lead to poor health and wellbeing or increased morbidity, mortality, unemployment and social isolation.
- Autistic people and families by raising the profile of high quality, community-led autism research or activity.
- Researchers by giving them access to skills training, assets and funding.
- Autistica by increasing our influence on partners and our ability to leverage future funding in autism-related activity or autism research.

We aim to control the risks of:

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- Harm to autistic people and their families from poorly directed research or activities from proposed partners.
- A lack of understanding or support from potential partners about meaningful involvement – planning, commitment, costs – and a culture that doesn't support meaningful partnership.
- Exploitation of autistic people, families, Autistica, our assets or autism researchers.
- Partnering in projects which knowingly use stigmatising language.
- Research or activities which don't meet a need for autistic people and their families.
- Reputational or actual damage to the charity.

Decision making

The following issues will affect Autistica's decision making on partnerships:

Is this an opportunity to undertake high quality and high impact research, policy, communications or any other activity related to Autistica's mission and vision?

Is the partner addressing a community need?

Is there reputational or actual risk involved which will affect Autistica's capacity to deliver on its vision?

Does our involvement increase the impact of the activity?

Is partnering in this activity more impactful than other opportunities we have available to us?

Does our involvement lead to wider impact beyond the scope of the project?

For each asset and type of support which Autistica could provide, we will ask:

What are the risks and benefits?

Can the partner communicate sensitively, intelligently and positively about autism?

If we don't do it, will someone else? Are we needed?

Is there a financial case/appropriate compensation for supporting this project?

Principles

No written agreement will ever compromise the independence of Autistica. There should never be any compromise to the independence of Autistica, or any attempt to modify Autistica policy. No contractual relationships will be entered into which contradict this principle. Autistica will withdraw from any collaboration if they believe their independence is ever threatened.

Partnerships will be considered with respect to the criteria and conditions outlined in this policy and will be subject to a full assessment and formal approval process. This is outlined in our "Partnerships – Process" and "Partnerships – Standard Operating Procedure" sections (outlined after this policy).

Where decisions become complex, we will engage with the autistic people, families, researchers and Trustees as per our process and standard operating procedure.

Process and decision-making regarding partnerships will be proportionate and will not be unduly onerous. The extent of review implemented will be assessed using the strategic questions listed above, our processes and standard operating procedure.

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Autistica should attempt to work in partnership where there is a need from the community that justifies partnership working. Where possible, evidence of community need will be based on robust quantitative and qualitative research, but that will not always be possible.

Autistica's decisions about entering into partnerships will be guided by the principles of "autonomy", "patient/personal choice" and "community need". On that basis, majority agreement will not always exist. For example, the majority may not want, need or believe medication is necessary, but some may wish to use medications for issues such as seizure management, mental health, and language and communication difficulties. We respect the rights, views and needs of all groups.

Autistica's views on specific issues may be different from that of the partner. This alone should not stop us either working in partnership or openly acknowledging those differences.

Partners will be charged or costed relative to the fit with Autistica's strategic priorities and their own financial position (where partners are industry-based).

Where partners are scientific, they should ideally adhere to the same scientific standards as Autistica, including supporting the principles of high-quality science (e.g. pre-registration of clinical trials, transparent reporting of results).

Autistica will only enter partnerships with industry with written agreements that all parties sign up to. Where appropriate, this will cover brand use, intellectual property, and independence. Autistica will not work with companies that have excessively lengthy, complex contracting and negotiating processes.

Any partnership should contribute to Autistica's existing research strategy.

The total amount of financial support from industry partners with a direct commercial interest in autism will not exceed 20% of Autistica's total budgeted income excluding legacies for the financial year, nor 10% from any one corporate partner. Any proposed exception to this will be subject to trustee approval.

No partnership will be entered into with an organisation whose product or service is considered to be detrimental to autistic people, nor any organisation who makes claims that their product or service benefits autistic people where Autistica considers that to be unsubstantiated.

Autistica welcomes opportunities to raise funds and awareness through cause related marketing and sponsorship. However, Autistica will not endorse any third party, nor its products or services.

Although confidentiality is occasionally necessary, where possible, partnerships will be transparent. Our policy, processes and procedure for entering partnerships will always be transparent.

Staff, trustees and any other consultants must state any conflicts of interest with partners when considering partnership.

Partners should be committed to reporting any results delivered from the collaboration in an objective manner regardless of their own interests.

In line with Autistica's privacy policy, Autistica will never share with partners any data shared with Autistica by supporters (including Discover members) unless notice is provided, and they provide clear consent.

Concerns directly related to engagement with the pharmaceutical industry

Partnerships with pharmaceutical companies will comply with the Association of the British Pharmaceutical Industry (ABPI) Code of Practice for the Pharmaceutical Industry – Relationships with Patient Organisations. Partnerships with UK pharmaceutical companies which are not members of the ABPI would only be considered by exception and with approval of Trustees.

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As per our own policy, membership of the Association of Medical Research Charities and governance, partnerships will not lead to preferential treatment.

Autistica will consider requests from industry to participate in company-hosted advisory board meetings or workshops but employees will not attend such events unless their involvement will contribute to Autistica's vision. No payment will be accepted for attending such events.

Where activities being supported by industry are linked to influencing or campaigning activities, Autistica will seek to work with a minimum of two partners in order to maintain, and be seen to maintain, independence and impartiality.

There may be occasions where Autistica will campaign for equitable access to a service or intervention for autistic people. Funding will never be accepted from pharmaceutical companies to support campaigning activity for any individual products. However, campaigning may be in respect of a class of medicine produced and promoted by pharmaceutical companies which have previously funded Autistica and the ethical appropriateness and reputational risk will be considered before undertaking such activity.

Written agreements as described above are mandatory.

Definitions

Risk: The likelihood of any action negatively affecting Autistica's ability to deliver on its vision. Risks can negatively impact on the welfare of our community or staff, operational, financial or reputational. Causes of risk can be internal, external or a proposed partner.

Impact: The impact on Autistica's charitable vision (long, healthy, happy lives).

Effort/Resource: The amount of Autistica time required or cost implications. Effort and resource will also be considered with respect to availability of the required expertise.

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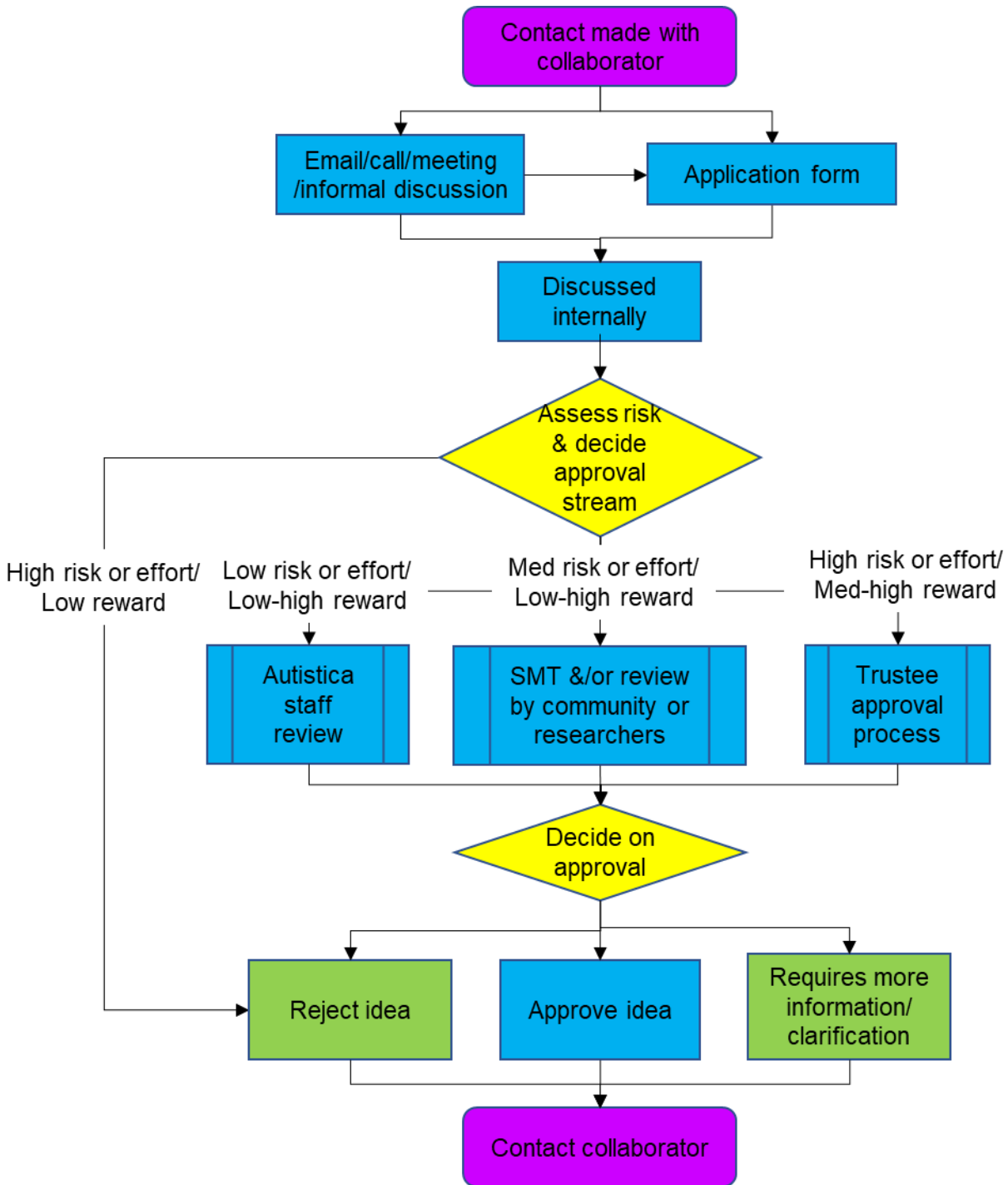
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Process for managing partnerships



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Standard operating procedure and review criteria

1. Initial engagement

Opportunities for partnership should occur via application form but may also occur through conversation or other forms of dialogue.

When an opportunity like this presents itself, the following questions will be asked to assess risk, resource and impact.

2. Assessment

Autistica staff are required to review any opportunity by asking the following questions and considering our partnership policy

Is there evidence of community need (do some autistic people and family members want this)?

Yes – We have existing evidence that autistic people and family members want this to happen.

No – Reject opportunity.

Unclear – If not confidential, engage with the insight group to consider whether activity could meet any needs. If needs to be confidential, contact community advisory group.

Is it novel? If we don't do it, will someone else?

Yes – Proceed

Unsure – Proportionately review landscape, then decide.

No – If adding nothing new, reject.

Are we confident the activity/science will be high quality?

Yes – proceed

Unclear/maybe – If necessary, engage with scientific and/or other relevant experts in the subject area or consider whether quality is sufficient to achieve any impact.

No – reject

Are we confident that the activity is ethically sound (if research, approved by an ethic committee) and safe?

Yes – proceed

Unclear/maybe – Ask for further information/clarification. As appropriate, engage with insight group (if needs to be confidential, contact community advisory group), scientists and risk committee.

No – reject

Are there any serious risks or reputational concerns?

No/low – proceed.

Yes, Medium – engage with senior management team and senior communications manager and insight group.

Yes, High – As above plus engage with risk committee, or reject.

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What is the level of resource required and, if appropriate, are we being appropriately compensated for our time?

Map out.

Does this comply with our partnership policy?

Yes - Proceed

Unsure – Engage with Senior Management Team, and if necessary the board.

No – Reject

What is the impact of this work and how does it align with our charitable objectives?

Assess and decide whether, if appropriate or necessary, staff should engage with the insight group, senior management team or the board.

Is the proposed activity sufficiently clear?

Yes - Proceed

No – Reject or request further information.

3. Decision

The senior management team or board of trustees should be engaged relative to risk, impact and resource required as detailed in our Partnership process flow chart. A decision should then be reached. There are three possible outcomes: a) approve, b) reject or c) requires more information or further clarification.