

**AIMS LEAP Project Proposal Form**

### Section 1: Project Overview

### Date (Submission)\*

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### Lead Investigator (name, Institution)\*

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### Additional Investigators (name, Institution)\*

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### Title of project\*

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### Research question(s)\*

Please specify the overarching research question(s) for your project here.

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### Lay Summary of project (approx. 200-250 words)\*

Please provide a short overview of your study (e.g., background, aims, method, implications) that can be understood by a member of the general public who is not an expert in your field.

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### Ethical approval information\*

Please indicate the ethical approval board/number (or equivalent), where your proposal for secondary analyses has been submitted and confirmed.

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### Section 2: Project Detail Information

### Technical Project Outline (Background, Aims/Objectives, Method, Implications; up to approx. 500 words)\*

Please provide a full overview of your study here.

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### Hypothesis/Hypotheses\*

Please specify directional/non-directional, concise, testable hypotheses for your study.

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### Context/Importance\*

Please detail the rationale for the proposed study (i.e., in terms of added value, areas of impact, implications/applications).

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### Sample\*

### Please specify parameters for your required study population from the LEAP cohort (e.g., whether you will have any additional inclusion/exclusion criteria, such as only including a certain age/IQ range vs. all participants).

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### Measures\*

### Please specify parameters around the measures you require access to in order to address the aims and hypotheses above.

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### Planned statistical approaches/analyses\*

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### Section 3: Data Management

### How will the data be managed and stored?\*

Briefly describe how the data will be stored, backed-up, managed, and curated during the course of the project to ensure that the minimum data security standards set out in the Data Use Agreement are adhered to.

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### Which formal information/data security standards will be followed?\*

Identify formal standards with which your study is or will be compliant (e.g., Institutional, regulatory).

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### What are the main risks to data security and how will these be managed?\*

Please summarise the risks specific to your research and how these risks will be managed. Do not write ‘not applicable’ under this heading.

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### How do you plan to share your data processing/analytics pipelines/metadata?\*

We strongly encourage those using AIMS data to share their processing/analytical code/metadata with the community (e.g., on OSF or Github).

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### Section 4: AIMS Consortium Principles

Ethical principles for external researchers using AIMS data are stated below. We ask those who wish to request access to AIMS data to engage with these principles, as follows.

1. **Improving quality of life for autistic people and those with co-occurring conditions**

*The core ethical principle underpinning the work of AIMS-2-TRIALS is beneficence. We are committed to improving outcomes and increasing quality of life for all people represented by our participant cohort through biomedical research.*

As a researcher requesting access to AIMS-2-TRIALS data, your research using this data must be in alignment with this principle.

* **Please outline below how you hope your research will benefit members of our participant communities (approx. 100-300 words).** 
  + This can include both direct benefits, e.g. addressing a known community priority, and indirect benefits, e.g. contributing to scientific rigour within a particular area of the autism research landscape which is insufficiently robust.
  + It can include short term benefits, e.g. analysis of data which yields new findings with immediate ramifications for the community, and long term benefits, e.g. addressing a gap in the literature which is currently a barrier to broader understanding.

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1. **Respect, trust-building and community inclusion**

*We are committed to respecting and building trust with our community partners, through inclusion and engagement.*

As a researcher requesting access to AIMS-2-TRIALS data, your research using this data must be in alignment with this principle.

* **Please outline the efforts you will make/have made to engage or include relevant stakeholder communities as part of your research process (e.g., conceptualisation, analysis, interpretation, dissemination; approx. 100-300 words).**
  + Examples of engagement could include research which is fully participatory from first principles, working with researchers who have lived experience, direct consultation with people who have lived experience, or where resources are scarce, engagement with materials produced to guide autism researchers, e.g. referring to [Autistica’s top 10 research priorities.](https://www.autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf)

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1. **Changing research culture and language**

*We are committed to changing aspects of current research culture and language which reinforce stigmatising and unhelpful narratives about autism.*

As a researcher requesting access to AIMS-2-TRIALS data, your research using this data must be in alignment with this principle.

Culture change

This will involve doing some background research to ensure that your research design, process and goals do not inadvertently reify stigmatisation or marginalisation of autistic people. See [Pellicano & den Houting (2021)](https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/jcpp.13534) for how deficit-focused design and interpretation of research can contribute to this.

Language change

This may involve using new wording when drafting articles or presentations, as well as where necessary, requesting that journals and other relevant fora (e.g. conferences) accept the use of this language. The AIMS-2-TRIALS external data access policy notes preferred language. See also [Bottema-Beutel et al., (2021)](https://www.liebertpub.com/doi/10.1089/aut.2020.0014) as a starting point for drafting future work.

Engagement with the community will also help to support you through both aspects of this process if you feel unsure.

**Please outline any aspects of your proposed work which might inadvertently reify unhelpful narratives about autistic people, and steps you could take to address this (approx. 100-300 words).**

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1. **Minimising direct and indirect risk**

*We are committed to actively considering and minimising risk for all individuals whose lives are affected either directly or indirectly by all aspects of our research activity, from study design to dissemination.*

As a researcher requesting access to AIMS-2-TRIALS data, your research using this data must be in alignment with this principle.

Most kinds of research, especially where people are being studied in some way, have the potential to impact their lives in many ways, both directly and indirectly. It’s important for all researchers working with AIMS-2-TRIALS data to understand how this might be the case with autism research (or research on features and traits associated with autism) so that the risk of research negatively impacting individuals and groups is kept to a minimum.

Direct risk is when a *participant* is affected negatively by what you do, for example, if someone is identified through how you handle their data.

Indirect risk is when a *non-participant* is affected negatively by what you do, for example, if your findings influence how autistic people are treated in society.

* Please clearly describe the relationship of your work to any ethical issues of relevance to autism research such as eugenics, prenatal testing, gene editing or the perceived “normalisation” of autistic people (list not exhaustive).
* **Please outline some of the direct and indirect risks of your research and steps you will take to mitigate these. It may be helpful to supplement your response with content from your approved ethics proposal where relevant (approx. 100-300 words).**

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1. **Protecting data rights whilst preserving data**

*We are committed to safeguarding the data rights and autonomy of our participants, while exploring ways to sustainably share data with external researchers.*

As a researcher requesting access to AIMS-2-TRIALS data, your research using this data must be in alignment with this principle.

Your responsibilities in accordance with this principle are to abide by all aspects of the Data Access Policy you have agreed to when requesting access to AIMS-2-TRIALS data.

**Please check the box to confirm you will read and agree to the Data Access Policy and will sign and abide by the Data Use Agreement, if granted data access** ☐

*I agree to design, conduct and disseminate my research in accordance with each of the above principles.*

Signed: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**References**

Autistica (2017). *Your Questions: Shaping Future Autism Research.* Available from: [Autism-Top-10-Your-Priorities-for-Autism-Research.pdf (autistica.org.uk)](https://www.autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf)

Bottema-Beutel, K., Kapp, S., Nina Lester, J., Sasson, N., & Hand, B. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood,* doi: https://doi.org/10.1089/aut.2020.0014

Pellicano, E., & Houting, J. (2021). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *The Journal of Child Psychology and Psychiatry.* doi: <https://doi.org/10.1111/jcpp.13534>