In FORM, our goal is research that is transparent and connected to improving real-world outcomes for autistic individuals and their families. The principles outlined here are intended to set expectations for efforts throughout the program including how teams will work with parents, caregivers, children, families with autistic children, the autism community, as well as biological samples and data. FORM applicants will be expected to agree that, to the best of their ability, they will adhere to these principles and to outline how they plan to do so beginning at the Proposal phase. Our hope is that in so doing, together, we will create a mutually respectful environment that allows for different points of view to be expressed as we work together in this spirit.

FORM Partnership and Trust Principles

1) Intent & language

The intent of the FORM program is to support healthy infant neurodevelopment with a particular focus on identifying whether the gut microbiome plays a key supporting role during sensitive developmental windows. If new connections are discovered between the accumulating set of stressors to the microbiome and neurodevelopmental challenges, including the more severe autism-related challenges that impact daily life, it could increase options for families. The FORM program does not seek to prevent all forms of autism or to erase autistic identity — only to provide improved understanding and support.

Given this intent, our goal is to learn *from* and speak *with* individuals and families, recognizing a shared sense of community. Researchers will do their best to avoid terms implying autism should be "cured," "eliminated," or universally "prevented." Instead, to recognize neurodiversity, distinguish identity from support needs, and focus on reducing health or developmental difficulties that can make daily life harder for children and their families. Public-facing summaries about the work, ethics submissions, and funder materials should use clear, plain language about goals, methods, and anticipated benefit.

2) Community partnership

Team members are expected to commit to co-design and partnership with autistic individuals, parents, caregivers and families, in ways that are tailored to culture, geography, and the individual project needs. And to put plans in place to do so.

Lived-experience involvement should be meaningful, embedded in research methods and execution, and appropriately compensated and budgeted for – including, but not limited to, consent materials, data privacy and storage, participant experience, and cultural appropriateness of any new screening, diagnostic, and intervention options.

3) Transparency and accountability

We expect team members to commit to sharing their goals and hypotheses in plain language; distinguishing early signals from established evidence; providing regular updates

on our progress as a program team, including major changes in direction; and sharing results openly and promptly – including negative findings.

4) Data stewardship, sharing, and participant agency

We expect researchers in the FORM program to commit to developing plans, ethical applications, and participant consent forms that provide details including:

- Data handling, access, storage, and governance, including privacy, regulatory and security standards, as well as the possibility, if any, of future research or commercial application.
- The right to withdraw data and/or materials; and any plans, if applicable, for long-term storage and access after the FORM program concludes.

The intent is clarity that enables participants to make informed choices about how their data may be used – now and in future – and how autonomy will be respected.

5) Informed consent and ethics

Informed consent is key; best practices will be used to create consents that are clear, accessible, culturally appropriate, and free of pressure. We expect layered, informed, and reversible consent wherever feasible; options for future or commercial use to be consented separately, as appropriate; clear explanations of risks, safeguards, and participant rights; and, that ethics review is tuned to work involving autistic individuals, parents, and mother–infant pairs.

Sharing data, including sensitive personal data, is likely to be needed across FORM program teams to make progress together. In such cases, ethics and consent will need to ensure that participants are explicitly aware of this research use and purpose.

6) Rigor, ethics, community engagement, and disclosure commitments from researchers

Researchers should outline their approach to ensuring scientific rigor in this complex area (including population and statistical requirements), specific ethical practices, as well as evidence of a commitment to work with and respectively engage the autism community. Transparency on relevant disclosures – including funding sources, partnerships, and data-sharing – must be provided.

Process: *At the abstract stage, applicants are asked to acknowledge that they will adhere to these principles and address them in their proposal. In a dedicated appendix at the full-proposal stage, applicants will need to include high-level plans outlining how they will address these principles and incorporate them into their activities. Researchers selected for the program will be expected to submit final plans and materials for review and approval with milestones and funding structured accordingly.*

Questions about these principles or suggestions aimed at constructive improvement can be sent to: form@wellcomeleap.org