**SAMPLE VETTING CHECKLIST (adapted from DSACT of Austin, Texas):**

|  |  |  |  |
| --- | --- | --- | --- |
|   | **Yes** | **No** | **n/a** |
| **Criteria** |   |   |   |
| Project has a benefit to the Down syndrome community  |   |   |   |
| Identification of the condition, disease or goal under study |  |  |  |
| Researchers use current, family-focused and positively-positioned terminology in recruitment, consent, and explanation materials |   |   |   |
| Researchers do not use of outdated terms or concepts (e.g., individuals with Down syndrome are always happy, “special” people, “angels”, vulnerable, etc.) |   |   |   |
| Study/trial/survey includes correct references to current, respected resources |   |   |   |
| Study/trial/survey has been approved by IRB, ERB |   |   |   |
| Study/trial/survey has adequate privacy protections in place (e.g. anonymizes participant data, or clearly states reason for not doing so) |   |   |   |
| Any compensation is simply stated, commensurate to effort, and is not overly emphasized |   |   |   |
| Study/trial/survey does not claim that participating will improve, cure, or treat any condition  |   |   |   |
| No person can be excluded from participating based on being a member of a protected class, unless there is a clearly stated reason (such as studying a particular age group)  |   |   |   |
| For medical or treatment-related research: a medical doctor well-versed with Down syndrome research has reviewed and approved the project and this MD's credentials and contact information are included in project materials |  |  |  |
| Researcher has submitted: Contact information and credentials of the requestor or the individual who will be the main point of contact for questions |  |  |  |
| Researcher has submitted: A thorough explanation/description (including time commitment) of the study/trial/survey |  |  |  |
| Researcher has submitted: Copies of trial/study process, consent forms, participant-facing materials and/or entire survey content |  |  |  |
| Researcher has submitted: Proof of regulatory oversight (IRB, ERB, etc.) |  |  |  |
| Researcher has submitted: Outline of participant eligibility parameters, along with any pre-screening criteria |  |  |  |
| Researcher has submitted: Timeline components of the request (project anticipated start or end date) |  |  |  |
| Researcher has submitted: Any other relevant information, including IRB-approved images, video, outreach language, and social media and digital channel language, as well as communications intended to be seen/received by health care professionals, other materials intended for a “non-participant” audience (e.g. board) |  |  |  |
| Researcher has submitted: Contact information and credentials of the requestor or the individual who will be the main point of contact for questions, along with an explanation of how they will manage follow-up  |  |  |  |



LuMind IDSC www.LuMindIDSC.org
20 Mall Road, suite 200 www.DSCTN.org
Burlington, MA 01803