



TEAM GLEASON FOUNDATION
Post Office Box 24493
New Orleans, Louisiana 70184
www.TeamGleason.org
EIN# 45-3689316

1. Purpose

You are invited to participate in the Team Gleason Foundation “Project Insight” image data collection (“Data Collection”) conducted by Team Gleason Foundation (“Team Gleason”), located at 930 Robert E Lee Blvd, New Orleans, LA United States. The purpose of the Data Collection is: (a) developing and evaluating: (i) machine learning models for eye gaze prediction; (ii) performing analysis and statistics to understand vision patterns, quality, etc. (this may involve sharing the data with third-party partners); (b) researching, analyzing, and improving products and services involving eye gaze prediction; (c) developing computer vision algorithms to detect facial features such as eyes and nose that work for people living with motor-neuron diseases and injuries or who use breathing assistance devices which fully or partially obscure the mouth or nose; and (d) other and future uses that relate to improving the quality of machine learning experiences, products and services at Team Gleason Foundation (collectively, the “Purpose”).

2. Participation

2.1 Qualification. By participating in the Data Collection you confirm: (a) you are of legal age in your jurisdiction or at an age of majority; (b) your participation will not violate any agreement with a third party, or create a conflict of interest; (c) have the authority to enter into this contract and grant Team Gleason Foundation all of the rights contained in this consent.

2.2 Voluntary Participation. Your participation is completely voluntary. If you choose not to participate or if you choose to withdraw, there will be no adverse consequences. If you wish to withdraw from this Data Collection, see Section 7 (“Questions”) of this agreement. You may not benefit directly from this Data Collection and you will not be compensated.

3. Data Collection, Retention, Use, Sharing, and Risks

3.1 General Collection Information. As part of this Data Collection, you will be asked to participate in various image tasks (the “Image Tasks”). The Image Tasks will require you to interact with several software applications that will be provided to you (the “Application”) for approximately a few hours. Please remember that the Image Tasks are

voluntary. You may be asked questions about your experience in completing the Image Tasks.

3.2 Image Tasks. As part of the Image Tasks, you will be presented with a number of visual targets moving across a tablet screen that you will look at in the Application. Additionally, you may be asked to upload different types of media (including, but not limited to, image and video) that may be relevant for the Purpose. While completing each Image Task, the Application may collect the following information (together with any content you upload or provide via the Application, the “Research Data”):

Image Task Data Collection:

- Date and time information associated with your image captures.
- Annotations associated with your image capture, including visual focus target, approximate gaze position, and other attention-related data.
- The email address you used to log-in to the Application.
- Usage analytics by the user of the tool, such as button clicks and screen views.
- Device information consisting of (i) the model and manufacturer of the device, (ii) the version of the operating system running on the device; (iii) device characteristics such as camera and other hardware peripherals; and (iv) device screen related data (e.g., size, DPI, resolution, etc);

3.3 Image Data Generation. As part of the Image Tasks, we may take your Research Data and use it to generate a composite facial image. This synthetic face will be used to generate additional image data. The synthetic face generated with your Research Data will not be used to identify you and shall be considered Aggregate Data as defined in this agreement.

3.4 Personal Identifier Data Collection. As part of this Data Collection, you will also be asked to provide a personal identifier (e.g., email address) for purposes of fulfilling any future request from you to delete your data and sending follow-up questions or surveys related to this data collection project.

3.5 Retention. Research Data will be retained for as long as needed to fulfill the purpose, but no longer than 10 years. Team Gleason Foundation may aggregate the Research Data with information from other participants in the Data Collection, to form an anonymous, aggregate data set which does not identify any individual (the “Aggregate Data”). There is no limit to how long or in what manner Team Gleason Foundation may retain, use, or share the Aggregate Data.

3.6 Use and Sharing. Team Gleason Foundation may share the Research Data with contractors and partners under obligations of confidentiality to annotate the data, create other metadata from it, or verify the quality and usefulness of the data for the Purpose. We may also share externally Aggregate Data. Team Gleason Foundation may permit third parties to submit queries or otherwise run analyses across the Research Data, provided that such research activities by third parties will not disclose or make available data that would personally identify you. Team Gleason Foundation, and third parties permitted by Team Gleason Foundation, may publish research studies describing the

Data Collection (including Aggregate Data), provided that the research studies do not disclose data that would personally identify you. You agree to permit all such uses and sharing.

Team Gleason Foundation will publish the Research Data, stripped of personal identifiers, to a public data collection of facial images under a restricted usage license where the data itself cannot be republished but anonymous, aggregate data sets can be derived and published. The purpose of the public sharing is to enable a wide network of machine learning developers and researchers to use the facial images and gaze target annotations to develop new machine learning models and algorithms for facial feature recognition and gaze prediction. The goal of this sharing is to remove data bias from existing datasets and algorithms used for facial feature and gaze prediction which today work better for the general public (~99.7% success) than for people living with ALS (~75% success). This data will be advertised and published to well-known repositories of computer vision algorithms and machine learning data, such as but not limited to Github (github.com) and Kaggle (kaggle.com). The data will be published with a restricted use license that forbids the use of the data outside of the scope of research and development for creating computer vision algorithms and/or anonymized aggregate data sets.

3.7 Risks. Participation in the Data Collection may involve some risk. You may experience physical discomfort, such as physical fatigue (e.g., eye strain, tiredness), or boredom while participating in the Data Collection. You may take a break or choose to discontinue participation at any time. Additionally, while Team Gleason Foundation takes steps to safeguard your Research Data, there is always a risk that Research Data may be compromised, misused, or made public by bad actors who have breached Team Gleason Foundation's data security efforts. While we will not publicly disclose your identity or personal identifier (e.g. email address) associated with this data, it is possible that a bad actor may use other facial recognition algorithms or databases to re-identify your facial images in breach of the limited use agreement. You may feel uncomfortable or embarrassed when answering questions, providing data, or while being photographed or filmed. As stated in Section 4.2, you may take a break or cease participation at any time.

4. Termination and Requests for Deletion

4.1 Termination by Team Gleason Foundation. Team Gleason Foundation may terminate the Data Collection or your participation in the Data Collection at any time. In such an event, you agree that the Team Gleason Foundation is released from any and all obligations to you under this agreement.

4.2 Termination by You. Your participation is voluntary and you may choose to cease participation in this Data Collection at any time. You can withdraw your consent to processing personal data at any time, so if you also wish to have your Data deleted, please see Section 7 of this agreement ("Questions"). If you request that your Data be deleted, Data that contains or is linked to your personal information will be deleted as soon as reasonably practicable, unless otherwise prohibited by applicable legislation or

legal process. Team Gleason Foundation may retain Research Data in a form that is not linked to your personal information and/or is anonymized.

5. Confidentiality and Intellectual Property

5.1 Feedback. During your participation in the Data Collection, you may provide comments, feedback, ideas, opinions, suggestions, data, or other information to Team Gleason Foundation (collectively “Feedback”). Feedback is separate from and not part of the Research Data. Team Gleason Foundation may use Feedback without restriction or compensation to you to develop and improve Team Gleason Foundation’s current or future products and services, but the Team Gleason Foundation has no obligation to use your Feedback. You agree that you will not disclose any third-party information that you are otherwise obligated to maintain as confidential.

5.2 Team Gleason Foundation Confidential Information. This agreement and any information provided to you by the Team Gleason Foundation during the Data Collection are confidential (the “Confidential Information”). You may use Confidential Information only for participation in the Data Collection and take care to prevent any unauthorized use or disclosure of such information. You may not photograph, record, or share any Confidential Information.

6. General Provisions.

Unless applicable law requires otherwise: (a) this agreement is governed by the laws of the State of Louisiana, excluding its conflict-of-laws principles; and (b) the exclusive venue for any dispute relating to this agreement will be New Orleans, Louisiana. Any amendments must be in writing. Failure to enforce any provisions of this agreement will not constitute a waiver. Section 5 will survive any termination of this agreement. You can contact your local data protection authority if you have concerns regarding your rights under local law.

7. Questions

If you have questions or concerns, if you want to withdraw from the Data Collection, or if you want to have your Research Data deleted, please contact ProjectInsight@TeamGleason.org. The subject of your email should be “Request for Project Insight Data Collection and your email should include enough information so that the Team Gleason Foundation can identify the Research Data collected from you (if applicable).

Participant Full Name (Print)

Date Signed

Participant (Or Legal Representative) Signature