



- SPECIAL OLYMPICS DATA REQUEST AND PROJECT PROPOSAL FORM

## 1. Background Information

Special Olympics International (“SOI”) makes available various data for use in research regarding people with intellectual disabilities, including de-identified data of Special Olympics participants’ health and non-identifiable data of the general population on attitudes. Access to data is subject to: (1) Institutional Review Board approval of the requesting researcher’s project, where applicable (2) the researcher’s agreement to and compliance with the Terms of Responsible Use outlined below, and (3) SOI’s approval, in its sole discretion, of the researcher’s qualifications and project proposal. **Please note, data users must hold at least a Masters level degree or higher to gain access to these data.** If the primary requestor is an undergraduate student or currently pursuing a Masters level degree, SOI requires that the resume or CV of an advisor, mentor, or supervisor with at least a Masters level degree also be submitted.

### Institutional Review Board (“IRB”) Approval, Where Applicable

College and university IRBs review research proposals in order to safeguard human subjects who participate in research. Because confidentiality and disclosure risk limitation is a primary concern of IRB review, some IRBs exempt analysis of de-identified data. SOI requires researchers requesting access to SOI data to provide an IRB approval confirmation or evidence that review is exempted by the researcher’s IRB. Please attach documentation of IRB approval or exemption with your request where indicated on this form.

### One-Time Use Policy

It is SOI’s policy to provide the best, most current, and most relevant data available for each approved project. As a result, SOI approves data proposals for a term of one (1) year, and generally does not allow researchers to “recycle” the same data for multiple research projects. Instead, users are required to delete data after completing each project. For each new research project, a new request must be submitted and approved. Any exception to this policy must be approved in writing by SOI.

#### **Special Olympics**

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## 2. Terms of Responsible Use

Users of SOI data and data collection tools agree to:

- Securely store data in order to prevent access by unauthorized individuals.
- Make every reasonable effort to use appropriate methodology and interpret data accurately.
- Use the data and/or data collection instruments only for the purpose detailed in the approved project proposal.
- Use data only for statistical analysis and reporting of aggregated information. Investigation of specific individuals is strictly prohibited, except as authorized in writing by SOI.
- Not release data and data collection instruments to third parties, except as approved in writing by SOI.
- Submit a new proposal to Special Olympics for approval if you decide to change your research question, topic, or any other information outlined in this proposal.
- Notify Special Olympics of your intent to publish or present any findings from the use of these data or data collection instruments via submission of draft manuscripts/posters/presentations for review with a minimum of two weeks allowed to Special Olympics for review and approval of drafts.
- Acknowledge Special Olympics in publications or presentations (specific language will be provided based on the method of sharing results). If you are using attitudes data, Kantar Millward Brown should also be acknowledged (specific language will be provided). If statistical assistance is provided, you agree to list the Special Olympics employee as a co-author.
- Destroy all copies of data files – including hard copy, electronic, and backups -- within six months after completion of research, except as approved in writing by SOI.
- Not use the data for commercial purposes.
- Not use the data in a way that is derogatory to Special Olympics, Special Olympics participants, or people with intellectual disabilities (for more information on appropriate terminology, please see our style guide<sup>1</sup>)
- Obtain written approval from SOI and the relevant national Special Olympics Program before publishing data specific to a national Program.
- Comply with any request by SOI to correct, delete, or update the data.
- Notify SOI promptly about: (i) any request for disclosure of the data by a law enforcement authority, (ii) any material violation of these Terms of Responsible Use, and (iii) any access to the data by unauthorized third parties.
- Hold harmless, release and indemnify Special Olympics, Inc. and all other Special Olympics organizations from any and all claims and liabilities arising from the use or release of the data by the undersigned user.

**CERTIFICATION:** By signing below, I understand and agree to my obligations as a responsible user of the data provided to me by Special Olympics. All data users must sign this form.

Name:	Signature:
Date:	

<sup>1</sup> 2018 Special Olympics Style Guide available at: <https://media.specialolympics.org/resources/brand-awareness-and-communication/marketing/Special-Olympics-Style-Guide.pdf>.

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### 3. Overview of Available Data

Below is a brief description of the data that can be requested.

#### Healthy Athletes Data

Since Special Olympics implemented the Healthy Athletes program in 1997, data have been collected, aggregated and analyzed to improve screenings and follow-up care, strengthen prevention programming, and inform improvements in the overall health system. Special Olympics currently holds the world's largest database on the health of people with intellectual disabilities. Data are available for six of the eight disciplines (see addendum below on MedFest and Strong Minds data), which combined total nearly one million observations. A data dictionary is available upon request.

#### Fitness Data

Special Olympics currently endorses three fitness models developed by SO Programs: Unified Fitness Club, Fit Families, and SOFit. The available fitness data was collected by SO Programs who implemented one of these three models and dates back to May 2016. Data are available on over 4,000 participants, and include biometric measures (height, weight, resting heart rate, blood pressure) behavioral measures, and measures evaluating physical activity. A data dictionary is available upon request.

#### Attitudes Data

In 2017, Special Olympics embarked on a Global Attitudes research project, conducted by Kantar, to understand the role of attitudes in promoting inclusion of people with intellectual disabilities. The main component of this project was a survey of the general population to measure implicit and explicit attitudes towards inclusion of people with ID. This Global Attitudes Survey, conducted from October 2017 to March 2018, was given to over 35,000 adults globally (included countries: USA, Austria, Belgium, China, Finland, Germany, India, Ireland, Japan, Malta, Mexico, Panama, Poland, Romania, South Africa, UAE, and the United Kingdom). Global and market-specific data can be requested, as well as the data collection instrument.

If you are planning to utilize the tool to implement/replicate the survey in your community, we strongly encourage you to work with Kantar Millward Brown; this will ensure consistency in the methodology of data collection, and will allow the data you collect to be compiled with existing data. Upon approval of your request, we will connect you with our contact at Kantar. If you are unable to use Kantar for survey implementation, please explain why in the form below.

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Name		Contact Number	
University/Institution			
Email Address			
Please upload your IRB approval or exemption for this project.	IRB approval or exemption		
Which data are you requesting? (required)	<input type="checkbox"/> Healthy Athletes <input type="checkbox"/> Fitness programming data (health data from SO Fitness model grants) <input type="checkbox"/> SOI Global Attitudes Survey data <input type="checkbox"/> SOI Global Attitudes Survey instrument		
If you are requesting Healthy Athletes data, which disciplines are you requesting?	<input type="checkbox"/> Fit Feet <input type="checkbox"/> FUNfitness <input type="checkbox"/> Health Promotion <input type="checkbox"/> Healthy Hearing <input type="checkbox"/> Opening Eyes <input type="checkbox"/> Special Smiles *See Addendum 4 for information about sharing MedFest and Strong Minds data		
If you are requesting Attitudes survey data, which markets are you requesting?	<input type="checkbox"/> All markets <input type="checkbox"/> USA <input type="checkbox"/> Austria <input type="checkbox"/> Belgium <input type="checkbox"/> China <input type="checkbox"/> Finland	<input type="checkbox"/> Germany <input type="checkbox"/> India <input type="checkbox"/> Ireland <input type="checkbox"/> Japan <input type="checkbox"/> Malta <input type="checkbox"/> Mexico	<input type="checkbox"/> Panama <input type="checkbox"/> Poland <input type="checkbox"/> Romania <input type="checkbox"/> South Africa <input type="checkbox"/> United Arab Emirates <input type="checkbox"/> United Kingdom
If you are requesting the Attitudes survey instrument, are you planning to work with Kantar Millward Brown to implement?	<input type="checkbox"/> Yes, please connect me with your contacts at Kantar <input type="checkbox"/> No, I am not planning to work with Kantar  If you selected No, please explain:		

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<p>Data specifications requested <i>(Please include dates, timeframes, geographic regions or other specifications that will be a focus of the analysis)</i></p>	
<p>What is the research question or objective to be answered by data collection or data analysis?</p>	
<p>How will you use the findings of this data collection or data analysis?</p>	
<p>How do you plan to share or disseminate findings? (required)</p>	<p><input type="checkbox"/> Journal Publication (name of journal, if known)</p> <p><input type="checkbox"/> Conference Presentation (name of conference, if known)</p> <p><input type="checkbox"/> Conference Poster (name of conference, if known)</p> <p><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> Don't Know</p>

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<p>Please list other individuals who will have access to the data and the reasons they need access (i.e., students).</p>		
<p>Are you currently an undergraduate student or pursuing a Master's degree?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No	
<p>Please attach your resume or CV.</p>	<p>Personal Resume/CV</p>	<p>Resume/CV of mentor or advisor</p>
<p>Permission to publish research question and contact information</p>	<p><i>In an effort to promote collaborative, non-repetitive research, SOI's Research and Evaluation Department shares a list of current, ongoing research projects conducted internally and externally. If you do not want this information shared, please check the box below to opt out.</i></p> <p>I do not wish to have my research question and contact information shared to promote collaborative, non-competitive research.</p>	

#### **4. ADDENDUM: Data Sharing Protocol for MedFest and Strong Minds Data**

##### MedFest

Special Olympics created MedFest to offer the physical exam that all athletes need to complete prior to participating in Special Olympics sports programming. The MedFest screening consists of several stations, including medical history, height and weight, blood pressure, a cardiology test, a musculoskeletal test, orthopedic tests, and an abdominal evaluation. While Special Olympics sometimes offers MedFest as part of its Healthy Athletes events, from a data collection and analysis perspective, MedFest is not like the other disciplines in the following ways:

- MedFest data contains highly sensitive medical information on athletes.
- MedFest data is not stored in the same data management system as the other disciplines and is therefore difficult to obtain at this time.
- MedFest data is entered by Program volunteers who are interested in collecting the data to establish whether an athlete may safely participate in Special Olympics sports. Therefore, the other medical data that is on the form may not be entered completely, but rather used to generate a recommendation for participation. Often, this results in incomplete athlete data.

Due to the differences outlined above, Special Olympics does not have the capacity to share MedFest data at this time. While the medical form contains rich information about the health status of Special Olympics athletes, it is not yet ready to be shared with external researchers in any capacity. However, it is the intention of Special Olympics to share this data with interested external researchers when it is ready to be shared for the purposes of analysis. If you are interested in being notified when this data is available, please send an email indicating your interest to [research@specialolympics.org](mailto:research@specialolympics.org).

##### Strong Minds

As Strong Minds is still in the early phases of development, Special Olympics cannot yet share the raw de-identified data in any capacity. When more data becomes available, it is the intention of Special Olympics to provide raw de-identified Strong Minds data to interested researchers. Currently, aggregate summary reports are available from select Strong Minds events. If you are interested in this type of data, please contact [healthdata@specialolympics.org](mailto:healthdata@specialolympics.org).

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**5. ADDENDUM: Additional signing forms for data users**

Please note, all data users must submit a signed certification using the form below to acknowledge the obligations as a responsible user of these data.

**CERTIFICATION:** By signing below, I understand and agree to my obligations as a responsible user of the data provided to me by Special Olympics. All data users must sign this form.

Name:	Signature:
Email address:	
Date:	

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## 6. Agreement Expiration: Destruction of Data

All data users whom signed at the beginning of the agreement must also sign to acknowledge its termination after one (1) year. All users must also confirm destruction of all form of any Special Olympics' data that pertain to this request.

**CERTIFICATION:** By signing below, I acknowledge the termination of this agreement and destruction of all Special Olympics' data pertaining to this request. All data users must sign this form.

Name:	Signature:
Date:	

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