Guidelines for sharing data from the Paralympic Injury and Illness Surveillance System

IPC Medical & Scientific Department

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1. The Paralympic Injury and Illness Surveillance System (ISS) is a long term, longitudinal project designed to characterize, document and disseminate information about injuries and illnesses that occur among Paralympic athletes. The Paralympic ISS is also intended to help inform the design, implementation and testing of injury and illness prevention strategies.

2. The International Paralympic Committee (IPC) welcomes and promotes collaborative scientific efforts with colleagues around the world.

3. The International Paralympic Committee and the IPC Medical Committee adhere to the international ethical guidelines for conducting research and the IPC Medical Code with regard protecting athletes’ health information.

4. In the spirit of maintaining the highest ethical and privacy standards, while simultaneously promoting collaborative efforts with medical and scientific colleagues around the world, the IPC delineates the following protocol for sharing research data:

I. Requests for data from the Paralympic ISS will only be considered from an official medical or scientific representative from a National Paralympic Committee or International Sports Federation.

II. Requests for de-identified data shall go to the IPC Medical Committee.

III. Collaborators must sign an agreement with the IPC indicating, in detail, exactly which data they are requesting, and what their intended uses are.

IV. A National Paralympic Committee may request data only on the athletes competing for that NPC.

V. An International Sports Federation may request data only on athletes competing in the sports supervised by that International Federation.

VI. The request for data must be accompanied by a written summary of the research or clinical protocol.
VII. If the intended use of the data is for research purposes, collaborators must obtain Ethics Board approval for their research from their host academic institution. Documentation of Ethics Board approval must accompany the request for data.

VIII. Researchers must collaborate with at least one member of the Paralympic ISS research team (the IPC holds the authority to select the IPC Medical Committee member who will be the collaborator on any data sharing that will be utilized for research) on their project. The purpose of this collaboration is so that the IPC can insure appropriate use of the data, including appropriate protection of athlete privacy.

Contact person to initiate data sharing agreements:
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