

*Informed Consent Form to Participate in a Research Study- COACHES*

**Study Title:** Understanding the health & wellness needs of athletes living with intellectual & developmental disabilities

**Principal Investigator:** Dr. Amy McPherson, PhD, Bloorview Research Institute, & University of Toronto

**Co-Investigator:** Dr. Yani Hamdani, PhD, Bloorview Research Institute, & University of Toronto

**Sponsor/Funder(s):** Mitacs, and Special Olympics Canada

November 7, 2017

Dear Coach,

My name is Amy McPherson. I am leading a research team that wants to know more about how athletes stay healthy in different areas of their lives. We would like to invite you to take part in this research study. We want to find out what athletes have done/are doing to live a healthy lifestyle outside of playing sports with Special Olympics Canada (SOC). This study will give SOC the information they need to create programs and tools to keep athletes happy and healthy!

Before agreeing to take part in this study, it is important that you understand how you will be involved. This consent form provides you with information to help you make an informed choice.

**What is the study about?**

We will be inviting SOC coaches, athletes (14 to 25 years of age) and parents/guardians to participate in interviews about the health and wellness of athletes. We will ask all participants to answer questions about athletes' wellness successes and goals. "Wellness" can take many shapes and forms. It can be how athletes deal with different emotions, how often they do activities outside, how they feel about themselves, and lots more! We want to know what areas of wellness SOC athletes are really great at. We also want to know which areas of wellness SOC athletes might be working on.

SOC and Special Olympics Ontario have provided funding for this study. They are hoping to learn more about the holistic health and wellness needs of their athletes in order to start working towards developing interventions and tools, to better help athletes achieve their wellness goals.

Our goal is to interview between 12 to 20 coaches for our study.

**How will I be involved in this study?**

You will meet with a Researcher for an in-person interview if you are located in the Greater Toronto Area (GTA) or by telephone if you are located outside the GTA. She will explain the study to you and answer any questions you have. This can happen before or after a Special Olympics event or practice or at time convenient for you. The Researcher will ask you questions about your perspective on wellness and goal-setting for athletes. You can choose to not answer some of the questions if you wish. The Researcher will record all of your answers using a digital audio-recorder. It will take about 45 to 60 minutes.

**Will anyone know what I say?**

All the information we collect about you will be kept confidential. We will use a pseudonym instead of your real name in the interview transcripts.

We will not make public anything that might identify you, unless legally required to do so. For example, the law requires us to give information about you:

- If a child has been abused;
- If you have an illness that could spread to others;
- If you or someone else talks about suicide (killing themselves);
- If the court orders us to give them the study papers.

Authorized representatives of the following organizations may look at your original (identifiable) research records at the site where these records are held.

- The Holland Bloorview Research Ethics Board who oversees the ethical conduct of this study
- Holland Bloorview representatives to check that the information collected for the study is correct and follows proper laws and guidelines.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your prior agreement. We will use a pseudonym for your name and any details about you will remain private and anonymous. We must keep the research data we collect for 7 years after study completion as required by Holland Bloorview.

**Do I have to do this?**

You do not have to take part in this study. Your decision will not affect your employment or involvement with SOC. If you decide to take part in this study, you can change your mind and stop at any time. If there are any questions that you are uncomfortable with, you don't have to answer those questions. Please note that you will be unable to withdraw your responses after the results have been analyzed. This is because the research team will not be able to identify responses once they are combined with the responses from other people participating in the research.

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information and we will ask you if you still want to be in the study.

**What are the risks and benefits?**

There are no known risks or immediate benefits to participating in this study. However, this study is the first step towards learning more about the wellness strengths and goals of SOC athletes.

If you decide to take part in this study, you will not waive your legal rights in the event of any research-related harm.

**What will happen with the results of the study?**

The results from this study will be shared through article publications and presentations. We will combine the data we collect and provide a report to the SOC. In addition we expect the results to be posted in the form of research summaries on the Special Olympics Canada and provincial chapters' websites.

You will only be asked to provide your personal contact information if you would like to know the results of this study after it has been completed.

**Do the investigators have any conflicts of interest?**

I, Amy McPherson, and the other research team members have no conflicts of interest to declare related to this study.

**Reimbursement:**

You can be entered in a draw to receive one of two \$75 gift cards.

**What if I have questions?**

If you have any questions, comments or concerns that you wish to bring to the Principal Investigator, please contact Amy McPherson at 416-425-6220, x 6378 or by email at [amcpherson@hollandbloorview.ca](mailto:amcpherson@hollandbloorview.ca).

If you have any questions, comments or concerns regarding your rights as research participant, please contact the Research Ethics Board at 416-425-6220 x3507 or toll free at 800-363-2440 or by email at [reb@hollandbloorview.ca](mailto:reb@hollandbloorview.ca)

**How do I participate?**

If you want to be a part of this study, you can contact Yani Hamdani by email at [yhamdani@hollandbloorview.ca](mailto:yhamdani@hollandbloorview.ca) or by phone at 416-425-6220 ext. 3583.

Thank you for thinking about helping us with this research study.

Yours truly,

Amy McPherson, PhD,  
Scientist and Principal Investigator,  
Bloorview Research Institute  
Holland Bloorview Kids Rehabilitation Hospital

Yani Hamdani, PhD,  
Postdoctoral Fellow and Co-Investigator,  
Bloorview Research Institute  
Holland Bloorview Kids Rehabilitation Hospital



INFORMED CONSENT FORM  
 HOLLAND BLOORVIEW KIDS REHABILITATION HOSPITAL

**Re: Understanding the health & wellness needs of athletes living with intellectual & developmental disabilities**

Please complete this form below and return it to the researcher. You will receive a signed copy of this form.

By signing this form, I confirm that:

- A member of the research team explained this study to me and answered all of my questions.
- I read the attached Informed Consent Form dated November 7, 2017 and understand what this study is about.
- I understand the known risks and benefits of participating in this research study.
- I understand that I may drop out of the study at any time. My decision about taking part in the study will not affect my employment or involvement with SOC.
- I am free now, or in the future to ask questions about the study.
- I know that study records related to me will be kept confidential except as described in this form.
- I understand that information that identifies me will not be shared with anyone without first asking my permission
- I agree to participate in this study.

Coach Participant's Name (please print)	Signature	Date
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I have explained this study to the above coach and have answered all their questions.

Name of Person Obtaining Consent	Signature	Date
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