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## Maximizing the use of Special Olympics International's Healthy Athletes database: A call to action

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### ABSTRACT

There is a critical need for high-quality population-level data related to the health of individuals with intellectual disabilities. For more than 15 years Special Olympics International has been conducting free Healthy Athletes screenings at local, national and international events. The Healthy Athletes database is the largest known international database specifically on the health of people with intellectual disabilities; however, it is relatively under-utilized by the research community. A consensus meeting with two dozen North American researchers, stakeholders, clinicians and policymakers took place in Toronto, Canada. The purpose of the meeting was to: 1) establish the perceived utility of the database, and 2) to identify and prioritize 3–5 specific priorities related to using the Healthy Athletes database to promote the health of individuals with intellectual disabilities. There was unanimous agreement from the meeting participants that this database represents an immense opportunity both from the data already collected, and data that will be collected in the future. The 3 top priorities for the database were deemed to be: 1) establish the representativeness of data collected on Special Olympics athletes compared to the general population with intellectual disabilities, 2) create a scientific advisory group for Special Olympics International, and 3) use the data to improve Special Olympics programs around the world. The Special Olympics Healthy Athletes database includes data not found in any other source and should be used, in partnership with Special Olympics International, by researchers to significantly increase our knowledge and understanding of the health of individuals with intellectual disabilities.

### What this paper adds

This paper is a “call to action” paper developed after a consensus meeting regarding the utility of the Special Olympics International Healthy Athletes database. Priorities are identified and recommendations for improvements to the database are presented.

### 1. Introduction

Decision makers need high quality data to make informed choices; whether their decisions are made at a broad policy level affecting whole populations, or at the level of the individual (Lin et al., 2014). Furthermore, the data used to drive health promotion

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agendas, health treatment plans, or health policy initiatives needs to be directly relevant to the population of interest. For example, there are physical activity guidelines for children and youth 5–17 years of age (World Health Organization, 2010), which differ significantly from the guidelines for individuals over the age of 65 (World Health Organization, 2010). However, for people with intellectual disabilities, health decisions both at a policy level and at an individual level are often made based on data or information from the general population. One reason for this is a lack of high quality, population level, data on the health status of individuals with intellectual disabilities (Lin et al., 2014; Lunskey, Klein-Geltink, & Yates, 2013). Much of what is known about the health status of people with intellectual disabilities comes from small scale studies conducted in developed countries (e.g. United Kingdom, USA, Australia, Canada) (Emerson & Hatton, 2014; Lloyd, Foley, & Temple, 2014; Temple, Foley, & Lloyd, 2015). Quality population-level information is needed to fully understand the health status, including health disparities, of various sub-sets of the population, and to develop health promotion initiatives that can be measured over time.

While people with intellectual disabilities make up a relatively small portion of the overall population, the proportion of people with intellectual disabilities in the population is rising (Lunskey et al., 2013; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; Westerinen, Kaski, Virta, Almqvist, & Iivanainen, 2007). Additionally, people with intellectual disabilities consistently experience high levels of health disparities (Cooper, Melville, & Morrison, 2004; Emerson & Hatton, 2014; Krahn, Hammond, & Turner, 2006; Lunskey et al., 2013). These health disparities include, but are not limited to, high rates of obesity (Lloyd et al., 2014; Temple et al., 2015), and diabetes (Balogh, Lake, Lin, Wilton, & Lunskey, 2015), high rates of congestive heart failure, chronic obstructive pulmonary disease, and asthma (Lunskey et al., 2013). Females with intellectual disabilities also have even higher health risks than their male counterparts (Balogh et al., 2015; Foley, Lloyd, & Temple, 2013; Lloyd, Temple, & Foley, 2012; Temple, Foley, & Lloyd, 2014), and receive fewer preventative health screenings than the general population (Lunskey et al., 2013). Further, people with disabilities use health care services far more than the general population, especially emergency rooms (Lunskey et al., 2013; Meerding, Bonneux, Polder, Koopmanschap, & van der Maas, 1998; Newacheck & Kim, 2005; Ward, Nichols, & Freedman, 2010); yet this population consistently experiences challenges accessing health care services (Ali et al., 2013). The patterns of health needs, and causes of death, differ for people with intellectual disabilities (Cooper et al., 2004). While there is convincing evidence of health disparities; there is little high quality scientific evidence relating to the health of people with intellectual disabilities, particularly from an international public health perspective (Lin et al., 2014; Lunskey et al., 2013). A meeting hosted by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (Bandini et al., 2015) resulted in a consensus statement highlighting the importance, and need, for high quality health research to develop the evidence base and identify best practices for both health promotion activities, and healthcare service delivery for individuals with disabilities.

### 1.1. Existing health surveillance of individuals with intellectual disabilities

Important health policy decisions are often informed by evidence from large cross-sectional or longitudinal surveillance; for example the National Health and Nutrition Examination Survey (NHANES) in the United States, the Canadian Health Measures Survey (CHMS) in Canada, or surveys distributed by the World Health Organization. However, individuals with intellectual disabilities are often under-reported, excluded, or inaccurately identified in national and international health surveillance (CDC/NCBDDD, 2009). In current large-scale health surveys, people with intellectual disabilities may be significantly under-represented due to sampling strategies (Emerson & Hatton, 2014). For example, the CHMS only samples people "...living in private households at the time of the survey. Residents of Indian Reserves or Crown lands, institutions and certain remote regions.... are excluded" (Tremblay et al., 2010, p. 8). While the CHMS does not specifically *exclude* people with intellectual disabilities, it does exclude people who live in community based assisted living homes (group homes) and does not account for proxy reporting if an individual with an intellectual disability is not able to answer a question or perform a particular measurement in a traditional format. Consequently, this limits the number of people with an intellectual disability who participate.

Analysis of administrative health records is an alternative to large-scale health surveillance, where available (Lin et al., 2014; Safran et al., 2007). However, this method is also wrought with identification issues and often focuses on health care utilization and prevalence of specific medical conditions (e.g. diabetes prevalence or emergency room visits) (Lunskey et al., 2013; Safran et al., 2007). The recent release of the *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* is an excellent example of how administrative health databases have been used to greatly further our understanding of the health individuals with developmental disabilities (Lin et al., 2014; Lunskey et al., 2013). This document focuses on prevalence estimates in Ontario, Canada describing the health status of adults with a developmental disability, health care utilization, and it examines how consistent their health care is in relation to the primary care guidelines. However, this document has focused on adults only, and is limited in its scope to Ontario (just one province in Canada) (Lunskey et al., 2013). Finally, large administrative databases are usually not able to examine the effects of health promotion initiatives (e.g. healthy eating, physical activity promotion, etc.), due to the constraints of what data is included in administrative health databases. Consequently, this limits the ability to use this data to understand how best to promote the health of individuals with intellectual disabilities, or to evaluate the effectiveness of a given health promotion program.

### 1.2. Special Olympics International Healthy Athletes database

Special Olympics is an international sport organization that provides year round opportunities for individuals with intellectual disabilities to engage in sport and physical activity opportunities (Special Olympics International, 2012, 2016b). For more than 15 years, Special Olympics International has been conducting free "Healthy Athletes" screenings to participants. The Healthy Athletes program conducts screenings in seven discipline areas: *Fit Feet* (podiatry), *Healthy Hearing* (audiology), *Special Smiles* (dentistry),

*Opening Eyes* (vision), *FUNfitness* (physical therapy), *Med Fest* (general health checkups) and *Health Promotion* (health and wellbeing) (Special Olympics International, 2012, 2016b). Within each discipline, trained health professionals conduct these screenings at local, regional, national, and international events around the world. In addition to the screenings, this program provides education and referrals for follow-up care for Special Olympic athletes at local, national, and international events (Special Olympics International, 2012, 2016b). More than 1.9 million health screenings have been conducted in over 135 different countries through the Healthy Athletes program (Special Olympics International, 2016b). After each screening event, the de-identified data is entered into the Healthy Athletes database; which is held, and managed, by Special Olympics International exclusively. Before participation in Special Olympics events, athletes and/or their guardians sign a consent form which includes consent for the de-identified data to be used to report on the health of Special Olympics athletes (Foley et al., 2013; Lloyd et al., 2012; Special Olympics International, 2012; Temple et al., 2014). It is important to note that parents, guardians and/or the athletes themselves specifically provide written consent in the consent forms for the data collected in Healthy Athletes screenings be used, in a de-identified and aggregate format, by researchers to understand the health of people with intellectual disabilities. In order to analyze and publish the data, researchers must complete a full research ethics review at their respective institutions and submit the approvals to Special Olympics International before any data is released for analysis.

The Healthy Athletes database is the largest known international database specifically on the health of people with intellectual disabilities. These data are strengthened by the fact that most of the items in each discipline are directly measured (Foley et al., 2013; Jenkins, Cooper, O'Connor, & Watanabe, 2012; Jenkins, Cooper, O'Connor, Watanabe, & Wills, 2011; Lloyd et al., 2014; Temple et al., 2015). While there is a dearth of information about the health status of people with intellectual disabilities in developed countries, the data is even more scarce in the developing world (e.g. Africa, South America) (Fujiura, Park, & Rutkowski-Kmitta, 2005). To better understand the health status of individuals with intellectual disabilities, data must be collected from as many regions of the world as possible to reflect the full diversity of this population. This is one aspect of the Special Olympics Healthy Athletes database that sets it apart from other administrative health databases; the screenings are conducted all over the world, thereby providing health information on people with intellectual disabilities from regions where virtually no data exists (Foley, Lloyd, Turner, & Temple, 2017; Lloyd et al., 2014; Temple et al., 2015).

Despite the rich data which has been collected over the past 15 years, there has been relatively limited dissemination of the results, particularly in the peer reviewed published literature. Special Olympics International has recently worked with research scientists who are interested in specific health questions that the Healthy Athletes dataset is able to answer. For example, on the topics of obesity and underweight, a team of researchers partnered with Special Olympics International to analyze the height and weight data collected in the Health Promotion discipline from all over the world. As a result, several published papers have greatly increased our understanding of the global prevalence of both underweight and obesity in this population (Foley et al., 2013; Foley, Lloyd, Vogl, & Temple, 2014; Lloyd et al., 2014; Lloyd et al., 2012; Rintala, Temple, Lloyd, Faro, & Foley, 2017; Temple et al., 2014, 2015). Data from the Fit Feet discipline (podiatry) have also been published in the peer review literature demonstrating that Special Olympics athletes are at increased risk of structural conditions in the feet that negatively impact gait, and that approximately 40% Special Olympics athletes wear shoes that do not fit (Jenkins et al., 2012; Jenkins et al., 2011). All these published papers received institutional research ethics permission from the respective authors' institutions to analyze the Healthy Athletes data. Despite the relative success on the topic of obesity and foot health, the Healthy Athletes database has not been widely employed by the research community to provide research to inform public health decision making. Over the past 15 years, Special Olympics International has been working to build active and meaningful collaborations amongst researchers, community stakeholders, medical professionals, and knowledge users to promote the health of individuals with intellectual and developmental disabilities through initiatives such as Healthy Athletes, but also Healthy Communities (Special Olympics International, 2016a). To drive this agenda forward, we held a one-day consensus-building stakeholder meeting to identify key recommendations for the use of the Special Olympics International Healthy Athletes Database.

### 1.3. Specific aims of stakeholder meeting

The primary aim of the meeting was to engage a multi-disciplinary group of key stakeholders to: 1) establish the perceived utility of the database, by the gathered experts, to answer research questions related to the health of individuals with intellectual disabilities, and 2) identify and prioritize 3–5 specific priorities related to using the Healthy Athletes database to promote the health of individuals with intellectual disabilities. Secondary aims included providing input to enhance the existing processes of data collection, data entry, as well as analysis and dissemination strategies for the Special Olympics International Healthy Athletes database built upon the priorities identified.

## 2. Methods

### 2.1. Meeting description

#### 2.1.1. Attendees

The meeting was one full day in Toronto, Canada with 19 invited attendees. All participants were from North America and represented the research community ( $n = 8$ ), Special Olympics International ( $n = 2$ ), Special Olympics Canada ( $n = 2$ ), Special Olympics Ontario ( $n = 2$ ), health professional (physician) ( $n = 1$ ), policy/government representatives ( $n = 2$ ), Special Olympics athlete ( $n = 1$ ), and a community partner ( $n = 1$ ). In addition to the attendees, there was one professional facilitator and two note-

takers participating in the program. Attendees were identified based on their affiliation (e.g. Special Olympics), established expertise in the health of individuals with disabilities, or their history publishing with the Healthy Athletes data (e.g. researchers, physicians), as well as their geographic location due to budgetary constraints.

### 2.1.2. Agenda and activities

Multiple methods were employed to guide the activities and discussion during the one-day meeting led by a professional facilitator external to the research team. The meeting began with two presentations followed by a pre-arranged panel response to the presentations. The first presentation was by the Director of Research and Evaluation from Special Olympics International where the Healthy Athletes program and the databases were explained in detail providing historical context as well as current practice. The strengths and limitations of the data were described from the perspective of Special Olympics International as well as their vision for the future of the database. The second presentation was by Dr. Gloria Krahn, internationally renowned health researcher and advocate for people with intellectual disabilities. She challenged the group to consider 1) how this data could be useful for improving the health as well as the lives of people with intellectual disabilities, 2) what data are needed to make a difference, and 3) how to ensure the quality of the data so interested stakeholders can maximize its use and impact. Following the two presentations, a panel of three participants individually responded to the two presentations with each member providing his/her perspective on the ability of the Healthy Athletes database to meaningfully contribute to increasing our scientific knowledge related to the health of individuals with intellectual disabilities. Following the panel responses, a discussion moderated by the facilitator aimed to elicit a diverse set of reactions to the information presented by the meeting participants linked to the specific aims of the meeting. This discussion centered on recommendations to strengthen the data for future use and dissemination.

Following the discussion, there was unanimous agreement that the Healthy Athletes database represents an incredibly unique opportunity to understand the health, and improve the lives of people with intellectual disabilities. With this agreement, participants were tasked with determining what needed to be done to realize the potential of this database. Participants formed breakout groups and were tasked with addressing the following questions: 1) Identify at least three priorities for the use of the Healthy Athletes database, and 2) describe why these priorities are important. The priorities from each small break-out group were presented to the entire group before breaking for lunch.

To ground the discussions in an athlete-centered perspective, and to emphasize how this data has the potential to actually help real people (King & Chiarello, 2014), at the lunch break the group heard from a local Special Olympics athlete who spoke from her perspective about how the Healthy Athletes program had impacted her life. Following the lunch-break, the participants regrouped to further discuss and record the priorities proposed in the morning and to identify the challenges and opportunities in fulfilling these priorities for the database. The afternoon session centered on consensus building and further delineating the importance of the identified priorities and establishing the top priorities as a group. Following the conclusion of the one-day meeting, the research team brought the identified priorities to two international disability health conferences to gain further input and consensus from an even wider audience (approximately 80–100 participants). Based on this extensive consultation by members of the 1-day meeting, as well as input from the experts at the 2 international disability health conferences, 3 of the identified priorities were deemed by the authors to be critical. This wider consultation served to triangulate the priorities and gain maximum input from a more diverse audience.

## 3. Results

### 3.1. Specific Aim 1: utility of the databases

The first specific aim was to establish whether the group of gathered experts perceived the Healthy Athletes database to be useful in answering research questions related to the health of individuals with intellectual disabilities. During the first presentation by Special Olympics International, background information related to the Healthy Athletes program, and database, was presented to ensure the group was fully informed on the status, depth, and breadth of the data. The Healthy Athletes database is different from other international health databases available to researchers because most of the screenings in each discipline are directly measured. For example, in the Opening Eyes discipline, participants have their vision tested for acuity by trained health professionals; they also screen the athletes for signs of disease. After the screenings take place, the athletes are provided with education and referral information to bring to their local health provider for follow up if necessary. Unlike other international health databases where surveys are distributed at specific time intervals in the form of self-report questionnaires, Healthy Athletes screenings occur around the world on a regular basis and the data is regularly entered into the Healthy Athletes database. Special Olympics International presented the information and the expert members of the group unanimously agreed that the Healthy Athletes database demonstrates a very unique opportunity for researchers and clinicians interested in the health of individuals with intellectual disabilities. The strengths and limitations of the data and the database were also discussed by the group (Table 1).

Special Olympics International reported that many of the limitations of the data, and the database, were being addressed with the selection of a new vendor for the data management system. Special Olympics International presented that the new system will allow for unique identifiers as well as tracking of athletes across Health Athletes disciplines and over time using personalized health records that the athletes themselves can access; however, these unique identifiers cannot be retrospectively added to data that has already been collected. Special Olympics International is also in the process of upgrading to a paperless data collection system at major Healthy Athletes events, which will attempt to minimize data entry errors reducing the burden of cleaning the data. Special Olympics International also reported that events are increasing outside of North America, enhancing the global representativeness of the data.

From the panel responses and ensuing discussion, the two primary improvements that the meeting participants felt would have

**Table 1**  
Strengths and limitations of the Healthy Athletes database.

Strengths	Limitations
<ul style="list-style-type: none"> <li>– International scope</li> <li>– Directly measured data</li> <li>– Multi-disciplinary data</li> <li>– Sample size</li> <li>– Has been successfully analysed and published in the peer reviewed literature</li> </ul>	<ul style="list-style-type: none"> <li>– Lack of unique identifiers</li> <li>– Limited to athletes only</li> <li>– Data requires cleaning</li> <li>– Majority of data collected in North America</li> <li>– Volunteer driven</li> <li>– No etiology of intellectual disability information available</li> </ul>

the greatest impact on the Healthy Athletes database are: 1) unique identifiers, and 2) ensuring the quality of the data. There was agreement that it is critical to ensure that every participant who participates in a Healthy Athletes screening is identified once in the database (with a unique identifier); multiple screenings over multiple years, or at multiple events, need to link to that one individual person. Additionally, for the data to be trusted and depended upon within the scientific and medical communities there needs to be confidence in the quality, reliability, and replicability of the data. Even within the context of the limitations associated with this database, there was unanimous agreement from the meeting participants that this database represents an immense opportunity to understand the health of individuals with intellectual disabilities both from the data already collected, and data that will be collected in the future, and it should be used to its maximum capacity.

### 3.2. Specific Aim 2: identified priorities

The second aim of this meeting was to engage a multi-disciplinary group of key stakeholders to identify and prioritize 3–5 specific priorities related to using the Healthy Athletes database to promote the health of individuals with intellectual disabilities. The group identified six priority themes from the initial visioning exercises (see Table 2).

Following the one-day meeting, further consultations took place at two international disability health conferences and three themes emerged as the top identified priorities:

- 1) Establish the representativeness of data collected on Special Olympics athletes compared to the general population with intellectual disabilities
- 2) Create a scientific advisory group for Special Olympics International, and
- 3) Use the data to improve Special Olympics programs around the world.

## 4. Discussion

Health promotion is at the forefront of international health agendas (World Health Organization, 2009); and prominent within this dialogue is the reduction of health disparities of vulnerable populations, including people with intellectual disabilities (Krahn et al., 2006). High quality, population level data on this population is limited. Special Olympics International has taken a significant leadership role in addressing the health concerns of their athletes around the world, as well as collecting directly measured health data through their Healthy Athletes program (Special Olympics International, 2012). This consensus meeting provided an opportunity for a diverse group of professionals to discuss and prioritize recommendations for how the data collected in the seven Healthy Athletes disciplines could be utilized to maximize the impact of the data to promote the health of individuals with intellectual disabilities.

### 4.1. Establish the representativeness of the data

Meeting attendees believed it is critical to establish whether health data collected on people with intellectual disabilities who participate in Special Olympics can be generalized to the broader population of people with intellectual disabilities. The published literature using the Healthy Athletes data has consistently pointed out that by virtue of regularly engaging in physical activity/sport, Special Olympics participants *may* be healthier than their counterparts who do not participate (Foley et al., 2013; Lloyd et al., 2014; Temple et al., 2015); however this has not been empirically established. If Special Olympics participants are healthier, it is unclear whether this is because they were healthier before they joined Special Olympics (thereby more capable of participating), or whether the engagement in sport and physical activity promotes further health benefits. If health data on Special Olympics participants is determined to be representative of broader population, then the Healthy Athletes database could be used to answer many questions related to the health of individuals with intellectual disabilities. If the health data of Special Olympics participants is not deemed to be representative of the broader population, then critical information about the health promotion effects of engagement in sport and physical activity for individuals with intellectual disabilities could be learned from the Healthy Athletes database. Either way, the Healthy Athletes database holds information that is not found in any other data source and should be disseminated to promote the health of people with intellectual disabilities.

**Table. 2**  
Priority areas and considerations.

Priority Action	Importance and Considerations
Examine Representativeness of Data	<ul style="list-style-type: none"> <li>● Explore the similarities and differences between those participating in Special Olympics and those who are not participating with intellectual disabilities; compare to the general population without intellectual disabilities</li> <li>● Find other databases that exist to find similarities or trends</li> <li>● Identify what we know from previous publications and identify gaps</li> <li>● Can health data on Special Olympics participants be used to generalize to non-Special Olympics participants?</li> </ul>
Use Healthy Athletes data to inform program development	<ul style="list-style-type: none"> <li>● Program/Sport improvement via Special Olympics International, Special Olympics Canada, and other regional chapters should be based on evidence</li> <li>● Use international database to create more interest in other countries and among international researchers</li> <li>● Use data, and data collection opportunities, to create capacity with clinicians</li> <li>● Examine the programs with the most impact based on evidence.</li> <li>● Use data to improve policy development as well as sport development locally and nationally</li> </ul>
Link across existing datasets	<ul style="list-style-type: none"> <li>● Map Healthy Athletes datasets onto data sets that are not (comparison groups) (e.g. administrative databases)</li> <li>● Link data between healthy and non-healthy athletes to broaden beyond those just with ID.</li> <li>● Explore information related to urban, rural etc. as well as income level.</li> <li>● Once the data is linked it expands what can be done with the information</li> <li>● Look for data to compliment Healthy Athletes data and provide more information on SO athletes</li> <li>● Use data to access populations not particularly well represented e.g. First Nations</li> <li>● Compare quality of athletes health across linked databases</li> </ul>
Evidence-based impact of sport/physical activity participation	<ul style="list-style-type: none"> <li>● Identify Special Olympics participants and their level of participation related to health outcomes</li> <li>● We need to be able to understand how participation influences health, therefore we need to link athlete, sport, event, community to health outcomes.</li> <li>● Ask questions about the health of those in different regions outside of North America</li> <li>● Allows for understanding of health promotion effects of participating in Special Olympics</li> </ul>
Create a Scientific Advisory Group	<ul style="list-style-type: none"> <li>● Proposed to be a distinguished group with representation from inter-disciplinary perspectives</li> <li>● Drive scientific agenda of Special Olympics</li> <li>● Translational interventions guided by a Scientific Advisory Group</li> <li>● What is the impact of Special Olympics participation?</li> <li>● Impact of interventions?</li> <li>● Benefits to athletes and/or other populations and/or clinicians, educators and donors</li> <li>● Knowledge translation activities</li> <li>● Loop how data can be used to create interventions – get more funding for more research and data</li> <li>● Ensure separation of Special Olympics advocacy agenda to allow data to stand on its own (using a Scientific Advisory Group). Separation between those conducting research and providing service</li> </ul>
Data Curator/Custodian	<ul style="list-style-type: none"> <li>● A custodian for the data is needed</li> <li>● Data cleaning procedures and cut points</li> <li>● Determine country specific needs and opportunities</li> <li>● Provide expertise e.g. epi, legal/ethical/big data</li> <li>● Collect the data better, with increased standardization</li> <li>● Examine common data elements</li> <li>● Ensure quality</li> <li>● Oversee privacy and the release of information</li> <li>● Sharing data and being a gate keeper</li> <li>● Linked to a Scientific Advisory Group function</li> <li>● IT advisory group</li> <li>● Could be an academic institution and be a collaborative effort with Special Olympics International</li> <li>● Requires funding – who will fund it?</li> </ul>

#### 4.2. Scientific advisory group

The establishment of a scientific advisory group made up of representatives from many different disciplines was also identified as a top priority. A scientific advisory group was envisioned to be able to provide the best scientific advice to Special Olympics International related to the use of the Healthy Athletes data that already exists, and what new data is needed to answer pertinent questions from researchers, as well as from an organizational perspective. Special Olympics International already has several advisory groups (e.g. Health Advisory Group) that provide guidance and support for them to achieve their mission and vision; however, at this time they do not have a scientific advisory group to help achieve their goals related to the dissemination and understanding of the Healthy Athletes data. Evidence is needed to inform decisions, especially in health. Evidence is also a powerful tool for advocacy; whether it be in fundraising, policy development, or raising awareness of the critical issues this population faces (Potvin & McQueen, 2008). A scientific advisory group could help to determine the impact of interventions, benefits of various programs to the athletes, coaches, clinicians and educators. Additionally, this type of group could facilitate knowledge translation of results and ensure that the data is used to its maximum potential reaching the widest possible audience.

### 4.3. Program development

Meeting attendees agreed that program development should be driven by evidence. In today's climate of limited resources, high-quality evidence of effectiveness or outcomes has the potential to facilitate resource allocation to either sustain or expand programs (Potvin & McQueen, 2008). Special Olympics is primarily a sport organization, and the Healthy Athletes database could be used to evaluate the effectiveness of the different sport and physical activity programs offered internationally. For example, the FUNFitness discipline of Health Athletes includes measures of cardiovascular fitness, strength, balance, and flexibility. These basic fitness measures could be used to inform future athlete training or development programs in various sports, which could in turn increase athlete, or team, success. This type of information could also be used to determine the effectiveness of training and/or coaching programs that are in place and allow ongoing adjustments to promote success.

In addition to the relevance to sport programs, Special Olympics also has health promotion programs in place around the world and is committed to promoting the health of individuals with intellectual disabilities. Evidence indicates that the health of athletes with intellectual disabilities participating in Special Olympics differs in different regions of the world (Lloyd et al., 2012; Temple et al., 2014), and when evaluated by world economic status (Lloyd et al., 2014; Temple et al., 2015). Therefore, given its reach, Special Olympics health promotion programs have the potential to have a positive impact on the health of individuals with intellectual disabilities around the world. The Healthy Athletes program also provides direct intervention related to the health of participants beyond providing education to the participants. For example, in *Special Smiles* if a participant is found to have a dental concern in need of attention it is either treated onsite (e.g. World Games), or a referral to a local provider is made. Likewise, in *Opening Eyes* screenings, prescription eyeglasses are provided to those who need them. There is however, an increasing demand for health promotion programs to demonstrate their value with data (Potvin & McQueen, 2008), particularly in the peer reviewed literature. The data from the Healthy Athletes database has the potential to inform both sport and health promotion initiatives around the world.

### 4.4. Recommendations to improve the Healthy Athletes database

#### 4.4.1. Unique identifiers

The meeting participants agreed that the most important change to increase the usability and impact of the Healthy Athletes database is to include unique identifiers for all athletes. This will allow the participants to be more accurately followed over time, across Healthy Athletes disciplines, as well as linking to the sport(s) the athlete participates in. This one change would significantly increase the ability of the data to be used by researchers, but would also increase the capacity of the local Special Olympics chapters to track their participants over time and the different sports. Unique identifiers would allow researchers to answer questions related to the health promotion effects of participating in sport, patterns in the emergence of health disparities over time, as well as differences in health profiles based on world region, sex, or other determinants of health. In the first presentation of the day, Special Olympics International indicated that “unique identifiers” was a priority for their new data management system. They are aware that the greatest limitation of the data they have already collected and they are taking steps to solve this problem for the future. However, with over 5 million participants in Special Olympics around the world, to assign each athlete a unique identifier is a significant undertaking and will take time to fully implement.

#### 4.4.2. Ensuring consistency

The Healthy Athletes program is volunteer driven and the screenings happen in all corners of the world, and in settings with diverse resources (Special Olympics International, 2012). Despite significant efforts to train the volunteers and standardize the data collection procedures, there are challenges ensuring data consistency in both how it is collected, and how it is entered into the database. These challenges are not unique to the Healthy Athletes program, all large-scale health surveillance strives to standardize data collection and entry to ensure accuracy (Tremblay, Wolfson, & Connor Gorber, 2007). One simple example of the challenge is where certain parts of the world record dates as day/month/year, and other parts of the world who record dates as month/day/year – clinicians in different parts of the world may complete this field differently on paper forms. This is an example of how electronic or tablet data entry systems could minimize the problems. When analyzing the data, the researchers need to be sure that the dates were all recorded and entered the same way to ensure that participant date of birth is correct. The establishment of a formalized data curator or data custodian would be critical to ensuring consistency in the database. A data curator would be responsible for data cleaning, ensuring quality, provide expertise around ethical, privacy and epidemiological issues related to the Healthy Athletes database.

While it is clear that the Healthy Athlete volunteers are very well trained, it is also recommended that volunteers receive updated training at regular intervals to ensure that data collected through the Healthy Athletes screenings in the United States is collected the same way as Healthy Athletes data collected in Kenya, for example. Additionally, the meeting participants felt that reliability tests on the data should be implemented, when possible, to increase confidence in the data. A secondary outcome of ensuring the consistency of the data is that training and reliability checks can serve to build capacity in the volunteer-clinicians who participate in the screenings. This additional training and experience, especially in developing areas of the world, allows more professionals to gain experience and confidence working with individuals with intellectual disabilities. This increased experience and confidence is then brought to their local clinical practice, which has the potential to positively influence the lives of even more people with intellectual disabilities. Evidence indicates that clinicians often do not receive adequate formal training related to working with people with intellectual disabilities (Lennox, Diggins, & Ugoni, 1997); therefore the capacity building that volunteer-clinicians engage in can have a positive watershed effect.

#### 4.5. Limitations

While this database is the largest international database on the health of individuals with intellectual disabilities, it is limited by the fact that it only includes Special Olympics participants (Lloyd et al., 2014). This sub-set of the population could be considered to be the healthiest due to their ongoing participation in sport and regular physical activity (Lloyd et al., 2012; Temple et al., 2014). Therefore, while the Healthy Athletes database addresses a significant gap in the surveillance of this population, those who do not participate in Special Olympics will still be under-represented in existing health surveillance. However, Special Olympics International has extensive reach among people with intellectual disabilities making it the organization with the single largest potential to both collect health information and have a positive impact on the health of individuals with intellectual disabilities through their various sport and health initiatives.

The recommendations and ideas put forward at this consensus meeting are not without their limitations. The first challenge, as is often the case in not-for-profit organizations as well as research, is funding – or more specifically, the lack of funding. Many of the recommendations put forward require either a one-time financial commitment or ongoing financial support. However, the research team, and the gathered participants, agreed that high quality evidence is the most effective way to advocate for funding from various levels of government, private donors, or research granting organizations. Therefore, the data in the Healthy Athletes database needs to be maximized to allow continued, ongoing efforts to raise funds. We acknowledge that the views of the meeting participants were from North America; the meeting would have benefited from more diverse perspective from around the world and from other health professions that were not represented (e.g. medical ethicist). This limitation was entirely driven by the financial constraints of hosting the meeting in Toronto, and our budget. However, the results of the meeting were presented at two international disability health conferences in building sessions to broaden the scope of the input and consensus. Therefore, we are confident that multiple diverse points of view are reflected here.

#### 5. Conclusions

Research into the health of individuals with intellectual disabilities is often based on small-scale studies from high-income countries (Emerson & Hatton, 2014). There is a critical need for high-quality population level data related to the health of individuals with intellectual disabilities. The Special Olympics Healthy Athletes database includes data not found in any other source. The data is directly measured, it is international in its scope, the screenings have been performed on more than 1 million Special Olympics athletes worldwide, and it has been relatively under-utilized by researchers. The results of this consensus meeting indicate that while some improvements are needed, this database should be used, in partnership with Special Olympics International, by researchers to significantly increase our knowledge and understanding of the health of individuals with intellectual disabilities.

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