The BASES Expert Statement on the Process and Outcomes of Developing Exercise Guidelines for Adults with Spinal Cord Injury

Produced on behalf of the British Association of Sport and Exercise Sciences by Prof Vicky L Goosey-Tolfrey FBASES, Dr Jan W van der Scheer, Dr Kristen Clements, Prof Jan Lexell and Prof Kathleen A Martin Ginis.

Introduction

Physical activity (PA) is essential for fitness, health and well-being, particularly for those with disabilities such as spinal cord injury (SCI). However, because of the related neurological, physiological (as illustrated in a former BASES expert statement by Goosey-Tolfrey *et al.,* 2013) and societal barriers to PA, persons with SCI are among the least active in our society (van den Berg-Emons *et al.,* 2010). Given the potential for exercise to reduce secondary health complications (e.g. type 2 diabetes, cardiovascular disease), exercise intervention studies have been undertaken among people with SCI (van der Scheer *et al.,* 2017). The purpose of this expert statement is to outline the systematic process and outcomes of a project to formulate evidence-based exercise guidelines that can be used to promote exercise in the SCI population.

The UK and World Health Organisation (WHO) PA guidelines (150 min/week aerobic exercise plus 2 times/week strength training) have not been specifically tailored to people with SCI. Moreover, SCI-specific risks during PA were not considered and there was no evaluation of values and preferences of the SCI population when these guidelines were formulated. For example, the recommendation of 150 min/week of "brisk walking that will cause adults to sweat a little and breathe harder" is neither possible nor safe advice for a wheelchair user with a complete autonomic lesion at the sixth thoracic vertebra (T6 and above) and who is at risk of upper-body overuse injuries (Goosey-Tolfrey *et al.,* 2013).

Given the importance of developing PA guidelines to improve a population's fitness and health, a Canadian team developed the first evidence-based, SCI-specific PA guidelines (Martin Ginis *et al.,* 2011). This group was also the first to adopt the systematic, rigorous and stakeholder-engaged process that is required for developing any clinical practice guidelines (WHO, 2014). As new evidence for fitness and cardiometabolic health outcomes and new exercise approaches have emerged (van der Scheer *et al.,* 2017), we recognised the need to revisit the SCI-specific PA guidelines.

Typical exercise options:

- Wheeling, arm cycle exercise (ACE), sports, circuit training, aquatics, combined ACE and leg functional electrical stimulation cycling
- Free weights, elastic resistance bands, cable pulleys and weight machines.

Background and evidence

In 2016, an international team was established to systematically review existing literature and to form evidence-based scientific guidelines. Consistent with the WHO's recommendations for developing clinical practice guidelines, Appraisal of Guidelines for Research and Evaluation (AGREE-II) was used as the framework for guideline development.

1. The scope and purpose of the project was determined: to develop scientific guidelines that specify the type and minimum dose of exercise necessary to improve fitness and cardiometabolic health in adults with SCI.
2. A systematic review identifying studies that had examined the effects of exercise on fitness, cardiometabolic health or bone health among adults with SCI (van der Scheer *et al.,* 2017). A total of 13,155 citations were identified and 211 studies met the review criteria. The team appraised the evidence for each outcome using the latest systematic review tools, synthesised the evidence for each outcome and drafted guideline recommendations in accordance with the Grading of Recommendations Assessment, Development and Evaluation (GRADE) (www.gradeworkinggroup.org) (van der Scheer *et al.,* 2017).
3. The recommendations of the review were deliberated at three expert panel meetings of researchers, clinicians, community organisations and people with SCI from Europe, North-America and Australia (Martin Ginis *et al.,* 2018). The meetings led to final consensus on the guidelines and recommendations for the preparation of international and national dissemination and implementation strategies (Martin Ginis *et al.,* 2018).
4. SCI clinicians and people with SCI evaluated the proposed guidelines through an online survey and workshop discussions. They rated the guidelines favourably in terms of appropriateness, utility and clarity (Martin Ginis *et al.,* 2018).
5. An independent consultant evaluated the guideline development process and rated it with the maximum score of 7 out of 7.

What are the guidelines?

To improve fitness (cardiorespiratory fitness and muscle strength), adults with SCI should engage in at least:

- 20 minutes of moderate to vigorous intensity aerobic exercise, two times per week
  AND
- 3 sets of moderate to vigorous intensity strengthening exercise for each major functional muscle group, two times per week.

To improve cardiometabolic health (body composition and cardiovascular risk factors), adults with SCI are suggested to engage in at least:

- 30 minutes of moderate to vigorous intensity aerobic exercise, three times per week.

The guidelines are complemented by a preamble providing details about the evidence base behind the guidelines, the groups to whom the guidelines apply, and other special considerations (Martin Ginis *et al.,* 2018). The difference in language between the fitness guidelines and cardiometabolic guidelines (i.e. "should engage" versus "suggested to engage") reflects differences in the strength of evidence for each guideline in accordance with GRADE; the fitness guideline being a "strong recommendation" and the cardiometabolic being a "conditional recommendation" (Andrews *et al.,* 2013). The conditional 'weaker' recommendation reflects that evidence for this guideline could be strengthened by including people with incomplete lesions and having more clarity about the impact of improved cardiometabolic health measures on long-term cardiometabolic health (Martin Ginis *et al.,* 2011). The need for a cardiometabolic guideline was considered grave, as cardiovascular disease is the leading cause of death in the SCI population (Garshick *et al.,* 2005).

Recommendations for implementation

The guidelines are positioned as scientific guidelines and not practice guidelines, for which there may be a requirement to tailor

Muscle strength work being performed by an individual with spinal cord injury
Courtesy Loughborough University

between clinical, community and sport contexts. Following an engagement process with key stakeholders, the guidelines will be refined (e.g. language, presentation) and the intended audience for the tailored guidelines are:

- People living with SCI, their families, attendant care and healthcare providers
- Qualified exercise professionals working in academic, healthcare or community settings
- Organisations that provide information and services to people with SCI.

Conclusions

This project brought together people from the sport, exercise and rehabilitation science disciplines. It challenged current conventional thinking and built a rigorous and sustained commitment to community engagement to deliver a programme of research that was authentically co-produced together *with* people with a disability rather than *for* people with a disability. Through this process:

- The previously published SCI guideline (Martin Ginis *et al.*, 2011) for cardiorespiratory fitness and muscle strength benefits has been endorsed: "at least 20 minutes of moderate to vigorous intensity aerobic exercise, two times per week AND 3 sets of moderate to vigorous intensity strengthening exercise for each major functioning muscle group, two times per week" (strong recommendation)
- A new SCI exercise guideline has been formulated for cardiometabolic health benefits: "at least 30 minutes of moderate to vigorous intensity aerobic exercise, three times per week" (conditional recommendation, reflecting that evidence could be further strengthened)
- An important step has been made towards international harmonisation of exercise guidelines for adults with SCI
- A foundation has been laid for developing exercise policies and programmes for people with SCI around the world.

Panel member comments

"As a healthcare professional working in the rehabilitation of newly injured individuals with spinal cord injury it is important that clear principles and guidance are imparted from the start, to both promote positive behaviours and prevent avoidable complications following injury."
Dot Tussler, Head Physiotherapist Spinal Injuries, National Spinal Injuries Centre, Stoke Mandeville Hospital

"People with spinal cord injury need all the information they can get to continue living the same fulfilling lives they aspired to before their injuries. Having the convenience of a simple set of exercise guidelines that are proven to have benefits is one more thing that they don't need to worry about."
Andy Barrow, Paralympian and Inspirational Speaker

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