Learning from ‘lived expertise’: engaging athletes and patients in sport and exercise medicine research and policy

Jane S Thornton,1 Dawn Richards2

Athletes’ and patients’ perspectives are critical in Sport and Exercise Medicine research1 and the voices of those most impacted by research, policy development and implementation must be actively engaged throughout the process—nothing about us, without us1. Athletes know about their experiences in ways that researchers/clinicians cannot, unless they live with the same conditions or injuries. For this reason, they bring ‘lived expertise’ that complements and is of equal importance to the scientific and medical expertise of others on the team. They bring different ways of thinking about problems and solutions, including context about their lives and jobs, which may not even be considered by others on the team whose experiences may be very different.

Since the British Medical Journal’s 2014 launch of its patient partnership strategy, most articles continue to be directed ‘to’, ‘about’ or ‘for’ rather than ‘with’ or ‘by’ patients and the public.2 Reasons for this may include not fully understanding the ‘why’, not knowing where to begin, or logistics such as funding or time limitations. Beyond the Journal’s mandate, Van Mechelen’s classic injury prevention framework has recently been revisited to urge inclusion of the athlete voice and context.3 A conceptual framework for the safe and effective engagement of survivors in safeguarding initiatives in sport has also been advanced.4

One of us lives with rheumatoid arthritis and osteoarthritis, and physical activity is an important tool in her treatment (along with medications, adequate sleep and a healthy diet). However, most of her advice on this treatment has come from her own research rather than from a healthcare provider. Our research on physical activity prescription taught us that when patients are involved in the design, implementation in the healthcare setting improves.5 Instead of counselling using generic physical activity guidelines, patients want physicians to provide individualised recommendations focused on proximal health goals which address environmental and social contexts. Patients also want physicians to recommend tools that incorporate planning, goal setting and goal monitoring features.6

Our goal with this article is to highlight the contributions that athletes and patients bring to research, and provide examples and resources to get started. We recently undertook a process to engage patient partners from start to finish, illustrated in Box 1. Ultimately, engaging athletes and patients can strengthen the research team and improve research outcomes, experience and dissemination.

TIPS TO GET STARTED

Engage athletes and patients early: from idea phase to dissemination

At the start, cocreate terms of reference to set up how the project will be undertaken and that outlines roles, responsibilities and expectations of all research team members, including athlete/patient partners.7 It should include information on compensation for athlete/patient partners (if they wish to receive it),8 how long the project is expected to take, etc. Our approach was to develop a ‘code of conduct’ and provide a detailed breakdown of each planned activity including duration, compensation and expectations (figure 1).

Be prepared to put in the time and resources

This may include a budget for dedicated personnel, athlete/patient partner compensation and expenses for athlete/patient partner involvement.9 We allocated funding for DR to facilitate sessions and help develop the agendas, and for compensation of patient partners including parking and transit costs as needed.

Be flexible

Find ways and times to engage athletes/patients that work best for them (which might not be Monday–Friday between 9:00–17:00 hours), do not expect 1–2 athletes/patients to represent all, and be prepared to offer supports that you may not usually offer to other research team partners (if they wish to receive it), costs for athlete/patient partner travel and accommodation.8 We allocated funding for DR to facilitate sessions and help develop the agendas, and for compensation of patient partners including parking and transit costs as needed.

Be flexible

Find ways and times to engage athletes/patients that work best for them (which might not be Monday–Friday between 9:00–17:00 hours), do not expect 1–2 athletes/patients to represent all, and be prepared to offer supports that you may not usually offer to other research team partners (if they wish to receive it), costs for athlete/patient partner travel and accommodation.


correspondence to Dr Jane S Thornton, Public Health and Family Medicine, University of Western Ontario Schulich School of Medicine and Dentistry, London, Ontario, Canada; jane.s.thornton@gmail.com
TIPS ON ENGAGING ATHLETES AND PATIENTS IN SPORT AND EXERCISE MEDICINE RESEARCH AND POLICY

Figure 1  Tips on engaging athletes and patients in sport and exercise medicine research and policy.

members. For us, that occasionally meant we could only meet in the evening, due to patient preference, or hold multiple meetings (with the same agenda) to be able to include everyone.

Be willing to talk, listen and be open-minded about outcomes of engagement

Athletes and patients help you understand the problem and find the solution. They need to know your ‘why.’ They should see themselves in the work and feel that the outputs developed make sense in their context. Outputs such as guidelines and resources should be accessible, readable with easy-to-understand language, codeigned, tested and engaging for everyone, not just practitioners. We learnt that our website was inaccessible to some based on the font size and background colour, some graphics were not relatable, and that simplified language was required.

Acknowledge athlete and patient partners in ways that work for them

This may include authorship, conference presentations or other ways that work for them.

From the idea phase throughout the project, co-create terms of reference to set up how the project work will be undertaken.

This may include a budget for dedicated personnel, athlete/patient partner compensation, and covering all expenses for athlete/patient partner involvement.

Find ways and times to engage athletes/patients that work best for them, (which might not be Monday-Friday between 9am-5pm).

ENAGE ATHLETES AND PATIENTS EARLY

Acknowledgements

The authors are grateful to our athlete and patient partners for their ‘lived expertise’ and would like to acknowledge Dr Becky Beau for her assistance in preparing the manuscript and Naomi Abayomi for her assistance in preparing the infographic.

Contributors  JST and DR contributed equally to idea conception, drafting and final review of the manuscript.

Funding  The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests  JST is an editor of the BJSM.

Patient consent for publication  Not applicable.

Provenance and peer review  Not commissioned; externally peer reviewed.

© Author(s) (or their employer(s)) 2022. No commercial re-use. See rights and permissions. Published by BMJ.

To cite  Thornton JS, Richards D. Br J Sports Med Epub ahead of print: [please include Day Month Year]. doi:10.1136/bjsports-2022-106190

Accepted 14 August 2022


ORCID iD

Jane S Thornton http://orcid.org/0000-0002-3519-7101

REFERENCES


