

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

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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 us'. 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 work 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

Box 1 Illustrative example on engaging patients and community members on physical activity and health

The authors have worked together on the 'Western Research Hub for Physical Activity and Health' over the past year, a project that has engaged researchers, clinicians and patients and community members from its start and in different ways. Engaging patients and the community is key for codesign. They have informed our knowledge mobilisation strategy from the beginning, including the development of a 'peer-to-peer' physical activity website 'My Active Ingredient' (myactiveingredient.org). Ensuring important and varied lived experiences and community perspectives informs research and strengthens impact, including through a knowledge translation approach. When we asked what physical activity means to them, patients and community members brought the following insights:

- ⇒ What seems important and feasible to researchers on how to advance physical activity implementation may differ from what patients and community partners find important and feasible.
- ⇒ Being physically active is more than simply being able to move—peoples' life circumstances (new immigrants, mental health, homelessness) impact their ability to be active no matter how motivated they may be.
- ⇒ Language matters in terms of building relevant and accessible resources.
- ⇒ Patient and community partners are essential for developing local collaboration and partnerships that we had not even heard of.
- ⇒ Patient and community partners are key to ensuring research findings are shared and implemented.

From this work, relationships were built that will continue throughout this project and beyond into others.

and help develop the agendas, and for compensation of patient partners including parking and transit costs as needed.

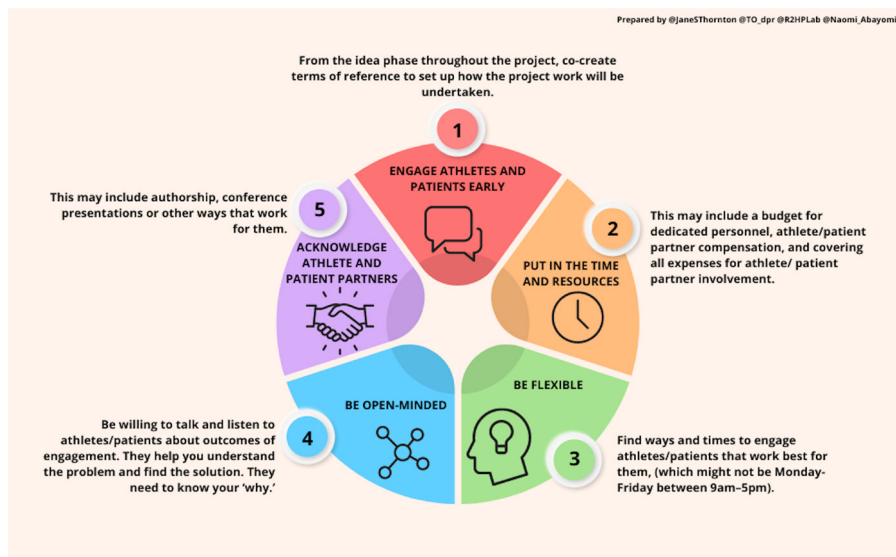
Be flexible

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

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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.

may not usually offer to other research team 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, codedigned, 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, written acknowledgement, having them present at conferences or other ways.¹⁰ We involved our patient and community

partners in a local conference as keynote speakers, panellists and planning committee members (based on what they were most comfortable with). Additionally, they have been given the opportunity to review and be acknowledged (with permission) in all documents sent on behalf of our research group.

There are also free online learning modules about patient engagement in research, which may be helpful when getting started (link). They were cocreated with patient partners associated with the Canadian Institutes of Health Research's Institute of Musculoskeletal Health and Arthritis (but are not specific to arthritis research).

By engaging the lived expertise of athletes and patients in our research we can help both patients and providers rethink how and why we move, improve access to physical activity and sport, and move another step closer to building a healthier world for all.

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