

# Recognizing the Research Participants Behind the Numbers: “Every Line of Data is a Story”

Zachary Y. Kerr, PhD, MPH; Johna K. Register-Mihalik, PhD, LAT, ATC; Avinash Chandran, PhD

Department of Exercise and Sport Science, Matthew Gfeller Sport-Related Traumatic Brain Injury Research Center, and Injury Prevention Research Center, University of North Carolina, Chapel Hill

Athletic training is a health care field that focuses on the care of patients and athletes across the lifespan. Human interaction, and specifically the rapport between athletic trainers (ATs) and their patients, is critical in this clinical paradigm. As the field of athletic training continues to expand its research space by emphasizing practice-based and clinical research, it is important to retain the element of human connection that is inherent to the field through relationships among researchers, clinicians, and patients.

Our research team at the Matthew Gfeller Sport-Related Traumatic Brain Injury Research Center includes ATs. But it also includes public health researchers who are trained to focus on population-level health rather than individual-based health. Such collaboration builds a confluence of diverse ideas and, more importantly, establishes ATs as agents of public health delivery in their communities.<sup>1</sup> However, as large data sets are created from our populations of patients, athletes, performers, and other individuals with whom we work, we must remember the human element of our work: at the end of the day, data collection and subsequent outputs represent human beings.

Typically, ethical concerns in research practice are considered in the contexts of informed consent, beneficence, and respect for participants' privacy and confidentiality.<sup>2</sup> Yet our obligation to research participants extends beyond their roles in our studies. As noted by Hesse-Biber,<sup>3(p77)</sup> research must be conducted “with your own ‘humanness’ in mind—be realistic and fair to all involved.”

Respect for research participants involves the recognition and acknowledgment of the origins of data. A defining moment during graduate studies for one of our team members (Z.Y.K.) came as part of an epidemiologic methodology lecture taught by Stephen Cole, PhD. In the lecture, Dr Cole asked the class to take a moment of silence in honor of the research participants whose data were being analyzed during that lecture: patients living with the human immunodeficiency virus or dying from complications related to AIDS during the 1980s and 1990s. Dr Cole urged the class to note that these individuals consented to participate in research despite their personal hardships (and

in some cases, proximity to death), in hopes of benefiting not only themselves but also those who might experience similar circumstances in the future.

As researchers, we should reflect on the importance of the origins of our data regarding sports injuries and athlete health. Each row of data represents a human being, whose story is being told through numeric representations. Irrespective of the severity of an injury being examined, as researchers, we must acknowledge its potential effect on the individual and appreciate his or her willingness to allow us to capture such information.

Moreover, we should consider why we are committed to the research we are doing. For instance, our research center is named after Matthew Gfeller, a young man who lost his life to a traumatic brain injury. One of the ways we honor the experience and stories of our athletes, patients, and research participants is through a large framed picture of Matthew that hangs at the entrance to our center. Often, as we enter our workspace, we take a moment to remember him and his family. Other research groups and centers, such as the Korey Stringer Institute, aim to honor individuals in similar manners. Similarly, a number of medical schools hold ceremonies to acknowledge their cadaver donors.

As we continue to conduct research and work with the populations we serve, it is integral that we not lose touch with the “humanness” that is inherent to athletic training. Arguably, this connection may not be too challenging for practicing ATs. Many readers of the *Journal of Athletic Training* are practicing ATs who care deeply about their athletes' somatic health and emotional wellbeing and strive to provide patient-centered care. This attitude is evident in the expansion of our field to include emotional and mental health as well as physical ailments.<sup>4,5</sup> Along with their clinical work, many ATs contribute data to large-scale surveillance projects such as the National Collegiate Athletic Association Injury Surveillance Program,<sup>6</sup> the National High School Sports-Related Injury Surveillance System, High School Reporting Information Online,<sup>6</sup> and the Athletic Training Practice-Based Research Network.<sup>7</sup> Athletic training researchers also use these data sources for secondary analyses, as evidenced by the increasing number of such publications in the *Journal of Athletic Training*.<sup>6</sup>

In order to recognize and remember the origins of the data that fill our publications, we encourage our colleagues to continue taking time to consider and appreciate the humans who populate our data. The generosity of our patients in providing access to their injuries and information helps us extend our understanding of injury prevention and management. Athletic training programs should incorporate curricula that encourage students to consider the importance of all contributions to research. Acknowledgments such as Dr Cole's are meaningful as they help to instill and nurture the culture of care that is paramount in athletic training. Such recognition can also be formalized in published journal articles. We urge instructors, mentors, and professionals of all ages to likewise consider integrating activities that embolden such respect for our patients and research participants.

## REFERENCES

1. Hoffman M, Bovbjerg V, Hannigan K, et al. Athletic training and public health summit. *J Athl Train.* 2016;51(7):576–580.
2. Guiding principles for ethical research. National Institutes of Health Web site. <https://www.nih.gov/health-information/nih-clinical-research-trials-you/guiding-principles-ethical-research>. Accessed June 18, 2019.
3. Hesse-Biber SN. *The Practice of Qualitative Research: Engaging Students in the Research Process.* 3rd ed. London, UK: Sage; 2017:59–89.
4. Cowee K, Simon JE. A history of previous severe injury and health-related quality of life among former collegiate athletes. *J Athl Train.* 2019;54(1):64–69.
5. Houston MN, Hoch MC, Hoch JM. Health-related quality of life in athletes: a systematic review with meta-analysis. *J Athl Train.* 2016;51(6):442–453.
6. Kerr ZY, Comstock RD, Dompier TP, Marshall SW. The first decade of Web-based sports injury surveillance (2004–2005 through 2013–2014): methods of the National Collegiate Athletic Association Injury Surveillance Program and High School Reporting Information Online. *J Athl Train.* 2018;53(8):729–737.
7. Valovich McLeod TC, Lam KC, Bay RC, Sauers EL, Snyder Valier AR. Practice-based research networks, part II: a descriptive analysis of the Athletic Training Practice-Based Research Network in the secondary school setting. *J Athl Train.* 2012;47(5):557–566.

---

*Editor's note: Zachary Y. Kerr, PhD, MPH, and Johna K. Register-Mihalik, PhD, LAT, ATC, are JAT Editorial Board members.*