ATLAS INSTITUTE FOR
VETERANS AND FAMILIES

Enhancing Veteran and Veteran Family engagement in research: Reflections from an interactive panel discussion

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EXECUTIVE SUMMARY

Researchers rely on people with lived experience (PWLE) to share their personal stories, which provides critical insight into how their experiences affect mental health, attitudes, behaviour and other aspects of life. However, too often there is a disconnect between researchers and research participants. Participants get little to no follow-up from researchers and may not even find out when the research to which they contributed is published.

To help address these concerns, the Atlas Institute for Veterans and Families held an interactive panel discussion on October 16, 2022, where researchers and PWLE could share their perspectives and needs. The goal of the session, which was moderated by Researcher Reference Group Vice-Chair Walter Callaghan, was to start creating a shared understanding of how to improve research outcomes and participant experiences by adapting the design and practice of research.

Panel presentations from Veteran Natalie Champagne, Veteran and PhD candidate Shauna Mulligan, and researchers Dr. Maya Eichler, Dr. Tammy Findlay and Dr. Anthony Nazarov offered some initial thoughts on the research process. The rest of the event was devoted to an open discussion among assembled Veterans (including former active service members, reservists, RCMP officers and first responders), Veteran Family members and researchers.

INTRODUCTION

Lived and living experience play a crucial role in research. Qualitative researchers rely on PWLE to share their personal stories so researchers can gain deeper insight into the experiences of military and RCMP Veterans and their Families, as well as the impacts on mental health and other aspects of life. For PWLE, participating in research can be an empowering way to make a difference in the findings, which can lead to greater availability of mental health services that better suit the unique circumstances and needs of military and RCMP Veterans and their Families. However, However, PWLE have said that they feel disconnected from researchers during the research process. They have reported feeling used in research projects rather than empowered. To address this, greater communication and understanding between Veterans, Veteran Family members and researchers are needed.

The Atlas Institute organized an interactive panel discussion on October 16, 2022 to bring PWLE and researchers together to foster mutual understanding, improve research outcomes and enhance participant experiences. Members of the audience included Veterans of the Canadian Armed Forces (CAF) and Royal Canadian Mounted Police (RCMP), Veteran Family members, as well as first responders, researchers and service providers.

The discussion, held on the traditional unceded territory of the Mi'kmaq, was opened by Elder Geri Musqua-LeBlanc of the Nakawe Nation (Keeseekoose First Nation) and the Bear Clan in Saskatchewan. Elder Geri encouraged the group to **approach the discussion using two-eyed seeing** to achieve a more holistic understanding of how the issues at hand.

The event was moderated by Walter Callaghan, a PhD candidate from the University of Toronto and co-chair of the Atlas Institute's Researcher Reference Group. With a background as both an ethnographic researcher and a CAF Veteran, Walter brought a unique perspective to the discussion. He was introduced by Fardous Hosseiny, President and CEO of the Atlas Institute.

To view the agenda and speaker bios for the Pre-CIMVHR Session: Research and lived experience interactive panel discussion, please visit our webpage at: **atlasveterans.ca/cimvhr-2022** or scan the QR code:

WHAT WE HEARD: KEY TAKEAWAYS FROM THE DISCUSSION

From the open discussion among Veterans, Veteran Family members and researchers, the following key themes emerged:

Sharing traumatic experiences is difficult	PWLE stressed the importance of researchers being sensitive to the impacts of the questions they ask. Participating in research can require PWLE to address experiences that may be emotionally challenging to discuss and the effects may linger. PWLE would like to see a mechanism that would enable researchers to access responses from other studies, reducing the need for them to repeat the same answers (and relive the same experiences) over and over.
Veterans and Veteran Family members want to help — and want to know they have helped	PWLE participate in research because they want to make life better for those who come after them. Better communication at the beginning of a study to outline its goals would help them feel more comfortable. They would also like to be notified when a study is published so they can see the impact of their contributions.
The way results are shared needs to be improved	After a study is over, PWLE often hear nothing further from researchers and have no idea when, where or how findings will be shared. Many would like to see findings published in channels that Veterans and Veteran Families are more likely to see and expressed in more accessible language and formats.
There is room for greater consideration for lived experience in ethics guidance	Some standard ethics requirements may be causing harm, particularly the requirement to cease contact between researchers and participants when a study is over. While these rules serve a vital function in research, there may be room to explore adapting them for participatory projects to better meet the needs of all community members. A first step would be to ensure PWLE are represented at the tables where these decisions are made.

PANEL PRESENTATIONS SUMMARY

Natalie Champagne

Natalie Champagne, a former member of the Royal Canadian Air Force, shared a story about the importance of getting the right support. Due to her experiences, travelling can trigger her anxiety and other post-traumatic stress disorder (PTSD) symptoms. While travelling to the pre-CIMVHR interactive panel discussion, Natalie made use of her usual coping strategies, including waiting for all other passengers to board to avoid having someone come up from behind. In this instance, a passenger did arrive after her and overtook her at the boarding gate but before her symptoms heightened, she noticed the man had dropped his Veteran identity card. Knowing how important this ID was, she returned the card to him and discovered they were both attending the event. They were seated near each other on the plane and shared a ride to the hotel. His presence helped Natalie feel calm and supported during her journey. This encounter highlighted how feeling supported and listened to can make a potentially traumatic situation more manageable.

Dr. Maya Eichler

Dr. Maya Eichler, professor at Mount Saint Vincent University and leader of a research centre on military and Veteran issues, discussed the definition and principles of research, based on Canada's Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS 2). She explained that qualitative research aims to understand how people think about the world and behave through in-depth interviews and focus groups. Dr. Eichler believes that research, when done well, can lead to significant change, but it is essential to recognize personal biases and conflicts of interest. To build the right relationships with research participants, she advises approaching research as a learning opportunity and thinking of participants as teachers, while being mindful of power differentials and fostering an empowering experience for all.

Dr. Tammy Findlay

Dr. Tammy Findlay, professor at Mount Saint Vincent University, conducts community-based research with a focus on feminist social policy. She described two recent projects that used an inclusive approach, involving extensive collaboration with the community to explore alternative solutions to identified problems and the impact on diverse perspectives.

According to Dr. Findlay, community engagement provides numerous benefits for both the community and research. Engaged communities can access venues to collaborate and work with academic experts and secure critical grant resources, including funding. Community engagement in research can also ensure that community voices and needs are represented in policy decision making. Researchers can improve the quality of their findings, uphold ethics and justice in their work, and achieve impactful results by engaging with communities and leveraging new methods.

Shauna Mulligan

Shauna Mulligan, a Métis Veteran who served in the Army Reserves from 1995 to 2002, brings her perspective as a researcher and PWLE to her PhD work in indigenous studies at the University of Manitoba. She incorporates storytelling and Indigenous ways of knowing into her research on Indigenous Veterans. Through her work, Shauna discovered that the requirements outlined in the TCPS 2 to cease contact with research participants after the study is completed can be counterproductive and harmful. She emphasizes the need to review policies to prevent unintended harm. Shauna concluded with a story about her visit to Sandy Bay First Nation in Manitoba. While approaching the research site, she felt inexplicably drawn to a tree and made an offering of tobacco. This experience left her with a powerful calling to actively listen in every conversation. As a researcher, Shauna believes her job is to hear and translate stories to benefit the tellers and their communities.

Dr. Anthony Nazarov

Dr. Anthony Nazarov, Associate Scientific Director of the MacDonald Franklin OSI Research Centre, co-founded ParticipAid, an online research participant recruitment and engagement platform, after he experienced difficulty in recruiting the right groups of people for studies. The platform enables users to find and enrol in studies, connect with research teams and track their participation and documentation. While hundreds of researchers now use ParticipAid, Dr. Nazarov emphasized that it is only one tool and more communication enhancements are needed to support community engagement. He suggested that researchers could benefit from sharing effective engagement practices and receiving more training in knowledge translation in order to communicate findings to wider audiences.

GROUP DISCUSSION SUMMARY

During the discussion period, attendees had the opportunity to share their thoughts and observations about research and their experiences with it. Several key themes emerged:

Veteran trauma is about more than combat

The event brought together military and RCMP Veterans, first responders, Veteran Families, researchers, clinicians and members of the public. One of the issues discussed was defining who is considered a Veteran. Reservists reported having been told they were not “real” Veterans and that their traumas are not comparable to military Veterans, which could hinder their participation in research. RCMP Veterans shared that they felt under-represented in Veteran research despite their high risk of PTSD and other mental health conditions related to their work. PWLE also emphasized that not all trauma is combat-related and that it is important to recognize and include trauma from other sources in research.

Veterans need to understand the research mission

Some attendees suggested that a critical piece of information for researchers to keep in mind is that Veterans tend to be highly mission-oriented. They want to know in concrete terms what the goal is and what is required to get there. They indicated that researchers who provide this kind of information up front are likely to get more out of Veteran study participants. That said, they acknowledged that research does not always work that way.

The emotional burden of participating in research can be high

Difficulty recruiting research participants can lead to the same Veterans being asked to contribute to multiple studies, including those from historically under-represented groups, such as women, Indigenous Peoples and 2SLGBTQIA+ Veterans and Family members. As the importance of diversity and inclusion in research is increasingly recognized, there is growing demand for these perspectives. However, the smaller pool of available participants increases the likelihood of that the same people will be asked repeatedly to participate across multiple studies.

PWLE recognize the importance of participating in research, but recounting the same traumatic experiences can be mentally and emotionally challenging. The lack of access to knowledge about the outcomes of the research can make it feel like they are not being heard. Some suggested creating a shared information bank for researchers to access to avoid repeating the same answers. Researchers recognized the benefit of the idea but cautioned that issues related to data storage, ownership, privacy and currency may present challenges. Improved national coordination of research was also suggested to avoid duplication of studies on the same topic.

Research participants want more information on what happens next

A common concern shared by PWLE who participate in research is the lack of follow-up. PWLE expressed a strong desire to know what happens to the research findings and how they will be applied. They feel that keeping the lines of communication open would increase positive outcomes and encourage future participation.

The researchers acknowledged this concern and said they were also frustrated by the rules that prevent them from following up with study participants. They noted that sharing findings takes time and can be delayed by analysis and peer review. As well, they indicated that it can take an average of 15 to 20 years for research to be adopted into policy and practice.

Engaging with lived experience offers tangible benefits

One researcher pointed out that when a large volume of information is gathered through a study, it can often be used to answer multiple different research questions. Engagement with PWLE can provide some guidance about which questions to prioritize in the data analysis phase.

Lived experience can also be highly beneficial when sharing research findings. PWLE generally agreed that they are interested in the findings but are unlikely to read academic papers behind paywalls. Researchers agreed this was an issue and invited suggestions about where and how to publish so that it would reach Veterans. One researcher noted that she now ensures all her papers go through community review as well as peer review, which helps ensure the findings are accurate, relevant and understandable to the community they are intended to help. Co-writing papers with Veterans was also recommended as a strategy. Veterans may be more inclined to read a paper if they know an author or see that an author has a military background.

Ethics boards do serve a purpose

Researchers felt it was important to point out that, even though the process can be frustrating, research ethics boards and protocols exist for a reason. A key reason is to ensure that the rights and safety of participants are protected. However, they acknowledged that intent and result do not always align and that some ethics boards requirements may hinder participatory models of research. Walter spoke about how the activities involved in ethnographic research, which are by nature unpredictable, can often make adhering to formal guidelines difficult.

Researchers recognized the need to advocate for new solutions that might offer more flexibility without removing vital protections. There was general agreement in the room that including PWLE on the ethics boards of more research institutions could be extremely helpful in this matter.

More attention is needed on prevention

Some attendees noted that most existing and ongoing research seems to focus on treating and managing PTSD and related conditions. However, they also wanted to know what was being done to prevent such conditions from developing in the first place. Atlas Institute President and CEO Fardous Hosseiny acknowledged the validity of this concern, noting that prevention and preparation is one of the core focus areas in the organization’s strategic plan. He added that these issues are also being explored in research conducted elsewhere.

Exposure to trauma can be unavoidable in the military, the RCMP and other first-response professions. A better understanding of the effects of trauma and how to manage them may help in developing strategies to improve resilience and prevent the onset of PTSD. In the words of one attendee, healing and prevention are closely related and “if you can solve one, you’ll solve the other.”

EVALUATING THE DISCUSSION: MOVING TOWARDS IMPROVED RESEARCH OUTCOMES FOR PWLE

This discussion represents an important first step in an ongoing conversation about how to enhance research outcomes through more effective engagement with PWLE. The insights gleaned during the session will help improve the experience for participants and researchers, and also produce research that is more relevant to the Veteran community and more effective in informing positive change in systems, policies and practices related to Veteran mental health.

The Atlas Institute is committed to engaging with PWLE and to including their perspectives wherever possible. The organization thanks those who participated in this session for their openness and willingness to engage, and looks forward to future opportunities for dialogue.

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