

## PAPER 47

### **Patient engagement in sarcoma research: benefits, challenges, importance, and implications**

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**Background:** Patient engagement can be described as the active participation of patients in research in collaboration with a research team or healthcare provider. This approach has begun to reshape the thought process behind conducting research with the aim of maximizing the relevance of findings for patients. Previous research has shown that patient engagement allows researchers to gain insight into the lived experience of patients as well as empowers patients by enhancing their knowledge surrounding their health condition. Noted challenges of patient engagement in prior studies include added complexity due to the need to communicate and consult with patients throughout the research process. Although past literature has outlined some benefits and challenges of patient engagement, there is a lack of current knowledge surrounding these issues in sarcoma research.

**Purpose:** This study aims to address the current knowledge gap surrounding the perceived benefits, challenges, importance, and implications of patient engagement efforts from the perspectives of sarcoma patients and researchers.

**Methods:** This study utilized a mixed model design comprised of qualitative data collected from a focus group discussion and quantitative data collected from a survey. The focus group consisted of three sarcoma patients who serve as patient advisors in a larger Patient-Centered Research Advisory Group which assists with the design, implementation, and dissemination of the Surveillance AFter Extremity Tumor surgery (SAFETY) randomized controlled trial. A semi-structured focus group guide was used to prompt the patient advisors to evaluate and provide feedback on the current ten-step SAFETY trial patient engagement plan. The focus group transcript was qualitatively coded to extract prominent themes. The survey component was distributed to the Centre for Evidence-Based Orthopaedics Musculoskeletal Oncology research team at McMaster University. This survey involved multiple choice and Likert-type questions surrounding the benefits, challenges, and implications of patient engagement as well as questions prompting the evaluation of current patient engagement efforts in the SAFETY Trial. Survey results were analyzed for trends and average scores for Likert-type questions were calculated.

**Results:** Following qualitative coding of the focus group discussion and identification of common themes, results showed that sarcoma patients value the opportunity to contribute to research and support future patients. Being a patient advisor also creates a sense of community and fosters support through building connections and communicating with other patients. One challenge noted from the patient perspective was a lack of background knowledge in scientific research resulting in a lack of understanding of study components and steps of the engagement plan. Members of the sarcoma research team noted that the most important and valuable aspect of patient engagement is the ability to identify patient relevant topics and gain insight into the improvement of patient care. However, an added challenge is the lack of current guidance surrounding the implementation of patient engagement in sarcoma research.

**Conclusion:** In conclusion, despite associated challenges, patient engagement is valuable to both sarcoma patients and researchers. Patient engagement aims to emphasize the patient's journey by involving patients in each step of the research continuum. This process enhances the study design and increases the relevancy of study findings for patients. The findings of this study emphasize the potential value of sarcoma patient

engagement while also highlighting the need for further research into best practices for the implementation of sarcoma patient engagement efforts. Effective and continuous patient engagement is crucial to the success of clinical research and guidelines that utilize a patient-centered approach are needed to ensure maximal benefit from patient engagement efforts.