

Sharing research results with research participants: experiences from the TeleYoga study

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In this HeartBeat, we describe our experiences with sharing our research results from a randomized controlled trial, the TeleYoga study (clinicaltrials.gov: NCT03703609).

Historically, much attention has been given to disseminating research results to the scientific community. However, it is encouraged involving study participants in all stages of the research process and engage them as equal partners. Unfortunately, participants rarely see the research results. Sharing research findings may have significance for the patient, but also for their families. Additionally, this can increase patients' sense of ownership of research outcomes, improve trust between researchers and patients, and encourage patients to be part of the development of research and participation in future research. In our study, the tele-yoga intervention was co-designed with members of a patient organization, yoga instructor, and an IT technician. It includes live-streamed group yoga sessions twice a week and an app with instructions on how to perform yoga independently. Our research group believes that patients and their caregivers have a right to receive the results of research they contributed to. Therefore, we sought a genuine and engaging way to share the results of the TeleYoga study, not only with the participants involved in the study but also with members of the patient organization that helped shape the study's design.

Finding an optimal format to share research findings, we had the following three criteria:

- (1) Accessibility for all: We considered the physical condition of the participants and possible challenges due to illness. The study participants that helped develop the TeleYoga study were patients with heart failure or other long-term illness. The mean age of the participants in the study was 66 years. Many relied on a caregiver for transportation. Participants were recruited from four different cities in Sweden, each at least 2 hours apart. Therefore, we planned local meeting each site, ensuring venues were accessible including parking facilities. The meetings, lasting a maximum of 4 hours, were announced on a website for registration. Participants in the study were informed about the meeting via email, postal letters, and follow-up phone calls by a research nurse. The patients in the patient organization also received an invitation.
- (2) Celebrating and showing appreciation: We aimed to ensure that patients felt valued for their contribution to the study, recognizing

that the study could not have been completed without them. We celebrated the end of the study by presenting and eating an occasion customized cake (Figure 1), involving all research members who wore a study-branded t-shirt.

- (3) Sharing information in an accessible way for all audiences: We aimed to involve patients and their caregivers in the study results and offer them a chance to share their insights and experiences. To achieve this, we presented the study's aim and procedures, intervention, and future plans through various speakers and formats. We also facilitated discussions with the research team during lunch, the meeting, and during a coffee break (Figures 2 and 3). Additionally, a film showcasing study findings and patients' experiences was played during the breaks. We invited the 'MediYoga' institute to present their activities as well. We had two meeting inviting participants from one study site at one meeting and three sites at one meeting. Participants travelling longer distance were offered travel compensation.

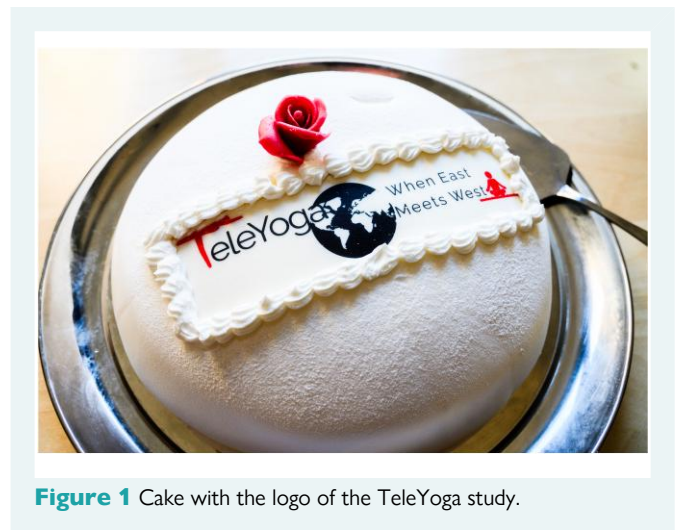


Figure 1 Cake with the logo of the TeleYoga study.

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Figure 2 A yoga session by the yoga instructors in the TeleYoga study.



Figure 3 The participants at one of the meetings listening to the results of the study.

Take-home messages

There was strong interest from participants, with positive feedback on both the duration and location of the meeting.

- Participants showed varying levels of interest; some were keen to learn about the results, while others focused more on practical issues, like where to practice yoga.
- For the researchers, the event offered a valuable opportunity to maintain connections with participants.

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Conflict of interest: none declared.

Data availability

No data was used to generate this publication.