

smartCARE Patient-led Workshops

In June and July 2023, the smartCARE patient-led workshop series brought together members of the cancer survivor community for the first time in a virtual setting. The aim was to gain insights into the diverse needs of users that should be integrated into the prototype app. These findings will also lay the foundation for future surveys that will help define the long-term objectives of the Cancer Survivor Smart Card.

At smartCARE, we truly understand the importance of putting our patient's needs first. That's why we organised workshops that were led by patients themselves, in collaboration with key stakeholders. Two workshops with pediatric cancer survivors and two with adult cancer survivors were organised, all of which followed a consistent format to ensure maximum participation and productivity. These workshops were held for 60 minutes each and provided a safe space for participants to share their thoughts and concerns.

The moderator of each group asked stimulating questions to encourage meaningful discussions about what the Smart Card can do to better meet users' needs.

During the workshops, participants stressed the importance of an app that is user-friendly and easy to navigate. They also emphasized the need for real-time updates, chat features, language translations, and compliance with information security laws like GDPR.

To empower patients and their caregivers, the app should contain content that can contribute toward:

- **Enhancing the quality of life:** mental well-being is of great importance. Coping with anxiety, engaging in activities that enhance concentration, receiving psychological assistance, and getting fitness advice were all highlighted as crucial elements for a fulfilling life.
- **Promoting informed decision-making:** the app should supply survivors with adequate information about their health conditions including clinical history as well as relevant clinical practice guidelines so that they can learn more about the long-term impacts of their treatment.
- **building a strong and caring community** Such a community would offer peer support, survivorship care, and practical assistance on a range of topics, including managing the disease, coping with work, and addressing sexuality.

Additionally, there were several other proposed features such as reminders for medication, care guidelines, therapy options, dietary advice, a tracker for treatment plans, and alerts for appointments.

In our workshops, we placed great emphasis on the essential preparations required for the smartCARE app. It is of utmost importance that the app offers a comprehensive understanding of the cancer patient and survivor community. As we proceed, we aim to ensure that smartCARE collaborates closely with survivors and health professionals to enhance the app and include them in a testing phase. Our concern for those affected by cancer runs deep, and we strive to do all that we can to alleviate their burden.

