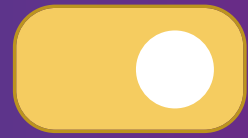


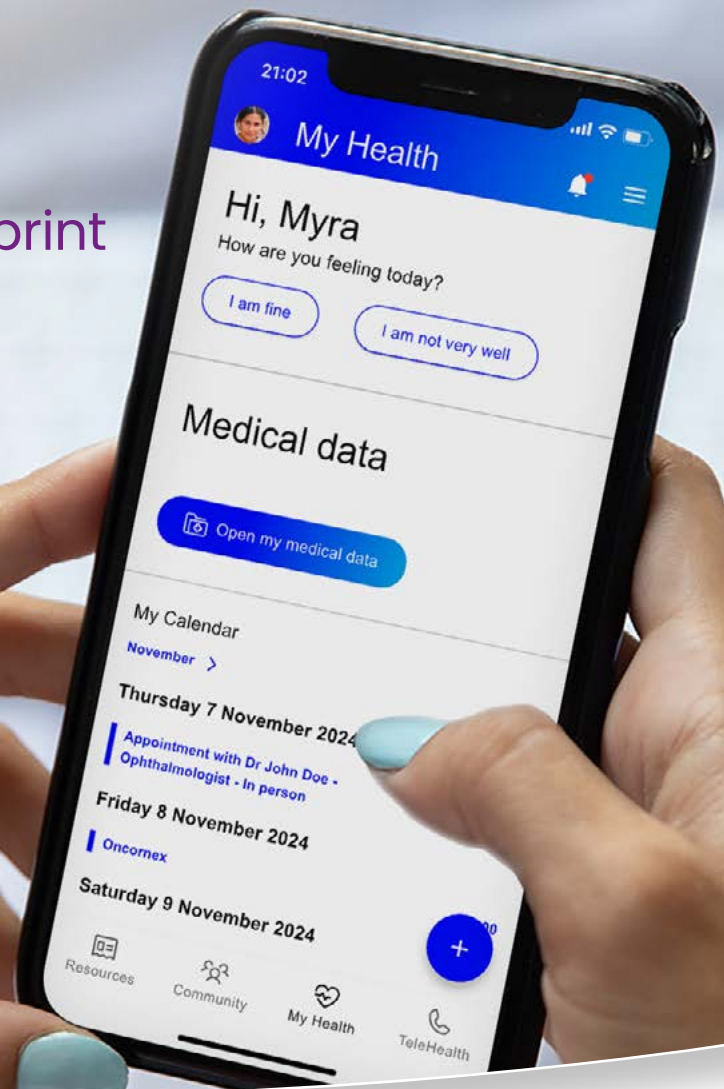
smartCARE



Empowering Cancer Survivors in Europe

Prototype for a Cancer Survivor Smart Card

Executive Summary of
the smartCARE Final Blueprint



Co-funded by
the European Union

Introduction

Europe's 20 million cancer survivors are a testament to the progress in cancer care over the years but surviving cancer is not the end of the story.¹ Cancer survivors continue to have specific needs stemming from their treatments, including late effects, side effects, complications and co-morbidities.

To help cancer survivors navigate these challenges, the smartCARE project is developing a Cancer Survivor Smart Card. Its first prototype, in the form of a mobile and web-based app, has already been created and tested.

The project, launched at the European Parliament in March 2023, has focused on creating a first prototype of a digital solution that can be integrated into different healthcare systems and made easily accessible to survivors and their families. Users will be able to track their medical data, communicate with healthcare providers, connect with other patients, survivors and carers, and access helpful resources.

The app is focused on:

- **patient needs, perspectives, and individual experiences;**
- **patient opportunities to participate in their own care ('self-management');** and
- **enhancement of the patient-clinician-nursing relationship.**

This effort began with a comprehensive, EU-wide, user needs assessment to better understand the daily challenges of survivors, patients, caregivers, and healthcare providers. The partners also worked closely with Billbomática, a consortium of third-party app developers who were selected by HaDEA in response to a separate call for tender, to develop the prototype based on recommendations from the user community.

smartCARE, part of Europe's Beating Cancer Plan, is aimed at helping countries meet the challenge of cancer survivorship and **providing tangible support to patients after treatment.**

This summary of the final 'blueprint report' highlights the lessons learnt and the recommendations from Europe's patient and clinician community for the development of a Cancer Survivor Smart Card application.



smartCARE is a landmark initiative, not just in reducing the communication gap between cancer survivors and healthcare professionals but also in placing cancer survivors at the centre of European Policy'

- István Ujhelyi, Former Member of the European Parliament (2014-2024)

¹ Lawler M, De Lorenzo F, Lagergren P, Mennini FS, Narbutas S, Scocca G, Meunier F; European Academy of Cancer Sciences. Challenges and solutions to embed cancer survivorship research and innovation within the EU Cancer Mission. *Mol Oncol.* 2021; 15:1750-1758. doi: 10.1002/1878-0261.13022 . PMID: 34053182



Defining the app with patients

The smartCARE project has made significant **effort to ensure that cancer patients, survivors, and caregivers are at the heart of developing a prototype app. The team has worked closely with the European Cancer Organisation's Patient Advisory Committee (PAC), soliciting its advice and implementing its recommendations.** PAC helped define an initial set of functionalities, which were then evaluated by the app developer, patient organisations, clinicians, and consortium members. This process resulted in the creation of the prototype's four core modules.

In the summer of 2023, these **modules were presented during patient-led workshops attended by 50 survivors of different cancers and age groups.** In addition, smartCARE participated in the International Brain Tumour Alliance World Summit, running a special workshop on neuro-oncology survivorship. Clinicians, survivors, patients, and caregivers then actively advised Billbomática, the prototype's developer.

An **extensive pan-European user needs survey, distributed in 18 languages, provided further insights,** which will help inform the next phase of development.

Disseminated in **18 Languages** the survey gathered over **1000 responses** from **52 countries.**

Results

Less than half of respondents reported satisfaction with follow-up care, and many found it difficult to track their health data. As EU citizens generally trust their healthcare systems, the integration of the EU Smart Card into National Cancer Plans could address many of these concerns. Harmonisation with other EU initiatives—such as promoting healthy lifestyles, preventive measures like vaccination, and psychosocial support—is essential. If made mandatory for cancer centres, the **Smart Card could become a key tool, establishing a new standard of care across the EU.**

Finally, the app **underwent pilot testing with end users, and the results were reviewed by PAC to ensure the prototype reflects their vision and the needs** of future users. Key findings from the pilot testing are summarised on page 6.

1028

1028 (76%) said they would use the app if it was recommended by their doctor, 296 (22%) said not sure yet, only 28 (2%) said no.

46.5%

Are satisfied with the follow up care they (or the person they care for) received this was lower amongst adolescence and young adult (30.6%)



smartCARE has the power to transform cancer care delivery and improve patient outcomes like never before. By leveraging digital technologies and innovation, we can create a patient-centred, integrated, and sustainable survivorship ecosystem that meets the needs of European patients and their families.'

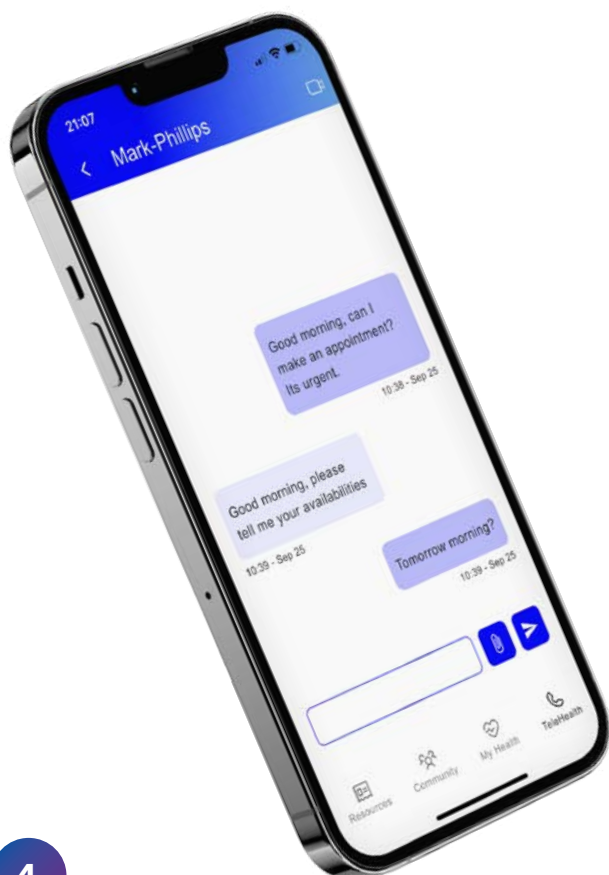
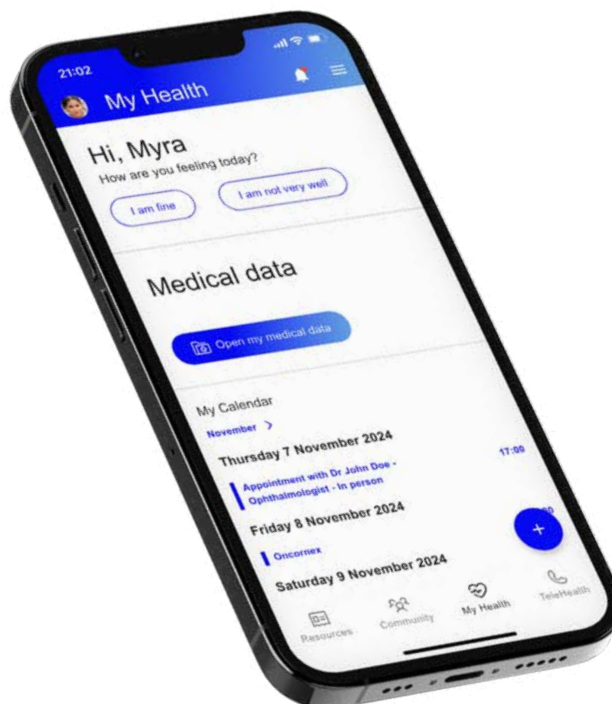
- Csaba Dégi, President of the European Cancer Organisation and Co-Chair of the smartCARE Steering Committee

The Prototype



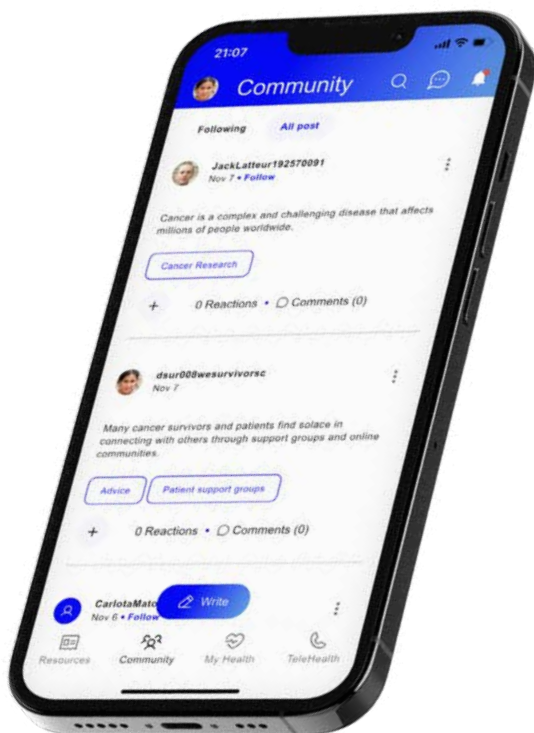
MyHealth

The MyHealth module is designed to provide patients and survivors with a **portable tool to access their medical data, share information with healthcare providers, while maintaining complete control of their files in a paperless format.** Users of the final app will be able to **upload their treatment data and generate a PDF summarising their medical history, track symptoms, medications, and appointments, and manage their habits** to support a healthy lifestyle. In addition, users of the Survivorship Passport tool will also be able to integrate their treatment summary into the app. The prototype currently includes early versions of these core functionalities, which will serve as a foundation for the second development phase.



Telehealth

The Telehealth module will **allow individuals to connect with their healthcare providers through video calls, text chats, and file sharing**, significantly reducing the need for in-person appointments. The current prototype contains an initial version of these functionalities and has been tested by potential users. Telehealth will offer flexibility for those managing ongoing health conditions or seeking routine follow-ups. Users will have the ability to connect directly with consenting healthcare providers they trust, and will **retain control over their personal data**, deciding which information is accessible to healthcare providers and sharing only what they wish.



Community

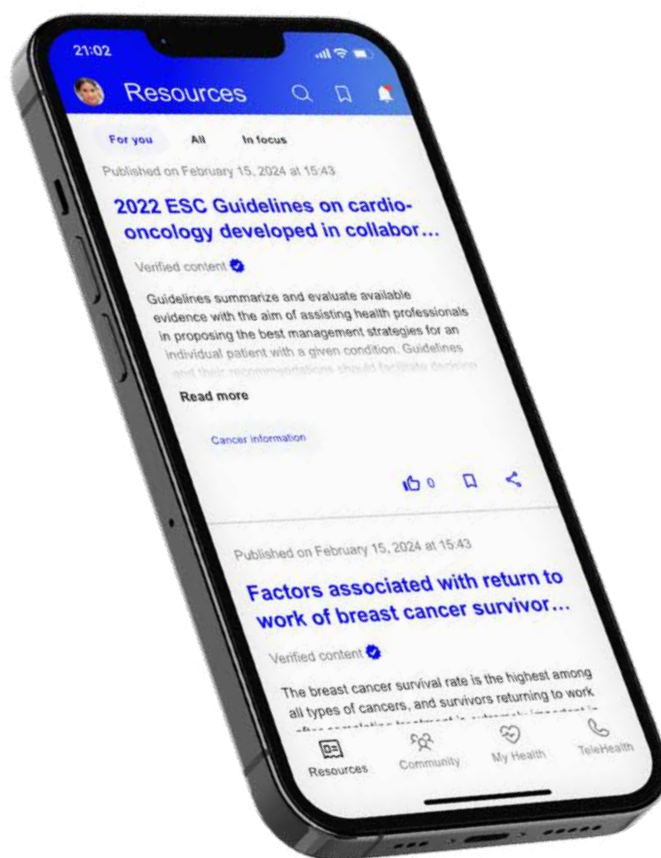
The Community module provides a **supportive platform for people who have experienced cancer, offering a space where they can connect, share personal stories, and provide emotional support to one another.** Users will be able to search for posts, photos, and videos that resonate with their experiences, while also creating, editing, or removing their own posts. Additionally, users will be able to engage with others through a private one-on-one messaging feature, commenting on posts, advancing meaningful conversations, and building a sense of solidarity and support within the community.



Resources

The Resources module provides **access to articles, guidelines, podcasts, videos, and more.** It currently features content compiled and validated by smartCARE or generated by automated tools from the app developer, Bilbomática. The resource library also includes a Personalised Resource Recommender System (PRRS) to suggest new content to users based on their previous likes, saves, and searches.

Given the sustainability concerns associated with the resource bank, a signposting system was proposed to help navigate the comprehensive resource library required by the PRRS. Signposting would leverage synergies with other European initiatives and will be tested in future versions of the app to determine its usefulness, based on feedback and improvement points gathered from PAC.



Piloting

To ensure that cancer patients, survivors, carers and clinicians are involved at every stage of development, **a pilot test was conducted which yielded valuable data on the prototype's performance, technical functionality and user satisfaction, guiding further app refinement and development.**

An **Observational Study** was conducted over several weeks to assess user perceptions of the prototype app. A total of 16 healthcare providers and 92 patients and survivors participated. They included survivors of childhood and adult cancers – covering a variety of different cancer diagnoses² from cancer centres in Czechia, Slovenia, Spain and Italy.

Usability Testing involved a hands-on evaluation where 50 cancer patients, survivors, caregivers, friends and family and healthcare providers interacted with the app prototype in different scripted scenarios to identify any usability issues. The testing assessed user interface, ease of use, and overall user experience (some of the feedback has already been incorporated in the latest prototype). Specific features examined included: visual appearance; navigation and layout; usability of features; support in health self-management and in communication with healthcare providers; and access to peer support.

Selected findings from piloting:

- Although the early prototype was tested before it was fully functional, patients and survivors rated it within the positive range on average for all performance measures examined. The average overall satisfaction with the prototype received a **positive average rating of 3.1 out of 5 in the observational study.**
- The app's top-rated feature amongst patients and survivors was improving communication between survivors and healthcare providers (3.9/5), with remote healthcare connectivity (Telehealth) rated most useful (4.2/5), and medical data management (MyHealth) also highly valued (3.9/5) in the observational study.
- **Two thirds of the patients and survivors in the observational study said they would likely be interested in using the app in the future and recommend it to other survivors or patients as well as to their healthcare providers. Similarly, over two thirds of healthcare providers said that it is likely they would continue using the finalised app.**
- 73% of patients and survivors shared their ideas for further improvements of the app, including on rethinking the name 'weeaneersurvivors' to a more formal name reflecting the EU's support.
- The **Task Completion Rate of passing the usability testing scenarios was 88-100%** for the 45 scenarios tested, confirming ease of navigation for users.

² Breast, colorectal, prostate, brain and spinal tumours, head and neck cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, leukaemia, neuroblastoma, skin and other types of cancer.



Recommendations for Future Development

➤ **Involvement of All Relevant Stakeholders**

Ongoing collaboration between patients, survivors, carers, healthcare providers, and technical developers has proven essential. Moving forward, diverse representation must be maintained to ensure that the app is relevant for all users. This, combined with patient organisation engagement, will foster a sense of shared ownership, reduce app fatigue, and promote greater buy-in.

➤ **Additional and Refined Functionalities Requested**

Cancer survivors and caregivers requested several additional features not included in the initial prototype due to time constraints. Many specific suggestions on refining the prototype were gathered through piloting. The project's second phase should look to include time and resources to develop these functionalities and potentially conduct further research with end users beyond the prototype.

➤ **Piloting of the Prototype**

A second, larger-scale piloting phase is crucial to refine the prototype into a fully functional app. The initial pilot provided valuable insights but a more extensive and diverse sample across additional EU countries will be needed to improve and deepen functionalities and also validate clinical integration and data governance.

➤ **Decentralised Application Architecture and Flexibility**

A digital readiness survey revealed significant challenges integrating external data processors (such as the Smart Card) with clinical medical systems. While the current prototype supports scalability, we recommend that future development takes a 'decentralised implementation' approach into account – given the significant differences that exist in medical data systems and standards between hospitals across Europe. This flexibility will also ensure the digital tool can be tailored to hospitals across Europe with different needs.

➤ **Integration and Synergies with Other Initiatives**

Establishing connectivity with the European Health Data Space (EHDS) is key for enhancing data sharing and broader dissemination, supporting the app's role in Europe's Beating Cancer Plan and ensuring its relevance in the wider health ecosystem. The next phases should prioritise linking the app with existing digital health tools, such as the European Cancer Patient Digital Centre and UNCAN.

➤ **Involvement of the EU**

The EU's support of the Smart Card builds trust among users concerned about data privacy and the oversaturation of the mobile health market. EU support allows the app to remain free of charge and assures users of strong data control, encouraging widespread adoption. It will also help significantly in facilitating the implementation of a final product within Member States.

➤ **Collaboration with Member States**

Successful rollout across the EU will require strong collaboration to integrate it with local hospitals within national strategic plans. To facilitate this, the app should be available in all EU languages.



The prototype is a really, really good start. You can see the fundamentally great things that this app is capable of. It has been amazing to see how much professional and patient expertise has gone into its development. It would be a pity to lose that. We need to continue working, to have an end product that the community and professionals are going to use to increase the well-being, to improve medical treatments, and to improve psycho-social treatments.'

– Hannah Gsell, Patient Expert & Project Manager, Childhood Cancer International – Europe, and leukaemia survivor.

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