# smartCARE

**Empowering Cancer Survivors in Europe** 

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## What is the Project?





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### About **smartCARE**

Develop a Cancer Survivor Smart Card to improve the quality of life and health status of cancer survivors, in the form of a mobile application, embracing the core attributes of patient centred care.



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### smartCARE: The App Empowering Cancer Survivors in Europe

### The application will facilitate patient empowerment:

The Smart Card will facilitate patient empowerment, allowing survivors to have an easy access to their treatment summary, being able to share it with relatives and professionals but also having access to a broad range of resources and functionalities enhancing quality of life.

### It will comprise of three main elements:





Follow-up care plan and self-management tools

### How will it achieve this:

Running an extensive user needs assessment and support the technical development and piloting of the app prototype.



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## Key Facts







2 year project that started in January 2023



€2.5 million euro budget funded under the EU4Health Programme



Key deliverables:

- Extensive user needs assessment
- Results of the prototype



Organisations from 17 EU and 20 European Contries involved



Coordinated by the European Cancer Organisation



## Work Packages (WP)

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### WP1

### Coordination, Recommendations & Sustainability

This Work Package will lead the alignment of all consortium activities with the project goals and consistency across all Work Packages and convey a sustainability Plan for the app.

### Leader:

European Cancer Organisation (ECO)

### WP2 Users needs

This Work Package will achieve the fullest understanding of the range of survivor, caregiver & healthcare professionals' needs associated with the development of the smartCARE app.

### Leader:

European Cancer Organisation (ECO)



### WP3 Co-creation & Piloting

Work Package 3 will collaborate with the third-party App developer to co-create an interoperable Smart Card solution usable across a variety of healthcare infrastructures and readily available to survivors, their families and other end users.

### Leader:

<u>The International Clinical</u> <u>Research Center of St.</u> <u>Anne's University Hospital</u> <u>in Brno (FNUSA-ICRC)</u>

### WP4 Evaluation

This Work Package will ensure the quality of the project design & outputs by continual monitoring and review actions.

Leader: PanCare



### WP5 Communication

Work Package 5 will maximise project visibility and promote project results through the dissemination and exploitation of communication activities.

Leader: SIOP Europe (SIOPE)





## Our consortium



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## Where is the Project Now?





## **User Needs Surveys**





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## **Key Milestones Achieved:**

### **Scoping Assessment**

Completion of scoping assessment of relevant digital tools. Included a literature review and interviews.

### Patient-Led Workshops

3 workshops were held in June (1 paediatric, 1 AYA and 1 Adult) with an additional workshop to be held in July.

### **IBTA Workshop**

Team kindly invited to hold a workshop at the IBTA World Summit on building neurooncology survivorship plans.

### Prototype

The initial features have been defined by PAC and turned into 6 modules. Development has begun on the prototype.

### Piloting Preperation

The protocol and ethical assessment are being drafted. Resource bank is being constructed.



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## The Prototype

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### smartCARE Prototype Wire-Frame Demo



\*The design, UI and exact wording is subject to change after discussions with the designer



## Patient-Led Workshops

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In addition to support from smartCARE Consortium Members in organizing the workshops, the patient organisations within the smartCARE project have helped considerably, including outreach to their networks to survivors and moderating the sessions to ensure they are survivor led.





### Co-funded by the European Union

## **User Needs Surveys**



- Understanding the needs related to **specific adult tumour types** (e.g. breast, prostate, bladder, colorectal)
- Understanding the needs related to **paediatric cancer survivors**
- Understanding needs related to survivors' experiences in respect of **co-morbidities and complications** (e.g., cardiovascular)

In addition:

• Understanding the perspective of *healthcare professionals* through a 2-hour roundtable/workshop

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## Piloting of the Prototype

### **Usability Testing**

- Use-related safety assessment and usability measurement.
- Specifically prepared fictional scenarios will be prepared.
- This will involve scripted one-on-one interviews.
- Participants will perform scenarios with a conductor to avoid bias and will be observed by a trained monitor.

### **Observational Study**

- Continued use of the prototype application in a close-to-real environment.
- Participants will be provided with the developed version of the prototype to interact with.
- Participants for the Observational Study will be recruited through 5 medical centers in four countries, covering both paediatric and adult cancer survivors and caregivers.





## The Current State of the Prototype





## Key Findings from the Patient-Led Workshops

- 1. The uploading and tracking of medical information (such as medication and treatment) and symptom and side effects into the app.
- **2.** Telehealth functionality and the ability to communicate with peers.
- 3. Useful informational resources.
- 4. Support for mental health and anxiety.
- 5. Accessibility features (including multilingual support) to ensure the app is usable for all cancer survivors.
- 6. Importance of data protection and ensuring the user has control over their data.
- 7. Gamification to promote healthy lifestyles.





## The Prototype

Please note all the screenshots are from a very early version of the prototype and therefore resources included, wording and the design have not been validated. These screenshot should be taken as a proof of concept.



### the European Union



## Module 1: Personalised Library

Resources

Communities

My health

Tele health

**Personalised Resource Library:** suggests relevant resources to users (i.e., news, podcasts, videos, guidelines) based on their preferences and behaviour.

Contains any informational resource that would be of interest for the survivor or caregiver such as guidelines, recommendations and best practices, but also videos, podcasts or eBooks.

Through patient led workshops that survivors and caregivers value other resources highly such as information on mental wellbeing materials, information on patient rights, legal advice, selftesting, nutrition, sexuality, PTSD, side-effect and complication, and rehabilitation.



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## Module 1: Personalised Library





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## Module 6: Information and Support

**Information and Support:** a static resource bank, so a set of pages that have descriptive text, and perhaps the link to an external website. We wouldn't want to include anything to technically complicated or too long here but think that some of the information here is important enough that it shouldn't be left up to module 1 as patients or the algorhythm may not know for example.

### Examples that were brought up by survivors:

- Glossary of scientific terms (including option to click on words in articles that then shows what the word means, based on the glossary we create)
- LBGTQIA+ information
- Contact points for HCP
- List of hospitals, medical institutions and cancer centres
- Right to be forgotten
- Nutrition advice
- Mental health support
  - PTSD
- Q&A

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- Clinical trial portals
- Sexuality information
- Information on rare cancers
- Work related support



![](_page_20_Picture_17.jpeg)

## Module 2: Community

**Community:** helps interaction between users using online forum or direct chat. It's a safe place to connect with other survivors, share experiences and get support.

Peer support groups were referenced in all patient-led workshops as something that would be very important to allow survivors to connect and share their experiences.

A number of survivors expressed feelings of loneliness as they can feel like no one understands their situation, which they explained, may be alleviated through a peer support system. However, moderation is critical given the risk of misinformation.

The AYA session also recommended including peer testimonies of long-term cancer survivors for inspiration.

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![](_page_21_Picture_7.jpeg)

My health

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## Module 2: Community

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![](_page_22_Picture_2.jpeg)

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Tele health

![](_page_22_Picture_3.jpeg)

![](_page_22_Picture_4.jpeg)

## Module 2: Community

![](_page_23_Figure_1.jpeg)

![](_page_23_Picture_3.jpeg)

![](_page_23_Picture_4.jpeg)

## Module 3: MyHealth

**MyHealth:** this module will contain all features related to the clinical aspects of the tool. Including storing health data to take to your doctor or across borders and symptom and medication tracking.

All 4 patient-led workshops pointed to the importance of being able to store medical information in the app. This included inputting information on treatment and medication that they are taking but also on symptom and side effect tracking. The workshops shed light on the different types of medical information that the survivor groups would like to see in such an app.

In addition, reminder, calendar and timeline functionalities were requested for medication and appointments. Multiple groups also wanted a diary feature to accompany this.

![](_page_24_Figure_4.jpeg)

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![](_page_24_Picture_6.jpeg)

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## Module 3: Wireframe DEMO

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![](_page_25_Figure_2.jpeg)

![](_page_25_Picture_3.jpeg)

![](_page_25_Picture_4.jpeg)

## Module 5: Telehealth

**Telehealth:** module designed to improve communication between users and HCPs. Aims to provide easier access to HCPs, facilitate remote consultations, ensure continuity of care, promote timely and convenient communication, empower patients, and overcome the limitations of inperson consultations.

Connection can be made with text or video and users will be able to send resources and attachments.

Telehealth was mentioned in all patient-led workshops as something desirable for survivors.

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## Module 5: Telehealth

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![](_page_27_Picture_2.jpeg)

## Module 5: Telehealth

![](_page_28_Figure_1.jpeg)

![](_page_28_Picture_2.jpeg)

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## **Modules for the Future**

![](_page_29_Picture_1.jpeg)

![](_page_29_Picture_2.jpeg)

![](_page_29_Picture_3.jpeg)

## Module 4: MyGoals

**MyGoals:** module designed to provide users with a motivational tool to help adopt and maintain a healthy lifestyle. This will be achieved through gamification, to help provide reminders and incentives for users to complete tasks or activities.

Gamification features were mentioned and supported in 3/4 workshops to help adopt a healthy lifestyle and manage anxiety and well-being.

These tasks and activities should cover physical, social and mental-wellbeing activities such as drinking water, going out with friends or wearing your nicest clothes for a day.

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## Module 4: MyGoals

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![](_page_31_Figure_2.jpeg)

![](_page_31_Picture_3.jpeg)

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# If you have feedback or input you would like included in the project please don't hesitate to contact me:

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