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STAKEHOLDERS' ENGAGEMENT ACTIVITIES REPORT 2





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Version history

Revision	Date	Editor	Comments
1.0	26/07/2024	Farmaki, Anastasia (CERTH)	First Draft
1.1	11/09/2024	Mantziari, Despoina (AUTh)	Second Draft
1.2	12/09/2024	Plomariti, Christina (AUTh)	Review
1.5	13/09/2024	Billis, Antonis (AUTh)	Final Review
2.0	14/09/2024	Leclercq, Victoria (Sciensano)	Final Version



Outline

List of contributors	1
Version history	1
List of Figures	3
Glossary of Acronyms	4
Executive summary	5
1. Introduction	7
2. Objectives	9
2.1. Task 8.1. Ecosystem building and stakeholder's engagement	9
2.2 Task 8.2. Participatory Design	9
3.1 Task 8.1 Ecosystem Building and Stakeholder's engagement	11
3.2 Task 8.2 Participatory Design	14
4. Results	
4.1 Task 8.1 Ecosystem building and stakeholder's engagement	
4.2. Task 8.2. Participatory Design	34
5. Conclusions	
5.1. Task 8.1. Ecosystem building and stakeholder's engagement	
5.2.Task 8.2. Participatory design	
6. Annexes	40
6.1. Annex A	40
6.2 Annex B	41
6.3 Annex C	43
Appendix	

List of Figures

- Figure 1. Tasks 8.1 and 8.2 interconnections with the others WPs
- Figure 2. Summary of main outreach mechanisms for each stakeholder group (Source: MS2.2 / WP2)
- Figure 3. Methodology about Focus Group Discussions about eCAN mobile application and eCAN dashboard
- Figure 4. HTWG Konstanz: Medical Summer School Cluster in Tirana, Albania (Sept 2023)
- Figure 5. Screenshot of the agenda of the CS_AIW online meeting in April 2024
- Figure 6. Professional occupation pie chart of the newly added stakeholders to the eCAN community during the EFMI STC 2023
- Figure 7. Shared Inspirational Material of FOR21 E+ for effective doctor-patient communication
- Figure 8. INE-CSC COST Action Annual meeting, Gdansk, Poland (August 2024)
- Figure 9. eCAN JA participating in the Planetree annual meet-up in Boston (Oct 2023)
- Figure 10. Clinicians & field experts in a family photo, after their participation in the brokerage event of eCAN JA at MEI 2024
- Figure 11. Prof. Panos Bamidis presenting at the "European and National Cancer Strategy: The Digital Leap Towards Improving Oncology Care". EU Parliament Event
- Figure 12. ENoLL hosting the EU Mission representatives, looking for the next steps in the public engagement in cancer research and care
- Figure 13. eCAN JA, represented by AUTH, at the 25th anniversary meet-up of the Panhellenic Public Health Conference, Athens Greece
- Figure 14. ELLOK hosting the 1st Greek Forum on Cancer policymaking and networking event
- Figure 15. eCAN panel during the 8th annual conference of ELLOK
- Figure 16. eCAN liaising with the PECan initiative, exchanging empowerment and patient involvement approaches in research, innovation and practice
- Figure 17. RSCN General Assembly 2023
- Figure 18. VITALISE H2020, powered by ENoLL H&W Symposium, Brussels, Feb 2024
- Figure 19. Key points scheme extracted from focus group discussions about the developed technologies
- Figure 20. Final User Requirements about telemedicine services



3 rd RHA	3rd Regional Health Authority of Macedonia
AUTh	Aristotle University of Thessaloniki
eCAN	Strengthening eHealth Including Telemedicine and Remote Monitoring in
	Health and Care Systems for Cancer Prevention and Care
EU – (MS)	European Member States
HCP	Health Care Professionals
INAB CERTH	Institute of Applied Biosciences of the Centre for Research and Technology
	Hellas
JA	Joint Action
FGD	Focus Group Discussion
WP	Work Package

Executive summary

ecan Strengthening eHealth for Cancer Prevention & Care

The Joint Action (JA) called "Strengthening e-health Including Telemedicine and Remote Monitoring in Health and Care Systems for Cancer Prevention and Care" (eCAN) started at September 2022 and aims to bring the benefits of eHealth to all citizens and patients across the European Member States (EU-MS), especially for those living in remote and rural areas. The project involves 16 countries and 35 key partners working in public health institutes, universities, hospitals, cancer centres and patient associations across Europe.

The Greek members of the consortium, led by the 3rd Regional Health Authority of Macedonia (3rd RHA), coordinate Working Package 8. The Working Package 8 focuses on "Stakeholder engagement, Education and Training" and consists of Task 8.1 (Ecosystem building and Stakeholder's Engagement), Task 8.2 (Participatory Design), Task 8.3 (Educational activities and information material for patients, caregivers and clinical experts) and Task 8.4 (Staff training & education and alignment with existing practice). This document is the Deliverable 8.2. which is an updated document depicting the final outcomes of Task 8.1 (Ecosystem building and Stakeholder's Engagement) and Task 8.2 (Participatory Design) of WP8, covering all the related activities of the second year of the project, during Months 13-24. The Deliverable 8.2 serves as the final report detailing all the user requirements of eCAN posing comprehensive requirements to the piloting WPs to ensure user engagement and the effectiveness of the designed interventions.

Within the context of eCAN JA, Task 8.1 has had the two-fold aim to a) explore the already existing stakeholder ecosystems and networks in the involved countries and in third-parties outside the project's consortium, in order to build a strong and active "eCAN community ecosystem", as well as b) provide methods and tools for the effective engagement of community's various targeted stakeholders to the different activities of the project, with a special focus on supporting the piloting activities of Working Package 5 and 7. The current document summarizes all the actions undertaken by WP8 partners towards the service of Task 8.1's objectives, as they are presented and analysed in the next chapters. Since Task 8.1 is a horizontal activity that runs throughout the entire lifecycle of the eCAN initiative, the included activities in D8.2 depict only a part of the ongoing actions regarding the Ecosystem Building and Stakeholder's Engagement, which were conducted during the second half of the project. In the second year of the project, after mapping the existing stakeholder ecosystem and consulting with partners via thematic workshops (D8.1), the focus shifted to making contacts with stakeholders and liaising with other organizations and networks, with a special

focus on stakeholders beyond the eCAN partners. This effort aimed to expand the impact of eCAN and increase its visibility. It is noted that just like the first year of the eCAN, Task 8.1's activities have been performed in strong collaboration with the WP2 "Communication" and the support of WP1 "Coordination" leading teams (ICO & SCIENSANO partners, respectively).

Task 8.2 aimed to define users' needs regarding telemedicine services, contributing to the scope of Working Package 4. The main goal was the participatory design of the developed technologies, undertaking activities to identify and adjust them according to end-users' real needs. The primary methods to achieve this were Focus Group Discussions (FGDs) and thinkaloud sessions. The FGDs aimed to support the participatory design framework through thematic analysis of the results. The first FGD was conducted in May 2023 (Milestone 8.5), involving key stakeholders such as patients, Healthcare Professionals (HCPs), and official caregivers, to elicit users' needs and perceptions about telemedicine. Additionally, Task 8.2 aimed to define comprehensive user scenarios following a user-cantered design approach, ensuring the sustainability of JA's outcomes through high user acceptance. To achieve this, 14 think-aloud sessions were conducted to gather potential end-users' opinions and check the usability of the mentioned applications. A second round of focus group discussions took place in December 2023 (M16) with two primary objectives: (a) Iterative assessment of the interventions' design and developed technologies, guided by "think-aloud sessions" (Milestone 7) and (b) exploration the feasibility of using corresponding applications in everyday clinical practice, considering factors significant to the users. The final purpose of all activities in Task 8.2 was to establish the final user requirements (Milestone 6). As a result, Working Packages 5 and 7, responsible for teleconsulting and telemonitoring pilots respectively, were provided with the identified user requirements. More details about the first FGD and think-aloud sessions are presented in Deliverable 8.1. Here, the Deliverable 8.2 contains the presentation of the second round FGDs as also the results of Milestone 6 as part of Task 8.2 activities.



ECAN Strengthening eHealth for Cancer Prevention & Care

The main purpose of eCAN is to bring the benefits of eHealth to all citizens and patients across the European Member States (EU-MS), especially for those living in remote and rural areas. Over the course of this two-year project (2022-2024), the consortium explored the impact of teleconsultation and telemonitoring by conducting multi-centric pilots in different populations of cancer patients, developing new applications. The main objectives of eCAN can be summarized as follows:

- I. strengthen telemedicine and remote monitoring in the cancer field by focusing on quality, users' needs and expectations.
- II. improve the health workforce's preparedness, in particular when the isolation of cancer patients is an urgent requirement, or patients live in remote areas and
- III. support capacity building and the development of modular and interoperable telemedicine solutions.

The WP8 (led by 3rd Regional Health Authority of Macedonia, 3rd RHA, Greece) has as objectives, among others, to improve the knowledge of cancer care workforce in the virtual consultations of patients and survivors, improve preparedness to respond to emergency and crisis situations and improve eHealth competencies to teleconsultation, telemonitoring services for providers, caregivers, patients. Also, some actions of WP8 are expected to contribute to the participatory design of telehealth applications developed within the JA. Thus, the Deliverable 8.2, depicts the final outcomes of Task 8.1 (Ecosystem building and stakeholder's engagement) and Task 8.2 (Participatory Design) of WP8.

In D8.2, the activities of Task 8.1, centered on its two key pillars—ecosystem expansion and enhanced stakeholder engagement—are comprehensively documented. This report provides a chronological overview of all actions undertaken by the eCAN consortium under the leadership of the WP8 Greek partners' team (AUTH, CERTH, 3rd RHA) during the JA's second year. The primary objectives during this phase were to build upon the existing networking groundwork established among the participating EU countries in the first year, facilitating the further development and expansion of the eCAN ecosystem. This was achieved through strategic collaborations with other clusters, networks, and organizations. Consequently, these synergies significantly contributed to raising awareness of eCAN across the EU and beyond. By presenting eCAN at various events and engaging with a wide range of stakeholders, we received invaluable feedback that has been instrumental in refining our project and guiding its activities, also receiving invaluable feedback for future extensions of the eCAN. Regarding Task 8.2, Deliverable 8.2 outlines all the actions taken to validate the intervention design during the development of eCAN technologies (mobile application and dashboard), including the incorporation of feedback collected during the think-aloud sessions. This validation was achieved through the second round of focus group discussions (FGDs) and their thematic analysis. Additionally, the Deliverable 8.2 details the definition of final user requirements for telemedicine services, which was accomplished through a comprehensive report on the results of the participatory activities conducted within the context of eCAN JA. To achieve all the above, this document has the following structure:

Section 2. Objectives: describe in detail, the objectives of Task 8.1. and Task 8.2. and how these are related with other actions and WPs of JA eCAN.

Section 3. Methods: describes the methodology followed in order to achieve tasks' goals

Section 4. Results: presents the results for each task

ECAN Strengthening eHealth for Cancer Prevention & Care

Section 5. Conclusions: summarize the key outputs of the described activities

Section 6. Annex: contains detailed reports of the relevant activities

ECAN Strengthening Helalth for Cancer Prevention & Care

2. Objectives

2.1 Task 8.1. Ecosystem building and stakeholder's engagement

During the second year of the eCAN Joint Action, the focus shifted towards strengthening and expanding the established ecosystem and deepening stakeholder engagement, as outlined in D8.1 and MS2.2. The primary objectives included the expansion of the identified, targeted stakeholders, who could play a crucial role in advancing the project's outcomes and ensuring their long-term impact. This involved a comprehensive strategy to build upon the mapping conducted in the first year, allowing us to identify our weak points and engage diverse groups across the quadruple helix of science, policy, industry, and society. Special emphasis was placed on reaching cancer patients, survivors, caregivers, healthcare professionals, and policymakers at the EU, national levels, and beyond.

To achieve this, the leading team concentrated on implementing the detailed stakeholder engagement framework under Task 8.1, as provided during the first year of the project to the entire consortium. This framework was designed to guide collaborative efforts and streamline communication with various stakeholder groups, particularly focusing on those with whom eCAN had previously had less access (D8.1). The process involved identifying the most relevant audiences, determining how consortium partners were best positioned to reach each stakeholder group, and defining the timeline, roles, and opportunities— such as events and online meetings—for engagement.

As a result, the outcomes of the eCAN initiative were widely disseminated through public events, EU project clusters, brokerage events, and other communication channels. These efforts were instrumental not only in promoting the eCAN initiative but also in gathering valuable feedback that has shaped the project's direction and ensured its alignment with the real-life needs of cancer patients, survivors, and **other key stakeholders**.

2.2 Task 8.2. Participatory Design

WP8, and specifically Task 8.2, aims to develop a participatory design framework following the user- centered design approach, contributing to the development of eCAN technologies (contributing to WP5 and WP7) and ensuring the sustainability of the JA's outcomes through high user acceptance (contributing to WP4). To achieve this, and continuing from the first year's activities (e.g., the first FGD and think-aloud sessions), CERTH's team needed to validate the interventions guided by the think-aloud sessions conducted in May 2023. This



was accomplished with a second round of FGDs (Milestone 7). Finally, an analysis of all identified user requirements was completed, marking the completion of Milestone 6, aiming to identify user requirements for the developed technologies as well as for telemedicine services in general. All the actions were taken in order to ensure projects' sustainability (contributing to WP4).

In the following figure, we depict how tasks 8.1. and 8.2. are connected with the others WPs of JA eCAN.

eholders mapping Focus Groups	ask 8.1 Ecosystem building & stakeholders engagement	Task 8.2 Participatory Design
natic workshops on stakeholder engagement "Think-aloud" sessions	keholders mapping ematic workshops on stakeholder engagement	

Figure 1: How the tasks 8.1 & 8.2 are connected with other eCAN WP

3. Methods

ecan Strengthening Health for Cancer Prevention & Care

3.1 Task 8.1 Ecosystem Building and Stakeholder's engagement

During the first year of the eCAN project, Task 8.1 undertook a comprehensive Stakeholder Mapping Survey to evaluate the current stakeholder landscape, identifying both strengths and areas needing improvement within our network. This survey was instrumental in highlighting where our stakeholder engagement efforts were robust and where gaps existed. Concurrently, we organized Thematic Workshops on Stakeholder Engagement, which provided tailored advice and strategic approaches for engaging various stakeholder groups. These workshops were designed to strengthen collaborations, enhance the impact of our initiatives, and boost the visibility of the eCAN project. This work was conducted in close coordination with ICO (WP2 lead partner) and Sciencano (WP1 lead partner), ensuring a cohesive and effective approach. A detailed analysis of these findings can be found in D8.1 and MS2.2 (Figure 2, Section 6.1 Annex A).

In summary, the survey results provided valuable insights into the eCAN project's stakeholder landscape. It was evident that participating organizations have considerable experience working with policymakers and the scientific community, consistent with their backgrounds in health authorities and research institutions. There is also notable experience with clinicians, given their roles in hospitals and clinical centres. However, the survey revealed a significant gap in engaging with the broader society, particularly with citizens and non-professional stakeholders. This gap presents a crucial opportunity to enhance our stakeholder engagement efforts as the project advances. Additionally, the survey highlighted the types of activities in which different stakeholder groups are involved. Policymakers and the scientific community are primarily engaged in agenda-setting, policymaking, and solution evaluation, while healthcare professionals focus on implementation and piloting. Conversely, civil society, including patients and caregivers, has predominantly participated in dissemination activities, with less involvement in policymaking and implementation. These findings underscore the necessity for tailored strategies to better integrate civil society into the project's core activities, ensuring that the eCAN initiative effectively meets the real-life needs of its target population.



Figure 2: Summary of main outreach mechanisms for each stakeholder group (Source: MS.2 /WP2)

Based on the main results of the survey, we identified key target groups and specified networks, organisations, other R&I initiatives and events that the eCAN initiative should aim to engage and integrate into its network. Specifically, the survey indicated a need to establish connections with a diverse range of stakeholders reflecting the quadruple helix model (engaging the Academia, industrial parties and professionals, policymakers and the civil society), with particular emphasis on those who were underrepresented in the existing ecosystem:

A. **Research & Innovation**: Engage and collaborate with research and innovation initiatives, research groups, and academic clusters

- HTWG Konstanz: Medical Summer School Cluster (Germany, Balkan Countries)
- The Cancer Survivorship AI for Well-being cluster (#CS_AIW)
- ECHoS Cancer Mission Hubs
- FOR21 Erasmus+ project

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- EFMI European Federation for Medical Informatics
- Implementation Network Europe for Cancer Survivorship Care (INE-CSC)

B. **Industry & Professional Organizations**: Liaise with healthcare organizations, innovators and healthcare professional associations

- Planetree Person-centered care International Network
- SIOG International Society of Geriatric Oncology
- Medical Education Informatics 2024 brokerage event and workshop with clinicians and in-field experts

C. **Public Health Authorities and Policymakers**: Engage and collaborate with policymaking actors

• "European and National Cancer Strategy: The Digital Leap towards Improving Oncology Care" European Parliament event (follow-up invitation of the LifeChamps H2020 European Parliament final event May 2023)

• Brokerage event with the EU Missions (powered by the European Network of Living Labs – ENoLL)

• Networking event in the framework of the Pan-hellenic Public Health Conference 2024

- Frequent reports of the 3rd RHA (WP8 Lead partner) to the Greek Ministry of Health
- 1st Greek Forum on Cancer: Policy, Research & Funding Strategies

D. Patient Groups and Non-Profit Organizations

- Hellenic Cancer Federation (ELLOK) Annual Conference
- Partners of Experience (PeCan) patient-led Living Lab, powered by Thess-AHALL
- Association of European Cancer Leagues EC

E. EU networks

- (Active and Healthy Ageing) Reference Site Collaborative Network (RSCN)
- VITALISE H2020 symposium, powered by the European Network of Living Labs

It is acknowledged that some of the identified organizations may overlap across multiple groups; however, this categorization has been organized specifically for the current reporting purposes. Additionally, media outreach activities are primarily within the scope of WP2 and, as such, are not detailed in this section.

A stakeholder engagement strategy was developed, reviewed, and regularly updated to support the networking activities of the eCAN initiative. The primary aim of this strategy was to enhance the impact and outcomes of the Joint Action by achieving significant measurable results that would facilitate the successful adoption of eCAN's innovative approach both during and after the project's completion. In this context, potential extension opportunities and feedback for improving proposed activities were also explored.

The strategy encompassed targeted activities designed to maximize engagement and impact. These activities included:

- **Engagement and Communication Activities**: Participation in scientific conferences and workshops, along with coordination and communication with similar projects, to ensure widespread dissemination and collaboration.
- Community Building and Liaison Activities: Collaboration and knowledge exchange with relevant health stakeholders across Europe, particularly in the fields of cancer and telehealth, to build a robust and interconnected community.

This engagement strategy was grounded in the principles identified and promoted through the stakeholder engagement toolkit, which was released in the first year of the eCAN project (D8.1). The strategy specifically addressed areas such as:

- **Patient and Healthcare Professional (HCP) Engagement**: Ensuring effective strategies for engaging patients and HCPs in project activities and outcomes.
- **Collaboration with Policymakers**: Strategies for maximizing the impact of the project's outcomes through effective collaboration with policymaking actors.
- Liaison with EU-wide Networks: Spreading the eCAN message across Europe by engaging with established networks, ensuring broader outreach and influence.

As the primary actor responsible for ecosystem-building activities, AUTH conducted networking communications and activities with all the identified stakeholders. Of these, two engagements remained at the initial interest and communication stage due to time constraints with the collaborating partners (ECL and SIOG). A detailed timeline of all activities is provided in Section 4.

3.2 Task 8.2 Participatory Design

The first step was conducting the second round of FGDs to gather feedback from potential end users about the intervention design. Two FGDs were conducted, each with two primary objectives. The first was the iterative assessment of the interventions' design of developed technologies within the context of eCAN JA. The second was aimed to explore the feasibility

of using corresponding applications in everyday clinical practice, along with the factors significant to the users.

To achieve these objectives, it was decided to conduct two slightly differentiated FGDs: a FGD about the eCAN mobile application and a slightly different FGD about the dashboard platform. The FGD about the application was conducted with the active involvement of patients as potential end users of the developed application. The second FGD revolved around the dashboard platform, involving HCPs as potential end users. This differentiation was made to gather insights and opinions from the end users who would possibly use the corresponding technology. It was considered that patients might not be able to provide valuable feedback on the usability and features of the dashboard platform, which is used by HCPs, and vice versa. However, the initial part of both discussions was identical to ensure that both groups fully understood the intended use of the technologies.

The FGD were organised along the following three phases, as Figure 3 also presents.

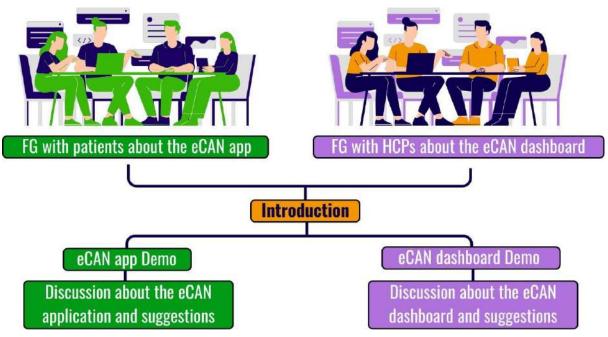


Figure 3: Methodology about Focus Group Discussions about eCAN mobile application and eCAN dashboard

Phase A: Introduction

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In both FGDs, a general introduction about the eCAN Joint Action project and its objectives was given in the initial phase of the presentation. Furthermore, to better convey the purpose of using the developed technologies (i.e., the application and the dashboard), emphasis was placed on describing the protocols **of clinical studies conducted within the project**.

Phase B: Presentation of the developed technologies



Focus group discussion about the eCAN mobile application

In the second phase of the FGD about the application, characteristic screenshots from the initial demo video of the application were used and compared with the corresponding screenshots from the final demo of the application. The selected snapshots were chosen to highlight the design interventions that occurred during the application's development, which either emerged from the partners' feedback during the testing period or from the "think-aloud" studies conducted by the INAB|CERTH team as part of Task 8.2 activities (Participatory design). Finally, a demo video of the final version was presented.

Focus group discussion about the eCAN dashboard

In the FGD on the dashboard, a demo video of the platform was presented, that focused on the features **available to the potential end user. The ability to connect via the dashboard to the Edumeet platform**, the completion of the patient's electronic case report form (eCRF), and access to electronic patient-reported outcome measures (ePROMs) were particularly highlighted.

Phase C: Conclusions

At this phase, the goal was to facilitate and coordinate a focused and meaningful discussion. For the achievement of this goal, targeted questions were used. For example, in the FGD about the application, questions such as "What did you think of the changes?", "If it were up to you, what would you add to the application?", "If it were up to you, would you use the application during your treatment?", "What would be a motivating factor for you?" were posed.

In the FGD about the dashboard, questions were posed such as: "Would you use a similar platform in your daily clinical practice?", "What would be a motivating factor for you?", "If it were up to you, what would you add to the platform?", "Is there another way you would prefer to read/view the data?", "How else would you use the data to support telemedicine services?".

Both FGDs took place online via the Zoom platform. The discussions were conducted in Greek and recorded for careful analysis of their content in a subsequent phase. The duration was scheduled to be 1 hour to prevent participant fatigue and maintain their interest in the discussion.

The number of participants chosen was five, and the sampling method was based on the common 'purposive' or 'convenience' sampling method. Considering the language used in the



discussions, availability, and positive feedback from previous FGD (referring to the FGD conducted in May), we chose to approach the Hellenic Cancer Federation, ELLOK, for the FGD about the eCAN mobile application. Eventually, five patients from ELLOK took part. Similarly, for the FGD about the dashboard, HCPs coming from the 3rd Regional Health Authority (3rd RHA), General Hospital Papageorgiou, and INAB|CERTH staff were approached. After all approaches, five HCPs participated: two psychologists from General Hospital Papageorgiou (both of whom are also involved in the pilot study), one physician coming from 3rd RHA, two psychologists coming from INAB|CERTH staff.

The first FGD regarding the application was conducted on the evening (18.00-19.00) of Monday, 11th of December 2023 while the second FGD was conducted on the morning (11.00-12.00) of Wednesday, 13th of December 2023. The presentation files are available in the Appendix (see 6.3 Annex C).

Following, a comprehensive analysis of all the participatory activities was conducted, in order to define the user requirements regarding telemedicine services and the eCAN developed technologies.



4. Results

4.1 Task 8.1 Ecosystem building and stakeholder's engagement

A detailed report on the ecosystem-building and networking activities carried out under Task 8.1 during the second half of the eCAN JA lifecycle and their main outcomes is provided below, categorized by targeted stakeholder group. A comprehensive timeline of all activities is available in the ANNEX section (see 6.2 ANNEX B).

4.1.1 Research & Innovation:

• HTWG Konstanz: Medical Summer School Cluster (Germany, Balkan Countries)¹:

The HTWG Konstanz Medical Summer School Cluster is a scientific coalition that brings together Germany and various Western Balkan countries, with participation from university medical and polytechnic schools. The cluster's primary focus is on promoting digital healthcare transformation across Western Europe.

Participating institutions include:

- Albania: Faculty of Information Technology, Polytechnic University of Tirana; Institute for Health, Social Policy and Research Development (IHSPRD)
- Bosnia and Herzegovina: Faculty of Pharmacy, University of Sarajevo
- Bulgaria: Department of Health Care and Social Work, New Bulgarian University
- Greece: Faculty of Health Sciences, Aristotle University of Thessaloniki; Faculty of Medicine, University of Thessaly; Department of Philosophy, National and Kapodistrian University of Athens
- Montenegro: Faculty of Electrical Engineering, University of Montenegro
- Romania: Department of Medical Informatics and Biostatistics, University of Medicine and Pharmacy of Timisoara
- Serbia: Faculty of Engineering, University of Kragujevac
- Germany: HTWG Konstanz Medical School

From September 4-8, 2023, the Summer School took place in Tirana, Albania, addressing critical topics related to the development of **sustainable and co-created telemedicine systems** in the Western Balkans. The agenda included discussions on sustainable

¹ <u>https://www.medical-summerschool.de/2023-2/</u>

telemedicine systems, interregional health policies, collaboration between healthcare professionals and patients, **the co-creation of telemedicine services**, **the development of a telemedicine roadmap**, and an ethics workshop.

The cluster engaged professors from all participating departments and early-stage researchers in the field, who collaborated throughout the week to address these challenges. The eCAN project was represented by the AUTH partner, who presented the Joint Action (JA) and its objectives. A live demonstration of the main components of the eCAN technical solution—including the mobile app and clinicians' dashboard—was conducted, which led to valuable feedback for further enhancements. Discussions also focused on the training program for empowerment (T8.3), with significant input received regarding content delivery and inclusiveness. Participating universities expressed a strong interest in a follow-up discussion after the completion of the eCAN project to review its outcomes.



Figure 4: HTWG Konstanz Medical Summer School Cluster in Tirana, Albania (September 2023)

• The Cancer Survivorship - AI for Well-being cluster (#CS_AIW):

The Cancer Survivorship - AI for Well-being cluster (#CS_AIW²) unites European-funded projects focused on Artificial Intelligence (AI) and other telehealth solutions aimed at enhancing healthcare and well- being, particularly in the post-cancer treatment phase. The cluster, which has been active since 2021, comprises twelve related projects (FAITH, MENHIR, ONCORELIEF, LIFECHAMPS, QUALITOP, CLARIFY, ASCAPE, REBECCA, PERSIST,

² <u>https://www.cs-aiw.eu/</u>

CAPABLE, BD4QoL, REVELIUM). It operates with a collaborative spirit, seeking external partnerships with experts in the field to share insights and best practices.

On April 5, 2024, eCAN representatives were invited to present the JA at one of the cluster's regular online meetings. AUTH, representing the eCAN consortium, highlighted the project's objectives, shared key lessons learned, and discussed challenges encountered in engaging stakeholders—especially patients— with new technologies. The cluster members expressed their support for continuing this collaborative network, inviting eCAN to participate in future meetings after the summer break. They also encouraged joint exploration of opportunities for expanding collaboration through events and future research initiatives.

URVIVORSHIP -			
WELL-BEING	Tentetine Annula		
FAITH	Tentative Agenda		
diameters.	5 th April 2024 - 1 hour (max).		
	1. Welcome. (Tom)		
	2. Business Angel sub-group – next meeting & status. (Tom)		
life¥champs	3. New sub-group. (Tom)		
	4. Exploitation, scientific paper production - status. (Manuel)		
QUALITOP	5. Video releases – status. (Alessandro)		
CLARTEY	6. European Commission meeting – readiness. (Tom)		
CLARTEY	- White Paper		
ASCAPE	- Better Practice Guide		
-	7. eCan project - collaboration invitation discussion. (Despoina)		
persist	8. AoB & next meeting. (Suggest Tuesday, 4 th June, 2024 3:15pm CET - 1 hr max)		
CAPABLE			
BD4@ob			

Figure 5: Screenshot of the agenda of the CS_AIW online meeting in Apr 2024

• EFMI – European Federation for Medical Informatics

In October 2023 a workshop presenting the eCAN project, the main technologies developed, the pilots and the evaluation framework employed was organized within the context of the EFMI STC 2023 conference. The workshop was leveraged as a liaison opportunity with various stakeholders, across the academic, health and technology sectors. Researchers from AUTH, CUT and Sciensano formed a panel, interacting with the audience and engaging into meaningful discussion towards the following core thematic areas:

- Adoption of telehealth from a clinical and technical perspective
- Digital literacy and empowerment of stakeholders towards telehealth
- Security and privacy issues in telemedicine

- Sustainability of telehealth concerning EHDS

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- Secondary use of telemedicine data and AI

After the end of the presentation and the conversation, the audience was prompted to join the eCAN stakeholders' network by leaving their connection details. 14 participants responded positively to the call and became a part of the eCAN community.

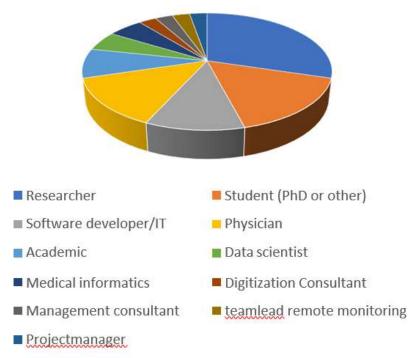


Figure 6: Professional occupation pie chart of the newly added stakeholders to the eCAN community during the EFMI STC 2023

• ECHoS – Cancer Mission Hubs³

GOEG partner, active actor also in the ECHoS project, extended an invitation to the eCAN for liaising with the Cancer Mission Hubs initiative in late July 2024. In the framework of the "Toolbox for citizen participation in Mission Cancer" that is under development within the ECHoS project, the GOEG partner looked for best practices, including the Living Lab methodology and other engagement practices. AUTH, as a Living Lab expert group, was interviewed, also sharing knowledge and advice from the eCAN Thematic Workshops on Stakeholder Engagement, implemented in 2023.

It is noted that ECHoS aims to support the Cancer Mission activities across Member States and Associated Countries by establishing Cancer Mission Hubs at various levels. Its broad scope extends beyond research to include cancer control areas such as employment,

³ <u>https://cancermissionhubs.eu/</u>

education, and socioeconomic aspects. By focusing on prevention, early detection, treatment, and survivorship, ECHoS ensures alignment with EU priorities like equity, sustainability, and digital health. This aligns with eCAN's objectives by integrating its innovative approaches into broader cancer policy and support remote care frameworks.

• FOR21 - Erasmus+ project

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The FOR 21 project, titled "Fostering the Doctor of the 21st Century: Education for Patient-Centered Communication," is an Erasmus+ Capacity Building in Higher Education initiative⁴. The project involves a consortium of prestigious institutions, including Aristotle University of Thessaloniki (Greece), University of Leeds (UK), University of Oulu (Finland), Asfendiyarov Kazakh National Medical University (Kazakhstan), North Western State Medical University named after I.I. Mechnikov (Russian Federation, partner until April 9, 2022), Samarkand State Medical Institute (Uzbekistan), Karaganda Medical University (Kazakhstan), and Tashkent Medical Academy (Uzbekistan). The project also includes associated partners such as Open Knowledge Foundation (Europe), the Association of Tyumen Region Therapists (Russian Federation, partner until April 9, 2022), National Association "Primary Health Care" (Kazakhstan), and the Association "Doctors of Uzbekistan" (Uzbekistan).

The primary goal of FOR 21 is to enhance medical curricula by developing educational strategies, methods, and tools aimed at improving doctor-to-patient communication. This includes building communication competence and social responsibility among medical professionals. The eCAN project engaged in a series of online and one face-to-face (at MEI 2024 Conference) communication sessions with the FOR 21 research team to explore potential synergies and knowledge exchange. These interactions focused on interactive, scenario-based learning activities and the development of content for the Empowerment Training Programme for patients, relatives, and clinicians (Task 8.3).

The collaboration, inaugurated during spring 2024, provided valuable insights and resources for improving doctor-to-patient communication, empathy, and trust. FOR 21 shared inspirational materials and lessons learned on effective communication practices, while eCAN contributed its expertise on transforming communication protocols, trust, and empathy in remote care settings.

⁴ <u>https://for21.eu/</u>



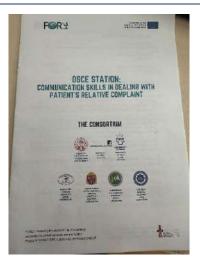


Figure 7: Shared Inspirational Material of FOR21 E+ for effective doctor-patient communication

• Implementation Network Europe for Cancer Survivorship Care (INE-CSC):

The INE-CSC COST Action⁵ is a transnational network currently comprising 190 members across various countries, including Australia. The primary objective of this COST Action is to systematically support the sustained integration of evidence-based interventions into routine clinical practice, focusing on creating a cross-boundary, systems-level cancer survivorship pathway to enhance the health and well-being of cancer survivors. This initiative aims to build a sustainable network of researchers, clinicians, patients, policymakers, and other stakeholders to integrate emerging knowledge on cancer survivorship, digital health solutions, and implementation science, fostering a sustainable model of care for cancer patients.

The COST Action employs an Implementation Science perspective to address the contextual factors impacting the effective implementation of cancer survivorship care in Europe. It identifies barriers across four levels: individuals and the public, healthcare professionals, healthcare organizations, and the environment. Working Group 2 (WG2) will map and develop preliminary models outlining these contextual factors, particularly focusing on the integration of digital solutions such as electronic patient-reported outcomes, virtual care models, artificial intelligence (AI), and solutions developed during the COVID-19 pandemic. Working Group 3 (WG3) will use the data from WG1 and WG2 to create a theory-based framework and toolkit to support the multilevel implementation of evidence-based cancer survivorship care.

⁵ https://www.inecancersurvivorship.com/index.html



The INE-CSC COST Action held its annual meeting and conference from August 28-30, 2024, in Gdansk, Poland. The event saw the participation of over 70 experts, researchers, and healthcare professionals. During this meeting, the AUTH team explored opportunities to feature the eCAN initiative as a leading example of digital health transformation in cancer care.



Figure 8: INE-CSC COST Action Annual meeting, Gdansk, Poland (Aug 2024)

4.1.2 Industry & Professional Organizations

• Planetree - Person-centered care International Network

Planetree⁶ is a global network with over 800 healthcare providers across 35 countries, dedicated to person-centered care that improves patient engagement, clinical outcomes, and staff retention. With a focus on digital transformation post-COVID-19, Planetree explores advancements in patient- centered care. At their October 2023 annual meeting in Boston, USA, the eCAN, alongside the LifeChamps H2020 project, led an innovation session titled "Living Labs: Patient & Family Engagement in Oncology Healthcare Innovation." This meet-up, renowned for uniting healthcare professionals committed to humanizing healthcare, provided a key platform to share insights and innovations. The session highlighted methods for engaging patients, families, and community partners in co-creating and evaluating solutions, addressing implementation challenges, and empowering professionals. The feedback collected during this event was instrumental for refining the eCAN engagement strategy for the pilots and the empowerment training programme.

⁶ https://www.planetree.org/



Figure 9: eCAN JA participating in the Planetree annual meet-up in Boston (Oct 2023)

• SIOG - International Society of Geriatric Oncology

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The International Society of Geriatric Oncology (SIOG)⁷ is a global multidisciplinary network dedicated to the care of older cancer patients, encompassing over 80 countries. This network includes geriatricians, medical oncologists, surgical oncologists, radiation oncologists, anesthesiologists, and allied **health professionals**.

Within this network, the AI in Healthcare Working Group, led by an AUTH partner, focuses on generating and disseminating educational content about the adoption and empowerment of digital technologies, including telehealth solutions, in clinical and care practice, one of them is the eCAN. In April 2024, Task 8.1 initiated a new round of discussions with SIOG to explore further collaboration opportunities with eCAN. However, due to time constraints on SIOG's side, these discussions did not progress as planned.

• Medical Education Informatics 2024 – brokerage event and workshop with clinicians and in-field experts

At the Medical Education Informatics 2024 conference⁸, the eCAN WP8 Greek Team, comprising 3rd RHA, CERTH, AUTH, ELLOK, G.H. Papageorgiou Hospital, and PASYKAF from Cyprus, organized a brokerage event and open-to-all networking session. This event gathered clinicians and field experts from Greece and beyond. During the conference, G.H. Papageorgiou and PASYKAF presented preliminary lessons and challenges encountered in their pilot studies with patients, emphasizing engagement and trust in telecare technologies.

⁷ <u>https://siog.org/</u>

⁸ <u>https://mei2024.org/</u>

Over 15 clinicians and health/tech providers were introduced to the eCAN JA, offered valuable insights and recommendations, and expressed interest in future collaborations. They also requested participation in upcoming pilot activities and indicated a desire to receive the final outcomes of the eCAN pilot studies.

Additionally, during the session the eCAN JA introduced to interested participants and offered a hands-on experience with the first module of the designed curriculum for the empowerment training program, managing to collect expert feedback prior to programme's official launch. The training programme focuses on enhancing skills in coping strategies, shared decision-making, patient rights, communication, psychosocial assessment, and managing difficult conversations. This activity is also part of Task 8.3 and **it will be covered in detail in D8.4**.



Figure 10: Clinicians & field experts in a family photo, after their participation in the brokerage event of eCAN JA at MEI

2024

4.1.3 Public Health Authorities and Policymakers:

• "European and National Cancer Strategy: The Digital Leap towards Improving Oncology Care" European Parliament event

On November 1, 2023, (currently former) Greek MEP Stelios Kympouropoulos and the Hellenic Cancer Federation-ELLOK, in collaboration with the LifeChamps H2020 project and the AUTH Medical Physics & Digital Innovation Lab, organized the event "European and National Cancer Strategy: The Digital Leap towards Improving Oncology Care." This event brought together key stakeholders to discuss innovative **approaches in oncology care**, **focusing on**:

- Progress, Challenges, and Prospects of Oncological Care in Greece

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- New Digital Tools for Cancer Management in Europe and Greece
- Leveraging New Healthcare Technologies and Innovative Pharmaceuticals for Cancer

During the second panel, Prof. Panos Bamidis, Director of the AUTH Medical Physics & Digital Innovation Lab, presented the eCAN Joint Action, highlighting "New Digital Tools for Cancer Management in Europe and Greece," along with other EU-wide best practices in digital cancer care transformation. The eCAN initiative garnered significant attention from policymakers and stakeholders earlier in spring 2023 during the final Parliamentary Event of the LifeChamps project. At this event, the eCAN Joint Action was represented by Sciensano, which highlighted that inequalities in cancer healthcare exist both within and between countries and a mean to address these, is by integrating telemedicine services to standard care.



Figure 11: Prof. Panos Bamidis presenting at the "European and National Cancer Strategy: The Digital Leap towards Improving Oncology Care." EU Parliament Event.

• Brokerage event with the EU Missions (powered by the European Network of Living Labs – ENoLL)

On May 30, 2024, Brussels hosted a pivotal networking and brokerage event showcasing the role of Living Labs in advancing EU Missions and Partnerships. Notably, the Cancer Mission was highlighted as a key area where Living Labs drive impactful research and innovation. The eCAN project was prominently featured, by AUTH partner, demonstrating its end-user

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engagement strategies and commitment to inclusive, participatory research and open innovation. The event underscored the significance of integrating diverse stakeholder perspectives to enhance cancer care and survivorship through Living Labs and other Public & Patient Involvement approaches. This gathering emphasized the need for collaborative, open innovation to address complex health challenges and advance the Cancer Mission's goals. The Mission's representatives emphasized the role of demonstrating projects in shaping the future funding calls and collaborating opportunities.

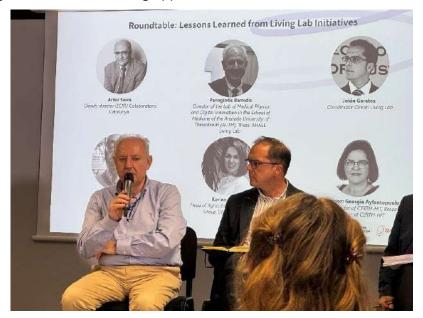


Figure 12: ENoLL hosting the EU Mission representatives, looking for the next steps in the public engagement in cancer research and care

• Networking event in the framework of the Pan-hellenic Public Health Conference 2024

Under the theme "Population Health in the Face of the Climate Crisis," the Panhellenic Public Health Conference, held from June 13-15, 2024, at the Public Health School of the University of West Attica (PA.D.A.), focused on the connection between the climate crisis and population health. As the annual meet-up also celebrated its 25th anniversary, a series of networking events among researchers, practitioners and public health policy making actors were organised. Specifically, the Hellenic Society of Public Health (E.E.D.Y.), as the organizer, along with the Department of Public and Community Health of the University of West Attica (PA.D.A.) and the Public Health and Social Medicine Forum, as scientific supporters, invited all relevant public health bodies, the scientific and academic community of medical and social sciences, as well as representatives from the private sector and scientific societies, to participate. Among the participants was the eCAN Joint Action (JA), represented by the WP8 Greek team, which presented the initiative's engagement and stakeholder involvement



strategy during the "Technology & Innovation in Health" session. The presentation captured significant attention and sparked interest in collaboration and knowledge exchange from the Medical School of Thessaly and the University of Ioannina, as well as from the Hellenic Society of Public Health (E.E.D.Y.), particularly in the areas of participatory and open innovation, aiming to drive the effective digital transformation of public healthcare services.



Figure 13: eCAN JA, represented by AUTH, at the 25th anniversary meet-up of the Pan-hellenic Public Health Conference, Athens Greece

• Frequent reports of the 3rd RHA (WP8 Lead partner) to the Greek Ministry of Health

The 3rd Regional Health Authority (WP8 Lead Partner) has consistently provided frequent reports to the Greek Ministry of Health and other key policymakers, detailing the progress of the eCAN Joint Action. These updates, spanning on a monthly basis from October 2023 to September 2024, have been accompanied by discussions aimed at engaging national policymakers in the activities of the eCAN and encouraging their contributions to its outcomes. This proactive approach has significantly facilitated the creation of synergies with high-level departments within the Ministry, effectively promoting the aims and scope of the Joint Action initiative across Greece. These efforts have extended beyond the Central Macedonia region, which is already participating in the eCAN, to other national health districts, ensuring a broader impact of the initiative.

• 1st Greek Forum on Cancer: Policy, Research & Funding Strategies

As Greece advances towards implementing its National Cancer Plan, the alignment of policies and funding strategies with European initiatives like the European Beating Cancer Plan and the EU Mission on Cancer is crucial. Within this context, the Hellenic Cancer Federation-



ELLOK, collaborating partner at the eCAN, organized the 1st Greek Forum on Cancer on July 1-2, 2024, in Athens. The Forum served as a policymaking event and a platform to explore these challenges and opportunities by engaging key stakeholders, including representatives from government, public health authorities, research institutes, and patient organizations. The discussions focused on integrating new digital technologies, achieving system interoperability, and enhancing the connection between research and healthcare services. Aligning closely with the liaison and engagement activities of the eCAN Joint Action (JA), which has been instrumental in fostering collaboration and knowledge exchange across Europe to support the effective digital transformation of cancer care, the WP8 Greek Team had a strong presence (3rd RHA, AUTH, CERTH). By participating in this Forum, eCAN JA aimed to further strengthen its role in bridging national and European efforts, ensuring that Greece can fully leverage European programs for cancer research and healthcare innovation.



Figure 14: ELLOK hosting the 1st Greek Forum on Cancer policymaking and networking event

4.1.4 Patient Groups and Non-Profit Organizations:

• Hellenic Cancer Federation (ELLOK) Annual Conference

Within the context of the 8th annual conference of the Hellenic Cancer Federation (ELLOK), a panel consisting of researchers from the Greek team, 3rd RHA, AUTH, CERTH and GNP was held introducing the eCAN project to cancer patients, survivors and caregivers, along with other relevant stakeholders from the policy-making sector. The attendees had the opportunity to engage in discussions with the panelists, while useful connections were made between the work of ELLOK and possible usefulness of the outcomes of the project for them. This liaison was of particular importance, as it gave the opportunity to the actual end-users of telehealth technologies to express their concerns and thoughts and offered the panelists the opportunity to collect points of view, different from the ones coming from the scientific community, as it it is usually the case with alike projects.





Figure 15: eCAN panel during the 8th annual conference of ELLOK

• Partners of Experience (PeCan) patient-led Living Lab, powered by Thess-AHALL

In the framework of the 5th Medical Education Informatics Conference, held in June 2024 in Thessaloniki, Greece, liaised with the "Partners of Experience in Cancer" (PECan) initiative⁹, participating in a thematic satellite event and represented by the 3rd RHA, AUTH and ELLOK. The PeCan, powered by the Thess-AHALL living lab and ELLOK with the support of Pfizer medical education grants, much like the eCAN initiative, emphasizes the importance of patient-centered approaches and stakeholder empowerment and active involvement in advancing cancer care. Both projects are committed to empowering patients and fostering collaboration between the research community, healthcare professionals, and other key stakeholders. The PECan Living Lab, self-governed by citizens, mirrors eCAN's efforts to integrate patient and stakeholder engagement strategies, ensuring that cancer care services and digital health tools are effectively designed and implemented. This alignment demonstrates a shared vision across Europe for enhancing cancer care through participatory research and open science, embodying the EU Beating Cancer Plan's recommendations and highlighting the potential for both projects to drive meaningful innovation in oncology.

⁹ https://imedphys.med.auth.gr/project/partners-experience-cancer-pecan

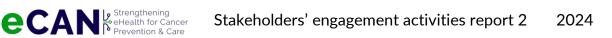




Figure 16. eCAN liaising with the PECan initiative, exchanging empowerment and patient involvement approaches in research, innovation and practice

• Association of European Cancer Leagues - ECL

The networking collaboration between the eCAN Joint Action (JA) and the - Association of European Cancer Leagues (ECL) was initiated during the LifeChamps Final Parliamentary event in the spring of 2023, where both entities were invited to participate. Following mutual interest and the potential to leverage ECL's network for disseminating the eCAN project and the empowerment training program, several online communications took place. However, these discussions have not progressed further at this time due to time constraints on the part of ECL.

4.1.5 EU networks:

• (Active and Healthy Ageing) Reference Site Collaborative Network (RSCN)

On November 13, 2023, the eCAN Joint Action (JA), represented by the AUTH partner, took part in the annual General Assembly of the Reference Site Collaborative Network (RSCN)¹⁰ during the AHL Napoli 2023 Conference in Naples, Italy. The RSCN unites all Active and Healthy Ageing Reference Sites and Candidate Reference Sites across Europe, including the 3-starred Reference Site "Thessaloniki AHA Ecosystem," also powered by the AUTH partner.

¹⁰ https://www.rscn.eu/

During the General Assembly, which was attended by representatives from the European Commission's Directorate-General for Research and Innovation (EC RTD), participants presented best practices and innovative healthcare services and systems aimed at advancing the digital transformation of Active and Healthy Ageing across Europe. Notably, telehealth solutions like those developed under the eCAN initiative were highlighted. The assembly also provided a platform to explore potential future collaborations with participating actors, including twinning actions, joint research activities, and grant proposal synergies.

It is noted that the RSCN is a European-wide, multi-stakeholder network, dedicated to promoting and facilitating the implementation and scaling-up of innovative digital solutions to support a life-course approach to active and healthy ageing.

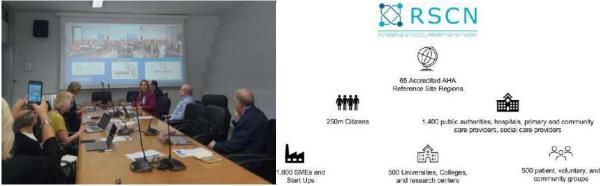


Figure 17: RSCN General Assembly 2023

VITALISE H2020 symposium, powered by the European Network of Living Labs

On February 20th, 2024, the VITALISE H2020 consortium, in collaboration with the European Network of Living Labs- ENoLL, successfully organized the "Health and Wellbeing Living Lab Symposium" in Brussels, Belgium. This symposium aimed to foster collective reflection with the European Commission, along with relevant stakeholders and beneficiaries of Health and Wellbeing Research Infrastructures. The discussions centered on shaping the future of open and community-engaged research infrastructures and innovation and policymaking initiatives, aligning with the liaison objectives of the eCAN initiative. The event provided a platform to explore how Research Infrastructures could serve as powerful tools for co-research, advancing the goals of both the VITALISE and eCAN projects in promoting collaborative and participatory approaches to healthcare innovation and policies.



Figure 18: VITALISE H2020, powered by ENoLL H&W Symposium, Brussels, Feb 2024

4.2. Task 8.2. Participatory Design

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The FGD concerning the eCAN application with patients indicated a positive reception, suggesting that the implemented interventions, guided by the "think-aloud" sessions, were well-received and considered satisfactory. In the broader context of the patient-centered design, significant key points were derived, elucidating essential aspects of patients' perspectives. (Figure 19) Simultaneously, the second FG, which focused on the eCAN dashboard and involved HCPs, provided essential key points. These findings offered valuable insights into the viewpoints of HCPs. The integration of insights from both patient and HCPs discussions contributes comprehensively to the ongoing assessment and refinement of the eCAN solutions, ensuring the sustainability of this JA. More details are presented in the Annex C, which is the report of Milestone 7.



Figure 19: Key points scheme extracted from focus group discussions about the developed technologies

The task of identifying user requirements for telemedicine services (both in general and specifically for the eCAN developed technologies) presented a significant challenge. Following a thorough analysis and a concise presentation, the final user requirements were derived, encompassing insights from various participatory design activities. These requirements serve as facilitators to understand and address the diverse needs and perspectives of end-users, reflecting the collective outcomes of the participatory design process. (Figure 20). In general:

1. Unobtrusive Communication:

• Communication should be unobtrusive for both patients and HCPs.

2. Motivation for Healthcare Professionals:

- Implement strategies to increase motivation for HCPs, including the establishment of novel reimbursement schemes.
- 3. Usability:

- Ensure the usability of all software modules, incorporating personalization capabilities for a better user experience.
- 4. Education and Training:
- Provide comprehensive education and training programs for both patients and HCPs to enhance their understanding and usage of telemedicine solutions.
- 5. Time burden reduction:
- Implement measures to reduce the time burden on HCPs, addressing issues related to overwhelming information load and time constraints.
- 6. Diverse communication means:
- Actively investigate and incorporate various communication means (e.g., email, SMS, telephone calls) beyond mobile apps and instant messaging in telehealth practice.
- 7. Legal standards and data privacy
- Ensure high legal standards, including robust data privacy measures, and provide legal support for HCPs in case of errors.
- 8. Focus on specific population groups:
- Tailor telehealth services to specific population groups, addressing the needs of people lacking mobility, minorities, and younger individuals for improved adoption and impact.
- 9. Clear terminology:

• Ensure clear and easily understandable terminology within telemedicine applications. This process should focus on end-users (e.g., the use of every-day language).

10. Address technical limitations:

• Address technical limitations such as screen size and compatibility issues with different devices and browsers.

11. Language options:

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• Include support for multiple languages within telemedicine applications to enhance accessibility.

12. Consistent information display:

• Ensure consistency in displaying information within telemedicine applications to avoid user confusion.

13. Additional features:

 Consider adding features such as language selection, a personal assistant (chatbot) for user support, and a clearer representation of scheduled sessions to enhance the user experience. Include a calendar/notebook feature for patients will help also to record their experiences and activities, allowing for a more detailed understanding of their well-being.

14. Enhanced data visualization:

• Enhance visualization of patient-reported data through diagrams for a more comprehensive understanding.

15. Concerns and impact considerations:

• Address concerns about the potential negative impact of results on patients' psychology, considering the timing and nature of pain recordings.

16. Involvement of end-users for feedback:

• Actively involve end users from clinical pilots for valuable feedback on the usability and functionality of telemedicine applications.

17. Benefits evident for both patients and HCPs:

• Ensure that the benefits of using telehealth applications are evident for both patients and healthcare professionals, contributing to a positive impact on patient care.

18. Live technical support (via telephone)

• Provide live technical support through telephone for users during the operation of telemedicine applications, ensuring prompt assistance and guidance.

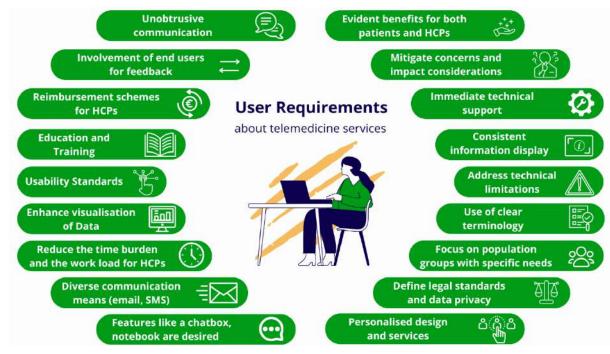


Figure 20: Final User Requirements about telemedicine services

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5. Conclusions

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5.1. Task 8.1. Ecosystem building and stakeholder's engagement

The ecosystem-building and networking activities conducted under Task 8.1 during the second half of the eCAN JA lifecycle have played a pivotal role in strengthening collaborations across various stakeholder groups, including research and innovation entities, industry professionals, public health authorities, and patient organizations. Through strategic participation in high-impact events, such as the HTWG Konstanz Medical Summer School, the Cancer Survivorship - AI for Well-being cluster, and the 1st Greek Forum on Cancer, the eCAN initiative has successfully engaged a diverse array of stakeholders. These efforts have not only facilitated the exchange of best practices and insights but have also fostered a collaborative environment that supports the digital transformation of cancer care across Europe. Notably, the eCAN's involvement with entities like the European Federation for Medical Informatics and the Reference Site Collaborative Network underscores its commitment to advancing telemedicine and person-centered care through co-creation and open innovation approaches.

The cumulative impact of these activities is evident in the expanded network of engaged stakeholders, the integration of innovative digital tools in cancer care, and the alignment with broader EU missions, such as the Cancer Mission and the EU Beating Cancer Plan. By establishing synergies with key actors, including the Hellenic Cancer Federation and the VITALISE H2020 consortium, the eCAN JA has positioned itself as a critical driver in shaping the future of oncology care in Europe. The proactive engagement of policymakers, healthcare professionals, and patient groups has ensured that the initiative's outcomes are both relevant and sustainable, contributing to a more equitable and efficient cancer care system that leverages digital health solutions to address complex challenges.

5.2.Task 8.2. Participatory design

Overall, valuable conclusions emerged from the final round of FGDs. While the developed technologies are well-received, there is always room for improvement. Both the team of physicians and the patients clearly expressed their view that the best and most useful feedback will come from the end users involved in the pilots.

Regarding the FGD with patients about the eCAN application, it is crucial to consider the significance they attach to usability study results, especially concerning the involvement of

individuals with varying levels of digital literacy. Concerning the application's usage, further emphasis and examination are needed on how patients whose health is deteriorating should be handled and how recording and immediate reading of their responses might impact them psychologically.

As for potential additional features for the application, the inclusion of a calendar was mentioned. This would assist patients in recording their daily activities and connecting them to their health progress. Additionally, there was a desire expressed for the patient-reported data to be visualized through diagrams or another visually improved method. This visualization could serve as an incentive for using such an application, as it would be evident that they have something to "gain," which is not apparent with a simple representation of numerical values. The visual representation of gains is crucial for the broader utilization of telemedicine technologies.

Regarding the FGD with HCPs about the eCAN dashboard, essential insights emerged also. HCPs emphasized the importance of the dashboard's adaptability to address unforeseen clinical needs in real- time conditions. They also highlighted the necessity for immediate telephone technical support, alleviating concerns about potential burdens in their workload or patient care. Equally valuable was the detailed guidance on navigating the dashboard.

Regarding their additional needs from a similar platform, the extraction and utilization of primary data to categorize patients and adapt therapeutic approaches were underscored. Furthermore, they deemed personalized dashboard design beneficial, considering that HCPs might follow diverse therapeutic approaches, thus having varying requirements.

However, it is noteworthy that HCPs engaged in the discussion aren't entirely inclined to exclusively use telemedicine solutions. Nevertheless, acknowledging the significant advantages they offer, they would consider utilizing them as complementary tools.

It is important to emphasize that these conclusions cannot be considered definitive as they need to be verified in the pilot studies with a larger number of end-users and of course in a real-life context as mentioned by the participants of both focus groups.

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6. Annexes

6.1. Annex A

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Part of MS2.2 "Develop and upkeep a stakeholder network, considering the stakeholders targeted by past / ongoing relevant Joint Actions related to cancer and digital transformation healthcare policies" (related to Task 8.1). Available online at: <u>https://ecanja.eu/downloads/eCAN_Stakeholders_Outreach_Approach.pdf</u>





6.2 Annex B

Timeline of the eCAN JA Ecosystem building and stakeholder's engagement activities (Sept 2023 – Aug 2024)

Date	Networking/Engagement Occassion	Targeted stakeholder Group (primary target)
September 2023	HTWG Konstanz: Medical Summer School Cluster	Research & Innovation
October 2023	EFMI – European Federation for Medical Informatics	Research & Innovation
October 2023	Planetree - Person-centered care International Network	Industry & Professional Organisations
November 2023	(Active and HealthyAgeing) Reference Site Collaborative Network(RSCN)	EU Networks
November 2023	"European and NationalCancer Strategy: The Digital Leap towards Improving Oncology Care" European Parliament event	Public Heath Authorities and Policymakers
February 2024	Hellenic CancerFederation (ELLOK) Annual Conference	Patient Groups and Non-profit organisations
February 2024	VITALISE H2020 symposium, powered by the European Network of Living Labs	EU Networks
March 2024	FOR21 - Erasmus+ project	Research & Innovation
April 2024	The Cancer Survivorship - AI for Well-being cluster (#CS_AIW)	Research & Innovation
May 2024	Brokerage event with the EU Missions (powered by the European Networkof Living Labs – ENoLL)	Public Heath Authorities and Policymakers
June 2024	Medical Education Informatics 2024 – brokerage event and workshop with clinicians and in- field experts	Industry & Professional Organisations
June 2024	Partners of Experience (PeCan) patient-led Living Lab, powered by Thess-AHALL	Patient Groups and Non-profit organisations

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Reports of the 3rd RHA (WP8 Lead partner) to the Greek	Public Heath Authorities
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6.3 Annex C

Final Focus groups about the developed technologies

Results

Focus group discussion about the eCAN application

From the first focus group discussion about the eCAN application with patients (P), it became evident that the interventions were acceptable and satisfactory. Within the broader context of the discussion, valuable key points (KPa) about patients' perspectives were extracted.

KPa1. During the usability studies, people with different levels of digital literacy should involved

During the discussion, two patients wondered if the usability studies included people with varying levels of digital literacy, and whether the changes observed came from people with different levels of digital proficiency. This would reassure them that the application is well-received by a variety of people. Here are some specific quotes:

P1: "Did you consider the digital literacy of the people who participated in the usability studies?... Maybe you could record the age range or technology education, to show that by testing it with a variety of end- users, what will be developed will be more acceptable."

P2: "I think the level of patients who participated and determined the changes plays a significant role."

KPa2. Enhancing Patient-Reported Data Visualization: Visualizing Information Beyond Numbers

During the discussion, there was a strong desire expressed for enhanced visualization of patient-provided information, particularly in the form of diagrams. Specifically, it was suggested that displaying responses in a different format than what they indicate would be preferable. For instance, concerning pain assessment, participants expressed interest in viewing a pain diagram in the results tab rather than just the numerical values they provided. This would serve as motivation, signifying that utilizing the application yields something 'novel' and valuable, beyond solely response recording. A diagram would be ideal as it would allow patients to better evaluate the progression of their health status visually. It appears that presenting pain levels solely through numbers did not meet the needs of the participating patients. Below is a characteristic quote:

P1: "The sensation of pain is very subjective and complex; perhaps the result as a number doesn't tell me anything.... I would prefer the responses in the form of progress diagrams to have a better picture.... The patient knows better the sensation of pain, and seeing the results makes the pain recording more intense, and I can show it more vividly to the doctor..... I would better understand what I have recorded."

KPa3. Concerns arise when the health condition deteriorates

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> Additional questions arose about the pain recording, e.g. whether it occurs at specific times and how negative results could affect the patient's psychology. Further analysis is necessary to understand what happens if the patient's condition worsens and how reading this recording directly might affect their psychological state.

> P3: "Is the pain recorded at specific hours/phases? Could recording during worsening moments result in negative impacts?"

KPa4. Expanding Features with a Calendar Functionality

When asked, 'If it were up to you, what would you add to the application?' the desire for adding a calendar/notebook feature was widely discussed. This key point emerged from a patient's wish to maintain a record of their activities, tracking their actions and their potential impact on their well-being.

P4: "When reporting stress levels, it would be beneficial for the patient to record their experiences throughout the week...In the end, they could see what helped or stressed them and have a picture. For instance, similar to a step-tracking application where I log my steps, I note why I didn't walk on the second day."

KPa5. The participation in the usability studies by the end users involved in the pilots was considered favorable

During the discussion, participants highlighted that the most valuable feedback on the application's usability would stem from those engaged in the clinical pilots. Their real-life application usage enables more dependable insights for enhancing usability.

P3: "In the end, there should also be a record with free-text entries detailing both positive and negative aspects observed by the participants during the usage of the application in the protocol"

P4: "When I read or someone explains the steps I should follow for the application's operation, I feel fine, but if I don't use it, I won't know if there might be a step I can't perform at some

point.....Perhaps those involved in the protocol can provide better feedback than someone who is outside and participating in a hypothetical scenario."

KPa6. The benefits of using the application should be evident for both the patient and the HCPs

A significant part of the discussion consisted of reflections on what would motivate both patients and HCPs to use a similar application in their daily lives. The main conclusion was that the benefits of using such an application must be recognizable and obvious to both sides. For example, the diagrams, as is also mentioned for KPa2, could act as an incentive for the patient by showing them what they get out of it, or demonstrate improved communication with their doctor, which is particularly important for the patient.

P3: "To demonstrate the expected benefit... perhaps through the presentation of a clinical study".

P5: "The doctor and the patient should be convinced of the benefit... For example, by graphically representing the patient's responses, the patient would feel like they are 'gaining' something from using the application."

P4: "When using a similar application, two key aspects for me are to have the freedom to use it and not be confined to a strict schedule...for example, having to report something every two hours and to feel that I'm gaining something from it (such as better visualized data, statistics, or some conclusions)".

Focus group discussion about the eCAN dashboard

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From the second focus group discussion about the eCAN dashboard with HCPs, valuable key points (KPb) about HCPs' perspective were also extracted.

KPb1. Enhancing dashboard adaptability: Addressing emerging needs in daily practice

During the discussion, it became evident that the dashboard platform needs to be adaptable from a technical standpoint. Specifically, this need was highlighted by the HCPs from the General Hospital Papageorgiou, who are also involved in the pilots. They emphasized that during the actual usage of the dashboard, certain needs arose that were identified and should be integrated into its functionality. For instance, as indicated in the following quote, there was a requirement to record specific information. According to the HCPs, similar needs should be easily accommodated within the dashboard from a technical perspective. The dashboard's adaptability is crucial for enhancing its adoption in everyday practice, addressing emerging needs effectively.

HCP1: "During the usage of the platform, there are different needs that may not have been predictable from the start... For example, how do I indicate when or where there is a change in condition... or a similar case, when we had a patient participating in the clinical study who couldn't use the application because they had a catheter and restricted movements, thus the need arose to declare this detail... The platform should adapt to these needs."

KPb2. Guidance from individuals who have used the platform in real conditions would be helpful.

Another obvious need that emerged from the discussion was that in some cases, the user step guide manuals or training videos do not fully cover the needs of end-users. It seems that during the actual use of the platform, significant details emerge that could be better described by experienced users for new users.

HCP2: 'While everything was very helpful (referring to the instructions), along the way, we discovered things that the next users would benefit from knowing. For instance, for the operation of the application by patients, the HCPs must have completed the eCRF"

KPb3. Immediate technical support during the operation of the dashboard platform is crucial

The need for an immediate response from technical support by telephone during the operation of the platform was highlighted once again. Within the scope of the project, emphasis was placed on the significance of prompt responsiveness from the respective partners to the HCPs participating in the clinical studies and how crucial this is for the smooth participation of patients in the pilots.

HCP1: "I need immediate communication and support because I have the patient right in front of me and I need to assist/guide them... Time is precious in the particular clinical environment of the hospital."

HCP2: "I cannot delay a patient who has just finished chemotherapy and wants to input their data if the application is delayed or something goes wrong with the platform."

KPb4. Enhancing primary data utility for improved patient care

When exploring alternative applications for the primary data, there was a notable interest in exporting data for personal statistical analysis and enhancing treatment planning.

ECAN Strengthening eHealth for Cancer Prevention & Care Moreover, emphasizing the integration of filters within the gathered data was crucial, as this would enable healthcare providers (HCPs) to identify patients with distinct needs. This approach could facilitate the classification of patients based on criteria like higher pain levels, increased session absences, or organizing them according to their treatment plans and monitoring their progress.

HCP3: "Can I export the data to perform some statistical analysis or use filters to see specific patients?"

HCP1: "Using filters would be very useful because I could identify patients who need more intensive therapy... for instance, if some had a stress level above 6, I could identify them and have more frequent contact, schedule extra sessions, etc."

KPb5. Personalized dashboard design aligned with individual HCP workflow

Expanding the discussion regarding what they would ideally want from a dashboard platform, it emerged that particular attention needs to be paid to the methodology and workflow of individual HCPs when developing these technologies. HCPs with different approaches have different methods of engaging with patients and therefore have different requirements.

HCP1: "I would like personalized features to be added....For example, we assign homework to patients or ask them to fill out a diary to record their thoughts... Perhaps the patient could record their thoughts... I would like these to be somehow integrated because I follow the approach of equal participation of patients and HCPs in our sessions, and it's important for me the patient learn to self-regulate through our sessions."

KPb6. A dashboard platform could be used as a supplementary tool to regular care.

Regarding the possible use of a similar dashboard platform in their daily routine, the predominant response was that this could be done in combination with conventional therapy. It seems that HCPs are not yet ready to use telemedicine services exclusively. However, they recognize the benefits and would include it as an additional tool in their daily clinical practice.

HCP1: "I could use it in combination, but I can't fully replace face-to-face communication."

HCP2: "I would use it as an additional tool... I would definitely want it as a tool, especially for patients who can only communicate with us remotely because they cannot travel."

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HCP4: "From my experience, the combined approach (remote and face-to-face communication) has the best response in patient treatment... I can draw more conclusions from the body language or the clothes they wear in face-to-face meetings...but of course, it will be useful to collect more data for my patient."

HCP5: "I understand the conveniences offered by electronic communication, but ideally, I would like the benefits of face-to-face meetings to be transferred to similar platforms... We still have a way to go to acquire the warmth of in-person meetings.



Appendix

Link for the presentation of the focus group discussion about the eCAN mobile application

Link for the presentation of the focus group discussion about the eCAN dashboard

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