STAKEHOLDERS' ENGAGEMENT
ACTIVITIES REPORT

eCAN

Strengthening eHealth for
Cancer Prevention & Care

DELIVERABLE 8.1

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Outline

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Glossary of Acronyms

3rd 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 Union (Member States)
HCP	Healthcare professionals
INAB|CERTH	Institute of Applied Biosciences of the Centre for Research and Technology Hellas
JA	Joint Action
WP	Work Package

Executive summary

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 centers and patient associations across Europe.

The Greek members of the consortium, led by the 3rd Regional Health Authority of Macedonia (3rd RHA), coordinate Work Package 8. The Work Package 8 focuses on "Stakeholder engagement, Education and Training" and consists from 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 8.1. which is a live document depicting the actual 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 first year of the project, including months 1-12. The final version will be delivered by August 2024 (M24) and will contain all the updated activities. Below, activities taken place regarding Task 8.1. and Task 8.2. are detailed.

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 Work Packages 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 D8.1 depict only a part of the ongoing actions regarding the Ecosystem Building and Stakeholder's Engagement, which will continue to be implemented to a wider extent during the second half of the project.

The two main objectives of this task were achieved through the implementation of related actions, including the mapping of existing ecosystems (via an online survey) and the

consultation with partners and knowhow exchange (via thematic workshops on engagement). It is noted that 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 had to define users' needs about telemedicine services feeding the scope of Work Package 4. This objective achieved by organizing a dedicated focus group with inviting key stakeholders (patients, healthcare professionals, official caregivers) and try to elicit users' needs and perceptions about telemedicine.

Also, Task 8.2. is dedicated to the participatory design of the developing applications which are going to be used in the JA's pilots. This objective is achieved by conducting "think-aloud" sessions in order to mine potential end users' opinion and check the usability status of the mentioned applications. In so doing, Work Packages 5 and 7 responsible for teleconsulting and telemonitoring pilots respectively, were fed with user requirements points before entered in the implementation phase.

1. Introduction

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 will explore 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 applications developed within the project. Generally, these actions of WP8 are expected to guide the provision of technical solutions in order to address any emerging needs, before the pilots start. Thus, the Deliverable 8.1, depicts the actual outcomes of Task 8.1 (Ecosystem building and Stakeholder's Engagement) and Task 8.2 (Participatory Design) of WP8.

In D8.1, all the activities of Task 8.1, related to the two pillars of a) ecosystem building and b) the effective engagement of stakeholders, are included. The document describes in a chronological sequence all the different actions, performed within the eCAN consortium, under the leadership and responsibility of the WP8 Greek partners' team (AUTH, CERTH, 3rd RHA), during the first year of the project.

The core aim of all the implemented activities in the first half of the eCAN project lifetime has been on the one hand, to explore the current status of networking among the participating EU countries, so as to provide best practices and ways towards the effective development and expansion of the eCAN ecosystem, and on the other hand, to understand the needs, strengths

and weaknesses of the consortium partners in terms of stakeholder's engagement, so as to provide them with suitable tools and methods through a comprehensive and inclusive framework (with a special focus on providing support to piloting activitiesWorking Package 5 & 7).

Regarding Task 8.2, D8.1 describes all the actions taken place, in order to define stakeholder's view about telemonitoring and teleconsulting as also to detect detailed the user requirements about the apps that are developed for the eCAN JA. In doing so, we not only fulfilled the primary objective of reporting and acquiring knowledge pertaining to user needs concerning telemedicine, but also made a substantial contribution to the testing phase of the technical solutions for the pilot projects.

Moreover, our efforts have significantly enhanced the sustainability of the outcomes within the context of Work Packages 5 and 7 by fostering a high level of user acceptance and mining/validating user requirements related to the development of applications.

To achieve all the above, this document has the following structure:

- Objectives: describe in detail, the objectives of Task 8.1. and Task 8.2 and how these are related with other actions and WP of JA eCAN.
- Methods: describes the methodology followed in order to achieve tasks' goals
- Results: presents the results for each task
- Conclusions: summarize the key outputs of the described activities
- Annex: contains detailed reports of the relevant activities as they have internally been circulated among consortium members (also in order to support the activities of the project as part of WP5 and WP7)

2. Objectives

2.1 Task 8.1. Ecosystem building and stakeholder's engagement

Ecosystem building and stakeholder's engagement are central to the eCAN initiative's objectives. One of the key objectives of the Task 8.1 has been to establish a comprehensive network of stakeholders, encompassing the quadruple helix of science, policy, industry (health/tech/care providers, clinicians, hospitals), and society (both patients and their relatives) (Mantziari et. al., 2019).

The ecosystem has to play a vital role throughout the eCAN project lifecycle, since its stakeholders will actively be involved in most of its activities, by performing piloting and testing of the technological solutions (WP5 & WP7), by participating in training activities related to the empowerment and cultivation of trust for telemonitoring/teleconsultation cancer care initiatives (WP8), by spreading the word of the eCAN initiative outside their community, as project's ambassadors (WP2), and by promoting the transformation of project's objectives and outcomes into future, concrete and bottom-up policies, based on cancer patients, their relatives and clinicians' real-life needs (WP4), bridging gaps in cancer care and telehealth. To this end, Task 8.1, as an ongoing task that runs throughout the entire project, involves the mapping of existing stakeholder networks across the participating EU countries and beyond them.

In the framework of Task 8.1, the mapping of existing stakeholder networks across the participating EU countries has been one of the main priorities of WP8, providing a foundational understanding of the current landscape.

This process was implemented in close collaboration with WP2 (interlinked with 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"), through the circulation of an online survey, aiming to identify within the consortium, already existing collaborations, networks, strengths & weaknesses and provide best practices for further community building.

Furthermore, in the context of Task 8.1, the development of a stakeholder engagement framework has been proved crucial to guide collaborative efforts and streamline communication among all stakeholders. This process, conducted through a series of online consultations with the eCAN partners (Thematic Workshops on Stakeholders Engagement), which have been invaluable in shaping the project's direction towards the effective communication and active engagement of the different types of targeted stakeholders, based on their needs, expectations, concerns.

Together, the ecosystem mapping and the stakeholder engagement form the cornerstone of the eCAN initiative, facilitating its mission to reduce disparities in cancer care, promoting synergies and activities to enhance the knowledge, adoption, and effectiveness of telemedicine to cancer patients, their families & healthcare experts/clinicians.

2.2 Task 8.2. Participatory Design

WP8 and especially the Task 8.2. has among others, the objectives to identify user needs about telemedicine, developing a participatory design framework and to achieve participatory design of the applications that are developed in the context of the JA eCAN contributing in the technical phase of the technical solutions for the pilots (WP5 and WP7) before they enter the implementation phase. To do that, CERTH's team had to define comprehensive user scenarios following the user-centred design approach, develop a participatory design framework by executing a dedicated focus group, and analyse the results to identify the user needs. In addition, a scenario-based "think-aloud" sessions approach was applied.

Results of the focus group, that took place in Task 8.2. activities, will contribute in WP4 (sustainability of the JA) and inform about user needs from telemedicine and will feed with usability key-points WP5 (teleconsultation) and WP7 (telemonitoring), the WPs that are dedicated to pilots. Along these lines, these outcomes will also produce crucial points about high user acceptance of the apps that are developing contributing once again to WP4, which is responsible for the sustainability of the JA.

Taking into account the targets of Task 8.2., CERTH's team organized a focus group with key stakeholders in order to collect their opinions about telehealth services, and analysed the results to identify the user needs, contributing to WP4. Next step was the execution of "think-aloud" sessions, using the first version of the Edumeet tool, which is developed to help the scope of the teleconsulting part of JA's pilots (WP5) and the first version of dashboard and app, which is developed to help the scope of telemonitoring part of JA's pilots (WP7).

The results of these usability studies were communicated to the relevant partners in order to inform them and improve the technical solutions for the pilots before they enter the implementation phase, achieving participatory design. Both actions served the scope of achieving high sustainability of the JA's outcomes (WP4).

In the following figure, we depict how Tasks 8.1. and 8.2. are connected with other eCAN's WP:

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

3. Methods

3.1 Task 8.1. Ecosystem Building and Stakeholder's engagement

The aim of Task 8.1 has been two-fold: on the one hand it builds a strong network of stakeholders, while on the other hand it ensures the active and effective participation and collaboration of the various targeted stakeholders, whenever and wherever necessary, in a way that maximizes impact, validity of outcomes and sustainability for the eCAN initiative. Taking this into consideration, the WP8 partners designed and implemented a bunch of different activities to cover in the best possible way the needs for Task 8.1 objectives to both ecosystem building and stakeholder's engagement.

Regarding the ecosystem building, the Task 8.1 responsible partners (AUTH, CERTH, 3rd RHA), in close collaboration with the WP2 lead partners (ICO), implemented an online survey to map the existing synergies with networks and stakeholder groups within the consortium (link with MS2.2). The results of this joint work fed the consortium with the deep knowledge of eCAN partners' previous experiences in working with different audiences to service different aims & scopes, as well as it highlighted the related weaknesses to be turned into strengths by the end of the project.

As for the crucial task of the effective engagement of stakeholders, their diversity, in terms of motivation, type of involvement, experiences, needs and concerns, highlighted the importance of developing and promoting a strategic framework to enable their active involvement in a way that maximizes impact for the eCAN initiative. The core principles towards the effective engagement of all the types of the targeted stakeholders were provided in a series of Thematic Workshops, organized under Task 8.1. The following sub-chapters describe how the Mapping

and Engagement activities were designed, as well the methods explored towards their successful implementation.

3.1.1. Stakeholder Mapping

In the beginning of 2023 (Jan 2023), WP8 and WP2 partners agreed to the circulation of a joint online survey within the eCAN consortium partners, aimed at the exploration and monitoring of existing collaborations with stakeholders and networks at the national level of each participating country, and particularly the ecosystem that each participating entity (consortium partner) maintains at their local level (see 6.1 Annex A).

Specifically, the main objective of this online survey has been the following: through a self-assessment report, each eCAN consortium partner (both main beneficiaries and affiliate entities) to provide a brief, but comprehensive status of their organization, in terms of existing synergies with stakeholders (at the local ecosystem level), as well as any previous experience/capacity in engagement strategies.

The goal has been to explore and create a common baseline of the standards & drivers within a consortium first ("what we have") -but not the needs ("what we want to have/achieve"). The outcomes of the survey were analysed under Task 8.1 and MS2.2 (see 6.2 Annex B) to launch the eCAN Stakeholder Community (MS8.1).

Moreover, the results of the survey have contributed to the deep knowledge of the consortium dynamics, weaknesses, and corrective actions towards the capitalization of the eCAN ecosystem -meaning the continuous and effective expansion of the existing stakeholder networks, and the maximization of their potential impact to the project and its objectives.

This has been a crucial and mandatory activity for all the eCAN partners, and thus each main beneficiary & affiliated entity has been requested to define one person responsible for the stakeholder community and networking (one person per partner). This person has acted as the local Community Manager, the main contact point and representative of their partner to the WP8 (& WP2) activities, related to stakeholder engagement and community building, as well as the person responsible to coordinate internally in their organization and report all the WP8/WP2 activities back to the WP8/WP2 leaders, when needed.

The rationale behind the mapping exercise has been to engage the eCAN project partners first, in a preliminary activity regarding the identification of existing collaborations and the importance of previous experiences, before building a stakeholders' community and an engagement framework. To this end, each eCAN partner entity was recommended to check

the survey internally for a couple of days, triggering an open discussion within their organization to make sure that all the different synergies with different audiences, as well as experiences (strengths and concerns) would be included in the survey answers.

Of course, it was noted from the very beginning to all the involved parties that there were no wrong or correct answers to the survey, while the information letter that was sent to the consortium clarified the following: "*The idea is to use this self-positioning survey to build a common engagement & community building strategy for ALL and learn from each other's positive & negative experiences while working with communities of people! This survey is to check "with whom we already have synergies" (MAPPING), so as to proceed to the extension of the network with specific strategies per stakeholder group*".

Following the standards of the GDPR legal framework, the survey was built on the EU Survey tool and it has a 30-minute duration to be filled in. A one-month period was given to partners as an internal deadline to answer the survey, while specific reminders and guidance were provided to those who faced some difficulties with its completion.

The survey was split in five main areas, as follows:

- General Information: main contact details of local community Manager
- Self-Positioning: frequency & level of stakeholders involvement in organization's activities (maturity of each organization)
- Stakeholder Mapping: indicative examples of collaborating actors (per stakeholder group)
- Stakeholder Engagement: examples of tools/methods used to engage stakeholders, as well as barriers/challenges
- Dissemination across the community: level of dissemination of organization's activities per stakeholder group, and channels used to perform effective dissemination

To ensure the accuracy of the survey results, the distributed online questionnaire is built upon a validated, existing tools and literature review, and part of it has already been implemented in the SISCODE H2020 project (within the eCAN context, we presented a shorter and modified version) (Smallman et. al. n.d.) However, as mentioned this is just a first version and part or entire questions might be added or removed to service the project needs, during the second half of the eCAN lifecycle, where the self-assessment activity will be repeated.

3.1.2. Thematic Workshops on Stakeholder Engagement

In spring 2023 (Apr-May), a series of four Thematic Workshops on Stakeholder Engagement was launched, under Task 8.1 activities, serving as focused mechanisms within the eCAN initiative, designed to foster meaningful interaction, collaboration, and knowledge-sharing among consortium partners. Thematic Workshops vital tools for projects, promoting collaboration and achieving objectives while building ownership among participants (Kumar 2012). These Task 8.1 workshops are meticulously crafted to address specific themes or topics of relevance to the project's objectives to engage all the quadruple helix representative stakeholder groups (science, industry, policymakers, society), to its activities to ensure stakeholders' input, insights, and involvement.

The four Thematic Workshops were organized on the ground of the '101 Design Methods' framework (Kumar 2012), having the following characteristics:

- **Targeted Engagement**: Thematic Workshops tailored to engage eCAN partners from diverse backgrounds.
- **Focused Themes**: Each workshop centers around a well-defined theme.
- **Interactive Discussions**: Prioritizing active participation and knowledge exchange.
- **Outcome-Oriented**: Aimed at generating tangible plans and recommendations.
- **Adaptive Format**: Tailored to specific needs, including discussions, groups, or activities.
- **Iterative Process**: Part of an ongoing series, building upon previous discussions.
- **Stakeholder Empowerment**: Involving stakeholders in decision-making.
- **Knowledge Sharing**: Facilitating diverse knowledge exchange.
- **Continuous Improvement**: Informing project adjustments for dynamic strategies.

The four thematic workshops, organized by AUTH partner, were built to provide guidance and support to all the eCAN partners, in order to maximise the impact and engagement of their local/national and external communities for the eCAN project and contribute to the extension of collaborations with stakeholders outside the consortium.

The Engagement Strategy Workshops were implemented as open dynamic dialogues with partners, during which appropriate levels and mechanisms/tools towards the effective engagement & collaboration with patients/relatives, healthcare professionals, policymakers, EU networks were presented.

Practical strategies for coordinating & performing effective recruitment, involvement & engagement (especially, in view of WP5 & WP7 recruitment & piloting phases) were shared,

based on Patient and Public Involvement (PPI) principles and previous experience of AUTH & 3rd RHA partners in working in Research & Innovation initiatives with cancer patients and HCPs will be shared.

The duration of each Thematic Workshop has been 2-hours, while the time plan and the specific topics, covered in each one of them, were the following:

Date	Topic	Objectives
20/04/23	Patient/HCP Recruitment and Engagement Strategy	To present the existing networks of stakeholders across the eCAN partners & capitalising them with additional stakeholder groups (eCAN Community) To raise and discuss the current challenges, related to patients/HCP's engagement (recruitment for PIs).
20/04/23	Collaboration with policymaking actors (how to maximise the impact of your work)	To share tips & tricks towards the effective engagement of Policymaking actors To identify & understand the needs of the eCan partners when working with Policymakers.
04/05/23	Liaison with EU-wide networks: spread the message across the EU	To share tips & tricks towards the effective collaboration with EU-wide networks/external organisations
10/05/23	Patient Empowerment Tips & Tricks for the use of teleconsultation solutions	To share tips & tricks towards the effective empowerment, adoption & use of teleconsultation solutions (trust, coping frames, patients' rights).

Table 1: Dates, topics and objectives of the Thematic Workshops

The final workshop on the 10th of May 2023, was also an introduction to Task 8.3 training activities, and the importance of empowering stakeholders (both patients/relatives & HCPs) in the embracement of telehealth solutions and the increase of their trust towards new technologies in health monitoring and remote consultation.

This has been an initial discussion on what comes next in WP8 and Task 8.3 during the 2nd half of the eCAN project, in relation to the crucial role of the community to its successful implementation. During this final workshop, the eCAN partners had also the opportunity to express their concerns regarding the effective engagement, motivation to participate ("What's

in it for me?") and any other needs for assist, during the organization and implementation of activities with primary stakeholders (patients & HCPs), policymakers and liaison with third parties.

3.2. Task 8.2 Participatory design

The activities of Task 8.2. are divided into two parts. The first one is about the focus group that was organized based on a live interaction with patients, doctors and patient assistant agents. The purpose of this action was to elicit the user's perception and needs about telemedicine services (i.e. telemonitoring and teleconsulting).

Our rationale was that the results will be useful for the WP4 activities, contributing to the understanding and adapting project's planning to European citizens' needs, achieving high sustainability of JA eCAN. The second part of Task's 8.2 activities are dedicated to the participatory design of the developing applications. "Think-aloud" sessions were conducted to collect user feedback and identify potential issues before the actual start of the WP5 and WP7 pilots. A more detailed description of activities follows.

3.2.1. Focus Group

The focus group conducted as part of the T8.2 activities was organized by Institute of Applied Biosciences of the Centre for Research and Technology Hellas (INAB|CERTH), Aristotle University of Thessaloniki (AUTh) and 3rd RHA and conducted virtually (via zoom), aiming to identify user needs based on a live interaction with key stakeholders, including patients, doctors and patient assistance agents (i.e., volunteers who support patients through their journey in the national healthcare system).

It should also be noted that all eCAN partners from Greece actively supported the focus group, i.e. ELLOK provided a number of participants on behalf of patients and Papageorgiou Hospital invited a number of healthcare professionals to participate.

The discussion was organized along the following three phases:

Phase1: a presentation of the project's goals, introduction of all the participants, and a presentation of the tools to be used. During this phase, several questions were also asked via an online questionnaire. (30 minutes)

Phase 2: three parallel discussions were conducted in break-out rooms (one for each participant group led by a CERTH team member/facilitator) where each participant group discussed specific issues. Furthermore, predefined "personas" were also elaborated and

challenges in terms of communication during treatment were identified. Furthermore, potential barriers regarding the use of telehealth focusing on the specific needs of each end-user group were discussed. (60 minutes)

Phase 3: a recap part, where the three CERTH team members/facilitators summarized the key points discussion in part 3 and a live discussion was conducted. (30 minutes)

The focus group was conducted late on the evening (19.00-21.00) of Thursday, 18th of May 2023 and it lasted a little more than 2 hours. The discussion was recorded and was retrospectively analysed by the CERTH team to identify the main "user goals" which could be used as a form of user requirements, and thus, they could provide valuable "user oriented" insights for the clinical trials to be conducted in the context of eCAN and the adjustment of the respective technical tools (WP5 and WP7). All the discussions were conducted in Greek. The focus group was disseminated through the project's WP2 communication channels.

The participants of the focus group participants were affiliated with the following organizations:

➢ Healthcare professionals (coming from Papageorgiou Hospital and INAB|CERTH staff)
➢ Patients (coming from the Greek association of cancer patients – ELLOK)
➢ Patient support agents (coming from the "K3" group)

The detailed participation can be outlined as follows:

- **Healthcare Professionals**: 4 o Psychologists o Physicians o Administrative stuff
- **Cancer Patients**: 5
- **Patient carers/supporters**: 4

The discussion was orchestrated by Pantelis Natsiavas. The three parallel discussions were facilitated by the INAB|CERTH team members.

- **Patients Room**: Pantelis Natsiavas
- **HCPs Room**: Panos Bonotis
- **Patient Supporter Room**: Anastasia Farmaki

For more details, you can see 6.1. Annex C.

3.2.2. "Think-aloud" sessions

The purpose of this activity was to assess the user experience and functionality of the eduMEET software (WP5), the eCAN mobile app and eCAN Dashboard app (WP7), specifically

targeting healthcare professionals (HCPs) and cancer patients, before entering the implementation phase.

The usability study followed a task execution scenario with the think-aloud approach, to bring to the surface any issues or comments a participant may have about a specific feature or screen that is part of the "script" to evaluate qualitative usability criteria. Also, a post-study questionnaire was used after each session to acquire and to also evaluate quantitative usability criteria as well.

The scales of the questionnaire cover a comprehensive impression of user experience. The usability-testing plan for the eCAN for native language reasons was conducted in Greek language. Iterations of the usability testing are suggested by the bibliography as well. Main points:

- 14 participants (7 patients and 7 HCPs)
- Greek speaking end-users in Greece
- 1,5-hour session remotely with each participant
- Think aloud session simulating real life conditions (scripted questions)
- Post-study questionnaire

All the above aim at ensuring sustainability of the JA's outcomes through high user acceptance (WP4).

For more info, see 6.3. Annex D

4. Results

4.1. Task 8.1 Ecosystem building and stakeholder's engagement

4.1.1. Stakeholder Mapping

The answers of the online self-positioning survey resulted in the analysis and synthesis of the eCAN stakeholder mapping, a joint work of WP2 and WP8 partners. The core outcomes of the survey were visualized and published in the project website by WP2 lead partners, while they were also included in the MS2.2, the related chapters of which have been added as an Annex at the end of D8.1 (see 6.2 Annex B).

The analysis of the survey led to the launching of the eCAN Community (MS8.1), also feeding the engagement community strategy and the Thematic Workshops that followed in spring

2023. A joint WP8WP8 online presentation took place on April 20th, as part of the 1st Engagement Thematic Workshop, where some preliminary results were provided to the eCAN partners.

The main two findings from this preliminary analysis have been as follows: On the one hand, the eCAN participating organizations (main beneficiaries & affiliates) are much more familiar with collaborating with policymakers and the scientific community (quite reasonable, taking into consideration their background and origin, since most of them are policymaking health authorities or research entities/universities) On the other hand, they have experience in working with clinicians (as many entities are hospitals, clinical centres, HCPs organizations), but not as much with citizens (Figure 2).

These findings fed the thematic engagement workshops of Task 8.1 and the engagement framework that will be implemented in the activities of the second half of the project, with a special focus on piloting (WP5 & WP7).
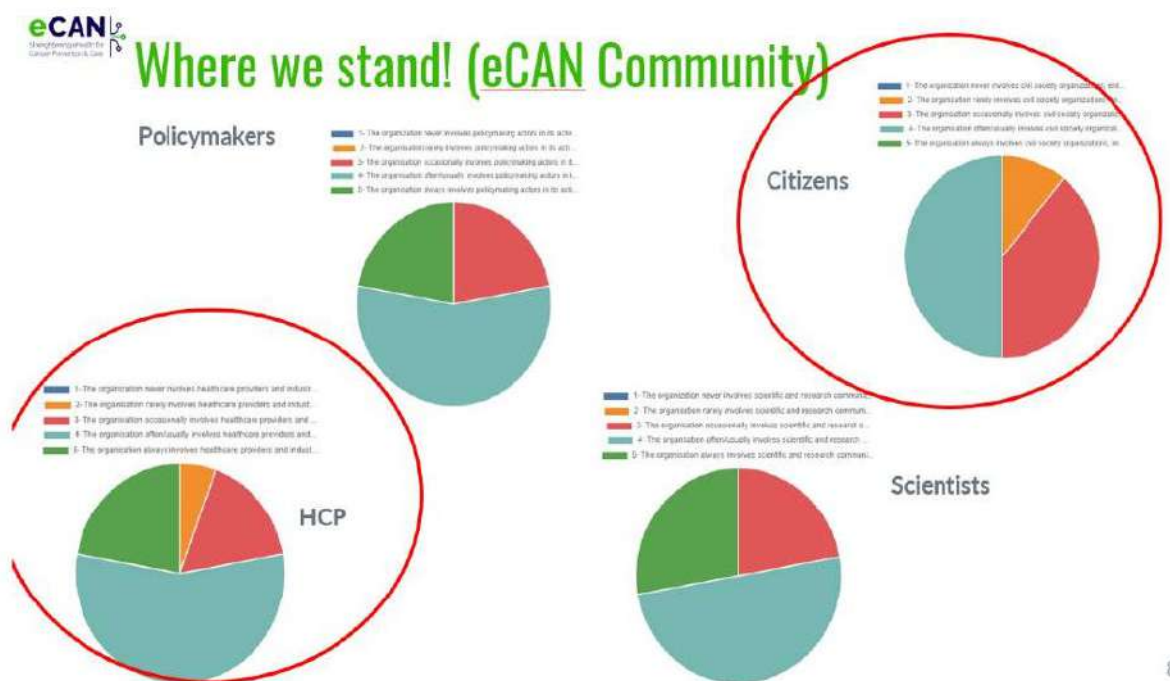
Figure 2: The pre-existing involvement of stakeholders in the eCAN partners' activities (before the JA)

These findings were also aligned with the identified needs for training the clinicians and PIs, before starting the recruitment phases of piloting on how to contact end-users and how to effectively perform the testing of the telemonitoring/teleconsultation solutions. The less experience of the eCAN partners in engaging the society & professionals in their activities has not been received as a barrier though, but as a driver for the WP8 team to better support them

to enhance this aspect, during the eCAN lifecycle, by providing them with best practices and tools.

Similarly, an interesting outcome has been the analysis of the type of activities in which the different stakeholder groups are often engaged (Figure 3). According to the collected answers the two groups, which used to be more involved by the eCAN partners to their activities, Policymaking actors, and the Scientific Community, have highly represented their primary expertise, by engaging in policymaking / agenda-setting & implementation / testing / evaluation of solutions activities, respectively.

Similarly, Healthcare professionals, as experts in-field, are more often involved in implementation (77.78%), piloting, testing (94.44%) & evaluation (61.11%) activities, as well as, less often, but also important to be mentioned, in solution co-design (55.56%), providing their views & concerns towards the development of a tool/method/solution, without having a core role in the agenda-setting & policymaking actions. It is worthy to note that the three previously mentioned stakeholder groups (Policymakers, Scientific/Academic communities, Healthcare experts) are also highly involved by the eCAN partners in dissemination activities, related to the promotion of a solution/policy, its expected outcomes, the mission & vision.

However, the most impressive outcome of this section is related to the primary stakeholders' group of the eCan, the main beneficiaries of its under-development solution, patients/family members/informal caregivers, represented by the civil society/citizens category in the survey. Here, the answers showed that the eCan partners, except for not being familiar in collaborating often with the civil society, when they engage them it is primarily in dissemination activities (72.22%), and then -at an equal degree- in policymaking actions (33.33%) & implementation (33.33%), piloting/testing of solutions (33.33%).

Where we stand! (eCAN Community)
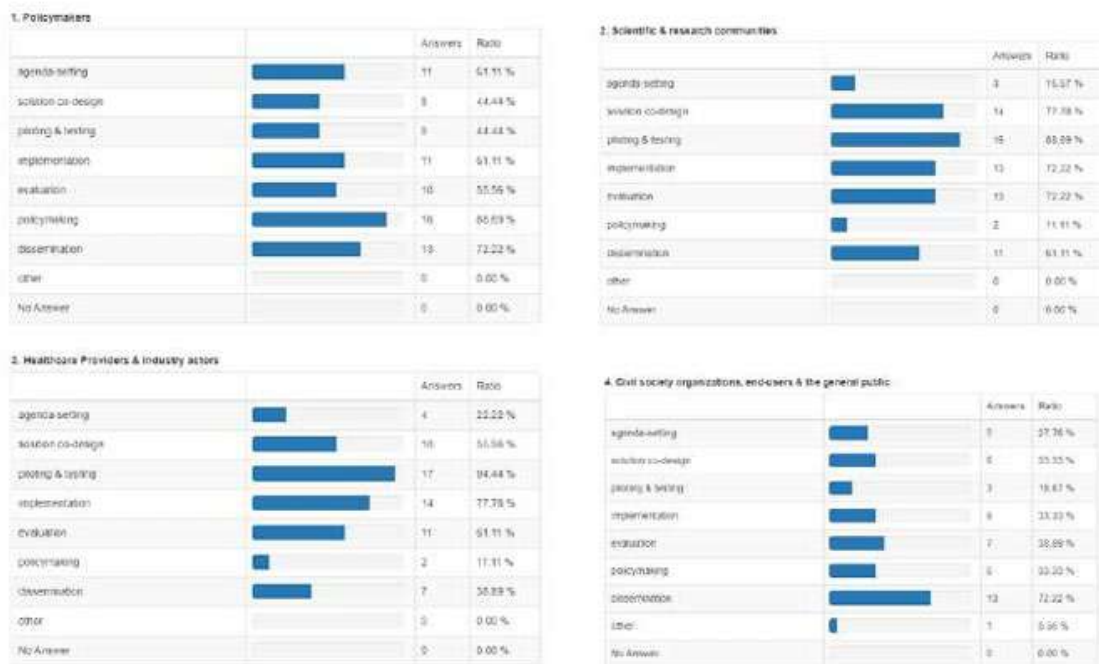
Figure 3: Type of activities in which stakeholders used to be involved (before the JA)

The list of eCAN stakeholders is the main output for the survey on stakeholders' mapping as for outreach and dissemination purposes and includes all the institutions identified as main stakeholders by each eCAN-participant organisation. The information has been compiled in country files that will be available at the website. However, except for the groups of stakeholders and the type of their involvement, the survey has also provided valuable information regarding the existing experiences of the eCAN partners regarding the dissemination of their work to stakeholders. Figure 4 summarizes the outreach of the eCAN Stakeholders, while Figure 5 presents a summary of main outreach mechanisms for each stakeholder group (Source: MS2.2 / WP2, responsible partner: ICO).
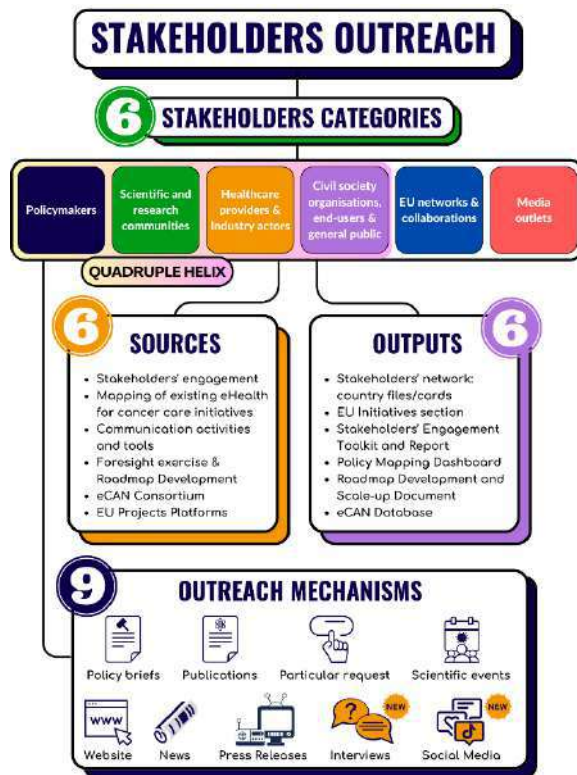
Figure 4: Graphic presentation of the eCAN stakeholders' outreach (Source: MS2.2 / WP2)

Figure 5: Summary of main outreach mechanisms for each stakeholder group (Source: MS2.2 / WP2)

For details, see 6.2 Annex B.

4.1.2. Thematic Workshops on Stakeholders' Engagement

A total number of 92 participants from all the eCAN consortium partners attended the four Thematic Workshops on Stakeholder's Engagement, while all of the sessions were recorded, after partners' request to be available via the project SharePoint for further use and self-pace attendance. The exact number of participants per workshops was the following:

Date	Topic	No. of participants
20/04/23	Patient/HCP Recruitment and Engagement Strategy	26
20/04/23	Collaboration with policymaking actors (how to maximise the impact of your work)	29
04/05/23	Liaison with EU-wide networks: spread the message across the EU	14
10/05/23	Patient Empowerment Tips & Tricks for the use of teleconsultation solutions	23

Table 2: Number of participants of the Thematic Workshops

A short summary of the main outcomes of each Thematic Workshop is provided below:

Patient/HCP Recruitment/Engagement Strategy: The inaugural internal workshop of eCAN saw the participation of 29 individuals. The primary objective of this event was to exchange practical approaches for enhancing stakeholder involvement in research projects, with a particular focus on recruiting and engaging patients and healthcare professionals. These strategies were grounded in the principles of Patient and Public Involvement (PPI) and drew upon previous experience in cancer research and innovation initiatives involving patients and healthcare personnel.

The workshop was organized and led by AUTH, one of the members of Work Package 8. During the workshop, AUTH presented the preliminary findings from a Stakeholders Mapping survey developed by WP8 to identify relevant stakeholders for the Joint Action eCAN project. The preliminary survey results indicated varying levels and types of involvement among stakeholders.

WP8 also identified both strengths and barriers related to establishing a sustainable and inclusive community of diverse stakeholders for the eCAN project. While policymakers and the scientific community typically play active roles throughout the project, collaboration with citizens and healthcare professionals appeared less frequent and active than desired. It was emphasized that involving citizens in testing and validating research activities is of utmost importance.

Furthermore, the workshop provided insights into key considerations for professionals when engaging with patients. Effective engagement was found to hinge on open communication, transparency, and clarity regarding research requirements and the role of patients, all of which are vital for building trust.

Collaboration with policymaking actors (how to maximise the impact of your work): The second workshop convened 26 participants with a keen interest in involving policymakers in research projects like the eCAN Joint Action. The primary objective of this online gathering was to disseminate practical strategies for effectively recruiting and engaging policymakers.

Similar to the previous workshop, the organization and facilitation of this meeting were undertaken by the AUTH partner, working closely in collaboration with the 3rd RHA, ICO, and Sciensano. During the workshop's group discussions, it became evident that when dealing with individuals from diverse entities and operating at various levels, an interdisciplinary approach is imperative.

To succinctly summarize the key takeaway: in projects such as eCAN, the goal extends beyond fulfilling the consortium's objectives; it aims to broaden its impact by proposing tangible

solutions for societal implementation. Consequently, the development and execution of a concrete methodology for efficient communication and collaboration with policymakers take on paramount importance in initiatives like eCAN.

Securing the commitment of policymakers is undoubtedly a formidable challenge, and significant hurdles must be surmounted. These obstacles pertain to both the policymaking process itself (including issues such as a lack of a culture of dialogue, the dominance of political priorities, inadequate long-term policy planning, rigid and opaque policy procedures, and more) and the institutional framework (marked by limited resources, weak incentives, and a restricted capacity for evidence-based policymaking).

In light of these challenges, project members can take proactive measures, such as creating a skills map that delineates the context and scope of each policymaker's role. This approach ensures transparent and clearly defined interactions with these individuals. The more explicit the roadmap and the role policymakers are expected to play, the more receptive they are likely to be in offering their assistance.

Liaison with EU-wide networks: spread the message across the EU: In the third workshop, participants (14 in total) were tasked with a crucial mission: to expand the influence of the eCAN initiative beyond the European borders, contemplating local, regional, or national approaches when disseminating information about the Joint Action.

This expansion is not merely about spreading awareness, but also aims at enlarging the network by engaging with partners and countries that were not initially part of eCAN, notably Germany. AUTH, as the main organiser & facilitator of the workshop, emphasized the need to enhance telemonitoring and teleconsultation across Europe by collaborating with external stakeholders and countries.

This outreach strategy has been envisioned to introduce eCAN to communities outside its existing ecosystem. By forging synergies and collaborations, the consortium will have the potential to harness the knowledge generated by the various Joint Action Work Packages and create opportunities for interaction with external entities, laying the groundwork for future collaborations. This could include sharing experiences, developing policies, and exploring avenues for joint initiatives, all of which would contribute to the broader objectives of eCAN and extend its impact beyond its initial scope.

Patient Empowerment Tips & Tricks for the use of teleconsultation solutions: During the fourth and final workshop, eCAN partners (23 in total) engaged in a constructive dialogue aimed at gaining insights into the requirements of stakeholders, which encompassed patients,

caregivers, and clinicians, for the upcoming piloting phase. They diligently identified these needs across various Work Packages and collaboratively developed effective strategies for implementing educational materials. The overarching goal was to equip all participants with the essential tools necessary to address these needs efficiently.

A pivotal theme that reverberated throughout the concluding workshop centred on the concept of patient empowerment. As defined by the World Health Organization (WHO), patient empowerment is a process that bestows individuals with greater control over the decisions and actions that impact their health. This principle forms a fundamental cornerstone of global health and social care strategies. AUTH, during the workshop, further elucidated the critical components encompassed within this concept.

These components encompass the utmost respect for the unique needs, preferences, and autonomy of patients, ensuring their access to suitable and personalized treatments, and actively involving them in decisions relating to their health. Patient empowerment also entails the facilitation of access to safe, high-quality services and support while providing trustworthy, pertinent, and easily comprehensible health information. Additionally, involving patients in the development of health policies is deemed essential to ensure that services are designed with a central focus on patient-centricity.
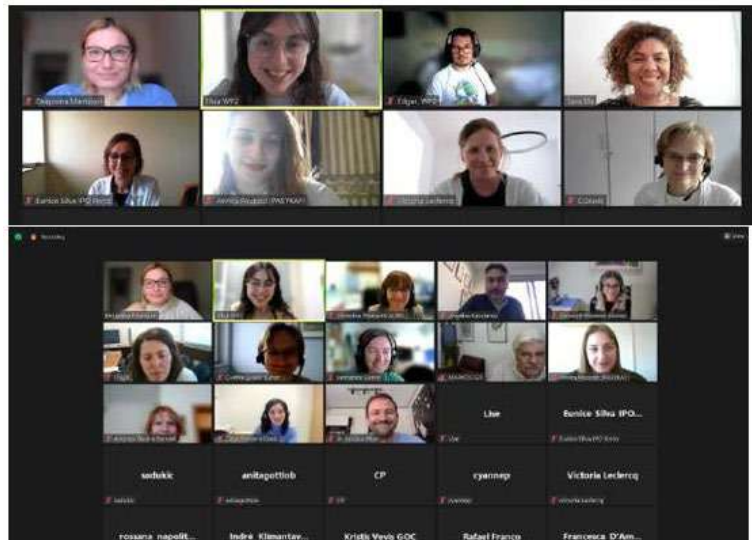
Figure 6: Indicative shots from the Thematic Workshops on Stakeholders' Engagement, held in Spring 2023.

4.1. Task 8.2 Participatory Design

4.2.1. Focus Group

As it was described at the methodology section, the discussion of the focus group was divided into 3 phases. The main results of each phase are summarized here, but you can find more details at the annex of this deliverable (see 6.3 Annex C).

Phase 1: Introduction

The results of the online questionnaire deployed as part of the phase I are summarized in the following figures.
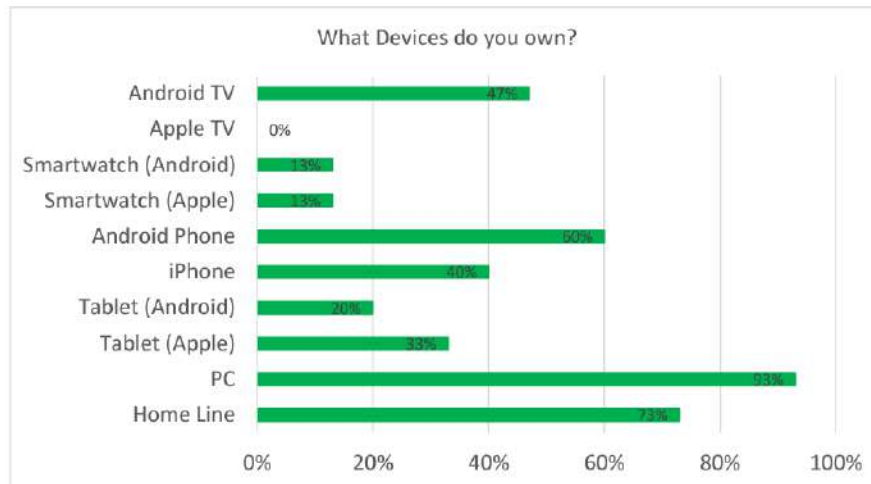
Figure 7: Answers to Question 1: What devices do you have?
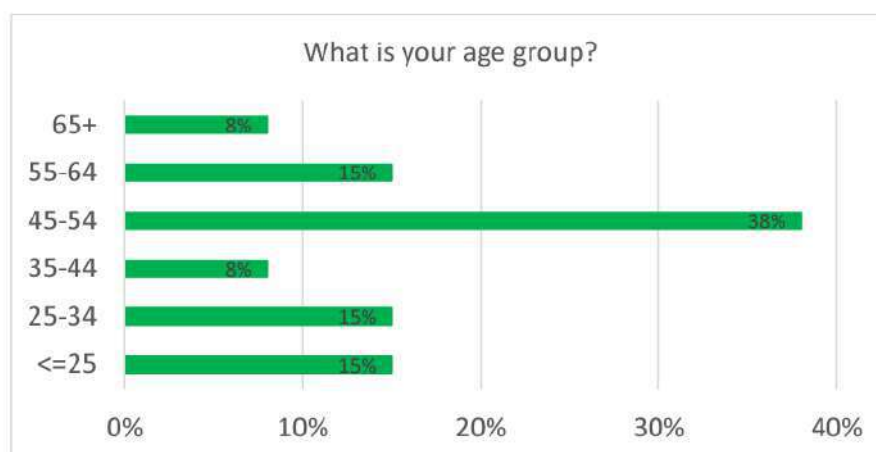
Figure 8: Answers to Question 2: What is your Age?
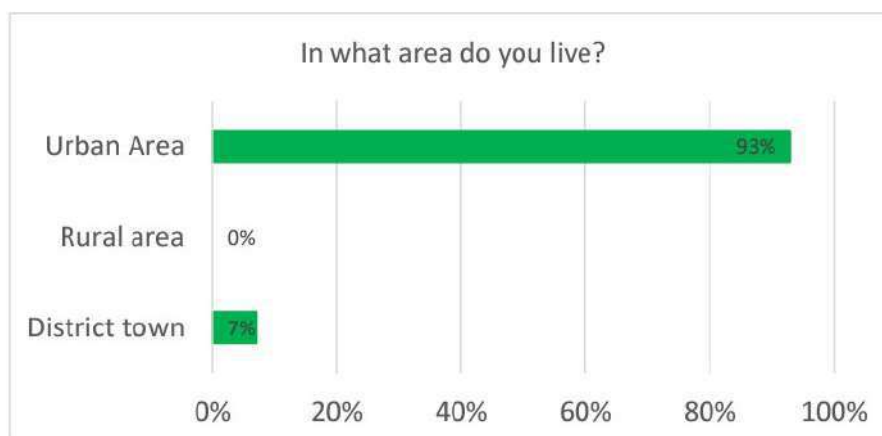
Figure 9: Answers to Question 3: Where do you live?
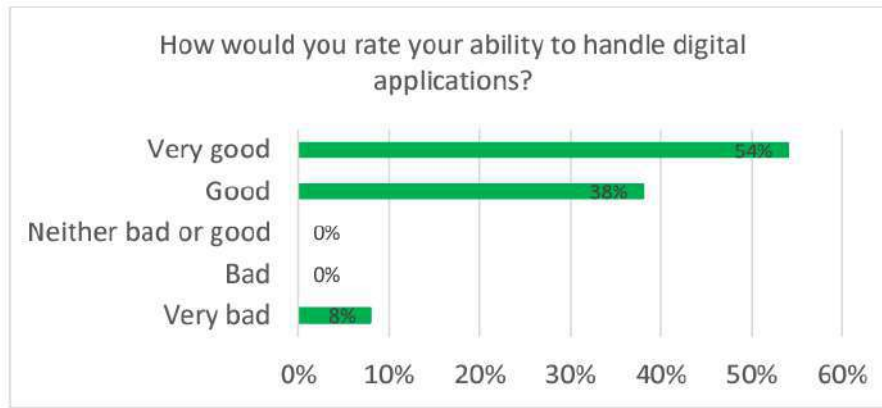
Figure 10: Answers to Question 4: How would you rate your ability to handle digital applications?

Phase 2: Discussion with each group separately (Break out room)

Detailed transcript of the focus group's discussions you can find at 6.3. Annex C.

Here, we present the key considerations of each break out room:

Room 1 – Patients

- Integrating widely used communication methods like email and telephone into telemedicine platforms.
- Addressing digital literacy challenges among older individuals with targeted education and training
- Prioritizing immediate and direct communication features for actively ill patients.
- Developing a reimbursement model for healthcare professionals practicing telemedicine.
- Recognizing the differences between public and private healthcare sectors and tailoring strategies accordingly.
- Focusing on effective communication practices and avoiding poor communication examples.
- Ensuring data privacy and GDPR compliance, while prioritizing usability and minimizing intrusiveness.
- Considering the specific needs of younger individuals and those with mobility issues.
- Addressing challenges related to the inclusion of minority groups.
- Utilizing collected data for research and improvement purposes.

Room 2 – Healthcare professionals (members of Papageorgiou and INAB|CERTH)

- Lack of official software for teleconsultation calls for the development of robust and reliable solutions.

- Some patients continue to rely on remote solutions, emphasizing the need for accessible and user-friendly platforms.

- Intensive use of telecommunication tools during the pandemic, especially for supporting hospital workers, highlights the importance of scalability and stability.

- Some hospitals are part of telemedicine networks but require further development to ensure seamless integration.

- National-level issues related to compensation and personal data protection require comprehensive resolution to ensure privacy and fair practices.

- Psychologists' limited experience with remote care due to varying patient needs necessitates training and support for effective telemedicine delivery.

- Recognizing the impact of patient characteristics, needs, and perceptions of illness on communication is essential for designing patient-centered telemedicine experiences.

- Paying attention to patients' actions rather than their words helps to assess their true needs and priorities.

- Active involvement and motivation of patients in their treatment contribute to better outcomes and engagement.

- Establishing trust and understanding patients' individual needs and instructions are crucial for effective communication.

- Addressing language barriers through improved communication and comprehension aids vulnerable groups in accessing and benefiting from telemedicine.

- Effective communication depends on patients' genuine motivation to improve and active engagement in their treatment.

- Building trust in the patient-doctor relationship is vital, and doubts about medical opinions should be addressed through open dialogue.

- Ensuring patients understand and follow instructions, even when their understanding differs, fosters better collaboration.

- Overcoming negative communication examples involving different expectations, refusal to follow procedures and caregiver assumptions requires clear communication strategies and improved patient education.

- Prioritizing the protection of doctors when making remote diagnoses is crucial to mitigate potential errors.

- Comprehensive data collection and accurate interpretation are essential to minimize risks associated with remote diagnosis.

Room 3 – Patient supporting volunteers (members of K3)

- Addressing patients' challenges in perceiving and using telemedicine tools, providing initial assistance and support.
- Recognizing doctors' lack of familiarity with telemedicine tools and the need for time-efficient integration within the public healthcare system.
- Building appropriate infrastructure and tools for electronic communication in peripheral or private settings.
- Considering regional disparities and economic constraints that affect patients' access to healthcare and their reliance on telecommunication with doctors.
- Tailoring telemedicine solutions to meet the specific needs and preferences of different patient personas, including elderly individuals and younger age groups.
- Emphasizing effective communication practices, such as providing comprehensive information, personal support, and acknowledging the importance of face-to-face interactions.
- Implementing supportive measures and improving telemedicine infrastructure to enhance overall patient experience and ensure successful adoption.

By considering these factors, all relevant stakeholders can contribute to the development of user-centered telemedicine solutions that address the challenges identified in the thematic analysis. Overall, the analysis reveals themes related to the patients' perspective, doctors' challenges, hospital settings, regional disparities, patient personas, and communication examples, highlighting the need for supportive measures and improved telemedicine infrastructure.

The above key-points could be summarized in the form of "user goals" (UGs) as follows:

- UG1: Unobtrusive communication is crucial for both patients and healthcare professionals and "unobtrusiveness" has been identified as a crucial part of a well-communication paradigm
- UG2: Increase motivation for healthcare professionals as they are the ones setting the "rules" in terms of communication, including the setting up of novel reimbursement schemes
- UG3: Usability has also been identified as a crucial step for all relevant software modules, including personalization capabilities
- UG4: Education/training needed for both patients and healthcare professionals

- UG5: Reduce time-burden for healthcare professionals as overwhelming information load and lack of time was clearly identified as a key barrier for well-communication

- UG6: Investigate telehealth as a way to provide treatment alternatives, especially for rural areas where the patients do not have many healthcare service providers to choose from

- UG7: Beyond the use of mobile apps and instant messaging, more mature and less obtrusive communication means (e.g. email, SMS, telephone calls etc.) should actively be investigated as part of telehealth practice guidelines and/or pilot studies

- UG8: Ensure high legal standards, including data privacy for patients and legal support for healthcare professionals in case of an error.

- UG9: In order to ensure trust, there should be transparency regarding which software tools are suitable for use in the eHealth context, perhaps through well-known certification schemes.

- UG10: Focusing on specific population groups (e.g. people lacking mobility, minorities lacking access to healthcare services, or younger people who would adopt eHealth tools easier) is crucial to maximize impact of the telehealth services, reduce risk of adoption and improve the risk/benefit ratio.

4.2.2. "Think-aloud" sessions

Here, we present the main findings of the 14 "think-aloud" sessions. You can find more details in the report of 6.4. Annex D. While conducting the usability study the participants were often encouraged to "speak their minds" each time they had a spontaneous thought or comment, no matter the valence of it. During these oral expressions of thought a few recommendations emerged. While some were direct, meaning they originated from the participants independently, some were elicited contextually during data analysis. These can be summarized as follows.

Before the enrolment

- **Need for quick guides**: It would be good to have quick guides for the HCPs where all the information needed will be there, for both the eCAN Dashboard app and the patients app. It is clear also in the case of the eCAN, that the HCPs attention span and time is limited and many pilot project fail because they don't consider that reality. Since the eCAN is a relatively simple project with few functionalities, a quick guide could prove much useful for HCPs. In addition, it would help a lot as a checklist for the enrollment of the patients. The same applies for patients as well but only in the case of

the "registration" to the study, meaning quick/ essential information regarding the download, installation etc, of the app and the smartwatch.

- **What if the IT takes too much time to create my patients credentials**: Many HCPs were surprised that they could not create credentials for their patients. One expressed a worrying feeling, that the IT would be responsible for many dropouts, because of the waiting times.

During the enrolment

- **A guide for HCPs to help patient with the showcase of the app**.
- **Scheduling of teleconsultations**: HCPs suggestions were not aligned. There seems to be a need for all teleconsultation meetings to be scheduled at the enrolment of the patient so the HCP wouldn't have to initiate communication via another medium. If the patient has a conflict they can always reschedule, but the dates and times should be prefixed. Another HCP claimed he wanted them to be ad-hoc since he wanted to accommodate the patient's schedule.
  - o This will highly depend on the final decision of the eduMEET use, but we would suggest keeping these in mind.

After the enrolment

- **Need for in app notification of status of other users**: While the patients and HCPs first login to the systems and had to interact in some way with the app they were inquiring about the possibility that the doctor or patient will be notified for certain statuses, e.g. "Your doctor has reviewed your questionnaires" or "Your patient has just completed the questionnaires", or your patient successfully logged in for the first time.

Regular use

- **Regarding eduMEET:** How will the HCPs contact the patients to provide them the links, if they are not communicated at the enrolment? This was also asked by an HCP. Since this will be a browser link and most communications happen via the phone. We propose to have all teleconsultations pre scheduled with the possibility of rescheduling when needed.
- **I need notification reminders**: Both Users expressed a need for in app notifications reminders. Patients wanted to have reminder notifications for both the consultations and the questionnaire submission and progression notifications for both the current

week and the overall study. HCPs requested to know in a way when the teleconsultations are and a countdown or display of status, to review the patient's answers before an upcoming meeting. Also I would appreciate after a call a pop-up message reminding me to keep a note of the meeting.

- **A Chatbot to help about obligations**: It seems a chatbot could be useful since patients have questions regarding the meaning of some questions in the QLQ and eCRF and it could provide simple, targeted and tailored information about the questions in the questionnaires.

End of the study

- It was obvious that guides are needed for the end of the study ass well, to remind patients to complete their PREMS, because it is obvious, they are not about their condition and there are indications that might not be thoroughly completed.
- Also, the HCPs will need guidance as to how to treat their patients, their data at the end to ensure security and avoidance of any accidental deletion.

Additional comments

- **eduMEET regular use and meeting links**: There must be a clear indication to users as to how eduMEET will be used. Will all teleconsultation calls be scheduled at the enrolment of the patient? Will they be at hoc? If so, how will they be communicated to patients? Through the app? Via email, SMS?

Technical issues

As providing early feedback to the rest of the eCAN consortium (including technical partners) was a key part of this activity, technical issues and potential problems were also discussed as they could play an important role in terms of end-user acceptance.

eCAN mobile app

The eCAN mobile app has been tested by 6 Participants (eCANTest21 - eCANTest26) with Android device. One participant knew that it would be available in iOS as well and had to reschedule so she had access to an Android device. Regarding the bugs and Technical issues:

Regarding the bugs and Technical issues:

1. **Screen Size**: Most participants devices had issues with showing the weeks tab

2. **Wordings of weeks**: The wording week 0 is not comprehensible by patients. The word "present week" is suggested plus the depiction of the week durations (e.g., 6/7/2023 – 14/7/2023). Also, I would suggest the info to be depicted in a calendar form, also marking clearly the start and end of the study.

3. **Message display**: The message in the Home Screen "Επιλέξτε την εβδομάδα για την οποία θέλετε…." appears to be mistreated as a "pop-up" message, and participants tried to dismiss it and wasted time there, they also did not like it being so big. It is better if it is not shown in that way and instead make it as a pop-up dialog box, with "got it" dismissing it.

4. **Need for more concrete information**: All participants expressed their expectation for a simpler explainable home screen with appropriate messages concerning their obligations and the timing for completion for questionnaires.

5. **Questionnaire wordings**: Questionnaires titles were not comprehensible by patients, especially the "QLQ" questionnaire and the "thermometer" word. Also, they found their reporting of "distress" confusing since distress has many meanings.

6. **Language**: All Questionnaires were expected to be in Greek and were not. Some participants could not practically complete them.

7. **Questionnaire thermometers**:
   a. **Screen Size**: The Thermometers do not fit in the screen and the submit button is not visible to submit. Scrolling is also not possible.
   b. **Choice selection**: Participants were under the impression that they needed to tap and hold on the zero value and slide all the way to their preferred one, which was not the case and frustrated some participants. We suggest either making it like a slider or changing the presentation of the thermometer so taping for the answer makes sense. (Could provide suggestions if interested)

eCAN dashboard

The eCAN Dashboard app has been tested so far by 6 HCPs (eCANDoctor23 – eCANDoctor28) with, both Mac and Windows devices all using Google Chrome browser.

- One tested it in Safari and could not log in since the SSO option would not open the new window to log in.
- Also, a user could not view the app in the correct way since by default her institution had windows XP and the page was showing limited information. (This is important to

consider before the pilots. Either design for older devices or make sure the participating clinics' infrastructures are compatible).

Regarding the bugs and technical issues:

1. **Login is confusing**: There is no reason to have two types of log in. Remove the option to enter username and password and enable only the option of "Login using SSO", and the change that as well to simply "to Log in click here"
2. **The options in the bottom screen do not work**
3. **Language expectations**: Most participants expected the UI to be changeable to Greek, and had difficulties during i.e., in the eCRF submission
4. **Profile "submit" of new information**: While the change of information is possible the fact that the "new password" and "old password" are there the participants were under the impression they had to do that every time they wanted to change something. Also, the button seemed to be unresponsive since nothing seemed to happen when pressing it.
5. **"Add patient" non responsiveness**: Every participant was confused with the Add Patient functionality since they expected that all patients are already in the system and what exactly does that do. They suspected sending an e-invite by entering a patient mail or making an account for the patient themselves.
6. **eCRF**: At the eCRF form many wordings were not comprehensible (e.g., "IC sign", Charlson Comorbidity Index (CCI), Household income was not clear it meant yearly etc.)
7. **PROMs and PREMs**:
   a. **Wording not comprehensible**: Both the term prom and prem as well as the QLQ is not comprehensible as clearly as we would like to believe.
   b. **Results not showing**: The PROMs and PREMs display is bugged, it is empty and not showing anything. Based on fake data entered by both me and the participants during testing.
8. **Author of notes**: Some participants believed it is needed to show the name of each note author or eCRF submitter since they might be needed later to solve disputes.

EduMEET app

The eduMEET app has undergone testing with six Healthcare Professionals (HCPs) and six Patients. Comprehensive testing, from call initiation to completion, was conducted. During the test sessions, HCPs utilized the app to inquire about patient questionnaire results and provide

psychological guidance. The results from the usability study suggest that integrating eduMEET into the eCAN dashboard app could be highly beneficial. However, there are some notable issues that surfaced:

- **Invitation Process**: One noteworthy challenge identified during the usability study was the complexity of the invitation process. Participants expressed difficulty in comprehending that HCPs had to copy the URL and manually send it as an invitation to patients. It is recommended to consider implementing a user-friendly button within the app. This button, upon clicking, should prompt the user to send an invitation with the link clearly visible, streamlining the process.

- **Login Confusion**: Some users encountered confusion at the beginning of the call process, mistakenly believing they needed to log in to the eduMEET platform. This misunderstanding led to unnecessary delays. Clarifying the login process or providing clear instructions can help alleviate this issue.

- **Permission Requests**: Participants often dismissed the "Allow access to microphone" and "Allow access to the camera" pop-up messages immediately upon joining the call in eduMEET. It is crucial to present these permission requests in a more user-friendly and less intrusive manner to ensure that participants pay proper attention and provide the necessary permissions.

Incorporating these improvements into the eduMEET app and considering seamless integration into the eCAN dashboard app can significantly enhance the user experience and overall usability of the platform. These enhancements should lead to more effective and efficient telemedicine interactions between HCPs and Patients.

5. Conclusions

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

5.1.1. Stakeholder Mapping

Task 8.1 has made significant progress in building a robust stakeholder network and promoting active engagement within the eCAN JA initiative. The collaborative efforts of WP8 partners, in conjunction with WP2, have yielded valuable insights into the diverse range of stakeholders involved in the project. The online survey conducted for ecosystem mapping has not only identified existing synergies within the consortium but has also shed light on areas that need improvement. The subsequent Thematic Workshops have laid the groundwork for a strategic

framework to ensure the active participation of stakeholders from various backgrounds, thereby maximizing the impact and sustainability of the eCAN initiative.

Moving forward, the eCAN Community, established as a result of the stakeholder mapping analysis, holds immense potential for fostering engagement and collaboration. The findings of the preliminary analysis have highlighted areas where eCAN partners excel and areas where they can benefit from additional support, particularly in engaging with citizens. The upcoming activities in the second half of the project, including piloting in WP5 and WP7, will be guided by the insights gained from Task 8.1, with a specific focus on enhancing primary stakeholder recruitment & engagement. Additionally, the identification of specific stakeholder groups and their primary areas of expertise has provided valuable guidance for tailoring engagement strategies.

Overall, Task 8.1 has set a strong foundation for effective stakeholder involvement, and the next steps should involve implementing the engagement framework, providing support where needed, and harnessing the power of the eCAN Community to drive the initiative forward. Furthermore, the compilation of a comprehensive list of eCAN stakeholders, as an outcome of the survey, is a crucial resource for outreach and dissemination efforts.

This country-based database, which is under analysis, in collaboration with WP2 and it will be available soon via the project website, will be instrumental in ensuring that the project reaches its intended audience and maximizes its impact. As the eCAN evolves, the Task 8.1 will continue the attempts to widening the existing networks of primary and secondary stakeholders, while the self-assessment online survey is aimed to be repeated before the end of the project to evaluate any changes and/or improvements of the current involvement/engagement levels that each participating entity has.

5.1.2. Thematic Workshops on Stakeholder Engagement

In conclusion, the eCAN workshops have proven to be invaluable forums for fostering collaboration, knowledge sharing, and the development of practical strategies for enhancing stakeholder engagement in research projects. Throughout these workshops, participants have embraced the vital concept of promoting their work to multiple stakeholders, engaging and recruiting patients, collaborating with external experts and policymakers, as well as they have embraced patient empowerment, recognizing it as a central tenet for the success of healthcare initiatives like eCAN (linked to Task 8.3).

By consistently adhering to the principles of patient empowerment and fostering patient-centricity in research and healthcare, eCAN can contribute meaningfully to improving healthcare outcomes and advancing the field of cancer research and innovation.

Moving forward, the suggested next steps, during the second year of the project lifecycle, entail putting the knowledge and insights gained from these workshops into action. A toolkit, compiling all the tools and methods of the Thematic Workshops, enriched with additional requirements for support will be available in the upcoming months to all the eCAN consortium partners, also publicly available to other interested parts via the project website. It is imperative to continue expanding the eCAN ecosystem, engaging with partners beyond European borders, and broadening the network to capitalize on collaborative opportunities. Furthermore, additional consultation meet-ups will be held in collaboration with other Working Packages and the PIs of the eCAN to support specific engagement needs and activities.

As the eCAN initiative progresses, continued efforts should focus on strengthening partnerships, sharing best practices, and adapting engagement strategies to meet the evolving needs and priorities of the diverse stakeholder groups involved (synergies with external organizations, liaison with their parties). By doing so, the eCan project can ensure that its telemonitoring and teleconsultation solutions are not only technically sound but also effectively integrated into healthcare systems and embraced by the broader community, ultimately achieving its goals of improving cancer healthcare outcomes and patient wellbeing.

5.2. Task 8.2 Participatory design

5.2.1. Focus Group

Focus Group achieved to inform WP4 and all the relevant partners about stakeholder's perception regarding the use of telemedicine services. So, a participatory design framework was created and the user needs were identified. But we must highlight the fact that, focus group was conducted to a Greek audience and the results could be considered as geographically biased. Also, the presented outcomes are mined based on the input of 14 people. Increasing the size of the people engaged in such processes could potentially improve the relevant outcomes.

Despite the above restrictions, we managed to elicit important users' needs and perceptions regarding telemedicine services. For example, the need for essential communication and trust between patients and HCPS was highlighted once again. Additionally, it is users' need

education/training actions, high legal standards, well-known certification schemes, reduce time burden, set a reimbursement scheme and more. Details you can find at 6.3. Annex C.

5.2.2. "Think-aloud" sessions

The usability evaluation of the eCAN mobile app, eCAN Dashboard app, and eduMEET software yielded valuable insights into the user experience and functionality of these applications. Overall, the evaluation revealed both successes and challenges in meeting the usability goals set for the applications. The comparison to usability goals showed promising results in tasks related to login and patient registration, indicating that the applications have strong foundations for basic navigation and essential functionalities.

However, certain tasks, particularly those involving questionnaires, raised concerns due to confusion and difficulties experienced by users. The identified issues highlighted the need for improvements in terminology clarity, technical optimization, multilingual support, and information display consistency. Details you can find at 6.4 Annex D.

6. Annex

6.1. Stakeholders' Mapping survey (T. 8.1)

A. Considering the current situation regarding your collaboration with various actors in your local ecosystem, situate your organisation within the following five-point scales:

* 1. Policymakers (i.e. Hearth Districts, Ministries, Municipalities etc.)

○ 1- The organization never involves policymaking actors in its activities
○ 2- The organisation rarely involves policymaking actors in its activities
○ 3- The organisation occasionally involves policymaking actors in its activities
○ 4- The organisation often/usually involves policymaking actors in its activities
○ 5- The organisation always involves policymaking actors in its activities

* 2. Scientific and research communities (i.e. universities, research centres, research groups etc.)

○ 1- The organization never involves scientific and research communities in its activities
○ 2- The organisation rarely involves scientific and research communities in its activities
○ 3- The organisation occasionally involves scientific and research communities in its activities
○ 4- The organisation often/usually involves scientific and research communities in its activities
○ 5- The organisation always involves scientific and research communities in its activities

* 3. Healthcare Providers and industry actors (i.e. hospitals (public/private), rehabilitation centres, health service providers, teleconsultation/telemonitoring providers, companies etc.)

○ 1- The organization never involves healthcare providers and industry actors in its activities
○ 2- The organisation rarely involves healthcare providers and industry actors in its activities
○ 3- The organisation occasionally involves healthcare providers and industry actors in its activities
○ 4- The organisation often/usually involves healthcare providers and industry actors in its activities
○ 5- The organisation always involves healthcare providers and industry actors in its activities

* 4. Civil society organizations, end-users & the general public (i.e. NGOs, patient associations, healthcare professional associations, family members, formal/informal caregivers etc.)

○ 1- The organization never involves civil society organizations, end-users & the general public in its activities
○ 2- The organisation rarely involves civil society organizations, end-users & the general public in its activities
○ 3- The organisation occasionally involves civil society organizations, end-users & the general public in its activities
○ 4- The organisation often/usually involves civil society organizations, end-users & the general public in its activities
○ 5- The organisation always involves civil society organizations, end-users & the general public in its activities

* 5. EU networks & external collaborations in the field of cancer and/or in telemonitoring/teleconsultation (i.e. European/international initiatives, the EU4Health programme, HaDEA, DG SANTE, WHO, EIPonAHA, ESMO, SIOG, collaborations with other EU consortia etc.)

○ 1- The organization never involves EU networks & collaborations in its activities
○ 2- The organisation rarely involves EU networks & collaborations in its activities
○ 3- The organisation occasionally involves EU networks & collaborations in its activities
○ 4- The organisation often/usually involves EU networks & collaborations in its activities
○ 5- The organisation always involves EU networks & collaborations in its activities

---

B. In which of the following type(s) of activities are your stakeholders most often involved:

* 1. Policymakers

☐ agenda-setting
☐ solution co-design
☐ piloting & testing
☐ implementation
☐ evaluation
☐ policymaking
☐ dissemination
☐ other

If you selected "other", please specify:

[   ]

* 2. Scientific & research communities

☐ agenda-setting
☐ solution co-design
☐ piloting & testing
☐ implementation
☐ evaluation
☐ policymaking
☐ dissemination
☐ other

If you selected "other", please specify:

[   ]

* 3. Healthcare Providers & industry actors

☐ agenda-setting
☐ solution co-design
☐ piloting & testing
☐ implementation
☐ evaluation
☐ policymaking
☐ dissemination
☐ other

If you selected "other", please specify:

---

* 4. Civil society organizations, end-users & the general public

☐ agenda-setting
☐ solution co-design
☐ piloting & testing
☐ implementation
☐ evaluation
☐ policymaking
☐ dissemination
☐ other

If you selected "other", please specify:

---

* 5. EU networks & external collaborations

☐ agenda-setting
☐ solution co-design
☐ piloting & testing
☐ implementation
☐ evaluation
☐ policymaking
☐ dissemination
☐ other

If you selected "other", please specify:

Stakeholder Mapping

Please, provide examples of your collaboration networks, specifying their position and field of work (policymakers, experts, industrial partners, research partners, civic society etc). Please, provide up to 10 examples for each category (namely: i.e. Greek Ministry of Health, Hippokrateion General Hospital, Greek Women's Breast Cancer Association "Alma Zois" etc).

* 1. Policymakers

* 2. Scientific & research communities

* 3. Healthcare Providers & industry actors

* 4. Civil society organizations, end-users & the general public

* 5. EU networks & external collaborations

Please, list any existing collaborations with organizations & entities with the non-participating countries of the eCan consortium (i.e Germany). Provide, as many as possible:

Stakeholder Engagement

Does your organization engage relevant stakeholders in a structured manner (please, give some indicative examples)?
(e.g. public events, occasional/ "world café" meet-ups, focus groups, public awareness campaigns, in-person invitations, exhibitions, conferences, social media invitations, panel management tools etc.)

* What are the biggest challenges/barriers your organization phases in terms of stakeholder engagement? (list the top 3)

Dissemination across the community

Does your organisation disseminate its projects' results, activities and contributions across the community using different media/communication channels*?
*i.e. specialised / academic publications
Academic media: e.g. papers, conference proceedings, books' chapters, specialised reports popularised publications shared across mainstream traditional media: e.g. television, radio, and articles in print media, press releases, leaflets, newsletters; communications shared across new media: e.g. blog posts, websites, social media, MOOC

○ Yes
○ No

If YES:
Describe the content, as well as the media/communication channels, your organisation uses to disseminate knowledge/results to each of the following stakeholder groups:

1. Policymakers

2. Scientific & research communities

3. Healthcare Providers & industry actors

4. Civil society organizations, end-users & the general public

5. EU networks & external collaborations

Link to the survey:

https://ec.europa.eu/eusurvey/runner/eCan-WP2-WP8-stakeholderMapping

6.2. Stakeholders' Outreach Approach (WP2 MS 2.2)

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)
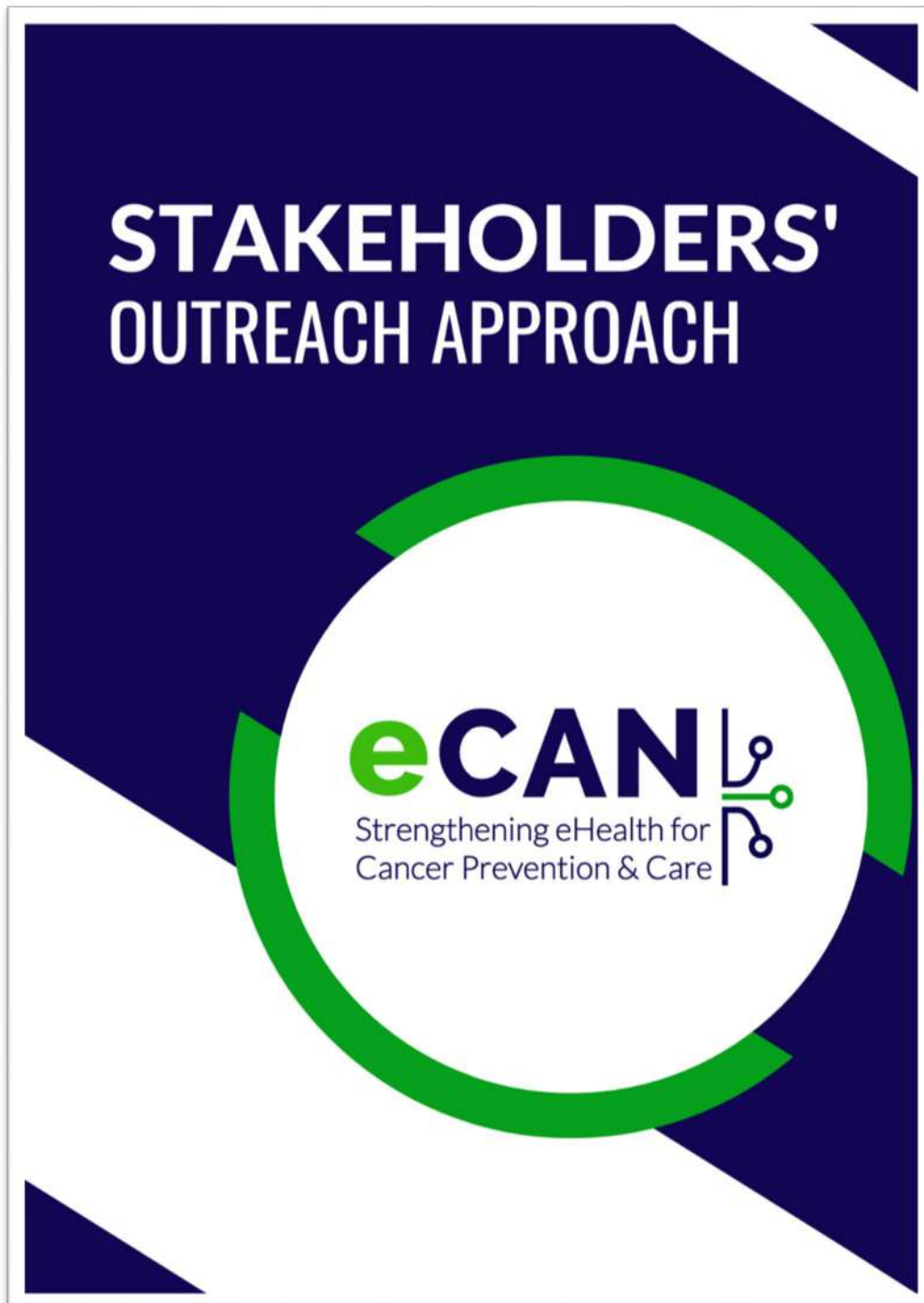
Link to the milestone:

https://ecanja.eu/downloads/eCAN_Stakeholders_Outreach_Approach.pdf

6.3. Participatory Design, 1st Focus Group results (Task 8.2.)

Exploring perceptions of the end-users on the use of telehealth for cancer patients

Pantelis Natsiavas, pnatsiavas@certh.gr

Panos Bonotis, pbonotis@certh.gr

Anastasia Farmaki, afarmaki@certh.gr

Rationale

The 1st focus group organized as part of the T8.2 activities was organized by INAB|CERTH, AUTh and 3rd RHA and conducted virtually (via zoom), aiming to identify user needs based on a live interaction with key stakeholders, including patients, doctors and patient assistance agents (i.e., volunteers who support patients through their journey in the national healthcare system).

It should also be noted that all eCAN partners from Greece actively supported the focus group, i.e. ELLOK provided a number of participants on behalf of patients and Papageorgiou Hospital invited a number of healthcare professionals to participate. The ultimate outcome of the focus group was to mine "user goals" in the form of take-away messages. The discussion was organized along the following three phases:

- **Phase 1**: a presentation of the project's goals, introduction of all the participants, and a presentation of the tools to be used. During this phase, several questions were also asked via an online questionnaire. (30 minutes)
- **Phase 2**: three parallel discussions were conducted in break-out rooms (one for each participant group led by a CERTH team member/facilitator) where each participant group discussed specific issues. Furthermore, predefined "personas" were also elaborated and challenges in terms of communication during treatment were identified. Furthermore, potential barriers regarding the use of telehealth focusing on the specific needs of each end-user group were discussed. (60 minutes)
- **Phase 3**: a recap part, where the three CERTH team members/facilitators summarizes the key points discussion in part (c) and a live discussion will be conducted. (30 minutes)

The focus group was conducted late on the evening (19.00-21.00) of Thursday, 18th of May 2023 and it lasted a little more than 2 hours. The discussion was recorded and was retrospectively analysed by the CERTH team to identify the main "user goals" which could be used as a form of user requirements, and thus, they could provide valuable "user oriented"

insights for the clinical trials to be conducted and the adjustment of the respective technical tools (WP5 and WP7). These are summarized in this report to be disseminated with the project consortium. All the discussions were conducted in Greek.

Logistics

The focus group was disseminated through the project's WP2 communication channels.   The participants of the focus group participants were affiliated with the following organizations: - Healthcare professionals (coming from Papageorgiou Hospital and INAB|CERTH staff) - Patients (coming from the Greek association of cancer patients – ELLOK) - Patient support agents (coming from the "K3" group) The detailed participation can be outlined as follows:

- Healthcare Professionals: 4
    - o Psychologists
    - o Physicians
    - o Administrative staff
- Cancer Patients: 5
- Patient carers/supporters: 4

The discussion was orchestrated by Pantelis Natsiavas. The three parallel discussions were facilitated by the INAB|CERTH team members.

- Patients Room: Pantelis Natsiavas
- HCPs Room: Panos Bonotis
- Patient Supporter Room: Anastasia Farmaki

Results

Phase 1: Introduction
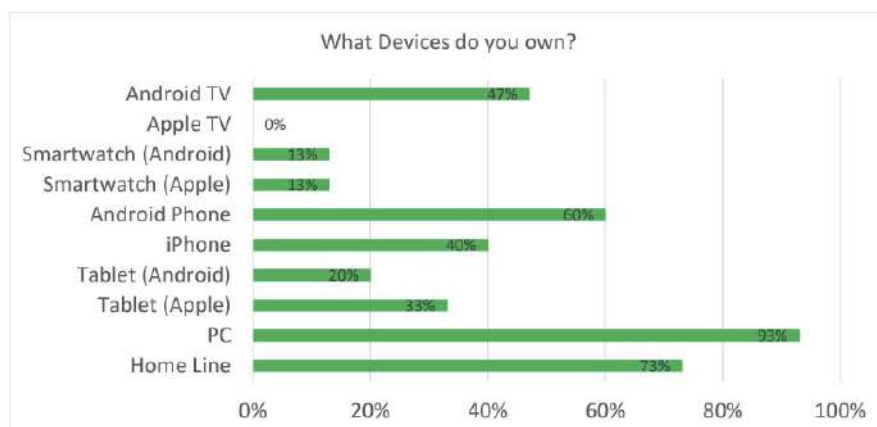
Figure 11: Devices the participants own and are familiar with their use.
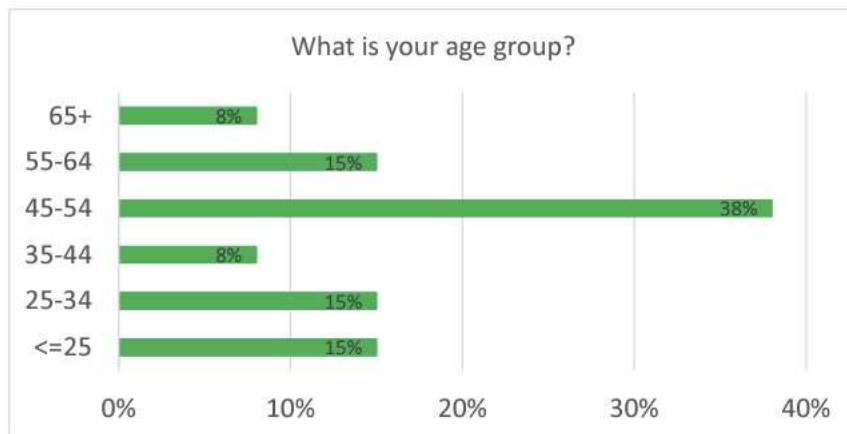
Figure 12: Age groups of participants
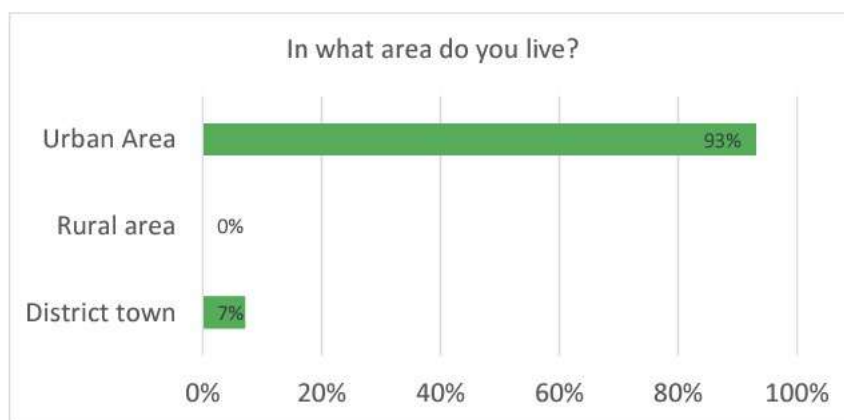
Figure 13: Type of living area of participants
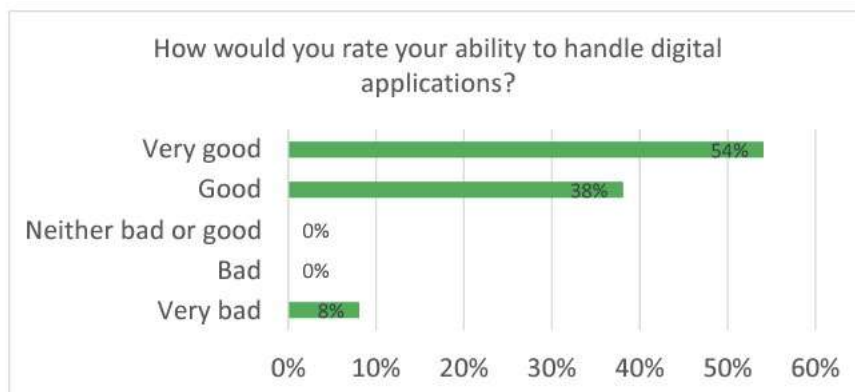
Figure 14: Participants perception on ability to handle digital applications

Phase 2: Discussion with each group separately (Break out room)

Room 1 – Patients

Based on the transcript of the focus group's patient advocate room, the thematic analysis provides the themes that emerged as challenging in the context of the study:

Teleconferencing Usage:

- Email is commonly used as a less intrusive means of communication.

- Telephone communication is also used

- Platforms like Skype and messenger are not widely used, despite their everyday use.

- However, they are utilized for psychosocial support, particularly for patients with mobility challenges.

Digital Literacy and Education:

- Older individuals (aged 60+) face challenges in digital literacy.

- There is a need for education and training specifically targeted at patients aged 60+.

Direct Communication and Cultural Shift:

- There is a need for immediate and direct communication, especially for actively ill patients.

- A cultural shift may be necessary, primarily among doctors who set the communication standards.

Reimbursement Model and Telemedicine:

- A reimbursement model needs to be developed for healthcare professionals practicing telemedicine.

Differences between Public and Private Sectors:

- There is a significant difference between the public and private healthcare sectors.

- Even older doctors are familiar with telemedicine practices.

- Burnout is evident in the public healthcare system, exacerbated by increased workload.

Examples of Effective and Ineffective Communication (to be considered during user-centered development):

- Good communication examples include doctors with a personal attitude, respecting patients' time, and providing prompt responses and follow-ups.

- Poor communication examples include a lack of respect for patients, long waiting times, adherence to protocols without personal interest, and a doctor who showed no empathy.

Tools and Barriers:

- Overall positive attitudes towards telemedicine.

- Data privacy and GDPR compliance are significant concerns.

- Ensuring usability and avoiding application intrusiveness is important.

- The integration of telemedicine into the public healthcare system requires time, infrastructure setup, and untested procedures.

- Younger individuals and those with mobility issues would benefit more easily from telemedicine.

- Inclusion of minority groups may pose challenges.

- Secondary data utilization from the collected information is crucial.

- Non-specialized doctors will greatly benefit from telemedicine.

Discussion

By considering these points the relevant stakeholders can enhance telemedicine implementation, communication, and overall user experience.

Room 2 – Healthcare professional advocates members of Papageorgiou and INAB

Based on the preliminary transcript of the focus group's healthcare professional advocate room, the thematic analysis provides the themes that emerged as challenging in the context of the study:

Use of teleconsultation platforms during the pandemic:

Telemedicine Platforms: The COVID-19 pandemic highlighted the need for teleconsultation platforms, but there is no official software available yet. Some patients still rely on remote solutions. The use of telemedicine was intensive during the pandemic, including support for hospital workers. Some hospitals are connected to telemedicine networks, although the development is still ongoing.

- Lack of official software for teleconsultation.

- Some patients still use remote solutions.

- Intensive use of telecommunication tools to support hospital workers during the pandemic.

- Some hospitals are part of telemedicine networks but lack full development.

Pre-existing issues with telemedicine:

Pre-existing Telemedicine Solutions: Telemedicine solutions existed before COVID-19, but there are general issues that need to be addressed at a national level. These issues include compensation and personal data protection, which have not been fully resolved yet.

- National-level issues related to compensation and personal data have not been resolved.
- Psychologists have limited experience with remote care due to different patient needs.
- Differences in patient characteristics, needs, and perceptions of illness affect communication.

Importance of patient-centered communication:

Patient Characteristics: Patients often exhibit characteristics that are common among many individuals. However, psychologists have limited experience with such profiles primarily due to differences in the needs of their own patients. Some patient characteristics, such as their needs and priorities, differ significantly from reality. Patients may pretend to be well or claim to have friends when they actually don't. It is crucial to focus on patients' actions rather than their words.

- Paying attention to patients' actions rather than their words.
- Active involvement and motivation of patients in their own treatment.
- Establishing trust and understanding patients' needs and instructions.
- Communication difficulties between doctors and patients due to language barriers.

Impact on vulnerable groups:

- Efforts are being made to improve communication in hospitals regarding the terminology used.
- Vulnerable groups face significant challenges due to the pandemic and communication issues.

Communication challenges and negative examples:

Effective Communication: Good communication is determined by the patient's genuine motivation to improve. Patients who actively engage in their treatment are excellent examples of effective communication. Trust is also vital in the patient-doctor relationship. Doubting the doctor's opinion can be detrimental. Understanding and following instructions, particularly when the patient has a better understanding of their condition, leads to better collaboration.

Negative Communication Examples: Poor communication occurs when patients have different expectations or refuse to follow established procedures. Trust becomes an issue when patients have already consulted other doctors and challenge the current doctor's treatment decisions. Caregivers sometimes hinder communication by assuming they know better and questioning

the doctor's opinion. In these cases, doctors tend to become distant in their interactions with patients.

Language Barrier: Patients across Europe often struggle to understand medical terminology. Efforts are being made to improve communication through research projects in hospitals, aiming to adapt the language to patients' level of comprehension. Vulnerable groups are particularly affected by the lack of understanding.

- Patients with different expectations who do not follow established procedures.
- Lack of trust when patients have consulted other doctors and question the provided treatment.
- Difficulties when caretakers think they know better and question medical opinions.
- Concerns about remote diagnoses and potential risks of errors.

Telemedicine tools:

Remote Diagnosis Risks: Telemedicine tools need to prioritize the protection of doctors. Remote diagnosis using various tools carries the risk of errors. For example, the telemedicine setup may not provide all the necessary information, leading to incomplete or inaccurate diagnoses. Ensuring comprehensive data collection and accurate interpretation is crucial for effective telemedicine implementation.

- Need for protection for doctors when making remote diagnoses to avoid potential errors.

Discussion

Based on the thematic analysis conducted in the focus group's healthcare professional advocate room, several key insights emerge that are relevant to coordinators, stakeholders involved in teleconsultation platforms and telemedicine solutions. The following bullet points summarize the key findings and recommendations:

- Lack of official software for teleconsultation calls for the development of robust and reliable solutions.
- Some patients continue to rely on remote solutions, emphasizing the need for accessible and user-friendly platforms.
- Intensive use of telecommunication tools during the pandemic, especially for supporting hospital workers, highlights the importance of scalability and stability.

- Some hospitals are part of telemedicine networks but require further development to ensure seamless integration.

- National-level issues related to compensation and personal data protection require comprehensive resolution to ensure privacy and fair practices.

- Psychologists' limited experience with remote care due to varying patient needs necessitates training and support for effective telemedicine delivery.

- Recognizing the impact of patient characteristics, needs, and perceptions of illness on communication is essential for designing patient-centered telemedicine experiences.

- Paying attention to patients' actions rather than their words helps to assess their true needs and priorities.

- Active involvement and motivation of patients in their treatment contribute to better outcomes and engagement.

- Establishing trust and understanding patients' individual needs and instructions are crucial for effective communication.

- Addressing language barriers through improved communication and comprehension aids vulnerable groups in accessing and benefiting from telemedicine.

- Effective communication depends on patients' genuine motivation to improve and active engagement in their treatment.

- Building trust in the patient-doctor relationship is vital, and doubts about medical opinions should be addressed through open dialogue.

- Ensuring patients understand and follow instructions, even when their understanding differs, fosters better collaboration.

- Overcoming negative communication examples involving different expectations, refusal to follow procedures, and caregiver assumptions requires clear communication strategies and improved patient education.

- Prioritizing the protection of doctors when making remote diagnoses is crucial to mitigate potential errors.

- Comprehensive data collection and accurate interpretation are essential to minimize risks associated with remote diagnosis.

Taking these findings into account will assist the relevant stakeholders in developing telemedicine platforms that address the challenges identified, improve patient-centered communication, and ensure the effective implementation of telemedicine tools.

Room 3 – Healthcare professional advocates members of Papageorgiou and INAB

Based on the preliminary transcript of the focus group's patient supporters advocate room, the thematic analysis provides the themes that emerged as challenging in the context of the study:

Patient's Perspective:

- Indirect perception of telemedicine and telecommunication, primarily from the patients' point of view.
- Difficulty in using the tools, expressed by patients, due to their perceived complexity (e.g., information overload, detailed symptom reporting).
- Phone as the only communication medium used in their experience.
- Additional psychological burden for patients when they had to believe in the usefulness and benefits of telemedicine.
- Patients more receptive to telemedicine when provided with initial assistance.
- Positive attitude towards the use of telemedicine, considering initial difficulties as challenges that can be overcome.
- Potential benefits for patients in remote areas, where technology can bridge the gap between patients and doctors for treatment.

Doctor's Perspective:

- Lack of familiarity with telemedicine tools among doctors.
- Time constraints faced by doctors within the public healthcare system to integrate telemedicine into their daily practice.
- Psychological burden resulting from the process of training on new data/programs, which is intensified for already overwhelmed individuals.
- Recognition of the need for supportive groups to facilitate telemedicine adoption.

Hospital Setting:

- Limited use of electronic communication tools in central hospitals.
- Construction of clinics with necessary infrastructure, networks, and tools for electronic communication in peripheral or private settings.

Regional Disparities:

- Patients in peripheral regions with different cultures and economic conditions rely on public urban hospitals as their only access to healthcare.

- Economic constraints limit their ability to seek private healthcare, making them "compelled" to use online communication with doctors from public hospitals.
- Preference for direct communication with doctors when geographical proximity allows it.
- Respect and understanding towards doctors' time constraints due to workload.

Patient Persona:

- Elderly individuals show reluctance in using electronic media and seek help from relatives or supporters to guide them.
- Greater acceptance of telemedicine among younger age groups.
- Lack of system support for doctors to have detailed patient interactions.

Examples of Effective and Ineffective Communication (to be considered during user-centered development):

- Good communication example: A helpful and direct doctor who has time to provide information about treatment, illness, and supportive groups. However, face-to-face communication is still essential.
- Poor communication example: Lack of communication with the doctor, which patients heavily rely on, whether due to time constraints, fatigue, or personal characteristics. Even a single look from the doctor can significantly impact their psychological well-being.

Discussion

Key considerations based on the thematic analysis include:

- Addressing patients' challenges in perceiving and using telemedicine tools, providing initial assistance and support.
- Recognizing doctors' lack of familiarity with telemedicine tools and the need for time-efficient integration within the public healthcare system.
- Building appropriate infrastructure and tools for electronic communication in peripheral or private settings.
- Considering regional disparities and economic constraints that affect patients' access to healthcare and their reliance on telecommunication with doctors.
- Tailoring telemedicine solutions to meet the specific needs and preferences of different patient personas, including elderly individuals and younger age groups.

- Emphasizing effective communication practices, such as providing comprehensive information, personal support, and acknowledging the importance of face-to-face interactions.
- Implementing supportive measures and improving telemedicine infrastructure to enhance overall patient experience and ensure successful adoption.

By taking these factors into account, all relevant stakeholders can contribute to the development of user- centered telemedicine solutions that address the challenges identified in the thematic analysis. Overall, the analysis reveals themes related to the patients' perspective, doctors' challenges, hospital settings, regional disparities, patient personas, and communication examples, highlighting the need for supportive measures and improved telemedicine infrastructure.

User Goals

The above key-points could be summarized in the form of "user goals" (UGs) as follows:

- UG1: Unobtrusive communication is crucial for both patients and healthcare professionals and "unobtrusiveness" has been identified as a crucial part of a well-communication paradigm
- UG2: Increase motivation for healthcare professionals as they are the ones setting the "rules" in terms of communication, including the setting up of novel reimbursement schemes
- UG3: Usability has also been identified as a crucial step for all relevant software modules, including personalization capabilities
- UG4: Education/training needed for both patients and healthcare professionals
- UG5: Reduce time-burden for healthcare professionals as overwhelming information load and lack of time was clearly identified as a key barrier for well-communication
- UG6: Investigate telehealth as a way to provide treatment alternatives, especially for rural areas where the patients do not have many healthcare service providers to choose from
- UG7: Beyond the use of mobile apps and instant messaging, more mature and less obtrusive communication means (e.g. email, SMS, telephone calls etc.) should actively be investigated as part of telehealth practice guidelines and/or pilot studies
- UG8: Ensure high legal standards, including data privacy for patients and legal support for healthcare professionals in case of an error.

- UG9: In order to ensure trust, there should be transparency regarding which software tools are suitable for use in the eHealth context, perhaps through well-known certification schemes.
- UG10: Focusing on specific population groups (e.g. people lacking mobility, minorities lacking access to healthcare services, or younger people who would adopt eHealth tools easier) is crucial to maximize impact of the telehealth services, reduce risk of adoption and improve the risk/benefit ratio.

Conclusion

This report is to be disseminated among the consortium members in order to support the iterative improvement of the applications to be used in the eCAN pilot and also (potentially) the pilot processes to be applied. Having said that, it should also be explicitly stated that, not all the above conclusions are applicable in the context of eCAN.

While the produced outcomes could be of great value, still, there are some limitations which should be identified. The presented outcomes are mined based on the input of 14 people. Increasing the size of the people engaged in such processes could potentially improve the relevant outcomes. Similarly, the produced user goals could be considered as geographically biased as the participants only come from Greece. Thus, applying similar processes for other European countries is necessary to generalize the outcomes of the process or produce novel knowledge.

As part of T8.2 activities, the following steps are envisaged:

- The applied methodology will be communicated to other consortium members so that they could organise future focus groups in other European countries so that the produced outcomes could be localized.
- Personalized "think-aloud" sessions to evaluate the usability of the apps to be used are also going to be elaborated to evaluate the software applications per se and provide insights on behalf of the end-user

6.4. Usability Study Targeted Report (Task 8.2)

Executive Summary

This comprehensive report presents the outcomes of an extensive usability evaluation conducted on three cutting-edge healthcare applications: the eCAN mobile app, eCAN Dashboard app, and eduMEET software. The purpose of this evaluation was to assess the user

experience and functionality of these applications, specifically targeting healthcare professionals (HCPs) and patients participating in the eCAN project's pilot studies.

The evaluation involved a diverse and representative group of participants, including healthcare professionals with varying technical skills and patients with different backgrounds and mobile device preferences. Throughout the evaluation, participants were engaged in simulated real-world tasks, allowing for meticulous observation of their interactions with the applications. Furthermore, valuable feedback was gathered through questionnaires and post-task interviews, ensuring a comprehensive assessment of usability and user experience aspects.

The findings reveal a promising usability landscape for key features such as login, patient registration, and meeting initiation, reflecting the applications' strong usability foundations. Participants exhibited high task success rates, and positive user satisfaction scores were obtained for these critical aspects. Such positive outcomes are pivotal in shaping the successful implementation of the eCAN project.

However, it is imperative to highlight certain challenges that surfaced during the usability evaluation. Notably, tasks involving questionnaires were met with confusion and suboptimal task success rates. Participants encountered difficulties in understanding the wording and layout of the questionnaires, leading to less-than-ideal user experiences. Addressing these issues is crucial to enhance the user experience and ensure seamless interactions with the applications.

Identified issues encompass a range of topics, including language clarity, technical optimization, multilingual support, and consistency in information display. Participants expressed the need for clearer wording and multilingual options to accommodate diverse user preferences and language backgrounds.

Technical limitations, such as screen size discrepancies and compatibility issues with specific devices, were noted and need to be addressed to ensure smooth application usage for all participants. Additionally, the absence of questionnaire results in certain sections raised concerns about data visibility and consistency, indicating the need for a cohesive user experience across the applications.

In response to the identified issues, this report presents a series of actionable recommendations aimed at elevating the usability and user experience of the healthcare applications. By revising language clarity, offering robust multilingual support, and addressing technical limitations, the applications can cater to a wider user base, fostering inclusivity and

accessibility. Moreover, the incorporation of additional features, such as language selection and user support chatbots, will elevate user satisfaction and streamline interactions within the applications. To enhance organization and usability, it is recommended to ensure consistent information display and implement a calendar-based representation for scheduled sessions.

Implementing these recommendations will empower healthcare professionals and patients, revolutionizing healthcare delivery through more efficient workflows, streamlined interactions, and improved patient care outcomes. By integrating user feedback and iteratively improving the applications, the eCAN project can truly transform the healthcare landscape, promoting patient-centric care and elevating overall healthcare experiences.

Despite the promising findings and actionable recommendations, it is essential to acknowledge the study's limitations. The sample size of the usability evaluation was limited, and the diversity of the participant pool could be further expanded in future iterations. Additionally, as the eCAN project progresses, continuous user feedback and involvement will be crucial in addressing emerging user needs and ensuring ongoing optimization of the applications.

In conclusion, this comprehensive usability evaluation report serves as a valuable guide for healthcare professionals and technical partners involved in the eCAN project. By heeding the findings and implementing the provided recommendations, the project can harness the full potential of these innovative healthcare applications, effectively bridging the gap between healthcare professionals and patients, and ultimately transforming the landscape of healthcare delivery.

Introduction

Background

In the context of the eCAN project, based on the description of the Task 8.2, the main objectives of the task are:

- To contribute to the testing phase of the technical solutions for the pilots (WP5, WP7) before they enter the implementation phase:
- To ensure sustainability of the JA's outcomes through high user acceptance
- An agile "participatory design" methodology will be adopted to identify the end-user (patients, general practitioners, hospitals etc.) needs and pose requirements to the technical/pilot WPs and more specifically, during the design phase of the JA's interventions. Additionally, scenario-based "think-aloud" sessions will be conducted to

collect user feedback and identify potential issues before the actual start of the WP5 pilots.

This study serves directly the 3rd bullet point's objective, specifically the "Additionally, scenario-based "think-aloud" sessions will be conducted to collect user feedback and identify potential issues before the actual start of the WP5 pilots" and indirectly the 2nd bullet point "To ensure sustainability of the JA's outcomes through high user acceptance".

Purpose of the report

While the purpose of this study was to test the software implemented to collect user feedback and identify potential issues, the purpose of this report is twofold:

1. To provide it to the technical partners, since it includes bugs, and technical issues with the overall software
2. To provide it to the clinical partners, since it includes proposals and suggestions, barriers, and opportunities, regarding the context of use and not a technical aspect of the design, that were uncovered during the study.

"Think aloud" approach of usability studies

The approach aims to assess the usability of the eCAN App to get a clear view based on usability-defined

Quality Attributes. Based on J. Nielsen, "Usability for the Masses", these usability quality attributes are:

➤ Learnability (How easy is it for users to accomplish basic tasks the first time they encounter the design?)
➤ Errors (How many errors do users make, how severe are these errors, and how easily can they recover from the errors?),
➤ Satisfaction (How pleasant is it to use the design?) and
➤ Utility (which refers to the design's functionality: Does it do what users need?).

Typically, these quality attributes are calculated by extracting data from interactions with the end users via various interaction forms, i.e., field studies, workshops, interviews, questionnaires etc.

"Think aloud" is an empirical name for a user participatory design approach where users think out loud as they run a simple execution scenario on a prototype, including the use of preliminary prototypes (e.g., simple draws on paper) in order to get user feedback22. In a

"think aloud" session, the participants are asked to use the system verbalizing their thoughts as they move through the user interface. Typically, a "think aloud" usability study, consists of three elements:

- ➢ Recruit representative users.
- ➢ Give them representative tasks to perform.
- ➢ Keep quiet and let the users do the talking.

The Think-aloud protocol provides qualitative data, which means the answers, comments, proposals, insights etc. are not documented via a survey or any quantitative medium. The participants responses and comments are analyzed (coded/annotated) based on an agreed rule-list (coding scheme) which also needs to be finalized and agreed upon as well by the analyzing team which entails the "usability issue categories" (e.g., Navigations issue, aesthetic issue, wording issue etc.). Sometimes after the session is ended, just before we send away the participants, we give them some questionnaires if we need to get quantitative results.

Limitations

As with every usability study, this study had some widely accepted limitations that should be considered. These include limited sample size, which may not represent the diverse user base, artificial environments that differ from real-world usage, a learning effect that impacts participant performance, limited context that may overlook broader user experience factors, time constraints that limit thorough exploration, and the Hawthorne Effect, where participants alter behavior due to being observed. Recognizing these limitations helps researchers interpret findings accurately and consider supplementary methods to complement the study's outcomes.

Methodology

The usability study followed a task execution scenario with the think-aloud approach, to bring to the surface any issues or comments a participant may have about a specific feature or screen that is part of the "script" to evaluate qualitative usability criteria. Also, a post-study questionnaire was used after each session to acquire and to also evaluate quantitative usability criteria as well.

The scales of the questionnaire cover a comprehensive impression of user experience. In the next section we present the usability testing plan. The usability testing plan for the eCAN for native language reasons will be conducted in Greek language. Iterations of the usability testing are suggested by the bibliography as well. Main points:

➢ 14 participants (7 patients and 7 HCPs)

➢ Greek speaking end-users in Greece

➢ 1,5-hour session remotely with each participant

➢ Think aloud session simulating real life conditions (scripted questions)

➢ Post-study questionnaire

Study Design

Every participant (either HCP or patient) was asked to simulate the journey, which was described in the usage scenario, a real eCAN user would make. To this end prior to the session the participants were briefed about the context of the project and its goals along with the usage scenario that we would follow to simulate the real journey a participant would take. They were also provided with the user manual and the appropriate links to the corresponding applications in testing, but without any credentials to login and get familiar with the applications. The participants are assuming the "naïve user" identity since the real users are not expected to receive any thorough training prior to their enrollment, based on the so far pilots' design.

Every session was expected to last 1.5-hour and took place remotely using the Zoom software and consisted of 3 parts for each participant:

➢ The introduction part where context was given to the participant for the project, the software to be tested, and the way the session will processed (how a think-aloud protocol is working). Also, some demographics were collected here!

➢ The Task execution process follows a usage scenario where tasks addressing each use case are provided to the participant to execute in a sequential order simulating real actions a user would make as much as possible. The participant is encouraged to speak his thoughts and the actions he is performing aloud while executing the task on the application.

   o A usage scenario was used by the facilitator which describes all the use cases of the application for the user we are testing the application with. It describes every action simulating real use conditions) that a user could perform in the application via a narrative style. E.g., "As you are sitting in the waiting room, you get a notification in your phone that requests you to fill in a questionnaire. With that information in mind please perform any actions you find necessary to fulfill this task. Let me know when you believe you completed it, or when you would

give up.". We call it a "scenario" because it is written in a way like movie scenarios.

- o During the execution the facilitator keeps notes for any remark that might give some insights.
- o Also, he inquires on the difficulty of the Task in a 5-point Likert scale and the satisfaction when completing the task in a 7-point Likert scale.

➢ When all Tasks were executed, a debriefing session with follow-up questions for failed or missed tasks were explored. Additionally, a post-study assessment type questionnaire was distributed to the participants, and we conclude the session.

What we want to know via this usability study:

- Is eduMEET easy to use?
- Do both user groups enjoy eduMEET as a teleconsultation tools?
- Does this tool require training?
- Is it an effective tool to enable teleconsultation?
- Is the eCAN app and Dashboard easy to use?
- Do both user groups enjoy the eCAN apps as telemonitoring and telerehabilitation tools?
- Do these tools require training?
- Are they effective tools to enable telerehabilitation and telemonitoring?

Participants

The Participants were only of Greek origin and their native language is also Greek, simply because the think-aloud usability approach is based on natural and fluent communication of thoughts which must be aligned with the facilitator's language. For this reason, every participant was Greek. Also, although the participants could have been introduced to the project prior to their participation in this study they should have no prior knowledge of the eCAN applications and the way they work. In essence every participant was expected to be a naive user without prior training in the software.

- The HCP participants should be preferably either psychologists or physiotherapists, but oncologists and other cancer-related profession was also permitted.
- The patient participants should be either past or current cancer patients not in a severe state and able to participate and provide their feedback.

- Every participant was requested for confirmation they reviewed the informational sheet and accepts the recording of the camera, screen and sound for the purposes of the analysis of the study.

Variables and Metrics

The data collected were both qualitative and quantitative in nature.

Qualitative data included the recorded verbalizations of the participants, and later their transcribed version based on the annotated usability category. The usability categories were decided during the analysis.

Regarding the Quantitative data, the collection included:

- the results of the follow-up questionnaires and their scores or means for the HCPs:
    - The PSSUQ (Post-Study System Usability Questionnaire) is a standardized 16-item questionnaire widely used to measure users' perceived satisfaction with a website, software, system, or product at the end of a study. It was used for the Dashboard app.
    - The SUS (System Usability Scale) provides a "quick and dirty" yet reliable tool for measuring usability. It consists of a 10-item questionnaire with five response options ranging from Strongly Agree to Strongly Disagree. It was used for the eduMEET app.
    - The UEQ (User Experience Questionnaire) is a quick and reliable questionnaire for measuring the User Experience of interactive products. The scales in the questionnaire cover a comprehensive impression of the user's experience. It measures both the aspects of classical usability (effectiveness, efficiency, reliability) and the aspects of user experience (novelty, arousal). There is a full version with 26 items which was used for the Dashboard app and an 8-item short version used for the eduMEET software.
- the results of the follow-up questionnaires and their scores or means for the Patients:
    - The mHealth App Usability Questionnaire (MAUQ) for Standalone mHealth Apps Used by Patients. It consists of 18-items inquiring on the usability of mHealth apps. It was used for the eCAN mobile app.
    - The Telehealth Usability Questionnaire (TUQ). It consists of 21 items and it includes more generic questions in the scope of telehealth usability. It was used for the testing of eduMEET.

- o The UEQ (User Experience Questionnaire) is a quick and reliable questionnaire for measuring the User Experience of interactive products. The scales in the questionnaire cover a comprehensive impression of the user's experience. It measures both the aspects of classical usability (effectiveness, efficiency, reliability) and the aspects of user experience (novelty, arousal). There is a full version with 26 items which was used for the Dashboard app and an 8-item short version used for the eduMEET software.

➤ the usage scenario task's completion difficulty perceived in a 5-point Likert scale ranging from Very difficult to Very easy and their mean

➤ and satisfaction results that were collected after the completion of each task in a 7-point Likert scale ranging from very unsatisfied to very satisfied and their mean.

➤ The demographic-related questions asked during the session.

➤ The status of the task on completion: whether it was successfully completed or failed.

Data Collection

Data was collected via electronic means and hardcopy notes the facilitator kept.

- The verbalizations and the qualitative data were collected using the Zooms software recording functionality and by key notes the facilitator noted and transcribed to excel.

- The quantitative data were collected via hardcopy notes the facilitator kept, which happened in the case of the task difficulty and satisfaction at the task completion and via the post-study follow up questionnaires. All quantitative data had their scores and means calculated

Data Analysis

The data analysis consisted of 4 parts for each participant:

1. Definition of the coding scheme for the verbalizations (the usability categories i.e., bugs, navigation issue, re-design proposals, etc.)
2. Transcription of the verbalizations and proper annotation based on the coding scheme
3. The transcription of every questionnaire and the calculation of scores and means
4. Thematic analysis of verbalizations
5. Interpretation of results based on the findings and procurement of proposals based on the UX domain.

Findings

Participant Demographics

The following tables provide details regarding the participants, including demographic information and skill levels related to the use of a similar application. Table 3 presents the participants in the HCP study, while Table 4 presents the participants in the patient study.

HCPs	HCP1	HCP 2	HCP3	HCP4	HCP 5	HCP 6	HCP 7
Sex	Male	Female	Female	Female	Female	Male	Female
Age Group	45-54	18-24	18-24	25-34	25-34	25-34	45-54
mApp skills (1 low – 5 high)	5	4	5	4	5	5	4
Web app skills	5	4	4	4	5	5	3
Virtual meeting software skills	4	4	4	4	5	5	2
Experience with similar apps	No	Yes	No	Yes	Yes	Yes	Yes
Mobile Devices	iPhone	Android	iPhone	iPhone	iPhone	Android	iPhone, iPad
PC OS	iOS	W 10	W 10	iOS	iOS	W 10	iOS
Workplace OS	iOS	W 10	W 10	W 10	W 10	W 10	W XP
Prior exp. with telecon.	Yes	No	No	No	Yes	Yes	No
Post-study Questionnaire submission	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 3: HCP demographics

Patients	P1	P 2	P3	P4	P 5	P 6	P 7
Sex	Female	Female	Female	Female	Female	Female	Female
Age Group	55-64	45-54	35-44	45-54	35-44	45-54	55-64
mApp skills (1 low – 5 high)	4	3	1	4	5	4	3
Web app skills	3	5	2	3	5	5	3
Virtual meeting software skills	4	4	3	4	5	5	3
Experience with similar apps	Yes	No	Yes	No	Yes	No	-
Mobile Devices	Android	Android, iPad	Android	Android, iPad	iPhone, iPad, iWatch	Android	Android

PC OS	W 10	W 10	W 10	W 10	W 10	W 10	W 10
Prior exp. with telecon.	No	Yes	No	No	No	No	No
Post-study Questionnaire submission	Yes	Yes	Yes	Yes	Yes	Yes	No

Table 4: Patient demographics

Usability Task Success status

The following tables provide an overview of the successful Tasks for both HCPs and Patients. Each task corresponds to a real use case of the applications. Each task can either be successful which means that the user completed the task and performed every action he/she needed to. The miss of a Task corresponds to the near miss of the successful completion of the task. Finally, the failure corresponds to the inability of the completion of the task. The success, the miss or the failure of a task corresponds directly to the usability of the features or functionalities needed for a user to complete the task. For Tasks not corresponding to real use cases but simply ask for impressions on specific features or elements of the software, are marked with n/a. For details regarding the failed and missed tasks look at the Key **observation section.**

HCPs Tasks	HCP1	HCP 2	HCP3	HCP4	HCP 5	HCP 6	HCP 7
T1: Login Page and first impressions	Success	Success	Success	Success	Success	Success	Success
T2: First Impression: Understanding application menu options	N/A	N/A	N/A	N/A	N/A	N/A	N/A
T3: Updating your Profile (Think-Aloud Practice)	Missed	Success	Missed	Success	Missed	Success	Failed
T4: Completing the Registering of a patient by submitting a eCRF	Success	Success	Success	Success	Success	Success	Success
T5: Checking responses to questionnaires (Week 4)	Failed	Failed	Failed	Failed	Failed	Failed	Failed
T6: Initiating a meeting	Success	Success	Success	Success	Success	Missed	Failed
T7: Conducting psychological support session	Success	Success	Success	Success	Success	Success	Failed
T8: adding a note	Success	Success	Success	Success	Success	Success	Success
T9: impressions of eduMEET	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Table 5: HCP Tasks success status

Patients Tasks	P1	P 2	P3	P4	P 5	P 6	P 7
T1: App Icon & Landing page Impressions	Success	Success	Success	Success	Success	Success	Success
T2: Login	Success	Success	Success	Success	Success	Success	Success
T3: First Impression: Understanding application menu options	N/A	N/A	N/A	N/A	N/A	N/A	N/A
T4: Week 0, 2, 5, 8 questionnaires	Failed	Failed	Failed	Failed	Failed	Failed	Failed
T5: : Weekly thermometer questionnaires (Week 1, 3, 4, 6)	Failed	Failed	Failed	Failed	Failed	Failed	Failed
T6: Joining a meeting	Success	Success	Success	Success	Success	Success	Success
T7: Psychological support discussion	Success	Success	Success	Success	Success	Success	Success
T8: Exiting the meeting	Success	Success	Success	Success	Success	Success	Success
T9: impressions of eduMEET	N/A	N/A	N/A	N/A	N/A	N/A	N/A
T10: Week 9 questionnaires	Success	Success	Success	Success	Success	Success	Success

Table 6: Patient Tasks success status

Task difficulty and satisfaction at completion

HCP study

The Mean for the task difficulties per task is as follows:

- Login : 3.57
- eCRF submission : 4.43
- Questionnaire overview: Failed Task
- eduMEET initiation: 3.83
- Telemonitoring questions: 4.17
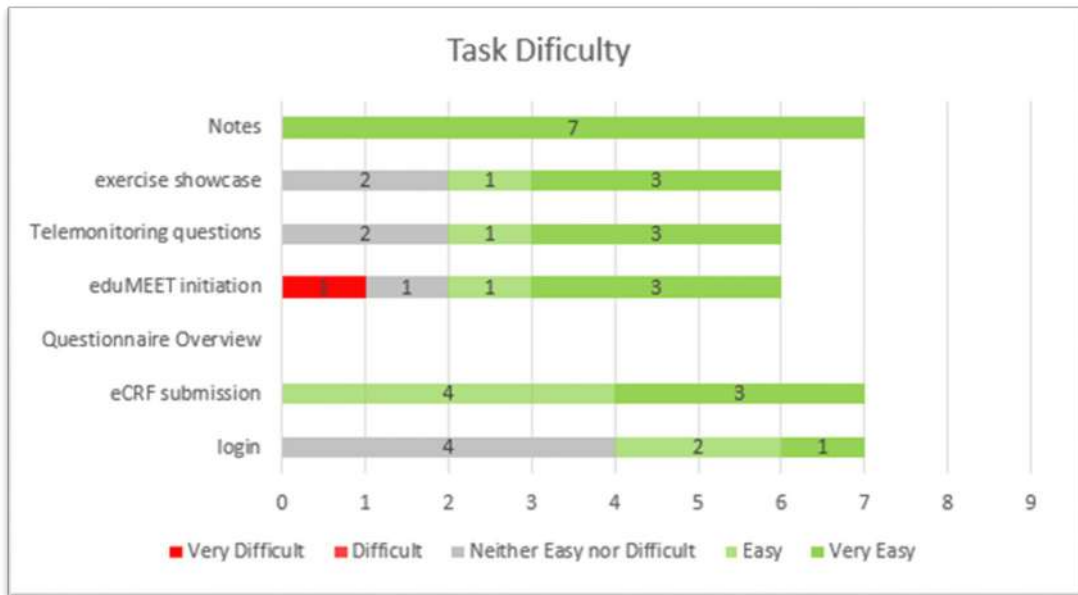- exercise showcasing : 4.17
- Notes: 5.00

Figure 15: Difficulty perceived by HCPs during specific tasks

All tasks were deemed above easy except the overview of the Questionnaires which was not displaying anything. The Mean for the task satisfaction at completion per task is as follows:

- Login: 4.43
- eCRF submission: 6.14
- Questionnaire overview: Failed Task
- eduMEET initiation   : 5.17
- Telemonitoring questions: 6.33
- exercise showcasing: 5.83
- Notes: 7.00

Figure 16: Satisfaction perceived by HCPs during specific tasks

All tasks were deemed satisfied except the overview of the questionnaires, which was not displaying anything.

Patient study

The Mean for the task difficulties per task is as follows:

- Login: 4.00
- Week 0,2,5,8 Questionnaires: 4.25
- Weekly thermometers: 4.50
- eduMEET initiation: 4.43
- Telemonitoring questions: 4.14
- exercise showcasing: 4.43
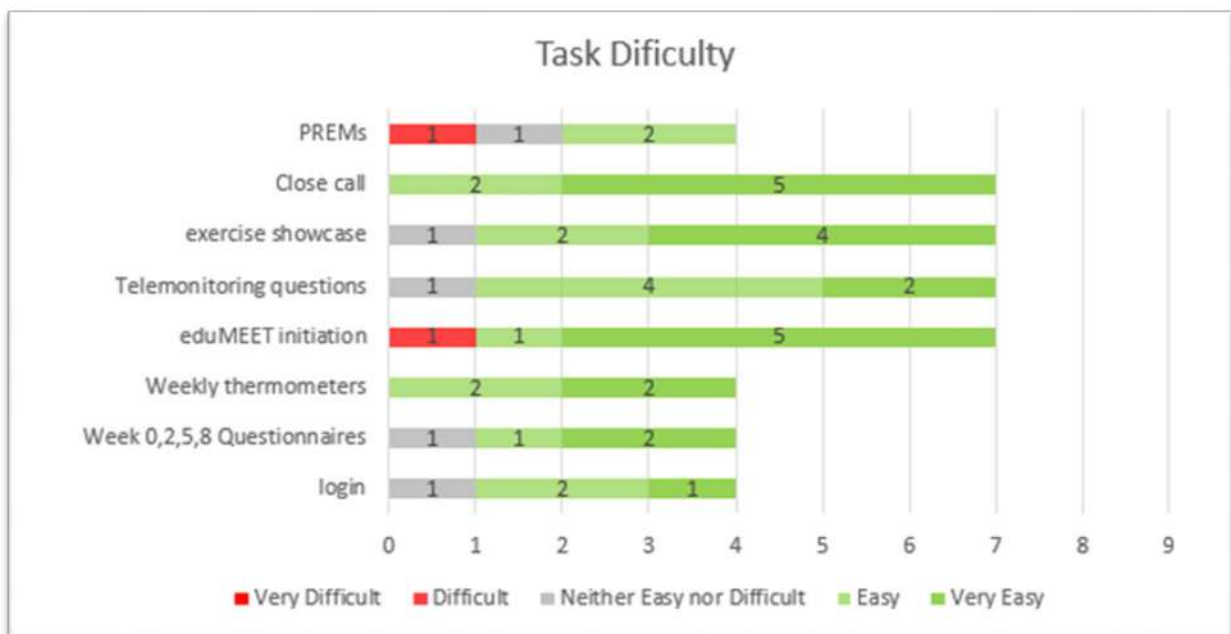- Close call: 4.71
- PREMs: 3.57

Figure 17: Difficulty perceived by patients during specific tasks

All tasks were deemed above easy except the overview of the questionnaires, which was not displaying anything.

The Mean for the task satisfaction at completion per task is as follows:

- Login: 5.75
- Week 0,2,5,8 Questionnaires : 5.00
- Weekly thermometers: 5.50

- eduMEET initiation: 6.29

- Telemonitoring questions: 6.29

- exercise showcasing: 6.43

- Close call: 6.29

- PREMs: 4.57

Figure 18: Satisfaction perceived by patients during specific tasks

All tasks were deemed satisfied except the overview of the questionnaires, which was not displaying anything.

Quantitative post-study questionnaires

HCP study

PSSUQ score for the eCAN dashboard:

- System Usefulness (SYSUSE) Score: 2.22

- Information Quality (INFOQUAL) Score: 3.00

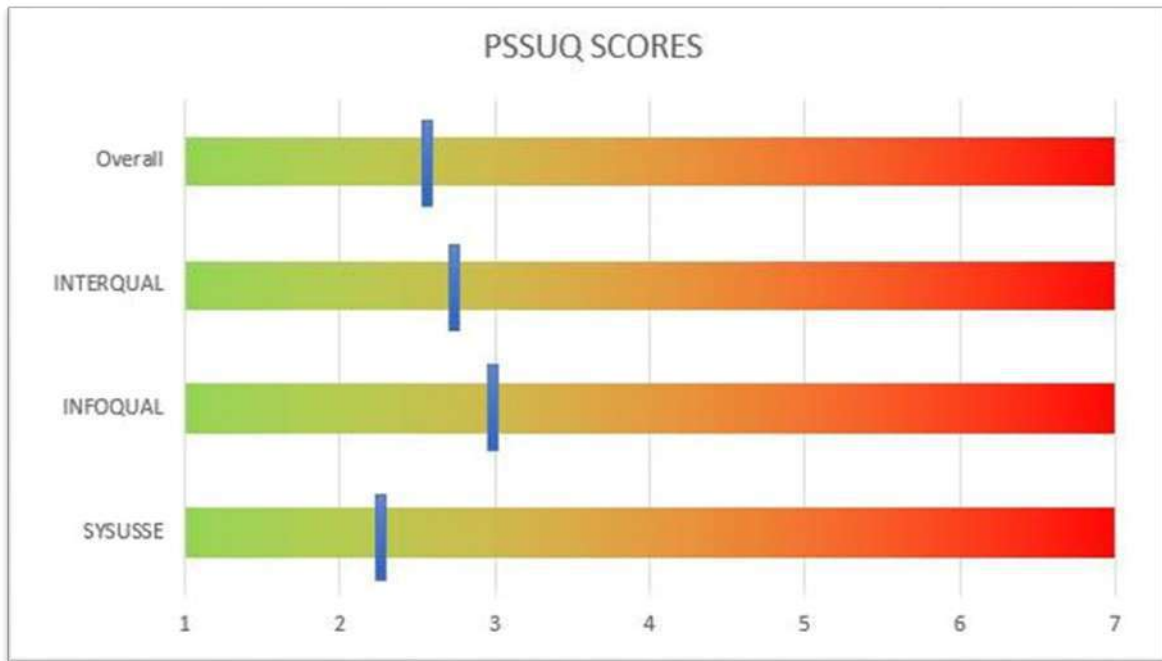- Interface Quality (INTERQUAL) Score: 2.67

- Overall PSSUQ Score: 2.63

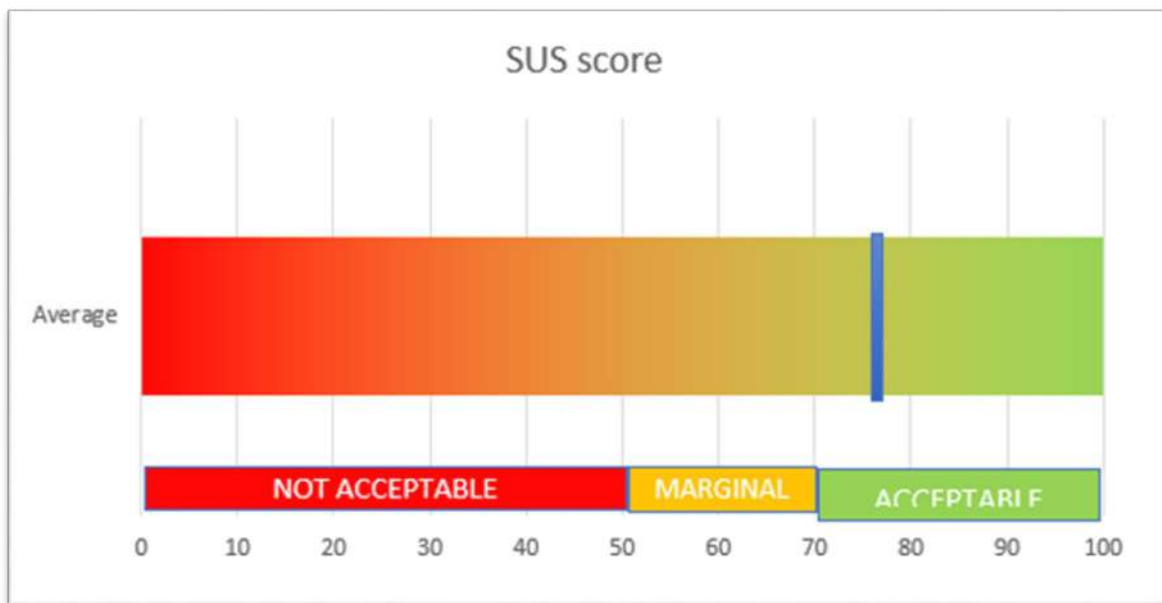*Figure 19: HCPs PSSUQ score visualization diagram of the Dashboard web app*

Figure 20: HCPs SUS score visualization diagram of the eduMEET application

UEQ Means and compare against benchmarking data for the eCAN Dashboard
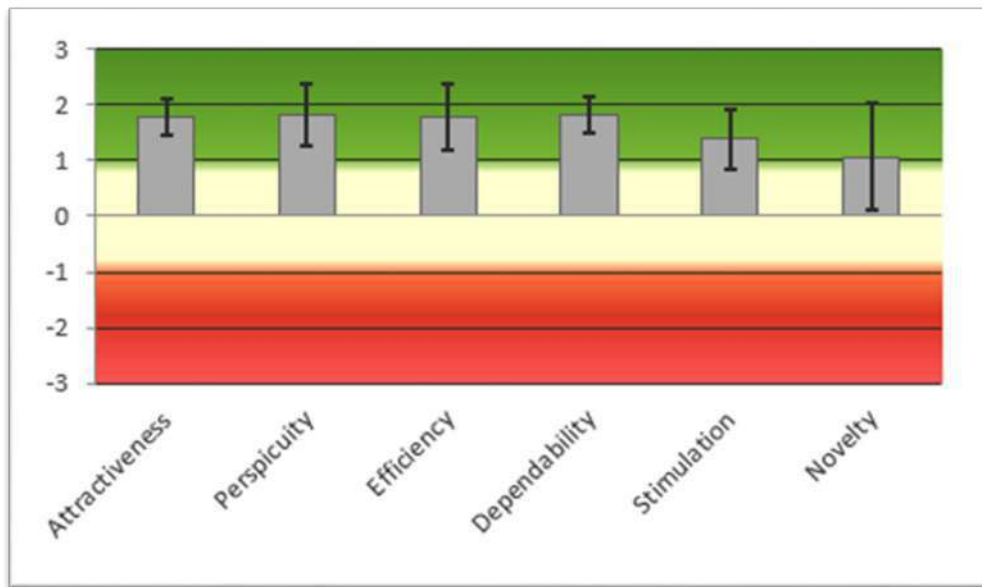
Figure 21: HCPs UEQ Means visualization diagram of the Dashboard web app

Figure 22: HCPs UEQ comparison of the Dashboard web app against benchmarking data

UEQ Scales	Attractiveness	Perspicuity	Efficiency	Dependability	Stimulation	Novelty
Mean	1.786	1.821	1.786	1.821	1.393	1.071
Variance	0.20	0.56	0.61	0.20	0.54	1.66

UEQ Means and compare against benchmarking data for the eduMEET software:

Figure 23: HCPs UEQ Means visualization diagram of the eduMEET application

Figure 24: HCPs UEQ comparison of the eduMEET application against benchmarking data

Short UEQ Scales		
Scale	Mean	Std. Dev.
Pragmatic Quality	1.625	0.518
Hedonic Quality	1.167	1.092
Overall	1.396	0.614

Patient study

mAUQ means for the eCAN mobile app: 4.67

TUQ mean for the eduMEET software: 5.62

Figure 25: Patient's TUQ for the eduMEET application and mAUQ for the mobile application

UEQ Means and compare against benchmarking data for the eCAN mobile app:
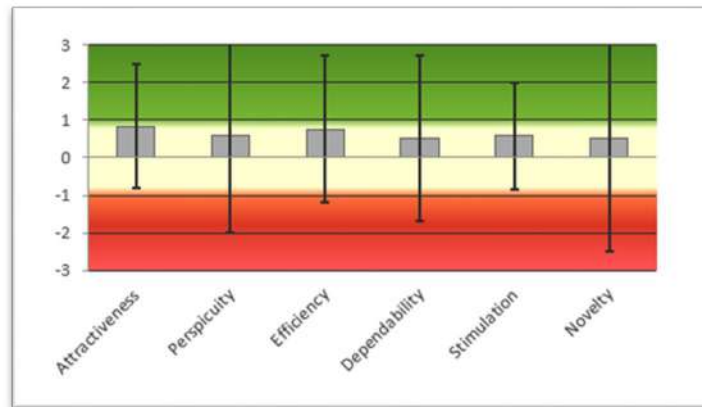
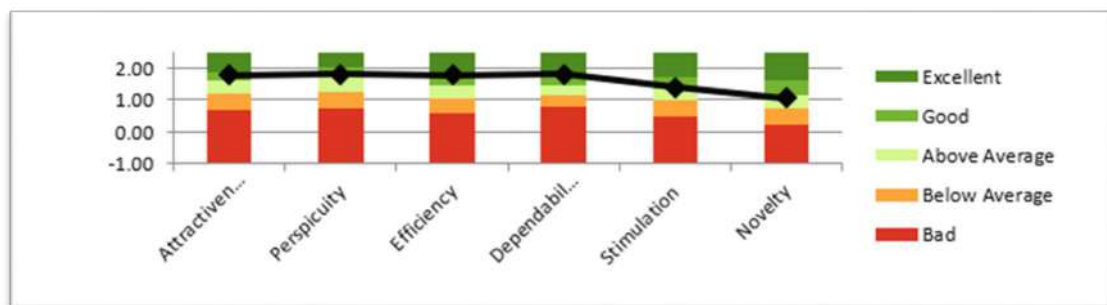*Figure 26: patients UEQ Means visualization diagram of the eCAN mobile app*
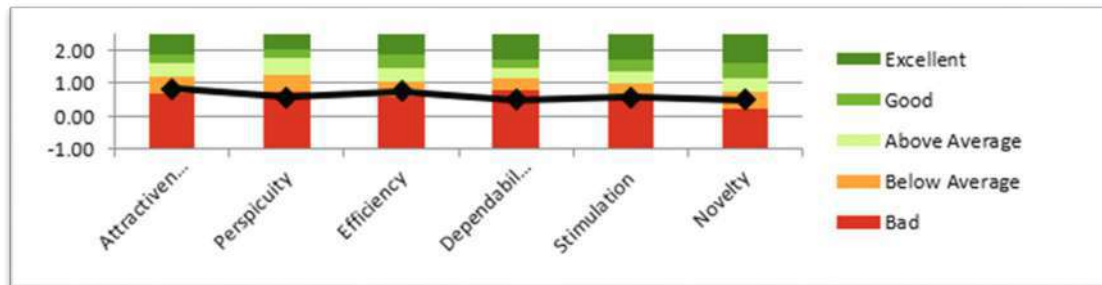
Figure 27: patients UEQ comparison of the eCAN mobile app against benchmarking data

UEQ Scales	Attractiveness	Perspicuity	Efficiency	Dependability	Stimulation	Novelty
Mean	0.833	0.583	0.750	0.500	0.583	0.500
Variance	2.11	5.15	3.00	3.81	1.58	7.00

UEQ Means and compare against benchmarking data for the eduMEET software:

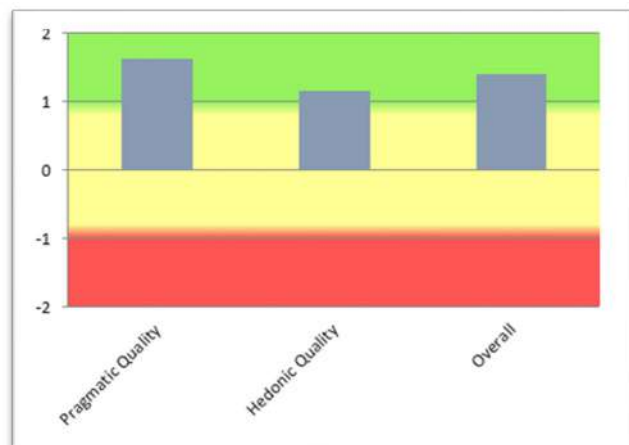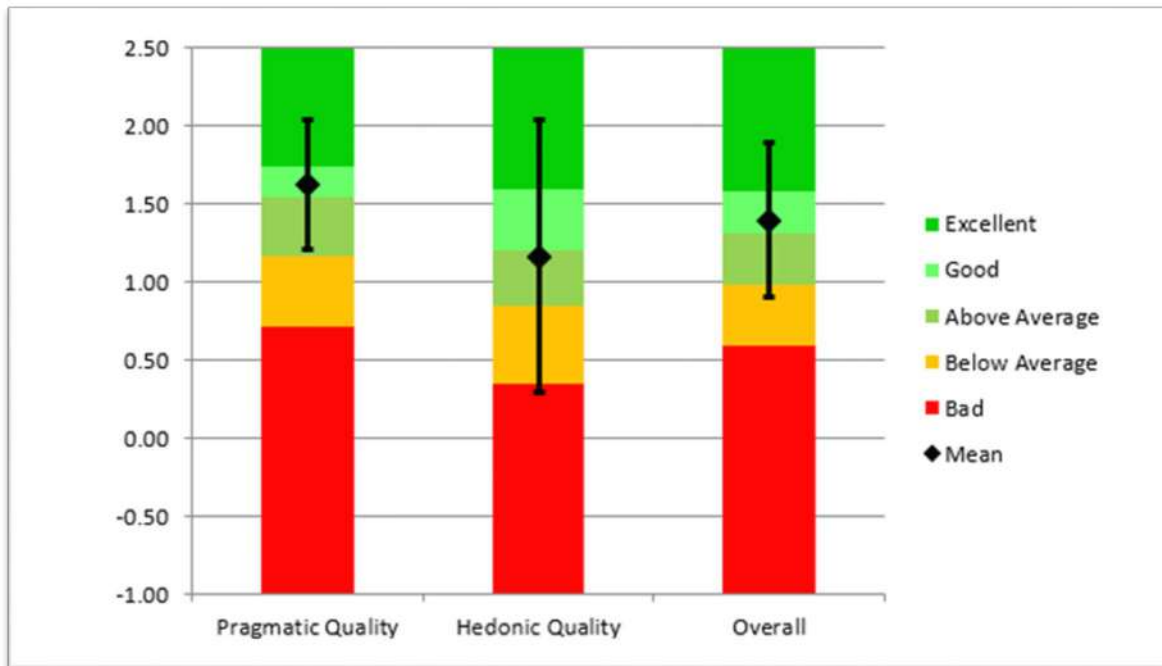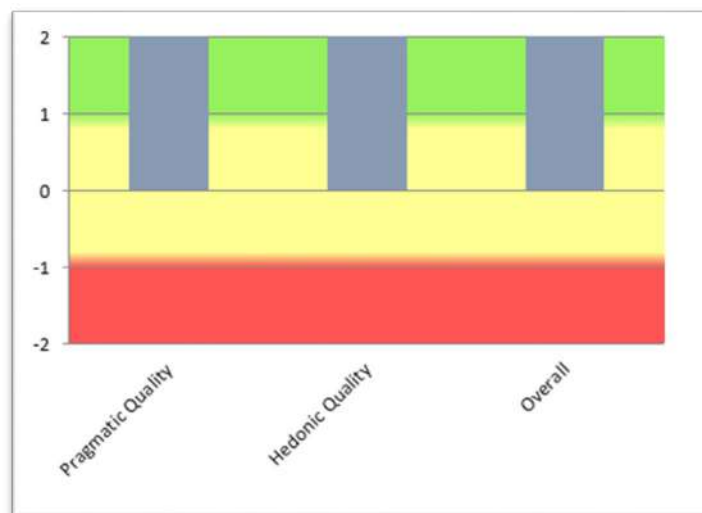*Figure 28: patients UEQ Means visualization diagram of the eduMEET application*
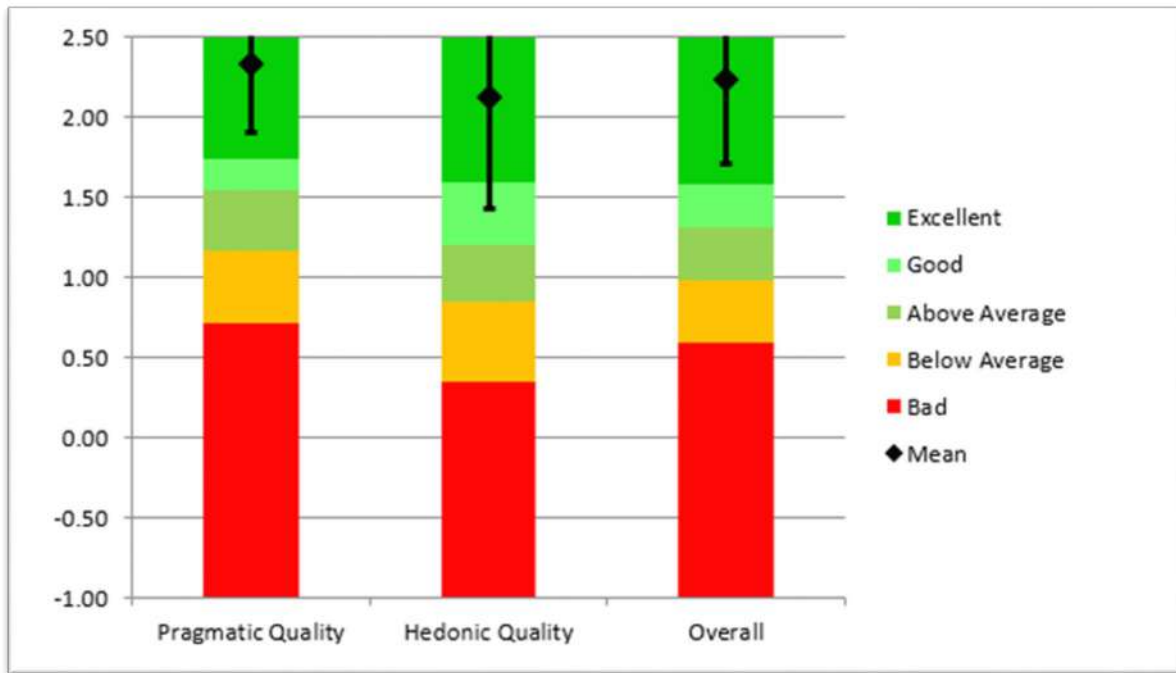
Figure 29: patients UEQ comparison of the eduMEET application against benchmarking data

Short UEQ Scales		
Scale	Mean	Std. Dev.
Pragmatic Quality	2.333	0.540
Hedonic Quality	2.125	0.862
Overall	2.229	0.644

Key Observations

Proposals and suggestions barriers and opportunities

Patient Study

Free answer at follow-up questionnaire from P5:

"The application is very user-friendly, and I believe it will be accessible even to users with no prior experience with technology. Keep up the good work!"

Thematic analysis of notes from the usability study:

- **User Interface and Navigation**:
  - Participants mentioned difficulties in understanding the app's navigation, such as not realizing they were already on the activities page.

o Some participants expressed dissatisfaction with the app's title, suggesting a preference for a more relatable name.

- **User Authentication and Password**:
    o Participants desired a simpler process for entering their real username and password, indicating a need for clearer instructions or a more intuitive interface.

- **Terminology and Understanding**:
    o Participants expressed confusion about terms such as "present week" and "week 0" in relation to the questionnaires.
    o The word "thermometer" was perceived as inappropriate and not functioning like an actual thermometer.
    o Difficulties in scrolling, finding the submit button, and perceiving the layout were mentioned, highlighting interface usability issues.

- **Questionnaires and Content**:
    o Participants questioned the number of questions in both the QLQ and PREMs, finding them invasive or time-consuming.
    o Some participants expressed a lack of interest in completing the PREMs.
    o Participants desired more clarity and specificity in questions related to support and rehabilitation.
    o The presence of English questions created difficulty for participants who only knew Greek.

- **Visual Design and Aesthetics**:
    o Participants expressed a preference for more visually appealing icons, less dark themes, and modern, colourful backgrounds.
    o Some participants requested the ability to enlarge fonts for better readability.

- **Functionality and User Experience**:
    o Participants desired a more calendar-based representation of daily activities and the option to view durations for each week.
    o Suggestions were made for a more multidisciplinary teleconsultation team and the inclusion of adverse reactions or after-effects in discussions.

- **Instructions and Guidance**:
    o Participants mentioned a need for information or guidance on how and when to connect to eduMEET.

- **Time and Length**:
    o Participants perceived the questionnaires as lengthy and time-consuming.

These findings highlight the importance of enhancing the user interface and navigation, improving clarity of terminology, considering cultural and language preferences, and incorporating visually appealing designs. Simplifying the authentication process, providing clear instructions and guidance, and addressing usability issues like scrolling and finding buttons can significantly enhance the user experience. Additionally, customization options, such as font size adjustment and the inclusion of open- ended questions, may contribute to a more inclusive and engaging experience for users.

HCP study

Free answer at follow-up questionnaire from HCP 2:

"It would be good to have additional features such as language selection and a personal assistant (like a chatbot) for questions/clarifications and support for people with disabilities. Additionally, a change in the platform's design, particularly in terms of colors and their intensity, might be useful to create a more pleasant user experience."

Free answer at follow-up questionnaire from HCP 6:

"To have PROMs and PREMs next to the Notes tab. To have separate rooms for each patient in edumeet, with a calendar displaying scheduled sessions, and a general calendar showing all the appointments for the month for all patients."

Thematic analysis of notes from the usability study:

- Additional Features:
    - Participants expressed the need for language selection and a personal assistant (chatbot) to provide support and assistance for people with disabilities.
    - Desired improvements in the platform's design, particularly in terms of colors and intensity, to enhance the overall user experience.
- Integration of PROMs and PREMs:
    - Participants suggested placing PROMs and PREMs next to the Notes tab for easy access and better organization.
- Separate Rooms and Calendar:
    - Participants requested separate rooms for each patient in eduMEET, along with a calendar displaying scheduled sessions.
    - They also mentioned the need for a general calendar that shows all the appointments for the month for all patients, facilitating better management.
- Functionality and User Interface Issues:

- o Participants reported encountering bugs in the home screen options and the submit button when updating profile details.
- o Questions and confusion arose regarding specific terms and abbreviations used in the eCRF, such as IC, treatment, comorbidities, and drugs.
- o Participants desired clearer explanations and better wording in app interfaces and questionnaires to avoid confusion and improve comprehension.

- Technical Limitations:
  - o Some participants faced compatibility issues, such as not being able to use the software from certain browsers or on specific devices (e.g., Windows XP).

- User Support:
  - o Participants expressed a need for pop-up notifications when updating details or completing tasks.
  - o They desired thorough explanations for each eCRF question to ensure understanding and minimize confusion.
  - o Some participants sought clarification on the purpose and meaning of PROMs and PREMs.

These findings highlight the importance of incorporating additional features for language support, accessibility, and user assistance. Improvements in the user interface, such as color design, clarity of wording, and explanation of terms, are crucial for enhancing the overall usability. Addressing technical limitations and providing comprehensive user support can further improve the user experience.

Regarding the Pilots

While conducting the usability study presented in this report, the participants were often encouraged to "speak their minds" each time they had a spontaneous thought or comment, no matter the valance of it. During these oral expressions of thought, a few recommendations emerged. While some were direct, meaning they originated from the participants independently, some were elicited contextually during data analysis. These are:

Before the enrolment:

- Need for quick guides: It would be good to have quick guides for the HCPs were all the information needed will be there, for both the eCAN Dashboard app and the patients app. It is clear also in the case of the eCAN that the HCPs attention span and time is limited and many pilot project fail because they do not consider that reality. Since the eCAN is a relatively simple project with few functionalities, a quick guide could prove

much useful for HCPs. In addition, it would help a lot as a checklist for the enrollment of the patients. The same applies for patients as well but only in the case of the "registration" to the study, meaning quick/ essential information regarding the download, installation etc., of the app and the smartwatch.

- What if the IT takes too much time to create my patients credentials: Many HCPs were surprised that they could not create credentials for their patients. One expressed a worrying feeling, that the IT would be responsible for many drop-outs, because of the waiting times.

During the enrolment

- A guide for HCPs to help patient with the showcase of the app.
- Scheduling of teleconsultations: HCPs suggestions were not aligned. There seems to be a need for all teleconsultation meetings to be scheduled at the enrolment of the patient so the HCP would not have to initiate communication via another medium. If the patient has a conflict they can always reschedule, but the dates and times should be prefixed. Another HCP claimed he wanted them to be ad-hoc since he wanted to accommodate the patient's schedule.
  o This will highly depend on the final decision of the eduMEET use, but we would suggest keeping these in mind.

After the enrolment

- Need for in app notification of status of other users: While the patients and HCPs first login to the systems and had to interact in some way with the app they were inquiring about the possibility that the doctor or patient will be notified for certain statuses, e.g. "Your doctor has reviewed your questionnaires" or "Your patient has just completed the questionnaires", or your patient successfully logged in for the first time.

Regular use

- Regarding eduMEET: How will the HCPs contact the patients to provide them the links, if they are not communicated at the enrolment? This was also asked by an HCP. Since this will be a browser link and most communications happen via the phone. We propose to have all teleconsultations prescheduled with the possibility of rescheduling when needed.
- I need notification reminders: Both Users expressed a need for in app notifications reminders. Patients wanted to have reminder notifications for both the consultations

and the questionnaire submission and progression notifications for both the current week and the overall study. HCPs requested to know in a way when the teleconsultations are and a countdown or display of status, to review the patients answers before an upcoming meeting. Also I would appreciate after a call a pop-up message reminding me to keep a note of the meeting.

- A Chatbot to help about obligations: It seems a chatbot could be useful since patients have questions regarding the meaning of some questions in the QLQ and eCRF and it could provided simple, targeted and tailored information about the questions in the questionnaires.

End of the study

It was obvious that guides are needed for the end of the study ass well, to remind patients to complete their PREMS, because it is obvious, they are not about their condition and there are indications that might not be thoroughly completed.

Also, the HCPs will need guidance as to how to treat their patients, their data at the end to ensure security and avoidance of any accidental deletion.

Additional comments:

- eduMEET regular use and meeting links: There must be a clear indication to users as to how eduMEET will be used. Will all teleconsultation calls be scheduled at the enrolment of the patient? Will they be at hoc? If so, how will they be communicated to patients? Through the app? Via email, SMS?

Bugs and Technical issues

eCAN mobile app

The eCAN mobile app has been tested so far by 6 Participants (eCANTest21 - eCANTest26) with Android devices, 1 Participant knew that it would be available in iOS as well and had to reschedule so she had access to an Android device.

Regarding the bugs and Technical issues:

1. Screen Size: Most participants devices had issues with showing the weeks tab
2. Wordings of weeks: The wording week 0 is not comprehensible by patients. The word "present week" is suggested plus the depiction of the week durations (e.g., 6/7/2023 –

14/7/2023). In addition, I would suggest the info to be depicted in a calendar form, also marking clearly the start and end of the study.

3. Message display: The message in the Home Screen "Επιλέξτε την εβδομάδα για την οποία θέλετε...." appears to be mistreated as a "pop-up" message, and participants tried to dismiss it and wasted time there, they also did not like it being so big. It is better if it is not shown in that way and instead make it as a pop-up dialog box, with "got it" dismissing it.

4. Need for more concrete information: All participants expressed their expectation for a simpler explainable home screen with appropriate messages about their obligations and the timing for completion for questionnaires.

5. Questionnaire wordings: Questionnaires titles were not comprehensible by patients, especially the "QLQ" questionnaire and the "thermometer" word. Also, they found their reporting of "distress" confusing since distress has many meanings.

6. Language: All Questionnaires were expected to be in Greek and were not. Some participants could not practically complete them.

7. Questionnaire thermometers:
   a. Screen Size: The Thermometers do not fit in the screen and the submit button is not visible to submit. Scrolling is also not possible.
   b. Choice selection: Participants were under the impression that they needed to tap and hold on the zero value and slide all the way to their preferred one, which was not the case and frustrated some participants. We suggest either make it like a slider or change the presentation of the thermometer so taping for the answer makes sense. (Could provide suggestions if interested)

eCAN Dashboard app

The eCAN Dashboard app has been tested so far by 6 HCPs (eCANDoctor23 – eCANDoctor28) with, both Mac and Windows devices all using Google Chrome browser.

- One tested it in Safari and could not log in since the SSO option would not open the new window to log in.
- Also, a user could not view the app in the correct way since by default her institution had windows XP and the page was showing limited information. (This is important to consider before the pilots. Either design for older devices or make sure the participating clinics' infrastructures is compatible).

Regarding the bugs and Technical issues:

1. **Login is confusing**: There is no reason to have two types of log in. Remove the option to enter username and password and enable only the option of "Login using SSO", and the change that as well to simply "to Log in click here"

2. **The options in the bottom screen do not work**:

3. **Language expectations**: Most participants expected the UI to be changeable to Greek, and had difficulties during i.e., in the eCRF submission

4. **Profile "submit" of new information**: While the change of information is possible the fact that the "new password" and "old password" are there the participants were under the impression they had to do that every time they wanted to change something. Also, the button seemed to be unresponsive since nothing seemed to happen when pressing it.

5. "**Add patient" non responsiveness**: Every participant was confused with the Add Patient functionality since they expected that all patients are already in the system and what exactly does that do. They suspected sending an e-invite by entering a patient mail or making an account for the patient themselves.

6. **eCRF**: At the eCRF form many wordings were not comprehensible (e.g., "IC sign", Charlson Comorbidity Index (CCI), Household income was not clear it meant yearly etc.)

7. **PROMs and PREM**s:
   a. Wording not comprehensible: Both the term prom and prem as well as the QLQ is not comprehensible as clearly as we would like to believe.
   b. Results not showing: The PROMs and PREMs display is bugged, it is empty and not showing anything. Based on fake data entered by both me and the participants during testing.

8. **Author of notes**: Some participants believed it is needed to show the name of each note author or eCRF submitter since there might be needed later to solve disputes.

eduMEET

The eduMEET app has been tested by 6 HCPs and 6 Patients so far! We tested the initiation of the call all the way to its completion. The HCP would ask some questions based on the questionnaire results of the patient and later would offer some psychological guidance.

It seems it makes much sense to somehow incorporate eduMEET in the eCAN dashboard app. The only problem emerged by the usability study is the difficulty in understanding that the HCP had to copy the URL and sent it as an invitation to the patients, whereas they would much

prefer a button were when clicking it would possibly prompt them to send an invitation with the link clearly visible.

Also, although the initiation of the call was simple some of them thought they had to login to the eduMEET and wasted much time in that fashion.

Finally, the "Allow access to microphone" and "Allow access to the camera" pop up messages when joining the call in eduMEET are almost instantaneously dismissed by the participants without paying attention. The permissions should be presented in a less sketchy from their point of view way.

Discussion

Comparison to Usability Goals

The usability evaluation of the eCAN mobile app, eCAN Dashboard app, and eduMEET software was conducted with the primary goal of assessing the applications' user-friendliness, efficiency, and overall user experience. By comparing the findings to the initial usability goals, we can identify areas of success and opportunities for improvement.

The success of certain tasks, such as login and patient registration, aligns well with the usability goals. These tasks demonstrated high success rates among both healthcare professionals (HCPs) and patients, indicating that the applications are well designed in terms of basic navigation and essential functionalities. This achievement is a positive sign, as a seamless onboarding process is crucial for ensuring user engagement and adoption.

However, the failed status of specific tasks, particularly related to questionnaire-related activities, raises concerns about the applications' effectiveness in facilitating crucial interactions between HCPs and patients. The usability goals aimed to create a user-friendly environment for questionnaire completion, but participants reported confusion and difficulties in understanding the wording and navigation of these tasks. This disconnect indicates the need for adjustments to achieve a more cohesive user experience in this aspect.

Identified Issues

The usability evaluation identified several key issues that require attention to enhance the overall user experience of the applications:

1.   **Confusing Terminology**: Participants expressed difficulty understanding terms such as "thermometer," "PROMs," and "PREMs." The use of unfamiliar or

ambiguous language may hinder users from fully engaging with the applications and may result in incomplete or inaccurate responses to questionnaires.

2. **Technical Limitations**: Screen size limitations and compatibility issues with certain devices and browsers were reported. These technical constraints may disrupt the user experience, leading to frustration and potential disengagement.

3. **Lack of Language Options**: Some participants expected the applications to support multiple languages, but this feature was not available. The absence of language options may exclude users who are not proficient in the default language, limiting the applications' reach and accessibility.

4. **Inconsistent Information Display**: The absence of information in the questionnaire overview section and the empty display of PROMs and PREMs results were highlighted as inconsistencies in the applications' functionality. These discrepancies may lead to user confusion and reduce the trustworthiness of the applications.

5. **Need for Additional Features**: Participants suggested features such as language selection, a personal assistant (chatbot) for user support, and a clearer representation of scheduled sessions. These additional features were identified as potential improvements to enhance user satisfaction and streamline workflows.

Potential Improvements

To address the identified issues and align the applications with the usability goals, the following potential improvements are recommended:

1. **Language Clarity**: Review and revise the wording used throughout the applications to ensure clarity and avoid jargon. Consider conducting user testing with representatives from different language backgrounds to ensure comprehensive understanding.

2. **Technical Optimization**: Conduct rigorous testing to identify and resolve screen size limitations and compatibility issues. Ensuring smooth functionality across various devices **and browsers is essential for a consistent user experience.**

3. **Multilingual** Support (eCAN Dashboard): Implement language options within the applications to cater to users with diverse language preferences and abilities. Providing multilingual support will promote inclusivity and expand the user base.

4. **Consistent Information Display**: Address the inconsistencies in the questionnaire overview section and ensure that PROMs and PREMs results are accurately displayed. Consistency in information presentation instills user confidence and reliability in the applications.

5. Additional Features: Integrate language selection and a chatbot for user support to enhance user satisfaction and provide personalized assistance. Consider incorporating a clear calendar- based representation of scheduled sessions for improved organization.

Implications for User Experience

The usability evaluation's findings have significant implications for the overall user experience of the applications. Addressing the identified issues and implementing potential improvements will result in the following benefits:

1. **Enhanced User Engagement**: By improving language clarity and providing multilingual support, the applications will be more inclusive and accessible to a broader user base. Users will feel more engaged and confident in navigating the applications, leading to increased usage and participation.

2. **Streamlined Workflows**: Technical optimization and the incorporation of additional features, such as the chatbot, will streamline workflows for both healthcare professionals and patients. This efficiency will save time and effort and contribute to a seamless healthcare experience.

3. **Improved User Satisfaction**: Consistent information display and the inclusion of requested features, such as language selection and a clear calendar view, will enhance user satisfaction. Meeting user expectations and preferences will create a positive perception of the applications and promote user loyalty.

4. **Enhanced Communication**: The integration of eduMEET into the eCAN Dashboard app offers the potential to improve communication between HCPs and patients through teleconsultations. Providing a simpler invitation process and ensuring compatibility will enhance communication efficiency and foster stronger patient-provider relationships.

Conclusions

Summary of Findings

The usability evaluation of the eCAN mobile app, eCAN Dashboard app, and eduMEET software yielded valuable insights into the user experience and functionality of these applications. Overall, the evaluation revealed both successes and challenges in meeting the usability goals set for the applications.

The comparison to usability goals showed promising results in tasks related to login and patient registration, indicating that the applications have strong foundations for basic navigation and essential functionalities. However, certain tasks, particularly those involving questionnaires, raised concerns due to confusion and difficulties experienced by users. The identified issues highlighted the need for improvements in terminology clarity, technical optimization, multilingual support, and information display consistency.

Recommendations

Based on the findings from the usability evaluation, we propose the following recommendations to enhance the usability and user experience of the applications:

1. **Language Clarity**: Revise the wording used throughout the applications to ensure clarity and simplicity. Conduct user testing with representatives from diverse language backgrounds to identify and address potential language barriers.

2. **Technical Optimization**: Conduct thorough testing to resolve screen size limitations and compatibility issues with different devices and browsers. Ensure that the applications perform seamlessly across a wide range of platforms.

3. **Multilingual Support**: Implement language options within the applications to cater to users with various language preferences. Offering multilingual support will promote inclusivity and widen the reach of the applications

4. **Consistent Information Display**: Address the inconsistencies in the questionnaire overview section and ensure that PROMs and PREMs results are displayed accurately. Providing a consistent information display fosters user trust and reliability.

5. **Additional Features**: Integrate language selection and a chatbot for user support to enhance user satisfaction and provide personalized assistance. Consider incorporating a clear calendar- based representation of scheduled sessions for improved organization.

Limitations and Future Research

While the usability evaluation provided valuable insights, there are limitations that should be acknowledged. The evaluation was conducted with a relatively small sample size of participants, which may not fully represent the diverse user population that will interact with the applications. Conducting usability testing with a more extensive and diverse sample could provide further insights into user preferences and needs.

Additionally, the evaluation focused on specific tasks and functionalities, but real-world use cases may present additional challenges and opportunities for improvement. Continuous user feedback and iterative testing during the pilot studies will be crucial to identify and address any emerging issues.

Future research should also explore the long-term user experience and acceptance of the applications in real-world settings. Conducting post-pilot studies with a larger user base will allow for a comprehensive assessment of the applications' usability, user satisfaction, and impact on healthcare outcomes.

In conclusion, the usability evaluation of the eCAN mobile app, eCAN Dashboard app, and eduMEET software provided valuable insights to guide improvements in the applications' design and functionality. By implementing the recommended enhancements and considering user feedback during the pilot studies, we can create user-friendly and efficient applications that empower healthcare professionals and enhance patient care.

Appendices

HCP scenario and Tasks

You are a healthcare professional who provides psychological support primarily to cancer patients in remission, and accessing the hospital or clinic is challenging for your patients. After informing your patient, you discuss the eCAN collaborative action and how the tools it offers can contribute to better support when in-person access is difficult. The situation is as follows:

- Under regular clinical conditions, sessions for psychological support would be conducted at regular intervals over a period of at least 8 weeks, regardless of whether the patient attends or not. During these sessions, patient feedback would be collected either verbally (through physician questions) or in the form of questionnaires (handwritten or electronic within the hospital or clinic) regarding quality of life, pain level, psychological state, etc.
- You inform the patient that these activities can also be conducted remotely through the eCAN application. By simply having the application, the patient can complete the questionnaires at their convenience at predetermined time points. Additionally, remote psychological support sessions can be conducted via teleconsultation tools. The patient is informed about the ease of using these tools.

Before the patient leaves:

The application is handed over to the patient, along with login credentials. Now, with this information in mind, let's begin with the following tasks:

1.   Task 1: Login Page and first impressions
2.   Task 2: First Impression: Understanding application menu options
3.   Task 3: Updating your Profile (Think-Aloud Practice)
4.   Task 4: Completing the Registering of a patient by submitting a eCRF
5.   Task 5: Checking responses to questionnaires (Week 4)
6.   Task 6: Initiating a meeting
7.   Task 7: Conducting psychological support session
8.   Task 8: adding a note
9.   Task 9: Impressions of eduMEET

Patient scenario and Tasks

You are a patient who is experiencing recurrent cancer, and accessing the hospital or clinic is difficult for you. After receiving relevant information from your treating physician, they discuss the collaborative action eCAN and how its tools can contribute to better support when in-person access is challenging. The situation you are in is as follows:

- Under normal clinical conditions, sessions would be conducted at regular intervals for a minimum of 8 weeks to provide psychological support (regardless of whether you attend the sessions or not). During these sessions, patient feedback would be collected either verbally (through physician questions) or in the form of questionnaires (handwritten or electronic within the hospital or clinic) regarding quality of life, pain level, psychological state, etc.
- Your physician informs you that these activities can be conducted remotely through the eCAN application. By simply having the application, you can submit the questionnaires at your convenience at predetermined time points. Additionally, psychological support sessions can be conducted remotely through teleconsultation tools.

Before you leave:

Your physician provides you with the application and gives you the login credentials. You also have a user manual in your possession (sent to you).

Now, with this information in mind, let's begin with the following tasks:

1.   Task 1: App Icon & Landing page Impressions

2.   Task 2: Login

3.   Task 3: First Impression: Understanding application menu options

4.   Task 4: Week 0, 2, 5, 8 questionnaires (Week 0)

5.   Task 5: Weekly thermometer questionnaires (Week 1, 3, 4, 6)

6.   Task 6: Joining a meeting

7.   Task 7: Psychological support discussion

8.   Task 8: Exiting the meeting Task 9: Impressions of eduMEET Task 10: Week 9 questionnaires

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