



Active Involvement of Potential End Users in Strengthening eHealth for Cancer Prevention and Care

Task 8.2

WP8 INAB|CERTH, AUTH, 3rd RHA (Greece)

January 2024

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Outline

List of Tables.....	3
List of Figures.....	3
Glossary of Acronyms.....	3
1. Introduction.....	4
2. Methodology.....	5
2.1. Focus Group Discussion about Telemedicine.....	5
2.2 Focus Group Discussion about the eCAN mobile application and eCAN dashboard.....	6
3. Results.....	8
3.1 Focus Group Discussion about Telemedicine.....	8
3.1.1 Final User Goals from the Focus Group about telemedicine.....	11
3.2 Focus Group Discussion about the eCAN mobile application and eCAN dashboard.....	13
3.2.1 Key Points summary from both group discussions.....	18
4. Conclusions.....	18

List of Tables

Table 1. Key points table extracted from focus group discussions about the developed technologies

List of Figures

Figure 1. Methodology of Focus Group about telemedicine

Figure 2. Methodology about Focus Group Discussions about eCAN mobile application and eCAN dashboard

Figure 3. 10 user goals about telemedicine

Figure 4. Key points scheme extracted from focus group discussions about the developed technologies

Glossary of Acronyms

eCAN	Strengthening eHealth Including Telemedicine and Remote Monitoring in Health and Care Systems for Cancer Prevention and Care
EU	European Union
ELLOK	Greek Association of cancer patients
FG	Focus Group
HCP	Healthcare professional
JA	Joint Action
KP	Key Points
WP	Work Package

1. Introduction

The European eCAN Joint Action (eCAN) commenced in September 2022 with the vision of mitigating cancer care inequalities throughout the European Union. eCAN seeks to enhance the effectiveness, efficiency and quality of prevention and cancer care, particularly addressing cross-border emergencies and health crises like COVID-19. Its strategic approach involves providing a comprehensive framework of recommendations for the seamless integration of telemedicine and remote monitoring into healthcare systems.

Central to the eCAN initiative is the careful consideration of end users' perspectives. Work Package 8 (WP8), responsible for stakeholder engagement, education, and training, holds, among others, the responsibility of enhancing eHealth competencies for teleconsultation and telemonitoring services among providers, caregivers and patients. As part of Task 8.2, Participatory Design, various actions were implemented to actively engage potential end users and gain a comprehensive understanding of their perspectives on eHealth services.

First, in May, a Focus Group discussion involving patients, healthcare professionals (HCPs), and patient assistance agents was conducted to understand their needs and concerns regarding telemedicine. The primary objective of the first FG was to immerse into end users' perceptions, challenges, needs, and motivations regarding the use of telemedicine solutions.

Then in December, after 14 usability studies sessions with potential end users regarding the developed eHealth technologies within the context of eCAN, two more Focus Group discussions were conducted as part of the participatory design, each with two primary objectives. The first was the iterative assessment of the interventions' design of developed technologies within the context of eCAN JA. The second was aimed to explore the feasibility of using corresponding applications in everyday clinical practice, along with the factors significant to the users.

To achieve these objectives, it was decided to conduct two slightly differentiated Focus Group discussions: a FG discussion about the eCAN mobile application and a slightly different FG discussion about the dashboard platform.

The Focus Group about the application was conducted with the active involvement of patients as potential end users of the developed application. The final Focus Group revolved around the dashboard platform, involving HCPs as potential end users. This differentiation was made to gather insights and opinions from the end users who would possibly use the corresponding technology. It was considered that patients might not be able to provide

valuable feedback on the usability and features of the dashboard platform, which is used by HCPs, and vice versa. However, the initial part of both discussions was identical to ensure that both groups fully understood the intended use of the technologies.

2. Methodology

2.1. Focus Group Discussion about Telemedicine

Thirteen participants, all of Greek nationality, were included in the study. This participant group consisted of four HCPs (coming from Papageorgiou Hospital and INAB|CERTH staff), five cancer patients (coming from the Greek Association of cancer patients – [ELLOK](#)) and four patient supporting organisation members (coming from the “[K3](#)” group), ensuring a diverse range of perspectives. The study was conducted remotely (via Zoom), primarily in the Greek language, to facilitate natural and fluent communication. The focus group’s duration was approximately 2 hours and 10 minutes. The session followed a structured agenda, as is described also in Figure 1.



Figure 1: Methodology of Focus Group about telemedicine

Phase A: Introduction

This phase included a brief presentation of the eCAN Joint Action project and an opportunity for participants to introduce themselves. They also were asked some demographic questions like “What devices do you have?”, “What is your age?”, “Where do you live?”, “How would you rate your ability to handle digital applications?”...

Phase B: Discussion with each group separately (Breakout rooms)

Participants were divided into three separate groups based on their roles: HCPs, patients, and patient carers/supporters. Each group engaged in discussions focused on what constitutes a pleasant/unpleasant communication between an HCP and a patient in the context of use addressed in the eCAN project, appropriateness of specific "personas" and targeted questions related to telemedicine tools.

Phase C: Conclusions

In the last part, conclusions from each group's discussions were presented, and further discussions took place to synthesize the findings.

After the online session, a thematic analysis of the recorded discussions was performed, involving the extraction of key themes and insights from the conversations. The results of the Focus Group were also used to elicit a list of user goals, which was circulated within the eCAN consortium to guide further development of the respective applications and to aid in the facilitation of the eCAN pilot studies' preparation.

2.2 Focus Group Discussion about the eCAN mobile application and eCAN dashboard

The focus group discussions were organised along the following three phases, as **Error! No se encuentra el origen de la referencia.** also presents.

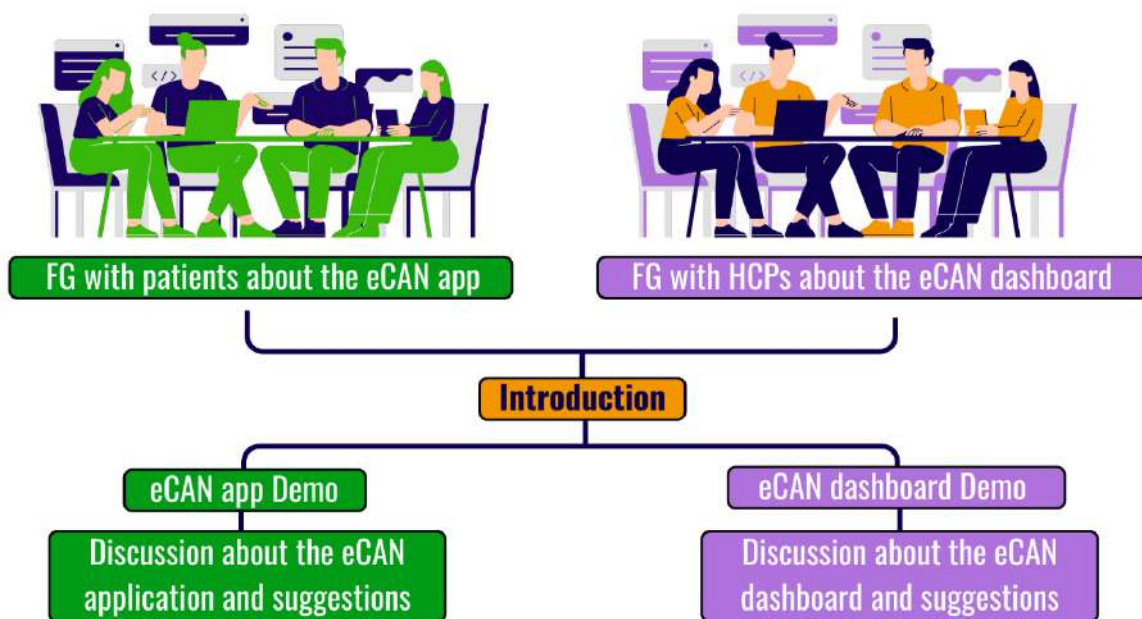


Figure 2: Methodology about Focus Group Discussions about eCAN mobile application and eCAN dashboard

Phase A: Introduction

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

Phase B: Presentation of the developed technologies

Focus group discussion about the eCAN mobile application

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

Focus group discussion about the eCAN dashboard

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

Phase C: Conclusions

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

In the focus group discussion about the dashboard, questions were posed such as: "Would you use a similar platform in your daily clinical practice?", "What would be a motivating factor for you?", "If it were up to you, what would you add to the platform?", "Is there another way

you would prefer to read/view the data?”, “How else would you use the data to support telemedicine services?”.

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

The number of participants chosen was five, and the sampling method was based on the common 'purposive' or 'convenience' sampling method. Considering the language used in the discussions, availability, and positive feedback from previous focus group sessions (referring to the focus group conducted in May), we chose to approach the Greek Association of cancer patients, ELLOK, for the focus group discussion about the eCAN mobile application. Eventually, five patients from ELLOK took part.

Similarly, for the focus group discussion about the dashboard, HCPs coming from the 3rd Regional Health Authority (3rd RHA), General Hospital Papageorgiou, and INAB|CERTH staff were approached. After all approaches, five HCPs participated. (two psychologists from General Hospital Papageorgiou (both of whom are also involved in the pilot study), one physician coming from 3rd RHA, two psychologists coming from INAB|CERTH staff).

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

3. Results

3.1 Focus Group Discussion about Telemedicine

Following the thematic analysis of the discussions conducted in the three “breakout rooms”, valuable conclusions emerged. The description of these follows. For a complete reading of the methodology and a detailed description of the conclusions, you can also visit the report on the [eCAN JA website](#).

Insights from the patients' room

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

perceptions of teleconferencing reveal diverse communication preferences. Email emerges as a commonly embraced and less intrusive method, serving as a widely accepted means of communication among patients. Telephone communication also prevails as a prevalent choice, facilitating discussions and exchanges.

However, despite their widespread use in daily communication, platforms like Skype and Messenger are not extensively adopted in this healthcare context. Interestingly, these platforms find specific applications in offering psychosocial support, particularly catering to the needs of patients facing mobility challenges.

The issue of digital literacy poses a significant challenge, particularly for individuals aged 60 and above. To address this, there is a pressing need for tailored education and training programs aimed specifically at patients within this age group. In addition, efficient and immediate communication is deemed essential, particularly for patients actively dealing with illnesses. Recognising this, there is a call for a cultural shift, especially among healthcare professionals who play a pivotal role in setting communication standards.

When it comes to the establishment of a reimbursement model tailored for HCPs engaging in telemedicine, this is identified as a crucial aspect. Developing a framework that aligns with the unique nature of telemedicine practices is imperative to support and incentivize practitioners.

A notable contrast exists also between the public and private healthcare sectors. Interestingly, even older doctors demonstrate familiarity with telemedicine practices. However, burnout is a prevalent concern within the public healthcare system, exacerbated by an increased workload. Addressing these sector-specific differences is vital for the overall success and sustainability of telemedicine initiatives.

During user-centred development, effective communication in telemedicine involves doctors with a personal attitude, respecting patients' time, providing prompt responses, and showing empathy. Conversely, poor communication includes a lack of respect, long waiting times, and adherence to protocols without personal interest. In terms of tools and barriers, there is an overall positive attitude toward telemedicine, but concerns about data privacy and GDPR compliance persist.

Ensuring usability, preventing application intrusiveness, and integrating telemedicine into the public healthcare system pose challenges. It is more accessible for younger individuals and those with mobility issues, but the inclusion of minority groups may be challenging.

Leveraging secondary data is crucial, and non-specialised doctors stand to benefit significantly from telemedicine.

Insights from the HCPs' room

In summary, the focus group with HCPs yielded crucial insights for the advancement of telemedicine solutions. One key observation emphasised the absence of dedicated software for teleconsultation, indicating a need for the development of reliable and purpose-built tools. Additionally, the continued reliance of some patients on remote solutions highlighted the importance of creating accessible and user-friendly platforms tailored to diverse patient needs.

The intensive use of telecommunication tools during the pandemic underscored the significance of scalability and stability in ensuring seamless support for hospital workers. While some hospitals are part of telemedicine networks, further development is necessary for seamless integration. National-level issues related to compensation and personal data protection require comprehensive resolution to establish a solid foundation for widespread telemedicine adoption.

The limited experience of psychologists in remote care highlighted the need for training and support, emphasizing the importance of specialized education for HCPs engaging in telemedicine services. Effective communication strategies were identified as vital for overcoming challenges and building trust in patient-doctor relationships.

Addressing language barriers emerged as a critical consideration, with improved communication facilitating accessibility for vulnerable groups. The active involvement and motivation of patients in their treatment were identified as key contributors to better outcomes. Ensuring the protection of doctors in remote diagnoses is crucial for minimizing potential errors.

In conclusion, these insights offer valuable guidance for ongoing telemedicine development, emphasizing the importance of dedicated software, accessibility, effective communication, and ethical considerations. These considerations collectively contribute to the advancement of telemedicine solutions for enhanced healthcare delivery.

Insights from the patient supporters' room

Patient supporters' perceptions regarding telemedicine underscore the importance of addressing challenges related to patients' understanding and utilization of telemedicine tools. Offering initial assistance and ongoing support becomes imperative in this context.

Additionally, the recognition of HCPs' limited familiarity with telemedicine tools emphasizes the need for efficient integration within the public healthcare system, necessitating targeted training and education initiatives.

The development of suitable infrastructure and tools for electronic communication, particularly in peripheral or private settings, emerges as a key consideration. They are acknowledging regional disparities and economic constraints influencing patients' access to healthcare and their reliance on telecommunication highlights the need for tailored solutions that address diverse needs.

To enhance the adoption and effectiveness of telemedicine, solutions should be designed to meet the specific needs and preferences of different patient personas, including elderly individuals and younger age groups. Effective communication practices, such as providing comprehensive information and personal support, are crucial, recognizing the significance of face-to-face interactions.

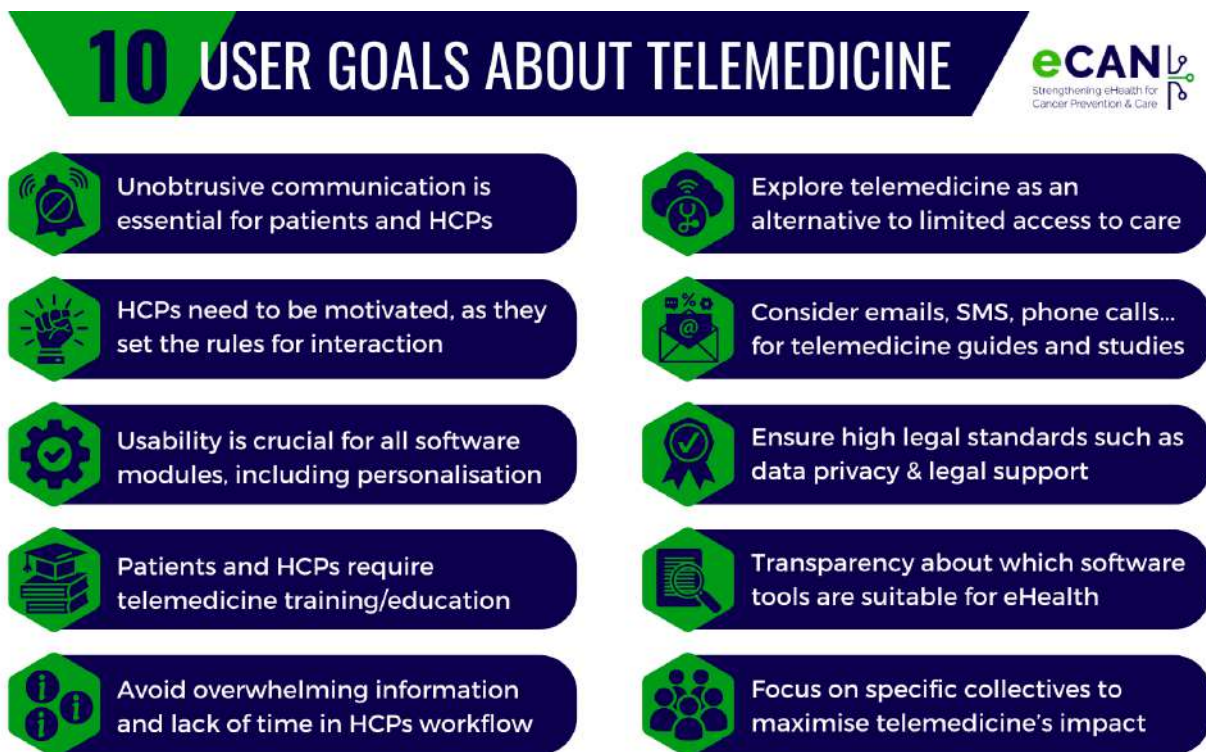
Implementation of supportive measures and continuous improvement of telemedicine infrastructure are vital for an enhanced overall patient experience, ensuring successful adoption. These insights from patient supporters emphasize the importance of a comprehensive approach to telemedicine that addresses various challenges, promotes accessibility and prioritizes effective communication for a positive impact on patient care.

3.1.1 Final User Goals from the Focus Group about telemedicine

All the above insights could be summarised 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 personalisation 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 were identified as a key barrier to 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: 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 maximise the impact of the telehealth services, reducing the risk of adoption and improving the risk/benefit ratio.



eCAN Task 8.2

Figure 3: 10 user goals about telemedicine

3.2 Focus Group Discussion about the eCAN mobile application and eCAN dashboard

Focus group discussion about the eCAN application

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

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

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

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

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

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

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

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

KPa3. Concerns arise when the health condition deteriorates

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

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

KPa4. Expanding Features with a Calendar Functionality

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

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

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

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

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

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

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

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

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

P3: *“To demonstrate the expected benefit... perhaps through the presentation of a clinical study”*

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

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

Focus group discussion about the eCAN dashboard

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

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

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

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

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

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

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

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

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

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

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

KPb4. Enhancing primary data utility for improved patient care

“When exploring alternative applications for the primary data, there was a notable interest in exporting data for personal statistical analysis and enhancing treatment planning. Moreover, emphasizing the integration of filters within the gathered data was crucial, as this would enable healthcare providers (HCPs) to identify patients with distinct needs. This approach could facilitate the classification of patients based on criteria like higher pain levels, increased

session absences, or organising them according to their treatment plans and monitoring their progress.

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

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

KPb5. Personalized dashboard design aligned with individual HCP workflow

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

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

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

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

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

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

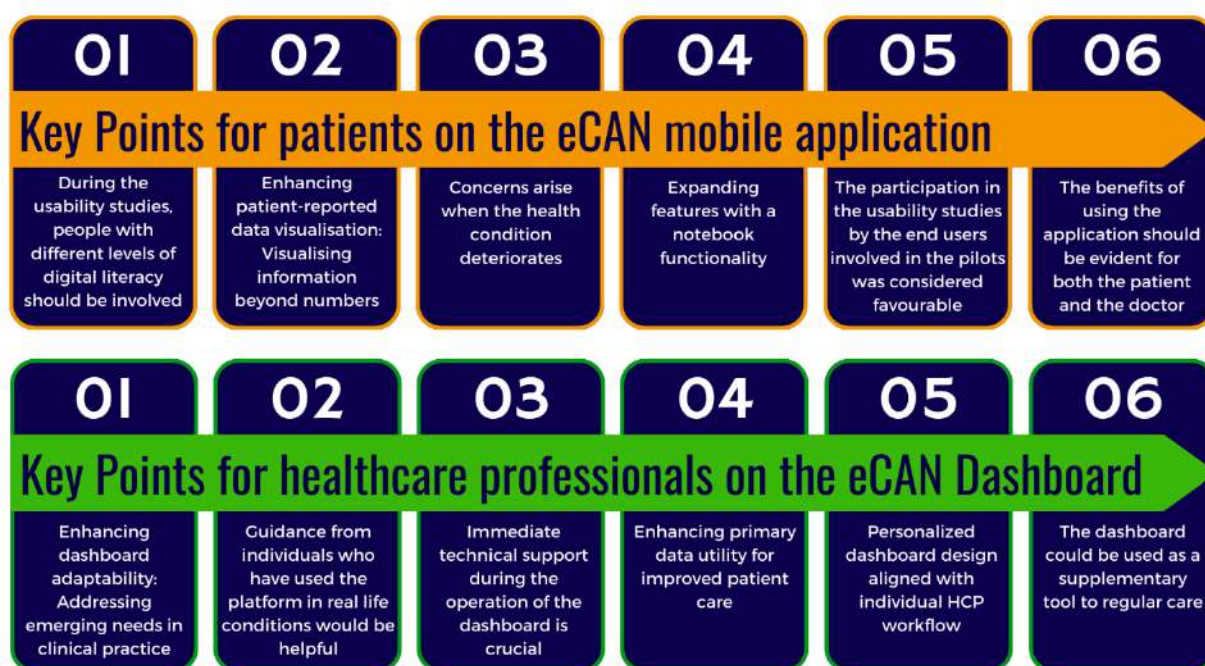
HCP4: *“From my experience, the combined approach (remote and face-to-face) has the best response in patient treatment... I can draw more conclusions from the body language or the clothes they wear in face-to-face meetings...but of course, it will be useful to collect more data for my patient”.*

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

3.2.1 Key Points summary from both group discussions

Key Points extracted from focus group discussions	
Patients	
During the usability studies, people with different levels of digital literacy should be involved	
Enhancing patient-reported data Visualisation: Visualising information beyond numbers	
Concerns arise when the health condition deteriorates	
Expanding features with a notebook functionality	
Participation in the usability studies by the end-users involved in the pilots was considered favourable.	
The benefits of using the application should be evident for both the patient and the doctor	
Healthcare professionals	
Enhancing dashboard adaptability: Addressing emerging needs in clinical practice	
Guidance from individuals who have used the platform in real life conditions would be helpful	
Immediate technical support during the operation of the dashboard is crucial	
Enhancing primary data utility for improved patient care	
Personalised dashboard design aligned with individual HCP workflow	
The dashboard could be used as a supplementary tool to regular care	

Table 1: Key points table extracted from focus group discussions about the developed technologies



eCAN Task 8.2

Figure 4: Key points scheme extracted from focus group discussions about the developed technologies

4. Conclusions

The insights from the telemedicine-focused focus group highlight numerous challenges and needs faced by patients, HCPs, and patient supporters. Effective communication, education, and support emerge as crucial elements for the smooth adoption of telemedicine.

Concerning the developed technologies, the FG discussions shed light on specific requirements and considerations. For the eCAN mobile application, patients expressed satisfaction and provided valuable suggestions, emphasizing the importance of usability, enhanced data visualization, and additional features like calendar functionality.

On the other hand, discussions about the eCAN dashboard revealed insights from HCPs, emphasizing the need for adaptability, immediate technical support, and the potential use of the dashboard as a supplementary tool to regular care.

To conclude, the telemedicine FG findings align with the developed technology-focused discussions by underlining the significance of user-friendly design, immediate support, and the clear demonstration of benefits for both patients and HCPs. Bridging these aspects is crucial for the successful integration of telemedicine technologies into healthcare systems, as envisioned by the eCAN Joint Action.