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# INTERIM TECHNICAL REPORT

eCAN

Strengthening eHealth for Cancer Prevention & Care

DELIVERABLE 1.1

# Outline



# Summary

By fulfilling the task T1.3. Technical and financial reporting, the Action Coordinator manages the submission of the Interim Technical and Financial Report for the eCAN JA. The activities resulted in the following deliverable: D1.1. Interim Technical and Financial Report (M12, PU, Electronic, English, 40 pages approx.), as detailed below.

**Note**: The interim financial report of the eCAN JA (15 September 2023 – 14 September 2023) is sensitive and is not accessible in this document available at the eCAN website.

# 1. Technical Report

This Joint Action (JA) called 'Strengthening eHealth including telemedicine and remote monitoring for health care systems for CANcer prevention and care (eCAN)' aims to bring the benefits of eHealth to all citizens and patients across the European Union, especially for those living in remote and rural areas. The project involves 16 countries and 35 key partners working in public health institutes, universities, hospitals, cancer centres and patient associations across Europe (Annex I). In this document, the baseline analysis eCAN and the progress of Work Packages (WPs) in the first year (15 September 2022 – 14 September 2023) are reported.

| Work Package (WP) | Leading institution |
|---|---|
| WP 1 Project management and coordination | Sciensano, BE |
| WP 2 Communication | Catalan Institute of Oncology, ES |
| WP 3 Evaluation | Maria Skłodowska Curie National Research Institute of Oncology, PL |
| WP 4 Sustainability | Austrian National Public Health Institute, AT |
| WP 5 Teleconsultation | Regina Elena National Cancer Institute, IT |
| WP 6 Legal, ethical framework and cybersecurity | Regina Elena National Cancer Institute, IT |
| WP 7 Telemonitoring | National eHealth Authority, CY |
| WP 8 Stakeholder engagement, education and training | 3rd Regional Health Authority, EL |

## 1.1. Baseline analysis

**SWOT analysis**

At the baseline of the project a SWOT analysis was performed by WP1 and WP3 with all work package leaders to establish the key strengths, weaknesses, opportunities and threats for the project. This analysis was further discussed during the kick-off meeting. The summary of the outcomes is presented below.

The eCAN JA has several notable strengths. Firstly, even though the eHealth in general is a complex and interdisciplinary area, the topic itself is highly focused - specific to cancer, which allowed to bring together a consortium of partners with relevant expertise enabling the eCAN JA to address cancer-related issues comprehensively. Another area of strength lies in the JA's expertise in conducting randomized controlled trials (RCTs) and engaging with cancer

patients. Furthermore, the JA benefits from strong collaboration among its members, building upon previous work with member states and patient organizations involved in the JA. This collaborative foundation enhances the JA's ability to effectively address cancer-related challenges. Another prominent strength lies in Belgium (Cancer Centre, Sciensano) leading the eCAN JA. The involvement of the European Institutions and organisations in Brussels allows for political buy-in.

Similarly, at the country level, the eCAN JA's focus holds significant importance for the Ministries. Hence, the JA enjoys broad participation, with a diverse array of countries joining the initiative. Many participating partners have also assumed roles in different JAs focusing on cancer and e-health. This collective participation not only enriches the JA's knowledge base but also fosters collaboration and shared learning among countries with varied experiences and between JAs operating in the same field.

However, some weaknesses were also noticeable at the beginning. It was important from the beginning to recognize the interdependencies between the WPs and the potential domino effect that delays in one WP could have on others. It was deemed crucial to ensure strong collaboration and cooperation among participating countries, with work across different WPs being more interwoven. Bureaucratic constraints in participating countries, difficulty in timely personnel recruitment, and a shortage of specific technical expertise in the job market added to the complexities. The overall timeframe of the JA, with just two years, poses an extremely limited timeframe for the completion of activities.

At a rather technical point, certain points in the proposal required further details, such as the design of the RCTs and the added value of teleconsultation in telerehabilitation and psycho-oncological support cases. The type of data collection, including whether it should be centralized or decentralized, was also unclear at the beginning. The enrolment of patients in RCTs at multiple locations within different contextual settings, including variations across countries and health systems, presents challenges. Harmonizing these diverse settings is essential for the smooth implementation of the trials.

Concerns were raised about data collection and data storage using a cloud solution, especially regarding the use of a single country platform and whether the data should be aggregated at the country level or collected individually from patients. Data transfer and patient randomization required further clarification, despite the fact that reaching a consensus among participating countries has been challenging during the proposal development. The limited timeframe for running three RCTs necessitates a focus on specific cancer types and

early rehabilitation right after surgery, as literature highlights the need in these clinical scenarios. The timeframe for patient enrolment and data collection was therefore expected to be limited, along with the definition of the data to be collected, particularly from wearables in WP7.

Notably, eCAN JA presents also several opportunities that can be leveraged for its success. Firstly, the fact that three eCAN participating countries are leading the EU presidency (Spain is leading in the second half of 2023 and Belgium and Hungary in 2024) provides a favorable environment for driving the JA's objectives forward. Establishing strong connections with the Ministries of Health for those countries is recommended to prioritize e-health on the policy agenda. Establishing strong connections with the Ministry of Spain is recommended to prioritize e-health on the policy agenda. It is advised to proactively initiate and foster contacts with relevant stakeholders.

Additionally, with cancer being a priority for the European Union, there is heightened interest and support from users, including patients and physicians. Notably, patient organizations in Cyprus (WP7 lead) have demonstrated significant interest, and the involvement of Cyprus leads in the European Health Data Space (EHDS) and MyHealth@EU app adds further value. The COVID-19 pandemic, rather than being a threat, presents an opportunity for the JA. The increased focus on infectious diseases has accelerated the adoption of telemonitoring and teleconsultation. Another notable opportunity lies in the collection of patient-reported outcomes (PROs) from RCTs. Gathering data outside clinical settings is traditionally challenging in oncological treatments. The eCAN JA's efforts will contribute to bridging this gap and improving data collection in such contexts.

Being able to address cybersecurity concerns is another opportunity the eCAN JA can seize. Europe has witnessed significant cyber-attacks on digital health platforms, necessitating clarity regarding the cybersecurity platform to be used and ensuring patient informed consent. The eCAN JA's work will contribute to enhancing cybersecurity measures and addressing these gaps. Moreover, tele-oncology, as a specific aspect of telemedicine, garners great interest, making the broader telemedicine services sector highly receptive to the eCAN JA's activities. Lastly, the JA can serve as a use case and provide valuable insights for several other e-health projects. Its experiences and outcomes can inform and guide future initiatives in the field.

The JA could face some threats that need to be addressed to ensure its success. Data security concerns pose a significant challenge, potentially affecting the acceptance of the JA.

However, higher involvement of patient organizations can help mitigate these concerns. The JA is also potentially vulnerable to cybersecurity issues linked to the application developed by WP7 and the collection of patient data. This threat is acknowledged and is being addressed in close collaboration with WP6.

Moreover, the presence of low-quality apps in the market can damage the reputation of telemonitoring applications, including the JA's, and erode end-user trust. The late interest shown by some Affiliated Entities in the JA's activities poses another threat. If such delays occur again in the future, the overall success of the JA could be jeopardized. Additionally, the establishment of a network of local organizations at the Member State level is crucial, and the failure to create this network could negatively impact the JA.

The legal basis for data transmission across borders in Europe remains uncertain, posing a threat to the JA's operations. Clarity regarding the regulations and guidelines governing cross-border data transfer is necessary for the JA's activities to proceed seamlessly. Moreover, the existence of other JAs in the field of e-health presents a concern, as overlapping projects may arise. Engaging in dialogue and coordination with other ongoing JAs is vital to avoid duplication and streamline efforts.

Additionally, close communication with Comprehensive Cancer Centers (CCCs) initiated in countries was deemed necessary to prevent overlapping projects in the e-health domain. Involving the EC in meetings with JA leads can aid in evaluation and sustainability aspects, ensuring a comprehensive view of ongoing activities. Streamlining survey activities not only within the eCAN JA but also with other JAs is crucial to optimize engagement with national stakeholders and prevent survey fatigue due to repeated contacts from multiple projects.

**Action points for WPs**

As for the smooth start of the project, the following action points were discussed. It was emphasized that the creation of the corporate image and logo should be prioritized early on, ideally by M1, as waiting until M3 could cause unnecessary delays in communication to different stakeholders. It was suggested that having draft versions available by M1 would be more beneficial. It was also proposed to conduct a stakeholder analysis at the EU level by M6. This analysis would involve exploring the work undertaken by other JAs to compile an internal report. WP1 expressed a willingness to support this initiative and facilitate connections between JAs to learn from their experiences. It was also suggested to work on generating political awareness by WP2 activities throughout the JA to garner support and participation.

The target audience for communication efforts was deemed to include not only technical experts but also the general public. Social media, including platforms like Twitter, would fall under the responsibilities of the Communication and Dissemination WP. Translation of communication materials was considered important were meaningful. While the translation into national languages was attributed to WP3 for better local outreach, it was suggested that translations in commonly used languages other than English, and especially eCAN JA pilot countries, could be useful for EU-level communication and stakeholder involvement.

Moreover, the establishment of local stakeholder groups was emphasized, with a focus on MS-level engagement rather than EU-level. These groups would be formed through ecosystems consisting of local organizations. It was crucial to start building these ecosystems promptly, as they would serve as the main contact points for other work packages when conducting surveys. The development of educational materials and activities was highlighted under MS8.2. Concerns were raised about the potential lateness of this milestone, as the pilots were set to begin in M9. The focus of these materials would be on e-health solutions rather than interventions performed in clinical settings. It was deemed essential for the educational materials to be available before the pilots commenced, including information on both e-health solutions and clinical interventions.

At a technical level, several topics related to telemonitoring were addressed. One of the milestones of WP7, MS7.1, involves conducting a mapping exercise of the telemonitoring landscape. The goal is to create a comprehensive understanding of the current state of telemonitoring, which would contribute to a peer-reviewed study. Each participating country would be required to provide information based on a pre-defined set of questions. The idea of collaborating with other work packages, such as WP1 and WP4, was also discussed to leverage their expertise and potentially enhance the outcomes of the mapping exercise. The discussion also touched upon the review of guidelines from previous European e-health projects, with the potential to result in a scientific publication. This review aimed to leverage existing knowledge and experiences to inform and enhance the telemonitoring efforts of the project.

The discussion also touched upon the devices to be used for monitoring. Concerns were raised regarding the scalability and sustainability of the system, particularly in terms of uploading data from different hardware or watches. While it was technically possible to integrate new devices, it was recognized that doing so within the project's timeframe would be inefficient and impractical. To address this challenge, the proposal was made for WP7 to

be in close collaboration with vendors and ensure that data collection through wearable devices is EU GDPR compliant.

Regarding data management, the pilots would involve the same patients receiving both telemonitoring and teleconsultation services. Patient data would be recorded, fully anonymised, and forwarded to a cloud server, with the database structure established within the cloud space. The ultimate goal was to integrate telemonitoring services into the overarching digital solution known as MyHealth@EU. Data ownership emerged as another important consideration. The question of whether the telemonitoring and teleconsultation data collected belonged to the patients or the hospitals was raised. In the case of Cyprus (WP7 lead), it was confirmed that patients held ownership rights over their data. However, it was acknowledged that data ownership legislation might differ among countries. Therefore, it was recommended that WP6 elaborates on the data ownership rules in Europe, particularly inquiring about the pilot countries' specific regulations.

As for the RCTs, WP5 aims to standardize trials in different settings during the preparatory phase and train patients for self-rehabilitation after the trial. Further discussion between WP5 and WP8 was deemed necessary to clarify the aims and timings of their respective training materials before the pilots start. It was mentioned that patients‘ data would also be extracted from standard care, but it was necessary to clarify the definition of standard care as it could vary among different countries. In addition to these points, there were discussions about the potential support of WP5 for WP3 and WP8, both of which were involved in focus group discussions related to the evaluation or education of piloting centers. WP5 emphasized the need to consider the burden on patients and avoid asking for excessive information, particularly for patients at an advanced stage of cancer.

The discussion also covered data and systems security in teleconsultations and telemonitoring, specifically through a survey about technical equipment among participating countries. It was clarified that this task in WP6 was dedicated to pilot countries and aimed to standardize the approach for participating patients. The survey outcomes would help determine whether data collection should be centralized or not. The question was raised about whether all the data should be stored in a single cloud solution. It was suggested that physicians should ideally have access to patients' teleconsultation and telemonitoring data, including patient-reported outcomes (PROs), during the RCT intervention. This would enable treatment improvements to be made throughout the intervention period.

Discussions about sustainability involved mapping and assessing the relevance of existing initiatives in European countries. Desk research is to be conducted to cover all European countries, with the possibility of using surveys for those that are not adequately covered through desk research. The mapping exercise aims to discover and compare activities in countries, focusing on country-level initiatives rather than EU-level initiatives such as JAs in the field of e-health. The outcome of the mapping exercise is to be integrated into the eCAN website in the form of a dashboard. Concerns were raised about the timing between the actual research for the mapping exercise, which would take place rather at the beginning of the JA, and the deadline for the dashboard. It was agreed that the dashboard should be made available before the end of the JA and subsequently updated with new information throughout the JA.

## 1.2. Progress

The following two sections give insights into the technical and scientific progress of the eCAN JA between September 2022 (kick-off meeting) to September 2023 (interim report).

**Technical progress**

**Work Package 1: Project management and coordination**

The main objective of the Coordination WP is to ensure that the Joint Action fulfils the necessary administrative and budgetary requirements, as well as fulfils the general and specific objectives set out in this proposal in compliance with the grant agreement.

| Tasks and descriptions | Progress |
|---|---|
| T1.1 Consortium management and networking | - Monthly organization of the leadership council meeting<br>- Quarterly organization of the steering committee meeting<br>- Bi-monthly organization of the Action coordinator meeting<br>- Regular meeting with each WPs<br>- Regular networking meeting with external organization relevant to eCAN |
| T1.2 Knowledge Management | - Regular monitoring of overall JA progress, milestones and deliverables in close collaboration with WP3 – Evaluation<br>- Sciensano Sharepoint available to all partners to manage project deliverables and internal documents during the course of the JA. |
| T1.3 Technical and financial reporting | - Submission of the Interim Technical and Financial Reports for the JA. |

| | |
|---|---|
| T1.4 Review of the teleconsultation capacity of countries | - Scoping review on inequities in the use of eHealth infrastructure among cancer patients |

WP1 is in close contact with all WPs with regular meetings to ensure smooth collaboration and synergy between them. The consortium agreement was signed by all parties and made available. WP1 is in the final stages of preparing the draft eCAN Grant Agreement amendment. WP1 opened the tender for pilots to proceed with the procurement of wearables and provided support to WP5 and WP7 regarding the tender specification and procurement of wearable devices.

Furthermore, WP1 has been actively broadening its reach by welcoming esteemed organizations such as the OECD (engaged in cancer inequalities registry project) and Observatory (engaged in a telemedicine project as part of a broader series on digital health interventions in countries) as observers of the JA. DG SANTE hosted a stakeholder webinar on 25 May 2023, coinciding with the European Week Against Cancer. During this event (open to the public and featuring high-level speakers, including Commissioner Kyriakides), seven selected projects, including eCAN, were presented.

Last but not least, WP1 is leading a scoping review on inequities in the use of eHealth infrastructure among cancer patients, scheduled for September 2023. This review aims to improve the accessibility and fairness of eHealth services in the context of cancer care. The results will be mapped according to the PROGRESS-Plus acronym to identify population and individual characteristics across which health inequities may exist as recommended by the Cochran group.

PROGRESS-Plus stands for Place of residence, Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Socioeconomic status, and Social capital, and “plus” captures other characteristics such as age or disabilities. The use of this framework will allow the extraction of equity-relevant data from the scientific studies identified through the literature search and provide an overview of the barriers and facilitators to the use of eHealth infrastructure.

**Work Package 2: Communication**

The general objective of the Communication WP is to maximize the impact of the JA by supporting the consultation with stakeholders and the dissemination and communication of the project and the project's results to the target audiences and society.

| Tasks and descriptions | Progress |
|---|---|
| T.2.1.1 Creation and updating of the dissemination and communication plan | - The dissemination and communication plan constitutes eCAN's deliverables D2.1 and D2.2. The final version of the document is dated April 2023. Its main purposes are:<br>o To describe and document the overall strategy of communication and dissemination activities of the eCAN project while defining the lines of communication for stakeholders and society.<br>o To provide a framework for coordinating all partners' activities related to dissemination and communication.<br>o To ensure high visibility and impact for the project by increasing the chances of linking the JA outcomes, results and findings to all potentially interested parties.<br>- The plan details the tools and channels developed in order to achieve such goals as well as a set of key performance indicators (KPIs) to monitor effectiveness of the communication activities and evaluate the project's impact. |
| T.2.1.2 Creation of a visual identity of this JA | - Achieved at very early stages of the project, the visual identity of eCAN contains some elements (logo, colours, fonts, templates) meant to appear in all the dissemination outcomes on this JA, such as the website, its social networks, videos and leaflets, reports, etc. All these elements altogether with a guide of use are available at the website. |
| T.2.1.3 Design, maintenance and updating | - The JA's website was released public in December 2022. The main cores of the website's design are the usability and accessibility, in |

| Tasks and descriptions | Progress |
|---|---|
| of specific webpages within the institutional website dedicated to this joint action | technical terms and also from the users' point of view. Continuous updates are performed to showcase the most recent news and ongoing activities performed in the JA. |
| T.2.1.4 Development and maintenance of the social media accounts | - The JA has six platforms to foster and enhance the dissemination and communication activities of the JA along with the health topics that are related to eCAN. The social accounts are open and active since January 2023.<br>- The publication rates vary among the six platforms according to their internal work mechanisms and the content flow. WP2 has decided to classify its accounts into written (Twitter, Facebook and LinkedIn) and audiovisual (Instagram, TikTok and YouTube) platforms. |
| T.2.2.1 Stakeholders' analysis | - By identifying and developing a stakeholders' network, the communication team (WP2) aims to enhance the impact of the eCAN JA, encourage the exchange of knowledge and establish potential synergies and collaborations with other EU initiatives.<br>- WP2 has elaborated a document that describes the main mechanisms used to reach out to each stakeholder group identified for communication, dissemination and visibility purposes. The document is public and accessible in the JA's website. |
| T2.2.2 Dissemination and communication of the different WP activities | - Diverse mechanisms developed to gather WP's activities for dissemination purposes:<br>o Organisation of communication sessions with WPs leads and the whole JA's consortium.<br>o Surveys to collect info on the activities performed by the different WPs.<br>o 3-step guide to get your eCAN activities disseminated |

| Tasks and descriptions | Progress |
|---|---|
| | - "Agenda" section at the website to display all these activities and spread the word about eCAN participants' events |
| T2.2.3 Dissemination of the project's results | - The project's results and progress are disseminated through specific documents, news, press releases, newsletters, interviews and social media posts. Social media campaigns also serve to highlight the existence and purpose of eCAN to important stakeholders. In the final stages of eCAN, they could be a good space/format to present the project results to new audiences.WP2 attends also to the EPH Conference 2023 for a poster presentation on the JA's results on social networks. |
| T2.2.4 Organisation of the final conference | - The final conference for this JA will take place in September 2024. WP1 has suggested to hold the meeting in Brussels to facilitate the attendance of some key actors and WP2 has agreed to transfer the budget assigned to the conference logistics. WP2 will be in charge of performing the final reporting and dissemination for the conference. |

WP2 finalized the dissemination and communication plan for the eCAN JA (DS 2.1; DS 2.2). At the beginning of the project, there was a highlight of the lack of content for the eCAN website and social network. Together with other WPs, WP2 agreed on the recurrence of the newsletter (estimated in four publications per year)) and could find ways to facilitate content collection (interviews). WP1 suggested names to interview for the newsletter and facilitated contacts. WP2 expressed openness to suggestions from other WPs regarding the content and welcomed their input in this regard.

A poster presentation proposal to the EPH Conference in Dublin has been accepted. WP2 organised a social media campaign around the World Cancer Day (February 2023) and another one during the European Week Against Cancer (May 2023), among others. Both were conceived as communication strategies to disseminate the work carried out by this JA and to define what is to be achieved throughout the life of the project.

**Work Package 3: Monitoring and evaluation**

The main objective of the Monitoring and Evaluation WP is to evaluate the achievement of JA objectives, to assess the overall satisfaction of JA participants, and to evaluate the pilots implemented in WP5 and WP7.

| Tasks and descriptions | Progress |
|---|---|
| T3.1 Monitoring and evaluation | - Development of monitoring framework<br>- Launching quarterly indicator-based surveys (4 completed)<br>- Regular meeting with other WP leaders in collaboration with WP1<br>- Quarterly progress reports (3 completed, 4th in preparation)<br>- Launching Interim Participant Satisfaction survey |
| T3.2 Development of pilot evaluation framework | - Development of Patient Reported Experience Measures (PREMs) Usability study protocol in line with the main pilot protocol.<br>- Development of the cost-consequence analysis framework for implementation of eCAN solutions for teleconsultations and telemonitoring in cancer rehabilitation and psycho-oncology<br>- Development of the SWOT analysis framework for assessment of implementation of eCAN solutions for teleconsultations and telemonitoring in cancer rehabilitation and psycho-oncology |
| T3.3 Evaluation of pilot experience and SWOT analysis | - Translation and validation of translation of PREMs questionnaires (validation ongoing)<br>- Development of SWOT study implementation plan<br>- Development of draft guiding questions for SWOT |
| T3.4 Evaluation of the pilots: cost-effectiveness analysis | - Development and translation of patient reported costs questionnaires<br>- Development of site cost-reporting form |

The monitoring tools for the eCAN JA have been completed, including the development of the monitoring framework based on the project key process, output and outcome/impact indicators and its implementation as an online monitoring survey (MS3.1). WP3 gets in touch with all WPs for the quarterly progress reporting of the JA. In addition, WP3 in collaboration with WP1 participates in regular meeting with other WP leaders to understand the key

challenges and mitigation measures undertaken by each of the WPs. Reported indicators, minutes from meetings with WP leaders as well as minutes from monthly Leadership council meetings form basis for progress reports.

Three reports have been finalized (MS3.3, MS3.4, MS3.7) and the fourth progress report is currently in progress. As for the pilots' evaluation and PREMs usability study, the protocol has been integrated into the main pilots' protocol for submission to the ethical boards of the respective sites (MS3.2). PREMs usability study is based on validated questionnaires, for which only the English language version was available. In order to ensure the comparability of results across the pilot sites WP3 engaged in translation validation process, including double forward translation by professional service and reconciliation translation by the translation contact points, nominated in each of the countries, where the pilots will take place. It was followed by backward translation and clarification between the translation contact points and WP3 team. Finally, the cognitive reviews by the target audience are carried out for each language to complete the process.

The development of a pilot evaluation framework and protocols for implementation in eCAN is ongoing (including cost-consequence and SWOT analysis), with WP3 actively engaging in discussions with WP5 and WP7 to finalize the usability protocols and design other evaluation activities for the pilots. The methodology (frameworks) for cost-consequence analysis and the SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis of the participating pilot sites was completed (MS3.5, MS3.6 respectively). However, both documents will remain live during the process of implementing these studies in eCAN, to benefit from the experience gained.

As part of the implementation process of the cost-consequence analysis the patient reported cost questionnaires were developed and translated into the pilot languages. To ensure the validity of the translation of the questionnaires, WP3 has reached out to the translation contact points of the piloting countries. In addition, the form for collection of the costs to the sites to measure among others the technical and staff training implementation and functioning costs is being developed in collaboration with WP5 and WP7. Similarly, the draft guiding questions for the focus groups, who will perform SWOT analysis in each pilot site, will be revisited after the pilots are launched, based on discussions with WP5 and WP7.

WP3 is moreover committed to publishing an Interim evaluation report by October 2023 (D3.1). Apart from the summary of the progress reports the interim evaluation report will also present findings from the participant satisfaction survey, which is currently ongoing. To

ensure coordination and avoid any overlaps between the Interim technical and financial report and the Interim evaluation report, WP3 is in close contact with WP1 throughout the process.

**Work Package 4: Sustainability**

The general aim of the sustainability WP is to develop a roadmap towards a sustainable and broad implementation of eHealth initiatives in cancer care that proves being beneficial.

| Tasks and descriptions | Progress |
|---|---|
| T4.1 Mapping and relevance of existing initiatives | - All Country Factsheets pre-filled with literature<br>- All Country Factsheets sent for validation by country health policy experts<br>- Several validations from country health policy experts received, deadline for review extended to end of August<br>- Dashboard for presentation of country information in development (indicator list finalised, dashboard set-up in finalisation) |
| T4.2 Foresight exercises and roadmap development | - The conceptual model for the foresight exercise and roadmap development finalized<br>- Two workshops (the first one with WP leads and the second one within a wider eCAN research group) conducted<br>- Three research teams conducted literature reviews on three research questions as preparation for three foresight surveys<br>- Discussions with EHDS stakeholders initialized for technical feasibility and interoperability |

WP4 developed a country factsheet template for CF pilot countries and finally includes also countries that are not part of the eCAN JA. After the CFs had been pre-filled by the team (already available), WP4 started to seek validation from country experts. All country factsheets were already shared with country health policy experts. To this aim, WP4 is in contact with e-health and cancer experts in the respective countries.

WP4 is in touch with WP2 regarding the development of the website for the WP4 dashboard. To expand the scope of eCAN JA contributions, WP4 submitted abstracts to the EPH Conference; a poster will be presented at the Conference. A conceptual model for the foresight exercise and roadmap development (T4.2.) has been finalized to provide insights into the future direction of the project.

**Work Package 5: Teleconsultation**

The main aim of the teleconsultation WP is to design and set up two pilot studies dedicated to three specific settings of cancer care. Pilot 1 (a & b) will explore the effect of a two-month teleconsultation program focused on rehabilitation after surgery and telemonitoring for patients with breast cancer (pilot 1a) and head and neck cancer (pilot 1b) on patient-reported outcomes measures (PROMs) and patients reported experience measure (PREMs) compared to usual care. Pilot 2 will explore the effect of a two-month teleconsultation program focused on remote psychological support among patients affected by advanced cancer at recurrence and telemonitoring on PROMs and PREMs compared to usual care.

| Tasks and descriptions | Progress |
|---|---|
| T5.1 Pilot 1 a/b | - Study protocol definition and Ethical Committee submission (pending approval in 9 centers)<br>- Weekly Meetings with WP1-3-5-6-7<br>- Site activation and training meetings with clinical centers |
| T5.2 Pilot 2 | - Study protocol definition and Ethical Committee submission (pending approval in 8 centers)<br>- Weekly Meetings with WP1-3-5-6-7<br>- Site activation and training meetings with clinical centers |

The final draft of the pilot's protocol has been completed and distributed to all participating centres. Pilot project proposals have been submitted to the ethical committees of each participating centre. Ethical committee (EC) approval has already been obtained by IFO-IRE in Italy, IDIVAL and SAS in Spain, NIO in Hungary and OIL in Slovenia. The EC approval is pending for the other centres. WP5 closely monitors the situation and ensure a timely start of the pilots by staying in touch with each piloting centre during check-in meetings.

Furthermore, during these meetings, WP5 explains the process of the study and provides some training (e.g. security advices, data flow of the pilots…) so that the centres are as prepared as possible for the launch of the pilots. Given the number of centres and patients involved in the pilot, a gradual activation of piloting centres should not pose a significant problem. The first pilots are scheduled to begin in mid-September instead of mid-June as initially planned. The results obtained through the pilots are the core of the eCAN JA.

A lot of work from the different WPs, in close collaboration, had to be done in advance for an optimal execution of the pilots. For example, the development of the application and dashboard, identification and implementation of the teleconsultation platform, integration of all the necessary data to be collected for each WP... In order to ensure that everything is properly set up and ready, we have decided to postpone the launch date of the pilots to mid-September. To address any questions or concerns related to the pilots, a weekly call is held with WP1, WP3, WP5, and WP7, and all WP leads are encouraged to participate.

WP5 is actively collaborating with experts in telemedicine, cybersecurity, and data protection from WP7 and WP6 to ensure the secure transmission of data to a centralized European platform. Moreover, to address the language barrier in pilots, discussions took place between WP5, WP6, and WP3 on the best approach to obtaining translations of materials (including PREMs and cost questionnaires) produced in English into the local languages of the pilot countries. Last but not least, WP5 presented eCAN at the EHMA 2023 conference in June 2023 that took place in Rome.

**Work Package 6: Legal, ethical framework and cybersecurity**

The aim of legal, ethical framework and cybersecurity WP is to produce guidelines and recommendations for health professionals concerning legal and ethical framework and cyber security in telemedicine.

| Tasks and descriptions | Progress |
|---|---|
| T6.1 Data and systems security in teleconsultations and telemonitoring | - Survey on single centre technical equipment.<br>- Focus on technical equipment in 5 selected centres (with telemedicine expertise) |
| T6.2 Data exchange issues: teleconsultation and | - Pilot protocol revision and data management plan integration.<br>- Centralized platform for telemedicine (EDUMEETS) selection and |

| Tasks and descriptions | Progress |
|---|---|
| telemonitoring scenarios and clinical care pathways | activation.<br>- Production of documents and recommendation for cybersecurity training and GDPR compliance |
| T6.3 Guideline and recommendations production | - Systematic literature review on legal and ethical issues in telemedicine practice in cancer care (protocol draft, panel of experts' definition) |

WP6 conducted a survey about technical equipment on systems security in teleconsultations and telemonitoring among participating countries. Initially, they planned to analyze the teleconsultation and telemonitoring systems already used among participating centers in order to list the software used, assess the platform for teleconsultation, and harmonize software requirements for GDPR and legal compliance. However, they had to face an unexpected situation where very few centers participating in the pilots were using teleconsultation systems. Since many centers lack expertise in telemedicine and do not have dedicated platforms, a decision has been made in collaboration with WP6 and WP7 to choose a centralized teleconsultation platform that fully adheres to GDPR. They have chosen the Edumeet platform and are in the final stages of testing. This platform will be used in the pilot to perform the teleconsultation among all participating centers.

WP6 supported WP5 in the final stages of completing the protocol and preparing the submission to the ethical board. A significant portion of their work was closely tied to the content of the clinical protocol. Ongoing meetings with WP7 focused on discussions surrounding data sharing and determining the types of data that can be collected using a centralized platform. Given the participating centers' limited expertise in telemedicine, there was a need to develop a standardized approach to educate clinicians on the use of telemedicine.

One of the milestones for WP6 was to assess various procedures, experiences, activities, and legal approaches to telemedicine in each country participating in the Joint Action. The aim was to harmonize and evaluate potential legal differences, particularly regarding GDPR compliance. The survey results highlighted the necessity of planning a centralized European cloud platform that fulfils the requirements set by GDPR for teleconsultation.

They also planned to conduct a systematic review on legal and ethical issues in telemedicine in order to complete the information obtained from the survey among the participating centres. All this collected information will allow WP6 to establish guidelines and recommendations about telemedicine utilization in cancer care and prevention in EU countries. In the coming weeks, WP6 with the support of WP7, will submit the Data Management Plan for the pilots to the European Commission, as outlined in Deliverable 6.1. The document is being finalized to cover not only pilot trial data but also legal and security aspects and other relevant information.

**Work Package 7: Telemonitoring**

The aim of the telemonitoring WP is to develop a telemonitoring system, the eCAN app, to monitor patient-reported outcomes measures participating in the pilot studies and set up a secure platform providing a dashboard for clinical decision support.

| Tasks and descriptions | Progress |
|---|---|
| T7.1 Telemonitoring systems landscape | - A review on telemonitoring systems has been completed. Review protocol was registered under prospero.<br>- A journal paper will be submitted along with the deliverable by the end of Beginning of October 2023 |
| T7.2 Monitoring system design and development | - Alpha prototype completed. July 2023<br>- Revised version based on comments available by August 31st 2023. |
| T7.3 Telemonitoring pilot test | - Telemonitoring pilot tests are expected to start by the 1st of September 2023 |

The main challenge in designing and developing the monitoring system has been determining the data to be collected and cover the workflow decided in the pilot protocol. Collaborative efforts with WP6 took place to address GDPR-related issues. A document outlining the architecture of the telemedicine system has been shared with the team, and discussions with WP5 and WP6 continue to refine the telemedicine system and the data management plan.

WP7 reached out to WP2 and WP8 to clarify how the training materials would be accessed. Regarding the telemonitoring system's development, WP7 is in the process of finalizing the dashboard and mobile application. Close collaboration with WP3 and pilots participating centres is underway for translations, while coordination with WP8 is ongoing to ensure the

availability of training materials for the pilot sites. Initial feedback was based on Mock-ups of the dashboard and mobile application presented to WPs. The deliverable on the review of the telemonitoring landscape is completed and submitted to WP1. Additionally, WP7 plans to submit a scientific paper on the topic in September 2023. Finally, WP7 has identified and selected the most suitable wearable devices to the main challenge in designing and developing the monitoring system has been determining the data to be collected and cover the workflow decided in the pilot protocol. Collaborative efforts with WP6 took place to address GDPR-related issues.

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The deliverable on the review of the telemonitoring landscape is completed and submitted to WP1. Additionally, WP7 plans to submit a scientific paper on the topic in September 2023. Finally, WP7 has identified and selected the most suitable wearable devices to collect physical parameters (such as heart rate, physical activity, and sleep). Although these data are not clinically validated, it will allow for the exploration of potential effects of teleconsultation sessions on the studied parameters. Only voluntary patients in the intervention group of the pilots will wear the watch. WP7 worked with WP1 to obtain the wearable devices. Furthermore, WP7 has also been in close collaboration with the vendor (i.e. GARMIN) to ensure that data collection trough wearable devices was GDPR compliant. An initial alpha prototype was then shared with a select group of partners chosen from the consortium. Taking into account their valuable feedback and comments, the system underwent necessary enhancements and adjustments to prepare for the upcoming pilot tests. The developed system includes a web dashboard for the clinicians, mobile apps (Android and iOS) for the intervention group patients and a web dashboard for the control group patients.

**Work Package 8: Stakeholder engagement, education and training**

The main aims of the Stakeholder engagement, education and training WP are to improve the knowledge of cancer care workforce in the virtual consultation of patients and survivors; to

improve preparedness to respond to emergency and crisis situations; To increase communication between different stakeholders to support knowledge-sharing; To allow for efficient coordination amongst policymakers (health authorities), general practitioners, hospitals and patients; to improve eHealth competencies to teleconsultation, telemonitoring services for providers, caregivers, patients and to support training needs of pilot participants prior to their enrolment in the study.

| Tasks and descriptions | Progress |
|---|---|
| T8.1 Ecosystem building and stakeholder's engagement | - Stakeholders' mapping survey launched in EU Surveys and circulated within the eCAN consortium<br>- 4 workshops on stakeholders' engagement strategies conducted between April and May 2023<br>- The eCAN stakeholders' community has been launched as a result of these activities<br>- regular (monthly and bi-monthly meetings)<br>- ELLOK engagement in progress |
| T8.2 Participatory Design | - 1st Focus Group of the Participatory design framework: Exploring Perceptions on Teleconsultation and Telerehabilitation in Cancer Care conducted and results analyzed<br>- Conducted 9 think aloud sessions with volunteer patients and HCPs, for validating the technology introduced in the eCAN ecosystem<br>- Provided feedback to WP7 on usability and user experience of developed technologies<br>- regular (monthly and bi-monthly meetings) |
| T8.3 Educational activities and information material for patients, caregivers and clinical experts | - Designed a booklet addressed to patients including useful information for pilot procedures<br>- Organized and carried out 3 train the trainers workshops where the use of the developed technologies was presented to |

| Tasks and descriptions | Progress |
|---|---|
| | the pilot representatives<br>- regular (monthly and b-monthly meetings)<br>- Produced materials (written and visual) to be distributed to the partners that explain the use of the technologies allocated to the project pilots |
| T8.4 Staff training & education and alignment with existing practices | - Designed and developed online website where educational materials for HCPs will be uploaded<br>- Established the intranet within eCAN website, where patients will be able to access educational materials addressed to them |

WP8 is actively engaged in stakeholder involvement and participatory design. The initial milestone, a stakeholder survey circulated within the Consortium, has been completed. The results of this survey, along with input from WP5 and WP7, guides the next steps for stakeholder involvement. To further reinforce the establishment of the stakeholders' network, WP8 launched a series of 4 workshops where different strategies for the engagement of different stakeholders of the quadruple helix were presented. The workshops resulted in the creation of a tips-and-tricks toolbox, available to the eCAN consortium.

The participatory design process has undergone some modifications. Originally intended to focus on digital tools used in the pilots, it will now centre on the adoption of eHealth solutions for cancer patients. Specifically, it will address the needs and perceived barriers of stakeholder groups related to telehealth and telemonitoring processes. To support this, WP8 has organized a workshop on focus groups for participatory design. Also, participatory processes were used to validate the tools developed for the purpose of the pilots. To ensure wider visibility, WP8 is in close touch with WP2 to share news about the upcoming WP8 workshop and stakeholder mapping survey in the next newsletter.

Moreover, WP8 focused on the development of educational materials and activities; WP8 will complete the materials regarding telehealth technologies before the start of the pilots. These materials will include video recordings of all technological solutions that will be used

during the pilots. Finally, a booklet that will be used by the participants has been created, to guide them through the pilot process.

**Scientific progress**

**Conferences, past**

| Name of the conference | Support | WP /Authors | Presentation title |
|---|---|---|---|
| 7th ATHEA conference, Vienna<br>23-24 February 2023<br>The Austrian Health Economics Association (ATHEA)<br>https://www.athea.at/en/seventh-athea-conference/ | Oral presentation | WP3<br>Florian Trauner Gerald Gredinger<br>Gesundheit Österreich GmbH | Study protocol: Health economic evaluation of a European eHealth intervention applying cost-consequence analysis and cost-utility analysis |
| Europe's Beating Cancer Plan,<br>First EU4Health Project Showcase, online<br>25 May 2023<br>EU Health Policy Platform, European Commission<br>https://health.ec.europa.eu/system/files/2023-05/20230525_hpp_ag_6.pdf | Oral presentation | WP1<br>Tugce Schmitt<br>Sciensano<br>Cancer Centre<br>Belgium | Projects linked to quality of life, eCAN JA |
| Integrating digital health technologies in cancer care<br>30 May 2023<br>Final event of the project Life Champs<br>https://lifechamps.eu/index.php/2023/06/10/lifechamps-final-event/ | Oral presentation | WP1<br>Tugce Schmitt<br>Sciensano<br>Cancer Centre<br>Belgium | Stakeholders' perspective on the role of R&I in the digital transformation of cancer care continuum |
| EHMA 2023, Rome<br>5-7 June 2023<br>Sustainable health management: designing solutions for evolving and complex health systems<br>Session: Challenges in telemedicine<br>https://ehmaconference.org/ | Oral presentation | WP5<br>Andrea Pace IRCCS Regina Elena Cancer Institute, Rome | The EU Joint Action on strengthening eHealth including telemedicine and telemonitoring for health care systems for cancer prevention and care – eCAN |
| Belgian NCP info session<br>about EU Funding Opportunities for R&I in the health domain, online<br>29 June 2023<br>https://ncp.brussels/events/eu-funding- | Oral Presentation | WP1<br>Marie Delnord<br>Sciensano Cancer Centre<br>Belgium | The eCAN Joint Action |

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|---|---|---|---|
| opportunities-for-ri-in-the-health-domain/ | | | |
| Annual Greek-speaking Conference of Communication Labs (cclabs2023) about best practices and use cases, regarding effective communication & empowerment of patients in R&I, online 1-2 July 2023<br><br>www.cclabs.gr | Oral Presentation | WP8 Authors : Despoina Mantziari (AUTH), Christina Plomariti (AUTH), Antonis Billis (AUTH), Stergiani Spyrou (AUTH), Panagiotis Bogiatzidis (3RD RHA), Panagiotis Bamidis (3RD RHA) and Andreas Veglis (AUTH) | Title : Συμμετοχή και επικοινωνία στην ασθενοκεντρική έρευνα: Η πρωτοβουλία eCan JA (Participation & Communication in Person-Centred Research : the eCan initiative) |
| HTWG Konstanz: Medical Summer School Towards building sustainable and co-created telemedicine systems in Western Balkan Countries Tirana, September 4-8, 2023 https://www.medical-summerschool.de/ | Oral Presentation | WP8 Panagiotis Bamidis (AUTH) Despoina Mantziari (AUTH) | Strengthening ehealth including telemedicine and remote monitoring. The eCAN Joint Action for health care systems for cancer prevention and care |

**Conferences, future**

| Name of the conference | Support | WP /Authors | Presentation title |
|---|---|---|---|
| 2023 European researchers' night 29 September 2023 https://lanitdelarecerca.cat/european-corner/ | Poster presentation | WP2 Hermida EP, Hans Cano E, Ela-Aguilar S, Ferro T. | eCAN pilots |
| EFMI conference European Federation of Medical Informatics (EFMI) 25-27 October 2023 https://www.stc2023.org/home-page | Workshop | WP8 Antonis Billis Christina Plomariti Pantelis Natsiavas Anastasia Farmaki Andrea Pace Magdalena Rosinska Tugce Schmitt Victoria Leclercq | Telehealth implementation for cancer care in EU: the eCAN Joint Action |
| EUPHA conference, Dublin 16th European Public Health Conference 2023 | Poster presentation | WP2 Hermida EP, Hans Cano E, Ela-Aguilar S, | Bringing an EU Joint Action to TikTok: the case of eCAN |

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|---|---|---|---|
| 8-11 November 2023<br>https://ephconference.eu/ | | Ferro T. | |
| EUPHA conference, Dublin<br>16th European Public Health Conference 2023<br>8-11 November 2023<br>https://ephconference.eu/ | Oral presentation | WP4<br>Claudia Habl, Katharina Habimana Gesundheit Österreich GmbH | JA eCAN roadmap towards a sustainable implementation of eHealth initiatives in cancer care. |

**Scientific publications**

| Title of the article | Type of article | WP /Authors | Journal | Status |
|---|---|---|---|---|
| Describing the landscape of cancer related telemonitoring systems in the EU | Review | WP7<br>Charalambous Andreas Christodoulou Fella Maria, Christofi Maria-Dolores, Cloconi Constantina, Tsitsi Theologia, Efthyvoulos Kyriacou, Christo Schizas | Not yet identified | In preparation |
| Scoping review on inequities in the use of eHealth infrastructure among cancer patients | Review | WP1<br>Victoria Leclercq, Marie Delnord, Tugce Schmitt, Leopold Vandervliet & Marc Van Den Bulcke | Not yet identified | In preparation |
| Relevance of telemedicine for cancer care – a case study | Review | WP4<br>Anita Gottlob, Katharina Habimana, Linda Justi, Morten Frydensberg, Magdalena Rosínska, Bernard Bieda, Maciej Burski | Not yet identified | In preparation |

The future activities of the eCAN JA will include:

- Recruitment of patients for the pilots (End of pilots is May 2023); overall monitoring
- Analyses of acceptability and benefits of teleconsultation and telemonitoring through SWOT and PREMs analyses
- Cost-effectiveness analyses
- Foresight study surveys; 3 levels: micro (patients), meso (HCO), macro (policymakers)
- Roadmap development

# ANNEX I – eCAN JA Consortium

- SCIENSANO, BE
- NATIONAL INSTITUTE FOR HEALTH AND DISABILITY INSURANCE, BE
- UNIVERSITAIR ZIEKENHUIS ANTWERPEN, BE
- SERVICE PUBLIC FEDERAL SANTE PUBLIQUE SECURITE DE LA CHAINE ALIMENTAIRE ET ENVIRONNEMENT, BE
- GESUNDHEIT OSTERREICH GMBH, AT
- REGION SYDDANMARK, DK
- INSTITUT CATALA ONCOLOGIA, ES
- FUNDACION INSTITUTO DE INVESTIGACION MARQUES DE VALDECILLA, ES
- SERVICIO ANDALUZ DE SALUD, ES
- DIOIKISI 3IS YGEIONOMIKIS PERIFEREIAS MAKEDONIAS, EL
- ETHNIKO KENTRO EREVNAS KAI TECHNOLOGIKIS ANAPTYXIS, EL
- ARISTOTELIO PANEPISTIMIO THESSALONIKIS, EL
- GENIKO NOSOKOMEIO PAPAGEORGIOU, EL
- HEALTH SERVICE EXECUTIVE HSE, IE
- ISTITUTI FISIOTERAPICI OSPITALIERI, IT
- ISTITUTO NAZIONALE TUMORI FONDAZIONE PASCALE, IT
- OSPEDALE SAN RAFFAELE SRL, IT
- VIESOJI ISTAIGA VILNIAUS UNIVERSITETO LIGONINE SANTAROS KLINIKOS, LT
- NACIONALINIS VEZIO INSTITUTAS, LT
- LIETUVOS SVEIKATOS MOKSLU UNIVERSITETO LIGONINE KAUNO KLINIKOS, LT
- MINISTRY FOR HEALTH GOVERNMENT OF MALTA, MT
- NARODOWY INSTYTUT ONKOLOGII IM MARII SKLODOWSKIE CURIE PANSTWOWY INSTYTUT BADAWCZY, PL
- ONKOLOSKI INSTITUT LJUBLJANA, SI
- NARODNE CENTRUM ZDRAVOTNICKYCH INFORMACII, SK
- NATIONAL EHEALTH AUTHORITY, CY
- TECHNOLOGIKO PANEPISTIMIO KYPROU, CY
- PAGKYPRIOS SYNDESMOS KARKINOPATHON KAI FILON 1986, CY
- ADMINISTRACAO CENTRAL DO SISTEMA DESAUDE IP, PT
- MINISTERIO DA SAUDE REPUBLICA PORTUGUESA, PT
- INSTITUTO PORTUGUES DE ONCOLOGIA DE LISBOA FRANCISCO GENTIL EPE, PT

- INSTITUTO PORTUGUES DE ONCOLOGIA DO PORTO FRANCISCO GENTIL EPE, PT
- SPMS SERVICOS PARTILHADOS DO MINISTERIO DA SAUDE EPE, PT
- INSTITUTO PORTUGUÊS DE ONCOLOGIA DE COIMBRA FRANCISCO GENTIL, PT
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