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eCAN
Strengthening eHealth for Cancer Prevention & Care

Roadmap for scaling-up

Deliverable 4.1

WP4, Sciensano (Belgium)

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Outline

Executive summary

This roadmap, a deliverable of the Joint Action 'Strengthening eHealth including telemedicine and remote monitoring for health care systems for CANcer prevention and care (eCAN)', is a strategic document exploring the integration of telemedicine services within health systems in the European Union (EU) and the implications of this integration. It provides a holistic view of current telemedicine practices, envisions the future landscape of digital health in the EU, and outlines steps that need to be taken to transition from the current to the future situation. Its development occurred based on co-creation method, with various stakeholders having been involved in its creation.

The insights that underlie the roadmap were acquired through work performed within the eCAN project, by means of desk research and literature reviews, surveys, focus group discussions, use cases or pilots, and a foresight workshop. All of this work ultimately led to a set of recommendations being proposed for effectuating a transition from the current state of play of telemedicine to the desirable scenario, where patients and healthcare professionals are highly open to adopting telemedicine tools and the policy environment enables this adoption as much as possible. These recommendations, integrated within the present document, span six areas of intervention:

- Regulatory, governance and policy framework
- Stakeholders' engagement an awareness to prioritise the integration of telemedicine into healthcare systems
- Infrastructure and technology development
- Training and education
- Implementation and integration into healthcare systems
- Evaluation and continuous improvement

The relevance of the recommendations was confirmed by representatives of health authorities from different European countries, who also suggested actions that can be taken to implement them, on the basis of their national experience. Their suggestions are included in this roadmap. Several of these will be taken up and addressed as part of a follow-up project, the Joint Action eCAN+, that will start in 2025.

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Glossary

Concept	Definition	Source
eHealth	The WHO defines eHealth as « the use of information and communication technologies (ICT) for health ». It also says that «eHealth is the transfer of health resources and healthcare by electronic means ».	(World Health Organization, n.d.-a)
Digital health	The EU defines digital health (dHealth) and care as referring to « tools and services that use information and communication technologies (ICTs) to improve prevention, diagnosis, treatment, monitoring and management of health-related issues and to monitor and manage lifestyle-habits that impact health ».	(European Commission, n.d.)
	The WHO defines digital health as « the field of knowledge and practice associated with the development and use of digital technologies to improve health. Digital health expands the concept of eHealth to include digital consumers, with a wider range of smart-devices and connected equipment. It also encompasses other uses of digital technologies for health such as the Internet of things, artificial intelligence, big data and robotics ».	(World Health Organization, n.d.-b)
Telehealth	The WHO defines telehealth broader than telemedicine « as it includes computer-assisted telecommunications to support management, surveillance, literature and access to medical knowledge ».	(DigitalHealthEurope consortium, n.d.-a)
Telemedicine	The EU Commission defines telemedicine as follows (EU Commission definition, COM(2008)689) : « Telemedicine is the provision of health care services, through the use of ICT, in situations where the health professional and the patient (or two health professionals) are not in the same location. It involves the secure transmission of medical data and information, through text, sound, images or other forms needed for the prevention, diagnosis, treatment and follow-up of patients ».	(DigitalHealthEurope consortium, n.d.-b)
Teleconsultation	PAHO describes teleconsultation (also sometimes referred to as remote consultation), as « interactions that happen between a clinician and a patient for the purpose of providing diagnostic or therapeutic advice through electronic means ».	(Pan American Health Organization, 2020)
Telemonitoring	No official definition for this term exists.	N/A

1. General aim and structure of the roadmap

This chapter provides a general introduction to the eCAN project and lays out the purpose and structure of the roadmap.

1.1. Introduction to eCAN

The Joint Action (JA) 'Strengthening eHealth including telemedicine and remote monitoring for health care systems for CANcer prevention and care (eCAN)' is one of the initiatives of the European Union (EU), responding to the critical need for equitable and advanced cancer care across Europe[1]. The relevance of telemedicine services was particularly underscored by the challenges posed by the COVID-19 pandemic, which has significantly affected cancer care. Indeed, especially in crisis times telemedicine has proven crucial in ensuring continuity of healthcare services through online consultations and real-time clinical data exchange. Yet, despite the promising outlook, the path to widespread telemedicine adoption in the EU health systems is not without its challenges. Issues such as regulatory frameworks at the country and EU levels, sustainable financing of digital health services in general, and infrastructural requirements must be navigated thoughtfully.

eCAN JA is committed to understanding these complexities, gathering relevant data, and offering scalable and sustainable telemedicine solutions. Spanning two years (2022-2024), this collaborative effort involves 16 countries and 35 key stakeholders, including public health institutes, universities, hospitals, cancer centres, health innovation centres, and patient associations[2]. With cancer cases projected to rise by a quarter by 2035 and existing disparities in cancer prevention, diagnostics, and care in the EU, eCAN JA envisions to leverage telemedicine's potential to make significant strides in cancer care, particularly for individuals in remote and rural areas. To be more precise, the objectives of eCAN are threefold: firstly, to enhance teleconsultation and remote monitoring specifically in cancer care, ensuring the services meet the quality expectations and needs of users; secondly, to increase the health workforce's capacity to manage isolated or remotely located cancer patients effectively; and thirdly, to foster the development of modular and interoperable telemedicine solutions that can be adapted to various contexts. Over the long term, the project seeks to harness telemedicine services across the EU to support cancer patients.

[1] For other initiatives, please see: https://ecanja.eu/home/eu-initiatives/
[2] Please see the eCAN JA website: https://ecanja.eu/

The primary focus of eCAN is to assess the effect of teleconsultation and telemonitoring services in different cancer patient populations through multi-centric pilots on Patient Reported Outcomes and Experiences (PROs and PREs). These pilots are integral to monitoring PROs and PREs through dedicated telemonitoring systems, thereby setting the stage for future innovations in clinical decision support systems. Pilot 1 focuses on rehabilitation for patients with breast (Pilot 1a) and head & neck cancer (Pilot 1b), employing teleconsultation programs to monitor and improve quality of life and manage pain. Pilot 2 centres on the psychological impacts of cancer, promoting a teleconsultation program aimed at providing remote psycho-oncological support to patients with advanced cancer. These pilots, conducted across various European countries, are not standalone projects but parts of a collaborative framework. The Work Packages (WPs) implementing pilots (WP5 and WP7) as well as other WPs that support pilots and ensure their sustainable implementation aim to share insights, foster mutual learning, and contribute to a future where telemedicine is an integral part of cancer prevention and care in Europe. Figure 1 below provides a brief overview of the Work Packages of eCAN JA, along with the institutes leading them. A full overview of all eCAN JA partners is given on the eCAN website. Figure 2 displays the countries participating in the project.

Figure 1. Overview of the eight Work Packages (WPs) of eCAN JA

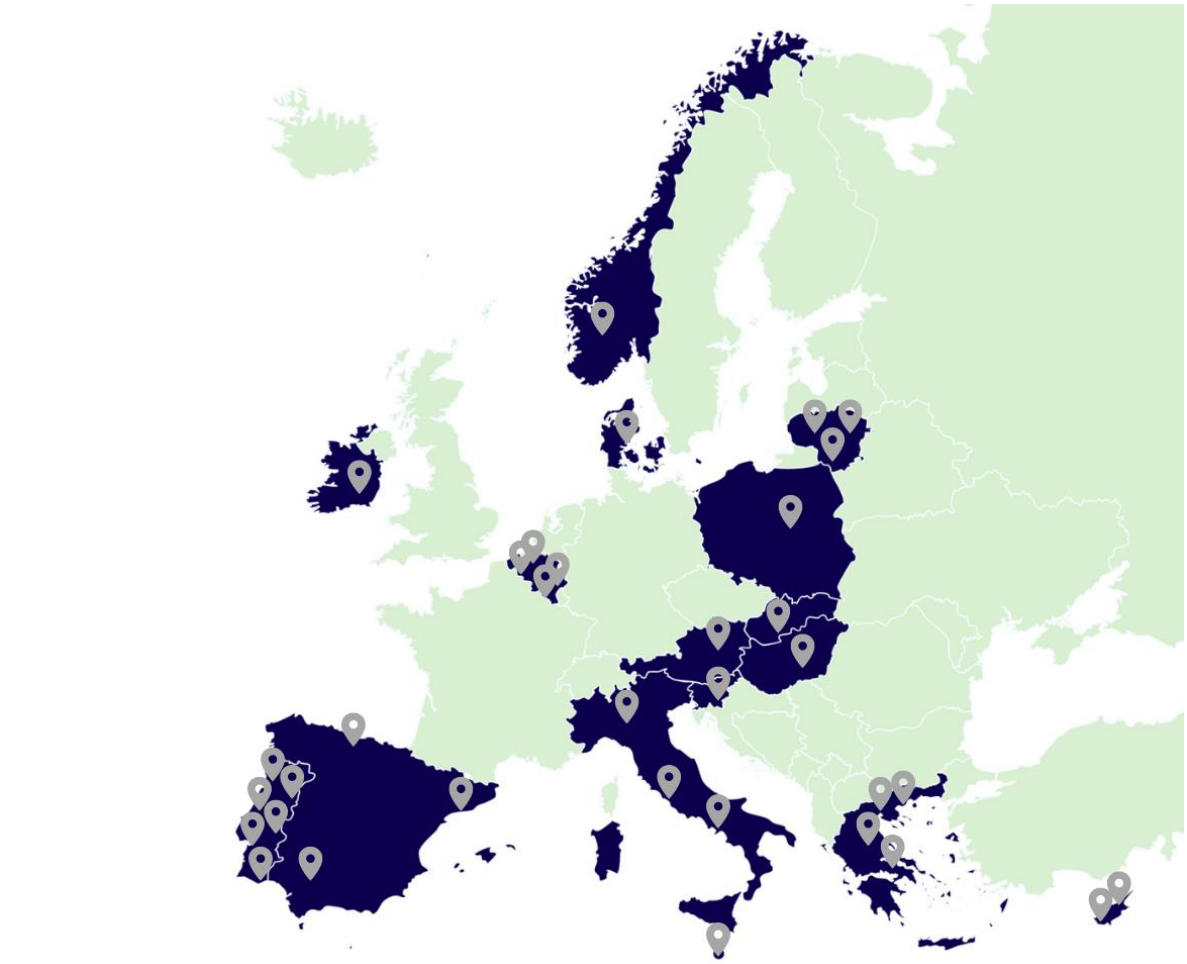


Figure 2. Overview of countries participating in eCAN JA, coloured in blue. The waypoints indicate the locations of the partner institutions.

1.2. The eCAN roadmap

As part of WP4 (Deliverable 4.1 - Roadmap for scaling-up), this document presents a comprehensive exploration of the integration and implications of telemedicine services within the EU health systems. It aims to describe the multifaceted dimensions of telemedicine, from policy and governance structures to patient-centred care in hospitals and data utilisation at the EU level, providing a holistic view of current practices and envisioning the future landscape of digital health in the EU. Its structure is based on a toolkit for creating roadmaps that was prepared by the European Commission (European Commission, 2020). While this toolkit was designed to be used in an administrative capacity building context, it can be applied more broadly to inform the design of roadmaps in general. In accordance with the definition used by the Commission, a roadmap is considered here to be a strategic and living document that incorporates a set of comprehensive actions and that defines and tackles specific issues by employing a strategy-driven approach which takes the short-, medium-, and long-term perspectives into account. As such, roadmaps outline the process of moving from the current

'as-is' to the desired 'to-be' situation. The present document closely follows the toolkit's structural suggestions and therefore encompasses six different chapters. Succeeding this introductory chapter (**Chapter 1**), **Chapter 2** explains the methodology that was used to compose the roadmap. Next, **Chapter 3** analyses across three subchapters the state of play of telemedicine in Europe in order to better understand the current 'as-is' situation. **Chapter 4** subsequently details what the desired 'to-be' situation looks like, drawing on the results of a foresight exercise and the insights of experts. **Chapter 5** then lists a number of recommendations emerging from the two preceding chapters that should enable the transition from one situation to the other. Finally, **Chapter 6** clarifies how these recommendations could be implemented in practice.

2. Methodology used to design the roadmap

This chapter explains the methodology that was employed to develop the roadmap, detailing the major stages of the development process, the sources of the data presented, the timeline followed, the stakeholders that were consulted, and the parties that reviewed and approved the document.

2.1. Major stages in designing the roadmap

As a deliverable of eCAN JA, the present roadmap was designed by the partners involved in WP4 of this project, based on an outline that was approved by the eCAN JA Steering Committee in which all of the members of the project consortium are represented. Each WP4 partner contributed to the chapters of the document that were assigned to them. Multiple rounds of revision were foreseen, during which draft versions were adapted to accommodate comments from the leads of the other WPs and updated with new content if additional project results had become available in the meantime. Once the internal review process had been concluded and the necessary changes had been made by the WP4 partners, the roadmap was restructured to match the specifications listed in the European Commission's toolkit for creating roadmaps (European Commission, 2020). Afterwards, the document was shared with eCAN JA's Governmental Board, which was composed of telemedicine experts affiliated with health authorities from different European countries (namely Austria, Belgium, Croatia, Cyprus, Czechia, Denmark, Hungary, Italy, Luxembourg, Malta, Norway, Slovakia, and Spain), and had been specifically established to provide external validation of the project findings. The input and feedback obtained from these experts were incorporated into the roadmap, alongside the results from analyses that could only be completed towards the end of the project. Eventually, after having been reviewed internally as well as externally, this eCAN JA deliverable was submitted to the European Commission, and, upon receipt of approval, published on the eCAN website.

As explained in section 1.2, this roadmap was developed using the methodology specified by the European Commission in its toolkit for creating roadmaps (European Commission, 2020). Several distinct approaches were applied throughout the duration of the eCAN JA to generate the contents of this document. An overview of these approaches and the roadmap chapters in which the findings from their application are detailed is presented in Table 1.

Approach		Corresponding chapters in roadmap
Desk research and (systematic) literature reviews		Chapter 3: State of Play – Subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems
		Chapter 3: State of Play – Subchapter 3.2: Using telemedicine at the EU level
		Chapter 4: Mapping the Future
Surveys		Chapter 3: State of Play – Subchapter 3.3: Insights from the eCAN JA pilot sites
		Chapter 4: Mapping the Future
Interviews		Chapter 3: State of Play – Subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems
Focus group discussions		Chapter 3: State of Play – Subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems
Use cases/pilots	**Randomised controlled trials: analyses of patient-reported outcome measures**	Chapter 3: State of Play – Subchapter 3.3: Insights from the eCAN JA pilot sites
	Cost-consequence analyses	
	Strengths, weaknesses, opportunities and threats (SWOT) analyses	
	Analyses of patient-reported experience measures (PREMs)	
	Analyses of site experiences	
Foresight workshop		Chapter 4: Mapping the Future

Table 1. Overview of approaches used to produce the content for the roadmap and the chapters of the roadmap capturing the results following from their use.

2.2 Info/data sources used

The information contained within this roadmap originates from a rich variety of data sources, including scientific literature (e.g. research or review articles from peer-reviewed journals), grey literature (e.g. policy documents), expert insights (e.g. responses to questionnaires), stakeholder views (e.g. answers during interviews), patient outcomes (e.g. analytics from eCAN app, dashboard or smartwatches) and pilot experiences (e.g. site perceptions of barriers to implementation of interventions).

2.3 Timing

Work on the design of the roadmap began in January 2024. The document was finalised in September 2024. The recommendations it contains will be gradually implemented over the decade following its publication. Some of these recommendations will be tackled as part of a follow-up JA starting in 2025 and lasting four years (JA eCAN+, see chapter 6).

2.4 Stakeholder involvement

A multitude of different stakeholders directly or indirectly contributed to the development of this document, namely patients (as participants of the pilots, surveys, and focus group discussions), patient associations (as participants of the foresight exercise), healthcare professionals (as participants of the pilots, surveys, focus group discussions and foresight exercise), policymakers (as participants of the foresight exercise and as part of the Governmental Board as explained in section 2.5), public health institutes (as participants of the foresight exercise), hospitals (as participants of the pilots and foresight exercise), payers (as participants of the foresight exercise) and cancer centres (as participants of the pilots and foresight exercise).

2.5 Consent and approval

As mentioned above, the roadmap was reviewed and approved by both internal (i.e. the eCAN JA partners) and external (i.e. the Governmental Board members and the European Commission, with the latter being represented by the Health and Digital Executive Agency [HaDEA] and the Directorate-General for Health and Food Safety [DG SANTE]) parties. However, it should be stressed that the deliverable's approval by organisations outside of the consortium does not necessarily constitute an endorsement of the views or opinions expressed herein.

3. State of play

This chapter, which outlines the state of play of telemedicine in Europe, is composed of three subchapters.

Subchapter 3.1 explains the significance of telemedicine in transforming health systems. By touching on current trends and potential future developments, it highlights the necessity of integrating digital solutions into health policies and practices. Moreover, it delves into the implementation of telemedicine services in the EU health systems and beyond, offering a detailed overview of governance structures, existing telemonitoring systems, and best practice example. Additionally, it explains the feasible ways to introduce telemedicine services to reach person-centred healthcare at the country level, focusing on patients' and hospitals' perspectives by presenting outcomes from focus groups, literature reviews, and survey results to offer a nuanced understanding of telemedicine's impact on healthcare pathways and physician-patient dynamics. It also features a review of inequalities in access to and use of telemedicine services among cancer patients in the EU.

Subchapter 3.2 explores the utilisation of telemedicine data at the EU level, discussing the integration of such data into electronic health records (EHRs), the potential of secondary data usage, and the incorporation of artificial intelligence (AI) and machine learning (ML) practices. It aligns itself with pivotal EU objectives, reflecting on the broader implications of data-driven healthcare.

Subchapter 3.3 shifts the focus to a more technical perspective, discussing the implementation of telemedicine services in the eCAN pilot sites. It encompasses the main results of the pilots, operational experiences, challenges, and considerations regarding ethical and cybersecurity issues, offering a reflective narrative on the practicalities of telemedicine deployment.

3.1 Relevance and use of telemedicine in the context of EU health systems

3.1.1 Relevance of telemedicine to health systems

Increased attention has been directed towards understanding the ramifications of telemedicine in scientific research, with many studies investigating its long-term advantages for both patients and healthcare providers, as well as its broader implications for the healthcare system. A wide body of literature in this field acknowledges telemedicine as a valuable instrument in modern healthcare, providing both convenience for patients and support for healthcare

workers, ultimately leading to better health outcomes (Armaignac et al., 2018; Saigí-Rubió et al., 2022). Specifically, it has been associated with cost-effectiveness, a high quality of care and increased accessibility compared to in-person care (Saigí-Rubió et al., 2022). According to recent OECD data (OECD, 2023), country experts agree that telemedicine services hold significant promise in improving various aspects of health system performance. This includes enhancing equity, efficiency, access, cost-effectiveness, and quality (including effectiveness, safety, and patient-centeredness) (OECD, 2020).

However, limitations must be considered – a literature review by Mostafei et al. (2022) on patient and HCP experiences of telemedicine during the pandemic in cancer care highlights that telemedicine complements but cannot fully replace in-person healthcare during crises or routine care for stable cancer patients. For instance, telemedicine was generally not found suitable for the first appointments and postoperative appointments. Patients' experiences with and perceptions of telemedicine are influenced by infrastructure and healthcare provider support. A lack of time and consideration of patients' emotional and mental needs by HCPs can therefore result in negative responses in patients. Frequently mentioned challenges in service delivery of telemedicine for cancer patients' literature regard issues like digital literacy, especially among older adults, and the need for equitable access across different demographic groups. Finally, Schaffer et al. (2023) identified significant research gaps addressing specific population groups such as older adults and comparing telehealth to in-person interventions. Additionally, emerging technologies and fully automated programs are under-reviewed, and economic outcomes and real-world healthcare utilization data are rarely analysed.

In cancer care specifically, the suitability of telemedicine use varies depending on factors such as patient demographics, types of cancer, and stages of treatment. Research indicates that healthcare providers should carefully consider any limiting factors (e.g., when diagnostic tests and examinations are required, low technological proficiency of the patient; internet connection; patients requiring more in person care such as children or those with metastatic cancers etc.) along with patient preferences, and effectively communicate any limitations to maintain the same quality of care as in-person consultations. Meta-analyses showed positive effects of digital health and telehealth interventions on quality of life, psychological outcomes, and screening behaviours, highlighting the benefits in terms of patient outcomes (Shaffer et al., 2023).

Telemedicine can also serve as a bridge for equitable access by addressing barriers for various demographic groups. It has been found to be especially advantageous for patients and survivors of different types of cancers living in remote, rural areas, with mobility issues and

those with limited resources due to cost reduction of travelling and accommodation. Telemedicine thus significantly reduces both direct and indirect costs in cancer care, such as travel, accommodation, and time off work, for patients and caregivers (Li et al., 2020, Yang et al., 2023). Further, due to reduced costs and increased flexibility - teleconsultations can offer a more inclusive treatment approach by allowing family members and caregivers of cancer patients to more easily participate in the patients' care (Xiao et al., 2023; Kwok et al., 2022; Salehi et al., 2022). Improved accessibility for trusted caregivers or family members can also provide additional support to patients facing language barriers or mental disabilities, especially those who face challenges in accessing professional support services due to limited resources.

Studies found telehealth and telemedicine to be a good alternative to in-person care in multiple treatment areas: especially in follow-up consultations or post-surgery consultations, palliative care, and rehabilitation and for cancer survivors (Yang et al., 2023). For example, Li et al. (2020), showed that telehealth interventions can be effective for cancer survivors of different types of cancer, as they can be tailored to the individual needs of cancer survivors, such as symptom management or education (Li et al., 2020). Furthermore, due to the heightened vulnerability of immunocompromised cancer patients to communicable diseases, telemedicine services can prove particularly advantageous to cancer patients during health crises by reducing exposure to infectious diseases (Shaffer et al., 2023). During the pandemic, for example, Salehi et al. (2022) found that telemedicine reduced exposure to the COVID-19 virus among patients, but also family members and health professional staff (Salehi et al., 2022).

Recognising the advantages that digital health services like telemedicine can have for the healthcare system in general, and especially in times of health crisis such as a pandemic, several initiatives aimed at advancing the progress and integration of digital health and telemedicine in European countries, have been collaboratively developed by the WHO European Region and the European Commission. These endeavours include broad-spectrum initiatives, such as the Global Strategy on Digital Health 2020-2025 (WHO, 2021) initiated by the WHO, aiming to integrate digital health and telemedicine into overarching policy frameworks (Saigí-Rubió et al., 2022). In 2022, the WHO European Region adopted the 'Digital Health Action Plan for the WHO European Region (2023-2030)' (WHO, 2022a) which aims to assist countries in enhancing and expanding digital transformation (including telemedicine) for improved healthcare by aligning digital technology investments with health system needs. The plan features four strategic priorities including conducting horizon-scanning and landscape analysis to identify patient-centred solutions scalable at the country or regional level, offering technical guidance and setting norms, improving country capacities for governing digital transformation

and promoting digital health literacy, as well as building networks for dialogue and knowledge exchange (WHO, 2022). There are also targeted efforts focused on implementation, such as the Horizon 2020 and Horizon Europe funding programs, along with the European Reference Networks (Cioti et al., 2019). The latter includes funding for projects emphasising digital health specifically (funded with 26 Million Euros in 2023) and funding for interdisciplinary/ intersectoral projects with focus on cancer and digital health such as eCAN (in 2023, the budget for cancer related projects was over 187 Million Euros). Furthermore, an overall share of €1.25 billion of the future EU4Health programme, will be used to support actions and initiatives outlined in the Europe's Beating Cancer Plan.

According to the WHO (Saigí-Rubió et al., 2022), pan-European initiatives aimed at leveraging the potential of telemedicine acknowledge the 'power of telemedicine to break down geographical barriers' but also recognise that there are still barriers and risks in telemedicine usage which need to be mitigated. EU-level strategies, recommendations, policy frameworks and synergistic cross-country projects are important as they can help identify commonalities and differences regarding barriers and facilitators, foster cooperation and solidarity, and ultimately support individual Member States in improving their telemedicine policies, infrastructure, and overall efficiency. Given the increasing demand for such sustainable transformation in health and cancer care towards easier access of services also through digital offers, the interconnection between the policy fields of digitalisation and cancer care will be required to further be strengthened through policies and the subsequent implementation in the Member States.

Key points from section 3.1.1 of subchapter 3.1

- In cancer care, telemedicine serves as a valuable tool by offering cost-effective, high-quality care with increased accessibility, particularly beneficial for follow-up consultations, palliative care, and cancer survivors.
- Initiatives such as the Global Strategy on Digital Health 2020-2025 by WHO and the 'Digital Health Action Plan for the WHO European Region (2023-2030)' aim to integrate telemedicine into policy frameworks to enhance healthcare efficiency and address barriers in healthcare systems at global and European levels.
- A key challenge of telemedicine in cancer care is its inability to fully replace in-person healthcare, particularly for critical situations such as first appointments or postoperative care. Factors such as the lack of physical examinations and the need for personal interactions can limit the effectiveness of telemedicine. Further

challenges include issues with infrastructure, healthcare provider support, digital literacy among patients, and equitable access across different demographic groups, highlighting the complexity of implementing telemedicine in cancer care effectively.

3.1.2 Implementation of telemedicine services in Europe

Within WP4 of the eCAN Joint Action on Sustainability, country factsheets with key insights into the current state of eHealth in each EU Member State and selected further European countries (Norway and Switzerland) were prefilled by JA partners and then sent for review to country experts on eHealth and cancer care (in most studied countries, two relevant persons with specific expertise were contacted accordingly). In total, 29 country factsheets were prefilled by WP4 colleagues, of which 18 were reviewed by country experts, while the remaining 11 were built on publicly available information only. Based on the data from the country factsheets, indicators were developed for three dimensions (1) governance, (2) strategies and policies, and (3) legislation with regards to eHealth in cancer care. The full country factsheets as well as a dashboard with the indicators are presented on the eCAN website. The following figures (Figures 3-6) visualise some key insights from these factsheets, across different dimensions.

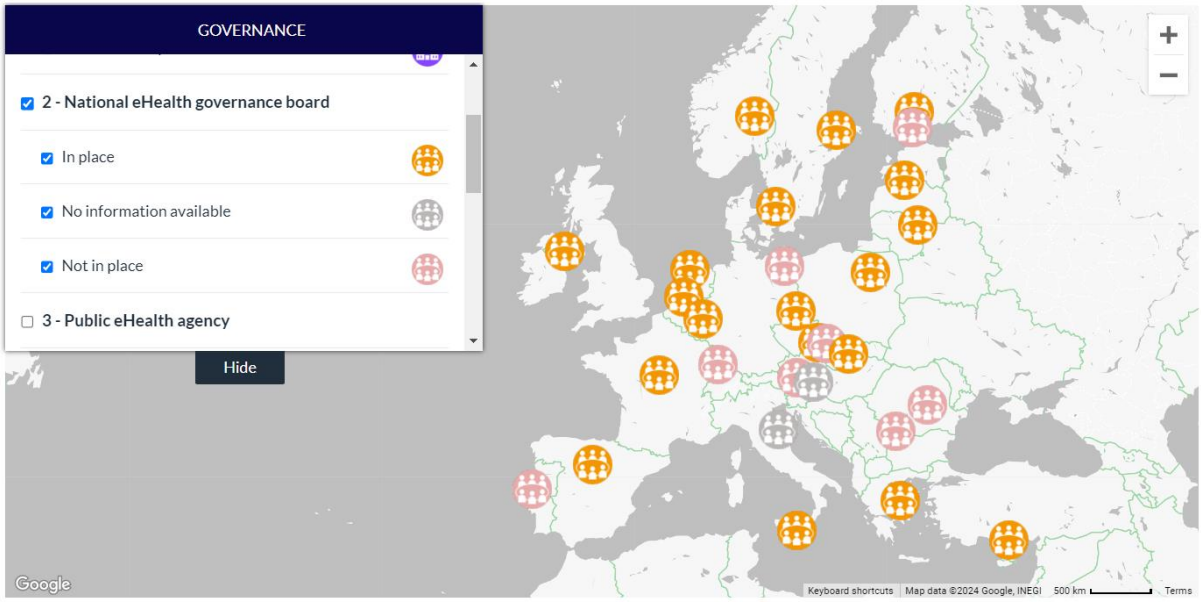


Figure 3. eHealth governance board implementation in Europe, source eCAN data (current as of 26 November 2024; latest version of the dashboard can be found on the eCAN website).

Figure 4. National eHealth strategy implementation in Europe, source eCAN data (current as of 26 November 2024; latest version of the dashboard can be found on the eCAN website).

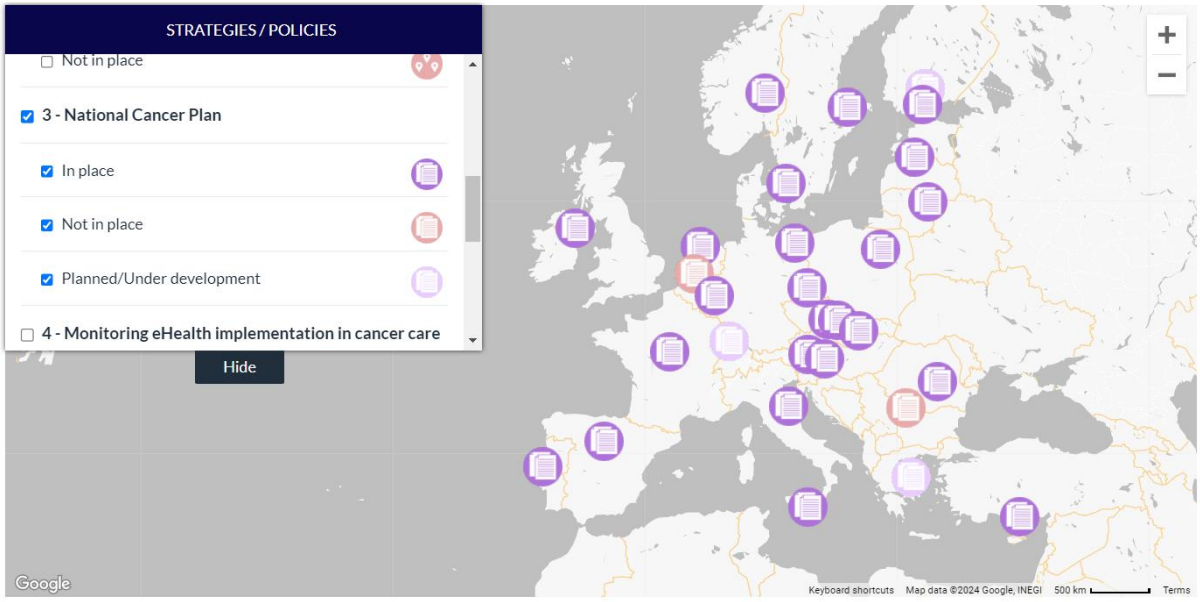


Figure 5. National cancer plan implementation and reference to eHealth in Europe, source eCAN data (current as of 26 November 2024; latest version of the dashboard can be found on the eCAN website).

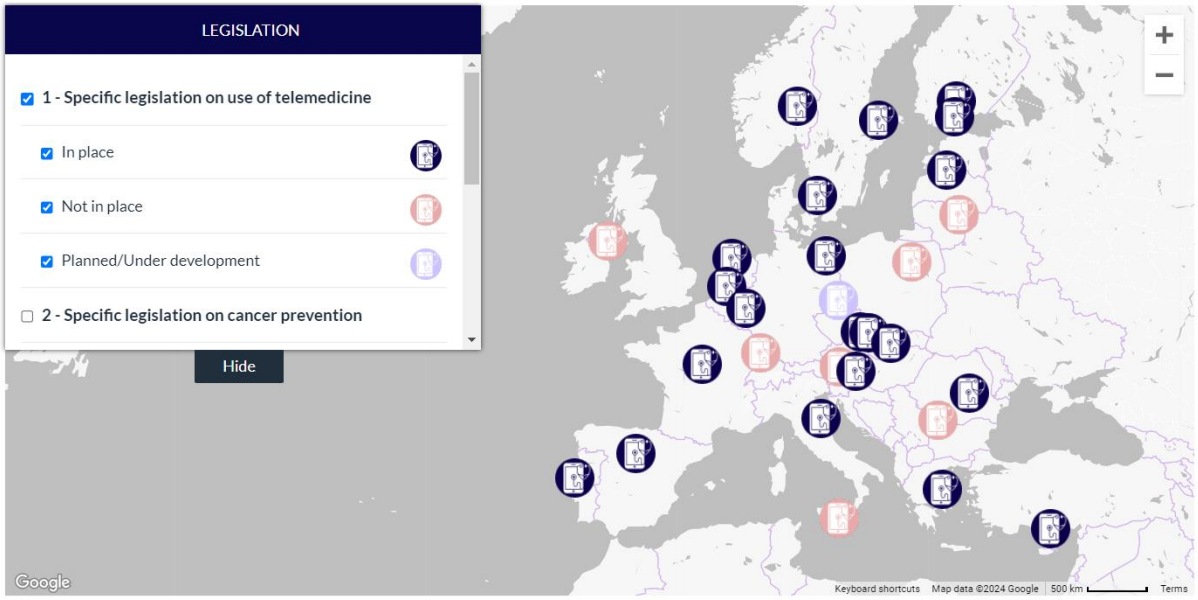


Figure 6. Legislation on the use of telemedicine in Europe, source: eCAN data (current as of 26 November 2024; latest version of the dashboard can be found on the eCAN website).

The eCAN country factsheets include an overview as well of implemented eHealth solutions along a cancer patient's trajectory and regarding the relevant digital ecosystem, including general access to digital patient records or e-prescription systems. Examples for types of tools and services implemented in the EU countries and an indication on the number of EU countries having implemented such services and tools (for which information was publicly available or was provided within the country information validation process) are presented in Table 2.

Area of application/ type of solutions	(Login) websites	Apps	Webinars	Tele-conferences (HCP-HPC)	Tele-consultation (HCP-patient)	Telemonitoring	Other
Ecosystem	Most countries (AT, BE, BG, CH, CY, CZ, DE, EE, ES, FI, FR, HR, HU, IT, LT, LU, MT, NL, PT, PL, RO, SE)	Many countries (AT, BE, BG, CH, CZ, DE, DK, FI, FR, HR, HU, LT, LU, MT, NL, PL, PT, SE)	Some countries (AT, BG, CH, FI, FR, LT, MT, PL, PT, SE)	Some countries (BG, CH, CZ, EE, ES, FR, LT, MT, PT, SE)	Some countries (AT, BE, CH, CZ, FI, FR, EE, LT, MT, NL, PT, RO, SE)	Some countries (BG, CZ, FR, PT, MT, SE)	Some countries (AT, BE, CZ, CH, DK, EE, FI FR, HU) e.g., general health information
Prevention of Cancer	Some countries (BG, EE, ES, LU, NL, PL, SE)	Some countries (AT, CY, DE, DK, EE, FR, IE, IT, PL, RO, SE)	Some countries (BG, CH, FR, IE, IT, LT, SE, SK)	Few countries (BG, LT, SK)	Few countries (BG, LT, LV, SE, SK)	Few countries (BG, LT, PT)	Some countries (CZ, EE, ES, FI, FR, LT, RO) e.g., portal on screening programs, digital media advertising
Treatment of Cancer	Some countries (BG ,DE, FI, IT, LT, NL, RO)	Some countries (AT, BE, BG, CZ, DE, DK, EL, FI, FR, IE, IT, LT, LU, NL, PT)	Some countries (BG, CH, FI, FR, IT, LT, NL, RO, SE)	Some countries (AT, BE, BG, CH, CY,DE, DK, ES, FR, IE, NL, LU, LT, LV, SE)	Some countries (BE, BG, CZ, EE, EL, ES, FR, IT, LT, LV, NL, PT, SE, SK)	Few countries (BE, BG, CZ, FR, LT)	Some countries (CZ, EE, FI, FR, IE, LT, LU, NL, RO) e.g., National Cancer Control Programme info portal, symptom monitoring), events with virtual participation
'Living with cancer'	Some countries (BG ,ES, FI, IT, NL, LT, LV, SE)	Some countries (AT, BG, CH, CZ, DE, DK, EE, EL, FI, FR, IT, LT, NL, RO, SE)	Some countries (BG, CH, ES, FR, NL, LT, SE)	Few countries (BG, LT)	Few countries (BG, LT, LV, SE, SK)	Few countries (AT, CZ, LT, PT)	Few countries (AT,EE, NL , LT) e.g., pain symptom monitoring, survivorship passport
Rehabilitation from Cancer	Few countries (BG, FI, NL, LT, SE)	Some countries (BG, CZ, EE, FR, NL, PT, SE)	Few countries (BG, FR, LT, NL, SE)	Few countries (BG, LV, SE)	Some countries (BG, NL, LT, PT, SE, SK)	Few countries (CZ, LT)	Few countries (LT)
Palliative Cancer Care	Few countries (BG, FI, NL, LT, SE)	Few countries (BG, CH, CZ, FR, LT)	Few countries (FR, LT, SE)	Few countries (BG, LT, LV, SE)	Some countries (BG, DK, ES, NL, LT, SE,SK)	Few countries (CZ, LT, SE)	Few countries (MT, LT) e.g., electronic referral form

Table 2. Overview of implemented eHealth services in cancer care in Europe. Note: No countries = 0 countries, Few countries = 1 to 5 countries, Some countries = 6 to 15 countries, Many countries = 16 to 22 countries, Most countries 23 to 28 countries, All countries = 29 countries. For some countries (partly) no information available.

Key points from section 3.1.2 of subchapter 3.1

- Within WP4 of the eCAN Joint Action on Sustainability, country factsheets with key insights into the current state of eHealth policies and implementation in each EU Member State and selected further European countries (Norway and Switzerland) were prepared and translated into a dashboard for country comparison.
- The comparison of the state of play in eHealth in cancer care through indicators gives an overview on different policies, governance, legislation and implementation in the EU and some further countries.
- It would be beneficial to continue monitoring the status of these indicators as well as to develop further indicators in the different dimensions policies and governance, legislation and implementation.

3.1.3 Person-centred healthcare with telemedicine

The use of teleconsultation in cancer care is a concept well-defined, with applications across the entire cancer care continuum, including but not limited to palliative care for advanced cancer patients (Hoek et al., 2017), diagnostics (Barnard & Goldyne, 2000), and disease management (Ricke & Bartelink, 2000). Although the applications of leveraging technology for added value in multiple phases of the disease are numerous, the integration of this routine in regular practice is not evident. On the one hand, there are economic and policy-related issues that complicate the generic use of telemedicine solutions in various settings. On the other hand, are the end users, patients, and healthcare professionals (HCPs) whose attitudes and beliefs towards the use of teleconsultation affects greatly the widespread use of it. This section is focused on the latter.

In workshops conducted within WP8 of the eCAN JA, individual and collective opinions of patients were presented and discussed, emphasizing the obstacles and the facilitators towards the use of teleconsultation. The views of HCPs are also included to further validate and discuss those of the patients. Furthermore, needs and gaps in delivery systems together with support requirements for the optimal introduction of said technologies in everyday practice were analyzed, to address the needs of populations with different levels of digital literacy and skills. The input presented here was obtained through participatory design methodologies and focus groups held with patients and HCPs. Additional opinions were collected through interactive discussions with interdisciplinary audiences in multiple related events. All results were further validated through extensive literature search, to try and capture this multidimensional matter with as much objectivity and from as many angles as possible.

Methodology for the collection of stakeholders' opinions: All data presented in this section were collected within the eCAN Joint Action. Opinions and views were collected from two open discussions with patients and experts in the field of telemedicine, taking place during relevant conferences. The patients' perspectives were gathered during the eCAN session of the 8th annual conference of the Greek Patients Association ELLOK and the experts' views were discussed in the eCAN session of the EFMI Special Topic Conference 2023 "Telehealth Ecosystems in Practice". More than 50 patients and 30 experts participated in both sessions and shared their views on the discussed topics. Additionally, a focus group was organized to bring patients and HCPs together to directly gather their attitudes and beliefs towards the eCAN ecosystem and the use of teleconsultation in cancer care in general. The focus group took place within the context of the stakeholders' engagement activities. More details on the specific answers received and the methodology employed can be found in the corresponding public deliverable, accessible on the eCAN website.

Stakeholders' reported opinions were as follows: Patients report that the most used modalities employed to achieve effective communication are audio-based (phone calls), text-based (emails, SMS and online chatting through social platforms) and video-based (dedicated or generally used teleconsultation software) (Shanbehzadeh et al., 2021). This statement is also supported by HCPs. Their use has declined in the post-COVID era, while they are still being utilized in cases where urgent need exists (patients immobilized or unable to reach the hospital due to sickness). The need to increase inclusion in cancer care and make it accessible for everybody, regardless of place of residence and mobility situation is among the stronger and most prominent arguments supporting the use of teleconsultation. Both patients and HCPs reported the importance of it, but still chose to rely mostly on direct face-to-face communication in the post-pandemic era.

The main reported reason for switching to traditional face-to-face communication appears to be the belief that it cannot be substituted. Disbelief towards the use of technology seems to stem in poor digital literacy of involved parties, especially in the case of patients, but also underlined by HCPs. During the focus group discussion, patients stretched out the lack of inclusion of interested parties in technologically centered solutions due to poor digital literacy. The need for extensive education and training towards the use of such technologies is remarked, especially in the case of older individuals, who report facing considerably more challenges (Wetzlmair et al., 2022). Another concern raised by most involved parties in all employed data collection modules is the data privacy issue (Pool et al., 2022). Patients appear skeptical towards the security of their personal information, while HCPs emphasized the lack

of specific regulations, paving the road for a number of ethical dilemmas in the use of teleconsultation services, especially in the case of cancer patients.

The establishment of an official software developed specifically for teleconsultation purposes, in a user-friendly and patient-centered manner, followed by a reimbursement scheme for physicians that utilize it are considered among the primary requirements indicated by both patients and HCPs as a pre-requisite for the establishment of effective teleconsultation protocols, that have the opportunity to be widely used in the post-COVID era. The increase of incentives from the physicians' side through the employment of a reimbursement scheme was recognized by the patients participating in the focus group discussion and was later identified by HCPs and experts in the field. Another important factor is the training of HCPs in its use, something that will help stir the medical world towards a cultural change, maximizing the adoption of said technologies. The belief that cancer patients will more easily accept and embrace telemedicine should they be encouraged by their physicians was prominent among all stakeholders, indicating that the beginning of this cultural shift should indeed start from within the hospital premises.

Apart from all the barriers identified and the needs expressed, the importance of the existence of teleconsultation tools and methodologies is explicitly underlined by involved parties and is further supported by corresponding literature (Atreya et al., 2020). The inclusion of healthcare for all citizens and their active involvement in their own treatment in a real-time manner hold the primary value among the facilitators and are the strongest arguments for the establishment of the wide use of teleconsultation services. Time management and cost-effectiveness stemming from the use of teleconsultation play also an important role, driving stakeholders to be more open in its adoption. More information on the barriers, facilitators, needs and requirements identified by patients, experts and HCPs during open discussions and the structured focus group can be found in Figure 7.

Although the outcomes of the wide collection of end-users perspectives help to shed light on the needs and requirements for establishing teleconsultation for cancer patients in regular healthcare practice, one important application of it was not mentioned during any procedure. The facilitation of doctor-to-doctor communication, through the establishment of reference networks (Smith et al., 2020). Telemedicine reference networks assist physicians with case management, allowing the sharing of expertise among them and facilitating long-distance consultations. To date, such a network for cancer care does not exist, at least not among the EU member states. The establishment of such a network would greatly benefit its direct end users (HCPs) along with the indirect ones (patients).

	Patients	Healthcare Professionals
Barriers	• Digital literacy • Data privacy • Available software and hardware infrastructure • Internet availability	• Digital literacy • Burnout • Lack of official software • Language barriers • Instruction following of patients • Interoperability • Ethics/regulations • Resistance to change
Facilitators	• Inclusion of minorities • Access to individuals with mobility issues • Younger patients familiar with technology • Immediate communication • Time efficiency	• Involvement of patients in own treatment • Remote access to treatment for all individuals • Cost-effectiveness • Coverage
Needs	• Immediate and direct communication • Secondary data utilization	• Protection of physicians during remote diagnosis • Recognition of patients' characteristics, needs and perceptions during the design of telemedicine solutions
Requirements	• Digital education • Cultural shift • Usability • Integration of widely used communication methods	• Training on specific technologies • Reimbursement model • Infrastructure setup

Figure 7. Outcomes of the focus group discussions

Several innovative approaches for telemedicine throughout the entire cancer care continuum are emerging; from digital health prevention and screening interventions (Schliemann, 2022), telepathology in the diagnostic phase (Sirintrapun and Lopez, 2018; Mremi et al., 2022), virtual multidisciplinary team conferences (Rajasekaran et al., 2021), telemonitoring for pain and symptom management (Knegtmans et al., 2020; Grašič Kuhar et al., 2020), tele-pharmacology (Collado-Borrell et al., 2020), telerehabilitation during survivorship (Uhm et al., 2017; Longacre et al., 2020) and tele-palliative care at the end-of-life stage (Tasneem et al., 2019; Hayes Bauer et al., 2024). All of the above are examples of how telemedicine can bridge the gap in the cancer care continuum. However, not all interventions might be suitable for all patients. As such, it is important that the healthcare organizations tailor their services based on the patient's needs, thereby placing the person at the centre of care.

Some inspirational examples can be given of how telemedicine solutions can bridge the gap in the cancer care continuum based on the patient's needs. In a randomised clinical study Cleeland et. al. (2011) find that telemonitoring of recently discharged postoperative lung cancer patient's symptoms demonstrates, that it not only offers valuable insights into the patient's symptoms, but that it can be used to streamline the process for earlier intervention. An automated telephone call (interactive voice response) was conducted twice a week measuring different symptoms and recording if the severity of symptoms was above a certain threshold. An e-mail alert could also be sent to the hospital with medical history and contact information. Such automated approaches provide an excellent opportunity to use information systems to

enhance the efficiency and efficacy of symptom management. Importantly, the solution minimizes additional work, by involving the healthcare professionals only when it is needed.

Similarly, multidisciplinary team conferences benefit from telemedicine's capabilities, streamlining collaboration among highly specialized healthcare professionals. These conferences, crucial in cancer care, are often challenged by logistical constraints and scheduling difficulties (Rajasekaran et al., 2021). It can be difficult to schedule a physical meeting with so many highly specialized healthcare actors. Video conferences facilitate efficient communication, transcend geographical constrains, and ensure broader representation of professions, including primary care nurses and general practitioners, in care planning discussions, ultimately placing the patient at the centre of the care.

This section summarised the views of patients and HCPs regarding the establishment and use of telemedicine in cancer care. Collecting the views of end users is of great importance, especially in the era of patient-centred medicine and for the creation of inclusive cancer care systems. Overall, the integration of tele-oncology in standard cancer care is a natural step in the digital transformation of the healthcare systems. However, it is essential to recognise that not all interventions add significant benefits to all relevant parameters, patient satisfaction, cost-effectiveness, and clinical outcomes. However, innovation for the sake of innovation is not desirable, we still need to conduct high-quality clinical research that can provide insights into whether further implementation and scaling is sustainable. A use case on tele-palliative care can be found in Box 1 below.

Box 1. Tele-palliative care in Denmark

Telemedicine has been a strategic priority in strengthening collaboration across sectors for many years in the Region of Southern Denmark (Health Innovation Centre of Southern Denmark, 2016). At times, local projects show a special potential, that makes them suitable for regional scaling. This was the case of the local best practice: *As much time in your own home* (Health Innovation Centre of Southern Denmark, 2022).

Originating from University Hospital of Southern Denmark (Health Innovation Centre of Southern Denmark, 2022), the initiative offers palliative oncology patients telemedicine services. The offer consists of a visit to the patient by the hospital's palliative team, where follow-up consultations conducted via video as a supplement to standard care. This service was also provided for patients who did not wish to be admitted to the hospital, but still needed care.

The patients could schedule video consultations instead of appointments at the hospital, but always be able to advance the meeting if deemed necessary. This flexible approach centres healthcare delivery around the patient's needs without compromising the quality of care. This initiative has yielded favourable outcomes for healthcare professionals, patients, and their families. To support this practice, a webinar on basic palliation was developed to strengthen the cross-sectorial collaboration between the specialized oncology unit and the local municipality which is responsible for home nurses and elderly care.

Thus, in 2020 it was decided to scale this initiative to the other hospitals via a regional Innovation Board (Region of Southern Denmark, 2020). However, it quickly became apparent that a one-to-one replication of implementation from one hospital to another was impractical, if not impossible, owing to inherent local variations. To ensure that the implementation of tele-palliative care aligned with user needs and maintained a high standard of care, a user-centred approach was adopted. This involved convening healthcare professionals from all regional hospitals to discuss patient requirements and the specific needs essential for success. In an interview, Anna-Britt Krogh (2024), the project manager responsible for the regional scaling project, stated that many healthcare professionals were concerned about the level of care and empathy through a digital interface. However, by including the patient's perspective and emphasizing the overall benefits of transitioning to tele-palliative care, a notable shift occurred in the mindset of healthcare professionals. She also states, that to have a successful implementation, competence development is crucial, to instilling a sense of security for both healthcare professionals and patients.

Key points from section 3.1.3 of subchapter 3.1

- Telemedicine has demonstrated potential in application across the entire cancer care continuum. However, integrating tele-oncology into regular practice faces economic, policy-related, and user-related challenges.
- Workshops, focus groups, and conferences revealed patient and HCP perspectives on the obstacles and facilitators of teleconsultation.
    - Barriers included low digital literacy levels, especially among older individuals; data privacy concerns, with patients and HCPs worrying about data security; and preferences for face-to-face communication, as skepticism exists towards technology.

- Facilitators identified were improved access, particularly for those with mobility issues; and enhanced time management and cost-effectiveness which benefit both patients and healthcare systems.
- Needs formulated related to both patients and HCPs requiring extensive education and training for a broader implementation of tele-oncology; and telemedicine services having to employ a person-centred design to integrate seamlessly into the clinical work flow.

- Addressing barriers, leveraging facilitators, and focusing on person-centered approaches can effectively integrate telemedicine into cancer care, ensuring equitable and efficient healthcare delivery.

3.1.4 Inequities to the access to and use of telemedicine among cancer patients

One of the aims of the eCAN JA is to reduce cancer care inequities across the European country exploring the role of teleconsultation and telemonitoring among cancer patients. As part of this JA, a scoping review on inequities to the access to and use of telemedicine services among cancer patients in Europe was carried out by WP1. More specifically, the aim was to identify barriers and facilitators contributing to access to and use of telemedicine services. Where access refers to the ability to access the resources required for digital health and use refers to variations in the ability of different groups that have access to resources to actually use digital health technology (WHO, 2022). For this scoping review, the inclusion criteria were articles concerning adults with any type of cancer, focusing on ehealth innovation in European countries, and published between 2018-2023. A total of 26 original studies were included focused on telemedicine, teleconsultation or telemonitoring services among patients with all types of cancer mainly from Western Europe. The majority of the studies focused on the follow-up or survivorship stages of the patients care pathway. All barriers and facilitators to the access to and use of telemedicine services identified through the scoping review are summarized according to the PROGRESS-Plus acronym below. PROGRESS-Plus acronym is used to identify population and individual characteristics across which health inequities may exist as recommended by the Cochran group (Welch *et al.*, 2013). 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 (O'Neill *et al.*, 2014). The use of this framework allowed to extract equity relevant data from the scientific studies identified through the literature search.

- Place of residence: Few studies have investigated the role of geographical location in telemedicine services access and use while telemedicine services are seen as a lever for reducing the health inequalities associated with geographical location.
- Race, ethnicity, culture, religion and language: Whereas telemedicine services could facilitate communication with cancer patients regardless of their origin or language, almost all reviews reported that the language of the patient may influence access to telemedicine services as few of them offer access regardless the language preference. Only two studies aim to facilitate communication with patients using telemedicine services. Alongside the language difficulty, one study reported that religious beliefs/affiliation could be a barrier to the use of telemedicine services as cancer is often seen as a taboo.
- Occupation: One study showed that being retired could be a barrier to the use of telemedicine services which can be explained by the fact that a worker is more exposed to a digital environment. Four studies indicated being in employment (versus being unemployed) made no difference to telemedicine services use among cancer patients.
- Gender: Large disparities in cancer burden by gender to the detriment of men has been proven (OECD, 2024). However, gender does not seem to influence the use of telemedicine services among cancer patients, as reported in four studies. Only one reported that being female facilitated access to telemedicine services, one study reported being female as a barrier and one being a men as a facilitator to telemedicine services use.
- Education: Not having sufficient digital skills is seen as a barrier to telemedicine services access. Moreover, having a higher level of education with goof digital skills, health and e-health literacy is clearly seen as a facilitator for telemedicine services use. And vice versa, low level of education is seen as a barrier. These observations strengthen the fact that burden of cancer is more important among individuals with lower education level(OECD, 2024)
- Socioeconomic status: Burden of cancer is more prevalent among people with lower socioeconomic characteristics including lower income(OECD, 2024). Unfortunately, telemedicine services can reinforce these already existing inequalities, since not having an internet connection and/or mobile devices is seen as a barrier and having one's own mobile as a facilitator to accessing and using telemedicine services. Furthermore, whether or not telemedicine services represent an additional cost may influence access and use.
- Social capital: The results of various studies show that on the one hand, the lack of social contact with telemedicine services is an obstacle to their use, while on the other hand the

increase in social contacts through the use of T telemedicine services M is seen as an advantage.

- Plus: age: Ageism also a source of inequalities among cancer patients since cancer is mostly a disease that affects people later in life(Van Poppel *et al.*, 2022). A large number of studies have demonstrated that age influences use of telemedicine services: being elderly was shown to be a barrier in six studies, and being young a facilitator in five studies. However, no effect of age could be demonstrated in six other studies.
- Plus: disability or complex health needs: Having comorbidities or other health conditions (smoker, frailty or anxiety) reduce the access to and use of telemedicine services. While the possibility offered by telemedicine services of reducing the risk of contamination or infection is seen as a facilitator. Evidence on the potential effect of cancer type, time since diagnosis and stage of the disease on the use of telemedicine services is not yet clear.

By proactively tackling barriers and benefit from facilitators throughout the implementation process, we can develop eHealth services that align more effectively with user needs, resulting in greater advantages for patients and caregivers.

Key points from section 3.1.4 of subchapter 3.1

- Regarding access to telemedicine services, socioeconomic status and language were the most cited influential factors, in addition to having an internet connection and a (mobile) device.
- In terms of the use of telemedicine services, level of education, digital skills and (e-)health literacy, social support, age, and presence of comorbidities are important influential factors.

3.2 Using telemedicine data at the EU level

This subchapter delves into the feasible options for the use of telemedicine health data at the EU level based on the upcoming Regulation on European Health Data Space (EHDS). The primary use of health data is the usage of health data in the context of healthcare (Proposal of the regulation on the European Health Data Space, 16048/23, REV1, Recital No.1). Section 3.2.1 of the subchapter gives insights into the collection of telemedicine health data in light of European infrastructure MyHealth@EU and the WP9 of the European project Xt-EHR that focuses also on the primary use of telemedicine health data at the EU level. As such, section 3.2.1 of the subchapter explores the future integration of telemedicine health data into

Electronic Health Record (EHR) datasets at the national level and datasets for European infrastructure MyHealth@EU at the EU level.

Secondary use of health data is the usage of health data for other purposes that would benefit society such as research, innovation, policy making, patient safety, personalised medicine, official statistics, or regulatory activities. (Proposal of the regulation on the European Health Data Space, 16048/23, REV1, Recital No.1). Section 3.2.2 of the subchapter describes how the health data have to be prepared (stored in registers, EHR systems, then pseudonymized or anonymized) for secondary use and how the secondary use of health data (also health data collected by Telemedicine services) will be organized on the European level. It touches also on the integration of Machine Learning (ML) and Artificial Intelligence (AI) practices gained in eCAN.

Telemedicine health data can be defined as the medical data that are generated from telemonitoring or teleconsultation sessions and exchanged using electronic communications, for the purpose of remote monitoring, evaluating and when possible, supporting the treatment of a patient during teleconsultation sessions between a patient and an expert physician (Wootton, 2001). Taking into consideration telemonitoring devices (e.g. Laptops, tablets, smart phones, wearable devices, etc.) along with the clinician's notes, health data can be collected using a structured, semi-structured or unstructured form. This is to maximize the health data collected from the teleconsultation sessions, aiming the analysis of health data for the primary use of results or saving health data and use them at a later stage as the secondary use of the collected health data.

3.2.1 Primary use of telemedicine data

During the eCAN project, the primary use of electronic health data is encompassed into a set of software tools aiming to provide remote support and health care provision through telemedicine services, tackling unplanned incidents related to the patient's health. This is in light of the usage of MyHealth@EU European infrastructure. The purpose of MyHealth@EU European infrastructure is described in the proposal of the regulation on the European Health Data Space, 16048/23, REV1, Recital No.24, and further in the text of the proposal. Also, the tasks of WP9 of the Xt-EHR project focus on the primary use of Telemedicine health data. Project Xt-EHR (Joint Action) was initiated in November of 2023, aiming also to support further the development of telemedicine use cases at the MyHealth@EU European infrastructure and set some initial guidelines in regard to standardizing the structure of the exchanged data including telemedicine data. Data exchange can be facilitated even during cross-border movement of patients, enabling freedom of the services provided according to the CBHC

directive (European Patients' Forum, 2016). The current state of play of the MyHealth@EU European infrastructure: there are some use cases running and transferring cross-border health data (e.g. ePrescription, Patient Summary).

Other use cases are in preparation (lab results, discharge reports, radiology reports and others). The European infrastructure MyHealth@EU is continuously enhanced. In the future the outcomes of the project Xt-EHR will show, if there will be any need to prepare separate use cases for telemedicine services or the data collected by telemedicine services will be part of datasets in the other use cases. The current challenges in this aspect revolve around the need to set guidelines related to the collection of data from telemedicine services, and standardize the structure of the data transferred, enhance the interoperability across countries, and ease the difficulty of analyzing the data for secondary use (Raposo, 2016).

eCAN pilots indicated that the collection of data through questionnaires such as Quality of Life (QoL), Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs), as well as the clinician notes that are collected through teleconsultation sessions, can provide valuable information both for the patient's health record as well as can be utilized for secondary use. The data collected from these pilots are structured in a relational way that makes them easily interpretable and analyzable from external software systems. Taking into consideration the technological accessibility, data protection and privacy of the patients. In this context, bidirectional communication mechanisms from/to the eCAN JA software solutions could be established through Application Programming Interfaces (APIs), to facilitate interoperable data exchange at the level of MyHealth@EU European infrastructure.

The interoperability could be achieved using already recognized, standardized data structures such as the Fast Healthcare Interoperability Resources (FHIR), that includes data structures and communication methodologies that are accepted by the vast majority of software systems, such as XML (Extensible Markup Language) and/or JSON (JavaScript Object Notation) (Amaro et al., 2021). In addition, the eCAN pilots could be expanded through MyHealth@EU European infrastructure into large-scale pilots, making the data available and accessible to other projects. Summarizing, the custom software tools that were developed and used during the eCAN pilots (e.g. web platform, mobile application), can be extended to support teleconsultation sessions and monitoring of patients at level of MyHealth@EU European infrastructure expanding the outreach of the project with a twofold expected outcome:

1. Making a larger volume of data available to the MyHealth@EU European infrastructure that can be a motivating factor for other use cases.

2. Enable the creation of national and EU databases for later use, facilitate the collection of a large volume of data that can be used for future analytics (secondary use of data), thus increasing the project's overall impact, and expanding the potential capabilities of Machine Learning (ML) and Artificial Intelligence (AI) models by using large training sets.

3.2.2 Secondary use of telemedicine data

Secondary use of health data involves actions to be taken with the goal of expanding the usage of the collected health data beyond patient evaluation and treatment. For instance, data collected can be analysed in order to produce scientific results related to specific case studies and examples, e.g., cancer treatment and/or prevention. The most crucial part in this aspect is the anonymization of the data to protect the patient's privacy, with respect to the GDPR regulations (Kayaalp, 2018). Information that can be discovered from the health data provided by Telemedicine services can be used to create/modify patient-handling policies based on telemedicine technologies. For reference, health data analysis could show that the involved users need additional training sessions for using the digital tools. In addition, the health data can be used for statistical purposes, teaching knowledge management, and other purposes as mentioned in the interests of EHDS (ESMO, 2023).

Machine Learning models can be used for correlation analysis to assist physicians with the diagnosis process and personalized treatment plans, as well as predicting the need for additional teleconsultation sessions, by analysing health data sets of similar cases (Cascella et al., 2022). On the other hand, adaptive AI-driven chat bots can be employed to enhance the initial patient interactions, collecting the patient's health information and symptoms. These bots could take into consideration the patient's age, mental and physical conditions and ask the appropriate questions for each case to facilitate "smart" data collection (Fadhil, 2018). This collection's results can then be used for machine learning models or presented directly to physicians for analysis and diagnosis. The health data provided to ML/AI models should always be anonymized to protect the patient's privacy according to the EU regulations regarding AI usage and AI Act. Currently, the European infrastructure called HealthData@EU is under construction. The purpose of HealthData@EU European infrastructure is described in the proposal of the regulation on the European Health Data Space, 16048/23, REV1, Recital No.55 and further in the text of the proposal. The European infrastructure HealthData@EU will be used for secondary use of health data.

At the moment, the provision of health data for secondary use is partially working in different countries on a national level. For example FINDATA, the institution dedicated for the support of secondary use of health data in Finland inspired the Regulation on EHDS in the area of

secondary use of health data through the analysis of a variety of sources for the purpose of secondary use, such as National registries, National Health Information System and Regional Health Information Systems. As the final text of the Regulation on EHDS is still under negotiation, it is not clear at the moment how use of health data collected by Telemedicine services for secondary usage will be regulated on the European level.

As described in the FINDATA presentation mentioned above, the sources of health data used for secondary use are national health registers, national electronic health records and other sources of health data. If the health data collected by using Telemedicine services will be stored in the future in health registers, and electronic health records (structured way of storage), they might be used later for secondary use. In the future European infrastructure HealthData@EU it will mean that national Catalogues of metadata on available datasets and European catalogues of metadata on available datasets will contain information on datasets containing health data collected by Telemedicine services. The real usage of such health data for secondary use will then depend on the potential customers (scientists, policymakers, experts in the area of statistics, etc.) who will be interested in the usage of health data collected by telemedicine services for secondary use. Below, an illustration can be found on the data collection as performed in eCAN JA and the division for primary and secondary use (Figure 8).

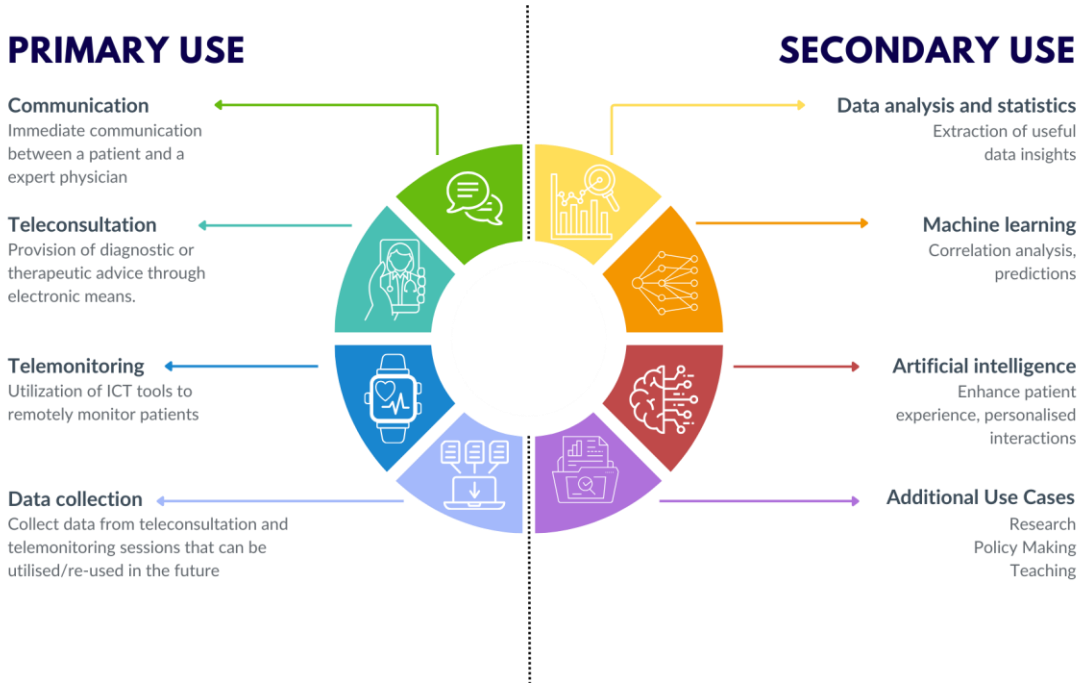


Figure 8. An overview of data collection as performed in eCAN JA and the division for primary and secondary use.

Key points from subchapter 3.2

- In accordance with the EHDS Regulation, telemedicine data can be employed for both primary and secondary use purposes.
- Primary use of telemedicine data focuses on direct patient care, incorporating data from teleconsultations and telemonitoring into EHRs and the MyHealth@EU infrastructure to enhance healthcare access and interoperability across borders.
- Secondary use of telemedicine data involves these data being anonymized or pseudonymized and then used for research or policy-making.
- Projects like Xt-EHR and eCAN have demonstrated how telemedicine data can be structured and standardized for interoperability and large-scale usage, potentially feeding into AI and machine learning models.
- The future HealthData@EU infrastructure will expand access to telemedicine datasets for secondary use, though further guidelines are needed to ensure consistent storage, accessibility, and privacy protection across the EU.

3.3 Insights from the eCAN JA pilot sites

3.3.1 Setup of the pilots

In the eCAN JA, three pilots evaluating the value of telemedicine in cancer care were implemented in 18 clinical centers. Most of them had little or no experience in telemedicine services including telemonitoring practices. Moreover, there were no standardized procedures for revalidation or psychological follow-up of cancer patients in and between pilot centres. Therefore, teleconsultation was performed using a centralised European open-source platform (eduMEET, 2023) available through a dashboard to registered health care providers (HCP) and patients. Telemonitoring included eCAN mobile application, where patients were able to submit data on patient-reported outcome measures (PROMs), patients-reported experience measures (PREMs) and smartwatch to register vital parameters. The system was piloted in three different clinical applications: Pilot 1a (post-surgery rehabilitation in breast cancer), Pilot 1b (post-surgery rehabilitation in head and neck cancers) and Pilot 2 (psycho-oncological support in advanced cancer) as presented in Figure 9 and outlined in Table 3. All pilots followed randomized clinical trial (RCT) design comparing the eCAN telemedicine programme with usual care, in 18 sites located in 10 countries (Figure 10).

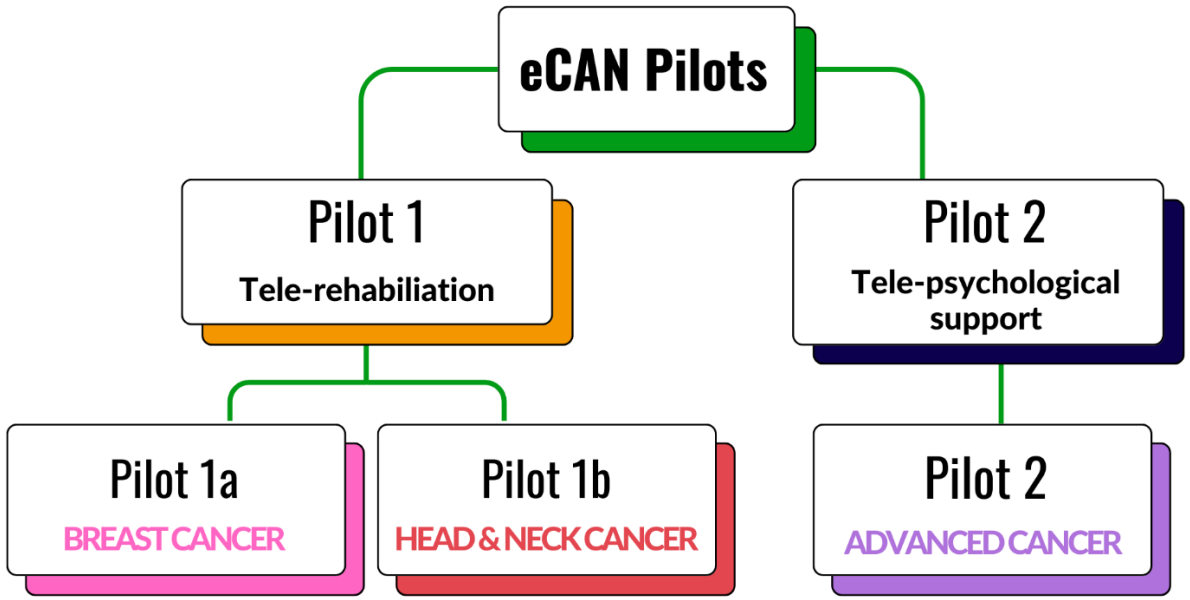


Figure 9. Design of the eCAN pilots

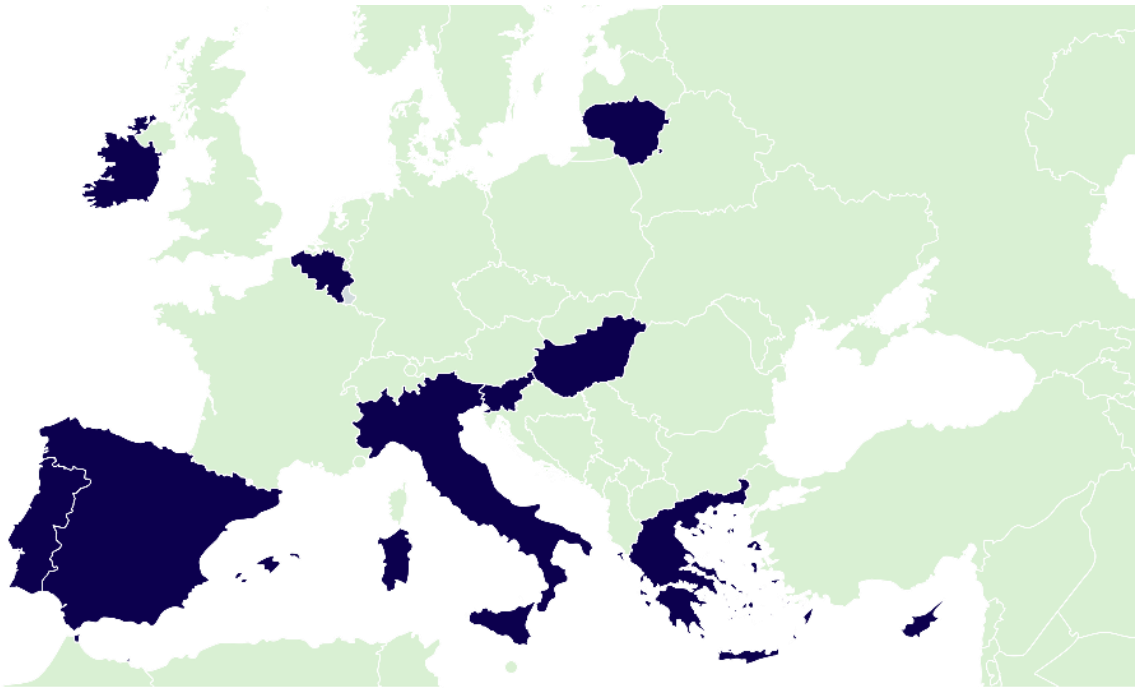


Figure 10. Map of Europe with involved Member States. All 3 pilots are in place in each of the Member States involved except Greece, where only pilot 2 is conducted.

	Pilot 1A Breast cancer patients	Pilot 1B Head and neck cancer patients	Pilot 2 Advanced cancer patients
Target patient group	Women, aged between 45 and 65 years old, who undergo a unilateral mastectomy plus axillary dissection for newly diagnosed breast cancer	Patients, aged between 18 and 75 years old, with histopathologically proven head & neck cancers, who are prescheduled for an en-bloc resection of the primary tumour, neck dissection, or reconstruction	Patients, aged between 18 and 75 years old, affected by **advanced/recurrent cancer** (including lung, prostate, colorectal, breast cancer)
Intervention	Weekly **tele-rehabilitation** intervention starting in the first month after surgery for **8 weeks:** exercises to maintain the correct range of motion of the upper limb	Weekly **tele-rehabilitation** intervention starting in the first month after surgery for **8 weeks:** exercises aimed at limiting muscle pain in the neck, shoulders and arms, strengthening the muscle groups affected by surgery	Weekly **psycho-oncology** teleconsultation for **8 weeks**: learning of techniques for managing negative emotions, for relaxation and for implementing effective behavioural and coping strategies
Primary/secondary endpoints	EORTC QLQ C30# / Pain Visual Analogical Scale (VAS)	EORTC QLQ C30 / Pain Visual Analogical Scale (VAS)	EORTC QLQ C30 / Distress Thermometer (DT)

Table 3. Overview of the characteristics of the different eCAN pilots

3.3.2 Evaluation of the pilots

We used the adaptation of the Model for Assessment of Telemedicine framework for integrated care (MAST-IC) (Kidholm et al., 2017, 2012; Vis et al., 2020) elaborated by the Joint Action to support the eHealth Network (JAseHN). Accordingly, the multidisciplinary assessment in 5 main and 4 secondary domains was considered, and addressed by analysing the outcomes of the pilot clinical trial (clinical and care effectiveness measured by PROMs (Aaronson et al., 1993; Nolte et al., 2019) as well as collecting the perspectives of patients through PREMs on the system utility (Parmanto et al., 2016; Zhou et al., 2019). The perspectives of the HCP as well as organizational, ethical, legal and socio-cultural aspects were

collected through Strengths Weaknesses Opportunities and Threats (SWOT) analysis, which involved conducting focus group discussions at each pilot site with the participation of different actors involved in eCAN pilots (doctors, nurses, physiotherapists, psychologists, IT staff, data protection officers, principal investigators, and others). Finally, a cost-consequence framework (Bergmo, 2015; Hunter and Shearer, 2019) has been developed to understand the economic aspects based on prior literature findings (Sülz et al., 2021). From the health care perspective, the cost categories considered in this framework included the implementation costs, which are related to setting up the infrastructure for telemedicine and training providers to use it, as well as the operational costs, which covered not only maintenance and licencing costs, but also the time the HCP spent consulting the patients. From the societal perspective, the framework took into account direct costs associated with the need to travel and with out-of-pocket fees, as well as indirect costs due to productivity loss of patients and caregivers.

Below, Table 4 provides a brief overview of the main outcomes of each pilot. The inclusion of multiple sites in Europe together with three diverse patient groups allowed us to look at the variability of the outcomes across different settings. The pilots ran between September 2023 and June 2024. In this report, we used the final results of the study. We enrolled 251 out of 354 patients expected, 71% of the planned final sample size. Enrolment rate per centre ranged from 0% to 100%. The final sample included 190 females (76%) and 61 males (24%). Of them, 27 patients dropped out and 224 completed the study. In pilot 1a, we observed a statistically significant improvement of the QoL for patients in the intervention group compared to the control group. In pilot 2, we observed a statistically significant decrease of distress in the intervention group compared to the control group. On the other hand, we did not observe any statistically differences for pain in pilot 1a, for both QoL and pain in pilot 1b, and for QoL in pilot 2. All these data are reported in Table 4. We also summarise the overall HCP satisfaction score and the usability score for the patient perspective. The results of the SWOT analysis are displayed in Table 5.

	Pilot 1a (Breast cancer patients)	Pilot 1b (Head and neck cancer patients)	Pilot 2 (patients with advanced cancer patients)
Key outcomes			

	Pilot 1a (Breast cancer patients)	Pilot 1b (Head and neck cancer patients)	Pilot 2 (patients with advanced cancer patients)
Number of participants (intervention / control)	107 patients (57/50)	40 patients (22/18)	104 patients (50/54)
Quality of life (median Global Health Status EORTC QLQ C30 score)	Intervention group: 75.0 Control group: 62.5	Intervention group: 58.3 Control group: 75.0	Intervention group: 66.7 Control group: 66.7
Pain level (median VAS)	Intervention group: 2.0 Control group: 3.0	Intervention group: 2.5 Control group: 3.5	Not relevant
Distress level (median DT)	Not relevant	Not relevant	Intervention group: 3.0 Control group: 5.5
Implementation and data quality indicators			
Recruitment rate with respect to intended sample size	107/118 (91 %)	40/118 (34 %)	104/118 (88 %)
Drop-out rate: #patients dropping out	13/107 (12%)	7/40 (17.5%)	7/104 (7%)
Compliance with questionnaire submission: # EORTC QLQ C30 questionnaires submitted at Week 0	96/107 (90% of expected)	35/40 (87.5% of expected)	93/104 (89% of expected)
Compliance with questionnaire submission: # EORTC QLQ C30 questionnaires submitted at Week 8	76/107 (71% of expected)	20/40 (50% of expected)	60/104 (58% of expected)
Proportion accepting telemonitoring with smartwatch	Of 190 devices distributed 67 (37%) were used.		
Patients and staff perspectives			
PREMS: TUQ (overall score)*	Intervention group, (participation rate 39/50, 78.0%): 6.1	Intervention group, (participation rate 11/18, 61.1%): 5.8	Intervention group, (participation rate 48/55, 87.3%): 5.8
PREMS: MAUQ (overall score)**	Intervention group, (participation rate 40/50, 80.0%): 5.9	Intervention group, (participation rate 11/18, 61.1%): 5.3	Intervention group, (participation rate 47/55, 85.5%): 5.2
Staff overall satisfaction score	71.8% (23/32 respondents) agreed or strongly agreed that overall they are satisfied with eCAN telemedicine service.		

*Table 4. Overview of the pilots' outcomes. #The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC -QLQ-C30); *Telehealth Usability Questionnaire, TUQ; ** mHealth App Usability Questionnaire (MAUQ) for Standalone mHealth Apps Used by Patients.*

For the HCPs and other site staff involved in the pilots, the findings of the SWOT analysis indicated that training prior to the initiation of any pilot activities can facilitate their smooth conduct, and that the accompanying training materials should focus on the patients'/end users' perspective, since their lack of digital literacy has been identified as one of the greatest weaknesses with regard to the use of digital tools. Additionally, the procurement of infrastructure, like hardware, dedicated rooms and licenced software along with the establishment of compensation schemes for the HCPs were recognized as important actions for the integration of telemedicine into regular practice.

For the patients participating in the pilots, the usability analysis based on PREMs collected from the intervention group indicated positive assessment of both the teleconsultation platform and the eCAN app. The average usability scores exceeded 5 on a 1 to 7 scale overall (TUQ: 6.3 [IQR 5.2 – 6.8], MAUQ: 5.7 [IQR 4.8 – 6.7]) and in each of the pilots (Table 4). By demographic group, no significant differences were observed by education, working status or place of residence, but significantly lower scores were given by patients in the age group 65 years or more: TUQ 5.4 [IQR 4.7-6.0] and MAUQ 5.0 [IQR 3.5-5.7]. This indicates the need to elicit and specifically address the needs of the oldest age group when improving the eCAN teleconsultation platforms and eCAN app.

Meanwhile, the cost-consequence and cost-utility analysis demonstrated that pain and distress scores decreased, but not significantly, because of low case numbers. The tele-rehabilitation intervention can be regarded as cost-effective, whereas this is not the case for the tele-psychological support intervention, which could be due to the short observation period. The results of this analysis are described in more detail elsewhere (see Deliverable 7.2 – Pilot Reports).

Strengths	Weaknesses
Center capacity and characteristics: • Reference center • Easy to find patients • Good capacity of center • Telemedicine service already in place • Staff experience • Available equipment **eCAN Implementation procedure**: • Straight forward protocol • Easy to use platforms	**Center capacity and characteristics**: • Professionals' lack of time • Slow internet connection • Staff not trained **eCAN Implementation procedure**: • Delays in ethics approval • Strict inclusion criteria • Technical issues • Not efficient technical support • Not efficient training materials

• Useful features • Good educational materials • Timely provision of materials • Easy patient monitoring • Easy ethics approval • Good data management **Internal and external management:** • Good management by eCAN • Regular meetings • Good internal coordination • Team communication **Stakeholder-related points:** • Patient compliance • Patient collaboration • Staff commitment **Governance/legislation/legal:** • No legal issues • Common practice similar to eCAN **General teleconsultation features:** • Cost effective • Time effective • Facilitate access to care • Few human resources involved	• Platforms not interconnected • No time for training • App unavailability for iPhone **Stakeholder-related points:** • Misinformation of patients on advantages • Doubts of patients on usefulness • Issues with group they were randomized • Patients leaning towards traditional methods • Compliance • Digital literacy **Governance/legislation/legal:** • Data security **General teleconsultation features:** • Not adapted to everyday practice • Lack of direct contact
Opportunities	**Threats**
Center capacity and characteristics: • Patient availability • HCPs well trained **Stakeholder-related points:** • Improved patient experience • Many patients in rural areas • Increased awareness • Young patients susceptible towards teleconsultation • Patients busy to attend in-person consultations **Governance/legislation/legal:** • Integration with electronic health record	**Center capacity and characteristics:** • No infrastructure • Staff training • Short staffed • Team experience • Slow internet connection **eCAN implementation procedure:** • Not efficient technical support • Wrong outcomes • Translation • Patient support **Stakeholder-related points:** • Patient digital literacy

• Integration of telemedicine in common practice • Health system digitalization • Data protection law already implemented **General teleconsultation features:** • All patients potential candidates • Home privacy • Time saving • Low cost • Comfort • Continuity of care • Improvement in quality of life	• Patient access to technology **Governance/legislation/legal:** • In person services free of charge • Administrative/legal issues • No compensation available • Data security • No remote rehabilitation supported by public health • No central funding

Table 5. Summary of the results of the SWOT analysis

3.3.3 Ethical and cybersecurity aspects

In the rapidly evolving landscape of health research, particularly with the increasing use of digital technologies and patient data, it is crucial to consider not only the technical aspects of cybersecurity but also the ethical implications that come with it. Researchers and healthcare professionals should ensure that their practices not only meet regulatory requirements but also adhere to the highest ethical standards. This dual focus on cybersecurity and ethics is essential for maintaining the integrity of research and the trust of patients. Doctors, by virtue of their profession, are already bound by strict codes of conduct and deontological responsibilities. These professional codes demand the utmost respect for patient confidentiality, informed consent, and the overall well-being of the patient. The ethical framework within which doctors operate is designed to protect patient rights and ensure that their medical information is handled with the highest level of care and discretion.

In the digital age, adhering to these ethical standards also necessitates a robust approach to cybersecurity. Cybersecurity is not merely a technical requirement; it is a fundamental aspect of ethical medical practice. Poor cybersecurity measures can lead to the illegal sharing of patient information, which not only breaches legal requirements but also violates the ethical duty of confidentiality that doctors owe to their patients. When patient data is inadequately protected, it becomes vulnerable to unauthorized access and exploitation, potentially leading to severe consequences for the patients involved. Moreover, unreliable cybersecurity practices can result in compromised data integrity. In the context of health research, this means that the data collected could be altered or tampered with, either accidentally or maliciously. Such compromises can lead to unreliable research results, which undermine the validity and

credibility of the research findings. Inaccurate data can also misinform clinical decisions, leading to dangerous mistakes in patient care. These errors can range from incorrect diagnoses to inappropriate treatments, both of which can have severe, even life-threatening, consequences for patients.

Ensuring robust cybersecurity measures is therefore a critical component of maintaining ethical standards in medical research and practice. It protects patient privacy, ensures the accuracy and reliability of research data, and upholds the trust that patients place in healthcare professionals by safeguarding sensitive patient information and ensuring that it is used appropriately and accurately. In practice, this means that healthcare professionals and researchers must be vigilant and proactive about cybersecurity. This involves implementing advanced security protocols, regularly updating and auditing security measures, and ensuring that all staff are adequately trained in cybersecurity best practices. It also means being transparent with patients about how their data is being used and protected, thereby reinforcing their trust in the healthcare system.

Telemedicine interventions, delivered through digital technologies, such as smartphones and websites, can improve cancer care delivery and contribute to the triple aim of health care, that is, better care, better health outcomes, and reduction in medical spending. The advent of telemedicine has created unprecedented opportunities to extend diagnostic and treatment services to individuals who would otherwise have limited or no access to healthcare. This technological advancement addresses a critical need in our global society, particularly for those residing in remote or underserved regions. The ethical significance of this capability cannot be overstated. Access to healthcare is a fundamental human right, and the disparity in healthcare availability between different socioeconomic groups is a pressing ethical concern. By leveraging telemedicine, we can work towards reducing these disparities and promoting a more equitable healthcare system. It ensures that no one is denied the care they need due to their geographical location or economic status. Telemedicine also enables the continuous monitoring of patients with chronic conditions. Regular follow-ups and timely interventions can prevent complications and hospitalizations, which are often more challenging for disadvantaged individuals to manage. This proactive approach to healthcare can lead to better disease management and improved quality of life for patients who might otherwise struggle to maintain consistent medical care.

However, the implementation of telemedicine must be approached with careful consideration of the ethical principles involved. Ensuring that telemedicine services are secure and that patient privacy is protected is paramount. The digital divide also poses a challenge; efforts must

be made to ensure that all populations have access to the necessary technology and infrastructure to benefit from telemedicine. The ethical commitment to expanding healthcare access through telemedicine also involves continuous evaluation and improvement of the technology and services offered. This means staying attuned to the needs of disadvantaged populations and adapting telemedicine solutions to meet those needs effectively. It requires collaboration between governments, healthcare organizations, and technology providers to create sustainable and inclusive telemedicine programs. Telemedicine is also accompanied by potential threats in terms of security risks and vulnerabilities, such as violating and exposing patients' sensitive and confidential data. Further, the network traffic data may vulnerable to interception attacks caused by a wireless type of communication and alteration of data, which could cause unwanted outcomes. Cybersecurity represents a crucial challenge for the telemedicine implementation and may influence the security, privacy, and quality of the provision of healthcare services, especially in interconnected systems and service.

Data security and protection of privacy are crucial in eCAN as pilot trials dealt with personal health data. Specific ethical and data security challenges and policy recommendations including cybersecurity risks have been explored in a dedicated work package of the eCAN JA (WP6) in parallel with the study conduction. Research on patient outcomes often requires access to detailed patient data, which is protected under various privacy and/or data protection regulations, such as the General Data Protection Regulation (GDPR) in the EU. Anonymisation involves the process of removing or altering personal identifiers within data sets so that individuals cannot be readily identified. This process is crucial for several reasons:

- Legal Compliance: By anonymising data, researchers can avoid stringent legal requirements associated with handling personally identifiable information (PII). This reduces the bureaucratic burden and facilitates smoother research processes.
- Ethical Responsibility: Protecting patient identity maintains the ethical integrity of the research, ensuring that participants' privacy is respected.
- Data Security: Anonymised data is less likely to be targeted by cybercriminals, thereby reducing the risk of data breaches.

Incorporating cybersecurity measures from the beginning of the research process is imperative and instrumental to comply with ethical and legal standards. This proactive approach ensures that cybersecurity and data protection are ingrained in the research methodology, rather than being an afterthought. Key steps include:

- Risk Assessment: Conducting a thorough risk assessment to identify potential vulnerabilities in data handling and storage.
- Secure Data Collection: Implementing secure protocols for data collection, ensuring that data is encrypted and transmitted through secure channels.
- Access Controls: Establishing strict access controls to limit data access to authorized personnel only.

Starting from the physical and transport layers, these goals have been approached by selecting a Data Centre and Internet Service Provider owning high-level security certifications, including those made mandatory by the Italian Law and set by the National Cybersecurity Agency to provide services to the Public Administrations. At operating system level, a Linux distribution has been selected, to allow the installation of Edumeet, a teleconferencing system for the interaction with the patients, this latter also distributed under an open source license. Leveraging open-source software and platforms provides multiple advantages for research projects, including the ability to perform independent security assessments and customize solutions to meet specific needs. The EU-funded Edumeet teleconferencing system is a prime example of how open-source platforms can enhance research security and efficiency:

- Independent Vulnerability Assessments: eCAN has conducted independent vulnerability assessments on Edumeet, allowing the research team to identify and address previously undiscovered vulnerabilities.
- Enhanced Security: The ability to patch vulnerabilities quickly has made Edumeet more secure, providing a reliable platform for teleconferencing and data sharing.
- Community Support: As an open-source project, Edumeet benefits from community-driven improvements and support, ensuring that the platform evolves to meet the latest security standards.

From the eCAN experience, the following recommendations should be taken into consideration:

- Early Cybersecurity Integration: Incorporate cybersecurity requirements at the outset of the research project.
- Utilize Open Source Platforms: Adopt and contribute to open-source platforms to leverage community support and enhance security.

The eCAN project provided useful insights also concerning the cybersecurity and data protection issues related to the use of commercial grade wearable devices such as fitbands and the development of customized apps interacting with those built by the fitband's manufacturer.

The increasing use of commercial-grade wearable devices, such as fitbands, in health research presents significant cybersecurity and data protection challenges. In this regard, there are key issues related to the use of these devices, particularly concerning the development of customized apps that interact with the manufacturer's software to collect users' data. Not being medical grade device, the wearables have not been used to produce scientifically valid findings, but only as a support to a proof-of-concept to see which —if any— benefits could come for a research project by using them. That said, eCAN choice was no to rely upon the fitband manufacturer's app per se, but to develop customized applications to interact with commercial wearable devices, to limit the personal information to be collected. This choice, however, made necessary to address several cybersecurity risks. These risks are primarily due to limited access to the device's operating system and the proprietary nature of the manufacturer's software:

- Limited OS Access: Custom apps often cannot access the full range of the device's operating system features. This restricted access hinders the ability to implement comprehensive security measures. For instance, critical system-level security protocols and updates managed by the manufacturer are beyond the control of the custom app developers.
- Proprietary Software Constraints: The inability to access and modify the manufacturer's application (the one providing the raw data collected by eCAN custom app) means that custom apps must rely on the existing software's security measures, which may not meet the specific requirements of the research project. This dependency creates a security gap, as the customized app cannot enhance or modify the underlying security features.

Another significant challenge is the lack of transparency and control over how wearable manufacturers handle user data:

- Data Privacy Concerns: Manufacturers collect and process data from wearable devices, but researchers have no control over how this data is managed, stored, or shared. This lack of transparency raises concerns about data privacy and the potential for misuse or unauthorized access to sensitive information.
- Inaccessible Raw Data: Researchers often cannot access the raw data collected by the manufacturer's app. Instead, they receive processed or aggregated data, which might not include all necessary details for research purposes and might be subject to the manufacturer's interpretation and processing algorithms. This may affect the reliability of the findings and the overall value of the research.

Therefore researchers must take extra precautions to ensure data integrity and security when using commercial wearable devices. Even though the raw data is captured by the fitband independently of the researchers, there is still a risk of data tampering during transmission, storage, or processing. Researchers need to implement robust encryption and secure data transmission protocols to mitigate these risks. At the very least, it would be necessary to conduct regular security audits of the customized app and the overall data handling process. This includes verifying that data is accurately captured, securely transmitted, and correctly stored without unauthorized alterations. Health data have been collected, managed and stored in line with GDPR and any other additional requirements in the country sites.

In the realm of patient data anonymisation, research methodologies are employed to ensure the protection of patient identities while enabling effective data collection and analysis Figure 11). The real-life experience has shown the importance of maintaining anonymity at the doctor-patient level, the necessity of training for healthcare professionals, and the relevance of the role of eCAN principal investigators (PIs) in safeguarding patient anonymity. Key aspects anonymisation protocols to be implemented at the doctor-patient level include the need that only the treating doctor knows the actual identity of the patient. Each patient is assigned an anonymous email address, which they use to access platforms like Edumeet for teleconferencing and outcomes reporting. The anonymous email address ensures that all further interactions and data exchanges occur without revealing the patient's true identity to those who don't need to know it. This method provides a reasonably secure channel for patients to report outcomes and participate in telehealth sessions without compromising their privacy. Real-life experience has demonstrated the critical need for thorough training of healthcare professionals in maintaining patient anonymity. Reported issues include:

- Doctors and healthcare staff must be trained not to use identifiable information, such as patient names, when labeling directories or teleconferencing rooms. This practice helps prevent accidental exposure of patient identities to third parties.
- Consistent Anonymisation Practices: Consistent and uniform anonymisation practices across all levels of patient interaction and data handling are essential. This ensures that patient identities are protected throughout the research process.
- No Access to Patient Identities: eCAN PIs must operate under protocols that prevent them from accessing the identities of the patients involved in the research. This separation of roles helps maintain the integrity of the anonymisation process.

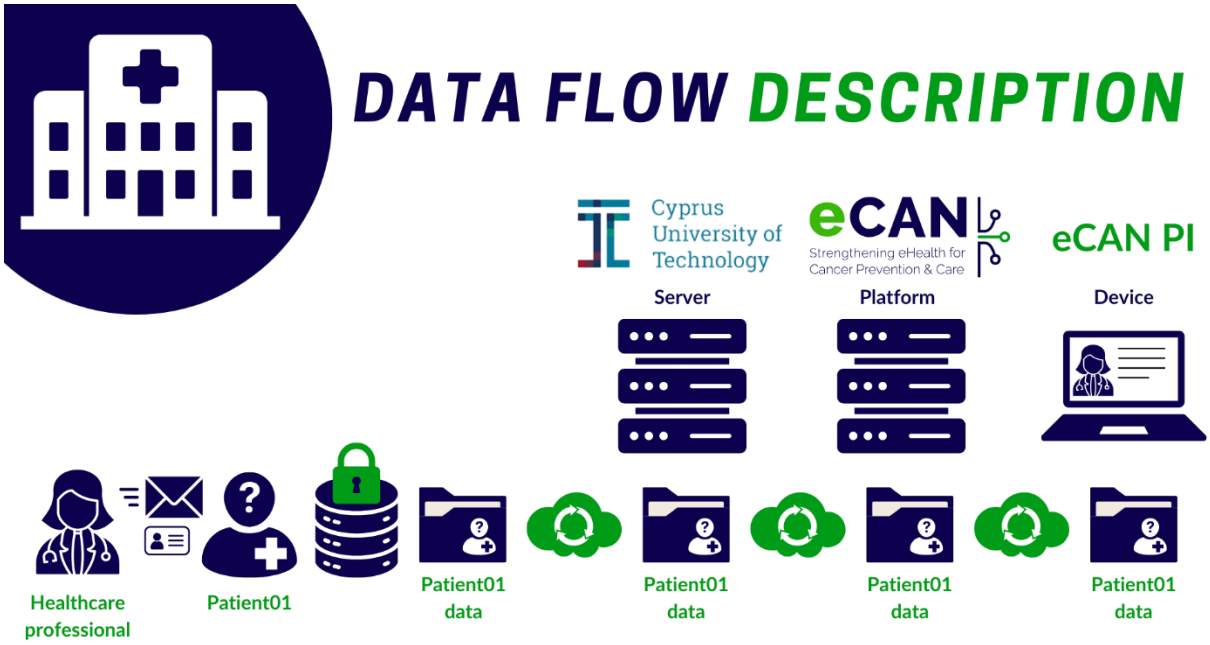


Figure 11. Procedure for anonymising data when a patient enters the study. Data flow description: anonymisation happens in hospital. The doctor assigns a dummy email to the patient and only the doctor knows the real identity of the patient. The dummy email also serves as the patient's ID and account for using the wearable. The dummy ID is first uploaded to a server managed by the University of Cyprus (CUT) to activate the wearable account. From there, the data enters the eCAN platform fully anonymised, as only the treating physician can deanonymise it. eCAN PIs access the eCAN platform from their premises without knowing the patient identity, while doctors can interact with their patients in full confidentiality.

In the context of the eCAN Joint Action, a teleconference platform was necessary to allow patients and physicians to perform visits remotely. Edumeet (https://edumeet.org/) was chosen as the software was developed specifically to provide a flexible, open source and GDPR compliant platform to Video Conferencing. To minimize the issues and breaches of the GDPR, no data about physicians or patients was stored in the machine: the only purpose of this server is to provide a videoconference platform delegating any other activity to other software in the projects.

As required, a security assessment was carried out by a third party (Moveax https://www.moveax.it/) in the form of a cybersecurity stress test. The penetration test revealed, in addition to 2 other vulnerabilities, a high risk vulnerability that allowed a possible malicious actor to bypass the authorization of some methods in the websocket server. This vulnerability could allow a malicious user to enter the videoconference before it is initiated by a moderator, remain invisible in the user list, send arbitrary chat message and impersonate another user. Moveax produce a PoC (Proof of Concept) demonstrating an actual exploit of

the vulnerability. Due to the possible high impact of this vulnerability, it is necessary to patch this vulnerability in the fastest and safest way possible.

The experience of eCAN pilot trial conduction shows that interdependent health organizations may have different levels of cybersecurity maturity and telemedicine skills, which can make it difficult to coordinate policies and practices effectively. The differences between clinical cancer centers across Europe might be very large, which can make it challenging to establish a common set of policies and standards. Managing cybersecurity policies requires common policies and standards, and the promotion of cybersecurity training and education for stakeholders involved in telemedicine clinical practice.

Key points from subchapter 3.3

- The eCAN JA conducted three telemedicine pilots across 18 clinical centers in 10 countries, using RCT designs to compare post-surgery telerehabilitation for breast cancer (pilot 1a) and head and neck cancer (pilot 1b) and telepsychological support for advanced cancer (pilot 2) against usual care, and collecting PROMs, PREMs and smartwatch data.
- The evaluation of the eCAN pilots encompassed multidisciplinary assessments across clinical, organizational, and socio-cultural domains. Patient outcomes were measured using PROMs and PREMs, while healthcare provider perspectives and organizational aspects were analyzed through a SWOT analysis. A cost-consequence framework was also applied to assess economic impacts.
- Pilot 1a showed significant QoL improvements for the intervention group, while pilot 2 saw significantly lower distress levels for the patients receiving telepsychological support. Pilot 1b did not yield similar results.
- Patients in the pilot study positively assessed the teleconsultation platform and the eCAN app, but those older than 65 gave lower usability scores, illustrating that their specific needs have to be addressed.
- A SWOT analysis highlighted the importance of pre-pilot training for HCPs and site staff, using materials that incorporate end users' perspectives to combat patients' lack of digital health literacy. It also underlined the need for infrastructure procurement and HCP compensation schemes to support telemedicine integration into routine practice.

- While the telerehabilitation intervention can be regarded as cost-effective according to the cost-consequence framework used, this is not the case for the telepsychological support intervention, which could be due to the short observation period.
- When using wearable devices and telemedicine platforms, robust cybersecurity measures are essential to protect sensitive patient data, maintain research integrity, and uphold ethical standards. This includes anonymizing data, adhering to regulations like GDPR, and proactively addressing risks, especially where vulnerabilities can compromise privacy and data accuracy.
- The eCAN project highlights the need for secure open-source telemedicine platforms, rigorous anonymization protocols, cross-border cooperation to ensure consistent cybersecurity standards, and the provision of training to healthcare professionals on these matters.

4. Mapping the future

This chapter reports on the eCAN JA foresight exercise, projecting scenarios for the future trajectory of telemedicine integration at micro (patient), meso (healthcare organisation), and macro (health system) levels. It presents a description of these scenarios, and provides actionable strategies for realising the most optimistic one among them.

The goal of a foresight exercise is to help policymakers systematically understand their environments and identify important upcoming issues early. This approach helps reduce unexpected challenges, provides them with more options, and makes governance more flexible. Our foresight exercise aimed to develop forward-thinking policies and gather ideas to make recommendations for the eCAN JA roadmap, preparing relevant stakeholders to effectively anticipate and respond to future changes. The exercise involved three key stages: Initially, it began with **three literature reviews**, conducted between May and September 2023 to help pinpoint the critical factors (barriers and facilitators) for implementing telemedicine at three different levels: patients (micro level), healthcare organisations (HCOs; meso level), and policymakers (macro level). Next, **three surveys** were sent to these groups, with each group receiving a dedicated questionnaire asking them to rank the critical factors discovered through the literature review on a Likert scale measuring the enabling or blocking capacity of the factor in question. This survey process involved 51 participants from 18 different EU MS (namely Austria, Belgium, Croatia, Cyprus, Czechia, Denmark, Estonia, Greece, Hungary, Ireland, Italy, Lithuania, Luxembourg, Malta, Poland, Portugal, Slovenia, Spain) and was finalised in December 2023. Lastly, an online **foresight workshop** was held with the survey respondents in February 2024 to clarify their responses and capture their expectations, impressions, and attitudes towards the implementation of telemedicine services in the future. 16 individuals from 13 countries (Austria, Belgium, Cyprus, Czechia, Greece, Hungary, Ireland, Lithuania, Luxembourg, Malta, Portugal, Slovenia, Spain) participated in this workshop and when necessary provided written comments afterwards.

Based on the results of the literature reviews and the pre-workshop surveys, four scenarios were developed for the future trajectory of telemedicine uptake in Europe (see Figure 12), categorised along the dimensions of patient openness (micro level) and degree of policy support (macro level). These dimensions, which were chosen because they emerged as important contextual criteria from both the literature reviews and the surveys, are further clarified in the scenario descriptions below. While HCP openness (meso level) does not explicitly feature as a criterion in any of the scenarios, HCOs did participate in the workshop

and were given the chance to comment on how they viewed their role in each scenario. Being positioned at the interface between the micro and macro level, these stakeholders provided useful insights which were taken into consideration when formulating strategies for achieving scenario 1 in the EU (see further below).

Scenario 1: In this optimistic scenario, health policymakers have established a strong, supportive framework for digital health, driven by an agenda that prioritises modern, integrated, and person-centred care. The broader EU agenda for digital connectivity and the widespread availability of technology bolster these efforts. Policies ensure trust, security, and confidentiality in telemedicine services, overcoming traditional barriers. This supportive policy environment is a result of prioritising digital health transformation and leveraging prior commitments to national projects that have laid a solid foundation for telemedicine. Patients, including the older population, respond positively to the enabling policy environment, with high uptake of telemedicine services. This enthusiasm stems from past positive experiences and the tangible benefits telemedicine offers, such as convenience, cost, and time savings. The design of telemedicine platforms focuses on user needs, offering clear, tailored information and easy navigation. Patients appreciate the continuity of care with their regular healthcare providers and the access to specialist services without the need for long travel. The high uptake is a confirmation of patients recognising the value of telemedicine in enhancing their healthcare experience.

Scenario 2: This scenario is characterised by a cautious approach of public authorities. In a policy environment that is not so conducive to the adoption of telemedicine, characterised by traditional norms concerning the role of family in informal care and concerns about data safety, patient privacy as well as bureaucratic hurdles, there is a noticeable disconnect between the availability of technology and its implementation at the policy level. These barriers slow the validation and authorisation of telemedicine, making it challenging to enable the technology being part of standard care. Contrary to the discouraging policy environment, patients show a high willingness to embrace telemedicine services. This willingness is driven by the direct benefits they perceive, such as convenience, the ability to maintain their daily routines, and significant cost and time savings. Even faced with potential drawbacks like losing personal connections with healthcare providers or technical issues, patients' positive experiences and the functional advantages of telemedicine outweigh their concerns, indicating a strong patient-driven demand for digital health solutions.

Scenario 3: In this scenario, the policy environment is highly supportive of telemedicine, featuring initiatives that promote digital health, connectivity, and the availability of e-health

solutions. Policies are in place that foreground modern health systems, prevention, and integrated care, ensuring a solid infrastructure for digital health services. The low uptake of telemedicine services among patients, despite the enabling policy environment, highlights significant barriers at the micro level. Concerns (of especially older population) about losing personal connection with healthcare providers, the perceived loss of the human touch in digital consultations, and technical issues deter patients from adopting telemedicine. This scenario suggests that even in a supportive policy context, addressing patient-specific concerns and enhancing the telemedicine user experience are crucial for increasing adoption rates among the target populations.

Scenario 4: This scenario illustrates a challenging backdrop for telemedicine, characterised by a policy environment that hinders the growth of digital health solutions. Traditional norms concerning the role of family in informal care, data safety, and privacy concerns, alongside bureaucratic processes, create significant barriers. The slow pace of validating and authorising new healthcare models due to these concerns results in a cautious and often discouraging approach by public authorities towards the use of telemedicine as part of standard care. Parallel to the discouraging policy environment, patient willingness to engage with telemedicine services is low. The reluctance stems from a preference for in-person consultations, concerns about the quality of care through telemedicine, and technical difficulties that detract from its perceived benefits. This low willingness among patients, coupled with the challenging policy environment, paints a picture of the hurdles telemedicine faces, emphasising the need for concerted efforts to address both policy-level barriers and patient-level concerns to foster a more favourable climate for digital health adoption.

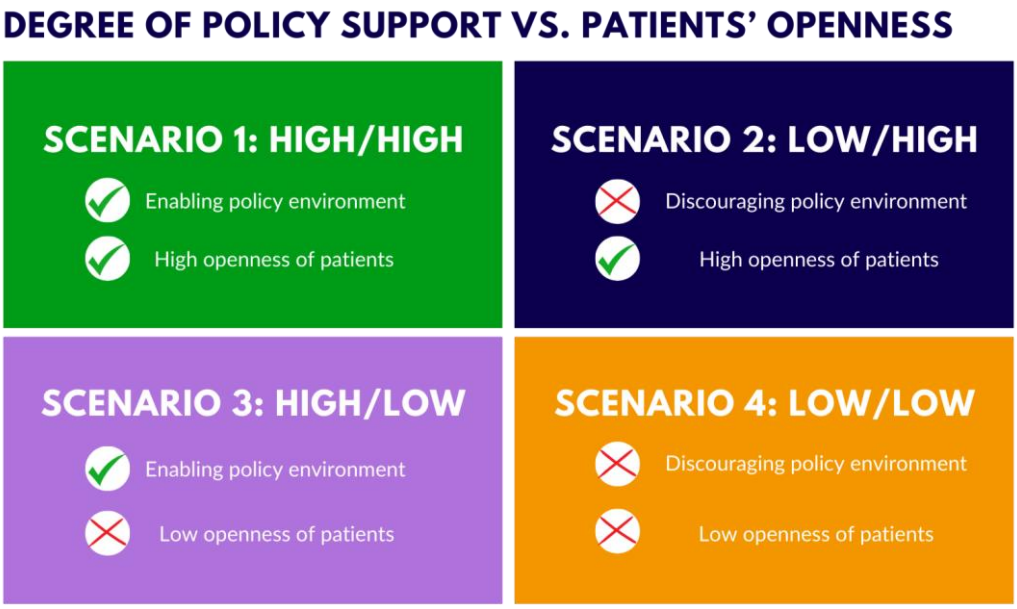


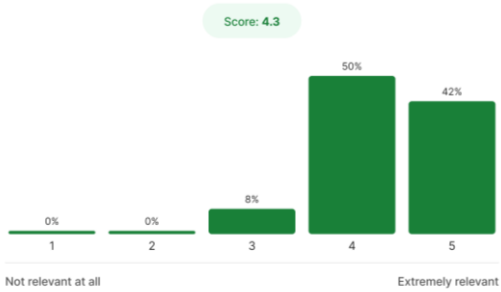
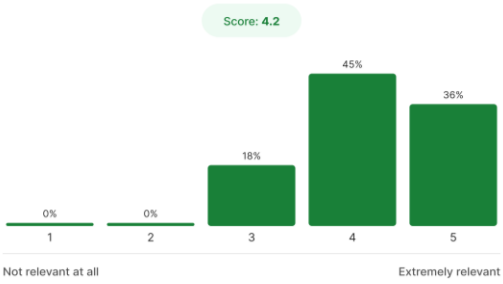
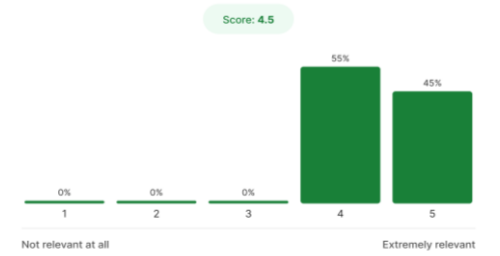
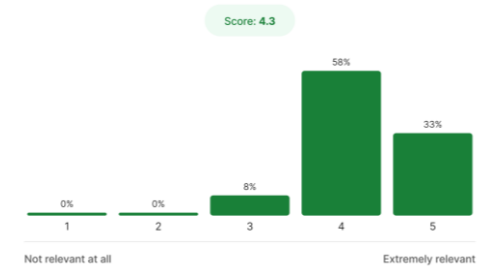
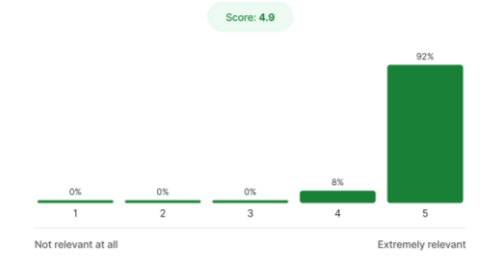
Figure 12. Four foresight scenarios discussed in the workshop

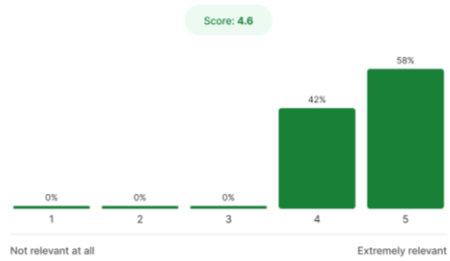
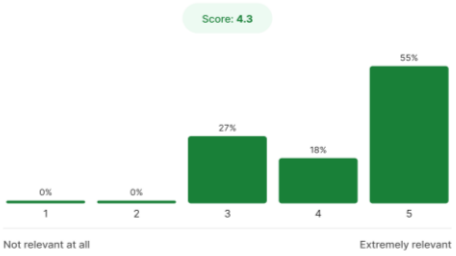
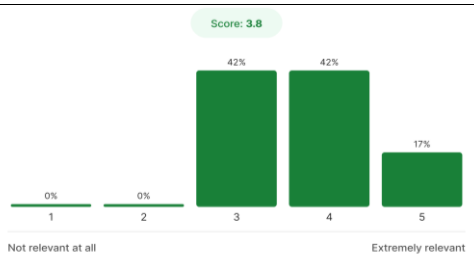
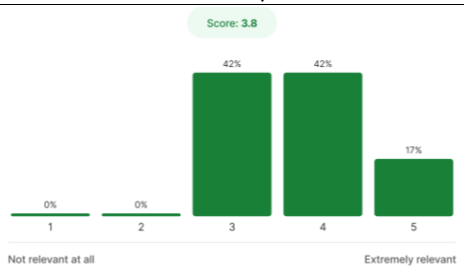
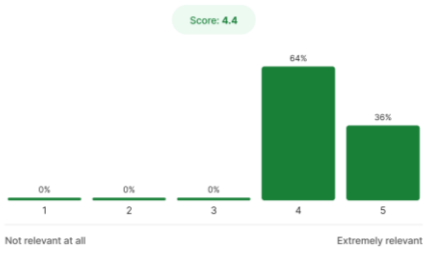
During the foresight workshop, the abovementioned scenarios were discussed with the participants. Using the input received during the discussions, strategies to achieve scenario 1 (high patient openness combined with an enabling policy environment for telemedicine) in the EU were developed, which are summarised in Supplementary Table 1 included in the annex to this roadmap.

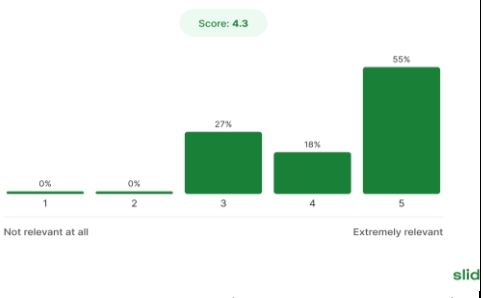
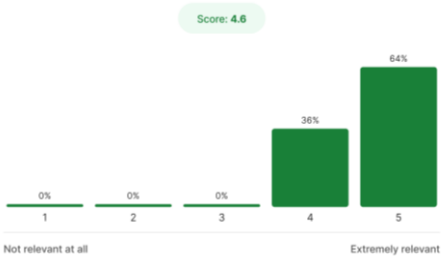
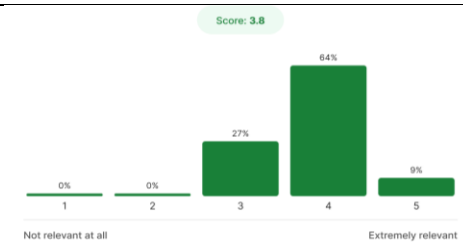
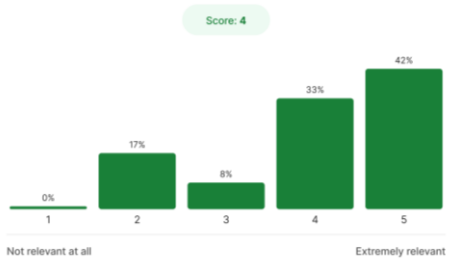
5. Identifying recommendations

In this chapter, a set of recommendations is given for effectuating a transition from the current 'as-is' (see chapter 3) to the future 'to-be' (see chapter 4, scenario 1: high patient openness combined with an enabling policy environment) situation with respect to telemedicine in Europe. In addition, an overview is provided of the perceived relevance of these recommendations from the perspective of different EU MS, originating from insights acquired from a meeting with the eCAN JA Governmental Board, a group of telemedicine experts from across Europe that was assembled to externally validate the present roadmap.

The eCAN JA recommendations were derived from the analysis of the state of play of the telemedicine field through various approaches (see subchapters 3.1, 3.2 and 3.3), as well as from the results of the foresight workshop and follow-up survey (see chapter 4). More specifically, after the findings from this workshop and survey had been processed, a prioritisation exercise was performed, which involved three members of the eCAN JA coordination team reviewing chapter 3 as well as the Supplementary Table included in the annex to this document and independently selecting recommendations that should be prioritised according to them. Their selections were compared and consolidated into a draft list which was shared with the eCAN JA work package leads for input. Once the feedback received was implemented, the revised list was sent to the experts who were part of the eCAN JA Governmental Board and discussed with them during a virtual meeting. More specifically, they were asked to score in an anonymous fashion the relevance of the proposed recommendations through the use of polling software. The results indicated that the Governmental Board members perceived all of them as relevant, thereby validating them. The validated list of recommendations is displayed in Table 6. These recommendations span across the entire implementation cycle of new interventions and have been divided into categories based on the specific step of this cycle they are intended to address, in accordance with the 'plan-do-study-act' method (Taylor et al., 2014). For each recommendation, the roadmap chapter(s) from which it is taken are included, along with the number of Governmental Board members that scored its relevance and the distribution of scores given.

Intervention area	Recommendation	Source of recommendation	Relevance score average and distribution
Regulatory, governance and policy framework	**Prioritization of telemedicine by decision-makers for its integration into health and care systems**	Chapter 4: Mapping the Future	 Relevance score: 4.3/5 (based on 12 votes)
	Developing guidelines addressing privacy, data protection, and patient rights aligned with GDPR	Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.2/5 (based on 11 votes)
	Enacting clear rules and legislation with respect to telemedicine services	Chapter 3: State of Play; subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.5/5 (based on 11 votes)
Collaboration and stakeholder engagement and awareness	**Establishing a collaborative framework with stakeholders for comprehensive telemedicine integration**	Chapter 3: State of Play; subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems Chapter 4: Mapping the Future	 Relevance score: 4.3/5 (based on 12 votes)
	Engaging patients in the design and testing of telemedicine services	Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.9/5 (based on 12 votes)

	Focusing on access to digital health technologies and improving health literacy for all demographics	Chapter 3: State of Play; subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems Chapter 4: Mapping the Future	 Relevance score: 4.6/5 (based on 12 votes)
Infrastructure and technology development	**Providing technological support and equipment to end-users**	Chapter 3: State of Play; subchapter 3.2: Using telemedicine data at the EU level Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.3/5 (based on 11 votes)
	Developing telemedicine platforms with interactive interfaces to provide more engaging and personal experiences	Chapter 4: Mapping the Future	 Relevance score: 3.8/5 (based on 12 votes)
	Ensuring the development of a solid IT infrastructure and the exchange of standardised data supporting the uptake of telemedicine services and the primary and secondary use of telemedicine data within and between the EU Member States	Chapter 3: State of Play; subchapter 3.2: Using telemedicine data at the EU level Chapter 4: Mapping the Future	 Relevance score: 3.8/5 (based on 12 votes)
Training and education	**Implementing strategies to enhance patient openness, including support and assistance for using telemedicine effectively**	Chapter 3: State of Play; subchapter 3.2: Using telemedicine data at the EU level Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.4/5 (based on 11 votes)

	Offering specialized training and resources to healthcare providers and care givers to assist patients in adopting technology	Chapter 3: State of Play; subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.3/5 (based on 11 votes)
	Enhancing digital health literacy among patients, care givers and healthcare providers	Chapter 3: State of Play; subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.6/5 (based on 11 votes)
Implementation and integration into healthcare systems	**Addressing hospital workload challenges to facilitate telemedicine implementation**	Chapter 4: Mapping the Future	 Relevance score: 3.8/5 (based on 11 votes)
	Utilizing telemedicine for follow-up monitoring and consultations in and outside hospitals (role of telemonitoring and teleconsultations and their interplay with in-person visits, need for more behavioural and cultural insights research) for evidence-based integration into the care pathway	Chapter 3: State of Play; subchapter 3.1: Relevance and use of telemedicine in the context of EU health systems Chapter 3: State of Play; subchapter 3.3: Insights from the eCAN JA pilot sites Chapter 4: Mapping the Future	 Relevance score: 4.0/5 (based on 12 votes)

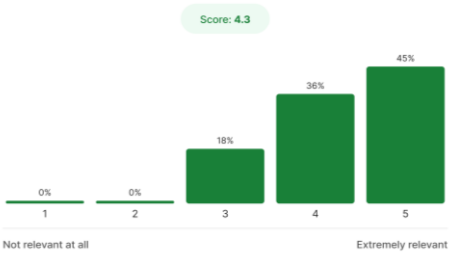
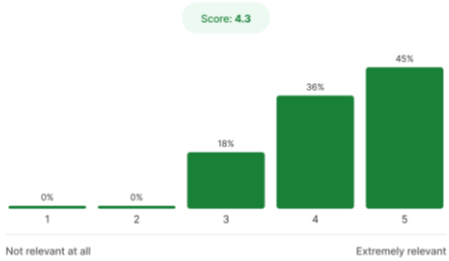
Evaluation and continuous improvement	**Defining clear metrics and evaluation criteria before telemedicine implementation**	Chapter 4: Mapping the Future	 Relevance score: 4.3/5 (based on 11 votes)
	Conducting thorough evaluations of health outcomes of new telemedicine services before and after integration	Chapter 4: Mapping the Future	 Relevance score: 4.3/5 (based on 12 votes)

Table 6: List of recommendations following from the eCAN JA and their perceived relevance from the point of view of the Governmental Board.

The recommendations were also the subject of a panel discussion that took place during the eCAN final conference on 29 November 2024 in Brussels, involving a policymaker representative from Norway, a payer representative from Belgium, two healthcare professional representatives from Lithuania and Portugal, and a patient organization representative from Cyprus, all of whom had been involved in the eCAN project. Key themes and points that were mentioned during this discussion are the following:

- **Improving telemedicine tools through patient engagement**: patients have to be made aware of the added value of telemedicine interventions. They need to understand why it is important to collect telemonitoring data, and they should receive feedback to increase their motivation and participation. In this respect, the design of the eCAN app needs to be improved through co-creation with patients.
- **Avoiding disparities in patient access**: telemedicine services should be designed to avoid creating a divide between patients who can use them and those who cannot. Ensuring inclusivity and accessibility is key to equitable healthcare.
- **Facilitating and enhancing patient-provider contact**: The aim of telemedicine services should be to strengthen and simplify the interaction between patients and healthcare professionals.
- **Ensuring a safe and secure environment**: A safe and secure platform is crucial for earning the trust of end-users. Security and trust must be prioritized in the design and operation of these services.

- **Providing comfort through telemonitoring**: Telemonitoring allows patients to receive care in the comfort of their homes, reducing the stress associated with traveling to healthcare facilities. It is important, however, to strike a balance between care at home and necessary visits to the hospital.
- **Addressing workforce shortages through telemonitoring**: Telemonitoring can help address the shortage of healthcare professionals and the long waiting lists for accessing care. This is especially important as the demand for healthcare professionals is expected to increase due to the aging population.
- **Integrating telemonitoring into cancer care pathways**: Telemonitoring should be better integrated into cancer care pathways to improve patient outcomes and streamline care processes.
- **Targeting the Children, Adolescents, and Young Adults (CAYA) population**: Young people are generally more receptive to new technologies, making them an ideal target group for telemonitoring interventions.
- **Referring to telehealth and telecare rather than telemedicine**: Using the terms "telehealth" and "telecare" is preferable, as they encompass a broader range of services beyond just medical interventions.
- **Balancing telemonitoring with in-person visits**: Telemonitoring should be used for simpler healthcare needs, while more complex issues should still be addressed during in-person visits.

6. Roadmap implementation

This chapter focuses on identifying actions that would be needed to implement the recommendations formulated in the previous chapter of this roadmap. The identification in question occurred based on the input received from twelve of the members of the eCAN JA Governmental Board (representing Austria, Belgium, Croatia, Cyprus, Czechia, Denmark, Hungary, Luxembourg, Malta, Norway, Slovakia and Spain), who were asked to reflect on the steps required to act on these recommendations, during a second dedicated virtual Governmental Board meeting as well as a series of eight subsequent bilateral calls between some of them individually and representatives of the eCAN coordination team. An overview of the concrete actions they proposed on the basis of their national experience categorised by recommendation as well as intervention area is provided in Table 7. It should be highlighted that the table offers a broad perspective, listing general actions that could be taken across the EU as a whole. However, since different countries have integrated telemedicine into their healthcare systems to varying degrees, not all actions may be equally relevant for every MS. It should be mentioned that the vast majority of these actions are targeted at national policymakers and that the role of the private sector was not fully explored here as a result of the restrictions imposed on the engagement of Joint Actions with commercial entities. Being an important group of stakeholders, manufacturers of telemedicine applications and tools could contribute significantly to the implementation of the recommendations, whether alone or in collaboration with other healthcare actors. It must also be specified that a new European project, the JA eCAN+, will start in 2025 which will already tackle some of these recommendations.

The following table (Table 7) presents an overview of potential actions that could be taken to implement the eCAN JA roadmap recommendations according to the eCAN JA Governmental Board. Note that these actions are based on the national experience of the members of the Board and do not necessarily reflect the opinion of the eCAN consortium. Recommendations that are underlined will be addressed in whole or in part within the context of the JA eCAN+.

Intervention area	Recommendation	Potential actions
Regulatory, governance and policy framework	**Prioritization of telemedicine by decision-makers for its integration into health and care systems**	Devise and put in place a dedicated digital health strategy that is evidence-based, enables the systematic consideration of digital solutions to address challenges in the provision of healthcare, and includes telemedicine as a priority area, with defined indicators to track progress towards achievement of objectives Assign the responsibility of implementing telemedicine services to a specific health authority Allocate a dedicated budget to the implementation of telemedicine services that takes into account their multidisciplinary nature by transcending existing budgetary siloes Develop and put in place a generalised telemedicine platform at the national level
	Developing guidelines addressing privacy, data protection, and patient rights aligned with GDPR	Assemble a multidisciplinary working group to develop the guidelines in a bottom-up fashion, including legal experts, patient advocates, hospitals' data protection officers, and medical societies Consider the guidelines as living documents, regularly reviewing and updating them Ensure that essential patient rights such as the right to informed consent and the right to access medical records are covered Ensure that specific privacy and security risks associated with telemedicine such as data breaches are addressed
	Enacting clear rules and legislation with respect to telemedicine services	Introduce a system of financial incentives for hospitals to provide telemedicine services Let healthcare insurance companies set the rules for reimbursement of telemedicine services Establish clear and fair reimbursement mechanisms for telemedicine services Move away from relying on temporary emergency measures adopted during the pandemic and adopt a standard legal framework Enshrine the definition and modalities of telemedicine and the associated criteria for data protection and privacy into a specific law, establish this law's scope of

		application to specify which healthcare services can be delivered remotely and under which conditions, and potentially foresee a transition period to smoothen the implementation Ensure alignment of telemedicine legislation with other relevant laws such as the GDPR Address legal and regulatory barriers hindering cross-border provision of telemedicine services Monitor and evaluate on a regular basis the implementation of telemedicine legislation and make adjustments to the law when necessary Determine the necessary qualifications and licensing requirements for healthcare professionals providing telemedicine services, ideally at an international level to facilitate the cross-border provision of such services Set standards of care for telemedicine services, ensuring that they are equivalent to in-person care Define technical requirements for telemedicine equipment to ensure its quality
Collaboration and stakeholder engagement and awareness	**Establishing a collaborative framework with stakeholders for comprehensive telemedicine integration**	Create multiple thematic working groups that each address different aspects of telemedicine integration, but operate under an overarching governance structure Create a single multidisciplinary working group with involvement of regulatory authorities, healthcare providers, payers, manufacturers and patients that evaluates reimbursement requests Identify key stakeholders and establish communication channels with them based on a pre-formulated strategy in the form of a communication plan Pilot the framework and adjust based on the results observed before scaling it up
	Engaging patients in the design and testing of telemedicine services	Establish clear rules on engaging patients during the conceptualisation and implementation of telemedicine solutions Provide support for patient engagement through organisation of patient fora and setup of a patient platform

		Tailor telemedicine services to patient needs identified and ranked in order of priority during co-creation workshops Recruit a diverse group of patients Measure satisfaction levels of patients engaged
	Focusing on access to digital health technologies and improving health literacy for all demographics	Offer elderly citizens courses on how to use digital tools taught by instructors of the same age group Ensure equitable access to telemedicine services by requiring telemedicine apps to be made available on all operating systems, setting up programs to provide patients who cannot afford smart devices with such devices, and ensuring that every citizen has access to broadband services, whether living in an urban or rural area Digitise public administrative services so that they are accessible online Measure health literacy levels of the population as part of national health surveys to establish a baseline and allow for more targeted interventions Develop clear and accessible health information using culturally sensitive and age-specific messaging Assess current access barriers to telemedicine by reaching out to and engaging with the patient community
Infrastructure and technology development	**Providing technological support and equipment to end-users**	Rely on support services offered by the manufacturers Develop a business plan outlining how centralised technological support services would be funded and how they would operate Ensure that there are different lines of technological support: a first line addressing basic support needs at local level, and a second line covering more difficult requests at regional or national level Monitor the use of technological support services and/or equipment and gather feedback from users
	Developing telemedicine platforms with interactive interfaces to	Consider user-friendliness and interactivity as criteria when evaluating whether specific telemedicine interventions should be reimbursed or when launching a telemedicine-related tender

	provide more engaging and personal experiences	Ensure that there is an interactive chat environment available where patients can ask questions, potentially by incorporating chatbots driven by artificial intelligence Integrate a link to the future European Cancer Patient Digital Centre into the platform so that patients can make use of the resources offered by the Centre Tailor the degree of interactivity to the specific care context Personalise the user interface in accordance with a user-centred approach Ensure the design is inclusive of all user demographics Make use of gamification techniques to keep users engaged Continuously improve the platform based on feedback received and tests performed
	Ensuring the development of a solid IT infrastructure and the exchange of standardised data supporting the uptake of telemedicine services and the primary and secondary use of telemedicine data within and between the EU Member States	Ensure that all hospitals are connected to the same IT backbone Standardise data flows through the implementation of data standards like HL7 FHIR and OMOP to ensure that telemedicine data are interoperable with the data from patients' electronic health records Establish technological standards and data exchange protocols for telemedicine platforms Set up public-private partnerships to allow for collaboration between health authorities, hospitals, manufacturers and electronic health record vendors on achieving interoperability of telemedicine and electronic health record data Ensure that any telemedicine platforms developed by the private sector are compatible with the national IT infrastructure, if any such infrastructure exists Develop a platform that allows for storage, advanced processing and large-scale analysis of health data in general, including telemedicine data Promote cross-border cooperation and standardization for infrastructure development

		Monitor the deployment of the IT infrastructure and make improvements if necessary
Training and education	**Implementing strategies to enhance patient openness, including support and assistance for using telemedicine effectively**	Provide guidance and training to patients both before and after they undergo telemedicine interventions Focus on the primary care setting for patient training activities by involving general practitioners and social workers Offer training courses for older patients and assist them with the digital management of their health Work with patient organisations and involve them early on in the process of designing telemedicine services so that there is shared ownership and they encourage their members to use these services Develop multilingual educational resources, including step-by-step guides and video tutorials, accessible via an online patient resource centre Establish a patient support helpline Create a patient ambassador programme Monitor and evaluate the effectiveness of training programmes
	Offering specialized training and resources to healthcare providers and care givers to assist patients in adopting technology	Provide guidance and training to healthcare providers both before and after they administer telemedicine interventions, including one-on-one support in the form of personalized sessions for those who may need additional help or have specific questions Focus on the primary care setting for healthcare provider training activities by targeting general practitioners Set up collaborations between health authorities and universities to ensure that the use of telemedicine is integrated into the curricula of nurses, doctors and other healthcare professionals Establish a network of medical universities and universities of applied sciences to exchange on the development of curricula which provide certifications Provide healthcare professionals with materials to facilitate the discussion on telemedicine opportunities with their patients

		Define minimum requirements for digital skills for various healthcare professions Establish specialised training offices in hospitals Train hospital managers and department heads on digital transformation processes and change management through hybrid teaching courses in digital leadership Involve experienced healthcare professionals as ambassadors and organise train-the-trainer sessions Establish an online platform as a community for caregivers to share experiences, challenges, and solutions related to technology adoption Monitor and evaluate the effectiveness of training programmes
	Enhancing digital health literacy among patients, caregivers and healthcare providers	Introduce a multi-level transversal training programme for patients, healthcare providers and caregivers to improve their digital health literacy through workshops and webinars and establish support structures and centres for this purpose Measure digital health literacy levels of the population as part of national health surveys to establish a baseline and allow for more targeted interventions Gather insights from patients, caregivers and healthcare providers to understand their challenges and needs regarding digital health tools
Implementation and integration into healthcare systems	**Addressing hospital workload challenges to facilitate telemedicine implementation**	Collect data to demonstrate that telemedicine services can reduce hospital workload and could potentially replace in-person care in certain settings Communicate to hospitals and healthcare providers that there is a learning curve and that the workload may temporarily increase in the beginning Compensate for steep learning curve and additional time spent to give explanations to patients by providing higher payments to healthcare providers in the first months of the implementation of telemedicine services Rely on automated data transfers and notifications to reduce need for manual actions from healthcare professionals

		Map existing hospitals work flows to see how telemedicine services can be optimally integrated into them in a complementary fashion Highlight virtual molecular tumour boards as a use case to demonstrate how digital tools can reduce healthcare professionals' workload Ensure a phased and gradual implementation
	Utilizing telemedicine for follow-up monitoring and consultations in and outside hospitals (role of telemonitoring and teleconsultations and their interplay with in-person visits, need for more behavourial and cultural insights research) for evidence-based integration into the care pathway	Identify care pathways where there is a need for telemedicine interventions, where evidence for their effectiveness is available, and where stakeholders are interested in change Provide reimbursement for telemedicine-incorporating care pathways as a whole rather than for individual telemedicine interventions Ensure that reimbursement conditions do not favour telemedicine services over in-person care, leaving the choice to the patients and their healthcare providers as much as possible Define clear criteria for the use of teleconsultations, including that there needs to be a pre-existing relationship between the healthcare provider and patient, that both parties agree to this use, that the healthcare provider considers these teleconsultations medically appropriate Take into consideration the needs and preferences of patients Come to an agreement with healthcare professionals on how much they can be compensated for providing telemedicine services and adjust compensation basis over time if necessary
Evaluation and continuous improvement	**Defining clear metrics and evaluation criteria before telemedicine implementation**	Define common evaluation criteria at the European level, while leaving open the possibility of tailoring them to the national context Ensure that the outcome measures are carefully chosen in advance and adapted to the specific context of care, not just looking at clinical but also organizational and patient-reported metrics

		Make use of established evaluation frameworks and models that incorporate patient perspectives (e.g. MAST, Model ASsessment of Telemedicine)
	Conducting thorough evaluations of health outcomes of new telemedicine services before and after integration	Conduct pilots before implementing telemedicine interventions at the healthcare system level Conduct health technology assessments of digital health technologies, looking at a variety of outcome measures Collect and analyse relevant secondary data before upscaling the implementation of telemedicine services Define process indicators and follow up on them during the integration process Report on the results of evaluations and implement quality improvement measures if necessary

Table 7: Overview of potential actions that could be taken to implement the eCAN JA roadmap recommendations according to the eCAN JA Governmental Board

Conclusions

In this document, a key deliverable of the Joint Action eCAN, we have explored the integration of telemedicine services within EU health systems in a strategic manner, by providing an overview of current telemedicine practices, envisioning a future where these practices are widely used and their use is broadly supported, and outlining steps that need to be taken to realize this vision. Based on insights obtained from undertaking literature reviews, surveys, focus group discussions, pilots, and a foresight workshop, we formulated sixteen recommendations for shifting towards a scenario where telemedicine is part of routine cancer care, across six critical areas. Representatives of health authorities from different European countries found these recommendations to be relevant, and proposed actions that could be taken to implement them, relying on the experience in their country. We encourage stakeholders from each EU Member State to contribute towards this implementation by carefully reviewing the eCAN roadmap and taking the recommended measures to stimulate the acceptance and uptake of telemedicine. National policymakers in particular can play a major role in this regard by launching or funding relevant initiatives. At the European level, the Joint Action eCAN+, a new project that will be launched in 2025, will give us the opportunity to build on our work in eCAN and take up and address several of our recommendations already.

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Annexes

Intervention areas	Process Methods, strategies and actions	Output Immediate results of actions	Outcome Ultimate aim
Regulatory, governance and policy framework	• Learning from the pandemic for sustainable transformation in healthcare • Leveraging regulations like EHDS to overcome policy barriers • Prioritization of telemedicine by decision-makers for its integration into health and care systems • Enacting clear rules and legislation, combined with timely and targeted communication efforts • Developing guidelines addressing privacy, data protection, and patient rights • Building on existing policy support for digital health services • Harmonizing telemedicine protocols across Europe • Identifying GDPR-compliant technological platforms	• Creating the transition from labour-intensive models to technology-integrated health services across the EU • Establishing a clear legal framework on telemedicine development and integration • Facilitating cross-border exchange of telemedicine data in the EU	• Improved healthcare through telemedicine, both within the EU Member States and across the EU borders
Collaboration and stakeholder engagement and awareness	• Working jointly with national and regional units or ministries • Collaborating at national and European levels for digital health strategies • Establishing a collaborative framework with stakeholders for comprehensive telemedicine integration • Implementing initiatives aimed at reducing socio-economic barriers • Engaging patients in the design and testing of telemedicine services • Focusing on access to digital health technologies and improving health literacy for all demographics	• Designing telemedicine services to be user-friendly and accessible to all • Integrating the concept of health equity into telemedicine solutions • Increasing the acceptance of telemedicine integration into the EU health systems	• Widespread adoption of user-friendly telemedicine services for equitable healthcare
Infrastructure and technology development	• Offering telemedicine services in multiple languages • Providing technological support and equipment to end-users • Developing telemedicine platforms with interactive interfaces to provide more engaging and personal experiences	• Ensuring the development of a solid IT infrastructure and data exchange that supports the use of telemedicine services and data within and between the EU Member States • Ensuring broader access to telemedicine in the population	• Telemedicine infrastructure in the EU with user-friendly technology and secure data exchange for primary and secondary use

Intervention areas	Process Methods, strategies and actions	Output Immediate results of actions	Outcome Ultimate aim
		• Creating technical infrastructure with end-users in mind	
Training and education	• Investing in communication campaigns to address patient openness and cultural resistance • Implementing strategies to enhance patient openness, including support and assistance for using telemedicine effectively • Offering specialized training and resources to healthcare providers and care givers to assist patients in adopting technology • Offering trial periods for telemedicine services • Integrating IT and digital health education into school curriculums • Communicating clearly that telemedicine complements, not replaces, face-to-face consultations	• Enhancing digital health literacy among patients, care givers and healthcare providers • Ensuring health professionals are thoroughly trained and familiar with telehealth platforms • Facilitating a cultural shift at all levels to fully embrace telemedicine	• Empowered end-users driving the widespread acceptance of telemedicine
Implementation and integration into healthcare systems	• Prioritizing the integration of telemedicine into existing hospital systems • Addressing hospital workload challenges to facilitate telemedicine implementation • Leveraging telemedicine for early disease detection and prevention • Utilizing telemedicine for follow-up consultations in hospitals after initial results • Implementing specialized telemedicine services for disadvantaged individuals • Adhering to ethical principles for digital health • Implementing pilot projects • Building telemedicine implementation gradually in challenging environments • Defining clear metrics and evaluation criteria before telemedicine implementation • Conducting thorough evaluations of health outcomes of new telemedicine services before integration	• Reducing the potential resistance among end-users towards telemedicine • Ensuring ethical and equal use of telemedicine • Providing evidence-base to scale-up telemedicine services	• Smooth transition to telemedicine services in healthcare organizations when and where necessary
Evaluation and continuous improvement	• Addressing barriers and evaluating progress in overcoming them through investigation and patient involvement	• Implementing continuous evaluation mechanisms for digital	• Continuously evolving and learning system for

Intervention areas	Process Methods, strategies and actions	Output Immediate results of actions	Outcome Ultimate aim
	• Capturing different trends for cross-border telemedicine services in the EU • Learning from countries using telemedicine and sharing experiences	health services towards cross-border care • Developing strategies to improve the existing system • Supporting evidence-informed policy-making	better health outcomes with telemedicine services

Supplementary Table 1: strategies to implement telemedicine services