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E-Health4Cancer



# Good Practices Guide

## E-Health4CANCer



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E-Health4Cancer



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# 01

# CONCLUSIONS

Across the globe, digital landscapes are shifting rapidly. New stakeholders, technologies, and needs are contributing to both a plethora of possibilities and a chaos of combinations. Currently, for cancer care in Europe, this potential and possibilities may lead to faster development and evolution of new technological pathways and options, but in many cases this potential is in fact challenged by the goldrush nature of this digital awakening. This fast development phase challenges all the possible potentials, whether this is seen from a patient and caregiver perspective, or as a healthcare professional (HCPs) or from a health system perspective.

For both health systems and policy makers, some of the following findings should be considered in building additional frameworks for future digital health tools and strategies:

## **1. Fragmentation leads to confusion**

From all our interviews, a common denominator mentioned is the low level of coordination across sectors, borders, and authorities. Fuelled by both a need for innovation and pressures on existing systems and resources, a lot of different stakeholders are developing and offering

solutions, often fuelled by internal needs (see below) rather than patient perspectives or needs. This fragmented approach often leads to low interoperability of tools and systems and thus adds to confusion rather than usability for both patients and caregivers that are trying to navigate both diagnosis, treatment, life, rehabilitation, digital ID, calendars, and more.

**Suggestions:** Additional studies from a patient pathway/perspective to better integrate solutions would be a good idea – some are already beginning to be used like the Danish sundhed.dk or the Norwegian-led Nordic Interoperability Project, but are yet often limited in scope or so far only applied to a wider digital strategy than cancer.

## **2. More ≠ better**

Considering the diversity of digital evolution, another finding in this context is also that more is not always better. In Denmark, while the interviewees reported a high number of tools being offered, this did not lead to an easy or useful interaction between the tools and platforms; patient and caregiver would still struggle to find clarity, coordinate or schedule appointments, share relevant data between



digital systems, or sometimes even access them as different ID and/or password systems made practical use cumbersome. This challenge could easily be exacerbated by simply encouraging more digitalization.

**Suggestions:** Interoperability as key requirement based on a user-centric approach. Ensuring a common data/access platform (using perhaps a platform that offers a modular expansion as common base for all national initiatives) would help. However, this needs to be supplemented by a cross-platform approach, so tools and information does not skip in a confusing mix of apps, websites, tele-services or across tablets, phone, computers, call-in etc.

### **3. No sustainability – no progress**

Many initiatives are built based on project funds or singular initiatives. They are left with a time-limited funding for development, little for continued service, and next to nothing for later upgrades or expansion. And are not integrated into reimbursement models.

And as maintenance and running costs continue, this leads to a lot of go-stop development stages where new ideas appear only to vanish or to die slowly without support. This leads to a lack of experience from both users, digital developers, or systems on how to further expand previous learnings into better models, better design, expansion, or upgrades – instead new solutions (sometimes more or less identical in design, usefulness, and flaws) are built in new projects or initiatives. This leads to a loss of experience and useful performance data that could have helped both research, quality of care, and system insights to evolve. It also leads to

indirect bias or gaps as new solutions use slightly different user assumptions than the previous as there's little data to guide them. Currently this is also very clear in shifting uses of information media across generations: lack of data from younger users leads to significant emphasis on text-based platforms (websites or apps – the “old” gold standard) and less so on audio-visual platforms or content. This lack of digital barrier also risks creating a lower adaptability among information systems and/or individual HCPs towards emerging digital cultures and a shrinking of actual access to trustworthy, knowledge-based information.

**Suggestions:** Design project funding with a specific tapered funding stream for continued use/implementation. Re-assess reimbursement/funding models to ensure funding for digital upgrades rather than reinventions. Health models can be inspired by a generalised pool built by a kind of Tobin Tax – a small, but specific funding stream, that ensures a path for evolution and not just continued attempts at innovations that fizzle.

### **4. Solving what, for whom?**

There is clear indication that several digital solutions are built to extend service performance or reduce systems burdens. And while this is a valid point for any health care investments, it can often lead to a lack of user focus and thus not deliver on the potential of the investment. Unless new systems lead to better (including ease of access) services, they risk being another challenge for these vulnerable groups, with an added risk of also perplexing HCPs and thus lead to frustration and burnout. So, making sure new tools are interoperable,



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integrated into existing systems, easy to access for all kinds of users, and lead to a reduction of workload for both HCPs and/or informal carers becomes paramount in new digital strategies. And new tools can likely only be introduced in a pace that existing digital literacy and capacity can support.

**Suggestions:** The initiative of the Greek Digital Ministry to build a Digital Skills Academy has strong potential for adoption in other European countries. By building a Digital Academy and adding an incentivization scheme (positive like microcredits and awards, not punitive) this can build user skills on all sides. At the same time, time to enable true co-designed development processes needs to be at the core. The former AAL project enabled a series of tools to ensure stronger user-based processes for digital design and development – these can and should work as inspiration for new requirements at European level.





# 02

# CARE FOR CANCER IN A DIGITAL AGE

In recent years, digital technology has transformed the landscape of caregiving. Digital tools have emerged as powerful aids, offering innovative solutions to address the diverse needs and challenges faced by informal carers. From providing access to reliable information and resources to facilitating communication with healthcare professionals and support networks, these tools have the potential to enhance the quality of care and bolster the well-being of both carers and patients.

Advancements in digital tools can thus also yield significant benefits for cancer patients in Europe, enhancing the support systems for both patients and informal carers. These tools can directly and indirectly contribute to improving the overall well-being and quality of life of cancer patients.

Across Europe, informal carers play a pivotal role in the care and support of cancer patients. Typically comprising family members or close friends, they offer invaluable emotional, practical, and sometimes medical assistance to their loved ones throughout their cancer journey. However, being an informal carer can be emotionally taxing and physically demanding, requiring a delicate balance between caregiving responsibilities, and maintaining one's own well-being.

Recognizing the importance of leveraging digital tools to support informal carers and cancer patients alike, this Good Practices Guide can provide insights, recommendations, and actionable strategies for the effective use of digital technologies in cancer caregiving in Europe.

Compiled with contributions from healthcare professionals, researchers, technology developers, and crucially, informal carers, this guide offers a comprehensive overview of the digital landscape and highlights best practices for optimising the use of digital tools.



Through a series of expert interviews, this guide presents a selection of useful case studies and insights that leads to practice-based recommendations. As part of these interviews, we will explore various aspects of digital caregiving support, including:

- **Information and Education:** How digital platforms can empower carers with relevant and up-to-date information about cancer, treatment options, symptom management, and available support services.
- **Communication and Coordination:** Strategies for using digital tools to facilitate communication and collaboration among carers, patients, healthcare providers, and other members of the care team, ensuring seamless coordination of care.
- **Self-Care and Well-being:** The role of digital technologies in promoting the well-being of informal carers, including stress management, self-care routines, and access to peer support networks.
- **Practical Support:** Innovative digital solutions that streamline caregiving responsibilities, including the organisation of appointments, medication regimes, and access practical assistance such as transportation and financial support.
- **Ethical and Legal Considerations:** Guidance on navigating ethical and legal issues, including privacy, data security, informed consent, and the ethical use of digital health technologies in caregiving.

By offering practical insights and actionable recommendations, the content and findings in this Good Practices Guide aims to empower cancer patients, informal carers, healthcare professionals, policymakers, and technology developers to harness the full potential of digital tools in supporting the invaluable contributions of carers to the well-being of cancer patients across Europe.

Through collaboration, innovation, and a shared commitment to improving the caregiving experience, we can work towards creating a more supportive and sustainable ecosystem for informal carers in the digital age.



## Digital aspects of better cancer care

Overall, leveraging digital tools in supporting cancer patients and their informal carers offers a wide range of benefits that enhance the caregiving experience, improve outcomes for both carers and patients, and contribute to a more sustainable and supportive caregiving ecosystem.

1. **Enhanced Communication:** Digital tools improve communication between patients and their caregivers, helping them to better articulate their needs, concerns, and preferences. This fosters a sense of empowerment and active involvement in their own care decisions.

2. **Access to Information and Resources:** Patients can leverage digital platforms to access dependable information about their condition, treatment options, potential side effects, and self-care strategies. By empowering patients with knowledge, these tools enable them to make more informed decisions about their care and treatment journey.

3. **Increased Social Support:** Digital tools connect patients with support networks, online communities, and peer-to-peer platforms where they can share experiences, seek advice, and find emotional support from others who understand their journey firsthand. This sense of belonging and connection can alleviate feelings of isolation and loneliness commonly experienced by cancer patients.

4. **Improved Symptom Management:** Certain digital tools, such as symptom tracking apps and telemedicine platforms, enable patients

to monitor their symptoms more closely and communicate changes or concerns with their healthcare providers in real-time. This proactive approach to symptom management can lead to early intervention, better symptom control, and improved overall health outcomes.

5. **Enhanced Care Coordination:** By facilitating communication and collaboration among patients, informal carers, and healthcare professionals, digital tools streamline care coordination processes. This ensures that patients receive holistic, patient-centred care that is tailored to their individual needs and preferences.







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## **6. Empowerment and Self-Management:**

Digital tools empower patients to take an active role in managing their health and well-being. Through features such as medication reminders, appointment scheduling, and self-care tips, patients gain a sense of control over their daily routines and treatment regimens.

## **7. Remote Monitoring and Follow-up Care:**

Telehealth platforms and remote monitoring devices allow patients to receive certain aspects of their care from the comfort of their own homes. This reduces the need for frequent hospital visits, minimises travel-related stress, and promotes greater convenience and accessibility to healthcare services.

By leveraging digital tools to address the diverse needs of cancer patients, we can enhance their overall care experience, promote better health outcomes, and empower them to navigate their cancer journey with confidence and resilience. Thus, as we strive to improve support for informal carers, it's imperative to recognize and prioritise the holistic well-being of cancer patients themselves.

# 03

## A GOOD PRACTICES GUIDE

The Good Practices Guide has been developed as part of the Erasmus+ project, E-Health Solutions for Cancer Patients and their Caregivers (2022-2-EL01-KA210-ADU-000097120). Its core objective has been to assess the current state-of-the-art digital tools of nonclinical support for cancer patients and their caregivers in EU countries, with a specific focus on those represented by the 'E-Health4Cancer' project partners, that is, Italy, Greece, Denmark.

This has been done through a multifaceted approach. The University of Naples (UNINA) led a systematic literature review on e-health solutions in Europe, whereas all partners including University of Naples (UNINA), Cancer Guidance Center (Kapa3), Greek Carers Network (EPIONI), and the Danish Committee for Health Education (DCHE) collected expert views from health-care associations and practitioners from partner countries, so as to identify the main gaps in support that adults affected by cancer and their caregivers receive. The Good Practices Guide is a direct result of the collaborative efforts of project partners and the sharing of useful initiatives in nonclinical cancer e-health solutions that can improve the quality of life of patients and caregivers alike.

In an ideal world, access to healthcare, and by extension, access to digital health tools, would be easy and timely enough to optimise both healthcare system performance, user satisfaction, and the overall quality of care. In a digitalised era, cancer patients and their caregivers would have access to a wide range of support services, educational resources, and self-care tools to enhance their quality of life, improve treatment outcomes, and navigate the challenges of cancer care more effectively.

But as care or information needs, resources, and rates of technological development and evolution vary across and within countries, the digital tools available can be highly diverse in focus, usability, and scope. This not only can create the structural basis for generating or perpetuating health inequalities, but also leads to challenges in terms of building digital strategies for care as the current level of care or information needs across countries, communities, or patients varies immensely. To a wide degree, these aspects are also reflected in our findings, presented in this Good Practices Guide.



## Good vs Best

A "good practice" can be defined as a method, an approach, or a strategy that has been demonstrated to be effective and beneficial in achieving a particular goal or addressing a specific challenge within a given context. Unlike "best practices," which typically represent the highest standard or most optimal approach, good practices are acknowledged for their reliability and success within a specific setting or circumstance. In a situation that is challenging in terms of needs, technological possibilities and practical implementation, promoting good practices, as opposed to solely focusing on best practices, can be beneficial for several reasons:

- Context Sensitivity: Good practices are often more adaptable to diverse contexts and varying resource constraints. They can be tailored to suit specific needs and conditions, making them more applicable and feasible in different settings.
- Incremental Improvement: While best practices may represent aspirational goals, good practices often reflect realistic and achievable steps toward improvement. By promoting good practices, organisations and individuals can make incremental progress and build upon existing successes over time.
- Flexibility and Innovation: Emphasising good practices encourages flexibility and innovation. It encourages exploration of alternative approaches and solutions, fostering creativity and continuous improvement.
- Local Ownership and Empowerment: Good practices are often developed and implemented by local stakeholders who possess first-hand knowledge of the context and community needs. Promoting these practices empowers local actors, fosters ownership, and strengthens community engagement and resilience.
- Learning and Knowledge Sharing: Good practices provide valuable learning opportunities for sharing lessons learned, exchanging experiences, and building collective knowledge. By promoting good practices, organisations and networks can facilitate peer-to-peer learning and collaboration, enriching the collective understanding of effective strategies.
- Resource Efficiency: Good practices are often more resource-efficient than best practices, requiring fewer resources and investments to implement while still delivering meaningful results. This makes them particularly valuable in resource-constrained environments.

In essence, while best practices represent benchmarks of excellence, good practices offer pragmatic, contextually relevant approaches that can drive meaningful change and improvement. By promoting good practices alongside best practices, organisations and stakeholders can foster inclusivity, innovation, and sustainability in their efforts to address complex challenges and achieve positive outcomes.

# 04

## SCOPE OF THE GOOD PRACTICES GUIDE

There are currently enormous, rapid advancements in the development of digital tools and systems. For the purposes of the Good Practices Guide, it is important to differentiate between digital tools intended for personal use among patients and caregivers, and those intended for derived use, such as machine learning or big data analytics, of health system support applications, like electronic health records (EHRs) or quality of care assessment tools.

As illustrated by the blue shape in the image below (adapted from the WHO), the scope of this Guide has been restricted to tools that an ordinary patient or caregiver would be independent/direct access to use; mHealth, Digital Health Literacy, Social Networks, and Telehealth solutions. In some countries, individual patients can access their own EHRs, but this is not the case everywhere across EU countries. For the purposes of this Guide, we have decided to focus on the tools and categories that are directly intended for patient/caregiver support at any stage of the care process.





# 05

## METHODOLOGY FOR THE GOOD PRACTICES GUIDE

### Definitions and Scope

The project partners initially did a thorough review of assessing relevant types of digital tools to build a Guide for data gathering in the three partner countries. A digital tool can be defined as any software application, platform, or device that utilises digital technology to perform a specific function, task, or service. These tools leverage digital data, algorithms, and computational processes to enhance efficiency, accessibility, and effectiveness in care or wider communication. This resulted in the selection of the following categories of digital tools to focus on:

- Websites (including navigation support tools)
- Mobile Apps
- E-learning
- Online support groups for patients and/or carers
- Blogs/Vlogs
- Medical technology with automated feedback (e.g., tracker devices)
- Telemedicine with or without video consultation

For each country, our main interest for gathering Good Practices was a focus on practice – to learn what kind of tools are accessible and in wider use, and on the experiences of users, patients, caregivers or other professionals when using those tools and in relation to cancer care.

In terms of services, our data collection was inclusive, embracing a broad spectrum of services provided via the platforms in question. We have thus collected practices of telemedicine, health monitoring and symptom tracking (including remote tracking), educational or informational, care supportive (including nutrition, exercise, stress management, and mental health), process supportive (including appointment management and care coordination), peer or community support and also end-of-life / palliative care support. Some tools examined multiple of these services – others are dedicated to a single purpose.



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## Interviews

In order to gather information, we decided to conduct semi-structured qualitative interviews with stakeholders in our three partner countries; Denmark, Greece, and Italy. For each country, we proactively sought to ensure the representation of a clinical perspective, a patient organisation's, and a digital developer's.

The Danish Committee for Health Education (DCHE) developed an interview guide for the four partners to use. Three experts per country were identified in Denmark and Italy, while four experts were identified in Greece, giving a total of 10 expert interviews. The interviews were conducted in local languages via digital meetings, then each partner entered interview data in English into a joint survey data system in order to gather and analyse.

The interviewees were asked a few initial questions related to their background and were then asked to both identify and rate digital tools for cancer that would fall into the following categories: Websites, Apps, E-learning, Online Support, Blogs, MedTech, and Telemedicine.

The interviewees were asked to share their views regarding the quality, usability, popularity, and impact of identified tools, and on the general approach and evolution of cancer care digital tool development in their country – to the best of their knowledge.

The interviewees were also asked to reflect on what they might hope will exist in the future in their country, thus adding an extra element to gathering expert input on existing good practices, which was to reflect on the rising needs of digital care for cancer and beyond.

These results were gathered and are shown in the following sections. Based on the data gathered and the comments provided by the interviewees, the consortium partners assembled the conclusions found in the end of the Guide.



# 05 RESULTS

Our 10 expert interviews gave a breath of data. We here present several digital tools from different categories identified by experts. We provide a description of each tool and a score given by the interviewees, which indicates how good the given digital tool is. Further, we also present a series of challenges faced in e-health for cancer in the three project countries and at European level, as well as a number of ideas/suggestions for improved digital cancer care services in the future.

The interviewees were asked to rate the digital tools that they mentioned in the interview on a scale of 1-5 (5 being best) based on aspects such as usability, accessibility, level of professionalism etc. The aim of having the interviewees assign a score to the digital tools was to get an indication of how good each tool is (according to the interviewee who mentioned the tool). A few of the e-health tools included in the tables below have not been scored by the given interviewee. In these cases, the tools have been marked with "a score was not assigned by the interviewee". Additionally, a few of the tools were not described by the interviewees and have therefore been marked with "no description was provided by the interviewee".

## Websites

From the 10 interviews we found a number of websites mentioned:

Name	Description	Score (1-5)
<a href="http://www.cancer.dk">www.cancer.dk</a> (DK)	Providing information on a general national scale.	4
<a href="http://www.Unobravo.it">www.Unobravo.it</a> (IT)	Online psychological paid service.	5
<a href="http://www.aimac.it">www.aimac.it</a> (IT)	Aimac is the main point of reference in the support of cancer patients in Italy.	5
<a href="http://www.regionh.dk">www.regionh.dk</a> (DK)	Local website targeted at residents in the Capital Region of Denmark.	4



## Apps

Name	Description	Score (1-5)
MinSP (DK)	An app for patients and informal caregivers at hospitals in the capital region of Denmark and region of Zealand.	2
Kapa3 (GR)	Information about the rights and solutions for social and economic problems which patients/informal caregivers may encounter.	5
My Alma (GR)	Information about the rights and some recommendations for patients with breast cancer.	5
Liven: Building Habits (IT)	A free habit app designed to enhance the quality of life by providing scientifically backed tools for self-discovery and personal development. The interviewee rated it 2 out of 5 because it is a recent app that is not well-established yet.	2
Meditopia (IT)	Meditopia represents the most complete and largest collection of meditation and mindfulness exercises to improve motivation, reduce stress and anxiety and fight insomnia for free.	4



Name	Description	Score (1-5)
Health Vademecum, Pianetaseno (IT)	Regarding mobile applications, Pianetaseno, is the point of reference for all those who want to correctly inform themselves about the prevention of breast cancer and what is made available by the National Health System in relation to this objective.	4
NUTRIENT (IT)	NUTRIENT allows the patient access to textual and multimedia content that responds to the most immediate nutritional needs (poor appetite, difficulty swallowing, increased energy needs, intestinal problems, etc.), but also to the desire for information regarding diets and nutritional behaviours, screw styles or even just to get answers to questions on the subject, aimed at dispelling the so-called "false myths".	3
Curia (IT)	Offers cancer patients the possibility of accessing accurate and structured information in an individualised way thanks to a questionnaire on their clinical picture. Artificial intelligence, monitored by a qualified team, collects information on therapies, clinical studies and experts from accredited sources, such as drug regulatory agencies and international clinical trial registries, keeping it constantly updated.	5
UngeKræfter (DK)	UngeKræfter, which provides this group of adolescents with the opportunity to access the community at any point in time during the day. The app was created in a co-creation process which included adolescents with cancer from Kræftværket and the app-development company DAMAN.	A score was not assigned by the interviewee.



## E - learning

Name	Description	Score (1-5)
<a href="https://ellok.org">https://ellok.org</a>	No description was provided by the interviewee.	A score was not assigned by the interviewee.
<a href="https://almazois.gr/programmata/seminaria-karkinos-mastou-apofasizw-giati-gnwrizw/">https://almazois.gr/programmata/seminaria-karkinos-mastou-apofasizw-giati-gnwrizw/</a>	No description was provided by the interviewee.	A score was not assigned by the interviewee.
<a href="http://www.Formazionecontinuaipsicologia.it">www.Formazionecontinuaipsicologia.it</a>	The first Italian learning community for online training and updating in Psychology and Psychotherapy.	5

## Online Support

Name	Description	Score (1-5)
Kræftværket (DK)	Community for young cancer patients - and empowerment.	4
BeStrong (GR)	Bestrong is a non-profit organisation which provides crucial information on issues related to cancer prevention as well as support to everyone with cancer experience. Also, it offers digital support via email and skype video chat and online support group for patients and carers.	4
Andos Velletri (IT)	The headquarter of Andos Velletri offers a private support group on Whatsapp with a psychologist to provide timely support of breast cancer patients.	5



## Blogs

Name	Description	Score (1-5)
Facebook groups - not specified (DK)	Facebook groups for patients/diseases (monitoring would improve the score).	3-4
Andos Onlus (IT)	Online forum moderated by clinician.	5
Facebook groups – not specified (IT)	Facebook group that is not moderated by an HCP.	1
Mattia Garutti (IT)	Mattia Garutti is an oncologist and nutritionist that opened his YouTube channel to share in an easy, intuitive and effective way some scientific truths about cancer and to share best practices in daily life that can help improve the quality of life of cancer patients.	A score was not assigned by the interviewee.

## MedTech

Name	Description	Score (1-5)
Rigshospitalet (DK) eg <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9577710/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9577710/</a>	Danish professors in PROMs at National Hospital have tested all kinds of popular digital devices - including intelligent clothing.	5
Softcare Studios (IT)	Italian startup of ehealth that develops VR experiences to manage pain without medications in patients during treatments.	A score was not assigned by the interviewee.



## Telemedicine

Name	Description	Score (1-5)
MinSP or other similar digital interactive tools (DK)	Standard solution for most General Practitioners in DK.	2-3
Andos and local authorities (IT)	During Covid Andos as well as local health authorities (ASL) offered some follow up telemedicine services made by clinicians but the patients reported a sense of loneliness and abandonment, thus as soon as the pandemic ended, they preferred to go back to traditional meetings with the doctors.	2

## Other

Name	Description
Elevate - Education with Continuing Education Credits (GR)	Information, Continuing Education
Social Media channels – Instagram, Facebook, TikTok, X (Danish Cancer Society)	We screen/recruit high-quality influencers to provide content. New site will have Instagram-integration to also provide live experience content. For the same reason we also utilise a lot of patient statements. They are good to help people realise they are not alone. We also have a TikTok responsible person that creates dedicated content - and similarly for Facebook. Sometimes also X. Strong organic reach via Facebook.



# 05

## GENERAL COMMENTS FROM THE EXPERTS

Below are general comments shared as quotes gathered from the interviewees. The overall feedback from these is the need for better information, better tutorials, as well as a call for more advanced tools to be deployed as technology allows.

“Public-Private Partnerships are needed. User Experience is still low - and the information is not personalised, e.g. difference in information targeted in age, social spheres etc - the digital back bone is there, but the implementation is too often left to individual HCPs (with little digital experience) to design. So better, stronger digital design would benefit everyone. Huge differences between types of solutions. But models for innovation and less silos would be good” (DK)

“There is a need for services and information targeted at informal caregivers of people with cancer” (DK)

“Public hospital resources” (GR)

“More cooperation between clinicians and patient organisations would be good” (DK)

“Yes, many of them...for example interoperability of the information about cancer and rights of the patients, how to solve socio economic problems about the patients and the caregivers.” (GR)

“There is a need for better telemedicine, and cancer specific mobile applications” (GR)

“As far as I know, and due to my work (in previous years as a community pharmacist and now as a research assistant), there are many applications being developed within the framework of projects (like Horizon or Joint Actions). However, I really can't recall any application widely used in Greece and known.” (GR)

“Wearable devices, such as smartwatches, have huge potential in remote monitoring and symptoms' prediction. However, the lack of comprehensive regulation can limit their full potential due to privacy concerns.” (IT)



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“There is a need for e-learning platforms to increase awareness on existing initiatives but also simple tutorials that can explain to elder people how to use them.”(IT)

“The German “Untire” app by “Tired of Cancer” helps cancer patients and survivors suffering from extreme fatigue, and is available also outside of Germany. The app contains a program to help users managing fatigue give tips and exercises to work on your energy level, based on clinically proven methods. The app addresses eight important themes: anxiety, worry, boundaries, sleep, nutrition, selfcare, activity and, of course, fatigue.” (IT)

# 06

## GOOD PRACTICES TO HIGHLIGHT

### **Kræftværket (DK)**

Kræftværket is a community for young Danes (age 15-29) with cancer who are receiving treatment at either Rigshospitalet or Herlev Hospital in Copenhagen. It is an opportunity for adolescents with cancer to encounter peers in an informal virtual (and physical) setting with the purpose of heightening their quality of life and focus on other aspects of their identity, rather than merely the cancer identity aspect. Encountering and establishing relations with other adolescents who have similar experiences, contributes to decreasing the feeling of loneliness and longing for a normal youth.

This virtual space/community also inspired an app called UngeKræfter, which provides this group of adolescents with the opportunity to access the community at any point in time during the day. It was the group of adolescents with cancer themselves who thought of creating an app for the community, as they would like to be able to “bring the Kræftværket-community along and keep it in their pocket”. The app was created in a co-creation process which included adolescents with cancer from Kræftværket and the app-development company DAMAN. The aim of the app is to; strengthen disease comprehension and management by using the app’s disease- and activity tracking device,

provide information regarding aspects of living with cancer (through the knowledge database of the app), create a community and decrease loneliness through the community aspect of the app. Originally, the app was developed on a local scale, targeted at the young Danes in the Kræftværket-community. However, the community wished for the app to be available to all adolescents who are going through cancer treatment in Denmark. From 2024, the app will be launched nationwide, while the target group will be extended to encompass 15–39-year-olds.

### **Curia (IT)**

Curia is an application (available for iOS and Android) that tries to do exactly this: it offers cancer patients the possibility of accessing accurate and structured information in an individualised way thanks to a questionnaire on their clinical picture. Artificial intelligence, monitored by a qualified team, collects information on therapies, clinical studies and experts from accredited sources, such as drug regulatory agencies and international clinical trial registries, keeping it constantly updated. And providing precise indications on how to move. The app has entered into a partnership with IncontraDonna Onlus, an association that deals



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with breast cancer prevention and it has been downloaded more than 1 million times.

## **Unobravo (IT)**

Unobravo is an Italian online psychological help that collects 4,000 psychologists and psychotherapists who belong to over 15 different therapeutic orientations. It is a paid service and employs a personalised questionnaire and an innovative matching system to pair patients with the therapist best suited to their unique needs and preferences. The interviewee rated it 5 out of 5 thanks to its efficiency and efficacy in enhancing mental health that is key from the diagnosis to the post cancer treatment as well as the well-being of informal caregivers.

## **MyAlma (GR)**

MyAlma is a free mobile application for every woman with metastatic breast cancer. It educates and supports women with metastatic breast cancer with all the necessary information, practical tips for daily life and gathers all the information about communication with support structures. It has been created by the Hellenic Association of Women with Breast Cancer "Alma Zois" and is available from Google play and the Appstore. The expert who was being interviewed on the matter stated, "I would recommend this tool to a cancer patient with metastatic breast cancer because it is specific for that type of cancer, offers all the later medical data and helps women to improve their quality of life through empowerment."

# 07

## **TOWARDS BEST PRACTICES: REFLECTIONS FROM THE 'E-HEALTH4CANCER' FINAL PROJECT MEETING IN THESSALONIKI APRIL 2024**

On April 5th, 2024, during the final meeting of the 'E-Health4Cancer' project entitled "Implementation of Digital Tools for Oncological Quality of Care – Barriers and Facilitators" in Thessaloniki, Greece, stakeholders in e-health and digital care, including health professionals, authorities, patients, caregivers, legal bodies, patient associations, and academic communities, were presented with a draft version of the 'Good Practices Guide'. The meeting attracted 237 participants, with 123 attending in person and 114 remotely.

After the meeting, participants were surveyed to measure their satisfaction with the event and their opinions on the Guide. The majority of respondents (total of 38) expressed optimism about its potential impact, with 75.7% anticipating a positive impact and 70% believing it will enhance digital tools for cancer care.

Regarding future digital health tools design, respondents (total n=38) emphasised the importance of digital tools being patient-centric (31%) and facilitating the work of health professionals (24%), while highlighting concerns about fragmentation leading to confusion (17%), no sustainability – no progress (16%) and that more tools does not equal better (12%).

When asked about priorities in digital cancer care, respondents favored equal access to digital tools and processes for all (19.4%), patient-centered design (19.4%), provision of high-quality digital tools to facilitate users (18.5%), improvement to health professionals' education (18.5%), empowerment of vulnerable groups (15.7%), and understanding internal structures and implementing new elements in the healthcare setting (8.3%).

Before and during registration for the event, participants were also asked to share their experiences on unmet needs in non-clinical digital health solutions. Key priorities identified included adapting to user needs, informing and training professionals and citizens, promoting participatory planning, ensuring user-friendly interfaces, providing free and accessible tools, prioritising continuous improvement, and addressing funding and sustainability challenges.



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## FINDINGS OF THE SYSTEMATIC LITERATURE REVIEW

To enhance the health literacy on digital non pharmaceutical care for supporting cancer patients in all the stages of their conditions, we decided to include a section of the Good Practices Guide to assess the current state-of-the-art of published scientific research on digital tools in European Union countries. Indeed, the University of Naples (UNINA) led a systematic literature review on existing studies on e-health solutions in EU as leading activity of their partnership within the Erasmus+ project, E-Health Solutions for Cancer Patients and their Caregivers (2022-2-EL01-KA210-ADU-000097120).

**Objectives:** In this systematic literature review, it has been tackled the urgent topic of assessing the diffusion and the effectiveness of digital healthcare solutions to improve the quality of life of cancer patients and their caregivers across European countries.

Namely, we have focused on (a) the existing published research in electronic solutions (e-

**Main goals of the existing digital tools:**

- Relieving bothersome physical side effects like insomnia, alopecia, gain or loss of weight, and helping alleviate

health) that have been proposed in the last decade that aim to make the everyday life for any cancer patients easier, and (b) investigating the scientific evidence of their effectiveness compared to traditional healthcare methods across all stages of illness from early diagnosis and prevention to postoperative treatment.

**Methods:** 275 peer-reviewed journal articles have been collected from three of the main electronic health-related scientific databases, namely EMBASE, Scopus and PubMed. We only considered primary studies (no protocols, feasibility studies, reviews, or commentaries) written in English and published from 2014 to 2024, that were proposing e-health initiatives to EU citizens diagnosed with any type of cancer at every stage of their illness. After the study selection, according to our inclusion/exclusion criteria, we analysed the full text of 54 articles, assessing their quality according to the mixed method appraisal tool (MMAT).

psychological ones such as anxiety, depression, and solitude;

- remote monitoring of vital signs and simplifying the check-up procedures during treatments;
- promoting the screening for cancer prevention;



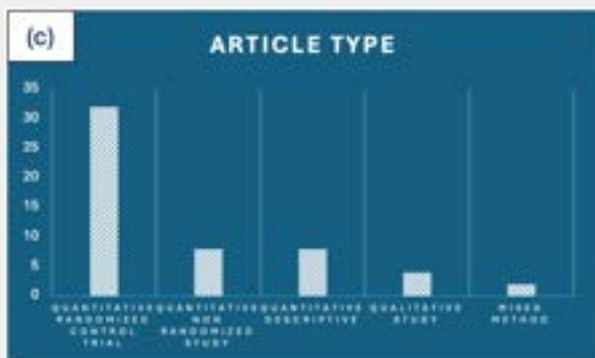
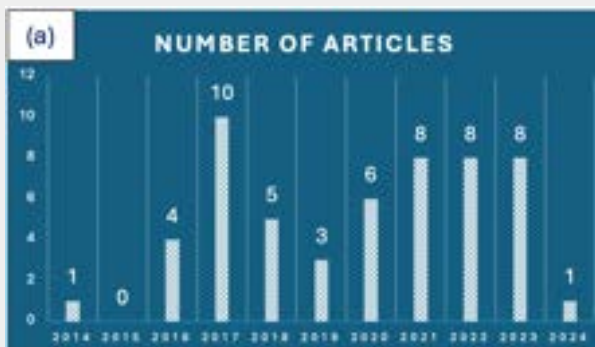


- Assessing and fostering health literacy or comparing costs in traditional healthcare and digital care.

According to other reviews recently published, also across EU countries, emerges, on one hand, the patients' need to be empowered, that is being provided with a more self-centered and personalised care, and on the other hand, that the diffusion and the acceptance of the usage of digital tools should be further promoted to engage both patients and clinicians to include these tools in their standard procedures.

Individuals included in intervention trials that have adhered to the full program show satisfaction and increased health literacy and/or improving of one or more aspects of quality of life analysed as well as a facilitation

in the follow-up checkups. Although not all studies were quantitative for inherent limitations in the data collection (e.g. small sample size, or self-reported outcomes), all quantitative studies agreed on the effectiveness of e-health solutions, and the cost-benefit ratio, when investigated, was shown to be high in mobile and web-based applications with respect to traditional healthcare. Hence, a good practice should be that of complementing the clinicians' guidance with web-based interventions that could enhance the patients' well-being. This would also partially solve the inherent resistance of healthcare practitioners to include remote tools in their routine and limit the risk of abandonment from the patients' point of view.



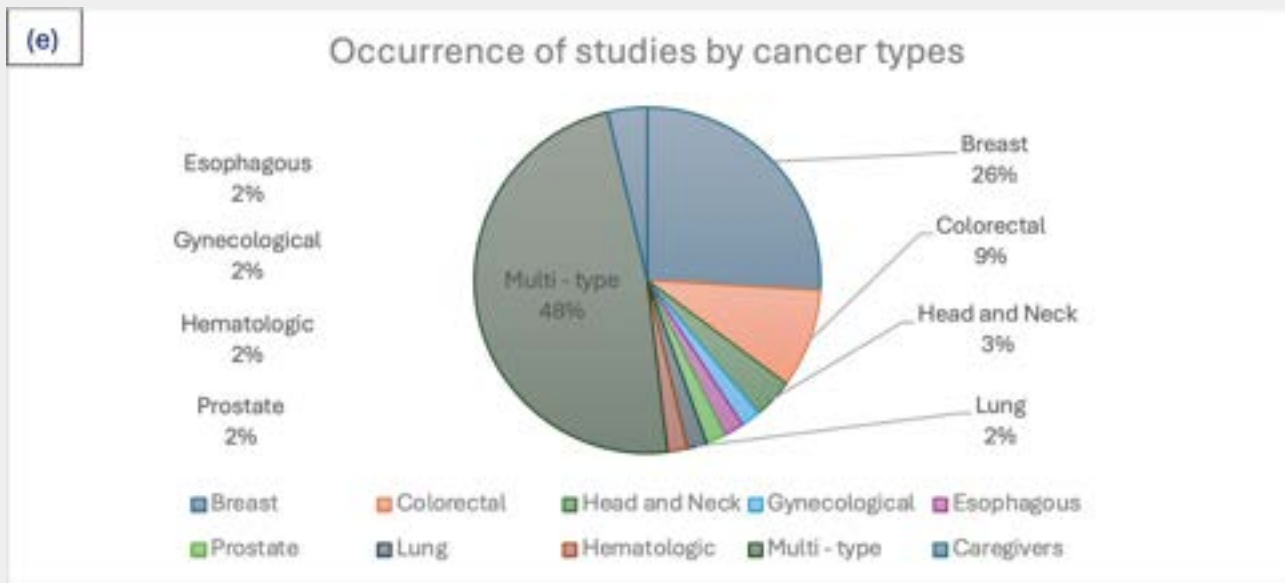


Figure 1. Starting from the top, in panel (a) shows an increasing trend in the number of publications included in the systematic review on digital solution for cancer patients in the last decades; in panel (b), the articles are stratified by the country of residence of study participants, showcasing a notable predominance of Dutch and German publications; in panel (c), the articles are stratified by study design, showing a strong prevalence of quantitative randomised control trials; in panel (d), the articles were grouped by quality level (with 1 and 5 being the lowest and highest scores, respectively), showing that, on average, they fulfil high quality standards; in panel (e), the studies are stratified by cancer type: almost half of the articles investigated a sample of patients affected by different types of cancer, while breast cancer emerged as the most frequently studied cancer type in studies focused of one type of cancer.

## Discussion:

Two surprising data emerge from this systematic literature review: the first one is that only little attention has been given to informal caregivers. They still act as unsung heroes from the point of view of the society and governments rather than being protected and assisted in their mission. Indeed, the digital solutions aimed to make their key tasks of supporting their loved ones still constitute a minority and too little attention has been given to ask for their needs. The second one is that e-health tools to promote screening for prevention are almost nonexistent across scientific publications across EU countries with respect to the numerous initiatives proposed for during and post treatment support of cancer patients. We remain optimistic that the results of our systematic literature review, coupled with the widespread diffusion of this Good Practice guide will unlock the full potential of e-health solutions. This, in turn, will offer cancer patients and their caregivers the extensive support and assistance they require.



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'E-Health4Cancer' was coordinated by the Cancer Guidance Center ([Kapa3](https://www.kapa3.gr)) in Greece, in partnership with the Danish Committee for Health Education ([DCHE](https://www.dche.dk)) in Denmark, the University of Naples Federico II ([UNINA](https://www.unina.it)) in Italy, and the Greek Carers Network ([EPIONI](https://www.epioni.gr)) in Greece.

Contact info:

Dedicated project webpage: <https://www.kapa3.gr/en/e-health4cancer/>

Email: [info@e-health4cancer.eu](mailto:info@e-health4cancer.eu)

[info@kapa3.gr](mailto:info@kapa3.gr)

Phone: (+30) 210 5221424

Address: 13 Kosti Palama, 11141, Athens, Greece



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