

# Women's health: APP in Health-literacy reinforcement programmes



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# Disclaimer

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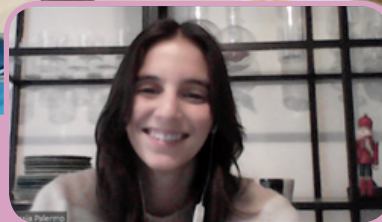
This handbook was developed in the framework of the Erasmus+ Prolepsis partnership, under the leadership of Cyprus University of Technology.

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# Abbreviations

<b>ANS</b>	Anziani e Non Solo
<b>BC</b>	Breast Cancer
<b>BSE</b>	Breast Self-Examination
<b>CUT</b>	Cyprus University of Technology
<b>HBM</b>	Health Belief Model
<b>HCPs</b>	Healthcare Professionals
<b>ICGs</b>	Informal Caregivers
<b>ICT</b>	Information and Communications Technology
<b>mHealth</b>	mobile Health
<b>MOH</b>	Ministry of Health

# Foreword

In the midst of everyday living, it is frequent for family caregivers of people affected by cancer to neglect their own health or to become ill themselves. The strains placed on the family caregiver are being exacerbated by the challenges that cancer poses. Advanced task management, role shifting, increased responsibility and decision-making are only but some of the challenges that caregivers face. These can be overwhelming and can negatively affect the ability of the person to effectively care for their own health including breast cancer. This tumour site is highly relevant for this group of caregivers as in their majority are female caregivers in the age range with the highest prevalence for breast cancer.

This highlights the importance of appropriate training and breast cancer awareness not only among the high-risk groups and the general public but also among the healthcare professionals. Patients and healthy people come in contact with many points of the healthcare system and these professionals need to be in a position to positively influence and guide people towards promoting breast cancer awareness and healthier lifestyles. The PROLEPSIS project has produced the Prolepsis Mobile Application which is a tool that reinforces the processes of breast cancer awareness and healthier lifestyle among female informal caregivers. The success of the mobile application relies on its best utilization by the user and this handbook provides a valuable resource on how to master this process.

The handbook foremost aim is to provide a comprehensive preparation to healthcare professionals including (but not limited to) social workers, care workers, adult educators and healthcare professionals active in community-based prevention programmes. As part of this comprehensive approach the consortium has collated a stream of information that cover all the aspects of breast cancer ranging from pathophysiology to prevention. The handbook has been prepared to be user-friendly, incorporating various learning methods and fostering the use of technology in the process. The consortium believes that this approach will allow more healthcare professionals in the field to utilize this learning resource in their daily practice and reinforce the efforts for early breast cancer diagnosis.

***“We have forgotten that curing cancer starts with preventing cancer in the first place”***

*David Agus*

Dr. Andreas Charalambous  
Principal Investigator of the PROLEPSIS project

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# 1. Introduction

Mobile apps have the potential to improve women's adherence to screenings programmes and their general health. The quality and usefulness of health information can lead to better outcomes (Broderick et al., 2014). The use of mobile apps in health-literacy reinforcement programmes is promising but also very challenging.

Analysing the needs of the caregivers and their knowledge regarding the impact of their behaviour on Breast Cancer (BC) development and the perception of formal caregivers was the starting point for the development of the Prolepsis App and the training program. Caring of a person with a chronic disease can be a contributing factor to poor screening adherence. Women who assume the role of the informal carer face additional challenges in engaging in health promotion practices such as breast cancer screening. Explicitly, studies on caregivers' health behaviours stress the presence of impaired health behaviours, such as neglecting health care appointments, eating a poor-quality diet. While the outcome of breast cancer treatment largely depends on the timing of its detection and the national health systems throughout Europe follow the EU's recommendations for the provision of mammography screening to detect breast cancer in an early stage (EC, 2021), women's adherence to screenings programmes is relatively poor. The average attendance in the EU is below the standard acceptable level that is 70% (Perry et al., 2016).

# The Prolepsis Project

The Prolepsis<sup>1</sup> project aims to develop a mobile phone-based health intervention, through the creation of an Application (App) for tablet and smartphone, as a means to enhance preventive health care behaviour among informal caregivers population with tailored individual messages, covering broad content areas while also overcoming restrictions to place and time of delivery.

The specific objectives of the Prolepsis project are:

- To create a methodology and relevant contents extending informal caregivers' knowledge regarding the impact of their prevention avoidance behaviour on BC development.
- To educate and enhancing them to assume control over this disease through adopting and maintaining changes in their lifestyle and living practices. These include modifications of their lifestyle habits, self-monitoring, self-assessment, and reinforcement of positive behaviours as well as encouragement of use of preventive BC services.
- To develop a personalized mobile application (i.e., personal characteristics, needs and preferences), which will support informal caregivers to better manage self-care and behaviour change in illness prevention.
- To produce a handbook on how to use the app in health-literacy reinforcement programmes targeting not only informal caregivers but women's health in general.

<sup>1</sup>To learn more: <https://prolepsis.eu/>



# The Prolepsis Handbook

This handbook was developed with the project partner countries of Cyprus, Italy, Portugal and Greece and it's oriented for educators working with informal and formal education and healthcare professionals working with women's health promotion, on how to use the app in health-literacy reinforcement programmes targeting not only informal caregivers but women's health in general.

The handbook is an e-book containing practical suggestions and guidelines for the two different target group which will be based on the lessons learnt through the previous project actions.



# 2. Health Promotion

## Health Literacy

Health literacy is a key factor in health outcomes that should be considered when creating mobile health promotion apps. This lies on the fact that the ability of the user to utilize the mobile application will affect how well the application has been used (e.g., full use of its features) and ultimately will influence its effectiveness.

Health literacy, defined as an individuals' ability to acquire, understand, and use the information needed to make health-related decisions (Promotion, 2012), is an especially important factor in patients' ability to manage their interactions with the healthcare system. Individuals with high levels of health literacy are often better able to find health-related information, understand it, and act on it compared to persons with lower levels of health literacy (Bo et al., 2014).



**Figure 1.** Health Literacy, c.f. Doyle, Cafferkey & Fullam, (2012).

Studies have shown that health literacy is a factor in health status and treatment outcomes (Berkman et al., 2004; Berkman et al., 2011; D.A. Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Sheridan et al., 2011). Low levels of health literacy are associated with lower likelihood of participating in cancer screening (Oldach & Katz, 2014). The importance of health literacy for health is underscored by studies that show that it is related to risk for mortality (Baker et al., 2007; Sudore et al., 2006; Wu et al., 2013).

Limited health literacy is associated with the limited use of preventive services across cultures and populations (Liu et al., 2020; Goto et al., 2016; Vandenbosch et al., 2016).

Explicitly, women with inadequate self-reported health literacy were less likely to have a mammography in the last 2 years (Fernandez et al., 2017). Additionally, inadequate health literacy has been linked to greater risk for cancer and presenting to cancer care systems at more advanced stages of the disease (Papadakos et al., 2018). Such delayed cancer diagnosis reflects on a poor prognosis especially in metastatic disease (Tesaw et al., 2020).

Data from various research areas conclude that health literacy aiming interventions can shift perceptions of women towards breast cancer screening (Noman et al., 2021; Sinicrope et al., 2020; Bashirian et al., 2020; Luque et al., 2019). Technology derived interventions are feasible and provide a cost-effective method of early breast cancer screening (Marino et al., 2020; Holt et al., 2019). Patients want and need information to maintain and improve their health. An enormous amount of information is available to them from providers, health care organizations, governments, and advertisers, but this availability itself creates challenges for individuals with low health literacy. The evaluation for the quality and usefulness of this information is also very important. An even larger challenge for many patients is the difficulty of understanding and using health information even when they find it (Diviani, van den Putte, Giani, & van Weert, 2015).

When patients succeed in finding the information they want and need, they often encounter a problem created by a discrepancy between the reading difficulty of the information and their own ability to understand and use it. Researchers and policy makers have called for written health information delivery to match patients' reading abilities, but even well-written presentations targeting the general public are often written at levels beyond the capacity of patients to read easily (Ownby, 2006).

The consortium of the Prolepsis project believed that persons with high levels of health literacy can be most efficiently helped by providing information and teaching skills in text-based format. Furthermore, it is believed that participants can be effectively helped when provided with straightforward written information accompanied by graphics and audio narration.

The Prolepsis project refers to providing health information about breast cancer to participants and can be used to tailor healthy behavior to increase their efficacy. In the context of promoting patient health literacy, the prolepsis project defines precision health information as giving patients the information they need, when they need it, in a form they can use and better understand.

Our findings showed that ICGs were fully informed about BC in general and comprehended the benefits of screening. Women were more likely to be consistent with screening methods when they had personal or familiar experience of breast cancer and when they received specific advice and encouragement by their physicians. Similar findings were supported by Hassan et al. (2015). This behavior can be explained by the fact that women take actions to prevent BC because they perceive themselves to be susceptible to the condition. Based on the Health Believe Model (HBM), engagement in mammography and ultrasound can be predicted by women's perceptions about BC derived from their knowledge about the disease (Hsieh et al., 2020; AlJunidel et al., 2020; Darvishpour et al., 2018).

The proliferation of patient information websites over the past several decades has made distance self-education for health widespread (Project, 2013). It is a method by which providers can give patients an “information prescription” (Burke, Carey, Haines, Lampson, & Pond, 2010) to learn more about their condition and how to manage it.

The implementation of patient education via remote methods is thus a logical strategy for those who provide health education interventions since they can reach those who need them at times and locations that are convenient for the learners. Perhaps equally important, remote health education interventions, depending on their format, may make fewer demands (compared to traditional methods of face-to-face learning) on providers’ time, depending on their degree of automation (Ownby, Waldrop-Valverde, Jacobs, Acevedo, & Caballero, 2013).

The whole philosophy of the creation of this mobile application is to provide caregivers the carefully selected information for the adoption and maintenance of health behavior in relation to breast health. It also aims to appropriately guide users in following the right steps for early detection of breast cancer and promote breast health. Providing properly selected information remains one of the main goals of this mobile application so that the caregivers are not lost or confused by the volume of information that exists freely on the Internet. The barriers that emerged from this study that influenced the behavior of ICGs, concerning early screening, might have been the result of the wrong perception women have on BC diagnosis. Therefore, providing programs that promote health literacy, focused on BC and the significance of screening methods, including BSE, could reduce concerns and motivate them to practice BSE in a systematic basis (Noman et.al., 2021; Sinicrope et.al., 2020; Luque et.al., 2019). The promotion of alternative, technology enhanced tools could facilitate the empowerment of women in such basis (Holt et al., 2019; Demiris et al., 2019).





# Health Belief Model

Recent years have witnessed a continuous increase in lifestyle-related health challenges around the world. Increasingly the role of a healthier behavior on the prevention of various diseases including specific types of cancer has been recognized. As a result, researchers and health practitioners have focused on promoting healthy behavior by employing various behavior change interventions. The decision to adopt a preventive behavior is a multi-dimensional process with various underlying components of behaviors and thoughts.

Personal expectations, perceived benefit or perceived constraints constitute parameters that determine adults' final behavior. Breast Cancer (BC) can be an early detectable disease partly due to the effect of specific health promotion activities that can be achieved through health education and health awareness that support behavioral changes. Such activities include the regular Breast Self-Examination (BSE) that can be performed by the woman herself at her own space and time. Furthermore, other early detecting activities include the Clinical Breast Examination (CBE) and mammography that can also lead to early detection and treatment.

Health promotion activities can be effective when the person actually believes in their values and is willing to incorporate these in his/her daily living. Therefore, for health promotion strategies that aim to promote the early detection of Breast cancer, there is a need to develop user-friendly tools, targeting on the utilization of early detection and preventive practices (Zielonke et al., 2021; Kumarasamy et al., 2017; Coleman, 2017; Akhtari-Zavare et al., 2015). In this context, the Health Belief Model (HBM) presents a structure pathway to facilitate the process of developing such health-promoting and behavior-change interventions.

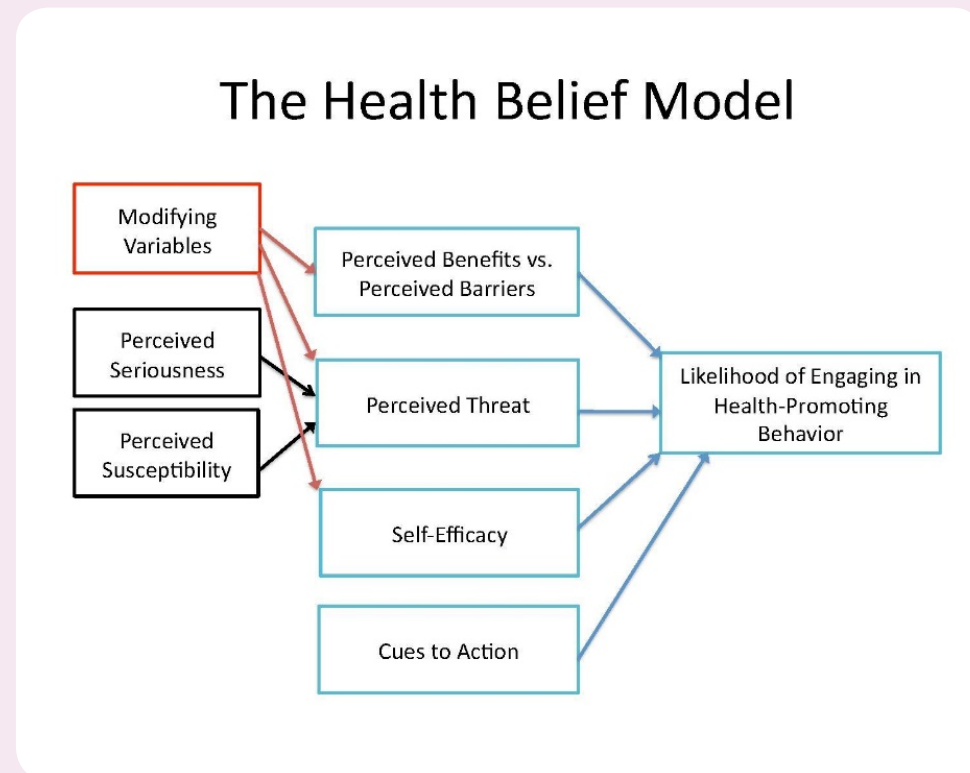


The Health Belief Model (HBM), developed in the 1950s to investigate why people fail to undertake preventive health measures, remains one of the most widely employed theories of health behavior. The HBM was developed to address problem behaviors that evoke health concerns. It postulates that an individual's likelihood of engaging in a health related behavior is determined by his/her perception of the following six variables: Perceived susceptibility (perceived risk for contracting the health condition of concern); Perceived severity (perception of the consequence of contracting the health condition of concern); Perceived benefit (perception of the good things that could happen from undertaking specific behaviors); Perceived barrier (perception of the difficulties and cost of performing behaviors); Cue to action (exposure to factors that prompt action); and Self-efficacy (confidence in one's ability to perform the new health behavior). These six health determinants identified by HBM together provide a useful framework for designing both long and short-term health behavior interventions (Glanz, 1995).

HBM focuses mainly on health determinants; therefore, it is the most suitable model for addressing problem behaviors that have health consequences (e.g., unhealthy eating and physical inactivity).

HBM was developed as a systematic method to identify, explain, and predict preventive health behavior (Janz & Becker, 1984; Rosenstock, 1974). According to Rosenstock (1966), the original goal of the developers of the HBM was to focus the effort of researchers who aim to improve public health by understanding why people do not take preventive measures to protect their health. The Health Believe Model (HBM) is used as the conceptual framework for the Prolepsis program. More specifically, it is used in the content analysis for the focus groups, for the effective design of the e-educational programme as well as the mobile phone application.

Studies showed that the majority of caregivers of people with major caregiving needs were unable to leave the care recipient alone and had to organize their time according to the daily activities of the recipients (Roth et al., 2020, Ross et al., 2020, Caputo et al., 2016). Other studies have shown a significant association between caregiving level and inadequate exercise and health promotion practices (Barbosa et al., 2020, Adashek et al., 2020, Rha et al., 2015). This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.



**Figure 2.** The Health Belief Model: © 2018 Upton RL.

# The Perceived Threat

The HBM posits that an individual is likely to perform a behavior if he/she perceives a threat from a disease or health condition. The threat perception is based on two beliefs: the perceived susceptibility of the individual to the disease and the perceived severity of the consequences of the disease for the individual.

**Perceived Susceptibility** refers to the probability that an individual assigns to personal vulnerability to developing the health condition. In other words, it is the subjective belief a person has regarding the likelihood of acquiring a disease or harmful state as a result of indulging in a particular behavior.

Perceived susceptibility explains that people will be more motivated to behave in healthy ways if they believe they are vulnerable to a particular negative health outcome (Rosenstock, 1966). The personal perception of risk or vulnerability has been found to be an important perception in promoting the adoption of healthier behaviors (Abraham & Sheeran, 2005). Individuals vary widely in

their perception of susceptibility to ill health condition or disease. Often, the higher the perceived risk, the higher the likelihood of an individual engaging in behaviors that decrease the risk.

**Perceived Severity** refers to how serious an individual believes the consequences of developing the health condition will be. It deals with an individual's subjective belief in the extent of harm that can be caused from acquiring the disease or unhealthy state, as a result of a particular behavior.

An individual is more likely to take an action to prevent gaining weight if s/he believes that the possible negative physiological, psychological and social effects resulting from becoming obese pose serious consequences (e.g., death, physical impairment leading to other health condition, financial burden, pain and discomfort, and difficulties with family and social relationships). Specifically, if the undesirable health outcome will not have a large impact on individual's life, s/he will not



be motivated to act to avoid it even when s/he is at risk. Although the perception of seriousness of any health condition may be based on medical knowledge, it may also come from one's belief about the difficulties a disease would create, or the effects it would have on his or her life in general (McCormick-Brown, 1999).

### **Behavioral Evaluation**

HBM also proposes that an individual is likely to perform a behavior if s/he perceives that performing the behavior will supposedly reduce the negative health outcome. The behavioral evaluation is based on two beliefs: the perceived benefit or efficacy of the target health behavior and the perceived costs or barrier to performing the target behavior. Perceived Benefit refers to an individual's subjective opinion of the value or usefulness of enacting a health behavior to offset the perceived threat.

Under perceived benefit, motivation to take action to change a behavior requires the belief that the precautionary behavior will effectively prevent the condition. The individual must perceive that the target behavior

will provide strong positive benefits.

Specifically, the target behavior must have the tendency of preventing the negative health outcome. For instance, individuals who are not convinced that there is a relationship between eating and gaining weight are unlikely to adopt a healthier eating behavior for the mere purpose of reducing their chances of getting obese.

Perceived Barrier refers to an individual's subjective evaluation of the difficulties or the hindrances associated with the target behavior. With perceived barrier, an individual may not perform a behavior despite his/her belief about the effectiveness (benefit) of taking the action in reducing the threat if the barrier outweighs the benefit (Rosenstock, 1966). The barrier often relates to the characteristics of the health promotion measure. It may be expensive, painful, inconvenient, and unpleasant.

These characteristics may lead one away from adopting the behavior. To adopt the new healthy behavior, people have to believe that the benefits by far outweigh the consequence

of continuing the old behavior (Center for Disease Control and Prevention, 2004).

### **Extensions to the original HBM**

The original HBM consisting of the four primary variables (susceptibility, severity, benefit, and barrier) has been modified by researchers. This subsection discusses how the original HBM has been extended with new variables over the years.

#### **Cue to Action:**

In addition to the four primary variables mentioned above, Rosenstock (1966) suggests that a combination of threat and behavioral evaluation variables could reach a considerable level of intensity without resulting in overt action unless an event occurs to trigger action in an individual. Thus, cue to action determinant was added to the model to denote a trigger for health behavior when appropriate beliefs are held (Rosenstock, 1966). In Rosenstock's original formulation, cues to action could include external cues such as a mass media campaign, social influence, or internal cues such as a negative change in bodily state or perception of symptoms. More generally, cues to action can be events, people, or things that spur people to change their behavior. Although cue to action have been identified as an important behavioral determinant, it is the most underdeveloped and rarely measured or researched variable of the model (Janz & Becker, 1984; Rosenstock, 1974).



**Self-Efficacy** was added to the HBM in 1988 by Rosenstock et al. It is a term that is used to describe an individual's belief about his/her ability to perform the behavior in question (Bandura, 1977). Generally, people may not want to attempt to do something new unless they think that they can do it. For instance, if someone believes that a new behavior is useful (high perceived benefit) but does not think that s/he is capable of doing it (low self-efficacy), chances are that s/he will not try the new behavior. While it seems intuitively clear that self-efficacy is a significant determinant of health-behavior following the wide adoption by health-promotion researchers, it is necessary to examine its impact in relation to other health determinants. Evidence suggests that self-management and self-efficacy improves people's motivation and confidence in their own ability, knowledge, experience and satisfaction (Tan et al., 2021). Interventions aiming on ICGs knowledge were shown to empower their self-efficacy (Yildiz et al., 2017; Hendrix et al., 2016). Supporting self-management also strengthens people's engagement in more healthy behaviors and encourages general behavioral changes (Papadakos et al., 2018).

Studies on the topic have identified several facilitators that have been found to promote increased mammography use in women. The noted factors include perceived benefits of mammography, self-efficacy, and susceptibility to BC (Ghaffari et al., 2019; Kim et al., 2010).



# 3. Breast Cancer Prevention

In 2020, 2.7 million people are expected to be diagnosed with cancer across the 27 EU Member States and 1.3 million to die from it. Almost half of cancer (40%) cases are appointed by OECD (2020) as being preventable, and mortality can also be reduced through earlier diagnosis as well improved care systems.

The last decades, were made significant efforts, investing in breast cancer screening programs and set-up specific population-based mammography screening programmes. This contributed overall to the improvement of early detection rates since 1980s (OECD, 2013).

In Europe, BC is the most frequent cancer among women, and it is expected that more than 355 000 new cases will be diagnosed in the EU in 2020- being the leading cause of cancer death among women.

During the COVID-19 pandemic and specially in the first half of 2020, many countries reported delays in routine screening- fear of being infected or shut down (EC, 2020). In a near future this may result in a greater proportion of women diagnosed at a more advanced stage OECD (2020). The prevention and early diagnosis of cancers play a major role in women wellbeing. The rate of mortality from breast cancer in the EU is expected to be about 34 per 100 000 women in 2020, without taking into account any possible impact of COVID-19 (OECD, 2020).



Cancer decrease incidence can only be obtained by two fundamental approaches: reducing exposure to cancercausing agents (primary prevention) and promoting early detection and treatment of pre-clinical forms of the disease (secondary prevention) (National Public Health Partnership, 2006).

Europe's Beating Cancer Plan- an EU flagship initiative, recognized three main cancer challenges (EuroHealthNet, 2020):

- the huge suffering cancers cause and seeks to put citizens, patients, and families
- the burdens which cancers impose on society as a whole and particularly health systems
- tackle inequalities.

An inclusive Europe should invest in prevention and early diagnostic and protect against the risk factors of cancer.

The most vulnerable are included and this should include ICGs.

According with the Prevention definition by the National Cancer Institute (2020) is an action that is taken to lower the chance of getting cancer. Each person's cancer risk is made up of a combination of genes, lifestyle, and the environment. Being a Protective factor- anything that decreases the chance of developing a cancer and a Risk factor- anything that increases your chance to developing cancer, any women's health promotion should invest in increasing protective factors and avoiding risk factors.

A substantial proportion of cancers could be prevented, including all cancers caused by tobacco use and other unhealthy behaviors. There are also risk factors cannot be changed: getting older, being born female, having a family history of breast cancer, inheriting certain gene changes, having a personal history of breast cancer, having dense breast tissue, having certain benign breast conditions, starting menstrual periods early, going through menopause after age 55, having chest radiation and exposure to diethylstilbestrol (American Cancer Society, 2020).

Indeed, one of the major risk factors for breast cancer is age: a 70-year-old woman has a 1 in 25 chance of being diagnosed with breast cancer next 10 years, comparatively with 30-year-old woman that has about a 1 in 200 chance (Howlader, Noone, Krapcho et al., 2020).

Culture, geography, ethnicity, race and socioeconomic status diverge in Breast Cancer Incidence and mortality (American Cancer Society, 2020). Investment in screening should be done to reduce Breast Cancer mortality as this allows to better identify cases for treatment at an earlier stage. It is essential to reduce late diagnosis.

Prevention and early diagnosis are in this way possible strategies to mitigate the impact of cancer on people and families.

Following the Ottawa Charter the concept of health promotion being defined as “a process that aims to create conditions for people to increase their capacity to control the determinants of health, in order to improve it “ (WHO,1987), the challenge is now to invest in methodologies to turn health promotion more efficient and cost effective to fight cancer.

Prolepsis project integrates a new era of health promotion, investing in primary and secondary prevention using a mobile App in Health-literacy programmes, specific oriented for BC prevention and Womens´Health Promotion.

# Countries` Breast cancer screening programmes

## Italy

To ensure access to early cancer diagnosis, the National Health Service carries out three free screening programs for the prevention of cancer, two of which are typically female, breast and cervix, and the third dedicated to her and him: screening for colorectal cancer.

Screening for early detection of breast cancer is aimed at women between the ages of 50 and 69 and is performed with a mammogram every 2 years. In some regions, efficacy is being tested in a wider age group, between 45 and 74 years old.

When the women reach the age for starting screening receive invitation letters from the Health Centers to attend a free mammogram exam.

Mammography is a radiological examination of the breast, which allows the early identification of breast cancer, as it is able to identify nodules, even small ones, not yet perceptible to the touch.

In Italy several civil society organization (for example AIRC or LILT) have an important role in the in the breast cancer prevention and fight, in particular in the research field and information and awareness campaigns.

# Cyprus

In 2020, 761 (14.5%) new cases diagnosed of breast cancer in Cyprus (Globocan, 2020). In addition, data by the Cyprus Ministry of Health (MOH), 15 out of 1,000 mammograms of women aged between 50 and 69 show indications of breast cancer.

With the total transition of the National Healthcare System in Cyprus and the introduction of Gesy, it is within the responsibilities of family doctors (GPs) and gynecologists to raise awareness on breast cancer prevention and early detection among women emphasizing the necessity of the breast cancer screening tests.

Free breast cancer screening programs (i.e. mammography) were offered by the MOH every two years for women between the ages of 50 and 69 since 2003 and is still the way for women to get tested. Special groups, such as those who have had cancer in the past are eligible for more frequent screenings.

Usually, the call to eligible women comes in the form of a letter from the MOH.

Under the old system around 40 per cent of women in 50-69 age group responded positively to the ministry's invitation for a free mammogram and made appointments to the designated centers in all districts. It is a low percentage, but this statistic only concerned the women who got mammograms at the designated centers by the This Breast Centers of Cyprus usually have specialized team that can provide advice, if necessary, while in the case also a biopsy is needed, they do all necessary tests in the same day so that women don't have to come back several times. health ministry. It did not include those who choose to go to private doctors and clinics for the screening tests.

# Portugal

The Portuguese League Against Cancer (2021) is a civil society organization with an important role in the problem of cancer. In activities related to the prevention of breast cancer, the Breast Cancer Screening started in the Center Region of the country since 1986, which has been able to diagnose hundreds of cancers at an early stage and, consequently, curable or controllable.

Women registered at the Health Centers receive invitation letters to undergo a mammogram (free exam) when they reach the age for starting screening, time establishment defined by Portuguese Health Authorities. The Breast Cancer Screening Program mainly uses Mobile Units that travel every 2 years to each municipality and Fixed Units. You can find more information of the location at the Portuguese League Against Cancer's site.

Autonomous Region of Madeira and Azores have specific Regional Structure and Organization. Madeira per example, use three existing breast cancer screening units and Azores implement the Programme Organized Screening for Breast Cancer in the Azores.



# 4.App in Health-literacy programmes





Mobile technology is indispensable for the development of sustainable health systems and can play a major role in the promotion of health literacy programmes.

About 100 million of the world's population due to out-of-pocket health expenses are into extreme poverty and 50% has no access to essential health care services. Yet, mobile technology can help reach this people as 80% of the population in developing countries owns a mobile phone (Kingdom of the Netherlands, 2019).

Smartphones can be helpful tools to support behavior change, with a notable advanced technology. Today they have more computational power than the one used to put the man on the Moon (Puiu, 2017).

Prolepsis develop a mobile phone-based health intervention as a means to enhance preventive health care among informal caregivers population. It is likely to provide low-cost and effective methods of contacting hard-to-reach populations with tailored individual messages covering broad content areas while also overcoming restrictions to place and time of delivery (Griffiths et. al., 2006). The growing of the eHealth and mHealth field has already proven to be effective in the realm of health behavior change (Wei et al. 2011).

Health literacy is defined as “the degree to which individuals have the ability to find, understand, and use information and services to inform healthrelated decisions and actions for themselves and others” (Santana, Brach, Harris et al., 2021). This is a Key factor in health outcomes as influences the patients' ability to manage their interactions with the health systems (Ownby, Acevedo & WaldropValverde, 2019).

Studies show inadequate levels of health literacy are associated with poor health outcomes, including increased risk of death (Fan, Yang & Zhang,2021; Wu, Holmes, DeWalt et al., 2013); difficulty to be able to find health-related information, understand and act on it (Bo, Osborne & Maindal, 2014); lower adherence in cancer screening (Oldach & Katz, 2014) and impacting cancer patients' behaviors and health care service use (Samoil, Kim, Fox, & Papadakos, 2021).



Health literacy promotion programmes through mobile health apps is beneficial but there are some points to consider: privacy and security concerns, no equal access to mobile technology and no familiarity or knowledge of using mobile health apps, (Kim, Goldsmith, Sengupta et al., 2019).

80% of the population in developing countries owns a mobile phone yet 50% of the world's population has no access to essential health care services (Kingdom of the Netherlands, 2019). The use of Apps in health literacy programmes can make the difference in peoples 'life.

Mobile health (mHealth) interventions assist a very fast growth over the past two decades (Grekin, Beatty & Ondersma, 2019), emerging in part due to smartphones and the ubiquity use of mobile devices and allowing guidance when is most needed. Indeed, just-in-time adaptive intervention has a huge potential for promoting health behavior change (Nahum-Shani, Smith & Spring, 2018).

This digital potentiality of mHealth interventions is enormous by empower citizens; help professionals and citizens address preventable risk factors associated with chronic diseases; allow the citizen to be actively engaged in prevention of chronic conditions, providing feedback on the quality of health and care, facilitate early detection of symptoms, timely treatment (EC,2018) and leads to an improvement in health behavior (Ghose, Guo, Li, & Dang 2021).

Designing Health Literate Mobile Apps is a challenge, and you should attend relevant aspects as: user needs, clinical benefit & safety, Accessibility, Usability, Personal data, Privacy governance, Information security, Health app security, Technical performance, interoperability (CEN, 2019). Another relevant approach identifies, positive regard, empathy and genuineness may play a critical role in therapy effectiveness in mHealth interventions (Grekin, Beatty & Ondersma, 2019).

Prolepsis Team aware of the importance to listen user needs conducted an empirical study, which results were integrated in the design of Prolepsis APP and the health promotion program.



# 5. Empirical Study

Breast Cancer early screening and detection is a main component for the outcome of the treatment and overall survival. Therefore, ways to optimally engage women (and men) in such screening programs should be further explored and integrated where possible as part of a wider a screening strategy. In this way, Prolepsis team developed a qualitative exploration of informal caregivers and healthcare professionals' perspectives on breast cancer and breast cancer screening, which results were used in the development of Prolepsis App.

## Resume of empirical study Background and methodology

The purpose of this study was to explore ICGs knowledge and perceptions, including educational and training opportunities or barriers, in promoting early detection practices for BC, as well as health care professionals' respective perceptions concerning informal caregivers in order to identify the need of selected health literacy interventions.

A qualitative focus group study was implemented in three European countries as a means to retrieve ICGs and HCPs perspectives on the topic. Five focus groups with 26 ICGs and three focus groups with 18 HCPs were formed using a purposive sampling. The interviews took place in three European countries, namely Cyprus (CY), Italy (IT) and Portugal (POR), using the interviewer's country local language. Each country recruited an experienced person as the moderator of the focus groups. The moderators were healthcare professionals with expertise in health promotion issues and relevant experience in focus groups moderation.

# Informal Carers Perspectives on the needs, Attitudes, Knowledge, Beliefs and Perceptions of Breast Cancer Prevention



## ICGs Focus Groups

Five themes emerged from the interviews of ICGs: Knowledge and perceptions on BC, Attitudes and Beliefs on BC, Motivational factors that influence early screening practices, Barriers influencing early screening practices and Personal involvement.

### Knowledge and Perceptions on BC

The participants reported to have knowledge of BC prevention practices including Breast self-examination (BSE) and clinical examination. They recognized the value of screening tests such as mammography, but not all of them follow the prevention programs. They considered self-breast examination value to be limited. Most of them felt safe with mammography and ultrasound screening tests (provided by national programs), considering BSE less important, with participants having the tendency to underestimate its value, *“Yes, for sure! Very important! And, if you find it, I think it will be easier to manage cancer if you find it at the earlier stage”* (P 7 CY). Greek-Cypriots and Portuguese women kept a positive attitude and an optimistic way of thinking about the diagnosis of BC. Participants reported that screening tests would help them with early detection and early intervention of BC, *“Yes, screening could help”* (P1, 2,3,4,5 IT).

## Attitudes and beliefs on Breast Cancer

ICGs attitudes towards BSE were linked to knowledge, beliefs and perceptions. Some participants avoided this practice, devaluing its benefits, *“Honestly, I do not perform BSE often, I feel safe because I am doing my mammography and ultrasound tests. Keeps me safe”* (P10 CY), *“I can’t do it... but I think it is partly because I feel safe from keeping up with my ultrasound and mammography tests... By this way I can detect cancer early”* (P 5 CY).

Fears were expressed, resulting from the lack of knowledge concerning examination procedure. For example, some participants reported that they were afraid of the radiation of the specific test (i.e., mammography). *“...is this safe to do every year mammography... I am afraid of radiation!”* (P 4 CY). *“Radiation will damage other organs, causing osteoporosis, etc.”* (P4 POR). On the other hand, participants who had a family history of BC, reported that they would undergo mammography on a systematic basis.

## Motivational Factors

Several factors were found to encourage participants in utilizing BSE including past illness experience, *“(Yes)... after my mom’s breast cancer I do mammography systematically, furthermore I have a mastopathy as well that I have to watch it”* (P 3 CY), the responsibility of the person they care for *“Positively, I need to take care of myself Informal Carers Perspectives on the needs, Attitudes, Knowledge, Beliefs and Perceptions of Breast Cancer Prevention in order to take care of others too”* (P4 IT), *“It scares me because I knew people who got cancer. For this reason, whenever there’s a chance to go to screening appointments, I take the opportunity and I go”* (P2 IT) and awareness campaigns from non-profit organizations *“Advertisements, Europa Donna”* (P 8 CY).

## Barriers influencing early screening practices

The barriers that emerged included lack of time to think about and perform BSE practices, *“Sometimes I have the feeling that I do not have enough time to have a shower and therefore performing BSE is somewhat a luxury!”* (P2 CY). Difficulties approaching health care settings due to caregiving role also emerged, *“I’m scared to receive bad news about illness. I’m a caregiver and I can’t get sick so, even if it’s a stupid reason, I prefer not to know”* (P 1 IT).

Other barriers that emerged were lack of knowledge and skills *“In my case, it’s the lack of knowledge”* (P7 POR)



# Health Professionals Perspectives on the barriers to Breast Self-Examination in relation to the role of informal carer



## HCPs Focus Groups Motivational Factors

From the HCPs interviews, the main themes that emerged included motivational factors and barriers towards BC early screening practices for ICGs.

According to HCPs, the sense of responsibility towards oneself comprised a considerable factor, *“Informal caregivers are usually looking for psychological support for own self, instead for the person who is ill and we really encourage this, because cancer is a stressful experience for the whole family and not just for the person who gets diagnosed with breast cancer”* (P2 CY).

Genetics determination of BC, also stood as an important motivator for seeking early BC screening, *“Informal caregivers have a potentially increased chance of developing breast cancer due to family history... they know this....it creates a feeling of responsibility of their health”* (P3 CY).

## Barriers

A substantial barrier towards early screening practices from ICGs, according to HCPs, was the lack of time, *“I agree it’s a matter of time...they also have the burden of caring for a sick person, so it is an additional burden that they have to take care of their own people, as a result they put themselves in a second place. If they have a mammogram, they will do for their mothers’ they will not do for themselves”* (P1 CY); *“Yes. In the final stages of the illness [of the patient] the exams are more often postponed or skipped by the informal caregivers”* (P2 IT ); *“women do not go because they are informal caregivers and call to say they cannot do the screening that day, at that time because they are taking care of a person (...) even more with cancer patients with comorbidities (e.g., dementia), in these cases informal caregivers can’t even leave them alone”* (P3 POR). All HCPs identified illness and suffering, as the main fears. Participants mentioned that if an ICG would get ill, they would no longer be able to take care of their loved one. *“There is a sort of sense of guilt because at that moment you are taking care of yourself rather than of your loved one”* (P1 IT).

## Conclusion

Motivating factors and barriers for BC screening adherence were linked to knowledge, beliefs and perceptions. Health promotion strategies and user-friendly tools should be developed, targeting on the implementation of BC early detection practices among ICGs. The establishment of a mobile application in order to increase the dissemination of information about BC and emphasize the importance of BSE and other screening methods, could lead to the early detection of breast cancer.



# 6. Prolepsis App

## Features



The design and the development of Prolepsis' mobile application was done by the technical partner Singularlogic, who was also responsible for the administrative platform. This App is available for iOS and ANDROID mobiles.

The aim of this mobile application is to be used as a means to enhance preventive health care behaviour among informal carers' population and other groups of women with tailored individual messages for motivating, advising, supporting and reminding, to educate and enrich their knowledge and health literacy on breast cancer through thematic modules, articles and videos and promote practices, such as BC screening, self-examination etc and as an overall effect, to encourage them in behavior that will lead to an early detection of breast cancer.

The content of the mobile phone-based health intervention is managed and updated from the administrative platform.

## Which are the contents?

### The pedagogical material in Prolepsis App covers different areas of intervention:

**Module 1.** Information on Breast Cancer

**Module 2.** Preventive lifestyle

**Module 3.** Self-monitoring

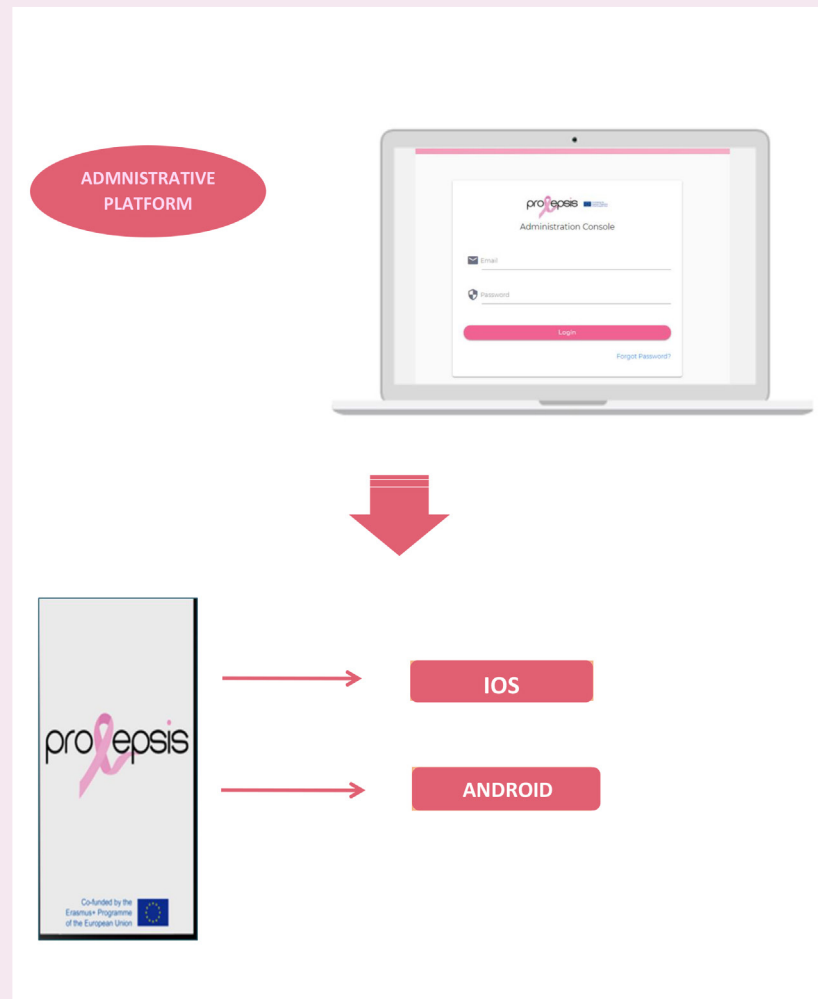
**Module 4.** Self-efficacy

The administrator has also the option to insert new articles, videos, thematic modules with the ability to combine, picture, articles and videos within one thematic, and recipes, as well. Moreover, it can add messages that will pop up at the mobile applications. The administrator has the option to insert new material, modify and delete the old ones. Through the platform the configuration is also administrated, as well as the setting of how the text will be presented through an editor (fonts, size, etc). All the above can be translated at 4 languages, so as to be shown to the respective language that the user will choose from the mobile application.

The mobile applications show all the information deriving from the administrative platform. Both the iOS and the ANDROID version, have implemented new but established technologies, based on the best practices. However, the development has taken into consideration certain principles, for the application to be user friendly, easy guided and easy to find out, simple in its presentation and its structure. The user interface was created in the basis of the selected colour of the logo to make a reference and also be pleasant for the user experience. Despite the esthetic and artistic part, combined with the practical aspect, attention has been given to the functionality of the application. The operations to work properly and enhance the achievement of the project's objectives.

An overview of the Prolepsis solution and the connection among the different systems can be understood in the diagram below and a synoptic view of the mobile application functionalities and features are presented in the following paragraphs.

# The Prolepsis Solution



The PROLEPSIS mobile application (iOS & ANDROID)

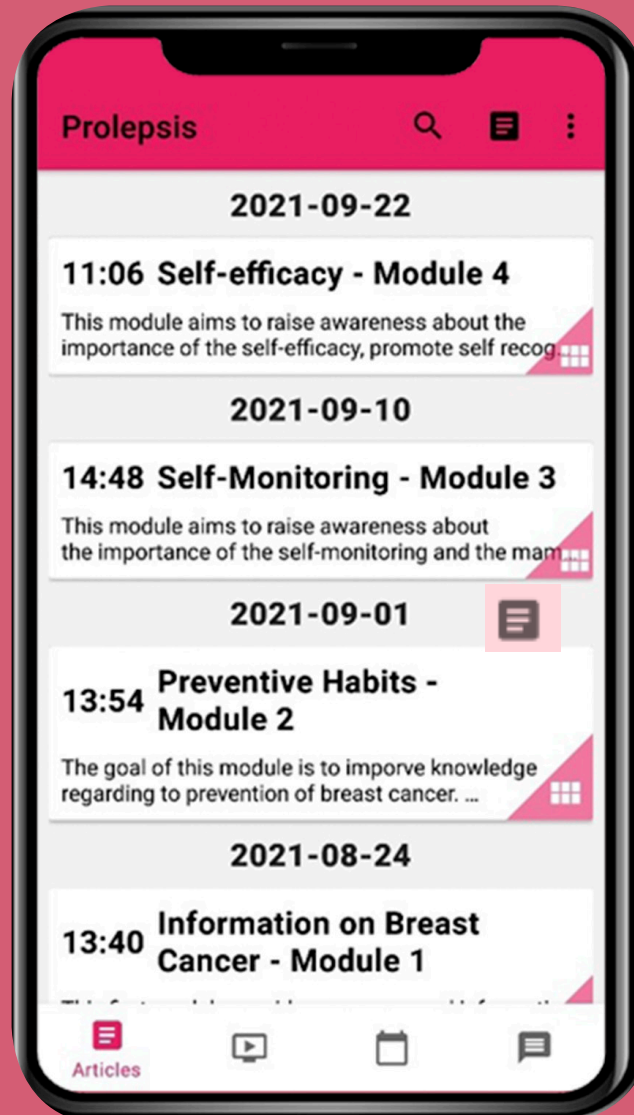
Which are the steps?

- Create New User - LOGIN – Forget Password
- Welcome Letter – Choice of not showing again
- INITIAL TEST – Evaluation of the user's current situation – Select Yes to start the test, No to skip it or Ask again tomorrow, if there is no time to complete at that moment / Always appear until it is completed (Option to complete another time, as well as complete again at any change of conditions). It is necessary to be completed, to be personalized for the user and to have access at all information and especially the personalized ones; otherwise, the application will only show the general information, at articles and videos.

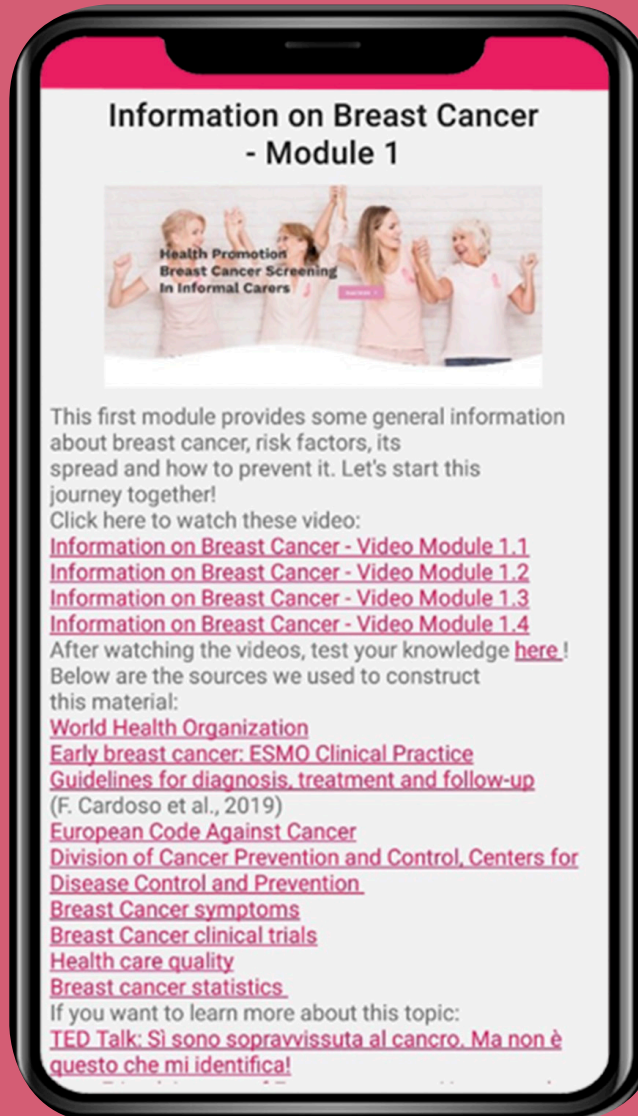
Tip: Do not forget to save the initial test each time you complete it!




- Menu bar at the bottom. Profile and help, up at the right.

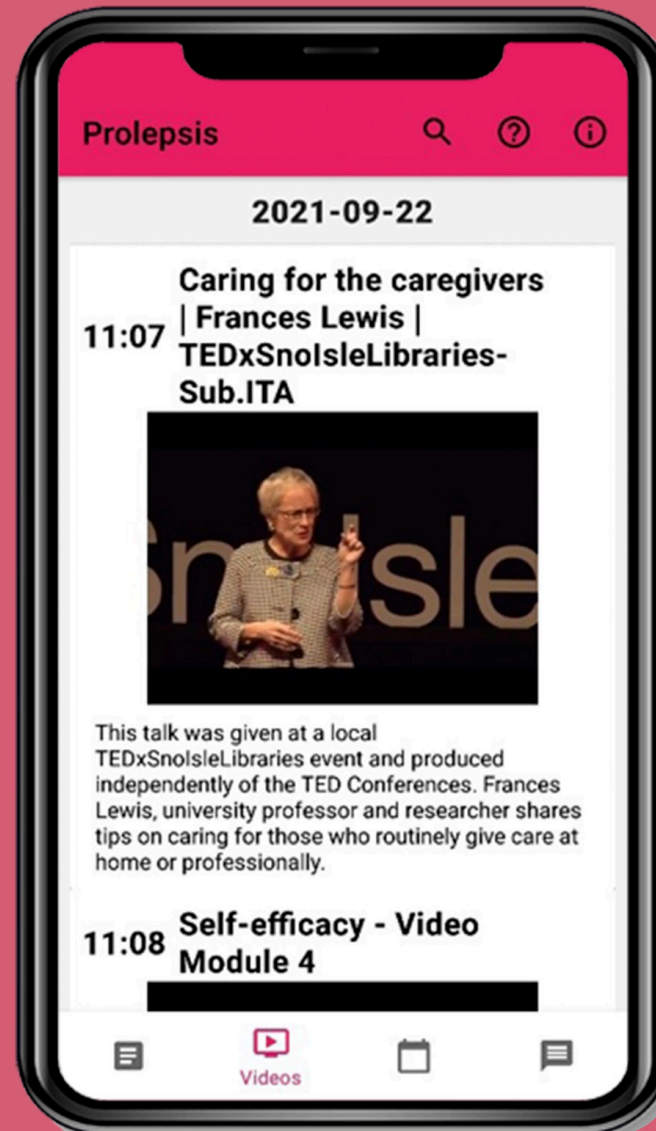


- Opens at “Articles” button  shows all MODULES with titles by date and hour of publication (click on each Module to see its content and click to the video links, the article links or the quiz links, to open in the web browser). It also show articles regarding breast cancer.





- The button “Video”  shows all the videos with title, date and hour of publication. Click on each video to watch it.

Tip: Each time a new article or video is published, the application notifies the user.




For the following features the user has to be signed in the:

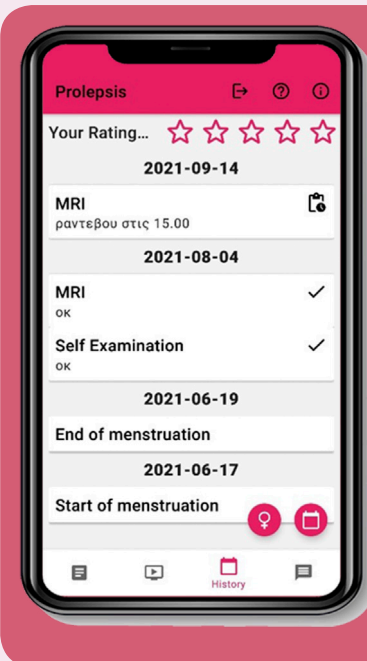
- Historic data: The “History”  button shows the appointments for the examinations by date and hour and their status. The user can always add a new appointment, with the calendar indication  and choose the examination type, by clicking on the examination type field, the date and the status. Can also modify and delete



Tip: When the user performs a self-examination, the stars will be filled with color!

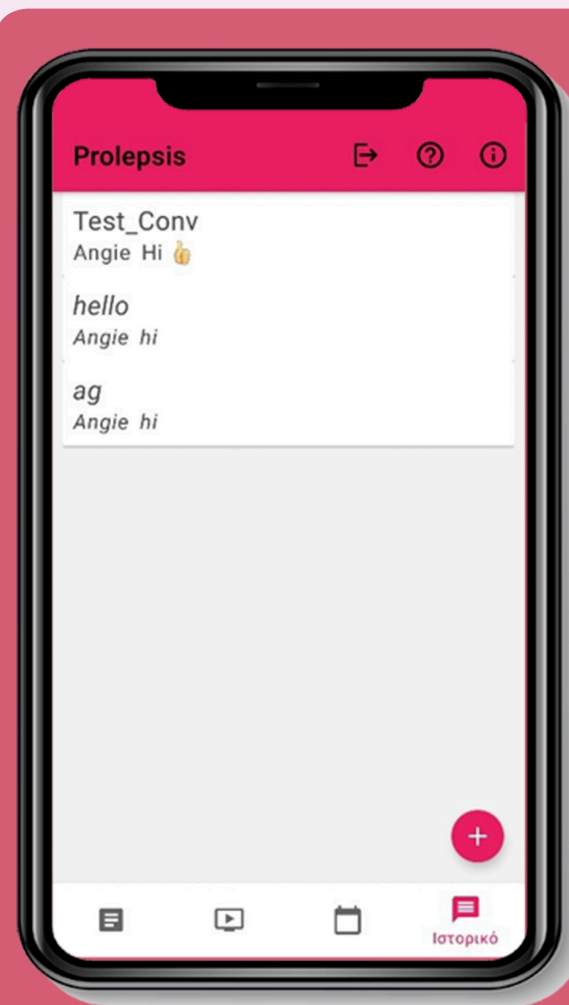
Tip: The system automatically sends a reminder message/notification at the mobile application at midnight (00.00) just before the beginning of the indicated day of the examination's appointment.


▪ By using the female symbol icon  opens a pop-up window with two different fields to input the first and last day of the menstruation. By clicking the date at each field, it opens a calendar to select the date.

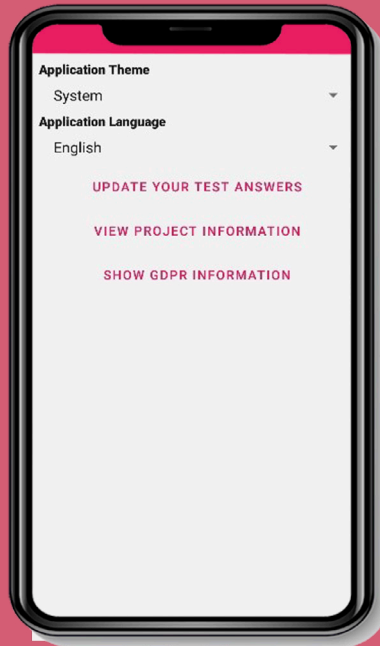
Tip: Every 5<sup>th</sup> of each month the system sends a reminding message/notification in the mobile application, for the self-examination. Grab the opportunity to enter a date that is the most appropriate for you and the system will send a reminder message at midnight (00.00) just before the beginning of the selected day.





▪ By selecting the “My circle” button  which actually is a kind of chat, the conversation history opens. With the use of the icon  the user starts a new conversation with a friend or group of friends that will be selected from the ones that have been accepted after invitation and given that they are users of the mobile application.



- The “Profile” icon  opens a list of options, as the:
  - Application theme (settings for the application background as dark, light, etc.)
  - Application Language: English, Portuguese, Italian, Greek. The user has the option to choose the language of the application, by selecting it and all the respective material of the application will be presented at the selected language.
  - Update user’s own test answers – the user can do again the initial test, if specific data, regarding the questions of the test, have changed. Remember to save!
  - View project information. The user can view the “Welcome to Prolepsis” letter with the information of the project.
  - Show the GDPR information. The application for iOS and ANDROID is aligned with the European Union, General Data Protection Regulation. Have implemented and integrated all the necessary steps and technology for the safety of the users’ data.



- The “Help” icon  opens a video that presents a short guide for the use of the application.
- At the end you log out with the respective icon .

Tip: No matter if the user is signed in, the system sends one personalized message/ notification every day, with motivating and encouraging expressions, health advice for nutrition, exercises, treatment, monitoring, etc.

To know more information please visit Prolepsis Site and download Prolepsis App.

# 7. Social workers, care workers and adult educators





A prominent type of intervention in health promotion and disease prevention includes communicating information (e.g., risk factors) to people stressing for the timely onset of this process. Breast cancer (BC) is a preventable disease partly due to the effect of specific health promotion activities that focus on primary prevention. This can be achieved through health education and health awareness that support behavioral changes, such as regular Breast Self-Examination (BSE), Clinical Breast Examination (CBE), and mammography (e.g., main methods of BC screening) and secondary prevention through early detection and treatment. BSE is an important screening method that can be performed by a woman on herself at no cost whilst its effectiveness in the early detection of BC has been systematically demonstrated (Kumarasamy et al., 2017).

While the outcome of BC treatment largely depends on the timing of its detection, women's adherence to screening programs is relatively poor. This can also be attributed to the fact that the general public's knowledge on the effect of screening programs is scarce and relevant research suggests that only 1.5% of the citizens of Europe know the actual benefits of participating in breast cancer screening (Henriksen et al., 2015). The risk of over diagnosis is unknown to the women invited for screening (Hersch et al., 2013).

Evidence also suggests that self-management improves people's motivation and confidence in their own ability, knowledge, experience and satisfaction. Supporting self-management also strengthens people's engagement in more healthy behaviors and encourages general behavioral change. Studies on the topic have identified several facilitators that have been found to promote increased mammogram use in women. The noted factors include perceived benefits of mammograms, perceived self-efficacy, and perceived susceptibility to BC (Kim et al., 2010). Limited health literacy is associated with the limited use of preventive services (Cho et al., 2008) and women with inadequate self-reported health literacy were less likely to have had a mammogram in the last 2 years (Fernandez et al., 2016). Earlier studies revealed that the knowledge of screening guidelines emerged as the single most important predictor of regular screening mammography uptake with greater knowledge increasing the likelihood of mammography uptake by over 10 times (Juon et al., 2004).



Social Workers, care workers and adult educators working with informal caregivers play a vital role in IC's life and might be willing to offer this Prolepsis training. To enhance knowledge of BC prevention let's review some key points to take in consideration in the capacitation of the ICGs Prolepsis training program and be better prepared to clarify ICGs.



## Information on Breast Cancer

Breast cancer is the most prevalent type of cancer in the world, especially for women.

However, prevention and early diagnosis practices have enabled many patients to intervene immediately in the disease where present and to heal. In fact, mortality occurs mainly in cases where the diagnosis is late.

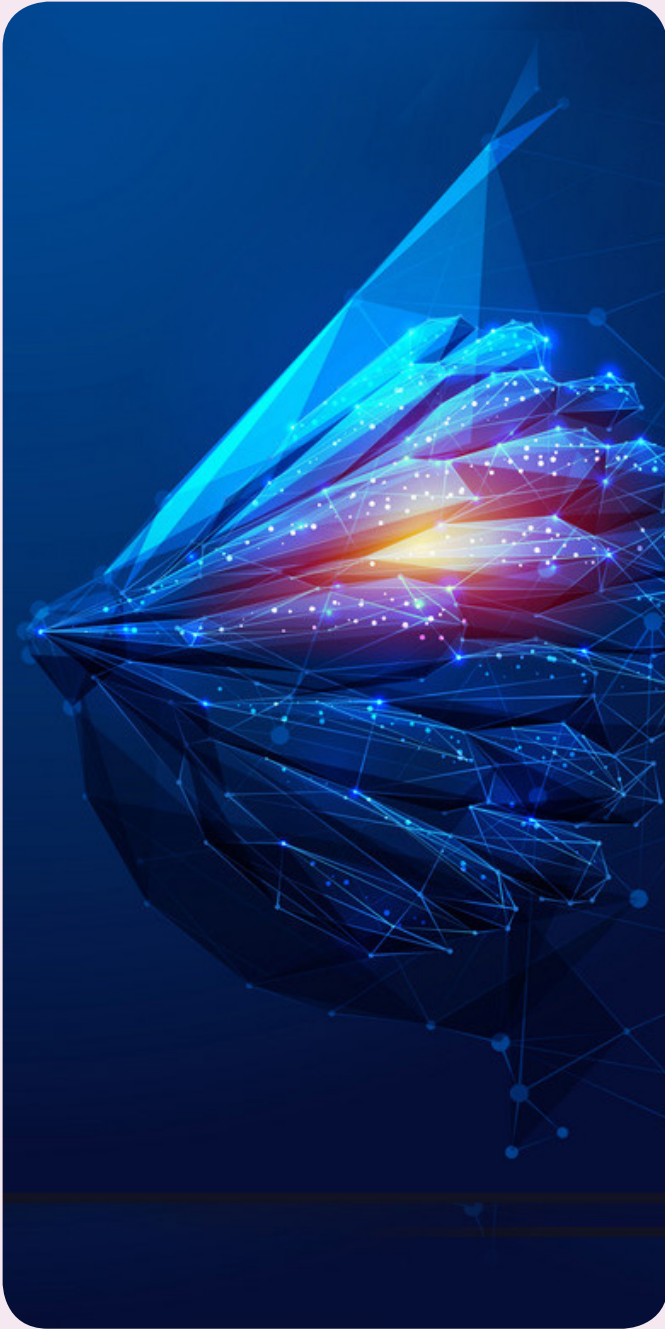
### What is meant by Breast Cancer?

Breast cancer is a disease in which cells in the breast grow out of control. There are different kinds of breast cancer. The kind of breast cancer depends on which cells in the breast turn into cancer.

### Anatomy

Breast cancer can begin in different parts of the breast. A breast is made up of three main parts: lobules, ducts, and connective tissue. The lobules are the glands that produce milk. The ducts are tubes that carry milk to the nipple. The connective tissue (which consists of fibrous and fatty tissue) surrounds and holds everything together. Most breast cancers begin in the ducts or lobules.

Breast cancer can spread outside the breast through blood vessels and lymph vessels. When breast cancer spreads to other parts of the body, it is said to have metastasized.



## Types of Breast Cancer

The most common kinds of breast cancer are:

- Invasive ductal carcinoma. The cancer cells grow outside the ducts into other parts of the breast tissue. Invasive cancer cells can also spread, or metastasize, to other parts of the body.
- Invasive lobular carcinoma. Cancer cells spread from the lobules to the breast tissues that are close by. These invasive cancer cells can also spread to other parts of the body.
- There are several other less common kinds of breast cancer, such as Paget's disease, external icon medullary, mucinous, and inflammatory breast cancer.

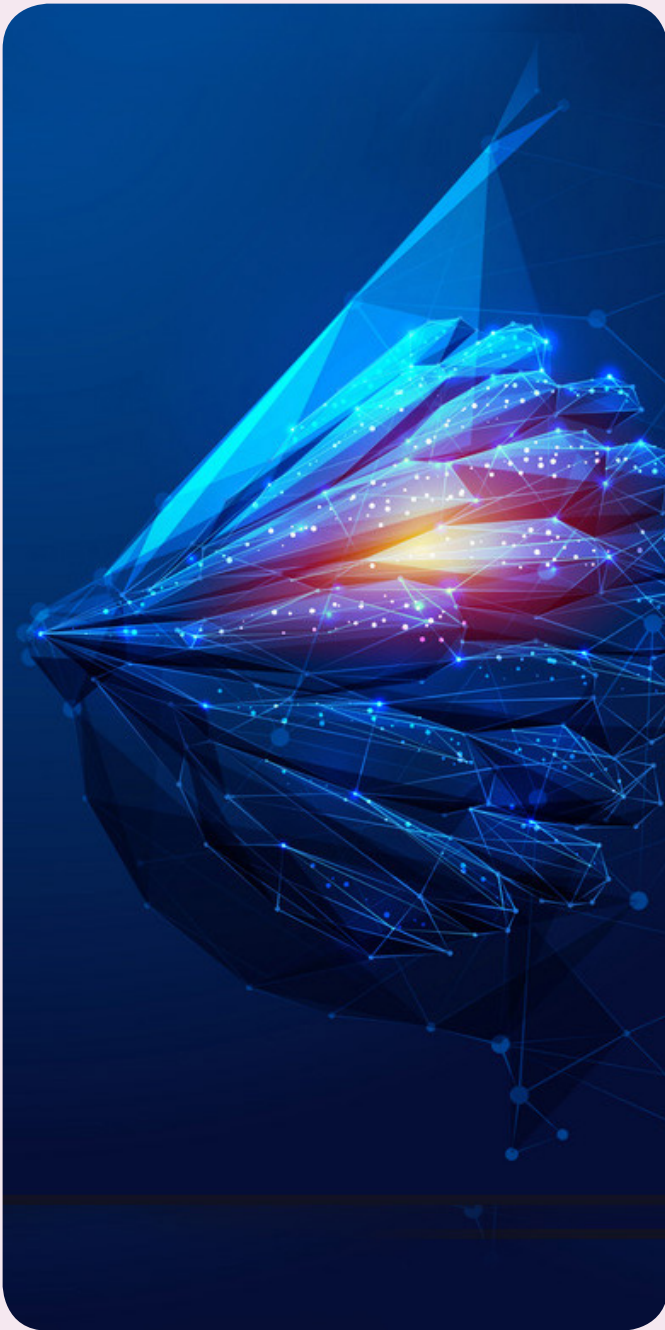
## Risks Factors

A “risk factor” is anything that increases your risk of developing breast cancer. Several of them for breast cancer have been well documented. However, for the majority of women presenting with breast cancer it is not possible to identify specific risk factors.

### I. Risk factors you can control

- Weight. Being overweight is associated with increased risk of breast cancer, especially for women after menopause. Having more fat tissue means having higher estrogen levels, which can increase breast cancer risk.
- Diet. Studies are looking at the relationship between diet and breast cancer risk and the risk of recurrence. The Women's Health Initiative Trial suggested that a diet very low in fat may reduce the risk of breast cancer.

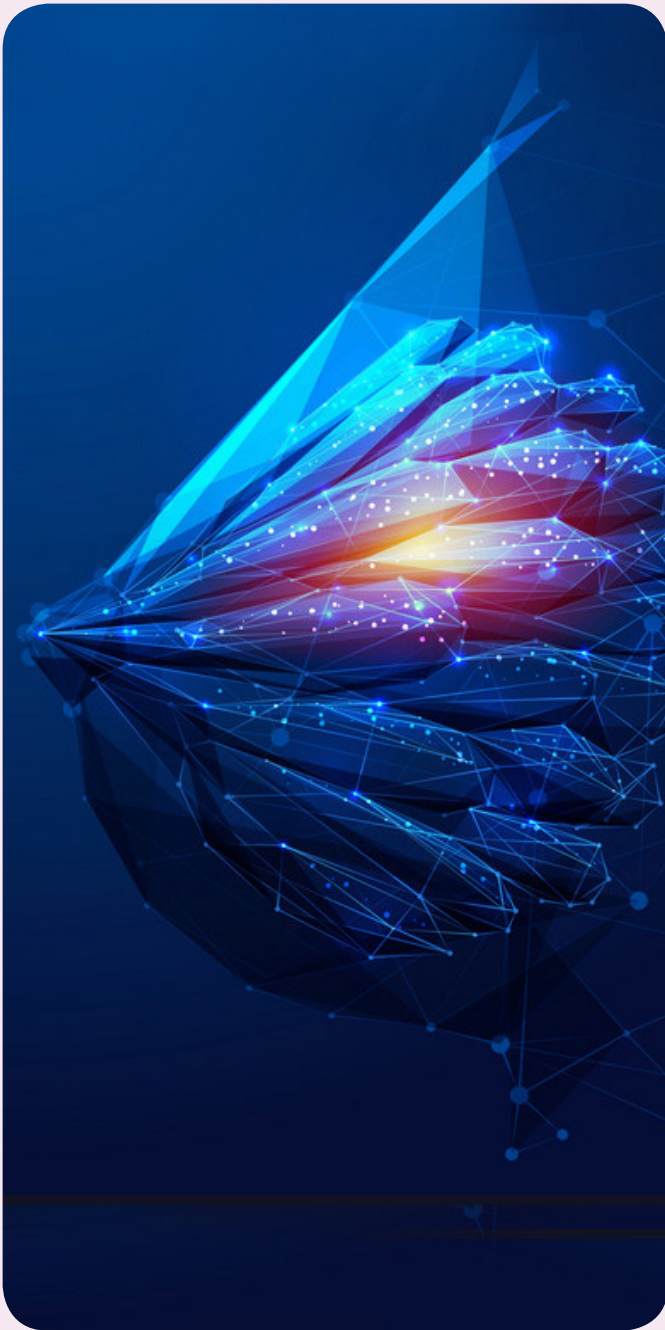




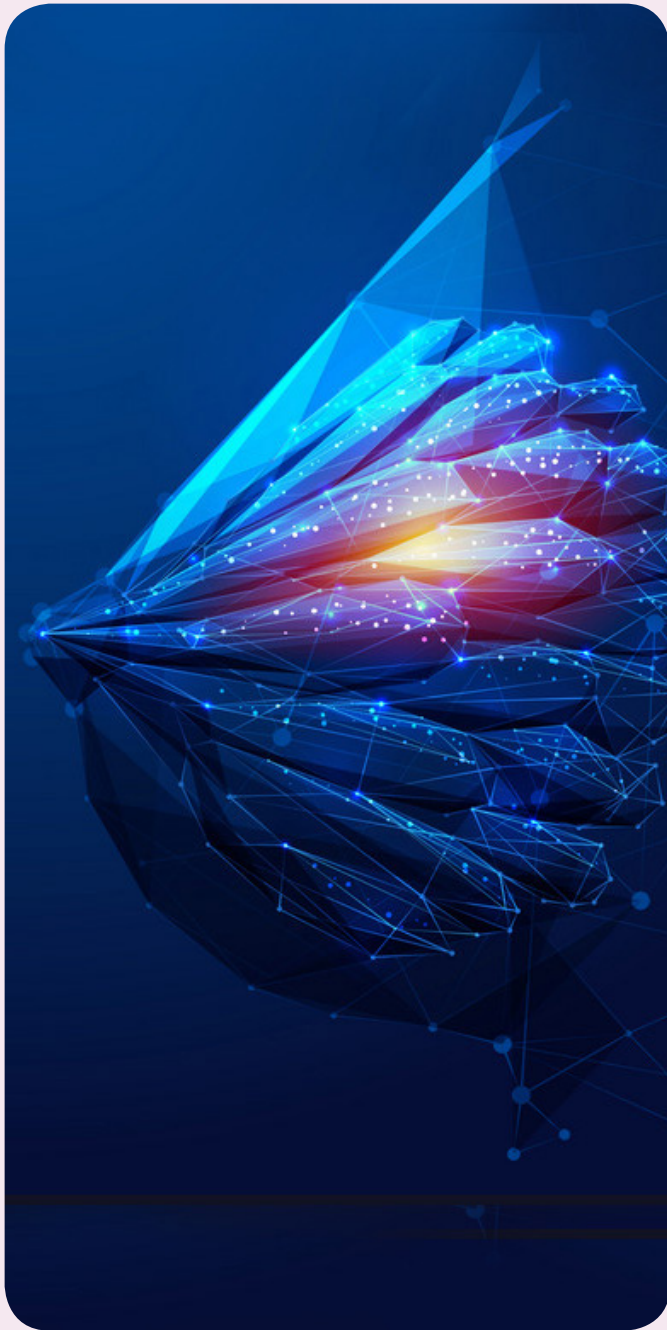
- Exercise. Evidence is growing that exercise can reduce breast cancer risk. The American Cancer Society recommends engaging in 45-60 minutes of physical exercise 5 or more days a week.
- Alcohol consumption and smoking. Studies have shown that breast cancer risk increases with the amount of alcohol a woman drinks and smoking. Alcohol can limit your liver's ability to control blood levels of the hormone estrogen, which in turn can increase risk.
- Recent oral contraceptive use. Using oral contraceptives (birth control pills) appears to slightly increase a woman's risk for breast cancer, but only for a limited period of time. Women who stopped using oral contraceptives more than 10 years ago do not appear to have any increased breast cancer risk.
- Stress and anxiety. There is no clear proof that stress and anxiety can increase breast cancer risk. However, anything you can do to reduce your stress and to enhance your comfort, joy, and satisfaction can have a major effect on your quality of life. Some research suggests that mindfulness practices can strengthen the immune system.

## II. Risk factors you can control

- Gender. Being a woman is the most significant risk factor for developing breast cancer. Although men can get breast cancer, too, women's breast cells are constantly changing and growing, mainly due to the activity of the female hormones estrogen and progesterone. This activity puts them at much greater risk for breast cancer.
- Age. Simply growing older is the second biggest risk factor for breast cancer. From age 30 to 39, the risk is 1 in 228, or .44%. That jumps to 1 in 29, or just under 3.5%, by the time you are in your 60s.
- Personal or family history of breast cancer. If you have already been diagnosed with breast cancer, your risk of developing it again, either in the same breast or the other breast, is higher than if you never had the disease.



- Genes. If you have a first-degree relative (mother, daughter, sister) who has had breast cancer, or you have multiple relatives affected by breast or ovarian cancer (especially before they turned age 50), you could be at higher risk of getting breast cancer.
- Ethnicity. White women are slightly more likely to develop breast cancer than are Black women. Asian, Hispanic, and Native American women have a lower risk of developing and dying from breast cancer.
- Radiation therapy to the chest. Having radiation therapy to the chest area as a child or young adult as treatment for another cancer significantly increases breast cancer risk. The increase in risk seems to be highest if the radiation was given while the breasts were still developing (during the teen years).
- Exposure to estrogen. Because the female hormone estrogen stimulates breast cell growth, exposure to estrogen over long periods of time, without any breaks, can increase the risk of breast cancer. Some of these risk factors are not under your control, such as:
  - starting menstruation (monthly periods) at a young age (before age 12)
  - going through menopause (end of monthly cycles) at a late age (after 55)
  - exposure to estrogens in the environment (such as hormones in meat or pesticides).
- Lack of pregnancy. Women who have never had a full-term pregnancy, or had their first full-term pregnancy after age 30, have an increased risk of breast cancer. For women who do have children, breastfeeding may slightly lower their breast cancer risk, especially if they continue breastfeeding for 1 1/2 to 2 years.

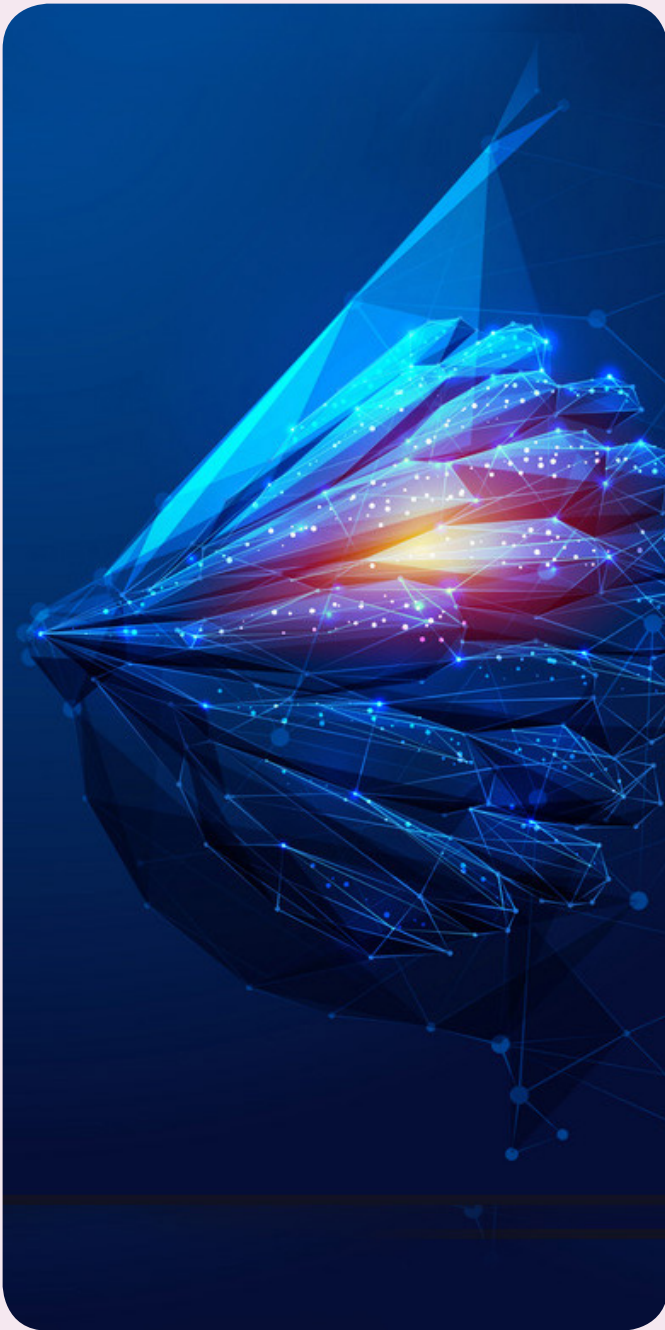


## How a breast cancer is categorized?

The stage at diagnosis for breast cancer is categorised according to the Tumour, Nodes, Metastasis (TNM) staging system:

- early or localized stages. Tumours without lymph node involvement or metastasis (T1-3, N0, M0)
- intermediate stage. Tumours with lymph node involvement but no metastasis (T1-3, N1-3, M0)
- advanced stage. Large Tumours with ulceration or involvement of the chest wall, and those that have metastasised to other organs (T4, any N, M0 or M1).





## Treatments

Following a diagnosis, the patient will be entrusted to a unit of specialists (oncologists, breast surgeons, breast radiologists, psychologists etc.) who will accompany him/her on his/her journey.

In this case it is normal to feel lost in an unfamiliar environment, stressed or anxious. The right time to be able to metabolize the news and to inform oneself through the healthcare staff will allow to cope psychologically with the treatment plan.

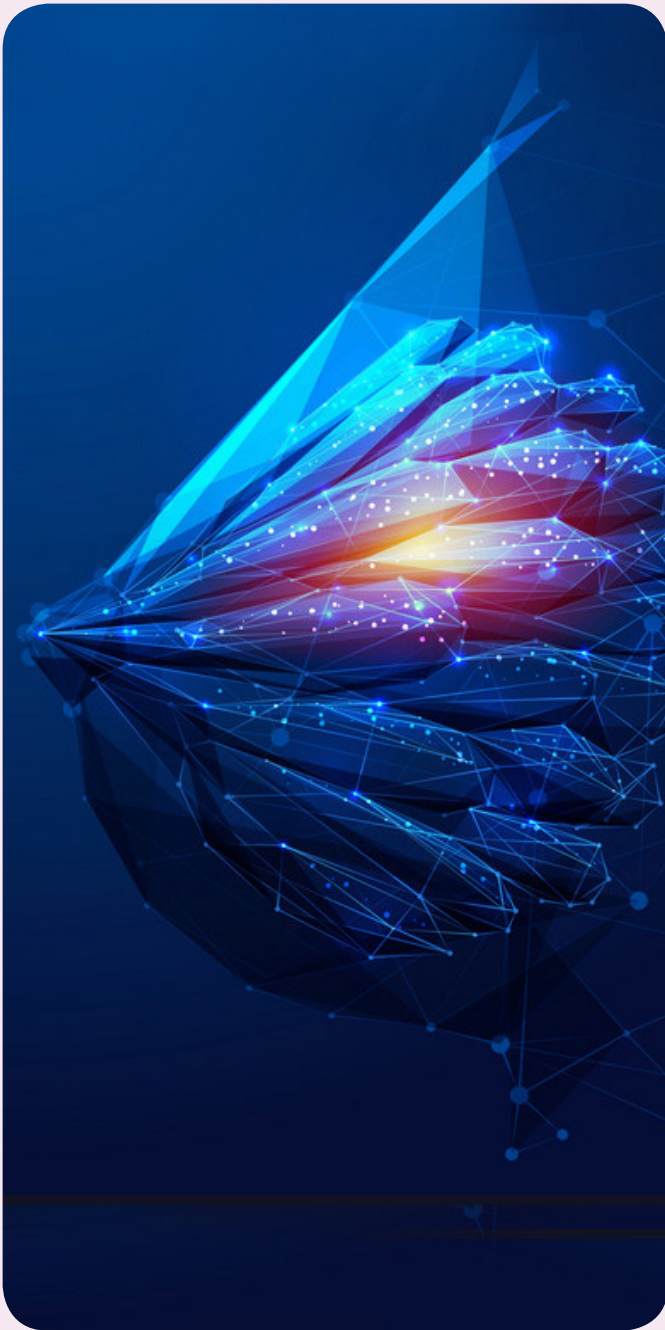
Some of the most common therapies\*

- Surgery
- Mastectomy
- Radiotherapy
- Chemotherapy
- Hormonotherapy
- Biological and other therapies

\*The therapy will be defined by the treating physician according to the specificity of the case

## Prevention

Frequent monitoring as well as effective prevention that promotes a healthy diet, physical activity and control of alcohol intake, overweight and obesity, can have a strong impact in reducing the incidence of breast cancer in the long term.



## Early diagnosis

Early diagnosis remains an important early detection strategy, particularly in low- and middle-income countries where the diseases is diagnosed in late stages and resources are very limited. There is some evidence that this strategy can lead to early recognition of the disease (“down staging”) to stages more favourable for curative treatment (Yip et al., 2008).

## Mammography screening

Mammography screening is the only screening method that has proven to be effective. The following recommendations are for women who do not have symptoms of breast cancer, who are not at high risk of breast cancer and want to know when they should attend screening and with which frequency.

- Women aged 40-44: no screening
- Women aged 45-49: screening every 2 or 3 years
- Women aged 50-69: screening every 2 years
- Women aged 70-74: screening every 3 years

Woman should follow doctor recommendations and not neglect the power of the screening.

### **Breast self-examination (BSE)**

The practice of BSE has been seen to empower women, taking responsibility for their own health. Breast self-exam can be an important way to find a breast cancer early, when it's more likely to be treated successfully. Performing breast self-exam in combination with other screening methods could increase the odds of early detection.

### **Clinical Breast Examination (CBE)**

A clinical breast exam is an examination by a doctor or nurse, who uses his or her hands to feel for lumps or other changes. This practice was particularly used before mammography produced such precise and sophisticated results. Nevertheless, it can be useful in producing risk awareness.



## Anti-cancer lifestyle

It is widely believed that in order to prevent a serious illness such as cancer it is necessary to undergo many expensive tests. However, this is not exactly correct: the early detection tests on which all experts in the field currently agree are however, few and relatively simple.

It has been certified that if everyone adopted a proper lifestyle, around one in three cases of cancer could be avoided. So, prevention is in everyone's hands.

### Physical Health

Physical well-being is a preventive factor that can be controlled by the person. It is determined by numerous factors, including primarily nutrition and exercise. Keeping physically active and having a proper diet are therefore key elements in the prevention of breast cancer. Let's explore in detail how this can be done.

### Nutrition

#### 10 points for better health

According to the American Institute for Cancer Research (AICR) more than 30% of cancers are directly attributable to incorrect diet, both in quantitative and qualitative terms.

A large percentage of cancers could therefore be prevented simply by a correct diet and a targeted choice of foods.



## What these 10 points for a healthy diet could be?

- **Weight.** To find out if your weight is in an acceptable range, it is useful to calculate the Body Mass Index (BMI = weight in Kg divided by height in meters squared: for example, a person who weighs 70 kg and is 1.74 tall has a BMI =  $70 / (1.74 \times 1.74) = 23.1$ ), which should remain within the range considered normal (between 18.5 and 24.9 according to the World Health Organization).

- **High-calorie foods.** High-calorie foods are generally industrially refined, precooked and pre-packaged and contain high amounts of sugar and fat, such as foods commonly served in fast food restaurants and sweets. If you can occasionally eat a very fatty or sugary food, but never on a daily basis, the use of carbonated and sugary drinks should instead be avoided, also because they provide abundant calories without increasing the sense of satiety.

- **Fruit and vegetables.** Base your diet mainly on foods of vegetable origin. These products are important because they provide carbohydrates (especially starch and fiber), but also vitamins, minerals and other substances of great health interest.





Add vegetables and fruit, at least five portions a day (for about 600g) are recommended; note that potatoes should not be counted among the vegetables.

- **Meat.** Limit the consumption of red meat and avoid the consumption of preserved meat. Red meat includes sheep, pork and beef, including veal. As they are not recommended, it is advisable for regular eaters to swap red meat for other protein-rich alternatives, as white meat or legumes). Note the difference between the terms “limit” (for red meat) and “avoid” (for preserved meat, including all forms of canned meat, cold cuts, hams, sausages), for which it cannot be said that there is a limit below which there is probably no risk.

- **Legumes.** Legumes (beans, chickpeas, lentils, peas etc.) are good sources of dietary fiber. Dietary fiber has no nutritional or energetic value but is equally important for the regulation of various physiological functions in the body.

- **Salt.** Limit the consumption of salt (no more than 5 g per day) and food preserved in salt. Avoid food contaminated with mould (especially cereals and legumes). Make sure

that the cereals and legumes you buy are in good condition and avoid storing them in hot and humid environments.

- **Water.** Generally, all European countries recommend drinking 1.5 or 2 liters of water per day. It’s important to try to anticipate thirst, drinking slowly, frequently and in small quantities. Water may be consumed before, during, and after lunch, as it does not affect digestion. Coffee and soft drinks not considered equivalent to water.

- **Alcohol.** Alcohol is not recommended, but for those who consume it is recommended to limit themselves to a quantity equal to one glass of wine (120 ml) per day for women and two for men, only during meals. The quantity of alcohol contained in a glass of wine is approximately equal to that contained in a can of beer and in a small glass of a distillate or liqueur. However, as scientific research findings show a clear correlation between alcohol intake and breast

- cancer, we strongly recommend minimizing alcohol consumption in favor of alcohol-free drinks. Indeed, even moderate consumption of alcohol has been linked to an approximate 30-50% increased risk in breast cancer.





▪ **Variety.** The easiest and safest way to guarantee an adequate supply of energy and nutrients is to vary the choices as much as possible and to combine different foods. The main groups of food, other than vegetables and fruit, which must always be present at the table are:

o **fats** must be present, limiting the consumption of condiment fats of animal origin (butter, cream, etc.) and preferring fats of vegetable origin (as olive oil).

o **milk** and derivatives (moderately) whose main function is to provide calcium. However, all cheeses contain high amounts of fat: choose skimmed milk, the leaner cheeses, or consume smaller portions.

o **fish**, white meat and eggs that provide high quality protein. Eat fish more often, both fresh and frozen (2-3 times a week). Among meats, prefer lean meat and eliminate visible fat. If you like eggs, you can eat up to 4 eggs per week, distributed over the various days.

o **cereals** (bread, pasta, rice, and other cereals preferably whole meal) must be present at each main meal, avoiding adding too many fatty seasonings.

▪ **Fun.** Yes, a colorful and creative diet can help us to maintain healthy habits without taking refuge in junk food. It would seem that one of the tricks to maintaining a healthy diet is always trying to invent new recipes. If you don't think you have time to do this, we can find a solution together!

Think of one of the dishes you do most often that makes you feel good! Does it follow the recommendations we have just listed? Can some simple changes make the dish healthier? Let's write the recipe and share it with each other, to create a recipe book and exchange advice on how to make our dishes tastier and healthier!





## Exercise

### Be physically active every day



A physical effort equivalent to a quick walk for at least half an hour a day is sufficient; however, as you feel fitter, it will be useful to extend exercise for up to an hour or practice a more demanding sport. The use of the car for travel and the time spent watching television are the main factors that favour sedentariness in urban populations.

Some advice on how to move almost without thinking about it:

- Take the stairs instead of the lift
- Whenever you can, choose to walk or cycle instead of taking the car
- Take some time to take a walk, e.g. during your lunch break
- Use a room bike while watching television
- Use APPs or videos in YouTube to do some simple physical exercises at home
- Visit Prolepsis APP, Module2.



## Psychological Health

### Mindfulness

The practice of meditation and reflective exercises can allow you to feel more in contact with yourself, free from the turbulence of your own thoughts and feelings.

### What is Mindfulness

Mindfulness is both the practice and the result. It entails being present, in the moment, being aware and open to experience as it comes.

A growing sense of calm and composure is a likely outcome, but that is not the goal you actively pursue while practicing mindfulness, nor is it a task to be completed

### How?

No specific posture or position is required, but it's highly recommended to find a comfortable one, that you can maintain with ease and without significant discomfort, one that makes you feel dignified and allows you to breathe easily.

### When?

What matters is to practice. Regularly and every day, if possible. Choosing a dedicated moment of your day and keeping it constant can be a great help. Practicing once or twice a day can be a good balance.

It's highly recommended to avoid the hours immediately after meals: the relaxing response elicited by mindfulness practice can interfere with digestion.





### Where?

You can meditate everywhere!

Mindfulness can be practiced with very little limitations with regard to your surroundings.

For beginners and for a regular practice, though, it's important to find a quiet place.

### Why?

Research suggest that mindfulness helps us tune out distractions and improves our memory and attention skills.

It also improves our ability to recall information. Helps regulate emotions.

Mindfulness allows us to make a change in our attitude towards thoughts, emotions, feelings and memories that we usually label as “troubling”.

It makes us aware and gives us a chance to choose how we might respond to those inner experiences. To be aware without being judgmental



## Self-evaluation

There are some applications that can help you to monitor your progress and track your improvements. These are not a substitute for expert opinion, but they can be useful in the daily management of your health.

Please visit Prolepsis App: Module 2 and Module 4 to know more about it and resources you can use to meditate and practice Mindfulness.

## Self-monitoring and Self-examination

Breast examination by the clinician or by the person is not recommended as the only screening method but rather as a complementary one.

**However,** it is important to educate women about breast awareness and to encourage them to report any breast concerns or changes to the clinician.





A breast self-exam is an inspection of your breasts that you do to determine any changes to your breasts and form a vital early detection method but [why is Breast Self Examination so Important?](#)

- Early diagnosis of cancer can result in improvements in both the stage of cancer at presentation and mortality from cancer.
- Research shows the decrease in breast cancer mortality in women under age 65 was due to improved early diagnosis and the provision of effective treatment.
- Similar improvements in breast cancer mortality were seen in other countries. If breast cancer is detected early, it can be cured completely.
- Reducing delays in care can have a significant impact on improving outcomes by providing care at the earliest possible stage.
- Women may choose to become familiar with their breasts by occasionally inspecting their breasts during a breast self-examination.
- If there is a new change, lumps or other unusual signs in breasts, women should consult a doctor.
- Optimally Breast self-examination needs to be performed monthly in order to be able to have a consistent monitoring of the breast status

### [When to conduct BSE?](#)

It's recommended that you examine your breast [one week after your menstruation](#) begins, if you no longer menstruate choose a date that is easy to remember and repeat the [self-exam](#) each month.



## How to perform the breast self-examination?

Perform yourself exam in each of the following positions: arms at your side; arms raised above your head and bending forward; hands on your hips and touching over.

### Inspection and Palpation are the crucial components of BSE.

For inspection stand in front of the mirror exposing the chest up to the Waist and Observe the breasts for any changes. Do inspection in different positions (Please visit Prolepsis APP Module 3, for videos ´demonstration and other resources such as how to perform BSE and alert signals).

For a correct palpation: palpate the breast using fingers for any increase in the thickness or lump.

- Use the palm surfaces of the fingers.
- Start with applying “minimal” pressure to feel they are just beneath the skin and then gradually increase the pressure to feel the tissue deeper within.

### This are the alert signs!

A swelling in your armpit or around your collarbone

- A lump or thickening that feels different from the rest of the breast tissue
- A change in skin texture such as puckering or dimpling (like orange skin)
- Your nipple becoming inverted (pulled in) or changing its position or shape
- Discharge (liquid) that comes from the nipple
- Constant pain in your armpit or in your breast
- Rash or redness on the skin and /or around the nipple
- A change in size or shape.





It's normal to feel nervous or anxious about a mammogram, but you should still go. “The whole experience can be anxiety-provoking — before, during, and after. It can be helpful to acknowledge that, and then move on to focus on why do it in the first place. Invest in early-stage identification!



### How can ICGs reduce the discomfort and anxiety related with mammogram?

- History: Inform the technician about any history of painful mammograms and fibrocystic breasts.
- Timing: Schedule the mammogram for the week after a menstrual period. During and immediately before a period, hormonal swings can increase breast sensitivity.
- Breathing: Taking slow, deep breaths prior to the imaging can reduce tension-induced pain, and it may ultimately help produce a more accurate image.
- Stay still during the imaging: Moving — even taking a breath — while the technician is actually taking the X-ray can blur the image.
- Delaying if breastfeeding: Anyone who is breastfeeding, but who will wean soon, may want to delay mammograms to avoid pain



### Tips to Deal with Pre-Mammogram Nervousness

Remember statistics are overwhelmingly on your side. Of all the breast tumors found through mammography, the higher percentage are benign

- Try to see your mammograms as a routine part of your life
- Schedule something you enjoy after your mammogram. Offer yourself immediate rewards for prioritizing your health! Just make sure to give yourself the rewards right away to give your brain the positive feedback it needs (ex. Go to manicure or pedicure or do something you like).
- Make a pact with a friend. Arrange with a friend to encourage each other (and hold each other accountable) to get screening mammograms on schedule. Talk also to friends and family and share experiences.

- Let the staff know you're nervous. They will be empathic with you and calm you, explaining all the steps.

- Push through your anxiety, because your health is worth it. Bring a friend to the waiting room with you if it helps, and/or read the next few pages of a great book on your phone or play a game or just talk with a friend in the social media. These strategies can distract you during your short wait time. Reduce your anxiety by using meditation, mindfulness, or relaxation techniques (there are CDs and apps for that!).

- At night, a drink like chamomile tea can help as this is a natural sedative

- If despite your best efforts to control it, your anxiety is unbearable, ask your physician for a short course of an anti-anxiety medication.

To know more about this, how ICGs can cope with the wait, how to deal with anxiety and fear, what comes after a positive result, how ICGs can prepare themselves for a breast biopsy and other resources please visit Prolepsis App Module 3.

# 8. Healthcare professionals







Healthcare Professionals who are active in community-based prevention programmes - willing to learn how to reach out to informal caregivers as a specific target group and to focus on their specific health prevention needs - take in consideration the following suggestions.

Being a IC it means she provides – usually – unpaid care to someone with a chronic illness, disability or other longlasting health or care need, outside a professional or formal framework (Eurocarers). Most of the ICGs don't recognize themselves as caregivers but they see care as an extension of their roles as family members, per example as mothers, daughters, wives

The vast majority of health care is actually provided by families, not by healthcare professionals.



Caring can really be a rewarding experience and make caregivers feel well and positive. But caregivers when not fully supported can experience:

- Power quality of life
- Poverty
- Loss of Income
- Unemployment
- Physical Health Problems (ex. difficulties in sleeping; headaches; hypertension and cardiovascular diseases)
- Mental Health Problems (ex. depression, anxiety)
- Difficulty to maintain included in the Labor market
- Less availability to participate in sport and leisure activities

Caregivers can feel stressed and overwhelmed. But each person is different. ICGs may feel sad, angry or worried. There is no right way for ICGs to feel. Ask ICGs to give some time to think themselves. Some feelings that may come and go are:

Some feelings that may come and go are:

- Sadness
- Anger
- Grief
- Guilt
- Loneliness

Ask ICGs to share their feelings with others. This can help to talk about how they feel.

## Why should Healthcare professionals invest in informal caregivers 'health promotion and BC screening?

Caregiving of a person with a chronic disease can be a contributing factor of poor screening adherence as well don't attain breast cancer information, neither adopting breast health behaviors. It is possible the caregiving role may reduce the amount of time available to engage in preventive health services. Studies show that most caregivers of people with major caregiving needs were unable to leave the care recipient alone and had to organize their time according to the daily activities of the recipients (Kinnear et al., 2010). Other earlier studies (e.g., Burton et al., 1997) have shown a significant association between caregiving level and inadequate exercise, inadequate rest and forgetting to take medication.

Caregiving has been identified as a significant factor that can lead to poor utilization of health care services in the early stages of BC (Kinnear et al., 2010). Informal caregivers may be less likely to meet their own health needs, may face higher allostatic load levels and have higher levels of mortality and morbidity as they age (Sheets et al., 2014). These studies emphasize on caregivers' impaired health behaviors, such as neglecting their own health care appointments and non-seeking cancer screening tests compared to non-caregivers (Son et al., 2007). As nearly two-thirds of informal caregivers aged over 50 years are women (Carretero et al., 2012), the burden of caregiving raises concerns regarding women's health including BC prevention.



## Behavioral characteristics of informal caregivers

Caregiving is an important public health issue, in part, because of what is considered the ‘caregiver burden.’

This is defined as the state of physical, emotional, and mental exhaustion resulting from the intense demands of caregiving. For those who take on caregiving roles, the prevailing view from the research literature, public policy statements, and the lay publicist that becoming an informal caregiver for a disabled family member is often a chronically stressful experience that can become overwhelming and may even become hazardous to the caregiver’s own health (Pinquart & Sörensen, 2003; Vitaliano, Zhang, & Scanlon, 2003; Schulz & Sherwood, 2008).

The defining characteristics of an informal caregiver typically include being a person who provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability. In addition to some definitional differences across studies, there is also considerable variability on many caregiving-related factors. Caregivers differ in the relationships they have with their care recipients (e.g., spouse, adult child, other relative, in-law, neighbor or friend), their living arrangements (e.g., co-residing vs. not living with the care recipient), whether the person is a “primary” caregiver or someone who provides more secondary and supplemental support, the clinical conditions of the care recipients (e.g. dementia, frailty, stroke, etc.), and other indicators of the extent and involvement in

providing care.

A major contribution to the physical and emotional toll of caregiving is that many caregivers do not identify themselves as such, and typically do not seek assistance for themselves.

Informal family caregiving is often described as a burdensome role that has all of the hallmarks of a chronic stress experience (Schulz & Sherwood, 2008).

Many studies also suggest that caregivers have poorer physical health when compared with various samples of non-caregivers (Pinquart & Sörensen, 2003; Vitaliano, Zhang, & Scanlon, 2003).

Although, European guidelines are in place for the provision of mammography screening for the early detection of BC, women for various reasons (e.g., lack of knowledge, limited health literacy) do not attend these screenings as expected despite their awareness on the availability of preventive cancer screening tests (Moudatsou et al., 2014). Women who assume the role of the informal caregiver face additional challenges in engaging in health promotion practices such as BC screening (Kinnear et al., 2010). Explicitly, studies on caregivers’ health behaviors stress the presence of impaired health behaviors, such as neglecting health care appointments, eating a poor quality diet, limited exercise time and forgetting to take prescribed medications, compared to noncaregivers (Burton et al., 1997).

### Why is important Self-efficacy?

Self-efficacy refers to the level of confidence in how well ICGs can accomplish a task or group of tasks.

In this way, this depends:

- In their own estimate level of capability to perform in the environment,
- their feelings of increased confidence in accomplishing a particular task, and
- Theirs' belief system that allows you to have control over their thoughts, feelings, and actions.

### Knowledge and skills are not the only things that determine if a task can be performed

If ICGs feel comfortable with a given activity, they are more likely to take part in it. People tend to stay away from activities that make them feel uncomfortable.

- Motivation has been directly linked to how capable a person feels.
- A very confident person will be more motivated.
- Promoting self-efficacy will promote their well-being as well the well-being person they care for.

**As Healthcare Professional please be certain you address ICGs' needs. Promoting capacitation, giving information about community resources and reinforce the role of self-care is very important. What advice you can give to ICGs?**

### What may you say to inspire ICGs?

- During the day, find space for your free time, even if it is only for an hour or less, and do something you like indoors or outdoors (read a newspaper, take a relaxing bath, learn a new language, exercise or relax, go for a walk, go shopping).
- Don't keep it all inside. If you are stressed or depressed, try to talk to someone about it. It often helps to talk about things with someone you trust rather than keeping it inside.
- Try not to take your loved one's anger personally.
- Cry and express your feelings if you feel the need to do so.
- Keep hoping. Remember that you are suffering from an experience that many other people have gone through. You will come out of it in the end, although it may be hard to believe at the moment.
- Be welcoming to yourself. Remember that no one is perfect, and chances are you are doing everything you can. Don't blame yourself!

### Key Points to always remember:

- Make time for yourself, for example involve yourself in outsider activities
- Give your self-time to stay in connection with **friends**
- You may feel too busy or worried about your loved one to think or even neglect your own health. Invest in prevention and healthy lifestyles
- Don't miss exams such as Mammography screening recommendations by your doctor
- If it's difficult to manage time with caring responsibilities, ask for help
- Try to be physically active everyday
- Try to eat healthy meals
- Get enough rest for your health. Sleep well
- Get informed to use community and social resources
- As a caregiver remember to Focus on your needs, too. Asking for help is not a sign of weakness or failure

Focus on what you have done well- and forgive yourself.

### Daily ICGs can live diverse challenges that can impact the way they spend time:

- They can feel tiredness, sadness, despair, anxiety
- Lack of motivation
- Low self-confidence
- Relationship and communication difficulties

**The first things to go when we're crunched for time are usually Nutrition and Physical exercise.**

**However, it's during times of stress that these things are more important than ever.**

- Do Exercise, it increases your levels of energy and can help you do more with the rest of the day.
- Also, Healthy eating can raise your mood alongside with exercise
- Prioritize self-care
- Spread positivity, when you feel good, the person you care benefit of your positive attitude
- Cultivate a Calm Mind
- Practice meditation
- Put things in perspective (most things are not urgent, ex. Does it really matter if ironing gets done today?)
- Breathe deeply and relax to gather your thoughts.

These and other resources can be accessed in Prolepsis APP, Module 4.

Healthcare Professionals who are active in community-based that want to Know how to reach out ICGs as a specific target group to develop Prolepsis training, please take in consideration these tips:

- Do partnerships with caregivers ´associations in your community
- Do synergies with local health and social providers
- Engage community using TV, radio and/or networks (like Facebook, Instagram, and Twitter) to invite ICGs to Prolepsis training sessions
- Use appealing marketing resources (ex. newsletters, card invitations), indicating the dates, times, and place of the trainings as well as contacts for information and registration.
- Involve other health/social providers or volunteers to care if is needed while ICGs participate in Prolepsis training program. Give caregivers an option to enhance the possibility to do Prolepsis Training-if needed.
- Networking between users of Healthcare Professionals services

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### 3 ΓΙΑ ΔΩΡΕΑΝ ΠΑΝΤΕΒΟΥ (ΣΥΝΑΝΤΗΣΕΙΣ) ΓΙΑ ΠΡΟΛΗΨΗ ΤΟΥ ΚΑΡΚΙΝΟΥ ΤΟΥ ΜΑΣΤΟΥ

**ΕΚΠΑΙΔΕΥΣΗ ΓΙΑ ΓΥΝΑΙΚΕΣ ΦΡΟΝΤΙΣΤΕΣ**

ΑΠΟ 6 ΕΩΣ 11 ΣΕΠΤΕΜΒΡΙΟΥ 2021, ΔΙΑ ΖΩΣΗΣ ΣΥΝΑΝΤΗΣΕΙΣ ΓΙΑ ΦΡΟΝΤΙΣΤΕΣ ΗΛΙΚΙΩΜΕΝΩΝ ΑΤΟΜΩΝ, ΑΤΟΜΩΝ ΜΕ ΕΙΔΙΚΕΣ ΑΝΑΓΚΕΣ Η ΕΞΑΡΤΩΜΕΝΩΝ ΜΕΛΩΝ ΟΙΚΟΓΕΝΕΙΑΣ

ΔΗΜΟΤΙΚΟ ΣΧΟΛΕΙΟ ΠΕΛΕΝΔΡΙΟΥ - ΛΕΜΕΣΟΣ  
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Image of three women smiling and holding hands.

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### 4 INCONTRI GRATUITI SULLA PREVENZIONE DEL TUMORE AL SENO

**FORMAZIONE RIVOLTA A DONNE CAREGIVER**

DAL 24 AGOSTO AL 21 SETTEMBRE 2021, 4 INCONTRI IN PRESENZA PER CHI SI PRENDE CURA DI FAMILIARI ANZIANI, DISABILI O NON AUTOSUFFICIENTI

SEDE DEL CORSO: FONDAZIONE CASA DEL VOLONTARIATO, CARPI (MO)  
INFORMAZIONI ED ISCRIZIONI: A.PALERMO@ANZIANIENONSOLO.IT  
WHATSAPP: 3939096596

Image of three women smiling and holding hands.

QR code

ON THE OCCASION OF **WORLD BREAST CANCER DAY 2021** THE PROLEPSIS PROJECT LAUNCHES ITS MOBILE APP!

BECAUSE **EARLY DETECTION PREVENTION IS IN OUR HANDS, START TODAY!**

DOWNLOAD IT ON YOUR DEVICE TO LEARN MORE ABOUT THE TOPIC THROUGH RECOMMENDED ARTICLES, BOOKS AND WEBINARS OR BY WATCHING INFORMATIVE VIDEOS ON HOW TO CARRY OUT ADEQUATE PREVENTION ON YOUR OWN.

FIND PROLEPSIS ON:

Image of a hand holding a smartphone displaying the Prolepsis app interface.

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# 9. Suggestions and Guidelines

The objective of this section is to share guidelines and suggestions based in the Prolepsis Pilot to better replicate the Prolepsis Training Program and how to use the Apps not only with ICGs but women's health in general. To do this, is shared the Prolepsis training course and major results. To know more about the organization, structure of the pilot in each country, as well the satisfaction with the training and the App we invite you to read the Pilot report available at Prolepsis site.



## Prolepsis Training Experience

### Pilot training program and partners' adaptation

Aim of the Prolepsis training is to build an e-health educational programme which enables participants to increase their knowledge of breast cancer and the importance of prevention and provides them with the skills to selfmanage their own health monitoring. The educational materials have been provided in accordance with the HBM model, mostly to increase female caregivers' awareness on Breast Cancer symptoms, on screening exams as mammography and to cultivate and improve their practices on preventive behaviours of BC including physical activity, healthy diet, and stress management techniques. The principle guiding all training modules is to increase perceived sensitivity and perceived seriousness about the threat of this malignancy and their understanding to the barriers in performing BC preventive behaviours. The pedagogical material covers different areas of intervention, which are:

- 1. Information on Breast Cancer:** what is Breast Cancer, which are the risk factors, epidemiology, and prevention methods.
- 2. Preventive lifestyle:** how to prevent BC through healthy lifestyle habits (e.g., physical wellbeing and psychological wellbeing), self-assessment of their own habits
- 3. Self-monitoring:** how to manage the self-monitoring of their own health, benefits of regular mammography
- 4. Self-efficacy:** how to alleviate feelings of tension prior to mammography screening/ strengthening positive beliefs about mammography and reduced anxiety about screening methods. To increase self-efficacy, the mobile app will provide information about practical steps that can be taken to maintain regular/ monthly BSE and it is envisioned to include a reminder system (based on user's personalized preferences) whereby the app will remind women (e.g., on-screen notifications) about their next scheduled screening test.

The model has been tested in Cyprus, Italy, and Portugal, respectively with the participation of 17 women caregivers in Cyprus, 10 in Italy and 10 in Portugal, for a total of 37 women involved, of which 28 completed the entire course. Below is a table summarising the planned training sessions and the learning outcomes of each.

## CYPRUS

The pilot was elaborated in 3 face-to-face sessions, instead of 4, over the duration of 3 weeks. The training was offered face-to-face, with self-directed learning by using the mobile application in each face-to-face meeting and was directed by three educators from the CUT research team.

The research team introduced the participants to the Prolepsis project, the pilot training, and the application.

They explained to the participants that the training will be partly delivered through the application and partly in person, developing in 4 modules. Finally, most of the time spent downloading the application together and trying out its use. The educators paid special attention in addressing all the questions made by the participants.





The training pilot plan for Cyprus stands as shown in Table 1

Format of the training (face-to-face, blended, etc)	3 face-to-face training
Duration of the training	3 hours each Module
Contents covered	Module 1 – Information on BC Module 2 – Preventive Habits Module 3 – Self-monitoring Module 4 – Self-efficacy
Total nr. of registered learners	17 registered learners
Total nr. of learners who completed the course	11 learners completed the course
Training methods used	We encouraged trainees to use the APP of Prolepsis, to watch videos for each module and make the quiz during their free time, to go through the other modules
Use of learning materials from IO2  (use of multimedia, use of all worksheets or partially, adaptations needed, etc)	We use the multimedia and a part of worksheets. Specifically, Module 1– Information on BC: multimedia + Quiz 1.1 Module 2 – Preventive Habits: multimedia + Worksheets from 2.1 to 2.5. Module 3 – Self-monitoring: multimedia and Module 4 – Self-efficacy: multimedia + Worksheets from 4.1 to 4.5.

TABLE 1.  
TRAINING PILOT PLAN FOR CYPRUS



## ITALY

The pilot course was led by a psychologist and a sociologist of ANS team, with consultancy of three experts from outside the partnership: a psychologist specialized in neuroscience and mindfulness techniques, a Doctor of Physical Sciences and personal trainer and a nutritionist biologist.

The course was organized in 4 face-to-face sessions of 1h30 each and a pre-session online, as foreseen in the programme. To facilitate the caregivers' participation, it was decided to keep only one meeting per week, on Tuesdays from 18:30 to 20:00 CET. This time schedule allowed the participation of those who are busy during the day, and the presence, only once a week, was manageable for most of them. Participants were engaged in all the sessions, but particularly in the one in which the presence of the experts allowed them to get specialist advice and suggestions – i.e., first and second sessions. The third session, on how to manage fears and anxiety on screening test, proved to be particularly emotionally intense for the participants, as narratives about the commitment to care may emerge and need to be managed and regulated by the trainers. However, the sharing of thoughts and emotions in all the course also motivated them to exchange their personal contacts to stay in touch with each other. This result is particularly important since the Prolepsis training course not only generates knowledge, but also a new social network.



The training pilot plan for Italy stands as shown in Table 2

Format of the training (face-to-face, blended, etc)	Blended mode (partly performed on the APP and partly in presence)
Duration of the training	6 hours in total, divided into 4 meetings of 1h30
Contents covered	The programme proposed within the Training Plan was fully covered with the following sessions: <ul style="list-style-type: none"> <li>• Online session via Zoom introducing the project and the Prolepsis APP</li> <li>• Module 1 – information on BC (totally online)</li> <li>• Module 2- psychological health and well-being</li> <li>• Module 2- physical health and well-being</li> <li>• Module 3- self-monitoring of health</li> <li>• Module 4- self-efficacy and the role of caregiver</li> </ul>
Total nr. of registered learners	10
Total nr. of learners who completed the course	8
Training methods used	<ul style="list-style-type: none"> <li>• Guided discussion</li> <li>• Brainstorming</li> <li>• Experiential learning</li> </ul>
Use of learning materials from IO2 (use of multimedia, use of all worksheets or partially, adaptations needed, etc)	All materials in the manual were used. Some changes have been made in terms of the order of the exercises and alternative exercises have been used where necessary, which are provided in the manual as possible choices.

TABLE 2.  
TRAINING PILOT PLAN FOR ITALY



## PORTUGAL

The course was organized in 3 face-to-face sessions. It was decided to do an intensive course giving the users the option of an additional day in order to enhance their participation and minimizing the possible dropouts.

Participated 2 researchers from Portincarers and were invited 2 experts: psychologist specialized in mindfulness and a public health nurse. All users were given specific instructions about Self-education online and the use of the APP.



Communication with users and trainers were potentiated using the WhatsApp. This facilitated continuous feedback (during the pilot), larger follow-up after face-to-face training sessions (for 3 weeks) as well promoted APP's features final tuning.

Caregivers reported a very positive experience overall, specifically in the first session referring to mindfulness exercises: they felt good and motivated to know more. The presence and the trainers assisting the download of the App was also considered very valuable specially by participants with vision problems and low digital literacy.

The training pilot plan for Portugal stands as shown in Table 3.

Format of the training (face-to-face, blended, etc)	Blended mode (partly performed on the APP and partly in presence)
Duration of the training	Originally 5,20 hours in total, divided into 3 meetings of 1h30 face to face training which evolved in the final to 6,90 hours in total.
Contents covered	The programme proposed within the Training Plan was fully covered with the following sessions: <ul style="list-style-type: none"> <li>• Introducing the project and the Prolepsis APP; Module 1-Information on Breast Cancer and Module 2- Preventive Habits.</li> <li>• Module 3- Self-monitoring.</li> <li>• Module 4- Self-efficacy.</li> </ul>
Total nr. of registered learners	10 registered learners
Total nr. of learners who completed the course	9 learners completed the course
Training methods used	<ul style="list-style-type: none"> <li>• Users encouraged to use Prolepsis APP</li> <li>• Guided discussion; Brainstorming</li> </ul>
Use of learning materials from IO2 (use of multimedia, use of all worksheets or partially, adaptations needed, etc)	All materials in the manual were used. Some changes have been made in terms of the order of the exercises.

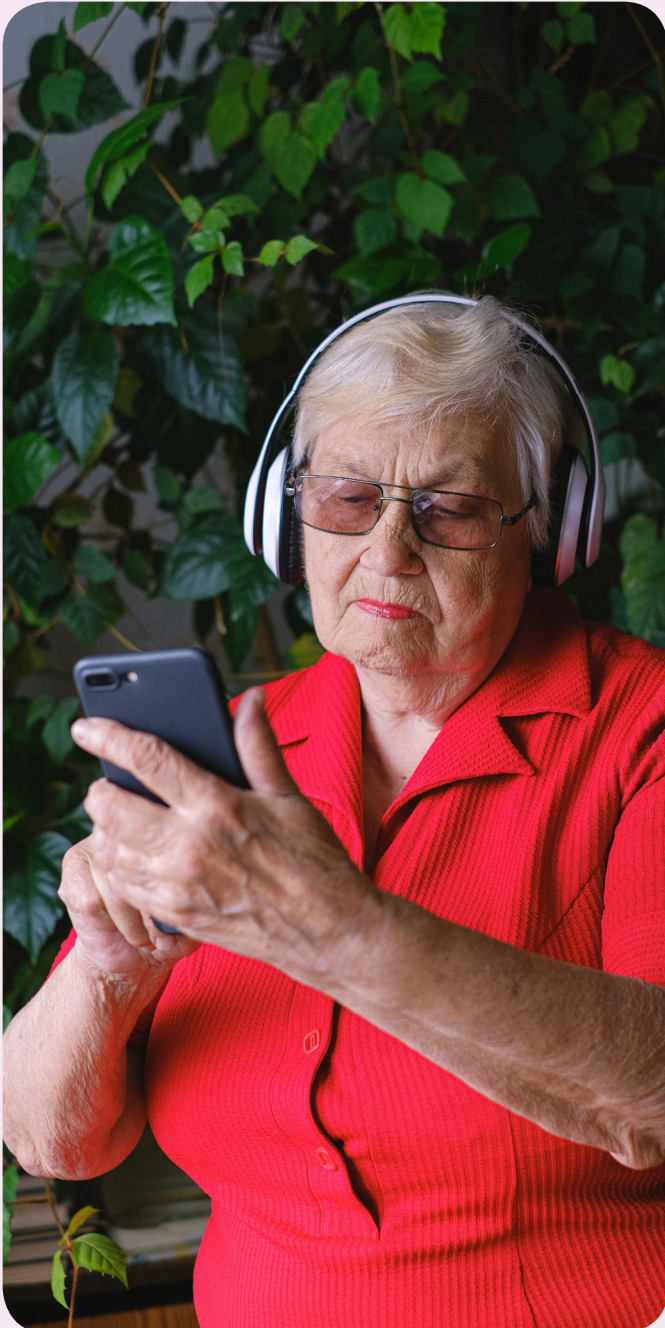
TABLE 3.  
TRAINING PILOT PLAN FOR PORTUGAL



## Challenges and suggestions to trainers

Organizing and implementing blended learning in the pandemic period obviously led to numerous challenges for the partners to overcome. The difficulties were of a different order, but mainly concerned the development of the training material and the implementation of the pilot training. The material was developed between September 2020 and April 2021: the uncertainty of the period led the partners to build exercises and activities that could also be implemented remotely in case the situation did not allow the completion of a training in presence. This aspect, which initially appeared complex to manage, later proved to be a great strength of the training programme, as it is flexible to different modalities also for future applications. Secondly, the recruitment of participants and the organization of the pilot was also particularly affected by the pandemic situation. However, the improvement in all partner countries of the situation in September 2021 made it possible to run the course as planned, i.e., partly with the Prolepsis app and partly in presence. The main challenges encountered by the partners during implementation are summarized below; they contain useful suggestions for future trainers interested in implementing the Prolepsis programme.





## Cyprus

The commitment of CUT research team to deliver a training program of the highest quality led to the decision for face-to-face training. The team considered that the value and opportunities to personally engage with the participants during the face-to-face focus group facilitate the maximization of the outcomes. Despite the challenges that technology might impose on potential users (e.g., difficulty in navigating through a mobile application), it was evident that these can be easily overcome with appropriate coaching but also with integrated properties within the application. It was considered a good opportunity to have feedback on their involvement in the research process at the same time by getting them familiar with the mobile application.



## Italy

The piloting experience in Italy was positive, welcomed by the participants and generally completed as planned.

Some initial challenges have been encountered in using Prolepsis App, which at the beginning of the pilot was not yet in its final version; this led to some difficulties for users – for example in understanding its functions, setting notifications and watching the suggested videos. However, feedbacks from them were crucial in arriving at the current version of the app, which has been optimised precisely because some caregivers gave their suggestions and advice for its improvement.

Moreover, having the course into 4 meetings had both pros and cons. On the one hand, it was possible to involve the participants for a short time at each meeting, not colluding with their care or work commitments. Also, the chosen time slot, from 6.30 p.m. to 8 p.m. (CET), was appreciated by them, as it gave them the possibility to participate at a time when they are generally more free. However, the duration of the whole cycle of one month implied that not all participants were able to participate completely, as each session had at least one of them engaged in other activities. Therefore, in view of this experience, in future adoption it would be more effective to condense the course into two meetings of three hours each, strategically chosen together with the participants, perhaps at the weekend. This would allow them to be present for the whole course.



## Portugal

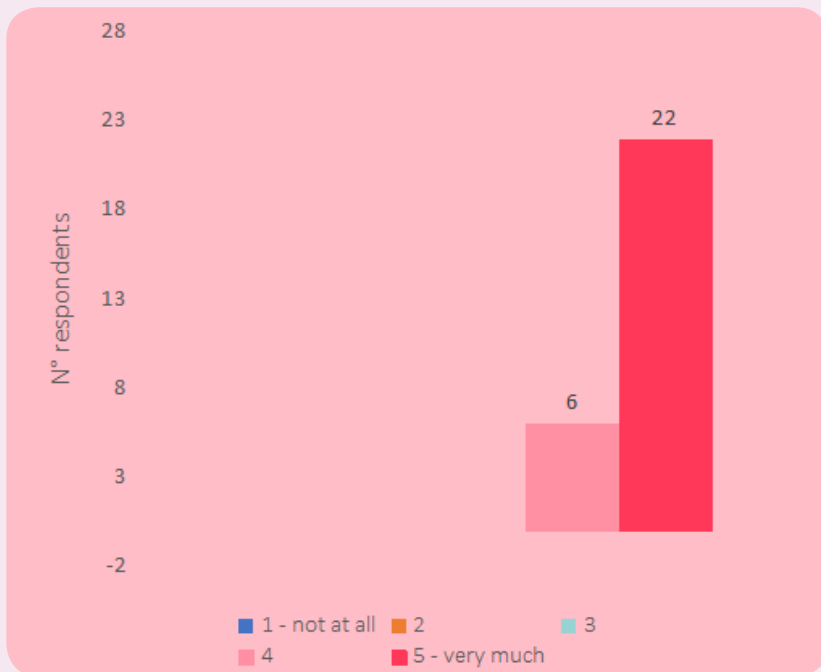
The experience in Portugal was also successful, overcoming every obstacle encountered. However, with the aim of avoiding participants dropouts related with carer responsibilities in future application of the Prolepsis programme, here are some further suggestions for trainers:

- To condensate for two days the training sessions face to face – as suggested by the other partners
- To offer a third day for those who can't attend the last day, which can be beneficial in order to promote the number of caregivers with full training
- To choose a strategic time slot, from 18.00 p.m. to 19.30 p.m. (CET), generally ideal for caregivers for conciliation with caring responsibilities. Would be beneficial to do a bigger session (2 to 3 hours) face to face but the challenge is for caregivers be present so much time out of their caring responsibilities.
- To use the Prolepsis App chat to promote communication between trainers and caregivers, fostering also group cohesion as well facilitated continuous feedback of caregivers 'experience with the App (this allowed research team to improve the App features). However, vision impairment and low digital skills can limit participants to download and login to the APP. Trainers must be free to assist caregivers to download the APP and do login. Indeed, app features and blended training have been optimized according with caregivers' feed back.
- To implement mindfulness activities as informal caregivers in Portugal (but also in Italy and Cyprus) enjoyed them very much. and appreciated the participation of a psychologist and a public health nurse. It's recommended the participation of these professionals in training sessions.
- To personalize the training to caregivers' characteristics, life story and specific needs, which can help to engage, motivate, and create empathy with caregivers.



## Prolepsis Training Pilot major results

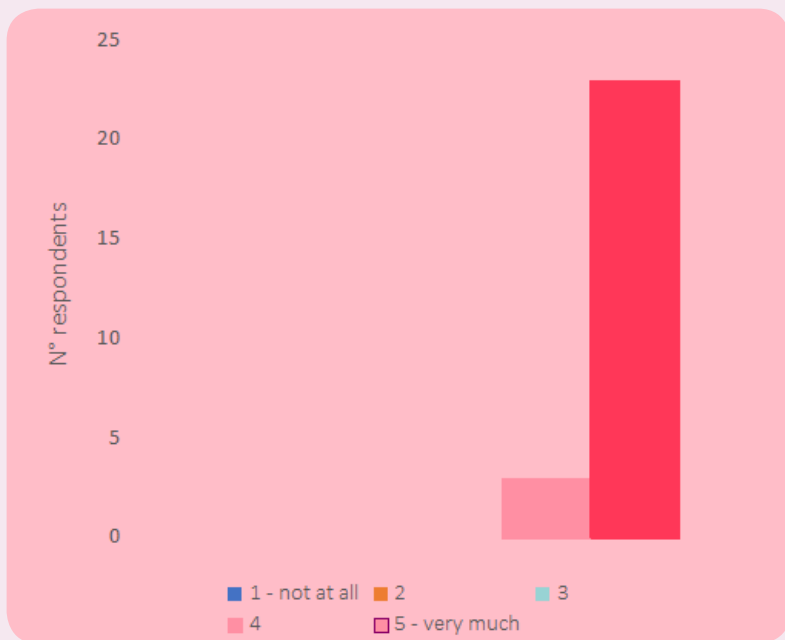
The Prolepsis training experience showed the importance of making preventive interventions aimed at women caregivers, who due to their caring commitments may engage in ineffective preventive behaviors. The use of a mobile application to transmit content and information, thus using an mHealth approach, can empower women themselves, making them more autonomous in their health management and making them responsible for their active role in prevention. Despite the challenges that technology might impose on potential users (e.g., difficulty in navigating through a mobile application), it was evident during the piloting that these can be easily overcome with appropriate coaching but also with integrated properties within the application. Having access to this digital portal gave women the opportunity to learn by accessing numerous online resources, tracked, and made available by partners. This opportunity was enthusiastically seized by the caregivers who participated in the course pilot, who were particularly satisfied.



### Level of satisfaction

The level of satisfaction of the participants was measured through a questionnaire, proposed by the partners in Cyprus, Italy and Porto. 28 participants responded to the questionnaires, specifically 11 from Cyprus, 7 from Italy and 10 from Portugal. The results were particularly positive, as all participants felt that the training, they received met their expectations and enabled them to learn new skills. Specifically, when asked if they were satisfied with their participation in the face to face training, here are the main answers:

- 78,57% said they are very much satisfied with their participation.
- 21,43% said they are satisfied – choosing the answer 4 in a scale from 1 to 5.



In terms of app satisfaction, the results also remain very positive. Resuming the answers:

- 81% of the 21 participants who answered said they are very much satisfied with the app;
- 19% of them answered they are satisfied, choosing the answer 4 in a scale from 1 to 5. Finally, when asked how they would rate the training overall, the answers were very positive, in detail:
- 88% of the 26 participants who answered said they are very much satisfied with the overall training performance
- 12% of them answered they are satisfied, choosing the answer 4 in a scale from 1 to 5.

Participants also showed their satisfaction with the training through their appreciation of the methods used by the trainers- 97% of them said they were very satisfied- as well as the usefulness of the content, which according to 75% of them were very much helpful, for 18% helpful in their knowledge of breast cancer and its prevention, and for the remaining respondents good, i.e., 2 out of 28, responding 3 out of 5.

Analyzing some of the concluding comments made by the participants, the answer to the question *“Please describe in more details your thoughts on the training in general terms”* where:

*“The training provided a very broad picture of the world of the caregiver and gave non-obvious insights into possible strategies to make this role coexist with self-love.”*

*“Competent people and useful content bringing people together at a delicate time”*

*“Very rewarding and interesting”*

**In conclusion,** it can be said that the training was appreciated by the participants and in their eyes was satisfactory, reflecting their expectations.



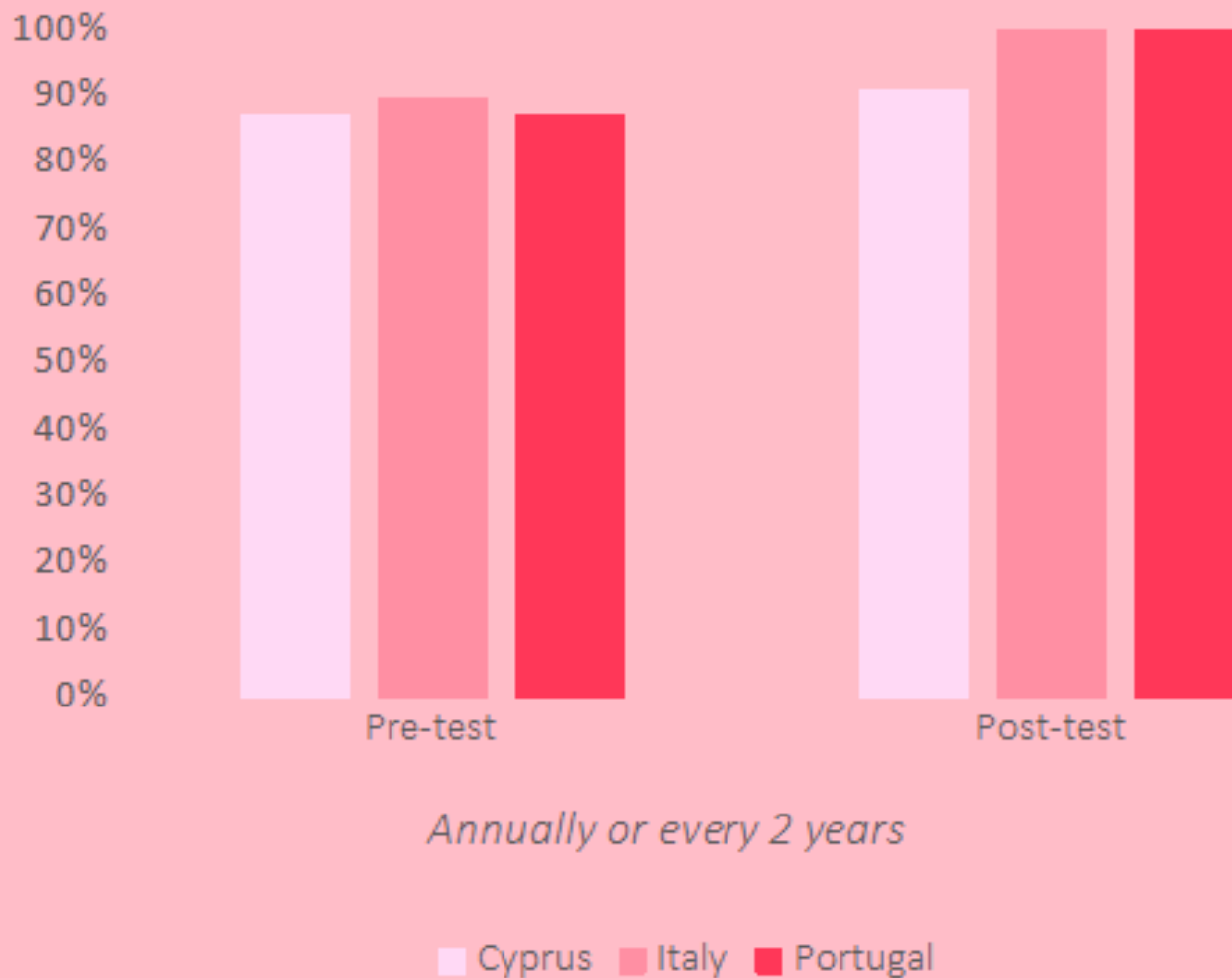
## Upskilling of Participants' Competences

The partnership elaborated a self-assessment questionnaire of 11 questions to be submitted to the participants before and after the training. The pre-test was sent to the participants at the end of the introductory pre-session on the project, thus before the training started. The post-test was sent one week after the end of the training, so that the participants had the opportunity to see the latest content uploaded on the app. In the pre-test questionnaire 35 participants answered, in the post-test questionnaire only 27, due to drop-outs.

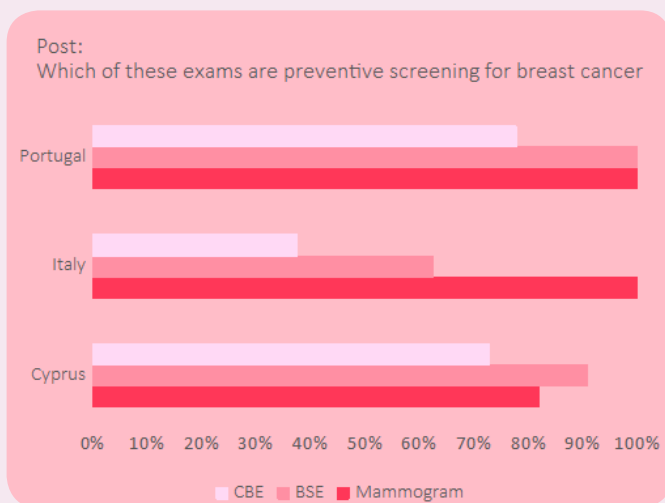
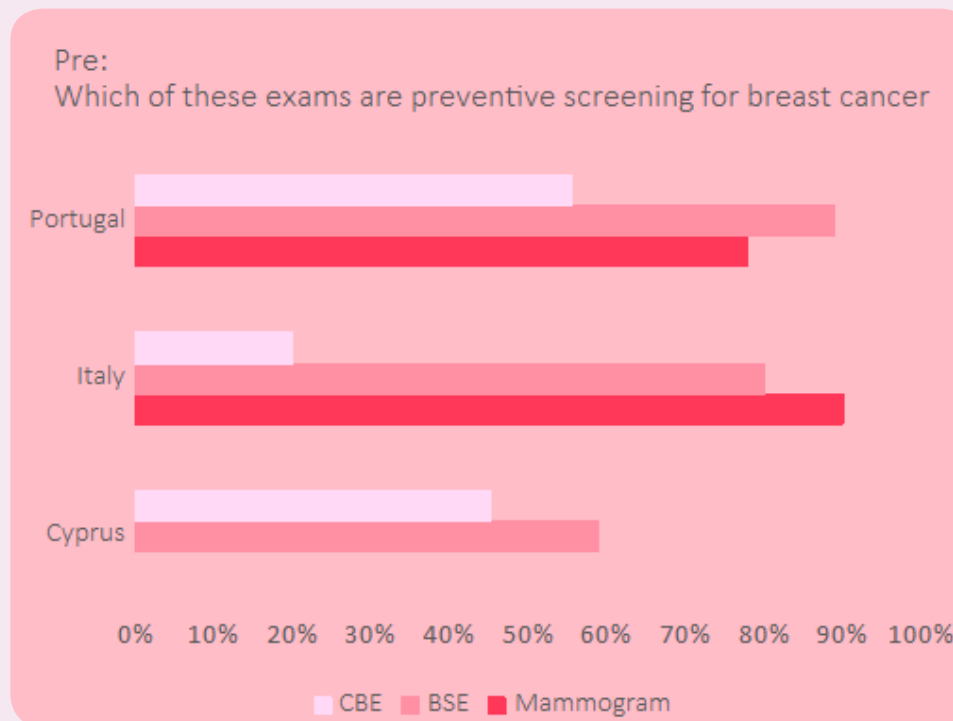
The comparison showed an overall increase in the participants' knowledge and skills after the training. As an example, the knowledge about the breast cancer risk factors (smoking, stress and anxiety, alcohol) was significantly higher in the post-assessment, compared with the pre-assessment.

Almost all women know how often a mammogram should be carried out for a woman between 50 and 69 years of age and how often they should perform breast self-examination.

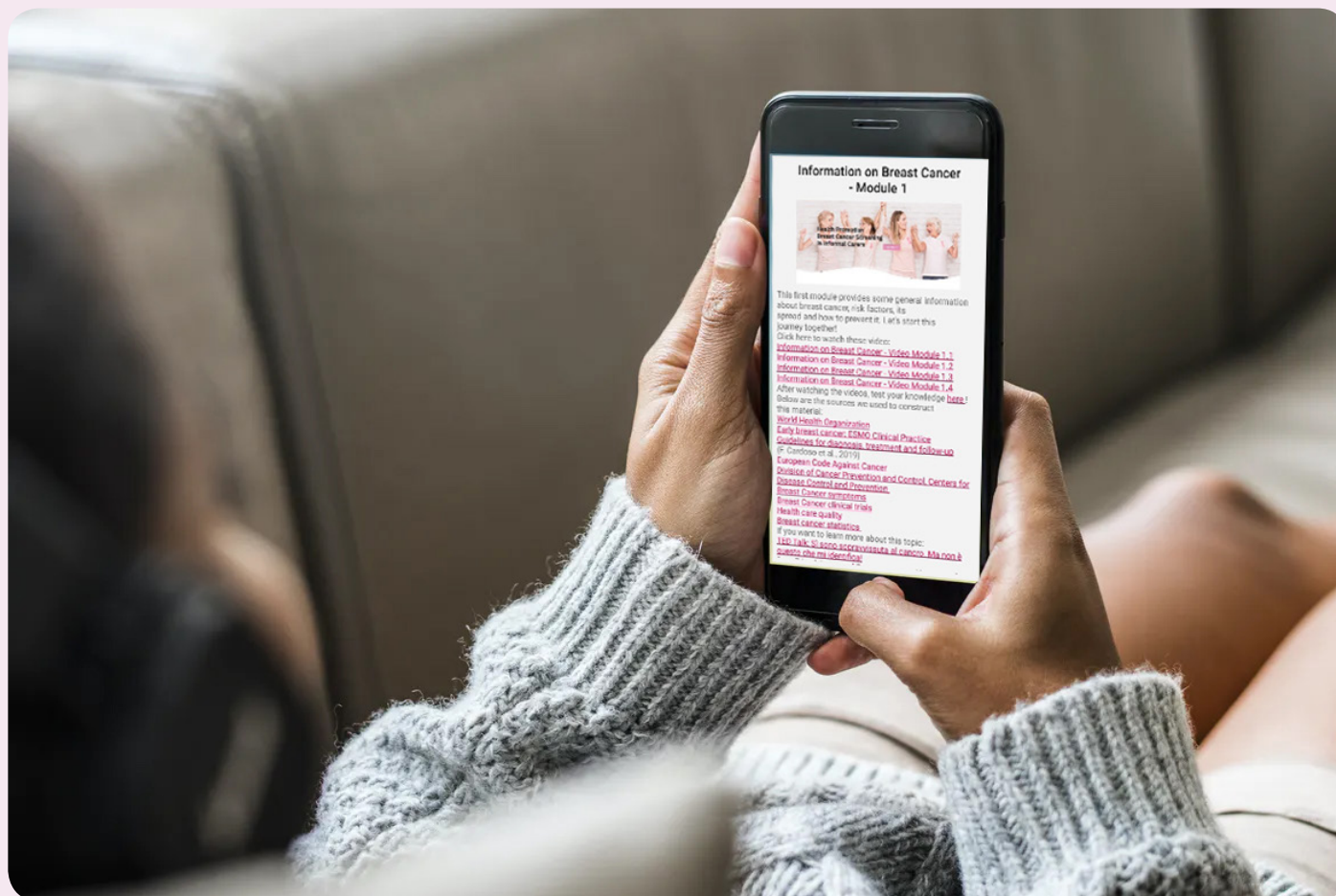
How often should mammogram be carried out for a woman 50-69?



Prevention screening was also better identified and understood after the training, as shown in the second table. With the pre- assessment was shown that the women knew little about Clinical Breast examination and Breast self-examination as preventive examinations. The results of the post-test show greater understanding, with reference to the starting point of each different nation.



**In conclusion,** these results show that participants generally improved their knowledge of breast cancer prevention, examination types and their frequency after the pilot training.



## Strategies for Developing Health Literate Mobile

This sector aims to share strategies to guide you - based in Prolepsis outcomes and scientific evidence (Wei, Y., Zheng, P., Deng et al., 2020; Grekin, Beatty & Ondersma, 2019; Broderick, Devine, Langhans et al., 2014) how to use the Apps not only with ICGs but also in the use of Strategies for Developing Health Literate Mobile Health Apps in the promotion of women's health in general.

## In the development of mHealth you should consider:

- Promote a self-efficacy strategy. This is a powerful tool to promote real change behaviors
- Invest in capacitation about primary but also secondary prevention strategies
- Listen ICGs and integrate them in the process asking their perceptions and preferences
- Involve Health and Social care Professionals in the process
- Personalize the App tailoring Women specific needs
- Engage users with a blended methodology (online and face-to-face). This facilitates positive regard and empathy. Users' like and trust more in a relational interaction
- Evaluate the users' experience and level of satisfaction with the contents, the training developed App features as well
- Well-designed mobile health interventions support a positive user experience
- Build a reliable alliance with end users, giving them quality contents and friendly use (e.g., incorporate audio and visual features, provide specific action steps)
- Display content clearly (ex. use images that facilitate learning)
- Update mobile App with suggestions from end users
- Promote interaction with App's end users (ex. using chat options, reminders, and popup messages)
- Challenge users to participate into health promotion proposing them activities they like
- Involve local and national authorities to enhance the number of participants and develop integrated strategies
- Define indicators and monitor users' engagement in long term
- Update APP's medium/long term with contents (e.g., suggesting new resources such as articles, videos). This can be other strategy to promote users' engagement
- Evaluate and revise your site (recruit users with limited health and digital literacy).



# 10. Conclusions and Recommendations





**P**rolepsis APP is an efficient mhealth tool that can be used to empower citizens to take a more active role. Promoting women's self-efficacy is essential but challenging. By using this APP, it enhances them to assume real control over this disease through adopting and maintaining changes in their lifestyle and living practices.

The high levels of satisfaction and the assessment results after Prolepsis pilot suggest a positive methodology based in a mix interaction with end users. This blended learning methodology is very rich as promotes the construction of a relation of confidence, with trainers also disposable to orientate, guide and support ICGs in a face-to-face interaction. It also allows women to manage better their time and access to Prolepsis contents in their chosen environment.

The development of Prolepsis App was followed by research with end users and professionals' experts in women's health promotion. This become of a great value as this personalized mobile application, attended in this way, the personal characteristics, needs and preferences of the end users, engaging them.

The potentiality of mHealth is enormous. Indeed, this APP can quickly be adapted on a large scale by healthcare, social care professionals and educators aware of ICGs' reality and BC prevention.

The quality of the contents, the features as well the planned training turn this APP reliable in the promotion of women's health. Also, the strategies suggested based in Prolepsis results, for developing health literacy can be of a great value in the development of future APPs orientated for health-literacy reinforcement programmes.

This results in a first stage are very positive as ICGs become engaged in the activities suggested and revealing updated skills. More studies should be conducted to analyse long term engagement and changed behaviour towards BC prevention.

In the future is also recommend doing an integrated approach. It would be beneficial to involve health, social and local authorities and scale these gains in the territory towards women's literacy and BC prevention. In this path, healthcare professionals, social care and educators can be the leaders and act as facilitators of the Prolepsis Training course in their community, making the difference in these women's life against cancer.

The successful implementation of this training course suggests that Prolepsis can improve health in ICGs and BC prevention. In the execution planning, it must be taken in consideration the specific characteristics of the users and the Prolepsis team suggestions.

Prolepsis App is a valuable resource to promote primary and secondary prevention, empowering women to be healthy, reinforcing the role and supporting the potential impact that mobile apps can have in the development of health-literacy reinforcement programmes.

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